

HOT

Parents say 4-year-old daughter dies after feeding tube dislodged at school

By MOLLY WILLIAMS The Winchester Star
Feb 24, 2025

A Frederick County family alleges that negligence at Northwestern Regional Education Programs (NREP), which serves special needs students in Frederick County, Winchester and Clarke County public schools, resulted in their young daughter's death on Saturday.

Four-year-old Faith Johnson, who had a rare genetic disorder called Cockayne syndrome, died at UVA Health University Hospital in Charlottesville on Feb. 22. Cockayne syndrome causes premature aging, sensitivity to light and dwarfism, among other complications.

She had been admitted four days earlier, on Feb. 18, following an incident the same day at NREP where her gastrojejunostomy (GJ) feeding tube, which she relied on for sustenance, was dislodged from her body.

An incident report written by NREP's dean of students, Roy Martin, which Faith's father, Bryon Johnson, provided to The Winchester Star, indicates that the incident occurred after Faith's feeding that morning, which lasted from 10:10 a.m. to 11:45 a.m.

The report states that Faith's GJ tube, sometimes referred to as a "G-tube," was confirmed to have been in place throughout the duration of her feeding.

Staff noted that Faith spit up a small amount during her feeding, but this was normal and not a cause for concern, according to the report.

After being fed, a staff member took Faith, who was strapped in her stroller, into a cubicle for a diaper change.

The report states that the staff member unbuckled the stroller straps and "attempted to lift Faith but felt resistance."

While untangling the stroller straps, the report states, the staff member held Faith a few inches above the stroller. The staff member did not see the GJ tube detach while untangling the straps, according to the report.

Once Faith was on the changing table, the report states that the staff member noticed that the tube had come out.

According to the report, the nurse heard the staff member say, “Oh my gosh, the tube is out, the whole tube is out.”

The nurse then confirmed that the tube “was completely removed from Faith’s stomach” and went to get the girl’s mother, Danielle Johnson, who had arrived at the school for dismissal.

Out of caution, the report states, NREP was placed on a hold status. The school resource officer was notified and called for an ambulance.

Bryon Johnson said that at this time, staff was unable to explain how the tube had become detached.

“We were asking them ... what happened,” he said, “and nobody knew.”

A GJ tube is held in place by an inflatable balloon inside the stomach that is filled with water, and Bryon Johnson said that sometimes the water in the balloon can evaporate, causing the tube to fall out of place. Initially, he and his wife thought this is what occurred.

He said that Danielle Johnson sent their older daughter back to their home to get a new, sterilized tube to replace the one that came out.

By the time the paramedics arrived, Bryon Johnson said that Danielle Johnson had already fastened the new tube into Faith’s stomach.

“So we’re thinking maybe things may be okay,” he said.

According to the incident report, Danielle Johnson declined medical transport, and the paramedics left NREP at 12:16 p.m.

Danielle Johnson took Faith home at 12:24 p.m., the report says.

At 2 p.m., when Faith's parents attempted to feed her at home, Bryon Johnson said that "all the food was coming out around the G-tube."

"And so we had to come to the hospital," he said.

He says that while they were at UVA Health University Hospital, NREP's then-program director Tabitha L. Reeves, who now works as Frederick County Public Schools' director of special instructional services, informed them that the incident was a result of Faith's tube getting caught on her stroller.

Had they known the tube was pulled out in such a way, Bryon Johnson said he and his wife would have immediately taken Faith to the hospital.

"That was never conveyed in the moment," he said, "... which ... kind of delayed what we needed to do."

Danielle Johnson said the incident renewed concerns about NREP following Faith's individualized education plan (IEP), which states that her feeding tube must be placed inside her pants after feeding so that it doesn't get caught on anything.

"We've had several IEP meetings, and we've had several face-to-face communications, and I've sent emails communicating with them about taking preventative measures for that tube not to get snagged outside of her body," Danielle Johnson said in a phone call on Monday. She said she "asked them several times to keep it tucked in her pants so it doesn't get snagged or hold on anything to prevent anything from harming her multiple times."

The Johnsons provided an email showing that on Jan. 29, Danielle Johnson messaged the school nurse at NREP with such concerns.

"I've been noticing that her (Faith's) GJ tube has been hanging on the outside of her pants more frequently when picking her up and I just want to make sure that you can let everyone know that the tube needs to be tucked into the pants when the tube is not in use and when it's disconnected from the pump so we are not snagging/pulling the tube on anything so we don't have any complications," she wrote.

Following the Feb. 18 incident, the Johnsons were supposed to have more IEP meetings with the NREP team.

Then over the weekend, Faith died.

“She started, like, bleeding in the inside, right?” said Bryon Johnson. “They [were] doing CPR, and a lot of blood was coming out. ... So she passed. So the doctor came over and just said, ‘I don’t know what happened here.’”

He said the doctor suggested that an autopsy be performed “considering the circumstances” of her death.

Even prior to Faith’s passing, the Johnsons were trying to raise awareness about the Feb. 18 incident.

On Friday, the day before Faith died, Bryon Johnson said in an interview that the lack of initial information on the incident was concerning and that it ultimately led to a delay in seeking appropriate care for Faith.

He said the situation was especially scary because Faith was nonverbal, so she wasn’t able to tell anybody what had happened.

Johnson and his family want to make sure that something like this doesn’t happen to another child.

Frederick County Public Schools, which oversees NREP as its fiscal agent, released a statement Monday that, “We are heartbroken to learn of the passing of one of our students at Northwestern Regional Educational Programs (NREP), and we extend our sincere sympathies to the family during this incredibly difficult time. Frederick County Public Schools is fully cooperating with all pending investigations. Extra support, including counselors, will be available at the school for as long as it is needed.”

Frederick County Sheriff Lenny Millholland said the Sheriff’s Office was involved with documenting and investigating the initial incident on Feb. 18, since an FCSO deputy was on site as a school resource officer (SRO).

“We’ve documented what’s happened, and you know, we’ve been in contact with UVA, just to make sure that, you know, all the t’s are crossed and the i’s are dotted,” Millholland said. “... And our folks don’t know anything after they left NREP on Tuesday.”

According to FCSO Lt. Warren Gosnell, after Faith's mother declined medical transport, "we assisted the squad as we generally would at that point."

"When medical treatment is denied and a person, even a child seems to be in well being, we don't take any further action at that point," Gosnell said.

Bryon Johnson said Monday afternoon that the autopsy has been conducted, and that the family is expecting results in about 90 days. He wrote in an email that he wasn't sure who performed the autopsy "as UVA is handling that."

He also said that his family intends to pursue legal action over Faith's death. They have not yet retained an attorney, he wrote in an email, but plan on doing so.

The Johnsons are meeting with Child Protective Services this week to answer questions about the incident, according to Bryon Johnson.

A [change.org](#) petition organized by Tristan Kabesa titled "Justice for Faith Johnson: Demand Accountability from Frederick Public Schools" currently has over 1,300 signatures.

The petition demands the immediate termination of staff members directly involved in the Feb. 18 incident, a full and transparent investigation by FCPS, policy reform regarding the care of special needs students and adherence to IEPs, transparency and accountability by FCPS and grief support for Faith's family.

— Contact Molly Williams at

mwilliams@winchesterstar.com

Molly Williams