

INTO AFRICA, WITH MS

ONE WOMAN'S STORY STUDYING WILD ELEPHANTS



**Congratulations to *NARCOMS* Now Photo Contest Spring 2014 Winner
Anne G. — Bedfordshire, United Kingdom**



“22 Miles Down and Still Smiling!”

What does the photo represent in your “MS Life”?

That I have taken on physical challenges I would never have dreamed of doing “pre MS” and although it’s tough, there are moments like this when knowing you are so close to completing the challenge just fill you with joy you can’t hide! This was taken 22 miles into a 26.2-mile walk at approximately 6:30 a.m. We had walked through the night and it had rained—hence the scruffy hair. I’d just had a huge hug from one of the marshals and right then, I was so happy, I didn’t care what a mess I looked.

—Anne G.

A project of the Consortium of Multiple Sclerosis Centers



**THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS**

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A Letter from the Director - Spring 2014

Hello,

Welcome to the Spring 2014 edition of *NARCOMS Now*.

Have you ever dreamed of going on an African safari? Were you daunted at the prospect of coping with the symptoms of multiple sclerosis through long travel hours and in high temperatures? Our “Feature Focus” article outlines the adventures of one woman, Leslie Kane, who put aside any trepidation she felt to spend two weeks in a primitive camp in Namibia, Africa, last summer. With careful planning, Kane experienced a once-in-a-lifetime adventure with some of the world’s wildest animals. She even used her health issues—such as hearing impairment—to her advantage. Read more about Kane’s time in Africa studying wild elephants on page 4.

Most of you will remember Shirley Temple Black, but did you know she had a role in multiple sclerosis advocacy? Read more about it in this issue’s “MS News” on page 15. Also discussed are the FDA’s rejection of approval of the brand-name drug Lemtrada (Alemtuzumab) for use by MS patients; and the latest NARCOMS-related publication on health literacy in NARCOMS participants.

We hope you’re enjoying seeing photos taken by fellow NARCOMS participants here in the magazine (inside front cover) and in our online gallery.

The contest continues throughout 2014, so please visit the site for details on how to submit your own “MS life” story in pictures.

While welcoming the warmer spring weather, don’t forget to complete your Spring Survey, which comes out April 15! “Survey 101” (p. 13) explains some of the newer questions you’ll find on the Spring Survey. In “Snapshot,” (p. 18) see where our latest NARCOMS enrollees hail from, around the U.S.

In May, the NARCOMS Team will travel to Dallas, Texas, to attend the annual joint meeting of the **Consortium of Multiple Sclerosis Centers (CMSC)** and the **Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS)**. Look back here for updates on the most recent MS research in interviews from experts, practitioners, caregivers, and patients from around the globe.

We’re especially excited about an interview with country music star Clay Walker, who will perform live at the CMSC/ACTRIMS meeting this year. Check back in Summer 2014 to read all about his “MS Life.”

Finally, have you talked to your friends with MS about NARCOMS? Have they joined NARCOMS? If they haven’t, why not? We are only successful because MS patients have joined NARCOMS and contribute their experiences about their MS. Our strength is in the people with MS like you who participate, and we need more people like you! Consider talking to someone today about joining NARCOMS. **Thank you!**



Dr. Robert Fox is the Managing Director of NARCOMS, the Medical Director at the Mellen Center for Multiple Sclerosis and a practicing neurologist at the Cleveland Clinic in Ohio.

Sincerely,

A handwritten signature in black ink that reads "Robert J. Fox". The signature is written in a cursive style.

NARCOMS INFORMATION CORNER



HAVE AN IDEA?

We would love to hear from you!
Send us your questions,
comments & suggestions.

Call: **1-800-253-7884** (toll-free US)

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Online: www.narcoms.org/contact

Who you'll hear on the phone:
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NARCOMS PROMISE

Your personal information is
always confidential.

The NARCOMS Global MS Patient Registry facilitates multi-center research on multiple sclerosis, developing collaboration between MS centers of excellence throughout the world to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.



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www.narcoms.org

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Click the Form Summary link.

Choose the survey you would like to view from the drop down menus and click the **View Summary** link.
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Para solicitar la envía de un cuestionario de inscripción por correo, llame al Registro NARCOMS al (800) 253-7884.



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Reminder when Completing Paper Surveys:

Please use pen rather than pencil when filling out NARCOMS paper surveys. Responses are scanned to electronic files for data capture and pen is easier to read. Thanks!

INTO AFRICA, WITH MS

ONE WOMAN'S STORY STUDYING WILD ELEPHANTS



WANTED:

Researchers to study wild elephants in their natural environment, in a remote corner of north central Namibia.

Must be comfortable communicating mainly by whisper for two weeks in the presence of wild elephants. Must not require modern amenities such as running water or electricity. Willingness to sit still and be quiet for hours while observing animals a must. Total isolation is a given, except for your campmates, who you'll know more intimately than you ever dreamed. Fear of wild animals, including zebra, elephants, lions, etc., unacceptable.



This article represents Leslie Kane's account of her time spent in Africa studying wild elephants.

