



EDITORIAL – Jill Edwards – Heart transplant 21 years – Chairperson and Editor



Hello everyone,

You will see I have now gained another title – that of Chairperson. I will, as always, endeavour to do my best. You will find details of the committee on the last page. We are all very approachable and if you have any problems I am sure any one of us would not mind a phone call or e mail from you and if we can, we will help. We have a small committee this year but I know that we will all work together well.

We had a good time at our Annual Reunion in Bournemouth a few weeks ago and Justine will give her account in this edition. One thing I thought was uncanny though was the raffle draw. Out of over 1,260 tickets sold, guess whose name I picked out for the first prize of £300 – yes mine!!!! Also the £50 prize was won by Alan our secretary and Henry Smith managed to pick out the ticket for a weeks stay in his own holiday home!! We all behaved like good little Hamsters and in my case I asked for the ticket to be redrawn. Alan asked for the money to go back into Hamster funds and Henry held an auction and raised another £150 for funds. Mr M Dyer also very kindly donated the money back to club funds. Thanks to everyone who bought tickets. It was the very first time we had ever tried a mail out draw. What a magnificent result and thank you so much. A list of the final winners is listed within these pages.

I had the dreaded angiogram last week performed by the one and only Dr Andrew Mitchell, loved by all. It was a bit different this time firstly because it was new equipment which took a little longer and secondly because at a certain time all the angio theatre staff became absolutely motionless for two minutes. Yes, I was honoured to be laying on the table at exactly 11.11.11. I am not sure if it was the occasion, the new equipment or the smooth operator, but I can honestly say it was the best angio I have ever had the privilege to be part of!!!!

As winter is now upon us I am still waiting for our bird feeders to be visited. I cannot understand it this year because apart from four goldfinches and a very faithful wood pigeon they have given us a very wide berth. Maybe they do not like the seed, although it is the same as last year. Possibly next doors food is nicer – maybe a cat is lurking nearby - whatever it is I miss them and look forward to their return soon. What birds do you get visiting your gardens?

That's my ramblings over, I am now handing you over to our ever faithful red wine drinker who did "TRY" to attend The Annual Fun Run in September.!!!

RAINY FUN RUN DAY – *Red Wine Drinker* – *anonymous as always!*



I had placed in my diary The Harefield Fun Run for Sunday 4 September and was looking forward to watching all the competitors running and walking for their impressive medals. Saturday had been a lovely day with a lovely sunset which augured well for Sunday. Having read our excellent newsletter, there was no way that I could emulate our champions with their gold, silver and bronze medals for their achievements. What a magnificent total they have and it was a delight to read about it all.

Sunday arrived. I looked at the weather, not good. It was a very dark cloudy day. It looked even worse to the west where the sky was very dark. I switched on the television for the weather forecast and it was rain. I was optimistic, as they do not always get this right. Nine a.m saw a glimpse of sunshine sneaking through a break in the clouds. Great I thought. I potted about for a while and then got ready. I looked at the weather again, where was that sunshine? I soon found out.

Driving away from home it began to rain, not heavy. The sky looked menacing and very dark. Heading for Harefield the rain became heavier and then began to pour. Oh! deary me. Then what I can only describe as a cloud burst, it was torrential, there was more water falling over the windscreen than the water of the Zambezi river tumbling across the Victoria Falls in Africa. Vehicles all had their lights on, windscreen wipers were thrashing backwards and forwards like a dog's tail when pleased, Everyone had slowed down considerably as visibility was very poor in such circumstances. At one stage the downpour ceased. Good it looked hopeful, but it was a forlorn hope. The roads were full of running water and there was no sign of pedestrians. Then another furious assault of rain, this was bad. I began to think of the many fun runners and their supporters, it was now midday and I still had a little way to go. I was not equipped for these wet conditions, no waterproofs, no Wellingtons, no sou'westers, no camping tents, no food or water as if equipped for the Glastonbury musical festival. The field of Harefield must by this time be saturated with water, and what of the tents, booths, participants, performers, they must be all washed out by now, and the people seeking every bit of cover they could find.

What to do? It was still raining. Transplants cannot afford to get colds and the like as they take a great deal of time to get rid of. I know. So reluctantly at the next roundabout near Ickenham I went right around it, and made for home. There was no improvement in the weather. It beat down at times during my journey home, sometimes torrential, when will all this end. It was still raining on arrival home. My thoughts were still at Harefield, which must be a quagmire by now. I was very disappointed, for not only myself, but everyone, including the dedicated organisers. It continued to rain where I live until 2.30pm. All I can say in conclusion is, the weathermen were right and that was some mammoth shower.

