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Adam Janusz and his wife, Saori, recently marked the one-year anniversary of his new heart.

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Photo credit: Chris Keels

Crohn's diagnosis helps 'The Big Street' find road to recovery


Brandon Street

At 6 feet 4 inches tall and more than 200 pounds, Brandon Street could easily be described as "big." In high school, his nickname was "The Big Street."

When this active young man who enjoyed playing sports began to have irregular and difficult bowel movements and occasional blood in his stool, he didn't worry too much. He thought his diet was to blame.

"I tried to hide it in high school. I didn't want people to know there was a problem," says Street, a native of Douglas, Ga.

But at 19, during his second semester at South Georgia College, Street started losing weight rapidly. He went from a healthy and vibrant 235 pounds down to 183 in a few weeks. "I knew something was wrong, and I couldn't hide it anymore," says Street, who spent six days in a local hospital. His diagnosis was Crohn's disease.

Crohn's disease is a form of inflammatory bowel disease (IBD), an inflammation of the lining of the digestive tract. This condition can lead to abdominal pain, severe diarrhea, bleeding and weight loss, says John Cangemi, M.D., a gastroenterologist at Mayo Clinic's campus in Florida. "The disease can occur anywhere from the mouth to the anal area, but it mainly affects the small or large intestine," Dr. Cangemi says.

The challenge for many patients with Crohn's — including Street — is that significant flare-ups alternate with periods of no symptoms. Over time, the inflammation caused by Crohn's disease can spread deep into layers of intestinal or bowel tissue and cause painful and debilitating — sometimes even life-threatening — complications.

The drastic weight loss and recurring episodes forced Street to take a year off from college. The bowel problems led to malnourishment and such weakness that sometimes his father had to push him around in a wheelchair. "That was the worst — to go from being 'The Big Street' to not being able to walk," says Street.

At his mother's urging, Street came to Mayo Clinic, which is nationally recognized for treating gastrointestinal diseases and researching new therapies.

"If anyone could help me, they could," says Street, who met with Dr. Cangemi, along with specialists in colorectal surgery, radiology, pathology and nutrition.

"Crohn's patients require a comprehensive approach to care," says Dr. Cangemi, "especially since they can be at risk for other health issues, including inflammation in the joints, eyes or skin; anemia; osteoporosis; and gallbladder or liver disease. Our goal, through the right mix of medicine and occasional surgery, is to create a better quality of life for our patients."

Street began a regimen of medication that, over time, relieved the symptoms and helped him regain his strength. Because doctors don't fully understand the disease, Dr. Cangemi says, it's hard to predict what triggers flare-ups. About half the patients who have lived with the disease for at least 10 years require surgery, Dr. Cangemi says.

But Street isn't worried. "I am doing well — perhaps too well," he says with a laugh, noting that the scale now reads 286 pounds.

Today, Street is back in school, this time working as the freshman hall director at Abraham Baldwin Agricultural College in Tifton, Ga., and he is thankful to Mayo Clinic for giving him the opportunity. "I thought I would be living on disability," Street says. "Now I have a retirement plan.

"I tell everyone, 'Don't go anywhere else. Mayo Clinic has the right team there for you.'"

"Our goal, through the right mix of medicine and occasional surgery, is to create a better quality of life for our patients."
– John Cangemi, M.D.

Caregiver support program reaches out to African-Americans

Floyd Willis, M.D., leads a caregiver training program.

Brenda Frinks knows all too well the challenges associated with Alzheimer's disease. For the past 25 years she has been the caregiver for her aging mother, now 93.

While Alzheimer's attacks the mind and memories of one person, the disease impacts many others, especially family members who serve as caregivers.

"I think the hardest thing about being a caregiver is dealing with the memory loss as it relates to conversation and communication," says Frinks, who lives in Jacksonville, Fla.

"We want to share what's going on now with her, but it's difficult. With my mom, sometimes she understands, sometimes she doesn't," Frinks says. "This past week, she was convinced her pills were not really her pills. She had forgotten the doctor changed her medication."

