

Syndrome Support Group

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

Dear Supporter

At long last there appears to be some chance of some warm sunshine and our thoughts turn towards meeting up with new and old friends involved with our very special Cri du chat Syndrome at the Family Weekend.

Following an increase in the number of families forwarding their annual subscriptions and the fundraising efforts of a marvelous few your committee have been able to heavily subsidise two nights away for each family. This opportunity for meeting others dealing with the day-to-day situations should not be missed, it only occurs once a year!

Have you reserved your place? You should already have received details and the booking form and we have to finalise numbers with the hotel and professional carers very shortly. Please contact our office as soon as possible.

The Annual General Meeting will also be taking place and will include the bi-annual election of officers. It is always necessary for any committee to constantly evolve and we welcome any interest in joining. Please contact me with any questions.

The last few months have seen several changes in our working practices, don't forget that your volunteer committee is made up of CDC parents as hard pressed as yourselves, and much of the ongoing administration is now undertaken by Lucy and Andy at their office in Norwich. They have been most instrumental in formatting the new website and hopefully you have found it to your satisfaction. Any feedback, good or bad, will be most welcome.

Following the completion of the three year "Understanding and Changing Challenging Behaviour" project we are now taking a short break from active research work.

However we have been represented at a workshop at Cambridge University where a collaboration of several Universities and syndrome support groups are seeking to obtain a major grant for a project that will look into "The lifelong health and well-being of adults with a neurodevelopmental disorder associated with an intellectual disability" There are unlikely to be any developments before the end of the year but we will keep you posted as events unravel.

Funding our activities remains crucial and I hope you will find the Fundraising page in this newsletter of interest.

See you at the Family Weekend, have a great summer.

Best wishes,

A handwritten signature in black ink, appearing to read 'Ray Clark'.

From the Administration office: You may have noticed some changes if you have contacted our office recently –as my husband, Andy, has started helping with the group – mainly on fundraising and the family weekend. We hope that by having two people in the office we can answer all group queries more quickly.

The group continues to grow and we have had several new members since the last newsletter and we are delighted to welcome them to the group. Every family has a story to tell and can bring their own experiences to the group – we are especially pleased when families feel they can volunteer – and I am very grateful for the families who have contacted me with suggestions for fundraising and raising awareness. We are a small group and it is this type of input that can make a real difference.

I have also been spending a lot of time dealing with queries about our family weekend. So far we have 20 families in attendance but we do have more spaces available. If you haven't yet booked – it isn't too late! - there is a booking form included with this mailing. If this would be your first time and you are not sure if it will be right for you and your family, please do get in contact. 4 of the families already booked are coming for the first time so you will be in good company.

Lucy Tetlow, Administrator

Want to meet with local families?

Whilst the annual family weekend remains the best way to meet other families we have often received suggestions from families who, for one reason or another, either cannot get to the weekend or wish to hold something local to them.

For several years one family has organised a get together in Essex where five or six families spend the afternoon in general fun-filled conversation, food and the odd drink or two! The Cri du Chat ages range from six to thirty-five and last year new parents with their young daughter joined the party.

The rareness of Cri du Chat syndrome means that the majority will not live in close proximity to another family but in the past we have also had other successful groupings – whether it just be two families or more. It is also a good opportunity to get extended family members involved.

Feedback from groups has always been positive and the Group wishes to encourage similar activities up and down the country. We have therefore set up a 'local family' grant which has a designated £200 per event amount to assist families in running these events.

The office can also advise on how to set up these events, contact other families on your behalf, and circulate details. If you are interested in running an event local to you then please do get in contact with Lucy Tetlow at office@criduchat.org.uk or 0845 094 2725.



Want to meet with other families – virtually?

Another way to meet families is through our new Facebook page.

This is a new venture for us but we are pleased that we already have 156 friends. We are even more delighted to see that, although there are plenty of familiar faces, we have lots of friends who have never been in touch with the group before – in some cases they have never even come across us before! Whether these new friends join as members or support us in other ways we are glad that we are in touch with them.

Thanks in no small part to the enthusiastic posting of Damian Haywood, Vicki McDonald and Pippa McIntyre, new friendship groups are springing up and families have an easy way to communicate with each other, get feedback, help with particular problems and just generally blow off steam with people who understand.

