

Freeman Heart and Lung Transplant Association

Minutes of meeting Tuesday 10th May 2016 at the Gosforth Library, Newcastle Upon Tyne 11am

Present: Derek Airey (Chairman) Jane Graham, Joan Whitney, Brian Wood, Adele Lambert, Jon Comb, John Coyle, Roger Pape, Penny Hartley, Michelle Saunders,

Vicky Pettersen. Specialist Organ Donation Nurse Lynne Robson.

Apologies: Adrian Woodcock, Barrie Braidford

Minutes of Previous Meeting

Minutes proposed

We received a Talk from Lynne Robson a Specialist Organ Donation Nurse who informed us of her role and gave us information about the upcoming Organ Donation Campaign for Organ Donation Week in September the Slogan for this Campaign will be

Turn an end into a beginning

Chairman's Report

- It has been agreed by all of the committee that there should be some policies made for our rules and regulations especially regarding Facebook and social media sites.
- Also disciplinary procedures to be reviewed and put in place.

Secretaries Report (Joan and Adele)

- Joan assured us that all was I place for the may ball on Saturday 14th may and that all payments had been received and all places were allocated.
- She informed us all that Richard Caulkin had resigned and that the post of Website Editor would need to be filled.
- Castle Computer a website provider have been contacted to see if they can provide a
 better service than our current provider, a meeting is being arranged for them to
 come and talk to us at the next meeting on 21st June.
- Joan also informed us all of a Research day at the Institute of Transplant on the 7th
 June 12pm -5pm aimed at raising awareness of transplantation.
- Professor Corris has now retired from the institute but he will still be involved in research.
- Adele informed us that she had carried out a stocktake of all of our fundraising items that she currently had and has given the information the Vicky.

- She has emailed all of the runners for the Great North Run to ask for the final payments as there are still 15 outstanding, Jane agreed to check the bank statements and inform Adele of any more payments received.
- Vicky has ordered the vests for the Great North run for Adele to send out.
- Adele obtained the contact details of the new committee members and will make a list for everyone.
- Adele informed everyone that she has a good supply of donor forms, and fundraising items that can be sent out to supporters, and also if any members of the committee need any items please don't hesitate to get in touch.
- Adele has posted 4 lots of t shirts and fundraising packs out to members/supporters in the last few weeks.
- Adele thanked Joan for taking over the secretaries' post for her while she was unwell.

Treasurers Report

- Unpresented cheques as of May 6th £2170.56
- Payment for the European games to date £9271.40
- Payment for the May Ball £1300
- Takkers final payment made £392.00 this includes bank charges
- Park Resorts Payment £308.00 for mobile home insurance.
- Young Adults Reimbursements £56.85 and £27.90
- Books payments £80.00 as of 26th April
- Fhlta new equipment for flats £345.37
- Outgoings for mobile home £205.99
- Awaiting final costs for Washington DC conference.
- Just Giving up to 8th April £2877.88
- Donations since last meeting £2419.39
- Memorials £2530
- Match funding £500 and awaiting £1000.00 more from friends of Sharon Widdowson

Children's Report

- Michelle would like to thank the committee for electing her to be the children's representative.
- Michelle said that she does not need any additional help with the children's team at the moment and if she does she will ask for volunteers.
- She has met with Chris Gray who agreed that CHUF would be prepared to support transplanted children and their families to attend the British Transplant Games in addition to FHLTA funding. They have also produced a leaflet for her to hand out to families in clinic and they are prepared to support the Children's team with sports equipment and kits.

- The advantage of this is the Children's team will not be asking for additional support for hardship families from the FHLTA and going forward they are prepared to support the children's team in future years with as many families that would like to attend.
- The number of Children for this year's games is 12 and there are around 49 supporters.
- Michelle asked if there was additional support available for the children transitioning to the adult team she was informed that additional support would be available and that individual cases would be assessed.
- Some families have expressed an interest in doing activities for Organ Donation Week
 would it be possible to have fundraising packs available to hand out to them at the
 games so that they can get involved. Adele agreed to liaise with Michelle to organise
 these if needed.

Sports Report

- Vicky has provided a full stock count.
- All payments have been made for the European Games there are 16 FHLTA competitors and 4 supporters.
- It was decided to top up team kit orders for new competitors and order 3 of each size.
- Lynne Stobbart contacted Vicky she is doing a talk on research at the institute of transplant conference on 7th June which Joan mentioned earlier.
- Vicky is contacting David Bloomfield to ask him if he would be willing to take over the running and administration of our website, he has since agreed.
- Vicky had a meeting with Laura from Marxists and has confirmed and signed a contract for the Christmas Party on 26th November 2016.
- She informed us that we can use our volunteer passes to gain discount for team/fhlta hotel bookings in the future.
- She has sent out fundraising parcels and vests for 5 members/supporters doing Edinburgh marathon a race in Ireland and a tough mudder one in memory of Sean McCoy.

Matters Arising

- The committee have received a letter from Dr Gerard Meachery asking if we would consider a proposal to set up an educational and training bursary to support and develop future members of staff who are committed to cardiothoracic transplantation.
- This would be in honour of Professor Paul Corris who has been a key figure in the development of the Freeman Transplant Unit over the past thirty years.
- This will also be an investment for the care of future transplant patients who will benefit from this initiative.

- The proposed amount considered is £30,000 per year or an amount agreed by the committee.
- The committee decided to ask Dr Meachery to give us more details about this before any agreement is made.

Organ donation Awareness

- Penny Informed us that she had been given the opportunity of a stand at fresher's week on 19th September 2016 at Northumberland University and one was also available at Newcastle University on 3rd November 2016. The cost for both events is £1000.00 in total this was approved by the committee.
- It was suggested that we use I pads that belong to the Fhlta to canvas at the university as well as paper forms.
- Organ Donation awareness week is 7th 14th September this year.

The meeting ended before we could cover all of the topics, the review of rules and regulations will be added to the next meeting.

The next meeting will be on Tuesday 21st June 2016 at 10am at the Institute of Transplantation, Freeman Hospital, Newcastle Upon Tyne.