

Including people living with MS in research



by Cyndi Zagieboylo



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President & CEO**

Research into the causes and treatments of multiple sclerosis goes on around the world. At the National MS Society, we seek to ensure that the research answers the questions that people with MS have, and that means we must ask and listen. People with MS need to be

included in the process of making decisions about everything we do, including funding research. This basic premise is key to designing research that is most relevant to people with MS and provides information that ensures people can live their best lives.

The premise of including people with the disease is core to how decisions about funding are made at the Patient-Centered Outcomes Research Institute (PCORI), whose work is featured in [Pressing questions](#). This nonprofit organization was authorized by Congress in 2010 specifically to fund research to answer practical questions focused on the quality of life of people living with various diseases.

PCORI leadership determined that they could have an impact in MS research, and the Society is pleased to work in collaboration with them to provide perspective on the questions people with MS have about managing symptoms and making treatment choices. We've worked with PCORI since it was first established. That includes sharing access to our research team, which focuses on keeping up-to-date on the state of MS research. We provided data collected from our strategic planning process where we asked people what they need to move their lives forward. We also share the topics people discuss with our MS Navigators. We recommended research reviewers-people with MS-to help with the selection of projects to fund. And we are thrilled that PCORI is funding topics that are relevant and important to people with MS. When combined with the research that the Society funds, it feels like a wonderful extension of our portfolio of research.

It's also gratifying to see that four of five of PCORI's recent grants were awarded to researchers whose careers were supported by the Society's fellowship program-these are scientists who are in the field of MS research at least partly due to the support they've received from the Society. Their research includes things like comparing the effectiveness of different strategies for treating symptoms of MS-related fatigue and answering questions about how long people can benefit from disease-modifying therapies. The Society's fellowship programs seek to attract and train promising young investigators and doctors in the field of MS, and many prominent researchers credit their ongoing focus on MS to the fellowships they received early in their careers.

Including the perspective of people living with MS is part of the Society's advisory process. People with MS are members of our own research program's advisory committee as well as the International Progressive MS Alliance's scientific steering committee, where they provide pivotal information and perspectives on the design of studies and weigh in on the most important research to fund.

If you'd like to learn more about the National MS Society research funding process, PCORI or the International Progressive MS Alliance, visit nationalMSsociety.org/research, PCORI.org and progressivemsalliance.org.

These combined efforts and others always have one thing in mind: to find answers so that people with MS can live their best lives and to, ultimately, achieve a world free of MS.

What are your thoughts about MS research? What would you like to know and how would you like to contribute? As always, I'd love to hear from you.

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