

# 119 | Clinical Case 16 (Pediatrics, Extremely Low Birth Weight) - with Dr. Sakina Butt

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**Speakers:** Sakina Butt, Ryan Van Patten, John Bellone



**Intro Music** 00:00



**Ryan Van Patten** 00:17

Welcome, everyone to Navigating Neuropsychology, a voyage into the depths of the brain and behavior. Brought to you by INS. I'm Ryan Van Patten.



**John Bellone** 00:24

And I'm John Bellone, and we are board certified neuropsychologists. Today we give you a pediatric clinical case with Dr. Sakina Butt. Sakina is a neuro psychologist and the neuropsych postdoctoral fellowship training director

at Johns Hopkins All Children's Hospital. She is board certified in clinical neuropsychology and in the pediatric subspecialty.



**Ryan Van Patten** 00:46

Sakina sees very young children including preschoolers and toddlers, for neuropsych evaluations. Today's conversation is centered around a four-year-old girl, and we will have several future episodes on even younger children. John and I find this idea of neuropsychology in littles to be fascinating and really important. We hope you enjoy the discussion as much as we did. And with that, we give you our conversation with Dr. Sakina Butt.



**Transition Music** 01:12



**Ryan Van Patten**

I have so much to learn from you because I know nothing about neuropsychology of two-year-olds.



**John Bellone** 01:30

We're both adult and geriatric neuropsychologists.



**Ryan Van Patten** 01:33

Yeah, this will be a whole new world for NavNeuro.



**Sakina Butt** 01:36

Hopefully it doesn't scare you off, in terms of...



**John Bellone** 01:42

All right, Dr. Sakina Butt, welcome to NavNeuro. We're really excited to have you on the show.



**Sakina Butt** 01:46

Thanks so much for having me, and I'm excited to be here.



**John Bellone** 01:49

So, why don't you launch us into your first case that you wanted to cover today.



**Sakina Butt** 01:55

So this is an interesting case that I chose because the outcome is not typically what you would expect. It's a four-year-old female who I've seen before. So I've been able to monitor this child's development over time. The child had a history of extreme prematurity and neonatal intraventricular hemorrhage. And I have been able to see the child starting in 2019, and have followed all the way up to this year. I really think this case is rich in terms of how early the child was born. Child was born at 23 weeks gestation. And for those of us who work with children and understand how early that is, the typical term baby, just to give people who don't know, context would be around 40 weeks. So that's pretty much like halfway through your pregnancy. And at no point does any mom want to hear that they're about to deliver a baby, let alone actually have it happen at 23 weeks.



**John Bellone** 03:04

Sakina, can I jump in? We spent some time in the NICU when my daughter was born, and I was asking the nurses all kinds of questions. They said that what kind of the edge of viability was from their perspective, about 23 weeks, 24 weeks. Is your understanding too?



**Sakina Butt** 03:21

Yes, absolutely. It wasn't that way before in the past, but it is now. And because of medical advances that we've had, we are able to have our infants be pretty viable at 24 and 23 weeks. That's not always the case, but we do have mixed long-term findings.



**John Bellone** 03:43

Gotcha. Sorry to derail you.



**Sakina Butt** 03:44

Yeah, well, and that brings me to kind of what I was going to say in the sense of, you know, because children who are born that early, there's always the assumption that there's going to be challenges long term. So that only challenges right after birth and in the postnatal period, which is why there's an extensive NICU or Neonatal Intensive Care Unit stay where you're managing all life systems, respiratory, pulmonary functions, feeding, growth, and heart as well as intestinal complications. You can have eye complications, hearing complications. So it can be a lot because the infant is just trying to grow and still develop those systems outside of the womb, which is not necessarily what we would typically expect or want. So they're not able to develop those systems in a protective environment like they normally would. But that doesn't necessarily mean that all babies who are born at 23 or 24 weeks gestation end up with severe complications. And I think being able to see multiple children who have this history, the question becomes, why is it that some do well, and then some don't?



**Ryan Van Patten** 05:03

Can you talk a little bit about long-term outcomes, I don't want to jump the gun, but just thinking about what we know right now for an infant child born so early. I don't even know if we have enough data, if we've had the medical advances that allow a 23 week old infant to survive, if that's been long enough for us to follow people who were born that early for their entire lives and to know their IQ, their health history, you know, heart disease, all those sorts of things, what, long term, what types of things do you think about?



