

## Multi Organ Transplant Support: Recorded minutes from AGM on the 15<sup>th</sup> October 2015.

**Venue:** The Berkshire Arms, Reading

**Time:** 10am – 4pm

**Present:** Emma Abdullah, Samantha Williams, Jenny Pinkstone, Alex Geiger, Jan Barnett, Rachael Green.

**Apologies:** Terry Faber, Cat Hamilton, Bev Size, Molly Smith, Gary Palmer, Kim Hughes, Grainne Skinner.

### Overview

The beginning of our AGM began with Emma announcing all of our achievements we have made as a charity since our last meeting in March of 2014. Please find attached a copy of the overview to this, which was handed out in the meeting.

### Supporting Children

This was the first point to be discussed on the agenda, as there has been much contact with family members of children who need support. BCH and Oxford Transplant Hospital have also stated that we could be a major role in helping and supporting children, who would be transitioning over to Addenbrookes by being a friendly face who have been there through their transplant. We put to the vote whether MOTS could help provide this support to under 16's who are having/or have had a multi-visceral or small bowel transplant. It was decided by a majority vote and all members approved this idea. We are now going to adapt our processes and constitution for this to become active so we, as a charity are abiding by the Charity Commissions Regulations. We will be offering our support to paediatrics who will be transitioning into adult care and also a Helping Hand Grant of up-to £120 to each under 16's member and this can be applied for either pre or post-transplant.

### Charity Structure

We discussed ways of improving the structure and number of members on the committee. Emma announced that there were 3 individuals who were happy to come on-board with us: Molly Smith, Gary Palmer and Kim Hughes. Each person will benefit our committee by bringing their own personal experiences as they have all experienced the transplant process and procedures. All members present were happy for new committee members to join, so welcome aboard Guys 😊

Emma also discussed on how the structure of the committee could be improved. As we have decided to give our support to transplant children and their families, we could divide the committee into sections and hopefully members would be able to commit a few hours per week to maintaining this structure.

- Mini Mots (name to be determined) – this section could have committee members who have either been treated as a child patient or members of the family who have gone or going through the experience. Our new member Kim Hughes would be ideal for this section.

- Transition – Members ideal for this section would be Molly Smith and Cat Hamilton as they have both experienced the transition from BCH to Addenbrookes Hospital.
- Adults – Emma Abdullah, Jan Barnett, and Alex Geiger have offered to be on this part of the structure as they have all been through the transplant procedure.

Other committee members would be really suitable for each section and all members have the option to help out with either of the different structures of MOTS. If any member of MOTS would like to do this, they can contact Emma or Sam who would be able to help with this.

### Charity Shop

Our new member Gary Palmer has suggested the idea of a charity shop in Brighton which would be run by himself and his family. The shop would be able to sell all of MOTS merchandise such as our T-shirts, Pens and Bands. Members present did like this idea so it is to be looked into to see whether MOTS is in the correct financial place to be able to run the shop – Overheads and How much Rental for premises would be for our charity need to be researched. We will need to discuss the prices of our merchandise to be sold in the shop if we can obtain a lease.

### Website

It was discussed on how we could improve the website and the amount of views it receives. Our media consultant, Alex, has confirmed he is happy to continue with the updates on the website. We also discussed on whether or not we needed to change our database and host so we can implement new sections such as a live chat forum and a hint and tips section. We are going to be looking into contacting individuals who will be able to do this, thanks to Rachael for the information. We need to consider the cost of a new host, our budget, data protection regulations, administration and who would need access to this information. A memorial page and a MOTS shop will also be added to our website and we will keep you updated with all changes when they take place.

### Support

We discussed how our members of MOTS could help us enhance our reputation. All present at the AGM have stated that they could help by promoting MOTS in their local area and we also thought it would be an idea if we could ask our members of MOTS and our followers on Facebook to like and share our Facebook charity page on the personal profiles as this could raise more awareness for us. Emma has also asked if anyone would be able to help give more support to multi-visceral patients by talking and supplying information. Could anyone commit any time to this??

