

Corpal Newsletter

Supporting those with ACC or Aicardi Syndrome

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Corpal is a registered charity providing support by way of information and signposting for parents, carers and those affected by ACC or Aicardi Syndrome.

All assistance is provided in good faith, without charge and by parents or carers. Registered in UK. Charity No: 1086019

Spring 2009

Well here we are again. We hope you are all well. Hopefully you'll have noticed our updated website went live in December 2008. We are now able to bring you scan pictures, an updated medical section (including glossary and details about on going research). We hope you find this a useful tool, and would love to have your views on what has been done well and what could be done better. Please send these to jean@corpall.org.uk. We've also dragged ourselves into the 21st century and set up a Facebook page. You are welcome to join and help us raise our awareness; please remember to post it to your profile. Our AGM will take place on Saturday 9 May, please read on for more details. If you have anything you would like to contribute to the Newsletter please contact kerrydowden@corpall.org.uk. We are especially keen to receive personal stories, which we know our readers always enjoy.

Spencer's March Hair Ball
by Jean Dalton

'A FANTASTIC EVENING' - I have to say I will be talking about Spencer's Ball for a long time. Liza Schwarz worked relentlessly with dedication to make this evening such a success.

On arrival at the venue - Peterborough Suite - at the East of England Showground, you were greeted with a Tequila Sunrise or an orange juice, and then you walked through into this amazingly decorated hall with beautifully covered chairs around many round tables. The food was delicious, and during the meal we were entertained by compare Nick Alexandra, plus we had music by Adiva, as well as guest singers from the tables.

Near the end of the meal the raffle was drawn with some wonderful prizes, the auction was held and run by Nick and Warwick Davis, whom you



Cathrine Brennan (Secretary), **Warwick Davis**
and **Jean Dalton** (Chairperson)

might have seen in the Harry Potter films. They worked well together convincing people what a bargain they were getting on all the auction items, their charm and humour raised the donations considerably! When the draws and speeches had finished, we all got down to some serious dancing. The atmosphere was great and I am sure that everyone thoroughly enjoyed themselves.

The evening, including a raffle, 'donate a fiver' and an Auction, plus other donations

from various sponsors, helped Liza raise over £6,600.00 which will be divided between Corpal, Phoenix School (attended by her son, Spencer) and a disabled access door for her Salon. Also, I would like to mention that Warwick Davis' wife won first prize of £212.50 in the 'donate a fiver' fundraiser, and she very kindly donated this back to the event.

We cannot thank Liza enough, our share will help keep our newsletter, website and annual event running. I would also like to say thank you to Liza's husband



Heather Robinson (Treasurer), **Cathrine Brennan**,

Liza Schwarz and **Jean Dalton**

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Karl, and her friends who were all there to help and support her.



Cathrine Brennan and others enjoying the Ball

Millie Richards' story by Andi, Millie's mother

My name is Andi, I'm a mum of two, Jake who is 12 (going on 22) and Millie who is 10 months. Yes, quite an age gap! I was overjoyed to find out I was pregnant again, I had a few past problems, and it seemed to take a lifetime to conceive and just as I was about to give up hope, it happened. Little did I know then that my life would never be the same again. I was under a consultant during pregnancy, because of my past medical history (C-section due to pre-eclampsia symptoms and a miscarriage), but I was determined to give birth naturally this time, and that I did.

Millie came along a bit unexpected, 4 weeks early and very quickly (about 2 hours labour). She was a very determined little thing to say the least. She was a good weight for her weeks, and had no apparent problems at birth apart from her eyes being sticky and closed for the first few weeks. This was the start of her long list of problems to come.

I initially raised my concerns about her eyes to the midwife and health visitor, as she

seemed to be not focusing properly, and we were referred to the Ophthalmology Dept, where we were told that Millie was going to be short sighted and that she has a muscle imbalance in her left eye, but she would be followed up on a regular basis. During this time other problems were becoming aware to me, she was not smiling, and seemed to be a very quiet, floppy baby. This to some, especially the quietness, would be a God send, but for some strange reason I knew that there was something wrong with my baby, call it mothers intuition, I don't know? I just knew that I had to get someone to hear my concerns.

