

Syndrome Support Group

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



Well we are here again with, fanfare please, the 40th issue of the Cri du Chat newsletter. Our first newsletter was printed in 1989 and we are very proud to have kept up this fine tradition. We hope you enjoy this edition and really do welcome any comments or suggestions you may have.

As we are in the run up to our family weekend this issue does focus on the topic and we hope that, by sharing stories of people who have attended in previous years, we will encourage new families to take that leap and come in 2013.

Not only is our family weekend full of information about Cri du Chat but we also hold our Annual General Meeting. This is your opportunity to find out (and ask questions) about

how the group works, how we spend the money that our supporters have raised and also, should you wish, to get involved yourselves. There are several ways that you can get involved but our main one is to join the Committee.

As a committee member you would be required to attend up to 4 meetings per year, normally held in Milton Keynes, and to advise and participate in the management of the group. As a charity it is essential that we comply with Charity Commission regulations and our management committee helps to ensure that we do and to plan for the future. And along the way I promise that we do have some laughs as well. If you are interested in becoming a committee member send an email to Lucy who can provide some more information about the role.

Darren Ayres, Chairman



I think it is entirely fitting that our 40th issue is centered around our annual family weekend. It is the high point of our support group year and the chance for you to meet other families and share your stories and experiences.

We try and get a good mix of speakers and workshops to cater for all the different age ranges but many families comment that it is the social time that they value the most. Friends made at a Cri du Chat conference really are for life!

As always I do hope that we will see as many families as possible at the weekend. If you would like to come but find either the travel costs or the price itself restrictive please do let me know. We do have limited funds to help out but they really are limited as this weekend is already heavily subsidised.

We also have grants to help with organising family get togethers in your region as well as to help purchase equipment. I will write more on both of these in the next edition but if you are interested please do get in touch with me for more information.

Lucy Tetlow, Administrator

You are hereby given notice of and are invited to attend and participate in the Group's AGM on Saturday 22nd June 2013, Chester Crowne Plaza Hotel at 10.30am.

The proposed agenda is as follows;

1. Chairman's welcome
2. Apologies
3. Minutes of the 2012 Annual General Meeting
4. Administrators report including membership report
5. Treasurer's report and Accounts
6. Election of Officers (if applicable)
7. Any other business

FAMILY WEEKEND



The best bit is meeting other families and sharing experiences not just about CdC but other day to day stuff too. We have had some brilliant speakers in the past that have been really informative. The weekend is just a great mix of fun, support and gaining information. Will be really sad to miss this year but know that everyone will have loads of fun and look forward to seeing the pictures and hearing all about it.

Pippa, mother of Gabriel and Committee member

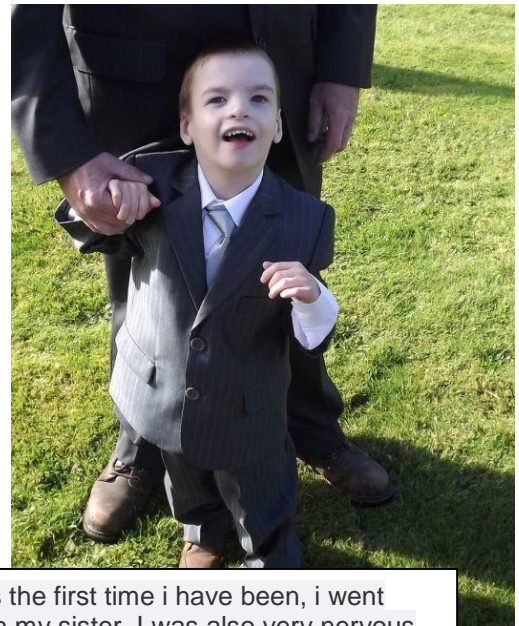
As a grandma it is lovely to see the mums & dads relaxed and chatting to each other, swapping day to day experiences of their children with people who are going through the same thing. These week-ends give hope to new families (and old) and shows what their children are really capable of achieving.

Shirley, grandmother of Harry



Newbies need to know that the first one is SCARY! The first one I went to, Sam was just 11 months old, but I found it so useful to meet others in the same situation, made some lifelong friends along the way and attended the next 19 on the trot! Everyone is approachable and happy to talk about their children, equipment, feeding tubes and all that stuff, so you get the real picture, not what the medics and therapists tell you!

Elaine, mother to Sam and Committee member



2012 was the first time i have been, i went along with my sister. I was also very nervous but wanted to go to understand my niece Paige's condition further. Meeting other families was absolutely fantastic all of the children were absolutely lovely and everyone was made welcome. I think any family members associated with someone with CDC should come along as it does help to understand things better. **Louise, Paige's aunt**

Just love seeing all the other families and especially watching all the children playing together and trying out each other's toys. The kids always have a great day out while the parents can have a few hours break while learning lots of useful things about CDCS and relevant therapies etc. I was nervous the first time I came, but now I really look forward to it every year. Wish it could be more often.

