One life, two donated organs and $5.7 million in bills – a tale of superbugs’ deadly costs

By Yasmeen Abutaleb, Ryan McNeill and Deborah J. Nelson | Filed Nov. 18, 2016, 1 p.m. GMT

Recovering from transplant surgery, Dan Greulich fell prey to a drug-resistant infection. What happened over the next five months shows the terrible human and financial price of an epidemic raging through the U.S. healthcare system.

LOS ANGELES – With good reason, Dan Greulich’s doctors called him “the miracle man.”

In the span of a decade, the insurance company executive engaged not once, but twice, in a race with death as he awaited replacements for failing organs. And twice, just as death was poised to win, he made it to the top of the national transplant list – ahead of thousands of other dying people. Donor organs became available, he was rushed into surgery, and he emerged with a new lease on life.
After Greulich’s second combined liver-and-kidney transplant in early 2012, his wife, Rae, sent a letter to the donor’s family. “You not only saved a man,” she wrote, “you saved a family.”

But then, less than three weeks into his recovery at University of California-Los Angeles Medical Center, Greulich contracted an antibiotic-resistant infection – a common and often lethal hazard of hospital stays. Over the next five months, according to thousands of pages of medical and billing records reviewed by Reuters, Greulich was attacked by no fewer than half a dozen different “superbugs,” most of them strains that are encountered almost exclusively in healthcare facilities.

Greulich’s immune system, suppressed by medications to prevent organ rejection, had no way to fight the bacteria. When the usual antibiotics failed to snuff them, he was pumped full of powerful alternatives, sometimes as many as half a dozen a day. Some had alarming side effects — hearing loss, severe pain, nausea. The infections kept coming.

Sepsis, a dangerous inflammatory response to infection, set in. Confined to an intensive-care unit (ICU), Greulich was frequently placed on mechanical ventilation, itself a common source of infection. He wavered in and out of consciousness. Doctors cut him open again to seek the source of the problem. At one point, they considered putting him back on the transplant list, but only if they could clear him of infection.

They couldn’t. On June 30, 2012, Greulich died, age 64.

Dan Greulich is one of the uncounted – the tens of thousands of people in the United States whose infections and deaths by superbug are not tracked by public health agencies.

As revealed in the first article in this series, deaths related to drug-resistant infections often aren’t recorded as such on death certificates. Greulich’s death certificate blames “cardiac arrhythmia,” or an irregular heartbeat. Even when superbug deaths are recorded, tens of thousands a year go uncounted because federal and state agencies are doing a poor job of tracking them. Today, the lack of a unified national surveillance system makes it hard to fight a scourge that officials 15 years ago declared to be a grave threat to public health.

Deaths like Greulich’s speak to the high human toll of superbugs. But Greulich’s death and, in particular, the effort to prevent it also speak to the enormous waste caused by the infections: two precious organs in a country where 22 people die every day waiting for one; thousands of hours put in by dozens of doctors, nurses and other medical workers to save a life; and big sums of money spent on drugs, surgery and hospital care, contributing to the billions of dollars superbugs add to the U.S. healthcare bill every year.

“Two people that could have gotten those organs died waiting for those organs,” Rae Greulich said.
“To see it become a failure is certainly devastating,” said Dr David Klassen, chief medical officer of the United Network for Organ Sharing (UNOS), the Richmond, Virginia, nonprofit group that coordinates all U.S. transplants.

It isn’t clear how Greulich contracted the superbugs that killed him. UCLA Medical Center declined to make anyone available to discuss his illness and hospitalization. In a statement emailed to Reuters, the hospital said: “We treat many severely ill patients who require complex care, and we have detailed procedures and protocols in place to prevent, detect and treat infections.”

Beyond the loss of viable organs that could have saved other lives, Greulich’s infections added to the growing national tab for treating them. Records show that from the time he first entered UCLA Medical Center in December 2011, until he died seven months later, Dan Greulich racked up a total bill of $5.7 million.

