



**Annual Membership Meeting  
MINUTES  
Monday, October 7, 2024  
10:30am-12:00pm CT  
Hyde Park Room  
Hyatt Regency McCormick Place, Chicago**

- I. Welcome – *Mark Rasenick, PhD, Chair*
  - A. Honoring Dr. Francis Kittredge Jr., ABC's Founding Board Member

Dr. Mark Rasenick, American Brain Coalition (ABC) Chair, welcomed members and guests, both in-person and virtually, to the annual membership meeting, celebrating 20 years of the Coalition's work and recognizing the ABC's Executive Director, Mrs. Katie Sale, who has been with the ABC since even before the Coalition was officially incorporated. ([see attendance](#))

Marty Saggese, Executive Director for the Society for Neuroscience (SfN), offered a few words on the history of the ABC, expressing his appreciation for the accomplishments over the 20 years, as well as the future impacts to come from the continued work of the ABC for those impacted by brain disorders.

Dr. Mark Rasenick honored Dr. Francis Kittredge, former President of the American Academy of Neurology, whose vision brought the ABC together. Dr. Kittredge imagined a united front of disease-specific patient advocacy organizations, physicians, researchers, and professional groups, all dedicated to the prevention, study, treatment, and cure of brain disorders. His leadership was instrumental in forming the ABC with the American Academy of Neurology, the Society for Neuroscience, and later, the American College of Neuropsychopharmacology, recognizing the importance of including psychiatric and psychological fields in this important effort. Dr. Kittredge passed away in June of 2024 at the age of 89. His legacy, however, remains at the heart of everything ABC does.

To honor his memory and commitment to collaboration, ABC is proud to announce the creation of the [Dr. Francis Kittredge Jr. Collaboration Fund](#). This fund will foster partnerships between brain disease patient advocacy groups, professional organizations, academic institutions, industry leaders, and government agencies. Through this fund, ABC will expand its programming and ensure that all voices within the brain community are heard. Together, we will continue to accelerate the discovery and development of treatments and cures for devastating diseases of the brain, while addressing the stigma and inequities faced by those who suffer.

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

- [Nonprofit Members](#): Brain-related patient advocacy organizations that represent patients and their families, as well as professional scientific and clinical organizations representing researchers and clinicians.
- [Nonprofit Academic Members](#): Universities and higher education institutions that offer brain-related programs.
- [Corporate Members](#): Pharmaceutical, biotech, and medical device companies committed to developing or marketing therapeutic and diagnostic products. These corporations not only support our mission but also maintain working relationships with our nonprofit members.
- [Observers](#): We are proud to have government agencies within the brain space as observers, helping ensure we remain connected to the broader landscape.

- [Friends of ABC](#): The ABC also engages with several "Friends of" groups that share our mission.
- [Partners](#): ABC works closely with a variety of organizations to support their initiatives and outreach efforts.

## B. Introduction of 2024 Members

This past year, ABC welcomed 21 new members:

### **Nonprofit Members**

Alliance for Headache Disorders Advocacy  
 BCI Pioneers  
 Black Women's Health Imperative  
 Brain Injury Association of America  
 Caregiver Action Network  
 Center for Innovation & Value Research  
 Chronic Migraine Awareness  
 Cory Heideran Charitable Foundation  
 Cover my Mental Health  
 Cure Brain Disease  
 FamiliesSCN2A Foundation  
 Friedreich's Ataxia Research Alliance  
 Koolen-deVries Syndrome Foundation  
 Lifespark  
 My Kool Brother  
 Rosalynn Carter Institute for Caregivers  
 Walt's Waltz

### **Academic Nonprofit Members**

Icahn School of Medicine at Mount Sinai  
 Indiana University School of Medicine  
 University of Illinois Chicago

### **Corporate Members**

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## C. Recognition of Outgoing and introduction of Incoming Board Members

Dr. Mark Rasenick thanked the three Board members who have completed their terms and are rotating off the Board this year:

- **Jason Kopinski**, Deputy Executive Director and Chief Operating Officer at the American Academy of Neurology.
- **Dr. Madhukar Trivedi**, Founding Director of the Center for Depression Research and Clinical Care, and the Betty Jo Hay Distinguished Chair of Mental Health at UT Southwestern Medical Center.
- **Dr. Marina Wolf**, Professor of Behavioral Neuroscience at Oregon Health & Science University.

Dr. Mark Rasenick introduced the [Board members](#) beginning their terms in 2024.

