



American Brain Coalition
Fall Membership Meeting Minutes - DRAFT
October 19, 2009, 8:00 – 9:30 a.m.
Lake Erie Room, Chicago Hilton

Attendance:

Dr. Joseph Coyle, Chair
Dr. Francis Kittredge, Past Chair
Dr. Mahlon DeLong, Treasurer
Amy Comstock Rick, Secretary
Dr. Jeffrey Samuels, Advocacy Committee Chair
Robin Elliott, Membership Committee Chair (Board member)
Catherine Rydell – American Academy of Neurology (Board member)
Dr. Robert C. Griggs – American Academy of Neurology (Board member)
Dr. Frances Jensen – American Epilepsy Society (Board member)
Janet Hieshetter – Dystonia Medical Research Foundation (Board member)
Suzanne Berry – American Epilepsy Society
Cynthia Joyce – SMA Foundation
Dr. Diana Shineman – Alzheimer’s Drug Discovery Foundation
Dr. Lana Shekim – NIDCD
Dr. Walter Koroshetz - NINDS
Gemma Weiblinger – NIMH
Marian Emr - NINDS
Dee Ragan – International Essential Tremor Foundation
Carol Rucker – International Essential Tremor Foundation
Dot Sowerby – National Spasmodic Dysphonia Association
Lyle Dennis – CRD Associates
Nick Cavarocchi – CRD Associates
Nicole Greer - ACNP
Mona Miller – SfN
Elizabeth Holcomb – SfN
Allison Kupferman – ABC Government & Public Affairs Director
Katie Sale – ABC Executive Director

I. Welcome – Joseph Coyle, MD, Chair

Dr. Coyle welcomed all members and guests to the Fall 2009 Membership Meeting. He also welcomed Amy Comstock Rick, who participated via conference call, as well as some potential members - Dr. Diana Shineman from the Alzheimer’s Drug Discovery Foundation and Dr. William Thies from the Alzheimer’s Association.

II. VOTE: Spring 2009 Membership Minutes – Amy Comstock Rick, Secretary

Amy Comstock Rick called for a motion to approve the Spring 2009 Membership minutes, which were unanimously approved.

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

A. New American Brain Coalition Members

Robin Elliott, Membership Committee Chair, provided an update on the potential members the Board will be voting to approve accepting during the Board Meeting. The Society of Biological Psychiatry has applied to become a Sustaining member. NORD and DBSA have applied as Associate members.

B. Potential Member Update

Dr. Coyle also added that he has had some discussions with the Dana Alliance for Brain Initiatives, who are interested in getting back into advocacy. Katie Sale will work with Dr. Coyle in putting some information together for DABI.

IV. Legislative Affairs - Jeffrey Samuels, MD, Advocacy Committee Chair

A. Lobbyist Update - Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates

1. FY 2010 and FY 2011 NIH and NSF Funding

Lyle first addressed science funding for FY 2010. He said that the Labor, Health and Human Services (LHHS) bill, which funds NIH, isn't likely to be finished until Thanksgiving. The LHHS bill is likely to be attached to a few other bills. It is unlikely to see more than a 2.5 to 3.0 percent increase. The National Science Foundation (NSF), which is in a separate bill, should increase about 6.5 percent. The FY10 process is very far along, and attention now needs to be turned to FY11 appropriations issues.

Regarding FY 2011, Lyle said that NSF is likely to see a 6.5 to 7.5 percent increase. The House and Senate put language into their committee reports that they expect to see more. The Ad Hoc Group for Medical Research, a coalition of like-minded health organizations, has begun talks about what levels to consider asking for NIH in FY 2011. One formulation is to take the FY 2010 level, add funding to account for the end of the ARRA money (presumably half of the research component of ARRA) and add a percentage increase that would be "predictable and sustainable" over the longer term.

2. New NIH Director Francis Collins

When addressing questions about the new NIH Director Francis Collins, Lyle points to the top five priorities that Dr. Collins has been addressing in numerous talks and town hall meetings. They focus on genomics and technology, translational research, tying science to healthcare reform, focusing on global health, and empowering the biomedical research community.

3. Comparative Effectiveness Research—Update

Next, Lyle discussed comparative effectiveness research. He notes that the Finance Committee version of the bill outlines a freestanding institute that resides outside of the government. Currently, the bill says it is to be governed by 15 private individuals—3 from pharmaceutical/biotech/device companies, 3 patients, 3 physicians, 3 from insurance providers, and 3 public representatives.

The House bill is constructed very differently, placing CER as a center in the Agency for Healthcare Research and Quality. Outside groups could be represented on advisory committees but would not be allowed to govern the process.

Both formats would provide the funding for CER through a tap into the Medicare Part A Trust Fund. The funding will be a serious bone of contention when the House and Senate conference on the bill as the Senate bill will be essentially transferring Medicare money to a private entity.

4. Health Care Reform—Update

The House bill H.R. 3200 (now HR 3962) is at the Congressional Budget Office (CBO) being 'scored', which means they are estimating how much the House version of the bill would cost. Lyle said that there wasn't likely to be action taken on the House bill until November.

