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	Board of Directors April 17, 2016 9:30 a.m. EST/10:30 a.m. CST/11:30 a.m. MST/12:30 p.m. PST Call-in number: 866-740-1260 Access code: 9286317		
	Kevin Goodno, JD, Chair; Terrence Cascino, MD; Robert Griggs, MD; Ralph Józefowicz, MD; John Mazziotta, MD; Jane Ransom; Jeffrey Rosenfeld, MD; Catherine Rydell, CAE; Martin Shenkman, CPA; Lisa Shulman, MD; Joseph Sirven, MD; A. Gordon Smith, MD; Thomas Swift, MD; Ben Utecht		a, MD; Jane Ransom; CAE; Martin Shenkman,
	Staff	Catherine Elliott; Timothy Engel; John Hutchins, JD; Lauren Ross; Suzi Sherman; Marlys Weyandt	
	Guests	Richard Essey; Ralph Sacco, MD; ABF consultants: Lela Diaz; Bob Carter; Kathleen Henrichs; Gail Thomason; Linda Hall	
	AGENDA ITEM *	Signifies Board action needed	PRESENTED BY
12:30 p.m. PST	American Brain Fou Order	ındation Board of Directors Meeting Call to	Kevin Goodno, Chair
	* *		Kevin Goodno
12:45 p.m.	Top level goals evidence	Strategic Plan rategic Implementation Plan s & strategies with supporting d for input and approval to move	Lisa Shulman, MD and Jane Ransom
2:00 p.m.	ABF's Emerging S Collaboration a	Strategic Plan and partnership with AAN	Kevin Goodno
2:45 p.m.	Update on AB	·	Jane Ransom
3:00 p.m.	Financial Report • Financial State	ements	Ralph Józefowicz, MD and Timothy Engel, CFO

• Financial Statements



3:15 p.m.	Audit Report • FY 2015 Audit	Ralph Józefowicz, MD and Timothy Engel, CFO
3:30 p.m.	Committee Reports	Committee Chairs
4:00 p.m.	Adjourn	Kevin Goodno



UNL	DATION _®
1	American Brain Foundation
2	Board of Directors Meeting
2 3	Friday, March 18, 2016
4	Held via Teleconference
4 5	
6	Call to order: Friday, March 18, 2016 at 9:03 a.m. (Central) by Kevin
7	Goodno, Chair. A quorum was present.
8	eccano, enam i i queram mae precenta
9	In attendance: Kevin P. Goodno, Chair; Robert C. Griggs, MD; Ralph
10	Józefowicz, MD; Jane Ransom; Jeffrey Rosenfeld, MD;
11	Catherine Rydell, CAE; Martin Shenkman, CPA; Lisa M.
12	Shulman, MD; Thomas R. Swift, MD; Ben Utecht
13	Shaiman, MD, Thomas IX. Switt, MD, Den Glecht
14	Staff: John Hutchins, JD, General Counsel; Timothy Engel, CPA, CFO; Suzi
15	Sherman
16	Sileman
17	Excused: Terrence L. Cascino, MD, FAAN; John C. Mazziotta, MD, PhD, FAAN;
18	Joseph Sirven, MD, FAAN; A. Gordon Smith, MD FAAN; Lauren Ross;
19	Marlys Weyandt
20	Out of the De Asselle IV de Eddese Obdelle Dheles
21	Guests: Lisa DeAngelis; Kris Fridgen; Christine Phelps
22	A Book I Olicia Book of Ma Conden and control of the condition
23	1. Board Chair Report: Mr. Goodno welcomed everyone and discussed the
24	agenda for the meeting.
25	
26	Minutes: Minutes from February 18, 2016 were reviewed.
27	MOTION to approve the ABF Board minutes from February 18, 2016.
28	Approved (unanimous).
29	
30	Mr. Goodno asked if there were any conflicts of interest and none were indicated.
31	
32	2. AAN Research Career Development Plan: The purpose of this update is to
33	share information across organizations so the ABF can take the AAN's programs
34	into account as we develop our own strategic plan. The ABF Board is not being
35	asked to weigh in on the AAN's program plan.
36	
37	Dr. DeAngelis presented the plan to the ABF Board and started by providing
38	background information to how the Science Committee got to this point – see
39	slides 6-8 of powerpoint.
40	
41	As seen on slide 9, there is a significant gap between the number of applicants
42	and the number of fellowships awarded each year. Science Committee would like
43	to try and meet the demand.
	to try and meet the demand.
44	

For the coming year, the committee is proposing to have the AANI expand its support of research. Recommending to change the names from "Fellowship" to "Scholarship" and also add two new awards: Neurology Research Training Scholars (NRTS) and Career Development Award (CDA) for Junior Faculty.

Slide 11 provides a breakdown of funded awards over the next 2 years by funding source.

Proposed awards would be for physician investigators only, not for PhD neuroscientists. Envision the CRTS (formerly CRTF) program would stay the same, which at this point supports some aspects of translational research. The NRTS or CDA would support translational work, but could require laboratory work as well. The RFA's are still being developed but envision them being open to any topic/discipline.

By 2018, it will take an increase from \$500,000 (now) to about \$1.8M for this program, so increment of \$1.3M. CDA is a much larger award, it's a 3 year award at \$150,000/year. Awardees will not be allowed to hold a CDA and K award simultaneously. Goal is to grow into what the CRTS (formerly CRTF) program is today.

The ABF and AANI will continue to collaborate on funding for this program. There will not be competition between the organizations for funding.

3. Executive Director Report: Ms. Ransom requested the Board's vote to approve a revised spending policy that was created to provide an easy understanding of how donor's dollars will be used. New policy states:

The ABF will spend a minimum of 5% of the average annual fair market value of each endowment fund, for the prior 12 quarters. Spending available for each fund will be used to cover grant distributions and ABF's administrative fee of no more than 1% of the principal.

MOTION to approve the revised spending policy. *Approved* (unanimous).

Annual Meeting: Ms. Ransom provided an overview of all of the ABF's activities taking place during the Annual Meeting and invites board members to join her at any of the events.

She also encourages board members to invite new guests to the Commitment to Cures event to increase awareness about the ABF.

Fund Development: The ABF is in the process of joining multiple workplace giving campaigns, over 300 private, corporate, state, and federal campaigns.

Still evaluating whether or not to repeat the Standing Strong event this fall.

4. Committee Reports:

• **Executive Committee:** Mr. Goodno reported that the committee is developing an incentive plan for ABF staff that will be presented to the board at a future meeting.

• **Governance Committee:** Mr. Goodno reported that the committee will present a policy that clarifies the board member term limit outlined in the bylaws and a proposal to align the expiration of terms at the next Board meeting.

• Strategic Planning Committee: Dr. Shulman reported that the committee will be meeting in person on March 25 in Minneapolis with the goal to integrate the reports on the philanthropic assessment, business model assessment, and program funding report. Hope to have a draft of a strategic plan that will be presented to the board on April 17, 2016 in Vancouver.

 Research Advisory Committee: Dr. Griggs reported that the committee will be meeting in person on April 16, 2016 in Vancouver and will discuss the Science Committee's report.

Reminded that the Board's fiduciary responsibility is to track how much is being spent on programming vs. administration. Mr. Engel will provide this information compared to prior year and what was projected in the budget on a rolling basis.

For 2016, the estimated projections are 70-75% are related to programming expenses and 25-30% are related to administrative expenses.

Meeting adjourned at 9:57 a.m. CST.

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AMERICAN BRAIN FOUNDATION DRAFT VISION, MISSION, GOALS & STRATEGIES

VISION

To cure brain disease

MISSION

To bring researchers and donors together to defeat brain disease.

GOALS

- I. <u>CORE BUSINESS MODEL</u>: Create a community to support research in brain disease.
- II. <u>CULTURE OF PHILANTHROPY</u>: Build an environment that meets the needs of donors to advance the ongoing health of the Foundation and defeat brain disease.

STRATEGIES

- 1. <u>Research Clearinghouse</u>: Construct a virtual platform to match the best science with the largest pool of committed donors to advance a continuum of research.
 - A dynamic research platform that fosters valuable fresh connections- where researchers pitch their best ideas to donors, where donors advance their own research concepts, where patient advocacy groups connect with new untapped populations, where the power of crowdfunding propels research forward.
 - A continuum of research from training fellowships, to career development awards, to high-risk/high-reward studies to the unique X-Prize attracting venture capital to fundamentally change the landscape of brain disease. The X-Prize will be awarded to the first team to reach the audacious goal of delaying the onset or progression of a major neurological disease.
- 2. <u>Public Engagement</u>: Build the ABF brand around our unique niche.
 - The whole brain approach: A cure for one brain disease is a cure for many.
 - The ABF is promotes key research for your grandmother with dementia, your uncle with stroke and your close friend with MS. Your ABF donation touches all of us since different brain diseases share common mechanisms.
 - ABF's collaborative relationship with the AAN "all-star team"

- Signature projects to "seize the moment" and promote research for timely topics (concussion, CTE, dementia, brain health).
- An awards program the "Nobel Prizes" of brain disease builds upon the ongoing AAN awards program.
- 3. Philanthropy: Develop full-fledged public support and deepen giving from AAN members.
 - Add additional staff to support growth
 - Confirm a strong unique case for support
 - Increase giving to the Annual Fund
 - Identify national foundations with an interest in brain research and advocacy
 - Look to broaden brand awareness of the ABF
 - Create a collaborative culture of philanthropy in partnership with the AAN
 - Develop public facing messaging and platforms to raise funds beyond AAN membership
- 4. Aligned Leadership: Create a thriving partnership with the AAN.
 - Align organizational ABF/AAN goals and strategies to foster a high-performing "winwin" environment with incentives for working together.
 - A structured AAN/ABF relationship with expectations and incentives for communication, synergy, transparency and trust.
 - Mutually beneficial transparent policies to facilitate communication, governance, fundraising and finances.

CONFIDENTIAL DRAFT

The American Brain Foundation in the Future: Five Years & Beyond

Mission: The American Brain Foundation supports vital research and education to discover causes, improved treatments, and cures for brain and other nervous system diseases.

Strategic Narrative

Summary

The American Brain Foundation (ABF) is a national voice for brain health and a dynamic force for bringing researchers and donors together to defeat brain disease.

The ABF's core business platform is a virtual clearinghouse featuring a broad selection of fundable proposals—submitted by scientific investigators from throughout the world—on research seeking to prevent, treat or cure one or more of the 400+ diseases of the brain and nervous system.

Donors of all types come directly to this comprehensive virtual clearinghouse to search out and contribute to specific projects which appeal to them, often because of their personal or institutional stake in a particular disease. But these donors are inspired to know that <u>all</u> of the research under the ABF's umbrella offers them hope. This is because the Foundation accepts fundable research proposals which include a solid case for how their discoveries may potentially be applied beyond a specific disease to other brain diseases.

The ABF is a grant making public charity whose major program is funding research grants. From time to time the ABF may choose to focus over a multi-year period on one or two strategic initiatives. The foundation also manages donor advised funds, which may be restricted to a variety of other purposes within the realm of brain disease research and education.

The ABF's unique research partnership with the American Academy of Neurology (AAN) is another powerful draw for donors. Donors have great confidence in their investments knowing that the ABF has access to the best and brightest minds—the world's largest association serving neurologists and the neuroscience community—to source the most high-risk and high-reward research cutting across various diseases of the brain.

At any given time the ABF plans to have one or more multi-year strategic initiatives in play. For the past five years, the central initiative has been developing the brain disease research hub/clearinghouse. Now the Foundation is turning toward developing a multi-million dollar national research prize (aka X-Prize) to fundamentally change the landscape of brain disease. The prize will be awarded to the first team to reach the audacious goal of delaying the onset or progression of a major neurological disease.

CONFIDENTIAL DRAFT

Most ABF initiatives are driven through its virtual hub/clearinghouse, including information one on youth sports concussion and special fundraising campaigns for select high-risk projects. In addition, the ABF remains committed to supporting early career clinical neuroscientists and funding their innovative research on diseases of the brain. These programs and ABF general operations are supported by the ABF's robust fundraising program and fees accrued through its philanthropic services, including the virtual clearinghouse and donor advised funds.

Making a Difference

Brain disease research is advancing more rapidly in the world because of the ABF's presence. Millions of new dollars are being channeled into brain disease research through the ABF virtual clearinghouse.

The ABF's slogan, "A cure for one is a cure for many," is taking hold in the public consciousness. Breakthrough discoveries resulting from ABF-funded research are shared via the Foundation's popular blog and through its special convening of researchers around the potential cross-disease applications of their discoveries.

The ABF has distinguished itself in the realm of neurology and neuroscience through its persistent approach of highlighting work on the connections between diseases of the brain and neuromuscular system. When the ABF seeks out, talks about, or funds brain disease research, its emphasis is consistently on common mechanisms. The ABF's distinct voice and approach is attracting new donors, enabling new kinds of partnerships, and fertilizing thinking across "disease silos."

ABF Partners

Donors

Attracted by the mission and giving opportunities of the ABF, donors have multiple giving options:

- Contributions to the ABF General Fund supporting:
 - ABF strategic initiatives (education & research)
 - ABF general operations

Contributions to the General Fund may be given in response to direct mail/e-mail appeals, AAN membership dues check off, ABF fundraising events, "Donate Now" appeal on ABF website, planned gifts, and grant proposals to individuals, foundations and corporations.

- Restricted Contributions supporting:
 - Disease-specific research
 - ABF virtual clearinghouse
 - New AAN Science Committee initiatives
 - ABF strategic initiatives (education & research)

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Researchers

The ABF's research partners include all individuals and organizations with research projects accepted into its virtual clearinghouse. This includes single-disease voluntary health organizations, the AAN, and other associations and institutions in the realm of neurology and neuroscience. Other constituencies include psychiatry, psychology, gerontology, AARP, and federal/state agencies.

Single-disease voluntary health organizations see value in their partnership with the ABF because the Foundation's virtual clearinghouse offers them a new platform for their research fundraising and attracts new donors for their work through this channel. They also appreciate how the ABF is breaking down "disease silos" with its funding, giving neuroscientists access to information that formerly may not have been shared.

American Academy of Neurology

The AAN is experiencing a return on its multi-year investment in the ABF which is now financially self-sufficient. The Foundation continues to support the ABF/AAN's flagship clinical research training scholars program. Furthermore, the ABF's research clearinghouse, which lists *all* of the AAN's multi-year research initiatives, has become a new funding stream helping to support its science agenda. And finally, in regular surveys AAN members consistently mention the ABF as a point of pride and a reason for retaining their membership.

The ABF accrues multiple positives from its strong, dynamic partnership with the AAN. First and foremost, the relationship is a major selling point with donors and potential donors who know that a team of 30,000 neurologists stand behind the ABF, and that this team's all-stars are vetting its research funding opportunities. In order to maintain a formal relationship, ABF bylaws require that at least ____ percent of its board of directors be members of the AAN.

The AAN has gradually withdrawn its financial support for ABF operations as the Foundation has gained traction. But the ABF still benefits economically from being housed at the AAN building, where it has access to the internal services of a large association (e.g., HR, finance, IT and legal) in return for a very reasonable, below market annual fee.

This association with the AAN keeps its activities visible to members and allows for AAN/ABF synergy in areas like advocacy, marketing and, of course, research. This is why the two organizations have made sure to keep in close communication about these areas through cross-representation on key board and staff committees.

The ABF and AAN have formalized communications in key areas through reciprocal representation on key board and staff committees in areas such as: research, marketing & communications, advocacy, and fundraising.

ABF Organization

Board of Directors

The ABF board is now composed of __ "public" (non-neurologist) members and __ members of the AAN. All board members, regardless of their profession, are passionate about the Foundation's mission and take responsibility for the fiscal health of the ABF, including giving and getting funds for the organization.

A number of high wealth, high profile individuals have been recruited into the public member slots on the board. The ABF has made sure to recruit people who have strong relationships in the corporate and entertainment worlds, as well as connections with high wealth individuals in key geographic areas of concentrated wealth in the US.

The AAN members on the board represent a diversity of younger and older leaders in the profession of neurology. They have the leadership skills to mobilize other AAN members to support the Foundation through oversight of its research agenda and outreach to caregivers and patients. The ABF's Research Advisory Committee is chaired by an ABF board member neurologist and is responsible for maintaining the research review process. Four years ago the Research Advisory Committee designed the ABF's new X-Prize to change the brain disease landscape.

Staff

The ABF staff has grown to 10 people. Its fund development department is now led by a chief development officer. The collective skillset of the fund development staff includes expertise in major donors, planned giving, annual fund, gift prospecting and grant writing.

The staff leadership of the program and marketing & communications have neuroscience backgrounds. They are able to manage research grant making, while, at the same time, translating the ABF's research investments into stories of hope, attracting patients, caregivers and the general public to give.

ABF's virtual clearinghouse requires an in-house IT staff member to work exclusively on the evolution and updating of the ABF's website.

REPORT FROM THE RESEARCH ADVISORY COMMITTEE OF THE AMERICAN BRAIN FOUNDATION

DR. ROBERT C. GRIGGS, CHAIR

BACKGROUND

I'd like to thank the Science Committee for the opportunity to discuss the emerging research funding program of the American Brain Foundation, as envisioned by the Foundation's Research Advisory Committee (RAC). The RAC was established last year when the Academy made the decision to invest in positioning the ABF as a highly influential, publicly-facing foundation—one that rallies the hearts, minds and pocketbooks of the American people, and even beyond, in the battle to cure diseases of the brain and nervous system.

Since the Science Committee is also concerned with the future of research on brain disease, I believe it is crucial that we share agendas and collaborate. Best case scenario from the ABF's perspective is for the Foundation to provide substantial, growing support for the evolving research agenda outlined in the Science Committee report from Dr. DeAngelis for last September's meeting of the AAN Board. We also envision providing funding outside of the Academy for other high-risk research projects.

The current work of our RAC is to determine the future of research funding by the ABF. This work is one leg of a larger strategic planning process recently undertaken by the ABF. The members of our committee include Drs. Carsten Bonnemann, Merit Cudkowicz, Shafali Jeste, John Morris, Ray Roos, Ralph Sacco, Ira Shoulson and myself as Chair.

EMERGING VISION OF ABF FUNDING

The ABF's RAC has met three times over the past four months. We've agreed upon an underlying philosophy to guide our approach to research. It includes three principles:

- Recognition of the need to continue and expand supporting young investigators
- Working in partnership with disease-specific organizations
- Funding high-risk but highly innovative research aimed at disease treatment

In this context we are considering a multi-tiered research funding program consisting of:

- Great Minds: Cornerstone program which identifies the best and the brightest early career clinical
 neuroscientists and funds their innovative research on diseases of the brain. Scientific and medical
 communities have called the shortage of investigators a crisis that will impact far more than the 100
 million Americans currently affected by a neurologic disease or disorder. Through funding clinical
 research training fellowships, the ABF will continue to create the next generation of premiere minds
 that will impact the study of diseases of the brain and nervous system in ways we can only imagine.
- 2. <u>Breakthrough Discoveries</u>: Higher-risk research to prevent or delay the onset of diseases such as Alzheimer's disease, dementia with Lewy body, Parkinson's disease, Lou Gehrig's disease (ALS) and others. Impact research across a wide-ranging set of brain and neuromuscular diseases through discovery of fundamental common mechanisms. For example, the ABF envisions supporting:
 - High risk, patient-centered discovery of new treatments: It is hard to find funding for the early phase therapeutic space, research showing that a drug reaches the target and has

a measurable beneficial on the course of the patient's disease. Grants in the \$1.5-2 million range are needed. Pharma has pulled back from funding this type of high risk research and Federal funding is limited and tends to favor studies de-risked by having the type of preliminary data that such high-risk research would facilitate.

- Common mechanisms of neurodegeneration and neurodevelopment: This research
 would need to be directed to specific diseases to attract donors who care about their
 own diseases primarily but would have the potential to benefit research in many
 diseases.
- 3. The X-Prize: An ABF prize attracting venture capital to invest in cutting edge, innovative and high-risk research that could forever change the landscape of brain disease. The prize (monetary value yet to be determined) will be awarded to the first team to reach the audacious goal of delaying the onset of a major neurological disease, such as Alzheimer's, multiple sclerosis, Parkinson's, MSA, diffuse Lewy body disease, Progressive Supranuclear Palsy, muscular dystrophy and ALS.

PRACTICAL APPLICATION

Already the ABF is seeing interest from some major donors in this approach—where we give them a "menu" of options along the continuum, starting with clinical research training fellowships and stretching all the way to the X-prize. In recent weeks we have provided such a menu to two different donors interested in each of two diseases/disorders—autism and ADHD. Disease-specific experts on the RAC have helped the staff to frame and propose much-needed research projects on the high-risk end of the scale.

QUESTIONS & OBSERVATIONS

- There are obvious overlaps between the preliminary research agendas sketched out by the ABF's RAC and the Science Committee. We should be collaborating for success all around. A good start at formalizing collaboration and communication might be to have overlapping memberships, i.e., a member of the Science Committee sits on the ABF's RAC and vice versa.
- We could be using the AAN's big awards, as well as the Public Leadership in Neurology Award, to educate the public, highlight research successes and secure donor funds. We could partner to develop a more exciting, more public platform for these awards.
- Similarly, the ABF public board members and donor base could be mobilized to strengthen the hand of the science constituency of the AAN in areas such as advocacy, Federal funding of research and in show-casing of AAN members making scientific breakthroughs.



Philanthropic Assessment Report

Prepared for American Brain Foundation

April 2016



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EXECUTIVE SUMMARY

Carter was commissioned to provide professional consulting services to assess the American Brain Foundation's (ABF) long-term philanthropic potential in the context of its strategic direction and implementation planning, and to recommend a multi-year fund development strategy. Carter also engaged internally with officers on staff and the strategic planning committee of the board to identify the nature of the philanthropic culture within the organization. The study's objectives are:

- To determine fundraising potential within various revenue channels
- To test the Case Summary among various constituents and determine which elements are most appealing to the different audiences
- To create a sense of ownership among key constituents by seeking their opinions and input on the proposed fundraising plans
- To develop an initial fundraising plan
- To identify major gift prospects
- · To identify fundraising leadership prospects
- To help establish or reinforce a culture of philanthropy
- To assess the public perception of ABF
- To establish early momentum

The approach taken for this study encompasses our discussions with the ABF leadership, the interviews with potential donors, our data gathering and analytics. With an objective of at least 20 interviews for this study, a total of 37 individuals, foundations and corporations were identified as top prospective participants for the interviews. Of those invited to participate, 18 interviews were completed. Among the remaining prospective participants, five declined to participate, several were not able to arrange interviews within the study period due to travel or other conflicts in their schedule, and five were unable to be scheduled through the American Academy of Neurology contacts.

ABF Staff complied this list in partnership with the Carter team. The list represents a diverse segment of individuals and institutions of importance to the philanthropic future of ABF regardless of their previous affiliation with the organization. It is essential that study participants represented a cross section of those whose participation would be considered vital in some way to the success of any fundraising efforts for ABF. Carter recognizes the desire to engage perceived outsiders "non-AAN members" however for any effort moving forward the study needed to incorporate feedback from the current donor base to better understand the current motivations and future potential of giving. The Carter team has over 70 years of combined experience in conducting assessments

and studies for organizations all over the world and in our experience both in studies and fundraising is that you must engage your closest constituents first before going out to broader groups that aren't connected with the mission. A listing of all study participants is below.

Acadia Pharmaceuticals*

Dr. Alessi*

American Epilepsy Society

Citizens United for Research in Epilepsy

Blanche Hawkins

Trish Jacobs

Dr. Jozefowicz*

Dr. Kenton*

Dr. Kutcher*

Margaret A. Cargill Philanthropies

Dr. Miyasaki*

Dr. Pedley*
Dr. Prusinski*

Richard M. Schulze Family Foundation (Best

Buy)

Martin Shenkman* Simons Foundation Susan Williams

Wolters Kluwer Health*

*existing affiliation with ABF and AAN

The personal interview and consultation format was designed to elicit advice, impressions, opinions and information relating to ABF, including perceptions of the mission, the understanding of the priorities, and the availability of philanthropic support. In preparation for the interviews, respondents were asked to review a case summary (Appendix A).

