

# April 2020 Newsletter



## Finding the Pathways to a Cure

A cure for MS can mean different things to different people. For some, it means alleviating symptoms or regaining lost abilities. For others, a cure would eradicate the disease. As part of a three-year strategic plan, the [National MS Society](#) is working with researchers and clinicians to develop an international consensus defining what are the pathways to cures. By engaging the global research community, the Society will establish a Pathways to Cures research roadmap to identify knowledge gaps, milestones, and accelerators to speed solutions for people living with MS today, as well as preventing MS for future generations. Three distinct Cure Pathways have been identified with significant points of overlap. They include: (1) Stopping disease activity, (2) Restoring function by reversing damage and symptoms, and (3) Ending MS by preventing new cases. ACP and the Society share common goals – speeding the pace of research towards cures for MS and enabling research that enables people affected by MS to live their best lives – and are working in partnership on Pathways to Cures.



The Society is committed to ensuring the Pathways to Cures research plan is informed and influenced by the perspectives of the entire MS community and especially by people affected by MS. [iConquerMS](#) (currently 5,500 members strong and growing every day) is a meaningful resource to gather both data and input from people affected by MS. The



Society and ACP developed a survey to collect the perspectives of the MS community on the initial direction of the Pathways to Cures research plan, and to ensure the current definitions of Stop, Restore, and End resonated. Once approved by the iConquerMS Research committee, the survey was hosted on iConquerMS. One of the advantages of hosting a survey on iConquerMS is that the collected data can be linked to data already collected from network members through [REAL MS™](#), including demographics, disease severity information and other characteristics. All of this information can be used to explore the answers to any survey hosted by the network.

The survey included a number of questions designed to gather the perspectives of people affected by MS related to a cure or cures. Respondents were asked to rank the cure pathways (Stop, Restore, End) in order of importance to them. They were also queried about whether or not they had seen signs of progress toward a cure since their diagnosis and their optimism about having a cure within the next 10 years. Other questions included, “What 5 words come to mind when you think about a cure? What would a cure look like to you? How will we know when we have a cure?”

Over 400 iConquerMS members completed the survey, 56% of whom had relapsing remitting MS and 34% had progressive MS. Results show that 99% of people affected by MS consider a cure to be important. Optimism about a cure within the next 10 years was mixed (44% were somewhat or highly optimistic, 22% were neutral and 34% were somewhat or highly pessimistic). The three key pathways – Stop, Restore and End – resonated with respondents, with restore being ranked most important (especially to those with a higher level of disability). In other words, results show those with more advanced MS want to get back to where they were prior to this disease.

A slight majority of respondents (58%) agreed with the question “In the time since your diagnosis, have you seen any signs of progress toward a cure?” Interestingly, the reason many agreed was because they saw the work of industry as one of the most prominent and well-known elements of research. In other words, the number of effective disease



## What Would a Cure Look Like to You?

"A cure would be that we could **halt MS** in its tracks as soon as its identified."

"Understanding the **cause of MS, stopping its progression** then **remyelination and restoration** of function."

"People would know if they were predisposed to develop MS and would know exactly what lifestyle/diet changes to make to **avoid it entirely.**"

"**Stop the disease onset** for those without MS at present so no more people get the disease. For those of us with the disease, a cure means **progression stops** and to some degree, symptoms are **reversed or eased.**"

"**No more people would have to live with MS** and current MS sufferers would **stop progression** and then start **remyelinating.**"

"Those with MS are **healed, no one new contracts MS.**"

"**Stopping MS & repairing nerve damage** for the rest of us."

"**Stop** progression completely. Then **repair** the damage already done. If MS can be **prevented** like polio was, even better."

*Sample responses from the Pathways to Cures survey*

iConquerMS is an innovative platform for alternate or novel study designs. The rich data collected from this research-ready cohort is being used to inform Pathways to Cures activities by providing both quantitative and qualitative feedback from the iConquerMS community, representing the broad perspective of those affected by MS. There are many ways the patient perspective can enlighten the implementation of the initiative moving forward, for example, understanding the best way to communicate work that is being done, or study results, to the MS community. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Every person that contributes their data advances MS research forward more rapidly! Already a member? Thank you for adding your voice to others working toward a cure for MS!

