It is a delight to greet you all again. From my perspective, the work to prevent cardiac events in children and young adults who are genetically predisposed to arrhythmias is going well. An important advance this last year was the introduction by Genaissance Pharmaceuticals of the Familial common genetic test for mutations causing Long QT and Brugada syndromes. The SADS conferences and seminars, noted elsewhere in the newsletter, also provided important opportunities for families to meet with knowledgeable physicians in their geographic area, to learn about new thoughts and technologies, and to have questions answered. SADS has a number of similar programs scheduled for this year. Thanks to all for the terrific work of spreading the word and developing contacts and resources!

There remains a lot of interest and activity in the medical community regarding the genetic cardiac arrhythmias. As an example, at the annual meeting of the cardiologists who are particularly interested in the cardiac electrical system and arrhythmias, held in New Orleans May 3-7, 2005, there were approximately 50 presentations on Long QT, Brugada and related syndromes during that meeting to help educate and update these physicians on these disorders and their diagnosis and management.

There do remain important gaps in our knowledge about LQTS and, thus, uncertainties about the most appropriate care for patients. The false negative results of genetic testing and the limited ability to predict risk of serious cardiac events in asymptomatic patients, particularly children, cause confusion about treatment options, particularly beta-blockers versus ICD implantation. Both of these topics will be discussed in some of the presentations I mentioned above. While no definitive answers to these complexities are yet available, work continues to progress and more information will be forthcoming in the not too distant future. There are a number of outstanding investigators and clinicians working on the genetically caused arrhythmias, and SADS plans to help keep you informed about the results as they become available.

I very much appreciate the opportunity to participate in the SADS Foundation activities and to work with many of you on our mutual goals. It is a great privilege. Again, I thank you all for your many contributions and encourage your continued support.

G. Michael Vincent, M.D.
Awareness/Prevention, Family Support, Medical Education, Advocacy

SADS provides Family Support, Awareness & Prevention, Medical Education, & Advocacy/Research. To give you a bit of an idea of what we do last year:

Awareness & Prevention
Family stories were published around the country, including in Arizona, California, Oregon, Texas, Utah, Georgia, Massachusetts, Nebraska, North Carolina, Washington and West Virginia.

2,010 posters distributed (168/month)

Family Support
Over 6,800 people visit our website every month

12 lively and energetic young people attended the 1st ever session for kids at our 3rd International SADS Foundation Conference this summer.

SADS staff refer 12 families to physicians each month

SADS held three family seminars around the country each month

Medical Education
SADS volunteers educated school nurses all over the country. We mailed over 700 packets of information, numerous presentations and gave a formal session at the Arizona School Nurses Association.

We attended 9 conferences to educate medical professionals and others about the warning signs of SADS, and distributed over 450 medical packets.

Advocacy/Research
A new condition that includes Long QT Syndrome—called Timothy's Syndrome—was found this year by Katherine Timmy and Dr. Mark Keating's lab.

Volunteer support
284 volunteers help us raise community awareness, educate medical professionals support families and advocate.

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

Awareness & Prevention

Costs for some SADS services last year:

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Seminars</td>
<td>$17,985.00</td>
</tr>
<tr>
<td>HotLine</td>
<td>$21,136.00 ($1,761 each month)</td>
</tr>
<tr>
<td>SADS International Conference</td>
<td>$35,209.00</td>
</tr>
<tr>
<td>Networking</td>
<td>$2,000.00</td>
</tr>
<tr>
<td>Heart Rhythm Conference</td>
<td>$6,624.00</td>
</tr>
<tr>
<td>Newsletter</td>
<td>$25,842.00 ($8,614 each issue)</td>
</tr>
<tr>
<td>Website</td>
<td>$15,674.00 ($1,306 each month)</td>
</tr>
</tbody>
</table>

Contributors
Continued from previous page

Woods, IL
Larry and Rosa Greenstein, Hawthorn Wds, IL
Mara Silverberg, Buffalo Grove, IL
The Ken and Keron Bailey Conference Fundraiser, Omaha, NE

