

Transplant Times

Organ Transplant Awareness Program September 1, 2020

Promoting Organ Donor Awareness; Supporting the Transplant Community

Hello,

It looks like we are finally getting some cooler weather in Albuquerque. There have been some virtual health fairs and awareness walks, but overall everything is quiet. The support group continues at my home. The next meeting is September 11, 2020 from 10:00 am until noon. There is plenty of room to socially distance and good air circulation. Please let me know if you will be attending by sending me an email rioreal@earthlink.net.

The good news is that organ transplants have returned to there pre-covid frequency. As editors before me have done, I am requesting articles regarding the transplant community for the newsletter. Please send in a pdf or Word document. I have included the transcript of an interview I did with KUNM last year. It is as pertinent today as it was then, we are especially fortunate to receive liver transplants in New Mexico. Forever grateful to my donors and the people who supported me.

-Evelyn



Liver recipient, Lynn Davis, and I at a Liver Foundation event in Albuquerque, September 2016.

Congratulations Transplant Recipients

Kitty Miller Kidney Recipient September 1, 2003 17 years

David Lopez Pancreas Recipient September 23, 2003 17 years

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Liver Waitlist Slots Are Scarce

By MAY ORTEGA · JUL 30, 2019



Evelyn Rivera sorts through her anti-rejection meds. She's had two liver transplants. MAY ORTEGA | KUNM

We've been exploring the difficulties New Mexicans face when they need a liver transplant, like the fact that we don't have a place to get one in the entire state.

That means it can be challenging just to get on a liver transplant waitlist.

You need a referral to get a liver transplant, but that's not a ticket onto a waitlist at a transplant center. You need to be evaluated first. Evelyn Rivera had to do it twice.

"The first time, I mean, the cancer is scary. That's a scary diagnosis," Rivera said. "I just didn't know if I was gonna make it."

"And then the second time, was it kind of the same?" I asked.

"The second time it was just totally miserable," she replied. "I couldn't do anything."

She was diagnosed with Hepatitis C in 2009. Then it turned into liver cancer. Her options were either get a transplant or die, but it wasn't completely her choice to make. She had to be a good candidate.

"I went through a three-day evaluation," she recalled. "Heart test, lung test, 25 vials of blood, where they check everything, everything."

After all that testing, Rivera was OK'ed for the list at the University of Colorado Hospital in Denver. There aren't any liver transplant centers in New Mexico.

Then to wait. For more than a year, Rivera didn't make any plans because she didn't want to be busy when the doctors called with a liver. Although she did need to get ready for something else.

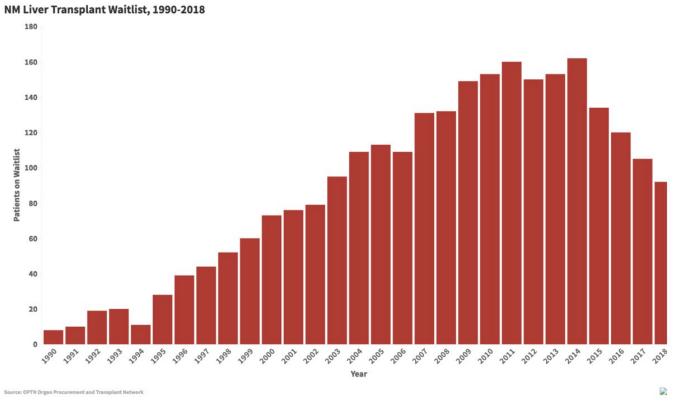
"Prepare for death," she said. "You do a will, you get all your things in order and just start to really enjoy each day."

After 18 months, it happened. She had the transplant. But she said she never felt quite right.

Turns out the liver wasn't working. She turned yellow and broke out in hives not long after her surgery. Her doctors said she needed another transplant – a year after the first.

"I went through another evaluation, was put back on the list and waited another 18 months," she explained. This time everything turned out great, and she's still doing well four years later.

It's incredibly rare to get on a waitlist twice. Most people don't make it past the evaluation once.



Nayan Patel co-directs Banner University Medical Center's liver program in Phoenix.

"The liver transplant evaluation is kind of a multi-step process," Patel explained.

First you're referred to a center. For New Mexicans, it's always out of state, remember, we don't have one. Then there's a financial assessment, to check if you can pay for this half-a-million-dollar surgery; insurance can only cover so much.

After that, you have medical and behavioral consultations to see if you're a good candidate.

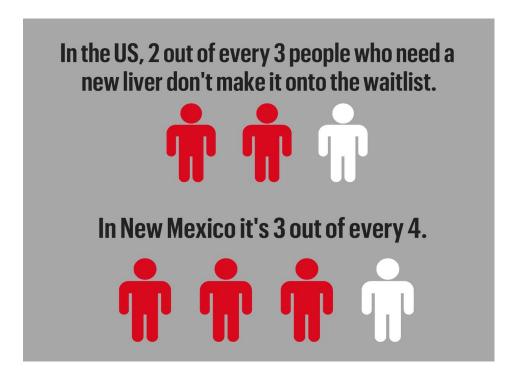
"Is the patient strong enough to undergo a liver transplant? Have they had the minimum six months of sobriety?" Patel said.

Shimul Shah is the chief of transplantation at the University of Cincinnati Medical Center and an expert in liver transplants.

"Only 33 percent actually get listed," Shah said.

He said that 33 percent – just a third of people who need livers getting on a waitlist – is common at many centers.

It's worse for New Mexicans. Only 25 percent of residents actually got on nearby waitlists in the last couple of years – even though we have the country's highest rate of liver disease and liver-related deaths.



At any given time, there are around 90 New Mexicans on the waitlist.

"I bet you there's 250 that need a transplant," Shah said.

Shah said rural folks are at a disadvantage. The nearest liver transplant centers we have are in Phoenix and Denver, more than 400 miles away from Albuquerque.

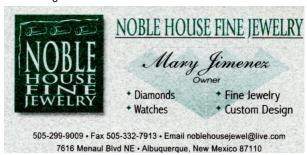
"Patients that try to come from far away – if they don't have a lot of means and we get the sense that they can't go back and forth for weekly visits, we're going to turn them down," Shah explained.

And even if you are waitlisted, there's no guarantee you'll actually get a new liver. Last year more than eleven hundred people across the U.S. died while waiting for one. More than 70 New Mexicans died on the waitlist in the last five years.

The rules that determine who gets a liver transplant were updated this year. We explain how that change could affect New Mexicans in the next part of our series, "Too Little, Too Late: Waiting For A Liver In N.M."

Rashad Mahmood and Lissa Knudsen did the data analysis, graphics and maps for this series.

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OTAP Mission Statement

The mission of Organ Transplant Awareness Program is to promote organ donation and support transplant community members including transplant candidates, donor families, living organ donors, transplant recipients, and transplant families. We promote organ donation by participating in a variety of community events. Our support group meets one time per month with those who need support or are seeking information about the transplant process.







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