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HAREFIELD TRANSPLANT CLUB NEWSLETTER

Edition 35, Spring 2023

DATES FOR YOUR DIARY

British Transplant Games
27th–30th July 2023
Coventry

Harefield 40th Annual Fun Run
10th September 2023
Harefield Hospital

Annual Celebration
22nd–24th September 2023
Riviera Hotel, Bournemouth

Organ Donation Week
18th–24th September 2023

A Word from the Chair…

Dear all

I am writing this piece on the day of Spring Equinox, and, in many ways, this is very fitting. For me, Spring symbolises new beginnings, change, and with that, hope and optimism that good things are on their way.

Whether that's fewer hospitalisations (or worse outcomes) due to Covid infections, new ways the club is connecting with its members, personal changes like engagements, change of career, first time competing at the World Transplant Games, reaching incredible transplant milestones, celebrating unthinkable birthdays, long overdue get-togethers… we have it all in our committee for this year – so I am sure you'll see some of it in your own lives.

February 14th saw National Donor Day, which is always close to my heart, as is UK Mother's Day. Both days make me think of my donor and her family, her mum that lost a young daughter just too soon.

February was a great month for another reason – we celebrated Heart Month and have collected some stories from heart transplant recipients at Harefield Hospital! Thank you so much to all of you who shared your experience! Please do consider sharing more stories on our Facebook page, too.

From 18th–24th September, we will be celebrating Organ Donation Week, which is a great opportunity to raise awareness for organ donation and transplant success! The Donor Family Network is hosting a couple of events (please check out their Facebook page) and Harefield Hospital is celebrating the 40th Annual Fun Run on 10th September. Please do come along and see is us at our stall! We are trying to win the Royal Brompton & Harefield Hospitals Charity Cup for the largest team entry so when you sign up for the event, please put 'The Harefield Transplant Club' as your team (see the article later in this edition for more details)!

A Word from the Chair, cont'd.

Sadly, we haven't had great news regarding Evusheld availability on the NHS, but by the time this newsletter has been published (or shortly after), transplant patients should be able to book their Covid Spring boosters online. With the days getting longer, warmer, and hopefully drier, those of us who are still living rather carefully in the pandemic climate will be able to enjoy more outdoor time and get-togethers with loved ones.

The committee is also in the middle of planning our first face-to-face club celebration for a few years – an event which has so far been cancelled/held online over the pandemic. We have booked a hotel for the weekend of 22nd–24th September – see the save the date notice in this edition! Our members will receive an email re. booking, and we will also publicise information via our website and Facebook group. We are VERY excited at the prospect of seeing as many of you there as possible!

I hope you are enjoying the change in the weather, milder days and budding flowers. Embrace a good spring-clean, walk in the park, try a new recipe or call a friend. Spring is the time to embrace change!

Janka

Covid 19 Spring Booster 2023 (England)

Source: www.gov.uk

Who is eligible?
People aged 75 years and older, residents in care homes for older people, and those aged 5 years and over with a weakened immune system will be offered a booster of coronavirus (COVID-19) vaccine this spring.

When can we get the vaccine?
You should be offered an appointment between April and June, with those at highest risk called first. This is likely to be around 6 months from your last dose, but you can have it from 3 months.

What vaccine will be given?
You will be given a booster dose of a vaccine made by Pfizer, Moderna or Sanofi and approved in the UK. These vaccines have been updated since the original vaccines and target different COVID-19 variants. For a very small number of people another vaccine product may be advised by your doctor.
These updated vaccines boost protection and give slightly higher levels of antibody against the more recent strains of COVID-19 (Omicron) than previous vaccines.
As we cannot predict which variants of COVID-19 will be circulating this spring and summer, the Joint Committee on Vaccination and Immunisation (JCVI) has concluded that all of these vaccines can be used and that no one should delay vaccination to receive a different vaccine.
The Sanofi vaccine contains an adjuvant (a chemical used to improve the immune response to the virus). This vaccine will only be offered to older people,. The adjuvant in the COVID-19 vaccine is similar to the one used in the flu vaccine which is routinely given to over 65-year-olds. The NHS website has more information about vaccine ingredients.

