FEATURE STORY

ACTIVATE YOUR VOICE THIS ELECTION SEASON

BY CHRISTY KIM

Twitter fights, viral videos and jabs about small hands? If you think this is a sequel to the 1999 classic movie “Election,” think again. It is election time in America.

With the 2016 campaign coming to a crescendo, politics dominates virtually every news outlet and certainly our minds. If this historic election cycle has taught us anything, it’s the importance of political participation. Every person affected by MS has a story to tell, and that story can be used to educate public officials and drive change in our government and policies. Whether it’s meeting your congressman face-to-face or voting, get out there and share your story.

TRAGEDY TO INSPIRATION

September 10, 2001, started out as any other day for Leigh Gilmore, who lived with MS and had mobility impairment. On a visit to New York City, she checked herself into a hotel that was located between the Twin Towers. When she got to her room, she noticed the grab bar in the bathroom was broken. In an act that would later prove to save her life, she promptly notified the hotel staff of the bar and went about her day.

September 11, 2001 — a day of infamy and tragedy. As the towers came crashing down around her, Gilmore had
trouble evacuating the hotel. Because she had reported her broken grab bar the day before, the hotel staff thought of Gilmore and rushed to her room in case she needed assistance. This sequence of events can only be described as luck and fortune, as Gilmore was able to evacuate the building safely with help from the staff.

When Gilmore returned to Chicago, she used her harrowing experience as motivation to put into effect proper emergency evacuation procedures for persons with disabilities. Working side by side with the Society and volunteer MS activists, Gilmore helped pass landmark legislation in Illinois that would require specific safety measures for persons with disabilities in high-rise buildings during an emergency.

Sadly, Gilmore passed away in 2009, but her legacy and instrumental role in passing this piece of legislation will save hundreds of lives for years to come.

**AFFECTING CHANGE**

Stories like Gilmore’s are what motivate Maureen Linehan Howard to share her story and advocate for issues important to people living with MS. As an MS activist since 1994 and chair of the government relations committee at Greater Illinois, Howard knows first-hand the power of MS advocacy.

“It is important to become an MS activist because we can make a positive difference in the world,” she said. “Many industries have high paying lobbyists representing their issues in government. We may not be high paid lobbyists, but nothing is more effective than a constituent educating his or her elected officials on the issues that affect them daily.”

Every year, MS advocacy goals are laid out by a set of issues that advocates across the country uniformly work to address through policy. Some of the issues on this year’s agenda include increasing MS research funding and establishing a home modification tax credit.

The Society offers numerous tools and support for MS activists to advocate for these issues and to get their stories heard. Activists can write an editorial piece for their local newspaper, Tweet their congressman, arrange a meeting with their district representatives or attend a town hall meeting – the possibilities for activism are endless. Additionally, dozens of volunteer MS activists and Society staff members go down to Springfield every year for MS State Action Day and meet with members of the House and Senate.

“Even if you don’t feel you have the time, all it often takes is sending an email or making a call to your elected official,” Howard explained. “We can accomplish many things as individuals, but as a group, MS activists are a force to be reckoned.”
HIT THE POLLS

Before you reach out to your representative, you have to put them in office first. On November 8, citizens will have the opportunity to exercise one of their most fundamental democratic rights: voting. Currently, about one out of seven eligible voters has a disability, yet the voter turnout rate of people with disabilities is nearly six percent lower than other Americans.

“The many hurdles, both practical and emotional, that a person with a disability might face when trying to exercise their right to vote only became apparent as I faced them myself,” shared Lauren Shryne, an MS activist who was diagnosed with MS in 2014. “At the height of an MS flare, when performing basic, necessary tasks requires momentous effort, voting might cede to more immediate concerns.”

The Society has a number of resources to help overcome the challenges people living with MS may face when voting. From finding out how to register to ensuring polling place accessibility, visit nationalMSsociety.org/voterinfo for more information.

There are hundreds of MS activists working diligently right now to help people affected by MS live their best lives. Reflect on your story and use your voice to influence the political conversation for the better.

