



American Brain Coalition
Fall Membership Meeting Minutes - DRAFT
November 17, 2008 - 8:00 – 9:30 a.m.
Renaissance Washington, DC Hotel 999 9th Street, NW
Meeting Room 12

Attendance:

Francis Kittredge, MD – American Academy of Neurology (Outgoing Chair)
Joseph Coyle, MD – American College of Neuropsychopharmacology (Incoming Chair)
Jeffrey Samuels, MD - American Society of Neurorehabilitation (Outgoing Treasurer & Advocacy Chair)
Amy Rick – Parkinson Action Network (Incoming Secretary)
Robin Elliott – Parkinson's Disease Foundation (Outgoing Secretary & Membership Chair)
Frances Jensen, MD – American Epilepsy Society (Board member)
Mike Amery – American Academy of Neurology (Board member)
Robert Griggs, MD – American Academy of Neurology (Board member)
Catherine Rydell – American Academy of Neurology (Board member)
Donald Price, MD – Society for Neuroscience (Board member)
Marty Saggese – Society for Neuroscience
Suzanne Berry – American Epilepsy Society
Cheryl-Ann Tubby – American Epilepsy Society
Janet Hieshetter - Dystonia Medical Research Foundation
Dan Christiansen - Dystonia Medical Research Foundation
Dale Dirks – Dystonia Medical Research Foundation
Jean Campbell – National Organization for Rare Disorders
Karen Ball – Sturge-Weber Foundation
Marybeth Godlewski – Hydrocephalus Association
Paul Aravich, MD – Society for Neuroscience
Robert Roth
Dr. James Beck – Parkinson's Disease Foundation
BK Schafen – Tremor Action Network
Peter Muller – Tremor Action Network
Alies Muskin – Anxiety Disorders Association of America
Mimi Moll – Society for Neuroscience
Dot Sowerby – National Spasmodic Dysphonia Association
Zack Lynch – Neurotechnology Industry Organization
Annie Kennedy – Muscular Dystrophy Association
Cynthia Joyce – Spinal Muscular Atrophy Foundation
Doug Franklin – Multiple Sclerosis Association of America
Laura Lay - Spinal Muscular Atrophy Foundation
Mark Rasenick, MD - American College of Neuropsychopharmacology
Bonnie Lee La Madeleine – CHDI Foundation, Inc.
Marian Emr – National Institute on Neurological Disorders & Stroke
Lana Shekim, PhD – National Institute on Deafness and Other Communication Disorders
Geoffrey Laredo – National Institute on Drug Abuse

Lisa Kaeser – Eunice Kennedy Shriver National Institute of Child Health & Human Development
Alison Bennett – National Institute of Mental Health
Lyle Dennis – Cavarocchi Ruscio Dennis Associates, LLC (ABC lobbyist)
Nicole Greer - American College of Neuropsychopharmacology
Allison Kupferman – ABC Advocacy Director
Katie Sale – ABC Executive Director

I. Welcome & Introduction – Francis I. Kittredge, Jr., MD, Chair

Dr. Kittredge welcomed our members and non-members, as well as the several representatives for NIH institutes at the meeting. It is noted that the ABC add 'Eunice Kennedy Shriver' to the beginning of the NICHD.

Dr. Kittredge encouraged participants to stay for the media session following the Board meeting.

Dr. Robert Griggs, AAN President-Elect, said a few comments about Dr. Kittredge's role with the creation of the ABC. Dr. Griggs remembers Dr. Kittredge's 'one voice' vision right from the start.

Cathy Rydell then spoke further to Dr. Kittredge's vision and commitment to the creation of the ABC. Cathy is happy to see that Dr. Kittredge's vision is becoming a reality. On behalf of the ABC Board and membership, Cathy presented Dr. Kittredge with a plaque for his hard work and dedication as the ABC Chair from 2005-2008.

Dr. Kittredge spoke of his appreciation for all of the ABC volunteers and members, and he is proud to say that the ABC is evolving to where he'd like it to be.

II. Approval of Spring 2008 Membership Minutes – Robin Elliott, Secretary

Robin Elliott asked for a motion to approve the ABC Spring 2008 Membership minutes, which were approved.

