

Clinical Perspectives: 7-Year-Old Girl Has 6 Organs Removed **June 17, 2009**

Welcome to this "OR-Live" Webcast presentation from New York Presbyterian Morgan Stanley Children's Hospital in New York City. Serving pediatric patients from around the world, New York Presbyterian Morgan Stanley Children's Hospital provides comprehensive care from diagnosis to recovery in general pediatrics and in the full range of medical and surgical subspecialties. Our experienced and skilled physicians surgeons, nurses and other health care professionals manage routine and complex conditions as well as address the psychological and family issues that accompany childhood illness. "OR-Live," the vision of improving health.

What we're going to tell you about today has at the very essence of it the notion that medicine increasingly, despite the challenge, can provide hope for people who are facing major illness.

In February of 2009 the transplant team at New York Presbyterian Morgan Stanley Children's Hospital made surgical history. Seven-year-old Heather McNamara underwent the first ever pediatric ex-vivo resection and multi-visceral auto-transplant procedure. The team, led by Dr. Tomoaki Kato, removed several of Heather's abdominal organs to resect a tumor that had wrapped itself around the structures.

The part that was out of the box, if you will, was transplanting the organs back in, especially when the patient is their own donor, okay. So it's auto-transplantation. So we transplant patients with multi-visceral organs all the time and people can have up to nine organs implanted into their abdomen and that's not new. What's new is removing the organs, taking out a tumor that was in essential to the organs and then putting them back in in a timely fashion before the patient either was hurt or whether the organs themselves had become damaged.

Post-operatively, the patient needed to go through a great deal of physical and psychological recovery.

I mean it's basically, you know, recovering from the insult that is an operation. Add to that a 23-hour operation the exposure, hypothermia, massive fluid shifts back and forth, you know, blood transfusion requirements. You know literally, not only her organs were replaced but her blood volume had been replaced. So there's a lot of aftercare that just goes into a routine operation.

When we found out that everything went well and she was actually coming out of the operating room, we couldn't have been happier. And then it turned to so what is the medical plan. How do we get her to a point where we can take her home. And with so many services involved and so many doctors involved, it become really difficult to get a concrete plan. So I really worked with the parents to advocate for family meetings, for getting everybody involved and on the same page, and for creating a clear plan that they could tolerate.

Over the next two hours, you'll hear from members of the clinical, surgical and post-operative teams that made this historic procedure possible. Now, let's join the doctors.

Hello, my name is Dr. Cara Ventura and I'm happy to welcome you to our live Webcast. Tonight we're going to discuss our experience with an ex-vivo tumor resection case which included multi-visceral auto-transplantation. We'll start tonight with an introduction of our panel.

Hi, my name is Steven Lobritto. I'm the Pediatric Medical Director for liver and small bowel transplant at Columbia Presbyterian.

Hi, I'm Tumoaki Kato, I'm the Surgical Director for Liver and Transplant Programs.

I'm Linda Ganowetter. I'm the Medical Director for Pediatric Oncology.

I'm Jean Emond, I'm the Director of the Transplantation Initiative at New York Presbyterian Hospital.

Dr. Emond, before we discuss the specifics about this case, would you like to talk a little bit about transplantation at New York Presbyterian?

This achievement was built on a long foundation of commitment to excellence in transplantation. Keith Reams and Eric Rose founded heart transplantation here many years ago. Mark Hardy, Peter Altman established pediatric surgery as a superior discipline. And over the years we have assembled specialists in medicine, surgery, nursing, social services and other components to provide holistic care to both adults and children needing transplantation. In 2006 and for the last several years New York Presbyterian has become the largest and busiest transplantation center in the nation. The ability to replace livers and intestines as part of this multi-visceral approach to transplantation is only possible in the setting of a comprehensive interdisciplinary program. And so this particular operation, which in the end did not require donated organs but succeeded in using the patient's own organs was built on a large foundation of expertise in transplantation.

I'd like to remind our viewers that you're more than welcome to e-mail your questions in, as we are progressing in our Webcast tonight. You can just click the "e-mail question" button on your browser. So Dr. Ganowetter, can you discuss for us Heather's diagnosis and what the usual treatment options are?

Heather has had a tumor called inflammatory myofibroblastic tumor. And, oddly enough, it's usually considered a benign tumor, meaning that it doesn't spread to distant parts of the body. Unfortunately in Heather's case, the tumor didn't act in a benign manner. It was very aggressive locally. She had been diagnosed after a long history of unexplained vomiting at another hospital where they found the tumor near the stomach and it was removed at that hospital and she did well for a time. Unfortunately, it came back and it came back very aggressively, involving multiple abdominal organs and causing clotting of blood vessels in the abdomen. At that time, there was some consideration of surgery but many surgeons felt that it simply could not be safely removed at that time, so medical therapy was tried as well. This is a tumor that sometimes responds to medicines like steroids, prednisone, sometimes responds to anti-inflammatory medicines as simple as Advil or more super strength non-steroidal anti-inflammatory medicines, and sometimes responds to chemotherapy. All three of those modalities were tried and were not successful at all, so the discretion of whether a surgery could in any way be possible was entertained again.

So Dr. Kato, when you first met Heather, what went into deciding whether or not this surgery was an option?

Well this was a really challenging case. We took a long time. It's not really long, long, but I think we took about a couple weeks time and discussing amongst the colleagues, each other, (inaudible) Dr. Emond and I had a long discussion how we can do this case possible and safe. I think that the best possible scenario is that we can remote the tumor with clean margin, then still to keep her own organ in so that she doesn't have to have an allotransplant. Is that really safely possible is the most difficult part that we have to decide.

So Dr. Lobritto, can you discuss a bit about what went into planning this surgery?

Well, given the multiple teams that would be necessary, we needed to have a coordinated plan of care. We sort of- it was going to be necessary to have multiple surgical teams available. There was a possibility the child would require liver transplantation so that needed to be prepared in case the father would need to donate. Child Life Services, the intensive care management, the interoperate management of the anesthesiologists, the blood requirements, pain management,

preparing the family and the nurses for the impact of this surgery. So it was really, you know, thinking about what needed to be done and the surgical feasibility and then what would be the support aspects of the operation that would need to be in place in order for it to be successful.

So let's review the CAT scan at this time. And Dr. Kato, maybe you can discuss exactly.

Maybe Dr. Emond, Dr. Ganowetter, everybody and help me too. This is four slices of the CAT scan. As you can see, she really had a big spleen. That explains her clotting of the splenic vein and she, in fact, had a tumor at the head of the pancreas and the splenic vein inside the tumor was thrombosed. Also, not only splenic vein, SMV and portal vein inside the tumor was also thrombosed. That gives significant congestion to the abdominal organs. The tumor, as you can see in the left upper side corner, was touching the liver very up in hepatic hilum, obstructing the bile duct. As you see in the right upper hand corner, the seriatric [sp], the root of the seriatric artery is encased by the tumor. It's just going through in the middle of the tumor. The left lower hand corner, you can see SMA, superior mesenteric artery, going through the tumor. And right lower hand corner showing that the lower part of the tumor is really bulging into the mesentery below the transverse mesentery.

So when we were discussing the surgical options that were available for Heather, I know that we had prepared her father for the potential to be a living donor for Heather. Dr. Emond, maybe you can comment as to why that might have been necessary.

