



Cri du Chat Syndrome Support Group  
Annual General Meeting,  
**Holiday Inn Milton Keynes, 500 Saxon Gate West, Milton Keynes, MK9 2HQ**  
Saturday 13<sup>th</sup> June 2015, 2pm

MINUTES

1. Apologies

Apologies were received from Caspar Hull and James Smith.

2. Matters Arising

There were no matters arising.

3. Administrators Report

The Administrator reported that most of the business of the group will be reported on by the Treasurer and the Chair so her report will be brief.

It remains a great pleasure to work with the group especially in such changing times. The greatest challenge remains getting committee members.

4. Treasurer's Report

For the financial year ended 31<sup>st</sup> March 2015

Assets were

Current Account 1	£3,283
Membership account Northampton	£1,014
Membership account Edinburgh	£315

Bonus Saver Account

£32,194

TOTAL:

£36,806

It was reported that the Group, for the first time in many years, showed a deficit for the year of £9,311 with income at £29,875 against expenditure of £39,186. The major expenditure related to the ever increasing cost of the heavily subsidised annual Family Weekend which was £23,582 - £4,916 income = £18,666.

Copies of the accounts were made available for perusal and those present accepted the accounts without change.

The Treasurer said, as with all small charities we are reliant on our families and their friends and relatives to maintain a regular flow of income to fund research, provide support and to cover the ever increasing cost of providing supported means for families to meet with other CDC families. Hence this year, rather than financing a Conference/Family Weekend, we will be subsidising local area get-togethers to hopefully reduce total outgoings whilst hopefully reaching more families.

Every family can help fund raise, We are most grateful to those who run marathons and ride bikes but for those less active there are other ways to help the Group. New Group initiatives, CDC day, 5p for 5p and used printer ink collection, have been introduced and our new website will provide details of all our fundraising initiatives. It is hoped that **all families** will play their part in some small or large way in encouraging their network of family and friends to support us all.

## 5. Chairman's Report

### Activities undertaken for June 2014- June 2015 and Plans for June 2015-June 2016.

- The committee have met on three separate occasions since the last AGM.
- Our discussions have included the following subjects :- 1) 2015 family weekend, 2) CAG and route map, 3) Fund raising, 4) Administration up dates, 5) Treasurer's up dates, 6) CDC day 5 May 2015, 7) Website, 8) Newsletter, 9) Face book page, 10) Local group meetings, 11)

Committee members, 12) Equipment fund, 13) New Focus for the group following results of survey.

- **2015 Family weekend** . We decided that following the survey conducted at the 2014 family weekend and a review of the group's finances that we would not hold a family weekend in 2015. Instead we would fund local group meetings and plan to hold a family weekend in 2016.

In the past planning the family weekend has taken up a lot of our resources both in people time and financially. We struggled to identify speakers which is an annual difficulty.

**Plan.** Make funding available for local group meeting. Committee to organise a family weekend in 2016

- **Clinical Advisory Group (CAG) and route map.** The CAG is made up of the following members. Casper Hull (Chairman and Osteopath), Damian Haywood (Public Health Consultant), Lisa Bowden (Occupational Therapist), James Smith (IT Consultant).

The CAG aims to provide both clinical and anecdotal evidence and advice to enquiries we have received across a wide range of issues from parents, carers and professionals who deal with the variety of issues faced with those with a CDC diagnosis. Enquiries continue to be received via the web site, directly to Administrator and through the FB page. This function is available to both members of CDCSSG and non-members.

Face book is now the primary platform for enquiries but a few are still coming through the web site.

I would like to encourage those who have queries to contact the group when they face difficulties they require support on.

The route map is now complete and can be seen on the web site.

**Plan.**

CAG to continue its role in supporting members and non-members with enquires.

