

24 Hours of Rare

7:00AM	UK - RARE Revolution Panel	7:00PM	Transplant Unwrapped
8:00AM	Iceland - Einstok Born	8:00PM	Encore Presentation RF 2020
9:00AM	Peru - Hunter Syndrome	9:00PM	Global Networks
10:00AM	UK - Timothy Syndrome	10:00PM	Little Zebra Fund
11:00AM	Canada - GBS/CIDP	11:00PM	Encore: Lessons from a Mongoose
12:00PM	US - Alagille & Rare New England	12:00AM	Ghana
1:00PM	Teaming up on Single-Gene Diseases Panel & Harmony for Hope	1:00AM	India - ORDI & The Rare World
2:00PM	Denver - All of Us	2:00AM	International Networking
3:00PM	California - CRFI, XLH Network, PS	3:00AM	Rare Diseases in Georgia
4:00PM	International Networking	4:00AM	Bahrain Kenya
5:00PM	Adenomyosis Advice Association	5:00AM	Israel Botswana Zimbabwe
6:00PM	New Zealand	6:00AM	France Italy Spain

Additional Highlights:

11a-1p Networking in Expo Hall

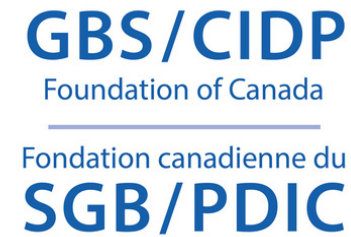
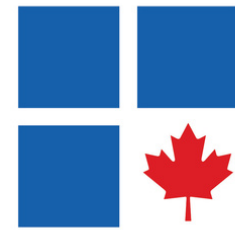
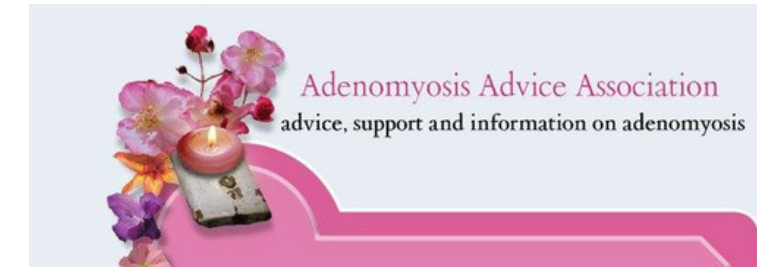
1p-2p Monogenic Rare Diseases Panel

February 28 | All Times Eastern

*Calendar subject to change



event participants



24 Hours of Rare

event participants



24 Hours of Rare



patient day

March 1

Agenda (All Times Eastern)

8:30AM	Kickoff with All of Us, a NIH Initiative
9:00AM	Rare Dad: Challenges and Opportunities
10:00AM	Building Patient Communities: A Listening Session
11:00AM	Gentle Yoga sponsored by Cystic Fibrosis Research Institute
12:00PM	Networking Break/Expo Hall Break
1:00PM	Youth Panel sponsored by Rare Revolution
2:00PM	Little Advocate Artists: <i>Live with Artist & Advocate Pat Guerre</i>
3:00PM	Introducing the Next Breakthrough in Health - You
4:00PM	Patient Day Wrap-Up
8:00PM	Patient Networking in the Lounges

Highlights

- Gentle Yoga
- Hot Topics Youth Panel by RARE Revolution
- Live Art Demo with Kneading Hope
- Little Artists Lounge Unveiling

Networking Opportunities

- Child Patient Meetup (13-17)
 - *Adult must accompany the child
- Adult Patient Meetups
 - 18-34, 35-54, 55+
- Evening networking in the patient lounges



Free patient & caregiver registration at
www.24hoursofrare.com

caregiver day

March 2

Agenda (All Times Eastern)

- | | |
|---------|---|
| 9:00AM | Caregiver Day Kickoff |
| 9:30AM | The Patient & Caregiver Story |
| 10:30AM | Reporting on Caregiving: A Panel Discussion |
| 11:00AM | Rare Dads Panel |
| 12:00PM | Networking Break/Expo Hall Break |
| 1:00PM | Physician Best Practices in Supporting Life Transitions for People Living with Rare - OPEN Health |
| 2:00PM | Introducing the Next Breakthrough in Health - You. |
| 3:00PM | Single Parents of Rare Disease Patients - A Panel Discussion |
| 4:00PM | In Sickness and In Health: How Chronic Medical Illness and Rare Diagnoses Affect Couples |
| 5:00PM | Caregiver Day Wrap Up |
| 8:00PM | Caregiver Networking in the Lounges |

