A PIONEER IN HIS FIELD

2014 JOHN DYSTEL PRIZE RECIPIENT FOR MS RESEARCH TO SPEAK AT ANNUAL RESEARCH SYMPOSIUM

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Piles of neatly stacked papers covered the desk and shelves of the office starting at the door and wrapping around the entirety of the room. Thick books filled the spaces between, and a microscope could be seen peeking out from behind a stack in the far corner. Looking around the office, it was hard not to be in awe of the sheer accumulation of knowledge blanketing every inch of space. Each pile of papers contained a small piece of several decades of important MS research, arranged into piles that only the office’s occupant, Dr. Barry Arnason, could truly discern.

He leaned back in his chair, staring at the wall and fiddling with the bridge of his glasses as he paused for a moment to consider his response. After a few seconds he smiled and said, “That’s a good question.”

He had been asked about what drew him to multiple sclerosis research, and having begun his work in 1959 as the National MS Society’s first fellow, a momentary pause to reflect on a lifetime of work was understandable.

His road to MS research began with an interest in overall neurology during his medical residency at the Massachusetts General Hospital in Boston. Four months in, Arnason attended a lecture on lymphocytes — small white blood cells that direct
Dr. Arnason’s road to MS research began with an interest in overall neurology during his medical residency at the Massachusetts General Hospital in Boston.

Massachusetts General Hospital, Neurology, 1966. Dr. Arnason is located front row, 2nd from left.

the body’s immune system response — given by a man named Dr. Byron Walksman. At the time, Arnason knew nothing about lymphocytes, but after hearing the lecture, he decided it was a subject he wanted to explore.

“I went up to [Walksman] and said, ‘I’d like to take some time off my residency and work with you,’” said Arnason. “It sort of took off from there.”

Using an antibody to lymphocytes developed by Walksman, they discovered that lymphocytes were somehow involved in causing damage in a disease called Experimental Autoimmune Encephalomyelitis (EAE), which was being used as a model for MS. In an effort to learn more about lymphocyte function, they removed the thymus gland — a small organ that develops lymphocytes — from newborn rats, finding that as the animals grew up without it, they had no small lymphocytes and did not develop EAE.

After further research, it became clear that the thymus lymphocytes, which came to be known as T-cells, were implicated in MS itself. That discovery led to the development of drugs that affect T-cell function to help control or modify the immune system response in people with relapsing-remitting MS.

Arnason was also interested in the immune system cells responsible for triggering MS attacks in people with relapsing-remitting MS. It was clear at the time that there were cells within the immune system that generated an immune response, essentially turning on the disease, but Arnason was more interested in suppressor cells, the immune system cells that turn the disease off.

“We first started looking at them in the 1970s, and we found that they had a surface marker that we could identify them by,” said Arnason. “They fell out of favor among immunologists who decreed that suppressor cells didn’t exist, so it was impossible to get funding to pursue that line of research for over a decade. We sort of snuck some experiments in periodically over that period of time, but I’m happy to say that the role of suppressor cells in MS has once again become accepted.”

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Looking back at what drew him to MS research, Arnason realized that he had been swayed by the work of Walksman because of another experience at the beginning of his medical education. Prior to his residency, while studying medicine at the University of Manitoba in Winnipeg, Canada, Arnason watched as a polio epidemic swept through the town. As people died all around him from the virus, he wondered why some became infected and others did not, unaware that the thought would help shape the course of his career.

“The polio vaccine was available the year after the epidemic that I was involved in,” said Arnason. “That, I think, also influenced me in terms of a career choice … the thought that such things could be cured or prevented.”

He hopes the same can be done for MS.

“Everyone always talks about a cure, but a cure is something you do after a disease develops,” said Arnason. He believes that there may be another way to end MS if a cure can’t be found.

“It might be possible to entertain the notion that we could eradicate MS if we had a vaccine that would prevent whatever it is that sets MS in motion.”

In other words, if MS can’t be cured, perhaps it can be prevented.

According to Arnason, most researchers agree that MS is set in motion by a viral infection. If researchers could pinpoint that virus and develop a vaccine, MS would not develop later in life.

“At the moment, the lead candidate is the virus that causes infectious mononucleosis,” said Arnason.