- **Fund raising.** Without the continued support from all our valuable fund raisers the family weekend and other activities we undertake would not be possible. We value every penny raised and if you require any ideas for fund raising please approach a committee member. Your feedback is essential when you have raised monies for the group to raise awareness and provided others with ideas. This can be done through the FB page or monthly newsletter. I would like to encourage articles to be sent to the administrator for publication. Fund raising is our only form of income and I would like to take this opportunity to thank all those who raised money or have plans to do so.

**Plan.** CDCSSG to continue to support fundraising activities through various means, ie web site, newsletter, FB page.

**CDC Day (UK) 5 May 2015**

- The first CDC day was launched in 2012. The day is devoted to fund raising and general awareness about CDC. The 5p collection kit is available from the web site. We will continue to grow the CDC day and any suggestions for how this may be done would be very welcome.

**Plan.** Discuss growth plans in coming committee meetings. Feedback from CDCSSG members is welcome.

### **Website**

- The web site is now fully operational and has been updated regularly.

**Plan.** Review and update of web site by the CDCSSG committee. Feedback from CDCSSG members is welcome.

### **Newsletter**

- The newsletter is no longer operational and has been replaced by a monthly newsletter via email. This is a valuable source of information and updates and has proved to be a success.

**Plan.** Sarah Brooks to continue to produce monthly newsletter. CDCSSG members to be encouraged to submit articles for the newsletter.

### **Facebook page**

- This has been a huge success and has become a valuable tool for CAG enquiries, updates on fund raising and general communication between members and non-members.

**Plan.** Administrator to monitor content of FB page. CAG to continue to support enquiries. FB page to be used for general communication between CDCSSG members and non-members.

### **Local Group meetings**

- The CDCSSG will provide a budget of up to £500.00 for local groups to meet in their geographical locations. Funds can be used for trips out, meetings at individual's homes, CDC events. Each application will be reviewed on an individual basis by the committee.

**Plan.** Committee to encourage local groups to meet through various means eg newsletter, web site and FB Page.

### **Committee Members**

- The CDCSSG committee are acutely aware that without a broad scope of members and new members the committee will not function. New ideas are essential in moving the group forward and without new members we struggle to keep the committee fresh. We meet up to 4 times a year and travel costs are met. All backgrounds, professions etc. are welcome.
- Both Ray Clarke, Treasurer and Darren Ayres, Chair will be stepping down at the 2016 family weekend.

**Plan.** To encourage CDCSSG members to consider a place on the committee and to facilitate this with paid transport and confidence in their role as a member.

All members are encouraged to approach the group if they are interested in becoming a member.

A new chair and treasurer to be identified prior to the 2016 family weekend.

Descriptions of the role have been made available for CDCSSG members to view.

### **Equipment fund**

- An equipment fund is now set up and we will be offering funds to support CDCSSG members if they are purchasing equipment to the value of £150.00 or part of the funds required for larger purchases.

**Plan.** Chair to advertise above to family weekend. Administrator to make details available on web site, FB page and newsletter.

## **6. Membership Model**

It was reported that in 2014 we carried out our questionnaire The Way Forward and, in particular, focused on what membership of the CdC meant to people.

The committee has discussed the results and feels that the group should no longer continue with the model of a membership organisation. We feel there is an important place for the group and that our help is still required but that it should take a different format.

Over the last few months we have made some significant changes to how we work and these include an increased focus on regional meetings, the move away from an annual family weekend and an increased focus on regular donations rather than membership.

It was felt that a lot of the things we do well – the support, our grants, our Facebook group and our email newsletter should not be restricted to people who have paid a membership and should be made available as widely as possible.

By moving away from having members we can still do all of these things but it will require us to ensure that we have regular donors and supporters. We will do this by through developing CdC Day (the fifth of May) and applying for grants throughout the year.

We hope that the current membership will be in agreement with this change (and even more so that they will leave their current standing orders in place as donations) but this does need the approval of the current members and an update to our Constitution.

This changed was agreed by those present at the AGM and the Administrator will communicate the changes.

## **7. Any Other Business**

There was no other business and the Chairman declared the meeting closed.