

Syndrome Support Group

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

Dear Supporter

It has been a very productive year for our charity so far. Plenty of imaginative fund raising events have taken place and this has helped fund some aspects of this year's family weekend. I would like to thank all of you for your continued support and commitment.

Our annual family weekend is a fundamental function of our group and I look forward to seeing all those who can attend on the 3rd June 2011 in Milton Keynes. The committee has worked hard to put together an interesting and thought provoking schedule that we hope will be both informative and interesting for families. The family weekend is all about meeting your needs and we welcome all comments – so if you have any issues or concerns please let us know and we may be able to address these at future family weekends.

We are also very proud of the achievements of our Clinical Advisory Group. CAG is a vital element of our organisation and provides a clinical and personal perspective on most issues relating to Cri du Chat syndrome. We have a robust team of experts in the group and they can be contacted via the website or by contacting the administration office. CAG will also be running workshops at the family weekend to address any issues you may have relating to the syndrome and will also have a workshop specifically on older and adult Cri du Chat matters.

A lot of work has gone into our website and we hope you find this up to date and relevant. Our administrators, Lucy and Andy, are instrumental in managing the up keep of the website and would welcome your input and ideas to improve this. They are also always looking for interesting articles and stories to add to the newsletter and would welcome any suggestions you may have.

Best wishes,

Darren Ayres, Chairman

From the Administration office:

Of course all attention is now focused towards the annual family weekend and, if you haven't already booked, I hope you will consider attending this year. We are currently putting the final touches to the programme but there will be lots of interesting speakers and sessions as well as plenty of informal time where you can meet other families and exchange experiences and knowledge. Full details of the current schedule can be found on page six of this newsletter.

Again I want to thank all the families who have been fundraising for us – there are really too many to mention but special thanks must go to the McDonald- Nobles, the Bates, and the Brooks. It has been so heartening for the committee to see a new generation of families joining the group and contributing in such positive ways.

We are working hard to increase the number of families we can help and all our members are part of this growing family. We have been exploring social media and networking and have found many new families through this route – families that we may not have spoken to otherwise. This has been a very useful exercise and exactly the type of work the group should be carrying out.

Between 2004 and 2005 Jo Moss at the University of Birmingham, visited a number of children and adults with CdCS around the UK, as part of her PhD project evaluating social-communication skills and repetitive behaviour in children and adults with CdCS. Families may remember that, as part of this project, Jo visited a number of children and adults with CdCS around the UK, observing their behaviour in different social situations.

She also assessed some people with CdCS at various family conferences that took place during that time. This year, Professor Chris Oliver has obtained funding from Cerebra for a new PhD student, Miss Lisa Cochran, to follow up all of the children and adults that took part in Jo's PhD study. A follow up study is important to find out about changes and progress over time and this research project will allow us to understand the long term outcomes for children and adults with CdCS, which is an area that, as yet, we know very little about. This is the first study to follow people with CdCS over such a long period of time and the results of this research will be important for understanding how people with CdCS develop over time.

Lisa will be contacting families very soon to invite them and the person they care for with CdCS to take part in this follow-up project. Participation at this follow up will provide new and valuable information that cannot be gained any other way. Please keep an eye out for a letter from the research team in the post! Lisa would be happy to speak with you if you have any questions or would just like more information about the study. Her contact details are LJC986@bham.ac.uk, 0121 4142855, Lisa Cochran Postgraduate research student Department of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Mencap: Planning for the Future Events

Mencap have organised some FREE information sessions where you can find out about setting up wills and trusts for the benefit of someone with a learning disability.