How can I get the vaccine?
You will be invited for your booster, your GP may offer you the vaccine or you can book using the NHS app for Apple or Android. You can also find your nearest walk-in vaccination site from the NHS website.

Note from editor: At the time of writing, it is not possible to book online. However, by the time of publishing this may have changed so please check for updates online. If you have any queries regarding the covid booster, please speak to your transplant team.

Heart Month

February was Heart Month, so we wanted to hear from some of you who have received a heart transplant to tell us what life is like now! A huge thank you to Dani, who has just celebrated her 33rd heart and lung transplant anniversary and was happy to answer some questions for us!

Janka Penthwell (HTC Chairperson): Hi Dani, thank you so much for sharing your story with us for Heart Month! Let's kick off with you telling us a little bit about how you came to have a transplant.

Dani: In February 1988, I suddenly felt breathless, which really happened out of the blue. I had never been ill before, not even measles or anything like that. So, I went to see the doctor, he heard a murmur and sent me straight into hospital to have my heart checked out. To cut a long story short, they found out that it wasn't my heart causing the problems, but my lungs! So, they told me (after a cardiac catheter examination) that I would need a heart/lung transplantation – otherwise I would die in about 3 months' time. As there was no real experience of this transplantation in Germany, I was brought to Harefield Hospital in the UK. The minute I met Prof. Yacoub, I knew right away that he was going to fix me. I trusted him from that first meeting and felt so secure. I wasn't allowed to fly back home, as my condition wasn't too good.

So, I stayed locally in the village and sometimes I needed to be admitted. I sat in a wheelchair for the whole waiting time of 21 months, needing oxygen, but always with a good amount of positivity and lots of laughing. Some patients got angry with me when they saw me laughing and couldn't understand why I still was so positive during that awful waiting time. But being sad and a pain in the neck wouldn't have changed anything, right? And more importantly, I needed to be strong for my family. One family member was always with me, with the rest of them staying back in Germany, which was hard on them, not only on me!

JP: Wow, that's incredible! Things have definitely changed since then, and Germany now has quite a few great transplant centers. Do you remember what the first few moments were like when you woke up after surgery?

Dani: When I first woke up, I asked for my glasses and knew exactly that I was going to make it. I know it sounds weird, but there wasn't a second of doubt. The third day after my transplant, I got up and I climbed the first flight of stairs with Ann (Physio). Wow, I will never forget this amazing feeling of breath going through my lungs! That motivated me so much that I trained my lungs with so much exercise that my RFTs showed great results in no time. I remember when Prof. Yacoub came for his ward-round in the night and said to me: "Daniela, I saw you walking on the hospital grounds, and I am so proud of you. Always remember that I can do 30%, but you must give the other 70%!"

JP: Yes, that's certainly still true now. What was life like before transplant, and what is it like now?

Dani: As I had 'only' been ill for roughly 21 months, it is nothing in comparison to patients who suffered from childhood on, like people with CF, for example. But I must admit I found it hard not to be able to do things on my own anymore. I couldn't wash or dress myself, I was not able to walk more than 20 meters, nor climb the stairs. We lived in the village on the 2nd floor, and they had to carry me piggyback up to the room. They didn't need a gym to build muscles!

After my transplant I had setbacks like everyone else has. But I really needed all my strength to pull through a second time... when I was diagnosed with cancer. Beating cancer was horrible. But, in the end, it made me who I am now. It made me even stronger, and life is even more precious, if that is possible at all. I live day by day. I hate making plans for longer than a couple of weeks.

Heart Month Story: Dani, cont'd.

I have learnt to rest and say no to things I really don't want to do. I enjoy being with family and friends, it is good to have people around who understand my situation and respect me for what I am and what I had to go through.

Even after 33 years, I am still a little careful. I travelled a lot, for example to Peru, Ecuador, USA, Greece, Spain etc. I have never been afraid of travelling abroad, but always been sensible. I still avoid crowds, not only during Pandemic, but I have also done this since I had my transplant. I have had lots of health issues the last couple of years, but I am not willing to give in for LIFE is worth every fight!

