



**American Brain Coalition
Fall Board Meeting Minutes
Monday, December 6, 2010
11:30am-12:00pm
Room Splash 10-11
Fontainebleau Miami Beach**

Attendance:

Dr. Joseph Coyle – ABC Chair
Dr. Jeff Samuels – ABC Advocacy Committee Chair
Dr. Francis Kittredge – ABC Past Chair
Amy Rick – Secretary
Dr. Wade Berrettini – Board member
Cathy Rydell – Board member
Robin Elliott – Board member
Mark Cason – Society for Neuroscience
Marian Emr - NINDS
Kathleen Welker – Tremor Action Network
JoAnn Taie – American Neurological Association
Dr. Paul Aravich
Lyle Dennis – ABC Lobbyist
Katie Sale – ABC Executive Director
Allison Kupferman – ABC Government & Public Affairs Director

I. Welcome – Joseph Coyle, MD, Chair

Dr. Coyle welcomed all members to the meeting, including those participating via conference call. Dr. Coyle explained to members that Congressman Kennedy has been devoting himself to efforts on behalf of brain issues, and will be meeting with the ABC at 1pm to discuss his vision for what he refers to as the “Neuroscience Moonshot”, which will be launched in May on the 50th anniversary of his uncle’s speech about going to the moon back in the 1960s.

II. VOTE: 2010 Board Minutes – Amy Comstock Rick, Secretary

Amy asked for a vote of the Spring Board Meeting minutes in Toronto, as well as the September Board conference call minutes.

A. April 12 Spring Meeting in Toronto

The minutes were approved.

B. September 23 Board Conference Call

The minutes were approved.

III. 2011 Budget – Joseph Coyle (on behalf of Mahlon DeLong, MD, Treasurer who was unable to attend because of an illness in the family)

A. Conversations with ABC Member Organizations

Dr. Coyle stated that the recent board vote concerning the new dues structure was approved. He informed the board that they may be asked to contact certain ABC members explaining this new structure and how we are asking for members to contribute 0.1% of their total annual revenue, and why it is important for them to contribute and remain members of the ABC.

B. VOTE: 2011 Budget

Dr. Coyle explained that at this spring's meeting, we were anticipating receiving only half of the 2010 budget's revenue; however, we are actually at 75% of the total budget.

Dr. Coyle explained that the 2011 proposed budget anticipates not all members increasing their dues since we are offering a transition year. We are hoping, but not expecting, to receive a few corporate members. There is no increase for the Government & Public Affairs Director's or the lobbyist's fees; however, if additional income is raised, these contracts need to be renegotiated. Dr. Coyle also stated that although it's not included in the budget, it would be worthwhile for Allison Kupferman to have a Blackberry type device since she only works 10 hours/week and is not available should someone need her.

Dr. Berrettini with ACNP commented on the importance of the Capwiz program, and feels it is definitely an important element within the budget.

The board approved the 2011 budget.

IV. VOTE: Nominating Committee Members – Joseph Coyle, MD, Chair

Dr. Coyle explained that the Board needs to approve his recommendation for the following members to serve on the 2011 Nominating Committee:

- Dr. Coyle
- Dr. Kittredge
- Cathy Rydell
- Dr. Don Price
- Amy Rick

These members solicit nominations amongst the membership, and will put a slate together to present the incoming Board and Executive Committee for 2011.

V. Other Business

Amy Rick asked the board to consider having a larger discussion over the gaps within the ABC and where the ABC is going. Board members agreed that we are an evolving organization, and it is very important to do this, while re-examining the ABC's mission. Over the next several months, the board will conduct a few conference calls that will be discussed and shared with the membership during the spring meeting.

