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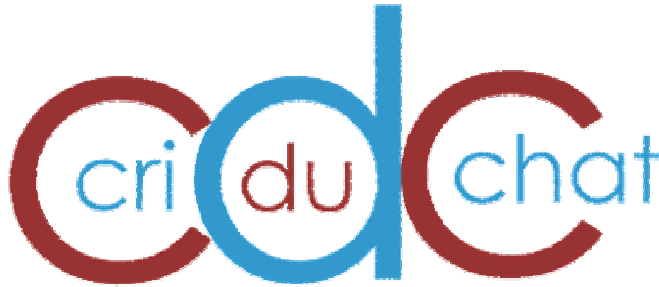
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Notice letter for Annual General Meeting enclosed



Conference 2007, are you attending?

Application packs were forwarded early April. Have you returned your registration forms? Have you booked the hotel? Please remember that unless forms are returned by the 1st June we are unable to guarantee a place in the Crèche.



Children enjoy a day out



The opportunity to meet and chat with others

If you have mislaid the pack it is available for download from www.criduchat.co.uk or you can telephone us on 0845 094 2725



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Research project

In February there was a meeting of the steering committee attended by representatives from University of Wales, Kings College London, University of Birmingham together with Angelmans, Cornelia de Lange and Cri du chat support groups.

Newly recruited staff are now in place at the three universities and the project is now underway. It is hoped that any families who are contacted will be happy to respond to the researchers, this is our biggest project thus far! Professor Chris Oliver and his team will be updating us of progress at Conference, another reason for you to attend and communicate directly with professionals with an understanding of our syndrome.

Thanks for fundraising and donating

£822 Cheryl Burbidge, who organises an annual Ceilidh night in the Midlands
£4275.65 KN Greenford Charity Golf day. Thanks to parents Graham and Karen Hill for their involvement
£200 Vicky Coulson and her work colleagues
£193 Lisa Bowden and Darren Ayres
£110 Brian Stone

Perhaps you are involved with local clubs and groups. Have you considered running a fundraising event of some kind? The Group needs a regular and varied source of income to continue research and subsidise the annual Conference. It seems unfair to always rely on existing contributors

HELP US TO SUPPORT OTHERS, CAN YOU HELP?

Has your Cri du chat child had an operation for the removal of adenoids and tonsils?

Rebecca Savin's daughter, Meghan aged 6, is due to have the operation and naturally the family are concerned that there may be additional complications because of the syndrome. Rebecca would be appreciative of a chat with any family with a Cri du chat child who have been through the experience.

Please help support Rebecca, she can be contacted at the telephone 01590 677192 or
Email: rebecca.savin@northfieldnursery.co.uk

Maria writes from Scotland, please reply to Mszandrowska@aol.com

Kevin cannot chew food but will chew everything in sight like shoes, feet, furniture, toys anything but food. Is there any thing out there that would help Kevin chew? I have tried placing food into side of his mouth which we do daily but he will not chew. I find this quite a big issue with the wee man, also help with speech, he's very vocal but no words lots of sounds and very loud and shouts at the top of his voice. Kevin is doing quite well with walking and understands a lot.

Enquiry from America.

I have had 2 cri-du-chat children, one in 1971 & one in 1976; at the time, the syndrome had not been identified. My surviving normal daughter is now pregnant. My children were severely affected and died at 10 years and 10 months. If my remaining daughter was not affected but is a carrier, what are the chances her baby will be affected? Is there a doctor in US you are familiar with that we can contact? Thank you for your help! MKRisteen

I assume you are aware that you have contacted the UK Support Group and as such we do not have direct links with professionals in the United States where the syndrome is more commonly known as 5p-. Have you contacted the US Group at www.fivepminus.org ?

Research suggests that only 15% of CDC births are hereditary. Here in the UK it is recommended that, where there has been a Cri du chat birth, that all family members should be tested prior to pregnancy and during the first few months. Presumably your local doctor should be able to arrange such testing?

Thank you so much. How wonderful that you are there to help!
Mary Kathryn Risteen

Enquiry from Argentina

We received an enquiry from Argentina as to how a family's CDC daughter may cope with oncoming puberty. The Group contacted several of our UK families who kindly responded. Mum Maria has again been in contact;

Thank you so much for your responses. I have to admit, that after reading several mom's comments I am starting to relax a bit. It has been very, very helpful.
I do enter your site very regularly, it is an excellent source of information, and I've used lot of

it to pass onto the professionals working with Maggie, since unfortunately I was not able to gather a group of families willing to do the same in Argentina.

I have to compliment too all of the research that you've published, I loved the part about parent's stress!!! Reading it does not bring my stress level down, but at least it makes me feel that I am not alone in this world.
Best regards to all families!
Maria Jose Rodrigo
mariajose@rodrigo.com.ar

How will my daughter cope with oncoming puberty?

