



**American Brain Foundation**  
**Research Advisory Committee Meeting**  
**February 25, 2022**  
**3:00 p.m. ET / 2:00 p.m. CT / 1:00 p.m. MT / 12:00 p.m. PT**  
**Conference Call**

**Meeting Minutes**

**In Attendance:** Robert “Berch” Griggs, MD, Chair; Jose Biller, MD; Jose E. Cavazos, MD, PhD; Jacqueline French, MD; Walter Koroshetz, MD; Mark Mehler, MD; Bruce Ovbiagele, MD, MSc, MAS; Ronald Petersen, MD, PhD; Gordon Smith, MD; Reisa Sperling, MD, MMSc; David Dodick, MD; Paul George, MD, PhD; Mary Post, MBA, CAE

**Staff:** Jane Ransom; Julia Miglets-Nelson, PhD; Samantha Ross; Michelle Maxwell

**Excused:** Na Tosha Gatson, MD, PhD; James Grotta, MD; Eugene Scharf, MD; Phyllis C. Zee, MD

The meeting was called to order by Dr. Robert Griggs at 2:00 p.m. CT. The meeting minutes of December 3, 2021 were approved.

1. **Neuroinflammation update:** Jane provided an update on the ABF’s neuroinflammation initiatives. Over the last year from talks from this committee, we have come up with the summary concept paper that is included in today’s materials, using the LBD initiative as a template. Based on feedback from donors and partners, we want to convene a group of organizations interested in partnership to help shape the initiative in scope and amount. We are now meeting with partners, including most of our current partners to talk with them about their interest in this initiative. We want to convene in April or May of this year to create the scope of the project by end of summer; then get funding commitments by end of 2022. RFA out in 2023, with funding to start in 2024. Major points from the RAC’s discussion follows:

Ron Petersen reported on meeting with Alzheimer’s Research UK (ARUK); wanted to know specifics about funding timelines. Wanted to know if this could be an international operation with collaborative funding between UK, US, and others. Tentative answer is yes. Felt like a positive conversation. I don’t know what magnitude they are interested in funding.

Jane Ransom: In addition to regular partners, Allen Institute, Dementia Discovery Fund, Gates Ventures, pharma. With pharma companies, the thought is that we would set up an advisory committee of pharma funders and they wouldn’t be on the core committee. An estimate between \$500,000-\$1M investment for this initiative at a minimum. ARUK knows the magnitude of the previous effort.

Berch Griggs – LBD initiatives was spearheaded by John Morris. In a way that was easier because of the focus. I’m not sure that the people we want to ask for money are the people we want to put the initiative together. Are there one or two senior people like Dr. Morris who could lead the charge?

Jane Ransom – One example might be Stephen Hauser. Also, members of this committee, or other appointed by the RAC.

Walter Koroshetz – Neurodegeneration, COVID, post-COVID, it's an exploding area with lots of good people doing research, but no one knows enough to go after \$ for long COVID.

Bruce Ovbiagele – For orgs that can't make the minimum investment, what happens to that enthusiasm and money?

Ransom – For LBD, we had tiers of recognition, but less access than the top donors.

Reisa Sperling – Howard Wiener could also be good. Working to increase neuroinflammation in Alzheimer's, and decrease in MS. Is an innovative thinker.

Berch Griggs – Jackie French, who has talked about this in terms of epilepsy. Probably everyone on this call has an interest in inflammation.

Walter Koroshetz – Amit Barr-Or ran a big project in Canada in MS before coming to Penn.

Jackie French – We should focus a little bit. Reisa's point about increasing/decreasing neuroinflammation is important. Are we going above or below the neck? Also try to focus on something that's more than one condition. If we understand a unifying mechanism across several different diseases, then important to focus on that. E.g., blood/brain barrier. Epilepsy is starting to port some treatments from MS. Second point – COVID might be useful because it's so relevant right now. One way – go with mechanisms, other, go after COVID. The question is if you go after COVID, what would happen in terms of any support you would get from pharma?