III. 2008 Financial Report – Jeffrey Samuels, MD, Treasurer

Dr. Samuels provided an update on the ABC 2008 financial status. He said we are trying to not function in the red and are cutting costs where we can. He also said it's extremely important for members to continue to financially support the ABC as best they can.

IV. Membership Committee Update – Robin Elliott, Membership Committee Chair

Robin informed members that the newly formed Membership Committee has contacted 62 potential members. They are still in the process of contacting these members, and will hope to obtain a number of new members at the Spring meeting. He also stated that the Membership Committee could use a few new members. Contact Katie Sale if you're interested in becoming a member of the Committee.

V. Advocacy Committee Transition – Francis I. Kittredge, Jr., MD

Dr. Kittredge thanked Dr. Mahlon DeLong for his four years of service as the chair of the Advocacy Committee. Under his leadership, the Advocacy Committee has:

- grown from 5 to 11 members;
- adopted 4 key legislative issues and monitored another issue;
- procured CapWiz and made it easier for ABC members to communicate with Congress
- worked with ABC lobbyists to adopt a legislative strategy for each year,
- and kept ABC active and motivated to help guide mental health insurance parity through Congress and on to the President for signature into law earlier this year.

Dr. Kittredge stated that on behalf of the ABC, we appreciate the time and energy that Dr. DeLong has devoted to the ABC.

Dr. Kittredge then welcomed Dr. Jeff Samuels, outgoing ABC Treasurer, as the new Advocacy Committee chair. He has great enthusiasm and ideas for new approaches the committee can take as we move forward into a new era and a new presidential administration.

VI. Legislative Affairs – Jeffrey Samuels, MD, Advocacy Committee Chair

Dr. Samuels expressed his enthusiasm as the new Advocacy Chair. He welcomes all members to provide their advocacy ideas to the committee for discussion.

A. Lobbyist Update & Look Toward the Future – Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates

Lyle informed members that Congress is talking about a second economic stimulus package, which might include a \$1.9 billion increase for NIH. It is unlikely to pass right now and if it did, President Bush would likely veto it. Therefore, the vote on the package isn't likely to occur until after the new Congress is sworn in on January 6, 2009, then sent to President Obama after his swearing-in. The argument being made in favor of the increase is that 6 years of underfunding has led to dismal paylines. Additional funds can be distributed quickly to approved but unfunded projects, leading to job creation and job retention for NIH researchers. House Majority Leader Steny Hoyer (D-MD) said that he wants to pass the FY2009 Appropriations bills in the new Congress. The fiscal year 2009 began on October 1, 2008, and the government is currently running under a Continuing Resolution (CR). Hoyer said he would plan to pass the bills sometime in January, in the hope that President Obama would sign the bills. However, Lyle cautioned that there is much unknown during such a transition. Part of the unknown stems from the fact that President Obama's FY 2010 budget would be released at the end of February/early March. Plus, the current harsh economic climate is sure to play a role in both the FY 2009 Appropriations and the formulation of the FY 2010 Obama budget.

Dr. Samuels asked how an Obama Administration would impact ABC's legislative issues. Lyle noted that current restrictions on federally-funded stem cell research are likely to be overturned almost immediately. Lyle referenced chronic care by saying that it will be addressed by the new administration, however, access to care is a real issue/focus for them. Universal health care is something that Obama mentioned as a particular health issue he would like to address, so we will see how he approaches it once in office.

One member asked about conflict of interest and Senator Chuck Grassley (R-IA). He also asked about the influence of science in the Obama Administration; specifically, if there would be a cabinet-level position for a science advisor. Lyle replied that conflict of interest bears vigilance because Congress often tends to overreach when addressing ethics questions.

Lyle said that there is talk of a cabinet-level position in the new administration and that Nobel Prize recipient and former NIH Director Dr. Harold Varmus was heavily involved in the Obama campaign and is rumored to be interested in such a position.

Another member asked if there will be a new Health and Human Services Secretary (HHS) and how the ABC can reach out to him or her. Lyle said that we could certainly seek to meet with the Secretary or Assistant Secretary for HHS. He said that even if we get a meeting with him or her, that we don't know if they can deliver on any requests in this strained fiscal climate.

