

Seizing Life, episode 125
An Extraordinary Life of Autism, Epilepsy, and Advocacy
Guest: Barbara D'Amora
(Transcript)

Kelly Cervantes: Hi I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Today, I'm happy to welcome Barbara D'Amora to the podcast. Barbara is here to talk about her son Nicholas, who lived with autism. Nick was non-speaking for the first 12 years of his life until a program called RPM gave him a way to communicate with the world and set him on a path of advocacy for the autism community. Tragically, Nicholas passed away from a seizure in May of 2023, but Barbara continues Nick's legacy through organizations and activities aimed at improving the lives of those with autism and changing the perceptions of the public around autism spectrum disorder. Barbara, thank you so much for joining us today. To kick things off, why don't you tell us a little bit about Nicholas as a person.

Barbara D'Amora: Thank you for having me Kelly. Nicholas is my favorite subject to talk about. He was my 25-year-old son and he was intelligent beyond measure that we didn't even know about. He loved music and he loved to cook. He wanted to be a chef. He loved to dance. He was very, very social, a bit of an empath. He was very loving and introspective and quite well aware of his sense of purpose. We talked about that a lot and he kind of knew he was a teacher. He knew why he was here: to help change minds and perceptions of the autistic.

Kelly Cervantes: That's amazing. Can you tell us a little bit about your journey to get an autism diagnosis for Nicholas?

Barbara D'Amora: I am a special education teacher, full disclosure. So although I never worked with the autistic population at the time he was born, mostly the learning disabled, I kind of started to have a feeling in my mommy gut of a stomach that things might be amiss around 15 months old, he wasn't reaching certain milestones, kind of seemed very in his own world as they say, as much as I hate that term. I got a formal diagnosis at 17 months old when I took him to a neurologist, they gave me a diagnosis of PDD-NOS, which is pervasive developmental disorder, not otherwise specified. It was kind of an umbrella diagnosis they were giving 25 years ago.

The neurologist told me to stay off the internet and just handed me a bunch of papers and scripts and said, "Get this service, get this service, get this service." But for those that don't know me, I jumped right on the internet and started doing my own research and everything kind of pointed to autism. So it was very like a punch in the stomach. It was quite emotional. I remember that evening, my husband and I crying over his crib looking at him as he was sleeping, almost like mourning what we thought was going to be, having to regroup about maybe the possibility of what was going to be. He started a full-time job, Nicholas, 20 hours a week of ABA, 5 hours a week of speech, 5 hours a week of occupational therapy and that continued until high school.

Kelly Cervantes: When you received the autism diagnosis, did anyone mention the common comorbidity with epilepsy and seizures?

Barbara D'Amora: Not at that time, not when he was a baby, no. It was never brought to my attention. It's not even something I came across in literature because I did so much research. I didn't find it, not 25 years ago, no.

Kelly Cervantes: And when was Nicholas ultimately diagnosed with epilepsy? When did he have his first seizure?

Barbara D'Amora: His first seizure was around puberty. It was what used to be called a grand mal seizure. It was a drop seizure. Now they call it tonic-clonic. We didn't know what was happening. It was so frightening and we took him to the hospital and that embarked us. The word epilepsy was never used, I have to be honest with you. How weird was that in the hospital? Was very much downplayed. They said, "You have to see a neurologist." We did that and we went into a video EEG study to study to see if he was having any other seizures and he wasn't.

So he was put on a medication and we were kind of sent on our way and his seizures were managed for years. He kind of would have one to two a year often when we were on a vacation as oddly as that sounds. I don't know if the anxiety, the lack of routine, I don't know what to make of that. But that's what happened to us, and I never dove into epilepsy the way I dove into autism. It wasn't something that ever smacked us in the face. It was rare. One to two a year.

Kelly Cervantes: I think we often cling to or dive deeper into the diagnoses that affect our daily life the most. I often hear this when the autism diagnosis comes first and then the epilepsy diagnosis because the autism piece is so impactful on daily life that the epilepsy doesn't register as much. And to a certain extent sometimes perhaps it doesn't need to. So you said his seizures were not controlled but they were managed with anti-seizure medications. Did you try any other treatments for him?

