

# Family Planning with MS: Navigating Contraception, Pregnancy & Birth

# Presented by: Alyx Rossi, FNP-B Lisa Doggett, MD, MPH, FAAFP, DipABLM Kimberly Carter, MD, MPP

# Kate Durack:

Welcome, and thank you for joining MSAA's live webinar, "Family Planning with MS: Navigating Contraception, Pregnancy, and Birth." During this presentation, neurology nurse practitioner Alyx Rossi, Dr. Kimberly Carter, and Dr. Lisa Doggett will discuss tips and strategies to help you navigate some important aspects of women's health in your MS journey. My name is Kate Durack. I'm the director of Communication and Patient Focus for the MSIN program of MSAA. I'm also a mom and I was diagnosed with MS in 2016. I have since given birth to two little ones, and I'm absolutely honored to be your host for today's program.

In case this is the first time you're joining one of our programs, I'd like to share information about MSAA and review housekeeping items. MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the MS community. Our initiatives are designed to advance educational wellness and supportive resources. Our free programs and services include a national helpline, equipment and cooling distribution program, educational programs, award winning publications, shared management tools, a peer to peer online forum, and more. For more information about our programs and services, please visit our website at mymsaa.org.

During tonight's program, you'll have the opportunity to submit your questions by using the Q&A chat box. As time permits, questions will be addressed during the Q&A portion of tonight's webinar. Even if we're not able to address all of your questions, we greatly appreciate them as they can help us create future meaningful content. Also, please know that this program is being recorded and will be available as an on-demand video on our MSAA's video library within the next few weeks. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and helps us develop future content and programs. A link to the survey will be included in the chat box.

As a friendly reminder, this program is for educational and informational purposes only and does not constitute formal recommendations. Please speak with your care team for specific questions or concerns.

And now I am so pleased to introduce our guest speakers for this evening. Welcome, Alyx, Kimberly, and Lisa, can you please take a moment and introduce yourselves? Alyx, how about we start with you?

# Alyx Rossi:

Hello everyone. I'm happy to see so many participants. Thanks for being here. I'm Alexandra Rossi. I am a neurology nurse practitioner. I currently practice in MS and neuroimmunology at the University of Texas Health Institution. And I will turn it over to Dr. Carter.

# Dr. Kimberly Carter:

Hi. Thank you very much for letting me have the privilege of being here. I am Kimberly Carter. I'm an OBGYN. I practice at the University of Texas Dale Medical School, Women's Health Department, and I practice out of a level four maternal level of care hospital, which means that we care for the highest of the high risk patients that deliver babies. Lisa.

# Dr. Lisa Doggett:

Hi, everyone. I'm thrilled to be here. I'm Lisa Doggett. I'm a family and lifestyle medicine physician, also at the University of Texas at Austin Dell Medical School. I was diagnosed with MS actually 15 years ago this month. I'm the author of a memoir called "Up the Down Escalator: Medicine, Motherhood, and Multiple Sclerosis" and I'm the proud parent of two daughters who are now teenagers, but they were 2 and 4 when I was diagnosed with MS.

#### Kate Durack:

Our first topic tonight is lifestyle medicine. And since it impacts so many aspects of our women's health topic this evening Lisa I'm actually going to turn it right back over to you.

#### Dr. Lisa Doggett:

Sure. Absolutely. So some of you probably aren't aware of what Lifestyle Medicine is. It's a newer specialty that was created around mid to 20-teens, focusing on prevention, treatment and even reversal of chronic conditions through adoption of healthy habits. And I'm really fortunate to have an opportunity to provide coaching and support to people with MS around lifestyles, helping them to form good habits and to prevent other chronic conditions, because I feel like having MS is more than enough, we don't need any other medical problems on top of that. So I'm really excited to share with you the six tenets of health from Lifestyle Medicine as defined by the American College of Lifestyle Medicine. And these are consistent with what I have found to be the keys to good health in my 22 years of working with patients, both in family medicine and then more recently with lifestyle health.

Healthy habits are so important to you. I mean, really for everybody. But they're even more so in people with MS. In addition to the uncertainty that comes with having multiple sclerosis, we face an increased risk of other chronic conditions like heart disease and diabetes. Health habits like regular physical activity and a nutritious plant predominant diet can do more to prevent chronic conditions than any medication in many cases. They also help a lot with MS symptoms like fatigue and depression. For women that are considering getting pregnant, or who are already pregnant, it's also really important to practice healthy habits to increase the likelihood of a healthy pregnancy.

