LIFE WITHOUT BRAIN DISEASE

2019 ANNUAL REPORT
WHO WE ARE

IMAGINE LIFE WITHOUT BRAIN DISEASE
That might seem far-fetched, but not to us. Since 1992, the American Brain Foundation has been committed to bringing researchers and donors together in the relentless pursuit of prevention, improved treatments, and cures for brain diseases and disorders. We know brain diseases are interconnected, and our innovative, whole-brain approach gives us an edge in understanding and combating them. We understand that when we cure one brain disease, we will cure many.

OUR GOALS
• To find cures for brain diseases and disorders
• To advance, support, and celebrate brain research
• To bring researchers, patients, and caregivers together
• To give hope to those affected by brain disease
Brain diseases such as Alzheimer’s and Parkinson’s disease, epilepsy, stroke and migraine affect one in six Americans. These diseases are among the leading causes of disability in the world. Another 100 million Americans live with mental health disorders and chronic pain, both of which are associated with functional and structural changes within the brain. As a result, there are very few among us who are not directly or indirectly touched by brain disease.

This makes our mission to defeat brain disease and find cures all the more important.

We would like to extend a very warm and special thank you to the supporters and partners who made it possible for the American Brain Foundation to support 28 early-career researchers studying over 12 brain diseases in 2019. With your help, we awarded over 2.5 million dollars to brain research and established three new endowments supporting research and initiatives in collaboration with our partner the American Academy of Neurology.

Our unique and critical partnership with the American Academy of Neurology means we can tap into the largest brain trust of neurologists and brain disease researchers in the world. Our awards champion research across the whole brain, leading to groundbreaking discoveries that could lead to cures not just for one disease, but for many. Take our Scientific Breakthrough Awardee Dr. Jerry Mendell as an example. His groundbreaking gene therapy treatment for spinal muscular atrophy is curing the disease in babies and being used effectively to treat Duchenne’s muscular dystrophy in boys.

In our pursuit of cures, the American Brain Foundation built a research fund to find a biomarker for Lewy body dementia and launched the Brain Squad, our monthly donor program. We also honored other leaders in the fight against brain disease, including Jeffrey Lurie and Ann Romney for their contributions to advancements in autism and multiple sclerosis research.

Thank you for helping us advance our mission and making scientific breakthroughs for brain research possible. Your contributions have helped us continue our ambitious project to become the largest national charitable organization for the brain. With your help, we won’t have to imagine a world without brain disease—we’ll be able to live in one.

David Dodick, MD, FAAN
Board Chair

Jane Ransom
Executive Director
Funding World-Class Research

The American Brain Foundation funds research across the whole spectrum of brain diseases and disorders, investing in new generations of clinical neuroscientists by identifying the best and brightest early-career scientific investigators and advancing their innovative research projects. In 2019, we invested over $2.4M in research projects led by 28 emerging researchers conducting investigations into brain diseases.

ALS
Suma Babu, MBBS, MPH
Massachusetts General Hospital
Peter Creigh, MD
University of Rochester
Jennifer Marsella, MD
University of Rochester

ALZHEIMER’S DISEASE, LEWY BODY DISEASES, AND OTHER DEMENTIAS
William Mantyh, MD
University of California, San Francisco
Bhavana Patel, MD
University of Florida

COGNITIVE AGING AND AGE-RELATED MEMORY LOSS
Kimberly Albert, PhD
Vanderbilt University
Christian Camargo, MD
University of Miami
Brice McConnell, MD, PhD
University of Colorado
Sanaz Sedaghat, PhD
Northwestern University

EPILEPSY
Lisseth Burbano, MD
Florey Institute of Neuroscience and Mental Health
Hiroki Narai, MD
University of California, Los Angeles

HEADACHE AND MIGRAINE
Faisal Amin, MD, PhD
Rigshospitalet

MULTIPLE SCLEROSIS
Omar Al-Louzi, MD
Massachusetts General Hospital
Emily Harrington, MD, PhD
Johns Hopkins University
Ulrike Kaunzner, MD, PhD
New York Presbyterian Hospital
Ryan Schubert, MD
University of California, San Francisco