Barbara D'Amora: Not at that time. If he had a breakthrough seizure we switched a medication. That's basically how the treatment protocol went. We'd go back to the neurologist. They were never alarmed at one seizure like okay, he had another one. It was a year ago. It was never, like I said, I never had this pressing feeling like, oh boy, we really need to get ahold of this or we need to do something until 2020 came and Nicholas suffered nine seizures in one year.

Kelly Cervantes: Oh wow.

Barbara D'Amora: Yeah.

Kelly Cervantes: And what was the response to that, to this increase in seizures? How did you cope and treat that?

Barbara D'Amora: Well I wasn't sure what caused it, I wish I knew but I don't, and how I coped with that was we went back to NYU Langone, New York Epilepsy Center, which is a world renowned center. We were under the care of Dr. Devinsky and his team. Different approaches were discussed. Of course they wanted to chase yet more medicine. They knew I was very conservative when it came to meds because Nick was able to communicate that the meds didn't make him feel so great. So I really didn't want to keep piling on one medicine after another.

So I kind of started searching for some alternative methods and that's how I found a great doctor, Dr. Carly Bell over at Veriheal who was a cannabinoid MD doctor, who was studying all the terpenes in the different medical marijuana to deal with some of the comorbid conditions. Nick did have some OCD, I don't know if that was increased by the seizure meds, but it seemed to exacerbate when he was on those meds. His mood sometimes could be on and off. And so I went down the more natural road of the cannabis and he took an oil tincture under the tongue, a gummy at night to help him sleep and relax and it worked. He was seizure-free from August until he passed in May of 2023.

Kelly Cervantes: I am so incredibly sorry for Nick's loss.

Barbara D'Amora: Thanks.

Kelly Cervantes: Epilepsy is so cruel and it's really frustrating and unfair and just my heart breaks with yours.

Barbara D'Amora: Thank you Kelly. Thank you.

Kelly Cervantes: Now Nick was nonverbal, which doesn't necessarily equate to non-communicative, which has been a common misunderstanding in the past. Can you share with us how you discovered that Nick was able to communicate?

Barbara D'Amora: Sure. It's funny you just said non-verbal is not the same as non-communicative. Nick's mantra in life became non-speaking does not equal non-thinking, and that is something he wanted the world to know and I certainly want the world to know that too. Around 2012 I went to see a seminar of a very nice woman, Chantal Sicile-Kira. She had written a book on puberty. I was always ahead of the game, so Nick wasn't even in puberty, just maybe embarking in another year and I went to see her seminar and she introduced her son Jeremy and he came up to the podium. I did not think for one moment he was going to be able to say anything because I saw him, how he was acting, very disconnected and almost appeared how most people would perceive not with us.

And he started spelling on a tablet and said, "My name is Jeremy I'm 21, I have autism." And I was blown away and she told me it was rapid prompting method and that Jeremy had seen Soma, I can't really pronounce her [inaudible 00:10:45], it's a lot of consonants in Los Angeles. And Chantal told me to go online. She told me she had moved to Austin, Texas, see if I could look it up. And

I did. And that night, I had booked a trip, me and Nick were off to Texas. And we went to see Soma the week before Thanksgiving and his life changed dramatically, the whole course of his autism changed dramatically, his world changed. It's like he was set free.

Brandon: Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: I would love for you to explain what the rapid prompting method is and how that works.

Barbara D'Amora: Sure. So rapid prompting is it's like a teach, tell, and ask paradigm. Something is presented to them through listening, auditory, something's read to them or told to them. And then immediately they're asked to answer a question based on something they just heard. And it's a hierarchy of learning because it starts with the concrete, something they just heard. And I'll give you something very simple. The boy lived in the blue house on the hill. And we would say what color was the house that the boy lived in on the hill? And then it starts out very basic, giving them a choice between a torn paper choice, blue and red, and they would hopefully pick blue. And then, okay, can you spell blue? And then they're given a stencil with letter board broken up and into sections. We never just start with 26 letters, would be too overwhelming. And then we would help them prompt them, that's where the word rapid prompting method comes in. Prompt them to spell the word blue if they couldn't by teaching them to point.

And sometimes it's really like a motor planning issue. This needs to be taught. We can't assume every kid can point. So it's a hierarchy of learning and it goes from the concrete questions that they just hear and it goes all along to open communication where they're expressing their thoughts and feelings. But that does not come right away. That comes through lots of back and forth practice.