The Senate Finance Committee version of the bill was scored by CBO at \$829 billion. The Senate Health Education Labor and Pensions (HELP) Committee version includes the public option, which is one of many controversial details. Conference and floor debate are expected to take a month or longer in the Senate. These are serious debates that will take time to iron out the differences between the multiple Senate versions, and then the subsequent conference between the House and Senate versions of the bill.

There was a brief question and answer session on health care reform and other related topics. When asked about comparative effectiveness research (CER), Lyle reminded the attendees that there is \$400 million going to NIH for CER in the stimulus package. Dr. Walter Koroshetz pointed out that NIH has been doing CER for years and that NIH is working with the Agency for Healthcare Research and Quality (AHRQ). Lyle pointed out that new NIH Director Francis Collins has spoken about CER. While also talking about the budget, Koroshetz said that NIH is finally completing construction of the John Porter Neuroscience Center this year. The group also talked a bit about health care reform and a report issued by the Institute of Medicine on what the Department of Health and Human Services did with \$100 million provided for CER in the stimulus package. Dr. Francis Kittredge asked about the real meaning of President Obama's doubling statement. Lyle pointed out that the life sciences are in and out of the definition of 'science' and Obama said he would double 'science funding' not just NIH funding.

C. Comparative Effectiveness Research Update - Jeffrey Samuels

Dr. Jeff Samuels, ABC Advocacy Committee Chair, informed the membership that the comparative effectiveness research working group had drafted an educational paper for the membership. It still has to undergo further review by the working group before being distributed to the larger membership.

D. Big Picture Discussion

1. Current Issues

Dr. Jeff Samuels reminded the members that our four advocacy priorities are federal science funding, chronic care, stem cell research, and the ethical use of animals in research. Dr. Samuels said that we must find ways to advocate for the members. We need to make all members aware of other member organizations' issues. He also considered how to get our member organizations to send ABC emails to their individual members.

2. Opt-In Strategy

Dr. Samuels shared his thoughts on how we can achieve greater participation. He mentioned a conversation he had with Society for Neuroscience Executive Director Marty Saggese about an 'opt-in' option. In this scenario, ABC would furnish all of its member organizations with an article about ABC, its legislative priorities, and would provide readers with an email address to opt-in to receive ABC legislative alerts. This would provide ABC direct access to the memberships of its member organizations, but only at the wishes of such individual members. Then, the ABC's reach would be far greater and would, hopefully, result in a higher number of letters when ABC issues a legislative alert.

The members attending were energized by the idea. They further refined the idea to take place in steps: 1) raise awareness of ABC amongst their own members through articles and linking to the ABC website; 2) provide the opt-in opportunity; 3) issue alert to those who opt in. Some members also felt that developing guidelines for using CapWiz would be helpful for an article topic. Sue Berry recommended that members put something prominent on their own web site that links to the ABC web site and in their newsletter each month.

3. New Issues

The group discussed whether the ABC should take a position on health care reform. Dr. Coyle introduced the topic by noting the sensitivity of the issue and noting also that a previous Board vote on the topic did not yield a consensus amongst the Board members. Thus, Dr. Coyle, explained, this was the reasoning for opening this discussion to all who are attending the membership meeting.

Concerns were raised about whether it was appropriate for the ABC to become involved in health care reform, when it already has four core advocacy issues that serve it well. An additional concern was whether the ABC could be effective on this issue. Still others felt that the ABC is uniquely positioned, because of our patient group base, to make the case for health care reform and that something needs to be done to fix the system. Another member pointed out that universal health care is something that is already listed amongst our priorities under chronic care, one of our existing four advocacy priorities.

Dr. Samuels mentioned that when he initially envisioned the document, it was going to be more like a list of what people ought to know about the health care reform bill. That idea resonated with the membership, who thought that a more educational approach and re-wording of the 'Guiding Principles' would be more appropriate and should be directed to the ABC members.

E. Collaborating With Our Member Organizations - Jeffrey Samuels

1. Joint Statements with ACNP
2. Involved on Animals Coalition with AAN

Dr. Samuels remarked that, in light of the big picture, we are pursuing new ways to collaborate with our membership organizations to achieve our legislative priorities.

F. Presentation of 2009 Advocacy Challenge Award- Jeffrey Samuels

Dr. Samuels announced that the Advocacy Challenge Award winner for fall 2009 is the Tremor Action Network. Their activities focused on advocating for federal research for movement disorders, personal healthcare concerns stemming from movement disorders, and access to drug treatments. They asked their members to visit their members of Congress during the summer congressional recess. Tremor Action Network also collaborated with other movement disorder groups. TAN did a wonderful job of meeting this summer's ABC Advocacy Challenge. We are pleased to present such a worthy organization with this award. We will also feature Tremor Action Network as the award recipient in the upcoming American Brain Coalition newsletter.

V. 2009 Financial Update & 2010 Budget Discussion – Mahlon DeLong, MD, Treasurer

Dr. DeLong informed members that we remain on budget for 2009, and noted that our budget is tight and every dues payment helps.

