



**BRAIN ANEURYSM
FOUNDATION**

Thinking Ahead

Fall/Winter 2017
Newsletter



On September 25, 2017 the Zakim Bridge in Boston, along with a number of other state landmarks, was illuminated in red in recognition of Brain Aneurysm Awareness Month (see pages 10-11).



NEWS
PAGE 4



ADVOCACY
PAGE 8



RESEARCH
PAGE 12



COMMUNITY EVENTS
PAGE 16



SUPPORT
PAGE 20

OUR BOARDS, STAFF, & EXECUTIVE COMMITTEE

We would like to give a special thanks to our Medical Advisory Board, which is composed of neurologists, neurosurgeons, interventional neurologists, and other specialists from around the world working at many of the world's most prestigious medical facilities. These specialists provide continued expertise and support to the foundation in a variety of ways and we are grateful for their time and dedication.

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It Is Never Too Early

CHRISTINE BUCKLEY,
EXECUTIVE DIRECTOR



Awareness month, September 2017, was very fruitful across the country and Canada, but it was particularly exciting in Boston. On September 25, 2017 in Boston, voices roared and lights brightly shone red for brain aneurysm awareness. I ask you to work with the BAF to replicate what happened on one single day in Boston in your state next year.

Survivors, caregivers, medical professional, families, legislators, and friends from across the state and neighboring states gathered in our State House with Governor Charlie Baker and Lt. Governor Karyn Polito to rally for the #1in50 people affected by brain aneurysms. It was not the proclamation from the governor making September Brain Aneurysm Awareness Month in Massachusetts that made this day so special. Rather it was the public recognition and coming together of so many, particularly those in positions to help us raise the level of awareness. People were talking about brain aneurysms, hearing recovery journeys from survivors, and learning the facts. People were listening! And news crews were recording.

Later that evening, we were fortunate to have a presentation of the governor's proclamation on the field of Fenway Park prior to a game. Many stayed to enjoy the game, but some of us went on a city tour to see the many structures in Boston lit red for brain aneurysm awareness. We are thankful to MassDOT for working with the foundation to make this possible. We traveled from Government Center, to South Station, to the Zakim Bridge to meet our new spokesperson, Kevan Miller of the Boston Bruins. From 9 AM to 9 PM on September 25, Boston was all about brain aneurysm awareness, and it was beautiful in every way. The beauty of the structures glowing red was amazing, but it was the glow from the hearts of those who made each step of this day possible that was the most gratifying.

Once I was home and able to reflect on this glorious day, I realized it was not enough, and it needs to be replicated in at least three to five other states next year. We created a model and it must be shared. I want other governors to speak in their state houses about the need for brain aneurysm awareness, education, and research funding. I want legislators from other states to realize who among them has been touched by this life-altering disease. I want the Empire State Building, the Willis (Sears) Tower, the Golden Gate Bridge, and the St. Louis Gateway Arch to be lit red in September 2018 for brain aneurysm awareness! Public recognition and greater awareness will save lives. It has been proven many times.

So please, let's work together **now** to raise the bar in other states in 2018. Reach out. You will be surprised who knows who, and what can happen. **Now** is the time to start making September 2018 **red** in your state. The Brain Aneurysm Foundation is here to help you.

Many thanks for your continued support of the foundation's mission of awareness, support, education, advocacy, and research funding. September 2018 here we come!

Warm regards,

Christine

New Board Member: Jeffrey B. Harvey



JEFFREY B. HARVEY

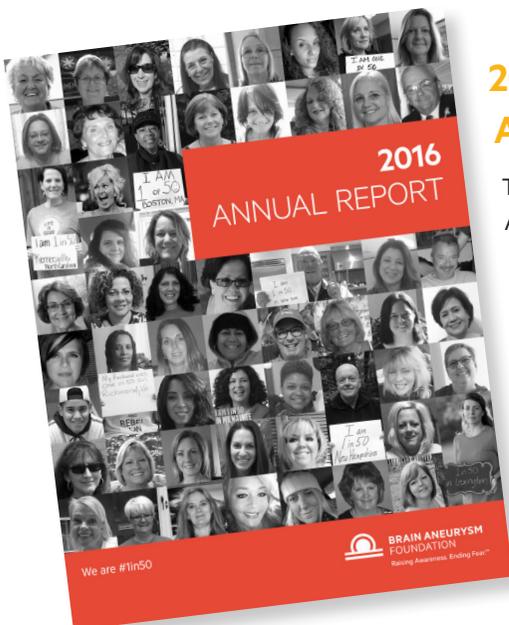
We are pleased to welcome Jeffrey B. Harvey of Buffalo, New York to the Brain Aneurysm Foundation Board of Directors.

Mr. Harvey is the CFO of Tonus Therapeutics, a biotech company in Williamsville, New York whose goal is the development of drugs that are active for diseases that involve biomechanics. The primary target is muscular dystrophy, the most common fatal genetic disease among boys.

Tonus Therapeutics is based on the work of Frederick Sachs, PhD, and his collaborators at the State University of New York (SUNY) at Buffalo, Thomas Suchyna, PhD, and Philip Gottlieb, PhD. The company was founded in 2009 by Mr. Harvey and Drs. Sachs, Suchyna, and

Gottlieb. Mr. Harvey also helped start Neurovascular Diagnostics, a small company that is working on a blood test to detect brain aneurysms.

Mr. Harvey's wife, Carol, died 15 years ago of complications following treatment for a brain aneurysm. In the years since her death, Mr. Harvey helped establish Buffalo's first brain aneurysm support group with guidance from the Brain Aneurysm Foundation.



