



TURN AUTISM AROUND
WITH DR. MARY BARBERA

Transcript for Podcast Episode: 071

Medical Conditions Associated with Autism:

Interview with Dr. Missy Olive

Hosted by: Dr. Mary Barbera

Mary Barbera

You're listening to the Turn Autism Around podcast. I'm your host, Dr. Mary Barbera, and I am thrilled that you are here today. I am doing a special interview with Dr. Melissa Olive. And Missy has a PHD. She's a doctoral-level BCBA and she's a licensed behavior analyst in three states. Missy is the executive director of Applied Behavioral Strategies, which is an LLC. She spent nine years conducting research and training special education teachers and behavior analysts at the University of Texas at Austin and the University of Nevada in Reno.

Mary Barbera

Missy has published over 30 peer reviewed articles and book chapters focusing on a wide variety of topics. Today, we're diving into her role as a sibling of a brother with autism and other comorbid conditions. We're also going to dive deep into gut and brain issues; how to solve picky eating for kids with autism; and we're also going to touch on chewing and pill swallowing, which are two issues that are faced with children with autism. So let's get to that special interview with Dr. Melissa Olive.

Welcome to the Turn Autism Around podcast for both parents and professionals in the autism world who want to turn things around, be less stressed and lead happier lives. And now your host, autism mom, behavior analyst and bestselling author, Dr. Mary Barbera.

Mary Barbera

Thank you so much, Missy, for joining us today for this special interview. It's great to have you here.

Dr. Melissa Olive Thank you. I'm honored to be here. I really appreciate it.

Mary Barbera Awesome. So I like to start with describing your fall into the autism world.

Dr. Melissa Olive A fall it was indeed; actually more like a birth, if you will. I was eleven when my sibling was born and I cried because he was a boy making it my fourth brother. My mom knew right away something was up. She was actually told to take him home and love him and pet him in an institution. He was, quote-unquote "a black baby" when he was born because he was asphyxiated. Mom thought he couldn't hear. And then she went through a period where she thought he couldn't see. And so he's one of those people with autism that showed the traits early on, in infancy.

Dr. Melissa Olive So my mom did just the opposite and got us enrolled in a parent training parent model of early intervention. We drove forty-five minutes from our rural home in Tennessee to the next biggest town where Phil Strain and Matt Tim ran a program called the Regional Intervention Program. They published Seeking Go and maybe we can pull those up and read them as a resource. And that's when I first learned how to do ABA.

Mary Barbera And what year was that about?

Dr. Melissa Olive So Mack was born in seventy-nine, so it would have been somewhere around eighty-one. So we were way, way ahead. And so from there I decided first that I wanted to be an OT. At the time that would have made me go outside of the state, and I didn't want to do that. And so I did special education and elementary education, which led me on to early childhood special ed, which I did at Vanderbilt, and Vanderbilt is incredibly behavioral and has been for as long as I've known their special ed department. And so that just further reinforced my love, you know, sort of this natural behavior analysts, if you will.

Dr. Melissa Olive And then Mack actually moved in with me right after I finished my master's degree; back when I thought that I knew everything. And then we went to the University of Minnesota, where I got my doctorate. And that was my focus on severe problem behavior. But I still had that love for early childhood. So it's sort of this mix of problem behaviors, early childhood and communication intervention, which I learned at Vanderbilt.

Mary Barbera Wow. So you got started as a sibling and then moved on to education and behavior analysis, and so Mack is now... You said early 40s?

Dr. Melissa Olive He just turned 41 last Saturday.

Mary Barbera OK. And he is still pretty impaired and usually lives in a group home.

Dr. Melissa Olive Correct. So he... I'm going to use quotations again. He has an IQ of 35. Developmentally I would say he's somewhere between 2 and 4, depending on what task you're looking he. And he has a lot of comorbid conditions, which requires extensive care. He moved into his first group home actually the year I was working on my dissertation. And then he moved back in my home and then back into a group home the year that we moved to Texas, and he's been in a group home since that time. And that's always challenging too, which is, you know, I still want to pick Rachel Taylor's brain about having ABA in group settings because we have not had a lot of luck in that domain.

Mary Barbera Yeah. Yeah. So my son is twenty-three and he remains with moderate-severe autism and has some other comorbid conditions. But before we talk more about that, and I know we want to focus... I don't know that we've ever met in person directly and we just got to talking online just last week and it seems like we have so much in common and have very similar opinions about a lot of things. So we decided that the focus of this talk could be on anything. Right. Your role as a sibling or severe problem behaviors or...

Mary Barbera But we want to focus on when children with autism or adults with autism have comorbid conditions of G.I. issues, gastrointestinal problems. And we're going to talk a little bit about feeding problems and pill swallowing and addressing all those things. But before we get to those specific areas, you did share with me that there is an assessment from the CDC published back in 2013, which I wasn't aware of, where we're going to link that in the show notes. So if you are listening and you go on MaryBarbara.com/podcast, you can find Missy Olive's episode and go to the show notes. And we're going to have any of these resources we talk about in the show notes for people to pull up, which is great.

