

If you had to choose between **PAYING YOUR BILLS AND TAKING YOUR MS MEDICATION**, what would you choose?

Through your generosity, the Society is amplifying the voices of people affected by MS and offering solutions to combat the high costs of MS medications



Steffany Stern (R) and her mom, Joan

In March, Steffany Stern, National MS Society Vice President of Advocacy, testified before the Senate Finance Committee to share the real-life effects of the high cost of MS medications for people living with MS, including her mother, Joan Stern, who has lived with MS for more than four decades.

For the first 15 years after diagnosis, there were no MS disease-modifying therapies (DMTs) available for her to take. In the years after the first MS medication came on the market, Joan joined the ranks of far too many others in the MS community who struggle year-to-year, or even month-to-month, to afford their medications. Joan is among the 70% of people with MS who have relied on patient assistance programs to be able stay on their disease-modifying treatment. But the need for that assistance is far greater than the supply. As Joan said, and the Committee Chairman, Senator Wyden, quoted, during the hearing:

“I’ve got coverage through Medicare, and I feel like I shouldn’t have to be begging for charitable assistance just to be able to afford my medication.”

Unfortunately, Joan’s experience is shared by many others living with MS. Forty percent of people with MS report that they have altered the use of their DMTs due to cost, with some skipping or delaying treatment. Steffany shared the stories of several people with MS from across the country who have had to make excruciating decisions to ration or even stop taking their medications. As she told the committee, **“It is unconscionable that in 2022, people with MS and other health conditions who cannot pay for their medications would be in the same position my mom was during the 1980s— with no treatment option.”**

Steffany further argued that the current system does not work in the best interest of people with MS, or for anyone living with other chronic health conditions. Through this opportunity to testify, Steffany brought the voices of thousands of people living with MS into the United States Senate and called upon Congress to take concrete action on greatly needed reforms.

YOUR SUPPORT IS DRIVING CHANGE

Most recently, the Society pinned down the economic burden of MS, estimated at \$85.4 billion annually, with 60% of those expenses attributed to the costs of MS medications. With this knowledge we can inform future policies to reduce the cost of MS and create better health outcomes for those living with MS.

Join us as we urge the Senate to improve the affordability and accessibility of MS medications and make lives better for those living with MS by visiting nationalMSSociety.org/Get-Involved/Advocate-for-Change/Become-an-MS-Activist

DIRECT MEDICAL COSTS \$63.3 BILLION

-  Disease modifying therapy
-  Other medications
-  Office and hospital visits
-  Medical equipment

INDIRECT COSTS \$21 BILLION

-  Missed work
-  Early retirement

NON-MEDICAL COSTS \$1.1 BILLION

-  Caregiving
-  Home/vehicle modifications

SPECIAL THANKS FROM YOUR PRESIDENT & CEO

Progress for people affected by MS continues to accelerate. New discoveries are yielding more treatments and better approaches to care than ever before. As a committed supporter of the National MS Society, you make this progress possible.

Most recently, you helped bring more voices and perspectives to the table. The voices of people with the toughest challenges and the voices of those seldom heard, are now louder than ever. As an organization by and for people affected by MS, when we take action to improve the lives of people affected by MS, we do so with the confidence that we are representing the needs and perspectives of **every person** in our MS community.

In this Summer 2022 issue of your Quarterly Donor Update, you'll read about how we're listening to those struggling to afford disease-modifying therapies and taking their stories to the Senate floor to advocate for affordable medications (page 1).

We describe how two award-winning scientists are aggressively searching for MS cures while keeping people with MS at the forefront of the process, inviting them to the table early and often (page 2). You'll read about how the Society is taking action to improve clinical trial diversity so that life-changing solutions that are tested and developed meet the needs of ALL people affected by MS, not just some.

No one should face MS alone. Thank you for your support so that no one has to.

Yours truly,



Cyndi Zagieboylo
President & CEO
National MS Society



SPOTLIGHT: DID YOU KNOW?

As research on the prevalence of MS continues to grow, evidence revealing variations by race, ethnicity and region is increasing as well. For example, Black people with MS have the highest mortality rates of all groups affected by the disease. The cause is thought to be a combination of factors: genetics, cultural factors such as medical mistrust, and socioeconomic factors such as limited access to high-quality healthcare and treatments. More research is needed to understand these differences, but with less than 1% of scientific publications focused on people of color, a new approach will be needed.

Less than 1% of MS scientific publications are focused on people of color

- 60,000 published articles on MS
- 113 focused on Black people
- 23 focused on Hispanic patients

One way to tackle health disparities among underrepresented communities living with MS is to

evaluate and promote the inclusivity of clinical trials. How trials are designed and how data is collected can greatly influence our understanding of MS. Excluding important perspectives can result in treatments and solutions that work for some, but not all.

Thanks to you, the Society is collecting ideas and taking bold action to change the inclusivity of clinical trials by:

- Listening and receiving guidance from leading experts working to advance research in underrepresented communities
- Rallying corporate healthcare and pharmaceutical partners to commit to actively address underrepresentation in clinical trials. Read the **consensus statement**.

Together we can tackle health disparities by promoting diverse and inclusive clinical trials so that all people living with MS have treatments and solutions that work best for their MS. Join us to declare your commitment and support of MS health equity by visiting nationalMSSociety.org/Donate.

CELEBRATING MS RESEARCH TALENT AND INNOVATION

MEET THE SOCIETY'S RECENT MS RESEARCH PRIZE WINNERS

2021 BARANCIK PRIZE FOR INNOVATION IN MS RESEARCH



Dr. Amit Bar-Or received this prize for his work to custom-tailor treatments, also known as precision medicine, to stop MS.

