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HEALTH

60 Lives, 30 Kidneys, All Linked

By KEVIN SACK FEB. 18, 2012

RIVERSIDE, Calif. — Rick Ruzzamenti admits to being a tad impulsive. He traded his Catholicism for Buddhism in a revelatory flash. He married a Vietnamese woman he had only just met. And then a year ago, he decided in an instant to donate his left kidney to a stranger.

In February 2011, the desk clerk at Mr. Ruzzamenti's yoga studio told him she had recently donated a kidney to an ailing friend she had bumped into at Target. Mr. Ruzzamenti, 44, had never even donated blood, but the story so captivated him that two days later he called Riverside Community Hospital to ask how he might do the same thing.

Halfway across the country, in Joliet, Ill., Donald C. Terry Jr. needed a kidney in the worst way. Since receiving a diagnosis of diabetes-related renal disease in his mid-40s, he had endured the burning and bloating and dismal tedium of dialysis for nearly a year. With nobody in his family willing or able to give him a kidney, his doctors warned that it might take five years to crawl up the waiting list for an organ from a deceased donor.

“It was like being sentenced to prison,” Mr. Terry recalled, “like I had done something wrong in my life and this was the outcome.”

As a dawn chill broke over Chicago on Dec. 20, Mr. Terry received a plump pink kidney in a transplant at Loyola University Medical Center. He did not get it from Mr. Ruzzamenti, at least not directly, but the two men will forever share a connection: they were the first and last patients in the longest chain of kidney transplants ever constructed, linking 30 people who were willing to give up an organ with 30 who might have died without one.

What made the domino chain of 60 operations possible was the willingness of a Good Samaritan, Mr. Ruzzamenti, to give the initial kidney, expecting nothing in return. Its momentum was then fueled by a mix of selflessness and self-interest among donors who gave a kidney to a stranger after learning they could not donate to a loved one because of incompatible blood types or antibodies. Their loved ones, in turn, were offered compatible kidneys as part of the exchange.

Chain 124, as it was labeled by the nonprofit National Kidney Registry, required lock-step coordination over four months among 17 hospitals in 11 states. It was born of innovations in computer matching, surgical technique and organ shipping, as well as the determination of a Long Island businessman named Garet Hil, who was inspired by his own daughter’s illness to supercharge the notion of “paying it forward.”

Dr. Robert A. Montgomery, a pioneering transplant surgeon at Johns Hopkins Hospital, which was not involved in the chain, called it a “momentous feat” that demonstrated the potential for kidney exchanges to transform the field. “We are realizing the dream of extending the miracle of transplantation to thousands of additional patients each year,” he said.

The chain began with an algorithm and an altruist. Over the months it fractured time and again, suspending the fates of those down the line until Mr. Hil could repair the breach. Eventually, he succeeded in finding needle-in-a-

haystack matches for patients whose antibodies would have caused them to reject organs from most donors.

Until now, few of the donors and recipients have known one another's names. But 59 of the 60 participants consented to be identified by The New York Times and to tell the stories, each with distinct shadings, that ultimately connected them.

Despite an intensely bitter breakup, a Michigan man agreed to donate a kidney for his former girlfriend for the sake of their 2-year-old daughter. A woman from Toronto donated for her fifth cousin from Bensonhurst, Brooklyn, after meeting him by chance in Italy and then staying in touch mostly by text messages.

Children donated for parents, husbands for wives, sisters for brothers. A 26-year-old student from Texas gave a kidney for a 44-year-old uncle in California whom he rarely saw. In San Francisco, a 62-year-old survivor of Stage 4 Hodgkin's lymphoma donated for her son-in-law.

On Aug. 15, Mr. Ruzzamenti's kidney flew east on a Continental red-eye from Los Angeles to Newark and was rushed to Saint Barnabas Medical Center in Livingston, N.J. There it was stitched into the abdomen of a 66-year-old man.

The man's niece, a 34-year-old nurse, had wanted to give him her kidney, but her Type A blood clashed with his Type O. So in exchange for Mr. Ruzzamenti's gift, she agreed to have her kidney shipped to the University of Wisconsin Hospital in Madison for Brooke R. Kitzman's transplant. It was Ms. Kitzman's former boyfriend, David Madosh, who agreed to donate a kidney on her behalf despite their acrimonious split.