“Leigh's story is the essence of activism – turning a negative experience into a positive outcome. Many lives will be saved because of her,” said Howard. “Leigh’s memory motivates me to continue with activism. I hope others will consider joining me.”

Learn all the ways you can join the movement as an MS activist at nationalMSsociety.org/advocacy.

Through the years, MS activists in Illinois have played a crucial role in getting important pieces of legislation passed. Take a look at some of our successes:

2016 - Step therapy reform
2013 - Creation of a statewide MS task force
2011 - Safe patient handling in hospitals
2009 - Pharmaceutical assistance adds 70 MS symptom management medications to the Illinois RX formulary
2008 - Creation of Illinois lottery “Scratch out MS” instant win tickets
2003 - Pharmaceutical assistance to cover prescription medications used in MS treatment
CONNECT AND LEARN AT RESEARCH SYMPOSIUM

21ST ANNUAL EVENT TO TAKE PLACE SATURDAY, OCT. 29, AT HYATT O’HARE

The Greater Illinois Chapter will host its 21st Annual Fannie and Charles Penikoff Research Symposium and Health Expo on Saturday, October 29, at the Hyatt Regency O’Hare in Rosemont, Ill. This free, all-day program is a unique opportunity to meet with hundreds of people across Illinois living with MS, and to hear the latest in MS research from leading national and local neurologists, medical professionals and researchers.

The event will kick off at 8:30 a.m. with a Health Expo that will feature vendors offering a variety of information, resources, products and services for people living with MS.

The morning will continue with a keynote address by Ralph Benedict, Ph.D., University at Buffalo, titled, “The Evolving Role of Neuropsychological Investigations in Multiple Sclerosis.” Dr. Benedict’s research on cognitive function in MS addresses a common issue – approximately half of all people with MS develop problems with cognition.

Following Dr. Benedict’s speech, audience members will have the opportunity to ask questions to a panel of expert local neurologists. Afternoon break-out sessions on gut bacteria and stem cell therapies will round out this jam-packed day!

“The exciting part of the Research Symposium is the opportunity to learn about cutting edge research from some of the country’s leading MS specialists,” said Susan Rubin, MD and board certified neurologist, who will moderate the Q&A portion of the event. “We bring in some of the biggest names in MS research from across the country to share their insights with all of us.”

Other event highlights include the chapter’s annual volunteer recognition ceremony and annual meeting.

For more information or to register, visit researchsymposiumil.org or call 1-800-344-4867. Space is limited, so secure your reservation! A waiting list will be created if the event becomes full. Call the 1-800 number to get on the wait list.
21st Annual Fannie & Charles Penikoff

RESEARCH SYMPOSIUM
Saturday, October 29

KEYNOTE SPEAKER:
Ralph Benedict, Ph.D., University at Buffalo
The Evolving Role of Neuropsychological Investigations in Multiple Sclerosis

8:30 a.m. to 3 p.m.
Hyatt Regency O’Hare | Rosemont, IL

REGISTRATION OPEN
For more information or to register, visit: researchsymposiumil.org
or call 1-800-344-4867

WE’VE MOVED!

OUR NEW OFFICE ADDRESS IS:
525 W. MONROE ST. STE. 1510
CHICAGO, IL 60661

SAVE the DATE

TOUR DE FARMS

NORTHERN ILLINOIS UNIVERSITY · DEKALB, IL
JUNE 10 & 11, 2017
RESEARCH

NEW EVIDENCE ON GUT BACTERIA

Researchers in multiple sclerosis have uncovered new evidence that gut bacteria, also called the “microbiome,” may play a role in MS.

In a study published in *Nature Communications* (June 28, 2016), Harvard researchers found significant differences between the gut bacteria of people with MS and people without MS. Even more intriguingly, they found differences between the bacteria in treated and untreated people with MS.

PROMISING POSSIBILITIES

The investigators, led by Drs. Sushrut Jangi and Howard L. Weiner, with colleagues from Harvard’s Brigham & Women’s Hospital in Boston, used advanced genetic tools to look at gut bacteria in 60 people with MS and 43 people without MS. In the group with MS, 32 were treated — that is, they had received interferon or glatiramer acetate for at least six months — while 28 were untreated, meaning they had not received steroids (for one month), interferon or glatiramer acetate (for three months), or other treatments (for six months).

