

Charlotte's View



Don Richer

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A heartwarming tale of how the birth of a special needs child can bring a family together and, at the same time, drive them apart. Charlotte, who is barely eight years old, tells the story through the eyes of her father. The reader will experience laughter, sadness, and joy, and will touch anyone who has had the pleasure of knowing a special needs child.

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Donald K. Richer

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First Edition

Chapter 1 – The Cave

The first thing I remember was being in this little cave which is ok because I remember being really little too. After a few months of being carried around by this cave I think that someone was taking pictures of me through the wall of the cave. They weren't really snapshots but almost like a short video. There was this circular motion on the wall of my cave. I didn't know to say 'cheese' then and I'm not sure that I could smile yet but I still thought it was intrusive seeing how I didn't know anybody yet.

I'm not sure what an embryo is or why people have such interest in them but these pictures are becoming increasingly annoying. It seems like it happened a lot and I was starting to get a little paranoid. Not to mention that I seemed to be growing faster than the cave. My paranoia apparently was justified. I don't know if I could actually hear just yet but I think there was some concern about the way the pictures turned out.

In order to get these pictures I was taken to this big building where I could sense a lot of muffled talking and felt a lot of moving around. On the way to this place I was thankful that the cave, which seemed to have a transport (Baba's car), had some great music to listen to. It was a bit noisy at first but I got used to it and I think I found out later that it was rock and roll. Ironically, rock and roll was what I was supposed to do *after* I got out of the cave.

But I digress. One time I had to go to a different big building to have my pictures taken....again. After that, I had to go to yet another big building in a place where there were hundreds of big buildings. This I found out later was a city. So far I had

preferred the country. But now my pictures had to be taken by more professional photographers and a lot more often. Something about enlarged ventricles in my brain.

Well I don't know what those are but apparently it was a concern for the people operating the cave and the ones developing the pictures. On the other hand (which I hadn't developed yet), they kept mumbling the number 10. If the ventricles were over 10, that wasn't so good. If they were under, that was good! And here I'd always thought that 10 meant you were perfect. Or maybe that thought came later.

Anyway, this went on for months. I was thinking that we could have nipped this in the bud if the cave owners had hired a proper photographer in the first place. And, here I am becoming more claustrophobic in this cave that doesn't seem to grow at the same speed as me. The only way to get someone to take notice is to kick out with what I think are my feet. The result that I get from that is a bunch of giggling noises and what sounds like oohs and aahs and people touching the wall of my cave. So I kicked some more as if to say, "I'm already cramped in here! Back off!" But nobody listened.

So I'm still here and now it's getting really tough to move although not to be a total complainer, the food is quite good. I'm not sure how long my sentence is but I'm really hoping to be outta here soon. I've been trying to find a way to escape but so far I'm stymied. Whatever extra room I have is filled with some sort of fluid but I can't swim yet and there is nowhere to swim to. It can't be long now so I'll try to stay patient and see what happens in the next little while.

I must have just had dinner because I'm feeling full. But the operator of this cave is becoming more unsteady each day. I feel like I'm being sloshed around from side to side and then

when that subsides, I feel like I'm falling. Not far, but it's as if the cave person has given up moving and has fallen and taken me with it. Then a big splash. But today seems a little different. We are in Baba's car again and end up in the first big building that we ever went to. Aside from sloshing back and forth into the big building I am now resting comfortably. I was wondering if they are ready to let me outta here because I'm ready to get out.

Everything seems pretty quiet for the moment and I'm taking a little rest to make sure I have all my energy when I get out. Just as I was thinking this, half my fluid disappears. What the heck? Am I getting out? There seems to be a lot of more voices now. I didn't flow out with the fluid which would have made sense to me but at least for now I have a little more elbow room. And I'm thinking; 'let's try this on for size'. So I start throwing elbows and feet on a random basis and things outside the cave are starting to heat up. Finally, I have someone's attention.

