



FALL 2012
GREATER DELAWARE VALLEY CHAPTER

MSCONNECTION NEWSLETTER



2012 ANNUAL MEETING & MS RESEARCH UPDATE FEATURING:

DAVID OSMOND

Just a few years ago, singer David Osmond was paralyzed in a wheelchair, afraid his performing days were behind him.

But due to circumstances he can only call miraculous, Osmond is now on his feet and on stage again. He will perform and give the keynote speech at the chapter's Annual Meeting on December 4 at the Crowne Plaza in Cherry Hill, N.J.

Osmond, part of the second generation of singers in the famous Osmond family – and a second generation living with MS – still must cope with symptoms including crushing pain in his legs.

But his outlook is decidedly optimistic.

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FACE OF MS: PAM TAYLOR

NATIONAL MULTIPLE SCLEROSIS SOCIETY

Greater Delaware Valley Chapter

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Greater Delaware Valley Chapter

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MSConnection welcomes letters to the editor. Send letters to pae@nmss.org or the address above. Include your name and a phone number or email where we can reach you, if necessary.

NOTE: we may edit your letter for length and content.

LOCAL EVENTS

TO REGISTER FOR THESE OR OTHER EVENTS, VISIT CALENDARMS.ORG.

OCTOBER 16 Social Security Disability Workshop, Philadelphia, Pa.

NOVEMBER 3 Jumpstart in Motion, Philadelphia, Pa.

NOVEMBER 9 Dinner of Champions, honoring Judith Von Seldeneck, Philadelphia, Pa.

DECEMBER 1 Is Eight Enough?, Trevese, Pa.

DECEMBER 4 Annual Meeting & MS Research Update, Cherry Hill, N.J.

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NEWS BRIEFS

MS SOCIETIES WORLD-WIDE COLLABORATE TO STOP MS PROGRESSION

Despite significant progress in the development of treatments for people with relapsing forms of MS, there are few treatment options for people with progressive forms of MS. The newly formed International Collaborative on Progressive MS has published an opinion paper outlining challenges in developing therapies for progressive MS and identifying key research priorities to propel efforts to stop MS progression.

The paper, by lead author Robert J. Fox, MD, identifies five key priority areas for research - experimental models, identification and validation of targets and repurposing opportunities for progressive MS, proof-of-concept clinical trial strategies, clinical outcome measures, and symptom management and rehabilitation.

RESEARCHERS CONTINUE WITH THEIR PROGRESS IN THE SEVEN SOCIETY-FUNDED CCSVI STUDIES IN MS

Seven research projects investigating CCSVI (Chronic Cerebrospinal Venous Insufficiency) and MS – launched with a \$2.4 million investment by the National MS Society and the MS Society of Canada – have reached the two-year milestone.

The research teams have recruited and scanned a broad spectrum of people with MS and others to build understanding of who may be affected by CCSVI. In addition they are refining CCSVI imaging methods for accuracy and consistency to reliably validate the occurrence of CCSVI and understand its implications in the MS disease process.

Already more than 900 people have undergone scanning with various imaging technologies being used by the studies, including the Doppler ultrasound technology used by Dr. Paolo Zamboni and his collaborators, as well as

MORE RESEARCH

Visit us online at nationalMSSociety.org/pae to stay on top of the latest MS research.

magnetic resonance studies of the veins (MR venography), catheter venography, MRI scans of the brain and clinical measures.

GENZYME APPLIES TO FDA FOR APPROVAL OF ALEMTUZUMAB TO TREAT RELAPSING MS

Genzyme announced that the company had submitted a new drug application to the U.S. Food and Drug Administration for approval to market alemtuzumab (proposed name Lemtrada™) for the treatment of relapsing MS, based on positive results from several clinical trials involving people with relapsing-remitting MS. Alemtuzumab is given by a cycle of IV infusions only once per year. The FDA now has 60 days to decide whether to file it so it can be reviewed; the review process generally takes from 6 to 10 months. ■

LETTER FROM THE PRESIDENT

CAST YOUR VOTE



TAMI CAESAR, PRESIDENT

As the election season reaches its peak, it is natural to wonder what the outcome on November 6 will mean for people living with MS and the people who

love them. And, as we've learned time and time again, the platforms of the candidates don't always turn into policy as it is difficult to get the branches and political parties to coalesce around an issue to turn it into policy.

Consequently, it is easy to become complacent about the electoral process. However, it's important to remember that in terms of advocacy on behalf of local people living with MS, you can make a difference.

Chuck Bassman knew that. One sunny afternoon in 2003, just three years after being diagnosed with MS, he found himself struggling to navigate the stairs at his favorite beach on the Jersey Shore. Chuck, who passed away earlier this year (see page 5), and his wife Mickey wrote a two-sentence petition for accessible beach access and circulated it throughout their neighborhood.

Within two weeks, they had collected more than 1,000 names, which they presented at the next Margate City Commissioners meeting. They followed up regularly with the commissioners and mayor about the issue, and months later were thrilled to hear that several beach entrances would be made more accessible. Just one year after they presented the petitions, a crane appeared on the Bassmans' beach to start creating a flat pathway through the bulkhead.

Chuck and Mickey saw the power in advocacy, as does the leadership of the National MS Society. It is for this reason that we have created a new advocacy position that will be filled by Karen Mariner. As the Vice President of Advocacy for New Jersey and Pennsylvania, Karen will lead the Society's charge in Trenton and Harrisburg, as well as having an impact on the nation's capital. And while Karen will be focused on major initiatives, she is also here as a resource for people like the Bassmans who simply want to preserve their right for a day at the beach.

It is important that you cast your vote when Election Day comes. But remember that making the needs of people living with MS a top priority, requires that we all make advocacy a priority every single day of the year.

Sincerely,

Tami Caesar, President

IN MEMORIAM

DR. CHARLES LEE (CHUCK) BASSMAN, LONGTIME VOLUNTEER AND ADVOCATE, PASSED AWAY ON AUGUST 16, 2012.

Chuck was a member of the chapter's South Jersey Government Relations Committee and was a passionate and tireless advocate for both federal and state issues. Chuck was most proud of being inducted into the National MS Society's Volunteer Hall of Fame for Advocacy in 2008 with his wife, Mickey.

Chuck was an avid beach lover and he and Mickey led the charge to secure disability-accessible beach access in their community. They were successful in their efforts to

make the beaches accessible in Margate City, N.J. The city also has invested in a loanable sand wheelchair to help people with disabilities reach chairs near the ocean.

A psychologist, Chuck was a kind and gentle person and was deeply committed to making a difference for those living with MS, a disease he battled for 12 years. Chuck would volunteer at every event and talk to anyone about the importance of advocacy. He will be deeply missed by all.



**DR. CHARLES LEE
(CHUCK) BASSMAN**

PUBLIC POLICY ESSAY CONTEST 2013

Every year in March, hundreds of volunteer activists and Society staff from across the country head to Washington, D.C. to meet with our federal elected officials to discuss a wide range of issues important to the MS community. For the past two years, the chapter has held an essay contest to identify volunteers to attend the conference. The essay contest will open November 1, 2012. For more information about the conference, and how to submit an essay, please visit:

**In New Jersey: MSactiveNJ.org
In Pennsylvania: MSactivePA.org**



**ALLISON COIA AT THE MS PUBLIC
POLICY CONFERENCE 2012**

ANNUAL MEETING

“MS is one of the greatest things that has ever happened to me because it has given me a new perspective on life,” he said. “I feel very fortunate to be able to share my story.”