In this report, we present observations and findings derived from the study's interviews; however, to ensure confidentiality, detailed interview notes are not included in this report. The findings also reflect data gathered during the study, and the experiences of the Carter team in philanthropic counsel, improving organizational efficiencies and effectiveness, and maximizing fundraising and philanthropic outcomes. Our recommendations emerge from these insights and expertise, focusing on specific areas for ABF to address to evolve its philanthropic culture and prepare to increase the total contributions received from its fundraising initiatives. The Carter team has included detailed planning tools that suggest financial targets.

Our findings are presented under three major headings:

- 1) Mission, vision, and focus
- 2) Donor engagement and stewardship
- 3) Revenue channel opportunities & challenges

Our recommendations focus on seven major topics:

Add additional staff to support growth

- 2) Confirm a strong unique case for support
- 3) Increase giving to the Annual Fund
- 4) Identify national foundations with an interest in brain research and advocacy
- 5) Look to broaden and strengthen brand awareness of ABF
- 6) Create a collaborative culture of philanthropy in partnership with AAN
- 7) Develop public facing messaging and platforms to raise funds beyond AAN membership

FINDINGS

The following represents the findings based on the study's interviews. They serve as the foundation for the recommendations presented in this report.

Mission, Vision and Focus

The vast majority of interviewees could not clearly articulate the work of the ABF without regard to whether they had a previous relationship with the organization. A time-tested principle is that "Without vision, institutions perish." For the ABF, its vision must be clearly articulated and consistently presented to all constituencies and stakeholders. The comprehensive plan to guide the envisioned fundraising initiative must align with the Foundation's vision for growth and sustainability. Donors and prospective donors must quickly trust and become enthusiastic about supporting ABF based on a mission and vision that reflects a capacity to change lives.

A clear and compelling organizational vision must drive all aspects of ABF's fundraising. In addition, a thoughtful and precise strategic plan can provide ABF's donors with an optimal vantage to appreciate the organization's roadmap for the future. This roadmap identifies the priorities and the action that will drive the organization forward and sustain its operations over the next three, five and ten years. It will provide a context for ABF's comprehensive fundraising program. It is critical for the success of the organization to identify the key differentiator that will frame the strategic vision over the coming years. The American Brain Foundation needs to establish a position in the minds of donors that is both unique and highly valued. Donors will need to be invited to engage in a variety of ways within the Foundation in support of the ABF's vision.

AAN Representative Comments:

- "I understand the mission but not their work or results."
- "ABF is the new iteration of the AAN foundation"
- "Is AAN running ABF? Always a lot of politics in the academies/associations. Need to have some clarity between AAN and ABF."
- "Needs to focus on awareness as well as research."
- "Like that they are expanding their vision for curing all brain disease."

Other Representative Comments:

- "Not familiar with their work"
- "Like the idea of identifying the best and brightest minds and starting them in research"

- "No one knows who ABF is"
- "Careful with terms like high-risk"
- "Value is ABF has all neurologists across all areas and can focus on things that cut across any one individual disease."
- "How is this distinct from what others are doing?"
- "Not familiar with foundation"
- "Focus on neuro-generation and mechanisms that underlie brain disease and disorders might have some appeal – pulling out those links that are proven and this is what needs to be funded because it will impact breakthroughs. Focus on the commonalities"

Case Summary

Many interviewees felt the Case Summary was compelling and provided a good overall message. A number of components within the case messaging resonated but no single over-arching priority emerged during the interviews. The first area that received the most interest was research; specifically, the funding of cross-cutting research (or the "whole brain approach) and the funding of young investigators. In addition, the concept of advocacy and a general awareness education effort about the whole brain and brain health resonated among interviewees. Overall the connection with AAN was continually sited, both by AAN members and Non-AAN members, as a major differentiating factor for ABF and could be a major part of the Case for Support moving forward.

Focused efforts like the Youth Concussion initiative and the X-Prize concept also received favorable feedback. Interviewees felt that a distinct program that can resonate with a broad audience, like concussions, could help generate awareness and traction. However, some mentioned that a focused program could dilute the message about finding a cure for brain disease. For these reasons, the concept of an X-Prize was also welcomed, though some cautioned a monetary prize may not be a motivating factor for all researchers.

The ABF case can be strengthened by focusing on the specific impact that the organization can have. The full Case for Support will need to provide greater detail, specific examples and demonstrated metrics-driven outcomes. Prospective major donors will require a presentation by the ABF that allows them to understand the overall approach, specific initiatives and expected impact. The interview process also revealed a desire for a greater focus within the six areas identified in the case.

The Case for Support serves as the key tool in articulating the vision of the organization. It provides the rationale for donors to engage ABF and contribute to its plans for the future. The Case must be easily understood, urgent, compelling, and emotional. It tells a story that appeals to the philanthropic interests and desires of donors as well as the entrepreneurial and business interests of investors. The Case offers a way for ABF to share its most powerful messages about why ABF is worthy of support. The Case also is vitally important in informing all other fundraising materials so that they align with a consistent message, brand and feel. Lastly, the Case must be constructed in a way that can be easily tailored to a specific audience or funding opportunity.

AAN Representative Comments:

- "'Cure statement' Needs more explanation some proof"
- "Reaches out to the public but maybe not doctors"
- "It needs to be all encompassing, but you also need to focus on what can drive funding and get people's attention"
- "Funding researchers. Finding the right people for research."
- "All the focus is on the future, not necessarily care and outcomes now. This is a seduction created by the cancer messaging. Need to have some focus on making an impact on lives today."
- "Getting people to identify with aspects of brain disease is important."
- "Education and advocacy is great and appealing especially education on how everything comes together in the brain."
- "How do you operationalize the "cure for one is a cure for many""
- "Like the graphic with the different diseases very powerful."
- "Too many things going on at same time."
- "Helps communicate a focused result"

Other Representative Comments:

- "Emphasize that everyone knows someone affected"
- "What is the ROI?"
- "Doesn't make the case to us"
- "A cure for what?" "Brave words" "Will people understand this"
- "Research is key to finding cures"
- "Need more detail about costs and impact"
- "Advocacy doesn't seem to connect to "cure for one" concept
- "Concussion already seems to be taken, see a lot in the news about this and never have seen ABF"
- "Awards are not motivating"
- "Like the graphic with the different diseases very powerful."
- "Love the "Did you Know" section"

Funding Strategy

The proposed approach for ABF fundraising provides an opportunity to focus on the aspects of philanthropy most valued by donors; specifically, the solutions that will be derived from their support, the impact they will have because they give. In the course of all ABF fundraising endeavors, a premium will be on story telling. Story telling will affect how the potential donor feels the connection with the "whole brain approach." At the other end of the initiative – at the stewardship side – story-telling is just as vitally important as these stories of impact bring one story to a conclusion and concurrently create opportunities for new stories and new support by donors who share the vision of the American Brain Foundation.

Based on our discussions, we believe that ABF's most likely short-term path to its longterm fundraising objectives begins by leveraging existing relationships and partnerships - specifically the Academy membership, Neurology Now readership, AAN industry partners and foundations with a health focus. ABF needs to sustain and expand their current fundraising efforts while simultaneously building credibility with the public. It is imperative that ABF can demonstrate to the public and institutional funders that their core base - neurologists - personally and financially support the mission of ABF. ABF can also leverage a strengthened relationship with their base by having them advocate and promote ABF with their own constituents – primarily patients and their families. ABF should explore effective ways to expand its fundraising strategies beyond "opt in" messaging on membership renewals. The objective needs to be increases in both the level of participation and the average gift amount. Identifying other ways for Academy members to support ABF is necessary; for example, implementing vehicles to raise awareness of ABF with patients and family members in the offices of their physicians. The Carter team recognizes the inherit challenges certain neurologists may have in raising funds outside their medical academic centers however effort should still be made to engage the various constituencies with AAN.

As an extension of its direct marketing efforts to the public, ABF is well positioned for crowd funding among the members of the general public that have been impacted in one way or another by the various brain diseases. While a relatively new approach, crowd funding has been demonstrated to be an effective means of bringing people closer to an organization. It offers an innovative way to source new donors, perhaps supplementing or even replacing the traditional practice of targeting the AAN membership. MobileCause research indicates that \$568 is the average amount raised by individuals for nonprofit organizations via crowd funding. The research also showed that 27 percent of the donors who give via a crowd funding opportunity will donate

again to one or more charitable causes. We recommend testing this channel of fundraising to assess its merits for ABF.

In addition to building its own workplace giving effort, ABF should implement strategies to participate in the workplace giving programs of corporations and public sector organizations. An effective strategy for gaining representation is to join an organization that places charitable organizations in private sector and public sector workplace giving campaigns. Average workplace giving gifts can exceed \$750. For donors, workplace giving via payroll deduction represents a convenient way to make recurring gifts to charity.

A growing trend among philanthropists is a preference for investments in long-term sustainable solutions over short-term projects. Such philanthropic investments give them an effective way to address – and even solve – major issues and problems both worldwide and in their own corner of the world. In the past, philanthropy could have been described as a relatively simple relationship between the donor, the charitable organization, and the recipients of services provided by the organization using the funds provided by the donor. Today, the relationship is far more complex. It is characterized by collaborative relationships driven by the donor's personal interest in problem solving, capacity building and organizational sustainability over the long-term.

The objective of contemporary philanthropists is creating organizational self-sufficiency and programmatic sustainability with an emphasis on partnerships and collaboration. No longer do philanthropists look favorably upon writing out checks year after year for a cause that may be commendable but not outcome-driven. Institutional donors also look very favorably on organizations that collaborate with others, not only reducing the risk of redundancy but also increasing the likelihood of achieving desired outcomes more efficiently. The successful charitable organizations today have the capacity to demonstrate that investments by philanthropists will support positive change that can be measured against metrics with analytics that incorporate both quantitative and qualitative data.

AAN Representative Comments:

- "Taking more of a national approach with media would make a difference"
- "Big problems in past is lack of brand recognition."
- "Membership should be targeted. Who best to support than your membership. Educating them on the importance of ABF and that it is evolving."
- "The target should be the Public at large. Specifically those with money and those with a personal interest in brain disease because of themselves or their families."

- "For smaller organizations, more focus is necessary. Larger groups like American Cancer Society can afford to focus on multiple things and projects."
- "Brand Strategy is HUGE"
- "Taking on a huge amount of diverse competition and that will be the struggle"
- "General public needs to understand connectivity of brain diseases"
- "How does this fit into government dollars and plans?"
- "Brand. Important for visibility with individuals and companies, government when advocating for funding."
- "Affiliation with AAN should be leveraged, as all neurologists should have a goal to cure all brain disease."

Other Representative Comments:

- "It could be very powerful but the public need to be educated."
- "Brand recognition is essential. I had not heard about this one and there is a lot of attention on issue and have never heard of them."
- "Would need to focus on public that is connected or has been touched in their lives. General public with no connection are not going to be interested in message."
- "Major donors that have been impacted by multiple brain diseases. Don't neurologists have front seat view of who those donors are? But in my experience physicians are not helpful"
- "Do they have the fundamentals to raising the money? Need a good board and strong leadership that can make the case."
- "Need to see more about impact to date...don't understand value of giving" "no, not focused enough"

RECOMMENDATIONS

Our recommendations have been developed as a guide for the ABF in moving forward to engage in a highly targeted fundraising initiative to secure private philanthropic support over the next three-to-five years.

The seven recommendations are:

- 1) Add additional staff to support growth
- 2) Confirm a strong unique case for support
- 3) Increase giving to the Annual Fund
- 4) Identify national foundations with an interest in brain research and advocacy
- 5) Look to broaden and strengthen brand awareness of ABF
- 6) Create a collaborative culture of philanthropy in partnership with AAN
- 7) Develop public facing messaging and platforms to raise funds beyond AAN membership

In the following section of this report, we provide detailed discussion regarding each of these recommendations.

Recommendation 1: Add additional staff to support growth

No organization successfully advances their fundraising without a team of creative and knowledgeable minds and an adequate level of staff. The current staff needs more support and does not have the capacity to grow fundraising efforts to optimal levels. The staff needs clear job descriptions, specific priorities, metrics-driven goals and objectives, and commensurate tactics and activities to achieve goals within defined timeframes. At the outset, ABF will require a small team of dedicated fundraising professionals. Ensuring that ABF builds a team with the talent and expertise to achieve the organization's fundraising vision will be a critical step in achieving fundraising success.

First, Carter recommends hiring a Chief External Affairs (CEA) position to oversee fundraising and marketing. The CEA will dedicate the appropriate time, energy, and attention to the important work of cultivating relationships, participating in high impact fundraising activities, and asking donors for gifts of a magnitude that are vital to successfully funding ABF's priorities.

This staff position will be responsible for donor and prospective donor relationships with

individuals, corporations and foundations. Leadership responsibilities may include but are not limited to comprehensive fundraising planning, annual giving, planned giving, corporate and foundation grants, fundraising events and all internal resources, accountability, structures and business systems needed to ensure fundraising success. This position will oversee and manage all aspects of the fundraising plan, fundraising programs, and volunteer management in the fundraising efforts. Reporting to the Executive Director, this position is envisioned as part of ABF's senior leadership team.

To quickly develop several specific funding opportunities, the CEA will likely need a grant writer/development writer to support this effort. Because grant writing will be an important element of this initial effort, we recommend that ABF consider outsourcing this work to a firm that specializes in major foundation and corporate grant acquisition. This step would provide an efficient and effective way for the ABF to ensure the preparation and timely submission of the grant proposals required by major public and corporate foundations.

ABF also needs a dedicated Major Gift Officer to work with donors capable of making commitments to the ABF at the 6- and 7-figure levels. A Major Gifts Officer can focus on this high-level activity without being distracted by other elements of the fundraising operation.

We recognize that investments in staff are not without expenses. According to a recent Compensation & Benefits Study by the Association of Fundraising Professionals, the top 25 percent of responding fundraising professionals earn more than \$90,000, and the bottom 25 percent earn \$50,000 or less. However, without investing in the necessary resources and staff, the ABF is at risk of moving into the future without reasonable expectation of measurable growth in its fundraising revenue..

In implementing a strong fundraising strategy, the organization takes on critically important roles and responsibilities; including, strategic direction, planning, prospecting, and donor engagement (e.g., cultivation and stewardship), and volunteer leadership support. ABF should establish goals for the fundraising team that are clear, challenging yet achievable. For example:

- Amount of gift income by each fundraising method
- Amount of total gift income
- · Average size of gift
- Program cost percentages
- Overall fundraising costs and return on investment

Recommendation 2: Confirm a strong unique case for support

The optimal case for support for the American Brain Foundation should:

- Be adaptable to include appropriate messages for specific audiences;
- Provide a summary of the reasons for ABF's existence and its proposed initiatives;
- Detail the envisioned innovations, research breakthroughs, and ideas; and,
- Identify metrics by which impact of ABF projects' outcomes will be measured.

The Case for Support offers the opportunity to describe the needs to be met, the challenges to be addressed, the people to be helped, and the ways that philanthropic support can help transform brain disease.

Our findings indicated that the Case for Support needs to increase its focus on the intended results, details about the needs, and specifics on envisioned programs and services. For prospective donors, ABF needs to demonstrate with data that "A cure for one is a cure for many." Philanthropists are looking for opportunities to invest in organizations and initiatives that can have a positive impact in the world.

As the platform and master resource for all communications with donors and prospective donors, the Case needs to be adaptable not only to its specific audience(s), but also to various formats and applications – including presentation in print and digital formats as well as via podcasts and YouTube. In addition, the Case likely can be use in abridged form within brochures, annual reports, and slide presentations. For it to be most effective, the ABF Case needs to be –

- Emotional
- Rational
- Compelling
- Persuasive
- Urgent
- Clear

The Case for Support is stronger when it includes a balance of powerful stories and quality data. As new evidence of program outcomes and impact become available, the Case should be continuously reviewed and updated to provide its select audiences with up-to-the-moment messages capable of eliciting support for ABF. The effectiveness of the Case for Support will depend on the quality of substantive references to impact and metrics. Unlike the Case Summary tested during the assessment, the Case for Support must be much more than an outline of the initiative; it must present a compelling story of why a prospective donor should fund the organization. Our experience time and again shows that the time invested in crafting

the right Case for Support is an invaluable contribution to the ultimate success of a fundraising initiative.

Recommendation 3: Increase Giving to the Annual Fund

Giving to the Annual Fund provides the organization with a reliable and predictable stream of unrestricted funding for its programs, services, and operations. The Annual Fund program for ABF should be enhanced and increased substantially over time as it has the potential to engage and educate an ever-increasing number of donors. The Annual Fund needs to incorporate a consistent annual campaign message that works across all communication channels. Donors to the Annual Fund provide an initial donor pool that can be researched to identify those who have potential to step up to major gift levels.

Direct Marketing is often the base of a successful Annual Fund especially for a new organization. Below are several fundamental aspects of effective direct marketing:

- Donor's value to the organization increases over the time that they are active
- The average cost to raise the first dollar ranges from \$1.15 to \$1.25 making donor retention imperative; the cost of the second dollar is typically just \$0.20
- Annual Fund donors must be researched and cultivated for larger gifts
- Increase the amount or frequency of gifts
- To be effective, the organization needs a 'single-minded position'
- The focus must be on the interests and aspirations of the donor. Talking about the organization does not engage a donor; communications with donors must be about the value that the donor brings to the organization NOT about how great the organizations is
- The strategy must be focused on the big picture, the details of which must be written down and followed. The strategy also must be tuned and adjusted to respond to the returns in the mailing plan

ABF's current Annual Fund has significant room for improvement. Gains will come with significant investments; but, there is the reasonable possibility for more immediate returns. Industry benchmarks are vital when considering ways to achievement improvements, but there is no set standards or best practices that we point to as conclusive. Often a one percent response rate is used, but truly that is only the point where we can start to truly trust improvement numbers; below one percent is generally too small to

ABF's 2015 Year End Campaign

82,856 solicited \$6,727 raised \$4,962.12 cost 78 gifts/ 77 donors 0.09% response rate properly analyze. We can see highly performing organizations with response rates approaching double-digit ranges. The ABF's 2015 Year End campaign results are well below what you would expect from a thriving direct marketing program, especially given that year-end is typically an organization's best time of year.

Acquiring new donors through the Annual Fund must become a priority. Concurrently, the organization needs to incorporate several methods (outlined below) to increase the pace of upgrades, expand the number of donors, and accelerate the pipeline for major gifts. We believe that it is as true for ABF as it is for many other charitable organizations that its best future donors are already giving. Optimal direct mail practices include:

- Segmented mailings (donor acquisition, repeat, upgrades, ask levels, constituency group, welcome, demographics, etc.)
- Tested strategies that allow the ABF to become more knowledgeable about its donors and better at communicating with its donors; the best organizations are constantly A/B testing their communications amongst various segments
- Informational mailings (e.g., newsletters) should be spaced in between solicitation mailings
- Communications should reference ways of getting in touch with or giving to the ABF
- Solicitation letters should contain a specific ask amount
- Communication need to lets the reader know immediately the purpose of the mailing
- Solicitation letters should suggest increased giving or giving twice when appropriate
- Solicitation letters should be sent to past donors, acknowledging past giving
- Solicitation letters should be sent 60 days prior to the anniversary of previous year's gift
- Select Annual Fund donors should be asked for their gifts in person.

By creating a more robust mid-level giving program that focuses on developing more meaningful personal relationships, ABF will continue to build a long-term pipeline for major gifts. Additional key elements:

- Enlisting volunteer leadership. An active Annual Fund Chair or series of regional Co-Chairs within the AAN membership
- Creating solicitation teams for face-to-face solicitation calls
- Engaging Board members and staff in stewardship, such as personalizing thank you letters and making thank you calls to higher-level donors
- Providing proper solicitation training and supervision

Events are complimentary to a successful fundraising program and are a great way to engage and steward donors. However, the ABF should be cautious with the amount of staff time and resources that are expended on all events. Events should serve a particular purpose; either:

- (1) To raise a large amount of money, or
- (2) To raise the awareness of the organization or its specific need for a significant number of potential donors.

Each fundraising-focused event should be measured against this gauge, and events that accomplish neither should be eliminated.

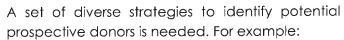
Major Gifts emerges directly from a robust Annual Fund program. Major gifts are acquired by developing personal relationships with prospective donors in a well-managed process that is effectively carried out by the staff. As part of ABF's management system, a monthly review meeting should be conducted to assign new prospects, to discuss strategy or challenges with an existing prospect, and to monitor performance and effectiveness. Broad participation in review meetings should be encouraged particularly with AAN staff.

To create an effective major gifts program that allows the organization to manage its prospective donors and move donors towards an appropriate gift decision, ABF should focus on several key elements; specifically:

- A personalized plan should be developed for each major gift prospect
- An initial visit should be conducted to qualify the prospect
- Additional visits should follow for the purposes of cultivation, solicitation, and stewardship
- Written interaction reports should be entered into the organization's database of donor records for each significant move in the process, including a brief summary of the meeting, identification of the next planned step in the process, and revision or validation of a personalized plan for the prospect; this information helps prepare staff and volunteers for the next step in the process
- Monthly reports (summary of contact activity) should be prepared that include the number of contacts by step in the process, i.e., initial visit, cultivation, solicitation, stewardship
- Pipeline conversion metrics need to be developed to measure such key metrics (e.g., leads qualified as prospects; number of qualified prospects in which an ask was made; and number of gifts from asks)

Prospective major donors should meet all three of the following conditions:

- Fiscal capacity to make a significant gift
- Personal interest in the ABF's mission, vision, values, and goals
- Viable connection with the ABF or ABF extended family



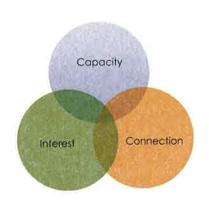
- Board introductions
- · Wealth Screening of database
- Networking at forums, health fairs and conferences
- Current donor referrals
- Data mining within AAN members
- Cold calling
- Speaking engagements of AAN members, doctors and subject matter experts
- Reputation in particular sector(s)
- Direct mail
- Crowd funding
- Fundraising galas

Finally, a Planned Giving program will strengthen the ABF's overall fundraising program by offering an effective way to build a long-term funding source and create an opportunity for donors and families to establish a legacy and lasting impact through the work of the American Brain Foundation.

The ABF should incorporate a planned giving message in its communications vehicles and promote the opportunities and advantages of planned giving throughout the year by incorporating into existing communications. Planned giving is a significant untapped resource for the ABF and will, over time through a concerted effort, be a vibrant addition to the fundraising team's overall work.

In addition to its current efforts, the ABF should consider:

- Targeting constituents that have been giving for more than 15 years at any level of giving
- Developing consistent marketing language and tools to use with potential donors
- Partnering with professional who can be helpful in identifying prospective planned giving donors (e.g., estate planners, attorneys, and accountants)



- Screening the database for planned giving prospective donors
- Asking all board members to join the APF's legacy society

Recommendation 4: Identify national foundations with an interest in brain research and advocacy

Foundations should be an immediate area of focus for the ABF. Typically, these relationships can move along the grant-making continuum more quickly than individual donors. Foundations generally have specific guidelines and can be researched relatively easily via a variety of online tools.

However, foundations are like any other donor in that they will want to be engaged in a personalized strategic way. A critical step in the process is research; ABF needs to be well prepared before engaging in an exploratory meeting with a potential foundation grantmaker.

In addition to the low transaction cost associated with foundation giving, the sector itself is seemingly more positive when it comes to trends for the next few years ahead. According to the Philanthropy Outlook for 2016-17 prepared by Indiana University Lilly Family School of Philanthropy, giving by foundations is projected to increase by 5.7 percent in 2016 and by 6.4 percent in 2017. The current projections for giving by foundations for the years 2016 and 2017 are above the historical 10-year average rate of growth for foundation grantmaking.

