



indousrare

**Celebrates
Nov 25th 2020**

We welcome community inputs on our progress & impact

IndoUSrare First Year Impact

16

patients alliance members



500+

rare diseases represented



15,000+

patients connected



50+

countries covered



Hosted **12** global events,
Invited Speaker at **8**
conferences



Partnered with
Global Genes and RARE-X



Policy inputs to US FDA
and Indian Govt on data
sharing and diversity.



Raised **\$35,000+**
through donations and
grants

Our Mission

Advocate	Advocate for the inclusion of Indian subcontinent in global clinical trials
Connect Patients	Connect RD patients in India and USA
Collaborate	Collaborate for RD policy development & implementation between USA, India and other countries
Conferences	Bring together stakeholders of rare diseases by organizing national and international conferences
Facilitate cross-border research	Facilitate cross-border research collaborations for genetic disorders

The IndoUSrare team

Board of Directors 2020

Sundee Agrawal, MD
Managing Director, Colt Ventures,
New York, NY



Charles Andres, PhD, RAC
Associate, Wilson Sonsini Goodrich and Rosati
Washington, DC



Narayanan Govindarajan, MS
Big Data and Analytics Industry Leader, UWorld
Dallas, TX



Reena Kartha, MS, PhD
Assistant Professor and Associate Director
Center for Orphan Drug Research
University of Minnesota, MN



Sanath Kumar, MS
Father of a boy with GPX4 mutation
Sr. Software Engineer, AWS
Seattle, WA



Harsha Rajasimha, MS, PhD
Founder and Chairman
Social Entrepreneur
Fairfax, VA



Frank Sasinowski, MS, MPH, JD
Director, Hyman Phelps McNamara PC
Washington, DC



The IndoUSrare team

Nisha Venugopal PhD
Research Program Manager
Bengaluru, India



Siddhee Sahsrabuddhe
Volunteer
PhD student at University of Minnesota
Minneapolis, MI

Arockia Jayaraj PhD
Volunteer
Post Doctoral Research Scholar
UT Southwestern Dallas, TX



Shashi Nadig
Director of community engagement
Greenville, SC

Rekha Narayan
Director of ROAR4RARE
SF Bay area



Srinivas Seshadri
Director of ROAR4RARE
SF Bay area

Sujaya Srinivasan
Genomics in Academic Healthcare at
Amazon Web Services (AWS)



Omnichannel Social Media Presence



Patients Alliance Program

Our Patients Alliance Members 2020



Research Programs

RAREX India Feasibility and Pilot Studies

- Partnership to assess feasibility of patient owned data registries in India and data sharing policy frameworks
- 50+ stakeholder discovery interviews



Patient Groups



Independent Patients and Disability Advocates



Physicians



Policy Professionals



Industry

- Contract Research Organizations (CRO)
- Biopharma sponsors, Service Providers, diagnostic labs

Education & Awareness Program

LIVE
WEBINAR

July 2020



IndoUSrare Webinar Series



**Inaugural Webinar
Guest Speaker**

Nicole Boice
Co-founder, Rare-X;
Founder, Global Genes

**The Rare Journey, Its
What Unites Us**

Saturday the 18th of July 2020
11am to 12 noon EST

Free Registration:
<https://bit.ly/indousrare>

Hosted by



Reena Kartha, MS, Ph.D.
Director of Research Programs
IndoUSrare

IndoUSrare builds collaborative bridges between the West & the East to accelerate clinical research. A non-profit 501(c)(3) tax-exempt organization for connecting Asian-Indian diaspora affected by RARE diseases with global clinical trials.
<https://indousrare.org>

Oct 2020



IndoUSrare Webinar Series



**LIVE
WEBINAR**

Guest Speaker

James Valentine JD, MHS
Attorney at Hyman, Phelps & McNamara;
2019 RARE Champion of Hope

**Rare Disease Patient Engagement with
FDA: Setting the Context for
Regulatory Decision-Making**

Thursday the 15th of October 2020
10 to 11am ET

Free Registration
<https://bit.ly/indousrare>

Hosted by



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Director of Research Programs
IndoUSrare



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Jan 2021



IndoUSrare Webinar Series



**LIVE
WEBINAR**

Guest Speaker

Dr Jayesh Sheth Ph.D., FICMCH
Diploma certificate in Reproductive Medicine and Biology (Geneva Univ)
Chairman Foundation For Research in Genetics and Endocrinology (FRIGE)

**Finding Commonality in Rare Diseases
- the Indian Scenario**

Jan 13, 2021 @10 am ET

Free Registration
<https://bit.ly/indousrare3>

Hosted by



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Director of Research Programs
IndoUSrare



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Global Advocacy and Outreach

Speaking Engagements and Panel Discussion



A glimpse of the IndoUSrare team at Conferences & Meetings

IndoUSrare team responds to Govt calls for public comments

Online Awareness & Fundraising Event

Natya Swara Sep 2020



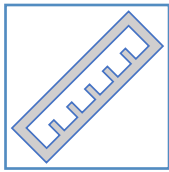
SAJAS – 5 High schoolers from Richmond, VA



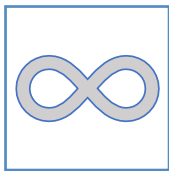
Funds Raised

\$6500

We welcome Community Inputs on



What Key Performance Indicators or Metrics should we use to assess Impact?



5 years from now, what do you wish to see IndoUSrare deliver?

The background features a dark blue field with colorful fireworks in shades of purple, blue, and yellow. Overlaid on this is a network diagram consisting of numerous white nodes connected by thin blue lines, creating a complex web of connections.

THANK YOU!