Osmond’s experience with MS started 24 years ago when his dad, Alan, was diagnosed with the disease.

His own diagnosis in 2006 at age 26 quickly put him in a wheelchair, as the crushing feeling made its way from his toes to his chest and arms. He could no longer sing or play the guitar.

As his condition continued to worsen, Osmond changed his diet and lifestyle dramatically with detoxification, supplements and natural therapies. At the same time, his doctor put him on a five-day “steroid blast” to reduce the inflammation in his nervous system.

The treatment allowed him to shuffle with a cane, but two months later, he was back in the chair.

“I FEEL UPLIFTED, EMPOWERED AND BLESSED TO MEET SO MANY PEOPLE FACING THE SAME CHALLENGES I DO... THAT’S WHY WE HAVE THESE EVENTS, TO ALL GET TOGETHER AND SHARE THAT CAMARADERIE AND KNOW WE HAVE THAT SUPPORT AS A FAMILY.” ~ DAVID OSMOND



DAVID OSMOND PERFORMING AT WOMEN AGAINST MS LUNCHEON 2011

Desperate to walk on his fast-approaching wedding day, he asked the doctor to try again. The therapy worked, and this time, his condition continued to improve.

“I do believe miracles happen every day, and I do believe I’m living one every day,” he said.

Performing at Society events across the country nourishes his spirit and gives him energy to continue his fight against MS, he said.

“I feel uplifted, empowered and blessed to meet so many people facing the same challenges I do – I feed on that,” he said. “That’s why we have these events, to all get together and share that camaraderie and know we have that support as a family.”

Donny and Marie Osmond’s nephew continues to find new challenges for himself. The latest test? Covering an Oscar-winning duet.

In a moving, new music video, Osmond and Jessie Funk belt out Falling Slowly from the

JOIN US FOR OUR 2012 ANNUAL MEETING & MS RESEARCH UPDATE

Meet National MS Society trustees and staff, hear about the successes and challenges of the past year and learn about the latest research and treatment news.

This program is for people living with MS and their guests. Dinner will be served. There is no cost to attend, but registration is required.

Please register by no later than November 16 by calling **1-800-FIGHT-MS** and pressing option 1, 9 a.m. to 7 p.m., Monday to Friday, or visiting **calendarMS.org**.

TUESDAY, DECEMBER 4 ■ 6:30 – 8:30 P.M.
CROWNE PLAZA CHERRY HILL
2349 WEST MARLTON PIKE
CHERRY HILL, NJ 08002

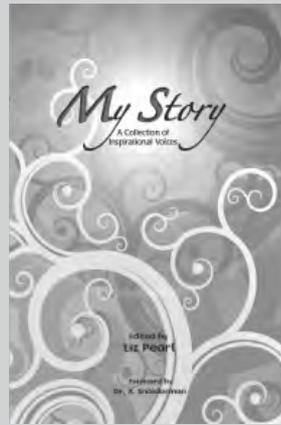
Free on-site parking is available.

Note: The chapter Annual Meeting includes a vote on the 2013 Board of Trustees. If you are not able to attend and would like to submit a vote by proxy, please call us at **1-800-548-4611**.

2006 film *Once*. The duet, originally performed by Glen Hansard and Marketa Irglova, won the Academy Award for Best Original Song.

Hear more of David Osmond's story at the chapter's annual meeting. See above for details. ■

BOOK SPOTLIGHT

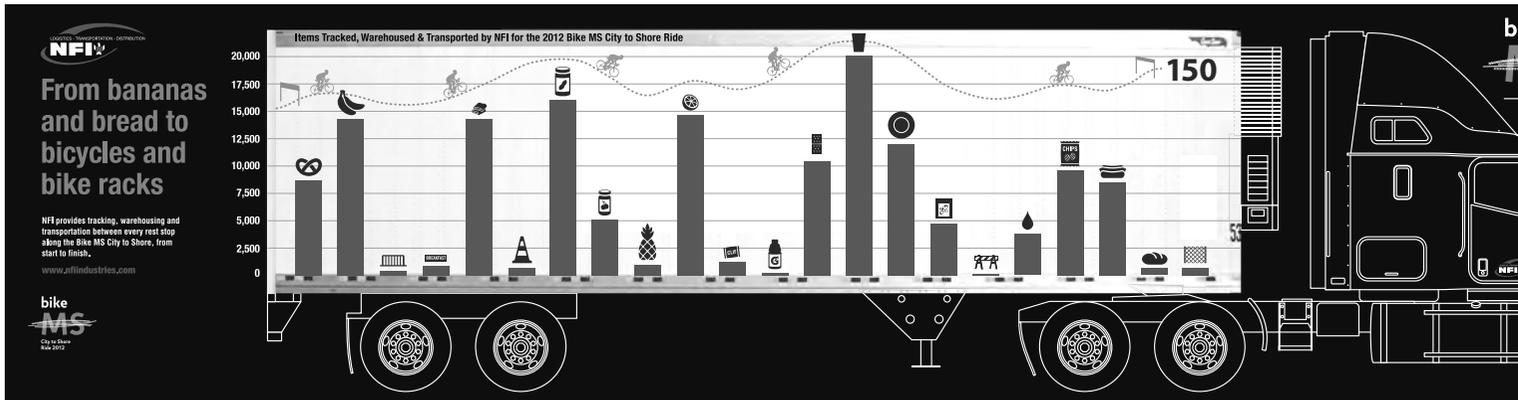


MS – MY STORY – A COLLECTION OF INSPIRATIONAL VOICES, STORIES ABOUT LIVING WITH MULTIPLE SCLEROSIS
EDITED BY LIZ PEARL

They never give up. They dream big and reach far. They think positively and believe faithfully. They love deeply. They demonstrate courage, determination and gratitude. They smile, laugh and sing. They rejoice and celebrate life. These are the inspirational voices of MS – My Story.

Liz Pearl, MEd, is an educator and therapist specializing in psychogeriatrics and the expressive art therapies. She is the co-editor of *Mourning Has Broken - A Collection of Creative Writing about Grief and Healing* and the editor of *Brain Attack - The Journey Back - A Unique Collection of Creative Writing about Stroke Recovery*, and *Living Legacies - A Collection of Writing by Contemporary Canadian Jewish Women Volumes I, II & III*.

Find it at <http://at.yorku.ca/pk/ms-order.htm>



FUNDRAISING BIKE MS TEAMS GO ABOVE AND BEYOND

FROM BANANAS AND BREAD TO BICYCLES AND BIKE RACKS - NFI DELIVERS

For the past 13 years, Team NFI has volunteered and cycled for the cause in the chapter's Bike MS: City to Shore Ride. Each year, riders and volunteers have raised funds and participated in the annual 150-mile bike ride from Cherry Hill to Ocean City, N.J. to help fight MS.

NFI, a supply chain management company based in Cherry Hill, is the official logistics sponsor for the event. For the third consecutive year, NFI leveraged its resources and provided full logistics, transportation, and warehousing services for supplies such as food and beverage items, bicycles, luggage and bike racks. The company partnered with the National MS

Society to ensure first-rate execution of the two-day journey for all 7,000 cyclists by warehousing, transporting, and tracking all items for each rest stop along the way.