NEUROMUSCULAR DISEASE
Katharine Nicholson, MD
Massachusetts General Hospital
Davut Pehlivan, MD
Baylor College of Medicine
Shruti Raja, MD
Duke University
Reza Seyedsadjadi, MD
Massachusetts General Hospital

PARKINSON’S DISEASE
David Coughlin, MD
University of California, San Diego
Anna Goodheart, MD
Massachusetts General Hospital

STROKE AND VASCULAR DISEASES
Xiaoyan Jiang, PhD
University of Pittsburgh
Kevin Keenan, MD
University of California, San Francisco
Juneyoung Lee, PhD
The University of Texas Health Science Center at Houston
Sunil Sheth, MD
The University of Texas Health Science Center at Houston

TOURETTE SYNDROME
Wissam Georges Deeb, MD
University of Florida
Jennifer Vermilion, MD
University of Rochester
“The clinical research training fellowship helped launch my career. Because of this fellowship, I learned how to bring new treatments forward to help my patients.... It is an honor to be part of the American Brain Foundation and to give back and support young investigators excited about research careers in neurology.”

Merit Cudkowicz, MD, Chair of Neurology at Massachusetts General Hospital, is a celebrated researcher dedicated to the study and treatment of patients with neurodegenerative disorders, including ALS. She received a Next Generation Research Grant in 1996 and has since become a member of the American Brain Foundation’s Research Advisory Committee.

The American Epilepsy Society and the Epilepsy Foundation of America have supported the American Brain Foundation’s Susan S. Spencer, MD Clinical Research Training Fellowship since 2010. The late Susan S. Spencer, MD, was a pioneer in epilepsy research and treatment and a past president of the American Epilepsy Society. The award was created to launch a new generation of top-notch, patient-focused epilepsy clinician scientists who will carry on the scientific and clinical excellence modeled by Dr. Spencer during her career.

“The partnerships like these allow us to pool resources and reduce administrative burden, ensuring that the majority of funding goes to the researchers doing the work.” – Epilepsy Foundation
Financial Highlights

Grant Expense by Disease

- Parkinson’s Disease: 17%
- Multiple Sclerosis: 7%
- Tourette Syndrome: 4%
- Stroke and vascular diseases: 12%
- Epilepsy: 7%
- Neuromuscular disease and disorders: 17%
- Headache and migraine: 6%
- Alzheimer’s disease, Lewy body diseases, and other dementias: 7%
- Cognitive aging and age-related memory loss: 14%
- ALS: 17%
- Grant Expense by Disease: 20%

Functional Expenses:
- Programming: $3,537,320
- Fundraising: $394,689
- Operations: $665,762

Program Expenses:
- Awards: $308,122
- Grants: $2,540,348
- Public Awareness: $688,850

Our audited financial statements are available on our website or by request.
IMPACT BY THE NUMBERS

28
Active research projects

$30 MIL.
Over $30 million has been granted for Next Generation Research Grants.

85%
More than 85% of our researchers have gone on to secure funding from the NIH and other entities.

250
Over 250 researchers have received scholarships and funding from the American Brain Foundation.

$2,365,347
Active grant dollars for research in 2019.

Total funds raised 2015-2019

2015 $787,219
2016 $1,395,664
2017 $4,467,308
2018 $3,251,402
2019 $3,853,425
2015-2019 $13,755,018
NEW ENDOWMENTS

Gifts from generous donors made it possible for the American Brain Foundation to establish three new endowed funds:

The Joseph B. Green Endowment
Funds clinical research training scholarships

The Cheryl A. Jay Endowment
Supports the American Academy of Neurology’s new lectureship in health care disparities

The Ted M. Burns Endowment
Underwrites a new American Brain Foundation award for humanism in neurology

TED M. BURNS HUMANISM IN NEUROLOGY AWARD

In order to maintain the idealism and compassion of neurology, humanism must remain primary as practices evolve. The Ted M. Burns Humanism in Neurology Award acknowledges the influence of the most benevolent and innovative in the field. The award aims to celebrate neurologists whose work embodies humanism—in patient care, education, advocacy, and everyday encounters. By recognizing outstanding neurologists, the award aims to inspire others to improve healthcare delivery and the lives of their colleagues and patients.

