

# Hemispherectomy Foundation Australia

## Newsletter

*Welcome to the second edition of the  
Hemispherectomy Foundation Australia newsletter  
October 2014*



It has been a busy few months for all at the Hemispherectomy Foundation Australia. In July several of us attended the United States Hemispherectomy Foundation conference in sunny California, America. As always, the event was a wonderful opportunity to meet other hemispherectomy families and hear the latest research regarding hemispherectomy surgery and rehabilitation. Particularly exciting was the inaugural Brain Recovery Project conference which was held in the two days preceding the Hemispherectomy family conference.

The Brain Recovery Project has been established to advance research into post-hemispherectomy rehabilitation, and the conference was the first time that medical specialists had come together to discuss how to improve outcomes for children once they have undergone hemispherectomy. The reality is there is just too much variation between the type and extent of rehabilitation that our children undertake once they have had their surgery. The objective of the Brain Recovery Project is to develop evidence-based rehabilitation protocols that can be used by hospitals and rehabilitation centres treating hemispherectomy children. While our children might need a hemispherectomy for a variety of different conditions, they are all in need of intensive physiotherapy, occupational and speech therapy following surgery if they are to achieve their optimal outcome.

In other news, we have welcomed many new families to our network, several of whom have children who have not yet had hemispherectomy surgery but who may require it at a later time. It is great for us to be able to provide the support and advice to families – particularly as the very support we are now able to provide families was missing when many of us were on the same very stressful path.

We have also written to our two paediatric neurosurgeons who perform hemispherectomy surgery in Australia – Dr Mark Dexter in Sydney and Dr Wirginia Maixner in Melbourne. We have asked both surgeons to provide information for our website on the different hemispherectomy techniques that are used in Melbourne and Sydney. Children who have hemispherectomies performed by Dr Dexter will receive the anatomical technique where the seizing hemisphere is removed, where in Melbourne Dr Maixner uses the functional technique where most of the seizing hemisphere is retained, however is disconnected from the “good” hemisphere.

We are hoping that the information from the surgeons will provide the pros and cons of the anatomical and functional hemispherectomy so families can make an informed choice about the surgery for their child.

### **UNITED STATES HEMISPHERECTOMY FOUNDATION CONFERENCE 2014**

A complete set of notes from the conference can be found on our website at [www.hemispherectomyaustralia.org.au](http://www.hemispherectomyaustralia.org.au)

Several of the sessions covered important topics such as:

#### **Hydrocephalus in hemispherectomy children**

- Occurs when there is a problem with reabsorption of the brain fluid
- Symptoms include headaches/vomiting/poor balance/seizures/lethargy
- Anatomical hemispherectomies are associated with a greater incidence of hydrocephalus after hemispherectomy, however can still occur with a functional hemispherectomy
- Hydrocephalus can be a medical issue at any time after surgery Intellectual functioning after Hemispherectomy

#### **Intellectual functioning after hemispherectomy**

- Be wary of standard IQ tests for our kids!
- Because their speed of processing will always be slower this will bring down the overall IQ score even when they have performed well in other components of the test
- If you are having a neuropsych assessment make sure you are provided with the scores of each of the components to understand their strengths and weaknesses. Pay attention to the underlying measures
- The assessor also needs to understand about hemi-neglect and cortical visual impairment
- Any neuropsych assessment should include recommendations for the school
- The assessment should inform some targeted interventions. We need to move beyond thinking just in terms of compensation – that is the remaining hemisphere will automatically pick up the functions of the lost hemisphere
- Areas affected after hemispherectomy include
  - o Attention
  - o Effort
  - o Focus
  - o Working memory
  - o Long term memory
  - o Emotional regulation
  - o Planning
- Research indicates children who have one-on-one support in the classroom have better outcomes
- In the home environment, co-construction of ideas is very important. That is, talk about the topic, help your child construct the ideas and how the task will be handled.

