



Annual Membership Meeting Minutes
Monday, November 13, 2023
2:00-4:00 pm ET
The Westin Washington, DC Downtown Hotel
Anacostia E, Ballroom Level

- I. Welcome – *Matthew Rizzo, MD, Outgoing Chair; Mark Rasenick, PhD, Incoming Chair; Katie Sale, Executive Director*

Dr. Matthew Rizzo welcomed members both in-person and virtually to the 19th Annual American Brain Coalition (ABC) Membership Meeting ([see attendance](#)).

A. Recognition of [Board Members](#)

As a nonprofit organization, ABC relies on the generosity of our volunteers. The insight each member provides, representing a variety of organizations, is what continues to keep our patient-focused work in the forefront as we seek to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through public education and advocacy. Dr. Matthew Rizzo thanked two ABC Board members who are completing their terms.

Ms. Janet Hieshetter, Executive Director of the Dystonia Medical Research Foundation, is rotating off as Past Chair of the ABC. Ms. Hieshetter will become one of ABC's prestigious Emeritus Board Advisors, assisting the Board on strategic initiatives.

Dr. John Greenfield, Department of Neurology Chair at UConn Health and represented ABC member, the American University Professors of Neurology.

B. "Passing of the Gavel" & Introduction of Board Members

Dr. Matthew Rizzo expressed his gratitude for his years as Board Chair and stated the advances made and the work ahead for the coalition. Dr. Rizzo introduced the American Brain Coalition's incoming Board Chair Dr. Mark Rasenick.

Ms. Katie Sale provided an overview of accomplishments attained during Dr. Matthew Rizzo's term as ABC Board Chair from 2019-2023. Under Dr. Rizzo's leadership, the ABC grew 25% despite the fact that it was during the COVID pandemic. Recognizing the importance of ABC educating and advocating on behalf of the very important BRAIN Initiative, ABC was invited

to sit on the BRAIN Initiative Alliance. In addition, ABC has taken over the BRAIN Initiative's social media platform and provides all outreach for the Initiative. ABC not only updated our mission and vision to better reflect our broad membership but recently adopted a five-year strategic plan. Under Dr. Rizzo's leadership, ABC presented the co-chairs of the Congressional Neuroscience Caucus with a Neuroscience Champion Award in 2021, recognizing their outstanding leadership of the CNC over the past 10 years. ABC's premier initiative, the Innovation Initiative, has expanded under Dr. Rizzo's leadership to include real partnerships with the FDA. Most recently, Dr. Rizzo recognized the importance of ABC being involved with the National Academies of Sciences, Engineering, and Medicine, and ABC has become a member of the National Academies' Forum on Neuroscience and Nervous System Disorders. Ms. Sale recognized Dr. Rizzo's commitment and dedication, presenting him with a plaque from the ABC Board of Directors.

Dr. Mark Rasenick introduced the Board members taking office during this meeting:

- Diana Felner, Vice President, Public Policy at the Tourette Association of America, will assume the Vice Chair position.
- Patrick McCartney, Executive Director of the International Essential Tremor Foundation, will serve as Treasurer.
- Bobby Heagerty will serve her second term as Secretary.

Additionally, the ABC Board welcomes the following new Board members beginning their terms in 2023.

- Dr. Erika Augustine is Associate Chief Science Officer at the Kennedy Krieger Institute and Associate Professor of Neurology at Johns Hopkins University, in Baltimore, Maryland.
- Christine Buckley is the Executive Director of the Brain Aneurysm Foundation
- Jennifer French is not only the Executive Director of Neurotech Network but a person with lived experience.
- Hannah Wesolowski is the Chief Advocacy Officer for the National Alliance on Mental Illness (NAMI)

C. Moving Forward

Dr. Mark Rasenick shared a few slides highlighting the members of the American Brain Coalition.

This past year, ABC welcomed 15 new members:

Nonprofit Members

Black Men's Brain Health
Council on Social Work Education
Dravet Syndrome Foundation
Dyspraxia DCD America
Maternal Mental Health Leadership Alliance
National Network of Depression Centers
Reason for Hope
Rural Minds
Seizure Action Plan Coalition
Society for Women's Health Research
TBI Action Alliance

Academic Nonprofit Member

Huntsman Mental Health Institute (University of Utah)

Corporate Members

Delix Therapeutics
Boehringer Ingelheim
Alkermes

ABC speaks with one voice for the brain, currently representing:

- 110 [nonprofit members](#) – large and small disease-specific patient advocacy groups and professional organizations, both in the brain and larger health space
- 7 [Academic institutions members](#)
- 21 [Corporate members](#) – both large pharma and small biotech companies
- 17 [Observers](#) who regularly engage with us and
- 4 [“Friends” of the ABC](#)

Dr. Rasenick announced that next year, ABC will be celebrating its 20th anniversary, and will begin the implementation of ABC's 5-year strategic plan. Dr. Rasenick outlined the aspirational goals ABC leadership will be implementing as follows:

1. Be highly relevant to our members.
2. Increase diversity to look like the US.
3. Increase public visibility and influence to help substantially increase funding of neuroscience research.
4. Influence the regulatory process to speed the translation of neuroscience research into life-changing therapies.

