



Episode 10: Medical Model: A Surgeon's Care

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[Upbeat intro music] Disarming Disability

Nicole:

Oh, hello. We're so excited that you made it back for yet. Again, another amazing episode of disarming disability. We cannot wait to share with you the guests that we have today and to deep dive into conversation, although before we do well.

I guess I should say. Hey, what's up? I'm Nicole Kelly

Sarah:

and hey, Sarah Tuberty.

Nicole:

Yep, but I almost skipped are intros because I was so excited for the secret to tell us about what's going on in her world Sarah. What are you surrounded by right now?

Sarah:

Okay, so I am surrounded by I kid. You not a million fruit flies.

I just came back to Philadelphia. I've been in Arizona for almost two months hanging out with my parents. Also, welcome humidity. Oh my gosh, I forgot about that. I walked off the airplane was like, whoa, so I'm trying to remember how to live in the humidity lifestyle again.

And then I came back up to my room to this really delightful party of fruit flies. So as you know, I love houseplants and I have a million house plants.

During the time that I was gone the fruit flies felt that they needed to take this space and just sort of hang out and multiply so they I then learned that fruit flies will lay their eggs in like moist soil.

So now I am surrounded by fly strips and I have some like fermented fruit in a cup to try to attract them. And and then I also looked up on the Internet about that you can buy

Aquarium rocks and put them on top of the the pots to try to help prevent the the larvae from coming out. It's just so you this last where I'm at. I it's been a delightful surprise.

They're all my friends now I suppose I don't know but um, yes, that's what I'm well, how are you doing? What are you surrounded by?

Nicole:

man? Nothing that exciting. I just spent my weekend. I actually did a deep clean of the apartment which again I feel like this makes me so old, I can't help it. It makes me feel so good to just like have my space clean and to have all the laundry done and to have like vacuumed and mopped the floor just to like really reset, you know, really be in control of your space and really yeah just like kind of refresh and renew,

but also I should mention that as part of my refresh and renew. I wandered to Walgreens and there's a handful of things- I live two blocks from Walgreens- in there that I needed to get while I was cleaning, right? like cleaning products.

While I was there I was like, I definitely need a new candle because I'm clean and I need a new scent but but I had not planned on getting many things. So I didn't have any kind of cart or basket with me. So I just had like piled things up in my arms. So I'm wandering around balance and like 12 thing in my one hand which you know where this story is going

Sarah:

Yup!

Nicole:

You know where this story is going, probably because you've been there before, as you probably understand. You understand so I like I'm doing so well,

I'd like totally piled everything up the candles on top where I can like keep an eye on it. And yes, it's in glass and yes, it's but like I'm keeping an eye on it. It's good and I make it to the register because I'm ready to finally check out with all of my goods and like in slow motion the glass candle falls to the ground and shatters absolutely everywhere.

and I'm just so disappointed because in that moment, there's okay. Here's some like one-handed truth knowledge that I'm about to drop. There is no way when you are in that situation to make the clerk who's like about to check check out the stuff like there's no way it's not going to be awkward because they are immediately going to be like, "aw shit that girl has one hand and aw shit. She dropped that can because she has one hand" which is totally true

Sarah:

And that like "I didn't help her"

Nicole:

And yeah, yeah. Yeah, and so I just was like, I just really did a fail for the one-handed world, but she- Luckily. She was really nice and you know, I cleaned up the big pieces of glass but you know, they quickly came and swept it up and it was no big deal and it was a passing moment and and the world moved on and it was okay, but you know, I had to move on without the new candle which is that it did it smells like birthday cake, which is really good.

Sarah:

Look at well we can get another birthday cake candle.

Nicole:

Know for sure for sure.

Sarah:

Yeah, speaking of birthdays that makes me think of the day that I was born in that I was born without you know, I was missing fingers on my left hand and again like really trying to work on that terminology. I don't totally love "missing" but I just I don't feel like there's another word to better describe stuff.

I was born with a congenital or I'm a congenital hand amputee- very shortly after being born. My parents were connected to Shriners' Hospital of Northern California, which is where I grew up at- in the Northern California area and my parents were linked up with Dr. Michelle James who is now the chief of pediatric Orthopedics Surgery at the Shriners Hospital in Northern California.

