



# SADS FOUNDATION

## 2017 ANNUAL REPORT



### HIGHLIGHTS FROM 2017

The 10th Annual International SADS Foundation Conference was held in Toronto, Ontario, Canada, and featured 120 families from 7 different countries who were a part of this conference's friendship and education including keynote speaker Yvonne Heath, Disease-Specific Sessions, and the first annual Scientific Posters Session.



*Painting with a Twist with Ashley Malewski*

The SADS Foundation and our families supported the studies of 4 Genetic Counseling students: Lauren Slevin, PhD; Susan Christian, PhD; Brittany Degreef; and Kacie Baker



*SADS Kids at 2017 Conference*

The combination of seminars presented by Dr. Michael Ackerman and trainings given by the SADS Foundation Speakers' Bureau resulted in 3,250 health care professionals learning about SADS conditions in 16 different states in order to increase accurate diagnoses and improve care.



*Mary Handies and Friends on a Virtual Take Steps to Stop SADS (above)*

The SADS Foundation worked as the conduit between SADS patients and expert research scientists in 17 currently enrolling research studies.

New Patient Line 801-948-0654 was created to provide a one-call service for SADS families.

Nearly 2,000 phone calls or emails were completed in service of SADS families.



*20th Hanss Layton Oktoberfest! (below)*

## Legacy Circle Members

### Platinum Legacy Circle \$100,000 Endowment

Sally Cleveland - Courts K.  
Cleveland Foundation

### Gold Legacy Circle \$99,999-\$50,000

Frederick and Diane Smith

### Bronze Legacy Circle \$24,999-\$10,000

Joanna Bewick  
Phil & Stephanie Howard  
Alan and Pam London  
Brooke Morrow  
Hollywood Independent  
Church - UCC



*Heart Necklaces made by  
Nancy Souillard and Team*

### Legacy Circle \$9,999-\$1,000

Michael Ackerman, MD  
Kelly Airey, MD  
Priscilla & Anthony Beadell  
Ellen Boles  
Carlos & Lois Ann Bowman  
Penelope Boyden  
David Bradley, MD & Nicole Frei  
Robert Campbell, MD  
Ruth Chesser  
MaryAnn & Christian Ciciarelli  
Scott Dailard  
Paul DePorre – DePorre  
Family Foundation  
Bob DiMeo  
Martin Elias  
Susan Etheridge, MD

*SADS Family Members at the Baltimore  
and DC Area Support Picnic*



**The Timothy Syndrome  
Alliance continued to  
expand and the CPVT  
support group met  
for the first time and  
is moving forward in  
establishing their goals.**

& Michael Pond  
Kori & Chuck Faulkner  
Todd & Sandra Gorder  
Bill & Janet Grube  
Ken Haller  
Michael Harrington  
Laurie & Steve Hooper  
Nathan Hurley  
Amy Hutchens  
Dale Irvin – Cigar Peg, Inc.  
Fred & Jill Jaccard  
Traci & Derrick Jensen  
Lynn Johnson, MD & Peter Kidder  
Jackie Kaas Vines  
John & Dawn Lambert  
Sharon & Jim Lentino  
Violette Levy  
Anthony & Cathleen Lucatuorto  
Juliette & Jacob Magers  
William Mays  
Phyllis McFarland  
Peter McMillan  
Conrad Mihalek  
Mary Palmer  
Jim Peterka  
Rhonda Rand, MD  
Lene & Jim Righeimer  
Ronda Robinson –  
Robinson Industries  
Frank & Cally Rogers-Witte  
Devon Rudloff  
Maureen & William  
Schulman  
Dan Schuman – Tommy  
Schuman Foundation  
Lindsey Shockley  
Glenda Stafford &  
La Donna Watson  
Judy & Philip To  
Nancy Walker  
Angela Watschke  
Lamar & Wanda White  
Eileen & James Wilkoff  
Cathy & Brian Zbanek

### \$999-\$500

Omar Alibrahim  
Melinda Asp  
James Baker  
Elliott & Emily Bauder  
Mary & Bruce  
Beauchamp  
Darren & Mariesol  
Chamberlain  
Brian & Lisa Beth  
Cooper

