



AMERICAN BRAIN FOUNDATION
 Research Advisory Committee
 September 27, 2019
 1:00 p.m. CST
 Conference Call

Committee Members	Robert C. Griggs, MD, FAAN, Chair; Raymond Roos, MD, FAAN, Vice Chair; Carsten Bonnemann, MD; Jose E. Cavazos, MD, PhD, FAAN; Merit Cudkowicz, MD, MSC; James C. Grotta, MD, FAAN; Mark F. Mehler, MD, FAAN; John Morris, MD, FAAN; Ralph Sacco, MD, MS, FAAN, FAHA; Eugene L. Scharf, MD; Ira Shoulson, MD, FAAN; Phyllis C. Zee, MD, PhD
Guest	
Staff	Jane Ransom, ED; Lisa Deutsch

	AGENDA ITEM <i>*Indicates Board Action Needed</i>	PRESENTED BY
1:00	Call to Order	Robert Griggs, MD, Chair
1:05	Approval of the August 2, 2019 Minutes	Robert Griggs, MD
1:10	Autism Summer Stipends	Jane Ransom on behalf of Shafali Jeste, MD
1:20	2020 Commitment to Cures Breakthrough Award	Robert Griggs, MD
1:30	Crowdfunding 2.0	Eugene Scharf, MD
1:40	AAN/ABF Partnership, 2020-2024	Ralph Sacco, MD
2:00	Adjourn	

Other Materials:

- Minutes of August 2, 2019 (pg. 2)
- Autism scholarship proposal (p. 5)
- Crowdfunding memo (p. 9)
- ABF Business Plan, executive summary (pg. 11)



**American Brain Foundation
Research Advisory Committee Meeting
August 2, 2019**

**9:00 a.m. ET/ 8:00 a.m. CT/ 7:00 a.m. MT/ 6:00 a.m. PT
Conference Call**

Meeting Minutes

In attendance: Robert Griggs, MD, Chair; Raymond Roos, MD, Vice Chair; Jose Cavazos, MD; Mark Mehler, MD; John Morris, MD; Christy Phelps, Deputy ED AAN; Ralph Sacco, MD; Eugene Scharf, MD; Ira Shoulson, MD

Staff: Jane Ransom, Natalie Baumgartner

Excused: Carsten Bonnemann, MD; Merit Cudkowicz, MD; James Grotta, MD; Sue Rodmyre, Director ED AAN; Natalia Rost, MD; Catherine Rydell, CAE; Phyllis Zee, MD

The meeting was called to order by Dr. Griggs at 8:03 am CT. The meeting minutes of March 22, 2019 were approved unanimously.

1. Chair's Report:

a. **Research Breakfast:** The Foundation's 2019 CRTS/CSDA recipients were honored at the Research Program breakfast, hosted by AAN. The recipients present on their research and are asked questions by the audience. Dr. Griggs recommended that the breakfast could be longer. The Foundation will take this feedback to the AAN

b. **Commitment to Cures:** The Foundation's premier event was sold out with 425 attendees (only 250 attended in 2018). Gross revenue was \$453K, of which \$149K is restricted.

The Foundation is determining how the \$60K in autism research will be used. At the suggestion of Dr. Shafali Jeste, the Foundation will use the sum for summer stipends to work in autism labs. The Committee agreed that more awards in child neurology should be considered. The Committee will revisit this topic during the next meeting.

c. **Cure One, Cure Many Award:** In 2019, Dr. Mendell received the Cure One, Cure Many award at Commitment to Cures 2019 for his success with spinal muscular atrophy treatments and its impacts on other neuromuscular diseases. The Committee discussed the importance of having awards for public advocates and celebrating the achievements of neurologists and neuroscientists at Commitment to Cures. The Committee should consider breakthroughs that could be celebrated in 2020.

The Committee expressed concerns around the term “cure”, which might burden the Foundation with finding practitioners who have found a “cure”. This might not always be possible. They suggested a “breakthroughs” award. The Committee will revisit this topic during the next meeting.

The Committee discussed the diagnostic blood test for Alzheimer’s a potential awards opportunity for a breakthroughs award. Diagnostic achievements result in better treatments and should be considered eligible for a breakthroughs award.

