

WE HAVE THE COVID-19 VACCINE!

At the end of last year we were looking forward to the vaccine to help protect us from Coronavirus. The majority of renal patients who are immunosuppressed and those on dialysis have had their jab. We thank and applaud our Renal Team for all their hard work in achieving this.

You must still follow the guidelines and wash your hands, wear a face mask and maintain social distance!

We have attended, with great interest, Covid-19 Vaccination webinars organised by Kidney Care UK. These were very informative and are well worth watching on www.kidneycareuk.org as they clear up many doubts and misunderstandings.

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In Memoriam – Jack Miller

With great sadness we are informing you that our KPA colleague Jack Miller died, aged 74, on 15th December 2020. He had been admitted to hospital to treat an infection and was improving when he tested positive for coronavirus. He was feeling remarkably well at first but finally succumbed. His wife, Alison and daughter, Caroline, were able to support him throughout his time in hospital and Caroline was with him at the end. They have told us that the NHS staff who looked after him were wonderful, especially the incredible nurses in Intensive Care who helped him so much in his last days. Alison, Caroline and Joseph, his grandson whom he doted on, miss him in so many ways but have fantastic memories of love, laughter, friendships and adventures.

Jack was a valued Trustee of the West London KPA for two years. He was a charming, friendly gentleman. His breadth of



knowledge was invaluable to the committee and he was always enthusiastic and helpful on our awareness event tables, enjoying interacting with patients and visitors. He was a very willing volunteer and an enormous help on the admissions table at the Kidney Patient Expo last year (our last actual event before the first Covid-19 lockdown).

After Jack retired from his career as a solicitor in banking, he devoted himself to following sporting events around the world: many major athletic events, rugby and cricket matches in particular. Jack was the Chairman of The British Athletics Supporters' Club for 10 years, boosting their membership and making them stronger in every area. In his younger years he played cricket, hockey and tennis and enjoyed lifelong links with the MCC, Lord's Taverners and Surrey Cricket Club.

We were all very fond of Jack and he will be sadly missed.

Cut your risk of serious COVID



NHS
Imperial College
Healthcare
NHS Trust

<INSERT Renal Centre or clinic name

COVID vaccines have been carefully tried and rigorously tested in thousands of patients without harm ...and are being **GIVEN SAFELY TO PEOPLE WITH KIDNEY DISEASE** with dialysis and transplants in London – Infection with COVID poses real risk to your life; the vaccine should protect you and it is safe.

The sad news is that 3 in a 100 people on dialysis had died with COVID by November 2020. Half of these were in younger people under the age of 65 years and from all backgrounds.

The GOOD NEWS is that if we vaccinate we can save lives
For example, if we vaccinated the 5000 patients on dialysis in London by the end of February 2021
...we would save **120 lives**
...and prevent **300 kidney patients needing hospital admissions**
...and prevent **72 Intensive Care Unit admissions**



- ✓ **Choose to cut your risk of serious COVID**
- ✓ **Choose to have the COVID vaccine!**
- ✓ **Protect yourself, family and your community**

Vaccine take up is supported by



GOLD
Gift of living donation

BRITISH ISLAMIC
MEDICAL ASSOCIATION

Updated info: <https://www.kidneycareuk.org/news-and-campaigns/coronavirus-advice/>

Charing Cross Hospital Dialysis – New Unit and New Challenges

by James Tomlinson

Charing Cross Hospital (CXH) was one of the first hospitals in the country to provide maintenance haemodialysis in 1964, then under the leadership of the late Prof Hugh De Wardener. Since the hospital moved from The Strand to Fulham Palace Road in 1974, the unit has provided maintenance haemodialysis to the people of Hammersmith and Fulham and neighbouring areas for over 45 years.

The CXH unit had long been in need of refurbishment but a lack of funds and previous uncertainty as to the future of the entire CXH site meant that investment was slow to come.

In November 2018, a fire broke out in one area of the CXH dialysis unit. Fortunately this occurred at night, when no patients or staff were in the area and no-one was hurt. An electrical fault in a ceiling mounted television sparked the fire that rendered the area unusable and so many patients had their regular dialysis sessions moved to nearby St Charles' Unit in Ladbroke Grove.