The results of the study showed increases in bacteria associated with inflammation in people with MS. These correlated with differences in the activity of genes related to the key pathways related to immune activity in MS. Also, the differences in certain types of gut bacteria between treated and untreated people with MS suggested that treatment may help normalize some of the MS-related changes seen in gut bacteria.

The National MS Society continues to support research in this area, most recently **The MS Microbiome Consortium**, a comprehensive analysis of gut bacteria in people with MS to determine factors that may drive progression and develop probiotic strategies for stopping progression. To learn more, visit imsms.org.

**A breakthrough therapy**

In exciting news for people living with a progressive form of MS, the experimental therapy ocrelizumab has been granted Priority Review Designation by the U.S. Food and Drug Administration, with a decision target of December 28, 2016. Genentech, a member of the Roche Group, filed for approval of ocrelizumab to treat primary progressive and relapsing MS in June 2016.

The designation was granted based on phase III trial results presented at the European Committee for Treatment and Research in MS in 2015. Compared to placebo, ocrelizumab significantly reduced the risk of progression of clinical disability by 24 percent in 732 people with primary progressive MS.
GIVING LOVE A CHANCE

AUTHOR WITH LOCAL ROOTS TAKES READERS ON HER MS JOURNEY

BY JEREMY BAREWIN

After being diagnosed with multiple sclerosis in 2007 at the age of 28, Cory Martin began looking for love in all the wrong places. While trying to put into perspective a disease that she knew little about and balancing her life as an up and coming writer in Hollywood for the television show “The O.C.,” Martin set out on a quest to meet the man of her dreams as a sort of panacea for coming to grips with her MS.

Am I lovable? Will I ever get married? Can I raise a family? These are questions that Martin pondered after her initial diagnosis. Nearly a decade later, Martin has penned her account of the trials and tribulations of dating with MS in her new book, “Love Sick,” published in February. The tongue-and-cheek account is a reflection of Martin’s personality, which is a blend of humor and honesty, while also providing a hopeful outlook for the future.

A native of Frankfort in Chicago’s southwest suburbs, Martin, who now lives in the Los Angeles area, was back in the Windy City for a book signing in late July at the Book Cellar in Lincoln Square. She read excerpts from "Love Sick" and held a meet and greet with a crowd of more than 30 fans, friends and family members.

This network of support has helped Martin through the uncertain times. She remembers lying in a heap on the floor of her apartment in L.A., crying hysterically after receiving the diagnosis from her neurologist.

“I called my parents, and I was like ‘what am I supposed to do with my life?’” she recalled. “My family has been amazing. During the year of diagnosis and all the tests and the spinal tap, they were there almost every month coming out to visit from Chicago.”
Martin began to chronicle her journey with MS almost from day one. She looked around the internet to see if there were any books on the market covering the topic of dating and MS for young adults, and was surprised to find none. This spurred her odyssey to bring that information to others going through a similar situation as her.

“I love that Instagram exists now,” she said. “I’ve connected with so many other MS warriors out there who are doing great things, and they’ve found the book and have reached out to me.”

What is Martin’s advice to individuals who are newly diagnosed?

“Definitely tell people what you are going through. Not just about the doctor’s appointments, but tell them all the emotions that are behind it and your fears, because that is the biggest part, the emotional fear of what’s next,” she explained. “I kept a lot of that to myself and only told a few people, and I wish I had been more open and reached out for help.”

And how has Martin’s own personal love story turned out, you might ask?

Well, she’s been dating her boyfriend Greg, who she met on Match.com, for over three years and couldn’t be happier being with someone who is a true partner in understanding MS.

“He Googles different symptoms for me,” she said. “His attitude is that ‘we will handle this together.’”