Well the critical issue was to establish that we could remove the tumor in a life-saving way, of course. Theoretically, it would be possible for the child to live without the intestine but the liver had to be preserved. The CAT scan, although we didn't see it on the cuts, suggested to us that both the hepatic arteries and the portal veins up high in the liver were intact, but we couldn't be completely sure. For that reason, we proposed - and the father was eager - to potentially serve as a living donor so that if we were unable to preserve the liver we would have that as a backup strategy to provide life-saving liver transplant as part of the overall operation. However, as Dr. Kato mentioned initially, we felt it was very important and favorable for the child to avoid getting a donated organ that would require her to be on immunosuppression and affect her long term result.

Now we do have an animation, which will be a concise representation of what actually occurred during the surgery. I just wanted to ask Dr. Kato, before we go into this did you want to-

Yes. So the fundamental concept of this surgery is to do surgery outside the body. The tumor is right in the middle of the abdomen, deep inside, wrapping many blood vessels so we can't just cut the tumor without cutting the blood vessel. So instead of making it possible and safe, we decided to take all the organs out including everything in abdomen - stomach to the colon, liver, pancreas and all the organ - together was outside the body, cut the tumor and put the organs back in. In this particular case, the pancreas is severely (inaudible) by the tumor. There was almost no normal pancreas. We couldn't save the pancreas. Spleen is, in addition to pancreas, couldn't be saved and the stomach was already operated once and also the blood vessels we couldn't really save well enough to save the stomach. So the stomach, pancreas and spleen has to be discarded. So it's more like we took all the organs out with the tumor and then separate the liver and large and small intestine from the organ block and then put them back in the body. In order to put them back in, there are several blood vessels necessarily that would be discarded in the tumor. In that purpose, we use the jugular vein for the portal vein, interpositional graft, and we used two Gore-Tex vascular graft for the arterial replacement.

So let's show that animation.

So this is where the tumor was at the head of the pancreas, encasing all these blood vessel and superior mesenteric veins, splenic vein and portal vein inside the tumor were thrombosed. So we took all the organs out, together with the tumor, flushed with the cold preservation solution,

separated the healthy organ from the tumor, and the liver and intestine separately, then go back into the abdomen. We using the jugular vein into position for the portal vein, Gore-Tex graft for the hepatic artery another Gore-Tex graft for the superior mesenteric artery and the superior mesenteric vein was (inaudible) most to the jugular vein graft. And the all the GI tract were reconstructed utilizing the intestine (inaudible) to the esophageal (inaudible) and (inaudible) and we created a stoma.

So at this time, we're going to go to actual footage from the operation. We'd like to remind you again you're welcome to e-mail your questions to us while the operative footage is being shown. And the panel will remain here to discuss some specifics about the case as it's being demonstrated to you.

So the first part of the surgery was jugular vein harvesting. This was done by our ENT colleague. So this is how the jugular vein is exposed and this is harvested. I believe the jugular vein makes the best vascular graft for the venous replacement, particularly for the portal vein. And it's been used in many other vascular procedures.

This was originally described for creating porta-caval shunts and may European surgeons have been using this. And in recent years it has become relatively common in pancreatic surgery for Whipple resections and we have favored it for portal reconstruction in transplantation as well as in cancer surgery.

So now we're going into the abdomen. There is some adhesion from the previous surgery. We're taking down the adhesion. As you see in the abdomen, maybe if you can see it in a little bit bigger view, all the abdominal cavity is very congested. We can see huge spleen and very much a (inaudible) bowel. So this is the first - about six to eight hours. I believe it was almost close to eight hours time were spent mostly mobilizing all the organ from the (inaudible) attachment. So at the end of this procedure, essentially all the abdominal organ were just connected with the two blood vessels: superior mesenteric artery and celiac artery. So this is the mobilization of the right side of the liver. We are moving the liver off the cava and this is the vena cava down there. And I think we will see it better later, but in the inferior vena cava right under the liver, if you see it in the right lower hand corner of the view, there was a fairly dense infiltrate. And I'm just touching that area. It's a fairly dense infiltrate of the tumor. So the vena cava has to be partially removed at that point. We're see that later. This is how we are attaching, examining the tumor to see the level of infiltrate up in the liver. Because if the liver is really infiltrated by the tumor, we have to go for the allotransplant approach by using the live donor. So this is sort of extensive (inaudible) mobilizing the duodenum on the right side of the colon from the (inaudible) attachment. I'm putting the ties because there was a very congested situation that, just by doing electrocautery could be a lot of bleeding. So this is the right side mobilization. Then we're going to - this is the lower border - and then mobilizing all the intestine upwards and then (inaudible) attachment and going to the left side. So what I have in my hand is the (inaudible) mesentery put up that way. And I think this is mobilizing the left side of the (inaudible) mesentery. It's not really to the level of pancreatic border yet. And I think this is same as in the similar area I just mobilized. And essentially, the whole idea is to remove- move the tumor, mobilize everything, all the organ, from the (inaudible) attachment. If the tumor is deep, very deep, it probably would have needed to replace part of the aorta. In this particular case it was not necessarily the aorta. We were able to move the tumor away from aorta without cutting the aorta. But like I said, in the vena cava there was infiltrate of the tumor that we would not- we are not able to move it, separate it, without cutting it. And in this area, I believe it was the area on the - again on the left side just moving the (inaudible) attachment.

I think you can see the right iliac artery there so we're moving up from below under the pancreas.

And this is the part, after gall bladder, I remote the gall bladder in order to get a better view of the hilum. And after removing the gall bladder, we are now encircling the hilum structure of the liver.

So at this point it started to seem like we would have- be able to have a margin on the liver.

Right.

-without doing the transplant.

Right, yeah. But I think the final determination is a little bit after this, because this area still it's very dense. So we are cutting to the liver (inaudible) a little bit and then moving it. And I guess this is the tying the inferior mesenteric. We're going back to the left side again. This is not an inferior mesenteric vein - I'm sorry - this is the lesser curvature, that hepatal gastric (inaudible) was moved.

Did you utilize an inter-op ultrasound to assess the vessel?

Yeah, I can show it in a little bit later, the final time to determine that the liver is saved by the interoperative ultrasound. This is a prior gastro (inaudible) we're taking it down in order to get a better view of that area. I just decided to divide the colon first because the left side of the colon does not have to be removed. In order to remote organ in block, we take celiac NSMA. So essentially all the organs supplied by these two blood vessel has to be going ex-vivo. But then the left side of the colon are supplied by the inferior mesenteric artery. That would be remain in the body. So we staple the colon right here, and in separating the colon, the right side of the colon which gonna go ex-vivo and the left side of the colon which will remain in the body. Essentially, this left side of the colon is only organ, abdominal organ, that stay in the body while we are going on ex-vivo resection. And this is the inferior mesenteric vein that we are dividing between ties. Now you can see there the very enlarged spleen there.

Seems like the blood loss wasn't too extensive during this part.

Right. At the beginning of the surgery, although it took a long time and there's some oozing but it wasn't so bad, wasn't so bad. After the organs are replaced, there was some time the patient developed coagulopathy and is some time that we need hemostasis. So this is the left- between the colon and the spleen has now been mobilized.