Mary Barbera So the CDC assessment paper published in 2013 basically says that it has been demonstrated that children with autism have much higher expected rates of many comorbid conditions, including eczema, allergies, asthma, ear and respiratory infections, gastrointestinal problems, severe headaches, migraines and seizures, and probably between Lucas' and your brother, his name is Mack...

Dr. Melissa Olive Yeah.

Mary Barbera So Mack and Lucas, probably between the two of them, they have all of these comorbid conditions because I know Lucas has been diagnosed with intellectual disability. He's had chronic sinusitis diagnosed in the past. He's needed seven years of allergy shots and he continues with those as well as allergy meds. And he has an autonomic nervous system dysfunction. He also has in the past been diagnosed with a pediatric autoimmune neuropsychiatric syndrome or PANDAS. And it's complicated. And I know that for Lucas, a lot of these comorbid conditions were actually causing or largely contributing to his self-injurious behavior and aggression, which is more of in our domain as behavior analysts. And so I'm particularly interested too, not only as a parent and a behavior analyst, but also as a registered nurse.

Mary Barbera So before we jump into your knowledge about gut issues and the comorbid conditions that we just discussed is, you know, why do you think so many behavior analysts discount gut issues, dietary changes, supplements, and they basically state that, you know, supplements and diets and anything that one might consider biomedical is pseudoscience, and we shouldn't be exploring that? How do you respond or what do you think?

Dr. Melissa Olive Well, you know, I don't fully understand why behavior analysts come with those presuppositions. I will say that where I was in one lifetime is very different than where I am today. Because I had a very bright student sort of wake me up. So some of this I stepped over that boundary and started looking at how the whole body interplays. As behavior analysts, if you think about why does ABA work? Well, presumably we are changing the way the sentences work in the brain. And if the brain is not functioning properly, doesn't it make sense that we would help make the brain function better so that then the child would benefit more from the ABA that we're going to do? So once that brilliant student turn me onto it I started delving into a whole other line of research to read, and that took me out of Java and it took me out of the journal Behavioral Education and into medical journals where I was truly reading about the medical side of intervention.

Dr. Melissa Olive And what I think is missing in our training for future behavior analysts is education. There is a whole other literature out there beyond Java. Our responsibility is to stay current in all the literature, not just our tiny little sliver. So I think it probably has a lot to do with our academics and how we're training BCBAs, you know. But in some of our other conversations you brought up media and the role that media may play. And so, you know, I would be curious in a survey of BCBAs getting a better understanding of why they have these views and why they're not considering these other views would be super helpful for the field.

Mary Barbera Yeah. And that is our ethical obligation to quote unquote, rule out medical problems before you treat problem behavior; before you treat a, you know, SIB, before you treat potty training. Especially if the child's older and past the age where normal potty training would be expected. You know, is it a constipation issue? Is it a G.I. upset issue? And we can't just have this knee jerk reaction. We are ethically obligated... And easier said than done, right? And I've done a few video blogs, which we can link in the show notes. You know, the importance of ruling out medical problems. I did a video blog... But at the same time, I said basically you can't. And if you rule out in your infection last week by looking in the child's ears, there's nothing to say that they couldn't have gotten worse this week.

Mary Barbera

Then the other huge issue is with kids that are not fully conversational, they can't tell you the pain is stabbing or like, Lucas can say, head hurts now. But it's usually after he bites his finger or hits his head or yells out, and he can't tell me the pain starts here and it's a stabbing pain that goes down to my ear or into my jaw. So then you are talking, is it a migraine? Is it an ear infection? Is it a jaw issue and, you know, a medical issue? And that can happen with any part of the body. And then... What really gets me concerned is I know what a struggle it's been to figure out Lucas's medical issues. Even though he is a little bit verbal, he is able to express some pain to a certain degree. I am a nurse, my husband's a physician. You know, I'm a behavior analyst, like with all of that, and it has been years and years and dozens of doctors to help me figure it out.

Mary Barbera

And what about the kids, especially the teenagers with severe problem behaviors that are in institutions or group homes that, you know, the answer is not to just put a helmet on or put bike guards on every staff member. And I've done a couple podcasts that we really should link in the show notes and some we will. One is with Lucas's psychiatrist, Dr. Michael Murray, who's also an autism dad, and he's a psychiatrist. And he really was the one to figure out a med that literally has been a life changer for Lucas. That's episode number 28. So MaryBarbara.com/28.

Mary Barbera

I also did an interview with Dr. Tim Volmer, who's an expert on severe problem behavior, and one of the things Dr. Volmer taught me was in every species, when there's biting involved, whether that's self biting or biting others, in every species that is usually under stress or pain. And if you think of the old cowboy movies where they bite on a towel before anesthesia was a thing. And so if kids are biting that makes me really suspicious that there is a medical issue and so. Are you finding that with your literature, you know, diving into the medical literature, are you finding the same kind of things that I'm talking about?

Dr. Melissa Olive

What's truly fascinating about all of this is back when Mack first moved in with me... So I just finished my masters. We were still at Vanderbilt and Frank Simons was there. And so Frank actually was one of the first people that was looking at the role of pain or some other neurotransmitter issue around self-injurious behavior. And so I enrolled Mack in one of those studies and what he was looking at is identifying when that problem behavior was occurring. And so doing a blood draw, you know, sort of immediately after this severe problem behavior. And then the baseline would be another day of the week at the same time when

there was no behavior to see if there was a difference in whatever measure he was measuring.

