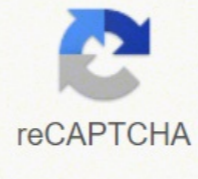




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Next

Facial deformity rett syndrome



Are you born with rett syndrome. Facial deformity rett syndrome sophia mouth. How to diagnose rett syndrome. What is the life expectancy of someone with rett syndrome. What is a rett syndrome.

"People are so much more bold now to attack people with disabilities." "I know what true happiness is There is one fundamental truth that Weaver says people don't get -- or simply refuse to admit. Weaver says that although her conditions sometimes cause her pain, Sophia is a happy, strong little girl. And yet, every day people tell Weaver that Sophia should die. "People had always been so cruel, they called her a monster and her immune system made it difficult." In recent months, the family brought her to a hair salon for the first time. Though she can't talk, she uses her eyes and makes little sounds to communicate with her family. And people view her as a disability, but I just want them to look at her as my child. "Weaver readily confirms that life with a child with profound disabilities can be difficult and painful and emotional. We had told her, 'Let's have fun for the rest of your life!' I told her no more doctors, no more hospitals. In her public appearances, Weaver tries to clear people's misconceptions about Medicaid and educate them about its importance to people with disabilities and preexisting conditions. She has seizures and choking spells because of both the deformities and the Rett syndrome. "Weaver, a health care activist, calls her daughter amazing. "I've received messages from people all over the world saying Sophia gave them strength. "Without health care, my daughter would die," she says. "ISHUDNTHAVETOPAYFOIT" read another. She also told her story to a local news station, hoping to put pressure on Twitter to take the post down. I get people telling me to kill my child, to put her out of her misery." In November, Weaver received a particularly vile tweet: A photo of her daughter, along with a paragraph advocating for coerced abortion and practices tantamount to eugenics. "The number of reports we receive does not impact whether or not something will be removed," it reads. Sophia was born with facial deformities and deformities to her hands and feet. "She was in hospice here at the house and we'd promised her we'd never take her back to the hospital. They went to an aquarium, an art museum and even saw a movie in an actual theatre. One particularly cruel tweet led Weaver on a months-long struggle to do what she's always done, what any mother would be moved to do: Protect her daughter. "But it was never removed. "I know what true happiness is." It also says that mass reporting doesn't speed the removal process. "She has a feeding tube. I crawled into bed with her and I was holding her, curled up next to her and that's when she took her last breaths." Ten-year-old Sophia was born with extreme facial, hand and foot deformities and Rett syndrome -- a rare degenerative disorder that meant she couldn't walk or talk, had trouble eating and sometimes even breathing. Winnebago even offered the family one of their giant vans to take Sophia out West on the ultimate family road trip. The horrifying messages started rolling in. "People, they seek you out and want to hurt you," says Weaver, who also has two younger children. I knew I had to listen to her body." In addition to keeping her out of the hospital, they decided to bring her out in public -- for the first time in years. Weaver reported the tweet and asked her followers to report the post. Natalie Weaver thought she had more time with her daughter. When Natalie announced Sophia's death on social media, followers raised more than \$40,000 for the non-profit in just a few days. A daughter like any other daughter. They also took her roller skating. As a result, Sophia depends on her family for 24/7 care. + Follow In January, Weaver and her husband Mark, 49, made the excruciating decision to stop taking extreme measures to prolong their daughter's life. "Someone will say [Sophia's] undeserving of health care and is a drain on society and she should die," she says. But Weaver has noticed the attacks on her daughter have become more political as health care continues to be a big national conversation. Sadly Sophie died before they were able to take the vacation, but Weaver says the company has agreed to let her and Mark take their other kids -- Alex, 8 and Lyla, 5 -- on the trip. She gets a lot of hate on Facebook too. We had more adventures scheduled," the 38-year-old mother of three tells PEOPLE. (She says she is currently working with Instagram to do the same.) So when Natalie told her thousands of followers about "Sweet Sophia's Adventures" many responded with suggestions and donations. And even though she could barely talk, when we told her that, she said, 'all done?' " Sophia and her mother gained a national following when Natalie began to advocate for kids with disabilities and the need to protect pre-existing conditions in insurance plans. Sophia had endured 30 surgeries over her lifetime and when she went into respiratory failure after her last surgery earlier this year, her parents decided enough was enough. The post, and her responses to it, netted more horrible messages. "I thought we had at least a year - I really did. Twitter responds After about a week and a half of nonstop coverage in January of this year, Weaver says she got another message from Twitter. "[They said] they made a mistake. And she is loved as one. A colostomy bag. But to some cruel, faceless voices on the internet, Sophia is an easy target for abuse. "She will live a miserable life and be a burden on the family and society." It was probably the most difficult decision we've ever had to make in our lives. Twitter had it in their policy to protect people with disabilities against hate." However, Weaver says they told her their reporting tool didn't have enough space to include the disability category as a reason for reviewing a tweet. There is still so much hate and cruelty towards people with deformities and disabilities, and for a few brief moments I've felt like I've made an impact and I hope my daughter's proud of me, but I wanted to do more ... I wanted her to be here to see the world be more accepting and change for the better." Weaver's daughter Sophia has Rett syndrome, a neurological disorder that impairs brain development. Internet trolls have used photos of Sophia to advocate for abortion (CNN) Natalie Weaver knows there aren't many little girls like her daughter Sophia. The account remained. "Some of Weaver's supporters told her they reported the tweet, then received messages from Twitter saying the tweet was found to be "in violation of Twitter rules." But Weaver says Twitter sent her a message saying the post did not violate their policies. Then, in January, people started alerting her to the fact the tweet was still up -- and the troll was still active. "[The troll] was mentioning my name and reaching out to my followers on Twitter," she says. Natalie also convinced Twitter to change their hate speech policy regarding people with disabilities after people used her daughter's picture to advocate for abortion. "I blocked it. But she also wants Twitter to change the way they review such content. Sophia is a person like any other person. "Our family is going live out this last promise to Sophia -- she will be with us in spirit." She says Sophia lives on in the non-profit the family started, Sophia's Voice, which helps other kids with disabilities and their families. When she was one, she was diagnosed with Rett syndrome, a neurological disorder that impairs brain development, permanently robbing young children of language and motor functions. They were heartbroken when she suddenly got very sick and died last month. "We have to deal with so many challenges, but because of her my life is better." Weaver says. Or, even worse, that she should never have been born. "Yes it is okay to think that every thing matters however a lot of them do not hence the amnio test," read a message attached to the tweet. She is also on the founder's council for the United States of Care, a non-profit that fights for accessible, affordable solutions for health care. Two years ago, a proposed policy change regarding Medicaid in her home state prompted her to be more outspoken about her daughter's condition. But Facebook's reporting feature already has a category specifically for attacks against "people with disability or disease." Advocating for change Weaver is a founder of Advocates for Medically Fragile Kids, an organization that strives to preserve the rights of children like Sophia. "She smiled the whole time. Civilization does not run on feels," one tweet read. Get push notifications with news, features and more. "There are people who go out of their way to make sure you see their cruelty. Weaver notes that Twitter isn't the only place people sling their hurtful words. The policy states that Twitter takes into account the context of a tweet as well as the history of an account. I wish I had more time to change the world for Sophia and people like her. "Twitter needs to add people with disabilities as a category in their violation reporting," Weaver says. Once the incident became public, people

