

My name is Lisa Kroh.

Our address is rural New Salem. We live 17 miles west of New Salem on a farm. We are in the voting district 36.

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Our Story

In our family we have 6 children, 5 boys and 1 girl. Ages 15, 13, 11, 7, The last 2 are twin boys 5 years old. 2 of our children have disabilities, only one receives services. His name is Benat. I stay home and my husband works full-time and is also a full-time student.

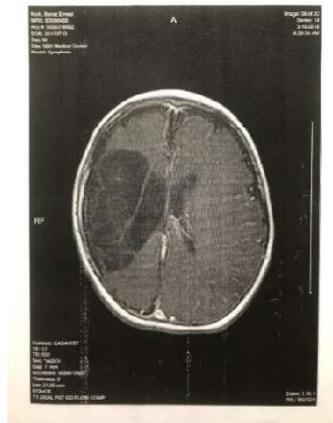


Benat was born premature at 33 weeks and is a twin. 7/13/2017



Within minutes after birth, we were told he had a **heart defect** and was flown to Mayo Clinic in Rochester, MN within 24 hours after birth. We were told he has a bicuspid aortic valve with severe stenosis of his aorta. At 10 days old he had open heart surgery. Luckily, he got to come home after only 4 weeks in the hospital. We were told that the fix was only temporary and by age 2 will more than likely have to have another surgery.

A about 6 months of age I noticed his left hand smelled bad and was clenched all the time. Asking BECEP why this might be, prompted me to further investigate. He had a head ultrasound done which showed there was damage. Then the MRI. He at some point in his short life had a stroke and is missing 80% of the right side of his brain. Meaning **cerebral palsy**. This affects him mentally and his left side physically.



MRI 3/16/2018

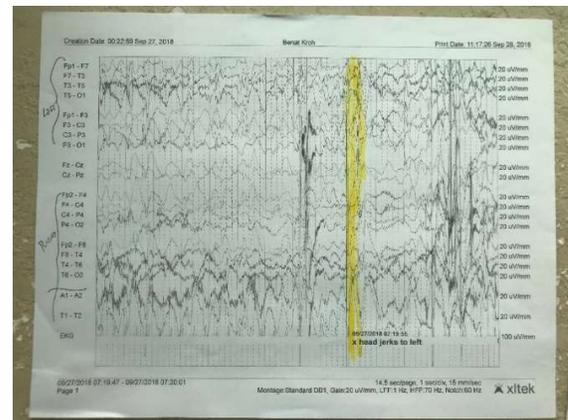
Shortly after finding this out, I noticed his eyes roll to back of head and he would twitch. Again, back to a doctor. 2 neurologists in ND then I asked to be sent to an epilepsy specialist in MN. After spending 10 days in the hospital, we found he was having 7-12 seizures a day and they were lasting 2-15 minutes. Partial and focal seizures. Basically, what I found out is his brain is so lit up they can't tell between brain activity and seizures. We now have it under control and have been seizure free for 4 years.



MN Epilepsy Group



It was like he was burping up!



Snap shot of EEG. WHAT?!?
How can someone function like this?

He has also been diagnosed with **visual issues (CVI), autism, speech delay, eating issues** (a lack of wanting to eat or drink without being continually prompted to eat) **and physical/mental processing delay**.

However, when tasks are programmed and learned it is evident that he is capable of things that are unimaginable to doctors given certain medical conditions and diagnosis that he has.

From the beginning of birth all I heard from doctors was “I’m sorry.” With no answers. Preparing for a life with a wheelchair and feeding tubes. Multiple appointments, lots of time traveling for unnecessary appointments. Paperwork. Wasting time and getting nowhere. I am a “listen to your gut” type person. We have got lots of guidance on our journey but it was Benat and I who get the job done.

Learning to eat, see, walk, talk, and now educate. He is an amazing little man.

My Daily Life:

Mondays, Thursdays, Fridays

5:45am – wake up 6 kids, Potty training Benat, Benat seizure meds and applesauce cocktail with miralax, help kids get ready for school.

6:45am – Bus picks up kids for school. Start laundry, vacuum, pick up house, work on morning dishes. Benat assists me with all these tasks. Some days we take the time for him to do them by himself with assistance. Takes forever!

8:00am – We go to learning room. I have set up a room in my house designated to Benat’s learning and therapies only. I have purchased mats, swings, wedges, therapy items, and school supplies out of pocket to help me with my son over the years.

9:30am – snack time/breakfast – takes him roughly 45 minutes with the use of tablet playing Blippi or Jack Hartmann to eat a bowl of cereal and drink a glass a milk through a straw with continual reminding to eat and drink. If he does not have a tablet, he will not eat.

10:15am – learning room

11:30am – free time

12:15am – Lunch (peanut butter and jelly with chips and cheese, glass of milk with straw)

1pm – Benat’s Nap time. I take dogs outside and tend to rabbits and chickens.

2pm – Finish house chores I didn’t get done in the morning.

3pm – wake up Benat. He is usually very crabby, lots of screaming, very mean for 45 minutes no matter what I try.

3:45-4pm – kids come home from school.

4pm – unpack backpacks, remind kids to get chores done, schoolwork all while Benat is at my side.

5pm – start to make dinner. We have a family dinner every night. All while Benat is at my side.

5:45pm – family dinner. I feed Benat and make sure that he eats. Again, can take 45 minutes+ for him to finish a meal. Often, I end up not eating.

6:30pm – family playtime

7pm – Bath time

7:30pm – Meds and TV time

8pm – Bedtime. Benat usually falls asleep around 8:45-9pm.