Now we had fully vaccinated her prior, about a month prior to this operation, in anticipation that the spleen might have to come out.

Right, right.

And Dr. Lobritto, can you discuss what the significance of the hypersplenism is, how it impacted Heather prior to the surgery?

Well, whenever you have obstruction of the vessels going to the liver, the organs that are trying to empty their blood flow into the liver are compromised. So the intestine will become boggy and the spleen will enlarge due to back-pressure. As a direct consequence, she may malabsorb nutrients and lose weight. The spleen enlarges, trapping blood elements and you can eventually develop bleeding in the gut if not addressed.

All right, so here is the esophagus is taped. And then we divided right at the- a little below the GE junction.

So you never went above the diaphragm?

Right, right. So at this point, so the spleen is there, the stomach and all the organs are mobilized. And the only part that was not mobilized from (inaudible) this vena cava part. I taping the vena cava above and below. This is area the tumor was infiltrated inside the vena cava - not inside the vein, I'm sorry, infiltrated onto the vena cava wall. It was really not intravascular invasion but it

was very dense adhesion to the blood vessel. Within the margin from here, the margins were clear, clean on the tumor as well. So once this is mobilized - so we did a sharp dissection here to leave a little bit of vena cava wall onto the tumor site. Once this part is done, then really that the only thing that connects the organ block to the body was the superior mesenteric artery and the celiac artery. So at this point, we're closing the hole on the cava now. At this point it's really the time that we have to do a final determination whether or not this procedure is possible or whether or not the liver transplant, liver allo replacement is necessary. Like Dr. Emond said, it's already, you know, kind of really getting the idea this can be done by this time already. But father was still in PO standby at this point. And we will be doing ultrasound after this and then determine this can be done without the organ from the father. So this is the ganglion around the (inaudible) the SMA and the celiac. You see the left renal vein right there and these are the ganglion around the SMA and the celiac trunk what's divided. So you see the (inaudible) in behind. Probably that's probably SMA and (inaudible) in behind. So you see this, almost everything is mobilized from the retroperitoneum. So this is intraoperative ultrasound to see the hilum structure, make sure the artery, the portal vein was okay. The artery (inaudible) wasn't divided in two. It was only single artery. We put the extension, I believe.

Yeah well the artery actually had to be repaired in the back table, creating a single from two separate arteries.

So once we cut the tumor and end up we are cutting the artery in a very small tiny branch and the main branch. That was one of the most difficult part of the surgery was done very nicely, as the magnification loop. So this is the time that we clamp the celiac and SMA. And now we are clamping the vena cava above and below the liver. So there's big lamps on the cava and small clamps that we saw was on the celiac and SMA. Now we're just cutting into the vena cava. We could have taken the vena cava out and replace with the Gore-Tex too, but this time we decided not to do and just to save the native vena cava and just cut the cuff of the hepatic vein and then reimplanted that patch into the vena cava, which has- doesn't have to be done that way but makes little bit else on the management not having the Gore-Tex, another Gore-Tex in the vena cava. So this is the area that all hepatic vein cuffs are cut. And the vena cava continued to exist, still intact, with just putting the clamps to close that area. But after some time we put the patch on the cava that we'll see it later. So now all the organs are taken out en block. So the organ, unblocked organs, are on this tray I am moving from the body to ex vivo back table. You see that fairly congested organ set for this age child. So then we're going to flush the organs. The little bit of difficulty here in flushing the organ was that when after we cut the arterial root, the (inaudible) and SMA, very went in deep inside the tumor. So at the beginning to flush the organ, we have to do some backflow technique to flow, backflow, back flush through the hepatic vein, or SMD as you see it later. But now after some flush is done we are making the cut in the root of mesentery. The tumor is upper hand.

How stable was the patient during the cross-clamp?

During the cross-clamp she can be very stable and she was really, in fact, stable but she can be very, very stable. And we are anticipating up to probably four hours, patient probably wouldn't need anything. After four hours, probably six hours, after six hours may become a little more acidotic and gets into trouble. But essentially all the abdominal aortic- aorta and vena cava continue, it is there. So it's not really that much of a big issue. And here I'm separating just a vascular root in order to flush it better because the SMA we couldn't really flush well through the root. And now we are cutting into- this is the SMV right below the transverse mesentery to canulate, in order to canulate and back-flush through the SMV.

What's the time pressure to get this flushed properly?

Well I think if it's already flushed somewhat at the time. It's not really that much of a rush. I think the blood is already halfway flushed all this time. But, of course, the sooner the better.

You can see the canula going into the artery finally for the very effective flush.

Right, right. So yeah this is the artery, just to kind of is going in now. And then after this is done, we- so this is the canula finally going to the SMA and a very effective flush is being done. But at this time, it's already fairly well flushed and organs are in a cold environment. Then we go into the liver side and divide the liver from the tumor. I don't know if you appreciate very well with this film, but this is really high up in the hilum where I'm cutting with the scissors. The bile duct was divided in two, right and left separately. And also the artery was, in fact, was divided in two. The portal vein was not divided in two.

You've got an open vein above the clotted area.

Yep, right, there was open vein above the clotted area. And we didn't really know how extensive the clots were but there was not much, once we goes about the tumor into the hilum, which really we knew at the time of the final ultrasound. This is a little small piece of liver, was densely adhered to the tumor. Now it's the liver is completely divided. So from here, once the liver is divided and once the liver is separated and then flushed again, from this point we separated our team in three. So this is the time that we have very busy in the operating team and three different team is working on three different area in the operating room. So the abdomen at this point, up to this point was fairly empty. Nothing was going on. But from this time, the one team, Dr. Emond took the lead of this part of the surgery, was dissecting the hepatic artery there and putting the extension graft. This arterial extension graft, we found it from the abdomen. Essentially we took the small artery from somewhere that was not necessarily but not (inaudible) by the tumor and then connected it as an extension graft. This is a fairly small caliber blood vessel.

So we were able to use a Y, a small Y-shaped piece of artery, because we had cut the hepatic artery above its division. So we had to do an end-to-end anastomosis to the left hepatic artery, another end-to-end anastomosis to the right hepatic artery, and then we had a nice single stump for implantation after we achieved this. You can see the bile ducts just behind, the two yellow circles there. That's the right and left bile ducts just behind. And the portal vein was cut very short as a single orifice, which encompassed the two portal vein branches. So this is the microvascular reconstruction. It's done with 6 power, 6 X magnification and simple interrupted sutures of very fine Prolene suture.

So here is another surgeon, Dr. Goldstein, is separating the bowel from the tumor. So the tumor is bulging into the mesentery, below the transverse mesentery. So there's several blood vessel had to be sacrificed. One of the bigger blood vessel has to be sacrificed and this was ilio-sacral artery. But there was enough blood vessel, blood supply, to preserve entire large bowel that was going ex vivo. But some of the- part of the small bowel has to be sacrificed: one that was connected to the stomach as well as some of the proximal (inaudible) was sacrificed in this procedure.

Does the congestion improve right away after flushing?

