

**Capital Reporting Company**  
**Sickle Cell Disease Public Meeting -- 2-7-2014**

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1 FOOD AND DRUG ADMINISTRATION (FDA)  
2 CENTER FOR DRUG EVALUATION AND RESEARCH (CDER)

3

4 SICKLE CELL DISEASE PUBLIC MEETING ON  
5 PATIENT-FOCUSED DRUG DEVELOPMENT

6

7 Friday, February 7, 2014

8

9 Food and Drug Administration

10 White Oak Campus

11 10903 New Hampshire Avenue

12 Silver Spring, Maryland 20993

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19 Reported by: Natalia Thomas

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1 M E E T I N G R O S T E R

2 (Continued)

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6             Kathy Robie Suh, MD

7             *DHP, CDER, FDA*

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1 P R O C E E D I N G S

2 Welcome

3 DR. EGGERS: Good morning, everyone. We're  
4 going to get started in a few minutes, so if I can ask  
5 everyone to start to move to their seats.

6 All right, I think we can get started, and  
7 as people join a little bit late, they can just feel  
8 free to come on in.

9 We are very excited to have our fifth  
10 Patient-Focused Drug Development Meeting on Sickle  
11 Cell Disease. We have done a lot of preparations, and  
12 Ann in a few minutes is going to give a welcome and do  
13 the proper thinking.

14 But my name is Sara Eggers, and I will be  
15 the facilitator for today, and I just want to go over  
16 a few housekeeping and agenda items. Before I do  
17 that, I do want to have my colleagues, my colleagues  
18 from FDA, introduce themselves. They'll be sitting up  
19 here throughout the meeting today.

20 DR. FARRELL: My name is Ann Farrell. I am  
21 the Division Director of the Division of Hematology  
22 Products in the Center for Drug Evaluation and

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1 Research.

2 DR. VERDUN: My name is Nicole Verdun, and I  
3 am Hematologist and Medical Officer here in  
4 Dr. Farrell's office.

5 DR. ROBIE SUH: Good morning. I'm Kathy  
6 Robie Suh. I'm one of the Medical Team Leaders in the  
7 Division of Hematology Products.

8 DR. FAULCON: Good morning. My name is  
9 Dr. Lisa Faulcon. I'm a Medical Officer in the  
10 Division of Hematology.

11 DR. MULLIN: Good morning. My name is  
12 Theresa Mullin, and I direct the Office of Strategic  
13 Programs in the Center for Drugs.

14 DR. BULL: Good morning. My name is Jonca  
15 Bull. I'm Director of the Office of Minority Health  
16 in the Office of the Commissioner.

17 DR. PARISER: Good morning. I'm Anne  
18 Pariser. I'm the Associate Director for Rare Diseases  
19 in the Office of New Drugs.

20 DR. EGGERS: Thank you very much.

21 I'm going to ask for the agenda slide.

22 So let me go over briefly what our day will

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1 look like today. We have a jam-packed day, and I'm  
2 happy to say that most of it is focused on listening  
3 to patients, caretakers, and advocates of people with  
4 sickle cell disease. After some opening remarks and  
5 some brief background context setting by my FDA  
6 colleagues and myself, we're going to go right into  
7 the discussion.

8           Our first discussion topic is on the health  
9 effects of sickle cell disease that matter most to  
10 you, and we're going to start that discussion by  
11 looking at the pediatric and young adults, so people  
12 about 22 and under, and then we're going to have a  
13 discussion, the same discussion, with adults, about 23  
14 and older.

15           Then we will go to lunch, and after lunch,  
16 we'll come back and have Topic 2 discussion in the  
17 same format, and I'm going to go over the panel format  
18 in my talk later on, so you'll have an idea of how  
19 that will run. The second talk will be on your  
20 perspectives on treatments for sickle cell disease.

21           Following that, after we have those two  
22 discussion topics, there will be an Open Public

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1 Comment, which will give anyone here, not just  
2 patients, but everyone, a chance to talk about other  
3 topics that may not have been within the scope of the  
4 first two topics.

5           And then following that, Kathy will give  
6 some closing remarks and we'll be done.

7           This meeting is being recorded today, both  
8 it will be on the webcast, and I want to give a huge  
9 shout-out to all the people who are on the webcast  
10 today, you play an important part of this meeting, and  
11 so we welcome you as well. The webcast is going to be  
12 streaming today. It will put up, it will be archived  
13 and posted on the website some days after the meeting.  
14 There will be a transcript, so everything that is  
15 being said is being captured today, and that will also  
16 be put on our website.

17           There are restrooms about as far away as you  
18 can be in this building, but they are just down this  
19 hallway, and then if you go to the end wall and go to  
20 the right, you'll see the restrooms. There is a kiosk  
21 where you can buy basic food, sandwiches and stuff,  
22 during lunch or anytime you want. And I do encourage

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1 you, if you need to get up and move around, please do  
2 so. This is a very informal setting. There is a  
3 hallway, there are some tables out there, if you need  
4 to stretch your legs and walk around or if you need to  
5 go use the restroom or get a snack.

6 I think that's it for the agenda and  
7 housekeeping. If you have any questions, my  
8 colleagues with name tags are sitting up here and  
9 around, just come find one of us and we will be happy  
10 to help.

11 With that, I will turn it to Ann, who will  
12 give a few opening remarks. Thank you.

13 Opening Remarks

14 DR. FARRELL: Thank you, Sara.

15 Good morning and welcome to this meeting on  
16 Patient-Focused Drug Development for Sickle Cell  
17 Disease. This is an important meeting, and we are  
18 delighted to hear today from patients about how they  
19 think about sickle cell disease. My name is Ann  
20 Farrell, and I am the Division Director for the  
21 Division of Hematology Products in the Center for Drug  
22 Evaluation and Research. Previously, I was in

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1 university practice where I was a hematologist  
2 oncologist taking care of patients with sickle cell  
3 disease.

4 I see we have a full room today, and I would  
5 like to thank all our panelists, patients, their  
6 families and caregivers, the advocates, and the  
7 numerous advocacy groups who are here today, the  
8 pharmaceutical industry, health care professionals,  
9 academia, NIH, CDC, and other government partners, the  
10 press, and interested observers for dealing with the  
11 recent Washington Metro weather and coming to today's  
12 meeting.

13 I would also like to thank all of those who  
14 are joining remotely via the web. I'm delighted to  
15 see a high level of interest from those of you who  
16 play a very important role in the drug development  
17 process. Thank you very much for coming here today  
18 and being part of this meeting.

19 A major mission of the FDA is to ensure the  
20 availability of safe and effective medicines to the  
21 American public. The FDA is also responsible for  
22 advancing public health by speeding innovations that

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1 make medicines more effective, safer, and more  
2 affordable, and by helping the public get accurate  
3 science-based information that patients need to use  
4 medicines effectively. While we at the FDA are part  
5 of the process, we are just one part of the process.  
6 FDA does not develop medicines or treatments for  
7 sickle cell disease nor do we conduct clinical trials.

8           CDER's Division of Hematology Products  
9 oversees the development and approval of medicines  
10 like hydroxyurea, which are used to prevent or treat  
11 the complications of sickle cell disease. While we do  
12 not develop medicines or treatments, we work with our  
13 partners to facilitate the research and development of  
14 safe and effective medicines.

15           Can I have the next slide, please?

16           Drug companies or manufacturers work with  
17 academic investigators and research and patients to  
18 conduct the necessary studies and clinical trials to  
19 submit applications for new drug products to the FDA.  
20 It is then the FDA's responsibility to ensure that the  
21 benefits of a drug outweigh its risks. The path a  
22 drug takes travels from the laboratory testing to your

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1 medicine cabinet can be a long period and each drug  
2 takes a unique route.

3           Typically, this work is done through a  
4 process that involves formal application to the Agency  
5 and investigational New Drug Application. Sponsors or  
6 manufacturers typically do initial preclinical animal  
7 testing. This is followed by manufacturers showing  
8 the FDA the results of the animal testing and making  
9 an application for human clinical testing. After  
10 considering the results of the animal studies and  
11 negotiating with the sponsor, the FDA decides whether  
12 it is reasonably safe to allow the conduct of human  
13 clinical testing with various agents. The testing in  
14 humans is a gradual process of the accumulation of  
15 safety and effectiveness data sometimes involving  
16 different populations, different dosages, and using  
17 different drugs sometimes in combination.

18           During this process, the FDA will meet with  
19 sponsors on several to many occasions as they test  
20 their product to discuss the findings and the path  
21 forward and hopefully the path to eventual approval  
22 for widespread use.

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1           How often the FDA meets with a sponsor  
2 varies. Along the way, some drugs are found to be too  
3 toxic and are never tested in humans. Other drugs are  
4 discovered to be toxic in early clinical trials and  
5 are never fully developed.

6           When enough data has been accumulated, the  
7 manufacturer submits an application to the FDA, this  
8 is called a New Drug Application to the FDA, to ask  
9 that the FDA consider approving the new drug for  
10 marketing in the U.S. The submission will contain all  
11 available animal and human data as well as information  
12 on manufacturing. The FDA then will perform a  
13 rigorous evaluation process looking at all aspects of  
14 the drug, including the manufacturing, inspecting  
15 sites, and the clinical trial data and analysis of  
16 trial conduct, and then we'll make a decision about  
17 the application and whether the manufacturer has  
18 submitted enough information to allow the marketing,  
19 which would be the widespread distribution and sale of  
20 the product.

21           All of us attending this meeting have  
22 different but very important roles in the development

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1 of effective treatments, from manufacturers who  
2 develop the product and perform the initial  
3 preclinical testing and work with the researchers and  
4 investigators and the Agency to design the clinical  
5 trials, the patients who participate in the clinical  
6 trials of experimental therapies, and the FDA, who  
7 will eventually make a decision regarding the product.

8           Pharmaceutical companies synthesize and  
9 manufacture agents to target those effects or  
10 identified causes of those effects, working together  
11 with clinicians and manufacturers, develop clinical  
12 trials to test the promising agent in patients. And  
13 patients, their families, and advocacy communities  
14 engage and participate in those trials to allow the  
15 verification of the beneficial effects of the drugs  
16 and help to understand what side effects can be  
17 expected.

18           We're very happy to be having this meeting  
19 today on sickle cell disease. As many of you know, we  
20 have a scarcity of products approved to prevent or  
21 treat the complications of this disease. Sickle cell  
22 disease is a chronic and debilitating disease that

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1 affects patients all of their lives. The treatment of  
2 sickle cell disease remains an area where there is a  
3 large unmet medical need. Hydroxyurea is not 100  
4 percent effective and transplant is not an option for  
5 everyone. Hence, we are interested in getting  
6 patients' perspective, patients' families'  
7 perspective, caregivers' and advocates' perspective on  
8 the aspects of their disease that affects their lives  
9 the most. This is an area where we really want to  
10 hear more from patients about how you experience the  
11 disease and how it affects your life, and what you  
12 would like to see in a potential treatment that might  
13 be approved.

14 Can I have the next slide?

15 Having this kind of dialogue is very  
16 important for us. Hearing about what you care about  
17 can help lead the way in figuring out how to best  
18 facilitate drug development for sickle cell disease.  
19 You can help us to better understand how endpoints  
20 that reflect the aspects of the disease that bother  
21 you the most can be incorporated in clinical trials to  
22 better define the benefit. And I'm talking about

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1 patient-reported outcomes, how you feel, your  
2 symptoms, those items that are most important to you.

3           We hope this meeting will be the first of  
4 many successful collaborations leading to the  
5 development and approval of effective therapies for  
6 sickle cell disease. Thank you very much for your  
7 participation here today. I will now turn it over to  
8 Theresa Mullin, who will provide the background on the  
9 FDA's Patient-Focused Drug Development.

10           Thank you.

11           Overview of FDA's Patient-Focused  
12           Drug Development Initiative

13           DR. MULLIN: Good morning. I'm going to  
14 take a few minutes to tell you about this broader  
15 initiative, and we are very happy that sickle cell  
16 disease is one of the disease meetings that we're  
17 including in this initial set of 20.

18           And we can go to the next slide.

19           So this initiative began with FDA making  
20 some basic observations, that really patients are  
21 uniquely positioned to give us a better understanding  
22 of the clinical context of the disease, and that would

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1 be critical to our benefit-risk assessments of new  
2 drugs. And we would also benefit from a more  
3 systematic approach to getting that kind of input on  
4 the severity of the condition from the patient's point  
5 of view and also the impact on their life and how they  
6 feel about the treatments that are currently  
7 available, and do that outside of the decision making  
8 around a particular drug, really try to do this in  
9 advance of and as a separate effort where really it's  
10 all about hearing what patients think because that  
11 would provide us a wonderful reference point for any  
12 applications that come in, including new drug  
13 investigational applications, as Dr. Farrell was  
14 describing, early on in development. It would help us  
15 in a much broader way. And the mechanisms we had  
16 available before this initiative really only gave us  
17 an opportunity to get that input in the context  
18 typically of an advisory committee meeting or when a  
19 particular product was under consideration, and there  
20 are all sorts of constraints that that places on our  
21 ability to get input. So we thought this was really  
22 an unmet need that we had.

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1           And so in 2012, as part of the  
2 reauthorization of the Prescription Drug User Fee Act,  
3 FDA committed to and built into our performance goals  
4 for ourselves development of a more systematic  
5 approach and one that would allow us to get that  
6 patient perspective and inform our understanding of  
7 their view of the context of the disease, which is,  
8 after all, it's the drugs are being made for patients,  
9 they are going to the experience the benefits and also  
10 the risks. So getting that input would really help us  
11 to do a better job of protecting patients and  
12 reviewing those applications.

13           And so we committed to at least 20 diseases  
14 in different specific disease areas and that we really  
15 view this as the first 20 where, quite honestly, we're  
16 really learning how to run these meetings or how to  
17 get this kind of input, even getting remote input and  
18 making the best use of those technologies to hear from  
19 as many people as possible. Not everyone can be here  
20 today. We're thrilled that you were able to make it  
21 to this meeting and that the people on the webcast are  
22 able to join. And so we're learning how to do this,

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1 and that's what these meetings will do, giving us this  
2 opportunity.

3           And so how do you choose that 20? There are  
4 so many diseases where patients have told us they need  
5 better treatments. And so to come up with an initial  
6 set of 20, we developed some criteria, we asked our  
7 review divisions to consider these criteria, we put  
8 these in a *Federal Register* Notice as well to ask for  
9 public input, and here is the set that we came up with  
10 to help us shape up an initial 20: diseases that are  
11 chronic, symptomatic, and affect functioning and  
12 activities of daily living; ones where there are  
13 important aspects of the disease that are not being  
14 formally captured in clinical trials today; ones for  
15 which there are no therapies or very few therapies,  
16 and the therapies don't address all of the most  
17 critical symptoms or perhaps any of them in terms of  
18 how patients feel, function, or survive. We wanted to  
19 get diseases that reflected a range of severity across  
20 patients affected where possible to understand that  
21 better and also look at diseases where there might be  
22 a particular subpopulation that is more affected by

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1 the disease. And, finally, as a set of 20, we wanted  
2 to capture a range of diversity in terms of the size  
3 of population affected and the kinds of input that we  
4 might get.

5           And so we came up with our initial list, it  
6 was almost 40. We published that FDA-generated list  
7 in a *Federal Register* Notice in fall of 2012, and we  
8 had a public meeting in October of that year and it  
9 was very well attended. We received about 4,500  
10 comments from the public docket. In those comments,  
11 20 -- or, rather, 90 diseases were identified as being  
12 ones we should be considering and of interest. And so  
13 we very carefully sifted through all this input, went  
14 back to the review divisions, talked to them about,  
15 "What should we focus on first here?" And what we've  
16 come up with so far is 16 diseases for the first 3  
17 years. We're going to come back and try to determine  
18 which diseases to pursue in the final 2 years of this  
19 5-year program later on.

20           And so on the next slide we have the  
21 diseases that are identified so far for the first  
22 couple of years, and as you can see, sickle cell is

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1 our first disease for this year, this calendar year.  
2 And so for each of these meetings and looking at the  
3 range of diversity of those diseases on that slide,  
4 you can see we really need to further tailor each of  
5 these meetings to some of the particular issues and  
6 the experiences of the population of patients who are  
7 experiencing that disease.

8           And so we have some standard questions that  
9 we'll be asking you today that we ask at each of these  
10 meetings related to the severity of the condition and  
11 your experience with it and how it's affecting your  
12 life and how the treatments available are working for  
13 you. We also bring in questions that the review  
14 divisions have asked to have included because there  
15 may be particular concerns or things that they see  
16 coming up in their reviews and they would like us to  
17 try to take the opportunity, the sort of unprecedented  
18 opportunity we have here, to get your input on those  
19 as well. So some of the questions or probing that we  
20 do today is to help the reviewers. And the review  
21 division staff come to these meetings to hear, it's a  
22 wonderful opportunity for them, and so we'll have

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1 questions of that kind as well.

2           And as I mentioned earlier, we're also  
3 trying to figure out how to use technology to poll and  
4 get responses to different questions, using  
5 interactive questions for the webcast to be able to  
6 get input from those who are participating remotely as  
7 well.

8           But common to all these meetings, we have  
9 found that patients and the caretakers and the patient  
10 advocates who come provide us with very insightful and  
11 powerful messages about what it's like to live with  
12 this disease and really have been invaluable to us.  
13 And the stakeholder involvement, even in preparing for  
14 these meetings and planning for them and gathering the  
15 input and outreach to other patients with the disease  
16 has been critical to the success of these meetings.

17           And, finally, what do we do with the  
18 information that we get in these meetings? Well, one  
19 thing that we will do is develop a meeting report  
20 which tries to capture very faithfully what we heard  
21 from the patients who come to the meeting or provided  
22 us with input and who have sent information into the

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1 docket as well. We keep a public docket, which is an  
2 electronic docket, so people can submit comments to  
3 that as well. And we analyze all this information and  
4 really try to make sure we keep the input in the words  
5 of the patients, use the language that they use,  
6 because we don't want to try to translate it, that's  
7 really authentically the input that we received, and  
8 that's one input. And the other, as Dr. Farrell was  
9 saying, is an opportunity for us to get a start on  
10 perhaps development of the patient-reported outcome  
11 measures that can be used to help capture more  
12 information in clinical trials to see if drugs that  
13 are being tested are addressing some of the symptoms  
14 and the concerns that we've heard from patients. So  
15 that's another longer term result that we can get from  
16 these meetings.

17           And with that, I'll stop and I'll turn it  
18 over to our next speaker. Thank you.

19           Background on Sickle Cell Disease and Treatment

20           DR. VERDUN: Good morning, everyone. My  
21 name is Nicole Verdun, and I'm a hematologist here in  
22 the Division of Hematology Products in the Center for

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1 Drug Evaluation and Research. And I also have treated  
2 several patients with sickle cell disease. Many of my  
3 mentors are either in the room or participating via  
4 webcast. And so we welcome you and we look forward to  
5 this discussion. And with that, I will get started.

6 I have been tasked with giving a very broad  
7 overview of sickle cell disease in 10 minutes. You  
8 can feel free to laugh because that's, of course,  
9 difficult to do, but here we are.

10 So the next slide. Thanks.

11 So I will be giving a definition of sickle  
12 cell disease, discussing a little bit about the  
13 genetics, the complications, and treatment.

14 So sickle cell disease truly is a global  
15 health problem with 100,000 people affected in the  
16 United States and millions affected globally. Sickle  
17 cell disease occurs in 1 in 500 African American  
18 births and in 1 in 36,000 Hispanic births. And sickle  
19 cell trait affects 1 in 12 African Americans.

20 Our goal here at the FDA is the development  
21 of safe and effective treatments for preventing and  
22 reducing the complications of sickle cell disease.

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1           Sickle cell disease is a multisystem disease  
2 associated with episodes of acute illness and  
3 progressive organ damage, and red blood cells change  
4 to a sickled shape in the presence of decreased oxygen  
5 and inflammation. Sickled red blood cells and white  
6 blood cells then become trapped in small blood vessels  
7 or the microvasculature.

8           Normal hemoglobin consists of two alpha-  
9 globin chains and two beta-globin chains, and  
10 hemoglobin S results from a point mutation changing  
11 the 6 amino acid in the beta-hemoglobin chain from  
12 glutamic acid to valine.

13           Sickle cell anemia, or homozygous SS,  
14 accounts for about 70 percent of sickle cell disease.  
15 There are several other forms of sickle cell disease  
16 that result from a coinheritance of hemoglobin S with  
17 other abnormal beta chains. So for example, sickle  
18 cell disease SC, S beta 0, S beta plus, SO-Arab, and  
19 SD.

20           There are significant differences in  
21 severity and complications that are somewhat  
22 attributable to genes and the type of sickle cell

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1 disease. So, for example, sickle cell disease SS and  
2 S beta 0 has a different phenotype than SC and  
3 different from S beta plus, but even within the same  
4 family or mutation, there are differences that exist.  
5 We do know that there can be coinheritance of other  
6 genetic factors that modulate the disease such as  
7 alpha-thalassemia and the hereditary persistence of  
8 fetal hemoglobin.

9           There are many sickle cell disease  
10 complications that can occur as early as infancy and  
11 continue through childhood and adulthood, and this is  
12 a not comprehensive list but does list several of  
13 those complications. Some of them are a direct result  
14 of the disease and others are a consequence of needed  
15 therapies such as iron overload.

16           Recurrent episodes of blood vessel occlusion  
17 and tissues not getting enough oxygen can result in  
18 progressive damage involving most organs: so the  
19 bones with complications such as avascular necrosis,  
20 the lungs can have restrictive lung disease over time,  
21 hepatopathy, kidneys, brain, retinopathy,  
22 cardiovascular system problems. Chronic hemolysis can

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1 result in varying degrees of anemia, jaundice,  
2 fatigue, gallstones, delayed growth and sexual  
3 maturation, and progressive damage to blood vessels.  
4 And increased rates of hemolysis can predispose people  
5 to pulmonary hypertension, priapism, and leg  
6 ulcerations.

7           One of the most common causes of stroke in  
8 children is sickle cell disease, and damage to blood  
9 vessels in the brain can start in infancy. Some  
10 people can have a progressive vasculopathy with  
11 recurrent strokes despite a transfusion program.  
12 Silent brain infarcts are recognized to have problems  
13 with neurocognitive deficits. Intracranial bleeds can  
14 begin in the twenties and thirties with moyamoya-like  
15 syndrome, cerebral aneurisms. Treatment is largely  
16 neurosurgical and limited in its scope and its ability  
17 to have an effect.

18           Acute chest syndrome is a form of acute lung  
19 injury with significant morbidity and mortality  
20 associated, and it's the second most common cause of  
21 hospitalizations in sickle cell disease outside of  
22 acute pain crises.

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1           People with sickle cell disease can have  
2 chronic damage to blood vessels in the kidney that can  
3 start at a very early age, and adults can develop  
4 chronic renal failure and require renal transplants.

5           Sickle cell disease can also affect  
6 pregnancy. The manifestations can vary. Some people  
7 with sickle cell disease will have an increase in  
8 acute painful episodes, an increase in the risk for  
9 thrombosis or clot formation, infectious  
10 complications, cardiac complications, and low birth  
11 weight.

12           The current treatment paradigm for sickle  
13 cell disease is a combination of preventive and  
14 supportive with each patient falling a little bit  
15 different in terms of where they are for prevention  
16 versus supportive based upon what's available for  
17 their individual disease.

18           Hydroxyurea was FDA approved in 1998 with an  
19 indication to reduce the frequency of painful crises  
20 and to reduce the need for blood transfusions in adult  
21 patients with sickle cell anemia with recurrent  
22 moderate to severe painful crises. The uses for

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1 hydroxyurea continue to grow in scope and are much  
2 broader than the indication. It works very well for  
3 some to decrease complications and has actually been  
4 shown to increase survival. The mechanism of action  
5 is not completely understood. Several people have an  
6 increase in hemoglobin and a reduction in hemolysis.  
7 There is an increase in hemoglobin F production, which  
8 allows red blood cells to live longer. Decreasing  
9 inflammation has been seen, and dilation of the blood  
10 vessels as a result of nitric oxide metabolism.

11           Other preventive treatments that are  
12 commonly used are penicillin prophylaxis, timely  
13 immunizations. The pneumococcal vaccine has really  
14 revolutionized infections in sickle cell disease. The  
15 influenza vaccine is very important. Folic acid is  
16 often used due to increased red blood cell turnover.  
17 Chronic red blood cell transfusion therapy can be  
18 indicated for some patients. All of the indications  
19 are beyond the scope of this talk. And although not a  
20 treatment, ongoing education of caregivers and  
21 patients is essential. And a lot of surveillance is  
22 done: Transcranial Doppler ultrasounds,

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1 echocardiograms, eye screening, urinalysis, et cetera,  
2 and monitoring for growth and development.

3           Stem cell transplantation can be curative,  
4 but there are significant risks during and after  
5 transplant that have traditionally limited its use to  
6 those with significant complications. There are also  
7 problems with finding match donors. Continued  
8 improvements in immunosuppression in the management of  
9 transplant-related complications are ongoing, and the  
10 criteria for consideration of a transplant are  
11 constantly changing.

12           I had to mention some of the limitations of  
13 the preventive treatments that are used. For example,  
14 chronic transfusion therapy, although effective for  
15 some, can have problems with iron overload, antibody  
16 formation, transfusion reactions, and infections,  
17 which limit their use in some patients.

18           And hydroxyurea, although a wonderful drug  
19 for several people, is not universally effective.  
20 There is laboratory monitoring that's required, you  
21 can have myelosuppression, and it can be harmful  
22 during pregnancy to an unborn baby. So we really do

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1 need further development of safe and effective  
2 treatments for sickle cell disease.

3           Treatment of complications is often a  
4 combination of antibiotics. Blood transfusions may be  
5 indicated in the acute setting. Surgery. Pain crisis  
6 management is largely supportive with a combination of  
7 hydration management, oxygen, anti-inflammatory  
8 agents, and pain medications. And acute chest  
9 syndrome management is also quite supportive. So  
10 really are here at the FDA interested in continuing to  
11 switch the treatment paradigm from supportive to  
12 preventive or curative.

13           So what is the future of sickle cell disease  
14 treatment? Well, there are several clinical trials  
15 that are in the planning stages or in process, but it  
16 really is not enough. We really do need more  
17 development to have the global impact on sickle cell  
18 disease that we need and that we feel is overdue.

19           Thank you.

20           (Applause.)

21           Overview of Discussion Format

22           DR. EGGERS: Thank you very much, Ann --

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1 Nicole, and Ann, and Theresa.

2           It's my pleasure to get the discussion  
3 started. I'm going to go over a few basic things  
4 about what our discussion will look like today, and to  
5 put you all at ease about how the day is going to run.

6           Can I have the next slide, please?

7           We have our two topics, we've gone over  
8 those a bit today, but I'll just briefly go over those  
9 again. The first topic is the health effects that  
10 matter most to you, and by "you," I mean patients, and  
11 if you're here as a caretaker, if you can speak on  
12 behalf of your loved one. What matters most to the  
13 person who lives with sickle cell disease?

14           We're going to discuss the pediatric and  
15 young adults first, and then we'll have a separate  
16 discussion on adults. So during the pediatric  
17 discussion, adults, please stay silent. And then  
18 during the adults, we'll ask the pediatric and  
19 caregivers to be in listening mode as well.  
20 Hopefully, you'll learn a lot.

21           We want to know what the specific ways that  
22 sickle cell disease affects your health. We want to

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1 hear about your average days with no acute pain crisis  
2 and your worst days when a pain crisis hits, and we're  
3 going to split those two topics up a little bit.

4           And then in the afternoon after lunch we'll  
5 come back and talk about your perspectives on the  
6 treatments that Nicole just described. What are you  
7 doing to treat your disease that includes those  
8 prescription treatments that she mentioned but also  
9 the range of other lifestyle -- other therapies that  
10 you do to try to manage your condition? How well do  
11 these treatments work for you? What would you look  
12 for in an ideal treatment? And what might you think  
13 about if you had a chance to participate in a study  
14 for an experimental new treatment?

15           So for each of those topics that I just  
16 discussed, we're going to first hear from a panel of  
17 patients and caregivers, and the purpose here is  
18 really to set a good foundation for our discussion.  
19 We have asked each of the panel members to give 2 to 3  
20 minutes of their story. Now, we all know that our  
21 stories could take hours to tell, but we've asked them  
22 to limit it to 2 to 3 minutes, and I'll nudge them

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1 along if they start to give a little bit more than  
2 that. But they're all very willing and they're happy  
3 to oblige so that we can get to our facilitated  
4 discussion, and that's the discussion where I'll come  
5 out and in more talk show style engage the rest of you  
6 in the audience, those who have sickle cell disease,  
7 care for someone with sickle cell disease or are an  
8 advocate of sickle cell disease patients. The purpose  
9 here is to build on the experiences that were shared  
10 by the panel.

11           So we're going to ask a series of questions  
12 and invite you to raise your hand to respond, and we  
13 have Andrea and Soujanya will be coming around with  
14 microphones. This is very talk show style, it's quite  
15 novel for FDA. So we're going to invite -- please  
16 raise your hand to respond. We have a huge crowd  
17 today, and I love to see that. It makes it a little  
18 bit of a challenge to try to get to everyone, but we  
19 will, we'll try to do our best, if you want to  
20 contribute, to let you do so. Please state your name  
21 before answering so that we can capture that. You  
22 just need to state a first name, that's fine.

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1           You'll also have a chance to answer polling  
2 questions, and here I'm talking about the people on  
3 the web as well as the people in person, and I'm going  
4 to ask that the little clickers that we're going to  
5 use in person to be handed out. So if you are a  
6 patient or a patient caretaker, please raise your  
7 hand, and we're going to have these little clickers  
8 come out. We're going to practice in a bit on how to  
9 use these. You just have to click the button to  
10 respond to the right answer.

11           On the web, it's a little bit easier for  
12 you, I think. There is Adobe on your webcast. You'll  
13 be able to click on the response that you want.  
14 Sometimes you'll have to scroll down because the  
15 responses won't always fit on the screen, so just  
16 scroll so you see all the possible choices.

17           So, web participants, you can also add  
18 comments through the webcast, and although we may not  
19 -- we won't be able to read all of the webcast  
20 comments today, but we will summarize those as best we  
21 can. They are important. We review all of them. And  
22 we will incorporate them into our report.

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1           We'll occasionally go to the phones to give  
2 you another opportunity to contribute, too, on the  
3 web. The phone line information will be provided on  
4 the webcast screen at the right time.