David Dodick – ARUK for example probably has a high level of interest if the money were used for neuroinflammation research as it pertains to dementia, versus for epilepsy. We'll donate as it's germane to our interest.

Gordon Smith – I like Jackie's points. Target the role of neuroinflammation and neurodegeneration – would that resonate? Be broad enough?

Dodick – depends on the funding source. Doing neuroinflammation research will be important to a funder as it relates to their disease area. We're going to get proposals for neuroinflammation as it relates to XYZ disease. Could then field several different proposals.

Ron Petersen – We pitched the program as a broad neuroinflammation effort as it pertains to dementia, but not disease specific. I would not be inclined to pitch towards neurodegeneration at this time; should be broader and more mechanistic.

Paul George – A broader basket tends to spark competition and applications. SC and RPS thought is that broader focus tends to yield the best research.

Jane Ransom – It would be helpful to put together a leadership group with some of the names that have come up today to have a conversation with the interested partners this spring. How broad or narrow are people thinking? Then go next step in shaping the initiative.

Berch Griggs – Hauser could be the John Morris of the committee and could help us pick people to guide. Ron Petersen, Wiener, others from our committee [*underlined in notes above*]. This wouldn't necessarily be the group to select but would start shaping ideas.

Action moving forward: set up call w/ Dr. Hauser.

2. **Strategic Initiatives** – Today we'll consider three ideas for future Major Initiatives:

**ALS** – presented by Berch Griggs

High awareness of the problems of this dreaded disease, and well known in the public. Aggressive, fast-moving disease; need to find the cause (old thinking). Now up to 50 different genetic causes for ALS. Still accounts for less than half of patients; no gene defined. 10% of cases are familial, and 90% are sporadic, but we now know that one of the genetic causes is a cause of sporadic. Will almost certainly find other genetic causes. All have a common pathway. There could be a way to find a common pathway to help us understand the disease. All of these genetic variations produce the same disease. Attractive as a target because likely many other diseases will turn out to have many genes responsible, e.g. Parkinson's and Alzheimer's. Don Wood at MDA is interested in such an initiative, plus there are other major ALS research-focused organizations.

Mark Mehler – Other disease will have common pathways like ALS. Approaching from the perspective you mention gives the illusion of real focus but making it broad enough that its applicability is profound.

Jackie French – Sounds great, but the success depends on the number of people that we can get excited about this. The funding side – from industry, are there a lot of people who will support this? From patient side, I assume that if you've ever been touched by this disease you would be interested in supporting research.

Berch Griggs – there has been a lot of industry investment, but no good handle on why a particular drug might work. Literally billions of dollars have been spent. In the commonest form of ALS is associated with a dementia as well.

Walter Koroshetz – NIH is just launching its strategic plan for ALS research. Bob Brown and Rita Satler are running the group. There was a December bill that asks the FDA to set up a public private partnership with NIH about moving therapies forward for ALS. Two papers just came out yesterday showing that there is a protein that gets aggregated in ALS; discovery is that things that shouldn't be put into the gene get put into the gene. There's a story now that crosses both the sporadic and the genetic.

Berch Griggs – ABF should talk to Bob Brown.

Paul George – I like the focus overall alongside common pathways. That seems like a nice way to direct research.

Berch Griggs – It might be a good idea to have a group of ideas that we want to work on, not necessarily in order of priority or chronology. Even if we're not quite ready to focus on a project, we could have a pipeline of projects that we're starting to structure.

Jane Ransom – I agree. Can see a good example of that with ARUK. WE just have to manage it in terms of fundraising expectations. WE don't want to do go over our capacity that then see like we're not making a difference. If we put timelines on projects, that could help.

David Dodick – ABF has previously had a focus on devastating diseases for which there has been no major advance in the past half century. Agree with the idea of a pipeline.

**Brain Health** – Presented by David Dodick

2022 is going to be a big year for brain health. WHO has made this a priority. Disease prevention and optimization of brain health. World Fed of Neurology has made brain health its primary focus. Prodromal detection of disease is emerging and is a growing area of interest. Delaying and preventing the onset of disease is very important and optimizing brain health to prevent progression of disease. Might be attractive to several foundations as well as to private philanthropy.

