

Corpall Newsletter

Supporting those with ACC or Aicardi Syndrome

Spring 2008

At long last we are pleased to bring you the latest copy of the Corpall Newsletter. We know that many of you have been asking about it and also what has happened to the Corpall website (we'll come onto that later). You may think the Committee has been very quiet over the last year but there has been a lot of work going on. You will see we have a new logo, which we hope you all like. There is now also a Corpall mailbox, which is monitored by Cathrine Brennan (Corpall Secretary) and Heather Robinson (Corpall Treasurer). So if you have any queries or would like to contact the Committee please send an e-mail to: info@corpall.org.uk. Our new look website is currently under construction but will be going live very soon. You will be able to access it at: www.corpall.org.uk. We are in the process of putting the final touches to this year's AGM, but please read on for more information.

We think you'll agree there has been some work going on and we would like to thank you for your patience. We hope you enjoy this Newsletter and if you have anything you would like to contribute please e-mail the Corpall mailbox: info@corpall.org.uk or kerrydowden@hotmail.com.

Over the next few issues we shall be printing the stories from our newest Committee members.

K's story - by Karen MacPherson, K's mother.



Following a relatively straightforward pregnancy for most of the duration, a routine scan at 38 weeks showed enlarged ventricles in my brain. As a result mummy was taken in and induced in order that the hospital could do further investigation.

I was born 5lb 6oz on 17 November 2004 and at 1 day old an MRI scan was ordered; which confirmed I had complete agenesis of the

corpus callosum (C-ACC) with focal heterotopia and polymicrogyria. My consultant did not know much about ACC; however as the corpus callosum is a mid-line structure which can affect adjacent areas of the brain additional tests were ordered to check my eyes, pituitary glands, blood sugar levels. Luckily all of these tests came back normal and I was allowed to go home with my mummy, daddy and big brother.

Before being discharged the consultant made a referral to a neurologist in the hope that he could give mummy and daddy more information on how ACC might affect me.

Unfortunately mummy and daddy had to wait till I was almost 1 before I saw the neurologist. In the intervening period mummy and daddy were sad and anxious as they really did not know what it might mean for my long term development. Mummy said she spent most of that time just worrying rather than enjoying time with me. When we eventually got to see the neurologist he said

that the brain scan showed fairly significant areas of the brain were affected. His major concern was related to the reduction in brain tissue associated with the enlarged ventricle which had formed with the corpus callosum being absent. He thought it likely this would result in a degree of learning difficulty; albeit quite mild. He did stress though that the MRI was only a picture and the best indicator to potential problems would be in what I actually achieved over the next few years.

I am now just over 3 and attend a main stream nursery 5 mornings a week. I love to go and play at the nursery with all my friends, and play with all the dolls, the kitchen and the cars. I also love to dance to Barney and The Wiggles.

I see a physiotherapist who works on my balance and co-ordination. To date my motor development has been my slowest area of development I rolled over at 9 months, sat unaided at 12 months, commando crawled from 18 months, traditionally crawled from 2 and started cruising about 27 months. I am currently not quite walking independently - but everyone is confident that I will when my balance and confidence improves. My fine motor is also a bit clumsy. However, I still love to go to soft play areas and climb all over the place and down the slides.

My speech is also a little behind but mummy says it has really flourished especially since the summer when I moved to the big girl's room in nursery. Otherwise, I am a healthy, happy mischievous 3 year old.

A's Story - by Tom, A's father.

A, 6, has complete agenesis of the corpus callosum. Shortly after she was born and whilst still in hospital, mum Helen noticed that Annabelle was breathing unusually.

As it happened, a Paediatrician was in the ward at the time and so was an ultrasound scan team, so A had an unusually rapid investigation conducted.

Of course, it was whilst looking for an anomaly

to explain the rapid and shallow breathing, that the ultrasound scan revealed the ACC. Helen and I were taken into the 'room with the plastic flowers and the box of tissues' to be told of their findings and what this might mean going forward. Of course, we were left in shock and wondering if the planned MRI scan would show a mistake had been made. But it wasn't a mistake and in February 2002 we started that horrible process familiar to so many families affected by this condition, of understanding ACC and the range of possible outcomes.

Over time, A showed she was not also affected by Aicardi's Syndrome and she showed the fine motor and co-ordination skills at the marker ages which the Paediatrician suggested might be evidence that A was little affected by her ACC. Her speech also developed normally.

A's eyes and vision have also been closely watched since birth, given that ophthalmic problems are commonly associated with ACC. Her vision was judged to be within the normal range for her age, but a lazy eye problem was leading to monocular vision which was affecting her ability to judge distance and consequently her comfort on stairs and during active play. This was corrected by an operation just after her fifth birthday and an almost immediate improvement in vision and confidence was noticed.

