

***About Health TV with Jeanne Blake***  
***Autism: Nancy Wiseman, Author, *Could it be Autism?****  
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JEANNE BLAKE: Welcome to About Health. I'm Jeanne Blake. It's estimated that one out of every 166 children has some form of autism. For any parent concerned about his or her child's social, emotional, behavioral, or communication development, this book, *Could it Be Autism?*, is a valuable guide. The author of this book shares what she learned through her personal journey with her daughter Sarah, who at age 2 was diagnosed with an autism spectrum disorder. Nancy Wiseman is also the founder and president of First Signs, an organization dedicated to educating parents, clinicians, and physicians on the early signs and interventions for developmental delays. Nancy, thanks for coming in to talk with us about this very long-term project that you've had. What were the first signs – you talk about red flags in your book – what were the red flags for you with Sarah?

NANCY WISEMAN: For me, and often with parents, it's the lack of first words coming in. In fact, a little bit earlier, somewhere between 6 and 10 months, it was the decline into babbling, so often it's the language. Then, later on, as she got a little bit older, it was the lack of responsiveness. Not responding to her name. Not interacting. That's what really raised some red flags for me.

JEANNE BLAKE: When we call this a spectrum of disorders, one of those, which Sarah was diagnosed with, was – and I'm going to let you describe it – PDD NOS. Tell us what that is.

NANCY WISEMAN: PDD NOS stands for pervasive developmental disorder not otherwise specified. It's one of multiple disorders on the autism spectrum. If you envision a continuum, a spectrum of neurobiological disorders consisting of autistic disorder, PDD NOS, Asperger's syndrome, Rett's syndrome, and it's really a spectrum from low functioning to high functioning. So in the low end

you would have autistic disorder, on the high end you would have Asperger's syndrome. We have video of Sarah pacing in her crib, and she was 18 months at this point?

NANCY WISEMAN: That's correct.

[VIDEO PLAYS]

JEANNE BLAKE: And she does interact with you. There are moments that I think are very dear, and very warm, where she looks right at you. And at this point, by the way, we can tell by the way that you're narrating the video that you had no idea that she was delayed. But were you concerned at this point?

NANCY WISEMAN: At this point I did have concerns, but mostly about her lack of words coming in, and her not responding. My mother, who is a school psychologist, had a lot more concern, and by this point she already figured out that she had autism. But – and this is common with a lot of kids – you have fleeting moments of eye contact, of social skills, but what you're really looking for, which is the healthy cornerstone of development, is that back and forth continuous flow, which is called social reciprocity, of language, of gestures, or pretend play. Sarah has no gestures whatsoever. None of the common things, which is pointing, giving, showing, waving, pretend play – she had none of those.

JEANNE BLAKE: You say that your mother already knew, and I know that in the book you describe that your mother and you were at the doctor, and she's asking to talk to the doctor. You also write very openly about the denial that you were indulging in, and you write quite a bit about that. I can understand why a parent would want to deny that there was something wrong with their child, but you warn against that and push really hard, because you say that time does matter.

NANCY WISEMAN: Time was critical. The earlier the diagnosis, whether it's a developmental delay, or whether it's any kind of disorder, the earlier the better.

JEANNE BLAKE: Because?

NANCY WISEMAN: The earlier the intervention, the better the outcome. The brain is much more malleable at an earlier age.

JEANNE BLAKE: So what did it take for you to find out that Sarah had an autism spectrum disorder? Was it challenging for you? Did you go from doctor to doctor to doctor? Or were you one of the lucky ones who was getting good care and could find out earlier?

NANCY WISEMAN: A little bit of both. It was challenging in the beginning because we did go from doctor to doctor. The first thing we did was to get an audiological evaluation, and we did go see a neurologist, who at first thought it was Landau-Kleffner syndrome –

JEANNE BLAKE: Whatever that is. What is that?

NANCY WISEMAN: It's basically, it looks a lot like autism, but it's a child who is having night seizures.

JEANNE BLAKE: OK, because Sarah did have some seizures, right?

NANCY WISEMAN: She had some mild seizures.

JEANNE BLAKE: But also, the reason that you had her hearing tested is because sometimes, when children aren't responsive, or they don't respond to their name, you think that perhaps they aren't able to hear. And so you want to rule that out.