5           You can also send us your comments. We very  
6 much want to hear what you have to say. If you have  
7 friends who weren't available to join in the meeting,  
8 have them send a comment. If you heard something  
9 today that really you want to comment more about, you  
10 want to describe in more detail, please send in a  
11 comment. If you want to describe your story, like the  
12 panelists are, your full story, please send in a  
13 comment. We review all of them. They're very  
14 important to us. The comments will be included in our  
15 summary report.

16           And I've just shown the website here that  
17 you can visit to go find it. It's on our meeting web  
18 page, and if you click on the "Comment Now" button, it  
19 will take you to a spot that you can upload your  
20 comment.

21           There are a few ground rules that we have to  
22 make sure the discussion is as beneficial as possible

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1 and as fair as possible. We very much encourage  
2 patients to contribute to the dialogue. Caretakers  
3 and advocates, you are very welcome to contribute as  
4 well. I hope you feel comfortable to contribute.  
5 You're in company of your fellow patients and in  
6 people who find drug development for sickle cell  
7 disease very important, so please feel free to  
8 contribute.

9           FDA is here to listen. My colleagues are up  
10 in the front and I know we have other FDA colleagues  
11 scattered in the room. Because we're in listening  
12 mode, we probably can't answer all the questions that  
13 you may have for us. There are a number of other  
14 topics. If we can't answer a question -- we won't be  
15 able to answer very many questions, and in that case,  
16 if you want to put your question in the docket  
17 comment, we might not be able to answer that directly  
18 either, but at least we know what questions you have  
19 and what things you want us to be thinking about and  
20 addressing when we talk to you in the future.

21           Our discussion today will focus on health  
22 effects and treatments. We know that there are many

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1 issues related to the care and support of people with  
2 sickle cell disease, and this doesn't mean that these  
3 issues aren't important. We do want to focus on the  
4 things that FDA can really manage and think about as  
5 we continue our role in drug development. There is an  
6 Open Public Comment period, and if you haven't signed  
7 up already, you can sign up at the registration table.  
8 It's first come, first served, so if it's filled up  
9 when you want to register, again that public docket,  
10 send us that comment with your comment, with your  
11 thought on another topic, too. We will be glad to  
12 read those.

13           The views today expressed here are personal  
14 opinions, and we want to respect everyone's personal  
15 opinions. I know that they are each individual  
16 persons. So maybe you hear something that doesn't  
17 quite reflect what you think about sickle cell  
18 disease, just remember that's their personal opinion.  
19 And, of course, respect for one another is paramount.

20           Also let us know how we're doing. There are  
21 some evaluation forms at the back, and we find those  
22 important. They will really help us as we continue to

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1 improve on our patient-focused meetings.

2           With that, I think we get to go into some of  
3 the clicker questions. I want to remind you, these  
4 clicker questions are going to be some demographic  
5 questions and then later on some discussion questions,  
6 and they are not scientific. This is not a scientific  
7 survey that we're doing. This is just to aid in  
8 discussion. It's completely voluntary, but again we  
9 encourage you -- it's anonymous, we encourage you to  
10 contribute to the polling questions. If you need any  
11 more clickers, just let us know at the front.

12           Can we go to the first clicker question?  
13 Okay. The first one is easy, we hope. It's: Where  
14 do you live? Do you live within the Washington, D.C.,  
15 area, including our suburbs? You would click "A" if  
16 you are in the room, you click "A" on your clicker,  
17 and on the web, you just hit the right choice. Or do  
18 you live outside the Washington, D.C., metropolitan  
19 area?

20           (Answering question.)

21           DR. EGGERS: I see we still have some  
22 clickers going around, so I'm going to give a few

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1 minutes.

2           And I will say, there are some empty chairs  
3 toward the front over here. If you're a patient or  
4 patient representative and you want to move up, it  
5 does make it easier for us to see you if you raise  
6 your hand to participate, so feel free.

7           Okay, let's go to the responses. If you  
8 missed that first one, it's our least important  
9 question. Okay. So it looks like two-thirds of you  
10 came from out of the area.

11           (Applause.)

12           DR. EGGERS: It's difficult to travel around  
13 D.C. if you live in the area, but if you came from  
14 outside of the area, our special thanks.

15           Okay, the next one, please.

16           Which of the following best describes you?  
17 Choose all that apply. A, I have sickle cell disease;  
18 B, I am a family member or caretaker of someone with  
19 sickle cell disease; C, I work for a sickle cell  
20 disease patient support or advocacy organization; D,  
21 I'm a health care professional who works with sickle  
22 cell disease patients; and "Other."

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1           And while you're getting that, let me just  
2 remind you, I'm sure not all of the health care  
3 providers, professionals, and advocates got a little  
4 clicker. Don't worry. This is not going to be seen  
5 as the be-all, end-all of who is in the room.

6           (Answering question.)

7           DR. EGGERS: Okay. Can we go on? Okay.

8           So does this give us the numbers at all?  
9 Okay, that's fine. We have a lot of people here who  
10 have sickle cell disease and so many family members  
11 and advocates. It's just wonderful to see you.

12          (Applause.)

13          DR. EGGERS: We're going to be doing a lot  
14 of applauding today, I think, I have a feeling.

15          Okay, let's move on. Now, for the rest of  
16 these, we really just want the patients and  
17 caretakers, and by "caretakers," I mean someone who is  
18 here on behalf on someone who has sickle cell disease,  
19 they aren't here and they aren't answering for  
20 themselves. So if your son or daughter is here  
21 answering for herself, please don't answer the polling  
22 questions. Okay.

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1           So what is your age or your loved ones age?  
2   Zero to 5; B, 6 to 12; C, 13 to 17; D, 18 to 22; E, 23  
3   to 49; or F, 50 and greater.

4           (Answering question.)

5           DR. EGGERS: Great. It looks like we have a  
6   diversity in the younger ages. We split those out  
7   because we wanted to know a little bit more in detail  
8   the ages. A lot of adults 23 to 49. But I want to  
9   give a special shout-out to the folks 50 and greater.  
10   It is fantastic to see you here.

11          (Applause.)

12          DR. EGGERS: Pujita, can I have on the web?  
13   Do we have -- or James.

14          MR. VALENTINE: Can you hear me?

15          DR. EGGERS: Mm-hmm.

16          MR. VALENTINE: Yeah. So we actually have  
17   some similar numbers for ages, except we have a little  
18   bit higher for 23 to 49 were almost 60 percent of the  
19   participants, and then we have about the same, about  
20   27 percent, for 50 or greater.

21          DR. EGGERS: Great. Thank you. Okay.

22   Moving on. Okay. Is your loved one male or female?

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1                   (Answering question.)

2                   DR. EGGERS: Okay, we won't give as much  
3 time for this one. Okay, two-third female and one-  
4 third male.

5                   And on the web, similar? It's similar on  
6 the web. Okay.

7                   Where do you or your loved one receive most  
8 of your sickle cell care? A, at a sickle cell  
9 treatment center with a hematologist; B, not at a  
10 sickle cell treatment center but with a hematologist;  
11 C, a primary care center, for example, a pediatrician  
12 or family medicine; D, only in emergency rooms and  
13 hospitals as needed; or, E, you're not sure. And  
14 we're asking you to choose just one in this case.

15                   (Answering question.)

16                   DR. EGGERS: Okay. At a sickle cell  
17 treatment center. So it looks like we have a mix of  
18 everything. Most people are treated by a hematologist  
19 in the room.

20                   Similar? And it's similar on the web.

21                   Okay. I think, is there -- yes. I think  
22 this is the final one.

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1           In the past year, how often have you or your  
2 loved one had to go to the hospital or the emergency  
3 room because of sickle cell disease? A, no times in  
4 the past year; B, one to two times; C, 3 to 5 times;  
5 D, 5 to 10 times; or, E, more than 10 times. And this  
6 is just approximate numbers.

7           (Answering question.)

8           DR. EGGERS: Okay. So we've had it looks  
9 like again a mix of experiences with those who are  
10 fortunate enough to not have to go to the hospital  
11 very often, but we are also represented by those of  
12 you who do go to the hospital quite often.

13           I forgot to ask at this point, but can I ask  
14 the panel members to come up, the first -- the  
15 pediatric panel members? So that would be Nancy,  
16 Dawn, Andrea, and Alana, if you're here. Okay.

17           Are there any more polling questions? Okay.

18           MR. VALENTINE: Well, just to note a  
19 difference on the web.

20           DR. EGGERS: Yes.

21           MR. VALENTINE: You do see a similar spread,  
22 but then for more than 10 times, a quarter of the web

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1 participants.

2 DR. EGGERS: Okay. I don't know if you all  
3 heard that, but a quarter of the participants on the  
4 web have been to the hospital more than 10 times. So  
5 those of you on the web who are in that position, your  
6 input is extremely valuable.

7 Pediatric (Infant and Young Children) Perspective on  
8 Topic 1: The Effects of Sickle Cell Disease  
9 That Matter Most to Patients

10 DR. EGGERS: Okay. So we are ready to begin  
11 our first topic. I'm going to have each of them  
12 introduce themselves as we go along. And they have  
13 come up. We have three caretakers and one person  
14 living with sickle cell disease, and they are going to  
15 be speaking on the pediatric perspective of the  
16 effects of sickle cell disease that matter most to  
17 you.

18 If I can have the next slide.

19 Nancy, Andrea, Dawn, and Alana. I don't  
20 know if you're in that right order, but that's okay.

21 And if we can go to the next slide.

22 What we've asked them to do is to talk about

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1 -- to give us again that brief summary of the ways  
2 that sickle cell disease affects their health, the one  
3 to three things that matter most to them, how sickle  
4 cell disease affects life on an average day and how it  
5 affects life on the worst days and what worries you  
6 most about how sickle cell disease could affect your  
7 health in the future.

8           So with that, I am going to -- let's start  
9 with Nancy. Oh, push your little red button.

10           MS. RENE: Good morning.

11           DR. EGGERS: Good morning, Nancy.

12           MS. RENE: First of all, I would certainly  
13 like to thank the FDA for selecting sickle cell  
14 disease as the topic of this patient-focused  
15 initiative. I know a lot of us are very excited by  
16 this event.

17           I'm the grandmother of a 10-year-old boy,  
18 Joseph, who lives with sickle cell disease. I'm also  
19 the Chair of the Board of Directors of the Sickle Cell  
20 Disease Foundation of California.

21           The greatest impact of sickle cell disease.  
22 In December of 2003, Joseph was 9 months old. He had

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1 just celebrated his first Christmas and was reaching  
2 those milestones every parent looks for. He was  
3 interacting with his family and pulling himself up to  
4 hang onto the furniture. All of that good progress  
5 stopped. He started crying and refused to eat or  
6 drink. His mom and dad realized that he was having  
7 his first sickle cell crisis.

8           His parents rushed him to the hospital, and  
9 although he was under a doctor's care, Joseph had a  
10 stroke when he was 9 months old. It left him  
11 partially paralyzed on his right side. He now walks  
12 with a severe limp and has difficulty grasping things  
13 with his right hand. He is on regular blood  
14 transfusions and had his spleen removed last year. He  
15 learns well, but his speech has been affected by the  
16 stroke, and he's hard to understand.

17           On an average day, Joseph has a hard time  
18 keeping up with his peers physically. He cannot run,  
19 climb, or play ball like the other kids do. Many  
20 times Joseph gets tired during family activities like  
21 going to the beach, walking, or hiking. Sometimes he  
22 can't even keep up with Grammy.

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1           On the worst days, Joseph had several very  
2 bad pain episodes. A child who is generally happy and  
3 curious began to slow down and ache with pain. He  
4 would become so weak that he couldn't manage the  
5 stairs in his house, couldn't climb into bed.

6 Although he was taking morphine, he was so weak and in  
7 so much pain that he simply couldn't move. As his  
8 blood counts dropped, it was decided to remove his  
9 spleen. For many of you, I know this is a familiar  
10 story.

11           I know Joseph would like to take part in  
12 team sports. It's hard to watch from the sidelines or  
13 be ignored by the other children. Whenever I pick up  
14 Joseph from school, the other kids are running around  
15 the track and Joseph is limping after them or sitting  
16 on a bench.

17           Currently, he is getting great treatment  
18 from his hematologist and nurse at Kaiser, who see him  
19 every 6 weeks for exchange transfusions. Their  
20 experience has made a real difference in his life.  
21 The family trusts them and knows that we're working  
22 together with the medical team. Not every family can

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1 get this kind of expert care.

2           In infants, newborn screening has really  
3 made a big difference, and it's good that his parents  
4 knew the Joseph had sickle cell disease because they  
5 were able then to understand what that first crisis  
6 was all about.

7           Luckily, Joseph only has to go for his  
8 transfusions once every 6 weeks, so he doesn't miss a  
9 lot of school, and, of course, he missed when he had  
10 his spleen out, but school issues are a problem for  
11 other children when they have to miss more often and  
12 always get caught up in the makeup assignments.

13           But I want to say that since this is the  
14 FDA, thinking about these problems has given me new  
15 insights. If there were a drug that stopped a pain  
16 crisis in its tracks, children wouldn't miss so much  
17 time from school, young adults could spend more time  
18 in college and beginning those first jobs. A drug  
19 that could stop or reverse the damage a stroke can  
20 cause would really help children like Joseph. A safer  
21 drug for pain control would be key to effective  
22 treatment and keep many out of the ER. And, of

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1 course, a drug that prevented red blood cells from  
2 sickling and causing organ damage would be seen as a  
3 cure.

4           According to data gathered by the CDC in  
5 California, 50 percent of people with sickle cell  
6 disease die before they are 50 years old. I don't  
7 want that to happen to Joseph. I hope that the  
8 interest by the FDA and the development of new and  
9 effective medications will help improve the lives of  
10 those with sickle cell disease.

11           Thank you.

12           (Applause.)

13           DR. EGGERS: Thank you, Nancy.

14           And we have Andrea next. Oh, push your red  
15 button. Yep.

16           MS. WILLIAMS: Good morning. I'm Andrea  
17 Williams, and I'm the Founder and Executive Director  
18 of Children's Sickle Cell Foundation, but for today's  
19 conversation, I'm Jonathan's mom. Thank you for the  
20 opportunity to share some insights from the parent  
21 perspective on the effects of sickle cell disease that  
22 matter most.

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1           As the mother of a 13-year-old boy, I'm  
2   faced with the realities of this debilitating, often  
3   fatal disease. Jonathan is living well with sickle  
4   cell while we hope and wait for a cure. It is my hope  
5   that as I share today and we share in this event, that  
6   we learn from what we do here in the coming report to  
7   be enriched and empowered by the voices of patients  
8   and families.

9           My son had acute chest syndrome eight times  
10   from the time he was 2 years old until we started him  
11   on hydroxyurea at 6. Since starting hydroxyurea, he  
12   has only had one episode of acute chest syndrome, as  
13   recently as this past December.

14           He has experienced sickle cell pain crisis  
15   more when he was younger, from 10 months to 6 years.  
16   These unpredictable, severe painful episodes have  
17   interrupted his education. Missing days of school at  
18   a time, he missed critical building blocks that caused  
19   him to have difficulties of reading early on. We were  
20   able to provide him with a professional tutor who  
21   worked with him, and he began reading proficiently in  
22   the fourth grade.

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1           Jonathan still has trouble concentrating at  
2 school and has a 504 support plan in place to assist  
3 him in succeeding academically. Other aspects of the  
4 504 plan include having him seated near the teacher so  
5 he may be redirected easily if he gets distracted or  
6 off task. He has an elevator pass and door-to-door  
7 transportation to assist him with getting to and from  
8 school and to and from class.

9           We are proactively addressing the areas  
10 where sickle cell disease affects his daily life by  
11 managing the areas where he has the most difficulty  
12 and by preventing sickle cell pain crisis by avoiding  
13 the triggers that usually cause the pain.

14           His participation in outdoor activities is  
15 limited when it is cold. He finds this frustrating  
16 when the weather is borderline and he is told to stay  
17 indoors. This can be difficult for any teenager, but  
18 it's more so for Jonathan because his passion is  
19 basketball. He tells me that he wants to be the first  
20 NBA point guard with sickle cell disease. I tell him  
21 I want him to be the one that used to have sickle cell  
22 disease.

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1 (Laughter.)

2 MS. WILLIAMS: He loves to play basketball  
3 in the backyard daily, and when the weather changes in  
4 Pittsburgh, we have to place time restrictions and  
5 sometimes complete restrictions on him for this. At  
6 times, he perceives this difference as a weakness  
7 because he can't do what he loves for as long as he  
8 would like, so we work on this perception, treating it  
9 as an adjustment that must be made so he can do what  
10 he loves and stay healthy doing it.

11 He is very in tune with his body and his  
12 limitations. He even knows the difference between  
13 sickle cell pain and other pain, so from muscle  
14 soreness from working out or injury. During pain  
15 crisis, whether at home or hospitalized, Jonathan  
16 describes this as an annoyance that once again has  
17 interrupted his life. Sickle cell has interrupted it  
18 with pain, fever, or an infection. The pain can be  
19 anywhere in his body, but usually in his back or his  
20 limbs. The severity ranges from mild dull aches to  
21 sharp and excruciating pain, but until it's well  
22 managed, it can be difficult to perform the tasks of

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1 daily living.

2           What worries me most about how sickle cell  
3 disease could affect Jonathan's health in the future  
4 is that a cure won't come in time and that the more  
5 severe complications of having sickle cell disease  
6 will begin to affect him or that he may start to  
7 experience the side effects of hydroxyurea.

8           Of the many different complications that can  
9 happen during adulthood, I tend to worry about  
10 pulmonary hypertension the most because he has had so  
11 many episodes of acute chest syndrome. They are all  
12 very scary. When I looked at the list that she put up  
13 this morning, I cringed in my chair like, yeah, I  
14 would want to forget about those, but you can't  
15 forget, and that's why we're doing all we can to  
16 preserve his health now while he's still very young  
17 and very healthy.

18           This disease is not only physically  
19 devastating but emotionally draining for the child and  
20 the family. The unpredictable nature of sickle cell  
21 disease weighs heavily as we make plans for vacations,  
22 holidays, and more. We address every situation on a

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1 case-by-case basis and live our lives knowing that  
2 we're doing the best that we can by getting him the  
3 best care, taking his medications, and teaching him to  
4 understand his body and limitations. A few months  
5 ago, Jonathan said to me, "Mom, I sometimes forget  
6 that I have sickle cell until you remind me to take my  
7 medicine." In that moment, I smiled because I knew  
8 that we were on the right track. However, I couldn't  
9 share with him that I never forget. I don't forget  
10 the pain of watching him writhe in pain, of watching  
11 him in his early hospitalizations for acute chest  
12 syndrome or others, the idea that sickle cell disease  
13 is affecting our lives even when we can't see it.

14 I remain hopeful that there will be better  
15 treatments -- (begins crying) -- more effective drugs,  
16 and a cure. When Jonathan was born, I was told that a  
17 cure could come in his lifetime, maybe even in the  
18 next 20 years, and we're 13 years in, and I'm looking  
19 forward to getting on to that, looking forward to  
20 contributing in any way we can to find a cure for this  
21 dreadful disease. Thank you.

22 (Applause.)

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1 DR. EGGERS: Thank you, Andrea.

2 (Applause.)

3 DR. EGGERS: These are hard stories to  
4 share, and we appreciate it.

5 Dawn?

6 MS. NELSON: That's hard to follow. Let her  
7 go first. (Begins crying.)

8 DR. EGGERS: Yes. Alana, can you go first?

9 MS. McCLINTON: Okay, I'll try to follow  
10 that. I'm Alana, and I'm 23, and I am living with  
11 sickle cell. First I would like to thank everyone for  
12 coming. (Begins crying.)

13 DR. EGGERS: You know what? I'm going to  
14 suggest something -- while we let the panelists --  
15 this is very emotional. We have a polling question,  
16 and I am going to ask to put up that polling question.

17 MS. McCLINTON: I wasn't expecting that.

18 DR. EGGERS: Because what we want to know in  
19 the panel, we've heard a lot about a lot of these  
20 symptoms, let's put this up and have you start to  
21 think about it. If you want to start to answer it,  
22 you don't have to answer it now, it's going to be up

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1 here, you can put your choices in. What we want to  
2 know about is for those pediatric and young adults,  
3 other than acute pain crisis, because we imagine that  
4 would be one of your top most significant health  
5 effects, so putting that aside for the minute, what  
6 health effects of sickle cell disease currently have  
7 the greatest impact on your child's life, or if you're  
8 the adolescent answering, on your own, on your life?  
9 Please choose up to three effects. And while you  
10 think about that, I'm going to let Dawn start her  
11 comments.

12 MS. NELSON: One good thing about being here  
13 is that I'm a mother of a sickler, she's 16, but I  
14 realize being here that I'm not a crazy person, that  
15 there are a room full of people that feel exactly the  
16 way that I do, and so it's actually comforting to be  
17 here to know that I'm not alone in the way that I  
18 feel.

19 As we're sitting here, my daughter -- we  
20 live in Michigan, and she goes to a boarding school,  
21 she's in 10th grade, and she's actually having a pain  
22 crisis and my husband is taking her to the hospital as

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1 we speak, and so this is very important for me to be  
2 here, and while I feel like I should go back home, I  
3 think this is -- she would want me to be here. All  
4 that I'm going to say are her answers, and I told her  
5 I would represent her well, so --

6 (Applause.)

7 MS. NELSON: She wanted to come, but she has  
8 already missed a week and a half of school since  
9 Christmas, and I told her that I can't explain her  
10 leaving school for anything other than health reasons,  
11 even to come to a meeting on sickle cell.

12 So when asked the question, "Of all the  
13 sickle cell diseases that affect your health, which  
14 one to three effects have the greatest impact?" I  
15 could give my answer, but I'm going to give you Maya's  
16 (ph) answers. She said nausea. Maya takes 1,500  
17 milligrams of hydroxyurea every day, which is a  
18 lifesaving thing for us. She was hospitalized over 60  
19 times, she has been in her life, and since she's been  
20 taking hydroxyurea since 2005, we have gone from being  
21 in the hospital seven or eight times a year to about  
22 one or two times a year.

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1           So she would say that nausea is her biggest  
2 debilitating symptom as well as chronic leg and arm  
3 pain, and she has chronic fatigue, which is often  
4 confused with laziness, but I'm happy to hear today  
5 that that's one of the symptoms that's up there, so I  
6 can stop getting mad at her.

7           (Laughter.)

8           MS. NELSON: When asked, "What are the  
9 activities that she can't do?" she answers this, she  
10 does not participate in physical activities like other  
11 kids her age. She experiences instant fatigue that  
12 may lead to a pain crisis. Other activities that are  
13 limited are swimming unless the water is 84 degrees.  
14 I've had swimming pools change the temperature to 84  
15 degrees just so she could learn to swim. Any kind of  
16 manual labor, raking leaves.

17           Because of the intermittent nature of sickle  
18 cell, her concentration during prolonged school work  
19 can be a problem. I'm actually going to do a research  
20 project soon on hearing loss and fatigue in sickle  
21 cell patients. Frequent breaks are often necessary.  
22 Playing in the snow is definitely out of the question,

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1 and we live in Michigan. I really could go on, but  
2 I'm sure many of you could to.

3 I'll go to the next question. When I asked  
4 her, "How does sickle cell affect your life on the  
5 worst days, such as days when you have a pain crisis  
6 or are hospitalized?" guess what her answer was. It  
7 surprised me, and I checked up on her just last week  
8 to make sure this is still her answer. Maya feels  
9 that the anticipation of going to the hospital, the  
10 anticipation of the pain crisis, and the enormous  
11 amount of back work that she will have when she gets  
12 back to school. She missed, as I told you, a week and  
13 a half of school in January, and she just started to  
14 cry, it was so overwhelming, and I had her write down  
15 all of her work so that her algebra teacher could see  
16 it. She had missed about 5 tests, 10 quizzes, and I  
17 said to the school, we have a 504 plan, you know,  
18 "This is the law, you have to help me with this," but  
19 for her, she says, "I'm going to the hospital this  
20 weekend, Mom, and I'm going to take my work with me."  
21 I said, "No, you're not. You need to get better."  
22 They just need to deal with it, it's not a choice that

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1 they have. But I said, "Are you sure it's not worse  
2 than the pain?" She said, "No, they have medication  
3 for the pain." That back work is what really gets  
4 her, and, of course, the social issues that we could  
5 all speak about.

6           Maya feels that when a pain crisis is  
7 brewing, she's very edgy, she's very nervous, she's  
8 very tearful, and it's been brewing for a while.  
9 There are also social consequences with the  
10 hospitalization. She is in boarding school, as I say.  
11 When she returns to school, her friends have moved on  
12 with life. Who you went to the cafeteria with last  
13 week, they've found another friend to go with this  
14 week. She's constantly trying to stay up with those  
15 friendships and stay in the loop.

16           Are there activities that she can't do? Her  
17 answer was this: she reported that she would like to  
18 be able to ski, to snowboard, hike, swim in a lake.  
19 She does not like to be an indoors person, she would  
20 like to be an outdoors person, however, they would  
21 evoke a pain crisis.

22           When Maya was a little girl, 4 years old,

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1 she fell at a skating rink, a roller skating rink, and  
2 her arm turned black and blue, and all the other  
3 mothers said, "Why are you catering to her? Everybody  
4 falls at a skating rink," but I knew that  
5 bloodcurdling cry was a little bit different, and that  
6 turned into a 2-week hospitalization for Maya because  
7 a mother reported to me when she played with her kids  
8 at home, "Is something wrong with Maya's arm? Because  
9 she won't catch the ball, she won't use that arm."  
10 She had fallen at the skating rink. When she was in  
11 gymnastics as a child, she did a forward roll like all  
12 the other children during the second class, I had  
13 already paid for it, and her back started to hurt the  
14 next week. To this day, she will not skate or do  
15 other strenuous physical activity. So I would say  
16 that avoidance is her method of pain reduction.

17           In the future, when asked what worries her  
18 most about sickle cell disease, she says that she  
19 worries most about having a healthy baby, getting  
20 cancer, or dying early. That's very painful to hear  
21 your 16-year-old say that. So I just confirmed that  
22 with her, and her answer hadn't changed.

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1           What specific concerns did I have about her?  
2   When she was a baby, some of them you have already  
3   stressed, not knowing when she was in pain or  
4   distressed, you would have to wait until she started  
5   to limp or something like that. I was also very  
6   afraid of fevers even though she took penicillin.

7           I'm a college professor, so anytime I know  
8   that she is going to get sick, I know that my entire  
9   schedule for the next 2 to 3 weeks is going to be  
10  messed up and I can't answer e-mails and that kind of  
11  thing. And so I would really like to talk to some  
12  other mommies around here.

13           (Laughter.)

14           MS. NELSON: I don't know how everyone else  
15  does it.

16           As an adolescent, what are we worried about?  
17  Maintaining social relationships is really a big one,  
18  as I said before. Getting the transition between  
19  reminding her to take her medication to now her  
20  transitioning to reminding herself to take her  
21  medication and training her to listen to her body and  
22  to know when back work is not as important as taking

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1 care of that, taking a day off of school.

2 I now begin to worry about depression. She  
3 had a breakdown on Sunday. I had never seen her as  
4 dismayed in my life. Her eyes were glazed over with  
5 pain. Worrying about her future. Transitioning from  
6 a pediatric wing to an adult wing, so I'm going to be  
7 very anxious to hear from the adult patients here.  
8 It's a fear of mine, but I guess I have to face my  
9 fear, which is why I took a plane to come here.

10 In older adulthood, she worries about organ  
11 failure, premature death, people believing that her  
12 pain isn't real and providing adequate pain  
13 management. When we've been hospitalized outside of  
14 Michigan, getting people to give her enough of a drug  
15 has been a big problem, and I'm like, "Don't just give  
16 her enough medication, I need you to kill that pain,"  
17 you know, but when I'm in Michigan with my doctors,  
18 they believe. I could call them from here and say,  
19 "Hey, Maya is going to show up today at 3:00, and they  
20 believe me."

21 So those are some of the issues that we  
22 face, and I look forward to hearing from everyone

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1 else.

2 DR. EGGERS: Thank you very much.

3 (Applause.)

4 DR. EGGERS: We'll be getting into the  
5 topics on treatments in the afternoon, so let's  
6 everyone remember what's been said.

7 And, finally, we have Alana.

8 MS. McCLINTON: I will try to keep it  
9 unemotional.

10 DR. EGGERS: You're okay.

11 MS. McCLINTON: Listening to your story --  
12 (begins crying).

13 MS. NELSON: You're okay, honey. You're  
14 okay. Just tell it. Yours is the most important  
15 story.

16 MS. McCLINTON: I so wasn't expecting to be  
17 this emotional.

18 MS. NELSON: It's okay.

19 DR. EGGERS: Let's give her a round of  
20 applause.

21 (Applause.)

22 MS. McCLINTON: This is why I don't wear

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1     makeup, Ma.

2                     (Laughter.)

3                     MS. McCLINTON:   Hearing your daughter's  
4     story, I feel like it's mine.   (Crying.)   At 23, I'm  
5     still going through the same things.   My average day  
6     consists of now of a Level 7 of pain at least.   There  
7     is this constant pain I can't get rid of.   Tuesday  
8     night, after speaking to Sara on the phone, I went  
9     into a pain crisis, having to take 15 milligrams of  
10    morphine just so that I could sleep for at least 2  
11    hours.   I haven't slept through the night since I was  
12    in elementary school, and I'm 23 right now.

13                    It's difficult to have to live with this  
14    pain everyday.   And your average day is your worst day  
15    sometimes, most of the time.

16                    I wish that I could -- thank you.   I'm okay,  
17    thank you -- it's just this is the first time I don't  
18    feel alone.   Seeing everyone and hearing everyone's  
19    stories, I wasn't expecting to be this way.   I had  
20    this big speech planned, and it so did not turn out  
21    the way I thought.

22                    (Laughter.)

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1 DR. EGGERS: Alana, could I say one thing  
2 that you told me in your thing? So I think -- correct  
3 me -- you have completed your bachelor's degree.

4 MS. McCLINTON: Mm-hmm.

5 UNIDENTIFIED FEMALE SPEAKER: Amen.

6 (Applause.)

7 DR. EGGERS: And you have completed your  
8 master's degree.

9 UNIDENTIFIED FEMALE SPEAKER: That's  
10 wonderful.

11 DR. EGGERS: And in education of some sort?

12 MS. McCLINTON: Adolescent education.

13 DR. EGGERS: Adolescent education.

14 MS. McCLINTON: Before my 23rd birthday.

15 UNIDENTIFIED FEMALE SPEAKER: Wonderful.

16 DR. EGGERS: And what Alana told me what she  
17 wants to hear, she can't wait to hear the adults speak  
18 today. What she told me is that she doesn't know how  
19 people -- she is scared coming out of school. She has  
20 finished school, she has her degrees, how is she ever  
21 going to be able to actually live up to those degrees  
22 and have a job and be able to function in her day? So

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1 I'm going to say that one of your summary for you  
2 because --

3 MS. McCLINTON: Thank you.

4 DR. EGGERS: -- I think that's a very  
5 important part and I personally want to commend you  
6 for finishing school.

7 UNIDENTIFIED FEMALE SPEAKER: Amen.

8 MS. McCLINTON: Thank you.

9 (Applause.)

