

Annual Report

January – December 2022

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Closing

Thank you.

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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 and stigma of brain diseases and conditions in order to improve lives of affected people.

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.

On behalf of all who live with neurological and psychiatric disorders, we invite organizations that share our concerns and goals to join us in our educational, engagement and advocacy efforts.





ANNOUNCING ABC'S NEW MISSION & VISION

VISION

To improve the lives of *all* people affected 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 lives of affected 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.





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Nonprofit Members

1 of 2



Nonprofit Members



2 of 2

Nonprofit Academic Members





MASSACHUSETTS GENERAL HOSPITAL

HARVARD MEDICAL SCHOOL







BREAKTHROUGHS FOR LIFE."





Corporate Members





CMS.gov Centers for Medicare & Medicaid Services





Neurodiagnostics and Neurosurgical Devices Branch (NDNB) Neurointerventional Devices Branch (NIDB) Neurostimulation Devices Neurology Branch (NSDN) Neurostimulation Devices Psychiatry Branch (NSDP) Physical Medicine and Rehabilitation Devices Branch (PMDB)





Eunice Kennedy Shriver National Institute of Child Health and Human Development

Healthy pregnancies. Healthy children. Healthy and optimal lives.



National Institute on Aging



National Institute of General Medical Sciences



National Cancer Institute



National Center for Advancing Translational Sciences



National Institute on Deafness and Other Communication Disorders (NIDCD)



National Institute of Mental Health



National Institute on Drug Abuse



National Institute of Neurological Disorders and Stroke

Friends of the ABC



Friends of the National Institute of Mental Health (NIMH)











Matthew Rizzo, PhD Board Chair

"I am ever grateful to be serving the American Brain Coalition, a unique marketplace of ideas for our many members and constituents, speaking together with one voice, to make heard the stories of over 100 million people living with 1,000 different brain disorders. Acting in concert in 2023, we will further advance strategic legislation and policies for greater neuroscientific discovery, care and cures for all Americans affected by these conditions".





Flow Chart



Board of Directors

EXECUTIVE COMMITTEE

CHAIR

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

VICE CHAIR

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

PAST CHAIR

Janet Hieshetter Executive Director Dystonia Medical Research Foundation

TREASURER

Diana Felner Vice President, Public Policy Tourette Association of America

SECRETARY

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

BOARD MEMBERS

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

(term began Fall 2022) Senior Director, External Affairs Cohen Veterans Bioscience

L. John Greenfield, Jr., MD, PhD Department of Neurology Chair UConn Health

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

John L. Lehr

Chief Executive Officer Parkinson's Foundation

Helen Mayberg, MD

(rotated off Fall 2022) Professor, Neurology, Neurosurgery, Psychiatry, and Neuroscience Icahn School of Medicine at Mount Sinai

Patrick McCartney

ABC Programming, Engagement & Outreach Committee Chair Executive Director International Essential Tremor Foundation

Craig Obey, JD

Chief of Government Relations American Psychiatric Association

Michele Oshman

Vice President, External Relations Biotechnology Industry Organization

Gentry Patrick, PhD

Professor, Neurobiology Section, Division of Biological Sciences, University of California, San Diego

Leslie S. Ritter, MA

ABC Advocacy Committee Chair Associate Vice President, Federal Government Relations National Multiple Sclerosis Society

Mar Sanchez, PhD

(term began Fall 2022) 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

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 Cathy Rydell ABC Founding Board Member 2004-2015

Emanuel DiCicco-Bloom, MD Board Member 2019-2021

Louise Vetter Treasurer 2014-2019



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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.

Yousuf Ali

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.

Beatriz Duque Long

Director, Strategic Alliances, Public Policy and Government Affairs Biogen, Inc.

Julie Garner

Vice President, Government Affairs and Public Policy Sage Therapeutics

Shannon Gilbert

Associate Manager, Marketing – Advocacy Lead Teva Pharmaceuticals

Natalie Green Vice President of Business Development Kernel

Marybeth Howlett Senior Director Eli Lilly & Company

Beth Keyt Vice President Government Affairs Pear Therapeutics

Anja Mett

Global Product Leader Neurology Pharmaceutical Diagnostics GE Healthcare

Jordann Phillips

Associate Director, Communications and Patient Advocacy Alto Neuroscience

Marsie Ross

Director, Provider Advocacy & Policy Harmony Biosciences, LLC **Christian Rubio** Vice President, Patient Advocacy Praxis Precision Medicines

Daniela Sharfstein Government Affairs Associate Director Jazz Pharmaceuticals

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.