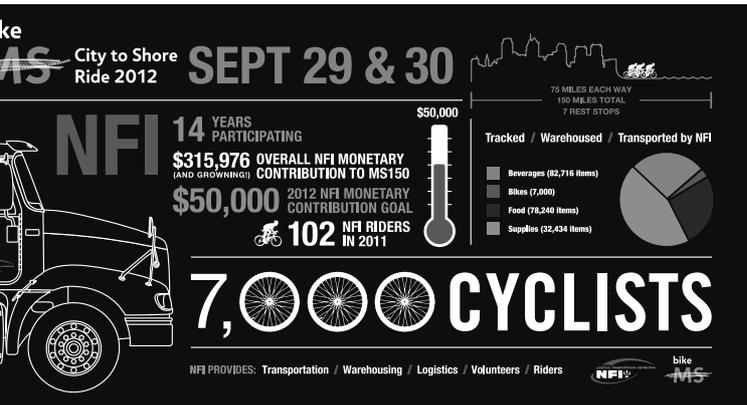
Furthermore, NFI built a team of more than 100 employees, friends, and family to ride and volunteer for the event this year. One of the company's core values is social responsibility, and the team was eager to uphold these values by riding for MS.

Throughout the years, Team NFI has contributed over \$316,000 to the Bike MS event and set a goal of raising \$50,000 for this year's event.

RIDING TO REACH \$1 MILLION

For Jersey's Team, this year's Bike MS: City to Shore Ride was a million miles in the making. After the round trip journey to Ocean City in September, Jersey's team hoped to be the third team in the ride's history to surpass the \$1 million cumulative fundraising total. Not to mention being the smallest team to ever do it. And they did it!

"Jersey's Team was started 13 years ago, in



honor of my father, Jerald (Jersey) Brownstein, who was diagnosed 20 years ago with Progressive multiple sclerosis,” said team captain Andrea Rosenthal. “In addition to riding to help raise money for MS, we also believe it is important to raise awareness of MS, what it is and how we can help those who are affected by a diagnosis.”

Having participated in Bike MS: City to Shore Ride for the past 10 years, Rosenthal was named the number one fundraiser after last year’s century ride. The Ambler, Pa. resident rode 175 miles in two days.

“My personal goal for this year is to raise \$20,000, and together with my husband and two daughters who also rode with me, as a family we hope to raise at least \$25,000,” Rosenthal said. “Our team raised over \$90,000 this year putting us over the \$1 million mark. I am in awe of how well our small team does with fundraising.”

Fundraising is not all that drives this team to greatness. They have become their own unique family. With this year’s team growing to about 100 riders; it is definitely a big family full of incredibly fun and giving individuals.

JERSEY’S TEAM AT BIKE MS: CITY TO SHORE 2011



“IN ADDITION TO RIDING TO HELP RAISE MONEY FOR MS, WE ALSO BELIEVE IT IS IMPORTANT TO RAISE AWARENESS OF MS, WHAT IT IS AND HOW WE CAN HELP THOSE WHO ARE AFFECTED BY A DIAGNOSIS.” ~ ANDREA ROSENTHAL

“We provide biking shirts for our team, sport shirts for our team and their families, a pep rally dinner,” Rosenthal said. “And for those pedaling both ways, we provide housing and a team dinner in Ocean City.”

“I am really proud of Jersey’s team,” Rosenthal said. “Not just for all that we accomplish as a team with fundraising and raising awareness but also for what we do for one another and being a part of ‘Jersey’s Team.’” ■

RESEARCH

FDA APPROVES NEW ORAL MEDICATION TO TREAT RELAPSING FORMS OF MS

The U.S. Food and Drug Administration has approved teriflunomide once-daily pills (Aubagio,[®] Genzyme, a Sanofi company) to treat relapsing forms of MS. This is the second oral disease-modifying therapy approved for the treatment of multiple sclerosis.

The therapy is expected to be available for prescription by October 1, 2012 in the U.S. The company has also applied for regulatory approval in other parts of the world.

“We are greatly encouraged to see a new oral therapeutic option become available to people living with MS,” advised Bruce A. Cohen, MD, Professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine, and incoming Chair of the National MS Society’s National Medical Advisory Committee. “As with any new therapy, the long-term safety of Aubagio will need to be carefully monitored,” he added.

Dr. Timothy Coetzee, Chief Research Officer at the National MS Society agreed. “With the collaborative research underway around the world today, this is an extremely hopeful time for anyone who is diagnosed with MS.”

Taking a disease-modifying therapy is currently the best way to reduce MS disease activity and future deterioration. Selecting an MS therapy should be done by people with MS in collaboration with their MS doctors, taking into account a variety of factors, including the effectiveness of any therapy they are currently using, and weighing potential risks and benefits, costs and lifestyle factors.

Read more about disease-modifying therapies and other treatments for MS and MS symptoms and the Society’s efforts to speed research in progressive MS at nationalMSSociety.org.

AT-A-GLANCE

WHAT IS AUBAGIO?

Aubagio (pronounced oh-BAH-gee-oh) is a small molecule that inhibits the function of specific immune cells that have been implicated in MS. It is related to leflunomide, a drug used to treat arthritis. Aubagio can inhibit a key enzyme required by white blood cells (lymphocytes), reducing the proliferation of T and B immune cells active in MS and also inhibiting the production of immune messenger chemicals by T cells. It is not thought to affect resting immune cells that are not in an activated state.

WHAT TYPES OF MS IS AUBAGIO APPROVED TO TREAT?

The FDA has approved Aubagio for the treatment of patients with relapsing forms of MS. In other words, people who experience periodic MS attacks, such as those who have relapsing-remitting MS or secondary-progressive MS with relapses.

HOW IS AUBAGIO TAKEN?

The pill is taken orally once per day.

HOW EFFECTIVE IS AUBAGIO?

Results from three phase III studies have been released. For the TOWER trial, 1,169 people with relapsing MS were randomly assigned to receive Aubagio 7 mg or 14 mg, once daily

by mouth, or inactive placebo, for 48 weeks. According to a company press release, Aubagio 14 mg (the dose approved by the FDA) reduced relapses by 36.3% versus placebo. In the 14 mg-group, the time to disability progression was reduced by 31.5%.

In the TEMSO trial, 1,088 people with relapsing MS were randomly assigned to receive 7 mg or 14 mg of Aubagio, or inactive placebo for 108 weeks; 796 (73.2%) completed the study. After two years, both doses of Aubagio significantly reduced the average number of relapses in a year by as much as 31.5% over placebo. Fewer of those on the higher dose (14mg) experienced progression of disability compared with those on placebo (20.2% progressed on therapy vs. 27.3% on placebo). On imaging scans, the total volume of tissue damage and active areas of damage were reduced significantly more in both Aubagio groups than in the placebo group.

For the TENERE trial, 324 people with relapsing MS were randomly assigned to receive Aubagio 7 mg or 14 mg, or Rebif® (interferon beta-1a, EMD Serono Inc. and Pfizer) 44 mcg three times per week subcutaneously for 48 weeks. The primary endpoint was “risk of failure,” meaning the first occurrence of a relapse, or permanent discontinuation of the study treatment, whichever came first. There was no significant difference in the numbers of participants who experienced events that constituted the definition of treatment failure among the Aubagio and Rebif groups, according to a company press release. Relapse rates did not differ significantly either.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF AUBAGIO?