10 DR. EGGERS: Is there anything else, Alana,  
11 that you want to say, or would you like us to go to  
12 the discussion?

13 MS. McCLINTON: I just want to say thank you  
14 for coming. You guys look so beautiful. (Crying.)

15 DR. EGGERS: Let's give Alana a thank-you.

16 (Applause.)

17 DR. EGGERS: And I'm going to ask you guys  
18 to stay up here. You're still part of the discussion.

19 Is that a microphone over there? Is there a  
20 -- do we have a floating mike for -- okay.

21 MS. McCLINTON: Oh, there is a microphone in  
22 front of me.

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1 DR. EGGERS: Okay. So now we're going to  
2 have the facilitated discussion. I'm going to come  
3 around to the front if I can find that there is a  
4 microphone for me. We're not a professional talk show  
5 up here, so bear with us as we go through.

6 I'm going to let my colleagues ask some  
7 questions as you need, and you feel free to join. I  
8 have to actually stand this way. Sorry. I need to be  
9 able to see this alarm clock over here, it's the only  
10 thing that keeps me on any kind of track. Okay.

11 Can I have a raise of hands of who is a  
12 caretaker or a young person in the audience today?  
13 Raise your hands. Be proud. Okay.

14 (Show of hands.)

15 DR. EGGERS: All right. Great. We're going  
16 to be focusing on you for this morning's discussion.  
17 And I really, I truly want to thank all the panelists.  
18 It does, it takes a lot of courage to be up here, and  
19 so a very sincere thank-you.

20 What we wanted to do is now listen more, let  
21 you build on Alana and Dawn and Andrea and Nancy's  
22 stories. And we wanted to put up a polling question

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1 that would help us get a sense of what you think are  
2 the most significant impacts, effects, of sickle cell  
3 disease on you or your loved one. So we put up this  
4 question, and we wanted to know, was chronic pain,  
5 that's A, if you haven't selected yet; B, multiple  
6 infections; C, stroke; D, acute chest syndrome; E,  
7 growth problems or a delay reaching puberty; F,  
8 priapism or painful erections; G, problems with the  
9 spleen; H, difficulty concentrating; or, I, something  
10 that's not listed here. There are a number of other  
11 symptoms. We couldn't capture them all. So if you  
12 could take a moment and pick up to three. And raise  
13 your hand if you need a clicker. And on the web, I  
14 hope that you're answering as well. Okay.

15 (Answering question.)

16 DR. EGGERS: Is everyone ready? Okay. Can  
17 we go to the results? Okay. Lots of "Others." Okay,  
18 we'll get to those.

19 So I know this is extremely hard to see, and  
20 my bifocals aren't doing me justice right now, but it  
21 looks like the number one thing, at 46 percent of you  
22 in here, is difficulty concentrating. We're going to

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1 delve into that a little bit. Chronic daily pain, I  
2 think we've heard a little bit about that. And then,  
3 D, acute chest syndrome.

4           Okay. So let's go into those topics a  
5 little bit more. Let's start with the difficulty  
6 concentrating. We heard that. I think, Dawn and  
7 Andrea, you talked about it. And, Nancy, you talked  
8 about it I think some. Does anyone else want to share  
9 some specific way how you would describe what effect  
10 difficulty concentrating has on your child or you in  
11 school or in some other reason? Raise your hand and  
12 then we'll come to you. Okay, over here. And if you  
13 could just state your name.

14           MS. BROWN-WATTS: Good morning, everyone.  
15 My name is Velvet, and I am from Oklahoma. I am a  
16 social worker, and I have a 9-year-old son who was  
17 diagnosed with sickle cell in 2004, and since his  
18 birth, Jeremiah has had a significant difficulty in  
19 retaining what he learns in school. He has IEP and he  
20 had significant problems with reading and language  
21 development. He's had three sets of tubes put in his  
22 ears, and even after having the tubes placed in and

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1 his hearing restored, he still struggles in speech.  
2 He's been in speech since he was 2 years of age, and  
3 he's in the third grade now.

4           And what I am hoping is that there can be  
5 some drugs that maybe deal with the difficulties in  
6 the cognitive abilities of the patients. I wake up  
7 every day wondering what's going to happen to him if  
8 he cannot maintain what he's learning in school. How  
9 will he be able to sustain a job or graduate from  
10 school or even when you look at college? He takes  
11 tutoring. We have him in everything that we can think  
12 of, but most of the days after school, the only thing  
13 he wants to do is take a nap.

14           We recently learned 2 years ago that  
15 Jeremiah's lung function was at 72 percent, so he had  
16 major problems with his lungs. When he was born, he  
17 had four pneumonias, two ileuses, and we kept kind of  
18 wondering what was going to happen. His lung function  
19 had never dropped. When we found out that his lung  
20 function had dropped, they took him out of gym, and  
21 the only thing he wanted to do was be normal. He  
22 says, "Mommy, I hate this disease." And he says, "I

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1 don't want to die." And I said, "I understand that  
2 and we're working to do everything we can to keep you  
3 healthy." He's on 5 liters of oxygen at night, and  
4 consistently we are working to maintain him getting  
5 educated.

6 And so there needs to be drugs to deal with  
7 the lung issues and concentration, and there needs to  
8 be a concentrated focus on education for individuals  
9 with sickle cell disease.

10 DR. EGGERS: Thank you.

11 (Applause.)

12 DR. EGGERS: Jeremiah's mom, I didn't get  
13 your first name?

14 MS. BROWN-WATTS: Velvet.

15 DR. EGGERS: Velvet. Thank you.

16 How many of you with the pediatric  
17 perspective or even as adults, that that was a problem  
18 for you, the concentration and difficulty with school?  
19 Do you want to raise your hands if you feel  
20 comfortable?

21 (Show of hands.)

22 DR. EGGERS: Okay, significant. Okay.

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1           Then I want to touch upon something else  
2 that you said, Velvet, which is you said -- let's go  
3 to fatigue. Fatigue wasn't on the chart, it should  
4 have been, it didn't make it up here, but you  
5 mentioned that when your son gets home from school,  
6 the only thing he wants to do is go to sleep. I think  
7 we heard some of that up at the front.

8           Can I just get a show of hands, about how  
9 many of you even when you were a young child, had that  
10 problem with some sort of fatigue?

11           (Show of hands.)

12           DR. EGGERS: Okay. Does someone want to  
13 describe the fatigue a little bit? Does it happen at  
14 a certain point of the day or did you notice some sort  
15 of triggers? Does someone want to share that? We'll  
16 go the -- let's see. Okay.

17           Yes. Go ahead. There is a microphone  
18 coming. When you were a child.

19           MS. STINSON: So for me it was literally my  
20 body felt like it was weighed down. Actually -- I'm  
21 sorry, I'll stand up. My name is Jocelyn.

22           DR. EGGERS: And what's your -- yes.

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1           MS. STINSON: I am 28 years old and I have  
2 sickle beta-S thalassemia -- sickle beta-plus  
3 thalassemia. It literally felt like I couldn't get  
4 up, like my -- it would just -- just my arms and limbs  
5 would just drop. I could not roll out of bed, it  
6 would just -- I couldn't move, it was that kind of  
7 fatigue, and I would sleep all day. My mom would try  
8 and wake me up, and she would wake me up to get food  
9 and water, and I would go right back to sleep, and I  
10 would sleep for hours straight. So it was really  
11 tough. I don't know if anyone else --

12           DR. EGGERS: And what was your name again?

13           MS. STINSON: Jocelyn.

14           DR. EGGERS: Jocelyn. Thank you, Jocelyn.  
15 And was this every day, Jocelyn?

16           MS. STINSON: No, it wasn't every day. I'm  
17 not really sure. It didn't have like a consistent  
18 pattern. It didn't happen around -- it was definitely  
19 when I considered myself 100 percent, meaning I hadn't  
20 been in the hospital for a couple of months or I  
21 hadn't had any pain crisis, but it was just considered  
22 those day-to-day issues that you have with sickle

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1 cell, I would classify it under that.

2 DR. EGGERS: Okay. Does anyone else feel  
3 what Jocelyn described, do they also experience it?  
4 Just with a show of hands, how many?

5 (Show of hands.)

6 DR. EGGERS: Okay. Yeah.  
7 Yes?

8 MS. HADNOTT: That percentage is so large,  
9 and I'm wondering if fatigue is there.

10 DR. EGGERS: Okay. Margaret raises a good  
11 question. And, Margaret, do you want to do co-  
12 facilitation with me? You can.

13 (Laughter.)

14 DR. EGGERS: How many people had put fatigue  
15 in their "Other" as the young people?

16 (Show of hands.)

17 DR. EGGERS: And we'll have the same type of  
18 question for the adults. Mm-hmm.

19 Anything that my colleagues want to ask  
20 about fatigue?

21 Jonca.

22 DR. BULL: I was just wondering if fatigue

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1 had any relationship as a warning sign for crisis, or  
2 was part of the outcome after a crisis? Did it have  
3 any relationship, any predictive value, in terms of  
4 your clinical course? I see a lot of heads nodding  
5 no.

6 DR. EGGERS: Yeah. Okay.

7 And I think, Alana, you had something to say  
8 about fatigue?

9 MS. McCLINTON: I was just going to touch on  
10 Velvet's concentration point. An experience I had all  
11 during college is the difference between being  
12 physically present in a class and mentally present.  
13 And, you know, in college you have a certain amount of  
14 absences you can have before they just fail you. But  
15 I was very up front about what I had, but a lot of  
16 times I had to just be physically present and not that  
17 mentally present where I'm actually there  
18 concentrating and focusing on, you know, whatever is  
19 at hand.

20 And then the fatigue point is a lot of  
21 times, you know, I did mention when I spoke of not  
22 being able to sleep at night. A lot of times when I'm

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1 in a crisis, especially an acute crisis and I'm in the  
2 hospital, I just want to sleep, it's that moment of  
3 peace you get when you're sleeping that you're not in  
4 pain. So I've never -- I mean, the people that I've  
5 spoken to with sickle cell, I've never heard of  
6 fatigue as a kind of a, I would say, coming attracting  
7 of a sickle cell crisis.

8 DR. EGGERS: So we're going to actually have  
9 to move on to -- oh.

10 DR. FARRELL: One question. I know this is  
11 the pediatric and young adult session, but when we get  
12 into the adult session, we have concerns that some of  
13 these what we call patient-reported outcomes may  
14 change over time, and so there may be the fatigue that  
15 you experience as a child or adolescent, and does it  
16 persist into adulthood? Because when we think about  
17 these measures of the effects on your life, we need to  
18 come up with good measures, and so if they're  
19 different from the pediatric and the adult  
20 perspective, we would like to hear about that.

21 DR. EGGERS: So I'll put a shout-out. We're  
22 going to have to move on from fatigue and

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1 concentration, but, please, it sounds like this is a  
2 very important and maybe not discussed, very much  
3 discussed, topic. So in the docket, when you submit  
4 your comment through our website, please address your  
5 issues with fatigue.

6           We have so much we want to cover, so I'm  
7 just trying to see where we should go. I think we'll  
8 save talking about chronic pain for the comments.  
9 Send us a comment through the docket. And things like  
10 strokes and acute chest syndrome, we heard the  
11 panelists, so if you have a story that's different  
12 from that.

13           I want to hear if there are any symptoms  
14 that are not on this list that maybe were in your  
15 "Other" category that you would say are in my top two,  
16 my top two symptoms, the effects that affects my child  
17 or the young person. Anyone want to comment on  
18 something?

19           Yes. We have --

20           MS. McNEIL: Hello. My name is Sameka. I  
21 have a 6-year-old girl, Jasmine, and one of the  
22 biggest things that I have, which is acute chest, but

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1 coming with acute chest is asthma. And Jasmine can  
2 get a cold that triggers acute chest that then goes  
3 into an asthma attack that just -- you know, so for  
4 me, understanding, as a parent, how the lungs are  
5 really affected, and she's had a total of four acute  
6 chest syndromes and has been hospitalized for each one  
7 of them, but since she has been on the asthma  
8 medication and has now been placed on the Singulair  
9 and we have a very aggressive treatment plan, if I  
10 hear a slight cough at all, I start the aggressive  
11 plan. It's because if I don't, the acute chest kind  
12 of rolls right into it. So the biggest thing is  
13 understanding the relationship between sickle cell and  
14 also having that asthma, which then goes into the  
15 acute chest.

16 DR. EGGERS: I see a lot of heads nodding.  
17 A lot of agreement with this statement?

18 Any other symptoms? Any other effects?

19 DR. FAULCON: Sara, perhaps we can hear from  
20 those that are on the webcast?

21 DR. EGGERS: Oh, yes. For -- mm-hmm. Can  
22 we have the webcast results of that polling?

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1           MR. VALENTINE: Okay. So moving through the  
2 list, very similar. We had about -- except much  
3 higher percentages, similar trends. We had about 83  
4 percent of the participants say that they had issues  
5 with chronic daily pain, about 25 percent with  
6 multiple infections, 12 percent with strokes, 29  
7 percent with acute chest syndrome, 12 percent with  
8 growth problems, 7 percent with priapism, 7 percent  
9 with problems with spleen. We did break out fatigue  
10 on the web, and we had about 80 percent confirm that  
11 they have fatigue, 44 percent with difficulty  
12 concentrating, and then about 32 percent with other  
13 effects not listed above.

14           DR. EGGERS: Okay. Thank you. That's very  
15 informative.

16           We're going to tee up the phones. We're  
17 going to go to the phone lines in a few minutes, and  
18 that will give a chance for a few web participants to  
19 call in. Now, if you're on the web and you want to go  
20 to the phone, there are going to be some instructions  
21 here. And what we're looking for is if you have a  
22 symptom that hasn't been mentioned that you want to

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1 talk about, this is our second time doing the phones,  
2 so if it doesn't go exactly smoothly, then my  
3 apologies in advance, but we're going to try. So that  
4 will be in a few minutes.

5           Are there any other symptoms that people  
6 want to talk about? Restrictive airway I hear. Okay,  
7 so that kind of goes with the breathing problems.

8           Okay, we have someone in the back? And  
9 while Andrea goes to the back, I'm going to come over  
10 here. Raise your hand in the back if you wanted to --  
11 okay.

12           MS. BAILEY: Hello. My name is Tara. And  
13 as a child in primary school, I had a lot of issues  
14 with stress causing sickle cell crises, so for me,  
15 during pretty much every year final exam, I missed  
16 every final exam for like 3 years in a row, just  
17 stressing about studying about it.

18           DR. EGGERS: I see a lot of heads nodding.  
19 Anyone had a similar experience? Do you want to show  
20 your hand?

21           (Show of hands.)

22           DR. EGGERS: Okay. It looks quite common.

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1           Okay. Sorry. Yeah. Let me go over here.

2   We have Francesca?

3           MS. VALENTINE: Hi. Good morning. My name  
4   is Francesca Valentine. I live on both side of the  
5   fence. I'm a registered nurse for 35 years. My son  
6   is 30. He'll be on the adult panel with sickle cell  
7   disease hemoglobin SS. Silent symptoms that can be  
8   ignored during school plagued us. I didn't know he  
9   had his first silent infarction because they switched  
10   school nurses and the new nurse hadn't looked at  
11   anything about sickle cell, so he was deemed being  
12   unruly when he was in the nurse's office with black  
13   spots in his visual field rearranging things on the  
14   desk, sent back to class. Then he was deemed as being  
15   not paying attention and lazy when he was tired and he  
16   could no longer spell in fourth grade what he learned  
17   to spell in second grade. And he couldn't tell the  
18   time on a watch face, a regular clock, and he could  
19   before. So in the midst of labels, they missed the  
20   symptoms.

21           DR. EGGERS: Thank you, Francesca.

22           Did someone want to say something up here?

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1 I thought I saw a hand.

2 Go ahead, Nancy.

3 MS. RENE: Yeah, as I work with the Sickle  
4 Cell Disease Foundation of California, I'm a former  
5 school principal, so I get a lot of these educational  
6 issues, and I tell you they are simply awful, just  
7 awful, from school people not believing that the child  
8 has sickle cell disease and not believing that the  
9 child is in pain, only believing the worst about a  
10 child, and even when we would go in to have the  
11 conferences with documentation, those beliefs did not  
12 change. And so that's the added stress on the child  
13 and on the parent. One of our parents was sent to the  
14 district attorney because they were accusing her of  
15 truancy for her child, and the child is in the  
16 hospital with a sickle cell crisis.

17 DR. EGGERS: Thank you, Nancy.

18 I heard a lot of murmurs, a lot of hands  
19 raising.

20 There is one comment back here, I think?

21 DR. PESANTE: Hi. My name is Maisha  
22 Pesante. Our "Other" is very different because my

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1 children have only AS, and we were told that it  
2 doesn't have any symptoms. I have three children with  
3 AS and two of them get very many of the same problems  
4 I'm hearing today.

5           My first child had got those symptoms when  
6 she would come home from school and go to sleep for  
7 hours, I thought she was just being unruly and lazy,  
8 me, as a parent, I thought that, because that was what  
9 I was taught, that sickle cell didn't cause a problem,  
10 sickle cell trait AS didn't cause problems. It took  
11 years, and until she had what was pretty much a sickle  
12 cell crisis at the age of 16 that I understood that  
13 you can have that happen with trait.

14           And it's been very, very painful when my  
15 son, who just turned 12 yesterday, had his first  
16 crisis at the age of 10 and was sick for an entire  
17 month, and we couldn't get anybody to believe us or  
18 even just give him fluids. And they gave him like a  
19 little bit of morphine, like 1 milligram, and he said,  
20 "Mommy, the morphine doesn't seem to help as much as  
21 the fluids," and I could get the morphine for him  
22 easier than I could get the fluids. It was an

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1 extremely painful experience.

2           He had 12 hours of priapism. They both have  
3 terrible fatigue. They get bone pain. They have  
4 trouble breathing. In school, when he was passing out  
5 from the crisis, they said he was faking it. EMS was  
6 called to the school. The EMS person told me that,  
7 "Oh, I don't think anything is really wrong with him,"  
8 but his blood pressure was like 70 over palp. And  
9 then when we got to the hospital, he couldn't walk,  
10 and the doctors and nurses there told him, "Oh, you  
11 can walk. There is nothing wrong with you."

12           So I am very sad listening to all of the  
13 stories. I'm thankful that they aren't as severe, but  
14 it's also scary because we can't get treatment because  
15 we're told that AS doesn't have any problems. He  
16 missed a lot of school that April. And by the way,  
17 he's a straight-A student, top of his class, skipped a  
18 grade. And my older daughter, who is here with me,  
19 she was doing great in school and then all of a sudden  
20 stopped doing well in school, and I missed it because  
21 I was told AS doesn't have symptoms.

22           So the fatigue and the priapism were the two

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1 symptoms that were scary to me because my son didn't  
2 even tell me, and then the pediatric hematologist  
3 said, "Well, this isn't sickle cell. I don't know  
4 what it is, but it isn't sickle cell."

5 DR. EGGERS: Thank you very much. Thank you  
6 for sharing your story.

7 (Applause.)

8 DR. EGGERS: We're going to have one more  
9 comment and then we're going to go -- oh, two more  
10 comments and then we're going to go to the web.

11 MS. HUGHES: Hi. My name is Tina Kay, and  
12 I'm from Birmingham, Alabama. One of the things in  
13 "Other," I have sickle cell disease, and I'm 40, but I  
14 mentor young ladies who are transitioning into  
15 college, and bullying is a serious issue. I've had  
16 one young lady who actually was put off of the  
17 basketball team by the coach, they wouldn't let her  
18 play volleyball, and the young ladies that played the  
19 sports with her were threatening to beat her up. So  
20 bullying is another issue, and that's why children  
21 with sickle cell disease want to hide it, because they  
22 don't want other people to know that they're

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1 different.

2           And another thing is loss of hearing. A lot  
3 of people don't talk about the loss of hearing. It's  
4 not just vision, but the small veins that go to our  
5 eyes also go to our ears as well.

6           DR. EGGERS: I think we'll hear about loss  
7 of vision in the next topic. Thank you for your  
8 point, Tina.

9           We're going to have to keep going if we want  
10 to make sure we get to the adults, to hear from the  
11 adults in the room.

12           Any quick follow-up questions from my  
13 colleagues?

14           DR. VERDUN: I was wondering if anyone here  
15 has experienced a stroke or silent infarcts as a child  
16 and want to speak about that experience.

17           DR. EGGERS: First before we do that, we've  
18 got someone in the back who has been waiting a long  
19 time to talk, so we'll let that person. Yeah.

20           DR. IVY: My name is Donnell. I wear  
21 multiple hats. I'm the Program Director for the  
22 Hemoglobinopathies Program at HRSA, I'm an MD, and I

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1 also have sickle cell disease. I was just going to  
2 say in the "Other," one thing you might want to talk  
3 about, because it does go to concentration and  
4 fatigue, is sleep disturbance. I know that even as an  
5 adult, I haven't had a crisis in years, but I still  
6 find it hard to sleep sometimes at night, so that  
7 could be a part of that "Other" that needs to be  
8 considered in terms of difficulty in concentration and  
9 fatigue.

10 DR. EGGERS: Thank you very much.

11 Okay, now, going back to Nicole's question  
12 about stroke. Okay, right here, go ahead.

13 MS. BAILEY: You asked about stroke as a  
14 child and silent infarcts, and I did experience that  
15 when I was younger. My first -- I was living in  
16 Indiana where I was the only patient with sickle cell  
17 disease in the entire city I lived in, so there wasn't  
18 a great deal of education, and also I did have a  
19 silent infarct. We've learned that the teachers, as  
20 you all have mentioned, are the best ones in a  
21 position to notice these changes, but for me it was  
22 just considered unruly, it was considered you're just

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1 not trying hard enough going from being a straight-A  
2 student to bringing home C's, and my mom didn't know,  
3 so no one understood, and I did have a stroke. I  
4 fell, I bumped my head, and they were saying that I  
5 was faking, and all of it was -- wasn't. And  
6 fortunately, I had a physician that was confident  
7 enough in herself and her ability to acknowledge that  
8 she didn't know anything about sickle cell and to  
9 contact those that did. So even before the study came  
10 out that blood transfusion helps with -- the chronic  
11 transfusion will stop a lot of that stroke, they put  
12 me on chronic transfusion to slow down some of those  
13 infarcts I was experiencing.

14 DR. EGGERS: Thank you, Lakiea.

15 So I think we get one more and then I really  
16 want to get to the folks on the phones. This is our  
17 last comment in person for the pediatric.

18 Go ahead.

19 MR. CUMMINGS: I'm speaking on behalf of my  
20 son, who is 25, when he was young had a series of  
21 silent infarcts culminating with a pretty major stroke  
22 when he was 9. One particular time it was

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1 precipitated after traveling on a plane, and he  
2 arrived and was having slurred speech and weakness on  
3 one side. We had a bad experience. We were going to  
4 an ED. We weren't believed that he was suffering from  
5 anything, and after 45 minutes when hydration had not  
6 started, we stormed out and went to another hospital  
7 where he had an exchange transfusion for 6 straight  
8 hours. He ultimately to this day still has difficulty  
9 with walking without assistance and takes a number of  
10 meds to control seizure activity. And he was  
11 eventually treated for the moyamoya condition with a  
12 type of surgery to correct the occluded carotid  
13 arteries with replacing I guess temporal veins so that  
14 they would reperfuse his brain from the top down.

15 DR. EGGERS: Thank you.

16 Are you John? What was your name?

17 MR. CUMMINGS: My name is Bill Cummings.

18 DR. EGGERS: Bill, Bill. Okay.

19 So as we go -- I'm so sorry we can't get to  
20 all of the pediatric. We will be able to touch upon  
21 the treatments for pediatric patients in the  
22 afternoon. But I hope this gives you motivation to

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1 write to us and submit a comment telling us your full  
2 story.

3           As the people -- we're going to have a web  
4 summary first of some of the comments, and I'm going  
5 to ask for the Panel 1, the pediatric panelists, to  
6 step down and for the adult panelists to come up.

7           Again, pediatric panelists, thank you so  
8 much.

9           (Applause.)

10           DR. EGGERS: And, James, can we have just a  
11 sampling of, or Pujita, a sampling of the symptoms  
12 mentioned?

13           MS. VAIDYA: Hello. So we've gotten a lot  
14 of comments on the web, and I'll just summarize and  
15 mention a few of them. Some participants have  
16 mentioned jaundice, fatigue related to menstrual  
17 cycle, so she has noted that it's gotten worse during  
18 her menstrual cycles, which we have not heard in the  
19 room. And some problems with eyesight and avascular  
20 necrosis.

21           DR. EGGERS: Thank you very much.

22           MR. VALENTINE: And I'll just note one other

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1 thing, that many comments have talked about the stress  
2 and depression resulting from pain and symptoms.

3 DR. EGGERS: Thank you. Okay.

4 We just have time for one or two phone  
5 comments. I'll just ask on the phone just in the  
6 interest of time just to keep your comments brief and  
7 focused on a symptom, a health effect, that you  
8 haven't heard mentioned today or one that very much  
9 bothers you.

10 Do we have the phone? Do we have our next  
11 caller?

12 MS. GAINES: Hello. Can you hear me?

13 DR. EGGERS: Yes.

14 MS. GAINES: Hi. My name is Marquita  
15 Gaines. I'm tuning in from Georgia right now. And  
16 I'm 21 years old, but I did want to just let the  
17 parents of the adolescents know that it is important  
18 to address the physical symptoms, and I actually  
19 talked to my doctor about how you can change the  
20 hospital environment, but because the turnover with ER  
21 doctors and students in training is so quick that the  
22 sensitivity and the care that you receive in the ER is

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1 I guess a little more cold and not as caring and  
2 comforting as it could be.

3           When I was younger, I did have the problem  
4 with being in advanced classes but missing so much  
5 school that, like Alana said, the seat time hours that  
6 you were required, you could have an A, but they would  
7 fail you because you weren't there. And I think it's  
8 important to talk to the children about how they're  
9 not alone and it's okay to feel confused because you  
10 know you're capable, but your body won't let you. And  
11 even now that I'm in college, I deal with that. And  
12 it's just important that we support each other and  
13 listen to the younger kids because as far as sports  
14 and socially, I would just want them to know that it  
15 does get better.

16           DR. EGGERS: Marquita, thank you. You might  
17 not be able to see this, but I see a few moms nodding  
18 their heads in agreement here on your excellent point.

19           MS. GAINES: Thank you.

20           DR. EGGERS: You're welcome.

21           One more phone comment? Pardon me? Oh,  
22 Operator, can we have the next caller?

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1           They have to train me for this.

2           (Laughter.)

3           OPERATOR: Sorry. It's Amorilla?

4           AMORILLA: Yes. Can you hear me?

5           DR. EGGERS: Yes, we can. Amorilla?

6           AMORILLA: Hi. How are you? I'm Amorilla,  
7 and I'm calling from West Hartford, Connecticut. My  
8 daughter has -- my daughter, Annemarie (ph), is 4  
9 years old and she lives with SS. As I've been waiting  
10 here listening to everything, so many people have  
11 brought up the points that I wanted to kind of just  
12 touch base on, which were asthma and its relation to  
13 acute chest syndrome, which my daughter has been  
14 diagnosed with asthma, as well as the sleeping  
15 patterns, which affect her as well, and because of  
16 them, she has had her -- because of her irregular  
17 sleeping patterns, she has had her adenoids and her  
18 tonsils removed, and it has helped, but it has not  
19 helped enough because it's still affecting her.

20           And also some people have brought up the  
21 loss of hearing, which I'm a little bit amazed to  
22 start hearing about. I didn't know that could happen

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1 at such a young age, and I feel like recently my  
2 daughter has kind of been complaining about not being  
3 able to hear.

4           But, you know, I think that it's totally  
5 amazing that this public meeting is taking place  
6 because so many of us have such diverse stories, and  
7 to kind of hear them all in one, I myself, listening  
8 to like the panelists and listening to everyone's  
9 personal stories, have been taken aback with so much  
10 emotion, and I'm sitting here crying because I'm just  
11 like, "Oh, my god, I'm not alone."

12           So I do look forward to hearing more about  
13 the relationship between asthma, breathing, sleeping  
14 patterns, and as well, my daughter has a lot of  
15 allergies, so that kind of makes it difficult as well.  
16 So I'm just looking forward to hear more about the  
17 relation of them all.

18           DR. EGGERS: Great. Thank you so much for  
19 your comment.

20           AMORILLA: Thank you for allowing us to be  
21 able to call in. This is amazing. And I wish that I  
22 could be there physically, but I'm glad that I was

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1 able to call in.

2 DR. EGGERS: Okay. We'll call this  
3 experiment a success.

4 (Laughter.)

5 AMORILLA: Absolutely. Thank you.

6 Adolescent and Young Adult Perspective on Topic 1

7 DR. EGGERS: Then with that, we're going to  
8 move into the next topic and focus on adults. I think  
9 there has been some overlap, so what we're going to do  
10 is focus on things, how your condition has changed  
11 since your adolescent and young years. We have four  
12 excellent panel members to share their stories. I  
13 think I'm going to step back at the podium. I'll  
14 relinquish my microphone.

15 I'm going to come back up here and let the  
16 panelists speak for themselves. Again, keep it to a  
17 couple minutes. We are going to be running short on  
18 time, so 2 to 3 minutes, and I will nudge you along if  
19 I have to. And I can't wait to get started.

20 Who wants to start first? Marcus or George?  
21 Let's have Marcus start. Let's let the young ones  
22 start. Just hit the button.

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1           MR. VALENTINE: Hello. Hi. My name is  
2 Marcus Valentine. I am 30 years old, and I have been  
3 living with sickle cell hemoglobin SS for all these  
4 years. This is my mom next to me. I'm from Illinois,  
5 and we came out here for the panel discussion on the  
6 topics that are concerning the sickle cell.

7           And for the first half of my life, I was  
8 just kind of wanted to be normal, and I heard the  
9 stories from the mothers of the pediatric people who  
10 were just up. They were similar, I was similar to  
11 that. And so if your children, which they sound like  
12 they have the strength I do, will get to where they  
13 should be, and that's doing something for the illness  
14 to further advance our survival and well-being.

