

## **Conference 2007, mark your new diary for 23<sup>rd</sup> and 24<sup>th</sup> June at Hinckley Leicestershire**

**Come along, meet other parents dealing with the Syndrome. Be in the company of others including professionals who understand and who may be able to offer some solutions.**



**Meeting other parents**



**Learning what may be available**



**Just getting on**

### **Conference 2006**

The Conference was again well received by all attendees. It provided an insight into Transition. Wills and Trusts, the Family Fund, appropriate toys and speech aids as well as an update on the research into behavioural problems. The full Conference report and minutes of the AGM are available from our website at [www.criduchat.co.uk](http://www.criduchat.co.uk) If you do not have access to the Internet please telephone 0845 094 2725 for hard copies.

### **Raffle winners 2006**

The winners of the three main prizes were;

- 1<sup>st</sup> Mary Smith, Sunderland.....TV
- 2<sup>nd</sup> Joyce Parratt, Gloucester....DVD Recorder
- 3<sup>rd</sup> Mrs Calvert, Guildford.....DAB Radio

**Application packs are due to be distributed early March, we'd love to see you all in Hinckley especially if you haven't joined us in the past.**

#### **YOUR WRITTEN PERMISSION REQUIRED**

**SNIPS, who care for the children at Conference, have supplied a lot of photos taken during the day out and at the college on the Sunday. The photos include the CDC children and their siblings. We would like to add them to the website so that you can see them all but Data Protection prevents us from so doing unless we have written authorisation from the parents. Please forward your signed authority to the address at end of this newsletter. It should be worded along the lines of "we agree to pictures taken at CDC events being utilised to promote the Cri du chat Syndrome Support Group"**

## The value of the ongoing Research projects, a mother writes;

We have taken part in the recent research about CDC.

The subject of self injurious behaviour is the main emphasis of the research but in order to study these researchers had to assess the physical health, weight, height, and developmental ages physically and mentally. Our child's level of communication and understanding was also studied and which behaviours were difficult, repetitive or obsessive. They looked at how she interacted with family, carers and strangers. Many of these results have been given to us in the form of a document. We have used the information when applying for extra respite care from social services and made applications to charities for assistance with costs for building work and wheelchair lift.

I feel having the information about our daughter's level of disability accurately documented has aided us in successfully getting the help we need. It was like getting a free educational psychologist assessment but in more detail.

The nerve conduction studies also highlighted that she was suffering from nerve damage in one arm as a result of the spinal brace she was wearing. This led us to peruse the avenue of surgery instead of bracing to reduce her scoliosis.

I hope this helps you and your families in making a decision whether to set aside the time and effort to **take part in the projects ahead**. I feel they not only help children like ours in the future but **can have direct benefit for you all now**.

## Dads dealing with Cri Du Chat – Feedback

In the last issues we featured an article from a book written by Casey Evans. Below is part of the e-mail I sent to Casey after reading the book and his response.

*"I have read the book and as a father to a 31 year old daughter your experiences reminded me very much of my own. In particular I too uttered the immortal CDC dad's line "she sounds like a cat"*

*As Chairman to the UK Support group I am very aware of the particular difficulties that fathers face in accepting the new circumstances. Besides the initial disappointment of seeing dreams for their child vanish here the problem seems often to be one of perceived isolation within the family group as mum has to deal with the hospital, school and other related professional visits whilst dad is at work."*

*"Thank you for your kind words and feedback about my book. I really hope it can help other fathers that are struggling to accept their children with CDC. The UK Support Group was the first web site or contact I had with a CDC support group. In fact, I don't know if you noticed but I used the poem from your site in my book (Blessings in Disguise are Difficult to Recognise). In addition, we posted a picture of Sean and Montel on the site long before the US had a web site. Any way, I feel a special affiliation to the UK Support Group – so your support of my book is really special to me."*

Casey

**We have a copy of the book, just contact us**

## Professor Chris Oliver has recently presented in Australia and during a subsequent exchange of correspondence we have received the following

It has been a long time since we have emailed and it was 1995 when we met at your conference.

It was great to meet Chris and get so much information from him that is relevant and useful to our families. We are very excited about the research **and appreciate the part the UK group has played in this. Thank you to you all.**

Regards, Margarette Christie, Australian CDC Group

**IF YOU HAVE ANY INTERESTING ARTICLES, OR KNOW OF ANY BOOKS THAT WE CAN FEATURE, PLEASE FORWARD TO MANDY CLARKE AT [info@criduchat.co.uk](mailto:info@criduchat.co.uk)**

## Last issue "lan moving on". Mum Mary Smith has, as promised, provided this update.

It has been six months now since lan left home.

We can hardly believe how the time seems to have flown by.

lan is doing so well and looks just fine. We visit 3 times a week and have a trip out for lunch, sometimes to the pub or a run to the coast to enjoy fish and chips. Picnics too are popular with lan.

He is always pleased to see us but just as pleased when we take him back to his new home. His signal for us to leave is a big sloppy kiss on our cheeks! We still miss him and our lives have changed so much.

