

The NOW MS Research campaign makes history as it nears its goal



Unprecedented progress, exciting results

by Mary E. King, PhD

STOP the disease. RESTORE lost function. END MS forever. The National MS Society's groundbreaking \$250 million No Opportunity Wasted (NOW) campaign has launched more MS research and driven more progress toward these three life-changing goals than has occurred at any other time in the Society's history.

Begun in 2010, the NOW MS Research campaign has in five short years already brought in more than one-quarter of the Society's total research investments since its founding in 1946. NOW has accelerated research breakthroughs that may forever change the lives of people with MS and lead to the end of this disease. We are closing in on completion of this historic campaign.

Progress toward goals

STOP MS



The NOW campaign has provided funding to some of the world's best and brightest minds to find answers to stop MS progression. For example, the exciting research of University of California, San Francisco, researcher Sergio Baranzini, PhD (see profile in tabs below), on the possible role of the gut microbiome in MS may help determine factors that initiate MS, drive

its progression and lead to probiotic strategies to modify the disease course.

We have also seen promising clinical trials of nerve-protecting strategies, including several aimed at progressive MS. In addition, NOW funding has made possible:

- Promising results on the repurposing of phenytoin, an oral epilepsy therapy.
- The establishment of the International Progressive MS Alliance, a collaborative initiative aimed at speeding treatments to people with progressive MS.
- The creation of the MS Outcome Assessments Consortium, a global effort aimed at developing a new tool to more easily measure MS progression—critical in testing new treatments for progressive forms of MS.

Other researchers funded in the STOP MS effort improved methods to speed the diagnosis of MS and uncovered new evidence for risk factors for MS progression, such as the effect of dietary salt on immune activity and the possible role of low vitamin D levels in MS disease activity and progression.

RESTORE lost function



Jessie Huisinga, PhD, and her team at the University of Kansas Medical Center (see profile in tab below) are developing a rapid, sensitive method to more accurately assess and track walking and balance changes in people with MS. This research may speed the development of better therapies to restore these critical functions.

Other researchers focused on restoring lost function have advanced new strategies for repairing myelin, the nerve insulation damaged by MS. Trials of several myelin repair strategies are now under way.

Additional projects aim to restore function and relieve MS symptoms through exercise, dance, memory training and other novel approaches. Researchers have also demonstrated the promise of various types of stem cells to restore function, though so far only in mice.

The real impact of the NOW campaign

- Invested close to \$250 million in research —over a quarter of the Society's more than \$900 million in investments since our founding in 1946.
- Expanded the MS treatment pipeline; there are now more potential treatments in trials than at any other time in history.
- Furthered the promise of myelin repair—three potential myelin repair treatments have entered trials in just the last five years.
- Advanced understanding of the causes of MS—more than 100 genetic variants have

been identified in just the last five years, and several risk factors have been confirmed.

- Recruited 137 new researchers to the field—nearly every thought leader driving advances today got his or her start with Society funding.
- Galvanized the world around solving progressive MS—11 countries and counting are collaborating through the International Progressive MS Alliance.

END MS forever



The NOW campaign also focused on ending MS forever. One grant awarded under this goal supported the work of Dr. Philip De Jager (see profile in tab below). He is collecting and assembling a vast amount of genetics data to learn more about disease progression and ultimately provide clues to MS prevention. Determining which genes put people at highest risk of developing MS will help researchers identify approaches to preventing the disease.

With the support of NOW funding, investigators at the International MS Genetics Consortium have identified more than 159 genetic variations that make people susceptible to MS triggers, and now researchers are collaborating to track the effects of more subtle changes in genes on the risk of developing MS.

NOW funding also allowed researchers to identify environmental and lifestyle factors that may affect MS risk—such as smoking and childhood obesity—and work is ongoing in this area.

Support from the NOW campaign also enabled the establishment and expansion of the Network of Pediatric MS Centers, to better understand the cause(s) of MS, the characteristics of this disease in children and the best options for treating children with MS.

Moving forward

Bruce Bebo, PhD, executive vice president of research at the National MS Society, is enthusiastic about what the Society has accomplished with this campaign and looks forward to the continued acceleration of progress.