COMMITTEE CHAIR

COMMITTEE VICE CHAIR

Chief of Government Relations

American Psychiatric Association

Craig Obey, JD

Leslie S. Ritter, MA Associate Vice President, Federal Government Relations 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

Derek C. Brandt, JD Director, Congressional Affairs American Academy of Neurology

Phil Cronin Legislative Consultant Cure Alzheimer's Fund Diana Felner Vice President, Public Policy Tourette Association of America

Katie Grady Senior Manager Advocacy & Federal Affairs Society for Neuroscience

Bobby Heagerty Emeritus Director, Community Affairs & Education Oregon Health & Sciences University Brain Institute

Megan May, Ph.D. Associate Director, Public Policy The Michael J. Fox Foundation for Parkinson's Research Helen Mayberg, MD Professor, Neurology, Neurosurgery, Psychiatry, and Neuroscience Icahn School of Medicine at Mount Sinai

Patrick McCartney Executive Director International Essential Tremor Foundation

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 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



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

Diana Felner *ABC Treasurer* Vice President, Public Policy Tourette Association of America

COMMITTEE MEMBERS

Jason Kopinski, CAE Deputy Executive Director | Chief Operating Officer American Academy of Neurology

John Lehr Chief Executive Officer Parkinson's Foundation

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

Mark Rasenick, PhD

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



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

Patrick McCartney Executive Director International Essential Tremor Foundation

COMMITTEE MEMBERS

Chinmayi Balusu Founder & CEO Simply Neuroscience

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

Bill Griesar, PhD Neuroscience Coordinator NW Noggin

Susan Gurley Executive Director Anxiety & Depression Association of America **Christine Harhaj** Director, Advocacy and Strategic Alliances PhRMA

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

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

Gabriella Rizzo, MD, MBA Resident Physician Department of Neurological Sciences University of Nebraska Medical Center







Katie Sale Executive Director



Sheila Stern Director of Engagement & Administration



Elizabeth Wells Social Media Intern





Review of 2022

ABC Strategic Plan

ABC's Board embarked in a strategic planning process in 2022. This initiative included the review and analysis of ABC's current Vision and Mission, which included the adoption of an updated Vision and Mission; completing an environmental scan (SWOT) of activities and resources, and the first steps of setting long-range goals based upon Vision, Mission, and Environmental Scan. More information will be circulated in 2023 regarding key goals and strategies for the next 5 years.



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2022 SWOT Analysis

Internal	Strengths	Weaknesses		
Factors	 Consistent revenue stream from committed 	Small organizational structure		
	members	- Part-time staff		
	Committed/experienced/engaged volunteer leaders	- Two employees doing all operations		
	• ABC is small – we can get things approved quickly	ABC is small – limiting its scope		
	 Executive Director's historical knowledge – been 	Some organizations may perceive the ABC as a		
	with ABC since the beginning	lobbying organization since we were a 501(c)4		
	• Willing to adapt to change – went from a c4 to a c3	Not many working committees		
	acknowledging the different role ABC was	Small operating budget		
	beginning to play	Inexperienced staff with 501(c)3		
	Only coalition for the brain community with wide	Challenges to providing value to larger nonprofit		
	membership base	members		
	 Strong reputation with government agencies, 	Limited diversity in revenue streams		
	especially NIH	Hard to engage all of the members we serve		
	Health community becoming increasingly aware of	Rely on dues of nonprofit and corporate partners		
	ABC as a resource	who could opt out at any time		
	• Now a 501c3 - able to obtain grants and individual	Competing with our member organizations' funding		
	donations	Unawareness of the ABC and its mission		
	 ABCl2 is moving along in a direction most are 	Misperception of engagement with corporate		
	comfortable with	partners		
<u>External</u>	Opportunities	Threats		
Factors	•	Other organizations could take on major programs		
	 Expanding ABC role with Congressional 	out-competing ABC in its mission		
	Neuroscience Caucus (CNC) could improve impact			
	 ABCI2 has better positioned us to work closer with 	disinterested in ABC.		
	FDA	Disengagement of corporate partners from patient		
	 Increased social channels allowing for better 	advocacy community		
	communication	Inability to adapt to external crises such as the		
	 Advancing patient-centered engagement of 	current pandemic		
	corporate partners			



