

British Heart & Lung Transplant Association

Annual General Meeting

15th November 2013

Wythenshaw Hospital, Manchester, M23 9LT

Present: David Walker (Chair), Judith Burgess, Nick Condon, Maggie Gambrell, Alan Lees, Janice Taylor and Joan Whitney.

Also present: Charles Gambrell

Apologies were received from: Tony Chapman

Minutes of the previous meeting

- These minutes were accepted as a true and correct record

Matters arising

- David pointed out that we had agreed to invite all members to our AGM but this had not been done.
- David went on to suggest that another meeting is held early next year, inviting all the members.
- Judith agreed with this and went on to say that this could be useful as the 2014 Heart & Lung Championship will be happening in July.
- It was agreed that Judith should contact each Team Manager of the teams affiliated to the BHLTA asking if they would like an AGM open to everyone, asking if they would attend this knowing that this will be at their own cost.
- David suggested that included in this email is a request to look at the BHLTA website and the minutes of the meetings held.
- David asked if one charity can pay a subscription fee to another.
- Judith pointed out that it is illegal to pay a donation from one charity to another but it may be different for subscription fees.
- It was agreed that Joan should contact the Charity Commission to enquire about this.
- If this is allowed it was suggested that we become a charity in order to do more fundraising.
- David asked if there has been any further correspondence with regard to the bequest of Dr James Griffin as no money has yet come through.
- Judith said she has not received anything further.
- David informed the committee that he has written to Roy Stevens to thank him for all the time and effort he has given to the BHLTA over the years.

Chairman's report

- David began by thanking Janice for the use of the room for the meeting.
- David went on to say that in his role of President of the EHLTF he has worked with other people in getting a Games organized for 2014.

- He went on to say that as he has served on the EHLTF committee for 10 years he was unable to be reelected again and therefore has no further input or effect to this committee although Judith now serves as Secretary.
- David went on to talk about the BHLTA and why we exist.
- He told the meeting that in order to attend the European Heart & Lung Transplant Championships all participants must belong to an association of their country and there can only be one association per country.
- This is why the BHLTA was formed although we are unique as our association is made up of four hospitals/patient groups.
- It was suggested that we form a closer link with Transplant Sport. Janice agreed to speak to Transplant Sport
- Alan suggested that we write to NHS England requesting that we are recognized as an official body.
- It was felt that our first step is to get charitable status.
- Charles suggested that this information of why and how the BHLTA exists should be included in the email sent out to Team Managers as this may help people understand what our aims are.

Treasurer's report

- Copies of the accounts had been circulated prior to the meeting.
- Nick gave a brief resume of the accounts.
- Nick reported that he had attended the General Assembly of the EHLTF as the British representative.
- Maggie asked why we have paid £365 to the EHLTF
- David explained that this is our membership fee. Each National Association has to pay €400 per year. This money is then used to hold meetings, put our political views to the European Union, insure that we are represented in all the correct places at European Union level.
- The EHLTF also get funding from Novartis and Astellas and until recently Roche, to enable them to promote and encourage new countries to join and develop.
- It was pointed out that no subscription fees have been received from Papworth for 2012 or 2013
- Nick explained that Papworth have a joint fund within the hospital and have to make requests for money.
- Nick went on to say that Kevin May, the new Team Manager, feels uncomfortable asking for £500 for the BHLTA membership.
- David agreed to write to Kevin with information about the BHLTA, and what the membership fee is for, to take to the hospital.
- Given the information Maggie and Nick relayed to the committee regarding the finances of Papworth, it was agreed that Papworth should still be invited to attend the European Heart & Lung Transplant Championships to be held in Vilnius in July 2014.
- Maggie questioned as to why each hospital should have to pay £500 annually and why the figure is set at £500
- Judith argued that she thought that this was a reasonable amount to ask each hospital to pay as the BHLTA have expenses to pay. Each person at this

meeting requires expenses, lunch is provided and expenses have to pay for those who attend the EHLTF General Assembly.

2014 European Heart & Lung Transplant Championships – Vilnius, Lithuania

- Judith reported that she could now give the prices for these Games
These are as follows €500 per person for double occupancy, €700 for single occupancy and €100 for any extra nights.
- There has been some confusion over how many nights this is for as Judith had stated 5 nights in her email but Ugne emailed her to say this cost is only for 4 nights. Following this Judith contacted Brendan Gilligan (President of EHLTF) who confirms this is for 5 nights.
- These costs will include Bed & Breakfast, lunch, all transport to and from venues, Opening Ceremony dinner and Gala Dinner.
There are discussions about providing Dinner as part of the costs.
- Judith reported that if anyone books separately will not be able to attend the Gala Dinner and will have to find their own transport.
- This could prove costly as the athletics field in the city which it is hoped will be used is not yet finished and if this is still the case in July a track 100 km outside the city will be used instead.
Joan reported that she is aware that two families have already booked outside of the package.
- David went on to say that if she knows who these families are, their hospital Team Manager and the British Team Manager has to be informed.
Judith gave a brief resume of all the sports venues.
Judith told the meeting that the athletics event has been changed to the middle of the week in case the track on the outside of the city has to be used.
- Maggie suggested that members are informed that these Games have been organized at short notice and have not had a huge budget so they should not expect 5* facilities.
- David agreed with this.
- Maggie reported that the kit that we bought last year is available for purchase again this year.
- Anyone who is not attending should offer the use of their tracksuit to someone else.
- It was agreed that we will provide kit for any new members.
- It was suggested that anyone going separately, not with the package, should not be offered kit (unless they already own one) – it was agreed that we find out more information before making a decision.
- It was agreed that anyone who has lost their kit will not be provided with a new one
- This is available for purchase of the website.