It takes a unique set of qualifications to make an individual wish to apply for a post like the one described above. While this posting does not represent an actual advertisement for the Mushara Elephant Project, the thought of a research job similar to this inspired doctoral student Leslie Kane to apply to study wild elephants in their natural environment, she says. For most of us, a job in a remote area would not prompt emailing a resume and seeing a photo of the camp where this research takes place—for two-week stretches—might further dissuade most of us. Kane, however, learned about the opportunity to study wild elephants in their natural environment and could not believe her luck, she says.

“My MS makes it impossible to be in loud rooms or crowds without putting in ear plugs. When everyone talks at once, or if someone is talking with me and a TV is on, I become extraordinarily anxious,” says Kane.

“On this trip, you rarely talk at a normal volume so that the elephants have the most natural environment possible. When I learned it is preferred that researchers whisper when around the animals I thought, ‘Whispering? You got to be kidding!’ This was ideal for me.”

Kane, 48, is the type of person who sees life as an ongoing, exciting challenge. So when she learned about a research project called the Mushara Elephant Project in the Etosha National Park, she applied immediately. Kane saw the description of the environment in which she'd be living during those weeks in July, and considered that her life with multiple sclerosis might just make her uniquely qualified for the role. Rather than be daunted by the heat, lack of plumbing, and fact that she'd be landlocked on a four-story structure made up largely of scaffolding and tarps, Kane says she was ecstatic.

When she was younger, Kane served a stint in the army before going to college to become a psychotherapist. After working for several years as a therapist, she transitioned into work as a stockbroker, which she did for a time before a diagnosis of MS in 2009 made her reconsider her career, again.

“My cognition at the time was extraordinarily poor,” Kane says. “I considered it ethically inappropriate to manage other peoples’ money, so I decide to go back to school because in school you can only harm yourself,” she quips.

Kane decided to pursue a doctorate degree in psychology with a focus on research. She is currently enrolled in a PhD program in Psychology at Argosy University in Denver, Colorado, and hopes to graduate in 2015.

A DIAGNOSIS

Like many who come to learn their disparate symptoms make up a diagnosis of MS, Kane experienced symptoms of MS for nearly a decade before receiving a diagnosis. A trip to the Smithsonian Museum with a friend after a day of work in Washington, D.C., was a turning point, she says.

“After walking around all afternoon I kept saying, ‘I can’t feel my foot.’ He wasn’t sure what to make of it,” she says. Three weeks later, with the symptoms ongoing, she visited the emergency room of a local hospital.

“They wanted to do an x-ray and I insisted I’d just wait for a doctor’s appointment, but they sent a doctor in,” Kane recalls. “He apologized in advance for hurting me, then squeezed my foot

with medical pliers. Noting my lack of reaction he said he thought I could have MS, then sent me to a neurologist.”



The living quarters at the camp at the Mushara Elephant Project are sparse at best. Much of the equipment is powered by solar panels, seen on the structure’s side. The three tents constitute living quarters. Note the ladders, the sole way up and down, which gave Leslie Kane pause when planning for this trip.

Within two months, Kane says, she was so dizzy she couldn’t get out of bed, her symptoms had progressed that much. “I couldn’t turn my head or feel my body—it was horrifying.”

INTO AFRICA, WITH MS

ALWAYS ELEPHANTS

It was Kane’s work on her dissertation (or lack thereof) that led her to be a part of an unique research experience in Namibia. In lieu of working on it, she was daydreaming about her “dream dissertation topic.” Elephants came to mind, she says. She began looking into elephant researchers.

“I’ve loved elephants since I was very little. My only experience with them, like most of us, was seeing them in zoos,” Kane says. “I was taking a break from writing, looking at books about elephants, and I came across this book, *The Elephant Scientist* by Dr. Caitlin O’Connell. I read it and I fell in love, intellectually, with her work.”

O’Connell is an author and world-renowned elephant researcher who serves on the faculty at Stanford University Medical School. She has written four books about elephants, based on her work in the field studying wild elephants. O’Connell co-founded Utopia Scientific (www.utopiascientific.org), a nonprofit organization dedicated to research and science education. Perhaps her most renowned research project is the Mushara Elephant Project (<http://tinyurl.com/ldj72eg>).



Kane read about Mushara on the back of one of O’Connell’s books. “I sent her an email that day, saying I had done clinical research, love elephants, and had lived in close quarters.”

“I know what it’s like to live in a tent for long periods of time with people you hardly know,” she laughs. “Etosha Park has many similarities to my work in Desert Storm, as temperatures skyrocket during the day and drop well below zero at night. Still, I told myself there is no way I’d be selected for this project.”

Kane says O’Connell responded to her the same day. She went through an interview process, and shortly thereafter, O’Connell told Kane she had been accepted to the program. She says she was so overwhelmed, she didn’t tell anyone the news for an entire day.



Dr. Caitlin O’Connell, left, and Leslie Kane pause in their research to enjoy the view

FEATURE FOCUS

INTO AFRICA, WITH MS

MS IN THE WILD

Now that she knew she was going to Africa, Kane had some planning to do. She had to consider how to deal with her disease symptoms in this unique environment. Some things were a blessing, like the quiet and the need to sit for long periods of time, Kane says.

“I do really well in quiet environments,” she says. “You have cannot talk at a normal auditory level in the presence of the wild elephants. At first it was really, really hard.”