5. Be highly engaged with our members and with like-minded organizations.

Collaborative Relationships

II. Food & Drug Administration (FDA) Total Product Lifecycle Advisory Program (TAP) – *April Marrone, PhD, MBA, TAP Advisor ~GUEST*

Dr. April Marrone, Advisor to the Food & Drug Administration (FDA) Total Product Lifecycle Advisory Program (TAP), provided attendees with an overview of the TAP Program as it enters into the neurological and physical medicine space. Dr. Marrone provided guidance on the steps and statuses of devices going through the program, emphasizing the importance of attaining expert guidance from their collaborators as they navigate forward.

III. National Academies of Sciences, Engineering, and Medicine Forum on Neuroscience and Nervous System Disorders – *Sheena M. Posey Norris, MS, PMP, Senior Program Officer ~GUEST*

Sheena Posey Norris, the Senior Program Officer for the National Academies of Sciences, Engineering, and Medicine Forum on Neuroscience and Nervous System Disorders, provided an overview of this important forum which ABC is honored to be a member of. Ms. Posey Norris shared the Neuroscience Forum plan to engage patients and patient advocacy groups moving forward.

Officer and Committee Reports

IV. Action: 2022 Annual Membership Meeting Minutes – *Bobby Heagerty, Secretary*

Ms. Bobby Heagerty, ABC's Secretary called for a motion to approve the 2022 Annual Membership Meeting minutes, which were included in the meeting agenda packet circulated prior to the meeting. [2022 Annual Membership Meeting minutes](#) were approved.

V. Treasurer's Report – *Patrick McCartney, Treasurer*

Mr. Patrick McCartney, ABC's Treasurer, provided an update on the ABC finances. The ABC continues to keep a very modest operating budget. This year's total budget is just under \$400,000, which means we do quite a bit with little resources.

Membership dues remain the largest portion of our income, with nonprofit membership dues making up over half of our income. We also receive a modest amount of income from a few sponsorships helping with our educational programming.

A more detailed end-of-year financial report will be included in ABC's Annual Report, which will be distributed at the end of 2023/early 2024.

On behalf of the ABC Board, Mr. McCartney thanked ABC's membership for their contributions.

VI. Advocacy Committee – *Leslie Ritter, Advocacy Committee Chair*

Ms. Diana Felner, ABC Vice Chair, provided an advocacy report to the membership on behalf of Ms. Leslie Ritter, ABC Advocacy Committee Chair. A Washington Update was circulated as a written report prior to the meeting and can be viewed [here](#). Any questions regarding this report can be submitted to Ms. Katie Sale, ABC Executive Director.

[Public Policy Priorities](#)

The ABC Advocacy Committee has developed a set of public policy priorities to direct our advocacy work. These priorities are regularly reviewed and updated. ABC's current policy priorities include:

- Chronic Care
- Ethical Use of Animals in Research
- Federal Investment in Brain Research
- Innovative Approaches for Developing New CNS Cures
- Mental Health & Substance Use Insurance Parity
- Stem Cell Research

The ABC has circulated a number of statements and letters this past year, led by either the ABC or your organizations, all of which support ABC's policy priorities. Our [letters, statements, and policy priority white papers](#) can be found on ABC's website.

[Congressional Neuroscience Caucus](#)

The ABC continues to work with the Congressional Neuroscience Caucus in hosting and organizing briefings on a number of topics to engage Congress and staffers on the brain.

The ABC welcomed a new co-chair of the Caucus this year: Congressman Morgan Luttrell from Texas. Representative Luttrell brings a personal passion to the Caucus after surviving a helicopter crash in 2009 that left him with a traumatic brain injury. Retiring from the Navy following an honorable 14-year military career, Congressman Luttrell achieved an advanced degree in Applied Cognition and Neuroscience at the University of Texas at Dallas and helps fellow veterans recover from PTSD and TBIs sustained in battle. The ABC is thankful to Representative Luttrell for his leadership in the Caucus.

