Lakeside ALS cluster draws attention but is still unexplained

B looms of algae are usually dismissed by most lake-goers in New Hampshire and Vermont as nothing more than slimy, unpleasant nuisances. But this past summer, the blooms gained a more menacing reputation when some nascent Dartmouth research about a possible link between blue-green algae and Lou Gehrig’s disease received prime-time media coverage.

The hullabaloo began in May, when Dr. Tracie Caller, a neurology resident at Dartmouth and one of the researchers studying the relationship, presented some preliminary findings at a workshop for the New Hampshire Volunteer Lake Assessment Program.

Risk: “We weren’t out promoting our own work,” says Caller, just sharing what her research group—led by a DHMC neurologist, Dr. Elijah Stommel—had learned so far. They’d found that the risk of developing Lou Gehrig’s disease, or amyotrophic lateral sclerosis (ALS) as it is officially known, seemed to be 10 to 25 times greater than average in several small towns near Mascoma Lake and one of the researchers study¬ing near the lake were diagnosed with the disease, which is quite rare nationally (there are only about two cases per 100,000 people each year).

Stommel’s group has identified smaller clusters around other New England lakes, too. But among the people and programs coming in for prominent media coverage in recent months was Dr. James Weinstein, who commented on two new studies of a treatment for osteoporosis. “The treatment, vertebroplasty, injects an acrylic cement into bones in the spinal column,” said the New York Times. The studies found that patients who got vertebroplasty were no better off than patients who did not but thought they had. “This is . . . no better than a placebo,” Weinstein told the Times. And to National Public Radio, he noted that the operation “probably shouldn’t be done anymore.”

With health-care reform the topic of the day (and week and month), “the Dartmouth Institute for Health Policy and Clinical Practice has become the gold standard of information about the costs of health care,” said U.S. News & World Report.

“Its studies—which look at variations in the cost, frequency, and outcomes of medical procedures—have taken center stage in a debate that could lead to substantial changes in the health-care sector.” And a top expert at the Institute was quoted in Time. “Patients in higher-spending regions get more tests, more procedures, more referrals to specialists, and more time in the hospital and ICU, but the Dartmouth research has found that if anything their outcomes are slightly worse. . . . ‘We’re flying blind,’” Dr. Elliott Fisher told Time. “‘We’re getting quantity, not quality.’”

The Washington Post sought policy insight from Dartmouth regarding the success of the Cleveland Clinic in providing high-quality care for less money than many other medical centers. “It’s a very well-established group practice that has over time become an integrated delivery system, both horizontally and vertically,” said Dr. Eugene Nelson, a professor at Dartmouth Medical School who is an expert in measuring the quality of health care.

A Wall Street Journal editorial was more skeptical about the Dartmouth research. “The reality is that after three decades of economic research, the reasons that spending varies are still highly uncertain . . . . The abiding mystery is why practice patterns oscillate so widely,” asserted the paper. But the Journal did note that “Jonathan Skinner, an economics professor at Dartmouth College, says the system suffers from too many bad incentives and waste.”

“Cheap, ubiquitous aspirin has long been known for health benefits from basic pain relief to heart attack prevention,” reported the New York Times. But experts “warn that the drug . . . also had its risks . . . . ‘If I were on a desert island, one of the drugs I would choose to have with me, hands down, maybe No. 1, is aspirin,’ said Dr. John Baron, a professor of medicine at Dartmouth Medical School. ‘It’s a fascinating, wonderful drug, a great drug. But it is a real drug, and it has side effects.’”

The Denver Post spoke to Dr. John Modlin, a Dartmouth pediatrician, about the swine flu vaccine. In order to get it to as many people as possible, it may be put into use before studies have been completed to prove its efficacy. “‘We have a population that’s virtually 100 percent susceptible,’” Modlin told the paper. “‘This is an entirely appropriate way of proceeding, one that to me seems both necessary and appropriate and prudent.’”

Time explored a new wrinkle in sleep medicine, online counseling, writing that “Americans filled more than 50 million prescriptions in 2008 for sleeping pills like Ambien and spent more than $600 million on over-the-counter sleep-inducing supplements . . . . Online therapies are typically simpler and less expensive . . . . Notes Dr. Michael Sateia, director of sleep medicine at Dartmouth-Hitchcock, ‘Sleep medicine is still in its childhood, and for decades we have lived in a culture where pharmacological therapies have been the mainstay. But we are beginning to change that mentality.’”

