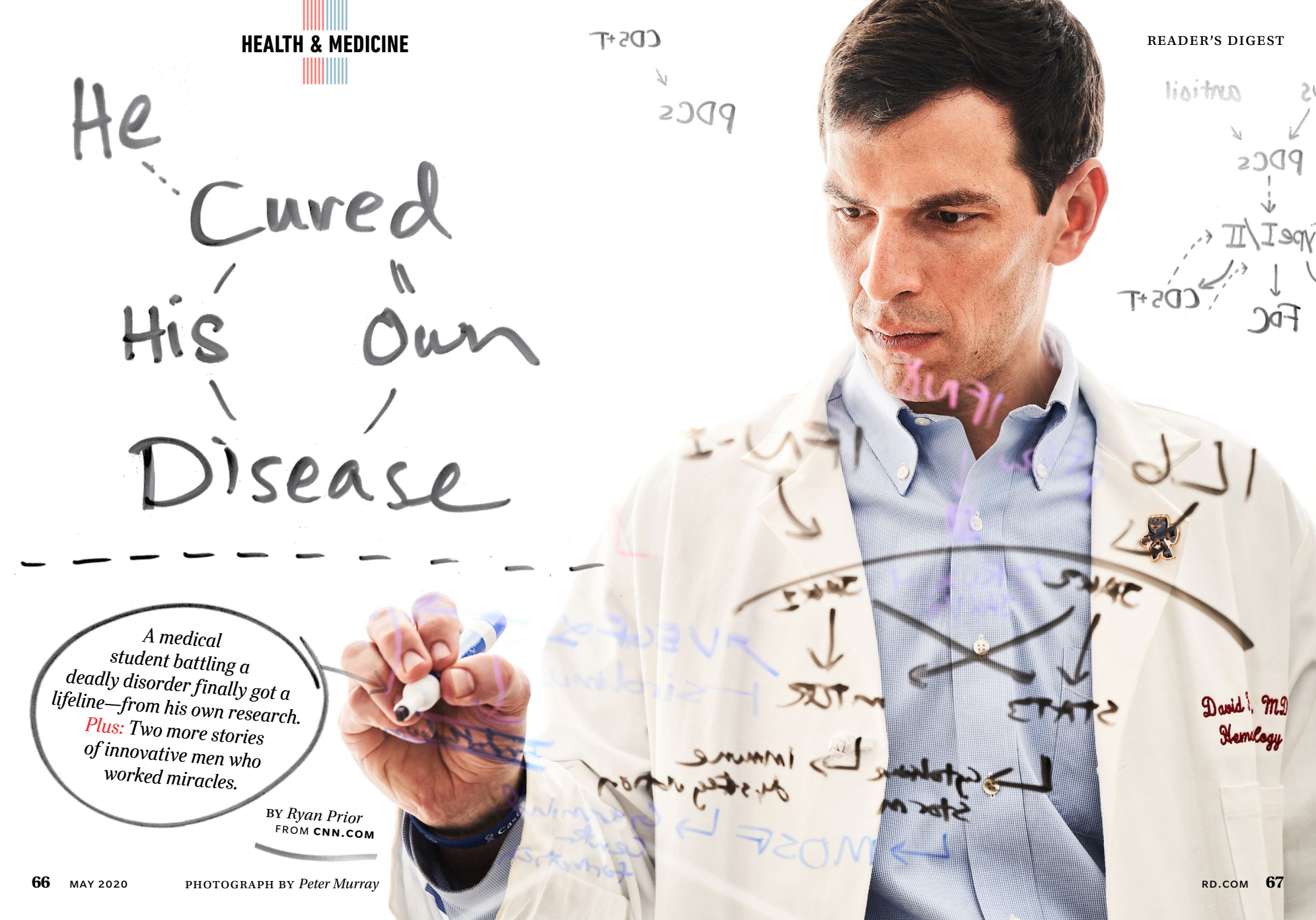
He Cured His Own Disease

A medical student battling a deadly disorder finally got a lifeline—from his own research. Plus: Two more stories of innovative men who worked miracles.

BY *Ryan Prior*
FROM **CNN.COM**



PHOTOGRAPH BY *Peter Murray*

It was just

after Christmas 2013, and David Fajgenbaum was hovering a hair above death.

He lay in a hospital bed at the University of Arkansas, his blood platelet count so low that even a slight bump to his body could trigger a lethal brain bleed. A doctor told him to write his living will on a piece of paper.

