Presented by:

Ohio Bleeding Disorders Council

Little Hercules Foundation

Ohio Rare Disease Summit

Thursday, September 11, 2025

Columbus Zoo Africa Center

4850 W Powell Rd. Powell, OH

Time	Topic	Presenter
8:00 - 9:00 AM	**Check-in/ Continental Breakfast**	
9:00 - 9:10 AM	**Welcome & Opening Remarks**	Lisa Raterman, Chair, Ohio Bleeding Disorders Council
9:10 - 9:35 AM	**What We Know About Health Outcomes, Access and Affordability in Ohio**	Amy Rohling McGee, President, Health Policy Institute of Ohio
9:35 - 9:45 AM	**Rare Disease Basics**	Tiffany Sammons, Education Programs Manager, National Organization for Rare Disorders
9:45 - 10:45 AM	**The Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study**	Kathryn Poe, State Policy Manager, Everylife Foundation for Rare Diseases
10:45 - 11:00 AM	**Break**	
11:00 - 11:20 AM	**Complex Care Coordination**	Murugu Manickam, MD, MPH, FACMG, is Section Chief of Genetic and Genomic Medicine, Nationwide Children’s Hospital
11:20 - 11:30 AM	**Complex Medical Help Program Overview**	Katie Bach, RN, BSN CMH Field Nurse Case Manager Supervisor Jennifer Warfel, RN, BSN CMH Field Nurse Case Manager Supervisor
11:30 - 11:45 AM	**Break - Box Lunch**	
11:45 - 12:15 PM	**RDAC Legislative Member Panel Discussion**	Moderator: Randi Clites, Rare Disease Policy Director, Little Hercules Foundation State Senator Beth Liston, Senate District 16 State Representative Crystal Lett, State Representative District 11

12:15 - 1:15 PM	**Patient Org Legislative Panel Discussion**	Moderator: Randi Clites, Rare Disease Policy Director, Little Hercules Foundation Matt Delaney, Government Relations Manager, National Bleeding Disorders Foundation Jess Myers, Communications and Advocacy Manager, Hereditary Angioedema Association Kathryn Poe, State Policy Manager, Everylife Foundation for Rare Diseases Allison Herrity, MPH, Senior Policy Analyst, National Organization for Rare Disorders
1:15 - 1:30 PM	**Break**	
1:30 - 2:00 PM	**Novel Gene Therapies**	Dr. Kevin Flanigan, Director, Jerry R. Mendell Center for Gene Therapy at Nationwide Children's Hospital
2:00- 2:45 PM	**Engagement Framework for Payers and Patient Organizations**	Michael Storey, PharmD, MS, Independent Consultant Michelle Rice, CEO/Owner, Michelle Rice & Associates, LLC Randi Clites, Rare Disease Policy Director, Little Hercules Foundation
2:45 PM	**Closing Comments**	Randi Clites
3:00 - 5:00 PM	**Zoo Adventures**	

Ohio Rare Disease Summit 2025
Speaker Bios

Amy Rohling McGee has served as the president of the Health Policy Institute of Ohio since 2010. With her leadership, HPIO has developed a reputation as a trusted source of data and evidence-informed policy analysis. McGee has more than 20 years of experience in management, government relations, policy development, strategic planning, stakeholder engagement, coalition building and communication. Her prior public-sector experience includes work in the executive branch of state government, focused on policy issues such as mental health, health insurance, health system improvement and Medicaid; and service in the state legislature as a Legislative Service Commission intern in the mid-1990s. Private sector experience includes five years as the executive director of the Ohio Association of Free Clinics. McGee earned her bachelor's degree and master's degree in social work from the Ohio State University.

Tiffany Sammons is the Education Programs Manager at the National Organization for Rare Disorders, where she has served since January 2022. In this capacity, she oversees the development and delivery of educational initiatives for patients, caregivers, and healthcare professionals within the rare disease community. Tiffany has also served on Ohio's Rare Disease Advisory Council since its establishment in 2021. In addition to her professional roles, Tiffany is a rare disease mom and caregiver to her son, Rowan, living with Coffin-Siris Syndrome.

Kathryn Poe earned a BA in Creative Writing from Capital University and is a student at The Ohio State University Wexner Medical Center, working toward their master's degree in bioethics, with a thesis on medical disinformation and conspiracy theories. As a bone marrow transplant survivor and rare disease patient, Kathryn is passionate about working with other patient advocates. They previously worked at Ohio-based public policy organizations like Equality Ohio and Policy Matters Ohio. Kathryn lives in Columbus, Ohio.

Dr. Murugu Manickam is a clinical geneticist at Nationwide Children's Hospital as a Professor of Clinical Medicine with a joint appointment at the Nisonger Center at The Ohio State University Medical Center He helped develop the ACMG Practice Guideline for exomes/genomes for the diagnosis of children/adults with genetic disorders and is also an expert in use of genetic screening for adult-onset conditions. Other areas of interest are the societal and ethical considerations of genetic testing and health disparities with genetics. His clinical interests include the care of children and adults with Down syndrome and Neurofibromatosis but sees many other rare disorders. Dr. Manickam has been an invited lecturer and moderator at national and international meetings on genetics and genomics

Katie L. Bach, RN, BSN is the CMH Field Nurse Case Manager Supervisor for the east side of Ohio with the Ohio Department of Health. She earned her Bachelor of Science in Nursing from Wright State University in 2000. Katie has over two decades of public health nursing experience, including roles as a CMH Public Health Nurse and Field Nurse Consultant across various regions in Ohio. Her primary professional interest is in the care of children and youth with chronic medical conditions.

