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\textsuperscript{th} 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\textsuperscript{th} 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 Untied 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 20th anniversary.

Objective 6: Work with an experienced consultant to develop 20th 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)