2016 Annual Report Available Online

The Brain Aneurysm Foundation's 2016 Annual Report (and previous years' annual reports) is available on our website. Among other information, the report contains highlights of the year, a financial summary, and a listing of donors. The 2016 Annual Report cover features survivors and family members from around the nation who participated in our successful #1in50 campaign.

Two New Medical Advisory Board Members: Stanley Berman, PhD, and Edward R. Smith, MD

We are pleased to announce that Stanley Berman, PhD, and Edward R. Smith, MD, have joined the Medical Advisory Board.



STANLEY BERMAN, PhD

A clinical psychologist, Dr. Berman is Vice President for Academic Affairs and an Associate Professor at William James College in Newton, MA. Dr. Berman was previously a staff psychologist at Boston Children's Hospital, as well as the Director of Training in Psychology at the Jimmy Fund Clinic of the Dana-Farber Cancer Institute in Boston. Dr. Berman has also served as a Visiting Associate Professor at Wellesley College, in Wellesley, MA. Dr. Berman's specialties are health psychology, child and adolescent psychology, and global mental health.

Dr. Berman is a survivor of a brain aneurysm, which assists him in his work as a health psychologist.



EDWARD R. SMITH, MD

Dr. Smith brings a deep expertise in pediatric aneurysms to the board and the foundation. Dr. Smith is the R. Michael Scott Chair in Pediatric Neurosurgery and Director of Pediatric Cerebrovascular Neurosurgery at Boston Children's Hospital, and an Associate Professor at Harvard Medical School. At Boston Children's, Dr. Smith is also Co-Director of the Cerebrovascular Surgery and Interventions Center. Dr. Smith is a Fellow of the American Association of Neurologic Surgeons and a member of the Congress of Neurological Surgeons.

A graduate of Dartmouth College, Dr. Smith received his medical degree from Columbia University College of Physicians and Surgeons, and a degree in Clinical Effectiveness from the Harvard School of Public Health. He did his neurosurgery residency and a research fellowship at

Massachusetts General Hospital, and completed his pediatric neurosurgery fellowship and a clinical research fellowship at Children's Hospital Boston.

Dr. Smith's clinical focus is pediatric cerebrovascular disease (including brain aneurysms) and brain tumors. His research focuses on the mechanisms of vascular regulation shared by both brain tumors and cerebrovascular disease, and he is interested in the development of tests to better screen for the presence, recurrence, and progression of these diseases using non-invasive biomarkers. In June, Dr. Smith gave an informative webinar on pediatric aneurysms for lay viewers, which can be accessed from the webinar archives on our website.

The Brain Aneurysm Foundation's Medical Advisory Board of Directors plays a vital role in the foundation's mission. Members, who include preeminent neurosurgeons, neurologists, interventional neurologists, and other brain aneurysm specialists from the world's leading medical centers, provide continuing expertise and support to the foundation.



L to R: Christopher S. Oglivly, MD, with Karen Holmes Ward and Champion Award recipient Bob Halloran of WCVB-TV.



L to R: Christopher S. Oglivly, MD, and Christine Buckley with Champion Award recipient Keith Lockhart of the Boston Pops.

Awards Honor Champions

The Brain Aneurysm Foundation held its first annual Champion Awards reception in March at the University of Massachusetts Club in Boston. The awards honor individuals who have made significant contributions to raising awareness of brain aneurysms.

The recipients honored at the event were WCVB-TV anchor and brain aneurysm survivor Bob Halloran; WCVB-TV president and general manager Bill Fine; and Beth Israel Deaconess Medical Center neurosurgeon and BAF Founder, Christopher S. Oglivly, MD. Among the many guests who attended the reception were Karen Holmes Ward of WCVB-TV; Jim Rooney, the Greater Boston Chamber of Commerce president; and Peter Healy, president of Beth Israel Deaconess Medical Center.

Keith Lockhart, conductor of the Boston Pops Orchestra, was also a recipient of a 2017 Champion Award. As he was unable to attend the March event, Mr. Lockhart was presented with his award at a reception at the Brain Aneurysm Foundation's Annual Night at the Pops in June. Mr. Lockhart's sister-in-law died from a brain aneurysm, and he has helped raise awareness in many ways, including being featured in a Brain Aneurysm Foundation video on our website.

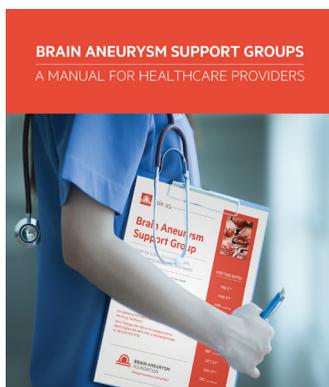
U.S. Senator Edward J. Markey of Massachusetts sent a heartfelt letter acknowledging the important work of the Brain Aneurysm Foundation and the honorees. "I am sincerely grateful for [the honorees'] efforts to raise awareness of brain aneurysm disease," wrote Senator Markey. The foundation is grateful, in turn, for Senator Markey's continued support and advocacy of brain aneurysm awareness and research funding.

Updated Detection and Treatment Booklet



Discovering that you have a brain aneurysm is a frightening and sometimes isolating experience. Our newly updated "Detection and Treatment" booklet provides you and your loved ones with accurate, timely information about brain aneurysm detection and treatment. Our goal is to help reduce the anxiety and isolation you may be feeling so that you can focus on your treatment and recovery. You can read or download the booklet from our website. To request a print copy of the booklet, please contact us at office@bafound.org or give us a call at 1-781-826-5556 or (toll-free) 1-888-272-4602.