They found Dr. Michelle James when I was about six months old and then became really connected with her, and I'm so excited to share that she's going to be our speaker for today and that she just she's so exciting and

Nicole:

Sorry to interrupt but I just I'm like so stoked for this connection and the fact that Dr. James has lit-er-ally been with you since you were six months old and had a relationship with you for that long and that she is so excited to be our expert. I'm sorry. I'll stop talking please go on

Sarah:

It's just been like such an important part of our family for so long and you know, I would go into shiners every couple of years as part of a couple follow-up study. So they were just sort of see what my functional development was like, you know as far as recommendations for surgeries or just like how

I'm doing- you know sort of comparison to kids that are you know are older and be able to use them as role models for the kids that are younger. I mean for years- I've been helping to serve like parent connections and then Dr. James so graciously allowed me to come into -when I was in college and really trying to explore what type of my trajectory was and what I wanted to study- She let me come in and help to hook me up with a really awesome volunteer position.

I got to observe tons of surgeries that she did enhancers and just like how cool is it to watch somebody who did a surgery on me and then like watch her do surgeries on another kid? Like it was very meta. It was so cool and just like so honored to be invited into that space and and and know that that's such a treat and then when so I've been a part of Shriners and a part of course of the Hand Team that way and then this past summer I did my doctorate project on creating

An online parent resources like an online parent Resource page and so I worked very I mean, Dr. James was my mentor. We worked very closely together as far as like how to best provide supports for parents because so much of that is like, "oh my gosh, what happened? When we do how do we support our kids?"

And so these were just sort of targeted strategies this everything that we know just initially so they can look at it here and then that can help guide their conversations as far as what they want to do what they want to seek treatment what treatment looks like all that kind of stuff.

So I just just I mean and and yeah so doctor I mean I've been over to her house for dinner. She's invited me there her daughter gave me a tattoo. Like I just I'm so excited and just like and so just thankful for the roles that she's had my life and such gave me such positive impact and really encouraged me and pushed me to really pursue all of this work and is really like put me in those spaces. So I'm just so thankful and so excited and she's so cool.

Nicole:

Yeah, yeah, let's totally yeah, let's get to it. Let's get to the interview with dr. James. So everybody can meet her and just know how how big of a badass she totally is.

Sarah:

Seriously!

Dr. Michelle James is a pediatric cancer surgeon. She serves as the chief of orthopedic surgery at Shriners Hospital for Children in Northern California located in Sacramento. She's the division chief of pediatric Orthopedics at UC Davis Medical Center and the professor of clinical orthopedic surgery at UC Davis and UCSF medical schools. Dr. James cares for children with hand malformations post-traumatic differences including Burns

and neuromuscular conditions things like brachial plexus injury spinal cord injury and cerebral palsy.

She focuses on the child's function and performance, especially from their own perspective. Her greatest professional joy is learning from a child or a parent that an intervention has improved her ability to accomplish a task that is important to them. From a personal perspective, Michelle met her wonderful husband in high school. They have been married for a very long time and have two adult daughters. We're really excited to welcome, Dr. James!

Sarah:

Hello and welcome to the really excited to have you on today's podcast and this is really exciting just for me personally because Dr. James has been my hand surgeon and I have known her my whole life with then looking sort of back on your bio has sort of been your career as well. So I'm excited to sort of talk about that and bring you on and welcome you. It's really appreciate you taking the time out of your day to be able to share with us your wealth of knowledge that you have

Dr. James:

Well, it's completely my pleasure. It's really a truly a pleasure to speak with those both of you.

Nicole:

Totally. I'm going to hop in here. Dr. James was Nicole and what can we just you know, as long and wonderful of career, can be can give us a little snippet of how that happened? Can you tell us how you became involved in children's hand surgery? And yeah, what have been kind of journey into where you are now.

Dr. James:

Well, it was sort of iterative. I first decided to be an orthopedic surgeon when I was in medical school and that was not a very typical decision at that time for a woman. We still are only about 9% of my profession and then it was less.

But I had some really amazing role models including one of the first women in orthopedic surgery when I was training and that had a huge impact on me. And I was attracted just to the partnership and problem-solving nature of the specialty where you you know, you sit down with someone and address what's important to them and that just was very satisfying to me.