Specific factors that will significantly influence foundation giving in 2016 and 2017 include:

- The above-average increases in the S&P 500 in preceding years, and
- The slightly below average to average projected growth in the Gross Domestic Product (GDP) in preceding years.

Available research indicates that these two factors will account for most of the predicted growth in giving by foundations. Trends in last year's S&P 500 will affect giving in the current year because foundations typically budget their giving on asset growth. As a result, above-average projected growth in the S&P 500 in 2015 and 2016 is expected to positively affect foundation giving in 2016 and 2017. Growth in GDP reflects an expanding economy. For projecting foundation giving, growth in prior years' GDP is linked with giving in the current year. This is an indirect process, as giving is the result of asset and institutional health. Thus, projected increases in GDP in 2015 and 2016 are expected to positively influence giving by foundations in 2016 and 2017.

Recommendation 5: Look to broaden and strengthen brand awareness of ABF

The ABF – as a brand – is something that needs to be developed within a carefully crafted plan. The brand identity of the American Brain Foundation is much more than just a visual identity – though the visual image of the organization is an important element in the branding process. We concur with the Rockefeller Foundation's former communications director, Diane Fusilli, who has noted, "A strong brand helps bring greater credibility and trust to a project quicker, and acts as a catalyst for people to want to come to the table."

While launching a robust brand development strategy can be an expensive and time consuming process, we recommend that the ABF nonetheless needs to identify and prioritize the audiences that need to have high levels of awareness and knowledge about the organization – including corporations, patients and families, physicians and the general public. Brand development efforts should focus at the outset on ways to leverage existing opportunities and relationships.

We believe there are significant opportunities to expand relationships with AAN corporate donors beyond sponsorship. It also is reasonable to pursue ways to partner with a national brand affiliated with brain disease that could help promote the ABF brand and earn un-paid/earned media exposure. ABF should also explore ways to leverage Academy memberships, particularly those directly serving patients and their families.

Recommendation 6: Create a collaborative culture of philanthropy in partnership with AAN

This proposed fundraising plan recognizes that philanthropic endeavors are, to a great degree, collaborative ventures. In today's fundraising environment, it is essential to balance sound fundraising strategies and tactics with creative communications and positioning initiatives that feature both informational and persuasive components. It is clear that one of the perceived fundraising strengths of ABF is its relationship and access to AAN members.

Also, a key strategy to quickly maximize fundraising potential is that the ABF needs to deepen and strengthen any existing or natural connections and relationships including those with potential through the AAN. We believe there is opportunity to jointly foster donor relationships that maximize the opportunities for both AAN and the ABF including

strategies like employee giving campaigns, volunteer opportunities, event and conference sponsorship, foundation support, marketing and media exposure.

This is why the Carter team believes that ABF's early success will be strengthened and accelerated by a collaborative culture of philanthropy with the AAN. A collaborative culture will foster open relationships with industry partners, pharmaceutical companies and other industry related businesses and organizations. It should be noted that during the study process there was significant concern expressed by the AAN team about whom ABF should be in contact with. It is our belief and experience that both organizations have much to gain from each other rather than creating barriers to each other's increased success.

Building a culture of philanthropy within an organization goes beyond a carefully crafted initiative or program but is practiced through a commitment of values that are shared, acknowledged and executed from the top of the organization. The shared values are incorporated and present in the core ethos of the organization's character. These values guide the perceptions, beliefs, evaluations and actions of stakeholders within and towards organizations including the larger community of funders, partners and constituents.

A culture of philanthropy is a byproduct of organizational values, practices and communication patterns that create an environment where an organization's entire community, from donors, to staff, to partners and beneficiaries has plenty of opportunities to engage with the mission in authentic and meaningful ways. Today, many organizations supported by philanthropy find themselves in need of more effective and efficient ways to engage donors and donor prospects; a strong culture of philanthropy is essential, especially in small development departments where resources, both human and capital, are limited.

One of the main principles of building a culture of philanthropy is that it cannot be done only by the fundraising team. A successful fundraising program is built around a culture that everyone in AAN and ABF has a role to play and embodies a humble and collaborative spirit. Given that philanthropic organizations are created with the main goal of service, therefore, individuals within these organizations must be mindful of individual responsibility to the collective process designed to demonstrate those shared values.

Establishing the ABF's identity, reputation, expertise, and credibility will require a substantive commitment of time and resources. We believe that achieving success in this effort will be a positive factor in strengthening its capacity to secure philanthropic

support and private investment. AAN and ABF have a unique history and have an opportunity to create a collaborative supportive fundraising model that we believe can better promote both organizations but in particular with ABF, the reliance on the network and support of AAN is vital to early success in fundraising. It is recommend that ABF and AAN develop a written understanding of their fundraising relationship and how they best can support each other to develop collaborative opportunities.

In addition to developing funding opportunities, ABF should revitalize its "brain" ambassador program through the AAN membership that can continue to help identify and make introductions with patients that express interest in philanthropy. It was also cited during study interviews that the "brain" patient community is the best immediate public facing audience that ABF should try to engage. The best way to access this community is through caregivers. They can speak passionately and emotionally about the ABF in a variety of settings, using such occasions to help build a community of stakeholders who see in their commitment substantive reasons to believe in the ABF mission and vision. Having a corps of volunteer leaders to help scale fundraising efforts and to advance the ABF would be an important ingredient in building a successful fundraising initiative. If ambassadors are unable to assist directly with patients they can also participate in small awareness gatherings as the subject matter experts.

Recommendation 7: Develop public facing messaging and platforms to raise funds beyond AAN membership

We believe the ABF should consider ways to develop public facing messages and platforms to raise funds beyond AAN membership (e.g., crowd funding, patients and caregivers). Getting the American Brain Foundation brand out in front of the general public – particularly individuals affected by, impacted by, or aware of various brain diseases – will be critical to ABF's overall fundraising strategy. In addition to growing the brand, ABF will concurrently need to educate the general public about its key messages; specifically, the "whole brain approach" and the "cure for one a cure for many" concept. To be bona fide prospective donors, individuals need to understand the value message; that is, why they should support ABF and how their dollars will be leveraged to support the whole brain approach and not just a single issue.

By developing mission-focused ambassadors, ABF can establish a corps of volunteers who can represent the organization in public gatherings and with the media. Mission ambassadors can add value to the efforts by the board and staff to increase awareness and knowledge about the ABF nationally through their own personal and professional networks and connections. In addition, the mission ambassadors can help

earn un-paid advertising and provide platforms for introductions and follow up.

Mission ambassadors also can be invited to host small gatherings with various networks to help build awareness and provide educational discussions about the "whole brain approach".

Also, we believe the ABF would advance its objectives by securing partners with national brands affiliated with brain disease. Together, ABF and such partners can collaborate in securing media attention for brain diseases.

FUNDRAISING PLAN

The commitment of adequate financial resources is necessary for any organization's fundraising effort to achieve its full potential. Budgeted resources are the lifeblood of fundraising. As such, these resources need to be allocated in direct proportion to the anticipated benefits. What is a reasonable portion of the budget that should be dedicated to fundraising operations? Three major watchdog organizations offer guidance on this question:

- The Better Business Bureau's Wise Giving Alliance suggests that charitable organizations should apportion at least 65 percent of their total expenditures to program activities and no more than 35 percent to fundraising and management.
- Charity Navigator scores charitable organizations based on the percent of total functional expenses allocated to fundraising, with ten percent or less scoring highest.
- CharityWatch considers a budget allocation of 35 cents to raise a dollar as "reasonable for most charities."

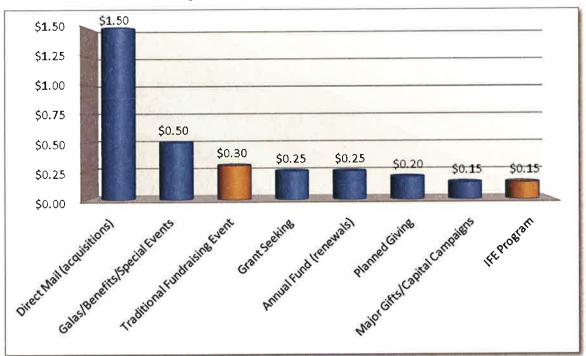
Overall budget and growth

Fundraising return-on-investment refers to how much organizations expect to raise for each dollar spent on fundraising activities. Research indicates that charitable organizations should anticipate a period of at least three years—and perhaps as many as five—to realize their optimal return on investment. The below budget was prepared by the ABF and is the basis for the budgeting and planning for this section of the report

Based on March 7, 2016 draft budget	2016 Budget	2017 Budget	2018 Budget	2019 Budget	2020 Budget
2018 didii bodgei	buager	Dougei	Douge	50090	77
Revenue	\$762,500	\$1,998,330	\$3,169,100	\$4,237,550	\$6,429,530
Grants & Gifts	\$1,200,000	\$950,000	\$750,000	\$600,000	0
AAN contribution	\$1,200,000	\$950,000	\$750,000	\$600,000	0
Total Support &					
Revenue (other					
misc. income	\$3,243,332	\$3,644,500	\$4,771,000	\$5,689,450	\$7,281,430
included-release					
from restrictions)					

Expenses	\$1,284,932	\$1,282,590	\$1,702,783	\$1,702,978	\$1,703,175
Research Grants & Awards	\$3,307,076	\$3,401,703	\$4,072,792	\$4,361,765	\$4,703,061
Salaries & Benefits, General, Marketing, Mg Fee, etc.	\$2,022,144	\$2,119,113	\$2,370,009	\$2,658,787	\$2,999,886
Total Expenses	\$3,307,076	\$3,401,703	\$4,072,792	\$4,361,765	\$4,703,061

Based on industry standards it takes approximately \$0.20 to raise \$1.00 for charitable organizations. The ratio depends on how experienced an organization is at raising money from its donor segments. The ratio can range between \$0.25 for every \$1.00 to as low at \$0.15 for every \$1.00. Organizations with more experienced and sophisticated fundraising programs can enjoy a lower cost-per- dollar-raised ratio. However, a newer fundraising program requires a commitment from its leadership for up front investments to build the initial fundraising department and program.



Based on the budget above, we believe that donors may view the ABF's ratio of program to administrative expense ration in an unfavorable light, given donors' likely experiences with other charitable organizations and their expectation that their support will have mission-driven impact. For this reason, we recommend that the ABF should develop a plan to improve this ratio. The ancillary – and important – outcome would be a greater amount of program-focused expenses that directly correlate to impact and dollars available for research and other program initiatives.

We believe the ABF has significant opportunity if they execute the above recommendations, confirm and move forward with the concept idea for the "online research clearinghouse". This could be the differentiating factor for the organization and could provide access to crowd funding and major gifts revenue if done effectively. ABF has a powerful concept that seems to resonate with donors. However, it will take a significant amount of time and resources to build a well-known brand that attracts broad-based philanthropic support. Below is an outline of the staffing requirements, based on our experience, to support the budget that has been provided by ABF, with several additional targets offered for consideration.

We note that a recurring theme in our recommendations is that the initial investments in fundraising will not yield the envisioned outcomes overnight and will need the proper amount of time to develop. For example, relationship-based fundraising can take up to 24 months for a donor to make a decision on a charitable investment.

ABF Fundraising Targets Based on Budget draft	2016 Budget	2017 Budget	2018 Budget	2019 Budget	2020 Budget
Revenue Grants & Gifts (current projections minus AAN revenue)	\$762,500	\$1,998,330	\$3,169,100	\$4,237,550	\$6,429,530
10% growth rate		\$838,750.0	\$2,198,163.0	\$3,486,010.0	\$4,661,305.0
15% growth rate		\$876,875.0	\$2,298,079.5	\$3,644,465.0	\$4,873,182.5
\$8,000,000 goal	\$1,000,000	\$2,000,000	\$4,000,000	\$6,250,000	\$8,000,000
\$12,000,000 goal	\$2,000,000	\$4,000,000	\$6,500,000	\$9,000,000	\$12,000,000

According to The 2016 Fundraising Effectiveness Project report, data from 9,922 survey respondents covering year-to-year fundraising results for 2014-2015, growth-in-giving performance varies significantly according to organization size (based on total amount raised), with larger organizations performing much better than smaller ones:

- Organizations raising \$500,000 or more had an average 10.7 percent rate of growth.
- Organizations raising \$100,000 to \$500,000 had an average 0.6 percent rate of growth.
- Organizations raising less than \$100,000 had an average loss of -11.8 percent.

We believe the ABF should be planning for a modest increase in philanthropy, in the range of 10-15 percent, particularly in years one and two of a new fundraising program and a still developing brand identity within the philanthropic community. Currently the ABF is projecting a more aggressive growth rate in the first two years, which we believe is a potential growth rate further down the road, as momentum builds for the ABF brand and its major gifts fundraising program.

We also believe the ABF would benefit from repositioning the gift from the AAN as "an anonymous donor covering all administrative costs over the next three years as the organization has to invest to grow." This strategy would allow the organization to dedicate all additional gifts from upgrades, lapsed and new donors directly to program related and mission-focused investments. We believe this messaging could help motivate the donor audience.

Whatever the trajectory for ABF, we believe more resources are needed to support the overall growth in fundraising. Below are some anticipated activities and outcomes, with a fully executed strategy, for ABF to use as it plans staff growth for the coming years. This does not factor in the support staff that will be needed. In our experience all sophisticated fundraising staff can be better enhanced and equipped and more effectively utilized with the proper support. Support staff may include prospect research, writing, events and stewardship.

FUNDRAISER AC Quarterly			
	Associate Senior	Associate Junior	Director
Prospect Interaction Activity			
# prospects in relationship management	120	80	50

# of prospects in Qualification	40	25	20
# of prospects in Cultivation	35	25	10
# of prospects in Proposal	20	10	10
# of prospects in Stewardship	25	20	10
Financial			
Total \$ raised from assigned prospects from mature portfolio annually (4+ years)	\$2,000,000	\$1,000,000	\$1,500,000
Total \$ raised from assigned prospects from new portfolio annually	\$500,000	\$250,000	\$500,000

Fundraising Projections by Staff	2017	2018	2019	2020
CEA	\$500,000	\$750,000	\$1,250,000	\$1,500,000
Staff-senior	\$500,000	\$1,250,000	\$1,750,000	\$2,000,000
Staff-junior	\$250,000	\$750,000	\$850,000	\$1,000,000
To support current estimated	Director, 2 Senior staff, 1 junior staff			
budget	Goal: \$1,998,330	Goal: \$3,169,100	Goal: \$4,237,550	Goal: \$6,429,530

Based on the above chart, we believe that through some strategic and successful hires and investment in staff, the ABF is well positioned to raise significant funds in the future after executing the before mentioned recommendations.

ESTIMATED BUDGET	2017	2018	2019	2020
Director of External Affairs	155,000	160,000	166,000	170,000
Senior Staff (3 positions)	270,000	279,000	288,000	300,000
Junior Staff (4 positions)	320,000	332,000	344,000	360,000
Admin Support – Writing	40,000	42,500	45,000	48,000
Admin Support – Gift Processing & Database Management	40,000	42,500	45,000	48,000
ΙΤ	7,000	9,000	9,000	9,500
Staff/Board Development & Training	50,000	50,000	40,000	35,000
Prospect Research	20,000	12,500	7,000	7,000
Communication Materials	20,000	18,000	15,000	15,000

Annual Totals (does not include benefits)	\$1,069,017	\$1,097,518	\$1,096,019	\$1,109,520
Fundraising Counsel & Advisory Services (marketing/direct marketing)	100,000	100,000	80,000	60,000
High-Profile Events	25,000	25,000	25,000	25,000
Donor Engagement & Stewardship	20,000	25,000	30,000	30,000

The above projected budget is based on the staffing requirements we believe are needed to aggressively grow a fundraising program.

Fundraising Revenue

Financial support for ABF will come from all sectors and at varying levels. As the fundraising culture develops within ABF, financial goals should be revisited. The following table was developed to demonstrate the activity needed and financial potential within the private sector based on ABF's current brand and leadership. Investing in the brand and developing the leadership within ABF will influence the ability to increase financial projections over time.

Currently ABF's pool of donors (current and lapsed) totals 154,579 records in the database of record that is represented below as of December 10, 2015, which is shared with AAN. The categories for constituents below are assigned by ABF.

Constituency code	Number of constituents	Number of donors	Number of gifts	Total given	Average given per donor	Percent of participation	Percent of total given
AAN Staff	IRO	110	1,118	\$55,574.19	\$505.22	61.11%	0.65%
Awards/Prizes Record	45	0	0	\$0.00	\$0.00	0.00%	0.00%
Clinic	1	0	0	\$0,00	\$0.00	0.00%	0.00%
College/University	16	1	1	\$2,500,00	\$2,500.00	6.25%	0.03%
Corporation	3,823	68	100	\$911,811.50	\$13,408.99	1.78%	10,66%
Fellowship Fund Record	39	0	0	\$0.00	\$0.00	0.00%	0.00%
Former AAN Staff	217	4	49	\$336.00	\$84.00	1.84%	0.00%
Foundation (Corporate)	8	5	17	\$2,804,276,53	\$560,855.31	62.50%	32.79%
Foundation (Private)	55	0	0	\$0.00	\$0,00	0.00%	0.00%
Foundation (Public)	18	б	7	\$216,832.50	\$36,138.75	33.33%	2.54%
Government	8	0	0	\$0.00	\$0.00	0.00%	0.00%
Hospital	5	2	2	\$11,000.00	\$5,500,00	40.00%	0.13%
Medical Device Company	11	3	4	\$12,050.00	\$4,016.67	27.27%	0.14%
Medical School	352	1	2	\$2,000.00	\$2,000.00	0.28%	0.02%
Member	35,016	1,214	1,448	\$232,074.86	\$191.17	3.47%	2.71%
Nonprofit	4	0	0	\$0.00	\$0.00	0.00%	W 20.00%
Pharmaceutical Company	88	28	121	\$3,793,660.00	\$135,487.86	31.82%	44.35%
Professional Association	4	1	1	\$5,000.00	\$5,000.00	25.00%	0.06%
Public Public	114.776	398	532	\$187,756.00	\$471.75	0.35%	2.20%
Volunteer Health Association	13	3	6	\$297,499.50	\$99,166.50	23.08%	3.48%
Board of Directors	14	10	48	\$20,982.00	\$2,098.20	71.43%	0.25%
Total:	154 579	1.852	3,456	\$8,553,353.08	\$4,618.44	1.20%	

Arrows coordinate with chart below

A few items to note as it relates to the strategy to increase revenue moving forward:

- The goal for board giving should always be 100%; currently the ABF Board is at 71%, which is below average. The Board should consider giving expectations and create a "give and get" policy that motivates board members to make ABF one of their top charities.
- Pharmaceutical Companies Planned giving Low currently make up a large percentage of giving for AAN. ABF needs to be in a strong position in partnership

ABF's Fundraising Channel Assessment				
Channel	Return Potential	Required Effort & Cost		
AAN members	Medium	Low		
Foundations and grants	Medium	Medium		
Corporations	High	Medium		
Direct response to public	Low	High		
Major individual gifts	High	High		
Workplace giving	Low	Low		
Planned giving	High	Low		

- with AAN to strengthen the relationships within this sector beyond sponsorships.
 Corporate and corporate foundation support is also going to continue to be key for AAN as well as ABF and will require targeting some strategic national partners
- that can help elevate the brand and awareness of both organizations.
 The largest underperforming sector is the "public" which has over 114,776 names and only 398 donors from this group a 0.3% participation rate. Significant time needs to be spent developing, qualifying and disqualifying individuals within this
- The AAN staff should be commended for their support for the ABF. Staff support should continue to be developed as part of the annual fund.

group to see who might be a legitimate prospect for the ABF.

Academy members are the next largest constituency group and have a
participation rate of 3.5%. Similar to the public this group needs to be further
developed, qualified and cultivated for increased revenue.

Timeline

Timing	Activity
May - July 2016	Begin search for CEA position
	Revise annual fund direct marketing plans for remainder of 2016.
	Evaluate mailing results within 30 days to determine the next mail
	campaign strategy.
	Board endorses recommendations
	Begin monthly major gift prospect review meetings (top 200 initially)
	Mission Ambassadors identified and recruited
	Prepare to test crowd funding

Board and staff giving campaign Meet monthly with AAN leadership for prospect review meetings and Brain Ambassador updates Identify and recruit Brain Ambassadors. Focus on 3-5 key markets Hire and bring on board the CEA Post additional positions (determined by CEA) Kick off meeting for Mission Ambassadors Test crowd funding Evaluate status of 2015 donors who have not yet donated in 2016; determine engagement strategy for each donor for closure by year-en January 2017 – June 2017 Kick off meeting for Brain Ambassadors (AAN Annual Conference) Identify and recruit additional Brain and Mission Ambassadors Launch crowd funding effort July 2017 – December 2017 Revise annual fund direct marketing plans for 2018 Conduct half yearly review of staff against goals Board and staff giving campaign Evaluate status of 2016 donors who have not yet donated in 2017, determine engagement strategy for each donor for closure by year-en Reevaluate progress to date to determine plan for 2018 Conduct reviews of staff Revise annual fund direct marketing plans for 2019 Board and staff giving campaign	August –	Revise annual fund direct marketing plans for 2017
Brain Ambassador updates Identify and recruit Brain Ambassadors. Focus on 3-5 key markets Hire and bring on board the CEA Post additional positions (determined by CEA) Kick off meeting for Mission Ambassadors Test crowd funding Evaluate status of 2015 donors who have not yet donated in 2016; determine engagement strategy for each donor for closure by year-en January 2017 – June 2017 Kick off meeting for Brain Ambassadors (AAN Annual Conference) Identify and recruit additional Brain and Mission Ambassadors Launch crowd funding effort Revise annual fund direct marketing plans for 2018 Conduct half yearly review of staff against goals Board and staff giving campaign Evaluate status of 2016 donors who have not yet donated in 2017, determine engagement strategy for each donor for closure by year-en Reevaluate progress to date to determine plan for 2018 Conduct reviews of staff Revise annual fund direct marketing plans for 2019	December 2016	Board and staff giving campaign
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	2018	Conduct reviews of staff
Board and staff giving campaign		Revise annual fund direct marketing plans for 2019
		Board and staff giving campaign

CONCLUSION

In this report, we have drawn on the information gathered during our interviews with the study participants; the information provided during our discussions with the ABF staff leaders; our research; and, our professional experience in national philanthropy and fundraising. In presenting these recommendations, we share our objective review, evaluation, and analysis of our findings, identifying the key steps that need to be undertaken to strengthen the prospects for a successful fundraising initiative by the ABF.

We believe this study offers timely guidance for the ABF's leadership. In our findings and recommendations, we have identified ways to infuse an innovative fundraising initiative with a capacity to move forward strategically and respond quickly to philanthropic opportunities. We believe the momentum created by the success of the Vancouver Conference and other gatherings will help generate enthusiasm and interest that the ABF can optimize as it proceeds with its next steps and pursues what promises to be a challenging and rewarding fundraising initiative. By following the recommendations and plan outlined in this report, the Carter team has confidence that the ABF has potential to be successful in achieving their goals.

ACKNOWLEDGEMENTS

The Carter team expresses appreciation to the American Brain Foundation for the honor of conducting this philanthropic assessment. The support provided by the organization's leadership and staff was essential to the successful completion of this study.

We are especially grateful to the individuals who participated in the study by consenting to interviews. They gave generously of their time, knowledge, beliefs, and suggestions. Their candor contributed to the validity of this study.

This report's findings and recommendations are presented as a vital first step in assisting the ABF prepare to build a fundraising strategy and plan that will produce optimal results for sustained growth.

Respectfully submitted,

Lela Diaz Executive Vice President

Jim Starr, Managing Director

Bob Carter, CFRE Chairman



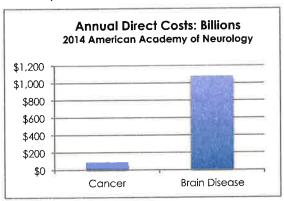
APPENDIX A

Investment Brief for the American Brain Foundation A cure for one is a cure for many

It is time to to defeat brain disease. Everyone knows someone afflicted with a brain disease. Over 100 million Americans, and 1 in 6 people worldwide, suffer from a disease or disorder of the brain. The prevalence of brain disease is both vast and growing. It is estimated that 50 percent of people aged 85 have some form of dementia. Ten percent of people over 65 have Parkinson's or other movement disorder. On the younger end of the spectrum, alarm is growing over youth sports concussions and traumatic brain injury in war veterans. All in all, brain disease is more prevalent in the population than cancer and much more costly to the public.

