



QUARTERLY UPDATE

FALL 2020

WE KEEP MOVING FORWARD THANKS TO YOU

There have been more breakthroughs in MS than any other neurological disease. This is a remarkable fact. Mission-focus and an ever-expanding MS movement ensure we keep moving forward to achieve more and more breakthroughs.

During these extraordinary times, we draw upon the MS movement for energy and encouragement. Despite the obstacles and financial hardship we face today, your generosity helps ensure our mission comes first, no matter what. There has never been a more crucial time to keep moving forward.

Thank you for your leadership in the MS movement.

Building this movement, increasing our connections and bringing people with diverse backgrounds and perspectives together, is key to tackling the most complex MS problems. Our willingness and drive to continuously adapt and innovate is the only way we can meet the ever-evolving needs of people affected by MS.

In this issue of the **Breakthrough MS Quarterly Update**, you will see that we are persistent in listening and learning from people affected by MS to ensure we respond as needed and stay ahead of challenges. We are confronting the disparities that exist within our movement, magnified by the pandemic, and are taking bold actions to understand the cultural, socioeconomic and genetic factors that are causing these disparities.

Read about the Tykeson Family and their passion in encouraging talented up and coming MS researchers, and about progress made by the International Progressive MS Alliance. The Alliance's recent publication in the prestigious scientific journal, **Neurology**, helps advance a novel biomarker for MS with the potential to detect disease activity through a routine blood test. This could result in a faster, easier, and less expensive means of determining MS treatment effectiveness. This possible breakthrough could speed new and effective MS treatments through clinical trials and get them to market, including those for progressive MS, and it could help clinicians monitor how well a drug is working, resulting in personalized MS care.

I hope you find this update encouraging and inspiring. Thanks to you, we are making progress. Thanks to you, we will keep moving forward!

Yours truly,

A handwritten signature in black ink that reads "Cyndi".

Cyndi Zagieboylo,
President & CEO
National MS Society



WE'RE LISTENING, LEARNING AND TAKING ACTION

The global pandemic has had a sustained and prolonged effect on our organizational resources.

At a time like this, and always, it is crucial that we make the most of the dollars you invest by keeping our finger on the pulse of what people with MS need right now to thrive. Surveying is a critical tool for active listening and we use this method to learn more about how the pandemic is affecting people's lives to fine tune the programs and support we offer and to help MS activists communicate the urgent needs of our community to legislators.

Top COVID-19 Survey results:

- The pandemic has taken a financial toll—24% of people responded feeling negatively about their economic security
- Risk exposure to COVID-19 is a top concern
- 17% have altered their use of an MS therapy due to COVID-19
- COVID-19 has highlighted income inequality between white and Black people in the MS community
- The pandemic is exacerbating depression and anxiety, already common symptoms of MS

"It has been difficult because I get disability income. We have needed additional supplies as I was diagnosed with COVID-19. My credit cards are maxed out."

– Survey respondent

In addition to the COVID-19 Survey, the Society's recent Policy Survey has been critical to solidifying issues important to people with MS that will require the focus and attention of MS activists as they work with legislators to advance solutions for all.

Top policy issues for people with MS:

- Making MS medications affordable and accessible
- Ensuring healthcare coverage when unemployment is at an all-time high
- Increasing federal funding of MS research at a time when charitable contributions are at risk and supporting research that will improve access to safe and effective stem cell therapies ■



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The number of bills MS Activists have helped to pass into law over the past year that improve the lives of people with MS.

INTRODUCING THE BLACK MS EXPERIENCE SUMMIT

Building upon the Society's longstanding African American Conference Series typically held in locations across the country each year, the Society launched its first nationwide virtual Black MS Experience Summit in late September. The goal of the Summit was to help build a more diverse and inclusive MS movement, and to help gain a better understanding of the relevant support and connections people living with MS from the Black community currently lack and need from the Society to thrive. Attended by 1,300 individuals, 20% connecting with the Society for the first time, the Summit offered participants an important forum for discussing shared experiences and the unique challenges they face, along with opportunities to learn more about scientific and clinical differences contributing to inequities in the care and treatment of MS for those in the Black community. ■



Black MS Experience Summit



"I am so honored to be a part of the Black MS experience. It's an opportunity to be able to be open, vulnerable and transparent. Get some information that is much needed to help you better handle your MS."

Tyler Campbell, diagnosed in 2007

ALLIANCE MAKES PROGRESS ON A BLOOD TEST FOR MS

The International Progressive MS Alliance recently published a paper in the prestigious scientific journal, *Neurology*, that helps further advance a novel biomarker for MS (neurofilament light or NfL) with the potential to predict disease activity and disability progression through routine blood tests.

INTERNATIONAL PROGRESSIVE MS ALLIANCE

More than hope. **Progress.**

Over the past several years, there's been a lot of buzz in the MS research community around a protein found in blood, neurofilament light (NfL), as a potential biomarker for MS. Mounting research suggests NfL's promise as a quick and easy way to predict disease activity and monitor response to treatment, representing a potential breakthrough for all people with MS but particularly those living with progressive MS who lack effective treatments due to gaps in objective clinical trial biomarkers.

In 2018, the International Progressive MS Alliance recognized the promise of NfL and convened several MS investigators around the world who had been working on NfL independently of each other. Through this connection point, the Alliance fostered global collaboration to advance the research community's collective understanding of this potential biomarker and its application for progressive MS in particular.