New Support Groups Manual



The Brain Aneurysm Foundation has more than 60 support groups throughout the United States and Canada. These groups provide vital support, information, and resources to survivors, caregivers, and other loved ones.

If you are a healthcare provider and are interested in starting a Brain Aneurysm Foundation support group at your facility, you can read or download our new “Brain Aneurysm Support Groups: A Manual for Healthcare Providers” from our website. The updated guide provides all the information you need to establish a support group, including lists of suggested topics and tips for spreading the word.

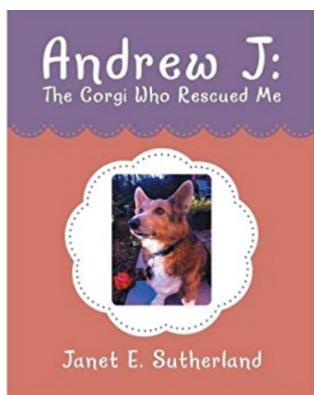
To request a print copy of the manual, please contact us at office@bafound.org or give us a call at 1-781-826-5556 or (toll-free) 1-888-272-4602.

Foundation at Congress of Neurological Surgeons Meeting

As it does every year, the Brain Aneurysm Foundation had an active presence at the 2017 Congress of Neurological Surgeons (CNS) meeting, held this year in Boston in early October. In addition to offering information about the foundation and its research grant opportunities in the event’s exhibit hall, the foundation hosted a reception for attendees, who travel from around the world for this educational meeting. This year, the Scientific Program Chair of the CNS meeting was Brain Aneurysm Foundation Medical Advisory Board member Brian Hoh, MD, chief of the Division of Cerebrovascular Surgery at the University of Florida.



Survivor’s Book Funds New Chair of Research



Brain aneurysm survivor and founding director of the Chicago Chapter of the Brain Aneurysm Foundation Janet Sutherland is also a successful children’s book author who wrote “Andrew J. — the Corgi Who Rescued Me,” about her rescue dog, a lovable Corgi named Andrew J. In an interview on WTMX radio, Janet talked about her aneurysm rupture in 2004 and how Andrew J., who had sadly been abused before she adopted him from a shelter, helped her with her recovery. Part of the proceeds from the sale of Janet’s book funded the Robert Sutherland Chair of Research, named in honor of Janet’s uncle. We thank Janet for her years of work on behalf of the Brain Aneurysm Foundation and wish her success with her book.



U.S. Senator Elizabeth Warren with brain aneurysm advocates on Capitol Hill.

Advocacy Matters

On the Hill: 6th Annual Advocacy Day A Success

On March 29, 2017, the Brain Aneurysm Foundation led a delegation of 123 people from 38 states to meet with legislators on Capitol Hill for its 6th annual Congressional Advocacy Day on Capitol Hill.

This was the largest turnout to date, demonstrating the growing commitment among those impacted by brain aneurysms for advocating for policies aimed at improving and saving lives. The delegation included brain aneurysm survivors and caregivers, family members who lost loved ones to brain aneurysms, healthcare professionals, foundation board members, and BAF corporate partners. The Bee Foundation, a non-profit brain aneurysm organization based in Wayne, PA, also participated in Advocacy Day 2017.

Ellie's Law

The busy day, during which delegation members met with 200 legislators, helped raise awareness of brain aneurysms and encourage support of Ellie's Law (H. Res. 1648). Introduced on March 21, 2017 by U.S. Representatives Yvette Clarke (D-NY) and Patrick Meehan (R-PA), this bill would provide \$25 million (\$5 million per year over five years) in federal funding for brain aneurysm research. Senator Richard Blumenthal (D-CT), is committed to introducing a companion bill in the Senate.

The bill honors a teenaged girl and three women who passed away as a result of a brain aneurysm: Ellie Helton, Lisa Colagrossi, Teresa Anne Lawrence, and Jennifer Sedney.

"Increased federal funding for brain aneurysm research through the passage of Ellie's Law is essential to finding new methods of preventing, detecting, and treating brain aneurysms and their consequences," said Christine Buckley, Executive Director of the Brain Aneurysm Foundation.



L to R: Karen Helton, Anna Helton, U.S. Representative David Price (NC), Grace Helton, and Todd Helton.



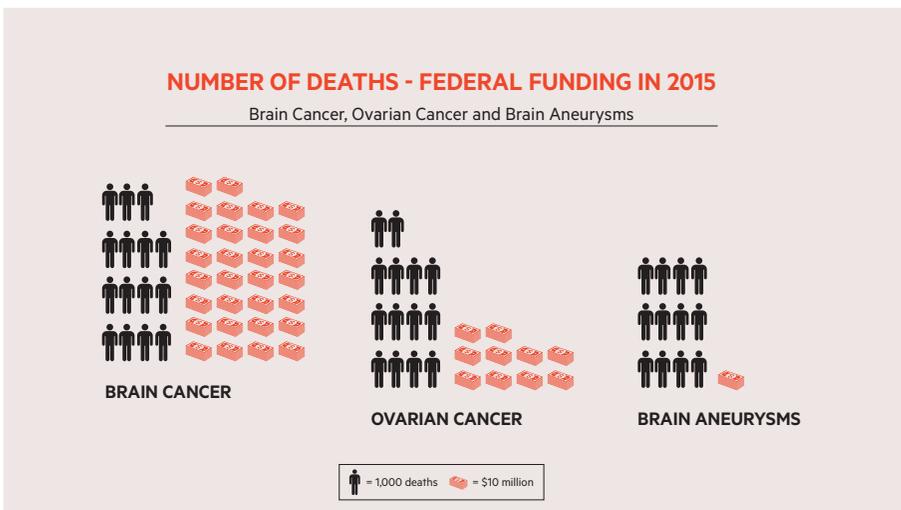
L to R: Joe O'Leary, survivor Michael O'Leary, U.S. Representative Michael Capuano (MA), Juliet O'Leary, and Christopher S. Ogilvy, MD

Funding disproportionately low

“Once legislators learn about the problem and the need, they are very supportive of increasing funding levels for brain aneurysm research, as well as supporting our awareness and education initiatives,” said Buckley. “We often hear from legislators we meet with that we’re the first group to bring this disease to their attention. Our visits to Capitol Hill each year are helping change that.”