15           But I am very happy to talk about the  
16 effects that sickle cell has on me and my daily life,  
17 which I have heart failure from it and the fatigue.  
18 And there is something that just developed with me,  
19 which is wounds, sort of like diabetic ulcer wounds,  
20 that I just developed on my ankles and --

21           UNIDENTIFIED FEMALE SPEAKER: Similar to  
22 that.

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1           MR. VALENTINE:  -- at first it was new  
2 because all the treatments that I get when I go into a  
3 crisis usually help, and I have a set plan, and it  
4 helps out, but the thing that I'm going through now,  
5 it's kind of like a different -- the treatments that  
6 usually work, are successful, are helping, but only to  
7 a certain point.  And so I was happy to hear that the  
8 FDA is having this conference about sickle cell and  
9 possibly developing new drugs so that we have  
10 something there, something extra, and something that's  
11 kind of our own that can help us get through life, our  
12 daily life, without these long pauses because when you  
13 get sick, it's like you have to just stop everything  
14 you're doing just to recover.  So I hope that some of  
15 what I say today can help further getting us to that  
16 next step.

17           My mom is going to talk for me because I'm  
18 not feeling too well today, so --

19           MS. VALENTINE:  I'm going to help him if  
20 that's okay.

21           DR. EGGERS:  That's fine.

22           MS. VALENTINE:  He developed wounds.  We had

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1 a flood, he got a scratch. It developed into a  
2 chronic non-healing ulcer, swelling, sickling to the  
3 surface of the skin and his tiny vascular,  
4 microvascular, system. So what you would do for, say,  
5 a diabetic or someone with other types of wounds,  
6 those don't all work for these sickle wounds. We  
7 learned early on you can't put him in compression,  
8 that's going to make it worse and cause more  
9 constriction, and the standard wound care, we have  
10 excellent wound care, but it's not enough. Everything  
11 has to go together, and there is no quick fix to this.  
12 The right one healed, it reopened. The left one  
13 developed cellulitis and had to be surgically  
14 debrided.

15           So wounds are a very debilitating  
16 complication on the lower limbs because you still need  
17 to walk to get where you have to go, and they're  
18 painful and require a lot of care. And I think he  
19 said to me right after he got out of the hospital, he  
20 says, "You know, I would almost rather have them take  
21 these feet and be done from above the wound and call  
22 it a day because," he said, "I'm so tired of this, of

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1 all my complications," which have included acute chest  
2 ventilation exchange, osteonecrosis, the list is very  
3 long, I won't even try to give it to you. But of all  
4 of this, he thinks the wounds hands down have really  
5 caused the biggest problem for him.

6 MR. VALENTINE: And then I started a film  
7 about sickle cell, and I just wanted to put that out  
8 to let people know that you're not alone and you  
9 should never be afraid to talk about this illness  
10 because that's how we advance and progress, we have to  
11 talk about it, because for such a long time I hid all  
12 of that. I didn't want to talk about it, I didn't  
13 want to deal with it, but the moment I started, it's  
14 what made me feel better and I was able to see the  
15 change in other sicklers. So, you know.

16 MS. VALENTINE: And one more thing, he --  
17 and I applaud him, his wound is on Facebook, and with  
18 the progression and what we're doing, and anything we  
19 find to help make it better, it will be on Facebook  
20 with a website for evidence-based proven from the  
21 physicians. Our physician is at Edward Hospital in  
22 Naperville, and our colleagues from the University of

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1 Illinois in Chicago, the collaboration is phenomenal.  
2 I'm a registered nurse, so I'm hoping through teaching  
3 future nurses, we need to bust a hole in the  
4 stereotype wall because while they're worrying about  
5 stereotypes and faking, we're dying.

6 (Applause.)

7 DR. EGGERS: Thank you. Thank you, Fran,  
8 and thank you, Marcus.

9 We've got a great young advocate on your  
10 hands here.

11 I think we're going to move on and have  
12 Helen. And Helen has -- oh, no, I'm sorry, we'll have  
13 Anthony.

14 Anthony, nice to meet you.

15 MR. BRAXTON: I do apologize.

16 DR. EGGERS: No, push your little red  
17 button.

18 MR. BRAXTON: I'm sorry. I apologize. I'm  
19 actually speaking on Topic 2, I kind of jumped the gun  
20 a little bit. So --

21 DR. EGGERS: You can come in the after --  
22 can you come back in the afternoon?

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1           MR. BRAXTON: Yeah, yeah. I'll be here all  
2 day, but --

3           DR. EGGERS: Okay.

4           MR. BRAXTON: So I'll pass it up for now and  
5 talk to you later.

6           DR. EGGERS: All right. Then we'll have  
7 Helen.

8           MS. SARPONG: Hello. I'm Helen. I'm 38  
9 years old. I have sickle cell SS, I'm sorry, sickle  
10 cell disease SS. I'm a mother to two twin girls, ages  
11 5. So I had this speech here that I've been working  
12 on, but after being here and hearing all the stories,  
13 I feel like there is so much that I can add and not go  
14 over time.

15                   So I'm just going to say that I've had my  
16 spleen removed, my gallbladder removed. I have  
17 avascular necrosis in both of my hips. And I am now  
18 starting to feel symptoms in my two shoulders. I've  
19 had problems with my eyes. I have a herniated disc.  
20 And I am also being followed for pulmonary  
21 hypertension.

22                   The symptoms that matter the most to me is

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1 the things that affect adults -- sickling cells, bone  
2 damage, obviously death -- but I'll tell you a little  
3 bit more about the road to becoming a mother. I never  
4 thought I would be a mother, it never crossed my mind.  
5 They told me that I would not live to be an adult, but  
6 at 32, I decided to give it a try. I stopped taking  
7 hydroxyurea. I had seven major crises. I also had  
8 sickling of the placenta -- sorry -- intense bone  
9 pain, and the swelling made it difficult for me to  
10 make it to my doctors appointments as well as  
11 birthing.

12           My doctors came to me and said that I needed  
13 to have a selective abortion. Obviously I was  
14 devastated because the idea that my body was  
15 malfunctioning and causing my babies to stress was too  
16 much for me to bear. My doctors decided that I should  
17 have an exchange transfusion, and I was able to carry  
18 my babies to 36 weeks and 4 days. The day that my  
19 daughters were born I felt that I had conquered sickle  
20 cell disease.

21           (Applause.)

22           MS. SARPONG: Five years later, I am still

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1 reminded how happy I was that day. Present day, as  
2 their mother, it's very difficult for me. I have  
3 intense bone pain, not crisis pain, intense bone pain,  
4 that is due to the complication of sickle cell  
5 disease. Most of my days are spent lying in bed  
6 unable to get out of bed. My husband has to get me  
7 out of bed while my daughters help me put on my shoes.  
8 I am often late taking them to school because I'm just  
9 having a lot of pain, again not crisis pain, but pain  
10 due to complications.

11           Herniated disc came at a time when my career  
12 as a pastry chef was advancing. I was able to go to  
13 my dream school and graduate with a lot of  
14 difficulties, but I made it. So, of course, when I  
15 was told that I could not be a chef anymore, I said to  
16 my doctor, "What do you want me to do now because I  
17 nearly died getting here?" and he told me to get a new  
18 career. I tried the new career and it did not work  
19 for me. I went from not having a crisis in 3 years to  
20 constantly having a crisis. I am unable to work  
21 because of complications, I cannot sit or stand for a  
22 short period of time without experiencing intense bone

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1 pain. It's hard because I'm a very outgoing person,  
2 I'm happy, but I suffer on a daily basis, again not  
3 because of crisis pain but because of complications.

4 I have a hard time concentrating. I should  
5 also say that I have a learning disability. I was  
6 diagnosed I think in junior high school, but I was  
7 diagnosed for sickle cell disease so that I could have  
8 accommodations, so that I could be able to take the  
9 cheese bus. So I never probably learned how to read  
10 until I taught myself at the age of 20. I always knew  
11 that I was smart, but I couldn't understand why I  
12 could not retain information or organize my thoughts  
13 or get my brain and my fingers and my eyes and my  
14 mouth to all kind of work together so that I could  
15 form a sentence.

16 When I decided I wanted to go to culinary  
17 school, I decided to seek help, and I got tested. I  
18 remember the psychologist who tested me said, "You  
19 know, your test scores does not reflect who you are  
20 because the numbers, they don't match. I have just  
21 met you, but I'm not understanding what's going on,  
22 and I don't know that much about sickle cell disease,

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1 but I think that years of you having these crises and  
2 these little tiny blood vessels, that is affecting  
3 every organ in your body including your brain,"  
4 because at the time I did not know the difference,  
5 "That could be the reason why you're having so much  
6 problem retaining information, paying attention in  
7 school, and just remembering conversations that you  
8 just had."

9           So that made a big difference for me, and  
10 that taught me that I had to, A, accept my learning  
11 disability, because it was a big deal for me, and,  
12 two, learn everything that I could about sickle cell  
13 disease and not hide. Once I did that, I learned how  
14 to study, I learned what my learning style was, and I  
15 learned to bring others into my life with sickle cell  
16 disease. In college, my father dropped me off and he  
17 gave me \$100 and he said, "This is all the money I'm  
18 going to give to you, and you have to support  
19 yourself."

20           Within minutes after my dad left me, I had  
21 the worst crisis that I can remember as an adult, it  
22 was an acute chest syndrome. Mind you, I had just

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1 been dropped off, so I didn't have time to make  
2 connections with roommates and friends, and here I was  
3 screaming on the floor begging for someone to help me.  
4 That was my first recurrence of acute chest as an  
5 adult. I really felt like I was going to die. I had  
6 never experienced anything like that before. So I had  
7 to, I guess, come out of my shell, not be scared, and  
8 invite people into my life with this disease, and once  
9 I did that, I got a lot of responses that I never  
10 thought I would get: the compassion, the willingness  
11 to learn, the support.

12           In college, I missed -- I think I X'ed out  
13 seven times, and that basically means that I would  
14 leave and stay away for 4 weeks because I missed 3  
15 days of school because the program was so vigorous and  
16 intense, there was no way how you could miss days, but  
17 I kept on coming back. And every time I was paying  
18 for that.

19           I managed to graduate culinary school, I got  
20 my degree, held a job for 3 long years, the longest  
21 time I've ever held a job, and then was diagnosed with  
22 AVN. So when I was diagnosed with AVN and didn't know

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1 what I was going to do with myself and couldn't get  
2 out of bed, could not work, I decided to start to have  
3 a family, and then I had my twins.

4           So as their mother, it's difficult. Like I  
5 said, they have to help me put on my shoes. You know,  
6 there are days when I hurt so bad they say to me,  
7 "Mommy, are you hurting today?" and I will say, "Yes."  
8 Okay, I'm so not going to cry. And I will say, "Yes."  
9 And they will say to me, "You know, I'm so sorry for  
10 you because you are the best mommy in the world, and  
11 tomorrow will be better." And tomorrow --

12           (Applause.)

13           MS. SARPONG: -- and tomorrow it does get  
14 better, but it gets better because I get out of bed,  
15 as painful as it is, I get out of bed. I have no  
16 choice, I have to function, I have to take care of  
17 them. On a daily basis, I cannot take pain meds  
18 because I need to be present and be able to raise my  
19 kids. My husband works to support us as well as  
20 support this endeavor that I have to tell my story and  
21 to help others. So I can't be on pain meds and not be  
22 able to function. So I've had to find other ways to

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1 deal with the pain.

2 DR. EGGERS: Helen, we'll be talking about  
3 the treatments in the afternoon, so can I -- so make  
4 sure you hold those thoughts and share them then.

5 MS. SARPONG: Sure.

6 DR. EGGERS: Do you have any other final  
7 thoughts you want to say?

8 MS. SARPONG: Okay, so I talked about bone  
9 pain, avascular necrosis and how it affects me.  
10 Right? Okay.

11 DR. EGGERS: Mm-hmm.

12 MS. SARPONG: Pulmonary hypertension,  
13 sickling in the placenta. I have talked about  
14 problems with my eyes and my learning disability, that  
15 I really believe that it's because of years of  
16 sickling. Having a learning disability is so  
17 frustrating. You know, not being able to concentrate,  
18 not being able to organize my thoughts the way that I  
19 want to is really challenging for me. And just  
20 knowing that I have so much that I want to do with my  
21 life, and sickle cell really is not my story, you  
22 know, it's just this road, this obstacle, that's

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1 getting -- it's keeping me from my story, my real  
2 path.

3           You know, I met these two women today,  
4 Margaret and Olga. They are like my dream because  
5 they are living their lives, and I want to live that  
6 long. I want to be able to do the things that they've  
7 done and just -- they talked to me for like 10  
8 minutes, and I have more hope than I did yesterday.

9           DR. EGGERS: And, Helen, we will be talking  
10 to -- we'll be learning from Olga in the afternoon.  
11 I'm going to wrap it up then and move on to the next  
12 person, on to -- is that okay?

13           MS. SARPONG: Yes. Thank you very much.

14           (Applause.)

15           DR. EGGERS: And we'll have Terri, please.

16           MS. BOOKER: Hello. I'm going to try to  
17 stay on task with my little thing that I wrote here.  
18 I'm 30 years old and I'm living with sickle cell SC.  
19 I am what one would call a healthy sickle cell  
20 patient. I would say I'm healthy because I don't take  
21 daily meds and I'm not in crisis often. Most people  
22 who know anything about the disease are usually

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1 surprised when I say I have it.

2           The effects of sickle cell disease that have  
3 the greatest impact on my life is the pain crisis,  
4 tiredness, and depression. I live with constant pain  
5 sometimes, and my tolerance for pain is significant.  
6 The meds given for pain have real side effects, and it  
7 includes possible dependency, hallucinations, and the  
8 dreadful detox, the sweats, the chills, the tossing  
9 and turning while trying not to take the meds in order  
10 to avoid dependency all while still being in pain.

11 Once coming off the meds, I thought that a gang  
12 attacked and killed my mother, but later I found out  
13 she was alive.

14           I'm always tired, and it's like someone said  
15 earlier, it's this heaviness that comes over your  
16 body, and it's like you just need to lay there, you  
17 just don't want to move. And there are things I would  
18 like to do, but I just can't because I'm just too  
19 tired. I have to make myself get up and get ready for  
20 the day. Sometimes it just feels better to lay down  
21 in the bed and not do anything. Once I get moving, I  
22 like to keep moving, so there is no time for me to

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1 think about me being tired. And unlike my colleagues,  
2 I'm an attorney, and so I'm like most of them, they  
3 can just keep working, working. I can't work  
4 constantly and forget to drink and just go, go, go. I  
5 always think about my health so I don't have a crisis.  
6 I stay hydrated.

7           Depression sets in after I've been sick and  
8 I'm not able to live normally. When I get sick, even  
9 a minor crisis, it just reminds me of the extra  
10 precautions I have to live by. Being a healthy sickle  
11 cell patient, quote/unquote, my life, my daily life is  
12 normal, quote/unquote, however, there are periods of  
13 time when I live with pain every single day. I'm  
14 constantly aware of the changes in temperature in the  
15 weather no matter what the season because it's always  
16 too cold. Summertime, it's too cold inside;  
17 wintertime, it's too cold outside.

18           (Laughter.)

19           MS. BOOKER: And when the cold gets into  
20 your bones, it's just like serious pain. One time my  
21 friend, she threw some cold water on my back as a  
22 joke, and I was hot, and it left me in the bed for 2

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1 days with a pain crisis. So there is no such thing as  
2 a normal day, but I try to make it as normal as  
3 possible.

4           The worst pain crisis I ever had was in  
5 2003, and it would be about 10 years before I had  
6 another one like that. I was a sophomore undergrad,  
7 and I was laying in my bed, and I couldn't move. I  
8 went to the hospital and got released, and I did  
9 everything real slow until a few days later I was back  
10 in the hospital and I didn't leave for a month. I  
11 received seven blood transfusions, I had kidney  
12 failure, lung failure, and I was intubated. I  
13 actually celebrated my 20th birthday in the hospital,  
14 all which was told to me because I was highly sedated  
15 and couldn't remember hardly anything.

16           When I left the hospital, I had to learn how  
17 to walk again. I was a semester behind in school. I  
18 was trying to get along with life and feeling okay for  
19 a little bit after the crisis, and then I was hit with  
20 the fact that I had osteonecrosis of the hip from the  
21 medicine that they gave me to help clear out my lungs,  
22 and I ended up having a full right hip replacement at

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1 the age of 21, and I also ended up in therapy. I had  
2 been walking with a cane for a whole year before that.  
3 So I was upset because it was a whole year before a  
4 doctor would even -- wouldn't dismiss my pain as just  
5 a pain crisis and actually just gave me an MRI to find  
6 that my pelvic bone had crushed my hip bone.

7           Now, as I'm a mature young adult, my health  
8 has become more of an issue for me. I have a huge  
9 fear of living alone. I would like to buy a house and  
10 move out, but it's scary because I've never lived  
11 alone. I've always had a roommate, someone who could  
12 make sure that I was okay. And although I'm capable  
13 mentally, I'm afraid to work alone, which would be  
14 really nice to do when you can't get a job that you  
15 want. I don't want to work alone because I feel like  
16 I will leave my work stranded if I get sick. There is  
17 no telling how long I could be out. I feel like I'll  
18 set myself up for failure by the mere fact of being  
19 the only employee in my business. And furthermore, I  
20 don't like telling people about my illness even when I  
21 work with a company because, one, I look healthy on  
22 the outside, so people don't really get how or why I'm

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1 sick. After explaining what it is, people still don't  
2 get it. And people treat you differently, and it's  
3 not always in a bad way, but it makes you feel a  
4 little uncomfortable, like, "Yes, I'm okay, don't --,"  
5 you know. But the thing that's worst of all is that I  
6 need to tell people because there are days that I  
7 really just don't feel well, and it's due solely to my  
8 sickle cell symptoms.

9           I'm looking forward to having a family one  
10 day, and as I grow older, I'm worried about carrying a  
11 baby with sickle cell. I know I will be a high-risk  
12 pregnancy. I know healthy people who have had rough  
13 pregnancies, so being a sickle cell patient, the  
14 questions come to mind, will I be able -- will I be  
15 healthy enough to carry a baby? Will I be on bad --  
16 high-risk pregnancy? How will it affect my baby if I  
17 have a crisis while I'm pregnant? Will I be well  
18 enough after I deliver to take care of my baby and do  
19 simple things like breastfeed?

20           My concern for infants and young children is  
21 the fact that I don't think people are being diagnosed  
22 early enough because doctors don't look for sickle

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1 cell symptoms. I wasn't diagnosed until I was 11, and  
2 it was a total accident. And my first real crisis  
3 wasn't until I was 19. For all ages, I worry about  
4 the care that sickle cell patients receive.

5           In medical school, I have two friends who  
6 are doctors. There is not much told about sickle  
7 cell. And once you go to the hospital where they're  
8 unfamiliar with your case and your disease, doctors  
9 always ask you, "So what do you do?" and the sad fact  
10 is you probably know better than they do. However,  
11 when dealing with a pain crisis, it can be hard to  
12 focus on a plan of action for your care when you went  
13 to the ER to get help.

14           I fear that the meds will just get stronger  
15 and there will be no search for a cure. I fear that  
16 it will always remain that sickle cell patients will  
17 not be able to get health care or life insurance  
18 policies. I fear that young patients will get  
19 pressured into taking medicine that they're not sick  
20 enough to take. Like when I was having issues with my  
21 right leg, they tried to pressure me into taking  
22 hydroxyurea, which was way too strong for me and I

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1 wasn't, quote/unquote, sick enough to take it. It  
2 would do more harm to me than good. So I can only  
3 hope that sickle cell patients are strong enough to  
4 know that they do have choices and to question and ask  
5 about their plan of treatment.

6           That's all.

7           DR. EGGERS: Thank you, Terri. Thank you.

8           (Applause.)

9           Older Adult Perspective on Topic 1

10          DR. EGGERS: And, finally, we have George.

11          MR. CARTER: My name is George Harris

12 Carter. I'm 68 years old and I suffer with sickle

13 beta thalassemia zero. Today I would like to

14 represent myself and members of Sickle Cell

15 Association of Richmond-OSCAR as its administrator,

16 and to patients within the nine chapters of Sickle

17 Cell Chapters of Virginia, where I also serve as

18 administrator.

19           Problems associated with sickle cell disease

20 include pain, which some people live with every single

21 day; chest syndrome; anemia; fatigue; infections;

22 breathing trouble; pneumonia; stroke; gallstones;

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1 organ and tissue damage; spleen and kidney  
2 dysfunction; complications during pregnancy; jaundice;  
3 leg ulcers; hand-foot syndrome, swollen hands and feet  
4 that become hot, red, and painful; vision problems;  
5 blood in the urine; slowed growth and delayed puberty  
6 in children; priapism or pain erections in men.  
7 Sickle cell often creates a need for hip replacements  
8 and/or shoulder replacements. We may develop  
9 pulmonary hypertension.

10           Loss of hearing is not listed in most  
11 publications. I've lost 80 percent of the hearing in  
12 my left ear and 30 percent in my right ear. Some  
13 years ago, during a sickle cell presentation by  
14 Dr. Wally Smith, who is here today, he mentioned that  
15 hearing loss was a problem. I stated that I had  
16 hearing loss in my left ear. Two other males said  
17 that they had hearing loss in their left ear also.  
18 Only four studies have been presented on hearing loss,  
19 and two of those by Dr. Smith.

20           Dental problems also occur. A nurse  
21 practitioner recently wrote, "Sickle cell disease has  
22 a great impact on oral hygiene. We have patients as

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1 young as in their thirties that have dentures, have  
2 lost all of their teeth, because of damage from lack  
3 of oxygenated blood and sickling in the  
4 microvasculature."

5 I have suffered from 14 of the above 23  
6 problems. In addition to the sickle cell, I have  
7 asthma, bronchitis, a hernia, two stomach ulcers,  
8 deteriorating rotator cuff in both shoulders, and now  
9 an inflamed stomach, which in part is from the use of  
10 ibuprofen for pain and inflammation as a result of  
11 that sickle cell.

12 When I have a sickle cell crisis, the pain  
13 keeps me from sleeping. I'm too tired to do some of  
14 my activities. The pain also limits my concentration  
15 and my mobility. Where in my body the pain is also  
16 determines how much I can do and how mobile I am. On  
17 the worst day, a Level 10 pain crisis, I will be in  
18 the hospital trying to get enough pain medication, IV  
19 fluids, and oxygen to get through the pain. There is  
20 no other activity I can engage in on these days. The  
21 pain has complete control to the point that three  
22 times in my life I prayed to God to let me die because

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1 I didn't think I could take any more pain.

2 Medical staff will often, on a scale of 1 to  
3 10, want to know what your pain level is.

4 (Laughter.)

5 MR. CARTER: Using that same scale in terms  
6 of my activities, if I have a Level 2 pain, I can  
7 probably go about my regular activities on a scale of  
8 8, or 80 percent. If I have a pain Level 4, then I  
9 can probably go about my regular activities on a scale  
10 of 6, or 60 percent. If I have a Level 6 pain, I can  
11 probably go about my regular activities on a scale of  
12 4, or 40 percent, and so on.

13 I worry about further hearing loss and organ  
14 damage and having a stroke, but hearing loss is one  
15 because I virtually cannot hear in my left ear. I  
16 always keep my wife on my right side so I know what  
17 she's telling me.

18 (Laughter.)

19 MR. CARTER: Thirty percent I've lost on my  
20 side. If I lose any more, the TV is going to be up so  
21 loud, she's going to leave home --

22 (Laughter.)

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1           MR. CARTER: -- so I can't afford that, but  
2 I'm 68 years old, and one of the ladies in our support  
3 group is 75.

4           (Applause.)

5           MR. CARTER: Thank you. We have overcome.  
6 So let that be a lesson to those who are younger who  
7 wonder. You can live, you can survive, you can enjoy  
8 life, and to God be the glory for all that we have.

9           (Applause.)

10          DR. EGGERS: Thank you, George.

11          And a sincere thank-you to all the  
12 panelists.

13          We are not on our schedule at all, so with  
14 your permission and the permission of the panel of  
15 everyone, we're going to go about 15 minutes into  
16 lunch. I don't think anyone here is going to mind too  
17 much, right? The lunch isn't that great anyway, the  
18 kiosk.

19          (Laughter.)

20          DR. EGGERS: Anyway, so we're going to have  
21 an abbreviated discussion, and our panelists, they had  
22 complicated stories, and it was really unfair to ask

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1 them to stick to 2 to 3 minutes. But I hope -- I'm  
2 going to get a raise of hands, how many of you felt  
3 that your experience was shared by one of the panel  
4 members? They shared a wide variety. How many felt  
5 that you saw a lot of your experience in theirs?

6 (Show of hands.)

7 DR. EGGERS: Great. Okay. We might not be  
8 able to get into all of the topics that we want to for  
9 today, but share your stories through the docket.

10 Let's put up the one polling question that  
11 we have. This will help a lot. It's the same polling  
12 question that we asked the pediatric group. So this  
13 is only for the adults, if you're about 23 or older.  
14 Other than acute pain crisis, because we know that  
15 would be in your top probably, what health effects of  
16 sickle cell disease have the greatest effect on your  
17 life or your loved one's life if you're here for  
18 someone else? Chronic daily pain; stroke; acute chest  
19 syndrome; fatigue; priapism or painful erection;  
20 problems with eyesight from sickle cell disease;  
21 damage to heart or pulmonary hypertension; kidney  
22 disease or gallstones; or something else not listed

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1 above.

2 (Answering question.)

3 DR. EGGERS: Okay. Has everyone had a  
4 chance? Can we go to the results? Okay. Yes. We  
5 thought that the "Others not listed above," would be  
6 pretty high, but it looks like our number one is  
7 fatigue. I don't think we're going to get into that  
8 because we did discuss it a lot for the adolescents.

9 So the second highest in the in-person is  
10 the chronic daily pain, and that has been eloquently  
11 shared by our panel members, so we won't get into that  
12 symptom as well.

13 Next -- I have to squint to see the problems  
14 with eyesight, but the next highest one is the  
15 problems with eyesight from sickle cell disease.

16 And then, of course, we have the "Other"  
17 category.

18 So I think my colleagues would really like  
19 to know now is to let's tease apart -- we have a  
20 limited amount of time, so let's tease apart that  
21 "Other." Other symptoms that you would put in your  
22 top three -- before we do that, on the web, does it

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1 look about the same?

2 MS. VAIDYA: Hello?

3 DR. EGGERS: Yes.

4 MS. VAIDYA: It looks about the same. The  
5 highest on the web is actually for chronic daily pain  
6 at 85 percent, and then next we have fatigue at 79  
7 percent.

8 DR. EGGERS: Okay. Thank you. And on the  
9 web, keep sending in your comments about your  
10 symptoms.

11 So that "Other," does someone want to share  
12 another symptom that they would put maybe even in  
13 their top two since time is tight?

14 Okay. Right here. I'm just going to --  
15 over here. If you could state your name.

16 MS. MURPHY: Theresa Murphy from New York  
17 City. I'm also 68. And I was -- sometimes ignorance  
18 is bliss because I didn't even know I had all these  
19 problems.

20 (Laughter.)

21 MS. MURPHY: But I think my most defining  
22 problems, and lately it's been hypertension, is

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1 extreme pain in my right calf, which is symbolic of  
2 getting embolisms, pulmonary embolisms, and I think  
3 that it is so striking it feels like someone has taken  
4 a baseball bat and just beat your legs in. But I tell  
5 you, ignorance is bliss because I had it for many,  
6 many years, and my youngest kids -- I have four kids.  
7 I was told I was going to die by the time I was 16. I  
8 tell you, ignorance is bliss. When I saw my  
9 hematologist after I had the twins, I said, "Thank God  
10 that I had tubal ligation because I would have about  
11 20 kids now."

12 (Laughter.)

13 MS. MURPHY: So don't believe a lot of  
14 stuff. But it's definitely, I just see so many people  
15 in worst shape than me with other diseases that I am  
16 so glad I made 68 years old.

17 (Applause.)

18 DR. EGGERS: Thank you, Theresa.

19 We have another symptom here and over here.  
20 Okay. I've got a couple hands.

21 MS. GRAY JOHNSON: Hi. My name is Judy Gray  
22 Johnson, and I have the SC disease. I'm a retired

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1 school teacher. And first of all, I would like to  
2 thank FDA and this panel over here for being here and  
3 attempting to do something for us. This is a very  
4 complicated disease. It's hereditary. Quite often  
5 when we go to the medical profession, we are made to  
6 feel like, well, maybe there is something we could  
7 have done or should have done before we got there. We  
8 didn't have any choice in this, and so we are here  
9 having to deal with whatever the symptoms are.

10 I looked around the room here. I'm 71 years  
11 old and --

12 (Applause.)

13 MS. GRAY JOHNSON: -- let me say this, and  
14 I'm thinking there are not many people in here that  
15 can relate to me because 71, having the experiences of  
16 a rural community in which there are very few blacks,  
17 and I was the lone child in the community with  
18 something strange. And have you heard of liniment?

19 (Chorus of yeses.)

20 MS. GRAY JOHNSON: That was what I -- the  
21 first 5 years of my life, I was treated with warm  
22 towels, just let the water run and all, and also from

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1 a poor background. And then from 5 until 16, I was  
2 treated with liniment. The doctor would just say, you  
3 know, splash it on me and that's it. So how did I  
4 make it to here? The pain just wore off. Every year  
5 -- but I did not talk about -- I learned over the  
6 years not to talk about it, and until -- because I  
7 said, Who is going to understand? Who is going to  
8 know? Who is going to understand? Who can help me?  
9 I wanted so badly for someone to help me.

10           When finally I got -- as time went on, I  
11 started thinking I've got to write a book because  
12 nobody is going to believe me. I wrote one book,  
13 *Living With Sickle Cell Disease: The Struggle to*  
14 *Survive*, and that is our experiences here.

15           Afterwards, I thought, wait a minute, I've  
16 got more to say, and that is, I wrote my second book,  
17 which will be out at the end of this month,  
18 *Resilience*. And I would like to ask that FDA, at  
19 least the panel members, read the books and then I  
20 want you to put it on your desk as a reminder of every  
21 time you make decisions or you're planning activities  
22 or whatever for sickle cell disease patients, this

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1 would be a constant reminder of what it's really like,  
2 and maybe, is there something else I should be doing?  
3 And my website is [www.judygrayjohnson.com](http://www.judygrayjohnson.com).

4 DR. EGGERS: Thank you very much, Judy.  
5 Thank you. Thank you.

6 (Applause.)

7 DR. EGGERS: Thank you. So over here we  
8 have symptoms?

9 MS. WOODSON: Hello. I'm from Richmond. My  
10 name is Sitrena, and I was diagnosed at 42, I have  
11 sickle thalassemia, but one of the symptoms that I  
12 really think I struggle with the most is stress, which  
13 increases my blood pressure, which increases my stress  
14 and mobility issues. I have a hip replacement and now  
15 I'm having a lot of pain my shoulders, and that just  
16 again increases the stress and the hypertension.

