Open Q&A

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[00:00:05] **Dr. Benjamin Greenberg:** I don't know if anyone from the panel would like to comment on, from what you've seen this weekend, is there anything that struck you in terms of being a take-home point or something you want to stress, something you'd want people to remember after being inundated with lots of different information?

[00:00:20] And I don't know, Sydney, if you've been up on stage yet or if this is your first. So, everybody should know Sydney Lee, our funded fellow, our James T. Lubin Fellow. She's with Stacey Clardy and the team in Utah and traded a Utah weekend for a Dallas weekend. So, that's a big trade; we appreciate you being here. But anything that stuck out to you, things that you'll take back to your practice relative to patients?

[00:00:48] **Dr. Sydney Lee:** Yeah. This is my first SRNA meeting and I'm so fortunate to be here and to meet all of you. And I think the main thing for me is just remembering how important the patient is, and it's really about getting to know you not just from a medical standpoint but on a personal level, and really looking at the whole person when we're talking about your diagnosis or your treatment, and just how helpful it is to have a community like this. I'm very excited, and I'm going to be taking a lot back with me as I go forth and see patients throughout my training.

[00:01:33] **Dr. Benjamin Greenberg:** Okay. I think we have a question from the online side, the virtual side?

[00:01:36] **Audience Member Online 1:** Yes. Well, that's a perfect lead in. Somebody just had a comment, and then I have several questions we've been collecting over this weekend. But somebody had a comment: Rosemary shared that she's been living five years with idiopathic TM and have seen a recurring theme of clear communication and networking and community that's vital to us all -- so right in line. Caroline asked about: For women who are menopausal with NMOSD, is it safe for them to take hormone replacement therapy?

[00:02:12] **Dr. Benjamin Greenberg:** How many on the panel are pediatric trained? Okay. I'm going to direct you. So, I guess, I'll take that one. The answer is: from a neurologic perspective, it's considered safe. There are risks and individualized risk for hormone replacement therapy relative to cancer, intervention, and other things, and so talking with your primary care provider around that. The one thing we do bring up is to make

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sure somebody doesn't have a history of clotting disorders relative to hormone replacement therapy. And we can do one more online, and then we'll go here.

[00:02:46] **Audience Member Online 1:** And then, Rosemary asked: if there's any research or studies being done on rare neuroimmune disorders with patients that have past mental and physical trauma? Any studies done with patients that have had drug and alcohol addiction and rare neuroimmune disorders?

[00:03:02] **Dr. Benjamin Greenberg:** Darina, do you want to comment on this?

[00:03:04] **Dr. Darina Dinov:** Hi. I think that there are studies. I know that there's one in Virginia and I think we have one here as well.

[00:03:13] **Dr. Benjamin Greenberg:** We do? I don't know.

[00:03:15] **Dr. Darina Dinov:** I'm sure other institutions have them as well. It's a pretty hot topic in neuroimmunology now.

[00:03:20] **Dr. Benjamin Greenberg:** Yeah. Denise, I know you've worked with Victoria at our center in terms of integrating into the clinic. Do you want to talk briefly about what she's doing in the clinic?

[00:03:29] **Denise Maddox:** Yeah. So, the study that she's doing is focused on people with MS, MOG, and NMO that are 12 or older and past traumas that they've had in their life, which include all the things that you talked about. And so, it's a questionnaire given a couple of times, I think. And so, we're in the middle of that.

[00:03:54] **Audience Member 1:** Thanks for bringing up the rear here, appreciate it. Curious, just a quick question, are there folks who are negative in blood tests for the panel like we did the Mayo autoimmune paraneoplastic panel, negative for blood but positive for CSF? We didn't get some of those markers for idiopathic TM. So, no hits but we didn't get it tested in CSF. Any sure thoughts on that? Is there a disparity between the two?

[00:04:33] **Dr. Benjamin Greenberg:** Yeah. Cynthia, do you want to comment on that?

[00:04:36] **Dr. Cynthia Wang:** That's a really great question. In terms of the antibody tests that we have for MOG and NMO, those tend to be more sensitive in blood. I think if you've had multiple test. They've been negative, and they were in the context not necessarily being treated, then I would say that's probably pretty reliable.