Federal funding for brain aneurysm research is disproportionately low compared to other diseases with similar prevalence and death rates, such as brain cancer. The Brain Aneurysm Foundation is the largest private funder of brain aneurysm research in the nation.

The BAF thanks its pro bono government affairs counsel Arnold & Porter Kaye Scholer, LLP, for making Advocacy Day possible, as well as Medtronic, which provided educational materials. Next year’s Advocacy Day will take place in March 2018. Check our website later in the year for the date and details.



Sources:

National Institutes of Health “Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC),” FY2015
American Cancer Society, “Estimated Number of New Cancer Cases and Deaths by Sex, US, 2015”
National Institute of Neurological Disorders and Stroke (NINDS), “Cerebral Aneurysms Fact Sheet”



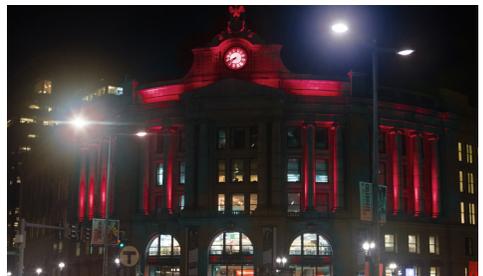
L to R: Christopher S. Ogilvy, MD, Bob Halloran, Tom Tinlin, Christine Buckley, Representative Paul J. Donato, and Governor Charlie Baker.

Brain Aneurysm Awareness Month Event at Massachusetts State House

The Grand Staircase of the Massachusetts State House in Boston was the setting for a Brain Aneurysm Awareness Month event on September 25. Speaking at the event were Governor Charlie Baker and Lieutenant Governor Karyn Polito; State Representative Paul J. Donato, also a BAF board member; Christopher S. Ogilvy, MD, a BAF co-founder and director of the Brain Aneurysm Institute at Beth Israel Deaconess Medical Center; and brain aneurysm survivors Thomas Tinlin, former Mass DOT Highway Administrator (see story on page 20), and Bob Halloran, a WCVB-TV anchor. Later in the evening, a number of state landmarks were illuminated in red in recognition of Brain Aneurysm Awareness Month (see photos).



Burns Bridge, Worcester



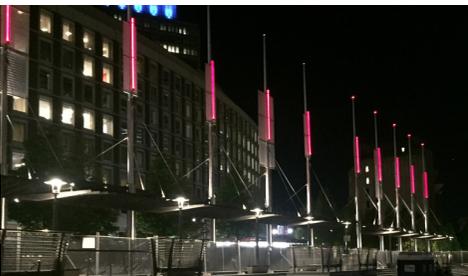
South Station, Boston



Zakim Bridge, Boston



Led by survivor Bob Halloran (holding microphone), a group of attendees at the State House event recorded a "Wake-Up Call" that was televised on WCVB-TV.



Government Center, Boston



City Hall, Boston



Keynote speaker L. Fernando Gonzalez, MD



Christopher S. Ogilvy, MD (seated, second from left) and L. Fernando Gonzalez, MD (standing, second from left), with some of the research grant recipients at the annual symposium in Durham, NC.

Research Grant Recipients Announced at Annual Symposium

The 11th annual Brain Aneurysm Foundation (BAF) Research Grant Symposium was held on September 28 at the Washington Duke Inn & Golf Club in Durham, North Carolina. The well-attended event included a new daytime program, a cocktail reception, and poster session of foundation-funded research, followed by a dinner program.

This year's guest speaker was Brain Aneurysm Foundation Medical Advisory Board member L. Fernando Gonzalez, MD, Co-Director of Cerebrovascular and Endovascular Neurosurgery and Associate Professor of Neurosurgery at Duke University.

A highlight of the evening was the announcement of this year's research grant recipients, who were selected by the foundation's Research Grant Committee, led by Medical Advisory Board President Robert Rosenwasser, MD, of Thomas Jefferson University Hospital in Philadelphia, PA.

Record amount awarded

This year, grants totaling \$445,000 — the largest amount ever awarded by the foundation and 43 percent more than last year — were awarded to 14 researchers whose work spans diverse areas of inquiry. Since its inception, the foundation has distributed more than \$2.1 million in research grants.

All current grant recipients attended the conference, in addition to last year's recipients, who provided updates of their research. Others in attendance included foundation Board and Medical Advisory Board members, survivors and caregivers, and family members and friends who supported a named Brain Aneurysm Foundation Chair of Research in honor or memory of a loved one. It was especially meaningful for those who named a research chair to have an opportunity to meet the researchers whose work they are supporting. Also present were the foundation's Executive Director Christine Buckley and co-founder Christopher S. Ogilvy, MD, of Beth Israel Deaconess Medical Center in Boston, MA.

