



## From the Executive Director

Its time again to reflect on what we all accomplished in 2005. As you read the partial list of accomplishments below, you will notice one of the SADS Foundation's major strengths—volunteers. Grass routes distribution of materials, organization and execution of seminars, youth programs, fund-raisers, support groups and even monotonous stapling of packets—this is the life of a volunteer. We so appreciate your efforts in 2005!



Knowledge of SADS conditions has continued to grow and change. Many more physicians are aware of these conditions and some real inroads have been made in screening—especially for athletes. The field of genetics is growing so rapidly! Issues like genetic discrimination are getting increasing attention and procedures such as genetic testing and autopsies that incorporate genetics are now becoming more widely available. Knowing your family health history is more and more important for all of us as a tool to improve our health.

Some of SADS Accomplishments in 2005

### SADS Awareness and Prevention Programs

- Special SADS Media Alert campaign in January; over 39 volunteers participated
- National SADS Awareness Month in September with 33 volunteers in 16 states
- More than 175 volunteers participated in awareness campaigns in 2005
- More than 4,500 SADS brochures, 930 posters, 3,000 LQTS brochures were distributed by volunteers

### SADS Family Support Programs

- Held SADS Seminars in Long Island, New Orleans, Philadelphia & Dallas
- Held a two-day conference in Chicago that included a large group of SADS volunteers, 60 family members and 12 teens—who had a fantastic session this year (with their own t-shirts)
- Over 350 individuals were networking through the SADS Networking program in 2005
- Quarterly literature review of newly published research (for our

Continued on next page

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 Brittany Valene Bracelet Sales, Carol Stream, IL - \$545  
 Widmann Family Event, Pilot Hill, CA - \$1,630  
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 Scott and Kathi Blum  
 Janet M. Clarke  
 Caldon and Bernadette Driscoll  
 Christopher and Denise Falzon

Continued on next page

**Mission:** To save the lives and support the families of children & young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

# SADS Foundation Statement of Activities

Year Ended December 31, 2005

INCOME	
Individuals	\$ 100,671.00
Foundations/Corporations	\$ 29,750.00
Events	\$ 42,460.00
In-Kind Donations	\$ 9,648.00
Misc	\$ 795.00
Conference Income	\$ 5,350.00
Interest	\$ 227.00
<b>Total revenues and Support</b>	<b>\$ 188,901.00</b>

EXPENSES	
Personnel	\$ 113,639.00
Postage	\$ 15,500.00
Printing	\$ 19,654.00
Travel	\$ 16,939.00
Occupancy	\$ 12,000.00
Meetings/Conferences	\$ 7,540.00
Telephone	\$ 6,349.00
Equipment & Maintenance	\$ 3,015.00
Office Supplies	\$ 1,957.00
Professional Fees	\$ 1,888.00
Miscellaneous	\$ 1,833.00
Insurance	\$ 1,413.00
Dues/Membership	\$ 952.00
Training	\$ 62.00

Total Expenses before depreciation \$ 202,741.00

Depreciation \$ 483.00

Total Expenses \$ 203,224.00

## Statement of Expenses by Program

Awareness	\$ 60,967.00
Family Support	\$ 68,444.00
Medical Professional Education	\$ 10,162.00
Advocacy	\$ 10,161.00
Volunteer	\$ 10,161.00
<b>Total Program Expenses</b>	<b>\$ 159,895.00</b>

Management \$ 12,713.00

Fund Raising \$ 30,616.00

Total Expenses \$ 203,224.00

Continued from previous page

- new member program) was initiated
- SADSCONnect listserv for teens was implemented with Mom's recruited to help supervise
- 79 people contacted SADS in 2005 for information after a recent family death
- More than seven people contacted us each week for a new family packet

## Medical Education Program

- SADS held Seminars in Dallas and Chicago for local medical professionals
- Over 136 school nurses responded to our campaign with 809 packets mailed to 34 states and Canada; There was also a special campaign in Oregon
- Participated in a Sudden Cardiac Death in the Young conference in Michigan
- More than 1,650 school nurse packets were distributed in 2005

