



Annual Report

January - December 2023

Contents

Who we are

American Brain Coalition (ABC) background, our vision and mission, and our members.

(pages 3-11)

Our Team

Board of Directors, Corporate Advisory Council, Committees, Staff.

(pages 12-20)

Review of 2023

How the ABC's unified voice was used in 2023 to advocate and educate for those with disabling brain diseases and conditions.

(pages 21-39)

Closing

Thank you.

(page 40)



Who we are...

The American Brain Coalition (ABC) is a nonprofit organization comprising many of the United States' leading patient advocacy and voluntary health organizations, as well as professional neurological, psychological, and psychiatric associations. We also enjoy the support of a small number of publicly traded corporations that actively engage in brain-related research. Together, we seek to advance understanding of brain functions to reduce the burden of brain disorders through public education and advocacy.

With an established presence in Washington, DC, ABC is a strong and powerful voice for the 100 million people with disabling brain disorders, bringing together organizations that represent concerned and interested patients, families, and professionals. This voice is used to advocate for increased support of research that leads to better treatment; services and support that improves patients' quality of life; as well as a national commitment towards finding cures for individuals with disabling neurological and psychiatric disorders.



ABC'S VISION & MISSION

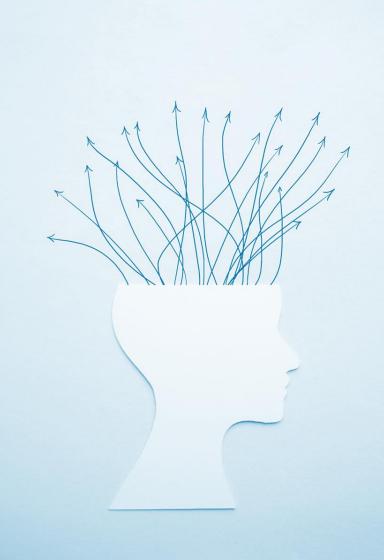
VISION

To improve the lives of *all* people impacted by brain diseases and conditions.

MISSION

We seek to advance understanding of brain functions to reduce the burden and stigma of brain diseases and conditions in order to improve the lives of impacted people by:

- 1. Convening organizations that provide brain research and treatment to create a sustainable platform for advocacy, innovation, and solutions.
- 2. Leading collaboration through member recruitment, engagement, and outreach, to develop expertise, strategies, processes, and policies.
- 3. Engaging the public, its representatives, and other stakeholders to enhance awareness, provide public advocacy, defeat stigma, and advance research opportunities.



Nonprofit Members





CLINICAL PSYCHOPHARMACOLOGY





Alliance for Patient Access



Association of America





American College of Neuropsychopharmacology























CHILD MEUROLOGY JOCIETY



The Headache

& Migraine



DYSPRAXIA

FOUNDATION USA





Cohen Veterans

Bioscience

Dyspra Na

DCD america

CARE SOCIETY











ANA NEUROLOGICAL ASSOCIATION















Association.

Cerebral

Research

Palsy











DYSTONIA













HAYSTACK PROJECT





















National Organization for













Multiple Sclerosis

Parkinson's

The Aneurysm and

Society

















Women's Health











SYNGAP1



















AWARENESS











Nonprofit Academic Members

















BREAKTHROUGHS FOR LIFE.®





Corporate Members

















































Observers



Agency for Healthcare Research and Quality

The BRAIN Initiative®

CMS.gov

Centers for Medicare & Medicaid Services

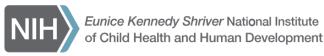












Healthy pregnancies. Healthy children. Healthy and optimal lives.



















Friends of the ABC



The Friends of the National Institute on Drug Abuse

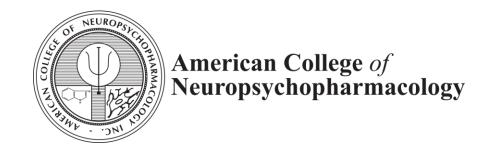
Friends of the National Institute of Mental Health (NIMH)