Established with a minimum gift of \$10,000, a Chair of Research provides funding for a researcher for one year. In 2017, seven new Chairs of Research were established. "These generous gifts are essential to our mission, as only through research can we improve outcomes for the thousands of people with brain aneurysms," said Ms. Buckley, noting that the foundation is the largest private funder of brain aneurysm research in the United States. The foundation thanks Duke for hosting this year's event.



2017 Grant Award Recipients

CYNTHIA LYNN SHERWIN CHAIR OF RESEARCH: \$25,000

\$25,000 Awarded to: STEFFEN-SEBASTIAN BOLZ, MD, PhD

Governing Council of the University of Toronto

Project: Surge Protection — Blocking Catecholamine Signaling in Subarachnoid Hemorrhage Prevents Secondary Hypertension and Reduces Brain Injury

DEBBIE FEIGER CHAIR OF RESEARCH: \$10,000

ROSTINI "TINI" GOMEZ CHAIR OF RESEARCH: \$10,000

\$20,000 Awarded to: AICHI CHIEN, PhD

The Regents of the University of California, Los Angeles

Project: Individualized Aneurysm Growth Prediction and Follow-Up Management

TIMOTHY P. SUSCO CHAIR OF RESEARCH: \$25,000

ANDREW DAVID HEITMAN FOUNDATION CHAIR OF RESEARCH: \$10,000

\$35,000 Awarded to: DAVID Y. CHUNG, MD, PhD

Massachusetts General Hospital

Project: Impact of Spreading Depolarizations and Subarachnoid Hemorrhage on Brain Connectivity

ANDREW DAVID HEITMAN FOUNDATION CHAIR OF RESEARCH: \$10,000

ELLIE HELTON CHAIR OF RESEARCH: \$5,000

1in50 CHAIR OF RESEARCH: \$5,000

\$20,000 Awarded to: ADAM A. DMYTRIW, MD, MSc

University of Toronto

Project: International Comparison of Endovascular Flow Diverters for the Treatment of Anterior Circulation Aneurysms

KRISTEN'S LEGACY OF LOVE FOR KRISTEN SHAFER ENGLERT CHAIR OF RESEARCH: \$20,000

BIDMC BRAIN ANEURYSM INSTITUTE CHAIR OF RESEARCH: \$10,000

CHRISTOPHER C. GETCH, MD, CHAIR OF RESEARCH (Sponsored by the CV Section): \$5,000

\$35,000 Awarded to: SYLVAIN DORÉ, PHD

University of Florida

Project: Is CO-Releasing Molecule a Potent Tool for Attenuating Vasospasm and Providing Neuroprotection after Subarachnoid Hemorrhage?

SHIRLEY DUDEK DEMMER CHAIR OF RESEARCH: \$25,000

ANDREW DAVID HEITMAN FOUNDATION CHAIR OF RESEARCH: \$20,000

\$45,000 Awarded to: WILLIAM T. GIBSON, MD, PhD

University of British Columbia

Project: Functional Approach to Missense Mutations in THSD1, a New Aneurysm Gene

STRODE FAMILY CHAIR OF RESEARCH: \$15,000

NEBRASKA'S HOPE FOR A BETTER TOMORROW CHAIR OF RESEARCH: \$15,000

\$30,000 Awarded to: MICHELLE A. T. HILDEBRANDT, PhD

University of Texas MD Anderson Cancer Center

Project: Genetic Predictors of Unruptured Intracranial Aneurysm Growth Behavior and Quantitative Imaging Biomarkers

NORTHWELL HEALTH - NORTH SHORE UNIVERSITY HOSPITAL BRAIN ANEURYSM CENTER
CHAIR OF RESEARCH: \$30,000

ANDREW DAVID HEITMAN FOUNDATION CHAIR OF RESEARCH: \$10,000

\$40,000 Awarded to: BRIAN L. HOH, MD

University of Florida

Project: Studying IL-6 and IL-17 in the Cerebral Aneurysm Development of VCD mice

TEAMCINDY ESCAPE FROM ALCATRAZ CHAIR OF RESEARCH: \$40,000

\$40,000 Awarded to: KOJI HOSAKA, PhD

University of Florida

Project: Mechanism of Aneurysm Progression and Healing: Telomere and Telomerase Activity in Cerebral Aneurysm

CAMI CLARK CHAIR OF RESEARCH: \$30,000

\$30,000 Awarded to: DAISUKE KUDO, MD, PhD

University of California, San Francisco

Project: Contribution of Microbiota to the Pathophysiology of Intracranial Aneurysm

TERRY A. KERSTING CHAIR OF RESEARCH: \$15,000

1in50 CHAIR OF RESEARCH: \$5,000

\$20,000 Awarded to: JOHN A. OATES, MD

Vanderbilt University Medical Center

Project: Inhibition of Lipid Peroxidation and Cerebral Vasospasm by an Acetaminophen-Based Regimen in Patients with Subarachnoid Hemorrhage

FIGHT LIKE FRANK CHAIR OF RESEARCH: \$15,000

TEAMCINDY ESCAPE FROM ALCATRAZ CHAIR OF RESEARCH: \$5,000

\$20,000 Awarded to: WILLIAM "CALEB" RUTLEDGE, MD

University of California, San Francisco

Project: Role of ADAM17 and Epidermal Growth Factor Receptor Pathway Signaling in Aneurysm Rupture

ELLIE HELTON CHAIR OF RESEARCH: \$40,000

\$40,000 Awarded to: DEANNA SASAKI-ADAMS, MD

University of North Carolina School of Medicine

Project: Novel Magnetic Resonance Imaging Sequence to Characterize Inflammatory Changes in Aneurysms in a Proven Rabbit Model and Assess Therapeutic Effect of Aspirin

