



**American Brain Foundation
Board of Directors Meeting
Friday, September 18, 2015
Minneapolis, MN**

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8 Call to Order: Friday, September, 2015 at 8:30 a.m. (Central) by Kevin Goodno, JD, Chair. A quorum
9 was present throughout the meeting.

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11 In Attendance: Kevin Goodno, JD, Chair; Terrence L. Cascino, MD; Robert C. Griggs, MD; Ralph F.
12 Józefowicz, MD; John C. Mazziotta, MD (via conference call); Jeffrey Rosenfeld, MD;
13 Lisa M. Shulman, MD; A. Gordon Smith, MD; Thomas R. Swift, MD; Jane Ransom;
14 Catherine M. Rydell, CAE

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16 Staff: Timothy Engel, CPA, CFO; John Hutchins, JD, General Counsel; Lauren Ross; Suzi
17 Sherman, Chloe Walbruch

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19 Guests: Linda Hall; Ben Utecht

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21 Excused: Orly Avitzur, MD

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23 Mr. Goodno welcomed everyone and discussed the agenda for the meeting. Mr. Goodno asked if there
24 were any conflicts of interest and none were indicated.

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26 **1. Mintues:** Minutes from August 10, 2015, BOD meeting reviewed.

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28 **MOTION** to approve the ABF BOD minutes from August 10, 2015.

29
30 *Approved* (Unanimous).

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32 **2. Finance Report:** Dr. Józefowicz provided an update on the financial status of the ABF. Overall the
33 organization is in a good position. For remainder of 2015, we are forecasting a \$470K net operating
34 increase, with revenue and expenses under budget. Reason for variance is because we have less staff and
35 conducted less travel than what was budgeted. The 2016 preliminary budget forecasts a net deficit of
36 \$160K and CRTF funding will drop from 20 to 10-12 grants. A final budget will be presented to the
37 board for approval in December.

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39 **3. Executive Director Report:** Ms. Ransom provided an update on the operations of the ABF and
40 highlighted what she has been working on her first three months including, implementing a \$200K major
41 donor campaign to underwrite the costs of the strategic plan implementation, planning the Standing
42 Strong event at the University of Minnesota on November 18 with Ben Utecht, planning the Commitment
43 to Cures event to take place during the Annual Meeting in Vancouver, hiring an Annual Fund manager,
44 and setting the framework and guidelines for the strategic plan. Ms. Ransom also briefly discussed a
45 public outreach opportunity to sponsor a 6 part PBS series called THE BRAIN with Dr. David Eagleman
46 and will have more details to share at the next board meeting.

47
48 Ms. Ransom suggested adding a category to the Alford Group's benchmarks called "Standards, Policies
49 & Procedures" that would include processes and guidelines for grants, endowed funds, donor privacy
50 rules, gift acceptance, and program vs. expense ratios.

1 Ms. Ransom also shared a slide that showed a 5 year revenue and expense projection (based on 2016's
2 budget) that shows management and fundraising expenses increasing as program expenses decrease. Ms.
3 Ransom is working with the AAN/AANI to determine how program revenue/expenses will be handled
4 between the ABF and AAN/AANI.

5

6 Mr. Goodno mentioned that he and Ms. Ransom are working on the governance structure and will be
7 forming a strategic planning committee. Mr. Goodno will be reaching out to each board member to find
8 out each member's area of interest and determine which committee they should sit on.

9

10 **Meeting adjourned at 9:00 a.m. (Central).**

American Brain Foundation Board of Directors Retreat
Friday, September 18, 2015
9:00 a.m. – 4:00 p.m.
Facilitated by Linda Hall

Intended Outcomes

By the end of the day we will further the ABF strategic implementation process by:

1. Sharing an overview of the ABF's recent progress and perspective from our Executive Director
2. Updating and deepening guiding principles, a problem statement, assumptions for use in all strategic implementation planning efforts
3. Improve and affirm the planning framework and charter for each critical issue area
 - 1) Program funding focus
 - 2) Fundraising
 - 3) Business Model
4. Identify themes and areas of agreement for an ideal future picture of the ABF

Hopes for the ABF

- ABF becomes household name
- Impact
- Use 28,000 neurologists to our advantage
- Big thinking, not more of the same
- Get young people involved in research with money and stretch grants
- Last but best chance to do something - cure brain disease, big steps
- Model of training young people
- X prize
- Cure patients with brain disease
- Improving quality of life
- Engage public
- Capitalize on rate of discovery- shared pathways
- Smash the bricks in AAN courtyard
- Give public hope
- Common mechanism between dissimilar diseases
- Innovation-do this differently
- Magnet or clearing house for donors and researchers
- Umbrella organization
- Everyone benefits
- High degree of professionalism
- Growing healthier brains
- Brain health
- Partner/collaboration

