

# Man treats his kidney failure at home with his family

By Quinn Russell Brown For The Herald

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It's 5 p.m. and Michael Goldberg has gone from professor to patient. He fires up the machine stationed next to his bed and fiddles with a pair of tubes that will be tethered to his arm for the next few hours.

His bedroom is his dialysis center. Most people with kidney failure go to a clinic three times a week for the blood-cleansing treatment, but Goldberg, 54, does it at home — five nights a week, five hours a night.

Setting up takes about 40 minutes and ranges from checking the flow rate to making sure he'll have creature comforts for the next three hours of captivity.

"Hopefully the Wi-Fi is working, both for me to do work and to get Netflix," said Goldberg, who teaches history and film at the University of Washington Bothell.

He takes a seat on the bed and plops his left arm onto a cushion. His wife, Elizabeth de Forest, comes in wearing a lab coat and latex gloves. It's hit or miss when she tries to insert a needle into her husband's fistula, a passage where a vein has been connected directly to an artery. The vein is about as thick as a piece of licorice — strong enough to draw blood from night after night.

De Forest removes the scab from the night before and tries to get the needle into the vein. No luck.

"You're basically trying to open a little flap, a little hole, with a blunt needle," Goldberg said. "Sometimes it takes a few times."

Several minutes later, the needle is in, but blood has burst from his fistula. His white T-shirt is now deep red and soaked.

He's unshaken.

"Stuff happens," he said. "You just keep rolling with it."

Studies have shown that home dialysis can reduce stress on the heart and improve survival rates. Still, 90 percent of dialysis patients prefer to have the process done by professionals. Things aren't this messy at a center.

Things aren't this cozy, either. Goldberg loves having his wife and two sons, Asher and Jonah, around to support him. There's a flat screen TV in the bedroom, with boxes of DVDs on one side and boxes of syringes on the other. Right now they're making their way through seven seasons of "Buffy the Vampire Slayer."

"It can be stressful at times but, you know, usually we're used to it," said Asher, 14.

"It's not just him on the machine," said Jonah, 12. "It's sort of like all of us."

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Goldberg's calm demeanor comes from experience. He's been dealing with medical issues for 40 years.

This isn't his first trip down the organ trail: his failing kidney is a transplant from nearly two decades ago.

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It all started at 15, when he was diagnosed with Type 1 diabetes, a disorder in which the pancreas stops producing insulin, a hormone that converts sugar into energy. Blood sugar levels rise, causing excessive thirst and urination, as well as potential organ damage down the line.

Looking back, he wishes he'd taken better care of his body after the diagnosis.

"I was probably not in good control for three or four years," he said. "It was a combination of I was a semi-alienated 15-year-old and I had ADD."

A 2.0 senior year GPA didn't stop him from enrolling at the University of California, Santa Cruz, where he found a good doctor and started to regulate his condition. But in 1986, while in graduate school at Yale, he was diagnosed with kidney disease.

Undeterred by his ailing organs, he earned a Ph.D. with a dissertation that would become a book, "An Army of Women: Gender and Politics in Gilded Age Kansas."

He married de Forest and took a professor position at UW Bothell in 1993. Months later, a routine workup revealed a kink in his heart, necessitating a single bypass surgery that knocked out his failing kidneys for good.

"I had to go on dialysis suddenly," he said. "There were a lot of complications, and it was tough."

Back then he received his treatments at the Seattle and Lake Washington locations of Northwest Kidney Centers, a nonprofit that pioneered the process of doing dialysis outside of a hospital setting.

Kidneys purify the blood by removing waste and disposing of it in urine. When they fail, dialysis artificially fills their role. Blood is drawn from the body, typically through a fistula in the arm, then cleaned and streamed back in.

In addition to needing a new kidney, doctors told Goldberg he needed a new pancreas. He was put on the waiting list for a pancreas-kidney transplant in 1995. Just nine months later, he received the organs from a cadaver donor — a recently deceased teenager whose parents wanted their son's organs to live on.

Three days out of UW Medical Center — a mask on his face and only 10 percent of his immune system working — Goldberg was back in the classroom.

"This is part of my crazy history of my medical condition and my teaching," he said. "I'm a pretty devoted teacher."

The new kidney fit right in for 17 years, which is outstanding for a cadaver donation. But the powerful medication that organ recipients must take can eventually be toxic to the donated organs.

"Most kidneys fail not because your body rejects them," Goldberg said. "It's because you've been scarring the kidney through the immunosuppressant drug."

Since he received both a kidney and a pancreas, he was on a high dose of the drug for many years. He later convinced his doctors to lower his intake, but the damage had been done. In the fall of 2011, the lab results came in: the pancreas was in good shape, but Goldberg needed another kidney.

