Twin-to-Twin Transfusion Syndrome

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Introduction

Andrew Schorr:
When parents are told they are having identical twins that can be joyful, but there can be also a concern, an uncommon one but not one to ignore, for a serious condition called twin-to-twin transfusion syndrome. We will hear all about it, and what can be done, from a leading specialist and a woman who experienced it, next on Patient Power.

Hello and welcome to Patient Power. I'm Andrew Schorr, and this is sponsored by the University of Maryland Medical Center. We're talking today about a serious health concern for a family that's found they're having identical twins, which can be a very joyful, shocking news, but it certainly can be joyful, but sometimes, not commonly but still sometimes, there can be a serious concern for the babies and even for the mom. It's called twin-to-twin transfusion syndrome.

We're going to hear all about it, and as we like to do we want to introduce you to someone who has experienced it, and that is Gabrielle Chidester who joins us from just outside Harrisburg, Pennsylvania. So Gabrielle let's tell your story. First of all you have a very healthy active girl, Lauren, who is going to be five before long, and you also have, happily now, twins Emily and Caitlin who are, how old are they now?

Gabrielle:
Seventeen-and-a-half-months old.

Gabrielle's Story

Andrew Schorr:
Okay, but getting to that point is a little bit of an adventure. So let's explain that. Let's flash back to April of 2007. You and your husband, Mark, get what kind of surprising news?

Gabrielle:
Well my regular OB/GYN, we went in for a regular checkup for our first pregnancy appointment. He did a quick scan and discovered that there were two heartbeats.

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Andrew Schorr:
Wow. So twins. You're told you are having twins. Now there weren't twins in your family, and this was news to you. Right?

Gabrielle:
Oh yes, yes. Extremely surprised. We had a "deer in the headlights" look for a while.

Andrew Schorr:
And you hadn't taken fertility drugs to expect a multiple birth pregnancy or anything like that.

Gabrielle:
No.

Andrew Schorr:
Okay. So there you go. So now you start to get used to it, and then subsequently there were obviously other ultrasounds. Tell us about that, when they started to say, 'Hmm, something is going on here. '

Gabrielle:
Sure. We had an ultrasound at the end of June, at about the 20-week mark where they measure the growing and make sure that the babies are the right size and look at the blood flow and check the fluid levels. So we went in for that ultrasound thinking we were just going to find out what we were having, not really thinking that anything bad would be discovered, but the fluid levels between the twins were very different. One was extremely high, and one was extremely low. The doctor at that point gave us a tentative diagnosis of the twin-to-twin transfusion syndrome. He recommended that we seek another opinion from somebody else. He recommended Dr. Baschat at the University of Maryland.

Andrew Schorr:
Alright. Well let's pick up the story with Dr. Baschat who is also with us today. So this is Dr. Ahmet Baschat, and he is Associate Professor of Obstetrics, Gynecology and Reproductive Sciences at the University of Maryland Medical Center, and he is also one of the leaders of their new advanced fetal care center (Center for Advanced Fetal Care) which opened in the fall of 2008 in Baltimore. Dr. Baschat what is twin-to-twin transfusion syndrome?

Twin-to-Twin Transfusion Syndrome

Dr. Baschat:
Twin-to-twin transfusion syndrome is a complication that is specific to identical twins. So Identical twins have one placental mass, and the cords of the baby insert into the placenta and usually break up into blood vessels that reach into the placenta to pick up nutrients.

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In all identical twins some of these blood vessels actually go on to connect to the cord of the other baby, and so blood can travel from one baby to the other, and under normal circumstances that transfer is balanced. So whatever passes from one baby to the other the baby gets back through some other channels, and so the volumes, the blood volumes, of both babies are typically equal.

In twin-to-twin transfusion syndrome what happens is that one baby ends up donating or sending more blood to the other baby than it's getting back, and so that baby becomes the donor twin and the other baby who receives more blood becomes the recipient twin, and that sets up sort of a sequence of events that can progress to different severities, and when that happens that is called twin-to-twin transfusion syndrome.

Andrew Schorr:
Now one might think that the baby receiving all this would do better, thrive, and it might have some complications for the one that is donating, but it doesn't exactly work that way. Both babies are at risk. Right?