Infectious mononucleosis — sometimes referred to as the kissing disease because of its oral transmission — is caused by the Epstein-Barr virus, which infects a large majority of the world’s population, though not everyone develops the symptoms. The rate of infectious mononucleosis in MS patients is higher than that of the general population, and there is a correlation between hygiene and MS development, which shows that late exposure to infectious mono due to better hygiene may increase MS rates, giving researchers reason to believe that the virus may somehow set the stage for subsequent MS development.

“We don’t have a vaccine for infectious mononucleosis,” said Arnason. “Maybe if we did and we vaccinated children, we could prevent MS and wipe it off the face of the earth.”

Of course, that is no easy task.

“Infectious mono has been around for a long time, so it has been very clearly adapted.”
explained Arnason. “Developing a vaccine for it could be interesting, but it’s trickier than that. It’s not really a fatal illness, after all, and most people don’t know they have it. It doesn’t really have an immediate effect, and I think that’s one of the reasons why there hasn’t been much enthusiasm about developing a vaccine.”

When discussing the landscape for the future of MS treatment and research, Arnason expressed a concern that getting funding for certain potentially important clinical trials would require a lot of convincing.

“Clinical trials are financed by pharmaceutical companies, and these companies are not interested in doing trials on drugs that were approved 15 or 20 years ago on which patent protection has expired, because the trials cost a lot of money,” he explained. “I think there are any number of drugs out there that are already approved for treatment of various things — including various problems in the nervous system — that have never really been tested in people with progressive MS, but we’ve never been able to persuade any drug company to sponsor a trial.”

Arnason believes that individually these drugs won’t make a major difference, but collectively they could lead to substantial improvement, particularly for more advanced cases of MS.

“We have to do better in terms of progressive MS than we do at the present time,” said Arnason. “We have to rethink what’s going on and come at it from a totally different direction. Sometimes you have to nibble, but if you can get a 15–20 percent effect with five different drugs and combine them, you may end up with a 75 percent effect. That may be one approach.”

He has already seen potential in some smaller scale studies. In one such study, Albuterol, which is used to treat asthma and other lung diseases, was given to MS patients who were receiving Copaxone, one of the drugs used to treat MS. The trial consisted of 50 patients: 25 to receive the drug and 25 in the placebo group. Of those in the placebo group, eight had attacks compared to only one in the Albuterol group.

“That was a small study, but a big difference,” said Arnason. “That drug is very cheap and it could be interesting to do a clinical trial, but we have to figure out how to do that without the support of pharmaceutical companies and without it costing $50 million a pop. If we can figure out how to do that in collaborative ways by testing five different drugs against one another and keeping the readout simple, we could come at a lot of drugs that might have individually modest but collectively substantial effects on progressive MS.”

Arnason has made amazing contributions to the field of MS research and to basic immunology, but his contributions go beyond his individual accomplishments. He is also responsible for mentoring many others who have gone on to make their own important discoveries in MS and other related diseases.

“Over the years I’ve been blessed with very good fellows and students, so I have had a hand in training a certain number of people who continue to be active in MS research,” said Arnason. “In fact, interestingly, two of my fellows got the Dystel Prize ahead of me.”

The Dystel Prize, a $15,000 award given jointly by the National MS Society and the American

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Academy of Neurology, recognizes outstanding contributions to research in the understanding, treatment or prevention of multiple sclerosis. The award is made possible through a contribution from the John Dystel Multiple Sclerosis Research Fund at the National MS Society, which was established by late Society National Board member Oscar Dystel and his late wife, Marion, in honor of their son, John Jay, an attorney whose promising career was cut short by progressive disability from MS.

This year’s award was presented to Arnason in recognition of his fundamental contributions to the study of immune attacks on the brain and spinal cord in MS, which led to the development of immune-directed MS therapies.

“It means the MS community feels that I have made a contribution that amounts to something in terms of advancing the cause of MS research. That’s something I can look back on with pride.”

Dr. Arnason on receiving the John Dystel Prize

addition to his continued work with suppressor cells, he is currently studying the effect of high-dose steroids on long-term disease progression.

“It’s standard practice to treat attacks of MS with high-dose steroids, and there is absolutely no question that when you give them high-dose steroids, the symptoms improve more quickly than they would without them,” said Arnason. “At the same time, if you compare patients who have been treated with steroids to those who haven’t and look at them 10–15 years later, the amount of disability between the two is exactly the same.”

He wanted to discover why this mismatch exists and how we can improve steroid effectiveness in the long-term, and he did. Through his research, he discovered a population of T-cells that are resistant to steroids.