NANCY WISEMAN: You want to rule out any kind of hearing problem, you want to rule out any kind of lead in the child's system, because often that can look like autism. So we did all of that, and we self-referred to our local early intervention program and had her evaluated. And this is where we learned that she has major deficits in all of the different domains – the language, the social skills, both expressive and receptive language, social, emotional.

JEANNE BLAKE: I want to jump ahead now, because this seems to be an ideal time for us to hear what some of those milestones are from Dr. Stanley Greenspan, a renowned psychologist who is working with you in an organization that you founded, as I mentioned, called First Signs. Before we hear from Dr. Greenspan, could you tell us what inspired First Signs?

NANCY WISEMAN: First Signs was born out of my own personal experience with my daughter. Within the first week of early intervention, my daughter spoke her first word, which was the word "help." It couldn't be any more important than that. I wanted, I had to really start from ground zero, and I didn't want parents to have to start all over again. I wanted to be able to let them know what were the critical milestones that a child reaches. The fact that even if it's a developmental delay or a disorder, if you catch it early enough you can get a child back on a healthy developmental path.

JEANNE BLAKE: We'll talk about some of the ways that you did that. But I just want to show – this is the kit that you developed, and oddly enough it's not for parents, although your target is reaching parents of children who are living with this spectrum of disorders.

NANCY WISEMAN: We have tools and training for professionals, and we have information and outreach for parents. So we're hitting from both angles.

JEANNE BLAKE: But you do trainings with health care professionals, so that they know what to look for.

NANCY WISEMAN: Correct. We can do trainings all around the country, and in fact fewer than 30 percent of primary care providers screen children for developmental delays. One thing that I really want parents and professionals to know is that every child should be screened at every well visit, starting at about 4 months.

JEANNE BLAKE: Why don't we just take a few minutes to listen to Dr. Stanley Greenspan and some of the benchmarks he says that children who are developing normally should meet. Here's Dr. Greenspan.

DR. GREENSPAN: [on tape] By 4 months of age, babies should be able to be very warm and engaging, very happy and very joyful, so when Mommy smiles at little Tommy, at 4 months old Tommy typically will go "Ah!" and lighten up, and just be so overjoyed that Mommy is smiling or Daddy is smiling. When you see a 4-month-old who's very self-absorbed and looks very despondent, for example, and has this kind of a face, and even when you work with that child, you try to make overtures, the child is staring off into space rather than at you, you know that expectable social, emotional, and cognitive milestone is not happening.

TAPE INSERT: Between 9 and 12 months, a huge shift occurs in babies' attention system that allows the baby to disengage attention from the object with which they are playing and shift it over to you and then back to the object with which they're playing. So that is a big thing, it's called joint attention, and

some people feel that if you don't develop that, that you won't develop language and you won't develop physical social connection. Also at 9 months, there's a shift in the way the baby babbles. Babbling becomes more complex, they introduce more sounds into their babbling in a systematic way. And then, between 12 and 14 months they start to get ready for their first real word.

DR. GREENSPAN: Even if the words are delayed, but the reciprocity is there, I rest easy. But if the language delay is part of a larger problem with the reciprocal use of vocalization, reciprocal use of emotions, and reciprocal use of motor gestures, then we need to get the child evaluated right away.

DR. GREENSPAN: So now we want two-way, reciprocal, back-and-forth communication with smiles, frowns, and other affect gestures, vocalization, motor gestures, but now we want the child to go one step further and to be able to do this in a problem-solving way. At 18 months, we want to see a lot of motor gestures – pointing, showing – a lot of subtle looking, we want to see all that orchestrated now as part of solving problems, finding toys. We want to see the beginnings of some pretending. Also, we want to see language coming in, but the key for language is language coming in in a functional way as part of this complex social interaction. “Mommy, hug!” But if the child does not show it, this complex social, emotional, motor, and language reciprocity, the two-way back-and-forth, then we want to do a complete evaluation yesterday. Now, what we typically look for at the 24-month period is movement now into imaginative play. Can the child engage in the doll being fed as part of, again, two-way communication with a caregiver?

JEANNE BLAKE: Hearing Dr. Greenspan outline the developmental milestones is important for health care providers, but for parents, so that when parents go in, the health care provider and the parents can have a dialogue about where the child is. That's got to be the reason that you are offering these on your website and also for physicians and other health care providers.