It's also very Hands-On. There's a lot of variety and in most of my specialty you end up seeing people of all ages. I narrowed down kids after a couple of years in private practice.

I fell in love with hand surgery when I was in Orthopedics resident just because of the nature of it- the anatomy is just fascinating and complex and directly related to function and and then when I started my practice I was all volunteering at a children's hospital and found that that was the favorite part of my week and ended up moving their full-time actually right around the time - Sarah was born this matter of fact because I was pregnant with my daughter who's the same age as here when I made the change and it was a I just never looked back.

It was it was I was just completely I just completely fell in love with working with kids and families and and just the whole sort of wrap around idea of looking at the whole person and and figuring out how to help their hands work. So.

Sarah:

I had to use it as a distinct memory sort of following up on you working with kids. I remember coming into shadowing when I was in that high school early college aspect and you're sort of working with toddlers and pulling out different stickers so that you could see what they're like rotations- if you know like a sticker on the back of their arm to look at their supination and pronation and their ability to rotate their arms around.

They think its fun because they are thinking they're playing with stickers that you are using that as a method to really assess function because toddlers aren't really great following directions and you moving hand specific ways.

So I just think that that's a really fun space that you can consider work with children with it.

Dr. James:

Oh, yeah. I mean most of the time I can't believe I get paid for what I do. I mean, we have a whole Clinic where we get down on the floor and play with babies, you know when they have a certain type of birth injury so we can figure out how they're using their arm and hands and just having a tape measure, you know the kind of where you pull out and then push the button and it retracts just handing that to a kid. I still have been doing it for I don't know 30 years and I still see kids do different things would tape measures and I've ever seen before.

So and you know, it doesn't matter how many fingers or hands they have. No use whatever they have to work with to make the tape measure work and it's it's just it's entertaining and fun and it's really cool for the parents to see you know, I love what I love watching the kid through the paradise to and having watching them realize. "Hey this she's going to be fine. You know, she's doing she's doing everything I could have hoped."

Nicole:

Well, I was just going to say how interesting that you bring that up Sarah and I talked a lot about kind of in our own world and in our own five how the child's experience and perspective is so different from the parent perspective.

Can you can you talk to us a little bit about the changes that you see and parents the parents who you know, bring you a newborn baby and then as you care for them, you know and then have a 30 year-old Sarah, you know in front of you who you worked on it.

What what what does that parent Journey kind of look like as you are are touching base with them and seeing these kids grow?

Dr. James:

That's a really perceptive question because that's one of the one of the one of my favorite things to do and I started - thanks to Sarah's work at our hospital last summer on a website that we put together which I refer people to every day.

I've started doing sort of better defined what do they call it in Pediatrics "anticipatory guidance"

Because the parent journey, I mean everybody's different but most typically- I love to see kids when they're newborns. I love to see them as you know as early as possible maybe not prenatally prenatal tough because all the parents know about the babies that they have a hand difference in they haven't seen you know that you look just like Grandma are you know, they don't know anything else about her yet.

So that makes it that's kind of a hard conversation. But once the baby's born, you know, I see parents who are who are worried or they underestimate the child's abilities. They worried that they're going to be teased you know, they worried that no one will want to hold their hand.

I mean they go through their all of us running through their head kind of whether they tell you or not. And usually I feel like if they're- if they trust me enough they're going to start crying because they're feeling you know, they're feeling grief. They're feeling sorrow, they didn't they didn't -the baby looks different than they expected or the they knew they didn't know that hand differences were even a thing.

And you know, so we kind of talked through that and I tried to give them some little hints of like, you know, you're going to come back here in six months and tell me you had the most wonderful child in the world who's doing everything you could have ever hoped and then in two years they're going to be driving you crazy and you know in five years is in eight years that and so I kind of go through the stages that Sarah really helped me understand and define.

So I use the guide of the website that she put together to kind of map it out for parents and I don't I don't drag them through the whole childhood, you know, but I just kind of try and talk about highlights and that early visit I think just kind of establishes a bond between us and then the next time they come back, you know, they're happy to see me because I told them "your kids going to be fine."

