

Global Genes Honors a Diverse Group of International Rare Disease Leaders at the 2022 RARE Champions of Hope Celebration

September 14, 2022 08:00 AM Eastern Daylight Time

ALISO VIEJO, Calif.--(BUSINESS WIRE)--[Global Genes](#), a leading rare disease patient advocacy organization, today announced its annual [RARE Champions of Hope](#) award winners, recognizing leaders and organizations for their inspiring work in driving innovation, advocacy and change in rare disease as part of the 2022 RARE Disease Patient Advocacy Summit in San Diego.

“In a community that is faced with ever-expanding needs and some extraordinary challenges, this year’s recipients were undaunted and forged ahead to accomplish extraordinary things on behalf of people living with rare diseases”

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This year, the celebration recognizes those who made a significant impact across seven categories in the areas of advocacy, industry, medical care, and science, as well as up-and-coming rare disease leaders.

“In a community that is faced with ever-expanding needs and some extraordinary challenges, this year’s recipients were undaunted and forged ahead to accomplish extraordinary things on behalf of people living with rare diseases,” said Craig Martin, CEO of Global Genes. “We are driven by their examples and inspired to meet the standards they’ve set for us through their determination, ingenuity, resourcefulness and tireless focus on making a meaningful impact.”

The 2022 RARE Champions of Hope are:

- **Champion in Advocacy (Individual):** Adrian Goretzki (founder, [Healthcare Education Institute](#)) for his lifetime of dedication to helping get treatment to those in need, and especially for his work in helping patients cross the Polish/Ukrainian border in 2022, ensuring access to therapy and other medical care.
- **Champion in Advocacy (Foundation):** [Lysosomal Storage Disorders Support Society India](#) (LSDSS India) for their work in India imparting advocacy and awareness at grassroots levels, counseling patients and parents about the disease, and bringing the community together. During the COVID-19 pandemic, LSDSS spearheaded the effort in getting ERT infusions delivered to patients in their homes.
- **Champion in Industry:** Arthur A. Levin, PhD (Chief Scientific Officer, [Avidity Biosciences, Inc.](#)) for his decades-long leadership and pioneer in the development of RNA therapeutics.
- **Champion in Medical Care and Treatment:** Dr. Yuriy Stepanovskiyy (founder, Ukrainian Association of Pediatric Immunology) for his advocacy work in getting vital medications to patients with rare immunologic and/or autoinflammatory diseases in the Ukraine.
- **Champion in Science and Technology:** Richard Horgan (founder and president, [Cure Rare Disease](#)) for the development of advanced, non-commercial therapeutics for ultra-rare, neuromuscular diseases, providing tangible hope for those impacted by diseases previously thought to be too rare to treat.
- **RARE Rising Star:** Nell Choi (author, radio DJ, speaker) for her advocacy and leadership for children in the rare disease community, providing hope through conversation and events, reminding them that a disease does not define who they are.
- **RARE Founder’s Award:** Joe and Cynthia Lang (founders, [Jordan’s Guardian Angels](#)) for their work in successfully campaigning for millions of dollars dedicated by California’s state budget for Jordan’s Syndrome research and treatment. As a recent outcome of this work, in 2022, 70 families were flown to Columbia University to gather natural history data and sample collection in preparation for clinical trials.

Global Genes is grateful for the support of the event sponsors: [Horizon](#), [Illumina](#), [Neurogene](#) and [Traverse](#).

For more information on this program and the awardees, visit www.globalgenes.org.

About Global Genes

Global Genes is a 501(c)(3) non-profit organization dedicated to creating a globally connected community committed to eliminating the challenges of rare disease. Together with our partners, we help people find and build communities, gain access to information and resources, and provide hope and support for the more than 400 million people affected by rare disease around the globe. If you or someone you love has a rare disease or are searching for a diagnosis, contact [Global Genes](#) at 949-248-RARE or visit our [Resource Hub](#).

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