

My Personal Story - By Dannielle Goodwin

Contents

Where I was raised as a child	2
Some facts.....	2
Getting in rolled for Pre School	2
Getting in rolled for Primary School	2
Having EEG at the RCH for 6 weeks with 1 week of 24hr video monitoring.....	3
Going to Secondary School	3
Getting employed for my first job.....	5
Getting referred to see a neurologist that deals with adults.....	6
Having my first date.....	6
Getting Engaged.....	7
Getting married for the first time.....	8
Moving into our brand new house.....	9
Finding out I am expecting for the first time	10
Having a baby for the first time (Sophie).....	11
Baby number 2 (Eric Barry).....	17
Baby number 3 (Jane)	19
Baby Number 3 (Jane) Diagnosed as being SCN1A Positive	20
Jane's first seizure.....	20

Where I was raised as a child

I was brought up on a dairy farm in Gormandale in Gippsland I was the fourth child out of five children. My mother and father had a next-door neighbour named Rhonda that would come and help voluntarily look after us because she enjoyed it and new my mother would appreciate a helping hand and I called Rhonda nanny when I started to talk. Rhonda (Nanny) was more of a grandparent than any of my blood related grandparents that didn't want anything to do with me when I was younger because of my disability because I was so much responsibility. My mother didn't get any help from family and relied on her next door neighbour Rhonda (Nanny) and had some help from her other neighbour Faye and Ian but mainly Rhonda.

Some facts

- I had my first seizure at 6 months after my needles
- My first paediatrician specialist appointment with Dr Ian Skeleton at 6 months and was later seen by Dr Joseph Tam
- I had my first paediatric neurologist appointment with Dr Kevin Collins at 15 months old
- Dr Kevin Collins first diagnosed me with epilepsy at 15 months old.

Getting in rolled for Pre School

I was enrolled at the Gormandale preschool when I was 4 years old for 2 years and had a teachers aid with me threw my pre school years and didn't have any trouble enrolling me at the time. When I had my first seizure at Pre School I had trouble with parents worried about their children seeing me seizure and getting frightened by my illness. Whenever a Childs birthday party came up I was despised of and was not invited but they would always invite my twin sister Prudence. Thank goodness I had the best pre school teacher ever Joan Kimberley and would have teddy bear picnics at her own family home where I was always invited to go and be part of with my pre school group.

Getting in rolled for Primary School

When getting enrolled for primary school my enrolment form was rejected, my mother was then told I would have to be enrolled into a disability school called Bringer at the time in Moe and was just under a 1hr drive each way to pick me up from there. My mother was at a disability conference in Geelong when she met Joan Kirner who was the guest speaker who at the time was premier of Victoria. My mother pleaded with Joan Kirner and said "as a mother to a mother would you please look into our situation I live on a dairy farm with five children and my husband is working away it is impossible for me to do 3hrs of driving to Moe there and back twice a day and run a dairy farm please I am asking you", Joan Kirner then intervened after my mothers plea for help and as a result I was able to go to a normal state primary school with a teachers aid at all times. My

mother said "I paved the way for other children with a disability to get into normal state primary schools."

Having EEG at the RCH for 6 weeks with 1 week of 24hr video monitoring

When having a EEG for 6 weeks on the top floor at the royal children's hospital was hard I couldn't leave my hospital bed at all and missed being at school and had to play card games with my mother like snap, uno and memory. My mother stayed with me the whole time I was there and would sleep in a normal hospital chair beside me I don't know how my mother did it. After a few weeks in hospital they organised for me to cook pancakes in bed and watch a video in bed at that point in time for me was like letting a child in a candy store. After my six weeks were up and trying to catch me having a seizure I didn't have not one seizure in that 6 weeks and was amazing at that point in time of my life. When it had come time to remove the EEG wires from my scalp I had a grow spurt and they were stuck on my scalp and the Doctor and nurses had trouble removing them I was screaming in pain while they were removing them and I wished that they had sedated me.

Going to Secondary School

Going from grade 6 from a small country primary school to having the same children you went to Pre School with to having only about five people you new from your primary school was hard. Going to high school to complete Year 7 that was in town it was hard for me because my mother had arranged the school to have Prudence and me to be separated and not be in the same classes threw my secondary school years. It was my first time been separated from my twin sister Prudence didn't have to worry about me I didn't know any one and my social skills at that time where very low, my mother and father had trouble with getting a bus driver to accept me on to there bus to pick me up and take me home because I was such a big responsibility, in the end it all worked out and a bus driver named Darren accepted to have me on the bus.

When catching the school bus for the first time it was difficult because I had to lug a back pack full of school books plus carry an oxygen tank with me to school and back home again and every body would ask on the bus when carrying the oxygen tank what is that for? Because at that time I was having more seizures than normal, After having so many questions and feeling so embarrassed carrying a oxygen tank with me I asked my mother could I please leave the oxygen at school at the office and bring it to school on Monday and bring it home on a Friday and my mother ended up saying yes ok, what a relief that was for me. I had a teachers aid with me threw my classes her name was Helen she knew my mother from garden group in town. When I had got a bit more settled at school my mother said to me to tell Helen she has a beautiful garden and Helen said to me why thankyou tell your mother my house is up for sale. So when I got home that night off the bus I told my mother what my teacher's aid had said and my mother just smiled.

That same week I had a GP appointment and the GP advised my parents to move in to town to be closer to medical facilities. The following week my parents went into town while I was at school and looked at my teacher aid house and of course my mother and father fell in love with it and decided to buy her house.

