WEDNESDAY, NOVEMBER 9th, 2022

6:00pm – 7:30pm ET | Welcome Reception (optional)

8:00pm - 10:00pm ET | Global Genes Global Advocacy Alliance Networking Event

THURSDAY, NOVEMBER 10th, 2022

7:15am – 8:15am ET | Breakfast

8:15am – 8:30am ET | Welcome

8:30am – 9:00am ET | Opening Keynote Address

Speakers:
• RDML Richardae Araojo, PharmD, MS, Associate Commissioner for Minority Health, Director, Office of Minority Health and Health Equity, U.S. Food and Drug Administration
• Sandra Retzky, DO, JD, MPH, MBA, Director, Office of Orphan Product Development, Office of the Commissioner, U.S. Food & Drug Administration

9:00am – 9:30am ET | The Diversity of Diversity

Explore, from different leaders’ personal and professional experiences, how disparities and distinct inclusiveness challenges can manifest differently across diverse populations in rare disease.
9:30am – 10:30am ET | **Addressing Bias and Barriers to Genetic Testing for Underrepresented Populations**  
**Moderator:** Lisa Toppin, MS, EdD, Global Vice President of Diversity and Inclusion, Illumina  
**Panelists:**  
- Barbara Harrison, MS, CGC, Genetic Counselor, Howard University  
- Maria Della Rocca, MS, PMP, CSPO, PSM I, Sr. Director of Patient Services, Global Genes  
- Ebony Madden, PhD, Program Director, Training, Diversity and Health Equity Office, National Human Genome Research Institute  
- Zhanzhi (Mike) Hu, PhD, cofounder and President, Project GUARDIAN

10:30am – 10:45am ET | **Break**

10:45am – 11:45am ET | **Experience Matters: The Importance of Rare Disease Education in Medicine**  
**Moderator:** Michael Gambello, MD, PhD, Chief of the Division of Medical Genetics, Emory University School of Medicine  
**Panelists:**  
- Leah Peer, Founder, Peer Med Foundation  
- Danielle Petilli, Patient Advocate  
- Yasmina Mansour, Patient Advocate

11:45am – 12:30pm ET | **Effective Communication with Patient Partners**  
**Moderator:** Matt Flesch, VP Communications and Patient Communications, Horizon Therapeutics  
**Panelists:**  
- Terri Booker, JD, Sickle Cell Advocate, Sick Cells  
- Analy Navarro, Founder & President, BA HERO  
- Jon Rodis, National Disability and Medical Advocate for Rare Disorders

12:30pm – 1:30pm ET | **Lunch**

**Breakout Sessions (in person only)**  
There are three options for breakout sessions, each of which will run twice, once from 1:30pm - 2:30pm and then again from 2:45pm - 3:45pm giving you an opportunity to attend two out of the three sessions. During registration you will be able to select one of the three options for Breakout Session 1 and a different option for Breakout Session 2.

1:30pm – 2:30pm ET | **Breakout Session 1**  
**Medical Gaslighting - What it is and How to Address it**  
**Moderator:** TBD  
**Panelists:**  
- AudreyStephannie Maghiro, Research Coordinator, Undiagnosed Diseases Network (UDN)  
- Nafisa Iqbal, Activist-Writer, MFA Candidate, Columbia University  
- Gina Lundberg, MD FACC FAHA, Clinical Director, Emory Women’s Heart Center Associate Professor of Medicine, Emory University School of Medicine  
- Luisa Leal, Founder & CEO, The Akari Foundation

**Journey to Leadership: Experiences of leaders from Diverse Backgrounds**  
**Moderator:** Beatriz Mallory, President, Executive Director, HEARD kids  
**Panelists:**  
- Lara Bloom, President and CEO, The Ehlers-Danlos Society  
- Akilah Cadet, PhD, MPH, Founder, CEO & Executive Coach, Change Cadet  
- Dakar De La Cruz, MBA, Director of Strategy & Planning for Global Patient Insights and Solutions, Alexion, AstraZeneca Rare Disease

*agenda subject to change*

Times in EST
Level up your Cultural Understanding to Include More Diverse Communities

Moderator: Rodney Samaco, PhD, Assistant Professor of Molecular and Human Genetics, Baylor College of Medicine

Panelists:
- Vanessa Hiratsuka, PhD, MPH (Diné/Winnemem Wintu), co-Director of Research and Evaluation; Assistant Professor, University of Alaska Anchorage, Center for Human Development
- Cory Lewis, Program Coordinator, Sick Cells