A yoga enthusiast, Martin is also the author of “Yoga for Beginners.” She is donating 10 percent of sales of “Love Sick” to the National MS Society. For more information or to purchase your copy, visit www.corymartinwrites.com.
LIVING THE EVOLUTION

Diagnosed 27 years ago at age 30, Donna Epps Garris says she has been through “the evolution of multiple sclerosis.” At the doctor’s office, she was told that there was nothing anyone could do for her. Today, she takes an oral treatment that works for her.

“We didn’t have computers or Internet,” Garris remembers, “so I would go to libraries and read about MS.” One book mentioned a doctor whose words resonated with her. “He said, there is no cure, but I can make your life comfortable living with MS,” she says. “I thought, this is the doctor I want to see.” So she drove eight hours to Atlanta from her home in Barr, Mississippi, to see him. Since then, she has tried different treatments to find one that was right for her. “It’s just been tremendous,” she says. “I’ve had only one exacerbation in two years.”

However, that’s not to say Garris doesn’t still face challenges, such as accessing care and support in a rural area, and with her job. As an independent sales representative, she is not covered by the Americans with Disabilities Act and has found it difficult to overcome misconceptions at work about her MS. “People with MS who work independently really are vulnerable,” she says. So she is turning her energy toward MS activism, working to support funding for MS. “I met with our local congressman last year and told him my story — how important it is to keep pushing through those funds.”

Garris also eagerly follows the world of MS research. “MS affects people in many different ways, whether it’s relationships, jobs or depression, and there are many different ways to help us live a life that’s manageable,” she says.

She cites “tremendous” family support and her husband, Pete, as important factors, as well. “I couldn’t do it without him. He knows exactly what to do” — things like bringing home a single rose or sending cards in the mail.

“I couldn’t do it without him. He knows exactly what to do.”

“Just little things like that,” she says. “It’s not all about physical intimacy, but things that keep the romance alive.”
summer recap

It’s officially sweater weather! But before we dive into our pumpkin spice lattes, we want to bid adieu to an incredible summer. From bike rides to golf swings, summer 2016 will be one to remember!

BIKE MS: TOUR DE FARMS

Hundreds of riders set out for the ride of a lifetime at our 35th annual Bike MS: Tour de Farms ride in DeKalb, Illinois!

Riders from this year’s top two fundraising teams, Wheeler Dealers and Petal Pushers, cruise along the route.

MS SLUGFEST

Team Barb’s Minion Sluggers won at the 16th annual MS Slugfest. This year, 22 teams participated in this softball tournament to knock MS out of the park.

MS SUMMER SOCIAL

Over 300 guests enjoyed a night of dancing, drinks and raffle prizes at the seventh annual MS Summer Social. The event raised over $27,000 to help end MS!

COHN WEIL MEMORIAL MS OUTING

Over 600 guests enjoyed a variety of events at our 38th annual Cohn Weil Memorial MS Outing. Here, we have golfers ready to play a friendly round of golf!

Honoree Pat Larmon and event chairman Joseph Weil (back row, third and fourth from the left, respectively) stand together with family and friends. All in all, the event raised over $1.2 million!
INVESTING IN THE FUTURE

The National Multiple Sclerosis Society has committed $25.3 million to 60 new MS research projects that hold promise toward stopping MS, restoring lost function and ending MS forever. In addition, funding for one-year grants for 11 new pilot projects will allow MS researchers to investigate high-risk, high-potential strategies to understand, treat and manage MS.

Studies that delve into genetic and environmental risk factors for MS include how vitamin D might protect individuals from developing the disease and how the influence of genes on immune cell activity might be a clue to stopping or preventing MS. Other studies are focusing on a range of strategies to stop MS progression or restore function. Following is a sampling of these promising projects.

THE WHY OF PROGRESSIVE MS

Despite advances that have produced disease-modifying therapies for relapsing forms of MS, treatments for progressive MS have remained elusive.

To address that gap, the Society is supporting a large-scale study, SUMMIT (Serially Unified Multicenter Multiple Sclerosis Investigation), to leverage extensive information from long-term monitoring of more than 1,000 people with MS to understand factors that lead to progression.

The National MS Society has also renewed its support of pediatric MS research.