If you haven't joined our Facebook group yet there is a link from our website www.criduchat.org.uk or a group search straight from Facebook will pick us up.

Fundraising activities

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

Dr Peter Green, mother's memoriam	£60.50
Amazon on-line sales	£38.94
Stephen Taylor	£673.87
Connie Spring	£160

And of course all those still raising funds through JustGiving →→→→

GLAM GIRLS 2010

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.

And while it may be a little late to buy a calendar for 2010 there is plenty of other merchandise to buy, all profits to again be split amongst the charities. You may see something you were already looking for here and the Support Group will also benefit.

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



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.



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

JustGiving is proving a major tool for the fundraising efforts of both our supporters, as they don't have to actually collect the pledged funds, and ourselves, who don't have the task of claiming the very profitable Gift Aid. In addition it is estimated that over 20% of funds are raised after the actual event has taken place and so funds are now being received regularly from the following;

Heath McDonald-Noble attempted the Three Peaks Challenge on 24th April
<http://www.justgiving.com/Heath-McDonald-Noble>

Emma and Keri ran the Sheffield half marathon on 25th April
<http://www.justgiving.com/KeriandEmma>

Gill Boorman ran the London marathon on 25th April
<http://www.justgiving.com/Gill-Boorman>

Damian Haywood will be attempting the British Three Peaks on 19th June
<http://www.justgiving.com/Damian-Haywood>

Pippa McIntyre will be running in the Maidstone Big Fun Run on the 10th October
<http://www.justgiving.com/Pippa-McIntyre>

Sheila Regan will be attempting the Three Peaks Challenge on 19th Jun
<http://www.justgiving.com/SheilaRegan>

Ellie Hartley will be running the "Down Flow Up Tow" half marathon from Windsor to Marlow on July 25th
<http://www.justgiving.com/EllieHartley>

Please support their most generous efforts NOW.

Of course in these difficult financial times your support group needs the assistance of as many supporters as follows and you may think that JustGiving is only geared towards Sportsmen or Sportswomen but that's not the case. People also raise funds by creating a JustGiving page instead of wedding gifts, birthday presents, for beard growing or shaving, and even outlandish activities such as bathing in baked beans!

Why not have a go, contact the office for more details.

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

Focus on: Advocacy

As we get older parents need to adjust to their child's/adult's changing requirements as an individual. Advocacy is a term being seen a lot lately and the following article should be food for thought to many of us. It was written by Viv Cooper who, as well as being Chair and Founder of the Challenging Trust Foundation, is also the mother of a Cri du chat adult. The Foundation has also produced a Guide for Advocates, free for family carers. Please contact our Office for details.



We all need champions!

Like most mums, I hope that I am someone my children can turn to for advice, or to be their champion when they need one.

Most of us have family members who fulfill that role, as well as friends and colleagues who also provide important input to our lives. Even though I am reasonably able to advocate for myself, it is good to know that there are people “there for me” if I need some support.

I worry that my son, who is more in need of support than most, is least likely to have it. He does have a supportive family, but he is more reliant on us because he is vulnerable. There are many who do not have family or a circle of support and they are even more vulnerable.

Advocacy is a powerful tool and we need to ensure that we make it available

Ironically it is those who are most in need of independent advocacy support who are least likely to access it. It seems it is a bit too expensive and too complicated to put in place. I have personally encountered “well why does he need an advocate, he’s got you” (countered of course by “well, you are his Mum and may have a conflict of interest” when it suits!) and “it’s not in his best interest to have one” (astonishing!).

I am fully aware of the dangers of appointing an advocate who is not properly independent, or who does not have the expertise to fulfill this important role. (Beware the person who says confidently “yes I can advocate for him” without spending significant amounts of time to get to know the person!) But advocacy is a powerful tool and we need to ensure that we make it available to those who need it – and that it is of high quality. That is why we have produced a new resource specifically for advocates and we are dedicating an issue of our newsletter, Challenge, to the topic.

My son has the same rights as everyone else to a good life. He just needs more support than most to access those rights – and independent advocacy is an important means to champion them.

Vivien Cooper,
Chair of Trustees and Founder of the Challenging Behavior Foundation

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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



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