15th June 2010

To Whom It May Concern,

Please find to follow Our story of life with a child with special needs and my views on a long term disability and support scheme.

Regards

Joylene Donovan
(Mum of 6 year old girl- Ava who has with Dravet Syndrome- Genetic Intractable Epilepsy)

To look at her she just looks like any other child but she is not, she is a special needs child with a life threatening syndrome.

Our journey with Epilepsy began on the 22nd April, 2004 when our beautiful 5 month old baby girl Ava had her 1st seizure. It was the day that our perfect family of 5 was thrown into the unknown, uncontrollable roller coaster of living with life threatening epilepsy. We had 2 other children Ella 3 and Finnbar 17mths and just when I should have been enjoying this special time with my babies and my husband, the normality of life that I took for granted was shattered.

Ava will be turned 6 in November and it has been a long journey to this date. We have a clinical diagnosis of Dravet Syndrome, which is a life threatening epilepsy syndrome due to the intractable nature of seizures and the difficulty in treating them. We have recently had confirmation of a genetic mutation SCN1a (sodium channel in the brain) through DNA research program with Professor Scheffer at the Austin Hospital in Melbourne. Ava's seizures are treated with 4 different types of anti convulsant medications which have been unsuccessful in fully managing her condition.

Dravet Syndrome effects only 1:40,000 children and falls into the 5% of epilepsy which cannot be fully managed by medication. Ava has the full range of seizures, Tonic Clonic, Tonic, Complex Partial and Partial . Her seizures are triggered by high temperature, illness, tiredness and sleeping(nocturnal seizures). If you can imagine how often young children are sick, have a runny nose, are teething, get tummy bugs, get a cold or a tired, then you can imagine how often Ava was fitting in the first few years of life.

It was a weekly encounter the ambulance trips, visiting Monash Hospital, neurologists, paediatricians often accompanied with hospital stays for several days either ICU for staus seizure episodes or in the ward for monitoring and further medical treatment.. You know you've become a regular when you see the same ambulance team weekly or the staff at the hospital know you by name when you are wheeled through the emergency door. We have been blessed with amazing doctors, particularly Ava's Neurologist Lindsay Smith who has been the one constant through out the whole experience. He has always made himself available to assist Ava whether in hospital, in his private rooms or by phone reassuring me with treatment advice. We were very fortunate to be referred to Lindsay very early in Ava's treatment by a proactive young registrar at the hospital and I will be forever grateful to her.
Add to this the daily juggle of medication regimes and financial strain life became one big simmering pot of stress.

There were times we wondered how much more we could take as individuals and as a couple. With no family close by to support us with the other 2 children, it meant the 2 of us juggling their care, my husbands business and trying to kept some form of normality for the other 2. Our daughter Ella did ok, as she had some wonderful friends from baby group, kinder and school who helped keep her life as normal as possible with play dates, sleep over’s etc but that’s not to say she didn't feel scared or worried for her sister or upset that I was not around.
It was our son Finnbar who really suffered initially, as he was already struggling with having to share his mum with a new baby when this all started, only to have that baby take her all away, not just for a bit but for days at a time. He had been such a happy affectionate little boy who became clingy, would cry a lot and even began to bite me when I returned home from hospital with Ava. He never once hurt Ava but he was so angry with me for leaving him. This added to the juggle and I felt so guilty my boy didn't get the time he deserved from me because Ava took up so much of my time. Over time things have got better for him as he has developed friends through kinder and school who have been great during times Ava has been ill. Both Ella and Finnbar have had some of the innocence of childhood taken from them and they both know that life doesn't always give you what

you want. They have had to miss out on or leave places and events early because of Ava's epilepsy and have learnt to accept that whilst it is hard for them its even harder for their sister. Ella and Finnbar have greater responsibility put on them then most children having to always look out for their sister and are often assisting me when her seizures occur. They have seen her being treated by ambulance officers in our home, in hospital and have witnessed very serious situations but we felt that they were going to have to live with this in their lives so there was no point sheltering them from the truth.

Family outings are challenging and intermittent, dependant on Ava's health. Outings are often dealt with either Jim or myself going with Ella and Finnbar and the other staying home with Ava. Weekend kids sport often sees Ella and Finnbar sent off with other families while I am at home with Ava and Jim may be working.

