

## Minutes from the AGM Meeting of M.O.T.S

Date: 23<sup>rd</sup> February 2016

Venue: The Four Horseshoes in Basingstoke, England.

Time: 11am – 4pm

Present: Emma Abdullah, Samantha Williams, Jenny Pinkstone, Rachael Green, Jan Barnett, Helen Walters, Catriona Hamilton (via Skype)

Apologies: Gary Palmer, Terry Faber, Grainne Skinner.

Minute Recorder: Samantha Williams

The above AGM meeting for the charity, M.O.T.S took place on the above date and was attended by both trustees and committee members. Introductions were made and apologies were given for those unable to attend this meeting.

### Introduction to new committee members

Emma introduced the two new committee members who have volunteered their time to help with M.O.T.S. We would like to introduce Gary Palmer and Helen Walters to the team. Emma also advised the members that the position of secretary was available and that Amanda Watts was interested in taking over this role. Amanda short introduction was introduced to the members and due to an unanimous vote, she has now been selected to take over this role. A constitution, data protection act form and committee member declaration will be sent over to Amanda so she can begin her work with us as soon as possible.

Unfortunately, this year we have had to say goodbye to some of our committee members who have resigned due to their own personal reasons. Bev Size, Molly Smith have left our committee and we wish them well for the future. We have also had to say goodbye to one of our Trustees, Rachael Green. Rachael was our secretary also and due to unforeseen circumstances has resigned from this role, but she will continue to remain on our committee and produce our quarterly newsletter. Rachael has contributed invaluable support to our members and will continue to help M.O.T.S as much as she can. We are extremely grateful to the time and effort Rachael has given to us and we are sad to see her leave as trustee, Thank you Rachael.

### Committee Structure

Chairperson/Trustee: Emma Abdullah

Treasurer/Trustee: Sam Williams

Secretary: Amanda Watts

Committee members: Rachael Green, Jenny Pinkstone, Grainne Skinner, Jan Barnett, Terry Faber, Kim Hughes, Gary Palmer, Catriona Hamilton

### Accounts

Sam prepared the accounts for M.O.T.S for committee members to see. The accounts were broken down into monthly transactions from October 2014, which was the date of the last AGM, so all incoming and outgoing expenditures was shown. This was available for all members present to view and acknowledge. There were no problems or questions relating to these accounts.

Our Public Liability Insurance was also available for all to see exactly what is being paid and what the insurance plan consists of and the cover it gives to the charity. The annual price for this is £183.00p and is with the company, Higos.

### Accommodation

Jan has voiced that he believes that it would be a good idea to invest in obtaining a small apartment/flat or house which MOTS could rent out to families in need. This is a great idea and it will be something that we could look into for the future but unfortunately at the present time, MOTS does not have sufficient funds available to be able to commit to this. We have to take into consideration also the upkeep of the property, for example: would there be anyone who would be able to maintain the property and keep up to date with all repairs and bills? It was also discussed if MOTS could organise a sponsor who would be able to cover the month's rent of a flat/house if we were able to take out a six-month lease with a company? Could any of our committee members help with any of this?

At the moment, when a patient is admitted to the ward and are in need of financial help with accommodation, the Transplant co-ordinator contacts Emma with the details and we then pay direct to Elsworth or Pemberton house. We have paid for 8 people to stay at least 7 days' accommodation since our last AGM and that totals £1156.00p. Emma and Sam will research the prices of all accommodation units we use and will see if there have been any increases made.

It was mentioned that the Kingston accommodation always seems to have empty units surrounding the area, could there be an agreement made with them to let out the units to transplant patients if there are not being used. It was agreed that this would be a good idea and Emma will organise to get in touch with Kingston.

Helen advised us that there are student flats surrounding the Oxford hospital and some of these are rented out to families in need of accommodation. Michael Seres has helped to raise funds, which were then used to decorate the flats that are rented out. Could we discuss this with the university to see if they have any accommodation we could rent out from them in Oxford and Cambridge? We will try to get in contact with Michael to see if there is any support he can give to MOTS regarding this.

## Support

Rachael put forward the idea that all of our committee members should be in the Facebook support group and make more of an effort to be interactive on there, so there can be a solid foundation in place for any members who have questions or worries. Some of our members are quiet on this site and it would be beneficial for all if we could try and connect with everyone.

We discussed that there are people in the support group who do not need to be in there and this could be a possibility on why some members are not joining in on the conversations online. One of our committee members stated that a neighbour of theirs was a member and they couldn't understand why as they have not or do not know of anyone who has gone through an organ transplant other than themselves. It was agreed that members of this group should be vetted before they are accepted into the support group. This way our members will have their privacy and will not have to worry about their information being shared with people they would feel uncomfortable knowing. We will organise for a post to be pinned on the support group page so new members will understand the protocol.

## Transplant Games

We discussed this with Cat as she has attended the games with her son on a few occasions. She has said it is a great way to meet new people and suggested that this could be our members yearly meet-up. Would you be interested in going to these games as a spectator? If we have enough members who are willing to travel here in July, we can arrange a budget that can be put in place for us to attend.

