[MUSIC PLAYING]

MIKEL PRIETO: Some patients with polycystic kidney disease, they have two big problems. One, their kidneys don't work, so they need a kidney transplant, and the other one, they have very large kidney that cause pain and other symptoms. We need to fix both problems.

We used to do them separately, and in many other places, they still do them separately. But today, we have come to the conclusion that the best way to fix this problem is doing both operations together. This is by far the best option for these patients. They recover quickly. In one surgery, you fix problems, and they have great long term outcomes.

The best way to do this combined procedure is if we can use minimally invasive techniques. What we do is we laparoscopically take both large kidneys out through a very small incision, and then we extend that incision just a little bit so we can do a kidney transplant. When the patient wakes up, he ends up having a fairly small transplant incision.

Polycystic kidney disease is a hereditary disease. And in families where they have this disease, typically, half of the children have it. So you have 50% chances of getting it. There's a genetic defect which causes the connective tissue to be lax, to be soft, and that causes several effects. One is some patients have brain aneurysm. Also, you develop cysts in different organs, like the liver, especially the kidneys, but also sometimes the pancreas. And also, you have weakness in some muscles. For example, these patients very frequently have hernias.

LYNETTE FIX: Typically, polycystic kidney disease is not diagnosed until around age 30. The cysts don't always appear on the kidneys until around that time frame, so a lot of the children don't know that they are a carrier of the gene. So we can do genetic testing to see if they are.

MIKEL PRIETO: In Jolinda's case, her mother had it and her grandmother had it, which is fairly typical. She needed to have both kidneys out and a transplant, because she had very large kidneys that caused a lot of problems, a lot of symptoms, pain and so forth.

Before Jolinda, we always did the procedure separately. We first did the transplant. We let them recover from that surgery. And four months later or six months later, we took the kidneys out. The reason for that was both surgeries are big surgeries and potentially dangerous surgeries.

When I met Jolene, I realized that she had very large kidneys, much larger than normal, and she also needed a transplant. She presented to me a compelling story to do the operation at the same time, because she was fairly miserable.

I felt maybe it was time to start offering the option of doing at the same time a living donor transplant and bilateral nephrectomy.

LYNETTE FIX: She did extremely well and was very grateful. When I went to visit her post-transplant, she said she felt wonderful having those kidneys removed. She could tell the difference, because she no longer had these large kidneys pushing on her or other internal organs.

MIKEL PRIETO: Since Jolinda, we have offered this option to a lot of patients. And we feel strongly now is the best way to go. Patients get one operation. They have both kidneys out and a transplant. And they're done, they're cured, they go back to a normal life. I'm glad to say that all the patients that have had this surgery here at Mayo have done very well.

The worst option, in my judgment, is to take the kidneys out first. And that's what's done sometimes in other centers. The problem with that is that, first of all, the patient needs to be on dialysis. Sometimes there are some side effects from having that surgery, like needing blood transfusions, which may jeopardize your chances of getting a kidney transplant later, because you develop antibodies. And also, we know that somebody without kidneys, especially when you take out these large kidneys, they can have severe hypotension for days, which can be life threatening. The mortality rate years ago for this, taking the kidneys out, was fairly high.

Everybody agrees that best kidney transplant is a kidney transplant from a living donor. Nationally, only 20% to 30% of the transplants that are done are from living donors. Fortunately, at Mayo, almost half of the transplants that we do are from living donors. And in fact, in one of our programs, it's up to over 80% of the transplants that are done are from living donors.

This is huge for our patients. Tremendous advantage. Those kidneys work right away. Those kidneys work for many, many years. And we try to offer this option to the vast majority of our patients.

One of the options that these patients have is to be part of the kidney pair donor program. If you have a living donor that doesn't match you for multiple reasons, we can put you in a pool of other pairs with the same issue and find a match.

Historically, this was a very serious disease with a fairly high mortality rate. Today, with good techniques for transplantation, for nephrectomies, and all the other options, we are able to offer these patients a very good long term outcome.