



FALL 2013
INDIANA STATE CHAPTER

MS CONNECTION NEWSLETTER

LIVING WITH MS

VITAMINS, SUPPLEMENTS AND MS



Dr. Brenda Banwell is the division chief of Neurology and professor of Pediatrics Neurology at Children's Hospital of Philadelphia and the University of Pennsylvania. After the

webcast, **Living Well with MS: Lifestyle, Diet and Complementary Therapies** (watch it at nationalMSSociety.org/webcasts), the Society sat down with Dr. Banwell to get answers to your questions about vitamins and supplements that are potentially helpful and harmful for people with MS.

Q: What other vitamins or supplements besides vitamin D do you recommend taking on a daily basis to help MS?

A: There really isn't anything else that's even close to vitamin D in terms of research support for its use in MS. However, I do a blood test of serum levels of vitamin B12



on myelin, which is important for neurological function and is a particular target in MS. In fact, B12 deficiency can actually look like MS in some people, and having low B12 if you have MS can further compromise the brain and spine. That said, healthy people who are eating a regular diet are rarely deficient in B12, and if they have normal levels, taking additional B12 has no proven value. People who are on some extreme diets or don't eat red meat are more likely to have low levels and should be treated if that's the case.

There's an ongoing debate about the benefits of omega-3 and other fatty acids. I caution parents of kids I look after about not giving too high a dose of fish oils or other oils – when you put too much oil into your gut, you actually absorb other nutrients less well. This can put you at risk of diarrhea and other nutritional problems. I strongly discourage the “a little bit is good, a lot must be *(continued)*”

(continued from cover)

great” philosophy. Very few things in nature are meant to be consumed in excessive amounts. Almost every species has what we call “satiety safety.” In other words, they stop when they’re full – and I think that’s a message that we as humans should not override.

Q: What supplements should people with MS avoid?

A: There are a lot of claims made for alternative remedies that may or may not be accurate. To be fair, we don’t fully understand the mechanisms for a lot of approved medications either. I recommend avoiding nutritional supplements or holistic remedies that claim to boost the activity of your immune system, which are commonly suggested for people who get a lot of coughs, colds, fevers or illnesses. Theoretically, boosting your immune system would not be something you want to do if you have MS. MS is a disorder that is characterized by an exaggerated immune response directed at the brain, spine and optic nerves – there *(continued on next page)*



MORE IS NOT ALWAYS BETTER WHEN IT COMES TO VITAMINS AND SUPPLEMENTS.

NATIONAL MULTIPLE SCLEROSIS SOCIETY

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Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National MS Society recommends that all questions and information be discussed with a personal physician.

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is a failure to turn down the immune response when it starts attacking your own body. So, to give someone something that boosts the activity of immune cells would go against what we want to do in MS.

When you seek out advice from alternative care providers, I suggest that you ask them what the substance they're recommending is supposed to do. Ask them why they think that would be effective in MS. Then, ask what they know about the disease. If they believe a supplement would help with immune control or with improvement in myelin or nerve regeneration, then I would advocate that you bring that information and the supplement to your primary healthcare provider so that he or she can analyze the substance and whether or not it would have any potential interaction with other medication you may be on.

Q: Do you have any other advice for people who are considering complementary or alternative therapies for MS?

I think an open, honest and trusting dialogue between people with MS, their families and

friends, and all of their healthcare providers is essential to ensure we're all on the same page and working together. Where we're seeing alternate treatments causing harm is when one healthcare provider doesn't know what the other is doing.

Some people with MS seem to feel that their healthcare providers aren't open to complementary and alternative medicine, but I think that's changing. When we're able to have a frank dialogue, I've been able to work with families to agree upon what is reasonable and what is potentially dangerous – and ultimately find a course of treatment we're all happy with.

CONTINUE THE CONVERSATION

Discuss your own experiences with vitamins, supplements and alternative medicines with other people affected by the disease and hear experts' opinions on other topics related to living well with multiple sclerosis at [MSconnection.org](https://www.msconnection.org).

LIVING WITH MS

PARTICIPATING IN CLINICAL TRIALS

Clinical trials help to determine if a drug is safe and effective for people with MS. People with MS who are willing to volunteer in these studies

make it possible for all of us to look forward to new and better therapies.

People with MS can take an active role in freeing the world of MS by participating in drug studies. Find out about local studies and what you need to know before you participate.

