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HAREFIELD TRANSPLANT CLUB NEWSLETTER

Edition 26, June 2019



DATES FOR YOUR DIARY

Cake Sale

Harefield Hospital
Thursday 27th June

British Transplant Games

Newport, Wales
25th–29th July

World Transplant Games

Newcastle
17th–24th August

38th Annual Fun Run

Harefield Hospital
Sunday 8th September

Club Reunion & AGM

Riviera Hotel, Bournemouth
25th–27th October



Well, we're nearly halfway through the year and I hope you have been more successful than me at sticking to your resolutions for 2019!



As summer comes into full swing, the warmer weather helps keep me motivated to get outdoors.

The birds singing when I walk the dog at 6am put a smile on my face, I open all the windows in the house and breathe in the delicious air, I feel incredibly grateful for life. Like many of you, I have lost some friends in the last few months due to rejection, infection or other horrible diseases like cancer. I miss them dearly but I try to channel the sadness into an energy much more useful to myself and others and this lovely weather makes that task a little bit easier.

I am incredibly excited for this year. So many of you are doing amazing things to raise awareness for organ donation and funds for the club. James, who only received his double lung transplant in August last year, ran his first half-marathon at the end of March. Mary, our Newsletter Editor, agreed to join me at the Blenheim Palace Triathlon

on June 1st. We survived and are keen to tackle another one before long! There are cake sales, fun runs, festivals, Transplant Games, and of course our club reunion – so we will all be kept on our toes – but if you are doing anything we are not aware of please let us know and we will promote your event... or even join you!

Harefield Hospital is doing fabulous work not just on the transplant front but also creating a beautiful garden by the entrance of the hospital, opposite the Gate House. There will be a hard surface, shelter and plants to allow bed-bound patients to be wheeled out into the fresh air. Ward Matron Helen Doyle is managing this project but is hard to reach directly so if you would like to make a donation or get involved, please contact me and I will liaise with Helen.

Janka



Annual Reunion Reminder

Hi All,

Just a reminder about this year's annual reunion dinner. We will be staying at the Riviera Hotel Bournemouth, October 25th to 27th.

For the oldies amongst us, you will remember this has always been a favourite of the club members. We have usually been blessed with excellent weather and the hotel has always looked after us. Because of previous reunions being held there, we have been extremely lucky to get an excellent deal.

The booking form for this reunion will be sent out later this month.

Here are a few pictures as a reminder about the hotel.

Look forward to seeing you there,

Karen and Paul



World Transplant Games 2019



It still seems a while away but the athletes that have been picked to compete for Team GB at the World Transplant Games in Newcastle this summer are already in full training mode. I am

extremely proud to say that **#TeamHarefield** will be represented by 11 competitors at this event!

Emma Hilton will be giving it her all on the volleyball court and on the track, with Doug also playing volleyball and joining fellow badminton players James Doherty, Prem Kathirgamarajah, Sam Roonan, Lisa Innes and Jade Carr in the competition. Howard Waters and Janka Penther will do their best in the pool. Jade will also compete at table tennis, Jason Gallagher will join the team for the darts event and Jo Peard

who has transferred from Great Ormond Street Hospital will make his WTG debut in the adult team at basketball.

We would love for supporters to join our athletes and cheer them on to bring back some bling! The WTG run from the 17th–24th of August, and all sport events can be attended free of charge. Organisers are also still looking for volunteers and you can sign up on the WTG website:

<http://worldtransplantgames.org/>

Fundraising events

On Sunday 2nd June, club Chair Janka Penther and Newsletter Editor Mary Forbes took part in another challenge for the Harefield Transplant Club. Together they swam/cycled/ran the beautiful grounds of Blenheim Palace in the Super-sprint category, celebrating life and raising money for the club. Janka and Douglas (Mary's husband and club Secretary) are both celebrating 6 years

with their new lungs in 2019 – a gift they will always be grateful for.

They both found the challenge exhilarating and would certainly do another one. If you're interested in trying this combination of sports, please contact Janka via email on janka.penther@hotmail.com and hopefully we can do another event as a larger team!



Karting at Buckmore Park



A team of transplants is competing in the 3-hour endurance race at Buckmore Park, north of Maidstone, on Saturday 8th June. Amongst the team are Ian Horner and James Doherty.

