



**American Brain Foundation
Board of Directors Meeting
November 15, 2020
10:00am CST
Video Conference Call**

In attendance: David Dodick, MD, Chair; Susan Schneider Williams, Vice Chair; James Essey, Treasurer; Jacqueline French, MD; Dan Gasby; Kevin Goodno; Robert Griggs, MD; James Grotta, MD; Frances Jensen, MD; Ben Lenail, Ronald Petersen, MD; Mary Post, CAE; Sean Sansiveri; Joseph Sirven, MD; James Stevens, MD

Guest Presenters: Maciej Mrugala, MD, PhD - Director of Neuro-Oncology, Mayo Clinic Arizona; Chair of AAN Neuro-Oncology Section. Ashley Logan and Warren Legner from Yakkety Yak.

Staff: Jane Ransom, ED; Kevin Myren, CFO; Kim Howard, Emily Christian, Lisa Dahlberg, Julia Miglets-Nelson

Excused: Shafali Jeste, MD, Secretary; David Eagleman, PhD; James Erwin; Sharon Klein; Cindy McCain; Suzanne Miller; Martin Shenkman, CPA

The meeting was called to order at 10:02 a.m. CT.

The minutes of the August 6, 2020 meeting were approved unanimously.

Board Chair Remarks (David Dodick, MD) Dr. Dodick thanked Sharon Klein for her four years on the board. She will be leaving at the end of 2020. It has been a tough year for non-profits and foundations. An estimated one-third of nonprofits have or will be closing their doors in 2020. There have been increased stresses on philanthropy and a shift in giving based on the incredible needs that have arisen during this pandemic. Jane and her team have rolled up their sleeves and shown resilience and creativity to help navigate the foundation through a very difficult period. The AAN has been understanding and supportive despite being seriously impacted by the pandemic themselves. We have weathered the storm and we will come out on the other end strong and poised for significant growth.

Executive Director Report (Jane Ransom) ABF is on track to meet our goals. Some nice wins in the last few months include \$1.5M for the LBD fund from the Alzheimer's Associations and \$1.65M from the McKnight Foundation to launch 10 new CRTS in age-related memory loss. Due to better visibility, larger gifts are coming in from people we do not know, including a recent \$200,000 gift to the LBD Fund. Jane thanked the staff and the board for all the work that has been done to keep us afloat and successful this year. The one challenge that we have not really advanced on is the idea Dr. Dodick brought to the February 2020 meeting, of a multi-milliondollar win. This is something we should start shooting for with the boards help.

Ransom referred Board members to her written Executive Director report in the meeting materials for a review of third quarter highlights. She highlighted several year-end activities:

- Developing a 2021 budget strategy which leverages COVID-19 savings to grow ABF through added spending for marketing
- Promoting planned giving through a planned giving newsletter and FreeWill software
- Pursuing grants and gifts through the Annual Fund Year-End Campaign, Give to the Max Day, Giving Tuesday, Major Giving Campaign, Grant proposals, and Commitment to Cures sponsorship solicitations
- Considering launching the LBD initiative in 2021 and considering how research funding could address neuro health care disparities.

Financial Report (Jim Essey) The Foundation has done well meeting financial goals despite the pandemic. The Finance Committee has developed an aggressive budget for 2021, created to exceed our 2020 goals even though AAN has nicely adjusted our goals back to the 2020 goals. We need to be prepared that people might not have the appetite for donating. We will have some savings this year, so we are proposing to reinvest that money in the organization to help build brand awareness for the future. We have set our budget so that over this two-year period we deliver the amount of we said we would to the AAN even though they said we did not have too.

September YTD 2020 Financial Statements & Updated Forecast (Lindsey Taveren) September YTD operating revenue is at \$4.4M, expenses are at \$3.6M, long term investment losses \$216K leaving a net operating increase of \$651K. The YTD actuals compared to YTD budget is very positive and that trend continues as we near the end of 2020. Here are the highlights:

- **Revenue** - Combining the restricted and unrestricted gifts together 83% (\$4.3M) of the fundraising goals have been achieved. Unrestricted revenue is at 92% of the YTD budget goal and restricted revenue is at 72% of the YTD budget goal. The PPP loan has been forgiven and will be recognized as revenue in November.
- **Expenses** – September YTD expenses are down 16% compared to what was budgeted. The major variances are in professional services, advertising and meetings and travel.
- **Financial Position** – September ended with total assets of \$14.2M, \$3.8M grants receivable and \$10.3M cash and investments. Liabilities are \$1.6M with grants payable of \$1.4M.
- **Operating Statement** – This is where you see the projected surplus for the end of the year has jumped to \$326K which is astronomical compared to our budget of zero for net income. The real driver of this surplus ins on the expense side. Expenses are about \$367K under budget when you compare the forecast to budget and that is driving that surplus. There is a \$50K contingency that was added in case of any unanticipated expenses at the end of the year. If that does not get used it would drop right down to the bottom line.

