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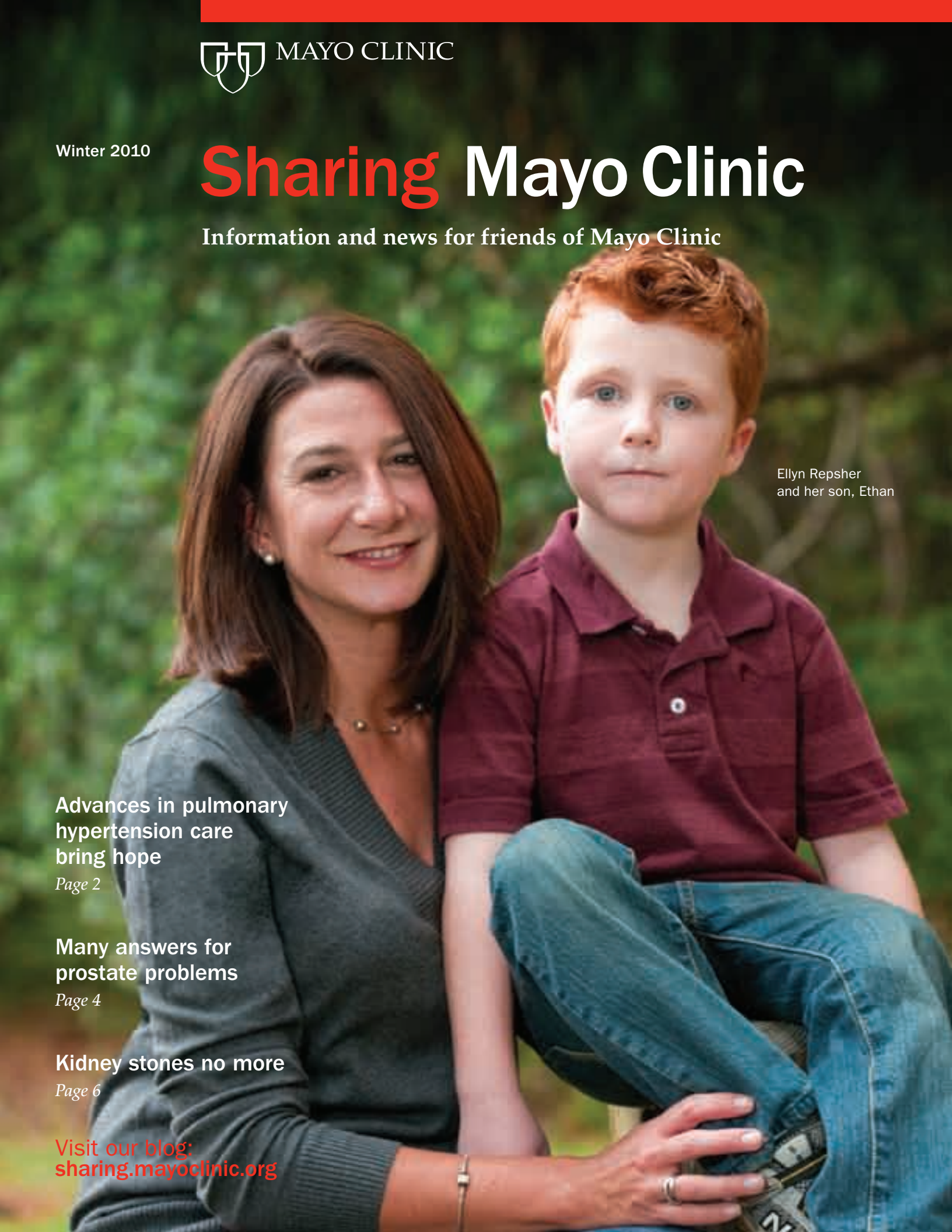

Ellyn Repsher and her son, Ethan

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Better Breathing

Advances in pulmonary hypertension care bring hope to patients with rare, devastating disease

Many people recognize the drug Cialis as a therapy for impotence, so when Ellyn Repsher tells friends about her prescription, she gets some funny looks.