After flush, yes. But you know, it takes some time and also preservation makes it somewhat congested and (inaudible). So this is the third team. I am putting the extension graft onto the siliac artery. Dr. Ventura was helping me this part here. This is a 5-millimeter thin wall Gore-Tex. I use it for the siliac artery extension graft. The siliac artery essentiality has to be connected to the hepatic artery because stomach and pancreas is removed. There's nothing else that siliac has to supply the blood to.

Do you do anything to accommodate growth of this vessel over time?

Yeah, we put a growth factor in there. But I think 5-millimeter Gore-Tex for the siliac or SMA should be good enough for very, very - pretty much all the time on the- for the adult site. And this is the view of the operating room. As you see, it is the three different team working at the same

time. So this is just a temporary patching of the vena cava. We thought at the beginning just to put in the clamps might be okay to keep the continuity of the vena cava. But it wasn't really that great so I put this temporary patch. This is the area that the vena cava or the hepatic vein was cut off. So that was just closed temporarily with a Gore-Tex sheath. And that was removed at the time of implantation of the organ.

That allows you to open up the clamps until you're ready to implant the liver.

Right, right. Even without this, there was some partial connection. There's some partial continuity of the vena cava but that made it much better. So this is the part Dr. Goldstein is finishing, the separation of the intestine from the tumor. So at that time, by the time the liver goes back in was about three hours from all the organs were removed. She really didn't have any issue of hemodynamics. She was always making good urine and was very, very stable at that time. So going back to the main table after this, in order to implant the liver, the liver needs the portal vein. But there's no portal vein because all the organs are removed. So we use the left renal vein as a portal inflow temporarily. It's not really temporarily, it stays on the left renal vein. But the reason why I say temporarily means that the SMV will be connected to the side of this extension graft. So essentially, this is not just the left renal vein. At the end it will become a mesenteric venous return. It's a little complicated. I don't know if I explain well enough. So the end of the left renal vein is connected to this jugular vein graft. This jugular vein graft will eventually be connected to the portal vein in the liver and the superior mesenteric vein of the bowel will be connected to the side of this jugular vein in the position graft. The left renal vein is completely divided here. This is a renal, portal anastomosis technique that's been done in the liver transplant in the past with some spontaneous (inaudible) renal (inaudible) case or the surgically created cases. So this is the jugular vein. The jugular vein really has good quality and size, very nice size match, makes a perfect size match for the portal vein. And I'm putting a little growth factor and tying the knot after the artery- the vein clamps are open. So now that we are ready to put the liver back in. So now we have a portal vein conduit ready, arterial conduit ready. The vena cava is ready and the arterial site, 5-millimeter Gore-Tex would have been too big for the hepatic hilum vessel but Dr. Emond put the extension graft with a Y shape. And then the other side of the Y shape - you will see it later - can be extended as the branch patch. So you will see that very nice size match after all. So this is the side of the vena cava is being closed. This is about how many hours? This is like-

Eleven.

This is like 2:00 in the morning.

About 2:00 in the morning.

Yeah about 2:00 in the morning. And this is really the time that I was personally very, very exhausted. And then it was a very, very hard time on the surgery. So Dr. Goldstein did that closure of the left renal. Then I took a quick break and then coming back to put the liver in. You see here this abdomen is pretty much empty. Everything is gone except for the left side of the colon. And now we are putting the organs back in. But essentially the organs were liver and small bowel and large bowel. So the vena cava is now cross-clamped again and this Gore-Tex patch is removed. So this is just a temporary closure.

To put the times into perspective, in regular transplantation when a donated organ is used, the liver can be stored in preservation solution or often as long as 12 and theoretically up to 20 hours. So that a total storage time for the liver of three hours is quite safe. And you'll see after this liver gets recirculated how nice and healthy it is, despite the begin outside the body for three hours.

So it's really the more tricky part here is not really the organ itself. The organ can be preserved up to 12 hours, like Dr. Emond said, but her body may not maintain the normal circulation after

certain hours. We estimated the time to be probably six hours as a maximum and after all, may have to consider some other bypass if in case that happens. So now the liver is going back in. But first we make a venous connection and hepatic vein. Just exactly where we cut, we are sewing it back. It's a little bit difficult.

So your renal inflow is because you wouldn't have SMA flow for quite a while.

SMV flow, right.

SMV flow, excuse me.

-flow for quite a while, exactly. So that's kind of temporarily for the flow to the liver until the SMV goes in. I think probably just reprofusing the artery may not necessarily be unsafe, but I think this makes a lot more safety and ensuring the liver reprofusion.

Doesn't seem to be any downside to doing it.

Right, right. Because you know, you need this type of connection anyway because the SMV to just connect to the liver, it really doesn't get stabilized too well. So if you just put the SMV directly to the liver with the jugular vein in the position it could be too long and redundant and also can get a kink or twist. To have this renal vein as a one side that stretch the vein to sort of fix the vein into the position makes it much better. So I think this is probably the better alignment done to just put this SMV directly into the portal with the interposition graft. So now the venous connection is done. The liver still doesn't get any blood flow yet. And first we connect the portal vein to this jugular vein interposition graft. So this is a regular 6.0 (inaudible) running suture, the portal vein.

This is all done with 6X loops?

No I generally use a 4-1/2 magnification. It's not really necessarily for the portal vein but I'm kind of used to using 4-1/2 almost all the time.

(inaudible) have gotten away from using microsurgery scopes because loop is sort of a standard now for- is that not true?

So the use of the operating microscope in liver transplant was introduced by the doctors from Kyoto about 15 - 17 years ago and for a while some- many teams have been using the microscope for small hepatic arteries in living donor transplants. But it's certainly not routine in abdominal transplantation. And you now standard loop magnification is the routine.

So after the portal vein is done and also put in a little growth factor, we could have just reprofused the liver with portal vein in the vein. But just putting the arterial anastomosis prior to reprofusion is sort of my choice of procedure even for regular liver transplant. But in this particular case, I think it was better because artery, there's some size mis-match and it's maybe a little bit more difficult to do arterial anastomosis in case there's some bleeding issue or congestion issue happens after. But, of course, it could have been done with this- without arterial anastomosis prior to the reprofusion. So this is the thing that I mentioned, the branch patch. So it's very, very nice size match. But if you see this here, you really can't tell that how much of the size discrepancy would have been if you don't put this extension graft. So with this extension graft, we have a nice size match situation but without it could have been very, very difficult to use this Gore-Tex. So now this artery is connected to this Gore-Tex extension. So the siliac artery is supposed to provide (inaudible) to liver and a pancreas and a spleen but here there's no pancreas and spleen and stomach. So essentially the siliac can be just connected directly to the hepatic artery.

So this very nice, soft thin-walled Gore-Tex conduit is a very useful replacement for arteries.

I think so, I think so.

-in extreme surgical situations where there's no natural artery available.

Would you comment a little on the use of the growth factor that you use when you anastomose these vessels?

It's a sort of, you know, a standard technique for the artery or venous anastomosis, which the expansion, the blood vessel by the blood flow because when you are doing anastomosis there's no blood going on or going in. So the blood vessel (inaudible) shrinks. But once, after the blood goes in, it expand again. So if you just tie a knot without the air knot, then it makes it too tight.

