

2009 Program Objectives

Goal: Enhance Patient & Family Support: To provide information, resources, and support to assist children and their families to make informed medical decisions and to live and thrive despite the challenges of these conditions.

Objective 1: Increase outreach to affected families, including African American and Hispanic families with relevant materials and support.

- Translate critical documents into Spanish and reach out to organizations serving Latinos for distribution;
- Develop new “living with” materials & booklets for LQTS & kids

Objective 3: Continue the family history/pedigree project: contact families, encourage pedigree expansion, work with genetic counselors, etc.

Objective 4: Enhance partnerships with other health and child-serving organizations to share materials and expertise.

- Continue and expand linkages with school nurses and coaches to provide information, development of school emergency plans and CPR/AED training
- Collaborate with groups such as Parent Heart Watch, HCMA, AHA, HRS, CJ SIDS Fdn, Project Adam and Project SAVE, etc;
- Identify and explore opportunities for collaboration with groups such as YMCA, Boys and Girls Clubs, local sports clubs, etc.

Objective 5: Provide opportunities for peer interaction and education about SADS conditions at SADS events and online

- Explore the advisability of holding a National SADS Conference to bring together affected families, medical professionals and others to share the latest medical and genetics information, strategies for living with channelopathies and opportunities for dialogue and peer interactions.
- Encourage SADS Support Groups
- Develop interactive capability on SADS website and encourage patients and families to become active participants in chats and SADS webinars with medical experts and board members;

Goal: General Awareness/Prevention: Proactively increase the general public’s knowledge of the warning signs of heart rhythm abnormalities that identify the child or adult at risk for sudden death

Objective 1: Develop and implement a strategic communications plan to achieve: 1) increased visibility of the Climb event in the state of Washington and nationally; 2) media focus on SADS conditions and SADS Foundation as a leader in sudden cardiac awareness and prevention; 3) well-prepared media spokespersons who have opportunities for media interviews and coverage; 4) engaged Foundation volunteers around the country who have materials and guidance on contacting their local media.

Objective 2: To plan and implement SADS Awareness Month in September.

Objective 4: Participate with other organizations in International Awareness (June) and in SCA Awareness Month in October.

Goal: Education—professionals: To facilitate early recognition and accurate diagnosis and treatment of heart rhythm abnormalities by implementing strategies to ensure that healthcare providers have all available current and relevant information.

Objective 1: To expand the SADS School Initiative to increase the awareness and knowledge of SADS conditions among school health professionals

Objective 2: Partner with PACES to develop expertise and assist with patient education and support.

- Sponsor the lecture at PACES dinner meeting.

Objective 3: Develop a cadre of SADS expert physicians, and trained nurses and family members, who are willing to speak to groups around the country about diagnosing and treating SADS conditions and living and thriving with SADS conditions; develop materials and presentations to support this outreach

Objective 4: Continue to partner with PGx Health (and others) to educate physicians (especially adult cardiologists/EPs) about SADS conditions

Objective 5: Partner with NSGC and others to develop & disseminate SCD guidelines for ME's and Coroners

Goal: Advocacy/Research: To promote research by advocating for increased funding and patient participation and to support non-discriminatory treatment

Objective 1: Continue to advocate for SADS families with insurance issues, medical challenges, etc.

Objective 2: Sponsor a SADS Young Investigator Award yearly through PACES.

Objective 3: Encourage continued innovation in medical technology and treatments, including ICDs, for children at risk of sudden death, screening protocols

Goal: Infrastructure: To ensure organizational stability and security by providing adequate resources to implement program goals and objectives.

Objective 1: Develop a succession plan and further develop policies and procedures to support this plan.

Objective 2: To hold a successful (raise \$100,000; local climber initiative/leadership; local media) Climb to Conquer SADS event.

Objective 3: Begin to implement the new volunteer plan/structure with the goal of trained SADS volunteers actively working around the country.

- Recruit, train and manage volunteers around the country.
- Begin to implement SADS Affiliates at a regional or local level
- Organize and conduct regular "meetings/trainings" for SADS volunteers
- Continue the services evaluation program utilizing email and phone follow-up to patients and families served by the SADS Foundation.

Objective 4: Continue to develop the new website to include medical information, extensive links to other resources, family stories and interactive areas and, especially, fundraising capacity and support for the Pedigree Project

Objective 5: Board development

Objective 6: Enhance system and database for tracking interactions with constituents