So that means managing stress, which is one of the tenets of good health. That's my little, kind of, lady meditating there at the top. This can certainly be a challenge. Of course, this is probably the worst one for me, is trying to control stress, but it is a good idea to think about areas in your life that are amping up your stress and develop ways to reduce or avoid those triggers, both before and during pregnancy. And really any time, but especially when you're seeking to have a healthy pregnancy.

Tools for stress management that I've found to be helpful include yoga, mindfulness, meditation, journaling. There's certainly many others. Those are personal preferences. And then, of course, regular exercise is another tenet of good health. It helps with stress as well, but it also improves mood, sleep and overall fitness. The other tenants of good health include sufficient and restorative sleep, and 7 to 9 hours per night is recommended. Another is avoidance of unhealthy substances, and hopefully you are all well aware that smoking and alcohol use of any amount is dangerous and can harm an unborn baby. Next, you know, a healthy plant predominant eating pattern is recommended at all stages of life and this is something we'll talk about later on in our presentation. And finally, my favorite tenet of lifestyle medicine is connection, connecting with others; healthy, supportive relationships. This is especially important during pregnancy when you're going to want to lean on your support circle. Especially as you get closer to your due date and after you bring your baby home. Next slide.

#### Kate Durack:

Thank you, Lisa. For the remainder of our time this evening, we're going to have some common myths vs. facts that guide us in our discussion. And some of these were actually created based on the pre webinar survey. So thanks to anyone who completed that. I am going to ask Alyx to lead us in the first myth vs. fact regarding family planning.

#### Alyx Rossi:

Thanks Lisa and Kate. Yeah, so I came up with these myths and facts I see, inherently a lot of women of childbearing age, as well as men who are looking to conceive with their partner. And so these are things that I see pretty frequently that I think that should be addressed.

So our first myth is: I should only discuss family planning with my MS provider if I'm actively trying to conceive. And the one thing that I wanted to debunk here is that you need to talk to your MS provider and your ObGyn, hopefully you're established with an ObGyn if you're trying to conceive, early and often, if you are of childbearing age, even if you're not trying to conceive. Weirder things have happened. There are surprise pregnancies, so this should be something, family planning, conception, contraception, that you're talking about at every visit with your MS provider.

And the second myth here: contraception methods are unsafe to take while on disease modifying therapy. And the fact here is that all methods of contraception appear to be safe to use in MS. It's important to note that while some oral contraceptions may interfere with the effectiveness of drugs you take to manage your MS symptoms, this is also kind of vice versa. So it's a discussion that you need to have with both your ObGyn and your MS provider for best guidance. This is kind of true across the board. You want both people, both teams to really be in sync to manage your MS care and your pregnancy planning. And then, Dr. Carter, I think there's a case here that you wanted to bring out about the Modafinil, which is frequently used, in MS for fatigue.

# Dr. Kimberly Carter:

Yes. Thank you. Mostly the way that the Modafinil metabolizes in your body, it can affect the absorption of oral contraceptives. And this is why you want to have discussions with your ObGyn as well as your neurologist as to what type of contraception is best for you. In general, most people with MS can take any type of contraception that matches with their lifestyle. We do have a few exceptions. If you have very, very decreased mobility where we would avoid estrogen containing medications, and if you are taking a DMT that can potentially affect the effectiveness of your birth control, then we would want to either use a backup method in addition to that birth control, or switch to a birth control that is not affected, its efficacy is not affected by what you're taking.

# Alyx Rossi:

And then one thing that I wanted to add, before we go into the next slide, is please participants, throw in some questions. This is meant to be interactive. So if I have said anything, if Dr. Doggett or Dr. Carter has said anything, I'd really like to take questions as we go, so that we don't, you know, forget or miss something that's important to you. So, please, you know, raise your hand, throw a question in the chat. Happy to answer it.

Myth, and this is a big one that I see: I should stop my disease modifying therapy if trying to conceive or newly pregnant. There is a lot of variation in the fact here, and really, like, the take home message of this is as soon as you think you're trying to conceive or you think you want to become pregnant or you are pregnant, you have to let your neurology team know. And the fact is, while the US DA, or sorry, the FDA has not approved any disease modifying therapies for use during pregnancy or breastfeeding, there's a lot of evolving guidance on their use during conception, pregnancy, and postpartum. Again, there's a ton of variances on how we use disease modifying therapy when it comes to timing, how long we can continue. So, you know, the actual insert on the medication says "can't use well while pregnant," you know, this might be trimester specific. So again, and I'll probably say this so many times that my face turns blue, talk to your MS provider early and often throughout your family planning journey so that you can make the specific choice based on your situation that's appropriate.