This new award is named in honor of Ted M. Burns, MD, a visionary in fostering trainees and colleagues and for foreseeing novel mechanisms to make the full scope of neurology accessible locally and abroad.

He has mastered the delivery of compassionate, patient-centered care, and has a track record of calling attention to and addressing disingenuous practices in medicine and inequalities in care.

Dr. Burns is currently the Harrison Distinguished Teaching Professor in the Department of Neurology at the University of Virginia. He has served as the director of UVA’s residency and clinical neurophysiology training programs, among other positions, and his skills have been recognized at UVA on multiple occasions. Dr. Burns has raised his voice to lobby professional organizations, pharmaceutical companies, the FDA, and the United States Congress on patients’ behalf. Dr. Burns is also a beloved friend and mentor to many, and his honest and kind approach to patient care does not go unnoticed.

Thank you to the generous donors who helped establish this new endowment.
Ted M. Burns Endowment Donors

Anthony A. Amato, MD, FAAN
Rowena Atzenweiler
Richard J. Barohn, MD, FAAN
Matthew J. Barrett, MD
Michael G. Benatar, MD, FAAN
Margaret Bettin
Thomas Brannagan
Dennis Burns
Jeffrey M. Burns, MD
Mark and Sara Burns
Roger L. Burns
Ann Camac, MD
Linda Carson
Micaela T. Chatman, MD
Stacey Clardy, MD, PhD
The Copaken Family
Marla and Stan Craven
Mr. Jason Crowell
Eugene Sorets and
Merit E. Cudkowicz, MD, MSc
Steven T. DeKosky, MD, FACP,
FANA, FAAN
Mazen M. Dimachkie, MD, FAAN
Stephen N. Donahue, MD
William Elias
Matthew Elliott
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Marsha D. and Robert A. Gross, MD,
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Jeffrey Guptill, MD, FAAN
Laurie Gutmann, MD, FAAN
Ludwig Gutmann, MD, FAAN
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Ikjae Lee, MD
Kenneth V. Leone, MD
Yuebing Li, MD, PhD
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Janice M. Massey, MD, FAAN and
Edward W. Massey, MD
Michelle L. Mauermann, MD
Nikolaus McFarland, MD, PhD
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Bradford B. Worrall, MD, MSc, FAAN
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Potamkin Prize for Research in Pick’s, Alzheimer’s, and Related Diseases

Funded by the American Brain Foundation through the philanthropy of the Potamkin Family

Randall J. Bateman, MD
Washington University School of Medicine

The Potamkin Prize is the highest honor in Alzheimer’s research that recognizes premier scientific research in Alzheimer’s disease and related dementias. The 2019 prize was awarded to Randall J. Bateman, MD, of Washington University School of Medicine in St. Louis, MO. Dr. Bateman was selected for his many contributions to the understanding of this brain disease, which include developing a blood test that detects the earliest stages of Alzheimer’s and more.

Sheila Essey Award: An Award for ALS Research

Funded by the American Brain Foundation through the philanthropy of the Essey Family

Aaron Gitler, PhD
Stanford University School of Medicine

The Sheila Essey Award recognizes an individual who has made significant research contributions in the search for the cause, prevention of, and cure for ALS. The 2019 recipient Aaron Gitler, PhD, of the Stanford University School of Medicine, was recognized for his research on a protein called TPD-43. These proteins are thought to play a major role in ALS when they clump together.
LIFETIME AND HUMANITARIAN AWARDS

Association of Indian Neurologists in America Lifetime Achievement Award
Sponsored by the American Brain Foundation
Ram Ayyar, MD, FAAN
An Invaluable Resource and Mentor to Neurologists
A Professor of Neurology at the University of Miami, Dr. Ram Ayyar is internationally recognized as a clinician, teacher, researcher, and leader in the field of neuromuscular medicine and electrophysiology. He has over 100 peer-reviewed publications and has presented on neuromuscular disease for audiences around the world. Dr. Ayyar has also been recognized for his excellence in teaching by both Wayne State University and the University of Miami.