Throughout our history, the American public has successfully rallied to beat back pervasive threats to our personal and public health, such as polio, cancer and HIV/AIDS. So why don't we take on brain disease?

For too long our gaze has been fixed upon specific diseases of the brain and nervous system—diseases with strange and dissimilar names like epilepsy, Alzheimer's or Parkinson's. The linkages between these



diseases have not been the focus of medical research or of public awareness. We talk about and worry about specific kinds of brain disease, such as, multiple sclerosis, ALS or dementia. But we fail to see these diseases as connected. Yet they are connected, often by common mechanisms of neurodegeneration.



The American Brain Foundation (ABF) is out to defeat brain disease. The ABF is uniquely positioned to have a significant impact on the lives of millions of people suffering from one of the more than hundreds of brain diseases because:

- Distinct approach. The ABF takes a "whole brain" approach, seeking out and funding research on mechanisms of neurodegeneration and neurodevelopment held in common by multiple diseases. We believe that a cure or discovery in one disease has the potential to cure many diseases of the brain.
- All Star Team. The ABF has a unique research partnership with the American Academy of Neurology, the world's largest association serving neurologists and the neuroscience community. This unique partnership has allowed ABF to have access to the best and brightest minds to source the most high-risk and highreward research cutting across various diseases of the brain.
- Track record. Over the past 20 vears the ABF has raised and invested millions of dollars for brain disease research, supporting more than 190 research fellows, developing the next generation of premiere minds that will impact the study of the brain. This success and commitment to the field has supported some of the most advanced science of this generation.

However, every year gifted researchers and cutting-edge projects go unfunded. Since 2009, ABF has received 588

applications from investigators and has only been in a position to fund 22 percent of them at \$130,000 per award. It's why at this moment, it is time to step

up and make additional investments in brain disease research".

The ABF has identified 6 strategic investment opportunities with a focus on Research, Education and Advocacy.

RESEARCH - Building the Brain Trust

1. Great Minds: Cornerstone program which identifies the best and the brightest early career clinical neuroscientists and funds their innovative research on diseases of the brain.

Research on one disease applies to many

Hristelina Ilieva, MD, PhD, a Clinical Research Training Fellowship cosponsored by the American Brain Foundation and The ALS Association in ALS Research. Ilieva, a native of Bulgaria, completed medical school and residency there, and eventually found her way to the lab of Don W. Cleveland, PhD, of the University of California, San Diego. "Dr. Ilieva's work in that lab really changed the field of neurodegeneration altogether," said Jeffrey D. Rothstein, MD, PhD, of Johns Hopkins School of Medicine, who is serving as Ilieva's mentor in her current fellowship. "She was the first to rigorously demonstrate that nonneuronal cells, microglial cells, are active participants in ALS through a series of truly elegant transgenic rodent and molecular genetic studies."

According to Dr. Ilieva, "ALS can present in different ways and be driven by different genes, but identification of common pathways may lead to feasible and realistic breakthroughs for a wider variety of patients." ABF continues to observe science discoveries that can impact multiple aspects of the brain and believes future investments need to be made.

- 2. <u>Breakthrough Discoveries</u>: High-risk research to prevent or delay the onset of the wide-range of brain diseases through the discovery of fundamental common mechanisms.
- 3. The X-Prize: A unique ABF prize to attract venture capital to invest in cutting edge, innovative, high-risk research to fundamentally change the landscape of brain disease. Promoting a national research prize will motivate researchers in ways the current system does not. The prize will be awarded to the first team to reach the audacious goal of delaying the onset or progression of a major neurological disease.

EDUCATION & ADVOCACY - Campaign for the Brain

- 4. Mobilize for the Brain. Engage the public and our network of supporters to connect with government officials to press for more public funding for brain disease research. For example, in 2015, the National Institute for Health provided only \$586 million in research grants for Alzheimer's disease whereas funding for Cancer was \$5.4 billion. The system is out of balance given the people who are impacted and the costs to our healthcare system.
- 5. <u>Protecting Young Brains</u>. A national youth sports outreach campaign to promote concussion safety and education. Brain injury is a silent epidemic that changes or takes a life every 19 seconds. The best step forward is prevention. By starting with organized youth sports in select markets and then growing nationally, ABF will educate future generations about brain safety and brain disease.
- 6. <u>Brain Awards</u>. An awards program—the "Nobel Prizes" of brain disease--that raises national awareness of the fight against brain disease by spotlighting neurologists, neuroscientists and key public advocates, on the front lines of our fight to defeat brain disease.

 ONE in SIX

DID YOU KNOW?

Every 90 minutes a person is diagnosed with ALS

Every 60 minutes a person is diagnosed with Multiple Sclerosis

Every 23 minutes a person in the US is diagnosed with Brain Cancer

Every 4 minutes a person is diagnosed with Epilepsy

Every 67 seconds a person develops a form of dementia

Every 40 seconds a person suffers from a stroke

Every 20 seconds a traumatic brain injury occurs

1 in 68 children in the US has an Autism Spectrum Disorder

The numbers are real and getting worse. It is time to take a different approach. A cure for one is a cure for many.

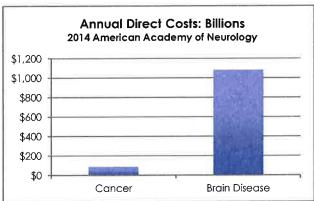


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Research on one disease applies to many

Hristelina Ilieva, MD, PhD, received a Clinical Research Training Fellowship cosponsored by the American Brain Foundation and The ALS Association in ALS Research. Ilieva, a native of Bulgaria, completed medical school and residency there, and eventually found her way to the lab of Don W. Cleveland, PhD, of the University of California, San Diego. "Dr. Ilieva's work in that lab really changed the field of neurodegeneration altogether," said Jeffrey D. Rothstein, MD, PhD, of Johns Hopkins School of Medicine, who is serving as Ilieva's mentor in her current fellowship. "She was the first to rigorously demonstrate that non-neuronal cells, microglial cells, are active participants in ALS through a series of truly elegant transgenic rodent and molecular genetic studies."

According to Dr. Ilieva, "ALS can present in different ways and be driven by different genes, but identification of common pathways may lead to feasible and realistic breakthroughs for a wider variety of patients." The ABF continues to observe science discoveries that can impact multiple aspects of the brain and believes future investments need to be made.

up and make additional investments in brain disease research.

The ABF has identified 6 strategic investment opportunities with a focus on Research, Education and Advocacy.

RESEARCH - Building the Brain Trust

1. <u>Great Minds</u>: Cornerstone program which identifies the best and the brightest early career clinical neuroscientists and funds their innovative research on diseases of the brain.



- 2. <u>Breakthrough Discoveries</u>: High-risk research to prevent or delay the onset of the wide-range of brain diseases through the discovery of fundamental common mechanisms.
- 3. The X-Prize: A unique ABF prize to attract venture capital to invest in cutting edge, innovative, high-risk research to fundamentally change the landscape of brain disease. Promoting a national research prize will motivate researchers in ways the current system does not. The prize will be awarded to the first team to reach the audacious goal of delaying the onset or progression of a major neurological disease.

EDUCATION & ADVOCACY - Campaign for the Brain

- 4. Mobilize for the Brain. Engage the public and our network of supporters to connect with government officials to press for more public funding for brain disease research. For example, in 2015, the National Institutes of Health provided only \$586 million in research grants for Alzheimer's disease whereas funding for Cancer was \$5.4 billion. The system is out of balance given the people who are impacted and the costs to our healthcare system.
- 5. <u>Protecting Young Brains</u>. A national youth sports outreach campaign to promote concussion safety and education. Brain injury is a silent epidemic that changes or takes a life every 19 seconds. The best step forward is prevention. By starting with organized youth sports in select markets and then growing nationally, ABF will educate future generations about brain safety and brain disease.
- 6. <u>Brain Awards</u>. An awards program—the "Nobel Prizes" of brain disease—that raises national awareness of the fight against brain disease by spotlighting neurologists, neuroscientists and key public advocates, on the front lines of our fight to defeat brain disease.

 ONE in SIX

DID YOU KNOW?

Every 90 minutes a person is diagnosed with ALS

Every 60 minutes a person is diagnosed with Multiple Sclerosis

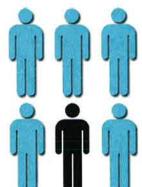
Every 23 minutes a person in the US is diagnosed with Brain Cancer

Every 4 minutes a person is diagnosed with Epilepsy

Every 67 seconds a person develops a form of dementia

Every 40 seconds a person suffers from a stroke

Every 20 seconds a traumatic brain injury occurs



The numbers are real and getting worse. It is time to take a different approach. A cure for one is a cure for many.

American Brain Foundation Strategic Evaluation

HENRICHS & ASSOCIATES CONCLUSIONS AND RECOMMENDATIONS

Henrichs & Associates was delighted to work with the American Brain Foundation (ABF) on this strategic evaluation. We were asked to identify best practices of medical foundations, both those linked to medical associations as well as disease-specific (voluntary health) organizations. The purpose was to help ABF determine a business model that fosters both independence and effectiveness in fulfilling its mission, understanding that there will be a transition process in achieving this model.

Data sources used included (1) interviews of ABF, American Academy of Neurology (AAN), and American Academy of Neurology Institute (AANI), Board members and staff (attached as Appendix A), and (2) examinations of five foundations linked to professional medical associations as well as seven voluntary health organizations (VHOs), through research as well as interviews of senior staff at each organization (attached as Appendix B).

Our overall synthesis and summary of these data appear below as conclusions, followed by recommendations. The reader is encouraged to review the data carefully for additional conclusions. The recommendations are based on all of the data sources described, plus our own experience working with foundations, including those that are related to membership organizations.

FILL UNIQUE NICHE

Conclusion #1A – The field is crowded with organizations engaged in research; they respect AAN's expertise but are split over the question of its entry into philanthropy.

AAN has Expertise and is Already Involved

- AAN works with disease-specific organizations in revising clinical practice guidelines, using AANdeveloped standards for quality of care, FDA guidance process (ALS)
- Senior staff of disease-specific organizations attend AAN conferences, find meetings valuable
- AAN has no major role in funding research, but has content expertise and access
 - o 29,000 experts
 - o real-time, ongoing academic and clinical information

All Disease-Specific Organizations Engage in Research

- "Power is in our science, our brand and our grassroots"
- Research (and support to patients and families) drives donations
- Research provides organizational credibility when engaged in advocacy
 - "Otherwise we are just asking others to fix things."
- Crowded field with many well-established organizations
 - High profile, successful organizations chasing donor dollars

Doubts:

- "Business to Business" vs. "Business to Consumer"
 - o It is not easy to turn from B-to-B (AAN) to B-to-C (ABF)

- Space is crowded, there is only so much "market" available -- what is an organization like ABF going to pursue if not B-to-B?
- O Curious why ABF is going forward facing (to consumer)?
- Understand that donors have to see impact of their funds on the ground
- Where is the Need? What is Missing?
 - "There are a lot of neurological disease-specific organizations, many of us are already talking about cross-cutting research (particularly ALS, Alzheimer's, MS, Parkinson's) that we should be funding together, so what is missing that AAN feels the need to establish another foundation that will compete with everyone else?"
- "1.4 million nonprofits in the US, 43 ALS organizations" (ALS Association convenes periodically)
- How will ABF be different than the Federal BRAIN Initiative?
- Conveners already exist:
 - National Health Council, Research America become conveners when we need them

Conclusion #1B – If ABF offers an opportunity to 'make something happen' that solves problems, it will be welcome by VHOs.

Voices for Collaboration:

- Foundations willing to work together to achieve common objectives, do so frequently
- Very intentional, must provide something we cannot do, or harder to do, alone
 - "We try not to get distracted from our goals/strategies when considering collaboration"
- "We look for partners who can Make Things Happen"
 - O Chosen by common interest & ability to drive our mission, not by organization/name
- Important role foundations can play in being a neutral gatherer, "marriage-maker"
 - Forced marriages never work
 - Creating environments where people see each other on a regular basis & then realize they are collaborating does work
- Convene people around issues
 - o "Industry only communicates when they have problems, we help solve those problems"

Opportunity:

- Potential that these diseases have underlying science, if not common elements
- ABF staking out a position on talking broadly to the public has benefit even if we (VHOs) are not going to change variety of groups talking about different things
- "We have moved from focusing on disease (stroke) to health (brain)" (AHA/ASA)
- "Corporate sponsors prefer to be <u>for</u> something (heart) rather than <u>against</u> something (stroke)"
- Disease and its effect on the personal -- is a motivating factor
- Data-driven decisions: How many people will this help?
- Clinical Trials both systemic site issues and patient recruitment issues
 - Disease-specific groups have large pool of potential patients to publicize need
 - ABF has access to medical infrastructure to think through application/approval process
- "Trying to find private-sector solutions to public health problems"
 - Ex: "X Prize for Housing Options: come up with housing solutions for 3 categories of adults with autism, the services and supports they need"

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Add Value:

- "Last 3 years, our foundation has published a trend report on federal and private funding on specialty training and research. It is shared with our membership organization -- they use if for advocacy -- and we report on our website. It shows where gaps need to be filled and is a leadership service that makes the foundation valuable, raising our visibility." (RRF)
- "We now co-chair a coalition of organizations that fund research and training because of the program work we have done." (RRF)

Conclusion #1C – Transformational Programming Drives Fundraising, Enthusiasm and Collaboration

- Leadership comes from providing unique product or service, solving others' problems
- "Our future will be in partnership, in collaboration and relationships that can inspire something different and new – keep your eyes on that."
- Cannot fundraise in a vacuum or as a pass-through organization product or service must be offered.

Recommendation #1 - Provide product(s) and/or services that are viewed as new and/or invaluable by others (the public, VHOs, corporations) and by AAN members.

RELATIONSHIP WITH LINKED MEDICAL ASSOCIATION

(The data for Conclusion 1A comes from internal interviews of AAN/AANI/ABF leadership, while the data for Conclusions 1B-1D comes from both internal and external interviews with senior staff at foundations linked to medical associations.)

Conclusion #2A - AAN has created, and is investing in, ABF with the expectation that it will succeed.

AAN Investment:

- \$4.8M from 2015-2019
- Leadership & staff spent time & effort creating ABF (establishing Board, hiring Executive Director)

AAN/AANI and ABF Board member and staff interviews revealed:

- Delivering high quality care requires innovation, new research
- AAN members have a passion, personal commitment for making an impact in the neurological disease area but ABF can provide better tools to meet that commitment
- ABF needs AAN's intellectual property access to professionals
 - AAN has issue/scientific expertise as to what needs funding
- If ABF can demonstrate success, it will bring added credibility to AAN while helping members
- Fear that ABF will become less aligned with AAN over time

Conclusion #2B -- Current AAN member confusion as to differences among ABF, AAN and AANI, and low external awareness of ABF as an organization apart from AAN, make it imperative for the organizations to act in concert and send consistent, unified messages about their sister organizations.

AAN/AANI and ABF Board member and staff interviews revealed:

Page 3

- Lines between the 3 organizations are blurry
- AAN rank and file is not clear on the differences among the organizations
- Missions of the 3 organizations, while different, need to be aligned

Conclusion #2C – In a transition from the current relationship (AAN as parent and supporter of start-up ABF) to a new relationship (AAN and ABF as independent, yet close collaborators), trust and transparency between the parties is essential for success.

- History, tradition, mindset, color current efforts
- Professional association (focused on individual advancement) vs. philanthropy (humanitarian need)
 creates inherent conflict among organizations
- Perceived threat to revenue:
 - View that AANI will be harmed
 - View that ABF cannot approach industry
 - Zero-sum view rather than 'growing the pie'
- Other foundations linked to medical associations work more seamlessly because they have overlapping staff
- ABF is the only foundation linked to a medical association that is solely publicly facing and not predominantly aimed at the profession
 - This creates a higher degree of difficulty, necessitating a more explicit effort

Conclusion #2D - It is the foundation's (ABF) responsibility to understand what is occurring at the association (AAN) and it is in the association's (AAN) responsibility to provide opportunities for the foundation (ABF) to do so.

Other Foundations linked to Medical Associations made it clear that, (1) as the smaller organization, it was incumbent upon them to understand their Medical Association, and (2) it was the Medical Association's responsibility to facilitate cooperation, foster that understanding and assist in the success of the Foundation.

Foundation-Medical Association Relationship

- We (philanthropy) can talk fluently about them (membership association) but not vice versa
- Sometimes their internal things are not useful, but we share lessons learned and collaboration has increased over time. We jump in to help where we can.
- We are respectful that we are a cog in a large machine.
- Foundation ED is considered a member of our Executive Team
- It has taken several years to get the staff balance right

Conclusion #2E – External relations with potential corporate donors can be sticky, but must be addressed (head on).

Other Foundations linked to Medical Associations revealed that Corporate Relations can be a particularly tricky issue to navigate between their medical association and their foundation.

From the corporate (donor) perspective:

- Different organizations in same building asking corporation for support can get confusing & annoying for them. They want one agreement with a large gift and we (foundation and association) figure it out, but association doesn't like that approach much.
- From association/foundation perspective:
 - Can't have one area asking for money while another is on the attack
 - Foundation going to ask for corporate money and afraid association was going to send harsh letter citing policy to corporation – difference between disagreeing with corporation and treating them as an enemy. (We worked it out with a phone call.)
 - Don't worry about zero-sum donations corporations spend on both foundation & association without choosing one over the other (we have found)
- Solutions (used by others):
 - Association staff in Corporate Relations shares everything with foundation ED
 - O Senior staff leadership: heads of association, foundation & corp relations all need to be in the loop
- Most corporations are set up with philanthropic and sponsorship arms.
 - Ex: One foundation said it can get to CEOs and high-level folks, so they are the best contacts for the association as a whole. Otherwise we (the association) just get an advertising representative or someone who doesn't understand strategic alignment.

Recommendation #2- Create structural relationship with AAN/AANI to ensure synergy, collaboration, trust, transparency, increasing growth, and success for all three organizations. Organizational interrelationships must be designed to provide incentives for working together. Formal structures are in place to bolster development of trusting, transparent relationships.

Recommendation #2A - Leadership Cross-Fertilization:

- Board: each Board (AAN & ABF) has 3 members from the other organization (2 voting, 1 non-voting)
 - Incoming leader of each organization (President Elect or VP, depending on succession rules
 of Board) so they become familiar with the other organization early in their tenure
 - O Current leader should participate (or second rising leader if current leader too busy)
 - o Executive Director of each organization sits as ex officio, non-voting member of other's Board
 - Ensures information flows both ways: ABF to AAN and AAN to ABF
- ABF should be used as a training ground for AAN leadership, not reliant on past leaders
- ABF Research Advisory Committee:
 - O Chair, an AAN member & leader, is ex officio ABF Board member
 - Leaders in their fields
 - AAN members (with rare exceptions permitted)
 - Combination of academic and clinical perspectives
 - Ensures continuing connection of AAN with ABF AND capitalizes on scientific expertise of AAN for the benefit of ABF

Recommendation #2B - Staffing:

- Executive Team of AAN includes Executive Director of ABF, who participates fully in Executive Staff meetings of AAN/AANI
- Corporate Relations Team implemented: Executive Directors and corporate relations/fundraising Executive Staff of each organization (AAN, AANI and ABF) of AAN, ABF meet regularly (not ad hoc)

- o Ensures issues are raised and addressed in a timely manner with all decision-makers present
- Ensures highest likelihood of success with outside corporations for all sister organizations and reduces risk of misstep

Recommendation #2C - Fundraising:

- Contractual relationship created to align fundraising interests, so no matter which entity approaches a donor, all entities benefit
- Formal structure with fundraising by each organization benefiting the others
 - Reciprocal formula negotiated for how unrestricted dollars raised by one might be shared by the other during the contract term

DELIBERATE TRANSITION

Conclusion #3A - Focus and Discipline are necessary.

All interviews indicated certain necessities:

- Have Clarity of Purpose
 - One VHO said, "we have really focused on drawing a hard line from activity to impact:"
 - "informed, continuous improvement is used as a discipline across our organization"
 - "how a tactic fills a strategy that relates to a goal, & the goal actually changing lives"
 - o Leading & Lagging Indicators: What will inform us?
- Focus, Focus, Focus
 - Board and Staff (must do so)
- Goals are Outcome-Oriented, not Process-Oriented
- Different Board Expertise Required of Professional, vs. Philanthropic, Organization

Conclusion #3B -- Creating a successful foundation takes time.

Every organization, especially the foundations associated with medical associations, said that success takes time:

- "Moving from membership organization to philanthropic organization takes time"
- "Getting marketing/communications message correct took time"
- "Getting Board composition correct took time"
- Staffing
 - o "Took 3-4 years to get communications right had to separate because we are not a membership organization, but are a charitable one and waters got muddied"
- "Because of our history we have people waiting and watching; they want to believe, but don't quite
 yet. Keep a positive attitude and prove it." (Medical Association-related Foundation)
- Gaining trust of players potential collaborators (foundations, industry) does not happen overnight

Recommendation #3 – Patience and Perseverance are required. Provide measures of impact that are not only process-oriented but are outcome-oriented to achieve success.

KEYS TO SUCCESS

Budget Must Look Compelling to Donors

- No more than 25% of budget should go towards Administration and Fundraising, 75% to Programs
 - O Michael J. Fox Foundation: administration 3%, fundraising 8% since inception (lowest)
- Donors must feel that their dollars are accomplishing something, not going to overhead

Storytelling not "Communications"

- Translate complex subject matter into compelling, relatable words and images
- "Most of our communications people are not from the industry -- we do in-house training in terms of science if need be"
- Communications people need to be able to convey story to the public in first paragraph, second
 paragraph is complex (what we are doing, why we are different, what progress we are trying to
 make) becomes a robust group effort"
- "Moral imperative not enough stop being angry people don't put us first and find the value proposition to sell the story"

Make Things Happen

Bigger is Not Necessarily Better

Because then you have to manage it

Stick to Core Competency, Don't Try to do Everything

Keep Board Small, Focused and Providing Desired Skills & Expertise

- Small:
 - O Best practice is to keep Board on the small side 6-12, no more than 15
 - "Boards that are too large require too much time of senior leadership & staff, waste resources"
- Ensure Board Development:
 - Understanding of fiduciary obligation
 - o Differences between philanthropy and membership association
 - Nature of alignment with AAN/AAN!
 - Role of Board member: direction and oversight, not operations
- Recruit individuals for specific expertise needed
 - Many Boards "originally populated with people affected by a disease who brought passion but not necessarily expertise"
 - o Include measurable goals and a reviewable action plan for each member that is agreed to when they are nominated to Board
- "Board needs to focus on governance, NOT on the business of the organization cannot get too 'in the weeds'"

Recommendation #4 - Remember - and periodically revisit -- the keys to success.



AMERICAN ACADEMY OF NEUROLOGY

2016 AMERICAN BRAIN FOUNDATION PRIORITIES SURVEY: REPORT ON RESULTS

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2016 American Brain Foundation Paramities Survey, Report on Resolts | Nature Adams 60 2016 American Academy of Neurology. All rights research

Methods

Objective

The American Brain Foundation (ABF) is interested in the philanthropic behavior of AAN members. A survey was developed to learn members' awareness and perceptions of the ABF, motivations to make charitable donations, and likelihood to make future donations to the ABF. Results of the *American Brain Foundation Priorities Survey* will be used to better-inform members of the ABF's existence and mission, and to better-appeal to members when soliciting donations. Furthermore, results will help to prioritize initiatives and gauge expected donations for 2016.