VI. Foundation and Corporate Support Discussion

Katie Sale informed members that although the ABC has a tax exempt number, we never actually filed for tax exempt status. Katie has worked with Association Resources in filing for tax exempt status, and we're waiting to hear back. Once we obtain our tax exempt status, Katie will begin the grant submission process. Katie asked that members review the list of corporate and foundation supporters, and email her with any additions or contacts they may know at these organizations.

VII. Other Business

There was no other business at this time. Dr. Coyle invited all members to stay for the Board Meeting.

VIII. Adjournment



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October 19, 2009
9:30 – 11:00 a.m.
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Lake Erie Room

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

Dr. Coyle introduced the new Associate Board members: Karen L. Ball from The Sturge-Weber Foundation and Janet Hieshetter from the Dystonia Medical Research Foundation.

Dr. Coyle thanked Dr. Samuels for his participation on the Board, as he rotates off. Dr. Samuels will continue as the Advocacy Chair.

The Board reviewed the new ABC letterhead, and asked about the significance of the ABC logo. The Board asked that the logo be reworked in conjunction with the Web site expansion project. The Board also asked that Board member terms be included behind each name on the letterhead (and that their terms be staggered). Dr. Samuels asked that his name be included as Advocacy Chair on the letterhead.

II. VOTE: Spring 2009 Board Meeting Minutes – Amy Comstock Rick, Secretary

Amy Comstock Rick called for a motion to approve the Spring 2009 Membership minutes, which were unanimously approved.

III. VOTE: New Advocacy Issues – Jeffrey Samuels, MD, Advocacy Chair

Dr. Samuels raised the issue of whether the American Brain Coalition should address health care reform and if the 'Guiding Principles' document was appropriate to reframe with the purpose of educating the membership. A robust discussion about whether the ABC was the right vehicle for tackling health care reform. One Board member wanted to know what the other organizations were doing on health care reform. The American Academy of Neurology said that it recently took a position on health care reform and issued guidelines. The Society for Neuroscience had conversations with Katie Sale prior to the meeting to indicate that they were intentionally not taking a position on health care reform. The American College of Neuropsychopharmacology board members indicated in their pre-membership meeting vote, that they were in favor of the ABC becoming involved and the 'Guiding Principles' document. The same concerns were raised as in the Membership Meeting, regarding whether we ought to expand beyond our four advocacy priorities into something as controversial as health care reform, whether the small ABC staff could handle another legislative issue, and whether the

'Guiding Principles' even reframed as an educational tool for the ABC membership is appropriate. Some members felt strongly that the ABC should be not involved in this issue and do not approve of the 'Guiding Principles' either as they stand or revised. The final vote was that the majority of the Board members voted in favor of reworking the 'Guiding Principles' into an educational tool.

IV. VOTE: New Members – Robin Elliott, Membership Committee Chair

The Board approved the following new ABC members:

Society of Biological Psychiatry – Sustaining member
National Organization for Rare Disorders – Associate member, but asks that NORD consider changing their status to Sustaining in future years
Depression and Bipolar Support Alliance – Associate member

The Coalition for Imaging and Bioengineering Research has asked for a reciprocal membership (at no charge to either coalition). The Board decided we should establish an informal working relationship with CIBR, but not commit to a reciprocal membership at this time.

V. VOTE: 2010 Budget – Mahlon DeLong, MD, Treasurer

The Board discussed the importance of trying to get some of our organizations with total net assets over \$5 million to change their status to Sustaining member, and organizations with total net assets over \$1 million to pay their Associate member dues. Dr. DeLong suggested that the Board needs to contact these members to 'pave the way' before Katie Sale follows up.

The Board agreed that the ABC Bylaws need to be reworked to include another level of membership that would include members who pay less than \$500/year in dues. Benefits for each membership category should be reworked and included in the bylaws. Sue Berry volunteered to work with Katie Sale on revamping the Bylaws.

The Board agreed that pediatric neuroscience should be elevated within the ABC. We will contact the Child Neurology Society to see if they would be receptive to changing their membership status.

Dr. Coyle will talk with Autism Speaks about elevating their membership. And, Sue Berry will talk with David Amaral at INSAR, as well as Michelle Marciniak at CURE.

A Board member asked how the ABC would stay afloat if we lost an Organizing member. It was pointed out that we do have a small reserve that we wouldn't want to tap into unless completely necessary, so we'll really need to work on getting a few more Organizing members. Katie Sale reminded the Board that a goal was to have a larger number of Organizing members, so their dues wouldn't be as high in years to follow.

Dr. DeLong went over the 2010 budget, which didn't include any significant increases. The Board approved the 2010 budget.

VI. Appointment of the 2010 Nominations Committee

The Board tasked Katie Sale with putting together a 2010 Nominations Committee, which would include paying Associate members, as well as Sustaining and Organizing members who haven't already served on the Nominations Committee. Katie will come back to the Board with a slate for approval.

VII. Other Business

The Board discussed the data collection project and how the ABC was uniquely positioned to spearhead such an effort. Lyle Dennis suggested staff contact the National Center for Health Statistics, as they have a number of surveys.

Dr. Jensen, Dr. Kittredge, and Janet Hieshetter agreed to form a working group to determine the next steps for getting this project rolling.

VIII. Adjournment