

LIVED EXPERIENCE

Diagnosed with polyarticular juvenile idiopathic arthritis over 30 years ago as a teenager, before biologics were available. Educated and fortified by multiple joint replacement and other corrective surgeries, intravenous infusions, injections, blood draws, and participation in other medical “sports”. Daughter, granddaughter, sister, aunt, and friend of/to many people with autoimmune diseases and arthropathies. Fortunate to live in an era of patient engagement and within a community of informed, engaged patients.

WORK EXPERIENCE

ExPPect

Arlington, VA

Founder, CEO, & Chief Patient Advocate, August 2019 – present

Lead the organization’s strategy to embed the lived experience and wisdom of patients into research and healthcare delivery, focusing on opportunities in pre and post graduate allied health professions training, research, and quality improvement.

Society to Improve Diagnosis in Medicine

Chicago, IL

Senior Patient Engagement Advisor, August 2019 – October 2022

Lead the organization’s patient engagement strategy, integrating the lived experience of patients and families harmed by diagnostic error into efforts to improve the quality and safety of healthcare. Created and launched the patient engagement infrastructure for the SIDM Seed Grant program, developed and presented patient engagement curriculum to clinicians and others in the SIDM and National Academies of Medicine Fellowship program, and led the patient engagement track for SIDM’s annual meeting.

FACTORx and Curatio CME Institute

Cherry Hill, NJ and Exton, PA

Curriculum Development, Patient Faculty, Patient Faculty Facilitator, February 2009 – present

Develop and execute CME courses that educate clinicians in the importance of early diagnosis, prompt referral, and appropriate team management of rheumatoid arthritis and other conditions. Provide from patient viewpoint, ideas for enhancing patient-medical team communication to improve patient outcomes. Facilitate the inclusion of patient partners as curriculum co-development and co-presentation.

Arthritis Foundation

Atlanta, GA

Director, Patient Engagement, September 2016 – August 2019

Develop and lead the Foundation’s Patient Engagement strategy, working to infuse the wisdom and lived experience of patients into clinical research, drug and device development, and many other aspects of the healthcare system.

Patient-Centered Outcomes Research Institute (“PCORI”)

Washington, D.C.

Deputy Director, Patient Engagement, February 2013 – August 2016

Build strategic relationships and support the mission of PCORI to fund research that matters to patients by ensuring robust engagement in funded awards and overseeing the collection of promising engagement practices in portfolio.

Patient Partners®, the University of Kansas School of Medicine
Kansas City, Kansas
Patient Instructor, September 1995 – January 2020

Kansas Health Institute
Topeka, Kansas
Health Reform Team Leader, January 2009 – January 2013

Developed and led KHI's health reform efforts which included legislative testimony, publications, and research and policy briefings to keep Kansas policymakers, providers, and consumers abreast of the Affordable Care Act's impact in Kansas and the U.S. Served as an expert resource to Kansas policymakers, providers and consumers on major state and federal health policy issues.

Arthritis Foundation, Greater Kansas City/Western Missouri Chapter
Prairie Village, Kansas
Public Policy and Public Health Coordinator, September 2006 – January 2009

Served as resource to individual patients and/or patient groups trying to navigate their arthritis diagnosis and the health care system. Engaged with fellow chronic disease organizations (ACS, ADA, MDA, e.g.) to address health policy issues via mobilizing our respective constituent bases. Lobbied federal and state lawmakers for better arthritis research funding and patient access.

Human Genome Project Ethical, Legal, Social Issues (ELSI) Grant, University of Kansas, Beach Center on Disability Policy Lawrence, Kansas
Legal Research Associate, November 2003 – August 2006

Interviewed and conducted focus groups with members of the disability community to better understand their hopes for and concerns about genetic research and technology. Dissected all relevant federal and state genetics-related legislation to identify areas ripe for genetic discrimination. Researched and published peer-reviewed articles about the potential benefits of genetic research and genetic technology, and the need for extensive patient protections within the field.

Shook, Hardy, and Bacon LLP
Kansas City, Missouri
Medical Analyst, August 1999 - July 2002

Served a medical liaison for a trial team. Participated in trial preparation including development of expert witnesses, production of demonstratives, and composition of direct and cross examination outlines. Conducted research in areas including pleural, pericardial, and peritoneal mesothelioma, emphysema, asbestosis, and autoimmune disorders.

