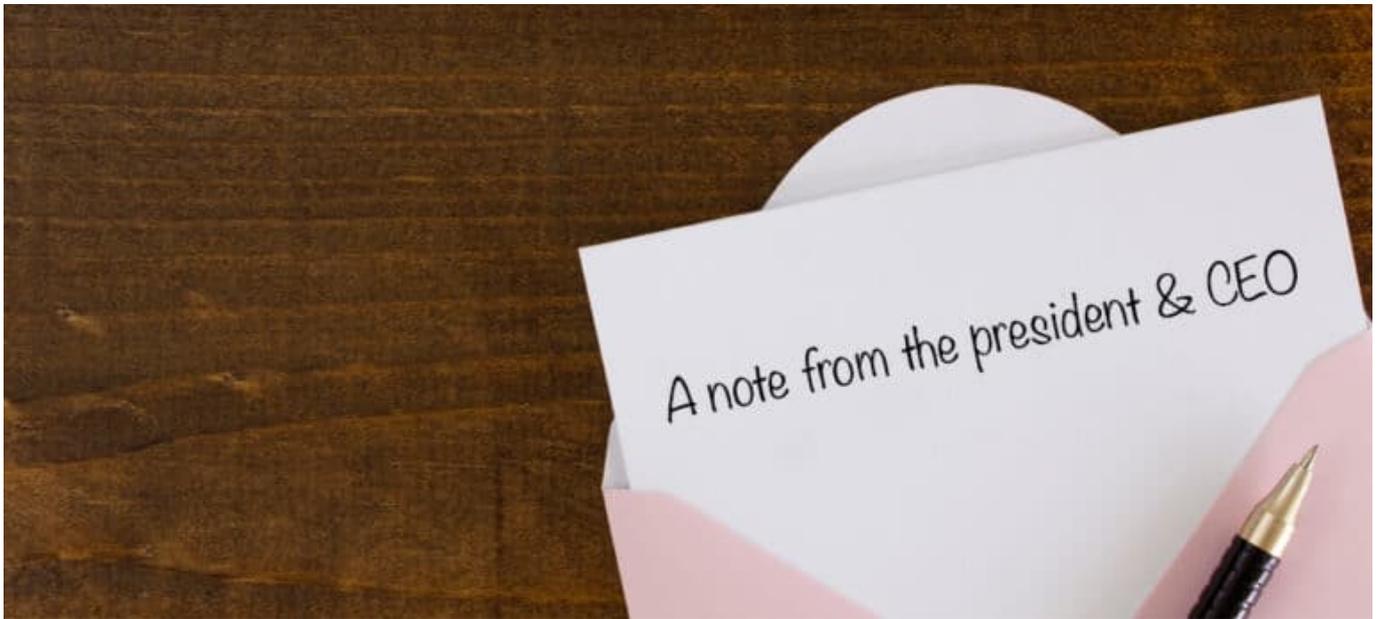


# A message from Cyndi Zagieboylo: People with MS push research forward



**Cyndi Zagieboylo,  
president and CEO**

We have achieved more advances in MS than have been achieved for any other neurological condition. But MS is still here, interrupting life in big and small ways. Funding research is one way we get answers and treatments, and eventually we will find cures.

To fund the most important research, we rely on people with MS to help decide what is most relevant. People with MS provide input on the important questions to answer. They provide their perspectives to scientists on clinical trial design. After all, people with MS participate in clinical trials — there wouldn't be any treatments available today if it weren't for people with MS volunteering for science.

The National Multiple Sclerosis Society's Community Review for MS Research Committee is made up of people affected by MS. This committee is responsible for rating scientific meritorious applications based on importance in finding MS solutions and cures. These ratings help determine which research the Society will fund.

Bonnie Higgins, vice chair of the national board of directors and longtime Society volunteer, was diagnosed with MS in 1994. She has participated in clinical trials, and she is a member of the Community Review for MS Research Committee. She also serves on the Scientific Advisory Committee to, in her words, "ensure the voice of the patient is heard."

She points out that including people with MS in the research process connects the science to the lived experience. "The ability to hear feedback from people with MS can influence the direction the research takes," Bonnie says. "An individual from the MS community may reveal a new problem that needs to be considered. Now that is patient-centric!"

Bonnie emphasizes that this approach provides a deeper understanding of the research process. "It's easy to get frustrated that research does not move quickly enough, but you learn an appreciation for everything that goes into each study, the hours and the critical checkpoints along the way."

And for Bonnie, there's a personal benefit: "It's building connections with others that share a similar journey to myself. We have developed long-lasting friendships through this shared passion."

Scientists appreciate our commitment to including people with MS in the process as well. Carolyn Whitacre, PhD, who spent several decades studying MS in academia, now lends her expertise as committee member and past chair of the National MS Society's Scientific Advisory Committee and chair of the Strategic Plan and Metrics Advisory Committee. Carolyn is also a vice chair of the Society's national board of directors.

She points out that the grant process to fund research used to be "confidential and secretive, with the notion that scientists knew best about the scope and direction of MS research."

Giving people with MS a voice in the decision process has many advantages, Carolyn says. "They see exactly how the process works and can voice their opinion on the impact of a given project."

She also says it can be "empowering for all people living with MS, knowing that people like them who understand what it's like to have MS are involved in decisions about MS research."

Finally, she points out that there's what she calls a constructive dialogue between people living with MS and the scientist reviewers. "The scientists benefit by hearing from the actual community they desire to help."

To reach a world free of MS it will take all of us. Together is the only way forward.

**Cyndi Zagieboylo**

President & CEO

National MS Society

Let me know your thoughts. Email me at [cyndi@nmss.org](mailto:cyndi@nmss.org).