Julia Eslinger  
Denise Falzon  
Rachel & Rolando Flores  
Jaye Ruth Friedman-Levy -  
Beatrice & Leon Friedman  
Charitable Foundation  
J. Patrick Gallagher  
Paul Gamache  
Christopher Garcia  
Ken Haller  
David Hammond  
Rosie & David Hollomon  
Peyton Hostetler  
Robert Kass  
Elizabeth Kaufman  
Dennis & Adelyn Klarin  
Sandra & Kenneth Kneipp  
John & Dawn Lambert  
Karen McCassey  
Janet Osborne  
Pamela Osterhout-Batten  
Douglas & Angela Parker

**We connected with 250 new  
SADS families to guide them  
through the SADS journey.**

Marilyn Parsons  
Richard Rogers  
Linda & Bill Shockley  
Larry & Margie Smith  
Anne Soto  
Katherine & Michael Timothy  
Wolfgang Wander



*Flat Bob and SADS Docs at HRS 2017*

### SADS Sustainers of Hearts

Michele Alatorre  
Darren and Mariesol Chamberlain  
John Contrata  
Melissa Davis  
Glennnda Dawley  
Julia Eslinger  
Rachel and Rolando Flores  
Mary and William Hardies  
Mark and Rebecca Knowles  
Kristen Kraunelis  
Juliette and Jacob Magers  
Barbara Mattison  
Erica Park  
Tenise and Anthony Rutledge  
Maureen and William Schulman  
Lindsey Shockley  
Glenda Stafford &



*Rebecca Knowles with son Cameron and the  
Rob L. Walker HSSA Champion Award*

La Donna Watson  
Wendy Strickland  
Zaharoula Viennas, MD  
Samantha Rae Wilder  
Jeralyn Zoch

### Corporations \$49,999-\$25,000

Abbott/St. Jude Medical Foundation  
Gilead Sciences, Inc.  
Invitae

### \$24,999-\$10,000

Ambry Genetics  
Boston Scientific  
Medtronic, Inc.

### \$9,999-\$5,000

Audentes Therapeutics  
GeneDX  
LifeSure, LLC  
Phosphorus, Inc.

### \$4,999 or less

Blueprint Genetics  
Kaiser Permanente  
Myokardia, Inc.

### Foundations \$10,000

Sorenson Legacy Foundation

### \$5,000 or less

Church of Jesus Christ of Latter  
Day Saints Foundation  
George S. and Dolores Doré  
Eccles Foundation  
Home for Orphans of  
Oddfellows of PA

### Matching Gifts

AARP  
Allstate Giving Campaign  
Ameriprise Financial Inc.  
Bank of America Foundation  
Boeing, Inc.



Broadridge  
Google Employee  
Giving  
HCA Caring for  
the Community  
IMPAC Charity  
Program  
Lockheed Martin  
Merck Foundation  
Microsoft Corporation  
Pfizer Foundation  
Matching Gifts  
Program  
SVB Financial Group  
TCF Foundation  
United Health Group  
Wells Fargo  
Travelers  
YourCause

## Living and Thriving Funds

Abrielle Watschke  
Adeline Dinin

**The first SADS Foundation blog  
facebook.com/sadschannel was  
established under the guidance of  
Jasmine Wylie and now has more  
than 200 followers.**

Aiden Bewick  
Alexis Valdez  
Alice Lara  
Alyssa Gutierrez &  
Britnee Hatch  
Amelia Gentile  
Annemarie Hickey  
Calkins  
Annie Lucatuorto  
Ashley Malewski  
Ayana Rutledge  
Bear Bock & Family  
Bill and Sally Layton  
Brianna Badger  
Bryan Price &  
Betty Glasheen  
Cameron Knowles

Chesser Family  
Ciciarelli Family  
Dara Emily Sadinsky  
Debbie & Les Feldman  
Eden Sollimo  
Emily Boone  
Dr. G. Michael  
Vincent  
Gregory Toter  
Isabella Flores  
Jake Horton  
Dr. & Mrs. Jay Cudrin  
Justin Paul  
Kathryn DePorre  
Kevin McCabe  
Kristen Kraunelis  
Laurie Smith Hooper

Lindsay Mitacek  
Lizzy Felgoise  
Dr. Lynn Johnson  
Madison Chesser  
Marsha Peterson &  
Kristi and Sam Yeager  
Mary Hickey Family  
Mason Clark  
Megan, Grady &  
Blake Komenda  
Nathan Hurley  
Phillip Breen  
Ryan Weidler  
Sam Yeager  
Samantha Rae Wilder  
Sharon Lentino  
Ty Egan  
Dr. Victoria Vetter

