



**Board of Directors Meeting**  
**Monday, April 24, 2017, 7:30-9:00 a.m. EDT**  
**Boston Convention Center - Room 102 B**  
 7:30 a.m. EDT/6:30 a.m. CDT/5:30 a.m. MDT/4:30 a.m. PDT  
**Webinar link: <https://cc.readytalk.com/r/e4zr3tz767tw&eom>**  
**U.S. & Canada: 866.740.1260**  
**Access Code: 7312994**

**Committee Members**

Kevin Goodno, Chair; Robert Griggs, MD, Vice Chair; Terrence Cascino, MD; Dan Gasby; Ralph Józefowicz, MD; John Mazziotta, MD, PhD; Bruce Miller, MD; Jeffrey Rosenfeld, MD, PhD; Catherine Rydell, CAE; Susan Schneider Williams; Martin Shenkman, CPA, MBA, PFS, AEP, JD; Lisa Shulman, MD; Joseph Sirven, MD; Gordon Smith, MD; Ben Utecht; Richard Essey; Ralph Sacco, MD, MS

**Staff**

Jane Ransom, Shelly Rucks, Suzi Sherman, Tim Engel, Catherine Elliot, Natalie Baumgartner

	<b>AGENDA ITEM</b>	<b>PRESENTED BY</b>
7:30am ET	<b>American Brain Foundation Board of Directors Meeting Call to Order</b>	Kevin Goodno, JD, Board Chair
	<b>Board Chair Report</b> <ul style="list-style-type: none"> <li>• Introductions</li> <li>• Review meeting agenda</li> <li>• Approve minutes of February 23, 2017 meeting*</li> <li>• Call for Disclosure of Conflict of Interest related to any agenda items</li> </ul>	Kevin Goodno
7:50	<b>Financial Report</b>	Ralph Jozefowicz, MD & Tim Engel, CFO
8:00	<b>Executive Director Report</b>	Jane Ransom
8:15	<b>Fund Development Report</b>	Shelly Rucks
8:25	<b>Commitment to Cures Committee Report</b>	Joe Sirven, MD
8:30	<b>Research Advisory Committee Report</b>	Robert Griggs, MD
8:40	<b>Strategic Planning Committee Report</b>	Lisa Shulman, MD
8:50	<b>Governance Committee Report</b>	Kevin Goodno
8:55	<b>Executive Session</b>	Kevin Goodno
9:00	<b>Adjourn</b>	Kevin Goodno

**ABF Board Scorecard – 2017**

Strategic Goal #1	Research Clearinghouse: Construct a virtual platform to match the best science with the largest pool of committed donors to advance a continuum of research.				
Outcomes		Actual	Threshold	Target	Max.
1. Number of peer-reviewed proposals posted on crowdfunding platform		2	10	25	50
2. Number of crowdfunding donors		NA	Benchmarking during 2017		
3. Amount of money granted to defeat brain disease		NA	Benchmarking during 2017		
Strategic Goal #2	Public Engagement: Build the ABF brand around our unique niche.				
Outcomes			Threshold	Target	Max.
1. Stakeholder awareness <sup>i</sup>			See endnote		
2. Increased site traffic <sup>ii</sup>			Benchmarking during 2017		
a. Users		a. 13,721	50,000	75,000	100,000
b. Pageviews		b. 29,185			
a. Increased site conversion (from visitor to donor)		NA	Benchmarking during 2017		
Strategic Goal #3	Philanthropy: Develop full-fledged public support and deepen giving from AAN members				
Outcomes			Threshold	Target	Max.
1. Total funds raised					
a. Restricted		a. \$201,492	--	\$ 480,000	\$ 937,000
b. Unrestricted / Operating		b. \$ 71,192	<u>\$1,350,000</u>	<u>\$1,350,000</u>	<u>\$1,350,000</u>
TOTAL		<u>\$272,684</u>	<u>\$1,350,000</u>	<u>\$1,830,000</u>	<u>\$2,287,000</u>
2. Major donor pipeline value					
a. Number of major donors solicited		a. 5	a. 20	a. 30	a. 40
b. Gift amount asked		b. \$100,000	b. \$250,000	b. \$500,000	b. \$1,000,000
3. Number of new donors		229	900	990	1188
4. Number of donors					
a. AAN members		a. 528	a. 1,830	a. 2,013	a. 2,416
b. Public		b. 186	b. 450	b. 495	b. 594

**Commented [JR1]:** When the McKnight Brain Research Foundation and Mary Goff Trust gifts are booked, these numbers will change as follows:

a. Restricted	\$1,961,492
b. Unrestricted/Operating	<u>236,192</u>
<b>TOTAL:</b>	<b>\$2,197,684</b>

Strategic Goal #4	A Thriving Partnership: Align the goals and leadership of the AAN and ABF.			
Outcomes		Threshold	Target	Max.
1. Number of AAN members who are aware of the ABF <sup>iii</sup>		See endnote – measured annually December 2017		
2. Number of AAN members donating to the ABF	528	See 4a above.		
3. Number of AAN staff donating to the ABF	28%	50%	70%	90%
4. New money raised for AANI research agenda- i.e., projected # of CRTS contracts signed by the end of the year.	3	10 <sup>iv</sup>	12	14

**Commented [JR2]:** 3 contracts signed inclusive of 5 CRTS's.

#### <sup>i</sup> Brain Disease - Public Understanding

Baseline: 59.64%

Benchmark: 64.9% ± 4.23%

#### ABF - Public Awareness

Baseline: 3.27%

Benchmark: 6.33% ± 2.15%

#### <sup>ii</sup> Based upon current ABF website. New website to be launched in Q2.

#### <sup>iii</sup> ABF - AAN Awareness

Baseline: 77%

Benchmark: 80.29% ± 2.62%

<sup>iv</sup> The threshold number was suggested to us by the Academy when the ABF took over a portion of CRTS fundraising.



