

SOCIETY EXTENDS COMMITMENT TO THE GLOBAL EFFORT TO END PROGRESSIVE MS

As the leading MS organization in the world, the National MS Society has recently committed an additional \$19 million to support the International Progressive MS Alliance’s work to rally the global community to come together and find solutions for everyone affected by progressive MS. This brings the Society’s total investment in the Alliance to €26 million (\$30 million), nearly half of the Alliance’s overall €57 million (\$66 million) investment. “We have enthusiastically reaffirmed our commitment because of the Alliance’s impressive impact. The Alliance is speeding research progress by convening thought leaders, determining and following an aggressive research plan, ensuring effective collaborations, providing funding, and engaging people affected by progressive MS in the research process,” says Cyndi Zagieboylo, CEO.

People living with progressive MS face uncertainty, losing ground each day as they experience steadily worsening symptoms and a loss of function. As the lead agency of the International Progressive MS Alliance, the Society ensures worldwide focus on solving progressive MS, which will lead to solutions for all forms of multiple sclerosis.

This international collaboration is already driving breakthroughs. Recent research outcomes include:

- Collaborative Network Award winner Dr. Francisco Quintana and his team traced interactions that help explain how diet and gut bacteria may limit inflammation and nerve damage in mice and people, which **could ultimately lead to new MS treatments**. Study results were published in **Nature** — one of the most prestigious scientific journals.
- Collaborative Network Award winner Dr. Arnold has collected data from 7,200 people, totaling 25,000 MRIs, to help support his research in **better understanding disease progression**.
- The rehabilitation and symptom management scientific and research community was convened to review what we know and discuss what we need to learn to **find breakthroughs to improve quality of life** for those living with progressive MS.

ACHIEVEMENTS OF THE ALLIANCE

Since 2014, the Alliance has made global research investments first through its Challenge Award — small awards aimed at stimulating research in new ideas — and on a larger scale through the Collaborative Network Awards. The Collaborative Network awards are first-of-its kind global networks focused on progressive MS encompassing 3 projects, 40 investigators, and 21 institutions across 9 countries.

WHAT’S NEXT?

Ending progressive MS, and improving the lives of those living with it, is an urgent and unmet worldwide need. That is why the Alliance remains focused on priorities to enable new treatment discovery, while reducing the time and cost of testing potential treatments.

The Alliance will focus efforts on filling the drug development pipeline, balancing discovery programs and tool development through its scientific priorities:



**UNDERSTANDING
PROGRESSION**



**ACCELERATING
CLINICAL TRIALS**



**ENHANCING
WELL-BEING**

The Alliance is committed to accomplishing these priorities through the Collaborative Network Awards. New research areas of these awards will include:

- Development of a data sharing platform to harness aggregated data to promote greater understanding of progressive MS, the development of better treatments and a cure
- Development of innovative clinical trial designs to speed up expansion of progressive MS therapies
- Creation of laboratory tests that can better diagnose, track progression, and measure response to therapy

(continued →→)

CHANGING LIVES HERE AND ABROAD

Multiple sclerosis is a complex disease that cannot be cured in isolation. Putting our collective passions and dollars to work to change the lives of everyone affected by MS, here and across the globe, has been core to our work since the Society was founded by Sylvia Lawry in 1946.

Even back then, Sylvia knew it would take a comprehensive approach to solve the complex problem of multiple sclerosis facing her brother and so many like him. She knew the power of collaboration and open communication. Through her dedication and passion, she launched an international effort to end multiple sclerosis, founding first the National Multiple Sclerosis Society in the United States and later, the Multiple Sclerosis International Federation (MSIF), a network of 48 MS organizations worldwide. We continue to be inspired by her resolve and persistence.