#### Kate Durack:

I actually wanted to add something, a personal story to that point, Alyx, the "early and often." I think I had the penultimate "early and often." I was diagnosed in 2016, as I mentioned, and so this was before I really knew when I wanted to have babies. And, I remember sitting in the office, and this was the actual appointment when I was formally diagnosed with MS, and before we even really went through my MRI and discussed kind of where I was at and all of that, my neurologist set everything aside, he scooted towards me, and he said, Kate, what do you want for your life? I'm not talking about your MS right now, I'm talking about your life. Do you want to be a mom? Like, what does this look like for you down the road, regardless of your MS? And so I was really able to have very open conversation about what it was that I would like to do. And then he gave me honest and timely feedback on how to do that in a safe way for me and for my babies.

And so I had that kind of built as the foundation that I carried through and still do today, so that I can have those open conversations with my entire care team, and really know how to self-advocate and know the importance of that. So I'm hoping that, number one, you have neurologists that are in your corner like that, and if you don't, just know that you should be starting those conversations. It's okay to be the one that brings that up. You absolutely should be the one that brings that up, early and often.

# Dr. Kimberly Carter:

These next few slides, I don't want to go through every single medication, what I'm hoping for is that you screenshot them for your own reference in the future. But what I've done is I made a table that went through the most common medications that we use, including if there's relapse during pregnancy, if it's safe to use during pregnancy. And what I want to nuance is that there's some medications that are known to be harmful, and there are some medications that are not known to be harmful but that, potentially, if we gave you doses that were 100 times more than what we normally would, that we have seen some things that might not be optimal in animal studies, but not necessarily in human studies. So when you see something that says safe to use, maybe, probably that indicates that there was an animal study that showed it extremely high doses that are not typical to be used in a human, that we might see some untoward effects.

The washout time is how long does it take that medication to get out of your system? So this is essentially five times the half life. So if there was a medication they are on and you want to know how long it takes to get out of the system so that there is no chance that the baby would be exposed to it, that is the washout time. So if you could just go through the next couple of slides and just pause and allow people to perhaps screenshot it, or at least know that you can go back and screenshot it, then that might be, I'm hoping that's going to be helpful to some of you.

And in regards to disease modifying therapy, ideally what we want is for you to be in remission at the time of conception, because the better you go into pregnancy, the healthier you stay during pregnancy. And we're going to talk later about how the risk of relapse decreases the longer you're pregnant. And ideally, you would simply be in remission at the time of conception. And I know everyone focuses on the risk of taking medications. And again, hopefully what you saw is that there's quite a few medicines that we would definitely want you to stay on if you need to be on them. And the one thing that I want everyone to know is that if the mother doesn't do well, the baby doesn't do well. So, this is a really important dyad relationship, and we don't want to consider just the health of the baby. And so one of the things that I wanted Alyx to talk about was what are the risks if you choose not to take the medication but you need the medication. So I will leave it to Alex.

# Alyx Rossi:

Yeah. And and Dr. Carter, when you talk about dyads, I think it's really important, you know, when we're conceptualizing this thought about remission, because I often find patients who feel like they have to be in remission for some specific amount of time. Right? Like, I haven't had a relapse in five years in my life. Am I safe now? Am I at risk? And the duality of that conversation and the dyad that you need is a really strong communication between your neurology provider and your ObGyn. Because, these decisions need to be a shared decision making type topic, where there needs to be a comfort going into the decision to conceive and go forth with childbirth. And I think that there's kind of this preconceived notion that you had to have been on, you know, a certain disease modifying therapy for, I hear the two year mark thrown around a lot. And I kind of want to debunk that myth a little bit, because it's really specific to your disease phenotype. You know, it looks a little bit differently if you are, you know, diagnosed early and you're put on high efficacy disease modifying therapy early, versus a patient, you know, that might have a very aggressive phenotype. And so it's a conversation you need to be having with your neurology providers.

So as Dr. Carter said, not only are there risks to continuing some medications, while some are safer, there are risks to stopping some medications when it comes to risk of relapse. And again,

while there's no FDA approved disease modifying therapies approved for use, several medications can be used very safely during the... we think that they can be used in the first trimester with minimal adverse effects to the fetus. The risk of relapse is generally lower, or, sorry, higher... higher during the first trimester and lowers gradually, and significantly by the third trimester. So there's some data to suggest that the risk of relapse in the third trimester is actually as low as the control that we have with our highest efficacy disease modifying therapy. So that should be reassuring to the newly pregnant individual.