I have never wanted anything so bad (actually I've never wanted anything except for food) as to be sprung from this cave. And seeing how it's something that somebody wants, me in this case, it seems to take forever. Like waiting for Christmas and Santa Claus but I didn't learn that until later. For the next few hours, days, or whatever unit of time they used, I started to hear these ungodly sounds. They came and went at first but eventually they were more frequent. I'm thinking that I've got to get outta here soon. This noise and now, it's like my body is all contorted – I feel like I'm upside down or something.

Then something wonderful happened. I'm not sure what it was but the cave operator was very still and I could sense, very happy. Prior to this happiness I remember being flipped onto

my side which really bugged me but a short time after there was a feeling of mellowness, bliss, euphoria even. Even so, I stayed put. I'm hoping this is some sort of going away party although it seems I'm the only one here. The cave dispatched a lot of the fluid giving me some room and now this feeling of imminent escape was overwhelming me. It could only be a matter of time.

All of a sudden I could feel something touching me...something that had never been in my cave before. I could hear those voices again too...and there seemed to be some sort of urgency for me to get out. For nine months all I wanted to do was to get and now I'm being evicted. And get out in a hurry. But wait. Apparently I couldn't fit through the door. Now I'm being shuffled around again although I swear someone actually touched me. It was only a few minutes before I felt contact again. But this time it was violent. I'm sure that someone was attacking me with a knife!

Well apparently I was right. The normal exit door was blocked and those people out there had to create a new one. Little did I know that the new door was very tiny, even for me. But I must have wanted to get out pretty quick because as soon as I saw daylight, I started to make noises that I hadn't heard before. Everything got really bright and there were a lot of people making a fuss. My eyes were killing me and then these hands were drying or wiping me off of all that fluid I had lived in. I'm not sure where I am right now but it looks a little more livable than my previous residence. I think I'm now on the other side.

Chapter 2 – The Other Side

Wow, this is different. From total darkness to bright lights. I'm crying like crazy and there are way too many people witnessing this. Someone is trying to wipe all this fluid off me and there is a strange man coming to take a picture of me....again. Only this time I can actually see the camera. I learned later this was my father...or Dada as I've come to know him. My mother, otherwise known as Baba, is lying on her back. Shortly thereafter I realized that that was where I came from. It had to be. No one else in the room seemed to be that happy and relieved that I was in the room on my own. This was my first feeling of satisfaction.

Everything was so overwhelming that I just wanted to sleep. So I did. The next thing I know is that my Dada started carrying me and took me to a much bigger cave. There were no restrictions in this cave....lots of room, no fluid surrounding me. There is Baba lying on the bed again and now I'm in her arms. Time to sleep again. But wait. There are now a dozen other people in here. All smiling and oohs and aahs it made we want to vomit! So I did. Except later I heard that it was just a spit up.

People certainly were giving me a lot of attention now. I guess that's what happens when you've been cooped up in a tiny cave for what seemed like 9 months. Everybody was celebrating and bringing me furry things that I had no idea about and if they noticed, it's not like I could actually hold them. But everyone wanted to hold me! I was passed around like a hot potato with more of these goo-goo sounds which I started to imitate later. The worst part was that I was starving. Seems my cave wasn't so bad after all. I could eat anytime I

wanted but now I can't find the tube that had the food. What does somebody have to do to get some food around here?

It turns out I was released from the cave on a Friday just after lunch. Whose lunch I don't know but it certainly wasn't mine. Now it's Saturday and apparently a bunch of other days come after that, not that I really care at this point.

Eventually the fuss died down and I got to sleep with Baba for a while. And then she introduced me to something that would give me food. I guess they took my tube and put it on her. Either way, I was just happy to fill my body. But that wouldn't last long. For some reason I had trouble finding enough food. A few women in some type of uniform (which I learned were nurses) took turns coming in to figure out why the food source wasn't getting to me. This would go on for a couple of days but without much success.

