2021 RARE Health Equity Summit Agenda

Welcome Reception*

Breakfast*

Welcome and Introductions Day One
Speakers:
  • Craig Martin, CEO, Global Genes
  • Tammy Boyd, Chief Policy Officer & Senior Counsel, Black Women's Health Imperative

Opening Remarks
Speaker:
  • Bert Bruce, MBA, Regional President, North America, Rare Disease, Pfizer Biopharmaceuticals Group

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

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
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
- Alexa Berk King, PhD, Head of Research and Real World Evidence, 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:** Behtash Bahador, MS, Associate Director, Relationship Management and Development, CISCRP

- **Challenges of RARE Adult and Elderly Patients**
  - **Moderator:** Nancy Kessler, MA, Independent

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

- **Addressing RARE Racial and Ethnic Disparities**
  - **Moderators:**
    - Linda Wade, President, CEO, and Co-Founder, Sickle Cell Association of Texas Marc Thomas Foundation
    - Sarita Edwards, BHSc, Founder, CEO & President, The E. WE Foundation

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

3:00pm - 3:40pm ET
**Workshops Debrief**

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

**Panelists:**
- Behtash Bahador, MS, Associate Director, Relationship Management and Development, CISCRP
- Nancy Kessler, MA, Independent
- Anna Laurent, Head of Programs and Initiatives, Our Odyssey
- Linda Wade, President, CEO, and Co-Founder, Sickle Cell Association of Texas Marc Thomas Foundation
3:40pm - 4:40pm ET
Reducing RARE Health System Biases*
Moderator:
  • Pamela Price, Deputy Director, The Balm in Gilead

Panelists:
  • Hannah Barnhart, Formerly- Genetics Clinic Coordinator (Currently- Genetics Navigator)
  • Christel Wekon - Kemani, MD, Resident Physician – Pediatrics, UNC Health Care
  • To be announced

4:40pm - 5:10pm ET
Closing Remarks
Speakers:
  • Joy Russell, Vice President, External Affairs, Genentech, A Member of the Roche Group

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:
  • Ricardo Correa, MD, Program Director, Endocrinology, Diabetes and Metabolism Fellowship, University of Arizona College of Medicine, Phoenix

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:**
- Bert Bruce, MBA, Regional President, North America, Rare Disease, Pfizer Biopharmaceuticals Group

**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

11:00am – 12:00pm ET
**Equity and Diversity Globally**

**Moderator:**

**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**