



Patient Centered Clinical Trial Design

A Focus on the Patient

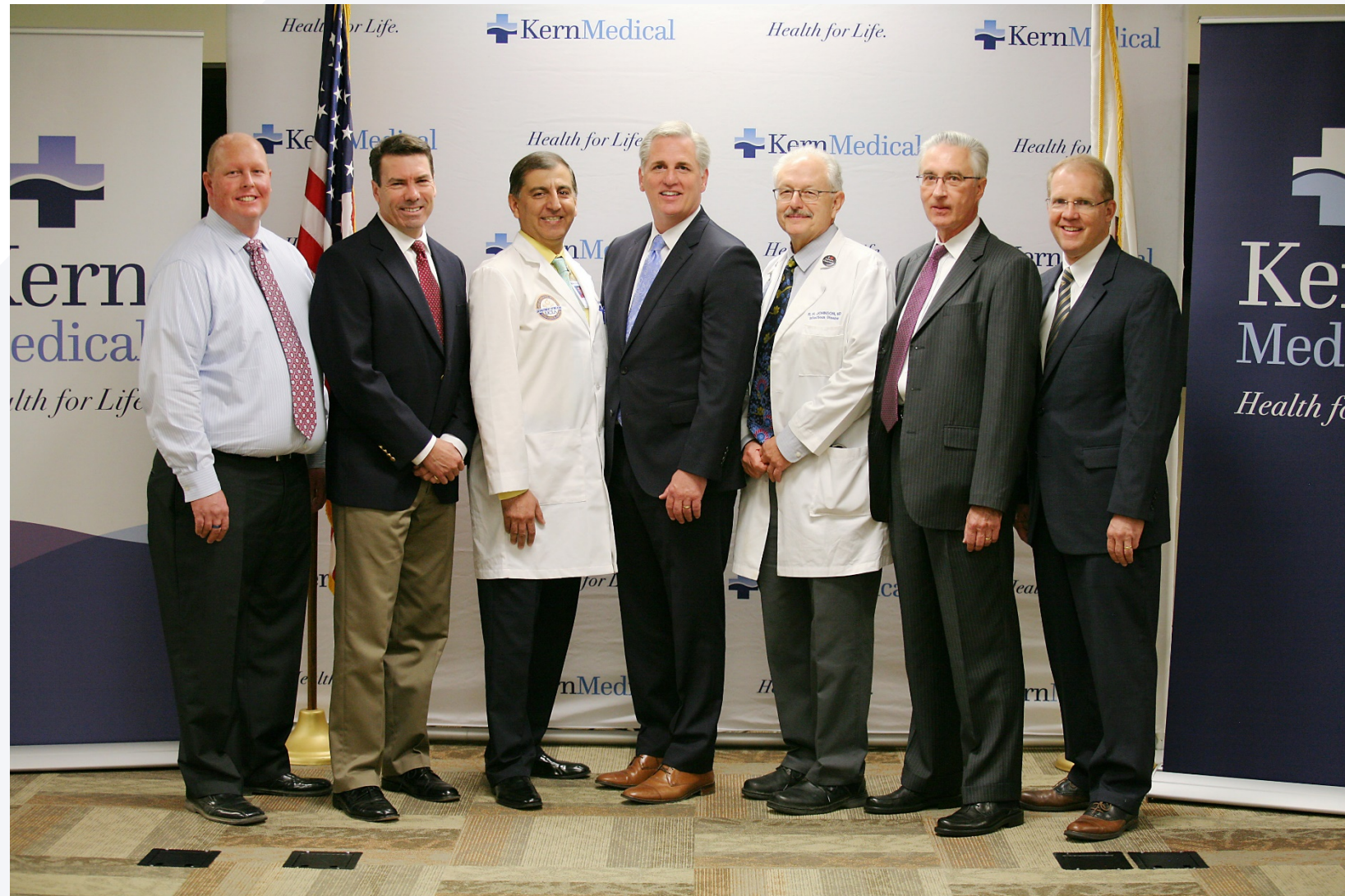
Rob Purdie

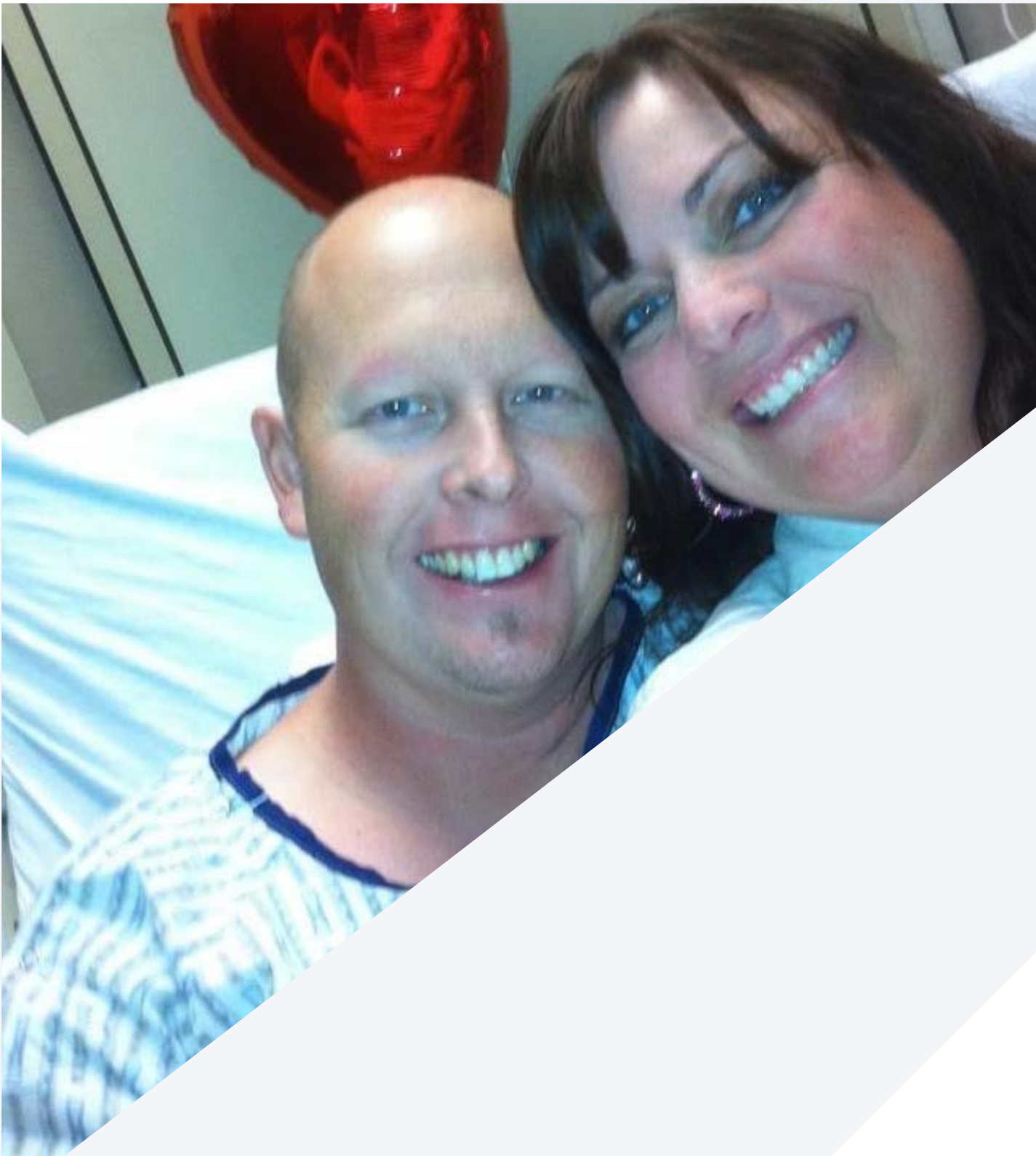
Patient & Program Development Coordinator

Valley Fever Institute at Kern Medical

Agenda

- My Experience
- Current Treatments
- Patient Perspectives
- The Valley Fever Institute
- Patient Centered Endpoints





My Diagnosis

- Symptoms began ~ 1/1/2012
- Diagnosed ~ 2/2012
- Discharged ~ 3/5/2012
- Symptoms partially resolved ~ 5/2012