No Ball At All-Dinner Committee, Nationwide
Mary and Charles Berg, Imlay City, MI
Suzi, Paul and Kyle Dollman, Fort Myers, Fl.
Denise and Christopher Falcon, Orchard Lake, MI
Caroline Kelly Figuia, Aurora, IL
Shirley Gaster, West Chester, PA
Larry and Rosa Greenstein, Hawthorn, IL
Jodi Wilmisnky Hill and Frank Hill, Lexington, MA
Kathy and John Ibbott, West Chester, PA
Barbara Laffr, Gainesville, GA
The Larive Family, Chicopee, MA
Sharon and Jim Lentino, Libertyville, IL
Robert P. Magner, Jr., Scituate, MA
Maude Gill and Sisters, Chicago, IL
John and Kathleen O'Hare, Harinsburg, PA
Terry and Vicki O'Neill, Fox Point, WI
Vladie and Gary Pimenber, Fort Worth, TX
Pamela L. Reich, Eumcaw, Lake
Dorothea and Jim Renner, Brooklyn, PA
Mark, Nettie, & Bobby Simpson, Nichols, WI
Alice Smith, Livonia, MI
Katherine Timothy, Kayville, UT
Jon and Martha Zaborowski, Colleyville, TX

Online Fundraising Hosts
Heather Koffman, Lillburn, GA
Cheryl Mioch, Farmington, UT
Jennifer Gesler, Pleasanton, CA
Walter Al & Mary & Tom Anglim, Falmouth & Bath, ME

Heroes $500-$999
Timothy J. and Margaret M. Abell, Goynded Valley, PA
Mary and Tom Anglim, Bath, ME
Ann and Steve Benton, Salt Lake City, UT
Par Bulas, West Jordan, UT
Sandy and John Benedict, Ada, WA
Merl Duncan, Montovia, CA
Cynil and Beverly Dunmire, Camp Hill, PA
Donald Gagnon, Jr., Seattle, WA
Patrick and Anne M. Gallagh, Glenview, IL
Shirley Gaster, West Chester, PA
Bill and Janet Gobe, Greenwood, IN
Blaine and Barbara Harmon, Salt Lake City, UT
Alan and Cory Harvey, Mouser, Andy, MD
Shirley N. Haynes, Phoenix, AZ
Jodi Wilmsisky Hill and Frank Hill, Lexington, MA
Howell Hunt, Lithia, FL
Dan Kennedy, Rochester, NY
Beverly Lepiere, Brooklyn Park, MN
Sharon and Jim Lentino, Libertyville, IL
Paul and Lucille Levine, Santa Clarita, CA
Alfred H. McKen and Kathryn Weiss-McKean, Dallas, TX
Patrice and Scott Nelson, Barryville, VA
Elaine O'Hara, Rancho Pala Verdes, CA
John Pratt, Beverly Hills, CA
Jean Schwartz, Roswell, GA
David M. Smith, Houston, TX
G. Michael Vincent, MD, Salt Lake City, UT

Friends $100-$499
Michael Ackerman, MD, PhD, Rochester, MN
Bill and Kathy Aller, Chapel Hill, NC
Robert J. and Bonnie Ammon, Palm Coast, FL
Mark and Susan Bagosy. West Chester, PA
Keron L. and Kenneth D. Bailey, Guide Rock, NE
Barry Bakal, Buffalo Grove, IL
Bruce and Elena Batz, Smithtown, NY
Arlene and Peter Barbagnols, Saratoga SPP, NY
Carl and Kathryn Bare, Stewardtown, PA
James and Muriel Benedet, San Pedro, CA
Richard Berning, MD, Trumbull, CT
Jeff and Amy Bernstein, San Diego, CA
Kendall and Brian Berry, Edmonds, WA
Ronald J. Bianchini, Orlando, CA
Judy and David Birdsell, Somers, NY
Les and Ruth Blyerson, Portland, OR
Hal Blackman, Atlanta, GA
Cristina Blasert, Baltimore, MD
Kathryn and Scott Blum, Modesto, CA
Arkida Bown, Riegsholw, NC
Carlos and Luis Ann Bowman, Medford, MI
Cathy M. Bradford, Huntington Beach, CA
Jeffrey and Diane Brosius, Jessup, MD
Steve and Annmarie Brown, Milford, MI
James Edward Brown, Livermore, FL
E. Jean Whorley Brown, Port Orange, FL
Paul and Nikki Bryant, Wichita, KS
James and Debbie Burrows, Beverly Hills, CA
David and Linda Callins, Merion Sta, PA
Lynn and James Callins, Elmhurst, IL
Mary and Don Campbell, Memphis, TN
Michael and Katherine Carducci, Baltimore, MD
John and Elizabeth Casey, Maple Glen, PA
Barbara Smith and Philip Chall, Chagrin Falls, OH
Mark and Diana Challenger, Bellingham, WA
Judith Chambers, Summerfield, FL
Christopher and Pennie Chamaus, Mc Lean, VA
Grant S. and Vida Chmielewski, Boise, ID
Karen and Bruce Christenson, Sheboyan, WI
David and Kathy Clemons, Chapel Hill, NC
Lendelf and Irma Cuckom, Tuscon, AZ
Federica Colia, Richmond, CA
John and Janet Connors, West Chester, PA
Randi and John Conway, Greenwich, CT
Sharon Cramer, Sarasota, FL
Richard and Julia Crumpton, Charlottesville, VA
Trudy and Ron Cuss, Spokane, NV
Nancy and Owen Cylke, Bethesda, MD
Mille and Jon Davidson, Vienna, VA
Debby and John Davidson, Peoria, AZ
Tim Delaney, Euclid, OH
Jennifer and Michael DiGiacomo, Stamford, CT
Michelle and Al Dilling, West Chester, PA
Suzanne Dollman, Fort Myers, FL
Mary Ann and Michael Domulewicz, Bloomfield Hills, MI
Marian and Jerry Doolin, Brooklaken, PA
John Doyle, Havertown, PA

