



INDOUSRARE ANNUAL CONFERENCE

29TH NOV - 2ND DEC 2021

#INDOUSRARE2021

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All times are in U.S Eastern Time (UTC - 5)

*Agenda is subject to change

29 November 2021

DAY 1

ADVOCACY DAY - Patient led Legislative Advocacy

Welcome note

10:00 AM to 10:30 AM

- **Narayanan Govindarajan, MS (Host)**
Board Director, Indo US Organization for Rare Diseases

Opening Address

- **Harsha Rajasimha, PhD**
Founder and Chairman, Indo US Organization for Rare Diseases

10:30 AM to 11:00 AM

Keynote Address

- **Dr. Madhulika Kabra, MD**
Professor, All India Institute of Medical Sciences, New Delhi, India

Panel Discussion

Moderators:

- **Harsha Rajasimha, PhD and Nara Govindarajan, MS**

Panelists:

11:00 AM to 11:50 AM

- **Dr. Ratna Devi, MBBS, MBA**
Patient Advocate, DakshamA Health
- **Mr. Manjit Singh**
Honorary President, Lysosomal Storage Disorders Support Society, India
- **Swapna Kakani, MPH**
Healthcare Keynote Speaker & Advocate, Director of Alabama Rare
- **Gina Cioffi Loud, JD**
Senior Manager, Public Affairs for Global Rare Diseases at Chiesi Group

11:50 AM to 12 NOON

Special Talk – Young Advocate

- **Krteyu Ramanathan**
Youth Ambassador, Indo US Organization for Rare Diseases

12 NOON to 12:30 PM

OPEN NETWORKING SESSION



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30 November 2021

DAY 2

RESEARCH DAY Patient led Research Programs and Initiatives

Welcome note

10:00 AM
to
10:05 AM

- **Reena Kartha, MS, PhD (Host)**
Director of Research Programs, Indo US Organization for Rare Diseases

Research Day Session 1

10:05 AM
To
11:00 AM

- **K. Thangaraj, PhD**
Director, Centre for DNA Fingerprinting and Diagnostics (CDFD), India
- **Ms. Sophia Zilber**
Board member and Patient Registry Director, Cure Mito Foundation
- **Vinod Scaria, PhD**
Principal Scientist, CSIR Institute of Genomics and Integrative Biology (CSIR IGIB)

Research Day Session 2

11:05 AM
to
12:10 PM

- **Dr. Julie Saba, MD, PhD**
Professor, University of California, San Francisco
- **Professor Lara Bloom**
President & CEO, The Ehlers-Danlos Society
- **Dr. Anaita Udawadia Hegde, MD (Ped) MRCPCH (London)**
Consultant Pediatric Neurology and President, Association of Child Neurology, India
- **Mr. Nathan Peck**
CEO, Cure VCP Disease, Inc.

12:10 PM
to
12:30 PM

OPEN NETWORKING SESSION



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1 December 2021

DAY 3

PATIENTS ALLIANCE DAY Patient Support, Awareness, and Education

10:00 AM

Welcome note

to

10:05 AM

- **Nisha Venugopal, PhD (Host)**
Program Manager, Indo US Organization for Rare Diseases

10:05AM

to

11:10 AM

Patients Alliance Day Session 1

- **Mr. Samir Sethi**
President, Indian Rett Syndrome Foundation
- **Arun Shastry, PhD**
Chief Scientific Officer, Dystrophy Annihilation Research Trust, India
- **Ms. Gitanjali Sehgal**
Co-founder, Families of Spinal Muscular Atrophy (India) TRUST
- **Shani Weber, M.S, ED**
Community Education Director, The Ehlers-Danlos Society

11:10 AM

to

12 NOON

Patients Alliance Day Session 2

- **Ms. Rubby Chawla**
President, Indian Patients Society for Primary Immunodeficiency
- **Mr. Marc Yale**
Advocacy & Research Coordinator, International Pemphigus Pemphigoid Foundation
- **Ms. Beth Bowerman**
Research Services Coordinator, National Ataxia Foundation

12 NOON

to

12:30 PM

OPEN NETWORKING SESSION



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2 December 2021	
DAY 4	INDUSTRY DAY - Patient Advocacy in Industry
10:00 AM to 11:00 AM	Welcome note <ul style="list-style-type: none">• Harsha Rajasimha, PhD (Host) <i>Founder and Chairman, Indo US Organization for Rare Diseases</i>
10:00 AM to 11:00 AM	Panel Discussion Moderator: <ul style="list-style-type: none">• Dr. Anish Bhatnagar <i>CEO, Soleno Therapeutics</i> Panelists: <ul style="list-style-type: none">• Ms. Kate Delaney <i>Senior Director, Global Patient Advocacy and Engagement BIOMARIN</i>• David Rintell, Ed.D <i>VP, Head of Patient Advocacy at BridgeBio Pharma, Inc</i>• Anil Raina, MPIB <i>General Manager (India) – Sanofi Genzyme</i>
11:00 AM to 12 NOON	Fire Side Chat with Frank Sasinowski, MS, MPH, JD In Conversation a Legend in the field of Rare Diseases Host: Harsha Rajasimha, PhD
12 NOON to 12:30 PM	OPEN NETWORKING SESSION

CONFERENCE ENDS



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