Learn more about local clinical trials as well as those available throughout the country at [nationalMSSociety.org/clinicaltrials](https://www.nationalMSSociety.org/clinicaltrials).

CONNECTIONS

MOVING FORWARD EVENT TO FOCUS ON FAMILIES

The National Multiple Sclerosis Society - Indiana State Chapter's Moving Forward event is an opportunity for the entire Hoosier MS community to come together in celebration of the ways in which we are moving toward a world free of multiple sclerosis. The annual event allows Chapter constituents to learn more about the many ways in which the Society is fulfilling its mission of mobilizing people and resources to drive research for a cure and address the needs of all people affected by MS.

This year's Moving Forward event will be held on Saturday, November 2 from 1:30 to 5:00 at the Hilton Indianapolis North Hotel. Moving Forward will have a focus on families in 2013 and will feature an address from Debbie Emmelkamp, MSW, LCSW about family relationships and wellness related to life with multiple sclerosis.

Debbie is the owner of Decision Point Consulting in St. Louis, an agency specializing in working with individuals and families who



LAST YEAR'S MOVING FORWARD EVENT FEATURED GUEST SPEAKER DR. ROBERT NAISMITH FROM WASHINGTON UNIVERSITY. THE 2013 EVENT WILL INCLUDE AN ADDRESS BY A LICENSED SOCIAL WORKER AND FOCUS ON HOW MS AFFECTS FAMILIES.

are coping with aging, health, mental health, and disability issues for more than 16 years.

The Chapter will also give out five MS Superstar Awards—Nurse of the Year, Physician of the Year, Volunteer of the Year, Business Supporter of the Year and Employer of the Year.

Be sure to watch your mailbox or visit nationalMSSociety.org/ini in the upcoming weeks for more information about Moving Forward and how to nominate someone for an MS Superstar Award. In addition, if you would like to nominate someone to the Chapter Board of Trustees, submit resumes to Leigh Ann Erickson, Chapter President, by October 18 to leighann.erickson@nmss.org.

MONEY MATTERS

MAKING HEALTH INSURANCE CHOICES

Starting October 1, most people who don't already have health insurance will have new options for coverage when the **Health Insurance Marketplace**—a component of the Affordable Care Act—begins enrollment for coverage to begin January 1, 2014.

The Web-based Health Insurance Marketplaces, (sometimes called “exchanges”) are a new way of shopping for health insurance coverage, allowing people to compare plans, get tax credits and other cost help. The program also includes government-certified “navigators,” who are expert health insurance counselors funded by the marketplaces to provide unbiased information, education and enrollment help to consumers at no cost. Coverage through marketplace plans is guaranteed regardless of pre-existing conditions, such as MS, and covers preventive and needed care, such as doctor's visits, hospitalizations, maternity leave, emergency room care and prescriptions.

Enrollment begins October 1 at healthcare.gov. Call the Society at 1-800-344-4867 or visit nationalMSSociety.org/ACAkickin for more information.

WAYS TO GIVE

GIVE AT THE OFFICE

Every year, people nationwide help create a world free of multiple sclerosis by contributing through their employer's charitable giving campaign.

Most campaigns kick off in the fall, so if you've been looking for an easy and efficient way to join the movement, act now. Simply designate your annual pledge to the National MS Society. Your donation will be automatically deducted from each paycheck to fund cutting-edge research and provide life-changing programs and services for people affected by multiple sclerosis.

Federal government employees and military personnel are eligible to participate in the Combined Federal Campaign (CFC), the nation's largest workplace giving program. If you participate in the CFC, designate your gift to the Society using **CFC#11409**.

If your company offers a workplace giving program, look for the Society listed under Community Health Charities. If your employer doesn't offer a giving program, talk to your benefits administrator or call us at **1-800-344-4867, option #2**, to see if we can help.



RESEARCH

FOCUS ON MS
RESEARCH

A joint meeting held May 29 to June 1 by the Consortium of Multiple Sclerosis Centers (CMSC) and the Americas Committee on Treatment and Research in Multiple Sclerosis (ACTRIMS) showcased the latest directions in MS research.

Here is a selection from more than 200 presentations on research seeking to **stop** MS in its tracks, **restore** function to those who have MS and to **end** the disease forever.

