



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Pediatric MS
Understanding Pediatric MS – Part One**

Tom>> Hello, I'm Tom Kimball

Tracey>> and I'm Tracey Kimball. Welcome to MS Learn Online. Most people think of MS as an adult disease. However, up to 10,000 children are living with MS.

Tom>> In this first of three webcasts on Pediatric MS we'll meet Channing Barker, a remarkable young lady who was diagnosed with MS as a teenager. She'll introduce us to some children and their parents who are living with MS and we'll hear their stories. We'll also meet some professionals who will tell us about this little known segment of the MS population.

CHANNING BARKER: Multiple Sclerosis is an unpredictable disease, but we're learning more about everyday. Currently, somewhere between 8,000 and 10,000 kids have been diagnosed with multiple sclerosis.

JoAnn Beeks: Juanita was initially diagnosed at the age of 11, and her symptoms first showed probably a year before that.

Kathleen Flaherty: Claire was seven when she was diagnosed with MS, but her symptoms first presented themselves at six.

Bob Brady: Nicholas first had symptoms and issues when he was about 2-1/2. We had heard doctors-- different doctors we went to mentioned MS, but nobody wanted to come out-- or we couldn't get an absolute diagnosis until he was about seven.

Lori Brady: They thought he was too little.

Nancy Kuntz: Every time I code multiple sclerosis in a child, the computer gives me an error message saying diagnosis inconsistent with patient's age.

Bob Brady: Kids don't get MS.

CHANNING BARKER: But kids do get MS. I know. I was one of them. I was 16 and on the cheer squad at school. I was at a game doing a routine I had done a thousand times before, and suddenly, for some reason, I couldn't kick or feel my right leg. I was the hospital four times in four months as my doctors tried and tried to figure out what was wrong with me. But I was lucky. I was diagnosed with MS pretty quickly. But for a lot of kids, symptoms can go on for years before they even know they have MS.

Lauren Krupp: These kids need our help and that's why we need to learn more about pediatric MS. But they're being under-diagnosed, misdiagnosed, and we need to change all that. These kids also need treatment, and the whole key in MS now is to treat early. How much early can you get than treating a kid with MS?

Deborah Hertz: MS is diagnosed in children in the same way it's diagnosed in adults. It's very challenging to diagnose kids with MS because there are childhood disorders that mimic MS, that have similar neurologic symptoms, and some of those may be a single episode that don't go on to a lifelong diagnosis of MS. So many

diseases and disorders have to be ruled out in children before a diagnosis of MS is made.

Robert Lisak: The very younger patients seem to sometimes present-- rather than the classic optic neuritis or double-vision or spinal cord, they sometimes present somewhat explosively, almost like the so-called post-infectious encephalomyelitis, ADEM, or sometimes present almost like a mitochondrial disease. And it's only with the imaging and with time that it becomes clear that they go on and have further episodes that are much more classic for MS.

Medical Professional: Here's the car. Look at the car.

Maria Milazzo: We'll have kids who have optic neuritis, and we don't hear about that. But we'll see that they're having trouble playing baseball or trouble riding their bicycle, and they'll tell their parent that. And then when we finally meet them in the office, they'll say, "Oh, yeah, this happened last year," and, "It happened six months ago," but it didn't affect them. They weren't in baseball season then, or it didn't bother them at that time.

Emmanuelle Waubant: So, for children MS can already create symptoms, and they are very often dismissed because they are thought to be fatigued because they worked too much at school or they go to bed too late or they are hyperactive or they just limp for a few days and then nobody pays attention to that, especially for children under 10, I would say, when they have difficulty finding the words to describe their symptoms

Maria Milazzo: For kids, often it's, "He slept funny. He played baseball too hard. He did something else." So sometimes it takes a little bit longer for the kids to get the diagnosis.

JoAnn Beeks: She began to fall. It was once a month, then once a week, then it was two or three times a week, and I said, "Okay, that's not normal."

Kathleen Flaherty: There were so many symptoms that Claire had been having that kind of clicked after we knew what was going on. It was kind of like that light going off in your head.

Maria Milazzo: One response we get often is almost a sense of relief. We found out what's wrong with them and we know it's not something worse. And often the kids will say, "Well, thank goodness. I thought I had cancer. I thought I had a tumor."

Lori Brady: So I think there was a little bit of shock that Nicholas had MS, but there was also a relief that we had a little bit more information about that disease and that we could pursue it and that there was already a community out there of people that had experienced the disease and learned how to survive and manage day-to-day.

CHANNING BARKER: Once I worked through the initial shock of finding out that I had MS, which wasn't easy, I had to learn how to manage it. Here's my private pharmacy. It can look pretty intimidating, but I'm sure grateful that I have these. Some of these are prescriptions, some are over-the-counter medications, and even some are dietary supplements. But the hardest thing for me at first was giving myself an injection. You know, it is amazing. After a while, you get used to it.

Maria Milazzo: Some kids are really averse to having injections, and so we might go with something that's only once a week. Other kids might find that it's easier just to have a routine, "Every day I need to take a shot." And then the most important thing is you're not committed to that for the rest of your life. So if you try something and it's three or four months and it's just not working, then let's talk about it. We want them to stay compliant and stay on medicines.

CHANNING BARKER: MS is an unpredictable disease, and over the years that I've had MS, the symptoms sometimes change. There

are times when it's not easy. But I found that with the help of my family, friends and my health care team, I am managing to stay on top of it.

Tracey >> Wow! As an adult I can find MS overwhelming at times and yet there are children facing the same challenges.

Tom>> But children do seem to have an amazing natural resilience to deal with many adversities, including a diagnosis of MS. In the next program, Channing talks about how she and other children and their parents find ways to live with this disease.

Tracey >> We hope to see you back then. Thanks for joining us.