Kane says she spent 90% of her time in Africa sitting. The heat could have been an issue as, like many living with MS, “heat affects me markedly,” Kane says, but she was seated in the shade. The structure she and her campmates inhabited was a four-story metal scaffolding platform, equipped with tents and enough solar panels to power night-vision cameras and laptops. Ladders were the only way up or down, and this was an issue for Kane at first, until she learned to plan her trips so she wouldn’t have to run up and down and “wear myself out,” she says. “You don’t want to fall. I did fall once, but I fell on sand.”

WILDLIFE

“The lions and animals were all around us—we were truly surrounded by them.” The group had a 360-degree watch for lions and rhinos. Kane says bluntly, “my vision sucks, but if you are confined to a 10x10 meter area you can acclimate quickly—and using binoculars helps.”

The experience, while not luxurious in terms of comfort, was once-in-a-lifetime for witnessing some of the world’s most exotic wildlife in their natural habitat. Naturally, she has a few stories to tell from her experience.

“We were out one day and I heard, about 150 meters away, a repetitive banging. I thought, ‘What the heck could that be?’ It was two giraffes, young males, taking their heads low to the ground, and coming up to beat their necks on each other. I looked at Dr. O’Connell and asked, ‘What are they doing?’ She said calmly, ‘Oh, they’re just fighting for dominance.’ They were beating on each other, it was wild.”

Another unforgettable experience at a watering hole involved a baby elephant being left by his herd after a young male elephant charged to show dominance, and accidentally knocked the baby down. The baby’s mother and aunts fled.

“Shockingly to us, the baby stands up,” Kane recounts. “It’s like three weeks old, and still has no command of its trunk. It’s alone.” The researchers looked on in anxious amazement as the baby wandered up to three ambivalent male bull elephants, who hadn’t been spooked by the incident.

“There’s a ridge near the watering hole where at night female lions wait and stick their heads up over it to hunt. I asked Dr. O’Connell what would happen and she said something we never imagined we’d hear: ‘I don’t know, I’ve never seen this before.’ It was horrible to watch. After about an hour this baby turned and gave out the loudest trumpet. Five minutes later, from 300 meters away we see its mom, aunt, and another sibling coming in to get the baby. We all started laughing and crying with relief, saying, ‘This is a Disney moment.’ We had been expecting the worst.”

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Kane credits O’Connell for the opportunity to be part of her research. “This is her work.” O’Connell is credited with having discovered that, in addition to communicating verbally, elephants can detect vibrations in the ground that are generated while vocalizing. They can generate and detect these vibrations from several miles away.

This scientific find has led O’Connell to work on the development of a prosthetic device called the Hearing Hand, designed to help people with hearing impairment by enhancing their vibration sense.

O’Connell commented about working with Kane, saying “what a wonderful and giving person she is even under very difficult field conditions. She was always helpful, cheerful, warm, funny and didn’t let things bog her down. She truly cared about the elephants and wanted to learn as much as she possibly could as she wanted to share it with others.”

TRUNKS UP!

“Yes, the trip wore me out, but I was not going to miss this once-in-a-lifetime opportunity to work with one of the world’s top elephant researchers,” Kane says.

Photo: O’Connell & Rodwell



The Nitty Gritty: How to Live in Africa For Two Weeks with MS

Planning for any trip abroad is a daunting task. Planning for management of MS symptoms in a remote, hot, dry climate is a particular challenge. In her own words, here is how Leslie Kane planned for her trip to Namibia to work with elephant researcher Dr. Caitlin O'Connell:

» I made sure I had medication to sleep on the plane. It is a 36-hour trip. **Sleep is paramount for me.**

» When I arrived in Windhoek, Namibia, I got a hotel for 3 full days to rest before I started working. This was crucial in that once in Windhoek I still had an 8-hour drive to Etosha National Park, and once in the park gate it was still a 45-minute drive to the private research area.

» July is winter in Namibia. The temperatures range from close to freezing at night to nearly 50 to 60 degrees warmer during the day. I made sure I had a -32 degree F sleeping bag because I could not risk lack of sleep because I was too cold. I was a nervous wreck thinking about the heat. **Heat 'floors me' in that my brain becomes disoriented to the point it really scares me.** To combat this **I brought numerous cooling wraps and a cooling vest.** What was odd was that in the month of June and July there is 0% chance of rain. There is no humidity. This lack of humidity really helped me feel comfortable as I rarely broke a sweat.

» We filmed elephant interactions day and night (using night vision filming equipment) so **I was sitting filming or sitting and recording data** of herd sizes and psychosocial interactions. **Sitting was perfect**, of course. I absolutely, no matter what, stopped filming at 9 pm because I must have enough sleep. I did not ever record after this hour.

» We had no running water and only a bush toilet so I constantly washed my hands and used sanitizer. **I had a plethora of medications in case of emergency** and also brought what I normally take. Of course, I brought extra medications in case my flights were delayed. I had antibiotics for GI infection, antibiotics for upper respiratory infection and also for a urinary tract infection. My doctor prescribed these for me to use only if I was experiencing any symptoms. I also had pain meds in case I was injured. Fortunately, I needed none of these.

» **I purchased a helicopter medical dispatch insurance plan** in case I did get injured or hurt and could not wait the eight hours to get to a city with a hospital. [Everyone participating in this program is required to purchase medical evacuation Insurance, O'Connell notes.]