**Sakina Butt** 05:40

So we do have longitudinal monitoring data, where we've been able to follow children through... a lot of the programs and studies will follow to two years of age, some will follow to four others to five. There are a handful of studies that are looking at kids in school age, so eight to 10. And so we do have some data, and it shows a range of intellectual functioning cognitive abilities, a range of challenges. So in terms of outcomes, I think it's probably best to think about it in what are the more immediate outcomes or immediate impacts in the developmental periods of infancy and toddlerhood. And then what could be some of these long-term later effects in school age or typical childhood as we like to think about it?



**Ryan Van Patten** 06:34

Right? Yeah, and we'll ask you a little bit more about the four-year-old in a few minutes. You mentioned intraventricular, hemorrhage, for which premature infants are at risk. Usually happens in the germinal matrix, that highly vascularized area in the developing brain. Talk about the relationship between prematurity or low birth weight and IVH.



**Sakina Butt** 06:55

So, there has been links to not only gestational age, so how early you're born, but also your birth weight. Sometimes babies are born at a, what we would say viable gestational age, but they may have had problems with their growth in utero. And so they may be born at a later period, 33 weeks, but if they haven't had the same rate of growth, they are just as much at risk for intraventricular hemorrhage, just like someone who's born at 23 weeks. And so what happens is that area in the brain is immature, and it's not able to do the regulation. And so it's very susceptible to bleeds. And majority of the time, you can see an increased fold of not only neonatal intraventricular hemorrhage, but also more severe, the lower the birth weight is. So children who are born 1000 grams or lower tend to be at an extreme risk for this occurrence. Whether it happened prenatally or while the child is still in the womb, right in the birth, or a postnatal period, or anytime in what we call the neonatal period while they're still in the NICU.



**John Bellone** 08:11

Is there anything we could do to prevent that problem or reduce the risks of IVH in, in an infant that's of that low birth weight,



**Sakina Butt** 08:18

Majority of what maternal fetal medicine does is try to prevent kids from being born that early in the first place. So that's kind of like the step one, if you will, is doing you know, any form of restricting a moms activity, medications, they're cerclage. They do a whole lot of things to help keep the baby inside the womb to increase the viability and chance and less chance for that. And once a baby is born, and you know they're coming early, having immediate supports for resuscitation, for stabilization. That can also help as a protective factor to prevent IVH. There are some prophylactic use of neuroprotective agents. And so there are some things that we can do. The main thing being maintaining blood pressure, maintaining heart rate, maintaining respiration. So, as we all know, those are the things where in a small child with a vulnerable and immature vascular system, any rapid changes or any problems with regulation, it's going to put more of a stress on that system, which means it's more likely to have a bleed.



**Ryan Van Patten** 09:32

Can you talk a little bit about neuroimaging and other assessment methods to detect IVH? Is it done regularly if the infant is born preterm at some level? How are we monitoring for IVH?



**Sakina Butt** 09:44

Yeah, the... it is done regularly. So typically, it's done within the first 10 to 14 days of life to screen for IVH, especially in children who are born preterm. There's likely to be subsequent screening for children, most likely, prior to discharge from the neonatal intensive care unit. The type of imaging is interesting because I think most of the time we would think MRI, and that's not necessarily what we're using. It's not necessarily what the American Academy of Pediatrics is recommending either. Cranial ultrasound is to go to. And so children will have an ultrasound, like I said, typically after birth. And then if there is a question of, or suspicion of, an IVH that might progress, they will have serial cranial ultrasounds at staged periods of time in between interventions, to make sure that that bleed is either stabilized, resolved and doesn't progress. And then typically, most neonates will have one before they're discharged.



**John Bellone** 10:55

I'd imagine the benefit of the ultrasound would be you can do it at the child's bed, right? Or their crib, rather than having to bring them to the the MRI machine. Right?



**Sakina Butt** 11:06

Yeah, and it's really helpful too to minimize the exposure to anesthesia with sedation for MRI, because if you think about MRI, you know, you're gonna have to sedate an infant. And I know I disagree and give a great presentation at INS about, we should be concerned about the amount of anesthesia we're exposing young brains to. And so I think all of those things, combined, feasibility, it gives us what we need. So the clinical utility of it, and also, the preventative nature and protective aspects of it is why the cranium ultrasound is the way to go. Now, I will say in some children, whether it be not just prematurity, but there could be a genetic anomaly or some other factor that's influencing that child's course postnatally, then an MRI may happen if there's a suspicion of a bleed or other damage in other areas of the brain. So like cerebellar injury, white matter outside of the area of the germinal matrix, then you can see a child have an MRI.



**John Bellone** 12:15

Yeah, that makes sense. And then how about, you know, we will definitely get back to your case at some point and talking about how the assessment and treatment went. But just in general, how does the assessment and treatment of these kinds of infants go in the management of IVH and the potential consequences?