Aubagio may cause diarrhea, nausea, hair thinning, back pain, abnormal liver tests, flu, and lowered levels of white blood cells, which can increase the potential for infections. It can also increase blood pressure. The prescribing information includes a boxed warning related to the potential for liver damage in persons taking Aubagio. There is also a warning that Aubagio is not indicated for women who are pregnant or women with childbearing potential who are not using reliable contraception. The prescribing information also contains information on how to clear Aubagio from the system in case that is required.

SHOULD I SWITCH FROM MY CURRENT THERAPY TO AUBAGIO?

The decision about whether to take Aubagio should be made in collaboration with your MS doctor. Important questions to be considered and discussed with your doctor in terms of Aubagio include:

- How am I doing on my current therapy?
- What is my tolerance for the risk of known side effects?
- What is my tolerance for the risk of adverse consequences that might emerge with longer-term use?
- How will my medication choice affect my ability or plans to become pregnant?
- What are the comparative costs of my current therapy versus Aubagio?

HOW DOES THE EFFECTIVENESS OF AUBAGIO COMPARE TO OTHER AVAILABLE THERAPIES?

Clinical trial results to date suggest that Aubagio has effectiveness against MS relapses in a similar range as the first generation disease-modifying therapies (interferons and glatiramer acetate). Aubagio has not been compared to all other available therapies, but in a comparison trial against Rebif, there were not significant differences in the outcomes tested.

HOW LONG WOULD A PERSON TAKE AUBAGIO?

There is no specified time limit for taking Aubagio.

WILL A PERSON TAKING AUBAGIO HAVE TO GET ANY SPECIAL MEDICAL TESTS OR MONITORING?

Before people begin taking Aubagio, they should have a blood test, or have had one within six months, to detect levels of liver enzymes and levels of blood cells (complete blood count). They should also have their blood pressure checked, and have a screening test for tuberculosis (tuberculin skin test). It should be verified in women of childbearing potential that they are not pregnant before taking Aubagio.

After starting Aubagio, blood tests to detect liver enzymes should be done at least monthly for the first six months, and then patients should be monitored for signs of liver damage. Patients should also be monitored for signs of infection, and blood pressure should be checked periodically.

WHAT WILL AUBAGIO COST?

The price has not been announced, but the actual cost to an individual who has MS will depend on the provisions of his or her insurance coverage and the degree to which that individual will be eligible for programs designed to assist with out-of-pocket costs.

WILL MY HEALTH INSURANCE COVER AUBAGIO?

Coverage will depend on individual insurance plans.

WHERE CAN I GET INFORMATION ABOUT THE SUPPORT THAT GENZYME WILL PROVIDE TO HELP PATIENTS?

For more information about support services provided by Genzyme, people can call the company's MS One To One line at: **1-855-676-6326**, or visit the company's website: **MSONetoOne.com**.

ARE THERE OTHER ORAL DISEASE-MODIFYING THERAPIES AVAILABLE OR IN DEVELOPMENT FOR MS?

Yes, there are other oral therapies available now or in development. Gilenya is an oral therapy approved for relapsing forms of MS to reduce the frequency of clinical relapses and to delay the accumulation of physical disability. Others are in development. Oral BG12 (sponsored by Biogen Idec), for relapsing MS, is currently being reviewed by the FDA for marketing approval. Another oral therapy in later stages

of development for relapsing MS is laquinimod (sponsored by Teva Pharmaceutical Industries).

IS AUBAGIO BEING TESTED IN PROGRESSIVE MS?

Not at this time.

WHY AREN'T THERE MORE TREATMENTS FOR PROGRESSIVE MS?

Virtually every therapy approved for relapsing MS has been tested, or is now in testing, in people with progressive forms of the disease, including primary-progressive MS and secondary-progressive MS. Up to now, clinical trials involving people with relapsing MS often rely on counting relapses or doing MRI scans to detect immune activity. The fact that there is no easy way to detect progression quickly is one reason why drug development for progressive MS is behind. Right now there are large clinical trials going on in progressive MS, including tests of Tysabri,[®] Gilenya,[®] Ocrelizumab, and Masitinib.

Aubagio is a registered trademark of Genzyme, a Sanofi company

Gilenya is a registered trademark of Novartis

Rebif is a registered trademark of EMD Serono and Pfizer.

Tysabri is a registered trademark of Biogen Idec and Elan Pharmaceuticals



ADVOCACY

MAKE YOUR VOTE COUNT

BY RENEE VANDLIK

Election Day 2012 is on the horizon, so get ready to cast your vote for who best represents the issues you care about. Here's what you need to know to vote in the elections on November 6.

THE BIG PICTURE

This fall, Americans will cast votes for the presidency, every member of the U.S. House of Representatives and one-third of the U.S. Senate. What's different? Since the 2010 census, 15 million Americans became eligible to vote and an anticipated 50 million more will vote this November due to stronger engagement in national campaigns. However, people with disabilities register to vote at a 16 percent lower rate than other Americans. And with 1 in 10 eligible voters having a disability,

that's a lot of people whose voices aren't being heard. Make sure yours is. Register yourself and learn how you can register others at usa.gov/Citizen/Topics/Voting/Register.shtml.

PREPARE TO VOTE

This year, citizens in 30 states will have to comply with voter identification laws, including Pennsylvania (see next page). Contact your local polling precinct ahead of time to find out what you'll need.

Also ask about accessibility: you don't want to show up, only to find out you can't get in the door. Since 2005, The Help America Vote Act requires every precinct in the country to have at least one voting machine or system accessible to persons with disabilities, including those with vision impairments. Learn more at aapd.com/what-we-do/voting/.

If it's difficult to vote in-person, plan to vote absentee. Learn more at longdistancevoter.org.

THE INFORMED VOTER

Go to nationalMSsociety.org/advocacy to learn more about issues important to people with MS, such as health care, accessibility and medical research. Then find out where the candidates stand on those issues – yourcandidatesyourhealth.org is one place to start. ■

ADVOCACY

ARE YOU READY TO VOTE?

Is your polling place accessible? Do you know that if you live in Pa. there are new voter-ID laws? To get answers to these questions, please go to bit.ly/vote-ms.

ACCESSIBILITY OF POLLING PLACES

The Help America Vote Act set forth standards for equipment and voting procedures. These standards were designed to protect the individual right to vote. All voting systems in the United States must meet the following criteria:

- A system that allows voters to review the accuracy of their selections indicated on the voting machine before the ballot is finally cast
- A means to allow the voter to correct any votes, including any over votes
- The provision of an audit of the votes cast, or a permanent paper trail of the votes cast, which would facilitate a more efficient and reliable recount
- A means to ensure that voters with disabilities, including voters with visual impairments, will be able to vote independently without third party assistance by providing each polling place with at least one direct recording electronic voting system or other voting system equipped for individuals with disabilities

- The furnishing of multi-lingual ballots in required election districts
- A system which produces an error rate that does not exceed the error rate standards established under section 3.2.1 of the voting systems standards issued by the Federal Election Commission
- Establishment of uniform and non-discriminatory standards as to what constitutes a vote

TO REPORT A POLLING LOCATION THAT DOES NOT MEET THESE GUIDELINES, YOU CAN CALL THE FOLLOWING:

PENNSYLVANIA: Contact the Department of State at **717-787-5280**

NEW JERSEY: Contact the N.J. Division of Elections at **609-292-3760**

VOTER-ID LAW

PA residents are now required to show ID in order to vote. There are also new rules for individuals voting by absentee ballot. For more information, go to votespa.com.