Alzheimer's is one form of dementia, an often misunderstood illness. Dementia is not a specific disease. Instead, it describes a group of symptoms affecting intellectual and social abilities severely enough to interfere with a person's daily functioning. Alzheimer's disease is the most common type, affecting about 5.1 million people in the United States. About 5 percent of those between the ages of 65 and 74 have Alzheimer's disease. By age 85, that number jumps to nearly half.

According to the Alzheimer's Association, older African-Americans in the United States are probably about two times more likely than whites to have Alzheimer's and other dementias.

"Some African-Americans are at a higher risk for high blood pressure and diabetes, which increases the risk of dementia," says Francine Parfitt, program director for Mayo's Memory Disorder Clinic. "More evidence points to a link between diabetes and Alzheimer's disease."

Research also finds that African-American caregivers are less likely to attend counseling sessions or support groups. And, most challenging, they are often caring for more than one patient. Frinks, for instance, also helps care for a 77-year-old cousin who has Alzheimer's.

"The added responsibilities often mean caregivers are at higher risk for depression," says Parfitt.

Mayo Clinic recognizes that caregivers also need care and, in partnership with Florida State University (FSU), has been striving to find the best way to support them. In 2009, Mayo and FSU launched the African-American Alzheimer's Caregiver Training and Support (ACTS) Program.

Led by Floyd Willis, M.D., of Mayo Clinic's Division of Family Medicine, the ACTS program helps caregivers provide the best support they can for loved ones with Alzheimer's or other dementias.

"The program offers caregivers counseling, whether in person or over the phone, support groups and respite care, allowing caregivers the opportunity to take care of themselves," says Dr. Willis. "We hope it will enable them to be healthy so they can remain actively engaged."

Frinks is one of many to experience the benefits of the program.

"It has been such a gift from God," Frinks says. "From the initial appointment, I was given validation — knowing that there was a medical reason. I was able to learn where my mother was in the process of the disease, what's normal and what's not."

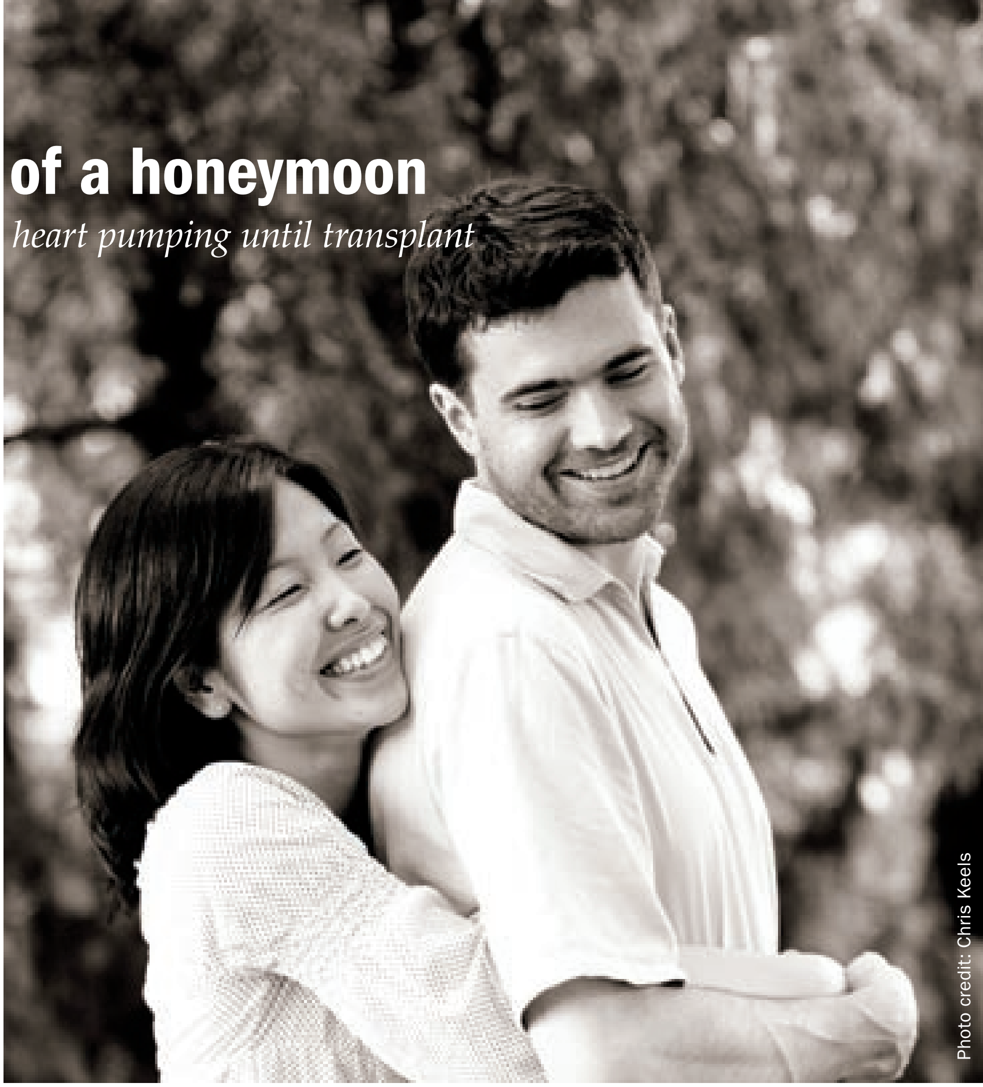
Through the ACTS program, Frinks says she has learned strategies on how to communicate, but also to take time out for herself. She has even used the knowledge to educate others.

