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HAREFIELD TRANSPLANT CLUB NEWSLETTER

Edition 36, August 2023

DATES FOR YOUR DIARY

Harefield Fun Run and Family Day
10th September 2023
Harefield Hospital

Club Celebration Weekend
22nd – 24th Sept 2023
Riviera Hotel, Bournemouth

Run for Healing Garden, Royal Parks Half Marathon (RBH fundraiser)
8th October

Transplant Sport Volleyball Event
4th November 2023
Nottingham Trent University

Transplant Sport Racquets Event
5th November, 2023
Nottingham Trent University

A Word from the Chair…

As I am writing this edit, the TV blares the latest Wimbledon results at me: Venus Williams has just lost to a young lady from the Ukraine. I am thinking that I cannot imagine what both women have gone through to get where they are now, the sacrifices they have had to make, the pain they had to endure and the effect it has had on their loved ones around them. Because it's not just the athlete, the warrior, the survivor that goes through this – it is also their families.

It made the reflect on my own transplant journey which I have now been on for a decade and who is still around me since that day in April 2013 – and who has joined me since. It has been a decade, but it may as well have been a century – I packed so much into these days, weeks, month, and years! I don't want to waste a second as I am so mindful that I live on borrowed time. Do some of you feel like this sometimes?

But in the end, it's the quality not the quantity of events, isn't it. Maybe better not to rush through the days but to savour them for what they are – extra time, bonus rounds, a gift that is so very precious it is difficult to put into words what it means.

But that's exactly what I have done. I put into words what this gift means to me and those around me. What my fears were then and what they are now and how grateful I am to be alive. That's what I put into the letter to my donor family that I sent 10 years after my transplant. Not to receive a letter back. But to say, "Thank you" and "I am so sorry for your loss". And "this is what you and your loved one gave me". I can only encourage everyone to write to their donor family, it is anonymous and safe and if you are stuck of what to say, Harefield Hospital will help. Just speak to the Transplant Coordinators.

Whist we are on the topic of gratitude – I would like to express mine to you all. I will not be standing as chair for the next committee (2023/2024). I have been part of the HTC committee for the past 8 years with most of this time spent as Chairperson – a role I have been very privileged to hold, especially with so much support from the club committee. Together, we have grown the club and raised

funds and awareness, we are now networking with other transplant and organ donation charities and now have open communication channels with Harefield Hospital, Great Ormond Street and the Royal Brompton as well as the Guys and St Thomas Trust. We have had continued support from Harefield Hospital and thanks to many of you, most of Harefield Hospital is now aware of us.

But I do believe in change and that it is necessary to continue progress. This club needs and deserves a chair who will commit more of their time than I can at the moment and whose passion and love for the club and our transplant community continues to move this fantastic club forward. However, this also means that our committee needs your support. We need more of you who are willing to get involved – otherwise this club will fold, which would be a great shame.

I can tell you first hand; it is an absolute privilege to work with a fabulous bunch of people who all have the same goal: To support others on their transplant journey – and those around them. Because just like those Wimbledon stars, they wouldn't be there without their support team!

So as this is my final piece as Chairperson of the Harefield Transplant Club – thank you.

Janka

40th Annual Harefield Fun Run and Family Day

The time of year is upon us – the Harefield Fun Run has its 40th anniversary this year, and Harefield Transplant Club will be there to celebrate on Sunday 10th September! There are fun and games to be had in the grounds of Harefield Hospital, and a 4-mile run/jog/walk route to navigate (there is also a shorter route if you prefer).

The grounds of the hospital are turned into a fun day with loads of stalls, food trucks, music and entertainment for everyone. Your Club will be there with a stall of our own – please come and say hello! We even have our own team for the run/walk – contact Janka Penther (janka.penther@hotmail.com) if you would like to join us!

British Transplant Games 2023

It was an absolute privilege to lead team Harefield at the British Transplant Games in Coventry this year.

We had a team of 11 athletes and 10 supporters, across lots of different sports – athletics, swimming, darts, squash, badminton, tennis, volleyball, bowling, archery, and cycling! We also had 3 first-timers on our team – Dawn Bostock, Lynne Ogden and John Conway – who were all fantastic, competing hard and doing themselves, Harefield, and their donors very proud.