Mike Amery noted that there is transparency in Senator Ted Kennedy's draft health care reform bill. It increases coverage for the uninsured, deals with chronic care, implements payment system reform. Health information technology and privacy are also issues that are addressed in the bill. He said that the ABC might go about approaching that. Mike said that the conflict with health IT is related to HIPAA and it is a stumbling block.

Geoff Laredo wondered if the ABC had targeted the Office of Management and Budget (OMB) yet. He notes that they [NIDA] experienced some traction. Lyle said that the short answer was no, and mentioned that they are historically a "tough nut to crack".

A. Advocacy Committee's Proposed Legislative Priorities for 2009

1. Federal Science Funding
2. Stem Cell Research
3. Chronic Care
4. Animals in Research - *for reconsideration*

Dr. Samuels went on to discuss the Advocacy Committee's discussion in weeks prior to the meeting about the legislative priorities for 2009. Specifically, he mentioned that the committee was still supportive of maintaining NIH funding, stem cell research, and chronic care among ABC's top issues. However, there are traditionally four issues and, with the recent passage of mental health insurance parity, the Advocacy Committee thought moving that to a 'monitoring' role was appropriate. In its place, the Advocacy Committee proposed moving the ethical use of animals in research from a 'monitoring' role back into a top issue place, where it once was. A rash of recent anti-research and anti-researcher activity by animal rights extremists, convinced the Advocacy Committee that this ought to be moved to a priority position for the ABC. Additionally, several ABC members also include the ethical use of animals in research among their legislative priorities.

On this particular day, People for the Ethical Treatment of Animals (PeTA) was calling for protestors to gather in front of the convention center where the Society for Neuroscience (SfN) meeting was taking place. They were to hold signs saying "It's not the animals who need to have their heads examined" with pictures of research monkeys with devices on their heads. SfN's Executive Director, Marty Saggese, was present to lend support for ABC's adoption of the ethical use of animals in research issue as a legislative priority. He also asked if ABC members would assist SfN in talking to the media in support of research during the hours the protest was supposed to occur.

C. Open Discussion of Proposed Legislative Priorities & Welcome Any New Proposals from the Membership

There were many questions from the ABC members on these issues. First, many wanted to know more about the kinds of anti-research and anti-researcher activities. Allison Kupferman noted that the anti-research campaigns by groups such as PeTA, the Humane Society of the United States (HSUS), and more radical groups like the Animals Liberation Front (ALF) are multi-faceted. These groups develop curricula, as well as fun and persuasive educational materials for children in K-12 to convince them that eating meat and conducting biomedical research are cruel to animals; therefore, becoming a vegan and protesting research are "cool." She also pointed out that these groups are also engaged in legal battles to establish 'standing' for animals in the courts, thereby giving them legal rights which would clearly complicate research as well as agriculture. Finally, the more extreme activity comes in the form of threatening and harrasing scientists doing research on animals. Allison mentioned instances where molotov cocktails, firebombs, breaking into someone's hotel room, and flooding someone's house with a garden hose are all very real examples of the kinds of harrassment and intimidation some researchers are facing on a constant basis. Animal extremists are also fond of giving out credit card information as well as the location of the reseachers' childrens' schools. Allison pointed out that its highly unsettling that PeTA, HSUS, and ALF have much more in their coffers relative to organizations like ours. They have celebrities of all ages backing their cause. Dr. Coyle said that his trainee - Dr. Edye London, a Professor of Neuroscience at UCLA, was a victim of these incidents and threats and that the issue is real.

Members wanted to know if the ABC has the resources available to combat such a large issue. Allison replied that there are a number of existing coalitions and organizations that the ABC can join on to stay on top of the issue and make our voices heard when necessary.

A member questioned the legislative aspect of this issue, especially if the Animal Enterprise Terrorism Act already passed. Allison clarified that there are also some state legislation, such as in California, that are being debated. Dr. Coyle suggested that maybe changing the title from "legislative priorities" to "advocacy priorities" would better encompass this new issue. Everyone agreed this change was better.

