

**American Brain Coalition
Spring Membership Meeting Minutes**

**April 3, 2006
9:00-10:30 a.m.
Mission Hills Room
San Diego Marriott Hotel & Marina
San Diego, CA**

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

The meeting was called to order at 9:10 a.m. by Francis Kittredge, Jr., MD. Dr. Kittredge reviewed the agenda and background materials. Dr. Kittredge explained that immediately following the Membership Meeting, all members will be invited to attend the Board Meeting. This meeting will be a town hall style forum, in which all members will have a chance to discuss all agenda items prior to Board vote.

II. Approval of Fall 2005 Membership Minutes – Robin Elliott, Secretary

The Fall 2005 membership minutes were unanimously approved.

III. Membership Update - Francis I. Kittredge, Jr., MD, Chair

a. Pending Associate Members

The three pending associate members – Hydrocephalus Association, National Spasmodic Dysphonia Association, and Parkinson Foundation of the Heartland – were approved as Associate members. This brings the Associate member total to 34, and the total ABC membership to 44.

b. Membership Involvement

- i. Interested Organizations
- ii. Legislative Activities
- iii. Collecting Economic Data – Barbara Vickrey, MD, MPH, FAAN

Barbara Vickrey, MD, MPH, FAAN, of UCLA provided the ABC with some facts on collecting economic data. She informed members that the National Foundation for Brain Research looked into the direct and indirect costs of disorders of the brain, including cost of delay of care. The Dana Foundation commissioned a report years ago, and the IOM has also done reports over the years. Dr. Vickrey indicated that the IOM may fund other reports. Cynthia Joyce mentioned that the National Dialogue of Medical Records may be helpful in analyzing data. Stephen Ashwal said the NINDS provided a study on the neurological burden of illness (data prevalence).

The question raised was how can the ABC capture the big picture with the small budget we have? The ABC will look into further, developing a model to include patients and families. It was decided that we would not reinvent, but need a fact finding survey on where we stand, to not duplicate what's already been done.

A work group will be formed to look into further, starting with what's already being/been done. Volunteers for the work group include:

- Barbara Vickrey, MD, MPH, FAAN, of UCLA
- Jane Pickett, Autism Tissue Program
- Cynthia Joyce, Spinal Muscular Atrophy Foundation
- American Epilepsy Society – Dr. Treiman & Sue Berry will get someone from AES
- Dr. DeLong will get some IOM people to help

IV. Legislative Update – Mahlon DeLong, MD, Advocacy Committee Chair

a. Lobbyist Update – Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates

Lyle Dennis provided a brief lobbyist update.

- b. 2006 Congressional Activities
- i. January 24: Physician reimbursement Memo and Sample Letter
 - ii. February 1: Function 550 Letter
 - iii. March 6: Functions 500 & 550 Letter
 - iv. March 8: Brain Injury Awareness Fair
 - v. March 10: Senate Anti-Methamphetamine Caucus Letter
 - vi. March 14: Senate Budget Resolution Legislative Alert
 - vii. March 16: Specter-Harkin Amendment Letter
 - viii. March 27: Traumatic Brain Injury Programs Letter
 - ix. March 27: House Budget Resolution Legislative Alert
 - x. March 31: House L-HHH Written Testimony (see handout)

Kerri Wade and Dr. DeLong summarized the 2006 ABC congressional activities.

Mike Amery provided an update on physician reimbursement. Discussion centered around how this issue relates to patients and their families, and the ABC agreed that our role would be to focus on the patient/family perspective. If advocacy groups have any stories to share related to this issue, they should send them to staff to disseminate. Stephen Ashwal will share a survey conducted by Dan Polsky with our members.

It was agreed to rename this issue 'Access to Care', NOT 'Physician Reimbursement'. A working group will be formed to look into this issue further. Working group members include:

- Stephen Ashwal, Child Neurology Society
- Robin Elliott, Parkinson's Disease Foundation
- Janet Heishetter, Dystonia Medical Research Foundation
- Kimberly Kuman, National Spasmodic Dystonia Association
- Mary Lou Thompson, Benign Essential Blepharospasm Research Foundation
- Linda McGillicuddy, American Headache Society
- An AES representative (Sue Berry & Dr. Treiman will provide an individual)

c. Proposed Ideas for 2007

- i. Maintain Phase One Activities
- ii. Legislative Alert Software

Kerri Wade introduced Capwiz and how this legislative software works. Once the ABC purchases Capwiz, staff will write an article on how it works for each member's newsletter.

iii. Committee of DC Volunteers

When ABC members go to the Hill for business related to their specific organization, they should inform the ABC staff, so that staff can provide them with information and talking points about the ABC.

iv. Capitol Hill Day Visits

v. Other Ideas?

VI. National Headache Awareness Week – written materials

VII. Other Business

VIII. Adjournment