Q: Dr. Bar-Or, can you tell us more about your work and how it's revealing insights into stopping MS in its tracks?

A: We've been very interested in how immune cells interact with and influence one another to drive or calm immune attacks, and how these cells interact with brain cells to mediate destructive inflammation in MS. We've developed a specialized tool that captures the range of these immune-response states that can be seen across individuals to help pinpoint how specific treatments can work better for some individuals than others.

Q: What excites you in your upcoming research?

A: In our work, we also study the basics of immune regulation...in the context of inflammation, injury, and repair of the central nervous system. We are working to develop additional tools that identify and monitor MS from its earliest stages with enough confidence to select and initiate treatments as well as switch and potentially stop interventions, while providing further insights into the biological processes driving MS from its early, through its later stages.

Q: Can you tell us how people with MS inspire your work?

A: Every person's experience with MS is different so our goal is to go from today's one-size-fits-all approach to clinical trials and treatment, to developing more personalized treatment plans that work best for each person with MS, and ultimately achieve a full stop to disease activity and progression.

About the Barancik Prize for Innovation in MS Research: The international prize is administered through the National MS Society and made possible by the generosity of the Charles and Margery Barancik Foundation.

2022 JOHN DYSTEL PRIZE FOR MS RESEARCH



Dr. Xavier Montalban received this prize for his work to understand, diagnose, and develop treatments for MS.

Q: Dr. Montalban, your work has been pivotal in improving the diagnosis of MS. Can you share more about other aspects of your groundbreaking research?

A: MS can be considered a chameleon...because you can have so many different symptoms that make diagnosis very difficult. Our work focuses on systematically collecting data from people at the earliest stages of MS and over time, creating a trove of information about the evolution of MS that continues to provide novel insights and new leads.

Q: Can you tell us about your interest in engaging people more deeply in MS research?

A: People with MS should be with us, at the same table, making decisions with us about the research and about the design of the trials. There is no other way, in my opinion, to move forward with any concrete progress without this level of involvement.

Q: What excites you in upcoming research?

A: One component of MS research which I'm very excited about is prevention of disease. When we're talking about prevention, we're talking about how external factors like vitamin D, microbiota, smoking, exercise and more are all aspects that could be instrumental in decreasing the incidence and therefore the prevalence of MS.

About the John Dystel Prize for MS Research:

The Dystel Prize is given jointly by the National MS Society and the American Academy of Neurology. The late Society National Board member Oscar Dystel and his late wife, Marion, established the Prize in 1994 in honor of their son, John Jay Dystel.

Learn more about the Barancik Prize for Innovation in MS Research and the John Dystel Prize for MS Research at [nationalMSSociety.org](https://www.nationalmssociety.org).

DONOR SPOTLIGHT: THE REMARKABLE LEGACY OF JEAN GRISWOLD

“My mother was a real mentor for people living with MS, and also to women with any kind of disability. Her message to them was that you ‘don’t have to give up on life just because you’ve been handed some lemons”

- Kent Griswold



A long-time supporter of the National MS Society, Kent Griswold recently donated \$130,000 to support the **Pathways to Wellness in MS** program in loving memory of his mother, Jean Griswold.

As a mom to three sons, Jean Griswold worked hard to give her children a great life as they grew up. Kent Griswold fondly remembers his mother’s kind nature and determined spirit, even after she was diagnosed with progressive MS in her thirties. After going to the library to learn everything she could about her diagnosis, Jean

found new ways to adapt to the changes happening to her body ... it wasn’t always easy for her though.

“I remember one time sitting with my father and watching my mother walk across the porch outside,” says Kent. “She had made a walker out of an old TV cart on wheels, but it caught, and she suddenly fell down. There were many bad falls like this throughout the years.”

At the age of 51, Jean lost out on a great job when her potential employer learned about her diagnosis. She decided to hire herself instead and created her own caregiving business as a way to give back to her community. She knew how important it is for people with disabilities, and the elderly, to have regular in-home care like she had been receiving from her husband. Her new business, Griswold Home Care, was a great success and still exists today. She proudly stayed at its helm until the age of 79, despite the challenges her MS presented.

During her lifetime, Jean was deeply involved with the National MS Society. She contributed time to her local

chapter and belonged to an MS support group. As her disease progressed and physical movement became more difficult, she found new ways to give back, including adding the Society as a beneficiary in her estate plans and being a cheerleader when Kent and his brothers Scott and Kurt, participated in the Bike MS®: City to Shore ride.

Kent will never forget his mom at the finish line of this challenging bike ride, holding up a sign that said: “YEA, YOU MADE IT.”

Jean’s dedication led to her receiving a leadership award from the Society. Kent traveled to accept the award on her behalf. He also stepped in to volunteer in Jean’s place, attending annual meetings and leadership conferences when his mother was unable to.

“While volunteering with the Society, I really got to appreciate the good work they were doing as an organization, and how professionally everything is run,” says Kent.

Kent knew that supporting the Pathways to Wellness in MS program would be a fitting tribute to his mother. “Prevention, wellness, education, and spirituality [surrounding MS] was so important to both my parents,” says Kent. “I thought this would be a very appropriate place to invest the funds.”

Jean’s contributions during her lifetime, and the legacy she left behind, are helping to create a positive future for those living with MS. It is because of devoted and optimistic people like her, that we will achieve our vision of a world free of MS.

Find out more about the **Pathways to Wellness in MS** program. To learn more about how you can join Jean in leaving a legacy of impact by including the Society in your estate plans, contact Kathy Newsome at kathy.newsome@nmss.org or 312-423-1146.