How much of that went toward treating Greulich’s superbug infections and how much went toward his transplant surgery and related treatments is hard to determine precisely. Too many other variables are at play. However, at $5.7 million, the charges for Greulich’s seven-month hospitalization were nearly five times what the National Foundation for Transplants says are the average first-year charges for a liver-and-kidney transplant.

Charges for antibiotics he was given in a failed attempt to beat his infections were at least $230,000, exceeding the $200,000 in charges for obtaining and transplanting a liver and kidney. Charges for seven months of “accommodations” at UCLA Medical Center totaled $2 million.

AN ELUSIVE NUMBER

Lack of reliable data hinders any effort to calculate how much superbugs add to overall U.S. healthcare costs. The Centers for Disease Control and Prevention (CDC) cites figures from a 2009 study sponsored by the Alliance for Prudent Use of Antibiotics that put the annual cost of antibiotic-resistant infections at more than $20 billion.

But that figure is extrapolated from data from a single hospital. And it uses infection rates from 2000, which were far less than what they are now.

Dr Stuart Levy, director of Tufts University’s Center for Adaptation Genetics and Drug Resistance in Boston and an author of the 2009 study, acknowledged the limitations of the analysis. “The important point was we were supposed to show this was a very costly consequence of doing hospital care,” he said.

Reuters undertook its own analysis to get an idea of how much superbug infections cost. Using national inpatient data from the federal Agency for Healthcare Research and Quality for 2013, the analysis of millions of records focused on infections from two superbugs: methicillin-resistant Staphylococcus aureus (MRSA) and Clostridium difficile.

The deadly epidemic America is ignoring

It found that an infection can add thousands of dollars to the cost of a patient’s hospital stay. The average MRSA infection added about $11,000 per inpatient stay, while *C. difficile* added about $5,200.

In all, Reuters found that the two infections combined added about $6 billion in charges to hospital stays nationwide in 2013. MRSA infections added about $4.1 billion, and *C. difficile* added about $1.9 billion. To calculate those numbers, Reuters used a method called propensity score matching to compare costs for patients with and without infection who are otherwise similar in terms of demographic characteristics, other illnesses, hospital setting and so on.

While MRSA and *C. difficile* are two of the most common and well-known drug-resistant pathogens, they are only two of 18 superbugs the CDC considers to be a threat to public health, suggesting a total cost much higher than $6 billion. Some of those other infections, while not as widespread, can be far more costly to treat.
Most superbug infections are contracted in hospitals and other medical facilities. The big bills that result are most often covered by health insurers and other third-party payers. This means that ultimately, the costs are passed to consumers in the form of higher insurance premiums, said David Cutler, a Harvard University economist who specializes in healthcare. “There is no other way to do it,” he said.

Private insurers generally do not deny reimbursement for treatment related to superbug infections. Even in cases where hospitals are held legally liable for the infections, they are often shielded from eating the full cost.

James Woodard contracted a MRSA infection at age 64 while in the University of New Mexico Hospital for back surgery in 2012. The infection led to a dozen more surgeries over four years and left him wheelchair-bound and with memory loss. But he hasn't forgotten the pain as the infection spread: “It felt like someone was hacking my body in half,” he said.

In a malpractice suit Woodard and his wife brought against the hospital, a jury earlier this year found the hospital at fault and awarded Woodard and his wife $4.25 million for medical costs, Woodard’s injuries and other damages.

But New Mexico caps malpractice awards. Within those limits, the hospital is asking the court to set the award at $700,000, said hospital spokesman Luke Frank. That is less than the $973,000 that Frank said the hospital received in payments from Woodard’s insurer.

Hospitals “make money on those complications,” said Woodard’s lawyer, Amalia S. Lucero. And Woodard could end up with even less if his own insurer recovers some of the money it paid to the hospital from whatever award Woodard receives.

More than half the states have imposed caps on malpractice awards in response to medical and insurance industry concerns that multi-million-dollar verdicts were driving up the cost of healthcare and premiums.

