



www.harefieldhamsters.org
charity no. 1060656



DATES FOR YOUR DIARY

British Transplant Games
28th – 31th July 2022
Leeds

European Transplant and
Dialysis Games
21th – 28th August 2022
Oxfordshire

Fun Run
Harefield Hospital Grounds
Sept 4th 10am – 3pm

Annual Club Celebration
Harefield Hospital
(alongside the Fun Run!)
More details announced
soon.

AGM (virtual)
October 23rd 10am, via video
conference
Details to be announced
soon.

HAREFIELD TRANSPLANT CLUB NEWSLETTER

Edition 33, July 2022



A word from the Chair...

I hope you have all enjoyed the extra bank holiday this year – whether you attended street parties, took a break away from all the hustle and bustle or simply enjoyed some time with family and friends.

Whilst we are still in a pandemic, I feel the mostly dry, if not sunny weather makes socialising that little bit easier as get-togethers can be held outside which for me personally is far preferable – it usually means my dogs are invited too!

It is great to see that Harefield Hospital is reintroducing some face-to-face clinics, the preparations for the British Transplant Games are in full swing and whilst the European Heart and Lung Transplant Championships were cancelled this year, the UK are fortunate enough to be hosting the European Transplant and Dialysis Games 2022 in Oxfordshire! We can even celebrate our annual get-together face-to-face again!

Our club members can continue their fundraising events and our Vice Chair James is fulfilling his dream of running the London Marathon this year – raising awareness for organ donation and funds

for this wonderful club! Many of you have been able to go away on their first holiday since the pandemic, resumed their jobs are even gotten new ones – please keep sharing your adventures! Whilst not always without challenges, it is a huge inspiration to others to see what is possible with this new lease of life!

I want to take this opportunity again to thank you all or your ongoing support, especially our committee who always go the extra mile for us all. Without them, this club wouldn't exist!

James Doherty – Vice Chair
Douglas Forbes – Secretary
Rob Longrigg – Membership -Secretary
Caroline Rutherford – Treasurer & Team Manager
Clare Lauwerys – Newsletter Editor
Alex Walker – Member
Tracey Baker - Member
Neil Henson - Member
Dawn Bostock - Member
Mary Forbes – Newsletter Team (not on the committee but a HUGE part of the team!)

I wish you all a great summer, keep well and enjoy the outdoors (whilst the weather is kind)!

X Janka

The British Transplant Games

Entries for this event have now closed but should you want to support Harefield Athletes and those from other hospitals, they are taking place from July 28th– 31st this summer in Leeds.

Leeds will be the first games for many team members and they have signed up for various events including badminton, cycling and athletics.

It is set to be the biggest



British Transplant Games to date.

If you want any more information do email me on caroline_r@hotmail.co.uk and I

will get back to you as soon as possible.

Caroline

London Marathon

Hi all, it's your vice chairman James Doherty here. Just a quick update that last year I entered the ballot for the London marathon and amazingly I got a place with thousands of other runners, out of hundreds of thousands of applicants.

I thought I would apply as I'm not getting any younger and I'm about as fit as I can be, so it is an excuse to train for something specific and challenging as there is no point doing something easy.

This is the last marathon in October from the pandemic rescheduling, so hopefully the weather will be cooler for running. In September it will be the 9th anniversary of my lung transplant and what better way to put my lungs to good work.

I will be setting a just giving page soon so keep an eye out for that as all money raised will be going to the transplant club.

Just need to do more training now!!!

James



Sun And Transplants

Woohoo! Summer is here - please no jokes about blinking and missing it.

If this is your first summer since your transplant, this is an important read for you. It's also useful reminder for the rest of us.

As transplant patients we have lots of things to keep in mind to protect ourselves (and thank you Covid for adding an extra item to our checklist). The Sun, yes the bringer of warmth and outdoor socialising, is another.

Sun Basics

The most common form of cancer in the UK is skin cancer, killing over 2,500 people each year in the UK.

Some people are more at risk of developing skin cancer than others. My hair and skin tone already put me at high risk, and I had a malignant melanoma removed more than 10 years before I even had a transplant. You can find a full list of risk factors here <https://www.britishskinfoundation.org.uk/are-you-at-risk-of-skin-cancer> if you're interested! Suffice it to say, our medication shoots us up the risk ladder.

