



Multiple Sclerosis Association of America

Brain Preservation and Cognition in MS Ask Me Anything (AMA) Facebook Event - March 19, 2018

Program Transcript

Background: As part of MSAA's 2018 MS Awareness Month campaign, we hosted a live Ask Me Anything (AMA) Facebook event on *The Importance of Brain Preservation and Cognition in MS*. During this online event, participants would type their questions into the Facebook discussion box and receive typed replies from the presenting MS experts. Please see below a transcript of the program's written questions and answers from this one-hour, live event.

Important Notes: Please know that replies were kept fairly brief in order to respond to as many inquiries as possible during the one-hour timeframe. It is also important to note the content presented during this program and in this transcript is intended for general informational purposes and does not constitute medical advice. For diagnosis or for determining treatment, you are urged to consult your physician.

Presenters: Rohit Bakshi, MD, FAAN and Jack Burks, MD

Dr. Bakshi is the Jack, Sadie and David Breakstone Professor of Neurology and Radiology at Harvard Medical School. He is also the Director of the Laboratory for Neuroimaging Research and a Senior Neurologist at the Partners Multiple Sclerosis Center, Ann Romney Center for Neurologic Diseases, Brigham and Women's Hospital.

Dr. Burks is the chief medical consultant for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies as well as new MS centers. He also advises patients, families, MS organizations, and healthcare groups. Dr. Burks is an adjunct professor at Nova Southeastern University and clinical professor of neurology at Florida International University. In addition, he has authored numerous textbooks, chapters, and articles on MS.

Program Questions and Answers:

Question 1: For relapsing and remitting MS what is the most common trend you see in terms of timing? How fast it progresses? Can we do something to avoid it at all?

Response from Dr. Burks: The results of research for relapsing-remitting MS are very encouraging. The treatment of RRMS may well lead to reduction of progression in MS. The treatment of progressive MS has made tremendous strides. We now have an FDA-approved treatment for PPMS and relapsing MS.

Question 2: What does brain preservation mean? Sounds scary!

Response from Dr. Bakshi: I agree that brain preservation is an awkward term. What we mean by that is keeping your brain healthy, without new lesions or ongoing atrophy from the MS disease process.

Question 3: What are current available courses of treatment for cognitive dysfunction associated with multiple sclerosis?

Response from Dr. Burks: MS experts recognize the serious issues of cognitive dysfunction and are dealing with it much more proactively than in the past. Professional help is critical for improvement. In addition, there are many things patients can do individually to improve their cognitive functioning such as using smartphone apps, making daily journal entries, using a filing system, learning memory strategies, creating to-do lists, and other skills.

Question 4: Which treatments “preserve” the brain? Are they in clinical trials right now or currently approved? Are they injections or orals?

Response from Dr. Bakshi: All of the FDA-approved therapies have shown some benefit in limiting the rate of brain atrophy in patients with MS. However, this is generally not recognized officially by the FDA as a proven benefit of therapy. In my opinion, having a patient on any one of the treatments is good for protecting the brain from atrophy.

Question 5: I just started donepezil 5mg QD for memory loss secondary to MS. I find doing brain games very taxing on me mentally. The Aricept seems to be helping. I have not been on it for a whole month yet. Do brain games help much?

Response from Dr. Burks: Medications for Alzheimer's such as Aricept may be tried in MS but the results have not been universally successful but some people may feel better. Stimulating brain activity is worthwhile whether it's brain games or other activities.

Question 6: Do most neurologists review your brain volume as a metric to monitor over time? I have never asked what my brain volume is or has been over the past 10 years. Where do I find this in my MRI scans?

Response from Dr. Bakshi: Most neurologists will read your scan to get a general idea of how much atrophy has occurred. There are still no widely accepted standard ways to provide a volume measurement for patient care.

Question 7: In cases of CIS and RIS, what types of treatments seem to be most effective?

Response from Dr. Burks: The treatment of CIS and RIS are important issues to discuss with your neurologist. There are a variety of opinions and having an MS expert with broad experience will be your best guide to discuss your specific situation.

Question 8: Is it possible after a diagnosis of MS to have no further physical symptoms or relapse of MS for a period of 5 years, but to suffer significant cognitive losses during that 5 year period?

Response from Dr. Bakshi: Yes. There are patients who have non-physical symptoms as their major manifestation of MS, such as fatigue, cognitive problems, mood changes, and other mental issues. We don't yet understand why MS is so different from one person to another. It is important to report all of these types of problems to your neurologist.

Question 9: What part does diet play in cognition?

Response from Dr. Burks: There are many avenues to help one's cognition -- nutrition is very important as is exercise, sleep habits, managing stress, and seeking help for depression. Dietary consultation with experts can make a meaningful difference in our eating habits and our functioning, including managing our MS.

Question 10: From what I understand, there are changes in both the grey and white matter. My lesions are stable but my cognition is going down the toilet. There's got to be more!

Response from Dr. Bakshi: The lesions we typically measure by routine MRI are white matter lesions. The gray matter lesions are difficult to see unless you go to a 3T scanner, and, even then, we can't see all of the gray matter lesions. This is a focus of research in my lab and in other research groups across the world, to find the hidden damage that may explain cognitive decline, such as gray matter lesions and gray matter atrophy, using 3T and even stronger (e.g. 7T scanners).

Question 11: I have had MS for a little over ten years, and although it doesn't LOOK like it (and it never has!) my cognition has begun to decline. Does the decline of my cognition INCLUDE my inability to keep my conversations with my peers at on an appropriate topic? My husband says I've lost social etiquette. Is that a cognitive thing? Is that an MS thing?

