Accelerating Rare Disease Research: Patients as Partners

MONDAY, FEBRUARY 27, 2023 FROM 1:30 - 5:30 PM ET
STREAMED LIVE FROM THE BROAD INSTITUTE AUDITORIUM

EVENT PROGRAM

1:30 PM  Invitation to the Broad Discovery Center Museum

2:00 PM  Welcome Remarks
  Anna Greka (Associate Professor, Harvard Medical School, Brigham and Women’s Hospital; Institute Member, Director, Kidney Disease Initiative, Broad Institute)
  Belinda Termeer (President, Co-Founder, and Board Member of The Termeer Foundation)

2:15 PM  Spotlight on Mitochondrial Diseases
  Vamsi Mootha (Professor, Harvard Medical School, HHMI Investigator; Institute Member, Broad Institute)

2:45 PM  Working Hand in Hand with Patient Foundations to Develop Therapies for Ultra-Rare Genetic Neurodevelopmental Disorders
  Yael Weiss (CEO and Founder of Mahzi Therapeutics; Termeer Fellow, Class of 2022)

3:00 PM  From Rare Disease Parent to CEO: Gene Therapy for Dravet Syndrome
  Daniel Fischer (CEO, President, and Co-Founder of Tevard Biosciences; Termeer Fellow, Class of 2022)

3:15 PM  Rare as One: Leveraging the Power of Patients to Accelerate Disease Research
  Tania Simoncelli (Vice-President of Science and Society, Chan Zuckerberg Initiative)

3:25 PM  Inherited Retinal Degeneration: Therapeutic Landscape
  Eric Pierce (Director, Harvard Ophthalmology Ocular Genomics Institute)

3:40 PM  A Panel Discussion: Partnering with Patients to Empower Progress
  Moderator: Samantha Baxter (Associate Director, Genetic and Genomic Data Sharing, Genetic Counselor in the Program in Medical and Population Genetics, Broad Institute)
  Panelists: Charlene Son Rigby (CEO, RARE-X; Co-Founder, TXBP1 Foundation)
  Eric Pierce (Director, Harvard Ophthalmology Ocular Genomics Institute)
  Daniel Fischer (CEO, President, and Co-Founder of Tevard Biosciences; Termeer Fellow, Class of 2022)
  Yael Weiss (CEO and Founder, Mahzi Therapeutics; Termeer Fellow, Class of 2022)
  Vamsi Mootha (Professor, Harvard Medical School, HHMI Investigator; Institute Member, Broad Institute)
  Tania Simoncelli (Vice-President of Science and Society, Chan Zuckerberg Initiative)

4:15 PM  Plans for a Rare Disease Initiative at Broad | Anna Greka

4:30 PM  Networking in the Broad Discovery Center

We are grateful to the Broad Institute of MIT and Harvard and The Termeer Foundation for hosting this event.