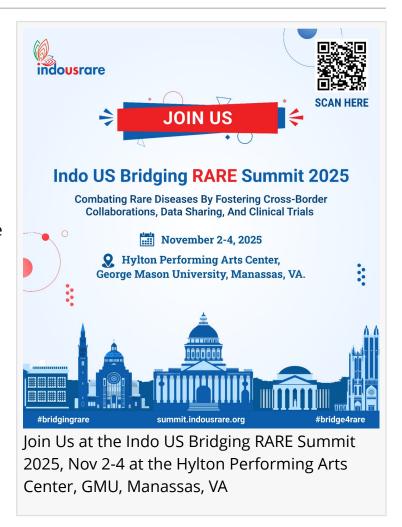


IndoUSrare Quietly Forges Collaborations Ahead of Bridging RARE Summit—Uniting the Global Village Amid Tariffs, Tensions

Patient-centric nonprofit accelerates practical partnerships across borders to keep rare disease research and care moving forward despite macro headwinds

WASHINGTON DC, DC, UNITED STATES, September 9, 2025 /EINPresswire.com/ -- Indo US Organization for Rare Diseases (IndoUSrare) today announced a series of cross-border collaborations in advance of the 2025 Bridging RARE Summit (November 2–4) at the Hylton Performing Arts Center at George Mason University in Manassas, VA.

IndoUSrare unites rare disease stakeholders across the United States, India, and the broader global community. The non-profit's quietly executed collaborations will support continuity in research, diagnostics, and patient care in the face of rising tariffs, supply chain uncertainty, and geopolitical tensions.



"Tariffs and tensions make headlines; patients can't wait," said Harsha K. Rajasimha, Founder & Executive Chair of IndoUSrare, and Founder & CEO of Jeeva Clinical Trials. "Our community is choosing focus over fear—linking investigators, patient groups, and industry partners across borders to reduce time to diagnosis, de-risk trials, and sustain access to care. Quiet collaboration is our superpower."

IndoUSrare's pre-summit workstreams emphasize practical, near-term impact while laying groundwork for durable global infrastructure. Priority lanes include:

- Cross-Border Patient Navigation & Registries: Coordinated intake and multilingual support to help families find specialists, trials, and financial assistance across jurisdictions.

- Investigator & Site Networks: Curated connections among clinicians and centers with rare expertise to accelerate feasibility, referrals, and natural history studies.
- Regulatory & Ethics Roundtables: Dialogue to align on patient protections, consent, data privacy, and import/export considerations to minimize delays.
- Remote-First Trial Enablement: Toolkits and partnerships for virtual visits, home health, and real-world data capture to keep studies on track.
- Therapy Access & Supply Chain Resilience: Convenings with manufacturers, distributors, and payers to mitigate disruptions and maintain continuity of care.

"Families tell us the same thing in every country—please help us keep moving," added Rajasimha. "That's exactly what these collaborations are designed to do."

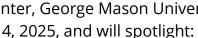


patients, caregivers, scientists, clinicians, regulators, payers, and biopharma/medtech leaders to accelerate equitable access to diagnostics, research, and treatments. This year's program will be held at the Hylton Performing Arts Center, George Mason University, Manassas, VA, from Nov 2-



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Harsha K. Rajasimha, IndoUSrare and Jeeva Clinical Trials



RARE Summit 2025

- Cross-border clinical research models that reduce costs and timelines
- Inclusive, multilingual patient engagement and concierge support
- Policy and reimbursement pathways enabling sustainable access
- Industry–NGO (non-profit patient advocacy organizations) partnerships that translate science into impact

Key highlights include:

- John F. Crowley, President & CEO of the Biotechnology Industry Organization (BIO), in a keynote fireside chat with

Rajasimha

- Keynote address from Dr. Vijay Kumar, Acting Director, Office of Therapeutic Products, US FDA
- Plenary keynotes and panels with senior leaders from the NIH and US FDA, Dr. Madhulika



Submit your Abstract to join us as a Speaker,

Poster, or Pitch4Rare contestant at the Bridging

Kabra from the Indian Council for Medical Research, Dr. Neerja Gupta, and Dr. Sheffali Gulati from the All India Institute of Medical Sciences, New Delhi

- Industry speakers include Dr. Anish Bhatnagar of Soleno Therapeutics; Karla MacDonald of Entrada Therapeutics; Dr. David Rintell from BridgeBio; Dr. Marshall Summar of Uncommon Cures; Sara Tylosky, CEO of Farmacon Global; Dr. Partha



Join us for the Bridging RARE Gala on the evening of 2nd November 2025

Mukherjee of Amicus Therapeutics, among others

- Patient Advocacy Alliance Speakers include Dr. Brian Tseng (The POLG Foundation), Dr. TJ Bichell (COMBINEDBrain), Jennifer Farmer (Friedreich's Ataxia Research Alliance (FARA)), Lara Bloom (The Ehlers-Danlos Society), and Jenifer Waldrop (Rare Disease Diversity Coalition (RDDC))
- Academic researchers from George Mason University, the University of Minnesota, Georgetown University, JSS Medical College, Vinayaka Mission's Research Foundation, and others
- Abbey Meyers Khushi Bridging RARE Awards Ceremony and Gala
- Startups from around the world attacking the rare diseases with innovative solutions will pitch during the #Pitch4Rare contest
- Four IndoUSrare Working Groups will expand and present their progress in developing a blueprint for US-India-EU Collaborations for rare diseases

The organizing committee thanks Gold Sponsor, Soleno Therapeutics; Silver Sponsors, Entrada Therapeutics, Fairfax County Department of Economic Development; Lanyard Sponsor, Prince William County Department of Economic Development; Session sponsors, Immigrant First, CloudThrottle; Raregiving Grant by the EveryLife Foundation for Rare Diseases; and other sponsors, including Amicus Therapeutics, and Virginia Bio.

The committee also gratefully acknowledges partnership support from the Institute of Biohealth Innovation at George Mason University, along with Aarogyaseva, American Bazaar, BioHealth Capital Region, BioHealth Innovation, Bullpen Club, DakshamA Health, Global Genes, Patientworthy, Rare Disease Diversity Coalition (RDDC), Rare Revolution Magazine, Sir Ganga Ram Hospital, New Delhi, Terrapinn World Orphan Drug Congress USA, and invites organizations aligned with IndoUSrare's mission to bridge geographies, disciplines, and sectors are invited to engage as speakers, sponsors, demonstration partners, or scholarship supporters for patient participation.

<u>Learn more or register interest</u>: https://summit.indousrare.org. For media & partnerships, write to admin@indousrare.org

About IndoUSrare (Indo US Organization for Rare Diseases)

IndoUSrare is a patient-centric nonprofit that advances cross-border collaboration to shorten the diagnostic odyssey, enable inclusive clinical research, and expand access to therapies for rare diseases. IndoUSrare is a Platinum member of NORD's Patient Advocacy Organizations Network, has achieved the Platinum seal of transparency from GuideStar, and has been consistently awarded the Top Rated Nonprofit Status by GreatNonProfits. By convening patient organizations, clinicians, researchers, regulators, and industry partners across the US, India, and beyond, IndoUSrare builds pragmatic bridges that turn scientific promise into equitable, real-world impact.

Learn more about IndoUSrare and the Bridging RARE Summit at https://indousrare.org/

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