



AMERICAN BRAIN FOUNDATION IMPACT REPORT

SUMMER-FALL 2022

AMERICAN BRAIN FOUNDATION

A LETTER FROM BOARD CHAIR DAVID DODICK, MD, FAAN, AND EXECUTIVE DIRECTOR JANE RANSOM

As we look to 2023, we are reminded that though the most difficult days of the COVID-19 pandemic are behind us, many challenges remain ahead. We face a growing public health crisis in the increasing prevalence of brain diseases like Alzheimer's, stroke, Parkinson's, multiple sclerosis, and others. Brain diseases are the leading cause of disability and the second leading cause of death. Since 1990, deaths from brain disease have increased by 39% and disability has increased by 15%.

The impact of brain disease is immense and far-reaching, affecting many family members and loved ones for each individual who is diagnosed. Brain diseases cut to the core of what makes us human, eroding foundational qualities like our sense of self, autonomy, and memory.

As sobering as these facts are, there is hope. Research offers us immense hope.

For every research study we are able to fund, we take another step closer to a future without brain disease. This year, our new class of 2022 Next Generation Research Grant recipients is giving us renewed hope of finding treatments and cures. Their projects span a wide range of brain diseases and disorders, investigating pathology, diagnosis, and treatment for conditions like ALS, epilepsy, stroke, multiple sclerosis, Parkinson's, Alzheimer's, Lewy body dementia, and many others. These early-career researchers will contribute to the development of new approaches and tests for early detection and diagnosis, more targeted and patient-centered treatments, and ways to identify genetic and other risk factors for all brain diseases.

The American Brain Foundation is unique in that we accelerate research by investigating mechanisms common to multiple brain diseases. This summer, we convened a distinguished panel of neuroscientists to oversee a research initiative in neuroinflammation. We look forward to advancing research in this area that affects nearly every major brain disease and people at all stages of life.

In April we hosted our most successful Commitment to Cures Gala yet, raising over \$874,000 for brain disease research. The in-person event in Seattle was live-streamed for virtual guests at no cost and celebrated advances in research, featured inspiring stories from patients and caregivers, and recognized brain disease advocates including actors Seth Rogen and Lauren Miller Rogen. The American Brain Foundation also continues its work raising awareness and sharing resources about brain disease and brain health through our webinars, blogs, social media, and events. We encourage you to follow us on social media and subscribe to our email list to receive timely updates.

Thank you for your continued support of the American Brain Foundation. Every research application we fund deepens our understanding of brain diseases and puts us one step closer to cures. With your help, life without brain disease is possible.



David Dodick, MD, FAAN
Chair, Board of Directors



Jane Ransom
Executive Director

CURRENT RESEARCH PROJECTS

The American Brain Foundation funds Next Generation Research Grants across many different brain diseases. These research projects advance a more comprehensive view of the brain and enable us to identify new biomarkers, risk factors, treatments, and cures.



Sanjana Shellikeri, PhD

MANAGING SPEECH IMPAIRMENT IN ALS, PARKINSON'S, AND LEWY BODY DEMENTIA

Dr. Shellikeri's research will develop speech assessment tools that will better enable doctors to screen patients for speech impairment indicative of ALS, Parkinson's, and Lewy body dementia. Speech impairment caused by difficulties moving the muscles needed for speech is a common concern in over 92% of people with ALS and over 86% of people with Parkinsonian and Lewy body spectrum disorders. It is also a good indication of a patient's risk of aspiration, a major factor contributing to death. By developing screening tools based on "real life" natural speech, Dr. Shellikeri's research will help doctors provide more accurate prognoses and specific treatments to manage these impairments.



Jeffrey Motter, PhD

IMPROVING DIAGNOSIS OF DEMENTIA

Accurate identification and diagnosis of different types of dementia is crucial to ensure that patients receive the best treatments and accurate prognoses. Dr. Motter's research will respond to this urgent need for simple, inexpensive, non-invasive, and easily available diagnostic tests for early detection of neurodegenerative diseases by exploring differences in odor memory across different types of dementia. The goal of this research is to lead to the development of a simple diagnostic test for multiple different but often very similarly presenting types of dementia.

For a full list of our current researchers, visit AmericanBrainFoundation.org/NGRG.