VI. Adjournment



**American Brain Coalition
Fall Membership Meeting Minutes
Monday, December 6, 2010
12:00-1:00pm
Room Splash 10-11
Fontainebleau Miami Beach**

Attendance:

Dr. Joseph Coyle – ABC Chair
Dr. Jeff Samuels – ABC Advocacy Committee Chair
Dr. Francis Kittredge – ABC Past Chair
Amy Rick – Secretary
Dr. Wade Berrettini – Board member
Cathy Rydell – Board member
Robin Elliott – Board member
Mark Cason – Society for Neuroscience
Marian Emr - NINDS
Kathleen Welker – Tremor Action Network
JoAnn Taie – American Neurological Association
Dr. Paul Aravich
Lyle Dennis – ABC Lobbyist
Katie Sale – ABC Executive Director
Allison Kupferman – ABC Government & Public Affairs Director

I. Welcome – Joseph Coyle, MD, Chair

Dr. Coyle thanked and introduced the members attending and via conference call. He thanked the ACNP for hosting the fall ABC meeting.

Dr. Coyle suggested to members that the ABC should try to have at least one of its membership meetings a year be held in DC. He has been speaking with Dr. Darrel Regier at the American Psychiatric Association, who is willing to host the Spring meeting. If other members are interested in hosting a future ABC meeting, they should contact Katie Sale.

Dr. Coyle explained that there have been a number of changes this year that we'll be going over in detail during the meeting. He also stated that following the meeting, Katie Sale will be circulating the revised Bylaws for a membership vote.

II. VOTE: Spring 2010 Membership Minutes – Amy Comstock Rick, Secretary

Amy asked for a vote of the spring 2010 membership meeting minutes, which were approved.

III. 2010 Financial Update – Joseph Coyle (on behalf of Mahlon DeLong, MD, Treasurer)

Dr. Coyle reminded members that this year's budget was reduced during the year and we anticipated the revenue being cut by half. Our revenue is actually up to 75% of the projected revenue, which means that we haven't had to dip so far into our reserves. Dr. Coyle reminded members of the importance of paying their dues.

The ABC board and business plan working group have been trying to figure out ways to improve our financial status, which will be discussed during the business plan portion of the meeting.

IV. Business Plan – Joseph Coyle

Dr. Coyle reminded members that a working group was established to put together a Business Plan. Members of the group include: Janet Hieshetter, Sue Berry, Cathy Rydell, Marty Saggese, Ronnie Wilkins, and Katie Sale.

A. Members & Nominating Committee

The Board has recently approved the section of the Business Plan that addresses the membership portion of the Plan. By only having one non-profit category of member, it allows for all members to have equal representation within the ABC. Dues are determined by approximately 0.1% of an organization's total annual revenue.

2011 will be a transition year where members for whom this would pose a hardship may request that they pay their 2010 dues. If an organization feels they are being incorrectly billed, or if for some reason they believe that total revenue is not an accurate measure of their organization's resources, they should provide a written statement to the Membership Committee, explaining what annual contribution best reflects their organization's true budget.

The board also approved the addition of Corporate members. They will pay an annual contribution of \$15K, which is the highest level of non-profit member dues. They will participate in a Corporate Advisory Committee (CAC), and one member of this committee may be asked to sit on the ABC Board. They will receive NO board or membership votes.

A board member voiced concerns over the Corporate member category, and making sure we members understand their contributions are unrestricted funds. The Advocacy Committee and board will look closely into any corporate requests that come their way. The Business Plan working group decided that all corporate/for-profit members must adhere to the PHARMA and/or AVAMED Code of Conduct.

A bullet will be added to the 'Members & Nominating Committee' portion of the Business Plan that will explain that the ABC will develop a document on its relationship with corporate members. The Parkinson's Disease Foundation and the American Academy of Neurology will share their codes of practice to work off of. Other members can send theirs to Katie Sale if they feel it would be helpful.

B. Volunteers needed for Membership Committee

Dr. Coyle asked if any member is interested in serving on the Membership Committee, they should contact Katie Sale. Current Chair is Robin Elliott & members include: Dr. Kittredge, Dr. Fred Goodwin, Kim Kuman and Dr. Coyle. Membership Committee responsibilities include reviewing dues requests, recruiting new members, and corresponding with existing unengaged members. Cathy Rydell volunteered to serve on this committee.

C. Goals Discussion

Dr. Coyle asked members to review the goals section of the Business Plan and provide Katie Sale with any additional goals they'd like the working group to discuss in the upcoming months.

