



**MS Learn Online
Feature Presentation
MS & Pregnancy: Kara's Story
(Part One)**

Tracey: Hi I'm Tracey Kimball

Tom: And I'm Tom Kimball, welcome to MS Learn Online.

Tracey: For many women with MS, the questions surrounding pregnancy and motherhood are complex.

Tom: This feature presentation is the first of a two-part series titled *Kara's Story: MS & Pregnancy*. It's a special look into one woman's journey with pregnancy and MS.

Tracey: We'll also hear from top neurologists who share their thoughts and concerns on this topic.

>> Initially, when I approached the National Multiple Sclerosis Society of my idea to make a video about MS and pregnancy, I had questions that I thought needed to be answered by an MS specialist, and that maybe other women had the same questions that I did.

It is my hope that this video will reach a wide range of people, extending from OB/GYN doctors to neurologists, to anyone with MS, and, of course to women with MS who are struggling with a decision regarding pregnancy.

I hope these women will see my experience and say to themselves, "Oh, gosh, I can do it, too!" And, of course, gain more knowledge or be inspired to get answers to their questions that were not answered on the video.

It's hard to believe that it has been two years since we started shooting the video, and I think the most important thing that I learned was that us women with MS are more like other women than not. And that's really a great feeling.

(Video)

>> When we decided that we wanted to get pregnant, we did as much research as we could.

>> The first step being just reading the typical books that any other soon-to-be-parent would read, and just trying to understand how a simple pregnancy will affect any partner's relationships and how they're going to move forward with that. So, that was the first step.

>> My cousin found a clipping in a pregnancy magazine about multiple sclerosis and pregnancy, which was a couple of pages long, and it was helpful. We're going to use this opportunity making the film as a learning tool as well. We'll learn along with everyone else, really dig out that information, the questions that we have.

My first symptom was probably in the summer of 1997. I had a bad case of bad dizziness. The next year I had a round blind spot in my left eye. The next year, in '99, I was all of a sudden, was having a hard time moving my right leg, and it was kind of having to make an effort to walk and be careful not to trip.

I went for a long walk one day thinking I'd walk it out, and got to my destination and realized that I wasn't going to make it home. So, I called my brother, to have him come pick me up, and he said, "Well, you should see a doctor."

>> For many women with MS, the prospect of becoming pregnant and raising a family is often filled with doubts and concerns.

>> In the bad old days, neurologists told women with MS not to have families and not to become pregnant. Unfortunately, this was not really based on any evidence.

>> But as research has progressed over the past few decades, the results have continually shown that women with MS can have safe pregnancies, healthy children, and viable family lives.

>> In general, MS does not affect a woman's ability to carry a child or bear a child, and thus the complication rate for women with MS would not be expected to be greater than somebody without MS with a similar health status.

>> But even with the reassurances of physicians and clinical studies, many women still find the thought of getting pregnant to be both intimidating and confusing. There are so many questions about drugs, fatigue, relapses, breastfeeding, and even whether or not the disease will be passed from mother to child, but trying to sort it all out requires a fair amount of research and patience. Fortunately, for modern would-be moms and dads, there are many resources for information. Given a little time and effort, some answers can be found. Considering the unpredictability of the disease, the answers you'll find are often surprisingly simple.

>> And so the middle of October, I went off my medication, because the doctors suggested to go off the medication two months before you intend to try. So, that was kind of a relief, because I do take the Copaxone, which is a shot every day. So, for the first time in a few years I didn't have to do a shot every day, and I was pretty excited about that. And was really feeling very healthy and felt pretty confident about going off the medication. Since I've done some lifestyle changes that have kept me healthy for a year or so, I felt pretty comfortable about that.

>> MS, as far as we know, has no effect on fertility, no effect on miscarriages, no effect on congenital malformations or any other area concerned with conceiving and carrying a child.

>> However, most doctors will recommend that women have their MS under control before trying to get pregnant. Keeping a routine that includes rest, exercise and a healthy diet is especially important to pregnant women with MS.

>> We certainly encourage pregnant women with MS to go about their normal routine and their normal activities as well as they can tolerate. Any woman who is pregnant is likely to incur increased fatigue, and this may be a little more of a problem for a woman with MS. So, it might be advisable for her to get a little extra rest. But other than this, she should go about her normal schedule, including work or recreation or exercise as she can tolerate it.

>> Patients with MS should carry on their routine activities when they're pregnant as if they were not pregnant. And, of course, that also includes MS patients avoiding heat, so, exercise outside in the summer, things like that.

>> So, mid-December rolled around two months after going off the medication, and I suggested that we casually start trying to my husband, and we did, and immediately got pregnant. And we got very lucky, and that was quite the blessing to get pregnant so soon.

>> The next question is often, "Can I pass this along to my child?" All things considered, while the hereditary risks are greater, the probability is fairly low, somewhere between 1% and 5%.

>> If a parent has MS, the risk of a child developing it is greater than the child of a parent who does not have MS, and this is approximately 5% for the daughter of a parent with MS, and 1% to 3% for a son of a parent with MS.

>> Oddly enough, women who have MS, often discover that the effects of the disease are reduced during their pregnancy.

