WEDNESDAY, NOVEMBER 9th, 2022

6:00pm – 7:30pm ET | Welcome Reception

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

Speakers:
- Craig Martin, CEO, Global Genes
- Jenifer Waldrop, Executive Director, Rare Disease Diversity Coalition (RDDC)

8:30am – 9:00am ET | Keynote Address: Health Equity to Advance Medical Product Development for Rare Diseases

Disparities in health exist in both access to and participation in rare disease clinical trials and access to medical products. These inequities impact multiple underserved and underrepresented communities. Join us to hear from representatives at the FDA who will highlight health equity efforts to advance medical product development for rare diseases.

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, Director, Office of Orphan Product Development, Office of the Commissioner, U.S. Food and Drug Administration

*agenda subject to change

Times in EST
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.

**Speakers:**
- RA Session II, CEO, Taysha Gene Therapies
- Eric Dube, PhD, President and CEO, Travere Therapeutics
- 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, Director, Office of Orphan Product Development, Office of the Commissioner, U.S. Food and Drug Administration

9:30am – 10:30am ET | Addressing Bias and Barriers to Genetic Testing for Underrepresented Populations
While genetic testing is one of the ways that rare diseases are diagnosed, testing is not accessible for all populations. Lack of access and lack of use of genetic testing in non-eurocentric communities is due to a variety of factors including:
- minimal access to testing outside of large urban centers
- a skewed genetic database towards European ancestry
- mistrust in the system due to historic discrimination and minimal workforce diversity
- a high cost / lack of coverage of testing from health systems

This session will look at ways we can better engender trust and empower individuals to take ownership of their family health history through genetic testing, and what can be done to remove the bias and barriers that exist for underrepresented populations.

**Moderator:** Lisa Toppin, MS, EdD, Global Vice President of Diversity and Inclusion, Illumina

**Panelists:**
- Barbara Harrison, MS, CGC, Genetic Counselor and Assistant Professor, Howard University
- Maria Della Rocca, MS, PMP, Sr. Director of Patient Services, Global Genes
- Ebony Madden, MS, 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
Rare disease education is lacking in many clinical training environments and formal medical studies curricula. As a result, there is a field emerging which seeks to build empathy in future physicians as the basis for a trusting relationship, and thus better care for people living with a rare disease and beyond. Join our panelists as they explore how a rare disease education can teach the next generation of healthcare professionals:
- that patients know their body best, therefore the best care can only truly be achieved if there is collaboration and shared decision making between the doctor and patient
- how lessons learned in the rare disease space can be applied to broader compassionate interactions with patients

The conversation will remind us of the hippocratic oath, that there is “power and hope in the pursuit of healing” - a reminder of the beauty of the unknown in medicine and our willingness to persevere despite it.

**Moderator:** Rachel Barron, Sr. Manager of Health Equity, Global Genes

**Panelists:**
- Michael J. Gambello, MD, PhD, Professor of Human Genetics and Pediatrics, Section Chief, Division of Medical Genetics, Vice Chair, Department of Human Genetics, Emory University School of Medicine
- Leah Peer, Founder, Peer Med Foundation
- Danielle Petilli, Patient Advocate
- Yasmina Mansour, Patient Advocate
- Umar Rehman, Medical Student, Rosalind Franklin University of Medicine & Science

*agenda subject to change Times in EST*
11:45am – 12:30pm ET | Effective Communication with Patient Partners

» “Patients are at the heart of everything we do”
» “We collaborate with patient advocates to ensure we are doing everything we can to support the patient community”
» “We listen and learn from those affected by rare disease”

Statements like the above can be found on almost every industry webpage but what do those statements look like in practice and how are they implemented? This session will explore when and how to include the patient voice and the expectations that patients and advocates have when engaging with researchers, and other industry professionals.

Moderator: Matt Flesch, VP Communications and Patient Communications, Horizon Therapeutics

Panelists:
- Terri Booker, Esquire, Founder, Hemoglobin Advocate Consultants, CoFounder, Young Adult Sickle Cell Alliance, Vice Chair, Sick Cells
- Analy Navarro, Founder and President, BA HERO
- Jon Rodis, National Disability and Medical Advocate for Rare Disorders
- Sarita Edwards, BHSc, CEO, and President, The E. WE Foundation

12:30pm – 12:45pm ET | Spoken Word Performance by Theresa tha SONGBIRD

12:45pm – 1:45pm ET | Lunch

Breakout Sessions (in person only)
There are three options for breakout sessions, each of which will run twice, once from 1:45pm - 2:45pm and then again from 3:00pm - 4:00pm 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.

