The Akari Foundation
www.theakarifoundation.org
Conexión En Español Para
Las Enfermedades Raras

Dear Akari Foundation Community

As we continue this journey together, I want to extend my heartfelt gratitude to each of you. Your strength, resilience, and unwavering support make everything we do possible. Every story shared, every hand extended, and every small victory celebrated reminds us why our mission is so vital.

Our mission is to provide educational resources, support, and advocacy to improve the quality of life for Hispanic families affected by rare diseases, especially Duchenne Muscular Dystrophy. With the recent elections in the United States, we know that new challenges lie ahead, and it may be more difficult for our community. But now, more than ever, we are committed to fighting for the rights of our families and ensuring that their voices are heard. We will fight tirelessly to protect your rights, provide support and resources, and ensure you do not face these challenges alone. We will not allow others to take advantage of our community's vulnerability and will keep fighting to protect and empower each of you.

How might this new administration and Project 2025 affect our community?

If policies similar to those of the previous Trump administration are reinstated, along with the proposed Project 2025, the Hispanic community—especially families facing rare diseases—could encounter several potential challenges:

1. Healthcare Access and Affordability: Project 2025 includes proposals to repeal the ACA and reduce Medicaid funding. This could significantly limit access to essential healthcare services, treatments, and medications for Hispanic families dealing with rare diseases. Such changes would especially affect undocumented families who already face substantial barriers to care.

2. Funding for Rare Disease Research: With a shift in federal funding priorities under Project 2025, resources for rare disease research may diminish, potentially impacting the advancement of new therapies. Reduced funding for clinical research could slow progress in treating rare diseases like Duchenne Muscular Dystrophy, affecting families who rely on these developments for hope and improved quality of life.

3. Support and Advocacy Services: Project 2025 proposes scaling back regulatory protections and social welfare programs, which may limit the effectiveness of nonprofits in advocating for and supporting the rare disease community. Reducing federal support for health and social programs could also make it harder for organizations like ours to provide essential services, counseling, and legal assistance, leaving some families without the necessary support.

4. Immigration Policy and Community Fear: Stricter immigration policies might deter undocumented families from seeking healthcare or support services due to fear of deportation. This could lead to untreated conditions, incredibly challenging for children and adults requiring specialized care for rare diseases, where early intervention and consistent treatment are critical.

5. Civil Rights, Diversity, and Inclusion Efforts: Project 2025 seeks to eliminate diversity and inclusion programs, reducing culturally relevant resources for Hispanic families. This shift could impact access to Spanish-language information, culturally competent care, and advocacy for equitable treatment in rare disease care.

Community support and rights advocacy will be crucial for families facing rare diseases, especially in a challenging policy environment.

We will not give up. We will keep pushing for change, ensuring access to the resources you need, and standing by your side every step of the way. Let’s keep moving forward, stronger and more united than ever, and continue to shine a light on those who need it most.

With immense gratitude and hope,

Luisa Leal

Luisa Leal
Founder & CEO, The Akari Foundation