# WE'VE ACCOMPLISHED SO MUCH, BUT THERE'S MORE TO DO

Because of dedicated donors like you, life with multiple sclerosis is better now than ever before. In fact, since the mid-1990s numerous effective disease modifying treatments have been made available. There have been more breakthrough treatments for MS than any other neurological disorder. It's amazing what a difference your generosity has made on the lives of so many including those you might not realize—children and teens.

Although MS occurs most commonly in adults, estimates suggest that there are between 8,000 and 10,000 children and adolescents in the U.S. who have the disease. It's hard to imagine how frightening MS symptoms can be for a child, let alone parents who are desperately trying their best to provide their children relief, while worrying about what the future might hold. As a donor to the Society, you are helping these families navigate the challenges they face today, and you are giving them hope that tomorrow will bring answers. In fact, I'd like to tell you about one family that has benefitted from your support.

### Joshua was diagnosed with MS when he was four years old, changing the course of his life.

Joshua was an energetic kid who suddenly lost the vision in his right eye and the feeling in the left side of his body. When Joshua's mom, Delissa, found out that her young son had MS, she was devastated and confused, but also determined. What would having MS mean for Joshua's life? At that moment, she wanted to learn everything she could about the disease, so she contacted the Society for help.

Delissa began to gain the knowledge and tools she needed to chart a positive path forward for Joshua. This included getting him a support dog named Skully and on a treatment that has prevented him from



"I wondered right away what Joshua's future was going to be like. Whether he'd enjoy his life. I also wondered if we'd be able to find him the best help, knowing that no one could love him the way that I do."

Delissa, mother of Joshua, diagnosed with MS at age four

falling and experiencing debilitating headaches. She's thankful that MS hasn't overtaken Joshua's life at this point and that he can continue to play and attend school like her other children. She has big hopes for his future and for the future of other children living with MS, including that today's research will lead to new testing and treatments that are less invasive and scary for children.

By being a supporter of the National MS Society, you are helping to create hope for children like Joshua and the people who love them deeply. There are 12 Pediatric MS Centers that are networked and collaborating across our country where children receive MS care and researchers are uncovering the key biological mechanisms underlying MS. Research with children is critical in understanding the cause of the disease and in ensuring appropriate treatments

#### CONTINUED – WE'VE ACCOMPLISHED SO MUCH, BUT THERE'S MORE TO DO

for their age. For example, recent research led to an FDA-approved expansion of the use of Gilenya for children 10 years or older with relapsing MS. This is the very first disease-modifying therapy that has been approved for pediatric MS—it's huge progress!

It takes all of us to achieve breakthroughs for everyone living with MS. Delissa is doing her part by helping us better understand what children with MS and their families need. Things like making sure to show positive examples of how kids with MS can live a full life and providing connections with others to share experiences. By telling her and Joshua's story, Delissa hopes to help raise awareness that children get MS, too, and to show other parents of children with MS that they are not alone. Some days will be better than others, but every day is a chance to enjoy your kids. With her help and yours, we are letting the public

know that the National MS Society helps adults and children affected by MS, so more families can connect to us early in their journey and get the support they need to live their best lives.

It's a pleasure to continue to provide you with updates on the difference you've made. You are having an immediate impact on the health and wellbeing of people affected by MS by choosing to support the work of the Society.

Gratefully yours,

Cyndi

Cyndi Zagieboylo, President & CEO National MS Society



# BRINGING HOPE AND CONNECTION TO PEOPLE ON THE MS JOURNEY

For several years, Tania Bentley has struggled with mobility symptoms caused by MS. She's found it difficult to face her on-going challenges and fears alone. Fortunately, Tania has found a community of belonging through the Society. In 2018, she had the opportunity to attend an MS Breakthroughs event to accept an award for outstanding team fundraising for Walk MS®.

MS Breakthroughs events bring together people in the MS movement, including passionate volunteers, fundraisers, and healthcare professionals to hear the latest in MS research. For Tania, being able to connect with her fellow "MS warriors" in person brought her a powerful and irreplaceable sense of togetherness and solidarity. She was delighted to see that she had an entire village behind her, ready to provide support whenever she needed it. "Hearing about research advancements made our mission more tangible and concrete," says Tania. "Personally, it gave me hope for the future and confidence in knowing that a cure will be found."