Contributors: Continued on next page

SADS Annual Report 2005
www.sads.org
Contributors: Continued from previous page

Linda Weber Collins, Dallas, TX
Dostal and Beverly Collins, Stamford, CT
Cecilia and Tom Collins, El Cajon, CA
Suzanne Cook, concord, CA
Joanne Cook, Irving, TX
John and Margaret Costa, Norwalk, CT
Anne Crisp, Dallas, TX
Clarence and Sue Crosby, Washington, DC
Rhonda Culp, watashchi, IL
Diana Decker, Fernville, PA
Ann Bailey Dee, Salt Lake City, UT
Kathleen Delaney, Euclid, OH
Ronald F. Delpratt, Carmichael, CA
Tami Delpratt, Addison, TX
Linda Demarest, Dallas, TX
Dee Ellen Devin, Dallas, TX
Donna and Tony DeSaulniers, Ocala, FL
Frances and Emilia Donlon, Riverside, IL
Lesa Donovan, Plano, TX
Sue and Tim Donovan, W. Bloomfield, MI
Susan D. Duncan, Lancaster, PA
Ellen Dunn, Fairfield, CT
Herbert and Bari Eagle, los Angeles, CA
Cheryl and Charlie Earlethy, Germantown, TN
Ronald G. Eby, marina, CA
Kim Ecker, Colorado Springs, CO
Theodore and Bonnie Edwines, Stamford, CT
Dancie Egan, Bethel, CT
Jane E. Ellenbogen, Palm Beach, FL
Maurine Ellis, Dallas, TX
Patterson and Roger Emerson, Dallas, TX
Julia B. Estinger, Lexington, MA
Ray and Arthut Eucken, Cumberland, IA
Sharon and Douglas Falcon, Franklin, MI
Beatrice W. Fisher, Decatur, IL
Jeffrey and Julie Friedman, Santa Barbara, CA
William Finnland, Colorado Springs, CO
Fred M. and Joan Fy, Commerce Twp, MI
Sue amy and Ben Fylym, Scio, MI
Jose Garza, Dallas, TX
Mary Lou and Dan Gebauer, Waterford, MI
Frank Guinta, Dallas, TX
Marion Glaze, Dallas, TX
Michael and Susanne Goldstein, Wayne, NJ
Brenda Gomez, Dallas, TX
Elizabeth Gonzalez, Plano, TX
Robert O. and Patricia C. Goodlett, Oklahoma City, OK
Alfred and Patricia Gonder, Santa Barbara, CA
Dr. Joseph Goodwin, Lexington, KY
Joseph and Rosemary Gourley, Wilmington, DE
Violin and Emily Goumas, Denver, CO
Paul Goulet, Dallas, TX
Mark Goulet, Dallas, TX
Thomas Goulette, Dallas, TX
Kari Gow, Carlsbad, CA
Nichol Gower, New York City, NY
Chris and Ben Gower, Evanston, IL
Maggie Nagy, Southfield, MI
Mr. & Mrs. Charles Neener, Broomfield, CO
Carolyn Neff, Dallas, TX
Mary Lou and John Newsom, Newport News, VA
Stephen Nicotera, ocean City, NJ
Chris and Dave Newenshuis, Deer Park, WA
Francis and John Oldham, Norwalk, CT
Nancy and Paul Olerman, Englewood, CO
Rose Lee Olsen, Carolton, TX
Rebecca Ordinario, Dallas, TX
Katherine E. O’Rourke, ille, Torrance, CA
Kevin Michal Osborne, Dallas, TX
Gerald Packard, MD, Vineland, NJ
Diane Palet, Farmers Branch, TX
Lynn Palmer, Dallas, TX
John and Jennifer Paul, Barrington, IL
Lisa V. and Raymond Pello, Newton, NJ
Marni and Steve Peterson, Emporia, KS
Ellen and Ed Peterson, woodland Hills, CA
Valerie Pilarski, Sherman, TX
Deborah Pius, Carmel Valley, CA
