

## **Freeman Heart & Lung Transplant Association**

Minutes of the meeting held on Monday, 9<sup>th</sup> July 2012 at the Institute of Transplantation, Freeman Hospital, Newcastle upon Tyne NE7 7DN

**Present:** Derek Airey (Chair), Barrie Braidford, Alf Brown, Judith Burgess, Tony Chapman, Janet Long, Joan Whitney, Brian Wood, Susie Wood and Adrian Woodcock

**Apologies were received from:** Simon Ripley

### **Minutes of the previous meeting**

- With regard to the air flight for £45 as recorded in Any other business should read 'a light aircraft flight around Northumberland'
- Following this amendment Brian Wood proposed that these minutes be accepted as a true and correct record. Joan Whitney seconded this motion. All were in agreement.

### **Matters arising**

- There were no matters arising

### **Chairman's report**

- Derek told the meeting that Tony Armstrong, a previous Chairman of the FHLTA had sadly passed away on 25<sup>th</sup> June 2012.
- It was agreed that flowers should be sent from the Association to his widow, Barbara.
- This week is National Transplant Week, 9<sup>th</sup> – 15<sup>th</sup> July 2012 and the FHLTA will be holding an awareness stall in the Gosforth branch of Asda.
- Derek asked for volunteers for this.
- Derek told the committee that he is unable to obtain Organ Donor Register promotional goods from the NHS.
- It was agreed that the committee apply individually for these goods and for future events we buy these goods.
- Derek told the meeting that £257 was raised at the recent Barbeque/Social event at the David Lloyd Fitness Centre.

### **Secretary's report**

- Judith told the meeting that as requested she had written to Pam Yanez to ask why she wished to meet with the FHLTA committee.
- Following her answer, via email, Judith forwarded this to all committee members.
- It was agreed that we go ahead and arrange a meeting with representatives of the other patient charities, these being Liversnorth and Tyneside Kidney Patients Association.

- Adrian Woodcock proposed that the three representatives from our Association should be Derek Airey, Judith Burgess and Tony Chapman. Barrie Braidford seconded this motion and all were in agreement.
- It was agreed that Derek, Tony and Judith should meet up before meeting the other representatives.
- Judith told the committee that she has received two grant applications from Mr Stephen Clark, Director of Transplantation, Freeman Hospital.
- The first one is requesting £5,000.00 as a contribution towards the funding of the Heartworks Trans-oesophageal echo/Trans-thoracic stimulator which will be used as a teaching/training tool locally and in due course nationally.
- Barrie proposed that we should fund this and this motion was seconded by Joan. All were in agreement that this contribution should be made.
- The second application is requesting £5,000 towards the cost the 25 years anniversary of the first successful infant transplant celebrations.
- It was agreed that Judith should write to Mr Clark asking for further clarification as to what this funding is being spent on and to who it applies as our remit covers promoting transplantation and the Organ Donor Register and supporting our members to attend this type of event.
- We would also require individual invoices for accommodation and travel.

### **Treasurer's report**

- Following the cancellation of the 2014 European Heart & Lung Transplant Games, the contribution of £2,500 which was made by the FHLTA towards the launch of these Games has now been cancelled.
- Joan told the meeting that the FHLTA pay an annual fee of £500 to the BHLTA, the organization that is responsible for getting the British Team to these Games, towards admin costs.
- As there are no European Heart & Lung Transplant Games yet planned for 2014, Joan asked if she should pay these costs.
- Judith proposed that Joan wait until August/September as there is to be an emergency Management Committee of the European Heart & Lung Transplant Federation to discuss the future of these Games.
- All were in agreement with this.
- We have had a £928 refund for the European Heart & Lung Transplant Games due to the change in the value of the Euro.
- Joan informed the committee that all is in order with the accounts.
- Joan went on to say that the Lunch provided at meetings cost £24.00

### **Children's report**

- Janet told the meeting that there will be 21 people attending the British Transplant Games in Medway and of these there are 5 child competitors.
- There are no other children's events planned to date.

### **Games report**

- Judith told the meeting that the European Heart & Lung Transplant Games had been very enjoyable and the Freeman team competitors had managed to win 16 Gold, 25 Silver and 9 Bronze medals between them.

- Judith went on to say that she has been appointed as the new Secretary of the European Heart & Lung Transplant Federation (EHLTF) taking over from David Walker, who is to be the new Chairman
- Judith feels very honoured to be asked to take on this role
- As the 2014 European Heart & Lung Transplant Games have had to be cancelled due to difficult circumstances, she asked if it would be possible for the FHLTA, with help from other sources, could organize this event
- Judith went on to say that she realizes that this is a massive event to organize but has been approached by Freeman Team members, offering help.
- Judith agreed to approach these members again.
- It was agreed to look into this further and perhaps approach prospective funders etc.

### **Website/Newsletter**

- Susie told the meeting that the Autumn newsletter is now in process.
- Judith asked that we get the same amount of newsletters printed as before and put these in clinic, doctors surgeries, libraries etc. This was agreed.
- Tony told the meeting that the FHLTA website is now up and running along with Facebook and Twitter.
- Tony asked for any news items to be sent to him so that he can keep the site updated.

### **Flats**

- There have been a number of double bookings.
- This problem arises when people request a flat for dates other than their standard review date.
- It was suggested that it is up to the individual patient to check that the flat they have requested is available before travelling.
- It was agreed that if there are no flats, patients should be allocated a room in the Adelphi hotel and the trust should meet the cost of this.

### **Any other business**

- Derek has received a letter via Lynne Holt, from Bobby Doherty's donor family, who live in New York, requesting financial help to attend the British Transplant Games in Medway, where Bobby will be competing for the first time since his Transplant.
- The first proposal was that we pay a contribution to the cost of the flight. There were two members in agreement with this.
- The second proposal was that we pay the full cost of the flight. Six members were in agreement with this with one abstention
- It was agreed that Tony should arrange the flight on behalf of these people.
- Judith agreed to write to Bobby to confirm these details with him.

**Date of next meeting:** Monday, 24<sup>th</sup> September 2012 in Room 2 (fourth floor), Institute of Transplantation, Freeman Hospital.

**FHLTA/JB/9.7.12**

