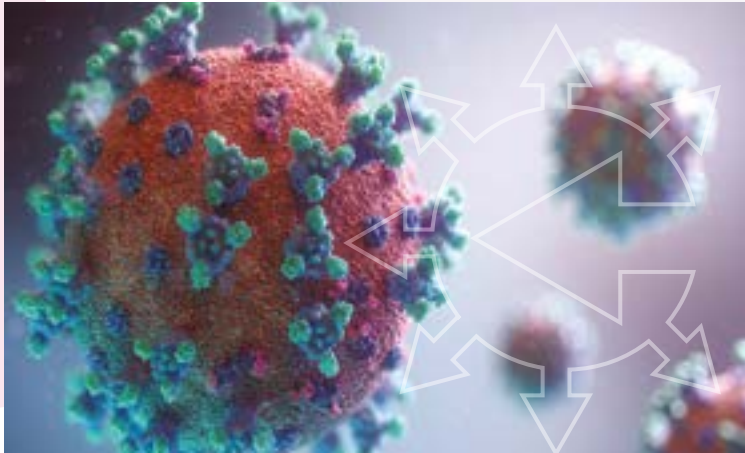


The West London Kidney Patients' Association
Newsletter

Summer 2020



Well, hello once again... Now, who would have guessed when we published the last newsletter (winter 2019) that this year was going to turn out like this?

I began writing this article way back, on the day storm Chiara was ravaging the country. Does anyone still remember life before coronavirus? How the world has changed in just a few months?

We sincerely hope that you have all been keeping strong and healthy over the past few months. I'm certain that we all know someone who has been afflicted with the virus. While many have responded well to treatment, some lives have tragically been cut short. The nation has however come together in a show of unity as we Clapped for Carers and those on the frontline in this global fight. At 8pm every

Contents

Page 1-3

Welcome back

Page 3

A kind gesture from

Sarah, the Duchess of York

Page 4

St Charles Renal Unit

– by Kathleen Lynch

Putting our best

foot forward

Page 5-6

Covid-19 Isolation unit at
West Middlesex Renal Unit

Page 7

For The Love Of Scrubs

– part one

Page 8

For The Love Of Scrubs

– part two

Page 9-10

An update from the team at
Hammersmith Hospital

Scrubs for the team
in Peters Ward

Page 11

Scrubs photo montage

Page 12

Scrubs scrubs glorious scrubs

Exciting update on research

Page 13

Covid19 Renal Study

Page 14

Irish Holiday Dialysis

Page 15-16

Diet: What's in
your store-cupboard?

Page 17-18

Lockdown Boredom Busters

Page 19

Organ Donation Law

Renal Counselling &
Social Support Service.

Page 20

Useful phone numbers

Thursday, the sounds of people clapping, pots & pans, drums and whistles have been reverberating in neighbourhoods across the country. It's given us a chance to become reacquainted with neighbours from the confines of our front doors. We must take this opportunity to offer praise and thanks to all the heroes in our NHS who have continued to provide an excellent level of care and support to all patients throughout this bleak period.

I began self isolating/ social distancing shortly after the Kidney Patient Expo which was held on the 4th March. The event was an amazing success despite the impending onslaught of the virus. We received amazing feedback from visitors *and* exhibitors who found the event to be enjoyable and of real benefit. We had around 200 visitors during the day which far exceeded our expectations.

Due to Covid-19, our World Kidney Day (WKD) planned awareness event was cancelled. However patient, Abdul Khares who is a

lecturer at Stanmore College, raised around £300 at a WKD event at his work place.

The British Transplant Games were cancelled this year due to the COVID virus. Next year they will be held in Leeds 5-8 August 2021 and in 2023 they will return to Coventry.

We will keep you posted of any developments on our website.

So, how have you spent your days in lockdown? Have you taken up a new hobby or are you mastering a skill you've always dreamed of doing? Personally, I did a bit of reading, writing and got hooked on day-time tv! Bargain Hunt, Eggheads, Pointless,

Richard Osman's House of Games and Joy of Painting are personal favourites of mine.

I also make it a point to call my wonderful kidney donor – Jean, every few days to make sure all is well. Regular readers of our newsletter may remember our article from last summer. You can read all of our newsletters online if you've missed any. If you would like to receive your own copy, you can sign up by filling in the membership form on our webpage



Our former colleague Ayyaz Kasmani and his wife continued their support of WKD from their optical store in Feltham

– www.westlondonkpa.org/subscribe. Currently the newsletter is only available on our website www.westlondonkpa.org. We will provide a link on our Facebook page www.facebook.com/WLKPA, or have it delivered to your inbox if we have your email address.

