Mayo Clinic
MAGAZINE

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THE PLAYING FIELD
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Answers

Anyone who has lived with an undiagnosed medical problem understands the fear and frustration that can come with not having answers to the questions: What is this disease? Is there a treatment? Is it going to get worse? What will happen to me?

To find answers, many patients undertake “diagnostic odysseys,” going from specialist to specialist, submitting themselves to test after test — blood draws, X-rays, CT scans, ultrasounds, MRIs, spinal taps, biopsies, gastroscopies, colonoscopies, and on and on. The deeper patients get into these odysseys, the more desperate for answers they become. How bad is it going to get? Am I going to die?

Mayo Clinic’s multidisciplinary approach excels at giving these patients the peace of mind they need. In this issue of Mayo Clinic Magazine, you will read about the odyssey of a runner who developed a brain condition that is so rare that it doesn’t yet have an official name. (Mayo Clinic neurologists were familiar with the disease and developed the treatment he needed.) You’ll read about a woman with amyloidosis, a rare, hard-to-diagnose blood disorder that mimics other diseases so that symptoms vary among patients with the same blood disorder. And you’ll read about a young man who suffered debilitating spasms nearly his entire life. After years of specialists and tests, a genetic evaluation at Mayo Clinic revealed a condition with only 100 known cases in the world. Today he plays baseball and basketball with his nieces and nephews.

As a benefactor of Mayo Clinic, you help Mayo Clinic provide these patients — and countless more like them — the answers they need. On behalf of Mayo Clinic and our patients, thank you for your compassion and support.

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Before Rob Swartz, Mayo Clinic Had Seen Only Six Cases
Can’t remember who pitched the only perfect game of a World Series? Check Google. Can’t name all the Spice Girls? Google can. Can’t recall the number that starts with a one and is followed by 100 zeros? Google googol.

The Internet search engine is so widely used and so good at producing the information we’re looking for that it long ago became part of our daily lives. There’s no need to sift through mountains of data and endless links to find the few nuggets we need. So naturally, when people have health concerns, one of their first stops is Google. But anyone who has searched the Internet to self-diagnose knows the dizzying, and sometimes scary, array of results.

To help give their users the best health information possible, Google now provides relevant medical facts upfront. For example, a search for arthritis will show, beside the resulting links, a few basic facts about arthritis and a definition. To ensure quality and accuracy, all of the gathered facts were confirmed by medical doctors from around the United States, which were then vetted by expert clinicians at Mayo Clinic.

The goal of this new feature is to provide medical information in a digestible way and to get basic answers quickly. Using Mayo Clinic as a primary source, Google provides information about symptoms and treatments, whether or not it’s critical, or contagious, what ages it typically affects, and more.

“We worked with a team of medical doctors, led by our own Dr. Kapil Parakh, to carefully compile, curate and review this information,” says Prem Ramaswami, Google product manager. “All of the gathered facts represent real-life clinical knowledge from these doctors and high-quality medical sources across the Web, and the information has been checked
by medical doctors at Google and the Mayo Clinic for accuracy."

He and Philip T. Hagen, M.D., Mayo Clinic’s Global Business Solutions’ medical director for Healthy Living, point out that the information is not intended to be medical advice, and it is presented for informational purposes only. Dr. Hagen notes that cases can vary in severity from person to person and that health information searchers should consult a health care professional if they have a medical concern.

“As an editor and physician, I know how difficult it is to present concise, useful information,” says Dr. Hagen. “I think these should be viewed as the first stop for those needing health information, and as people need more information, they can quickly connect to a medical website like MayoClinic.org.”

The goal is to provide medical information in a digestible way and basic answers quickly.
Thank You!
Your Compassion Helps Patients Every Day

Gratitude built Mayo Clinic. Everything we have is a gift, and everything we give is a gift — a gift of hope, a gift of healing and a gift of health.

The spirit of giving strengthens Mayo Clinic is expressed in extraordinary ways, such as the longtime benefactor who has been a patient for 50 years and has seen the return on investment in the form of new treatments; the employee who gives back to Mayo Clinic after witnessing miracle after miracle that give patients hope; the corporations and foundations that partner with Mayo Clinic to make a healthier world; or the first-time visitor to Mayo’s website who is inspired to help others through an institution they’ve never visited.

Such gifts of kindness and hope have helped Mayo Clinic recently reach a major milestone in transforming health care for all — YOU ARE … The Campaign for Mayo Clinic in 2014 topped $2 billion in donations to help patients. But we still have a long way to go. With the goal of establishing a new world standard in health care, the campaign aims to raise $3 billion by Dec. 31, 2017.

To join YOU ARE … The Campaign for Mayo Clinic, please visit mayoclinic.org/give.

THE CAMPAIGN FOR MAYO CLINIC
2014 TOTALS

$483M RAISED
130,000 BENEFACCTORS
205,850+ GIFTS 90% of gifts came from grateful patients.
962,822 GIFTS
(39,446 from corporations and foundations)

374,257 BENEFACCTORS

$2B RAISED

1,645 Estate Gifts

TOTALS TO DATE

461 Gifts over $1 million

BREAKDOWN OF CAMPAIGN GIFTS:

36% ENDOWMENT
Gifts that ensure a strong Mayo Clinic for generations to come.

62% OPERATING
Gifts Mayo Clinic can put to use immediately.

2% CAPITAL
Gifts that provide patients the best facilities and technology available.

THE CAMPAIGN FOR MAYO CLINIC
"When I kiss her, I still close my eyes," Allen Zderad says with a smile, causing his wife, Carmen, to bounce with laughter over a joke she’s probably heard hundreds of times. They are in a doctor’s office for another consultation to treat Allen’s retinitis pigmentosa, a degenerative eye disease that has made Allen legally blind all his life. “It’s an inherited disease that involves the degeneration of a cell type in the retina called photoreceptors, which are sort of like the pixels in our eyes,” says Raymond Iezzi Jr., M.D., who has selected Allen to be the first patient to receive a radical new treatment — a bionic eye.

The “eye” is made up of a camera, mounted on glasses, sending images to a computer. The computer analyzes and processes the images before sending them to a transmitter, which then beams visual information into a device implanted around Allen’s eye and wired into his retinal nerve through 60 electrodes. The implant interprets that information and sends series of impulses to the retina, which the brain interprets as vision.

A few weeks after Allen has the surgery placing the implant, he sits in a room filled with his children and grandchildren. Dr. Iezzi asks Allen how he’s doing.

“I’m on pins and needles,” Allen says, then adds with a laugh, “or electrodes I should say.” Carmen sits directly across from Allen, the two facing each other, as Allen lets out a loud breath. Then Dr. Iezzi turns the glasses on. At first Allen isn’t sure what to make of the new visual information. It’s black and white, unfocused and very pixelated. Then Carmen moves and someone asks, “What do you see?”
Allen quickly holds up his hands and says in classic Midwestern understatement, “Yeah.” Then he grabs Carmen and pulls her close. Tears mix with laughter as Allen sees his wife for the first time in two decades. Allen falls back to his chair, and the two hold both hands, just looking at each other.

A few minutes later, Allen and Carmen are standing alongside Dr. Iezzi as Allen describes what he sees.

“It’s going to take interpretation of the shape of the light that’s flashing because it’s a pulsing light, not like regular vision where it’s constant. It’s a flash, and I’ve got to be able to interpret the changes in that shape.”

Dr. Iezzi says that’s exactly right, and Allen punches his right hand with his left in excitement. He turns to Dr. Iezzi and quickly grabs his hand — “I picked you out!” Dr. Iezzi is only the second person Allen has seen after years of darkness. Carmen gives him a long, laughing, weeping hug.

“This is crude, but it is significant,” Allen says, while grasping Dr. Iezzi’s hand. “It’ll work.”

Dr. Iezzi leads Allen and Carmen around the clinic, letting Allen get used to the new visual information. He brings Allen to a sun-filled window.

“You’ve just seen your first sunshine,” Dr. Iezzi says.

“No,” Allen says and nods toward Carmen.

“That was her.”