Mridha Spirit of Neurology Humanitarian Award
Sponsored by the American Brain Foundation and funded through the philanthropy of the Mridha Family
James H. Bower, MD
Serving Humanity with Dedication, Kindness, and Care
Dr. Jim Bower truly epitomizes the ideals of the Mridha Spirit of Neurology Award. He has served populations in Ethiopia, Egypt, Senegal, Nigeria, and Tanzania with compassion, integrity, and altruism for almost twenty years and led the way in supporting neurologic resources and educational needs in sub-Saharan Africa.

Additional Scientific Awards
American Academy of Neurology Awards funded by the American Brain Foundation
Bruce S. Schoenberg International Award in Neuroepidemiology
Dreifuss-Penny Epilepsy Award
Founders Award
Harold Wolff-John Graham: An Award for Headache/Facial Pain Research
Irwin Schatz Award for Autonomic Disorders
John Stolk Award in Movement Disorders for Young Investigators
Neuro-oncology Investigator Award
Neuro-oncology Scientific Award
Norman Geschwind Prize in Behavioral Neurology
Michael S. Pessin Stroke Leadership Prize
Mitchell B. Max Award for Neuropathic Pain
Movement Disorders Research Award
Neuroendocrine Research Award
Sleep Science Award
S. Weir Mitchell Award
Wayne A. Hening Sleep Medicine Investigator Award
We celebrated advancements in brain research, brought the neurologic community together, and honored those who have made contributions to our cause at our annual event, Commitment to Cures. Thank you to those who attended this incredible night and donated. With your help, we raised $387,835. Here are those we honored at the event.

**2019 HONOREES**

**Ann Romney**  
**Public Leadership in Neurology Award**  
**An Ambassador for Brain Health**  
We honored Ann Romney, the former First Lady of Massachusetts, for her leadership in the fight to defeat multiple sclerosis (MS) and all neurologic diseases. Through her inspiring book *In This Together*, Romney shared her personal experience with MS. She is an ambassador for the health of the whole brain and spearheaded pathbreaking MS research by helping establish the Ann Romney Center for Neurologic Diseases at the Brigham & Women’s Hospital.

**Jeffrey Lurie**  
**Commitment to Cures Award**  
**Raising Awareness and Philanthropy for Autism**  
An accomplished movie producer and the owner of the Philadelphia Eagles, Jeffrey Lurie knows autism intimately after having grown up with a brother with the disorder. His personal philanthropy has directed millions of dollars toward autism research and awareness. Lurie also created the Eagles Autism Challenge that featured Philadelphia Eagles players, alumni, coaches, executives, cheerleaders, and mascot.

**Edgar J. Kenton III, MD, FAAN, FAHA**  
**American Brain Foundation Board Chair’s Award**  
**Champion of Philanthropy and Diversity**  
The American Brain Foundation honored Dr. Kenton posthumously for being an invaluable member of the Board and a champion of philanthropy and diversity in the field of neurology. He was a distinguished neurologist, longtime supporter of the Foundation’s research mission, and leadership donor.

