2021 RARE Health Equity Summit Agenda

WEDNESDAY, NOVEMBER 17TH, 2021

6:00pm – 8:30pm ET
Welcome Reception*

THURSDAY, NOVEMBER 18TH, 2021

7:30am - 8:30am ET
Breakfast*

8:30am - 8:45am ET
Welcome and Introductions Day One
Speakers:
• Craig Martin, CEO, Global Genes
• Tammy Boyd, Chief Policy Officer & Senior Counsel, Black Women’s Health Imperative

8:45am - 9:15am ET
Opening Remarks
Speakers:
• To be announced, Pfizer, Inc.

9:15am - 9:45am ET
Keynote Address
Speaker:
• Monica Webb Hooper, PhD, Deputy Director, National Institute on Minority Health and Health Disparities

Fireside chat Moderator:
• Linda Blount, MPH, President and CEO, Black Women’s Health Imperative

9:45am - 10:00am ET
Break

10:00am – 11:00am ET
Understanding the RARE Diagnostic Odyssey of Underserved Patient Communities
Moderator:
• Sika Dunyoh, Associate Director of Patient Advocacy, Travere Therapeutics

Panelists:
• Eric Sid, MD, MHA, Program Officer, National Center for Advancing Translational Sciences
• Jessica Biggs, MPH, Health Equity Program Development and Outreach Specialist, Angioma Alliance
• Grace Whiting, JD, CEO, National Alliance for Caregiving

*In-Person Only
11:00am - 12:00pm ET
**Building More Inclusive Data Sets and Clinical Research Programs**

**Moderator:**
- Isaac Rodriguez - Chavez, PhD, MHSc, MSc, Senior Vice President for Scientific and Clinical Affairs, ICON plc.

**Panelists:**
- Eric Marsh, MD, PhD, Clinical Director, Orphan Disease Center
- Clare Thibodeaux, PhD, Vice President, Scientific Affairs, Cures Within Reach
- Nasha Fitter, MBA, Vice President, Rare and Neurological Diseases, Citizen
- Erin Chu, DVM, PhD, Digital tech/AI in healthcare representative, Amazon Web Services

12:00pm - 1:00pm ET
**Lunch**

1:00pm - 2:45pm ET
**Workshop Breakout Sessions**

**Select (1) of (4) breakout sessions**

- **Improving RARE Health Literacy**
  - **Moderator:** To be announced

- **Challenges of RARE Adult and Elderly Patients**
  - **Moderator:** To be announced

- **Challenges of RARE Young Adult Patients**
  - **Moderator:** Anna Laurent, Head of Programs and Initiatives, Our Odyssey

- **Addressing RARE Racial and Ethnic Disparities**
  - **Moderator:** Linda Wade, President, CEO, and Co-Founder, Sickle Cell Association of Texas Marc Thomas Foundation

2:45pm - 3:00pm ET
**Break**

3:00pm - 3:40pm ET
**Report out from Workshops**

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

3:40pm - 4:40pm ET
**Reducing RARE Health System Biases**

**Moderator:**
- To be announced

**Panelists:**
- Hannah Barnhart, Independent
- Christel Wekon - Kemani, MD, Resident Physician – Pediatrics, UNC Health Care
4:40pm - 5:10pm ET
Closing Remarks
Speakers:
  • To be announced, Genentech

6:30pm - 9:30pm ET
RARE Champions of Hope Celebration

FRIDAY, NOVEMBER 19TH, 2021

7:30am – 8:30am ET
Breakfast*

8:30am – 8:45am ET
Welcome and Introductions Day Two
Speakers:
  • Christian Rubio, MA, MBA, Vice President, Strategic Advancement, Global Genes
  • Tammy Boyd, Chief Policy Officer & Senior Counsel, Black Women’s Health Imperative

8:45am – 9:15am ET
Opening Remarks
Speakers:
  • Eve Dryer, Vice President, Patient Advocacy, Travere Therapeutics

9:15am – 9:45am ET
Keynote Address
Speakers:
  • To be announced

Fireside chat Moderator:
  • Linda Blount, MPH, President and CEO, Black Women’s Health Imperative

9:45am – 10:00am ET
Break

10:00am – 11:00am ET
Expanding Access to Underserved Patient Communities
Moderator:
  • To be announced

Panelists:
  • Cynthia Kuan, MBA, Program Director, ARM Foundation
  • Shonta Chambers, MSW, Executive Vice President Health Equity Initiatives and Community Engagement, Patient Advocate Foundation
  • Claudia Hardy, MPA, Program Director, O’Neil Comprehensive Cancer Center at UAB
  • Daron Watts, JD, Managing Member, The Watts Group LLC

*In-Person Only
11:00am – 12:00pm ET
Equity and Diversity Outside of the United States
Moderator:
• Markus Gemuend, US-Africa Inclusive Research Strategy, Genentech

Panelists:
• Lara Bloom, President and CEO, Ehlers-Danlos Society
• Harsha Rajasimha, MS, PhD, Founder & CEO, Jeeva Informatics Solutions Inc.
• Mohua Chakraborty Chaudhury, PhD, Post-Doctoral Policy Fellow, DST-Centre For Policy Research, Indian Institute Of Science, Bengaluru
• Joseph Lubega, MD, MPH, Associate Director, East Africa Pediatric Hematology/Oncology Fellowship Training Program, Texas Children’s Hospital

12:00pm – 1:00pm ET
Lunch*

1:00pm – 2:15pm ET
Partner Updates

2:15pm – 2:45pm ET
Closing Remarks & End of Summit