CAROL W. HARVEY CHAIR OF RESEARCH: \$25,000

DAWN BREJCHA CHAIR OF RESEARCH: \$10,000

ROBERT SUTHERLAND CHAIR OF RESEARCH: \$10,000

\$45,000 Awarded to: VINCENT M. TUTINO, PhD

State University of New York at Buffalo

Project: Feasibility of Detecting Brain Aneurysm Biomarkers in Whole Blood on a Diagnostic Platform

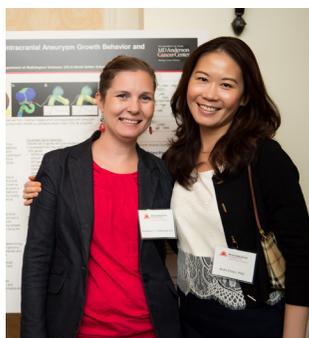


CHANCE MEETING LEADS TO COLLABORATION

Research May Help Guide Treatment Decisions

One of the most vexing decisions doctors currently face when caring for a patient with an unruptured aneurysm is whether to treat it or follow it over time. With some exceptions, such as when the aneurysm is very large or causing symptoms, there is no reliable way to know which aneurysms are likely to grow and potentially rupture and which are probably safe to leave alone. While it might seem prudent to treat all unruptured aneurysms, that is not the solution, because treatment — whether endovascular or open surgery — carries some potentially serious risks.

An unlikely partnership of two scientists — one a cancer researcher from Texas and the other a brain aneurysm researcher from California — formed during a chance encounter could help resolve this medical dilemma.



L to R: Michelle Hildebrandt, PhD, and Aichi Chien, PhD

In the summer of 2015, Michelle Hildebrandt, PhD, a cancer epidemiologist at MD Anderson Cancer Center in Texas, was attending an early career women faculty leadership workshop in Denver. She started chatting with fellow attendee Aichi Chien, PhD, a researcher in the Department of Radiological Sciences at the University of California, Los Angeles.

Later, over a glass of wine, Dr. Hildebrandt learned that Dr. Chien's area of research was brain aneurysms. Immediately Dr. Hildebrandt's interest was piqued; the previous fall, she had been treated for a brain aneurysm diagnosed after a year of chronic, painful headaches. It was clear that both women shared an interest in brain aneurysms and — as luck would have it — complementary expertise, so it wasn't long before they started talking about a research collaboration. "It was an 'aha' moment for both of us," says Dr. Hildebrandt.

Dr. Chien has a database of angiographic images from 600 patients with unruptured aneurysms who are being followed over time. Her research involves connecting the shape of aneurysms and the characteristics of blood flow with the risk of growth and potential rupture. Dr. Hildebrandt has strengths in epidemiology and genetics that can be translated across disciplines.

"The mechanisms underlying aneurysm formation, growth, and rupture are complex," says Dr. Chien, adding that incorporating genetic information into existing information may hold the key to being able to predict which patients have aneurysms that are likely to grow quickly. Says Dr. Hildebrandt, "Based on this research, in the future it may be possible to identify from a blood sample which patients have a genetic susceptibility to rapid aneurysm growth, which may signal an increased risk of rupture and the need for treatment."

Both researchers received grant funding from the Brain Aneurysm Foundation in 2017 (Dr. Chien also received funding from the foundation in 2015). Both were also present at the annual Brain Aneurysm Foundation Research Symposium in North Carolina in September (see page 12) to accept their awards and meet the families whose generous donations are supporting their work.

Dr. Hildebrandt's project, "Genetic Predictors of Unruptured Intracranial Aneurysm Growth Behavior and Quantitative Imaging Biomarkers," was funded by the Strode Family Chair of Research and Nebraska's Hope for a Better Tomorrow Chair of Research. Dr. Chien's project, "Individualized Aneurysm Growth Prediction and Follow-Up Management," was funded by the Debbie Feiger Chair of Research and the Rostini "Tini" Gomez Chair of Research.

Volleyball Tournament Honors Rostini (“Tini”) Gomez

Funds Establish a New Chair of Research



Rostini “Tini” Gomez

California residents Flor Bueno and Rostini (“Tini”) Gomez met in kindergarten and were best friends throughout elementary school and high school. They remained close while they attended different colleges and following graduation, as they began their careers: Flor as an accountant in Oakland and Tini as a pre-school teacher in Pleasanton. Among the many things Flor and Tini shared over the years was a love of volleyball. Tini was especially dedicated to the sport, playing on intramural teams throughout her high school and college years.

On Christmas night in 2015, Tini complained of a bad headache and went to bed. That night, the 27-year-old suffered a ruptured brain aneurysm and died. Flor, Tini’s mother, Leticia Rodriguez, and her two younger siblings; and many other family members and friends were shocked and devastated. “Her death was such a huge

loss to so many,” said Flor. “Tini had so many wonderful qualities: she was vibrant, silly, honest, and loved life.”

Determined to honor Tini’s all-too-short life and to help raise money for those affected by brain aneurysms, Flor and Leticia decided to organize a fundraising event in Tini’s honor. In recognition of Tini’s passion for volleyball, the two decided on a volleyball tournament to raise funds for the Brain Aneurysm Foundation.

On April 8, 2017, the 1st California Brain Aneurysm Awareness Volleyball Tournament was held at Los Medanos Community College in Pittsburg. Many pitched in to help make the day a success: one of Tini’s former coaches helped organize the teams, a local DJ donated his services, and a nearby restaurant donated food. More than 150 people — including family, friends, colleagues, and former teammates of Tini’s— turned out to play volleyball, watch the teams compete, enjoy the fun, and honor a special young woman whose life was lost to a brain aneurysm.