Kelly Cervantes: So it is a process. This is certainly not something that happens overnight. How long did the process take from going and receiving the training to Nicholas being able to do open-ended communication?

Barbara D'Amora: Well Nicholas was able to spell right with Soma in Texas and it was just life-changing. He answered questions like she asked him, "Do you know what a marathon is?" And he said "Running for a cause." And then he read her a very depressing story about a man in prison in a quarry in the thee thou though ages of the Middle Ages and Nicholas said "It's better to have autism than to be in prison." And those were open-ended answers. Again, he was 12, he wasn't like 5. So we were just shocked, where did he learn to spell? How did he get this language? And then I thought he was going to be able to do that for me and everyone else that was working with him.

So I came home and I told the world and I told every teacher and therapist that he had and I wanted everyone to do it and Nick just shut down because really and truly, I didn't realize you need to master this with one person, almost like a dance partner before you can teach someone else to do that same dance with them. So it was a process. It took me almost two years to get Nicholas out there fluent. A lot of people didn't believe us, they didn't think it was his words. The teachers that were working with him thought I was crazy, I was on them. "Please stay with it, please let's keep going, please, please, please." And it finally happened and he broke through with one very special teacher, Suzanne Canella. And then from there she turnkey and he went to having proficiency on the letter board with a dozen people.

But a lot happened in between those two years. It was a lot of fighting, Kelly. I had to convince the powers that be who were testing him with standardized tests where he would score between one and four percentile, which was like his IEP was like for a baby, matching things and sorting colors. I had to convince him to please test him with the letter board, let him answer the questions and they said, "Oh we can't do that because then it's not standardized." So I begged them, "Okay then report your standardized way but also report in there that you did this another way." When they did it through with the letter board, Nick came out in the above average intelligence range. The examiner was crying, she was apologizing to me. She said, "I have never seen anything like this. I don't even know how to report this. I'm going to have to word this" because she did have to say that he bombed on the standardized way which was talking to him, but he was non-speaking so he certainly couldn't answer those questions. And then she reported that he did it this way.

That was the floodgates that opened for Nicholas because his IEP changed. It was no longer matching and sorting. It became meaningful. He was doing high school level math without paper. He was able to do algebra and his head, he learned about history and was reading college level material. He was the happiest I had ever seen him because he felt like, wow, they found me. I'm free.

Kelly Cervantes: It is so exciting to hear and that must have just been such an incredible experience for you and for the whole family.

Barbara D'Amora: My family, our family got to know Nick in a way, it was such a gift because we would've never been able to know his true feelings, his thoughts, his opinions, that he was funny and had a sense of humor. And the thing I hold the dearest to me now that he's not here was how appreciative he was of us. He knew how hard. He said, "Mom, we're a team. You work so hard for me. You're giving me such a good life." I can't even tell you what those words mean to me today because I probably would've never heard them had he never been able to communicate. But I knew how much he loved us and he knew how much we were advocating for him and he had a very good life, very happy life.

Kelly Cervantes: I mean, Nick is so incredible. He didn't just stop with being able to communicate personally. This was something that he became an advocate for to bring this

communication to other individuals who were nonverbal. Tell us about the seminars that he used to attend and teach and the impact that he left on his community.

Barbara D'Amora: I don't know if you can see my tattoo. It says Nick the Changer, and he got this nickname and I wear a bracelet too that says Nick the Changer. He got that nickname because while he was out speaking in those engagements and seminars, he literally changed perceptions, he changed minds, he changed hearts. He gave hope to so many because I remember parents sitting in that audience crying thinking, can this be my child? Can my child do this? A lot of them didn't think, they said, "Oh no, Nick has something special. Nick is cognitively with us." And I said, "No, no, no. Nick presented the same way as your child. Nick looked like he wasn't with us for many, many years, but he was listening, he was learning." So I tell parents, "Don't think your child can't do this."

So Nick did live Q&A when he would do these seminars with me and he answered questions to parents. They were just amazed. And if I had a penny for every time someone said to me, "I will never look at an autistic kid the same way again after meeting Nick," I would be so rich because that's all everyone said after they met him. They were so encouraged and he was so honest. He told them what it felt like to be autistic. He even gave them insight too sometimes. They would ask, "Why is my child doing this or that?" He would tell them, "Your child is frustrated or your child is being aggressive because they have no way to communicate." I mean he just was so, like I said, introspective and he and I talked a lot. There was times where he didn't want to do the seminar sometimes. He said, "Mom, I'm tired of doing these seminars if there's no action." He wanted people to take action like, "Please let's bring this to the masses." He didn't want to just talk about it. He wanted action.