1:45pm – 2:45pm ET | Breakout Session 1

Medical Gaslighting - What it is and How to Address it
Effectively treating patients starts with believing that they know their body best. Join our panelists as they share experiences of medical gaslighting, discuss its ties into the larger intersection of gender, race, and sexuality, and what action we can take to prevent it from happening in the future.

Moderator: Mia Keeys, Director of Federal Affairs, Hologic, Inc

Panelists:
- AudreyStephannie Maghiro, Research Coordinator, Undiagnosed Diseases Network
- 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 and CEO, The Akari Foundation

Journey to Leadership: Experiences of leaders from Diverse Backgrounds
Encouraging diversity in leadership means more than encouraging leaders with different experiences. In this session, panelists will investigate not only how to cultivate diverse leadership, but how to create and maintain a culture of inclusivity. They will explore how to uncover the unconscious biases we all have, recognize the discomfort that is going to exist, and how to push through that discomfort to implement policy reflecting a larger culture of inclusion.

Moderator: Beatriz Mallory, President, Executive Director, HEARD kids

Panelists:
- Lara Bloom, Founder, President, and CEO, The Ehlers-Danlos Society
- Akilah Cadet, DHSc, PhD, MPH, Founder, CEO and Executive Coach, Change Cadet
- Dakar De La Cruz, MBA, Director of Strategy and Planning for Global Patient Insights and Solutions, Alexion, AstraZeneca Rare Disease

GLOBALGENES.ORG | #GGHealthEquity

*agenda subject to change

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

Social determinants of health, such as working and living conditions, language, cultural differences, and access to quality healthcare, contribute to health inequities. In order to effectively and respectfully engage with patients, we have to listen to and learn about their diverse beliefs, attitudes, values, and behaviors. In this session, panelists will address:

- the importance of health literacy and cross-cultural communication
- the recognition that cultural humility is an ongoing process that requires an awareness and acknowledgment of implicit biases
- how to best engage with diverse populations through community leaders

The session will teach us that by asking questions and building a greater understanding of cultures and beliefs that differ from our own, we can correct misunderstandings and build trust ultimately resulting in improved patient outcomes.

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

Panelists:
- Cory Lewis, Program Coordinator, Sick Cells, Founder, RedMoon Project
- Diana Tran Chavez, U.S. Group Creative Director, Evoke Mind+Matter
- Johanne I. Laboy, PhD, MBA, Head of Community Engagement, SiteBridge Research Inc.

2:45pm – 3:00pm ET | Transition to Second Breakout

3:00pm – 4:00pm ET | Breakout Session 2

Medical Gaslighting - What it is and How to Address it

Effectively treating patients starts with believing that they know their body best. Join our panelists as they share experiences of medical gaslighting, discuss its ties into the larger intersection of gender, race, and sexuality, and what action we can take to prevent it from happening in the future.

Moderator: Mia Keeyes, Director of Federal Affairs, Hologic, Inc

Panelists:
- AudreyStephannie Maghiro, Research Coordinator, Undiagnosed Diseases Network
- 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 and CEO, The Akari Foundation

Journey to Leadership: Experiences of leaders from Diverse Backgrounds

Encouraging diversity in leadership means more than encouraging leaders with different experiences. In this session, panelists will investigate not only how to cultivate diverse leadership, but how to create and maintain a culture of inclusivity. They will explore how to uncover the unconscious biases we all have, recognize the discomfort that is going to exist, and how to push through that discomfort to implement policy reflecting a larger culture of inclusion.

Moderator: Beatriz Mallory, President, Executive Director, HEARD kids

Panelists:
- Lara Bloom, Founder, President, and CEO, The Ehlers-Danlos Society
- Akilah Cadet, DHSc, PhD, MPH, Founder, CEO and Executive Coach, Change Cadet
- Dakar De La Cruz, MBA, Director of Strategy and Planning for Global Patient Insights and Solutions, Alexion, AstraZeneca Rare Disease
Level up your Cultural Understanding to Include More Diverse Communities

Social determinants of health, such as working and living conditions, language, cultural differences, and access to quality healthcare, contribute to health inequities. In order to effectively and respectfully engage with patients, we have to listen to and learn about their diverse beliefs, attitudes, values and behaviors. In this session, panelists will address

» the importance of health literacy and cross-cultural communication
» the recognition that cultural humility is an ongoing process that requires an awareness and acknowledgment of implicit biases
» how to best engage with diverse populations through community leaders

The session will teach us that by asking questions, and building a greater understanding of cultures and beliefs that differ from our own, we can correct misunderstandings and build trust ultimately resulting in improved patient outcomes.