2:30pm – 2:45pm ET | Transition to Second Breakout

2:45pm – 3:45pm ET | Breakout Session 2

Medical Gaslighting - What it is and How to Address it

Moderator: TBD

Panelists:
- AudreyStephannie Maghiro, Research Coordinator, Undiagnosed Diseases Network (UDN)
- Nafisa Iqbal, Activist-Writer, MFA Candidate, Columbia University
- Gina Lundberg, MD FACC FAHA, Clinical Director, Emory Women’s Heart Center Associate Professor of Medicine, Emory University School of Medicine
- Luisa Leal, Founder & CEO, The Akari Foundation

Journey to Leadership: Experiences of leaders from Diverse Backgrounds

Moderator: Beatriz Mallory, President, HispanAmérica Health

Panelists:
- Lara Bloom, President and CEO, The Ehlers-Danlos Society
- Akilah Cadet, PhD, MPH, Founder, CEO & Executive Coach, Change Cadet
- Dakar De La Cruz, MBA, Associate Director of Patient Marketing for Rare Disease NMOSD, Alexion Pharmaceuticals

Level up your Cultural Understanding to Include More Diverse Communities

Moderator: Rodney Samaco, PhD, Assistant Professor of Molecular and Human Genetics, Baylor College of Medicine

Panelists:
- Vanessa Hiratsuka, PhD, MPH (Diné/Winnemem Wintu), co-Director of Research and Evaluation; Assistant Professor, University of Alaska Anchorage, Center for Human Development
- Cory Lewis, Program Coordinator, Sick Cells

3:45pm – 4:45pm ET | Global Equity and Inclusion: Access to Diagnostic Tools and Expertise, Clinical Trials and Treatments

Moderator: Rodney Dickson, Senior Director, Therapeutic Policy and Advocacy, Takeda

Panelists:
- Charles Hammond, MD, MPhil, FWACP, FGCP, Consultant Pediatric Neurologist, Komfo Anokye Teaching Hospital, Kumasi, Ghana, Senior Lecturer, School of Medicine and Dentistry, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana
- Plinio Gherardi, Director of International Relations, Casa Hunter - Brazil
- Vicky Arteaga, MBA, Treasurer / Latin America Director, SynGAP Research Fund
- Durhane Wong-Rieger, PhD, President & CEO, Canadian Organization for Rare Disorders and Institute for Optimizing Health Outcomes, Chair, Rare Diseases International, President, Asia Pacific Alliance of Rare Disease Organizations, Chair, Canadian Heart Patient Alliance

*agenda subject to change

Times in EST
FRIDAY, NOVEMBER 11th, 2022

7:30am – 8:30am ET | Breakfast

8:30am – 8:45am ET | Welcome

8:45am – 9:45am ET | Underrepresentation in Rare Disease Research – Driving Promise to Practice Health Equity
Moderator: Isaac Rodriguez-Chavez, PhD, MHSc, MSc, Senior Vice President for Scientific and Clinical Affairs, ICON plc.
Panelists:
- Veronica Ajewole, PharmD, BCOP, Assistant Professor of Pharmacy Practice, College of Pharmacy and Health Sciences, Texas Southern University
- Magnolia Wang, Founder, STAC3
- Nicole Kressin, RN, MSN, Co-Chair, Diversity Committee, Rare Diseases Clinical Research Network
- Deanna Portero, Management Analyst, Division of Rare Diseases Research Innovation National Center for Advancing Translational Sciences

9:45am – 11:15am ET | RAREly Told Stories Film Viewing
Moderator: Ajani Murry, actor
Filmakers: TBA

11:15am – 11:30am ET | Break

11:30am – 12:30pm ET | Representation in Rare Policy
Moderator: Daron Watts, JD, Managing Member, The Watts Group LLC
Panelists:
- Durhane Wong-Rieger, PhD, President & CEO, Canadian Organization for Rare Disorders and Institute for Optimizing Health Outcomes, Chair, Rare Diseases International, President, Asia Pacific Alliance of Rare Disease Organizations, Chair, Canadian Heart Patient Alliance
- Julia Jenkins, Executive Director, EveryLife Foundation for Rare Disease
- Felicia Brannon, MPA, Co-Founder, MarylandRARE

12:30pm – 1:00pm ET | Closing Keynote Address
Speaker: Charles Hammond, MD, MPhil, FWACP, FGCP, Consultant Pediatric Neurologist, Komfo Anokye Teaching Hospital, Kumasi, Ghana, Senior Lecturer, School of Medicine and Dentistry, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

1:00pm – 1:10pm ET | Closing Remarks & End of Summit

1:10pm - 2:10pm ET | Lunch

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