As for my husband and I, we have been tested to the cores of our being. Its like living with a time bomb but not knowing what time it has been set to go off. There is a continual knot in your stomach and I can not remember what its like to relax anymore. Deep sleep is a thing of the past as you sleep with one ear/eye open in case of a seizure.
For us, time as a couple became non existent, 1. because Ava was with us 24/7 and 2. finding anyone willing to sit with Ava was almost impossible. If we did, we were limited to being no further than 5-10mins from home and it always required one of us to be driving in order to get home in an emergency. For Jim, he has had to give up hobbies like coaching rugby in order to help out more at home and feels all he does is work and home.

My view is at least he has work! I have had to for go all that I work hard to achieve. Having worked in nursing, OH&S, Work Cover/ Rehabilitation over a period of 12 years and originally planning to go back to work after having my children, I have now been out of the paid work force for nearly 10 years. I see no hope of returning to paid work because of the 24/7 commitment to caring for a child like Ava. To have no choice in whether you work or not is difficult but to not be able to financially assist your partner also adds to the guilt of not being in paid work. Whilst I did get carers allowance and Ava has a healthcare card which assisted with medication costs, I have only recently started to receive for Carers Payment after a projected application process of 6 months.. This process consists of time consuming forms, forms and more forms. Best get the doctor to repeat himself too just incase they didn't get the picture in the first form! It also cost us financially ($400.00)to do the paper work as our accountant was required to submit paper work for us that Centre Link had the information for but did not have the ability to read simple tax returns. I struggle with the fact that after nearly 6 years I am still proving that Ava has an untreatable life threatening illness. One that is known and recognised yet I am still asked to continually prove it.

Ava's Seizures are unpredictable and often require life saving medication to be administered. Seizures regularly occur in clusters at night so she sleeps in our bedroom to ensure we are always able to hear her should she fit. During these clusters Ava can have anywhere up to 15-20 seizures in a 12 hour period and I have only in the last 12 months got to a point where I can juggle emergency treatment(Nasal Midazolam) at home effectively, where previously we would end up in hospital. During these periods of high risk it is not uncommon for me to go without sleep for anything up to 24-48 hours. Whilst I have got better at dealing with it, Ava is older and more resilient, combined with better drug mix in day to day treatment, the constant demand to be always on alert is physically and mentally draining.

There seems very little available in way of respite or family assistance for families in our position due to the medical requirements/emergency treatment needs our children have.
With long waiting lists for flexible in home respite and being met with brick walls and uncertainty from many government services(both local & state).

I have found the whole process difficult and time consuming with very little direction of any sort as to the best services available for Ava. Phone call after phone call saw me told to go somewhere else, we don't offer that service, someone will call you back(maybe never!). It is a mind field of maybes with no real clear direction for families.
After 6 years of caring for Ava we finally received some flexible care hours. The difference that made to our life was incredible and made it even more obvious what our family had been sacrificing in our lives to care for Ava. Those hours have now run out so we are back on the waiting list until some more free hours come up.

We have been fortunate to have access to respite with Very Special Kids(VSK) which offers family support and care to families caring for children under 18 years of age with life threatening illness. Whilst Ava meets the criteria of Very Special Kids ie. life threatening illness, I felt disheartened that it had come to a point that my only choice for her was a clinical care based setting when she could be cared for just as well in her own home and surroundings by a qualified person. I believe that there is a big gap in the respite service area for children like Ava. I could get plenty of assistance if I was present(which I don't call respite by the way!) it became almost impossible when you mention administration of emergency treatment in case of prolonged seizures. Our children have a right to care in their own homes and should not be duck shoved into clinical settings because it all becomes too hard. As parents we should have the right to regular time out with our other children and our spouses without having to live with the guilt of leaving our children in a clinical setting.
The respite we have available to us in invaluable but is intermittent and not a given that you will get it due to the high demand on such a wonderful organisation. We must apply 3 months in advance and can have up to 3 weeks per year which can be taken in time frames of up to 1 week at a time. Ava is quite self sufficient in most areas and whilst there seems to be ample services for children with physical disabilities, those to assist with medical needs are limited.
However respite with VSK is not a given as we found out this long weekend. Our respite was cancelled due to an emergency case and we were left to make the best of our weekend that we had been so looking forward to. It had been 7 months since we had last used this charity based service and given waiting lists and demand on such a wonderful place likely to be a further 3 months before we get the opportunity again. It has been over a year now since my husband and I slept in the same room, a simple thing most would take for granted.

