

Fall 2010

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Liver transplant means a second chance for Trevor Bougill Page 4 Relief from 'electric shock' facial pain Page 2

Checkup a lifesaver for busy executive Page 6

National survey: Mayo Clinic is tops Page 7

Ouch! Too much Wii can cause injury Page 8

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Surgery lets patient smile easy again

Trigeminal neuralgia causes 'electric shock' facial pain

magine living in constant fear that at anytime you could be stricken with pain so severe you want to die. Worse yet, was not knowing the cause of the pain or when it would strike.

For seven years, that was Flocerfida Webb's life. Crushing pain on the right side of her face made it impossible for her to do simple things like eat, drink or even laugh. But just as life altering was the uncertainty of when the pain might come again.

"It was like an electric shock, and it hurt so bad that I wanted to scream but could not," recalls Webb, 48, of Fernandina Beach, Fla. "I was afraid to do anything because the pain could be triggered at any time. It didn't matter what I was doing." Something as gentle as the wind blowing across her face or kissing her husband goodnight could trigger the pain, which started at her upper lip and shot up to her right temple.

For a woman who loved to dance, ride bikes and swim, life was a constant challenge. Work became increasingly difficult, too, since talking on the phone might prompt the onset of pain.

> After surgery to treat excruciating facial pain, Flocerfida Webb is looking forward to feeling the wind on her face — without pain.



Over the years, Webb visited doctor after doctor. A dentist thought the pain was caused by temporomandibular joint (TMJ) disorder, which causes pain and tenderness where the lower jaw meets the skull. A friend suggested Mayo Clinic and advised her to call. After a consultation with William Cheshire, M.D., a neurologist on the Florida campus, Webb had an answer: trigeminal neuralgia.

Attacks easily triggered

Trigeminal neuralgia is a nervous system disorder that affects the trigeminal nerve, which is responsible for relaying sensory information in the face and controlling the chewing muscles. Trigeminal neuralgia causes intense, stabbing pain to the face. The attacks can be triggered by almost anything that touches the face or involves movement of the mouth, says Dr. Cheshire.

"Even mild stimulation of the face, such as brushing your teeth or putting on makeup, may trigger a jolt of excruciating pain," he explains.

Trigeminal neuralgia affects approximately five in every 100,000 people and is most common in those over age 50. Women have a slightly higher risk than men of developing the ailment. The pain signals a disturbance in the normal function of the trigeminal nerve. While the cause is not always known, in many cases the pain is linked to a blood vessel near the base of the brain that puts pressure on the trigeminal nerve. Less often, a tumor may compress the trigeminal nerve.

For many patients, the pain may elude an accurate diagnosis for years. "It's not unusual for patients to see a dentist before a neurologist because the pain may seem to be coming from a tooth," Dr. Cheshire explains.

And because trigeminal neuralgia tends to resolve for a time then return suddenly, "many patients live in fear that the pain could strike again without warning," says Dr. Cheshire. Trigeminal neuralgia also progresses over time, and patients may initially experience short, mild attacks that can evolve into longer, more frequent bouts of searing pain.

While on a flight to visit family in the Philippines, Webb had an attack that lasted 35 minutes. "It seemed like hours. On a scale of 1 to 10 for pain, this was a 20. I thought my life was over. I didn't want to live," she says.

Medication not solution

Webb was thrilled to finally have a diagnosis and eagerly began a regime of medication to help limit the attacks and



William Cheshire, M.D., neurologist, and Ronald Reimer, M.D., neurosurgeon, worked together find pain relief for Flocerfida Webb.

manage her pain. But the treatment began to affect her liver.

"In rare cases the medication can cause suppression of bone marrow function, low sodium, allergic reactions, or in Fida's case, liver impairment," says Dr. Cheshire.

"I was nervous about what else could be done because I didn't want to live my life in that kind of pain again," says Webb.

Surgery has long been available for trigeminal neuralgia patients, but it is usually an open, complex procedure. Called microvascular decompression (MVD) of the trigeminal nerve, the surgery requires an opening to be made in the back of the skull to allow the surgeon access to the nerve. But there are other choices.

