

Hemispherectomy Foundation Australia

Newsletter

*Welcome to the first edition of the
Hemispherectomy Foundation Australia newsletter*



It's difficult to believe that in 18 months, the Hemispherectomy Foundation Australia has grown from a great idea (of our President, Karen White) to a registered health promotion charity. In this short time we have developed an incorporated governing structure, built a website, developed and distributed brochures and posters, submitted funding applications (keep your fingers crossed!) and held our first Annual General Meeting. Our family network continues to grow as more Australian families impacted by hemispherectomy surgery become aware that we have been created.

As well as existing hemispherectomy families we have also welcomed several families to our network who have children who have not yet had hemispherectomy surgery but may require it in the future. For these families, reading the stories of our hemispherectomy children and asking questions through our facebook and website has been of tremendous comfort and support.

We hope you enjoy reading our newsletters which will update you on what our incredible hemispherectomy children and families have been up to, both personally and on the rehabilitation front. We will continue to keep you updated on the introduction of the National Disability Insurance Scheme (NDIS) and what it means for us. Natalie Hood one of committee members has made it her mission to navigate this particular maze for everyone and we are all very grateful!

If you would like to become involved in Hemispherectomy Foundation Australia please contact us on info@hemispherectomyaustralia.org.au

RARE DISEASES WORKSHOP

Kylie Hockley

On the 15th March I attended a Rare Disease Workshop which was held at the Children's Hospital at Westmead, Sydney. The theme was exploring the impacts of rare diseases - your child, your family and the health system. The workshop was specifically designed for parents, carers and support groups. It was a great opportunity to meet up with other parents/carers and share stories of our amazing children. The speakers were very informative and enlightening, sometimes confronting, and it did make me realise that I am very lucky that Gemma has had such a good outcome following her surgery. I handed out a few 'Hemispherectomy Foundation Australia' brochures to some interested parents and I hope in time we can be of assistance to these families.

FUNCTIONAL ELECTRICAL STIMULATION – 'FREYA's' TRIAL



For the past three months we have been trialling the use of Functional Electrical Stimulation (FES) to resolve Freya's shoulder subluxation. Shoulder subluxation can be a big problem for hemiplegics, as the paralysed arm can hang heavily causing the shoulder muscles to weaken and the shoulder to become dislocated from the joint. While having shoulder subluxation doesn't worry Freya at the moment it

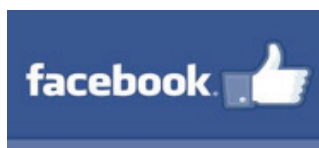
is inevitable that over time it will cause her pain and a reduced range of motion. For this reasons we need to resolve it now and keep on top of it. Last year the

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Rehabilitation Service at the Royal Children's Hospital (Melbourne) bought about 20 FES machines from the United States to use on children with muscle tone issues following brain injury.

The FES is easy to use and has been well tolerated by Freya, who as an independent teenager is now reluctant to participate in anything that has much to do with "therapy." Two electrodes sit either side of her shoulder and are attached to a small unit that she can clip to the top of her jeans or pyjama pants. The electrodes send a fairly gentle electrical impulse to the muscles causing them to contract – visually it looks like she is hunching the shoulder. She uses the FES for 90 minutes each evening – usually while watching TV or doing her homework. It's now a well-incorporated part of our evening routine. Since using the FES Freya's shoulder subluxation has been reduced from about 5cm to about 2cm. She is now able to put her shoulder back in the joint by slowly raising her arm and it is staying in place for longer periods. We will continue with the FES for another few months to see whether the muscles are strengthened to the point of being able to hold her shoulder in place permanently. Then it will be an experiment to see how much we can reduce the usage by, while still maintaining the muscle control. I will keep you posted.

HEMISPHERECTOMY FOUNDATION AUSTRALIA DOES FACEBOOK!



If you aren't already a member of the HFA Facebook group please consider joining. It is a closed group which means that only Australian hemispherectomy families and friends can join and anything can be discussed amongst members in complete privacy. The group already has about 20 members and is growing as news of the HFA's formation is spreading through the hemispherectomy community. It is a great resource, allowing the experienced hemispherectomy members to provide information and support to those that are either early post surgery or yet to have surgery. Natalie is continuing to post new materials on disability organisations and aids, the NDIS and other information relevant to hemi children.