2. **LBD Award:** The Michael J. Fox Foundation has given the Foundation a \$1.5M matching grant, and the Mary E. Groff Charitable Trust has given \$250K. The Foundation needs to raise a total of \$5.5M. The Foundation expects that public outreach activities will continue to build interest. For example, the Foundation has consulted on the Robin Williams documentary (Dr. Melissa Armstrong reviewed the movie on the Foundation’s behalf), and the documentary will feature a link to our website for donations. Ms. Ransom will send the Committee the LBD packet after the call.
3. **CRTS/CSDA program bias:** The Foundation is currently receiving applications for the 2020 CRTS/CSDAs, but in the past, recipients have been heavily concentrated along the coasts. Only two 2019 recipients were from the Midwest.

The AAN has addressed concerns about geographical bias in the past. Considerations for a handicap system have been discussed and disregarded in preference for giving the award to the best and brightest. However, Ms. Phelps, along with the Selection Committee, will consider new ways to engage non-coastal institutions to increase applications. If Midwest institutions have perceived a bias toward the North East, more could be done to engage these regions. There are a substantial number of applicants, which means a large group of investigators go unfunded each year. Ms. Phelps will check that broad representation is being considered in the selection process to ensure that applicants are not being discouraged from applying.

Ms. Phelps recommended Drs. Morris, Cavazos, and George discuss broad geographical representation in the selection process of CRTS/CSDAs for the 2020 cycle. Drs. Morris and Cavazos will report back to the Committee.

4. **Targeting Research Awards to Regions or Institutions:** The Foundation would like to consider applying for grants that would limit awards to a specific state or institution. The Foundation does not want to leave money on the table.

The Committee suggested that limiting awards to applicants from specific regions or institutions opens the Foundation to bias. The Committee discussed the difficulties in managing this award but t a regional award would be an acceptable alternative. Dr. Mehler suggested that the Foundation set up a consortium to fund institutions instead of directing an award to an institution or state. Ms. Ransom and Dr. Mehler will discuss this further.

5. **ABF Status Update:** Ms. Johnson resigned from the Foundation, and Ms. Baumgartner will fill her role in the interim. The Foundation will have a multi-channel crowdfunding

campaign to promote the 2019 CRTS in Tourette Syndrome. The Foundation has also raised \$200K from memorials in honor of Ted Burns and Cheryl Jay. The AAN and Foundation will meet to discuss their ongoing relationship at the AAN's September Board meeting.

The 2020 CRTS/CSDA application window is open, and the Committee will receive emails to promote these awards to their networks.

Adjourn 9:00. a.m. (Central).

DRAFT

American Brain Foundation Medical Student Autism Research Scholarship

ABOUT:

Designed for medical students with limited research experience relevant to clinical or neuroscience fields who are interested in a career in research in neuroscience with a focus in autism. This award is intended to be a springboard into the AAN's Research Program or other programs focused on early-career investigators through access to autism labs and neuroscience professionals. The research project is to be conducted at a US or Canadian lab, hospital, or clinic that specializes in autism and jointly designed by the resident and mentoring physician. The application process will be competitive and is intended to prepare the applicants for early-career grant applications and introduce applicants to autism as a subspecialty. In its inaugural year, there will be three awards offered at \$3,000 each.

BENEFITS:

Offers medical students a stipend to conduct a project related to autism in a clinical setting where there are ongoing programs of research, service, or training, or in a private practice setting.

ELIGIBILITY:

- Only applicants from schools with established Student Interest Group in Neurology (SIGN) chapters
- The program is not intended for medical students with an extensive background in research; therefore, these students should not apply. Extensive research refers to multiple publications and multiple years of research experience at a graduate school level.
- Project must not be an already completed project.

APPLICATION REQUIREMENTS:

Project Requirements:

- The project is to be undertaken in either an institutional, clinical, or laboratory setting that has ongoing programs of research, service, or training, or in a private practice setting
- The research being conducted MUST be neuroscience-based and have a focus in autism
- Recommendation letter and committed guidance from a mentor. A mentor CV is encouraged.
- Mentor must confirm compliance with local IRB requirements regarding resident's role in human subjects' research.