“While it was an emotional, bittersweet day for Tini’s mom and all of us who loved her, it was also a happy day to celebrate her life and do something to help others with brain aneurysms,” said Flor. “Tini would have loved it, and been super excited by the competitions.”

The tournament was a big success, raising \$12,000 for the Brain Aneurysm Foundation. “We were really pleased to have raised this amount, especially as this was our first event,” said Flor.

The funds from the event were used to establish the Rostini “Tini” Gomez Chair of Research in Tini’s memory (see page 13). The chair is supporting the research of 2017 BAF research grant recipient Aichi Chien, PhD, of the University of California, Los Angeles, whose project is entitled “Individualized Aneurysm Growth Prediction and Follow-Up Management.”



More than 1,000 people joined the 16th Annual Arterial Challenge at Fenway Park in Boston. Next year's Arterial Challenge is April 22, 2018.

16TH Annual Arterial Challenge Raises Record Amount

On a beautiful Sunday morning in April, more than 1,000 people of all ages converged on Boston's historic Fenway Park for the Brain Aneurysm Foundation's 16th Annual Arterial Challenge, a 5K timed run/2.5K walk. This year, the run/walk wove through the "Fens," a scenic park that is part of Boston's historic Emerald Necklace.

Among those who turned out to run, walk, or just enjoy the festivities — which included a band, refreshments, and a chance to soak up the sun from Fenway Park bleachers — were survivors, family members, friends, board members, healthcare providers and executives, and many others eager to support the foundation's mission.

The Arterial Challenge is one of the BAF's most well-attended and successful fundraising events. This year, the event raised a record-breaking amount, nearly \$106,000, which will be used to support brain aneurysm research, awareness, advocacy, and support programs.

As it did last year, the BAF partnered with hospitals in the region that provide treatment for people with brain aneurysms: Beth Israel Deaconess Medical Center, Massachusetts General Hospital, and Tufts Medical Center, in Boston, and Eastern Maine Medical Center, in Maine.

Each hospital had a team that competed for the role of top hospital fundraiser. This year, as last year, that honor went to the Beth Israel Deaconess Medical Center team, which raised \$19,000. Half of that amount was given back to the hospital as a grant for brain aneurysm research, while the rest was used to establish a Beth Israel Deaconess Medical Center Chair of Research.

Among the local luminaries who ran in the 5K were WCVB-TV anchor and brain aneurysm survivor Bob Halloran, and Peter Healy, president of Beth Israel Deaconess Medical Center.

Events: Past and Upcoming

More than 45 fundraising events have been held throughout the country and Canada since the first of this year. The Brain Aneurysm Foundation helps event organizers plan and run successful events in their own communities. Walks, runs, bowling, comedy, concerts, soccer matches, volleyball and golf tournaments are just a few of the creative, fun ways our supporters have helped raise awareness and funds to help the Brain Aneurysm Foundation fulfill its mission.

Here are highlights of some recent events. The foundation is very grateful to the organizers and supporters of these and all community events. You can find all past BAF events at: bafound.org.



MAY 6, 2017 - Minneapolis, MN

1st Annual Minneapolis Brain Aneurysm Awareness 5K Fun Run

Raised: \$8,300



JUNE 25, 2017 - London, Ontario

3rd Annual Running Against Ruptures

Raised: \$20,426



JULY 8, 2017 - Wentzville, MO

4th Annual Teeing Off for Terry Tournament

Raised: \$30,000



AUGUST 20, 2017 - Falmouth, MA

Falmouth Road Race

Raised: \$47,200



SEPTEMBER 16, 2017 - New York, NY

4th Annual TeamCindy Run for Research

Raised: \$54,600



OCTOBER 14, 2017 - Cary, NC

3rd Annual Ellie Helton Memorial 5K and Fun Run

Raised: over \$45,000

UPCOMING EVENTS

Here are some upcoming events around the country. For a complete listing of all upcoming events visit: bafound.org. If you are interested in organizing an event in your area to benefit the Brain Aneurysm Foundation, please email us at office@bafound.org and we will help get you started.

NOVEMBER 11, 2017 - Albuquerque, NM

1st Annual Brains Matter 5K

April 22, 2018 - Boston, MA

17th Annual Arterial Challenge 2018



One Survivor's Story: Tom Tinlin



For more than 30 years, Tom Tinlin worked in a high-stress environment, most recently as Administrator for the Highway Division of the Massachusetts Department of Transportation. In that role, Tom, a married father of two who lives in South Boston, was responsible for massive, complex projects like transitioning to all-electronic tolls on the Massachusetts Turnpike and choreographing the rebuilding of a bridge on a major route into Boston with minimal disruption to traffic.

For Tom, 52, the pressures of a demanding job were nothing new. So in April, when he went to his new primary care doctor about the sudden onset of a “horrible, horrible headache” that persisted for three days, and the doctor said it was probably caused by stress, Tom was doubtful.