It was hard to get into a new routine, and the washing machine thought it had been made redundant!

The staff have been so very good and feel like part of our extended family now. Still no regrets about making the decision but wouldn't like to go through it again.

## A Different Perspective on Caring for a child with Cri-Du-Chat

I met Louise and Caspar Hull when I was nannying for a family locally twelve years ago. I started to attend NCT (National Childbirth Trust) coffee mornings with Louise and her son Anthony, who was about three at the time. Over the years we became friends and I have provided nannying, childminding and babysitting services for the Hull family. I have offered respite care for Cicely (who has cri-du-chat and was ten in October 06) since she was very young. Cicely is very special to us and is considered as part of our family. My eldest daughter is nine (seven months younger than Cicely) and plays a very active role in supporting Cicely with her daily activities when she comes to stay. My youngest daughter Chloe is seven and although she does not have the same level of devotion to Cicely she will always look out for her and make sure she is happy.

The idea of me providing respite is to give Louise and Caspar a break so that they have the opportunity to spend time with their three other children without having the complications that come with a child who has disabilities. However, I am not sure who provided who with the respite! When it is planned that Cicely comes to stay with us (usually from a Friday afternoon until a Sunday afternoon, every 2-4 weeks) we arrange to do fun activities and days out. Where as our normal weekend would involve my husband working overtime, lots of household chores and DIY, lots of sibling rivalry in between shouts of "I'm bored!" Therefore our Cicely weekends are usually our most enjoyable as we are out and about seeing new sights and generally feeling more relaxed. We firmly believe that Cicely should be able to experience what we experience and come with us wherever we choose and not specifically looking for wheelchair friendly places! This has sometimes caused us to encounter difficulties but nine times out of ten it is a rewarding experience!

When we are at home with Cicely she likes to watch her favourite "Marlin" video (more commonly known as "Finding Nemo"), go for a walk with our dogs, (although she seems to prefer the view from her all terrain buggy). She also enjoys taking a jacuzzi bath with lots of bubbles, gazing at the fish in our fish tank and pond, looking at books, painting and puzzles. We have also bought a trampoline with the direct payment funds we receive for the respite we provide, which Cicely loves...even if my girls only have to jump tiny jumps to make Cicely spring into the air! (thankfully we also bought a safety net which surrounds the trampoline!)

Cicely has taught us so much.....

1. Another language...in the form of Makaton, which the children sign to me even when Cicely is not with us.
2. Cicely has taught my girls to treat others gently and with respect, thinking about how others feel and what makes them happy...which is not a behaviour that they practice on each other!
3. Cicely has taught my husband and I to feel appreciative of our children and our circumstances but we also feel honoured to have the opportunity to know and care for Cicely.
4. Cicely has enabled our family to experience life in our wheelchair unfriendly world however we have also met some very caring and considerate people who have restored our faith in human nature.
5. When Cicely comes to stay our family starts to work together as a team more.... as caring for a child with disabilities often requires 44 pairs of hands!

Cicely is an example to us all and every day she spends with us we are amazed by her courage, her easy going nature and all the little things in life which make her so happy. She has been through so many difficult medical procedures and illnesses but comes through it all still smiling! Cicely is a delight to care for and is responsible for bringing a smile to so many faces!

By Di Davis, new facilitator of the Cri du chat Syndrome Support Group.

## Specialist Chairs

**I have been corresponding with a family in Romania whose seven-year-old son has fairly severe Scoliosis. They enquired about specialised seating for feeding etc and there may be some of our families interested in the following from the Scoliosis Association**

"I have telephoned the Children's Seating Centre to see if they could help with this enquiry. Unfortunately, they do not have a sloping chair to suit a child of that age. But suggested that you check their website: [www.backinaction.co.uk](http://www.backinaction.co.uk) as they have various products which may help – such as a posture pack and a sloping seat wedge.

Perhaps you could also try your local Independent Living Centre. Usually these centres have an equipment section with various aids on display. Also the Disabled Living Foundation – Telephone Help-line: 0845 130 9177 or website: [www.dlf.org.uk](http://www.dlf.org.uk)"

I should also give mention to Louise Hull, committee member, who had previously advised of the following.

"It is difficult to recommend a seat as seating needs change all the time. We have had very supportive seats with all sorts of straps and pads to try to keep Cicely's posture good. It meant she slouched more and leaned on the straps and was of no overall benefit. I think the normal chair has been the best with a little of our own foam padding added for comfort and she can be encouraged to sit up straight with verbal prompts.

In some back care catalogues you can get a BACK SUPPORT that folds in half and is transportable. You can carry them wherever you go, and can get somebody handy to add straps and a clip. Might be more useful and certainly much cheaper"

Ray Clarke

### **On the move, physical activities, have you tried karate?**

As a parent I am conscious of allowing my children to pursue activities that will improve their development, both physically and mentally. This seems to be easy with children who are considered to be the norm, there are lots of avenues available and a myriad of activities that they can subscribe to. What I found difficult was to find activities for Boo.