- The intention of the scholarship is to provide research funding support to students with limited research experience relevant to clinical and neuroscience research in autism; projects already completed will not be considered
- There must be a registered SIGN chapter at the student applicant's institution; however, there does not need to be a SIGN chapter at the site where the research will be done, although this is encouraged
- **Applicants must be current AAN members and SIGN chapter members at their institution at the time of application submission**
- Applicants must not have received the scholarship previously
- If the project preceptor and SIGN faculty advisor are the same person, two separate letters should be provided. The first letter should focus on how the student is involved with the SIGN chapter and the second should focus on the role he/she will play in the research project.
- The student should write the proposal, clearly delineating his/her role in the project. More details on this may be found below.
- Applications in which the role of the student is not clearly defined will not be considered.
- Multiple sources of funding are allowed; however, applicants must provide information regarding what funds have been applied for and/or received
- Application and reward process will occur in 2019 with completion of the research within one year.
- **The awardee will be required to present results at a future AAN Annual Meeting**

Note: Project proposal, budget proposal, CV and bibliography should be Arial, 11 point font or greater, and have at least 0.5 inch margins.

- 1-2 page project proposal
- 1 page budget proposal
- 1-2 page Curriculum Vitae
- 1 page bibliography
- 2 letters of recommendation: one from the project preceptor/mentor and one from the SIGN faculty advisor or from neurology or neuroscience faculty.

Student will include in the Project Proposal:

- Student name and contact information including phone and email address
- Faculty mentor name and contact information including phone and email address
- Title of project
- Specific aims of the project (List as specific aims, the specific objectives for the research proposed. If the research is part of a larger project, briefly describe the goals of the overall project and how the proposed research is related. The student should concisely state his/her specific role in the project, and the outcomes expected for each Specific Aim).
- Background and Significance (Explain the importance to biomedicine of the problem motivating this research, here and elsewhere; indicate citations by number in parentheses, corresponding to their order of appearance in the Bibliography).
- Experimental Design (Keyed to the Specific Aims, describe the experiments/studies intended and the experimental and analytical methods that will be used)

- Bibliography (authors, titles of article, journal, book, volume, pages, year; list citations numerically in the order in which they appear in the application).
- Time-Line (Present a 10-week time-line identifying anticipated key points in the progress of the research).
- Mentorship (Describe arrangements made with the mentor and lab associates for structured guidance).
- Formal budget for research. Students are encouraged to think practically and realistically about the cost of their proposal. Note: The scholarship amount is \$3,000 regardless of how much your formal budget is. The formal budget is an exercise to give you experience in writing a formal budget. For guidance, some basic budget categories could include:

Personnel Materials and Supplies: This should include animal costs (cost for animal and cost for housing), costs to pay human subjects (if applicable), and/or costs for supplies (including molecular biology kits, pipette tips, assay supplies, etc.). Include any new equipment that needs to be purchased for the project as well as costs associated with presenting data at meetings (includes cost of registration + travel expenses).

AWARDEE EXPECTATIONS:

Resident will return the following upon being notified of award:

- A Statement of Intent form, signed by resident and mentoring physician, supplied with award notification letter.
- W-9 or W-8BEN Tax form for Canadian citizens

Resident will submit the following within 3 months after project completion:

- A one-page abstract of the project
- Evaluation forms completed by the resident and mentoring physician, supplied with the winner notification letter
- Students are encouraged to submit completed abstracts to the AAN

Award, Presentation and Publication

- Any publications resulting from the funded project must acknowledge the support of the American Brain Foundation and American Academy of Neurology. Upon publication, copies should be forwarded to the AAN.
- Recipient will provide the AAN with name, year of Resident Research Scholarship award received, hospital or clinic, publications, presentations and/or awards related to the research project, presentations relating to the research project.
- Scholarship winners agree to submit their abstract to the AAN for the Annual Meeting Scientific Program. The AAN's acceptance of the abstract is not guaranteed.

APPLICATION TIMELINE:

This scholarship is offered once during the year.