Legally blind all his life, Allen can now see shapes through a glasses-mounted camera that sends signals to an implant wired into his retinal nerve.
Abba C. Zubair, M.D., Ph.D., always wanted to be an astronaut. Throughout boyhood and into his career, he constantly kept one eye on space. So when he noticed that gravity might be slowing down the growth of stem cells in the lab, he thought, “Why not remove that impediment? Why not grow the cells in space?”

“On Earth, we face many challenges in trying to grow enough stem cells to treat patients,” says Dr. Zubair, the medical and scientific director of the Human Cellular Therapy Laboratory at Mayo Clinic’s campus in Florida. “It now takes a month to generate enough cells for a few patients. A clinical-grade laboratory in space could provide the answer we all have been seeking for regenerative medicine.”

After developing microgravity experiments on Earth that suggest he’s onto something, Dr. Zubair began working with the Center for the Advancement of Science in Space to deliver stem cells to the International Space Station. He specifically wants to expand the population of stem cells that will induce regeneration of tissue damaged during hemorrhagic stroke, which took the life of his mother.

“This is something that is personal to me,” Dr. Zubair says. “A stroke killed my mother, and I’m very much interested in finding a cure for stroke so that nobody else will lose his mother because of this disease.”

If successful, these experiments could impact how stem cells are generated for many other diseases of the heart, bone, muscle, nerves and blood.

“If you have a ready supply of these cells, you can treat almost any condition and can theoretically regenerate entire organs using a scaffold,” Dr. Zubair says. “Additionally, they don’t need to come from individual patients — anyone can use them without rejection.”

Dr. Zubair is working with engineers at the University of Colorado who are building the specialized cell bioreactor that will be taken to the space station, 268 miles above Earth.

“I don’t really think growing cells in space for clinical use on Earth is science fiction,” he says. “Commercial flights to the space station will start soon, and the cost of traveling there is coming down. We just need to show what can be achieved in space.”
The International Space Station:
- Has had continuous human occupation for nearly 15 years
- Has orbited Earth more than 80,000 times and traveled nearly 2.25 billion miles
- Has hosted 184 spacewalks, totaling more than 1,152 hours, or 48 days
- Spans the area of a U.S. football field, including end zones
- Weighs 924,739 pounds

This image is a composite of a photograph recording the aurora australis from aboard the International Space Station (courtesy of NASA) and microscopic imagery of cells captured by Mayo Clinic researchers (on planet Earth).
Susan Evans knew something was wrong. She had always been active — volunteering in the community, teaching and providing spiritual direction, hiking, and doing yardwork. So why was she struggling with energy? Why could she no longer keep up with household chores? And why would it take so long to recover after playing with her grandkids?

Sue described her symptoms to her Mayo Clinic primary care doctor, Elaine B. York, M.D., who immediately began a series of tests, looking for the cause.

“I had doctors who would take time to listen to me,” Sue says. “I know that isn’t always the case, especially for women with vague symptoms like being tired all the time. They believed me when I said I knew my body and knew something was wrong.”

Sue met with endocrinologists, pulmonologists, cardiologists and more. No one could find the answer. A year or more into her medical odyssey, her symptoms worsened with classic cardiac symptoms — shortness of breath, shoulder pain and jaw pain — but testing revealed nothing. She also kept developing urinary tract infections. Around the time of the fourth infection, she met with endocrinologist John M. Miles, M.D.

Dr. Miles suspected nephritic syndrome and sent her to specialists, who ordered a kidney biopsy. However, Sue had problems with excessive bleeding in the past. So before the biopsy, she had bloodwork to measure her bleeding tendency.

That test showed evidence of the rare blood disease amyloidosis.
The Mimicking Disease

Amyloid is a blood protein that is normally broken down in the body. However, in patients with amyloidosis, these proteins accumulate to toxic levels. It’s difficult to diagnose for two reasons: One, it’s incredibly rare — less than 0.0001 percent of Americans are diagnosed each year. Two, it can mimic a host of other diseases. For instance, if amyloid collects in the heart, it mimics heart disease. If it collects in the brain, the patient displays symptoms of brain disorders. For Sue, it collected in her kidney, causing her urinary infections and fatigue.

“It can affect the skin, the bowel, lung, nerve, heart, tongue, eye — anything,” says Morie A. Gertz, M.D., chair of the Department of Internal Medicine at Mayo Clinic in Rochester, Minnesota. “At other institutions, many doctors have never seen amyloidosis before, and it’s very hard to diagnose something you’ve never seen in your career. But at Mayo, we’re very good at it because of our multispecialty approach. There are cardiologists, hematologists and endocrinologists who are sensitive to amyloidosis and it’s on their page.”

Luckily, Sue was a patient at Mayo Clinic, where doctors diagnose about 200 cases per year, making it one of the premier amyloidosis diagnostic centers in the world. Sue’s amyloidosis was caught early.

Seeds of Life

Less than 20 years ago, amyloidosis was uniformly fatal. Doctors knew of nothing to stop bone marrow from producing the protein. Then researchers had an idea — why not replace the bone marrow? They noticed that amyloid production mimicked some blood cancers, which doctors had been treating with bone marrow transplants for a couple of decades.

“Bone marrow is where the blood is produced,” explains Dr. Gertz, who is the Roland Seidler, Jr., Professor of the Art of Medicine in Honor of Michael D. Brennan, M.D. “It’s basically a garden that produces normal blood. But with amyloidosis, the garden has some weeds in it. In the form of chemotherapy, we apply weedkiller that kills the weeds but also destroys the garden. You can’t live without the garden. So we collect seeds — stem cells —
“So once the weeds are killed, we reseed the garden with the stem cells, which no longer produce the amyloid substance.”

— Morie Gertz, M.D.

and freeze them. So once the weeds are killed, we reseed the garden with the stem cells, which no longer produce the amyloid substance.”

Because it’s these seeds — the stem cells — that are the active agents, doctors today usually call the treatment a stem cell transplant. In 1996, 10 years before he diagnosed Sue, Dr. Gertz and Mayo Clinic opened a clinical trial to refine the technique to treat amyloidosis and set safety standards.

When Sue received her lifesaving stem cell transplant, more than 40 percent of the recipients in the original clinical trial were still alive.

**Growing the New Garden**

A stem cell transplant is an option of last resort. For many, the treatment’s immediate effects feel worse than the disease itself. It can take years to recover.
“I think it’s an incredible miracle that the stem cells are put into your body and they know what to do.”

— Susan Evans

To ensure patients have the support they need, Mayo Clinic requires that everyone who goes through the process have a caregiver, such as a friend or family member. Sue had Annie Kramer, who had been helping with household chores as Sue’s health declined.

In the six weeks between Sue’s diagnosis and the transplant, Annie and Sue learned everything they could about the process. They trained with other patients going through the treatment, which comforted Sue because she saw she wasn’t the only one. She also saw how much experience the Mayo Clinic care team had with stem cells transplants.

“Everyone was so confident,” Sue says. “They told me at one point that nothing should go wrong with the transplant, but if it did, they knew what to do and I’d be in intensive care immediately. That was very reassuring.”

The process of harvesting the stem cells, applying chemo therapy to kill the remaining marrow and reintroducing the stem cells all went smoothly. But then four days after the transplant, diarrhea set in, and Sue’s potassium levels crashed. She couldn’t maintain a normal blood pressure and was running a fever.

Soon she was in the hospital, where she stayed 21 days.

When she got home, her immune system was severely compromised, which is normal for people who’ve had stem cell transplants. Sterile conditions needed to be maintained at home, and she had few visitors. As she had been trained, Annie supervised her diet, which, for the first 100 days, was mainly canned or frozen food to reduce the risk of infection. Profound exhaustion was a daily reality.

“For two years, I didn’t do much that involved mingling with crowds,” Sue says. “We were very cautious. It’s hard to get out of that mindset that the world is going to hurt you.”

It took nearly five years before Sue had normal energy levels.

‘An Incredible Miracle’

Before Sue’s treatment, amyloidosis had nearly destroyed her kidney, wearing holes right through it. Physicians said it was likely she’d eventually need dialysis or even a transplant. But then a remarkable thing happened.

During follow-up visits to Dr. Gertz over following five years the transplant, Sue learned that her kidney had completely regenerated. There was no sign of damage.

“I think it’s an incredible miracle that the stem cells are put into your body and they know what to do,” Sue says. “They are able to go where you need them, to restore whatever is needed, like my bone marrow and my blood.”

