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Accelerating Global Access to Affordable Therapies for Rare Diseases Through Innovative Collaborations

IndoUSrare's expansion of its Corporate and Patient Alliances sets a bold vision in response to major shifts in leadership at the US FDA and NIH.

WASHINGTON, DC, UNITED STATES, April 22, 2025 /EINPresswire.com/ -- The Indo US Organization for Rare Diseases (IndoUSrare), a U.S.-based nonprofit dedicated to improving global access to rare disease research and care, proudly announces the expansion of its Corporate Alliance Program, with founding members representing the orphan drugs Biopharmaceutical, Contract Research Organization (CRO), Diagnostic, MedTech, Finance, and Digital Health sectors.

The IndoUSrare Corporate Alliance offers members a unique opportunity to align their corporate social responsibility (CSR), innovation, and global access strategies with a mission-driven community

This milestone advances IndoUSrare’s mission to bridge global gaps in rare disease care. The Corporate Alliance unites forward-thinking companies, patient advocates, researchers, and health systems to co-create sustainable, inclusive innovations that improve diagnosis, treatment, and quality of life. This milestone marks a significant step forward in IndoUSrare’s mission to bridge the global inequities in access to rare disease care. The Corporate Alliance aims to foster sustainable, inclusive innovation that improves diagnosis, treatment, and quality of life for rare disease patients worldwide by bringing together forward-thinking companies, patient advocates, researchers, and health systems.

Founding members of the Corporate Alliance include Aceragen Inc., Beaini Financial Solutions, Engage Health, Exela Pharma Sciences, Larimar Therapeutics, Shivanka Research LLC, and

Soleno Therapeutics—organizations that embody the alliance’s values of collaboration and patient-centered innovation.

Despite more than 300 million people worldwide living with a rare disease, most lack timely diagnosis or access to effective treatments. While 90% of rare disease clinical trials take place in the US and Europe, regions comprising just 10% of the world’s population—millions elsewhere remain underserved. Since 1983, the U.S. has led the development of over 1,200 orphan drugs, yet rare disease therapies still take twice as long and cost twice as much to develop as treatments for common conditions.

Launched in response to this stark imbalance, IndoUSrare has established both the Corporate Alliance and a Patient Alliance, now comprising over 70+ member organizations across five continents. These alliances foster meaningful, cross-sector collaboration, empowering companies to co-create scalable solutions informed by patient and community engagement.

World Orphan Drug Congress USA 2025!

Speaks On

Fireside Chat:

Engaging emerging markets in orphan drug clinical trials is critical for rare diseases

Register Today!

Speaker

Dr. Harsha Rajasimha, Ph.D.

Founder and Executive Chairman of Indo US Organization for Rare Diseases

Speaker

Dave Pearce, Ph.D.

Chair, International Rare Disease Research Consortium (IRDIRC)

April 22-24, 2025 Boston, MA

Dr. Rajasimha will host a thought-provoking fireside chat with Dr. Dave Pearce, Chair, IRDiRC, titled: “Engaging Emerging Markets in Orphan Drug Clinical Trials is Critical for Rare Diseases.”, at the WODC USA in Boston on April 24

The recent leadership shifts at the US FDA and NIH open new doors for the rare disease community. The current administration is prioritizing efficiency and global cooperation, creating opportunities to strengthen ties globally.

"As a rare dad and a former NIH-trained scientist, I’ve experienced firsthand the challenges patients, families, researchers, and drug developers face globally,” said Dr. Harsha Rajasimha, Founder and Executive Chair of IndoUSrare. “By collaborating with global leaders of national and international organizations, including National Organization for Rare Disorders (NORD), Everylife Foundation for Rare Diseases, Global Genes, Rare Disease Diversity Coalition, RareGivers, Fondation Ipsen, Combined Brain, International Rare Diseases Research Consortium (IRDiRC), George Mason University, Virginia Bio, Biohealth Capital Region, All India Institute of Medical Sciences (AIIMS), and members of our Patient Alliance, we have assembled a multinational team of leaders committed to bridging these gaps.”

