

## SADS Foundation 2012 Program Goals & Objectives

### MEDICAL EDUCATION

**Goal: Medical Education:** 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:** Conduct medical education seminars in 8 target areas with expert physicians and other trained healthcare providers to expand knowledge about diagnosing and treating SADS conditions.

- Two of these will be multi-speaker educational seminars with CME credits

**Objective 2:** Partner with PACES, NSGC and other synergistic groups to assist with patient and physician education (speakers bureau) and support SADS outreach campaigns.

**Objective 3:** Focus on two non-cardiac medical groups (ME & school nurse) to expand upon the knowledge base for SADS conditions. This will include attending conferences, developing targeted materials etc.

**Objective 4:** Utilize the power of advisors (SADS Scientific Advisors, Referral Physicians, etc.) to educate the medical community, provide expertise to SADS members and assist us to determine best practices.

- Develop another advisory board for medical professionals (physicians, nurses, genetic counselors)

**Objective 5:** Rework our existing website to enhance its use among physicians and healthcare providers and become a resource to our medical community.

**Objective 6:** Site visits with board physicians and advisors to cultivate and better collaborate, with them, their colleagues and staff who can be an invaluable resource to the SADS mission.

### FAMILY SUPPORT

**Goal: Continue Developing and Improving Patient & Family Support Services to reach a wider audience and more families:** 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: Improve patient support materials, electronic and hard-copy**

- Maintain accurate, current disease materials and develop new “living with” materials, booklets & website information (including youth materials).
- Create a more searchable library database for current articles, etc.
- Healing Wall and Living and Thriving wall continued and increased (20 years of stories).

**Objective 2: Expand and promote the Pedigree Project to improve appropriate screening and awareness.**

- utilize and refine the online database and integrate it into the services SADS’ provides.

**Objective 3: Roadmap: checklists to guide patient families from first contact through all SADS services.**

- Tracking system improved upon to ensure all patients receive appropriate follow-up and personalized care from entire team.
- Structure includes consistent evaluation and oversight.
- Optimize SDRP (Sudden Death Response Plan) and FOP (Family Outreach Plan)

**Objective 4: Develop programming for SADSConnect youth services**

- Create special section of website for youth
- Enhance youth services at conferences and seminars
- Support and encourage youth involvement in fundraising and awareness
- Special Youth sections of newsletters with stories and articles written by youth
- Parent materials optimized and increased

**Objective 5: Family Seminars and Retreats**

- Plan and execute 2 regional family seminars and the International Conference in 2012.
- Explore the possibility of a retreat-model family support group.

### **Objective 6: 20<sup>th</sup> Anniversary**

- Review and highlight the 20 years of family stories the SADS Foundation has gathered.
- Thank and recognize people who have made a difference in the SADS Foundation for the last 20 years.

### **Objective 7: Family Support Volunteer System**

- Create training and guidelines for Family Support Volunteers
- Provide training session at International Conference
- Maintain database of active and successful volunteers

## **AWARENESS**

**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, utilizing the 20<sup>th</sup> Anniversary focus for each month, to engage Foundation volunteers around the country.

- ♥ **Heart Month:** January—February 2012  
Message/Focus: general heart/genetic education, SADS warning signs
- ♥ **Athletics:** March—June 2012 (CPR/AED week June 1-7, 2011)  
Message/Focus: awareness of emergency response (CPR/AED), SADS warning signs
- ♥ **\*Annual SADS Safe Schools Campaign (National)** July—September 2012  
Message/Focus: risk assessment for students, CPR education, SADS warning signs  
\*Pilot Project expansion for states of Arizona, Utah, and New York.

**Objective 2:** Continue the comprehensive outreach plan to Medical Examiners and Coroners:  
Message/Focus: inform surviving family members of genetic conditions and proper screening, preserve decedent's genetic material for potential testing,

**Objective 3: Volunteer Development:** To engage and properly train a selection of dedicated volunteers who can independently monitor community awareness via media, local events, and other awareness opportunities.

## **ADVOCACY/RESEARCH**

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

**Objective 1:** Partner with researchers to recruit participants and assist SADS families to be an informed and active research subjects. Facilitate the "bench to bedside" transfer of new research.

**Objective 2:** SADS Young Investigator Award(s).

**Objective 3:** Support efforts to identify appropriate **screening** protocols to determine who should be tested, by what means and how often.

**Objective 4:** Continue to advocate for SADS families with insurance issues, genetic discrimination, medical challenges; encourage medical emergency plans that include placement of automated external defibrillators (AEDs) in all schools throughout the United States and promote CPR/AED training as a requirement for high school graduation.

**Objective 5:** Continue our leadership role in the SCA Coalition and participate in other national initiatives.

## **DEVELOPMENT and MARKETING**

**Goal: \$709,000 indicating continued and steady growth.**

**Objective 1: Increase focus on major donors and strategic donor cultivation opportunities.**

Piggyback on Family support and Med Ed seminars to cultivate major donors, either by inviting them to the event or organizing one-on-one meetings to introduce them to senior SADS Fdn staff.]

**Objective 2: Continue to increase annual donor gifts – both in number and in size**

Add an additional program-specific appeal (Fam Support). Encourage recurring monthly/quarterly gifts and corporate matching in newsletters and appeals



**Objective 3: Continue to build strong networks of donors – both corporate and individual.**

Organize a Corporate Council to assist.

**Objective 4: Focus time and effort to raise awareness of SADS conditions and funds in Utah and the Intermountain West.**

(Use Anniversary and Conference as entre to meet with 12+ local foundations & corporations.)

**Objective 5: Focus on event planning to maximize net donations**

(Brittany's Trees--test in other markets; Consider replicating Jump-a-thon in other markets; Where's Bob?). Hire an events associate. who will also help with 20<sup>th</sup> anniversary.

**Objective 6: Work with an experienced consultant to develop 20<sup>th</sup> anniversary communication and marketing plans.** Utilize interns to assist in the implementation of the plan.

**2-3 year objective:** Work toward creating a 'research endowment' for the SADS Foundation with establishment of \$1,000,000 that would generate \$40,000-\$50,000 a year for research.

## ADMINISTRATION

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

**Objective 2:** To continue to integrate all program areas (and staff) into SADS projects and to develop policies and procedures to support each project.

**Objective 3:** To implement an improved data collection and reporting system that will maximize data accuracy and minimize staff time.

**Objective 4:** To integrate and organize all support systems (mass email, library, file synchronization, information-sharing).

**Objective 5:** Board development: to review and revise the board membership to include all necessary skills.

- Develop appropriate committees/task forces (finance, corporate council, medical, family support)