After a while I was hearing this strange noise that was constant and really bothering me. Then Dada would be there to pick me up and the noise would go away. Whenever he put me down it started again. Eventually I realized that the noise was coming from me and if I wasn't happy then it started all over again. Besides, I was still hungry. That first night my Dada carried me around one of these big buildings, down halls and around corners and I slept most of the time. As soon as he put me down, that noise come back. So he'd pick me up again and he would start our walk all over again. This went on for another day or so but I had no way of explaining that I was just hungry! And slightly tired.

More people are coming to my room; some I've already met and some new ones too! This goes on for a couple of days but by Sunday I overhear someone say that I'm checking out on Monday. Well that sounds good if I knew where the heck I was

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going. All of these people just talk in some strange language that I can barely understand. If I could I would just speak up and make them let me in on the secret.

On Monday I am still not feeling that well and I AM STARVING! I get some food down but it doesn't seem to stay in or even fulfill my body. How much can it take? I'm barely 3 days old! You would think that there would be enough food in Baba's tubes to fill me up but it's not working. Anyway, it looks like everybody is packing up to get ready to leave. One of those nurses picks me up and takes me to another small cave. Then she puts me on this ice cold metal thing and everyone went into a panic. Well good for them...I'm frozen!

Chapter 3 – Unexpected Delays

As I was on this scale there seemed to be some concern. The nurse told Dada and Baba that I had lost nearly 20 per cent of my body weight in the 3 days since my birth. I heard that 10 per cent was within normal (there is that number 10 again; normal, not perfect). And I wondered just how bright these people were! I have been crying and making noises for days because I'm hungry and I can't find enough food to eat. And this is the first time somebody weighed me?

So my trip home...I assumed that was where I was going, was put on hold and they started to feed me something called formula. Well at least it was something. And then they stick in me in an incubator which is something that helps baby chickens grow but apparently has other uses. They put these funky rubber sunglasses on me because the light was so bright. This cave is small like my first cave but at least it has windows. For 36 hours I am in this thing and now everyone that comes to see me can't touch me and they peer through the glass like someone watching an animal at the zoo. I'm getting a little more food though, which is good, but I'm still feeling like crap.

I don't want to do anything except lay here waiting for my next meal. If that wasn't enough, they take me out of the incubator and move me to another room (I thought it was an upgrade to the penthouse suite but later learned it was the neonatal intensive care unit). The surprise was that there were a half dozen other people my size in the same sort of accommodation. Not much privacy for sure but I figure if these babies have been here a while it can't be all that bad.

On Wednesday, around feeding time (which was all the time as far as I was concerned), this man was checking me out. He had

a long dangly thing hanging from his neck and a white coat that looked pretty official. He poked and prodded and lifted my arms up and then let go of them. They just fell back down because I didn't have the strength to hold them up. He started talking to Baba and Dada and said that I was lethargic and that he would like to consult with a specialized Children's Hospital (a hospital is one of those big buildings that I visited when I was in the little cave). Well apparently everyone agreed that this was a good idea. Within 90 minutes of this decision, I find that I have been taken from this big building into another transport called an ambulance. A bigger transport to be sure but with a lot more bells and whistles.

The crazy part is that Baba and Dada are no longer around! I saw them leave the hospital without me and left me in the hands of strangers. I wasn't sure what I did wrong but obviously it was pretty bad for my family to leave me. I didn't know if I would see them again. Even though I didn't know them for very long, I felt some sort of attachment to them and was surprised that they had given me over to people I had never seen before. Although these strangers fawned all over me like all of the other people did that visited me, they also fitted me with tubes and masks and put me in the ambulance.

Little did I know that I was going on my first vacation straight down the highway that leads into the city and yet another hospital. The ride in the ambulance was exhilarating, sort of, complete with flashing lights and sirens and twists and turns that you wouldn't believe if you've never been on this highway. I don't know how long this was supposed to take but apparently these sirens and flashing lights take a back seat to no one. Well, except for the uneducated driver. There are a few of those in the city. But I was at my new resort in no time. The 4 people who collected me and arranged my transportation

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were all good sports I guess but they hustled me out of the fancy ambulance and into this special hospital.