When every thing had gone through to buy my teachers aid house my mother and father brought my 2 brothers and 2 sisters and myself in to town and said we have something to show you and they took us to a house with a real estate agent and said this is our new home we are going to move in Melbourne cup weekend.

So I was very excited moving into town coming from having just a dirt track with lots of mud from dairy cows to walk and ride on and no shops to having concrete footpaths to ride a bike and walk on and having a shopping centre with in a short walking distance was great! Between year 8 and year 9 I asked my teachers aid to help some one else that needed help when I didn't require her help because I was starting to get confident in certain classes, because I didn't feel I needed help in the classes I was comfortable with. I asked for her assistance with classes I was not confident with.

But I didn't like having a teachers aid with me in class because I felt such an outcast in the class.

In year 7 to year 9 I was a loner in the school ground I would often spend my recess and lunchtime periods sitting in the office or library just for company until I asked the office ladies would they like a hand with some of there chores and one of the office ladies named Helen said " yes you can help me young lady, can you please put the labels on these envelopes" And I of course I was delighted to be helping someone and doing something to fill in my recess and lunch time periods and from there my office skills and social skills blossomed I ended up getting trained for everything from writing up the teachers read out in the morning to answering the school telephone to delivering mail to pigeon holes to photocopying faxing ect... as well as representing the school on very many occasions. When I had to leave the year 7 to year 9 campuses I found it hard because I got so comfortable with the office ladies and had to say goodbye and start all over again. When I got to the senior campus I was nervous because I didn't know any one and I had lost my teachers aid from the junior campus.

But can I say I gained a much better teachers aid that understood me much better than my junior campus lady, she would make me try and do things on my own to boost my confidence and can I say that's what I really needed to boost my confidence and if I hadn't got some thing right on my first try she would give me clue but not the answer.

I ended up getting offered at the senior campus that deals with year 10 to year 12 to do my administration certificate II and I accepted. When I went into year

11 the start of VCE I did do some VCE subject but not all of them I only did the ones I was confident on doing I got offered to do a new program at that time and it was called VCAL (Victorian certificate applied learning) I was also doing my class for certificate II in office administration.

Through VCAL I got to do a lot of things from swimming to a defence-driving course to completing my learner permit and passing all of them. Including that year I also did my debutant ball and had to have dancing lessons.

Getting employed for my first job

On the same week as my debutant ball I found out I had been accepted for my first employed job at MacDonald's, two days after completing my debutant ball I had my first 3 hr shift at MacDonald's. I was so nervous with my first shift but I was thankful that my twin a few months before hand had got a job there so my crew trainer was very nice to me because she knew my sister. I had tried to get a job at MacDonald's the same time as my sister and got a interview but kept on looking at the floor because I was so shy and nervous so at school they helped me to make eye contact with people because that was my only failure in my first interview.

3 months later being employed at MacDonald's I was told secretly I was rookie of the month by my twin sister but was not acknowledged for it because they were trying to cut cost over those few months when the store was quiet. When your 3-month trial is up your job is safe so I had a heap of good news all at once and made me extremely happy.

When school Christmas holidays came up I had lots of shifts on the roster and I was thrilled. I started saving money and buying glory box things for when I got a house of my own later in life. I remember my sister saying to me you will never get married or have a boy friend because you just don't fit in because she was annoyed that I had more shifts in that week than what she did. The following year was year 12 it was a very exciting year because it was the end of my school years and it was my final year of VCAL and doing my certificate II in administration plus taking on certificate II in Retail Operations threw MacDonald's and completing some exams for a VCE score but was not worried what my VCE score result was because I wanted to get straight into the workforce and earn a income rather than go to uni to study. Closer to the end of the year I got asked to represent the school to collect a plark from parliament house in Melbourne for being one of the first schools to have VCAL as a program to learn and had been completed for the first time.

At the end of year 12 we had a formal graduation where I got to collect two certificates one for completing office administration II and VCAL. At that point in time I had sold some paintings that I had painted for teachers that they had asked for me to complete for them for Christmas presents to give to others. I

remember my nanna saying why is it granddaughter that you can sale your paintings and I can't and I have been painting picture for years and have not sold one.

Seeing Kevin Collins for my last appointment was hard because I had been seeing him since I was 15 months old. At my last appointment I gave him a gift and it was a painting, I had painted a picture of a mother seal with her baby siting beside the rocks at the beach from that last painting I haven't done any more. I remember Kevin Collins saying to me I have been looking for the right person to take over my care for you for a long time and have found some one I am extremely happy with I got someone very special to look after you that will help you deal with thing when you are a adult she will have all your answers that I cant answer because I deal with children so I am referring you to see Prof Ingrid Scheffer she is very good at the work she puts in to others and is very good at her job.

Getting referred to see a neurologist that deals with adults

Meeting Prof Ingrid Scheffer for the first time was exciting but nerve racking because it was my first appointment with her I had just turned 19 years old and had to go threw all questions to know the ins and outs of me.

At one of my appointments Ingrid asked me to have a trial test to see if I carry a gene that may cause my epilepsy and of course I said yes after completing that test I found out the I carry the SC1NA gene known today as Drave` t Syndrome that day my mother cried because she was so relieved to find out the reason for my bad history of seizures.

But when I would like to have a family my options were to have IVF to harvest all my eggs and then test all the eggs any egg that carried the gene was then disposed off or conceive naturally and have a 50/50 chance of having a baby with the gene and get the baby tested at 12 weeks to see if the baby carried the gene and if the baby had the gene to then have abortion IVF was going to be the safest way on paper.

