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# **Sanjay Gupta MD**

Unraveling the Mystery of Autism; Talking With the CDC Director; Stories of Children with Autism; Aging with Autism

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SANJAY GUPTA, CNN HOST: Good morning and welcome to a special edition of HOUSE CALL, "Unraveling the Mystery of Autism."

(BEGIN VIDEO CLIP)

UNIDENTIFIED FEMALE: I don't think I've let myself think too far ahead into the future.

UNIDENTIFIED FEMALE: He started kind of slipping away from us.

UNIDENTIFIED FEMALE: The doctors keep on saying that boys develop slower than girls.

UNIDENTIFIED MALE: The early intensive behavioral intervention is the best way to deal with autism.

UNIDENTIFIED FEMALE: You think you're dealing with something that's going to come and go. And ther you get your child back. And then you don't.

UNIDENTIFIED FEMALE: You have to become an expert on education because you are the advocate for your child.

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(END VIDEO CLIP)

GUPTA: Rates of autism are jumping, an alarming 10 to 17 percent every year. The numbers can be overwhelming, but today, our goal is to investigate, empower, and educate, giving real answers to the thousands of questions surrounding this medical mystery.

(BEGIN VIDEOTAPE)

THERESA CEDILLO, MOTHER OF DAUGHTER WITH AUTISM: Hi, Michele. I see you.

GUPTA (voice-over): Watching old videos, Theresa Cedillo sees the child her daughter Michele could have been, happy, engaged, playful. Michele's childhood has turned out very different. She's autistic. Now 13, she can't walk without help. She gets her nourishment from a feeding tube. And she needs constant monitoring for seizures.

CEDILLO: You think you're dealing with something that is going to come and go. And then you get your child back. And then you don't. And you just have a very sick child.

GUPTA: Teresa and Mike Cedillo blame vaccines for causing their daughter's autism. And they've sued the federal government through the National Vaccine Injury Compensation Program. The Cedillo's case is more than 4900 claiming a vaccine autism link. They're being considered together in a so-called vaccine court, part of the U.S. Court of Federal Claims.

Last year, Michele Cedillo's claim was chosen as the first of nine test cases to determine whether the vaccines could plausibly trigger autism. More testimony is scheduled this year.

CEDILLO: She was a normal and healthy developing child.

GUPTA: The Cedillos say their daughter was sickened by a combination of the measles, mumps, and rubella or MMR vaccine, and the mercury containing preservative thimerasol, which was in childhood vaccines at the time. As a precaution, thimerasol has since been removed from all childhood vaccines and only remains in some flu shots.

While the court considers the vaccine autism case, the medical establishment has already passed judgment.

PAUL OFFIT, DR., CHILDREN'S HOSP. OF PHILADELPHIA: It's been asked and answered. Vaccines don't cause autism. I mean, about 20 percent of children with autism will regress between often the first and second birthdays. So statistically, it has to happen where some children will get a vaccine. They will have been fine. They get the vaccine. Then they're not fine anymore.

GUPTA: Theresa and Mike Cedillo hope the vaccine court will decide vaccines can cause autism and award them enough money so Michele can be well taken care of when they're gone.

# (END VIDEOTAPE)

GUPTA: And one of those 4,900 cases was the case of nine-year- old Hannah Polling, which has been making a lot of news lately. Luckily, we have the director of the Centers for Disease Control and Prevention Dr. Julie Gerberding here.

We're talking a lot about autism, as you know. I should remind people that the -- my understanding is the federal government conceded that vaccines caused her autism like symptoms. First of all, is there a difference? I mean, does she have autism or autism like symptoms? What's the difference?

JULIE GERBERDING, DR., CDC DIRECTOR: Well, you know, I don't have all the facts because I still haven't been able to review the case files myself. But my understanding is that the child has a -- what we think is a rare mitochondrial disorder. And children that have this disease, anything that stresses them create a situation where their cells just can't make enough energy to keep their brains functioning normally. Now, we all know that vaccines can occasionally cause fevers in kids. So if a child was immunized, got a fever, had other complications from the vaccines. And if you're predisposed with the mitochondrial disorder, it can certainly set off some damage. Some of the symptoms can be symptoms that have characteristics of autism.

GUPTA: Yes, I have a two-and-a-half-year-old and a one-year-old as you know. And you know, you know, you think about this all the time. Are we ready to say right now as things stand that childhood vaccines do not cause autism?