17 DR. EGGERS: Thank you so much.

18 Okay. All right, here. We'll go here and  
19 then we'll go over on that side of the room to the  
20 gentlemen.

21 MS. BAILEY: Hi. My name is Kamilah Bailey.  
22 I have sickle cell anemia with beta-plus thalassemia,

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1 and the symptoms that I experience in the "Other"  
2 category are sleeplessness where my mind is awake but  
3 my physical body is extremely tired, and I cannot  
4 reconcile my mind with my body in order to get a good  
5 night's rest, and that prolonged, that going over  
6 several weeks or several months, puts me into  
7 depression because I feel like I'm never going to come  
8 out of this pattern. And so medications for -- sleep  
9 medications and pain medications, and on top of all  
10 the medication, it's difficult to function. So the  
11 sleeplessness and the inability to reconcile my mental  
12 fatigue with my physical fatigue and get the rest I  
13 need.

14 DR. EGGERS: Thank you very much. Thank  
15 you.

16 We had a gentleman over in the middle?

17 MR. KARGBO: Hello, everybody. My name is  
18 Ibrahim Kargbo, and I have been living with sickle  
19 cell for 27 years. And I'm going to be honest with  
20 the audience. Until about 2 years ago, I actually  
21 stayed away from sickle cell support groups. I stayed  
22 away from anybody who wanted to talk to me about some

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1 of these symptoms of sickle cell disease because I was  
2 scared. Who wants to hear that they may not make it  
3 past the age of 18? Who wants to hear that they may  
4 not be able to have children? And who wants to hear  
5 that they will not be able to graduate college because  
6 they have sickle cell disease, something that they had  
7 no control over?

8           And one of the symptoms or consequences that  
9 I have experienced with sickle cell disease is not  
10 being able to spend time with my friends and family.  
11 I can deal with the pain. I go home, take my  
12 oxycodone, my Dilaudid, the Tylenol, call it a day.  
13 If I have pain that I can't handle, I go to the ER. I  
14 can deal with the pain. It's really the social  
15 aspects of sickle cell disease that's cutting deep  
16 into my soul. Not being able to take the person I am  
17 with to dinner because my joints are aching, that's  
18 really what I go through with sickle cell disease.

19           DR. EGGERS: Thank you. And I hope that  
20 you're hearing in here that you can make it past 18,  
21 you can go to school, you can have children, so it's  
22 an inspiring message from all of us here.

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1           Are there -- pardon me? On the -- do we  
2 have web summaries? Okay. And I want to -- let's  
3 see. I'm going to tee up for one phone call, one  
4 lucky phone person, to talk about a symptom that they  
5 haven't heard. Please keep it to a symptom that you  
6 haven't heard described today. And we're going to go  
7 with a summary of what we've heard on the web.

8           MR. VALENTINE: Okay. So we've been putting  
9 together a list of symptoms that went into that  
10 "Other" category, and we've received a lot of  
11 comments, so we'll try to run through quickly.

12          DR. EGGERS: Great. Thank you, web.

13          MR. VALENTINE: One we received is issues  
14 related to pregnancy such as miscarriages and ectopic  
15 pregnancy, gout, sinusitis, allergies, mental effects,  
16 several comments about insomnia, migraines, teeth  
17 issues, severe ear infection leading to hearing loss,  
18 brain aneurism, ulcers, and jaundice.

19          DR. EGGERS: Okay. Thank you.

20                I heard a lot of echoes of that. Is that a  
21 list that you in the room agree with? Raise your hand  
22 if you heard your own symptoms in there.

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1 (Show of hands.)

2 DR. EGGERS: Great. Okay. Before going to  
3 the phone, colleague. Okay, yes, yes.

4 MS. PETERSON: Hi. My name is Nikki  
5 Peterson. I'm 40 years old, hemoglobin SS. I've had  
6 four strokes and two TIAs. One of the symptoms that  
7 I've suffered with is compression fractures in my  
8 back. I have compression fractures T1 through T5 and  
9 L4 level, and that has really been a problem that I  
10 have suffered with for the last I would say 3 or 4  
11 years, and each time I get a compression fracture, I  
12 have to start all over with rehab, with learning how  
13 to walk, and sometimes with speech.

14 And also one of the problems I've had as a  
15 female is going through menopause at an early age,  
16 being 20 years old and having a crisis in my ovaries  
17 and my uterus and going through menopause and not  
18 being able to have children, and that's been one of  
19 the symptoms that I've suffered with. It's not only  
20 physically, a physical problem, but it's also an  
21 emotional problem being a young woman who would love  
22 to have children one day, but I'm not able to. And so

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1 that's one of the problems that I go through.

2 DR. EGGERS: Thank you so much. Okay.

3 Any symptoms that my colleagues wanted to --  
4 any final questions from my colleagues?

5 DR. VERDUN: I just wanted to touch on  
6 retinopathy in particular since it was close to 30  
7 percent, and if anyone wanted to touch on retinopathy.

8 DR. EGGERS: Okay. Back there. And if you  
9 could just state your name again, please.

10 CAROL: Carol from New Jersey. I have  
11 sickle cell retinopathy. Oh, I have so many surgery  
12 on my eyes. Actually, my mom lost her vision in her  
13 left eye, and she died from complications to pulmonary  
14 embolism. But about three times I almost lost my  
15 vision. I was at work one day and I saw this big  
16 black circle in my left eye, and the circle got  
17 bigger, I had no clue what it was, and because I work  
18 in occupational health, I went to the clinic to ask  
19 the doctor what was happening, and they rushed me to  
20 the hospital right away, and then they told me there  
21 was so much blood in my eye they couldn't do anything.  
22 The doctor sent me home and I slept upside-down for

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1 like two nights, and then I went back and had surgery,  
2 and they had to coagulate so many vessels. At least  
3 it saved my sight, so I can see now, but I have  
4 tremendous problems with my eyes.

5           But one of the issues that was never  
6 discussed there, growing up in Jamaica, I did not know  
7 I had sickle cell. I found out I had sickle cell when  
8 I was 25 years old. And as a child, I had severe  
9 pains in my mouth, and it felt like neuralgia, and I  
10 lost half of my teeth because they were trying to  
11 figure out how my teeth look well, but I was having  
12 this pain, they didn't know where the pain was from,  
13 so they took half my teeth out. But I still have this  
14 pain up to this day, and the pain would start in my  
15 mouth, go up into my ears, into my head. So whenever  
16 it gets cold, like anything below zero, I do not go  
17 outside, because I end up with that pain.

18           So there are other things, too, but I won't  
19 go through that.

20           DR. EGGERS: Thank you. Okay. And do we  
21 have one phone comment, Operator?

22           OPERATOR: Nikki, your line is open.

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1 DR. EGGERS: Hello?

2 OPERATOR: Nikki's line is open.

3 DR. EGGERS: Nikki?

4 NIKKI: Hello?

5 DR. EGGERS: Hi, Nikki. This is Sara. Do  
6 you have a comment?

7 NIKKI: Oh, yes. I'm sorry, I had the phone  
8 put down for a second. Yeah. I had a comment. By  
9 the way, I'm 25 years old, and I was diagnosed with  
10 sickle cell when I was 5 months old, which is pretty  
11 young. But some of my struggles that I have is I was  
12 diagnosed with pulmonary hypertension when I was  
13 around 20, and it has taken a devastating toll on my  
14 life period. I have to have oxygen all the time.  
15 With sickle cell, you're already oxygen deprived. So  
16 I have to have oxygen to breathe everywhere that I go  
17 all the time, and being 25 years old, that's really  
18 difficult in itself. I've had a thoracotomy of my  
19 lungs completely in the hospital. I also had my  
20 gallbladder removed and my spleen, and that was all  
21 before I was a teen. So my life has been a big  
22 struggle with it, so day in and day out I am extremely

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1 tired, exhausted. Some days I can't even get out of  
2 bed. And I live in Florida and there is a lot of  
3 hostile weather. A lot of people think that it  
4 doesn't get cold here, but it gets really cold here.  
5 And our weather changes, so that was like the other  
6 day I went to a Super Bowl party and it was 80  
7 degrees, and now it's -- it snowed. So my body, my  
8 body generally doesn't get to adjust to the weather  
9 change, so today I'm like having a lot of pain because  
10 the weather has drastically changed within, you know,  
11 a day.

12 DR. EGGERS: Thank you very much for that  
13 comment, Nikki. One final thing?

14 NIKKI: My final thing would just be I  
15 definitely have fears and worries in regard to my  
16 sickle cell, but just watching and listening to the  
17 comments that have been said today, I am so proud to  
18 be here and be able to listen to people that have  
19 actually made it so far. I thought I was not going to  
20 make it past 9 years old, and I'm 25 now. So it  
21 really gives me hope and I think it gives all of us  
22 hope to let us know that we can make it further than

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1 what is expected definitely.

2 DR. EGGERS: Great. Thank you, Nikki. I  
3 think that is a perfect comment to end before lunch.

4 I know everyone didn't get a chance to  
5 speak. There is still another topic coming up in the  
6 afternoon.

7 We're going to take 45 minutes for lunch if  
8 that's okay. So please come back at 1:30, and we will  
9 have our Topic 2 discussion. And if you have any  
10 questions, come find us. Thank you.

11 (Lunch.)

12 Afternoon Welcome

13 DR. EGGERS: Okay. Can we start to make our  
14 way in and we'll get started? And as you make your  
15 way in, I'll refresh what we're going to be talking  
16 about in this topic. The format is going to be the  
17 very same. We're going to be focusing this afternoon  
18 on patients' perspectives on treatments for sickle  
19 cell disease. This includes what you're taking, what  
20 you're doing, how well those are working, what's not  
21 being addressed as well, what do you look for in an  
22 ideal treatment? And then we'll also have a

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1 discussion on if you imagine you had the opportunity  
2 to participate in a clinical trial, and what would  
3 your thoughts be on that?

4           And as we get started, I am going to make an  
5 obvious observation that the lunch line was very long,  
6 and we apologize for that. We thank you so much for  
7 your patience. And if you need to finish your lunch  
8 and come on in or bring your lunch on in, please feel  
9 free to do so.

10           And so with that, we're waiting on one  
11 panelist, or a couple of panelists. If you're on the  
12 Topic 2 panel -- actually, if you are finishing your  
13 lunch and you're on the Topic 2 panel, go ahead and  
14 finish it and then come on in when you want. This is  
15 a very informal setting. We have some fantastic panel  
16 members here today to give us just a flavor of what  
17 it's like, about your experiences with treatments, and  
18 then we will broaden it to the facilitated discussion.

19           Are all the photo ops done? We've got all  
20 the pictures?

21           Panel Discussion on Topic 2: Patients'  
22           Perspectives on Treatments for Sickle Cell Disease

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1 DR. EGGERS: So we have one caretaker, and  
2 I'm going to let him get started in the discussion,  
3 and that is John, and then we'll work our way down.  
4 Again, please try to keep it to 2 to 3 minutes and  
5 focus on the discussion questions that we have. Can  
6 we put the discussion questions up? You guys already  
7 know the discussion questions, but for everyone else  
8 in the room, these are the types of questions we are  
9 asking them to address.

10 All right, John. Oh, and I'm sorry, push  
11 your little red button on your mike. There you go.

12 MR. MOORE: Good afternoon, everyone. My  
13 name is John Moore. I have a 14-year-old son who has  
14 sickle cell and it's been a real challenge for 14  
15 years trying to keep him healthy and happy. As a  
16 parent, you really feel an obligation to give your  
17 children the best, and when you feel that genetically  
18 you've given them something detrimental to their  
19 health, it really hurts, and watching your children  
20 suffer is something I wouldn't wish on anyone.

21 We are at this point considering a bone  
22 marrow transplant because we really haven't found any

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1 of the treatments to be totally effective at  
2 diminishing or eradicating his pain. He's had a  
3 really bad year this year, hasn't been to school more  
4 than maybe 2 months out of the whole school year. So  
5 we are definitely on the track to try to get him  
6 cured, and as far as we know, the bone marrow  
7 transplant is the only cure.

8           At this point, he has gone through  
9 everything that we've been told is a way to treat  
10 sickle cell pain, and I don't really know that it  
11 treats his pain, but it does make it tolerable. He's  
12 taking morphine-based medications, supplying heat  
13 during all kinds of Jacuzzis, anything to massages, to  
14 try to ease it, but it's just so systemic that it's  
15 very hard to deal with.

16           At this point, we're just hopeful that this  
17 bone marrow transplant is going to be the cure, and  
18 now that they have a haplo method, his mother can be  
19 the donor, his mother or I can be the donor, so we  
20 don't have to have an exact match, and they don't have  
21 to totally stop the production of his bone marrow, it  
22 only has to be suppressed for a period of time. So

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1 knowing that it's not as life risking as it had been,  
2 we're willing to take the chance, and he's all gung-ho  
3 for it. So we just at this point have decided that  
4 that's the only thing that we hold out hope for.

5           So I look at all you adults out here, and I  
6 know that your parents have gone through what I went  
7 through, and it's just a really hard thing to watch  
8 your children suffer. I don't know why the bone  
9 marrow transplant hasn't been more broadly advertised  
10 because as far as I know, speaking to all of the  
11 people that are adults who have had sickle cell, their  
12 childhood was very, very tough. Fortunately for us,  
13 our son was diagnosed as having it at birth, so he was  
14 treated from the very beginning. We have one relative  
15 who was never diagnosed until she was maybe 7. They  
16 even thought her parents had been abusing her because  
17 she was having these pains that they couldn't identify  
18 the source of, so in the State of Pennsylvania,  
19 fortunately they do test for it at birth.

20           At this point, I was wishing my son was  
21 here. We had a blood transfusion yesterday. He's  
22 feeling better, but he just wasn't up to coming. So

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1 as his representative, I want to thank everybody here  
2 and anyone who has any power to do anything to make  
3 sickle cell a more publicly aware disease that should  
4 be treated, I would say, more aggressively, I thank  
5 you for your efforts.

6 DR. EGGERS: Thank you, John.

7 (Applause.)

8 DR. EGGERS: And next we have Tina Kay.

9 MS. HUGHES: And they told my mother, "You  
10 need to have a hysterectomy so you won't have any more  
11 children like this." She was pregnant with my  
12 brother, and the doctor was referring to me. My  
13 mother had choice words on the Army base in rural  
14 Georgia, and she never went back.

15 Today, treatment for sickle cell patients is  
16 go to the hospital, wait, wait, wait some more, and it  
17 doesn't matter that you're at a Level 9 or 10, it  
18 doesn't matter that you're in the midst of a stroke,  
19 it doesn't matter that you can't walk, it doesn't  
20 matter that the ambulance brought you in on a gurney  
21 and they sit you out in the hallway.

22 Treatment is push things like hydroxyurea on

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1 us, which one clinical doctor told me was nothing but  
2 rat poison, and that's when I stopped taking it. I  
3 figure my people lived in this world way before pills,  
4 so I started to look for other things to do, like  
5 acupuncture, cupping, massage therapy, the TENS unit,  
6 and, of course, everybody's favorite, the heating pad.

7 (Laughter.)

8 MS. HUGHES: I think we're all like Lionel  
9 (sic) on *Charlie Brown*, if we don't have our heating  
10 pad, we're not going to make it. But I think that in  
11 today's time, research is moving a little faster, and  
12 believe it or not, there are researchers in  
13 Birmingham, Alabama, where I am from, who are looking  
14 at more than just a bone marrow transplant, they're  
15 looking at, how can we cure us, us brown people, with  
16 our own skin? It's not in the medical journals yet,  
17 but, believe me, in the next couple of years, you will  
18 be hearing about it.

19 My life as a child, was pretty -- I had a  
20 pretty good childhood. I stayed outside a lot. And  
21 believe it or not, Howard University has done research  
22 showing that Vitamin D from the sunshine is the best

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1 thing for us. I worked a job where I worked outside  
2 about 80 to 90 percent of my job, and I traveled the  
3 country for close -- about 250 to 300 days out of the  
4 year. I never had a crisis, I never had a cold,  
5 because I was in the sunshine all the time. So maybe  
6 it's something that God is trying to give us, but  
7 we're staying in the house in the bed. Maybe we need  
8 to go pull a lounge chair out in our yard and get some  
9 sunshine.

10 (Laughter.)

11 MS. HUGHES: I've tried other things like  
12 compound pharmacy, eating natural organic ingredients  
13 in foods to help decrease the pain. I've tried Zija,  
14 Ambrotose, Body By Vi. You all know them all because  
15 they approach us saying, "Oh, you can be cured."

16 So I contracted hepatitis C unfortunately  
17 from a blood transfusion in the '80s. And sometimes  
18 the things that we think are helping us can sometimes  
19 help hurt us.

20 Another thing that we were talking about  
21 during lunch is constipation. Because we have so many  
22 toxic things in our bodies, it's so easy for us to

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1 become constipated. So eat your green vegetables, the  
2 fruits. A lady shared with me, a doctor in the crowd,  
3 nana (ph), nana juice. I'm going to try it. Alkaline  
4 water, I drink that religiously to try to help get my  
5 pH balance back into balance because we are really  
6 acidic from the toxins that we have in our bodies.

7           So don't be afraid of other things. Try  
8 other things. Mix Eastern medicine with Western  
9 medicine. It's something for the Chinese to be able  
10 to live until they're more than 100 years, it's  
11 something to our ancestors who lived past the 100  
12 years old by going back to the earth. Maybe that's  
13 what we need to start doing.

14           DR. EGGERS: Tina, do you have one more  
15 thing?

16           MS. HUGHES: Okay. I spend my time as a  
17 journalist. I write nationally for several  
18 publications. I'm a published author. I have two  
19 radio shows that can be heard across the world. I  
20 speak all over the country. And don't own this  
21 disease, don't say it's yours. It's something that  
22 you carry around with you, but don't own it.

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1 DR. EGGERS: Thank you so much.

2 (Applause.)

3 DR. EGGERS: And you'll be followed by  
4 Lakiea.

5 DR. BAILEY: Thank you. I am --

6 DR. EGGERS: Oh, put your --

7 DR. BAILEY: Oh, sorry. Thank you. Better?

8 DR. EGGERS: Yes. Great.

9 DR. BAILEY: I am Dr. Lakiea Bailey. I am a  
10 research scientist and patient advocate. I have  
11 sickle cell disease hemoglobin SS. Well, actually I  
12 have hemoglobin S, hemoglobin Monroe. Monroe is  
13 another mutation for the hemoglobin, and it makes  
14 completely unviable hemoglobin. So essentially I just  
15 have one gene that works, and it produces sickle cell,  
16 so that's sort of how I present.

17 Our first question was about medical  
18 protocol, what we do. I am currently on folic acid  
19 and naproxen and hydrocodone as needed. I receive a  
20 monthly infusion of Desferal for the iron overload.  
21 Blood transfusions, but I typically insist that my  
22 hemoglobin fall below about a 6.2 before they

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1 transfuse me, especially if my retic count suggests  
2 it's going to rebound on its own. My baseline is  
3 about 7.4, so 6.2 would be really too low for some  
4 people, but for me, it's doable.

5           Naproxen works really well for the bone  
6 pain. Supplemental oxygen but only during travel or  
7 when I'm going to conferences in high -- like I have a  
8 particular yearly conference I go to that's in the  
9 mountains of North Carolina, oxygen too low, so I take  
10 my oxygen then, but that's the only time I use the  
11 supplemental.

12           When hospitalized, I'm typically treated  
13 with morphine and Benadryl. It makes the pain  
14 somewhat more tolerable, but then I need the Benadryl  
15 for the itching. I have not come across anything that  
16 really does a great job on the pain.

17           My main objection -- it asked about that --  
18 my main objection with my current medical treatment is  
19 that it only addresses pain. I was determined to be a  
20 non-responder for hydroxyurea, so a lot of people take  
21 the Hydrea, but I was a non-responder, and there is a  
22 small percentage of the population that just does not

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1 respond. My fetal hemoglobin did not increase, but  
2 what did increase were the things that you don't want  
3 to increase, fingernails turned black, hair fell out.  
4 I would have dealt with all of that because, I mean,  
5 they make some awesome wigs, but I wasn't getting any  
6 support, it wasn't helping me, so I was a non-  
7 responder for the Hydrea, so that wasn't an option for  
8 me.

9           The oral medical for iron overload that most  
10 people take, put it in the orange juice, drink that  
11 chalky orange juice, one of the rare side effects is a  
12 decrease in hearing acuity, and they measured that my  
13 hearing decreased while on it, so I couldn't take  
14 that, so that's why I have to do the infusions for the  
15 Desferal to treat the iron overload.

16           Alternative treatments, so other than those  
17 things, I attempt to treat and prevent sickle  
18 complications with diet. I have noticed a very strong  
19 correlation with not only what I eat but when I eat it  
20 and how I feel the next day. So I try to use my diet  
21 a lot to monitor that.

22           This will sound weird, but I take a men's

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1 vitamin. Okay, so iron overload, I have to avoid  
2 iron. When you grab the women-formulated and the men-  
3 formulated multivitamins, if you look on the back,  
4 they're generally the same except the men does not  
5 have iron in it. And so my multivitamin is a men-  
6 formulated multivitamin, which is the same, I haven't  
7 turned into a man, but it doesn't have iron.

8 (Laughter.)

9 DR. BAILEY: So I take that. I drink  
10 dandelion tea for the liver complications. It tastes  
11 the way I imagine freshly mowed grass probably would  
12 taste --

13 (Laughter.)

14 DR. BAILEY: -- but I have noticed that it  
15 helps with the liver pain, the inflammation upon  
16 palpation. It helps with the liver. So I don't  
17 remember who told me about dandelion tea, but I drink  
18 that. It's, like I say, gross, but it really does  
19 help.

20 And then one of my alternative treatments --  
21 and I know a lot of people do this -- I try to detox  
22 with detoxing stress in my life. So I go home, I go

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1 let my mom just mommy me, and I find that waking up at  
2 3:00 a.m. to my 5-month-old nephew bouncing around and  
3 screaming actually does wonders for my health. So I  
4 do that.

5 (Laughter.)

6 DR. BAILEY: And my other alterative  
7 treatment, if you would consider alternative, would be  
8 faith and a whole lot of prayer.

9 Untreated complications was the next thing.  
10 My current treatment focuses entirely on pain and iron  
11 overload. I would love treatment that would address  
12 the underlying anemia and the vaso-occlusive events.  
13 The anemia, of course, is linked to the excessive  
14 fatigue, and the fatigue is a major, major issue for  
15 me, and then the blood transfusions, which causes the  
16 iron overload.

17 So if I could address that as well as those  
18 vaso-occlusive events, mostly my treatments, they're  
19 looking at downstream, they're looking at afterwards,  
20 but I would like to address upstream. Can we look at  
21 it before things get that bad?

22 Another untreated issue is memory and the

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1 retention of information, that's a constant. I am  
2 completely incapable of learning in class. I show up  
3 because it was required of me. I have to learn at  
4 home, just study on my own. I learn more 20 minutes  
5 on Google than I will 3 hours in class. And I was at  
6 a talk recently that actually showed a very strong  
7 correlation between vascular pain and memory loss, and  
8 I looked into it, and I didn't see any studies where  
9 they looked in it with sickle cell or even sickle  
10 mice, but it makes sense to me that if it's the case,  
11 the particular type of pain we experience, vascular  
12 pain, vaso-occlusive pain, might be related to some of  
13 the mental acuity deficits that we're experiencing.  
14 So that's untreated.

15           And I have had the -- and then this actually  
16 came up during the talk -- I have had the uterine  
17 crisis before. It never occurred to me that that  
18 could lead to early menopause and infertility until  
19 others started talking about it. So that was good  
20 information for the individuals that shared that, I  
21 really appreciate that, and that is another thing to  
22 put on the altar.

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1 DR. EGGERS: Lakiea -- oh.

2 DR. BAILEY: My ideal treatment, you had  
3 ideal treatment. My ideal treatment would decrease  
4 duration of sickling events and increase my  
5 hemoglobin.

6 And you asked about experimental treatment  
7 participation. When considering whether or not to  
8 join experimental drug trials, I typically weigh the  
9 known and theorized risk of the drug against its  
10 potential benefit. I also consider the phase the drug  
11 trial is in, how long it's been tested, and the number  
12 of previous patients enrolled. So the severity of my  
13 disease is not yet to a point where I am bold enough  
14 and comfortable enough to be among the first few  
15 trials. I know that sounds counterintuitive and kind  
16 of hypocritical as a research scientist, but right now  
17 I feel like I want everybody else to go first.

18 (Laughter.)

19 DR. BAILEY: And so that addresses all of  
20 the different points that you asked.

21 DR. EGGERS: Thank you very much, Lakiea.

22 (Applause.)

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1 DR. EGGERS: And then we have Olga.

2 MS. BARNWELL: Good afternoon, everyone.

3 I'm glad to be here. I am 61 years old, living with  
4 sickle cell disease. I am the oldest of four  
5 siblings, three who do have sickle cell as well, two  
6 with the trait. My protocol is basically folic acid,  
7 elimination of stress. Say no to stress as fast as  
8 you can. Okay? I use a lot of therapeutic methods.  
9 I work with a team of naturopathic physicians, and a  
10 big part of my protocol is aromatherapy. I have  
11 included with that aromatherapy massage therapy. I do  
12 Yoga and Tai Chi. The Yoga helps with the breathing,  
13 okay, and when we get shortness of breath, it does  
14 help with breathing. Meditation is also wonderful for  
15 that. So I typically try to get my meditation in, in  
16 the mornings, and then there are evening meditations  
17 that are done as well.

18 During my daily routines, I have a pain  
19 medication, a pain oil, that I carry with me. So I  
20 don't have to take the pharmaceutical meds that they  
21 prescribe for us to carry, I just have my pain stick,  
22 rub and go, rub and go. So that's basically what I

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1 do, I rub and go.

2           Side effects that I do have, in June I did  
3 have a TIA, so I am being treated with that, for that,  
4 and I'm undergoing quarterly blood exchanges for that.  
5 I'm doing that on an outpatient basis basically. And  
6 what I do is I prep with my oils when I go in to have  
7 the lines put in, and then after the line is taken  
8 out, I have certain oils that I do use as well that  
9 helps with the incision, healing of the incision, and  
10 help reduces some of the pain as well that I  
11 experience from that. When I'm having those  
12 exchanges, I do have lack of energy, and it takes me a  
13 couple of days to bounce back from that because of the  
14 exchange of the blood that occurs.

15           Basically this is a lifestyle choice for me.  
16 We do have choices. God did not put these plants and  
17 herbs here for us not to use. The side effects from  
18 the natural therapy, I have none, I have no side  
19 effects. We have to find what works best for us and  
20 stick with that protocol. When I do have to go into  
21 the hospital, I have my oils with me, I'm using them,  
22 I'm prepping myself before I go in, and the medication

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1 I use is Dilaudid if I go, and the last time I went  
2 in, I had a bad reaction to that. So I'm like my body  
3 is just rejecting all of the pharmaceutical medicines  
4 because they're toxic. So my eating, I try to do as  
5 much organic eating as possible, do juicing, juicing  
6 your fruits and your vegetables as much as you can as  
7 well as --

8 DR. EGGERS: Okay, any final thoughts?

9 MS. BARNWELL: Pardon me?

10 DR. EGGERS: Any final thoughts?

11 MS. BARNWELL: Final thoughts is to continue  
12 to live every day out and make every day a victory,  
13 make every day a victory.

14 (Applause.)

15 DR. EGGERS: Thank you, Olga. Thank you.  
16 And next we have Anthony.

17 MR. BRAXTON: Hello. My name is Anthony  
18 Braxton. I'm 31 years old. I have sickle cell SS.  
19 And I've been through many complications of sickle  
20 cell. When I was 14, I had my gallbladder removed.  
21 About 5 years ago, I had an ulcer on my ankle that I  
22 couldn't explain, had no idea where it came from.

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1 Also, about 7 years ago, I had issues with priapism  
2 that it started as an adolescent, but about 7 years  
3 ago I had a priapism that lasted 4 days, and I went  
4 from ER to ER and no one really could help me. And I  
5 went to Johns Hopkins, I'm from the area, local area,  
6 and I went to Johns Hopkins in Baltimore, and they  
7 were able to help me. And they also have a sickle  
8 cell infusion center, it's the only one in the area,  
9 where we can go and get treatment and meds and not  
10 have to wait in the ER lines, and they have the  
11 doctors that specialize in sickle cell, and that's one  
12 thing that we actually have to do, is create more  
13 sickle cell infusion centers because, as all of the  
14 other panelists and patients and the audience knows,  
15 waiting in the ER for hours and hours and no one knows  
16 what to do is excruciating, there is no other way to  
17 put it.

18           At the current time, I'm on several  
19 different medications. Hydroxyurea, I was actually on  
20 2,500 milligrams starting in 2004. Lately I had to  
21 reduce that because I started seeing the effects, the  
22 side effects, of it, and it became more of a

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1 hindrance, and it also developed kidney issues with  
2 me. I have FSGS, a form of kidney disease, and that  
3 was kind of in correlation to the high dosage of  
4 hydroxyurea that I was on, so that's been reduced.  
5 Folic acid, OxyContin and oxycodone as needed. And  
6 lisinopril, I take that from the gout that I have  
7 developed from sickle cell as well. I have pain,  
8 swelling in the feet, leg area, very often.

9           The combination of these medicines and  
10 treatment has greatly reduced my hospital stays and  
11 the frequency of my severe crises. For the present  
12 time, this seems to be the best combination I've had,  
13 you know, in my 31 years, and I'm pretty satisfied  
14 with these treatments.

15           The treatments that I am on now, I do a  
16 monthly red blood cell exchange. I have an implant  
17 Vortex port, and that helps with the exchanges.  
18 Throughout my life, I've been hospitalized over 100  
19 times, so most of my veins became scar tissue, so that  
20 was always an issue. Within the last year, I remember  
21 being hospitalized and having eight different people  
22 try to place an IV in me, and it was terrible. So the

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1 Vortex port is something that was implanted, and it's  
2 been pretty good in my treatment.

3           Downside of it, when they access the port,  
4 it's painful, it's painful. It gets clogged, so they  
5 have to put declogging medicine in it, and it's a  
6 process. But I've learned that the things that may  
7 hurt me now may help me to have a better future, so I  
8 kind of deal with that.

9           Aside from the treatments and medicines that  
10 I'm on now, I have a regular exercise routine for the  
11 most part. As we get older with sickle cell, you kind  
12 of learn what you can do and what you can't, so when I  
13 can, I try and exercise, and I never try and do too  
14 much because it will end up hurting me in the long  
15 run, but I do try to incorporate exercises daily, even  
16 if it's only for 10 to 15 minutes, I try to get as  
17 much physical activity as I can.