Between us, we managed 15 medals! 7 golds, 6 silvers and 1 bronze – not bad for a small team! The donor run, as always, was a highlight, and we brought along a large group – all standing out in our bright-red Harefield kit and some very funky headgear! After that came the now traditional team meal at Nandos, at which we had 16 of us – along with a team of kidney transplant recipients from St Heliers hospital, and all had a great time!

Anyone who would like to be part of future transplant games, the next British Transplant Games will be in Nottingham, from 1st to 4th August 2024. And there will also be European Transplant Games in Lisbon, Portugal, from 30th June to 6th July 2024, which anyone can enter, too!

Contact me on team. harefield@harefieldhamsters.org for more details!

Pete

Club Celebration Weekend

We're getting ready for our weekend event – the Harefield Transplant Club Celebration Weekend! Formerly known as the Club Reunion, we're holding it at one of our favourite venues – the Riviera Hotel in Bournemouth (www.rivierabournemouth.co.uk). It's the first chance since Covid for our members (and those still to join!) to get together and celebrate the gift of life and the second chances many of us have received as a result of the generosity of our donors and their families.

We have a weekend of fun, games, music and dancing planned! It's always good fun and wonderful to meet new friends (and old)! It's a chance to meet your Club Committee and participate in our AGM, to see the real nuts and bolts of Harefield Transplant Club and influence decision making. We're always on the lookout for new Committee members, so if you think you might be interested, please do come along (or let us know, if you can't make it).

Please contact our chief organiser Tracey Baker (traceybaker8@icloud.com) **if you are interested in coming along** – or if you have any questions. **Even though the official deadline has passed for you to register your interest, we might well be able to squeeze you in!**

HAREFIELD TRANSPLANT CLUB

HTC Celebration Weekend
Come and join the fun!

HAREFIELD TRANSPLANT CLUB

Location: The Riviera Hotel, Bournemouth, Friday 22nd–Sunday 24th September 2023

Friday- Fancy dress dinner, quiz, DJ. Theme is anything YELLOW

Saturday- AGM, board game afternoon, multiple local attractions & tours, celebration dinner with raffle, DJ, Karaoke

Sunday- Walk and home time

To find out more details and how to book please visit the Harefield Transplant Club web page harefieldhamsters.org or Facebook page or email traceybaker8@icloud.com

You do NOT have to be a member of the club to come along to the weekend.

A Harefield Wedding!

Congratulations to Emma Hilton and Craig Jones on their wedding, on 3rd June 2023! Emma received a heart transplant at Great Ormond Street Hospital when she was a child, which saved her life, and Craig was lucky enough to receive a lung transplant in 2017 at the Freeman Hospital. Both have had their fair share of challenges post-transplant, but both have had absolutely amazing times, including competing for Team GB at the World Transplant Games. Now they have decided to spend the rest of their lives together and we wish them all the very best!

Congratulations, Emma and Craig!

Pharmacy Guidance

Medications in the summer

If you would like further information or have further questions please contact the transplant pharmacy team via email; transplantpharmacy@rbht.nhs.uk or call via the transplant clinic on 01895 828 663 (ask for pharmacy).

Fun in the Sun?

With the recent heatwaves we've had in the UK recently it would be easy to have the same mentality of other Brits of soaking up the sun. But we have a couple of helpful reminders on how to stay safe in the sun over the summer.

Your anti-rejection medications increase your risk of skin cancer and so extra care is needed in the sun. Please try and avoid sunlight exposure as much as possible.

