

# Social media a godsend for those with rare diseases

**BY ERIN MEYER**  
 Chicago Tribune

CHICAGO — Deb McGarry had just delivered the eulogy at her grandmother's funeral when pain shot through her chest. A wave of nausea followed.

"Something is wrong," McGarry whispered to her husband as an arm went numb and the lump in her throat turned to panic.

McGarry, a mother of two from Naperville, Ill., suffered a heart attack a few hours later in an emergency room. She was diagnosed with a rare coronary condition that can affect otherwise healthy young women and is often fatal.

Stricken in January 2011, McGarry left the hospital after five days feeling isolated and confused. Finding information about the ailment — "spontaneous coronary artery dissection," or SCAD — was difficult and doctors were unable to help, she said.

McGarry eventually discovered a thriving online community that provided details about her condition and, more important, encouragement. With a few clicks of a mouse, she was able to plug into a wealth of information and support.

From places as far away as New Zealand, Australia and the United Kingdom, these survivors are part of patient-driven revolution in the world of rare diseases who mobilize through social networks, experts say.

"With rare diseases, you can't walk in to your doctor's office and find the support and information you need," said McGarry, 39. "...It's absolutely amazing to be able to get on your computer and find people who are experiencing the same thing as you."

Experts caution that the Internet is a double-edged sword. Although people find

support, they also can be scammed and seduced into believing information that isn't true — especially on sites that aren't sponsored by hospitals or a medical institution.

Thanks to efforts by McGarry and the on-line network of SCAD survivors, doctors at the Mayo Clinic in Rochester, Minn., have launched the first large-scale research project to learn more about the disease.

The study is breaking new ground by using social media to recruit SCAD patients from around the world, doctors say. The plan is to input each individual's medical history into a database in hopes of identifying patterns.

The Mayo Clinic also will create a bio-bank of blood samples from patients with SCAD, along with samples from their parents and children.

The hope is that it may lead to answers about the role genetics plays in the disease, said Dr. Sharonne Hayes, director of Mayo Clinic Women's Heart Clinic.

The methods used could have applications for many other rare diseases, she said.

"This goes far beyond SCAD," Hayes said.

Spontaneous coronary artery dissection begins with an unexplained tear inside the artery wall. The loose tissue folds over, blocking blood flow and leading to clots, arterial blockage and often a heart attack.

According to Mayo Clinic doctors, little research has been done on the disease, which has no cure or standard treatment. So far, doctors can't say with much certainty what causes the condition, whether it is likely to recur or if it can be passed along genetically.

For many, not knowing such crucial details can be as debilitating as the physical symptoms, patients said.

In McGarry's case, when she arrived at the emergency room almost two years ago, doctors could find nothing wrong with her, she said. But an hour later, surrounded by friends and family, McGarry suffered a heart attack. Doctors implanted two stents to open up the artery, then sent her home several days later with more questions than answers, she said.

"I was freaking out; I immediately got online," said McGarry, recalling the anxiety she felt as she entered the search terms into a web browser for the first time.

According to the National Institutes of Health, a rare disease is one that affects fewer than 200,000.

The institute tracks roughly 7,000 diseases considered rare and coordinates and supports research, according to the NIH website.

A 2011 study by the Pew Internet and American Life Project found that one in five Americans uses the Internet to find people with similar health concerns.

"We have this ancient instinct to find other people who share our same problems so we can solve them together," said the project's associate director, Susannah Fox. With the Internet "it's faster and easier, but it's that same old wish."

For patients and those who care for them, social networks can offer solace from what can be a lonely battle for survival, Fox said.

At the same time, patients who organize themselves in cyberspace can offer new opportunities for researchers.

"The real magic happens when someone with a great idea is able to connect



(COREY R. MINKANIC/CHICAGO TRIBUNE/MCT)

**SCAD survivor Deb McGarry takes part in the SCAD Walk for Research in Naperville, Illinois, on May 5, 2012.**

with one of these patient groups who stand ready and willing to help," Fox said.

In the Information Age, the consumer adage, "buyer beware," still applies.

"It's really patient beware," said Stefanie Putkowski, a nurse with the National Organization of Rare Diseases, or NORD.

Nearly 30 million Americans suffer from rare diseases, according to NORD, a nonprofit group that aims to help patients and their caregivers through education, research and other services.

Putkowski polices the many online organizations and message boards the

organization sponsors under the name "NORD Nurse."

Although she believes the web is a key ingredient in medical innovation and treating a myriad of rare diseases, the Internet can also be a dangerous place where misinformation prevails and scammers prey on the vulnerable, she said.

"If you are desperate and not savvy, you can spend your money and waste it, and you can get hurt," said Putkowski. "But if it's a good organization, it can be a lifesaver. Short of getting a treatment or a cure, at least you are not alone."

## YMC Recognized For Quality Lab Services

Yankton Medical Clinic, P.C. Laboratory has met all criteria for Laboratory Accreditation by COLA, a national healthcare accreditation organization. Accreditation is given only to laboratories that apply rigid standards of quality in day-to-day operations, demonstrate continued accuracy in the performance of proficiency testing, and pass a rigorous on-site laboratory survey. Yankton Medical Clinic, P.C. Laboratory has earned COLA accreditation as a result of a long-term commitment to provide quality service

to its patients.

COLA is nonprofit, physician-directed organization promoting quality and excellence in medicine and patient care through programs of voluntary education, achievement, and accreditation.

COLA is approved by the federal government and sponsored by the American Academy of Family Physicians, the American Medical Association, the American College of Physicians-American Society of Internal Medicine, and the American Osteopathic Association.