“We are at a pivotal moment in our funding initiatives. Our unprecedented level of investment in research, made possible through the NOW campaign, is already yielding discoveries that hold great promise for changing lives. That is why our research investments must continue to increase beyond the NOW campaign,” he says. “We will continue to focus attention on the issues that matter most to people with MS, and where we can create the greatest impact. We need to build on the momentum created through the NOW campaign so that people with MS can live powerfully as we pursue a world free of MS.”

Mary E. King, PhD, is a freelance medical writer in Boulder, Colorado.

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The NOW Research campaign has made a difference for scientists, advocates and people living with MS. Click on each tab to read the stories of these dedicated individuals.

Baranzini

Dr. Sergio E. Baranzini

Professor, Department of Neurology; Heidrich Family and Friends Endowed Chair in Neurology, University of California, San Francisco



Photo courtesy of
the National MS
Society

When I was working on my PhD in human molecular genetics, I was studying a disease caused by changes in a single gene. But soon after, I became intrigued by multiple sclerosis, a genetically more complex disease. Much less was known about it, and I hoped my research might help us understand what causes the disease and how MS unfolds.

I've been studying the genetics of MS for 15 years now. However, two or three years ago, my team and I became interested in the microbiome—the term for the hundreds of trillions of bacteria and other microorganisms that live in the human gut and assist with digestion, and also play a role in the immune system. The topic seemed to complement what we had already learned in studying MS genetics. Early on, however, I couldn't get funding because not much work had been published about the microbiome in MS yet—a Catch-22 for those of us trying to get grants. But the Society stepped up and supported us. Thanks to the NOW MS Research campaign, we, together with researchers at Mount Sinai School of Medicine;

Caltech; and the University of California, San Diego, received a collaborative award for our new project, the MS Microbiome Consortium.

We are already seeing some intriguing results that may eventually lead to new paths to developing treatments. Early findings show differences in gut bacteria between people with and without MS. Also, in people with MS, the gut microbiome differs between those who have been treated with glatiramer acetate and those who have not.

The Society provides MS researchers with a little more room for exploration. Although it is a careful steward of its funds, the Society is forward-thinking and willing to take more of a gamble on researchers with novel ideas.

—As told to Mary E. King, PhD

Sample

Bill Sample

Donor and volunteer, Seattle, Washington



Photo courtesy of
the National MS
Society

As the corporate vice president of worldwide tax at Microsoft, I became involved in supporting MS research when one of the employees in my department was diagnosed with the disease. I soon realized that many of my friends and colleagues know someone with the disease. I think it's important to take a leadership role in doing something about it.

In 2007, I joined the Greater Northwest chapter board and have since donated \$300,000 to the Society through its Fast Forward commercial research program, which closes the gap between promising discoveries and the commercial development necessary to get new

treatments to people with MS, and about \$200,000 to other Society programs. Supporting research is the best way I know to find answers and create impact. The cause (or causes) of MS are still unknown—a pretty fundamental question that we need to answer, and research will help us do that.

The Society creates impact by making every dollar invested go as far as possible. One of the ways they do this in MS research is through Fast Forward, the Society’s version of what many of us know as a venture capital fund. A lot of promising research fails because it’s hard to raise money at what’s called “the valley of death” stage—when you need to demonstrate proof of concept. So the Society focuses Fast Forward on promising research projects to help them through that stage. For instance, the Society invested \$1 million for research on two new drugs, and that money then led to another \$250 million in additional investments. That’s how you get impact.

While my goal is to get people to support MS research at a meaningful level for their financial situation, I think it’s equally important to donate time and energy. Regardless of your ability to contribute financially, the Society is a great place to volunteer. I get a great sense of fulfillment working with people who want to end MS forever and are trying to have a big impact on that.

—As told to Vicky Uhland

De Jager

Dr. Philip De Jager

Associate Neurologist, Brigham and Women’s Hospital; Associate Professor of Neurology, Harvard Medical School

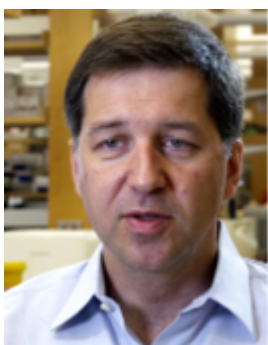


Photo courtesy of
the National MS
Society

I became involved in multiple sclerosis research when my scientific interest in understanding the genetics of brain inflammation and my clinical interest in improving the lives of people with MS converged. The clear need to better understand the disease—so we can identify novel treatments for MS—is an important motivator for me. We're at an unprecedented time in the field of biomedical research, and the new technologies that are available allow us to ask new questions that we could never ask before.