EDUCATION

University of Kansas School of Law
Lawrence, Kansas
J.D., May 2005

- Journal of Law and Public Policy, Staff Member, Writer (2004-2005)
- Summer Institute: Comparative Law and Politics, Cambridge, England (2003)
- Bioethics Research Assistant to Dr. Jerry Menikoff, (2002-2003)

Kansas State University
Manhattan, Kansas
B.S. Biology, Pre-medicine, May 1999

OTHER ACTIVITIES

Guest Lectures

University of Maryland, Baltimore, Public Health Services Research Program
Lecturer, Patient-Centered Outcomes Research, Comparative Effectiveness Research, and Health Technology Assessment, Fall 2023

Uniformed Services University Reflective Practice Course
Lecturer, Learning from Medical Mistakes, Fall 2022 - present

Johns Hopkins University, Pre-Medicine Program
Lecturer, Understanding the Patient Experience, Fall 2020 – present

Jefferson College of Life Sciences, Jefferson University
Lecturer, Patient Engagement in Drug Development, Fall 2020 - present

World Health Organization (WHO)/Patients for Patients Safety, US
United States

Champion, November 2022 – present

International Atomic Energy Association Radiation Risk Consultancy
WHO Patient Safety **Representative**, February 2023

Innovation and Value Initiative

Alexandria, VA,
Board of Directors, **Member**, December 2022 – present

Geneva Foundation

Bethesda, MD
Scientific Advisory Board, **Member**, February 2021 - present

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Bethesda, MD
Advisory Council, **Member**, February 2021 – present

University of California, San Francisco and National Quality Forum, Optimizing CT Radiation Dose While Lowering the Risk of Radiation-Associated Cancer Project

San Francisco, CA
Technical Expert Panel, **Patient Representative**, February 2019 – December 2022

Food and Drug Administration, (Inaugural) Patient Engagement Advisory Committee (PEAC)

White Oak, MD
Voting member, October 2017 – present

International Society for Pharmacoeconomics and Outcomes Research (ISPOR)

Global Patient Council, **Chair**, January 2020 – June 2022
Patient Representative Roundtable, **Chair**, February 2017 – May 2019
Health/Science Policy Committee, **Member**, May 2017 – June 2022

Patients as Partners Conference

Philadelphia, PA
Patient Co-Chair, 2017, 2018, 2019

Medical Device Innovation Consortium, Science of Patient Input Steering Committee

Washington, D.C.

Member, December 2016 – August 2019

Professional Responsibility in Medicine & Research (PRIM&R)

Washington, D.C.

Member, January 2015 – January 2021

Kansas Bar Association

Topeka, Kansas

Member, February 2011 to present

Federal Grant Reviews

Center for Medicare and Medicaid Innovation (CMMI)

- **Reviewer**, Bundled Payments for Care Improvement Initiative, September, 2012
- **Grant Reviewer**, Affordable Care Act Health Care Innovation Challenge (HCIC) Grant, February 2012
- **Reviewer**, Congressionally Directed Medical Research Programs, Peer Reviewed Medical Research Program (CDMRP)
- **Consumer Reviewer**, American Institute of Biological Sciences (AIBS) Peer Review Process—Arthritis Panel, June 2012 – January 2013

State Grant Reviews

Kansas Association for the Medically Underserved

- **Reviewer**, Capital Improvement Grant Review Team, June 2012 – January 2013
- Office of Primary Care, Kansas Department of Health and Environment
- **Reviewer**, Primary Care Clinic Grant Review Team, May 2009 – January 2013

State Arthritis Steering Committee, Kansas Department of Health and Environment,

Topeka, Kansas

Committee Member, April 2004 – January 2009

Arthritis Foundation—Kansas City

Kansas City, Missouri

Board Member, January 2002 - January 2003, **Committee Member and Volunteer**, September 1999 – January 2013

