

# August 2022 Newsletter



## August 2022 iConquerMS Spotlight

### And the survey says...



## Pediatric Survey

iConquerMS is expanding its community to include children, adolescents and their family members. Three surveys were launched in February 2022 to obtain feedback about participating in research from those who were diagnosed with MS as a child or teen, parents and guardians, healthcare providers and researchers. This information is instrumental as we design and implement support for pediatric MS within iConquerMS. Below is a summary of data that has been collected from 47 participants to date. Interested in completing these surveys? They are still [open](#) and we welcome your input!

### 1. iConquerMS

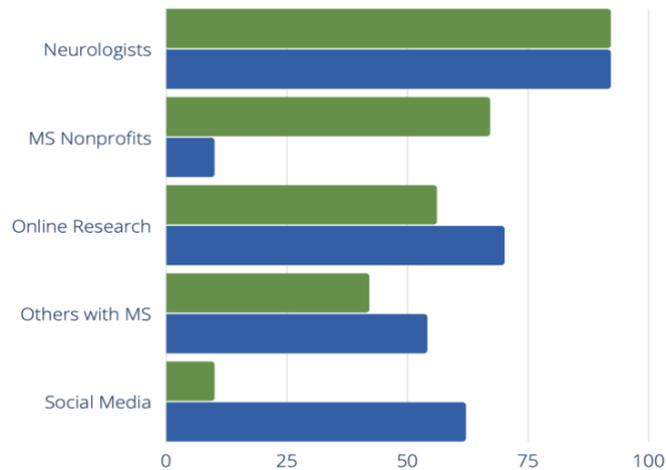
**Children & Teens** indicated they would likely sign up for iConquerMS. The most common questions included how to join, how much time is required, and what membership entails.

**Parents & Guardians** indicated they would likely enroll themselves for iConquerMS and sign up their child, if they wanted to participate.



## 2. Information Sources

The most common sources of information about MS for **Children & Teens** and **Parents & Guardians** were:



## 3. Most Common Questions About MS

**Children & Teens** wanted to know:

- Why do I have MS?
- What are MS treatment options, and which work best?
- What to expect with my MS in the future?
- What types of research are taking place?
- How do I manage symptoms?

**Parents & Guardians** wanted to know:

- How can we manage medication and side effects?
- How can we manage symptoms?
- How can I best support my child?
- How does COVID affect MS?
- How to navigate life transitions (e.g., starting college, the future).



## 4. Participation in Research

More than half of **Children & Teens** had participated in MS research in the past. The most common ways of learning about these activities were through an MS nonprofit, their neurologist, or a support group.



46% of **Parents & Guardians** had a child that participated in MS research. The most common ways of learning about these activities were through a support group, their child's neurologist, or social media.

## 5. The Positives of Participating in Research

**Children & Teens** liked the following about participating in research:

- Being part of finding a cause or cure for MS
- Inclusivity of Black people in research
- Gaining more knowledge about MS
- Financial incentives
- Meeting others with MS and feeling part of a community

**Parents & Guardians** liked the following about their child participating in research:

- Taking an empowering and active role in their MS and contributing to the MS community
- Ease of participation
- Direct health benefits (e.g., sleep patterns)
- Opportunity to think about and reflect on feelings toward their diagnosis
- Being able to meet peers with MS



## 6. Motivation

84% of **Children & Teens** were motivated to participate in MS research to help others, contribute to new breakthroughs, and learn more about it.



74% of **Parents & Guardians** said they would like their child to participate in MS-related research. Over 80% were interested in gaining access to new information and in helping other families feel less alone in their situation.

## 7. Healthcare Providers and Researchers

100% of **Healthcare Providers & Researchers** were interested in working with iConquerMS to conduct pediatric MS research studies. Over 85% were interested in codeveloping studies with our support. They were also interested in providing input on how iConquerMS could serve the research community.

**Healthcare Providers & Researchers** felt iConquerMS could meet the needs of pediatric patients and families by providing ways to identify gaps in clinical care, create informational resources for younger people about their MS, and provide opportunities for them to participate in research studies that better reflect their needs and priorities.



100% of **Researchers** surveyed had difficulty accessing funding for studies on pediatric MS. Over half had difficulty obtaining access to participants and biosamples. Recruitment strategies included directly inviting patients, asking colleagues to share information, and working with research collaborators. Nearly half of the **Researchers** included the perspective of patients and families when designing research studies.

**Healthcare Providers & Researchers** felt the most needed resources for those with pediatric-onset MS are:

- Mental health resources and support groups
- Videos, webinars and forums for kids to express their concerns
- Better explanations of MS and the available therapies
- Information about cognitive testing and school accommodations
- Tools and better access to care for those with limited socioeconomic means