

Mayo Clinic News Network

Man with world’s largest kidneys gets complicated transplant surgery at Mayo

Clinic after unique marketing to attract donor

Video	Audio
(Gene’s comeback video)	(Eye of the Tiger plays in video)
	This is a story about genes.
(:31 – :37) 826G1891	“My father had polycystic kidney disease.”
	...and family...
	“We didn’t know it at the time when we were young.”
	Gene Okun has his father’s genes.
(1:11 – 1:14) 826G1891	“Lo and behold it came and he ended up on dialysis.”
	Some of them good.
(1:21)826G1891	“I was a bodybuilder for many years and a powerlifter.”
	Some not so good.
(1:17)826G1891	“The long and short of it is I inherited it from my father. Didn’t know I had it.”
(00:15 - 00:23) 826G1892	“It creates a lot of difficulties in my life.”
	Difficult is how life is when you have polycystic kidney disease.
00:01:08 Fouad Chebib, M.D. Nephrology Mayo Clinic	“So what happens is the patients who have this genetic defect or mutation will start forming kidney cysts. Those are fluid-filled sacs in the kidney. So as they are growing, the kidney starts to fill with fluids and kind of grow and grow. They have multiple, multiple cysts, and that damages the kidney, leading to kidney failure.”
(2:19)826G1892 Gene Okun Patient	“In my situation, the average kidney is supposed to be the size of your fist.”
	Gene’s are quite a bit bigger.

	In fact, his kidneys might well be the largest kidneys ever recorded.
	Over time, Okun went from looking like this to this.
(2:28 – 2:41)826G1892	“We’re not quite sure how big because I can’t do a full scan properly with dye. But the guess is that they’re over 10 lbs. each or more.”
(3:27 – 3:29)826G1892	“It really kind of affects everything in my life.”
	And the larger they got, the worse they functioned.
	And though he has his father’s genes, Gene didn’t want to end up like his father.
(1:46 – 1:48) 826G1892	“We chose a different path.”
	Instead of letting himself deteriorate until he had to go on dialysis, he decided to seek a kidney transplant.
(8:30 - 8:57)826G1892	“The doctors that I had gone to before, the surgeons had all given me different opinions on how they thought they were going to do this thing.”
	Not satisfied with what he was hearing, someone suggested he go see Dr. Mikel Prieto at Mayo Clinic in Rochester, Minnesota.
00:02:25 Mikel Prieto, M.D. Kidney Transplant Program Mayo Clinic	“We offered him to have the opportunity to have not only a kidney transplant but at the same time take those large bothersome kidneys out.”
	Though Dr. Prieto acknowledged that Gene’s were likely the biggest kidneys anyone had ever operated on, he had successfully performed the surgery several times before and was confident he could do the same for Gene.
(00:24 – 00:50)826G1893	“For me that was a big deal, because I had an uneasy feeling all the way along with where am I gonna do this? And who’s gonna do it? And I didn’t have comfort with either of those organizations, which are very good and world-renowned. But it wasn’t until I came here to the Mayo until I felt very

	good about this is where I'm gonna have the surgery done and this is who's gonna do the surgery."
	But he still needed a healthy kidney.
	As a resident of California, Gene knew the average wait time for a kidney from a deceased donor was roughly 7 to 9 years.
	But at the rate his kidneys were deteriorating, he would be on dialysis long before that.
(montage of clips from the Gene's Big Dumb Kidneys videos)	So he took a unique approach to finding a donor.
(9:26 – 9:37) 826G1893	"The idea was to create a little bit of humor, and to take that and take a serious, serious situation and put a little humor on it that would get people to look at it."
(Gene's Big Dumb Kidneys videos)	The result was a series of videos about Gene's Big Dumb Kidneys.
	And it worked.
(6:17 – 6:28) 826G1894	"It's very moving to meet people and talk to people that they don't even know you, but they're willing to give a kidney. And not for money. Not for anything, but just because they have a good heart."
	In the end, though, it was someone quite close to Gene who ended up being the best match.
(1:40 – 1:55) SULL0005	"I can only say it's probably God's hand, because I looked for a long time. And he's an amazing guy, an amazing individual, and a very unselfish person to do this for me."
	Bill Callahan, a business colleague and one of Gene's closest friends ended up being almost a perfect match.
	But testing showed Callahan needed to drop some weight.
(4:18 - 4:24) SULL0007 Bill Callahan Kidney Donor	"So, I was a prime candidate for heart attack. So it motivated me to go back to the gym, which I did."