Today, A attends regular school and is coping well so far with writing, spelling and arithmetic, but the latter sometimes fluctuates day to day. In subtle ways the ACC plays out, or at least it seems to. But, as an only child, we only have the spectrum of personality types, abilities, preferences and idiosyncrasies of her classmates by which to benchmark her progress.

A is a very intelligent, caring and considerate little girl, hugely loved by everyone who knows her. She is a perfectionist, loves art and crafts and tries very, very hard to get things right.

This determination will probably become her

single biggest asset going forward.

Her teachers have been very happy so far, but we know that as she moves through school and it becomes more demanding, there may well be condition related difficulties to overcome. But we just don't know. We aim to tackle them as they arise and not make a big fuss unnecessarily.

A Special Child, Not a Child with Special Needs - by Sally. (This article was first printed in 'Mother and Baby' magazine in June 2007).

I wanted to write this article for 2 reasons. Firstly to help myself by getting my feelings down on paper and secondly to hopefully help others who may be experiencing a similar situation.

My little boy A is now nearly 10 months old. He is our first baby and like most expectant parents my husband and I presumed that we would have a happy healthy baby. Yes we knew there was a possibility that there may be something wrong but having passed the 12 week and 20 week scans without any hiccups, we thought we were home and dry.

A was born by caesarean section, weighing a healthy 8lb 4oz. He passed the apgar tests with no problems and I was able to breastfeed almost straight away. He was gorgeous and we couldn't have been happier when we left hospital.

The next few weeks were a struggle as for all new parents with sleepless nights, crying and what seemed like constant feeding. A seemed generally content but had dropped down to 7lb and he wasn't gaining weight. We were assured everything was fine and to carry on as we were. But I just knew something wasn't right. I don't know how I knew but I think all Mum's just have that feeling. I wanted to believe everyone else, sure I did, but the niggling feeling in the back of my mind wouldn't go away.

When A was about four weeks old I took him to Maidstone Hospital A&E department.

He had been vomiting a lot and his weight was still a concern, but after a 2 night stay, thorough checks and some basic tests, they told me he was fine and to go home and to carry on breastfeeding and maybe supplement with a bottle. So for the next 2 months we tried to do this but he refused a bottle and although I was feeding him every two hours day and night the weight gain was painfully slow. I also noticed around this time that A wasn't smiling or fixing and following with his eyes. Visits to the GP followed and referrals for eye tests made, but no-one seemed to be too concerned and assured us that A would soon catch up.

At three months old, during the hot weather of June, A lost interest in feeding completely and concerned with his fluid intake I took him back to A&E at Maidstone. No cots were available so we were referred to Pembury. They were superb with A and started to ask more questions, carry out more tests and offer help with getting A onto a bottle so we could monitor how much fluid he was getting. I felt some relief at this point. This may seem strange that I was almost happy to be in hospital during the hottest spell of the summer and missing the World Cup (I'm a big footie fan), but it finally felt as though people were listening to me and saying yes you're right there may be something wrong here. During our stay we managed to get A onto a bottle and he gained a little weight. We left hospital feeling more positive that we were now getting some help and people were taking us seriously but also apprehensive with what the test results would show.

We had more follow-up tests done at Maidstone hospital, including a lumbar puncture, metabolic testing, chromosome testing and a CT scan. No-one at this stage would give any ideas on what may be wrong or what they were looking for, I think they were just trying to eliminate as many things as possible. I seemed to be chasing results constantly but getting no answers; It was only when A was admitted to hospital with a chest infection that things moved forward. As we were now an inpatient they were able to chase up the test results and get us some answers.

I will never forget the day they told me something was wrong with my little boy. It was the 3rd of July and I was on my own at the hospital with A. My husband Richard was at work, we had had so many hospital stays and visits that he was struggling to get time off from work and so was just visiting in the evenings. The diagnosis I received was that A has agenesis of the corpus callosum or ACC for short. I had never heard of it as I'm sure none of you have. It basically means the bundle of nerve endings that join the two halves of the brain were missing. How this could affect A could range from mild learning difficulties through to severe mental retardation. There would be no way of knowing how A would be affected only time would tell. There was also no treatment or cure available. At that moment I thought my world had ended, I knew something was wrong with him, but I hadn't let myself for one minute think that it could be that serious. I don't think I even heard the consultant say mild learning difficulties, I only heard severe mental retardation, may not be able to talk, vision may be affected, may not walk. That's all I heard.

We stayed in hospital for the next week and it was awful. I won't pretend it wasn't. I started a journey of emotions that week in hospital, sadness and grief, anger, disbelief, guilt, just wondering 'why us'? What did we do wrong, how will we cope, can we have any more children? For me the hardest part of all was, and still is, the unknown. Not knowing what we can expect for the future. But as someone at the hospital said to me, how many of us know for sure what the future holds for our children?