**Amanda Becker** – Senior Director, Practice and Advocacy, American Academy of Neurology  
**Dr. Andrea Gropman** – Chief Executive Officer and President, Child Neurology Society  
**Dr. Barbara Jobst** – Chair and Professor of Neurology, Dartmouth Geisel School of Medicine  
**Dr. Charlie Nemeroff** – Matthew P. Nemeroff Endowed Chair  
**Jon Nelson** - Lived Experience Expert in Mental Health

**Dr. Mary Phillips** - Distinguished Professor in Psychiatry and Clinical and Translational Science, Pittsburgh Foundation - Emmerling Endowed Chair in Psychotic Disorders, Director of the Center for Research in Translational and Developmental Affective Neuroscience, Director of the Collaborative on Mood Disorders Research, Director of the Mood and Brain Laboratory, Department of Psychiatry  
University of Pittsburgh

**M. Elizabeth (Betsy) Ross** – President, American Neurological Association

**Leah Schust-Myers** – Executive Director, Families SCN2A Foundation

**Laura Weidner** – Chief Advocacy and Government Relations Officer, Epilepsy Foundation

### **Collaborative Relationships**

#### II. National Institute on Drug Abuse (NIDA) 50<sup>th</sup> Anniversary – *Nora Volkow, MD, NIDA Director ~GUEST*

This year marks the 50th anniversary of the [National Institute on Drug Abuse \(NIDA\)](#). Dr. Nora Volkow provided attendees with an overview of the impact of translational neuroscience approaches on the treatment of substance use disorders. Beginning with educating on the multiple factors involved with addiction to understand how this influences the brain affecting the course of treatments. Dr. Volkow explained the underlying gene factors which also impact psychiatric and mood disorders as well as the importance of understanding brain development and how it relates to addictions.

Dr. Volkow concluded with an update on two significant NIDA-funded research studies: the HEALTHy Brain and Child Development (HBCD) Study, which explores early brain development in relation to substance exposure and other environmental factors, and the Adolescent Brain Cognitive Development (ABCD) Study, which focuses on the brain maturation process during adolescence and how it interacts with substance use. These studies reflect the necessity of collaborative efforts and continued scientific innovation to push forward the frontiers of addiction research, with the goal of improving prevention, treatment, recovery outcomes, and one day a cure for addiction.

#### III. BRAIN Initiative® 10<sup>th</sup> Anniversary – *John Ngai, PhD, Director, NIH BRAIN Initiative®, National Institutes of Health ~GUEST*

The [BRAIN Initiative's](#) 10th anniversary is a significant milestone, marked by progress in understanding brain function at deeper and more comprehensive levels. Dr. John Ngai's update highlighted the initiative's key accomplishments, patient engagement efforts, and ongoing research projects. The Annual BRAIN Initiative® Conference is transitioning to a biannual event, with the next one set for 2026.

Dr. Ngai emphasized the initiative's success in incorporating patient perspectives into its research goals, particularly through the ABC. He also touched on the initiative's focus on building a foundation for future breakthroughs, with many long-term research projects already yielding preliminary insights. A key highlight was the *FlyWire* project, recently featured in *Nature*, which delves into the brain of the fruit fly at the cellular and synaptic levels. Additionally, Dr. Ngai shared a powerful video showcasing the real-world impact of BRAIN-funded technologies. The video featured a gentleman with ALS who, thanks to innovative brain technology, was able to communicate with his family and co-workers.

Dr. Ngai concluded his update by providing an overview of BRAIN Initiative® funding, detailing its trajectory over the past decade and outlining expectations for the future. He emphasized the importance of sustained investment to ensure the continuation of groundbreaking research and technological innovations.

The ABC remains a [strong advocate](#) for securing the critical funding needed to drive these advancements forward, ensuring the initiative's long-term success and its potential to transform neuroscience for decades to come.

#### IV. National Academies of Sciences, Engineering, and Medicine Forum on Neuroscience and Nervous System Disorders – *Sheena M. Posey Norris, MS, PMP, Director, Forum on Neuroscience and Nervous System Disorders, NASEM ~GUEST*

ABC is a member of the National Academies of Sciences, Engineering, and Medicine (NASEM) Forum on Neuroscience and Nervous System Disorders, and has been actively contributing to broader discussions in the neuroscience field. Ms. Sheena Posey Norris provided an overview to attendees, reflecting on the Forum's history, its recent activities, and membership meetings over the past year. She noted that 2024 has been a significant year for growth and raising awareness about the Forum and its work.