ABF Board of Directors Meeting, February 23, 2017

By Telephone Conference Call & Webinar

## MINUTES

**Attendance:** Ben Utecht; Cathy Rydell; Joe Sirven, MD; Kevin Goodno; Lisa Shulman, MD; Martin Shenkman; Ralph Jozefowicz, MD; Robert Griggs, MD; Susan Williams, Terrence Cascino, MD

**Excused:** Gordon Smith, MD; Jeffrey Rosenfeld, MD, Dan Gasby

**Staff:** Jane Ransom, Shelly Rucks, Suzi Sherman, Marlys Weyandt

### Board Chair Report

Board Chair Kevin Goodno called the meeting to order at 9:05 a.m. CST. He reviewed the meeting agenda. He asked for and was given approval of the Dec. 15, 2016 Board of Directors meeting. He reviewed the meeting asked for and was given no disclosures of conflicts of interest related to any agenda items on the meeting agenda.

Goodno welcomed Dan Gasby to the Board of Directors. He also discussed the need to set a Board fundraising goal for 2016. Last year the ABF received \$30,480 in annual gifts from Board members<sup>1</sup>. Goodno asked that the Board consider a 2017 that exceeds this significantly, especially since we will take the approach that every gift (including honoraria or event tickets purchased) will count toward the Board goal.

### Financial Report

Board Treasurer Ralph Jozefowicz provided the financial update. Unaudited financial statements show that the Foundation ended the year with a net operating increase of \$707,000. Program expenses trended down because of the initial investments in marketing, website, and staffing that the Foundation is making in order to pursue its new strategic plan. The return on invested assets matched the 8.8% policy target.

### Executive Director Report

Executive Director Jane Ransom discussed how the Foundation is staffing up to support the strategic plan implementation. Recruitment is underway for the following positions: Executive Coordinator, Special Events Coordinator, Marketing Specialist, Development Associate. Progress made against each of the Foundation's four strategic goals includes:

Research: The new crowdfunding platform is set to launch at the Annual meeting. Suzi Sherman is the Foundation's new Program Officer, Research & Digital Grants, and will be heading up the crowdfunding initiative. New CRTS partnerships have been established with the International Headache Society, the Muscle Study Group, and the Mary E. Groff Charitable Trust.

Public Engagement: In January, the ABF conducted a p.r. campaign on Dan Gasby joining our Board of Directors, collecting 103,160 headline impressions over 28 days. Weber Shandwick delivered a 2017

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<sup>1</sup> This number does not include restricted gifts from Board members.

marketing plan and is working on a signature video about the ABF. The ABF is recruiting for a part-time digital marketing consultant.

Philanthropy: Total 2016 fundraising revenue was \$1.6 million--\$798,000 toward operations and \$802,000 in restricted grants. The Foundation is working on two special events: (1) Commitment to Cures with Board leadership from Dr. Sirven; and (2) possible Super Bowl event with Board leadership from Ben Utecht. The Foundation is in discussion with the McKnight Brain Research Foundation, the Conrad Hilton Foundation, and the William Randolph Hearst Foundation about possible grants. Gordon Smith and Dan Gasby have helped us make these connections.

#### Thriving Partnership with AAN

The ABF and AAN signed a Management Services Agreement effective 1/1/17 which makes the ABF a co-employer of its staff with the Academy and forecasts \$294,000 in fees to AAN for financial, operational, and IT services, as well as for sublease of facility space and lease of equipment.

### **Governance Committee**

Kevin Goodno, Governance Committee Chair, reported that the committee is pursuing three goals for 2017: (1) renewing and/or filling officer positions; (2) strategy for replacing neurologists as they term-out from the board; and (3) developing and cultivating a pool of additional public members.

### **Research Advisory Committee Report**

Committee Chair Berch Griggs reported on two upcoming beta tests of the new crowdfunding site, and on continuing work to populate review panels with the help of the Academy's Science Committee. He also spoke about the several venues in which the Foundation will be publicizing the new crowdfunding initiative at the AAN Annual Meeting.

### **Strategic Planning Committee Report**

Committee Chair Lisa Shulman reported that the first 2017 meeting of the Strategic Planning Committee would occur in April. At that time the committee will review the Board scorecard for the first quarter of the year.

### **Commitment to Cures Committee Report**

Committee Chair Joe Sirven discussed the effort to involve research universities and institutions in this year's Commitment to Cures event as sponsors. So far, the Harvard Departments of Neurology have pledged a \$16,500 sponsorship. Several requests are outstanding. Board members are asked to encourage their institutions to buy tables and to purchase their own tickets if they have not already done so.

### **Compensation Committee & Executive Committee Report – *In executive session***

At 9:45 a.m. CST Kevin Goodno called for an executive session so that the Compensation & Executive Committees provided their recommendations regarding 2017 executive director salary and staff incentive for 2016 performance.



Date: April 11, 2017  
 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: March 2017 YTD Financial Results

The enclosed materials present the financial performance of the American Brain Foundation (ABF) for three months ending March 31, 2017.

**Statement of Operations**

ABF realized \$76K in revenue as of March 2017. This is 2% of budgeted revenue. Operating expenses exceeded revenue for the period by \$151K. Long-term investment earnings (non-operating revenue) is \$152K as of March 2017.

