THE AKARI FOUNDATION

Luisa Leal
Founder | Chief Executive Officer

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Our Mission
Educate and empower the Hispanic community about rare diseases, help with resources, awareness, advocacy, and education, entirely in Spanish, specializing in Duchenne muscular dystrophy.

Our Vision
We aim to create a world where the Hispanic community affected by Duchenne muscular dystrophy and other rare diseases is united, educated, empowered, and equipped with the necessary resources and support to thrive and overcome challenges, all done exclusively in Spanish. We envision a future where everyone, regardless of background, has access to comprehensive information, compassionate care, and a strong network that fosters awareness, advocacy, and education in our primary language.
**Problem: Lack of medical literature and resources in Spanish**

You receive your child’s diagnosis of Duchenne / Becker Muscular Dystrophy. It’s often heartbreaking, confusing and overwhelming.

**What now?**

Most parents turn to the internet for answers. For help. For suggestions. For support from others.

But what does that same situation look like for the 68.2% of Hispanic adults living in the USA that are not native English speakers?

31.8% of patients diagnosed with Muscular Dystrophy identify as Hispanic. Yet, the vast majority of materials and resources available are exclusively in English. Official websites, Medical Reviews, Patient Advocacy Programs, Duchenne Registries, Support forums... all target English-Speaking demographics. Those offered in Spanish are poorly translated or require additional, sometimes difficult or confusing, steps NOT required for English-speaking participants.
Problem: Access to Education and Resources for Spanish-Speaking Families / Patients / Caregivers

22.5% of the U.S. population living under the poverty line are Hispanics.

Compound the stress of the diagnosis with the realization that

- you can’t afford the care or medical devices your child needs to survive
- You are unable to adequately communicate your needs to the medical community, doctors and agencies
- You do not have insurance to cover the costs
- You are unable to safely transport your child to appointments, therapy and elsewhere
- You can not quit your job to care for your increasingly dependent child…but you also can’t afford a caregiver
For many families, language barriers, financial constraints, lack of caregiver education and limited mobility create a sense of isolation.

These obstacles often make it difficult to provide proper medical care and support for their children.
The Akari Foundation has provided translation services to families, including a simple introductory guide to Duchenne and a customized New Diagnosis Kit.

Lack of medical literature and resources in Spanish

The Akari Foundation ran 10 programs. Our Education program hosted over 32 Spanish-speaking webinars and 15+ pharmaceutical partner presentations, spanning from patient care to clinical trials. Education opportunities extended through our social media webinars, blogs, and our new podcasts. Over 1,100 families have participated in these virtual educational events.

Access to Education and Advocacy groups for Spanish-Speaking Families / Patients / Caregivers

The Akari Foundation planned and executed four in-person full-day workshops providing crucial information, support and resources to families in the United States and Puerto Rico. Akari also hosted a monthly “Cafe con Akari” (Coffee with Akari) for parents/caregivers.

Community Support & Networking
Ensuring Spanish-speaking families receive crucial support by removing financial, language, and geographical barriers

**Akari Education Programs**

Ensuring Spanish-speaking families receive crucial support by removing financial, language, and geographical barriers

**TOPICS:**
- General Knowledge about Duchenne/MD
- Clinical Trials
- Financial planning
- Psychology & Behavioral Issues
- Emotional Support
- Approved & Emerging therapeutics
- Genetic education
- Patient Advocacy
- Nutrition
- Importance of community involvement in medical advancements

**Webinars**

**Blogs**

**Zoom Meetings**

**On-Demand Support**

**Virtual Group Chats**

**Lunch & Learns**

**Personalized advocacy and dedicated resource coordinator**
In-Person Event Attendance

San Juan, PR
56%

Chicago, IL
50%

San Juan, PR
67%

Madera, CA
62%

Adults
Children
AKARI WEBSITE:
IMPRESSIONS & REACH

Total Reach (YTD): 267,562
Social Media Reach

417,365 Total Impressions
94,426 Views of Akari YouTube Videos
92,994 Views of Akari’s “What is DMD?” Spanish video!
Akari: Our Growing Reach