GERBERDING: What we can say absolutely for sure is that we don't really understand the causes of autism We've got a long way to go before we get to the bottom of this. But there have been at least 15 very good scientific studies on the Institute of Medicine who have searched this out. And they have concluded that there really is no association between vaccines and autism.

GERBERDING: Well, I'll never be comfortable with everything we know. I mean, I think we have to have an open mind about this. We know that there's very little chance that it's something related to a vaccine that's

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going to cause a serious problem for a child. We also know how life saving vaccines really are.

GUPTA: Yes.

GERBERDING: You know, something like 33,000 children a year are saved from death associated with the

vaccines...

GUPTA: Right.

GERBERDING: ...because of our immunization program. That's a huge benefit.

GUPTA: Yes.

GERBERDING: One of the things that concerns me is while the attention is focused on vaccines, in a sense, it means people are not looking for other causes. I mean, we've got to keep reminding ourselves that the vaccine story has been one that's been debated for many, many years now. We keep looking and looking and

looking. And we really cannot turn up any information.

GUPTA: How do you -- how does the -- should the government be doing more to try and address this controversy, especially in the minds of, you know, so many people out there who worry about this and live

with this, as you say, every day?

GERBERDING: Well, one thing that I remember is that the government is actually composed of moms and dads. And there are a lot of moms and dads at CDC who look at this the same way. Many of the people in our immunization program are parents of young children. So they understand the dilemma that a parent feels But it's kind of our job to do the science to help clarify and separate concern from scientific fact. Autism is a huge challenge. And it is much more common than I think anyone realized. And we aren't doing enough. And we need to do more.

ind we need to do more

GUPTA: Yes.

GERBERDING: We need answers not only to the cause, but we need answers for treatment and for management. And certainly on autism awareness day, we need to understand how we can detect this disease

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GUPTA: Our viewers have a lot of questions. I'm so delighted you were here to help answer some of them.

GERBERDING: Thank you.

GUPTA: We're going to stay on this. And we hope you'll join us again.

GERBERDING: Appreciate that. We're staying on it, too.

GUPTA: Thanks so much, Dr. Gerberding.

GERBERDING: Thank you.

GUPTA: Appreciate it.

Become a part of researching the cause and treatments of autism. Log on to the Interactive Autism Network at ianproject.org. Families share what works for them. And researchers hope the information will help find effective treatment options. CNN is covering autism on a global scale. Beyond the sound bites, you're going to find interviews, expert blogs, and stories of hope at cnn.com/autism.

(BEGIN VIDEO CLIP)

UNIDENTIFIED FEMALE: It was almost as if a switch, somebody came to our house and turned the switch off.

(END VIDEO CLIP)

GUPTA: Parents know when something doesn't seem right. Just ahead, signs you can look for in your child. And later, we really want to help you navigate the frustrating red tape so you can get what your family needs We'll bring in the experts to connect you with the latest information. Stay with us.

(COMMERCIAL BREAK)

(BEGIN VIDEO CLIP)

UNIDENTIFIED FEMALE: Do you know how special the word "mama" is? When I waited over four years

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(END VIDEO CLIP)

GUPTA: We're back with this very special HOUSE CALL, "Autism, Unraveling the Mystery." You know, what I found in my reporting on autism is that early diagnosis is critical. More and more of the latest research shows real progress is possible with early intervention. And the key to that is knowing when to seel help.

(BEGIN VIDEOTAPE)

UNIDENTIFIED FEMALE: My husband and I both, we felt something was not right.

UNIDENTIFIED MALE: We knew what the stereotypes of autism. Dustin Hoffman character in "Rain Man."

UNIDENTIFIED FEMALE: There were so many milestones that other children hit that he just did not hit.

UNIDENTIFIED MALE: We thought that maybe he had a speech delay.

UNIDENTIFIED FEMALE: No matter how many times I changed the symptoms around or left one or two off, it kept coming back, autism.

UNIDENTIFIED FEMALE: In the area of social communication, these are children who don't establish eye contact. They don't share common enjoyment. They don't offer comfort. They don't have the skills to approach a person, say hello, start a conversation, or interact in a game in an appropriate way.

JUDITH STEUBER, TWO SONS HAVE AUTISM: He was just finishing kindergarten when he started talking, which is not what other kids do.

UNIDENTIFIED FEMALE: Children with autism don't necessarily develop expressive language skills. Many times, children who do have verbal expression make up their own words, don't use pronouns appropriately, and have difficulty really understanding some of the common conversational language that we use in our society.