And then, I do want to kind of hit home a little bit. There's no one disease modifying therapy that we recommend per se. It's really based on lifestyle and what is best for the patient. But I really urge my patients, that are of childbearing age that may want to conceive soon to consider use of B cell therapies before pregnancy. And the logic here is that we kind of have more bang for your buck, if you will, with B cell therapies, because you get to extend the prevention of disease benefits, meaning that you're covered from relapse while the drug is not actually bioavailable in the system. And I think there's a question here that I can get into a little bit more, after we finish this slide, or perhaps later. But yeah, you're still covered from relapse, for the most part, while your baby's not exposed to the drug.

And this is a key point that I wanted to talk about. So, careful consideration should be taken when stopping or tapering from medications in the S1P class. These medications are Gilenya, Mayzent, Zeposia or Tysabri. And the reason here being is that stopping these medications abruptly puts the patient at risk for rebound disease or relapse. And this is not specific to pregnant patients, this is specific to all MS patients on these drugs. So rebound is disease, and this is another point that I want you to take away, is that rebound disease, after you stop these medications and don't start another medication, can occur up to six months after stopping these. So it's not just, you know, immediate rebound disease. It can occur a couple months after. So there needs to be a lot of planning. Women of childbearing age who are on these medications, again, should discuss this with their neurology provider.

#### Dr. Kimberly Carter:

You know, one of the things I just want to jump in and add is that life is meant to be lived, and we don't want this disease to make the path that you choose, you need to choose the path and not let the disease lead you. We can deal with almost everything that you throw at us to some extent and to most extent. And so I don't want people to delay childbearing because they want to be in remission for X amount of time. I don't want anyone to think that they should delay childbearing because they want to be off the medication for X amount of time. Instead, what we want you to do is always consider that if you want to have a family, what are the steps that you need to take in order to have a family with the least risk to both you and the baby?

#### Kate Durack:

I love that, thank you Kim. And we do actually have a question that came in. Someone asked what you might suggest for... Okay, so someone asked what the doctors might suggest for birth control for someone who's on one of the treatments that are recommended to be avoided during pregnancy. So how would you have that conversation?

# Dr. Kimberly Carter:

So those types of medications that are known to cause harmful effects to a fetus, those we really prefer long acting reversible contraception, like IUDs, NEXPLANON are going to be our favorites for that. Depo-Provera also works very well. And then our second line is going to be the NuvaRing. And then of course third line would be birth control pills. So we really want things

that take user error out because we know in, what, 24 of our states, we have problems with access to all women's health care, and we don't want to put people in positions where they have to travel in order to get full health care If they need that. So long-acting reversible contraceptions are preferred.

#### Kate Durack:

Alyx, anything to add from you for that one?

#### Alyx Rossi:

No. I would say, you know, great point, Dr. Carter on talking about, like, that there doesn't have to be, you know, this fear going into it, that there are always choices for the patient. And I think that should be empowering. Meaning that, you know, if now is not the time in your life, and you're on one of these medications and ten years down the line, you know, you're saying, okay, you know, now is the time to create a child. That is okay. We have options. We can make different moves, we can escalate therapy, we can choose other therapies. You know, again, that's what we're here for. That's what we're here to help you navigate with. And so, you know, just initiate that conversation, be honest with your providers and we can help you navigate it either way.

#### Kate Durack:

I was going to say the same. I mean, it's just there is no rule against connecting your providers either. So, you know, my ObGyn talks to my neurologist. And, you know, we're all on the same page. We're all good. Yes. So bring those people together. I mean, you are that glue. So speak up, ask those questions.

#### Dr. Lisa Doggett:

And I'll just add one thing, which is that if you talk to your primary care physician, if they're not someone that usually does obstetrics, which is not very common these days in primary care, they may not know about these medicines. They are probably not the best person to advise you. You really do need to talk to your neurologist or to your OB provider. And this is just such a subspecialty that a lot of family physicians and even internists aren't necessarily going to know the medicines very well and know how to advise you and may actually think that, you know, they may provide bad information even about making you scared about getting pregnant with MS, when in fact you're very likely to have a perfectly normal pregnancy.

#### Kate Durack:

Thanks for that Lisa. All right, back to you, Alyx.

#### Alyx Rossi:

Okay. This is one that I think is not talked about enough. So the myth is that fertility treatments such as in-vitro fertilization can increase the risk of relapse. And there's a recent large study that shows that participants who actively manage their symptoms and control disease with disease modifying therapy did not find an increase in relapses with fertility treatment.

#### Dr. Kimberly Carter:

One of the other things I can add is that if you want to save your genetic material and you're on one of these medications that can cause bad side effects, surprisingly, you can still do egg retrieval with an IUD in place and save that for later and then fertilize it. Do your things. The point, and I don't want to get into all the how we do that, but the point is that you have a lot of options. You just may not know them if you're not talking to your healthcare providers. So we just want to continue just to encourage you to just imagine the world that you want to have or the family that you want to have, and let us worry about the details on how to get you there.