We all know the role of the immune system in fighting illness, and we all know our immunosuppressive medicines mean it's harder for us to battle infections. What you might not realise is that the

immune system also involved in preventing cancers. Some cells of the immune system recognise cancer cells as abnormal and kill them. As this isn't always enough in "normal" people to prevent them from developing cancer, we with our reduced immune systems are in an even weaker position.

Ultraviolet (UV) radiation from the sun can cause damage to the skin which may lead to skin cancer. UV exposure is the main preventable cause of skin cancer and fortunately it's not too difficult to protect our skin.

Sunscreen #101

The first thing most people think of when it comes to sun protection is sun cream. In fact it's not the top thing – clothing is – but I know you'll be think sun cream so I'll start with that.

When choose a sunscreen make sure it protects against both UVA and UVB rays. All sunscreen products protect against UVB rays, which are the main cause of sunburn and skin cancers. But UVA rays also contribute to skin cancer and premature aging.

Choosing a sunscreen has a sun protection factor (SPF) 30 or higher. The SPF number is the level of protection against UVB rays. Higher SPF numbers do give more protection, although once you get to a certain point the extra protection is minimal.

SPF	UV light filtered
15	93%
30	97%
50	98%
100	99%

The SPF number tells you how long you can be out in the sun before your skin reddens when using the sunscreen properly versus the amount of time without any sunscreen. If you could be in the sun for 5 minutes without sunscreen then with an SPF 30 properly applied you could spend $30 \times 5 = 150$ minutes in the Sun. Applying more sunscreen throughout the day doesn't mean you can extend those 150 minutes. The correct repeated use allows you to spend 150 minutes in total. To get the SPF stated on a bottle of sunscreen, you need use roughly two milligrams of sunscreen per square centimetre of skin. That's quite hard to imagine, isn't it!



Sun And Transplants, Cont'd.



In more practical terms, it's:

- 2 teaspoons of sunscreen if you're just covering your head, arms and neck.
- 2 tablespoons if you're covering your entire body while wearing a swimming costume.

And don't forget sunscreen needs to be reapplied every couple of hour two hours; more frequently if you're swimming, sweating a lot or rubbing it off with a towel. UVA protection has a star rating; you should see a star rating of up to 5 stars on UK sunscreens. The letters "UVA" inside a circle is a European marking and means the UVA protection is at least a third of the SPF value. Which is something I learnt while checking some details for this!

Clothing, Hats and Sunglasses

Clothing should always be the first line of defence against the Sun, and you should aim to cover as much of your skin as is possible.

A hat with a wide brim is best,

as it will shade the head, face, ears and neck. Baseball caps do not shade the ears or neck, and so a 'legionnaire' style hat is recommended by the experts.

UV light can make you more likely to get cataracts or age-related macular degeneration, neither of which sound like fun.

Fun Fact! Darker tinted lenses don't necessarily provide more UV protection and wearing sunglasses with dark lenses but not enough UV protection can actually be worse than wearing no sunglasses at all. This is because they can cause the eyes' pupils to dilate and let in more harmful light.

Make sure your sunglasses meet International Standard of ISO 12312-1:2013 (en). Check the label when buying and if you're wearing a pair you picked up for a couple of quid, it's probably time to upgrade them.

Fun Fact #2! You still need sunglasses when it's cloudy as the Sun's rays can be just as tough on an overcast day; cloud cover only reduces the amount of UV light by 10 percent. I've got two pairs (Boots were having a special offer on) and keep one pair in my car and one pair in the house so I've always got a pair handy. The ones I keep in the house live in the wine rack in the kitchen – look, it makes sense to me!

If you're venturing into the water, consider wearing a t-shirt and hat. I'm a firm favourite of UV tops as they don't stretch in the water like a t-shirt does and they dry out quickly. It's hat, sunglasses, and UV top for me in the pool in a sunny climate. Up to 40 percent of UV rays can penetrate shallow water and water also reflects a lot of UV rays.

The best thing to always do is to seek shade, especially between particularly from 11am to 3pm.

Checking Your Skin and What To Do If Worried

The Cancer Research UK has a really good guide on what to look out for (<https://www.cancerresearchuk.org/about-cancer/skin-cancer/symptoms>) I've checked the photos and there's nothing too scary.