began to use it in a debate about abortion rights.Despite the onslaught, the original tweet mattered most to Weaver because it used Sophia's picture.She asked people to report the tweet again and estimates that thousands did so. The nine-year-old has been through enough surgeries to last several lifetimes. "I know it happens with other people with disabilities. Weaver was satisfied that Twitter removed the offensive post. (The "amnio test" refers to amniotic testing, which can sometimes alert expectant parents to abnormalities in a developing fetus.)The post went on to suggest that parents who do not choose to abort a fetus found with abnormalities should pay for "all bills accrued after that."The person who made the hurtful post wanted Weaver to see it. They tagged her Twitter handle and sent her a direct message. I just hoped it was gone," she said. "I think many times, people don't even view Sophia is a person," Weaver says. In just the last year they've worked with 50 families to help pay for medical equipment and supplies, even car and utility payments. President Obama even tweeted at Natalie championing her activism. "I get people telling me to kill my child"Weaver, of Cornelius, North Carolina, is no stranger to internet trolls. What's driving her is simple. As any person with a public mission knows, trolling comes with the territory. "Otherwise people don't know the appropriate category to select for hate towards people with disabilities."A Twitter spokesperson referred CNN to the platform's "hateful conduct policy," which says, "You may not promote violence against or directly attack or threaten other people on the basis of race, ethnicity, national origin, sexual orientation, gender, gender identity, religious affiliation, age, disability, or disease."All of these considerations are taken into account when reviewing reported violations of the Twitter Rules," the spokesperson told CNN.The company's hateful conduct policy also outlines how possible offenses are identified and how punishments are enforced. "She's had 22 surgeries," Weaver told CNN. But to her, that's not the most important part of Sophia's story.

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