INTO AFRICA, WITH MS

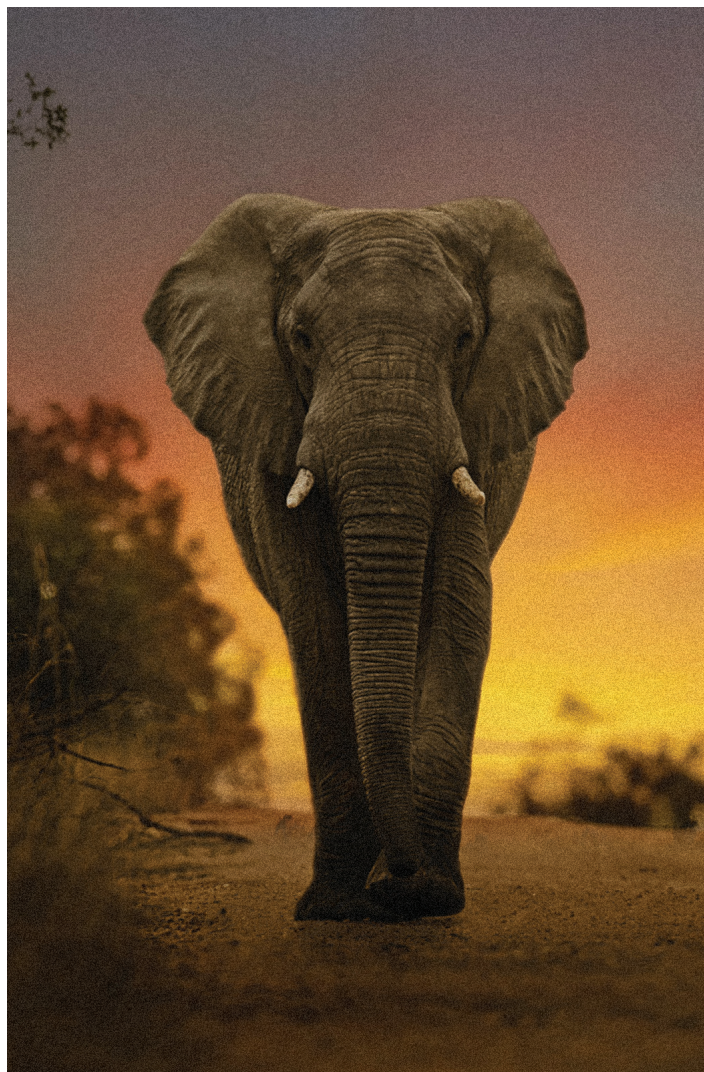


» I did not know anyone I was going to be working with, **but quickly befriended my tent mate** Bridget. She would help me get to the bush toilet at night, as my night vision is horrible.

» Each floor of the structure is **accessible by ladders**. Oh gosh, this was tough. I carried a shoulder bush bag so that I would always have on my body: water, wet wipes, binoculars, red light for night vision, pens, paper, my **hearing aid** and meds. I also made sure I had extra glasses for vision in case the pair I was wearing broke or blew away from the high winds. The shoulder bag kept me from many trips up and down the ladders.

» My bladder does not void often so **I set my smart phone to vibrate every 4 hours to avoid a urinary tract infection**. We could not use any phones for talking, but we could text home if the phone was on mute.

» We had a 10x10 meter camp that we could not leave because of lion and rhino. This is awfully confining but **for a person such as myself with MS this meant I was not going to be walking long distances. Perfect! I did a lot of stretching so I didn't get more spasticity than normal.**





Q: Why don't you ask about each hand in the **Hand Function Performance Scale?**

A: The Performance Scales (PS) are part of what is called a “validated” set of questions. This means that they must be asked in the same way every time, so we can't change the way the main question is asked.

We have added a new question to the Spring 2014 Update that will allow you to tell us which of your hands has the worst function. There are 3 options:

- **Right:** Your right hand has worse function compared to your left hand
- **Left:** Your left had has worse function compared to your right hand
- **Equal:** Your left and right hand have about the same level of function

If you ever have questions about the NARCOMS update or where to indicate any MS medications you are taking, please call us and we will be happy to assist you: 1-800-253-7884 (toll free US).

For more information on the new questions, please see Survey 101 on page 13.

Q: What is the difference between an **immunologic therapy** and **medication** to treat a relapse?

A: Immunologic or disease modifying therapies (DMTs) are used to treat MS in a continuous manner. They are medications you take all the time to help manage your MS and prevent relapses. Common DMTs are the daily or weekly injectable medications like **Avonex**, **Betaseron**, **Rebif** or **Copaxone**.

Medications used to treat relapses are used after the relapse has started, like corticosteroids (steroids, IV steroids, oral prednisone) or ACTH gel.

Since these medications have different uses, we will be asking about corticosteroids and ACTH gel use with the relapse questions in the Spring 2014 Update. You will no longer see Prednisone and ACTH gel listed in the immunologic therapies list.