Dr. Baschat:
That's correct. So typically it's easier to understand the risks of the recipients. So the recipient's heart is only designed to deal with a certain amount of blood volume, and when the baby receives more blood then the only way to deal with that is the heart has to pump harder. So the heart is actually stressed to a certain degree, and then what happens is also the blood, the circulation, or the heart sends more blood to the kidneys, and that's where the liquid component, or the fluid component, is filtered out of the blood. So the baby starts producing more urine. More urination increases the fluid volume around the baby, and that increased fluid starts now distending the uterus and stretching the uterus, and puts the patient at risk for pre-term delivery from uterine distention. So that's kind of the sequence of events. When the heart of the recipient is over-stressed it can go into heart failure, and that can actually lead to stillbirth or death of the recipient if severe.

Now on the donor side the baby has low blood volume and so the opposite happens. The circulation isn't full enough to send enough blood to the kidneys to produce a lot of urine, so urine production becomes less and less and less. So the volume of urine produced and the amniotic fluid volume becomes less for that baby, and that baby sort of gets wrapped in its own membrane, and eventually the circulation may actually be very inefficient, and that baby may pass away from either heart failure from low volume or because the placenta and the overall nutrients are not sufficient to sustain life.

The problem with identical twins is because there are existing blood vessel connections; you know nothing happens in isolation; so when one baby is in danger the other baby is in danger as well because if one baby passes away then the

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surviving baby can lose a lot of blood now into the circulation of the dying twin. So their fates, as it were, are always linked. That's a complicated situation.

Andrew Schorr:
Right, and we also should remember that there are risks to the mom as well as you mentioned. So it's a severe situation that needs to be investigated. We're going to talk in a minute about how you can intervene at your center at the University of Maryland but I want to pick up the story again with Gabrielle. So Gabrielle you were told that this seemed to be going on with now your identical twins, and they referred you to the University of Maryland Medical Center and Dr. Baschat. So what were they observing going on that gave the clue? Was it this fluid discrepancy? Was it that?

Gabrielle:
Yes. I don't remember the exact numbers but I believe one side, there is a measurement that they do inside each amniotic sac. I think it's between the baby and the edge of the amniotic sac, and I believe one side was about 16 centimeters and the other was less than three, which is a significant difference. You could see one baby looked like she was swimming all around because she had all this room, and the other baby was trapped.

Treatment Options

Andrew Schorr:
Oh my. So you and Mark are worried. You go right away within a day or two you see Dr. Baschat, and you have a very extensive ultrasound Dr. Baschat. So you do an evaluation and based on that detailed evaluation of fluid and blood flow you make a recommendation. So these are options that were presented to Gabrielle and Mark. What are some of the options you discussed doctor?

Dr. Baschat:
The decision what to do is actually very personal, and different families decide to do different things, but in terms of the treatment option we always discuss first the laser therapy because the reason why the twin-to-twin transfusion syndrome happens is because there are open vessel connections that propagate this ongoing imbalance of blood transfer from one baby to the other. So the only way to fix that is to interrupt those blood vessels connections.

So when both babies look otherwise healthy and we estimate that after you do the surgery that they will have enough placenta, you offer to the patient the therapy that gives them the highest chance to have two healthy survivors, and to end the syndrome or to treat the syndrome which is with fetoscopic laser therapy. That's principally why patients also get referred to us because we do that procedure, and that's what we talked about as well. Then we discussed some other treatment options that weren't really that relevant for Gabrielle and her husband.

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Andrew Schorr:
Okay Gabrielle so Dr. Baschat presents you and Mark options. Where did you go? The cafeteria somewhere to talk about it?

Gabrielle:
Yes.

Andrew Schorr:
So you go and it's weighing on you of course, but I'm sure you felt like you came to the right place.

Gabrielle:
Right, and I think we did understand the severity of the situation and that we needed to make a decision on what we wanted to do relatively quickly because things can progress. Everybody's different, but things can progress quickly. So we did need to make a decision as soon as possible. So we made the decision that afternoon to set up the appointment to have the fetal laser surgery.