Chapter 4 – My First Vacation

There wasn't much fanfare when I arrived though and I was starting to wonder if I had the right travel agent. More people with dangly things and white coats, green uniforms and serious faces began to poke and prod again. Haven't they had enough? No! Now they take me into this room (a room is a large cave by the way) and start putting little round stickers on my chest and back and head. All of these stickers have some sort of string attached to them and are hooked up to machines that weren't around at the hospital that I came from.

I think they were doing a CT scan which means absolutely nothing to me. All I want to do is eat. And the tube that Baba had provided wasn't around. Well, they didn't starve me...they gave me something to eat that was unknown to me but I didn't really discriminate at the time. After this ordeal, they took me to another, bigger room, also known as a neonatal intensive care unit. I figure this must be a chain and I'm starting to give my travel agent a little more credit.

I don't have to live in the incubator anymore and there is more space than I could ever have imagined. Talk about luxury! The down side was that I had these stickers all over me again along with some plastic tubes in my nose and hands. Later in my life I loved novelty stickers and so did all the other kids. I assumed that they went through this same rigmarole when they were babies. I found out later that most did not.

Lo and behold, when I opened my eyes for the first time, there was Baba and Dada. Apparently they left me at the other hospital to go home (whatever that was, the only 'home' I knew was one of these hospitals) and pack. Oh joy, oh rapture (to quote a famous scarecrow but that is another story). They

didn't abandon me at all. Their packing took a longer time and they didn't have the benefit of sirens and flashing lights driving down the highway like I did. Lucky for me, I don't have much stuff so I travel light. Ok, so I feel much better now that there are people here that I am familiar with.

Now that they were here I was hoping they could stay but with the other guests in the NICU it was not allowed. The resort did have a waiting room where they could stay but I heard it wasn't that comfortable. Here I am in luxury accommodations and Baba and Dada are trying to nap on couches that are too hard, too soft but none just right. Another story I heard about 3 bears but that comes later.

So I spent the first few nights on my own but had Baba and Dada with me for most of the days. And never mind all of the stickers and wires; they were actually inserting very thin metal objects into my skin! Each time it hurt like heck and I let them know it but did it make them stop? No! Picture this.

At some point (excuse the pun) they couldn't find a suitable insertion area in my hand, arm, leg, etc. for some concoction to feed me and replenish my fluids. I guess they thought that this was crucial to my future existence. So, in their infinite wisdom and after scoping out the rest of my body, they decided that the only option was to stick this sharp thing in my skull! If that wasn't bad enough, they shaved almost all of what little hair I had off of my head. I was left with a strip down the middle and I'm sure I heard giggling and some reference to someone named Mr. T. In the meantime they stick this thing in my head that hurt like the dickens and was attached to a tube going who knows where to who knows what and that was it. They put me back in my barred cell and now some beeping noise started and continued without interruption. I'm fairly sure that I had heard

these beeping noises before with other monitors but this was getting ridiculous. If the beeping wasn't enough there were these voices that seemed to come out of the walls! What planet am I on?

Over the days to come, I was hooked up, looked up, poked, prodded, fitted with more stickers but on a good note; fed. I heard later that Dada had bought a pump or something so that Baba's tube could provide food for me. Not sure why they needed a middleman but don't look a gift horse in the mouth. Or something like that.

During the first 24 hours or so, a white coat (now referred to as a doctor) had examined me extensively. It was mostly physical although I had a feeling they were looking at the fluid that they kept stealing from me as well. This doctor, who was a geneticist, was concerned about my physical features. No one had showed me a mirror so far so I wasn't exactly having an inferiority complex just yet.