JP: Do you think many things have changed in the transplant world since your transplant?

Dani: I am sure there is an increase in demand for organs. Rejection medication and treatment has changed since my time, too. I also think they learnt a lot from long-surviving patients, which is a great benefit for newly-transplanted patients. Social media is a good thing to use to exchange and get information much more quickly, which we didn't have in my early days. Improvement of medical devices and techniques of operation are a good thing too, for sure.

JP: Is there anything you wished you'd known before transplant that you know now?

Dani: Actually, I have often thought about this myself! I would say no. For example, having known before that the waiting time could come up to 21 months, ohhhh that would have been difficult for me to cope with. Or all the setbacks I had, the pain I had to endure – definitely NO, I would not have wanted to know before!

JP: Tell us about your greatest achievements since your transplant?

Dani:
1. Birth of Moritz! My son is the biiiiggggest achievement I could have imagined. He is the most wonderful son in the world and gives me all the strength I need to go on. He was married in 2021 and I hope to get the chance to have a grandchild.

2. My pilgrimage in 2021 (when I was 31 years transplanted). Actually, this was something I had on my bucket list directly after my transplant, but I couldn't do it all those years before. It was planned for my 30th transplant birthday, but had to be cancelled due to the Covid pandemic. To me, it was the most important thing I could do to express my gratitude to Harefield Staff and, of course, to my donor… but also, it was important to show other patients what you can do after your transplant. That is why I wrote a daily report and put it up on Facebook! I wanted as many patients as possible to take part in my adventure and, of course, I took the chance to collect some money for Harefield. This 128 km walk in 5 days was, at the same time, the hardest and best thing I have ever done in my life!

3.To keep my positivity and humor no matter how difficult times had been after my transplant. And, believe me, there were quite a few of them.

JP: Wow, that's definitely a lot of amazing things! Congratulations on all of them. I know you had your transplant over 3 decades ago so things may have been different then, but have you ever written to your donor's family?

Dani: Funny that you ask this question. Only two weeks ago, I contacted Harefield to find out how to write to my donor's family. I know it is late, isn't it?! But I only learned about this possibility a couple of months ago on Facebook. I still fight with myself – my heart says yes, but it is such a long time ago and I don't want to reopen old wounds by contacting the family. So, I really haven't made up my mind yet. My own heart was given to someone else, as we both lay together in Harefield Hospital, so it was obvious who the recipient of my heart was therefore it was easy to get in touch.

JP: Again, I am stunned! I can't imagine what it would be like to know where my heart had gone to! From personal experience (and speaking to members of the Donor

Heart Month: Dani cont'd.

Family Network), I can only recommend writing. The donor family will be made aware that the/one of the recipient/s have written and they can then decide of they feel in a position to read the letter. Everyone of the DFN with whom I have spoken said they were so glad to hear from recipients. It didn't relieve them of the grief they felt about losing their loved one, but it made things just that little bit easier, knowing somebody was alive thanks to their decision.

JP: How are you managing in the pandemic? What (if any) changes have you made to your life?

Dani: I was very, very careful and strict. No contact to other persons unless they kept a sufficient distance to me and showed a negative Lateral Flow Test. Disinfection was my second name! Wearing gloves and mask was a must. Well, the mask still is a must when I go shopping. But I didn't feel lonely or left out during lock down. I went for long walks with my dog and family in the woods, we still had a lot of fun although we had to stay at home. We cooked together, played games, jigsaw puzzles with many little pieces (up to 2000!). I had no problem really and never got infected, lucky me!

JP: That's great to hear! Last question... What are your plans for 2023?

Dani: In May, I will be flying out with my husband to Washington to see my sister

and her family. It's her 60th birthday and my niece is getting married at the end of May. I am so looking forward to it! Otherwise, no more plans yet, but I am sure we will work out something. Let's see what else life has in store for me...!

Amazon Smile Has Ended / Give As You Live

Just a little thank you from your vice chairman James, to everyone who used Amazon Smile over the past few years. Unfortunately it has now come to an end.