As a result of all this, and it was that time of day – early. I did not even think of having a wee tippie in consolation of my experience. How could I when so many peoples day was spoilt by the weather. I did have a very nice bottle of red Monte Noble 2007 wine, but I was not in the mood. Most unusual for me! I haven't caught a cold have I?

Dear readers, if any, and I am sure some of you were at Harefield for The Fun Run, it would be most interesting of hear of your experiences that day in the rain.

WE ALL GET FRIGHTENED SOMETIMES - *Desiree Robbins- Heart transplant 23 years*

My name is Desiree Robbins, married to Adam. I am 46 years old and I have had my new heart now for nearly 24 yrs! I had my heart transplant back in 1987 at St. Georges, I was 22 then and single! I was moved to Harefield back in 2000ish! I have been much happier at Harefield, the staff are fantastic and everyone is on first name basis. For many years my health has been really good but I always have the odd worry, concern. I think we all do. Last year I was rushed to my local hospital with Streptococcal Pneumonia. My lungs stopped working and I was very poorly. I have been on a Nippy 3 breathing machine ever since. Later, after seeing Dr. Banner the same year I received a drug change from Neoral Cyclosporin to Tacrolimus. The same year Dr. Mitchell carried out one of his famous Angios and recommended a stent, what joy!! The stent went in in January this year. It was a nasty 18 months for me and my family. Since these changes I have not felt my best. Doctors say this medication is better for me. What do I know!! I get the odd big thud, funny beats and slow to fast heart rhythms which I am told are nothing to worry about, which is easy for the doctors to say! Many tapes later and still things are the same; I'm being told not to worry, I'm only human, I'm going to worry! Since the stent I do feel different, doctors say all is fine! I feel concerned and think, does anyone else feel the way I do?

I would love to sit and chat with other like me who have had a transplant, in clinic this often happens. We could all do with chatting to other recipients to see how they feel. One afternoon in clinic I did just that, I got chatting to a lovely man who I found out also had his transplant at St. Georges and told me about the staff, how they were getting on etc. Then asked me what I was doing in clinic, was I ok.... Well, I soon found that he too had the same problems as me and he gave up work saying it was probably stress related! He was over 55, I felt I am too young to retire!! I also felt a lot better talking to him realizing I was not alone in how I was feeling. Recently I was talking to my doctors about my worries, I could not eat at the time, lots of anxiety. It was then offered to me, would I talk to a psychiatrist? I spent six weeks de-stressing and learning to relax. It's still not the same though as sharing problems and talking to other who are and have been in the same situation as yourself. We all get scared now and again.

They say talking is good... I was thinking; why can't we talk to each other more openly? We all come up for diff appointments, bloods, doctors etc. I think it would be good if we set aside one day every month to come up to Harefield and chat to others like ourselves, how we are feeling, our worries, concerns. We are not doctors, doctors do their best looking after us, sorting out our medications checking our test results, what is best for us.. Family and friends are there for us, what we really need occasionally is each other? Sharing the same concerns, worries, do you feel as I do? What we feel etc. I am sure we, at some time or other will look forward to popping up one month knowing we can talk openly to each other about diff thuds, medication how it affects us, do we all suffer the same, does our hair fall out? Do we get tingly fingers? We are all in the same situation and we can see how others are coping? I know it would do me good. 24 years is a long time of having a heart transplant with feelings and experience and sharing with others? Is there anyone out there who would like to get together, pour out our problems in a group of unique people who have all gone through something amazing, talking about our worries and concerns from time to time – I would - would you?

SECRETARYS BIT – *Alan Lees – Heart transplant 14 years*



Key points from the AGM

- The resolutions on the constitution were all approved.
- A way forward on the Presidency of our Club was agreed, details to follow when the appointment is confirmed.

Points of interest from the meetings in September (fun run day) meeting

The most significant news is that the judicial review has deemed the manner in which the consultation of children's heart surgery had been held is unlawful. Full information on www.rbht.nhs.uk or please write to me if you require information.

Other points from the meeting:

- Approved the funding for another batch of pins for 20 and 25 years.
- A draft of a new membership form, with provision for VAD patients as associate members had been circulated.

Space in the Newsletter necessitates a synopsis of the meetings. If you require a copy of the latest version of the constitution then please contact me: secretary@harefieldhamsters.org - or by mail to Secretary, Harefield Transplant Club, Welchwood House, 45 Parsons Heath, Colchester, Essex, CO4 3HX.