## Advocacy & Research Programs

- Promoted the Genetic Nondiscrimination Act, Teague Ryan Act, Rural AED Act, ADAM's Act (national clearinghouse), NIH research funding and the Research Availability Rules—over 350 people

responded & took action at some time during the year

- Attended the NIH training for advocates in January
- Participated as an agency in advocacy campaigns with Genetic Alliance, NORD, Sudden Cardiac Arrest Alliance, Coalition for Genetic Fairness, Alliance for Taxpayer Access and others
- Helped make new research results available through the Quarterly Literature Review and articles in SADS newsletters & e.newsletters
- Attended the American Association of Human Genetics conference

## www.sads.org

- People from an average of 74 countries visited our website each month.



- More than 107,575 people visited our website last year and accessed over 209,000 pages of information. This represents almost 9,000 visits each month.

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Pamela Kaplan and Kelly Cunningham, Swampscott, MA  
Conrad and Barbara Kawel, Farmington Hills, MI  
Charles Keeney, Yorktown Hts, NY  
George and Cecilia Keith, Commerce Twp, MI  
Joseph and Rosemary Kelly, Wilmington, DE  
Elizabeth Kelly, Chapel Hill, NC  
Laura Kelly, Howell, NJ  
Judith and Vin Khanna, Orchard Lake, MI  
Bernice Kianlenas, Detroit, MI  
Russell Kilmer, Avondale, PA



Eugene and Leandra King, South Jordan, UT  
Donna Klar, Wixom, MI  
John R. Klotzbach, Independence, IA  
Gloria Knoll RN, Harrisburg, PA  
Lloyd and Marilyn Koeberl, Bird Island, MN  
Marilyn Koehler and Diane Skaar, North Babylon, NY  
LaRene Kokones, Commerce Twp, MI  
Margie and Travis Korda, Renton, WA  
Daniel and Deborah Lacey, Dayton, OH  
Gloria LaPerle, Spring Hill, FL  
Don and Sue Larkin, Glendale, AZ  
John and Christine Law, Chelsea, MI  
Cassie and Michael Lawless, Colorado Spgs, CO  
Robert Leivers, Manitou Spgs, CO  
Kevin and Barbara Levasseur, Hollis, NH  
Gary and Ruthanne Link, Miamisburg, OH  
Mrs. Annalie K. Lorgus, West Chester, PA  
Sandra Lovejoy, Tustin, CA  
Cindy and Jerry Lucey, Alta, WY  
Susan and Sam Mancuso, Bloomfield, MI  
John and Lynn Matthews, Glenmont, NY  
Joan M. and Bernard G. McArdle, Williston Pk, NY  
Jan, Jim, Kat and Lisa McAvo, Sammamish, WA

Jim and Diane McCausey, Lutz, FL  
Benjamin McMakin, Brighton, MI  
Shirley McMillin, Fort Worth, TX  
Emily McNaughton, Alexandria, VA  
Shirley Medved, Commerce Twp, MI  
Daniel V and Alyce R Miller, Plattsmouth, NE  
Douglas Miller, Laurelvile, OH  
Kevin Mitchell and Carol Roubal Mitchell, Orchard Lake, MI

Dave and Lorraine Schenone, Beaverton, OR  
Jeanette and Mark Schumacher, Westland, MI  
Donna and Jim Scott, Media, PA  
Robert Sengbusch, Brillion, WI  
Elizabeth and Gerald Shaw, W. Bloomfield, MI  
Daniel Sheff, Lexington, MA  
Kathy and Brian Sheffield, Santa Clarita, CA  
Debra A. Shellenbarger, Fort Wayne, IN  
Bob and Kate Siftar, Ester, AK