Dr. Gertz gave her another good piece of news. When Sue asked how the people who received the transplant 15 years earlier were faring, he replied with a smile, “They’re alive.”
The Power of Regeneration

Before John H. Noseworthy, M.D., became CEO of Mayo Clinic, he had a neurology case that he suspected was amyloidosis. He sent the patient to see Morie A. Gertz, M.D., who made the diagnosis and treated the patient with a stem cell transplant.

Seeing the power of stem cells firsthand, Dr. Noseworthy came to understand their promise. “We’ve come a long way since that realization,” Dr. Noseworthy says. “Right now, Mayo Clinic is treating some patients with osteonecrosis — those with bad hip joints — with injections of their own stem cells, which can heal the hip and prevent the need for total hip replacements. Beyond that, our researchers are developing methods to build whole new, patient-specific organs such as the lung and liver, treatments that could transform lives.”

Mayo Clinic’s Center for Regenerative Medicine leads the nation in translating the promise of stem cells into actual treatments. Its researchers are conducting clinical trials applying stem cells to diseases of the nerves, kidneys, bone, heart and digestive system. Later this year, Mayo Clinic will begin enrolling patients for the United States’ first final-phase clinical trial applying stem cells to strengthen heart muscle damaged by a heart attack.

“Regenerative medicine is an exciting component of modern health care,” says Andre Terzic, M.D., Ph.D., the Michael S. and Mary Sue Shannon Family Director of the center and the Marriott Family Professor of Cardiovascular Research. “We firmly believe that regenerative medicine will transform the practice of medicine, fundamentally changing how we treat disease.”
Imagine a 55-year-old man living with undiagnosed depression. Simply getting up and going to work in the morning takes all of his strength. When he comes home from work, he retreats from family, seeking isolation and anything that will numb the persistent hopelessness that weighs on him like strands of rusty chains. Like many Americans suffering similarly, he refuses to acknowledge this crushing burden — not with his wife, not his friends, not his doctor. No one.

It’s a situation all too common. According to the Substance Abuse and Mental Health Services Administration, an estimated 1 in 5 adults in the U.S. lived with a mental health condition in 2013. More than 24 million of them failed to receive treatment.

Even for those who do seek treatment, they find a U.S. health care system that is unwieldy and complex. For many patients who churn through its gears, calling it a “system” is a misnomer, with order, reliability and efficiency difficult to find.

On a societal level, mental health issues carry a $444 billion price tag, with health care expenses accounting for one-third of the cost and the majority of lost wages, according to the National Institute of Mental Health.

It’s a vicious downward cycle — depression resulting in lost income, which results in increased stress and hopelessness, which makes it harder to function, which results in more lost income. And on and on.

To help these patients, researchers in the Mayo Clinic Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery and the Division of Integrated Behavioral Health are looking at the system holistically. They apply systems science, operations research, engineering principles and computer modeling to fix some of the most pressing issues in health care, including how the nation cares, or doesn’t care, for its mentally ill.

An estimated 1 in 5 adults in the U.S. lives with a mental health condition. Over 24 million of them fail to receive treatment.
Nowhere to Go
Overcoming the social stigma of mental illness is one of the biggest barriers to care and prevents many people from seeking help in the primary care setting. When untreated symptoms spiral out of control — depression turning into suicidal thoughts or self-inflicted harm, for example — these patients may visit the emergency department until their condition is stabilized or, in the most serious cases, until they can transfer to an inpatient treatment facility.

This is where they hit another wall. Over the past half-century, inpatient treatment facilities have disappeared from the health care landscape, as attitudes shifted from state institutionalization to community-based care at local hospitals — and full investment in community-based care has never been fully realized. Without adequate funding or staffing, these hospitals reduced their number of psychiatric beds to dangerously low proportions.

With nowhere for patients to go, the hospital emergency department becomes the de facto safety net. A patient with a mental health crisis may stay for days or even weeks until a transfer can be made, which chokes the system and makes it harder for others to access emergency care.

Kalyan S. Pasupathy, Ph.D., wants to find a way for all patients to receive timely care. A health sciences researcher and scientific director for the clinical engineering learning laboratory at Mayo Clinic, Dr. Pasupathy and a team he co-leads with medical director Thomas R. Hellmich, M.D., are looking at the problem through an engineer’s lens.

“Many of the problems we face in health care are systemic problems,” Dr. Pasupathy observes. “With mental health care, we face issues around coordination of primary care and the availability of inpatient care facilities.

To help patients receive timely care, Kalyan S. Pasupathy, Ph.D., Ronna L. Campbell, M.D., Ph.D., and Thomas R. Hellmich, M.D., are looking at the problem through an engineering lens.
At the end of the day, these factors affect the emergency department. If we study them in silos, we risk shifting the problem from one area to another.”

The clinical engineering learning laboratory is just one way the Mayo Clinic Kern Center for the Science of Health Care Delivery plans to dismantle those silos. Embedded in the emergency department at Mayo Clinic Hospital — Rochester, Saint Marys Campus, it’s the first of its kind in the nation to study the delivery of care in a live patient environment rather than a simulated research suite.

The lab tracks patients, caregivers and medical equipment in real time using technology such as radiofrequency. Data readers built into the walls capture this information round-the-clock, so researchers can map the collective emergency department experience from start to finish. Using this computer model, they can then answer key questions: How does extended boarding of patients with mental illness impact overall patient access? What prevents these patients from inpatient placement? How can resources both in the emergency department and beyond be reallocated to address gaps in care?

This team of systems engineers, informaticians and social scientists works with providers such as Ronna L. Campbell, M.D., Ph.D., an emergency medicine consultant who also chairs the Behavioral Health Workgroup in the Department of Emergency Medicine.

“We’re collaborating with the center to model mental health care delivery from a much larger perspective, larger than what we see as providers on a day-to-day basis in our own emergency department,” Dr. Campbell says. “We can see what’s changing and what’s happening using our data, but the center can look further out and see how we connect to the health system and how the system connects to statewide resources.”
Getting Ahead of the Problem

Clearing the pathway to emergency mental health services is just one way physicians and researchers aim to get patients the care they need at the right place and time. Another is preventing those emergencies in the first place.

Mental health crises can result from a snowballing of obstacles. Ashamed, many patients deny they have a problem, says David J. Katzelnick, M.D., a psychiatrist and chair of the Division of Integrated Behavioral Health at Mayo Clinic. Even when they do acknowledge symptoms, their family doctor might not feel confident or have enough resources to provide care beyond prescribing medication or referring the patient to a psychiatrist — and the wait for a psychiatry appointment could be months. Meanwhile, the patient’s condition declines.

Mark D. Williams, M.D., a psychiatrist and population health scholar with the Mayo Clinic Kern Center for the Science of Health Care Delivery, believes the remedy is a more proactive, patient-centered approach. He leads implementation of Mayo Clinic’s Depression Improvement Across Minnesota, Offering a New Direction (DIAMOND) program. The model, initially implemented at 80 practices in Minnesota, including Mayo Clinic, is part of a statewide effort led by the Institute for Clinical Systems Improvement to better coordinate community-based mental health care.

The first step in DIAMOND is earlier identification of who needs help. When patients visit their primary care providers for a regular checkup, they fill out a questionnaire that assesses depressive symptoms. If they score in a certain range, their doctors will invite them to participate in DIAMOND. Patients who sign up for the program are matched with a nurse care coordinator, and together they spend around an hour creating a thorough history of the patient’s condition. The nurse care coordinator works with the primary care provider and a psychiatrist to translate this history into a care plan. As a result, the patient has access to personalized mental health resources within a week, rather than months.

“Now that nurse is involved in the patient’s life, aiming to get them into remission,” Dr. Williams says. “The nurse may call the patient weekly or monthly depending on the case and will challenge them to set goals: What are you willing to do to change? Cut down on alcohol? Try to exercise? Try a different medication? Did you make it to therapy? The patient can also call the nurse anytime, typically once a week in the beginning, but once a day if in crisis. The nurse becomes the patient’s advocate.”

From Dr. Katzelnick’s perspective, DIAMOND has significantly streamlined the delivery of mental health care so people encounter fewer roadblocks.