Dr. Melissa Olive And so, you know, Frank is a behavior analyst and has done a lot of great work in this area. And we had to turn to and look at, you know, what he's recommending. And I do just one loop back in, and you probably said this in your podcast when you're talking about the ethics of doing the medical rule out, I jumped for joy when the 2016 code of ethics came out. Because that is when they added the medical rule that had not been in the previous. And so I was so happy about that. But now I feel like people will post on Facebook and they'll say, I've already done the medical rule out. And as you just you listed, let 16, 17, 18, things? How could you possibly rule out all 18, you know, and still talk about pika and still be talking about self-injurious behavior?

Mary Barbera And so how can you rule out 18 things when you have a nonvocal child or adult? I mean, you know, the doctor is not a behavior analyst. I do have a video blog on a calendar system that I developed based on like the fact that I had to keep track of things. And so in Lucas's calendar, I have years and years of calendars, I put in red pen any self-injurious or aggression... aggression is down to zero and self-injurious is almost down to zero. I also put his allergy shots when he's due, any headaches, any requests for pain medicine, any fevers or tics, because he can get ticks if he has pandas. Any change in medication dosages? I think this is a great strategy. The physical calendar where you're actually writing down, because then I take my physical calendar and we look and that's the way we adjust medications for Lucas. I don't know if you have another way or...

Dr. Melissa Olive I have all of Mack's seizures in an Excel spreadsheet. I started doing that in 2017 because we have seen an uptick. And thank God all the doctors that we've worked with listened to me and take, you know, my historical knowledge... I can remember all way back to that when he was an infant. So I can remember the different medications that he's been on and what works and doesn't work.

Dr. Melissa Olive And his neurologist is so sharp that I could tell from his logs and the Groupon that he was having seizures and they were missing them. And so I brought him back here to do a few nights in a row. And in that time, he had three seizures in five days, which is highly unusual. So I called the doctor and she said he has an

infection. This is indicative of an infection. And so we need to find out what the infection is. Two days later, the results of his endoscopy came back and he had H. Pylori, which is extremely painful. But all you have to do is Google H. Pylori and seizures, and the rate of your seizures increases drastically when you have an H. Pylori infection.

Dr. Melissa Olive And so, again, she was ahead of me medically. But recognizing that there are medical underpinnings that we have a duty to get to the bottom of, which means we have to read and expand our scope if we're going to work with this population of individuals who have all these comorbid symptoms and know how to recognize what is a comorbid symptom.

Dr. Melissa Olive Can I just say one thing too: you are the second BCBA that I've met that has a loved one with Pande slash pandas and I learned about pandas quite a while back, shortly after I had my eyes opened up and have studied that as well. We're going to talk about feeding, but I'm going to head us off on feeding... we got called in a school district, called us because the student in their school district had been hospitalized in an emergent situation. He had just quite frankly stopped eating. He had also regressed in that his normal, limited communication had really tapered off and his SIB had skyrocketed. And so our duty was not to solve the problem, but to make sure that we could get him to eat again...

Dr. Melissa Olive They were going to put a feeding tube in him. And he was 15, 16, 17. He was fairly, you know, older. And so we were able to get him to eat and preventing him from having that invasive procedure. And then a consulting BCBA came in because it was going to be a transition right out of the hospital back to his normal life. And so the consulting BCBA came in and he said, what do you think this is? And I said, I'm just going to throw the puzzle out there. He had a huge change in his eating behavior. He had a huge change in his SIB. And he also stopped talking. That to me says that there's a sudden onset of something, and I'm gonna go with pandas or pans. And I was so happy that he didn't judge me for thinking about a medical situation and one that has sort of been questionable among other medical professionals. And if it wasn't for the parents advocating for what they know their kid had, it might not have gotten the attention that it's gotten today. And as it turned out, there was some underlying infection around a panda slash pans issue. But it was just so nice to know that there are other BCBA's starting to learn about this and talk about this and bring this to the forefront.

Mary Barbera Yeah, I learned about pans when Lucas was 6, so he's 23, so a long time ago and I wasn't even a behavior analyst at that point, but he started having acute onset tics and motor tics. And so every day it got worse to the point where I had my little clicker counter and I counted like five hundred in a day and I was studying to be a behavioral analyst. So he's trying to figure out the functions stuff. And I was just like, oh my God, this is a mess. And at the same time, Lucas got open lesions on his legs and it was the June and it looked like he had like infected mosquito bites. And I said to my husband, you know, if it's a staph infection on skin, would Zithromax work? Because I knew he would take liquids Zithromax at the time. He's like, yes. So it was just Googleable, you know... it must be like 2002. So he said Zithromax would help both staph and strupp.

Mary Barbera And so we put him on a five day dose of for Zithromax. And by day five, his tics went from five hundred to zero. And so when people are like, I don't believe in pans, I don't care if you believe in pans. Well, I have some data. And you know what? It's never gonna be published. But I know and I know that he had tics for years and we've treated with antibiotics. Then he developed burping tics like whoever even knew that was a thing? I still haven't ever seen that. I've seen sneezing tics. I've seen an episode on like the doctors or The Today Show with sneezing tics. And if Lucas starts to burp, and he's twenty three, we know there's an infection. So. Yeah. All right.