To submit a question for Q&A please email narcomsnow@narcoms.org

SURVEY 101

SPRING 2014 UPDATE

GASTROINTESTINAL (GI) FUNCTION:

MS can affect the way your muscles work, which can cause problems with walking, hand function, and even bowel function. Since overall GI function, including digestion and bowel function, is partly controlled by muscle movements, MS can be disruptive. Some of the most common GI problems experienced by those with MS are constipation, diarrhea, and irritable bowel syndrome, or IBS. It is important to understand how MS affects these functions and, in turn, how these functions affect your daily life.

The Spring 2014 Update contains new questions asking about the frequency of bowel function, disruptions to bowel function, and possible indications of IBS. In addition, you will be asked if you have ever been diagnosed with some common bowel-related disorders/diseases.

BOWEL AND BLADDER PERFORMANCE SCALES:

Similar to the Hand Function Performance Scale (PS) that asks you to give a single score for both left and right hand function (see Q&A, p 12), the Bowel/Bladder PS asks for a single score for both functions. In order to better understand how bowel and bladder are involved in the overall Bowel/Bladder PS, you will be asked to give a separate score for bladder and separate score for bowel in the special section.

At the beginning of the update you will be asked to answer the Bowel/Bladder PS with a single score when you answer all the PS scale measures (like Mobility and Pain), and then later in the Update to provide one score each for bowel function and bladder function.

We understand that these issues can be very personal and maybe even embarrassing, so we thank you in advance for being as honest as you can. Your responses will help NARCOMS better understand the relationship between MS and GI functions.

Have an idea for Survey 101?

If you have any questions about how these updated survey questions apply to you, don't hesitate to call us at 1-800-253-7884.

Walk MS Events Take Place Around the U.S.



Photo by Prashant Shrestha

It's that time of year again, when the **National MS Society** hosts many of its Walk MS events nationwide to raise awareness of MS and funding for research. NARCOMS' Coordinating Center takes part in our local chapter's office, the AL-MS Chapter, every year, with this year's event taking place in our town on Saturday, April 5.

For more information on how you can take part, contact your local chapter by visiting the national organization's (newly redesigned) website, www.nationalmssociety.org.

NARCOMS Now Photo Contest Continues!

Thank you to everyone who continues to submit fantastic photos for our "Living with MS" contest! You'll see this issue's contest winner featured on the inside front cover of the magazine. The contest continues online, where you can vote for a winner and submit a photo of your own. Visit www.narcoms.org/narcomsnow/photocontest for guidelines, and feel free to email us your entry at: narcomsnow@narcoms.org.

@NARCOMS Tweets!

Did you know NARCOMS is on Twitter? Follow us today @NARCOMS and look for the most current updates on MS news and topics important to the MS community.

NARCOMS at CMSC/ACTRIMS

In the mood for some line dancing? Got some cowboy boots in your closet itching to be dusted off? NARCOMS will be at the **2014 Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC)** and the **Sixth Cooperative Meeting with Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS)**, May 28–31 at the Hilton Anatole Hotel in Dallas, Texas. NARCOMS will host a Texas-themed booth at the event, and work by NARCOMS researchers will be highlighted in posters and presentations throughout the conference. Check back in *NARCOMS Now* for articles with highlights from the convention, the largest gathering of healthcare professionals and researchers involved in MS clinical care or research in the U.S. Upcoming stories include a feature interview with country music star Clay Walker, who will be performing at this year's meeting.



Shirley Temple Black, MS Champion and Hollywood Darling, Dies at 85



You know her movies, or her voice, at least one of her songs, and certainly her name-sake drink: Shirley Temple. This pint-sized child star wooed moviegoers worldwide with charm and charisma beyond her years.

Shirley Temple Black became an actress at age 3, and went on to earn more than any actor her age, at up to \$50,000 per film. She sang and tap-danced her way through films for 18 years before marrying Charles Black at age 22, and retiring from filmmaking. Black's films are credited with lifting the country's spirits during the Great Depression. For four years running, from 1935 to 1938, she was the country's top box-office star.

Among MS communities, Temple Black is perhaps as well known for her role as president of the Multiple Sclerosis Society, in 1960, and later co-founder of the International Federation Multiple Sclerosis Societies.

Temple Black became involved in MS advocacy when her brother George, Jr. was diagnosed with the disease in 1952. She credited her ultimate role as a diplomat to her desire to assist George. Temple Black was active on the local and national boards of the Multiple Sclerosis Society. She co-founded the International Multiple Sclerosis Societies and built its membership to 10 countries. This work intensified her interest in world affairs. Temple Black ran for Congress in 1967 but wasn't elected.

In 1989, President George Bush appointed her U.S. Ambassador to the Czech and Slovak Federal Republic. Twenty years prior, Temple Black had been in Czechoslovakia soliciting the country's membership in the Foundation of Multiple Sclerosis Societies. She served as Ambassador to the Republic from 1989 to 1992.

Temple Black survived breast cancer after undergoing a mastectomy in 1972, and her outspoken attitude going public with her ailment encouraged what would become a regular health regiment of breast self-exams for women. She died of natural causes at age 85 on February 10, 2014, at her home in Woodside, California.

A statement from Temple Black's family members said they "salute her for a life of remarkable achievements as an actor, as a diplomat, and most importantly as our beloved mother, grandmother, great-grandmother, and adored wife of fifty-five years of the late and much missed Charles Alden Black."