Monday 23rd May, 12.30pm – 2.30pm
Abbeycroft Leisure Centre, Beetons Way, Bury St Edmunds, IP33 3TT

Tuesday 24th May, 12.30pm – 2.30pm
Council Chamber, Braintree Town Hall, Market Square, Braintree, Essex, CM7 3YG

Wednesday 25th May, 12.30pm – 2.30pm
Wellspring Family Centre, 35 Neathered Road, Dereham, Norfolk, NR19 2AE

Thursday 26th May, 12.30pm – 2.30pm
Mrs Howard Memorial Hall, Norton Way South, Letchworth Garden City, Herts, SG6 1NX

Friday 27th May, 12.30pm – 2.30pm
Cathedral Centre, Palace Green, Ely, Cambridgeshire, CB7 4EW

To book your place contact Gina Collins, Wills & Trust Team, Freepost WD3537, London, EC1B 1AA or call 020 76960 6925

On behalf of all our families many thanks to all the following for their kind and most appreciated efforts in supporting the CDC support Group

Anne Smith and Len Taylor Wedding donation rather than presents £288.46

Pippa McIntyre ran the Maidstone Big Fun Run on 10th October £215.90

Penny Smith and All Star Family Fortunes £10,000

J and J C Sorbie donation £10

The Bates family donation £25.40

Gill Boorman ran the 2010 London marathon and we have already advised of receipt of £138.22 via JustGiving, we have subsequently received cheques to the value of £358

H Upjohn donation £15

M H and M Gowar donation £17

G M and J A Gilroy donation £20

Beacon Recruitment Services donation £367.72

E F Stack donation £250

Mrs S Todd held a coffee morning £150

Blacktoft Parochial Church donation £110

Mrs A Plant donation £100

Lane End Players performed on our behalf and raised £425

Stone and Carr donation £20

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

Thanks to Vicki McDonald-Noble for her sterling efforts in selling our new wrist bands to families all across the world from Australia, Netherlands, USA to Panama! These wrist bands were generously provided by Beacon Recruitment Services Ltd

Rich Bates is also kindly running a cartridge recycling scheme to benefit the group. For more information please get in touch with the administration office.



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;

Jamie Ross ran in the Virgin London Marathon on the 17th April 2011, and has already raised over £4000 from his sponsors. Help him to reach his £5k target, you can still sponsor him at <http://www.justgiving.com/Jamie-Ross>

Karen Carr's son, Sean, and friends will be running in the Bupa Great North Run on 18th September 2011, please sponsor them at <http://www.justgiving.com/Karencarr66>

Heath McDonald-Noble will be running in the 57th Annual Yorkshire Three Peaks race on 30th April 2011, please sponsor him at <http://www.justgiving.com/Heath-McDonald-Noble0>

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 possible. If you are not a Sportsman or Sportswoman you can 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!

Jamie Ross (Lardy Boy) completed the marathon in the time of 4hrs and 32 minutes. His training went well and was all in his very funny blog. He is still running and plans to run 1000 miles for the group in 2011. Follow his progress by visiting his excellent blog

<http://lardyboylm2011.blogspot.com/>

Just a brief note on current research into CdC. We have received an update from the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG) and they advise;

“In 2009, we started a brief research project funded by the UK Lifelong Health and Wellbeing Cross-Research Council Programme. In this study, we wanted to learn more about how genetic knowledge might be used to improve the health and social care of adults with a neurodevelopmental syndrome associated with an intellectual disability. The initial hope was that this pilot work might lead to a more extensive funded study but this was not the case. However, important lessons were learnt which are summarised in this article. A paper is also being prepared for submission to the Journal of Intellectual Disability Research.”

Several of our families and committee took part in the initial pilot and, although the results are pretty predictable, the full article can be found on our web site. We will, of course, keep you up to date with any new developments.

Long term outcomes of individuals with X Syndrome [Cri du Chat amongst others]

The consortium of Cerebra, Birmingham University, Kings College London and the Institute of Psychiatry, are continuing with their study on several syndromes of which CDC is one;

Background to the study:

This is a follow up study so that we may look at how individuals with X syndrome develop and progress over time. The results of this study will be important for understanding how people change as they grow older. Currently, very little is known about how people with X syndrome progress and change over time.

Route Maps for Rare Conditions

We are also at the draft stage of producing our Route Map for Cri du Chat Syndrome. Thanks must go to the members of the research committee, in particularly to Damian Haywood. This project involves working with Genetic Alliance UK (GAUK) and thanks must also go to Jessica Burke, from GAUK, who has worked closely with us and provided a lot of helpful background information.

The Project Summary is:

The Route Maps for Rare Conditions project is a new and creative approach to improving access to health and social care services for patients and families with rare conditions across England.