PEER REVIEWED PUBLICATIONS

Anyane-Yeboah, Adjoa MD, MPH¹; Bermudez, Helen MD^{1,*}; Schrandt, Suz JD²; Narain-Blackwell, Melodie BA³; Bender, Steve BA⁴; Afzali, Anita MD, MPH, FACC⁵. S977 **Health Disparities in the Care of Patients With Inflammatory Bowel Disease: A Focus on Preventive Care & the Patient Perspective**. The American Journal of Gastroenterology 118(10S):p S737, October 2023. | DOI: 10.14309/01.ajg.0000953548.14907.c0

Bitá R. Naimi, Stephanie R. Hunter, Katie Boateng, Nancy E. Rawson, Emily Garvey, Pamela H. Dalton, Jenifer Trachtman, Claire Murphy, Paule V. Joseph, Suz Schrandt, Pamela Silberman, Alexander Duffy, Gurston G. Nyquist, **Patient Insights into the Diagnosis of Smell and Taste Disorders in the United States** [Preprint], doi: <https://doi.org/10.1101/2023.09.20.23295861>.

Perfetto EM, Love TR, Oehrlein EM, Schoch SC, Schrandt S; National Health Council Patient-Centered Core Impact Set Advisory Committee. **A Foundation for Patient-Centered Core Impact Sets: Key Learnings from Past and Existing Approaches**. Patient. 2023 May 19. doi: 10.1007/s40271-023-00630-1. Epub ahead of print. PMID: 37204700.

Predmore Z, Chen EK, Concannon TW, Schrandt S, Bartlett SJ, Bingham CO, Xie RZ, Chapman RH, Frank L. **Treatment goals for rheumatoid arthritis: patient engagement and goal collection**. J Comp Eff Res. 2023 May;12(5):e220097. doi: 10.57264/ceer-2022-0097. Epub 2023 Mar 28. PMID: 36976963.

Perfetto, E, Schrandt, MS, Escontrias, O, Burke, L, **Patient-Centered Core Impacts Sets (PC-CIS): What They Are and What They Are Not**, February 2023 INNOVATIONS in Pharmacy 14(1):3

Wiegand, Aaron A., Dukhanin, Vadim, Sheikh, Taharat, Zannath, Fateha, Jajodia, Anushka, Schrandt, Suzanne, Haskell, Helen and McDonald, Kathryn M.. **"Human centered design workshops as a meta-solution to diagnostic disparities"** Diagnosis, vol. 9, no. 4, 2022, pp. 458-467.
<https://doi.org/10.1515/dx-2022-0025>

Neale, H, Schrandt, S, Abbott, BM, et al. **Defining patient-centered research priorities in pediatric dermatology**. Pediatr Dermatol. 2022; 1- 8. doi:10.1111/pde.15199

Perfetto, E,...Schrandt, MS, **"A Blueprint To Advance Patient-Centered Core Impact Sets"**, Health Affairs Forefront, June 14, 2022. DOI: 10.1377/forefront.20220610.963313

Kanter, MP, Schrandt, MS, **Thanking patients for their role in research is part of wider cultural change**, *BMJ* 2022;376:o451

Bell SK, Bourgeois F, DesRoches CM, Dong J, Harcourt K, Liu SK, Lowe E, McGaffigan P, Ngo LH, Novack SA, Ralston JD, Salmi L, Schrandt S, Sheridan S, Sokol-Hessner L, Thomas G, Thomas EJ. **Filling a gap in safety metrics: development of a patient-centred framework to identify and categorise patient-reported breakdowns related to the diagnostic process in ambulatory care**. *BMJ Qual Saf*. 2021 Oct 16:bmjqs-2021-013672. doi: 10.1136/bmjqs-2021-013672. Epub ahead of print. PMID: 34656982.