FRIENDS OF VA MEDICAL CARE AND HEALTH RESEARCH FOVA



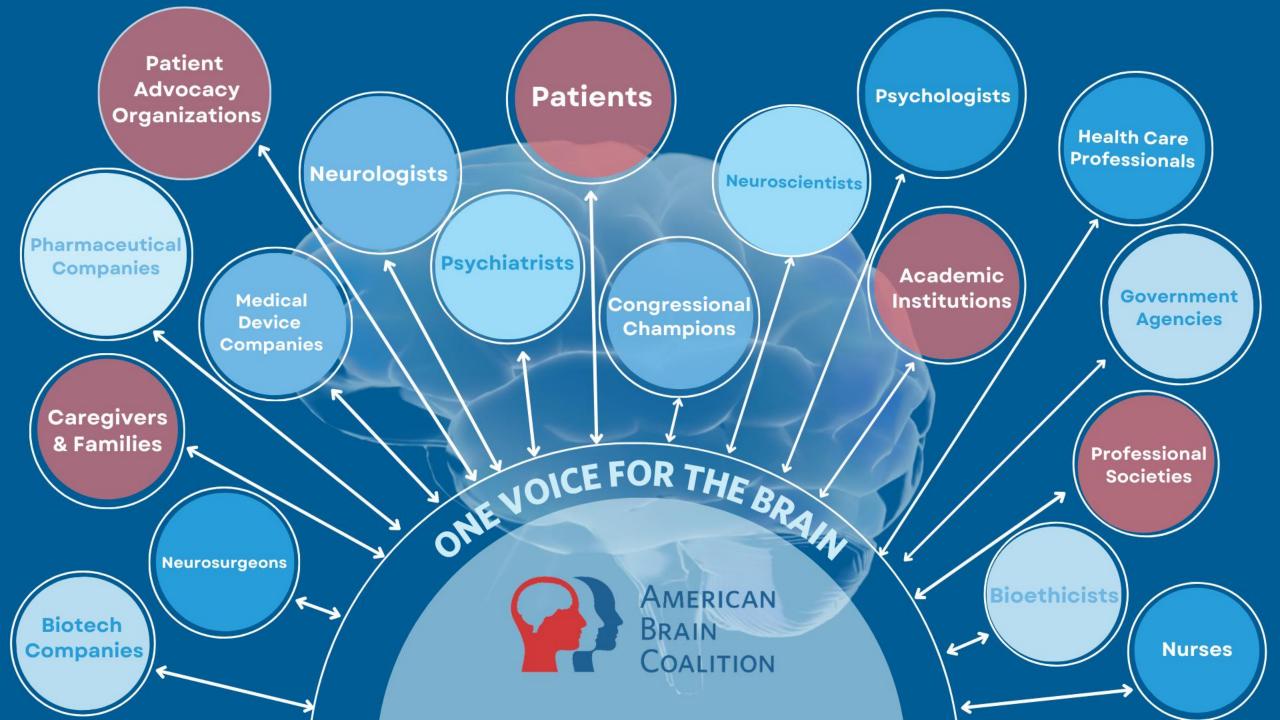
The ABC Receives Support From

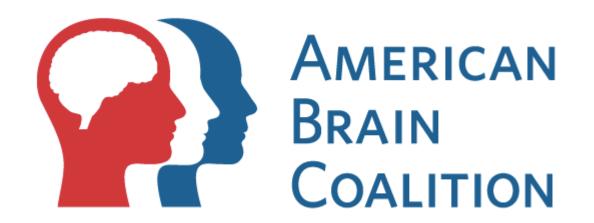






SIMONS FOUNDATION





Our Team

Passing the Gavel

On November 13th, 2023, the American Brain Coalition welcomed its sixth Board of Directors Chair.



Matthew Rizzo, PhD Past Board Chair



Mark Rasenick, PhD **Board Chair**

"I'm extremely thankful to Dr. Rizzo for his leadership these past four years. Among many of Dr. Rizzo's accomplishments, he was instrumental in ABC becoming more involved in the BRAIN Initiative with ABC formally joining the BRAIN Initiative Alliance. We look forward to working with Matt in his role as Past Chair.

I am excited for ABC to enter its next phase, as we begin our 20th year! We have an ambitious 5-year Stategic Plan, which will set us on the right path. Our entire Board looks forward to working with each and every member organization."



Board of Directors

EXECUTIVE COMMITTEE

CHAIR

Mark Rasenick, PhD Distinguished Professor of Physiology & Biophysics and Psychiatry University of Illinois, Chicago Caregivers

VICE CHAIR

Diana Felner Senior Director, Caregiver & Mental Health Policy Rosalvn Carter Institute for

PAST CHAIR

Matthew Rizzo, MD Frances and Edgar Reynolds Professor & Chair Department of Neurological Sciences University of Nebraska Medical Center

TREASURER

Patrick McCartney **Executive Director** International Essential Tremor Foundation

SECRETARY

Bobby Heagerty Emeritus Director. Community Affairs & Education Oregon Health & Science University

BOARD MEMBERS

Erika Augustine, MD, MS (term began Fall 2023) Associate Chief Science Officer Kennedy Krieger Institute

Christine Buckley (term began Fall 2023) **Executive Director Brain Aneurysm Foundation**

Josie Cooper **Executive Director** Alliance for Patient Access

Damien Fair, PA-C, PhD Professor, Department of **Pediatrics** University of Minnesota School of Medicine

Chantelle Ferland-Beckham, PhD

ABC Programming, Engagement & **Outreach Committee Chair** Senior Director, External Affairs Cohen Veterans Bioscience

Jennifer French (term began Fall 2023) **Executive Director** Neurotech Network

Theanne N. Griffith, PhD Assistant Professor. Department of Physiology & Membrane Biology University of California, Davis Jason Kopinski, MS, CAE

Deputy Executive Director, Chief Operating Officer American Academy of Neurology

Michele Oshman

Vice President, External Relations Biotechnology Industry Organization

Leslie S. Ritter. MA ABC Advocacy Chair Vice President. Healthcare Access National Multiple Sclerosis Society Mar Sanchez, PhD

Division Chief & Core Scientist. **Developmental & Cognitive** Neuroscience **Emory National Primate Research** Center

Stephen Strakowski, MD

Executive Director, Stone Center for Child and Adolescent Psychiatry, Indiana University School of Medicine, Indianapolis Associate Vice President, Regional Mental Health, University of Texas Dell Medical School, Austin

Sarah Tellock

Associate Director, Federal Affairs & Alliance Development Manager Alzheimer's Association

Madhukar Trivedi. MD

Founding Director of Center for Depression Research & Clinical Care Betty Jo Hay Distinguished Chair of Mental Health University of Texas Southwestern **Medical Center**

Hannah Wesolowski (term began Fall 2023) Chief Advocacy Officer National Alliance on Mental Illness

Marina Wolf. PhD

Professor, Behavioral Neuroscience Oregon Health & Science University

Emeritus Board Advisors

Over the years, the following individuals have been true assets and friends to the American Brain Coalition (ABC). Their leadership has been instrumental in the ABC's growth, advancing links between our advocacy, professional, corporate, and academic partners and communities. The ABC Board will consult from time-to-time for the wisdom of our Emeritus Board Advisors on ABC strategic issues.

