# ANNUAL REPORT 2015



The Brain Aneurysm Foundation is neurologists from around the world working at many of the world's most prestigious medical facilities. These doctors provide continued expertise for the time contributed and the of our Medical Advisory Board partnering with the foundation to and research locally, nationally and

The Brain Aneurysm Foundation is Members who give very generously perspective providing inspired

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# A Word from:



# The Executive Director

2015 was a busy year for the foundation!

With the support of many we were able to accomplish so much. We continued growing our support groups, provided many fabulous webinars from top notch medical experts, had another successful lobby day on Capitol Hill, provided the largest amount of research funding to date, and started the work on three great awareness initiatives.

The awareness initiatives are critical in our efforts together to eliminate brain aneurysm ruptures and promote early detection to save lives. Emmy Award winning producer Mitchell Stuart of HQ Creative in New York created a dramatic PSA and an aspirational video documentary on the short life of Ellie Helton. An early detection video was created by Cramer productions to highlight for many in the medical community the signs and symptoms of brain aneurysms, the importance of knowing when to perform a scan, and what happens if a diagnosis is missed. Each video is powerful, uniquely communicating necessary information in their own way. I call on all of you to please share each video any way you can, with as many people as you can.

The Brain Aneurysm Foundation relies on all of you to help us do all we can in the fight against brain aneurysms. So please join us to continue raising awareness with the ultimate goal of saving lives!

Thank you all again, for supporting the mission of the Brain Aneurysm Foundation. YOU are with us every step of the way as we continue to Raise Awareness and End Fear.

I look forward to **OUR** achievements in 2016.

Best wishes - Christine Buckley, Executive Director



# The Medical Advisory Board Executive Director

On behalf of the Medical Advisory Board, I congratulate all who have contributed to the success of the foundation in 2015. Your generosity given in so many ways allowed the foundation to award \$265,000 to 13 different research projects this year! This is a tremendous accomplishment and brings the total funds awarded by the BAF over the past nine years to approximately \$1,300,000. These funds are critical to improve identification and treatments of unruptured aneurysms and outcomes for all those affected by brain aneurysms, as well as aneurysmal subarachnoid hemorrhage and its associated complications, such as vasospasm and stroke.

I look forward to 2016 being an even better year and that through our research, lives will be saved.

Thank you all for your support of the Brain Aneurysm Foundation!

Christopher S. Ogilvy, MD, Founder, Brain Aneurysm Foundation

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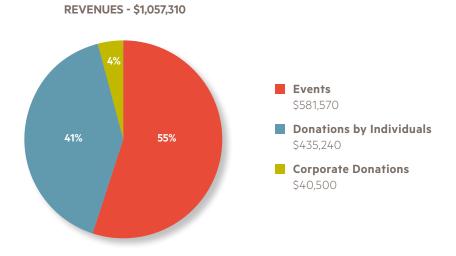
Frank Eeckman, MD, PhD

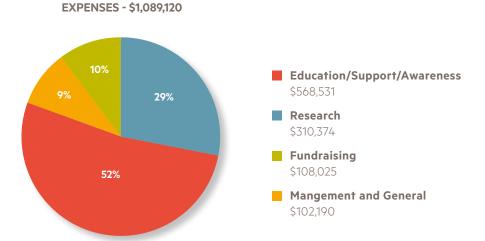
Jov Fischer

John Rogers

Joe Roonev

# 2015 FINANCIAL SUMMARY





Since 1994, when the Brain Aneurysm Foundation was established in Boston on August 19, 1994, as a public charity, our funding has been targeted to providing critical awareness, education, support and research funding to reduce the incidence of brain aneurysm ruptures.

The foundation has no endowment; every dollar we raise is deployed to advance research to reduce the incidence of brain aneurysm ruptures, to create wider awareness of brain aneurysms, to provide support for those affected by brain aneurysms, and to educate patients, their families, and the medical community about brain aneurysms. The Brain Aneurysm Foundation keeps a sharp eye on expenses and strives to maintain a low overhead.

\*Audited financial results for 2015 not currently available.

# 2015 RESEARCH GRANTS

# In 2015, the Brain Aneurysm Foundation awarded thirteen grants totaling \$265,000 supporting our commitment to invest in brain aneurvsm research.

