

Women's Health within Neuroimmunology

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[00:00:02] **Krissy Dilger:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This episode is titled, "Women's Health within Neuroimmunology." My name is Krissy Dilger, and I moderated this episode. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org.

[00:00:30] "Ask the Expert" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and UCB. For this episode, we are pleased to be joined by Dr. Sonia Singh. Dr. Singh is a neurologist and assistant professor of neurology at Medical University of South Carolina, Charleston, who specializes in neuroimmunology. You can view her full bio in the podcast description.

[00:00:57] Welcome and thank you, Dr. Singh, for joining me today.

[00:01:01] **Dr. Sonia Singh:** Good to be here.

[00:00:30] **Krissy Dilger:** Today we're talking about women's health within the context of neuroimmunology. After a rare neuroimmune diagnosis, women might have concerns about how their diagnosis may affect fertility or pregnancy. We're happy to have you on with us to talk about these topics and answer questions that our community members may have. To start off, can you talk about how fertility is affected by a rare neuroimmune diagnosis, if at all?

[00:01:32] **Dr. Sonia Singh:** That's a great question. It is challenging to draw conclusions about fertility, given the lack of high-quality data and the differences between each of these different rare neuroimmune diseases. The most common ones are NMOSD or neuromyelitis optica spectrum disorder, MOGAD, and autoimmune encephalitis.

[00:01:55] Most of what I'll be talking about relates to these diseases. We do know that the presence of some other coexisting diseases, like, thyroid diseases can impair fertility. We also know that older age can affect fertility, and some of these diseases like NMO are diagnosed in women who are older.

[00:02:17] We also know that some immunosuppressant medications like cyclophosphamide can reduce your ovarian reserve, and the rates of miscarriage do appear to be higher in women with aquaporin-4 positive NMOSD. If you cannot get pregnant within 3-6 months of optimal conception attempts, we always advise that you be referred to a fertility clinic to optimize time of treatment.

[00:02:50] **Krissy Dilger:** Can someone with MOG antibody disease, NMOSD, or another rare neuroimmune disorder become pregnant?

[00:02:59] **Dr. Sonia Singh:** Yes, of course, you can get pregnant. Your neurologist will work closely with your obstetrician during the different stages of your pregnancy. If you are of childbearing age, it's important to address your reproductive plans at every single visit with your neurologist. We know that life happens, we know that things can change, and we want to be prepared for whatever it is you envision for yourself and your family.

[00:03:26] Your neurologist will need to take your reproductive plans into consideration when we decide what immunosuppressant medications you're on. And our goal is to ensure that your treatment is well controlled while also being safe for conception, and sometimes even continuation of this treatment during pregnancy.

[00:03:48] If you are of childbearing age, regardless of whether or not you are looking to have children or become pregnant, it is advisable that you are up to date on all the vaccines that are recommended for the general population, and then if you are planning to conceive, getting those that are recommended before pregnancy.

[00:04:10] I've mentioned this before, but discussing family planning at every visit is really important because if you do not plan to get pregnant, then we need to ensure that you are on an effective birth control method that is easy for you to adhere to and is effective while also being easy to reverse in case you do change your mind. If you do plan to become pregnant, then we need to obviously be coordinating with your obstetrician because some of the diseases like NMOSD are considered high risk pregnancies.

[00:04:48] **Krissy Dilger:** That leads me to my next question. Is someone with a rare neuroimmune disorder at greater risk of relapse during pregnancy? And how about after pregnancy?

[00:05:00] **Dr. Sonia Singh:** While we know that pregnancy is an immunotolerant state, meaning that you are less likely to have relapses during pregnancy, they can still occur. In fact, some women may have their first attack of NMOSD or MOG during pregnancy.

[00:05:20] This risk of relapse does increase after delivery, especially in the first few months of that postpartum state. With NMOSD, we know that relapses during pregnancy and postpartum are closely related with how well your disease was controlled prior to conception, which is why establishing care with a neurologist becomes very important.

[00:05:46] **Krissy Dilger:** I guess, going off of that question, can preventative treatments be taken during pregnancy for someone with a rare neuroimmune disorder, or would they need to pause any long-term therapies until after delivery?

[00:06:04] **Dr. Sonia Singh:** This is usually decided on a case-by-case basis with your neurologist and depends on your disease activity. We are starting to collect more data, and if needed, we do have medications for neuroimmune diseases that can be continued safely during pregnancy if needed.

[00:06:24] **Krissy Dilger:** What changes can someone expect to their disease activity during and post pregnancy?

[00:06:34] **Dr. Sonia Singh:** We've already talked a little bit about the higher relapse rate during pregnancy, especially during those first few trimesters. It's also important to note that with NMO, one of the rare neuroimmune diseases, there are other risks that come along with the disease that include a higher rate of miscarriage, preeclampsia. The risk of preeclampsia is higher if you also have other autoimmune diseases like lupus or APLS.