Discussion:

- A question was raised about the \$14.2M we have in reserves, how much of that is encumbered and how much is actually true reserves, and do we have a target? Lindsey confirmed we have \$12.6M in net assets, and as of September \$4.6M is unrestricted so that is all the prior year's surpluses that have built up over time that we have primarily invested in long term investments. ABF policy establishes a reserve equal to 75% of the average of the last two years actual expenses, and the succeeding years budget. Our current target is \$1.7M which we easily meet since we projected our surplus of \$4.2M in unrestricted net assets at the end of the year.
- **MOTION:** A motion was made to affirm the actions of staff to submit the forgiveness documents to the Payroll Protection Program with proof that all qualifications were met. The motion was approved unanimously.

Mr. Essey reiterated that in the middles of a pandemic, we were able to deliver on our budgeted goals exceeding them significantly by \$326K and you will see how this comes into play in 2021. This is a very positive story, and the outlook is good as we move to 2021.

2021 Budget – The strategy is to leverage the savings from 2020, as well as continued savings in 2021, to expand the advertising and public awareness campaigns. The 2021 budget proposes a deficit of (\$261K) which would be funded from unrestricted assets in the operating reserve. The combined net income between 2020 and 2021 equates to \$66K, which matched the combined net income in the 2020 and 2021 business plans.

Highlights of the 2021 budget include:

- 2021 Operating Revenue - \$4.7M
 - \$1.25M AAN Grant
 - \$850K Unrestricted Fundraising Goal
 - \$2.6M Release from Restrictions
- 2021 Operating Expenses - \$4.9M
 - The expense strategy in 2021 is to leverage continue savings due to COVID-19 environment (ie limited travel and virtual Annual Meeting/C2C event) and the available prior year surplus to expand advertising and public awareness.
 - Assumptions included the following:
 - Remain at 8 FTE
 - 3% increase to management fee agreement with AAN
 - New CRM implementation expense of \$150K
 - Significant investment in Yakkey Yak professional services of \$400K
 - Significant investment in advertising of \$112K
- Restricted Fundraising Plan - slides illustrating the 2021 Fundraising Plan as well as the prior year's funds raised and the grant/award expense goal from the business plan were shared. We are in a very good position, most of the funds have already been raised for 2021 and 2022 and even some for 2023 and 2024. Our 2021 fundraising is really geared towards future years.

MOTION: A motion was made to approve the 2021 budget as presented and it was approved unanimously.

American Academy of Neurology Update (James Stevens, MD) Dr. Steven's began by reaffirming that we have a very strong mutually beneficial relationship with the ABF. Their members and their patients greatly benefit by supporting research to find cures and improve quality of life as well as increasing engagement and the reach of AAN patient education resources. The AAN Vision to be indispensable to their members and the Mission to promote the highest quality patient-centered neurologic care and enhance member career satisfaction was shared.

- World's largest association of neurologists at 36,000 and that is projected to increase at the end of 2020 to almost 37,000.
- The AAN Goals were shared and the goal to "Expand neuroscience training and research funding" was highlighted because that fits right into our goals and partnership with the ABF.
- The AAN founded the ABF in 1992 and each organization is committed to the success of the other organization through support and strategic collaboration.
- The AAN is committed to providing unrestricted funds for ABF's operating expenses from 2020-2024, this funding is subject to ABF's ability to achieve performance metrics.
- The AAN's support of the ABF includes:
 - Free advertising and editorial space in multiple publications throughout the year.
 - AAN management of Clinical Research Training Scholars program.
 - Access to AAN science experts to review research projects.
 - Free direct outreach to AAN members and Brain&Life subscribers 3x per year.
 - ABF donation request is included in AAN membership renewal campaign.
 - AAN is the largest sponsor of C2C event (\$35,000)
 - Exposure at AAN Annual Meeting (prime booth location & free advertising in publications)
 - Free featured booth space at the Brain Health Fair, Bike Helmet Giveaway and Fall Conference.
 - Access to AAN staff for donation campaigns.

