

Hemispherectomy Foundation Australia

Newsletter

Welcome to the third edition of the
Hemispherectomy Foundation Australia newsletter
Winter 2015



Well winter has arrived with its customary days of grey and gloom – for us in the southern states at least, however while the skies are low our hemispherectomy children continue to thrive and achieve.

This year we have welcomed several new hemispherectomy families into our small Australian community. While behind every hemispherectomy surgery there is grief and anguish, we are so pleased that new families have made the choice to become connected with the Hemispherectomy Foundation Australia and other Australian hemispherectomy families.

Our Facebook group continues to grow in membership and remains very active, in no small part to our President, Natalie Hood and her prolific posts. Natalie manages to source a wide range of relevant information to share with the group. If you are not a member of the group please consider joining – it really is a terrific place to remain across the latest developments in rehabilitation therapies, assistive technologies and aids. It is also a great forum just to raise any questions you may have about your child's challenges or behaviour. It is a closed group with all members approved by the Hemispherectomy Foundation Australia website administrators, Natalie and Kylie. Joining the group is simple – just go to Facebook, search for Hemispherectomy Foundation Australia and once you find us, click on the request to join group button on the right hand side of the page.

This newsletter contains a comprehensive update from Natalie about her experiences with the National Disability Insurance Scheme (NDIS). Natalie lives in the Hunter region of New South Wales which is one of the seven regions where the scheme is being trialled. It's great to have her insights and experience which is valuable foresight for when we become NDIS users as the scheme is rolled out across Australia. The federal government has just released a progress report on the NDIS and indicates that user satisfaction with the scheme is very high. The full report can be accessed at <http://www.ndis.gov.au/progress-report-2015>



The Brain Recovery Project
Rebuilding the Developing Brain

The Brain Recovery Project

The Brain Recovery Project has been established in the United States to help children who have had hemispherectomy surgery reach their full potential. By funding research to better understand how a child with half a brain can learn to walk, talk, and read, the Project is working to establish rehabilitation programs and protocols, provide parent education programs, including family conferences, online videos, and educational guides.

Recently the Brain Recovery Project has released a guide for educators of hemispherectomy children. It is an extremely valuable document as it explains all of the functional, cognitive, social, emotional, behavioral and sensory challenges that our children may experience after hemispherectomy children. The guide also explains the science behind why a child may experience a particular challenge or deficit. While our children are all different in the challenges they face following surgery and will not experience all the deficits covered in the guide, it is comprehensive and parents can alert their child's educators to those which their child does experience.

The guide has been included in the "Resources" section of the Hemispherectomy Foundation Australia website or can be downloaded directly from the Brain Recovery Project website under their "Resources" tab.

Hudson the Queenslander Trail Blazer!!

By Mum Janelle

Hudson is an identical twin who was funnily enough born on April Fool's Day in 2013.



At just 9 weeks of age, Hudson started having seizures. He had a massive tonic clonic seizure, which resulted in his head and eyes deviating to the left for four months and his right side becoming paralysed.

We went to our pediatrician who sent us off for an urgent MRI and at just 10 weeks of age we were told our beautiful little boy had suffered a major stroke.

After some investigations it was found that Hudson had actually suffered his stroke whilst he was in the womb. He had suffered a MCA and lost approximately 75% of the left hemisphere, it had affected all 4 lobes, the left basal ganglia, thalamus and hippocampus.

Due to his epilepsy Hudson has been on a number of anti-convulsants from 10 months old.

During the Christmas period of 2014 for some unknown reason Hudson's anticonvulsants stopped working. He went from having 1 or 2 seizures a week to having at least 45 seizures a day.



Hemispherectomy Foundation Australia



Because we live rurally we were first admitted to the Rockhampton Mater Hospital and after a one week stay were flown to the Lady Cilento Children's Hospital in Brisbane. Over the next nine weeks neurologists tried all available anticonvulsants and the Ketogenic Diet.

