

RTS SUPPORT GROUP COMMITTEE MEETING
Saturday 7th November 2016

PRESENT:

Siobhan Lund	SL
Dawn Elliker	DE
Max Aldred	MA
Barbara Baron	BB
John Peat	JP
Mags Ruck	MR
Becky Lawlor	BL

		ACTION/ INITIALS
1.	<p>APOLOGIES: Liz Halstead (LH)</p> <p>Siobhan opened the meeting by welcoming both Becky and Liz to the Committee.</p>	
2.	<p>MINUTES OF LAST MEETING:</p> <p>Minutes from the 2nd July 2016 were agreed to be a true record.</p> <p>Minutes from the 4th October 2016 were also agreed to be a true record.</p>	
3.	<p>MATTERS ARISING:</p> <p>Item 3 – Matters Arising – MA reported that she is working through updating the website with both current policies and minutes of previous meetings.</p> <p>Item 4 –Treasurers Report - The letter re our financial situation has not been done, this will be discussed under Treasurers Report at this meeting.</p> <p>Item 10 – Future of RTS Support Group Re Emails SL reported that she had contacted Mags re the emails, but did not have access to them, SL will contact Andrea who looked after the email database prior to leaving the committee</p>	<p>MA</p> <p>SL</p> <p>SL</p>
4.	<p>TREASURER’S REPORT:</p> <p>BB had circulated three reports dated from the 01/01/16 to 02/11/16 prior to the meeting re Just Giving / My Donate and Virgin Giving.</p> <p>Money raised so far this year from each online platform is as follows;</p> <p>Just Giving - £2694.56 My Donate - £770.00 Virgin Giving - £1459.82</p> <p>The committee found these reports very useful and informative.</p> <p>DE had circulated the Treasurer’s Report prior to the meeting, to date the bank balances are;</p> <p>CAF Cash Account - £5061.88 CAF Gold Account - £11,049.31</p>	

	<p>DE reported that the Friends account has now been closed, and the Friends fund is now in the current account.</p> <p>A discussion took place about setting an amount for our reserves, because following the International Conference our reserves had been used, DE explained that if we set a reserve of £5000 it would cover running costs for the next 18 months if needed. It was unanimously agreed that we set the reserves at £5000, DE will invest this amount in a Savings Account.</p> <p>DE reported that we were waiting for a £1000 grant from Genes for Genes, which should be in our bank shortly.</p> <p>Also the Sportsman Dinner monies is not all in the bank yet, DE has not speculated how much is coming in. JP reported that the amount coming to the group should match last year or even surpass it.</p> <p>DE advised that we should not run the accounts below £3000. This was agreed.</p> <p>Charity Checkout – A discussion took place and it was decided that we have three online platforms at the moment that people use, and we unanimously agreed that we did not want proceed with Charity Checkout at this time. DE will inform Charity Checkout of our decision.</p> <p>The letter mentioned in Matters Arising was discussed and it was agreed that a letter should be sent to the members explaining the financial situation of the group and the cost of producing newsletters etc. and the difficulties we are encountering raising money for the group. We have made the decision to post the newsletter online instead of sending out by post as at this moment in time we cannot afford to produce and post out the newsletter in the traditional way. SL & DE will write the letter and BB will post out to all members as we do not have emails for everyone and some of the emails are not current.</p> <p>MR will print the labels and send to BB.</p> <p>BL suggested using the Facebook to highlight the importance of keeping email addresses up to date. This would target some of the families but not all, a suggestion was put forward to also add it to the letter.</p>	<p>DE</p> <p>DE/JP</p> <p>DE</p> <p>SL/DE/BB</p> <p>MR</p> <p>BL</p>
5.	<p>AGM/MAY EVENT:</p> <p>SL asked MA how much does a day event cost against an overnight event. The cost of the a day event is approx £3,500 and a overnight event is approx £10,000.</p> <p>A discussion took place and SL suggested we do a day event combined with the AGM in May, this was unanimously agreed as we do not have the funds to do an overnight event.</p> <p>We have to take into consideration a venue where we will get most families attending as we need to have a quorum; the committee would be able to attend to run the event; a nearby Premier Inn /Travel Lodge near venue;</p>	

