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Rare illness doesn't preclude safe pregnancies

A team of experts makes this first (and second!) possible

For Rachel Willenberg and her husband, Seth, the path to parenthood made a detour and several stops in the Cardiology Department of Mayo Clinic. Now, they have a baby and a preschooler, and these young parents couldn't be happier.

Willenberg has fibrosing mediastinitis (FM), a rare, progressive disease that causes scar tissue to build up in major blood vessels and airways. Her Mayo Clinic doctors could find no documented cases of women with FM giving birth.

Willenberg's first symptoms appeared when she was 19. One morning she awoke to see an unfamiliar face looking back from her mirror. "My entire face was swollen and looked as if I was having an allergic reaction to something," she says.

Through her college years and early military career, Willenberg endured other baffling symptoms: breathlessness, bruising on her chest, and swelling on her upper arms. Rigorous exercise took an enormous toll on her. Doctors couldn't find a reason for her symptoms.

In 1998, she got an answer and a big measure of uncertainty. Willenberg, then age 22, was diagnosed with fibrosing mediastinitis. Many physicians believe mediastinal fibrosis to be an abnormal immunologic response to antigens released by the soil-based fungus *Histoplasma capsulatum*. Whatever the cause, there is no cure. Doctors do damage control — intervention to remove scar tissue and blockages and treatment to help prevent complications.



Rachel and Seth Willenberg wanted children in spite of Rachel's illness. They found a team at Mayo Clinic to help make Rachel's safe pregnancies possible. The happy family includes big sister Ariana and baby Aleah.

When she was diagnosed, a CT scan showed that Willenberg's superior vena cava (SVC) was blocked with fibrous tissues. The SVC is the large vein that returns blood to the right atrium of the heart. She underwent several invasive procedures to reopen the SVC and, for a time, it helped.

In 2002, while she was working as a nurse at William Beaumont Army Medical Center in El Paso, Texas, Willenberg's health nose-dived. Tests revealed that her right pulmonary artery was severely narrowed, and she had developed blood clots.

"There was no one at the medical center with the expertise to care for me," she says. Willenberg's pulmonologist called major medical

centers requesting a response from anyone who would treat her. Mayo Clinic responded.

First trip to Mayo by air

An Air Force plane transported Willenberg to Mayo Clinic in Rochester, Minn. Allison Cabalka, M.D., a pediatric interventional cardiologist, performed a cardiac catheterization procedure to place a stent in the narrowed right pulmonary artery. A year later, Willenberg returned to Mayo Clinic for three more stents in the SVC, providing more permanent relief from symptoms — and for the first time in a long time, hope for her future.

In April 2003, Rachel and Seth Willenberg married. In September, she left the military with a medical discharge. She and Seth settled into a new life in Columbia, Mo., and made a big decision. They wanted children.

“We understood there would be serious risks and that specialized care would be necessary,” says Willenberg. “I knew from my experience that Mayo is a great medical facility and that they would care for me throughout my pregnancy.”

Planning for pregnancy involved coordination of care between Mayo Clinic physicians and an obstetrician in Missouri. “Dr. Cabalka sent Rachel to me in 2004 to discuss the risks of pregnancy,” says Sabrina Phillips, M.D., a Mayo Clinic cardiologist who specializes in adult congenital heart disease. “There really are no documented cases of pregnancy with FM. We were in new territory.”

FM could result in low blood flow to the lungs and heart, which

makes low blood flow to the uterus a concern. In addition, Willenberg has a blood clotting disorder, which increased her risk and required close monitoring of blood thinners.

In the next 18 months, Willenberg had two miscarriages. In September 2006, she returned to Mayo for a procedure to reopen her SVC. And in early 2007, Willenberg was pregnant again. She and Seth traveled to Mayo Clinic regularly to consult with Drs. Phillips and Cabalka, and Carl Rose, M.D., a Mayo Clinic high-risk obstetrician.

A team with expertise in complex cases

“We may not have quite as many obstetrics patients as some medical centers, but we see a high volume of complex cases,” says Dr. Rose. A significant benefit for Mayo Clinic patients is that physicians can easily consult with colleagues from other disciplines. Willenberg’s team consulted with specialists in adult congenital heart disease, pulmonary

medicine and rheumatology, all of whom had experience with other FM patients.