The Brain Aneurysm Foundation awards research grants for basic scientific research directed at early detection, improved treatment modalities, and technological advances that will ultimately improve outcomes for patients with brain aneurysms. The foundation's Research Grant Committee is headed by Robert Rosenwasser, MD, FACS, Professor of Radiology and Neurosurgery at Thomas Jefferson University Hospital. He, along with other members of the Medical Advisory Board, scores all grant applications to determine the grant recipients based on the highest scores.

William Gibson, MD, The University of British Columbia, Child & Family Research Institute Cynthia Lynn Sherwin Chair of Research: \$25,000

Awarded for: Exome Sequencing Study of Dominant Mutations in Familial Brain Aneurysms

#### Itender Singh, MD, Washington University in St. Louis

North Shore University Hospital Brain Aneurysm Center Chair of Research: \$25,000 Awarded for: The Role of Cyclophilin A in Blood-rain Barrier, Neurionflammation and Vasospasm after Subarachnoid Hemorrhage

Justin M. Caplan, MD, Johns Hopkins University School of Medicine

Step for Hope Chair of Research: \$25,000

Awarded for: The Role of Neural Stem Cells in Learning and Memory in Experimental Subarachnoid Hemorrhage

#### **Ashish Sonig, MD,** University at Buffalo

The Shirley Dudek Demmer Chair of Research: \$25,000

Awarded for: MicroRNA in Unruptured Intracranial Aneurysms: Fostering a Mechanism of Early Detection

#### Koji Hosaka, PhD, University of Florida

Kristen's Legacy of Love Chair of Research: \$20,000

Awarded for: Mechanism of Aneurysm Progression and Healing: Differential Roles of Macrophages in Distinct Phases of Inflammation

#### Kimberly P. Kicielinski, MD, University of Alabama at Birmingham

The Maine's KAT Walk & Karo-5K Chair of Research: \$25,000

Awarded for: Correlation of Cerebral Aneurysm Wall Structure on OCT Images with Flow Models of Wall Shear Stress: A Pilot Study

Aichi Chien, PhD, The Regents of the University of California, Los Angeles

Timothy P. Susco Chair of Research: \$25,000

Award for: Longitudinal Analysis of Aneurysm 3D Morphology Changes and their Influence on Rupture Risk in Clinically followed Growing Aneurysms



#### Douglas J. Cook, MD, Queens University

The Ellie Helton Chair of Research: \$15,000

Awarded for: Probing the Link between Indolent Aneurysmal Dome Infection and Brain Aneurysm Growth and Rupture

#### Hui Meng, PhD, The State University of New York at Buffalo

The Carol W. Harvey Memorial Chair of Research: \$25,000

TeamCindy - Alcatraz Chair of Research: \$10,000

Awarded for: Development of Blood-Based Biomarkers for Brain Aneurysm Detection:

Stage II Model Development

#### Christoph J. Griessenauer, MD, Beth Israel Deaconess Medical Center

The Doris A. Connor Memorial Chair of Research: \$15,000

Awarded for: The Role of Anti-Angiogenic Factors Soluble Fms-Like Tyrosine Kinase-1 (sFlt-1) and Soluble Transforming Growth Factor B (TGFB) Co-Receptor Endoglin (sEng) in the

Pathophysiology of Delayed Cerebral Ischemia

#### Jung M. Park, MD PhD student, University of Iowa

Karen M. Schurr Memorial Chair of Research: \$10,000

Awarded for: The Role of Inflammation and Myeloperoxidase in Cerebral Aneurysm

Formation and Rupture

#### Mohammad Amin Adibi, University of Calgary

Christopher C. Getch Chair of Research (sponsored by the CV Section): \$10,000 Awarded for: Intravenous Mesenchymal Stem Cell Therapy on Aneurysm Formation in a Rabbit Model

Shakira Brathwaite. St. Michael's Hospital

Dawn Brejcha Chair of Research: \$10,000

Awarded for: Role of Toll-like Receptor 4 Signaling in Experimental Subarachnoid Hemorrhage

# **Back on Capitol Hill -Lobbying for Brain Aneurysm Awareness**

On May 13, 2015, the Brain Aneurysm Foundation returned to Capitol Hill. We had 40 people, representing 15 states, including: Rhode Island, Illinois, Indiana, Iowa, Kansas, Maryland, Massachusetts, New York, North Carolina, Ohio, Pennsylvania, Texas, Virginia, Washington and Wisconsin.