"People usually laugh when I tell them what medication I take," says Repsher, who as a woman is clearly not part of the drug's target market — men who have erectile dysfunction.

But tadalafil, the generic name for Cialis, received Food and Drug Administration (FDA) approval last summer for use in treating pulmonary hypertension, a type of high blood pressure that affects the lungs and the right side of the heart. It joins sildenafil citrate, the generic name for Viagra, which has been approved to treat the condition since 2005.

Pulmonary hypertension is relatively rare, affecting about 30 people in one million. About 20,000 people in the United States are being treated for the disorder, which can develop on its own or can stem from other medical conditions. Some contributing causes are use of certain diet pills or the presence of scleroderma, a chronic autoimmune disease.

The disorder occurs when arteries that carry blood to the lungs gradually narrow. Charles Burger, M.D., medical director of the Pulmonary Hypertension Clinic at Mayo Clinic's Florida campus, relates the condition to "a kink that develops in a water hose." And like a kinked hose, pressure builds up, forcing the right side of the heart to work harder to increase blood flow to the lungs. Eventually, the heart enlarges and fails, Dr. Burger says.

"Historically, this has been a very difficult disease to manage," says Dr. Burger, who works with six other physicians at Mayo's Pulmonary Hypertension Clinic, one of the largest centers for treatment of pulmonary hypertension in the Southeast based on patient volumes.

The median survival for patients with pulmonary hypertension used to be less than three years after diagnosis, Dr. Burger says. It was commonly misdiagnosed and often progressed to late stage by the time it was accurately identified. And since it typically affects young women in their childbearing years and requires a lifetime of medicine, the disease can impact one's life considerably.

Repsher was 24 when she was diagnosed in 1999. "I knew something was wrong because I had shortness of breath doing things that you wouldn't be short of breath doing — like carrying a laundry basket or walking up a single flight of stairs. Even going to the bathroom and walking back to bed, I had trouble," she says. Typical symptoms also may include excessive fatigue, dizziness or fainting, chest pressure, ankle swelling and bluish-colored lips.

"We're hopeful with the new therapies, survival can be doubled and more." – Charles Burger, M.D.

When doctors confirmed pulmonary hypertension, Repsher says she was surprised. "I didn't know anything about it," she says. "You hear the word hypertension and think high blood pressure. But mine was normal."

Perhaps most shocking to her, she says, was the warning doctors gave her. "They said don't get pregnant; a

Climbing stairs used to leave Ellyn Repsher breathless, but advances in pulmonary hypertension therapy now help her keep up with an active son.

pregnancy can kill you. Here I was 24, newly married and suddenly I'm told that. That's a big life change," Repsher says.

Because pulmonary hypertension impacts the arteries, a pregnancy can severely compromise a woman's system, Dr. Burger says. "The actual amount of blood flow increases 30 to 50 percent during pregnancy as you approach gestation. If the lung arteries are too narrow, there can be significant strain on heart function. If the heart enlarges and fails, it threatens not just the life of the mom but that of the baby."

Repsher was put on a regimen of several drugs, including one given via a 24-hour infusion pump. "I had to carry it around, and it was extremely cumbersome," she says. "The drug had to be kept cold so I had to carry around ice packs; it was only stable for so many hours so I had to physically mix it up myself. And I was on high blood pressure medicine and blood thinners, too. I had a lot of medicine I had to take several times a day."

The medication and condition also limited her activities. "I couldn't enjoy going on vacation to New York, for instance, where the only way to get to the top of the Statue of Liberty is to climb stairs. I couldn't do that," she says. Going to the beach near her home in St. Augustine, Fla., was difficult because the pump was awkward to carry and had to be kept dry while the medicine had to stay cold.

But advances in research — including a national clinical trial network designed to test new therapies — have led to more options for patients with pulmonary hypertension.