Elaine Morell, Colorado Springs, CO  
Linda and Mark Murray, Easton, MD  
Anthony G. Musci MD, Salt Lake City, UT  
Joan and John Myles, Gloucester, VA  
Margaret Nagy, Southfield, MI  
Jeff Nesbitt, Conshohocken, PA  
Charles and Linda Newmark, Chapel Hill, NC  
Anna Niziol, Norcross, GA  
Francis and John Oakland, Novi, MI  
Maureen O'Connell, Philadelphia, PA  
Janet and Don Odell, Monument, CO  
Connie and Darrell Ogden, Layton, UT  
Robert Panaccio, Phoenixville, PA  
June and Robert Paul, Barrington, IL  
Richard Paul, Vernon Hills, IL  
Alice and Joe Perazzo, Marcus Hook, PA  
3 Margaritas, Colorado Springs, CO  
Marsha and Steve Peterson, Emporia, KS  
Rose Mary Piper, Winchester, MA  
Daniel and Deborah Pitsos, White Lake, MI  
Edith and William Plotkowski, Pleasant Rdg, MI  
Jodi Pugsley, Mukilteo, WA  
Christine M. and Dennis C. Puricelli, Chandler, AZ  
Tim and Joyce Rankin, Tiltonsville, OH  
Melissa Raskin, New York, NY  
Mary Ratensperger, Wasaga Beach, ON  
Melinda and Angelo Ratini, Bristol, PA  
Brenda Riddell, Newton, NH  
Lene and Jim Righheimer, Fountain Vly, CA  
Matthew and Ashley Ritchie, Lithia, FL  
Emanuel and Irene Rizzo, Port St Lucie, FL  
Barbara Robertson, Bloomfield, MI  
Marc and Saralee Roland, West Bloomfield, MI  
Ruthe and David Rugh, Bothell, WA  
Victor W. Russell, Chicago, IL  
Mark and Rebecca Sassak, West Bloomfield, MI

Daniel Silva-Thwaites MD, Modesto, CA  
Marcey E and Peter J Sipes, Round Rock, TX  
Tim and Shari Sippola, Emporia, KS  
Colleen and Bud Slegle, Salt Lake City, UT  
Beth and Ronald Slaven, Indianapolis, IN  
Robert C. and Debra Smith, Bronson, IA  
Molly Smith-Shafer, San Antonio, TX  
Stacy and Melissa Stevens, Bonne Terre, MO  
Robert and Dierdre Stiffer, Chapel Hill, NC  
Joanne and Robert Stille, Holland, MI  
Carol and William Strasshofer, Hereford, AZ  
Dawn Swetnam RN, W. Bloomfield, MI  
Richard and Mary Beth Swor, Dearborn, MI  
Mr. & Mrs. Henry Taca, Palm Beach, FL  
Thomas Talbot, MD, Salem, OR  
Kathy Taylor, Warsaw, IN  
Joan and Mike VanHeck, Macomb, MI  
Thomas and Kay VanScyoc, W. Bloomfield, MI  
Constantine G. Vasilidis, Mahwah, NJ  
Susan Walsh, RN, Coatesville, PA  
Stephen and Shelley Washuta, Modesto, CA  
P. H. Watson, Lower Gwynedd, PA  
Gloria and James Webber, Orchard Lake, MI  
Jeffrey Weiss, Dearborn Hts, MI  
Donald Werschky, Colorado Spgs, CO  
Jean and Bob West, Laurelvile, OH  
Regina Wilking, Orchard Lake, MI  
Jane and Bill Willhoit, Colorado Spgs, CO  
Joanne and Nate Williamson, Olympia, WA  
Bryan and Elaine Wilson, Lubbock, TX  
Philip Witman, Elkins Park, PA  
Kenneth and Karen Woodside, Northville, MI  
Ralph and Helen Zech, Enumclaw, WA  
Diane Zetlemoyer, Marysville, PA  
Kathryn Zietlow, Holt, MI  
Alan H. and Paula Zuckerman, Mount Laurel, NJ

## Warning signs for every parent

Your child should be seen by a doctor if she/he has:

- 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