## Yankton Medical Clinic's Dr. Young Conducts Free Skin Care Screenings

Yankton Medical Clinic, P.C. Board Certified Dermatologist James W. Young, D.O., FAOCD, conducted free skin cancer screenings on May 1. Approximately 36 people, many of whom had never been examined before by a dermatologist, attended the screening.

Dr. Young volunteered his time to conduct free skin cancer screenings in support of the national program sponsored by the American Academy of Dermatology and Yankton Medical Clinic, P.C.

Of the 36 people screened, many had suspicious lesions which will necessitate follow up, several of those could possibly be

non-melanoma skin cancer, or melanoma skin cancer, the most serious form of skin cancer.

More than one million Americans will probably get skin cancer this year.

However, if detected and treated early, this disease can often be cured. If we learn the early warning signs of skin cancer and conduct self-examinations, we can put a stop to this ever-growing disease.

Dr. Young has been in practice at Yankton Medical Clinic, P.C. since 1998. For appointments at his dermatology outreach clinic in Freeman call 605-925-4219 and in Vermillion call 605-624-8643.

## Mind Games: Mental Exercises Are Key To Better Brain Function

**BY ROBIN ERB**

Detroit Free Press

DETROIT — Go ahead — do it: Grab a pencil. Right now. Write your name backward. And upside down.

Awkward, right?

But if researchers and neurologists are correct, doing exercises like these just might buy you a bit more time with a healthy brain.

Some research suggests that certain types of mental exercises — whether they are memory games on your mobile device or jotting down letters backward — might help our gray matter maintain concentration, memory and visual and spatial skills over the years.

"There is some evidence of a use-it-or-lose-it phenomenon," says Dr. Michael Maddens, chief of medicine at Beaumont Hospital, Royal Oak, Mich.

Makers of computer brain games, in fact, are tapping into a market of consumers who have turned to home treadmills and gym memberships to maintain their bodies, and now worry that aging might take its toll on their mental muscle as well.

But tweaking every day routines can help.

Like brushing your teeth with your non-dominant hand. Or crossing your arms the opposite way you're used to, says Cheryl Deep, who leads "Brain Neurobics" sessions on behalf of the Wayne State Institute of Gerontology.

At a recent session in Novi, Mich., Deep encouraged several dozen senior citizens to flip the pictures in their homes upside-down. It might baffle houseguests, but the exercise crows the brain out of familiar grooves cut deep by years of mindless habit.

"Every time you walk past and look, your brain has to rotate that image," Deep says. "Brain neurobics is about getting us out of those ruts,

those pathways, and shaking things up."

The idea of mental workouts marks a dramatic shift in how we understand the brain these days.

"We want to stretch and flex and push" the brain, says Moriah Thomason, assistant professor in Wayne State University School of Medicine's pediatrics department and in the Merrill Palmer Skillman Institute for Child and Family Development.

Thomason also is a scientific adviser to www.Lumosity.com, one of the fastest-growing brain game websites.

"We used to think that what you're born with is what you have through life. But now we understand that the brain is a lot more plastic and flexible than we ever appreciated," she says.

Still, like the rest of your body, aging takes its toll, she says.

The protective covering of the neural cells — white matter — begins to shrink first. Neural and glial cells, often called the gray matter, begin to shrink as well, but more slowly. Neurotransmitters, or chemical messengers, decrease.

But challenging the brain stimulates neural pathways — those tentacles that look like tree branches in a cluster of brain cells. It boosts the brain's chemistry and connectivity, refueling the entire engine.

"Certain activities will lay more neural pathways that can be more readily re-engaged," Thomason says. "The hope is that there are ways to train and strengthen these pathways."

Maddens explains it this way: Consider the neurons of your brain like electrical wires and the white matter like the insulation. When the insulation breaks down over time, things can misfire.

## Yankton Medical Clinic Receives Award For The Healthcare Examiner

Yankton Medical Clinic, PC received the South Dakota State Medical Association Media Award for its direct-mail publication, The Healthcare Examiner.

The award was presented to Yankton Medical Clinic's Director of Marketing, Joanna L. Mueller, and Dr. James W. Young, at the 2012 South Dakota State Medical Association Banquet on June 1.

The award-winning quarterly publication was developed and created for the Clinic by Julie Anderson Friesen of Anderson Friesen Creative, LLC in Sioux Falls. The Examiner features health-related articles contributed by physicians of the Yankton Medical Clinic, P.C. and Vermillion Medical Clinic and includes a comprehensive

photo directory of all of the primary and specialty care providers at both clinics.

Mueller, expressed "The Examiner has truly been a team effort for nearly 10 years. My role as publisher includes soliciting relevant and timely material from our clinic physicians and medical staff while overseeing content and final approval. Julie Anderson Friesen is our editor and drives the editorial calendar, creative content, language styling, and patient communication standards. Heather Pearson, for Anderson Friesen Creative, pulls all of this together into one creative and consistent template, managing layout, graphic design, and printing."

In addition to ongoing content about relevant health care topics and new medical

equipment and procedures, The Examiner has evolved to include wide-ranging information. It has welcomed patient requests for stories through surveys, introduced new physicians to the community in a friendly Q&A format, included celebratory ads to acknowledge physician achievements and medical scholarship recipients, and also to announce programming for the radio "talk show" version of the Examiner.

Mueller stated, "We are really pleased to be recognized for our efforts in communicating with the patients we serve in so many communities. Health care discoveries in care and treatment are happening all the time and "The Examiner" is the single best way for us to dialogue with our patients outside of the clinic. We are honored to be awarded for something we've been so dedicated to distributing."

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