

LIVED EXPERIENCE

Diagnosed with Polyarticular Juvenile Idiopathic Arthritis 27 years ago as a teenager, several years before the first biologics were available. Bilateral total knee replacements in 2002, right wrist fusion in 2009, left wrist replacement in 2015, and other joint replacements and corrective surgeries pending. More intravenous infusions, injections, blood draws, and participation in “medical sports” than I can count. Daughter, granddaughter, sister, aunt, niece, and friend to many people with autoimmune diseases. Very fortunate to be part of a supportive and vocal community of patient advocates.

WORK EXPERIENCE

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

Helped create patient engagement infrastructure including the PCORI Engagement Rubric and built strategic relationships to support the mission of PCORI to fund research that matters to patients. Worked to ensure robust engagement in funded awards and 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 – present

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 as 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.

EDUCATION

University of Kansas School of Law

Lawrence, Kansas

J.D., May 2005

Kansas State University

Manhattan, Kansas

B.S. Biology, Pre-medicine, May 1999

OTHER ACTIVITIES

Patient Representative Roundtable

International Society for Pharmacoeconomics and Outcomes Research

Boston, MA

Chair, February 2017 – present

FasterCures Patients Count Patient Leadership Council

Washington, D.C.

Organizational Representative, March 2017 – present

Patients as Partners Conference

Philadelphia, PA

Patient Co-Chair, March 2017

Medical Device Innovation Consortium, Science of Patient Input Committee

Washington, D.C.

Member, December 2016 - present

Professional Responsibility in Medicine & Research

Washington, D.C.

Member, January 2015 - present

Kansas Bar Association

Topeka, Kansas

Member, February 2011 to present

Federal Grant Reviews

American Institute of Biological Sciences Arthritis Panel

Reviewer, 2012 – 2013

Center for Medicare and Medicaid Innovation

Reviewer, 2012

Congressionally Directed Medical Research Programs

Consumer Reviewer, 2012

State Grant Reviews

Kansas Association for the Medically Underserved,

Reviewer, 2012 - 2013

Office of Primary Care, Kansas Department of Health and Environment,

Reviewer, 2009 - 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

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>.

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, LCSW, 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, (In press) **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 PRESENTATIONS

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

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.

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

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, **Best Practices in Patient Engagement**, Panel Discussion, Institutes of Medicine Roundtable. M. Suzanne Schrandt, J.D., et al. Washington, D.C.

December 27, 2013, **“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, **“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, **“PCORI and Mental Health”**, National Alliance on Mental Health National Convention. M. Suzanne Schrandt, J.D. San Antonio, TX.

July 2012, **“How the Supreme Court Ruling on the ACA Affects Health Insurance in Kansas”**, Kansas Health Institute, M. Suzanne Schrandt, J.D, available at: khi.org.

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

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

February 2012, **“Medicare Changes Include Care Coordination and Prescription Drug Costs”**. Kansas Health Institute, M. Suzanne Schrandt et al., available at: khi.org.

February 2012, **“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, **“Health Insurance Coverage in Kansas, Pre and Post-Health Reform”**, Special Legislative Committee on Financial Institutions and Insurance. M. Suzanne Schrandt, J.D., Topeka, KS.

September 2011, **“The Impact of Health Reform on Insurance Benefits and Mandates in Kansas”** Kansas Health Institute, M. Suzanne Cleveland, et al., available at: khi.org.

May 2011, **“The Business of Health Care”**, Kansas Public Television segment, 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, **“The Who, What, Why and When of Health Reform: A Guide for Kansans”**. Kansas Health Institute and The United Methodist Health Ministry Fund. M. Suzanne Cleveland, J.D., et al., available at: khi.org.

April 2010, **“Medical Debt: Consequences and Policy Options”**, Kansas Health Institute, M. Suzanne Cleveland, J.D., available at: khi.org.