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**Hosts:**

Holly Carmichael  
Michael Murray

**Guest:**

Crystal Gallagher

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**Introduction:**

A garrison is a safe place where an army gathers. In the same way, the Disability Garrison Podcast is a place for the army of disability rights advocates to gather and discuss complex issues. We are unafraid to identify problems in our world and have difficult conversations about them. But we are not just here to complain. We spend our time brainstorming solutions with generals in the disability rights movement. Together, we take action to make positive change and lead the fight for justice and equality.

**Holly Carmichael:**

My name is Holly Carmichael.

**Michael Murray:**

My name is Michael Murray. This is the Disability Garrison.

I'd like to start the podcast by asking you to use your imagination for a moment. Imagine that you have a beautiful child, sweet, someone that you've either adopted or given birth to that you love dearly. And imagine for a second that your child needs an organ transplant. You go to the doctor. You go through all the process. You are hopeful that this organ transplant that could save their lives is going to happen. And then you're told that you don't qualify, and you're sent home to watch that beautiful person that you love die.

Now envision for a moment that you didn't know why they didn't qualify for that life-saving treatment. And imagine for a moment that the reason that they didn't qualify is for something that had absolutely nothing to do with the success of the transplant. It could be their eye color or their hair color or in the cases that we're going to talk about today, discriminated against purely based on their IQ.

**Holly Carmichael:**

This is happening all across the country. In fact, 85% of pediatric transplant centers consider a child's intellectual or developmental disability when factoring whether or not they qualify. They're making this judgment based on this child's perceived quality of life, what their contribution to society might be, and it's downright wrong.

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**Michael Murray:**

It's disgusting.

**Holly Carmichael:**

The American Academy of Pediatrics came out with a policy statement, a paper clarifying heavily that this does not impact the success of the transplant, the health of the participant in any way.

So why is this happening? It's plain and simple discrimination, and many people who we talk about don't even realize that it's happening. But it's real stories. It's a little seven-year-old boy named Griffin in Missouri, a little girl named Bethany from North Carolina, Cole in Mississippi, Ivy in West Michigan right where we're headquartered, and Lucy in Minnesota.

Today we'll get to dive in and hear firsthand Lucy's story and account and how she was able to finally get to the bottom and discover that this discrimination was happening and find a transplant center that would not discriminate against her. And spoiler alert, Lucy is doing amazingly well.

**Michael Murray:**

So today this is the problem that we want to look straight in the eyes. People with disabilities are being discriminated against when it comes to organ transplants. What can you do about it?

I am so excited. I'm always excited, but I'm so excited about our guest today. Can you tell us about our guest?

**Holly Carmichael:**

Yes, Crystal Gallagher. She's a dear friend of mine, and I'm thrilled to have her as a guest. She has a background graduating from the University of Minnesota with a Bachelor's in Sociology and actually worked in the healthcare industry as an ECG technician and a phlebotomist. She's currently a full-time caregiver to her beautiful daughter, Lucy. Lucy was born with a rare disease called PMM2-CDG and as a result of that ended up needing a liver transplant. And Crystal's going to share with us her story.

**Michael Murray:**

Such a powerful story.

**Holly Carmichael:**

Yes. Let's dive in.

**Crystal Gallagher:**

Hi, guys.

**Michael Murray:**

We're really excited that you're here. What do you love about Lucy?

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**Crystal Gallagher:**

What is there not to love about Lucy? She is just pure joy. I mean her face radiates joy. She is the happiest kid. I mean she has had so many struggles, but through it all, she just is happy. I mean she has the best giggle, and she is just such a fighter. And not only is she so joyful, she just brings joy to everyone that she meets and just really enriches other people's lives.

**Holly Carmichael:**

She does. Oh my gosh, she does.

**Michael Murray:**

I saw some pictures. I was just like, ah, this is such a cute kid.

**Holly Carmichael:**

Even through images, that joy comes through.

**Michael Murray:**

Absolutely. So we're going to get into Lucy's story a little bit and how that went. But let's lay some groundwork. Holly, what is an organ transplant? Let's assume that people don't know what an organ transplant is. Why is it important and who needs it?