They're going to surprise you and do everything you could hope and then they come and tell me that and if it's very very satisfying it really is and just the part about my job that I think I love the most is the building the relationships and talking to people over time and watching it grow up is is just really rewarding.

Nicole:

I love that.

Sarah:

It's fun. They don't all turn out quite like Sarah.

Can you share with us sort of what are different things you can also sow sparingly and anything that was building that rapport and then, you know, you sort of have different kids and families will come in for various follow-up visits at what what we do you sort of discussed surgical intervention is there's always an answer.

What did I do to you just have kids that sort of follow up periodically over time, you know, like they forgot to schedule it. They come in every couple of years or do they just sort of come in when they need something? What does that sort of look like when you're offering sort of your role in their care at Shriners?

Dr. James:

Well, it could look it can look different depending on the condition. But the general idea is to respond to the needs of the child and family and sometimes sometimes that's reassurance. Sometimes we end up whatever providing surgery or a device or a splint or a prosthesis. We just check in on them.

And early on the frequent term the visits are more frequent because kids changing more rapidly. So I mean, I don't personally have concerns about the development of a child with a unilateral hand difference with the hand difference on one side. I know that they're going to develop just fine.

But parents have concerns so, you know just just following up and having checking on them. They feel sometimes people will feel better if we're if we're checking on them.

And also I can do the anticipatory guidance. Okay, when she's 5 you're likely to run into this when she's eight this and so on.

When we talk about surgery most of the surgery that I do but the vast majority of it is elective and that means that it's shared decision making between me and the parents when the a child is younger between me and the child when they're older.

And there's pretty good evidence that most kids are able to make this stable decision about things like surgery as long as you can take fear after that, you know, as long as they're not afraid of pain- they can make a pretty stable decision by about age 9.

So they're the it just seems you know, they look at things the same way as adults do In terms of way and things- they are pretty concrete still- but as long as you can make the information fairly basic and concrete, you know, most nine year olds can make a stable decision. Does that answer the question?

Sarah:

Yeah. I remember. I mean I only had two surgeries for me, right? Dr. Davis the first when I was a year and a half 13 months old, so I don't remember that one, but I do have pictures of casts that I had them feed and they're all decorated with this fun,

but I do remember and probably the earliest memories that I have are of the surgery that happens when I was five when we did the web deepening from to sort of separate out some for me to be able to engage in pinching.

and I remember talking to you about that. I remember talking to my parents about that. I remember the dream that I had in the operating room. I remember waking up in the recovery room. Yes, like it's just such a vivid memory, but I remember how cool it was and that I was very excited to be able to pinch onto stuff with my left hand.

And we're talking about being able to grab markers being able to grab pencils and things like that with my left hand and remember being really excited about that and member like understanding was happening.

And then I remember being really excited once the cast was removed and I actually got to start using and I remember doing like a presentation to my kindergarten class about what my surgery was.

This is so funny how vivid all of those memories are, but I remember that being a decision that we all need together and being really thankful for it. It's improved the function of my left hand pretty only in my own personal life. So I'm thankful that I was a part of that position. So thank you.

Dr. James:

Yeah. Well you were a little younger than most kids who would be able to stable decision that I'd you know, I remember I think in the operation we did on you when you were an infant is actually something you and I talked about that something we no longer

do because it doesn't work as well as we thought it did and that's that's something that you know, I mean that you know, how how I feel about that. I mean that's kind of thing that if you've got an operation on someone and it doesn't work. It's a really really sad feeling. I mean you really did. We really don't feel good about that.

You turned out fine,

Sarah:

Just to recap what that surgery was and there it was a toe transplant surgery. So I am- Dr. James and I believe your father has worked on that surgery as well. Is that correct?

Dr. James:

He may have helped me with yours, but I don't think that he had any other connection with that. Yeah, okay, we worked together for a long time.

Sarah:

Yeah, I want to say both of you worked on that operation, and you worked with him or he worked with you and they/ you both bones from my toes on my what- I should actually know their names, but what? my 3rd and 4th toes on my right foot and my middle toe on left foot – and sue those bones to transplant on top of my numbs, I have little nubs and helped extend those and that's a little bit longer to help improve function

Because toes have a little bit of like length to them so they would grown but that's the sort of theory behind that surgery and it didn't grow as expected and send I should have have small toes as result of that just to sort of explain what that surgery was.