[00:05:02] I believe there are some labs, maybe not commercial, that will test MOG in CSF. I've seen very few reports of it being just positive in the CSF. I think it's more common in some of the autoimmune encephalitis that we see. We're very insistent on getting CSF. With that said, I think perhaps there are maybe other things looking at the profile of the CSF that could be helpful in terms of clinical decision-making or treatment selection.

[00:05:32] **Audience Member Online 2:** Another question from online. Arthur asked, what's the consensus on smoking marijuana? I've heard from different doctors to avoid smoking because it's a carcinogen or because it may make my lesions worse. Is there any truth to that?

[00:05:48] **Dr. Benjamin Greenberg:** Do you have advice for your patients in terms of marijuana smoking?

[00:05:56] **Dr. Sydney Lee:** Yeah. So, I think there's been a lot of talk about this over the weekend, and as we know, there's a lot of evidence that we still need to gather. So, I think it's really hard to say whether or not that

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leads to any particular worsening, and we know that different marijuana products have different ingredients. So, it really depends on what you're using, how much you're using, where you're getting it from.

[00:06:24] So, I think we just don't know, we don't have the studies just yet. So, I really take it on an individual basis: What symptoms are bothering you the most? What are we really trying to target? And if marijuana is going to be something that works for you, then we can explore that. But just knowing that there are different formulations and different patients are going to respond differently. So, what works for one person may not work for everybody. But we just don't have the evidence now to really understand its impact in the long-term and on the underlying disease itself. Yeah.

[00:07:05] **Dr. Benjamin Greenberg:** And I would just add, at least from the limited data we have in MS, the one concern that comes up with regular use is on cognitive profiles. There is an impact on cognition with regular use and it's also a dose effect. And then from the pediatric perspective, the conversation I have with younger populations is, there is a link to regular use before the age of 25 and increased risk of psychosis later in life. And so, part of the recommendation is age dependent of the individual taking it. So, if you're over 25, enjoy on a reason. No, I'm just kidding. Just kidding, just kidding. Yeah.

[00:07:40] **Audience Member 2:** I've been trying to think of a good way to compactify this question. If it turns out to be a bad question, I won't be upset with a bad answer. But a lot of us are on B-cell depleting therapies to control our autoimmune diseases, and as a result of that, many of us get sick. And I know the traditional therapy for that is IVIG every four weeks or every three week cycle. Is there any work or studies being done to identify specifically what kinds of infections would be seen in that population? And at what point would that become a medical emergency where you need to get to the ER if you're suffering through one of these events?

[00:08:27] **Dr. Benjamin Greenberg:** Cynthia, do you want to take a stab first? It's a great question.

[00:08:33] **Dr. Cynthia Wang:** Yeah. That is a really great research question. If there's a young person in the room, Dr. Lee, if you want to take that off. What types of infections – (crosstalk)

[00:08:40] **Dr. Benjamin Greenberg:** You're a young person too. I'm going to go ahead and just --

[00:08:43] **Dr. Cynthia Wang:** I'm seasoned -- well, not that knowledgeable. But I don't think we know. I think I just generally counsel it, whatever's going around in the world -- COVID, flu -- do what you can to get vaccines. But certainly, we do see the low IGG hypogammaglobulinemia, and that might be something they follow and assess to start IVIG. But I think equally as much, I see people who have low IGG and they're fine. So, I think it's something that has to be made as a full-picture decision.

[00:09:22] I'm not sure if I answered the first part of your question, but the second part of your question is: When should you go in? When should you be concerned? I think any prolonged fever, anything leading to inability to eat, drink and do normal things. I think probably having a low threshold, just to call your neurology office and talk to them and see where you should go. Sometimes, it might be better to go to a larger center who would not have to Google your diagnosis when they're getting your history. But I think low threshold to go and seek help, get tested, because there are some infections like flu and COVID. There are treatments that can be given early but not as helpful if they're given later.

[00:10:05] **Dr. Benjamin Greenberg:** Denise, this is a call you get all the time on the front lines in the clinic of, "I'm having X concern for infection, what do I do?" How do you on the front lines when talking with families and individuals help people triage this information? Because it's hard.

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[00:10:21] **Denise Maddox:** I mean, usually, hopefully if it's not a Friday afternoon but --

[00:10:25] **Dr. Benjamin Greenberg:** It's always a Friday afternoon.

