Family Support, Awareness & Advocacy

Matt Siemionko, MPH
The SADS Foundation
Overview

- Summary of Family Support Programs
  - Identification
  - Support
  - Advocacy
  - Awareness

- Disclaimer:
  - East Coast native = fast talker
What is SADS?

- Sudden Arrhythmia Death Syndromes (SADS) are genetic heart conditions that can cause sudden death in young, apparently healthy people.
What do we do?

- Support patients and families
- Raise awareness of SADS conditions
- Educate physicians and medical professionals
- Advocate for our families
How do we support families?

- Locating and reaching out to families
  - SDRP/FOP Process
  - Family/Physician Referral

- Direct Social and Emotional Support
  - Email
  - Phone Calls
  - Referral

- Advocacy and Awareness
Who do we reach out to?

- Family members
- Press/Media
- School (Where applicable)
  - Principal
  - Coach
  - School Nurse
Locating Families

- Sudden Death Response Plan (SDRP)
  - The SADS team monitors the web and media for news of sudden unexplained death.
  - Initiate comprehensive outreach and support plan for the affected community.
  - Materials, support, and education provided on SADS conditions
Locating Families

- Family Outreach Plan (FOP)
  - The SADS team monitors the web and media for news of affected families.
  - Initiate comprehensive outreach and support plan for the affected community.
  - Materials, support, and education which aims to ensure families are connected to communities, have access to knowledgeable physicians, and are screening any family members who are also at risk.
Locating Families

- Family/Physician Referral
  - Affected families and physicians provide referrals directly to the SADS Foundation website and/or staff members
Direct Family Support

- Phone calls
- Email
  - Social support
  - Emotional support
  - Physician Referral
  - Family Referral
  - Advice on next steps
The Infamous Facebook

- Myriad support groups online
  - Long QT Syndrome
  - LQTS Children and Families
  - Women with SADS Over 40
  - Long QT 1
  - Long QT 2
  - Long QT 3
  - Timothy Syndrome
Physician Referral

- Physician Referral Network
  - Interested and well trained physicians
  - Sign up to be referral doctor
  - Patients can access directly on website
School Programs

- Heart Safe School Accreditation
  - 7 Elements
  - “Do it Yourself” program
  - Accreditation period of 3 years

- SADS Safe Schools
  - Awareness campaign
  - Risk Assessment of every child
  - Care Plan for every at-risk child
Advocacy Activities

- Advocacy Alerts
  - Legislation
    - Genetic Information Nondiscrimination Act
    - Legislation requiring CPR/AED training in high school
    - Insurance coverage for genetic testing
    - Insurance coverage for AEDs for affected families
  - CEO has met with members of Congress in the past on issues related to SADS conditions
Awareness Activities

- Heart Month
- E-Newsletter and Newsletter Articles
- Conferences
  - School Nurses
  - Medical Examiners
  - Cardiologists
  - Family Seminars
Physician Education
What can YOU do?

• Take the SADS Risk Assessment
• Learn CPR
• Know the SADS Warning Signs
• Advocate for:
  ✓ Medical emergency plans w/AEDs in schools
  ✓ CPR with AED for all high school graduates
SADS Warning Signs

• Family history of unexpected, unexplained sudden death in a young person

• Fainting (syncope) or seizure during exercise, excitement or startle

• Consistent or unusual chest pain and/or shortness of breath during exercise
We are making progress!

- Every day – an increasing number of people are learning the warning signs of SADS – and are taking appropriate action

- More and more physicians are being educated about SADS conditions

- Lives are being saved!
We Need YOU!

Families are central to the mission of SADS

Matt Siemionko, matt@sads.org

801.531.0937

www.StopSADS.org
Questions?

SADS Foundation