“It looks as if the reason is because they have a transporter that pumps the steroid out, so it goes in and gets kicked out,” Arnason explained. “If we can succeed in showing that we can block that and make those cells sensitive to steroids, then maybe we’ll have a better effect on the long-term.”
Arnason has a great deal of hope about the future of MS research, and he believes that his patients do as well.

“They are more optimistic about their futures with MS now than they were when there were no treatments available,” said Arnason. “The attitude has shifted rather dramatically, and there’s no question in my mind that giving vigorous treatment early has a substantial effect on lessening the severity of MS in the longer term. Almost all of us now who deal with MS patients believe that they should be started on one of the immunomonitoring drugs as soon as they are sure of the diagnosis — none of this waiting to see if you’ll have multiple attacks or not.”

Still, with all the progress made in the treatment of MS, a gap still exists, and Arnason hopes it can be filled.

“We did not foresee at all that drugs that would work in relapsing remitting MS would not work in progressive MS; we thought they were two variations of a single theme, but they aren’t,” said Arnason. “That begs the question: How do you deal with someone who already has MS and some disability and has developed the slowly worsening form of the disease?

“And there, it seems to me, we have to sort of do better … we have to do better.”

Dr. Arnason will be the keynote speaker at this year’s Annual Research Symposium, taking place Saturday, Oct. 18, in Rosemont, Illinois. To learn more about the event or to register online, visit MSillinois.org. Registration is nearing capacity. If full, call 1.800.344.4867 to get on the waiting list.

Join hundreds of the city’s young professionals for cocktails, casino games, a multi-restaurant chef tasting, a silent auction and a raffle where someone will win a six-night stay in Maui, Hawaii! Purchase tickets at MSsoiree.org
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ADVOCACY

BE A DIGITAL MS ACTIVIST

In 2012, MS activists sent tens of thousands of emails, placed hundreds of phone calls, and made hundreds of in-person visits to members of Congress asking for their support on issues important to people with multiple sclerosis and their families. And now there are more ways for MS activists to connect—online.

DRIVING CHANGE

Digital MS activists—like all MS activists—want to drive change and do so by amplifying their voice and connecting with elected officials over social media.

At nationalMSsociety.org/digiMSactivist, learn how to share your story, connect with other MS activists and build relationships through social media and email. The webpage includes ways to:

- **Get informed.** Become part of the MS Activist Network. Receive e-newsletters and Action Alerts about important pieces of legislation. Send emails with a few clicks of your mouse.

- **Rise up.** Learn where your elected officials stand. Speak out on issues important to you as a person affected by MS.

- **Take Action.** Build relationships with elected officials by posting on and liking their social media pages and by thanking them on Facebook or Twitter for their supportive actions.

- **Recruit.** Encourage others to join the movement by directing them to our video at ntl.ms/YouCanBeAnMSActivist, or to nationalMSsociety.org/digiMSactivist.

Become a digital MS activist and help shape the conversations today that will drive change tomorrow—we promise you, people will listen!

DEAR COLLEGE

“Dear Colleagues” are important tools in supporting legislation that impacts people with multiple sclerosis. They are letters sent by one or two members of Congress to fellow members, usually asking for co-sponsors on a new bill or seeking to influence recipients’ votes on a particular issue. The Society often helps compose letters that support legislation important to people with MS. MS Activists help gain signers through Action Alert emails.

This spring, Dear Colleagues were circulated in Congress to support $10 million in funding for the MS Congressionally Directed Medical Research Program, $32 billion for the National Institutes of Health, and $2.5 million for the Lifespan Respite Program. The Congressional MS Caucus and MS activists are working in coalition with other groups to preserve these funding levels for FY 2014. To join the effort, go to nationalMSsociety.org/MSActivist.
MONEY MATTERS
MANAGING YOUR MONEY WITH MS

Gloria Dady had envisioned spending the rest of her working life taking care of people. She never expected that, in her 50s, multiple sclerosis would force her to start drawing on her retirement nest egg. It was unsettling — until she reached out for help from the National MS Society.

Through the Society’s partnership with the Society of Financial Service Professionals, people affected by MS can get free financial counseling from trained professionals through the Financial Education Partners (FEP) program. Doug Head, CLU, ChFC, a financial advisor with Edward Jones in Tukwila, Wash., is one such volunteer.

Head helps people plan for a life with MS by talking about basic budgeting, different ways to save, how to maximize health insurance benefits and more. But he lends more than his number-crunching know-how. He and other FEP volunteers also offer hope that any financial challenge can be tackled with patience and planning.