Jennifer Warfel, MSN, RN has been a Field Nurse Case Manager for over 20 years with the Ohio Department of Health's Complex Medical Help Program. She resides in the Toledo area with her husband and adult son who is on the CMH Program. Prior to her work at ODH she was a hematology/oncology nurse at an Ohio Children's Hospital.

Senator Beth Liston represents Ohio's 16th Senate District, covering parts of northern Franklin County, including Dublin, Worthington, and Westerville. A physician and professor at The Ohio State University, she brings her background in medicine and science to the Statehouse, where she focuses on improving health care, strengthening public education, and advancing evidence-based policy. Before joining the Senate in 2025, she served three terms in the Ohio House of Representatives. Senator Liston serves as Ranking Member of Health and Medicaid Committees. She lives in Dublin with her husband and two children and remains deeply engaged in both her medical and local communities.

Representative Crystal Lett serves Ohio's 11th House District, representing parts of Franklin County including Dublin and Hilliard. A graduate of The Ohio State University and a longtime advocate for mental health and disability rights, she brings both professional and personal experience to her role. Motivated in part by her son's rare genetic disorder, she works to improve access to care, strengthen public education, and promote equity. In the House, she serves as Ranking Member of the Children & Human Services Committee and serves on the Medicaid Committee.

Matt Delaney is the Government Relations Manager at the National Bleeding Disorders Foundation, advocating on behalf of NBDF chapters and patients on state policy in 23 states, and federally on blood and product safety priorities. Matt is a patient with VWD Type IIA and a platelet disorder. Prior to joining NBDF, Matt served as a Legislative Aide in the New York State Senate, and in behavioral health policy and intergovernmental relations for New York State. Within his federal role, Matt coordinated activities of the American Plasma Users Coalition (APLUS), focusing on plasma safety and supply, and is an Investigator on the Patient Reported Outcomes Burdens and Experiences (PROBE) study for clinical trials. Matt continues to live in New York, is completing his Masters in Public Administration and Policy at the Rockefeller School of Government Affairs, and enjoys golf and playing bass guitar.

Jess Myers is the Communications and Advocacy Manager at the Hereditary Angioedema Association (HAEA). Diagnosed with HAE at age 15, Jess was the first in her family to be diagnosed. She became involved with the HAEA during college, where she found a supportive community of individuals who shared similar experiences navigating life with HAE. Jess holds a Bachelor's degree in English Literature from the University of Pittsburgh and a Master's degree in Communications from the University of Akron. In her role at the HAEA, Jess is dedicated to empowering advocates and helping them make a meaningful impact for the HAEA community. Outside of her work, Jess enjoys spending time outdoors and hiking with her husband and their dog.

Allison Herrity is a Senior Policy Analyst at the National Organization for Rare Disorders (NORD). She became involved with NORD in 2018, shortly after being diagnosed with a rare condition herself. In her seven years with NORD, she has worked on a wide range of policy issues including access to adequate health coverage, telehealth, and coverage of medical nutrition products. In her current role, she is responsible for NORD's policy work on issues that impact access to diagnostics, primarily focused on newborn screening and genetic testing. Allison holds BS and MPH degrees from the George Washington University's Milken Institute School of Public Health, where her capstone project focused on potential regulatory frameworks for third party interpretation of raw genomic data obtained from direct-to-consumer genetic testing services. In her free time, she enjoys sewing, reading, and Pilates. Allison lives in Cincinnati with her husband and two cats.

Michael Storey, PharmD, MS has held various roles in pharmacy administration over the last 15 years, including managing clinical, operational, and financial pharmacy services for various service lines, including hematology, oncology, neurology, and neuromuscular. Most recently, he held the role of Medication Use Strategist at Nationwide Children's Hospital, where he managed Pharmacy and Therapeutics Committee activities, and led the onboarding of new therapies to the organization, with a particular focus on high-touch therapies like gene and cell therapies. Earlier this year, he stepped away from direct practice, and is currently independently collaborating with other parties in the system to advance conversations related to patient access.

Michelle Rice, CEO & Founder, Michelle Rice & Associates, LLC has 34 years of experience in healthcare policy and advocacy. She is a nationally recognized leader in driving collaborative solutions that enhance patient care and improve healthcare sustainability. As the CEO and President of Michelle Rice & Associates, LLC, she leverages her deep expertise to foster consensus among diverse stakeholders, including legislators, state regulators, clinicians, payers, patients, and the pharmaceutical industry. Michelle is known for her solution-oriented approach, visionary leadership, and ability to cultivate open communication and mutual respect among key stakeholders. She is widely regarded as fair, trustworthy, and authentic, ensuring that all voices are heard in the advocacy and policymaking process. Through her work, Michelle continues to champion policies and initiatives that enhance healthcare access, quality, and affordability, making a lasting impact on patients and the broader healthcare landscape.