Mr. Madosh's kidney flew to Pittsburgh for Janna Daniels, a clerical supervisor, who got her transplant at Allegheny General Hospital. And her husband, Shaun, a mechanic, sent his kidney to Mustafa Parks, a young father of two at Sharp Memorial Hospital in San Diego.

On and on the chain extended, with kidneys flying from coast to coast, iced down in cardboard boxes equipped with GPS devices and stowed on commercial aircraft.

In a system built on trust, one leap of faith followed another. The burdens of scheduling operations all across the country — so donors would not have to travel — meant that operations were not always simultaneous, or even sequential. The most worrisome risk was that donors would renege once their loved ones received kidneys.

After John A. Clark of Sarasota, Fla., got a transplant on Sept. 28 at Tampa General Hospital, his wife, Rebecca, faced a 68-day wait before it was her turn to keep the chain going. Ms. Clark said that it crossed her mind to back out, but that she swatted away the temptation.

“I believe in karma,” Ms. Clark said, “and that would have been some really bad karma. There was somebody out there who needed my kidney.”

An Organ to Spare

It is considered a quirk of evolution that humans have two kidneys when they need only one to filter waste and remove excess fluid from the body. Yet when kidneys fail, whether from diabetes or high blood pressure or genetic disorders, they tend to fail in tandem.

Death can arrive in a matter of weeks for many renal patients if they do not have their blood cleansed through dialysis. The process takes almost four hours, three times a week, and leaves many too drained to work. Only half of dialysis patients survive more than three years.

Many of the 400,000 Americans who are tethered to dialysis dream of a transplant as their pathway back to normal. But with the demand for kidneys rising faster than the number of donors, the waits have grown longer. While

about 90,000 people are lined up for kidneys, fewer than 17,000 receive one each year, and about 4,500 die waiting, according to the United Network for Organ Sharing, which maintains the wait list for the government.

Only a third of transplanted kidneys come from living donors, but they are coveted because they typically last longer than cadaver kidneys. For kidneys transplanted in 1999, 60 percent of organs from live donors were still functioning after 10 years, compared with 43 percent of organs from deceased donors.

Although other living tissue can be transplanted — slices of pancreas, liver and intestine, bone marrow and lobes of lung — kidneys are uniquely suited because donors have a spare and the operations are almost always successful.

A reason there are not more live kidney donations, however, is that about a third of transplant candidates with a willing donor find that they are immunologically incompatible. Some, because of previous transplants, blood transfusions or pregnancies, may have developed antibodies that make them highly likely to reject a new kidney.

Using a blood-filtering technique known as plasmapheresis, doctors can now lower the odds that a recipient will reject an incompatible kidney. But the procedures are taxing and expensive.

Domino chains, which were first attempted in 2005 at Johns Hopkins, seek to increase the number of people who can be helped by living donors. In 2010, chains and other forms of paired exchanges resulted in 429 transplants. Computer models suggest that an additional 2,000 to 4,000 transplants could be achieved each year if Americans knew more about such programs and if there were a nationwide pool of all eligible donors and recipients.

Such transplants ultimately save money as well as lives. The federal Medicare program, which pays most treatment costs for chronic kidney disease, saves an estimated $500,000 to $1 million each time a patient is removed from dialysis through a live donor transplant (the operations typically cost $100,000 to $200,000). Coverage for kidney disease costs the government more than $30 billion a year, about 6 percent of the Medicare budget.

Dialysis, which in the United States is almost always administered in outpatient clinics, saps the productivity of caregivers as well as of patients. Nearly two years ago, Kent Bowen, 47, of Austin, Tex., gave up his job hanging gutters, and much of his freedom, so he could provide dialysis at home to his mother, Mary Jane Wilson.

Before donating a kidney for her as part of the chain on Dec. 7 at Methodist Hospital in Houston, Mr. Bowen said he looked forward not only to helping his mother, but also to a long-deferred fishing trip.

“In all actuality,” he said, “giving a kidney is a small price to pay for getting my life back.”

Understanding the Pain

Garet Hil and his wife, Jan, may never fully recover from the snowy night in February 2007 when they took their 10-year-old daughter in with flu symptoms and emerged with a shocking diagnosis of nephronophthisis, a genetic kidney-wasting disease. They could not imagine sacrificing her youth to dialysis.