“Dealing with the challenges of MS often leaves people feeling that their finances have gotten away from them,” Head says. “The first thing I ask is, ‘What are your two or three major financial concerns?’ This helps us focus on what’s really important to them.”

Dady appreciated talking to a finance professional who could explain everything clearly and compassionately. Head discussed strategies to lower her tax payments and keep her retirement savings intact, even as she drew on it for income. Over the past four years, Head has offered free financial advice to more than 100 people who have been referred to him by the Society. “The people I’ve met are wonderful,” Head says. “I’ve been inspired by their journeys.”

People living with MS can talk in person or over the phone with FEP volunteers about financial topics such as insurance analysis, retirement, estate planning and legal planning. To learn more, visit nationalMSsociety.org/financialplanning or call an MS Navigator at 1-800-344-4867.

This article was originally written by Liz Murtaugh Gillespie of Moore Ink. PR & Fundraising Communications and was published in the Spring 2014 issue of the Greater Northwest Chapter’s MSConnection.
RESEARCH

NEW RESEARCH ON WELLNESS AND MS

BY NICHOLAS LAROCCA, PhD

The Annual Meeting of the American Academy of Neurology (AAN), held April 2014 in Philadelphia, featured thousands of presentations on neurological diseases. I was increasingly impressed with how many of these addressed wellness and lifestyle in people with multiple sclerosis. Entire sessions were dedicated to topics such as “Diet and Hormonal Influences in MS” and “Cognition and Fatigue in MS.” We are becoming more aware of the diverse paths toward finding solutions for everyone with MS.

DANCING WITH MS

And even salsa dancing! Mandelbaum, Lo and colleagues (Providence, R.I.) reported on a study in which they enrolled eight people with MS in a four-week salsa program. Individuals participated in dance sessions twice a week. Dancing resulted in significant improvements in gait and balance both right after the program and in a three-month follow-up. The National MS Society is now funding Dr. Lo of this team to conduct a larger study that may lead to more widespread use of dance as physical therapy for people with MS.

FINDING SOLUTIONS FOR FATIGUE

Fatigue is a significant problem that affects many people with MS – and one for which we don’t yet have enough solutions. I heard a report from Dr. Barak and a team from Israel on MS-related fatigue. Based on the increasing evidence that too-low levels of vitamin D may be a risk factor for MS, they administered a compound similar to vitamin D (alfacalcidol) or an inactive placebo to 158 people with MS once daily for six months. The group treated with alfacalcidol had significantly less fatigue, improved quality of life, and even reductions in relapses. I think this study presents a promising lead for reducing fatigue that certainly warrants further study.

SALSA DANCING MAY HELP MS-RELATED GAIT AND BALANCE ISSUES.
Another group of researchers reported on other factors that might contribute to fatigue in people with MS. They used polysomnography – advanced technology used to diagnose sleep disorders – to examine 206 people with MS who reported that they had fatigue, but who had not reported sleep problems. This test revealed that 68% actually had obstructive sleep apnea. It was great to hear that there might be a way to reduce fatigue in MS by diagnosing and addressing sleep problems.

**GOING WITH YOUR GUT**

One of the most interesting factors in the complex picture of MS, to my mind, is the growing body of research on the role of the “gut microbiome.” Each of us has millions of bacteria living in our guts. Most of these bacteria are harmless as long as they remain within the inner wall of the intestine. But in MS, these bacteria may be contributing to the MS immune attack. Dr. Jhangi and colleagues at Harvard examined microorganisms in people with MS who were not on any disease-modifying treatment, those who were on treatment, and healthy controls. Certain bacteria that are known to promote inflammation were found to be increased in those with MS. Another type of bacteria known to block inflammation was lower in people with MS versus controls, but higher in those who were receiving one of the MS disease-modifying treatments.

Inflammation occurs in MS when the body’s own immune cells attack the nervous system, damaging the myelin that insulates nerve fibers. Researchers are hopeful that by finding ways to reduce inflammation they may be able to limit the damaging effects of the disease. From this preliminary study, it’s too early yet to say how emerging information on the gut microbiome might impact future treatment of MS, but it’s fascinating to think that, down the road, we might affect MS by altering our internal bacteria.