- We advise the following:
- Keep your skin covered as much as possible
- Always apply suncream with a high sun protection factor (SPF), at least factor 30
- Never let yourself get sunburnt
- Avoid being in strong sunlight particularly between 11am and 3pm
- Wear a wide-brimmed hat and sunglasses

Team Harefield in Perth Report

The first post-Covid World Transplant Games were held in Perth, Australia in April this year, and Harefield were represented by 4 athletes out there, among a British team of over 250 people. We had 2 heart transplant recipients, with Caroline Rutherford (our Treasurer) competing in swimming events, and John Allen in squash and badminton, as well as two lung transplant recipients – Peter Knox (that's me) in tennis and squash, and Amanda Chalmers (who's had 2 lung transplants, among other things) in tennis and table tennis. First of all, it was an amazing experience for all of us to be out there, enjoying the gift of life but also meeting other transplant recipients from all over the world. The opening ceremony in Optus Stadium was spectacular – team GB was the second biggest behind the hosts Australia, and we certainly made our voices heard!

Once the games began, John and I started in the best possible fashion, both winning gold medals for squash in our age groups. The next day, Caroline followed up by absolutely smashing it in the pool – she got a frankly ridiculous 4 gold medals (all of which were world records), 2 silvers and a bronze – not bad for a day's work!

The medals kept coming the next day, as I and Amanda competed in tennis singles events. It was an incredibly long, hot day in the sunshine (lots of suncream, water and salt tablets required!) and at the end, I came away with a gold medal and Amanda a silver. I also managed a silver medal the next day in men's doubles, partnering with a heart transplant recipient from Liverpool, then Amanda and I teamed up in the mixed doubles – we didn't manage a medal but competed well and had a great time. While this was going on, John was also busy competing in his second event – the badminton men's doubles, where he managed another bronze medal for our tally.

On the final day of competition, Caroline competed in the swimming leg of the team triathlon, which (though I wasn't there to see it) was apparently a complete mess organisationally, and her team didn't manage to get a medal sadly. Amanda also competed in the table tennis doubles on this day – no medal, but she loved the experience and she's already training for next time!#

All in all, we've all had a fantastic time out there – it's a real privilege to be able to represent our country and Harefield, and to celebrate the gift of life in this way. We're all looking forward to going again – the next World Games are in Dresden, Germany in 2025, and there will be European Transplant Games in Lisbon, Portugal next summer. We'll also all be competing at the British Transplant Games 27th – 30th July this year, so come and say hello and support the team!

Pete

John Allen's World Games Report

Following 8 years of heart failure, I finally had my heart transplant at the Harefield Hospital in April 2018. These guys really looked after me and I feel extremely lucky to be looked after by all the staff there!!

Very, very quickly, my health improved significantly and, just a few short weeks following my discharge, I was able to begin cycling again.

Feeling well and strong early in 2019, I approached Dr Dar and the Cardiology team and asked if I could return to playing squash. Without a second's hesitation I was told that I could…. with no conditions attached.

Covid-19 intervened for a few years, but then in the British Transplant Games held in Leeds in July 2022, I managed to achieve a Silver Medal at Squash. On the strength of this result, in Sept 2022, I was privileged to be selected

by Transplant Sport UK to represent Great Britain at The World Transplant Games in Perth Australia in April 2023.

So, travelling to Perth with approx. 120 other GB competitors, (including some from Harefield, see the image below), I was able to win a Gold Medal in the squash over-60's competition. A fantastic, unforgettable experience, and one I hope to be able to repeat in Dresden in 2025.

All of this has been made possible because of organ donation and – of course – the expert care given at Harefield. It would be wrong of me to single out any individual, so all I can do is pass on my thanks to everyone there. I never tire of visiting despite the distance involved.

I hope that my brief story can give some hope to those in a similar position to that which I found myself in back in 2010.

John

"*You got to have some faith when you're in the lions den.*" (Ray Wylie Hubbard)

Travel Check List

Many of us will be going away this summer, whether that's enjoying fish and chips at the British seaside or travelling abroad. Post-transplantation there are a few handy tips and things you need to do prior to going away to ensure a smooth and safe holiday.

- 1 month before going away check your supply of medications and arrange additional if required (don't leave this until the last minute!)
- If travelling abroad, contact the transplant clinic for a fit to fly letter, as well as a list of your current medications.
- When packing take an extra 2 weeks medications away with you, just in case.
- If you're flying make sure you pack your medications in your hand luggage, so they can't get lost by the airline.
- Protect your skin from the sun
- Stay hydrated

And most importantly…. HAVE FUN!