Among them are drugs like tadalafil and sildenafil citrate, which open up blood vessels to the lungs and increase blood flow, the same mechanism that treats impotence caused by narrowed arteries.

"Many treatments for pulmonary hypertension are quite expensive and can have side effects. So, it is really important for patients to have a health care team work with them in finding the right agent at the correct dose," Dr. Burger says.

"These new agents, along with other inhaled therapies recently approved by the FDA, offer greater options and longer life to many patients," Dr. Burger says. "We're hopeful with the new therapies, survival can be doubled and more."

To help quantify the impact of new therapies, Mayo Clinic campuses in Minnesota and Florida are participating in a national registry that will enroll 3,500 patients with pulmonary hypertension to help determine, among other things, if the new treatments are more effective for patients, Dr. Burger says.

Thanks to the changing therapeutic landscape, Repsher's regimen has been modified and her condition is stable. She's still on several medications daily and continues to carry a pump. "But it's lighter and more manageable. I can even remove it for several hours at a time," she says.

In 2003, she finally became a mother when she and her husband adopted a son. Today, she spends her days volunteering at his school and enjoying the outdoors. "There was a time, when I was at my worst, that I was worried I wouldn't be able to play with him. But I'm better than I was before, and most people don't even know I have this disease," she says.

"I think it's fabulous that science has given us this much information," Repsher says. "I'm grateful that at Mayo Clinic the doctors work with you to tailor treatments to your lifestyle."

Prostate health: Many concerns, many answers

Four different men with four different prostate issues. Mayo Clinic had answers for each of them. *U.S. News & World Report* consistently ranks Mayo Clinic's Urology Department as one of the best in the country.

Pit stops under control after laser surgery

Stock car racer Paul Hamernik noticed over time that his "pit stops" to empty his bladder were impacting his ability to compete. A medical test showed his PSA level was rising.

"PSA, or prostate-specific antigen, is a normal substance produced by the prostate, usually found in an increased amount in the blood of men who have prostate cancer, infection, or inflammation of the prostate, and benign prostatic hyperplasia," says Lance Mynderse, M.D., Mayo Clinic urologist.

Thankfully, Hamernik didn't have prostate cancer. At Mayo Clinic, Hamernik, of Winona, Minn., learned about a pharmaceutical trial studying a drug to prevent prostate cancer. He decided to participate.

As part of the trial, a urine flow analysis showed Hamernik's bladder held three times the normal amount of urine. He could not completely empty his distended bladder.

"Paul's bladder problem was caused by an enlarged prostate, which often leads to bladder outlet obstruction and restriction of urine flow," says Dr. Mynderse. "Paul's condition was caused by benign prostatic hyperplasia (BPH) — a natural aging process that happens in virtually all men."

Hamernik underwent photoselective laser vaporization of the prostate (PVP) to treat BPH. Twelve hours after the outpatient procedure, the catheter is removed. "The patient is able to urinate immediately," says Dr. Mynderse.

"I left the hospital the same day and with no pain," says Hamernik. "I enjoy life the way I used to."

Mayo Clinic urologists pioneered this use of laser energy to treat benign prostatic hyperplasia in the 1990s. Mayo Clinic is one of a handful of medical centers in the U.S. that *Medical Economics* magazine has designated a "Clinical Center for Excellence" in using PVP and other laser therapies for BPH treatment.

Routine physical exam with surprising result

All the signs were pretty ordinary: healthy male, 59 years old, routine physical exam. But it didn't turn out to be an ordinary day for Tom and Dottie Krull of Wisconsin.

A nodule was discovered on Krull's prostate. He went to a university medical center where he was diagnosed with an aggressive, regionally advanced prostate cancer. Physicians said surgery was not an option, and treatment could only be palliative.