**Holly Carmichael:**

Yeah. So an organ transplant is essentially if you have an organ that is impacting your life in some way, there's an option to get a transplant, and any organ in your body pretty much can receive a transplant. Today with Lucy's story, we're going to be talking about the liver in particular. But this discrimination issue impacts any type of organ, not just liver transplants for people with intellectual developmental disabilities. And essentially, the process of when you need an organ, you're obviously receiving care through your doctor and you're at some type of hospital or transplant center and they're making a determination on your case. And some of this is based on you can get on the transplant list. That's essentially what we'll be talking about today, who gets to get on the list.

**Michael Murray:**

So Crystal, let's talk about Lucy. Why did Lucy need an organ transplant? Let's start there.

**Crystal Gallagher:**

Sure. In August of 2017, Lucy was diagnosed with cirrhosis. Just to lay a little groundwork for that, children with her specific disease, she also has PMM2, they often have organ issues or they'll have elevated liver enzymes. But it's very rare that it develops to cirrhosis. And when she was a year and a half old, they had done an ultrasound of her liver. It's a pretty routine thing for kids with CDG to have ultrasounds and scans of their organs to see what they look like and kind of track them as they grow. At that point, her liver looked 98% normal. There were a couple fatty spots on it so there wasn't anything that was indicating this is going to develop into full-blown cirrhosis very rapidly.

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Her pediatrician had kind of deterred me from getting involved with GI. I had asked several times, "I'd like to see a GI specialist. Can I have a referral?" She gave me a lot of resistance on it, and the reason being that I kept asking was she was having all these digestive issues. And the explanation I kept getting was, well, that's just what happens when a child has a metabolic disease. They really struggle with GI issues. It's normal. You just have to deal with it.

**Michael Murray:**

Can I just say how often, I delivered both of my kids and both times, and I mean not intentionally, it was in the back seat of a car, and both times had medical professionals look at us and say, you don't know what you're talking about?

**Holly Carmichael:**

Yeah.

**Crystal Gallagher:**

And you know so much. As a parent, you know.

**Michael Murray:**

Right? I'm just like, "I am looking at my wife. She is about to deliver a baby."

**Crystal Gallagher:**

You have intuition. Your feelings are usually spot on. That's what I have learned. Well, we ended up in the emergency room, of course. They did an ultrasound, and her abdomen was full of fluid. It's called Ascites. It's a symptom that happens when you have cirrhosis. And that was really our first indication that she had cirrhosis. So it developed so rapidly. That was really the start of the journey. That's how I found out. It wasn't fun. It was a total shock.

At that point, Lucy had her first paracentesis which is a procedure that removes the fluid from the abdomen, and she's had I think over 20 of them. That was kind of one of her bigger symptoms of cirrhosis. So she had up to two liters of fluid removed from her abdomen. So it would go away, and then it would come back. Sometimes we'd be in the hospital twice a week to do that.

**Michael Murray:**

Yeah. So you get to this place in this process where there's a realization. My daughter needs a liver transplant. And I want everyone who's listening to this for a moment whether you've got kids or you've got a family member to put yourself in the shoes and say, oh, I have a family member who in order to live needs a transplant. And so you go to the doctor. You're looking into this. And your first thought is, I would give any part of my organ to see my kid be healthy. Talk to us about what that was like for you.

**Crystal Gallagher:**

It was devastating. It was so much to process. And honestly, they didn't ever bring up transplant. It was something that I came up with from reading. It was more like, your child has cirrhosis, and now we're

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going to treat the symptoms. And finally, I just flat out asked, “does my child need a transplant?” And they just said, well, yes, but no one's going to consider her for transplant. And I'm like, “wait, what do you mean? Hold on. No one's going to consider her? Why not?” And the answer was, “well, because of her underlying condition.” That was them being polite. “Because of her underlying condition, no one will consider it.”

**Michael Murray:**

But just to be clear, the underlining condition that we're talking about here has zero effect on the viability of having a good transplant, right?

**Holly Carmichael:**

As evidenced by Lucy. For sure.

**Michael Murray:**

As evidenced by so many other things. Yeah.