By this time Millie was 5 months, she had started smiling (thankfully) but all other milestones had not been met. She couldn't hold her head up, so I was referred to my GP who then referred me to a Consultant. At the first appointment Millie (7 months) was examined head to toe, numerous questions were asked, and it was then that I realised my fears were not me being a paranoid or maybe an over-protective mum, but they were real.

The consultant was fantastic; she was very honest and said that she was concerned, and that Millie would need to have an MRI plus various blood tests. My heart sank! Not only at the fact that she may have something wrong with her brain, but also the fact that she would need to have a general anaesthetic! I was reassured this was quite safe and was necessary to get to the bottom of Millie's problems. So it was a case of waiting for the MRI and being as brave as possible, during this time Millie started to show strange jerky movements with her head and in the arm and hip area. I rang our Consultant, who again seemed concerned

and said she would like Millie to go for an EEG the next day, to hopefully rule out some possibilities.

Millie had to be sedated for the procedure but otherwise it was OK, and we had the result back before we left which showed no epileptic predisposition but did show the jerks she was making. We were told these were of no real concern. The Consultant told us she was bringing the MRI forward and was getting a neurologist on board to help with the diagnosis.

This takes us to Nov 2008, Millie was nearly 8 months old, she was still showing no signs of improvement, although head control was getting slightly better, she still couldn't sit or roll unaided, she had quite severe hypotonia, and she was still a very quiet baby, having very vacant moments, as if she were 'empty'. One week before the MRI, we had a consultation with a neurologist who examined Millie and suggested that a lumbar puncture and more bloods be taken whilst she was having the MRI. A chest x-ray and ECG were to be performed too. I could not believe that my baby was going through all this,



Millie and her brother **Jake**

and all before her 1st birthday. It didn't seem right, but I had to keep focused and think it was for the

best to have all the tests done, and hope that we'd soon get some answers.

The day of the MRI arrived, I don't think I slept a wink, we arrived on the ward, and after a short wait we were taken up for the MRI. I lay Millie down on the bed and a mask was put over her face until she went to sleep. Leaving her, lying there helpless, was the hardest thing I've ever had to do in my life! We were told it would be an hour's wait, which turned into nearly two, and in which time we were getting extremely anxious and worried. It was the longest 2 hours of my life!

We were finally able to see her, but as she was coming around, she was making a strange high pitched cry, certainly not normal for Millie and one that I never want to hear again. They kept her for observation for a short while, and then we were allowed back on the ward. What a relief it was when she woke properly and started to look and sound like 'our Millie' again.

It's now the middle of November and the day of the results. We'd already had the news that there were some 'brain abnormalities' but we were having a meeting with Millie's consultant to tell us the details. I'll never forget the words "Millie has part of her brain missing" for as long as I live. She carried on explaining in more detail what this meant, but I don't think I really heard any of it. My mind was full of fear and dread. My dear Mum came with me who was as shocked and upset as me, but somehow, between us, we managed to gather our thoughts and listen to what we were being told. After all the conditions, or illnesses I thought 'It' was, this had got to

be the most bizarre! So complex! It was, and still is, mind blowing! How can a person live with part of their brain missing? And will they survive in the future? All these questions and thousands more enter your head. That's without the 'whys' and 'what ifs'. We came away from the hospital in total shock and disbelief.

It's now January 2009, present day, Millie is 10 months old. She has made some progress with the help of a brilliant team of specialists and a loving family. She has better head control now, although sometimes a bit shaky and floppy. She still has hypotonia, which is making picking her up a bit tricky, as it feels as if she is going to slip



through my hands: she has very bad constipation (although now on medication), and she sweats like you wouldn't believe. She still isn't sitting, but has just started to roll on her side. She is still a very quiet baby, although she has started to make different sounds and loves blowing raspberries!

She is currently under a team of specialists, she has physio and speech therapy and we are waiting for occupational therapy and a paediatric neurologist to come on board. She's recently had more bloods and urine taken

as the chromosomes are being further looked into, and the pituitary gland has been checked and some results (thyroid and kidneys) were borderline, so they are being repeated. She's also had a x-ray on her skull, which wasn't very nice for her, as they are concerned about the size and shape of her head. So it's still, very much a waiting game, but I think that's something we all have to get used to with this condition.