Prof Ingrid Scheffer also asked My twin sister and me to go into a twin study, we then agreed to have the twin study and found out we have the same DNA as each other and have the same IQ and still today they are trying to find out why I have the sodium channel gene and my identical twin doesn't.

Having my first date

After finishing high school my twin sister went to get a higher payed job so she was able to save money for her nursing studies to go to uni the following year. When she started her new job at a call centre she meet a man at her work that livid in the same town as us and began to share the cost of travelling to work by car pulling. One day my sister invited that man into our family home for a drink

after work and my mother offered for him to stay for dinner and he accepted to have dinner with us. After he had dinner with my family he thanked my mum for a lovely dinner and went home to his house as normal and said to my twin I will see you in the morning as he was hopping into his car.

The next day my twin sister had a big grin on her face after she had finished her shift at her work and said I know some one who is interested in you and I just smiled thinking she is playing games and she said know I am serious and I said who? You know that man that is car pulling with me and had dinner with us last night he said to me today "g I like your sister" and I said "that's nice I will believe you when you prove it" my twin then said to me "know I am serious I have invited him for dinner" and my twin said to my mother at that time "I hope that is alright with you mum" mum replied "yeah know worries he seams nice" and he arrived about 30 minutes later for dinner my twin had set it up like a blind date when he was around the night before I took no notice of him because I was helping my mother preparing dinner so my twin was in my ear before he arrived make sure you look at him and talk to him and I got so nervous of course and hardly said a thing.

It was the end of the working week and my twin sister had arranged for herself and her boyfriend to go to the movies and invited me and the man she car pulls with to go on the same night. That same night I had already arranged to catch up with a friend that was a man from school so I sat in the middle between the two of them and I was thinking in my mind whom do I go for? And I decided to go for the man that car pulls with my sister and in that movie we held hands for the first time and accepted to have him as my first date.

In that point in time I was saving some money to fly up and see my nanny in Queensland and asked my new boyfriend Daniel would he like to come and he said yes that sounds great in that trip we went to the gold coast for 3 days then flew up to Bundaberg where my nanny lived and had some time with her for 4 days then flew back home.

Getting Engaged

9 months into our relationship Daniel asked to have dinner with my parents without me and I clicked straight away that he was going to pop the question soon, that night after my parents had dinner with him my mother had a big smile on her face, that was a dead give away for me.

When I saw him the next day I confronted him and said "you asked my parents to have my hand in marriage didn't you" Daniel said no with a silly look on his face, I said "why would you ask to talk to my mother before talking to me on the phone and ask my parents to have dinner with you last night and not invite me, come on Daniel I am not that silly you asked my mum and dad could you marry me" Daniel said to me "why did you have to spoil it for I didn't want to tell you

now I wanted to make it a surprise and take you some where nice and now you have ruined it." I was in shock and Daniel said to me "will you marry me Dannielle?" and I said jokingly "I will have to think about it" then Daniel said "ok that's fine I understand" then I said "yes of course I will marry you" that night I told my family I am engaged. The following day we had arranged to go out for dinner to have our parents meet for the first time.

The following day my mother asked me when would you like to have the wedding and I said " I haven't thought that far ahead, I need to make a weekend to have the Engagement party first and get the invites posted out then I will think about the big day." My mother then said "you do realise people will ask you when the big day is at the engagement party."

So after I had got the invites posted I started to think about a wedding month not a date and decided to get married 1½ Years later in November. When the engagement party came around every body congratulated us with lots of kisses and hugs, when it came time to do a speech from Daniel how we meet each other and thanked every body for coming my nanna pipped up to the end of Daniels speech and said, "When is the big day?" Daniel replied, "in the middle of November we are still making a decision on the date but November is the month we have choose yes."

Getting married for the first time

The time after our engagement went so quickly it was time to make arrangements for the wedding and to start looking at dresses, booking a venue, and choosing a reception and who I would like to have for my bridesmaids. We decided to get married in my mother and father garden at home and had our wedding venue just 1 kilometre away in a function room at a bistro just down the road.

After deciding where we are having the venue and reception I was able to start making my own invites for the wedding what a job can I say, finding the write paper, background colour, ribbon to go with it with the write colour and write size envelopes that would fit the invites in was a pain but I was very happy with the end product that I had hand made. The night before the big day had arrived and I was so excited, I slept on the couch at my mother and fathers house because my elder sister had travelled from Geelong and was down for the wedding and slept in my room with her husband and 7month old son. The next morning was the big day and I woke up feeling tired but at the same time I was excited any way and was worried that I was going to muck up my words in front of every one.

The race of time was on it was raining that morning and the phone at my mother and fathers house was ringing of the hook with offers of marques and help to change the venue but my mother said it will be ok it will clear and declined the

offers. I had to go to the hair dresses and get my hair done in the morning followed by my make up I was so worried about my make up and hair being ruined before I had to walk down the isle because it was still raining out side.

By midday the rain had started to clear and the sun came out what a relief that was I was on the final touches of my hair and make up being done and had to arrange all the other last minute things to be picked up from flowers, cake and balloons.

Then the last hour till the wedding started people started arriving early with offers of help once everything was done my mother decided to invite people in the house for a hot drink where I was trying to get ready for my special day and not wanting people to see me before I walked down the isle because I wanted it to be a surprise for every one, so I stayed in a my room for 45 min and then called out to my mother asking could she please ask people to go out side so I can be more comfortable with my sisters helping me to get ready and not have to stay in one room.