**Crystal Gallagher:**

Yeah. And so I was very angry. I was angry that that came from her primary GI doctor that they had just assigned to us, and I felt really hopeless. If you go on Google and you type in this facility, they get great reviews for pediatric GI. And I'm thinking to myself, how can this be possible? How can they be one of the best and not want to help or try? But that was the reality.

And by the time end of September had come around and Lucy had been in and out of the hospital, they said, we really think at this point, your best option is going to be to consider hospice. And that was a whole other shock. Wait, what? First, my daughter has cirrhosis, and now you're telling me I need to put her on hospice? My only personal experience with hospice is with adults, grandparents, things like that. And I said, how long do you think she's got to live? That was like a big question I had. And they just said, at this rate, maybe six months to a year. And just kind of left me at that. And it was hard.

**Michael Murray:**

Yeah. I think one of the things when I first heard your story and Holly was telling it to me that just blew my mind is you say underlying condition, but really what they did is they said, Lucy's going home, she's not going to live. And the concept that I made this decision just based off of her intellectual and developmental disability was not part of the conversation. It's not like they looked at you and said, hey, your daughter has blonde hair so we're not going to give her a lifesaving treatment. We're just going to send her home. And it was mind-blowing. You would have never known otherwise.

And so you get connected with this beautiful community of incredible parents like Holly and Dan. And what happens?

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**Crystal Gallagher:**

It took a little bit of time. So I joined the group. I didn't make a post saying my daughter has cirrhosis. I actually was searching for other families in Minnesota and found another mom that has a son with Lucy's exact same sub type of CDG. And we connected, and we became friends. And I didn't even tell her right away because it was just such an awful, shocking thing. My fear was like I don't want somebody else to take this on. Like what if this happens to their child and I don't have any hope to offer them?

But as she became sicker, I started talking about it and sharing a little bit. And we were out walking. It was May. And in May, we have CDG Awareness Day so we had gotten together for that. And she just encouraged me. She's like, you need to fight. You need to email Dr. Morava. And I was like, I don't know. She doesn't live in Minnesota. I'm just going to randomly email her? And it took me a couple weeks to get the courage to email her which is now just silly thinking about it. She is like one of the most incredible human beings I have ever met.

**Holly Carmichael:**

Agreed, agreed.

**Crystal Gallagher:**

I actually didn't even really start out asking about transplant. She was moving to Minnesota to start this natural history study. And I emailed her, and I said, my daughter's really sick, but I'd still like to see you. I really want to get her in the study. Maybe her experience can help another child. Maybe we can prevent this from happening. And her response was, hold on a second, we're not talking about the natural history study. Let's try to save your child's life.

**Michael Murray:**

Yes.

**Crystal Gallagher:**

She had never met me. She wasn't living in the same state as us at that time. She just got right to work. And it was the best feeling I have ever had in my life, just knowing another human being who has power to do something was willing to do it, to take it on, to be there for me, to be supportive, to help Lucy even just feel better. So that's really how it started. And I believe in God, and I really just, I believe everything happened the way it did for a reason as hard as that is to accept. So we just had the dream team from the start. She knew somebody right when I had already emailed her. It just was incredible.

**Michael Murray:**

Yeah. So Dr. Furuya, if you're listening to this, we love you. And—

**Holly Carmichael:**

Dr. Morava.

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**Michael Murray:**

Yeah, we love you too.

**Holly Carmichael:**

And they shouldn't be the exception to value a human's life and to say this child is worth saving. Every child is worth saving. It should not matter. If you are a doctor out there who is taking this into consideration, taking intellectual developmental disability into consideration, shame on you. This should not be a case. Lucy, who brings so much joy to the world and contributes so much value, you have no idea the quality of life that she has and what she adds to this world. It's shame on you.

**Michael Murray:**

Absolutely. So we get people fighting. We get people alongside you who are saying, yes, let's try to figure this out. When they actually said we're going to consider Lucy, what went through your head? How did you feel?

**Crystal Gallagher:**

I felt scared. I was scared that we were going to do all this, it was going to be awful, and then the answer was going to be no. I'm going to put my child through more. She's already having so many problems, so many struggles. She's not feeling good. And then the answer is going to be no. I was so scared the answer was going to be no.