Millie is such a happy, content little girl, who has the most beautiful auburn hair colour, and brown-green eyes, her smile would light up any room, and although she does not laugh out loud, I'm sure she is laughing inside. I must drive her mad trying with constant

tickles and funny faces! She is my little angel, and her big brother loves her to bits. As do all the family. We couldn't imagine life without her now, and I certainly wouldn't change her for the world. A friend said to me, that special children are only ever given to special people, and that's Gods way of making sure that they're looked after.

So that goes to all of you at Corpal, with my love and best wishes.

Welcome to Corpal

Welcome to one of our newest families - Teresa, Dylan and their daughter Kiera Thomas who live in Powys. Kiera was diagnosed at 11 weeks with complete ACC. Her Dad says "She's progressing well; she's feeding normally with a bottle and solid food. She's quite a strong character and has a wicked smile. Her eyesight is slowly improving the medical adviser is pretty certain that Kiera has delayed maceration, which means that her sight may take up to 8 years to become fully developed. She has limited head control at the moment, but this is slowly improving. A lot of her delayed development is due to her limited eyesight which we are hoping will improve in time. My partner and I feel very blessed to have our daughter, she's a very special little person.

She's also quite a celebrity in our local area as she switched on our local Christmas tree lights and publicised our local hospice's Christmas Santa run. Kiera attends this hospice which is called Hope House Hospice in Oswestry, Shropshire"

Keira's parents would love to hear from other parents/carers (especially those living close to them), if you would like to contact them please e-mail Kiera's mother (Teresa), her email address is: esmdn@aol.com

CORPAL VACANCIES - WE NEED YOUR HELP

TREASURER ASSISTANT

Due to our increasing members and fundraising events, we are looking for someone who could help our treasurer with the



Baby Kiera relaxing

administration of Gift Aid Donations and VAT issues. Do we have a member (or a friend of a member) who could help her? Heather has been our treasurer for over 10 years, but her son now needs more of her time, therefore an experienced person to assist her on the more complex issues of our monetary matters is needed.

If you are interested please call Jean Dalton on 020 8949 6598 to discuss the issue further.

FUNDRAISING CO-ORDINATOR

We are looking for a member (or a friend of a member) who would like to take on the task of co-ordinating our fundraising events. This would entail being the contact for anyone who is holding an event, thinking about it, sending our promotional items, looking into fundraising ideas for Corpal and anything that can benefit Corpal through fundraising.

FUNDRAISING ASSISTANT

To assist and work closely with the co-ordinator, therefore two friends working together could be ideal.

COMMITTEE MEMBERS 2009 - 2010

We are looking for new pro-active committee members who can commit to a few hours a week to help Corpal move forward. Over the last year we have seen our membership increase, a new website born, and many more diagnosed with ACC, which in turn brings more demands on the group. So that we can effectively help our members and give them the support needed, your help would be much appreciated. These positions will commence from Saturday 9th May.

If you would be interested in helping us allow Corpal to grow even further, please consider joining us.

Please contact Jean Dalton on 020 8949 6598 or email jean@corpall.org.uk for further details on the above positions.

All the above positions are on a voluntary basis and need a few hours commitment per week, plus availability to participate in quarterly tele-conferences (at mutually arranged times). Full support will be given and reasonable expenses paid.

UK ACC Research – participants sought

Interested in research with minimal commitment?

As part of the Medical Genetics Research Group in Manchester I am looking for participants to be involved in our research into the genetic causes of agenesis of the corpus callosum. Finding the genes which cause ACC can help us to give families more accurate information about diagnosis and management.

Participants will not be required to travel and the majority of your involvement can be completed over the phone or during a meeting with me. I would like to contact individuals with agenesis of the corpus callosum and their families. If you are interested in becoming involved in this research, would like more information, or have any other questions please feel free to contact me. Information sheets and consent forms are available from me at the address below. A summary and contacts are also available on the Corpal website. Many thanks to those of you who have already expressed an interest.

Dr Mary O'Driscoll

Specialist Registrar in Clinical Genetics

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Manchester
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Email: maryodriscoll@nhs.net



Dates for your Diary:

Annual General Meeting (AGM) 2009.

This year's AGM will take place from 9.30am - 3pm on Saturday 9th May. It will be held at All Souls Clubhouse, 141 Cleveland Street, London W1T 6QG.