Dr. Cheshire invited Webb to meet his colleague, Ronald Reimer, M.D., a neurosurgeon. Together, they shared information about a minimally invasive procedure known as percutaneous balloon compression. "This is a brief and very targeted procedure. It blocks the pain sensations through the trigeminal nerve and yields excellent results," says Dr. Reimer.

With the patient under general anesthesia, doctors insert a small needle via the cheek to the base of the skull where the trigeminal nerve exits. A thin, flexible catheter is attached to a balloon and then threaded through the needle.

"The balloon is temporarily inflated to a specific pressure, then deflated and removed. This result blocks the pain sensation," says Dr. Reimer. Patients may have some numbness following the procedure. Mayo Clinic Florida has performed more than 200 balloon compression procedures.

Though nervous about surgery, Webb was ready. She underwent the half-hour outpatient procedure on April 28, 2010. Pain relief was immediate, and she was ready to return to her active lifestyle.

"The surgery was a success. I had a little numbness for a short time, but I can laugh and smile and do things I couldn't before," says Webb. She found pleasure in small things, such scrubbing her face the morning after surgery without worries about pain. "I am so thankful to Mayo Clinic to have my life back," she says.

Today, Webb works out at a gym five times a week and runs three miles daily. And this fall, she'll complete driver education classes to obtain her motorcycle license. She is looking forward to the wind blowing against her face — and feeling no pain.

Lab expansion increases options to diagnose neurological disorders

Mayo Clinic unveiled a newly expanded neurophysiology laboratory on its Florida campus in September.

"With the new equipment and expanded availability, our physicians can more effectively perform and interpret both routine tests as well as more complicated, very specialized tests for complex neuromuscular disorders," says Devon Rubin, M.D., neurologist and head of the neurophysiology lab.

The lab is open to Mayo Clinic patients and to patients referred from community practitioners for testing.

Tests performed at the neurophysiology lab include:

Electromyography (EMG) — These studies help physicians understand the origin of muscle weakness and numbness — symptoms of disorders and conditions such as peripheral neuropathy, brachial plexopathy, muscular dystrophy, Lou Gehrig's disease and myasthenia gravis.

Electroencephalography (EEG) — These tests help physicians diagnose seizures as well as memory or other cognitive disorders.

Autonomic testing — Mayo Clinic is one of the only centers in the region that offers this testing, which is used to diagnose autonomic nervous system irregularities that can affect the heart rate and blood pressure.

Movement disorder testing —

Specialized studies can help diagnose tremors or other movement disorders.

Cancer-free after liver transplant

Trevor Bougill benefits from Mayo Clinic expertise in treating rare cancer

When he was 21, Trevor Bougill had big plans. He was going to spend two years in the Peace Corps in South America after graduating from college in New York state. But on his 22nd birthday, he received a "gift" he wasn't expecting: a diagnosis explaining why he'd been sick for months.

Bougill had primary sclerosing cholangitis (PSC) — a chronic inflammatory disease of the large bile ducts. PSC is progressive, leading to liver damage and eventually, liver failure. As birthday gifts go, it wasn't exactly what he'd hoped for, but Bougill was relieved to know what was causing his jaundice and weight loss. He says doctors in New York initially attributed his symptoms to hepatitis of unknown origin and told him he would be fine. Instead, his symptoms worsened.

"I remember looking in the mirror and seeing this emaciated, deteriorating figure, and I was really scared of what was going to happen next," he says. He sought other expertise and learned that a liver transplant was his best option.

"I looked up liver transplant programs on the Web and found that Mayo Clinic in Jacksonville had the fastest organ procurement time in the nation and the best survival rates," Bougill says. "I saw that the average wait for a liver transplant in New York was two to three years, and I knew I didn't have that long."

After being evaluated by physicians at Mayo Clinic's Florida campus in early 2009, he received more bad news. His PSC has progressed to bile duct cancer, or cholangiocarcinoma. Patients with



Denise Harnois, D.O., hepatologist, considers Trevor Bougill cancer-free. After his successful liver transplant, she gave the clearance for travel to the Netherlands and Germany.

