

I am testifying today in support of SB 2276, Family Paid Caregivers. Hello, my name is Jen Zahn, my daughter Rylie is 11 and has Non-verbal Epilepsy and a rare genetic disorder called SCN2A. I am writing this letter today to tell you about her story. Her journey started with her first seizure, which was the morning of October 8th, 2013. She was 18 months old. We took her to St. Alexius hospital where they did not do anything for her to help find out what was going on. They just told us that she had a fibril seizure and shrugged it off. We then asked for a second opinion and decided to go to Minnesota. There we got seizure control for about 1 ½ years. The seizures then came back so we decided to go for a third opinion to Boston Children's Hospital in Massachusetts where we were for 12 days. At Boston Children's Hospital they told us that they felt that she was on the wrong medication, but they could not do anything unless we moved there. We then had another decision to make, move to try another hospital. My husband did some research. Cincinnati, OH, or Phoenix Childrens Hospital were among the top choices. I had family in Phoenix, so we quit our jobs, packed up everything we owned and moved to Arizona. Due to the severity of her seizures, I then had no choice other than to be a stay-at-home mom. We could not trust anyone other than ourselves to care for our daughter. Family and friends were able to help a little bit, but they also have their own lives as well. We were living on one income, and applied for respite but were never approved. As the time went by, we found it difficult to live on just one income so we decided that I would need to go back to work. I worked during the day and my husband worked at night, in order to maintain the proper care for Rylie. Phoenix Children's Hospital doctors were able to gain seizure control. After 5 years living in Arizona, we talked to our Neurologist to see what she thought about us moving back home. She stated since she has gained seizure control, she feels like it would be ok.

We moved back to Bismarck at the end of June 2020. Luckily, we were approved for respite care, and my husband and I both started new jobs. But, having a constant worry at work to make sure a stranger, who does not know our daughter is following the correct steps, watching her, tending to her needs, and most importantly making sure she takes her daily meds that she needs for seizure control is beyond nerve racking. We have since gone through 2 agencies, both have proven that me, her mom, needs to be her full-time caregiver. We have had our respite quit numerous times. The agency has no backups, so that means that I call into work and do not get paid. Our respite has been late numerous times so that meant me going to work late and me losing hours. My employer once asked me when do you anticipate this getting straightened out? I had to tell them that I was not sure as the agency is short-handed and they are trying to find workers but are not having any luck. My job is on the line everyday as I cannot trust that the agency will have coverage for Rylie or that they will be on time, and I could get fired. We had a respite worker have a real problem with germs and one morning my daughter had made a mess in her bed during the night when she was sleeping as she is not potty trained and always wears a pull up. She texted me that it was everywhere, and she wanted advice!?!?! I am sorry you need advice on what to do. You work for an agency that deals with special needs children every day so you should not need advice on what to do. I had to tell her to put her in the bath and get her all cleaned up, get her dressed, brush her teeth, etc. It is no different than any other morning, just have to give her a bath. She also asked if we had any gloves as she did not want to get anything on her hands. We at the time did not have gloves but I told her that we could purchase gloves if it would make her more comfortable, which we did. If you have that much paranoia from germs, I feel that working with special needs kids is not the right place for you. On another occasion we had a respite worker who was taking her to therapy and got in a car accident. I had to call Red Door Therapy and let them know what happened and to cancel her appointment. Rylie has never been in a car accident under my (our) care. She was not hurt as she was

checked over by the firefighters that arrived at the scene. Our daughter is completely nonverbal, so she is unable to tell you what her wants or needs are. As her parents we are familiar with her wants and needs and should be there to address them at all times. Not someone that does not know her and is not familiar with her. She also does not feed herself or able to use a fork or a spoon properly. She cannot drink from a straw or cup, is not potty trained, cannot bathe herself, dress herself, brush her teeth, brush her hair, tie her own shoes, put her jacket on or any of the normal everyday life things that kids her age can do. As her mother with everything that I have just explained as to what we have gone through over the last 9 years. Parents absolutely need to be the ones to take care of their special needs children.

I thank you for your time in consideration and I encourage a DO pass on SB 2276.

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My husband was getting her ready for daycare and she had her 1st seizure. He immediately called 911 and they took her to St. Alexius we packed up all our belonging and relocated to Arizona. hospital by ambulance. They did not run any tests and marked it off as a fibril seizure and sent us on our way.

Exactly a week later she had another one. Once again, we called 911 and were taken by ambulance to St. Alexius. While we were waiting our daughter had another seizure, so they started to run tests. We spent a couple of days in the hospital while they ran test after test and drugged her up to get the seizures to stop. Bismarck hospitals were not finding anything, so we traveled 6 hours to Minnesota for a second opinion. We started at Minnesota Children's Hospital where we stayed for a month while they ran more tests after test, hooked up to EEG's for days, trying all sorts of different medicines and found nothing. While one of the doctors was in the room talking to us Rylie had another seizure and he asked what that was. My husband and I just looked at each other and we said that it was a seizure. Rylie has had every kind of seizure, grand mal, drop seizures, myoclonic seizure, infantile spasms, absence seizures and focal seizures. He then realized that we were dealing with something more and made the call to Minnesota Epilepsy Group and we were transferred by ambulance. We met with Dr. Doescher and tried some other meds. We were at the Minnesota Epilepsy Group for a week while they ran more tests, EEG's, medicines changes until he found the right medicine that eventually stopped them, and we got the diagnosis that she has Epilepsy. We got to go home but had to go back every 6 months as we were also doing genetic testing to see if we could find out anything. Through all those trips we got a result back that our daughter Rylie has a rare genetic change called SCN2A and that causes Epilepsy and non-verbal autism. She went 1 ½ years without seizures. One of the doctoring trips that we took Dr. Doescher decided that we should try to wean her off of medication as he thinks that is why she is not talking. He took her off of Keppra but kept her on Topiramate. Well, that did not last exceedingly long as her speech never came back, and the seizures started back up again. He put her on a different med called Onfi instead of the one that she was on when she was seizure free from 1 ½ years. He told us that he believes these are the 2 medicines that she needs to be on, and we told him that we did not agree with his decision. We then knew that we needed to go somewhere else. We asked him who he suggested for another opinion. He mentioned Dr. Randa Jarrar at Barrow Neurological in Phoenix Arizona. So, we made the decision to move to Arizona in January of 2016. While I was in the shower Rylie was napping and she had a seizure that she bit the inside of her cheek, and it was bleeding. We called 911 and they came and checked her out and she was fine, and they told us that it would heal. We did not have an appointment with Dr. Jarrar until March, but she needed to be seen sooner. We went to the emergency room, and we were able to get in sooner. We met with Dr. Jarrar, and she told us that she spent 3 ½ hours reading Rylie's medical history. That amazed both my husband and myself as NO doctor has done that since we started this journey. We then knew that we had made the right decision. She immediately asked us why she was on Onfi. We told her we did not know and that it was the medicine that Dr. Doescher says that he believes she should be on. We told her that we did not agree with his decision and that he would not listen to us. She immediately stated we are going to change that as that is absolutely the wrong medicine for her.