In the time people have been using it, we have generated over £170 for the club by doing nothing more than shopping through Amazon Smile, as opposed to the normal Amazon site.

But all is not lost! There is another site that you can shop through, which is 'Give as you Live'. You sign up with email and password, then select the Harefield Transplant Club as your chosen charity.

Click the link to your chosen store's page, then shop as normal! This seems to work in a similar way to 'top cashback' (for people who have used that!). So far, our supporters have raised £160.37!

World Transplant Games 2023

The WTG 2023 are being held in Perth, Australia from 15-21 April. We are so proud that 5 transplant athletes from the Harefield Adults team were selected to join Team GB & NI. The following individuals were able to accept the invite and we wish them good luck at their competitions, have fun and safe travels!

John Allen (Squash)
Jade Carr (Table Tennis)
Amanda Chalmers (Tennis)
Peter Knox (Squash, Tennis)
Caroline Rutherford (Swimming)

Heart Month: Chris Hannah, 36 + 36 and beyond!

In November 1986, I was admitted to the Brompton Hospital. On the day of arrival, I was placed on the urgent heart transplant list with a call out across Europe. As it transpired, the brilliant team kept me alive until a transplant was possible, one of the very first led by Professor Magdi Yacoub at The Brompton Hospital.

I was one month into my 36th year and who would have possibly imagined that I would be alive 36 years later in 2023 – past my peak, but fitter now than I was in the years 1951-86. My consultant at The Brompton said to me one day that, if I got through the transplant, I could go on to live something like a normal life expectancy. I never pinned too much hope on this and rather supposed I would not out-live my parents. They both died of cancer in the mid 90's. In retrospect, I feel these words of encouragement, believed or not, have a very powerful effect and come to our aid at what can be many moments of doubt and despair.

I was transferred to our lovely Harefield about week after the transplant, and nine days later I began a back-and-forth transition between stays at Harefield (to treat rejection) and back home, after nearly four months away. On the day of arrival at Harefield, my ever-loving wife Clare arrived before me. I was travelling in a rickety old Ambulance, a white-knuckle ride wondering if we would make it, no police escort this time. Clare was greeted with the question, "Are you the transplant's wife"? Thank goodness that way of talking has ended. Being constantly asked "Are you a transplant?" was very strange, and I began to wonder if I had an identity before this time! Of course, this was the practice then, with no intention other than to provide the best possible care. But thank you to everyone that enabled us to be seen for who we are and not simply our medical condition.

About a year after my transplant, I returned to work and renewed my hope to continue training as a family therapist. This went well and gave me a means to help other people over the next 30 years until I retired. I now continue with a small supervision and training practice.

Thank you everyone who has supported me all these years and enabled a wonderful life to unfold. Three now adult children and three grandsons.

Chris Hannah born 1951, transplanted 1987. 2023... enjoying life in Brighton. Let me know if you are visiting Brighton and I'll buy you a great coffee or a full fat ice cream!

British Transplant Games: Coventry 2023

Hi my name is Peter Knox, Team Manager for this year's British Transplant Games. I had a Lung Transplant due to CF 6 years ago, and this will be my 3rd British Transplant Games – and first as Team Manager!

The Games are in Coventry this year from 27th–30th July, and I'd love to have as many Harefield athletes and supporters there as possible. There are events suitable for all abilities, ages and levels of competitiveness, plus great social events to meet other transplant patients from transplant centres around the country.

It's a fantastic experience and I really can't recommend it enough. If you're interested, you can get more info (including schedule of events) at https://www.britishtransplantgames.co.uk, or drop me an email at team.harefield@harefieldhamsters.org. I hope to see you there!

Pete Knox

Heart Month: Caroline Rutherford

I am now only a few months away from my 5-year heart transplant anniversary, which is definitely a milestone I hope to reach! This time, 5 years ago, I'd had my LVAD in situ for about 15 months after a stint on ECMO. Although some things were frustrating (e.g. showering once a week in the summer – it was a sink-wash on the other days), or carrying around spare batteries), I genuinely felt extremely lucky to be alive. After taking many months to recover and regain my physical strength, I was still able to meet up with friends, have a part time job, be a bridesmaid to one of my best friends, and attend my friend's wedding in Barcelona.