>> I disagree with what was done decades ago, where women with MS were told not to have children. And the reason I disagree with that is because what will happen when they have a child is during pregnancy they'll be protected somewhat -- well, actually, significantly from relapses in the last half of the pregnancy.

>> We now have decades of data that tell us that women with MS certainly can become pregnant and bear children, and this does not affect their long-term disability. And we have recent data that tells us that pregnancy is actually very protective. So, in general, I try to encourage my patients who want to start families to go ahead and do that.

>> One often wonders, what is this protection during pregnancy mean? Does it mean that my symptoms are going to get better, or does it mean I'm not going to have a relapse? So, to be very specific, what the protection during pregnancy means is that during the last trimester, and really, approximately the last half of pregnancy, there will be a decreased probability of having a relapse. And, of course, that is a new symptom that comes over a day or two and lasts for weeks.

So, there is a decreased probability of having a relapse. It does not mean that preexisting symptoms will necessarily get better or worse; it just means you are less likely to have a relapse.

>> Having a family has always been a dream of mine and my husband's. We both were raised in big families and really cherish what a family brings.

Well, I don't know if you remember this, but February 3 of 2000 was the day I was diagnosed with MS. I am hoping to tell my sister today, February 3, because it's a day that I kind of want to replace. "Today I'm going to replace that bad memory with a great one, and tell you that I'm pregnant."

Instead of it being my diagnosis day, it's going to be my new good news day. So, I'm really excited to do that. I'm excited to follow in my mom's footsteps and my sister's footsteps.

The pictures are incredible. This is only after eight weeks, and they were able to measure the baby and give an estimated delivery date. Watching them become great mothers and being great mothers, it's a challenge I want to take on. I think it's going to be wonderful.

In this picture you can see a little tiny hand up by the face. There was a little hand waving around the whole time.

>> Another question on the minds of women with MS is the issue of breastfeeding. Again, MS creates more complications.

>> One of the difficult decisions that a woman with MS who is pregnant may have to make is whether to breastfeed or whether to resume her disease-modifying therapy soon after delivery.

>>All doctors would say not to take disease-modifying drugs and breastfeed, at least in the United States. I don't know and I don't believe the drug

companies know whether the disease-modifying agents go through the breast milk. We need to know that answer. And so as long as you don't know the answer and it's possible that they go through, we generally are very cautious and tell women to go off the disease-modifying agents, or stay off of them while they're breastfeeding.

>> We can never predict if and when someone is going to have a relapse, but it is reasonable to assume that women who have had a lot of disease activity, that is, a lot of relapse before they were pregnant, will probably be somewhat more prone to have relapses after they deliver. In these women it's probably preferable for them to resume their disease-modifying medication sooner rather than later.

>> So, there is a really difficult issue, and that is balancing the benefits of breastfeeding, which would be good for the baby, versus their own health, which they are taking a risk if they're not on their disease-modifying agents and they're breastfeeding. So, this comes up a lot. And I certainly don't give them the answer, because there is no answer. It's very individual.

>> Breastfeeding is up in the air, depending on when you want to start your medication back again. If you want to start it immediately, then they say plan on not breastfeeding much, and that was a little disheartening.

>> One might consider, though, before they feel guilty about not breastfeeding for months and going back on their disease-modifying agents; before they feel guilty about not doing the bonding thing and looking at their own health first because they want to go back on disease-modifying agents, the might think of themselves not being quite so selfish. Because I think the baby would really like, also, to have a mother who is in good shape.

>> Even with the advantage of reduced symptoms of MS during pregnancy, women with MS will still need the support of everyone in their lives to reduce possible complications and to create a positive outcome. So, for women with MS, the need to plan and to create a network of support is critical for a successful pregnancy.

>> Women with MS may often want to have a team of healthcare professionals that work with them during the pregnancy. This is an excellent idea. It should certainly include their obstetrician or their midwife, their neurologist. There may be a nurse that works with them, a physical or an occupational therapist may want to get involved during the later stage of the

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pregnancy, if some activities of daily living become more difficult. Additionally, these rehabilitation specialists will be invaluable in helping the women to carry out her activities of daily living and care for the baby after the delivery.

>> First of all, I think it's very important to have a support team and not just a hard-core medical support team, meaning your OB/GYN, your neurologist. But I think you need other support mostly in the sense of help after the baby is delivered. Because this will be the most critical time, and this will be the most difficult time, because they may be very fatigued and they may have a relapse. And so I think just social support and physical help with taking care of the child will be extremely important.

So, I would hire a nanny or someone to come into the home, or maybe a mother or a sister, an aunt, whatever, a relative to come and help. And have a commitment to be there and help possibly every day for six to nine months, just to get the woman through that period.

>> The support I get from my mom is just unmeasurable. Right next to Eddie, her and my dad are my support system, my backbone.

>> She's the one that really has to take the step and have the courage, and I'm there to support her in that in every step of the way.

>> He's a good supporter. You're my hero!

>> You're funny.

Tracey: What a heartfelt journey we are on with Kara and her husband.

Tom: Indeed. Look for the second part of this webcast as we watch Kara through her pregnancy and into motherhood.