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## Vision after hemispherectomy

- Peripheral vision loss can lead to the eyes drifting apart (the child may be trying to get wider vision) – surgery may not fix this as it is the brain that is requesting the eyes to drift apart is not a muscle. May choose not to attempt to fix – however if the eye drifts down then surgery is required
- If the child does not read to the end of the line (left hemispherectomy) or does not return all the way to the left (right hemispherectomy) then:
  - o Use a rule on the left or right as appropriate so the child knows the end or start of a page.
  - o In younger children turn the page on the side so the child reads up and down!
- Prism glasses can be used and require training. The glasses are for movement and for obtaining information about the environment.
- Interestingly, there is an above average response to stimuli on the blind side (black and white images only) which suggests the brain can still “see” images in the blindside. Variable by subject.

## Reading after hemispherectomy

- More research is now being undertaken to understand how hemispherectomy children acquire reading skills
- Spatial neglect is a problem for problem for all hemispherectomy children. Right hemispherectomy children will often not read to the start of the sentence on the left, and left hemispherectomy children may not complete reading the sentence
- Consider teaching children to read vertically – that is holding the book vertically rather than horizontally!
- The potential of the right hemisphere is not well understood in terms of reading
- Left-hemispherectomy children require specific strategies to learn or re-learn to read.
- For left hemispherectomy children, the whole word approach to reading is better suited than the more traditional phonics reading strategy (which breaks words down)
- Right hemispherectomy children do better with the phonics approach
- All hemispherectomy children will have difficulty deciphering non-familiar words
- Bi-lingualism is possible after hemispherectomy. The area of the brain that supports language development can support both languages, and in fact learning a second language may be particularly helpful for the hemispherectomy child as it activates this area/s
- Right hemispherectomy children will struggle with:
  - o Communication intent
  - o Conversational turn-taking
  - o Tonal inflections eg. Sarcasm
- Language will stay where it wants to be (usually the left hemisphere) until it is forced to move. An functional MRI was

shown indicating language being preserved in small pieces of cortex when the rest of the hemisphere was damaged

- Longer duration of seizures have been associated with poorer communication outcomes
- Further reading Danelli et al “Language after Left hemispherectomy” (2013).

## US Hemispherectomy Foundation Conference 2014

Kylie Hockley

Gary, Gemma, Kristen and I were very excited to board the Hawaiian Airlines flight in late June and leave chilly Sydney bound for the “Hemispherectomy Foundation Conference” in Anaheim, California. We landed in Honolulu and then spent an amazing seven nights cruising around the Hawaiian Islands on the “Pride of America” cruise ship.

We flew to Los Angeles and after arriving in Anaheim we headed straight for the “Happiest place on earth,” Disneyland and spent the next three days exploring the park and its surroundings.

On Thursday it was finally time to register for the conference and we were greeted by the conference organising team and given our lanyards and goodie bags. We then made our way to “Downtown Disney” where the families met up for the first time. It was great seeing and meeting these families knowing that they all have travelled the same journey as you or are about to embark on this path known as “hemispherectomy surgery.”

On Friday, after the kids were all settled in “Kids Club,” we made our way to the conference room and the morning session commenced. Several speakers gave very interesting insights into hemispherectomy surgery and rehabilitation after hemispherectomy.



During this session Gemma, and her hemi-sister Freya from Melbourne, were asked if they would participate in some research studies so they went off with the researchers where they were tested on their reading, visual fields and emotions and were both asked to come back at the end of the day to be filmed together talking and interacting with the researcher.

It was a free afternoon on the first day so a lot of families came together by the pool once again to meet and swap stories while the kids had a wonderful time swimming and having fun on the water slide.

Day two of the conference was a full day of different speakers on varying subjects and during the afternoon they ran concurrent talks so Gary would go to one conference room and I would go to the other so as to not miss out on any information we were being provided. That night we were entertained at the conference dinner by wonderful children’s choir and Hawaiian hula dancers while enjoying a delicious buffet dinner. It was the perfect end to a great experience.