Amanda, mother of Amelia



FAMILY WEEKEND



I like the social side, as Ashley is an adult the speakers although very interesting, aren't of interest to us now that Ash is 28yrs old. We've been there done that etc. lol. But I love chatting with the other parents and think it's great that we can be of help to families of younger children. And felt so proud of Ashley keeping some of the families entertained! All in all I think the family weekend is a nice relaxed fun weekend for all the family. **Gill, Ashley's mother**

It's just so nice to meet up with everyone again after a year of rushing round sorting things out etc. It's just so nice to stop and chat with everyone. It feels like for the first time for a year, I can actually relax and have an extremely good time. We are all really friendly and it feels that while we are all together, we all look out for each other's kids. The kids go on a day out with carers and have a great time while parents/carers can concentrate on the conference side of things. Usually, parents have a more relaxing day when the kids go off knowing that the kids are being well cared for. **Lisa, mother of Natalie**



I really enjoyed meeting all the families but especially the children and seeing how each of them are doing, seeing the huge age range was good from 2-46 Paige being the youngest just! Can't wait to see everyone again and see how well they are all doing since we last got together! The geneticist was another good thing for me as I understood more about the cause and effect whereas when Paige was first diagnosed I was too upset and not in a place to take it in, gonna make sure I take her deletion information this time though as I didn't have it then. **Clare, mother of Paige**



In 2013 our Family Weekend will be held in Chester the weekend of 21st -23rd June.

If this is your first time attending and you want to speak to people in advance of the meeting please do let us know and I will put you in touch with other families. We also have a New Families session on the Friday evening.

It's seeing the other families and the children! It's great! And I was nervous too the 1st time but can't wait for the next time!! The speakers etc. are good and informative but the social side is good too!! **Vicki, Nathaniel's mother and Committee member**



CASPAR HULL: The Clinical Advisory Group (CAG) is still very active in our remit in answering specific questions, so if you have any specific questions then please contact us through the website, we normally have replies within 2 weeks.

The Research Committee is currently working on our Route Map, funded by Genetic Alliance UK, and are looking at ways to publish this in electronic form. We have also been asked to support Prof. Chris Oliver, Neurodevelopmental Disorders (Cerebra Centre) to develop online and related resources for our group (as well as others) which will work well with the Route Map. This is still in the planning stages but we will keep you up to date with its progress.



PIPPA MCINTYRE: I was lucky enough recently to be asked to join a working party to develop a new programme for the parents of preschool age children with learning disabilities – who often receive little support and, often, only once a difficulty such as challenging behaviour has already arisen and begun to impact upon the family. This was the underlying issue identified by Dr Nick Gore (Tizard Centre) and the aim of the eventual programme, which has the working title SMILE, is to provide clear, practical advice, guidance and support to parents and will be offered before any difficulties have been experienced.

SMILE will hopefully consist of six 2 hour sessions, delivered by a range of professionals with co-facilitation by a family carer. Each session will cover a useful key topic area, identified by the working group, and the main objective is to provide parents with the tools to decrease the likelihood of future behavioural and emotional difficulties. The exciting and unique thing about this programme is not only that it will be offered proactively but also the way in which it is being developed and, following a pilot programme, also how it will be delivered – with a family carer at the centre of the process. This is why I am excited – it won't be a whole load of professionals telling parents 'what is best' for their child but will be a professional giving invaluable advice with a parent who have truly been there. I know that by the time this programme is rolled out across the country it will be too late for the majority of us as our children are older now but it is exciting for the future and I for one wish this kind of programme had been available when Gabriel was of preschool age.



RAY CLARKE: We received the following in December and thought it might be of interest to some of our readers:

“Institutions like Winterbourne View will become a thing of the past – thanks to you taking action. The government has promised that people with a learning disability will no longer be sent away to distant institutions where they are at risk of abuse. They have committed to a strong action plan that we hope will dramatically reduce the number of people with a learning disability who are being sent away to assessment and treatment units like Winterbourne View, and will return as many people as possible to their communities.

In its final report into the abuse at Winterbourne View the government has set out an 18 months plan for change. Local authorities and the NHS have six months from now to work together and review where they have sent people to hospitals for people with a learning disability or autism. They will then have to prepare plans for every person in these places, and develop appropriate local services so people can return to their communities –no later than 1 June 2014.

DONATIONS: On behalf of all our families many thanks to all the following for their kind and most appreciated support.

