

# Hemispherectomy Foundation Australia

# Newsletter

**Welcome to the fourth edition of the  
Hemispherectomy Foundation Australia newsletter  
Autumn 2016**



Welcome to the Autumn newsletter of the Hemispherectomy Foundation Australia. With Christmas, school holidays and the new school year behind us, the HFA committee is working hard to make our first family conference a reality. While we have applied for a number of grants to support the conference, the reality is that securing grant funding is becoming more difficult due to huge competition for a limited numbers of grants, both public and private. Commonly, many charities now outsource their grant applications to professional grant writers who can gain the upper edge with slick applications. However, for a small Foundation like ours, which relies entirely on volunteers, we need to rely on our own resources and fund raising efforts to support our Foundation and our activities.

**To assist with our fundraising Kylie Hockley, our Treasurer will be hosting a high tea on 15 May in Seven Hills, Sydney. Details on the event are at the back of the newsletter.**

Please join her if you can and if you can't, think about hosting your own high tea and invite a few workmates or friends to join you. Every dollar raised will go toward supporting our family conference and making it as affordable as possible for everyone. As the HFA is a registered charity with ATO tax concessions status all donations are tax deductible.



## The Rory Report

Rory has worked tirelessly with diligence and with outstanding determination during his Higher School Studies. Applying himself overwhelmingly to the position of school captain at Camden High School. He excelled in his HSC Exams PDHPE, General Maths. and Music (playing piano with one hand).

Rory is the youngest member of CIFA Camden International Friendship Association. He had a great desire to return to Japan and on his 18th

birthday this wish was to be granted by generous birthday gifts. He travelled unaccompanied and stayed in self contained accommodation, joined friends daily for wonderful excursions. With the use of only one arm there were many practice sessions prior to departure to equip him to apply his arm brace, adjust travel bags etc.

There were many doctors appointments to attend and coaching sessions for Rory and on the 9th October 2015 he wrote 'I am overjoyed and lost for words that I got a Early Entry into University

of Wollongong for a Bachelor of Arts Psychology'. On the 7th December 2015 at the Camden High School Presentation Night it as announced that Rory had topped his school in English and Biology and was presented with the Sibella Macarthur Onslow, CBE Award –English Standard; and the Camden RSL Award – Biology and to top the evening off he received the schools highest Special Award being the Melanie Andrews Memorial Award for a year 12 student showing outstanding levels of determination, strength of character, dignity and strong social conscience.

Amongst all his studies he attended the gym to help with muscle strength, and was on a busy learning curve to find a new medical team, as he is no longer attached to the Westmead Children's Hospital. Rory obtained high ATAR marks for his studies of Arts, Psychology at Wollongong University, and has just completed week one and is preparing to approach the next six years as he did with his school studies. He has discovered that the uni desks are designed for right handed people a little difficult for a left hemi. The stairs at uni are a battle daily, rising at 5.20am to prepare for departure to Wollongong a challenge and the long walks from the car park to lecture rooms take extra time. Not being allowed to drive due the hemi surgery he is most grateful to his friends for their lifts this semester.

His achievements have not come easy but his perseverance, application and dedication is an inspiration to others including able bodies.

Rory has demonstrated the ability to never say never, despite the sometimes huge misgivings of his mother. He now makes all his own appointments, attends some appointments alone and stands up for himself in the wilderness of the public health system. He has come such a long way, and his cheerful determination is astounding!

Rory has also diligently applied for scholarships at school and uni, such as the Variety scholarship and the uni equity scholarships. These have, and will enable help with transport, books, tutoring and so on.

It has been a long 2 years doing the HSC. I encourage all our wonderful hemi kids to reach for whatever stars they fancy. You just never know!

## The Karley Report



Karley underwent an anatomical right side hemispherectomy on September 22nd 2015 at the Sydney Children's Hospital Westmead. The surgery was performed by the amazing Dr Mark Dexter. We as a family were very pleased to be given the opportunity for Karley to have this radical life changing operation. Karley also needed major skull reconstruction to repair significant damage to her skull caused by her Sturge Weber syndrome and a brain herniation.