**Holly Carmichael:**

But you actually had a chance to be evaluated. You're describing this evaluation process, and before, they didn't even let you get through that door.

**Crystal Gallagher:**

Right. They wouldn't actually even let me talk to anyone in the transplant center. So I said, "I don't understand this. Can I talk to somebody in transplants? Can I have their information?" The answer was "No. They're not going to consider it. We're not wasting their time."

I just wanted at that point some sort of closure for myself or peace, and they would not offer that. And looking back now, I wish I would have gone to another hospital, gotten another opinion. However, not every hospital is a transplant hospital or they only transplant certain organs.

**Holly Carmichael:**

How would you know? There's no way you should know that. Like you checked their reviews. You did everything right.

**Michael Murray:**

Yeah, yeah. You shouldn't be allowed to take it into consideration. You shouldn't have to wonder, is my doctor taking my IQ into consideration when deciding whether or not I should have a lifesaving procedure?

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So I'm going to fast forward you just a little bit to that point where you actually hear yes, she qualifies and this could actually save her life. What's going through your head?

**Crystal Gallagher:**

That was like Christmas on steroids. I remember Dr. Furuya calling me and telling me that she was going to be listed. At that point, her and I were talking all the time. She was calling me. She immediately quit what she was doing to go start the process of actually getting her on the list. She's like, I'm leaving my office. Like it just was incredible. I felt my faith in humanity had been restored at that point.

**Michael Murray:**

Yeah. So tell us how's Lucy doing right now? She has had the transplant how long ago now?

**Crystal Gallagher:**

She was transplanted in 2019, so January 22nd is the exact date.

**Michael Murray:**

How's she doing?

**Crystal Gallagher:**

She is doing amazing. Very shortly after her transplant, she started drinking water orally out of the sippy cup. Now she'll drink out of a cup. Her physical strength has grown immensely. She learned how to give a high five. I think significantly more interactive than she was before, very visible physical differences. She can stand with assistance now. Before, she couldn't even put her legs down.

**Michael Murray:**

This is such a powerful story to hear the incredible investment that that you've made into fighting for Lucy those who have been against you and then ultimately those who came alongside you and the victory that we have seen here demonstrates that all life is worth living. That it is worth saving and that getting behind ensuring that everyone has the right to access these kinds of lifesaving opportunities shouldn't even be something that we're having a conversation about. But we are.

**Holly Carmichael:**

In 2021, no doubt.

**Michael Murray:**

But we're going to fight for this.

**Holly Carmichael:**

Yeah, yeah. I want to give you a chance, Crystal. If there's anything you can say to those physicians or around the world because I believe this is a worldwide issue. We're talking in the U.S. specifically. But to those physicians, especially Lucy's who said her life wasn't worth it, what do you want to say to them

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now, knowing you've gone to the other side? Lucy is high-fiving, bike riding, adding joy. What do you say to them now?

**Crystal Gallagher:**

I want to say, you were wrong. You were so wrong. But also, have a heart. Where is your heart? Why did you become a doctor? Isn't it to help people to better their lives?

**Holly Carmichael:**

All people.

**Crystal Gallagher:**

Not just those that have struggles. And really the range of disability is so vast, and to me, it doesn't matter which end of the spectrum you're on. I think all people with disabilities add value to the world.

**Holly Carmichael:**

Yeah.

**Michael Murray:**

Crystal, thank you.

**Crystal Gallagher:**

You're welcome.

**Michael Murray:**

Thank you for being an awesome mom, thank you for being an incredible advocate, and thank you for bringing Lucy into the world and fighting for her so that she could continue to be a gift to all of us.

**Holly Carmichael:**

Lucy's worth it. I can't thank you enough for sharing your story, walking us through it, walking our listeners through it because I really think people don't realize this is actually happening today. It could be you. Your kid could acquire a disability, and it could be you going to that hospital center trying to get your kid lifesaving treatment like we all would and just be sent home.

**Michael Murray:**

Without even knowing why you're being sent home.

**Holly Carmichael:**

Yeah, behind the scenes.

**Michael Murray:**

Thank you, Crystal and Lucy, for helping us see that today.

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**Crystal Gallagher:**

You're welcome.

**Michael Murray:**

Wow, Crystal and Lucy's story.