Mary Barbera So let's talk about gut issues and breathing issues and what you know about that and how picky eating and feeding problems are related to these gut brain issues.

Dr. Melissa Olive So, you know, when you were talking about when did you first learn about pans? I was going back in my head calendar, when did I have that brilliant student wake me up? Her name is Rebecca Ryan, by the way. She's a BCBA and an attorney. She's wicked smart. And she opened me up probably I'm going to say 2004, 2005. And so shortly thereafter, I actually left my academic position and went to work for CARD, the huge ABA agency.

Mary Barbera What does card CARD stand for? Just for our listeners.

Dr. Melissa Olive The Center for Autism and Related Disorders. And so Jonathan Tarbox, Amy Kinzer, Michelle Bishop, the research team was pretty freaking fantastic, right? So all BCBA PHD level doing research in within that agency in the office where I was located had aligned with a medical clinic that was very interested in doing a lot of the medical treatments around the autism. And they had this amazing nutritionist by the name of Kelly Barnhill. And Kelly really taught me about diet. And so in learning that then I started just delving down the medical literature on the role of food in G.I. conditions. And so when you look at celiac or when you look at PKU or when you look at inflammatory bowel disease or Crohn's disease, the standard medical treatment for any of those G.I. conditions is a dietary intervention. It's sometimes a medication to reduce the inflammation in the gap. And so in delving into that literature, you didn't have to go very far to also see that role of how the gut and the brain interplay.

Dr. Melissa Olive So since then, I've also expanded my readings to include the work of M.D. who are every day increasing our knowledge on the role of the gut-brain interaction. And so David Perlmutter is one of my favorites. I actually started reading his book because we're a family member with Alzheimer's and she was going to be living with us. And I thought, well, let me read and then I'll make sure that we feed her properly. And he basically helped me see that I had a gut problem in my over addiction to sugar. And so I removed all my sugar, had a huge withdrawal from pulling those sugars from my diet, but had improved my own overall health as a result of that. And that includes my sleeping. And so, you know, we know from all this other medical research that if your gut is inflamed, things will pass through your intestines and because they're not being stopped by your intestines, they are now crossing into that into your bloodstream. And so because they don't normally enter your bloodstream in that way, they're able to cross the blood-brain barrier. So they've got direct access to the brain, which then impacts to your functioning.

Dr. Melissa Olive And, you know, the best joke or sort of analogy that I ever saw was when a researcher said to me, why don't we go have a beer and talk about it? And I don't always get subtle jokes, and so I had to process it for a little bit. And I was like, oh, alcohol goes into your gut and you go straight to your brain. It immediately impacts the way that you think and the way that you feel. And so why wouldn't food do that, right?

Mary Barbera

Yeah, processed food is like sugar, you know, everything that's processed down and changed, as you know. And that's the thing is like, I did a video blog on can autism be prevented? And you know, I recommended that pregnant women be healthy, avoid toxins, you know, take supplements that their doctor recommends. And a BCBA had a big problem with what I said. It's like, why is it a problem to say avoid toxins when you're pregnant? You know, most people are like, you know, oh, there's nothing to that gluten casin and free diet. Well, a lot of us have to be on special and like sugar addiction, alcohol addiction. It does change your brain. And why wouldn't it also changed the brains of kids, especially little babies and infants?

Mary Barbera

And, you know, if you can try dietary interventions early on, it certainly can't hurt the situation. Right. When you have control over the food, the more organic, the more fruits of vegetables, the less stride through, the less, you know, I think can only help the situation.

Dr. Melissa Olive

Right. Well, I have to say so... Mac was born in seventy nine. And by the time he was two years old, so my mom already knew something was up, but by the time he was two, she knew there were food problems. So we we were on a farm. We didn't we didn't milk our own cows, we were still buying our milk in the store. But we did have a lot of fruits and vegetables or whatever front from the farm. Well, we did grow our own corn, but we got our bread at the store. But my mom figured out really quickly corn was a problem and milk was a problem. And so she had always told us teachers not to feed him any corn. And I will never forget the day that he came home and pooped out a bunch of corn, and mom took his diaper and she walked straight to the school, and she said, I told you not to feed him corn, yet you did. It's probably where I learned all my advocacy skills.

Dr. Melissa Olive

But along with the dairy, there are studies out there that are showing us the role of dairy in the brain and they call it an opiate effect. And so she recognized that he tolerated the acidophilus milk better than regular milk. And what is acidophilus? Well, it's rich with probiotics. So here's my mom with no Internet connection and no Google, no nothing. She figured that out on her own by whatever, you know, manipulation she was doing that I was not privy to because I was still a young child. But if it wasn't for these moms figuring these things out, I think we would be much further behind than we are.