UNIDENTIFIED FEMALE: He kept washing his hands, he was flipping the light switch on and off.

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signs, flag poles, sewer covers, very strange things. Other children, they have interests in lining things up, or playing with just very specific parts of toys, spinning wheels on a car, or opening and closing doors, or switching lights on and off, or running from one room to the next. So the activity that they engage is in is sort of a meaningless activity.

UNIDENTIFIED MALE: You would have horrible, horrible tantrums, an inability to calm down from those Everything that we did, it affected.

UNIDENTIFIED FEMALE: Any time a behavior results in a tantrum or in crying or in re-establishes the routine of the families, any time that child's behavior is really running the family, now that certainly is a great red flag that something's wrong.

Early intervention can really circumvent the development of those behaviors. And certainly, early intervention can assist in minimizing those behaviors if the behaviors emerge.

JEFF CHIUSANO, FATHER OF SON WITH AUTISM: It's remarkable how far he's come along. He now has complex speech. He interacts with other kids and wants to. He can recognize social cues. He's funny. He has a personality. It is 180 degrees from where we were.

#### (END VIDEOTAPE)

GUPTA: And here's another idea. As a doctor, I believe clinical trials are a great way to get cutting edge treatment for your child and help with research. Go to clinicaltrials gov like we did. Search for autism and you'll find studies recruiting for culation (ph) therapy, acupuncture, various medications and more.

Of course clinical trials are just one piece of the puzzle. Parents must become the best advocates for their autistic child. We have expert advice coming up on navigating the system and finding all the right tools and resources. Plus, an incredible mom and her pediatrician with their advice.

# (COMMERCIAL BREAK)

GUPTA: There is a way you can help cause change. Go to cnn.com/impact. Impact your world by donating to groups researching the causes and treatments of autism.

Now we've talked about signs to look for, but what's next? What should you do when you know something's

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(BEGIN VIDEOTAPE)

ELIZABETH COHEN, CNN MEDICAL CORRESPONDENT (voice-over): In many ways, Justin Kinninger is your typical seven-year-old. He loves math, pizza, and Pokemon.

CHILDREN: I pledge allegiance to the flag.

COHEN: But from the very beginning, Justin's mom Shannon says something wasn't right.

SHANNON KINNINGER, MOTHER: When he was supposed to be sitting up, he wasn't sitting up. When he was supposed to be holding his head up, he wasn't holding his head up. When he was supposed to be rolling over, he wasn't rolling over.

COHEN: But when Shannon took Justin to the pediatrician...

KINNINGER: The doctor kept on saying that boys develop slower than girls. I was very frustrated.

COHEN: Finally when Justin was four, Kinninger found a specialist, a developmental pediatrician, who knew immediately what was wrong.

KINNINGER: He's autistic. And I'm thinking finally we got a diagnosis.

COHEN: From getting a diagnosis to getting the right schooling, parents of children with autism have to be tenacious, even relentless sometimes to get their children what they're entitled to. First, getting a diagnosis is crucial. If your doctor isn't listening to you, be persistent. The Kinningers lost valuable years. The earlier your child gets help, the better.

STEUBER: Don't wait -- don't just wait for him to grow out of it. In order to get some services you have to have a diagnosis.

COHEN: The problem, your doctor may not notice your child's behavior during a short office visit. So you might need to videotape your child at home. Also, a letter from a daycare provider or a preschool teacher discussing your child's behavior might help. The diagnosis is just the beginning. Parents need to push for services in school.

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COHEN: In the end, says both Kinninger and Steuber, it's always good to go with your gut.

STEUBER: You really do have to trust yourself.

KINNINGER: You are the best advocate for a child.

COHEN: With this week's "Empowered Patient," I'm Elizabeth Cohen.

(END VIDEOTAPE)

GUPTA: We have been stressing early intervention. And parents can log on to nichy.org/states to learn how to apply for services in your community. You can also click onto cnn.com/empowered patient. You'll see Elizabeth's column there, which includes tips ranging from ways to finding support, to knowing your kid's rights at school.

Now staying fit is tough for anyone, but when sounds and sensations are overwhelming, imagine the challenge. We're going to have some great tips you won't want to miss.

And up next, beyond the childhood years, aging with autism. There's some hope for families. Stay with us.