Francis Kittredge, Jr. MD
ABC Founding Chair
2004-2008

Joseph Coyle, MD Chair 2008-2011

Robin Elliott
Chair 2011-2015

Janet Hieshetter Chair 2015-2019 Cathy Rydell
ABC Founding Board Member
2004-2015

Louise Vetter
Treasurer 2014-2019

Emanuel DiCicco-Bloom, MD Board Member 2019-2021



Corporate Advisory Council

Corporate members within the ABC are comprised of leading companies who recognize the importance of partnering with those committed to helping people with brain diseases and disorders. Corporate members include pharmaceutical, biotech, and medical device companies that are developing or marketing therapeutic or diagnostic products.

ABC corporate members may designate one individual to represent them on the ABC's Corporate Advisory Council (CAC). The Council provides unique opportunities for companies to engage with experts in the brain disease community, not only with patient advocacy organizations, but also with top scientific, clinical and policy experts and leaders in the worldwide central nervous system space.



Medical Director, Neuroscience U.S. Clinical Development and Medical Affairs Novartis Pharmaceuticals Corporation

Deena Andreola

Director, Therapeutic Policy & Advocacy, US Public Affairs Takeda Pharmaceuticals America

Nancy Bayerlein

Director, Patient Engagement and Support Mitsubishi Tanabe Pharma America

Reina Benabou, MD, PhD

Vice President & Head of Medical Affairs Janssen Neuroscience US

Todd Bledsoe

Executive Director, Patient Engagement & Advocacy Neurocrine Biosciences, Inc.

Benjamin Collins

Senior Manager, Strategic Alliances and Advocacy Biogen, Inc.

Lara Crissev

Lead US Patient Advocacy & Professional Relations Team Patient Engagement for Therapeutic Areas Boehringer Ingelheim Pharmaceuticals

Caroline Fisher-O'Neill

Director of Alliance Development, Government Affairs and Public Policy Otsuka America Pharmaceutical

Julie Garner

Vice President, Government Affairs and Public Policy Sage Therapeutics

Shannon Gilbert

Associate Manager, Marketing Advocacy Lead Teva Pharmaceuticals

Peter Norman

Senior Vice President, Policy & Government Relations Alkermes

Natalie Green

Vice President of Business Development Kernel

Karas Gross

Senior Director, Federal Government Affairs Jazz Pharmaceuticals

Marybeth Howlett

Senior Director Eli Lilly & Company

Ross Martin

Director, Patient Advocacy Praxis Precision Medicines

Retsina Meyer, PhD

Head of Corporate Strategy Delix Therapeutics



Jordann Phillips

Associate Director, Communications and Patient Advocacy
Alto Neuroscience

Marsie Ross

Director, Provider Advocacy & Policy Harmony Biosciences, LLC

Maureen Sheltry

Executive Director, Advocacy Relations Sunovion

Heather Strawn

Vice President, Government Affairs Lundbeck Pharmaceuticals LLC

Michael Tunkelrott

Vice President, Marketing Synaps Dx Biomarker Technology



Advocacy Committee

The American Brain Coalition (ABC) Advocacy Committee recommends and reviews the ABC's legislative priorities to the Board. The Advocacy Committee communicates the legislative priorities to ABC members, as well as to policymakers and their staff. The Advocacy Committee monitors and reports back to the membership any congressional and agency activities and policy relevant to the ABC.



Leslie S. Ritter, MA Vice President, **Healthcare Access** National Multiple Sclerosis Society



COMMITTEE MEMBERS

Juliane Baron

Executive Director Federation of Associations in Behavioral & Brain Sciences (FABBS)

Wade H. Berrettini, MD, PhD

Director.

Center for Neurobiology & Behavior University of Pennsylvania

Katherine Bloom

Advocacy Associate Society for Neuroscience

Phil Cronin

Legislative Consultant Cure Alzheimer's Fund

Bobby Heagerty

ABC Secretary

Emeritus Director, Community

Affairs & Education

Oregon Health & Sciences University **Brain Institute**

Helen Mayberg, MD

Professor, Neurology, Neurosurgery, Psychiatry, and Neuroscience Icahn School of Medicine at Mount Sinai

Patrick McCartney

ABC Treasurer **Executive Director** International Essential Tremor

Foundation

Kelly McCone, MPA

Senior Congressional Affairs

Manager

American Academy of Neurology

Eileen Murray, MM, CAE

Chief Executive Officer American Epilepsy Society

James Ramsey

Advisory Board Member Center for BrainHealth

Mar Sanchez, PhD

Division Chief & Core Scientist, Developmental & Cognitive Neuroscience **Emory National Primate Research** Center

Stuart Spielman

Senior Policy Adviser and Counsel **Autism Speaks**

Sarah Tellock

Associate Director, Federal Affairs & Alliance Development Manager Alzheimer's Association

Jose I Suarez, MD, FNCS, FANA, FAAN

Past President Neurocritical Care Society, Founding & Past Chair **Neurocritical Care Research Network**

Madhukar Trivedi, MD

Founding Director of Center for Depression Research and Clinical Care Betty Jo Hay Distinguished Chair of Mental Health University of Texas Southwestern **Medical Center**

Michael Ward, MS

Vice President of Public Policy and **Government Relations** Alliance for Aging Research

Sallie Weart

Associate Director, Government Relations The Michael J. Fox Foundation for

Parkinson's Research

Laura Weidner, Esq.

Vice President, Government Relations & Advocacy **Epilepsy Foundation**

Monica Weldon

President & Chief Executive Officer SYNGAP1 Foundation

Justine Welsh, MD **Assistant Professor Emory University School of Medicine**

Olivia Woodrich

Policy Coordinator Tourette Association of America



Finance Committee

The American Brain Coalition (ABC) Finance Committee assists the Board of Directors in its fiscal management responsibilities, overseeing annual budgeting and financial practices, reviewing financial best practices, and making recommendations in accordance with ABC's mission and objectives.