If you want to support the team: Practice from 3.30pm, with the race starting at 4.15pm. Presentation and bar around 7.30pm.

James Beeching for Organ Donation

When James, who was born with cystic fibrosis, received his double lung transplant in August 2018, he vowed he would do something to help others get that same chance.



Now he is not only doing this himself, but has also drummed up some considerable support! Together with a team of 30

runners and fundraisers, he has completed the Hastings half-marathon in aid of the Cystic Fibrosis Trust, who have supported him all throughout his life.

Everyone on his team wore a pink I DONATE T-shirt to spread the word about organ donation and show the amazing impact organ donation has on lives like James'. They even had a mascot! Well done James and his team of runners!



Fundraising events, continued

Harefield Fun Run 2019



The annual fundraiser for Harefield Hospital is taking place on Sunday 8th September and we are looking for helpers at our stall as well as keen walkers/joggers/runners who are keen to join **#TeamHarefield**.

Come along to meet up with old friends, make new ones, and celebrate the second (or third!) chance we got in life by supporting our wonderful hospital.

To get involved, please contact Janka at:

janka.penther@hotmail.com

Meadowlands Festival

Ana, a friend of Janka's, is organising a fun family day festival in aid of the Harefield Transplant Club to be held on Saturday August 17th from 11am–9pm near Oxford.

Ana says, "I wanted to organise something fun and family friendly for the people of Wootton to enjoy whilst raising money for the Harefield Transplant Club. We think that raising valuable funds for a charity who support those who have had or are waiting for a life-saving organ transplant and their families,

whilst bringing the village together to have some fun, is a great idea.

It will be a full day of music on two separate stages, food stalls, a bouncy-castle and of course a bar! We hope that we can really put on a great party!"

We are planning to have a stall with info about organ donation and another one selling some art and other wonderful creations so



VOLUNTEERS ARE NEEDED!

If you are available on that day and are happy to help out (if you are a transplant recipient would you be happy to share your story on stage?) please contact Janka at

janka.penther@hotmail.com

Ready, steady, bake...!

On Thursday June 27th, from 10am–3pm, we are hosting a cake sale at Harefield Hospital. This is a fundraiser for the club and a great opportunity to catch up and eat cake while getting bloods/clinic appointments done!

The cake sale is always a huge success thanks to your fantastic support, so we are once again asking you to put your aprons on and pretend



you are working for one of Paul Hollywood's famous handshakes! Alternatively, you can pop into your local shop and buy something nice... We don't mind, it all sells like hot cakes.... (pun totally intended!)

If you are able to promote the event in the hospital and in the village (flyers will be provided by the club), can donate something delicious or are available to help out on the stall, please get in touch with Brian Unwin at:

b_unwin@yahoo.co.uk

Getting to Know Your Committee

You know they love Harefield Hospital, but have you ever wondered what you might *not* know about the Club committee?

They've volunteered some fun facts to help you get to know them a bit better. All you have to do is match the fact to the person. Easy, right? Answers on page 8.

1. "I competed in a school cross-country event where three competitors were disqualified for hitching a lift on a milk float on the road section."
2. "I spent the day on Salisbury plain playing ambush with the army in a warrior tank."
3. "I once took paid work as a palm reader."
4. "I performed in front of hundreds when I took my Westie to Crufts as part of a demonstration team."
5. "I refuse to eat Haribo sweets that haven't been kept in the fridge."
6. "I appeared on the Channel 4 quiz show 15-to-1, and made it through to the second round."
7. "I can't bend my big toes as I have screws going through them."
8. "I was cast in a commercial as a baby and did modelling shoots until I was school-aged."
9. "I was one the face of a national charity fundraising campaign, with my poster on bus stops around the country."

- A. Janka Penther
- B. Rob Longrigg
- C. Alan Lees
- D. James Doherty
- E. Paul Taylor
- F. Karen Taylor
- G. Maggie Williamson
- H. Douglas Forbes
- I. Mary Forbes

30-year Pin Thank You

I am Ingrid Bergman from Holland and I would like to thank you for my 30-year pin received in 2018.

I express my feelings of gratefulness in this way:

Here it all happened: the best hospital & staff, and the Hamsters!