Lynn and Chris Polackzy, Deerborn, MI
Thomas and Susan Porcini, Oxford, OH
Ed and dorris Portley, salem, NH
Ara Redd, Chula Vista, CA
Audrey Raskin, Palm Beach Gardens, FL
Pat Ridon, Somers, TX
Emmanuel and Jesse Rizzo, Port St. Lucie, FL
Jason Robinson, Dacula, GA
Mr. & Mrs. Reid Rooney, Cincinnati, OH
Sandra Rose, Dover, NH
Barbara Rosenblatt, Pans, TX
Karen Ross, Colorado Springs, CO
Joy Rosentz, Sharon, MA
Caroline and Walter Rohrer, Flushing, MI
Shelli and Jim Sado, Highland, MI
John and Dawn Saroni, Canton, MI
Ronald Schaffer, burlington, VT
Dave and Lorraine Schenone, Beaverton, OR
Herbert and Anna Schild, branford, CT
Joseph A. Sestito, Cohasset, MA
Renee Shamba, Claremont, CA
Paul and Linda Shamblin, Harrisburg, PA
Debra A. Shellenberger, Fort Wayne, IN
Eileen Shomo, Boothwyn, PA
Carolyn N. and Andrew singer, Denver, CO
Marilyn Kocher and Diane Sklar, North Babylon, NY
Juanita Shome, Pans, TX
Helen Slota, Philadelphia, PA
John and Patricia Smir, Duluth, GA
Deborah Smith, Dallas, TX
Alice Smith, Livonia, MI
Donna Sonnenberg, Kingston, NY
Donna L. Spagnola, Willowbrook, IL
Nicole Stambelis, Stamford, CT
Amrita Thomas, Stamford, CT
Bob and Shannon Sters, Chesire, CT
Peter and Janis Steinfield, Portland, OR
Stacy and Melcia Stevens, Bonnie Terre, MO
Joanne and Robert Still, Holland, MI
Tina Stone, Al, TX
Ken Storm, Greenwich, CT
Sada and Linda Suberman, Wilmington, DE
Kim and daryl Swol, Chesapeake, OK
Thomas Talbot, Salon, cheyenne, WY
Kathy Tamms, S. ill, IL
Russ Talbert, Pans, TX
Terry and George Taylor, Ft. Wayne, IN
Amanda Tibbodue, bentonville, AR
Cherise Thomas, Rosenberg, TX
Suan Thompson, Dallas, TX
John Thompson, Wellington, FL
Carol J. and Ralph S. Tillet, Alexandria, MN
Katherine and Michael Timothy, kayville, UT
Deborah Lynn Usher, oakl, CA
Dan Vanotenbeek, Malvern, PA
Mary and Harry verse, Lewes, DE
Jeff and Patti Vogt, Redwood, NJ
Bob and gene Volkes, Volusia, FL
Jennifer L. Walker, Rockford, MI
Carole Walker, Dallas, TX
Susan Walch RN, Coopersville, MI
Freda Warren, West Palm Beach, FL
Jolie Warpol, Orchard Lake, MI
Gloria and Stanley Warren, Bartow, FL
Gloria and James Webthy, Orchard Lake, MI
Luisa Caporali and Marlene Wecker, Malvern, PA
Joel Custer and Lucinda Wigracz, cape Elizabeth, ME
Alexander Wentzel, Laguna Beach, CA
Donald Weschley, Colorado Springs, CO
Julie Whitty, barnstow, MA
Karl R. White, Pasco, WA
Beverly Wilder, Marshalltown, IA
Ann Williams, Tallahassee, FL
Janet and Greg winburn, MAINe
Jennifer R. Winslow, Norwalk, CT
Larry Wright, Geulp, OH
Ralph and Helen Zech, ennumac, MAINe
Kathyrn Zierol, Holt, MI
Corporations matching employee donations

J. P. Morgan Chase Foundation

Merrill Lynch Foundation
Microsoft Giving Campaign
Temecula Healthcare Foundation
Oracle Corporation