Over 100 meetings were held with Members of Congress to garner support for resolutions in both the House and Senate aimed to designate September as National Brain Aneurysm Awareness Month. The response and support we received during these meetings was overwhelmingly positive. In the meetings we also expressed the importance for Congress to ensure that insurance companies are required to pay for patient screenings as deemed appropriate by medical personnel and provide more coverage for rehabilitative care. We were able to continue to develop significant relationships with key members of Congress who have become champions for our cause. In particular, Congresswomen Renee Ellmers (R-NC) and Yvette Clarke (D-NY) supported the Brain Aneurysm Foundation's efforts this year to increase awareness of brain aneurysms and make the case for additional federal funding for brain aneurysm research.



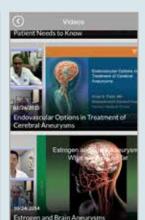
# **Check Out Our Free App**

The Brain Aneurysm Foundation has announced the release of its new mobile application "Brain Aneurysm" for use on Apple and Android devices. The free app, now available for download on iTunes and Google Play, is designed to provide the general public with useful information about brain aneurysms, whenever and wherever they may need it.

The Brain Aneurysm App was created in conjunction with The Neurosurgical Atlas and Dr. Aaron Cohen-Gadol, a leading neurosurgeon from Goodman Campbell Brain and Spine and Indiana University Department of Neurosurgery. This new application is an innovative way to increase awareness and educate individuals about brain aneurysms. The app features educational videos about aneurysms, treatment and recovery and patient advocacy. The app also provides access to a variety of blogs about brain aneurysms, discussion groups, upcoming events and fundraisers and much more.







# Virtual Library of the **Brain Aneurysm Foundation Webinars**

The Brain Aneurysm Foundation live webinars have used the power of the Internet to create a webinar forum where patients can reach experts to discuss important details of their care, and most importantly, have the ability to ask questions while they are at home, at no cost. The BAF webinars have been very successful in reaching the above mentioned goals to satisfy the mission of the Brain Aneurysm Foundation. Dr. Aaron Cohen-Gadol, an aneurysm surgeon and a member of the BAF Medical Advisory Board, has been moderating these webinars. We continue to receive very positive feedback from our members who attend these webinars from all over the world. These webinars are archived and are available for viewing shortly after the presentation of the live webinar on the BAF website.



The Brain Aneurysm Foundation would like to acknowledge and thank the following doctors who delivered webinars in 2015:

**Vitaliy Rayz and Michael Lawton** — Presented patient Specific Computational Models for Predicting Post-Surgical Blood Flow in Brain Aneurysms

**Ali Aziz-Sultan** — Presented Advances in Cerebral Aneurysm Repair

**Ali Alaraj** — Presented Critical Care Management of Acute Subarachnoid Hemorrhage

# **Educational Booklets Available in Three Languages**

Over 25,000 educational pamphlets for brain aneurysm treatment options and recovery were distributed across the country and internationally, to medical facilities treating brain aneurysms, as well as our 64 support groups. The booklets are available in English, Spanish and Chinese. The Chinese translation was provided by: Qiyong Mei, MD of Shanghai and proofing by Rose Du, MD, PhD. The Brain Aneurysm Foundation would like to thank Mizuho for providing the funding for the production of our rebranded and updated patient educational booklets.



# 2015 SUPPORT SERVICES

The Brain Aneurysm Foundation eases the diagnosis, procedural and recovery process for survivors and families by providing phone support, email support, support groups, our main website, and our support website.





Support groups offer brain aneurysm survivors and their families the opportunity to share life experiences, work through challenges and find new ways to adapt to changes in their life. The goal of support group meetings is to help alleviate fears and concerns through education and group discussions facilitated by a medical professional. Survivors realize that they are not alone. Survivors and caregivers share their experiences and show support to those that are in need. There are now 64 support groups located in the following states: MA, NH, ME, NY, NJ, PA, DE, MD, VA, IN, WI, IL, MN, MI, OH, MO, KS, TN, GA, FL, NC, CT AL, CO, TX, AZ, CA, WA, OR and Canada.