In memory of the late Mary O'Grady	£350
MA & J Bowden	£20
Wychwood School	£367.96
Parish of St John the Divine – Rastrick	£200
R and A M Sage	£30
Amy Elston 5p for 5p	£36.40
MJ & EM Crossley	£40
In memory of Donald Sinclair	£5
Friends of Ormerod School	£50
Rebecca Horne and Jeremy Johnson got married	£455
J A McIntyre Donations instead of wedding presents	£335
Mr and Mrs John Miles 40th Wedding Anniversary	£1,115
Mr and Mrs Bradshaw	£15
Mary Smith	£25

You may remember the excellent efforts of Phil Cox who cycled from Land's End to John O'Groats to raise funds for the group. Not only did Phil cycle his little heart out but also organized lots of events to publicise and raise awareness of both this fundraising and Cri du Chat syndrome.

Not content with this Phil has now written book about his experiences. Part anecdotes from the ride itself and part descriptions of each day's cycling this will be of interest to those of you who want to find out more about taking part in fundraising challenges but also those who are just interested in what type of person puts themselves through something like that (only joking, Phil – you are clearly just a star)

I have had a sneak preview of this – which will be available later this year – and it is really a funny book and even better all proceeds will come to the group.

FUNDRAISING THROUGH JUSTGIVING

Rhiain Harris	£566.25
Tanya Walker	£288.75
Gareth Buckley	£335
James Noakes	£272.50
Vicki McDonald-Noble	£901.44

THOSE STILL RAISING FUNDS THROUGH JUSTGIVING

Faye Andrews and friends ran both the Bristol half marathon on 30th September and the Amsterdam full marathon 21st October 2012
<http://www.justgiving.com/Friendsrunningincircles>

Rebecca Barrow participated in the Nishkam Charity Sky Dive on the 29th September 2012, <http://www.justgiving.com/Rebecca-Barrow>



JAMIE ROSS continues to raise funds for the group in 2013 with many sponsored runs including the Brighton Marathon in April – good luck to Jamie!

Visit his fundraising page
www.justgiving.com/LardyBoy2013

Just Giving enables you to make secure on-line donations and create your own fundraising page – it's very easy. To find out more visit www.justgiving.com/criduchat



Fundraising ideas and checklist

We are always so grateful when people take the time and effort to fundraise for us. If you are interested in joining the ranks of people doing weird and wonderful things for us or whether you want to raise funds in a more sedate fashion then do get in touch and we will do all we can to help support your event. We want to keep your fundraising safe, legal and fun and aim to produce helpful information over the next few months –which will be on our website.

Last year we held the first Cri du Chat awareness day – on the 5th May. In 2013 we intend to do the same and we featured examples of what people did for us in the last issue of our newsletter. We want 2013 to be bigger and better.

AT HOME

- X Garden party
- X Coffee morning
- X Pamper party
- X 5p wine bottle

PUB

- X Quiz night
- X Wine & cheese night

AT WORK

- X Dress down day
- X Bake sale



SOLO

- X Car boot sale
- X coin collection
- X Collection tins in shop

- ✓ Brainstorm the fundraising idea that you want to do – perhaps the ideas above can inspire you?
- ✓ Set up your online fundraising page on JustGiving (www.justgiving.com) and share this link with everyone you know. Ask the people who are most likely to sponsor you first as this sets a precedent for others to follow.
- ✓ Tell your friends – put up posters, send invitations, get as many people involved as you can think of. What about your children's school, where you work or any social groups you belong to?
- ✓ Tell our friends. You can write on our Facebook wall www.facebook.com/CDCSSGUK, follow us on Twitter and tweet @CDCSSGUK
- ✓ Contacting your local paper or radio station is a great way to create some buzz and also help us to raise awareness of Cri du Chat Syndrome. If you need help writing a press release then get in touch with us but there are some great templates available on the internet. Mail this to the news desk of the paper or radio station around 10 days before the event and invite them to take a picture if they find the story interesting. After the event email them your own photo and tell them the story of the event – why you are doing it and what you achieved. Remember to give out a contact name and number to tell them how to get in touch with you.
- ✓ We can provide materials to help you fundraise. We have posters, banners, t-shirts, pens, wrist bands and if we don't have what you want let us know and we will see what we can do. These all help you to raise extra money and create awareness of the group.
- ✓ If you are organising an event it is really helpful to write a to do list and ask your friends and family to help you out. Check whether you need permission for anything? Do you need helpers for the day? If you are planning a raffle then can you ask local shops and businesses to donate prizes?
- ✓ Remember to ask for Gift Aid – this means that for every £1 you give, we can claim an extra 25p from HM Revenue and Customs (as long as you are a UK taxpayer). This helps your donations go even further.
- ✓ After the event thank everyone that helped you – whether it was through sponsorship, attending, volunteering their time or donation or prizes. If you want someone to receive a special thanks let us know and we'll send them a card.

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Charity No: 1044942