David was rushed to a CT scan. Tears streamed down his face and fell on his hospital gown. He thought about the first patient who'd died under his care in medical school and how her brain had bled in a similar way from a stroke.

He didn't believe he'd survive the scan. But he did.

David was battling Castleman disease, a rare autoimmune disorder involving immune cells attacking vital organs. It wasn't the first time a relapse had threatened his life. Massive "shock and awe" chemotherapy regimens had helped him narrowly escape death during four previous attacks, but each new assault on his body weakened him.

David Fajgenbaum's football body fell victim to organ failure associated with Castleman disease (right).

OPENING SPREAD AND STORY: HAND LETTERING BY MARIA AMADOR. THIS PAGE: COURTESY PEYTON WILLIAMS/ACCPHOTOS.COM

COURTESY DAVID FAJGENBAUM

"You learn a lot by almost dying," he says.

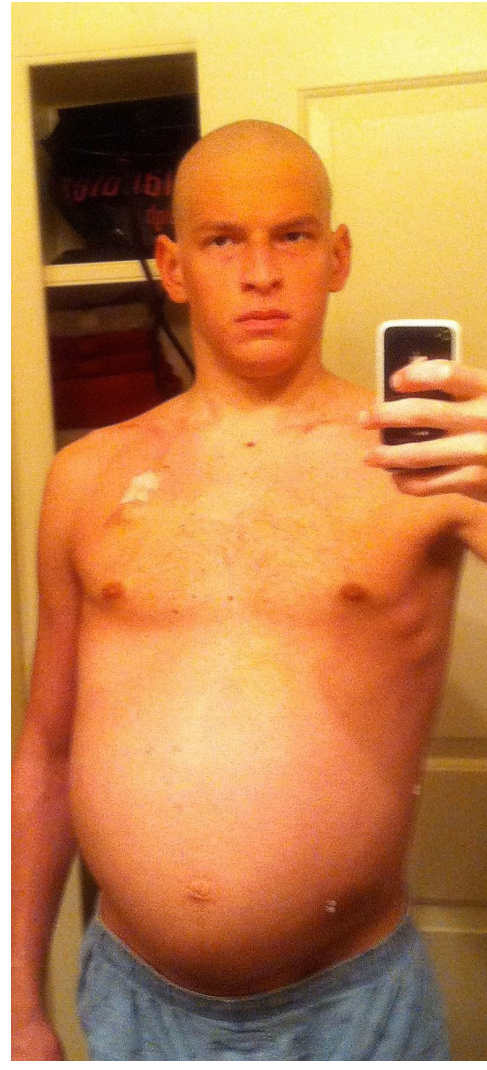
He learned enough to surprise his doctors by coming up with a way to treat his disease. Six years later, he's in remission, he and his wife have a baby girl, and he's devoting his medical career to saving other patients like him.

As a boy in Raleigh, North Carolina, David spent Saturdays watching the North Carolina State Wolfpack football team with his dad, the team's doctor.

At age seven, he was obsessed with becoming a Division I athlete. In middle school, he would wake up at 5 a.m. to go running. The walls of his bedroom were covered with football play charts.

He achieved his dream, making the Georgetown University football team as a quarterback. But in 2004, during his sophomore year, his mother died of a brain tumor.

His obsessive focus deepened, helping him learn to appreciate life's precious moments and understand that bad things happen to good people. "I know people far more worthy of miracles than I am who haven't gotten them," he says. David founded a support group for grieving college



students at Georgetown called Students of AMF—an acronym for Ailing Mothers and Fathers, as well as his mother's initials. (*Reader's Digest* wrote about his group in May 2008.)

David went on to earn a master's degree at the University of Oxford, where he learned how to conduct scientific research so that he could fight the disease that took his mom. That relentless focus and scientific rigor would one day save his life.

David entered medical school at the University of Pennsylvania to become a doctor like his father—specifically, an oncologist, in tribute to his late mother.

In 2010, during his third year, he got very sick and was hospitalized for five months. Something was attacking his liver, kidneys, and other organs and shutting them down.

The diagnosis was idiopathic multicentric Castleman disease. First described in 1954, Castleman presents partly like an autoimmune condition and partly like cancer. It's about as rare as ALS; there are around 7,000 new cases each year in the United States.

The disease causes certain immune-signaling molecules, called cytokines, to go into overdrive. It's as if they're calling in fighter jets for all-out attacks on home territory.