Even prior to the fire, refurbishment plans and business cases had been developed to

refurbish and reconfigure the CXH dialysis unit to improve patient experience and safety. The fire,



Before

was in many ways a catalyst for these plans to move forward as part of the unit needing structural work was made empty and some funds were recovered from insurance monies. In addition, a generous benefactor had left a significant sum of money to the CXH dialysis unit and, along with investment from Imperial College Healthcare NHS Trust, a

business case was finally agreed in December 2019.

Building works started in early 2020 and despite the COVID-19 pandemic, these were completed in October 2020. The new area is larger and improves upon the

previous layout by connecting all areas to become one large unit, providing much more spacing between stations, natural light and areas to accommodate patients on beds from the hospital wards. The Imperial Health Charity were extremely supportive from the outset and coordinated a team of graphic designers for large artworks for the unit walls and picture frames for a new staff room. We were able to involve patients' and staff members' feedback and preferences throughout the development of the artworks and even choose the colour coordination of the couches.

COVID-19 pandemic.

People with end-stage kidney disease can have weaker immune systems and those needing to travel to dialysis units three times a week cannot realistically shield at home. Since March 2020, the spread of COVID-19 in North West London dialysis units was limited by providing dialysis in designated units for people suffering from the virus and during the first surge, this was at the West Middlesex, St Charles and CXH units.

During this first surge in March, we learnt a great deal about how to provide care for patients suffering with COVID-19 on dialysis. For example, how to predict which people may become unwell and how best to monitor them; what settings to use on dialysis sessions; how to coordinate logistics; the importance of supporting infrastructure such as pharmacy input, oxygen supply and the ability to treat and admit people

quickly who might become unwell during the dialysis session.

For these reasons, dialysis provision for people suffering from COVID-19 during a second surge was best done within the hospital infrastructure on the CXH site. The new dialysis area at CXH was opened in October 2020 and the first patients to dialyse there were those at the start

of the second surge. Since then, over 150 patients suffering from COVID-19 have safely dialysed on the CXH unit since October. Not only has the newly built unit provided this extra capacity, but also made it an extremely safe and



After

pleasant environment in which to be treated and to work. Working in the midst of the COVID-19 pandemic is gruelling and many healthcare workers are fatigued and becoming unwell themselves. The strength of character and sense of duty exhibited by our dialysis unit staff across NWL has been impressive and inspirational. Similarly, patients dialysing at our units have shown amazing resilience and adaption to challenging circumstances. The last nine months has been such a difficult time for many, but the mutual support displayed amongst patients and staff alike has warmed hearts and given confidence that we will emerge from this, very much together.

A BIG Thanks From Us to You

The WLKPA are very grateful for the kind generosity of the patients, family members and friends who have made donations to us over the past twelve months. We know that times are difficult for everybody at the moment but we are determined as ever to put our funds to good use.

Over recent months we have funded:

- Christmas Scrubs and scrub hats
- Xmas gift vouchers to say **Thank You** to the fabulous renal staff
- Repair and replacement TVs at St Charles Dialysis Unit
- Covid-19 Antibody test kits



WORLD KIDNEY DAY – Living Well with Kidney Disease Thursday 11th March 2021 – by Sarah Ilic

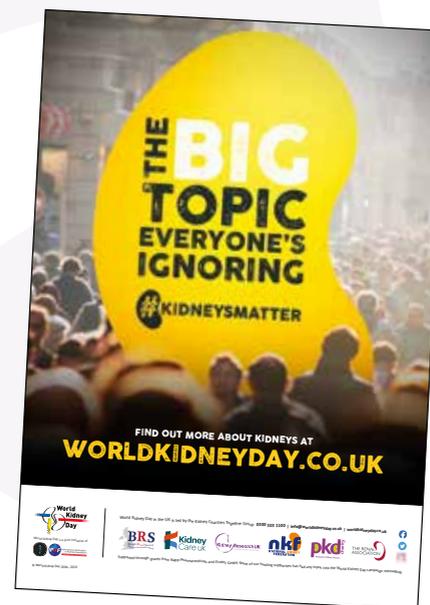


people, some who have wanted to discuss or ask questions about their renal journey and some who wanted to learn what renal health is all about.

World Kidney Day (WKD) is a global campaign aimed at raising awareness of the importance of our kidneys for our overall health.

We also receive generous donations which enable us to make important funding decisions to help kidney patients in many varied ways.

Every year on the second Thursday of March we hold events to create awareness about what your kidneys do, preventative behaviours, risk factors and how to live with a kidney disease, because kidney health is for everyone.



