

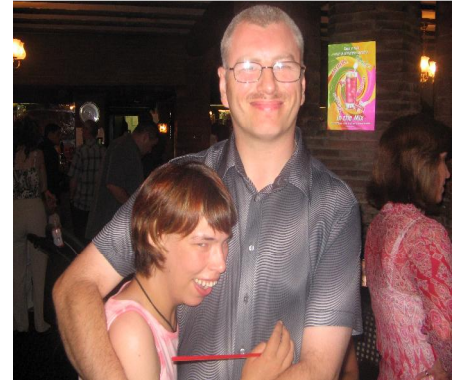
Conference 2006, June 24th and 25th

Have you registered yet? Have you reserved accommodation at the Hanover Hotel?

You should have received the application pack that was forwarded at the beginning of April. Don't forget that to guarantee a place in the crèche your booking must be received by the 1st June.



*It's beneficial
to meet with
other families
(Conf 2005)*



AGM 2006

As always a very necessary part of Conference proceedings, it is particularly important to ensure that the next committee is able to take forward the requirements and ideas of all our registered families, old and new.

Dear Member,

**Annual General Meeting Saturday 24th June 2006
at William Bradford Community College**

You are hereby given notice of and are invited to attend and participate in the Group's AGM which has been allocated time during this year's Conference. As a registered charity it is essential that the Group is conducted in line with the constitution and the committee would welcome your involvement. Ideally you will wish to serve on the committee to ensure that your expectations are being met. If so please contact me beforehand so your details are ready for advise to the meeting.

The proposed agenda is as follows;

- 1. Chairman's welcome.**
- 2. Apologies.**
- 3. Minutes of the 2005 Annual General Meeting.**
- 4. National Coordinator's report.**
- 5. Membership Secretary's report.**
- 6. Treasurer's report and Accounts.**
- 7. Election of Officers and an amendment to the Constitution**
- 8. Any other business.**

Ray Clarke, chairman

Election of officers forms an important part of this year's AGM given that a number of your existing committee members have served the maximum terms allowed for in the Constitution. Organisations such as our Support Group do require a healthy turnover of committee members to ensure that the needs of all are met, too long in office is not necessarily beneficial.

Even if you can't attend Conference this year perhaps you may be interested in getting involved, please contact Ray Clarke. The Support Group needs you!

Sssh Ray's 60



Debbie ensuring her grandparents were being looked after

I am not sure that Ray will be happy with letting everyone know he celebrated his 60th in November, however I just wanted to say a few words about Debbie's part in the celebrations. We decided to have an adults only party at the local Leisure Club that we belong to, Debbie loves it there and thinks it is basically her club. We arrived prior to our guests and asked Debbie if she would be the hostess with the mostest and boy was she. She showed everyone as they arrived where to go, asked if they wanted a drink and when the food arrived helped everyone to the buffet. Debbie loves to be with her extended family and close friends, she enjoyed every minute of the whole event, perhaps even more so than Ray?

Mandy Clarke

You should find the following articles helpful.

Sibling Pen pals

You will all know, particularly those who have attended Conference and Group run seminars, that along with parents siblings may also be having difficulty adapting to life within a Cri du chat family. Comments at school, from friends and the general community are often hidden from parents because of the wish not to burden Mum and Dad further.

Louise Hull, a mum, suggests that it may help for siblings to have contact with similar aged children in other CDC families. In this technological age of texting, e-mail and MSN messaging perhaps your other children, they may have met other siblings previously, would appreciate contact.

It is understood that parents should be aware that contact is taking place but the confidences exchanged may need to remain personal between the children.

Perhaps your family will wish to discuss this suggestion and if you wish to take forward parents should contact Ray Clarke on 01268 411666 or ray@criduchat.co.uk

Dribbling Surgery

Dribbling can be a major problem for many of those with Cri du chat. Our daughter Debbie did so rather badly from a young age and it was very unpleasant for all those around her. For us elimination of the problem was a priority and the success of the surgery allowed us to get on with the development of her social and interactive skills.

We are advised that in some areas of the UK consultants are advising that the Submandibular Translocation operation is not necessarily successful. We have obtained the following and have a full research paper on the subject. Should you wish to see this paper please contact Ray Clarke.