Because Mr. Hil and his daughter shared the same blood type, he assumed he would be able to give her one of his kidneys. But two days before surgery, doctors canceled the operations after discovering that his daughter had developed antibodies that would most likely cause rejection.

Jan Hil and six other family members volunteered but were also ruled out. Mr. Hil and his daughter joined several of the registries that had started to arrange kidney exchanges, but the pools were small and they never found a match. Fortunately, one of Mr. Hil’s nephews then was tested and was able to donate.

After the successful transplant, Mr. Hil, a veteran business executive, could not shake his frustration that a more effective registry for paired kidney donation did not exist. “The exchange systems out there weren’t industrial strength,” he said.

By the end of 2007, the Hils had formed the National Kidney Registry and rented office space in an old clapboard house in Babylon, N.Y. The couple invested about $300,000 to start it, and Mr. Hil, who is now 49, ran the registry without a salary.

“The goal was very simple: get everybody transplanted in under six months if you had a living donor,” he said. “One of the things that drove us was the enormity of the problem. The other thing that drove us was that we understood the pain of being in that situation.”

Mr. Hil turned out to be the right person to infuse the budding science of kidney exchange with an entrepreneurial spark. A former Marine reconnaissance ranger with an M.B.A. from the Wharton School, he had managed a series of data and logistics companies in Boston and New York and understood the worlds of both computing and finance.

He had made his money and could step off the career track to give the registry his time and the resources of his software-consulting firm. He had a background in quantitative math and enough drive to plow through medical texts about organ compatibility. Over time, he led a team in designing sophisticated software that evolved to build ever-longer chains.

Disney-hero handsome, with a cleft chin and thick wavy hair, Mr. Hil marketed his registry to hospitals with PowerPoints and passion. The transplant world initially regarded him as an interloper. But he has now persuaded 58 of the country’s 236 kidney transplant centers, including many of the largest, to feed his database with information about pairs of transplant candidates and their incompatible donors.

Starting at 5 a.m. each workday, Mr. Hil manipulates several hundred pairs into transplant chains with a few clicks of a mouse. Last year, he arranged 175 transplants this way, including the 30 in Chain 124, more than any other registry. On average, patients received transplants about a year after being listed.

The same year that Mr. Hil's daughter got sick, Congress amended the National Organ Transplant Act to clarify that paired exchanges do not violate federal laws against selling organs. The blessing from Washington broke down resistance in many hospitals just as the National Kidney Registry was opening for business.

The Evolving Chain

Although the first live kidney was transplanted in 1954 in Boston, three decades passed before a Stony Brook University surgeon named Felix T. Rapaport first theorized about kidney swaps in a 1986 journal article. Korean surgeons completed the first exchanges in 1991, but they were not successfully attempted in the United States for nearly another decade.

Simple swaps among two pairs, with the operations performed at the same hospital on the same day, quickly evolved into complex exchanges among three pairs and then four and then six.

Then in 2007, a transplant surgeon at the University of Toledo Medical Center, Dr. Michael A. Rees, had a forehead-slapping insight. If an exchange began with a Good Samaritan who donated to a stranger, and if the operations did not have to be simultaneous, a chain could theoretically keep growing, limited only by the pool of available donors and recipients. Dr. Rees reported in 2009 that he had strung together a chain of 10 transplants.

Mr. Hil seized on the idea and set out to build an algorithm that would enable even more transplants. Nowadays, his pool typically consists of 200 to 350 donor-recipient pairs. That is enough to generate roughly a googol — 10 to the 100th power — of possible chains of up to 20 transplants if all of the pairs are compatible, said Rich Marta, the registry's senior software designer.

The program quickly eliminates matches that will not work because of incompatible blood types or antibodies, or because a transplant candidate insists that a donor be under a certain age or a close immunological match. It then assembles up to a million viable combinations at a rate of 8,000 per second.

The algorithm ranks the possible combinations by the number of transplants they would enable, with weight given to chains that find kidneys for hard-to-match patients and those who have waited a long time.

There are several registries like Mr. Hil's, each with a distinct approach. Largely unregulated by government, they invite sensitive questions about oversight and ethics, including how kidneys are allocated. A number of medical societies are convening in March to seek consensus on that and other issues related to paired exchanges.