Instrument

The Member Research Subcommittee approved the concept of the *American Brain Foundation Priorities Survey* in October 2015. The instrument was developed by Nellie Adams, Member Insights Research Analyst at the AAN; Jane Ransom, Executive Director at the ABF; and Suzi Sherman, Senior Manager of Major Gifts at the ABF. Lisa Shulman, MD, FAAN, Chair of the ABF's Strategic Planning Committee, reviewed and approved the instrument, which was finalized in February 2016.

Sample

AAN members of all member types, ages, and countries of residence were included in sample consideration. Members were removed from sample consideration if they:

- Had received an AAN survey in the past 6 months
- Had previously opted out of receiving surveys
- Did not have an email address on file with the AAN
- Had reviewed the survey
- Were on the AAN or AANI Board, or were on the ABF Board, Strategic Planning Committee,
 Development Committee, or Nominations Committee

The sample was randomly pulled from a population of 24,332 and consisted of 900 members. After data collection, 17 members were removed due to repeated bounced emails, for a final sample size of 883.

Data Collection

The survey was distributed via email. The first email was distributed on February 22nd, 2016. The email was sent under the alias of Lisa Shulman, MD, FAAN. Follow-up emails were sent to non-respondents on March 1st and 8th, and data collection was closed on March 15th.

Sweepstakes

U.S. members who completed the survey or who sent an email to AAN staff were entered into a drawing, which was advertised in the survey invite email. For legal reasons, only the 668 U.S. members were eligible for the sweepstakes; international members received a separate email without mention of the drawing. The winner was offered a choice of a 2015 Annual Meeting on Demand hard drive or a pair of tickets to the ABF's Commitment to Cures reception at the 2016 Annual Meeting.

Demographics and Representation

Demographic Comparison

Comparison of population to sample: When compared to the entire population of AAN members, the sample differed in membership type and world region. The sample under-represented nurse practitioners and members from South America, Asia, and the Middle East; and over-represented trainees, research coordinators, and members from the U.S. The full comparison of these two groups can be seen in Table 1 below.

Comparison of respondents to non-respondents: When compared to non-respondents, respondents differed in world region and age. Respondents under-represented the U.S. and over-represented Africa, Asia, and Europe. Respondents were older than non-respondents. The full comparison of these two groups can be seen in Table 2 on the following page.

Response Rate and Margin of Error

Out of 883 sample members, 222 responded to the survey, for a response rate of 25.1%. The margin of error, at a 95% confidence interval, was ± 6.6 %. Survey results should be generalized with caution due to the differences between the population and sample and between respondents and non-respondents.

Table 1. Demographic characteristics of sample and population pulled from the AAN's internal member database

Demographic charac	teristics	Sample (n=883)	Population (n=33,735)	Significance
Age ¹ (mean years)		44.6 (SD=16.1)	45.1 (SD=15.6)	p=.381 ⁵
Gender (%) ²	Male	62.9	65.5	p=.114 ⁶
	Female	37.1	34.5	p=,114
	Board-certified neurologist (certified by ABPN, AOBNP, RCPSC) ³	45.9	43.0*	
	Corresponding (certified by another body)	6.3	5.7	
	Not board certified (associate)	8.0	8.2	
AAN membership	Business Administrator	0.9	0.8	p=.012 ⁶
type (%) ³	Nurse Practitioner/Physician Assistant	1.4*	2.9	
	Research Scientist/Fellow	2.8	2.6	
	Research Coordinator	0.9*	0.4	
	Trainee	34.7*	31.0	
	Senior	5.4	5.5	
	Africa	0,6	0.9	N IV
	Central America/Caribbean	0.2	0.3	
	South America	2.2*	3.3	
World region (%) ⁴	United States	79.9*	75.8	
	Asia	4.5*	6.6	p=.017 ^{6,7}
	Europe	4.6	4.7	p017
	Middle East	1.8*	2.7	3 3 3
	Australia/Oceania	1.3	1.1	
	Canada	4.2	4.0	
	Mexico	0.6	0.6	

Table 2. <u>Demographic characteristics of respondents and non-respondents pulled from the AAN's internal member database</u>

Demographic chara	cteristics	Respondents (n=222)	Non-respondents (n=661)	Significance
Age ¹ (mean years)		47.0 (SD=16.4)	43.9 (SD=15.9)	p=.015 ^{5,7}
Gender (%) ²	Male	67.0	65.1	6006
	Female	33.0	34.9	p=.609 ⁶
	Board-certified neurologist (certified by ABPN, AOBNP, RCPSC) ³	39.3	40.1	
	Corresponding (certified by another body)	5.3	9.5	
A A NT	Not board certified (associate)	8.0	8.1	
AAN membership	Business Administrator	0.9	0.9	p=.2648
type (%) ³	Nurse Practitioner/Physician Assistant	1.4	1.4	
	Research Scientist/Fellow	2.7	3.2	
	Research Coordinator	0.8	1.4	
	Trainee	36.8	28.4	
	Senior	4.8	7.2	
	Africa	2.3*	0.5	
	Central America/Caribbean	0.9	0.2	
World region (%) ⁴	South America	3.6	3.2	4
	United States	67.3*	78.6	12
	Asia	11.4*	5.0	00178
	Europe	7.3*	3.8	p=.001 ^{7,8}
	Middle East	2.7	2.7	
	Australia/Oceania	0.5	1.4	
	Canada	4.1	3.9	
	Mexico	0.0	0.8	

Age data missing for 4% of respondents and 4% of non-respondents.

¹Age data missing for 4% of sample and 4% of population.

²Gender data missing for 2% of sample and 2% of population.

³American Board of Psychiatry and Neurology, American Osteopathic Board of Neurology and Psychiatry, Royal College of Physicians and Surgeons of Canada.

⁴World regional data missing for 1% of sample and <1% of population.

⁵t-test

⁶Chi square

⁷Statistically significant.

^{*}The sample over- or under-represents this demographic as compared to the population.

²Gender data missing for 2% of respondents and 2% of non-respondents.

³American Board of Psychiatry and Neurology, American Osteopathic Board of Neurology and Psychiatry, Royal College of Physicians and Surgeons of Canada.

⁴World region data missing for <1% of respondents and <1% of non-respondents.

⁵t-test

⁶Chi square

⁷Statistically significant.

⁸Liklihood ratio

^{*}Respondents over- or under-represent this region as compared to non-respondents

Summary of Results

Past Philanthropic Behavior: General

Of those who made monetary donations in the past year, about three-quarters (76%) had donated to organizations supporting medical research, patients and caregivers, or public health. When asked their reasons for their most recent donation, the most common responses were "It seemed like the right thing to do" (49%) and "To fund research for a specific disease" (33%).

Awareness and Perception of the ABF

Prior to the survey, 77% of respondents had heard of the American Brain Foundation. This was similar to the amount (78%) who were aware of its earlier and longer-standing counterpart, the American Academy of Neurology Foundation. The most common ways respondents first became aware of the ABF were while joining or renewing membership at the AAN (31%), at a booth or on a sign at the Annual Meeting (23%), and via email (21%). From a list of 10 choices, the top terms respondents associate with the ABF are "American Academy of Neurology" (61%) and "Neurology research" (59%). Thirty-four percent selected the ABF's vision, "Cure brain disease", as a term they associate with the ABF.

Past Philanthropic Behavior: ABF

Of all survey respondents, a large portion (85%) had <u>never</u> donated to the ABF. When asked why, the most common reason was a lack of expendable income (38%). The second-most common reason was choosing to donate to other organizations instead (29%); when asked to specify which ones, the vast majority of commenters indicated a preference to donate to organizations in their own communities.

A demographic comparison of the 32 respondents who had donated to the ABF, and the 162 who hadn't, was conducted. No significant differences were found between groups, however, the testing may have been unreliable due to low cell counts in the donor group. See Demographics of Donors on page 21 for the full comparison table.

Future Philanthropic Behavior: ABF

When asked to rate their likelihood of donating to the ABF in the coming year, over half (51%) were somewhat/not at all likely to do so, while about a quarter were either neutral (23%) or very/somewhat likely (26%). Respondents were asked to explain their likelihood to donate; the most common write-in reasons among those who were neutral or unlikely were a lack of funds and a tendency to donate locally (especially among international members, who preferred to support their home countries' foundations). Those who were somewhat/very likely to donate expressed a desire to do so, but said it would depend on their financial situation.

ABF Priorities

A list of 7 potential ABF initiatives was displayed to respondents. When asked to rank the three initiatives they would most like the ABF to focus on, the far-and-away top priority was to support cutting-edge research to prevent or delay the onset of a neurological disease. The second- and third-place priorities were to expand public/governmental funding of brain research and provide early-career investigators with research grants.

Conclusion and Recommendations

Although three-quarters of respondents had heard of the American Brain Foundation, just 15% had donated in the past year. To increase donations from <u>AAN members</u>, the ABF could consider the following methods:

- Create a community-level presence: Many respondents who don't donate to the ABF prefer to give locally, and some international members do not like the idea of donating to a first-world country. The ABF could create country, state, and city-level presences to appeal to this group.
- Spend resources on targeting groups who are most likely to donate: Qualitative analysis suggests that U.S. members and those <u>not</u> in training are more likely to donate.
- Advertise support of cutting-edge research: Respondents' top priority for the ABF was to support cutting-edge research; efforts to fulfill this initiative should be communicated.
- Solicit small sums: Quantitative and qualitative research suggests that respondents' top reason for not donating to the ABF is a lack of funds. The ABF could appeal to this group by asking for small amounts of money, or communicating that any amount will help.
- **Appeal to morals:** The top reason respondents had made a donation to a health-related organization was that it seemed like the right thing to do. The ABF could use this to appeal to potential donors' moral sensibilities.

As neurology professionals who presumably work with patients and caregivers, respondents were asked how the ABF could appeal to the general public for donations. According to commenters, to increase donations from the general public, the ABF could consider the following methods:

- Advertise: Increase visibility via social media, national advertisements, and publications.
- Appeal to specific diseases: Share patient stories and past successes related to the most prevalent and "popular" brain diseases; "brain diseases" may be too broad a term for the general public.
- **Communicate successes:** To foster a sense of what donations can do, communicate past and potential impact the ABF has had, or could have, on brain disease.

Survey Frequencies

1. Prior to this survey, had you heard of...

	Yes	No
The American Brain Foundation? (n=219)	77.2%	22.8%
The American Academy of Neurology Foundation? (n=218)	78.0%	22.0%

Logo was displayed to survey respondents.

Questions 1a and 1b were displayed only to respondents who indicated, in question 1, that they had heard of the American Brain Foundation.

1a. How did you first hear about the American Brain Foundation?² (n=165)

20.6% Email

4.2% Postal mail

22.4% Booth or sign at the AAN Annual Meeting

30.9% While joining or renewing membership at the AAN

0.6% Public service announcement

3.0% Colleague or friend

5.5% Other (please explain):³

12.7% Unsure

1b. Please pick the three phrases you most closely associate with the American Brain Foundation:4 (n=163)

27.0% Political, advocacy-oriented, lobbying

1.8% Old, established

12.9% Patient and caregiver resources

38.0% Donations, philanthropy

60.7% American Academy of Neurology

32.5% Funding, grants

58.9% Neurology research

33.7% Cure brain disease

3.7% Science education for kids

6.1% A cure for one is a cure for many

1.8% Other (please specify):⁴

²Response options 1-6 were displayed in random order.

³See comments on page 11.

⁴Response options 1-10 were displayed in random order.

2. Of all the monetary donations you made in the last year, about what percent went to organizations supporting medical research, patients and caregivers, or public health (e.g., the American Heart Association, the American Cancer Society, etc.)?

n=54

25.1% This question is not applicable to me/I prefer not to answer⁵

n=161

24.2% 0 percent

39.8% 1-20 percent

11.8% 21-40 percent

8.1% 41-60 percent

6.8% 61-80 percent

9.3% 81-100 percent

⁵The 54 respondents who selected this option were excluded from analysis.

3. The <u>last time</u> you donated to an organization supporting medical research, patients and caregivers, or public health, what were your reasons for donating? *Mark all that apply*. 6,7

n=43

20.3% N/A⁸

n=169

32.5% To fund research for a specific disease

23.1% To honor someone close to me who has/had a certain disease

21.9% A friend, family member, or colleague asked me to donate

23.1% I felt professionally obligated

49.1% It seemed like the right thing to do

4.7% Other reason (please explain):⁹

4. Have you ever donated to the American Brain Foundation? (n=213)

15.0% Yes

76.1% No

8.9% Unsure

⁶Due to respondents selecting more than one response, total adds to over 100%.

⁷Response options were displayed in random order, with N/A always at the bottom.

⁸This response option was exclusive. The 43 respondents who selected this option were excluded from analysis.

⁹See comments on page 11.

Question 4a was displayed only to respondents who indicated, in question 4, that they had donated to the American Brain Foundation.

4a. What are your reasons for choosing <u>not</u> to donate to the American Brain Foundation? *Mark* all that apply. 10 (n=159)

- 12.6% I was not asked to
- 11.3% I tend not to donate to any organizations
- 28.9% I donate to other organizations instead (please specify which types of organizations—e.g., medical, educational, community-based):¹¹
- 38.4% Lack of expendable income
- 13.8% It is unclear where my money would go
- 18.9% I don't understand how my donation would be used
- 6.3% I work for or am on the board of another foundation
- 8.2% Other reason (please explain):¹²

5. The American Brain Foundation uses its donations to fund neurology initiatives. Which specific initiatives would you like the American Brain Foundation to focus on in the next year? Use the numbers 1-3 to rank your top three choices, with 1 being your top priority. 13 (n=189)

Rank sum¹⁴

- 324 Support cutting-edge research to prevent or delay the onset of a neurological disease
- Expand public/governmental funding of brain research (e.g., lobby the NIH)
- 230 Provide early-career investigators with research fellowship grants
- 82 Create a hub to connect researchers with donors
- 69 Develop a youth sports campaign to promote concussion safety and education
- 66 Create a research award in the style of an XPRIZE® (e.g., venture capitalists agree to contribute over a million dollars to a pool awarded to the first team to reach a certain goal)
- 62 Create an awards program to spotlight those who are on the front lines of the fight against brain disease
- 32 Other (please explain):15

6. How likely are you to donate to the American Brain Foundation in the next year? (n=202)

- 7.4% Very likely
- 18.8% Somewhat likely
- 22.8% Neither likely nor unlikely
- 21.3% Somewhat unlikely
- 29.7% Not at all likely

6a. Please explain your response:

See comments on page 13.

¹⁰Due to respondents selecting more than one response, total adds to over 100%.

¹¹See comments on page 12.

¹²See comments on page 13.

¹³Response options were displayed in random order, with "Other reason (please explain):" always last.

¹⁴A rank of 1 received a score of 3; a rank of 2 received a score of 2; and a rank of 3 received a score of 1.

¹⁵See comments on page 13.

See comments on page 16.	7.	In your opinion, what does the American Brain Foundation need to do to encourage donations from the general public (e.g., patients, caregivers, foundations, etc.)?
		See comments on page 16.

2016 American Brain Foundation Priorities Survey | Final Results 3/23/2016 | Response Rate 25% (222/883)

Survey Comments

Grammar and spelling were altered only where corrections were crucial to understanding meaning.

1a. How did you first hear about the American Brain Foundation?

Other (please explain):

- Internet (2)
- While googling for information about brain cancers
- On the internet, while looking for neuroscience foundations and associations.
- Mike Emry
- Memeber of the Science committee
- journal
- In Neurology or Neurology Today journal
- AAN

1b. Please pick the <u>three</u> phrases you <u>most closely associate</u> with the American Brain Foundation:

Other (please specify):

- Auction at AAN meeting
- Child Neurology
- Conflict
- Don't know
- no idea, I haven't heard of them before!
- none
- None of the above
- not clear exactly what is the scope
- Nothing
- To look after the interest of the neurologists

3. The <u>last time</u> you donated to an organization supporting medical research, patients and caregivers, or public health, what were your reasons for donating?

Other reason (please explain):

- An organization asked me
- Emergency situation
- family case
- memorial
- specific interest in little funded area
- Support local clinic for indigent people
- To schools or professors whose research interests are similar to ours.
- To stimulate research among younger colleagues

4. What are your reasons for choosing <u>not</u> to donate to the American Brain Foundation?

I donate to other organizations instead (please specify):

- community-based (4)
- ALS association (2)
- AAN PAC, Alzheimers association, many local charities
- All of the above
- ALSA, Alzhemier foundation.
- arts, community-based
- Basado en la Comunidad
- charitable, schools/colleges
- Church
- community
- community based organisations in india
- community-based, educational
- Community, educational, medical
- Educational
- Educational, development
- Foster Parents Plan the Netherlands
- graduate schools
- Heifer International
- Homeless shelter, community-based, environmental, international aid
- IRCCS Mario Negri Institute
- med, educ, other
- Medical
- medical and relief
- medical research/educational
- myasthenia gravis, MDA
- Natl. MS Society, Amer. Heart Association
- Ones in my community
- Red Cross
- Semper Fi Fund
- several
- specific medical conditions, animal and childhood issues, educational
- St. Johns ambulance, Great Ormond Street, Save the Children
- Tsc alliance
- Unicef, NAMI, Smiletrain

4. What are your reasons for choosing <u>not</u> to donate to the American Brain Foundation?

Other reason (please specify):

- had never heard of it
- hasn't hit my radar or risen above other medical donation sites
- I am an overseas member
- I donate to organisations in my own country
- I prefer to donate to fields in which I am not directly involved

- I'm European, so I've preferred other organizations.
- live abroad
- never heard of the foundation
- Not heard about this foundation
- not familiar with it
- not yet familiar with organisation; also tend to donate in my home country
- Rarely supports causes and research than I am interested in advancing
- The ABF conflicts with the fundraising I do for my academic research. It also is not apparent to me that the AAN puts patients first

5. The American Brain Foundation uses its donations to fund neurology initiatives. Which specific initiatives would you like the American Brain Foundation to focus on in the next year?

Other (please explain):

- · Create an EMR for neurology and child neurology
- Don't Know
- Expand Brain + Psychiatric overlap programs/initiatives. Where does epilepsy fall in all of this?
- expand clinical research funding
- Helping patients with neurologic disease lead fulfilling lives rather than just funding research to prevent disease
- I am not interested
- I object to emphasis on the brain and not the neuromuscular system
- Involve medical students in research and create mentorship opportunities as early as in college and university both local and international students.
- patient support
- Support Clinical Research to non-academic departments of Neurology
- Support clinicians-in-training interested in research involvement
- Support Neuro Rehab Research
- Teaching all members about current advances and changes in the field

6a. How likely are you to donate to the American Brain Foundation in the next year?

Please explain your response:

Very likely

- Committed to the Susan Spencer research fund
- generally donate at AAN each year
- I would like to give my humble help to prevent or cure neurologic diseases. People who work in American Brain Foundation are serious and they are doing a great work in my opinion.
- We desperately need a therapeutic measure to slow down dementia by 5 years.
- we donate as a private practice group

Somewhat likely

- American Brain Foundation seems very broad & nebulous. Seems like donations would go towards diseases that are "trendy". Is there a formula or procedure that determines where the money goes or what initiatives are funded etc....
- Aware and supportive of their work now
- Because so many good groups, charities, foundations, etc. are experiencing difficulty in raising monies, I have been overwhelmed with requests for donations. Medical research has always been very important to me so I am more likely to contribute to request for donations. However, these, too, have become quite aggressive in their fund raising so I am now much more selective in where I will give.
- Depends on how much money I have
- Depends on which specific projects I'm asked to support
- Happy to donate once I understand purpose
- I can donate next year for the American Brain Foundation.
- I contribute to many organizations, and this is one more expense. I specialize in MS and lose money seeing patients (as do all MS Centers), but make some income with other activities (research and teaching), so I don't have a lot of money to donate.
- I need to divide my donation budget.
- I plan to do so, though I also have other giving obligations and plans so cannot commit firmly to giving to the ABF at this time
- If I get chance I will donate to foundation
- My "ship" may come in this year.
- This survey shows they are really interested in hearing feedback and improving the society as a whole.

Neither likely nor unlikely

- At this time I do not have much disposable income so that is the primary deterrent to donating.
- Depend on the case
- Easiest to add donation to dues renewal
- Expendable income is the issue
- I am Egyptian, preferring to donate to my poor country.
- I am not often asked
- I don't think that I am at such a position to donate to an international organisation.
- I'm currently an Irish medical student
- If the opportunity easily presents itself in a time when I have funds that I deem available to donate.
- It completely depends on my income; currently cannot based on my income compared to educational loan payments and expenses of daily living, but I could end up with a higher income during the next year.
- Live abroad
- Lots of competing options
- No expendable income
- Not sure about any donations
- Not sure of relationship to the AAN.
- Trying to recruit us during meeting registration or paying due is challenging b/c I'm already chapped by the high cost of AAN meeting (we get nickled and dimed for everything) and the pricey annual dues on top of all the other professional costs we have.
- Until now I haven't been in closer contact with the American Brain Foundation.

Somewhat unlikely

- Again it does nor strongly support fields of research than I am interested in advancing and it
 has a bias toward outcomes and immediate translation rather than mechanisms of disease.
 Board recently selected a candidate that never launched a project nor crated new avenues of
 research.
- For me as a European academic neurologist membership fees for professional societies (without donations) are already pretty expensive. I am a member of five professional societies, costing more than €2000/year.
- I am a 4th year medical student about to start residency and do not have expendable income that I can donate currently
- I am a student with limited finances.
- I am based outside the US and prefer to support local initiatives
- I am on the Board of another foundation and put my energy and money into that. Once I rotated off, I may donate to the ABF
- I am retired with a reduction of income. My donations are now small, and I'm not likely to take on support for a new organization.
- I donate mostly to programs that directly support patients. I don't give a lot, so I want the money I give to help specific people. I feel that it is the NIH and government's job to support research initiatives, which is why I think money would be better spent directly helping patients and their families who are affected by these terrible illnesses.
- I'd rather donate to Portuguese institutions 1st
- If I learn more about it I might be inclined to support it.
- Lack of expendable fund, and if at all not in the US.
- Limited funds with many worthwhile causes
- not a US citizen
- not enough expendable income yet, have 3 other organizations that are local/impact personal friends that are of higher importance to me personally
- other priorities for my limited funds
- shrinking income.
- Still in medical school with no income
- There is no accountability or transparency on how the money is used.

Not at all likely

- No expendable income (2)
- Academy is not paying much attention to the needs of its members. Board recertification is just an example. The response from the academy has been timid
- am already donating to organisations in my country
- American foundation, and I am from Belgium.
- An overseas member. I donate to local organisations with more emphasis on patient support
- As stated above, I think the ABF is a bad idea since it competes with our academic efforts to raise money for our research. The AAN should be helping patients live with their diseases, establish outreach to the poor and underserved who cannot afford care (including international) and advocating for the value of neurology to the government and payers.
- currently a medical student but would consider donating in the future
- Financial.
- Focusing primarily on debt repayment; charitable donations will be to Canadian organizations
- I am not rich enough to donate. I do great community service to my patients.

- I already donated an excessive amount of money to my medical career. My level of debt and interest payments are outrageous. I will not give any more money to anything related to medicine.
- I don't think my donation will make much of an impact.
- I donate for other purposes.
- I have no money, I am a severely indebted intern.
- I just retired and am pursuing other interests
- I live in a foreign country with economic and financial difficulties.
- I object to the emphasis on the "brain" by a neurological association that is supposed to represent all neurologists, even those specializing on the peripheral nervous system and/or the neuromuscular system.
- If the peer review process was more fair and grants are less competitive, I would donate. There would have to be some tangible benefit for someone like me who is new to research. RO1 awards should be expanded for more researchers instead of a privileged few with connections. Remember, Eric Kandel received an NIH grant very early in his career. If our system would revert back to that golden age of basic research, then I would definitely donate.
- Lack of expendable income
- New practice less money.
- No spare cash
- Not a day goes by that I am not asked to donate money to some worthy cause. I have charity fatigue.
- not necessary
- Retired now and on a limited income.
- These initiatives do not directly impact me as a Canadian physician.
- Try to help patients individually have never donated to any organization
- We already have our charitable donations allocated for others
- we have already committed to our donations for the next year.