	2017 YTD			2017	
	Actual	Budget	Variance	Budget	2016
<b>Operating Revenue</b>	\$ 76	\$ 537	\$ (461)	\$ 4,071	\$ 2,949
Expenditures	(439)	(559)	120	(4,067)	(2,757)
<b>Net Increase</b>					
<b>(decrease) from operations</b>	(363)	(22)	(341)	4	192
Investment earnings	152		152		315
<b>Net increase(decrease)</b>	<u>\$ (211)</u>	<u>\$ (22)</u>	<u>\$ (189)</u>	<u>\$ 4</u>	<u>\$ 507</u>

### **Revenue**

AANI's general operating support grant of \$950K was awarded (formally approved) in late March. The actual grant agreement was signed after March 31 and therefore not reflected in first quarter revenue.

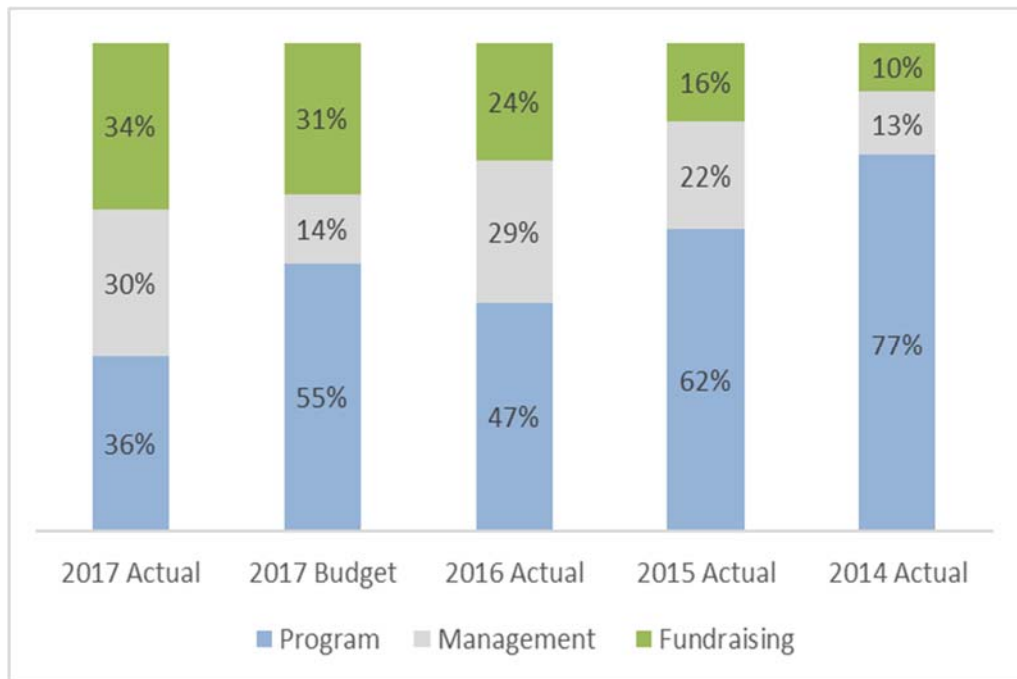
### **Operating Expenses**

Expenses are \$120K under budget in the first quarter and the primary reasons for the net positive variance are as follows.

1. Salaries and benefits under by \$74K, due to unfilled and open positions.
2. General Office under by \$37K, timing of printing and postage
3. Software over by (\$22K), related to additional Raisers Edge module for crowd funding
4. Professional services over by (\$18K), website redesign costs expensed pending detail review of capital versus period expenses.
5. Meeting and travel under by \$20K, less staff travel for donor development/fundraising
6. Grants/Awards under by \$37.5K, planned crowd funding grants delayed.
7. Management Fee over by (\$8K), additional cost from staff expansion not anticipated when fee was determined by AAN.

### **Functional Expense**

The following schedule displays the breakout of ABF's functional expenses. The budget for 2017 projects program expenses at 55% and management at 14%. Allocation of expenses for 2017 will be reviewed throughout the year to insure proper allocation.



### **Fund Raising Efficiency Ratio**

Fund Raising Efficiency Ratio is 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 has declined from 2014 to 2016. The 2017 ratio is expected to improve as the year transpires and new grant revenue is realized.

	<u>2014</u>	<u>2015</u>	<u>2016</u>	<u>2017 YTD</u>	<u>2017 Budget</u>
Grant Revenue	\$ 3,189,559	\$ 2,819,224	\$ 2,963,961	\$ 104,832	\$ 4,058,668
Fundraising Expense	\$ 423,256	\$ 515,659	\$ 648,986	\$ 147,995	\$ 1,256,592
Efficiency	\$ 0.13	\$ 0.18	\$ 0.22	\$ 1.41	\$ 0.31

### **Statement of Financial Position**

The Foundation ended the March 2017 with total assets of \$10M. Cash and investments total \$9.8M, 97% of total assets. Liabilities are \$976K and which includes grants payable of \$562K.

(in thousands)	<b>March 31,</b>		
	<b>2017</b>	<b>2016</b>	<b>Difference</b>
Total Assets	\$ 10,092	\$ 10,508	\$ (416)
Total Liabilities	976	1,148	(172)
Unrestricted Net Assets	2,639	2,393	246
Temporarily Restricted Net Assets	4,757	5,347	(590)
Permanently Restricted Net Assets	1,720	1,620	100
Total Liabilities and Net Assets	\$ 10,092	\$ 10,508	\$ (416)

Provided in the following pages are these financial statements:

1. Statement of Financial Position
2. Operating Statement
3. Schedule of Temporarily and Permanent(Endowment) Assets



**AMERICAN BRAIN FOUNDATION**  
**STATEMENT OF FINANCIAL POSITION**  
**AS OF MARCH 31,**

	<u>2017</u>	<u>2016</u>	<u>Net Change</u>
<b>ASSETS</b>			
<b>CURRENT ASSETS</b>			
Cash and Cash Equivalents	\$ 2,997,177	\$ 3,238,342	\$ (241,165)
Grants and Gifts Receivable, Net	135,009	1,284,302	(1,149,293)
Accounts Receivable		397	(397)
Other Assets	92,757	58,352	34,405
Total Current Assets	<u>3,224,943</u>	<u>4,581,393</u>	<u>(1,356,450)</u>
<b>FIXED ASSETS</b>			
Office Equipment	10,725	10,725	
Less Accumulated Depreciation	<u>(10,725)</u>	<u>(8,640)</u>	<u>(2,085)</u>
Net Fixed Assets	<u>-</u>	<u>2,085</u>	<u>(2,085)</u>
<b>LONG TERM ASSETS</b>			
Investments	6,758,278	5,914,412	843,866
Grants and Gifts Receivable, Net	108,605	10,423	98,182
Total Long Term Assets	<u>6,866,883</u>	<u>5,924,835</u>	<u>942,048</u>
Total Assets	<u>\$ 10,091,826</u>	<u>\$ 10,508,313</u>	<u>\$ (416,487)</u>
<b>LIABILITIES AND NET ASSETS</b>			
<b>CURRENT LIABILITIES</b>			
Accounts Payable	\$ 217,854	\$ 110,069	\$ 107,785
Grants Payable	405,000	939,333	(534,333)
Deferred Grants	196,667		196,667
Total Current Liabilities	<u>819,521</u>	<u>1,049,402</u>	<u>(229,881)</u>
<b>LONG TERM LIABILITIES</b>			
Grants Payable	<u>156,726</u>	<u>98,766</u>	<u>57,960</u>
<b>NET ASSETS</b>			
Unrestricted	2,638,825	2,392,809	246,016
Temporarily Restricted	4,756,583	5,346,905	(590,322)
Permanently Restricted	1,720,171	1,620,431	99,740
Total Net Assets	<u>9,115,579</u>	<u>9,360,145</u>	<u>(244,566)</u>
Total Liabilities and Net Assets	<u>\$ 10,091,826</u>	<u>\$ 10,508,313</u>	<u>\$ (416,487)</u>

**American Brain Foundation**  
**Income Statement**  
**For the Three Months Ending March 31, 2017**

	2017 Actuals	YTD 2017 Budget	Variance Favorable (Unfavorable)	2017 Forecast	2017 Budget	Variance Favorable (Unfavorable)	Final 2016 Actuals
<b>REVENUE</b>							
Grants & Gifts	\$ 71,647	\$ 83,751	\$ (12,104)	\$ 1,050,000	\$ 1,050,000	\$	\$ 857,990
Released from Restrictions		450,000	(450,000)	3,008,668	3,008,668		2,076,650
Interest Income	3,369	2,874	495	11,500	11,500		11,545
Other Revenue	752		752	500	500		2,450
Total Support and Revenue	75,768	536,625	(460,857)	4,070,668	4,070,668		2,948,635
<b>EXPENSES</b>							
Salaries & Benefits	135,194	209,463	74,269	813,776	813,776		773,766
General Office	24,368	61,549	37,181	169,265	169,265		58,745
Software	46,153	23,751	(22,402)	95,000	95,000		111,163
Professional	145,564	127,525	(18,039)	460,442	460,442		502,099
Meeting/Travel Related	13,679	33,890	20,211	310,530	310,530		159,283
Grants/Awards		37,500	37,500	1,718,668	1,718,668		962,628
Contingency				200,000	200,000		
Depreciation/Miscellaneous	332		(332)	37,503	37,503		4,186
Management Fee	73,524	65,424	(8,100)	261,732	261,732		184,651
Total Expenses	438,814	559,102	120,288	4,066,916	4,066,916		2,756,521
Long Term Investments	151,807		151,807				315,297
<b>UNRESTRICTED NET ASSETS</b>	<b>\$ (211,239)</b>	<b>\$ (22,477)</b>	<b>\$ (188,762)</b>	<b>\$ 3,752</b>	<b>\$ 3,752</b>	<b>\$ -</b>	<b>\$ 507,411</b>
<b>TEMPORARILY RESTRICTED NET ASSETS</b>							
Grants & Gifts	\$ 32,595						\$ 2,006,321
Investment Income	71,430						202,959
Net Assets Released from Restrictions							(2,076,650)
Beginning Balance	4,652,559						4,519,929
Ending Temporarily Restricted Net Assets	\$ 4,756,584						\$ 4,652,559
<b>PERMANENTLY RESTRICTED NET ASSETS</b>							
Grants & Gifts	\$ 590						\$ 99,650
Beginning Balance	1,719,581						1,619,931
Ending Permanently Restricted Net Assets	\$ 1,720,171						\$ 1,719,581