However, the LVAD was not a forever solution for my condition, and it carried many risks, such as infection through the drive line and device malfunction. I am now one of the extremely lucky people who have had a heart transplant and, whilst the 'big' life events are wonderful, I absolutely love the day to day 'little' things. For example, popping in to see my parents every Saturday after kayaking for a cup of tea and chat, watching a good movie on the sofa with my boyfriend, and babysitting my 8-month-old nephew. Being allowed to shower every day again is also pretty great!

Annual Club Celebration!

Friday 22nd–Sunday 24th September 2023

Riviera Hotel Bournemouth

We are super excited to announce that we will have a proper get-together this year, to celebrate life, our donors and those that have been supporting us! The first ANNUAL CLUB CELEBRATION (formerly known as the Reunion) since the pandemic is open to all (you don't even have to be a registered Club member)! But please feel free to join Harefield Transplant Club via the link below, as we are incredibly grateful for your support – and the first year membership is completely free! https://harefieldhamsters.org/join/

Our Club Events Manager Tracey Baker is leading the events team, but we need a little help to make sure this party will be AWESOME! (Further details to be confirmed, including cost and booking info.)

If you could spare a little bit of time to help out, please email Tracey on traceybaker8@icloud.com.

40th Fun Run at Harefield Hospital

On Sunday 10th September from 10am to 3pm, Harefield Hospital is hosting its 40th Fun Run!

Of course, we will be there with our stall (if you are happy to help out a little, that would be great – please contact Janka at chairperson@harefieldhamsters.org).

The Club are also running, walking and crawling the course! We are trying to win the Royal Brompton & Harefield Hospitals Charity Cup for the largest team, so please join us! When you sign up for the event, just add 'Harefield Transplant Club' to your team info and come see us at the HTC stall!

We look forward to seeing you there!

Register online here: https://www.rbhcharity.org/Event/the-40th-annual-harefield-fun-run-and-family-day

Memorial: Steve Syer

Our very own Henry Smith wrote this memorial piece about the beloved Steve Syer, shortly before Henry himself passed away last year. These two icons of the Club are sorely missed by all.

I had known Steve for thirty-one years, joining the Club after my Heart & Kidney transplant at Harefield in March 1991.

He was a very good friend; he & Chris came several times to support the fundraising Charity Ball that we organised to help funds for the Club.

Steve was Chairman of the Club for twenty years, both he & Chris did so much organising the Annual Reunion Weekends that we all enjoyed. We always thought they were like a second family gathering. Unfortunately, nether Margaret or I could attend Steve's funeral, as Margaret had Covid and I was in hospital. I hope that there were many members of the club present, as Steve spent so much time going to many meetings to help the club & hospital.

Rest in peace, Steve.

Henry & Margaret Smith

Thank You

The club committee would like to extend a huge THANK YOU to Alan Lees for making a very generous donation to cover the club's overheads for 2023 (for example, stamps, printing, trophies, leaflets, etc.). Donations like these allow us to allocate funds raised, as well as your membership fees, to support projects that help other transplant patients, as well as our wonderful hospital!

Congratulations!

Almost 10 years after his double lung transplant, our Vice Chair James Doherty popped the question to his girlfriend Natasha – and she said YES! I am sure you will all join me in sending massive CONGRATULATIONS to the happy couple! Wonderful news, and a great way to celebrate life!

Donor Family Network Thanksgiving Event

This year, the thanksgiving event will be held at the start of organ donation week. It was at the start of week last year, which people felt was a good time to reflect on the Donors as, without them, there would be no organ donation or transplantation. Location: Alrewas, Staffordshire.

For more information, please contact the DFN directly via email on: info@donorfamilynetwork.co.uk

From Pandemic Panic to Penthwell Dog Training

Changing career and starting my own business during I have always been mad

about dogs and when I was 'unemployable' after my transplant in 2013, due to twice weekly trips from Cornwall to Harefield Hospital, I decided to start my own dog-walking business.

