



Multiple Sclerosis Association of America

Healthy Living with Primary-Progressive MS Ask Me Anything (AMA) Facebook Event - March 27, 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 *Healthy Living with Primary-Progressive MS*. During this online event, participants would type their questions into the Facebook discussion box and receive typed replies from the presenting MS expert. 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.

Presenter: Steven Bromley, MD

Dr. Bromley is the Director of the South Jersey MS Center at Bromley Neurology, PC. He is board certified in neurology and headache medicine and specializes in multiple sclerosis, clinical neurophysiology, and smell and taste.

Program Questions and Answers:

Question 1: Is secondary-progressive MS treated differently than primary-progressive?

Response from Dr. Bromley: Yes, by definition these are distinct processes (at least the FDA qualifies them that way). However there is tremendous overlap in the pathology of each condition. Secondary progressive disease implies that at one point your MS was manifesting as inflammatory disease that waxes and wanes over time, then later becomes more of a consistent decline clinically. Unfortunately, we define the type of MS by what we can see clinically (symptoms, signs) rather than what is going on in the brain pathophysiologically.

Question 2: Do you recommend using pure CBD oil for the treatment of PPMS?

Response from Dr. Bromley: It is certainly not FDA-approved (as of yet), and it is not considered a therapy for MS. However, many patients report feeling symptomatic relief with CBD supplementation. We also need to watch out for the fact that there is little consistency from manufacturer to manufacturer with CBD and you often don't know exactly what you are taking.

Question 3: I would like to know which is the better of the two: the stem cell treatment that involves the chemotherapy, or the treatment where they just harvest and infuse your own stem cells back into you, or are both treatments for RRMS?

Response from Dr. Bromley: There is a lot of promise with stem cells. The trial that is the closest to being formally completed and possibly associated with an approved therapy is the stem cell trial associated with multiple chemotherapeutic agents (and stem cell transplantation). Expect more on this by the end of 2018 (so we are told). The effectiveness with this is close to amazing but you need to consider the risks -- some people may not survive the treatment and there is a potential for cancer later on. The mesenchymal stem cell transplantation that you refer to is woefully lacking in data with controlled trials and is -- at this point -- akin to "selling snake oil" since it is largely based on anecdotal reports. But please note I am not saying it may not have a beneficial effect for some patients. At this point we are still in the wild west with these therapies.

Question 4: I take Baclofen four times a day and still have spasms. I was wondering, is there anything else to take?

Response from Dr. Bromely: Certainly yes, but it depends a lot on your specific medical condition. For many patients there are options for other anti-spasmodic medications, including tizanidine, cyclobenzaprine, metaxalone, etc. However, you may also be a candidate for local injection therapy (e.g. Botox injections). One needs to make sure with the doctor that any specific medication is ok with your other medications and medical conditions. Non-medical therapies should also be considered with every patient, including additional PT/OT/ home exercise/ chiropractic/ acupuncture/ etc.

Question 5: After taking a second dose of Lemtrada and still declining for almost a year, what's next? A third round?

Response from Dr. Bromley: Possibly, upward of 30% of patients from the original trials (CARE MS I and II) opted to have a third course. However, this needs to be discussed with your neurologist. Remember your DMT isn't everything -- you need to look at other aspects of your medical condition and life to see if there are treatable co-morbid conditions contributing to making you feel clinically worse (e.g. depression, recurrent infection, sleeping problems, nutritional problems, etc.).

Question 6: I'm having trouble falling asleep, what's your suggestion?

Response from Dr. Bromley: Sorry to hear. I would start with adapting good sleep hygiene... For example, go to bed and sleep at the same times every day. Do not do certain things prior to bed (eating, exercise, watching an exciting movie, fighting with the wife...). Avoid stimulating therapies and foods during the second half of the day if possible, including anything with caffeine. Also avoid alcohol prior to bed (a night-cap is actually a bad idea) since alcohol has a short half-life and can wake you up more in the middle of the night. There are many sleep induction medications to consider (if that is deemed appropriate for you). FYI the most common cause of insomnia (in everyone with or without MS) is anxiety/ stress.

Question 7: Is a B12 injection helpful for MS fatigue?

Response from Dr. Bromley: It may be, and it certainly should be considered -- especially if your blood level is below 400. Sometimes our diets are not enough to get the amount of B12 you need since your body's levels are highly dependent on how much you absorb and how much your body uses (which is more in MS).

Question 8: In all honesty, how do you feel about marijuana treatment?

Response from Dr. Bromley: Medical marijuana can be extremely helpful for MS patients, particularly with spasticity and pain. I am a fan of it for some patients, mostly as a therapy for symptoms at this point. It is quite frustrating as a physician that there is a fundamental lack of control and consistency with what patients are receiving and using from day to day. This needs to be fixed with more centralized control and regulation (acceptance) by the federal government (not just a variable state-based thing).

Question 9: Why does it seem that the older you are when you receive a diagnosis, it's primary-progressive MS?

Response from Dr. Bromley: This is not necessarily the case, although it can certainly be some people's experience. There is a wide range of ages for which relapsing and progressive forms can be finally diagnosed. While it commonly presents in the 2nd through 4th decades of life, some patients can be diagnosed later in life because a relatively "mild" course of the disease (they may have actually had it for many decades before diagnosis).

Question 10: I was taking Zinbryta injections, but this medication has been taken off the shelf. Should I be concerned?

Response from MSAA: Please refer to MSAA's recent news article that provides further information on the topic of Zinbryta withdrawal: <https://mymsaa.org/news/fda-helping-with-zinbryta-withdrawal/>.

