RARE Health Equity Forum – Saturday, September 28, 2024

7:00 AM - 12:00 PM
Registration

West Foyer - Ballroom Level

8:00 AM - 5:00 PM
Exhibitors

City Beautiful Foyers

8:00 AM - 9:00 AM
Breakfast

Sponsored by Takeda

City Beautiful D

9:00 AM - 9:30 AM
Keynote: Living Rare Within Rare
Dr. Wright will discuss the historical contexts, complex issues, arduous challenges, and unconscious biases in the diagnosis and treatment of people of color who are "rare within rare," while sharing how her husband's unique rare disease journey inspired and led to their mission and commitment to advocating for underrepresented populations.

- Michele Wise Wright, Ph.D., Co-Founder, National Organization of African Americans with Cystic Fibrosis

City Beautiful E

9:30 AM - 10:15 AM
Lessons from the Field: Best Practices for Engaging Community Partners
This session will explore trust as a concept of something that is earned, and will identify the changes needed from healthcare institutions to do so. Pulling on success stories, panelists will discuss how to actively empower the community as a partner.

- **Moderator:** Teneasha Washington, Ph.D., Diversity, Equity & Inclusion, Global Genes
- Claudia Gonzaga-Jauregui, Ph.D., Assistant Professor, International Laboratory for Human Genome Research (LIIGH) of the National Autonomous University of Mexico (UNAM)
- Siwaar Abouhala, Clinical Research Coordinator, The Broad Institute
- Cecile Jones, Alabama Community Health Ambassador, All In. Rare - A Global Genes Program

City Beautiful E

10:15 AM - 10:35 AM
The Monarch Initiative: Informatics and Open Data Sharing
The Monarch Initiative is an international consortium focused on developing rare disease standards and methods for leveraging biomedical knowledge to connect genotypes with phenotypes to improve genetic diagnostics. The ultimate goal is to help clinicians diagnose patients and researchers to develop the best treatments faster.

- Melissa Haendel, Ph.D., Director, Precision Health and Translational Informatics, University of North Carolina at Chapel Hill

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10:35 AM - 10:45 AM - **Break**

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10:45 AM - 12:30 PM
Dear Rare Disease, a Storytelling Workshop
Storytelling is a powerful form of advocacy. It can engage us to express our feelings and thoughts in ways that allow others to relate to, and understand the impact of our experience. In this session, attendees will participate in a combined writing and art workshop to capture their rare experience.

- Suzanne Edison, Mental Health Coordinator, CureJM

City Beautiful D/E

12:30 PM - 2:30 PM
Lunch & Table Talks

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2:30 PM - 2:50 PM
Data Driven Music: An Exploration of Rare Disease Harmony

Professor Taylor will discuss music driven advocacy through demonstration of his music composition based on a catalog of 230 rare diseases that was curated by Dr. Aditi Kantipuly. Twelve categories of disease correspond to the 12 Indian chakras, which provide a background harmony for each category.

- Stephen Taylor, Professor of Music, University of Illinois at Urbana-Champaign

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2:50 PM - 3:25 PM
Film Screening: “*Holding Moses*”

Holding Moses chronicles the heartfelt story of a queer mother and Broadway performer who learns how to parent her profoundly disabled son. This documentary folds together several areas in the DEI space including assumptions about caregivers, shame narratives around disability, and LGBTQ parents.

- **Moderator:** Daniel DeFabio, Director, Community Engagement, Global Genes
- Randi Rader, Featured Subject, Frankly Speaking Films
- Rivkah Beth Medow, Director, Frankly Speaking Films

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3:25 PM - 4:10 PM
Diversity in Rare Clinical Trials: What’s Working and What Isn’t

Historically marginalized racial groups, women and other minoritized communities are notably underrepresented in clinical trials, despite efforts and investment by advocates and health equity leaders. This panel will discuss effective strategies to address the lack of diversity in clinical trials.

- **Moderator:** Kim Moran, Ph.D, Senior Vice President and Head, U.S. Rare Diseases, UCB
- R’Kes Starling, Founder & CEO, Reveles
- Richie Kahn, Clinical Researcher, Co-founder and COO, Canary Advisors
- Tanvee Varma, M.D., Resident Physician, Brigham and Women’s Hospital

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4:10 PM - 5:00 PM
Rural Rare Healthcare

Rural residents often encounter barriers to healthcare including workforce shortages, health insurance status, transportation issues, health literacy, and stigma in rural communities. These disparities are even greater among historically marginalized communities and rare disease patients. Panelists will discuss the work they are doing to combat these challenges.

- **Moderator:** Shobana Kubendran, Genetic Counselor, KU School of Medicine-Wichita
- Ana Cohen, Ph.D., Assistant Director, Molecular Genetics Laboratory, Children’s Mercy
- Nadia Falah, M.D., Clinical Geneticist, Johns Hopkins All Children’s Hospital
- Abdallah F. Elias, M.D., Chief Medical Officer, Shodair Children’s Hospital

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5:00 PM - 5:15 PM
Closing Remarks

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5:30 PM - 7:30 PM
Closing Reception

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Agenda subject to change