Something was wrong

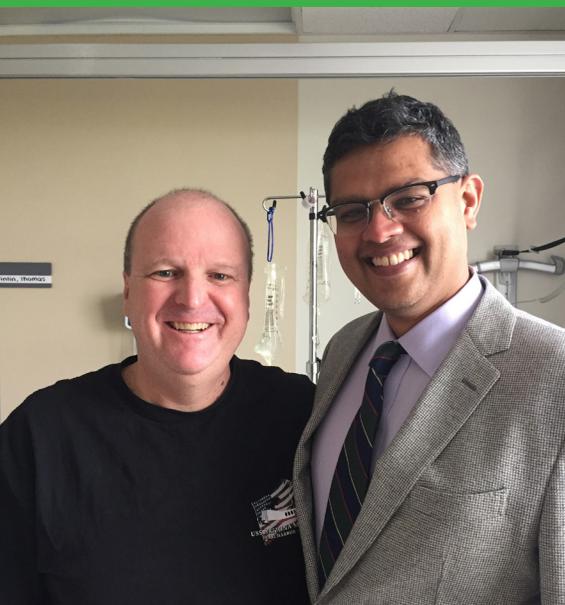
“I knew something was wrong and it wasn’t stress,” he recalls. But like most patients, he trusted his doctor’s judgment. He was sent on his way with a prescription for pain and sleep medications to take for a week.

On Sunday, April 30, just six days after that first severe headache, Tom was volunteering as an auctioneer at a local fundraising event when, “I felt like I got hit in the head by a baseball bat,” he says. “I also had the sensation of liquid pouring over my head, sounds were muffled, my eyes were out of focus, and I was sweating.”

Tom’s wife, Heather, was with him that day. “I told Heather that I needed get to the hospital right away,” says Tom. Heather rushed her husband to Beth Israel Deaconess Medical Center (BIDMC), where Tom underwent tests revealing that he had suffered a ruptured aneurysm. Treatment (endovascular coiling) was scheduled for the next morning.

Tom’s neurosurgeon was Ajith Thomas, MD, who is a member of the Brain Aneurysm Foundation’s Medical Advisory Board and co-director of the BIDMC Brain Aneurysm Institute. Dr. Thomas works closely with Brain Aneurysm Institute nurse practitioner Deirdre (Dede) Buckley, NP, who co-founded the Brain Aneurysm Foundation and is on the Board of Directors. “Dr. Thomas and Dede were wonderful and provided outstanding care, as did all the nurses and everyone else at BIDMC,” says Tom.

After the procedure, Dr. Thomas informed Tom that he had a second aneurysm, but that it should be carefully followed rather than treated. After 12 days in the hospital, including two days in the Neurosurgical Intensive Care Unit, Tom went home.



Tom Tinlin with his neurosurgeon Ajith Thomas, MD, of Beth Israel Deaconess Medical Center, Boston. Dr. Thomas is a member of the BAF's Medical Advisory Board.



L to R: Massachusetts Lieutenant Governor Karyn Polito, Governor Charlie Baker, Heather Tinlin, and Tom Tinlin at Tom's farewell party.

A smooth recovery

Tom's recovery has been steady and smooth, in part because of his sense of humor, support from family and friends, and realistic expectations. "I gauge progress from week to week, not day to day, and try to challenge myself every day," he says.

Tom still has some headaches at night, and tires more quickly than in the past, but his healthcare team reassures him that these symptoms will resolve with time. "Dr. Thomas said that in terms of my outcomes, I 'hit the lottery,' as so many others with a ruptured aneurysm either die or have lifelong disabilities, so I feel very fortunate."

Recently, Tom stepped down from his position with the Department of Transportation and plans to find a job that will give him more time to devote to his family, which was hard to come by with his former 24/7 role. "This experience made me re-prioritize my life: now it's family first, then job," explains Tom. His colleagues understood his decision but were sorry to see Tom go: Governor Charlie Baker was among those who attended Tom's farewell party.

Making a difference

As a person who has always volunteered and wants to continue to make a difference, Tom is now helping the Brain Aneurysm Foundation raise awareness about brain aneurysms so that perhaps others will be spared what he and his family endured.

"It frustrates me that my experience was avoidable had my primary care doctor been more aware of the symptoms of a brain aneurysm. My hope is that we can educate more healthcare professionals and the public about brain aneurysms so that fewer people have to suffer or die."

Tom is volunteering his time and expertise to the Brain Aneurysm Foundation, and was instrumental in planning the BAF event at the Massachusetts State House on September 25 to recognize Brain Aneurysm Awareness Month (see story, page 10).



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Support a Chair of Research

The Brain Aneurysm Foundation is the largest private funder of brain aneurysm research in the United States. In 2017, the foundation awarded \$445,000 to researchers tackling many important areas of investigation (see pages 12-13). A major source of these funds are donors who establish a named Chair of Research. Chairs of Research help provide critical funding to brain aneurysm researchers at leading hospitals around the world. These chairs are established with a minimum gift of \$10,000. Please consider supporting a Chair of Research today in honor or memory of a loved one. To find out more, visit our website:

bafound.org/chairs-research.

The nonprofit Brain Aneurysm Foundation is the globally recognized leader in brain aneurysm awareness, education, support, advocacy, and research funding.

OUR MISSION

Provide information about and raise awareness of the symptoms and risk factors of brain aneurysms to prevent ruptures and subsequent death and disability.

Work with medical communities to provide support networks for patients and families.

Advance research to improve patients' outcomes and save lives.

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The best
defense against
brain aneurysms . . .
knowing the facts!

Boston Bruins defenseman
Kevan Miller #86



Kevan Miller, Boston Bruins Defenseman, Named BAF Spokesperson

The Brain Aneurysm Foundation announced in September that Boston Bruins defenseman Kevan Miller (#86) has become its official spokesperson. In this role, Kevan will help raise awareness about brain aneurysms through attendance at select BAF events, on traditional and social media, and other outreach efforts.

“Kevan represents the determination, resourcefulness, and commitment shown by so many aneurysm survivors and their families and caregivers,” says BAF Executive Director Christine Buckley. “We are excited to have an athlete of Kevan’s standing help us with our mission.”