



National  
Multiple Sclerosis  
Society

## MS Learn Online Feature Presentation

### Programs and Services for the Whole Family Featuring: Diana Schneider and Nancy Law

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>>**Kate Milliken:** Hello. I'm Kate Milliken, and welcome to MS Learn Online. When one person in a family is diagnosed with multiple sclerosis, the entire family is affected. The National Multiple Sclerosis Society has a variety of services and programs for those of us living with MS, but it also has programs for family members who are affected by the disease. To discuss these programs, I'm sitting here with Dr. Diana Schneider, President of DiaMedica Publications. Her partner, John, was diagnosed with multiple sclerosis in 1984.

We are also joined by Nancy Law, Executive Vice President of the Program and Services Department at the National MS Society. Welcome to both of you to MS Learn Online.

>>**Nancy Law:** Thank you, Kate.

>>**Kate Milliken:** So, Diana, what are some of the needs that you have as a result of having someone in your family with MS?

>>**Diana Schneider:** Well, early on, our biggest need we had was for information. You know, when you're diagnosed with any disease, you want to know what's going to happen to me. Am I going to continue to work? Will it ruin my social life? Will I be able to travel? All the questions you have and you want to know more about the disease itself. So, the Society was very helpful. He was diagnosed before you could just go on the Internet and get information. And there were booklets at that time, which these days you can download from your computer, but then came to you in the mail.

We also took advantage of the New York Chapter's annual program, which dealt with advances in research, because, again, when your diagnosed with something like MS, you want to know is there going to be a cure, and that thrust runs through.

As it became clear that John had the primary-progressive form of MS, and the new drugs, the DMTs became available starting in 1993, none of them were suitable for him, you began to think, again, what is going to happen to me? At that point we began needing additional services. What was great was being able to call the Society and say, "Can you recommend a physical therapist?" And they would send someone who would be very helpful do a home evaluation.

Now, John is quite progressive and in the advanced stages of MS, so our needs again have changed. A few years ago I joined a support group for family members, spouses and partners group, for people living with someone who has MS, and the group has just been fabulous. We have two sessions a year of 12 weeks each, and the group has become very bonded. We do things together outside. We feel that we have something to talk to, and the Society has always been there to support the group. And, again, we'll still call periodically for additional information. So, I think the theme running through this is information.

>>**Kate Milliken:** Diana, it is clear from your telling me about your support group that being connected to other people going through what you are has been incredibly important. Nancy, from your perspective, how can you relate?

>>**Nancy Law:** I think one of the most important things that the National MS Society can do is, indeed, help connect people to others who are going through the same thing. For Diana, it's been other people who are going through a care-giving experience. Many times we see entire families who connect at our family programs, whether it be an MS Day at the Zoo, or a day at the baseball game, where families may have lost some of the fun of enjoying time together. And maybe they've been a little afraid to go out because you go to the zoo, you don't know if it's going to be hot, you don't know where the bathrooms are. And yet if you go there and it's a National MS Society event, you know you're going to be taken care of and somebody is going to have looked after those things.

And we also see families joining the movement and entire families turning out for things like Walk MS, and really enjoying that time together. And the magic is, as we see families connect and people meeting other people going through the same things,

and children who perhaps have never met another child or teen who has a parent with multiple sclerosis, and realizing that their life is normal.

>>**Kate Milliken:** Nancy, besides information and support and research, are there other issues that you see people coming to the MS Society that they want to find help with?

>>**Nancy Law:** Well, certainly. I think what I would want our viewers to know is that the Society is there for every person whose life is affected by multiple sclerosis. And a person like Diana, who lives with MS every day but doesn't have the disease, is a person in her own right, with rights of her own and needs of her own, and we're there to help address those as well. So, not just so she can be a better caregiver or a better partner for John, but so that she, herself, can live the fullest life you can with a disease like MS.

So, we do provide, as Diana said, a lot of information. We also many times will help people get to the counseling that they need. We provide -- all of our chapters provide financial assistance for goods and services, sometimes including perhaps respite care. So, someone who has a lot of heavy-duty care-giving needs for someone with more progressed MS can perhaps get out and take a break, perhaps a mini vacation or just time away sometimes to get the grocery shopping done. We offer help with obtaining important medical equipment that can make it easier for someone, if we can help somebody perhaps access their insurance and help with the co-pay for somebody to get an electrical wheelchair as opposed to someone needing to push someone. It can make everybody feel more independent. So, those kinds of goods and services are important for family members as well.

>>**Kate Milliken:** So, Diana, after so many years of being in touch with the MS Society, what do you think has been the biggest benefit for you and John overall?

>>**Diana Schneider:** I think the feeling that, as Nancy just described, that there is an organization that really cares about you. You know who some of the people are, you begin to know who to call, and you know that if you need something, if the first person you talk to is not the right person, they will make sure you get to the right person. So, it's been an invaluable support in terms of knowing that your needs are going to be helped by that contact.

>>**Kate Milliken:** And, Nancy, in some of the family programs you were talking about, if someone actually wants to actively get in touch with somebody about the family programs, who should they call?

>>**Nancy Law:** Well, if you call our 1-800 number, 1-800-FIGHTMS, you'll be connected with an MS Navigator, and they can talk to you about all the different things that are available. People may not realize we actually have a children's newsletter called *Keep S'myelin*, that helps parents and kids to communicate about multiple sclerosis, so that you can begin to talk to kids about what happens with MS in a way that they can understand. And I think many people don't realize that we also offer a scholarship program for kids of people who have a parent with MS. And this is for high school seniors, because we know the financial impact of MS can be tremendous and it affects not just the person with the disease, but the entire family. So, this last year we funded nearly \$1 million in scholarships for about 400 young persons who live with multiple sclerosis, most of whom were those who have a parent with MS.

>>**Kate Milliken:** Wow! Diana and Nancy, thank you so much for joining us.

>>**Diana Schneider:** It's a pleasure, Kate.

>>**Nancy Law:** Thank you.

>>**Kate Milliken:** If you would like more information on the programs and services provided by the National MS Society, please go to [nationalmssociety.org](http://nationalmssociety.org). This is Kate Milliken.