

**MINUTES OF MEETING OF THE BOARD OF RUBINSTEIN TAYBI
SYNDROME SUPPORT GROUP
Held on 18th April 2016,
Skype Meeting**

Attendees:

Siobhan Lund (Chair)	<i>SL</i>	Director
Dawn Elliker	<i>DE</i>	Director
Max Aldred	<i>MA</i>	Director
Mags Ruck	<i>MR</i>	Director
Andrea Simpson	<i>AS</i>	Director
John Peat	<i>JP</i>	Director
Barbara Baron	<i>BB</i>	Director
Charlotte Baron	<i>CB</i>	Director

1. Welcome & Apologies

SL welcomed everybody to the meeting. There was no apologies

2. Minutes of the last Meeting

The minutes of the last meeting 19/01/16 were agreed to be a true record and approved.

3. Matters Arising

There were no matters arising from the minutes.

4. Treasurers Report

DE presented the end of year accounts, which the board unanimously agreed to be a true and correct record. SL will sign the accounts in readiness for the AGM.

DE then went on to explain the current financial situation, to date we have £52,535 in the current account this includes our reserves. We were successful obtaining a Lottery Fund Grant of £10,000 toward the upcoming conference, and a small grant from Baily Thomas of £500 which is earmarked for some research being carried out by the Psychology Team. As yet we have not heard whether we have been successful obtaining a grant from Genes for Jeans. We are still hopeful we will be successful.

However that leaves us with a shortfall between the cost of the conference and available funds. The exact amount is still unknown but is likely to be in the region of £10,000.

The budget for the conference was agreed at the beginning of this process but we have not had the grants come through as anticipated, also there has been a lack of support for fund raising over the last year.

We all agreed that it is not an option to cancel the conference. DE has spoken to our accountant and asked the best way to bridge the shortfall. We are not eligible to take out a loan. However 3 Directors, namely SL, DE and MA have offered to fund the shortfall equally, with the agreement that the Support Group will pay back the amount as funds become available after the conference, and to be paid back ASAP.

SL asked whether we were all in agreement for the 3 Directors to loan the money interest free and for it to be paid back equally as soon as funds allow after the conference. This was unanimously agreed and that the situation will be reviewed quarterly. Loan agreements had been prepared for use if required. At the first meeting after the conference we need to discuss the newsletter/bulletin and to look again at our financial situation.

5. International Conference

MA had produced a report re the conference and we went through and discussed each heading in turn.

Attendees – We had all received the latest attendee list. We are in the process of booking a couple of families at full conference cost. MR has prepared the draft attendee list and has sorted out the printing of the badges and lanyards etc.

Speakers – MA had produced a schedule for the timings of the seminars, and the names of the professionals presenting. We need to contact professionals for biographies and also copies of their presentation electronically so we can upload them on to a thumb drive for the families to take away on the day.

Families will book on seminars at registration. MR will liaise with MA re registration packs.

BB will email the professionals and liaise with Max and Siobhan.

There will be 1:1 sessions with Raoul, Adam, Chris and Jane over the weekend and BB has prepared a form for families to complete to book these sessions.

A discussion took place re Sunday Morning it was decided that there will be seminars at 9.30-10.00am and then there will be an open discussion for an hour in the main room.

Followed by refreshments and check out from the hotel. There will then be the closing of the conference followed by lunch.

Parking - Parking at the hotel is £9 per night, if the car park becomes full the hotel uses the NEC Car Park. MA will need to know if anyone is a Blue Badge Holder and hopefully places can be reserved for these vehicles on the hotel car park.

Meals – MA circulated some menus; we need to decide two weeks before which ones we want, so MA asked us to look at the menus over the next couple of weeks. There will be cash bars in the rooms where we have our meal. The RTS Support Group will not be liable for any costs whatsoever with regard to drinks.

Creche – This is in the process of being sorted, MA will keep us updated.

AGM –The AGM will be held at 5pm on 20th May in the Westminster Suite, Hilton Metropole Hotel, NEC, Birmingham.

Saturday Evening Entertainment - A suggestion was put forward to have the usual RTS has Talent, and then a disco (not too loud), allowing families to socialise.

6. Merchandising

CB had circulated quotes from a few companies for USB, Pens, Notepads and Tee Shirts. A discussion took place and it was decided to order the USB, Pens and Notepads, but due to financial constraints it was decided not to buy the Tee Shirts. However CB will price getting the committee Tee Shirts so we will be easily recognisable on the weekend so they know who to go to for any queries.

BB to bring the key rings, merchandising we already have and the donated TV.

7. Adoption of Policies

The following policies were circulated before the meeting and all were unanimously adopted.

- Complaints Policy
- Conflict of Interest Policy
- Investment Policy
- Risk Policy
- Volunteer Policy

These policies will be posted on the Trustee section of the website.

8. AGM

The AGM will take place at 5pm on Friday 20th May in the Westminster Suite.

AS to draft Agenda and collate all the paperwork this will then be circulated by email. BB will post out to families who do not have email address.

Directors retiring by rotation this year are; JP/MR/DE.

AS will resign at the end of the AGM. The committee thanked her for all her valuable support and hard works over the years.

9. AOB

A letter of resignation has been received from MR stating her intention to resign at the AGM in 2017. SL thanked her for giving 12 months notice this allows us to find someone to take over. SL to forward letters of resignation to Barbara and Dawn for the record.

JP reported that the fund raising night Q&A session with Leeds Rhino's players was progressing well, he doesn't know how much profit this will make as this is a new venture, but it will definitely make a profit. He will need some raffle prizes. Leeds Rhino's are advertising this on their website and hopefully will be advertised in the local paper. The committee thanked JP for all his hard work and wished him good luck with the night.

AS said even though she will not be a Director she is happy to upload items to the website until we appoint someone to maintain the website. MA volunteered to do this and AS will train her up.

Also we need a second person to receive the emails for the group DE volunteered to do this. AS to notify Karl Craig-West.

10. Date and Time of Next Meeting

The next meeting will be held Saturday 2nd July 10am at Rawdon Golf and Tennis Club, Leeds. JP to book the venue.