Jeanne M. Regnante, Suzanne Schrandt, Nicole A. Richie, Jamie Roberts, Guy Yeoman, Nicholas Brooke, Roslyn F. Schneider, Mary Stober Murray, Ify Sargeant, Marilyn A. Metcalf, Craig Lipset, Stephen Yates, Fabian Somers, Elizabeth Manning, Anne Marie Hamior, Alicyn Campbell, Bray Patrick Lake, Cynthia Grossman, Sylvia Baedorf Kassis, Barbara E. Bierer, **Chapter 5 - Patient voice in clinical trial programs in industry**, Pragmatic Randomized Clinical Trials, Academic Press, 2021, Pages 47-70, ISBN 9780128176634, <https://doi.org/10.1016/B978-0-12-817663-4.00026-X>

Clifton O Bingham, III, Alessandra L Butanis, Ana Maria Orbai, Michelle Jones, Victoria Ruffing, Anne Lyddiatt, Mary Suzanne Schrandt, Vivian P Bykerk, Karon F Cook, Susan J Bartlett, **Patients and clinicians define symptom levels and meaningful change for PROMIS pain interference and fatigue in RA using bookmarking**, *Rheumatology*, 2021; keab014,
<https://doi.org/10.1093/rheumatology/keab014>

Schifferdecker KE, Butcher RL, Knight E, et al. **Stakeholder Development of an Online Program to Track Arthritis-Related Patient-Reported Outcomes Longitudinally: Live Yes! INSIGHTS**. *ACR Open Rheumatol*. 2020;2(12):750-759. doi:10.1002/acr2.11203

Correll, C,...Schrandt, MS, **"Identifying research priorities among patients and families of children with rheumatic disease living in the United States"**, *J. Rheumatol*. 2020 Feb 15. pii: jrheum.190934. doi: 10.3899/jrheum.190934.

Schanberg, L,...Schrandt, MS, "**Toward Accelerated Authorization and Access to New Medicines for Juvenile Idiopathic Arthritis**", *Arthritis & Rheumatology*. 2019 Jul 16. <https://doi.org/10.1002/art.41043>.

Ollendorf, D,...Schrandt, MS. "**Practical Next Steps in Improving Value Measurement and Use, Value in Health**". 2019 June. Volume 22, Issue 6, S29 - S31.

Knight, A,...Schrandt, MS, "**Engaging patients and parents to improve mental health for youth with systemic lupus erythematosus**", 13th International Congress on Systemic Lupus Erythematosus (LUPUS 2019), San Francisco, California, USA, April 5–8, 2019. DOI: 10.1136/lupus-2019-lsm.92

Morgan, EM, ...Schrandt, MS, "**Establishing an updated core domain set for studies in juvenile idiopathic arthritis: a report from the OMERACT 2018 JIA Workshop**", *J Rheumatol*. 2019 Feb 15. pii: jrheum.181088. doi: 10.3899/jrheum.181088. [Epub ahead of print] PMID:30770499.

Forsythe L., Frank L., Tafari T., Cohen S., Lauer M., Clauser, S, Goertz, C., Schrandt S., "**Unique Review Criteria and Patient and Stakeholder Reviewers: Analysis of PCORI's Approach to Research Funding**", In press. Available [here](#).

Forsythe, L., Heckert, A., Margolis, M., Schrandt, S., Frank, L., "**Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute**", *Journal of Quality of Life Research* (2017), <https://doi.org/10.1007/s11136-017-1581-x>.

Smalley, JB, Fleece, MJ, Schrandt, MS, Sheridan S, "**Chapter 30: USA, Comparative Effectiveness Research**", *Patient Involvement in Health Technology Assessment*, Springer: 2017.

Forsythe, L, Frank, L, Sheridan, S, Schrandt, S, "**The PCORI Engagement Rubric: Promising Practices for Partnering in Research**", *Ann Fam Med* 2017;15:165-170. <https://doi.org/10.1370/afm.2042>.

Ellenberg, SS, Culbertson, R, Gillen, DL, Goodman, S, Schrandt, S, Zirkle, M, "**Data Monitoring Committees for Pragmatic Clinical Trials**", *Clinical Trials* 2015 Oct;12(5):530-6. doi: 10.1177/1740774515597697. Epub 2015 Sep 15.