**Sakina Butt** 12:34

In the NICU, it's a pretty long course. So if you were born pretty early, like 23 weeks, then you're staying in the NICU probably until around term, maybe a little bit longer, just depending on how well you're able to achieve adequate stabilization of all of their systems: making sure that they're feeding, making sure that they're breathing on their own, making sure that they have good function in terms of all the other bodily systems. And so a lot of the times it is a touch and go there can be ups and downs, and this is pretty dramatic to families.



**Ryan Van Patten** 13:14

Yeah, the brain is developing along with the rest of the body, of course, but with this early insult, having the IVH, which I imagine, we think of there's more plasticity early in life, which can help. There's a lot of organization happening in the brain. But having high plasticity as a young person does not, is not a shield from long term problems if you have a major brain injury. So we have your four year old girl with IVH, born 23 weeks early, tell us more about her, how she presented, and the course of your evaluation.



**Sakina Butt** 13:53

Yeah, and I mean, I think, before we get into her, thinking about plasticity in children, one of the things that I like to teach parents and also those that I train is if you bear with me with a football analogy here, but if you think of it as a, you're at one of the goalposts and you're looking down the length of a football field, and if the football field, the yard lines mark, kind of the age at which the child is and the football field is the expanse of development across the lifespan. And if you have a child who is standing at the 50-yard line, so halfway, let's say late adolescence, young adulthood, anything that's behind that individual has, in theory, already been developed, solidified, those are skills that have come online in terms of thinking about brain development. And

now what we have to consider is everything that is in front of us. And yes, that person still has half a football field to go which is still pretty significant. But at least there is a substantial amount of foundation To build on. And Ryan, like you said, when you talk about a young child, where this happened right at their beginning, so that young child is either at the goalpost, or even, I would say, behind the goalpost, and they're looking at the entire expanse of the football field. There's limits to plasticity, it's only going to go but so far. And then so now you have to, with your, whether it be your amazing run or pass game, you have to make it all the way down that field of development, with this atypical alteration in the way things are coming online, how they're being connected in the brain, how they're being developed. And that's a hard thing to make up and a hard thing to overcome, for some.



**Ryan Van Patten** 15:49

That's a great analogy. If I if I ever saw children, I might steal it and use it with patients. But I don't see that happening in my career. But thanks, thanks for sharing.



**Sakina Butt** 15:59

I find it helpful to use metaphors and analogies because it is hard because I think a lot of families are taught well, "you know, they're young, and they're plastic, and so it's going to be okay," not really understanding the limits or the considerations of plasticity and what we mean when we say, reorganization and plasticity. I mean, there's only so much that can be reorganized. And usually reorganization comes at a cost. And so it's not just like things just move around but everything still has equal amount of function and weight. It's usually the brain starts prioritizing.



**Ryan Van Patten** 16:34

Right.



**John Bellone** 16:35

That's a really difficult topic and one that's hard to kind of grasp, because you hear of kids getting hemispherectomies is where an entire hemisphere was removed. And then due to reorganization, plasticity, they are able to use both sides of their body and a lot of those abilities end up being developed to some degree. But you're right there so that we're balancing this this plasticity, which is an awesome power, but also the limits of what can be achieved, given just what happened. So yeah, I don't know how you how you hold both of those, when you talk to patien... to families about it. I'm assuming you, you talk about plasticity and hope, but also the constrictions to the process.



**Sakina Butt** 17:17

Right. And usually allowing them to understand almost the brain function in terms of a hierarchy needs adaptively. Right. So motor functioning, is it an adaptive need, that a lot of us feel like would be very high on the hierarchy of things that we use language, again, in some shape or form would be high on that priority list. Complex executive functioning skills? Maybe, maybe not, you know, and so explaining to families that some of these lower level basic abilities, that's what you're talking about when you're speaking of reorganizing. What is in your environment, in that child's life? What are they needing to use in order to survive? That's going to be reorganized. These more complex, nuanced higher level skills, that maybe we need to reason or we need to be able to think, you know, metaphorically, or, you know, think in terms of higher level conceptual ability, that's not necessarily going to reorganize to the same extent, and having parents understand that. So that's why when you're a younger child, which we'll get to with our case, you may not see a lot of these significant challenges right away, sometimes you will see some delays, there'll be early intervention, and then you won't really see any of the true long lasting issues until after they reach a certain age, and then the demands get higher, and then you start to see the imbalance between their ability and the demands. If that makes sense.



