



**American Brain Foundation
Board of Directors
June 24, 2018
8:00 a.m. CST
Minneapolis, MN**

Call to Order: Sunday, June 24, 2018, by Board Chair Kevin Goodno

In Attendance: Kevin Goodno, Chair; James Essey, Robert Griggs, MD; Ralph Józefowicz, MD; Catherine Rydell, CAE; Jeffrey Rosenfeld, MD; Ralph Sacco, MD; Martin Shenkman, CPA; Lisa Shulman, MD; Gordon Smith, MD; Ben Utecht; Susan Schneider Williams

Staff: Jane Ransom, Shelly Collins Rucks, Tim Engel, CFO; Natalie Baumgartner

Excused: David Eagleman, PhD; Dan Gasby, Shafali Jeste, MD; John Mazziotta, MD; Joseph Sirven, MD

Mr. Goodno welcomed everyone and discussed the agenda for the meeting.

Call for disclosure of conflicts of interest. Ms. Rydell, Dr. Sacco, and Dr. Smith acknowledged their connections to the AAN.

1. **Minutes:** Minutes from February 16, 2018, Board of Directors meeting were reviewed.

MOTION to approve the ABF Board of Directors minutes from February 16, 2018.

Approved (Unanimous).

2. **Governance Committee Recommendations for filling vacant neurologist slots:**

a. **Dr. Brenda Banwell:** A vote to elect Dr. Brenda Banwell the Foundation Board was put on hold at the request of the AAN. The Board agreed that it would be best to complete the AAN/ABF's new partnership planning process before adding new board members who also sit on the AAN board.

b. **Dr. James Grotta:** Dr. Grotta was unanimously elected to the Board, to fill the slot vacated by Dr. Edgar Kenton, whose first term began on 1/1/18.

The Board discussed the process for filling vacant positions, why the current vacancies were being filled with neurologists, and whether we should be trying to achieve representation across different neurological sub-specialties. Mr. Goodno addressed these concerns by reminding the Board that the Foundation needed to fill two neurologist slots because of Dr. Kenton's death and Dr. Miller's resignation.

The Governance Committee will continue to look for two new neurologists and two new public members to begin first terms on January 1, 2019. The Governance Committee has been less concerned about subspecialty than about identifying strong ambassadors (neurologists and non-neurologists) from key wealth centers in the United States. Some

board members felt there should be more attention to representation of subspecialties. The example of TBI was mentioned.

The Governance Committee recruitment process includes using a board development plan, identifying gaps in skills and interests on the board, and soliciting suggestions for candidates from the rest of the board to identify candidates to fill those gaps and meet other key criteria.

3. Resolution on Restricted Gifts: The Board approved the following resolution:

Resolution: It is the policy of the American Brain Foundation to charge a program fee in the amount of ten (10) percent on the total amount of every restricted gift so as to fund the core operations which make restricted programs possible. Exceptions may be made by the Executive Director for contributions from nonprofit organizations or as a result of negotiations with donors for documented reasons.

4. Board Chair Report: Kevin Goodno reported that the Foundation hosted a leadership dinner with the AAN to discuss the future partnership between the two organizations. Both parties understand that the current management agreement and strategic plan were visions of the past which should be updated. The ABF and AAN leadership need a retreat to reimagine what the relationship looks like. The AAN would still like to be a vital partner of the Foundation.

5. Executive Director Report: Jane Ransom reviewed the past three years in relation to the benchmarks set by the AAN in 2014 as a condition for contributing to the ABF's core operations from 2015-2019. The ABF is proving that the concept of a public-facing charity funding research across the spectrum of brain diseases and disorders is feasible and exciting. The ABF has made substantial progress in fundraising and building the CRTS/CSDA program. In Year Three, the Foundation raised three times more than the fundraising benchmark, and it reached all other performance markers. The net benefit of the ABF to the AAN is increasing, most directly through the Foundation's funding of CSDA/CRTS's.

While the ABF Board Scorecard shows increasing fundraising revenue and support for AAN research, it also shows that the Foundation is not reaching its core fundraising goals and has low brand recognition. The reinvented ABF is showing proof of concept, but the Foundation needs more time to increase its donor base and increase brand recognition.