The project will involve promoting the use of a template, developed by GIG (Genetic Interest Group) in an earlier project, to create Route Maps – guidance leaflets to help patients and families with rare conditions to access information, treatments and health and social care services.

The project will involve working closely with user-led patient support groups to facilitate the development of a series of condition-specific Route Maps. Each Route Map will provide a comprehensive resource for use by patients, families and health professionals and will have the potential to play a key role in a personalised health and social care system for patients and families with rare conditions.

The Project will take place over three years and will involve:

- ☐ Working with user-led patient support groups to facilitate the development of at least 12 condition-specific Route Maps.
- ☐ Conducting a comprehensive evaluation of the effectiveness of this approach.

CdC Syndrome Support Group Events

The date of our next Annual Family Weekend is the 3rd – 5th June 2011.

The Full registration includes two nights B&B, all lectures and seminars, a day trip for the children and a buffet meal on the Friday and Saturday evening. Registration for up to 2 children under 15 is free.

Full registration:	£57.75 per adult
Day registration:	£11.55 per adult
Extra room (for older CdC, Siblings)	£57.75 per room
Extra room (carers, grandparents, extended family)	£92.40 per adult

To book please contact office@criduchat.org.uk

What the families say



Hi I'm Vicki, mummy to Nathaniel, a 3 year old boy with lots of smiles and a lovely personality! It was our first time at the Family weekend last year and before we arrived I had such a rainbow of emotions ranging from excitement to fear. I had changed my mind several times as to whether to go or not as didn't know what to expect at all.

But I finally made up my mind and decided to go with Heath and Nathaniel to Milton Keynes and it was the best decision I made in 2010! After we checked in at the Holiday Inn we went down to the bar where we met Lucy and Andy and a couple of other families.

It was good to finally put faces to names – I had been emailing and in contact with several families and Lucy in the previous months. Everyone made us so welcome and it was nice to find out that we weren't the only ones attending the Family Weekend for the first time too! As soon as I began talking to people all my fears and anxieties melted away and it felt like I was in the right place, talking to families who understood exactly what Heath and I were going through. Nathaniel was only 2 years old then and even though he was so young he was interacting with the other children and adults and that made me even happier! When it came to sending Nathaniel to Whipsnade Zoo the 'neurotic mother' in me came out, but then, when we met his carer for the day I started to relax and when they arrived back he was so smiley and happy - he had had an amazing day and been such a good boy. He will most certainly be going back to Whipsnade Zoo this year! On the Saturday we went to the church next door to the hotel and had several talks by professionals. They were very enlightening and I learnt many things that I hadn't known before. I had previously not wanted to ask questions as I felt like I should already know everything as I was Nathaniel's mummy and he relied on me for everything, but seeing others participate gave me the courage to speak up and ask those questions.

During the day we were given chances to join in different groups ranging from CAG (Clinical Advisory Group), Siblings Group to a group about the Support Group itself. I chose the group about the Support Group as I was interested to see what happened within it. I came out of the meeting with a new found vision and decided that I wanted to be a part of the support group and make a difference. After dinner we all went into the main room and it was the committee's June meeting. They asked if anyone would like to volunteer to be a member of the committee and I thought to myself 'why not?' And from that moment I have been on the committee for the Cri du Chat Support Group and am very proud to be a part of it. Heath, Nathaniel and I are going to the Family Weekend this June without any hesitation or fears and cannot wait to see our friends that we made last year and meet new friends!

For photographs from previous Annual Family weekends please visit our Facebook page or our website.

Cri du Chat Syndrome Support Group

Annual Family Weekend 3rd – 5th June 2011, Milton Keynes

You are hereby given notice of and are invited to attend and participate in the Group's AGM .