NASEM has made several of its publications readily available, aiming to increase accessibility by offering shortened versions and brief video summaries on its [website](#). Ms. Norris highlighted new collaborative efforts with LivedX for Neuro and Rare Neurological Diseases, aimed at fostering partnerships and addressing research gaps. She also pointed to upcoming workshops that will explore critical research needs, including the unmet needs in traumatic brain injury (TBI) among older adults, as well as applying neurobiological insights on stress across the lifespan.

V. Food & Drug Administration (FDA) – *Katie Sale, Executive Director*  
A. Total Product Lifecycle Advisory Program (TAP)

Ms. Sale provided an overview of ABC's ongoing collaborative efforts with the [FDA and the Total Product Lifecycle Advisory Program \(TAP\)](#), a partnership made possible through a generous grant from the Dana Foundation. ABC plays a crucial role in facilitating engagement between brain-related communities and other key stakeholders within the FDA TAP Pilot. Acting as a liaison and convenor, ABC ensures that a diverse range of voices, including the lived experiences of patients and their families, are integrated into the important conversations and decision-making processes of TAP.

Ms. Sale highlighted ABC's efforts to raise awareness of TAP through various stakeholder engagement opportunities, including meetings, webinars, listening sessions, and tabling at events. ABC has also participated in both in-person and online panels. In addition to these events, ABC has developed an [interactive web page](#), along with web-based materials and fact sheets, to support the initiative. To date, nearly 40 TAP partners have joined the program, and ABC has created detailed profiles for each.

Ms. Sale encouraged members who have not yet joined the TAP program to reach out for more information on how to become a collaborating partner.

B. iBCI Collaborative Community – *Ian Burkhart, BCI Pioneers Coalition*

ABC is now a proud partner of the [iBCI Collaborative Community](#). This dedicated collaborative community aims to unleash the potential for collective progress, knowledge sharing, and interdisciplinary collaboration to address challenges faced by individuals with neurological conditions. By fostering innovation and improving outcomes, the iBCI Collaborative Community brings together diverse stakeholders to work towards enhancing the quality of care and support for those affected by neurological disorders.

C. CDRH Patient & Caregiver Connection

ABC is now a formal partner in the [Center for Devices and Radiological Health \(CDRH\) Patient & Caregiver Connection](#). This partnership facilitates broad and timely access for CDRH staff to patient and caregiver experiences, enhancing the regulatory process with real-world insights. As part of this collaboration, partner organizations, including ABC, will collect feedback on specific issues from their members and share this valuable information with CDRH. This patient feedback regarding the impact of medical conditions on individual patients will provide critical context for regulatory decision-making.

D. Neurology Drug Program

ABC continues to lead the effort in advocating for the [FDA's Neurology Drug Program \(NDP\)](#). A recent significant milestone for the NDP was the Senate appropriations committee approving an increase in NDP funding to \$5 million in the FY2025 budget.

ABC has secured a virtual forum with the FDA to discuss recent advancements and insights into the NDP. This forum is scheduled for Wednesday, October 23, and will feature presentations from Drs. Teresa Buracchio and Michelle Campbell from the FDA's Center for Drug Evaluation and Research (CDER). Ms. Sale extended a special thanks to Ian Kremer, Executive Director of the LEAD Coalition, and Laura Weidner, Vice Chair of ABC's Advocacy Committee, for co-moderating the upcoming session.

Members are encouraged to look for an invitation and links to register, which will be shared soon.

## **Officer and Committee Reports**

### **VI. Action: 2023 Annual Membership Meeting Minutes – *Dr. Rasenick on behalf of Bobby Heagerty, Secretary***

Dr. Rasenick called for a motion to approve the 2023 Annual Membership Meeting minutes, which were included in the meeting agenda packet circulated prior to the meeting minutes. [2023 Annual Membership Meeting minutes](#) were approved.

### **VII. Treasurer's Report – *Patrick McCartney, Treasurer***

Mr. McCartney, ABC's Treasurer, provided an update on the Coalition's finances. He highlighted that ABC continues to maintain a very modest operating budget. This year, ABC received a generous grant from the Dana Foundation to collaborate with the FDA on the Total Product Life Cycle Advisory (TAP) Program. With this grant, ABC's total operating budget for 2024 is \$580,000, demonstrating the organization's ability to achieve significant outcomes with limited resources.

Mr. McCartney noted that membership dues remain the largest source of income for the ABC, with nonprofit membership dues accounting for over half of the coalition's revenue. In addition to the grant from Dana, ABC also receives a modest amount of income from a few sponsorships that support its educational programming.

