

## LIVED EXPERIENCE

Diagnosed with polyarticular juvenile idiopathic arthritis 30 years ago as a teenager, before biologics were available. Educated and fortified by multiple joint replacement and corrective surgeries, intravenous infusions, injections, blood draws, and participation in other medical “sports”. Daughter, granddaughter, sister, aunt, and friend to many people with autoimmune diseases and arthritides. 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 and quality improvement.

- *Create novel patient-generated health data (PGHD)-based curriculum for continuing medical education courses in autoimmune and inflammatory diseases.*
- *Serve as patient workstream co-lead for the Learning Ecosystems Accelerator for Patient-centered, Sustainable innovation (LEAPS), Massachusetts Institute of Technology.*
- *Facilitate patient engagement for rheumatoid arthritis value and assessment project.*
- *Developed and facilitated the patient engagement track for the 2019 and 2020 Pediatric Dermatology Research Alliance annual conferences.*

### Society to Improve Diagnosis in Medicine (SIDM)

Evanston, IL

**Senior Patient Engagement Advisor**, September 2019 – present

Lead the patient engagement strategy for the organization including serving as liaison to the Patient Engagement Committee, and facilitating the involvement of patients in the Diagnostic Errors in Medicine conference, Seed Grant program, and other SIDM projects and strategies.

- *Lead PCORI-funded Tlediagnosis project, exploring the barriers and facilitators to the rapid upscale of telemedicine during the COVID pandemic.*
- *Inform through speaking engagements and lectures, methods for partnering with patients and families to reduce diagnostic error.*
- *Serve as SIDM liaison and co-lead on the PCORI-funded WomenHeart convening to discuss and address disparities in diagnosis of heart disease in women.*

### Arthritis Foundation

Atlanta, GA

**Director, Patient Engagement**, September 2016 – present

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.

Rheumatoid Arthritis: Primary care initiative for Improved Diagnosis and outcomes (RAPID)

Curatio CME Institute, Accreditation through Penn State Medical College

Exton, PA

**Curriculum Development Steering Committee Member, Patient Spokesperson**, February 2009 – present

Develop and execute CME courses that educate primary care clinicians in the importance of early diagnosis, prompt referral, and appropriate team management of rheumatoid arthritis. Provide from patient viewpoint, ideas for enhancing patient-medical team communication to improve patient outcomes.

Patient Partners®, the University of Kansas School of Medicine

Kansas City, Kansas

**Patient Instructor**, September 1995 – January 2020

As part of the curriculum at The University of Kansas School of Medicine, teach medical students musculoskeletal examination techniques to discern signs and symptoms of arthritis and to enhance communication skills with patients.

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

### Geneva Foundation

Bethesda, MD

Scientific Advisory Board **Member**, February 2021 – present

### International Society for Pharmacoeconomics and Outcomes Research (ISPOR)

Global Patient Council, **Chair**, January 2020 – present

Patient Representative Roundtable, **Chair**, February 2017 – May 2019

Health/Science Policy Committee, **Member**, May 2017 – present

### 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

- *Winner, James May National Award for Young Adult Leadership (2006)*
- *Winner, Local Chapter Patient Services Award (2002)*
- *Keynote speaker at 2000 Eastern Missouri Juvenile Arthritis Conference in St. Louis, Missouri.*

### PEER REVIEWED PUBLICATIONS

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/acr.2.11203

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)

August 18, 2020, “**Combatting Diagnostic Error: How Patients and Families are Leading the Charge Toward Safety**”, Institute for Patient and Family-Centered Care 9<sup>th</sup> 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 Monthly 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)

February 2012, Presentation: "**Update on the Affordable Care Act: What has happened and where are we now?**" before select Kansas House and Senate Health Committee Members. M. Suzanne Schrandt, J.D. Topeka, KS.

October 2011, Testimony; "**Health Insurance Coverage in Kansas, Pre and Post-Health Reform**", Special Legislative Committee on Financial Institutions and Insurance. Topeka, KS.

September 2011, Cleveland, Mary Suzanne (et al.) "**The Impact of Health Reform on Insurance Benefits and Mandates in Kansas**". Kansas Health Institute. (publication)



May 2011, Kansas Public Television appearance “**The Business of Health Care**”, M. Suzanne Cleveland, J.D. and Jim McLean. Footage available at: <http://www.khi.org/news/2011/may/17/khis-cleveland-talks-news-station-about-business-h/?research>

May 2010, Cleveland, Mary Suzanne, **The Who, What, Why and When of Health Reform: A Guide for Kansans**. Kansas Health Institute and The United Methodist Health Ministry Fund. (publication)

April 2010, Cleveland, Mary Suzanne, **Medical Debt: Consequences and Policy Options**, Kansas Health Institute. (publication)