We will be making a small charge this year of £5.00 per single person or £10.00 per family. This will help cover the room hire costs as well as a buffet lunch. If you would like more information, or to register, please contact Catherine Brennan via catherine@corpall.org.uk or tel: 01277 356797.

Aicardi Syndrome Conference in Nancy, France – 8-10 May 2009

This is a biannual event, which gives families the chance to meet and share experiences. There will also be several talks from professionals on a number of subjects.

For further details please see their website www.aicardi.info. Please don't be put off that the site is in French you have the option to select an English translation.



Fundraising News:

London Marathon 2010 – We have been approached by a Corpal member who has very kindly volunteered to run the London Marathon next year to help raise money for us. These places are allocated by a ballot system to charities and we hope to enter into the draw for next years places. We need to know how many places to apply for so if you would be interested in dusting off your running shoes

please email jean@corpall.org.uk,

Many thanks to those of you who've been using easysearch.org.uk and easyfundraising.org.uk. You've helped us raise over £70.00 just by shopping on line and searching the web. Please keep using it, and if not, please register, it's free and helps increase our funds.



Celebrations -

Do you have some good news you would like to share?

Well done to Gina Dalton (ACC) - who passed her driving test. Her theory test was passed on the third attempt (rote learning was the key to this success. The whole family learnt the Highway Code at the same time). Gina passed her practical test on her FIRST attempt and now drives and cares for her own car.

Gina has also passed her British Horse Society Stage 1 in horse care and riding (November 2007) and Horse & Road Safety Exam (July 2008). She is now working towards her Stage 2 in horse care and riding.

Gina has been working at local stables (part-time) since September 2006.

In summer 2008 Gina worked at Chessington World of Adventures as a ride operator.

The Dalton family are very proud of Gina. Ten years ago it was difficult to see what type of future lay ahead of her, as she had no confidence and low self esteem. She found it difficult to understand her condition, but now if she wants something she will go for it, (possibly with mum tagging along for reassurance).

And well done to Patrick Brennan (below), Patrick (P-ACC) - has received his Grade 1 for horse riding with school.





ZSL
LONDON
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SPECIAL CHILDREN'S DAY
Saturday 13th June 2009

Children under 3 years	no charge
Children 3 - 18 years	£7.50 (normal price: £15)
Adults	£10.00 (normal price: £17)
Carer (essential only)	free (maximum one per family)

(Applies to tickets pre-booked and pre-paid before 6th June 2009)

This is an annual day for children with special needs and their families, organised by London Zoo. Special events include British Sign Language interpretation for all talks and displays; Animals in Action: Gorilla Kingdom, Meet The Monkey's: face painting and a live band. For more details and a booking form, contact: Steve Marriott on 020 7449 6551 or email: steve.marriott@zsl.org



Useful information

Special Needs Toothbrush

Children with special needs often have an oral sensitivity that makes tooth brushing difficult, or may resist having their teeth brushed. The Collis Curve Toothbrush* claims to be easier and more effective to use than a straight bristle toothbrush "cleaning all the teeth's surfaces simultaneously whilst using simple backwards and forwards brushing". Collis Curve has a range of toothbrushes aimed at people with special needs, including children. Read more at www.colliscurve.co.uk or tel: 01934 862415

* Corpal does not endorse these products; we simply think they may be of interest to some of you.

SenseToys*

SenseToys is an online shop offering a large range of toys and games which are particularly suitable for young children with special needs. The range is categorised into Verbal Play Skills and Non-Verbal Play and then broken down into specific skills targeted by each toy, e.g. eye/hand co-ordination; self help; fun with language; or listening skills. The website also offers information and advice on which toys to choose, how to use them and why they work. Visit www.sensetoys.com to see the range.

Many thanks to those of you who've opted to receive this Newsletter by email. Not only does this reduce our production costs, but it also enables you to receive it ahead of others and save the planet too!

If you would prefer to receive email information from us please send your full name and address to kerrydowden@corpall.org.uk

Please remember, we are only a very small charity and rely heavily on your donations. Although we don't charge a joining fee, there is a £10.00 voluntary subscription. If you are a UK taxpayer, please *giftaid* your subscription. (Forms are available via the Corpal website.) This means that for every pound you give, we get an extra 28 pence from HM Revenue and Customs. Cheques (payable to Corpal) should be sent to:

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