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## Georgia's news

Kate Marchbank

Georgia is currently studying for the HSC, her first exam starts on 13 October, and she finishes on 3 November. We will all breathe a huge sigh of relief once that last exam is completed!

Consistent with all milestones for our kids, there has been a lot of paper work and admin to complete via the Board of Studies to request Georgia has extra provisions during her exams, eg extra time and a scribe. These were thankfully granted to her, and have provided Georgia with more confidence. She did really well in her Trials (only just failed one subject) – and we are trying to keep up the momentum and motivation until November!

What I find tricky is the time frame leading up to the HSC exams. All Year 12 students graduate at the end of Term 3, and then have to manage their own study time until the actual HSC (approx. one month). This is challenging enough for 'normal' kids, but for Georgia – where planning and organisation is still somewhat of an issue - it is not ideal. We are trying to stick to a study timetable, and I am paying for a tutor twice a week (just for an hour each time). However, I am a full time working single mum so my ability to supervise, provide a nice tempting lunch or encouragement during the day, is rather limited!

Georgia would like to do an undergraduate degree in primary education, and we visited several University Open Days. A lot to digest!

I have also discovered (rather late), that Georgia ought to have been assessed by the Department of Human Services in order to determine what support she may require, either in transitioning to uni and/or work. We have an appointment lined up for this Friday from the Cerebral Palsy Alliance, and I am hopeful that this will be helpful to Georgia, as she is – by her own admission – rather daunted with stepping out into the world as an independent student/worker. Either way, it is encouraging to know there are people out there to provide this important support.

Georgia missed a lot of schooling during her illness; hence she is 19 – a year older than her peers. This means she has an increased sense of urgency to complete her studies and –

incredibly – wants more independence by moving out of home! I have no idea how she thinks she will support the cost of it – however, I find it immeasurably pleasing that she has those aspirations. I never want to put limits on what may be achieved.

That's all from us but I hope Georgia's update has been useful and here is a photo of her this winter with her lovely boyfriend, Liam.



## Max's News

Jo Symons

So Max and I went to Los Angeles for the whole of July, for him to attend specialist physiotherapy and for me to attend a scientific hemispherectomy workshop and family conference. How did Max go?



Max has gone from hardly using his right arm at all, and being super resistant to anyone touching it, to now willingly using it for many, many activities. His walking is stronger, thanks to an hour a day on a supported weight treadmill watching the Wiggles! As a by product, his talking has come on leaps and bounds too, probably due to an undistracted mother 'in his face' the whole time.

The contribution this trip has made to Max's progress is indescribable. Aside from the immediate physical improvements, we have been able to plan with refreshed ideas on Max's holistic rehabilitation. I am now busy trying to plan with his team at home here, contextualising what we learnt there to the Australian situation.

Importantly, I feel my work here is now to try and influence availability of therapies here for children like Max. This is now my goal. Next year I hope, with the help of the Hemispherectomy Foundation Australia team to raise funds for other children to be able to access this brain rebuilding therapy too!

## Rory's HSC Year, Mark 1

Karen White



Well, Rory has had a big year. Unfortunately the year began with Andrew, his father getting sick with a mystery disease which saw him laid up for a few months. Rory found this hard but battled on through his first term of studies. He was very busy with captaincy duties, heading off to State Parliament House, hob-nobbing with polities and governors alike, giving speeches at school and elsewhere and hosting visitors from Japan and Cowra! He managed to squeeze in an 18th birthday party as well.

In between engagements, Rory stuck to a study plan to which he was fervently committed. He had several periods a day off class (Rory is doing the HSC over 2 years), so he used his time to make study notes and liaise with his teachers. At home, he had several tutors, so his afternoons were full. In the times not spent hitting the books, Rory attended his gym, doing his core strengthening exercises and his work on 'righty', who has grown a muscle!

