The North Florida Chapter of the National MS Society is excited to host The Living Well with MS Conference. Formerly known as The Blueprint of MS Conference, the Living Well with MS Conference is our largest educational program of the year.

The goal of the Living Well with MS Conference is to connect those with MS to a lifestyle of health and wellness. Wellness is a lifelong journey through which people develop an awareness of, and make positive choices about, their behaviors, lifestyle and activities that enable them to lead their best lives. For a person living with MS, the road to wellness involves more than treatment of the disease and its symptoms. Equally important are health promotion and prevention strategies, satisfying personal relationships, a strong support network, fulfilling work and leisure activities, a meaningful place in the community, and adequate attention to one’s inner self.

The theme of this year’s Living Well with MS is to focus on living well, while managing MS and another condition. MS isn’t always the only health problem a person has to manage — another condition could have preceded the MS or appeared well after the MS diagnosis. This means that many people living with MS are also dealing with common problems like allergies or headaches, or more serious illnesses like diabetes, heart disease or cancer. Some people also have more than one immune-mediated disease to deal with.

By attending this free educational event, you will have the opportunity to learn about adaptive exercise and the impact that an active lifestyle can have on multiple sclerosis and other conditions. In addition to the physical aspects of wellness, education and awareness are also a key part in adapting a healthy lifestyle. To connect the MS Community to current MS updates, The Living Well with MS Conference will present health care providers, neurologist and researchers as speakers. Additionally, the Living Well with MS Conference will provide resources that are available throughout the year to keep you updated on various aspects of life impacted by multiple sclerosis. Finally, this conference is a great way to connect with others impacted by MS. Meet new people, connect with a local Self Help Group and learn about ways to get plugged-in to your community.

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LETTER FROM THE PRESIDENT

Friends,

My favorite morning of the year is Day 2 of Bike MS: PGA TOUR Cycle to the Shore.

Just before dawn, 2,000 riders are lined up along the Daytona Beach boardwalk ready for the last leg of their journey along the coast to the finish line in Ponte Vedra Beach or Marineland. The sun slowly begins to rise over the Atlantic Ocean and the music starts pumping. Riders are tired, sore, sunburned… but completely undaunted.

They know that while the road ahead is long, it’s because of them that we have come so far in understanding and treating MS. They know that without them the National MS Society couldn’t be the number one source of information and support for families living with MS every day.

They know that one day we may not need to host Bike MS. Maybe one day they will wake up at sunrise and ride for another cause because we will have solved this mystery. But until that day, they will wear spandex, fuel up with goo and snow cones and pickles, and ride mile after mile to end MS forever.

On a bike or off, there is a way to get involved in Bike MS October 10th and 11th. Grab your bike and your friends and get registered at bikeMS.org. Volunteer for the route safety team or join our new Spirit Squad to cheer the riders across the finish line. And don’t forget to donate! Every dollar brings us closer to more treatments, more connections and more ways to create a world free of MS.

See you at Bike MS,

Corrina Steiger Madrid
President, North Florida Chapter
National MS Society | Corrina.Madrid@nmss.org

The National MS Society is proud to be a source of information about MS. The content is based on professional advice, review of independent research, published experience and expert opinion. The National MS Society makes no warranties regarding the information provided and the information is provided for your educational purposes only. Any provided medical information is of a general nature and should not be substituted for the individual therapeutic recommendation or prescription by a medical person. For specific information and advice relating to your personal medical condition, always consult your personal physician.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at nationalMSsociety.org or 800-344-4867.

CORRINA MADRID

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FALL RESEARCH
UPDATES

BY MEGAN WEIGEL, DNP, ARNP, FNP-BC, MSCN Chapter Research Advocate

It is important that the research update provides a comprehensive review of what is happening in the realm of MS research. For this issue, I thought readers would find it interesting to review highlighted articles from some of the major peer-reviewed medical/scientific journals in MS. I have chosen articles addressing disease progression, behavioral therapy, rehabilitation therapy, and comorbidities (other medical conditions) in MS. I hope you find a peek into what your MS care provider is reading helpful!

Novotna and colleagues performed a study looking at how good recovery versus poor recovery from initial relapse and first 5-year average of MS relapses affects the development of progressive MS. This was published online in Neurology, the official journal of the American Academy of Neurology, on July 24th. Relapsing-remitting and progressive MS (both single attack to progressive MS, and secondary-progressive) patients were reviewed. Results revealed that about half of those having a good recovery, defined as complete or almost complete recovery in the defined time periods, developed progressive MS at approximately 30 years after MS onset. About half of those who had a poor recovery developed progressive MS by about eight years after MS onset. This information provides us with another tool that may be useful in predicting the course of MS.