Ransom proposed that the ABF needs to scale up in three areas: (1) public awareness, (2) donor base expansion, and (3) crowdfunding. Scaling up in these areas means becoming a \$10 million organization, whereas we are now a \$4 million organization. Investments in these areas will allow for the growth needed to begin a \$25 million endowment campaign in five years. A \$25 million endowment can then support much of the Foundation's core operations.

The re-invented ABF considers itself a start-up. It has reached the stage in start-up funding where infusions of venture capital are needed to scale up and reach new customer segments.

The Board asked why the Foundation needs an additional five years before an endowment campaign can begin. Development Director Shelly Rucks shared a gift analysis of a typical \$25 million endowment campaign. The ABF's current donor base is not large enough to support the gifts needed at most of the giving levels.

The Board wanted to understand how the Foundation is undertaking wealth screening of its donors. Ms. Rucks mentioned that even the best wealth screening tool are about 40% right. The Foundation does have individuals in our current donor base, who can be brought to a higher level of giving, but the pool of donors still needs to be expanded. It takes patience and persistence to raise support. The Foundation needs to capitalize on its unique vision and connection with the AAN.

6. Strategic Crossroads – Scaling up for Success: The Board identified strategic imperatives to have:

- **A clear strategic partnership model for:**
 - Co-funding
 - Co-branding
 - Scientific awards
 - Research grants
- **Strategic positioning on the playing field (brain space)**
 - What differentiates us?
 - What is our focus?
 - What is our product?
- **A re-imagined, re-defined relationship with the AAN**
- **Ramped up investment in:**
 - Public awareness
 - Donor base expansion
 - Crowdfunding promotion
- **A donor-centric approach**
- **A defined culture for winning**

There was further discussion about why an endowment campaign can't be started much sooner than five years from now. The problem is the depth and breadth of the ABF's donor base. The Foundation needs greater investments in public awareness, donor expansion, and crowdfunding precisely to develop a donor base to support a big endowment campaign.

The Board discussed the option of using the Foundation's reserves to fund operational expenses. This strategy would not be sustainable. But the idea prompted a discussion of setting a target reserve policy for annual spending which staff will work on. The Foundation should set

the reserves at a certain level, and anything above that level should be available to flow back into the organization. The Foundation's reserves should continue to get higher. The goal should be at 70% of the Foundation's operating budget.

There was further discussion of clarifying and strengthening the Foundation's strategic partnerships, including with the AAN. Are we competitors or partners? Is the ABF receiving enough recognition to inspire others to become donors? Is there a culture of collaboration? The Board recognized that a vision for the partnership between AAN and ABF was not created at the outset. Now is the time to create one.

7. Financial Report

a. Financial Statements for the period ending 4/30/18

In reviewing the financial statements, Tim Engel CFO explained that the Foundation's goal is to achieve \$1.3 million in unrestricted revenue by the end of the year. The Foundation has achieved approximately 50 percent of that goal to date, but there is still potential that the total goal will not be met this year. The Foundation will continue to monitor its expenses closely.

b. 2017 Audited Financial Statements

The recent audit went well. ABF management was well prepared. The auditors made no adjustments and issued an unmodified opinion on the Foundation, which is the highest level of assurance.

The Foundation's functional expense ratio improved substantially in 2017 compared to the last few years. This is because of an increase in grant making and the institution of a new time-keeping system which more precisely tracks how staff members are spending their time. Foundation expects to see the same ratio in 2018.

The auditor's internal control letter discussed three areas of review. First, they recommended developing a policy on when to acknowledge unconditional revenue released alongside conditional revenue. This issue may arise when recognizing grants. Second, they questioned why the Foundation recognized donor advised funds (DAFs) as temporarily restricted revenue. Other organizations recognize contributions to DAFs as revenue upon receipt, but the Foundation does not want to overstate their revenue from year to year. The Foundation will need to create policy to document this process. The auditor's final note was on crowdfunding revenue. The Foundation offers to return contributions of \$5000 or more if a crowdfunding project is not fully-funded. This process needs to be documented with a policy that clarifies steps.

c. 2017 IRS 990 Filing

Mr. Engel reviewed the 990, including its preparation and review by the Joint Audit Committee in April 2018. He was asked why we limit the number of contributors shown on Schedule B. He explained that the IRS requires only a list of the major contributions. Ms. Rucks added that the Foundation's forthcoming annual report will list all donors. Mr. Engel agreed to research whether

overreporting donors would be beneficial to the Foundation. Schedule B is not provided to the public; it is only used for IRS purposes.