Along with the high risks associated with seizures there are developmental and physical issues associated with Dravet Syndrome to contend with as well. Ava has a severe language delay and behavioural issues which require regular assistance from therapist at Glenallen Special Needs School. Characteristics of this syndrome can be similar to that of Autism so it requires a great commitment to behaviour modification programs and therapies. What has been very concerning for me is that whilst Ava has quite significant deficites in her cognitive and speech development, she does not meet criterias for special needs schooling. Ava is in the area of “not up to normal standards but not eligible for special needs', she is in the grey area where we will once again have to prove that she has a life threatening illness that requires monitoring and because of this condition has educational needs requiring extra attention to that of the average child.
The government needs to acknowledge that these children need extra guidance and support to aid their learning due to poor language development, cognitive deficites, behavioural difficulties and poor health.
Ava started school this year at Glenallen, a wonderful special needs school that does not have an IQ criteria but takes children based on disability and high medical needs. I spent most of last year sourcing information as to where the best place was for her and was extremely surprised that those who were employed to assist families prepare the child for school/ kinder etc. were unaware of this. Had I accepted the view that there was no place for Ava due to her IQ being low average(88) I would be going through the mind field of mainstream with inadequate funding for a full time

assistant for her and teachers having to deal with a child they are not trained to deal with.
Ava is currently on a dual learning program, 4 days at Glenallen and 1 at local catholic school. What Glenallen has taught Ava and physical programs given in 6 months of school, mainstream kindergarten(with full time aid) could not achieve or give in 3 years! Yet I still find that Ava is the minority in both settings. Ava is one of five in her class, 2 in wheelchairs, 2 poor mobility, 2 of them non verbal while Ava is reasonably verbal and very mobile. One of the children's parents actually said to me "there's not a lot wrong with Ava is there" My reply was "no not physically that you can see" and had to explain Ava's disability. While at our local catholic school she is obviously different to the other kids in her behaviour and learning ability and I spend a lot of time explaining her disability too. Because Ava's syndrome is mostly silent until she fits, there appears to be little wrong with her physically.
We are now waiting to see where Ava's development will go from here. There is a view that development in these children tends to drop off by age 7 so all we can do as parents is take it one day at a time and deal with the issues as they arise.
I was fortunate to hear Bill Shorten, along with Anna Bourke speak at the school regarding the National Disability Scheme. While there is still a long way to go it is heartening to at least have it acknowledge that the current system is in such a mess and willing to work toward fixing it.

I believe that children with such medical needs like Ava has, have placed an overwhelming burden on our mainstream kindergartens/schools/teachers, which they have not been trained to do or signed up for in the first place. If they had, they would be working in a special needs school in their area of expertise. We feel blessed that Ava is in an environment where she is understood and is most importantly safe with a full time nurse on site should the need for emergency medication for prolonged seizure.

I am concerned about her future and what lies ahead of Ava. It is heart warming to hear it acknowledge that the current system is a mess. I have watched my brother and his wife battle the system for the past 20 years for their son who has server Autism and know that they are one of the many families currently in limbo as to what and who will look after their son in the future.
Lets hope that our stories are heard and finally someone in government will stand up and take action.

So what do I/ We Need from a National Disability Scheme

Firstly I would like to see the definition of disability broaden to include illnesses and conditions that are not just physical but cover those with high medical needs such as with Dravet Syndrome.

I would like to see things put into place to ensure children like Ava are not discriminated against because of fear or lack of knowledge or resources in our education system. I would also like to note that whilst most people are aware of epilepsy and many take a view that it is treatable, it is those with the uncontrollable syndromes that are least known about and need to be given a voice.

I am hopeful for the future for Ava. I pray that the government will continue to fund the vital genetic research currently being undertaken and the possibility of better and more appropriate drug therapies for hard to treat syndromes. There are many costs of new drug therapies for hard to treat syndromes where drug trials end and cost of these medications fall on to families. Eg. Ava is currently eligible to take part in trial of drug which has had great success but likely trial will end soon. When it does drug therapy for a year will be approx $12,000. We would love to give Ava this chance but would not be able to fund it should trial be pulled. Families need to be assisted when these issue arise particularly if the treatment is life saving.
I would like to see greater consideration given to the cost of current medications to families and individuals with epilepsy. Whilst many are on the PBS there are some that still require full

payment(such as Midazolam) making Health Care Card benefits void. All treatment for life threatening illness need to be fully funded.