**American Brain Foundation**  
**Schedule of Temporarily and Permanent(Endowment) Assets**

	<u>Temporary</u>	<u>Permanent</u>	<u>Total</u>
<b>Awards</b>			
AAN Resident Fund	\$ 15,005	\$ -	\$ 15,005
Awards other	1,000	-	1,000
Jon Stolk Award in Movement Disorders for Young Investigators	43,295	-	43,295
Potamkin Prize for Research in Pick's, Alzheimer's, and Related Diseases	100,000	-	100,000
Sports Neurology	5,000	-	5,000
	<b>164,300</b>	<b>-</b>	<b>164,300</b>
<b>Crowd Funding</b>	<b>2,000</b>	<b>-</b>	<b>2,000</b>
<b>CRTS Funding</b>			
ALS	1,110	-	1,110
Alzheimers/Dementia	2,160	-	2,160
Epilepsy	925	-	925
General	2,565,792	-	2,565,792
Headache	55,505	-	55,505
Lewy Body Dementia	1,620	-	1,620
MS	220	-	220
Parkinson/Movement	1,245	-	1,245
Stroke	195	-	195
	<b>2,628,772</b>	<b>-</b>	<b>2,628,772</b>
<b>Donor Advised Funds</b>			
Martin Shenkman and Patti S. Klein, MD	<b>205,000</b>	<b>-</b>	<b>205,000</b>
<b>Endowment Awards</b>			
Debasish and Chinu Mridha Spirit of Neurology Award	7,801	100,010	107,811
Alliance	3,314	26,021	29,335
Neuro Oncology Investigator Award	11,613	96,950	108,563
Neuro-Oncology Scientific Award	4,050	53,750	57,800
Calvin L. Calhoun, Sr., MD, Diversity Research	15,341	49,310	64,651
George C. Cotzias Lecture	51,800	45,375	97,175
Dreifuss-Penry Epilepsy Award	72,857	71,557	144,414
Norman Geschwind Prize in Behavioral Neurology	42,618	46,351	88,969
Association of Indian Neurologists in America (AINA) Lifetime Achievement Award	22,247	50,000	72,247
Wayne A Hening Sleep Medicine Investigator Award	32,885	51,380	84,265
Kenneth M. Viste, Jr., MD Patient Advocate of the Year Award	39,266	73,128	112,394
Harold Wolff-John Graham Award: An Award for Headache/Facial Pain Research	45,432	50,000	95,432
Mitchell Max Neuropathic Pain	28,907	67,890	96,797
Movement Disorders Research Award	37,048	49,929	86,977
Neuro-Infectious Disease Research	7,929	33,055	40,984
Michael S. Pessin Stroke Leadership Prize	46,944	56,957	103,901
Bruce S. Schoenberg International Award in Neuroepidemiology	59,389	83,027	142,416
Sidney Carter Award in Child Neurology	74,669	101,206	175,875
Sleep Science Award	37,152	50,000	87,152
	<b>641,262</b>	<b>1,155,896</b>	<b>1,797,158</b>
<b>Endowment Research</b>			
Baumel-Eisner Alzheimers/Dementia Research Fund	28,380	60,000	88,380
General Research	28,444	49,300	77,744
Multiple Sclerosis Research and Patient Care Training Fellowship	176,490	334,505	510,995
Susan S. Spencer Epilepsy Research	25,303	120,470	145,773
	<b>258,617</b>	<b>564,275</b>	<b>822,892</b>
<b>Operational</b>	<b>670,500</b>	<b>-</b>	<b>670,500</b>
<b>Public Education</b>			
Pain	17,711	-	17,711
Parkinsons	27,383	-	27,383
Stroke	95,492	-	95,492
Young Adult Stroke	45,547	-	45,547
	<b>186,133</b>	<b>-</b>	<b>186,133</b>
	<b>\$ 4,756,584</b>	<b>\$ 1,720,171</b>	<b>\$ 6,476,755</b>



**TO: ABF Board of Directors**  
**FROM: Jane Ransom**  
**DATE: April 24, 2017**  
**SUBJECT: Executive Director's Report**

At the upcoming Board meeting, I hope we will begin discussion about some key strategic challenges facing the American Brain Foundation, and then devote more time to them in Minneapolis on June 18<sup>th</sup>. We are looking at our next set of organizational challenges in the context of successes like the launch of our crowdfunding initiative and the \$1.65 million McKnight Foundation for Brain Research Grant. Only one quarter into the implementation of our new strategic plan, the Foundation is gaining traction.

Some of the strategic issue Kevin and I have been discussing include:

1. Sustainable Growth. The Foundation has had some recent fundraising successes of dollars restricted to research; but increasing revenue for operations is more challenging. What are some ideas from other nonprofits about sustainable growth to learn from? What factors do we need to consider in developing our own sustainable growth strategy?
2. AAN Member Support. As staff members hold discussions with potential donors, we are learning that AAN member giving is very important to their sense of confidence in the Foundation. Deepening AAN members' support is therefore crucial in leveraging contributions from the public. How do we develop a game plan to deepen member giving and who needs to be involved?
3. Governance & Strategic Plan Execution. With the execution of our strategic plan underway as of January 2017, we are in new territory. Are the Foundation's committees focused on the right issues? Is the Board getting the right information and discussing the right topics? Are Board and staff roles clear?

Here are general updates for organized by our key strategic goals:

**Strategic Goal #1: Research Clearinghouse. *Construct a virtual platform to match the best science with the largest pool of committed donors to advance a continuum of research.***

The ABF's new website with crowdfunding, which emerged originally through the work of the Strategic Planning Committee last year, will launch on schedule for the AAN Annual Meeting. Two beta tests were successfully conducted in March. There will be at least six projects on the site when we go live.

The feedback on our site from our Board and the Research Advisory Committee, as well as from reviewers and researchers who participated in beta tests, has been very helpful. Several fixes were implemented immediately after staff received the feedback. For example, the titles of all projects have been rewritten for the public audience. Another concern that came up more than once was related to the lock-step beta testing schedule which was difficult for researchers to work within. Please be assured that going forward there will be no timing requirements for researchers to submit their applications.

Some of the input we determined to require feedback from the Research Advisory Committee. In your materials for this meeting you will find a report called "Website and Crowdfunding Site Feedback" listing all feedback in broad categories, showing which feedback has been addressed by staff and which we are bringing to the Research Advisory Committee meeting scheduled for 4/25 in Boston.

**Strategic Goal #2: Public Engagement. *Build the ABF brand around our unique niche.***

The American Brain Foundation will be visible in the local press during the Annual Meeting through media outreach underway to publicize the Public Leadership in Neurology Award, going to B. Smith and Dan Gasby, and our Commitment to Cures dinner. On Sunday April 16<sup>th</sup>, the Foundation also sponsored a broadcast of the PBS documentary on Alzheimer's—Every Minute Counts—on WGBH TV, the PBS local affiliate in Boston.