**Jerry Mendell, MD**  
**Scientific Breakthrough Award**  
**Pathbreaker in Spinal Muscular Atrophy Research**  
The American Brain Foundation believes that curing one brain disease means curing many. At our Commitment to Cures gala, we honored Dr. Mendell with the Scientific Breakthrough Award for his gene therapy research for spinal muscular atrophy. His work is not only curing the disease in babies, but it is also being used effectively in treating boys with Duchenne’s muscular dystrophy.
Raising Awareness about Brain Health

Bike Helmet Giveaway | Minneapolis, MN, June 2019
The American Brain Foundation helped distribute 1,000 bike helmets to families at the American Academy of Neurology's event in June. Families stopping by the Foundation's tent played a giant version of Connect 4, won prizes, and donated in support of brain disease research.

Brain Health Fair | Philadelphia, PA, April 2019
The American Brain Foundation participated in the American Academy of Neurology's annual Brain Health Fair. The Brain Health Fair is a free event where neurology patients, caregivers, and members of the public interested in brain health and the science of the brain can connect with experts to learn about the brain.

“Robin’s Wish” Screening | Mountain View, CA, November 2019
The American Brain Foundation held a private screening of the forthcoming documentary “Robin’s Wish” at the Mountain View Center for the Performing Arts. The film deepened our understanding of Robin Williams as a beautiful human being, detailed his head-on collision with Lewy body dementia and stressed the importance of brain disease research. Board members Susan Schneider Williams and David Eagleman, PhD, introduced 80 people to the American Brain Foundation in their remarks following the screening. The event was graciously underwritten by the Hand Foundation.
The American Brain Foundation is unique in its scope, vision, leadership, and its emphasis on training and funding the next generation of neuroscientists.

– David Anderson, MD, FAAN

Recurring Gifts Make a Difference

The American Brain Foundation launched the Brain Squad, a special community of dedicated monthly donors. The Brain Squad provides critical sustaining support that keeps researchers in the lab working to identify causes, improve treatments, and discover cures for brain diseases and disorders—creating hope for patients and their loved ones.

Monthly donors are the backbone of the American Brain Foundation. Their ongoing support allows us to spend less time fundraising and more time finding a cure for brain disease.

Join the community!

It’s Affordable. Give at the level that fits your budget.
It’s Easy. Your gift processes automatically each month from your checking account or credit card.
It’s Impactful. Cure one, cure many. Our research spans the spectrum of brain disease.
It’s Rewarding. Make a difference in advancing treatments and diagnoses.

Visit americanbrainfoundation.org/brainsquad
Individual Giving

Rowland Circle Members

$1,000,000+
Rita Green, PhD* and Joseph B. Green, MD, FAAN

$500,000 - $999,999
The Essey Family *

$25,000 - $49,999
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Jill Kawahigashi
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$10,000-$24,999
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Madigan Linnane
Kaval Malhotra, MD
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Charlotte L. Max
Launee Metz, MD
Ellen S. and Aaron E. Miller, MD, FAAN
Carol A. and Ted J. Murray, DDS
Ahsan M. Naduvil Valappil, MD
Sandra F. Olson, MD, FAAN
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Jeffrey and Marsha Perelman
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James R. Poston, MD
Oscar E. Pradilla
Gil D. Rabinovici, MD, FAAN

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Joyce Thompson
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David Werntz
Nick Wiseman
Donna T. Shen and Bradford B. Worrall, MD, MSc, FAAN
Pamela W. and George K. York, III, MD, FAAN

15
Our awards champion research across the whole brain, leading to groundbreaking discoveries that could lead to cures not just for one disease, but for many.
Legacy Donors

The American Brain Foundation proudly recognizes donors who have included the Foundation in their legacy plans.