It was first described in children where the artery had to grow. So when you see, when you use a single suture to do all the way across the anastomosis, it can't stretch unless you tie it very loose. We call that an air knot or a loose. And then as the artery expands, it spreads out. And also, particularly if you're operating on a child, that will grow. The artery can expand over time and it doesn't have a fixed-

Now we're reprofusing the liver so the vein clamp goes off first and then the portal vein is open and reprofused. It's not essentially a portal vein, it is a renal vein. Renal portal anastomosis is open for the portal reprofusion and arteries open for the hepatic artery refusion. This refusion was very uneventful with any problem, without any issue at all. So now the liver is back in. So the abdominal cavity now had the liver but nothing else essentially except for the left side of the colon and the esophagus. So now we're putting the bowel back in. So here I'm putting the extension Gore-Tex, another 5-millimeter Gore-Tex on the SMA.

Dr. Kato?

Yes.

How much time elapsed from the organ block excision to the reimplantation and reprofusion? Can you just review that?

Yes, so the liver reprofusion, it took about three hours. So from the organ removal to the liver goes back in in three hours. And the intestine was reprofused in four hours. So total time the organ this time was four hours- not organ list but total time that required to reestablish the organ inside the body was four hours.

These events are all simultaneous. There someone else is preparing the bowel, the tumor is being respected while the liver was being reconstructed.

Right this cannot be done without the very nice teamwork of it's really three separate team work together at the same time to minimize the time. So this surgery really took a long time but the time the organs were out was not that long.

Right.

So this father somewhere in here was given the green flag to eat since we-

He left about 11 p.m.

-sort of refused for like a least another six hours or even nibble on anything in anticipation.

He was afraid that he would be called on to provide an organ for his daughter.

So here the SMA is connected to the Gore-Tex extension great. Now this part is not really well visible. This is always the case in putting the bowel, whether that is an autotransplant or allotransplant because bowel is a very difficult organ to really sit in a small place. It's very moving, it's large.

One of the hardest things I learned from Dr. Kato is it's harder to hold the bowel than it is to sew it in.

Right.

You've got to keep it just right so it's not stretched.

Exactly. Right, it's really like this assistant Hanna is doing exactly the right way of holding the bowel right in place doesn't move at all but it's not really easiest thing to do.

Is there any issue with kinking when you reposition the bowel?

Yeah, but you know so you really have to make it short enough not to have that kinking happen. That makes it even more difficult to sew in the bowel.

I remember one of my teachers many years ago, Frank Stewart, who was a kidney transplant surgeon, to this same issue because you have to work on the kidney but if it's too long, the vessels are too long, they can kink. And he used to say you have to make it uncomfortably short. And that's the same way here because if the artery is too long, it could fold and kink when you put the organs back in.

Now your venous graft is going to go to the jugular interposition now?

Right. So the SMV of this bowel goes into the jugular vein interposition graft between the left renal vein and the portal vein. So now we are putting this side-biting clamp on the jugular vein .

Is the concern with using Gore-Tex in a vein more so than using it in the artery?

Right, so the thrombosis rate really is not- is higher in a synthetic graft than a vein compared to the jugular vein.

How about artery versus- you know using it as a venous anastomosis as opposed to the artery anastomosis? I would think the lower pressure of the venous system would make it a higher risk for thrombosis.

Well this is why we chose a jugular vein for the portal replacement. And our experience at replacing the vena cava with Gore-Tex is a relatively high thrombosis rate, particularly over a long period of time.

Would there be possibilities of erosion of the artery into the bowel over time?

You're talking about this-

Aortic and enteric fistulas or-

Well any vascular anastomosis close to the bowel has that issue, as we all know in vascular surgery. But you know this is the only way to reconstruct. There's nothing to connect between if you don't have the graft. And if you use the allo-graft or some other graft that also has an issue of thrombosis. And again, it's not really that much different using the synthetic or non-synthetic in terms of creating the enteric fistula. So this is the final vascular anastomosis that is connecting the SMV to this jugular vein interposition graft, side of the jugular vein interposition graft. I really

think that probably sits very nicely with using the left renal vein on one side and holding the vessel.

This is a running suture now?

Yeah, this is a running suture, 6.0 Prolene running suture, you know very much well preferred size of the suture for this size of blood vessel.

Dr. Kato, we have a viewer who's wondering if you could discuss possible complications of bleeding during the reimplantation in the event that a vein or artery was severed.

Well of course there could- some of the major blood vessel connection, it has to be done right. If it's not done right it could be a disaster. There are several things can cause really big disasters like vena cava anastomosis if it's really not done right and end up bleeding. Or also if it's not done right, end up causing stricture. That also very serious consequence.

The main area where there might be small veins, there's nothing to bleed in the abdomen because all the large veins are seen and accounted for. But in the bowel there can be small arteries and veins that are not tied during the dissection outside the body. That's the main source of bleeding after reprofusion. You saw the liver bleeding wasn't much at all. But the bowel has many more little vessels that can be bleeding.

So now the bowel is reprofused too, so you see that the small bowel and large bowel regain their color with the blood flow. So now that the bowel is back in - large bowel, small bowel - intestine is back in (inaudible) back in. So at this point, you know we are as if we did a total gastrectomy, total pancreatectomy and splenectomy. Because you know we took all the organs out and only put the three organs back in, so the six minus three makes it like three removal of the organ.

Now there's more metabolic stress when the bowel was reprofused than when the liver was reprofused.

It could have been. In this particular case, really didn't see any change. But it could have been, yes. And here the esophagus is connected to the GE junction. So this is like we do a total gastrectomy. When we do total gastrectomy the esophagus has to be connected to gignum. From the surgical colleague I think it's fairly common way of reconstructing has no question. But for more of a (inaudible) that had quite a few question about how come she can eat without a stomach and what did I do to create the stomach. But the reality is not. You don't really have to have a stomach. Stomach is more of a reservoir function to have food stored there. So it really doesn't have to have the stomach to eat. Of course, you can't eat the big meat- not the big meat the big portion of the food at a time. But like gastric bypass surgery, you really create the very, very small stomach and connect the small pouch of stomach to this small bowel.

Probably the dumping syndrome that you might see after this kind of a surgery, I guess you wouldn't see necessarily if you didn't have a pancreas. People don't get the exaggerated insulin response.

Right, yeah. So here is really, this is a total pancreatectomy. So we don't really see that dumping syndrome but it's really the concern is her long term diabetes. So we did achieve the tumor removal with very clean margin. But on the other side that she has to lose her pancreas. So that was a total pancreatectomy and she has to live with diabetes.

Will she ever be a candidate for an islet cell transplant?

I think she can be a candidate for either islet transplant or pancreas transplant in the future. At this point I don't think it is a good time to do it. But she has to recover from surgery and the oncological standpoint of view it is better not to have immunosuppression.

We had hoped to be able to isolate her islet cells but unfortunately there was not enough pancreas.

Right, right we were ready to freeze the pancreas to isolate the islet cell. But there was really no pancreas at all at least to be a visible pancreas. She must have had pancreatic function of the producing insulin prior, but all these insulin producing cells are probably pretty much inside the tumor and infiltrated by the tumor.

How hard has the diabetes been to manage since she's gone home?