VITAL SIGNS

M E D I A  M E N T I O N S :  D M S  A N D...
Forbes.com reported that “children who get the annual flu vaccine, especially those who have asthma, may be more likely to be hospitalized than children who don’t get the shot, a new study shows.” But, the site went on, “the study has too many unknowns and covers too wide an age range... to indicate any change in recommendations,” said Dr. Hank Bernstein, a member of the committee on infectious diseases of the American Academy of Pediatrics and a professor of pediatrics at Dartmouth. “We know that the efficacy of the vaccine can be limited in younger children,” he said.

CNN.com covered the story of a Washington State teenager who suffered for years from stomach pain before diagnosing herself while examining her intestinal tissue in high-school science. Her problem turned out to be Crohn’s disease, which “is often misdiagnosed or diagnosed very late,” says Dr. Corey Siegel, director of the Inflammatory Bowel Disease Center at Dartmouth-Hitchcock Medical Center. “Granulomas are oftentimes very hard to find and not always present at all,” Siegel said.

The Baltimore Sun asked Dr. Gilbert Fanciullo, director of pain management at Dartmouth-Hitchcock Medical Center, about the importance of clearly labeling drugs. “There are over 200 different products which contain acetaminophen, and when I get to the drugstore and I want to pick up a cold medicine, the writing is too small. . . . I can read what’s on my Corn Flakes box, but not my Excedrin box.”

“There’s no denying that water is good for you, but does everyone really need to drink 64 ounces or more every day?” asked Scientific American. The answer came from Dr. Heinz Valtin, a retired professor of physiology from Dartmouth Medical School who . . . spent 45 years studying the biological system that keeps the water in our bodies in balance. . . . After an extensive search in 2002 for the origins of what is commonly referred to as the ‘8x8’ guideline and a review of associated health claims, he reports finding no scientific evidence supporting the notion that healthy individuals need to consume large quantities of water.”

“Nearly every body part susceptible to cancer now has an advocacy group, politician, or athlete with a public awareness campaign to promote routine screening,” said the New York Times, “even though it is well established that many of these exams offer little benefit for the general public. . . . Cancer awareness campaigns can be a disservice. . . . making people overestimate their risk of dying from cancer, according to Dr. Steven Woloshin, a researcher at Dartmouth. Thyroid cancer, for example, is a rare disease that kills an estimated 1,600 Americans a year. But the campaign called ‘Check Your Neck’ makes it seem as if everyone should worry about the disease, Dr. Woloshin said.”

The New York Times also covered the benefits, fiscal and psychic, of patient-centered primary care. “The model seems to be working, according to a 2008 study by Dr. John Wasson at Dartmouth. His research showed that patients in patient-centered practices were more likely to say they were informed about how to manage chronic diseases and got the care they needed. . . . If the goal is to deliver patient care when and how they want and need it, this is the way to go,” Dr. Wasson said.

Boston Globe columnist Judy Foreman made the case for incorporating hope and kindness into the practice of medicine, even when a cure is not possible. “It’s part of what Dartmouth geriatrician Dr. Dennis McCullough calls ‘slow medicine.’ Especially toward the end of life, said McCullough, author of My Mother, Your Mother, a book about caring for aging relatives, . . . ‘You have to make a covenant with patients to, in all circumstances, be a part of their support and not to abandon them.”

“we don’t know if the blooms are actually causing the disease or just happen to be by chance related,” Callier is careful to point out. “Things cluster by chance in nature anyway.”

**Nuances:** Such nuances were lost when the Union Leader, New Hampshire’s statewide newspaper, reported the findings on June 7 in an article titled “NH lake linked to ALS cases.” More newspapers, as well as television and radio stations, covered the story in the weeks that followed and, to varying degrees, attempted to convey the uncertainty of the findings.

ALS is a progressive disease that destroys nerve cells in the brain and spinal cord. Motor neurons, which control muscle movement, degenerate, causing weakness and paralysis. Only about 10% of people with ALS have a family history of the disease, according to the ALS Association. In the other 90%, the cause is unknown, though many theories exist, says Callier.

One theory is that exposure to a neurotoxin called BMAA, which is produced by some species of blue-green algae, may trigger ALS. The most compelling evidence for this theory comes from studies in Guam, where rates of neurodegenerative diseases are fairly high, natives consume a diet high in BMAA, and BMAA has been found in the brains of people who’ve died from such diseases.

**Neurons:** Furthermore, BMAA can cause motor neurons to die in cell cultures, explains Callier, and it works through the same biological pathways as one of the