A member asked whether the ABC might remove stem cell research from the list of priorities, since it was likely to be addressed by the Obama Administration. Dr. Samuels and Lyle cautioned that it would be prudent to leave it on the list of priorities and we could always change it when we see what happens with the Administration.

A member noted that the current stem cell statement needed to be fixed and updated. Allison will work on updating and correcting the statement.

Dr. Samuels then expressed his wish that our members feel a part of the ABC and are welcome to share any ideas for new advocacy priorities. He reminded members that the founding principle of the ABC was that we speak with one voice, and that together we are so much more powerful than we are separately.

A member stated that electronic medical records (EMR) and a more comprehensive IT system might be a new issue for ABC. She said that this is a tactical issue, but she doesn't know the status legislatively. Mike Amery said that e-prescribing is enforced and that EMR is supported by doctors but it is complicated. The problem is the question of who pays? Who sets the platform for organizing? Dr. Samuels propose that Allison, Lyle, and Mike look at what other organizations are doing on this. Dr. Samuels said the ABC could develop an issue paper on this, depending on what the findings are.

A vote was taken on the new 2009 ABC Advocacy Priorities of NIH funding, chronic care, stem cell research, and the ethical use of animals in research. The priorities were approved.

D. Capwiz Tutorial – Allison Kupferman, Advocacy Director

Allison gave a demonstration of how to use CapWiz. She began with the text of a past ABC Legislative Alert, which always includes a link to the ABC CapWiz site (<http://capwiz.com/americanbraincoalition/home/>). Allison then pointed out a box on the CapWiz site that says "Take Action!" and lists the alert topic, for example 'Support Mental Health Parity Legislation'. Click on 'Support Mental Health Parity Legislation' and it will take you to the next page that gives background on mental health parity and provides a sample letter. The message shows to whom it is being sent: your Representative, your Senators, or sometimes both. That information is already input by ABC staff. Allison pointed out that the text is editable, but that customization is not necessary unless ABC staff specifically asks for you to customize. Congressional staff are looking at the sheer number of letters they receive. CapWiz then asks for your name and home address. Allison explained that this is so CapWiz can determine your Members of Congress, it is not for any marketing purposes. Finally, just click on the 'Send Message' button at the bottom of the screen. Your letter is sent and you will receive a confirmation email saying that your message has been sent. Allison took some brief questions from the attendees, and offered her assistance to members the next time an alert is sent.

E. Presentation of Advocacy Challenge Award

This year, ABC announced a new Advocacy Challenge Award. We invited our member organizations to do educational or outreach activities with their Members of Congress either on Capitol Hill or in their local area. Then we asked members to tell us about their experience. One of our members has gone above and beyond and is highly deserving of this award. The Dystonia Medical Research Foundation (DMRF) conducted advocacy activities this year that run the gamut from sending out legislative alerts to giving an award to a Member of Congress while doing visits on Capitol Hill.

Also amongst their achievements, DMRF joined with like-minded organizations to form the Dystonia Advocacy Coalition (DAC). The DAC aims to develop, implement, and manage a legislative and policy agenda to meet the needs of the Dystonia community. This includes tracking legislative issues, developing Congressional relationships, and identifying Dystonia Champions. As part of their coalition efforts, DMRF convened the DAC members' individual patient advocates to conduct visits on Capitol Hill.

First, DAC participants received training on how to conduct a visit on Capitol Hill and what to expect. DMRF provided participants with talking points, so they felt comfortable when speaking. After training, participants met with their elected officials. Finally, DMRF insured that thank you notes were sent to the Members or staffers with whom participants met.

The DAC presented a Public Service Award to a member of Congress who works to Rep. Jim Walsh (R-NY) for his efforts on getting Dystonia on the VA's list of disorders that would be covered under congressional-listed research funds.

DMRF has done many impressive activities over the year, and are very deserving of this award. It is with great pleasure that the ABC presented Janet Hieshetter, Executive Director of the Dystonia Medical Research Foundation, with the 2008 ABC Advocacy Challenge Award.