I think initially it was we had some difficulties even though we tube-fed her initially so we had sort of a steady state situation. But I think it was the family's adjustment. I mean at this point they're going really quite well. Her father is amazing at taking care of it. They're very comfortable with the adjustments. The insulin pump makes it much easier (inaudible) you can administer when she takes higher dextrose intakes, he can administer quite easily and it hasn't been a major issue but it will be a lifelong issue until we get pancreas transplant where it needs to be.

So your (inaudible) ducts are still left on anastomosis at this point.

So this is the first GI anastomosis, so that's connecting the esophagus to the jejunum. So once this is done, the other reconstruction will be bile duct and the large bowel.

We had chosen not to put a jejunal tube in at this time because of the concern that it would be another area for potential infection. So Dr. Kato actually marked in the area on the bowel that we later were able to localize externally and have interventional radiology place a J tube.

Is that right? Very nice.

There was a conscious decision.

Just this length of complex surgery, anything to avoid a potential complication is important. And sometimes all this seems to be a small part of the procedure, can be really a tricky part of the operation in terms of the post-operative management.

And any nasal tube in her would have been a nasal jejunal tube by definition, since she didn't have a stomach. It wasn't exactly a feat. It looks like it didn't (inaudible) than it did the liver, my friend.

Well it's more than editing.

Are you having flashbacks of exhaustion?

I think at that time I was almost- I think I was a little recovered. The worst time was right at the time the liver- we were putting the liver in. And that was really a big stress and long surgery.

We've done one endoscopic stretch, a balloon dilatation of this area, when she had some complaints of things getting stuck, which has gone rather well and she hasn't had recurrent complaints. Imagine acid reflux is not a problem.

That's right.

Would radical work?

There's some anastomosis technique can be used, the stapler, but I prefer to do a hand-sewing for most of this type of an anastomosis because it's just more of a preference thing. But I believe

it bleeds less, particularly the organs that were reprofused. Cold preservation and reprofused tends to get more bleeding issue than non-reprofused, non-preserved organ. So this is a (inaudible). We are dividing the giumum in order to create (inaudible) length for the bile duct reconstruction. So that's the (inaudible) done, just very short.

So you were seeing good bowel flow from the ducts at this point after the liver was profused?

Yeah, she was- the liver was producing a lot of bile already at this time. And the bile duct was already dilated with the colonic obstruction. So this bile duct anastomosis, although this was a tubal duct, wasn't so tricky. This is first bile duct anastomosis. This looks very big and a large bile duct but this is not the larger one. This is the smaller one of the two. And I do bile duct anastomosis mostly a continuous suture. This is a PDS continuous anastomosis. Maybe you can see the bile flowing there, you know the yellow color coming. This is a very, very good fast recovery of the- sign of a fast recovery of the liver.

You obviously felt that her liver was the most life-threatening issue going into this, you know how healthy the liver would come out of it. So this was very exciting when things went well with the liver reconstruction, with the tumor being able to come off of the liver and eventually with the good function going back in.

Right, right, yeah.

Every time we do liver transplant, you know, to see the bile is always a good sign. If you see more bile than the blood, that's always a good sign.

Good general rule, yeah.

How much blood did she receive during this surgery?

I don't have that data with me. How much is it, Cara?

If I remember, I think she received about-

Five units, four or five units, yeah something like that, yeah. Yeah at one point, I think it's right before this anastomosis or maybe somewhere in between the GI reconstruction we went to develop terrible coagulopathy. It's a (inaudible) so every single stitch- not the stitch, the area on the (inaudible) area started to bleed. And it took about two hours to just resolve coagulopathy. So we didn't really show it in this video but it was in between these GI reconstruction. There's a time that she was very- the field was very soupy with the blood. But that was kind of anticipated problem with this type of long hour surgery with preservation of organ outside. So this is the second bile duct. I usually put the internal stent like that. And this size of big bile duct, we probably didn't have to have it, but that's the stent. That's supposed to come out from the stoma or from the bottom.

We had neglected the stent to the family and they came running into the office and we were all happy to see it but they were a little upset when it passed in her stool.

Is it supposed to be passed inside a stool.

It was a good event.

So here's the bile duct anastomosis down, thus we have only left to do is the large bile anastomosis. Before I do the large bile anastomosis, I'm pulling out the loop ileostomy so that the bowel content doesn't go into the anastomosis from this farther. And this is the large bowel of the reprofused bowel to the bowel, large bowel that was left in the body. The large bowel part we really didn't have to resect anything.

My understanding was you did the ostomy so that we would be able to monitor perfusion to the organ.

Right, monitor perfusion is one and also ensure the healing of the colonic anastomosis because if this colonic anastomosis doesn't heal well, it leaks, it could be a disaster because there's a lot of measure vascular anastomosis right underneath this area. So contaminating the vascular anastomosis with the intestinal content would have been very, very bad this type of surgery.

And you don't like the stapler for this either, huh?

Yeah that's more of a preference. I think it could have been stapled, but like I said I think the reperfused organ after preservation tends to have more bleeding. So hand-sewing to ensure no bleeding is important. So that's all the anastomosis is done. So that's the bowel duct anastomosis, (inaudible) colonic anastomosis. Yes you see still the bowel is not really normal. It's very edematous. But that's always the case after ischemic reperfusion of the bowel. And then we are putting the JP drain in both side.

Is there any technique to laying the bowel in, tacking it down, anything to recreate the mesentery [crosstalk]

Well that's also a very frequently asked question for the bowel transplant. And this is the same as a bowel transplant in a way. But somehow it's never necessarily and it just sit in the right place. If you do an experiment or transplant an animal, it's been an issue. You have to tuck it but in the human bowel transplant, somehow the bowel finds its right way and it's very unlikely we need anything if you have all this proximal and distal connection and done in a regular way, unless you have a very tricky positioning of the bowel.

Similar to an allograft since the lymphatics are not anastomosed. Well you would expect her to have fat absorption issues in the immediate post-operative. So we used- when we did eventually feed her, we used a modified diet.

Dr. Kato, did you want to show the animation again to recap what we did?

Sure, sure.

So let's show the animation again please. You know, Dr. Emond, I think I remember at one point in the surgery when the three teams were divided you just looked around and said, "This is so cool." I'm sure some of our viewers would agree.

So again, this is the same animation, the bowel, the tumor is right at the head of the pancreas encasing all the blood vessel. Some of the blood vessels are thrombosed. So we took entire abdominal organ outside the body except for the left side of the large bowel and separated the tumor and stomach and pancreas out of the organ block and liver and bowel separately, and using Gore-Tex graft to the siliac and SMA and jugular vein graft to the left renal vein, to the portal vein. And SMV was connected to the side of the jugular vein graft. And the gignum-esophageal gignostomy [sp] (inaudible) gignostomy, colidocal gignostomy and then cholocholostomy with the loop iliostomy to protect anastomosis as well to see the perfusion of the organ.

Great. So I'm going to review some questions from our viewers at this point. One of our questions is wondering what- excuse me, one of our viewers is wondering what would be the life expectancy of a patient with an ex vivo tumor resection and is there a possibility of multi-organ failure, being that the body was put through so much stress?

Do you want to translate that question?