Please always remember that this is your kidney patients' association. If you have something to say, we are always happy to listen. If you would like to contribute an article in a future issue, we would love to hear from you. Those of us on the committee are all mainly patients just like you and we do the best we can, voluntarily. It's thanks to the kindness and generosity of funds we receive from generous donors that we are able to do the work we undertake for the Imperial College Renal Transplant Centre (ICRTC).

A kind gesture from Sarah, the Duchess of York

A special thanks to Sarah, Duchess of York for her kind donation of toiletries to the Renal department in Hammersmith Hospital. The Donation was so big that they were shared between Peters Ward, De Wardner Ward, Handfield Jones Ward and Kerr Ward.



Staff members with gifts donated by Sarah, Duchess of York.



The Duchess also arranged a delivery of cakes to the Renal unit at Northwick Park which were organised independently via a local baker - @chouxandflours.

It all started with a request from the Peritoneal Dialysis COVID-19 ICU Ward for toiletries or care packages for patients who were being sent to the COVID wards directly from ICU. Quite often patients arrived with no over night provisions and families were not allowed to visit. NHS supplies, understandably were basic. The request for the toiletries was made in order to help improve patients' experience in very difficult and scary times. Through the Duchess of York's charity, WLKPA managed to source the items for donation.

St Charles Renal Unit – by Kathleen Lynch

**At the height of the pandemic, the dialysis unit at St. Charles was instrumental in the treatment of Covid19 patients
Thankfully, all is back to normal now...**

We treated over 100 patient's with coronavirus on site here at St Charles and were always astounded by their patience and tolerance in the midst of their fear and anxiety; it was a privilege to meet so many from our sister units in such difficult circumstances. Thank you to all patients and their families for making the best of a very difficult time. After almost 2 months I am thrilled to have opened up H block to our own patients, with a few new for good measure :-) the place looks amazing after the biggest clean since we opened 11 years ago last month. It is so lovely to see the regular attendees back and smiling. We look forward to settling back to some sort of new normal soon.

Nothing was above or beneath any of the staff

Putting our best foot forward



Image shows Renal Home Therapies Team at Hammersmith Hospital

During the pandemic, we have provided Scrubs and 1000 disposable shoe covers which have been shared between the Renal Home Therapies Unit at Hammersmith Hospital and the COVID Ward (for dialysis) at West Middlesex Hospital.

Covid-19 Isolation unit at West Middlesex Renal Unit

The West Middlesex Renal Unit is part of Imperial Healthcare NHS Trust and one of 8 satellite haemodialysis units. The government health advice for patients testing positive for Covid-19 was to remain home in isolation for 7 days. For a haemodialysis patient, to go without treatment for this length of time may have fatal consequences. To support our haemodialysis population, the West Middlesex Renal Unit was designated as the first Covid-19 isolation haemodialysis centre.

All current patients were given a letter of explanation, informing them they had to leave West Middlesex and dialyse at Northwick Park Hospital. Many patients have been at the West Mid Centre for decades and decanting them all to another centre in 48 hours was a daunting task.

No patients protested, all were very understanding, and some were extremely relieved knowing there was a designated Covid haemodialysis centre, should they contract Covid.

The next 48 hours was a flurry of activity converting the unit into a



safe and effective isolation facility. Redesigning the unit to have a designated pathway for positive patients to prevent cross infection and contamination of “clean” areas took some creative planning.

The West Mid team underwent rapid training in the use of specialised PPE and received the first Covid-19 positive haemodialysis patients on March 17, 2020. The unit usually operated as a nurse led centre. When we started treating Covid-19 positive patients we needed on site medical cover. Consultant Nephrologist Marina Loucaidou committed to providing a daily medical presence and was supported by Anand Muthusamy, Transplant Surgeon and Renal Registrar, Tina Thomson.

We had to rapidly develop a new set of operating standards to treat patients who suddenly deteriorated, became extremely unstable and in some cases required emergency admission.

In 8 weeks, 106 patients were treated at West Mid. It was an emotional roller coaster for patients, staff, and families. The positive collaboration of the team putting aside their own fears and anxieties to provide well-organised safe

care for all patients in extremely challenging circumstances was truly outstanding.

Perhaps the most humbling aspect of the Covid-19 crisis were the views from patients who had recovered. Many patients assumed it was a one-way street and were unsure if they would survive Covid-19. Patients who were subsequently de-isolated and repatriated back to their previous renal centres commented on the care and professionalism from all the staff that had looked after them. They reported receiving a warm welcome from staff and fellow patients on return to their own renal centres which generated a great deal of optimism for other haemodialysis patients at risk from contracting Covid-19.