Kelly Cervantes: I watched a video that showed Nick communicating and so it is when you talk about the letter board, that is what it is. It is a white sheet that has the alphabet written on it and then he is pointing to each letter or number and spelling out as he goes along to say what he is looking to say. Is that correct? Is that how that works?

Barbara D'Amora: Well it starts out very low tech with the stencils in sections and then you move to a 26 letter letter board, it's laminated, and then you can move on to a keyboard or an iPad or a phone. It's a hierarchy. We prompt them in the beginning with verbal prompts. "Get that letter up there right in the corner, you got it, go for it." Right next door, we'll prompt them to get it down pat but we're not touching them or anything like that. But it is up and coming and spelling to communicate and IASC which is an organization that we model and work from is global now.

Kelly Cervantes: Tell us about IASC and what that stands for and what that organization does.

Barbara D'Amora: Right. IASC stands for the International Association for Spelling to Communicate and it is a global organization of individuals from the non-speaking and neurodivergent communities and they seek to make spelling accessible to all speakers, unreliable speakers and non-speakers. And they have many practitioners all over the world now. Elizabeth Vossler, who is the head of that, goes all over and does these outreaches and she's been to countries and cities all over the world and practitioners come out of the program and that's one of the reasons IASC was born because we needed people to learn this, to bring it to the community. One person can't do it all.

So we needed all these practitioners to be trained and come out there and spread the word. And Nick was an ambassador for everyone, including all the other spellers that there are out there. There are many prominent spellers who are also ambassadors. Nick certainly wasn't the only one. I don't know if you or your listeners have seen things in the news, it's been on the news where valedictorians from colleges like Elizabeth Bonker have been chosen and they are non-speakers. They typed their valedictorian speech.

Kelly Cervantes: That's incredible. I mean sort of to your point, it shouldn't be. It should just be understood as another form of communication. And it's not incredible, it is not a earth-shattering because they're people with thoughts and there's no reason to think otherwise. It's just a disability like any other.

Barbara D'Amora: Right. Well, one thing I want to stress is it's not as simple as just putting a letter board onto someone. There is a whole hierarchy and protocol and one piece that we have not addressed that's really important that almost every single speller addresses is that they are trapped in very tricky bodies that don't cooperate with their minds. So that becomes a very big motor and sensory challenge of how the world is coming at them, how they perceive the world and how they act out towards that world. So many of our non-speakers who appeared not to be with us are channeling, trying so hard to control that unreliable body, the body that's not in sync with their minds. So they appear behavioral, they appear to be stimming and moving and have uncontrolled issues. Those are the poor kids that fall through the cracks that get put in the classes with the lowest expectations.

Parents, I tell them all the time when we speak, "You can't keep the bar low because that's where they're going to meet you. You need to raise that bar and they'll meet you there. You have to presume competence. You have to treat them with dignity and respect and talk to them like nothing was wrong with them." They are in their listening, they are learning. It's an output problem, not an input problem. So It's really, really important to understand that there's a big component to help regulate those bodies before they can spell. It's not like you can spell and then we're going to deal with your behavior or your sensory issues or your motor challenges. No, we work with the body simultaneously while we're teaching the spelling.

Kelly Cervantes: That's a very important distinction that there is all of these other aspects that are at play that are compounding the ability to communicate. Barbara, you mentioned Nick being able to tell others, other parents what was going on with their child or what they were experiencing or why they were doing something. What did Nicholas say about living with autism?

Barbara D'Amora: Well, if you wouldn't mind, I'm going to read his words right from this book because he wrote a chapter in a book called Leaders Around Me: Autobiographies of Autistics Who Type, Point, and Spell to Communicate. And Dr. Edlyn Peña from Cal State Lutheran chose Nicholas as one of the authors and he was so floored and honored to be calling himself an author. So this is something else I have to always treasure, but I will read this for you what he said. It said, "Soma opened my world and gave me the key to unlock every challenging door I was facing. I learned to communicate the most freeing obstacle in my life. Since that time, I've been practicing my spelling and teaching my body to cooperate, which has been a difficult struggle. I now had a voice and a way to reach the world. When I was little, I knew I was different. My first recollection was when I joined a typical preschool, I could see that the other kids had more control over their bodies and everything seemed so easy for them.