The Corporate Alliance Program offers members a chance to align corporate social responsibility, innovation, and global access goals with a mission-driven community. Benefits include:

- Thought leadership, brand visibility, speaking opportunities at the annual Indo US Bridging RARE Summit and the Abbey Meyers Khushi Bridging RARE Awards Gala, and numerous IndoUSrare-hosted events
- Direct impact on global patient communities for deeper insights and ethical patient-centric research designs
- Participation in co-developed pilot programs focused on awareness, education, and access in underserved regions
- Cross-sector collaboration with academic institutions, health systems, and civil society organizations
- Co-Lead one of our working groups on Diagnostics, Newborn Screening, Novel therapies development, Manufacturing, and supply chain innovation.

IndoUSrare is honored with the prestigious "Incredible Inc. 50" award by the US-India SME Council (USISME) for impactful contributions to Global Rare Disease Advocacy and Education.

IndoUSrare has earned the trust and collaboration of hundreds of organizations in the US, India, France, the UK, and globally. IndoUSrare is a recipient of the RAREis grant from Amgen for the last two years to deliver impactful projects, research grants from Takeda Pharmaceuticals, and sponsorships or grant support from companies including Amicus Therapeutics, ashibio, AstraZeneca, Bridgebio, Biomarin, Dr. LalPath Labs, Entrada, Kiwitech, Jeeva Clinical Trials, Medgenome, Pfizer, Premas, Strand LS, Sanofi, Synergy, Travere, and Ultragenyx, among others.

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> We are at a turning point in global health. The time to act is now. We welcome partnerships with visionary companies prepared to seize the new opportunities to advance patient-centric therapies.”
>
> *Dr. Harsha Rajasimha,*
> *Founder and Executive Chair,*
> *IndoUSrare*

“This initiative brings hope to our community,” said Ms. Shikha Metharamani, President & Co-Founder of the Indian PWS Association and Rare Warriors of Bengal Association, and IndoUSrare Patient Alliance member based in India. "Following FDA approval of a Prader-Willi Syndrome treatment by Soleno Therapeutics, it is imperative that we take proactive steps to ensure accessibility for Indian patients. IndoUSrare, with its deep understanding of regulatory pathways in both the United States and India, is uniquely positioned to bridge this critical gap."

Momentum is building ahead of the Bridging RARE Summit 2025, taking place November 2–4, 2025, at the Hylton

Performing Arts Center in Manassas, Virginia. The Summit will gather global leaders to co-create actionable blueprints under the theme: “Spotlight on the 6 Pillars for Accelerating Inclusive and Accessible Patient-Centric Clinical Research in Rare Diseases” and address key issues such as clinical trial diversity, newborn screening, regulatory harmonization, and digital health’s role in early diagnosis. Corporate Alliance members will play a key role in shaping the agenda, participating in high-impact discussions, and launching new initiatives.

“The Bridging RARE Summit is a launchpad for sustainable change,” said Dr. Rajasimha. “We’re engaging our Alliance members in working groups to help shape an inclusive, actionable, future-ready global agenda for rare diseases in this new and fast-changing global environment."

As IndoUSrare looks to expand its impact in 2025 and beyond, it invites new partners to join the Corporate Alliance. Organizations interested in contributing to global health equity, strengthening their rare disease portfolios, or driving inclusive innovation are encouraged to reach out.

“We are at a turning point in global health,” added Dr. Rajasimha. “The time to act is now. We welcome partnerships with visionary companies ready to drive patient-centered innovation.”

To learn more and engage in meaningful discussions with current and prospective corporate partners to drive the change needed at this crucial juncture, Rajasimha will be meeting with leaders at the World Orphan Drug Congress (WODC) in Boston, 22-24 April 2025. IndoUSrare is also planning a side event around Biotechnology Industry Organization (BIO)’s international convention in Boston in June 2025.

For more information about IndoUSrare and its programs, please visit www.indousrare.org or https://summit.indousrare.org for the Bridging RARE Summit 2025

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