In past years we have been present in the community and in the West London Renal & Transplant Centre building and Hammersmith Hospital foyers. We have enjoyed your company and had conversations with many

This year, like last year, we are not able to be there in person, but we would still like to help you and ask you to help us too. If you have any good ideas how you could raise awareness and also raise funds for us by doing a sponsored walk around your home or garden, or any wakey ideas we'd

love to hear from you. Please email: info@westlondon.org with any questions or fundraising ideas you may have.

During February, the community and hospital case numbers of Covid-19-positive people continued to decline, giving hope that the second surge will end, although we do not know when or for how long. There remains extreme pressure on intensive care unit teams and those who have been redeployed.

There has been a substantial impact on staff, with high sickness rates due to Covid-19. In other instances, staff are required to isolate, meaning that there are fewer staff available to meet the service's needs. Redeployment has been implemented widely across the Trust to relieve more pressured areas, and mass staff vaccination continues with hubs on the main hospital sites.

The renal service has implemented a number of changes to meet current demands including:

Inpatients

The renal ward beds are being carefully managed to separate Covid-positive and Covid-negative patients. Regular planning takes place every few days to assess the need for Covid-positive and Covid-negative patients and make sure that the correct number of beds is made available to each group. This involves deep-cleaning areas that were previously available to Covid-positive patients and also ensuring that the correct PPE and staff training in donning and doffing procedures takes place prior to the beds being allocated. The ward staff have been doing a great job at embracing the regular changes as required. Regular testing of both patients and staff takes place in all wards to identify Covid-positive patients early and thereby reduce the risk to other patients and staff.

Out-patients

Clinics have implemented systems whereby the responsible clinician triages every patient appointment a few weeks in advance to decide whether it is more beneficial for each patient to stay at home or attend in person. Patients are then contacted via text message,

letter and/or telephone to confirm whether their appointment will go ahead. In many cases, face-to-face appointments are changed to either videoconference or teleconference to reduce the number of people that need to physically attend the Outpatient clinic, this improves patient safety both for those with virtual appointments and for those attending face-to-face as social distancing is better enabled with fewer patients in the Outpatient waiting area.

Out-patient dialysis

The Charing Cross Hospital dialysis service is the sole provider of outpatient haemodialysis to Covid-positive patients. At the start of February, this was being provided across four shifts a week in two areas of the centre. A transport hub has been set up to run six days a week and includes staff from Imperial College Healthcare NHS Trust and FALCK to make sure that patient journeys are rearranged for those who need to attend the Covid-positive dialysis service. Regular testing of both patients and staff takes place in all outpatient dialysis services to identify Covid-positive patients early and thereby reduce the risk to other patients and staff.

Transplantation

All London (and many other UK) centres have halted their transplant programmes, this decision is reviewed fortnightly and will be reopened as soon as this is safe for staff and patients.

Surgery

Urgent surgery continues where this is life- or organ-saving; this includes the insertion of peritoneal dialysis catheters. Non-urgent surgery is postponed; this decision is reviewed regularly and will be reopened as soon as this is safe for staff and patients.

Sharp Scratch – by Chetan Joshi

Life is nice after a transplant. but it's not the end of the renal journey

I received my kidney transplant in August 2015. After a couple of years on haemodialysis which was... lets say "turbulent", I was elated when I got The Call. I was looking forward to regaining the 12 hours + per week that I was missing due to dialysis treatment.

In the early days after my transplant, I was in and out of hospital quite frequently as the new kidney adjusted to its new home in my body.

The warning "Sharp Scratch" is one that has left an indelible mark in my mind. It is usually followed by an intense stinging sensation as the

needle punctures my skin. I know that this isn't common but I do always wonder, "where do my veins disappear whenever I enter hospital?"

The elusiveness of my veins inevitably

leads to several attempts by the phlebotomists to locate them. Each attempt is preceded by the same warning "Sharp Scratch!"

Along with other transplant patients, I now attend the transplant clinic every three months. However last year, because of the disruption that Covid-19 brought, my 3-monthly blood test didn't happen

in the summer. So when I attended the clinic in September and had a blood test, I received an urgent call the following day. I was informed that I had to come straight back as the test results were not quite as expected. So I hastened back to Hammersmith Hospital where I had another blood test. When the results came back, I was told

that my Creatinine level was sky high. It was more than double my normal rate! Although I felt fine, I was told that I would have to stay in hospital to undergo

further tests and hopefully get to the bottom of what was happening. After a few moments of disbelief, I drove back home, packed some clothes and arranged to return to hospital. Knowing how expensive car parking is, I wasn't going to risk leaving the car in the car park indefinitely so my sister brought me back and returned home with the car.