PSC are at increased risk for this rare cancer.

In the past, treatment for bile duct cancer was limited, and surgery was an option for only some patients, says Denise Harnois, D.O., a Mayo Clinic hepatologist. Since cholangiocarcinoma is often diagnosed in advanced stages, there was often nothing physicians could offer.

In 1994, physicians at Mayo Clinic in Rochester, Minn., developed a treatment regimen that combined multiple therapies over a period of months leading up to a liver transplant. "The protocol was

A rare cancer

Cholangiocarcinoma, cancer of the bile duct, is extremely rare and typically strikes people ages 50 to 70. About 5,000 cases are diagnosed in the United States each year, but the incidence of bile duct cancer is on the rise. The tumors usually grow slowly and spread gradually. Most cases are diagnosed in advanced stages. developed as a way to extend life for our patients," Dr. Harnois says. "We don't just want to treat the disease but to find a cure and improve the quality of life for our patients.

"Mayo Clinic is one of the few facilities in the country with a clinical trial for treating bile duct cancer with a liver transplant, and it's a national referral center for PSC patients," she says.

Once cholangiocarcinoma is diagnosed, treatment must begin promptly. Mayo Clinic's team approach — with hepatologists, medical and radiation oncologists, endoscopic specialists and transplant surgeons all working together — make that coordinated care possible. "The combination of several therapies and our integrated approach to delivering therapy is designed to ensure the best possible result and give our patients a better quality of life," Dr. Harnois says.

Bougill underwent chemotherapy and radiation treatments to shrink the tumor, and in June 2009, he was put on the waiting list for a liver transplant.

"Sometimes I struggled to stay positive," he says. "I had to confront my own mortality and that was hard. But without a doubt, the hardest part was the waiting. It's hard to live your life when you have to put everything on hold."

Attending support group meetings helped. "I felt better knowing that there are people with transplants feeling good, living life. Sharing experiences helped me to endure the wait for transplant," he says.

Bougill's wait ended on Dec. 2, 2009 — the day he received his transplant. Today, he is cancer-free, and Dr. Harnois considers him cured. "I don't say that a lot and even though it hasn't been long, I believe he's cured," she says.



Trevor Bougill, thankful for his second chance, is active in transplant support groups and works to raise awareness about organ donation.

With his doctors' blessing, Bougill was cleared to travel — something he loves — and he spent two weeks in the Netherlands and Germany.

Bougill says he is glad he came to Mayo Clinic. "I don't know if I would be alive otherwise. Mayo Clinic is the best place to go," he says. "They address every aspect of care — from spiritual to social. And their shared medical experience means they all look out for you and what is best for you."

Although the cancer prevented him from serving in the Peace Corps, Bougill has channeled his humanitarian spirit into transplant support groups and raising awareness about organ donation.

In April, Bougill joined Mayo Clinic's cycling team and participated in the Katie Ride for Life, an event that promotes organ donor awareness. He finished the 18-mile event in 90 minutes.

"I got a second chance, so I want to ensure others can benefit as well," Bougill says.

Life beyond cancer, beyond transplant

By Trevor Bougill

It's been almost a year since my liver transplant. But every morning I still wake up and look at the small, thin line imprinted on my abdomen, which serves as a constant reminder of how fragile life can be.

When I first learned I would need a transplant, I felt like my world was imploding. Sometimes I told myself that I didn't need a liver transplant, I was fine. I developed this false sense of well-being to try and separate myself from my illness.

My self-imposed denial lasted only so long. When I got the call that a liver was available, it became real again.

The differences of a new liver were immediate. The same day I had surgery I was up and walking the hall. I had a renewed spirit.

Post-transplant, my health takes precedence. I exercise more, and I eat better. I have the opportunity to explore, to have new experiences, achieve new goals.

For those dealing with cholangiocarcinoma or waiting for a liver transplant, know without a doubt that there is a very gratifying life to be lived afterward. Life beyond cancer, beyond transplant is even better than you can imagine.

