

Freeman Heart & Lung Transplant Association

Minutes of the meeting held on Monday, 28th July 2014 at the Institute of Transplantation, Freeman Hospital, Newcastle upon Tyne.

Present: Derek Airey (Chair), Barrie Braidford, Jane Graham, Adele Lambert, Janet Long, Vicky Petterson, Joan Whitney and Brian Wood.

In Attendance: Mavis Wood to minute meeting, Kay Johnstone (Secretary Transplant Association, Ireland), Lynn Holt (Transplant Co-ordinator).

Apologies were received from: Susie Wood and Adrian Woodcock.

- Derek informed the meeting that Kez Greenwood resigned from the committee due to work commitments but will retain his role as Volleyball Captain.
- Derek introduced Adele Lambert.

Minutes of the previous meeting

- Joan asked that the following amendment be made to the minutes:
 - The Annual Amble Harbour event should have read Alnmouth event.

Chairman's report

- Derek informed the meeting that Transplant week is 7th – 11th July was a success. As far as he knew 45 people had signed up to the Transplant Register.
- There was a stall at Gosforth ASDA as well as in the Freeman. The latter was manned by Committee members who were not at the games in Lithuania.
- Joan sent thank you letters to two people who volunteered.
- A discussion ensued about members of the committee not attending meetings. One in particular had not been to a meeting for approximately 8 months.
- Brian informed the meeting there was nothing in the rules to cover this.
- It was agreed that Joan send a letter to ask if they wanted to continue on the committee and to find out if the absence is due to work commitments. If this so case would they like to resign to make way for others who may want to join the committee.
- Derek and his family had a superb day fundraising at the Alnmouth event.
- Jane said she had joined them on the Sunday and that Derek and his family had been superb.
- Jane sent a card and a bouquet to John and Lesley to say thank you for the use of their house and garden.

Secretary's report

- Joan wrote to Simply Health following a conversation with Neil Wrightson. They informed her that they do not fund medical equipment or staff training but may be interested in something to do with children.

- Simply Health have funded 12 families to enable them to attend the children's games.
- Janet will put a proposal together for 2015 games to apply for funding for the children.
- Joan will send an e-mail to the person she was dealing with to inform her that a full report on the children's games will be sent to her.
- Janet to do a report from the games to send to Simply Health.

Kay Johnstone – Secretary of the Transplant Association Ireland

- Kay informed the meeting that they have been successful in fundraising via social media sites.
- Their remit is to support anyone involved in organ donation – both recipients and donor families and that they are involved with Kidney as well as Heart and Lungs.
- Most of the transplants that take place are carried out in England.
- They have £2,000 to donate to the Freeman Hospital which they want to go specifically to the transplant side.
- They would like the money be spent on equipment for the flats i.e. new television in the common room.
- Derek informed Kay that the flats they currently use are being demolished but they will be given Beechwood and at his point in time they are not sure what will be required it may be kettles or a settee etc.
- Kay asked that a plaque to say who donated the goods be displayed.
- Brian reminded the meeting that because of the Charities Commission goods and not cash would have to be donated.
- Joan will liaise with Kay.
- Kay left the meeting at this point.

Treasurer's report

- Joan gave an update bank and saving accounts.
- Money donated via the Just Giving website increased considerably in June.
- Joan reported that the FHLTA had paid registration and accommodation to enable two people to go to the World Winter Games.
- This cost was shared with the Children's Transplant Team.
- Joan distributed copies of an email she had received regarding the application to become a Limited Company by Guarantee. This has gone ahead and we are now registered with a new charity number. This has to be formalised.
- The new charity number can be used from 29th July 2014 or 1st November 2014 which is our financial year.
- Jane suggested passing a resolution now that the changes take place on 1st November 2014. All in agreement.
- Janet proposed and Jane seconded it.
- All members have to be notified of the changes which will be done in November. However the bank does have to be notified now.
- It was agreed not to order anything with the charity number on until the changes are made.

- Joan informed the committee that the signatures for the accounts will have to change and that she will be coming off and Jane will go on.
- Joan has paid the hotel for Bolton.
- P.I. Insurance due on 6th August. Joan will pay this.
- An application to fund one of the Research Nurses to attend a two day course to be held at the Freeman Hospital on 14th December 2014 had already been approved by Stephen Clarke.
- Brian reminded the committee that Finance said they funded all of these courses.
- It was agreed by all that the FHLTA would fund it.

