

## Syndrome Support Group

Providing support, information and friendship for families, carers and professionals

### Welcome to the latest edition of the CDC Newsletter

This publication is full of information regarding the group and its members and we hope that this will be a useful and informative resource. To ensure that we were able to publish as much as possible we have not always provided the full transcripts of stories in the newsletter – however this information is available in full on our website or by paper copy obtained from the office.

As always we would like to thank all those who have contributed to our newsletter – we really do value hearing about your experiences. If any other member has anything they would like to contribute then please let us know. The next edition is due for publication in May 2008.

We are delighted to introduce our new Administrator, Lucy dos Santos, who will work for us on a part time basis. Lucy has ten years experience working for associations, charities & societies and can be contacted by email on: [admin@criduchat.co.uk](mailto:admin@criduchat.co.uk)

### Help to raise funds for the CDC

We have set up some great website based initiatives to allow our supporters to help us raise vital funds, without costing them a penny. These are great initiatives to start before Christmas and we hope that our members and their friends and families will use these sites and help make 2008 an even bigger and better year for the group.

The logo for amazon.co.uk, featuring the word 'amazon' in its signature font and '.co.uk' below it.

These websites are all free to register and use and allow you to shop with each retailer in the normal way. The only difference being that the CDC will receive a donation on every purchase made using our links. Many of you will be familiar with the variety of products and high quality service provided by amazon.co.uk but [easyfundraising.org.uk](http://easyfundraising.org.uk) is also a useful tool when shopping on the internet as it features over 400 well known retailers such as Next, DELL, John Lewis and Debenhams. To find out more or to register for free please use the link [www.easyfundraising.org.uk/cdcsg](http://www.easyfundraising.org.uk/cdcsg)

The logo for easyfundraising.org.uk, featuring the text 'easyfundraising' in a bold font and '.org.uk' below it.

And there is even something for January – when all our pockets are a bit lighter. Using <http://cdcsg.easysearch.org.uk> as your search engine can generate one penny per search for the group.

The logo for easysearch.org.uk, featuring the text 'easysearch' in a bold font and '.org.uk' below it.

Full details of all links are available on [www.criduchat.co.uk/fundraising.html](http://www.criduchat.co.uk/fundraising.html) or please contact the office for the advice sheet “The internet and helping raise funds for the CDC.”

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## CDC Conference

The 2007 Conference, held at Earl Shilton was a great success with over 25 families attending.

Our conferences are designed to provide families and carers with the most up to date information on Cri Du Chat and are also an ideal way of meeting other families. We are delighted to announce that the 2008 Conference will be held at The Holiday Inn, Stratford Upon Avon between 21 – 22 June. We will confirm details of speakers and planned workshops shortly but, to be the first to hear details, please express your interest by contacting [admin@criduchat.co.uk](mailto:admin@criduchat.co.uk)

## **Research Update**

The 3 Syndromes Project headed by Prof. Chris Oliver at the University of Birmingham is now fully up and running and the team have already conducted assessments with about a dozen families across the UK. Many thanks to those of you who have contacted us about the project. The project is funded by the Big Lottery Fund and aims to examine challenging behaviour and family adjustment in Cri Du Chat, Angelman and Cornelia de Lange syndromes. We are now recruiting individuals aged 2 to 19 years who show self-injurious or aggressive behaviour at least once a day. If you are interested in taking part, please contact Chris Oliver on 0121 414 4909 or [c.oliver@bham.ac.uk](mailto:c.oliver@bham.ac.uk) for further information.

We are also pleased to announce that a new PhD student at the University of Birmingham will be spending the next 3 years researching Cri Du Chat syndrome. At the CDC family conference in June, the research team, with help from the CDC Committee, conducted informal workshops with families to find out what issues were important to them. One of the things that was mentioned very frequently was the high levels of sociability displayed by individuals with CDC, to the extent that sometimes it is inappropriate. Laurie Powis, a Birmingham University Graduate is going to examine sociability in CDC alongside several other syndromes. Her research will involve meeting families and conducting interviews and observations to learn more about this behaviour. So watch this space!

## **MENCAP**

We have been in contact with Mencap's Wills and Trusts Information Service, who support and advise over 3000 parents and carers of people with a learning disability on how best to make a will and set up a trust.

For more details on the types of free services they provide please look on our website [www.criduchat.co.uk/articles/mencap.pdf](http://www.criduchat.co.uk/articles/mencap.pdf) or contact the office.

## **Challenging Behaviour Foundation Information Sheet**

In this useful information sheet Diane Langridge, Nurse Consultant for Challenging Behaviour, gives an overview of health and medical conditions prevalent among people with learning disabilities, and shows how health and medical conditions can be a contributory cause to challenging behaviour.

### Case study:

Rob is 29 years of age and he lives in his own flat with 24-hour support. He has a moderate learning disability but has major difficulties with communication, e.g. he is unable to express himself verbally and can understand basic language only. He has managed to learn a few signs but unfortunately most of his carers are unable to understand them. Rob enjoys the company of others and participates well in his local community. He does not usually present with any challenging behaviour but on the odd occasion may show some aggression which his carers are at a loss to understand.

One Tuesday afternoon Rob's carer is getting ready to take him on his usual trip to the local college. Unfortunately and unbeknown to the carer Rob isn't feeling too good.