"Over the holidays, I brought out my ACTS book and shared with other family members who are going through what I'm going through," she says.

For more information on the Mayo Memory Disorder Clinic, visit www.mayoclinic.org or call 904-953-7103.

New ♥ instead of a honeymoon

Ventricular assist devices keep heart pumping until transplant



A year after his heart transplant, Adam Janusz says he and wife, Saori, eventually will take their delayed honeymoon. "For now," he says, "I feel lucky just to be here."

Photo credit: Chris Keels

Instead of honeymooning in Ireland, Adam Janusz and his wife, Saori, took a journey of the heart.

Janusz, then 32, was diagnosed with a rare heart ailment, requiring ventricular assist devices (VAD) to keep his heart pumping. Eventually, he'd need a heart transplant.

The couple's odyssey started when they'd been married for less than two years and were preparing for a delayed honeymoon. Then Janusz got sick with what he thought was a cold. His lungs felt congested. An X-ray indicated pneumonia. He didn't feel any better a week later, and he began to notice his pulse "wasn't right." He had difficulty eating and sleeping.

In March 2009, Janusz went to an emergency room in Phoenix, where he experienced cardiac arrest. The physicians determined he was in heart failure. They contacted a team from Mayo Clinic in Arizona, led by Francisco Arabia, M.D., a cardiothoracic and transplant surgeon, and transferred Janusz to Mayo Clinic for specialized care.

At Mayo Clinic, Janusz was diagnosed with giant cell myocarditis, a rare, devastating disease that usually affects young, otherwise healthy individuals. Symptoms include chest pain, shortness of breath and fatigue. Heart failure, heart attack or sudden death can occur. The cause of the disease is unknown.

At Mayo Clinic, Janusz received two VADs — one for each side of his heart. In July 2009, he was strong enough to go home. He was outfitted with portable VADs to replace the large units he used in the hospital.

"When you have VADs, you have to have a lot of trust — that the devices will keep you alive, that you understand how the technology works and what you need to do to keep them functioning," he says. "I had confidence in everyone who cared for me at Mayo, so I trusted that everything would go well."

The damage to Janusz's heart was severe, and it became clear that he would need a heart transplant. He received a heart in October 2009.