- Mutually beneficial relationship with Academy and members
- Measurability of advance/outcomes
- Public visible impact
- Visible/known/public awareness
- Use promised and core values as way to focus and communicate

ABF Planning Process: Part 1 Critical Issues Charter

Critical Issue #1: Program Funding Focus

1. What are the essential questions/issues the planners must address?
 - What sets us apart?
 - Do we focus on a singular area?
 - Where do we focus?
 - Where is there opportunity to fill gaps?
 - Should prevention be a priority?
 - How do we change behavior of the public and neurologists?
 - Are CRTF's still a priority?
 - What should be the priority?
 - Are we funding neurologists or neuroscientists?
2. What resources/information do we need to answer the questions and make a plan?
 - Need research to know which funding mechanisms will resonate with donors
 - Determine how we effectively partner with other organizations
 - What are others doing?
 - Do we need consultants for this?
 - Need to know how to promote our brain
 - Environmental scan
3. Who do we need to consult or involve to create the best plan?
 - Disease specific charities
 - AANI Staff
 - Past, present and future major donors
 - Research Advisory Committee
 - Other professional neurological foundations
 - Do not need outside consultants
4. What obstacles or challenges should we anticipate?
 - Realistic messages - rethink our vision: Cure Brain Disease
 - Focus
 - Bridging public and researchers understanding of our messaging

Critical Issue #2: Fundraising

1. What are the essential questions/issues the planners must address?
 - What are we raising money for?

- What is the *what*?
 - Who are the givers?
 - Who has greatest capacity?
 - How to deal with ethical conflict of neurologists and institutions?
 - Is there benefit to test partnership with disease specific organizations?
 - How do we market to disease specific organizations?
 - How is information shared with public and different demographics?
 - What is benefit to aligning with risk groups (NFL, little league)?
 - ABF to provide information on brain disease
 - What are benefits of sharing information across brain disease organizations?
 - Do we need other resources for philanthropic scan?
 - Who in business sector can we connect with for information and partnership for the brain?
 - Look at all industries and determine what resources do we need to reach industries?
 - Are we leveraging AAN resources correctly?
 - How do we connect with public to get their visions on what the ABF can provide?
 - Will exposing our brand appropriately result in increased money?
 - Ways to creatively involve patients and connect with them outside traditional channels
 - Look beyond traditional competitors
 - Look at connecting with public in areas of their philanthropic interest- religion, schools, profession
 - Who can we consult with in retail industry?
 - How do we use AAN membership?
 - Major donor vs. individual donor
2. What resources/information do we need to answer the questions and make a plan?
 3. Who do we need to consult or involve to create the best plan?
 - Consult other areas - patient rehab providers and groups
 4. What obstacles or challenges should we anticipate?

Critical Issue #3: Business Model

1. What are the essential questions/issues the planners must address?
 - Are we aiming to become completely independent and what does it mean?
 - What are the areas of entanglement?
 - Which are good and which are bad?
 - What are the trade-offs?
 - What is the appropriate mix of neurologists and non-neurologists on the Board?
 - How do we attract members?
 - How do we make the transition?
 - What is the role of the board?
 - What attributes do we need in our Board members?

- What are the relationships we want with other organizations?
 - Should there be a percent ratio established for program vs. fundraising expenses, and what?
 - What will the staff culture and structure be?
2. What resources/information do we need to answer the questions and make a plan?
 - What do other organizations do? (From medical to broader organizations)
 - How do they focus?
 - How do we identify the right trustees?
 3. Who do we need to consult or involve to create the best plan?
 - Major donors - new and old
 - List on worksheet
 - Broader medical research foundations
 - Accounting consultant
 4. What obstacles or challenges should we anticipate?
 - Resistance to change
 - There is no ideal solution
 - Disease specific organizations - competitors
 - Dependence from Academy

ABF Planning Process: Part 2 Planning Building Blocks

Adjustments to Problem Statement

1. Look at last sentence - choose different examples
2. Mechanism → common features
 - a. Inflammation
 - b. Cell death
 - c. Common feature
3. Out of box thinking
4. Young investigators difficult to fund
5. Incrementalism
6. Jane will re-word last sentence and will get further feedback from neurologists on the board

Strategic Narrative Input

Ideal Future Themes

- Cure brain disease
- Common mechanism between dissimilar diseases
- Innovation—doing things differently
- Hub—magnet or clearing house for donors, researchers
- Umbrella organization bringing parties together; connector
- Partners/collaborations
- Everyone benefits
- High degree of professionalism
- Growing healthier brains
- Brain health
- Mutually beneficial to Academy members

- Measurable advancement—outcomes
- Publicly visible impact
- Visible, known, public awareness of ABF and its message
- Awareness and philanthropy