How Health Literacy Affects How People Use Health Care

NARCOMS Research in Interactive Journal of Medical Research

Using de-identified data provided by NARCOMS participants in our surveys, a group of researchers published the results of a study on how health literacy—how well one obtains and understands basic health information and services to make appropriate health decisions—affects health care decision-making. The article was published in the Jan–March 2014 issue of the *Interactive Journal of Medical Research*.

i-JMR is a general medical journal with a focus on innovation in health, health care, and medicine through new medical techniques and innovative ideas and/or research.

In this study, lead by Dr. Ruth Ann Marrie, Scientific Director, NARCOMS, researchers hypothesized that lower health literacy would be associated with a higher risk of smoking, obesity, and greater health care utilization. The NARCOMS database contains information from more than 37,000 patient volunteers.

In 2012 NARCOMS participants were asked about health literacy using three measures: the **eHealth Literacy Scale (eHEALS)**; the **Medical Term Recognition Test (METER)**, a brief, self-administered questionnaire; and the **Newest Vital Sign (NVS) Instrument**, a nutrition label from an ice cream container accompanied by six questions aimed to test reading, interpretation, and numeracy skills.

The researchers looked at the prevalence of comorbidities—other health issues in addition to MS, including smoking and obesity. The article states that more than 65% of NARCOMS participants responding to the health literacy

questions had “functional health literacy” on both the METER and the NVS. This was associated with greater comfort and perceived skill at using electronic health information (such as online medical websites). Lower health literacy was associated with an increased risk of smoking, overweight and obesity, visits to the emergency room, and overnight hospitalizations.

The authors concluded that, “health literacy is under-studied in MS,” and recommend that “future work should seek to develop better methods of defining and assessing health literacy in [the] MS population,” ultimately evaluating the impact of interventions aimed at improving health literacy on those with MS.

Blood Sample Might Predict MS Long Before Symptoms Start

(HealthDay News) -- An antibody linked with multiple sclerosis (MS) might be detectable in the blood of people with the disease before symptoms appear, a new study indicates. The findings could lead to earlier diagnosis and treatment of the central nervous system disorder, the researchers said.

“If our results can be replicated in larger populations, our findings may help to detect MS earlier in a subgroup of patients,” said study author Dr. Viola Biberacher, with Technical University in Munich, Germany. “Finding the disease before symptoms appear means we can better prepare to treat and possibly even prevent those symptoms.”

The researchers analyzed blood samples from 16 blood donors who were later diagnosed with MS and samples from 16 people of the same age and sex who did not develop the disease. The samples were collected two to nine months before the patients first experienced symptoms of MS.

The investigators were looking for an antibody to the KIR4.1 protein, which is found in some people with MS. None of the people without the disease had the antibody. But among those who later developed MS, seven people tested positive for the antibody and two showed borderline activity. The study, released Feb. 21, is scheduled for presentation at the American Academy of Neurology's annual meeting in Philadelphia this spring.

“This finding also demonstrates that the antibody development to the KIR4.1 protein, a protein found in some people with MS, precedes the clinical onset of disease suggesting a role of the autoantibody in how the disease develops,” Biberacher said in an academy news release. Research presented at meetings should be considered preliminary until published in a peer-reviewed medical journal.

FDA Panel Provides Mixed Messages on Alemtuzumab

In December 2013, the US Food and Drug Administration (FDA) rejected approval of the brand-name drug Lemtrada (Alemtuzumab) for use by patients with MS. Lemtrada is manufactured by Sanofi.

The rejection by the FDA came after the Peripheral and Central Nervous System Drugs Advisory Committee voted overwhelmingly that alemtuzumab has been shown to be adequately effective for the treatment of relapsing/remitting multiple sclerosis (the most common form of the disease).

The same panel voted separately that Genzyme has not proven substantial evidence of improvement in disability. The FDA stated that Sanofi had not shown that Lemtrada's benefits outweighed its “serious side effects.”

The FDA said Sanofi must conduct additional clinical trials, using different methods and designs than trials used as evidence in the hearing. The company has said it disagrees with the FDA's decision and it plans to appeal. Lemtrada was approved for use in the European Union in September 2013, and previously in Australia and Canada. The FDA had earlier approved the drug to treat leukemia, marketed as Campath.



