

Syndrome Support Group

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

Dear Supporter

As the winter months settle in your committee looks toward next summer and the 2010 family weekend for which we will need to obtain major fundraising. Through the efforts of a gallant few we are well on the way but we still need more sponsorship monies to ensure we are able to subsidise the event. If you are aware of any marathon, triathlon, bike rides etc please enquire as to whether those involved will raise funds for the Group. **It is your Support Group** and we need your help.

Our one-day event last July was a success and encouraged several new families to attend. We had noted that in recent years the full weekend scenario had not been attended by many new families. It seems that the format is a little daunting for some new parents who, for their first visit to a Conference, prefer for a one-day event with or without an overnight stay. **To help us with our planning for future conferences** we would welcome any views you might have on the subject. Perhaps you have been reluctant to attend for a similar reason?

With funding the Conference always an additional major issue perhaps, in order to meet the needs of all our families, we should be considering the two types of event, each on a bi-annual basis. What do you think, please let us know?

The three-year research project into "Understanding and Changing Challenging Behaviour in Cri du Chat Syndrome" has been completed and the booklet and DVD is forwarded to all registered families with this newsletter. We hope you will find it of assistance, please let us know your views. Our grateful thanks are extended to all those families who took part, without such involvement research cannot be undertaken.

I have to say how pleased I am at the now fully established Clinical Advisory Group (CAG). It has enabled us to answer a range of questions, with our own committee's ongoing knowledge of the Syndrome and the access to medical professionals where required. CAG is there for all parents of Cri du Chat children/adults to use, please do contact us with any queries.

Best wishes,



Ray Clarke, Chairman

**The Committee of the
Cri du Chat Syndrome Support Group
wishes you and your families a very Happy
New Year.**

Lucy Tetlow, Administrator

I am glad to be able to report lots of good news this edition. The first is that the conference in 2009 was a great success with over 20 families (5 of them first timers and new members!) storming Milton Keynes for the day. Feedback was very positive with most expressing a desire to have even more of a good thing so we are delighted that in 2010 we will be going back to the weekend format and, on the wonderful suggestion of new committee member Karen Hill, we will be renaming it the Family Weekend.

If you have not been to one of our weekends before then please do try and get to this one. The date will be the weekend of the 25th June 2010 and will, again, be held in Milton Keynes. On Friday evening we will hold a family get together in the Holiday Inn Milton Keynes, a chance for you to meet other families, committee members and some of our speakers in relaxed surroundings. On Saturday we will have a full day of speakers followed by our AGM before retiring back to the hotel for an informal dinner and more socialising time. We hope to arrange a day out for the children to allow parents, carers and relatives to take advantage of all the exhibitions, workshops and sessions that will be available during the day. The best news is that we hope to be able to offer all of this for £50 per adult for the full weekend including accommodation.

As a group we feel it is very important that as many families as possible come to our weekends in order to share experiences, research findings and support. However we can only subsidise the event to this level by embarking on a major fundraising campaign. We are very grateful to the families who have already helped us fundraise for this event but we do still need more – so if you have ideas for fundraising or want to support in any way please do let us know.

As you may know we offer a Clinical Advisory service via our website (www.criduchat.org.uk). The professionals on this team obviously deal with a wide range of queries but we have had quite a few enquiries of late that relate to mosaicism and 'regression' with age.

The latter is quite a difficult question to answer as it is on a subject that we have very little evidence based knowledge. This is partially due to the relatively new diagnosis of Cri du Chat Syndrome and partly due the fact that the syndrome does not get the research into it that some other syndromes get.

The question of balanced translocation has already reared its head which has given us an opportunity to acquire some firsthand anecdotal experience from our members which will be useful in handling this query when it happens again. It has also given us the chance to discuss the feelings of siblings of those with the syndrome and their worries and wishes for genetic testing. These anecdotes will be available shortly on the website.

An American speech pathologist student also contacted us about speech defects in children with the syndrome and I will chase her up about her research shortly to find how it has progressed.

We also had an enquiry from a mother whose new baby had a mutation at 5P15 and a search on the website lead to us.

We have also been chosen to be part of a pilot study into 'rare diseases' (one of 12) to be looked into which should help with national standards/protocols of treatment in CdC.