Andrew Schorr:
Alright. So you had that very quickly.

Gabrielle:
The next day, yes.

Andrew Schorr:
So doctor let's talk about that just so people who are listening understand. So people are familiar now with laparoscopes and all that. So it's a very tiny little device you are putting through the abdomen of the pregnant mom into the uterus, and you have both a camera and a little laser. Is that right?

Dr. Baschat:
That's correct. So the laparoscope has two channels. One is for the actual scope, the camera to look inside, and the second smaller channel to bring the laser fiber in, and the procedure is done with local anesthetic so you anesthetize the skin all the way down to the uterus; make a very small thin incision. Then you look inside, you bring that scope into the uterus with the guidance of the ultrasound. So you scan as your putting in the scope so you know that the babies are safe. Then once you are inside you identify the edges of the placenta, the membrane between the babies and then the vessels that pass between one baby to the other because those are the ones that you are selectively going to target and close.

Andrew Schorr:
And then when you are all done and you correct that transfer place, if you will, those vessels that you wanted to zap, if you will, then we notice that in this case there was a fluid imbalance. Do you take some fluid out as well?

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Dr. Baschat:
Yes. I mean you will always reduce the fluid of the recipient. I mean you are going into the recipient sac because that's the sac with the highest fluid volume, and what you do at the end of the procedure is you take some of that fluid out because you want to minimize the risk of pre-term labor from uterine distention, and you sort of want to normalize the fluid volumes. So you always take some fluid out and try to get the maximum vertical pocket back to a sort of normal range.

Andrew Schorr:
Gabrielle, things worked out didn't they? I mean I know there was a lot of anxiety with the procedure. There would be for sure, but as far as correcting the problem and the development of your kids now, Emily and Caitlin, the rest of the pregnancy was monitored of course but went well. I know you had a C-section, which was recommended, and many people with multiple birth pregnancies have that, but as best you know everything proceeded properly, and the kids have been developing well?

Gabrielle:
Oh yes. Yes they're right on target developmentally for everything.

Andrew Schorr:
When you look back on this intervention with Dr. Baschat and the team and the center how do you feel about it?

Gabrielle:
I don't know if words can really express how grateful we are that that resource was available to us. They really did take the time to explain everything and made sure that we understood what was going on. Dr. Baschat kept pushing us to ask questions and kind of snap us out of the funk we were in. There is a lot of information to absorb in a short period of time. I can't imagine having to explain to my older daughter. She knew that we were having two babies, and if something had happened I can't imagine having to explain to her that she wasn't going to be a big sister anymore, or she was only going to have one little sister. So extremely grateful doesn't even begin to touch on how we feel about the services that they were able to provide for us.

Andrew Schorr:
And we should mention for anybody wondering, we should explain that the kids are napping now, but your days now are filled with chasing them around.

Gabrielle:
Oh yes. Chasing them, entertaining them, running around.

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Andrew Schorr:
Well we'll come back to you in a couple of minutes for what you would say to other parents who may be listening who are in the throes of this, but I want to talk to Dr. Baschat for a couple of minutes.

Diagnosing TTTS

Andrew Schorr:
Dr. Baschat so this was observed on ultrasound. So first she got the news that she had twins, and later in a later ultrasound, much later, I believe Gabrielle at 20 weeks. Right? So halfway through a full term pregnancy they were seeing this fluid, but in so many areas, and I know in fetal development, you want to intervene earlier or know what you're dealing with earlier. So take us through what you recommend when people find out they're having twins to pursue whether they're having identical twins and look for any abnormalities.

Dr. Baschat:
First of all I'd just like to say very briefly that there are a lot of new observations that have been made about identical twins. So a lot of these publications are recent, and we understand a lot more now. So I think what is very important is when you get a diagnosis of twins it's extremely important to make the distinction between identical and non-identical twins because what can happen, the complications are very specific and they are very different in identical to non-identical twins, number one.