18           Also, I have changed my diet. I eat a low  
19 sodium diet, also a lot of organics, natural foods.  
20 The things that are easily accessible for us to eat  
21 are the things that are so bad for us, you know. And  
22 what we need to do as a whole is just concentrate on

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1 going back to nature, going back to these natural  
2 foods, natural supplements, herbs, all types of  
3 things, instead of all of these manmade products and  
4 all of these things that are loaded with so many bad  
5 things.

6 DR. EGGERS: Any final thoughts, Anthony?

7 MR. BRAXTON: Yes. My thoughts is there are  
8 treatments out right now for sickle cell and curing  
9 sickle cell, but what we need to do is, yes, we need  
10 more volunteers, and like she said, nobody wants to do  
11 it, but you have to think long term. If any of you  
12 guys have kids, you know, would you rather your kids  
13 go through the process of being in trials or would you  
14 rather do it for them?

15 DR. EGGERS: Thank you so much, Anthony.

16 (Applause.)

17 DR. EGGERS: And, finally, we have Adam.

18 MR. BUNDUKARMA: Is this thing on?

19 DR. EGGERS: Yes.

20 MR. BUNDUKARMA: Hi. I'm Adam, and I'm 48  
21 years old, and like everybody else, I have sickle cell  
22 disease, and I hope to get to 68 and 71 like everybody

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1 else.

2 I have a lot of issues that everybody else  
3 has, so I'm not going to bore you with the long list.  
4 I'm nervous enough as it is. But there is a lot of  
5 titanium and plastic and chemicals and tape and nails  
6 holding me together, so, you know.

7 (Laughter.)

8 MR. BUNDUKARMA: Yeah, okay, so the  
9 questions are right here. I guess I'll just stick to  
10 those.

11 Okay, yeah, so I'm taking a lot of  
12 medications, and they help, various treatments. Like  
13 my friend here, I have kidney issues which developed,  
14 and that was the craziest thing in my life because  
15 that added a lot more treatment to my plan, I guess I  
16 should say. Yeah, and I have like everything that  
17 everybody else has. I feel like really stupid sitting  
18 here listing off things because I actually feel pretty  
19 lucky.

20 I had medical parents, my parents are in the  
21 medical profession, so I got really good treatment  
22 when I was a kid, and my pain was managed really well.

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1 I actually never saw a hematologist until I was, gosh,  
2 maybe 36 years old. And I actually see the wonderful  
3 hematologist at Johns Hopkins, and thanks to her and  
4 her staff, I'm still alive. She's the best  
5 hematologist in the world. Sorry.

6 (Laughter.)

7 DR. EGGERS: So, Adam, you had some really  
8 interesting thoughts on participating in a clinical  
9 trial, and I'm going to ask you to share those.

10 MR. BUNDUKARMA: All right, you wanted me to  
11 mention that stuff.

12 Okay, yeah. So like I was -- I guess when I  
13 was 18, 19 years old I participated in the trials for  
14 hydroxyurea because my parents made me, not because I  
15 wanted.

16 (Laughter.)

17 MR. BUNDUKARMA: And I'm really glad that  
18 it's helping people today, so, you know. I didn't  
19 want to do it, but now it's great. At this point,  
20 they, my hematologist and her team, they present me  
21 with any options for doing trials or tests or things  
22 like that, and I always, always say yes. There has

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1    only been one that I haven't qualified for because of  
2    some issue, but, yeah, I do anything I can to help.

3            One of the things that I do believe in now  
4    -- I haven't always -- is being vocal about sickle  
5    cell just because I think that I'm probably in the  
6    place that I am because I've spent my life being quiet  
7    about it trying to fit in and be like everybody else.

8            So, yeah, one of the things that I have to  
9    say is a big struggle with managing sickle cell is  
10   stress, like everybody else says, but the stress for  
11   me comes with not wanting to actually do it, and also  
12   because I fought so hard to be a success in my life  
13   because I've had parents who were super successful,  
14   drove me crazy.

15           (Laughter.)

16           MR. BUNDUKARMA:   So like I have like a  
17   really demanding job, and it's really, really hard to  
18   manage all the doctors appointments, medications,  
19   different treatment options, things like that, and  
20   work a full-time job and, you know, live. And so,  
21   yeah, that's one of the biggest, biggest problems.

22            I don't know, nobody mentioned today -- a

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1 lot of people mentioned stress, but I don't think  
2 anybody really mentioned today that I believe with  
3 sickle cell patients that it's -- we don't ever relax,  
4 and I don't ever relax. I would love to see somebody  
5 make some famous horse pill or something --

6 (Laughter.)

7 MR. BUNDUKARMA: -- that would just, I don't  
8 know, calm me down or something. I never relax, it's  
9 so annoying.

10 I wasn't going to tell anybody this, but I  
11 had two joint replacements on my knee and my hip  
12 because of avascular necrosis and it advanced and I  
13 had so much pain I couldn't walk and everything, and  
14 they told me that the only thing they could do was do  
15 the joint replacements, so, yeah, that's where the  
16 titanium comes in. But, yeah, when I was recovering  
17 from those, it was really hard just because sickle  
18 cell patients, our muscles are really, really tight,  
19 and so it's hard to do things where it requires  
20 flexion

21 I don't know. What else do I want to add?

22 DR. EGGERS: Any final thoughts?

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1           MR. BUNDUKARMA: Yeah, yeah. I'm going to  
2 shut up now.

3           (Laughter.)

4           DR. EGGERS: These were fantastic.

5           (Applause.)

6           Large-Group Facilitated Discussion: Topic 2

7           DR. EGGERS: Is it on? Yeah.

8           I want to extend another sincere thank-you  
9 to the panelists. It really does take a lot of  
10 courage to come up here in front of a large crowd and  
11 share such personal stories, and you each gave such a  
12 nice range of treatments that you're taking, and I  
13 think it really gave us a good picture of sort of your  
14 whole treatment. Were there any clarifying questions  
15 from any of the panel, any of the FDA panel, for any  
16 of the panel members?

17           DR. FARRELL: I think we would like to know  
18 something about the use of iron chelators, what  
19 percentage.

20           DR. EGGERS: Did any of the panel, did any  
21 of you use iron? Okay. We'll get into that in a  
22 second.

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1           Okay. Let's put up the polling question.  
2    You still have polling questions in the afternoon.  
3    The afternoon isn't free of polling questions. What  
4    we would like -- and this is for everyone, this is the  
5    pediatric and the adults, to give us a sense of how  
6    much -- what the range of treatments you might be  
7    taking. In the past year, have you or your loved one  
8    used prescription medicines or medical treatments to  
9    treat sickle cell disease? So this is in the past  
10   year, and you can check all that apply. Folic acid,  
11   prescription pain meds, hydroxyurea, blood  
12   transfusions, oxygen therapy, antibiotics,  
13   transplants, other prescription medicines or medical  
14   treatments, no prescription medicines or medical  
15   treatments, or you're not sure.

16                   (Answering question.)

17           DR. EGGERS: And on the web, you may have to  
18   scroll down to see all those answer choices if you're  
19   on the web.

20                   (Answering question.)

21           DR. EGGERS: Okay, has everyone had a chance  
22   to answer? Good. Okay, we'll go on.

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1           Okay, there are a lot of treatments being  
2 used. Folic acid and the prescription pain meds as  
3 well as the antibiotics. Let's see, I'm looking, G.  
4 So 14 percent of you have had transplants, bone marrow  
5 transplants. We'll follow up on that in a second to  
6 get your thoughts on that. Very few of you are taking  
7 nothing, 4 percent.

8           On the web, are they similar numbers?  
9 Pardon me?

10           MS. VAIDYA: It's similar.

11           DR. EGGERS: Oh, similar. Okay, we're  
12 getting the A-okay that we're similar on the web.  
13 Okay.

14           So the few treatments that we want to follow  
15 up on in particular, and the first one, the one that  
16 Ann said.

17           Ann, can you repeat which one you want to  
18 know about?

19           DR. FARRELL: I'm just wondering about iron  
20 chelator use.

21           DR. EGGERS: Okay. Does someone in the  
22 audience want to talk about that first? I know we

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1 have Lakiea. Okay. The microphone is coming.

2 MS. RENE: You can hear me.

3 UNIDENTIFIED FEMALE SPEAKER: For the web.

4 DR. EGGERS: Actually for the webcast, we  
5 would have --

6 And your name is Nancy.

7 MS. RENE: It's Nancy. And my grandson  
8 takes Exjade, and he's been on it since he was  
9 probably 2 years old when he started his blood  
10 transfusions, and we're very thankful because  
11 otherwise he would have to be in the hospital hooked  
12 up to an IV in order to chelate. This he just does at  
13 home, and he hasn't had any ill effects.

14 DR. EGGERS: Back there?

15 MR. VALENTINE: I take Exjade as well, but  
16 mine was put on hold because I've been getting like a  
17 lot of burning every time I drink it as well as I had  
18 real bad auditory and visual hallucinations, and I  
19 started losing my hearing. So I did have it before  
20 when I was younger, like you have, with chelation. I  
21 had the chelation before and didn't have any of the  
22 side effects like I do now when I take the Exjade, so

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1 -- does it work for you, the chelation, does it work  
2 better than the --

3 DR. BAILEY: The intravenous?

4 MR. VALENTINE: Yeah.

5 DR. BAILEY: It works well for me, yes.

6 MR. VALENTINE: Did you take both? Were you  
7 on the --

8 DR. BAILEY: I did. I tried the oral. I  
9 had the decreased hearing, so I had to come off of it,  
10 and it was working and I would have stayed on it  
11 except for the hearing, so I had to go intravenous.

12 MR. VALENTINE: And, now, do you guys use  
13 the cups? I met an Exjade rep and she gave me a --  
14 like I guess there is supposed to be cups given to us  
15 where it actually has like whatever dose you're on,  
16 and then you mix it, and it gives you a certain time?  
17 So it's battery-powered and it has a timer which  
18 you're supposed to go by to mix the medication instead  
19 of have to constantly redoing it and --

20 DR. FARRELL: Thank you very much.

21 DR. EGGERS: Did that answer your question?

22 DR. FARRELL: Yes. I was interested in

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1 seeing how well these medicines work, and clearly  
2 there is a need perhaps for the development of more  
3 effective iron chelators, especially with the side  
4 effects.

5 DR. EGGERS: So maybe I could ask a question  
6 with a show of hands. How many feel that those  
7 treatments are working for them, those of you who are  
8 taking it? Show your hands?

9 (Show of hands.)

10 DR. EGGERS: A couple? And how many of  
11 those of you who are taking those find them not as  
12 effective as you would like?

13 (Show of hands.)

14 DR. EGGERS: Okay. All right.

15 As far as other treatments, are there other  
16 treatments that you would like to know about?

17 Hydroxyurea? We heard a variety. We heard that  
18 Lakiea was a non-responder.

19 Anthony, you felt like it was working well  
20 for you.

21 Does anyone else feel like it's -- want to  
22 share their story of how it's working well for them?

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1                   (Show of hands.)

2                   DR. EGGERS: Okay, in the back there with  
3 the tan shirt.

4                   MS. McCLINTON: I wouldn't say working well.  
5 I was on hydroxyurea when I was younger, as a child.  
6 At the time I needed it, I was averaging about three  
7 hospital stays a month, and I also lived in Boston at  
8 the time, so cold weather was horrible for me.

9                   I took myself off of it when I was an adult  
10 because at the time the doctors couldn't tell me the  
11 long-term effects of taking the drug. I don't want to  
12 substitute sickle cell for another disease that I know  
13 nothing about. I've been living with sickle cell for  
14 a long time, I kind of know what to expect. I don't  
15 want to trade it for something else. So I'm one of  
16 those who get pushed hydroxyurea all the time, but I  
17 refuse it. I don't want to take it.

18                  DR. EGGERS: Okay. Thank you. Over here?  
19 I think in the pink? Right here first with Judy.

20                  MS. GRAY JOHNSON: Yes. I initially was  
21 introduced to hydroxyurea many years ago when I was in  
22 the hospital and I had been hospitalized several times

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1 close together, and this doctor, hematologist, just  
2 suddenly appeared and did not examine me or anything  
3 and just wrote out a prescription for me to take  
4 hydroxyurea. And so I was released home, and I did as  
5 expected, filled the prescription, and eventually I  
6 became paralyzed and I remember calling the doctor  
7 saying, "Something is wrong," but they did not respond  
8 quick enough, so I took myself off of it.

9           So for many years after that I would not  
10 take it, but now after that, a few years ago, maybe  
11 about 4 or 5 years ago, I was going to the hospital  
12 many, many times, and I was really getting scared, I  
13 said maybe I better take another look at this, and I  
14 had been discussing this with my new hematologist, and  
15 he put me on 500 milligrams of hydroxyurea. So that,  
16 coupled with Procrit, has kept me out of the hospital  
17 for the last 3-1/2 to 4 years. So it worked in that  
18 regard.

19           DR. EGGERS: Thank you, Judy.

20           MS. GRAY JOHNSON: One thing I wanted to say  
21 about the Exjade, I've been on that, too, and I took  
22 it for about a month and a half, that was because I

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1 had a high iron, and that medicine is very, very  
2 expensive. You're talking about 5,000-plus dollars  
3 for a 1 month's supply. So when people are asking for  
4 it, just know that we need help with that. It just so  
5 happened that my insurance took care of most of it,  
6 but my copay, in addition to all of my other  
7 medication, I mean, you know, that made it even higher  
8 for me, but I paid \$50 a month.

9           So while, yes, it can work and it can work  
10 and all, but it's very expensive and sickle cell  
11 patients need help with that.

12           DR. EGGERS: Thank you, Judy.

13           MS. GRAY JOHNSON: \$5,000 for 1 month,  
14 5,000-plus for 1 month, that's saying a lot.

15           DR. EGGERS: Thank you, Judy.

16           Yes. Yes. Go ahead, Jonca.

17           DR. BULL: I'm just wondering, given the  
18 large role that transfusions play, if there have been  
19 any challenges with transfusion reactions.

20           DR. EGGERS: Okay, we have some hands.

21           Go ahead, Andrea, you go.

22           NICOLE: Hello. My name is Nicole. I have

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1 sickle beta thal. I would say in regards to  
2 transfusions, because I've had a number of them over  
3 time, I've developed a number of antibodies that has  
4 caused me a couple different things. One thing would  
5 be future blood accessibility to that blood. When you  
6 do develop so many antibodies over time, it takes you  
7 longer to get blood that you may need for a  
8 transfusion. And then also I would say for the  
9 transfusion part was -- ooh, that must be the memory  
10 thing we were talking about earlier --

11 (Laughter.)

12 NICOLE: -- being able to have transfusions,  
13 I actually got an antibody that caused me to have  
14 pulmonary embolism. So there are a lot of different  
15 side effects to having a number of transfusions over  
16 time.

17 DR. EGGERS: Thank you.

18 One more on this and then we'll go on.

19 YOMI (ph): My name is Yomi. I have sickle  
20 cell SS. I was actually on hydroxyurea for about 11  
21 years, and it was working good for me, but I wanted to  
22 have kids. So in talking with my hematologist, they

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1 recommended transfusions. And we started out with  
2 whole body transfusion, the full exchange. They would  
3 draw out almost everything and give you equal volume.  
4 That was okay for a while, but then I developed  
5 antibodies and I actually had a miscarriage that we  
6 were wondering whether it's because of the antibodies  
7 and everything. So now she has changed it to simple  
8 exchange where they will take out 1 pint of blood and  
9 give me 2, and so far it's been good. It seems like  
10 some of the antibody thing has been -- I don't know if  
11 it's red to white, but the results look better, but  
12 we're still experimenting because that's just like 3  
13 or 4 months.

14 DR. EGGERS: Okay. Thank you.

15 Yes, Tina.

16 MS. HUGHES: I failed to talk about  
17 pregnancy, and when I was pregnant, I had to get blood  
18 exchanges, and they also thought that my baby, while  
19 inside of me, would have to get transfusions as well.  
20 So weekly I would have to go to the high-risk doctor  
21 to make sure she was getting enough blood supplied to  
22 her brain. But I've had really bad reactions to

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1 transfusion therapy, well, exchange now. I blew up  
2 like a Michelin Man. It's real hard for me to find  
3 blood, for them to find blood for me, now because I  
4 have lots of antibodies. Sometimes I have to wait 3  
5 to 4 days for them to find blood somewhere in the  
6 country.

7 DR. EGGERS: Thank you.

8 Okay. Any more questions on -- okay. I was  
9 going to ask about transplants. Do you want to -- was  
10 that your -- okay. Let me ask about transplants, and  
11 then I'll come to you.

12 So there were some in the room who indicated  
13 that you've had a transplant. Would anyone share  
14 their story about how that's their experience with  
15 that?

16 (Off mike comment.)

17 DR. EGGERS: I'm going to -- is it -- no, I  
18 don't think it has to be specifically.

19 (Laughter.)

20 DR. EGGERS: Okay. We'll come to you,  
21 Margaret.

22 MS. MORGAN: Yes, my name is Gwen Morgan.

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1 I'm from Atlanta, Georgia, and I have a son with SS  
2 disease. He received a transplant last April.  
3 Because he's the only child, we could not find a match  
4 through the bone marrow registry, so we did a half  
5 match with his dad, and the closer we got to the 90  
6 days, he lost the graft, so his bone marrow was  
7 unsuccessful. But I've heard stories of -- success  
8 stories, and I'm just hoping and praying that we'll  
9 find a cure soon.

10 DR. EGGERS: We had one more over here, and  
11 then we'll go over there to Margaret.

12 MS. WOOLFORD: Hi. My name is Teonna. So I  
13 actually had a bone marrow transplant 2 years ago.  
14 Just like what she was saying, I could not find a  
15 match, so I did a clinical trial at Hopkins, and my  
16 mother was my donor. About 90 days into it -- I mean,  
17 they were doing testing like weekly, and my numbers  
18 weren't looking good. I definitely had more of my  
19 cells than my mom's cells, but, you know, we were  
20 still praying, we were still faithful, we were  
21 hopeful, and then I just got really sick, I started  
22 having really high fevers, and basically what

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1 happened, my bone marrow, instead of kicking and  
2 revving back up like it was supposed, it shut down for  
3 140 days. So I wasn't making platelets, I wasn't  
4 making any kind of cells. I was rejecting what they  
5 were putting into me, and I had to get bone marrow  
6 aspirations like every 3 days, and the slides, it was  
7 like nothing to look at.

8           But at the same time, I do know of people  
9 who have had the transplant and they are doing really,  
10 really well. So I think it's just very personal for  
11 everybody. And, I mean, my story, everybody's story,  
12 is really unique, but I am also very hopeful that  
13 within a year or 5 years -- that's what I've been told  
14 -- that bone marrow transplants will be a little bit  
15 more successful, so that's what I'm hoping for.

16           DR. EGGERS: Thank you very much.

17           We had one over here? Margaret?

18           MS. HADNOTT: I was listening to Adam, it  
19 is? Adam, you said you had a transplant? A kidney  
20 transplant.

21           MR. BUNDUKARMA: No, no, I didn't have a  
22 transplant. I had joint replacements.

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1           MS. HADNOTT: Oh, okay. I had a kidney  
2 transplant because over the years my doctors told me  
3 that my kidneys were wearing down, and between that  
4 and high blood pressure, between sickle cell and my  
5 high blood pressure, my kidneys went down. So even  
6 though I'm going to be 70 years old this year, I have  
7 quite a few replacement parts.

8           (Laughter.)

9           MS. HADNOTT: I have a new knee, I have a  
10 new hip, and my daughter gave me a kidney. So I'm  
11 still here.

12           (Applause.)

13           MS. HADNOTT: And I want you to know the  
14 only medicine I take every day is folic acid. But  
15 over the years I've had my share of crises. I don't  
16 anymore. But one of the things I really would like to  
17 stress is to get rid of stress. "No" is a complete  
18 answer.

19           DR. EGGERS: Thank you very much.

20           MS. HADNOTT: And the other thing is your  
21 nutrition, and that will help save your kidneys  
22 because over the years it does happen to sickle cell

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1 patients.

2 Thank you.

3 DR. EGGERS: Thank you very much.

4 Ann, you had a question?

5 MS. PARISER: Yes. I just had a question  
6 about clinical trials in general. Can people share an  
7 experience perhaps they've had participating in  
8 clinical trials or if you decided against it or if you  
9 would like more information on research, what are some  
10 good ways to communicate these across the community?

11 DR. EGGERS: I'm actually going to hold on  
12 Ann's question because we're going to be coming up  
13 with that question in a few minutes, so when we're  
14 done, if we haven't answered all your questions, then  
15 we'll come back to it.

16 I want to see on the web if there are any  
17 web comments on the treatments that we've talked  
18 about.

19 MR. VALENTINE: All right. So we've had a  
20 lot of comments coming in through the web. I'll try  
21 to summarize these as best I can.

22 We have had some people say they've had

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1 success with a bone marrow transplant. Another  
2 specific experience that was shared were that a  
3 patient with SCD said that pain meds were less  
4 effective for them. Some of the broad alternative  
5 treatments included broadly alternative medicine,  
6 faith and prayer, and nutrition, and more specifically  
7 mentioned were sunlight through optic nerves has  
8 increased endorphins to fight pain and fatigue,  
9 Vitamin D supplementation, using prenatal vitamins to  
10 avoid that issue of iron, B-12 for energy, pears and  
11 apples for energy as part of nutrition. For  
12 supplementation, dandelion, L-arginine, and  
13 L-methionine for slowing the sickling cycle.

14           There were a couple of comments about being  
15 mistreated using detox or other -- being treated as  
16 having drug-seeking behavior when coming to the  
17 hospital, so there are some concerns about that.

18           And as for things that people would like to  
19 see, they said treatments that would create new gene  
20 activity to produce blood that does not sickle. Also  
21 a unique comment was they would like to see a home  
22 blood test like for diabetes.

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1 DR. EGGERS: Okay. All right. Thank you.

2 I'm going to go to our next polling question  
3 because it gets at the other types of therapies that  
4 people have been talking about. We've heard a lot  
5 about that today and we heard that on the web. So  
6 let's just get a poll to see a sense in the room.

7 In the past year, have you or your loved  
8 ones done anything besides those prescription  
9 medicines to treat your sickle cell disease? And you  
10 can check all that apply. Over-the-counter pain meds;  
11 massage or acupuncture; vitamins or dietary  
12 supplements; D, take extra fluids; E, followed a  
13 special diet such as avoiding certain foods; F,  
14 attended some pain program or support group; G, use  
15 some other therapy; H, if you don't use any of these  
16 therapies; or, I, if you're not sure.

17 This may take a while for some people, I  
18 think, who have maybe several of these.

19 (Answering question.)

20 DR. EGGERS: Okay. If everyone is about  
21 done, we'll go on to the results. Very high numbers  
22 here. So it looks like 83 percent take over-the-

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1 counter pain meds. Now, can I get a show of hands how  
2 many -- let's just see a show of hands, how many take  
3 a prescription pain medicine every day or almost every  
4 day regularly?

5 (Show of hands.)

6 DR. EGGERS: Okay. And how many take an  
7 over-the-counter pain medication daily or almost every  
8 day?

9 (Show of hands.)

10 DR. EGGERS: Okay. Thanks.

11 And then, let's see, what's D? Extra  
12 fluids. Okay.

13 Vitamins, dietary supplements, and herbal  
14 remedies. I think we heard a lot from the panelists  
15 and on the web about that.

16 Gosh, I have a hard time reading these  
17 letters. E, what's E? I've got to get right up  
18 close.

19 Okay. So are there any of these other  
20 therapies? I know we've heard a lot from the panel  
21 members. My colleagues?

22 (No audible response.)

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1 DR. EGGERS: Okay. All right.

2 I have a question for a show of hands in  
3 that how many of you would say that overall these non-  
4 drug therapies or these non-prescription therapies are  
5 as important to your overall treatment regimen as any  
6 prescription medicines or therapies that you do?

7 (Show of hands.)

8 DR. EGGERS: Okay. Thank you.

9 Yeah, sure. If you think about your non-  
10 drug therapies, such as the ones listed, would you say  
11 that those are as important to you in your overall  
12 treatment as the prescription medicines that you take  
13 or the therapies?

14 Tina, yes.

15 MS. HUGHES: One other therapy that hasn't  
16 been talked about is art therapy. And a lot of  
17 organizations get a lot of money for art therapy  
18 because it releases endorphins that makes you feel  
19 good. It's a feel-good chemical that helps you forget  
20 about the pain for just a little while. And art  
21 therapy can consist of dance, poetry, music, anything  
22 that comes under the auspices of the arts.

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1 DR. EGGERS: Thank you, Tina.

2 Okay. We'll take two more comments on these  
3 non-prescription therapies, and then we'll move over,  
4 I have another general question.

5 Right there?

6 MS. VALENTINE: Another form of therapy we  
7 discovered wasn't offered to the sickle cell  
8 population was hippotherapy. That's the use of  
9 equines to warm your muscles prior to kinesio or  
10 physical therapy and also equine-assisted or forms of  
11 animal therapy. It's routinely offered to patients of  
12 cerebral palsy, stroke. We use comfort dogs for  
13 veterans returning from war for PTSD. That has not  
14 been offered to the sickle cell community, and it is a  
15 form of therapy you can seek out in your neighborhoods  
16 you need to find. If you even Google it, "animal-  
17 assisted therapy" or "equine therapy," it will also  
18 help with mobility and it also helps with low impact  
19 stretching and motion especially if you have  
20 acetabulum AVN.

21 DR. EGGERS: Okay. Thank you.

22 Okay, one more? And I'm going to let

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1 Soujanya pick the person.

2 DR. HSU: I'm Dr. Hsu from the University of  
3 Illinois. I'm not a patient, but you have to mention  
4 heat and warmth. Everybody is using that, and that's  
5 not included. And sometimes there are hospital  
6 restrictions about what kind of temperature you have,  
7 and it puts a crimp on what kinds of non-drug  
8 therapies you can have.

9 DR. EGGERS: Thank you.

10 Okay. So I'm going to -- we have time -- by  
11 the way, would anyone mind, if the meeting, since we  
12 started a little bit late after lunch, if we go till  
13 about 4:15 to end? Of course, you can leave early  
14 when you want, but we're going to plan to go until  
15 about 4:15 if that's okay.

16 I have a general question for a show of  
17 hands, and that is, when you think about all of your  
18 therapies together, how many of you would say that you  
19 are able to keep your sickle cell disease and its  
20 effects in decent control? How many of you feel like  
21 your sickle cell disease is being pretty well managed  
22 right now?

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1                   (Show of hands.)

2                   DR. EGGERS: Okay. And how many of you  
3 would say that it is very much not being well managed?

4                   (Show of hands.)

5                   DR. EGGERS: Okay. Let's take for those who  
6 are not being well managed, those that just raised  
7 your hand, if you can give me in a few words what your  
8 ideal treatment would address better, what would it  
9 be?

10                  UNIDENTIFIED FEMALE SPEAKER: Hi. My ideal  
11 treatment is that sometimes I don't need to go to the  
12 emergency room. And I notice that for a lot of other  
13 diseases, there are some form of home therapy. I  
14 think it's imperative that people with sickle cell  
15 anemia, especially people with ports for IV saline  
16 solution, IV saline therapy, that we could do that at  
17 home, and oxygen therapy, things like that can be done  
18 at home, and when I asked my doctor about these types  
19 of treatments, I was always met with opposition  
20 because the fear from the medical community was that  
21 having something where you can have a port and have  
22 saline therapy that abuse, that people would put

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1 things into their ports at home that they were not  
2 supposed to have, but I think that with the proper  
3 education and the proper training of patients so we  
4 could handle a lot of things at home and kind of  
5 eliminate some of those ER visits, that's what I would  
6 like to see.

7 DR. EGGERS: Thank you. Thank you.

8 Someone else.

9 MS. OLA: I just wanted to say for me the  
10 therapy that's not being addressed is the tissue  
11 damage. I understand the pain, I can deal with the  
12 pain on a variety of levels, but what I feel is being  
13 most effective to my future and I'm most concerned  
14 about is the fact that my organs are dying, my tissues  
15 are dying, every time I'm having a sickle cell  
16 episode, whether I'm in the hospital or I'm at home.  
17 And when you go to the hospital, the only thing that  
18 they're giving you generally is pain medicine, but  
19 nothing addresses the tissue damage that's occurring  
20 with every single crisis.

21 And for people that die from sickle cell,  
22 it's never on the death certificate that they died

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1 from sickle cell pain, it's always they died from  
2 complications of sickle cell, and these complications  
3 are coming because of the tissue damage that's  
4 occurring, and really that's what I want treatments to  
5 address.

6 DR. EGGERS: Great. Thank you.

7 (Applause.)

8 DR. EGGERS: Two more, if there are two  
9 more.

10 MR. MOORE: Well, for my son, the reason  
11 we've decided to do the bone marrow transplant is  
12 because he's pretty healthy right now. He hasn't had  
13 to have any of his organs removed or replaced or  
14 treated. So we kind of want to take this opportunity  
15 while he's pretty healthy. He had a good response to  
16 hydroxyurea for a while, but after a while it didn't  
17 do anything.

18 So we don't feel -- it's like being caught  
19 between a rock and a hard place, you really don't have  
20 options. You are kind of damned if you do, damned if  
21 you don't. So we're hoping that we can preserve what  
22 little general good health he has now and benefit from

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1 it. We don't want to wait until he's had a stroke or  
2 he's had to have his spleen removed. So we're trying  
3 to hold onto the good health while he's still young  
4 and make that move and just pray that it works.

5 DR. EGGERS: Thank you, John.

6 I'm going to tee up on the phone. We can  
7 take one or two callers on the phone. I would ask you  
8 just to keep to the specific topic of, what would you  
9 look for in an ideal treatment? What would it address  
10 in your health? And we'll do that in a few minutes.

11 One other comment, one other person who  
12 wants to talk about the ideal health -- ideal  
13 treatment, I'm sorry.

14 MS. BROWN-WATTS: I would like to see an  
15 ideal treatment that addresses the whole, the whole  
16 person. We have a lot that is compartmentalized, and  
17 we miss a lot of other psychosocial, mental health,  
18 things of that nature, that directly affects the body.  
19 Your mind directly affects your body. And I would  
20 like to see some systematic comprehensive strategies  
21 to address the whole person.

22 DR. EGGERS: Thank you very much.

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1 (Applause.)

2 DR. EGGERS: On the web, do we have any  
3 other new comments in on ideal treatments?

4 (No audible response.)

5 DR. EGGERS: Okay. Then I think I -- oh,  
6 let me just go to the phone first. So I think I've  
7 learned my lesson.

8 Operator, are there any calls?

9 (Laughter.)