### Fundraising

At the moment, we currently have £5.5k in our charity account and our aim would be for this to be increased to £10k by our next AGM meeting which will take place in March 2015. It was discussed that this should be divided between committee members to try to reach this target. Emma, Sam and Jenny have agreed to take on the challenge of raising £2.5k and Alex, Rachael, and Jan will take on the challenge of getting the target of £2k by the next AGM. We would love it if our other committee members can help us with reaching this target. 😊 Ideas to fundraise given were bag-packing in our local supermarkets such as Asda or Tesco. We will have Public Liability Insurance in place soon, as this is being researched at the present and Emma and Sam are comparing companies who could help us with this. We are looking to have an agreement for one year and this will protect us for these type of events.

We have also decided to create an annual meeting where we can release purple balloons with personal messages attached in memory of members of MOTS who have passed away and of our special angels: Our organ donors. A date has not yet been confirmed but will be discussed at the next AGM meeting so we can implement this event next year.

Do any of our members know of anyone who could help us with fundraising or have any ideas for us to raise funds? Any input from you guys is much appreciated and will help us massively.

### Budget, Expenses and Grants

Please find listed below the budgets that were discussed and the amounts decided for the present time.

Budget for website: £120 for the 1<sup>st</sup> year. We do have a payment of £75 each year from the company, FreeSpirit and this will be allocated towards our costing of running the website each year.

Budget for Grants: £120 for a Helping Hand Grant which is to be capped for all members.

Budget for Accommodation Grant: This has been increased up-to £178 which could provide 7 full days for a patient or their family members.

Budget for Now You are Home Pack: £10 per pack. These packs should be advised that they are available and are offered to our members when they are due to go home and they should be given one time only.

Budget for Bereavement Pack: £20 per pack which could include a Star which has been bought for the family and named after their loved one.

The Hospital packs and supplies will be distributed and supplied evenly to each hospital we are helping.

Rachael now has a mission which is to try and contact companies who could help either to sponsor or donate to us on a regular basis. One company that was discussed to contact was Snack-a-Jacks as members have stated that these snacks helped restore their appetite after surgery.

Jan has also put forward the idea of raising the prices of some of our merchandise, such as the T-Shirts and Hoodies that are available to buy. Due to the quality of our merchandise, could and

should we increase the prices of these items? Prices will be listed shortly on our new shop page on our updated and improved website 😊

The purchase of a Drink's Machine was mentioned. Emma has been in touch with a company who could supply us with this machine at a low rental price which could be set up in Addenbrookes day room, where we have our DVD players, DVDs and books already stored. What needs to be considered is whether or not our profits from purchases of drinks would cover the yearly cost of the rental of machine and the purchase of the drink sachets needed. We would also need to gain permission from the ward manager of G5 and we would have to arrange a day where committee members could meet and rearrange the dayroom so this can be added without causing clutter. Dates will be announced, when we have obtained permission to move the room around. Could any of our members offer to help us with this?

### Expansion of MOTS.

This topic was discussed in length as there are many options that have been offered to us. We have already had meetings with the Transplant teams in BCH and Oxford and they are very excited to be working with us, Emma and Sam just need to clarify where our support will be needed within their hospitals. We also have a future meeting with King's College Transplant Team too and hopefully we will be working alongside each hospital in the very near future. We will keep you updated with this 😊 By working alongside these hospitals we are hoping to be able to form alliances and contacts with other charities such as Ronald McDonald house and HMBTT so care and support can be provided around the U.K. We have already established communications with Williams Wishes and we will hopefully be able to help each other in the near future.

It was also discussed if there was a possibility that we as a charity could host quarterly stalls in each hospital we are in touch with. If this could be done, MOTS could visit and meet the medical teams and patients within these hospitals and offer our support. This would also be a way that members would be able to visit each hospital and see the help we provide. Budgets and arrangements are to be researched and confirmed at a later date.

MOTS would also like to be able to provide accommodation to patients or their family members by being able to rent or lease a room to them. We will be contacting some of the local guesthouses near the hospital to see if they could help us make this a reality. If we can provide this room, we would be able to make sure that there were provisions such as toiletries, nightwear and blankets available and we could decorate the room and make it feel more homely than most places where patients usually have to stay.

### Our Aims to have met by next AGM in March 2015.

- 10k in the charity account
- An increase in all of our grants
- Provide more support to MVT or SBT children and adults
- Each hospital to have the same materials supplied at the same cost
- Ideas for a MOTS Members Event 2015
- Ideas for a MOTS members calendar
- Up-to date order form to be created and available electronically as well as in paper form

- Can we find a regular sponsor?
- Coffee mornings to be arranged all over the UK for our members
- Could we find a medical team to have on our committee?