We're also inspired by the crucial role of volunteer leaders in moving this global effort forward. Directors and trustees across the country, like Jay Brammer who is

featured in this issue, have special insights and influence. Their generous support demonstrates their confidence that we have a solid plan, are disciplined in our work, and focused on having the most impact possible. And I hope that gives you confidence that there is strong oversight, guidance and involvement of smart and passionate community leaders across the country doing whatever it takes to get results.

By looking beyond our borders, the Society is driving global change that will end MS here and abroad. Together, we have a unique opportunity to expand our global movement, remove barriers and accelerate progress for everyone affected by MS. Please join us.

Yours truly,



Cyndi Zagieboylo, President & CEO
National MS Society



ADVOCACY IMPACT: BELINDA

“When I was diagnosed and learned how much drugs and procedures cost, I realized that **without my good insurance I wouldn't have been able to treat my disease.** I led the local support group, and there were members who could not afford it, they just **go without treatment**, and I think that's a travesty. **That really drives my advocacy.**



Belinda, diagnosed in 2008, at the Society's Public Policy Conference

I spoke to my congressional representative about the Restoring the Patient's Voice Act, a month or so after it was introduced in Congress. He thought about it and decided to **co-sponsor the bill.**

Having a chronic disease, it's easy to dwell and not move forward, but if I focus outside myself — **I feel empowered and like we are doing something good.** ■

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- Development of imaging and medical technology that will speed up identification of disease modifying treatments
- Platform to coordinate research on rehabilitation and symptom management that will help people with progressive MS live their best lives

Stopping progression, repairing the damage and expediting drug testing in clinical trials specific to progressive MS is crucial. We must have effective treatments for everyone — not just for some. The Alliance's investments in groundbreaking research will enable the global research community to overcome the barriers and gaps in understanding progressive MS, changing the world for all those living with this disease.

As the largest contributor to the Alliance, the Society leads by example and inspires MS Societies worldwide to rise to the challenge of solving progressive MS. Together, we will fuel breakthroughs toward effective treatments. Your generous gift ensures that discovery will advance faster as we address the urgent needs of those with progressive MS here at home and across the globe. ■

ANNUAL PUBLIC POLICY CONFERENCE EMPOWERS THE VOICES OF PEOPLE AFFECTED BY MS TO DRIVE CHANGE

Every year in March, hundreds of MS activists gather in Washington, D.C. to learn how to strengthen relationships with elected officials and address their legislators on the federal policy initiatives and priorities most critical to people living with MS. These activists, who include people affected by MS, staff, and volunteer leadership for the National MS Society, come together to hear from panels of experts about each of the Society's policy priorities, network with others who share their passion to end MS, and attend meetings with congressional offices, sharing their personal stories to drive change.

The goal of the Society's advocacy and public policy efforts is to find systemic solutions for people affected by MS - changing lives by creating or expanding resources and engaging people affected by MS in driving change. Current policy priorities include such issues as MS research funding, access and affordability of MS medications and quality healthcare.

By **influencing government** and societal changes, we **remove barriers, create resources, and pave the way** for breakthroughs that will **change the world for people with MS.**

The critical priorities that our activists take to the Hill during the Public Policy Conference are recommended each year by the Society's Activism Advisory Committee. This group of passionate activists with a variety of expertise and perspectives including people with MS, family members, legislative and policy experts, healthcare providers, researchers and staff, convenes in the fall to provide advice that will help set the advocacy priorities for the Society. Their work is informed by survey results from MS activists across the country to identify and confirm the public policy issues of greatest importance for people affected by MS.