Frank, L., Forsythe, L, Ellis, L., Schrandt, S., Sheridan, S., Gerson, J., Konopka, K., Daugherty, S., January 6, 2015, "**Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute**", *Quality of Life Research*. (2015) 10.1007/s11136-014-0893-3

Erika Blacksher, Ph.D., Gina Maree, LSCSW, Suzanne Schrandt, JD, Chris Soderquist, BS, Tim Steffensmeier, PhD, Robert St. Peter, MD, "**Health Policy, Ethics, and the Kansas Legislative Health Academy**". *American Journal of Public Health*. (2015) 10.2105/AJPH.2014.302333

H. Rutherford Turnbull, III, Matthew J. Stowe, Ann P. Turnbull, and Mary Suzanne Schrandt, "**Public Policy and Developmental Disabilities: A 35-Year Retrospective and a 5-Year Prospective Based on the Core Concepts of Disability Policy**" in Samuel L. Odom, *Handbook of Developmental Disabilities*, Guilford: 2007.

H. Rutherford Turnbull III, Matthew J. Stowe, Rack, Jennifer, Schrandt, Suzanne, Laub, Leslie, Pence, Ray, "**The Importance of Attitudes Toward and Understanding of Disability and Science in the Age of Genetics**", *Research and Practice for Persons with Severe Disabilities* 09/2007; 32(3). DOI:10.2511/rpsd.32.3.190.

H. Rutherford Turnbull III, Matthew J. Stowe, John Agosta, Ann P. Turnbull, M. Suzanne Schrandt, John F. Muller, **Federal family and disability policy: Special relevance for developmental disabilities.** *Mental Retardation and Developmental Disabilities Research Reviews*, 13: 114-120, 2007.

Stowe, M.J., Turnbull, H.R., Schrandt, M.S., & Rack, J., **Looking to the future: Intellectual and developmental disabilities in the genetics era.** *Journal on Developmental Disabilities, Volume 13, Number 2, 2007.*

SELECT PUBLICATIONS AND MULTI-MEDIA PRESENTATIONS
(Full list available upon request)

October 4, 2023, **“The Future of Patient Activation and Patient Engagement”**, Patient-Centered Outcomes Research Institute Annual Meeting, Opening Keynote, Washington, DC.

September 18, 2023, **“Engaging Patients for Medical Radiation Safety”**, World Health Organization World Patient Safety Day, speaker, virtual platform.

October 16, 2022, **2022 Patient Summit**, Co-creating solutions to diagnostic errors. Society to Improve Diagnosis in Medicine Annual Meeting, speaker, event lead, Minneapolis, MN.

September 21, 2022, BioMarin North American Virtual Patient Advocacy Forum, entitled: **“Mind the Gap Making the Therapeutic Lifecycle Understandable and Accessible for Patients and Patient Communities.”** speaker, virtual platform.

August 17, **“Patient-Centered Core Impact Set Dialogue”**, National Health Council, speaker and facilitator, virtual platform.

August 3, 2022, **“Pre-Conference Rheumatology Intensive Adult Track”**, Rheumatology Nurses Society annual meeting, patient faculty member, Orlando, FL.

Diagnosis June 23-24, 2022, **“Patient Engagement in Medical-Product Research and Development”**, ISPOR Short Course, speaker, virtual platform.

March 30, 2022, **“From Sideline to Quarterback: Realizing the Full Potential of Patients as Team Members”**, ACHE Congress on Healthcare Leadership, speaker, Chicago, IL.

March 23, 2022, **“Addressing opportunities and challenges that enable medical affairs to play a key role in driving a patient-centric culture”**, MAPS 2022, speaker, New Orleans, LA.

February 24, 2022, **“Engaging the Expertise of Patient and Family Educators in Medical Education”**, Institute for Patient and Family Centered Care Webinar, co-host/panel facilitator, virtual platform, available at: <https://www.ipfcc.org/events/webinar-recordings.html>

February 22, 2022, **“Learning Through Lived Experience: Partnering with Patient Faculty in the Virtual Learning Environment”**, Society for Academic Continuing Medical Education Annual Meeting, speaker, virtual platform.