ABC Strategic Planning Steering Committee

COMMITTEE CHAIR

Stephen Strakowski, MD Executive Associate Dean, Professor of Psychiatry University of Texas Dell Medical School, Austin

COMMITTEE MEMBERS

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

Mark Rasenick, PhD ABC Board Vice Chair Distinguished Professor of Physiology & Biophysics and Psychiatry University of Illinois, Chicago

Janet Hieshetter ABC Board Past Chair Executive Director Dystonia Medical Research Foundation Josie Cooper ABC Board Member Executive Director Alliance for Patient Access

L. John Greenfield, Jr., MD, PhD ABC Board Member Department of Neurology Chair UConn Health

Theanne N. Griffith, PhD ABC Board Member Assistant Professor, Department of Physiology & Membrane Biology University of California, Davis

Louise Vetter Former ABC Treasurer & Board Member President & CEO Huntington's Disease Society of America, Inc.



New Vision & Mission

ORIGINAL Vision

ABC is a powerful voice for people with brain disorders bringing together organizations that represent concerned patients, families, and professionals. This collaborative voice will be used to create awareness and understanding, and advocate for increased research and resources that will improve patients' quality of life and enhance a national commitment toward cures for patients with brain disorders.

ORIGINAL Mission

Annual Report 2022

The American Brain Coalition, a nonprofit organization, seeks to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through education, public advocacy, and outreach.

BRAIN

NEW Vision

We will improve the lives of *all* people affected by brain diseases and conditions.

NEW Mission

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

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

2022 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



ACNP 2022 Public Service Award

The Public Service Award has been established in recognition of substantial contributions to affect public policies or other activities related to improving the health of the public with an emphasis on patients with brain diseases. This year the ABC nominated Congressional Neuroscience Caucus Co-Chairs Congressman Earl Blumenauer and Congresswoman Cathy McMorris Rodgers. <u>View</u> <u>nomination video</u> by Katie Sale, ABC Executive Director. View full <u>press release</u>.



Representative Cathy McMorris Rodgers (R-WA) Co-Chair, Congressional Neuroscience Caucus

Watch Acceptance Speech



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

Watch Acceptance Speech

2022 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.

March 8, 2022

The Importance of Brain Donation for Treating and Curing Brain Diseases (View Video) (View Summary)

Briefing was co-hosted with The Brain Donor Project and featured opening remarks by Congressman Earl Blumenauer (D-OR) and Congresswoman Cathy McMorris Rodgers (R-WA). The panel of speakers included Walter Koroshetz, MD, Director of National Institute of Neurological Disorders and Stroke (NINDS); John Ngai, PhD, Director, NIH Brain Research Through Advancing Innovative Neurotechnologies® (BRAIN) Initiative; and Kathy McKenzie, a patient/family advocate.

May 18, 2022

Long-Haul Neurological and Psychological Impacts from COVID-19 (View Video) (View Summary)

Briefing co-hosted with the AAN, ACNP and SfN, featured opening remarks by Congressman Earl Blumenauer (D-OR) and Congresswoman Cathy McMorris Rodgers (R-WA). The panel of speakers included Dr. Igor Koralnik, Chief of Neuroinfectious Disease & Global Neurology at Northwestern University Feinberg School of Medicine, Danielle Kirk, patient advocate and Dr. Eric Lenze, Wallace Renard Professor of Psychiatry, Washington University School of Medicine in St. Louis

September 21, 2022

Potential of Psychedelics in the Treatment of Psychiatric Diseases: A Long, Strange Trip Toward Future Therapy

(View Video) (View Summary)

Briefing featured opening remarks by Representative Earl Blumenauer (D-OR) and Representative Cathy McMorris Rodgers (R-WA). The panel of speakers included Dr. Nora Volkow, Director of NIDA, National Institutes of Health, Marcus Capone. Former Navy Seal & Founder & Chair of VETS Inc., and Dr. Rachel Yehuda, Professor of Psychiatry and Neuroscience of Trauma, Icahn School of Medicine.

Innovation Initiative (ABCI2)

In 2017, the ABC established an <u>Innovation Initiative (ABCI2)</u>, a collaborative program to stimulate private investment in brain-related research and strengthen the entire research and development 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 a number of resources to the ABC membership, including a guide to navigating <u>Public-Private Partnerships</u>.