**Holly Carmichael:**

It is pretty powerful, I mean especially for me, knowing Maggie has the same condition and could be in that same point, that same place at some point in her life. She could need a liver transplant because of her CDG.

**Michael Murray:**

And just as a parent myself, I see in Lucy my son Isaac, my little girl Ellie. And watching the roller coaster that they went through. And I'll tell you, we always close this out with actions that our listeners can take. You can't listen to a story like we just heard and put yourself in the shoes of Lucy and not want to do something. And that's what we're all about. We're about taking action and what can we do as the disability rights movement in order to make a difference.

And there's something really simple that you can do. Become an organ donor. We're going to put on our website how you can easily make that happen and how you can become an organ donor and make sure that you're able to give a life-giving organ when you die.

But you can also just be sure to tell your loved ones that, hey, this is what I want. I want to ensure that after I leave this planet, that my organs go and are donated to help others, and this can avoid confusion. But it also can just give you an opportunity to talk with your loved ones about why you're making this decision and why it's powerful to do it.

**Holly Carmichael:**

It's really easy, and you get this really cute heart on your license plate or on your driver's license I mean, not your license plate.

**Michael Murray:**

We should put it on the license plate. That's a great idea.

**Holly Carmichael:**

We should. I'm an organ donor. Yeah.

**Michael Murray:**

That's right. I'm an organ donor. I am proud to be an organ donor.

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**Holly Carmichael:**

Yes, me as well. And if you become an organ donor, share it with us. I'd love to see posts of people becoming organ donors from listening to this podcast because Lucy's life has value. She adds value to this world. She's so important and critical. And there is no way in heck she should be denied having a transplant simply because of developmental disability.

There's some other really important things you can do. Many people I talk to about this are like, "how is this legal, how is this allowed?" And it still is. We need legislation passed that makes sure that this discrimination doesn't happen. And luckily, there is some great work done by organizations who have really pushed forward and done a lot.

We have a little over half of the states in the U.S. that have legislation passed, many of them, over half of those passed in just the last couple years. But there's some national legislation that you can support directly by calling your representatives in Congress to support HR1235, the Charlotte Woodward Organ Transplant Discrimination Prevention Act. This does some simple things like prohibits disability-based discrimination to get an organ transplant. It shouldn't be there. It shouldn't exist already, but it does.

I'd also ask because I'm a Michigander myself, my fellow Michiganders, I need your support. We've got a bill passed in the house but not the senate. I need you to call your state senators and get Bill 4762. It's really short. It's 13 lines because this is a simple topic. You shouldn't discriminate based on intellectual disability. This is a simple thing.

So we ask you to go online on our website. We make it really easy for you to find out who you should call, who you should write to. Please, please we're asking you to do that. Tell us about doing that and take this action today to help kids just like Lucy.

**Michael Murray:**

Absolutely. And we want to make sure that all across the U.S. there is clear legislation that discriminating against people with disabilities as it relates to transplants is illegal. You can't do it.

**Holly Carmichael:**

Yeah, it's not allowed. It has no effect, zero effect on the success. This is simply discrimination based on a person's disability, on their perceived value, and that's not okay.

**Michael Murray:**

And last, we always like to end out by supporting an awesome organization. And in this particular area, The National Down Syndrome Society is doing a lot of work to pass this national bill. And so we'd like to encourage you to go onto their website and offer them financial support. So they support and advocate for Down Syndrome throughout communities by focusing on areas of resource and support policy and advocacy, community, and engagement. So we will have some links on our website that will support everyone and help everyone be able to find this organization and financially donate to them.

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**Holly Carmichael:**

Absolutely.

**Michael Murray:**

So thank you, everyone. Thank you for listening. Thank you for being a part of this movement and a part of the Disability Garrison. Let's go out and make a difference.

**Conclusion:**

Thank you for listening to the Disability Garrison Podcast. My name is Scott Labarre and I direct my daughter's services in Michigan through GT Independence. What I like most about directing her services is the freedom that allows me to align the resources to my daughter's needs. For the links and resources mentioned in this episode, please go to [www.GTIndependence.com/podcast](http://www.GTIndependence.com/podcast). Thank you.

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