Cri du chat Syndrome Support Group, providing support and friendship for families and carers

Sophie's Skiing Holiday

Some of you may recall I wrote a couple of years ago about Sophie trying out skiing. Well, we had our latest skiing holiday in the French resort of La Rosière in February this year and Sophie has progressed to 6 one hour lessons a week. She had a rather nice instructor called Clem, who soon realised Sophie just wanted to have fun. Whenever Sophie felt tired, they just lay in the snow and laughed! The lady lift operator remembered Sophie each day and would make her a snowball to throw back at her.

Each day she would have her lesson with Clem, and then we would ski together as a family. Even though she needs to hold onto a ski pole or ski between her dad's legs, she still managed to descend the slope. Skiing is

hard work on Sophie's legs (and her dad's), so she is only on the slopes for about 2-3 hours a day, but it allows her to join in the family fun. What makes skiing even more fun, is Sophie's birthday always seems to fall when we are on holiday.

At the end of the week Clem presented Sophie with a certificate and a medal! We were all very proud of her.



Sophie and Clem

We are still looking for the "ideal" resort to take Sophie to, but I'm sure we will find it soon.

Diane Stanley

Jessica's story

Our daughter Jessica was born 7 weeks premature along with her twin brother Bradley. She has had feeding problems from the start and was NG tube fed in the first 7 months of her life as it was noticed that she was aspirating on her feeds when bottle fed. Then unfortunately she started suffering from severe reflux which was horrendous having to cope with changing clothes up to 3 times a day and covering her in plastic bibs in wait for the reflux to happen after a feed. All this was exhausting not only for us as parents but for our Jessica who didn't really seem to have much energy or progressing very well and obviously was tired with it all. Then at 7 months old she was admitted to Great Ormond Street for a Gastrostomy and Nissans Fundiplication which involved having her stomach wrapped around her oesophagus (not sure of spelling) and a button inserted just above her belly button for feeding. As with all parents it was a worrying time and something we never wanted to happen, to put our child through an operation, but if it was going to

improve Jessicas' quality of life we had to do it. Her operation went ahead and was a success and since then we can honestly say that she has progressed tremendously as her feeding is no longer a worry and a big issue in her life. She gets all the nutrition she needs on her feeds which she now has 4 times a day. She is happy, very sociable, loving, and has bundles of energy now. She has just started a special school 3 days a week and they all love her to bits there. We have got used to going out with her little black feeding bag and it has become a way of life feeding her through her gastrostomy. She does love food however and we do give her little tastes everyday (even when we have an indian meal!!). We hope that eventually she will be able to eat like us as she is showing so much interest in food now, but only time will tell and with a little help from her speech and language therapist we are keeping our fingers crossed, but until then we are enjoying the energy and love Jessica gives to us all.

Karen and Graham Hill

Cri du chat Syndrome Support Group, providing support and friendship for families and carers

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Contact us by

telephone 0845 094 2725, Website: www.criduchat.co.uk or Email: info@criduchat.co.uk

- Raises funds to promote and provide research in to the syndrome.
- Actively encourages and is involved in several ongoing research projects.
- Raises awareness of Cri du chat syndrome amongst the medical profession, carers and the public.
- Provides information to interested parties.
- Provides contact with members in similar situations.
- Organises an annual conference and a family meeting for those involved with Cri Du Chat, where families, carers and medical specialists can gather together to discuss issues and exchange information.

Care for the older Cri du chat

We have received two moving stories from the parents of 17 year old Charlotte Noneley and 37 year old Susan Godfrey. Unfortunately there is insufficient space available in this newsletter to provide the full transcripts but just **contact us to obtain copies**. The following are very brief overviews;

Dad Jeff Noneley writes "As you know Charlotte is one of the most difficult to handle kids in the CDC group and we have faced many

emotional difficulties within the family and with Social Services. Charlotte is now in residential care Monday to Friday, she is happy and the family are able to get on with their lives"

Susan lives in a supported living scheme and mum Jan Godfrey writes "The way my daughter lives now is something I never thought would happen. She is so happy. It is a real achievement, when Susan was a baby the Consultant told us she would be a "cabbage" all her life"

If self-injurious behaviour is a major problem this may help

We have received the following from the Challenging Behaviour Foundation whose founder has a son with Cri du chat who, from an early age, exhibited very severe self injury. You may wish to have a copy of the video/dvd, it is free to direct carers.

What causes self-injurious behaviour? What action should parents and carers take?

*Professors Chris Oliver and Glynis Murphy, the UK's leading authorities on self-injurious behaviour, join forces to offer clear and practical information and advice to families caring for individuals with severe learning disabilities. In this 45 minute video/DVD learn how self-injurious behaviour has affected lives of families, and how some simple, straightforward steps can help to reduce self-injurious behaviour. Cost: £30.00 plus p&p; **free to parent carers**.*

NB.

*This DVD is specifically for self-injurious behaviour in children and adults with **severe** learning disabilities and behaviour.*

For details of how to order visit www.challengingbehaviour.org.uk or telephone

The Challenging Behaviour Foundation on 01634 838739



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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.