

Syndrome Support Group

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

Dear Supporter

It has given me great pleasure to be named as Chair of the Cri du Chat Syndrome Support Group at the very successful 2010 annual weekend. Many of you will be well used to Ray Clarke as Chair. I hope to follow in his footsteps in chairing a sound, well thought out and decisive committee that listens and acts on your welcome suggestions. I have been a member of the committee since 2006 and many changes have taken place in the last 4 years. The current committee has a wide range of skills and knowledge forming a sound base. I feel this ensures best practice in operating a charity of this nature. I would like to thank Pippa McIntyre, Tom Precious and Vicki McDonald-Noble for their welcome commitment to the group as new committee members. Ray has been key in driving the charity for the last 14 year but he has not left us, he is now the appointed Treasurer and has kindly agreed to be my guide in this new role. I would like to thank Ray for his past and continued input into the group and acknowledge we would not be where we are without him. We must also not take away anything from the founder of the charity Ann Wilson and especially Angie Stokes for her positive contribution to the survival of the group.

This year we have seen an unprecedented amount of charitable donations. The sheer pain people have gone through to raise money is humbling. Climbing hills, running marathons, etc, etc, have all helped towards providing funds for the Family Weekend, research and general running of the group. This has not gone unnoticed in these hard times when charities are screaming for money, however, we seem to be doing well out of it. Our membership is increasing and our interests are becoming broader in much of what we do as a charity. The Clinical Advisory Group (CAG) is one of these vehicles. I am an Occupational Therapist by trade and value the professionalism this group provides to our mission statement. This is an area in which we can boast the input of Doctors, Therapists, Osteopaths and researchers. We couldn't be in better hands.

But first I am Evie's dad and this complicated and difficult syndrome throws up all sorts of issues in our children's/adults' daily lives. If you have any queries, difficulties or merely want guidance I urge you to contact the CAG for support and advise.

Currently we are organising the 2011 Family Weekend. The committee have secured speakers on a variety of subjects that we feel would best serve our interests. However, your suggestions are paramount to the success of the weekend and we would welcome your input. If you have a particular issue affecting you, your child/adult or your family we would be very happy to hear from you. The group is here to try and meet your needs.

I look forward to the Family Weekend in 2011 and hope to meet many of you there. We have a common interest in providing the best possible lives for our children whether they are newly born or living as an adult and any suggestions are welcome and needed to keep this charity as good as it can be.

I am passionate as a parent that we use our group to best serve our loved ones. If you are unable to attend because of cost then we may be able to help financially. Please contact the office for further details.

With best wishes

Darren Ayres.

From the Administration office: Fundraising has been a major part of the work of the group at the moment with an explosion of wonderful supporters prepared to do weird and wonderful things for us (more details on page 3)

We are developing a selection of fundraising tools to help you with your events- from leaflets, to posters, to t-shirts and our brand new wrist bands. If you need anything just let us know or if you have any ideas please get in contact.

One thing we do want to do in 2011 is to encourage as many of you as possible to hold an event in your region. Whether it is a coffee morning in your house, or just a get together at the pub we can help. If you are interested please be aware there are funds available to help you as well as administrative support. We cannot give out addresses of other families in your area without permission but we can send them invitations on your behalf and ask them to get in touch.

So if you have ever felt that it is too far to come to a group event – then please get in touch to arrange your own!

Lucy and Andy

The enclosed minutes from this year's AGM include reference to this proposed new project being headed by researchers from Cambridge University. Unfortunately we have just heard that the initial grant application was declined and we can but hope that the University will have success with their further funding efforts.

Those of you with older children/adults will recall that we have previously tried to establish research into the aging process and it is again disappointing to learn that we are no further forward.

Route Map project

The Route Map project has been accepted by our committee in October, whereby £3,400 will be at our disposal to produce a route map of our CdC condition to show medical and social traits, to produce a medical and a consumer 'maps' of their wholes lives and times.

The grant is from the Genetic Alliance UK [nee Genetic interest group GIG] which is sponsored by the Government/NHS. They recognise that rare diseases are common when you put them all together.

We are one of ten varied groups to be chosen to do this. These 'Maps' could then be used as templates to 'pick and mix' many other 'similar' diseases so that each time a medic or social service or educational establishment comes across a sufferer, there will be guidance [if we provide it].

We will produce a CdC route map with your help and the services of our research committee and Clinical Advisory Group (CAG).

We will probably be asking you for help with a detailed questionnaire survey to give numerical backing for our map, as well as quality of service you experienced, [there is so little research of our disease] to back up our claims or advice. We want to emphasise the aging process to which we have very little evidence.

Exciting? Yes I think so. Sorry to put upon you all for a survey again. It will be in all your interest so be prepared, think back to all the medical interventions and educational/social hurdles you experienced and aspirations you want. The more info we get the more detailed Route Map and help we may get.