So life expectancy would depend on a couple of things. One is that there was no multi-organ system failure, so the patient survived this. Her life expectancy, I think, is a function of her tumor reoccurrence possibility and a function of the diabetes and the possibility of her having some other end organ injury from diabetes. In general her nutrition status is quite good. There was the organ we were concerned most about was the liver. And given that the liver did well, she was going to do well. The coagulopathy was a concern but expected in the latter part of the operation and that resolved quite quickly. So her life expectancy, if her tumor does not reoccur, is similar to anyone else with diabetes that's well controlled.

I do have another question here. One of the viewers was asking, Dr. Kato, if this surgical procedure is possible in adults, and I know that you do have some experience with that.

Yeah it can be done, doesn't have to be children. I think the recovery could be faster in children, adult may take a longer time. But I've done one case in Miami when I was in Miami with a colleague in Miami to do a similar surgery in a 63-year-old lady. She's been doing very well.

Great. Did Heather require any anticoagulation therapy after this procedure?

Did she require or did we give it to her?

Did you give it to her?

Yes we did.

(inaudible)

Since she had Gore-Tex, since she had these artificial portions of blood vessel, we're concerned about the clotting rate. And since they were feeding her major organs, we decided that we would anticoagulate her for a period of time. And we've since reduced that in its nature and actually I think eliminated it. You know the vessels- the Gore-Tex grafts develop endothelial lining and the clotting, I think the clotting risk is probably greatest in the early period and improves over time.

Great. Does anyone have any other comments they'd like to provide on the surgery? No?

I think that, although the surgery was dramatic and you saw a very detailed description of it, the total effort into taking care of this child and helping her family is really just the beginning now. And the medical and social and nursing support that comes after and continues is really enormous. And so we, as the surgeons, are very grateful for the support we get. And obviously, the patient can't survive without that medical and nursing support.

I think it was important that the medical team was involved, even though not a big part of the surgery itself, was involved in the planning of the surgery, the anticipated problems that we might encounter and then we continue to partner. And it's been the milestone or the basis of our program that we would have a med-surg approach to things. And I think it's worked out well for these dozens years and it will work for the next dozen.

So I'd like to thank Dr. Emond, Dr. Granowetter, Dr. Kato for joining us for this part of the Webcast. And, as you mentioned, this takes an extensive amount of time in recovery. And our next panel of doctors will be discussing Heather's recovery period.

We could show you our team video now. There is one reason why we continue to push medical technology and that is for the patients. It's not for notoriety or recognition or for papers that we write. It is really about the children here. And I'm fortunate enough to see the excellence of this team is every day.

In this center, Dr. Emond's vision for recruiting Dr. Kato is because we are unsatisfied with routine, that we need to perfect our routine and we need to push the envelope as far as innovation. It is not the surgical team, the medical team, the ICU, it is the institution. It is the child-like people coming (inaudible) feel comfortable. It's the physical rehabilitation people coming in there and getting them mobilized. It is a team effort and this was an institutional success, not an individual success, except for the patient. It was an individual victory for her if she is cured.

Of course, all of this is supported by a very superb medical staff as well as a nursing staff. And so the fundamental need for a team oriented approach I think is no better demonstrated than the transplantation center.

I have to give credit to all the nurses that took care of her. It wasn't only me. It's the 24-hour care. And like I said, when the (inaudible) taking care of her, it was like everyone's goal to make her better and see her walk out of her. They visited her on the floor and was just amazed by her progression.

(inaudible) the course of her (inaudible) it was mainly Dr. Kato or the transplant service surgeon as well as the transplant service, liver service and ourselves. And at the very end, when they're ready, when she was ready to do to the floor, it's those services, plus the pain service. Once we leave, or once she leaves from the unit, we want specifically some people to look after her in terms of pain requirements and that sort of stuff. From the support staff that we have here in the unit, of course, nursing is obviously very important in our work. And of course on daily rounds they do they are represented and they're always there by her side and by the room. The respiratory therapists are an integral part of the pediatric intensive care unit. We also have social workers that would both help the family and also her as she gets a little bit more awake, particularly for our teenagers. For her, since she was younger, we have our Child Life service that comes by and that helps both her as well as her sister.

We have social workers for every service that you can think of. Here there are general medicine social workers. With this particular family, we involved the diabetes social worker and oncology social workers. But there are social workers up in the intensive care unit who have met her. There are social workers on the general medicine floor who have met her.

I think I have really enjoyed working with this team because we do have a high acuity here so we get to see wonderful things. And since we're not a huge department but we're not too small, I have a lot of colleagues that can support and help me and we can bounce ideas off each other so we do still have great teamwork even through we do have our own individual floors and individual needs.

What I do here is to me not even the issue, it's what we do here. We have a really strong collaborative group of oncologists who work I think near seamlessly to provide the best care we can for kids with cancer or other similar diseases. The social workers, the Child Life, the complementary care people, the clinical research associates, the fellows, the attending physicians are all here for the kids. And as the clinical director, I like to oversee that and try to make it as smooth as possible. But it's all about being here for the kids and looking for children who face real challenges.

In this hospital, the culture was really that ready to accept the challenge, surgical challenge, something to do in (inaudible) procedure. They accept that. The culture here is to accept this. So that was one probably biggest things. But not only that, of course we need a surgical team, medical team, nurses team and everything to take care of this complex situation. Although this was the first time in his hospital the team here did it as if they had done it many times in the past, which was a great thing and improved that this hospital capability.

So thank you for continuing on with us. At this point we're going to discuss the recovery for this patient. And I'll have this team, this new panel, introduce who they are. As you can see, Dr. Lobritto has remained with us. Dr. Hum..

I'm Stanley Hum, I'm one of the pediatric critical care physicians.

I'm Stephanie Boro the pediatric, liver and small bowel transplant social worker.

And I'm Elizabeth Yulehorn and I was Heather's Child Life specialist.

So Dr. Hum, you received Heather immediately out of the operating room. What challenges were presented to you and your team?

So I mean I think the challenges for Heather kind of started, from the ICU point of view, much before she actually got to us because it was unclear exactly how long she would be in the operation. And as it turned out, I believe that it actually went through about three nursing shifts before she got to us. So the first part of the open planning on that is that basically the nursing. They had to make sure that there was always somebody available to receive her throughout the period of time because we really didn't know what- how long it was going to be. We knew that it was going to be a complex surgery but we also didn't know kind of what type of complications there may be, what type of issues would happen. We knew that it was a possibility that she could actually have a liver transplant. So all of these sort of things have to be kind of prepared for much earlier than when she actually gets to us. We're pretty lucky here because, as a routine, we talk to the people in the OR and the anesthetist and anesthesiologists, the nurses talk to the nurses there and we hear about what's happening in the surgery from time to time to give us a little bit of warning and so that we can prepare.

And actually one of your fellows and one of the nurses did come down to the surgery while it was going on.

Yeah so we do do that and by the time she had gotten up to us, we had prepared some of the infusions she was on. She was on some cardiac medications - a small amount. She was clearly still on mechanical ventilation and so she still needed heavy sedation and anesthesia. And we continued that through her immediate post-operative period. We knew that she had- that Dr. Kato had to remove the pancreas and so we knew that she was going to need insulin. And once that happens, then we can prepare for all of those. Once she arrives, and then we- it's our routine to gather with nursing, the operative team, the surgeons, the medical team that took care of her before she went into the operating room to kind of discuss exactly what happened in the OR. And we were very fortunate that everything seemed to have gone very smoothly. Although it's a very complex surgery it went very smoothly. And through her stay, I think that reflected that as well.