“The scale and reach is dramatically wider, and the people I’m seeing in person are not random, but the ones who are most in need of the highest level of care.”

— David J. Katzelnick, M.D.
David J. Katzelnick, M.D., and Mark D. Williams, M.D., are developing a more patient-centric approach to care.

"With a relatively small investment of resources, DIAMOND allows many patients to get much better care. As a psychiatrist working with the care team, I can provide input on 100 to 120 patients in one morning. The scale and reach is dramatically wider, and the people I’m seeing in person are not random, but the ones who are most in need of the highest level of care."

To prove whether those benefits can be replicated broadly, Dr. Williams is collecting data to demonstrate DIAMOND’s impact on long-term health care spending, patient outcomes, patient satisfaction, reduction in emergency department visits and other indicators of value.

“How should you design your interventions to make the best impact and do the best for all your patients? It’s not something we’re always taught in our medical education,” Dr. Williams reflects. “We’re more taught to look at the individual, but after seeing 100 patients, you wonder if there was a pattern in the people you saw, and if you changed one element in the delivery of their care, to what degree do they get better?

“We need rigorous ways to assess these changes so that we make the right investments in better care for our patients. That’s what the center offers: tools to understand and improve upon models like DIAMOND so that more patients get evidence-based care.”

For those feeling lost amid a broken health care system, that evidence may be the thread that mends. ■
Sunday afternoon is family time at Virgil and Linda Bennett’s rural Georgia home, and a steady stream of kids and grandkids flows in and out. The adults carry salads, hot dishes and cakes to go along with the two smoked hams. The children fan out to the swings, the four-wheeler, Bonnie the horse, the golf cart — and their uncle Dustin, who is ready and eager to take on his nieces and nephews in one sport after another.

Baseball: Dustin unloads pitches with pinpoint accuracy.
Football: Dustin powers through the defense.
Basketball: Dustin sinks shot after shot.
Linda watches Dustin from the porch and says wistfully, “He wanted to play ball so bad at school, and he couldn’t do it.”
She calls what she is watching “a miracle.” Mayo Clinic physicians and researchers call it delivering on the promise of genomic sequencing.

A Diagnostic Odyssey
The Bennetts became Dustin’s foster parents when he was an infant and adopted him at age 4. “By then, he was ours,” Virgil says. By then, they also knew something was terribly wrong.
As a toddler, Dustin could not keep his balance and fell over a lot. As he grew, he would suddenly suffer painful, rigid and jerking spasms, which would disappear just as mysteriously. Sometimes, he couldn’t walk or talk. He developed learning disabilities (now age 23, Dustin functions at the intellectual level of a 6 year old).
Linda took Dustin to doctor after doctor, getting different tests, diagnoses and medications, with one doctor suggesting Dustin’s problems were psychological.
Linda Bennett says seeing her son Dustin play sports with his nieces and nephews is a miracle.
“I wasn’t willing to give up because I felt there has to be an answer somewhere,” Linda says. Then a physician suggested Dustin go to Mayo Clinic in Jacksonville, Florida, which in 2013 became one of the few institutions nationwide to offer whole-exome sequencing for patients like Dustin, who are on a diagnostic odyssey.

At Mayo, they met neurologist Zbigniew K. Wszolek, M.D., who requested the sequencing and interpretation from Mayo Clinic’s Center for Individualized Medicine.

**Fewer Than 100 Known Cases**

Whole-exome sequencing scans a patient’s DNA for mutations in all 22,000 genes at once, rather than focusing on one gene at a time. For Dustin, both his biological parents and sister provided a medical history and blood samples. Mayo then compared those with Dustin’s DNA to establish a family genetic mutation. A team of physicians, researchers and geneticists compared that mutation with known genetic disease markers, as well as the genome of the healthy population.

“Whole-exome sequencing allowed us to make the diagnosis precisely and quickly,” says Dr. Wszolek.

They found that Dustin has episodic ataxia type 1, a rare nervous system condition with fewer than 100 known cases in the world. There’s a medical test for several types of ataxias, but not Dustin’s. The other types of ataxia — all of which also affect movement and coordination — are easier to diagnose because the signs and symptoms are more consistent than Dustin’s random, episodic onset of symptoms. Without whole-exome sequencing, Dr. Wszolek says, Dustin might never have been correctly diagnosed.

“Dustin’s diagnosis is a wonderful example of how genomic sequencing can be used in the clinic to find meaningful answers for patients,” says Alexander S. Parker, Ph.D., Cecilia and Dan Carmichael Family Associate Director for the Center for Individualized Medicine in Florida. “Before, we had to guess where in our DNA the problem might be and look at genes one at a time in the hopes we were looking in the right area. Now genomic sequencing technology is faster and more affordable, so instead of guessing where the answer lies, we can look at all of our DNA at the same time and find the answer.”
There is no cure for Dustin’s condition, but Dr. Wszolek is working with Dustin and his family to get to the best combination of medications for him. Already, he is seeing great improvement in Dustin’s physical and cognitive functioning.

“When I saw Dustin for the first time, he was not able to function from the motor standpoint,” Dr. Wszolek says. “He was clumsy, falling and had episodes of wracking movements. Now he is able to do activities such as playing basketball and going to school.

“Different man.”

‘This Is a Miracle’

Back in the Bennetts’ yard, Dustin’s bat connects with the baseball. Crack! He races off around the bases, nieces and nephews scrambling after the ball and him. The aroma of ham is wafting from the windows, and everyone has worked up an appetite. The family gathers in the living room to say a simple, solemn grace, then piles their plates high with home cooking.

Dustin finishes off two platefuls. It’s been a joyful day of playing the sports he loves, surrounded by the family that loves him.

“We’re so grateful to everyone,” Linda says. “This is a miracle to us.”
To train a new generation of physician leaders, Mayo Medical School has bold plans for the future. Over the next two years, the school will establish a national footprint with expansion into Arizona and Florida, more than doubling its student body. Mayo Medical School will also transform the traditional medical school curriculum. Through the Science of Health Care Delivery, Mayo will provide students the tools they need to fix the nation’s health care system.
When Jack Jeng graduates from Mayo Medical School, he’ll enter an uncertain U.S. health care system: unsustainably high health care costs; deep complexities that keep patients from getting the right care at the right time; an aging population and increasing burden of chronic diseases: a precarious political environment.

“It’s an interesting time to go into health care because we don’t know what the future holds,” says Jack, 27, who is a fourth-year student.

Many experts wonder if medical schools across the country are doing enough to ready graduates like Jack. The traditional education model is often criticized as being woefully inadequate for 21st century needs.

“The reality is that most medical schools are teaching the same way they did 100 years ago,” Wyatt W. Decker, M.D., CEO of Mayo Clinic’s campus in Arizona, said in a recent Wall Street Journal story. “It’s time to blow up that model and ask, ‘How do we want to train tomorrow’s doctors?’”

One tool the school is targeting for change is the Science of Health Care Delivery. Jointly developed with Arizona State University, this four-year curriculum teaches subjects such as systems engineering, health care policy and biomedical informatics so that students can understand the health care system and have the tools to fix it. Mayo Medical School is the first program in the country to jointly confer a certificate in the Science of Health Care Delivery along with a medical degree. By completing additional credits, students can choose to earn a master’s degree in the field from Arizona State University.

“We need physicians to learn things that have not traditionally been taught in the medical school curriculum,” says Michele Y. Halyard, M.D., the Suzanne Hanson Poole Vice Dean of the Mayo Medical School who is serving as interim dean. “We want to lay these principles right from the beginning so that we’re training and cultivating our students with the skills and abilities that they need to not only heal patients and advance the science of medicine but heal the health care system as well.”

“We need physicians to learn the kinds of things that have not traditionally been taught in the medical school curriculum.”

—Michele Y. Halyard, M.D.
But impacting health care will take more than teaching the Science of Health Care Delivery to 200 students. (Mayo Medical School in Rochester, Minnesota, is one of the most selective medical schools in the country, with 50 students accepted per class out of over 4,750 applicants.) With the support of Mayo Clinic and benefactors, over the next two years Mayo Medical School will establish a national footprint and more than double its student body. At the same time, with a grant from the American Medical Association (AMA), it will transform its curriculum so students like Jack will have the training they need to provide the best care possible in the 21st century — with a curriculum that can be replicated across the U.S.