"Since the transplant, I tire more easily, but I feel pretty great, considering what I've been through," he says.

Janusz and his wife now live in Los Angeles, and they recently returned to Arizona for his one-year post-transplant checkup. They climbed Camelback Mountain (elevation 2,706 ft.) in Phoenix.

"I was slower than I used to be, but I made it to the top of the mountain," says Janusz.

Janusz says he is still astonished by the VADs and heart transplant. "What an unusual and amazing thing to imagine and be part of," he says. "I am honored to have benefited from the extraordinary expertise of the Mayo doctors."

Janusz and his wife still haven't had their honeymoon. "We had a crash course in marriage," says Janusz. "This experience has made me enjoy observing life and its intricacies and not let it sweep by quickly.

"We'll get our honeymoon. For now, I feel lucky just to be here."

How Jack Stiehl got a second birthday — thanks to a VAD

Jack Stiehl, 71, Sun City West, Ariz., was diagnosed with congestive heart failure in 2004. He had difficulty breathing and was easily winded. In 2007, with ever-worsening symptoms, Stiehl recalls his local physician saying he was out of options; he wasn't a candidate for a heart transplant.

Then, a friend suggested Mayo Clinic. "I was severely debilitated when I went to Mayo, but I was hopeful they could help me," says Stiehl. "I didn't want to die."

A week after his first appointment, Stiehl had open heart surgery to implant a ventricular assist device (VAD) to support his ailing heart. Now, Stiehl celebrates two birthdays — his actual birthday on Nov. 21 and the day he received his VAD, Jan. 10, 2008.

"The VAD gave me a new lease on life," he says, noting that at two weeks post-surgery, most pain was gone. Still, Stiehl spent six weeks recovering in the hospital.

Linda Staley, VAD coordinator at Mayo Clinic in Arizona, says 21- to 30-day hospital stays are typical for VAD recipients. "They often are in less than ideal condition before surgery," she says. "While they're in the hospital, we need to help them get strong enough to go home and teach them how to live with a VAD."

Stiehl says maintaining the VAD becomes part of the daily routine. "I change the battery once a day. My wife, Charlotte, changes the sterile dressing," he says.

Stiehl is back to golfing two to three times a week, and he sings in a chorus and a church choir. "There's very little I can't do," he says.

Stiehl participates in a monthly support group for VAD patients at Mayo Clinic in Arizona. Patients and family members share tips and encourage each other, says Tisha Pathuis, heart transplant social worker and support group coordinator.

"Once you're a VAD patient at Mayo, you're a patient forever, and they never stop caring about you and for you," says Stiehl. "Every night, I say thank you to God and to Mayo Clinic."

Jack Stiehl attends a monthly VAD support group meeting at Mayo Clinic.

All about the VAD

A ventricular assist device (VAD) is an implantable mechanical pump that can be used to aid a failing left ventricle, right ventricle or both. It's used as a:

- Bridge to transplant. It's removed when a new heart is implanted.
- Bridge to recovery for patients with temporary heart failure or who are recovering from heart surgery.
- Permanent treatment for heart failure when patients are not eligible for transplant.

A VAD is implanted via open heart surgery. In addition, the patient wears a control unit and battery pack outside the body. It's connected to the VAD through a port in the skin. This procedure is done at campuses in Rochester, Arizona and Florida.

"There is a window of opportunity during which we can implant a VAD in an end-stage heart failure patient," says Francisco Arabia, M.D., a cardiothoracic and transplant surgeon at Mayo Clinic in Arizona. "Ideally, the patient sees us before other organs are affected and the patient is relatively healthy. A VAD can increase the patient's survival and improve quality of life."

Linda Staley, VAD coordinator at Mayo Clinic in Arizona, teaches patients and their caregivers about all aspects of VADs while the patient is hospitalized. She also visits patients at home to make sure the equipment is set up properly. Staley even alerts the local electric utility and police and fire departments.