But, the following conclusions were reached. I had a diamond shaped eyebrow...only one. My ears were too low on my head. I had a webbed neck. My palate was arched, my chest sunken and breasts too far apart. Finally, my skin was mottled and two of my toes on each foot crossed each other. Talk about building my self-esteem. I don't remember the doctor looking like a runway model either! Preliminary diagnosis: Turner's Syndrome. More on that later.

Having been in my accommodations for the rest of my first week, I could count on the visits from Baba and Dada. Although I remember that on the Saturday (this is part of the weekend but it's all the same to me), the nurse was informing Baba and Dada that I was nearly out of food. Well, that didn't sound too good to me. Where is the middleman in all of this? I

heard Dada tell the nurse that there was plenty of food in the freezer at home and if she had only mentioned it on the telephone that morning I would be having a feast!

So while Baba stayed, Dada had to return to the food cache, up the twisty turny highway that he'd already conquered that morning, and stock up on supplies for his favourite person.....me! At least I think I was his favourite. We seemed to have gotten quite close in just a few days. He was back as quick as possible and while I had enough food to tide me over, there is a distinct satisfaction from knowing that food is close at hand.

It also seemed that the nurse was a bit testy and I could sense somehow that Dada and Baba weren't too happy with her attitude. She didn't apologize then and you could cut the tension with a knife! (Which I am still afraid of)

Dada and Baba came to see me religiously over the next few days and I was feeling more comfortable in my surroundings. After a myriad of more probing tests over this time, we finally heard some good news. I was getting my own room! No other guests, only the sound of my own crying instead of a cacophony of wailing voices from my roommates in the NICU. And the testy nurse? Suddenly she was a big softie and gave me a butterfly shaped pillow from NICU with the initials of the hospital. I still have it today and I think Baba and Dada looked at her much more favourably. And more good news awaited me.

Chapter 5 – Syndrome, What Syndrome?

In case you haven't been following the timeline, I'm only 9 days old so far. When I signed up for this mission, no one informed me that I would be the subject of extra-terrestrial research! And, much more to come. And there is not a darn thing I can do about it.

Turner's syndrome is a condition that only can happen to girls. In order to determine if I have it, a test of all of my chromosomes must be completed. The ultimate test is to find out if I have two X chromosomes. Ok, I am a girl so if I don't have two Xs, somebody is in big trouble. All girls are supposed to have two and I'm thinking I should be ok. I have two arms, legs, hands, eyes, ears, nostrils and of course two parents. Pretty good odds yeah?

The repercussions of having only one X are this. A massive chance that I will not be able to reproduce when my Dada gives me permission (which will be a long time). The growth of my hormones will be stunted, pubic and breast development will be slow or non-existent and a myriad of other horrible things could happen. Well, they're horrible if you are a girl. The geneticists are always looking for new genes to be tested as this diagnosis is a work in progress. But the main thing is I really need to have two Xs.

So while they extract more of my precious fluids to conduct these tests, I am told that it can be many days, weeks even before the results are in. Actually they didn't tell me but I overheard it I think. So, we'll see how my odds go in a while.

In the meantime, lots of other stuff is going on. And the best part is that my new exclusive room at this resort has a live-in guest! The first night in my new digs seemed to last forever but

in a good way. Usually Baba and Dada would leave me alone each night to let others look after me. Tonight, when it was time for Baba and Dada to go, Dada ended up leaving alone. I'm thinking something is weird here but it's not the first time Dada had to leave only to return again in a little while. But this time it didn't happen. Well at least not that night.

There is one spot in my room for a parent to sleep and Baba is now my permanent roommate! No offence to Dada but at least I got one of them. I sleep most of the time but they don't know that it's always with one eye open. I don't miss a thing. Dada will be back I know, but it sure is comforting to know Baba is there to help me listen to the beeping machines and squawking wall boxes all night and I decide to close 'both' eyes and get a good night's sleep.