Mary Barbera

Yes, I just published a podcast on the role of autism mothers in history in and it is quite powerful. And it is a lot of the science, a lot of the movement has been autism parents and especially autism mothers. So let's talk about picky eaters and how that can be related and why that is related. I know I have a toddler preschooler course as well as a verbal behavior bundle and in both courses I cover picky eating and how to get kids to eat healthier and better. And what I found is that they're not only picky eating and they're not eating regular textures, they're not eating with utensils, they're not moving food around right in their mouths. They're addicted to pacifiers and bottles and so forth. And so I find that you show me a child that's very delayed with speaking and they probably have something going on with feeding as well.

Dr. Melissa Olive

Right. Oh, absolutely. So my brother had difficulty eating. He moved in with me when he was 13. You can do the math and figure out I was still very young and clearly thinking I knew everything. But he came to me in diapers and he could vocalize that he was about to poop and he wanted to be arranged in a certain way prior to pooping in his diaper, standing up. And he also came to me on stage three baby food. And I, you know, unlike a lot of behavior analysts, I actually had a course on feeding, positioning and motor and feeding because I also loved kids with significant disabilities and so sort of embarked on that path, you know, in my coursework. So I had had some feeding training. And so I said, I know behavior analysis and I know how to change behavior. And I'm going to teach him to eat table food. Now, of course, I didn't do all the things I should have done, and I knew nothing about diet and did get him to table food.

Dr. Melissa Olive

But, you know, fast forward many years, he has dysplasia because... Actually the cord around his neck and he was without oxygen for it for a long time. And so that resulted in a cerebral palsy diagnosis. And it's not uncommon for individuals with c.p to have dysplasia problems. So I goofed early on as a young professional because I should have done a rule out. And so looking at that swallowing piece or having a professional whose scope of practice is look at that swallowing pieces is one thing. Also, over the years I have gotten additional training. We have an expert in Connecticut by the name of Lori Olin, and Lori is a speech language pathologist who specializes in tongue ties. And she's taken coursework after coursework after coursework and learning how to recognize it. She's trained me so well, I actually didn't diagnose, but I said, this sounds like it's one time you need to go get that ruled out. And the mom called six months later and she's like, how did you know? You didn't see my child. You know, you totally screened over the phone. I'm so thankful my child's eating everything under the sun now.

Dr. Melissa Olive And so one of the things that Lori taught me is there are two kinds of tongue ties. Sometimes there is a frontal... what they call an anterior. And then there's the back one, which is the posterior. And so the frontal one is easily recognizable by professionals. So the child can't stick their tongue out past her lips. So it's kind of obvious. But when they have one in the back of their mouth, what it does is it... so it's tying the tongue down way back here. So you go and you put food on the kid's tongue and the tongue is tied down. So the tongue doesn't arch like this. Well, now the food is back here and it's going to roll into the throat and cause choking problems. And so if a child has this kind of tongue tie, they're going to have the choking, which then causes fear, which then makes them not want to try new foods because they don't know what to do with the foods. It also may make them restrict based on texture. Right. Because liquid, thick liquid especially that's sitting back here, is not going to roll down your tongue in the same way that a big chunk of food might. So that's certainly one thing that must be ruled out before you do anything.

Dr. Melissa Olive And you had to also know that a child can have a tongue tie and that tongue tie can get corrected and it can grow back. Or it could have been an improper untie or whatever the correct word is... Procedure. And so even though they say, oh, he had a tongue tie but it's gone, you need to make sure that it's truly gone.

Mary Barbera And is that an ENT, the ear, nose and throat doctor that would examine for that? I think that's part of the problem is who, you know, I have some friends that are very big on baby tongue ties and clipping them right away at the newborn period. But if it goes past that, I mean, who examines kids for a tongue ties when they're infants and then who do you go to if you think there might be a problem later?

Dr. Melissa Olive So the pediatrician or the OBGY, as soon as the baby's delivered, they do their investigation. And then obviously the pediatrician will be the next person to see the baby. They're both supposedly qualified. But, you know, when Lori was training me, she's like, Missy, you have no idea. They get a 15 minute class on it. And so you really want to make sure you go to an expert who has this extra training in recognizing tongue ties. Lori, again, is an S.O.P. And so she can spot it and then she can make that referral to an appropriate medical personnel who can do the tongue clipping, if you will.

Dr. Melissa Olive And sometimes you can see when their lips are tied, too, which can impact the speech and lip closure on the utensil. We rule out both of those things. So that the other medical rule out that we do is we ask do you have any constipation or diarrhea or any mixture thereof, because that's a red flag that there's other problems in the long list of G.I. conditions that can go with a feeding problem. You just want to make sure that you've screened for those.

Dr. Melissa Olive But we also haven't a fully talked about the role of food allergies and intolerances and those things can affect the stomach. And again, if you look at the opiate literature around this, what happens is you eat food that your body doesn't know how to digest. And so what your body does is it creates a histamine effect, and so you get high off of your food and everybody likes being higher. Most people like being high. And so when you come off the high, what do you want? You want more of the thing that made you feel good. And so you actually end up eating a lot of the food that you shouldn't be eating in the first place because you keep going for that high. And that also explains that withdrawal. Right.

