The Akari Foundation 2024 Strategic Plan:

About The Akari Foundation
The Akari Foundation, a non-profit organization, is committed to assisting individuals and families dealing with rare diseases in the Hispanic community. Our services include support for DMD, BECKER, LGMD & SMA, resources, digital-social media education, and free therapy with psychologists. Despite these new expansions, Duchenne remains our primary focus. The Akari Foundation works in the following five areas:

1. Educate: We conduct outreach programs and educational initiatives to empower the Hispanic community with knowledge about rare diseases, emphasizing Duchenne muscular dystrophy. We aim to ensure that individuals and families have the information they need to make informed decisions regarding their health and well-being.

2. Empower: We offer valuable resources and support services to help those affected by rare diseases navigate the complexities of their conditions. This includes assistance with medical care, financial aid, and emotional guidance.

3. Raise Awareness: The Akari Foundation raises awareness about rare diseases, concentrating on the Hispanic community's unique challenges. We strive to eliminate the stigma surrounding these conditions through targeted campaigns and events and foster a more compassionate and understanding society.

4. Advocate: Our organization actively lobbies for policy changes at various levels of government, advocating for improved access to healthcare, treatment, and support for individuals with rare diseases, mainly focusing on the Hispanic population.

5. Education in Spanish: We remain the only organization in the USA dedicated to providing information entirely in Spanish, ensuring that language barriers do not hinder access to crucial resources and knowledge. This commitment underlines our aim to make our programs more accessible and inclusive.

Programming in 2024
Our 2024 Programs are thoughtfully designed to serve this mission, divided into three main areas:

1. Community Programs and Education: We are dedicated to educating and empowering our community through informative programs. These initiatives aim to raise awareness,
promote knowledge, and create a sense of unity within the Hispanic population facing rare diseases.

A) Community Programs and Education.
- This includes two websites, one in English and the mail, one in Spanish, our blog, social media education snippets, and our new podcast.
- Akari Virtual Educational Webinars
- Akari Industry Education Webinars

2. Family Support and Resources: We are here to provide unwavering support and essential resources to families impacted by rare diseases. We aim to make their journey more manageable and give them the tools they need to thrive.

A) Family Support & Resources
- Akari Resources & Support Program.
- Akari Ambassadors (Includes ten free sessions with a licensed psychologist).
- Akari Diagnosed kit. (backpack program with educational materials in Spanish)
- Akari aid program for Urgent needs (providing medical equipment in USA, Mx & Latam)

3. Advocacy, DEI, and Awareness of Rare Diseases & Duchenne Programs: Advocacy, Diversity, Equity, and Inclusion are at the core of our efforts. We strive to raise awareness and advocate for change, ensuring that the needs and rights of individuals with rare diseases, including Duchenne muscular dystrophy, are recognized and addressed.

A) Advocacy, Diversity, Equity, Inclusion, and Awareness of Rare Diseases & Duchenne Programs.
B) Akari Advocacy and Public Policy Program
C) Akari Outreach & Awareness.
D) Akari Legal Support & IEP Program

Through these programs, we look forward to making a lasting impact on the lives of those within the Hispanic community, offering hope, education, and support on their unique journeys. To align with the three main areas of our programs, maintaining a focus on education and empowerment in the context of Duchenne muscular dystrophy (DMD) within the Hispanic community, entirely in Spanish:

The Akari Foundation is a 501c3 registered tax-exempt nonprofit organization, EIN #82-2557369.
A non-profit organization for kids with Muscular Dystrophy Duchenne
Community Programs and Education

**Akari Virtual Educational Webinars:**
Our commitment to community education is unwavering at The Akari Foundation. In our Virtual Educational Webinars, we go the extra mile by inviting Spanish-speaking healthcare professionals as speakers or trainers. Their expertise ensures the community receives accurate and comprehensive information about Duchenne Muscular Dystrophy (DMD) and rare diseases. These webinars are conducted entirely in Spanish, catering to the needs of the Hispanic community and enabling us to create a meaningful impact by sharing knowledge, promoting awareness, and fostering understanding among individuals and families affected by these conditions.

**Akari Industry Education Webinars:**
These webinars are designed to inform our community about the latest developments in Duchenne Muscular Dystrophy (DMD) treatments and care. Our collaboration with pharmaceutical companies allows us to offer webinars that delve into essential topics like clinical trials, advancements in research, and cutting-edge therapies and treatments for DMD. These sessions will be conducted entirely in Spanish, ensuring accessibility and inclusivity for our Spanish-speaking audience.