The International Journal of MS Care published a randomized, controlled study authored by Mackay and colleagues examining the effect of biofeedback as a psychological intervention in MS (May/June issue, 2015). Two groups were studied. Both received an intervention of relaxation, mindfulness, social support, and education, and one group also received biofeedback. Both groups had significant improvement or trend towards it in anxiety, fatigue, stress, and in anxiety/depression scores. There was no statistically significant difference between groups, though the biofeedback group trended towards improvement in breathing rate and muscle tension. Results confirm that both methods are helpful as psychological interventions, but one is not necessarily better than the other.

In MS and Related Disorders, Savant and colleagues performed a review of the effectiveness of TENS for the management of central pain that was published in April of 2015. Results of four studies were combined and it was determined that the use of TENS therapy demonstrated a statistically significant effect on the management of central pain in MS. Central pain is the type of pain caused by MS plaques in the brain or spinal cord that causes feelings of burning, pins and needles, or similar sensations.

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LIVING WELL WITH MS CONFERENCE 2015
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This year’s Living Well with MS Conferences will be held in early November. For more information on speakers and registration please call 1-800-344-4867 or visit NationalMSSociety.org/FLN.

All Conferences will take place from 10 a.m. to 1 p.m. Registration opens at 9:30 a.m.

SATURDAY, NOVEMBER 7, 2015:

Jacksonville – Adam W. Herbert University Center - 200 Alumni Drive, Jacksonville, FL 32224

Pensacola – Hilton Garden Inn Pensacola Airport/Medical Center - 1144 Airport Blvd, Pensacola, FL 32504

SATURDAY, NOVEMBER 14, 2015:

Gainesville – Best Western Gateway Grand - 4200 NW 97th Blvd, Gainesville, FL 32606

Tallahassee – Tallahassee Community College Workforce Development Building 38 - 444 Appleyard Drive, Tallahassee, FL 32304

DELIVER THE DREAM

The National MS Society is partnering with Deliver the Dream for an MS Family respite and retreat weekend. Deliver the Dream retreat will be held November 13-15, 2015 at the FFA Leadership Training Center in Haines City, Florida for families impacted by multiple sclerosis.

This three day retreat is at no cost to you and your family. Families attending this weekend will be involved in structured, therapeutic, family-centered activities that offer respite, relaxation, and recreation for those who are experiencing similar challenges. Sydney Ward, age 18, attended Deliver the Dream with her family last year. Here’s what Sydney had to say about her experience: “Deliver the Dream impacted me by showing me that other people have MS and I’m not totally different. It taught me to be more positive and learn about new resources. Other families should be involved because it is truly an experience you’ll never forget. You’ll make new friends that will become part of your family. I had no idea what to expect but once we got there and met the amazing staff and went to our first activity I knew I was going to have a blast and learn new things.”

If you are interested in applying for this once in a lifetime opportunity please e-mail Kinsey.Stewart@nmss.org or call 954-564-3512 and ask for the Program Department.
VOLUNTEER SPOTLIGHT

This month’s volunteer spotlight is on Harold Tool, who has served as Chapter Chair from 2013-2015.

How has MS impacted your life?
I joined the Board in 2008 to give back to the community. But, in the last year, my sister-in-law was diagnosed with MS. She had struggled for a long time trying to determine why she had the symptoms she had. She had seen many doctors and had many tests done. She went for many years without a proper diagnosis. Her diagnosis gives me another reason to give and support the Society.

You’ve served as Chair of the board since 2013. What’s something you are most proud of during your tenure?
I’m proud of the resiliency and tenacity of our staff and volunteer leadership. The Chapter has not just overcome challenges but has really thrived and become stronger, better, and more resourceful. We are raising more money in our community and doing even more to serve those impacted by MS.

Where do you work and how do your coworkers get involved with the Society?
I am the CFO at PPR Talent Management Group. PPR is a leader in healthcare staffing, recruitment and workforce solutions. PPR has had a team participating in Bike MS since 2007.

You are known as the “Grill Master” for the Team PPR tent at Bike MS. What’s your favorite part of Bike MS?
I enjoy serving lunch to our bike team, our volunteers, our employees, and all of our friends and families and, at the same time, raising money and awareness for those impacted by MS.

How would you encourage our readers to “join the movement”?
Raise money for this important cause. One of my favorite things about serving the Society is the knowledge that we have the ability to end this disease. I have great confidence that we will find a cure. The Society is providing more money to research than ever before. Every dollar we raise gets us closer to a cure. You may not know it, but you know someone with MS, and you can help find the cure.