We are very fortunate in Leicestershire in that we have a special needs youth club and dance class both of which she attends most weeks. What these don't provide however is real physical stimulation and exercise for her. There is a disability swimming club nearby but logistics are difficult. Both Charlotte my youngest child and I partake in Karate and I wondered if this would be an activity that Boo could do too. Karate is a wonderful leveller. It doesn't matter if you are 5 or 50, overweight or under weight. The club that we belong to have a wonderful attitude, allowing their students to train at their own level, no one is challenged or made to stand out if they are not able to do all techniques correctly. Anyone who knows me will know that I am not svelte and athletic. I found karate a challenge to begin with and still do at times. It took time to sort out co-ordination and fitness but as the weeks passed I suddenly realised that I wasn't feeling as 'dead' as I was after the warm up when I started and actually I was keeping up with everyone else in the room.

Other benefits that I found were that my body started changing and where previously there was jelly, there now appeared to be some semblance of muscle tone. Because of the changes I could see in myself I decided that this may be a good thing for Boo to try. She attends 2 lessons a week and has a helper stand in front of her as response times are slow for her. The benefits are already starting to show. Her **co-ordination has improved**, her **concentration is definitely getting better** and she is able to partake in a whole lesson without too many disruptions. One of the biggest benefits we have seen so far is in **her balance**. Previously, Boo could not stand on one leg for more than 1 second without having to hold something or falling over. Now she is able to lift her leg up and kick in the direction required with ease and with no extra help.

Each week I see improvements, she enjoys going and is getting on well with the other members of the class. The little kids really respond well and she joins in their chase games. Boo went for her first grading last month and was awarded her Yellow belt. The chief instructor was very impressed at her concentration and effort and was very happy to have her there. I am not sure how far she will get through the belts as some things we are still working on and may take a long time to achieve but that doesn't matter. The fact she is enjoying it and wants to go is a good basis for continuing.

**Angie Stokes**

# Fundraising

**A special thanks to all the following for their contributions to the Group**

£100 Helen Smith, sale of Alistair the massive bear

£24 Raffle held at office of Aon UK compliance department

£2710.77 Aon Three Peaks Challenge

£420 Holly Donaldson and her friends Shantell and Emily took part in a Lifestyle Challenge during the school holidays, organising a sponsored walk and doing odd jobs for people. Funds donated to CDC as they are friends of 4 year-old Alex Roach in North Lincs.

£1322.21 Jon Emberson, honorarium for presentation in Barcelona

£337.50 Annual CDC Barn dance in Essex.

£822 Cheryl Burbidge, who organises an annual Ceilidh night in the Midlands.

**Perhaps you are contemplating an event, or simply wonder how you can help. Please read next page.**

## Fundraising, AON UK style



Madhat colleagues of mine at Aon UK Ltd decided on a way to spend the early part of the year training for and then undertaking the Three Peaks Challenge. That is scaling major peaks in Scotland, The Lake District and Wales, all within 24 hours. In addition to the actual climbing, there was a great deal of travelling involved.

The organisers had identified three charities to benefit from their efforts and Cri du chat were fortunate to be included. In addition to the money raised from individual sponsors Aon the company also donated a sum for each of the participants and the result was that our support Group received **£2710.77**

**Perhaps you have family, friends or colleagues who are contemplating a Fundraising activity. Don't forget to mention the Cri du chat Syndrome Support Group. Please do contact us for information as to how you may be able to assist.**

**Mandy Clarke**

## Helping to raise funds for the support group

As you can see from the various events above there are lots of ways in which you can help the support group to raise money. If you are contemplating a local event, fete, dance, disco, etc, please first check with us that you will be covered under our general liability insurance cover. In some instances we do have to advise the insurers.

We are now registered for the Gift Aid programme which enables us to claim money back from the government for tax that you paid on a donation etc. If we send you a form to claim this tax back please fill it in and return it to us, there is also a form downloadable from the website. We can claim up to 28% on money that you have donated to us over the last few years. This money will be used for the general administration of the group and help pay towards the annual conference each year

Another way you can help is by going via the website when you are purchasing online from any of the adverts you see on the fundraising link. When you go through these links and buy goods online, a percentage comes back to the group as a referral fee. So all you Amazonites out there go through our link and we'll reap some benefit.

**It is an aim of the Group to subsidise attendance at Conference in the near future but we need your help, every little bit helps.**

### Contacting us.

The Group is evolving and we have changed our contact details to;

Telephone – 0845 094 2725

E-mail at [info@criduchat.co.uk](mailto:info@criduchat.co.uk)

Website – [www.criduchat.co.uk](http://www.criduchat.co.uk)

Post – Cri du chat Syndrome Support Group, 5 Latimer Drive, Steeple View, Laindon, Essex, SS15 4AD

Have **you** checked out the new website, further updated during November? Any ideas for improvement will be most welcome. Contact [webmaster@criduchat.co.uk](mailto:webmaster@criduchat.co.uk)



### Disclaimer:

**The view, ideas and comments contained in this newsletter are those of the individual writers and do not necessarily represent the views of the Group.**