



CRI DU CHAT SYNDROME SUPPORT GROUP, COMMITTEE MEETING
SATURDAY 13th June, 11 AM
Holiday Inn Milton Keynes, 500 Saxon Gate West, Milton Keynes, MK9 2HQ

MINUTES

In attendance: Darren Ayres (Chair), Ray Clarke (Treasurer), Sarah Brooks, Jamie Sparkes, James Smith (JSm) (by Skype), Damian Haywood.

Lucy Tetlow (minutes), Kate Carpenter

1. Apologies for absence

Apologies were received from Caspar Hull.

2. Minutes of last meeting

These were accepted without amendment.

3. Matters arising

In advance of the decision about whether the group would still be based on the membership model the question of what the group actually does was raised. It was noted that the way we help families had changed beyond recognition and the group must constantly innovate to ensure that we help as many families as possible. It was noted that this discussion would be best had after the AGM and that an agenda item of forward planning would be added to the next meeting.

The question of whether the group could provide a more formal visiting and advice service for new families was considered. It was agreed that this could be implemented very simply immediately but this would be restricted to only providing information on how the group could help families and what the group did.

However we could offer a more formal and useful service to families subject to the correct training.

Action: DH to research a more formal approach including an analysis of training by next committee meeting

4. Treasurer's Report (RC)

The Treasurer Reported that the balances on the 1st June were:

Current Account	£7,253.74
Membership (old) Account	£15.00
Membership (new) Account	£65.00

Bonus Gold Savings £32,197.07

Total: **£39,530.81**

The Treasurer reported that the monthly income continues to be in excess of our expenditure and without the hitherto annual June/July major expense of Conference, we should continue to be in a healthy position come the end of this financial year.

At the meeting a cheque was passed over for £5,000 from Harry's Fund. The committee thanked the Trustees of Harry's Fund and a thank you certificate and letter will be sent.

Action: certificate to be sent to Harry's Fund

5. Administrator's Report

a) Membership

It was reported that, as we were waiting for the AGM to ratify the committee's decision to stop being a membership organization that the Administrator had not been pushing membership.

It was reported that there were approximately 100 people who have paid by Standing Order since March 2015 and they would have been sent a confirmation of payment message that did not specifically mention membership.

Action: LT, SB and JS to put together a letter to send out to all current members explaining the changes.

b) Gift Aid

It was reported that a gift Aid claim has been prepared and approximately £1000 of giftaidable transactions have been identified.

c) Telephone Line for the group

It was explained that we currently pay £5.94 per month for a telephone line which is hardly ever used.

It was agreed that this should be changed to a voice mail box which would send a message when a voicemail was left. This was to ensure that we received the message.

Action: RC and LT to change the telephone line

6. Research Committee, and CAG

a. Proposal to include CdC Research on the website

This agenda item was in reference to an email communication in May where it was suggested that we have a page on the website that links to relevant CdC research. There was some discussion about how best to manage this to ensure that we only link to papers that stand up to scrutiny. It was also suggested that it may be better if DH wrote a layman synopsis for the website of each paper in order to avoid any copyright issues.

Action: DH to speak to CH and present a plan to the next meeting

7. Grants and Regional Events

It was reported that there have been the following regional meetings had already taken place in 2015 and a planned West Country weekend would take place in October.

South Eastern	18.01.2015
South West	07.02.2015
Northern	04.05.2015
Northern Ireland	17.05.2015

The questions of having a large family weekend was also raised and it was agreed that these would now take place every other year. In the years where there is not a family weekend then a larger emphasis would be placed on 5th May (5p day) in order to provide a focus for fundraising in each year.

A subcommittee was established to investigate locations and formats for the 2016 family weekend and the weekend of 2nd May 2016 was suggested.

The subcommittee will be formed of LT, DA, SB and JS.

Action: LT to start initial search for a suitable venue and report back to the next committee meeting

8. Website and Newsletter Report

It was agreed that the question of ease of updating the website needed to be addressed. JSm reported that it should be easy to transfer to a different system but equally the current system could be improved.

Action: JSm to bring to the next meeting a proposal of how to improve the current editing system in order to decide the next steps.

9. AOB

The question of whether we could hold some meetings in London was discussed and it was

agreed that this would be fine in principle but a suitable location would need to be found.

Action: Suggestions for locations to be sent to the administrator

The question of new committee members was raised and Kate Carpenter showed interest in joining. It was agreed that she could attend the next meeting, should she wish, and take it from there.