The conference (aka the Family Weekend) was a very useful and informative day and including speakers such as Chris Oliver, Kevin Mann and one to one workshops with Mohnish Suri. We are working on the lineup of speakers for the 2010 conference and if anyone has any particular topic they wish us to cover please email us at office@criduchat.org.uk

The website is our most effective means of communicating with families and professionals and we are pleased that the new website will make asking queries of the Clinical Advisory Group so much easier. If you have any questions you can either email us at office@criduchat.org.uk

Also in the pipeline is the production of downloadable fact sheets in 'word' and 'PDF' format covering the most common queries which will be useful for informing the new families and their medical teams.

But one of the most exciting things that has happened recently is the production of the new DVD produced by Chris Oliver and his team at the University of Birmingham. This DVD called "Understanding and Changing Challenging Behaviour in Cri du Chat Syndrome" is free to members and is included in this mailing.

If you want extra copies then it is on sale from the administration office for just £5 (plus P&P of £2).

Thanks for this fascinating DVD goes to all the team – Chris Oliver, Jo Moss, Jane Petty, Penny Tunnicliffe, Richard Hastings, Pat Howlin, Gemma Griffith, Leah Bull, Darrelle Villa and Michael Yip.

Some years ago we attempted to develop a project on the effects of aging in those with Cri du Chat but failed to do so because of a lack of grant funding. Following the very successful 3 Syndrome project we have now been approached to become involved in a new study into the lifelong health and well-being for people with a genetic syndrome. It is early days but we thought you would wish to see the initial background we have received

A research study on the lifelong health and wellbeing for people with a genetic syndrome

There is a lot of information available about wellbeing and it is considered to include concepts such as equality, human rights, reaching your full potential, being in control of your life and valuing relationships.

However, little is known about how much measures of wellbeing apply to people with learning disabilities (LD). People with LD are more likely to have poor physical and mental health and to be less included in social activities. Because of these differences between people with LD and the general population, it is important to investigate the guiding values for wellbeing for people with a learning disability, and to what extent wellbeing for the general population can be used to consider wellbeing amongst people with LD.

We are carrying out research focusing on a particular group of people with learning disabilities, people who have a neurodevelopmental disorder associated with an intellectual disability, like Cri du Chat syndrome. What are the particular factors that contribute to wellbeing for people with a syndrome? Are these factors related, but different from those contributing to wellbeing in the general population?

We have received a 10-month grant from the Medical Research Council to investigate this. During these 10 months, we are forming a network made up of people from different disciplines and we are carrying out some preliminary research with a view to apply for a large grant. The network consists of experts of the field of genetics (Prof Angus Clarke), psychiatry (Prof. Tony Holland), psychology (Prof Chris Oliver, Prof Pat Howlin and Dr Jo Moss) and sociology (Dr Marcus Redley); participating syndrome support groups like the Cri du Chat Syndrome Support Group; and consulting members like Mencap and the Genetic Interest Group (GIG). The preliminary research involves conducting telephone interviews with parents and representatives from the syndrome support groups. We are delighted to have the support of the Cri du Chat Syndrome Support Group, and we look forward to working with the organisation, and interviewing the parents, who will have a wealth of information which will help us in our research in improving wellbeing for people with a genetic syndrome.

Fundraising activities

Thank you to all our members and supporters who have donated or organized events on our behalf.

Mary Pearson, sponsored slim	£1,751.67
James Moon, Iron Man UK	£2,201.54
Annual Barn Dance in Essex	£548.00
S and K Allsop, bike ride	£215.00
Mrs Iris Hill, in lieu of 80th birthday presents	£200.00
Mary Smith, donation for Conference	£15.00
Amazon, online sales	£25.20
Easy Fundraising, online sales	£24.09
Via Tanya Walker	£3,275
Michael Maguire	£120



Team Amelia: Stu Temple, Stephen Taylor (Middle) and Paul Gearing

GLAM GIRLS 2010

The winner has now been chosen, the photographs have been taken and the calendar is in production.