The last 6 months have been difficult but have also been incredibly rewarding. Although A cannot yet support his head or sit-up unaided he can now roll over with help, hold toys and is showing more of an interest in the world around him. He is also starting to smile. I know there is still a long path ahead of us and there are still days when I just want to sit and cry. But I'm glad I trusted my instincts and got the diagnosis as early as we did. A is now receiving excellent care, and I

know that with help I will make sure he reaches his full potential, whatever that is.

I believe everything happens for a reason but 6 months ago I couldn't see that reason. Even now it is cloudy, but I am starting to realise that there are positives to be taken from this. Had we not had the diagnosis I would now be back at work and A in nursery. Instead I'm lucky to be at home full time with him and not miss a thing. I wouldn't have joined the various support groups and met some fantastic inspiring people and made so many new friends. I have learnt not to take anything for granted. I have learnt to really appreciate everything in life. I have become a better, more tolerant person, someone who is stronger and now makes time for the little things. I have coped with more than I thought possible because you have to, not because I'm brave or special just because as a Mum you do what you need to for your child. Every little change in A is a huge milestone for us, and I have learnt to really treasure every moment with him.

I am proud to be A's mum and I am proud of who I have become because of it.



Date for your diary -
Annual General Meeting (AGM)

This years AGM will be held on Saturday 10 May at RIBA (Royal Institute of British Architects), 66 Portland Place, London W1B 1AD.

We hope to bring you crèche facilities again, drinks and a buffet lunch. You should have received details via a separate letter.

Professor Gregory O'Brien (Psychiatrist) who has done much research on the behaviours associated with ACC has agreed to do a presentation. A further speaker has still to be finalised.

There will be a Question and Answer session

with each of the speakers. We will also ensure there is the usual 'catch up' session for all of our families towards the end of the meeting.



Fundraising news - Many thanks to all of those who have raised money over the last year. Most notably:

• Gemma and Tony Crocombe, who together with Tony's sister Louise put on a gig in aid of Corpal. Louise is the lead singer of a band and they were absolutely fantastic. Cathrine Brennan who attended the gig said "The music was excellent and they had everybody up dancing. I took 5 friends with me and we all had a great evening". They raised a phenomenal £2,239 from ticket sales, raffle and donations. And...congratulations to Gemma and Tony on the birth of their 4th daughter, Rosie. Hope you are all doing well.



Louise, Gemma and Millie (on lap)

• Tyrone Williams who raised a fabulous £125 from charging friends and family £1 (or more) to sign his cast after he had an operation on his leg last summer. Hope your leg is better.



Yvonne Williams, Joshua Nurse, & Tyrone

• Rachael Rusling who completed the Peterborough 5k fun run. She did it in 45 minutes and collected £118.

• Bastion Security Installations Ltd, whose kind donation in the region of £7,000 has enabled us to design and develop our new Corpal logo, stationery and website. It is also funding the design and production of a new leaflet for parents/carers outlining ACC and Acardi Syndrome.

We are also able to raise money by collecting and selling on old/used stamps. So please start tearing them off your letters, get your friends and family saving them too and send them to: Heather Robinson (Coral Treasurer), 20 Tollbar, Rushden, Northants NN10 6DP.



Celebrations - Do you have some good news you would like to shout about?

We hope to put together a 'celebrations' page where we will print details of our children's achievements. So if your child has just become potty trained, taken their first steps, said their first word or written their name for the first time, let us know so we can share it with our readers. Please e-mail your contribution, with a photo if you have one to: kerrydowden@hotmail.com.

We hope you have enjoyed reading this Newsletter. As we are only a small registered Charity we rely heavily on donations in order to support the work we do. This is just a gentle reminder that there is a £10 annual voluntary subscription. Cheques should be made payable to Corpal and sent to Heather Robinson (Coral Treasurer), 20 Tollbar, Rushden, Northants NN10 6DP. Thank you in anticipation.

Don't forget this Newsletter is for you and about you. So if you have an article you would like to publish or some information you would like to share please e-mail: kerrydowden@hotmail.com



Putting families in touch

It can be very helpful and comforting to contact/speak with other families who are going through a similar situation to you. It is often good to share ideas and information and also to offer support to each other. As it has been a long time since we circulated contact details of families living near each other, we thought now would be a good time to do so again. To ensure we are complying with the Data Protection Act 1998 we need to have your written permission to circulate your details to other families. Can you please indicate on the form below whether you wish to stay on the Corpal database and if you are happy to have your details sent to families living within your area.

Name:.....
Address:.....
.....
Tel No:.....
E-mail:.....
Name of child:.....
DoB:.....Male/Female:.....ACC or Aicardi.....

I would like my name to be registered on the Corpal database to receive newsletters and any relevant information on the condition.

Signature..... Date.....

I would like to be put in contact with other families, and give my permission for the personal information above to be sent to people listed on the Corpal database.

Signature..... Date.....

Please return this form to: Cathrine Brennan, Corpal Secretary, 12 Hope Close, Mountnessing, Brentwood, Essex CM15 0TN