Medication Timeline

 Fluconazole Monotherapy ~ 10/9/12

 Itraconazole Monotherapy ~ 1/15/2013

 Voriconazole Monotherapy ~ 6/2013

  Voriconazole and Intrathecal Amphotericin ~ 6/18/2014
(Clinically Successful, failed twice due to QOL)

Current Treatment

 Posaconazole and Intrathecal Amphotericin since 12/2015





Approved vs Therapeutic

Approved Dosage

Stop if you experience these Side Effects

- Excessive Tiredness
- Loss of Appetite
- Nausea

Therapeutic Dosage

You will experience these side effects & more

- Excessive Tiredness
- Loss of Appetite
- Nausea



The Burden of Disease

Direct Cost

- Hospitalization
- Procedures
- Treatment
- Testing

Indirect Cost

- Missed work or school
- Deteriorating personal relationships
- Depression & isolation

Clinical

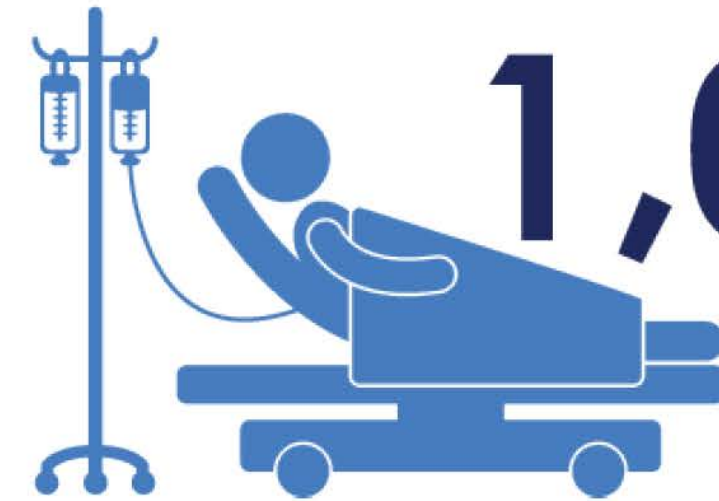
annually



2,400
Clinic Visits



480
Intrathecal
Treatments



1,080
IV Infusions

Research Team



3

Infectious Disease
Physicians



3

Pulmonologists



1

Infectious Disease
Fellow (July 2021)



12

Research Assistants



1

Infectious Disease
Clinical Pharmacist

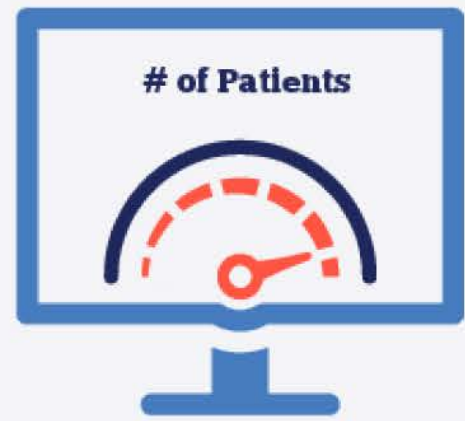


1

Research Nurse

Research

current or active



Patient
Database

2,765



10 Case
Studies

Research
Projects



5



Patient & Program Coordinator

Valley Fever Institute Patients

- Onboard New Patients
- Assist with Patient Navigation
- Patient Support Group

Advocacy & Education

- Collaborate with Community Stakeholders
- Community Events
- Occupation Health Education



Patient Reported Outcomes

Quality of Life Surveys

- SF 12
- SF 36
- PROMIS
- EQ-5D-5L

Cocci & Depression Research Study



Patient Expectations

Treatment Goals

- Manageable Disease
- Manageable Cost
- Manageable Side Effects

Ideal Outcome

- Resume Normal Life
- Resolution of the Disease



Patient Centered End Points

Survey Considerations

- Patients want to Participate
- Available in Primary Language
- Appropriate Literacy Level
- Length of questionnaire



Patient Centered End Points

What Matters

- How a Patient **Feels**
- How a Patient **Functions**
- How long a Patient **Survives**

Questions?

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