Today, I am thankful for cancer. It is a strange gift. Cancer changed my perspective on life. It taught me to live for the moment and to take advantage of what life offers. Ironically, I never imagined that my journey would take me to Mayo Clinic to work.

In telling my story about my cancer and transplant, I shared my goal of earning a degree in public affairs, and maybe working in the health care industry. Today, I'm one step closer. I recently joined Mayo's public affairs team as an intern. Certainly, working at Mayo Clinic is very different than being treated as a patient, but just as profound. I'm thankful for the opportunity to give back to Mayo for all they did for me.

'You have to go to know' Executive touts importance of comprehensive checkup

George Roberts will tell you he's a busy man — too busy to worry about a physical.

As vice president of a Florida-based road construction and contracting company and chair of two industry groups, he's got a lot to oversee. Taking time for a doctor's visit wasn't on his schedule.

However, Roberts, 46, refused to be absent when his wife, Stephanie, was scheduled for a preventive surgical procedure at Mayo Clinic earlier this summer.

With her urging, he agreed to schedule a checkup at the same time. His wife's insistence and that physical exam probably saved his life.

Roberts was eligible to participate in Mayo Clinic's Executive Health Program, best described as a comprehensive physical taking place over one to three days. The specialized program has served busy executives for more than 30 years and offers an efficient, cost-effective way to proactively manage health.

During a typical visit, patients undergo screening tests for early detection of cancer, heart disease and other serious conditions, as well as a body composition test and complete blood

George Roberts is grateful that his wife, Stephanie, insisted he schedule a checkup at Mayo Clinic. It likely saved his life.

work. Mammography and pelvic exams are standard for women as are urology exams for men. A review and update of medications and immunizations as well as a lifestyle assessment are included. About 13,000 company leaders from around the country are seen every year at one of the clinic's three locations in Florida, Arizona or Minnesota.

Upon arrival at Mayo Clinic, Roberts says, he was stressed about work and nervous about his wife's procedure. He recalls, "I almost canceled, but she insisted."

Although Roberts says his overall health was good, he had frequent heartburn and reflux. But his family's

history of coronary disease made his physician, Manuel Rodriguez, M.D., take notice.

"The initial tests were not conclusive," says Dr. Rodriguez, one of four internal medicine specialists dedicated to the executive health program. "And knowing his concern over family history, I wanted to find a definitive answer. For any patient with conditions that could be life threatening — in this case, heart issues you want to be as certain as possible."

> A more thorough evaluation found that one of Roberts' main coronary arteries was about 90 percent blocked.

"I'm in the road-building business," says Roberts. "If you want a road, I can build you a great one. But I don't know anything about fixing hearts. I told them to do whatever needed to be done. I have a family, a company to run and lots of people who depend on me."

Roberts was rushed in for an emergency angioplasty and stent insertion to open the blockage.

Not until afterward, when Roberts was recovering down the hall from his wife, did he realize the severity of his situation. "They told us later that this particular type of

blockage was known as a 'widow maker' because of its location," he recalls. "Had I had a heart attack and gone to a regular ER, there would be no guarantee."

After three days, Roberts was getting back to work and advocating that others schedule physicals.

"You have to go to know," Roberts said. "I had no symptoms. If it were not for Mayo Clinic — and my wife's diligence in making sure I made my appointment — I would not be here to tell my story."

— I would not be here to tell my story.

To learn more about Mayo Clinic's Executive Health Program and how to schedule an appointment, e-mail ExecHealth@Mayo.edu or call 1-800-851-9022 (toll-free).

Around Mayo Clinic

Chest Pain Center earns honors

Mayo Clinic's commitment to heart health has won the Florida campus designation as an Accredited Chest Pain Center. It is the first in the Mayo system to be awarded the honor by the Society of Chest Pain Centers.

This recognition affirms Mayo Clinic's commitment to providing rapid, quality care for patients who present to the emergency department with chest pain, cardiac distress or other symptoms of a heart attack," says Michelle Markum, chest pain and heart failure coordinator on the Florida campus.