" A modified Wilkie procedure, consisting of submandibular gland resection and parotid duct transplantation, has proven to be successful in controlling drooling in over 90 per cent of 120 patients with cerebral palsy and/or mental retardation. Follow-up ranges from one to six years. The operation is safe, effective and appears to be permanent."

PS

If dribbling is only a minor problem you may wish to visit www.dribble-bandanass.co.uk for alternative clothing etc.

Dads dealing with Cri Du Chat

Dads often have different apprehensions to other family members and sometimes feel a little isolated. Because of work commitments it is often mum and other supportive family members who undertake the visits to hospital, schools and other professionals. We have received the following that looks at caring for a child with Cri du chat from a father's perspective.

Her Name is Montel



My name is Casey Evans and I would like to briefly share with you some of the reasons I had for writing my recently published book, Her Name is Montel (Montel is the name of my daughter with CDC). First though, let me apologise up front if some of my forthcoming observations and comments about books in the special needs genre are obsolete and inaccurate. Probably like many of you, when my daughter was very young there was approximately a 2 – 3 year window when I read nothing but books dealing with special needs children, parenthood, sibling relationships, etc. My daughter is now 12 years old however, and I must confess it has been several years since I have read any special-needs type books.

Anyway, back when I was immersed in reading children with special needs books I noticed none of them were from a male perspective. Actually there was one, but the author was speaking more as a professional psychologist than as a parent (he had a boy with autism). I thought it was important to write a book about having a child with special needs from a father's perspective.

Another common theme I noticed with the books I read was how the parents were always immediately heroes and advocates for their child. Regrettably that was not the case for me, I really struggled to accept Montel and I found it difficult to believe that I was the only person in the world with such apprehension. I thought it was important for me to tell the story of how I changed. I wanted to let others know that if they are struggling with acceptance of their son or daughter they are not the only ones to have done so, and that it is perfectly okay, they will get through it. But perhaps more importantly than how I changed, I wanted to document who was able to change me. It was the power of the pure and loving spirit of my own daughter, Montel. I am hoping that new parents someday may be able to gain from my experience and realise that while it may not feel like it at the time, their own son or daughter with Cri du Chat truly is a very special human being, and quite possibly one of the greatest blessings they will ever receive in their lives.

You may obtain the book from www.amazon.co.uk, I want to let everyone know that in addition to getting what is hopefully a good book, a portion of the proceeds from the sale of each book benefit the 5p-(Cri du chat) Society in the United States.

Casey Evans
casey.m.evans@pacbell.net

The Group has obtained a couple of copies of the book, a paperback only 78 pages, and they will be available at Conference. Alternatively any interested dad can contact Ray Clarke on 01268 411666 or ray@criduchat.co.uk

Makaton and television.

Have you seen the "Something Special" series that was first shown on cbeebies and recently re run on terrestrial TV? The presenter uses Makaton signing all the time and several of our families have commented on how beneficial they found it as a teaching aid not only for their child but also for **them**. You may wish to visit www.bbc.co.uk/cbeebies/grownups/about_cbeebies/shows/somethingspecial.shtml Dvds and videos are available from www.bbcshop.co.uk

Fledglings, a marvellous contact for those special products that can be difficult to find.

At the last annual conference one of the speakers Ruth Lingard an experienced social worker came to talk about the company she set up 7 years ago to research products to meet the needs of disabled children and adults.

Many of us have the use of the Internet and can source products but there are so many out there what do we choose? Unless you try something you may pay lots of money only to find the product does not meet your need. Fledglings are a not for profit charity. The volunteers have researched a range of products that have been tested and reviewed by helpful families. Some of the products are equally useful for children with no learning difficulties and aid their development. They produce a brochure and have a web site.

Fledglings will help you find a product to meet your needs if you ring them up and add it to their list of supplies and if necessary find a company to make a product for you if it is not on the market but would be useful to you and others.

I will give you an example. The special school that Cicely attends insists that she wears a swimming nappy at school when they take her. She just loves swimming so much that she often poos in the changing room or on the way into the pool with excitement. They insisted we sent disposable swimming nappies as the public pool does not have the facilities to wash it out. I know because I have tried to wash the washable nappy out and was horrified to have blocked the sink plughole and the bowl would not drain. Yuck!