As we launch the new crowdfunding platform, the Foundation's most immediately important audience is neurologists. Research Advisory Committee members, including Dr. Griggs, Dr. Sacco, and Dr. Scharf, will be speaking about and/or demonstrating the platform at the Frontiers Plenary, on the Experiential Learning Stage, and in a meeting with NINDS. Hands-on demonstrations of the site will be the focal point of the ABF booth. Announcements of the crowdfunding site will also show up at Commitment to Cures and in AAN publications distributed at the meeting. I believe that the honoring of Dr. Francis Kittredge, and of B. Smith and Dan Gasby will provide the touch that connects our audience emotionally with our mission.

Staff welcomes Board members' suggestions on post-annual meeting opportunities for making neurologists aware of the site.

At the end of March, the Foundation hired Deb Erickson, a digital marketing consultant, to work with us on marketing the new crowdfunding site. Post-annual meeting, her focus will be on pushing out the first six projects on the crowdfunding site to audiences sympathetic to the disease areas of these researchers. Later in the year, when we have more projects on the site, and are sure it is working well, there will be a media campaign about the entire site.

**Strategic Goal #3: Philanthropy: *Develop full-fledged public support and deepen giving from AAN members.***

As you know, we have had some great fundraising success recently, especially for Clinical Research Training Scholarships, specifically:

- McKnight Brain Research Foundation grant of \$1.65 million over 5 years for 10 CRTS's in memory loss and cognitive aging
- Mary E. Groff Trust grant of \$260,000 over 6 years toward CRTS's in Lewy Body Dementia

A \$100,000 request for CRTS funds is under consideration by the William Randolph Hearst Foundation currently. My sincere thanks to Gordon Smith, Susan Williams, and Dan Gasby for their leadership in securing these grants and opportunities.

Now that the Foundation has the right fundraising staff in place, focused on the right activities, we are positioned to collaborate with individual members of the Board to pursue larger gifts like these, from both individuals and institutions. New Foundation staff who joined us at the end of March include: Nicole Hecksel, Special Events Coordinator; Megan Tschumper, Development Associate; and Natalie Baumgartner, Executive Coordinator.

I am excited about our Commitment to Cures event this Wednesday night. For the first time ever, the Foundation is walking into this event with money in hand--\$65,000 raised from elite institutions in neurology, with the American Academy of Neurology as our platinum level donor.

I want to thank Joe Sirven for his leadership as committee chair for the event. He had a small, but disciplined, committee whose members included Dr. David Dodick and Dr. Francis Kittredge. Thanks, too, to the ABF Board members who are table hosts and ticket holders, and who also got their institutions to buy table sponsorships.

Also, let me underscore the significance of these donations from the neurology community. As we increasingly place ourselves in discussions with current and potential major donors, we are frequently being asked how much neurologists are giving to the ABF. As our strategic plan states, the Foundation needs to "deepen giving from AAN members." We on the staff understand that we can't pursue old strategies where only a

few people have felt they were being asked to give. We need a broader, systematic strategy that puts the Foundation in front of many segments of AAN members, from international members, to ELF members, to section members, to CRTS recipients, and more. I look forward to digging into this more with the neurologists on the ABF Board.

Another bit of fundraising news related to the 25<sup>th</sup> anniversary, is that we will be conducting a campaign for gifts in honor of this anniversary. We have three initial pledges of \$25,000 each, including one from our Board Chair, Kevin Goodno.

In addition, at Commitment to Cures, Dr. Griggs will make a special tribute to Dr. Lewis “Bud” Rowland, the visionary who started the Foundation 25 years ago. It is our intention to name a leadership circle, to include donors making annual gifts of \$2,500 or more, in honor of Dr. Rowland. We will announce this at Commitment to Cures and launch it during our year-end campaign later this year.

In the face of some great success in raising restricted funds for research, the Foundation does need to take a close look at our less successful performance in raising operating support. This is a strategic issue I would like the Board to work on at the June meeting.

For 2017, the staff leadership has been laying the groundwork for a special event focused on the 2018 Super Bowl in Minneapolis, as a strong opportunity for raising unrestricted dollars to support the mission of the Foundation.

Our new Director of Development Shelly Rucks, will report more about this at the April 24<sup>th</sup> Board meeting, including planning meetings with Ben Utecht, Dan Gasby, the NFL Players Association, and the Academy. We also hope to do a comedy night special event in October.

**Strategic Goal #4: A Thriving Partnership: *Align the goals and leadership of the AAN and the ABF.***

The ABF and AAN continue to collaborate closely on the Clinical Research Training Scholarship fundraising from non-pharma partners. I view the work of deepening giving from AAN members, discussed above, as an important next step which will require close collaboration with the Academy, because of its obvious access to, connections with, and nuanced understanding of their membership.

## **Website and Crowdfunding Site Feedback**

**Feedback Participants:** The following Board, staff, and RAC members provided feedback

- |                             |   |
|-----------------------------|---|
| 1. Susan Schneider Williams | 6. Lisa Shulman                         |
| 2. Ralph Jozefowicz         | 7. Anonymous                            |
| 3. Lisa DeAngelis           | 8. Jeffrey Rosenfeld                    |
| 4. Anonymous                | 9. Gordon Smith                         |
| 5. Tim Engel                | 10. David Knopman (Expert Review Panel) |

### **1. Comments on look and feel of website:**

- The site looks great.
- Suggest giving more thought to what fits on the screen for different screens of computers, laptops, smartphones etc. so that the visitor sees the priority info easily. Similarly, suggest reviewing font sizes e.g. font was often small.
- Great job overall!

#### **➤ Actions Addressing Feedback**

- ✓ Website development team and graphics consultant have tested the site to assure that it is user-friendly on all types of devices.

