

FDA to regulate vitamins and herbals

Many people choose a vitamin or herbal supplement by studying the label first. They may want vitamin C because they've been feeling run down. They might consider vitamin D because it may help fight osteoporosis. But, until now, there's been no guarantee that what they see on the label matches what's actually in the pill.

What's in that pill

Since 1994, manufacturers of dietary supplements have been



responsible for making sure their products were safe. No other regulation was in place. However, in the last few years, cases of subpar ingredients in supplements have been hitting the headlines. In 2004, the U.S. Food and Drug Administration (FDA) discovered illegal pesticide residues in ginseng. In 2006, the FDA found supplements that were "significantly subpotent" in some nutrients, including vitamin A, folic acid, and vitamin C. Then the active ingredients from

medicine for erectile dysfunction were found in some supplements.

Getting what you paid for

In June 2007 the FDA announced a final rule for regulating dietary supplements. The manufacturers will be required to test the ingredients for purity, identity (i.e., making sure it is what it's supposed to be), and strength—in addition to reporting any adverse events to the FDA. According to the FDA, this rule will help regulate dietary supplements for quality, contaminants or impurities, and accurate labeling. It's certainly a step in the right direction.

The final rule will become effective in June 2008 for large businesses, with a three-year phase-in for small businesses.

Medicare Part D: sign up or switch for 2008

The enrollment period for Medicare's Part D prescription drug plan is here: **November 15 to December 31, 2007**. Medicare beneficiaries (with rare exceptions) can join or change their plans **only** during this time.

If you already have a prescription drug plan, you should have received a notice from your insurance carrier about changes to your plan for 2008. Now is the time to consider how well the 2008 plan meets your needs. Compare your current coverage with the 2008 offering. Are there higher premiums, deductibles,

or co-payments? Has coverage during the "donut hole" period changed? Most importantly, does the plan cover all the medications you take? If you have questions or you have not received the notice about changes, contact your plan right away.

Whether you are signing up for the first time or not, find out what's available in your area by using the Medicare Prescription Drug Plan Finder at

www.medicare.gov. Or call Medicare, 1-800-633-4227.

To stay with the plan you have, do nothing.

For help with choosing a plan, use the link on the Medicare site

to State Health Insurance Programs (or SHIPs). For more information, go to www.nationalmsociety.org/Medicare. For in-person assistance, contact your chapter at **1-800-344-4867**.



New program helps people “Navigate” MS

Navigators guide ships and airplanes through the hazards of weather and currents to arrive safely at their destination. Like their namesake, MS Navigators can guide people through the seas of life with MS.

The Society has just launched the MS Navigator program. It connects a skilled professional partner to anyone whose life has been affected by



MS. The MS Navigator can help people understand their options and learn about and discuss possible solutions. From dealing with workplace issues to figuring out Social Security benefits, the Navigator can guide people through bureaucratic byways, directing them to useful resources and services and providing research and follow-up when needed.

To speak with an MS Navigator, call your chapter at **1-800-344-4867**.

Survey on technology yields eye-opening results

Many people with MS are not taking full advantage of features that could make their computers and electronic devices easier to use—features that might help on the job and in everyday life. On the other hand, technology plays a vital and increasingly important role in the lives of people with MS. These are some of the key facts that surfaced in an important survey fielded this summer.

“Staying connected”

Conducted by StrategyOne and Harris Interactive on behalf of the MS Technology Collaborative, the survey asked 2,390 people with MS questions about living with and managing their

People with MS are tech savvy

Use computers With MS: **93%**

General population: **80%**

Use the Internet **93%**

75%

Use cell phones **91%**

69%

disease, their interest in technology, and their use of it to do their work and to be connected to the world. The survey had a margin of error of less than plus or minus 2 percentage points.

In October, the MS Technology Collaborative reported on some of the results.

Nearly all respondents use computers (93%), the Internet

Moving research Fast Forward

The National MS Society has launched Fast Forward to kick-start development of promising drugs for MS.

By committing significant sums to support clinical trials and by forging better connections between university-based MS researchers and investors from the business community, Fast Forward will increase the number of MS drugs in the development pipeline.

Funding decisions will be made by the Fast Forward Advisory Committee which brings leading MS scientists and business executives to the table together. Drawing on the experience of both groups, the committee will identify top opportunities and leverage the financing needed to speed development of the new treatments.

To learn more about this ambitious program, see page 71 or go to **www.fastforward.org**.

(93%) and cell phones (91%). These rates are higher than the general population, which stood at 80%, 75%, and 69%, respectively, in a national consumer survey conducted in 2005–06.