For more information, please contact Karen Mariner via email at Karen.Mariner@nmss.org or call **1-800-548-4611**.

ADVOCACY

MS ACTIVISTS SUCCEED IN 2012

BY RENEE VANDLIK

Together on the frontline, the National MS Society and MS activists nationwide connect with decision makers, work with like-minded partners and create change to impact the greatest number of people possible. As a united MS Movement, we want to do something about MS now. Here are our 2012 federal and state successes that show what can be achieved by MS activists.

FEDERAL SUCCESSES

MS activists...

- Added an aggressive form of MS to qualify for the “Compassionate Allowances Initiative” at the Social Security Administration. This will allow people with MS who qualify to receive Social Security Disability Insurance (SSDI) quicker than the average applicant
- Established new federal funding avenues that have yielded over \$20 million for MS research
- Introduced legislation that would allow Medicare Part D to cover off-label drugs for people living with MS



MS ACTIVISTS IN FRONT OF THE U.S. CAPITOL

- Promoted awareness and importance of a wide range of caregiving initiatives for the people who care for people with MS. This included advocating for increased funding for and reauthorization of the Lifespan Respite Care Program, which improves access to quality respite for family caregivers, and supporting the introduction of legislation to support Adult Day Achievement Centers
- Promoted increased awareness of MS on Capitol Hill by hosting legislative briefings and national recognition of MS Awareness Week
- Formed and continued to grow the first Congressional MS Caucus in the Senate and the House of Representatives. More than 25 percent of representatives in both chambers has shown their commitment to developing policy solutions for people with MS by joining the Caucus

STATE AND COMMUNITY SUCCESSES

- Several states across the United States addressed the cost of MS disease-modifying therapies (DMTs) through legislative action. Louisiana and Texas contained the cost of DMTs during a contract period and require transparency in pricing. A Maine state law prohibits prescription drug pricing that exceeds the dollar amount for non-preferred brand drugs, while Delaware made recommendations to limit increasing prescription drug costs. A Vermont state law will limit out-of-pocket prescription drug expenses, while Virginia is examining the issue. These actions build upon a 2010 New York law to prohibit co-insurance pricing for prescription drugs. Co-insurance pricing is a rapidly growing insurance practice that requires the consumer to pay a percentage of a medication's cost, rather than a fixed co-payment
- Rhode Island secured 13 new accessible taxis to serve 17 communities
- New Hampshire, Illinois and Missouri strengthened accessible parking laws in various ways, including imposing fines for blocking access aisles and requiring more accessible parking spaces for vans
- Colorado, Connecticut and Virginia provided utility coverage for people with medical conditions who would be adversely impacted by discontinuation of services
- Kansas, Missouri, Ohio and Virginia aim to create or preserve state income tax credits for accessible home modifications that maintain independence.



ACCESSIBLE TAXIS

- New Jersey created an MS Task Force, charged with developing strategies to identify and address the unmet needs of people with MS in the state
- Missouri, New York, North Carolina, Oklahoma, Pennsylvania and South Carolina offer state license plates with the MS logo to raise awareness of the disease
- State tax forms in Delaware, Louisiana, Missouri, Oklahoma and Wisconsin now offer a voluntary designation to benefit MS. To date, more than \$1 million has been raised
- Illinois passed legislation to amend the Illinois Lottery Law and offer instant scratch-off tickets, so far raising more than \$3.9 million for MS research

As MS activists, we want everyone on the frontline with us. To effect change in our area, join the MS Activist network at nationalMSsociety.org/advocacy or call us. Share your personal stories with us and policy makers to create understanding, engagement and action. ■

ADVOCACY

WE ARE ACTIVISTS

BY KAREN MARINER, MSS, MSCIR

If you've looked at any of the National MS Society's information on our website, or in this newsletter, you may have seen this *We Are Activists* moniker. What does it mean? *We Are Activists* means that each and every one of us touched by the mission of the National MS Society has a role to play in making a difference for those living with multiple sclerosis. For some, that may mean getting involved on an advocacy committee. For others, it may mean that you use any political connections you have to secure a meeting with an elected official to discuss MS legislation. *We Are Activists* means what you want it to mean, but it means doing something!

HERE ARE JUST A FEW WAYS PEOPLE HAVE ANSWERED THE WE ARE ACTIVISTS CALL:



Mary Ellen Crowley is a walk team captain. Prior to the spring, she may not have called herself an MS Activist. Encouraged to introduce herself to Assemblyman Warren

Kampf at her walk site, Mary Ellen mustered the courage to tell her story to the Assemblyman. He listened and was touched by how MS affected her life. He gave her his card

and encouraged her to get in touch with his office. Mary Ellen called the chapter knowing she needed to learn more about our advocacy priorities. Mary Ellen was encouraged to try and secure a meeting with the assemblyman, which she did. Mary Ellen attended the meeting, sharing her story and helping to establish a new relationship with a legislator

“THE NUMBER OF GRANTS FUNDED BY NIH HAS DECREASED STEADILY OVER THE LAST EIGHT YEARS. THIS AFFECTS NOT ONLY THE PATIENTS WHO WILL NOT RECEIVE THE BENEFIT OF THE RESEARCH BUT ALSO EMPLOYMENT IN THE RESEARCH COMMUNITY AND TRAINING FOR FUTURE SCIENTISTS TO ENSURE A CONTINUUM OF RESEARCH PROGRESS.” ~ DR. JUDITH GRINSPAN



Dr. Judith Grinspan is one of our local MS researchers. In addition to receiving funding from the National MS Society, Dr. Grinspan also has received support from the National Institutes

of Health (NIH). Proposed funding cuts to MS research is what called Dr. Grinspan to action. Dr. Grinspan attended a meeting with Congressman Patrick Meehan to urge his support on increased NIH funding. Dr. Grinspan explained that without this funding, labs that have dedicated their professional

focus on MS may close; the next generation of MS researchers will leave the field.



John Marmarou, DPT, is a physical therapist dedicated to providing the best possible care for people with MS. John answered the call by working with the chapter to host an open house at his

facility with Congressman Jon Runyan to bring attention to the issues people with MS experience when trying to receive appropriate rehabilitative care.



Lee Domenico answered the call to be a County Captain for Atlantic County, N.J. Lee is going to lead local efforts to develop relationships with legislators and to identify local policy issues.

SO, WHAT DOES WE ARE ACTIVISTS MEAN TO YOU? HOW WILL YOU GET INVOLVED? HERE ARE SOME WAYS YOU CAN MAKE A DIFFERENCE:

LEGISLATIVE LIAISON: The Legislative Liaison serves as the community liaison between the National MS Society and state legislators and officials. The liaison shares research, programmatic and other updates important to the MS Society. The liaison also works with the National MS Society to coordinate legislator's presence at community events such as Walk and educational programming.

POLICY RESEARCH ANALYST: Use or develop your own specific policy expertise related to health care, long term care, disability rights, or other areas of concern to the National MS Society. Conduct policy research, write background papers, monitor and analyze legislative proposals. Suggest legislation for MS Activists to champion or evaluate proposed legislation as introduced by others.