A heart and lung transplant: 02-07-1988

Really lucky I was, and blessed

Extra years added to my life: 30(!) already

Forever grateful

Ingrid Bergman is my name

Every year a burn a candle on my "special day"

Love I feel for my husband, family... and life!

Donor: it is all about YOU!!!



Ingrid Bergman

Did You Know I've Had a Transplant??

Rob Longrigg shares his approach to talking about his health

I was always very secretive about my CF when I was growing up. I don't know if I was ashamed of having CF, or if I believed that if I didn't acknowledge my illness it didn't really exist. The first time my mates found out about my CF was when we returned from our first lads holiday (1990 – Aya Napa) and I was admitted straight into the Brompton with a chest infection. No more secrets then!! After this experience, I started to grow up. When I moved to university, my attitude to CF had changed. When I first met people in my halls, I told them (they would hear me doing physio anyways). Gradually, as I made friends, I found it easier to talk about CF and answer the barrage of questions.

When I received my transplant I couldn't keep quiet about it. In the first year, I would often introduce myself immediately followed by: "Did you know I've had a transplant?".

I felt very proud of the fact that I had received a transplant and wanted to shout it from the rooftops. In those early days of my transplant, it was my whole identity. I struggled psychologically with the impact. Why did I receive a transplant and friends didn't? Why did my donor die and I lived? I had to deal with the elation and guilt of still being alive. In time, I realised that my

transplant wasn't my whole identity. It enabled me to find my character and personality through good health. This in turn changed my approach to talking to people about my transplant.

The most important person in my life, Mel, my wife, I didn't even have to tell about transplant. Mel was a supporter of the HTC team at the Loughborough 2005 Transplant Games. She saw me win my first medal (silver in swimming) and, after my amazing performance in Speedo's, she worked it out for herself. It was definitely worth all the hard work training in the pool!

I knew that getting back to work post-transplant was crucial for my rehabilitation. I took the approach that honesty was the best policy, whether for a paid or voluntary position. I always informed potential employers that I would be need time off for hospital appointments and to be prepared for health issues. I took the view that they would select me if my skills were best suited for that particular role. And if I wasn't successful, that was their loss.

This attitude seems to have worked. I have been very fortunate to have understanding employers over the past 15 years. I have had numerous weeks off work

with complications related to transplant. I believe I have been able to establish a relationship of mutual respect and trust, starting with that first meeting explaining my health and the impact it may have on the job.

On each occasion that I have been off sick, I have looked forward to going back to work as soon as I have been well enough and I have been welcomed back by all.

Having a transplant is something to be extremely proud of; we are a fortunate bunch. I generally like to get to know someone a little bit before I talk about my operation, shortly followed by asking them if they are on the Organ Donor Register and their views on transplantation. Having a transplant has enabled me to find my confidence and reaffirm my identity. Talking to people about transplant has helped me get this place.

Rob Longrigg

Memories of George Compton, of Live Life Give Life

As many of you may know, February saw the sad news of George Compton (AKA Sproglet) passing away.

George had a double lung transplant in August 2015 following on from continued poor health due to CF. She then had 3.5 amazing years with her new lungs. Sadly, in December she faced rejection and, following this, a string of infections which sadly took her life. She died in her mother's arms on 26th February. When George was told her fate by the doctors she said, "If the worst does happen, I want my legacy to be that I lived, I loved and I did it all with a smile on my face". This she certainly did. You would never see her without her beautiful smile.

George wholeheartedly made the most of her life with her shiny new lungs. Every day was a true gift, she was full of life. She was the life and soul of the party and lit up any room she walked in to,

she always had everyone in stitches. George loved to have fun, but alongside this she was a caring and supportive friend to everyone who knew her. She was always there when you needed someone to talk to, whether it was about your health or general life problems (or just Love Island gossip!).

Alongside living 'her best life' and making memories, George worked continuously trying to raise awareness of Organ Donation and was constantly trying to help others. She was a pillar to the community in both the CF world and to the transplant society. The world will certainly be a quieter place without this cheeky little one around. Even in her final days she was organising a fundraising project to renovate the area outside Rowan ward into a lovely garden so patients pre- and post-transplant can enjoy some fresh air and sunshine (let's not forget George loved the sun). George will be remembered by so many for various different

reasons, but all I think will remember her for her bubbly personality and her huge heart.

