



the rare fair

the only 100% virtual event for the
global rare disease community

9.1.2020 - 9.3.2020

7 a - 7 p ET

www.therarefair.com

Sponsored By



DAY ONE

Welcome | 8:30 AM ET | Auditorium

Eden Lord, MSM | Founder & CEO | My City Med

Jeff Lord, MS | CTO | My City Med

Panel | 9:00 AM ET | Auditorium

Moderated by Eden Lord

"Unrepresented: The Forgotten Subsets of the Rare Disease Population"

Panelists

Marni Cartelli | Rare Disease Patient and Advocate

Allison Peck | Rare Disease Spouse

Live from Zimbabwe | 9:30 AM ET | Auditorium

A Musical Performance by Tinn Tinn, Rare Disease Advocate

*Exhibit Hall and Digital Resource Room Virtual Ribbon Cutting | 9:45 AM ET | Auditorium

Keynote Speaker | 10:00 AM ET | Auditorium

Meg Talley Dyer | Rare Disease Advocate, Patient, Caregiver, and Parent

"Lessons from a Mongoose"

Patient/Advocacy Tracks | 11:15 AM ET | Auditorium

Kirsten Wilson | Educator and Founder | The Bulldog Educator Podcast

"The Future of Online Education: Ensuring Ongoing Accessibility"

Open Live Chats | 12:00 PM ET | Networking Lounge

COVID-19 Concerns in the Rare Disease Community

Rare Disease Spouses

Young Adults

Screening | 12:30 PM ET | Auditorium

Lisa Bayha Deck

Rare New England Screening

Panel | 1:30 PM ET | Auditorium

Jenna Swan | Associate Director, US, Orchard Therapeutics | Moderator

"Driving Change for Your Disease Community: Policy and Advocacy in the The Rare Disease Landscape"

Panelists

Tara Britt | Founder and President, Rare Disease Innovations Institute

Meghan Perry | Director, US Public Affairs and Advocacy, Orchard Therapeutics

Sumathi Iyengar, MD | Executive Director, Wiskott-Aldrich Foundation

Dylan Simon | Newborn Screening Policy Fellow, EveryLife Foundation

Patient/Medical Tracks | 3:00 PM ET | Auditorium

Allison D'Ambrosio Bones | President & CEO | T.E.A.M. 4 Travis

"When the Flu isn't Just the Flu"

Networking Event | 5:00 PM ET | Networking Lounge

Advocate Networking

Join other rare disease advocates to network and discuss challenges facing the rare disease community and how we can address them together.

Closing | 6:30 PM ET | Auditorium

Eden Lord, MSM | Founder & CEO | My City Med



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DAY TWO

Welcome | 7:45 AM ET | Auditorium

Jeff Lord, MS | CTO | My City Med

Research | 8:00 AM ET | Auditorium

Armé Hendriksz | Head of IT | FYMCA Medical Ltd.

"Making the World Local: How Making the World Local Gives Opportunity for Rare Patients to Receive the Best Care Regardless of Geography"

Panel | 9:15 AM ET | Auditorium

Moderated by Jeff Lord, MS | CTO | My City Med

"Rare Dads: Building a Support Network"

Panelists

Bo Bigelow | Co-Founder | The Disorder Channel & DISORDER: The Rare Disease Film Festival

Jonathan Dicks | Emergency RN

Bo Govea | Director of International Business Development | Knok Care

Luke Rosen | Founder of KIF1A.ORG | Accelerated Development & Community Engagement at Ovid

Keynote Speaker | 10:30 AM ET | Auditorium

Samuel Agyei Wiafe, MD | Clinical Psychologist, Founder & Executive Director, Rare Disease Ghana Initiative

"Rare Diseases and Mental Health: Focus on Indigenous Populations and Developing Nations"

Live Chats | 12:00 PM ET | Networking Lounge

Rare Moms Chat

Rare Dads Chat

Grandparents Chat

Screening | 12:00 PM ET | Auditorium

Rare New England Screening

Panel | 1:30 PM ET | Auditorium

Sean Gordon | Founder & Chief Volunteer Officer | Rare Funding Team

"Rare Tech: Rare Disease and Evolving Technology"

Panelists

Dr. Femida Gwadry-Sridhar | CEO | Pulse Inframe

Gavin Jones | Director of Rare Disease | OPEN Health

Jeff Lord | Founder & CTO | My City Med

Cecile Ollivier | Chief Innovation and Regulatory Science Officer | Aparito

Patient/Medical Tracks | 3:00 PM ET | Auditorium

José Bastos | Co-Founder & CEO | Knok Health

"Telehealth Technology"

Rare Family Dance Party | 4:00 PM ET | Networking Lounge

Breakout your best zebra gear and join us for an hour of dancing at our virtual family dance party!