**Ryan Van Patten** 19:00

It does. You know, the cost that you mentioned earlier, the cost of reorganization often comes out and these higher level complex abilities that aren't so important in a two or three year old, but that come on board as children, people age, and therefore we see inefficiencies or problems as the child gets older.



**John Bellone** 19:20

I think we should finally let you get back to your case.



**Ryan Van Patten** 19:23

This is great. I could sit and sit and listen to Sakina teach all day long. So if you want to keep going in the plasticity topic, feel free, but whenever you want to go back to the four year old, that's fine, too.



**Sakina Butt** 19:35

Well, I'll come back to the four-year-old because we can explore those things as we talk about this individual. So some things to consider with this four year old is speaking about access to services. So not everyone is in an area that has a level four NICU with all of the bells and whistles in terms of access to higher level medical interventions and access to an organized Follow Up program. So fortunately, this patient did have access to all of that and was able to go through starting at immediately after discharge, and then followed up in a sequential periodicity that's very targeted to development and when we know challenges can happen. And so the NICU Follow Up program follows with medical providers at three months, at six months, at nine months, and so there's pretty consistent and close sequential following, even before they're one year of age. And that gives time to highlight any challenges that might be developing and get families hooked into early intervention supports. And fortunately, that's what happened with this little one. Able to start with early intervention and early steps,



get targeted therapies to promote all of the different areas of development. And so by the time that I saw this individual, at one year of age, already had all of that going for the whole first year of the life, which I love to see, because that's when you know, the system worked.



**Ryan Van Patten** 21:16

Right? What are those therapies looking like? Physical, speech, occupational, neurodevelopmental, all the above?



**Sakina Butt** 21:25

All the above. Might be some feeding therapy thrown in there, but definitely looking at physical therapy, because there can be a lot of motor challenges very early on, that can happen if you think about where the germinal matrix is and the vulnerability of the subcortical areas. And so if you think of your neuroanatomy, that development of those cortical spinal tracts, and those areas that are coordinating movement, are very much impacted. And so physical occupational therapy, at a very young age is really targeted to helping increase tone, improve that control of the body, improve the muscle strength, and then also improved coordination for things like sitting up, crawling, and walking. And then the speech and language therapy, a lot of the times in young children is targeted to feeding, there can be some swallowing issues. If you think coordination, to eat, even just to suck from a breast or suck from a bottle, you have to pace breathing and eating. And so you know, you think about it, like we do this all the time, hopefully well, but when we're thinking of our little infants, this is a hard task. I mean, when they were in the womb, then and have to do that. So now they come out abruptly. And then you know, they kind of look at you like, "What? You expect me to breathe and eat at the same time?" like you do it. And then we teach them how to do it, and hopefully, they can learn the pacing and the strategy of regulating their respiration while they're able to intake that support by mouth. But sometimes, that can be a difficult task in and of itself. And it takes a lot of feeding therapy to help stimulate that coordination, help parents with pacing. But it can also be that that intervention isn't enough. And sometimes we need to put in supports like a G-tube.



**John Bellone** 23:24

Yeah, and in utero, and even in a full-term baby, those sucking and swallowing skills don't even start developing till like mid-30 weeks into it. Right? So I can imagine even harder for a kid that was born at 23 weeks, 24 weeks to have to do that.



**Sakina Butt** 23:44

Right, they're having to learn all the things that they would have mastered while they were in the womb. They're gonna... they're having to learn them outside in a setting that is pretty chaotic, and not necessarily friendly in terms of tons of stimulation, not being able to be supported, not always being able to be held or comforted by caregivers. So not not the most ideal situation.



**John Bellone** 24:08

Right. And then on top of that all, you know, their organs are still developing. And this... the four-year-old that you assessed, she I know she was 23 weeks when she was born, but she was extremely low birth weight, right? I don't remember if you said how much she weighed. I think it was like a pound, a pound and a quarter.



**Sakina Butt** 24:27

Yep, she was.



**John Bellone** 24:28

So she's still very much... all of her organs are developing. And so yeah.



**Sakina Butt** 24:34

Yeah. And she really did kind of have the typical course in utero, not only beforehand, but also when she came out in the NICU with all the typical complications that you would expect, but seemed to do well once she was able to discharge home, which is a good sign. She seemed to progress pretty well. She still has nearsightedness and has prescription lenses from her retinopathy of prematurity, which means that immature retina before they're able to be born, and it can impact vision acuity later on. And she seems to be still a little picky about what she will allow herself to be open to in terms of food, different choices, but parents have worked with her with the benefit of therapies and have been able to not only get her to eat by mouth, but also get her to be able to eat a variety of foods as much as we would expect a young child of four to eat. So in that sense, it's a win.