EUROPEAN HEART AND LUNG TRANSPLANT GAMES 2012 – *David Walker – Team Manager*



In 2012 these friendly Games will take place in a town called Apeldoorn in the Netherlands. Apeldoorn is 75 minutes by train east of Amsterdam and the date of the Games is from **27 June to 1 July**.

In my role as a member of the Management Committee of the EHLTF I visited Apeldoorn recently to review their Games arrangements.

They will use three separate hotels which are each situated in a woodland setting.

Coaches will take athletes and supporters to the various sports venues and the shuttle bus service will enable participants to move between sports, hotels and the town.

The sports facilities are excellent and those taking part I think will be suitably impressed.

Participants who wish to attend these Games will pay £450 approx.(€500) per person. This covers a 5-day fully inclusive package and includes hotel accommodation, transportation to and from the station to your hotel, the shuttle bus service, all meals; breakfast, lunch and dinner and a full social program.

The only extra cost is travel and participants can make their own arrangements to suit themselves. How you travel is of course entirely up to you. I am sure quite a number will drive. The current cost of diesel in the Netherlands is €1.28 per litre. The train fare from Schiphol, Amsterdam's airport, to Apeldoorn is €14 per person each way.

I will send out a full games information pack in December to those who are interested, by email. Anyone who needs a copy by post should telephone me (see end of Newsletter).

Further information is already available on their web-site: www.apeldoorn2012.com

EUROPEAN HEART AND LUNG TRANSPLANT GAMES – 2014 – David Walker –



Earlier this year on behalf of the British Heart and Lung Transplant Association I made a successful bid to host the 2014 Games to be based in and around Uxbridge.

The date of these Games will be the 24 to 29 July 2014. Please put this in your diary now as I hope you will all attend.

To support the bid I obtained agreement from the London Borough of Hillingdon to use their 50m Swimming pool, a Golf Club, the Cycle Park and the new Athletic stadium, with stand.

I also have agreement from Brunel University to use their sports venues for Tennis, Table Tennis, Badminton and Volleyball, and for the host countries special event, Archery.

I also visited the Park Inn hotel which is situated on the Bath Road next to Heathrow airport and have a provisional price for rooms and the offer of a separate dining room.

To organise such a major event takes a lot of hard work. I have already asked a number of people to become the core of a management group and there are a number of others I have approached to organise, help and assist with a variety of tasks.

Anyone else who would like to be involved please let me know as your help will be much appreciated.

Over the next few months we shall be producing a web-site and various other publicity materials. Please keep a watching brief on our progress.

We need to raise a substantial amount of funding to be able to put on these Games and I remain confident, despite the recession, that we will be successful. Gifts, donations, lottery winnings all very gratefully received.

Please contact me if you have any offers of help, money or suggestions.

RESULTS OF RAFFLE DRAWN AT REUNION WEEKEND – Jan Cherry – Heart transplant 19 years and Bob Cherry- Webmaster

Thank you all for taking part in our first raffle for the club, and thank you for the great response. We know that we all get swamped with requests for money, but this is all for a good cause.

We sold 1260 tickets for the raffle and a further £200 was donated in addition to the tickets sold.

The results of the draw :-

1 st Prize	£300 Mrs J. Edwards – She kindly put the prize back and the first prize was redrawn
1 st Prize	£300 (second try) Mr E. Rosenbaum
2 nd Prize	£150 Mr A. Hipkin
3 rd Prize	£50 Mr A. Lees (The prize money was donated back to the club - Thank you)
4 th Prize	£50 Mrs M. Hill
5 th Prize	£50 Mr M. Dyer (The prize money was donated back to the club - Thank you)

£752 was added to the clubs coffers

SPACE CADET 56 BOOK 1 PUBLISHED ON IPAD – James Tottle – Heart transplant 14 years

I have recently published a multimedia app, with an apps developer called IntoHand. It is an illustrated book with 200 cartoons and 7 original rock music tracks. I am doing some test animations which I hope to add animation to the free app version and updated version by December. Here is the link to the preview page in the apple itunes apps store:

<http://itunes.apple.com/gb/app/space-cadet-56-book-1/id468642876?mt=8&ls=1>

I am 14 heart transplant recipient from Harefield Hospital, one of the songs in the app is called "Cut Me Some Slack" and is about my heart and is dedicated to my donor and donor family. My co-author David Inker has had the major challenge of being a quadriplegic wheel chair user, after he had an accident in the army.