The Centers for Medicare & Medicaid Services (CMS) penalizes hospitals for high infection rates by reducing payments from the huge Medicare government health-insurance program for the elderly. And the agency does not pay the added costs of some types of preventable infections, such as catheter-associated urinary tract infections, if they are contracted in the hospital.

Hospitals have found a way to get around the CMS payment restrictions. Several studies have shown that hospitals sometimes use a strategy called “upcoding,” whereby they manipulate the codes for submitting reimbursement claims so that they receive payment for infection-related treatments. For instance, a hospital could claim an infection was present when the patient was admitted, rather than acquired in the hospital. Or it could not mention an infection at all.
A 2015 study from the Stanford Graduate School of Business estimated that CMS reimbursed for more than 10,000 “upcoded” claims from 2009 to 2010, costing Medicare a total of $200 million.

As for Dan Greulich’s $5.7 million bill, his widow, Rae, said the couple paid about $10,000 themselves. Most of the balance was covered by Dan’s employer-sponsored insurance with Anthem Inc.

The insurance company declined to comment. Hospital charges are typically a starting point that insurers end up negotiating down. Payment records for Greulich’s seven-month stay at UCLA Medical Center show that Anthem paid at least $2.9 million.

LONG ODDS

One day in February 2000, Dan Greulich failed to show up for work as a senior vice president of property and casualty insurer Western Mutual at the company’s Agoura Hills, California, office. His son, Tim, found him lying unconscious on the floor at home.

At the hospital, doctors told Greulich that his liver and kidneys were failing, damaged beyond repair from his years of heavy drinking. He probably wouldn’t live more than a couple of months. His alcoholism disqualified him for a life-saving transplant.

“Two people that could have gotten those organs died waiting for those organs.”

Rae Greulich
Greulich began attending Alcoholics Anonymous meetings while undergoing dialysis four times a week. “He completely gave up [alcohol] the second he went to that hospital,” Tim said. “He never picked up a drink after that.”

By the end of 2000, he was on the transplant waiting list. The hospital entered his information into a computer system run by UNOS, the transplant coordinator, which uses information from hospitals and organ-procurement groups across the country to match donors with recipients.

The odds were against him. In 2001, the 6,080 people who died and became donors didn’t come near to covering the 86,000 people waiting for organs.

As Greulich waited, his health deteriorated. He struggled to make it through each workday. He spent lunch hours napping in his car.

Then, in July 2002, he got his first transplant. Recovery, according to Rae, was complicated by his first encounter with superbugs: He contracted a MRSA infection, which kept him in the hospital until September.

A month later, after about two years as a couple, Dan and Rae got married. Tim, Dan’s son from a previous marriage, lived with them. Dan returned to work, paring down his hours from 60 to 45 a week. He and Rae bought their dream home in Simi Valley, in the mountains 40 miles outside of Los Angeles. They had fruit trees in their backyard – lemon, orange, pomegranate – and kept horses.

For nine years, Dan remained healthy and was “very religious” about taking his transplant medications, according to medical records.

In 2011, he began taking an herbal remedy called St. John’s wort to cope with stress at work. He didn’t know the plant could block the effects of anti-rejection drugs. On Dec. 6, nearly a decade after his first double transplant, Dan was back in UCLA Medical Center, his donated liver and kidney failing.

He was soon relisted for a transplant. Again, as he waited, his health declined. On Jan. 5, 2012, medical records show, he was vomiting blood, and he was moved to an intensive-care unit. He was charged the next day for his first night in the intensive-care bed: $10,400.

His skin grayed. He spent more time sleeping. Every day, it seemed more likely that he would die before he made it to the top of the transplant list.

In the early morning hours of Jan. 25, Rae received a call in her hotel room: A 40-year-old woman had died, and she was an organ donor. Dan was at the top of the waiting list.

“Everything’s going to be OK,” Rae said she was thinking hours later, as Dan was wheeled into surgery.
A second transplant is far more complicated and risky than the first, said Dr Fady Kaldas, an associate professor of surgery at UCLA specializing in liver transplants who was part of Dan’s medical team. Dan was losing so much blood during the operation that doctors spread the procedure over two days to give his body time to stabilize. At one point, Rae recalled, doctors told her they were losing Dan.