[00:10:26] **Denise Maddox:** Always a Friday afternoon. I mean, I want to know what they're on, right? And if they're on a really strong immunosuppressant, then it's always going to be, “Try to call your PCP first and go see what's going on.” Sometimes, we'll just go ahead and do blood work and urine, and if it's something that we can treat, we'll try to do that to help, because the last thing I want to do is send you to the Emergency Room where a bunch of sick people are, but sometimes we have to. But usually, it's, "Try to get to your PCP as quickly as you can." And usually, anybody that's immunosuppressed and you're sick, I always say, “I probably would treat that a little bit quicker than I would just your regular kid that you would let fight it for a few days.”

[00:11:10] **Dr. Benjamin Greenberg:** And I will just say, if anyone in the room is having issues with recurrent urinary tract infections, that's one of the more common ones, you can ask your provider to put in what's called standing lab orders, which means you could go to the lab to get testing without talking to your doctor. So, instead of waiting for them to call you back, it's there. You can call your doctor say, "I'm going in for the lab test, be on the lookout for the result." And that usually saves some hours and some time and some callbacks. So, if this is a recurring issue, it's something to consider. So, we're going to do two last questions, here and here. So, yeah.

[00:11:45] **Audience Member 3:** So, obviously, complicated a little bit by low numbers and not having had many cases since 2018, but is there any current ongoing research with AFM?

[00:11:56] **Dr. Benjamin Greenberg:** Yeah. So, I'll answer this one. So, the answer is, yes. So, there were two task forces nationally formed around AFM: the CDC task force and an academic center task force. The CDC one has shut down as the numbers have gone down, but the national one stays alive and well. We have a monthly or every-other-month teleconference with ongoing research questions both around the cases that have occurred in the past, recovery rates, and those types of things and interventions, as well as monitoring for new cases. So, there still is active research going on.

[00:12:30] **Audience Member 4:** Thank you. I'd just like to give a quick shout out to the remote audience if there are any still with us from New Zealand, Australia or the West Coast of California. And the other thing, I just want to offer a comment on the issue of cannabis products. I've never used them, I've never studied them, but I did some outreach work for the New Zealand Cancer Society about 30 years ago. And I remember seeing a list of products of combustion of cannabis product in New Zealand at that time, and it was a pretty atrocious list of chemicals that were residuals. And I'm concerned that any burnt product has an inherent risk with those products.

[00:13:21] And currently, there's some horrendous stories coming out of the legal cannabis industry in California, of lax regulation on spray chemicals being used, not just on the illicit growers, which are an enormous problem in much of the states, but also the licensed and there are supposedly regulated growers. So, I think if you're 75 and older, it's not going to matter if you get cancer in 15 years. But if you're a kid, I'd rather go for the edibles, so just saying. And thanks so much for all your help.

[00:14:00] **Dr. Benjamin Greenberg:** So, thank you for that. So, in our final minute I'll ask each of our panelists about 15 seconds. If you want to leave both the in-person audience and our online audience with any message or anything to take away from all of this, what would that be? And Denise, I'll put you on the spot, we'll work our way down. What's the most important takeaway that you would want people to have?

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[00:14:23] **Denise Maddox:** I think it's, if you're seeing, and most of you are seeing multiple providers, is to have a system that they can all discuss with each other your case so that you're not left trying to be the one person that goes to all of them and then getting different answers. And I think that was probably a big one from Sandy. Just trying to get all of them as a group rather than you trying to herd cows to try to get them all together.

[00:14:56] **Dr. Darina Dinov:** I think probably for me, it was having a community and a support system because I think that's really key. You can have all the medications in the world, you can have all the therapists, but if nobody's helping you and in your corner, it's going to make things tougher. So, having that.

[00:15:19] **Dr. Sydney Lee:** And I think for me, what I would say is, if you have questions or things that you're worried about, don't be afraid to ask us. Even if you think it's out there or you're embarrassed about it, please bring it up at your appointments. We love working with you and talking through these issues and helping you out the best that we can.

[00:15:43] **Dr. Cynthia Wang:** I think just in whoever's online and here participating in conferences like this, I think, just like Darina said, the community that SRNA has built is just so incredible. Watching those videos, they're just so moving, and I think there's so many commonalities and themes and how scary it is to get the diagnosis, how many questions remain once you have the diagnosis and don't know what treatment. And I think just relying on the support network and friends that you've built just in person or remotely, I think that's what will carry people through this. And I'm just so grateful to be part of the community.

[00:16:28] **Dr. Benjamin Greenberg:** Well, thank you all.

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