“We’re taking advantage of all of the expertise that we have across Mayo, along with the support of our benefactors and the unparalleled support of the AMA, and bringing them to medical education,” Dr. Halyard says. “No other medical school in the country has a national presence like ours will have.”

More Diverse Opportunities
To provide opportunities across the U.S. nation, Mayo Medical School will expand in 2016 to include complete third- and fourth-year programs in Jacksonville, Florida. The following year, the school will launch a four-year campus in Scottsdale, Arizona, enrolling 50 additional students per class.

Mayo Medical School will preserve its high faculty-to-student ratios, which is a key Mayo Medical School advantage. Using a singular, unified curriculum across campuses, the school will also employ many online learning modules that integrate educational aids such as video clips, interactive animations and assessments. Developed in partnership with Arizona State University, the modules give students personalized flexibility in learning and give professors better student interactions and the ability to adjust the curriculum if assessments show students need further discussion on a topic.

“It’s not just a slideshow or a videocast of a lecture,” says Darcy A. Reed, M.D., Mayo Medical School’s senior associate dean for Academic Affairs. “This is really innovative education that’s created to provide flexibility for students and ensure better long-term subject mastery.”

With a national school structure, students will gain experiences across a broad spectrum of patient populations in multiple practice settings. Up to eight Rochester students per year will be able to complete their final two
years in Florida. Arizona- or Rochester-based students will be able to do a number of rotations at other Mayo campuses. Mayo Medical School is also collaborating with health organizations near each campus and Mayo Clinic Health System, which is Mayo’s family of clinics, hospitals and health care facilities serving over 70 communities in Iowa, Georgia, Wisconsin and Minnesota.

“Students will experience different patient demographics, but we’ll also give students exposure to different parts of the country and unique health care challenges in those areas,” Dr. Halyard says. “Some students may prefer to be closer to home or to see the different way health care is practiced or a different patient mix, the different cultural mix of the Southwest versus the Midwest or Southeast. Part of the national expansion is also that we really have the ability to take advantage of all of the expertise across Mayo. Our students will have experiences like no other.”

The Leaders of Tomorrow
Starting this year, the Science of Health Care Delivery will be the first subject for first-year Mayo Medical School students. It’ll expand beyond the classroom so students can learn in real-world environments.

“When you put the Science of Health Care Delivery upfront, it emphasizes the importance of this to their training,” Dr. Reed says. “It’s core. It’s integral. Coupled with the right clinical experiences, it can transform careers.” First-year students will shadow patients trying to acquire appointments to learn about their experiences in terms of what is working and what can be improved. They’ll visit community health clinics off campus to gain a broader understanding of the patient experience and resources available.

During their third and fourth years, students will dive deeper into the various factors that influence the value and cost of care. For example, through a computer program called Checkbook, they will look critically at diagnostic tests to see if they are necessary, evidence-based and of high-value.

“Just letting them see those numbers helps them get a better understanding of costs,” Dr. Reed says.

Mayo Medical School’s new curriculum is already gaining national attention. In 2013, the school’s proposal to create an educational model based on the Science of Health Care Delivery earned it a grant from the American Medical Association’s Accelerating Change in Medical Education Initiative. Mayo Medical School was one of only 11 schools selected across the nation for this five-year initiative.

As part of this grant, Mayo Medical School and the Mayo Clinic Health System are partnering to develop novel educational opportunities beyond the classroom for first-year medical students.
to learn and work in interprofessional teams providing high-value care — a cornerstone of the Mayo patient experience.

In another learning experience, students connect with patients having challenges managing their diabetes in order to understand the often complex situations that make it difficult for them to complete lab tests or get blood sugar or blood pressure under control.

After personal interviews with patients, students follow up with the patients’ physicians to understand the decisions leading up to the treatment plan.

“The students reach out to get the patients’ perspectives on their diabetes and why they are struggling to get it under control, what their goals are and what their barriers are to accessing health care,” Lotte N. Dyrbye, M.D., principal investigator on Mayo’s AMA grant, says. “From the patient’s primary care doctor, students gain perspective on how the doctor works with the patient, what systems are in place to encourage the patient or facilitate care for the patient. Then the student analyzes opportunities for improvement. So the learning incorporates patient, provider and system improvement perspectives.”

Additional experiences are being developed for students to use data analytics to identify opportunities to improve patient care outcomes while reducing cost. The experiences help prepare Mayo medical students to thrive in a changing, highly regulated health care environment and still improve the health of patients.
Student Quincy Nang’s experiences with care systems both inside and outside Mayo Clinic prepare him to adapt to any health care environment.

Through Mayo’s partnerships across the country, student Jack Jeng experienced a diversity of conditions and patient populations.
Finding Their Passion

While hands-on learning across the country will become more common after the Arizona and Florida campuses open, Mayo Medical School students have already started taking advantage of these opportunities.

For third-year student Quincy G. Nang, a hands-on experience during a recent rotation in Jacksonville showed him what he might want to do with the rest of his life. He was on a general surgery rotation and was called in to help a urologist.

“I got to work directly with the chair of the department, and he is amazing,” Quincy says. “What an experience! Just like that I started considering pediatric urology very strongly.”

Quincy also gained experience with a Mayo Clinic partner organization in Arizona — the Maricopa County Jail. There he observed the psychiatric practice, which broadened his outlook.

“It was invaluable being exposed to that environment — think of something outside of the Mayo system,” Quincy says. “I really wanted to be prepared to handle everything that is thrown on my plate in my career and to be able to adapt to many different scenarios and ways of providing care, and I’ve been able to do that through experiences like these.”

Jack Jeng also spent time with a Mayo Clinic partner in Arizona, the Phoenix Children’s Hospital.

“Not only did I get to see a lot of bread-and-butter things, but I also saw rare pediatric diseases that I may not have seen in Rochester because of the high pediatric patient volume at a Mayo collaborator — Phoenix Children’s Hospital,” Jack says. “There were many Spanish-speaking families and patients who were uninsured or on Medicaid. Those are issues I didn’t really deal with before because the patient population in Rochester is a bit more homogeneous.”

“Coordinating care was a challenge because patients might not have a primary care physician or access to specialists. Hospitalized patients that were uninsured or did not have in-network providers in their area covered by their insurance had a very difficult time getting the follow-up care they needed after discharge.”

Dr. Halyard says these varied experiences across the country combined with the Science of Health Care Delivery curriculum will position Mayo Medical School students to be even stronger leaders in the future.

“They’re entering into a world where medicine is changing,” Dr. Halyard says. “We are creating the next generation of empowered physicians. We want physicians to have a voice in that change. We want them to improve the quality of medicine — continual improvement — and we want our future physicians to be at the table with the skills to be able to implement change.”

“— Michele Y. Halyard, M.D.

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When Bill and Penny George sit down to a table overlooking a tree-lined park in Minneapolis, it’s amazing they can even catch their breath. It’s the first morning either has been back in their beloved home city after traveling for 17 days straight.

But they won’t be home long. At least Bill won’t. He needs to get to Dallas for an Exxon board of directors meeting, but ice is forcing airlines to cancel flights. As he works with his assistant to find travel options, Penny decides to sit this trip out. Why fight the weather when it is only going to be a one-day trip anyway?

During conversation with two others sitting at the table, Penny suddenly realizes it is 19 years to the day that she had surgery to remove breast cancer.

“Today it was? Wow!” Bill says and raises a glass of water. “Toast the glass.” As the four around the table clink glasses and coffee cups, Bill continues. “Nineteen years ago today you were cancer-free. Nineteen years ago yesterday you were anything but.”

When cancer struck Penny, she had just finished her doctorate of psychology and formed her own psychology consulting firm with a colleague. She had two sons and was married for 25 years to Bill, who was chairman and CEO of Medtronic, a medical device company based in Minneapolis. Suddenly she was face-to-face with death.
This Medicine Is Not Alternative

The Georges' 20-Year Vision to Transform Medicine

Bill and Penny George
A New Path for Penny

In a sunlit room at the George Family Foundation, Penny recalls what it took to heal and how she integrated the traditional, doctor-prescribed treatments of chemotherapy, hormonal therapy and surgery with tai chi, yoga, massage and energy medicine, what people then called “alternative medicine” (more on that term later).