Dr. Melissa Olive So we had a family... We tell the families about this like, OK, it looks like your child might be reacting to dairy or to corn or rice or to fill in the blank. You know, when we stop this cold turkey, you could have this withdrawal effect. And if you if you look at the literature on withdrawals, they all look the same. You get lethargic, you even can sweat and have a fever and vomit. And so those are the things that we prepared the family for. And this one family's dad is an ER doc, and he's like he's like, I get it. I totally get it. This is not alcohol so she's not going to be at risk for dying, but we're ready for whatever side effect is going to happen. And she did, she went right through it and he's like, oh, my God, you nailed this. And I said, yes, I did. But guess what? Now they're going to withhold milk because they saw what it did to their kid.

Mary Barbera Yeah, so. So looking at constipation, diarrhea, I know I did a potty training podcast in the past and around 2011, 2012, I found out about this book called It's No Accident, which basically is written by a pediatric urologist. But a lot of his work deals with kids, with constipation, with urinary problems based on constipation, like night wetting can be constipation, even though 90 percent of the parents that come to the clinic with their kid don't report constipation, it's

amazing how many kids are actually constipated and impacted. And you know, there are great Western diet is certainly at play. So it's all related.

Mary Barbera So what do you know about... What research is do you have on pill swallowing or taking supplements? That seems to be a big thing.

Dr. Melissa Olive Yes. So this is another area that CARD got me into because they were working in conjunction with a medical clinic in that facility, was specifically looking at DGI conditions. And so it's pretty invasive. You have to put someone under to do a scope. But there's this new technology... It's not new anymore. But there was the technology of a pill camera. So you swallow the pill and the pill has a camera and it's taking six images per second. And so it allows the G.I. to see in areas that they would not be able to see unless they cut you open. So they can only go so far endoscopy and then they can only go so far with colonoscopy. So this gets everything in.

Dr. Melissa Olive So the hope was that we could teach people to swallow pills and then ultimately swallow the pill camera. And so I started looking at some of the earlier literature... I have one of the studies up. The first study that I'm familiar with was 1984, where they actually use ABH strategies, verbal instruction, modeling, stimulus fading, reinforcement to teach this child to swallow pills. And so what the team at CARD had done was take that in some of the other subsequent research in and put this protocol in place. And it is stimulus fading. Right. So you start with something teeny tiny, and then...

Mary Barbera Like a piece of rice.

Dr. Melissa Olive Or not something like candy. Right. Because you're encouraging chewing. So what you want is something that if they do chew it, it's almost like a punisher.

Mary Barbera So, yeah, swallowing like a piece of rice or a little bean or something that's edible, but that's not like a tic tac. Like a lot of people say tic tac. And I've

learned that its rice or bean, and you systematically get the thing a little bit bigger.

Dr. Melissa Olive And I can send you the list so you can include it. So the order that works well and then you work with a compounding pharmacy to make allergy friendly pill samples. So you can go down as small as a size 4four. And it's the opposite in terms of gradient. So a pill size four it's teeny. And a double zero or a triple zero is fairly big. And so our hope was to get kids to a double zero. But what I learned along the way with this model was that if you had a picky eater, they weren't going to participate in your pill swallowing protocol because you're eating foods that would be novel. And so what we learned to do was first address picky eating. And then about six weeks or so after they learned to chew and swallow, then you brought them back in. Because now they'll put anything in their mouth. Right. And so you bring them back in and say, now we're just going to swallow no chewing and sort of reteach that approach. And we had huge success. It was amazing, like when you read the protocol, you think there's no way this is going to work. And just like all the other, you know, just like the toilet protocol, it's almost miraculous how that ABA is so darn effective.

Mary Barbera Yeah, yeah, and I know I did quite a bit and Lucas has always been a picky eater. We did a feeding program when he was little. And then, you know, he still is pretty, pretty picky, although he will eat some novel things here or there. But for pill swallowing we started when he got diagnosed with pans. When he started showing symptoms when he was six, we treated him on and off for his tics. And then at 14, he was actually diagnosed. And then the doctor wanted him to take prednisone as well as an antibiotic to kind of kick the burping tics out. Just a 21 day dosing of prednisone, which is a steroid. And he said they're teeny tiny pills and it's nasty. You can't smash him up, which is what I was doing. And it's not a liquid. So just stick it in applesauce or pudding or something. And I was used to crushing things up and putting it within pudding or applesauce anyway, and that's the way Lucas was taking his pills. So I just dumped the little prednisone in. And then we started just dunking everything in applesauce.

Mary Barbera So... I know some adults in nursing homes, being a nurse, some adults take their pills that way. Is there a problem with that? Is that kind of the wimpy way out? Like a gun to my head I could probably teach Lucas to swallow pills, but at this point, it's like not worth it because he's used to his routine. He actually does it Monday through Friday. He dunks them and he's really independent with it.

Dr. Melissa Olive I totally embrace choose your battles. And when you have loved ones who are as complex as Lucas and Mac are, we have to choose what battles we're going to fight. Mack is a champion pill swallower. He actually learned how before I learned how to teach it. His group home will put them in like a little paper cup that, you know, like a dispensary cup and he'll just put them all... And he takes it takes fish oil. And we had previously chatted about the fish oil in mental health. So he takes fish oil, but he also developed osteoporosis as a result of his anticonvulsants. And so he takes vitamin C. I mean, vitamin D and also calcium. And then he has his anticonvulsants. And so he's got quite a few things that have to go down and he just tips it back. And I don't let him do that here. I give him one at a time and make sure that he doesn't chew.

