

# A bounty of knowledge



**Cyndi Zagieboylo,  
President & CEO**

## **A note from the President & CEO**

“For man, autumn is a time of harvest, of gathering together,” Edwin Way Teale, a Pulitzer Prize-winning writer, famously said.

And so it is for the National MS Society. After many months of conversation with thousands of people affected by multiple sclerosis, we have a deeper and clearer understanding of what it means to live with MS today. As I noted in the last issue of Momentum, we initiated these conversations to guide us as we develop the strategic plan that will carry the Society forward in 2016 and beyond.

We asked people to describe to us what their big life goals are, as well as their ordinary day-to-day realities, and how MS affects each of those. We asked about the pivotal moments in people's MS journeys, and what they have learned along the way. And we listened.

Now, we are harvesting those responses, gathering them together, seeking to understand. And we have been deeply moved. We heard several recurring themes: that self-empowerment, adaptability, positive focus and a strong supportive family, no matter how a person defines it, are critically important to living well with MS. We learned that people want to take control of their MS through nutrition, exercise and other wellness approaches. We heard the deep frustration that people with progressive MS feel at the lack of treatments for their disease course. And we came to know more intimately the financial burden that MS creates in many people's lives.

One resounding theme was the yearning for true connection—not just with others who have MS, but with those who are in similar circumstances in other ways, too. A young mother with MS, for example, may want to connect with another young mother; a single Latino man, perhaps, wants to connect with someone of similar background.

Upon hearing the results of our outreach, one of our board members was reminded of a time in 1993, shortly after his wife was prescribed Betaseron®, the first disease-modifying treatment for MS. She went to her local pharmacy to get the new medicine and the pharmacist said: "You're the second person to come in for this prescription. And the first person told me, 'If another person comes in for Betaseron, please give her this.'" The pharmacist handed over a note with a name and phone number. The connection was made, and the result was a life-long relationship; these two women and their husbands became friends and supported each other through decades of living with MS—and it started with the shared experience of taking an MS medicine.

Connections are powerful. We want to give people every opportunity to connect with others like themselves, because that kind of connection can be life-changing. This must be a key component of the Society's strategic plan as we continue to provide comprehensive information about MS, seek answers through MS research, and amplify the voices of people living with MS. We must expand and galvanize the MS movement to ensure people affected by MS live their best lives.

The Delegate Assembly will vote on the Society's 2016-2018 strategic plan at our annual meeting in November. Watch for the details.

As always, I'm interested in what you think. Let's keep in touch.

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Let me know your thoughts about the Society's future. Email me at [cyndi@nmss.org](mailto:cyndi@nmss.org).