The Board unanimously approved the completed 2017 Form 990 as presented.

8. Strategic Crossroads – Leveraging the ABF/AAN Partnership: The Board moved into two groups to do a SWOT analysis of the following questions: 1) What can we contribute to the partnership to minimize the weaknesses and threats? 2) What do we need from our partner for this partnership to be beneficial?

Dr. Sacco presented for the group which discussed these questions from the AAN perspective.

The strengths of AAN/Foundation partnership for the AAN are:

- Funding the research mission and young investigators
- Public awareness and support
- The AAN does not have to pay for all the research
- The Foundation is a neutral party
- The Foundation helps meet the AAN's strategic goals

The weaknesses of AAN/Foundation partnership for the AAN are:

- Financial risk
- Competition
- Loss of control
- Lack of staff alignment
- Duplication of resources
- Lack of partnership vision
- Mistrust
- History is getting in the way
- Discomfort of being the “parent”
- Overreliance on members of support
- Competing interests of AAN members
- Brand diffusion and Confusion

The threats of AAN/Foundation partnership for the AAN are:

- Loss of control
- Pharma funding could be undermined
- Undermining of AAN Brand
- The Foundation could negatively affect AAN partnerships
- Threat to AAN's professionalism
- Financial threats
- The Foundation could fail – would the AAN reabsorb?
- Competing advocacy efforts
- Belief that the Foundation will not give AAN credit

The opportunities of AAN/Foundation partnership for the AAN are:

- Engage AAN volunteers
- Greater synergy
- Raising awareness of brain disease

- Financial – to fund research
- To be second only to the NIH in funding research
- Advocacy – greater voice to influence
- Efficiency
- Benefit from the Foundation’s public members
- Improved pipeline to get people excited
- Attract more people to the field
- Greater presence/visibility for all AAN events
- Mutual pride
- Opportunities for members to be involved
- Opportunity to develop broader corporate relationships
- Fund Chair’s agenda in more research
- Fund disparities program
- Fund non-research programs

The AAN team summarized their observations further, identifying the need to:

- Work with the Foundation to develop a joint vision statement
 - Increase AAN Board awareness for the Foundation
 - Clearly delineating roles and responsibilities to improve efficiency and reduce mistrust
 - Coming from the top, the highest level of the board needs to buy in
 - Ensure the Foundation’s stability
 - Strengthen the collaborative nature of relationships
 - Tracking ROI
 - Building vision into metrics of AAN scorecard
 - Engage members in something larger
 - Joint discussion amongst boards – team mentality
- Be successful – raise money
 - Need clarity on what the AAN is getting
 - Sense of shared culture
 - Mutual transparency

Kevin Goodno presented for the group which discussed these questions from the Foundation’s perspective:

The strengths/opportunities of AAN/Foundation partnership for the Foundation are:

- Future leaders applying for Research
- AAN infrastructure
 - Business infrastructure
 - Knowledge
 - Relationships
 - Neurologists
 - Comprehensive
- AAN leaders to Board – knowledge and relationships
- AAN’s reputation & connection to neurologists – this network enhances the Foundation’s abilities

- Raise more money than others
- Financial support from AAN
- Instinctive good will
- Stronger together – the partnership is our unique value proposition
- Open communication at leadership level – trickle down to staff
- Stronger collaboration
 - Public awareness
 - Integration on a day to day level
 - Award presentation
 - AAN fundraising

The weakness of AAN/Foundation partnership for the Foundation are:

- Most AAN members are unaware of the Foundation
- Cost structure – the staff benefits may not be sustainable for the Foundation if they were to separate from the AAN
- Reliance on the AAN – how long should we have this reliance?
- Limited fundraising prospects (pharma, etc.)
- The Foundation is not a focus for AAN staff
 - Not maximizing joint opportunities
 - Lack of a true partnerships
- Burn-out of neurologists
- The Foundation provides no public education
- Needs more financial support from the AAN
- No shared understanding of future relationship – the Foundation is the little sister
- Conflicts amongst governance
- Neurologist support of PAC vs. the Foundation
- “MN Nice” mentality
- Founders Syndrome

The Foundation team summarized their findings as follows: 1) The Foundation and AAN are stronger together, but there needs to be open communication at the leadership level to filter down to staff. All of the ABF’s nonprofit partners compete for funds independently, but the Foundation has restraints. The AAN and the Foundation have an existing relationship that would allow both organizations to distinguish themselves. 2) The Foundation and AAN need a stronger collaboration around public awareness, integration on a day to day level, award presentations, and AAN fundraising.