Along came the Trial HSC, and Rory was very pleased with most of his marks and he decided on new plans of attack for the others. He has become the Flashcard Meister, and can rattle off reams of facts about health and physical development. So much for hemi kids and memory problems. Rory has found that the more he tries, the better he memorises. It doesn't stay in there too long, but long enough is good enough for us!

Graduation in October was a stellar occasion, with Rory acting as MC for the ceremony and giving a very well-received valedictory speech. His grandparents came along, even great Uncle Billy was there – it was a great night. Mum was bursting to stand up and yell out, "That's ma boy!!" in fact, she wishes she had.



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Now it's exam time. We are 2 days away from his first exam at the time of writing this. He is very nervous. Mum has the rescue remedy at hand but Rory is not a believer in things herbal. He is working hard each day, enjoying the nice lunches you get when your mum is on study leave with you! By the 22nd of October he will be a free man. Sort of. He has to put on his uniform and go back to school. He is finding this hard, as all his mates will have left, but is resigned to it. At least he has 21 days in Japan this Xmas, so he is looking forward to his first solo trip. Mum isn't. Even Dad isn't.

He will see his friends at the Formal in November, so that will be a fun event. We've had the suit altered for righty, and the shoes are awesome, black and pointy-no AFO for the night!

So that's Rory's year for 2014. Watch this space for more news next time, including HSC results part one, and Rory does Japan!

P.S. I forgot the million appointments for arms, legs etc!

## Happy 2nd Hemiversary Aaron!

Aaron and his friend Roy



Two years ago this month Aaron had a left anatomical hemispherectomy.

He continues to be committed to his 'home grown' therapy (there are no hospital based or therapy protocols in place).

He attends school full time and after school loves to be involved in physical activities. He plays golf weekly with a Disability support group, swims and gyms on other afternoons with a companion/mate (Roy) and plays table tennis twice a day

while at school. His keen interest in table tennis has lead us to investigating competition and this month he will attend a training camp in Brisbane to see if he can be categorised for tournaments which cater for those with disabilities. It made us laugh when we were asked if he is able to play against 'abled' bodied opponents. He has no option as there are no others around who have similar disabilities and he can now soundly whip all his family members and a lot of the other year 11 students.

## Aaron and transition

Transition, transition, transition... This is a word and concept as your children get older you will hear a lot of. Transitioning out of children's medical services, transiting out of school, transiting into work or study. These changes can be scary and are filled with uncertainty. Please remember to link into organisations like 'My Future My Life' and ask about a 'Transitional OT' or protocols regarding the end of access to child services. RCH – Rehab



Brisbane has Amanda Francis employed in this role. Ideally transition occurs slowly so that there is a clear management pathway with all options being explored; and we as parents, need to be well informed to give our hemi kids the best possible chance of making this huge change smooth.

## Hemi Hug Packs

Kathy Payne

The first of our packs have made it to a family and child who has recently had a hemi in Sydney. The packs are the Foundations way of saying "We understand," "We care," "We are here for you." Kylie Hockley was our very able ambassador and delivery service with a smile.

Now that our Foundation is financial we will be able to replenish these packs as needed.

The packs contain:

- Hemi waterbottle
- Hemi pendant (without change...there would be no butterflies)
- LeReve refreshing Facial Mist
- Box of chocolates
- Hemi hug bear
- The Hemispherectomy Foundation Australia pamphlet and poster
- Message of support

"We hope you enjoy the 'Hemi Hug Pack,' delivered with love and support.

Take comfort in knowing there are others who have walked similar journeys. Everyone has individual challenges and experiences and you are joining a unique group of Australia's who have a child with half a brain or are a person who has had a hemispherectomy.

Please take some time to read the enclosed pamphlets, visit our website at [hemispherectomyaustralia.org.au](http://hemispherectomyaustralia.org.au) and/or join our facebook site to have the opportunity to connect with others who may have experienced some of what you have before you."

Brain Recovery Project website

click the link below

[brainrecoveryproject.org/](http://brainrecoveryproject.org/)