COMMITTEE CHAIR

Patrick McCartney

ABC Treasurer

Executive Director

International Essential Tremor Foundation

COMMITTEE MEMBERS

Mark Rasenick, PhD

ABC Board Chair
Distinguished Professor of
Physiology & Biophysics and Psychiatry
University of Illinois, Chicago

Diana Felner

ABC Board Vice Chair
Vice President, Public Policy
Tourette Association of America

Matthew Rizzo, MD

ABC Past Chair
Frances and Edgar Reynolds
Professor & Chair
Department of Neurological Sciences
University of Nebraska Medical Center

Jason Kopinski, CAE

Deputy Executive Director | Chief Operating Officer American Academy of Neurology

Stephen Strakowski, MD

Executive Director, Stone Center for Child and Adolescent Psychiatry Indiana University School of Medicine, Indianapolis Associate Vice President, Regional Mental Health University of Texas Dell Medical School, Austin

Marina Wolf, PhD

Professor, Behavioral Neuroscience Oregon Health & Science University



Programming, Engagement & Outreach Committee

The American Brain Coalition (ABC) Programming, Engagement & Outreach (PEO) Committee is responsible for developing, implementing, and monitoring educational programs, and membership and community engagement and outreach efforts offered by the Coalition. The Committee will also evaluate and recommend to the ABC Board of Directors any partnerships or collaborations that will contribute to the program goals of the ABC.

COMMITTEE CHAIR

Chantelle Ferland-Beckham, PhD Senior Director, External Affairs Cohen Veterans Bioscience



Chinmavi Balusu

Founder & CEO Simply Neuroscience

Jennifer French

Executive Director Neurotech Network

Bill Griesar, PhD

Neuroscience Coordinator NW Noggin

Susan Gurley

Executive Director Anxiety & Depression Association of America

Christine Harhai

Director, Advocacy and Strategic Alliances **PhRMA**

Bobby Heagerty

ABC Secretary Emeritus Director, Community Affairs & Education Oregon Health & Science University

Chevanne Lewis

Junior Specialist Department of Physiology & Membrane Biology University of California, Davis

Susan Raymond, PhD

Director, Foundation and Nonprofit Relations Medical Technology Enterprise Consortium (MTEC)

Gabriella Rizzo, MD, MBA

Resident Physician Department of Neurological Sciences University of Nebraska Medical Center



Staff



Katie Sale **Executive Director** ksale@americanbraincoalition.org



Sheila Stern Director of Engagement & Administration sstern@americanbraincoalition.org





Review of 2023



2024-2029 Strategic Plan

To better align with our new Vision and Mission, ABC's Board adopted a strategic plan which outlines aspirational goals, initial strategies, and metrics and tactics for reaching these goals. ABC's Aspirational Goals – what we strive to be -include:

- 1. Be highly relevant to our members (Convening).
- 2. Increase diversity to look like the US (Convening).
- 3. Increase public visibility and influence to help substantially increase funding of neuroscience research (Leading).
- 4. Influence the regulatory process to speed translation of neuroscience research into life changing therapies (Leading).
- 5. Be highly engaged within our members and with like-minded organizations (Engaging).

View ABC's 2024-2029 Strategic Plan in its entirety.

2023 Public Policy Priorities

ABC has developed a set of public policy priorities to direct our advocacy work. Advancing these public policy priorities brings the ABC closer to fulfilling its mission to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through education, public advocacy, and outreach. As part of that mission, the ABC is dedicated to reducing the burden of illness, injury, disability and mortality among minority populations and older adults. In all we do, the ABC is working toward the elimination of health disparities, whether resulting from race/ethnicity, economic states, or stigma against brain disorders.

The following public policy priorities, which guide ABC's advocacy, are listed in alphabetical order below. Click on each priority for full description.

Chronic Care

Ethical Use of Animals in Research

Federal Investment in Brain Research

Innovative Approaches for Developing New CNS Cures

Mental Health and Substance Use Insurance Parity

Stem Cell Research

Congressional Neuroscience Caucus

PRESS RELEASE Announcing New CNC Co-Chair~ March 16, 2023

Congressman Luttrell Named Congressional Neuroscience Caucus Co-Chair



Representative Earl Blumenauer (D-OR)
Co-Chair, Congressional Neuroscience Caucus



Representative Morgan Luttrell (R-TX)
Co-Chair, Congressional Neuroscience Caucus

2023 Congressional Neuroscience Caucus (CNC) Briefings

The bipartisan Congressional Neuroscience Caucus (CNC) promotes a better understanding of how the brain develops, functions, and ages. Co-chaired by Representative Cathy McMorris Rodgers (R-WA) and Representative Earl Blumenauer (D-OR), the caucus seeks to raise awareness about the millions of Americans afflicted with neurological disorders or mental illnesses. As emerging research has demonstrated the profound impact of COVID-19 on the brain, ABC has leveraged its relationship with the CNC to provide information to Congressional staff and the public to promote advances in neuroscience and brain health and recruit additional champions of neuroscience in Congress.

May 3, 2023

The Real-World Impact of NIMH Research (View Summary) (View Recording) Congressional briefing held by the Friends of NIMH, in conjunction with the Congressional Mental Health Caucus and the CNC focusing on the importance of research supported by the NIMH. Opening remarks provided by CNC co-chairs Representatives Earl Blumenauer (D-OR) and Morgan Luttrell (R-TX). The panel of speakers included Dr. Joshua Gordan, Director of NIMH, Dr. Rebecca Price, Associate Professor, University of Pittsburg, Dr. David Mohr, Professor, Northwestern University, Feinberg School of Medicine, Eden Shaveet, Patient Advocate and moderator, Theresa Nguyen, Chief Program Officer, Mental Health America.