The Krulls learned Mayo Clinic did offer options to patients with advanced prostate cancer. In fall 2008, Jeff Karnes, M.D., Mayo Clinic urologic surgeon, performed a radical prostatectomy, the surgical removal of Krull's prostate gland, along with removal of multiple lymph nodes. "The night of surgery Dr. Karnes told us that he had restarted the clock for Tom," says Dottie Krull.

At 19 months post-diagnosis, Krull's cancer test results remain clear.

"What was wonderful about Mayo doctors was that they would not just give up on Tom," says Dottie Krull. "They worked as a team to use multiple innovative combinations of treatment in the hopes of giving us more years ahead."

Far left, stock car racer Paul Hamernik underwent photoselective vaporization of the prostate to resolve bladder obstruction.

Left, Tom Krull, shown with his wife, Dottie, came to Mayo Clinic for prostate cancer treatment after a university medical center recommended only palliative care.

Far left, for Randall Minion, M.D., a family physician in Fort Dodge, Iowa, robot-assisted surgery was the best treatment for prostate cancer.

Left, after a procedure called *holmium laser enucleation* (HoLEP), Richard Dooley can enjoy riding without frequent restroom breaks.

Robot-assisted surgery removes prostate cancer, preserves functionality

The results of a yearly prostate-specific antigen (PSA) test surprised Randall Minion, age 49, a family physician in Fort Dodge, Iowa. Further testing showed prostate cancer.

"Dr. Minion was younger than most patients we treat with prostate cancer," says Igor Frank, M.D., Mayo Clinic urologist. Especially in younger patients, doctors strive to remove the cancer from the prostate while sparing the surrounding structures responsible for sexual function and urinary control.

They recommended surgery using a robot-assisted device called the da Vinci Surgical System. "This would give Dr. Minion the treatment he needed without compromising his quality of life," explains Dr. Frank.

Using the da Vinci, Mayo Clinic surgeons direct robotic "hands" to perform the delicate, complex surgery. The benefits of this approach include decreased blood loss, fewer blood transfusions, smaller incisions and shorter recovery times.

Dr. Minion left the hospital the day after his surgery. "I don't have any side effects or limitations from my treatment," says Dr. Minion.

Always on the go — until HoLEP procedure reduces prostate size

As a printing press operator in the Minneapolis/St. Paul area, Richard Dooley made five to six trips a day to the restroom.

"Even though I didn't produce a lot, I needed to go — often," says Dooley, who now lives in Ogilvie, Minn. The frequent restroom stops interrupted the active man with four children, a full-time job, and a passion for deer hunting and reading.

Dooley's problem wasn't new. Nearly 20 years ago, his doctor diagnosed an enlarged prostate gland. Dooley had a surgical procedure — known as TURP (transurethral resection of the prostate) — to trim extra prostate tissue. The procedure brought Dooley some relief.

As the years passed, severe symptoms returned. "I was getting up three to four times each night to use the bathroom," says Dooley.

Dooley and his wife, Karol, met Mayo Clinic urologist Amy Krambeck, M.D. A second TURP remained an option, but Dr. Krambeck also described a new laser technique. Holmium laser enucleation of the prostate (HoLEP) removes excess tissue with less risk of bleeding, pain or urinary incontinence than surgery. They decided HoLEP would be the best treatment option.

Dooley needed one night's stay in the hospital after the procedure. After a few days' recovery at home, Dooley was good to go — for hours at a time — before needing a restroom break.

"The last time I saw Dr. Krambeck, she asked how things were going," Dooley says with a chuckle. "I said, 'Like a fire hose!' and gave her the two thumbs up sign."

Advances in detection, treatment

Michael Wehle, M.D., a urologist at Mayo Clinic in Florida, says "radical" changes have taken place in prostate diagnostics, early detection of cancer, research and therapies.

"Thanks to advances in accuracy in PSA testing, we now find 80 percent of prostate cancer early — when the condition is still localized and highly treatable," says Dr. Wehle. Just 20 to 25 years ago, 80 percent of prostate cancers were identified at an advanced stage.