Why are my veins so difficult to find?

After a couple of attempts at fitting me with a canula (more Sharp Scratch warnings!), a couple of days went by in the Renal Haematology and Triage Unit. I was eventually admitted to Peters Ward where a bed space had become available. It was around midnight when I was wheeled into my new home. It's always a nervous feeling being the last person in to a four bay room with three strangers. Memories of previous hospital stays came flooding back. "Will they be normal people (just like me)?" I wondered. Fortunately it was night time so I was confident of getting a good night's sleep at least!

The following morning, I woke up feeling fairly ok. The fever I had the previous day was on its way out. I assessed the new environment I was in although it wasn't entirely new as I had been in the ward previously, after my transplant. The nursing staff introduced themselves to me and were very welcoming. I had a suspicion that one or two of my fellow patients were not going to be very communicative, but that was ok. The chap opposite me seemed nice and we got on well. We were all a mixture of transplant and dialysis patients with one or another complication in common so we would compare notes and

observations and have a good laugh at shared experiences.

Over the following days, patients were discharged and new patients arrived. It's in situations like this when you find yourself outside of your normal comfort zone, that you learn to get along with people that you would never normally come across. Being in hospital, during a pandemic isn't everyone's idea of a good time but it's an experience that certainly adds a richness to life. I must say that the staff in Peters Ward were absolutely great with all of the patients as I'm sure they are in other wards. I was there for just under two weeks so got to know some of them well. I feel so privileged knowing that my health is continuously monitored and potential complications are detected and dealt with so swiftly. We are so fortunate to have the NHS in this country.

West London is a vibrant, multi cultural and multi racial part of the capital. It's full of diversity among both patients and staff. Despite the language barrier often presenting a challenge, the hospital environment is a melting pot where unity is found in the diversity of the people that use it.

Latest Covid Vaccination News –by Wendy Brown

As of 04/02/2021 all eligible dialysis patients in-centre and across 9 satellite units plus those on home haemodialysis and home peritoneal dialysis have been offered their first dose of the vaccine.



In addition, many transplant patients, CKD 5 and immunosuppressed glomerulonephritis patients have also been vaccinated at one of our Imperial sites. This has been possible through the leadership of consultants Professor Liz Lightstone and Dr Michelle Willicombe who led the programme and galvanised teams of pharmacists, nurses and doctors who have willingly volunteered to vaccinate everyone across

all sites within the past 4 week period.

Much thanks must go to Professor Liz Lightstone who was tenacious in her campaign to source permission to vaccinate our clinically extremely vulnerable patients by liaising with Trust covid vaccination leads, local GPs, multiple CCGs, many district general hospitals and vaccine hubs which was no small task and required much discussion



and coordination but in the end the support from everyone was amazing as this felt so positive and just the right thing to do for our kidney patients. Thanks also to Sister Kathleen who kick started the vaccination programme at St Charles dialysis unit who, as a result of her excellent relationship with the local St Charles community team, set a serendipitous precedence and model to roll out to all our other renal areas applying her infectious encouragement and positivity that certainly got the ball rolling.

Thanks to Dr Michelle Willicombe too who has been instrumental in galvanising the staff



vaccination “troops” but also has another important role in this campaign. Michelle and her team of researchers are busy collecting blood samples and data to determine how well the vaccine will work for people with kidney disease compared to people who do not have kidney disease. In the not-too-distant future, Michelle will have very important data to share with you all but also to share with the renal community nationally and internationally to ensure we provide the best protection for you in the future.

In the meantime, we are pleased to report there have been no significant side effects. The vaccine has been generally well tolerated. Have a fair amount of vaccine hesitancy but overall, there has been a very good uptake and we are delighted.

Our work will continue; in the next few weeks we will return to offer the vaccine to those that couldn't have it on the first round because of having COVID and hope to prioritise some for an early second dose based on need for immunosuppression.



We will also continue to provide information for people who have been hesitant to

receive the vaccine so that they can make the right decision for themselves. We also encourage people who are concerned about having the vaccine to access the excellent information and webinars provided by the kidney patient led Kidney Care UK team. www.kidneycareuk.org

All clinically extremely vulnerable (CEV) people should be offered the vaccine by February 14th;; if you have not been contacted and offered the vaccine by then, either contact your GP to ensure they have you registered as CEV or contact your kidney care nurse or doctor for further advice.