V. Legislative Affairs - *Jeffrey Samuels, MD, ABC Advocacy Committee Chair*

Dr. Coyle said that this year, ABC has been busy with its usual legislative activities, and we have also added some items to our repertoire. Jeff Samuels is our Advocacy Committee Chair, and has been involved in many decisions about new items and approaches.

Dr. Samuels thanked Dr. Coyle for the introduction. He went on to say that there have been a lot of advocacy activities going on this year that he will leave to Lyle Dennis and Allison Kupferman to update you on. He addressed an issue of ongoing importance. He once thought that ABC would gain immediately in followers and impact of our communications. However, Samuels said that he must have been mistaken and that building momentum has taken and will continue to take some time. Yet, he pointed out that recent interest in ABC news has increased, through our Twitter presence and most notably through the ABC News Updates. Dr. Samuels said that he hopes that our members will allow ABC to communicate directly with their members and to share ABC communications with their members.

A. Legislative Update – *Allison Kupferman, Government and Public Affairs Director; Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates*

1. Election Outcome & Impact on Health Funding
2. Outlook for FY 2011 and FY 2012 NIH and NSF Funding

Lyle said that he would combine these two topics to present a larger overview. He first reported on the election outcome, noting that the Senate is very much the same but that the House saw a great shift of power to 242 Republicans and 192 Democrats in the House. There is just one election left which is undecided. This will impact federal science funding inasmuch as the hands of power have also changed, bringing new decision makers to the table. In the Senate, Tom Harkin (D-IA) is the chair of both the Appropriations Subcommittee on Labor, Health and Human Services, Education and the Health, Education, Labor and Pensions (HELP) Committee. In the House, Lyle discussed several candidates for the Energy and Commerce Committee, including Reps. Joe Barton (R-TX), Fred Upton (R-MI), John Shimkus (R-IL), and Cliff Stearns (R-FL). *A day later, Upton became the Energy and Commerce Committee Chairman.* There are also a variety of choices for the House Appropriations Subcommittee Chairman for Labor, Health and Human Services, Education Subcommittee.

For FY 2011, the work is still not done. The current Continuing Resolution (CR) takes the federal budget through December 18. The Democrats are trying to push through a 12-bill omnibus (one large appropriations bill including several spending bills) bill which would include a 3.2 percent increase for NIH and a ___ percent increase for NSF. Some are pushing for a full-year CR, the impact of which would be that NIH and NSF would lose any increases. There is some talk that Republicans only plan to make the CR go through February and then they would subsequently reduce spending when they take power.

Regarding FY 2012, as you know, President Obama's budget will be released in early February 2011. The Deficit Commission is recommending FY 2011 spending levels which could mean, in reality, FY 2010 funding levels. Therefore, NIH and NSF funding would be continually decreasing. Perhaps our best bet, Lyle tried to infuse some positive sentiments into his report, is to take heart in the Cut & Invest Committee's statement that it would recommend investing in research and development in "critical areas"—so we just need to be sure that NIH and NSF are considered critical areas.

Lyle noted that the Ad Hoc Group, who generally leads the way for the advocacy voice in the health community, is advocating for \$35 billion for NIH in FY 2012. It is not that they believe NIH will see those kinds of increases, but they believe we need to continue to push and the alternative is not to hope for much and not receive much.

3. National Neurological Diseases and Surveillance System Act H.R.1362

Allison also said she would switch the order of items discussed and would talk about the NNDSS bill and then stem cells.

She noted that the National Neurological Diseases and Surveillance System Act is something that ABC has been working on for the past 9 months. Allison pointed out that the bill first came to ABC's attention in February from Society for Neuroscience, who put ABC in touch with Rep. Chris Van Hollen (D-MD)—in whose district NIH resides. Van Hollen had written and was introducing a bill that would create a national registry for MS and PD, and would therefore be useful in terms of learning more about the natural history of disease, quantifying the burden of disease, incidence and prevalence, etc. Allison reminded participants that this kind of information was something that ABC members felt strongly about and had asked for on numerous occasions and was the center of many prior discussions.