It worked. Not surprisingly, though, the experience changed Penny. First, it made her question her life’s direction — was psychology her intended purpose? Second, it made her realize how poorly U.S. medicine helped patients harness transformative moments to chart their own healing.

“Through integrative health and medicine, we’re working both bottom up and top down,” Penny says. “We’re working with Mayo, But we didn’t have a focus. What changed was we felt we could really make a difference, a transformational difference, maybe in a couple of areas. Certainly health care was one, which is more than just medicine.”

Through Penny’s experience with cancer and Bill’s experience leading a medical device company, the couple understood firsthand the limitations of modern medicine. Too often health care is focused on specific diseases and not enough on the whole person. So a treatment might alleviate a symptom, but not enough health care providers are addressing root causes or giving patients the tools they need to make sustainable life changes.

Within the past few years, Mayo Clinic has recognized the importance of moving upstream and helping people live healthier lives before they come to Mayo Clinic with a problem. Penny and Bill recognize that Mayo’s mission has always been patient-centered, so they decided to support Mayo’s efforts to develop and distribute whole-person care.

“We’re one integrated body, so if we treat it as one integrated body, one integrated being — mind, body and spirit — the odds are far greater for living.” — Bill George

A New Path for Penny and Bill

By the time Penny came to this conclusion, the two of them had already established the George Family Foundation, but it didn’t have a singular mission.

“We practiced checkbook philanthropy,” Penny says. “But we didn’t have a focus. What changed was we felt we could really make a difference, a transformational difference, maybe in a couple of areas. Certainly health care was one, which is more than just medicine.”

After Penny George was treated for breast cancer, she went on a 10-day vision quest to find a new course for her life.

After Penny healed, she went on a 10-day vision quest to find her new course, traveling to the middle of the desert and fasting for four days. Two weeks later she dropped psychology and devoted herself to changing the course of medicine.

“I remember one day we were driving out to Colorado,” Bill recalls, “and she looked at me and said, ‘You know, I’m going to change the way medicine is taught and the way it’s practiced.’”

(For the record, Penny doesn’t quite remember it that way — “That sounds really crafted,” she teases Bill — but she does remember talking about the limitations of modern medicine and Bill remarking that’s just the way it was, to which she replied, “Well, then we’ll just have to change it.”)
trying to get them to see something different and supporting those things they already see differently and getting behind that philanthropically. Philanthropy really is the engine of social change in America. Philanthropy can be there in a hurry.”

**A New Path for Mayo Clinic**

Bill and Penny are building on the work started by Dan Abraham, founder of SlimFast. Thankful for the care he and his family have received at Mayo Clinic, Dan returned the gift of wellness to Mayo employees by establishing the Dan Abraham Healthy Living Center for Mayo Clinic staff. In 1998, he helped open a second facility. Then in 2007, he and his wife, Ewa, gave Mayo Clinic employees a three-story state-of-the-art facility with exercise equipment, wellness classes, workout rooms and lessons to cook more nutritiously.

Last year, the Abrahams supported a five-story expansion of the center to include the Healthy Living Program, which opened similar services to the public. Today, anyone can join the program, which begins with a thorough online questionnaire to assess lifestyle habits and overall health. Participants then come to the center, where experts help them understand their habits and craft a tailored health plan to meet specific goals, such as eating healthier, losing weight, reducing stress, getting more exercise, etc. Together, participants and wellness coaches develop strategies to attain those goals after the participants leave.

With Bill and Penny’s partnership, the program is expanding its access through online portals and apps. Libraries of videos and education modules will enable people to take Mayo Clinic with them wherever they go. Games and health monitoring will keep participants engaged and focused on their goals.
“If we give that kind of support to people, empower them and teach them how, I think we really change health tremendously and even transform Mayo in the process because it opens up a much broader audience of people who can come to Mayo to maintain and improve their health, rather than waiting until they are at the end stage of disease,” Bill says. “It’s about helping people take control of their life. It’s how you eat, how you sleep, particularly how you deal with stress, how you exercise.

“All of these things are really critical to your health. We have to understand how the body works. We’re one integrated body, so if we treat it as one integrated body, one integrated being — mind, body and spirit — the odds are far greater for living. We’ve seen the data on this.”

A New Path for Medicine

Bill and Penny stress that this is evidence-based care. Mayo Clinic’s Healthy Living Program bases all its programs on research outcomes and measurements that show how wellness affects health. The program is constantly conducting ongoing research to enhance its offerings.

As alluded to earlier, Bill and Penny have no patience for those who apply the label “alternative” to techniques such as acupuncture and meditation.

“The media calls this alternative medicine,” Bill says. “Please don’t do that because it’s not alternative. No one is suggesting that if you have breast cancer that you shouldn’t have surgery or you shouldn’t have medical therapy. What we’re suggesting is that we integrate these therapies with allopathic therapies. That’s the key.”

They believe that supporting Mayo Clinic will help drive this integration more quickly across the country, thereby achieving Penny’s vision to transform medicine.

“Mayo is a benchmarking organization,” Penny says. “People pay attention to what Mayo does. It’s a bit of a Good Housekeeping seal of approval. If Mayo is doing it, you know it’s rock solid.”
The Science of Wellness

In a crowded health and wellness marketplace, knowing what’s fact versus myth and effective versus ineffective can be a challenge. It may also be an obstacle for some people to find a sound and practical lifestyle program they can maintain over time. In 2014, Mayo Clinic launched the Healthy Living Program to help people adopt healthy behavioral changes in diet, exercise and stress management to improve their overall quality of life.

The program is based on research and designed to break down barriers, dispel myths and give participants a comprehensive wellness experience tailored to their individual goals. What makes this program unique is that it doesn’t end once the person leaves the campus. It offers ongoing support long after the person returns home.

“Mayo has been dedicated to the health and wellness of individuals for 150 years, and this program continues that tradition by offering life-changing experiences to people seeking whole-person wellness who want to maximize their health,” says Donald D. Hensrud, M.D., medical director, Mayo Clinic Healthy Living Program. “We’re committed to partnering with each participant to design an individualized wellness plan to help them reach their wellness goals, so that their success continues once they return home and are immersed back into the reality of their busy lives.”
The Thin Line Between Life and Death
Helping Rural Hospitals Reduce ICU Mortality by 41 Percent

The patient, in her late 40s, was admitted to Mayo Clinic Health System in Austin, Minnesota, with pneumonia. Although she wasn’t critically ill when she arrived, Danny T. Muskardin, M.D., Ph.D., the attending hospital physician, suspected she was teetering between stabilization and taking a turn for the worse. He transferred her to the Intensive Care Unit just to be safe.

Within a few hours, Dr. Muskardin’s intuition proved correct. The patient developed septic shock, the body’s inflammatory response to infection that can result in organ failure and even death.

administering antibiotics, oxygen and intravenous fluids, a new team member entered the room — not through the door, but on a monitor.

“I’ve been alerted that her blood pressure is still trending downward,” the physician on the monitor said. “I’ve got a few ideas to try and stabilize her, but we may need to think about transferring her to Rochester.”

Filling the Gap
In the ICU, the difference between life and death can be something as simple as noticing trends — subtle changes over time in blood pressure, heart rate, body temperature and other indicators. Missing these trends can result in a patient crashing in an instant. Unfortunately, rural hospitals often lack the resources to monitor these longer term trends. Many simply don’t have the round-the-clock ICU specialists, known as intensivists, and subspecialists that major medical centers can provide.

Mayo Clinic’s Enhanced Critical Care is filling this gap. “Enhanced Critical Care is designed to standardize the approach to intensive care for patients across Mayo Clinic Health System,” says Sean M. Caples, D.O., the program’s medical director. “We have a lot of resources at Mayo Clinic in Rochester, Minnesota, and we can bring those to places that otherwise don’t have them.”

With video chatting now common for people of all ages, the “tele-ICU” concept behind Enhanced Critical Care is a logical next step in connecting patients — no matter where they live — to medical experts. From Mayo Clinic in Rochester, Minnesota, a team of

“Enhanced Critical Care is designed to standardize the approach to intensive care for patients across Mayo Clinic Health System.”