VII. Strategic Planning Committee Update - Francis I. Kittredge, Jr., MD

Dr. Kittredge stated the many successes of the ABC:

- 53 members
- Established a Membership Committee
- Established a Strategic Planning Committee
- Procured Capwiz
- Initiated a newsletter to our members and affiliates
- Developing Educational seminars
- Developing an RFP for the data collection process

Dr. Kittredge explained a number of challenges the ABC faces:

- Expand our membership to all brain-related organizations and advocacy groups
- Develop mechanisms to include all advocacy initiatives – lobbyists and staff working together
- Develop broad based financial resources to carry out our initiatives
- Participation of all organizations and named liaisons for each issue
- Criteria for how effective our initiatives are – bench mark and bring back to the board and the membership

VIII. Other Business

No other business.

IX. Adjournment



American Brain Coalition
Fall Board Meeting Minutes - DRAFT
November 17, 2008
9:30 – 11:00a.m.
Renaissance Washington, DC Hotel
999 9th Street, NW
Meeting Room 12

I. Welcome & Introduction of New Board Members – Joseph Coyle, MD, Chair

Dr. Coyle welcomed all Board members and ABC members who stayed for the Board Meeting. He explained that he is honored to Chair the Coalition, and looks forward to working with the many volunteers.

II. Approval of Spring 2008 Board Minutes – Amy Comstock Rick, Secretary

Amy asked for a motion to approve the Spring 2008 Board minutes, which were approved.

III. Approval of 2009 Budget – Jeffrey Samuels, MD, Outgoing Treasurer on behalf of Dr. Mahlon DeLong, Treasurer

Dr. Samuels asked that everyone review the 2009 budget and noted that we cut back where we could. He then asked for a motion to approve the 2009 budget, which was approved.

IV. Appointment of Bylaws Revisions Taskforce - Joseph Coyle, MD, Chair

With a number of new initiatives under way, Katie noted that the ABC Bylaws are in need of a revision. Dr. Coyle asked for volunteers to work with Katie in revising the current ABC Bylaws. Dr. Kittredge volunteered to serve. If anyone else is interested, they should contact Katie.

V. Approval of new ABC Members – Robin Elliott, Membership Committee Chair

Robin asked that the Board approve the three new Associate members, as well as the two Observers. The Board approved the new members and Observers.

a. Associate Members

- i. CHDI Foundation, Inc.
- ii. Multiple Sclerosis Association of America
- iii. The Myelin Project

b. Observers

- i. National Institute on Deafness and Other Communication Disorders - NIDCD

ii. National Institute of Mental Health – NIMH

VI. Approval of Rapid Response Mechanism - Joseph Coyle, MD, Chair

Dr. Coyle asked that the Board approve a rapid response mechanism should the ABC need a rapid response of an issue that arises in between Board meetings. The recommendation was approved with the addition to include inviting all Board members to participate in such discussions as they arise.

“A rapid response group would be comprised of at least one member of the ABC Executive Committee (Chair, Secretary and Treasurer), one member of the ABC Board, as well as ABC members who are knowledgeable in the issue at hand (if it’s an advocacy issue, the Advocacy Committee chair and the ABC’s lobbyist would be included – if it’s a financial issue, the ABC Treasurer would be included, etc). All Board members would be invited to participate in the discussion, as well. The issue would warrant a conference call discussion with any supporting materials provided by the organization or individual making the request. Once a decision has been made by the rapid response group, the decision is then shared with the requesting party and the ABC Board.”

VII. 2010 World Parkinson Congress Organizational Partner - Joseph Coyle, MD, Chair

Robin spoke on behalf of the 2010 World Parkinson Congress and strongly encouraged the Board to participate as an organizational partner, as no cost to the ABC. The Board approved the request to participate.

VIII. Other Business

Dr. Shekim introduced herself as a Program Director with the National Institute on Deafness and other Communication Disorders, and is excited to work with the ABC.

Suzanne Berry gave an update on the Cisco grant, which is an equipment grant for video conferencing that they hope to make available for ABC board members. Sue will continue to provide updates.

IX. Adjournment

Dr. Coyle encouraged members to participate in the media session ‘The Truth about Wooing & Winning the Media’. (Notes from this session are attached.)