[00:07:07] We also need to remember that certain diseases like NMO can have symptoms that mimic pregnancy-related symptoms, such as the area postrema syndrome, which can present as intractable nausea. So, if somebody has a diagnosis of NMOSD and is vomiting uncontrollably, their obstetrician and neurologist need to wonder if she's indeed having a new attack related to a new lesion in that part of the brain.

[00:07:39] **Krissy Dilger:** I guess going off of that, if someone were to unfortunately have a relapse during their pregnancy, how would that relapse be treated?

[00:07:51] **Dr. Sonia Singh:** So, if you have new symptoms, prompt evaluation is necessary. Please let your neurologist and your obstetrician know that you are having new symptoms. The first step would be repeating a neurological exam. We can get MRIs, though these will be done without gadolinium contrast.

[00:08:09] The first line of treatment is very similar to what you would expect outside of pregnancy. We do treat acute relapses with methylprednisolone and prednisone. If these are not effective, we can utilize IVIG and plasmapheresis. For autoimmune encephalitis, there are additional steps that might need to be taken, such as treatment of seizures or a section of ovarian teratomas that can be done laparoscopically.

[00:08:41] **Krissy Dilger:** When does treatment resume after delivery?

[00:08:47] **Dr. Sonia Singh:** Ideally, we would like to resume treatment as soon as possible after delivery because each attack, especially for diseases like NMOSD, can leave you with disability. We generally will recommend resuming it as soon as possible, but, again, this requires careful consideration of your breastfeeding goals and the state of your disease.

[00:09:10] That's why we would recommend that you follow-up with your neurologist during your pregnancy so that you can discuss these things beforehand, and then get everything ready so that after delivery, in addition to having the responsibility of taking care of your child, you don't have to worry about some of these other things.

[00:09:32] **Krissy Dilger:** You mentioned breastfeeding goals, so can someone with a rare neuroimmune disorder breastfeed?

[00:09:40] **Dr. Sonia Singh:** They can definitely breastfeed. We know that breastfeeding has benefits for both the mother and the child. Many of the medications that we can use to suppress these neuroimmune diseases are safe during breastfeeding, especially medications like rituximab that have more recently been found to be safe during breastfeeding.

[00:10:01] **Krissy Dilger:** Are children of someone with a rare neuroimmune disorder at risk of getting their same disease?

[00:10:09] **Dr. Sonia Singh:** Antibody mediated diseases of the central nervous system like NMO are multifactorial. While there are familial cases, we observe that the risk of genetic transmission is low, but there are certain genetic factors like HLA types that can make it easier for somebody to develop autoimmune diseases and we see that. Wherein multiple members of the same family might have different autoimmune diseases such as lupus, myasthenia gravis, and Sjogren's disease.

[00:10:40] **Krissy Dilger:** My last, I guess, official question is, how can a neurologist be involved with their patient's care during pregnancy?

[00:10:53] **Dr. Sonia Singh:** As mentioned before, your neurologist is on your team every step of the way. Discuss with your neurologist when you plan to get pregnant so that we can ensure that your disease is well controlled so that you are at a reduced risk of relapse, both during pregnancy and postpartum. We need to make sure that your medications are safe.

[00:11:13] I think a very important role that your neurologist has is following up with you during pregnancy to ensure that all the appropriate care for you is organized. Women with many of these rare neuroimmune diseases have spinal cord lesions and can have pelvic floor dysfunction from the lesions that can get worse after pregnancy.

[00:11:41] Organizing things like pelvic floor physical therapy and discussing resumption of immunosuppression or anything else that you might need can be done during pregnancy to ensure sufficient time for scheduling and insurance approvals to really take that off your plate to ensure that you have enough time, enough headspace to be able to deal and cope with being a parent and not have to worry about these other things.

[00:12:13] **Krissy Dilger:** Well, thank you so much. That's kind of the last of my questions, but I did want to give you the chance to, I guess, close this out if there's anything else you'd like to add.

[00:12:27] **Dr. Sonia Singh:** Well, I just wanted to end with saying that this is an exciting time for neuroimmune diseases. We have a lot of new medications out there, and we have great researchers all over the world studying how these treatments can be used during pregnancy and during breastfeeding. I think it's really important to stress the importance of teamwork. Your neurologist is a member of the team, so is your obstetrician, the neonatologist.

[00:12:29] One of the most important parts of treating any neuroimmune diseases is collaboration, working closely with different specialists, whether that be pulmonologists if you have sarcoidosis, urologists if you have pelvic floor dysfunction, and the same really applies to pregnancy. We need to work together to ensure that you and your child have the best outcome.

[00:13:21] **Krissy Dilger:** Well, thank you so much. This has been great, and we're happy to have you on today and hopefully we can continue this conversation in the future.

[00:13:30] **Dr. Sonia Singh:** Thank you.

[00:13:35] **Krissy Dilger:** Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

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