

Transplant in Children

Shennan Mao: And today as previously stated, I'll be discussing the role of transplantation and children. I have no disclosures for this activity and thank you kindly for the biography. Just to add on a personal note, I love spending time outdoors biking, swimming, hiking and exploring the world with my two-year-old.

My goals for our talk today are to really review all aspects of transplant care in children. And to give you all a good idea of what you and your child could expect from both the kidney transplant evaluation and the subsequent surgical process for kidney transplantation. To discuss the immediate post-transplant recovery period and kidney transplant and to help parents support your children after living donor and deceased donor kidney transplant in the long-term process.

Give a road map for transplantation. I know we all hope that the road is straight, and the path is forward. There can be some meanderings along the way. But overall, our goal is to get you to a kidney transplant as quickly as possible. The elements of transplant that we'll talk about today, including include the importance of early consideration of kidney transplantation for all patients, regardless of age. Some guidance in selecting your transplant program going forward an overview of what the transplant evaluation process includes, as well as some specific considerations for pediatric patients.

A good idea of what to expect from the transplant operation and the day of transplant, an overview of the post-transplant care, and finally to talk about long term follow up and some specific considerations for our children and teens. And I hope to prove to you that although the path may appear long now, the route to a kidney is bright and in the future.

First of all, I think it's extremely important to advocate and give early consideration for kidney transplant. And this is where we as patients, clinicians, caregivers, and advocates can really help our patients the best, you do not need to be on dialysis to be considered for or to receive a kidney transplant. And in fact, the earlier referral the better so that we can get through

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the entire process, and potentially even get your child transplanted before you'd ever need a kidney transplant.

And so I empower everyone in the room to truly request an early referral and consideration for a preemptive rare kidney transplant before you'd ever need to go on dialysis. The next important consideration is what candidates and what conditions may come forward when we talk about kidney disease specifically in children. And there's no limitations on what disease processes can be transplanted in kids.

The most common reason for transplant is congenital abnormalities. This would include changes in the kidneys such as urinary tract obstruction, and other such things. A few disease processes are also common. But really the other category in which our polycystic kidney disease falls is the most common reason that kids are transplanted. So polycystic disease is a wonderful indication to come forward and to ask for a transplant evaluation.

Moving on to talking about the role of selecting a pediatric transplant program, there are some important considerations that we think about more than just the building or the space where your child is going to be transplanted. First and foremost, I think it's of critical importance to select a program that has proximity to your support system.

The transplant period and the immediate post-transplant period is going to be extremely important for you and your family. And having a program that's close to you or close to a support system that provides opportunities for housing and lodging and support for the entire family is extremely important. It's also important to ensure that you select a program that has pediatric specific care and that can support your child or team through all aspects of the transplant process.

Out comes both in terms of how many patients are listed each year as well as those that go on to receive a transplant and how they do is extremely important. And I've linked a federally regulated website called The SRT, srt.org, the

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scientific registered theory of transplant programs, which groups all of the different transplant programs it includes a special section for pediatric training transplant where you can look at the total number of transplants that are done by a senator and compare one or two of these programs that may be close to you to help make the decision of where it's best suited for your child.

And it's also important to consider whether something such as a dual listing or having your child listed at more than one transplant program is a good opportunity. This may be a specific consideration if you're located between proximately geographically between a few programs or if, for example, your child or loved one may have had more than one transplant are received a number of blood transfusions and are what we call sensitized or would react to a number of different donors in the population listing at more than one program could have increased their access and allow them to potentially be transplanted more quickly.

Another reason to consider dual listing as if someone may be interested in being a living donor, offering a kidney on behalf of the pediatric recipient. Some programs have more aggressive or stringent criteria for living donors than others. And considering listing at more than one program might increase your opportunities for a successful living donation.

Once you've selected your transplant program, the next step is the transplant evaluation. The transplant evaluation is very complex process, but we do our best to boil it down and keep it simple for everyone. Each center is slightly different in how they do the transplant evaluation and how long the process takes. But especially for children. Our goal is to condense that evaluation as much as possible.