And it is interesting and then that's what is the day that my father wrote a letter about while they made that decision because again, I was a year old and I believe that was mostly effective – or had higher rate of being effective where when inserted at that time period

so he wrote me a letter while we were in the operating room just saying this is why we made this decision. This is everything that we know and like please forgive us if this isn't something that you want when you're older because we didn't have the opportunity to ask you.

and so my family was- very I mean all of us all of us a new view and my parents and this is something that we talked a lot about and has been a large part of my narrative growing up and I really appreciate that level communication.

Sarah:

Yeah, that was I have really good memories of talking with your family.

Nicole:

This is all so again, this is called jumping in here. And this is so it's totally an honor to hear you guys talk about this and kind of talk about personally when it needs and and you know things that that maybe we're hopeful that would work that didn't work. Of course, you would think that over, you know, a 30-year career that things would change.

That there would be things that I'm going to say that you grow out of that you the findings aren't exactly what you want.

But again the things that I'm very struck by in the what most you have been saying, Dr. James and you Sarah is just the conversation of how it's not just, you know, a patient who you are looking to provide to provide a surgery whether will become function. It also is partly emotional and it also involves that third-party of the parents.

And so that's very interesting for me to hear because in my brain surgery and it's either practical or it's not if user gives function or it doesn't but also there are so many other factors to consider and it's so interesting kind of listen to to how that gets to be a part of it and how and the decision-making that gets to go along.

That yes, that's more a comment. I don't have a question. I just I think that that is a that's why you away from listening to you.

Dr. James:

Well, you made me think of I mean, I remember when I became a parent so I went from you know, I had my older daughter in the first about when I was about two years into practice, but before that, you know, I was somewhat I was patient with parents. I thought that in retrospect I think somewhat condescending you know, like people are get crazy when they're talking it up her kid.

I mean behavior shouldn't be really crazy when your kid is, you know when your kid is the topic of a discussion. As soon as I had a baby. I had like a complete conversion to the point where preoperatively I'd be talking to a family and they'd start crying and I'd start crying.

I thought this is not this is not helpful to them in your suregon is crying while they're crying, but it really changed my focus to you know to understand. Okay I'm talking about somebody's kid here. This is you know that stuck with me for my whole career.

You know, we're talking about somebody's kid when we're talking about surgery we're talking about, you know, somebody's kid which is the most important person in the world to them.

And you know, that's that helps that helps and actually where I work that is did so Universal feeling it's the culture and that just makes it a you know, that makes that it

makes our job seemed very, you know, honorable and you know, too we feel privileged to be able to have that that kind of an opportunity.

Nicole:

I'm wondering I know that you have done a ton of research and you've written and published a lot. I'm wondering if you can tell us a little bit about the some hand specific research that you've done. What has that look like what have you found? What's what's been interesting from? Yeah from the reach research aspect of you.

Dr. James:

Probably the most interesting research project I did is about 15 years ago on kids who are born with one hand so below elbow deficiency is what we call it. All those are has acknowledged different and that's great. Yes. We did a we did a large study of 400 and almost 500 kids with that condition at about eleven hospitals and we had them we started out saying, you know, why don't these kids always wear their prosthesis some of them do some of them don't is if the type of prosthesis is it the training? is it you know, what is it?

Why aren't they wearing this at their parents personality? I mean we had all kinds of questions about this.

So we tested that and we tested kids with their prosthesis on and off if they had chosen to wear and then kids who had chosen not to where we just tested without a prosthesis and we found that for the daily activities that we were testing the prosthesis didn't help. In fact, it seemed to actually get in the way for daily activities.

We later found in a less scientific way that prosthesis for kids with one hand can be helpful for other activities that you know requires that are designed to have two hands archery, you know, not really not really riding a bike. But some kids need him for a bike. I mean various things that we've that we now can make them as a tool but the prosthesis did not work and look like a hand for most kids.

And so we ended up with a totally different finding that we started with it was not a popular thing to present or publish because it wasn't kind of what anybody really wanted to hear. And you know, it was a I think it was probably the most impactful project I've done.

But it was it was not satisfying.