IN MEMORY OF...
Beverly Eckhart
Nedra Sweet
Wendy Smith
Foley & Lardner
Jane Grower

IN HONOR OF...
Judy Kenke
Lois Chilleo
MORE THAN 2,000 MILES TO END MS

Bob Doughty is a Jack of all trades when it comes to his involvement with the National MS Society. His story with the Society began in May of 1976 when his wife Cathy was diagnosed with MS after showing symptoms for more than two years. Since then, Bob's involvement has ranged from attending self-help group meetings with his wife, to participating in fundraising events, to giving back to the MS community by volunteering for MS Service Day.

Right after Cathy was diagnosed and for many years after, Bob attended monthly self-help group meetings with her in their hometown of Savannah, Georgia. He says that the meetings were great because they were able to meet others who were either living with MS or caring for loved ones with MS.

In 1982 Bob and Cathy packed up their belongings and moved south to Jacksonville. The move to Florida was a turning point for Bob and his involvement with the Society. In the spring of 1989 he and Cathy participated in their first fundraising event for the Society, the inaugural Walk MS event in Jacksonville. Bob still participates in Walk MS today.

In 2003, Bob set a personal goal for himself and decided to participate in his first Bike MS event. He began training, bought himself his first road bike and kicked his fundraising into high gear. In a couple of months he had raised $1,700 and was ready to head out for his first Bike MS ride. Bob says that Bike MS is his favorite event and he looks forward to it all year. He also loves riding with his teammates from team Big Bananas each year.

In 2016 Bob will join people from all across the US in his hometown of Savannah for his fifth Challenge Walk MS event. He says that the best part about Challenge Walk is the people and the passion they all have to end MS.

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MORE THAN 2,000 MILES TO END MS
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When asked why he participates Bob said, “Cathy passed away in 1994. It is too late to cure MS for her, but I participate for the people who are living with MS now. Cathy was the first person I knew with MS, but over the years I have met numerous people who have MS, I participate for them all.”

His favorite part about all of the events, “The experience, and all of the friends I have made.”

Over the years, Bob has participated in nearly 50 National MS Society events. He has raised more than $60,000, walked more than 270 miles, and cycled more than 1,800 miles - all to help end MS forever.

Bob invites you to join him as a volunteer or participant at any of our events throughout the year.

UPCOMING EVENTS:

Bike MS: PGA TOUR Cycle to the Shore
October 10-11, 2015

Challenge Walk MS: Savannah 2016
February 26-28, 2016

Walk MS: North Florida 2016
April 9, 18 & 23, 2016

For more information about Bike MS, Challenge Walk MS or Walk MS please contact us at 855-372-1331 or FundraisingSupport@nmss.org or visit our website at nationalMSsociety.org/FLN

FALL 2015 RESEARCH UPDATE
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These findings suggest that TENS is a safe and effective way to manage central pain, and could possibly decrease the use of pain medication and even decrease costs of rehabilitation therapy.

A special issue of the MS Journal was published in February of 2015. This issue reviewed the incidence and prevalence of comorbidities in MS. Over 7000 studies were considered, and 249 underwent detailed review for statistical analysis. From this data, the following is noted: the five most prevalent comorbid medical conditions in MS are depression, anxiety, high blood pressure, high cholesterol, and chronic lung disease; thyroid disorders and psoriasis are the most prevalent comorbid autoimmune diseases; the risk of meningioma (a usually benign and slow growing brain tumor) and urinary system cancers was higher than expected; and stroke, heart disease, congestive heart failure, arthritis, inflammatory bowel disease, seizure disorder, sleep disorder, bipolar disorder, and alcohol abuse were found to occur more commonly than previously thought.

These findings provide your MS care provider with valuable information to ask you during your visits, and also provide more evidence for the importance of having an excellent primary care provider on your MS team to monitor for other medical problems.

As you can see from this research, it takes a village to take care of MS. Having a variety of health care providers in your tool box will ensure that you as a whole are cared for, and that you are living a life of wellness!
ASK AN MS NAVIGATOR

Finding answers and making sound decisions relies on having the right information at the right time. That’s what the National MS Society provides – answers to your questions and access to information about all of the options available to you. Our MS Navigators are highly-skilled professionals, equipped to respond to your needs.

The Society puts the latest and most accurate information, resources and programs to work for you, so you can:

• Understand what you need to know when you or a loved one is newly diagnosed
• Identify appropriate treatment options and symptom management strategies
• Connect to resources in your community and nationwide
• Access optimal healthcare
• Meet workplace challenges

• Understand benefits such as health insurance
• Face financial challenges and planning for the future
• Team up to face challenges as a family
• Manage difficult life changes
• Find support when MS progresses

MS Navigators can help you explore all of the resources available to you. We can help you:

• Connect with others living with MS
• Access support from others living with MS
• Find what you need to maintain independence
• Deal with a crisis
• Access comprehensive educational programs and more

Contact An MS Navigator Today:

Phone: 1-800-344-4867
Email: contactusnmss@nmss.org
Facebook: facebook.com/NavigatorMS