NANCY WISEMAN: That's absolutely critical. Parents need to form a partnership with their primary care provider, whether it be a family physician or a pediatrician. They need to be able to know what the expected social, emotional, and communication milestones, be able to discuss that with their primary care provider. Ask for a developmental screening at every well visit. And don't accept, if the child is delayed, let's wait and see.

JEANNE BLAKE: That's right. You repeat that throughout the book. No let's wait and see.

NANCY WISEMAN: Three months in the life of a 12-month-old is a very long time, and there's a lot you can do in three months.

JEANNE BLAKE: And once you found out that Sarah did have a disorder, you took action immediately. Tell us what you did.

NANCY WISEMAN: I first researched so I knew what the options were. I put together a good team with a developmental pediatrician, a pediatric neurologist, a psychiatrist, a psychologist, a team of educators, a team of clinicians that consisted of a speech and language pathologist and occupational therapist. We didn't need a physical therapist, but somebody might need a physical therapist.

JEANNE BLAKE: And the results have been good for you and for Sarah.

NANCY WISEMAN: They have been incredibly dramatic. If you look at footage of when Sarah was 18 months, or when she was 2 or 3 years old, and now look at her at the age of 10, she is mainstream, she is probably more social than most typically developing kids. Back at 3 she had no words, now Sarah doesn't stop talking.

JEANNE BLAKE: I talked with her on the phone this morning. I can tell you that's absolutely true.

NANCY WISEMAN: And I'm surprised she didn't tell you her whole life story.

JEANNE BLAKE: You credit what you call floor time, a technique called floor time, with helping Sarah develop and emerge. Tell us what that is.

NANCY WISEMAN: There are actually two things that I credit for her incredible success. One is the floor time, which was developed by Dr. Stanley Greenspan, and it's literally getting on the floor with your child and connecting with the child, and getting an interaction going, and before you know it, a communication going, whether it's by language, by play, or by gestures. And these are all child-led activities, so if the child wants to be banging on something in a repetitive way, I don't deny her that activity, I sit down on the floor and maybe start doing that with her, and then, all of a sudden, take the mallet and do something silly with it, maybe put it on my head. And she'll look, and she'll connect, and she'll laugh, and that's a connection.

JEANNE BLAKE: Help me understand, help our viewers understand the theory behind that.

NANCY WISEMAN: Well, the whole theory is that you need to get the social reciprocity in place, that back and forth. First you have to have the connection, and then you need that back-and-forth, continuous flow. So it needs to be an activity that the child is interested in at the moment.

JEANNE BLAKE: Because we're talking about a spectrum of disorders, do you think that children who have the most severe forms of autism would be able to do what she did? Would they be able to respond, to some degree?

NANCY WISEMAN: Absolutely. It may take more work. With Sarah, for instance, she was on the moderate end of the spectrum, and it took a lot of hard work and floor time. For me it was not easy. I thought I knew how to play with my child, but most parents are not taught how to play. But it required grander gestures, higher accent in my voice, just everything bigger, greater. That was difficult for me, I have to admit. I had to teach myself how to do that. But all kids can have some result from it, whether it's small or it's big, and you just have to keep working. What I did was round the clock, so it becomes engrained in every aspect of our life. At bath time, at feeding, at book time, whenever. In the car.

JEANNE BLAKE: It was ironic that I was preparing to talk with you today and this morning's New York Times talks about the parents of children with autism, three parents murdered their children, or in one case it was a suicide-murder, and the person who writes this op-ed piece is also an author of a book about autism, and suggests that sometimes the expectations may be too great on parents with children with autism, that there maybe needs to be a level of acceptance that the child won't every fully develop and reach the goals that you want, so that there's not that ongoing frustration. Because it is terribly hard work for a family with a child who has autism.

NANCY WISEMAN: I talk about this in my book, first in terms of accepting your child. Your dreams may be different of what your child may be later on in life, but they're not necessarily gone, it just means you need to redirect your dreams. It's also accepting the diagnosis and what may be and how that future is going to change. But there has to be hope. for parents to be able to bring their child along the spectrum and to be able to do things that you never thought possible. Now, not all kids are going to be able to come off the spectrum. There is no cure. There is no known cure at this point. But kids can lose their classification on the spectrum. That is possible. But I think that their expectations need to be set at a reasonable place.