BUILDING LIFELONG RESEARCH CAREERS

American Brain Foundation grants help launch long-term careers for the next generation of clinical neuroscience researchers. Their research is establishing the foundation for the treatments and cures of tomorrow, so that one day we can all enjoy life without brain disease.



Carolina Barnett-Tapia, MD, PhD
Neuromuscular Neurologist,
University of Toronto

Dr. Barnett-Tapia received a 2012 Clinical Research Training Fellowship for work that attempted to capture what people living with myasthenia gravis found important about their own symptoms. Her research resulted in the development of a new symptom evaluation scale for measuring patients' self-reported symptoms and incorporating their experiences and perspectives into clinical assessments. Her current research focuses on patient-centered outcomes in neuromuscular disorders and using patient perspectives as a way to identify and better understand gaps in care. She is also working with colleagues to develop additional symptom evaluation scales for ALS and other diseases.



Lidia Maria Moura, MD, MPH, PhD
Director, NeuroValue Lab,
Massachusetts General Hospital

Dr. Moura was a 2014 Clinical Research Training Fellowship recipient. She went on to receive additional research support from the American Epilepsy Society and the Epilepsy Foundation, as well as the National Institute of Health, to investigate epilepsy quality measures and patient-centered outcomes. Her current work with the NeuroValue Lab draws from neuro-psychiatric epidemiology and incorporates clinical, behavioral, and economic perspectives to design coordinated care delivery models for neurological care.

ANNOUNCING NEW CURE ONE, CURE MANY RESEARCH AWARD

UNDERSTANDING NEUROINFLAMMATION

In the first part of this year, the American Brain Foundation began convening patient organizations and neuroscientists to address the urgent need for research in neuroinflammation. Nearly every major brain disease involves complex and unique changes in the body's immune response. Some of these changes may be detrimental, and others may be beneficial. Understanding this continuum will allow us to identify more precise targets for treatment in diseases as disparate as multiple sclerosis, brain tumor, epilepsy, Parkinson's disease, Huntington's disease, Alzheimer's disease, stroke, ALS, migraine, and others.

Neuroinflammation is a crucial underlying mechanism that contributes to each of these neurological diseases. However, there has been no large-scale, coordinated research effort to understand the precise mechanisms of inflammation in brain diseases. Understanding both the beneficial and detrimental effects of neuroinflammation is essential to developing therapies and treatments across all brain diseases.



2022 COMMITMENT TO CURES GALA

Our 2022 Commitment to Cures fundraising gala was held in Seattle, WA on April 6 and live-streamed to a virtual audience. The event celebrated leading brain disease researchers and advocates and featured stories of people impacted by brain disease. With your support, we raised **\$874,727** to fuel the next advances in brain disease research!

If you missed the gala, you can view the full event at AmericanBrainFoundation.org/c2c2022.



Actor Lauren Miller Rogen receiving the 2022 Public Leadership in Neurology Award for her advocacy work together with husband Seth Rogen, presented by Richard Isaacson, MD.



Journalist and author Susannah Cahalan, recipient of the 2022 Ambassador Award, and her neurologist, Souhel Najjar, MD.



Stephen Hauser, MD, recipient of the 2022 Scientific Breakthrough Award.



Guests enjoy the cocktail reception at the Hyatt Regency Seattle.



Guests enjoy the dinner and program.



David Dodick, MD and Sean Sansiveri, Commitment to Cures Event Chair and recipient of the 2022 Board Chair Award.



Lenora Higginbotham, MD speaks about the impact her ABF-funded research grant has made on her career.



Guests bid during the Fund-A-Mission Auction.

SAVE THE DATE:
2023
COMMITMENT TO
CURES

April 26th, 2023
Boston, MA

Our 2023 Commitment to Cures event will be held in-person in Boston and live-streamed at AmericanBrainFoundation.org.

We hope to see you there!



OUR SUPPORTING PARTNERS

We partner with the most respected organizations, foundations, and nonprofits working to defeat specific diseases of the brain and nervous system. Thank you to the following groups for their support and partnership, and thanks to our founder and research partner, the American Academy of Neurology.