Lately I have been referred to as Miss Charlotte. I'm pretty sure Dada coined it and it seems that it has caught on. It still sounds pretty garbled but at least I can hear it and know that they are talking to me (or about me). You know what they say, whether they say good things or bad, as long as they're talking about you. Sounds lame. After a couple of days in my new room, Dada comes to visit and covers up a piece of the glass door with a sheet of paper. Apparently it says, Miss Charlotte's Room. The nurses laugh and the other people in the neighbouring rooms notice it but I am happy considering that after only 12 days of life, I have my name on a piece of real estate.

Pretty much every day I have to take a ride to another room and have another test. I don't know what it is with these people but they are very much prying into my personal life. I have now been assigned to an occupational therapist. Or she was assigned to me. That title sounds like she is a therapist that has

an occupation. Kind of redundant don't you think? Anyway, she is there to make sure I improve my eating habits. Now, I have been eating much better lately and I feel sated for a period of time. I am gaining weight, very slowly but surely and the mood around this resort is somewhat optimistic.

But there are test results yet to come so I'm not out of the woods yet. After another week or two, the big test results have come back. Of all the tests that I've had, the results seem to come back slower and slower. One person orders the test, another performs the test, and another analyzes the test and sends the results back to the one that ordered the test. Seems to me that there could be a shorter circuit but what do I know?

Now I am not that involved in that whole rotation, nor do I really care at this point. But I can sense that Dada and Baba are somewhat anxious in receiving these results. It looks like that the person who ordered the test, receives the results but they are rarely in the hospital at the same time as Baba and Dada.

One evening I noticed, sleeping with one eye open of course, that there was some tension in my resort accommodations. From what I could make out, this pretty, young female doctor came in while Baba and Dada were there. A few minutes after she left my Dada told me not to touch her because she was HOT. She was. But in the meantime Baba and Dada were eager to hear the results of the latest tests never mind the previous ones that were sketchy. Baba and Dada were persistent in learning my fate. It looked like the answers were incomplete and the tension increased.

After two or more weeks of hearing some answers and results, but not all, everyone was getting pretty antsy. The doctor asked Baba and Dada if they had actually left the resort for some downtime to be on their own. I was thinking, if you're already

at a resort then why would you need downtime somewhere else. Well Baba hadn't and Dada did in the sense that he wasn't allowed to stay overnight but he also had a job to do. I still don't know what a job is and I don't care. But they agreed with the doctor! They left me there and went out to dinner. I don't know what their menu was but when they returned it certainly smelled a lot better than the stuff they were giving me. And the bonus was that Dada's kind boss, Mike, told him to put the dinner cost on his expense account! Again, means nothing to me but I got the impression that Dada was pretty happy about it.

During all this time, I keep hearing some familiar words and it seems that they're coming from Dada's voice. He's reading a book to me from this doctor, can't remember his name and don't remember meeting him but apparently he knew some cat that wore a red and white striped hat and got himself into all kinds of trouble. The words were something I had heard before and frightfully I thought I had heard them in the first cave that I was in. Well it was true. When I was in the small cave, I kept hearing this muffled sound each night and could barely make out the words. But it made me feel oh so satisfied and I looked forward to hearing them time and time again. For a time I wondered how Dada got in that cave with me but I later learned that he was reading to me through the wall of the cave which of course was Baba's stomach.

Now that I could hear these words without the confines of a cave wall, it was even more satisfying to me. I didn't know about books then and I wasn't up on all the latest children's authors, but this one held a particular stranglehold on me. Although I love all books now, especially the ones that I can rip, this one would be my favourite. I may not have the title right but I think it was called, 'Baby the places you will go'.

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Which was quite appropriate because I have been so many places already! The only place I haven't been yet is *home*.

Chapter 6 – Two Xs?

So far at this resort I have been subjected to all of the tedious tests and whatever they entail. But one thing has happened that has been particularly enjoyable and continues to be. A bath! Baba and Dada and whatever nurse is around at the time put me in what amounts to a big bowl of water with a little of some scented stuff that doesn't smell that bad...and then they caress my whole body! I find it very exhilarating and I get this treatment pretty much every day. Travel agent is definitely in the good books.

