



QUARTERLY UPDATE

SUMMER 2019

NEW TREATMENTS PROVIDE HOPE FOR PEOPLE WITH MS

Thanks to your support, exciting breakthroughs to improve the lives of people affected by MS are being achieved. Recent progress includes the approval of two new treatments for MS. These two medications—siponimod (Mayzent®) and cladribine (Mavenclad®)—have been approved by the FDA for people with relapsing forms of MS, including active secondary progressive MS. People with active secondary progressive MS have had progression of disability but still experience acute relapses or new MRI activity.

Thousands of people like Brian who have been living with progressive MS for many years have held out hope for treatment options that could address their disease. Now there are more options for today and greater feelings of hope for the future.

This news is so promising and only made possible by the generosity of committed donors like you, but new therapies like this are only steppingstones to arriving at our vision of a world free of MS. We know that ending this disease forever will take dedicated investments into exploring all possible pathways to a cure—whether it's stopping MS progression, reversing damage and restoring lost function, or preventing the disease from occurring in the first place. You are a vital part of the team working together to create a brighter future for people with MS.

There are now so many promising pathways that could lead to cures for MS—we'll get there by working together!

“For many years, progressive MS patients have been told there is nothing else that can be done for them, but now there is something else we can try—there is hope! It's beautiful to hear that we have new options.”

– Brian, diagnosed in 1999



Until a cure is possible, we ensure people affected by MS can count on the National MS Society as a lifetime supportive partner in living their best lives. All the while, we are galvanizing the world to find more and better solutions for treating MS, particularly progressive forms that impact so many like Brian, and ensuring those solutions are affordable and accessible to everyone.

Our 2019–2021 Strategic Plan specifies the importance of gaining international consensus on pathways to a cure on our way to delivering breakthroughs to a cure. “We can't go at it alone,” says Dr. Bruce Bebo, Executive Vice President of Research. “The Society will seek the broad input that will inspire global agreement on the most promising pathways, and speed the identification of cures for people living with MS.” Global focus on the most promising research and international collaboration accelerates progress.

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CONTINUED – NEW TREATMENTS PROVIDE HOPE FOR PEOPLE WITH MS

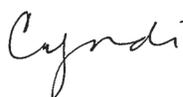
In other news, we are also funding a clinical trial to use people's own stem cells to treat progressive MS. Stem cells have the potential to decrease or even halt the progression of MS by slowing or repairing damage to the nervous system. Clinical trials help scientists study the optimal cells, delivery method, and safety of stem cell treatment. These trials are critically important in identifying breakthrough therapies.

Donors like you are helping fund 14 new pilot research grants this year to test novel, high-risk/high-reward ideas. One of these pilot projects focuses on the way that probiotics combat changes in the gut microbiome during MS. Results of the study, if confirmed by larger trials, could potentially identify a dietary supplement to reduce MS symptoms. Ongoing wellness research like this helps to provide people with MS more options to

proactively manage their disease through lifestyle choices. This investment is part of our most recent round of research grants, **totaling \$24.4 million.**

Thanks to leaders like you, we are making great progress on our \$1 billion Breakthrough MS® campaign goal. I look forward to sharing even more life-changing advancements that you've helped to make possible.

Yours truly,



Cyndi Zagieboylo,
President & CEO
National MS Society



ADVOCATING FOR THE AFFORDABILITY OF NEW MS TREATMENTS

Diagnosed with MS in 1979, Diane Whitcraft started getting Betaseron® injections shortly after the FDA first approved the drug. For 23 years, this therapy helped to slow the worsening of her disease and protect her brain from damage. However, in September 2016, Diane's insurance coverage changed and the price of Betaseron went from \$11,532 in 1993 to a whopping \$82,884 a year. Diane was forced to choose between her health and her family's financial security.

Escalating drug prices are creating significant barriers to MS treatment. Because of rising drug prices and the design of most insurance plans, a greater financial burden is being put on patients, putting some life-changing treatments out of reach. For Diane, the increase in cost for Betaseron was just too much for her and her husband to afford. "I contacted all the available resources for assistance," says Diane. "But we do not qualify. I felt guilty that my chronic disease costs us so much."



Diane Whitcraft (diagnosed in 1979) with Senator Tammy Baldwin (WI) at the 2019 State of the Union.

In 2017, Diane was forced to take the last dose of the drug that had helped her successfully manage MS for more than two decades.

New treatments for MS cannot make a difference in people's lives if they're not accessible. With drugs coming to market at prices as high as \$99,500 per year, it's important that the Society continues to help combat high drug prices. Our activists are talking to legislators about this issue, as well with pharmaceutical companies about how unaffordable drugs create barriers for patients. Together, with our community of supporters, we amplify the voices of people with MS who are forced to make difficult choices about their treatment.