His health spiraled downward. Goldberg went back to Northwest Kidney Centers, but this time it was for training rather than treatment. He and de Forest learned how to do home dialysis and set up shop in their bedroom in August 2012.

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“If you can read a recipe, you can do dialysis,” said Connie Anderson, vice president of Clinical Services at Northwest Kidney Centers. “All the procedures are written out. The supplies you need, these are the ingredients. This is what you do: step one, step two, step three, step four.”

Seventeen percent of patients at the Northwest Kidney Centers do home dialysis, which is nearly twice the national average.

“Those that dialyze at home are going to feel so much better,” Anderson said. “Dialysis doesn’t become the center of your life. Your life goes on, and your dialysis becomes secondary to all the other things you can do.”

Goldberg’s kidney hasn’t completely shut down yet, and there’s no telling when it will. It doesn’t filter toxins, so he needs dialysis for that, but it still passes liquid, allowing him to use the bathroom like everybody else.

“Otherwise it’s all gotta come out of here,” he said, pointing to the machine.

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Fighting to stay healthy is a full-time job. Goldberg spends about 25 hours a week on home dialysis and can have up to 10 medical appointments a month. He’s on partial paid leave from UW Bothell, down to teaching only one class per quarter.

Work isn’t the only thing he’s had to cut back on. He’s part of UDubB Jammin’, a band made up of faculty and staff, but it’s difficult to find time to jam.

“I mostly play guitar,” Goldberg said. “I got a mean one-handed keyboard. I used to play piano, but I lost it. Play harmonica, some blues harp.”

His sons are musicians, too.

“The younger one plays drums and the older one plays viola and piano,” he said. “They both sing. It’s fun to play stuff with them, but I don’t get much chance.”

Instead, the father-son bonding happens in front of the TV, watching actress Sarah Michelle Gellar slay vampires.

Goldberg can relate to all the blood sucking.

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The organ waitlist looks a lot different now than it did in 1995. What once took six to nine months can now take up to five years depending on blood type. For Goldberg, whose blood type is A, it’s two to three years.

According to the United Network for Organ Sharing, there are more than 119,000 people who need an organ, and about 18 of them die waiting each day. Kidneys are the most sought after. Skyrocketing rates of obesity and diabetes mean more people need them, while modern vehicular safety laws have reduced cadaver donations from car crashes.

Goldberg doesn’t even know his place on the list.

“One of the problems is the list changes all the time,” he said. “There are different priorities: health, immediate need versus long-term survival, perfect matches.”

A perfect match refers to a patient matching an organ in six categories that predict transplant success, in which case the patient may skip ahead in line.

In America, people choose whether to be donors when they get their driver’s licenses. This is known as an “opt-in” system. As of 2012, about 43 percent of adults had opted in, but that doesn’t necessarily mean their organs will be donated when they die.

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“Ideally, I think if a person signs up as a donor on their driver’s license, then that should be legally binding,” Goldberg said. “But there are places where doctors will go with the family’s wishes, or even in some cases don’t want to deal with it.”

The alternative to the waiting list is finding a living donor. Often family members or loved ones volunteer to help out. Goldberg found out the first time around that his close family members have positive crossmatches, meaning his antibodies will reject their blood cells.

He had a donor lined up last spring, a friend whose kids attend school with his, but it fell through. Doctors discovered a rare condition in her kidney that meant she wasn’t a candidate.

Donating a kidney traditionally required the removal of a rib. Now there’s a less invasive laparoscopic procedure with improved success rates and recovery time. Research shows giving a kidney doesn’t affect long-term health or lifespan.

“You never know, there are people now donating kidneys who don’t know anyone,” Goldberg said, referring to so-called altruistic donations. “They just say, ‘I want to donate a kidney,’ and get connected.”

For now, it’s five nights a week on the machine.

“It can be a challenge,” Goldberg said. “It’s emotional. I think we deal with it really well. You’re dealing with your body — you’re dealing with needles and blood and those sorts of things.”

De Forest took this year off from teaching at St. Mark’s Cathedral Preschool to be at her husband’s side.

“I’m pretty much on call if anything happens,” she said.

“It’s really remarkable what she’s been able to do,” Goldberg said. “My kids have dealt with it really well. Still, it’s tough to see their dad...”

He shrugged.

“On the other hand, there is ‘Buffy.’ You ever see ‘Buffy’? It is remarkable.”

### Read more

For more about Goldberg’s story, go to [caringbridge.org/visit/michaelgoldberg](https://caringbridge.org/visit/michaelgoldberg).

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