But fewer respondents said they use and even know about available “accessible” technology. (For more on this, see MS Technology on page 40.)

- One-third said that MS makes it harder for them to learn to use new technology.
- 56% said that they might use newer technology if they had more information.
- 48% felt that using new technology to adapt to MS changes would be too expensive. They did not know that many adaptations are standard features on the average home computer.

The good news

Fully 70% of the people surveyed expressed an interest in keeping up with and using the latest technology and about half said that they have already increased their use of technology since their MS diagnosis.

Complete survey results can be downloaded at www.mymyway.com or from the Society’s Web site, nationalmsociety.org.

About the MS Technology Collaborative

This groundbreaking research was commissioned by the MS Technology Collaborative, an innovative partnership linking the National MS Society,

Microsoft, and Bayer HealthCare Pharmaceuticals. The mission is to provide people with MS the information, resources, and technology know-how they need to stay connected to the world and to move their lives forward.

Red Cross now accepts blood donations from people with MS

For years, Sarah Buckbee regularly donated blood to the American Red Cross. But after being diagnosed with MS in 2001, she was devastated

from donating due to having an ‘autoimmune disease of unknown origin.’” She added, “I left the place in tears.”

There is absolutely no scientific evidence that MS is contagious or can be transmitted via blood, and two years ago the American Red Cross quietly changed their policy. Now people with MS “who are healthy and well on the day of donation” will be accepted by the American Red Cross, said Stephanie Millian, director of Biomedical Communication. She added that “most medications taken for chronic conditions will not disqualify a donor.”

As for Sarah Buckbee, she has an appointment to donate, “if they’ll let me, since I’ve been to South Africa in the last 12 months,” she added. (The American Red Cross requires a deferral for one year if someone has traveled to an area at risk for malaria.)

“At least my MS is no longer the reason I can’t give blood.”



to hear they would no longer accept her donations.

“The medications I had to list on the questionnaire triggered questions about what they were for,” Buckbee said. “I was given a form letter telling me I had been deferred

MS publications available

Interested in a deeper dive into MS clinical practice and research? Two valuable publications may help.

The **Multiple Sclerosis Quarterly Report** is a joint publication of United Spinal Association and the Consortium of MS Centers/NARCOMS (North American Research Committee on MS). It is focused on MS research and provides an authoritative overview of current developments, feature stories, breaking news, and details on current clinical trials in MS. Although written for laypersons, the reading level may at times be challenging. But MS often spurs people to master unfamiliar material.

The catch

The **MSQR** is free to people with MS who have signed up with the NARCOMS Registry, an important resource for MS researchers. Participation involves filling out a detailed questionnaire twice a year, online at www.narcoms.org or on paper (call **800-253-7884**). Strict confidentiality is maintained.

Names in the registry are never given out without the indi-



vidual's written permission. The questions include demographic information, MS-related medical history, drug therapies and health-care services used, and a series of performance questionnaires that reflect disability in eight domains of function. NARCOMS notifies registry participants of

clinical trials they might choose to participate in and lets researchers use only de-identified data sets, without names or any other identifying information.

Preview the **MS Quarterly** at www.unitedspinal.org/publications/msqr—and consider registering with NARCOMS whether you want the publication or not. The data helps answer MS research questions and could speed the way to cures.



The **International Journal of MS Care** is the official publication of the Consortium, Rehabilitation in MS, and the International Organization of MS Nurses. Published by and

for health-care professionals, and peer-reviewed for accuracy, the articles are not written with non-professionals in mind. But the journal does reward those who have become familiar with medical literature by conveying what professionals in MS care are thinking about. The journal is available online at www.ms-care.org.



“Café con Leche” connects Spanish speakers

There's nothing quite like a **café con leche**—a cup of coffee with hot milk—shared with friends and family in the afternoon. It's a time to gossip, to laugh, and above all, to share.

A chance to connect

The Society is recreating this Hispanic tradition with a national Spanish-language telephone support group program being piloted this year. Developed by the New York City Chapter, Café con Leche meets by phone once a month, offering a chance for Spanish-speaking people with MS from select chapters around the country to discuss common challenges and solutions. Three times a year, expert speakers join the conversation to cover topics of interest. Meetings are facilitated by Moyra Rondon, LCSW, program director of Public Education and Hispanic Outreach for the NYC Chapter of the Society.

A rosy future

According to Maria A. Reyes-Velarde, MD, MPH, manager of the Society's Underserved Population Program, the results of Café con Leche will be evaluated in December. If continued, the program, which is funded by a grant from the Medtronic Foundation's Patient Link program, will be open to all chapters across the country.