The five-year study will bring together two MS Centers of Excellence, Harvard’s Brigham and Women’s Hospital and the University of California, San Francisco, to develop a database of invaluable information that will be open to researchers anywhere in the world.

Another study, led by Dr. Claudia Lucchinetti and Charles Howe, PhD, at the Mayo Clinic and Foundation in Rochester, Minnesota, will conduct “metabolic profiling” of people with MS in order to better understand the role that metabolic stress, which spans a variety of problems in cells, including energy deficits and failure to recycle unneeded proteins, may play in MS progression.

An interesting study at Washington University School of Medicine in St. Louis explores the role that sex differences may play in the transition of relapsing-remitting MS, the most common form of the disease in women, to secondary progressive MS. Researchers have found that the entry of harmful immune cells into the brain during MS is partially mediated by a molecule called S1PR2,
which occurs in high levels in women with MS. Blocking S1PR2 in mice with an MS-like disease appears to improve disease severity in female, but not male, mice.

RESTORING LOSSES
Research dedicated to restoring what’s been lost in MS focuses on understanding how nerves and their protective myelin coating normally work, how we can repair those critical tissues, and how restoring function may also include new strategies to manage common issues of MS.

One study at John Hopkins University is focusing on a promising compound that may improve cognitive function in MS. The compound, a molecule called GCPII, was shown in mouse studies to improve cognitive performance, but only in very high doses administered via injection. Now, with the help of a drug discovery team with expertise in GCPII pharmacology, investigators are synthesizing and evaluating 20 to 30 new compounds to try to create an oral version. If they are successful, the compound could move to clinical trials to prove its safety and benefits.

Another study at St. Joseph’s Hospital and Medical Center in Phoenix hopes to follow how a type of immune cell called a Natural Killer (NK) cell interacts with brain cells, possibly interfering with the repair process. These cells have been found to remain in the brains of people of MS and in mice with an MS-like disease; eliminating NK cells in the latter was found to significantly improve their recovery.

LIVING WITH MS
Restoring function may also include new lifestyle and wellness approaches. Studies focusing on these areas include an international multicenter trial of an online program to reduce MS-related depression.

While depression is a common symptom of MS, MS symptoms such as fatigue, cognitive challenges and mobility issues can make it difficult to attend in-person therapy sessions. The online program, called Deprexis, can be used in an individual’s home, eliminating the need for travel. Preliminary results have already indicated that the program may reduce depression in MS and researchers are now conducting a phase 3 trial at five MS centers in the U.S. and Germany in 400 people with MS.

Recent research has also suggested that some individuals with MS have difficulty in “emotional processing” — specifically, recognizing emotions from people’s facial expressions. A team at Kessler Foundation Research Center in West Orange, New Jersey, is examining the effects of an intervention aimed at improving emotional processing. The intervention includes interactive training and a computer program to help improve facial affect recognition.

To learn more about MS research and stay up to date on current studies, visit nationalMSsociety.org/research.
LIVING WITH MS

IN PRAISE OF CAREGIVERS

BY JOE SALACKI

My wife, Becky, and I will celebrate 23 years of marriage this month. We will reminisce through memories of our steamy romance and the early years of our relationship. We will not celebrate that numbness in my right hand that has been there a long time, nor the tight feeling around my torso that started in the late 1990s, nor the fact that I stumble a lot.

I saw the first doctor in the spring of 2000. Not quite two years later, in 2002, I was diagnosed with multiple sclerosis. I suspected that I had the progressive type, and that suspicion was confirmed. This is not relapsing-remitting MS. There is no treatment. I’m not getting better. In fact, I will get worse as time goes on. I told Becky to go have a life but she wouldn’t hear of it. I know she was hurting then and I know it hurts her to see me struggle now, but she is strong. When I got my first assistive device, the mobility was liberating but my confidence and self-image were really affected. Her strength helped me through that first trip. She opened the doors and cleared the obstacles as she still does for me today.

An accessible home, a specially equipped van, a custom computer work station at home, a shower chair and a ceiling track system have become part of our daily lives. We live in a retirement community that provides endless opportunity to positively impact the lives of 100 or so seniors. I know all of our neighbors by name. I feel safe and secure here, and I know that is a load off of Becky’s mind.