PROTECT-V: PROphylaxis for paTiEnts at risk of COVID-19 infecTion

PROTECT-V
PROphylaxis for paTiEnts at risk of COVID-19 infecTion

Currently there is a nationwide trial being conducted of how well certain medication works as a prophylaxis for patients who are extremely vulnerable to COVID. As part of this trial, Harefield Hospital may contact you to offer you a space on the study. Please find some key information below. If you are interested in taking part, please contact Harefield at this address: hh-research@rbht.nhs.uk

1. The purpose of the trial

COVID-19 is an international health emergency which impacts the lives of all individuals in the UK. There is an urgent need for medicines that can prevent or treat the infection. There has been a large effort to create vaccines against COVID-19 to prevent infection. Unfortunately, vaccines do not work for everyone. In particular, those that have an immune system that doesn't work normally, or that take medicines which suppress the immune system, may not get as good protection from vaccines.

PROTECT-V is a platform trial. A "platform trial" is a clinical trial with a master protocol, which allows for multiple treatments to enter or exit the trial over the course of the study. PROTECT-V is testing a number of medications to see if they help protect against COVID-19 infection. The focus of this trial is on prevention of disease, rather than treatment once disease occurs. This will be measured by comparing if COVID-19 develops in people who take the trial treatment (a monoclonal antibody), against those who receive a placebo ("dummy") treatment. A monoclonal antibody is a laboratory made protein which is designed to act like human antibodies and help our immune system recognise and bind to specific proteins; in this case on the virus that causes COVID-19 infection. Monoclonal antibodies have been used successfully to treat many other diseases.

2. What are the drugs being tested in this part of the PROTECT-V trial?

The drug being tested in this specific arm of the trial is called Sotrovimab. It is a monoclonal antibody which is designed to block COVID-19 virus particles from binding to the cells of your body. Research using this drug so far has suggested that people with COVID-19 infection who are given this treatment early on are less likely to develop severe disease. It is hoped that the medicine will protect people from COVID-19 if they have had a poor response to a vaccine. The medicine has been used to treat thousands of people with early COVID-19 and it has been tolerated well.

Though the medicine has been used in thousands of people before, this is the first time this particular dose of the medication has been used.

Sotrovimab is administered into a vein by infusion. The infusion lasts approximately 30-60 minutes. You would have one infusion and it is hoped the effect of the medicine will last up to 24 weeks (about 6 months).

Randomisation
This trial is a randomised, double-blind, placebo controlled-trial. What does that mean?

Randomised: As we don't know which way of treating patients is best, we compare a group who take active drug with a group who do not. You will be allocated to one of the groups in a random way (by chance), so we can be sure that the groups are as similar as possible. This way, any differences between groups can be attributed to the treatment they received rather than any other differences between groups. In this trial, the size of the two groups will be the same; therefore you will have a 50% chance of receiving sotrovimab.

Double Blind: This means neither you nor your trial doctor will know which treatment you are receiving. If necessary, your trial doctor can find this out.

Protect-V, cont'd.

Placebo: This is sometimes called the 'dummy' treatment. It looks the same as the treatment but does not contain any of the active ingredients.

Please note participants will not know what they have been given, whether this is the medication or a placebo.

In-person visits
You will be asked to attend in-person at the hospital on 5 occasions; screening, day of infusion and then 4 weeks (29 days), 12 weeks (85 days) and 24 weeks (169 days) after you receive the study medication or placebo (4 occasions if you are having the screening and infusion visit on the same day). There is some flexibility around dates of these visits, and the local study team will give you options so that the in-person visits are done at a time that is convenient to you. At these visits, you will be asked to complete the same questionnaires but you will also have a blood and urine sample taken. If you are at the Cambridge or Birmingham clinics you will have a saliva sample taken.

Will I be paid for taking part?

You will not receive any payment for participating in this trial, but Harefield Hospital will reimburse any reasonable travel-related expenses incurred by you for participation in this trial. However, trial visits are to an absolute minimum, and wherever possible they will be scheduled to coincide with your routine hospital appointments.