7. In your opinion, what does the American Brain Foundation need to do to encourage donations from the general public (e.g., patients, caregivers, foundations, etc.)?

- Don't know (5)
- Advertise (4)
- AAN needs to spread information about neurological diseases and necessity of donations for developments of scientific researching.
- ABF need to explain to the public regarding the excellent work being undertaken to support the general population
- Advertise aggressively on TV and the lay press
- advertise better
- Advertise more.
- Advertise specifics of what the donation money would go to; have options for supporters to choose how their donated money would be used.
- advertise where the money is going to
- advertise. Not sure. Economy is bad.
- advertise/educate
- Advertising through media
- Be more present in social media. Be more present with TV ads. Lobby governmental bodies. Be more present in research communities (e.g. AAN and SFN conferences). Globalize by connecting with a similar European organization

- Be present, or more visible to public. I have not seen any references to this organization outside of professional meetings
- Be specific about certain diseases, since most of these are dedicated to one disease. These
 groups need to know that the ABF is funding or looking to fund research in their specific
 diseases.
- Be specific about where money will be used
- be visible in lay publications. I do not hear about it except at AAN national conferences. Write about it in Neurology Now. Tell a story using patients or researchers. Make it more personal. But avoid hype. I really like Neurology Now and its style. So something along those lines but in magazine or newspaper articles.
- become better known
- Become famous for something.
- better explanation of where the money goes grant funds, administration, projects being funded.
- Better public ad campaigns at least. You have to make a more noticed brand name. Obama had his little "Brain Initiative" that got much more marketing than it deserved; do something similar, get the same campaign manager.
- Clearly state what the money is being used for.
- Create awareness among masses about diseases and need to help those suffering from them
- create more awareness
- creating awareness about incurable diseases like Parkinson's and Alzheimer's
- Demonstrate bench to bedside effects
- Demonstrate that neurological disease are common, are for the moment often not curable, but show recent breakthroughs that allow for hope
- Demonstrated what is has accomplished so far and how the foundation's affect the general public
- differentiate itself from other needy programs
- Don't have enough information to answer this question
- E.G., Publicity associated with sporting events given the focus on concussions in football
- Empathetic support and requests
- Emphasis patient support strategies in addition to research initiatives
- emphasize specific priorities like curing common conditions: Alzheimer's, Parkinson's, MS, etc
- Enhance education to physicians and community
- Expand its outreach
- Expand research
- Explain each of them about therapeutic successes in neurology
- explain more how the donations are used and the importance of these
- explain their mission
- Explain what they do and why they do it and what general good they think will come from what they do.
- Focus foundation's efforts on a few goals (right now "Brain" is too diffuse for people to resonate with it). Find a few key spokespeople to galvanize support and raise awareness (think Michael J. Fox for Parkinson's). Use that awareness to provide opportunities/events for people to get involved and see themselves as contributing to something meaningful. Then ensure the Foundation has clear, achievable goals that are transparent to all, and keep donors informed of progress (also a la MJFF).
- Focus on very common diseases that impact many such as Alzheimer's

- Get more in the public and advertise on things like Netflix and other channels. As well maybe try to fund documentary projects. (For example on Netflix you find the documentary on the Virunga park in Congo, and at the end there is a big cry out for donations.) Also let Leonardo Di Caprio be the godfather, and money will flow.
- Give examples of funded activities and results.
- Good for the USA. Not really relevant to my practice.
- Government
- Have a clear and specific goal related to a specific disease.
- Help the researcher and patients of developmental countries
- I don't know and really don't care.
- I donate for the diseases that I mostly deal with closely
- I had never heard of the American Brain Foundation, so starting with educating the public about its goals would be a better start before thinking about encouraging donations.
- I know of organisations who go directly to the hospitals (with consent of hospitals and doctors) and explain individually to patients what they offer to the patients and in turn ask for a contribution
- I think I'm not competent in giving advice for strategies of fund raising.
- I would like a better understanding of what the organization does and where the money is generally spent. I would also like to make sure the majority of the resources are not funneled into academic institutions or academic physicians only.
- If AAN members don't understand what it's for, how will you explain to the public? or donors?
- Increase awareness
- Increase awareness of what the foundation is and where the donations would go to and thus what cause is most directly being supported.
- Increase name recognition
- increase public awareness of ABF
- Increase public awareness. Help to improve the public awareness & opinion of scientists & clinical researchers.
- Increase public outreach
- It has to show how the money is used and the impact it has created since its inception.
- Local chapters.
- Make people think of brain research as a THING. Not 'my relative had a stroke, I wish we could have prevented it 'or 'my relative has dementia, that's sad' but rather with broader perspective, we can work toward preventing and fixing a whole range of diseases
- Make the public more aware of the impact neurological disorders have on society.
- market
- media campaign, social networking
- more active patient care & research
- more events to expand visibility
- more marketing, publicity; foundation is not generally known by the general public
- more PR/get the word out/increase awareness. I don't hear much from the general public about the American brain foundation
- More public exposure, but to be honest I am a neurologist based in the UK so I may not be aware of many of the advertising campaigns in progress. An annual showcase of the impact the ABF has had upon research, quality of care, investments, achievements ec.
- More publicity-people oftentimes want to give to a specific cause but the brain is so vast and mysterious, people may not know what they are funding
- N/A

- Name recognition
- Needs to have more visibility
- No comment
- No idea.
- No!
- None
- Not sure. I don't respond well to most marketing efforts. If you were able to show individual families supported by the Foundation's efforts, I would be more likely to give.
- Not sure. Giving is a private endeavor.
- nothing
- Partner with advocacy groups
- Place publicity in appropriate media
- PR
- Presence in social media
- Present personal stories of patient struggles
- Promise them results.
- Promocion...mas publicidad [Promotion...more publicity]
- Promote awareness
- Propaganda of reflection of projects on the public.
- Prove worthy of funds donated with exciting research proposals from proven researchers.
- Provide educational activities, such as Brain Fair, targeted and useful lectures to inform patients/caregivers and rally their support, and make available the specific ways that the money has been used. For example I have donated but I still am not clear n the specific achievements of the past year.
- Public awareness. Focus on people and initiatives the general public can get on board with
- public campaigning
- Public service announcements and engagement in and with community service organizations by way of academic centers
- publicize its program
- Publicize itself
- Publish the research outcomes
- public awarness about its values and mission
- Que se sienta la ayuda en paises tercer mundistas [The money should be going to third-world countries]
- Seems not differentiated from others
- Send the money in new research
- Shopping mall
- Show tangible impact.
- Show that a large portion of funds received directly impact either research or patient care
- Show them what you use their donations for. The impacts their donations have had. And also give an online certificate or a thank you certificate to donors or something similar.
- Show to the people what American Brain Foundation did and have done in neurological diseases
- Specific goals stated
- Sponsor patient education material
- Stroke education

- Stronger marketing/advertisement. I would market through social media such as Facebook (perhaps using the AAN Facebook page), and also would see about advertising through Doximity, a social network site geared toward physicians and medical workers.
- Sure but again "brain" foundation is too broad......it would be nice if the "brain" foundation also overlapped w/ psychiatric causes...also "brain" related I think. To the general public, it may be quite confusing..
- Take notes from Susan G Komen. How have they achieved such massive marketing success?
- The name is a bit generic; people want to know specifically where their money is going
- They need to be more visible about funds raised and awards granted.
- They need to make the American Brain Foundation more visible to create a larger awareness for those that are unfamiliar with the foundation.
- Through social media
- To promote its activities
- Try to reach out to people and convince them more
- We need to ask the Gates foundation and other similar big donors for research monies. We also need the government to be aware of the economic impact of dementia on society and a desperate need for a remedy. We should follow the success of our colleagues in lobbying against heart disease and AIDS. Without coordinated efforts involving the pharma industries, the government and the academic institutions, we will have a hard time to achieve our goals.
- yes
- Yes. Why wouldn't you?

Appendix: Demographics of Donors

The below demographic information was pulled from the AAN's internal membership database.

Demographics are compared for survey respondents who indicated that they had or had not ever donated to the ABF. Due to the low number of respondents in the Donors group, p-values should be interpreted with caution.

Table 3. Demographic characteristics of donors and non-donors

Demographic chara	acteristics	Donors (n=32)	Non-donors (n=162)	Significance	
Age ¹ (mean years)		48.8 (SD=14.0)	46.0 (SD=17.0)	p=.374 ⁵	
Gender (%)2	Male	58.1	69.8	p=.2006	
	Female	41.9	30.2	p200	
	Board-certified neurologist (certified by ABPN, AOBNP, RCPSC) ³	56.3	36.4		
(certified by ABPN, AOBNP, RCPSC) ³ Corresponding (certified by another body) Not board certified (associate) Business Administrator Nurse Practitioner/Physician Assistant Research Scientist/Fellow Research Coordinator Trainee	3,1	11.1			
	Not board certified (associate)	12.5	6.8		
	Business Administrator	0.0	1.2	p=.204 ⁷	
	Nurse Practitioner/Physician Assistant	3.1	1.2		
	Research Scientist/Fellow	3.1	3.1		
	Research Coordinator	3.1	1.2		
	Trainee	15.6	2.1		
	Senior	3.1	6.8		
1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1	Africa	3.1	2.5		
	Central America/Caribbean	3.1	0.0		
I THE LIGHT	South America	6.3	2.5		
	United States	81.3	64.4		
**** 11	Asia	3.1	13.8	p=.051 ^{6,7}	
World region (%) ⁴	Europe	3.1	7.5	D031	
	Middle East	0.0	3.8		
	Australia/Oceania	0.0	0.6		
	Canada	0.0	5.0		
	Mexico	0.0	0.0		

Age data missing for 0% of donors and 5% of non-donors.

²Gender data missing for 3% of donors and 2% of non-donors.

³American Board of Psychiatry and Neurology, American Osteopathic Board of Neurology and Psychiatry, Royal College of Physicians and Surgeons of Canada.

⁴World region data missing for 0% of donors and 1% of non-donors.

⁵t-test

⁶Chi square

⁷Liklihood ratio



TO:

ABF BOARD OF DIRECTORS

FROM:

JANE RANSOM, EXECUTIVE DIRECTOR

DATE:

UPDATED NOVEMBER 7, 2015

SUBJECT:

FRAMEWORK FOR ABF STRATEGIC IMPLEMENTATION PLANNING

The purpose of this document is to suggest a framework for the strategic implementation planning recommended by the Alford Group. I am seeking agreement on the process we will follow, including the methods by which we will test the feasibility of strategies and build out an implementation plan through budgeted, multi-year scenarios.

Background: Why Implementation Planning?

In 2013 the ABF Board of Directors adopted a bold new strategic direction to become a public-facing foundation—less reliant upon the traditional support of professional neurologists—with increasing philanthropic investments in medium-to-high risk research. An organizational assessment by an outside consultant endorsed the new direction as viable, but recommended that the specific goals referenced in the planning document be tested through a process of strategic implementation planning. Moreover, crucial issues such as assessing the fundraising potential of the Foundation, further defining the ABF's program and grant making niche, and outlining the future partnership between the ABF and the American Academy of Neurology were identified as the items needing further, careful study.

Purpose of Strategic Implementation Planning

To create a road map for implementing the ABF's strategic direction.

Guiding Principles

- Honor and build upon the ABF's past achievements
- Be bold, but verify—audacious goals, but fundable, data-driven and achievable in scope
- Make new friends, but keep the old—make the shift to public support while valuing our relationship with traditional supporters
- Enthusiasm for vision "Cure Brain Disease"
- Independence from and thriving partnership with the AAN

¹ Alford Group Recommendations Report, June 16, 2014.

Problem Statement

The pace of new discovery and opportunity in our understanding of neurological disease is in great contrast to the current funding opportunities that drive that discovery. Accordingly, the ABF Board of Directors has determined that the Foundation must build upon its traditional support of young investigators by extending our funding to include higher risk, cutting-edge medical research, and more innovative and creative ideas to speed the development of prevention, treatment and cures for brain diseases across-the-board.

Traditional medical research funding sources, such as government entities, take an incremental approach toward finding cures, leaving gaps in funding for higher risk research. Grants are awarded on a disease-by-disease basis, whereas the ABF has the freedom to fund across the spectrum of inter-related brain diseases.

As it moves toward a more innovative funding model, the ABF must also "go public"—i.e., go beyond the relatively small cohort of neurologists who have historically supported the Foundation and appeal to the public to support its mission. The American public understands "Cancer" as a single medical challenge, while at the same time understanding that there are many different forms of cancer. While there are more than 400 brain disorders, many share common disease mechanisms leading to neurodegeneration. Therefore, the ABF has the potential to rally public support around "Brain Disease" as an umbrella term, while supporting work focused on individual brain disorders including Alzheimer's disease, ALS, multiple sclerosis, Parkinson's disease, concussion and beyond. If we understand one, we can cure many.

Critical Issues

- **ABF Funding:** What would be the ideal distribution of grant funds for fellowships, high risk grants and possible X-Prize where funds are very limited now, and in the future, anticipated situation, where funds are more plentiful?
- Philanthropic Assessment: What is the ABF's fundraising potential?
- **Business Model:** How will the ABF do business, sustain itself and generate revenue to fulfill our mission?

Roles & Responsibilities

- 1. Board of Directors
 - Establishes guiding principles and adheres to them
 - Identifies critical issues
 - Approves process plan and budget
 - Agrees on impact goals and measures of success
- 2. Strategic Implementation Planning Committee
 - Analyzes data, ideas and issues on major topics under inquiry, e.g.:
 - Funding Priorities
 - o Philanthropic Assessment
 - o Business Model

- Synthesizes information
- Identifies questions and decisions to be brought before the Board
- Reviews drafts and financial scenarios

3. ABF Staff

- Jane Ransom, Executive Director
 - o Leads process overall in consultation with Board
- Suzi Sherman, Project Manager
 - o Manages planning activities/logistics along agreed upon timeline
- Lauren Ross, Sr. Manager, Major Gifts
 - o Resource to philanthropic assessment
- Chloe Walbruch
 - o Research assistant

4. ABF Current & Potential Stakeholders

- Who?
 - o Donors (AAN and non-AAN)
 - o Patients and Caregivers
 - Foundations & Corporations
 - o Disease Organizations
 - AAN/AANI staff and board
- How?
 - o Focus groups
 - o Surveys
 - o Personal interviews

5. Outside Consulting

- Overall process and facilitation
- Philanthropic assessment
- Business model analysis

Process

The outcomes of the August 10th and Sept. 18th ABF Board meetings we will be:

- create the key criteria for making decisions about the plan (i.e. guiding principles)
- define the critical questions which must be answered through the plan
- identify knowledge gaps and how to fill them

Following these meetings, with the help of Board members, staff and consultants, the ABF will do its homework to fill the knowledge gaps through data collection and work out potential strategies.

Many strategies will be inter-related. For example, the Research Advisory Committee may identify 2-3 priority research strategies, but do any of them resonate with our current and

potential donors? We will need to synthesize the strategies from the three critical issue areas and build one or more scenarios which include financial forecasts.

We will look to a Board level Strategic Planning Committee to participate in the synthesis and review of scenarios. A final scenario with strategic plan will be recommended to the Board for discussion and approval.

Timeline

WHAT	WHO	WHEN
Situation Analysis Briefings on historic and current situation.	ABF Board with Alford Group	June 16, 2014
Guiding Principles	ABF Board	August 10, 2015
Define key criteria for making decisions about this plan.		
<u>Critical Issues</u>	ABF Board	Sept. 18
Select handful of critical issues that <u>must</u> be addressed in the plan.		Retreat
Identify gaps in data for each critical issue and our approach(es) for filling them.		
Critical Issues 1st draft white paper on critical issues (with knowledge gaps exposed)	Executive Director for review by Board	Sept. 25
Strategy Development	Research Advisory Committee	Sept. 27
Strategy Development Data collection and strategy development for each critical issue	Staff, consulting partners, Board, volunteers	Oct. 1, 2015 – Jan. 31, 2016
	Strategic Planning Committee and/or Board monthly conference call	Oct. 15, 2015
	Strategic Planning Committee and/or Board monthly conference call	Nov. 15
	Strategic Planning Committee and/or	Dec. 15

	Board monthly conference call	
	Strategic Planning Committee and/or Board monthly conference call	Jan. 15, 2016
Scenario Development Synthesize work groups' proposed answers/strategies and create alternative scenario	Strategic Planning Committee with CFO	Feb. 15
	Strategic Planning Committee with CFO	March 15
Select Scenario	Board of Directors	April
Review scenario alternatives and select our option.		Board Retreat
Draft Strategic Plan Write and budget first draft of plan.	Strategic Planning Committee and/or Board monthly conference call	May 15
	Strategic Planning Committee monthly conference call	June 15
Draft Strategic Plan Write and budget final plan.	Strategic Planning Committee and Executive Team	July 15
Adopt Strategic Plan	Board of Directors	Aug. 1



TO: ABF Board of Directors

FROM: Jane Ransom

DATE: April 17, 2016

SUBJECT: Executive Director's Report

CURRENT OPERATIONS

1. **Finance**. In the first two months of 2016 the ABF is trending under budget in both expense and revenue. This is not surprising considering that our major fundraising activities for the year are only beginning to unfold now in Vancouver.

On April 7th the AANI approved a two-part financial request submitted by the ABF with the assistance and support of the Executive Staff of the Academy.

- Part one was a request for \$1.1 million toward ABF operations in 2016. This request aligns with the AANI's prior decision to invest \$4.8 million in ABF operations over 5 years toward the transformation of the Foundation. Thanks to the AANI's granting of this request, the \$1.1 million can be applied to ABF operations for the 2nd of that 5 year period.
- Part two was our request that the ABF's \$650,000 surplus from 2015 be placed in a restricted fund toward the programmatic costs of implementing the ABF's new strategic plan. We explained that the ABF did not use all of the funds granted to us in 2015 because we were not prepared to make the most prudent and strategic decisions about the use of the money without first doing our homework per the recommendations of the Alford consulting group. The Alford Group specifically recommended doing further strategic planning, including a philanthropic assessment. We did not want to use AANI money unwisely without a strategic business plan to guide spending. When we discuss our emerging strategic plan at today's meeting the financial needs required to begin executing the plan will emerge as well. So it is great news that the AANI granted this part of our request in addition to part one.
- 2. **Fund Development**. Most of our fund development efforts are currently focused upon the annual meeting we are now attending. I'd like to thank Lauren Ross, Suzi Sherman and Marlys Weyandt for the great effort they have put into ABF fundraising at the annual meeting:

- ABF booth in convention center throughout the week
- ABF booth at Brain Health Fair (April 15)
- Commitment to Cures, ABF fundraising event (April 16,)
 - o 5-6 pm VIP reception with Susan Williams
 - o 5:30-8:30 p.m. main reception and program, main speaker is Susan Williams who is receiving an award
- Presidential Plenary (April 17, 9:00 a.m.-12:00 noon)
 - o ABF board officer will present an award to Susan Williams
 - The ABF will ask plenary participants to pledge a contribution to the ABF using an electronic pledge form on the AAN app.
- Awards Luncheon (April 19)
 - Dr. Mazziotta will present the ABF Public Leadership in Neurology Award for Bob Woodruff to his wife Lee Woodruff.

Post annual meeting, we will turn to direct mail appeals, producing the 2015 annual report, the fall Standing Strong fundraising event, and major giving. In addition, we'll be carefully reviewing the Carter philanthropic assessment and how to move as quickly as possible to get on track with the challenging recommendations in that report.

I am happy to report that the ABF and AANI are moving toward an agreement whereby the ABF will be the primary fundraiser of Clinical Research Training Fellowship money. Confusion and tension about who is doing what with the fellowships will dissipate when we become aligned around this important program with defined responsibilities wherein the ABF raises charitable dollars and the AANI administers it. This does not signal abandonment of "closer to the cure" research funding by the ABF. On the contrary, it solidifies a foundation on which we can build so that we can raise and invest more in higher risk research.

- 3. **Human Resources.** You probably noted that the Carter report recommends a doubling of our fundraising staff, starting with the hire of a Chief of External Affairs with responsibility for marketing and fund development. Post-Vancouver I will begin working with AAN H.R. staff on preparing to fill that position.
- 4. **Marketing & Website.** If the Board is in agreement with today's recommendations, we will similarly begin positioning the ABF for investments in marketing, including a new website which pilots a virtual brain research fundraising platform.

STRATEGIC IMPLEMENATION PLANNING

Along with your board materials, you are receiving a large packet documenting our findings in the strategic implementation planning process. Yes, there is an executive summary, but I urge you to look at the reports of the Research Advisory Committee and consultants as these findings and recommendations stand behind the goals and strategies brought to you for today's meeting by the Strategic Planning Committee.

Implicit in the goals and strategies you are considering today, is the need to review our relationship with the AAN and to determine what it needs to consist of in the future for the ABF project to meet with success. I will talk further about this at the board meeting

and look forward to a May meeting with the leadership of the ABF and AAN boards to create the alignment, transparency and collaboration needed for success.

I am very excited to be bringing these recommendations and hopeful about the future of the ABF. As I have indicated above, if the Board approves the goals and strategies, much post-Vancouver staff time will be spent creating a supporting budget and positioning ourselves to begin executing the plan as soon as possible. I envision final adoption of the ABF strategic implementation plan to occur at the June 23-24 meeting of our board.



Fundraising Report



Cash/Pledge: Displays all cash gifts and pledges received during the 2015 and 2016 periods outlined above, all payments made on pledges were excluded.

Cash/Pay-Cash: Displays all cash gifts received during the 2015 and 2016 periods outlined above, including all payments made on pledges.

¹High variance between 2015 and 2016 attributed to payment of the 2015 Q4 AANI match (\$198,767) processed in February 2016.

Date: April 11, 2016

To: Members of the Board of Directors

From: Timothy Engel, CPA, Chief Financial Officer

Catherine Elliott, Finance Business Manager

CC: Jane Ransom, Executive Director

Subject: February 2016 YTD Financial Results

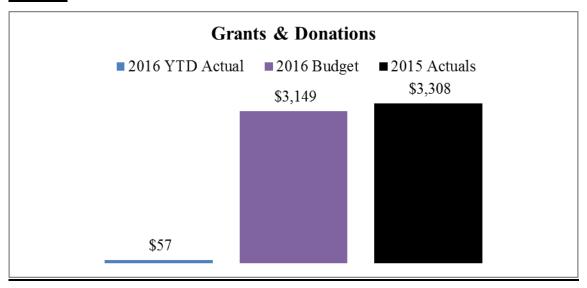
The enclosed materials present the financial performance of the American Brain Foundation for the two months ending February 29, 2016.

Statement of Operations

ABF realized \$59K in revenue as of February 2016. This is 2% of budgeted revenue. Long-term investment earnings realized a loss (non-operating revenue) for first two months of 2016. However, preliminary result for March 2016 is showing an increase of \$265K so the first quarter of 2016 net would be \$37K.

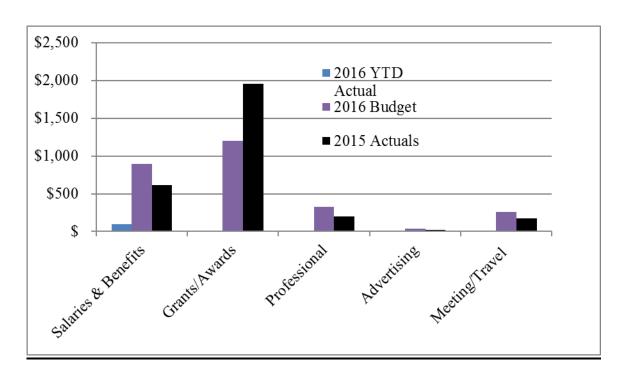
2016									
	Actual	2015							
Operating Revenue	\$59	\$3,157	\$(2,816)	\$3,341					
Expenditures	(210)	(3,255)	2,787	(3,289)					
Net (decrease) from operations	(151)	(98)	(30)	52					
Investment earnings(loss)	(227)			(34)					
Net increase(decrease)	\$(378)	\$(98)	\$(30)	\$18					

Revenue



The AANI Board approved a 2016 general operating grant of \$1,100,000 for the ABF in April and revenue will be recognized in April. The 2015 general operating support grant from AANI stated that any unused funds are to be returned to AANI. ABF realized a net increase of over \$650K in 2015 and therefore \$650K was required to be returned to AANI. ABF requested that the ABF be allowed to retain the \$650,000 excess for use at ABF's discretion towards major program initiatives resulting from ABF's strategic planning and philanthropic assessment. The request was approved.