Information by request

Participants request the topics to be discussed by guest speakers. So far, these have included optic neuritis, discussed by Dr. Gabriel Pardo, the medical director of the MS Center of Oklahoma at Mercy Neuroscience Institute, and urinary incontinence, discussed by Dr. Johanna C. Figueroa from North Nassau Urological Associates in Glen Cove, New York. "Both guest speakers are bilingual doctors of Hispanic descent," Reyes-Velarde explained.

A little something extra

Café con Leche steps beyond the telephone when needed. If a participant brings up a difficult issue and wants additional help, the moderator can contact the person's chapter.

Whether it's chatting and relaxing with a cup of coffee in one hand, or getting extra help working through a problem, Café con Leche looks forward to a steaming hot future.

Training new MS specialists

MS care and research both begin with the encouragement and training of young doctors and nurses. Today's recipients of Society fellowships in research, clinical care, and nursing will soon bring their expertise to people with MS.

More nursing fellows than ever

This year there are seven John Dystel Nursing Fellows, up from only two nurses a year previously. While it's not yet "1,000 MS nurses"—the vision of Oscar Dystel, the father of John Dystel, in whose honor the program was founded in 2002—it is certainly on its way.

"This year, there's a great variety of nurses from different settings," said Dr. Nancy Holland, the vice president of Clinical Programs, citing recipients in seven states. Carolyn Jones, RN, MN, plans to become a liaison between the Augusta MS Center and physicians in the South Carolina countryside. One of her goals is to increase the number of MS support groups in rural areas.

For more information about the John Dystel Nursing Fellowship, visit nationalmssociety.org/Dystel.

Training MS specialist physicians

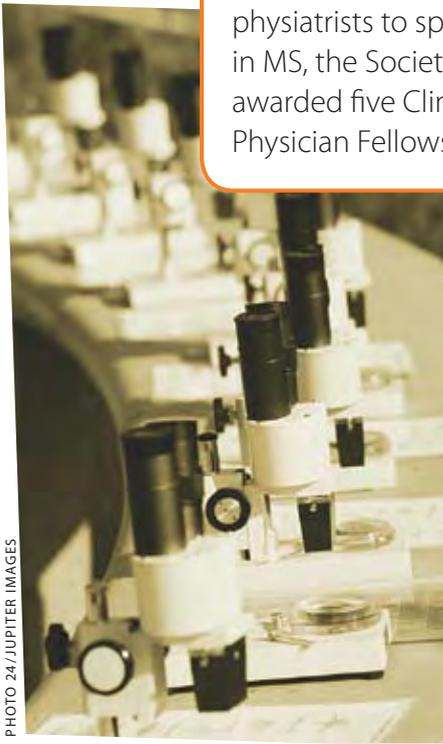
To encourage young neurologists and physiatrists to specialize in MS, the Society has awarded five Clinical Care Physician Fellowships. In the 12-month program, fellows do new patient consultations and follow-up evaluations under the supervision of an experienced MS specialist physician. They participate in a multidisciplinary team and attend lectures and professional meetings as part of their training.

For more information on Clinical Care Physician Fellowships, visit nationalmssociety.org/PRC.

Meet Yolanda Harris

Yolanda Harris, ASN, BSN, MSN, is a first in more ways than one. She is the first John Dystel Nursing Fellow-





To encourage young neurologists and psychiatrists to specialize in MS, the Society has awarded five Clinical Care Physician Fellowships.



Encouraging young researchers

Jai S. Perumal, MD, is using a new technique to measure and compare optic nerve damage in African-Americans and Caucasians with MS. Lahar R. Mehta, MD, is exploring memantine, a medication used for Alzheimer's symptoms, as a potential treatment for spasticity.

As research possibilities in MS continue to expand,



ship recipient to specialize in pediatric MS care. She's also the first African-American recipient of the Fellowship, which pairs a nursing fellow with an experienced MS nurse at an MS clinical facility. (In fact, Harris says she is lucky to have two mentors, Willie Whatley, RN, MSCN, BSN, and Beverly Layton, RN, CCRC, MSCN).

Harris is training at the newly established Pediatric MS Center of Excellence at the University of Alabama and the associated MS Center. Once she has completed her training, she will be one of a select few experienced

pediatric MS nurse practitioners in the United States.

"I've seen how chronic illness impacts not only the child, but the entire family," said Harris, who worked as a pediatric nurse for eight years. She hopes to become "one of the leading people doing research and finding ways we can enhance the care of our patients." Eventually she would like to mentor other nurses interested in pediatric MS. "As technology improves, diagnoses will increase and more nurses will be needed in this area," she observed.

so does the need for young researchers like Drs. Perumal and Mehta, who are this year's recipients of the Sylvia Lawry Physician Fellowship Award.