If you would like to express interest in taking part in this trial please contact Vicky via email on: V.Gerovasili@rbht.nhs.uk

Lung Transplant Stories

In May we celebrated LUNG month, and Tim van Someren and Rob Emery (who received their double lung transplants at Harefield Hospital) have kindly shared their stories with us.

Rob's Story

My journey started when I was 3 years old. I came down with pneumonia and measles. My lungs collapsed, and I was told I died around 4 times.

I was diagnosed with Bronchiectasis and, over the years, I was in and out of hospital. I had breathing problems and was told I would not see the age of 16, made it to 16, and to be told I would not see 18, 21, or 25.

In 2001, I was assessed at Harefield and put on the Transplant list for a double lung transplant.
My 1st call came, and they asked me to come into Harefield as they had found lungs for me – I was so scared! I was on standby for another person just in case there were not well enough for the operation. Fortunately for them, they were, and they got their new lungs on that day.

I had a few false calls whilst waiting, which can happen as all organs have to get tested before they are transplanted, and some will fail this test. When my 6th call came in, asking if I could make my way to Harefield, I went again. A few hours later I was informed I was going down to have the transplant.

Went down for the transplant at 07:30 on the 25th November 2003, and got home on the 22nd December 2003 – just in time for Christmas!

I was born in July 1969 and I'm still going. This year I will be 54. I will be 20 years post-TX this year, and still going strong.

Rob

Lung Transplant Stories

Tim's Story

I was diagnosed with Pulmonary Fibrosis in 2013. I was told that it was a terminal disease, with no cure, and a life expectancy of around 5 years. I was 41, very happily married; our kids were 8 and 5.

A slow decline in lung function followed; A year in, I started to need oxygen – at ever increasing rates. By 2017, my consultant at the Brompton said we needed to think about a lung transplant.

There was no decision to make; I was definitely going to die without one, so any risk was worth taking. I took the tests the following year and was wait-listed in Spring 2018.

My health started to decline quickly from then. By new year 2019, I could hardly walk without getting terribly breathless. The feeling of gasping for air that doesn't seem to be there is still vivid, 5 years later. By April I couldn't stand, eventually I could hardly sit-up. I got into bed one day and didn't get out again for 4 months.

I had a call from Harefield in June of 2019. We called an ambulance, who were fantastically gentle in carrying me down the stairs. Although I now weighed only 44kg, so I don't think I was much of a burden.

At Harefield, I was prepped for surgery before it was found that the donor lungs were not good enough. But I wasn't sent home – Harefield decided to admit me, and I was placed straight onto ECMO and put into the ITU.

Two weeks passed. Still very underweight, and with some potential heart issues (I'd gone into peri-arrest twice in that time), the team were beginning to doubt whether I had the strength to go through a transplant.

My wife Chloe and I had so far kept our kids (now 14 and 11) away from the hospital. We thought it would be too much for them. But a consultant explained that time was running out and, if I did get the surgery, I had around a 60% chance of surviving it as I was very weak. He stressed that it was important that the kids came to visit – for them and for me.

We arranged for the boys to come by on a Sunday. The nurses covered up the ECMO and let the kids in through the staff entrance, to avoid the main ITU ward. A little later my transplant coordinator dropped by. She had some news.

5 years before I'd been given 5 years to live. I was weeks, maybe days from proving that prediction accurate. But now, on the day my kids had come to visit, she'd secured some lungs. I would be going in for transplant in a few hours.

When I woke from surgery, I was on a ventilator, with a tracheostomy.

With a "trachy" your windpipe

Tim's Story, Cont'd

is blocked by a small balloon. Below it, you have a hole in your throat, which leads to a vent, which was pushing air into my new lungs.

When you are chronically ill, you know one thing for sure – tomorrow will be worse. Maybe only a tiny bit, but you are always in decline.

After transplant, I felt as ill as I had before. But I knew tomorrow would be better. This one thing, this difference, was everything.

I hated the trachy. Fluid would collect above it, making me feel like I was choking. I was unable to swallow, and they weren't sure why, or if it would get better, so I didn't know if I would ever eat normally again. I couldn't speak, as my vocal cords were paralysed – again we didn't know if they would ever recover.