DATA ENTRY: This is a great opportunity for someone who wants to volunteer from home and help in our activism efforts. We need people with data entry experience to enter all Pa. and N.J. legislators into our system-wide database.

ADVOCACY STORY VOLUNTEER: It is your voice and your story that really captures the attention of our representatives. It is crucial that we provide a detailed picture of how multiple sclerosis impacts you, your family and community. We are seeking stories of individuals living with multiple sclerosis willing to let us use those stories at policy meetings and events.

Are you ready to get involved? Need more information? Call **1-800-548-4611** or email Karen Mariner at **Karen.Mariner@nmss.org** to learn more.

CONNECT WITH US

PA: facebook.com/MSPACAN

twitter.com/MSCANPA

NJ: facebook.com/MSNJCAN

twitter.com/NMSSNJCAN

ADVOCACY

IS YOUR REPRESENTATIVE A MEMBER OF THE MS CAUCUS?

The Congressional MS Caucus is comprised of dedicated members of the U.S. Congress who raise awareness about MS on Capitol Hill and together, seek creative federal policy solutions to the challenges facing people living with MS and their family caregivers.

Our goal is 100% participation-you can help us get there!



CURRENT MEMBERS OF THE MS CAUCUS:

PA SENATE:

Bob Casey

NJ SENATE:

Robert Melendez

PA HOUSE:

Jason Altmire (PA-4)

Mike Critz (PA-12)

Mike Doyle (PA-14)

Tim Holden (PA-17)

Tim Murphy (PA-18)

Joe Pitts (PA-16)

Todd Platts (PA-19)

Allyson Schwartz (PA-13)

NJ HOUSE:

Rob Andrews (NJ-1)

Scott Garrett (NJ-5)

Rush Holt (NJ-12)

Frank LoBiondo (NJ-2)

Steve Rothman (NJ-9)

Jon Runyan (NJ-3)

Don't see your representative on the list? Contact Karen Mariner to find out how you can encourage your representative to join the caucus. Email Karen.Mariner@nmss.org or call 1-800-548-4611. ■

SERVICES

NEW PA
EMPLOYMENT
PROGRAM:
MSWORKS

The Pennsylvania chapters of the National MS Society are pleased to announce the partnership and collaboration efforts of MSWorks, a new employment program available to individuals living with MS in Pa. MSWorks' services may include career exploration, skills and interest assessments, career counseling and guidance, job seeking skills training, explanation of legal rights, referrals to local and federal agencies, resources, symptom management techniques and programs to help you make informed decisions about your employment situation.

The society recognizes many people living with MS leave the work force prematurely before exploring all options available to them, and MSWorks was designed to provide the necessary tools and resources to help reverse this trend. Whether you're employed, considering a career change, thinking about leaving the work force or hoping to get back in, the MSWorks service can provide career counseling and walk you through the local,

state and federal resources available to you.

MSWorks is spearheaded by Christina L. Forster, MA, CRC, employment services manager at the Greater Delaware Valley Chapter. Before joining the Society, Christina worked as a rehabilitation counselor for the Virginia Department of Rehabilitative Services, the state vocational rehabilitation agency. Christina also completed an internship at the National Capital Chapter of the National MS Society in Washington, D.C. Christina has a master's degree in rehabilitation counseling and is a certified rehabilitation counselor.

Forster joined the chapter in January 2009 to lead the MSWorks employment services. The MSWorks service is now available to members living with MS who are members of the Greater Delaware Valley Chapter, Central Pennsylvania and Western Pennsylvania chapters.

For additional information about MSWorks visit MSWorks.org or call [1-800-FIGHT-MS](tel:1-800-FIGHT-MS).

RAY, MEDIA EXECUTIVE, DIAGNOSED IN 2003



MONEY MATTERS

HEALTH INSURANCE 101: MANAGING THE PAPERWORK

BY KAREN MARINER, MSS, MSCIR

It can be overwhelming keeping track of health insurance information. However, for people with chronic conditions such as multiple sclerosis, it is crucial to keep track of this information. Four years ago, the chapter launched a new program called the Health Insurance Initiative Project. The purpose is to provide assistance to people with multiple sclerosis in navigating the complicated process of individual health insurance appeals.

Health insurance companies deny claims for a variety of reasons. Many times a service is denied because the item or service in question is not covered as part of the benefits plan. It is very important to make sure you have a copy of your benefit plan handy. Insurance companies base their decisions on what your coverage plan allows. You should have received a copy of your benefits plan book when you enrolled in your plan. If not, you can usually find your benefits plan information on your insurance company's website. Keep your benefits plan information with your insurance paperwork.

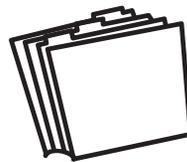
We are all familiar with the paperwork that is generated when a claim is processed. This

paperwork is essential in managing a successful insurance inquiry or appeal. Paperwork that you will receive includes:

- Explanation of benefits (EOB)-this is your insurer's statement detailing how much they will cover and what you owe
- Provider bills/invoices-you may receive two invoices, an initial invoice and a final invoice. These bills provide detailed information on date of service, type of treatment given and the price for that treatment

It is imperative that you keep all paperwork related to a single claim. Don't throw anything away. This is your written record, your documentation that will need to be referred to for an appeal.

The appeals process can be made much easier if you have all of your health insurance related paperwork in order. Being proactive in managing your paperwork can help reduce stress when an issue arises. Here are some handy tips for keeping your health insurance paperwork organized:



Purchase a **heavy duty expanding file**. Many are available in numerical, alphabetical or monthly indexes. Use the system that works best for you and your family



Keep all information, EOB's, invoices and notes related to the specific claim together by **paper clip** (don't staple-you may need to make photocopies and you don't want to have to keep pulling the staples out)



Purchase a **plain notebook or journal** (with easy tear out sheets). This is your health records journal. Use this notebook to track all conversations with your provider and health insurance provider. Make sure to date and note who you spoke with in the margins next to your notes from the conversation. Also, always write down the reference number your provider

gives you for an ongoing issue. You can also go on our website and download a record keeping template. Go to: **bit.ly/mshealthinsurance**.

If you do need help with an appeal, the chapter is ready to help. You can find more information on the Health Insurance Appeal Initiative Project by going to our website. ■



Save the date for 2013!
APRIL 21, MAY 4 & MAY 5



walk4MS.org
1-800-883-WALK

LIVING WITH MS

MS SYMPTOMS AND WINTER WEATHER

BY JULIE STACHOWIAK, PHD

Most of us with multiple sclerosis are heat intolerant to the point of being unable to function outside during peak summer temperatures. But when I asked people with MS on my blog at ms.about.com what their MS temperature “limits” were, I was surprised when several people said that the cold wasn’t so great for them, either.

Many people complained of increased spasticity in cold weather. Readers mentioned that their limbs “felt like wood” or that their joints ached during lower temperatures. A couple of people also mentioned that the MS “hug” could be intolerable in the cold. (The MS hug is the gripping feeling around the torso that is caused by a lesion in the spinal cord that results in spasms in the tiny muscles between the ribs.)