Since MS is so highly variable, clinical trials of therapies for MS are complex. To conduct them, researchers need expertise and knowledge. This award helps young researchers acquire these skills under the supervision of established MS investigators.

For more information about the Sylvia Lawry Physician Fellowship Award, visit nationalmssociety.org/LawryFellowship.



“Moving Forward Together” in Dallas

More than 1,000 people met in Dallas for the Society’s 2007 National Conference this October determined to move together toward a world free of MS.

The Conference honored MS activists who are leading the way as Society volunteers, Bike Team captains, corporate partners, and research scientists.

Caroline C. Whitacre, PhD, updated attendees on the status of MS research. Society president and CEO Joyce Nelson inspired the crowd as she reported from the front lines of the movement to end MS. Country singer Carrie Smith and the legendary Texas band Reckless Kelly got everyone’s boots tappin’.

World class concert pianist Dawn Bailiff shared her life experiences with a rapt audience. Hailed by Leonard Bernstein for the “sublimity of her artistry,”

Dawn was forced to give up her concert career because of MS. She is now an MS activist, teacher, and composer.

Other speakers included Mikela and Philip Tarlow, who talked about how personal stories can be used to generate income for non-profits, and author Tim Richardson, who inspired the audience at the Celebration Dinner.

A first for this year: five films developed and produced by people whose lives have been affected by MS were presented during the general sessions. Look for a link to view them on the Society’s Web site in late November.

This year’s National Conference also gave attendees many opportunities to attend comprehensive, expert-led workshops that delivered ideas and provided the resources and “how-to” tactics to keep the MS movement going strong.

Thank you, Corporate Partners

Nearly two dozen corporations—from Bank of America to Wieden + Kennedy—were honored as Corporate Stars at the Society’s 2007 National Conference in Dallas. These organizations contribute millions of dollars and thousands of volunteer hours to the movement to end MS. For a full list of Corporate Stars, see nationalmssociety.org/corporatestars.

Special recognition was given to our Corporate Partners: Condé Nast, Crocs, Developers Diversified Realty, Pure Protein, The Vitamin Shoppe, and Westfield. Thousands of national and local businesses are partners in the movement to end MS through events, product donations, point-of-purchase donation programs, or by sponsoring Bike and Walk Teams. For more about the Society’s Corporate Partners, visit nationalmssociety.org/corporatepartners.

A Shining Star

Christopher & Banks received the Shining Star award for raising thousands of dollars this year through Walk Teams and their “MS Collection” jewelry sale. Check out this “sparkling way to give” at nationalmssociety.org/mscollection.



Sally Buegeleisen: fighter

The Society's National Board announced the passing of longtime national volunteer Sally Buegeleisen on August 6, at the age of 82. She raised well over \$1 million for the MS cause with annual letter-writing campaigns and fund-raising events. She served tirelessly, first as a trustee

funding and advocating for families, while helping Alan maintain as much independence as possible. She was an accomplished pilot who completed a transcontinental race in 1967 and she held a master's in speech therapy from Columbia University. She wrote a column



Sally, Alan
and Abbott

for the Mid Florida Chapter and then as a National Board member, where she championed research and family caregiver support. Sally had ample personal knowledge of family challenges.

Sally and Abbott's son Alan was 27 when he was diagnosed with primary-progressive MS. That was 30 years ago. They became Alan's caregivers as the disease relentlessly stole his abilities.

Sally met the emotional and physical demands with characteristic flair, pursuing research

for **Flying** magazine for several years and authored articles for **InsideMS** (the magazine that preceded **Momentum**).

In the mid-1990s, the family established the Alan Buegeleisen Research Fund at the Society's Mid Florida Chapter, with a special focus on stem cell research. "Sally was a fearless champion in the battle against MS," said Tami Caesar, Mid Florida's president. Abbott, Alan, and her daughter Monia survive her—as does the determined spirit she shared so generously.

MS Caucus gains momentum

This summer the Society announced the new Congressional Multiple Sclerosis Caucus in the U.S. House of Representatives.

The MS Caucus provides us with champions in Congress we can count on to support MS issues.

Congressmen Russ Carnahan (D-Missouri) and Michael Burgess (R-Texas) are co-chairing and, as of October 1, more than 45 members of the House have joined. (Go to **msactivist.blogspot.com** to see the most current list.)

To be effective, the Caucus needs as many members as possible. Ask your congressperson to join! Go to **nationalmssociety.org/advocacy**, click on Announcing New Congressional MS Caucus, and enter your ZIP Code in the space provided.

The Caucus gives the movement to end MS a powerful presence on Capitol Hill.