## Memorial Funds

Abbey Wambach  
Aiden Bewick  
Allison Bauer



SADS Family Volunteer Sharon Lentino and Jan Schiller

Dalton Motlow  
Danny Mauriello  
Donnie Prestianni  
Dwayne Arthur Chow  
Elisa Feldman  
Elizabeth Barry  
Elizabeth Hart  
Elizabeth Noone  
O'Hara  
Emily Puricelli

John Vickroy  
Jonathan R. Cowley  
Jonathan Welki  
Justin Viker  
Kaden Daniel Echols  
Kerry Ann Schulman  
Kevin McCabe  
Lee Ciciarelli  
Luke Magers  
Mandy Danielle Smith  
Mariah Michelle Davis  
Mathew Chiappetta  
Michael London  
Dr. Peter Paul  
Rebecca Righeimer  
Rhonda Joi Spencer  
Richard J. Barrett  
Robbie Kaas  
Ryan Weidler  
Tommy Schuman  
Valorie Muraco  
Victor A. Nigro  
Wayne Sawyer Jr.  
Windland Smith Rice  
Zachery Hollomon

For a complete listing visit  
[StopSADS.org](http://StopSADS.org)



Young Investigator Awardee Najim Labrouchi, MD

**Each month of 2017 featured a monthly  
awareness activity including the always  
popular Flat Bob, Red Kit, SADS Safe School  
Packet, and Family Pedigree campaigns.**

Andrew Palmer  
Ann Bailey Dee  
Barbara Masters  
Brian Falzon  
Brittany Valene  
Casey Shockley  
Challis Blum  
Christiy Tolosky  
Colin O'Kane  
Cynthia Daillard

Francis Carleton  
Strand  
Geneva Jackson  
Gianna Rice  
Gray Solana  
Ian Hyzy  
Jacob Eisner  
Jake Kiester  
Joe & Daniel Talomie  
John Thalhimier

## Board of Trustees

### Board President

Michael J. Ackerman,  
MD, PhD  
Rochester, MN

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Salt Lake City, UT

### Board Secretary

Scott Dailard  
San Diego, CA

### Board Treasurer

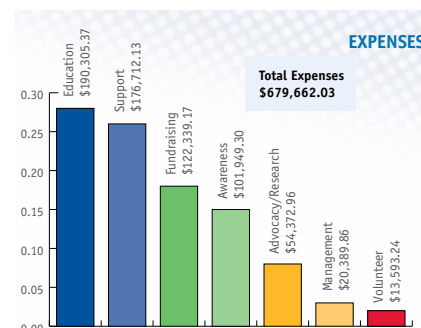
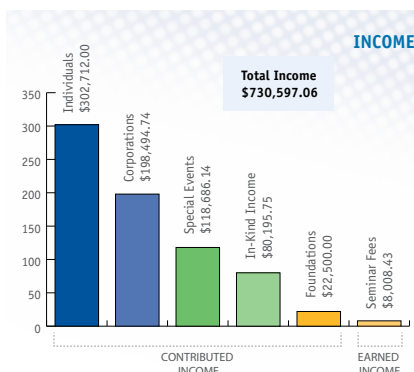
Joanna Bewick  
Boston, MA  
Robert Campbell, MD  
Atlanta, GA  
Mary Ann Ciciarelli  
Charlotte, NC

Kathryn Collins, MD  
Aurora, CO  
Brynn Dechert-  
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Laurie Smith Hooper  
Nashville, TN  
Phil Howard  
Redwood City, CA  
Alan London, MD  
Indianapolis, IN  
Anthony Lucatuorto  
New York, NY

### SADS Founder & Emeritus Trustee

G. Michael Vincent, MD  
Salt Lake City, UT

## 2017 Income & Expenses



## Thanks to our Medical Education Seminar Hosts in 2017

University of Miami/Holtz  
Children's Hospital  
Miami Children's/Nicklaus  
Children's Hospital  
Joe Dimaggio Children's Hospital  
Wayne State/Detroit Medical Center  
Henry Ford Medical Center  
Mount Sinai School of Medicine  
Weill Cornell Medical College  
Kaiser Permanente  
California Pacific Medical Center  
University of California  
– San Francisco

