

**\*All sessions held in the Auditorium**



**Keynote Speaker | 8:30 AM ET**

**Sivasangaran Kumaran, Rare Disease Advocate/Father of Swathi (Infantile Pompe) | Rare Disease Malaysia**  
"Developing Effective Rare Disease Policies and Improving Access to Care: The View from Malaysia"



**Drug Development & Clinical Trials | 8:30 AM ET**

**Alison Bateman-House, PhD, MPH, MA**  
**NYU Langone Health Department of Population Health**  
"Non-Trial Access to Investigational Medicines"



**Research and Resources Track | 9:00 AM ET**

**Dr. Femida Gwadry-Sridhar | Founder & CEO, Pulse InfoFrame**  
"Patient Registries: Does Your Population Need One?"



**Drug Development & Clinical Trials | 9:00 AM ET**

**Dr. Barbara Handelin | Founder & CEO, Audacity Therapeutics**  
"Repurposing Pathway For Drug Development"



**Community Building | 9:30 AM ET**

**Rebecca Stewart | CEO, Rare Revolution Magazine and Co-Founder & Trustee of Teddington Trust**  
"Think Local, Act Global"



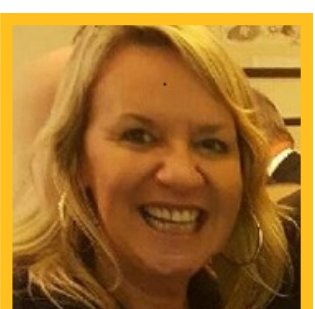
**Physicians & Providers | 9:30 AM ET**

**Helena Baker | Rare Disease Nurse Network**  
**Tracey Murray, RGN, DipEd Nursing | Rare Disease Nurse Network Trustee**  
"Nursing in the Rare Disease Environment"



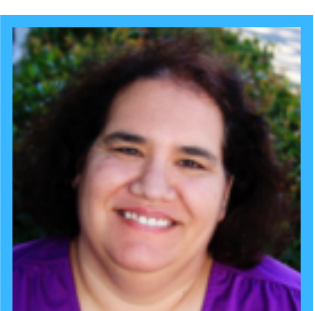
**Community Building | 10:00 AM ET**

**Dawn Torrence Ireland | President of CDHi**  
"Building a Non-Profit"



**Advocacy and Legislation | 10:00 AM ET**

**Tara Britt | Associate Chair, NC Rare Disease Advisory Council**  
**Founder, NC Rare Disease Innovations Institute**  
"Building a Rare Disease Advisory Council in Your State"



**Community Building | 10:30 AM ET**

**Carrie Ostrea | Executive Director and Co-Founder, Little Miss Hannah Foundation**  
"Empowering Your Rare Disease Community to Become Advocates"

**\*All sessions held in the Auditorium**



**Physicians & Providers | 11:00 AM ET**

**Stacey Koenig, MSM, CCLS | Senior Director, Patient & Family Support Services, Children's Mercy Hospital**  
 "Child Life: Strength Among the Unknown"



**Drug Development & Clinical Trials | 11:00 AM ET**

**Dr. Lorna Speid, Ph.D., M.R. Pharm. S. | President of the Board of Directors, Putting Rare Disease Patients First!**  
 "The Seven Things You Need To Know About Clinical Trials as a Rare Disease Patient/Parent"



**Physicians & Providers | 11:00 AM ET**

**Stacey Feuer, PsyD, MLD | Patient Advocate, Speaker & Health Psychologist**  
 "Psychosocial Aspects of Living with a Rare Disease"



**Rare Adult Booth | 11:30 AM ET**

**Sharon Rose Nissley | Founder & Executive Director, Klippel-Feil Syndrome Freedom**  
 "Living Rare: The Other 50%", a moderated discussion for Rare Adults



**Advocacy & Legislation | 1:30 PM ET**

**Becky Abbott | NFED Advocacy Committee Co-chair National Foundation for Ectodermal Dysplasias**  
 "Advocacy in Action"



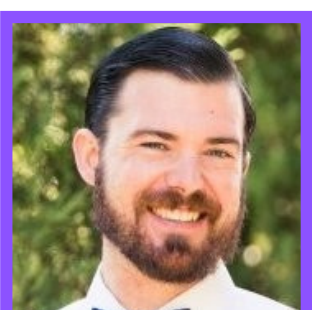
**Research & Resources | 1:30 PM ET**

**Laura Quinn | Managing Director, ASSAI Health Solutions**  
**Holly Snyder | Board-Certified Genetic Counselor, Illumina**  
 "New Genetics Course for People Affected by Rare Disease"



**Physicians & Providers | 2:00 PM ET**

**Neena Nizar, EdD | Founder & Executive Director, The Jansen's Foundation**  
 "From the Lab to the Patient: Challenges of Translational Science in Rare Disease Drug Development"



**Physicians & Providers | 2:30 PM ET**

**Nicholas Dryer, PharmD | Community Pharmacist**  
 "A Community Pharmacist's Role in the Management of Rare Diseases"



**Patients & Caregivers | 3:00 PM ET**

**Cambria Lord | Rare Disease Advocate, The Cambria Lord Foundation**  
 "What Your Rare Disease Kid Wants You to Know"

**\*All sessions held in the Auditorium**



**Community Building | 3:30 PM ET**

**Stephanie Fischer | Executive Committee Member, Rare Advocacy Movement**

"Utilize Social Media to Raise Awareness, Advocate, and Build Connections in 15 Minutes a Day"



**Research and Resources Track | 4:00 PM ET**

**Olivia Montano | PROS Foundation**

"Natural History Studies: An Overview"



**Advocacy & Legislation | 4:30 PM ET**

**Steve Silvestri | Policy Director, The Everylife Foundation**

"Newborn Screening: An Update on Progress"



**Research & Resources | 5:00 PM ET**

**Anna Laurent | Everylife Foundation, YARR member**

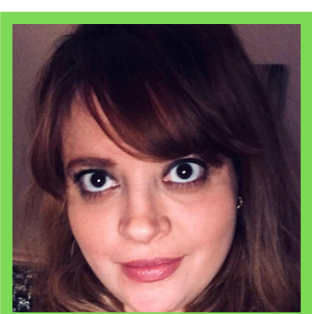
"Young & Rare: Meeting Young Adults Where They Are"



**Patients & Caregivers | 5:30 PM ET**

**Meg Talley Dyer | Rare Disease Advocate & Parent**

"Fighting for My Daughter. Advocating for Myself."



**Research & Resources | 6:00 PM ET**

**Eden Lord, MSM | Founder & CEO, My City Med**

"Diagnosis Road Maps: Cures Ahead"



**Advocacy & Legislation | TBD**

**Carole Herman | Rare Disease Parent Advocate**

"Rare Disease in France"