The second thing that's important is the best time to make the diagnosis is in the first trimester. So when you see twin pregnancies in the first trimester as a physician I think you really should try very hard to make a distinction if they are identical or not. If you make the diagnosis of identical twins there is very good evidence now that if you look again at 16 weeks that you are going to be able to predict about 60 to 70 percent of cases of TTTS or selective growth restrictions that are going to develop before they get severe enough to cause pre-term labor or other issues, and so that's what I would recommend. So 11-to-14 weeks for first trimester scan, 16 weeks another scan to look if there are any signs of fluid discrepancy, bladder discrepancies, size discrepancies and if there are then send them to a specialized referral center to look further if there is any evidence of complication.

Andrew Schorr:
Right, and certainly the interventions like the laser treatment or others, that's better earlier.

Dr. Baschat:
Well the survival numbers are definitely better when you are at lower stages of twin-to-twin transfusion syndrome.

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Andrew Schorr:
Alright. Obviously we have an audience of families listening so just explain to them first if you find out with the first ultrasound that there are twins, then just a few weeks down the road it would be worth going back like at I think you said 16 weeks, take a look again. Are these identical twins, and basically we're looking for just one placenta. Right? Then you are looking at the characteristics of the placenta.

Dr. Baschat:
No. No. To be clear on that at 11-to-14 weeks, so in the first trimester, it's the best time to diagnose identical twins.

Andrew Schorr:
Oh I see.

Dr. Baschat:
So when you get that first scan and someone tells you that you have a twin pregnancy you should ask, 'Are they identical or not.' It's important to make that distinction as early as you can. Once you make that diagnosis then the 16-week scan is to look for early signs of differences between the babies. There may be a hint to either TTTS or selective growth restriction of one baby.

Andrew Schorr:
We haven't explained that one. So let's explain that. So you explained very well the twin-to-twin transfusion syndrome. What is selective growth restriction, and can these go hand in hand?

Dr. Baschat:
Right. So basically when you have identical twins there are two things that may be mismatched. So if there is a discrepancy in volume, so one baby has too much volume and the other one too little, then you have TTTS. Now the other thing that can be discrepant is the amount of placental mass that is shared. So in an ideal world each baby would have 50 percent of the placenta to draw from for nutrient support. Sometimes that's unequal. So sometimes one baby may have only 30 percent or 20 percent or so, and because that baby has less nutrients to draw from it ends up being restricted in its growth and can develop what we call growth restriction. Because that only affects one baby's size it's called selective growth restriction or selective IUGR.

So when you look at the overall spectrum about 10 percent of twin pregnancies are at risk for TTTS, about 10 percent for selective growth restriction and maybe sort of another 5-to-10 percent may have something that is a little bit of both, and that's sometimes difficult to figure out, but what is of course different in identical twins because all these pregnancies have those linking blood vessels, you know, nothing that affects one baby just is confined to that one baby. The fates of the babies are

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always linked, and whenever you have to make a decision as a physician or a parent, you can't consider both babies in isolation, each baby in isolation. They are always together, and you have to make decisions that are going to affect both babies.

Andrew Schorr:
Yes I know, and those can be hard decisions, and I think we have to help people understand while with Gabrielle she was able to give birth to the two healthy babies, and I think Gabrielle you were telling me before we started our program that you had a college roommate who had a similar experience, right?

Gabrielle:
Yes. She had monoamniotic monochorionic twins, which means they are in the same amnionic sac and share the same placenta.

Andrew Schorr:
And healthy babies.

Gabrielle:
Yes.

Andrew Schorr:
But doctor we have to acknowledge that it doesn't always happen, and sometimes there are difficult choices whether to continue with both babies or even acknowledging that there could be a risk to development of babies that are born, right?

Dr. Baschat:
That's correct, yes.

Andrew Schorr:
So these are the tough decisions. So Gabrielle from your point of view as a parent, it's worked out happily for you. I imagine maybe you've connected with others and are aware that it isn't always that way, but for somebody where the jury is out and they are going down this journey, what would you say to them to encourage them first as far as getting specialized care and just having hope that things can work out.