He survived — one of 462 people to get a double transplant that year. His new liver soon began working on its own. His sister, Pat Herbert, said he told her he would make it to Florida for her birthday in May. His rosy color returned. Even when his new kidney didn’t take, meaning he would have to rely on dialysis, he remained optimistic.

Then, in early February, as nurses were removing post-surgical drains from Dan’s abdomen, a nauseating stench filled the ICU room, Rae recalled.

Rae suspected something was awry. She was right. Dan’s medical records show that lab tests of fluid from the drains found two drug-resistant pathogens, Citrobacter freundii and Aeromonas. And they weren’t Dan’s first infections. He was already fighting a fungus called Candida albicans, which can be especially dangerous in transplant patients.

MODERN DANGERS

Modern medical advances – complex organ transplants, drug therapies, devices such as ventilators and dialysis machines – sustain life for people who would otherwise die. But they come at a cost. They leave many people – cancer patients, people with HIV, premature infants, anyone with a suppressed or weakened immune system – particularly vulnerable to bacteria. At the same time, many of the bacteria that thrive in the hospitals where these people are concentrated have developed resistance to antibiotics.

Dan Greulich was the perfect target. Transplant patients take drugs for the rest of their lives that suppress their immune systems so that their own bodies don’t reject the donor organs. That leaves them vulnerable to opportunistic pathogens like the two that showed up in Dan’s lab tests. Both rarely cause illness in otherwise healthy people; for the immune-compromised, they can be deadly.

Hospitals have well-established protocols to contain the threat. At UCLA Medical Center, once Greulich tested positive for drug-resistant infections, everyone – doctors, nurses, technicians, Rae, other relatives – had to don a gown and gloves before entering his room and discard them when leaving.
Rae said she repeatedly asked nurses about Dan’s post-operative drains. They told her only that he had a fungal infection, she said. No one told her the names of the pathogens, or that they were resistant to multiple drugs, or how dangerous they were. UCLA Medical Center declined to comment.

Dan was now battling sepsis – life-threatening inflammation that is triggered throughout the body in a haywire response to infection. His blood pressure was abnormally low. His heartbeat was rapid and weak. Breathing was difficult, and he was often placed on mechanical ventilation, inserted through a tracheostomy, a hole surgeons cut into his windpipe. He was receiving dialysis through a port in his groin. He received fluids and drugs – including increasing amounts of ineffective antibiotics – through multiple tubes inserted into his veins and arteries.

He was seldom lucid. Occasionally he would utter an “I love you” to Rae or ask how his recovery was going. Rae usually lied. “You’re doing so much better,” she would say, to encourage him to keep fighting.

Doctors were desperate to locate the infection behind Dan’s sepsis. On Feb. 22, they wheeled him into surgery again and opened his abdomen, distended with retained fluid.

This was risky in a patient so ill. “It’s not necessarily the easiest thing to take somebody who’s so stressed and sick and take them back to surgery,” Kaldas said.

The surgery failed to reveal a definitive site of infection. Dan’s medical bills show at least $20,000 in related charges – for the operating room, the procedure, anesthesia and a liver biopsy.

In March, Dan tested positive for a drug-resistant strain of *Enterococcus*. Unrelenting sepsis caused his body to swell. His skin was stretched tight and easily punctured. When Rae tried to clip his fingernails one day, he bled.

Doctors had put Dan on drugs called vasopressors, which constrict blood vessels and thus raise the dangerously low blood pressure that sepsis causes. But that same mechanism also decreases essential blood flow to new organs, putting them at risk.

“That’s what makes sepsis such an evil process ... It just wreaks havoc on your body, including a delicate transplanted liver,” Kaldas said. “It’s always a game of what’s going to happen first. Are these organs just going to fall apart from being on vasopressors for a week, or is the infection going to go away first?”