To date my local Sainsbury's have stocked Huggies disposable swim nappies. Cicely is 9 now and the toddler range was getting too small but recently they have stopped all sales of these products due to poor demand. I went on the Fledgling web site and there are 2 suitable products. Hydro briefs which are waterproof and fit over a conventional nappy up to a 42" waist and Aquatherm swimming shorts which come with a top. They are waterproof, thermal, UV protective, stretchy, lightweight and breathable. They can be pulled over the nappy and the nappy stays dry. It will help Cicely as she loses heat so easily because of her skinny frame. I can also use it at the seaside to keep her warm. They have all sizes including adult and do a made to measure service.

The Fledglings website is at www.fledglings.org.uk, telephone 0845 458 1124, fax 0845 458 1125 or email: enquiries@fledglings.org.uk

Try your luck. It is so difficult to shop with young children and especially disabled children.

Louise Hull

Most urgent "We need your assistance!"

All those registered on our database have **twice** now been requested to complete and return updated registration forms as required under the Data Protection Act. Unfortunately a significant number are still outstanding and a subsequent telephone contact exercise has revealed that a number of our records may now be incorrect.

Some families appear to have moved since first registering and/or changed their telephone number and there is concern that much needed voluntary funds are being wasted on postal costs where the intended recipient is not receiving our correspondence.

A requirement of the Data Protection Act is that where there has not been contact during the past five years the name should be deleted from the database. You will appreciate that return of the registration form will provide that contact.

If you have not yet returned the form please do so as soon as possible. If it is no longer to hand please obtain a copy Ray Clarke on 01268 411666, ray@criduchat.co.uk

*This requirement is most urgent, we will be most grateful for your cooperation. **Thank you***

Thoughts Of An Older Carer

Decision time.

Our son Ian is 35 years old now, and I think this is one of the hardest decisions we have ever made. It's time for Ian to leave home and move on. Our health is not so good and day-to-day life at home has become a struggle for us.

We have had tremendous support from the Social Services, Ian's Day Centre and also his respite care home. Plans have been made and home visits (with me sitting weeping) completed. Ian has visited his new home, enjoying coffee and a chat with the staff many times. Introduced to his new house-mates. He has had an overnight sleep over.

We know we can visit Ian, take him out, and phone whenever we wish, BUT the heartache is tremendous. I shed tears every time I talk about the move BUT trying hard to think positive now. My dear friend Val of many many years and who knows Ian so well sent me a card with these words.

The time is right, the place is right, you are not losing Ian, you are sharing Him.

I thought this was lovely, I shall let you know how it goes.

Mary Smith.

P.s. Ian has been in his new house for 4 weeks now, he looks well, the staff think he is a lovely young man, His room is beginning to look more like home too, with all his own things around him. We too are feeling much better. (Still could take him home with us) - but no regrets so far about our decision. Time will tell.

**The Group's network of Area representatives
aims to provide families with local area support
and assistance. Perhaps you'd like a chat?
Please feel free to contact any of the following:**

Bristol, Avon and South West - Louise Hull 01225 703911, louisehull@blueyonder.co.uk

East Anglia – Irene Clark 01284 724908 irene@shodan1stdan.f2s.com

**East Midlands and Leicester – New Parent coordinator, Angie Stokes 01455 841680 ,
angie@criduchat.co.uk**

Eire – David and Marylou Girvan 00 3531 2353535, david.girvan@indigo.ie

Home Counties – Elaine Precious 01442 875052

London and South East – Chairman, Ray and Mandy Clarke 01268 411666,

ray@criduchat.co.uk

Manchester and Northwest - Sue Dilkes 0161 3442114

Midlands and Birmingham – Treasurer, Darren and Lisa Waldron 01527 456806,

darren@criduchat.co.uk

North East – Mary Smith 0191 534 2781

Northern Ireland - Gladys Smyth 02892 639037

North West – Sian and Jeff Noneley 01925 764620

Scotland – Gordon Levack 01592 200809

South and London – Heather Symons 01256 882387, heather@criduchat.co.uk

Wales – Margaret Owen 01407 730139

Yorkshire – Membership Secretary, Steve Gregory 01757 701890,

steve@gregorys61.freeserve.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