Moderated Live Chat | 5:00 PM ET | Networking Lounge

"Rare Siblings" Moderated by: Landrey and Cambria Lord

Join rare advocates and siblings Cambria and Landrey Lord as they discuss the ups and downs of living with rare disease as siblings. (This chat will be monitored by My City Med staff.)

Networking Event | 5:00 PM ET | Networking Lounge

Non-Profit Networking

Join other rare disease non-profit leaders in groups and 1:1 to network and discuss challenges facing the non-profit community.

Closing | 6:30 PM ET | Auditorium

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DAY THREE

"Live from Zimbabwe" | 7:45 AM ET | Auditorium

Rare advocate and performer Tinn Tinn joins The Rare Fair from Zimbabwe

Welcome | 8:00 AM ET | Auditorium

"Keep on Fighting" | 8:15 AM ET | Auditorium

World Premier by Jacob Thompson, Winner NCATS Rare Diseases Are Not Rare! 2020 Challenge

Patient Education | 9:00 AM ET | Auditorium

Dr. Julie Eggington | Co-Founder & CEO | Center for Genomic Interpretation

Megan Garlapow | Center for Genomic Interpretation

"Spotting False Positives In Your Genetic Test Result and COVID Era Challenges to Delivery of Clinical Genetics"

Keynote Speaker | 10:30 AM ET | Auditorium

Kevin Mott | Member, Board of Directors | NephCure International

"Rare Diseases, Common Challenges"

Panel | 11:00 AM ET | Auditorium

Kevin Mott | Member, Board of Directors | NephCure International

"Paving a New Path: Building a More Inclusive Rare Disease Community"

Panelists

Sika Dunyoh | Associate Director, Patient Advocacy | Retrophin

Joyce Nortey, MPH, MSBH | Founder & Lead Advocate | Norkai Advocates

Adrian Palau-Tejeda | Diversity & Inclusion Fellow | The Everylife Foundation

Angela Urbano | Founder & Executive Director | Blount's Disease Strong

Live Chats | 12:00 PM ET | Networking Lounge

Adult Chat (55+)

Diversity and Rare

Research and Rare

Screening | 12:30 PM ET | Auditorium

Rare New England Screening

Panel | 1:30 PM ET | Auditorium

Bo Bigelow | Co-Founder | The Disorder Channel & DISORDER: The Rare Disease Film Festival

"Media as a Bridge: Bringing Rare Disease into the Mainstream"

Panelists

Lisa Bayha Deck | Host, Rare New England

Janet Kennedy | Podcast Founder & Host | "Get Social Health" & "People Always, Patients Sometimes"

Nicola Miller Gelati | Editor-In-Chief | Rare Revolution Magazine

Georgia Hart | Rare Revolution Youth Ambassador

Patricia Weltin | Activist & Citizen Scientist | Beyond the Diagnosis

Patient Track | 3:00 PM ET | Auditorium

Effie Parks | Host | Once Upon a Gene Podcast

"Find Your People"

Patient Track | 4:00 PM ET | Auditorium

Nahzi Forrest | Sickle Cell Advocate | Nahzi Thee Baker

"Source for Good"

Rare Young Adult Dance Party (18+) Hosted by Nahzi Forrest | 5:00 PM ET | Networking Lounge

Calling all Rare Young Adults - join us for an international dance party from your own living room!

Networking Event | 6:00 PM ET | Networking Lounge

Industry Networking (Hosted by Eden Lord)

Join other rare disease stakeholders to network and discuss challenges facing the rare disease population and how industry can partner with them to source new solutions.

Closing | 6:45 PM ET | Auditorium

"Live from Zimbabwe" | 6:50 PM ET | Auditorium

Rare advocate and performer Tinn Tinn joins The Rare Fair from Zimbabwe