The ABC has recently learned that Congressman Blumenauer will be retiring after serving in Congress for 27 years. He will be greatly missed as co-chair of the Congressional Neuroscience Caucus. The ABC will keep the membership updated on his replacement.

Innovation Initiative

The ABC is working with the Food & Drug Administration (FDA) on advancing the recently funded Neurology Drug Program. We engaged with the FDA back in October with a very good meeting with Dr. Patrizia Cavazzoni, Director of CDER, along with 9 of her senior staff.

During this meeting, Dr. Cavazzoni expressed her appreciation for the brain community's advocacy efforts in funding this program. She also suggested that an initiative similar to the Cancer Moonshot program would help move the needle on the development of neuroscience treatments and drugs. She affirmed the FDA's appreciation and the need to work together with advocacy groups like ABC to increase the quality of their programs and their development. The ABC will continue to keep the membership updated as we work with the FDA on this important initiative. Any interested nonprofit members are encouraged to join the ABC's Advocacy Committee. If interested, please reach out to Ms. Katie Sale.

VII. Programming, Engagement & Outreach Committee – *Chantelle Ferland-Beckham, PhD, PEO Committee Chair*

Ms. Chantelle Ferland-Beckham, ABC's new Programming, Engagement & Outreach Committee Chair provided an update to the membership.

ABC conducted a number of educational webinars this year including:

- Regulatory 101
- What is ARPA-H?
- Ensuring Underserved Populations are Included in Brain Donation
- Research with Psychedelics – A Discussion with the DEA
- Inflation Reduction Act 101

Webinar recordings can be viewed on [ABC's website](#).

Members were encouraged to listen to [ABC's podcast series](#), Advocacy Champions: Voices for the Brain. This series was released in January of this year and already has 21 episodes. In each episode, Ms. Katie Sale highlights a different ABC member organization. This series allows the brain community to hear the exciting work of our members, and how important collaboration is for advancing brain health. If your organization wishes to participate in a podcast, please contact Ms. Sheila Stern.

ABC's social media platform is very active on [X](#), [Facebook](#), [Instagram](#), and [LinkedIn](#). Members are encouraged to be sure they are following the ABC on these social media platforms.

Lastly, one of ABC's best resources is its eNews & Updates, circulated every other week. This Update includes Government News, Blogs & Press Releases; ABC Member News, and Calendar Items highlighting the important events of ABC's membership. Any interested nonprofit members are encouraged to join the ABC's Programming, Engagement & Outreach Committee. If interested, please reach out to Ms. Sheila Stern.

From National to Neuronal: Science to Solution

VIII. National Institutes of Health (NIH) Guest Panel

A. Walter Koroshetz, MD, Director, National Institute of Neurological Disorders and Stroke

Dr. Walter Koroshetz provided an NINDS update to the membership, including the announcement of the new NIH Director, Dr. Monica Bertagnoli. Dr. Koroshetz provided an overview of the research areas within NINDS and the breakdown of funding for each area. Additionally, he updated the membership on the NINDS Nonprofit Forum each year and the success stories of approved treatments for four disorders. Lastly, Dr. Koroshetz provided an FY2024 budget overview for NINDS and plans for initiatives and strategic plans moving forward.

B. Shelli Avenevoli, PhD, Deputy Director, National Institute of Mental Health

Dr. Shelli Avenevoli provided a 75th Anniversary update for the NIMH, sharing their history and past accomplishments, including being a co-lead for The BRAIN Initiative®. NIMH will be hosting a yearlong 75th anniversary celebration of symposiums, lectures, and sessions at scientific meetings. Dr. Avenevoli provided an update on future initiatives for NIMH including the Accelerating Medicines Partnership® Program – Schizophrenia (AMP® SCZ) and two parallel research initiatives on mental health: the “Innovation Funnel” approach to treatment selection for depression and IMPACT.

C. John Ngai, PhD, Director, NIH BRAIN Initiative®, National Institutes of Health

Dr. John Ngai provided an update on 2023 NIH BRAIN Initiative® events, including a summary of the hybrid 9th Annual BRAIN Initiative meeting and a Congressional Neuroscience Caucus Briefing both held in June. Dr. Ngai provided an overview of current BRAIN research areas and BRAIN Initiative Transformative Projects with a look forward to their 5-year plan.

Dr. Mark Rasenick thanked the membership for participating in the Annual Membership Meeting and reminded members that ABC could not do what we do without each member

organization. Dr. Rasenick encouraged members to reach out to Ms. Sale with any ideas they have for ABC as we move into our strategic planning implementation.

Dr. Rasenick concluded the meeting by stating his excitement for the next phase of the American Brain Coalition!

Meeting was adjourned.