**IT’S FASCINATING TO THINK THAT, DOWN THE ROAD, WE MIGHT AFFECT MS BY ALTERING OUR INTERNAL BACTERIA.**

This is one small part of the AAN reports on wellness and lifestyle in MS. I am excited about the growing prospects for improving the daily life of people with MS. You can read more by browsing through the abstracts at abstracts2view.com/aan.

Nicholas LaRocca is the vice president of Health Care Delivery and Policy Research at the National MS Society.

To follow the latest research news on wellness in MS, visit nationalMSsociety.org/research, or sign up to receive MS eNews monthly via email at nationalMSsociety.org/signup. Talk about your own wellness strategies at MSconnection.org.
Programs

Launch of National Teleconference Series

Since its conception in 2009, the Midwest Regional Teleconference has grown immensely. Only three years after its launch, the teleconference series has reached over 2,000 individuals in the Midwest, averaging over 200 participants per call.

In response to the success of the Society’s telelearning program, not only in the Midwest but also in various regions across the country, the National MS Society plans to broaden the program’s scope by transitioning from a regional to a national scale.

Consistent with the regional teleconference series, the national series will feature topics covering different aspects of living with multiple sclerosis. Topics will be presented by professional experts via phone with online presentations and a Q&A session. Launch of the new Nationwide Telelearning Program will begin on Nov. 18. Individuals can register by calling 1-800-344-4867 or by visiting nationalMSsociety.org/telelearning, where the telelearning schedule and topics can also be viewed.

Programs

Partner in MS Care – Roberta Winter

The Partner in MS Care program has continually encouraged strong partnerships between MS clinicians and the National MS Society. The program develops mutually beneficial partnerships between a broad range of health care professionals and the Society, the existence of which promotes optimal care and support for individuals living with multiple sclerosis. In October, Roberta Winter will receive a certificate from the Greater Illinois Chapter recognizing her as a Partner in MS Care in the area of mental health, making her the newest addition to the Partners in MS Care program.

Winter, who received her master’s degree in social work from Columbia University, is a Licensed Clinical Social Worker (LCSW) and a Multiple Sclerosis Certified Specialist (MSCS). She currently serves as the outpatient care manager at the Chicago Center for Family Health.

Over the years, Winter has maintained a longstanding relationship with the Greater Illinois Chapter. In 2002, she was inducted into the National Volunteer Hall of Fame for her distinguished service to the Chapter. Currently, she serves on the Chapter’s Programs Committee and acts as the MS support group facilitator at the Rehabilitation Institute of Chicago.

To connect with MS Care Providers like Roberta Winter, visit nationalmssociety.org/Treating-MS/Find-an-MS-Care-Provider/Partners-in-MS-Care.
PROGRAMS

APPLICATIONS FOR MS SCHOLARSHIPS NOW OPEN

The financial impact of multiple sclerosis on individuals living with MS and their families too often challenges aspirations of receiving a college education. Believing that multiple sclerosis shouldn't stand in the way of education, the National MS Society developed its scholarship program to combat this monetary obstacle.

Since the program first launched in 2003, it has continued to expand. In 2014, the National Multiple Sclerosis Society awarded scholarships to 718 scholars, totaling over $1 million. Of these scholars, the Greater Illinois Chapter was able to award scholarships to 15 high school graduates, including Taylor Spooner.

Currently starting her first year at Aurora University, Taylor plans on majoring in both elementary education and early childhood development, hoping to become an elementary school teacher. Taylor, whose father is living with MS, is thankful to the National MS Society for helping make her dream a reality.

“Due to having a one-income family because of the impact of MS on my household, this scholarship has helped me cover the expenses of college so I can follow my passion of becoming a teacher,” said Taylor.

Highly qualified high school seniors, like Taylor, who have been diagnosed with MS or have a parent living with MS are encouraged to apply to the scholarship program. Awardees stand to receive a one-time scholarship ranging from $1,000 to $3,000 a year. Applications for the 2015 Scholarship Program can be submitted online beginning Oct. 1, 2014 through Jan. 15, 2015 at nationalMSsociety.org/scholarship.

REGISTRATION IS NOW OPEN FOR 2015!

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Volunteer Opportunities - Call 1-800-344-4867 or email us at volunteerillinois@nmss.org. Internships are available in the areas of Grant Research, Corporate Sponsorship, Event Planning, Volunteer Recruitment, Marketing and Accounting.

- MS Ambassador - Speak and represent the Society at community events and health fairs.
- Walk MS - May 3, 2015 – walkMS.org
- Bike MS - June 27 and 28, 2015 – bikeMSillinois.org

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