



Nicole Boice (founder and CEO of Global Genes) witnessed her childhood friend struggle to find out what was happening to her oldest son, who was born with extra fingers and toes and showed delayed development, among other issues. He went several years undiagnosed in Orange County, a place with some of the best medical resources available, before he finally got his diagnosis. He was finally diagnosed with [Joubert Syndrome](#), not by a Doctor or a Geneticist, but by his physical therapist.

Nicole was aggravated by the fact that her friend's son went so long without a diagnosis that she became determined to make a difference in the rare disease community. In 2008, she founded "The Children's Rare Disease Network," now known as [Global Genes](#) with the mission to eliminate the challenges of rare disease.

Today, Global Genes is a leading rare disease advocacy organization with global reach to the worldwide rare community of patients, caregivers, and clinical partners; each day promoting the needs of our community under the unifying symbol of hope- the [Blue Denim Genes Ribbon™](#).

Facts about Global Genes-

- Since 2011, annual revenue has increased from \$270k to over \$2.5 million
- Primarily funded by Biotech and Pharmaceutical industry (See Supporters [Here](#))
- The Board of Directors currently consists of: Nicole Boice, John Crowley, Natalie Douglas, Hugh Hempel, Caroline Loewy, Brad Margus, Peter Pellizzon, Wendy White, and Matt Wilsey, (See more information on Board of Directors [Here](#))
- There are 14 members of the Global Genes Team (See Team [Here](#))
- 28 members varying from MDs, PhDs, MBAs, clinicians, geneticists, scientific researchers, to professors, sit on the Global Genes' Medical Scientific Advisory Board. (See MSAB [Here](#))
- As of 2014, Global Genes offers 12 Programs to the RARE Community:
(Click on the program to learn more)
 - Two Educational Programs
 - [RARE Webinars](#)
 - [RARE Toolkits](#)
 - Five Collaborative Partnership Programs
 - [RARE Corporate Alliance](#)
 - [RARE Foundation Alliance](#)
 - [RARE Meetups](#)
 - [The Undiagnosed Patient Program](#)
 - RARE Concierge (RARE Concierge is a program focused on providing answers, resources and information to the community via email, website, or social.)
 - Three Annual Events
 - [The Tribute to Champions of Hope Gala](#)
 - [RARE Patient Advocacy Summit](#)
 - [World RARE Disease Day](#)
 - Two Awareness Platforms
 - [The RARE Daily](#)
 - [RARECast](#)