The American Urological Association recommends that all men consider beginning prostate screening at age 40 with a PSA and digital rectal exam.

Skipping stones

Calcium is good for you — in most instances. But when the body has trouble processing calcium and other crystal-forming substances such as uric acid, kidney stones can develop.

While many stones are small enough to pass unnoticed, some are so painful they send sufferers to the emergency room for treatment.

For many people, passing the stone brings only temporary relief. After having one stone, the chance of getting a second one is 5 to 10 percent each year. "Once the first stone occurs, you become a stone former," says William Haley, M.D., a nephrologist at Mayo Clinic's campus in Florida. "You'll continue to make stones until someone finds out why and changes things."

Jeff Conn knows all too well the pain associated with kidney stones. He's had more than he can count over the years. Now 63, the Ponte Vedra, Fla., resident has lived with kidney stones for more than 25 years.

"There was a time in the late 70s, as a young man living in south Florida, that I had stones that I couldn't pass," says Conn, a real estate developer. "Those were painful times. I finally passed the stones after going to the hospital emergency room, but I'd always continue to make them."

A stone flare-up in 2008 caused an infection that brought Conn to Mayo Clinic's hospital, where he was referred to the Kidney Stone Clinic. That subspecialty clinic brings together specialists from urology, nephrology, radiology and emergency medicine to diagnose and treat patients with stone disease.

"Most patients are of the belief that you have an attack and then you call us," Dr. Haley says. "But that's not what you have to be stuck with. Ours is a focused, yet personalized, patient-centered approach to treating acute kidney stone episodes. But we also work to find the cause to prevent stones from growing and new ones from forming."

Kidney stones are tiny, hard mineral deposits that interfere with the kidney's ability to remove excess water, minerals and waste products from the blood. They cause severe pain for about one out of every 1,000 adults every year.

Doctors trying to understand kidney stone formation are intrigued by research that indicates various factors play a role, including the environment, diet and age.

Kidney stones tend to affect older men more than women and people who live in the Southeast more so than those who live elsewhere, says Michael Wehle, M.D., a Mayo Clinic urologist.

"Most patients pass their first stone between the age of 20 and 50," Dr. Wehle says. "But our hope is that with the stone clinic we will be able to correct the problem early on."

For patients who require immediate treatment, the stone clinic offers state-of-the-art laser technology and other minimally invasive techniques. Then doctors set out to stop new stones from forming.

They review a patient's stone history, metabolic condition and genetics, as well as obtain blood samples and kidney scans. Additionally, they review a patient's diet.

"Our integrated workup of patients with kidney stones is unique," Dr. Wehle says. "As a result, with a combination of diet and medication, we often can prevent patients who have formed stones once from forming them a second or third time."

Clinical research has helped them evaluate preventive treatment and find the best ways to manage the condition.

"We found that 90 percent of the time we could stop patients from making stones, even those who were making an average of one a week," Dr. Haley says. "We've had patients who passed 50 kidney stones a year and now pass none. It's very dramatic and satisfying for patients."

Conn says when he was first seen at Mayo Clinic, X-rays showed many kidney stones in both kidneys. Ongoing attacks loomed in his future.

"But I had those resolved and nothing since," says Conn. The resolution involved changing his diet. Conn was surprised at the dietary restrictions doctors gave him, which included having a dairy product at each meal but no spinach, colas, nuts or chocolate.

"There is a great comfort in knowing someone is overseeing this and I don't need to worry," he says.

Drs. Michael Wehle and William Haley (right) personalize preventive treatment for kidney stone patients such as Jeff Conn (far left).

Around Mayo Clinic

Surgeons complete 2,000th liver transplant in Florida

The McCalla Transplant Center on Mayo Clinic's Florida campus celebrated a milestone Nov. 22 when surgeons completed the 2,000th liver transplant. The facility, which began doing liver transplants in 1998, has been the highest-volume liver transplant center in the Southeast over the last five years, according to the Scientific Registry of Transplant Recipients.