I knew at that point I was going to have to fight hard in order to keep up and fit in. Having autism is a minute by minute challenge and people don't realize that my body can be a total disorganized mess. My impulsive movements, stims, and complete lack of control at times can be exhausting. There are times though that I feel autism is a gift and I see it as my way in which to advocate for myself and others like me. Ever since I've learned to communicate, I've been wanting to find many ways to tell my story and spread awareness about how autism works. There were moments when I wanted to give up and stay hidden and run away, but I had so many people encouraging me and supporting me. I knew it was time to start helping others at that point.

I had to put my fears aside and start living for myself. If I wanted to grow more independent, I needed to face the world and tell my story. I've done numerous speeches, conferences and seminars. I've spoken to schools, committees, agencies, colleges, and even doctors. Surprisingly, they all listened and accepted what I was saying. For the first time, large amounts of people were finally listening to me and I was amazed. This gave me the courage and determination to keep going."

Kelly Cervantes: Wow. To hear that he recognized in preschool that he was different is heartbreaking.

Barbara D'Amora: It breaks my heart too because he was in what we call here, a six-to-one-to-one program, which was the class for the most challenging, many times for the behaviorally challenged because they were considered the lower functioning of the bunch. And he always got pulled in there because he didn't speak and he bombed on all those tests and that's where he was placed. But in spite of all

that, he had incredible teachers and I as his mother was that parent that probably everyone wanted to run from at first. I would be rewriting his IEP and making sure what he did not get in school, he got it home after school, and he was able to have a very full life and for that I'm so thankful.

Kelly Cervantes: Now I know that you co-founded CrimsonRise together with Nick. Tell us about that organization.

Barbara D'Amora: Well, first was the GRACE Foundation when Nick was really small. The GRACE Foundation is an acronym for Getting Resources for Autistic Children's Equality. It's no longer just children. We've evolved now and we also serve adults, but it was founded in 2000. It now serves hundreds of kids. Myself and others founded, other parents founded it because we just felt we needed more services than what was out there. So we have respite programs, day programs of events and we're committed to supporting and educating and enhancing and empowering the quality of life for children and families that are dealing with ASD. So GRACE came first and then after years of flourishing, Nick started to spell and we started to put our gears in motion for adult life and what was going to happen in the future.

And my son and three other non-speakers, [inaudible 00:30:44], Chris and Will started CrimsonRise, which is an organization founded, the first one ever founded by non-speakers with sensory impairments, movement and communication differences. That's important. And we are committed to providing communication access and regulation support so that they can enjoy everything that everyone else enjoys. We really want them to have a quality of life and have all the things come to them that they could never participate in because let's face it, they were the most marginalized of the autistic population, the non-speaking. And opportunities don't always come their way because they can't communicate. So we wanted to make sure that together with their allies, that we could create and sustain inclusive, enriching opportunities for their life.

Kelly Cervantes: It is such an impressive legacy that Nick has left. How do you want him to be remembered?

Barbara D'Amora: I want Nick to be remembered as a pioneer, an advocate, someone who broke through and wanted to make a difference in this world for others. He didn't just keep it for himself. Like you said, he really, really was about helping others. So I want people to remember him as the Changer because that's who he was. He changed minds, hearts, perceptions, and I want him to be remembered forever.

Kelly Cervantes: We will remember him. Thank you so, so very much. This has been an incredible conversation and I hope opens the eyes and ears for people better understanding those that are nonverbal.

Barbara D'Amora: Thank you, Kelly. Be well.

Kelly Cervantes: Thank you, Barbara, for sharing the amazing and inspirational journey of your son, Nicholas. We wish you all the best as you carry on Nick's legacy and continue to improve the lives of those touched by autism spectrum disorder. Mothers like Barbara are often on the front lines advocating for their children with health challenges and disabilities. 25 years ago, CURE Epilepsy was founded by a group of mothers who could no longer accept the status quo of epilepsy care. In that time, CURE Epilepsy has raised more than \$90 million to fund epilepsy research and other initiatives that will lead the way to a cure for epilepsy. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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