Some centers offer evaluation and as short as one to two days. Others that process takes a few days to even a couple of weeks to complete. Typically, one of the first people you'll meet with during your evaluation is a pediatric specific nurse coordinator. This individual will help to navigate the entire transplant

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journey and provide guidance as you go through the process that can also help with some of the challenging coping mechanisms for the entire family.

Your child will need a pediatric transplant nephrologist someone who can provide guidance and support for the medical management both prior to transplant as well as after transplant. It's also important to know that you will continue to maintain a relationship with the nephrologist that the patient is already seeing their pediatric nephrologist both pre- and post-transplant will meet with a transplant surgeon who specializes in the care of the pediatric patient.

Nutritionists who are specialized in helping to understand the nutritional needs prior to transplant, as well as those needs after transplant will meet with social workers who can help address some of the concerns of the family related to supporting the child supporting the whole family, including parents, caregivers support team members and other children.

The transplant pharmacist will help to discuss some of the new medications that the patient will be receiving. And critically important is the role of child life to support and help the child who's going through the transplant process as well as any siblings, close friends or family members who need some additional support to understand truly what's happening to their body or their friend or loved one's body.

Laboratory studies will be performed with the goal of certainly consolidating those into as few of laboratory drawers as possible and as least stressful as possible for the patient. Imaging tests which is usually an ultrasound, a painless procedure that we are probably most familiar with for our patients that for pregnant patients that are taking a look at their babies. Similarly, an ultrasound can be used to take a look at the child's belly. Sometimes this tickles but doesn't cause pain and it can be pretty exciting for kids to see what's going on inside their bellies.

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And then finally, some children do need a bladder evaluation. This is particularly common in someone who may have needed dialysis for a period of time to ensure that the bladder is large enough to allow for normal drainage of the urine.

Once the patient has completed the full transplant listing, the next of the full transplant evaluation, the next step is the listing for transplant. You'll go to the selection committee. There's nothing that a patient needs to do for this. But all of the people that you've met during the course of the transplant evaluation will discuss the case and determine whether transplant is an excellent opportunity for the pediatric recipient.

Once the decision has been made that will be communicated, each senator can communicate somewhat differently. This can be done either by a phone call a letter, or both after the committee has met, and the potential opportunities for decisions include accepted for transplant, differ because some additional testing may be required, or that transplant may not be in the pediatric patient's best interest at that time, and we'll get we'll discuss why and criterion for which it might be reconsidered.

Once the patient is accepted for transplant, they're listed with what's called the United Network for Organ Sharing, or UNOS. This is a website-based program that allows for offering of organs to appropriate candidates off the deceased donor waiting list, I think is really important to mention specifically related to pediatric transplant is that children receive priority for deceased donor offers for any donor that's less than thirty-five years of age.

And the reason for this priority is truly to match children with organs that are statistically more likely to last longer and really to be a kidney first, just as long as possible for these children. Also, for anyone that might have a teen considering transplant, the priority does continue until the candidate has been transplanted, meaning that if you are listed for kidney transplant, for example, at the age of seventeen, and to not go on to receive a transplant until you've

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turned nineteen years of age, you do still retain that priority until you've gotten transplanted. So, it doesn't go away when you have your eighteenth birthday.

Another excellent opportunity or way to get transplanted is that of a living donor. And I know that's been discussed in a lot of different opportunities during this meeting and others. But again, I would stress the importance of considering living donation as an opportunity to get a pediatric patient transplanted more quickly. Donors can be anyone from friends, family members, sometimes even strangers would offer a kidney on behalf of a patient who needs one.

When we look at the numbers of pediatric kidney transplants performed, there are nine hundred and sixty-six patients added to the waiting list each year. This is data from 2018. The last time it's been reported. The majority of candidates receiving a transplant within the pediatric population are aged eleven to seventeen years with greater than 60% of these patients falling into that category.

