Strategic Plan 2019 - 2021

Our Mission

The SATB2 Gene Foundation, Inc. was established to enrich the lives of individuals with *SATB2*-associated syndrome, including those diagnosed with the condition and their families, through support, research, and education.

Our Vision

Our vision is to build a community of partners that navigates the path of disease diagnosis, treatment, and management together, so that individuals and their families achieve the highest quality of care, and the highest quality of life.

How We'll Get There

- Raising awareness about the characteristics of *SATB2*-associated syndrome
- Providing support to families
- Supporting research in a wide range of issues related to *SATB2*-associated syndrome

Our Achievements

- We have hosted, in partnership with the Arkansas Children's Hospital and PCORI funded grant, two family conferences (June 2017 & June 2018) for over 80 families. Each conference included social activities, clinic visits with expert medical professionals, and research updates from Dr. Zarate and his team.
- We've developed an array of educational materials to share with caregivers, providers, advocates, and newly diagnosed individuals and families to generate strong communication and diagnosis outcomes including: SATB2 Quick Reference Information Sheets for both families and medical professionals.
- We hosted the first annual SATB2 Awareness Day on August 22, 2018, resulting in over $25,000 of philanthropic support.
- Partnered with Wheelchairs 4 Kids to support an SATB2 family through a grant to fund a medical stroller for their child.
- Obtained our 501 (c)(3) status through the IRS
- Launched the official SATB2 Gene Foundation website and social media channels to include Facebook, Instagram and Twitter.
- Obtained pro bono law firm to help create SATB2 Gene Foundation International Affiliate Agreement and fostered starter conversations with several countries about how to partner and work in each of their respective countries.
- Obtained Trademark status of logo for use in Class 44 for website. Submitting evidence of use for Class 41 for educational services, namely providing conferences and seminars in the field of rare diseases, and Class 36 for charitable fundraising services.

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Our Strategic Drivers for 2019-2021

Our four strategic drivers are intended to support our vision over the next three years, with each driver intended to compliment the efforts of the others.

Supporting SATB2 Families

We will connect individuals/families to other families and the medical professionals, advocates, and industry partners they need to feel supported, enhance care, and optimize quality of life. **We will do this by:**

- Developing tools and resources to encourage interdisciplinary education within a community of partners that navigates the path of diagnosis, treatment, and management.
- Cultivate and strengthen relationships between SATB2 families that foster connective opportunities and friendships.
- Support family grants that help alleviate the cost burden of required medical equipment, encourage regional and local community building, and access to clinic visits at Arkansas Children's Hospital.
- Partnering with International families to develop best strategy to work within each country.
- Creation of the SATB2-associated syndrome Family Support Guide which will serve as a collection of resources, steps, and helpful suggestions for families with a newly diagnosed SATB2 individual.

Raising Awareness

We will raise awareness of SATB2 by developing a supportive framework of providers and partners who, as stakeholders, are equal partners in care. By connecting families, medical professionals, and research communities with information and resources about SATB2, we hope to shorten the diagnostic journey for new families and empower families to make informed decisions. **Key efforts will include:**

- Creating collaborative partnerships and education opportunities with providers through annual medical conferences and associations, such as: American Cleft Palate-Craniofacial Association, American Speech-Language Association (ASHA), and the Academy of Pediatric Dentistry.
- Equipping families to become SATB2 ambassadors through educational resources and advocacy efforts.
- Be active participants in the rare disease community at large.
- Annual SATB2 awareness day on August 22nd.
- Participate in Rare Disease Day annually on February 28th.

Supporting Research

We will support research on SATB2-associated syndrome by participating in collaborative research projects, promoting research papers and research leaders, and eliminating barriers to access of research. **We will do this by:**

- Supporting and promoting credible and health-literate content and research papers to expand the range of conditions associated with SATB2.
- Establishing a Medical and Scientific Advisory Board of experts in various fields that study and treat SATB2.
- Providing research grants that support projects such as, but not limited to, graduate students, lab equipment, publication fees for publishing research materials, and other related efforts.
- Promoting the official SATB2 Clinic Day(s) at Arkansas Children's Hospital.
- Leverage the bi-annual family and scientific conference to incorporate and include medical researchers, providers, and industry partners.

Organizational Strength

We will connect with the continuum of organizations serving individuals with SATB2, rare diseases, and special needs as a strong, reliable, and respected partner, by capitalizing on organizational strengths, and identifying areas of improvement where other partner organizations can fill in. **Key efforts will include:**

- Taking a deliberate approach in continual assessment of our role within the rare disease community.
- Optimizing the SATB2 Gene Foundation's financial position to meet our mission.
- Acquiring and retaining quality Board of Directors members.
- Acquiring and retaining committee volunteers.
- Maintaining and expanding the SATB2 family directory.
- Serve as first point of contact for families new to the diagnosis.

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Our Resources

To support our strategic vision, we have created a series of resources, tools, and materials for the SATB2 community to utilize.

- **eNewsletter**: a quarterly newsletter to update the SATB2 community on relevant research updates, family news, and upcoming events.
- **Website**: our website features a library of research articles, upcoming events, access to foundation news, and opportunities to support the Foundation through gifts of time, treasure, and talent.
- **Social Media**: various social media channels to help bring awareness of SATB2 and individuals and families with SATB2 to a broader community.
- **Webinars**: a quarterly webinar series that covers a range of topics, from special needs estate planning to adaptive technologies and developmental-stages in individuals with SATB2.
- **Family & Provider Quick Reference Information Sheets**: high-level reference guides for families to use when meeting with new providers, medical professionals, education professionals, and other caregivers.
- **Family & Research Grants**: these grants are to support the efforts of families and the research community for a variety of uses, such as family medical equipment and travel expenses to research paper open access fees and graduate student support.