Mayo's protocol-driven approach also resulted in the clinic receiving honors for percutaneous coronary intervention (PCI), the typical procedure patients receive that widens part of a blocked blood vessel, allowing more blood to flow.

One of the most important factors in treating patients with chest pain



is prompt identification of those who need quick intervention in the cardiac catheterization lab, says Markum. The national goal for the time to triage and diagnose a heart blockage and then re-establish blood flow is 90 minutes or less. Mayo's average is significantly less.

Michelle Markum consults with Steven Ung, M.D., chair of cardiovascular diseases, about the protocols used to triage patients with chest pain.

Prevent diabetes, avoid dementia

Here's another reason to manage your health to avoid diabetes and its complications.

Researchers at the Mayo Clinic campus in Florida discovered that causes of dementia in diabetics differ from those in patients without this disease.

"Our research suggests that dementia seen in diabetics appears to be related to small blood vessel disease and strokes. This type of dementia can potentially be averted if diabetes is prevented altogether," says Neill Graff-Radford, M.D., Mayo Clinic neurologist. In patients who do not have diabetes, plaque deposited inside the blood vessels is a likely cause of dementia with Alzheimer's disease.

Mayo Clinic in Florida provides a comprehensive program for evaluating memory disorders and is a state-designated Memory Disorder Clinic. Services include medical evaluations and care for individuals suffering from memory loss, counseling and referrals to community programs and training and educational programs for caregivers.

Tops in patient satisfaction

Mayo Clinic in Jacksonville, Fla., ranks higher than almost all health care institutions nationally, regionally and locally for inpatient and outpatient services, according to two patient satisfaction surveys.

The government survey, Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), found that 85 percent of patients who had overnight stays at Mayo Clinic hospital in Florida ranked their experience as a 9 or 10 on a scale of 0–10. That grade far surpassed the national average of 65 percent, as well as the 59 percent average for hospitals in Florida.

Ninety percent of respondents said they would recommend Mayo Clinic hospital to their family and friends. In addition, Mayo Clinic and Mayo Clinic's Florida campus outperformed other well-known medical institutions on questions about doctor-patient communication, patient pain control, patient medication instruction and patient room cleanliness.

In the second survey, Mayo Clinic came out on top in a survey of more than 200 other hospitals nationwide. Professional Research Consultants (PRC) awarded Mayo Clinic the PRC Top Performer Award for achieving the highest score for excellence in overall quality of care.

All HCAHPS data is available online at www.hospitalcompare.hhs.gov.

of respondents said they would recommend Mayo Clinic hospital to their family and friends. Mayo Clinic works with hundreds of insurance companies and is an in-network provider for millions of people. In most cases, Mayo Clinic doesn't require a physician referral. Some insurers require referrals, or may have additional requirements for certain medical care. All appointments are prioritized on the basis of medical need.

To make an appointment, contact us by phone or online:Arizona 480-301-8484Florida 904-953-2272Minnesota 507-284-2111www.mayoclinic.org



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Wii-what? Beware of overuse injuries from video exercise games

Playing tennis, bowling or golf in the family room? Thanks to the Nintendo Wii (pronounced WEE), people of all ages and fitness levels can actively partake in these activities in their homes.

But too much Wii action can cause injuries.

"Wii-itis is an all-encompassing catchphrase to describe overuse injuries associated with the Wii and other interactive video games," says Jennifer Roth, M.D., a sports medicine specialist at Mayo Clinic's campus in Florida who has treated patients with Wii-related pain.

Overuse injuries can cause inflammation and pain in the shoulder, wrist or elbow. Additional injuries, such as muscle strains and occasional tears, can occur as well, says Dr. Roth. The Wii can be an effective way to exercise when used properly, and it is a great tool to introduce fitness for people who are inactive, she adds. The key is moderation and awareness.

> "It's important to heed the warnings and use the gaming equipment properly. Don't overdo it," advises John Sperling, M.D., an orthopedic surgeon at Mayo Clinic's campus in Rochester.

> > When playing active Wii games, plan a reasonable amount of time, 20 to 30 minutes. If you experience injury, home care includes rest and anti-inflammatory medication. If pain persists, see your doctor.