A more detailed end-of-year financial report will be included in the ABC's Annual Report, which is set to be distributed in early 2025.

On behalf of the ABC Board, Mr. McCartney expressed gratitude to the membership for their contributions, acknowledging their vital role in sustaining the organization's efforts.

### **VIII. Advocacy Committee – *Dr. Rasenick on behalf of Leslie Ritter, Advocacy Committee Chair***

Dr. Rasenick provided an advocacy update to the ABC membership noting that a "[Washington written report](#)" with key updates had been circulated prior to the meeting.

ABC's Advocacy Committee has refined the [coalition's policy priorities](#) to ensure they are aligned with ABC's goals and federal advocacy strategies. These updated priorities, along with [white papers](#) designed for use during Capitol Hill visits, are now available on the [ABC website](#).

Dr. Rasenick highlighted the pivotal role ABC has played in advancing the [Congressional Neuroscience Caucus \(CNC\)](#). This year, Congressman Morgan Luttrell has joined as CNC co-chair, replacing Cathy McMorris Rodgers. Congressman Luttrell brings a deeply personal perspective to the role, having sustained a traumatic brain injury in a 2009 helicopter crash during his military service. After a distinguished 14-year career in the Navy, he earned an advanced degree in Applied Cognition and Neuroscience and now works to support veterans recovering from PTSD and traumatic brain injuries (TBIs) sustained in combat.

Additionally, Congressman Mike Thompson of California will replace Congressman Blumenauer as CNC co-chair. Representative Thompson has been a strong advocate for brain health, particularly in the area of mental health. Last

year, he introduced the Mental Health Research Accelerator Act, which aims to incentivize industry investment in brain disease research through a tax credit for translational research.

Dr. Rasenick noted that an official announcement from Congressman Blumenauer about the new co-chair is expected soon.

IX. Programming, Engagement & Outreach Committee – *Katie Sale on behalf of Jennifer French, Interim PEO Committee Chair*

Ms. Sale provided a brief overview sharing key updates on ABC's 2024 programming, engagement and outreach initiatives.

#### [ABC's 2024 Educational Webinars](#)

ABC hosted five educational webinars this year, all of which are available for viewing on ABC's website. Ms. Sale encouraged attendees to suggest topics for the 2025 webinar series and welcomed ideas, inviting members to reach out to her or Ms. Sheila Stern with suggestions.

#### [Mental Health Innovation Summit 2024](#)

ABC is excited to announce the second annual Mental Health Innovation Summit, taking place on Tuesday, October 29, 2024. This year's summit will focus on scalable solutions to address mental health inequities across diagnosis, care, research, and innovation. Building on the success of last year's event, the 2024 summit will emphasize actionable, solutions-based approaches. The format will feature TED-style talks from mental health leaders, followed by a panel discussion to explore real-world strategies for addressing today's pressing challenges. The event is open to everyone, and Ms. Sale encouraged members to share the invitation with their networks and colleagues.

#### [Podcast Series: Advocacy Champions – Voices for the Brain](#)

ABC's "Advocacy Champions – Voices for the Brain" podcast series continues to thrive, featuring interviews with various organizations. Ms. Sale invited members who have not yet participated to join the 2025 series, describing it as a fun and impactful way to share their work with the brain community.

#### [ABC's Bi-Weekly eNewsletter](#)

ABC distributes a bi-weekly eNewsletter that provides members with the opportunity to share their updates, events, newsworthy items, and press releases with the broader membership. Ms. Sale encouraged members who have not yet contributed their updates and events to take advantage of this platform and begin sharing their news through the newsletter by contacting Ms. Stern at [sstern@americanbraincoalition.org](mailto:sstern@americanbraincoalition.org).

#### [ABC's Social Media Presence](#)

Ms. Sale noted ABC's active presence on social media and encouraged members to ensure they are following ABC and vice versa. ABC has a social media presence on Facebook, Instagram, LinkedIn and X (formerly Twitter).

#### [ABC Staff](#)

In closing, Ms. Sale acknowledged her growing ABC team: Ms. Sheila Stern, Director of Engagement & Administration, Ms. Serena Crawford, ABC's Communications Assistant and Ms. Keirra Irby, Coordinator, TAP & Special Projects. Ms. Sale encouraged attendees to reach out to any ABC's staff members for questions or support.

Dr. 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 and her team with any ideas they have for ABC moving forward.

Meeting was adjourned.