Unfortunately, despite being on 5 anticonvulsants and the Ketogenic Diet, Hudson was still having seizures every five minutes to 45 minutes and his cognitive and physical development had regressed so much that he could no longer take steps, sit, talk, eat or communicate and it was decided that surgery would be his only option.

Due to the severity of Hudson's stroke he already had the diagnosis of a right hemiplegia and right hemianopia, which meant he had nothing to lose from the surgery except for the seizures.

On 20 May 2015 Hudson underwent a left functional hemispherectomy. This was the first hemispherectomy performed at the Lady Cilento Children's Hospital and although his neurosurgeon Dr Martin Wood had performed many similar operations, it was Dr Wood's first hemispherectomy.

Following Hudson's surgery unfortunately he suffered a collapsed lung and pneumonia and ended up on high flow oxygen for a week. Due to this he ended up in PICU for 6 nights before being transferred to the ward.

Hudson is now almost six weeks post surgery and although his hemi side is denser at the moment, he is once again sitting independently, rolling over, four point crawling independently, saying a few words, holding a bottle, starting on solids again (he had not eaten for over six months, so has lost the ability to swallow anything except formula) and when he is in his walker is able to take steps again.

He is progressing much quicker than anticipated by the neurologists and neurosurgeons now the seizures are no longer an issue and we are very excited for his future.

Aaron and transition, transition, transition cont...

Transition, what it means for our hemi children? As our children get older and can no longer access children hospitals, formal schooling and children's activities it is vitally important to always be considering the NEXT STEP.

Post school options can be quite limited for those with disabilities, especially in rural areas. The key messages I have received from organisation like My Future, My Life and the Transitional OT at LCCH (Lady Cilento Children's Hospital) is to be mindful of having activities and options which span the bridge between school/turning 18 and adult life so, with the end of school there is not an end to a routine or activities which are important. Look at what the young person's passions are and what gives them a sense of purpose. Plus, look at options outside of the norm. Remember children with disabilities can often complete year 12 over a two-year period and incorporating schooling into a gradual transition into post school life can be an advantage.

In our case we are attempting to build in a combination of recreational and occupational options. Aaron is in year 12, turning 18 in November. He has had a number of opportunities to

participate in work experience at two nurseries/garden centres, a sporting complex and the golf club. He continues to enjoy his sport, participating in golf, gym and table tennis every week. He also volunteers when we are involved in community activities and will possibly join the rural fire brigade as a volunteer at the end of school.



School continues to provide him with learning practical skills and hopefully at the end of the year he will have successfully completed a cert 2 in Agriculture.

Through My Future My Life Aaron has received funding for a pair of work boots and equipment to assist him to do cattle work with one hand. Check out his new boots with the twist fasteners and build up constructed at the LCCH to assist with his leg discrepancy.

Kathy Payne

Hemi Hug Packs 2015

It's both good and bad that the Hemispherectomy Foundation Australia has had the opportunity to deliver a number of Hemi Hug Packs in the past few months. It's a shame that children have to undergo a hemispherectomy but lovely that our Foundation can support these families who have come from NSW, Victoria, South Australia and Queensland. The packs are delivered by Foundation volunteers whose aim to bring a little joy to the family and the opportunity to link in with the Australian Hemispherectomy community.



We acknowledge the most recent wonderful donators who have made the packs the special gifts they have become.

- Sue Cruikshank – from Warwick donated her time and talent to make the beautiful butterfly travel bags.
- In Essence Aromotherapy – kindly donated 12 bottles of sleep easy pillow mist. Valued at approx. \$240.

Check out the cute bears which come with a patch on their heads.

Hemispherectomy Foundation Australia

National Disability Insurance Scheme (NDIS) Update

Natalie Hood

I can't believe it's been 12 months and we are into our second NDIS plan already which started in May. Overall, I have been pleasantly surprised with it after hearing all the horror stories people were having with their plans. I had joined the facebook group "NDIS Grassroots" which has been extremely helpful in navigating the process as there are some very knowledgeable members there.