Gabrielle:
I think the first thing is understanding the TTTS and what it is as much as you can, and asking the doctor you're seeing as many questions as you can think of so you can understand what's going on better. Then I think just trying to figure out the pros and cons of each option that's available. I mean we were extremely lucky that there wasn't a size discrepancy yet in either one of the babies, none to speak of too much. So we were lucky in that respect that it was caught when it was. Another week or so and it might have been a whole different story. We might have had to

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think of different options. So I think understanding what's going on is extremely important, and then trying to figure out what is right for you and what is right for your family and what you are comfortable in doing.

Questions from Listeners

Andrew Schorr:
Doctor we've received some e-mail questions. One was from Catherine in Washington D.C., and I think you spoke about it. She used a different term. So I just want to make sure we have it right. Catherine asks, 'What is the difference between TTTS and an abnormal placental sharing or discordance problem?' So am I right that that abnormal placental sharing is what you called the selective growth restriction?

Dr. Baschat:
Yes.

Andrew Schorr:
Okay. So you explained that. Here's a question from Marsha in Chicago. Marsha wrote in, 'I had TTTS with my twins who are now three years old and healthy. I'd like to have another child but fear complications with that pregnancy. Am I at higher risk for complications because I had a complication with my last pregnancy?'

Dr. Baschat:
No. No. I mean the recurrence risks for identical twins are very, very low and then for TTTS are even lower.

Andrew Schorr:
Do we have any idea what causes this?

Dr. Baschat:
Well there are some risk factors that we know. It has to do with how a single fertilized egg splits, and there are certain risk factors that have to do with maternal age that we know about, but what exactly causes twin-to-twin transfusion syndrome and identical twinning per se is not figured out yet.

Andrew Schorr:
Now Gabrielle you were how old when the babies were born, or let's say when you became pregnant how old were you then?

Gabrielle:
34-years old.

Andrew Schorr:
Okay. So would a woman in her 30s, would this be something that is more likely to come up doctor versus a 22 year old?

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Dr. Baschat:
It is associated with higher maternal age. We call it advanced maternal age. It's not really a fair term. It is a little bit more frequent as the mother gets older. Some report is also associated with assisted reproductive technology, so IVF therapy and ICSI. So those circumstances definitely play into it.

Andrew Schorr:
Tell us a little bit about your center. So here is Gabrielle and Mark who came down the road from Harrisburg, Pennsylvania, but they had an OB and good hospital certainly back there. You're a very specialized center. So if someone comes for a consultation or one of these procedures does that mean that they necessarily have their baby there or all the follow up care, or do you work with the referring physicians?

Dr. Baschat:
Well first of all the center is a team of people who have really worked together for a long time. We' have fortunately some very high-level fetal therapy specialists working here. So they are very attuned to the anxieties and questions that parents have prior to referral, and they usually organize all that. So that's very good. Our aim in all fetal therapies that have to do with twin-to-twin actually is that we try to do a treatment that will enable the patient to go back to their OB and deliver as close to term as possible.

There are certain fetal conditions, other fetal conditions, that may require to be delivered here just because of the care that the babies need after delivery, but with TTTS specifically you'd like to do the laser, you'd like to fix it so that the parents can go back.

Andrew Schorr:
And Gabrielle that's what happened with you is there remained a lot of active communication between Dr. Baschat and his team and your doctors in Harrisburg, but that extended team worked out well.

Gabrielle:
Oh fabulously.

Andrew Schorr:
And you had a little bit of a rocky road around 33 weeks?

Gabrielle:
Yes. For my weekly ultrasound they noticed that the difference in the amnionic fluid levels was, there was a little too much of a difference again. One was a little bit too high, and the other one was getting a little bit too low out of their comfort zone. So they did admit me into the hospital that day, and I stayed there until I delivered at

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36 weeks. I had electrolytes, an IV in me for the whole time and an ultrasound every day. So they checked them every day and everything remained stabilized for that time, and I delivered at 36 weeks.

Andrew Schorr:
Well multiple birth pregnancies are always an adventure. Dr. Baschat just before we let you go, just to put all this in perspective, how likely is this? So we talked about understanding, are you pregnant with twins? Yes. Are you pregnant with identical twins? Yes. Then if you are in that situation how likely is this twin-to-twin transfusion syndrome, or also the selective growth restriction complication? Was that about a 10-percent chance for each one?

