



RARE HEALTH EQUITY FORUM

EQUITY IN ACTION



SEPTEMBER 18 - 19, 2023 | SHERATON SAN DIEGO HOTEL & MARINA, SAN DIEGO, CA

MONDAY, SEPTEMBER 18TH, 2023

All Sessions will be held in Pacific Jewel C&B unless otherwise noted

12:00pm - 12:10pm PST | **Welcome**

Speakers:

- Charlene Son Rigby, CEO, Global Genes
- Jenifer Waldrop, Executive Director, Rare Disease Diversity Coalition (RDDC)

12:10pm - 12:40pm PST | **Keynote Address: Racism - A Historical Foundation for Systemic Disparities**

Racial inequities persist in all of our systems and institutions, including the healthcare system. This talk will focus on the historic roots of those inequities, and the role the scientific community played in cementing those disparities. Although attempts have been made to address these gaps in health outcomes, few—and limited—gains have been made. We will examine these flawed methods and consider ways in which we can become more effective systems-change-agents.

Speaker: Mario Estevez, Organizer / Trainer, Racial Equity Institute

12:40pm - 1:40pm PST | **The Intersectionality of Identity, Culture, and the Rare Disease Experience**

In order to build cultures of equity through community engagement, we first need to understand the root of each culture and ways in which a person's lived experience, beliefs and cultural values impact their interaction with the healthcare system. In this session, panelists will discuss their different lived experiences and cultural backgrounds, how their rare journey is unique and what health equity means to them.

Moderator: Michelle Rivas, MBA, MA, Senior Manager, Communications, Horizon Therapeutics

Panelists:

- Vanessa Hiratsuka, PhD, MPH (Diné/Winnemem Wintu), Assistant Professor, University of Alaska Anchorage, Center for Human Development
- Daniel Price, Adult Regional Coordinator, TSC Alliance
- Neena Nizar, EdD, Founder & Executive Director, The Jansen's Foundation

1:40pm - 2:40pm PST | **Engagement Strategies: How to Find and Leverage Partnerships with Community Leaders**

Building relationships with local stakeholders to co-create community informed and centered solutions is essential to addressing health disparities and dismantling systemic inequities. Strategically engaging with community residents involves investing time and resources to nurture authentic, trusting, and sustainable partnerships. In this session, attendees will hear from organizations that have successfully established relationships in underserved and under-resourced communities. Attendees will walk away with a better understanding of how to establish connections and work within community systems to meet patients' needs.

Moderator: Maria Della Rocca, MS, PMP, Senior Director, Support & Education Programs, Global Genes

Panelists:

- Connie Lee, PsyD, CEO, Alliance to Cure Cavernous Malformation
- Italo M. Brown, MD, MPH, Assistant Professor, Emergency Medicine, Stanford School of Medicine
- Karlla W. Brigatti, MS, CGC, Research Operations Director, Clinic for Special Children

2:40pm - 2:55pm PST | **Break**

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2:55pm - 3:45pm PST | **Health Equity In Action: Health Equity Grant Recipients and RDDC Fellows**

Speakers:

- Aditi Kantipuly, MD, MS, Rare Disease Equity Fellow, Rare Disease Diversity Coalition
- Rewaa Elgazar, Undergraduate Student, Johns Hopkins University
- Rob Long, Executive Director, Uplifting Athletes
- Katie Stevens, Executive Director, Team Telomere

3:45pm - 4:25pm PST | **The New Generation of Medical Care?: Bringing Health Equity and Positive Health Outcomes to Rural and Underserved Populations**

Promoting health equity requires collaboration among key stakeholders in health and social systems, developing strategic partnerships, and engaging across institutional boundaries to identify local needs. In this session, panelists will discuss the importance of cross collaboration between interdisciplinary care teams and what the medical care system is doing to support underserved communities in unique ways.

Moderator: Shruti Mitkus, PhD, Director, Genetic Education & Navigation, Global Genes

Panelists:

- Samuel Nokuri, MD, MBA, FACP, LTC USAF, Founder & CEO, Premier Health Express Urgent Care
- Jevon Gibson, CEO, Fulton-DeKalb Hospital Authority
- Kendal K. Whitlock, MPH, Head of Digital Optimization, RWE Clinical Trials, Walgreens

4:25pm - 5:05pm PST | **Leveraging Underutilized Health Services to Support Underserved Populations**

Our communities of most need are often those who are intentionally excluded and economically neglected from investment opportunities in all areas. Nowhere is this more prevalent than in health. In this session presenters will dive into how health professionals can utilize existing place-based whole person care providers (such as Community Health Workers, Peer Support Specialists, and Health Ambassadors/Navigators) to address patients' unique health needs while supporting social needs and risk factors, providing health education, and building client and community capacity. In addition, we will provide an example of how place-based whole person care providers are currently being used in the All In. Rare project.