Application period: December 1, 2018 - February 28, 2019 (11:59 pm Central Daylight Time)

For more information, contact grants@americanbrainfoundation.org



TO: Jane Ransom, Executive Director
FROM: Marie Tuhy, Director of Mission Advancement
DATE: August 19, 2019
SUBJECT: Refreshed Crowdfunding Strategies

American Brain Foundation's crowdfunding site is being reinvigorated to align with ABF's new brand rollout and recent website refresh. As part of the crowdfunding refresh we have reviewed crowdfunding trend data and revisited our crowdfunding strategies to assess if they align with best practices.

After reviewing the crowdfunding analysis, we are proposing pivoting our project messaging from funding entire projects (less likely to be successful) to elements of a project with smaller price tags (statistically more successful in crowdfunding platforms).

Crowdfunding Benchmarks ¹

Kickstarter – 36.84% meet goal
GoFundMe – 10% meet goal
Indiegogo – 9.8% meet goal

What Does the Average Successful Crowdfunding Campaign Look Like?²

- **The average successful crowdfunding campaign is around \$7,000. (ABF average = \$48,962)**
- On average, it takes 11 days to prepare a successful crowdfunding campaign.
- The average campaign lasts around 9 weeks.
- The average crowdfunding campaign donation is \$88.
- Campaigns that can gain 30% of their goal within the first week are more likely to succeed.
- 42% of funds are raised in the first and last three days of a crowdfunding campaign.

Shorter campaigns tend to do better, with campaign lengths of 20 to 40 days seeming to be the sweet spot.

¹ <https://grasshopper.com/resources/tools/crowdfunding-platforms-kickstarter-gofundme-indiegogo/>

² <https://www.startups.com/library/expert-advice/key-crowdfunding-statistics>



Success breeds success: Once a campaign has reached 40%, visitors stay on the campaign page for 31% longer and are 22% more likely to donate.

Different markets bring in different levels of crowdfunding. Here's the percentage of the total crowdfunding top five markets, listed from most to least.

Business and Entrepreneurship: 41.4%

Social Causes: 18.9%

Films and Performing Arts: 12.2%

Real Estate: 6.2%

Music and Recording Arts: 4.5%

Next steps:

- Research Advisory Committee approves ABF crowdfunding messaging change for smaller crowdfunding grants in order to increase project success rates which will ultimately build trust and applications for projects to be featured.



American Brain Foundation

Life Without Brain Disease

Business Plan

August 30, 2019

Contact Information

Jane Ransom, Executive Director
jransom@americanbrainfoundation.org
612-928-6317
www.americanbrainfoundation.org
201 Chicago Avenue
Minneapolis, MN 55415

I. Executive Summary

Vision

To have the American Brain Foundation recognized as the largest national charitable organization for the brain—one which serves as a clearinghouse for brain research across a broad spectrum based on the philosophy that brain diseases are interconnected, so that curing one means curing many. ABF's credibility will be strengthened by its close affiliation with the American Academy of Neurology.

Opportunity

Science has beaten back many challenging diseases. Polio can be prevented. HIV/AIDS can be managed. Rates of childhood leukemia have declined dramatically. Diseased hearts, lungs, and livers can be transplanted.

Mass public support for scientific research has been key to each of these advances.

The American Academy of Neurology (AAN) and the American Brain Foundation (ABF) share a remarkable opportunity to mobilize and increase mass public support for research on neurologic disease.

This opportunity is not accidental. It is the result of the new partnership between the AAN and the ABF that began in 2015 when the AAN Board decided to develop the ABF as the nation's charity for the brain. The idea was to create an organization which would shift fundraising and marketing activities away from total reliance on neurologists and instead focus them towards the public. The ABF Board would be increasingly led by influential members of the public. It would also recruit a new ABF staff to achieve these objectives, rather than using internal AAN resources as had been done before. Recognizing that, as a start-up, the ABF would have no funds to hire and pay staff, the AAN agreed, as a first step, to fund the organization's operating expenses on a declining basis over a five year period which is now coming to an end.

These investments and activities have put the ABF on a path to growth which parallels the trajectories of organizations that have famously mobilized financial support for medical research from the general public, including the March of Dimes, the American Heart Association, and the American Cancer Society. A key indicator is the AAN's +344 percent return on its investment in the ABF in 2018, which was driven by the expansion of ABF grants for the AAN's research program, made possible by growth in donations to the ABF from public individuals and institutions.