The surgery was a complete success although the recovery process was pretty daunting at first. Her ability to tolerate the given pain medications caused a little concern but she managed reasonably well considering. Fluid retention post op was very disfiguring but due to the nature of the surgery this was to be expected.

We spent a total of 3 weeks in hospital; Karley was having a slight issue with tolerating food and constant vomiting. Repeat MRIs were regular just to check for any changes or infections. All clear and normal. The most outstanding and rewarding outcomes we could have imagined. Her vision deficit remained unchanged. Homonymous Hemianopia's stable. Most exciting and pleasing for her future is that Karley has also retained use of her left arm and fine motor skills. A little stiff post op but through strength and determination daily physio and OT she is more alert, happy and ready to face the next chapter of her life.

Yes she is now nearly 6 months seizure free. Not one episode to report post op and medications which she has taking for over 14yrs has been reduced dramatically. She continues to take Diamox for fluid build up due to still having a few holes in her skull which will be likely to be repaired in the upcoming few months. Overall I believe that without taking our leap of faith and leaving Karley's life in Dr Dexter's miracle hands her epilepsy would be still destroying her. #livingwithhalfabrain

## Freya's not-so-fabulous fractured fibula



Just before her Year 10 exams at the end of last year Freya had a fall that we all could have done without. Tripping over the legs of some girls sitting on the path at school, Freya fell awkwardly managing to break her right fibula. The break required surgery and the insertion of a plate and screws to put it back together.

Falls are not uncommon for our hemispherectomy children and

Freya is no exception, but this fall had an enormously detrimental effect on her mobility and independence. While we always understood that Freya's hemiplegia was quite severe, we did not realise how weak her left (hemiplegic) leg was until it was required to support her. As she was not able to take any weight through her weak left leg, she was wheelchair bound and required manual lifting from the wheelchair to a bed, toilet and shower chair. All extremely difficult with a tall 16 year old girl. Reflecting on our experience, there are a couple of lessons from our experience that I would like to share.

### Lesson One

Keep the weak side as strong as possible. Freya had given up on her up on her daily left leg exercises about a year ago. I'm sure that had she continued with her daily leg squats and foot flexes her left leg would have had the strength to at least assist with transfers from the wheelchair by being able to take some of her weight.

### Lesson Two

A broken limb is not just a broken limb for hemiplegic children! Despite efforts to obtain an early referral back to Freya's rehabilitation team, the orthopaedic team at the hospital could not seem to appreciate that only having one good limb (her right arm) was actually very challenging, not only for Freya but for her parents too! Happy to discharge us a mere 12 hours after surgery, it was only our insistence that she see an occupational therapist or physiotherapist that allowed her an extra night in hospital. At discharge we needed to arrange a wheelchair, shower chair, commode and ramp for the steps into our house. Had we been under our normal rehab team we would have had the support of working with therapists with a greater understanding of the functional implications of a limb break for hemiplegic children. I am confident that we would have also had a home assessment to ensure our home was safe for Freya, just as occurred prior to her discharge after the hemispherectomy.

After approximately three weeks of "managing" at home we did eventually receive a referral to Freya's rehab physiotherapist who was quickly able to get her on her feet for short periods. Twice weekly appointments gradually returned strength to Freya's right leg and she was back on her feet again just in time for the last week of school!



## Rasmussen's Encephalitis – Unlocking the puzzle, piece by piece



One of the conditions that hemispherectomy is most regularly performed for is Rasmussen's Encephalitis. Rasmussen's Encephalitis is a rare paediatric epilepsy syndrome causing inflammation and neurological deterioration confined to one hemisphere of the brain. It is a devastating disease causing uncontrolled and severe seizures and progressive decline in the functions in the hemisphere with RE – hemiparesis, hemianopia, intellectual deterioration and aphasia if the dominant hemisphere is affected. Hemispherectomy is the only known cure for RE but comes at great cost.