Dr. Melissa Olive But, you know, as long as they will swallow with the applesauce, that's fine. There's also the or a flow cut that you hide the pill in there and you drink it and just all goes down the hatch together and that's fine, until you piss your child off and they think that they can't trust you anymore because you're going to be hiding things. So the flow cup is great as long as they know that there's a pill that's going to be going down, too. Otherwise, if you're just going to start from the ground up, just teach them how to do it.

Mary Barbera Yeah. Yeah. I don't like smashing up things and like hiding it and things in general, or putting it in juice and then you don't know if they took it then all the stuff is at the bottom; or hiding it in peanut butter. I mean, I've been there and I understand the struggle. The struggle is real. But it is an important skill, and so I'm glad we talked about it. And you have a resource that we'll put in the show notes for this as well to tell.

Dr. Melissa Olive I want to say, you have to be careful with some medications because they may be time release, which means they need to go down the stomach hole or they might have an intimate coating which changes the way the doses administered. And so you really have to be careful about what you're doing with what medicine. So, you know. You should always consult with the physician, right?

Mary Barbera

Right. A lot of pills can't be crushed and or need to be given in a certain time or with food or without food. And it's all really important. And so throwing things willy nilly into cups of juice and stuff is just not a great idea. OK. Let me ask you one more question before we move on. Some kids early on in early childhood, whether they have autism or signs of autism, they tend to chew on things like chew on non-edible things like chew on pencils, chew on their shirt. Is that related to these gut issues and what can we do about that?

Dr. Melissa Olive

So, you know, I don't know of the literature around that and what makes there an underlying medical condition that makes you want to have something in your mouth often. But I do know if you look at our hand mouthing literature, we've been able to show that hand mouthing has different functions for different people. So it should totally be an individualized approach. Looking at are we stimulating the fingers? Are we stimulating the mouth? How are we stimulating the tongue? Or is it about the olfactory that comes from having those hands in the mouth all the time?

Dr. Melissa Olive

And so when we think about wired kids chewing on their shirt collars or why they constantly having something in their mouth, I think we have to look further at one: Is there a dental problem that could be contributing to that? We know that PICA is greatly influenced by deficiencies. And so you want to make sure that these kids don't have some underlying deficiency of either seeing or some other supplement. And then kind of get into the functional piece, is there a tongue issue? Is this about the smell that may be coming off of their wet shirt? You know, so we can't just go and assume it's self-stimulating. We have to look at what element might be underplayed there.

Mary Barbera

Yeah, I do have some experience with chewing; Lucas was a big chewer early on and several of my clients also, and I do have a video blog on supplements. And one of the big thing when you said zinc is, is a lot of kids with autism their zinc to copper ratio is messed up. And so they need to avoid a lot of multivitamins that have copper. And so you want to make sure your multivitamins are anything you're giving as copper free. And then for kids, and especially for chewers, I have found again, I don't really have a reference to throw at you, but I have found that kids with low zinc levels do tend to chew. So that's not like a common, you go to the doctor and they check zinc and a copper level and do the zinc to copper ratio, but in more times than not, I have found that the chewing could be related. And Lucas has been on zinc since he's been three.

Dr. Melissa Olive So here we are, right? We're recording in the middle of a Corona crisis. Zinc is actually a really good natural antibiotic, and so to take zinc to improve your immune system is certainly one thing. We've had three kids referred to our feeding clinic who the doctor simultaneously put them on zinc. And so we did follow-up calls with family, like we need your paperwork so we can get you in. And they're like, oh, we started zinc and we don't have a feeding problem anymore. Zinc deficient, the way that food smells, the way that food taste is different. And so it will impact your feeding, but then it might also impact your chewing. And so one hundred percent look at zinc.

Dr. Melissa Olive I had a nutritionist teach me that again, a medical professional can test for zinc deficiency fairly quickly by taking liquid zinc and asking the child to take a sip. Liquid zinc looks like water. And so if they drink it and think its water, they're zinc deficient. Whereas if they drink it and they make a face, because zinc really tastes bad, then it has a sort of an iron or metallic flavor to it. And so if you drink zinc and your zinc levels are OK, then you can taste it and you reject it. Again, do not try this at home. This is for medical professionals to do.

Mary Barbera And everything we're talking about, you know, this is not medical or behavioral advice, especially when we're talking about medical issues. And that's one of the dangers of the Internet is parent sharing. Oh, well, my son took X, Y and Z. 50 milligrams, and it worked and it helped his chewing or whatever. It helped his whatever. And then you literally have parents who are desperate comparing notes. And meanwhile, that child's 30 pounds. My son's 230 pounds. And so, I mean, it's not funny. I'm laughing, but it's serious.

Mary Barbera Do you have any research studies on zinc and its relation to feeding?

Dr. Melissa Olive I'm going to look that up.

