

**MINUTES OF MEETING OF THE BOARD OF RUBINSTEIN TAYBI  
SYNDROME SUPPORT GROUP  
Held on 19<sup>th</sup> January 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>JP</i>	Director
Andrea Simpson	<i>AS</i>	Director
Barbara Baron	<i>BB</i>	Director
Charlotte Baron	<i>CB</i>	Director

**1. Welcome & Apologies**

SL welcomed everybody to the meeting and apologies were given from JP.

**2. Minutes of the last Meeting**

The minutes of the last meeting 10/10/15 were agreed to be a true record and approved.

**3. Matters Arising**

There were no matters arising from the minutes.

**4. Treasurers Report**

DE reported that all HSBC accounts are now closed, and the CAF Accounts are all open including the online service.

Year end accounts are with the Accountants.

As of 12/01/16 our total funds are £44184.30.

DE also presented information re Just Giving & Virgin Giving with a comparison of the charges and asked the question should we use one or both of these. It was decided to defer to the first meeting after the International Conference.

BB reported that Just Giving had raised £2,261.52 in 2015, which was significantly down from 2014. We have received donations via Virgin Giving totalling £120.79, since December 2014 when it was first used.

## 5. Fundraising/Grants

MA reported that she had received some information regarding a Fire Walk which is being organised by the Rotary Club of Newton Abbot, they organise the event but people can take part to fundraise for their chosen charity, after a discussion it was decided to publicise it on the website/facebook. MA will forward to AS.

JP had submitted a fundraising report, explaining the Sportsman Dinner in October was once again a great success raising approx £4800, there may be some money to come in yet.

JP reported that a new fundraising event will take place on Friday May 13<sup>th</sup> this will be a Legends Night Q&A with a hot supper. Cost of tickets £20.

JP reported that this year's Golf day will be held on 22<sup>nd</sup> July 2016. Due to the hilly nature of the course, JP is hoping to get some golf buggies to use for the day.

Suggestions for future fundraising events; Day at the Races, Summer Ball.

Thanks to JP for all his hard work and funds raised.

**Grants** – MA reported that we have applied for two grants.

SL & JP presented to the committee of Genes for Jeans and we should hear about this grant by February.

MA reported that we had also applied for a Lottery grant we should hear something in 6-8 weeks.

Jane Waite (psychology team) suggested us applying for a grant from a small charitable fund Baily Thomas we have applied for this for some research to be carried out at the International Conference.

As soon as anyone hears any news they will let the committee know.

AS suggested Children in Need, but MA has looked into this and we are not eligible.

## **6. International Conference May 2016**

MA reported on the organisation of the International Conference. A number of families are coming from abroad; there are a number of families still to register from the UK. They have expressed their interest on facebook.

MA to follow up on enquiries from families who have expressed an interest, to encourage them to register for the event.

A number of people have commented on how easy it is to book through Guaranteed Events.

MA & AS have visited the Hilton and the venue is very good it has everything we need, lots of facilities.

A discussion took place about workshops, BB to contact Queen Elizabeth's Teaching Hospital to contact any therapists e.g. OT/Physio/SALT who would be willing to do a presentation.

MA reported that there will be a closed door crèche, play area as usual and a siblings area.

CB reported she had spoken to a Sibs group and was having a further conversation in the next day or two, they can provide workshops at a cost approx £400. CB felt that it is important that the emphasis should be on fun. CB to report back to the committee.

MA reported that the final programme would be available once we have secured all the speakers, there would be a pack going out to all families who have registered.

## **7. Merchandising**

CB asked what merchandising she needed to price the event. She reported that we have enough keyrings. After some discussion it was decided to price for printed tee shirts, memory sticks, and note books.

CB to look into this and report back to the committee.

MA reported that DE and herself were looking for exhibitors to display at the conference.

## **8. Bulletin**

It was decided that a bulletin should go out at the beginning of February advertising the conference/AGM details/Christmas family day/Future fundraising events.

## **9. Website/Social Media/Emails**

AS to upload information re JP fundraising days on to social media and website.

Conference information to be sent out to any new families.

## **10. Policies**

Deferred to next meeting. BB to put on as agenda item "Policies for Charity Commission".

DE to circulate a list of policies we need updating. BB to list on next agenda.

## **11. Future of RTS Support Group**

Deferred to next meeting. BB to add as agenda item.

## **12. Date and Time of AGM Meeting**

It was decided to hold this at the end of June/July. BB to contact Marjorie and see if the church would be available on any Saturday.

## **13. AOB**

After discussion it was decided not to have an Annual Draw this year.

## **14. Date and Time of Next Meeting**

MA will do a doodle poll to sort the meeting date, but it was decided to hold it in April.