Caspar

Clinical Advisory Group FACTS

- **We now have 11 members of our Clinical Advisory Group including a Occupational Therapist, a Clinical Geneticist, an Osteopath and a Physiotherapist;**
- **In 2009 we answered 22 queries;**
- **In 2010 we have, so far, answered 36 queries;**
- **These queries have been from as far afield as Brazil, Australia, Canada and Mexico. Not forgetting the UK families we have helped;**
- **Queries have ranged from requiring details for High School Projects to advice on Gastro-Oesophageal Reflux Disorder (GORD) to providing copies of the CdC Growth chart (now on our website);**
- **Families can ask questions of our Clinical Advisory Group by contacting the administration office – either by email, telephone or by post;**
- **It takes, on average, 2 days for the Clinical Advisory Group to answer a query but we hope to reduce this to 24 hours in the near future;**

Fundraising activities

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

Heath McDonald-Noble, The 56th annual Three Peaks Race on 24th April raised £980

Emma Calvert and Keri O'Riordan, Sheffield half marathon on 25th April, raised £823.38

Gill Boorman, London marathon on 25th April, raised £138.22

Damian Haywood, Three Peaks Challenge on 19th June, raised £3518.08

Sheila Regan, Three Peaks Challenge on 19th June, raised £520.77

Ellie Hartley, Down Flow up Tow half marathon on July 25th, raised £1621.44

James Moon, Ironman UK Triathlon on 1st August, raised £243.59

I and C Spring donation £160

Lizzie Dicken donation £234

Leicester Co-op Ratae Players donation £147.56

F W and GH Brooks donation £20

Mrs J Purser donation £100

Ray and Mary Smith, Golden Wedding donation instead of presents £400

Eric Skeels 80th birthday donation rather than presents £310

Chloe Bates and Friends donation £950.20

North South Contracting donation £500

W F Brown donation £51

Barn Dance £407

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

We are also very grateful to new family, Charly and Roger Upjohn who kindly volunteered to help us buy our brand new wrist bands. As you know these are a popular way of raising awareness for groups.

If you would like a band for yourself please contact the office. They are a £1 each or, if you would like to sell them to your local community please let us know. We also have collection tins and t-shirts available.

THANKS AGAIN TO the Upjohn's at **Beacon Recruitment Services Ltd.**



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;

Pippa McIntyre, ran the Maidstone Big Fun Run on 10th October and is still receiving donations at <http://www.justgiving.com/Pippa-McIntyre> Please sponsor her.

Jamie Ross will be running in the Virgin London Marathon on the 17th April 2011, please sponsor him at <http://www.justgiving.com/Jamie-Ross>

Please support their most generous efforts NOW.

We are most appreciative of all these marvellous supporters and, on behalf of all our families, offer our most grateful thanks. Following their efforts we are now able, with some degree of financial confidence, to proceed with the planning for next year's "Family Weekend"

But more is needed, last June's event cost the Group around £9000!. 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!

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

[Read Jamie's blog](#)

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

If you do not fancy the London Marathon yourself share Jamie's pain from the comfort of your own armchair *

* Jamie has promised to keep the language clean for the most part.

CdC Syndrome Support Group Family Weekend

The date of our next Annual Family Weekend has been confirmed as the weekend of 3rd – 5th June 2011. We are very pleased that the Holiday Inn and the CCC in Milton Keynes have welcomed us back as guests as we were so happy with their facilities in 2010.

Confirmed speakers and workshops include: Dr Mohnish Suri, Charlotte Mawby, Independent Continence Advisor, Sam Hancock, Relationships and Sexuality Development Officer and Lance Tilley who will run a session and clinics on Personal Budgets. Other topics we hope to include are Scoliosis and practical Makaton sessions.

We are grateful to Darren Ayres who has again agreed to chair the very popular Clinical Advisory Workshop.

We will also be repeating the day trip for children to Whipsnade Zoo and are pleased that Allied Health Care will provide registered carers for us.

Registration will open in January 2011 and we will run an early bird discount until the end of March.

We hope we can build on the success of previous years and look forward to welcome you and your family next year.

EARLY BIRD RATE

Full registration:	£52.50 per adult
Day registration:	£10.50 per adult
Extra room (for older CdC, Siblings)	£52.50 per room
Extra room (carers, grandparents, extended family)	£84.00 per adult

Price for the weekend

AFTER EARLY BIRD DEADLINE (31st March 2011)

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 be placed on our notification list please contact office@criduchat.org.uk

If you are interested in speaking at our family weekend or have a topic you would like to be covered please contact us.



For more photographs from the 2010 Annual Family weekend please visit our Facebook page or our website.

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

Cri Du Chat Syndrome Support Group,
5 Latimer Drive, Steeple View, Laindon,
Essex, SS15 4AD
Email: office@criduchat.org.uk
Telephone: 0845 094 2725
www.criduchat.org.uk

Charity No: 1044942