FDA Engagement: Speeding the Delivery of Cures and Treatments

Over the past two years ABC has been advocating with both Congress and the FDA to make efforts to address the unmet need for treatments and cures for brain conditions, with a particular emphasis on improving patient engagement in the FDA process. While we began our efforts by advocating for the creation of a Neuroscience Center of Excellence (NCOE) at the Food and Drug Administration (FDA) to increase capacity at the agency and advance a more transparent, innovative, and patient-guided approach to product development and provide clearer guidance to researchers and developers.

Through conversations between legislators and FDA officials, it became clear that FDA does not have the appetite to advance a NCOE at this time. Without the agency's support, our congressional champions were hesitant to force the authorization of an NCOE. While a full NCOE is still a long-term goal, ABC shifted to advocating for incremental efforts at FDA that will help speed the delivery of safe and effective treatments to individuals with brain conditions.

We continued to advocate for improvements before Congress, and ABC leadership met with FDA Commissioner Robert Califf and other senior FDA officials in September. We intend to continue our dialogue with FDA, including providing guidance on how the agency can improve patient engagement in the effort to mitigate the unmet need for cures and treatments for brain conditions.

Thanks to the advocacy of the American Brain Coalition and our partners, as well as key champions in Congress, we were pleased to see that the recently passed omnibus appropriations bill included \$2 million for a Neurology Drug Program at FDA. This program will focus on policy and guidance that keeps pace with scientific discovery in neuroscience, to advance the prevention and early detection of brain conditions.

With the input of ABC members and leadership ABC will continue to advocate for progress at FDA that advances our goal to speed the delivery of safe and effective cures and treatments to the millions of individuals impacted by brain conditions.







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 (<u>View Press Release</u>). 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.

ABC held two BRAIN Initiative Briefings in 2022:

June 23, 2022 - Congressional BRAIN Initiative Briefing on the Importance of Neuroethics (View Video) (View Summary) Briefing co-hosted with the ACNP, the Dana Foundation, the International Neuroethics Society, and Simons Foundation featured opening remarks by Congressman Earl Blumenauer (D-OR) and Congresswoman Cathy McMorris Rodgers (R-WA). The winners of the 2022 BRAIN Initiative Teen Challenge were highlighted and announced by ABC Chair, Matthew Rizzo, MD, the briefing moderator. The panel of speakers included Dr. Joseph J. Fins, President of the International Neuroethics Society, Dr. Jayatri Das, Chief Bioscientist at the Franklin Institute and Dr. Claire Weichselbaum, Barbara Gill Civic Science Fellow at Arizona State University.

October 19, 2022 - Congressional Briefing on the Importance of BRAIN Initiative Funding (<u>View Video</u>)

Briefing featuring Dr. John Ngai, Director of NIH BRAIN Initiative, National Institutes of Health and moderated by Dr. Justin Jordan, Vice Chair, Health Policy Subcommittee, American Academy of Neurology.















National Science Foundation WHERE DISCOVERIES BEGIN

SIMONS FOUNDATION







AMERICAN

BRAIN

Explore the <u>ABC's BRAIN Initiative website page</u> for additional information and resources!

Appropriations

The Fiscal Year (FY) 2022 appropriations process did not end until nearly six months into the fiscal year, when President Biden signed an omnibus spending package on March 15. The long-awaited package included important increases in funding for federal institutions that support brain and central nervous system (CNS) research. The FY 2022 agreement included a program level of \$44.959 billion for the National Institutes of Health (NIH), a 4.7 percent increase over FY 2021; \$8.84 billion for the National Science Foundation (NSF), a 4.1 percent increase over the FY 2021; and \$882 million for the Veterans Administration's Prosthetic and Medical Research Program, an 8.2 percent increase. The BRAIN Initiative received a total of \$620 million. Last, the agreement provided \$1 billion for the Advanced Research Projects Agency for Health (ARPA-H).

Following the delays in enacting FY 2022 appropriations, the FY 2023 federal budget and appropriations process got off to a slow start. The President's budget was delayed by more than a month, but the House Appropriations Committee was able to advance all twelve of its bills through the committee. The Committee's Labor, Health and Human Services, Education, and Related Agencies (LHHS-Ed) bill included \$47.46 billion for NIH, a proposed increase of \$2.5 billion, and \$620 million for the BRAIN Initiative. The House bill also proposed \$2.75 billion for ARPA-H, funded separately from the NIH budget. Though the House LHHS-Ed bill passed in committee, it did not reach the House floor for a vote.