Lynn Holt – Rocky Mountains, Canada

- Lynn has been approached by the Rocky Mountaineer Train Company who has chosen organ transplantation as their nominated charity this year. They want to invite two families to Canada who would never have such an experience. The donor recipient will also meet their donor families.
- The Rocky Mountaineer will pay for the families when they get to Vancouver. They will join the train on Tuesday for two days and get off in Calgary on the Thursday when they will fly home.
- The Rocky Mountaineer Co., have chosen the two recipient families and their donor families.
- Lynn is looking for funding to support the flights and possibly some food. Unfortunately, she does not know how much this will be yet. She stated that she will be going along with the families but she is not asking for funding for herself. She will find her own fare.
- Lynn has suggested the families do some fund raising themselves.
- As well as the publicity in Canada Lynn will make sure there will be plenty of local and national publicity in this country.
- Lynn left the meeting at this point to enable the committee to make a decision.
- A vote was taken and by a majority decision it was decided and agreed to pay a contribution per person to cover the deficit of their flights. A maximum sum was agreed.

Children's report

- Janet reported that the response to the Family weekend had been poor and that she was going to put it on Facebook as well as speak to people at the Bolton Games.
- Janet asked the committee for advice on providing contact details to a third party. The response was that she would need to have the permission of the people concerned before doing so.
- Vicky is going to contact Transport Sport to clarify the position about out individual details.
- No word has been received from a couple who were doing some fundraising. Janet will chase them up to see how it went.

- There was some discussion about them receiving no support from the FHLTA during their fundraising.
- It was stated that they were provided with goods and were contacted by telephone. The committee was not however, asked to provide any physical support with the fundraising.
- Janet will write to ask about the support they thought they should have received.
- It was agreed to put on the next agenda how the FHLTA can support people with fundraising.

Games report

- The Volleyball Tournament will take place on 22nd November 2014 at Gateshead.
- The European Games were a huge success with the Freeman Team winning 46 medals.
 - 15 Gold
 - 19 Silver
 - 12 Bronze
- Petanque players also gained medals.
- Thirty seven competitors have paid their hotel fees for the British Transplant Games in Bolton.
- There are no Gala Dinner tickets left for Bolton.
- Two friends of Vicky's are doing the Great North Run. They also had a Garden Party and raised money.
- One friend held a competition with work colleagues and raised some money. He hopes this will become a regular event.
- Vicky is organising a Cycling Event at Middlesborough which she hopes will take place in May or June 2015.
 - It will include a 5k and 10K ride for adults as well as a children's event.
 - There will also be cycle rides for all levels of ability and experience.
 - Cycles will be available to hire free of charge and there will be a range of styles i.e. ordinary, three wheeled, tandem, wheelchair etc.
 - Timing will be by a chip attached to the shoe.
 - There will be a registration fee.
 - Event will conclude with a Gala Dinner.
 - All participants will receive a medal.
 - Vicky's Cycle Club will provide catering and refreshments to be paid for by participants.
- Transplant Sport are happy to be involve however, Vicky made it clear this is not a Transplant Sport event.
- Vicky will contact Transplant Sport to find out if they would be willing to provide a float to get started which will be paid back to them.
- Joan suggested having a fund raising to raise money for a float.
- It is also, a non-profit making event.

- Vicky asked for permission to go ahead and organize the cycle event which was agreed.
- Proposed by Brian, Seconded by Barrie.
- The Rackets Event will take place on 30th May 2015.

Flats

- Derek is attending a meeting today to find out what is happening with the flats.
- Beechwood is being converted for the FHLTA who will be provided with 12 flats.
- All furniture will be transferred from old flats to Beechwood.
- A discussion took place as to where to put transplant patients in the interim. Especially those who have long distances to travel.
- Derek is looking at hotels.
- May possibly lose the revenue from the flats.
- Flat turnover is approximately 60 patients per week.

Any other business

- Jane informed everyone of a fundraising event taking place at Bamburgh on the 24th August 2014. She will be provided with goods and also received offers to go along and help out from Barry and Brian.
- Joan explained that the support fund had helped out a couple of people.
- Derek informed the committee that a new large noticeboard will be placed in the outpatients clinic.
- Joan had e-mailed re the passes but has not had a reply.
- Brian informed the committee that he had been talking to someone on the Kidney Transplant committee and that they did not have to go through the process the FHLTA have.
- Adele was co-opted onto the committee which was proposed by Brian and seconded by Joan.
- Adele will not become a full member until the A.G.M.
- Adele agreed to take over the role of Secretary.

Date of next meeting: Monday 8th September 2014 at 10.00 am.

FHLTA/MW/28.07.2014