“This interdisciplinary approach is critical, particularly when there are many unknowns,” says Dr. Phillips. “We combine experiences and data from other specialties to deliver the best care possible.”

Willenberg and her physicians had planned for a delivery in Rochester, but baby disagreed. Ariana was born a bit early — but without complications — on Sept. 9, 2007 in Columbia.

A temporary move: Second baby on the way!

The couple was overjoyed when Willenberg became pregnant again in 2008. She stayed in close contact with her local obstetrician, who exchanged updates with Drs. Rose and Phillips. In the last three weeks of her pregnancy, the couple moved to Rochester (temporarily) to be close to her caregivers.

Willenberg saw Dr. Phillips regularly. “Rachel was monitored closely as she was kept on heparin for her clotting disorders. When swelling in her face became a concern, an echocardiogram was ordered. She got a cohesive team approach that few centers in the country could offer,” says Dr. Phillips.

On June 29, 2009, the Willenbergs welcomed their second daughter, Aleah, into the world.

“I know people might try to scare someone with FM into thinking that a family is impossible,” says Willenberg. “With proper medical care, you can have a normal life filled with love, laughter and children. I am so glad that I pursued my treatment at Mayo Clinic. I received both the physical and emotional support I needed to start my family.”



Allison Cabalka, M.D., pediatric interventional cardiologist, left, and Carl Rose, M.D., an obstetrician who specializes in high-risk pregnancies, were part of the team caring for Rachel Willenberg.

Prostate health: Many concerns, many answers

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

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.

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.

Fast-growing brain tumor removed; active life resumes

In 2006, Kevin Colburn, age 32, felt like he was living inside an echo chamber. Sounds bounced around inside his head. His physicians suspected a plugged ear canal, fluid in the canal or allergies. The recommended treatments — allergy medications and antihistamines — didn't stop the clamor.

Colburn and his physician pursued more tests to find the cause. They didn't like what they found: a tumor, nearly eight-tenths of an inch long, coming from the eighth cranial nerve, which leads from the brain to the inner ear. Called an acoustic neuroma, this benign tumor typically grows slowly. It can cause ringing in the ears, dizziness and hearing loss.

"We learned that treatment is surgery or radiation," says Colburn, of Osceola, Wis., who works as a diesel mechanic. After managing for a year with symptoms, he decided he could forgo treatment a bit longer, at least until after deer hunting season.

But the status quo didn't last. Soon, the right side of Colburn's face was numb. He could not feel his tongue. At times, he felt off balance. He had to park a new Harley-Davidson motorcycle that he and his wife, Jolene, had recently purchased. In December 2007, his friends and family insisted that he seek a second opinion.

At Mayo Clinic, Colin Driscoll, M.D., Otorhinolaryngology, confirmed Colburn's diagnosis of acoustic neuroma. An MRI scan showed the tumor pushing on critical surrounding structures, causing progressive hearing loss and facial numbness. "The tumor was aggressive," says Dr. Driscoll. "After

Expertise in brain tumors

Mayo Clinic cares for more than 2,200 patients with brain and nervous system tumors each year. Mayo Clinic physicians are experts in diagnosing and treating acoustic neuroma tumors, one of the most common brain tumors, as well as other tumors of the brain and nervous system.

six months, it had nearly doubled to 1.4 inches long."

Driscoll's Mayo Clinic team advised surgery. "Given his young age, symptoms and the size of the tumor, the next step — surgery — was clear," says Michael Link, M.D., Mayo Clinic neurosurgeon. "We needed to remove the tumor to take the pressure off the brainstem and surrounding nerves."

Because of the size and location, removing the tumor would result in deafness in the right ear. For Colburn, the choice was clear. He'd take the hearing loss to be rid of dizziness, echoes in his head and facial numbness.

On Jan. 3, 2008, he underwent

surgery. "I was happy when I woke up because I had the feeling back in the right side of my face," says Colburn. A year later during Coburn's checkup, there were no signs of tumor recurrence.