George was an inspiration to all. No matter what life threw at her she still had that smile on her face. She was funny, kind, brave, loving and above all she was George and she loved her life. "I can honestly say I will die the happiest girl ever and look back and say 'Yeah you know what, I made the most of that.'"



A note from your committee

You are welcome to contact the newsletter editor (editor@harefieldhamsters.org), should you wish to play tribute to any transplanted HTC members who have recently passed away. However, from the next newsletter issued, any tributes will be limited to the member's

name and type of transplant, along with any dates you feel are necessary to include.

We hope you understand our decision.

Answers to Committee Fun Facts

1C , 2E , 3I , 4F , 5A , 6B , 7D , 8G* , 9H

*Evidence! Young Maggie:



Harefield Transplant Club Committee Members' Details 2018-2019

CHAIRMAN Janka Penther



I am 35 years old, have Cystic Fibrosis and received a double lung transplant at Harefield in April 2013. I joined the club in 2015 and became a committee member after my first AGM in Witney (2015). I was appointed Chairperson at the AGM in Bournemouth (2016). I was also Team Manager for the Harefield Team at the British Transplant Games in Scotland 2017.

chairperson@harefieldhamsters.org

TREASURER David Walker



I have been a member and supporter of the club for 30 years. My son Alex is the transplant (heart) patient. I have been on the committee a long time. I became treasurer 4 years ago.

01895 6737770 / 07737 462731
walkerdavid525@gmail.com

VICE CHAIRMAN Alex Walker



I had my heart transplant 30 years ago and I have been a member of the club since day 1. I have been a member of the committee for many years, including as Chairman in 2016-17. I have competed in the British Transplant Games ever since my transplant.

01795 590130

SECRETARY Douglas Forbes



I had a double lung transplant in August 2013, as a result of CF, and have been a member of the club for a year. I am a relatively new member of the committee, appointed at the Bournemouth AGM (2016).

TEAM MANAGER Brian Unwin



I have been a club member for many years and have held many committee positions over the last ten years or more, including 3 years as Chairman. Since my heart transplant in 1988, I have been selected to represent Great Britain and Northern Ireland in 3 world transplant games.

MEMBERSHIP SECRETARY Rob Longrigg



I have been a member and supporter of the club since 2005. I had a double lung transplant in October 2003 due to CF. I joined the committee at the AGM in 2015.

NEWSLETTER EDITOR Mary Forbes



I joined the club in 2015 with my husband, Douglas Forbes, 2 years after this lung transplant. I am a keen supporter of Team Harefield at the British Transplant Games and have newly taken on the role of Newsletter Editor.

editor@harefieldhamsters.org

COMMITTEE MEMBER
Karen Taylor



I have been a member and supporter of the club for 30 years. My husband Paul had a heart transplant in 1987. I have been the Newsletter Editor for 5 years.

COMMITTEE MEMBER
Maggie Williamson



I am a new committee member, having been appointed at the 2018 AGM. I had my lung transplant 4 years ago, in the USA, and am now loving life in the UK.

COMMITTEE MEMBER
James Doherty



I have been a member for around 2 years now. I had a double lung transplant in September 2013. I have been on the committee since the AGM in Oxford in 2017.

COMMITTEE MEMBER
Paul Rooney



I had my heart transplant 20 years ago at Harefield. I have been an associate member of the club for many years but have held a full adult membership for 4 years and joined the committee after the 2015 AGM in Witney. I'm a regular attendee of the British Trnasplant Games and have a long-running association with Harefield Children's and Adults.

COMMITTEE MEMBER
Alan Lees



I joined the club shortly after my heart transplant in 1997. I have served on the committee since 2011.

secretary@harefieldhamsters.org

COMMITTEE MEMBER
Paul Taylor



I have been a member and supporter of the Club for 30 years since I had my heart transplant. I have been on the committee for a number of years and have previously held the position of Membership Secretary.

Reminder that the Committee meeting minutes are freely available.

Email, phone or write to:

The Secretary
40 Fairfield Parade
Cheltenham
GL53 7PJ

01242 462 226

Royal Brompton and Harefield website: www.rbht.nhs.uk/about/news-events



Harefield Transplant Club

www.harefieldhamsters.org



@HarefieldTxClub