So by the time my mother organised for the house to be cleared of guest and only had immediate family inside I was able to come out and my grandfather was sitting at the table finishing his drink and said you look stunning granddaughter then my nanna walked in and said wow don't you look beautiful I was just thinking time is running out and I said to my nanna and granddad you need to go out side the music is going to start in a minute, then my father walked in and said are you ready to go and I replied and said "yes I am" then we walked out of the house a down the isle where my future husband Daniel was waiting to marry me I got to the end of the isle and my mother was waiting to give me away with my father. Once both my parents agreed to give me away I held hands with Daniel and said our vows.

After we had said our vows and exchanged rings every body applause and congratulated us and our guest headed off to the reception while my immediate family stayed on for our photo's done in my mother and fathers garden Once we had gone to the reception and completed our wedding waltz we cut the cake and thanked every body for coming. The following day we had breakfast at my mother and father house with family and friends then we set off to Melbourne dock lands to go on the spirit of Tasmania for our honeymoon.

When we got back from our honeymoon we moved into my mother and fathers house until our house that we designed our self was finished getting built and was able to move in a few months later in February.

Moving into our brand new house

February came around very quickly and was time to pick up the keys for our brand new family home. After collecting the keys for our new home I had to

clean all the floors, bench tops, and wipe out cupboards before I placed any of our new house hold items because there was still some of the builder's dust left behind that would have settled after the lady that cleaned it roughly before change over.

Once I got my lovely new house all cleaned and moved the furniture where I thought it would look best and packed all the cupboards and made all the beds it was 3am in the morning.

Finding out I am expecting for the first time

6 months later I had another appointment with Prof Ingrid Scheffer and of course she asked how is my epilepsy going? How you going with work? Do you like living in your new home? Have you settled in ECT... 2 weeks later after having a appointment with Prof Ingrid Scheffer I started to having shocking nausea and vomiting and tiredness and just thought I was stressed and had a bug this went on for more than 2 weeks and decided to make a doctors appointment because I was loosing a lot of weight from vomiting and was starting to feel I was getting a bit dehydrated. I went to the doctors appointment that my mother had booked for me because I was working a lot of hours at the time, I went to the doctors and she asked me a heap of questions and then said I would like you to have a blood test just to check every thing is normal and of course had the blood test and found out the test result on the same day and found out I was pregnant for the first time. I had tears rolling down my face because I was in shock my mother was smiling with delight and said to me "you are going to have a baby your first child how exciting" the doctor smiled and said where is your husband are you going to give him a call and tell him and I said "no I will go to his work and tell him in person".

So we then left the doctors and went to Daniels work and arrived there and I couldn't get out of the car because I was still in shock and said to my mother "I cant do it I am a teary wreck I cant go in looking like this" and my mother said "someone has to tell him I will go in and tell him the news" My mother walked into Daniels work and told him the news that he is going to be a father for the first time and Daniel came out of his work door after my mother came out to the car to see me with the big gist smile in the world.

Daniel said "wow honey we are going to have a baby when are you due?" I said I don't know I have to have another appointment tomorrow to get ultra sound scan form but in the end of April or May some time by the blood test result. I then phoned Prof Ingrid Scheffer and let her know that I was expecting a baby for the first time and was delighted with the news but was worried about the sodium channel gene and asked me to have a appointment with Dr Mac Gardner who was into genetics at the Royal Woman's Hospital and explained that there would be a 50/50 chance of conceiving a baby with Dravet syndrome and offered me to have the baby tested at 12 weeks for the dravet syndrome gene

and have a small chance of a miscarriage, If the baby had tested positive then I was offered to have the baby terminated. I then declined the offer because I didn't want to be responsible for a miscarriage if it was a perfect healthy baby. A week later I had an ultra sound with my mother and Daniel in the room and sore for my own two eyes my baby heart beat on the screen, I had a tear roll down my face with delight and held my husband hand that bit tighter with a smile on my dial. At the time I was suffering excessive vomiting (hyperemesis gravidarum) and working and loosing a lot of weight but was able to keep my self hydrated by having small amounts of fluid at a time.

When I was 4 months into my pregnancy my excessive vomiting had cleared up and had lost over 25kg over those few months of vomiting every day. The last 4 months of my pregnancy went very quickly, I finished getting shifts as MacDonal'd's at 32 weeks and can I say I was devastated because I had a lot of energy at the time and enjoyed working the only thing I had trouble towards the end was a pregnant brain on some days but not all, taking some ones order on front counter and putting the wrong burger on my customer tray.

I got called into work when I was 36 weeks pregnant to work 2 emergency shifts over two days I remember my manager saying now you tell me if you need anything or if you are feeling sick at all. I was quiet pleased to get those shifts at the time because it was my last week living by myself for a month with out my husband home because he only came home on weekends at the time. After Daniel finished working a month away at Mornington the time was coming closer for our baby to be born Daniel only had a 3 weeks left of work and he was counting down the days to finish working.

Having a baby for the first time (Sophie)

I was 39 weeks pregnant and Daniel had finished his last shift at work and we where counting down the days till I was full term at 40 weeks and thought the baby would come between this time how wrong was, I was 40 weeks pregnant and was sick of being pregnant because I just wanted the baby out because I was hot and bothered and uncomfortable Daniel was constantly asking me each day have I had any pains since he started his holidays when you are a pregnant lady that gets very frustrating and out right annoying.

A week had passed and I was one week overdue I went to my mother and fathers house to help look after my great grandmother that was nearly 100 because my mother was unable to look after her because she had to work. I started getting Braxton hicks pains about 3:30pm in the afternoon one every 30 min but kept on being the same time and not getting shorter so I didn't worry too much about it and focused on looking after my great grandmother.