Strategic Narrative Questions

1. Five years from now and beyond, what is made possible in the world by the ABF's efforts is:

- Awareness
- Giving patients and caregivers hope in prevention, treatments, and cures
- Improved quality of life by those affected with brain disease
- Groundbreaking research impacting multiple diseases
- Increased collaboration between other disease specific organizations
- Innovative ways to give financially
- Promotion of brain health
- Fewer people with neurological diseases
- Revolution in public thinking about brain disease which translates in to huge amounts of money
- Unified effort to cure brain disease
- Biomarkers to predict responses to treatment
- Opportunities
- Memory care centers put out of business
- Sustainable careers in research

2. The unique niche and role the ABF plays in the landscape of those working to cure brain disease includes:

- Providing a huge piece to cure major neurological diseases
- Engage neurologists to support ABF
- Showing connections between multiple diseases of the brain
- Being the whole organization in which all brain disease is included
- Proved the "muscle" to develop treatment to prevent more brain disease
- Partnering with other brain disease specific foundations
- Funding the less fundable
- Seeing ABF as the go to organization for funding
- Being the great connector between patients and public to research and making connections among disease specific organizations – use phrase, "Impact one, impact many"
- Making connection between disease and organization
- Teaching public to look at brain disease the way they look at cancer – as brain diseases and not as a disease of the brain
- Providing support and opportunities for researchers

- Focus on overall brain function
- Funding most innovative research
- Funding young investigators

3. The ABF Board and organization are characterized by:

- Data driven decision making and meaningful goal setting
- Experience
- Highly effective and efficient fundraising
- Passion
- Rapid and flexible response to a donor or partner
- Innovation, integrity, and effectiveness
- Holistic, complete organization
- Integrity, loyalty, humanity
- A single purpose
- Aspirational thinking
- Impact on American culture
- Defined and relatable mission
- A diversity of voices
- Clearly identifies uses of donations and impact
- Positive outlook
- Being mission driven
- Willingness to question how we do things - better and different
- Meeting and exceeding industry standards
- Being grateful
- Having measurable outcomes

4. Our important stakeholders now include:

- State high school sports leagues and amateur organizations
- Patients, caregivers, and their families and friends
- Public
- People with great ideas and money
- All people with a brain
- Armed forces
- Students, teachers, technology industry
- Professional sports leagues
- Other disease specific organizations
- Young people wanting to go into research
- A committed Fortune 500 partner
- Leadership in entertainment industry
- Americans
- Clinical neuroscientists

- Chairs of departments of neurology
- Local state and federal policy leaders
- NIH and other major funding organizations
- Philanthropic firms
- Insurance industry

5. Our ideal mutually beneficial relationship with the AAN is characterized by:

- Seamless perception in the public
 - Publically distinct from the AAN, but mutually supports
- Academy's continued commitment philosophically and financially
- Clearly understood and defined
- Both organizations demonstrating value of neurology and neurology research
- Both use each other as trusted resources
- ABF can fund the research need of the AAN
- General understanding of impact of brain disease by the public
- Partner on different programming
- Showing the value of neurology
- Independence for the ABF but members of the Research Advisory Committee are appointed by the AAN
- Efficiency and transparency
- Brilliant collaborations
- Research indispensable to Academy members

6. As a foundation we are known & valued for:

- Raising tons of money
- Leading the way in the fight against brain disease
- Funding tons of grants
- Integrity, efficiency, and outcomes
- Having cured a major brain disease
- The place for brain health
- Saving the minds of Americans
- Improving quality of life for those affected by brain disease
- Go to source for info on brain disease
- Our presence in the brain disease community
- Identifying and funding most impactful research
- Demonstration of impactful research that has improved patients' lives
- Funding novel, higher risk ideas
- Being donor centric
- Flexibility and responsiveness to partners
- Innovative approach to achieving our mission
- Increase number of neurologists entering and remaining in research careers

7. Our progress and success is measured by:
- Reaching our well defined and measurable goals
 - Money raised
 - Outstanding researchers funded
 - Positive impact on people with brain disease
 - Level of public awareness
 - Healthier patients
 - Results in curing brain disease
 - Ratio of funding to discovery
 - 100 million people reached or impacted by the ABF
 - Common household name
 - Number of partners
 - Public's ability to define what a neurologist is

Common themes drawn from critical issues and strategic narrative

- Common mechanism between dissimilar diseases
- Innovation - doing this differently
- Hub to cure brain disease
- Magnet or clearinghouse for donors and researchers
- Umbrella organization bringing patients together
- Everyone benefits
- High degree of professionalism
- Growing healthier brains
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- Measurability of advanced outcomes
- Public visible impact
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Wrap up and adjourn

Follow-up items

1. Notes from session reproduced by ABF staff
2. Give strategic planning committee the charge to address approach to mission/vision using key ideas from strategic narrative
3. Framework document will be updated with board's feedback and provided to the Strategic Planning Committee
4. Feedback regarding critical issues will be shared with the planning teams