Being such a rare and confounding disease, RE had previously suffered from the fate of many rare diseases and was put in the too hard basket by researchers. However, since the establishment of the RE Children's Project about five years an unprecedented amount of research has been supported in an attempt to unravel the mystery of RE. The RE Children's Project is the product of the drive and commitment of one RE parent in the United States, Seth Wohlberg. Seth has galvanised the efforts of some of the world's top neuroscientists to participate in research to better understand RE with a vision to create treatments that can cure the disease, or at least halt its progression, negating the need for hemispherectomy surgery.

While scientists have long suspected that RE is an autoimmune disease in which the brain is attacking some unknown antigen, such as a virus, latest research coming from both the United States and Europe confirms that RE is caused and perpetuated by a T-cell attack (involving of a limited range of T-cells) against a specific, probably viral, antigen. Although the antigen has still not been identified.

It is likely that there are already a number of immunotherapy drugs that could be successfully used in RE, next steps will be to identify these and commence clinical trials. It is the clinical trial stage that will be the most challenging for researchers given that RE almost exclusively affects children and is so rare. A patient registry is planned that will help researchers identify suitable candidates for clinical trials.

## UPDATE ON OUR NDIS PLAN – Natalie Hood

Alicia's plan is coming up for review in May again. This time the review is being done over the phone. This is a recent change due to not enough hours in the day for everyone to have a face to face meeting for reviews. You can ask to have a meeting if you wish, but I'm happy at this stage for a phone review, as I'm hoping it will be straight forward. Our goals and needs haven't changed much since last plan, so hopefully there won't be many changes.

I have been happy with the current plan, to which there have been a couple of additions over the year, which did take a few months, emails and phonecalls to organise. About ½ way through 2015 there was a need for Alicia to see a Psychologist regarding social issues at school and further development of social/relationship skills. Family Planning were the only service available who could provide what we needed and only accepted NDIS clients. So I contacted our planner and she advised me that psychologists were covered by the Mental Health Care Plan provided by Gps, and when I explained that Family Planning only accept NDIS clients, the planner had to make her own enquiries to ensure this. It took about 2 weeks, but then further funding for 6 sessions with Family Planning were added to our plan, which have been really beneficial to Alicia. However 6 sessions was not enough to cover all the issues, so Psychologist submitted report to NDIS at the end of 2015 requesting a further 6 sessions. This was approved late February, so funding for a further 6 sessions has been added to our plan. At the end of these sessions, the psychologist will have to submit a report to NDIS of the outcome and if further sessions will be required.

Also in 2015, funding allocated for physio (through CPA) was used for the therapist to meet us at our local hydrotherapy pool where she set up an exercise program for Alicia. Alicia has been swimming once a week with Special Olympics group since she was 3 and we have found it to be one of the best forms of exercise for her, but was bored with this. She enjoyed the exercise program and did it until the weather was warmer and could use our pool at home.

Funding also paid for a meeting with the therapist at our local gym (not the gym membership) where she assessed and instructed Alicia on an inclined treadmill walking program to improve drop foot and calf muscle tension. Alicia did this 5 days a week for a month but unfortunately there was no improvement.

She sees the physiotherapist every couple of months for assessment and maintenance. The last appointment was in the Christmas school holidays where it was assessed that she needed a new AFO and shoes. This had already been approved in our plan, but funding had not been allocated for it. The therapist had to submit a report and quote to NDIS, and we are still waiting on the funding for this. Alicia uses Keeping Pace shoes (to which a raise is added) with her AFO, and cost about \$200, which NDIS pay for as well.

In January 2016 Alicia was due to have upper limb Botox, but it was cancelled and rebooked for late February. Normally she has her lower arm/wrist plaster casted after Botox, so this has to be organised with OT at CPA (Cerebral palsy Alliance), so I also had to reschedule this appointment. The Botox went ahead in February and Alicia currently has her arm in plaster casting for 2-3 weeks (which is covered by NDIS).