But we do perform transplants for all age groups. The least common is those children under the age of one. And that's primarily due to a relative low prevalence of disease, as well as a need for the child to be medically stable and physically large enough to tolerate the transplant operation.

When we talk about pediatric kidney donation, last reported data in 2018 was there were seven hundred and fifty-six pediatric kidney transplants under the age of sightseen performed in the United States. In the orange bar, you'll see the total number of transplants performed annually from the years 2006 to 2018. And the donor types for these organs, with deceased donors being the most common living donors representing a steady percentage of these transplants.

When we talk about donor selection for our pediatric patients, this is really similar whether it is a pediatric patient or an adult patient. People often ask me, "A living donor versus a deceased donor and what is the best option?" And

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what I truly tell patients is the option that allows the quickest transplant for the patient, whether they're a pediatric patient or an adult patient is the best option.

Oftentimes, this is a living donor transplant, because there's no waiting time for a living donor transplant. Specifically, as soon as the donor and the recipient have gone through the evaluation, which in some centers can be done at the same time, we can schedule a date for surgery. Deceased donors are also an excellent option and opportunity for these patients. And as I previously stated, we do have priority listing for pediatric candidates, which can allow for an earlier transplant.

Living donor transplants on average do work more quickly than deceased donor transplants. Sometimes the events that have led to the deceased donors passing away can cause some stress to the kidney that it may be little bit sleepy and not start working right away.

In addition, deceased donor candidates, on average tend to last a bit less long as living donor candidates, however, again with the priority given to our younger donors going to younger recipients that is less prevalent in pediatric donor population. Other things that you may hear talk about at this meeting and others includes the importance of HLA matching or the idea of kidney for life, which is really taking off as an exciting discussion point at this time.

The general idea of matching a donor to a recipient is the most important consideration is having a compatible blood type. However, as we learn more about kidney transplant, we also know that it's important to match called HLA antigens. These in broad terms are six antigens that show how genetically similar patients are. And we know that there are, in general improved outcomes with a higher match between a donor and a recipient.

Recently, within the last few years, there has been some discussion also of applet matching. Applets are considered a smaller component or a smaller part of the antigen. And so, some programs, especially living donor programs, are

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considering the use of a cheek swab from both a donor and the recipient to try to find the best possible genetic match.

The National Kidney Foundation, which you can see addressed at the bottom slide, is has a kidney for Life program where they're attempting to use a living donor paired exchange to find the best possible match for our candidates. And they have shown with some early data. Sounds like my audio has gone off. Is everybody able to hear me again?

Jim Myers: Yes, ma'am.

Shennen Bao: Okay, excellent. Where? Where did we cut off at? I'll go back. I apologize for that.

Jim Myers: The bottom part of the last slide, Doc.

Shennen Bao: Okay, excellent. So again, the idea is that applets or a small component of antigens are the important sort of matching or combining a genetic match between our donors and our recipients. The National Kidney registry, which is referenced at the bottom of the slide, is a National Living Donor paired exchange that has really started an exciting effort to match our donors to our recipients by using a cheek swab and trying to find the best possible genetic match in order to demonstrate a comparison of reduced rejection, reduced and lower long term immune suppression and improved overall long-term outcomes for these patients.

So, the exciting day has come, it's time for the kidney transplant operation. And whether this is performed with a living or a deceased donor transplant, the processes is the same. You'll come to the hospital, make sure there's been no changes in the health status of your child. And then it's time to go to surgery.

Pediatric patients, there's a highly specialized team of pediatric specialists including an anesthesiologist, nursing staff and a transplant surgeon. Depending on the hospital, there may or may not be the opportunity to go back

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to the operating room with your child. Other centers have you say goodbye in the preoperative area, and the team helps the child back to the operating room.

The general expectation and again, it's variable between different centers and different children. The expectation is generally around three to six hours. Have some surgical time, but do anticipate additional time for the anesthesiologist and the nursing staff to prepare the patient for the transplant operation. And I always tell patients to be prepared for a possible stay in the pediatric ICU after transplant.

