



Spanish Connection
Rare Neuromuscular Diseases

Advocacy

What we did in 2024

The Akari Foundation

2024

- We Joined EveryLife Foundation's Community Congress Regulatory and Newborn Screening committees and are now involved in all four available working groups.
- Member of Rare Disease Legislative Advocacy's Rare Disease Cohort
- Member of Rare Disease Legislative Advocacy's Rare Disease Congressional Caucus
- Partnership and support of Rare Disease Diversity Coalition
- Active attendee and participant in the Chan-Zuckerberg Initiative (CZI)
- Attendee and supporter of Racial Equity Institute
- Attended Rare Disease Week, met with legislators and staffers from four (4) states with dedicated meetings with TX and AZ congressman.
- Supporter of TeleRare Health, virtual care for rare & genetic diseases
- Proud member of the Child Neurology Foundation's Neurology Social Services Network, receiving referrals to assist Spanish-speaking DMD/SMA families from physicians and clinics nationwide
- Co-hosted the 4ta. Jornada Iberoamericana LGMD presents education and resources to Spanish-speaking families
- Interviewed by Sheffield University in the UK regarding "Research interviews on rare disease patients access to treatment/medicine."
- Luisa Leal, the founder and CEO of the Akari Foundation, was awarded the Gordon Hartman Family Foundation's Heart of Gold Wall of Fame Award for community innovators who have helped the special needs community.
- Annette E. Hatcher Brito, The Akari Foundation CFO, received nominations for GlobalGene's RARE Champions of Hope Awards: RARE Champion in Health Equity and RARE Champion in Research.

Letters of Support:

- Accelerating Kids' Access to Care Act (H.R. 4758/S. 2372)
- Safe Step Act (H.R. 2630/S. 652)
- Creating Hope Reauthorization Act (H.R. 7384)
- Medical Nutrition Equity Act (H.R. 3783)
- Newborn Screening, California (AB2563)

Direct advocacy with legislators (virtual or in-person):

- Accelerating Kids' Access to Care Act (H.R. 4758/S. 2372)
- Creating Hope Reauthorization Act (H.R. 7384)
- PROTECT Rare Act (H.R. 6094)
- Health Equity Innovation Act of 2023 (H.R. 5520)
- Newborn Screening for various states



Issues actively participating in:

- Accelerated Approval Pathway
- Access to Therapy
- Barriers to Care
- Co-Pay Adjustment Programs
- Diagnostic Odyssey
- Discrimination
- Drug Development
- Drug Utilization Review (DUR) / Pharmacy & Therapeutics (P&T) Processes
- FDA Approved Treatments
- Genetic Counseling
- Newborn Screening
- Orphan Incentives
- State Policies
- Telehealth