#### Kate Durack:

Kimberly, I had no idea that was an option. Hadn't even thought it. So thank you for sharing that. That's awesome. All right, back to you, Alyx.

#### Alyx Rossi:

All right. One that comes up in my clinic all of the time, and Dr. Carter, feel free to jump in, because I'm sure that you have some things that you see as well: MS can increase the risk of miscarriage, stillbirth or congenital disorders. And there's absolutely no evidence that MS leads to any of these, which should be very reassuring to everyone on this call. So several studies of large cohorts of women have repeatedly demonstrated that pregnancy, labor and delivery and the incidence of fetal complications are generally no different in women with MS than women without MS.

#### Dr. Kimberly Carter:

Yeah, I would concur with that. I have to say, in planning for this webinar, so much of this was me just saying, you're going to be fine. You're going to be fine. There's really... we're going to treat you the same, because so much of MS is just not affected by being pregnant and vice versa, which is great.

So, this is part of now and in the future. The genetics behind MS are not specifically known. There are over 250 different genes that may be associated with why you have MS. There's also environmental factors. For example, we know that if you're born in a colder month or in a colder climate, you seem to be more likely to have MS. So there seems to be not one thing that we can point to. We have noticed that there is a slight increased risk of MS in your children, but this risk is very, very small. It's 2%. And as we learn more in the future over how genes might interact and cause MS, then that's still going to empower us to potentially affect those genes in the future. So, this should not be a reason to not move forward. I have these same conversations with people who have a variety of other genetic illnesses, from having heart defects to having neural tube defects. There are many things that you could potentially pass on to your children besides your eye color or your hair color. This is one of them. And while you may really want to avoid this, just know that we're still working behind the scenes on the science part in order to make this perhaps not a part of the future of your children. So it shouldn't be a reason to not move forward with the family that you want to have. But this is the reality of the statistics as we know them today.

#### Alyx Rossi:

Yeah. And Dr. Carter, one thing I want to add to that, and the things that I tell patients in my clinic is, you know, of course it comes up, will I pass down MS to my children? And the one thing that's reassuring is there is not one genetic carrier that increases your likelihood. So when you talk about linear hand-down, there's not one genetic piece that we have identified where you can pass down MS from that. And MS development, again, what Dr. Carter is speaking to is that, and this is the crux of, you know, finding out a cure for MS, but what we found, and Dr. Carter has it here in her slide, is that it's a variation of factors. So, to develop MS, we found that you not only have to have a genetic predisposition to have an autoimmune disorder. So there's kind of this likelihood of inflection where your, where you have an autoimmune cascade and we

haven't quite figured out that piece, but it's also environmental. So it has to be that predisposition plus an environmental exposure.

#### Dr. Lisa Doggett:

So, I'll take this slide. But before I do, I just want to, I guess, validate the concern as a mom of kids, and after myself having MS, that it is something that I certainly worry about, my kids risk, it is small but it is still higher than average. I feel, and we've actually had gone through a period where I thought my daughter had weird symptoms and I was like, oh my gosh, could she have a MS. Pediatric MS is quite rare. So that's good to know. And also, I think that if you have MS and your kid has weird symptoms, even if they're, you know, as they're growing up, you're going to be more tuned in. If they do have MS, it's much more likely you'll catch it early. The medicines are great now compared to where they were even when I was diagnosed 15 years ago and they're getting better all the time. So I definitely am a lot less worried about my kids' risk of MS and what that would look like than I used to be.

But anyway, moving on to the slide. So the myth is: I need to significantly alter my nutrition and exercise routine when pregnant with MS. The fact is that lifestyle modifications required for pregnancy are the same, regardless of an MS diagnosis. And, just to kind of touch on what those lifestyle recommendations are, there are some foods that you need to avoid during pregnancy, certain kinds of fish that may have high mercury levels, soft cheeses, for example. There are others as well. But during pregnancy, a healthy diet is really more important than ever. Having MS doesn't change that. You don't need a special diet because you have MS. You do want to try to eat a whole food plant predominant diet, which is rich in fruits and vegetables, whole grains, nuts, seeds, legumes. You want to avoid or minimize red meat, especially processed meat, as well as sugar sweetened beverages or anything that has added sugar and salt. And this is true whether or not you're pregnant, whether or not you have MS. I feel like it's even more important because of MS, but it's really good for everybody.