The Board agreed that any areas of distrust between the organizations need to be addressed by a small group to determine next steps, like the one created for the AAN/Foundation dinner. A retreat between the two boards would be beneficial on an annual basis. Ms. Rydell explained that the AAN board is made up of neurologists, who understand that the Foundation has celebrity public members, but they do not know these members. They do not understand how public members can enhance the potential of the Foundation. Non-financial issues may excite the AAN Board about the Foundation’s work.

- 9. Branding Architecture Update:** Stephanie Olson, Marketing & Communications Manager, discussed a refreshed brand focus in messaging and in creative. Recommendations include a slight tweak to the mission with a swap of the word “cure” for the current “defeat”. They also added “and disorders” to the mission. The vision has not yet been updated. There is also a recommended shift in the “1 in 6” message to “1 in 4,” in order to broaden our scope to include mental illness.

The Board questioned the use of “all” in the mission. They felt “all” was too broad and the mission would still work without it. The word “all” will not be used.

On the creative side, Fellow modified the logo to be more modern with bright colors and open circles for the brain. The Board questioned the use of the open circles. They do not look enough like a brain and are like the Olympic circles. The old logo was more neurological with 4 lobes and a cerebellum. Another member suggested the use of an umbrella or a tree to show that all brain diseases fall under common mechanisms. The Board agreed that the open circles could look more like a brain. The messaging could be more accurate, some words were not depicted in the presentation.

The Board discussed whether the Foundation includes mental illness under its mission now. There is overlap between brain disease and mental illness. Alzheimer’s is a good example. Many neurology departments include both neurologists and psychiatrists. The inclusion of “disorders” in the mission is about public perception. Including disease and disorders gives the public a sense of who we are.

The Board suggested a t-shirt contest to have artists submit a brain drawing. There could also be neurologists who are interested in creating something. The brain cloud typography could be more patient-focused including the roles of people in your life, such as “mother”, “brother”, “grandmother”, etc.

- 10. How is the Board Doing?** Lisa Shulman reported that the Strategic Planning Committee’s role may be moving toward environmental scanning to make the Board aware of timely issues. These issues might include leveraging the talents of a hybrid board or discussions of strategic partnerships. Moreover, Shulman expressed concern that Board members don’t know each other well, and that this can hinder its effectiveness.

Ms. Ransom reported in from her conversations with every board member in late May and early June. Board members are asking for streamlining the number of phone calls, fewer oral reports (with more in writing), less focus on process, and much more focus on high-level strategy and policy.

The AAN does extensive external and internal scanning, and Ms. Rydell would be happy to help the Foundation determine how and what that portion of the Board does.

There was support for creating a finance committee. The Governance Committee will help the Foundation determine if new committees are necessary and how to best plug

people into the committee structure, including adding non-Board members to committees.

11. Committee Reports:

a. Research Advisory Committee: Jane Ransom reported that the Foundation made a presentation to the AAN Science Committee earlier in the week. Points that were touched upon included the RAC's new consensus statement on funding research on mental illness where it overlaps with neurological disease, and the RAC's Lewy Body Dementia Subcommittee which is designing grants in LBD diagnostics in response to donor interest.

b. Governance Committee:

There will be a survey going to all Board members to help inform the development of the next slate of officers. There was more discussion of the board structure, including the idea of a co-leadership between a neurologist and a public member. Any new structure needs to make sure that we are properly leveraging the knowledge and connections of its neurologists. The Research Advisory Committee is doing a good job with its focus on research, keeping the ABF on the cutting edge of science.

c. Commitment to Cures Committee: The Foundation raised approximately:

- \$110,500 in sponsorships
- \$85,000 in individual gifts
- \$400,000 in in-kind gifts

In 2019 the Commitment to Cures dinner will be hosted at the Union League in Philadelphia on Wednesday, May 8.

Adjourned at 3:00 pm CST.