JEANNE BLAKE: Depending on where their child is.

NANCY WISEMAN: Depending upon where their child is, and depending upon what kind of progress they're seeing.

JEANNE BLAKE: Who do you think can best help a parent establish a realistic goal? From what you've said, a third of physicians aren't checking for those developmental stages and the milestones, so is the health care provider the best person, or is it a support group? Where do you get that realistic expectation?

NANCY WISEMAN: That's a good question. What parents want to look for is an expert in diagnosing and treating autism spectrum disorders. That may be a developmental specialist, a pediatric neurologist, a psychiatrist, a psychologist. But what's important is to have expertise in diagnosing and treating a lot of kids, because it's very easy to spot for the trained eye, but for the untrained eye it's not that easy. But what the parents need to do is have a good balanced team, and there are lots of treatments that you can try, and it doesn't mean you have to try one, there are lots that you can try, as long as you do it in a methodical way and you're working with a team of experts, and you're not doing it in a vacuum.

JEANNE BLAKE: It's really a full-time job, and it's expensive. This op-ed piece says that it costs a family between \$10,000 and \$50,000 a year to care for and receive services for a child with autism. What do families do that don't have the resources?

NANCY WISEMAN: It's very difficult. The emotional and financial stress that this puts on families. It can cost upward, for many parents, even as much as \$100,000 out of pocket. We need to change the insurance laws. Insurance is not reimbursing families the way they should be. You can have two families who are on the same insurance plan with the same diagnostic code with the same exact practitioner, and there's complete inequity in what the reimbursement is.

JEANNE BLAKE: And on an emotional level, you're now doing this as a single parent. You're raising your daughter as a single parent. Your marriage suffered as a result of, do you think some of the stress related – you said there were pre-existing conditions.

NANCY WISEMAN: I think they were pre-existing. I think it would have happened anyway, but clearly, the impact that it had on my marriage was profound, because I was spending all of my time with Sarah and all of my time with First Signs, and it was very difficult. Prior to her diagnosis, I had a full-time career, so I had to leave my career, and there went 50 percent of our household income. But the financial drain on a family is unbelievable. I downsized my home two times to be able to accommodate the out-of-pocket costs.

JEANNE BLAKE: What do you say to the support around a family? I'm assuming that your extended family is tremendously supportive. What would your words be to people who are members of an extended family where there's a child with autism?

NANCY WISEMAN: Whether it be actual family members or friends, extended family, it's very important that you have the support in place in terms of getting the proper respite that a family needs. Parents need to be able to have downtime, to be able to go out as a couple. I never had that. Parents need to be able to spend time with the other siblings, because it affects all members of the family. Just to be able to go out and go grocery shopping. A lot of these kids have other co-morbid or overlapping disorders. In the case of my own child, it was ADHD, colitis, and bipolar. For me it was very difficult because my daughter would have violent rages. There were days on end when I couldn't get out to the grocery store. So whether it be a neighbor or a friend or a family member, just to be able to pitch in and help, to be able to talk on the phone and have that emotional support. To be able to take a grandparent or a spouse or a friend to a diagnostic evaluation or a pediatric visit. To be able to have the help, to be able to take notes at an IED meeting for school.

JEANNE BLAKE: And you write an entire section in this book on how to navigate the school system, which we all know that when there's a child with special needs, that in itself is a full-time job. So you're wearing many, many hats, Nancy.

NANCY WISEMAN: And it's very exhausting. There are nights when a lot of us don't get any sleep. We'll be up e-mailing parents through the middle of the night. And parents who have children with special needs rely on other parents with special needs children.

JEANNE BLAKE: I was just going to say, you really can't know unless you've been there. But your book, *Could it Be Autism?*, does give some insight and it's a valuable guide, as I said earlier, to parents who are just beginning to question or have just been given a diagnosis. It will save them a lot of the research that you went through, and I hope that people will learn about your screening, maybe it'll expand into even more states. Nancy, thank you for coming in to talk with us today.

NANCY WISEMAN: Thanks for having me, Jeanne.

JEANNE BLAKE: We'd like to thank you for joining us on About Health. I'm Jeanne Blake, and I'll see you next time.

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