Alexion	Jani-Dhuna Foundation
The ALS Association	Kingsbury Sibling Group Fund of the Community Foundation of New Jersey
Alzheimer's Association	
American Academy of Neurology	The Mary E. Groff Charitable Trust
American Epilepsy Society	Mayo Foundation for Medical Education and Research
American Heart Association	McKnight Brain Research Foundation
Amgen Inc.	MdDS Foundation
Association for Frontotemporal Degeneration	Michael J. Fox Foundation for Parkinson's Research
Bob Burros Family Memorial Fund of the American Brain Foundation	Mitsubishi Tanabe Pharma America
	Muscular Dystrophy Association
CReATe Consortium	Myasthenia Gravis Foundation of America
Dan and Kathy Grubb Family Foundation Fund of the Arizona Community Foundation	National Multiple Sclerosis Society
Edgar J. Kenton, III MD Foundation, Inc.	Neuromuscular Study Group
Eisai Inc.	Parkinson's Foundation
Epilepsy Foundation	Potamkin Advised Fund of the Aspen Community Foundation
Fanatics	Teva
The Foundation for Peripheral Neuropathy	Tourette Association of America
Hearst Foundations	Wood Next Fund

How You Can Help Find More Treatments and Cures for Brain Disease



JOIN THE BRAIN SQUAD

Brain Squad members are monthly donors dedicated to fueling the next generation of researchers. Their ongoing support builds bridges between diseases and breaks new ground in research and application.



INCLUDE THE AMERICAN BRAIN FOUNDATION IN YOUR FUTURE PLANS

Legacy gifts in your will or other estate plan are impactful ways to support brain disease research and ensure the future of research for generations to come. In 20 minutes or less, you can protect the people you love and make a lasting commitment to those affected by brain disease. Use this online tool to write a legal will for free:

[Freewill.com/americanbrainfoundation](https://freewill.com/americanbrainfoundation)



DOUBLE YOUR IMPACT WITH A MATCHING GIFT FROM YOUR EMPLOYER

Many employers offer a workplace giving or matching gift option for their employees. Contact your employer directly for more details about matching gifts they provide.



HELP SPREAD AWARENESS OF THE NEED FOR RESEARCH

Start your own social media fundraiser, follow our social channels, and subscribe to our monthly email newsletter for brain news, research discoveries, and stories from those impacted.

UNDERSTANDING CAREGIVING AND HOW TO SUPPORT CAREGIVERS

In June we hosted a webinar with Hilarity for Charity Executive Director Bonnie Wattles and author and caregiver advocate Dan Gasby about the challenges caregivers face and how we can better support them.



“Caregiving is one of the most mind-bending, surreal, frustrating, exhilarating, and lonely experiences that one person can go through.”

— Dan Gasby, Caregiver Advocate and Co-Author of *Before I Forget*

The webinar covered a range of things caregivers experience, including the journey toward acceptance, learning the difficult skills of patience and understanding, and coping with the emotional demands of caregiving. Gasby emphasized the importance of discussing a caregiving plan with loved ones before the need arises. Wattles discussed Hilarity for Charity’s mission to normalize mental health conversations around caregiving and help people connect with a larger community of caregivers so they know they’re not alone.



Today there are about 48 million individuals caring for an adult family member or friend—11.2 million caregivers are caring for somebody with Alzheimer’s or dementia in the Alzheimer’s space alone. That number is expected to triple by 2050.”

— Bonnie Wattles, Executive Director of Hilarity for Charity



Brain disease has a devastating impact not only on the individuals who are diagnosed, but also on family members, friends, and caregivers. Events like this one are a crucial part of our focus on educating and spreading awareness about the impact of brain disease.

Watch the webinar recording at AmericanBrainFoundation.org/events.

REGISTER FOR UPCOMING WEBINARS WITH LEADING RESEARCHERS

Meet the Researchers Funded by the American Brain Foundation

Tuesday, September 13, 8 p.m. ET

Managing Parkinson’s Disease and Multiple Sclerosis

with Dr. Lisa Shulman and Dr. Ellen Mowry

Monday, October 10, 8 p.m. ET

Navigating Migraine: Treatment and Research

with Dr. David Dodick and Dr. Faisal Mohammad Amin

Monday, November 14, 8 p.m. ET

You can see our entire event calendar and watch previous events at AmericanBrainFoundation.org/events.

AMERICAN **BRAIN** FOUNDATION

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