June 14, 2023

The NIH BRAIN Initiative: Accelerating Discovery Toward Cures (View Summary) (Held in-person)

Briefing co-hosted with the Allen Institute, ACNP, Dana Foundation, and Simons Foundation. The panel of speakers included Dr. John Ngai, Director, The NIH BRAIN Initiative®, Katie Whitson, Baylor College of Medicine BRAIN Study Participant, Dr. Nicole Provenza, Postdoctoral Fellow, Baylor College of Medicine, Dr. Ed Lein, Senior Investigator, Allen Institute for Brain Science, Jennifer French, Executive Director, Neurotech Network and moderated by Dr. Kafui Dzirasa, Ranga Rama Krishnan Professor, Duke University Medical Center

September 20, 2023

<u>Back-to-School Congressional Briefing on Social Media</u> & Youth Mental Health

(View Recording) (View Summary)

Briefing was co-hosted by ACNP, American Psychological Association, and Dana Foundation and featured opening remarks provided by CNC co-chairs Representatives Earl Blumenauer (D-OR) and Morgan Luttrell (R-TX). The panel of speakers included Dr. Gaya Dowling, Director, ABCD Study® National Institute on Drug Abuse, National Institutes of Health, Dr. Elizabeth Hoffman, Senior Scientific Program Manager, ABCD Study® National Institute on Drug Abuse, National Institutes of Health, Dr. Mitch Prinstein, Chief Science Officer, American Psychological Association.

November 13, 2023

Brains, Bagels, Synapses & Schmears Social

(<u>View Summary</u>) (Held in-person)

Briefing was co-hosted with Allen Institute and the Dana Foundation. Northwest Noggin was back on Capitol Hill in DC, bringing their energizing and engaging approach to Members of Congress & staffers, who learned a bit more about neuroscience while creating some art of their own and holding real brains. Neuroscientists, undergrad, and grad students from the Pacific Northwest explored the importance of basic research, public outreach, and how an arts-integrated approach to STEM education helps bring knowledge, understanding, inclusion, and excitement to all of us.

November 14, 2023

<u>The Invisible Threat: Understanding, Recognizing, and Treating PTSD</u> (View Summary)

As part of Neuroscience 2023, the Congressional Neuroscience Caucus in cooperation with the Society for Neuroscience and the ABC, hosted a Congressional briefing on post-traumatic stress disorder. The briefing featured opening remarks provided by CNC co-chairs Representatives Earl Blumenauer (D-OR) and Morgan Luttrell (R-TX). An expert panel of speakers discussed the latest fundamental research and discoveries into post-traumatic stress disorder (PTSD).

Innovation Initiative (ABCI2)

In 2017, the ABC established an Innovation Initiative (ABCI2), a collaborative program to stimulate private investment in brain-related research, remove regulatory and financial barriers to research, and strengthen the entire R&D system for expedited translation of neuroscience research into life-changing therapies and cures. This ABC advocacy effort is comprised of key stakeholders within the brain community, including patient advocacy groups, professional societies, and industry, collaborating to advance policy positions, legislation, and regulations that will strengthen incentives to invest in neuroscience research – positively impacting brain disorders. This program has provided several resources to the ABC membership, including a guide to navigating Public-Private Partnerships.

FDA Engagement: Speeding the Delivery of Cures and Treatments

FDA Neurology Drug Program

Over the past few years, ABC has been advocating to address the unmet need for treatments and cures for brain conditions, with a particular emphasis on improving patient engagement in the Food and Drug Administration (FDA) process. Thanks to our member organizations and key partners' efforts, as well as key champions in Congress, an omnibus appropriations bill included \$2 million for a Neurology Drug Program in Fiscal Year 2023. This program will focus on policy and guidance that keeps pace with scientific discovery in neuroscience, the advance the prevention and early detection of brain conditions. ABC continues to meet with FDA leaders to ensure psychiatric and psychological conditions are included in this program, as well as patient engagement at all levels.

Earlier this year, Dr. Rizzo presented written testimony to the Senate Agriculture, Rural Development, FDA, & Related Agencies Subcommittee (where NDP funding is included) requesting additional funding for this program.

In March, ABC led a brain community effort and sign-on letter to the House and Senate to provide \$3 million for the Neurology Drug Program.

FDA Total Product Life

On January 10, 2023, ABC submitted comments to FDA regarding the launch of its Total Product Life Cycle Advisory Program (TAP) Pilot. The TAP Pilot aims to spur rapid development and widespread patient access to safe, effective, and high-quality medical devices. ABC's comments were built around our goal to mitigate the unmet need for safe and effective treatments for brain and central nervous system conditions. The TAP Pilot was originally limited to the Office of Health Technology 2 (OHT2): Office of Cardiovascular Diseases. Our comments requested that FDA expand the TAP Pilot to OHT5: Office of Neurological and Physical Medicine Devices to address the brain and CNS disorders that impact more than 100 million Americans. Additionally, ABC encouraged FDA to focus on patient engagement and offered our coalition and expert member organizations as a resource for FDA and product sponsors as the TAP Pilot gets underway.

In October of this year the FDA Total Product Life Cycle (TPLC) Advisory Program (TAP) Pilot officially expanded into devices overseen by the Office of Neurological and Physical Medicine Devices. The American Brain Coalition is excited to collaborate with FDA in engaging the larger brain stakeholder community. We'll continue to keep you updated, provide resources, and ask for input in 2024.