This book is aimed at 12+ audience (teen fiction market), and is a colourful story about a man who thinks he's an astronaut. His only problem is he's stuck in a New York mental hospital and no one believes him, except a nurse called Hope. The book is a basis for a TV series or movie.

Any further information - James Tottle

01225 465990 – 07910 967965 – www.sc56.org.uk

HAMSTER WEEKEND FRENZY - *Justine Laymond – Double lung transplant 5 years*



What happens when you mix a weekend full of spare parts, a mystery red wine drinker writer, masks, and plenty of giggles? Hamsters partying! I have wanted to attend one of the Harefield Hospital weekend reunions, but every year I have been away. Finally, my holiday done and dusted I was free to meet up with approximately 90 people, and about 30 of those who were actual transplantees.

I was overwhelmed with the amount of people and told normally more go! It was especially great for me to meet and chat with people who perhaps don't attend the transplant games and to be inspired by hearing other people's stories. The first night was that of a theme 'mask' night and was great to see many people dressed up for the occasion. I have a fuller account on my blog www.justinedoublelungs.blogspot.com with plenty photos too (for anyone who would like to read/see more). A lovely three course meal was served, all fancy foods and very tasty indeed! I had a mission for myself to find out who was the 'mystery red wine drinker' who writes for this Hamsters newsletter. So in my disguise started to see who was drinking red wine...ok ok.....after a glass myself I decided this was a mission impossible judging by the about of red wine drinkers!

After the meal we all paraded onto the dance floor with our masks and lucky me I won and was given a bottle of champagne ☺ The jokes were also on Jamie Baxter who got 'cloned' with about 20 Jamie masks, guess you had to be there – but it was VERY funny!

The next day was a lovely stroll into Bournemouth itself along the beach front and the sun shone gloriously, such an awesome day. It was great to be able to spend time exploring the markets. Lunch was at a local pub followed by a little bit of shopping at Primani (Primark) and then a nice walk back to the hotel. I was actually a little bit worn out and hoping to get what seemed like a children's fun train back along the beach (to cut out a lot of walking). But it was a long wait, so, as a group we slowly walked back and up a hill to the hotel (obviously with few 'breathe' stops).

Phew.....back at the hotel and I almost collapsed in a chair and needed to chill for sometime before getting ready for another fun filled evening. The night involved another luscious three course meal followed by music and dancing. I was asked along with a few other ladies to help sell raffle tickets so my opening line was, "£1.00 for a strip".....needless to say I sold many ;)

I had such an amazing weekend and appreciated meeting new people and loved the whole ambience from the weekend. Next year, is the 30th celebrations and you bet I will be there – just try and stop me! So, what are you waiting for, come along and join in on the fun! x

YOU'LL NEVER WALK ALONE - *Debbi and Kat - E Ward Nurses*

It's a song all the Hamsters know the words to. To all intents and purposes it's their anthem, and it's the Transplant Games' anthem as well. The words of the song evoke the atmosphere of the weekend which is that of a large family.

We both had a sense of apprehension when we got there which was, 'did we have the right to be there?' however this feeling very quickly dissipated and we were made to feel very welcome. We felt like we were being invited to join a family. It's easy to tell that the Hamsters are a family. We were told about numerous pranks that have occurred over the years. We even witnessed several pranks. There is also an amazing sense of camaraderie and friendship, the transplant wives who are still friends after 30 years, even though some of their husbands are sadly no longer with us. The Hamsters are a friendship that lasts a lifetime.

During the AGM the transplant families and friends headed into Bournemouth for a little shopping (Primark's profits are bound to have increased considering the number of shopping bags that appeared back at the hotel in the afternoon!)

After the struggle up the hill from the beach and the walk back from Bournemouth on the Friday we took the land train back on the Saturday, to conserve energy for the evenings' dancing (and the hill of course!)

The weekend has enabled us to reconnect with the reasons why we decided to join the Transplant Unit, and has given us both a sense of how important it is that the Hamsters continue to grow. We will take every opportunity to inform our patients about the Hamsters and the extra support it can offer newly transplanted patients. We can only say to any Transplant staff that read this article that if you have the chance to go a Hamster's event that it is a must! You will not meet a more sociable group of people and you will laugh all weekend. All that is left to say now really is thank you all very much for such a fantastic weekend. You gave us both such a fantastic insight into post transplant life and we hope to get the opportunity to see you all again (outside the hospital of course! Unless you're just visiting).