For some centers, this is done as a routine. Others use it only in certain specific cases. Again, the operation will start with the child going to sleep and general anesthesia. This process is usually about an hour where a central venous line is typically placed in the neck. This will be a large line that will be present when your child comes out of surgery. There will also be placement of a Foley catheter, which is a catheter that goes through the urethra and into the bladder to monitor urine. There'll be temperature monitoring blood pressure and other things at the time of the transplant, then the surgical procedure will start that usually lasts about three hours.

Young children under that twenty-thirty-pound limit will typically have an incision that's in the middle part of their belly. Older children and teens, the incision will be more similar to an adult typically on the right side going from the hip bone down to the bone at the base of the tummy, though it could also be on the left side. This is an overall schematic of how the kidney transplant procedure looks at the end of the operation. The kidney in an older child is typically placed on the large blood vessel that will eventually feed the leg and a younger child, that kidney is typically placed a bit higher because of the size the blood vessel and the importance of getting good blood flow to your kidney.

There is an artery that brings the fresh blood into the kidneys. That's the first connection that's made than a vein that drains the blood from the kidney. That's our second connection that's made. And then the final connection is what we

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call the ureter or the urine tube. It connects the kidney to the bladder and allows your child to go to the bathroom in the normal fashion. That connection is often protected with a little plastic stent that will be on the inside. It is something that is typically removed after the transplant surgery under a small procedure under local anesthesia.

Of note the kidneys that the patient was born with, do typically stay inside. If they are giving significant problems to the patient. Though the most common with polycystic kidney disease is problems related to increased pressure, pain, cysts popping and so on. They could be removed either at the time of the transplant, or sometimes that's done before transplant and a patient on dialysis or at some point after transplant.

The immediate post-transplant here again depends on the transplant center and the program that you're at. Some centers go straight to the pediatric transplant floor, and other centers consider the use of the ICU as a routine practice. Probably the most exciting thing for patients and their families is that many times that kidney starts working right away someone that hasn't been making urine will all of a sudden start to make lots and lots of urine. And for many of the younger children, it's pretty exciting to watch that urine start to collect and gather in the bag.

Some kidneys, as I stated earlier do have what we call delayed graft function, or DGF. Those are kidneys that don't work right away. They're a little sleepy from the events that have led to the donor's death of the transplant process. But we fully expect them to wake up and start working within a week or two after transplant. And if for some reason your child needed ongoing dialysis, it won't hurt the kidney. And the most important thing is to really support that kidney going forward.

While in the hospital and multidisciplinary team many of the same people you met during the evaluation will be providing care. And I think it's really important to stress the role again of child life to support the patient as they

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adapt to their new transplant and provide age-appropriate activities and education about medications and post-transplant challenges.

The hospital length of stay is highly variable some of it is center specific. It may also depend on whether the child's native kidneys needed to come out at the time of the transplant, but average is somewhere between four to ten days after the transplant process.

Complications can happen after kidney transplant. Thankfully, they're relatively rare and experienced transplant program knows how to handle and manage these complications. And they will keep you and your family informed if a complication is expected. They can be broken up broadly into two categories surgical and medical. And surgical complications typically occur early after transplant.

You can see the size of these connections here. And this is a typical kidney size for an older child or a teen. You can imagine utilizing a smaller kidney from a younger donor may have even smaller vessels. Those connections are about the size of a pencil, and they can scar or link that can require additional surgery for us to correct or fix. In addition, that urine tube could scar or leak and that could require additional surgery or a trip to the radiologist to fix.

Finally, a slightly more common but still relatively uncommon complication would be problems with the child's incision. That's something that's a relative minor nuisance at the time of surgery and can require some extra care but doesn't have a long-term impact on the child's experience, transplant or overall long term outcome of the kidney.

Medically there can be complications as well. The most scary that we fear but thankfully also the most rare, far less than 1% would be that a kidney would be transplanted and for some reason not work. That's we call primary non-function if that were to happen, the kidney would likely require removal. Not always but often. And you would retain priority on the transplant waiting list anytime that

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you had accrued would be maintained and we would get you a new transplant as soon as possible.