The proposed agenda is as follows;

- 1. Chairman's welcome**
- 2. Apologies**
- 3. Minutes of the 2010 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**

Programme (subject to change)

Friday 3rd June, check in from 3pm

Holiday Inn, Milton Keynes

7.00 – New family welcome, *bar area of hotel*

7.30 – 9.30pm

Buffet (Residents only), *private conference rooms*

Saturday 4th June

Church of Christ the Cornerstone

Enter through main reception

9.30 – 10.00 Trip Registration and coach trip

Guild Hall

10.00 – 10.30 Conference Registration and Refreshments

Guild Hall

Start of Clinics with Dr Mohnish Suri (please book on day)

10.30 – 11.00 Welcome by Darren Ayres, Chairman

Main Hall Area

11.10 -12.00 Lance Tiley

Main Hall

12.00 – 1.00 Caspar Hull

Main Hall

1.00 – 2.00 Buffet Lunch

Guild Hall

Start of Clinics with Lance Tiley (please book on day)

2.15 – 3.00

Workshops (please book on day)

- Support Group

- CAG Workshop

- CAG Workshop (older children and adults)

3.15 – 4.00 Charlotte Mawby

Main Hall

4.00 – 5.00 AGM, Conference feedback and close

Main Hall

Children to arrive back from trip.

7.00 Meet in hotel bar before buffet at 7.30 (Residents only unless by arrangement)

Holiday Inn, private conference rooms

Sunday 5th June

There are no formal sessions on the Sunday but we usually meet for breakfast in the hotel and residents may use the hotel swimming pool and facilities after check out.

Speakers, Workshops and Clinics

Clinics

Dr Mohnish Suri is a Consultant in Clinical Genetics at the Nottingham Clinical Genetics Service. He provides a Cancer Genetics Service to families in Nottinghamshire and Southern Derbyshire and he has a special interest in the genetics of prostate cancer. Dr Suri is also the author of a book on Clinical Genetics and several peer-reviewed articles.

Speakers

Caspar Hull is an osteopath with twenty years experience, chair of the CdC Clinical Advisory Group and father to Cicely, aged 13, who had spinal fusion for scoliosis 4 years ago. Caspar will be talking about scoliosis, what is it? What to look for and how it may be relevant for CdC. Caspar will also be discussing whether there is a need for research into it.

Charlotte Mawby R.G.N. R.S.C.N is an Independent Paediatric Continence Nurse who has had 5 years as a Senior Clinical Specialist Nurse - Paediatric Continence, 7 years – Clinical Nurse Specialist – LEA Special School, Children with Severe & profound Learning difficulties many with Complex Health care needs. Charlotte will talk about toilet training, understanding bladder and bowel.

Lance Tiley

Lance has nearly 30 years experience as a Senior Social Worker with an Inner London Local Authority before pursuing his career as a Social Support and Health and Safety trainer. Whilst working for the local Authority Lance worked as a Residential Social Worker having been manager of a home for young adults with profound physical and learning disabilities and also for a home for adults with a dual diagnosis of learning disabilities and mental health problems. Lance has a wide knowledge of residential resources specifically for adults who have a Learning Disability. Lance will talk about the transforming social care agenda with regard to personalisation and Individual Budgets.

Workshops

Workshop 1: Support Group Facilitator: Lucy Tetlow

An open session for those who wish to know more about the support group – whether it be how you can get involved with fundraising or how you access grants to arrange regional family meetings. We are also interested in hearing how we can help you more. All ideas and comments welcome!

Workshop 2: CAG Forum Facilitator: Darren Ayres

An open forum to discuss anything to do with Cri du Chat.

Workshop 3: CAG Forum (Older children and adults) Facilitator: Ray Clarke and Caspar Hull

An open forum to discuss anything to do with Cri du Chat in older children and adults

CdC Syndrome Support Group Events: Regional

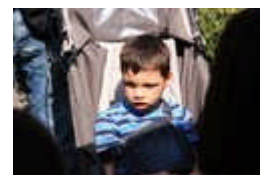


Following interest from families on a message thread on the new website forum, the CdC Support Group offered to fund a day for people in the north of England affected by CdC, to meet each other and give families an enjoyable day out.

The event was held on Saturday 9th April, and the weather was fantastic. We met near Leeds at a petting farm with a soft play fun barn. Five families came along; with children (CdC and siblings) ranging from 3 months to 15 years in age, the venue ensured there was something to interest everyone. We met in the morning, and spent some time getting to know each other whilst looking around the farm. For lunch we managed to commandeer one side of the picnic area with all our wheelchairs, buggies and picnic paraphernalia! The afternoon was spent looking at more of the animals and some of the more energetic among us worked off their lunches with some time in the fun barn.