#### Northeast

- Beth Israel Deaconess Support Group, Boston, MA
- Massachusetts General Hospital, Boston, MA
- Brigham and Women's Hospital, Boston, MA
- Plymouth Massachusetts Group, MA
- The South Shore Support Group, Norwell. MA
- Cape Cod Brain Aneurysm Injury Support Group, Sandwich, MA
- Dartmouth Hitchcock Brain Aneurysm Support Group, Lebanon. NH

- Maine Medical Center Brain Aneurysm Support Group, Portland, ME
- Yale New Haven Hospital, CT
- Long Island Support Group, Manhasset, NY
- New York Methodist Hospital Brain Aneurysm Awareness Group, Brooklyn, NY
- New York City Support Group, NY
- Eastern Long Island Brain Aneurysm Support Group, Stony Brook, NY
- Brain Aneurysm Support Group Western New York, NY

- Aneurysm/AVM Support Group at Capital Health Medical Center, Pennington, NJ
- Aneurysm/AVM Support Group at Virtua Voorhees Hospital, Voorhees, NJ
- New Jersey Brain Aneurysm and AVM Support Group, New Brunswick, NJ
- Philadelphia Support Group, PA
- Western Pennsylvania Chapter of the Brain Aneurysm and AVM Support Group, Pittsburgh, PA
- Hospital of the University of Pennsylvania, PA

#### Midwest

- Goodman Campbell Brain and Spine Aneurysm Support Group, Indianapolis, IN
- Madison Area Cerebral Aneurysm Support Group, WI
- University of Illinois Hospital & Health Sciences System Dept of Neurosurgery Support Group, IL
- Chicago Northwest Suburban Brain Aneurysm Support Group, IL
- The Neurosciences Institute at Central DuPage Hospital Brain Aneurysm Support Group, Winfield, IL
- Loyola University Medical Center Brain Aneurysm Support Group Maywood, IL
- St. Joseph's Hospital Support Group, St. Paul, MN
- The University of Michigan Brain Aneurysm and AVM Support Group, Ann Arbor, MI
- Tri-State Brain Aneurysm Support Group Cincinnati OH
- Brain Aneurysm Support Group, St. Louis. MO
- Post Brain Surgery Support Group, Springfield, MO
- Brain Aneurysm Support Group, Kansas City, KS
- Ohio Brain Aneurysm and Awareness Support Group, Columbus, OH
- Spine and Brain Imaging Center Support Group, Franklin, WI
- Mayo Clinic Support Group, MN

#### **Southeast**

- Skyline Medical Center Support Group, Nashville, TN
- Vanderbilt University Support Group Nashville. TN
- Atlanta Support Group, GA
- University of Miami Brain Aneurysm Support Group, FL
- Naples-Fort Myers Brain Aneurysm Support Group, FL
- Orlando Brain Aneurysm Support Group, FL
- Deerfield Beach Support Group, FL
- Florida Brain Aneurysm Support Group, Gainesville. FL
- Lee Memorial Health System Support Group, Fort Meyers, FL
- Mayo Clinic Support Group, Jacksonville, FL
- Brain Aneurysm Support Group, Birmingham, AL
- Duke Raleigh Hospital Brain Aneurysm Support Group, NC
- Novant Health Neurology, Charlotte, NC

#### Midatlantic

- Delaware Brain Aneurysm Support Group, Newark, DE
- Baltimore Brain Aneurysm Foundation Support Group, MD
- Falls Church Brain Aneurysm Support Group, VA

#### **West Coast**

- Bay Area Aneurysm and Vascular Malformation Support Group, San Francisco, CA
- Sacramento Support Group, CA
- UW Medicine Brain Aneurysm Survivor Support Group, Seattle, WA
- Swedish Cerebrovascular Support Group, Seattle, WA
- Oregon Brain Aneurysm Support Group, Portland, OR
- Brain Aneurysm/AVM Support Group, Newport Beach, CA
- Los Angeles Brain Aneurysm Foundation Support Group Support, CA

#### Southwest

- Littleton Colorado Brain Aneurysm Foundation Support Group, CO
- Brain Aneurysm Support Group at Memorial Hermann-Texas Medical Center, Houston, TX
- San Antonio Support Group, TX

#### Canada

- Nova Scotia Support Group, Halifax, ON
- Brain Aneurysm Support Group, Calgary, AB



# 2015 SPECIAL EVENTS

The Brain Aneurysm Foundation would like to recognize and thank all those who organized, volunteered, or participated at one of the over fifty events held across the country in 2015 to benefit brain aneurysm awareness, support, education and research.