Progression from 2020 thru 2023
# Financials

## INCOMES BY PROGRAM

<table>
<thead>
<tr>
<th>Program</th>
<th>2023 Total</th>
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</thead>
<tbody>
<tr>
<td><strong>Akari Resource Program</strong></td>
<td>$159,306.00</td>
</tr>
<tr>
<td><strong>Akari Educational Webinars Program</strong></td>
<td>$44,356.00</td>
</tr>
<tr>
<td><strong>Industry Educative Webinars Program</strong></td>
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<tr>
<td><strong>Akari Ambassadors Program</strong></td>
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<td><strong>Akari Diagnose Kit Program</strong></td>
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<td><strong>Akari Legislative Advocacy Program</strong></td>
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<tr>
<td><strong>Akari Awareness &amp; Outreach Program</strong></td>
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<tr>
<td><strong>Akari Lawyers Support Program</strong></td>
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<tr>
<td><strong>Akari Awareness Program</strong></td>
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<tr>
<td><strong>Akari Patient Support Program</strong></td>
<td>$40,056.00</td>
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**TOTAL INCOMES FOR 2023:**

$593,696.00

**TOTAL EXPENSES FOR 2023:**

$638,192.00

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**Akari Educational Programs**

Program Management, Overhead, Materials & Equipment

2023 Total: $160,868.00

**Akari Resource Program**

Strategic Partnerships with Organizations, Healthcare professionals, Full-Circle Wellness Support and Education, Education and connection to resources for Clinical Trials, Psychological, Behavioral and Emotional education and support

2023 Total: $159,306.00

**Industry Educative Webinars Program**

Zoom webinars, Project management, Administrative Overheads, Advertising and promotional material

2023 Total: $24,496.00
Future Roadmap

**Akari Hispanic Rare Disease Registry**
*24/7 Family/Caregiver Support Community Chat*
Platform to collect and aggregate medical surveys, bidirectional communication with Akari Team and chat-capabilities to allow families to connect and support each other.

$189,200.00

**Akari Supplement Kit**
Nutrition training and supplement kit tailored to each patient (physician prescribed) with continuous nutrition support and guidance.

$18,000.00

**Akari Awareness**
Awareness campaign that includes a 5K run, our 1st Annual Awareness, Educational and Fun Family Gathering and continued presence at industry conferences and events to establish the Akari name, brand and garner financial support.

$69,250.00

**Akari Aid Program**
Program dedicated to meeting the urgent needs of families who are unable to receive assistance from programs like Medicaid and other organizations. This program focuses on items like medical equipment and quality of life assistives.

$40,000.00
Akari Aid Program

UGRNT NEEDS: MET

- Orthopedic devices (night splints, folding wheelchairs, scooters, standing frames)
- Electronic respiratory assistive devices (BiPap), Cough Assist Lung exerciser (system to exercise breathing by inspiration)
- Nutritional Support: Supplements and education in Nutrition
- Self-Stretching items (adjustable wood incline board / Calf incline Board)
- Other devices - Removable (folding) access ramps, pressure ulcer mattress pad
The Gift of Mobility

“A dream come true”

“I have always wanted to move freely in the park”

“a blessing and motivation to help him move”

“Beautiful gift”
The Gift of Mobility

"It is as if I had been allowed to walk once again"

"This will give me the freedom to move"

"a blessing and motivation to help him move"
At Akari, we know that education alone doesn’t solve the daily struggles our patients and families face. We strive to serve and support in any way that we can. These additional efforts are 100% funded through the generosity of grants and donations from the KOMD Foundation/The Curran Family.
Karger - Neuroepidemiology - “Racial and Ethnic Differences in Timing of Diagnosis and Clinical Services Received in Duchenne Muscular Dystrophy” 16-MAY-2023
“males with definite or probable DMD” “20.5% Hispanic”

Rare Disease Advisor - Duchenne Muscular Dystrophy (DMD) - 31-DEC-2011
“501 patients were of non-Hispanic white origin, 55 were of non-Hispanic black origin, 175 were of Hispanic origin, and 110 were of other racial and ethnic origins.”