Question 11: What is the feedback from any of your patients who have now had their six month full dose of Ocrevus (after already having the first two half doses six months prior)?

Response from Dr. Bromley: The experience I have had with my patient's reporting back is that most people feel like they are "better in some way" or "nothing happening for better or worse." Remember, the trials were two years in length for a final endpoint (of significance) -- but these trials were averages of large populations of study patients (called "cohorts"). Individual results can certainly vary from averages seen in the trials.

Question 12: I was wondering if you can get the chills from MS? If so how bad and how long? I have been having them for over a month!

Response from Dr. Bromley: Sorry you are dealing with these symptoms. I am not sure exactly what is meant by the experience of "chills". Often they are typically understood as a non-specific sensory response to rapid cooling or even an infection (e.g. a virus moving through your blood stream). Problems with your endocrine system (e.g. thyroid) may make you more sensitive to certain temperature changes. It needs to be said that "chills" may also represent a form of L'Hermitte's phenomenon where a spinal lesion causes sensory changes that often move up or down the spine (particularly

with flexing one's neck). The short answer is that yes, you can get chills with MS, but you can also get them with other things. Please discuss this with your doctor.

Question 13: I'm a quadriplegic with PPMS. Apitherapy was great for six years, but now it is no longer effective. Any suggestions?

Response from Dr. Bromley: I am assuming that you are referring to bee-sting therapy. However, the data for this is lacking overall and what you are experiencing clinically is not always consistent with what you get under the surface (at the brain and spine level). In other words, just because you were feeling good for 6 years does not mean your condition was entirely under control. I would discuss this with your doctor since there may be a number of medical reasons why you are now not feeling great.

Question 14: Is there any definitive information regarding nutrition and its ability to combat MS symptoms/progression?

Response from Dr. Bromley: There are a number of diets that are reportedly better for patients with inflammatory diseases, including the Wahl's diet, gluten-free diets, and even the Mediterranean diet (to name a few). The key with any medical condition is to find balance in your life -- avoid excessive use of carbohydrates or fats (since these are major parts of our American diet). We also tend to over-eat, eat too late, and drink insufficient amounts of water (not soda!!). Please refer to MSAA's article: <https://mymsaa.org/publications/motivator/summer-fall15/cover-story/> for more information on nutrition and MS.

Question 15: Why does it hurt so much when I walk?

Response from Dr. Bromley: Boy that is a good question! Pain is a sure sign that there is a problem -- but you need to be evaluated by a doctor about that pain -- like where it is, when it actually appears, what makes it worse or better, etc. This may actually not be related to MS at all. Good luck.

Question 16: Any other drugs due to be approved soon that look promising? I also saw an article on siponimod that should be approved soon, is that Gilenya reformulated?

Response from Dr. Bromley: There are NUMEROUS medications in the pipelines of the pharmaceutical companies for MS. We will most likely see a few orals next, like ozanimod, cladribine, and siponimod. The FDA will need to review and accept the data prior to approval for any new meds. Siponimod is actually not "Gilenya reformulated" but actually a distinct new medication that is in the same class as Gilenya (S1P receptor modulator). The data on Siponimod from its phase II trial in secondary progressive MS looked really good last year.

Question 17: Is a Meningioma tumor a result of having MS?

Response from Dr. Bromley: Not likely. Meningiomas are actually much more common than MS. Meningiomas are typically benign growths that are on the linings of the brain and spine. Meningiomas can be triggered by such processes as radiation exposure (not cell phones), infection and trauma. Please note that nothing is actually ever "benign" if it is a space-occupying lesion in the skull and ultimately displaces the normal brain parts. A person with a meningioma may need to be evaluated by a neurosurgeon as well as a neurologist.

Question 18: I was diagnosed in 1995 with RRMS and I have been secondary-progressive for approximately ten years. In 2017, I was diagnosed with muscle weakness in the muscles to my lungs and diaphragm. December 2017 testing showed 20% intake and output with muscles fatiguing very quickly. I have been on oxygen at night and as needed during the day at home only since June 2017. I am ambulatory so this is a rare situation, do you have any treatment suggestions?

Response from Dr. Bromley: So sorry you are dealing with this. Assuming this is from your MS, it is a very difficult situation and may ultimately require ventilatory assistance. At the very least, make sure that you are not keeping your muscles of respiration in an environment that stresses function -- in other words, stay nourished, stay hydrated, do not smoke, take vitamin supplements as recommended, aggressively treat infections (including upper respiratory infections), and aggressively treat allergy/ reactive airway issues (including asthma, seasonal allergies). You need to be followed closely by a pulmonologist, neurologist, and physical medicine and rehab physician/ PT/OT. Good luck.

Question 19: What should a person do if their neurologist ruled out MS with one MRI of the brain and spine?

Response from Dr. Bromley: Not sure since I have not seen the images or know your story. However the standard criteria used is the McDonald criteria and these criteria were recently revised again. Remember, one really can never "rule-out" MS -- one can only "rule it in" using the criteria. Other conditions that could look like MS need to be excluded with testing, including blood tests, MRIs, and occasionally lumbar punctures (not necessary these days for a diagnosis) or electrophysiological testing. MRI often needs to be repeated over time to see if new lesions appear or grow -- helping to confirm the fact that lesions are actually separated in time and space (e.g. appear in different locations of the central nervous system white matter at different times). Remember, to always ask your doctor "why" if you are unclear as to the thinking behind a medical decision.