— Sean M. Caples, D.O.
intensivists, critical care nurses, critical care nurse practitioners and physician assistants work with patients, families and care teams in ICUs across several Mayo Clinic Health System sites. Team members can monitor patients 24/7, and software alerts them when a patient takes a turn for the worse. They can also “video in” to a patient’s room in emergency cases like Dr. Muskardin’s or to join routine patient assessments with the bedside team in real time.

In no way does Enhanced Critical Care replace the local team, Dr. Caples points out. “It’s all about collaboration. We want patients to stay in their home community with the doctors and nurses they know and also have the comfort that an extra set of eyes is looking out for them.”

Reducing Mortality
Compared with the year before its launch, Enhanced Critical Care helped reduce ICU mortality at participating hospitals by 41 percent and overall hospital mortality by 27 percent. But those statistics don’t tell the whole story, says Sarah J. Bell, R.N., the program’s nurse manager.

Bell oversees a team of nurses who practice in both the Enhanced Critical Care
operations center and the ICUs at Mayo Clinic Hospital — Rochester. This mix is unique compared with other tele-ICUs in the nation, where many nurses only practice in the virtual setting.

“Because Enhanced Critical Care nurses also work in the ICUs in Rochester, one may have already cared for a patient remotely, received reports and video-assessed the patient before the transfer,” Bell says. “So now that nurse can give a detailed report to the nurses in the ICU here and even help the family find lodging. That’s really providing a seamless transition to Rochester.”

Similarly, Dr. Muskardin notes that, the Enhanced Critical Care intensivist can streamline patient handoff to the receiving Rochester specialist so that he can spend more time with patients in Austin.

“This program is a huge asset to the doctor in the rural hospital as we try to manage our most ill patients,” Dr. Muskardin says. “It puts the patient first no matter how critical their needs are. We need to do whatever we can to benefit the patient.”

Mayo Clinic, Where and When You Need It

Enhanced Critical Care is just one strategy from the Mayo Clinic Center for Connected Care, a newly formed center charged with harnessing advancements in technology to improve access, service and affordability of health care.

“With Connected Care, we can extend the patient-care team relationship so that patients can get their health care needs met in just the right manner,” says Steve R. Ommen, M.D., a cardiologist and the center’s medical director. “Increasingly, this will mean patients can get Mayo Clinic information, guidance and care closer to home rather than traveling to one of our facilities.”
A Better Road to Recovery?
Going Fully Under May Not Be Best Option for All Hip and Knee Replacement Surgeries

Rebecca L. Johnson, M.D., is a card-carrying Iron Ranger, a native of the northeastern Minnesota region that boasts iron ore, Bob Dylan and an unapologetic blue-collar, close-knit, work-hard-play-hard culture.

Meeting this clinical anesthesiologist at Mayo Clinic in Rochester, Minnesota, is as effortless as chatting with your fishing buddy about the latest catch. In fact, as an avid hunter, fisher and camper, she may tease out a fishing yarn during your medical consultation. (If Dancing with the Stars is more your thing, don’t worry. She has a small obsession with TV shows and movies, too.)

Putting patients at ease through common interests is important, Dr. Johnson says, because the window of time for establishing trust is very narrow.

“The morning of surgery is the first time a majority of patients meet their anesthesia provider, which is a huge disadvantage,” she says. “It’s when you’re most vulnerable, many times wearing just a very thin piece of cloth. You’re overwhelmed by the experience, asking yourself questions like, Am I going to be safe? Am I going to make it out of this procedure? When am I going to be able to return to work?

“You’ve likely talked about anesthesia with your surgeon in prior consultations, but in those moments with the anesthesiologist, you need to make a final choice,” — be put fully under for the surgery or be lightly sedated.

A Pivotal Decision
Total hip and knee replacements are among the most common procedures performed at hospitals across the country and account for billions in annual Medicare expenditures. With an aging population and high rates of obesity, the volume of these procedures will only grow in the coming years. However, today there is no solid evidence guiding patients or doctors about which anesthesia choice — sleeping but breathing on your own with spinal anesthesia or going completely under with general anesthesia — is more effective or less costly in the long run.

Many people may think being completely “knocked out” is the easiest route to go, but Dr. Johnson observes that for certain groups spinal anesthesia with light sedation may result in a quicker recovery time and less pain after 30 days.

“I help guide patients based on what I see from my perspective — how well patients recover with one choice of anesthesia versus another.”

— Rebecca L. Johnson, M.D.
“I help guide patients based on what I see from my perspective — how well patients recover with one choice of anesthesia versus another,” she says.

The Health Care Delivery Scholars Program is helping her develop those observations into concrete evidence for patients and providers. As a scholar in the program, she systematically reviews current literature on anesthesia used for hip and knee replacement surgery and analyzes large data sets from hospitals and insurance companies to understand long-term patient outcomes on a national level.

Dr. Johnson’s work is part of Mayo Clinic’s larger effort to apply scientific techniques and data to evaluate the quality, safety and value of health care globally. Housed in the Mayo Clinic Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery, the Health Care Delivery Scholars Program trains clinicians through mentorships with the center’s leading experts in epidemiology, health care economics, surgical outcomes, data analysis and other research fields.

Dr. Johnson credits mentors in both the Department of Anesthesiology and the Mayo Clinic Kern Center for the Science of Health Care Delivery for seeing her potential to make a difference. “This opportunity comes with a lot of responsibility, and I take it seriously,” she says, armed with an Iron Ranger’s grit to get the job done.
He Saw Patients in Need and Wanted to Help
Cancer Physician-Scientist Leads Individualized Medicine Efforts

He was half a world away, interning on a bone marrow transplant ward at the Glasgow Royal Infirmary. There he witnessed young adults in the very prime of life struggling with the ruthlessness of often-fatal blood cancers and the vicious side effects of treatment. But the intern also saw the doctors’ compassion, patients’ resolve and the clear need for better therapies. So he dedicated his life to fighting blood cancers.

“He cancer is driven by genetic damage, and during my hematology training, I learned that determining the disrupted genetics behind the disease would be critically important,” Keith Stewart, M.B., Ch.B., says. “I went to do research in Boston, where we were sequencing single genes back when, in what now seems like the dark ages, it was hard to do. In the early 1990s, we read one gene a month, if we were lucky.”

Now, 25 years later, Dr. Stewart is a renowned multiple myeloma researcher. And sequencing a person’s entire set of more than 20,000 genes — known as the genome — takes only a day or two.

Dr. Stewart brings his passion to his new role as the Carlson and Nelson Endowed Director of the Center for Individualized Medicine. The center is Mayo Clinic’s foremost effort to translate the promise of genomic sequencing into daily patient care. He succeeded acting director Richard Weinshilboum, M.D., the Mary Lou and John H. Dasburg Professor of Cancer Genomics, and past director Gianrico Farrugia, M.D., who became CEO of Mayo Clinic in Jacksonville, Florida, on Jan. 1.

“The center has undergone a phenomenal period of growth and infrastructure building,” Dr. Stewart says. “The next phase of this exciting mission will be to drive what we have built into the clinical practice of all of our physicians. I’d love it if each and every Mayo Clinic patient could benefit from some form of individualized medicine in the next decade, no matter what stage of life they’re at, whether they are well and want to stay that way, or sick and need our help.

“Patients come to Mayo Clinic with hope. They want Mayo Clinic to deliver solutions they might not be able to obtain elsewhere. It is a foregone conclusion going forward that these solutions will include genomics, which will revolutionize our ability to better quantify risk, diagnose disease early, select or discard an intervention, make treatments safer and drive down costs in the system. In other words, offer real value to their care.”

Dr. Stewart believes that with the price of sequencing dropping every year, it’s inevitable that one day everybody will have their genome sequenced routinely. However, before that happens, it’s his mission to make sure Mayo Clinic leads this rapidly evolving field to understand all the things the genome is telling us.

Dr. Stewart, the Vasek and Anna Maria Polak Professor...
Dr. Stewart wrote about thalidomide in *Science* last year — “The 55-year history of the drug thalidomide is Shakespearean in scope, awash in unintended consequences, tragedy, resilience, driven characters and redemption ... Less well-known has been the resurgence in its use as a therapy to treat hematologic malignancy.”