## Thanks to our 2017 Conference CME Program Directors and Speakers

### Program Directors

Susan Etheridge, MD  
Robert Hamilton, MD  
Danna Spears, MD

### Speakers

Dominic J. R. Abrams, MD  
Michael J. Ackerman, MD, PhD  
Peter Aziz, MD  
Anjan S. Batra, MD  
Virginie Beausejour-Ladouceur, MD  
Elijah Behr, MD

David J. Bradley, MD  
Melanie Care, MSc, CCGC  
Heather Cartwright  
Kris Cunningham, MD  
Aamir Jeewa, MD  
Andrew Krahn, MD  
Martin LaPage, MD  
Shubhayan Sanatani, MD  
Penny Sneddon, PhD  
Elizabeth Stephenson, MD  
Martin Tristani-Firouzi, MD  
Adaya Weissler-Snir, MD

## Thanks to our 2017 Conference Family Speakers

Dominic J. R. Abrams, MD  
Michael J. Ackerman, MD, PhD  
Peter Aziz, MD  
Anjan S. Batra, MD  
Virginie Beausejour-Ladouceur, MD  
Elijah Behr, MD  
Rob Boudreau, ACP  
David J. Bradley, MD  
Heather Cartwright  
Mary Ann Ciciarelli  
Bettina Cuneo, MD  
Brynn Dechert-Crooks, CPNP  
Paul Dorian, MD  
Aamir Jeewa, MD  
Connie Ens, RN  
Susan Etheridge, MD  
Rachel Flores, RN  
Robert Hamilton, MD  
Michael Hawkins, MD, FRCPC  
Kathleen Hodgkinson, PhD  
Pam Husband  
Charles King, PA-C, MPAS  
Mark Knowles, EMT, MHFA  
Rebecca Knowles, RN  
Martin LaPage, MD  
Alice Lara, RN  
Sharon Murphy Lentino  
Alan London, MD  
Lisa Mills, RN, BSN  
Maria Norris-Boudreau, RN  
Laura Robb, MSc, CGC  
Jan Schiller  
Penny Sneddon, PhD  
Danna Spears, MD  
Katherine Timothy  
Greg Toter, BSN, RN  
Martin Tristani-Firouzi, MD  
Courtney Waller  
Jennifer White, MD

The Timothy Syndrome Alliance continued to expand and the CPVT support group met for the first time and is moving forward in establishing their goals.



Running for Our Lives with Stephanie Tubergen and Friends



Madeline Petersen and Friends at Lemonade Stand

## Volunteer Fundraising Events

|                                    |               |                                    |
|------------------------------------|---------------|------------------------------------|
| Brittany's Trees                   | Illinois      | Tony Valene, Jim Guthrie, and Team |
| Brittany's Trees                   | Illinois      | Lentino Family                     |
| Heartoberfest                      | New York      | Tolosky Family                     |
| Oktoberfest                        | Colorado      | Layton Family                      |
| All for AI                         | Illinois      | Bauer Family                       |
| Celebrate Ian 5K                   | New York      | Hyzy Family                        |
| Eden Sollimo's Birthday Party      | Virginia      | Sollimo Family                     |
| Gertsberg Memorial 5K              | Connecticut   | Gertsberg Family & Friends         |
| Jonathan R. Cowley Golf Tournament | Virginia      | Linda Cowley                       |
| Jumpathon                          | Texas         | Betty Glasheen                     |
| Keep Little Hearts Beating         | Missouri      | Clark Family                       |
| Kiester Party for Jake             | Illinois      | Kiester Family & Friends           |
| Lemonade Stand for SADS Foundation | Illinois      | Petersen Family                    |
| Painting with a Twist              | Michigan      | Ashley Malewski                    |
| Posie Hollomon Birthday Party      | California    | Hollomon Family                    |
| Rachel's Race                      | Wisconsin     | David and Sarah Lancour            |
| Round Ball Rumble Tournament       | Georgia       | Solana Family                      |
| Running for Our Lives              | Michigan      | Stephanie Tubergen and Family      |
| Ryan Weidler Golf Tournament       | Pennsylvania  | Carol Weidler and Megan O'Donnell  |
| Sweet 16 Guys and Girls Night Out  | Illinois      | Jeannie Balsam                     |
| Take Steps to Stop SADS            | United States | SADS Families                      |



Pam Husband receiving Volunteer of the Year Award from Dr. Michael Ackerman



Brittany's Aunt Jan putting lights on a Brittany's Tree