Of course, Allison said, ABC was mindful that this bill is an authorization bill and that nothing in the bill can be realized unless there is an appropriation of federal funds behind it. Nonetheless, ABC strongly supported the effort and issued legislative alerts and letters of support to House Chair and Ranking Members of the Energy & Commerce Committee and its Health Subcommittee.

However, HR 1362/S 1273 is not moving anytime soon. Allison said that the Senate Health, Education, Labor and Pensions Committee (HELP) held a markup in mid-November, but it mostly passed things that could be moved by Unanimous Consent, and unfortunately, the NNDSS bill wasn't one of them. Coburn and the Republicans pushed hard against it—meaning no “disease-specific” or new programs. Allison expressed skepticism that this bill would have any traction in the lame duck session and is unlikely to be introduced in the next congressional session, given the shift of power.

B. Congressional Outreach

1. Rep. Earl Blumenauer (D-OR): Neuroscience Caucus *Lyle Dennis, CRD*

Dr. Coyle spoke about his interaction with Rep. Earl Blumenauer supporters at an event at Oregon Health Sciences University in November. He expressed his excitement about the Neuroscience Caucus and working with folks to move this initiative forward.

Coyle then asked Lyle to share his thoughts. Lyle gave background on the Caucus, saying that Rep. Blumenauer created it with Rep. Cathy McMorris Rogers (R-Washington). He pointed out that even though Blumenauer created the Caucus, the power shift in the House technically puts McMorris Rogers as Chair of the Caucus. Thus, outreach and conversations with her staff are critical to the success of the Caucus. Lyle reminded ABC members that in order for the Caucus to be successful, there will have to be some ‘ask’ of ABC member organizations, to be able to fund briefings on Capitol Hill. He said that sponsoring speakers to travel or to provide box lunches and sodas for such an event would be tremendously helpful in getting the Caucus established. Lyle told members to keep an eye out for ways to help boost the Caucus.

2. Rep. Patrick Kennedy (D-RI): Future collaboration *Joseph Coyle, ABC Chair*

Dr. Coyle mentioned that ABC has an ongoing relationship with Congressman Kennedy and his staff. He passed over to Allison to speak further about that relationship.

Kupferman noted that while the Congressman is retiring at the end of this session, his commitment to brain disorders has not waned. She mentioned ABC coordinating with Kennedy's office to draw attendees to a summer meeting he held. She also spoke about Kennedy being an integral force in organizing a hearing this summer on PTSD and TBI in our veterans returning from war. His leadership on brain issues is an inspiration. Allison reminded participants that Congressman Kennedy is joining ACNP leaders and ABC members following this meeting, to share his thoughts. She pointed out that this is a unique opportunity for ABC to gain insight into Kennedy's vision for the “Neuroscience Moonshot” and the future of public health opportunities.

3. Rep. Chris Van Hollen (D-MD): NNDSS Act *Allison Kupferman, Director of Government and Public Affairs*

Adhering to time constraints, Allison said that this topic was covered thoroughly previously, and noted that we would maintain relationships with Rep. Van Hollen in the future.

C. Social Media—*Allison Kupferman, ABC*

1. Facebook Launch

After Twitter, ABC is seeking to expand its social media presence. Allison said that ABC hopes to launch a Facebook page in the coming weeks, certainly by January. The page would provide an opportunity to cross-post with ABC member organizations. Allison said she would welcome any and all comments on the page from members to help amplify the messages.

2. Twitter used for news stories and highlighting ABC member activities

Allison spoke about continuing to use Twitter and offered to again share sample newsletter articles to drive ABC members to the Twitter account.

D. Opt-In and Get Active—*Jeff Samuels, Advocacy Chair*

Dr. Samuels again encouraged ABC member organizations to participate in our various media, to showcase ABC and give your individual members a chance to tap into ABC resources directly, without you having to pass on. Dr. Samuels said that ABC has sample newsletter articles for ABC member organizations to share with their members, and directed members to Allison Kupferman if they would like them.

1. Newsletter Articles
2. Twitter
3. ABC Updates

E. Open Forum: Collaborating With Our Member Organizations--*Jeff Samuels*

In light of time constraints, we moved to invite participants to share any of their thoughts before adjourning.

VI. Other Business

No participants raised issues at this time.

VII. Adjournment