#### \$50,000 or greater

- The 7th Annual Long Island Jones Beach Walk, Wantagh, NY
- TeamCindy

#### \$40,000-\$49,999

- 14th Annual Arterial Challenge at Fenway Park, Boston, MA
- The Ellie Helton Memorial 5K and Fun Run, Cary, NC
- 3rd Annual Sharp Race Towards Brain Aneurysm Awareness, Omaha, NE
- Quarry Fundraising Campaign in Memory of Mary Ryan, Naples, FL

#### \$30,000-\$39,999

- Brain Bolt for Brain Aneurysm Awareness, Indianapolis, IN
- Philadelphia Aneurysm and AVM Awareness Event, Philadelphia, PA

#### \$20.000-\$29.999

- Awareness 5K in Memory of Beth Behr, New Rochelle, NY
- 5th Annual Step for Hope 5K Run/Walk, Carol Stream, IL
- 2nd Annual Kristen's Legacy of Love, Seaside Park, NJ
- 2nd Annual Pittsburg Brain Aneurysm Run/Walk, Pittsburgh, PA

- 4th Annual Doris A. Connor Memorial
   Race/Walk and Kids Fun Run Brewerton NY
- 8th Annual Brain Aneurysm Race for Awareness - Susco 5K, Reston, VA

#### \$10,000-\$19,999

- 2nd Annual Teeing off for Terry Golf Tournament, Wentzville, MO
- 5th Annual Bunny Hop 5K, St. Mary's, PA
- Fight Like Frank, Philadelphia, PA
- 3rd Annual BAAR: Brain Aneurysm Awareness Run, Wayne, PA
- 6th Annual Survivor in the City, Chicago, IL

- 6th Annual Brejcha Memorial Softball Tournament, Escondido, CA
- 4th Annual Debbie Feiger Memorial Softball Event, Wilmette, IL

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

- 2nd Annual Danielle Lebron-Guzman Golf Outing, Kenilworth, NJ
- 3rd Annual Brooklyn Walk for Brain Aneurysm Awareness, Brooklyn, NY
- 3rd Annual Awareness to Gain ~ Walk for Your Brain, Waukesha, WI
- 5th Annual Delaware Brain Aneurysm 5K and Wilson Walk, Newark, DE



- BAF Night at the Boston Pops Symphony Hall, Boston, MA
- Juniper Hills Gala, Pocatello, ID
- 4th Annual Ragnar Relay, Chicago, IL
- 6th Annual Denny's Drive for Early Detection, Front Royal, VA
- 3rd Annual Appreciation for Life 5K Walk/Run, Braham, MN
- Melody Hill Golf Tournament, Harmony, RI
- 5th Annual Awareness in September Happy Hour, Greenville, DE
- A Walk to Remember Mona Ann Boesen, Minneapolis, MN
- 4th Annual Laughter is the Best Medicine, Saugus, MA

#### \$1,000-\$4,999

- 3rd Annual Race for Awareness 5K with Mary, Thibodaux, LA
- Fred Taylor Golf Tournament, Columbus, OH
- 2nd Annual Fundraiser in Remembrance of Chris Bibeau, Manchester, NH
- Griffin Brain Aneurysm Movement 5K Run/Walk. New Orleans. LA
- Brain Aneurysm Awareness 5K, Des Moines, IA
- 1st Anniversary Awareness Walk in Honor of Rhonda Martin, Westwood, NJ
- 2nd Annual Walk in Memory of Olivia McGinness, Phoenix, AZ

- CIS Brain Aneurysm Walk, Hillsborough, NC
- Where There's a Jill There's a Way 5/10K, Attica, NY
- 4th Annual Berdine Wilson Walk. Shepherd, TX
- 3rd Annual Walk in Memory of Lissa Anne Been, Arnold, MO
- Bowling for Brains in Memory of Brad Baddeley, Lincoln, NE
- Julie Messick LuvYerGuts Tournament, Springfield, MO
- Dye, Newsome, Rogers Golf, Canton, OH
- Thales Academy Family Bingo Night, Apex, NC

- 1st Annual Ricardo M. Espiritu Bowling Tournament, Dallas, TX
- 1st Annual Golf Outing Benefit for Audrey Doperalski, Green Bay, WI
- 7th Annual Betty Koch Epperson Walk, Winston-Salem, NC
- 3rd Annual Linda McClam Curtis 5K, Washington, DC
- 2015 Lenny Diederich Yoga Memorial Fundraiser, Cleveland, OH
- Jean's Day Events

# 2015 TOP FUNDRAISERS



The Brain Aneurysm Foundation is very grateful to our wonderful fundraisers of 2015! Their fundraising efforts greatly contribute to the success of the events as well as the mission of the Brain Aneurysm Foundation.