I also know that some people with MS tend to feel more fatigued in winter months. This could be an indirect result of coping with some of the symptoms mentioned above. It could also be that the shorter days and limited sunlight exacerbate depression, which can be a

symptom of MS. New data is emerging all the time on the role of vitamin D in MS. Perhaps we feel our symptoms more acutely when our vitamin D reserves are at their winter lows, although this hasn’t been confirmed yet by scientific studies.

Here are a few tips to help you enjoy the colder months if you are bothered by frigid temperatures.

- Soak up sunshine during the warmest part of a sunny winter day to help your body produce vitamin D
- Don’t overdo the heat. When I get cold, I tend to take really hot showers. Recently, I got dangerously dizzy during one. Remember, extreme heat is not our friend, either
- Warm yourself from the inside. Drink a hot beverage to take the chill off

Like many other situations that we must navigate through with MS, a little strategic planning of winter activities can help you have some control over symptoms. Put some thought into what you enjoy doing in the winter, take a couple more precautions and get the most out of the cold months. ■

Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of **The Multiple Sclerosis Manifesto**.



WAYS TO GIVE

VOLUNTEERING: THE EXPERIENCE OF A LIFETIME

BY HELEN MARIE RUSSON

Since my diagnosis with MS in 1997, the Society has been my rock – providing me with information and community resources. It only makes sense that I would want to give something back. In doing so, I have gained at least as much as I have (hopefully!) given.

One way I’ve volunteered is by participating in community projects such as giving people rides to their doctors or teaching someone how to use a computer. Joining my chapter’s Talk MS Speakers Bureau was another excellent way to volunteer. In speaking to various groups, I’ve helped to educate the public about what MS is – and is not. When I feel less energetic, I contribute in more sedentary ways. My chapter can always use someone to stuff envelopes, put in a shift at the front desk, or help with updating volunteer lists. And it goes without saying that the “office atmosphere” is far from traditional! ■



WE NEED YOU TO VOLUNTEER

Volunteering for the Society can be the experience of a lifetime — and we need your experience. More than 500,000 volunteer positions keep the Society running. Visit our Volunteer page to register and let us know your interests, skills and availability. Or call **1-800-548-4611** to speak to our volunteer manager, Joy McManus.

Here is a sampling of ways to volunteer.

- **MS Ambassadors:** Raise awareness about MS and the Society. Represent the chapter at health fairs. Make presentations to community groups. Seek out opportunities to speak
- **Office Volunteers:** Help with mailings, data entry and other office tasks. Assist people when they visit our office
- **Fundraising Events:** Walk MS and Bike MS events run on volunteer muscle and expertise to deliver supplies, prepare and serve food to hungry participants, or cheer people on at the finish line. Call us today to take part!

LIVING WITH MS WITH A LITTLE SUPPORT

BY VERONICA MCTIERNAN

For several years after I was diagnosed with multiple sclerosis in 2004, I insisted that I did not need any assistive aids in order to continue living my life as I wanted.

At first, my MS affected me minimally. I had some balance issues, and some weakness on my right side. I walked with a little hippity hop, but did not trip, was able to do stairs as long as there was a rail or a friend to lean on, and could walk a fairly good distance. These activities often wiped me out, but I could do them, and that is what I focused on. I routinely dismissed using a cane, saying I didn't need it and was able to do just fine without it, but in reality it



VERONICA WITH HER "GARDEN CANE"

was pride that was playing with my head. I simply did not want others to see me using an assistive aid.

Then one day in 2006, I happened to find a cane in my closet that I had been storing for someone else. I decided to use it to walk along my uneven yard to fill the bird feeders. Then I started using it while gardening to help me get up and down and in and out of flower beds. Yes, I was self-conscious about what the neighbors would think, but I felt the freedom of using the cane immediately, and I soon started calling it my "garden cane."

However, other challenges began cropping up. While my garden cane helped, it didn't address my fatigue when digging with a regular shovel or garden fork. I needed both hands to manage these heavy tools, which left me no arm to use to lean on anything and no strength to dig while standing. My Internet searches for "adaptive gardening" only brought up suggestions of raised flower beds. This didn't help me with my already-established perennial beds, so I would just get discouraged and think I had to settle for a half-hearted garden full of weeds.

Then one day I thought to search for "adaptive gardening TOOLS." I learned about ergonomic tools with extensions and cuffs for attaching to one's forearm. Now I could successfully garden with one hand while standing (and leaning on my garden cane, of course!). The hand tools also gave me the leverage I needed, and the garden seat I ordered completed the package for

me. The first day I got the tools I spent two hours in my garden, and I did so much work that I got a blister on my thumb. It was a badge of accomplishment for me: my first gardening blister in 10 years. I was delighted that what I felt when I finished was a very satisfied tiredness, and not the dreaded MS fatigue.

My new mantra? “I cane so I CAN.” Now, without embarrassment, I can whip out my collapsible cane from my bike bag after completing a ride on my bicycle if I feel the need. Or I can use a pink cane to match my dress for my niece’s wedding.

I wish I didn’t have MS, and I dream of gaining back what I have lost, but in the meantime, I will continue to use my cane, adaptive gardening tools and whatever else I find I need. Where I used to see assistive aids as pointing out my weaknesses, I am now so aware of them being just the opposite. They allow me to be who I am, and to do what satisfies my soul. What else is there in life? ■

Consult a physical or occupational therapist about mobility devices that will work best for you, and how to use them safely. An occupational therapist will also be able to recommend both low- and high-tech assistive aids for various activities of daily living – call the Society at **1-800-FIGHT-MS** for referrals. For more information about the range of assistive aids available, search for “assistive devices” at nationalMSSociety.org or browse abledata.com.

PROGRAMS

NEW WELLNESS PROGRAM ANNOUNCED: JUMPSTART® IN MOTION

SATURDAY, NOVEMBER 3 ■ PHILADELPHIA, PA

JUMPSTART® IN MOTION is a free one day in-person program for clients living with MS. Lunch is provided.

PRESENTATIONS AND WORKSHOPS:

- Keynote: Exercise, it’s Not Just for Fitness Anymore, Alex Ng, PhD, FACSM
- Maintaining Motivation for Physical Activity, Dave Engstrom, PhD, ABPP
- Start Moving, Stay Moving, Beth Gibson, PT
- Support Partner Workshop, Peggy Crawford, PhD

For more information and to register, visit calendarMS.org.



BRYANT WEZNER WITH HIS MOM



LIVING WITH MS

A CHAPTER IN MY LIFE: BRYANT WEZNER'S STORY

BY: AMANDA CAROSI

Each person has a story to share with the world. Some hastily scribble these tales on the pages of magazines, while others never allow anyone past the cover art. However, like any memorable story, a life can be broken into distinct chapters. This particular chapter of Bryant Wezner's life begins when he was diagnosed with multiple sclerosis at the age of 31. His life became quickly saturated with difficult choices like which treatments to investigate or how to explain the diagnosis to his family. However, the one thing that never wavered was his

passionate commitment to knowledge and a comprehensively healthy lifestyle.

Everything seemed to be going wonderfully for Bryant Wezner. He was residing in Houston and just landed his dream job as a marketing manager for one of the largest companies in the world. One morning on the way to work, he felt a strange stinging in his eye. Assuming that there was an external cause to the irritation, he carried on with his day. Later in the afternoon, the pain had become so severe that a co-worker urged him to seek immediate medical care. Bryant rushed to an emergency meeting with a renowned ophthalmologist and was later diagnosed with multiple sclerosis.

