

Nehemiah Bauer

Looking into the smiling face and incredible blue eyes of three-year-old Nehemiah Bauer, you would never know the little boy suffers from a disease that creates havoc with his sturdy frame and fragile mind. Nehemiah, the youngest son of Alana and Nate Bauer of Mobridge suffers from a severe case of tuberous sclerosis complex (TSC), which causes him to have frequent seizures, from grand mall to mild, on a daily basis. Nehemiah has brain tumors that are believed interrupt the normal function of his brain and trigger the seizures. He was diagnosed with disease when he was three months old and it is something that he will live with as there currently is no cure. His older brothers Nathan, seven and Noah, five, are not afflicted with TSC (although Noah was born with spinal bifida but shows no signs of it now) and are protective of their little brother. He needs 24-hour supervision, the bulk of which falls on the shoulders of his family.

"I don't know what I would do if my mother (Gwen Grad) wasn't here," said Alana. "She takes care of the boys if we have to go to the hospital and is there to give me 'mental health' breaks."

Most people have no clue what tuberous sclerosis complex is, let alone that it is a disease that 50,000 Americans have and that more than 1 million people worldwide are afflicted with. It is a genetic disorder that causes tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. TSC occurs in both sexes and in all races and ethnic groups. It is a genetic disorder that is the result of a genetic mutation over which a parent has no control. It is often first recognized in children who have two neurological symptoms-epileptic seizures and/or varying degrees of mental handicap. Nehemiah has brain and heart tumors that affect the normal functions of those organs.

His mother first notice that Nehemiah was not showing normal behavior patterns when she was nursing him and became concerned with the eye fluttering that he displayed. The fluttering increased at an alarming

rate and the Bauers knew their child needed to be seen by specialists. He was diagnosed by a doctor in Bismarck.

"When the seizures first started he was having nearly 100 a day," said Alana. "There is no pattern, no rhyme or reason. Drugs work for a while, then we need to try something different or a new combination." The seizures can vary from small interruptions in his activities (he loves to run and climb on things) where will he stop and just stare at a wall, to the "drop" seizures where he will simple go limp and drop in his tracks. Some seizures are so severe Nehemiah quits breathing and must be intubated (an air tube inserted in his throat) to help his body receive oxygen. When he is medicated for a grand mal seizure, he must be taken to the hospital for emergency care. He has become a "regular" at the Mobridge Regional Hospital though he hasn't had a seizure that required hospitalization in the past eight months.

Nehemiah is now having full body seizures that turn into drop seizures. Trips to the hospital are frequent events for Nehemiah and Alana said the Emergency Room staff at Mobridge Regional Hospital is "wonderful" in helping her son, who they affectionately call "Nemo." There is a box with his name on it that holds the supplies they need to help Nehemiah in the Emergency Room. The Bauer's neighbors all know of the situation and help when Nate and Alana must leave the other boys behind to get their youngest son to the emergency room. The older boys take care of each other until someone else arrives, when their parents drop everything to run to the hospital. Nehemiah is very active physically, running, climbing and smiling brightly as he climbs into a lap for affection. He makes small sounds, but doesn't communicate verbally. He speaks to his mother through his eyes and she understands what he is saying even though there is no verbal exchange.

"He has a way of telling me what he is thinking," she said. "I have conversations with him, but I am the only one speaking."

There is a small bed for "Nemo" in the master bedroom, but he mostly sleeps between his parents at night.

"He has a seizure at about 2:30 and again at 4:30 a.m. and about once a month his brain will not shut down and he is awake all night," said Alana. "I don't know if I am physic or if it is mother's intuition, but I know when he is going to have a drop seizure. He knows too, because he will seek one of us out just before he drops."

The Bauers "tag team parent" said Alana, with one staying home with Nehemiah while the other attends activities with the other boys.

"We used to go to all the ballgames, but he is at point now where he doesn't want to be contained and we can't just let him run with the other kids," she said. "Nate and I still have a normal life, just not together."

Nehemiah wears a protective helmet to keep him from injuring himself during his daily routine but he has a number of small scars on his forehead, a telltale sign of the struggle for him to have as normal childhood as possible with his condition.

"We don't want people to feel sorry for us, we just want people to be aware of what he has and how it effects him," Alana said. "Our biggest challenge is balancing the lives of our children and also trying to figure out the appropriate approach to education and communication for Nehemiah."

He attends preschool at Freeman Davis and his parents couldn't be happier with the care he receives from the Para-professional, Carrie Stroeder, who visited the family home for two months prior to having to care and teach Nehemiah at school. Alana said the staff at the school has been extremely helpful and that the preschool teacher, Amy Sanquist, along with Stroeder, make it easy for her to let him go to school.

"The teachers are just wonderful with him," Alana said. "Carrie is like a second mother to him."

Since Nehemiah can't ride bikes or many other of the activities other children participate in, the Bauers found that a program in Aberdeen that seemed to work well for their son. "Nemo" loved to ride the horses in the SPURS program, a therapy program for children with disabilities. Alana said he connected with horses and was the outwardly more verbal than normal during his rides.

Unfortunately, the trips to Aberdeen became increasingly difficult for the family as cell phone service is spotty and Alana faced an emergency situation in which she could not reach the help she needed while on the road. It was a serious enough situation that the Bauers had to make the choice not to risk driving the distance, no matter how much their son loved the therapy and the benefit he received. "I wish we could find something here for him (riding horses)," said Alana. "He really loved the time he had with the horses."

It is just one of the "gut wrenching" decisions they have had to make while dealing with his condition. Another is on the horizon as Nehemiah faces surgery for one of the tumors on his brain that has increased in size and may cause an interruption of fluid flow to the spine. The choice between the surgery and radiation is a difficult one for the family, but the rate of growth in the tumor will play a role in the decision. The seizures have increased in frequency in the past two weeks. A trip to Sioux Falls for an MRI (magnetic resonance imaging), a test performed every six months, will determine which course of treatment is best.

There is also a possibility of surgeons implanting a nerve stimulator in his brain, to interrupt the seizures and lessen the effects the constant seizures have on his brain.

The family will make that decision soon, after the method of treatment for the brain tumor has been decided.

Finding the balance for their boys and for themselves is a challenge the Bauers will face as they have the others they have overcome. Although this disease affects the quality of life of those who have it, it does not affect the life expectancy. A life of challenges lay ahead for the Bauer family.

"For as long as I can remember I wanted to be mother," said Alana. "We were blessed with Nehemiah so I could take care of him. I am lucky to be able to stay home and do that."

On Saturday, May 12, the Bauers sister-in-law Patty Grad will be participating in a TSC Walk for a Cure in Minneapolis. People interested in donating to the fundraising effort, can visit the website at salliance.org, go to the St.Paul page, click on sponsor a walker and type in Patty Grad.

--Katie Zerr

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