Response from Dr. Burks: We do see some patients whose cognitive decline is also associated with behavioral changes such as inability to keep focused or have socially inappropriate remarks. Also, there are comorbidities (such as anemia and low thyroid) so it's important to have good general medical check ups. Also, there's a condition called pseudobulbar affect (PBA) where patients express inappropriate behavior such as laughing or crying at inappropriate times. This is a treatable condition and should be discussed through one's physician.

Question 12: Are there other ways other than treatment to prevent atrophy? Reading, activity, brain stimulation?

Response from Dr. Bakshi: In my opinion, the current disease-modifying treatments are likely to help prevent atrophy, as has been shown in several studies and patient trials. Other than that, I don't know if any scientific evidence of other ways to prevent MS-related brain atrophy. This would be a good topic to discuss with your neurologist.

Question 13: I was diagnosed with MS in 1985. Not being able to walk for three years has been my most obvious sign of this disability; however, I have realized that I am more forgetful and less able to hold concentration. After going to a nutritionist, I was told that I am low in vitamins B and D. Is there a more helpful diet plan to follow to capture more of these proper vitamins?

Response from Dr. Burks: A nutritionist is a vital part of your wellbeing in MS. Vitamin deficiency can play a role in cognitive decline but there are many other aspects that

need to be considered. Be very cautious about anyone selling supplements without scientific validity. I would depend on your general medical doctor and neurologist for guidance in selecting a reputable nutritionist. Specifically vitamins B and D are very important in general wellbeing and vitamin D may have a specific value in MS. I believe that MS patients should have their vitamin B and D levels checked.

Question 14: If someone has gait or balance issues they may be prescribed physical therapy and put on an exercise program. What does one do if they have cognitive issues? Is there "physical therapy" for that?

Response from Dr. Bakshi: Yes - there is a cognitive type of therapy available. There are also coping strategies you can use at home or at work. This would be something to explore with your neurologist and perhaps get evaluated by a neuropsychologist to make a therapy plan.

Question 15: Is there any way to "turn your brain off" so you can sleep? I'm up for hours before I can sleep. I keep regular hours and don't change my hours to (try) sleep. Between lack of enough sleep and then the fatigue, it's a wonder I keep going!

Response from Dr. Burks: This is a very common issue with MS patients and requires professional help. Thank you for drawing attention to it during the AMA since it's important for people talk with their physicians about this. It may be a sign of depression or anxiety, which can be treated.

Question 16: Is the 6-8 hour mental test the best way to determine whether or not one's issues are being caused by MS, chemical imbalances, or both? My neurologist recommended the test to determine the best course of treatment for my progressing cognitive issues.

Response from Dr. Bakshi: Yes - getting a formal evaluation by a neuropsychologist is very helpful to understanding the cause of cognitive problems, and to make a therapy plan.

Question 17: I can be in the middle of a conversation and totally forget what I'm saying. Help?

Response from Dr. Burks: Sometimes we all have that issue so it may or may not be a part of your MS. It is very distressing though. I would check with your neurologist to see if your MS could be getting more active. In the meantime, I would prepare notes for important meetings to which you can refer and to not be so hard on yourself.

Question 18: I tend to pay close attention to the advice given in order to avoid Alzheimer's, would this be a safe assumption as an MS patient?

Response from Dr. Bakshi: We don't know how to avoid getting MS. The best way to tackle this disease in my opinion is to be followed closely by a neurologist and, for most patients, to be treated with one of the approved therapies.

Question 19: I was diagnosed a little over a year ago with RRMS. Had a scare in December when I suddenly lost ability to write legibly and my speech was also slightly difficult. My

cognition was fine, though you wouldn't know it to see my handwriting. Thankfully this resolved after Solu-Medrol infusions, but any information to reduce the likelihood of a similar episode would be very welcome.

Response from Dr. Burks: Thank you for bringing up this important issue. You have had a successful treatment of your relapse but not your MS. Steroids are not a treatment for MS long term. You should work with your neurologist to determine the best disease modifying therapy and commit to being adherent to that therapy or switch to a therapy that works for you but adherence is key.

Question 20: Can cognitive loss be remedied or regained?

Response from Dr. Bakshi: Yes - possibly. There are rehabilitation strategies that might be effective. Some of our MS therapies may help to reduce lesions and improve brain function. These are not necessarily proven outcomes, but you should discuss with your neurologist.

Question 21: My question is about prevention. What can I do to keep my mind functioning, keep the ability to concentrate and focus on a task without losing track and jumping from thing to thing? I'm almost 40, living with MS for the past 15 years, but lately, I am experiencing mind scatteredness, forgetting things that were on my mind just a minute ago. Is it age or MS? Otherwise, I'm doing well, changing carriers, going back to school and applying for a graduate degree. I hope I keep my wits and finish school successfully. I also interact in two different languages on a daily bases which I think is very helpful cognitively. What are your insights?

Response from Dr. Burks: Wow! First, let me commend you on all you are doing! Congratulations. There is now a treatment modality that may be worth pursuing called Cognitive Behavioral Therapy (CBT) which helps to anchor negative thoughts to realistic positive associations. Good feelings are an important step to progress. This may be worth considering, although you're already applying many positive aspects to your life.

Question 22: Does the loss of cognition have anything to do with the loss of social etiquette?

Response from Dr. Bakshi: Yes - it can affect socialization and social functioning. There are many types of mental effects that may result from MS, such as mood changes, personality changes, and anxiety. All of these, combined with cognitive effects, can affect inter-personal communication.