Bringing more people into the MS movement



by Cyndi Zagieboylo



Cyndi Zagieboylo, President & CEO

More than 500,000 people living with multiple sclerosis have signed up with the National Multiple Sclerosis Society. People who have reached out for resources and information, to participate in programs and events and to make connections. That's more than the 1975

estimate of people with MS in the United States. Is it possible that everyone diagnosed with MS has joined the MS movement?

Several years ago, we commissioned an MS prevalence initiative and the results were recently published in the prestigious scientific journal Neurology. So, we have a much better estimate of the number of people with MS in the United States—it's twice as many as the '70's study estimated. That means there are almost twice as many people with MS who have not joined their National MS Society!

On one hand, that's understandable. Every day, people living with MS go about their lives. They take care of their families. They go to work. They navigate the challenges of their disease and find creative solutions to manage their symptoms. But when you have MS, things can go wrong. Managing the effects of the disease can be overwhelming. Yet some people don't reach out. Sometimes they want to forget about MS and just go about their lives. We get it! When people tell me they don't need anything from the Society, my response is "OK, I understand, but we need you. Together, we are stronger."

We know that when people connect with their National MS Society, they do better. They're more informed. They're more resilient and less isolated. They live better lives. So, we need to break through the barriers and connect with people as quickly as possible to establish a lifelong supportive partnership. To let them know that they don't have to figure it out by themselves. They have a National MS Society with comprehensive information and resources and people to help sort through what's most important right now. Like the right information about MS and treatments at the right time. Like MS Navigators, who can help make the overwhelming manageable. Like another person living with similar life circumstances who can share what worked for her.

How powerful would it be if everybody affected by MS were connected to our movement? That's twice as many people living with MS we need to join. We need twice as much awareness, twice as many resources, twice as many participants, twice as many donors, twice as many volunteers. Wouldn't it be great if Walk MS was twice as big?

What are your thoughts? What can you do to bring more people into the MS movement?

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Let me know your thoughts. Email me at cyndi@nmss.org.