We only ended up using half of our funding approved. We used the entire amount allocated for O.T and physio but only a small portion of speech therapy, mainly because we just couldn't fit it in. The rest of the unused funding was for respite hours, which wasn't used mainly because of the unavailability of support workers, not because we didn't want or need it. This plan included two hours Monday to Friday to help Alicia get ready for school and take her to the bus stop (also including some therapy exercises). We were already getting two hours a week with Newcastle Temp Care but this support worker wasn't available to do more hours with us. You can actually find your own support worker and employ them yourself (self managing the funding) or have a service provider employ them on your behalf. We had a friend who was interested in this position, so she was employed by Newcastle Temp Care on our behalf and although this took a couple of months to happen it has worked out great for her and us.

We also had extra respite hours for access to social and community activities, so the support worker would sometimes take her to drama on Saturdays and on outings in school holidays. (Sometimes she would just come to our home for a few hours and do therapy or exercise with her). The only downside of respite taking her on these outings is that transport isn't covered, so we had to pay for this which is about 80cents/km, but I recently found out that the worker can use our vehicles as long as our vehicles are fully insured, which is what we will be doing from now on.

This year Newcastle Temp Care started up a Teen group holiday program for high functioning special needs teens (mild aspergers, learning disabilities, mild physical disabilities) which the support worker took Alicia to a couple of times in the last set of holidays (horse riding, shopping and a movie). Alicia loved it all and gets to hang out with others who have similar issues. (Alicia still struggles socially and although she has friends at school she doesn't have a close friend, and doesn't often get invited anywhere, so we keep her busy with structured and organised groups, plus spending time with family and family friends.) Being a teenager, Alicia also loves it because she gets to do things independently of her parents.

Once again, the funding used depends on the availability of the support worker, and although we had the funding there, the support worker was often not available for weekends and holidays. We had requested other support workers through Newcastle Temp Care as a backup, and eventually they found someone else.

The only other hiccups we've had has been with co-ordinating plaster casting after botox. Last September Alicia had botox and normally any plaster casting was always done through the CP clinic at the hospital, but now they don't provide for NDIS clients.

I spent a month organising for plaster casting to get done. We chose to use CPA as our service provider for physio (we see private OT and speech), and they are the only other place in the Hunter area who do plaster casting, so I had to go back to our planner for her to approve funding for plaster casting with CPA. As she needed her hand and leg plastered this involved a physio and an OT. As Botox only lasts a couple of months with Alicia, the planner organised this as quick as she could, and we were able to get really good results with the plaster casting. We didn't get any extra funding for this as the planner approved that we could use some of the unused amount from speech and respite. (The policy has now changed that you don't need the planner's approval to use funding for a different purpose that it was allocated for, as long as the service/therapy/activity is already approved in the plan).

When the renewal of the plan was coming up in May I had heard that the planners were approving a lot less in the plans and were being much stricter, so we were expecting to get less in the new plan, especially as we had only used half of it. We still had the same goals, so the requests were pretty much the same as last year. We had decided that we didn't need as much for speech as it was unlikely that we would manage to fit as much in again. I also explained that the unused respite funding was due to lack of availability of support workers, but this issue is now resolved.

By the end of the planning meeting, most of our requests were approved and we had actually been allocated more funding than in our first plan. I was shocked to say the least. This included funding for Second Skin splints, an AFO and AFO shoes with a raise in the right one as this leg is shorter. Once again she has monthly physio appointments approved and this can include learning how to ride a bike as this is something that Alicia wants to do. The only one we are still waiting on is funding for the private OT. The planner has queried our reasons for seeing this OT on a monthly basis (but it has been more like bi monthly) and wanted to confirm with the OT exactly what her goals/therapy were for Alicia. Alicia has been seeing this therapist since she was about 2 and in my experience of OT's she is one of the best. Alicia has always progressed and achieved with her. The goals have slightly changed as Alicia is no longer interested in doing therapy to improve function of the affected hand, but there are still other things to work on, and adapting to living life one handed.