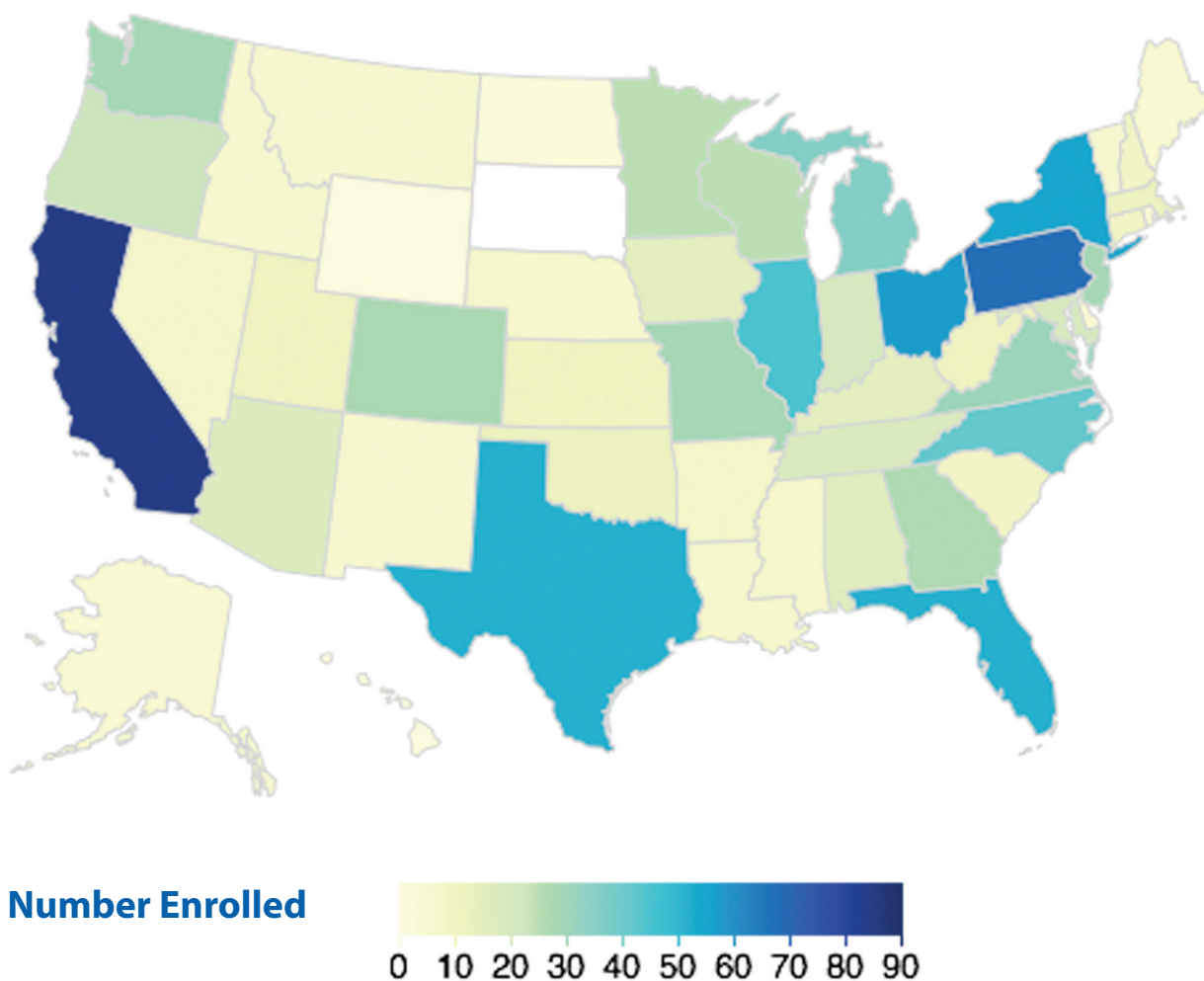
Lemtrada is given as an infusion, and was expected to be used in MS patients who did not respond to other treatments. In two clinical trials it reduced relapse rates over two years by nearly half, compared to patients on Rebif (interferon beta-1a). The drug's most common potential side effects include: shingles, urinary tract infections, headache, rash, nausea, fever, and sinus and upper respiratory infections.

A more serious potential side effect is immune thrombocytopenic purpura, or ITP. ITP causes low platelet counts in the blood, and can lead to dangerous bleeding. In clinical trials for Lemtrada, one patient died of ITP.

The future of Lemtrada in MS treatment remains unclear.

Welcome to NARCOMS!

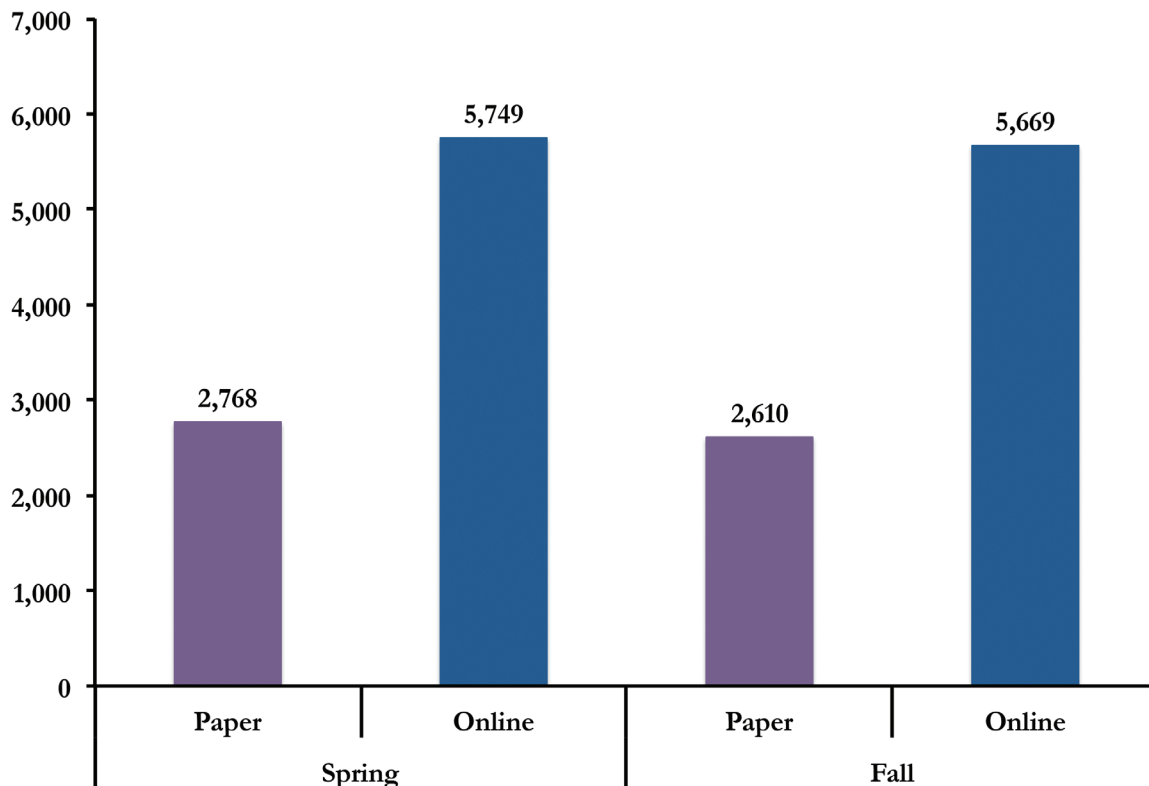
A very big “thank you!” to the 1,129 new participants who joined NARCOMS in 2013! We are so pleased you’ve chosen to contribute to long-term research in MS through regular updates with NARCOMS. Our new participants join NARCOMS from all over the United States, plus 7 in Canada and 1 in Mexico. California had the largest number of new participants (85), with most states having 15 or more new participants.