I didn't know my love of water would carry over later in my life but man, I just love the stuff. Feed me six times a day; bathe me four times a day. Miss Charlotte will be one happy girl. I'm steadily gaining small amounts of weight and the occupational therapist is changing the contents of my food every few days. Now, whatever the middleman is providing is mixed with something they call rice. I guess this helps and it doesn't taste too bad but the important thing is that they keep feeding me.

I have been here for a couple of weeks now and the service is pretty good. But the scenery is becoming all too familiar and I only see the same old faces. Baba and Dada must have thought so too so they started putting me in this little transport called a stroller. From there we could go into another transport that went up and down. When it starts to go down I feel a little flutter in my tummy but later learned that this was normal and that I was being introduced to gravity. Gravity isn't so bad.....keeps your feet on the ground.

When we get to ground zero, I go outside...essentially for the first time! Outside is a place where they don't have any walls,

floors, ceilings, beeping machines and squawk boxes. But there is this beautiful thing up in the air in between all of these big buildings and its blue! Well most of the time but sometimes it looks a little white with these big puffy things and sometimes the puffy things are gray and it looks a little gloomy.

So I go rolling around in my stroller and find that there are a lot of interesting things to see. A lot of people to be sure but a lot of transports driving down the street. But the noise, noise, noise! Just when I thought I had escaped the beeping and wall boxes, I am subjected to a lot of other beeping from the cars on the road....different but still annoying. Anyway, it's still better than being cooped up in a room and I get to see new things all the time. I don't understand what they are yet, but I'll get it.

Around this time one of the doctors delivers some news to Baba and Dada. I'm thinking I should be in on this but I'm not able to voice my opinion just yet.

The results of my chromosome tests have been mostly completed but the most important part is that I have TWO X chromosomes! Diagnosis of Turner's syndrome.....Negative. This doesn't mean much to me right now but Baba and Dada are elated and relieved. The joy on their faces is equal to the joy I felt getting out of that first cave and it actually relaxes me even though I don't know exactly what is going on. If Baba and Dada are happy, I'm happy. But I am one thing for sure.....I am a girl in the truest sense.

But not so fast. While I am out of the woods with Turners, there is apparently a backup affliction. Doctors always have a backup plan right? Now they tell Baba and Dada that in spite of my negative diagnosis for Turners, there is a mirror image of this condition that can exist in boys and girls. It is called Noonan's syndrome and all of the symptoms remain the same

except for the X chromosomes. Can you believe it? Of the two, girls can potentially have either of these syndromes while boys can only get one. Hardly fair. But I learned later that girls always have choices and boys don't. So I can't really complain too much. And besides, this would be the lesser of two evils.

It doesn't help me too much to know but there are other genetic testing procedures for the doctors to do to determine if I actually have Noonan's. So, out of my millions of genes there are 3 possible genes that they can test. And then getting the testing done is no walk in the park. In fact, I heard the doctor tell Baba and Dada that the testing had to be done in another country! At great expense! But, if our government run health plan was so inclined, they would cover the expense. So I'm thinking, what if they don't? And I am also thinking what if they do. Not a darn thing I can do about it one way or another. And even if they do, I can't change the outcome of the tests anyway.

In the meantime, there are other tests to be conducted. What a surprise. Has anyone heard of an evoked potentials test? No? Me either. Not Baba, not Dada, not Santa Claus or the Easter Bunny. So this is what they do. I told you about the stickers and the sunglasses before. The stickers and wires they plaster on you are beyond belief. They're all hooked up to more beeping machines and to top it off, they make me wear these funkier sunglasses than I had in the incubator. These things looked like they came off a circus clown.