In his hospital bed, David felt nauseated and weak. His organs were failing, and he noticed curious red spots on his skin. He asked each new doctor who came in his room what the "blood moles" meant. But his doctors, focused on saving his life, weren't interested in them.

"They went out of their way to say they didn't matter," David says. But the med student turned patient would prove he was on to something.

"Patients pick up on things no one else sees," he says.

Castleman disease struck David four more times over the next three years, with hospitalizations that ranged from weeks to months. He stayed alive only through intense chemotherapy "carpet bombing" campaigns. During one relapse at a Duke University hospital, his family called in a priest to give him his last rites.

"I don't think I would have felt comfortable trying the treatment on another patient; there were too many unknowns. Who knew what problems could arise when you shut down a volatile immune system like mine."

DAVID FAJGENBAUM, IN HIS BOOK **CHASING MY CURE**

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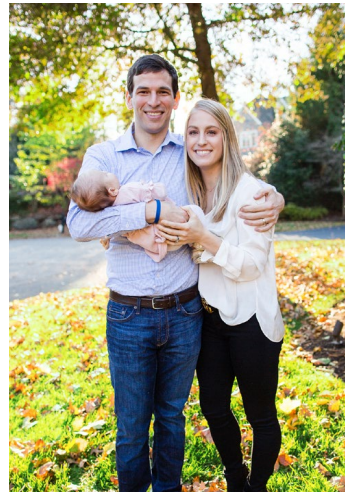
After all the setbacks, all the organ failure, all the chemo, David worried that his body would simply break. Yet despite it all, he managed to graduate from medical school. He also founded the Castleman Disease Collaborative Network (CDCN), a global initiative devoted to fighting Castleman disease.

Through the CDCN, he began bringing the world's top Castleman disease researchers together for meetings in the same room. His group worked with doctors and researchers as well as patients to prioritize the studies that needed to be done soonest.

Rather than hoping for the right researchers to apply for grants, they recruited the best researchers to investigate Castleman.

David also prioritized clinical trials that repurposed drugs the FDA had already approved as safe rather than starting from scratch with new compounds.



David Fajgenbaum with his wife and daughter (left), and in his office

COURTESY RACHEL UTAIN-EVANS/RACHELUTAINEVANS.COM (LEFT). PETER MURRAY (RIGHT)

Meanwhile, he never knew whether the next recurrence would finally kill him. Staving off relapses meant flying to North Carolina every three weeks to receive chemotherapy treatments.

Even so, he proposed to his college sweetheart, handing her a letter written by his niece that said, in part, "I'm a really good flower girl."

"The disease wasn't a hindrance to me," says his now-wife, Caitlin Fajgenbaum. "I just wanted to be together."

But in late 2013, Castleman struck again, landing David in that Arkansas hospital. It marked his closest brush with death yet.

Before he and Caitlin could send out their save-the-date postcards, David set out to try to save his own life.

After examining his medical charts, he zeroed in on an idea that—more than 60 years after Castleman disease

was discovered—researchers hadn't yet explored.

A protein called vascular endothelial growth factor, or VEGF, was spiking at ten times its normal level. David had learned in medical school that VEGF controls blood vessel growth,

"I was marrying the girl of my dreams, a woman who had recently been packing my body with ice like I was a coho salmon at Whole Foods. Here she was saying 'In sickness and in health, until death do us part,' and I didn't have to guess that she really meant it."

DAVID FAJGENBAUM, IN HIS BOOK **CHASING MY CURE**

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and he hypothesized that the blood moles that had shown up with every Castleman relapse were a direct result of that protein spike, which signals the immune system to take action.

He also knew that there was an immunosuppressant called sirolimus that was approved by the FDA to help fight the immune system when it activated against kidney transplants.

After consulting with a National Institutes of Health expert, David asked his doctor to prescribe the drug. He picked it up in February 2014 at a pharmacy less than a mile from his home. "A drug that could potentially save my life was hiding in plain sight," he says.

So far, it's working. David has been in remission from Castleman for more than six years. He's not the muscular football player he once was, but he's close to full strength. He is now an assistant medical professor at the University of Pennsylvania, running a research lab and enrolling patients in a clinical trial for the drug that has given him his life back.

In 2018, he and Caitlin became parents when their daughter, Amelia, was born. "She's such a little miracle," Caitlin says. "We're so lucky to have her."

David hopes his story offers lessons far beyond medicine about what people can do when they're backed against a wall.

