In partnership with RDDC THE RARE DISEASE DIVERSITY COALITION

Agenda subject to change
All times are in U.S Eastern Standard Time

**In-Person Only*

WEDNESDAY, NOVEMBER 17TH, 2021

6:00pm – 8:30pm ET
Welcome Reception*

THURSDAY, NOVEMBER 18TH, 2021

6:00am – 8:30am ET
Breakfast*

8:30am - 8:45am ET
Welcome and Introductions
Speakers:

- Craig Martin, CEO, Global Genes
- Tammy Boyd, Chief Policy Officer and Senior Counsel, Black Women's Health Imperative

8:45am - 9:15am ET
Opening Remarks - Lessons from a Pandemic: What COVID-19 Taught Us About Health Equity
COVID-19 brought health equity to the forefront like never before. Hear perspectives from Bert Bruce, Regional President, North America, Rare Disease, Pfizer, on how the pandemic challenged the scientific and public health communities to address health disparities from the lab to the frontline, and what lessons can be applied to our efforts to accelerate innovations for patients living with rare diseases.

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

9:15am - 9:45am ET
Keynote Address - Moving Toward the 4th Generation of Research to Address Health Disparities in Rare Diseases and Beyond
Disparities in access to high quality healthcare and health outcomes in both common and rare diseases are longstanding. The field is encouraged to push full speed ahead into 3rd, and 4th generation health disparities research with the goal of assuring health equity. Authentic community-engaged approaches that seek to understand and address social determinants, including structural racism and discrimination that increase the risk of poorer health outcomes are needed to ensure that populations disproportionately affected are not further left behind and receive the needed culturally and community competent care.

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

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10:00am – 11:00am ET

Understanding the RARE Diagnostic Odyssey of Underserved Patient Communities

On average, it takes 7 years to get to a rare disease diagnosis, but for some patients, it may take longer due to systemic biases and barriers that prevent them from receiving accurate and early intervention. In order to discuss barriers to equitable diagnosis for underserved patients, both system changes as well as individual action must be addressed. This session will explore ways we can better engender trust and empower individual patient experiences while addressing bias and improving diagnostic algorithms to account for a diverse patient population.

- Examine and define what 'underserved' means
- Identify barriers and biases to equitable diagnosis for underserved patient communities
- Navigate better ways to conduct outreach and provide more tools and resources to patients and families at different health literacy levels

Moderator: Sika Dunyoh, 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

Diversity in RARE Research

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 equity in rare disease research and treatment. This starts with building trust between those completing the research and those being served by the research. This session will explore how digital health technologies, repurposing, decentralized clinical trials, and community outreach can lead to better equity, diversity, and inclusion in rare research.

- Address current challenges in rare research including socioeconomic status, health literacy levels, method of information dissemination, unconscious bias, lack of trust, and need for improved cultural competency
- Discuss how community trust, decentralized clinical trials, and technological development can work together to bring more inclusivity to research

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

- Clare Thibodeaux, PhD, Vice President, Scientific Affairs, Cures Within Reach
- Alexa Berk King, PhD, Head of Research and Real World Evidence, Ciitizen
- Erin Chu, DVM, PhD, Digital tech/AI in healthcare representative, Amazon Web Services

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12:00pm - 1:00pm ET

Lunch*

1:00pm - 2:45pm ET

Workshop Breakout Sessions*

Select (1) of (4) breakout sessions

- **Workshop 1 | Improving RARE Health Literacy**
  - *Moderator:* Behtash Bahador, MS, Associate Director, Relationship Management and Development, CISCRP

- **Workshop 2 | Challenges of RARE Adult and Older Patients**
  - *Moderators:*
    - Nancy Kessler, MA, Independent Consultant
    - Terri Booker, JD, Sickle Cell Advocate, Sick Cells

- **Workshop 3 | Challenges of RARE Young Adult Patients**
  - *Moderators:*
    - Anna Laurent, Head of Programs and Initiatives, Our Odyssey
    - Dominique Goodson, President, SCD Forum

- **Workshop 4 | 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 and President, The E. WE Foundation

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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 Consultant
- Terri Booker, JD, Sickle Cell Advocate, Sick Cells
- Anna Laurent, Head of Programs and Initiatives, Our Odyssey
- Dominique Goodson, President, SCD Forum
- Linda Wade, President, CEO, and Co-Founder, Sickle Cell Association of Texas Marc Thomas Foundation
- Sarita Edwards, BHSc, Founder, CEO and President, The E. WE Foundation

3:40pm - 4:40pm ET
Reducing RARE Health System Biases
One of the most powerful ways that bias works is through the lack of re-examining norms that were created with inherent bias. This can be seen throughout the healthcare system from intake forms to patient questionnaires and the method in which patients receive care. During this session, panelists will explore the root cause of various barriers that exist within our health system as well as what has been done to address those barriers and what challenges still exist.