Appropriations cont.

The House Appropriations Committee also approved the Commerce, Justice, Science and Related Agencies (CJS) Appropriations bill with a total of \$9.6 billion for the National Science Foundation (NSF), an increase of \$800 million over FY 2022. The full House did not vote on the CJS bill. Last, the Committee advanced the Military Construction, Veterans Affairs, and Related Agencies (MilCon/VA) Appropriations bill with \$926 million, an increase of \$44 million, for the VA Medical and Prosthetic Research Program. The MilCon/VA bill passed in the House as part of a package of six funding bills.

Like last year, the Senate Appropriations Committee did not take any formal action on FY 2023 appropriations. The Chair of the Committee, Sen. Patrick Leahy (D-VT), posted draft bills on the committee's website on July 28. The draft Senate LHHS-Ed bill also included increased resources for ABC's priorities, including a total of \$47.96 billion for NIH. While the overall NIH number appears higher than that proposed by the House. The Senate bill includes \$1 billion funding for ARPA-H within that total, supplanting potential increases for existing NIH institutes and centers. The Senate draft also proposed \$700 million for the BRAIN Initiative, an increase of \$80 million. Additional draft Senate bills include \$10.3 billion for NSF, representing an increase of \$1.5 billion, and \$916 million for the VA Medical and Prosthetics Research Program, an increase of \$34 million.

Appropriations cont.

Congress was unable to enact legislation to fund the federal government in FY 2023 prior to the end of the previous fiscal year on September 30, 2022 and had to extend funding through a series of continuing resolutions (CR) into late December. The threat of longterm CR—or worse, a government shutdown—loomed. While CRs can be a necessary tool to keep the federal government operating, they add uncertainty to the federal grant making process and limit new research opportunities, stalling progress in brain research and other fields. ABC continued to advocate for bipartisan funding agreement that included increased investment in brain and CNS research.

On December 20, 2022, Appropriations leadership in the House and Senate released an omnibus spending agreement that included increased funding for federal research institutions.

The FY 2023 Consolidated Appropriations Act includes \$47.5 billion for NIH, an increase of \$2.5 billion and \$680 million for the BRAIN Initiative, an increase of \$60 million. It also included an \$9.54 billion for the NSF's base budget, an increase of \$700 million and \$916 million for the VA Medical and Prosthetic Research Program, an increase of \$34 million.

The Senate passed the omnibus bill on December 22, 2022, and the House followed on December 23, 2022. The President signed the measure on December 29, 2022.

AGENCY	FY 2022	FY 2023
National Institute of Neurological Disorders and Stroke	\$2,611,370,000	\$2,813,925,000
National Institute on Aging	\$4,219,936,000	\$4,407,623,000
National Institute of Mental Health	\$2,216,976,000	\$2,337,843,000
National Institute on Alcohol Abuse and Alcoholism	\$573,651,000	\$595,318,000
National Institute of Drug Abuse	\$1,595,474,000	\$1,662,695,000
National Center for Advancing Translational Science	\$882,265,000	\$923,323,000
BRAIN Initiative	\$620,000,000	\$680,000,000
Advanced Research Projects Agency-Health	\$1,000,000,000	\$1,500,000,000
National Science Foundation	\$8,838,000,000	\$9,539,011,000
VA Medical and Prosthetics Research Program	\$882,000,000	\$916,000,000

SIGN-ON OPPORTUNITIES

February 11, 2022 - Support of the Conrad 30 Reauthorization Act

The American Brain Coalition circulated a letter in support of S.1810/H.R.3541, the Conrad State 30 and Physician Access Reauthorization Act. The bill would extend and expand the Conrad State 30 program, which allows qualified foreign-trained physicians to provide care in underserved communities.

March 11, 2022 - Response Letter to Congress for NIH Letter on Animal Research

The American Brain Coalition signed onto a letter being circulated by National Association for Biomedical Research (NABR) supporting the appropriate and ethical use of animals in research to help understand and treat diseases.

March 17, 2022 - One pager in support of the VA Neurology Centers of Excellence

The American Brain Coalition signed onto a one-page letter being circulated by the American Academy of Neurology endorsing the VA Neurology Centers of Excellence.