Years after thalidomide was taken off the market, doctors, including Dr. Stewart, discovered it was effective for treating certain blood cancers, though they had no idea why. But once researchers had the power to see how the drug interacts with our genomes, it became clear.

“The genomic research explained everything,” Dr. Stewart says. “It explained why the drug got to the market and was considered safe in the first place — because we learned that mice didn’t have the right genes for the drug to work, so it didn’t expose them to the terrible birth defects seen in humans. It explained why the drug damaged pregnancies, why it activates the immune system, why cancer cells die after treatment, and it explains who responds to the drug and who doesn’t respond. It’s all because of a drug-gene interaction.”

Based on the new genetic understanding of the response, Dr. Stewart and colleagues around the world studied a modern thalidomide derivative called lenalidomide. They paired it with two other well-known cancer-fighting agents to treat 800 people with multiple myeloma. Nearly 9 out of 10 patients responded to the treatment, which trumped a different regimen considered the standard of care.

“In just the past couple of years, we’ve contributed here at Mayo Clinic to understanding why these drugs work, using genomic techniques,” Dr. Stewart says. “Mayo is now developing a test that we can use to determine whether you’ll respond to these drugs. Now that’s individualized medicine.”

Thirty years ago, when Dr. Stewart was an intern, survival with multiple myeloma averaged three years. Today survival has tripled, and more and more patients are being cured without the side effects of older chemotherapy. Dr. Stewart is confident that by using the genome to individualize treatments, match the right drugs to the right patient at the right time and discover new chinks in cancer’s armor, the unmet needs and unnecessary suffering of many cancer patients will begin to be no more than a bad memory.
In 2010, a couple of friends convinced Rob Swartz to enter the first triathlon of his life. Like many of us, he wanted to exercise more and thought this would be a perfect opportunity. He instantly fell in love with the sport. Within months he was in the best physical shape of his life, going on to complete 13 triathlons of various lengths, a 100-mile bicycle race and a full marathon, all during the summer and fall of 2011.

Then one early February morning in 2012 he woke up a little lightheaded. A couple of days later his hands began trembling. He had experienced similar symptoms about six years earlier. At that time, he put himself through a battery of tests in his home state of Michigan, but all the results came back normal and his symptoms disappeared. After six frustrating months, a local doctor diagnosed it as a passing case of viral meningitis.

“Last time symptoms lasted months, and I never received a definitive diagnosis,” Rob says. “I did not want to go through that again, and this time I wanted answers, so I chose to go to Mayo Clinic.”

By the time Rob and his wife, Danielle, arrived in Rochester, Minnesota, he had frequent headaches and tunnel vision and would occasionally go blind for a few seconds. His hands shook severely, and vertigo spun the world around him. Every few steps he needed to grab hold of something for balance.

At Mayo Clinic, neurologist James H. Bower, M.D., prescribed a regimen of tests to rule out the usual suspects — endocrine problems, autoimmune problems, tumors or autonomic nervous system disorders. But when he saw Rob’s MRI, he promptly called Rob. New game plan. He canceled Rob’s remaining tests and set up a spinal tap. As Rob was in the recovery room after that test, Dr. Bower paged Rob’s nurse — he wanted Rob to skip lunch, have one more procedure, and come back to the doctor’s office immediately.

The MRI revealed many puzzling abnormalities; Rob’s brain scan showed what appeared to be hundreds of small white dots that went throughout his brain and down his spinal cord.

“Dr. Bower looked me right in the eye and said, ‘You have something very rare, and I’ve never seen a case such as this. I want to refer you to a colleague of mine,’” Rob says. “I didn’t know what to do. I could barely walk for months. This summer he hopes to be running marathons again.
never felt more faint than I did then. A mere six months earlier I was finishing my second IRONMAN 70.3; now I was looking at an image wondering, ‘What is that? What is going to happen to me?’

Dr. Bower referred him to Allen J. Aksamit Jr., M.D., a colleague in the Department of Neurology who specializes in inflammatory disease. Dr. Aksamit narrowed it down to rare lymphoma, neurosarcoïdosis or a really rare autoimmune disease. The only way to find out for sure was a biopsy.

The next day Rob met with neurosurgeon W. Richard Marsh, M.D. The day after that, Dr. Marsh temporarily removed a piece of Rob’s skull and took a sample of his brain. The results revealed an autoimmune disease so rare that there’s no official name. In fact, Dr. Aksamit, who has seen thousands of patients with some of the world’s rarest disorders, had seen exactly six before Rob.

The white dots on the MRI scan were signs of inflammation — Rob’s own immune system was attacking his brain and spinal cord. The condition is chronic and lifelong, but Dr. Aksamit gave Rob the best news of his life — it was treatable.

A Negative to a Positive
Over the next several months, Mayo Clinic specialists worked with Rob’s doctors in Michigan to deliver an aggressive treatment of steroids, oral prednisone and immunosuppressive drugs. During that time, Rob could barely move and had to use a walker as his condition worsened. It took a number of months for the medication to bring his immune system under control. He even relapsed twice before a high-enough dose of daily immunosuppression was found.

Understandably, the experience made him re-examine his life and goals. “Instead of lamenting, ‘Why did this disease happen to me?’ I thought about, ‘What can I do with it? What can I

“I may have to fight this disease every day for the rest of my life, but I will not let it beat me.”

— Rob Swartz
accomplish? Realizing how truly lucky I am, what can I give back?”

Combining their love for racing with Rob’s experience with a rare neurologic disease, Rob and Danielle formed Team Lucky 7, a nonprofit private foundation. (The name is a nod to Rob being Dr. Aksamit’s seventh case.)

Team Lucky 7 raises funds for a number of neurologic research areas, including Alzheimer’s disease, multiple sclerosis and amyotrophic lateral sclerosis, or ALS. Racers who join Team Lucky 7 can raise money for the cause no matter where they compete. Within five years, Rob hopes to have 5,000 racers on the team.

“Think of the potential of that,” he says. “If each runner raises just $500, that’s $2.5 million.”

Rob plans to be one of those racers this summer. He and Danielle are looking for a marathon they can run together.

“I may have to fight this disease every day for the rest of my life, but I will not let it beat me,” Rob says. “I am truly lucky.”

Danielle agrees. “Running a marathon is a great analogy for the journey we have been on together. We are truly lucky.”
Thank You Gifts of all sizes strengthen health care for people everywhere. Mayo Clinic is deeply grateful for each gift and finds inspiration in your support.

MAKING AN IMPACT

Cumulative Philanthropy
Mayo Clinic recognizes each benefactor for philanthropic giving of $100,000 to $10 million or more in the Hall of Benefactors at Mayo Clinic in Rochester, Minnesota. We also recognize those who support our work in Florida and Arizona in the Hall of Benefactors on the respective campuses.

RECOGNITION LEVELS
- Philanthropic Partners $10 million or more
- Principal Benefactors $1 million to $9,999,999
- Major Benefactors $100,000 to $999,999

LEAVING THE WORLD A BETTER PLACE

Planned Giving
Committed benefactors who want to make a difference and provide a legacy of philanthropy can do so through planned gifts. Benefactors who support Mayo Clinic through a bequest in their will or another type of planned gift become members of The Mayo Legacy. Mayo Clinic recognizes these members in electronic recognition kiosks in the Halls of Benefactors at all Mayo Clinic campuses.

Alumni Philanthropy
Having seen and felt the direct impact of philanthropy, Mayo Clinic alumni know the difference it makes better than anyone. Many become benefactors of Mayo to help maintain the highest quality of patient care, research and education. Mayo Clinic recognizes their generosity in electronic recognition kiosks in the Halls of Benefactors at all Mayo Clinic campuses.

RECOGNITION LEVELS
- Mayo Alumni Laureates $100,000 or more
- Doctors Mayo Society $10,000 or more; bequest of $25,000 or more
- Edith Graham Mayo Society $1,000 (Mayo School of Health Sciences)

GIVING BACK

Annual Giving
Some benefactors choose to support Mayo Clinic’s work with yearly gifts, and Mayo Clinic recognizes them in electronic displays at Mayo Clinic’s campuses in Minnesota, Florida and Arizona. Six levels honor benefactors for annual philanthropy of $1,000 to $99,999.

RECOGNITION LEVELS
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