My mother had arrived home from working 48 hrs just before dinner, I said to my mother "I had been having pains since the late afternoon but they keep on

coming the same time and they don't get shorter apart" my mother said " don't worry about it they will go away but no having a baby tonight I have just finished a 48hr shift of working so keep your legs crossed" So I had some dinner with my family as normal and my twin had offered to stay the night at my house and I said to Prue " don't worry about it I will be all right" then Daniel said to Prue "I would like you to stay if that's alright and Daniel said early night for you my dear.

We then finished having a conversation at the dinner table and said goodnight to everyone, my mother walked us outside to our car as we were opening the car door to hope in my mother said to me "now no having a baby tonight I have just worked 48 hrs and I am not fit to drive a car to Melbourne so keep your legs crossed." I hopped in the car and said goodnight to my mother, Daniel at the time was still talking to my mother while my twin sister Prue grabbed something to wear to bed, my mother said to Daniel "baby's are born on cold nights like this" after Prue and Daniel hopped into the car and we left to go home. As I got ready for bed after going to the toilet I lost my mucus plug and panicked and asked my sister to hope out of bed I said to Prue what is this? She said "owe its ok it's your mucus plug congratulation I think you are in labour go and hope in bed and try to get some sleep.

So I went and hopped in bed and tried to go to sleep but couldn't. 45 minutes later I started having more pains closer together and Daniel said, "Are you ok Dannielle? I said "no my pains are getting worse". So Daniel then hopped out of bed and woke Prue up and said to her "Dannielle pains are getting worse and that she would like to head off to the hospital" Prue replied, "I need to ring mum and give her some time to get ready".

So Daniel was trying to comfort me and had phoned the hospital we were on our way down Prue was trying to get a hold of my mother by phone my mother answered the phone fairly quickly and said "Dannielle is in labour isn't she" and Prue replied and said "yes mum its time to go to the hospital" my mother said "I have only got home from taking my grandmother home to my Aunty house and have just hopped in bed I will quickly get dressed and grab some things and be around in 10 minutes".

My mother finally arrived at my house and she said "Dannielle you hope in my car where you will have more room and you will be able to focus on your contractions" I hopped in the back seat of my mothers car because I didn't want to go with Daniel because the car seat was in the car with all the pram, bags and I didn't want Daniel distract while he was driving. So Daniel followed behind my mother and then Daniel realised owe I don't have enough fuel to get to Clayton.

So we had to stop a Pakenham for fuel and believe me I was not happy because I had been in Daniel's ear saying make sure the car is full of fuel because I will be

deeply annoyed if you have to get fuel when I am in labour. After Daniel filled up his car we were on our way to Monash Medical Centre to have my first baby.

When I arrived I got my mum to get a wheel chair and hopped into it we got the lift up to the birthing suites and Daniel told the desk we have arrived there was a birthing suite available so I was able to get into a bed straight away as the midwife was finished helping me from the wheel chair to the bed she asked me "are you having a boy or a girl? I replied and said "we don't know it's a surprise whenever we had a scan the baby would always have its leg crossed". The midwife analysed me and I was 3 centimetres at the time and asked me if I would like some pain relief and I said, "No thank you I would like to go with out it for as long as I can cope".

It was a hour after the nurse offered pain relief and the contractions were getting stronger they were getting so strong and intense I couldn't do it by myself anymore and called the nurse and asked "could I please have some pain relief?" the nurse said "of course you can I will just analyse you first and then I will get you some pain relief you are doing great you are 5 centimetres.

The nurse and Doctor asked me what I would like for pain relief and I said, "What is best for me and they said we would like you to have an epidural just in case we have to do an emergency C section. I then said "ok what ever just please help me with the pain". The antithesis arrived to put the epidural the lady asked me "can you curl up into a ball for me and lean forward I no its hard and uncomfortable bit it will only be for a few minutes until I get the needle in place after a few goes the lady got it in. I asked the antithesis how long will it take to work the Dr said it will take about 20 minutes and then you will get some relief would you like some gas while the epidural is kicking in? I said "yes please what ever that will help me with the pain".

20 minutes after the epidural had been in place I was still having gas at the time I could still feel every single contraction an epidural is meant to num you from your waist down but in my case it didn't. So towards the end of my labour I felt like I couldn't go on and started to feel I was going to pass out from the intensity of the pain and then the Doctor and midwife checked me and said "you are 8 centimetres dilated when I tell you to push you must take deep breath a push".

So I was on a adrenalin rush when I heard them say that, I pushed whenever I was told to and I got to full dilation, towards the end my membrane were still in place and was in front of the baby head when ever I pushed they just bulged out and wouldn't burst an hour had past of pushing and the doctor asked me would you like me to just touch the membranes because they are just sitting there and see if they will burst and sure enough they burst and 1 big push after that our baby was born, the doctor announced it was a little girl Daniel cut the

cord and kissed me and said "wow we have a baby girl" and we named our beautiful little girl Sophie at 7 pound 6 ounces after Daniel had cut the cord my twin sister was collecting the cord blood for testing of Drave` t Syndrome.

My mother was beside herself with joy because it was the first granddaughter & great-granddaughter & great great granddaughter in my family side. I said to Daniel you must ring Pro Ingrid Scheffer and let her know and Daniel got a hold of Ingrid and was delighted of the news that she had received and came down after she had finished her day at her office and came up and visited me and had her first hold of Sophie.