2019 ADVOCACY PRIORITIES

1. Access to medications
2. Surprise billing
3. Research funding

Since she stopped taking Betaseron, Diane Whitcraft has been tirelessly advocating in favor of lowering prescription drug prices, even connecting directly with legislators to help them understand the effects of policy decisions on people living with MS. Diane is connected with 70,000 other concerned people working to drive change through our MS activist network. This passionate group is standing up to help increase critical government funding for MS research, as well as advocating for new government policies that make medical research, treatment and community support, possible.

Diane's advocacy work to promote better access to medications amplifies a key priority for the Society's advocacy efforts, highlighted at this year's Public Policy Conference. The conference brings together nearly 300 MS activists from across the country to educate elected officials in Washington D.C. about the needs of people living with MS. For Diane, the experience of being an activist has been incredibly rewarding. "MS robs you of some of the things you're good at," Diane says. "Being an MS activist gives this disease purpose and gives me an opportunity to do good and help others."



Diane Whitcraft and Wisconsin MS Activists at the Society's 2018 Public Policy Conference.

Advocacy work on behalf of MS patients is absolutely vital to helping people with MS who are in similar situations as Diane. By supporting the Society, you are helping to ensure that those diagnosed with MS have access to the treatments that will help them live their best lives possible. ■

"With a condition like MS, I have numerous obstacles to live through. Access to healthcare and having affordable insurance shouldn't be on the list. **Our government needs to support better benefits and continued coverage.** How would our officials feel if this terrible and disabling disease struck a family member and they had nowhere to go and couldn't afford care?"

– Jennifer Dempsey, #MyHealthcareVoice

A LEGACY FOR PEOPLE AFFECTED BY MS

The course of Lori Ann Jacobson's life was forever changed when she was only ten years old. This was the year her mother was diagnosed with multiple sclerosis. Since Lori's father traveled during the week for work, Lori and her four siblings were left to care for their mother alone. This caregiving eventually included dressing her, feeding her, and making sure she was comfortable. By the time Lori entered high school, three of her siblings had left home, making Lori and her younger brother the sole caregivers for their mother.

It was difficult for Lori and her siblings to watch their mother lose the abilities she once had—from not being able to walk without dragging her leg, to having to use a walker, then a wheelchair. Lori's sister, Kay, remembers the toll her mother's illness took on their family: "Mom had been dealt a difficult hand in life and she was angry about it, which made our childhood difficult," says Kay. "We didn't have much support, and it would have helped us a lot to have someone that we could talk to who understood."

Despite her early challenges in life, Lori went on to build her own business and become a successful museum consultant. She never forgot the balancing act she had to live out as a child caring for her mother. According to her husband, Jason, it became very important to her to make sure that other family members of people with MS, particularly children, would have the resources and support she lacked.

"Lori really wanted to give back and help," says Jason. "Lori's mother didn't have the resources she needed back then, and the weight of that fell on her kids. It was important to Lori that there were programs for families and kids caring for someone with MS."

Before Lori passed away she made the decision to leave a bequest, in the form of a designated IRA, to the National MS Society. Her wish was that the money be used to fund programs and services that equip family members with the information, connections, and

IN LOVING MEMORY

Lori Ann Jacobson was born in Story City, Iowa in 1958 and passed away at home in California on January 31, 2018, surrounded by her husband Jason and siblings.



Her life was characterized by joy, optimism, and her unbounded love for family and friends.

support they need to assume the role of caregiver. She wanted to ensure that the children of parents with MS could rely on the Society as a supportive partner throughout their caregiving journey and as a place to forge meaningful connections with other people affected by MS so that they weren't alone.

Lori's legacy gift of more than \$140,000 is now providing families the support, connections, and resilience needed to care for their loved ones living with MS.

Because of Lori's decision to leave a bequest to the National MS Society, more people affected by MS will have the support and resources they need to live better lives. Neither Lori's sister Kay, nor her husband, Jason, are surprised that she would choose to leave such a generous gift after she was gone.

"Lori really cared about people and always looked for the good in others," says Jason. "She was a beautiful spirit with a matching smile, kind, warm, caring, gentle, optimistic, inspiring, always grateful."

Kay agrees: "My sister didn't want other children to go through what we did growing up. I want her to be remembered as the wonderful, caring, and positive person that she always was." ■

Creating a lasting legacy to change the world for people with MS is one critical way that generous donors like Lori, and you, make a big impact. You can learn more about planning for retirement and options for leaving a planned gift to the National MS Society at plannedgiving.nationalmssociety.org