Mr. Hil knows the patients in his pool only by code names and leaves all personal interactions to the hospitals. He keeps several chains running at a time, and says tending to them is like playing three-dimensional chess.

Chain 124 even included one pair that was immunologically compatible. Josephine Bonventre, a 40-year-old real estate agent from Toronto with Type O blood, could have donated a kidney directly to a fifth cousin, Cesare Bonventre, a 27-year-old tile worker from Brooklyn with Type B.

But a second level of matching requires the synching of six antigens, a series of proteins that determine compatibility. By joining the chain and donating down the line, on Dec. 6 at NewYork-Presbyterian Hospital, Josephine enabled Cesare to get a stronger match — three antigens instead of one. Her donation as a valued Type O then set off the final 11 transplants.

The registry did not charge transplant centers for its services until 2010, when Mr. Hil imposed fees to help cover costs. Hospitals now pay membership dues and a charge of $3,000 per transplant that is reimbursed by many private insurers but not by Medicare. The transplant recipients must be insured.

Each year, the registry's chains have grown longer, with Chain 124 topping the previous record by seven transplants. "We've just scratched the surface," said Mr. Hil, who wears gold kidney-shaped cufflinks.

Long transplant chains save more lives than short chains. But they come with trade-offs because the longer they grow, the higher the risk that a donor will renege or that a link will break for other reasons.

The record-breaking chain survived its share of logistical setbacks. On Aug. 29, after the first five transplants, Mr. Hil lost a link because a donor could not take the necessary two to four weeks away from work. Later that day, he lost another when a transplant coordinator informed him that a potential recipient was an illegal immigrant and therefore could not be covered by Medicare.

In late October, an entire segment fell apart when a donor at California Pacific Medical Center in San Francisco backed out for unexplained "personal reasons." It was as if one domino had fallen short of the next, leaving those still standing frozen in place.

"This makes us all sick," Dr. Steven Katznelson e-mailed Mr. Hil. "We did not see this coming."

"Wow," Mr. Hil wrote back. The donor "just put 23 patients at risk."

The dependency of each link on the others kept patients on edge. "Things can happen," Candice Ryan fretted a few days before her Dec. 5 transplant at Massachusetts General Hospital. "You just pray that everything goes well. I can't relax until I'm asleep and on the table."

Depending on the makeup of his registry at any moment, Mr. Hil likes to stretch his chains as long as reasonable and then end them if a donor is difficult to match or if one chain is draining others of potential transplants.

He does so by arranging for the final kidney to go to a fortunate transplant candidate like Mr. Terry who does not have a willing donor.

The Initial Link

Until recently, hospitals regularly turned away Good Samaritan donors on the working assumption that they were unstable. That has changed somewhat with experience. But when Rick Ruzzamenti showed up at Riverside Community Hospital asking to give a kidney to anyone in need, he still underwent rounds of psychological screening as well as medical tests.

The doctors and social workers did not know what to make of Mr. Ruzzamenti at first. He had a flat affect and an arid wit, and did not open up right away. As the hospital's transplant coordinator, Shannon White, pressed him about his motivations and expectations, he explained that his decision seemed rather obvious.

"People think it's so odd that I'm donating a kidney," Mr. Ruzzamenti told her. "I think it's so odd that they think it's so odd."

The hospital wanted to make sure that he was not expecting glory, or even gratitude. Mr. Ruzzamenti stressed that no one should mistake him for a saint.

He had, after all, been a heavy drinker in his youth and had caroused his way through the Navy. He could be an unsmiling presence at work, where he helped manage a family electrical contracting business. He admitted that he did not visit his parents or grandmother enough.

Despite his occasional surliness, Mr. Ruzzamenti said he felt driven to help others when possible. And as he considered the relative risks and benefits of organ donation, particularly to relieve a whole chain of suffering, it just made so much sense. "It causes a shift in the world," he said.

Perhaps, he said, there was some influence from a Tibetan meditation he had practiced when he was first drawn to Buddhism six years ago. It is known as Tonglen. "You think of the pain someone's in, and imagine you take it from them and give them back good," he said.

Mr. Ruzzamenti said he was in a position to donate only because the economy had dried up so much of his work. He was essentially unemployed and could take time off to recuperate. The 30 kidney recipients, he observed dryly, could "all thank the recession."