I quickly realised that most of my clients' mutts lacked the basic training to join our off-lead pack walks, so I trained them all to my own standard – mainly, to make my life easier! But soon my clients started to talk to me about their dogs being so much better behaved as a result, so I offered a 'walk & train' service.

When I met my (now husband!) Rob and moved to Oxfordshire in 2017, I gave up my business and, as we weren't quite sure where we would settle down, went back into my earlier career of hospitality and event management. By the time Covid hit, I was an in-house Recruitment Consultant for a national charity, and I had a wonderful manager who made sure I would work from home before anybody else, equipped with all the technology and support I needed to do my job. But, unfortunately, circumstances changes and by the time we were apparently 'out of the pandemic', I had a new manager who thought I needed to be back in the office. This would have involved sharing toilets with over 100 other colleagues and, if I wanted to protect myself, I would have to sit at my desk with a mask on for 8 hours every day.

I had just taken 2 weeks off for my wedding and, during that time, I realised what was important to me: my mental and physical health, my family and friends, and spending as much time as possible with them. At that point, that meant not getting Covid! So, after a pep-talk from Rob, I handed in my notice and started studying for my dog behavior qualification.

I'd been helping out a local gundog trainer for a while

on weekends, but I was really into behaviour and pet scent detection, which is a fairly new dog sport in the UK. I started my training as a City and Guilds certified Scent Detection Instructor, but I started helping other dog owners with Foundation Training like lead walking, recall, etc., straight away. I set up my website (that was a real challenge, as I am not tech-minded at all!) and decided on my brand, pricing, etc. (which was also a challenge, as I'd do all of this for free, but I also need to pay my bills!). I got some flyers printed and started the distribution. It didn't take long for people to get in touch, and soon I had the majority of my clients through word of mouth. It was great to be able to choose my own schedule, I worked part-time and so had no issue keeping medical appointments and keeping up with training my own dogs!

My young Labrador Trudy recently passed her assessment to become an operational scent detection search dog, which is very exciting! We must decide what we want to do, but I would love to be an 'explosives search team' with her! We will see what 2023 has in store for us on that front. Rob adopted a rescue Springer Spaniel two months ago, so I am currently training him up to work alongside Rob as a gundog. I think I'd like to do part-time Scent Detection Search Team work and some pet training sessions for clients and their dog on weekends,

Pandemic Panic to Penthwell Dog Training, cont'd.

which would be the best of both worlds.

What have I given up? Security. As I'm self-employed, I don' get sick pay, I need to save my money to pay taxes at the end of the year. I don't qualify for benefits, and I don't have a regular pay cheque every month. But I get to spend every day doing the things I love – all day long! I don't have to ask anyone if I can take time off to see a friend and I can spontaneously go on a lunch date with Rob. That makes it all worthwhile for me, and I wouldn't change it for the world!

Janka Penthwell

Penthwell Dog Training

Learn together, thrive together!

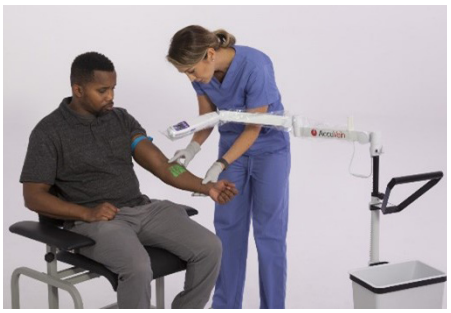
Creating pawtnerships that last a lifetime.

Club donation: Accuvein technology

We are always incredibly grateful for your support, and thank you for your donations, fundraisers, and membership fees. We have been able to donate to another wonderful project at Harefield Hospital! In December last year, we were contacted by one of the Transplant Coordinators who had managed to raise some monies from Harefield's charitable funds to purchase

a piece of equipment which helps with Vein Identification. This will hopefully make taking blood easier, for those patients who have veins that are difficult to access.