	Luckily for Callahan, the guy hoping to get his kidney happened to be a former world-class bodybuilder.
(3:21 - 3:30) SULL0005	"I helped him a little bit with some good diet tips and really kind of give him an idea of how much cardio he would need to do to lose weight."
	A few months and 50 lbs later, two best friends lie in neighboring beds preparing to go into surgery.
(9:53 – 9:56) SULL0005	"Hey, buddy. How ya doing? That's my donor next door. This is great."
	For a dedicated friend giving a piece of himself...
(6:02 - 6:08) SULL0007	"It's an arduous process, but probably the most worthwhile thing I've ever done."
(00:34 – 00:35) SULL0010	"Say goodbye to Big and Dumb."
(1:35 – 1:46) SULL0050	"We are ready to go." "Showtime." "Showtime, bro. Get 'er done. See ya."
SULL0125 (00:02) – Dr. Prieto reaching hand through cuff into Gene's abdomen	For 12 hours, Dr. Prieto felt his way around Gene's abdomen...
00:04:38 DR. MIKEL PRIETO_1: SULL0129 (00:15) SULL0132(:52) SULL0139 SULL0133 SULL0134 SULL0135 SULL0149	"With a laparoscopic procedure, we have freed them out from all the surrounding structures. We have staple across the artery. We have staple across the vein. So they are free floating inside. And at this point, they need to come out and for them to come out, we need to drain a lot of the fluid out and sometimes that's kind of a little bit of a – kind of aggressive approach because those kidneys, they are hard to get out and then only by poking a lot of cysts – most of the time I do it with hands – I manage to get them out.
SULL0156 –	And then on to the second one.
SULL0182 – SULL0196 – ***SULL0198 –	
SULL0208 –	After all of that, only halfway through.
SULL0221 –	Now Callahan's healthy kidney must come out.

SULL0222 – SULL0231 – SULL0232 – SULL0233 –	Dr. Prieto and his team work quickly to prep the healthy kidney to transplant into Gene.
(Fade to black with surgery nats)	
G(1:58 – 2:13) SULL0001 (post surgery)	“Just opening my eyes after that kind of thing was amazing. I felt like I’m alive! And then the next thing was I have a new kidney in my and my stomach was completely flat. I could see my feet. And I was just blown away.”
	And blown away by his friend who gave him this gift.
G(2:18 - 2:28) SULL0001	“Knowing that, um, I’m not going to be on dialysis is just a very big blessing. And, obviously, my hero made it possible.”
	One of Gene’s two heroes.
	The other: Dr. Prieto.
G(4:57 - 5:06) SULL0002	“One surgery, one day. Two big kidneys out, one kidney in. Same guy doing the surgery. That’s a superhero right there.”
	A superhero equally impressed by the resilience of a patient who might well have had the biggest kidneys ever.
	How big?
00:03:57 DR. MIKEL PRIETO_1:	“I think we had on the – on the suction canisters about 19 liters of fluid, and that doesn’t include all the stuff that we took out, like, through the wound and so forth. So they were very large.” “Nineteen liters you said?” “Nineteen liters.”
G(5:19 – 5:28) SULL0001	“I actually weighed in this morning at 236 from 286. So, 50 lbs came off. And I’m actually holding water from the fluids they’ve been pumping into me.”
	This is a story about Genes...
	G(7:42 – 7:51) “I love you, buddy.”

	...and family...
	"I love you too, bro."
	For the Mayo Clinic News Network, I'm Ian Roth.