If you find something that gives you concern either see your GP or speak to Harefield. Consultant dermatologists visit Harefield regularly, although not every week so it's impossible to know whether your GP or Harefield would be quickest. And of course, there are all sorts of backlogs. The important thing to remember is that soon you get it checked, the sooner you can have treatment.

I had a malignant melanoma removed over ten years before I had my lung transplant and it

Sun And Transplants, Cont'd.

was only discovered because I was a bit concerned. The GP I saw carried out minor surgery in the practice and only removed it to be on the safe side. To this day, I'm still not sure who was the most surprised when it came back as cancer. This is why I'm keen to spread the message about taking care of your skin in the Sun.

The Australian Cancer Council

came up with a brilliant campaign back in the 80s to tackle the rise of skin cancer and updated it 2010. So even if you skimmed read this, here's a summary in five easy to remember points.

- Slip on some sun-protective clothing that covers as much skin as possible.
- Slop on broad spectrum, water resistant SPF30 (or

higher) sunscreen. Put it on 20 minutes before you go outdoors and every two hours afterwards. Sunscreen should never be used to extend the time you spend in the sun.

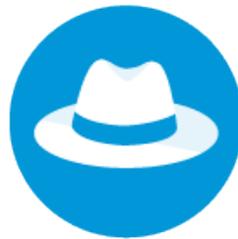
- Slap on a hat – broad brim or legionnaire style to protect your face, head, neck and ears.
- Seek shade.
- Slide on some sunglasses.



Slip



Slop



Slap



Seek



Slide

Image from SunSmart, (<https://www.sunsmart.com.au/>) Cancer Council Victoria (Australia)

Cardiothoracic Patient Advisory Group – CTAG

As chairperson of HTC, I was asked to attend the CTAG meeting last month. This group is a mix of patients, patient support groups and medical professionals in the UK.

We discussed topics such as:

- Psychological support available at transplant centers in the UK
- COVID: treatment and pre-exposure prophylaxis available to transplant patients in the UK.

You may be aware that Melissa Sanchez has been replaced as clinical psychologist at HH by

Shehla Brown, whom I haven't met yet but I have asked for an introductory call. I hope soon to pass on information around her availability. This is particularly important as the survey from CTAG on how supported patients felt in their mental health by their transplant hospitals, showed some concerning results across the UK – and particularly at Harefield Hospital. We as a Club need to support our hospital to provide the best possible service.

We also discussed COVID treatment and the appreciation of the anti-viral infusion which

has helped many of us get over the virus. Unfortunately, the UK government not yet purchased pre-exposure prophylaxis treatments like Evusheld, which provides immunocompromised individuals with antibodies. There is work being done to communicate the importance of this to local MPs, the club as well as HH staff are working hard alongside this. If you are interested in what is being done nationally, please join the Facebook group **Evusheld for the UK**.

Janka

Covid: Vaccinations and testing positive

Everyone should hopefully be aware that as per JCVI guidance Transplant Recipients are now eligible for a second booster vaccination 6 months after their last vaccination. Please note that this means you are eligible for a 4th dose (3 months after your 3rd dose) and 5th dose (3 months after your 4th dose).

<https://www.gov.uk/government/news/jcvi-advises-a-spring-covid-19-vaccine-dose-for-the-most-vulnerable>

Please liaise with your GP or your local vaccination centre for your booster dose.

Harefield hospital and the transplant clinic are looking at an opportunity to facilitate this vaccination schedule. If you have an upcoming in-person clinic appointment, please be aware that a staff member from Guys & St Thomas Hospital may be in

touch in regards to a booster vaccination if you have not yet had yours and you are eligible, as there will be opportunities to facilitate having your booster in clinic. If you do not have an upcoming clinic appointment and are having difficulties having your vaccines locally, please contact the transplant clinic.

Please remember that if you have a positive lateral flow test (whether you have symptoms or not), contact the transplant team immediately as changes to your medications may be needed. Transplant recipients can sometimes be eligible for additional treatments in the community. These currently include:

- adding/changes to steroids
- an antibody intravenous infusion that has no drug interactions, such as **sotrovimab**
- antiviral – **Remdesivir**, given as an intravenous infusion
- oral (tablet) antiviral,

molnupiravir, taken twice a day for 5 days.