February 16, 2022, **Patient Engagement Session**, National Academies of Medicine Scholars in Diagnostic Excellence/Society to Improve Diagnosis in Medicine Fellowship in Diagnostic Excellence Program, presenter, speaker. Enduring content available here: <https://dxescholars.nam.edu/>

February 2022, **Patient Advocacy: The Growing Voice of Healthcare**, Value and Outcomes Spotlight, JAN/FEB 2022 VOL. 8, NO. 1, contributor. Available here: <https://www.ispor.org/docs/default->

[source/publications/value-outcomes-spotlight/january-february-2022/ispor_vos_february-2022_online1ba7d8902e6442a6a1d5f027aa8f8f1b.pdf?sfvrsn=c5c39a2d_0](https://www.ispor.org/2022/01/27/2022-01-27-1ba7d8902e6442a6a1d5f027aa8f8f1b.pdf?sfvrsn=c5c39a2d_0)

January 27, 2021, “**Patient Engagement: Deconstructing Terminology for Efficiency and Effectiveness**”, HPI Press Ganey PSO National Safe Table, speaker, virtual platform.

October 25, 2021, **Learning and Leading Through Partnership: Spotlight on Three Projects Grounded in Transformative Collaboration**, Diagnostic Errors in Medicine Annual Meeting, speaker, virtual platform.

September 30, 2021, “**Precision for Whom? Partnering with Patients to Ensure that Precision Medicine Targets What Matters**”, MIT NEWDIGS LEAPS Project Research Brief, 2021L309v054. Accessed at: <https://newdigs.mit.edu/sites/default/files/RB%20Px%20Engagement%202021L309v054.pdf>

August 15, 2021, “**Improving TeleDiagnosis: A Call to Action**”, Final Project Findings, Society to Improve Diagnosis in Medicine, PCORI EAIN-00177. Accessed at: <https://www.improvediagnosis.org/wp-content/uploads/2021/09/TeleDx-Final-Report-Update.pdf>

July 13, 2021, “**Addressing Missed and Delayed Diagnosis of Heart Disease in Women**”, National Hospital Alliance Annual Meeting, WomenHeart, speaker, virtual platform.

May 26, 2021, “**The power of partnership: How patients can—and do—partner to improve diagnosis in medicine**”, Working Together to Improve Diagnosis Conference, Constellation/lowa Healthcare Collaborative/SIDM, keynote, virtual platform.

March 27, 2021, “**How Innovation Changes Patients; How Patients Change Innovation**”, Thomas Jefferson University Graduate Class on Drug Development, Philadelphia, PA, virtual platform.

January 27, 2021, “**Exploring Gaps in the Literature**”, Convening on Missed and Delayed Diagnosis of Heart Disease in Women, WomenHeart and the Society to Improve Diagnosis in Medicine, speaker and facilitator, virtual platform.

December 1-2, 2020, “**Committee on Security of America's Medical Product Supply Chain**”, Public Workshop, National Academies of Medicine, End-user reactor panel, virtual platform.

October 19, 2020, “**Flipping the Script: Patients as Partners in Clinical Education**”, Workshop, Diagnostic Error in Medicine Annual Conference, speaker, virtual platform.

September 29, 2020, “**Using Patient-Preference Information in Medical Device Regulatory Decisions: Benefit-Risk and Beyond**”, ISPOR/FDA Summit, welcome and opening address, virtual platform.

August 27, 2020, “**Voice of the Patient**” Summit, Alliance for Health Policy, discussant, virtual platform.

August 18, 2020, “**Combatting Diagnostic Error: How Patients and Families are Leading the Charge Toward Safety**”, Institute for Patient and Family-Centered Care 9th Annual International Conference on Patient- and Family-Centered Care, virtual platform.

June 17, 2020, “**Putting the Drive in Patient-Driven Publications**”, International Society of Medical Publication Professionals 2020 Annual Meeting, Panel Discussion, virtual platform.

May 7, 2020, “**The Patient Perspective in Healthcare Quality**”, Pharmacy Quality Alliance 2020 Annual Meeting, Panel Discussion, virtual platform.

April, 24, 2020, **“Turning Harm into Power: How Patients and Families Are Helping to Drive Diagnostic Quality at the Society to Improve Diagnosis in Medicine”**, PFCC Partners Webinar, presentation, virtual platform.

November 6, 2019, **“Big Healthcare Data: Endless Opportunities for Research and Learning”**, International Society of Pharmacoeconomics and Outcomes Research ISPOR Europe Meeting, Plenary Panel, Copenhagen, Denmark.

September 26, 2019, **“Who’s got my health data?”**, AcademyHealth Health Data Law Institute, Panel Discussion, Washington, D.C.