Alicia has worn upper arm Second Skin splints since she was a toddler and these have also been approved in the plan for renewing, and funding will be allocated when needed. At an appt in Jan 2016, it was assessed that the splints were too small, and a new set to be measured and made. This required a report and quote from the Second Splint OT to NDIS and a month later the funding was added to our plan.

I mentioned in my last update that Alicia was looking for a part time job and we had 3 hours a week in the plan for a support worker to assist her in the job if needed. Unfortunately, she hasn't been able to secure a job, so she is looking at volunteering somewhere to get some work experience skills. We have been able to utilise the 3 hours a week to assist with daily living skills and access to community activities. A support worker has also been taking her to a couple of teen respite group activities in the holidays, also funded by NDIS.

We have 2 support workers who assist Alicia, dependent on their availability. One of them is my friend who was employed by the respite service on our behalf. We could employ her ourself and self manage all the funding etc, but there is a lot involved in this, so I prefer to do it through the respite service and they charge the services to my plan. Another family friend, who is 18, is interested in working with people with disabilities, so she has now also been employed by the respite service to also work with Alicia, when the other 2 workers aren't available. I find this an ideal situation, as our friend already knows Alicia really well, so for Alicia it will be like hanging out with a friend rather than a support worker.

Well, that's about it for this update. I hope some of our experience is helpful and enlightening.

## **CEREBRAL PALSY ALLIANCE MENTOR PROGRAM – Natalie Hood**

As Alicia was born with Cerebral Palsy, we have been receiving services from the Cerebral Palsy Alliance (previously known as The Spastic Centre), since she was little, and have continued with them in our NDIS plan. We attend our local service known as The Stuart Centre.

Last year Alicia (who is 15 ) was invited to participate in their teen mentor program organised through CPA with the Greater Building Society, where staff from The Greater volunteer to be mentors to participants in this program. Alicia absolutely loved it and it has been so good for her. They met once a month, on a Tuesday night from 5.30pm-7.30pm, where the mentors and teens would participate in a group activity and have a meal as well, all sponsored by The Greater Charitable Foundation. Some of the activities they did included wheelchair basketball, a shopping centre treasure hunt, trivia night and the highlight was meeting the Newcastle Jets soccer team who held their hands and walked on the field with them. Alicia was so happy because she got to hold the captains hand and walk on the field first. The program only went for a few months last year, but this year it is continuing once a fortnight for 8 months. Although there will be a few fun activities (including an overnight stay in Sydney), most sessions will involve the mentor offering guidance and discussions with the teens relating to personal issues such as selfworth/esteem, life goals, relationships, school, work etc.

The teens involved all have similar abilities to Alicia, so most wear an AFO and can only use one hand, so they are all on par with each other and have no problems fitting in with the group. There may even be some special friendships formed. The only involvement the parents have is to drop them off and pick them up. While the kids are there, some of us meet and have dinner, which has been great for the parents involved.







# Hemi High Tea

Hemispherectomy Foundation Australia is dedicated to children and families impacted by hemispherectomy brain surgery. In 2016/2017 the Foundation's aim is to hold a "Family Conference" whereby hemi-families from all over Australia will come together and meet for the very first time.

In order to achieve our goal, you and your guests are invited to attend a Fundraising "High Tea."

There will be lucky door prizes, a raffle, prize giveaways and more.

Details are as follows:

**Date:** Sunday 15th May 2016

**Time:** 2pm

**Place:** Iris Room

Lily's Function Centre

162 Prospect Highway, Seven Hills 2147

(enter via Quinn Avenue)

**Cost:** \$45 per person which includes "bubbles" or soft drink on arrival, delicious afternoon tea treats served on a three tier platter and a selection of teas. (Coffee is available on request.)

**RSVP:** Kylie via SMS on 0417 326 599 or email [gkgkhockley@gmail.com](mailto:gkgkhockley@gmail.com) by 1st May 2016.

Full payment is required by this date to reserve seating.

Payment can be made by cash, cheque (made payable to Hemispherectomy Foundation Australia) or by direct deposit to account number:

012478 – 190 668 262

(please include full name if payment is by direct deposit).