After being 24hrs at Monash Medical Centre I could be transferred that morning to the hospital near where we lived and I stayed there for 5 days. As the paediatrician Dr Tam was doing his rounds at the hospital as normal he came across me and said " I know your face but cant put a name to it" I said to Dr Tam you looked after me when I was a little girl and now I have a baby of my own I bet that would make you feel older" Dr Tam laughed and "said it does actually, wow you have your own little girl and she is in perfect order congratulations" after our time at hospital we brought our baby daughter home for the first time and settled in and I got a phone call from Prof Ingrid Scheffer " Dannielle I have some great news the cord blood test results are in your beautiful little girl doesn't have the gene for Drave` t syndrome she is a perfect little girl congratulations." I feel to my knees and thanked God for the wonderful miracle he had done for me. We were so excited about our great news we invited our whole family for dinner and popped a bottle of Champaign.

A few weeks after I had Sophie I walked into my work to show my friends my baby girl and got asked by my store manager Kylie "when I would like to come back to work?" and I said to my store manager Kylie "I am not ready just yet I will let you know next week" my manager then said "ok just let me know with your decision" I went home and thought about and couldn't decide and thought I will go back in a few days and have a chat to Kylie after that few days I decided to walk down and to go and have a chat to Kylie but was not a work at the time and at that point in time I had a dreadful feeling come over me and God spoke to me and told me not to return to work so I walked home and typed up my resign form and walked down the following day and my store manager was there and said to me "would you like to start work next week?" I replied and said "no thankyou I am actually hear to put my resign letter in and thankyou for giving me the opportunity to work hear I have decided to be a full time mother" my manager replied "it has been a pleasure working with you and I wish you all the best with mother hood."

The first 6 weeks of being a first time mother was challenging because I didn't know why Sophie was crying so much we then found out that, a baby has crying time and this starts from a week old and slowly peeks at 3 weeks the baby will

then reach its full peak crying time and then slowly declines for the last 3 weeks and is usually finished at 6 weeks but Sophie just kept crying and would always vomit after a bottle and kept pulling her legs up and just wouldn't settle we decided to put Sophie on wind drops because we were having trouble getting her to bring her wind up and would some times take over a hour we then used half the recommended dose in her bottle one night because as first time parents we were a bit unsure how it would affect our baby girl and guess what we had our first full 8hrs sleep that night.

We then continued doing that for another few nights and worked every time and then realised Sophie was suffering from colic we then continued the wind drops until she was able to bring her own wind up.

When Sophie was 6months we decided to have her dedication and on that same week I was starting to not feel well and had a seizure for the first time in 2 $\frac{1}{2}$ years I complained to the paramedics that my throat was sore and they checked my throat but couldn't see anything but a bit of redness they also had taken my temperature and it was 40c when I arrived at the hospital the emergency doctor checked me over for meningitis but was given the all clear after having a lumbar puncher results and I discharged my self.

The following day my throat was that swollen I had trouble drinking some water I went into the bathroom and got a torch and looked at the mirror the same time and realised I had tonsil litis while taking my medication that morning I was struggling to get my tablets down my throat and had never before struggled to take my medication. I made a GP appointment that morning because I was finding it so hard to take my tablets I went to the GP and found out I had sever tonsil litis and also had strep in my throat and was put on a strong dose of antibiotics. After my tonsil litis cleared up I then asked my GP to get them removed because I was having it every month before getting that bad dose, I then had my tonsil removed and haven't had any more trouble.

My daughter dedication had arrived I had over 60 people invited and my oven was not working at the time because I was still waiting for it to be fixed under warranty by Bosch and had no way of heating the sausage rolls and mini egg and bacon pies I was devastated.

I had to give all the hot food to my mother to heat up at her house and bring it in foil oven trays. It was 1 hour before Sophie dedication and I was laying down because I felt so tired and lethargic with a shocking headache and was on antibiotics at the time my mother arrived at my house and said "you need to get up it only a hour until every body will be hear make sure you take some pain relief I will take the sausage rolls out of the fridge with the egg and bacon pies and I will heat them up I have the oven on at home so I will be back at the time you have requested us on the invitation so the food will be hot I will see you soon

don't forget to smile and greet every one I know you are in pain but its only for a few hours and then you can go back to bed Dad will help you cook the barbeque food you have home made so you don't have to worry about that, see you soon".

Of course that time went very quickly and every body had started to arrive and every body said to me as I greeted them at the door they you look awful Dannielle what is a matter? Of corse I told them what had happened and they all said why didn't you cancel? I then said, "I was looking forward to seeing everyone and didn't want to disappoint every one but I have to say I was thinking about cancelling today and they all said how thoughtful of you we are glade to be hear today and thankyou for inviting us" A few weeks after Sophie dedication it was Sophie first Christmas and we were so excited and brought a lot of things for her that year because she had hardly any toys at the time.

6 months had past and it was Sophie 1st birthday and had a party for her, five days after Sophie had turned 1 she took her first steps by herself and we were so thrilled. Things that she could not reach when she was crawling before she could now reach and had to put things up higher because her little hands were on a mission to grab something that she shouldn't have so that was interesting. From there my life with my first child was enjoyable but challenging dealing from toilet training to tantrums.

When Sophie was 1 $\frac{1}{2}$ we had trouble of her climbing out of the cot and decided to buy her a toddler bed that was challenging because she didn't want to stay in bed at that time, in the end Sophie accepted to sleep in her toddler bed. Six months had past and was time for Sophie 2nd birthday and decided to celebrate it at the Melbourne zoo with immediate family and had a barbeque lunch there.

Another 7 months had past and was only a few weeks to Christmas I was suffering anxiety and had a seizure while taking diazepam for treatment and lost seizure control while on my normal medication. I then stopped taking the diazepam after I had that seizure.