The Florida liver transplant program has reported some of the highest volumes, lowest median wait times, and highest survival rates in the country. According to the registry, the average median wait time for a liver at Mayo Clinic in Florida is one month, compared to a national average of 16.1 months. Survival rates are 99 percent at one month, 93 percent at one year and 83 percent at three years, all higher than the national averages.

"We are proud that this vast experience has enabled us to continually evolve our practice and successfully prolong the lives of some of the most seriously ill patients out there — often the ones that other transplant centers have turned away," says Thomas Gonwa, M.D., chair of the Department of Transplantation at Mayo Clinic in Florida. "We offer those people, in particular, a chance at life that might not otherwise be available to them."

Research: Brain inflammation doesn't trigger Alzheimer's

In a surprising reversal of long-standing scientific belief, researchers at the Mayo Clinic campus in Florida have discovered that inflammation in the brain is not the trigger that leads to buildup of amyloid deposits and development of Alzheimer's disease.

In fact, inflammation helps clear the brain of these noxious amyloid plaques early in the disease development, as seen from studies in mice that are predisposed to the disorder, say the researchers in the online issue of the *FASEB Journal*.

"This is the opposite of what most people who study Alzheimer's disease, including our research group, believed," says the study's lead investigator, Pritam Das, Ph.D., an assistant professor in the Department of Neuroscience. "And it also suggests that we can take advantage of the brain's own immune cells by directing them to remove amyloid plaques from the brain, thus protecting the brain against their harmful effects."

Radiation after prostate surgery: few side effects

Prostate cancer patients treated with radiotherapy after prostate-removal surgery experience few complications, according to a Mayo Clinic study published in the October issue of *Radiotherapy and Oncology.*

Men in this study received radiotherapy after a prostate-specific antigen (PSA) test following surgery indicated that their cancer had recurred. Researchers say the findings from Mayo Clinic's campuses in Florida and Minnesota suggest that patients and their physicians should not overly worry about toxicity and side effects from the treatment, known as salvage external beam radiotherapy.

"There is a general fear of this kind of radiation treatment on the part of some patients and their physicians, but this study shows that it not only effectively eradicates the recurrent cancer in a substantial number of patients, but that there are few serious side effects," says the study's lead investigator, Jennifer Peterson, M.D., a radiation oncologist at Mayo Clinic in Florida.

"In men without a prostate, a rising PSA level indicates that cancer has recurred," says Dr. Peterson. "After a recurrence is detected, there is only a narrow window of time during which radiotherapy will be beneficial in controlling their cancer."

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Chain of action: Six surgeries, three kidney donations

It was not a typical living-donor kidney transplant. On Oct. 7, 2009, Lawrence Walsh, 66, of Benson, Ariz., received a lifesaving kidney transplant at Mayo Clinic in Arizona.

In a first for Mayo Clinic, the donor kidney was part of a "swap" that began with a donor at Cornell University in New York. That donor kidney was shipped to a patient at California Pacific Medical Center in San Francisco. In turn, California Pacific reciprocated by sending a matching kidney from one of its living donors to Mayo Clinic for Walsh.

Walsh's son, Brian, 41, of Tucson, Ariz., had hoped to be his dad's kidney donor, but was not a match. But he got his chance to contribute the gift of life when his kidney was removed at Mayo Clinic early on Oct. 7 and was then shipped to a patient in need at UCLA Medical Center in Los Angeles.

Transplant recipient Lawrence Walsh and his wife, Arlene

The chain that began in New York involved six surgeries, four hospitals and weeks of careful orchestration. "This exchange means that three patients were able to get a compatible kidney when none would have been possible otherwise," says Raymond Heilman, M.D., nephrologist at Mayo Clinic in Arizona. "Because of the limited supply of available organs, this is a way to increase the number of patients receiving organs."

Dr. Heilman reports all recipients and donors are doing well.