Each of the 12 supported charities have been given a month in their glamorous calendar and the subject for our month (March) is the movie *The Blue Angel* but other months are *Breakfast at Tiffany's*, *The Seven Year Itch*, *Bonnie and Clyde*, *Cleopatra* and *Cabaret*. All profits from the sale of this calendar will be split between the charities.

To find out more visit <http://www.glamourgirlloftheyear.org>



Stephen Taylor ran the Swindon Half Marathon on behalf of the CDC support group raising over £1,000. Stephen is still collecting sponsorship so please do visit his page www.justgiving.com/stephentaylor75

Stephen writes

Although it was a very wet day we had a great day. Amelia did a 2 mile fun run with my son and wife and had a fantastic time doing so.

My half marathon was a little more challenging but I managed a personal best of 1:56:12 and look forward to doing it again (and beating my time) next year.

Looking forward to seeing everyone at the next conference.



JustGiving is a great website where you can create your own fundraising page. Registration is easy (and free!) and makes it easy to raise money on behalf of the group.

www.justgiving.com/criduchat/raisemoney

Good luck to Heath McDonald-Noble who is currently training for the National Three Peaks Challenge in June and will be raising funds for the group.



Help the Group

We are always looking for new committee members to join. We have three or four meetings per year (usually in Milton Keynes) with the rest of the business being transacted by email or telephone. If you are interested in helping please contact the chairman by email ray@criduchat.org.uk for further details.

Perhaps you have knowledge of similar events being undertaken, could you obtain sponsorship for the group?

Family stories: introducing a new family

Rich, Liz and Harry Bates

I would like to introduce you to Harry Bates (below). Harry was born on the 11th February 2008 and was diagnosed with Cri du Chat at around 8 weeks. You will know how this can knock you back hearing that news, the hospital was helpful the way they explained the condition to us, but we found it hard to take in.

Over the next few months we had loads of help and advice from the NHS and what we read on the internet. The one thing we did learn from the beginning is that Harry would give us all the love and happiness any parent could wish for. We know Harry will be at home most, if not all, of his life and will need a great deal of help from the family which we are well placed to give.

We have tried to contact other families with similar experiences but have been unsuccessful. I know some people find it hard to talk about it but I would strongly advise all to talk if possible to other families - even if just by email. The only contact we have made so far is two families one in Australia and one in New Zealand which we have exchanged our experiences which has helped us come to terms with Cri du Chat as all three lads have reached the milestones together although Harry is slightly behind on some of them but I am led to believe this could be due to the amount of the deletion to chromosome 5 as Harry is missing down to 13.1, which is quite a bit.

As for Harry so far he has had to have 2 hernia operations and suffers from reflux but the medication keeps this under control, this month (January) Harry is going back into hospital for an operation on his kidneys because they are joined together in what they call a horse shoe shape which one of them has a blockage which could affect the good one so hopefully he will come through this ok.

I think we will be going to the next meeting as I think meeting other families is our next step but we would like contact with someone before that, we can be contacted at richliz@richliz.karoo.co.uk or myself on 07709483488 and rbates@cbuildings.co.uk if not then we hope to meet you at the next meeting.

Harry also has a page on the Australian web site which will be updated after his operation.

We know there are others who have not had the opportunity to make contact with families in similar situations.

This is where we can help.

If you want to get in contact with other families please contact the administrator and we will be able to put you in touch.



Is obtaining Travel Insurance a problem? Trying to obtain reasonably priced travel insurance can be a problem where a family member has a medical condition. Premiums can escalate, as much as three times the price of the actual holiday in some cases! An associate of GIG (Genetic Interest Group) is an insurance broker and, having been diagnosed with breast cancer, had to face this additional problem. She believes the problem lies with being rated at the perceived rather than the actual risk of a condition.

GIG is now liaising with **insurancewith** to tackle the issues surrounding not only breast cancer but all conditions where the risk is not being assessed correctly. To do this they need **consumer champions** to help them understand specific conditions.

Have you had trouble in obtaining a reasonably priced policy to cover your Cri du chat child? As if we don't have enough problems in getting away on holiday! You may wish to act as a **consumer champion** for our syndrome, please get in touch with the office and we will provide you with the contact details.

It would be great if your story led to a reduction in premiums.

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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