Evoked potential tests are designed to assess the level of my hearing and sight senses. Well, at least at this point. As for my other senses I know I can taste and my smell takes in the aroma of food with no problem. I can feel stuff but other than skin from Baba and Dada it doesn't really interest me. To tell you

the truth, I can't remember a thing about this test and I don't know if they have sedated me or it was just a good time to crash.

What they do is send signals to my eyes and ears and whether or not I am awake or asleep, it sends a signal back to see how I react. Pretty clever stuff. So, a couple of eternities later the results come back. Okay, not eternities but a day or two. My eyes are fine. More on that later. Hearing good in one ear...not so good in the other. 3 out of 4 isn't bad I figure. But it doesn't get me out.

Speaking of senses, I mentioned that the smell of food was one of my favourite things. I have this memory of a Saturday evening. Dada hadn't been there that day and I was again getting worried that he was gone forever. Then, all of a sudden, there he was. He was carrying what was called a picnic basket. He thought Baba could use a good home cooked meal. The scent of that aseptic room went from, well aseptic, to the most beautiful aroma I had ever experienced. I assumed of course that it was food but I didn't learn until later that it was exactly that. Not just food. Barbequed food. And I was also told later that the menu was strip loin steaks, baked potatoes, corn on the cob and a bottle of red.

Naturally I wasn't interested in the red, but for the other food my sense of smell was getting an overdose. All this stuff I learned to love later and I think it came from that night. But the bad side was that Baba and Dada sat on the floor and ate the whole thing in front of me! Not an offer of a bite, not even a whiff under my nose. I thought it was pretty selfish until I found out that I wasn't quite ready for that stuff. But I tell you, I could smell that all day long.

Chapter 7 – Paroled

I'm about 4 weeks old now and while the resort isn't bad, it is getting a bit tedious. We do all the same routines each day and the main focus is to make sure that I gain weight and stabilize my eating habits. This seems to be working although at a relatively slow pace. The middleman keeps coming through so that's good. I still get my gravity rides and my tours of the outdoors and that's pretty enjoyable. Baba still lives here of course and Dada is there every day for a time.

I'm not totally unhappy and I am becoming closer with these nurses and occupational therapists. The most successful OT is named Wendy, I think. She visits me whenever she can and if I could tell her that I'm mostly happy with my food, I would. Test results continue to come back but nothing is proving that there is anything wrong with me but the beat goes on. So it is determined at this point that the main point of my stay here is to gain weight and develop normal eating habits. Hey, that was fine with me from the beginning. Let me eat, eat, eat! It's up to these other people to figure out how. Sheesh!

About two more weeks go by and the routine stays pretty much the same. I've gotten to know a lot of people here and they all treat me right. Even though there are many other kids here who have a lot more to worry about than I do, I feel like I'm the centre of attention. This is good for my esteem and I'll exercise that feeling later in life. Little do my parents know at this point in time.

On a Tuesday, the doctors have talked to Baba and Dada and not unlike the X chromosome story they seem happy and relieved. A lot of the test results haven't come back yet but the

doctors assure us that they will be in touch because on Wednesday I'm going home.

Home! I don't know where home is but I don't really care at this point. I'm going home! Some of the nurses have dropped in to say goodbye and a couple of the other parents whose kids were worse off than me. I hope I had a positive effect on them and that they could look optimistically at the recovery of their kids.

All of the stuff that I had was taken out of the room. I didn't realize that I had that much stuff but we were apparently setting out for greener pastures with nothing to be left behind. For the first time since the cave, I was back in Baba's car but was strapped in like a prisoner in jail. Like I had done something wrong. What could I do wrong at this age? But I learned that it was for my safety so it didn't matter. And besides, I was going *home*.

Charlotte's
View



Don Richer

A heartwarming tale of how the birth of a special needs child can bring a family together and, at the same time, drive them apart. Charlotte, who is barely eight years old, tells the story through the eyes of her father. The reader will experience laughter, sadness, and joy, and will touch anyone who has had the pleasure of knowing a special needs child.

Charlotte's View

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