So with exercise, you really, during pregnancy is safe and actually recommended to exercise. So exercise guidelines call for us to exercise 150 minutes per week of aerobic exercise. That's about 30 minutes, five days a week. In addition to that, strength training of all major muscle groups, like doing core exercises or weights or you could do resistance bands, that's recommended twice a week for all adults. This is true even during pregnancy, though the exercises may need to be modified, especially as you're getting closer to term or if you're having complications or a high risk pregnancy. During my pregnancies, I continued to run. I love to run. I did not yet have MS, but I probably would still, I still do it even having MS, I still have continued to run. And I ran up until my third trimester. I did not run the entire time. I got to be just kind of awkward and uncomfortable towards the end. But then I switched to walking, and I really think it made for a much easier labor process for me. Certainly swimming is a great exercise during pregnancy because you're just... you don't have the weight as much. And then also even light weight-training during pregnancy is something that I did. And I think that's very reasonable. It's going to improve your overall fitness. It'll reduce your risk of complications. If you have complications of pregnancy, sometimes you do have to stop exercise and modify your therapy, your activity, but in general, staying active up until delivery is recommended and it's going to help you have an easier delivery process. Kim, do you have anything you want to add to that?

#### Dr. Kimberly Carter:

No, I think you summarized that very well. I will say that exercising a lot during pregnancy has the reward of decreasing the risk of cesarean section and decreasing how long labor lasts. So...

Dr. Lisa Doggett: Excellent.

#### Kate Durack:

I loved my yoga during pregnancy.

#### Dr. Lisa Doggett:

Oh, me too. It was great.

#### Kate Durack:

Got to connect with other moms too, which was also lovely. I highly recommend. Back to you, Alyx.

#### Alyx Rossi:

Kate told me that this was her favorite because she didn't know this before going into it. So, the myth: I can't undergo MRI while pregnant. You, in fact, can. You just can't get contrast. So MRI can be safely conducted during pregnancy for those with MS. The use of gadolinium contrast, which is what we use in contrasted studies, is not recommended. This is really important when you're talking about, perhaps, transitioning off of disease modifying therapy or using a disease modifying therapy that may not extend through the duration of your pregnancy if new symptoms come up. We, as a practice, do not just, you know, especially when you're pregnant, throw around steroids. And so it's really important to know if there's truly new disease in order to identify if you need to be treated. So MRI can be a very good tool both in pregnancy and postpartum.

#### **Dr. Kimberly Carter:**

Yeah. I think the message that people need to especially hear is that your care for MS should not be affected because you are pregnant. The evaluation should be the same. The options that we give you might differ somewhat, but we're still going to treat you, because, again, it's very important that you do well for the baby to do well.

#### Alyx Rossi:

And then I think this one's me too. So, myth, and Dr. Carter was alluding to this: I can't be treated for disease relapse during pregnancy. So, the fact here is that steroid usage may be possible and is possible in some cases when pregnant to treat disease relapse. It's important to work with your medical providers to determine, again, if these symptoms are due to true disease flare and new disease or if they're a symptomatic flare, which we can see sometimes.

#### **Dr. Kimberly Carter:**

So this one is in regards to how you deliver. And the reality is that there really is no difference for how you deliver. Some people are going to deliver by cesarean section because the passenger is too big, or the pelvis is too small, or you just don't have enough contraction power to get that baby out. And some people are going to deliver by vaginal delivery, but the MS is not going to be a factor in how these babies come out.

#### Kate Durack:

We actually just had a great question come in for the previous slide, and that was: Are there specific symptoms or signs when you're pregnant versus not pregnant that would show that you have disease progression? Alyx.

#### Alyx Rossi:

So the short answer is no. What you're looking for is all of the same neurologic symptoms that you are taught to look for when you're not pregnant. These, again, you have to distinguish, and this is a day in the life of my clinic, is you have to distinguish what is a sign of new disease and what is perhaps a flare of your existing or presenting symptoms, which can be kind of intermittent and can also take a little bit. But if you ever have any question, I urge all of my patients, come to your provider, name out your symptoms, go for a physical exam if there's any suspicion that your provider should be sending you for MRI, if there's a thought that there might be a new disease, and there is no harm, no foul in doing that. All of the provider team would much rather know if you have new disease than just kind of sloughing it off. So, please communicate if you're worried about new disease or if you just don't know what to look for. So looking for focal neurologic deficit, what does that mean? That means any new motor weakness or any weakness anywhere that's abnormal to you. Any sort of sensory symptoms. So new loss of sensation, any neuropathic pain. Of course, any persistent visual issues needs to be brought to your provider. Any trouble walking, urinating, or stooling needs to be talked about as well. And, you know, kind of the list goes on and I'm happy to talk about that more. But in general, that's what I kind of caution my patients to look for for new disease.