With Cri du Chat being so rare, opportunities to meet others affected by the condition are invaluable - to swap notes and just to be able to talk to people without feeling like you are sometimes talking a different language.

Thank you to the CdC Support Group from us all.



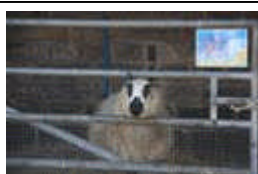
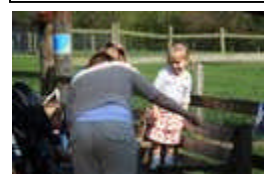
From the Committee: Whilst the annual family weekend remains the best way to meet other families we have often received suggestions from families who, for one reason or another, either cannot get to the weekend or wish to hold something local to them.

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 per event amount to assist families in running these get togethers.

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.



Family Stories, links and networks

Older families will recall the input at Conferences and newsletter articles over the years of mum Mary Smith from Sunderland. In her own inimitable style she has penned this poem in celebration of son Ian's 40th birthday.

Ian

We are not telling lies, not being naughty

But can't believe that you are Forty,

What a fantastic life you have had

Give him a medal – you clever lad,

You've had many ups and sometimes a down

But lots of smiles and perhaps a wee frown,

Meeting plenty of folk along the way

Not always good things they had to say,

But when your back was against the wall

You have always surprised us all,

And just bounced back to let them see

Aren't I clever- just look at me,

To show the people you have met

You are able to surprise them yet

Your eyes just tell us when you can't speak

To "say" you are happy when we meet,

We enjoy our outings by the sea

Sandwiches, ice-cream, cups of tea,

But you certainly can let us know

When you've had enough and want to go!

Happy Birthday dear brother, dearest Son

Congratulations Ian and very well done.

Sharon Terry, CEO of Genetic Alliance in the US recently sent out an email listing resources that may be of use to some families. These were compiled after she attended the Rare Diseases of Children Advancing Research and Care Conference.

1.) Disease InfoSearch

(<http://www.geneticalliance.org/diseaseinfosearch>) is an online search tool and database that is a compilation of information on genetic conditions as well as a listing of the disease-specific advocacy organisations that are part of Genetic Alliance's network. This resource is utilised daily by patients and healthcare professionals. To create a listing for your organisation, email Alyson Krokosky at akrokosky@geneticalliance.org

2.) Genetic and Rare Diseases Information Center (GARD)

(<http://rarediseases.info.nih.gov/GARD/Default.aspx?PageID=4>) serves as a resource to any member of the public – patient, health care provider, teacher, etc. - who has an unanswered question related to genetic conditions and rare diseases. Trained information specialists will provide individualised answers to questions not already answered and shared through their Q & As.

4.) Resource Repository (<http://www.resourcerepository.org/>) is an electronic collection of documents, links, audio, and video files, that relies on contributions from the community in topic areas such as newborn screening, family health history, genetic testing, reimbursement, research, and drug development.

5.) WikiAdvocacy (http://wikiadvocacy.org/index.php/Main_Page) is a community driven resource that shares lessons learned and practical information about starting and sustaining a support group. Add in your experience today!

FORUM

The CdC Support Group has launched a new forum on our website. So far we have had quite a few users registering and posts on a variety of subjects. It is still early days but we hope that families will join and participate.

A major benefit is the way that people can get in touch easily. So far we have already organised one local meeting via the forum when families got together online and arranged this. We also have a user map where you can add your location (general not specific!) so you can easily be contacted by nearby families. We hope this will help to answer the question that we often get asked – who is nearby? And help you to make contact easily and safely – as you control the information that is given out.

The Forum is not set up to replace our Clinical Advisory Group but is another way of asking questions and getting responses from a wide variety of families. We still have CAG if you need specific, professional advice, but we hope families will also help answer questions and provide their own experiences and advice. The forum is monitored on a regular basis but please be aware that we cannot control the responses given there and the opinions and advice given is not officially from the group.

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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