Margaret Nevin – Head Nurse West Middlesex Renal Unit

With special acknowledgement for staff members:

Sarita Paudel, Cristina Serra,
Gince Paul, Marlyn Lajabassal,
Sadhana Malla Sahi,
Janumole Mathew,
Adeniyi Oyelesi, Marion Garrett
and Kim Pryde.

For The Love Of Scrubs – part one

I remember reading an article in the Metro about a group of volunteers making well needed scrubs for the NHS...



I joined the group and volunteered to look after Hammersmith Hospital. Volunteers started coming forward wanting to help. It was amazing !

Chatting with Sarah Ilic a fellow transplant patient and friend she mentioned the WLKPA would be more than willing to help support us with funding the fabrics we needed. Sarah enquired around the units if anybody needed scrubs and the orders started rolling in !

It's been a really positive experience in these strange times – Penny

More volunteers came forward offering to sew, drive, cut up and drop off fabric with such a positive

energy as everybody had at some point in their life been under the care of the NHS and wanted to say Thank You for everything ♥

It has been great to feel I am being useful in these tough times – Jane

Volunteering really lifted my spirits and helped my mental wellbeing during this challenging time. I've met some lovely people (virtual friendships) and doing this was my own way of saying THANK YOU to all the staff in the Renal departments at Hammersmith Hospital for all their care and support I've received over the past 20 years. ♥

All together we made 250 + Scrubs, 370 Scrub bags, 40 Scrub hats and 18 head bands for 11 hospital units. For a small team we were all so super pleased !

<https://www.facebook.com/groups/158440602069114/>

Gilly Kellner



For The Love Of Scrubs – part two

We are all too aware of the shortage of suitable Scrubs for staff to wear as they tackle the Coronavirus.

With many front-line staff working long shifts during the peak of the pandemic, WLKPA and Hammersmith Hospital - For The Love Of Scrubs group's Sewing Volunteers worked flat out to produce adequate supplies of Scrubs, Scrub bags and Hats and headbands.

Photo shows the dialysis team at Hayes modelling their new Scrubs.



Imperial College Healthcare NHS
186 Trust

Hayes Renal Dialysis Unit
Grange Road
Hayes
UB3 2RR
Tel: 020 8383 9801
www.imperial.nhs.uk

29th May 2020.

Dear West London KPA and Volunteer Seamstresses,

I am writing to you on behalf of all the staff at Hayes Renal Unit to thank you all very much. We would like to thank the KPA for funding the materials to provide our staff with a set of scrubs each as well as scrub bags and hats. We would also like to thank the seamstresses for their amazing work in providing us with a colourful array of scrubs to wear at work and in such a short time!

I have attached a photo of the Hayes Staff in our new attire!

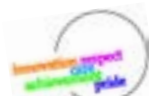
It has been really difficult working every day throughout this crisis with only 3 uniforms each! Washing and ironing uniforms after long and difficult days at work is not always possible. Having the extra set of scrubs has not only been helpful but has also been fun and has helped to raise our spirits!

With thanks from all of us for this thoughtful and generous gesture.

From,

Sharon and the team at Hayes Renal Unit.

Left: A thank you letter from the Renal team at Hayes Renal Units.



Renal Outpatients' Department

Currently we are managing the Outpatient very differently...



Patients must attend at their appointment time only, they are met at the door by a senior member of nursing staff and most likely a Doctor.

They will have their temperature checked and given a mask to wear if they are not wearing one

All staff will also be wearing masks. **ONLY PATIENTS ARE ALLOWED INTO CLINIC - NO VISITORS**, this is standard practice

for the entire hospital. We ask that you do not wear Gloves, if you are wearing gloves we will ask you to remove them and wash your hands. Infection control advice is not to

wear gloves but to wash your hands regularly and use Antibacterial gel where possible.

I would like to say a massive thank you for our beautiful scrubs.

– Katie Tansey

They will be asked to declare any symptoms ie fever / temp/ new cough and If they answer yes to any of these questions, or there

is anything to suggest they are displaying signs of Covid 19, they will be redirected away from the Renal Outpatients immediately & reviewed in an area which is safe to do so.

We would ask that you still bring a urine sample as always and we will measure your blood pressure if you cannot do this yourself at home.

For 80% of patients you will then leave and go home and the Doctor will call you within 24 hours of your appointment to go through your results and advise you when to come back.