Tania (L), diagnosed in 2017

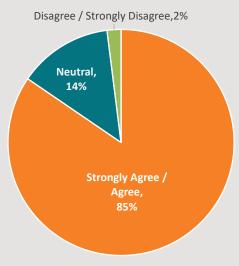
#### **PROGRAM HIGHLIGHT: MS BREAKTHROUGHS**

Engaging, connecting, and recognizing volunteers in our movement

### 5,606 PEOPLE in 43 COMMUNITIES

gathered to learn about progress in research and services, connect and engage with each other and to the Society, and to celebrate progress

#### **Confidence to Address the Challenges of MS**



- 85% of participants feel more confident in addressing the challenges of MS after attending MS Breakthroughs, a 13% increase from 2018
- 92% of participants reported making connections to information, resources, people and/or other sources of support
- **87%** of participants stated they plan to take action on something they learned following the program, a **9% increase** from 2018

In addition to the MS Breakthroughs events delivered across the country, your ongoing generosity supports a multitude of other programs that create lasting connections and support to those who need it to live their best lives. Living with MS comes with many unique questions and challenges. Our wide spectrum of programs and resources empower people with the information and support they need. Committed leaders like you played a direct role in this incredible and inspiring success, and for that, we are so grateful. We are committed to innovating and evolving our programming based on insights from people affected by MS, along with emerging trends in research and care.

Your gifts in 2020 will also help us continue to support people affected by MS across the country. We'll build resilience by connecting people with each other, providing new tools that will positively affect people's lives, and maintaining the most up-to-date information on MS.

People affected by MS need to be equipped with knowledge, tools, and connections that help them become more powerful than the challenges they face. Donors like you are helping to bring this strength into the lives of so many, by using your support to show how much you care.

"It's very important to connect with other people that have MS because they understand what you're going through."

- Carlos, diagnosed with MS in 2001

### A LIFE-CHANGING MEMORIAL GIFT

After the death of her beloved daughter, Molly, Ann Hyer and her family knew right away that a generous gift should be made in Molly's memory. Together, they decided that Molly would have appreciated a donation be made to the National MS Society—a cause that was close to her heart since her brother Bart has MS.

Bart and Molly were always very close. The family knew that a gift to the Society in Molly's name would have a double impact: remembering a beloved family member, while also benefitting Bart and other people who have MS. When Bart learned what the family had decided, he and his wife Heather (a Society staff member) were deeply moved.

"They called me and just said, 'Mom, wow,' Ann says.
"They were taken aback but in such a good way, which made me really happy as well."

Ann remembers the day that Bart first told her that he'd been diagnosed with MS. She felt so emotional but tried to stay strong for her son. Having already had a friend with MS, Ann stressed to her son that his diagnosis was not a death sentence. Seventeen years later, Bart is still doing well and continues to be someone who focuses on the positive side of life. Ann is hopeful that the gift in memory of her daughter will help more people live their best lives.

Built with a \$100,000 donation, the **Molly Donegan Wininger Memorial Endowment** was created to support people with MS today and in the future.

The family made the decision that their contribution should be used to support and sustain the MS Navigator program. According to Ann, when they learned about the program, they all knew that it was the perfect choice.



Left to right: Parker (Molly's son), Ann, Bart, Abby (Molly's daughter), Greg (Molly's husband) and Molly

"We knew we wanted to do something that could help as many people as possible," says Ann. "MS Navigator offered a multitude of ways to offer assistance. Whether people needed a wheelchair, medicine, insurance, or help paying a doctor bill, we knew that whatever good care meant to them, they would have help to achieve it."

Ann hopes that Molly's children will also be inspired by the gift in their mother's name, and that they will go on to make their own contributions to the Society in the future. Their gifts—no matter how small—will give them a chance to remember their mom, and support the care available to their uncle and many more across the country who have MS. To Ann, this is a win-win situation all round. ■