"This experience, while a horrible one to go through, was brightened and lightened by the exceptional care provided by the physicians and health care staff," says Colburn.

"We thank them for the life they allowed us to keep living," adds Jolene Colburn.

That life means Colburn was back deer hunting last fall. He bagged a doe. And the couple is happily revving and rolling on their Harley-Davidson.



Kevin and Jolene Colburn had feared that their riding days were over because of Coburn's tumor. "We put our faith in Mayo and received a blessing," says Jolene Colburn. "We are able to ride and enjoy life without limitations."

'Lucky' Mary Wood prevails through brain aneurysms

Two years ago, Mary Wood was enjoying an evening at home, watching James Bond's "Casino Royale" with a friend. She lost consciousness, fell and for a time couldn't speak or move.

Wood, of Rapid City, S.D., was experiencing a ruptured brain aneurysm. An aneurysm is a bulge or ballooning in a blood vessel in the brain. It can look like a berry hanging on a stem. When it ruptures, blood seeps between the brain and surrounding tissues and can lead to a stroke or death.

Wood, age 52, had no idea of her risk. She had experienced similar falls in the past. Tests found nothing unusual. That evening, she says, "I wasn't alarmed, just numb." Her friend helped her to bed where she nursed a lingering headache.

After three days of bed rest, Wood's daughter insisted on taking her mom to the emergency room. A CT scan showed the ruptured brain aneurysm.

"So this is my goodbye," Wood recalls thinking. Her trepidation was based on experience. Her mother had died of a ruptured brain aneurysm. "My doctor told me my best chance of survival was to be flown to Rochester that night." Wood and her daughter boarded an air ambulance for Mayo Clinic.

Aneurysm repair or not? Research helps doctors decide

An estimated 2 percent of Americans, about 6 million people, have brain aneurysms. It's estimated that brain aneurysms rupture in about 25,000 people each year.

A large international study led by Mayo Clinic found that the risk of a brain aneurysm rupturing depends on its location and size. Presented in 2008, the study included 4,059 patients with unruptured brain aneurysms at 61 medical centers in North America and Europe. Patients with relatively small aneurysms — under ¼ inch in diameter — in the front portion of the brain had the lowest risk of rupture. Patients with larger aneurysms, and those who had aneurysms on arteries in the back part of the brain, had the highest risk. This research has helped physicians determine whether surgery or another intervention is needed.



Mary Wood enjoys time with her grandson, Nicholas.

Mayo Clinic neuroendovascular surgeons successfully repaired the rupture. They inserted a hollow plastic tube (catheter) into an artery in Wood's groin. The catheter was threaded to the aneurysm. Then, they fed a soft platinum wire through the catheter and into the aneurysm. The wire coils up inside the aneurysm and seals it off from the artery.

But Wood's worries weren't over. Doctors found two more brain aneurysms at risk of rupturing. Wood went home to recuperate, and then returned to Mayo Clinic for two procedures about a month apart. One was a craniotomy, a surgical incision in the skull, where surgeons placed a tiny metal clip on the neck of the aneurysm to close it off from the artery. The third repair was done by accessing the aneurysm through the artery. Eventually, after all three procedures, Wood says, "I could do everything I could when I walked in."

"Mary is extremely fortunate," says Giuseppe Lanzino, M.D., a Mayo Clinic neurosurgeon. "Most people have no symptoms and the results of a ruptured aneurysm are devastating.

"Mary's case also exemplifies that there is no one ideal treatment for this complex and challenging disease," he says. Surgery, endovascular repair or watchful waiting may be the best approach, depending on the location and size of the aneurysm.

Wood is relishing life. She's newly married and moved to Newcastle, Wyo. At a recent checkup, there were no signs of aneurysms. She hopes that sharing her story will increase awareness of brain aneurysms and their risk. "I was watching 'Casino Royale' when something awful happened to me," she says. Like James Bond, she persevered through peril.

Says Wood, "I was the lucky one."

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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



Transplant recipient Lawrence Walsh and his wife, Arlene

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.

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.