"It's important to know what to do if the power goes out or if an ambulance must be dispatched to the patient's home," says Staley. "We anticipate these scenarios and proactively prepare the patient's community and support system. It takes a village to take care of VAD patients, and we're happy to be part of that village."

Racing to find a cure for breast cancer

Edith Perez, M.D., a Mayo Clinic oncologist, leads research funded by the 26.2 with Donna marathon.

Every February, runners from around the country descend on Mayo Clinic's Florida campus to participate in the 26.2 with Donna — The National Marathon to Finish Breast Cancer.

Named in honor of three-time breast cancer survivor Donna Deegan, a Jacksonville, Fla., television news anchor and Mayo patient, the marathon starts and finishes on Mayo Clinic's campus and attracts more than 8,000 participants. Organizers say it's the only marathon that donates most of its proceeds to breast cancer research to find a cure for the disease. This year marks the event's fourth anniversary.

More than $1 million has been contributed to Mayo over the past three years. Researchers at Mayo Clinic Cancer Center have used the funds to staff and operate a new Breast Center Translational Genomics Program, which aims to identify specific genes responsible for breast cancer so new therapies can be developed.

One of the key initiatives of the center is to identify every gene and protein related to breast cancer. That information has the potential to change all aspects of breast cancer care — from diagnosis to treatment to prognosis, says Edith Perez, M.D., the Mayo Clinic oncologist leading the marathon-funded research.

"We need to make cancer care more effective, and science is the way to reach that goal," says Dr. Perez. "Identifying the genes and proteins causing breast cancer in each patient will help us to individualize treatment and develop new therapies."

New Discoveries

To help achieve their goal, Mayo Clinic researchers are using a "next generation sequencer," a machine that can scan a person's entire genome in less than a week. That's no small feat, since there are more than 2 billion base pairs of DNA, the building blocks for every cell in the body. As recently as two years ago, compiling such a mountain of genetic data would have taken months.

It will take many years to achieve the goals that Dr. Perez and her colleagues have for the future of breast cancer care. But they already are discovering exciting leads about the genetic factors that influence breast cancer. For example, the team has identified several fusion gene products — when two previously separate genes become one and sometimes cause cancer — that have never been seen before in breast cancer tumors.

"The progress that has been made to date is just the beginning," says E. Aubrey Thompson, Ph.D., a scientist and member of Dr. Perez's team. But thanks to the discoveries, Mayo researchers focused on other cancers are also benefiting, Dr. Thompson says.

"Collaboration is just part of the DNA here at Mayo," he adds, noting that the gene-sequencing equipment and information gleaned from the breast team is also being used to launch projects in cancers of the lung, pancreas, colon and thyroid. "We're in a race to find a cure for cancer. Without the support of the 26.2 with Donna Foundation and the proceeds from the marathon, we wouldn't be anywhere near where we are. We have a long way to go but we're making great strides."

Info: breastcancermarathon.com. More information about breast cancer treatment at mayoclinic.org.

Around Mayo Clinic

A happy ending that keeps on giving

“It isn’t a big article,” Kristie Naines says when asked about her appearance in the October issue of *Good Housekeeping*. “It’s just a few paragraphs.” She’s being modest. It’s kind of a big deal.

Those “few” paragraphs describe how, at age 32, Naines was diagnosed with Stage IIIC breast cancer and told that she had a 30 percent chance of surviving for five years. With an 18-month-old daughter to care for, the young mom had no intention of waiting to see what happened. “My goal was to see my daughter go to kindergarten, to watch her walk through that door,” Naines says.

Kristie Naines

Surgery, chemotherapy and radiation followed. And doctors told Naines that her best hope would be Mayo Clinic in Florida where she could enroll in a clinical trial. The trial, led by Mayo researcher Edith Perez, M.D., was testing the effectiveness of the drug Herceptin. Naines says, ”I was fortunate enough to benefit from Dr. Perez’s groundbreaking trial, and I have no doubt it saved my life.”