I would like to see an easier more understanding Centrelink system for Carers and those with a disability. The repetition of the information required, the continual questioning and the need to make it all so difficult that some people would just give up amazes me. Perhaps that's what they are banking on, that some people will just give up because they don't have the skills, the language, the emotional strength to compete with Centrelink. I have to say that's what it felt like at times, a battle of the wills, a mind game and only those willing to stand strong will make it to the end.
In our case because one individual could not read tax return information from our accountant, they wisely added business expenses to our earnings as they had not been itemised(even though they were but obviously not in simple enough terms!). This was all done even though right in front of them they had confirmation from the Australian Tax office that our figures we had supplied them were accepted and we were being paid family allowances base on that for the past year. Because of this need to continue to be difficult we were forced to pay our accountant a further $400.00 to prove what they already knew. A total of 6 months, endless forms and more a less being made feel that we were lesser human beings for asking for this assistance. Not only were we unconvinced so was our daughters neurologist. He had to fill out forms 3 times with the same information, which I might add he never charged for but did comment how difficult Centrelink make his life.. The first time I was given the wrong form so he did it again and the 3rd time he had to re do it because the form had been re formatted after we got the 2nd form. Go figure, obviously they couldn’t match the ticks with the questions!. This specialists time could be spent much more valuablely then re doing forms over and over with the same information.
I would hate to think how difficult it is for families where English is their second language and I now know why I waited 6 years to pursue such an epic effort. There is no way you could cope with this when you are in the early stages of diagnosis and struggling to come to terms with where you are at! I will say that now we have our pension card it has had a huge impact on our life and has taken a great deal of guilt from me in terms of not being able to commit to work due to our daughters situation.

I would also like to see funds and awareness raised towards training seizure alert/ assistance dogs so that all individuals with life threatening illness and their families can achieve the independence others take for granted. Recently friends of ours who also have a child with Dravet Syndrome had to raise money for their sons dog. They managed to raise the full $30,000 required to train these puppies but it was just another thing to stress over on top of caring for their son.

I would like to see more public awareness regarding these debilitating syndromes like dravet in the hope that there will be greater understanding of the effect on individuals and their families.

What would of made my journey easier?

I often think about what would of made my journey with this easier. This is not an easy one to answer.
I wish that I had been given an information pack about what’s available to me and who does what. It would have saved me hours of phone calls, filling out irrelevant forms, hours of searching the internet for groups, information or services.

Names of Doctors and programs appropriate for your child’s needs.

This needs to managed from the emergency room/hospital. At the point where a diagnosis occurs, families need to be referred and assisted and not left to their own to find their way. It is impossible to focus on what you need when you are struggling just to deal with what is happening in front of you. I am aware of books available but I do believe parents /families need more guidance in the early stages of any diagnosis. A team of assessors with in our hospitals would be an ideal place to start, who could then direct to appropriate regions and services.

When Ava was 3 and I began to have concerns about her development I had to ask to be referred to Early intervention. My referral was placed with the wrong area, I was sent to information sessions irrelevant to Ava and I and it was only after I queried when someone would call me that the error was found and rectified. I wasted 12 weeks gathering irrelevant material only then to have to wait another 3 weeks for someone to see me. All up it took nearly 10 months for Ava to receive any intervention and 18 mths before I got to see a social worker. NOT GOOD ENOUGH!

I struggle to understand why funding has to be broken into regions but fully understand why case management is. Several times there were services in one region I would of liked to have accessed but because I was using funding from another region was not eligible. As I lived on a boarder I was entitled to access some from either region but neither offered exactly what Ava needed. If I could of picked the specific services of choice Ava's program would have been more precise for her and not to the special needs sector as a whole. Funding needs to be in one big pool and families apply for a package amount per term/year. Case management needs to be driven from the diagnosis point whether hospital or doctor based and at the point where families are struggling. There needs to be flexibility in services to pick what you need for your child and where you go for that service rather than you are in this region so her is what’s on offer.

I would like to see greater expectation put on to local government councils to be willing to work with families and assist them with their needs. In the council I live in it is a non flexible mentality with no effort to connect with other service providers to develop agreements to link the two. Eg. I could get respite through the council but I would have to be home. Interchange suggest that I discuss having those hours transferred to them so I could use in the flexible package. Reply “Sorry we don't do that with Interchange but we do have an agreement with another service.” I would have to apply to the other service, have the usual wait and no guarantee I would get any hours anyway! Shouldn't the priority here be the child and family getting the support they require and not sending them on another paper trail to get a few hours of respite. Something needs to be done to link all services so that funding comes from the same pot if it is used for the same thing regardless of who delivers the service.

Thank you for allowing me to tell my story. May this inquiry be the start of opening the minds of those listening to our stories of the struggle of life with Dravet Syndrome or any disability.

Kind Regards

Joylene Donovan