August 27, 2019, **“A Call to Action: Patients as Partners in Healthcare Professions Education”**, International Association of Medical Educators Annual Conference, Keynote Plenary, Vienna, Austria.

June 13, 2019, **“Multidisciplinary Workshop on the Future of Health Data”**, Yale Law School, Discussant, New Haven, Connecticut.

April 30, 2019, **“If things go wrong; The role of patients in designing and distributing alerts”**, Council of International Organizations of Medicine and Science, Open Meeting on Patient Involvement in Development and Safe Use of Medicines, Presentation, Geneva, Switzerland.

March 25, 2019, **“Principles of Patient Engagement”**, EXCITE Health Technology Global Summit, Patient Panel, Washington, D.C.

March 18, 2019, **“Enhancing the Incorporation of Patient Perspectives in Clinical Trials”**, FDA/CTTI Stakeholder Meeting, Patient Panel, Silver Spring, MD.

March 11, 2019, **“How the Device Industry uses the Science of Patient Input to Impact the Total Product Lifecycle”**, Patient Panel, Philadelphia, PA.

November 13, 2018, **“Transforming Health Care: The Impact of Patient Engagement”**, ISPOR Europe 2018, Panel Presentation, Barcelona, Spain.

September 27, 2018, **“Who’s Got My Data? Rethinking the Role in Consumer Role in Healthcare Data”**, Academy Health Data Policy Strategy Orientation, Panel Discussion. Washington, D.C.

August, 10, 2018, **“Putting Patients First in Drug Development: A Dialogue on FDA’s Guidance”**, National Health Council Dialogue with Commissioner Scott Gottlieb, Patient Panel. Washington, D.C.

August 2, 2018, **“Externally-led Juvenile Idiopathic Arthritis Patient-Focused Drug Development Meeting”**, Arthritis Foundation, Co-Organizer/Facilitator. Washington, D.C. Proceedings available [here](#).

June 25, 2018, **“A Day in the Life: Making Patient Engagement Real”**, Drug Information Association Annual Meeting. Boston, MA.

May/June 2018, **“Measuring Meaningful Patient Engagement: A Multi-Stakeholder Representative Roundtable”**, International Society of Pharmacoeconomics and Outcomes Research Value and Outcomes Spotlight, Schrandt, S., Tesoro T., Cooblall, C., and ISPOR Patient Roundtable Participants. Available [here](#).

May, 21, 2018, **“Defining Patient Centeredness and Engagement in HEOR: Proposed Definition and Stakeholder Response”**, International Society of Pharmacoeconomics and Outcomes Research Annual Meeting, Baltimore, MD.

March 16, 2018, “**Crossing the Patient Engagement Adoption Chasm**”, Patients as Partners Annual Meeting, Panel discussion. Philadelphia, PA.

November 5, 2017, “**Patient Engagement in Research**”, American College of Rheumatology Annual Meeting, Panel presentation. San Diego, CA.

November 2, 2017, “**Making Patient Involvement Routine—and More Relevant**”, Eye for Pharma, Annual Patient Summit, Panel discussion. Philadelphia, PA.

October 30, 2017, “**Accelerating Meaningful Outcomes Through Patient-Reported Outcomes Measures**”, Healthcare Payment and Learning Action Network, Annual Meeting, Panel discussion. Washington, D.C.

June 21, 2017, “**Patient Engagement in Medical Affairs**”, Panel Discussion, Drug Information Association Annual Meeting, M. Suzanne Schrandt, J.D., et. al. Chicago, IL.

March 8, 2017, “**Externally-led Osteoarthritis Patient-Focused Drug Development Meeting**”, Arthritis Foundation, Organizer/Moderator. Washington, D.C. Proceedings available [here](#).

November 14, 2016, “**Partnership as a Tool for Engagement in Product Development**”, Rapid Fire Panel, Partnering For Cures, M. Suzanne Schrandt, J.D., et al. New York, NY.

October 27, 2016, “**Patient Engagement in Research**”, CIHR-IMHA Joint Session, Arthritis Alliance of Canada Annual Meeting, M. Suzanne Schrandt, J.D., et al. Montreal, QC, Canada.