Our new plan also included respite for school readiness again, one day a week in school holidays for the teen group program/social/community activities, plus three hours each week for social/community access. I mentioned that Alicia is keen to get a casual job now that she is 15, which she may need assistance with depending on the type of work, so the extra respite hours can also be utilised for this if the employer is agreeable. We are also looking at seeing an exercise physiologist (covered by the EPC plan and recommended by the physio) to build up fitness, so a support worker can also assist Alicia with whatever the physiologist recommends. The physio has also recommended Alicia do three months of walking on an inclined treadmill to improve her drop foot, which the respite funding can also be used to assist her with. Some planners have also approved gym memberships, but I didn't request this as we already have access to a treadmill.

In the last physio appt with CPA prior to the end of the first plan, it was recommended that she have plaster casting again as she had received Botox again in April. (At the end of a plan all services

Hemispherectomy Foundation Australia

National Disability Insurance Scheme (NDIS) Update cont...

have to provide a report to NDIS about therapies etc and results, as well as recommendations for future.) This was to be approved in the new plan in May, and CPA wouldn't book her in until it had all been approved. As soon as the new plan was approved I let CPA know, but they didn't have any appointments available for a couple of months, and by then the Botox would no longer be effective. I made inquiries about having casting done elsewhere with a negative result. Not happy with the situation I spoke with the manager of CPA expressing my discontent with the debacle (and she agreed it was their fault as Alicia had been placed on the appointment list but had been overlooked), and managed to find an appointment with one of the OT's to get her upper limb casted, but no physios available for another month for lower limb. I was happy with this, as the leg hadn't been botoxed but the hand/arm had been, so it was important that the upper limb get done before the botox wore off. (She had the upper limb casted a few weeks ago and is now waiting for an appointment for leg). CPA have been inundated with new clients since introduction of NDIS.

From my experience, I have a couple of tips to offer about the process - join the Facebook group NDIS Grassroots; read the guidelines on the NDIS webpage; know the right terminology to use; and ask for more than what you want or expect to get, as you never know you may just get it. This also gives you some negotiating power in that if you are willing to accept the non-approval of something you don't really want then you will be seen as being co-operative and hopefully planner will be more

accommodating with other requests that you really do want. For example, even though Alicia's swimming and horseriding would come under NDIS approval of maintaining health, it was not approved, but I decided to accept this as the planner was then happy to approve all the other requests that were more important to us. I could appeal the swimming and horse riding, but I really don't want to go through this process and am happy with what we got.

The only other important fact I'd like to mention is that the NDIS does not approve therapies for maintaining function. It is approved for improvement and progress of the person, so keep this in mind if you want to see a therapist, and that their reports reflect this. When you have a planning meeting you do not need to get updated reports from specialist, as the planner will chase these up if they want further information, but just make sure that you and the therapist are on the same page.

The planners also tend to approve the services you are already getting. So if you want NDIS to approve something for you that you are not getting now, then I suggest you look at starting that therapy now. The planners seem to believe that if you aren't doing something already, then you must not need it, rather than a case of you can't afford it or it's just not available.

I hope that my NDIS experience has been enlightening and I'm happy to answer any questions if you want to post them for my attention on our facebook group or message me privately.

Natalie

Gemma lives her dream!

This winter was an extra special one for Gemma. To celebrate her 16th birthday she realised her dream to swim with the dolphins.

As part of the birthday festivities she also got to spend some time with her hemi-sister Freya in Melbourne. Happy 16th birthday Gemma!

Gemma and the dolphin



Gemma and Freya



Jasper



Jasper

A new member to our hemispherectomy community is little Jasper who had his hemispherectomy in mid May at the Royal Children's Hospital Melbourne aged ten months. Nicole says that everyone is excited about the gains Jasper has made post surgery and will continue to make. He is a totally different child!