I then found out my grandad had started bleeding internally and was in and out of the hospital. My granddad then had a scope done and was later diagnosed with stomach cancer after he was diagnosed he started chemotherapy.

When I came to visit him in hospital nearly every day while he was having chemo therapy he just kept saying to me "I am so glade you are hear Granddaughter with me I am so sorry I never visited you in hospital, and hear you are with me I don't deserve to have you here with me at my side" I said to my granddad "someone has to forgive you and that's me if I hadn't forgave you I wouldn't be hear today".

I then held my granddad hand and said "I also want to make a promise to you if I have a boy next I will name him Eric Barry so he has your whole name back to front would you like that?" My granddad then had a big smile on his face as a tear rolled down his face. He then said "congratulations" I said what for granddad? He said "congratulation on being pregnant" I then replied "owe no granddad I am not having another baby just yet, yes we would love to have another baby when the time is right but I am not expecting not that I am aware of I am on medication for anxiety so I highly doubt it".

Then god spoke to me and said "congratulations you are pregnant" I thought to my self did I hear that right and kept that message to myself and didn't say anything to Daniel or granddad at the time because I wanted to Waite until I had it on paper in black and white.

A week later I had a missed my period and made a doctors appointment with Daniel and had a check up for my anxiety problem and asked to have a blood test to confirm if I was pregnant just to be on the safe side before I told my family and especially my granddad.

Baby number 2 (Eric Barry)

The next day I got a call from the doctor to say "congratulations Dannielle you are pregnant again with your second child and hopefully a boy for Daniel because I know how much Daniel wanted to have a son so all the best". I was thrilled at the time and then I remembered I have the SC1NA gene and had a 50/50 chance of passing it onto the baby when naturally conceived and went from a high to a low.

Then god spoke to me and said "trust in me my child, why do you have such little faith in me". I then put all my bad thoughts aside and put my whole trust in god and when I had called Prof Ingrid Scheffer to let her know I was pregnant Ingrid said to me "congratulations how fare along are you?" I then replied and said "I am 4 weeks by the blood test I am due on the 8th of October" Ingrid then said " I am excited for you I am just worried about the gene being passed on to the baby would you like to have the test done a 12 weeks or would you like to leave it?" I then said to Ingrid "no thankyou my baby is not going to have the gene it going to be a perfect healthy baby and I believe it is a boy this time because what I have promised my granddad and how it all fell into place" Ingrid then said "a boy and a girl that would be nice well I wish you all the best and let me know if you need anything before I see you at 33 week gestation".

After I had talked to Prof Ingrid Scheffer I then told my family and my granddad that was dieing from cancer at the time I was so happy to be able to tell my granddad before I lost him a couple weeks later from cancer.

I went to all my obstetrician and GP appointments and didn't have any problems through my second pregnancy until the end where I went into pre labour for a few days a week early from full term and was told by my GP to drive to Monash Medical Centre to be induced and was induced the following day. The day I was induced I was in labour for 16hrs in 15 hours of that labour I didn't require any pain relief and decided to have an epidural put in because the Doctor was worried because I hadn't had any sleep for nearly 48 hrs and was in a high possible rate of having a seizure.

So I accepted to have an epidural put in place and got offered by the new shift change over doctor to have my waters broken and accepted I asked the doctor to wait until Daniel had got a hold of my mother because my mother was at dinner and show with my father and had visited with my little girl through the day and I told my mother to go to her show and don't cancel it because I had already been in 11 hrs of labour at that point in time and the dilation hadn't changed for 9 hrs.

When Daniel got a hold of my mother and father and told my mother that they were going to break my waters my mother decided to leave the show with my father and made their way down to Clayton. I then waited until the doctor got back into my room after she had a quick break while Daniel had finished talking to my mother I then gave the doctor the thumbs up to break my waters when she had returned.

The doctor then broke my waters and it was on for young and old I asked the doctor for the gas because I was not fully numb and was getting pain in my hip at the time within 18 minutes my mother and father had arrived and my father waited in the waiting room while my mother and Daniel watched me give birth 2 minutes later in the delivery room to my handsome little son Eric Barry at 7 pounds, the cord blood was then taken at birth and was sent away to be tested to see if my baby son had Dravet Syndrome. A week later had passed and got a phone call from Prof Ingrid Scheffer and said "I have the test results for the cord blood that was taken to be tested for the Dravet syndrome gene and have some lovely news your baby doesn't have the gene for Dravet syndrome.

How did you know that the baby was going to be free of the gene? I then said to Ingrid "God told me and I knew all along that my baby boy was going to be perfect and healthy". Then Ingrid said "you are a very lucky lady but just remember it's a 50% chance of passing the gene on to your baby if you decide to have any more children naturally".

After speaking with Ingrid I then called my mother and father to tell them the great news that I had received and wanted to go out and celebrate the great news, but declined because my little niece at the time was very ill in hospital and passed away a month later.