In fact, the trial was so successful that the Food and Drug Administration ended the study a week early to get the drug out to more women. Now, seven years later, Naines is cancer-free and just watched her daughter walk through the door to the third grade.

The story doesn’t end there. Well, in the magazine it does, but for Naines, things took another happy turn. After being a patient, she joined Mayo Clinic as an employee in 2006, becoming a major gifts officer in the Department of Development.

Naines is happy to share her story, she says, whether it’s with a magazine that’s promoting Breast Cancer Awareness month, with an interested benefactor, or with someone at the 26.2 with Donna marathon. (She has run in all three of those marathons. See story on Page 6.) “The gratitude you feel toward the organization that saved your life and the people there who worked on your behalf — that’s immeasurable,” she says.

Robot arm aids partial knee replacement

Orthopedic surgeons at Mayo Clinic’s campus in Florida have a new robotic arm system that helps them replace a small area of the knee with an implant in people who have limited joint degeneration.

“This device allows us to be precise in removing as little bone as feasible, replacing it with a small implant that mimics the healthy knee surface,” says orthopedic surgeon Mary I. O’Connor, M.D.

Patients who benefit from partial knee replacement surgery tend to be younger, which is why preserving the natural knee structure is so important, adds orthopedic surgeon Cedric Ortiguera, M.D., “Osteoarthritis, which occurs when cartilage wears down, can lead to more widespread degenerative knee disease,” he says. “So when you take away as little bone as possible in this robot-arm-assisted procedure, you can replace the entire knee at some point years into the future, if needed. This is one option for younger patients experiencing knee pain — perhaps from athletic overuse or from arthritis — who are not candidates for a total knee replacement.”

Recurring abdominal discomfort?

The Clinical Studies Unit is looking for individuals with:

- Chronic abdominal discomfort
- Bloating
- Early or excessive fullness following meals

The study will look at the effects of two medicines on symptoms after eating and the movement of food through the stomach. The nine-month study (three months on medication, six months of follow-up) involves questionnaires, laboratory tests, a nutrient drink test and a gastric emptying study. Visits will range from two to six hours. Study participants receive compensation for their time.

For more information, call 904-953-0703 or send an e-mail to mcjdyspepsia@mayo.edu.

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 480-301-8484	**Florida 904-953-2272**
Minnesota 507-284-2111	**www.mayoclinic.org**

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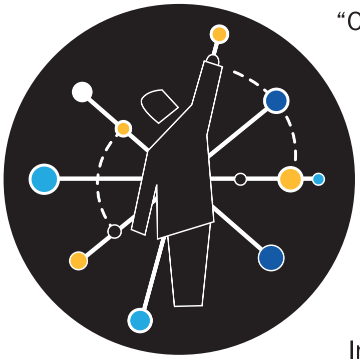
Mayo Clinic now "in-network" for UnitedHealthcare

Mayo Clinic works with hundreds of insurance companies and is an in-network provider for millions of people. In November, many more people gained in-network access.

Mayo Clinic announced a new network relationship with UnitedHealthcare commercial plan customers, providing in-network access to Mayo Clinic physicians and hospitals.

UnitedHealthcare offers a full spectrum of health benefit plans and services to individuals, public sector employers and businesses of all sizes, including more than half of the Fortune 100 companies.

The new network relationship covers all Mayo group practices and hospitals in Jacksonville, Fla., Scottsdale/Phoenix, Ariz., and Rochester, Minn.



"This national agreement with UnitedHealthcare will allow even more people to experience Mayo Clinic," says John Noseworthy, M.D., Mayo Clinic president and CEO.

"Our patients tell us they come to Mayo for our team approach to health care, our ability to find answers and the peace of mind they have knowing that they receive care from many leading experts in their fields," says Dr. Noseworthy. "We welcome the opportunity to serve UnitedHealthcare's commercial plan participants."

In most cases, Mayo Clinic doesn't require a physician referral. In fact, more than 8 out of every 10 patients come to Mayo Clinic on their own, without a referral from another physician.

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