FROM AN 'OLD HAND' - *Mandy Hipkin- Artificial heart nurse specialist*

As usual I enjoyed the weekend. It was good to see everyone and catch up on your news. Well done and thank you to the organising team.

As some of you are already aware, I have been asked to speak at the British Association of Critical Care nursing conference in April next year on the Transplant Games and Harefield Hamsters. I would like to include some patient's points of view and what they mean to you, your family and friends.

If anybody else would like to contribute please feel free to e-mail me at m.hipkin@rbht.nhs.uk with your comments, type of transplant and how many years post transplant you are. Thank you to all those that have already contributed, I have some great quotes and none will go to waste.

ANNUAL AWARD WINNERS 2011 – David Walker

Each year at our Annual Dinner your Committee present various cups and awards. The names of the winners are recorded in the Club's hall of fame to be found in our showcase in Transplant Outpatients. The winners keep their Club trophies for a year and as a memento of their achievement also receive a replica which they keep forever.

Best Newcomer

The cup for the Best Newcomer is awarded to the outstanding Harefield athlete who achieves the best result at their very first British Transplant Games. This year the award was won by **Lisa Muscutt**.

Junior Trophy

In 1995 the Committee decided it was time to start awarding a special Trophy for Junior members of the Club. The purpose of the award is to acknowledge and encourage ex-Harefield children taking part at the British Games. This year the award was won by **Jade Carr**.

Pinfield Prize

The Pinfield Prize was originally presented to a competitor in recognition of the amount of effort put in but which was unlikely to ever bring home a medal from the British Transplant Games. This year there was no suitable person, so the award was not given.

Special Award

The Hamsters Special Award is presented to the person whom the Committee feel has epitomised the true spirit of the Club during the past year. We try and look further than just sporting achievements. Other factors which are also considered include: personal profile, commitment to the Club and its members, fund raising, the Clubs external profile, the individuals giving of themselves selfishly for the benefit of others. The committees unanimous decision was to make this award to someone who has been a member of the committee on and off for many years and who quietly and efficiently takes her responsibilities very seriously. The winner was **Ann Woodbridge**.

Ladies Swimming Trophy

This cup was kindly donated in 2003 by Mrs Katie Soonawalla and is awarded to the best female swimmer at the British Games. This year's winner was **Emma Hilton**.

I'm sure all club members join in wishing hearty congratulations to the winners. We hope that all members of the club will endeavour to enjoy their lives and we look forward to presenting these awards again next year.

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HAREFIELD TRANSPLANT CLUB - COMMITTEE DETAILS 2011/12

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DIARY DATES

**14th European Heart and Lung
Transplant Games**
27 June – 1 July 2012
Appeldoorn – Netherlands
Contact – David Walker

TEAM MANAGER

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British Transplant Games

23 – 26 August 2012
Medway
Contact – Brian Unwin

COMMITTEE

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Annual Reunion Weekend

19 – 21 October 2012
Hilton Hall Puckrup Hotel
Tewkesbury



*Well everyone before I sign off I just want to remind you of a very very important event next year. It is the 30th Reunion of our wonderful, unique club. Arrangements are already in hand and the venue is booked. It will be at The Hilton, Puckrup Hall Hotel in Tewkesbury. The cost will be £75 per person per night – to include Dinner, bed and breakfast, incorporating our Gala dinner on the Saturday evening. So please put this date in your diary and join us for what promises to be a very special weekend - **19-21 October 2012**. More details will follow next year.*

All that remains is for me to wish you all the seasons greetings because by the time you receive this, it will be that time of the year. So from me and all the committee – we wish you all “A Very Happy Christmas and a Healthy 2012”

Jill – Chairperson and Editor

P.S.- Sherrie Panther – (Modern Matron) says - “The whole Transplant Unit staff would like to wish you all a Merry Christmas and Happy Healthy New Year”. Here are some of her jokes!

What does Mrs. Clause use to make her cakes? Elf-raising flour.

Where do snowmen dance? At a snowball

Who takes Christmas presents to the police stations?..... Santa Clues

What did Adam say on December 24th?..... It's Christmas, Eve.

What do gorillas sing at Christmas?..... Jungle Bells, Jungle Bells...

What does Rudolph want for Christmas?..... A snowy sleigh station!

What do you get when you cross a vampire and a snowman?Frostbite!

What goes ‘oh,oh,oh’?..... Santa walking backwards!

What did one snowman say to the other?..... Can you smell carrot?

