



Cri du Chat Syndrome Support Group
Annual General Meeting,
Chessington Safari Hotel, Leatherhead Road, Chessington, KT9 2NE
Friday 27th June 2014, 7pm.

Darren Ayres, Chairman of the Group, thanked all families for attending and staying for the AGM.

1. Apologies

Apologies were received by Ray Clarke, Treasurer.

2. Matters Arising

The minutes of the AGM held on 22nd June 2013 were accepted without amendment.

3. Administrators Report

The Administrator reported that membership is currently at 140 people – that is people who have paid. We have other registered people who do not pay but we can send out information to.

It was reported that a questionnaire, named The Way Forward Questionnaire, had been sent out to members and so far had received 20 responses. The administrator said that she hoped that everyone present would take the time to complete this as well.

We have started adding more and more information to the website with a regular post with either a family story, grant report or something of interest to families. We are always looking for contributors to this so please do get in touch if you want to participate in this.

4. Treasurer's Report for financial year ended 31st March 2014

It was reported that the group's Assets were

Current Account 1	4910
Membership account Northampton	995
Membership account Edinburgh	361
Bonus Saver Account	29851
1 year fixed deposit matured 7th April 2014	<u>10000</u>
	<u>46117</u>

The Group showed a surplus for the year of £1977 with income at £30891 against expenditure of £28914. Our major expenditure related to the cost of the heavily subsidised annual Family Weekend which was £20251- income £5566 = £14685 for 2013 event.

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 run the ever increasing cost of the Family Weekend.

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.

Copies of the draft accounts were available if members wished to view them and submit questions.

5. Chairman's Report

Activities undertaken for June 2013- June 2014 and Plans for June 2014-June 2015

- The committee have met on three separate occasions since the last family weekend.
- Our discussions have included the following subjects :- 1) Next year's conference, 2) CAG and route map, 3) Fund raising, 4) Administration up dates, 5) Treasurer's up dates, 6) CDC day 5 May 2012, 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.
- **2014 Conference** . We set up a working group to manage the organisation of the 2014 Family Weekend. Lucy Tetlow lead the sum committee, The Chair and Treasurer were included in the process plus all other committee members for support.

Planning the family weekend has taken up a lot of our resources both in people time and financially. The accounts for the cost of the family weekend will be available in due course. We struggled to identify speaker which is an annual difficulty.

Plan. Encourage all attendees of the family weekend to complete the survey so we can establish how our members would like the group to progress next year and coming years.

Make the survey available to all paying members of the group.

Collate the data and discuss ways forward at the next committee meeting.

- **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.

We also hope to produce a mobile phone app to support the route map.

Plan.

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

- **Fund raising.** We have managed to achieve charitable as per the treasurers report. However, 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 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.

- **Administrator report and Treasurers reports.**

We have already heard from both and the reports are available for any member to view.

Plan. The reports will be submitted to the Charities Commission along with the Chairs report

CDC Day (UK) 5 May 2014

- 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 by James Smith and Lucy Tetlow in the last week (18.06.2013)

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

Newsletter

- The newsletter is available to all CDCSSG members and is sent by post twice a year.

- **Plan.** Administrator to continue to produce newsletter. CDCSSG members to be encouraged to submit articles for the newsletter.
- Committee to discuss the future of the newsletter and if it is still appropriate in a multi media age

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 between £50 and £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.

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.

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 report above to family weekend. Administrator to make details available on web site, FB page and newsletter.

6. Any Other Business

There was no other business.