When Mr. Ruzzamenti told his wife, My Nhanh, about his plans, she made it abundantly clear, despite her rudimentary English, that she would leave him and return to Vietnam if he followed through. She had immigrated only eight months before, after a marriage largely arranged by the Buddhist temple where Mr. Ruzzamenti volunteered as a groundskeeper. If he died on the table, she demanded, how would she get by in a country where she felt so out of place?

"I wanted to scare him," Ms. Ruzzamenti, who is known as Lucy, said as she combed her husband's close-cropped hair with her fingers. "And to tell him that it scares me."

Mr. Ruzzamenti was impressed by his petite wife's ferocity — "She's a bully," he said — but he disregarded her threat. He knew research showed that the risk of death from kidney retrieval surgery was 3 in 10,000 and that people with one kidney live as long as those with two. To him, there was little doubt that any good he created would far outweigh any temporary discomfort to him or his wife.

As it happened, Mr. Ruzzamenti experienced an unusual level of pain during his recuperation at Riverside. It sometimes left him balled up in agony, and the Demerol only made him hallucinate. He did not really want company. But when the pain stirred him awake at night, he could see Lucy sleeping in the hospital bed beside his.

Acts of Devotion

There were other love stories along the way.

Gregory Person and Zenovia Duke, both now 38, had been junior high prom dates in 1987 in Astoria, Queens. They lost touch and then reconnected on Facebook after each had divorced. They saw each other occasionally, but he lived in Queens and she near Albany, so the relationship never got serious.

Not long after they reconnected, Mr. Person's half-sister died of kidney failure and he pledged to help someone else beat the disease if ever given the chance. Then Ms. Duke learned that she needed a transplant.

On Aug. 31, Ms. Duke received a kidney from a woman in California and Mr. Person sent his to Ohio. As they recuperated at NewYork-Presbyterian, Mr. Person found himself regularly hobbling down to her room. Once they were both back on their feet, they started dating more regularly.

"I've never had any person in my life actually do what they say they're going to do," Ms. Duke said, "especially men. It spoke volumes that he was a man of his word."

It was a different kind of devotion that led David Madosh, 47, to donate a kidney for Brooke Kitzman, 30. Their four-year relationship, which had produced a 2-year-old daughter, soured just as he was getting tested as a potential donor. The breakup, caused partly by the strains of her illness, was ugly enough that when Ms. Kitzman later matched to become part of the chain, she put the odds at no better than 50-50 that Mr. Madosh would still donate.

But Mr. Madosh, who lost his mother when he was 5, did not want his daughter, Elsie, to lose hers.

The youngest of 12 children, he said he had been passed from one foster home to the next, eight in all, some that he described as little more than labor camps. "I don't want my daughter to have to experience that," said Mr. Madosh, a tree cutter by trade. "No matter what it takes, a daughter needs her mother."

Ms. Kitzman said she was grateful for Mr. Madosh's kidney, and had told him so when they visited in a hospital corridor. But both made it clear that his act of charity had barely eased the tension between them.

Mr. Madosh said he took satisfaction enough from seeing Elsie at play with her re-energized mother. “When her mama comes to get her, and she gives her hugs and kisses, that’s it right there,” he said.

A Wish Come True

On Dec. 19, Chain 124 hurtled toward its conclusion with a final flurry of procedures at Ronald Reagan U.C.L.A. Medical Center in Los Angeles. Between dawn and dusk, three kidneys were removed and three were transplanted in neighboring operating rooms. One flew in from San Francisco. The last took off for O’Hare.

At the end of the cluster were Keith Zimmerman, 53, a bearish, good-humored man with a billy-goat’s beard, and his older sister, Sherry Gluchowski, 59. She had recently moved from California to Texas but returned to donate her kidney.

The siblings had always been close, although family members marveled at their ability to bicker for 15 minutes over the proper way to construct a peanut butter sandwich. Their mother, Elsa Rickards, remembered teaching them as children “that they might not have their mommy and daddy all the time, but they will always have each other.”

Mr. Zimmerman, who runs a repossession firm with his wife in Santa Clarita, had been given a diagnosis of kidney disease 25 years ago. With the help of a nutritionist, he had managed to avoid dialysis until the very last day before his transplant, when his doctor said the procedure was needed to clear his body of excess fluid.