September 8, 2016, “**On Involving Patients in Clinical Development: The Patient Perspective**”, Big Data, Patients and the Real World in Pharmaceutical Medicine and Drug Development, European Centre of Pharmaceutical Medicine, M. Suzanne Schrandt, J.D. Basel, Switzerland.

July 26, 2016, “**US Perspectives on Patient Engagement**”, Measuring What Matters Most, International Society of Quality of Life Research, M. Suzanne Schrandt, J.D. Washington, D.C.

June 14, 2016, “**Patient Centricity and Patient Engagement: Why, When, Who, What, and Where?**”, Patient Engagement Symposium, Geisinger Health System, M. Suzanne Schrandt, J.D. Danville, PA.

March 22, 2016, “**Patient Engagement: Opportunities across the Healthcare Continuum**”, DIA Medical and Scientific Affairs Keynote, M. Suzanne Schrandt, J.D. Orlando, FL.

November 13, 2015, “**Partners in Arthritis: A Hands-On Workshop in Patient-Delivered Musculoskeletal Curriculum**”. Where’s the Patient Voice in Health Professional Education?”, University of British Columbia, M. Suzanne Schrandt, J.D., Meghan Adams, ARNP, Nancy Brown, Maureen Knell, PhD, Betty Prost, Darlene Twymon. Vancouver, BC, Canada.

October 20, 2015, “**The Value of Patient Engagement**”, National Academy of State Health Policymakers, M. Suzanne Schrandt, J.D. Dallas, TX.

September 24, 2015, “**Rare Disease and PCORI**”, Global Genes Annual Meeting, M. Suzanne Schrandt, J.D. Huntington Beach, CA.

May 18, 2015, “**Patient Engagement: Updates from the field**”, ISPOR Patient Engagement Roundtable, M. Suzanne Schrandt, J.D. Washington, D.C.

November 27, 2014, “**PCORI: Engaging Patients in the Research Process**”, INVOLVE Annual Conference, M. Suzanne Schrandt, J.D. Birmingham, England.

November 19, 2014, “**Nothing about Us without Us**”, American College of Rheumatology/Association of Rheumatology Health Professionals. M. Suzanne Schrandt, J.D., Amye Leong, Monique Gignac. Boston, MA.

March 26, 2014, Panel Discussion: **Best Practices in Patient Engagement**, Institutes of Medicine Roundtable. M. Suzanne Schrandt, J.D. Washington, D.C.

December 27, 2013, Presentation: “**Patient Engagement at PCORI**”, Pain Action Alliance to Implement a National Strategy Annual Meeting. M. Suzanne Schrandt, J.D. Washington, D.C.

September 17, 2013, Presentation: “**Disparities in Musculoskeletal Care**”, 2013 National Caucus on Arthritis & Musculoskeletal Health Disparities, Movement is Life, M. Suzanne Schrandt, J.D. Washington, D.C.

June 29, 2013, Presentation: “**PCORI and Mental Health**”, National Alliance on Mental Health National Convention. M. Suzanne Schrandt, J.D. San Antonio, TX.

February 25, 2013, Roundtable: “**Partnering with Patients to Drive Shared Decisions, Better Value, and Care**”, Institute of Medicine. M. Suzanne Schrandt, J.D. Washington, D.C.

July 2012, Schrandt, Mary Suzanne, **How the Supreme Court Ruling on the ACA Affects Health Insurance in Kansas**, Kansas Health Institute, M. Suzanne Schrandt, J.D. (publication)

June 2012, Schrandt, Mary Suzanne, **The Affordable Care Act Ruling and What it Means for Kansas**, Kansas Health Institute, web tutorial available at: <http://www.khi.org/news/2012/jun/28/affordable-care-act-ruling-and-what-it-means-kansa/>.

May 2012, Video: **The Great Health Reform Debate**, Mary Suzanne Schrandt, J.D. and other invited guests, Kansas Health Institute, Available at: <http://www.khi.org/videos/>

February 2012, Schrandt, Mary Suzanne (et al.) **Medicare Changes Include Care Coordination and Prescription Drug Costs**. Kansas Health Institute. (publication)

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