Nicole:

it well and that's so strangely affirming for me as a child who of course was put in prosthesis all growing up and who was a child who never

wanted to wear them to kind of hear and to understand that that yes, the people who are in charge of crafting and creating that we're doing the research and trying to figure out why and what was going on and how to make it into a tool that would be useful.

Sarah:

So switching gears a little bit as a sort of ending with the down because I know we're all busy and we all have things to work on and we want to be respectful of your time. Do you have any sort of like hurting wisdom or things that you would like other people to know both like parents and children and other Healthcare professionals sort of as reflecting in being so prominent in your career in being a pediatric cancer surgeon?

Dr. James:

Oh gosh. Well, I think I would say that the single biggest joy of my career has been being able to being privileged to take care of kids from when they are small until they grow up and seeing watching them grow up and interacting with families as they grow up and then about 10 years ago.

I saw my first Next Generation by surprise where I was doing surgery on a little baby and I went out to tell the parents that everything was going well and realize that I already knew the father because I had done his surgery when he was a baby and I hadn't even realized that beforehand and I think that just I mean when someone comes to me with their with their child and I was their surgeon that's really really wonderful and an honor.

And I guess probably the main my main take-home is and I learned a lot of this from you Sarah and that is that, you know, I feel totally comfortable saying with authority to people now your kids going to be fine. You know, they're going to be fine. You just I mean you're going to worry because your parent but you know your kids going to be fine.

Sarah:

Yeah. yes, we're all gonna be fine. There's different things that come up but largely and I think that's too I just remember again shadowing you over the various years that I've had the fortune to be able to come into Shiners and really hearing a lot of parent questions and concerns and again, like they don't feel that they could ask these to their community because they don't see anybody else in their lives it necessarily hand differences and and there is also that like worry and guilt and "will my kid be able to do this? Will my kid be able to do that?"

And I remember there was one boy that we went in and saw and he had he was younger maybe six and his parents were just like, "you know, how do can he play football and volleyball and it will people notice?"

And I've been getting there the whole time I didn't I wasn't hiding my hands and I think I felt encouraged to say something like "well, this is what my hand looks like" and they

were just like, “oh my gosh, I didn't even know” that I said it was like, yeah that there is such a moving element of the two.

Dr. James:

Yeah, and I learned the other thing I learned from you and it really has changed how I approach family since you spent time with me. Last summer is the whole concept of stigma. I didn't have words around that before and I didn't really, you know, I would use words that that didn't quite get at it but the concept of stigma and then the concept of community I could lift like five more things I learned from you but those are some of the most more important things, you know, and the other one more one more really important thing is controlling a conversation.

I mean that's such a useful life skill and now I have that conversation several times a day about you know, giving kids sort of, you know, the the idea that they can control the conversation if it's about their body, they don't have to you know, follow it anybody else wants to do or say they can they can wrap it up if they're done.

Sarah:

Yeah, they can and they get to say so these are the words that I like to describe myself and you know, these are words. I like to use and like like I don't want to talk about this anymore and that's okay so that they don't, you know, just because they have the same with different doesn't mean that they then get to be interrogated by everything and if they want to talk about it great if they don't want to not say that was very liberating for me in my own life to come to that realization as well and it was pretty powerful but I really love it.

Dr. James:

I love it.

Nicole:

Hugely yes. Dr. James. Thank you so much for your time. Thanks for joining us. We just so appreciate having this conversation with you and of course. We thank you for all the work that you do within our community. You are that conduit and you have cared for so many of us. So thank you for being that expert and thank you for being that caretaker to our people. We are very thankful.

Dr. James:

It's totally my pleasure. Totally my pleasure and privilege. Thanks.

Sarah:

Thank you for spending part of your day with us. We want to give thanks to our Network Public House media for intro beads to Jason birds with cybernetics. For our Logo Art, we want to remember Patrice. You can find his work at [normal person's.com](http://normalperson's.com).

Nicole:

Be sure to follow disarming disability on Facebook and Instagram and lastly be sure to check out our website [disarming disability.com](http://disarmingdisability.com) where you can find all 13 episodes of season 1 links to resources transcriptions and discussion questions for each episode and

Check out our blog where we feature amazing Disability Advocates. See you next week.
Bye.