Speakers:

- Mariah Chrans, IBCLC, PhD, Programs Director, Community Health Council of Wyandotte County
- Teneasha Washington, PhD, MPH, RARE-X Diversity, Equity & Inclusion Lead, Global Genes

5:05pm - 5:10pm PST | **Closing Remarks**

Speaker: Molly Keane, LCSW, MPH, Senior Manager, Horizon Therapeutics

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5:10pm - 5:30pm PST | **Break**

5:30pm - 6:00pm PST | **RAREly Told Stories Viewing**

6:00pm - 8:00pm PST | **Reception**

Location: Eventide Garden

TUESDAY, SEPTEMBER 19TH, 2023

7:00am - 8:00am PST | **Breakfast**

Location: Pacific Jewel A and Eventide Garden

8:00am - 8:05am PST | **Opening Remarks**

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

Brought to you by  **TRAVERSE**
THERAPEUTICS

8:05am - 8:35am PST | **Keynote Address: Disease, Distrust, Disparities and Direction: American Indian and Alaska Native Socio-political Histories, Historical Trauma, and a Pathway to Wellness**

American Indian and Alaska Native (AI/AN) peoples have been targets of genocide since early European arrival. Some of the strategies included the use of disease as biological warfare. It is important to understand this history and the continued effects of historical trauma to implement true systems of equity. Cultural respect and healing are key to working effectively in AI/AN people. It is integral to building trust and respect for traditional epistemologies, which lay the foundation to build culturally-attuned, effective systems for prevention, early intervention and care.

Speaker: Esther Lucero, MPP, CEO, Seattle Indian Health Board

8:35am - 9:35am PST | **Uniendo Voces, Unlocking Solutions: Advancing Hispanic Inclusion in Rare Disease Advocacy and Research**

This panel discussion aims to shed light on the unique challenges and opportunities that arise when incorporating the Hispanic population into rare disease advocacy and research efforts. Panelists will delve into the importance of inclusivity, understanding cultural nuances, meeting language needs, and addressing barriers faced by the Hispanic community in accessing Spanish-language information, resources, and high-quality care. Experts from diverse backgrounds will share insights and best practices to drive collaboration, empower patients, and increase representation of the Hispanic population in the pursuit of improved treatments and support for rare diseases. Join us as we explore how addressing health disparities burdening Hispanic patients can drive innovation and ensure equitable outcomes for all.

Moderator: Deborah Requesens, PhD, Cofounder, Sociedad Hispana de Enfermedades Raras (SHER)

Panelists:

- Victoria Arteaga, MBA, Co-founder, Sociedad Hispana de Enfermedades Raras (SHER)
- Mario Estevez, Organizer / Trainer, Racial Equity Institute
- Beatriz Mallory, Executive Director, HEARD Kids
- Carlos Martinez Villela, Project Manager, America's Health Foundation

9:35am – 9:45am PST | **Break**

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9:45am – 10:55am PST | **Table Talks**

10:55am - 11:20am ET | **Actionable Steps to Improve Diverse Engagement in Clinical Trials**

Women of Color have the highest prevalence and worse outcomes for sarcoidosis, a rare disease. In an effort to address this issue, FSR launched a national awareness campaign, Ignore No More, resulting in over half a million media impressions in just 5 months. Phase II of the *Ignore No More* Campaign, was focused on *Advancing Clinical Trial Equity (ACTeNow)*. FSR conducted several initiatives to better understand what steps we need to take to improve representation of the black community in clinical trials. From this case study, learn how to build effective health equity national campaigns from concept all the way to the halls of Congress and be a part of the actionable recommendations.

Speaker: Mary McGowan, CEO, Foundation for Sarcoidosis Research

11:20am – 12:05pm PST | **Understanding the Patient Perspective - How to Ensure Diverse Patient Participation in Clinical Trials and Research**

Improving equity in clinical trials and research requires considering barriers to patient participation at multiple levels and identifying strategies to help address specific issues at each level. In this session, panelists will discuss how patients can/should be on the front lines with their community ecosystem, and what that relationship should look like between community leaders and researchers.

Moderator: Mary McGowan, CEO, Foundation for Sarcoidosis Research

Panelists:

- Maria Santaella, PhD(c), MSN, RN-BC, CPHON, VP Research, National Hemophilia Foundation
- Yasmeen Long, MA, Director, FasterCures
- Trudy Nyakambangwe, Founder, Child And Youth Care Zimbabwe
- Lolita Smith-Moore, MA, Program Manager, Rare Disease Diversity Coalition

12:05pm – 12:10pm PST | **Closing Remarks**

Speakers:

- Charlene Son Rigby, CEO, Global Genes
- Jenifer Waldrop, Executive Director, Rare Disease Diversity Coalition (RDDC)

12:10pm – 1:10pm PST | **Lunch**

Location: Pacific Jewel A and Eventide Garden

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