### **2. Comments on the site from point of view of donors searching for and funding projects of interest to them:**

- As noted, the titles of the projects need to be understood by the general public.
- The biggest issue is the title of the projects and their "overly scientific" choice of words, even in their description. Everything needs to be at the level of a lay person - which is usually defined as about 8th grade reading level.
- Project names- move away from scientific description, needs to be written so individual donor, non-doctor can easily understand what the research project is going to accomplish. Consider displaying a patient picture for each project. Need to touch the donor's feelings regarding the impact of the neurologic disorders.
- Agree with comments by attendees on the call.
- It is hard to answer this question as we did not experience the search function. The projects need titles and descriptions that lay people will understand. Some of the disease category groupings could be improved (e.g. ALS and Neuromuscular. Why is ALS singled out?

#### **➤ Actions Addressing Feedback**

- ✓ ABF has asked medical writer to rewrite the research project names to be understandable by the general public.



### **3. Comments on the site from perspective of researchers applying to have their projects crowdfunded:**

- A minor issue - I don't understand the requirement for IRB approval or exemption for laboratory-based work. The IRB doesn't "exempt" lab work and you would be asking institutions to "vet" something they don't do. This is a problem.
- The focus needs to be on the donor not the researcher.
- Also hard to answer this as one would need to submit a proposal to provide an authentic evaluation.
- As discussed on the call, a good idea to have some milestone thresholds for the funding; amount to start the project, amount to obtain preliminary results, amount to completion. Better than all or none funding on the status bar. Also, duration and timing of the posting may need more discussion. Certain times of the year will be more popular. Competing projects posted simultaneously may also be a strategic disincentive

#### **➤ Actions Addressing Feedback**

- ✓ Ask Research Advisory Committee to revisit the necessity of IRB approval or exemption for laboratory based work
- ✓ Ask Research Advisory Committee to decide whether milestone thresholds for funding should be created, and, if so, what they will be; i.e. amount to start the project, amount to obtain preliminary results, amount to completion.

### **4. Comments on informational pages on our researchers and brain diseases:**

- Again, needs to be simpler. Ultimately video is better than still photographs.
- Need to see more.
- Impossible to answer without reading them. Worry the brain disease information pages will be difficult to keep up to date. Is it wise to include these?
- These have to be worded very carefully so as not to imply a bias toward a particular area of research that may (or may not) be represented in the available projects.

#### **➤ Actions Addressing Feedback**

- ✓ ABF will ask the Research Advisory Committee or its chair's designee, to annually review and update these pages.

### **5. Comments on video on homepage:**

- On the one hand I liked the movement and "artsy" nature of it (it looked like Picasso drawings), but on the other hand I'm not certain it will "speak" to the public - no color, not real people, etc. I think people like stories of individuals that can feel relevant to their situation. However, maybe your marketing research shows I'm wrong.
- Need to view it again

- I liked the video in both the themes and the tone- not sure how the link will appear on the homepage.
- *Actions Addressing Feedback*
  - ✓ Keeping video as in. ABF will review video in 1-2 years and determine if a new video is needed.

## 6. Other suggestions/comments:

- Great job! Love the pride in partnership between ABF and AAN throughout.
- It isn't clear to me what happens to money donated to a project, that doesn't meet goal and the project gets taken down. I think that's critical for a donor to understand. Maybe also we should "highlight" what we think are priorities. This is thorny but could be helpful when there are a lot of projects up - or will the landing page keep circulating different people every 10-20 sec for example?
- Home page picture - is that the final. I would want to see a patient. Use layman's language in project descriptions. Donations- reverse order start with \$10,000 and then decrease. Requests always start high, if you can't do \$10,000 then what about \$5,000. Is there any space dedicated to recognizing major donors or for advertising?
- If an IRB approval has already been obtained there ought to be a way to submit that at the time a researcher first submits their project. This would save a step and fast-track a posting. Having project samples posted on the opening pages might be an unfair advantage relative to the projects that must be searched for in the body of the website.
- *Actions Addressing Feedback*
  - ✓ The FAQ section on the website answers questions above posed by RAC and Board.
  - ✓ ABF will evaluate the donation levels and their order.
  - ✓ Ask the RAC if some projects should be highlighted on the crowdfunding site when the list of projects grows to be more than 12.

## 7. Crowdfunding LOI/Full Application:

- In the future you consider requesting a compiled PDF. Cutting and pasting into the form results in lost formatting and is just clunky. Some will want to submit an image or graph, probably worth having rules about this. To ask that people type in references one by one is an extreme example, I've never seen this done. We all use reference management software and if you really want individual documents ask for a PDF upload.
- The website does not provide a COI form. I completed an extremely extensive online form with the LOI I believe (I was struck it was more probing than others). I tried to find a form and gave up and instead uploaded an NIH other support document. So it would go in.
- You need to provide instructions for some of the sections. I completed the abstract and narrative as I would an NIH grant, but not all will know (and perhaps I did this incorrectly).
- You asked for a CV with the LOI, but usually one submits an NIH formatted biosketch. I would suggest doing this for uniformity of formatting and ease of review.

- You don't say what you are looking for in the institutional support letter. I took my best shot.
- It's not clear how much detail you want on the budget, and there was no clear instruction regarding a justification. I put both in one document.
- There is no place to indicate co-PI or co-investigators. I'm doing this with one of our junior faculty (which is a strength in my opinion) but there was no place to put this information.