During ABF's early years, it became obvious that many funders were only interested in funding research, not an organization's operating expenses. We have instituted a requirement that 10% of any donations received must be for unrestricted needs. But some entities have refused to agree to this. ABF's fundraising, marketing, program, and other operational expenses are projected to be an average of \$2.8M per year for the next five

years.¹ For the ABF to cover these expenses, we would need to raise a minimum of \$28M annually which is unrealistic for a start-up organization. As a result, despite the ABF raising more funds than were expected of it (exceeding its cumulative fundraising benchmark of \$5.7M for 2015-2018 by \$4.2M), it still finds itself in need of continuing support from the AAN to help fund its fundraising, marketing, program, and operating expenses. That is the purpose of this proposal.

Partnership Proposal

Through continuing our close relationship—with the AAN as research partner, and the ABF as philanthropic partner—we will move the project of building a philanthropic movement supporting research on brain disease to a higher level, both qualitatively and quantitatively.

This business plan focuses on the next five years, in which there is opportunity, through fundraising and public awareness, to raise \$39M, to include \$26M for grants and awards for research, over 90 percent of which will be directed to the AAN's research program, with the remainder going to other research institutions. In addition, we also plan to raise \$14M over the period which will be used to support our operating expenses.

But to raise these funds, we need additional financial support from the AAN to pay toward our staff and other operating expenses. As such, we propose revising our financial relationship between the AAN and the ABF, for the period 2020-2024, in this way:

- AAN provides the ABF operating support averaging \$1.2M per year (to add to the \$1.5M per year we plan to raise ourselves toward these costs)
- ABF provides the AAN reimbursement for management fees for shared services of an average of \$360,000 per year
- ABF provides the AAN an average of \$3.8M per year in grants.

Net outflow from the AAN to the ABF for the 5 years: \$6M - \$1.8M = \$4.2M

Net inflow from the ABF to the AAN for the 5 years: \$19M

ROI = \$19M/\$4.2M = 450%. Said another way, for every \$1 AAN gives to the ABF, it gets \$4.50 back.

By the end of five years, the ABF will be fundraising at a higher level, which will result in more unrestricted funds being made available through the 10% fee, so that is why we are reducing AAN's contributions to ABF operations over the five years.

But besides providing a strong financial ROI, there are important non-financial returns on investment created by our partnership:

- Better treatments, prevention and cures for patients in the hands of neurologists

¹ These expenses include the management fee paid to AAN by ABF, forecast to average \$360K annually over the next five years.

- More public influencers and leaders actively advocating for research dollars from both government and the public
- Career growth of clinicians and scientists (many of whom are AAN members) in the field of neuroscience due to funding from the ABF
- Greater public awareness of the value of neurologists and the neurology profession
- Growing public understanding of the need to contribute to research

The partnership between the AAN and the ABF will be based upon an extension of the *Principles of Joint Collaboration* which have governed our relationship since 2016. To reap the most rewards from adhering to these *Principles*, both organizations must strive for strong communication and transparency, and for a creative, collaborative relationship at the Board and staff levels.

Focus

From 2020-2024, the ABF will focus on growing its base of public donors while, at the same time, increasing grants for research on neurologic diseases. Our fundraising goal is \$39M. Fundraising will be based upon strategic analysis and segmentation of our database to target major donors with capacity to make 5-, 6-, and 7-figures gifts, as well annual fund donors at several levels below \$2,500 per year giving.

Fundraising tactics at the major giving level will include in-person, individual solicitations; development of our leadership giving program, the Rowland Circle; customized proposal-writing for individuals and family foundations; and social events organized around the ABF's program and mission. The ABF's major giving work will be focusing in regions/cities with the greatest concentrations of high wealth individuals, including Houston, Bay Area, Los Angeles, greater NYC, and Chicago.

Annual Fund tactics will include multi-channel fundraising appeals (including direct mail, social media, advertising and website appeals); outreach at AAN and other conferences; and the development of a sustaining donor program in which donors contribute a set amount to the ABF monthly.

Through its grant writing program, the ABF will target corporations, foundations, and nonprofit brain disease organizations to fund both research grants and ABF operations.