Another month, another infection. In early April, it was vancomycin-resistant *Enterococcus* (VRE), another common menace to hospital patients with weakened immune systems.

A few days later, Rae recalled, two of Dan’s doctors sat down with her for a talk. Imaging showed that his new liver was a potential site of infection and a probable source of his sepsis.

If they could clear Dan of the infections, they would consider him for a third liver-and-kidney transplant. In notes dated April 18, 2012, Dr Leonard Irwin Goldstein wrote that another transplant would provide “his best chance for long-term survival.”
Only now, Rae said, did she realize that Dan’s struggle was not to recover from transplant surgery, but from a barrage of infections. “Nobody said he had a laundry list of infections,” she said.

She started researching infection control and keeping a close eye on the nurses caring for Dan. In the ensuing weeks, she wrote three letters to the ICU’s nurse manager to urge vigilance against further infection and to list lapses she noticed in her husband’s care.

In a May 7 letter, she described stopping a nurse from starting an intravenous line when she saw that the nurse wasn’t going to change gloves after touching cabinet drawers and other potentially contaminated surfaces. UCLA Medical Center declined to comment.

Since February, Dan had undergone increasingly aggressive antibiotic therapy. By the end of March, records show, he had been charged about $45,000 for the drugs. Then, for April alone, the amount ballooned to more than $110,000. Of that, $93,000 covered charges for 169 doses of Synercid, a combination of quinupristin and dalfopristin that is one of the few drugs that can beat back VRE.

In just one day — May 2, 2012 — Dan was given six different antimicrobial drugs: amikacin, cefepime, daptomycin and Synercid, all of them commonly used to treat multi-drug-resistant infections; Bactrim; and caspofungin, an anti-fungal.

Many of these drugs are hard on the body. The Synercid caused severe bone pain. Dan, who for months hadn’t complained about his pain, uttered to his wife, “I’m in agony,” according to Rae.

At Rae’s request, doctors eventually stopped the drug.

“Antibiotics beat you up,” said Kaldas. “Imagine somebody on nuclear weapons of antibiotics, and they’re on 10 of them, or five of them, or three of them. It’s a lot to ask.”

By June, the continuing antibiotic therapy had left Dan nearly deaf. His hair had fallen out. On and off a ventilator, he had suffered several bouts of pneumonia.

Doctors now said Dan would never be well enough for another transplant. He was going to die. They urged him to sign a “do not resuscitate” order.

He refused. Rae posted a sign above his bed: “Mr. Greulich very clearly stated NO DNR and wants aggressive treatment.”
For Dan’s medical team, giving up on a third transplant was an admission of defeat.

“What we worry about is putting yet another organ into somebody that’s going to go the same way as the last organ,” said Kaldas. “You’ve developed a relationship with this patient ... There’s nothing you want more than to see them get better. But you have to take a step back and say, well, a third liver will not make this person get better.”

After months of illness, pain and confinement, Dan began to lose his will to live. He told Rae he felt worthless and that he knew he wasn’t ever going to recover.

On June 29, Rae walked into his hospital room a little before 9 a.m., as she had nearly every day for the past seven months. He was sitting up in bed, alert and almost perky, she said.

“I want to die,” he told her.

The next day, Rae and Dan’s son, Tim, 24 years old at the time, stood at Dan’s bedside, holding his hands. They said their goodbyes. Just before 11:30 a.m., doctors turned off Dan’s dialysis machine. He soon lost consciousness. Rae and Tim watched as the tracing on Dan’s heart monitor slowed and slowed and then flat-lined.

Greulich’s death certificate did not mention sepsis or the infections that caused it. His autopsy report, however, lists at least five pathogens present in samples taken from his body, most of them drug-resistant. The report states: “The autopsy findings and microbiology studies support the clinical diagnosis of septic shock, which appears to be the immediate cause of death.”

“It was clearer than anything that he died of septic shock,” Rae said. “When I got the death certificate, I was staggered.”

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The Uncounted

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