With best wishes from your kidney team

Proposed closure and sale of the St. Anne's Holiday Dialysis Centre – by Oliver Pearcy

KPA members may be aware of the West London Hospitals Holiday Dialysis Trust and its St. Anne's Holiday Dialysis Centre in Emsworth, Hampshire. For many years the WLHHD have offered dialysis to renal patients and their families who wish to spend a short holiday away from home. This has involved a great deal of hard work and commitment by staff and volunteers over the last forty years.

The Board of the WLHHD have been reviewing the role of St Anne's in delivering services to renal patients. With the wider availability of holiday dialysis facilities, particularly in warmer countries, numbers using St Anne's, which were never a particularly large percentage of the total eligible renal patient group, have been declining. At the same time it has been increasingly difficult (and expensive) to maintain dialysis provision to increasingly demanding modern standards in what is a very small unit.

The dialysis service at St. Anne's had been withdrawn for some time due to the lack of securing appropriately qualified nursing staff.

Then the COVID-19 virus hit, forcing the complete closure of St. Anne's. This led the Board to review whether the provision of holiday dialysis service at St. Anne's was an appropriate way to continue to fulfil the Trust's charitable purpose of;

"The promotion of the health and medical welfare of, primarily, the renal patients of West London Renal Services and, secondly, other renal patients"

Their conclusion was that the Trust would be able to support a much wider range of renal patients and in particular of their holiday activities by disposing of St. Anne's and carrying out a review with West London renal patients of what they would all find most helpful in the future. It is not the Board's intention to widen the services offered to other renal patients unless this offers specific benefits to West London renal patients; but we will be looking in particular at more flexible ways in which we can make holiday support available.

St. Anne's will shortly be offered for sale.

British Transplant Games 2021 Leeds – Update (part of the statement taken from www.britishtransplantgames.co.uk/leeds-2021)

We would like to update you on the current situation regarding the British Transplant Games 2021, in the light of the current Covid pandemic.

Preparation for the Leeds Games started two years ago, with development of the athletic and social programmes including planning the opening and closing ceremonies. This complex process also included finding and checking suitable venues, reserving accommodation and enrolling volunteers as well as finding sponsorship for £250,000 worth of funding.

The uncertainties of the current Covid pandemic make planning an even greater challenge. The safety of the participants, their families, the managers and volunteers remains paramount and we are aware that most of the participants are at a greater risk of consequences of infection than the general public.

The current position of Transplant Sport and MLS, the Games Organisers, is summarised below:



While we are very keen that the full Games goes ahead in Leeds in 2021 as planned, this will only occur if we are convinced that this can be done safely for all participants.

We, with the Stakeholder Committee and the organisers are

still planning a full Games, while recognising that there may be modifications this year.

While we are booking venues, accommodation and making other plans, we are limiting financial commitments or spend until we are sure the Games will take place.

For further information, please visit britishtransplantgames.co.uk

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	020 3313 6627
Brent Renal Unit, Central Middlesex Hospital, Renal Unit	020 8453 2017
Charing Cross Hospital , Renal Dialysis Unit, 1 South	020 3311 1752 / 020 3311 1034
Ealing Hospital, Renal Unit	020 8967 5737
Hammersmith Hospital , Renal Home Therapies (HD)	020 3313 6649
Hammersmith Hospital , Renal Home Therapies (PD)	020 3313 6647 / 020 3313 6665
Hammersmith Hospital , Renal Out-Patients' Clinic – Currently joined with St Mary's Hospital, Renal Unit	020 8383 8333
Hayes Renal Unit	020 37048 450 / 020 3704 8444
Northwick Park Hospital, Renal Unit	020 8869 3245
Pam Sasso Unit (PIU), Hammersmith Hospital	020 3313 6682
Renal Dietitian, Nutrition & Dietetics	020 3311 1034
St Mary's Hospital, Renal Unit – Currently closed. Joined with Hammersmith Hospital, Renal Out-Patients' Clinic	020 8383 8333
St Charles Dialysis Unit, E & F Block	020 8962 5197/5196
St Charles Dialysis Unit, G & H Block	020 8962 4816/4815
Watford General Hospital	01923 217243

**Contact us: info@westlondonkpa.org
Or visit www.westlondonkpa.org**

The West London Kidney Patients' Association (WLKPA) Newsletter is published four times a year.*

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