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

Panelists:
• Cory Lewis, Program Coordinator, Sick Cells, Founder, RedMoon Project
• Diana Tran Chavez, U.S. Group Creative Director, Evoke Mind+Matter
• Johanne I. Laboy, PhD, MBA, Head of Community Engagement, SiteBridge Research Inc.

4:00pm - 4:15pm ET | Break

4:15pm – 5:15pm ET | Global Equity and Inclusion: Access to Diagnostic Tools and Expertise, Clinical Trials and Treatments

Our panelists will discuss how similar issues of cultural barriers, limited access to healthcare, and regulatory challenges lead to limited access to diagnoses and clinical trials globally. Specifically sharing their experiences within the health systems in Ghana, Canada, Colombia, and Brazil, they will explore next steps and solutions, sharing what internal and external organizations can do to support greater access to healthcare worldwide.

Moderator: Linn Parrish, Head of Health Equity Alliances and Partnerships, Center for Health Equity and Patient Affairs, Takeda

Panelists:
• Charles Hammond, MD, MPhil, FWACP, FGCP, Consultant Pediatric Neurologist, Komfo Anokye Teaching Hospital, 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 and 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

5:15pm – 5:35pm ET | Closing Remarks

Speakers:
• Eve Dryer, Vice President, Patient Advocacy, Travere Therapeutics
• TBD, Southern Christian Leadership Conference

7:30pm – 9:30pm ET | Reception at the National Center for Civil and Human Rights (additional fees apply)
FRIDAY, NOVEMBER 11th, 2022

7:30am – 8:30am ET | Breakfast

8:30am – 8:50am ET | Welcome
Speakers:
• Steve Scalia, President, Tanner Pharma Group
• Jevon Gibson, CEO, Fulton-DeKalb Hospital Authority

8:50am – 9:20am ET | Keynote Address: Removing the Hurdles in the Clinical Care of Rare Diseases in Low-resource Settings
There are major barriers and disparities in the access to healthcare in low- and middle-income countries. The lack of newborn screening programs, limited expertise and infrastructural resources, coupled with cultural myths and misconceptions about rare diseases make the patient's journey a difficult one. It will take a carefully planned collaboration between clinicians, patients, industry partners and policy makers to remove these hurdles and improve the care of persons living with rare diseases in low-resource settings.
Speaker: Charles Hammond, MD, MPhil, FWACP, FGCP, Consultant Pediatric Neurologist, Komfo Anokye Teaching Hospital, Senior Lecturer, School of Medicine and Dentistry, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

9:20am – 10:20am ET | Underrepresentation in Rare Disease Research – Driving Promise to Practice Health Equity
Access to treatment starts with more inclusive research and clinical trials that are representative of the diverse patient population needing to be served. A multi-pronged approach must be used to establish and maintain equity in rare disease research and treatment. This starts with building trust among clinical research participants, collaborators, support systems, and end-user patient population. During this session, panelists will dissect the value, advantages and challenges of clinical research and explore key concepts that are needed to engage under-represented populations in clinical research design from bench-top to bedside including:
• access to research in a rural vs. urban settings including factors that propagate socioeconomic disparities in our healthcare system
• the value and limitations of technology enabled trials, including telehealth-driven consultations
• the importance of workforce development, diversity, and preparedness as well as participant diversity and engagement
• challenges to promoting improvement tactics unique to the field of rare disease research
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, Editor-in-Chief, PennScience
• 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

*agenda subject to change

Times in EST
10:20am – 11:20am ET | Policy: To Address Important Rare Disease and Health Equity Issues

In this session, panelists will delve into the gaps that must be addressed to support greater access to treatment and clinical trials, relating global health policy decisions back to actions that can be taken at the national and community level. They will discuss current policy solutions that are in place as well as what more can be done and how we can implement policy to optimize care and outcomes for diverse, underserved communities through a variety of lenses, including urban development, infrastructure, environmental health, and politics.

**Moderator:** Daron Watts, JD, Founder, 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
- Anne Quinn-Young, MPH, Chief Mission Officer, Multiple Myeloma Research Foundation
- Mia Keeys, Director of Federal Affairs, Hologic, Inc

11:20am – 11:30am ET | Break

11:30am – 1:00pm ET | RAREly Told Stories Film Viewing

**Moderator:** Ajani Murry, actor

**Films:**
- Amy & Demi’s Scleroderma Journey
- Black Butterflies
- WonderGirl Saida
- You Got This
- 3,2,1 A Rare Journey
- Davis out of the Unknown

1:00pm – 1:15pm ET | Closing Remarks & End of Summit

**Speakers:**
- Craig Martin, CEO, Global Genes
- Jenifer Waldrop, Executive Director, The Rare Disease Diversity Coalition (RDDC)

1:15pm - 2:15pm ET | Lunch