➤ Actions Addressing Feedback

- ✓ ABF will add field for them to upload images/graphs
- ✓ ABF will add field for them to upload references instead of listing them individually
- ✓ ABF will remove the COI upload request in the full application as this is requested in the LOI
- ✓ ABF will update CV area to ask for a CV or NIH formatted biosketch
- ✓ ABF will add more details about what information should be included in the institutional support letter, and will add an FAQ on this as well
- ✓ ABF will update budget language on full application to request a detailed budget and budget justification
- ✓ ABF will add fields for 2 co-investigators information
- ✓ Ask the RAC to provide more detailed instructions for the specific sections, i.e. abstract, narrative, specific aims, etc. Should provide better idea of the type of information applicant should include in the section

**Reviewer Feedback:**

- I think that a reviewer should have access to what other sources of funding the applicants have. I suppose you can be liberal on overlap, but it still seems like something I would like to know and that the AAN should know before signing off on posting the application.

➤ Actions Addressing Feedback

- ✓ ABF will ask more clearly for applicants to supply their other sources of funding.



**Research Advisory Committee  
Meeting of March 20, 2017  
10:00-11:00 am CT  
By conference call**

Attendance: Robert Griggs, MD; Ralph Sacco, MD; Eugene Scharf, MD; Lisa De Angelis, MD; Ira Shoulson, MD; Jane Ransom, Suzi Sherman

Excused: Ray Roos, MD; Shafali Jeste, MD

The meeting was called to order at 10:05 a.m. by Dr. Griggs. The committee approved minutes of the meeting of Feb. 21, 2017.

ABF Major Giving

Jane Ransom provided a report on recent major gifts including:

- \$200,000 donor advised fund for MS research
- \$5,000 donor advised fund for pediatric neurology
- \$100,000 fund for humanitarian award to a neurologist working with the under-served

Update on Crowdfunding Beta Testing

The committee discussed the first beta test. The mechanics of the system worked well, but committee members would like to know why certain reviewers voted no on some LOIs.

The second beta test is scheduled to begin on March 22. Committee members expressed concern that the time between the approval of the LOI and the deadline for the full Application was too short. Staff assured that this timeline only applied to the beta test and would not be applicable once the site goes live.

The committee would like projects to have funding benchmarks showing what could be accomplished on the project with minimum, mid, and maximum funding levels.

Promotion of the Crowdfunding Site to Neurologists

The new initiative will be highlighted in several on-site publications and speeches at the AAN meeting. Committee members suggested also publicizing it at the Brain Health Fair, stressing that word must go out to the public to attract donors.

Upcoming Live Tour of the ABF Crowdfunding Platform

Jane Ransom said that a live tour of the beta site via webinar for members of the ABF Board and Research Advisory Committee would be announced soon. Members will be invited to provide feedback.

#### Increase Clinical Research Training Scholarship Award

The committee discussed a letter from Dr. Videnovic to Dr. Griggs informing the American Brain Foundation that the AAN has decided to increase CRTS awards from \$130,000 to \$150,000. The amount has not changed in many years and is becoming uncompetitive. There was agreement that the change is appropriate and overdue. But this change was not budgeted by the American Brain Foundation. Further discussion will be needed about how to persuade current partners to take on most, if not all, of the increase.

#### Adjournment

Dr. Griggs adjourned the meeting at 11:00 a.m. CDT. The next meeting will take place in-person at the Boston Convention Center, room 103, on Tuesday, April 25 at 7:45 a.m.

**American Brain Foundation  
Strategic Planning Committee Meeting  
April 17, 2017**

**9:45 a.m. EST/8:45 a.m. CST/7:45 a.m. MST/6:45 a.m. PST  
By Telephone Conference Call  
Call-in number: 866-740-1260  
Access code: 9286317**

**In attendance: Lisa Shulman, MD, FAAN; Jeffrey Rosenfeld, MD, PhD, FAAN; Martin Shenkman, CPA, MBA, PFS, AEP, JD; A. Gordon Smith, MD, FAAN; Ben Utecht**

**Staff: Jane Ransom and Natalie Baumgartner**

**Excused: Kevin Goodno**

- Welcome and introduction of attendees: Dr. Shulman welcomed everyone and discussed the agenda and objectives for the meeting.
- Approval of Meeting Minutes from 10/10/2016: Dr. Shulman requested committee approval for the previous Strategic Planning Committee's meeting. Approval was unanimous.
- Summarized Shared Documents:
  - ABF Scorecard: Ms. Ransom walked the board through the Strategic Goals individually.
    - Strategic Goal #1: Ms. Ransom explained that an additional 4-5 projects would be placed on the crowdfunding site within the week.
    - Feedback: The committee raised concerns around where and how projects are being sourced for the crowdsourcing website. They stressed the importance of diverse project focus. They also discussed the importance of establishing relationships with new donors in proportion to the increase in crowdfunding projects.
    - Strategic Goal #2: Ms. Ransom discussed website users, pageviews, and conversions.
    - Strategic Goal #3: Ms. Ransom started with highlighting the importance of refocusing ABF's fundraising efforts on including operational costs rather than solely on restricted funding. Ms. Ransom outlined new initiatives that target unrestricted giving.
    - Feedback: ABF needs to address marketing and fundraising campaigns that target unrestricted giving. The Committee will keep an eye on these numbers.
    - Strategic Goal #4: Ms. Ransom talked about new and major donors.
    - Feedback: The Committee was concerned that ABF was missing marketing opportunities in general, and also at the Annual Meeting. In

response, Ms. Ransom outlined the Annual Meeting events, explaining their importance and support of fundraising and donor campaign goals.

- Additional Board Feedback: Dr. Shulman asked the committee if they had any additional feedback on the current scorecard. The committee discussed:
  - Giving: Need to deepen giving amongst AAN members
  - Emotional Appeals: Use real people and their stories to build support for ABF.
  - Timeline: Establish Committee and Board timeline, which strategically discusses Annual Meeting events with time for implementation.
- Adjourn: 9:42 am CT

DRAFT