10 OPERATOR: Yes. We have a couple.

11 Cassandra, your line is open.

12 CASSANDRA: Hello?

13 DR. EGGERS: Hi, Cassandra.

14 CASSANDRA: Hi. Can you hear me? Sorry.

15 DR. EGGERS: We can. We can. What are you  
16 looking for in an ideal treatment?

17 CASSANDRA: I would like to see more going  
18 towards like holistic treatment. You know, a lot of  
19 foods can cure a lot of ailments, celery helps with  
20 inflammation. You know, just something that isn't  
21 really going to poison our bodies and have so many  
22 side effects that we're suffering from sickle cell, we

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1 don't want to suffer from like any other side effects  
2 other than what we've been dealt with.

3           So I just would really like to see like  
4 maybe a turn towards more natural holistic, like Yoga,  
5 not necessarily just foods, just taking care of your  
6 body in a natural way.

7           DR. EGGERS: Thank you very much, Cassandra.

8           One more on the phone, Operator, please.

9           OPERATOR: Jonathan, your line is open.

10          JONATHAN: Hi. I have a very interesting  
11 question. It's not one that gets brought up a lot.  
12 As I was growing up, my parents did their best to  
13 teach me the basics, what I need to know to take care  
14 of myself, but I lost them early on in my teen life  
15 and grew up pretty much by myself, and there were no  
16 groups, there were nothing in the hospital to help me  
17 out. And I just wanted to see, what can you do to --  
18 if they're ever in that situation when they're alone  
19 and they don't have anywhere to turn to? And myself,  
20 I've ran into a lot of uncaring arms and a lot of  
21 opposition because I looked like I was normal most of  
22 the time, and people were just never around when I was

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1 ill.

2 DR. EGGERS: That is a great question. I'm  
3 not sure if we're going to be able to -- I think that  
4 question would take hours to answer. So here is what  
5 I'm going to suggest -- oh, we have an answer. Sorry.

6 MS. LaMAR: Hi. I'm Mary Bentley LaMar with  
7 the Sickle Cell Association of New Jersey. We're part  
8 of the Sickle Cell Disease Association of America  
9 national network of community-based organizations. I  
10 would encourage that individual and anyone dealing  
11 with sickle cell disease to connect with an  
12 organization like ourselves or like or similar  
13 organization in their area so that they can connect  
14 with other individuals who are dealing with it and  
15 help raise awareness so that more people know about it  
16 so it's not a foreign concept when they encounter  
17 someone who is dealing with sickle cell disease.

18 DR. EGGERS: That is a great point.

19 Yeah, go ahead.

20 MS. MURPHY: I'm from New York, and I was  
21 diagnosed in 1956. What I am surprised about, in the  
22 Bronx, the biggest hospital is Montefiore; in

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1 Manhattan, it's Columbia Presbyterian; in Brooklyn,  
2 it's Interfaith. Each has a sickle cell department.  
3 I have spoken to each of these doctors that works with  
4 sickle cell. They don't know each other. That's a  
5 major problem. How can you be getting funds or lack  
6 of funds and not know if I say "David Diuguid," not  
7 know his name, or whoever at Montefiore or whoever  
8 at Interfaith? That is a serious problem. And why  
9 aren't they having groups themselves? As other, as I  
10 wait, because I have to go for Aranis (ph) every 3  
11 weeks, the oncologists, those people, they have  
12 organizations in the same hospital, and they'll speak  
13 to them, and I say, "Well, how come they ain't coming  
14 over to me?"

15 DR. EGGERS: So this is a very --

16 MS. GRAY JOHNSON: I would just like to add  
17 to what they have said. Listen, every hospital should  
18 have a patient representative, and if they don't, then  
19 you can inquire why or whatever, but that, number one.  
20 And if so, make sure that you maintain a relationship  
21 with that person and report everything to that patient  
22 representative. Now, if for some reason or another

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1 that is not -- that they don't have it or you're not  
2 satisfied or whatever, get familiar with the Joint  
3 Commission, it's out of Chicago, Illinois, and they  
4 will listen to whatever problems that you're having.  
5 We're hearing too much of this, but there is -- but we  
6 all have to be vigilant, and we just can't sit back  
7 and complain, we have to do something.

8 DR. EGGERS: Thank you, Judy.

9 MS. GRAY JOHNSON: Thank you.

10 DR. EGGERS: This is a very important topic,  
11 and we're going to have to move on from the caller's  
12 important question. But I do encourage you, we have a  
13 docket, and so use that if you have a point that you  
14 would like to make on this topic. Please send it to  
15 our docket.

16 Okay. I forget your name. Fran. You've  
17 raised your hand a few times, so we'll go to you, and  
18 then we're going to have to move on, we want to get to  
19 an important discussion on clinical trials.

20 MS. VALENTINE: There is something called  
21 Home Telehealth. It is more and more we're using  
22 technology to our advantage. We currently monitor

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1 heart failure, COPD, hypertension, diabetes.  
2 Registered nurses where they're case managers, they  
3 monitor their vital signs and answer health questions  
4 every day. They red alert, I call them. I watch  
5 their weight. They gain 1 to 3 pounds? We're  
6 contacting the doctors. I think sickle cell patients  
7 could benefit from that. They can also do home IV  
8 therapy we do. Our hematologist, he hooks to a CAD  
9 pump and goes wherever he has to go if he can't  
10 hydrate by mouth adequately. So I think it's a  
11 physician preference.

12           But speaking to the barrier, of breaking  
13 down barriers, everyone with your young children,  
14 start your to-do list. Make them articulate,  
15 outspoken. People that meet you will not know  
16 anything. I will not even be able to tell you over  
17 the years, the 35 years, being a nurse how many times  
18 I've given an on-spot teachable moment for sickle  
19 cell. Do that. Start them young because we have to  
20 advocate also not be fragmented, yes. But Telehealth,  
21 you can Google it, but it may be something that could  
22 be beneficial.

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1 DR. EGGERS: Thank you very much.

2 Patient Perspectives on Participating in a  
3 Clinical Trial to Study Experimental Treatments

4 DR. EGGERS: Okay. We're going to move on  
5 to a discussion on clinical trials because this is an  
6 important topic that my colleagues would really like  
7 to know a little bit more about.

8 We're going to read a scenario of a clinical  
9 trial, but before doing that, we have one polling  
10 question to ask, which is: Have you or your loved one  
11 ever participated in a clinical trial studying  
12 experimental treatments for sickle cell disease? Yes,  
13 A; B, no; or, C, I'm not sure.

14 (Answering question.)

15 DR. EGGERS: Okay, and we'll go to the  
16 results. Oh, half and half. Okay. Is that -- okay.

17 All right. So we have lots of experience in  
18 the room as we go on to the next few slides.

19 So for a few minutes I would like you to  
20 imagine that you have been invited to participate in a  
21 clinical trial to study an experimental treatment for  
22 sickle cell disease. The early research in animals

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1 and people shows that this treatment may decrease the  
2 number of pain crises or hospitalizations in some  
3 people with sickle cell disease. Now, the purpose of  
4 the study is to better understand how well this  
5 treatment works and its safety. The study will enroll  
6 1,000 participants with sickle cell disease. Also  
7 imagine that the clinical trial lasts 1 year and  
8 involves four clinic visits each occurring every 3  
9 months.

10 More common side effects of this therapy may  
11 include nausea, diarrhea, fatigue, headache, and rash,  
12 and rare but more serious side effects may include  
13 infection, bleeding, and life-threatening allergic  
14 reaction.

15 So the question I have is, what comes to  
16 mind as you hear this scenario?

17 Raise your hand if you would like to speak  
18 and we'll try to take -- someone who hasn't spoken  
19 much. Okay, in the back there?

20 MS. ROBINSON: Hi. My name is Mattie. I'm  
21 with the William E. Proudford Sickle Cell Fund, a  
22 community organization, but I have a very intimate

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1 relationship with sickle cell disease. I was born  
2 with sickle cell SS and I also have persistent fetal  
3 hemoglobin, and I chose a career until recently in  
4 biomedical research specifically doing research on  
5 treatments for sickle cell.

6           So the thing that jumped out at me in that  
7 hypothetical scenario is the phrase, "This drug is  
8 expected to help some people." If I were vetting this  
9 therapy and trying to decide whether or not I wanted  
10 to subject myself to this experimental medication, I  
11 would want to know exactly how some people were  
12 determined, what exactly you used to determine who  
13 this helps, because I think in the end you need clear  
14 guidelines of, who are the people that are going to be  
15 helped by the therapy? And we've seen here that there  
16 is a lot of diversity in the symptoms that people have  
17 and their experience with sickle cell disease. So if  
18 it's a drug that helps people who have ulcers, I might  
19 not be the best person for that study. So I think  
20 very detailed and clear information is necessary.

21           DR. EGGERS: Okay. Thank you. Anyone else?

22           DR. BAILEY: Sara, may I?

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1 DR. EGGERS: Yes.

2 DR. BAILEY: That is exactly the type of  
3 questions that I would want to know. How is this  
4 going to help sickle cell? What's its method of  
5 action? Is it something that I would benefit from?  
6 Is it something that I need that outweighs the risks  
7 of it? For the one or two times that I have been  
8 involved in drug trials, these are the questions that  
9 are the most important to me. I need to know not just  
10 this is going to help sickle cell but this is going to  
11 help treat the persistent acute chest syndrome that  
12 you're dealing with by approaching this particular  
13 target area.

14 Those are the kind of questions because when  
15 you're talking about research studies that don't  
16 involve inhalation or injection or infusion of a  
17 medicine, then I'll participate in that as much as I  
18 can, but when it comes to actually taking a drug into  
19 myself, I would need to know more about how that drug  
20 is going to work and why you think that's something  
21 that would work for me.

22 DR. EGGERS: I heard a lot of positive

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1 reactions to that.

2           Anyone else? Over here?

3           MR. SWEET: Hi. Oh, excuse me. Hi. My  
4 name is Jay. And this exact scenario reminds me of  
5 when I went to Duke University with their sickle cell  
6 clinic. I absolutely hated it. I've learned, thanks  
7 to them, just because it says it's a clinical study  
8 and it's supposed to help sickle cell does not mean  
9 it's going to help sickle cell, it does not mean it's  
10 going to help you. It's going to help them first and  
11 then it's going to help you, if it helps you, because  
12 when I went to Duke University -- and I moved to North  
13 Carolina because I thought -- I heard so much great  
14 things about Duke helping sickle cell and having  
15 studies and some of the best doctors from all over the  
16 world were going there. I never met more  
17 disrespectful doctors in my life and --

18           DR. EGGERS: I think we don't want to focus  
19 on any particular people or organizations in here,  
20 so --

21           JAY: I get that. Long story short, because  
22 of the experience that I've had, I would be more

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1 questioning about what is the final result you're  
2 looking for, and is it going to help me out in the  
3 long run? Like she said, the drugs going to your  
4 system, I don't want to be a lab rat to know, I just  
5 want, is it going to help me more versus kill me?

6 DR. EGGERS: Okay. Thank you. Thank you.

7 We have a few polling questions that are  
8 going to tease out a little bit of your thoughts, and  
9 we can build upon that for a bit to give you kind of  
10 all a chance to weigh in here.

11 So there are many, many factors that go into  
12 your decision about whether to participate in a  
13 clinical trial, and we have pulled out just a few of  
14 those factors that are sort of the most relevant to  
15 FDA and what we think about as we think about clinical  
16 trials.

17 So of the following factors, which two would  
18 you rank as most important to your decision about  
19 whether to participate in a clinical trial to study an  
20 experimental treatment? Is it the common side  
21 effects? Is it the rare but serious side effects? Is  
22 it considerations about how the treatment might

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1 improve your particular health? How the trial might  
2 affect your current treatment plan, what you're  
3 currently doing to treat your sickle cell? Any  
4 requirements of the trial, such as whether you have to  
5 go for regular blood tests or go to the hospital? Or  
6 length of the trial? So of those factors, if we said  
7 please pick two that would be most important to you,  
8 which two would those be?

9 (Answering question.)

10 DR. EGGERS: Okay. So the most common on  
11 the in-person, in here, the most common response was  
12 the common side effects -- no, I'm sorry, the rare but  
13 serious side effects. I've got to read the bigger  
14 words here. The rare but serious side effects,  
15 followed by how the treatment might improve my health,  
16 and then kind of equally split between common side  
17 effects and the treatment plan followed lastly by the  
18 requirements of the trial.

19 And on the web, do we have something  
20 similar?

21 MS. VAIDYA: So on the web, we have 90  
22 percent who say rare but serious side effects, and

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1 then the next is 51 percent, how the treatment might  
2 improve my health, and then goes on to how the trial  
3 might affect my current treatment plan, at 32 percent.

4 DR. EGGERS: And I think we've heard from  
5 the panelists and from the comments, we've heard about  
6 each of these factors. I'm going to turn to my  
7 colleagues and see any factors that you want to follow  
8 up on why someone picked one of these things.

9 Anne, did you have any other questions about  
10 the clinical trial participation?

11 DR. PARISER: Yes. I would like to follow  
12 up on there is a lot of research going on. What are  
13 some of the best ways to communicate information? How  
14 do you get your information? What are some of the  
15 best sources? Where would you like to hear this from?  
16 And where would you like to get more information?

17 MS. OLA: Hi, again. I'm Tosin Ola from  
18 Sickle Cell Warriors, and this was one of the  
19 questions that we asked our community, and most of the  
20 people that participate in clinical trials or would be  
21 interested in participating in clinical trials, the  
22 main gripe that we get is that they don't hear about,

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1 and one of the ways that most people stated in that  
2 question -- we got 93 responses -- 30 percent said  
3 that they wanted to see commercials on television,  
4 PSAs, just like we have for other diseases and other  
5 conditions, on the radio and where they would get  
6 their information anyway, have news reports on the  
7 news, things like that.

8           The other group said that they would like  
9 more online information accessible to them. And a  
10 couple of patients mentioned that they had gone to  
11 clinicaltrials.gov and it was really hard to navigate  
12 the site and really hard to figure out what trials  
13 they were eligible for and what hospitals were doing  
14 the trials and things like that.

15           And then the third resource was just  
16 community-based organizations that they were  
17 affiliated with and that if their physician or their  
18 hematologist told them about it, they would like to  
19 hear mostly from there. And most of the things that  
20 we hear is that their doctors are their trusted  
21 source, but some reason their doctors don't even know  
22 about the clinical trials, so when they hear about it

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1 and they ask their doctors about it, the physicians  
2 don't know about it, and this is just their  
3 hematologist and their regular doctors.

4 DR. EGGERS: Okay. Does that resonate with  
5 folks here, that that's how you would like to know  
6 about these things?

7 DR. BULL: Sara, I have a quick question. I  
8 was just wondering of I guess the previous poll that  
9 found that 49 percent had participated in a trial, how  
10 did that come on your radar if it's not being  
11 communicated by the health care providers? How did  
12 you find out? How did participation come about?

13 MS. NELSON: The same way I found out about  
14 this meeting, a friend happened to tell me about it, I  
15 happened to hear about a clinical trial. My  
16 physicians don't even know about this meeting, and  
17 they're at the University of Michigan.

18 MS. MURPHY: I heard it on a radio station  
19 that's tended to gear itself to the black community,  
20 but I only heard it that one time.

21 DR. EGGERS: Back there. Right behind, one  
22 row behind.

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1           MS. ROCHESTER: Thank you. My name is  
2 Gloria Rochester. I'm from New York. I hold two  
3 hats. I'm a parent of a 40-year-old daughter who was  
4 diagnosed with sickle cell. I'm also a part of the  
5 national SCDAAs organization. We are a community-based  
6 organization. And rearing my daughter, I did not hear  
7 a lot of the information that I get in the hospital; I  
8 get it on the outside. My daughter was born in the  
9 early '70s, and I had to go outside and learn how to  
10 cope with it and take care of my daughter.

11           Most of the things that are going on, I  
12 think the community base serve a very vital role in  
13 the community. Of the people right in our backyard,  
14 we do the assessment and the survey. So things like  
15 this coming through, we have the people right in front  
16 of us. It's not only by one hospital, but we will  
17 deal with hospital right around the different  
18 boroughs. So I think things like this would be really  
19 important to go through the community board  
20 organization.

21           Thank you again.

22           DR. BULL: One follow-up question. One of

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1 the things that we've witnessed in recent years has  
2 been galvanizing, gathering of, patients around social  
3 media, sharing stories on Facebook sites, developing  
4 their own independent lists. So I'm just wondering,  
5 does that exist in the advocacy community for sickle  
6 cell?

7 (Chorus of yeses.)

8 DR. BAILEY: Yes. That is actually one of  
9 the best ways to access the patient population. And  
10 just in my personal experience when I was recruiting  
11 for studies, I just needed a tube of blood, doing it  
12 through the clinics, you get a few patients, but  
13 patient-to-patient networking through the community-  
14 based organization, for our community specifically,  
15 it's unlike any other disease I've ever worked with,  
16 most people, they go to clinicaltrials.gov, they go to  
17 the doctors, but in this disease specifically, we go  
18 to each other, and it's -- Tina Kay's radio show she  
19 mentioned, it's Sickle Cell Warriors, Sickle Strong,  
20 supporters, and it's these groups that the information  
21 gets out. Even for this meeting, a majority of us are  
22 here because we found out about it through pushing it

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1 through social media. That is one of the -- in my  
2 opinion, the most effective way to reach this  
3 particular patient population, is through these  
4 organizations.

5 DR. PESANTE: I want to echo what Dr. Bailey  
6 said first, that's absolutely correct. I'm also a  
7 family physician, and I didn't hear about this through  
8 being a family physician. It wasn't in the *American*  
9 *Academy of Family Physician* magazine, it wasn't in the  
10 *New England Journal of Medicine*, there was nothing  
11 coming to me as a physician to tell me about this. I  
12 found out through *What'z Da Count Radio, LA Talk Live*,  
13 through Dr. Bailey actually.

14 I think one of the issues that we're not  
15 really addressing in this whole, "How do you get the  
16 word out and how do we communicate?" the young man  
17 over there began to try to articulate an issue that's  
18 kind of an elephant in the room that we've touched on,  
19 which is the trust and the communication between our  
20 community and the medical community.

21 (Applause.)

22 DR. PESANTE: If we can change those

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1 dynamics such that our community receives the same  
2 respect as the mainstream community in how we're dealt  
3 with by the medical community, that would greatly  
4 improve another way of getting things out. So, yes,  
5 we could use social media, but we would also trust the  
6 physicians to guide us on which trials were good and  
7 which ones weren't and it would be a completely  
8 different dynamic.

9           There has to be more respect and more trust  
10 between our community and the medical community. I  
11 think a lot of that comes from the medical community,  
12 and it starts in medical school, the way the doctors  
13 are trained. I saw so many episodes of differential  
14 treatment with the exact same symptom profile that was  
15 different based on the color of skin, and so if we  
16 change how we train our medical practitioners and  
17 include more cultural sensitivity at that level and  
18 more education about sickle cell -- everything I  
19 learned about sickle cell I had to study on my own,  
20 which is crazy, because I went to medical school. So  
21 I think that that's another aspect that we need to  
22 address to fix this problem.

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1 DR. EGGERS: Thank you very much.

2 (Applause.)

3 MS. HUGHES: Also, when we do hear about the  
4 clinical trials, we aren't given a whole lot of  
5 information. It's just a clinical trial, it's a  
6 flyer, but there is not a lot of information. So why  
7 would I want to participate in something where you're  
8 not giving me enough information to make an  
9 educated --

10 UNIDENTIFIED FEMALE SPEAKER: Decision.

11 MS. HUGHES: -- decision.

12 DR. EGGERS: Okay. Nicole has a question.

13 DR. VERDUN: So those that have participated  
14 in clinical trials, was that through a large academic  
15 center or did you -- after you found out about the  
16 trial, enrolled in the trial, was that through a large  
17 academic center or through some other avenue? And if  
18 you could speak to that, that would be helpful.

19 DR. EGGERS: Maybe a show of hands. So if  
20 you've participated in a large academic center, raise  
21 your hand.

22 DR. VERDUN: Specifically adults, sorry,

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1 because I think the childhood community is a little  
2 bit different.

3 (Show of hands.)

4 DR. EGGERS: And then some other way.

5 (Show of hands.)

6 DR. EGGERS: Okay. So do you want -- yeah.

7 Someone in the --

8 JONATHAN: Hello?

9 DR. EGGERS: Yes. Hi, Jonathan.

10 JONATHAN: Hi. I have to speak for my wife.

11 She's not feeling well. But we've been going to a  
12 sickle cell comprehensive center for 8 years now, and  
13 we've participated in a few studies over those years,  
14 but only one of those times did her hematologist  
15 actually tell her about the study, and it was only in  
16 passing, if we happened to see the director, who we  
17 became familiar with by going to the center so often,  
18 that we found out about these studies. So they were  
19 never brought to our attention. And we've discovered  
20 after they're done, there was a study that we would  
21 have been interested in participating in that we never  
22 heard about. And I just think there is an extreme

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1 lack of knowledge about what's even out there going  
2 on, and I think you could get a lot more participation  
3 if that was communicated properly.

4 DR. EGGERS: Okay. One other comment?  
5 Someone raised their hand? Someone who hasn't -- in  
6 the back I think. Sorry, we're trying to make sure  
7 that we get everyone's voice.

8 MS. ROBINSON: Hi. I know I spoke earlier  
9 in this same segment, but I just wanted to say that we  
10 live in these bodies. We have the information that is  
11 useful to learn more about sickle cell disease and to  
12 help gauge whether a treatment is effective or safe.  
13 So the most important resource here is not tapped  
14 effectively, and I think by changing that, we will  
15 progress in leaps and bounds.

16 DR. EGGERS: Yeah.

17 MS. BROWN-WATTS: I know you may think it's  
18 different for children. No. We're not getting the  
19 information either. And I live in Oklahoma and I ask  
20 the doctors about trials. They have no idea what  
21 trials are happening, what trials are going on, they  
22 can't tell me anything. So it's not different for

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1 children.

2 DR. EGGERS: One more comment on this?

3 UNIDENTIFIED FEMALE SPEAKER: I participated  
4 in a couple of the trials, but I first learned about  
5 it through an organization in New York called SCAC,  
6 and my doctor -- because I didn't know much about  
7 sickle cell when I was diagnosed, I asked a lot of  
8 questions, and I am one who will not do something  
9 until I know the benefits or the pros and the cons of  
10 it, and she was gracious enough to explain it to me.  
11 She explained it in detail. She never flinched at any  
12 questions I asked, and it made me feel comfortable.  
13 And that's where the level of trust comes in because  
14 if you can't communicate with your doctor and ask  
15 questions, why are you going to participate in  
16 anything? So because of that trust factor that I  
17 developed in my doctor, I was willing to participate  
18 in that study.

19 DR. EGGERS: Thank you so much.

20 On the web, do we have any comments? I  
21 mean, we have a lot of comments, but maybe just a  
22 select few of those.

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1           MR. VALENTINE: Right. So we did have some  
2 trends in what some of the clinical trial  
3 considerations for being involved were. Many echoed  
4 what were said in the room, but many people talked  
5 about how the short-term side effects would be  
6 manageable for a trial but there would be much more  
7 concern about the long-term side effects or potential  
8 side effects. Someone mentioned that they actually  
9 have trial burnout from being in many trials as a  
10 child and they don't know if they have the emotional  
11 strength to go back through and deal with unknown or  
12 unanticipated side effects as an adult.

13           As was talked about in the room, people want  
14 more information about the motive of those sponsoring  
15 trials. Someone mentioned actually they would want  
16 transparency in information on the actual animal  
17 trials, the pre-human trials. And then someone also  
18 mentioned it would depend on the distance of trial  
19 sites and if they would be able to keep their same  
20 community doctors while they were participating in a  
21 trial.

22           And then there was an overwhelming response

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1 of people on the web saying that, yes, they find out  
2 about trials through either socially geared websites  
3 or social media.

4 DR. EGGERS: Okay. Thank you.

5 We have one more polling question I think to  
6 wrap up the discussion on the clinical trials, and  
7 that is, just after hearing our discussion and  
8 thinking about that scenario, we are definitely not  
9 holding you to this answer, it's just to get a sense  
10 of your thoughts, if your loved one had the chance,  
11 had the opportunity, to participate in a clinical  
12 trial to study an experimental treatment, one that  
13 looks kind of like that scenario that we presented,  
14 which of the following would best describe your  
15 thoughts? Yes, I would want to know more, but I'm  
16 generally willing to consider participating; no, I  
17 would probably not consider participating; or maybe,  
18 I'm just not sure whether I would be willing to  
19 consider participating or not. This is your last  
20 polling question and then you can put the clickers  
21 away. Oh, please don't take the clickers out of the  
22 room, though.

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1                   (Laughter.)

2                   DR. EGGERS: They have to stay here.

3                   (Answering question.)

4                   DR. EGGERS: Okay. Can we see the results?

5                   Okay, so it looks like there is a general willingness  
6                   to at least learn more and consider with the majority,  
7                   with the highest response, at 46, saying yes, and very  
8                   closely followed by maybe. And it sounds like you  
9                   need a lot more information on the trial, you need a  
10                  lot more communication to you, and I think you've made  
11                  that point very clear.

12                  On the web, do we have similar results?

13                  MS. VAIDYA: Hello. We have very similar  
14                  results on the web saying 48 percent say yes, about 38  
15                  percent say maybe for participating.

16                  DR. EGGERS: Okay. Thank you.

17                  I'm going to turn to my colleagues, and you  
18                  have one last chance if you had any other final  
19                  questions to ask.

20                  (No audible response.)

21                  DR. EGGERS: Okay. We have been at a  
22                  discussion for several hours, and that is a lot of

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1 work on your part, it's a lot of work on our  
2 panelists' part. I want to thank the panelists again  
3 for having that courage and taking the time to share  
4 their thoughts. And I want to thank everyone in the  
5 facilitated discussion. This is a hard thing to do.  
6 Thank you for your patience. Thank you for your  
7 dialogue and your building upon one another as you're  
8 speaking. I think we've really gotten what we need.

9           Kathy is going to close and provide some  
10 final comments after -- not yet, Kathy. We have a  
11 public comment period that Pujita is going to manage.  
12 And this gives people a chance, if you signed up for  
13 it, to talk about something else besides the topics.

14           So with that, my job here is done and I'm  
15 going to turn off the mike and just say thank you.

16           (Applause.)

17           Open Public Comment

18           MS. VAIDYA: Hello, everyone. I would like  
19 to thank you all for coming here today once again.  
20 And we are now going to move on to the Open Public  
21 Comment session. And for those of you who are not  
22 aware, the purpose of this session is to allow an

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1 opportunity for those who have not had a chance to  
2 speak on issues that are not related to our two main  
3 discussion topics. This is also an opportunity for  
4 folks who are not patients or patient representatives  
5 to comment. Please keep in mind that we will not be  
6 responding to your comments, but they will be  
7 transcribed and will be part of the public record.

8           Since we would like this to be a transparent  
9 process, we encourage you to note any financial  
10 interests that you have that are related to your  
11 comment. If you do not have such interests, you may  
12 state that for the record, and if you prefer not to  
13 provide this information, you can still provide your  
14 comments today.

15           So we have collected sign-ups before the  
16 meeting and during the break. We have 12 people  
17 signed up and about 30 minutes for this session, so  
18 please be respectful for your other colleagues here  
19 and other patients and please try to stick to the  
20 about 2-1/2-minute limit. We won't have a timer, but  
21 I will have my phone here keeping track of time. So  
22 if you approach the 2-1/2 minutes, I will let you know

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1 to start wrapping up.

2           So I will briefly run through the order of  
3 speakers, and I apologize if I mispronounce your name.  
4 We have Lakiea Bailey, George Carter, Johnnie Tidwell,  
5 Marybeth McAfee, Tosin Ola, Jay Sweet, Wani (ph)  
6 Thompson, Lewis Hsu, Kim Smith-Whitley, Ibrahim  
7 Kargbo, Tina Kay Hughes, and Dawn Nelson.

8           So could we have Lakiea Bailey first?

9           DR. BAILEY: Thank you. I actually just  
10 signed that and then you suggested -- well, first just  
11 to say that it isn't very often that there are so many  
12 of us patients from all over in one place, and so with  
13 that in mind, we have reserved the restaurant  
14 Friendly's for 6:00 p.m. tonight just for all the  
15 patients to come out, if you are interested, have  
16 dinner, we can all have dinner together, and just  
17 fellowship with each other. And Friendly's Restaurant  
18 is at 12046 Cherry Hill Road. It's about 4 miles from  
19 here, and that is at 6:00 tonight, just if you are at  
20 all interested. We'll be there, we'll have a section  
21 set up just for us just to spend time together. Thank  
22 you.

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1 MS. VAIDYA: Thank you, Lakiea.

2 Next we have George Carter.

3 DR. EGGERS: While George is coming up, can  
4 I just ask Lakiea to say the address again?

5 DR. BAILEY: Of course. That's Friendly's  
6 Restaurant. It's 12046 Cherry Hill Road, Silver  
7 Spring, Maryland. It's about 4 miles from here. And  
8 actually you can get on friendlys.com to look at their  
9 prices and menu and things like that.

10 MS. VAIDYA: Thank you, George.

11 MR. CARTER: Thank you for this opportunity.  
12 A family of someone with sickle cell disease faces  
13 numerous circumstances that challenge their lives.  
14 Sometimes these challenges overwhelm them and put a  
15 strain on relationships. Psychosocial problems have  
16 overcome many clients and their families because of  
17 the physical and mental suffering that they have gone  
18 through.

19 In Dallas, September 27, 2006, the PR  
20 newswire said sickle cell disease is one of the most  
21 prevalent and costly genetic disorders in the United  
22 States today. One in every 4,000 Americans is born

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1 with a form of SCD and many experience chronic anemia,  
2 stroke, spleen and kidney dysfunction, pain crisis,  
3 and susceptibility to bacterial infections. Moreover,  
4 the National Institute of Health, NIH, estimates that  
5 almost one-third of adults with SCD develop pulmonary  
6 hypertension, a life-threatening condition resulting  
7 in a tenfold greater risk of death.

8           Due to this high disease burden, the Sickle  
9 Cell Disease Association of America reports that  
10 sickle cell disease results in an estimated 750,000  
11 hospitalizations a year. The cost of these  
12 hospitalizations was estimated then at \$475 million.  
13 According to the National Institute of Health report  
14 in 2007, nationally the number of hospitalizations  
15 among adults with sickle cell disease was 83,149. In  
16 the *American Journal of Hematology* in June of 2009, a  
17 study reported that the annual cost of medical care in  
18 the United States for people who suffer from sickle  
19 cell disease exceeded \$1.1 billion. The high  
20 proportion of sickle cell disease costs associated  
21 with inpatient hospitalizations suggest that the  
22 interventions that reduce complications such as pain

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1 crisis could be cost effective and cost saving. Allow  
2 me to repeat two sentences for the research and  
3 medical community and drug community. The American  
4 Journal of Hematology, a study says those who suffer  
5 from sickle cell disease, the cost is \$1.1 billion and  
6 that if there were more interventions, then this would  
7 be cost effective and cost saving.

