

Strategic Plan 2023 – 2025 Executive Summary

The SATB2 Gene Foundation was launched in January 2018 with a mission to enrich the lives of individuals with *SATB2*-Associated Syndrome (SAS), including those diagnosed with the condition and their families, through support, research, and education.

Our last strategic plan outlined activities for 2019 – 2021. Who knew a pandemic would emerge in the middle and extend that plan? Even so, the SATB2 Gene Foundation has accomplished many of the goals we set. Some of our highlights include:

- Creation and dissemination of informational brochures in multiple languages for patient advocacy, caregiver education, and clinical education.
- Funding of research and specific cell lines.
- Connection of families through social networks and virtual meet-ups.
- Establishment of family conferences and networking opportunities.
- Creation of a robust educational series of webinars and videos.
- Funding of the Family Assistance Program, which provides financial assistance to families for items to improve the quality of life for their SAS loved ones such as communication devices, strollers, access to speech therapy and so much more.
- Creation of the Medical and Scientific Advisory Board.
- Improved infrastructure through the Board of Directors development and professionalization.

Our Vision

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

How We'll Get There

- Raise awareness about the characteristics of *SATB2*-associated syndrome
- Provide support to families
- Champion research in a wide range of issues related to *SATB2*-associated syndrome

Our Strategic Drivers for 2023 - 2025

Supporting SAS Families

Supporting SAS Families is at the core of all our programs. Over the next three years, we will continue to offer and enhance our current family support programs like the Family Assistance Program, SAS clinic travel grants, the bi-annual conference, and virtual meetups for families. Additionally, **we will:**

- Identify and address the needs of families and SAS patients of all ages. Offering programs and support for families at the different stages of life and disease discovery.
- Launch a Regional Ambassador program to better respond to and engage with families to foster connections for peer support and localized resources.
- Host bi-monthly virtual meet-ups that will focus on a range of topics important to our families.
- Develop programming and materials to support the whole family, including siblings.

Raising Awareness

Continuing to raise awareness of SAS in general, and especially among medical and scientific communities, is of utmost importance. The greater the knowledge and awareness of SAS in medical communities, the more patients will be able to receive proper diagnosis and care at earlier ages. **We will:**

- Create and distribute symptom specific informational materials for families and providers.
- Conduct educational webinars and produce videos.
- Create and disseminate an in-depth tool kit about SAS to help families navigate the various areas of SAS within the medical community and also in day to day life such as education, health care, aging, and more.
- Be active participants in the rare disease community at large.
- Implement the annual SAS Awareness Day on August 22nd.
- Participate in Rare Disease Day annually on February 28th.

Championing Research

Since the establishment of the annual Research Grant Program, the Foundation has awarded a total of \$124,000 for seven research grants. Funding has advanced the collective knowledge of SAS in addition to the development of research tools such as the induced pluripotent stem cells (iPSCs). We will continue to focus on supporting research in three fundamental areas as outlined in the Research Strategic Plan completed in 2021:

- Clinical Foundations
- Therapeutic and Supportive Care
- General Research Tools

Organizational Infrastructure and Sustainability

As the SATB2 Gene Foundation continues to grow and serve more families, we must also expand and strengthen our organizational infrastructure to maintain our services and programs. **We will become:**

- An organization with a professional staff and cadre of volunteers to increase and expand family, patient, and research programming to enhance clinical and social outcomes for patients and caregivers.
- An organization with a clear trajectory and defined authority to exercise duties of care and loyalty of its assets, including financial, intellectual, and human resources through staff and volunteerism.

To learn more about our resources and how to get involved, please visit our website at www.satb2gene.org or email us at info@satb2gene.org