**Family Support & Resources**

**Akari Resources & Support Program:**
At The Akari Foundation, our Akari Resources & Support Program is your compass through the challenging journey of Duchenne Muscular Dystrophy (DMD). We are dedicated to helping families find the support they need at every level. Through strategic partnerships with other organizations and healthcare professionals, we provide essential guidance on navigating the healthcare system, understanding treatment options, and accessing education on clinical trials. But our support goes beyond the practical — we are here to offer emotional support, ensuring that families affected by DMD never feel alone in their fight. Our mission is simple: to connect families with the help and resources they need to face the challenges of DMD with confidence and hope.

**5. Akari Ambassadors:**
Our Akari Ambassadors Program is all about peer-to-peer support. We connect newly diagnosed families with experienced "Veteran families" who have walked a similar path. These Veterans offer guidance and a compassionate understanding of the challenges of the disease. Additionally, we understand the importance of mental health, so we offer ten free sessions with

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licensed psychologists, conducted entirely in Spanish, to address these families’ emotional and psychological needs. We welcome every family member, providing both individual and family therapy options. Our goal is to ensure that no one feels alone in their journey and that they have the support and resources they need to navigate the complexities of a rare disease diagnosis.

**Akari Diagnosed Kit:**
We are dedicated to providing valuable support to individuals and families facing rare diseases. Our Diagnosed Kit is a testament to this commitment. We collaborate closely with healthcare professionals to curate and review the educational materials within our backpack kits, ensuring their accuracy and cultural relevance in Spanish. To extend our reach, we partner with medical experts, clinics, and hospitals across the United States to distribute these printed materials. Our mission is to empower and educate, offering a vital resource for those recently diagnosed and providing the information and support they need during a challenging time.

**Akari Aid Program for Urgent Needs:**
This program addresses urgent medical equipment needs for individuals battling Duchenne Muscular Dystrophy and other rare diseases. This program provides crucial assistance, including wheelchairs, ramps, Hoyer lifts, CPAP machines, and bi-paps, ensuring that individuals can access the essential equipment required for their well-being. Our mission is to offer swift support during times of urgency, enhancing the quality of life and promoting independence for those in our community, all while easing the burdens associated with urgent medical needs.

**Advocacy, Diversity, Equity, Inclusion, and Awareness of Rare Diseases & Duchenne Programs**

**The Akari Foundation Legislative & Policy Program:**
The Akari Foundation is deeply committed to empowering and advocating for the Hispanic Duchenne Muscular Dystrophy community and individuals facing rare diseases. In alignment with this mission, we collaborate closely with advocacy groups such as TX Rare, Every Life Foundation, and others. Our Legislative & Policy Program focuses on joining forces to shape and support legislative and policy initiatives that will make a meaningful difference in the lives of those affected. Together, we strive to ensure that the voices of the Hispanic rare disease community are heard and that policies are in place to enhance their well-being and access to vital resources.

**The Akari Foundation Outreach & Awareness Program:**
Our Outreach & Awareness Program is at the heart of our mission. We're actively attending conferences and community events to raise awareness about rare diseases within the Hispanic community.
population. Our outreach programs and partnerships with medical clinics, grassroots organizations, and other like-minded entities enable us to extend our reach and provide crucial support. By collaborating with diverse stakeholders, we aim to ensure that individuals and families facing rare diseases, particularly in the Hispanic community, can access the information and resources they need to navigate their unique challenges and achieve better health outcomes.

**Akari Legal Support & EIP Program:**
The Akari Foundation is dedicated to providing comprehensive support for individuals with Duchenne Muscular Dystrophy (DMD) and their families. Our Legal Support & EIP Program connects healthcare professionals with legal expertise to assist in cases related to DMD. This program ensures that individuals with DMD receive proper representation and support in navigating complex legal and healthcare systems. Our services extend to helping families access healthcare, navigate appeal processes, and provide support with school-based Education Individualized Programs (EIP). We are committed to advocating for the best interests of those affected by DMD, facilitating access to the care and education they deserve.

**Financial Transparency**

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<tr>
<th>Programs</th>
<th>Total</th>
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<tr>
<td>1. Akari Virtual Educational Webinars</td>
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<td>2. Akari Industry Education Webinars:</td>
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<td>4. Akari Resources &amp; Support Program</td>
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Conclusion
The Akari Foundation remains dedicated to serving the Hispanic Duchenne Muscular Dystrophy community and providing critical resources that will positively impact our families. Any funding received will create a more inclusive and empowered future for the Hispanic community affected by rare diseases, allowing us to continue to break down the multiple barriers that have kept many Hispanic, rare-disease families from receiving proper care and services.