# Dr. Kimberly Carter:

And then I would encourage you to talk about that to both of your providers, your ObGyn as well as your neurologist, because pregnancy does have some aches and pains that are typical for pregnancy. We have some people in the second trimester who have urinary retention because of the way that the uterus is positioned in the pelvis, and it just is because you have a retroverted uterus and not because you have MS. We have round ligament pain that happens in the first trimester, sciatica, lateral cutaneous syndrome, a whole lot of things that are normal. And so we're always going to have a heightened awareness if you are a patient with MS, and we're still going to want your neurologist involved in any new symptoms, but oftentimes we can allay those fears pretty quickly by saying this is pretty typical. Even your eyeball shape changes during pregnancy and all the wildness that comes with it without the worry that it's just something that's going to happen to you during pregnancy where you might have a relapse. Because again, the reality is, is that the overwhelming majority absolutely do not have relapses. And the longer you're pregnant, the less likely a relapse is to occur.

#### Kate Durack:

I love that, Kim. Thank you. I have a few things to add from our conversation. So, Kim, to your point, I think, and actually, Lisa, you mentioned something similar earlier. as a person living with MS, I am so attuned to my body. I mean, maybe too much sometimes, let's be honest. But I think what's great about it is, a positive, is that I do pass on that to my kids. Right? So, I want them to be in tune. I want them to be telling me when something doesn't feel right. I want to be sure that I'm listening because all those things are important. And then being able to weigh kind of what we're doing about it, what's the severity, and that kind of thing. When I was pregnant, I was actually traveling for work at the time and I was at a hotel. I had gotten my morning coffee, and I was sitting there and I was holding it in my right hand, and all of a sudden I looked at my hand and I couldn't tell if I was holding the cup. And that sounds so strange. But my brain, I thought I was going to drop it, but I knew I was also holding it strongly enough. It was the weirdest disconnect of mind-body, and I was so nervous that I was having a relapse. But I was able to connect with my neurologist and my midwife at the time, and they kind of just helped me through it. And it was not progression. It was just like a little flare from hormones and all was well, but it was good to just have that team to support me in that time that was really scary

because there are so many things that are, unexpected that happen with MS, and just instant changes with your body. And so it's really important to be in tune with those, to bring those up to your care team and to keep those conversations going.

We did have another audience question. Are there any interactions or complications identified between gestational diabetes and MS?

#### Dr. Kimberly Carter:

So yeah, we actually do know that there are not. So the gestational diabetes is something that happens because of a specific protein in your placenta. And MS does not affect your placental functioning in any way. So if you have gestational diabetes, you just have gestational diabetes.

#### Kate Durack:

And I will attest that it is not fun. And I'm sorry and I understand what you're going through. My son was more than 9 pounds. He was a rather large baby, and I did all the finger pricks everyone wanted to do during their pregnancy.

I actually have one other question. I think it gets a little bit past birth, but I think that it's something that a lot of us think about when we're pregnant and living with MS, and that is the increased risk of relapse, disease progression, after birth and labor. So, Kim and Alex, could you talk a little bit about that?

#### Dr. Kimberly Carter:

Yeah. I mean, I can say that we really want people to work closely with their neurologist because there is an increased risk of relapse after birth. Again, on the list of medications I put in if they are compatible with breastfeeding because we don't want to think that anyone is detracting from their baby if they're on medication, we want you to be on medication. If you need to be on medication just in step.

#### Alyx Rossi:

Yeah. And Dr. Carter, the conversation, the way that I approach it in my clinic, again, we're having these meetings every couple of months of, like, what's the plan going into pregnancy? What are we doing with disease modifying therapy? What are we going to do after? And so we very much have a plan of, like, what are we doing after? And, there are patients that choose to resume disease modifying therapy and breastfeed, and they do so well, and the patients that l've known, they've done it quite safely. Their babies turn out just fine. There are several studies that support specifically B cell therapy can be safe while breastfeeding. B cell therapy is a very large molecule. So the availability for it to actually affect the child is almost nil. And so the way that I approach it is I present my patients with data, I show them the studies, we have, again, a shared conversation about it. And then I ask them to bring this information to their pediatrician. I say establish with the pediatrician, bring it to your ObGyn, your maternal fetal medicine specialist, your pediatrician, and have that same conversation with them. Because I want everyone in the room to agree on what we're doing. And most patients do quite well with that conversation.

#### Dr. Lisa Doggett:

I'll add one other thing. Just, at that same time, you want to be thinking about your post pregnancy contraceptive plans. So that needs to be part of the conversation in terms of starting a therapy again for MS.