BRAIN Initiative

The American Brain Coalition was thrilled to become a member of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative Alliance in 2021. Comprised of federal and non-federal members and affiliates, the BRAIN Initiative Alliance mission is to coordinate and facilitate communications from its members related to the BRAIN Initiative.

Visit the <u>BRAIN Alliance site</u> for more information on how each Alliance member is contributing to this coordinated effort.



On June 14, 2023, the Congressional Neuroscience Caucus (CNC), in partnership with the American Brain Coalition, the Allen Institute for Brain Science, the American College of Neuropsychopharmacology, the Dana Foundation, and the Simons Foundation hosted an in-person Congressional briefing highlighting the groundbreaking research carried out by the Brain Research Through Innovative Neurotechnologies® Initiative, or The BRAIN Initiative®, within the National Institutes of Health (NIH).





















National Institutes of Health



View the summary of the briefing.

Appropriations

Looking back, on Dec. 29, 2022, President Joe Biden signed the Fiscal Year (FY) 2023 Consolidated Appropriations Act, 2023 into law, which included \$1.7 trillion in discretionary government funding for all 12 annual spending bills and several other health care provisions. The bill contained \$226.8 billion for Labor, Health and Human Services, Education, and Related Agencies (LHHS-Ed), an increase of \$15 billion – 7.1 percent – above FY 2022. The package pledged \$47.5 billion to the National Institute of Health (NIH), an increase of approximately \$3 billion, and \$9.5 billion to the National Science Foundation (NSF), an increase of approximately \$700 million. The BRAIN initiative received \$680 million, a significant increase of \$60 million. Finally, the agreement provided \$1.5 billion to the Advanced Research Projects Agency for Health (ARPA-H), a half-billion-dollar increase.

From the start of 2023, ABC continued to advocate for an increase or maintenance in funding levels for brain research and health to advance our mission to reduce the burden of brain diseases and conditions for those impacted. We entered the calendar year on the heels of a successful appropriations process. Thanks to the advocacy of ABC and partner organizations, Congress made significant investments in biomedical and brain health research programs. However, the political landscape in 2023 presented barriers that were difficult for Congress to overcome in order to set spending levels for FY 2024.

Before Congress could fully move to FY 2024 appropriations, they faced the daunting task of addressing the federal debt ceiling. On May 27, 2023, President Biden and then Speaker Kevin McCarthy (R-CA) reached an agreement to suspend the debt ceiling, just days before the Treasury was expected to run out of operating funds. The Fiscal Responsibility Act averted potential economic disaster by extending the suspension of the debt limit until January 2025. It also established spending caps for discretionary programs in FY 2024 and FY 2025 and encouraged Congress to pass all FY 2024 spending bills by January 1, 2024, or OMB would implement a 1 percent cut across all non-defense discretionary programs in April.

Appropriations cont.

From the start, the FY 2024 appropriations process was set to be a struggle for Congress. The two parties held firm and contrary positions on funding levels, with many Republicans calling for even steeper spending cuts than those outlined in the FRA, and Democrats looking for opportunities to boost funding where they could. As the appropriations process began at the committee level, few anticipated the extent of challenges that would unfold later in the year.

While the Senate Appropriations Committee successfully advanced all 12 appropriations bills out of committee for the first time in five years, the summer months did not go as smoothly in the House. The House Appropriations Committee was unable to advance all its bills as some Republicans insisted on controversial policy riders and funding cuts that went beyond the parameters of the FRA. The House Freedom Caucus sent a letter to then-Speaker McCarthy on July 10, 2023, stating that they would not support Appropriations bills that are above FY 2022 levels. The large disparity between House and Senate appropriations bills caused a funding standoff and President Biden released a statement stating he will not sign anything into law that is below his released FY24 budget.

Upon the return from August recess and with a government closure looming on September 30th, then-Speaker McCarthy flirted with the idea of a stopgap funding bill to keep the government open through November or early December. The Republican Conference was not in favor of this stopgap option and vowed to vote in opposition. At the last minute, Speaker McCarthy collaborated with the Democrats to pass a clean continuing resolution (CR) until November 17th. This CR was signed into law by President Biden, averting a government shutdown.

Appropriations cont.

After Speaker McCarthy passed the CR with the support of Democrats, a small group of Republicans led by Rep. Matt Gaetz (R-FL), led a successful effort to remove McCarthy from the Speakership. After 21 days without a Speaker, and with no ability to make progress on appropriations or other legislative activities, the House Republican Conference eventually rallied behind Rep. Mike Johnson (R-LA) to fill the vacant post. The leadership vacuum in the House stalled the appropriations process, but difficulties, including disagreements over funding levels and policy riders on controversial topics like abortion and law enforcement policy, remained.

As the struggle to pass individual appropriations bills dragged on, the House voted on November 14 to pass a "laddered" CR to extend FY 2023 spending and avoid a government shutdown. The following day the U.S. Senate voted to clear the stopgap measure, sending the bill to the President's desk for signature. The "laddered CR" has two separate expiration dates for two groups of annual spending bills: Ag/FDA, MilCon/VA, Energy & Water, and Transportation-HUD are extended through January 19, 2024; and LHHS-Ed, CJS, Defense, Financial Services & General Government, Homeland Security, Interior-Environment, Legislative Branch, and State & Foreign Operations are extended through February 2, 2024.

Congress adjourned for the year without agreeing on topline numbers for a final spending agreement and face a challenging task as members return from the holidays to struggle with two impending deadlines that could result in a partial or complete government shutdown if bipartisan negotiations fail.

On January 7, 2024, Congressional leaders announced they had come to a deal on overall budget numbers that could lead to a final appropriations agreement for FY 2024 so, as of this writing, bipartisan negotiations to finalize FY2024 spending can begin in earnest.