UNITED STATES HEMISPHERECTOMY FOUNDATION – ANAHEIM, CALIFORNIA, JULY 2014



This year several Australian families will be travelling to sunny California for the US Hemispherectomy Foundation conference. This year's conference is back at the Paradise Pier Hotel, Disneyland, where it was held in 2011. The US Hemispherectomy Foundation conference is an amazing opportunity for hemispherectomy families to connect and hear about the latest thinking on rehabilitation techniques specifically for hemispherectomy children. The US Hemispherectomy Foundation is dedicated to ensuring that hemispherectomy children are able to reach their physical, social and cognitive potential. They do extraordinary work in bringing together clinicians and professionals involved in the recovery of hemispherectomy children. These experts speak on the latest knowledge and thinking around best-evidence post hemispherectomy physical and occupational therapies and educational strategies to get the best from our children.

For many families that attend it is a once-in-a-lifetime opportunity to meet others who have travelled the same lonely path that has led to their precious child having hemispherectomy surgery. For the children, many of whom will have never met another hemiplegic child (let alone another hemispherectomy child) the opportunity to meet and mix with hemispherectomy children, make friends and share stories is priceless.

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MY NATIONAL DISABILITY INSURANCE SCHEME (NDIS) EXPERIENCE

Natalie Hood

I've been following the NDIS since it became an idea and even made a submission to the Productivity Commission, so I'm quite excited about it being rolled out in our area (Lake Macquarie) in July 2014. Since being rolled out in Newcastle and other trial sites last year, I have heard varying reports about the scheme being positive (clients are now living independently and actively participating in community, much needed supports are being funded) and negative (planners not being knowledgeable about the scheme, budget resources not being able to sustain the scheme, funding allocations decreasing and not adequate).

Applying for NDIS was easy. Its just a matter of completing the Access Checker on the website to register. You then contact your local NDIS office with your registration number and they send you application forms to submit, which also requires some form of documentation confirming the disability (I submitted a copy of Alicia's Better Start Health Plan as it has everything in it.) There is no need to organise any other reports at this time, as the planner will organise them if needed. After this it all happened a lot quicker than I expected. The local office contacted us and the planning meeting was organised in less than a month, which was 2 weeks ago and the plan was finalised last week. To prepare our plan I did a lot of reading of the Operational Guidelines and joined related facebook groups to find out exactly what supports and funding Alicia would be entitled to.

First we had to establish her goals and aspirations for at least the next 2 years and long term. The next step was to work out what supports she would need to achieve these goals/aspirations. As part of the process you are given an information pack to help you with this, which basically involves recording the daily life/activities/needs and supports of the person. Our first meeting lasted for about 2 hrs and I found it very mentally draining, as a lot of detail was required about Alicia and her life. (When it was over I felt like I'd been studying for a major exam and felt such relief when it was over.) Although the planner was quite young she seemed competent, (previously an Exercise Physiologist with Allied Health) and I asked quite a few questions which she was able to answer.

Although, there were a couple that were in the grey area, so she had to liaise with the co-ordinator. Alicia was not required to be at this meeting, so I chose not to bring her as she wouldn't have contributed much and would only have been bored. However, the planner did request to meet her at the following weeks meeting, where she went over everything with Alicia that we had discussed. It was very thorough and we were happy with the outcome. The plan covered funding for therapies and a support worker for personal care and assistance to participate in community activities. I had requested several other supports to be funded but these did not qualify under the criteria. The plan will be reviewed in 12 months but it can be altered at any time if something else is required.

Overall, I was happy with our experience and the outcome. Although I felt more supports could have been funded, Alicia is definitely getting more support than she was before. At some stage I will put a more detailed account of our experience and plan on our facebook page, so stay tuned.

THE BRAIN RECOVERY PROJECT IN LOS ANGELES

Jo Symons

The excitement is intense at the Symons household at the moment! Our son Max had a left hemispherectomy at 9 months of age, at Westmead Children's Hospital in Sydney. As we all know, it is important to try and get therapy whilst our kids are so young while their neuroplasticity is at its peak. Whilst the therapy we receive is good, it is difficult as the condition and surgery are so rare, that the therapists are working with no previous experience of someone with his condition.

We have a goal to attend the Brain Recovery Project in the USA <http://brainrecoveryproject.org>, a dedicated research and therapy service in Los Angeles that focuses on 'rebuilding the developing brain.' Being a physiotherapist myself, I am not setting my hopes on some overseas 'miracle cure'. However, I have done much research and conclude that this intensive therapy provided by an experienced paediatric physical therapist who predominantly treats hemispherectomy children will be of great benefit.

