

CDC tells parents, docs to watch for rare, neurologic condition in children this fall

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One morning at breakfast six years ago, as Dawn Sticklen's healthy 13-year-old son tried to eat a bowl of cereal, his arms started shaking and got so weak he couldn't feed himself.

"We thought maybe it was because he had been sick for a few days and

maybe he was just kinda weak from not eating properly," said Sticklen, who lives in Joplin.

"But he just kept saying it was getting harder and harder to move his arms. So we knew something was wrong. We got him in to see the doctors and they all were like, 'this doesn't look right.' "

Joplin doctors sent the family to Children's Mercy in Kansas City, where Billy Sticklen was quickly diagnosed with a rare neurologic condition called acute flaccid myelitis, or AFM.

It left him temporarily paralyzed, unable to move anything but his hands and feet, like he had polio.

Billy's case is just one of several hundred recorded in the United States since 2014. Since then, AFM has peaked every two years, with cases typically popping up from August to November.

On Aug. 4, the Centers for Disease Control and Prevention alerted doctors and parents that AFM is expected to peak again this year—one more thing to watch out for other than COVID-19 this fall.

A big clue that a child might have AFM: Their limbs, some or all of them, go weak suddenly, like what happened to Billy.

"This is an incredibly [rare disease](#)," said Dr. Jennifer Schuster, a pediatric infectious diseases specialist at Children's Mercy, one of seven sites in the United States helping the CDC research the condition.

"What the CDC is very wisely doing ... is recognizing that we have seen clusters in 2014, 2016, 2018, even-numbered years. And here we are in 2020, and we are very distracted by another infectious disease that is circulating.

"So the CDC is reminding us that there are other things that we need to be mindful of, particularly during this time."

Billy is now 19, getting ready to start his sophomore year at the University of Missouri. He's been golfing enough lately to almost make up for the fact that, as his recovery stretched out over years, he was too weak to play during high school.

"Billy still has some lingering weakness in his left shoulder, left arm, but other than that he's actually doing remarkably well," Dawn Sticklen said.

"You wouldn't know if you saw him that anything had ever happened to him. For that we're really thankful, but he's worked really hard to get there. It's a lot of work and a lot of expertise went into that, to help him get to where he is."

AFM "has been around for quite some time," Schuster said, but gained renewed attention in 2014 when clusters popped up across the country.

That year, the year Billy got sick, the CDC recorded 120 cases. Cases began peaking every other year—153 in 2016, then 238 in 2018 in 42 states, the largest peak yet, according to the CDC.

"We had seen children with limb weakness previously, but this was a cluster that occurred around August to November, and it was something that was seen in multiple children's hospitals across the United States," Schuster said.

"This was unusual compared to what we were familiar with, which was we might see a case of limb weakness here or there."

At the same time, doctors saw a spike in a respiratory illness caused by the enterovirus EV-D68.

Physicians at Children's Mercy were among the first in the nation to recognize that the virus, once considered rare, was causing an outbreak of severe respiratory illnesses in the summer of 2014. Almost all the cases were among children, many with a history of asthma.

Researchers originally thought EV-D68 was causing what was happening to Billy Sticklen and other children across the country experiencing paralysis. But they couldn't establish a direct link and still haven't, though the CDC says enteroviruses, particularly EV-D68, are likely responsible for the peak in AFM cases.

"These two things kind of came hand in hand in 2014," Schuster said. "We started to see these (AFM) cases around August, September, 2014, and then really by November the cases had subsided, which was unusual. And we've learned something new every year since 2014."

For one thing, "we know there are a number of different viruses that can cause acute flaccid myelitis," Schuster said. "So we are still trying to learn more, whether there are multiple different viruses that are causing this, or whether there is a predominance of one virus."

The majority of AFM cases have occurred in people younger than 21, Schuster said.

"However, we know that the predominance of these symptoms of AFM have occurred in our early school-age children, so around 5 years of age," she said, though there have been reported cases in infants as well as adults older than 21.

It's tough for parents to know what symptoms to watch for, said Dawn Sticklen, "because there are so many other things that can be happening that can cause the same response in a child's body."

"And of course now we're dealing with COVID-19 so there's a whole myriad of things going on right now."

Weakness in the limbs is a main sign, which might be difficult to detect in toddlers, Schuster said.

A teenager or older child might simply stop using the arm that goes weak.

But, "in a younger child, particularly a toddler or a preschool-age child who may have leg weakness, this may look like changes in how they walk, or changes in their gait," Schuster said. "So parents (should be) aware of things that just don't quite look normal in their child, from a neurological point of view.

"In those situations, what we would expect is a parent who tells us that they have a preschool age child who has no problems walking, that is all of a sudden not walking."

Less-common symptoms, Schuster said, include droopy eyelids and difficulty swallowing or talking.

"On very rare occasions, children have had difficulty going to the bathroom, either they have held their urine or they've lost control of their urine," she said. "So if that is unusual for your child, that is something that you're gonna want to talk to your medical provider about as well."

Some children recover fully from the weakness in their limbs, Schuster said. "We know that a large subset, unfortunately, do not have full recovery, and some children have some varying deficits remaining. Which is why we are really, really trying to learn more."

Billy Sticklen makes annual visits to Children's Mercy as part of his ongoing recovery. The hospital spotlighted his case in early 2015 when it introduced him to the public after months of physical therapy helped him to walk again, with a cane.

The cane is gone. But he still works out with a personal trainer.

"He doesn't talk about it very much," Dawn Sticklen said. "But, at the same time, he's overcome a lot. He has come a long way. He's quite a trooper."

Sticklen keeps up on AFM research through the handful of other families in the country that have been touched by it. They've learned lessons along the way.

"What we try to tell people ... is if your child starts running a fever, and then shows any form of weakness, don't rule it out," Sticklen said.

"And, if (doctors) ask you 'do you want to have a spinal tap done and an MRI,' do it. Even though it seems like it's invasive or an over-reaction, the sooner that they're able to intervene, the better, the less damage that's done.

"It's not until you get the [spinal tap](#) with the MRI combined that you realize that there's inflammation in the spinal cord, and that's what causes the paralysis."

In its recent alert to the public, the CDC said AFM should be considered a [medical emergency](#), emphasizing that even in places where there is a lot of COVID-19, patients need to get help as quickly as possible.

The medical community has been concerned for months that [sick people](#) are avoiding doctors' offices and emergency rooms out of fear of

catching the coronavirus.

But someone with AFM can decline quickly, over a matter of hours or days, the CDC cautioned. Waiting to seek help can make matters worse—for instance a child being placed on a ventilator, permanent paralysis and/or "life-threatening complication of respiratory failure in previously healthy patients."

Though AFM is not caused by a coronavirus, whatever virus is causing it can be spread the same way—close contact with an infected person, touching a contaminated surface then touching your mouth, nose or eyes, doctors say.

There's some thought that the precautions people are taking to avoid COVID-19 might help keep cases of AFM down this year.

"Many people may remember that when we started putting many of these risk mitigation and strategies in place back in March and early spring, when we started increasing hand hygiene, physical distancing and wearing masks, influenza went away rather quickly, quicker than we would expect for a typical flu season," Schuster said.

"So we know these strategies will work against most respiratory viruses. We don't know how this will affect what we would typically expect for this season's acute flaccid myelitis."

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