But again, thankfully, this very feared complication is extremely rare in pediatric and uninjured transplants. Other things such as rejection can occur. And that's why it's so important to follow with the transplant team and take the medications as recommended for rejection episode does happen. It can almost always be managed with medications and your transplant team will work with you and your child to understand this is the best.

Recurrent disease is thankfully not an issue and polycystic kidney disease. The donor's kidney will not have polycystic kidney disease, and it will not affect the new transplant. But if another process were occurring, if your child had additional for example, problems with the ureter or the bladder, or perhaps another medical disease process contributing, we would need to monitor for that after transplant as well.

Once the patient is discharged with their family from the hospital, those first three to six weeks after the transplant can be a pretty busy time. There'll be lots of visits to the transplant center, more laboratory tests and more opportunities to see that kidney with the new ultrasound this is a beautiful kidney lining up kind of like a sunburst pattern on the ultrasound early after transplant we do have a few surgical restrictions. The most prominent include avoiding swimming or tub bathing for typical-

Double check I think the sound is trying to cut as the sound okay, I think it tried to cut out there for a second. Are we able to hear okay? Perfect.

In addition, we want to avoid any heavy lifting or context for works for at least eight weeks. And again, some of these restrictions may differ from transplant center to transplant center. So, I encourage you to discuss these with your transplant program.

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Long term after transplant, I always tell patients and their families that my goal for pediatric or adult kidney transplant recipients is to live a full and typical life. I don't want to put a lot of restrictions on you and the sky is truly the limit. Transplant recipients have climbed mountains, ran marathons and been successful screening playwrights, swam competitive distances. And most recently, I think many of us have heard about Selena Gomez and her selection her excellent kidney transplant outcomes as well.

So, beyond the immediate post-transplant period, discuss your concerns with your transplant provider. And as your child considers new activities have a shared decision-making process with them going forward. We expect excellent kidney transplant function regardless of donor type. On the left, you can see the results of deceased donor transplants on the right living donor transplants. And you can see that the vast majority of these patients enjoy excellent kidney transplant function at one year, and that very, very few single digit percentages have less than adequate kidney function or may need dialysis at that twelve-month period.

When we talk about protecting your child's health after transplant, this is also extremely important. Transplant really is a lifelong journey for the kidney transplant recipient, and especially for pediatric kidney transplant recipients. They will be taking daily medications. But what I encourage parents and children to remember is that patients are often on several medications before transplant. And so, we're replacing one set of medications with another and that these medications will be stable once we get out of that immediate post transplant period.

Regular laboratory studies will be important. And finally yearly visits with your transplant team. They become a family and we want to keep seeing our patients and really preventing any complications that may arise before they become a challenge for your patient.

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A few other important reminders. transplant recipients because of the nature of immuno suppression do have an increased risk of skin cancers. And I always tell my patients especially living in Florida, make sure you wear your sunscreen at least SPF 30 and try to avoid sunburns and excessive Sun exposures. Avoid raw and undercooked foods, again for the risk of having challenges with your immuno suppression or infection and ensure your child is up to date on all of their vaccinations.

When we talk about teenagers specifically, there are some additional challenges of teens after transplant. The teenage years are tough, and the support system for teens after transplant, or even children that grow to the age of teenagers with a highly successful transplant may benefit from additional support. When we're thinking about some of the changes that teens are going through. It's extremely important to discuss sexual health with your transplant, as well as your primary care providers, pediatricians' family, practice providers, there is an increased risk of sexually transmitted infections among transplant recipients again primarily related to immuno suppression.

So, the importance of protection should be discussed. And the medications that patients take for transplant can cause birth defects. So, it's important to make sure that if patients choose to become sexually active birth control is discussed while on these medications. And once an individual is ready to consider having a family and family planning that again should be something discussed with the transplant provider. Smoking avoidance is extremely important, as patients on immuno suppression are at an increased risk of smoking related complications.