Usually each transplant team, unit or hospital have their own accommodation for the games, but unfortunately we will not be able to meet the deadline to organise a team this year, but we will be looking into how we can organise a team and free accommodation for the players on the team for hopefully next year. We need to speak to the organiser of the games to see how we can begin the process of becoming a Transplant Games team.

Cat also suggested that MOTS could contact the games and offer to sponsor a trophy so we can begin to establish ourselves there and we could offer to sponsor the trophy for a MV patient. We could also set up a stall there for one day, which would be the Sunday as it has the most visitors this day, which we would be able to sell some of our products and advertise the support MOTS can give. Sunday is the day where the track and field games take place. This could be a great awareness campaign and create publicity for our charity. Please could you let us know if this would be something you are interested in being part of.

## Transition

BCH can only look after or operate on their child MV patients until they turn 18, and at this point they should transition over to an adult transplant hospital, but unfortunately this isn't always the case and they can be left in limbo. Is it a funding issue or to do with available resources on the ward on why children patients cannot be transitioned over to Addenbrookes/Oxford/Kings? MOTS would

like to be able to help with this period of time and give support to the patient. Emma and Sam have offered to contact each hospital to see if there are any ways in which we can help as a charity or assist the individual. We will keep you updated on this.

Cat has also offered to be our main point of contact between BCH and Addenbrookes. The consultant at BCH, Dr Guypte, knows of the charity MOTS and has met with Emma and Sam previously. We are going to get in touch with him and the ward managers to see if there is a possibility of creating a leaflet or document consisting of the Literature of Transition and to build a communication path between us.

At BCH, on Saturday 14<sup>th</sup> May 2016, there will be an Intestinal Family Day held. Cat suggested that Emma and Sam to attend this as it could open up many opportunities for MOTS as a charity. We are going to contact the organisers of this to see if it will be possible for us to attend. We will keep you updated guys.

### Donations made

Jan has advised us at the meeting that the donations we have given to ward G5 are not being utilised to the best of their ability, such as the hairdryers and fans. This is due to lack of advertisement on the ward relating to what MOTS has donated and can help with. The ideas that were discussed to improve this situation are to create a poster for the ward and to speak to the ward manager to see if there is a possibility that this information can be shared with new patients.

### Data Protection Act and POVA

Sam introduced to the members present, forms which will need to be completed by all our trustees and committee members. These forms have been created as due to the sensitive data that is collected from our members, we have to be certain that this information is not disclosed to any other parties or is discussed with other members. Our members have the right to keep their personal information confidential and as a charity we must respect their wishes and abide by the Data Protection Act 1998 rules and regulations that Charity Commission require us to follow.

Due to us visiting some of our members who may find themselves in hospital, we have to protect them and ourselves by signing these forms. When people are in hospital they can be classed as a vulnerable person and as trustees, Emma and Sam have to be certain that all committee members understand this as we need to make sure that nobody can be put in a situation that can be misconstrued and that the decision for visits are being made fairly. For any committee member who is visiting someone in hospital, they need to have their I.D present at all times and inform Emma/Sam that they are planning a visit so we can log who they are visiting. For example: name, date and which ward.

It was also discussed about carrying out CRB's for our committee members as of the sensitive nature of our position within the charity structure. All of our committee members present agreed to this. So we will be in touch soon to let you know the process of completing one of these checks.

### Membership

Membership was discussed also and at the moment we have 58 members, could are committee members try and promote MOTS to try and help boost these numbers. We also need to have up to date newsletters and flyers in the waiting rooms of Addenbrooks and Oxford. Could these be put in a doctor's surgery near you, please contact us if you can help with this.

### Day Room

In Addenbrookes day room, we have some of our donated items such as dvds and books, but each time one of our committee members have visited the ward, it is very untidy in there. Emma has suggested that the room needs to be altered so the level of tidiness can be kept. One idea was to put up shelving to create more room. Do any of our members have any other ideas on how we can improve the room and utilise it to the best we can?

### Charity/Fundraising

Our Just Giving account has helped us to raise significant funds, thanks to the pages that have been set up by fundraisers. In the last year a total of £ was raised. It was discussed how our members can help with this and it was decided that if our members share on media websites or by word of mouth a fundraising page that has been created on Just Giving, this will help.

M.O.T.S has accounts set up with Just Giving, Easy Fundraising and PayPal so if our members could remember to use these when shopping or fundraising, M.O.T.S can benefit monetary as some proceeds could be donated to us.

Can our committee members commit any of their time to our fundraising this year? Even if it is handing out flyers or leaflets, could you spare any time? Please get in touch with us if you can.

Our new committee member, Helen has offered to help us with fundraising and any competitions we may be doing in the near future.

### Future Aims.

Provide more online support via the support group on Facebook

Introduce the Buddy System online

Aim for better accommodation for patients and their families

Contact Michael Seres

Be present at the Intestinal Family Day on the 14<sup>th</sup> May 2016

Transition draft for the website to be completed by Cat

Resources for other support to be added to the website

Meet ups with committee members to be organised

Increase the number of members of MOTS

Communication paths to be built between MOTS and hospitals for the transition period

Day Room to be improved

Sponsor a trophy for the Transplant Games