Summary of Congressional Action on Appropriations ABC follows

As of this writing, no FY 2024 funding bills have been enacted into law.

Military Construction, Veterans Affairs, and Related Agencies (MilCon/VA)

- The House Appropriations released its MilCon/VA Appropriations bill on May 17, 2023, with \$938 million allocated towards the Veteran's Affairs Medical and Prosthetic Research, a \$22 million proposed increase. The House passed the measure on July 27, 2023.
- On June 22, 2023, the Senate Appropriations Committee approved its version of the MilCon/VA bill, which also included \$938 million for the VA Medical and Prosthetic Research Program. The Senate passed the MilCon/VA bill on June 22, 2023, as part of a package of several appropriations bills called a "minibus."

Commerce, Justice, Science, and Related Agencies (CJS)

- On July 13, 2023, the Senate Appropriations Committee passed its CJS bill, proposing funding for the National Science Foundation (NSF) at \$9.5 billion, about \$40 million short of the FY 2023 allotment.
- On July 14, 2023, the House Appropriations CJS Subcommittee passed its CJS bill. The bill proposed \$9.6 billion for the National Science Foundation (NSF), almost exactly equal to the allocation from FY 2023.
- Later, House Republicans attempted to bring the CJS bill directly to the House floor, bypassing full committee consideration, but failed to pass a rule for debate in the House Rules Committee and the bill moved no further.

Summary of Congressional Action cont.

Labor, Health and Human Services, Education, and Related Agencies (LHHS-Ed)

- On July 27, 2023, the Senate Appropriations Committee advanced its FY 2024 LHHS-Ed bill, including funding for NIH of \$47.7 billion, a \$265 million increase over FY 2023 funding. The BRAIN initiative was listed at \$680 million, which is equal to the FY 2023 funding level. ARPA-H was also listed at the same funding level as FY 2023, with \$1.5 billion proposed.
- The House LHHS-Ed Subcommittee advanced a bill proposing drastic cuts across the board. However, the bill did not immediately advance through the full committee. When the report was made publicly available later in the year it showed potentially devasting proposed cuts to essential health and research programs. The House measure called for \$44.6 billion for NIH, a cut of more than \$2 billion; \$172 billion for the BRAIN Initiative, a drastic cut of more than \$500 million; and \$500 million for ARPA-H, a \$1 billion cut.
- In November, House Leadership brought the LHHS-Ed bill to the floor, bypassing the full committee. The House began debate on the LHHS-Ed bill, considering numerous amendments, before ending debate on the bill when it was not expected to pass.

Agriculture, Rural Development, Food and Drug Administration, and Related Agencies (Ag/FDA)

- The Senate Appropriations Committee advanced its Ag/FDA bill on June 22, 2023, and the measure passed the Senate on November 1, within in the three-bill minibus. The measure included \$3 million, an increase of \$1 million, to support the Neurology Drug Program at the FDA, a key priority of ABC.
- The House Committee advanced its Ag/FDA bill on June 14, 2023, but when they brought the bill to the House floor in September, it failed to pass. The House version of the bill did not include funding for FDA's Neurology Drug Programs

SIGN-ON OPPORTUNITIES

February 13, 2023 - BENEFIT Act Support Letter

The American Brain Coalition signed onto a letter being circulated by Parent Project Muscular Dystrophy in support of the BENEFIT Act, which would ensure that patient experience, patient-focused drug development (PFDD), and related data be considered as part of the risk-benefit assessment.

March 3, 2023 - Ad Hoc Group FY24 Recommendation for NIH

The American Brain Coalition signed onto a letter being circulated by The Ad Hoc Group for Medical Research outlining their recommendation for Fiscal Year 2024 and urging lawmakers to continue to support patients and discovery and to ensure a funding allocation for the Labor-HHS Subcommittee that allows for the necessary investment in NIH and other agencies.

March 7, 2023 - AHRQ FY24 Appropriations Letter

The American Brain Coalition signed onto a letter being circulated by Friends of AHRQ requesting \$500 million in FY24 appropriations for AHRQ; the same level advocated for in FY23.

March 10, 2023 - Support of CARE for Long COVID Act

The American Brain Coalition signed onto the CARE for Long COVID Act one-pager.

March 13, 2023 - FY 2024 FOVA Recommendations for VA Research

The American Brain Coalition signed onto a letter being circulated by FOVA supporting their FY 2024 recommendation of \$980 million for the VA Medical and Prosthetic Research program.

March 13, 2023 - BENEFIT Act Support Letter

The American Brain Coalition signed onto a letter being circulated by Parent Project Muscular Dystrophy in support of the BENEFIT Act, which would elevate the patient voice in the FDA drug development process.

March 23, 2023 - LHHS FY 24 3023(b) Allocation

The American Brain Coalition signed onto the Coalition for Health Funding, Committee for Education Funding, Campaign to Invest in America's Workforce, and Coalition on Human Needs joint sign-on letter calling for an LHHS FY24 302(b) allocation that builds on FY23's \$226.8 billion to address the gap created by years of underfunding.

March 24, 2023 - FY 24 BRAIN Initiative Funding

The American Brain Coalition circulated a letter requesting the Committee provide at least \$740 million for the BRAIN Initiative in FY 2024.

March 24, 2023 - Neurology Drug Program FY 24

The American Brain Coalition circulated a letter encouraging the House and Senate to provide \$3 million for the Neurology Drug Program, which will help speed the delivery of safe and effective treatments for brain diseases, mental health conditions, and brain injuries.

April 7, 2023 - Tardive Dyskinesia Awareness Week One-pager

The American Brain Coalition signed onto a letter being circulated by the Movement Disorder Policy Coalition regarding Tardive Dyskinesia Awareness Week 2023.