Gathering the activist community to equip them with information on legislative priorities and how to effectively tell their story to influence policy is just one of the benefits of this annual gathering. Public Policy Conference is also an empowering opportunity for MS activists to gather with one another, build each other up, and share their story to drive meaningful change for themselves and everyone affected by MS:

“It's exciting to come every year to the MS Public Policy Conference ... you are able to connect with other MS activists throughout the country and there is power in numbers, so together even though we are working on different issues in our states and our communities, we are here united in one goal, and one voice.”
– **Jennifer Gomez-Chavez, diagnosed in 1995 and 2007**

“Being a part of the public policy conference is an amazing experience. As soon as you walk into the room with all of the other MS activists, it's almost like there is an electrical charge ... the energy goes right through you and you cannot help but be inspired. One of the things that I get out of attending the Public Policy Conference, as someone who does not have MS but whose family does, is seeing so many people who are living with MS rising up and acting in such an empowered way by advocating on behalf of their own needs. I cannot even describe the sensation, it's beyond amazing.”
– **Jon Strum, husband of Jean who lives with progressive MS**

People with MS now and into the future will achieve life-changing breakthroughs when they have affordable access to effective treatments, long-term care services and supports, equal employment opportunity, and accessible public spaces. Vital funding for MS research will lead to the breakthroughs we need to stop the disease in its tracks, restore what has been lost, and end MS forever. Your gift toward advocacy will support the Society's efforts to inspire and empower activists, helping them realize they have the power to make change happen. ■

SOCIETY TRUSTEE LEADS BY EXAMPLE WITH \$1 MILLION GIFT TO ADVANCE PROGRESSIVE MS RESEARCH

Steadfast Society supporter, Indiana Board of Trustees member, and long-time co-captain of a leading Walk MS team, Jay Brammer, has advice for others looking to change the world for everyone affected by MS: “Whether you are most interested in helping people live better lives today or funding research towards a cure, there is no better place to support than the National MS Society.” Heeding his own advice, Jay, and his wife Becky, will be gifting the Society \$1 million over the next two years to fund research that will change the lives of those with progressive MS, and all forms of MS, across the world.

For Jay and Becky, this gift to accelerate MS research breakthroughs is deeply personal. They have witnessed what it’s like to live with MS up close through their daughter, who was diagnosed with relapsing-remitting MS in 2014. Though their daughter lives with the challenges of stress, sleep deprivation, heat sensitivity, and occasional blurry vision, she remains upbeat. She finds ways to overcome the challenges of MS, like taking her young child outside in the evening to spend time together when it isn’t as hot. Jay says, “having a family member with MS, you worry about the future for them” and that his gift is motivated by assuring a better future, not only for his daughter, but for the “many brave, wonderful people living with MS” across the country, including those he has met through his many active volunteer roles with the Society.

Jay and his family are thankful for the many advancements and treatments available today for those who live with the relapsing-remitting form of MS but acknowledge that “today we have very few choices for those affected by the most severe form of the disease.” He lauds the Society’s prioritization of progressive MS research and its leadership in this important global effort through its integral role in the International Progressive MS Alliance. He sees the Society and the Alliance’s work as key to the fact that more is being learned about progressive MS today than ever before and that’s why he has supported this effort so generously with this gift. “The nature of progressive MS means we need answers more quickly,” Jay says “and with relapsing MS very often leading to progressive MS we need to double down and find answers for the benefit of all living with MS.”



Becky and Jay Brammer

As a member of the Indiana Board of Trustees, Jay also has a front row seat to the inner workings of the Society and the tireless efforts of its staff and volunteers to drive breakthroughs that change the world for everyone affected by MS. “The Society’s volunteer leaders are the most supportive and active contributors to the organization because they best understand what the Society accomplishes every day for millions of people through its’ programs, research and legislative advocacy,” Jay shares. He says that he and his fellow trustees show their “leadership, support and confidence in the Society” not only through the gift of their time but through their meaningful financial contributions as well.

For Jay, a cure for MS will come not just through one individual gift, albeit a substantial one, but through the collective impact of many. He calls on his fellow trustees and donors to give generously to the Society because it is the collective contributions of many that will help the Society continue to affect millions of lives. “Today the Society makes choices on what to fund,” Jay says. “I believe it makes good, well-vetted decisions ... but with more resources the Society would be able to do more. Who knows what area of research is not yet funded but that will prove to unlock the key to ending MS in the future?” ■