The Doctor emails the admin team to organise the bookings so you do not need to call in to book your

follow up appointment. You will get a letter/ email.

A small handful of patients will be seen Face to Face but this is only when absolutely essential.

We ask that if you need medication that you ask when you come into have your bloods done and we can generate a prescription at that time.

The best number to reach the clinic on is 0208 383 8333 or email address imperial.transplantclinic@nhs.net

And also please visit www.kidneycareuk.org for further up-to-date advice.

Scrubs for the team in Peters Ward



The team from Peters Ward – Hammersmith Hospital beaming with their new scrubs

The WLKPA are proud to have funded scrubs for numerous renal units. We supplied Peters Ward with eleven sets.

See next page for a Montage of photos sent to us from the “Scrubbers”, volunteer Scrub maker who swung into action to provide scrubs for staff during the Coronavirus pandemic.





Scrubs Scrubs Glorious Scrubs

Maura and Staff in Auchinacute Dialysis Unit at Hammersmith Hospital were delighted with their scrubs headware. Here's what she had to say...

"... we got them yesterday and the staff love them. We have all just gone back into uniform this week but scrubs are on standby care of any isolated patients.

We have staff from all over the world and with lots of different hairstyles. Long hair has been difficult to gather into disposable hats. The scrub hats are adjustable and suit all. Male staff included !"

Update on research: Test kits on the way

Good news for patients and staff! The KPA have funded the purchase of state-of-the-art Coronavirus testing kits. These will be used to great effect in the fight against Covid-19 over the coming weeks and months.

Additionally, the Trust is planning to pilot finger-prick Creatinine testing in the clinic over the coming weeks. If successful, they may allow patients to start checking their creatinine levels at home! This will be helpful if Lockdown continues for several more months.

A testing kit is also being piloted which allows patients to check for urine infections from home.

As with all new innovations, they need to undergo stringent testing before being made widely available.

Covid19 Renal Study

Thank you to all patients who have consented to partake in this study. The team has been working hard and would like to update you with what has been done so far.

Covid19 Antibody Testing

Testing COVID antibody levels in patients has shown how reliable the test is amongst dialysis patients. Imperial College Healthcare NHS trust is now rolling this test out to all patients.

Ongoing research will answer many questions:

How long do these antibodies remain in dialysis patient?

Do they protect patients from repeat infection?

Why do some patients make antibodies and others don't?

The body's fighting response to COVID19

Research doctors and scientists in the team have analysed the proteins produced by dialysis patients during a covid19 illness and compared them to healthy dialysis patients. This work has already given interesting results showing how the body responds to the infection and potential targets for treatment. These results are ready for publication so the knowledge, you have helped us obtain, will be shared with the international research effort to fight COVID19.

Many more experiments and analyses are still going on and will give valuable information. We will let you know about all publications.

Future work.

There are many experiments that are still ongoing and we thank you for your continued support with providing blood samples. Without these none of this work could be done.

We are still recruiting patients to the study. If you have not given consent yet but are interested then please let the nursing staff know and we will organise for a doctor to collect your consent

COVID19 Renal Study Team



**Imperial College
London**

Irish Holiday Dialysis



There was a time when it was difficult to visit Ireland if you were dialysis dependant. However, that changed in 2017 when Irish Holiday Dialysis clinic opened its doors and holidays to the emerald isle were now on the map for kidney patients!

The clinic was set up and is run by experienced renal nurses, who are not only aware of the positive benefits of holidays, but also the disruption the treatment can have on the experience - so with this in mind a traditional Irish cottage with authentic countryside views was chosen as the location. It is situated in North Cork, perfect for holidaying in Ireland's scenic south/southwest region.

It's our philosophy that the necessary nuisance that is dialysis treatment should be a pleasant part of a holiday rather than an interruption to it, and it's been very much appreciated by our clients, who find a sense of calm relaxation, being close to nature in a non-hospital setting.

Enquiries for bookings can be made by phone or email and it takes 4-6 weeks usually to return all completed paperwork. Patients must be clinically stable on treatment with well-functioning blood access and be free of blood bourn viruses. Though open year-round, the 'shoulder seasons' of Spring and Autumn are particularly popular as is Christmas time.