In this moment, Bryant realized he was responsible for carefully crafting the upcoming chapters of his life story. He decided to learn as much as he could, spending long hours in the local library to gather information on the disease. Bryant explains, "I found myself so curious all the time as I continued to read, because in 1994 when I was diagnosed, MS was not a household known disease. I really didn't even know what it was, and more importantly, how it would change my life." Along with this newfound knowledge, Bryant began a steroid treatment to ease the increasing pain in his legs.

As time and the treatments continued, Bryant's symptoms almost entirely dissipated and he focused on maintaining his healthy lifestyle. Despite feeling extremely fatigued, he was committed to exercising seven days a week and following a strictly regimented diet. During his extensive research, he had learned which foods to avoid and which would help



WEZNER EXERCISING

healthy lifestyle choices, Bryant's story significantly calmed down and years spent responsibly managing his MS seemed to fly by. However one blistering winter evening in 2010, Bryant was thrown a twist that no one could have predicted.

While leaving his house to have dinner on February 14, Bryant slipped and fell on the sidewalk and badly shattered his ankle. The injury forced him to use crutches for several months, which put an extreme strain on his spine. The imbalanced walking from the cast and crutches eventually caused a ruptured L5/S1 disc in Bryant's back. In October, he was required to undergo intensive surgery on the damaged area. This procedure caused severe scar tissue to form, which left Bryant in constant and excruciating pain. Several back and spine procedures later, the sciatic nerve was still trapped in between scar tissue. This resulted in consistent pain down his left leg and throughout his entire lower back.

manage his MS. He decreased saturated fats, increased polyunsaturated fats and began taking Evening Primrose/ Flaxseed Oil and several other researched supplements.

Due to his extremely

Since this time, Bryant has been working with multiple doctors in the Abington area, several pain management specialists, surgeons, an acupuncturist and a specialized chiropractor who administers deep tissue massages to the back that only slightly relieve the chronic nerve pain.

When facing these unfortunate turn of events, it would be easy to accept defeat and succumb to the MS that Bryant still faces every day. However, Bryant has consciously chosen to write an alternate end to this chapter. Despite being in debilitating discomfort, he still manages to exercise every morning. Some days the pain is so unbearable that he can only stretch or do light cardio. However, he is deeply committed to correctly managing his MS, which should always include some form of physical activity. In fact, other gym members often approach Bryant to assist them with proper weight lifting techniques due to his advanced knowledge on the subject. Bryant states, "I will always get out of bed at 6 a.m. I will never give up".

Despite this painful situation, his commitment to healthy living has also inspired Bryant to give back. He believes that an individual with MS can be the most effective in training others who also live with it. "I am well aware of the physical capabilities that these people are working through". With a degree in biology from The University of Dayton, he is no stranger to the sciences and plans to pursue his certification in personal training solely to assist those who have been diagnosed. ■

FACE OF MS: PAMELA TAYLOR

Walk MS champ, acclaimed flutist and now City to Shore cyclist, Pamela Taylor is not holding back.

Diagnosed with MS in October 2006, the Easton, Pa. resident has added the title of "Bike MS: City to Shore cyclist" to her repertoire. Encouraged by her team captain, Mike Stellabotte, Pam took part in this year's ride.

I was first in contact with Mike in 2009, when he chose me as his champion. As with a few of the other riders who chose me, we struck up an email conversation, and this one struck. He decided he wanted to be the one to put the medal on me at the MS walk in 2010, and he did (though he didn't recognize me at first!).

In 2010, we started talking about having me at the finish line for the bike event. We also bandied about the possibility of me riding tandem with his daughter, Deanna. Neither could happen, due to my symptoms of weakness and lack of money to get there.

Since then, as of the summer of 2011, I started to gain strength. By early spring this year, I was back on the bike and able to ride short distances (I used to be an avid cyclist and had done a few centuries, but now I'm thrilled with being able to put in 20 miles at a time). With that development, I decided to go for it. The thought of seeing those who had been supporting me and the cause, and to be able to cross the finish line



PAMELA TAYLOR, DIAGNOSED IN 2006

on my own, fill me with excitement and joy.

I had experienced symptoms since I was nine years old, but things started coming together in 2004, when I had a massive bout of vertigo. I was in the hospital for four days, and it was there that the possibility of MS was first mentioned to me. A little over two years later, after leg weakness also became a problem, the diagnosis of MS became official.

I have experienced the gamut of what MS presents to its targets. I have boundless gratitude that I am able to function at nearly

a normal level these days, and if there's any way that I can pass the word along to people with MS that they can have some control over their lives through a healthy diet, exercise, and mindset, I'll gladly make use of it.

I am (was?) an avid cyclist, hiker and skier before the symptoms started to drag me down. Now, if I choose to spend some time following those pursuits, I must plan on not being able to move at all the following day (or two). A normal day for me used to be hitting the black diamond ski slopes hard from 8 a.m. until 5 p.m., grabbing some dinner, and then going skating for a few hours that night. It feels strange, kind of surreal, to reconcile that self with my present self.

In my work life, I have had to slow down quite a bit. That means teaching fewer early childhood music and movement classes, due to the physical nature of the classes. I've had to decrease the number of my performances (I'm a flutist), as well because, though I can still perform without too much impact from the disease, the driving to and from the performance location and schlepping of supplies fatigues me. Also, during the summer season, our concerts are on outdoor stages, so I have to contend with the heat (and a cooling vest isn't quite formal enough concert attire!).

Of course, the decrease in work as well as the high medical expenses have had a financial impact on me and my family. Everything about this disease affects my family, as well as me. On a personal level, I have found out who my true friends are. It's actually a good thing to know that some 'friends' could be put off by simply

considering whether or not an entertainment destination is accessible. I have been learning to have more patience with myself through all of this. I have also been learning to be more flexible (funny for someone who has been doing yoga for more than thirty years!).

Now, I'm climbing a hill that I never thought I would encounter. On a daily basis, I find new definitions for the word. On some days, even a curb can seem like a mountain. Living with MS is a mostly uphill ride. It's good to know we're climbing this one together. It might be an uphill battle, but I'm convinced this is one we can win. ■



MS DINNER *of*
CHAMPIONS

HONORING
JUDITH M. VON SELDENECK
FOUNDER, CHAIRWOMAN
& CEO OF DIVERSIFIED SEARCH

Friday, November 9 • 6-8 p.m.
Philadelphia Marriott Downtown
Business/cocktail attire

For more information about this event
or to purchase tickets (\$350 each), please
contact us at **1-800-548-4611**
or by email at
dinnerofchampions@pae.nmss.org.



**National
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Society**
Greater Delaware
Valley Chapter

30 South 17th Street, Suite 800
Philadelphia, PA 19103

ADDRESS SERVICE REQUESTED

1 800 548 4611 ■ nationalMSsociety.org/pae

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Free Matter
for the
Blind or
Handicapped



Thank you!

Many thanks to the thousands of cyclists and volunteers who made Bike MS: City to Shore Ride a success this year. Your dedication to this ride has moved us ever closer to our goal: a world free of MS.

The ride, which took place on September 29 and 30, has become one of the foremost cycling events on the East Coast.

We welcome feedback from current and potential cyclists and volunteers as to how our 2013 event can be better than ever.

Contact us at MScycling@pae.nmss.org.