2016 European Heart & Lung Championships

- Judith reported that a bid for the 2016 Games has been received from Finland. A copy of the letter that Judith has received, as Secretary of the EHLTF, from Ilkka Vaas, the Secretary General of the Finish Association was circulated to all in the meeting

It is proposed that this is held along with the European Transplant & Dialysis Games.

- The opinion of the majority present was that this was better than no Games at all.
- Both Judith and David outlined that if this should go ahead the EHLTF could possibly lose their identity.
- Judith informed the meeting that the EHLTF are unhappy about this but the final decision will be left to the General Assembly which will be held during the Games in Vilnius.
- Judith asked on behalf of the EHLTF if it would be possible for the BHLTA to re-evaluate their position towards putting on a Games.
- David reported that after the discussion with John Timms of MLS a pro forma had been sent which he was prepared to send out to venues/towns of Britain. This was to cost the BHLTA £300 - £400
- This was not taken any further partly because the BHLTA is not a whole unit but made up of the four hospitals paying in money leaving us fragmented.
- David explained that this would involve commitment from people who live within 5 to 10 miles of an area.
- Having now seen how Ugne from Lithuania has managed to put on a Games at short notice and on a budget, Judith told the meeting that she feels quite embarrassed that Britain cannot put on a Games as one of the largest teams.
- David suggested that we possibly look into putting a bid in for the 2018 Games, feeding off the venues and hotels used for the 2015 British Transplant Games.
- This was agreed in principle.
- There was some discussion as to the merging of the European Games.
- It was felt that the Transplant & Dialysis Games totally contradicts the promoting of Organ Donation because if you are fit enough to do sport whilst on dialysis there is no need for organ donation.
- Both David and Judith pointed out that if this happens once, it may happen in following years therefore losing the European Heart & Lung Transplant Games.
- David asked Judith to write and ask for more information, i.e. is this a one off.

Membership fees

- It was agreed that this should remain at £500 per annum.

General Assembly

- As Nick had attended the previous year's GA, It was suggested that he should attend as the representative of the BHLTA again in 2014 so that there is some continuity.
- It is hoped that at some stage someone will become a member of the committee of the EHLTF as our representative.

Report on EHLTF

- Judith reported that the EHLTF have decided not to go ahead with the European Capacity Building Programme.
- David explained that this programme obtains money from the EU in order to help and educate organizations, to improve the way they work, making them more professional, increase their ability to do fundraising or look at the structure of their organization and management and identify any areas of weakness so that they can get help to improve this.
- David noted his disappointment that the EHLTF have decided not to go along with this.
- Funding for the EHLTF has been granted from Astellas and Judith informed the committee she is in the process of completing a Grant application to Novartis.

Any other business

- Judith told the meeting that she is currently having arguments with 1&1 regarding the invoices she has been sent for the BHLTA.
- It was agreed that Judith should ring them and ask the questions rather than email them.
- Although Tony Chapman has not attended he is still interested in being involved and asks that his role be clarified.
- It was felt that he can accept articles for the website from anyone and that as he has a lot to offer we are happy for him to attend meetings.
- Alan reported that he is doing a climb to promote Organ Donation and asked if there could be any lung transplants available for this as this will be good publicity.
- Each hospital to ask their members.
- Joan reported that the new Institute of Transplantation is now open
- The FHLTA hosted the Transplant Volleyball tournament in Gateshead.
- Janice reported that last year Wythenshaw had carried out 22 heart and 26 lung transplants.
- Janice went on to say that there have been 35 transplants within the first 8 months of the financial year.
- There have also been approx 15 LVADS.
- The 2014 British Transplant Games are to be held in Bolton but as Bolton do not have a transplant unit they will be called the Bolton/Manchester Games.
- Bolton council has funded the Games.
Alan reported that the sister of Harefield, the Royal Brompton is having some major refurbishment done so everything is being taken to the one site.
- With this a hybrid operating theatre is being introduced so that all imaging equipment and surgery can be carried out in one location.
- Alan reported that Harefield are pioneering an organ care system. A purpose built unit with a bypass system.
- This will mean donated organs can be transported for a time period of 12 hours rather than the usual 3 hours.
- Maggie reported due to the sad passing of Barry Matthews there is now a new Team Manager, Kevin May.

- Maggie reported that Papworth have carried out 6 hearts, 2 heart/lungs, 4 single lungs, 11 single lungs and 13 LVADS from the period January – August 2013.

BHLTA/JB/15.11.13