- Discuss the benefits and barriers of telehealth
- Examine how racial and other biases can impact healthcare delivery and outcomes
- Explore how lack of diversity in healthcare providers and researchers leads to avoidance of care due to lack of trust and cultural proficiency

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
- Mandi Pratt-Chapman, MA, PhD, Hon-OPN-CG, Associate Center Director, Patient-Centered Initiatives and Health Equity, GW Cancer Center
- Sherrie Williams, LCSW, Chief of Operations,Global Partnership for Telehealth

4:40pm - 5:10pm ET
Closing Remarks - Genentech's Commitment to Health Equity
Genentech is approaching DEI in a multitude of ways, by fostering belonging across our organization throughout all of our individual teams, by leading initiatives to advance inclusive research and promote health equity, and by transforming society. Our work internally on fostering belonging begins with open and honest conversations, but also includes efforts to diversify our talent and workforce through inclusive hiring practices, increasing gender and racial diversity among our senior leaders and officers, and throughout our workforce. We are also leaders in advancing inclusive research, all of our molecule teams include population-specific assessments, and inclusive research action plans.

Speaker: Joy Russell, Vice President, External Affairs, Genentech, A Member of the Roche Group

6:30pm - 10:00pm ET
RARE Champions of Hope Celebration

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FRIDAY, NOVEMBER 19TH, 2021

7:30am – 8:30am ET
Breakfast*

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

8:45am – 9:15am ET
Opening Remarks - A Rallying Cry for Diversity, Equity, and Inclusion in Rare Disease Innovation
The acknowledgment of historic healthcare injustices is only just beginning, let alone dismantling the many barriers to equitable treatment. Disparities in rare disease research, diagnosis and treatment are a singular example of wrongs that must be righted. We have the responsibility to level the playing field, so that all rare disease patients and families have access to quality healthcare, and are proactively encouraged to participate in pathways to innovation.

Speaker: Eve Dryer, Vice President, Patient Advocacy, Travere Therapeutics

9:15am – 9:45am ET
Keynote Address - The Importance of Cultural Considerations in RARE Healthcare
We all come from different backgrounds, traditions, and family dynamics, and have different ways of navigating and managing our healthcare. In order to build a more inclusive world, we need to better account for cultural considerations and differences. In this session, Dr. Ricardo Correa will touch upon the importance of remaining culturally humble and open minded when working with people in the rare disease community with a specific focus on the Latino/Latina/Latinx/Hispanic and transgender communities.

Speaker: 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
What can we do in our organizations to address inequities in access without requiring the patient to do anything? Today's healthcare system is better at treating individuals when problems arise than it is at educating the medically underserved population about the importance of preventative care. While some progress has been made, the system still assumes that individuals are starting from the same baseline, knowledge, and access. It does not account for the biases against rare disease patients and people of color that were created when the system was invented. This session will look at what needs to happen at every level for that system to change.
- Examine how community health workers are key in facilitating connections and trust within the healthcare system
- Share outcomes from other disease spaces that can be applied to rare disease to prevent the same disparities from happening
- Address the social context of health through the lens of the social determinants of health

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

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11:00am – 12:00pm ET

Equity and Diversity Globally

Broadening representation from the wider community in rare disease research, treatment, and access, requires an in depth look at the challenges and biases in rare disease from a global lens. In this session, panelists will explore research as a driver for access and why low/ middle income countries should care about rare.

- Discuss the differences and challenges in rare disease research, treatment, and understanding globally
- Explore how a lack of global clinical trials and data shapes our U.S.-centric definition of what qualifies as a "rare disease" and thus our approach to research, treatment, and advocacy
- Discuss using globally inclusive data and definitions to create a comprehensive approach to achieve better access

Moderator: Markus Gemuend, Executive Director, US-Africa Inclusive Research Strategy, Genentech, A Member of the Roche Group

Panelists:

- Lara Bloom, President and CEO, The Ehlers-Danlos Society
- Harsha Rajasimha, MS, PhD, Founder and CEO, Jeeva Informatics Solutions Inc.
- Mohua Chakraborty Choudhury, PhD, Post-Doctoral Policy Fellow, DST-Centre For Policy Research, Indian Institute Of Science, Bengaluru
- Joseph Lubega, MD, MS, CPE, Associate Professor, Baylor College of Medicine / Texas Children's Hospital

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12:00pm – 1:00pm ET

Lunch*

1:00pm – 2:00pm ET

Partner Updates

2:00pm – 2:15pm ET

Closing Remarks & End of Summit

Speakers:

- Craig Martin, CEO, Global Genes

Global Genes®

RARE HEALTH EQUITY SUMMIT