**Ryan Van Patten** 25:43

Right. So what I've heard thus far is that she had a lot of challenges early on: born 23 weeks gestation, IVH, very low birth weight, but then was very resilient and had a lot of therapies to which she responded very well. So then you see her when she's four. Paint a picture for us as to strengths, weaknesses, where she was at developmentally relative to expectations, neuropsych testing, which I'm still wrapping my head around neuropsych testing with a three, four year old, two year old and what that's like, so yeah, enlighten us.



**Sakina Butt** 26:21

Well, so I'll start with what it looks like. Because it looks pretty much like what you're used to, in the sense of, yeah, they're little, but we're able to do all the things like greet them in the waiting area, explain what we're doing, build rapport, quickly get them to separate and take them to the testing area. They pretty much can sit at a table and you know, just like you would expect, examiner sits across from them, they're sitting down and you bring out your, you know, typical measures, I like to use the Differential Ability Scales, but things like the

Wechsler Preschool Scale of Intelligence, or Stanford Binay. So very similar to a WAIS, and you're looking at the same cognitive functions that we would in standard childhood, adolescence, and adulthood. So we're looking at verbal comprehension, verbal expression, attention, working memory, visual spatial functions, processing speed, and we're looking at basics of executive functioning. A lot of times at this age, this is impulse control regulation. So we're looking at it through that lens, not really looking at more eloquent executive functions, but it's developing and usually if you can start to develop the basics of inhibition and impulse control, that really does help with some of the later skills that come online, like organization and planning. And so when I saw her when she was four, she was pretty much average across the board. In terms of the testing using the differential ability skill. Her verbal composite was in the average range, her nonverbal reasoning composite was average, her spatial composite. So for those of us who do a lot of Wechsler scales, that's a mix of, like, a block design type of a task and they also have a copying task. So anyone who does any kind of visual motor testing, where you're presented with shapes, and then the individual has to copy them. So that's what they mean by that spatial composite. And also looked at some pre-academic skills like her early learning, and that was also within the average range, letting us know that she's picking up skills that we would expect her to learn. So she is doing really well. And I think if you saw this evaluation, the results, and you didn't know the history, like you just saw this as a four-year-old child, I don't think anyone would ever guess that this is a child who was born at 23 weeks gestation, who was less than two pounds. And that's what I love about this case, because I think it really is such a good illustration of when things work, and early intervention can be extremely powerful.



**John Bellone** 29:18

Yeah, this is incredible. Would you anticipate the potential for problems later on when some of the higher level skills come on board? Is that something you would be wanting to monitor? Keep an eye on?



**Sakina Butt** 29:31

Absolutely. And so the program typically monitors children. And when I say program, I mean the Neonatal Follow Up program will monitor development for children through age five, but for a child like this knowing the start they had to life, I typically will continue to follow them in the neuropsych clinic well after five. Want to get them settled in school because you're exactly right. We are assuming that there is a higher chance for more complex attention, a higher chance for some regulation issues later on, to develop. And so it could be that we're just in this nice sweet spot where she's keeping up with the demands, but the demands don't necessarily change in a nice incremental fashion either. Like as kids grow, sometimes demands will change a little bit between year to year and other times it's, it's like a mountain. And that child is expected to leap that mountain pretty effortlessly, without supports and like rope and, you know, rock climbing gear. And so I think for her, talking with a family about how, "Yes, she's doing great. I'm so glad we're seeing development on track. She's looking good. Okay, so now we're at four. Here's what we're going to be looking out for in the next year, then we'll reevaluate her at five, and we'll do the same thing. Here's what we're going to be looking out for in the future."



**John Bellone** 30:57

Excellent. Anything else you wanted to say about this case before we wrap up?



**Sakina Butt** 31:01

No, I think that was pretty much everything.



**John Bellone** 31:04

Awesome, thanks.



**Exit Music** 31:05



**John Bellone** 31:09

Well, that does it for our first conversation with Sakina. Be on the lookout for additional clinical cases with Sakina. We also have upcoming content related to neuropsychiatric symptoms in degenerative diseases, Parkinson's disease, cognition and addiction, chronic traumatic encephalopathy, and other topics. As always, thanks so much for listening and join us next time as we continue to navigate the brain and behavior. The Navigating Neuropsychology Podcasts and all the linked content is intended for general educational purposes only, and does not constitute the practice of psychology or any other professional health care advice and services.



**Ryan Van Patten** 32:10

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