Anonymous (2)  
Robert H. Ackerman, MD, FAAN  
Elaine and James R. Allen, MD  
Patricia Smith Cook, MD, FAAN  
Jane A. Daroff, DCSW, LISW and Robert B. Daroff, MD, FAAN  
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Jane and Bruce Sigsbee, MD, FAAN  
Dee E. Silver, MD  
Deborah R. Syna, MD

John E. Taylor *  
Lynne P. Taylor, MD, FAAN and Bruce Bagamery, PhD  
Debra S. and Raymond W. Valpey, MD  
* deceased

Organizational Giving

$1,000,000+  
American Academy of Neurology

$100,000 - $999,999  
The ALS Association  
Anonymous  
McKnight Brain Research Foundation

$50,000 - $99,999  
Alzheimer’s Association  
Potamkin Advised Fund of the Aspen Community Foundation  
Muscle Study Group  
International Headache Society  
Myasthenia Gravis Foundation of America Inc.  
Parkinson’s Foundation  
Society of Vascular & Interventional Neurology  
Tourette Association of America

$25,000 - $49,999  
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Epilepsy Foundation of America

The Mary Elizabeth Groff Charitable Trust  
Muscular Dystrophy Association

$10,000-$24,999  
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University of Pittsburgh Medical Center  
Department of Neurology  
Virginia Commonwealth University  
Department of Neurology  
Washington University School of Medicine  
The Weichert Palestrini Team  
West Virginia University Department of Neurology
"We opened our donor-advised fund with the American Brain Foundation several years ago because we firmly support the mission of the Foundation to help cure brain disease. The Foundation’s tagline, ‘Cure One, Cure Many,’ resonates with us in that there are so many common links between different brain diseases.

We believe that supporting brain research through the Foundation leverages our other donations to brain research, since every project we support is part of a larger effort to cure brain disease generally.”

– Martin and Patti Shenkman

Endowments and Donor-Advised Funds

Alliance Fund
Anonymous Fund
Association of Indian Neurologists in America Lifetime Achievement Award Fund
Baumel-Eisner Alzheimer’s/Dementia Research Fund
Bruce S. Schoenberg International Award in Neuroepidemiology Fund
Calvin L. Calhoun, Sr., MD, Diversity Research Fund
The Carter Virginia Copp Memorial Fund
The Cheryl A. Jay Endowment
Debasish and Chiru Mridha Spirit of Neurology Award Fund
Dreifuss-Penny Epilepsy Award Fund
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Harold Wolff-John Graham Award Fund
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Meet Our New Directors

Jacqueline French, MD, FAAN

Dr. Jacqueline French is Chief Medical and Innovation Officer of the national Epilepsy Foundation (Maryland); a professor in the Department of Neurology at NYU Grossman School of Medicine; and co-director of epilepsy research and clinical trials at the NYU Langone Health Comprehensive Epilepsy Center. She is also the president of the Epilepsy Study Consortium.

James Erwin

Jimmy Erwin is Executive Vice President of Chicago Title Commercial. Erwin and his wife, Pam, co-founded the Will Erwin Headache Research Foundation in honor of their son, Will, who suffered from debilitating cluster headaches until age 28 when he took his own life due to the excruciating pain. WEHRF is dedicated to finding a cure for headaches and providing relief for those who experience them.

Frances E. Jensen, MD, FACP, FAAN

Dr. Frances E. Jensen is a Professor of Neurology, Chair of Neurology, and Co-Director of Penn Translational Neuroscience Center in the University of Pennsylvania’s Perelman School of Medicine where she focuses on epilepsy and stroke and how epilepsy interacts with other disorders. She also co-authored The Teenage Brain: A Neuroscientist’s Survival Guide to Raising Adolescents and Young Adults (Harper Collins, April 2015).

Cindy McCain

Cindy McCain has dedicated her life to improving the safety, health, and well-being of women, children, and families. Her advocacy work includes combating brain disease. This work is deeply personal, as her husband, the late U.S. Senator John McCain, died of glioblastoma, an aggressive form of malignant brain tumor. She also lives with migraine and advocates for those with this debilitating disease.

Sean C. Sansiveri

Sean C. Sansiveri is Vice President of Business and Legal Affairs for the National Football League Players Association where he leads the NFLPA’s health and safety initiatives. His efforts have resulted in the creation of standardized protocols governing the evaluation and management of concussions, the development of team-specific emergency action plans and the utilization of independent neurotrauma specialists on the sidelines of all NFL games.