STOP MS

Researchers at the Colorado Blood Cancer Institute in Denver reported two-year results on a study following 24 people with highly active relapsing-remitting MS who were treated with bone marrow transplantation. Both relapses and disease activity observed on MRI scans were significantly reduced; however, there was significant loss of brain volume the first year, which then stabilized, and one person died. Other adverse events included excessive levels of uric acid and liver enzymes, and decreased potassium levels. Participants are being followed for a total of five years, and additional research is needed to determine the risks and benefits for people with MS of this experimental procedure.

A study at the University of California, Los Angeles, tested whether male and female sex chromosomes influence the response of the nervous system to injury. In female mice genetically engineered to express the male (XY) or female (XX) chromosome, XY mice experienced a more severe MS-like disease. However, immune responses did not differ. If confirmed in further studies, such findings may help to explain why MS progression occurs faster in men, even though MS is more common in women.

RESTORE: REHABILITATION

A Society-funded study at the University of Illinois at Urbana-Champaign found that video-chat sessions with a behavior change coach improved results of a six-month physical activity program among participants. The results also showed reduced fatigue, depression and anxiety.

In addition, three separate studies reported results on falling issues.

- Debra Frankel, vice president, Programs, Services and Clinical Care at the Society, reported that participants in the Society's Free from Falls program improved in balance and walking, and that the psychological impact of falls was reduced, even six months after the program. (For more on how to participate in the Free from Falls program, call **1-800-344-4867**, or visit **nationalMSSociety.org/freefromfalls**.)
- At the University (*continued on next page*)

of Illinois at Urbana-Champaign, researchers found that fall risk decreased significantly and balance improved in 10 people with MS who participated in a 12-week, home-based exercise program, compared with 12 people who did not participate. The Society is funding a continuation of the study to determine how exercise can be used to prevent falls in people with MS.

- Researchers at the Oregon Health and Science University in Portland found that in 53 people with MS taking a range of medications, those taking no medications had a 27% risk of falls and that the risk of a fall increased 33% with each additional medication. Larger studies are needed to confirm how medications might affect the risk of falling, so that clinicians can consider this important aspect of MS management.

RESTORE: REPAIR

Investigators at Endece, LLC reported that the molecule NDC-1308 reduced cell death in the spinal cord of mice with an MS-like disease and activated genes important in the development of myelin-making cells. The company is supporting preclinical research to develop NDC-1308 as a possible future treatment for repairing damage in MS.

END MS

A Society-funded study at University of Miami found that 287 Hispanic/Latinos with MS were more likely to experience symptoms

of motor weakness, ataxia (problems with muscle control) and bladder problems, when compared to 275 non-Hispanic whites with MS. Hispanic/Latinos also responded more favorably to interferon treatments. For MS resources in Spanish and information about Hispanic/Latinos living with MS, visit mueveteMS.org.

A study at University of Utah, Salt Lake City, using a new technique called “deep sequencing,” found that the activities of genes that instruct retroviruses was significantly increased in 14 people with primary-progressive MS. Further studies in larger numbers of people to determine the significance of these findings are about to get underway with Society funding.

Data collected from the Sonya Slifka Longitudinal MS Study, established by the Society in 2000 to study demographic and disease characteristics, use and cost of health services, access to care, quality of life, treatment and much more, is being made available to qualified investigators for studies on the direct and indirect costs of MS. These include the financial impact of out-of-pocket costs, informal caregiving, pregnancy and mental health treatment.

To read more about the joint meeting and other recent MS research, visit nationalMSSociety.org/research or sign up at nationalMSSociety.org/signup to have MS eNEWS delivered monthly to your inbox.



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VOLUNTEERS

HALPERN FAMILY HONORED NATIONALLY

The Halpern Family of northwest Indiana has been named to the National Multiple Sclerosis Society's Volunteer Hall of Fame in the Funding the Mission category.

The Halperns' commitment to the Society began shortly after Donna's diagnoses with multiple sclerosis in the 1980's. While life-altering for their family, they embraced Donna's journey together, resulting in amazing strides toward ending MS forever by rallying



FRED AND DONNA HALPERN (RIGHT), THEIR SON AND DAUGHTER-IN-LAW JOSH AND ASHLEY (LEFT), AND FRED'S BROTHER, CHARLIE (MIDDLE), TOGETHER WITH THEIR TEAM AT ALBERT'S DIAMOND JEWELERS, HAVE RAISED MORE THAN \$475,000 FOR THE SOCIETY.

their community and providing more than \$475,000 for Society research and programs through personal giving and their annual Albert's Auction event.

They will be honored for their support and efforts to engage others in the MS Movement at the Society's annual Leadership Conference in Denver this November.