In his hospital room before surgery, with seven family members shoehorned into every nook, Mr. Zimmerman calmed his nerves by listening to Aaron Neville on his iPod. He said he considered himself “the lottery winner” in the chain because his kidney would be coming from a healthy 28-year-old, Conor Bidelspach of Bend, Ore.

The surgery to remove a kidney, known as a nephrectomy, is remarkably bloodless these days. With Mr. Bidelspach on the table, Dr. Peter G. Schulam cut four dime-sized incisions on the left side of the abdomen. Through

tubes inserted in the openings, the surgeon and his team maneuvered their cauterizing scalpels and a laparoscopic camera, which relayed images of Mr. Bidelspach's insides to monitors overhead.

The scalpel's superheated pincers clamped down like crab claws, searing the kidney from surrounding tissue. There was no need to cut any muscle.

Once the kidney was free of connective tissue, Dr. Schulam clamped and snipped the renal artery and vein and ureter. He captured the kidney in a plastic bag, cinched it shut, and withdrew it quickly through a finger-length incision along the pelvic line.

The doctor poured the kidney into a bowl of ice and drained it of remaining blood. The slush in the blue bowl turned fruit-punch pink.

As others stitched up Mr. Bidelspach, Dr. Schulam wheeled the kidney on a cart into an adjoining operating room, where Mr. Zimmerman was already anesthetized. After stretching a hole in Mr. Zimmerman's midsection with a metal retractor, Dr. Jeffrey L. Veale lowered the kidney into place and sewed in the renal artery and vein. As soon as he unclamped them, the kidney pinked up with blood flow. Before attaching the ureter to the bladder, he gently massaged the tip of the narrow tube between two fingers and watched it spurt a few drops of urine.

"No more dialysis for Mr. Zimmerman," Dr. Veale declared. "This total stranger's kidney is making him pee." He left Mr. Zimmerman's own kidneys to shrivel harmlessly in place (removing them would add to surgical risk).

Meanwhile, Dr. Schulam was in yet another operating room removing Ms. Gluchowski's kidney. He placed it in a plastic bag filled with a preservative solution and knotted it shut, like a goldfish brought home from the pet store. It was packed in a plastic tub, topped with ice, and loaded into a cardboard box marked "Left Kidney — Donated Human Organ/Tissue for Transplant — Keep Upright."

A courier in one of Quick International's big red vans drove Sherry Gluchowski's kidney through stop-and-go traffic on Interstate 405 to the Los Angeles airport. Cynthia Goff, an operations supervisor for the courier company who had volunteered to accompany the kidney to Chicago, rolled the box into the terminal strapped atop her carry-on with a bungee cord. A pit bull, waiting to be placed in its travel kennel, strolled by and sniffed.

After security agents checked the box with a desktop scanner, Ms. Goff rolled the kidney down the concourse, past a currency exchange and a store selling Elmo dolls for Christmas. Escorted onto United 564, an overnight flight that would land in Chicago at 5 a.m., she stowed the box in the business-class closet, next to a flight attendant's overcoat.

Airplanes carrying donor organs are granted special status, allowing them to move to the front of takeoff lines and ahead of air traffic. Mr. Hil, who tries to avoid routing kidneys on connecting flights and always schedules backups, said none of his registry's transplants had been held up by transportation problems.

By the time Ms. Gluchowski's kidney made it to Loyola and was transplanted into Mr. Terry, it had been cold for almost 12 hours. Early studies have found no evidence that shipping live kidneys such distances affects their immediate function.

Chain 124 ended at Loyola because Mr. Hil had arranged for the final kidney to go to a hospital that had produced a Good Samaritan donor to start a chain in the past, thus closing a loop. Dr. John Milner, a transplant surgeon at Loyola, said he then selected Mr. Terry to receive the kidney because he was the best immunological match on the hospital's wait list.

When Dr. Milner called with the news in early December, Mr. Terry was floored at his remarkable good fortune. Having felt unfairly condemned when he was first placed on dialysis, he now wondered what he had done to deserve a gift that 90,000 others needed just as much.

As it sank in that his would be the last of 30 interconnected transplants, Mr. Terry began to feel guilty that he would be ending the chain. “Is it going to continue?” he asked Dr. Milner. “I don’t want to be the reason to stop anything.”

“No, no, no,” the doctor reassured him. “This chain ends, but another one begins.”

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