8           So this is a good measure for you all to  
9 take to heart so that you can find what we need to put  
10 this disease behind us. Thank you.

11           MS. VAIDYA: Thank you, George.

12           (Applause.)

13           MS. VAIDYA: Next we have Johnnie Tidwell.

14 So if you could just raise your hand.

15           MR. TIDWELL: Good evening. I just want to  
16 say -- oh, speak up.

17           (Laughter.)

18           MR. TIDWELL: I just want to say we, as  
19 people, those that have sickle cell, my mom always  
20 said a squeaky wheel gets the grease, and we are  
21 starting to squeak.

22           I would like to say thank you to the FDA for

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1 this opportunity, but just keep on keeping on. You're  
2 going to leave here, you're going to die with  
3 something, if it's nothing but old age, something is  
4 going to take you out of here. So just keep on  
5 keeping on. Do what you have to do. Empower others.  
6 Help others. That's what we need to do, and I'm sorry  
7 I can't make this meeting at Friendly's because I'm on  
8 my way back to Newport News, but we need to stay in  
9 contact through whatever means and keep on keeping on.  
10 Keep on putting pressure on our congressmen, our  
11 senators, until we get the results that we need.

12           Sickle cell is here, we're alive, we're  
13 living, and we're living longer. I am 60 years old.  
14 They told me that I would never reach to see 15. Then  
15 they told me I would never reach to see 20. Then they  
16 told me I would never reach to see 35. I'm still  
17 here. By the help of the good Lord, I'm still here  
18 and I'm going to hold on and I'm going to hang on  
19 until He calls me home.

20           (Applause.)

21           MS. VAIDYA: Thank you, Johnnie.

22           Next we have Marybeth McAfee.

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1           MS. MCAFEE: That's a little bit hard to  
2 follow, but my name is Marybeth and I am the Associate  
3 Director of Health Information at Genetic Alliance.  
4 We are a nonprofit umbrella organization, and we're  
5 made up of about 10,000 health-related organizations  
6 including 1,200 support and advocacy groups.

7           We applaud the FDA and its Patient-Focused  
8 Drug Development initiative. We have followed the  
9 FDA's engagement thus far and are eager to offer the  
10 public tools to make it easier to share one's  
11 experience. Through an unrestricted educational grant  
12 from pharma, Genetic Alliance is using a new online  
13 tool to gather perspectives of individuals affected by  
14 sickle cell disease and some of the other conditions  
15 on the FDA list. Our goal is to give people who  
16 cannot come to the FDA or easily access the docket a  
17 way to be heard. We hope to collect a robust dataset  
18 of opinions and to offer a diverse range of  
19 perspectives to the FDA.

20           Several sickle cell organizations, including  
21 Citizens for Quality Sickle Cell Care, located in  
22 northern Connecticut, North Alabama Sickle Cell

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1 Foundation, Sickle Cell Disease Association of America  
2 in Southern Connecticut, and the William E. Proudford  
3 Sickle Cell Fund in Baltimore and D.C. area have  
4 customized our new tool for collecting the experiences  
5 and opinions of people affected by sickle cell disease  
6 as well as their families and caregivers. The portal  
7 is called Platform for Engaging Everybody Responsibly,  
8 or PEER, and each organization has a survey portal on  
9 their website. Each individual taking the survey  
10 chooses meaningful sharing of privacy and data access  
11 preferences that reflect his or her needs and  
12 interests. Simply put, you control who sees the  
13 answers to your survey.

14 Over the next 2 months, these organizations,  
15 as well as we've recently been joined by Sickle Cell  
16 Warriors, and our Genetic Alliance portal will be  
17 collecting information. We will put all of the survey  
18 answers that we have permission to share in the FDA  
19 docket.

20 It is a privilege to work with the various  
21 sickle cell organizations involved in this initiative.  
22 We have heard the voices of you who have shared your

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1 stories here today, and we will work as hard as we can  
2 to use our social network platform to help you and  
3 your loved ones be heard. It is our greatest desire  
4 to let all of your voices be heard loud and clear. We  
5 stand with you.

6 MS. VAIDYA: Thank you, Marybeth.

7 (Applause.)

8 MS. VAIDYA: Next we have Tosin Ola, if you  
9 could raise your hand.

10 MS. OLA: Hi, everyone. I just want to  
11 really thank everyone that came out today, especially  
12 I refer to sickle cell patients as sickle cell  
13 warriors because every day that you are able to get  
14 out of bed, you are winning the battle that day. And  
15 I know that many of you can completely resonate with a  
16 lot of the experiences that have been shared today in  
17 one way or another.

18 And I just want to encourage everyone to  
19 stay active in advocacy. More people need to speak  
20 out and more people need to talk about how sickle cell  
21 affects them. I believe that part of the reason why  
22 sickle cell has not received the treatment modalities

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1 that it can compared to other conditions is because  
2 this is a disease that many people were taught to be  
3 ashamed of, and this is a unique opportunity for us to  
4 lift that veil. You no longer have to be ashamed of  
5 having sickle cell disease. It's okay to tell people  
6 that you have sickle cell disease.

7           Sickle Cell Warriors is dedicated to  
8 promoting advocacy within the sickle cell community,  
9 and we are offering several advocacy classes  
10 throughout the year for people who want to sign up for  
11 advocacy. In addition, the community did resonate  
12 that they were very interested in clinical research,  
13 and they expressed that they wanted more opportunities  
14 made aware to them. So we would like to serve as a  
15 liaison. If there is any clinical research and you  
16 guys are looking for participants or you want people,  
17 you can come to us, and we can disseminate the  
18 information to the community. We're definitely  
19 opening ourselves up to that.

20           The third thing that I wanted to mention is  
21 that there is a lot that goes on to sickle cell that  
22 is not just about the drugs, and I know that FDA is

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1 focused about the drugs and on clinical research, but  
2 there are so many psychosocial issues that we deal  
3 with on a regular and daily basis. You're talking  
4 about work, you're talking about school, you're  
5 talking about the issues with your family, and  
6 maintaining social relationships. All these issues  
7 need to be addressed obviously in a different forum,  
8 but, please, if you do have the ability and the  
9 opportunity to do so, please consider sickle cell  
10 because it is a disease that affects more than 100,000  
11 people in the United States, and it's definitely --  
12 that number is astronomically growing because there is  
13 not enough education on sickle cell trait awareness,  
14 which needs to be a major medical standpoint that has  
15 not really been addressed.

16           So thank you very much to the FDA for  
17 inviting us and allowing us to participate, and we  
18 really do appreciate being given the opportunity to  
19 speak out about sickle cell disease. And once again,  
20 I'm just reiterating, keep talking about sickle cell  
21 because things are happening and it's because of every  
22 single one of you in this room, and we are grateful.

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1 Sickle cell disease affects single tribe, every single  
2 nation, every single person under the sun, and it's  
3 not just a black disease, this is a human disease, and  
4 we are all affected in one way or another. So we all  
5 need your help to eradicate sickle cell disease  
6 forever. Thank you.

7 MS. VAIDYA: Thank you, Tosin.

8 (Applause.)

9 MS. VAIDYA: Next we have Jay Sweet.

10 MR. SWEET: I just have something that I  
11 wanted to say about how I've been treated and how I've  
12 seen sickle cell over my short stay on this planet.

13 Can you hear me now?

14 (Chorus of yeses.)

15 MR. SWEET: Good. Sorry. Meds, it messed  
16 up my voice.

17 I've done the McDonald's March of Dimes, I  
18 have participated in school fundraisers for cancer  
19 awareness, I've given change to the AIDS stands in  
20 front of Walmart or the Salvation Army. I even see  
21 billboards about donating cars to the blind. I'm  
22 done. I'm tired of seeing every other chronic

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1 illness, STD, or whatever get all kinds of funds and  
2 publicity while sickle cell shares none of the  
3 limelight. I'm now waiting, wanting, and working  
4 towards a sickle cell, maybe a walk, a drive, march,  
5 fundraiser, something, something more than a website  
6 and a meeting that we have once in a blue moon.

7           A couple years ago I was going to the store  
8 and I saw one of those cancer stands out in front, and  
9 the guy asked me to donate, and I said, "No." The  
10 person behind me had the audacity to tell me I'm  
11 heartless and cheap. "You can't donate to cancer?  
12 That's just wrong. You have no heart," and went on  
13 about how I'm the problem. And I looked at him and I  
14 just said, "Do you know what sickle cell is?" and he  
15 was like, "No." That's the problem.

16           There is not enough support for the sickle  
17 cell community. Sure, there are websites, there are  
18 Facebook pages, there are support groups, the SCANJ,  
19 the SCDA, that's all well and good, but that's not  
20 enough. We need to have a march of sickle cell  
21 anemia. We need to stand outside of Walmart with  
22 buckets and collect change. We need to have

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1 billboards, awareness in schools, not just for the  
2 students but for the teachers as well. We need to do  
3 this, not just some rich person who has a girlfriend  
4 or boyfriend who has sickle cell, not the doctors who  
5 are looking for another trial study, we, my sickle  
6 cell brothers and sisters, we need to do this.

7 MS. VAIDYA: Excuse me, Jay. I would like  
8 you to wrap up and possibly just mention your final  
9 words.

10 MR. SWEET: The treatment for sickle cell  
11 patients in hospitals is downright disrespectful. I'm  
12 not a drug addict, I'm not faking it, I'm not looking  
13 for my next fix. I'm looking for help so I can find  
14 -- so I can get in and out. Just because I know what  
15 exactly I need in the ER does not mean I'm an addict,  
16 it means I'm trying to get in and out.

17 Doctors, you need to stop asking me in the  
18 ER what normally happens when I get into a crisis. If  
19 you haven't read my medical records and you have no  
20 intentions of giving me what I normally get, then  
21 don't ask me.

22 MS. VAIDYA: Thank you, Jay.

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1           MR. SWEET: Just because -- and last thing.  
2 Just because I'm calm and collected does not mean that  
3 I'm faking it, it means I've had great practice. I'm  
4 in pain a lot. Just because I don't show it to you  
5 and crying does not mean I'm not in pain. And we need  
6 the doctors, the nurses, to understand that we're not  
7 faking it. The ones who are faking it, kick those to  
8 the curb, but don't penalize the majority of us  
9 because of what the few do.

10           (Applause.)

11           MS. VAIDYA: Thank you, Jay. Thank you for  
12 your comments. And you are welcome to submit to the  
13 docket as well.

14           Next we have Wani Thompson.

15           MR. DOZIER: Donnie (ph) has given me her  
16 microphone. She says everything has been covered.

17           My name is Farron Dozier. I'm a retired  
18 Sergeant First Class, United States Army, and I have  
19 the sickle cell trait. I have an organization called  
20 *What'z Da Count* on sickle cell trait prevention and I  
21 host the radio show WDC Radio that I've created, that  
22 God blessed me with, to advocate for sickle cell trait

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1 and disease. You can't talk about one without the  
2 other.

3           Just a few key points that I want to  
4 mention. Language is so important, the way we  
5 describe it, the way we say it, the way it feels to  
6 us. Everybody's individual expression and language is  
7 different. Sickle cell disease is an individual  
8 disease. Everybody is affected differently, different  
9 pain issues, different crises, different triggers.  
10 It's individual. I don't know how you're going to get  
11 a medication to take care of an individual person's  
12 disease when it's -- I don't understand that.

13           You talk about prevention. I'm a prevention  
14 advocate. You can prevent sickle cell disease.  
15 100,000 are born with sickle cell, we know it's  
16 probably more than that, but 3 million or more have  
17 the sickle cell trait. So why are you not talking to  
18 us with the trait who can have a choice when it's time  
19 to have a child versus not knowing after the fact?

20           (Applause.)

21           MR. DOZIER: We all know in other diseases  
22 that diet is important. Sickle cell disease, lupus,

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1 cancer, those are all triggers from our diets. If you  
2 look at your ancestry in sickle cell disease, where it  
3 derived from, we probably should be eating to our  
4 ancestors, where we came from. You know, some of the  
5 things, Mexican food, we probably don't need to be  
6 eating.

7 (Laughter.)

8 MR. DOZIER: Natural foods, electrolytes,  
9 alkaline. There are some natural studies out there,  
10 oxyhemo plus ImmunoBoost and sea moss. I have an  
11 advocate who is actually on this study right now, that  
12 just started it.

13 Language again for me is important. You say  
14 sickle cell is a disease, but it fights malaria, so  
15 how can a disease fight something like a virus? I  
16 don't understand that one.

17 Donation. We have to talk about blood  
18 drives and bone marrow drives. That's so important,  
19 people. Our nationality, we do not donate blood. We  
20 need our ancestry bloodlines to donate to each other.

21 Preventive measures for sickle cell  
22 disease --

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1           MS. VAIDYA: Excuse me. Sorry.

2           MR. DOZIER: Is that it? Okay.

3           MS. VAIDYA: I need to ask you to please  
4 wrap.

5           MR. DOZIER: Okay. And the last thing I  
6 just want to say is just again knowing that sickle  
7 cell trait is in your genes, you want to talk to those  
8 people who carry the trait, thalassemia trait,  
9 hemoglobin C, hemoglobin D, all those when come in  
10 contact with sickle cell disease -- sickle cell trait  
11 is a form of sickle cell disease.

12          MS. VAIDYA: Thank you.

13                    (Applause.)

14          MS. VAIDYA: Next we have Lewis Hsu.

15          DR. HSU: My name is Lewis Hsu. I am here  
16 on behalf of the Sickle Cell Disease Association of  
17 Illinois and the support group of the University of  
18 Illinois Sickle Cell Center. And my financial  
19 disclosure is that my whole job is about sickle cell,  
20 and so if we get rid of sickle cell, I'll be out of a  
21 job, I'll be very happy.

22                    (Laughter.)

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1           DR. HSU: Just a few sound bites. One is  
2 from Ms. Beverly Chickwidozi (ph) in Chicago, is that  
3 what sickle cell has meant for her a lot is absences,  
4 absences from work, absences from school. She had  
5 pain episodes the day that she was taking her GRE  
6 exam. She had pain on her wedding night. And how  
7 much this was impacting her was that even though she  
8 is trying to be a dependable worker, she finds it hard  
9 to do that because of her sickle cell disease, and  
10 this is impacting her quality of life as well as her  
11 work, but she soldiers on nevertheless.

12           From Ms. Gloria Gilliam (ph), who is in her  
13 mid-seventies in the University of Illinois in  
14 Chicago, sickle cell has impacted her mobility. So  
15 this is a very lively lady who was a beauty queen, but  
16 is now in a wheelchair. She has AVN of the hips, of  
17 the shoulders. She needs to have a personal health  
18 aide to help her with even such things as grooming  
19 herself and reaching up for things, but she still has  
20 such joy in life that she wants to sign up for  
21 wheelchair dance classes so that she can get out to  
22 meet more people.

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1           She also passed on the message that she is  
2   somebody who participates in clinical trials and is  
3   such a sophisticated clinical trial participant that  
4   she would list out seven or eight questions that she  
5   would ask people about, "What is this trial about?  
6   What is going to be involved? What is going to be  
7   asked of me? How many days, weeks, or months will I  
8   be committing this? And, lastly, how will I learn the  
9   results of the experiment?" So she was very  
10  interested in that. And she will be in the support  
11  group often and say, "I helped make hydroxyurea  
12  possible because I was in those clinical trials, and  
13  if there is another clinical trial, let me know about  
14  it, I can sign up."

15           I have other patients who say that, "I'm on  
16  disability, I can't work, and therefore participating  
17  in clinical trials is my way of giving to society and  
18  also channeling my frustration with my bad medical  
19  care or the lack of treatments."

20           And then, finally, the two elements of the  
21  quality of life measurements that have been mentioned,  
22  one is that fatigue does affect many, many people, and

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1 sometimes it's fatigue when you are having exertion,  
2 sometimes it's not able to walk 5 blocks or to climb  
3 the stairs or gym.

4 MS. VAIDYA: Excuse me.

5 DR. HSU: Yes. Wrapping up.

6 MS. VAIDYA: Could you please wrap up?

7 Thank you.

8 DR. HSU: But sometimes it could also be  
9 fatigue just at rest, and there is a difference there  
10 for heart failure. And bone marrow transplant is one  
11 of the things that can really help quality of life.  
12 One of my patients said that before going to bone  
13 marrow transplant he couldn't go work out because he  
14 would get pain episodes after just a gym workout, but  
15 now after transplant, he's working out, his biceps are  
16 twice the size they were before. So he's very happy  
17 about it.

18 MS. VAIDYA: Thank you, Lewis.

19 DR. HSU: Thank you.

20 (Applause.)

21 MS. VAIDYA: Next we have Kim Smith-Whitley.

22 And I would like to remind everyone to please try to

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1 stick to the 2-1/2-minute limit just to stay on time  
2 so that we don't get out of here too late.

3 DR. SMITH-WHITLEY: Hello. My name is Kim  
4 Smith-Whitley. I am the Clinical Director of the  
5 Children's Hospital of Philadelphia Sickle Cell  
6 Program and also the Chief Medical Officer for the  
7 Sickle Cell Disease Association of America.

8 So I only speak, as far as nomenclature is  
9 concerned, as regards to children and adults living  
10 with sickle cell disease as patients today because  
11 that is the common theme that providers, the FDA, and  
12 us in the community are really addressing this very  
13 important issue collaboratively all in the room  
14 together to work for a final endpoint.

15 So I just wanted to point out that we have  
16 heard many themes today. We've heard about pain,  
17 we've heard about lessening the intensity, the  
18 duration of the pain. We've actually heard about  
19 different types of pain and how to address those  
20 issues. And we've also heard about the silent impact  
21 of sickle cell disease, the chronic organ damage, the  
22 kidney disease. We've heard about the need to address

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1 the whole patient and to focus on survival, to focus  
2 on survival.

3           So when we really summarize what's happened  
4 today and we take these messages back to our  
5 communities, I really would like everybody to empower  
6 themselves, to spread the message about the importance  
7 of clinical trial participation. And to change the  
8 framework in which we're doing it, we really need to  
9 be responsive to this public docket that is going to  
10 be open until April of this to go on and write your  
11 comments and maybe ask yourself, "As I take my folic  
12 acid, as I take my penicillin, as I participate in the  
13 care that exists now, that has let me live this long,  
14 somebody participated possibly in clinical research to  
15 get me here. What can I say in this open docket so  
16 that we can do things differently that encourages  
17 people in this room today to participate in clinical  
18 trials so that 10 years, 20, 30, 40 years from now  
19 there are fewer people sitting in this room trying to  
20 address the same issue?"

21           Thank you.

22           (Applause.)

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1 MS. VAIDYA: Thank you, Kim.

2 Next we have Ibrahim Kargbo.

3 MR. KARGBO: First I would like to say thank  
4 you to the FDA for providing an opportunity for us to  
5 come express our thoughts and our experiences.

6 We all know that developing trust, whether  
7 it's with your hematologist or with a government  
8 organization, requires us sharing an issue and us  
9 seeing action being taken. So I'm addressing this  
10 specifically so everybody sitting down with the FDA,  
11 you have learned a lot about us, we have opened up to  
12 you in ways that many of us do not open up to our  
13 hematologists, we've opened up to you in ways that  
14 many of our families have never seen us before. So  
15 now we are asking you, what should we expect in terms  
16 of action? We know how slow government moves --

17 (Laughter.)

18 MR. KARGBO: -- but when it comes to dealing  
19 with the lives of people every day, we need quicker  
20 action.

21 Thank you.

22 (Applause.)

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1 MS. VAIDYA: Thank you, Ibrahim.

2 DR. FARRELL: I want to really thank all the  
3 participants. As I said earlier in my opening  
4 remarks, we're all part of this community trying to  
5 solve this problem, and I think as Dr. Whitley was  
6 very eloquent, we all are part of that solution, and  
7 we had a wonderful participation from all the  
8 communities that are involved -- the pharmaceutical  
9 community, academia, patient groups, advocacy groups,  
10 the press, and interested observers -- and so I think  
11 working together is how we're going to solve the  
12 problem of this chronic and debilitating disease.

13 Thank you.

14 MS. VAIDYA: Thank you, Ann.

15 Next we have Tina Kay Hughes. If you could  
16 raise your hands.

17 MS. HUGHES: I host two radio shows that  
18 come on the internet and that are heard around the  
19 world. I'm always looking for sickle cell patients  
20 and parents, caregivers, to tell their stories because  
21 our stories need to be told. So if you want to tell  
22 your story, please see me afterwards.

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1           Also, I have a book and a CD for sale and I  
2 do have them with me. And my website is www.tinakay  
3 -- T-I-N-A-K-A-Y -- .net. And I'm just going to share  
4 a small piece from my CD.

5           I feel like there is an urgency on my life  
6 because they say the life expectancy of a sickle cell  
7 patient is 45, maybe 50 years old. God has given me  
8 this duty, this calling, to be his mouthpiece and not  
9 just a pretty face on a sickle cell poster board.  
10 Even days that my body aches to no end, I remember the  
11 stories from other people who have sickle cell disease  
12 just like me going into bankruptcy, debtors court,  
13 losing their jobs, using up their 401(k)'s they once  
14 had when they could work, pawning belongings to make  
15 ends meet, driving themselves to the emergency room  
16 because this disease is just too much for their own  
17 families to be there for and with them.

18           I hear the voices and I hear the stories,  
19 so, yes, I take up the torch of light like the torch  
20 from the Olympics being passed on so this disease will  
21 not remain some dark curse that many sickle cell  
22 patients think it is. Yes, I take up the torch for

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1 those who need to be educated. I take up the torch to  
2 let whoever is clueless about what they have deemed an  
3 orphan disease, that they say plagues 100,000 brown  
4 people but a census has never been taken in this  
5 country. I will even take up the torch to reveal the  
6 imbalance between different diseases when it pertains  
7 to different races receiving far more than what we  
8 get. They get funding and support and all kind of  
9 education. So, yes, I stand here with this torch in  
10 my hand and I will carry it, I will light up the way  
11 even when the road is narrow --

12 MS. VAIDYA: Tina --

13 MS. HUGHES: -- even when my body seems to  
14 be failing me, even when there is only God with me,  
15 until I can carry this torch no more."

16 (Applause.)

17 MS. VAIDYA: Thank you, Tina.

18 And last we have Dawn Nelson.

19 MS. NELSON: I would like to thank the FDA  
20 for having this meeting. And it was worth missing  
21 work to be here and fly here. But one of the things  
22 -- I've lost passion for my work because my daughter

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1 has sickle cell. And I don't know if other people  
2 feel that way. Nothing else seems really important  
3 when you're fighting this battle all the time. But  
4 I've gotten a lot of information, a lot of passion, a  
5 lot of -- I'm so happy to see that people are 71 years  
6 old and 68. And she texted me, and she's in her  
7 hospital room.

8           But one thing I've heard that I could  
9 probably get some passion from -- I'm an audiologist  
10 -- is that there is lots of hearing loss, and we  
11 haven't discussed that today because our agenda is a  
12 little bit different. And I know that a gentleman  
13 here has done some studies in hearing loss, and that's  
14 my area, balance and hearing, and I just wanted -- but  
15 I knew that this is a -- if I wanted some patients and  
16 if I wanted to get some subjects for a research study,  
17 I've got a whole room full of people, but I have no  
18 way to get in touch with you. And so I asked if there  
19 could be a sign-up sheet. There is probably a HIPAA  
20 violation, there is probably some other name for it in  
21 this setting, for the FDA to give me the names of the  
22 people that are here.

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1           But I would first of all like to get an idea  
2 of how many people are affected by hearing loss. The  
3 room is kind of empty now, and I would just like to  
4 get a feel for what that is about and if that's  
5 something worth looking at. And what about balance  
6 issues? So, you know -- thank you.

7           Andrea? Where is Andrea? Did you set up --  
8 there's a sheet outside? There is a sheet outside on  
9 the table, and if you would be willing to put your  
10 name on it and your e-mail address, then I can go back  
11 and talk to Fred Bess at Vanderbilt, and we're  
12 interested in doing some sickle cell research, that's  
13 something I could develop some passion about. And I  
14 would happy to look into that. And I can see a  
15 career, another -- I mean, I have a career, but I  
16 would love to -- a career path that I think that I  
17 could make a difference.

18           But I would love to be able to learn more  
19 from you and to get more from you, do surveys, some of  
20 this information that we need, but we need to be able  
21 to get in contact with you. So if you would sign that  
22 sheet, give your e-mail address, I would be happy, and

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1 I can work with Andrea to get your information.

2 MS. VAIDYA: Thank you so much, Dawn.

3 Thank you, everyone, for your comments.

4 So before we get started with our last  
5 agenda items, I would like to ask you to please pass  
6 your clickers to the far ends so that our FDA staff  
7 will be able to pick it up.

8 And now I would like to call Dr. Kathy Robie  
9 Suh --

10 DR. EGGERS: Pujita, could I interrupt?  
11 This is Sara.

12 MS. VAIDYA: Ooh, right over here.

13 DR. EGGERS: Yeah. I just want to interrupt  
14 for one minute.

15 MS. VAIDYA: Okay.

16 DR. EGGERS: And that is, we've had some  
17 questions on the web about how people can find out  
18 more information about future patient meetings. And  
19 so FDA has a Patient Network website. If you go to  
20 fda.gov, you will -- oh, if you go to -- he gave me  
21 the website. If you go to [www.patientnetwork.fda.gov](http://www.patientnetwork.fda.gov),  
22 you will find information for patients and patient

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1 advocates, and it's a place that patients can learn  
2 more about participating in clinical trials and other  
3 FDA topics as well as sign up for the Patient Network  
4 Newsletter, which highlights meetings like this one  
5 that happened today.

6 MS. VAIDYA: There's a sign back there.

7 DR. EGGERS: Oh, there's a big sign back --  
8 oh, look.

9 (Laughter.)

10 DR. EGGERS: It comes. There's a sign.

11 MS. VAIDYA: Thank you, Sara.

12 And now I would like to call Dr. Kathy Robie  
13 Suh to the stand.

14 Closing Remarks

15 DR. ROBIE SUH: Well, we have come to the  
16 end of what has been a stimulating and productive day.  
17 Your discussion today underscores the need for  
18 treatments for sickle cell disease as an unmet medical  
19 need. The information, comments, and perspectives you  
20 have provided today will help us at the FDA as we work  
21 to advance development of treatments for sickle cell  
22 disease that address patient needs.

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1           Before I thank you all for coming here, I  
2 want to just take a moment to recap just a few of the  
3 points of the discussion today.

4           You discussed the health effects of sickle  
5 cell disease that are most significant to you as  
6 patients and caregivers. You discussed the specific  
7 impacts that the serious health effects have on your  
8 daily lives, on school attendance and concentration,  
9 on work, on caring for your children and families.

10           We heard that especially for young patients  
11 in school, concentration and ability to focus  
12 mentally, the challenge of being mentally present, the  
13 challenge of maintaining social relationships with  
14 friends and peers are critical to you.

15           We heard that sleep disturbance is very  
16 common.

17           We heard that you worry about dying early,  
18 about a cure not coming in time.

19           We heard that you worry about being able to  
20 work to your potential and about being able to have  
21 children and a family.

22           We heard that physical activity is often

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1 severely limited.

2           We heard that pain is a constant and chronic  
3 problem that is managed with varying degrees of  
4 success, but that pain medications have effects of  
5 their own that can make your daily life more  
6 difficult.

7           We heard about the long pauses sickle cell  
8 disease causes in your lives.

9           You provided insights into the range of  
10 approaches and things that you are doing to manage  
11 your disease, including hydroxyurea and transfusions,  
12 iron chelation, but more broadly, non-prescription,  
13 diet, lifestyle changes, and alternative therapies.

14           You discussed the challenges to making the  
15 best use of what's available and you commented on the  
16 limitations and shortcomings in your interactions with  
17 the health care system.

18           You discussed the physical toll sickle cell  
19 disease has taken on your lives: splenectomy,  
20 cholecystectomy, compression fractures of the spine,  
21 chronic bone pain, avascular necrosis, joint  
22 replacements, leg ulcers, stroke, loss of hearing,

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1 vision problems, priapism.

2           You talked about things that you would want  
3 in an ideal treatment including a direct effect on the  
4 disease and something to stop the tissue damage.

5           You shared your perspectives on current and  
6 emerging treatments and on clinical trials or more  
7 experimental treatments.

8           We heard that sound rationale for expecting  
9 a benefit and a complete explanation, full  
10 explanation, of a clinical study, and being treated  
11 with respect are important to you in considering  
12 whether to participate in a clinical trial.

13           We heard that you are concerned about rare  
14 but serious side effects of medications.

15           As Dr. Farrell described to you in her  
16 comments at the beginning of today, the development of  
17 new treatments is a long and arduous process. Your  
18 contributions today will help us at FDA work with the  
19 manufacturers, academic community, health care  
20 community, advocacy groups, and patient community to  
21 work toward designing trials that will focus on  
22 developing the new treatments for sickle cell disease.

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1           On behalf of the Division of Hematology  
2 Products and all of us here at FDA, thank you all for  
3 participating in today's discussion. We thank both  
4 those who are here present in the room and those who  
5 are participating on the web. In particular, we  
6 especially appreciate and thank the patients' parents  
7 and caregivers who have taken the time and effort to  
8 come, speak, and write or voice their experiences,  
9 concerns, and perspectives on living with sickle cell  
10 disease. Expressing this requires a certain amount of  
11 bravery, and we appreciate that. We especially thank  
12 all the panelists for their articulate and strong  
13 testimonies of their experience with sickle cell  
14 disease and its treatment and what sickle cell disease  
15 means in your daily lives.

16           And, finally, we also thank the health care  
17 providers, representatives of the pharmaceutical  
18 industry and academia, other government agencies, and  
19 FDA colleagues for taking the time to listen as well.

20           Again, thank you for participating and a  
21 safe journey back for all of you who are traveling.

22           (Applause.)

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1           DR. EGGERS: With that, I will officially  
2 close this meeting. And I will echo Kathy's remarks,  
3 I hope that you have safe travels, whether you're just  
4 getting around the Beltway or whether you're flying to  
5 Chicago or California. Thank you very much.

6           UNIDENTIFIED FEMALE SPEAKER: Evaluations in  
7 the back.

8           DR. EGGERS: Oh, yes. Thank you for doing  
9 my job for me. We'll take evaluations in the back.

10           (Whereupon, at 4:06 p.m., the Sickle Cell  
11 Disease Public Meeting on Patient-Focused Drug  
12 Development was adjourned.)

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