(COMMERCIAL BREAK)

(BEGIN VIDEO CLIP) UNIDENTIFIED MALE: Even with all of the stress factors associated with raising child with autism, I would never want Cameron to be anything than what he is. He has shown me what unconditional love means, what, true happiness is. And he has taught me more about life than life itself.

(END VIDEO CLIP)

GUPTA: Ten years ago, only a handful of scientists were investigating autism. Now they number more than 1,000. Unraveling the mystery is an ongoing struggle for parents. They not only worry about caring for their children today, but worry about what the future holds. So here is a story of success that will provide some hope.

(BEGIN VIDEOTAPE)

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BOB ESPOSITO: Hi, how are you?

GUPTA: Bob works at the College of New Jersey. His day starts off with instructions from his supervisor.

UNIDENTIFIED MALE: What I want you to do is, since it's cold out this morning, I want you to go to Fresino.

ESPOSITO: Sounds good.

UNIDENTIFIED MALE: OK? Then after lunch, I want you to go out and pick up. OK?

ESPOSITO: Sounds good.

GUPTA: Bob's held this job for more than 15 years. Bob has autism, a developmental disorder that causes substantial difficulties with social interaction and communication and unusual or repetitive behavior in young children. Autism doesn't go away. But with early and intensive therapy, children with autism can learn skills that will allow them to succeed as they grow older.

Bob began receiving intensive behavioral therapy at New Jersey's Princeton Child Development Institute when he was eight-years-old. The institute has students as young as three and as old as 43. Its executive director Greg Macduff has been working with Bob since 1977 when Bob moved into their first group home.

GREGORY MACDUFF, PRINCETON CHILD DEVELOPMENT INST.: Well, not everyone will get to Bob's level where they can choose whether they're going to go out for dinner or go to a movie. But many of these, the students, are choosing what kind of work tasks they're going to do. Some of them are choosing the order of their work. They're choosing what kind of rewards they purchase.

GUPTA: Bob still gets help from therapists who teach him new skills like paying bills on his computer. UNIDENTIFIED FEMALE: That's excellent, Bob. That's clicking the selected checks. Good for you.

ESPOSITO: Thanks.

GUPTA: Bob lives a fairly independent life. For the past two years, he has shared an apartment with another person with autism. He makes his own schedule, shops, cleans, does his own laundry, and he loves to cook.

MACDUFF: I think he enjoys the fact that he pretty much controls his life at this point. He makes the decisions about what he eats, where he goes, how he spends his money.

ESPOSITO: It's great. You know, I'm just enjoying life and everything. So it's pretty cool. It's a pretty cool thing.

# (END VIDEOTAPE)

GUPTA: We're still trying to change the future of autism. For more information on family services, treatments and resources for your child, log onto autism speaks.org.

Coming up, getting kids to play outside and be fit can be a struggle for any parent. But for children with autism, there are different challenges. So just ahead, the perfect workout and why it's so important.

#### (COMMERCIAL BREAK)

GUPTA: Here on HOUSE CALL, our mission is to help everyone live longer and healthier lives. Eating right and being fit can be especially challenging for families in a battle with autism.

Challenge number one, finding the appropriate exercise venue. That's because people with autism often have a very different way of processing the world. And they may tend to avoid social activities, including sports. But experts tell us there may be both physical and cognitive benefits specific to people on the autism spectrum.

#### (BEGIN VIDEO CLIP)

GAYLE MCGEE, DR., EMORY UNIVERSITY: You sort of get two benefits for the price of one in terms of both the physical health, the physical appearance, and I guess that's three benefits in terms of reduction of self stimulatory behaviors. The research that exists shows that if children with autism are doing very vigorous, extremely vigorous exercise of any variety for at least 20 minutes a day, that there's actually a significant decrease in their self stimulatory behavior.

# (END VIDEO CLIP)

Consider this. There's often a deep appreciation of rhythm and pattern. So the repetitive movements of walking, swimming, ballet, even martial arts are often recommended. And there are physical fitness programs specifically tailored for people with autism.

You can visit the National Center on Physical Activity and Disability Web site at ncpad.org to find a program near you.

Autism is such an important issue. We must continue to search for answers. Now if you missed any of today's show, be sure to check out my podcast online at cnn.com/podcast. Also, tune in for CNN's special coverage of world autism awareness. That's starts on Monday.

Remember, this is the place for the answers to all of your medical questions. Thanks for watching. I'm Dr. Sanjay Gupta. Stay tuned now for more news on CNN.

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