



CONTACT:

Christina Janes
Director, Outreach and Awareness
Jordan's Guardian Angels
(925)899-7420
cjanes@jordansguardianangels.org
www.jordansguardianangels.org

FOR IMMEDIATE RELEASE

TOP RARE DISEASE AWARD GIVEN TO FOUNDERS OF JORDAN'S GUARDIAN ANGELS

San Diego, CA (September 2022) - Global Genes, a leading rare disease patient advocacy organization announced its annual Rare Champions of Hope Awards. **The night's top honor went to the Rare Founder Award recipients Cynthia and Joe Lang, Co-Founders of non-profit Jordan's Guardian Angels.**

The RARE Founder's Award recognizes those who exhibit commitment to connecting, empowering, and inspiring the rare disease community through lifetime contributions and achievements advocating for people living with rare disease.

"What can we do for our children?" asked Joe Lang to parents in the room during his acceptance speech. "You all truly are the champions of hope and maybe most importantly our children themselves. They are the hope, the hope that we have and the hope we carry with us in all of these efforts," Lang said.

Jordan's Guardian Angels, a Sacramento, California-based 501(c)(3), is leading groundbreaking research into a rare genetic mutation which causes Jordan's Syndrome. Research into Jordan's Syndrome could unlock some of our greatest medical mysteries including intellectual disabilities, Autism, Parkinson's, Alzheimer's, and even cancer. There are approximately 300 known cases of Jordan's Syndrome presently. However, it is estimated that 200,000 people worldwide suffer from Jordan's Syndrome and are either undiagnosed or misdiagnosed.

Jordan's Syndrome is a mutation on the genes PPP2R5D, PPP2R5C, and PPP2R1A. The syndrome can cause low muscle tone, global developmental delays, larger head size, seizures, Autism, and behavioral challenges among other symptoms. The research effort piloted by Jordan's Guardian includes top universities across the United States and around the world.

The story of Jordan's Guardian Angels began with one family and their beautiful little girl. Today, the group has united hundreds of families around the world and is on a mission to make a better future for children with Jordan's Syndrome, and potentially millions more, through research that world-renowned medical experts believe will change the world.

###