Becky works downtown; her commute is around 75 miles round-trip. We get up together at 5 a.m. because I need her help showering and dressing. We spend a few minutes together before she hits the morning rush at 7 or 7:30 a.m. She goes to work in the busy, high-stress corporate world and comes home 11 hours later. Then it’s time to fix dinner. She can’t even eat in peace because she has to feed me. If we’re lucky, we get a few moments of downtime before it all starts over again the next day.

The weekends are busy too because there’s always something to do. We do what we have to do, and we hope there’s time left over to...
relax and enjoy some fun together. We enjoy music, good friends and good restaurants as often as we can. And we both love the St. Louis Cardinals baseball team. We don’t miss a game on TV — unless we are there in person for 10 to 15 games each year, thanks to Becky’s connections. And she fundraises! Becky has raised more than $100,000 for the Gateway Area Challenge Walk MS® and has walked 500 miles in 10 consecutive events.

“I IF YOU HAVE A CAREGIVER, BE SURE TO THANK THEM AND TELL THEM — OFTEN — HOW MUCH THEY MEAN TO YOU.”

I know she gets tired. I can see it in her face and hear it in her voice. It breaks my heart. It takes a special person to care for someone with MS. I am needy. I hate it. But Becky never, never, never makes me feel like a burden. She cares for me like no one else could. Sometimes I feel guilty. I wonder if I could do the same things for her if the situation was reversed.

Becky is so dedicated and so tirelessly giving. Caregivers are special people, and Becky is a special caregiver.

Just one last thought. Becky was in charge of a big corporate conference in Hawaii this spring. She could have buried herself in her work in the tropical paradise, but that’s not my wife. Instead, she talked me into going. Imagine the challenges of getting me to Hawaii! Well, she did it. Not only did she run the conference flawlessly, she made sure that I had an incredible experience as well.

I can’t imagine life without my Becky. I tell her so all the time. If you have a caregiver, be sure to thank them and tell them — often — how much they mean to you. Not just this month, but as often as you can.

Becky and Joe Salacki met in Rocky Mount, North Carolina. They have lived in Wildwood, Missouri, a suburb of St. Louis, for 16 years.

November is national caregivers month

While caregivers, also known as care partners, play a valuable role in the lives of people with MS every day, now is a great time to tell them how much you appreciate them.

For more ideas on how to celebrate the caregiver in your life, visit nationalMSsociety.org/carepartners.

The Greater Illinois chapter also provides support groups for caregivers in Algonquin, Aurora, Orland Park and Sandwich. Please visit MSillinois.org for more information.
Mailing Label Changes
Please check the appropriate box below, correct the label then return to National MS Society, Greater Illinois Chapter

☐ Name change or misspelled
☐ Address change
☐ Remove from mailing list
☐ Received more than one copy
☐ To cut costs for the Greater IL Chapter, I will download an electronic .pdf from their website.

Enjoy volunteering and make a difference in the lives of people affected by MS. Call 1-800-344-4867 or sign up online for these upcoming events:

• Finish MS at the Chicago Marathon, October 9 (Chicago) tinyurl.com/16FinishMS
• Research Symposium, October 29 (Rosemont) tinyurl.com/16MSsymposium
• MS Soirée, November 19 (Swissôtel, downtown Chicago) tinyurl.com/16MSsoiree

Stay connected to learn about ways to volunteer - Join the Volunteer Group on Facebook: facebook.com/groups/MSGreaterILVolunteers or Twitter @msgreateril

SAVE the DATE

RESEARCH SYMPOSIUM
ROSEMONT, IL - OCTOBER 29, 2016

MS SOIREE - SWISSOTEL
CHICAGO - NOVEMBER 19, 2016

MS AWARENESS MONTH
NATIONWIDE - MARCH 2017

WALK MS
STATEWIDE - MAY 2017 (DATES TBD)

BIKE MS: TOUR DE FARMS
DEKalb, IL - JUNE 10-11, 2017

Go to our website for updates on these and other upcoming events at MSillinois.org.