To find out more about the unfolding scene please visit [www.criduchat.co.uk/articles/challengingbehaviour.pdf](http://www.criduchat.co.uk/articles/challengingbehaviour.pdf) or for the full information sheet visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

# Letters, questions & fundraising activities

## Letter from Sue Durno

"Hi Ray and the Committee, Just to say thanks for a great conference! I really enjoyed my time – even if it's just time to spend with Simon and my parents. I found the majority of speakers interesting and helpful: the 3D morphology was fascinating, Chris Oliver is always so enthusiastic and informative (for me personally and work based!!!) and I 'm even looking into booking my family onto a refresher course for First Aid!! Once again Ray and Mandy, thanks for your support in the group when we split into family groups, and we are in the "others". Hope to see you next year"

## Raywell writes from China:

"I am a Chinese father. My daughter, XuanXuan, is diagnosed with CDC at 6 months. She weigh 2kg at birth and doesn't like eating since birth. Her crying sound is weak and like a cat. My wife and I are very anxious and feel upset. Is there any hope for my daughter?"

## Ray Clarke writes in reply:

*It is always difficult to reply to families from another country because we are unaware as to the professional facilities available etc. However it seems that you have obtained the genetic testing necessary for an accurate diagnosis... Many of your questions are covered in our booklet, available from the website, which was produced following a two year research project.*

To read the full contact visit [www.criduchat.co.uk/articles/raywell.pdf](http://www.criduchat.co.uk/articles/raywell.pdf)

## RAFFLE WINNERS 2007

Gemma Thornily.....Television

Karen Clarke ..... DVD

Sally McLachlan.....Hamper

The Committee would like to express thanks to all those who took part in the raffle and those who donated the prizes

**£90 The late Mrs Edna Keith who had requested, rather than flowers, that family and friends donate to their favourite charities**

**£46.08 Walkwood Middle School**

**£25 Mary Smith & family**

**£410 Brian & Renate Stone who requested donations rather than presents at their wedding. Congratulations from us all.**

**£227 Waitrose, thanks to the efforts of Darren Ayres & Lisa Bowden**

**£10 Dr Sally McLachlan**

**£219 Dr Sally McLachlan who won the hamper in the National raffle but asked that it again be raffled at Group's barn dance**

**£450 Annual Barn Dance, Essex**

**£102.50 from the friends & family of Mary Arnot**

**£20.00 from J & L Beard**

**£40.00 from K & J Spurgeon**

**Message to those who attended 2007 Conference** Attendees at the Hinckley Island Hotel restaurant on the evening of the 23<sup>rd</sup> June will recall that there was a major let down in their service. The Support Group forwarded a letter of complaint and the outcome was that all the 30 rooms booked under our bulk reservation number should have received a refund of £30 to the credit card used in effecting payment. Should anyone not have received the refund, perhaps you didn't use a card, please contact Ray Clarke on 0845 094 2725.

# Parents & Carers section

## Shared advice, experience & observations

### Evie

When Evie was a baby, newly diagnosed with Cri Du Chat syndrome, the future seemed uncertain, even bleak. I made a lot of assumptions at the time, many of which I now realize were wrong. One of the things I assumed was that Evie would receive all of her education, from nursery onwards, within the special schools system. Therefore in the summer of 2006 as Evie approached two years of age, I went to visit all of the local special schools. However none of them felt right for Evie, so taking advice that she may get extra support within a mainstream setting I then investigated some mainstream nurseries. It was at this point a friend suggested a local Montessorri nursery called Colourwheel. Within minutes of walking into the building I knew I had found the right place for Evie to start her nursery education.

To read more about Evie visit [www.criduchat.co.uk/articles/evie.pdf](http://www.criduchat.co.uk/articles/evie.pdf) or contact the office

### Cicily

#### **Teeth**

Do you have difficulty cleaning your CDC child's teeth? When Cicily was smaller she used to resist contact with her face, arching her back and withdrawing. It was as if she was too sensitive. I believe the face and hands are very sensitive areas of the body compared to others and Cicily was what you would term tactile defensive. She didn't like the feel of sand, grass or anything unusual on her hands so I suppose the same was true of her face. The sensation of a kiss or touch was either too exciting or horrible to cope with... She could decide to pucker up and kiss me but not the other way round. Over time as her teeth started to emerge we tried to clean them but it was such a struggle and traumatic with her fighting us we did not make it a regular routine.

To read more about Cicily visit [www.criduchat.co.uk/articles/cicily.pdf](http://www.criduchat.co.uk/articles/cicily.pdf) or contact the office

#### **Orthotics or supports for the feet**

When Cicily was a small child her feet were so mobile she would be able to move them around by 180 degrees. She would curl up her toes and they would seemingly writhe round at the end of her feet like eels. This posed a problem when trying to fit foot wear as she would curl up her toes and point her feet and then I couldn't get her feet in a shoe.

For more about Cicily visit [www.criduchat.co.uk/articles/orthoticcicily.pdf](http://www.criduchat.co.uk/articles/orthoticcicily.pdf) or contact the office

### Eleanor

#### **Visit to the theatre**

We took Eleanor to see an amateur operatic production of "Iolanthe" in Bolton Town Hall last year. After the performance, the woman sat behind us asked if Eleanor was our daughter, and when we said yes, she said "It has been a privilege to sit here and share her enjoyment of the show".

To read more about Eleanor visit <http://www.criduchat.co.uk/articles/eleanor.pdf> or contact the office

Thanks to Lisa Bowden, Carl Gregson and Louise Hull for sharing their stories of Evie, Eleanor and Cicily. If you have a story you would like to share then please contact the office.

***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***

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