And then it's extremely important to support teenagers and medication management, medications and taking medications as a part of the patient's ongoing life. And it's so important to come up with an excellent strategy to help remember these medications and for teens to take charge. We do know that historically, the teen years are when often times transplants are lost. And that is in part due to compliance on the part of the patient and so supporting the

teens in their newfound independence and medication management is important.

And teenage support groups are wonderful mechanisms for teens transplant recipients to meet and connect with others. And as we talk about the era of technology, never underestimate the importance of a virtual support group going forward. These can be in person or virtual, you can really help the team connect and understand the process and what they're going through with other patients.

And then finally, I do want to stress the importance of that transition to an adult care team as the team continues to age and starts thinking about the next step. Whether that be college military service, a new job or moving away from the home, it's extremely important to make sure that they're connected and have access to care wherever the next step in their life may be.

Overall, share some five-year patient data and pediatric kidney transplants. And what's extremely exciting is that patient survival percentage is 98.4%. And this is for all comers with pediatric kidney transplant. These rates do not differ based on the age of the child, whether there was a living or deceased donor transplant potential. So, it's extremely exciting and offers a wonderful opportunity for pediatric recipients to live as close to a normal life as possible. And we're so excited to support all of our pediatric kidney transplant recipients and their families going forward.

I hope in today's talk, I've been able to provide an overview of what you can expect from the transplant evaluation and the process particularly related to children. That I've given some guidance on the immediate post-transplant recovery period that first four to six weeks, and also some guidance and advice for supporting a child long term after kidney transplant.

Thank you all for joining us today. And I look forward to any questions that the group may have, please feel free to share in the chat. And we'll look forward to taking those questions.

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I see the first question coming through regarding the choice to leave the diseased kidneys intact. Absolutely! There are circumstances where the cystic kidneys are removed. If the child is having significant symptoms from those cystic kidneys, for example, if we think there is a decrease in weight gain, because they're feeling very full and unable to take in a diet. If they're having frequent episodes of pain, infection or cyst rupture that absolutely those kidneys could be removed either at the time of the transplant.

Sometimes it's actually important to remove those kidneys even before transplant and those symptoms are preventing the child from enjoying a good quality of life. Gaining weight and developing appropriately. This decision may even be made to take those kidneys out before the transplant. And typically, after the transplant as those polycystic kidneys continue to shut down, they usually stay the same size or make it a little smaller. But that doesn't happen in all patients.

Some patients develop symptoms even after transplant. And once the patient is on a stable medication regimen differs under various centers, many will wait a year some centers will wait six months, they could also be removed after transplant. And that removal, depending on the age of the child, the size of the kidneys can either be done with an open incision, or there are some centers in larger children, teens that are considering use of a laparoscope to make that incision a bit smaller to get those kittens out safely.

Jim Myers: Does anyone have any more questions for Dr. Mao? All right, I'm not seeing anything at the moment Dr. Mao. So, well. Thank you for your excellent presentation. And very interesting talk on pediatric kidney patients and transplants. Thank you so much, Doc.

Shennen Mao: Absolutely. It was a pleasure to see everyone today and I look forward to hopefully meeting many of you in the in the transplant world going forward. Thank you and enjoy the rest of the meeting.

Jim Myers: Thank you.

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Shennen Mao: Have a great day.

Jim Myers: Have a great day. Bye everybody.

Shennen Mao: All right. Well, thank you very much for moderating this session. And I look forward to connecting again at some point in the future.

Jim Myers: We will do that I; I do a live broadcast Doc and I'd love to have you come on sometime and talk to my audience.

Shennen Mao: No, absolutely. In my emails, probably the best contact. It's just my name. So, I'm mao.shennen@mayo.edu and I'd be happy to happy to join and chat further.

Jim Myers: Thank you so much, Doctor. We'll talk soon.

Shennen Mao: Okay, have a wonderful day. Thank you. Bye-bye now.

[Audio Ends]