Highlights

- Caregiver Panel
- Rare Dads Panel
- Life Transitions Panel
- Single Parents Panel
- Couples Session

Networking Opportunities

- Caregiver Meetup
 - children of rare parents
- Caregiver Meetup
 - parents of rare children
- Caregiver Meetup
 - spouses and partners



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medical day

March 3

Agenda (All Times Eastern)

8:30AM	Medical Day Kickoff
9:00AM	Collaborative Patient and Physician Relationships in the Treatment of Pain
10:00AM	Developments in Pediatric Neuro Ophthalmology
11:00PM	The Use of Genetics in Cushing Syndrome
12:00PM	Networking Break/Expo Hall Break
1:00PM	Careers in Genetics Presented by Rare New England
2:00PM	Research Opportunities for Rare Diseases at NICHD/NIH
2:00PM	COVID. Make a Difference from a Safe Distance.
3:00PM	Gigantism and Genes: What We Do (and Don't) Know
3:00PM	Overview of Kids First and CBTN Platforms
4:00PM	Medical Day Wrap

Highlights

- What Patients Want Their Doctors to Know: A Listening Session
- NIH Physician Presentations
- Genetics Careers
- Kids First and CBTN Platforms

Networking Opportunities

- Medical Student & Rare Disease Patient/Family Meetup - 4P Eastern
- Medical Professional Meetup - 4P Eastern
- Evening networking in the medical professional lounges - 8p



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non-profit *day*

March 4

Agenda (All Times Eastern)

9:00AM	Non-Profit Day Kickoff
9:30AM	Cultural Barriers Impacting Access - A Panel Discussion
9:30AM	Finding Creative Ways of Supporting Moyamoya Patients
10:00AM	Building Impactful Stakeholder Communities: A Listening Session
11:00AM	What are the Ethical Preapproval Considerations for Rare Patient Groups? A Panel Discussion
12:00PM	Networking Break/Expo Hall Break
1:00PM	The Importance of Collaboration Among Charity Leaders to More Effectively Raise Awareness and Find Treatments
2:00PM	The Importance of Early Screening for SD
2:00PM	Introducing the Next Breakthrough in Health - You
3:00PM	Non-Profit Wrap-Up

Highlights

- Gentle Yoga
- Hot Topics Youth Panel by RARE Revolution
- Live Art Demo with Kneading Hope
- Little Artists Lounge Unveiling

Networking Opportunities

- Advocate Meetup - 3pm
- Non-Profit Meetup - 3pm
- Evening networking in the non-profit lounges



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industry day

March 5

Agenda (All Times Eastern)

8:30AM	Industry Day Kickoff
9:00AM	The Intersection of Big Data and Health IT Panel
10:00AM	Building an Accessible Rare Disease Model for All Stakeholders: A Listening Session
11:00AM	Building Trust Through Appropriate, Proactive Engagement and Communication Strategies
12:00PM	Networking Break/Expo Hall Break
2:00PM	Introducing the Next Breakthrough in Health - You
3:00PM	The Future Path of Rare Disease (A Panel Discussion with Industry Leadership)
4:00PM	Decentralizing Clinical Trials: A Case Study
5:00PM	Wrap-up and Next Steps

Highlights

- Big Data Panel
- Rare Disease Model: Listening Session
- Industry Leadership Panel
- Decentralized Clinical Trials discussion

Networking Opportunities

- Industry Meetup - 1p
- Networking Block - 12-2p
- Next steps - sign up to join us for future sessions



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networking lounges

March 5

Network in a variety of disease-specific, geographical, or stakeholder-based lounges.
Engage via text or video with other attendees in the lounge 24/7.

Single Parents

Africa

Single Parents

Asia

Single Parents

Australia

Single Parents

Europe

Highlights

- Industry Panel

Networking Opportunities

- Submit science report



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patient groups

A variety of patient groups will be in attendance from across the globe.

Growth Hormone Disorders

Pompe

SMA

Duchenne

Hemophilia B



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