I couldn't lift my arms or head, I was so weak, I could only lie there bored, uncomfortable, anxious.

But I'd deal with all of it - because I wasn't dying anymore.

The only way, when you are at the bottom, is up.

It took two months over the summer of 2019 to get better.

I got used to the trachy and was slowly weaned off the ventilator.

I moved from ITU to HDU to the ward.

I did manage to have the crash team called on one occasion. I was sitting in a chair in my room, having some time beathing without the vent, when I just keeled over. I couldn't breathe - but I felt surprisingly relaxed about it. Suddenly a doctor was there, using a resus bag to push air into my trachy, and I came back to life. The theory was that a mucous plug had blocked my airway for a moment. The resus bag had probably cleared it.

To get my strength back, I had twice daily physio visits. "Learning to walk again" is a bit of a cliché; but having literally been there and done that I appreciate its full meaning.

In stages I was unplugged. Drainage tubes were removed; lines taken out; my NG tube replaced by a PEG directly into my stomach. Each thing that was pulled from my body was one more step towards recovery.

Finally, the physios set me my final test. I needed to climb a flight of stairs and walk 100 meters. I achieved both targets, and I was qualified for discharge.

I went home on August 23rd, 2019.

My vocal cords and swallow fully recovered after a few months.
I'm now feeling better than I have at any point in my life, even after turning 50 last year.

When I was being wheeled down to my transplant, I thought about the odds I'd been given of waking up afterwards – about 60% they'd said. And I wasn't afraid.

I realised that there was nothing, absolutely nothing I could do about it.
And that knowledge was a gift.

Some things I can control - I can exercise, take my meds, stay healthy, listen to my doctors.

But anything can happen tomorrow and there's nothing I can do about it; so I'm not going to worry about it.

I'm going to enjoy my new life, eat well, travel, love my family.

We're here for a good time, not a long time. I'm making the most of it.

Tim

Harefield Transplant Club
Committee Members' Details 2022-2023

CHAIRPERSON
Janka Penther

I was born with 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 Harefield at the British Transplant Games in Scotland 2017 and will take on this role again for the BTG 2020 in Coventry.

chairperson@harefieldhamsters.org

TREASURER
Caroline Rutherford

I'd had an LVAD for about 18 months when I received my last call for a heart in June 2018. I joined the committee after the 2019 Harefield reunion as I wanted to contribute, when possible, to the fantastic club. I love sport and am a keen member of the BTG team.

VICE CHAIR
James Doherty

I had a double lung transplant in September 2013 due to cystic fibrosis. I have been on the committee since the AGM in Oxford in 2015 and took on the role of Vice Chair in 2019. I am also the hospital representative for the European Heart and Lung Transplant Championships.

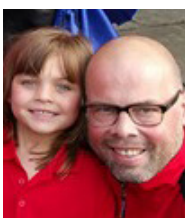
SECRETARY
Douglas Forbes

I had a double lung transplant in August 2013, as a result of CF, and have been a member of the Club since 2015. I joined the committee at the Bournemouth AGM (2016) and took on the role of Secretary in 2018.

COMMITTEE MEMBER
Tracey Baker

I worked at Harefield from 1998 to my early retirement in 2018, and have been an active member of the Club for many years. I joined the Committee in 2020.

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.

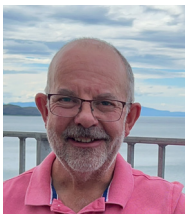
BTG TEAM MANAGER
Peter Knox

My lung transplant was in 2017, due to Cystic Fibrosis. I joined the Committee in 2022, and took over as BTG Team Manager for the 2023 Games in Coventry. I have competed at the BTG, European Games and World Games. I'd love for you to join Team Harefield at the BTG!

COMMITTEE MEMBER
Dawn Bostock

I joined the Committee after the AGM in 2021, having had my double lung transplant (due to CF) in 2008. I want to help the Club reach out to more people, in particular those who are isolated and lonely.

COMMITTEE MEMBER
Clive Donaghue



I had a heart transplant in 1984 and joined the Committee in November 2022.

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**