Baby number 3 (Jane)

It is now two years later and have just found out I am expecting my third child. I was quiet hesitant of telling my family due to there own thoughts with my previous pregnancies. So when I found out after having a blood test I phoned my husband at work to let him know. I then phoned Prof Ingrid Scheffer and left a message for her about the news. I then waited for my husband to come home and went around to my parent's house and told them they are going to have another grandchild but my mum was just worried about my health and the health of the baby. When it came time to organising an obstetrician appointment my referral from my GP was rejected which has never happened before. I got told by the hospital that I was not a high risk pregnancy and do not require to have my unborn child at a specialist hospital. I took it as a complement and then thought I don't want to have my baby at my local hospital due to making a lot of mistakes in the past with situations like mine. So I got into contact with Prof Ingrid Scheffer and gave her a copy of the letter I received in the mail and of course she was furious, then of course the rest is history. I then started having my appointments with my previous obstetrician. In the time I was heavily pregnant I got a water leak in my kitchen and had to have a whole new kitchen put in. In that time I had organised for my whole house to be painted inside. I then started packing up my kitchen and lugging the boxes of kitchen belongings out to the shed for my new kitchen to be ripped out and a whole new one put in. After lugging the boxes out to the shed I started having contractions and phoned my husband to take me to my local GP. I then arrived at my GP and my GP said "I want Dannielle to go to the hospital where she is planning to deliver and get checked out" So we got in the car and travel 2 hrs in the car to the hospital. I then got checked by a doctor and said "you are not in labour." "What were you doing at the time when the pains started?" I said I was packing up my kitchen due to renovating, and was doing a lot of the lifting" I then got told "No more lifting and no more mowing the lawns take it easy" the doctor then looked at my husband and said "look after Dannielle make sure she takes it easy". We then hoped in the car a drove home. A couple months later I started losing my mucus plug but had no contractions. So I went to my local hospital to get checked and the doctor said "yes you have started to loss your mucus plug, it is common when you have your second or third child." "I will inform your hospital where you wish to deliver about this so they know" I said "thankyou" and went home. A couple days later I got a phone call from my midwife to say "my induction is booked at the hospital where I wanted to deliver my unborn baby and are you willing to have this date?" I said "yes thankyou that sounds great" I then phoned my husband to let him know that he needed to take this period of time off. Soon enough those weeks went very fast and the induction date was on our doorstep. It was the day of the induction and was early in the morning and was pouring with rain outside and I thought what a great day to give birth. So they started with breaking my waters and nothing happened after one hour. So they then started the drip and offered to have a spinal tap put in, I then accepted to have

a spinal tap put in. My mum said "well I am going to go and get a coffee because last time it took a while for the contractions to kick in". I then said to Daniel "you go and have a drink with mum and keep her company I will be right" Daniel said "Are you sure" I said "yeah I will be fine". Well as soon as Daniel and my mum left the room my contractions started one after another. I called the nurse and said "my contractions are getting so strong please can I have some gas" the nurse then rang the antithesis to top up my epidural. The nurse said that the anesthesiologist is busy with another patient and will come as soon as he can. Time was passing and I was getting more dilated by the minute and then my baby heart beat dropped and Daniel and my mum had just arrived in the room as all this info was happening. The emergency button was pushed and doctors all run in the room and the paediatrician got all the forceps ready to deliver my baby. The paediatrician said to me "you are 8cm dilated, are you ok to push when I tell you to? Otherwise if you are too tired I will use the forceps" I said "I am ready to push; I will give it my best go". A few pushes and my little girl Jane was born. Jane was then looked at by the paediatrician to make sure she was doing all the right things and got the thumbs up she is in perfect health, I then got to have my first hold of my baby girl.

Baby number 3 (Jane) diagnosed as being SCN1A Positive

In the time all the kayos the cord blood was taken to be sent to get tested for SCN1A gene. The cord blood was tested three times and each time it tested positive for the SCN1A gene and I was in disbelief that my daughter can't have the gene there has to be a blood mix up with all the chaos that went on when Jane was born. So I asked for a forth test to be done and had a mouth swab taken and a few days later I got a phone call to say that Jane is positive for the SCN1A gene. Can I say I was in shock I truly believed that my daughter was going to be free of the gene. I got offered to start Jane on medication straight away from my neurologist but I declined I said "I wish to wait until something happens and I hope nothing happens".

Jane's first seizure

A few months later my husband was just playing with her on his lap and Jane arched her back and started a tonic clonic seizure, I knew it was a seizure and called an ambulance.

When we arrived at the hospital I was running on adrenalin and just prayed for the seizure to stop and the doctors were just about to inject her with midaz and the seizure stopped on its own. We then had to make the decision to start her on medication and started her on one anti epileptic medication. I then brought a seizure monitor for at home. I have had to give my daughter Midaz at home while waiting for the ambulance to arrive and can I say I know how nerve racking waiting for the seizure to stop is. I give her medication on a daily bases and have a seizure kit with me at all times. Was I heartbroken? Yes I was, but what can you do to change what's going on you can't but you can always give it your best

shot. Did it bring up memories of me as a child? Yes it did, do I wish this gene upon anyone? No I don't because it's tough.

I do the very best I can not to let her get too warm and not to let her get over tired. I can only give her medication and check on her on regular bases during the day and we activated her seizure monitor at night so we are able to get some sleep. I check on her when I get up during the night to go to the toilet and I pray for her before I go to bed for the night. I have been told this is a world first diagnosis and we are doing everything we can possible for research this is were my daughter and I case is studied.

If you wish to make a donation to help us find a cure for Dravet Syndrome please donate to:

The Florey Institute of Neuroscience and Mental Health,
Melbourne Brain Centre - Austin campus,
245 Burgundy Street,
Heidelberg, Victoria, 3084, Australia.
Telephone: (+61 3) 9035-7000
Email: reception-austin at the florey.edu.au domain.

I am very blessed to have three miracle children and I love being a full time mother to all of them, yes it is stress full with a 7year old, 3-½ year old and having a baby as well but I do manage. I do my own entire housework and cooking for my family. I don't require any assistance off the government to help me. I try to ask my mum for help as little as possible because she has other grandchildren and is working and I like to stand on my own two feet.

It was a privilege to be asked to be a guest speaker today and thankyou for having me, I hope you enjoyed listening to my own personal story.