Expenses



Expenses for 2016 YTD were \$178K under budget. The budget anticipated more activity related to strategic planning and website redevelopment. The following areas are the primary sources for the net positive variance.

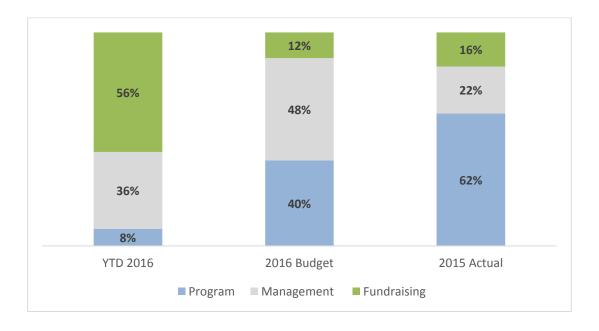
- 1. Salaries and benefits under by \$30K
 - a. Staffing has one additional position open.
- 2. Professional services under by \$90K
 - a. Strategic Consultant under by \$34.8K
 - b. Website Redevelopment under by \$50K
 - c. Other under by \$5.2K
- 3. Meeting and travel under by \$18.8K
 - a. Less staff travel for donor development/fundraising
 - b. Timing of expenses

Program/Grant Expense

ABF has committed \$1M to AANI for support of 14 Clinical Research Training Fellowships. Support of \$406,666 is provided by three associations or foundations and \$600K from ABF restricted grant funds raised in prior years.

Functional Expense

The following schedule displays the breakout of ABF's functional expenses. Program expenses for 2015 were 62%. The budget for 2016 projects program expenses at 40% and management at 48%. Allocation of expenses for 2016 will be reviewed throughout the year to insure proper allocation.



Fund Raising Efficiency Ratio

The amount spent to raise a \$1 in charitable contributions. This ratio is calculated by dividing fundraising expenses by total contributions (grants) received. ABF efficiency improved in 2015. As ABF continues to invest in the infrastructure in 2016 the efficiency ratio will likely decline.

	<u>2014</u>	<u>2015</u>
Grant Revenue Fundraising	\$3,189,559	\$2,819,224
Expense	\$423,256	\$515,659
Efficiency	\$0.13	\$0.18

Statement of Financial Position

The Foundation ended the year with total assets of \$9.3M. This consisted of cash and investments of \$9.1M, 97% of total assets. Liabilities totaled \$1.2M and which includes grants payable of \$1.1M.

(in thousands)	February 29,						
	2016 2015			5 Difference			
Total Assets	\$	9,349	\$	10,817	\$	(1,468)	
Total Liabilities		1,243		1,671		(428)	
Unrestricted Net Assets		1,965		2,393		(428)	
Temporarily Restricted Net Assets		4,522		5,181		(659)	
Permanently Restricted Net Assets		1,620		1,572		48	
Total Liabilities and Net Assets	\$	9,349	\$	10,817	\$	(1,468)	

A complete set of financial statements is included in the following pages for your review.

AMERICAN BRAIN FOUNDATION

STATEMENT OF FINANCIAL POSITION AS OF FEBRUARY 29,

	2015	2014	Net Change			
ASSETS						
CURRENT ASSETS						
Cash and Cash Equivalents	\$ 3,433,722	\$ 3,094,462	\$	339,260		
Grants and Gifts Receivable, Net	189,625	1,105,744		(916,119)		
Accounts Receivable	397			397		
Other Assets	63,386	83,998		(20,612)		
Total Current Assets	3,687,130	 4,284,204		(597,074)		
FIXED ASSETS						
Office Equipment	10,725	10,725				
Less Accumulated Depreciation	(8,640)	(5,065)		(3,575)		
Net Fixed Assets	2,085	5,660		(3,575)		
LONG TERM ASSETS						
Investments	5,649,478	6,054,529		(405,051)		
Grants and Gifts Receivable, Net	10,423	472,524		(462,101)		
Total Long Term Assets	5,659,901	6,527,053		(867,152)		
Total Assets	\$ 9,349,116	\$ 10,816,917	\$	(1,467,801)		
LIABILITIES AND NET ASSETS						
CURRENT LIABILITIES						
Accounts Payable	\$ 183,943	\$ 91,155	\$	92,788		
Grants Payable	959,803	822,500		137,303		
Total Current Liabilities	1,143,746	913,655		230,091		
LONG TERM LIABILITIES						
Grants Payable	98,766	 757,324		(658,558)		
NET ASSETS						
Unrestricted	1,964,818	2,393,310		(428,492)		
Temporarily Restricted	4,521,855	5,180,707		(658,852)		
Permanently Restricted	1,619,931	1,571,921		48,010		
Total Net Assets	8,106,604	9,145,938		(1,039,334)		
Total Liabilities and Net Assets	\$ 9,349,116	\$ 10,816,917	\$	(1,467,801)		

American Brain Foundation Income Statement For the Two Months Ending February 29, 2016

		YTD 2016 Actuals		TD 2016 Budget	Variance Favorable (Unfavorable)		2016 Budget		Final 2015 Actuals
REVENUE									
Grants & Gifts	\$	57,386	\$	339,260	\$	(281,874)	\$ 1,962,500	\$	673,752
Released from Restrictions	·	,		,	·	, ,	1,186,666		2,634,123
Interest Income		1,415		1,250		165	7,500		7,917
Other Revenue		500		,		500	•		25,359
Total Support and Revenue		59,301		340,510		(281,209)	3,156,666	3	3,341,151
EXPENSES									
Salaries & Benefits		97,283		127,684		30,401	895,026		613,920
General Office		2,009		4,097		2,088	35,572		39,393
Software		54,312		54,312		·	95,000		101,640
Professional		16,091		106,372		90,281	324,249		194,731
Marketing		1,000		3,054		2,054	34,730		20,613
Meeting/Travel Related		7,764		26,510		18,746	257,125		177,334
Honoraria/Stipends/Awards		•		1,600		1,600	1,198,266	1	,955,479
Contingency				33,334		33,334	200,000		
Depreciation		596		596			30,182		3,575
Management Fee		30,781		30,774		(7)	184,651		182,057
Total Expenses		209,836		388,333		178,497	3,254,801	3	3,288,742
Long Term Investments Income(Loss)		(227,298)				(227,298)			(34,432)
CHANGE IN UNRESTRICTED NET		<u> </u>							
ASSETS	\$	(377,833)	\$	(47,823)	\$	(330,010)	\$ (98,135)	\$	17,977
TEMPORARILY RESTRICTED NET ASSETS									
Grants & Gifts	\$	1,927						\$ 2	2,092,462
Investment Income									(15,761)
Net Assets Released from Restrictions								(2	2,634,123)
Beginning Balance	4	,519,929						5	5,077,351
Ending Temporarily Restricted Net Assets	\$ 4	,521,856						\$ 4	1,519,929
PERMANENTLY RESTRICTED NET ASSETS									
Grants & Gifts								\$	53,010
Beginning Balance	\$ 1	,619,931						1	,566,921
Ending Permanently Restricted Net Assets	\$ 1	,619,931						\$ 1	,619,931

MEMORANDUM

To: Members of the Board of Trustees

From: Joseph Berger, MD, Chair, Joint Audit Committee

Timothy J. Engel, CPA, Chief Financial Officer

Date: April 17, 2016

Subject: Audit Committee Report

The Joint Audit Committee of the American Academy of Neurology (AAN) and American Academy of Neurology Institute (AANI) met on April 16, 2016. The purpose of the meeting was to meet with Clifton Larson Allen (CLA) to review and discuss their audit reports on the consolidated financial statements. The committee voted to approve the Financial Statements of American Brain Foundation for the year ended December 31, 2015

The Audit Committee is charged with review of the financial practices of the ABF and its affiliates. We retain an outside auditor independent of ABF Trustees and through them the members and contributors to the ABF. Management is responsible for the financial statements and the financial reporting process, including the system of internal control. The audit committee discussed with the independent auditors, who are responsible for expressing an opinion on the conformity of those audited financial statements with generally accepted accounting principles, their judgments as to the quality, not just the acceptability, of the organization's accounting principles and such other matters as are required to be discussed with the committee under generally accepted auditing standards. In addition, the committee has discussed with the auditors their independence from management and the organization.

The audit committee discussed with the organization's independent auditors Clifton Larson Allen with and without management. The independent auditors presented the results of their examinations, their evaluations of the organization's internal control, compliance with laws and regulations and the overall quality of the organization's financial reporting; in addition to peer financial data benchmarking and trends. The audit went very well, with the auditors noting in their report an unmodified opinion (the highest opinion a company may receive); no problems were encountered during the audit, no reportable internal control deficiencies noted during their testing, no material weaknesses and no significant deficiencies. CLA also stated that the Academy Finance staff was very prepared and cooperated fully.

The audited financial statement of the American Brain Foundation for period ending December 31, 2015 is included as informational report to the Board and no action is required.

The following reports are provided for your review:

- Audit Report
- Governance Communication Letter
- Internal Control Communication Letter
- Internal Control Management Response Letter

AMERICAN BRAIN FOUNDATION FINANCIAL STATEMENTS YEARS ENDED DECEMBER 31, 2015 AND 2014

AMERICAN BRAIN FOUNDATION TABLE OF CONTENTS YEARS ENDED DECEMBER 31, 2015 AND 2014

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NOTES TO FINANCIAL STATEMENTS	8



CliftonLarsonAllen LLP CLAconnect.com

INDEPENDENT AUDITORS' REPORT

Board of Directors American Brain Foundation Minneapolis, Minnesota

We have audited the accompanying financial statements of the American Brain Foundation, which comprise the statements of financial position as of December 31, 2015 and 2014, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.



Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of American Brain Foundation as of December 31, 2015 and 2014, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

CliftonLarsonAllen LLP

Minneapolis, Minnesota April 16, 2016



AMERICAN BRAIN FOUNDATION STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2015 AND 2014

	2015	2014
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 3,507,852	\$ 3,521,448
Grants and Gifts Receivable	709,137	1,455,914
Accounts Receivable	20,885	14,743
Other Assets	67,264	90,469
Total Current Assets	4,305,138	5,082,574
EQUIPMENT, NET	2,681	6,256
OTHER LONG-TERM ASSETS		
Funds Held With Others	5,876,776	5,926,970
Grants and Gifts Receivable, Net of Current Portion	6,673	472,524
Total Other Long-Term Assets	5,883,449	6,399,494
Total Assets	\$ 10,191,268	\$ 11,488,324
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES	ф 07.40 7	Ф CC C4.4
Accounts Payable and Accrued Liabilities Grants Payable	\$ 87,487 1,457,303	\$ 66,614 1,650,000
Related Party Payable	65,202	45,442
Total Current Liabilities	1,609,992	1,762,056
LONG-TERM LIABILITIES		
Grants Payable, Net of Current Portion	98,766	757,323
Total Liabilities	1,708,758	2,519,379
NET ASSETS		
Unrestricted:		
Undesignated	2,339,969	2,318,417
Invested in Property and Equipment	2,681	6,256
Total Unrestricted	2,342,650	2,324,673
Temporarily Restricted	4,519,929	5,077,351
Permanently Restricted	1,619,931	1,566,921
Total Net Assets	8,482,510	8,968,945
Total Liabilities and Net Assets	\$ 10,191,268	\$ 11,488,324

AMERICAN BRAIN FOUNDATION STATEMENT OF ACTIVITIES YEAR ENDED DECEMBER 31, 2015

2015 Temporarily Permanently Unrestricted Restricted Restricted Total **SUPPORT AND REVENUE** Grants and Gifts \$ 673,752 2,092,462 \$ 53,010 2,819,224 \$ Dues Conference and Educational Fees Royalties Investment Income (Loss) 7,917 (15,761)(7,844)25,359 Other Revenue 25,359 <u>2,634,</u>123 Net Assets Released from Restrictions (2,634,123)3,341,151 Total Support and Revenue 53,010 2,836,739 (557,422)**EXPENSE Program Expenses** 2,054,101 2,054,101 Support Services: Development 515,659 515,659 General and Administrative 718,982 718,982 **Total Support Services** 1,234,641 1,234,641 3,288,742 Total Expense 3,288,742 **TOTAL CHANGES IN NET ASSETS BEFORE** NON-OPERATING INVESTMENT INCOME 52,409 (557,422)53,010 (452,003)Non-Operating Investment Loss (34,432)(34,432)**TOTAL CHANGE IN NET ASSETS** 17,977 (557,422)53,010 (486, 435)Net Assets - Beginning of Year 2,324,673 5,077,351 1,566,921 8,968,945 **NET ASSETS - END OF YEAR** 2,342,650 4,519,929 1,619,931 8,482,510 \$

AMERICAN BRAIN FOUNDATION STATEMENT OF ACTIVITIES YEAR ENDED DECEMBER 31, 2014

2014 Temporarily Permanently Unrestricted Restricted Restricted Total **SUPPORT AND REVENUE** Grants and Gifts \$ 660,980 2,473,079 \$ 64,500 3,198,559 Dues 690,000 690,000 Conference and Educational Fees 9,000 9,000 Royalties 25,615 25,615 Other Revenue 25,248 25,248 Investment Income 8,961 121,553 130,514 Net Assets Released from Restrictions 2,562,672 (2,562,672)4,078,936 Total Support and Revenue 3,982,476 31,960 64,500 **EXPENSE Program Expenses** 2,655,057 2,655,057 Support Services: Development 423,256 423,256 General and Administrative 558,299 558,299 **Total Support Services** 981,555 981,555 3,636,612 **Total Expense** 3,636,612 **TOTAL CHANGES IN NET ASSETS BEFORE** NON-OPERATING INVESTMENT INCOME 345,864 31,960 64,500 442,324 Non-Operating Investment Income 142,783 142,783 **TOTAL CHANGE IN NET ASSETS** 31,960 488,647 64,500 585,107 Net Assets - Beginning of Year 1,836,023 5,045,391 1,502,421 8,383,835 **NET ASSETS - END OF YEAR** 2,324,670 5,077,351 1,566,921 8,968,942

AMERICAN BRAIN FOUNDATION STATEMENTS OF FUNCTIONAL EXPENSES YEARS ENDED DECEMBER 31, 2015 AND 2014

			2015						
					Ge	eneral and			
	Program		Development		Administrative			Total	
Salaries and Benefits	\$	53,784	\$	212,367	\$	347,769	\$	613,920	
General Office		494		27,358		21,072		48,924	
Software and Maintenance		-		101,640		-		101,640	
Professional Fees		27,198		14,215		158,972		200,385	
Management and Service Fees		15,432		63,456		103,169		182,057	
Meeting and Travel		1,714		96,512		79,109		177,335	
Grants and Awards		1,955,479		-		-		1,955,479	
Depreciation		-		-		3,572		3,572	
Other Expenses				111		5,316		5,427	
Total Expenses	\$	2,054,101	\$	515,659	\$	718,979	\$	3,288,739	
			2014						
					Ge	eneral and			
		Program	De	velopment	Adr	ministrative		Total	
Salaries and Benefits	\$	224,737	\$	168,783	\$	261,369	\$	654,889	
General Office		20,102		49,343		26,117		95,562	
Software and Maintenance		78		95,954		-		96,032	
Professional Fees		75,898		7,729		98,012		181,639	
Management and Service Fees	4	38,971		31,541		57,756		128,268	
Meeting and Travel		107,468		69,892		98,201		275,561	
Grants and Awards		2,184,937		-		560		2,185,497	
Depreciation				-		7,493		7,493	
Other Expenses	_	2,866		14		8,791		11,671	
Total Expenses	\$	2,655,057	\$	423,256	\$	558,299	\$	3,636,612	

AMERICAN BRAIN FOUNDATION STATEMENTS OF CASH FLOWS YEARS ENDED DECEMBER 31, 2015 AND 2014

	2015	 2014
CASH FLOWS FROM OPERATING ACTIVITIES		
Changes in Net Assets	\$ (486,432)	\$ 585,107
Adjustments to Reconcile Changes in Net Assets to Net	,	
Cash Provided (Used) by Operating Activities:		
Depreciation	3,572	7,493
Permanently Restricted Contributions	(53,010)	(64,500)
(Increase) Decrease in Current Assets:		
Grants and Gifts Receivable	1,212,628	856,755
Accounts Receivable	(6,142)	40,655
Other Assets	23,205	(9,408)
Funds Held With Others	50,194	(1,764,336)
Increase (Decrease) in Liabilities:		
Accounts Payable	20,873	27,782
Grants Payable	(851,254)	711,021
Related Party Payable	19,760	(142,197)
Deferred Revenue	 	 (100,000)
Net Cash Provided (Used) by Operating Activities	(66,606)	148,372
CASH FLOWS FROM FINANCING ACTIVITIES		
Permanently Restricted Contributions	 53,010	 64,500
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	(13,596)	212,872
Cash and Cash Equivalents - Beginning of Year	3,521,448	3,308,576
CASH AND CASH EQUIVALENTS - END OF YEAR	\$ 3,507,852	\$ 3,521,448

NOTE 1 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Organization

The American Brain Foundation (the Foundation) is a not-for-profit corporation established to support vital research into finding cures for brain disease, and is committed to improving patient care, quality of life and public understanding of brain disease. Its vision is to cure brain disease.

Financial Statement Presentation

Net assets, support, revenue, expenses, gains and losses are classified based on donorimposed restrictions. Accordingly, net assets of the Foundation and changes therein are classified and reported as follows:

<u>Unrestricted</u> – Resources over which the board of directors has discretionary control.

<u>Temporarily Restricted</u> – Those resources subject to donor-imposed restrictions which will be satisfied by actions of the Foundation or the passage of time.

<u>Permanently Restricted</u> – Those resources subject to a donor-imposed restriction that they be maintained permanently by the Foundation.

Cash and Cash Equivalents

The Foundation considers all highly liquid investments with an initial maturity of three months or less to be cash and cash equivalents. The Foundation maintains cash in bank accounts which, at times, may exceed federally insured limits. The Foundation has not experienced any losses in such accounts.

Receivables

Accounts, grants and gifts receivables are stated at net realizable value. Accordingly, the Foundation accounts for uncollectible accounts by the reserve method, which is based on management's judgment considering historical information. Payment is required 30 days after receipt of the invoice. Individual accounts past due more than 90 days are individually analyzed for collectability. When all collection efforts have been exhausted, the receivable is written off against the reserve. The Foundation had no allowance recorded at December 31, 2015 and 2014.

Equipment

Equipment is recorded at original cost. Additions, improvements or major renewals at or over \$5,000 are capitalized. Any gains or losses on property and equipment retirement are included in the current year operations.

Depreciation is computed using the straight-line method at rates based on estimated service lives and is computed using the straight-line method over a three year service life.

NOTE 1 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Funds Held With Others

Funds held with others are made up of reserved investments held at the American Academy of Neurology Institute for purposes of earning long-term investment income. These funds are pooled with the investments at the American Academy of Neurology Institute. The Foundation has two board members that serve on a joint investment committee that oversees and monitors the investment pool. The Foundation has the ability to liquidate their investments at any time subject to he redemption restrictions on the individual investments. These investments in marketable securities are recorded at fair value and consist primarily of equity funds and corporate bond funds. Investments in certificates of deposit are recorded at cost. In addition, the investments include three limited partnerships that are diversified funds of hedge funds, reported at the estimated fair value of the Foundation's share of the fund, calculated monthly by the custodian. Investment securities, in general, are exposed to various risks, such as interest rate, credit and overall market volatility.

Grants Payable

Grants payable consist of awards and grants approved for various research projects and fellowships. Grants payable are recorded at the signing of the contract with both the researcher and the institution. Long-term grants payable are discounted based on the year to be paid.

Grants and Gifts

Grants and contributions received are recorded as unrestricted, temporarily restricted or permanently restricted support, depending on the existence and/or nature of any donor restrictions. Contributions are recognized at fair value when the donor makes a promise to give to the Foundation that is, in substance, unconditional. Conditional promises to give are recorded when the condition has been satisfied. When a restriction is satisfied, temporarily restricted net assets are released to unrestricted net assets.

NOTE 1 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Fair Value Measurement

The Foundation categorizes its investments measured at fair value into a three-level hierarchy based on the priority of the inputs to the valuation technique used to determine fair value. The fair value hierarchy gives the highest priority to quoted prices in active markets for identical assets or liabilities (Level 1) and the lowest priority to unobservable inputs (Level 3). If the inputs used in the determination of the fair value measurement fall within different levels of the hierarchy, the categorization is based on the lowest level input that is significant to the fair value measurement. Investments valued at fair value are categorized based on the inputs to the valuation techniques as follows:

Level 1 – Inputs that utilize quoted prices (unadjusted) in active markets for identical assets or liabilities that an entity has the ability to access.

Level 2 – Inputs that include quoted prices for similar assets and liabilities in active markets and inputs that are observable for the asset or liability, either directly or indirectly, for substantially the full term of the financial instrument. Fair values for these instruments are estimated using pricing models, quoted prices of securities with similar characteristics, or discounted cash flows.

Level 3 – Inputs that are unobservable inputs for the asset or liability, which are typically based on an entity's own assumptions, as there is little, if any, related market activity.

Subsequent to initial recognition, the Foundation may re-measure the carrying value of assets and liabilities measured on a nonrecurring basis to fair value. Adjustments to fair value usually result when certain assets are impaired. Such assets are written down from their carrying amounts to their fair value.

Revenue Recognition

Revenue related to conference and educational fees and management services is recognized at the time the events take place or the services are performed. Revenue that is received for future periods is recorded as deferred revenue and recognized in the periods to which the service relates.

Membership dues are recognized as revenue over the period in which the dues relate. Dues represent services rendered on a calendar year basis. Dues collected in advance are recorded as deferred revenue until they are earned.

Donated Goods and Services

Donated services are recognized as contributions if the services (a) create or enhance nonfinancial assets or (b) require specialized skills, are performed by people with those skills, and would otherwise be purchased by American Brain Foundation. Donated goods are valued at market value on the date of donation. There were no donated goods or services for the years ended December 31, 2015 and 2014.

NOTE 1 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Allocation of Expenses

The Foundation's costs of providing its various services have been classified on a program basis in the statements of activities. Accordingly, certain costs have been allocated among the program and support services benefited. Expenses are charged directly to programs and support services where possible. Remaining expenses are allocated based on actual time spent on programs and support services.

Income Taxes

The Foundation is organized and operates on a not-for-profit basis and its tax exempt status has been recognized by the Internal Revenue Service under Section 501(c)(3). The Foundation is classified as an organization which is not private foundations under the Internal Revenue Code and charitable contributions by donors are tax deductible. The Foundation is subject to unrelated business income taxes under the Internal Revenue Code for federal and state tax purposes.

The Foundation follows the provisions of FASB ASC 740-10-25, which requires that a tax position be recognized or derecognized based on a "more likely than not" threshold. This applies to positions taken or expected to be taken in a tax return. The Foundation does not believe its financial statements include any uncertain tax positions. The Foundation's tax returns are subject to review and examination by federal authorities.

Other Concentrations

The Foundation also has a potential credit risk in contributions receivable since the balance is due from a limited number of individuals and corporate contributions.

Use of Estimates

The presentation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Subsequent Events

In preparing these financial statements, the Foundation has evaluated events and transactions for potential recognition or disclosure through April 16, 2016, the date the financial statements were available to be issued.

