



Cri du Chat Syndrome Support Group
Annual General Meeting,
Ramada, The Butts, Earlsdon, Coventry, CV1 3GG
Saturday 7th May 2016, 2pm

MINUTES

James Smith welcomed everyone to the AGM and explained that, as acting Chair, he was taking the meeting in Darren Ayres absence. James Smith explained that copies of the minutes of the last meeting, agenda and all reports were available on the Cri du Chat Syndrome Support Group website.

1. Apologies

Apologies were received from Darren Ayres, Kate Carpenter and Ray Clarke.

2. Minutes of last meeting and Matters Arising

There were no matters arising.

3. Chairs' Report

Committee

At the 2016 AGM, we are seeing a big change in the charity committee, with Darren Ayres our chair, and Ray Clarke our treasurer and previous chair both stepping down. We owe them both a great deal of thanks for all their hard work over the very many years they've been involved in running the charity. Sarah Brooks also stepped down from the committee in early 2016, and we would like to thank her for her efforts as well.

That means that both the chair and treasurer positions are up for election. James Smith has agreed to stand as chair, and Damian Haywood has agreed to stand as Treasurer. Nominations and voting are both open though, so anyone may stand if they wish to, in the vote to be held at the AGM.

We have created an official post of Fundraising Coordinator, which is now filled by Jamie Sparkes. His role is to help us encourage and support our amazing fundraisers in any way we can.

Unfortunately, losing three members of the committee leaves us with only four, so we need new volunteers to get involved and help out. Please let a committee member know if you wish to volunteer.

Meetings

The committee has met 3 times in person since the AGM, in Milton Keynes and London, and a number of times online. We hope to use more online meetings in future.

Minutes of all these meetings will be made available on the website in due course.

Regional Events

We did not hold a national family weekend in 2015, instead providing grants for regional events instead, with the intention of reaching more families.

During 2015, 4 regional events were held:

- South East in January
- South West in February
- Northern England in May
- Northern Ireland / Eire in May
- South West in October

We also held an event in Scotland in February 2016. The committee welcome any feedback from group members about the success of this approach.

Membership

At the 2015 AGM, the committee agreed that we would change from a membership model to a donation-based model instead. This was done because our membership offering was unclear, given the support people receive via Facebook, and offering charged membership did not seem like good value for money.

We intended to remove membership completely, but have since reconsidered due to technicalities of our charity status. Membership will instead continue to exist, but will be free and open to all. Money will still be raised purely through donations instead of membership.

Existing membership standing orders will be converted to regular donations instead of a paid membership. Please contact Lucy Santos with any questions.

Map

We have introduced a map of members on the website, showing roughly where our families and others are located. We will build on this to provide a way to find and get in touch with nearby families more easily.

Fundraising

We have been lucky to have the support of many donors this year, raising almost £12000. We are especially grateful to Lankyats, Harry's Fund, and the Lloyd's Charities Trust for major donations in the last year.

On top of that, individual fundraisers have raised over £7500 through sponsored events using JustGiving.

It costs us over £10000 a year to run the charity, and around £20000 to run a family weekend, so you can see that those donations are absolutely essential. We are hugely grateful to everyone who raises money for us; this would not be possible without you.

If you have ideas for fundraising, please talk to Jamie Sparkes so that we can support you and raise as much as possible!

Plans for 2016

Committee plans for 2016 include:

- Encouraging and supporting more regional events through 2016 and 2017 to get more people involved and able to access them
- Encourage more uptake of our equipment grants
- Support research into issues affecting people with CdCS; we are particularly looking at supporting a research project on scoliosis, which Caspar Hull is already working on
- Provide better support for new families affected by CdCS, either in person, online or by phone
- Continue to review how we best support our families
- Work on better ways to raise awareness of CdCS
- Scale up our fundraising to support more events and more help for families

If you would like to join the committee and help make these happen, please get in touch.

4. Treasurer's Report

Assets were

Current Account 1	4799
Membership account Northampton	959
Membership account Edinburgh	315
Bonus Saver Account	<u>37213</u>

43283

The Group showed a surplus for the year of £6477 with income at £21220 and expenditure at £14743. These figures reflect greatly against the previous year's deficit of £9311 which included The Family Weekend cost of £23532 - £4916 = £18616.

Because of the ever escalating cost of the weekend the committee took the decision to hold future Family Weekends bi-annually and to promote and help finance Local Area Family gatherings. Thus in this financial year we didn't hold a weekend event and the cost of the local grants amounted to £564 and it is hoped that more families will wish to help organise events in the future.

Copies of the accounts are available here now for perusal, this AGM should accept them so that they can be forwarded to the independent auditor before being made available to the Charity Commission

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. 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 website provides 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.

Finally, and on a personal basis, this is my last report as Treasurer and committee member. It is very unfortunate that I could not be here at the weekend, we had booked a holiday before the date was announced. I hope that all families will continue to support the committee and Group. Over my 22 years of involvement the Group has evolved to a very important place for everyone dealing with the difficult Cri du chat Syndrome.

5. Election of Officers

NAME	POSITION	PROPOSER	SECONDER
James Smith	Chair	Amanda Smith	Angie Stokes
Damian Haywood	Treasurer	James Smith	Caspar Hull
Caspar Hull	Committee Member	James Smith	Damian Haywood
Jamie Sparkes	Committee Member	Amanda Smith	Agnes Noble
Kate Carpenter	Committee Member	Damian Haywood	James Smith
Angie Stokes	Committee Member	Kate Carpenter	Caspar Hull

As per the Articles of Association the following members of committee and officers were proposed and seconded.

James Smith explained that if anyone else was interested in joining the committee it was possible to attend a meeting as an observer to see how the committee was managed.

It was also noted that the group can use the skills of people in other ways, not just as committee members, and there were different ways to show your support – from asking your company to choose the group as their charity of the year, volunteer to be on our Clinical Advisory Committee or help us provide fundraising materials.

6. Any Other Business

It was reported that the group has applied for spaces on the 2017 London Marathon and were interested in exploring other fundraising opportunities.

Damian Haywood reported that the group had signed up to support the Changing Places campaign. We would consider officially supporting other relevant campaigns and if there were any suggestions please contact the Administrator.