Berch Griggs – We know how to prevent stroke, for example, but changing behavior is harder. E.g., AHA. Area of implementation research. Different than the traditional basic neuroscience approach.

Bruce Ovbiagele – It is difficult, but it's encouraging to see over the past 2 decades, the risk of stroke has gone down about 25% due to preventive measures. The bigger issue is trying to get people to modify lifestyle. Also needing translating the proven therapies into the real world. Likely leads to many disparities in race, etc. Especially for vulnerable and underserved populations. We need more implementation studies embedded in communities in the real world.

Walter Koroshetz – NINDS program called "Mind Your Risks". National Forum is also running a "Know Your Numbers" campaign for blood pressure. Implementation research, and messaging. The issue with prevention is that everyone is at risk, so there's not a specific audience. Would be great to have AAN to join some of these things. ABF could have more of a role around messaging rather than research. Maybe implementation research. Million Hearts campaign by US Gov't. The research around messaging is being done by the advertising industry.

Berch Griggs – Behavior change needs to happen over years, not for a period of a few weeks/months. Different type of research than what most neurologists are interested in.

Bruce Ovbiagele – We need research into what is effective in communication/messaging around these changes.

David Dodick – Former CDC director is working on hypertension w/ Michael Bloomberg. How do we get the word out about what we know works?

Reisa Sperling – This is a very important initiative, but how do we make this different from others? Vascular risks are important not only for stroke, but also a decrease in dementia. Barriers in diverse populations are especially interesting. How do we communicate the prevention of risk, and what are the barriers preventing people of color from benefiting? What are the specific research and interventions we want to address? What research would really make a difference in diverse communities.

Ron Petersen – AARP is addressing this as well.

David Dodick – Partnership with AHA? Opportunity for co-creation.

Berch Griggs – Develop 2-3 approaches for this to discuss at future RAC meeting.

Gordon Smith – Has done work in this space for peripheral nerve disease. Not just stroke and dementia where this is important. Parkinsons, etc. There are other stakeholders – American Diabetes Association – funding researchers doing this implementation work. Must be community-based work. Doesn't happen in academic health centers. Verily – Google – and ability to use technology to serve populations that need resources.

Paul George – We have a track record w/ ABF with connections with possible partners at these orgs. Implementation and brain health is important, along with pre-diseases brain health. Different ways to assess disease risk before you get the disease. Can motivate patients to do some of these things.

David Dodick – Richard Miller developed National Institutes of Aging model. There may be an opportunity to plug into some anti-aging and longevity research.

Mark Mehler – A paper just came out this week showing caloric restriction to 14% increases longevity. First time shown in humans. Concept of resilience. Different than active measures you do to try to ward off disease. Common brain pathway that mediates resilience. If we understood that, we could mitigate and treat a lot of diseases.

Ron Petersen – AARP has a Global Council on Brain Health that he sits on. Generated a dozen reports over the past five years looking at different factors. Current one is on behavior change. AARP has 38M members, so huge audience.

Walter Koroshetz - For the implementation research for brain health-Issue is that would have to construct an infrastructure that links neurologists with the broad audience. Need to reach an audience that neurologists don't see.

Berch Griggs – Bring back some of these ideas to the RAC at a future meeting.

NaTosha Gatson – also need to consider the rural health population.

**Brain Tumor** – Presented by NaTosha Gaston

Rural vulnerable populations also have much worse outcomes in brain tumor treatment. Things that keep them away from care and treatments create worse outcomes.

Berch Griggs – Brain tumor is one of the neediest areas for research. Infinitesimal gains in terms of survival. Work on blood brain barrier seems most important in terms of research. Will come back to Tosha at next meeting about this.

3. **CRTFs** – Julia provided an update on the 2022 and 2023 CRTF program, and the program needs for the future.

Berch Griggs - for next meeting, we need to talk about a strategy for bringing in funding partners.

David Dodick – thanked this group – we launched the LBD award earlier this week, which wouldn't be possible without the RAC's help.

**Adjourned 2:59 p.m. CT.**