The ABF will continue to raise money through its signature event, Commitment to Cures, and other events in the regions where we focus major donor fundraising.

The marketing plan will support the fundraising goals, through tactics that attract strangers and evolve them into visitors, supporters, and then donors. Focus will be on improving social media engagement and followers to drive donations, and on building a structure to constantly monitor and change marketing tactics. Tactics will rely upon

multiple channels: Web; paid and organic social media; public relations and earned media; in-kind print media; media buying; and video production.

Data analytics show that the ABF has 13,942 constituents in our data base with high social influence (SI) scores who have the potential to reach 341,336 people. Special attention will be given to engage with these constituents in order to expand our reach.

The grants focus of the ABF will include \$18M in grants to the AAN’s research program to build the next generation of researchers through Clinical Research Training Scholarships and Clinician Scientist Development Awards, supporting an average of 14 of these awards per year.

The ABF will appropriately scale projects for our crowdfunding platform, helping researchers to pitch their programs to the public, and granting \$334K to their projects.

We will continue a special initiative, already underway, to establish a \$5M award to find a biomarker for Lewy Body Dementia and provide the first three-years of funding to the AAN’s research program to administer the program.

The ABF will also grant \$900K to underwrite AAN scientific awards (from existing endowments administered by ABF); to fund the Potamkin and Essey awards; and for our own awards to public champions for research.

Expected Results

The overall goal of our fundraising plan is to raise \$33M, not including the operational support from the AAN, by 2024, with \$26M raised for research and \$8M raised without restrictions to support core operations. The fundraising strategy includes Major Giving, Annual Fund, Special Events, and Grants from Institutions (foundations, corporations, and nonprofit partners). Annual fundraising forecasts:

<u>2020</u>	<u>2021</u>	<u>2022</u>	<u>2023</u>	<u>2024</u>
\$4.7M	\$7M ²	\$5M	\$7.3M	\$9.5M

² Significant fundraising bump in fundraising for 2021 includes \$3.2M raised in special one time LBD biomarker project fundraising campaign.

Expenses

Our average annual staff budget will be \$1.25M.

Our average annual marketing, communication and similar expenses total \$1.56M

And the ABF foresees extending our Management Services Agreement with the AAN, paying a total of \$360,000 per year to receive financial, operations, facilities, and information services. ABF will continue to contract with outside counsel for legal services.

Average Total Expenses per year: \$2.8M

Performance Measures

We envision a joint ABF/AAN scorecard with which to measure the success of our partnership. Further collaboration will be needed to develop this joint scorecard; however, the ABF expects to be measured by metrics such as:

- Fundraising
 - Expansion of number and value of gifts raised for research
 - Increase in the number of unrestricted grants and gifts raised
 - Increase in number of donors
- Grantmaking
 - Expansion of value of grants made for research
 - Increase in the number of restricted and unrestricted grants
- Marketing
 - Increase in awareness of the ABF and its mission
 - Increase in unique web visitors
 - Expansion of social media audience and engagement
 - Increased contributions from new donors
- Operations
 - Improving Functional Expense Ratio
 - Increasing financial ROI for AAN
 - Improving Fundraising Efficiency Ratio
 - Decreasing cost of raising \$1
 - Increasing revenue raised per FTE

An ABF scorecard for these metrics is in the Appendix, Attachment A.

The ABF will continue to provide detailed and consistent financial reporting, as it has since 2015, through:

- Quarterly and annual reports to the AAN

- Financial reports to both the President and the CEO of the AAN provided regularly to them due to their *ex officio* positions on the ABF Board of Directors
- Participation on the AAN/ABF Joint Audit Committee and the joint audit which provides full transparency to AAN regarding:
 - Finances and operations
 - Functional expense ratios
 - Adherence to generally accepted nonprofit standards

The ABF appreciates the AAN's suggestions of metrics for measuring its role in our partnership, such as:

- Measures of success of AAN research program
- Increasing number of AAN members who contribute to the ABF and increasing value of their contribution
- Increasing public awareness of brain disease
- Measures of the management services it provides to the ABF
- Measures of the quality of collaboration between AAN and ABF