And he feels his suffering means something when he looks in the eyes of his patients with Castleman disease. One girl, named Katie, was diagnosed at age two and endured 14 hospitalizations.

Then her doctor prescribed David's drug after the family reached out to the CDCN. Katie hasn't been hospitalized since and just finished kindergarten. She has even learned how to ride a bike.

He Fixed His Own Heart

BY *Sorrel Downer*

DAVE IMMS

WHEN TAL Golesworthy (above) was told he needed lifesaving heart surgery in 1993, he said no.

Golesworthy has Marfan syndrome, a genetic condition affecting the strength and elasticity of connective body tissues, including blood vessels. Back in 1993, when he was living in Cheltenham, in the west of England, his doctor told him that a major artery in his heart, the aorta, was so enlarged that it would inevitably rupture unless he underwent major surgery.

"They talked through the surgical options," says Golesworthy, "and I was not interested. The operation really didn't look attractive." What he particularly didn't like was having to be on blood thinners after the operation, something that would prevent blood clots but presented its own risks: "I was riding motorbikes then, and skiing, so my whole lifestyle would have been affected."

By 2000, however, his condition had worsened. Realizing something had to be done, Golesworthy put his years of experience as a

research-and-development engineer with the United Kingdom's National Coal Board to good use. He decided he would fix himself.

"Learning new stuff and developing new ideas, that was my job," Golesworthy says. A bulging aorta, he reckoned, was much like a bulging hydraulic hose—it needed external support. And wrapping something around the outside of the aorta would require a less invasive operation. So Golesworthy subjected himself to 30 hours in an MRI scanner; used 3D printing to create a physical replica of the faulty part of his heart (the aortic root); and then used soft, porous textile mesh to make a sleeve to fit around it.

"Luckily, I'd done a lot of work with technical textiles, looking at filters for flue gases in coal-fire processes," he says.

Sheer determination coupled with an original yet practical solution won him the support of two leading cardiothoracic surgeons and helped him raise the money to develop his idea. In May 2004, at the age of 47, he became the guinea pig for his own invention, the ExoVasc Personalised External Aortic Root Support (PEARS). The operation was a success. It has since been used by surgeons in the United Kingdom, Ireland, Belgium, Czech Republic, New Zealand, Australia, and the Netherlands. "When you're as motivated as I was," Golesworthy told mosaic.com, "you make things happen."

He Created an Eye-Saving App

BY *Marc Peyser*

The telltale white spot in Noah's right eye (left); Elizabeth and Bryan Shaw with Noah (far right) and his siblings

COURTESY BRYAN SHAW (LEFT). MARIAH EVANS (RIGHT)

LIKE ALMOST EVERY SET of new parents, Bryan and Elizabeth Shaw started snapping pictures of their son, Noah, practically from the moment he was born. When he was about three months old, Elizabeth noticed something odd when she took his picture. The flash on their digital camera created the typical red dot in the center of Noah's left eye, but the right eye had a white spot at the center, almost as if the flash was being reflected back at the camera by something. When Elizabeth mentioned the strange phenomenon to their pediatrician, she shined a light into Noah's eye, saw the same white reflection, and immediately sent the family to an ophthalmologist. A white reflection instead of a red one is a telltale sign of retinal cancer, and that is exactly what Noah had. He endured months of chemotherapy and radiation, but doctors ultimately could not save his eye.

Retinoblastoma, the scientific name of Noah's tumor, is treatable if caught early. Bryan Shaw couldn't help but wonder whether there were signs he'd missed. He went back over every baby picture of Noah he could find—thousands of them—and discovered the first white spot in a photo taken when Noah was 12 days old. As time went on, it appeared more frequently. "By the time he was four months old, it was showing up in 25 percent of the pictures taken of him per month," Bryan, a chemistry professor at Baylor University in Texas, told *People*.

It was too late for Noah's eye, but Bryan was determined to put his hard-won insights to good use. He created a database that charted the cancer's appearance in every photo. He also collected photos and compiled the data from eight other children with retinoblastoma. Armed with that data, he began to work with colleagues in Baylor's computer science department to develop a smartphone app that can scan the photos in the user's camera roll to search for white eye and can be used as a kind of ophthalmoscope. Called White Eye Detector, it is now available for free on Google Play and in Apple's App Store. "I just kept telling myself, I really need to do this," Bryan told *People*. "This disease is tough to detect. Not only could this software save vision, but it can save lives." R