This has no known drug interactions with transplant medications, however it is not recommended for pregnant women, and women who can become pregnant should avoid pregnancy while receiving this medication

- However, **DO NOT ACCEPT Paxlovid** – this should NOT be used in transplant recipients due to very strong drug interactions with your anti-rejection medicines

If you are very unwell with Covid-19 or have low oxygen levels, you should still call 999 or attend your local hospital urgently, and request the local medical teams contact the transplant team at Harefield Hospital.

Haifa Lyster and TX team members

Pin Thank You

Thank you to Harefield Transplant Club for my 20 year pin!

I had my heart transplant at Great Ormond Street Hospital at 12 years old and moved to Harefield when I was 18.

It's crazy to think when I was transplanted the life expectancy was 5 years. 20 years later and I've been able to achieve some amazing things thanks to my donor and I'm looking forward to getting married next year!

Thanks to all the staff who keep me going! Such an amazing hospital!

Emma Hilton

The European Transplant and Dialysis Games

The European Transplant and Dialysis Games are being held in Oxford this year from 21st – 28th August. Athlete registration closed on 20th June but you can still come along as a spectator if that interests you. Radley College is the base for a lot of the sports and Blenheim Palace is being used for a number of events including the cycling.

The opening ceremony will be on Sunday 21st August in the city centre and will be a fantastic opportunity to promote organ donation awareness to the wider general public. I have been told that at least 20 countries have said that they are bringing athletes,



which is wonderful news. The games are set to be one to remember so if you want any more information do email me on caroline_r@hotmail.co.uk

and I will get back to you as soon as possible.

Caroline

We want your news!



We would love to have more contributions for the newsletter from our members. The Club is here for you and your input is essential.

We have a few limits on the length of articles as we do have to print some newsletters to post those don't have email.

Anniversary Pin Thank You

300 words

Other Items

600 words

Don't worry if you go slightly over. I don't want you be desperately cutting 10 words to make the limit.

Got something that needs more words?

Get in touch for a chat. We want to encourage people to write for the newsletter so we can look at options for longer pieces.

Photos

Photos are an amazing way of showing people what you've been doing. If they are accompanying an article you are sending in, please put a note the piece where the photo should go and send the photo as a separate attachment; this makes it easier when the newsletter is being edited. It also really helps if you name the photo something more meaningful than img35263297.jpg.

Thank you!

Clare

Jubilee Quiz – How well do you know the Queen?

1. What other language is the Queen fluent in?
2. How many horses does it take to pull the Gold Coach?
3. The Crown asserts ownership of which white bird?
4. What dog breeds does the Queen own?
5. Which Football Team does the Queen support?
6. How many bedrooms does Buckingham Palace have?
7. Where were Prince Philip and Princess Elizabeth married?
8. How old was the Queen at her coronation?
9. Princess Elizabeth trained as a mechanic in the military: TRUE or FALSE?
10. What is reported to be the Queen's favourite cocktail?



Answers at bottom of page!

Fun Run Experience

I always try and take part in the annual Fun Run at Harefield Hospital. It's a great event to get together, celebrate how far we have come in our transplant journey and encourage others to keep as well as possible until their call comes.

Nobody has to actually "run" the distance. Some people really push themselves physically and mentally, but most people jog or walk. I have done the run a couple of times with my dog but we both prefer eating and socializing, so that's what we end up doing most on that day!

Janka



Pic from the Fun Run 2018, from L to R: Douglas Forbes, Mary Forbes (with Silas), Janka Penther and Maggie Williamson

Join us at the Harefield Hospital Fun Run on 4th September 2022 10am – 3pm at Harefield Hospital and come and say hello at our stall!

Harefield Transplant Club Committee Members' Details 22-23

CHAIRMAN 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

COMMITTEE MEMBER Neil Henson



I had a double lung transplant in August 2018, aged 54, due to having IPF. I joined the Committee in 2019.

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.

NEWSLETTER EDITOR Clare Lauwerys



I had a single lung transplant in 2008 as I have lymphangioliomyomatosis (LAM for short). I was LAM Action's newsletter editor for several years. As my focus is more transplant related these days, and having taken a break from LAM Action (well mostly) I was keen to offer my skills to the Club.

editor@harefieldhamsters.org

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.

COMMITTEE MEMBER 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.

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
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

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.

Reminder that the Committee meeting minutes are freely available.

Email, phone or write to:

The Secretary
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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**