

Interview with Asude (Nurse/Nanny)



- 1. Could you give us some information about the patient?**
Her name is Ruby, she lives in Etobicoke with her parents and her older brother. Her condition is 13 q chromosome deletion and she goes to Beverley School.
- 2. How old is Ruby?**
Ruby is 9 but she looks like 4 because of her delayed development. Doctors say that her life expectancy is 13 years old. Oh also, her hair does not grow.
- 3. Could you describe us her disorder?**
Biologically, during fusion of sex of cells there was an abnormality that caused this disorder. The baby is born with missing materials from the long arm of DNA. This is neither a genetic or a heritable disease. It increases the risk for problems such as birth defects and growth and it causes development delay. With this disease, it depends how much material has been lost, so cases vary significantly. There are many that can walk, talk and eat. However, this disease was diagnosed 20 years ago, so not a lot of info has been found yet. We only know that it is very very rare and that there are not a lot of information about it. There is only one doctor who kind of have an idea at Sick Kids, that is it. We just know that Ruby is the worst case. She has a very weak immune system and she is extremely weak when she has a cold. Also, because it is neurological disease, even though she is in a wheelchair she is not paralyzed, she feels everything.
- 4. What is her condition if you were to give a 'quick explanation' and how it affects her everyday life? Does her condition gets worse?**

Ruby is fully dependant and needs supervision at all times. She can't talk, eat or walk. Her condition does get worse but she would have periods where it even gets worse than before. She will get a seizure daily for a full week, then not get any for 3 months, so her case is very unpredictable. She also had eye cancer on her left eye, she had a treatment and she is okay now but she is wearing glasses and her eye sight is 7.

In terms of eating, she eats through her G/J Tube feeding pump which feeds her formula food to her. The fee of the formulas is covered by the government. The tube goes through her small intestines. She does not eat from her mouth and she does not use her stomach during this process. She is drooling a lot and we have to be careful because she does not have the reflex to swallow since she has never eaten from her mouth. Imagine as if there is tube coming out of your abdomen where there is an opening and closing system, almost like a lid where we connect her pump whenever we feed her. The pump works during the day for 4 hours then stops for 2 and this cycle repeats itself. During night, it works continuously with a lower speed. Oh also, she can taste food but she would not swallow it.

In terms of walking she can't walk but I have taught her how to sit straight, and I am really proud of it! Ruby uses strollers and her wheelchair. She has a stander that stabilizes her and helps her stand up because she cannot balance herself.

5. What are some activities that she can do independently?

Unfortunately, she is fully dependent. Ruby can feel and understand textures, she can hold on to an object if it is given to her, but she can't grab an object by herself. Also, she can take her glasses when she is frustrated. She also can move her legs and arms at the same time, so she can swim with a life jacket on.

6. What is one specific area that she needs help most with? Eating, getting around, communicating, basic necessities, etc.?

Like I said before she is fully dependant for everything but sometimes the most challenging thing is to carry her. She is heavy and I do have a lot of back pain because it is very hard to carry her because she is heavy and I have to do it a couple of times when I am changing her position from wheelchair to stander, putting her to bed, changing her diapers, giving her a bath... Also, she is very sensitive to hot, cold and sunlight.

7. How do you communicate to her?

Even though Ruby cannot talk at all, she shows expressions or uses sounds to communicate. I really do not know how much she understands but I always talk to her, sing to her and she responds with the biggest smile or clap which means that she is happy. When she gets frustrated because she is unable to communicate her needs, she would cry or make sounds. In that case, I would try to understand if it is because she needs stimulation, hugs, kisses or she if she needs to get her diaper changed or maybe because she is in pain. She also does not like change, she likes routine and repetition, maybe that is why she also gets frustrated sometimes. She sometimes hits her head because she needs a lot of stimulation. She sometimes shows her frustration by taking off her glasses or by putting her right leg high and kicking it repetitively. Physical touch is very important to Ruby. Stimulation is key to her happiness, I always hug her, give her kisses, caress

her cheeks, just give her lots of love. She always calms down when you give her hugs, or turn on the songs that she likes.

8. Does she have any learning difficulties?

We're not sure how much Ruby processes or understands, but she can associate things. For example, at school one of her teachers took her hand and pressed a button which made music play. Later on, at home I have put a button in front of her, put on one of the 13 kid songs that she loves and suddenly I have stopped the music and she pressed the button! So we know that she can associate and connect things but she also forgets. I usually try so that she does not forget but sometimes she does not press the button. So maybe she forgets?

9. What does a typical day look like in Ruby's life?

Ruby wakes up at 6 am to go to school. When she is up, she gets her 3 medications and gets her diaper changed. The bus comes to take her to school and she spends around 7 hours at school where she has movie time, swimming time, reading time, stretching time, playing time, and lunch time. Sometimes teachers would put food in her mouth so that she can taste and she does not feel excluded when everyone is eating but of course she would never swallow. After she goes back home, a PSW, a person who works for the government, takes care of her for 2 hours. During that time, they bath her, change her diapers, start her formula and play with her. When the PSW leaves, she spends time with me. I take her to the park, play with her, listen to music, sing songs and make sure she sits up and get some exercises by giving things to her hands to hold. In the evening her parents come home, spend some time with her, then they put her to bed, give her 3 medications and change her diaper.

10. What are the three medication she is taking?

I think one of them is for sleeping, another for seizures, and the third helps her with digestion.

11. Does she have a favourite toy, if so what is it?

She has a bouncing chair that she loves. She always kicks her legs and has the biggest smile. When she gets bored, I think she likes to get dizzy. Maybe that is why she hits her head repetitively? That is also another reason why she needs to be supervised all the time. When she does that I always give her a hug and she stops, she always needs some kind of stimulation.

12. What is her favourite activity?

Swimming is her favourite activity. She needs a lot of stimulation and swimming is really good for that because it is like a huge hug. She has to wear a life jacket and have supervision all the time. Since her tongue is always out (doctors are not sure of the reason), it is possible that she will swallow water which is very dangerous. I think her tongue is always out maybe because she does not have the reflex to swallow? Or maybe it is because she is scared to swallow her tongue?

13. Are there any products that make her life harder, any accessibility issues?

There aren't specifically products that make her life harder, or at least she is not using it. But, there isn't a lot that makes her life easier either. Parks, paths, schools, etc. are not accessible for her, and she is limited to the places where she can be. Lack of ramps in some places makes it harder to use her wheelchair. However, this does not stop me or her parents to take her out. Her

parents would take her outside to dinner sometimes. I would say if there was a product that helped to pick her up that would be really helpful.

14. Are there any designs or tools that makes her life easier?

Her wheelchair, it kind of looks like a stroller actually, life jacket for swimming, her bouncy chair, her pump and G/J tube, and definitely her stander. I would also say music makes her life easier in some ways.

15. How is she with strangers? Does she recognize people?

When she hears her mother or me, she would turn her head and try to see which is something she usually does not usually do so we know that she recognizes her mother and me. She also loves strangers, she is definitely a social person.

16. What are five most important things in her life?

Definitely her family, her wheelchair, music, love and me of course !