Dr. Baschat:
Yes. I would estimate that that is probably true. About 10-percent for the TTTS, 10-percent for the selective IUGR, and 10 percent of pregnancies probably have something that's in between, not quite as severe, but may show benefit from increased surveillance.

Andrew Schorr:
All right, so it sounds like you have the laser procedure that is working well at a specialized center like yours. What's next? You're a research institution as well, and you get together with your very specialized colleagues from around the world to offer even better options.

Dr. Baschat:
Well I mean we just had a big meeting for the North America Fetal Therapy Network. I think the next step really is rather than developing better options, make sure that more patients can avail from that, and you know one of the recommendations that are going to be issued from the NAFTNet, the North America Fetal Therapy Network, is actually some advice to physicians how identical twin pregnancies should be approached in terms of monitoring, recommendations, when to do scans, what I just talked about earlier on, so patients will benefit from earlier detection and also earlier referral. So that's the specifics of TTTS.

The other therapies that we are exploring is once you do a fetoscopy then you can potentially do other conditions, treat other conditions, and one of the conditions that we are working on is the a diagrammatic hernia where you put a balloon into the trachea or the windpipe of the fetus to expand the lungs again and make them grow for babies that have diagrammatic hernia where the bowel is in the chest. So that's a very specific condition, but that's sort of the next development I think in minimally invasive fetal treatment.

Andrew Schorr:
Wow. So this is all in utero?

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Dr. Baschat:
Yes.

Andrew Schorr:
It's incredible what you are able to do. So Gabrielle a question for you, and that is so somebody maybe gets this diagnosis of TTTS, they're terrified. Any counseling for them because it's easy to think the worst right off the bat?

Gabrielle:
Oh absolutely. The Internet can be a good and bad thing. Thankfully we had just moved into a new house so we didn't have the Internet at home yet. So that was part of the reason why we had so many questions for Dr. Baschat is because we didn't have all the information of the web available to us. If there is a mother of twins group around your area, I joined one of those and found a couple of people who had had TTTS through them. There are also a couple of websites that I'd gone to. One is the Twin-to-twin Transfusion Syndrome Foundation and the other one was called Fetal Hope, and I just went through their message boards and read other people's posts and looked at their outcomes and how their situations were similar or different to mine. It's just comforting sometimes to talk with a random person who understands what you are going through because there really aren't too many people who can understand what you are going through. You might know someone who has had twins, but the chance that they have gone through, I mean everyone's experience is different, but the chance that they have gone through this type of thing is pretty slim. So it's nice to be able to connect with people that truly understand what the heavy decisions are that you have to make.

Closing Comments

Andrew Schorr:
Right. Right. Well that's all good advice. So I want to wish you well with Lauren who is going to be five soon, but these two little crazy people, Emily and Caitlin, and you are so blessed. Is there anything that you want to say publicly to Dr. Baschat?

Gabrielle:
Well he knows "thank you" isn't enough, and I think he has said we can't say "thank you" until we hear the babies cry, and we did, and we knew at that point that we had made it, that everything we had gone through was worth it. At the time it was the hardest thing, and probably will be one of the hardest things that we've ever as a family had to go through, but in the end it all turned out great. So we're extremely blessed and extremely thankful.

Andrew Schorr:
Well it makes it worthwhile doesn't it Dr. Baschat?

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Dr. Baschat:
Absolutely.

Andrew Schorr:
Well I want to thank you both; Gabrielle Chidester joining us from your Harrisburg, Pennsylvania with a great life and three weddings to go to maybe someday.

Gabrielle:
Oh gosh.

Andrew Schorr:
And pay for. Right? So start saving, college and all that. Dr. Ahmet Baschat with the Advanced Fetal Care Center at the University of Maryland Medical Center thank you so much for being with us.

Dr. Baschat:
Thanks for having me.

Gabrielle:
Thank you.

Andrew Schorr:
This is what we do on Patient Power, and we're delighted with the support from the University of Maryland Medical Center to connect you with really these complicated topics and demystify them and give you hope that things can be helped through modern medicine.

I'm Andrew Schorr. Remember knowledge can be the best medicine of all.

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