As my engagement in the field of MS grew, I found that the Society played a critical, ongoing role in accelerating whole fields of research. One good example is the Society's leadership in supporting the launch of the International MS Genetics Consortium (IMSGC). Before the launch, little was known about the genetic component of MS, and NOW funding enabled us to drive this work forward. As a result, the IMSGC has already identified more than 159 genetic variations related to MS. My group is now investigating the specific immune cells and proteins that are affected by these variations.

As a result of NOW funding, I've also been able to explore novel pathways to understand the causes of MS, and in 2014 I received the Society's Barancik Prize for Innovation in MS Research.

This research has yielded considerable advances in our understanding of the genetic factors that make some individuals more likely to develop MS. However, this is just a start, as we now have to understand how these risk factors affect the immune system to trigger the disease, and how to use this new genetic information in a clinical setting. I'm excited to see where this path leads and to hopefully impact the care of people with MS and their families in the near future.

—As told to Mary E. King, PhD

Huisinga

Jessie Huisinga

Assistant Professor in Physical Therapy and Rehabilitation Science; Director of the Human Performance Laboratory in the Landon Center on Aging, University of Kansas Medical Center



Photo courtesy of
Jessie Huisinga

I was working toward my PhD in biomechanics at the University of Nebraska Medical Center when I learned that 85 percent of people with multiple sclerosis report balance problems. However, there was a large gap in our understanding of these issues, including how to sensitively identify changes in walking and balance in people with MS, or how to treat these problems. It was an area where I felt I could contribute.

The National MS Society has a focus on, and commitment to, funding research that covers all aspects of MS—from rehabilitation and new treatments to the reasons why people develop this disease. With this wide-ranging commitment, the Society understood that research into walking and balance could have a very large and direct effect on the quality of life for people living with MS. My initial support, as a Society Research Fellow, helped me continue learning ways to measure balance problems in different populations.

In my current position at the University of Kansas Medical Center, I received a Society grant, supported through the NOW MS Research campaign. The award is enabling my laboratory to adapt “motion capture” techniques to assess walking and balance problems in individuals with MS. To do this, we attach wireless sensors to the legs, arms and trunk of each person in our study, and “capture” their movements on a computer. This allows us to more precisely measure even small changes in gait and balance.

We are looking at these factors very early in the disease process because we want to clearly determine whether, and precisely how, these problems worsen. We hope these techniques will allow researchers to better assess whether interventions to improve gait and balance, such as physical therapy or a medication, are having an impact in people with MS. Ultimately, we hope this will help people with MS have customized care that keeps them moving.

—As told to Mary E. King, PhD

Martin

Melissa Martin

Research participant with MS, Evansville, Indiana



Photo courtesy of
Melissa Martin

I was diagnosed in 2009 with progressive multiple sclerosis. Within a year of my diagnosis, I was falling, bumping into walls, sleeping 16 hours a day. I wasn't able to bathe or dress myself. And I wasn't able to walk unaided—I used a wheelchair or a walker. My symptoms were so severe that four years ago, I had to leave my home so I could receive 24-hour care.

But I've never stopped believing that research is key to understanding this disease. In 2014, I joined a 26-month double-blind clinical study for a new MS medication. My hopes weren't very high that it would improve my symptoms, since I didn't even know if I would receive the study medication or the placebo; mainly I hoped the research would eventually help other people.

I'm still in the study, and I can now walk a mile and half three times a week as a result of the medication. I can do everything but drive. And I've moved back home with my husband.

Research has had such a personal effect on my life that I never stop challenging people to get involved in MS research in any way they can. It's the key to finding a cure for this disease. Outside of clinical trials, there are all kinds of ways to become involved in MS research. For the last five years, I've been a Walk MS: River Valley team captain in southern Indiana and Kentucky. In the last two years, we've raised \$4,700 for MS research. I tell everyone I meet not to give up, because eventually we will find a cure.

—As told to Vicky Uhland

To contribute to the NOW campaign's final goal, contact your chapter before Dec. 31.

For more information on the NOW campaign, visit nationalMSSociety.org/NOW.