May 5, 2023 - Non-defense discretionary spending letter

The Am<mark>erican Brain Coalition signed onto a letter to Congress being circulated by the Coalition for Health Funding, Coalition on Human Needs, Committee on Education Funding, and Campaign to Invest in America's Workforce to reject cuts to non-defense discretionary (NDD) appropriations.</mark>

May 7, 2023 - National Brain Donation Awareness Day

The American Brain Coalition signed onto a letter being circulated by the Brain Donor Project in support of the House Resolution stating May 7th as National Brain Donation Awareness Day.

May 15, 2023 - FY24 Psychedelics Appropriations

The American Brain Coalition has signed on to a FY24 Psychedelics Appropriations letter being circulated by the Coalition to Heal Invisible Wounds which asks for \$80 million to the VA in support of scaling clinical research into psychedelic compounds.

June 20, 2023 - FY24 Appropriations

The American Brain Coalition has signed on to a FY24 Appropriations letter being circulated by the LEAD Coalition encouraging the keeping of momentum toward the National Alzheimer's Plan goals and the commitment to advancing science, care and support, and public health.

September 20, 2023 - FY24 BRAIN Initiative Funding

The American Brain Coalition circulated a letter in support of the Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies providing robust funding to the BRAIN Initiative in FY24.

September 25, 2023 - CHANGE Act

The American Brain Coalition signed onto a letter being circulated by the LEAD Coalition supporting the CHANGE Act (Concentrating on High-Value Alzheimer's Needs to Get to an End Act.

October 1, 2023 - FIND Act

The American Brain Coalition signed onto a letter being circulated by the Medical Imaging & Technology Alliance in support of the FIND Act.

ABC 2023 Statements & Letters

Based on our policy issues, the ABC regularly provides statements and letters in support of or opposition of legislative bills.

Statements:

October 27, 2023 - ABC Submits Comments in Response to RFI on the NIH

September 28, 2023 - ABC Submits Comments in Response to Mental Health Parity Proposal

September 25, 2023 - ABC Submits Al Comments to Senator Cassidy

April 5, 2023 - ABC FY24 Outside Witness Testimony to the Senate

April 5, 2023 - ABC FY24 Outside Witness Testimony to the House

January 10, 2023 - ABC Comments to FDA on Total Product Life Cycle Advisory Program (TAP) Pilot

Letters:

November 9, 2023 - ABC Appropriations Letter to Congress urging the passing of a continuing resolution

July 12, 2023 - ABC Letter encouraging the advancement of the nomination of Dr. Monica Bertagnolli for NIH Director

Resources

The American Brain Coalition is committed to providing its members and the public with resources on the brain to advance understanding about the cause, impact, and consequences of neurologic and psychiatric illness in our society.





Responsible Use of Animals in Research

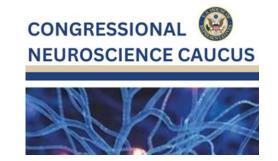


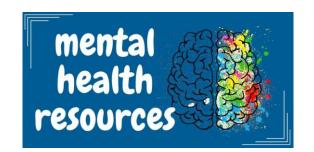






















Neuroscience in the midst of COVID-19

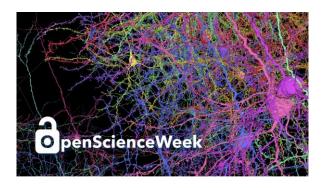
Ways to Get Involved...















Stay Connected with the ABC

One of the many ways we can work together is through our social media accounts! We encourage all of our members to make sure they are connected to our accounts so we can share stories, events and valuable resources as we continue the work for the many affected by brain disorders.











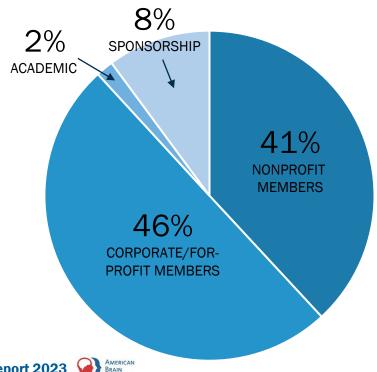
#ABrainCoProud

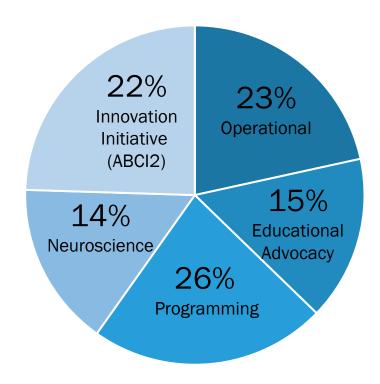
Financials

ABC relies on the generous support of membership dues, along with a small amount of sponsorship, to help ensure our modest total operating budget, which was just over \$400,000 in 2023. This revenue is used to support ABC's educational and advocacy programming.

2023 Revenue

2023 Expenses



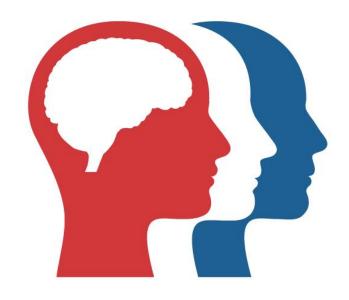




We will be celebrating our 20th Anniversary in 2024!

Stay tuned for events throughout the year as we celebrate the accomplishments of the past 20 years and look forward to the impactful innovations and advancements to come.





AMERICAN BRAIN COALITION

Thank you

Thanks to your commitment and collaboration, we know next year will be even better than the last.

We look forward to working together.

<u>communications@americanbraincoalition.org</u> <u>www.americanbraincoalition.org</u>