AAN is repositioning for lingering disruption into 2021 because of the pandemic, and that is why they froze the metrics for the ABF. The financial forecast remains promising for 2020 since they just received the \$10.7M insurance payment for the cancelled 2020 Annual Meeting. 2021 is projected to be challenging. Dr. French asked about the trends towards virtual meetings and Dr. Stevens confirmed that the AAN virtual meetings so far have exceeded registration goals, so they hope to see this as an option going forward.

The leadership of the ABF has been incredible at keeping the lines of communication open with the AAN and that has done nothing but improve the bond that was already there. Dr. Stevens thanked Dr. Dodick and Jane Ransom for those efforts.

Presentation: Brain Disease Education - Glioblastoma, Marciej Mrugala, MD, PhD, Mayo Clinic

Dr. Mrugala provided an educational session on Glioblastoma that included what Glioblastoma is, where we are in terms of treatment and care and where our priorities and focus should be for the future.

The challenges of why it is so difficult to detect and treat Glioblastoma:

- Imaging does not show the full extent of the disease
- We do not have a biomarker
- Blood-brain barrier impedes penetration of drugs into the tumor
- Heterogeneity of the tumor
- Lack of reliable targets
- Imperfect design and conduct of clinical trials
- Poor understanding of the risk factors
- Gender difference in incidence and response to treatment.

What is needed:

- Better understanding of the biology.
- Uniform bio-banking on every single case of GBM.
- Uniform use of molecular testing for treatment planning.
- Improved detection methods and biomarkers.
- Improved ways to understand tumor response to therapy.
- Faster and better target identification strategies.
- Improved clinical trials that would allow fast turnaround time and less patients to reach the conclusions.

Glioblastoma may be considered an Orphan disease, but it truly deserves our full attention. It has a huge cost at the individual, family and society level. There is so much funding going to other cancers and so many discoveries in other cancers but not so much in Glioblastoma, so we need to focus on this disease. Together the ABF and AAN could certainly make a difference and be an advocate for this disease to get better funding.

Dr. Mrugala hopes that someday we will be able to use the data gathered from all the new research that will be funded to put all the imaging data, molecular data into an algorithm and use Artificial Intelligence to predict the response of a patient with Glioblastoma even before anything happens. We can then plan what would be the best surgery, radiation, or chemo treatment for this patient to survive a long time and not to have to worry about tumor progression.

Research Strategy (Robert Griggs, MD) Dr. Peter Goadsby is the awardee of the 2021 Scientific Breakthrough Award. Dr. Goadsby will be recognized for his amazing work on headache, migraine, and vascular headaches. His early discovery that CGRP is a major generator of migraine and possibly other disorders. Thirty years later we have the first mechanism-based drugs in the field. His work has clearly had an impact on patient care helping more than a million people worldwide that suffer from migraines.

His work on CGRP is now being evaluated on other brain disorders, specifically concussions and even COVID-19. It is an elegant example of translational science that has led directly to impacting millions of patients around the world. We plan to approach the seven pharmaceutical companies that market these CGRP drugs to support this award and research going forward as a way to give back. Dr. Dodick also summarized the more formal selection process that was established this year that will be used in future years.

The Research Strategy Group (ABF board members & RAC members) recently met to discuss strategy. The RAC will establish three workgroups to pursue:

1. Expansion strategies for Next Generation Research Program.
2. Establishing one or more high-risk, high-reward initiatives. (i.e. Glioblastoma, Neuroinflammation)
3. Creating a health care disparities research agenda in collaboration with the AAN, our ideas have been shared with them.

Discussion and follow-up items:

- Dan Gasby referred to these health and wellness issues amongst the black community a quiet crisis that needs to be addressed. Dan offered to work with Michael Blumberg and his team related to these health disparities and diversity issues to see if they can do something to push this initiative forward. Jane is going to work with Dan on this.
- Dr. French asked the board to consider there are not enough people and fewer and fewer people involved in clinical trial methodology. The institutions work very hard against people being involved in that area as a career choice because it means you must work with the companies that develop the drugs and that still has an enormous stigma in that field. ABF could be very powerful working on that stigma piece encouraging young people to pursue a career in clinical trials rather than clinical research. Dr. Griggs mentioned that AAN is working on establishing a Section that includes Industry, currently Industry neurologists are forbidden to serve in any leadership position in the Academy so that this section will include people from Industry as well as have a focus on developing training in experimental neuro-therapeutics. Jim Essey added that he has a good friend that owns one of the larger staffing companies that staff these clinical trials, and he would be very interested in trying to help create interest and excitement in people focusing on this.
- Jim Essey suggested the model Dr. Dodick is using for pursuing Industry related to the Scientific Breakthrough Award could be used each year to potentially create a major initiative on behalf of ABF for larger amounts of money than our typical CRTS's. Dr. Dodick said it would be based on the awardee, we might not have this opportunity for some of these awards.
- Dr. Jensen suggested exploring creating a common platform where discoveries are put out with bankable samples for more general use is something we could explore, especially in the case of brain tumors because we have many small independent brain tumor banks around the country and information is not being shared.
- Dr. Grotta suggested that most dementia in black and Hispanics is not due to Alzheimer's, it is due to small vessel disease. This is another area that cuts across multiple specialties and is a huge public health problem. Natalia Rost is a leader in this field, Dr. Grotta suggested she speak at one of our future meetings on the opportunities in this area.

Governance Committee Report (Kevin Goodno) In 2020 the committee is working to fill two 2021 Board positions, one neurologist and one non-neurologist and renew 3 RAC members. In addition, the committee is working with the RAC to update its mission and role. In 2021 the committee will be working on filling three 2022 Board positions, filling 6 RAC positions and developing the Officers Slate for 2022.

2021 Marketing Outlook (Emily Christian) Yakkey Yak has become a part of our ABF team and marketing arm as we had hoped. Over the past several months we have been ramping up our marketing efforts and here are a few highlights:

- Regular content development is up and running as of August, evidenced across ABF channels.
- New content highlights the need for brain research, our unique approach to research, patient and caregiver stories as well as information about brain disease and brain health (aggregated from Brain&Life).
- Showcased ABF researchers and various awards in new ways.
- Executed Robin's Wish event in September with very high engagement.
- Supported our fundraising by revamping the Annual Fund multi-channel campaign, helped create our new leadership circle as well as new leadership in planned giving and stewardship touch points for donors.
- Established regular marketing meetings with the Academy for continual alignment to promote and elevate both brands.

New reports were shared looking at data collected over the last three months, this data will become the baseline numbers as we grow, and the results are as follows:

Website – traffic growth increased by 38%, 37% increase in new users, users are spending more time on our pages.

Social Media

- Instagram – 74% of the new followers came in 2020, 80 new followers per month over the last three months (44% increase), and engagement was up 38%.
- Twitter – 40 new followers per month over the last three month (19% increase), engagement has increase by 150% compared to last year.
- Facebook – 43 new followers per month over the last three months (34% increase), and engagement is up 214% compared to last year.

Email – Emails are sent to donors and non-donors. Donor emails are seeing strong engagement rates surpassing industry averages for open rate and click through rate (CTR). Non-donor emails have room for improvement, we are looking for ways to improve this and have already updated our welcome letter and will start a monthly newsletter.

2021 Marketing Strategy & Approach (Ashley & Warren from Yakkety Yak)

The common goal remains to establish the ABF as a credible and essential resource for brain disease information and support, engaging in building trust with the patient community in order to raise funds in support of brain disease research. The main goals include rebranding brain disease, positioning the ABF as innovation leader in brain research and fund research.

Commitment to Cures 2021 (Joe Sirven, MD and Sean Sansiveri)

Dr. Sirven shared that Jim Cramer has agreed to host the event again. Dr. Sanjay Gupta (PLINA Award) and Cindy McCain (Ambassador Award) have confirmed the acceptance of their awards. The virtual event components will include:

- Message from Dr. Dodick
- Presentation of awards to celebrity advocates
- Mission Moment: Video featuring patient stories and ABF impact
- Fund-a-need
- Musical performance
- Award-winning Brain Research: Scientific Breakthrough, Potamkin award, and Essey award

Sean Sansiveri presented the sponsorship benefits for sponsorship levels ranging from \$1,500 to \$100,000. The goal with the virtual event is to offer more presence and visibility to our sponsors through digital promotion, name recognition and logo placement.

\$50,000 has already been raised anchored by the generous \$35,000 sponsorship from the AAN. The committee needs the Board's help with securing additional sponsorships. Our consultant Judy from Fluid Events will reach out to the board members following this meeting about how to get more involved.

Dr. Dodick reiterated that we have had a really good year despite what we have gone through as a country. He thinks 2021 will be even better and could be our best year ever and is feeling very optimistic.

Meeting adjourned at 12:50 p.m. CT

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