NOTE 2 GIFTS AND GRANTS RECEIVABLE

Grants and gifts receivable at December 31 are as follows:

	 2015	 2014
Less than One Year	\$ 709,137	\$ 1,455,914
One to Five Years	 7,000	476,335
	716,137	 1,932,249
Less: Discount to Present Value	 (327)	(3,811)
Net Contributions Receivable	\$ 715,810	\$ 1,928,438

Amounts are presented in the statements of financial position as follows at December 31:

	 2015	 2014
Current	\$ 709,137	\$ 1,455,914
Long-Term	 6,673	 472,524
Total	\$ 715,810	\$ 1,928,438

Contributions expected to be received beyond one year are reflected at the present value of future cash flows at the date of donation using a discount rate of approximately 1% to 3%.

NOTE 3 EQUIPMENT

Equipment consists of the following at December 31:

	 2015	2014		
Equipment	\$ 10,725	\$	10,725	
Less: Accumulated Depreciation	 (8,044)		(4,469)	
Net Equipment	\$ 2,681	\$	6,256	

NOTE 4 FUNDS HELD WITH OTHERS

The investments of the Foundation are pooled with reserve investments at the American Academy of Neurology Institute and are recorded as funds held with others on the statement of financial position. The allocation of the percentage of underlying investments held by the Foundation consists of the following at December 31:

	2015			2014		
Reserves:			-		·	
Cash	\$	-		\$	352,358	
Corporate Bond Funds		1,817,804			1,531,559	
Equity Funds - Foreign		1,126,912			1,061,688	
Equity Funds - Mid-Cap		594,701			614,906	
Equity Funds - Large Blend		1,874,126			1,930,357	
Funds of Hedge Funds		463,233			436,102	
Total Investments	\$	5,876,776		\$	5,926,970	

Investments in the corporate bond funds, money market mutual funds, equity securities and equity funds are recorded at fair market value. The fund of hedge funds are recorded at the estimated fair value of the Foundation's share of the fund, calculated monthly by the custodian.

The Foundation's share of the underlying investment income, which includes earnings on the sweep and demand deposit accounts, consists of the following:

	2015		2014	
Interest and Dividends	\$	7,918	\$	8,961
Realized Gain on Investments		-		21,162
Unrealized Gain (Loss) on Investments		(50,194)		243,174
Total Investment Income (Loss)	\$	(42,276)	\$	273,297

The realized and unrealized gains and losses are included in investment income on the statements of activities. The Foundation maintains long-term reserve investments through long-term investment holdings. These investments are separated from the Foundation's general checking and savings accounts. All investment returns on long-term reserve investments are considered non-operating.

NOTE 5 FAIR VALUE MEASUREMENTS

The Foundation uses fair value measurements to record fair value adjustments to certain investments and to determine fair value disclosures. For additional information on how the Foundation measures fair value refer to Note 1 – Summary of Significant Accounting Policies.

NOTE 5 FAIR VALUE MEASUREMENTS (CONTINUED)

In determining the appropriate levels, the Foundation performs a detailed analysis of the assets and liabilities. At each reporting period, all assets and liabilities for which the fair value measurement is based on significant unobservable inputs are classified as Level 3.

The following table presents the balances of assets measured at fair value on a recurring basis by level within the hierarchy at December 31:

	2015							
	Lev	/el 1		Level 2	Lev	/el 3	Fa	ir Value
FUNDS HELD WITH OTHERS								
Investment Pool Held with Others	\$		\$	5,876,776	\$		\$ 5	5,876,776
Subtotal - Fair Value	\$	-	\$	5,876,776	\$	-	\$ 5	5,876,776
				20	14			
	Lev	/el 1		Level 2	Lev	/el 3	Fa	ir Value
FUNDS HELD WITH OTHERS		,						
Investment Pool Held with Others	\$		\$	5,926,970	\$		\$ 5	,926,970
Subtotal - Fair Value	\$		\$	5,926,970	\$	-	\$ 5	5,926,970

NOTE 6 GRANTS PAYABLE

Grants payable include the following at December 31:

	 2015	 2014
Current Portion of Grants Payable	\$ 1,457,303	\$ 1,650,000
Long-Term Portion of Grants Payable	 98,766	 757,323
Net Grants Payable	\$ 1,556,069	\$ 2,407,323
Amounts Due:		
One Year or Less	\$ 1,457,303	\$ 1,650,000
One to Five Years	100,000	764,999
Discount to Present Value	 (1,234)	 (7,676)
Net Grants Payable	\$ 1,556,069	\$ 2,407,323

Grants expected to be paid beyond one year are reflected at the present value of future cash flows using a discount rate of approximately 1% to 3%.

NOTE 7 NET ASSETS

<u>Unrestricted – Invested in Property and Equipment</u>

The designated funds are those that were used to purchase equipment.

Temporarily Restricted

Temporarily restricted net assets are available for the following purposes as of December 31:

	 2015		2014
Education, Research and Award Funds	\$ 3,683,796	\$	4,891,218
Operational Support	650,000		-
Annual Meeting and Other Programs	 186,133		186,333
Total	\$ 4,519,929	\$	5,077,551

Permanently Restricted

Permanently restricted net assets as of December 31 are restricted to investments in perpetuity, the income from which is expendable to support the following activities:

	2015			2014	
Research Endowments:					
Multiple Sclerosis Endowment	\$	334,305		\$	334,305
General Research Endowment		49,300			49,300
Alzheimer's		60,000			60,000
Epilepsy		121,970			128,970
Neuroinfectious Disease		32,855	_		33,305
		598,430	-		605,880
Awards		1,021,501			961,041
Total	\$	1,619,931		\$	1,566,921

NOTE 8 NET ASSETS RELEASED FROM RESTRICTIONS

Net assets were released from donor restrictions by the Foundation incurring expenses satisfying the restricted purposes or by occurrence of other events specified by donors as follows:

	 2015	 2014
Education, Research and Award Funds	\$ 1,984,123	\$ 1,174,085
Annual Meeting and Other Programs	 650,000	 1,388,587
Total	\$ 2,634,123	\$ 2,562,672

NOTE 9 ENDOWMENT

The Foundation's donor-restricted endowment consists of 22 individual funds established to support research and awards and, as required by generally accepted accounting principles, net assets associated with those endowment funds are classified and reported based on the existence or absence of donor-imposed restrictions.

The Board of Directors of the Foundation has determined the presentation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds absent explicit donor stipulations to the contrary. As a result of this interpretation, the Foundation classifies as permanently restricted net assets (a) the original value of gifts donated to the permanent endowment, (b) the original value of subsequent gifts to the permanent endowment, and (c) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund.

The remaining portion of the donor-restricted endowment fund that is not classified in permanently restricted net assets is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by the Foundation in a manner consistent with the standard of prudence.

The Foundation considers the following factors when making a determination to appropriate or accumulate donor-restricted funds:

- 1. The duration and preservation of the fund
- 2. The purposes of the Foundation and the donor-restricted endowment fund
- 3. General economic conditions
- 4. The possible effect of inflation and deflation
- 5. The expected total return from income and the appreciation of investments
- 6. Other resources of the Foundation
- 7. The investment policies of the Foundation

The Foundation has adopted investment and spending policies for endowment assets that attempt to provide a predictable stream of funding to programs supported by its endowment while seeking to maintain purchasing power of the endowment assets. Under this policy, as approved by the board of directors, the endowment assets are invested in a manner that is intended to produce a real return, net of inflation and investment management costs, of at least 8% over the long term.

Actual returns in any given year may vary from this amount. To satisfy its long-term rate-of-return objectives, the Foundation relies on a total return strategy in which investment returns are achieved through both capital appreciation (realized and unrealized) and current yield (interest and dividends). The Foundation targets a diversified asset allocation that places a greater emphasis on equity-based investments to achieve its long-term objective within prudent risk constraints.

NOTE 9 ENDOWMENT (CONTINUED)

The Foundation has a policy of appropriating for distribution each year 4.5% of its endowment fund's moving average fair value over the prior 12 months through the calendar year-end preceding the fiscal year in which the distribution is planned. In establishing this policy, the Foundation considered the long-term expected return on its endowment. Accordingly, over the long term, the Foundation expects the current spending policy to allow its endowment to grow at an average of the long-term rate of inflation.

This is consistent with the Foundation's objective to maintain the purchasing power of the endowment assets held in perpetuity for a specific term as well as to provide additional real growth through new gifts and investment return. From time to time, the fair value of assets associated with individual donor-restricted endowment funds may fall below the level that the donor or UPMIFA requires the Foundation to retain as a fund of perpetual duration. There are no such deficiencies as of December 31, 2015.

Changes in endowment net assets for the fiscal year ended December 31 consisted of the following:

	Temporarily	Permanently	
	Restricted	Restricted	Total
Balance, December 31, 2013	\$ 688,651	\$ 1,502,421	\$ 2,191,072
Investment Income	121,553	-	121,553
Contributions	-	64,500	64,500
Appropriation of Endowment Funds	(39,898)	<u> </u>	(39,898)
Balance, December 31, 2014	770,306	1,566,921	2,337,227
Investment Loss	(15,761)	-	(15,761)
Contributions	-	53,010	53,010
Appropriation of Endowment Funds	(41,141)	<u> </u>	(41,141)
Balance, December 31, 2015	\$ 713,404	\$ 1,619,931	\$ 2,333,335

NOTE 10 RELATED PARTY TRANSACTIONS

All employees are employed by the American Academy of Neurology (AAN) and then leased to the Foundation. The Foundation pays all direct costs relating to employees and pays a management fee for services which include: marketing, information systems, legal, management oversight, and program activities. Costs provided to the Foundation by AAN as of December 31, 2015 and 2014 was approximately \$95,957 and \$70,853, respectively. As of December 31, 2015 and 2014, the Foundation has a payable to AAN in the amount of \$82,537 and \$34,770, respectively, which is included in related party payable.

The Foundation also utilizes space and related costs from the American Academy of Neurology Institute (AANI). The total amount of space and related costs provided to the Foundation by AANI as of December 31, 2015 and 2014 was approximately \$86,100 and \$57,414, respectively. As of December 31, 2015 and 2014, the Foundation has a payable in the amount of \$2,330 and \$22,149, respectively.

The Foundation awarded grants to the AANI for the years ended December 31, 2015 and 2014 in the amounts of \$1,971,790 and \$181,000. The Foundation owed the Institute \$854,333 and \$-0-, respectively, for these grants for the years ended December 31, 2015 and 2014.

AANI contributed approximately \$2,031,595 and \$1,671,955 for Clinical Research Training Fellowships and operating support for the years ended December 31, 2015 and 2014, respectively, including the matching grant listed below. This represents approximately 61% and 40% of total operating and non-operating revenues for the years ended December 31, 2015 and 2014. The Foundation received a grant from AANI for \$3,000,000 and requires a Foundation 1:1 match. A total of \$731,595 and \$1,131,955 was matched in 2015 and 2014, respectively. As of December 31, 2015 and 2014, ABF had a receivable from AANI of \$418,767 and \$1,028,855, respectively, for these grants.

NOTE 11 SPLIT-INTEREST AGREEMENTS

The Foundation is a beneficiary to interest in two gift annuities held at a community foundation. The value of the gift annuities at December 31, 2015 and 2014 was \$62,950 and \$72,381, respectively.

The Foundation is also the beneficiary of other trusts and other assets in situations in which it has not been notified of the interest; the Foundation's interest may be conditional or revocable; or the value of our interest may not be readily ascertainable. In such circumstances, no contribution receivable has been recorded.



Audit Committee American Brain Foundation Minneapolis, Minnesota

We have audited the financial statements of the American Brain Foundation (the Foundation) for the year ended December 31, 2015, and have issued our report thereon dated April 16, 2016. We have previously communicated to you information about our responsibilities under auditing standards generally accepted in the United States of America, as well as certain information related to the planned scope and timing of our audit. Professional standards also require that we communicate to you the following information related to our audit.

Significant audit findings

Qualitative aspects of accounting practices

Accounting policies

Management is responsible for the selection and use of appropriate accounting policies. The significant accounting policies used by the American Brain Foundation are described in Note 1 to the financial statements. No new accounting policies were adopted and the application of existing policies was not changed during 2015.

We noted no transactions entered into by the entity during the year for which there is a lack of authoritative guidance or consensus. All significant transactions have been recognized in the financial statements in the proper period.

Accounting estimates

Accounting estimates are an integral part of the financial statements prepared by management and are based on management's knowledge and experience about past and current events and assumptions about future events. Certain accounting estimates are particularly sensitive because of their significance to the financial statements and because of the possibility that future events affecting them may differ significantly from those expected. The most sensitive estimates affecting the financial statements were management's estimate of:

- Present value of long-term pledges receivable
- Valuation of funds held with others and alternative investments
- Selection of depreciable lives
- Methods and allocation of functional expenses

We evaluated the key factors and assumptions used to develop the above estimates in determining that they are reasonable in relation to the financial statements taken as a whole.

Financial statement disclosures

Certain financial statement disclosures are particularly sensitive because of their significance to financial statement users. The financial statement disclosures are neutral, consistent, and clear.



Difficulties encountered in performing the audit

We encountered no difficulties in dealing with management in performing and completing our audit.

Uncorrected misstatements

Professional standards require us to accumulate all misstatements identified during the audit, other than those that are clearly trivial, and communicate them to the appropriate level of management. Management did not identify and we did not notify them of any uncorrected financial statement misstatements.

Corrected misstatements

Management did not identify and we did not notify them of any financial statement misstatements detected as a result of audit procedures.

Disagreements with management

For purposes of this letter, a disagreement with management is a financial accounting, reporting, or auditing matter, whether or not resolved to our satisfaction, that could be significant to the financial statements or the auditors' report. No such disagreements arose during our audit.

Management representations

We have requested certain representations from management that are included in the management representation letter dated April 16, 2016.

Management consultations with other independent accountants

In some cases, management may decide to consult with other accountants about auditing and accounting matters, similar to obtaining a "second opinion" on certain situations. If a consultation involves application of an accounting principle to the Foundation's financial statements or a determination of the type of auditors' opinion that may be expressed on those statements, our professional standards require the consulting accountant to check with us to determine that the consultant has all the relevant facts. To our knowledge, there were no such consultations with other accountants.

Significant issues discussed with management prior to engagement

We generally discuss a variety of matters, including the application of accounting principles and auditing standards, with management each year prior to engagement as the Foundation's auditors. However, these discussions occurred in the normal course of our professional relationship and our responses were not a condition to our engagement.

Other audit findings or issues

We have provided a separate letter to you dated April 16, 2016, communicating internal control related matters identified during the audit.

Our auditors' opinion, the audited financial statements, and the notes to financial statements should only be used in their entirety. Inclusion of the audited financial statements in a document you prepare, such as an annual report, should be done only with our prior approval and review of the document.

* * * * * *

Audit Committee American Brain Foundation Page 3

This information is intended solely for the use of the audit committee, board of directors, and management of the American Brain Foundation and is not intended to be and should not be used by anyone other than these specified parties.

CliftonLarsonAllen LLP

Minneapolis, Minnesota April 16, 2016







Audit Committee and Management American Brain Foundation Minneapolis, Minnesota

In planning and performing our audit of the financial statements of the American Brain Foundation (the Foundation) as of and for the year ended December 31, 2015, in accordance with auditing standards generally accepted in the United States of America, we considered the Foundation's internal control over financial reporting (internal control) as a basis for designing audit procedures that are appropriate in the circumstances for the purpose of expressing our opinion on the financial statements, but not for the purpose of expressing an opinion on the effectiveness of the Foundation's internal control. Accordingly, we do not express an opinion on the effectiveness of the Foundation's internal control.

A deficiency in internal control exists when the design or operation of a control does not allow management or employees, in the normal course of performing their assigned functions, to prevent, or detect and correct misstatements on a timely basis. A material weakness is a deficiency, or a combination of deficiencies, in internal control, such that there is a reasonable possibility that a material misstatement of the Foundation's financial statements will not be prevented, or detected and corrected, on a timely basis.

Our consideration of internal control was for the limited purpose described in the first paragraph and was not designed to identify all deficiencies in internal control that might be material weaknesses. In addition, because of inherent limitations in internal control, including the possibility of management override of controls, misstatements due to fraud or error may occur and not be detected by such controls. Given these limitations, during our audit we did not identify any deficiencies in internal control that we consider to be material weaknesses. However, material weaknesses may exist that have not been identified.

Other deficiencies in internal control and other matters

During our audit, we became aware of one deficiency in internal control that is opportunity for strengthening internal control and operating efficiency. While the nature and magnitude of the deficiencies in internal control is not considered important enough to merit the attention of the audit committee, it is considered of sufficient importance to merit management's attention and are included herein to provide a single, comprehensive communication for both those charged with governance and management.

Agreements with Related Parties

Currently, the Foundation has formal and informal agreements with both the American Academy of Neurology and the American Academy of Neurology Institute including management services, investment services, receipt of operational and matching grants and payment of grants related to the Clinical Research Training Fellowships. In certain cases, these agreements may be informal and we recommend going forward that relationships be formalized into written agreements and that the Foundation continue to evaluate whether additional separation from the Academy is appropriate in circumstances such as the audit committee structure.



Audit Committee and Management American Brain Foundation Page 2

We also recommend that the terms of grants either received from or paid to the Institute are clarified upon signing of the grant agreements. It was noted in 2015, the grant awarded from the American Academy of Neurology Institute for \$1.3 million in operating grant funds included few definitions around what was considered operations and could be expended towards this grant. This will reduce the need to interpret the terms of the agreement after the fact.

Accounting Standards Updates

<u>Upcoming Changes to Non-Profit Accounting Standards</u>

The Financial Accounting Standards Board (FASB) has taken on the task of improving financial statement reporting for non-profits at the recommendation of its Non-profit Advisory Committee. FASB is expected to issue an Accounting Standard Update in 2016. This update is expected to include changes to net asset classifications to move towards the statement of activities including a with donor restrictions versus a without donor restrictions format. In addition, the changes will require qualitative liquidity disclosures in the footnotes to the financial statements. FASB is also expected to issue a later update on whether they will require changes to the statement of cash flows, requirements for presentation of functional expenses and quantitative liquidity disclosures in the footnotes.

This communication is intended solely for the information and use of management, audit committee, and others within the Foundation, and is not intended to be, and should not be, used by anyone other than these specified

CliftonLarsonAllen LLP

Minneapolis, Minnesota April 16, 2016

Memorandum



To: **Joint Audit Committee**

From: Timothy Engel, CPA, CFO

> Susan Corcoran, Associate Director of Finance **Catherine Elliott, Finance Business Manager**

Date: April 16, 2016

Subject: Response to Internal Control Letter from CLA

Clifton Larson Allen (CLA) when assessing the risks of material misstatement in our entities' financial statements does a review of the internal controls annually. Through that review an area of our internal controls was identified to be potentially deficient to merit the attention of management but not to the nature or magnitude to merit the attention of the audit committee. However, management would like to address this issue with the audit committee in an effort to maintain transparency.

We have a board reviewed and approved internal control document that guides our processes to ensure system integrity and provides security to the organization and our staff. This internal control document is reviewed annually for any possible changes to strengthen internal controls. Any material change to the internal controls would be presented to the Audit committee for review and Board approval. AAN's Finance staff completed a full review of the controls in 2015/16. The review resulted in no material changes.

In the area outlined below CLA have identified an area of deficiency:

Agreements with Related Parties

As a multi-company entity there are transactions between the various companies. Some of the transactions accompany written agreements while other transactions are less formal. These include management services, investment services, receipt of operational and matching grants and payment of grants related to the Clinical Research Training Fellowships. During 2015 updated revised agreements were completed and signed with UCNS and CNF. We are in the process of using those agreements as a basis for updating the relations with and between ABF, AAN & AANI.

For clarity of AAN and its related entities, management is working diligently with AAN's legal staff to provide more clarity and formal agreements for these transactions going forward. Management agrees that this will reduce the need to interpret the terms of the agreement after the fact.

MEMORANDUM

To: ABF Board of Directors

From: ABF Governance Committee - Kevin Goodno, Chair; Terrence Cascino, MD; John

Mazziotta, MD; Catherine Rydell, CAE; Thomas Swift, MD

Date: March 16, 2016

Subject: Board Composition & Term Policy, and Revised Terms

1. **Issue**. Consider two motions from the Governance Committee to: 1) clarify the Board's interpretation of the ABF bylaws regarding Board composition and term limits; and 2) to amend the current term end dates for three Board members to adhere to the policy of aligning all terms of ABF directors and officers to a calendar year.

2. **Proposed motion(s)**.

- a. Motion to approve the *Board of Directors Composition & Term Policy*.
- b. Motion to amend the current terms of Drs. Shulman, Swift and Rosenfeld to end on December 31, 2017.
- 3. **Discussion**. The purpose of the proposed *Board of Directors Composition & Term Policy* is to clarify the intent of certain language in Article IV, Sections 1 and 3 of the bylaws concerning Board composition and term limits. Specifically, whether ex-officio, non-voting members of the Board should be included in the total count of Board members and in what scenarios does the exception for officers to serve beyond the stated term limit of three, two-year terms apply? The Governance Committee discussed these questions and offer their recommended answers in the enclosed Policy. The Committee also suggests that the individual designated by the Editor-in-Chief of *Neurology Now* be designated by the Editor-in-Chief and approved by the Board *annually*.

Over the past year the Board has made an effort to align all terms of ABF directors and officers to a calendar year. Drs. Shulman's, Swift's and Rosenfeld's current terms are set to expire on March 31, 2017. The Governance Committee recommends, and these Board members agree, to conclude their terms early on December 31, 2017, to align with the end of the calendar year.

- 4. **Fiscal impact**. Approval will not impact ABF's Financial Position.
- 5. **Legal/policy implications**. Counsel agrees with the Governance Committee's interpretation of the relevant sections of the ABF bylaws and assisted in drafting the proposed Policy. No bylaws amendments are required. Recommend approval.
- 6. Enclosures. Draft Board of Directors Composition & Term Policy
- 7. **Executive Director's recommendation**. I agree with these motions from the Governance Committee. The clarity on how to interpret ABF bylaws will help staff provide greater assistance in the board development process.

DRAFT

BOARD OF DIRECTORS COMPOSITION & TERM POLICY

American Brain Foundation

- **1. Purpose**. The purpose of this American Brain Foundation ("ABF") Board of Directors ("Board") Composition & Term Policy is to clarify the intent of certain language in the ABF bylaws concerning Board composition and term limits.
- **2. Board Composition**. Article IV, Section 1, of the ABF bylaws states that the Board shall be "comprised of at least five and no more than twenty-one members." Ex-officio, non-voting members of the Board, as described in the bylaws, shall not be included in the total count of Board members.
- **3. Term Limit**. Article IV, Section 3, of the bylaws states: "The Regular Directors shall be elected for a two-year term, which may be renewed twice by election. The term of each ex officio Director shall coincide with the term in which they hold their office. Officers of the Board of Directors may be elected to serve a term(s) beyond the six years served as Director." Article V, Section 8 of the bylaws states: "Officers shall serve for one two-year term, which may be renewed consecutively for one additional two-year term."

The exception for officers to serve beyond the stated limit of three, two-year terms, applies in three scenarios. First, an individual currently serving a term as officer when the total term limit would expire may serve the remainder of his or her then-current term as officer, before rotating off the Board. Second, an individual serving as Chair may serve as Past Chair for two consecutive, two-year terms immediately following his or her service as Chair, beyond the total term limit. Third, an individual serving as an officer, other than Chair or Past Chair, may serve as Chair for two consecutive, two-year terms, and as Past Chair for two consecutive, two-year terms immediately following his or her service as an officer of the Board, other than as Chair or Past Chair, in the office held when the board term limit restriction would normally have been applied.

4. *Neurology Now*® **Designee**. Article IV, Section 1, of the bylaws states: "Ex-officio Directors shall include the chair of the Foundation's Research Advisory Committee, the President of the AAN, and the Editor-in-Chief of Neurology Now or the Editor-in-Chief's designee if approved by affirmative vote of a majority of the Board, all of whom shall have full voting rights."

The individual designated by the Editor-in-Chief, and approved by the Board, shall be designated by the Editor-in-Chief and approved by the Board annually.

Policy History: Approved by ABF Board of Directors on [DATE].