April 7, 2022 - FOVA Recommendations for FY 2023, Department of Veterans Affairs

The American Brain Coalition signed onto a one-page letter being circulated by the Friends of VA medical Care and Health Research (FOVA) detailing their recommendations for FY 2023, Department of Veterans Affairs.

May 10, 2022 - Public Health Data Modernization Initiative

The American Brain Coalition signed onto an annual appropriations letter in support of improvements to the United States' public health data infrastructure.

May 16, 2022 - LEAD FY 2023 Appropriations Letter

The American Brain Coalition signed onto a letter being circulated by the LEAD Coalition encouraging the continued financial support in FY 2023 toward the National Alzheimer's Plan goals and to advancing science, care and support, and public health.

June 1, 2022 - FY23 Animal Research Appropriations Letter

The American Brain Coalition signed onto a letter being circulated by NABR outlining concerns related to animal research language in appropriations bills and reports.



July 14, 2022 - Understanding the implications of Long COVID

The American Brain Coalition signed onto a letter being circulated by the American Academy of Neurology urging Congress to explore the growing issue of long COVID.

July 29, 2022 - Conrad State 30 and Physician Access Reauthorization Act (Letter to the Senate) (Letter to the House)

The American Brain Coalition signed onto letters being circulated by the American Academy of Neurology urging Congress consider and pass the Conrad State 30 and Physician Access Reauthorization Act.

September 7, 2022 - Neurology Drug Program

The Ame<mark>rican B</mark>rain Coalition circulated a letter expressing our thanks to members of the Senate and House Agriculture appropriations subcommittee for including funding support of a Neurology Drug Program at the FDA in a recent Senate Agriculture-Rural Development-FDA draft bill.

September 7, 2022 - Medical Marijuana and Cannabidiol Research Expansion Act (MMCRE)

The American Brain Coalition circulated a letter urging the Senate to consider and pass the MMCRE Act which has already passed the House and would provide for research on medical marijuana and CBD and new therapeutic options for patients based on the research.

October 28, 2022 - National Plan to End Parkinson's Act

The American Brain Coalition signed onto a letter being circulated by the Michael J. Fox's Foundation for Parkinson's Research in support of the National Plan to End Parkinson's Act (HR 8585, S 4851).

November 4, 2022 - NIH Base Budget for FY 2023

The American Brain Coalition signed onto a letter being circulated by the Ad Hoc Group Steering Committee being sent to the House and Senate Appropriations Committee leadership, urging swift passage of at least the House Appropriations Committee-passed \$47.5 billion for the NIH base budget for FY 2023.

December 6, 2022 - FY 2023 Omnibus Spending Bill

The American Brain Coalition signed onto a letter being circulated by Research!America encouraging the secure passage of the FY 2023 Omnibus Spending Bill before the expiration of the current resolution.

December 7, 2022 - VA Infrastructure Powers Exceptional Research Act (VIPER Act)

The American Brain Coalition signed onto a letter being circulated by the Association of American Medical Colleges and American Psychological Association encouraging the Senate to pass the VIPER Act before the end of the year.

ABC 2022 Statements & Letters

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

Statements: June 21, 2022 - <u>ABC Statement on Health Equity</u>

July 29, 2021 - ABC Statement to advance a NCOE for PDUFA Hearing

March 9, 2022 - ABC FY22 Omnibus Appropriations Summary

Letters:

November 30, 2022 - ABC Welcome Letter to Dr. Arati Prabhakar, Director, Office of Science and Technology Policy

September 15, 2022 - ABC Letter to Senate Health, Education, Labor and Pensions Committee on inclusion of Cost of Mental Illness Act

August 3, 2022 - ABC Letter of Appreciation to Senator Collins regarding Neurology Drug Program at FDA

March 7, 2022 - ABC Animal Research Tabak Letter Response

March 3, 2022 - ABC BENEFIT Act Support Letter



Website 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.



Ways to Get Involved...





Adolescent Brain Cognitive Development®



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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.



Financials

ABC relies on the generous support of membership dues to help ensure our modest total operating budget, which was just over \$400,000 in 2022. This revenue is used to support ABC's educational and advocacy programming.



16%

Educational

Advocacy

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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.

communications@americanbraincoalition.org www.americanbraincoalition.org