	<p>A number of areas were mentioned; Daventry/Luton/Oxford</p> <p>MA to get the costing for some venues.</p> <p>MA suggested mentioning in the letter that we are holding a day event first maybe in the Midlands, and then hopefully in the future an overnight event elsewhere.</p> <p>BL suggested we use Social Media for a poll to ask for feedback on whether they would travel to venues in specific areas ie use 3 choices. This was agreed it was worth a try.</p> <p>MA reported that we would also need to think of a couple of interesting speakers, perhaps reusing speakers we have had before as we have a number of younger families with young children.</p> <p>MR suggested we ask LH for any contacts she may have for speakers. MA to contact LH.</p>	<p>MA</p> <p>BL</p> <p>MA</p>
6.	<p>SPORTSMAN DINNER</p> <p>JP reported that he was able to attend the Sportsman Dinner and it was a very good evening and should be very profitable, the speakers gave their time free and final profits are not yet all in. It is definitely worth repeating next year.</p> <p>The committee asked JP to pass on our thanks to Dave who did the majority of organising of this event for a job well done and has offered his help with financial organisation for future events.</p>	<p>JP</p>
7.	<p>FUNDRAISING</p> <p>JP reported that the date for the Golf Day next year as yet to be confirmed. There will be some changes and JP is in negotiations at the moment, but hopefully it will a very successful event. JP will keep us updated with any progress.</p> <p>BL reported that the annual event Charlie's Trophy will be held on the 4th August 2017, and this should raise some more funds for the group.</p> <p>BL suggested pushing fundraising on social media. This was agreed to be a good idea.</p> <p>We have supplied running vests if people are taking part in a fundraising event, this helps to promote the group.</p>	<p>JP</p> <p>BL</p>
8.	<p>SOCIAL MEDIA/WEBSITE</p> <p>It was reported that it is good value for money paying the monthly fee for the website as we have a more secure website and also 1 hr of training each month. Also they we help upload items onto the website.</p> <p>BL explained the difference between twitter and Facebook and there uses. Twitter is quite basic but is good for contacting companies for prizes for fundraising events. Facebook is more personal it is a good platform to pass on information to families, promote current events ie Carers Rights Day, Trustees Week. BL is keeping social media current and giving feedback.</p>	<p>BL</p>

<p>9.</p>	<p>AOB:</p> <p>Books: BB had circulated an email from Professor Hennekam re a book that has been written by a mother of a RTS child, he has written a foreword for the book, and had been asked if he could ask the support groups he was aware of and to ask if we could promote the book.</p> <p>It was also mentioned that another family had written a book, and it was felt we should promote both books on the website. RL to contact the writer of the book and get the details.</p> <p>BB to reply to Prof Hennekam.</p> <p>Birmingham Research: An email had been distributed from Jane Waite re some research and it was agreed that we would send out the information if Jane would write a covering letter. BB to email Jane.</p> <p>SL has been contacted by Lauren from University of Birmingham, she explained that saliva samples would be collected as part of their latest research project to try to link behaviour with genetic diagnosis. The team would be unable to report on genetic results to individual families. SL has asked if the saliva sample could be replaced by previously established genetic diagnosis by Professor Hennekam. Lauren agreed this could be done with the necessary consent.</p> <p>Also there is a new clinical psychology trainee starting and may have some capacity to do some specific work around behaviour, anxiety. A discussion took place and it was agreed that BB to email Jane and ask what it will involve, how many families can they take on, and what criteria would be needed to take part.</p> <p>SL reported that she had twice contacted the research team for a steer on what content would be needed to optimise support for their application but had no response.</p>	<p>MA/BL</p> <p>BB</p> <p>BB</p> <p>BB</p>
<p>10.</p>	<p>DATE OF NEXT MEETING:</p> <p>Face to Face Meeting Saturday 11th or 18th March 2017</p> <p>Date and Venue to be confirmed by email</p>	