Whilst the Transplant Coordinators managed to buy the actual machine, they were lacking funds for the purchase of the stand that enables only one clinician to use the machine (as opposed to having two people – one to hold the equipment and one to do the procedure).
The Club committee is delighted to confirm that a donation of £1000, for the cost of the stand, was unanimously



approved and the ACCUVEIN is going to be situated in transplant outpatients' clinic. Supporting these projects is only possible thanks to you who fundraise, donate, and contribute with membership fees to the club. Thank you so very much for all your love and support!

Masks

During our first virtual coffee morning, we got chatting about how transplant patients are coping with Covid still being around whilst any furlough scheme has now ended, meaning a return to "face to face" work for lots of people. One of our club members, Alan, shared his recommendation on masks, which are rated FFP3. They are reusable masks with a flexible face seal and adjustable straps.

Type "Moldex 3408" into the search engine. A box of 5 masks is available for around £30, so £6 each. Expensive but they do seal around the face; an important issue with which the less expensive masks struggle.

Evusheld Update

Source: NICE National Institute for Health and Care Excellence

On 16 February 2023, NICE issued draft guidance for public consultation which does not recommend Evusheld for preventing COVID-19 in adults who are unlikely to have an adequate immune response to COVID-19 vaccination, or who can't be vaccinated.

Evusheld is not recommended for adults who are at high risk of severe COVID-19 because there is not enough evidence of its effectiveness against current variants and those likely to be circulating in the next 6 months.

This draft guidance comes after January's decision by the US drug regulator to withdraw its emergency use authorisation for Evusheld as a preventative treatment, which said there was insufficient evidence that Evusheld works against the dominant variants of COVID-19 in the US.

NICE's independent appraisal committee has reached the same conclusion having considered evidence which shows Evusheld is unlikely to prevent infection with most of the variants circulating in the UK now and in the near future.

NICE has also announced that it is developing a new process to update recommendations on the cost-effectiveness of COVID-19 treatments so they can be made available more quickly to patients if they show promise and are found to be cost-effective.

Helen Knight, director of medicines evaluation at NICE, said: "We know that today's decision will be disappointing for the many thousands of people who do not get the same protection from vaccination against COVID-19 as most people, and who therefore continue to significantly modify their behaviour to avoid infection.

"The rapidly evolving nature of COVID-19 means we need to have a way of establishing the cost effectiveness of existing medicines against current variants in an agile way. That is why we are developing a process to monitor real world data and re-evaluate the medicines as needed against that data in a faster way than we currently do for other drugs. The ambition is that we will be able to produce updated recommendations in as little as 6 to 8 weeks from receiving a positive signal of effectiveness."

In developing the draft guidance, the committee heard from patient experts who described the challenging ongoing impact of COVID-19 on their lives and the lives of others with a high risk of severe infection who are not protected following vaccination.

The committee also heard that the only evidence showing any clinical benefit for Evusheld was from a trial completed earlier in the pandemic when different variants of the COVID-19 virus were circulating.

Evusheld did show some effectiveness against some older Omicron variants in the in vitro studies. However, the studies showed clearly that it did not work against the current common and fastest growing variants.

The draft guidance is open for public consultation until 9 March 2023 (now closed). The committee will consider any comments received at a meeting currently due to take place on 4 April 2023.

Edit Janka Penther (Chair of the Harefield Transplant Club):
• If you would like more information about the current campaign for the rollout of Evusheld in the UK, please join the Facebook group ***Evusheld for the UK****.*
• If you are considering obtaining Evusheld privately, please contact your transplant team at Harefield Hospital.

Harefield Transplant Club Committee Members' Details 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.

treasurer@harefieldhamsters.org

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.

secretary@harefieldhamsters.org

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.

membership@harefieldhamsters.org

BTG TEAM MANAGER
Peter Knox

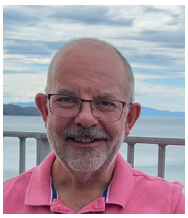
My lung transplant was in 2017, due to Cystic Fibrosis. I joined the Committee in 2022, and took over as BTG Team Manager for the 2023 Games in Coventry. I have competed at the BTG, European Games and World Games.

team.harefield@harefieldhamsters.org

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

secretary@harefieldhamsters.org

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