Mary Barbera OK. If we can find something, that would be awesome. OK. So just to kind of wrap up here before we go on to our very last question. So what advice do you

have for parents and professionals regarding communicating, working with a child's health care provider or their doctor or the nurse practitioner, their nutritionist? What advice do you have for us parents and ABA professionals to work with the health provider to assess and treat gut issues and picky eating and all these issues that we've talked about today?

Dr. Melissa Olive So the first thing I would say to parents is do not settle on a medical professional that doesn't listen to you. There are plenty more medical professionals to choose from... Well, unless you're in a very, very rural area. But align yourself with one that actually listens. We have the best primary care right now for my brother and his depth of trying to understand Mack and all of his complexities, he just he will not leave a page unturned. And so don't settle for your medical professional. For BCBA's who are practicing, and parents, you should demand that your BCBA's do this with you, you can't work in a silo. You have to be able to reach across to those other care providers and make sure that you're thinking about the whole picture because we're talking about a whole child. And so thank God for what Lori Unumb has done with helping get all 50 states passed legislation to cover ABA for kids of autism. By making ABA a medical treatment we're now treated like a medical professional, and when we have our concur abuse, they're asking for specifics or required coordination of care. And so what we've done in our practice and hopefully others will do this as well, we get Hippa consent from the family physician or the GI or whoever else is involved, so that each of the six months when we're sending our update, we send it to them so that they have a better understanding of all the data that we're taking in, all the interventions that we're working and how effective ABA is.

Dr. Melissa Olive And then they should use us and collaborate with us if there needs to be a medication change. Sometimes, you know, they want to make a medication change and not tell people. And we help them see that the BCBA can keep a secret. And we just won't tell the RBTs and the BTs who work working directly with the child. And then they will let us know if there's a change. We'll track it with our data and we'll be able to put that line in and show the doctor exactly what's working and what's not working. So we have an ethical duty to collaborate with all the care providers so that we have a truly well-balanced treatment plan.

Mary Barbera Yeah, I think that's excellent. OK. So my very last question, part of my podcast goals is for parents and professionals listening to be less stressed and lead

happier lives. So do you have any self-care tips or things that help you reduce your stress?

Dr. Melissa Olive We're under a unique time period today. Hopefully we'll be out of it by the time this podcast airs. But, you know, some of the things that we know work are making sure that you eat properly. It is so easy right now to turn to the crunchy food, to turn to the processed food. But we know that that puts your gut in an off kilter, which is going to impact your brain. You also need to make sure you sleep. I woke up... We have to sleep with the monitor because Mack has seizures. And so something woke him up, and then that woke me up. And then I couldn't go back to sleep because I started thinking about all the things that need to happen for him. So eating well, sleeping well, movement.

Dr. Melissa Olive I'm a huge exerciser. I always have been, and different people are only going to be able to tolerate different levels of working out, but trying to at least give it a daily walk or some type of physical movement. I think fresh air is better than basement air. And that's where I've been relegated to working out as my basic basement. But we've been taking family walks and family hikes to get that fresh air in. I don't know if you saw, but wine sales are up a staggering amount since the Covid. And I sometimes feel that I'm responsible for 100 percent of that growth because I started turning to the glass of wine every night when I had done so well about only drinking on the weekends. And so you want to hydrate properly and try not to turn to alcohol or other things to control that mood.

Dr. Melissa Olive And also just taking that moment to meditate and think positive thoughts, because no matter how tough your medical struggles are, no matter how tough the behavioral struggles are, you will get through it with your perseverance. And you need to have your mind and body in a good place to enable you to go down that difficult journey. So this is a few of the things that we know from other research really are helpful.

Mary Barbera I think that's great advice. We are at the time of this recording in lockdown mode and social distancing mode. So our stress levels have definitely increased, and our kids and our clients stress levels have also increased. I was on a live Q&A yesterday and somebody said my you know, my clients who can talk are really upset because we can't give them a date. A date when this is all going to end.

Like, I'm right with you. I want to date. I want to know how this is all going to turn out. And we just have to keep going, put one foot in front the other and just try to stay as least stressed as possible. But I really enjoyed this interview. I'm happy that I reached out to you. Happy to get to know you better. I feel like we are on the same page with so many things, so I would love to keep in touch and maybe have you on again. Talk about a whole other topic, but I really appreciate your ideas about gut issues, feeding problems, pill swallowing, chewing and those comorbid conditions. It's great to have a sibling on, too. I'm hoping to do a sibling show soon because I really do think that siblings of kids with autism and other disabilities are a special bunch of people. And I appreciate you both as a sibling, as a behavior analyst and as an advocate for our kids. So thank you for all of your service to our field. And it's great to get to know you better.

Dr. Melissa Olive

It's been great to get to know you, too. Thank you again for having me.

If you're a parent or an autism professional and enjoy listening to this podcast, you have to come check out my online course and community where we take all of this material and we apply it. You'll learn life-changing strategies to get your child or clients to reach their fullest potential. Join me for a free online workshop at MaryBarbera.com/workshop, where you can learn how to avoid common mistakes. You can see videos of me working with kids with and without autism. And you can learn more about joining my online course and community at a very special discount. Once again, go to MaryBarbera.com/workshop for all the details. I hope to see you there.