#### Superstars, \$10,000-greater

Lawrence Rosenthal Jolie Schwell-Lehmann Fundraising

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

Tyler Beardsley Kendyl Coretti Amber Rivera

#### Sensational Stars, \$2,500-4,999

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#### Amazing Stars, \$1.000-\$2,499

Mary Ann's Aneurysm Attackers Three Little Birds Team Brosnan Mali Chad Tristin Clark

Ray Fortune Momma Ro's Garden Alanna Gino Eugene Greenberg Neile Hartman Bob Hovt Jessica Kasten Valerie King Robbie Lazarus Dana Lazich Pierre Le Leannec Simon Lonabottom Anie-Maniacs Cheryl McDonald Yolv I. McGuire Julia Murphy Nefco Incorporated Sharon Nelson Greg Payan Nelson Resto Fundraiser Kiira Rodriguez Brian Shea Lauren Sherwin Kristen Short Anita Stevens Team Fred Battline Team Billy

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Team Liz - Red Roses

#### Stellar Stars, \$100-\$499

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Elizabeth Bass

Jennifer Battline Donna Bauer Diane Axler Baum Michelle's Belles Mandy Bennett Kim Beringer Michelle Boruchow Holly Giffrow Bos Mary Bowser Ashley Boyd BrainSTRONG Scott Brannon Don Brester Robin Brester Meredith Brosnan Ed Buchanan Deidre Bucklev Danielle Buda Christine Burgess Wilma Busse Virginia Wilson-Butler Becky's Butterflies Seth Butvnski Mary Cacciatore Anna Caldwell Chervl Campbell Scott Campbell Stacy Campbell Jeanna Carlson Arthur Cassano Alyssa Celona Harrison Chad Cynthia Chen John Cingolani Kate Cingolani Susan Clancy Lopez Claribel Danny Clarke John and Josephine Clarke Mary T. Clarke Krvstal Clouden THIS IS MY COILING!

Dawn Colon

Lisa Connolly

Jennifer Cook

Caron Cox Titanium Cranium Devin's Camo Crew Jaymie Cybak John D'Agostino Valerie D'Agostino Karen Daly Lauren Dalv Heather DeFlumeri Patricia DeFlumeri Jocelyn Delaney Still Stepping Denise Minions for Ellie Sarah Emblev Emma Lauren English 3 F's Heidi Eshbach Andrea Fee Jackie Fee Wendy Feilen Sarah Fellman Lisa Fisher Kerri Fortune Fight Like Frank Chris and Friends Family of Friends SueEllen's Family and Friends Marie Friguegnon Beth Fulk Katie Fusco

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Sandy Markiewicz

Knitted by MaryAnn

Vicky McLain

Jacqueline McMenamin Shannon McStravock Linda Messer Alyssa Migliore

Thales Academy 3rd Grade

Minions Walking Miracles Michelle Mitchell Heather Moore Esther Morris Theresa Mulcahy Ian Mvers Robert Myhre

Charles Myrick Draining Brains & Taking Names

Nora Neely Susan Pollak Nelson Kristv Nilson

The Nilsons Sharon Norwood Carlin Olson Daniel O'Neal Shari Opfermann Araceli Ornelas Alvce Osborne Patricia Ott Brice Owens Karen Owens Meagan Padgitt Susan Parker Pathfinder Shelly Plummer Katrina Powell Ralph Powell Pink Power Judy Price

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Mark Schuette Steve Schurr Temple-Area-ly Screwed

Jim Scully Cecelia Shafer Kathy Shafer Paul Shafer Jan Shea Brian Shields **Amy Simmons** Candice Singer Michelle Singewald Carin Sink Janie Smith

Marjorie Smith Matthew Twomey-Smith Barbara Sparcie

Giant Sparks Lynn Spooner Kristen Stafford Lucky Stars Joseph Stewart Mike's Brain Storm Maggie-Ann Story Michelle Stremmel Brian Strong

Sherwood Strong

Kim Strother

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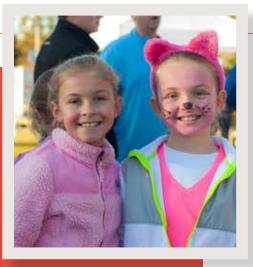
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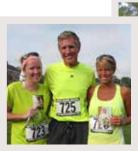
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To promote early detection of brain aneurysms by providing knowledge and raising awareness of the signs, symptoms and risk factors. Work with the medical communities to provide support networks for patients and families, as well as to further research that will improve patient outcomes and save lives.