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The excitement is all down to our wonderful friends who have organised a fundraising lunch in Brisbane on 1st June 2014 to financially assist this treatment for Max, and travel for Max and myself to the US. We are having a raffle and auction will be held, the prizes donated have blown us away. We are really very lucky to be in a position where we have such a wonderful group of friends and supportive community. Max is well and happy and full of life, and we are all determined to see him achieve his greatest potential.

A few of the committee members from Hemispherectomy Foundation Australia are attending the Hemispherectomy Conference in Los Angeles in July 2014, which I will also attend. We will let you all know how the conference and therapy go in the next newsletter!

HEMI HUGS PACKS

Kathy Payne

We are nearly ready to go with our Hemi Hugs Packs. These packs will provide new hemi families with some items of comfort and much needed information as they begin the next leg of the gruelling hemi journey, plus connect them with other hemi families.

The Australian Hemispherectomy Foundation is so grateful to our kind donators –

Lesley Carrie an Independent Le Reve Consultant (6 bottles of refreshing Facial Mist),
BOA (50 hemi printed water bottles),
Sue Cruikshank (6 travel bags),
Natalie's mother for 6 hand knitted "hemi bears."



AARON'S UPDATE

Kathy Payne

It is just over 18 months since Aaron had a left functional hemispherectomy. This time has gone fast and has been marked by many significant changes and life adjustments. Aaron is now 16½ and at the start of 2014 began attending a large state high school



in year 11. He is keen to get there every day and happy and excited by the variety of subjects and new experiences. Due to the hemi Aaron lost his ability to read and now relies on sign words and produces limited written sentences, yet can comprehend most short notes, read a simple phone text, send a simple text and follow his complex school time table. At school he is supported in some classes to assist with two handed tasks and note taking. He is enjoying the practical subjects of Agriculture, Physical Ed., Hospitality (we are loving the cooking which comes home each week) and woodwork. He is definitely enjoying a better quality of life post surgery. Recently we camped with a number of other families. It was a relaxing experience and great that Aaron could join the other teens around the fire and sleep in his own swag.

When it comes to therapy, we are really on our own at this point. No regular contact with either the local or RCH rehab teams. Therapy consists of two structured afternoons at the gym with a young male physio graduate we have employed, one day of swimming and the other of gym exercise. Aaron then goes to the gym by himself whenever he can. Plus he uses the EMS daily on his affected hand, in the hope of stimulating some thumb and forefinger movement. We have seen some improvement with flickers of movement. I'm happy to share more about this in future newsletter but at present we are mainly focused on the Mitii program (Move it to improve it) – Aaron was selected to be part of a research project undertaken by Brisbane RCH and the University of

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Queensland. It is a novel internet-based rehabilitation program for children with congenital hemiplegia which hopes to provide therapy at intensities sufficient to drive neuroplasticity (remodelling the brain) to improve outcomes. Mitii is a multi-modal training program comprising upper-limb, cognitive and physical activity training. Unlike conventional therapy, Mitii is made fun by delivering therapy using an interactive computer game, which is controlled by movement of the hands and body. All that is required is a home computer connected to the internet and a web-camera. A Physiotherapist, Occupational Therapist and a Psychologist act as virtual trainers, remotely accessing the Mitii program regularly to set up and progress an individualised series of games.

www.som.uq.edu.au/research/research-centres/cerebral-palsy-and-rehabilitation-research-centre/our-research/move-it-to-improve-it.aspx

Aaron has been on the program for approx 6 weeks, already we feel there has been an improvement in his working memory and maths. We are keen to see the objective results at the end of the four months.

HEMI “BESTIES” FREYA AND GEMMA CATCH UP IN SYDNEY

Carolyn Pinto

In the 18 months since Freya (right hemi for Rasmussen’s) and Gemma (left hemi for Rasmussen’s) met they have established a firm friendship. Meeting for the first time at age 13 the girls immediately hit it off, scurrying off to Freya’s bedroom from where Kylie and I proceeded to hear copious chatter and giggles. While Freya lives in Melbourne and Gemma in Sydney both girls chat frequently by Skype and Facetime – often spending hours at a time talking and laughing.

Freya’s 15th birthday present this year was a return flight to Sydney to visit Gemma and be thoroughly spoilt by the Hockley family. Over the Anzac Day weekend the girls enjoyed Yum Cha, movies and other “secret” activities that Freya will not divulge!

It is a beautiful and very special friendship, and although created due to a devastating disease such as Rasmussen’s, brings the girls and their families much joy.