# Dr. Kimberly Carter:

And we usually try to have those conversations while you're pregnant.

#### Dr. Lisa Doggett:

Oh, absolutely.

# Kate Durack:

I actually, with my second son, I had my boys very quickly. They're 16 months apart. And, after my second son, I had a plan through both pregnancies, I kind of knew how I wanted to map it out with treatment, because I had been talking to my neurologist during both pregnancies. And so, I decided that if it was possible, I would breastfeed for four months, and then I would switch to formula and I would get started on my DMT. And so I knew that going through, I knew there was a risk of relapse even in that plan. And it did happen. I did have a relapse during that four months. And it was scary. I'm going to be very honest. But at least I knew that it was a possibility. And I had that conversation. I had prepped myself mentally as much as possible for that to be part of my journey postpartum. And I felt, you know, pretty prepared for it. So, that being said, I also just wanted to share that there is absolutely no shame coming from my end over here about choosing formula over breastfeeding if that means that you need to start your DMT again or something along those lines. So I don't know, Kimberly, if you wanted to speak to that from your clinical perspective.

# Dr. Kimberly Carter:

So we consider it successful breastfeeding if you breastfeed for two weeks. That's the standard. And while it would be great if you did it longer, the reality is, is that formula is not poison. It's actually really well formulated to mimic breast milk. It even has a long chain fatty acids in it now. And so we need to do what's best for the family. Period. So some people need to not breastfeed. And then it's not just because of medications. We have patients who can't breastfeed because they have breast cancer. We have patients who are on chemotherapeutic drugs for other diseases. There is a whole host of reasons why women cannot breastfeed. And it's... there should be, just, in general for any decisions you make, whether it's how you deliver, how you breastfeed, many things, we need to be supportive of each other and not have any judgments on how this goes. There's a lot of this that is simply out of your control, and we really want to be supportive. And how just to make you the healthiest family that we can.

#### Kate Durack:

Okay. Thank you. We have another audience question. Are there any studies on cord blood treating MS?

#### Alyx Rossi:

I'll take that. So there's not any data to suggest... I'm like, is there a neurologist, an anonymous attendee here, challenging me? Whoever it is is quite bright because I appreciate these questions. There are no known studies that have proved significance with treatment of cord blood in MS. there are several trials going on with stem cells. So, self-harvested stem cells is something that we're looking at for relapsing remitting MS, and there's several institutions, academic institutions, that are showing some promising results with self-harvested stem cells. So not cord blood.

# Dr. Kimberly Carter:

I think I can add that, not to whether or not it works, but if you're considering that you want to do cord blood collection, because what if that is a possibility in the future? One thing that I want you to know is that right now, we have enough cord blood in our cord blood banks for free for everyone who needs it. And so you don't have to spend thousands of dollars, especially if that would be detrimental to your family to spend thousands of dollars for something that we don't know will work and that we don't even know if it's going to be able to be retrievable, depending on how it was collected. I would always think about cord blood collection as an insurance policy that you hope you never have to use, and if you do have to use it, you just have to know that there's no standardization in how we collect it. Some are stored in plastic, some are, stored in glass, some are using the heparin solution, some are using a saline solution. And so going out 9 or 10 years and using this in order to do something that is right now just a myth is not something that I would encourage anyone to use. And again, I want to emphasize we have public cord blood banks. And if this becomes a real treatment, if you didn't save your baby's stem cells, it doesn't mean that that treatment option will not be available to you in the future.

# Kate Durack:

That's really good to know. Thank you. I think we have time for one more quick question, and that is: Assuming there's an increased risk of relapse postpartum, generally, about how long after giving birth does relapse occur?

# Alyx Rossi:

I'll take this. So this looks, again, this looks very different for everybody. Generally, we say the relapse, the chance for relapse starts to really kind of hike up around three weeks, four weeks. Now, that number can be a little bit skewed by somebody that exclusively breastfeeds. But I really discourage using that as a way by which to modify disease. Because again, you know, these are very variable depending on what your disease looks like. But typically, we try to get that dose of disease modifying therapy, that first dose in between anywhere from two weeks postpartum to six weeks postpartum, really, because that number starts to climb at about that time.

#### Kate Durack:

Thank you so much. A huge thanks to the three of you for all your valuable insights. I'm very excited to see where our conversations go from here, and I hope to be back with the three of you soon. And our planning sessions were also super fun. So thank you. I learned so much. This concludes our webinar. And on behalf of MSAA, we want to thank you for your time and participation. Remember that this program was recorded and will be archived on MSAA's website in the coming weeks. Please take a few minutes to complete the brief survey. And thank you to all of you for attending and have a wonderful evening. Bye.