Great. I just want to remind the viewers that if you have any questions for Dr. Hum in terms of her critical care management and early post-operate period, feel free to e-mail us and we will address those questions. So I'm going to move to Liz at this point. Liz, I spent a lot of time I promise with this family ahead of time trying to explain to them what exactly Heather would be experiencing in terms of life changes and dealing with body image issues and changes to her body, in terms of having a G tube and an ostomy. What was your experience with Heather when you first met her?

Well I met Heather as we was waking up from surgery. And I really wanted to meet her as quickly as possible to help explain to her what she was experiencing, what she was feeling, and seeing and hearing because they're all very new and unfamiliar experiences, which can be very anxiety-producing and scary for a child. One of the ways we do that is by using our teaching dolls because this way we can show them in a more non-threatening manner and they can also actually manipulate things on the doll to increase their understanding. So this was actually- this

was one of our transplant pieces. These dolls can be adapted for any procedure that she'll be experiencing. This also has an IJ adaptation, which she was very anxious about, getting her stitches out and having this taken out. And she was able to actually try and remove the stitches herself from the doll so she knew exactly what the doctors would be doing at that time. And not only did I want to explain to her what was happening then, but I wanted to explain to her all of her upcoming procedures that she would be having because she would now be awake for those and experiencing that. For example, that day she was receiving a PICC line, so I used the doll to explain to her exactly how that would happen and we talked about different ways that she could- what she could do to help herself cope. Her parents weren't able to be in the room with her, so I stayed with her and we worked out her coping plan and I helped distract her and keep her calm. She actually chose to use her "High School Musical" songs and we talked through each song during it and she talked me through the movie and that helped keep her distracted and calm so she wasn't so focused on the actual procedure itself.

Now do you use these dolls for all children in the hospital?

Yes we do. Like I said, they can be adapted for almost anything. I also have- this is the G2 adoption which we also used when she got her button and I can really use it for anything, which is nice. And we can adapt it for all age levels what is developmentally appropriate for that child.

Do you want to mention Heather's daddy doll?

Oh sure. Another thing that we use are these blank cloth muslin dolls. And these aren't used so much for teaching but more for allowing a child to gain mastery over what's happening and allowing them to really express themselves. So when they use these dolls, they're allowed to take medical equipment and it's very child-centered. And she can kind of decide what's going to happen to the doll and it gives her control over the situation. So she has a few of these dolls but her favorite was called her daddy doll. And she used it almost every day and she slept with it and she took it home with her. And the daddy doll constantly had new procedures happening to him and as Heather would have something done, so would daddy doll.

Great. Stephanie, you spent a lot of time with the family trying to help prepare them for this intervention. What was your experience with the family?

So social work evaluation begins pretty much the same time as the surgical evaluation. And my role is to meet with them in the clinic well before the surgery even happens and assess what are the social barriers to transplant and how can we overcome them. So does the patient have a support network and a family. And from the beginning, my family- my job was pretty easy with this family because they were so highly motivated. They had an amazing informal support network. And they were willing to do whatever to get Heather better again. My support then continues inpatient helping to develop a plan, to get Heather home safely, to get her home in a way that the parents are able to manage her. And providing psycho-social support, obviously having a child with so many medical issues is very anxiety-provoking for the parents as well. So part of it is working hand-in-hand with Child Life in order to address both the patient's needs and the parent's needs and the sister's needs in order to make their stay do-able. And then outpatient follow-ups, so seeing them in clinic, checking in with them and making sure that Heather's on the road to getting back to a normal life.

Was it difficult coordinating her discharge because there were so many specialties involved?

It gets to be a challenge when there are so many specialties involved because everybody has an idea in mind of what they would like to see happen and when. And unfortunately for parents, it can be hard to tolerate different answers to the same question. So it was very important for them to get all the providers together to get a clear plan and make sure it's something that they were able to handle, which we found it the end. And luckily, especially her father is so proactive in

taking care of her that she didn't need rehab, she didn't need private duty nursing, dad is the private duty nurse. And we're very fortunate for that.

How do you think she's doing socially now?

I'd like to see her back in school soon but she certainly is doing socially very well in our clinic. She's a really precocious little girl and I think she'll do just fine.

So, Dr. Lobritto and I have had the pleasure of seeing Heather multiple times since her discharge. She has been readmitted once, which was a scheduled readmission for ostomy take-down and removal of her feeding tube. Dr. Lobritto, maybe you could talk a little bit about what her recovery has been since she's left the hospital.

Well her initial recovery, after her ICU stay, involved the adequate delivery of nutrition and to get her basically mobilized again after a major operation. So he did require TPN with nutrition intravenously for a period of time. About two weeks after her operation, we had an interventional radiology placed J tube and she would receive feeds through that, was able to come off her TPN and then also started taking oral feeds. Since then we've removed her J tube, we removed her ostomy and she's a normal kind that eats normal meals. She has issues with simple sugar intake, you know, which she loves, so we cover her with her insulin. He has an insulin pump. She's a very active young lady. She's unrestricted without anything hanging off of her. She's looking forward to her pool time during the summer. You know we are following her tumor. She's had two scans since her operation, so now we're talking about five to six months out. And she's actually doing extremely well in that respect. So this is a child who's had a major operation, who's recovered from the operation, though still has sequelae, diabetes-wise, who I anticipate will do quite well going forward.

So do you see any future challenges for her?

Well the diabetes has issues long-term. You know, compliance with her parental support, she has a structured diet. I imagine the cold pizza and beer eventually will be her staple in college. You know then we're going to have some challenges going forward, but I do hope that with advances in diabetes and our endocrine colleagues that we will be able to offer her a solution in the near future.

Great. Does anyone have anything they want to add?

I think that one of the remarkable things was, despite having such a long surgery, despite being it so complex, her recovery in the pediatric ICU was remarkably short and really quite easy. She really came off of any cardiac medications within the first 24 to 36 hours and she was pretty much extubated and breathing on her own within four days. And she really didn't stay very long in the pediatric ICU.

I think the thing that's important to stress that this was not a triumph. This is a triumph for this child but it was not any individual that you heard speak today- everyone had a part in this, that this was an institution that was able to provide a high technology service to a child in need and it was the coordinated effort and the utilizing of our institutional resources that made this possible. It's a kind of thing that we're proud to offer at Columbia and New York Presbyterian Hospital now and going forward in the future. I think we're never satisfied, that with innovations and with partnership with all the people here and the future partners in the institution that we'll continue to be able to provide services such as this going forward. And we're repaid by seeing this young lady come back to clinic without tumor and with a full life ahead of her.

Exactly. And she will be starting school in September. And she actually is looking forward to it. So I just wanted to mention that our website will be up for some time. You can continue to e-mail questions and I will do my best to respond to them over the next few weeks. And we'd really like

to thank you of rejoining us this evening. So I think, if nobody has anything else, we're going to wrap up. Thank you.

Thank you for watching this "OR-Live" Webcast presentation from New York Presbyterian Morgan Stanley Children's Hospital in New York City.

"OR-Live," the vision of improving health.