3rd Monday of the month is IEP PT at Prairie View Elementary 10:30-11:15am

Tuesdays and Wednesdays

Mornings are the same but no learning time at 8:00am, instead we leave to go to town for therapies and shopping.

Tuesday 9:30am-10:30am Sanford PT in Bismarck then shopping (Walmart or TSC)

Home by 1pm for naptime. This is the only day I get to go to Bismarck/Mandan.

1st Tuesday of the month IEP PT at Brave center 8:30am-9:15am

Wednesday 8-8:45am OT and 8:45-9:15am SLP with Little Lights Therapy from Bismarck but services are at PVE in New Salem, (they travel). Then we head to Mandan Brave Center for vision therapy at 10am for 30 minutes. Home by 11:30am.

Weekends my husband does schoolwork for the past 3 years. So, between tending to Benat and trying to spend time with other kids I am just existing.

Benat does receive Respite. He has received respite care starting with 10 hours weekly 7 months after birth to currently max hours weekly. I was going through agencies here in Bismarck for these services. Poppy's Promise, Easter Seals and was going to attempt trying a 3rd before going self-directed. My issue with the agency's is no one wanted to travel. And when someone did accept the position, they only worked 1 time or she was 70 years old and only came for 8 hours a week. She had a hard time getting up off the floor, where we spend 80% of our time. She came for only 8 hours a week when there was a possibility of 75 hours a week. Then someone was clocking in under wrong client and they sent me a bill. They pay an employee \$13 per hour but charge me \$33.80 per hour. WHAT!?! That is the day I went self-directed.

I find my help through Care.com, posting flyers in New Salem / Glen Ullin and word of mouth. The problems I mainly have is no one wants to travel. The weather prevents people from wanting to travel. Benat can be very challenging and loud. If one kid gets sick in our family, they don't want to work and get sick themselves. I totally understand but that sometimes can take 8-16 weeks to run through a household of 8.

If an employee quits it takes 30+ email to individuals through Care.com and over 3 months to get a response. When I do get a response it's an additional 2 weeks before interview, another 6-8 weeks for paperwork and background checks. I had gals come to interview, fill out paperwork and never hear from them again. I've had gals only work 1 day some 1 week. Most 3 months. I had an employee give me her 2 weeks in July this past year. I was unable to find help until October only for the new hire to work a week or two then have a family emergency and need to take a leave of absence until January. Currently I have 3 respite workers employed, but still can't seem to fulfill hours or have consistency.

I never had to put my kids in daycare because I was fortunate enough to stay home.

Benat should have been in kindergarten this year with his twin brother but due to severe issues with the school system in rural town the past 2 years and the fact that he has certain needs that they can't address, he is not attending school this year and might not be

attending in the future. There is nothing but problems in that school for kids with disabilities and if I want Benat to be educated and become productive at all then I am forced to homeschool, which has been mentioned as an option multiple times during meetings.

Everyone is feeling the financial burdens recently with what is going on in the world. Everyone seems to be affected. I don't feel like I have enough on my plate, so I decided this past summer I'll get a job at a local restaurant (20-minute drive), so we have extra income to help pay for things. I got to work 2 wonderful days. I showed up late 4 hours on the first day and 3 hours late the second day, due to respite not showing up and having to wait for husband to get off work. Then she put her 2 weeks in, so I ended up quitting. It was a sad day for me.

Cost of everything going up, can't afford to travel. I used to travel 4 days a week for Benat's therapies now we are down to 2 days a week. He and I were going to the chiropractor which was helpful to both of us however have now stopped because of financial difficulties. I used to get mental health services but now because of some recent changes to insurance I no longer get that. Our family wears glasses. Kids need eye exams and new glasses. How do we pay for it? Clothes? Food? School lunches? How do we pay for it? The kids want to be in school activities that's extra fuel and expense. Future appointments in MN. We have already refinanced.

My last real solution is for me to work between the hours of 8pm and 5am while the family sleeps. But then when do I get to sleep.

It's not that I don't want respite help, I need respite, Benat needs respite, but it seems to not be consistent therefore makes it hard for me to be able to have a life, the whole reason for respite. To give me a break. It's seeming impossible for me to have a job. I have asked many times, why can't I be paid for my services helping my son if someone isn't showing up. I have proven time and time again that he is making great gains beyond the doctors' expectations. I am saving a lot of money and paperwork doing things myself. Benat and I have done all the work with guidance along the way. I struggle to get things I need for Benat due to financial difficulties. Things that are not covered by insurance or Medicaid. If I were to get paid that would relieve financial stress and allow Benat the things he needs to become successful instead of waiting 6 months for something to go through the system and be denied. It would also relieve the financial stress of everyday life. Maybe I could leave the house more often because I could pay for fuel.

This past December 2022 at a cardiology appointment we got confirmation that Benat has entered surgery phase meaning every day that goes by his heart is getting worse and as long as he can tolerate it and ECHO show no enlarging or thickening on the left side of heart then we wait. He needs to grow and gain as much weight as possible before surgery.

May 30, 2023 we will be travelling back to Mayo in Rochester, MN to have another open-heart surgery to not fix but replace his aortic valve. Until then we wait unless something changes with him, and his heart goes into failure. With that in mind I have no idea what's going to happen or how long we will be there when it does. Will the girls that are hired respite still be here when we get back or will I have to start over again looking for help. Could you wait as an employee for a month with no paycheck? I still don't know how we are going to afford to travel and pay for hotel?

With that thought, I want to thank you for your time serving our state and for listening to my testimony. I urge you to vote yes on Senate Bill No. 2276. Families are in crisis, we need help now.

Lisa Kroh – imchorty@yahoo.com - (701) 319-0118