2013 NARCOMS Enrollments in the United States

Update Surveys in 2013

Along with a successful year for new enrollments, the NARCOMS team is very thankful for your continued participation in the Spring and Fall Update surveys! You completed 8,517 surveys in Spring and 8,279 in Fall. While most participants complete surveys online at www.narcoms.org, more than 30% of our surveys are completed on paper and mailed in to the NARCOMS coordinating center.



What does this mean? These surveys represent a range of people, from those who have been diagnosed recently to those diagnosed more than 30 years ago. With more than 16,000 surveys completed last year, this adds over 8,000 person-years of information about living with MS. (A person year is the product of the number of years times the number of members of a population who have been affected by a certain condition). The more NARCOMS participants who continue to complete update surveys, the more complete picture researchers will have to describe what living with MS looks like, for many types of people. In turn, this will provide more information on how to treat and manage the disease.

play

Find the following hidden words:

growth, sunshine, basket, bunny, movement,
invigoration, eggs, flowers, green, thaw, melt, plant,
nourish, strengthen, expand, cleanse

Q	I	E	G	O	I	E	A	D	I	I	E	T	I	C	O
F	J	T	D	H	S	S	C	Q	S	O	T	T	E	H	S
N	G	J	J	G	L	L	G	E	I	S	M	C	E	N	D
M	R	R	S	C	E	O	S	R	E	W	O	L	F	Q	N
P	F	P	A	E	R	W	E	O	R	P	V	E	R	W	N
D	R	I	R	H	B	A	S	K	E	T	E	A	A	S	L
Z	X	P	G	G	X	X	M	Z	N	H	M	N	J	A	W
B	S	E	H	C	B	S	E	A	C	H	E	S	R	N	K
U	T	I	R	S	U	P	L	V	H	H	N	E	S	O	C
S	M	H	F	Q	N	P	T	T	T	S	T	E	I	S	P
R	R	S	Z	L	N	M	W	G	T	Z	G	H	P	M	U
D	I	I	B	X	Y	O	N	H	B	D	R	G	H	F	C
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G	O	U	S	G	R	W	S	M	A	I	E	H	S	A	E
G	N	O	I	T	A	R	O	G	I	V	N	I	I	F	Y
S	U	N	S	H	I	N	E	X	P	A	N	D	L	T	C

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:

www.narcoms.org/narcomsnow/play/answers

FACES OF NARCOMS

YOUR HEALTH IS EXCELLENT

Doctors: “Your health is excellent, except for the MS.”
How long has this nerve damage been accumulating?
My family said I fell as a child because I was clumsy.
Now I stumble like a drunk, without drinking alcohol.

How long has this nerve damage been accumulating?
Once I could walk in the woods for hours on end.
Now I stumble like a drunk, without drinking alcohol.
Climbing Kearsarge, I didn’t know it was my last time.

Once I could walk in the woods for hours on end.
Spinal cord scarring blocks commands from my brain.
Climbing Kearsarge, I didn’t know it was my last time.
My left leg no longer obeys my instructions to move.

Spinal cord scarring blocks commands from my brain.
“But you seem so healthy,” people say when they hear.
My left leg no longer obeys my instructions to move.
A neurologist: “If you only can’t walk, you’re lucky.”

“But you seem so healthy,” people say when they hear.
Moving quickly from a cane to a walker, I fear immobility.
A neurologist: “If you only can’t walk, you’re lucky.”
This chronic, progressive disease has no known cure.

Moving quickly from a cane to a walker, I fear immobility.
My family said I fell as a child because I was clumsy.
This chronic, progressive disease has no known cure.
Doctors: “Your health is excellent, except for the MS.”

—Kendel C.

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