Last month's **Neurology** paper represents the collective analysis of expert stakeholders on the potential of NfL as a biomarker in MS, and progressive MS in particular, and outlines additional research needed to advance the field and actions that need to be taken to signal NfL's promise with regulatory entities in the U.S. and Europe.

Through your support, the National MS Society and the International Progressive MS Alliance will take the lead on these next steps to further accelerate this potential breakthrough for those living with MS. ■

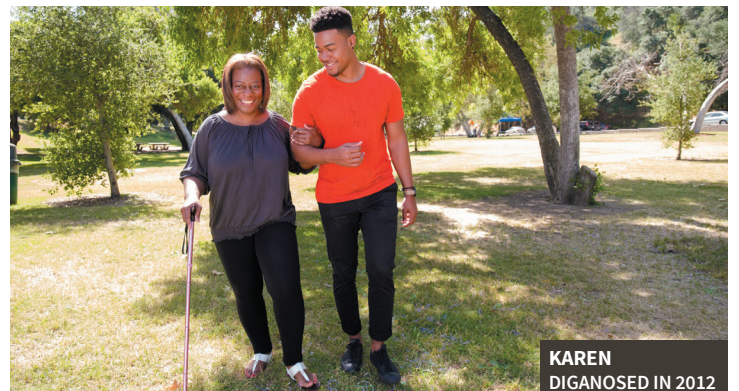
UNDERSTANDING RACIAL DIFFERENCES IN DISEASE ACTIVITY



JOSEPH (L)
DIGANOSSED IN 2008

Black and Latinx people with MS more often experience an aggressive disease course compared to white people with MS. To understand why this is so, Society-funded researchers at Weill Cornell are investigating immune cell differences in Black and Latinx people to better predict and treat MS in these populations. A previous study found a higher concentration of immune antibodies in the spinal fluid of Black and Latinx people with MS compared to white people, so the Weill Cornell team is asking whether B cells, which make antibodies, are present in greater numbers or have a greater inflammatory function in these populations.

The outcomes of this study will not only help to better inform treatments strategies for Black and Latinx people, but insights gained will help contribute to a larger body of knowledge on what causes MS and how to stop it in all populations. ■



KAREN
DIGANOSSED IN 2012

A FATHER'S LEGACY: TYKESON FAMILY CONTINUES WHAT THEIR DAD BEGAN

“I’m very proud I had the opportunity to see a trailblazer like my father up close.”

– Amy Tykeson

Amy Tykeson’s father, Don, was an entrepreneur from a very young age. While still in high school, he started a successful business raising Chester White pigs, and soon after, won a regional speech contest by impressing the Future Farmers of America with his thoughts about the future. He would eventually decide not to become a farmer and instead, went on to attend the University of Oregon, before building a very successful broadcast and cable company.

Amy has fond memories of time spent with her dad as she grew up. She remembers taking road trips to national parks and camping as a child, jogging and chatting with him when she was a bit older, and finally, being able to share her love of the cable industry with him for nearly 40 years. “He was an incredible role model for me,” says Amy. “He was a believer in doing what was right, taking the long view, and he was very generous. My dad often said that he wished he’d earned his money sooner so he could have given more of it away.”

Although Amy and her siblings didn’t realize it when they were younger, Don was diagnosed with relapsing-remitting MS when he was 35. It was not until the kids were in their teens that their father had noticeable symptoms. He was, however, reluctant to take help for his movement issues. Amy remembers him pushing through without complaint about access issues, such as a steep flight of stairs in front of him. “Dad made every effort to show up and not give up. He never allowed the diagnosis of MS to interfere visibly with his goals or how he wanted to live his life.”

Don was drawn to the science of finding a solution for MS. He was not afraid to try new treatments and would take advantage of technologies to help him get around. He was vigilant about his diet and exercise regimen—being an active golfer, runner, and swimmer—which no doubt contributed to him living to the age of 90.

In 2008, Don helped to launch the biennial Tykeson MS Research Fellows Conference. The conference exists to bring together research and clinical fellows to learn and share about their latest research efforts. Amy says



From the left: Eric Tykeson, Amy Tykeson, Don Tykeson (diagnosed in 1963), Willie Tykeson, and Ellen Tykeson

The Tykeson Family Foundation has recently made a generous grant of \$500,000 to continue support of the Tykeson MS Research Fellows Conference. Don Tykeson’s children know this support is what their father would want them to do.

that her dad was taken with the idea of the conference because he himself was a collaborator. He felt that scientific breakthroughs related to MS would happen quicker if people could get together, network, and share progress, to supplement the somewhat solitary time working in a lab.

Amy believes that Don would want his children to continue to support the conference. This is what motivated Amy and her sister and brother to renew their support through the Tykeson Family Foundation.

“This conference is a way to press forward what Dad would have wanted, which is to find a cure for MS and help people get back to having an active life.”

Throughout his life, Don often made himself available to answer the questions of people who had been newly diagnosed with MS. He believed in sharing ideas, networking and listening to what people were going through to help them. Thanks to his children, his vital commitment to MS will continue.

“Dad was a wonderful steward. He strove to leave things better than he found them,” says Amy. “Every time I hear about someone with MS, I think of my dad. He would want us to do what we can to help.” ■

Help ensure everyone affected by MS, can receive the support they need from the Society now and always. Give today. <https://ntlms.org/ResponseFundCOVID>