Due to the current Covid19 Coronavirus outbreak, like many holiday centres globally we are not currently taking booking until travel restrictions are lifted in compliance with health service advise.

www.irishholidaydialysis.ie

What's in your store-cupboard?

by Anri Horne Renal Dietician, Imperial College Healthcare

The new socially-distanced world has really changed the way we eat. While we wait for pubs and restaurant to (hopefully) open some-time in July, we continue to rely largely on grocery stores and supermarkets to feed ourselves. For most of us, lockdown has changed the shopping experience into a bit of an ordeal, with some of us having to wait in long queues outside to allow the store to control the number of shoppers inside, and for others having to rely on friends or family to do shopping on their behalf. Either way, it's safe to conclude that doing one large shop is by far preferable to having to frequent the grocery store often!

How do you ensure not needing to do more shops?
Let's get into the pantry to help you create delicious
home-cooked meals using minimal ingredients.

Store cupboard essentials and what to look out for:

- **Tinned fruits:** tinned fruit is lower in potassium than fresh fruit if you drain off the juice. Choose fruit packed in syrup if you're looking for added calories, or if you're trying to minimise sugar go for fruit packed in its own juice, then drain it before eating.
- **Tinned vegetables:** Look for reduced-salt or no salt added vegetables, and avoid things that come in brine. If low salt versions are not available, you can take regular tinned vegetables and drain them under cold water for 1 minute; this removes one third to half of the salt!
- **Breads, cereals, starches:** Compare sodium content and watch out for items with phosphate additives. If you have freezer space, bread can be frozen and toasted before eating.
- **Condiments:** Look for lower sodium (and lower sugar if needed) sauces, stock up on cooking oils (olive/canola/rape seed), and opt for long-life dairy/alternatives (long-life milk or almond, oat or coconut milks). Check with your dietitian on which brands are best for you.
- **Spices:** If you have high blood pressure, limiting salt becomes very important to control blood pressure. Why not invest in an herb and

spice rack and lose the salt? You could stock it with oregano, thyme, basil, curry powder, salt-free lemon pepper or other herb and spice blends. Make sure to check that there is no salt or potassium chloride additives (note: salt alternatives such as LoSalt are usually high in potassium!)

Store-cupboard recipes

Simple store-cupboard ingredients can make nutritious and delicious meals, here are some ideas to get you started:



Lentil ragu: Lentils are a fabulous source of protein, fibre, iron and folate. You can make a super easy and healthy lentil ragu with a pack of red lentils and tinned chopped tomatoes and other veg. If you are restricting potassium, aim to have half a tin of tomato per meal and avoid adding tomato puree and eating other high potassium foods with this. You could also make big batch and freeze your leftovers for a speedy midweek meal.



Easy paella: If you've got rice and frozen veg, you can make a delicious one-pan paella by basically throwing in whatever ingredients you've got in the kitchen! Find a recipe online that you like the look of and substitute the protein and vegetables with what you've got on hand. Although frozen foods have a bad reputation sometimes, they often retain more vitamins than people think and can make up a very nutritious meal.



Tuna and sweetcorn fishcakes: Tinned fish can be a real lifesaver when you're running out of fresh food! You can make fish cakes using simple ingredients such as tinned sweetcorn and tuna, breadcrumbs, eggs and boiled potatoes. Serve them with a side salad and you have a delicious, balanced meal. Plus, fishcakes freeze really well if you want to save some for later.



Bean curry: Tinned beans provide an excellent source of plant-based protein and help to control blood sugar levels. You could combine them with a tin of chopped tomatoes, onions, garlic, smoky paprika and garam masala for a delicious dinner. Scatter with coriander and serve with basmati rice to soak up the juices.

Lockdown Boredom Busters

Being stuck at home for weeks on end during lockdown, can really increase boredom and make our teeth itch! There's nothing interesting on tv, the radio plays the same music every day and there's no one to chat with. Everyone else is isolating at home too.



Well, fret not! We've compiled a list of fascinating (FREE) things you can do on the internet that is sure to appeal to everyone whether you're a *culture vulture* or not.

www.thejigsawpuzzles.com

Keep your brain cells buzzing with countless jigsaw puzzles covering almost any topic of your choice.

www.thesudoku.com

For those who fancy numerical puzzles, this site is great for sudoku puzzles.

www.themahjong.com

If you want something more high brow, have a go at mahjong

www.earthcam.com/network

Going on holiday this year may not be possible. Here's the next best thing. Watch **live** camera footage of places around the globe that most can only dream of visiting.

lightsoverlapland.com/virtual-aurora-tours

Discover the wonder of a 3D panoramic reindeer sled ride in Lapland and gaze at the magiical Northern Lights. Take an awe inspiring flight over mountains. and marvel at the amazing Ice Hotel.

www.fullers.co.uk/fullers-virtual-pub

For those of you who have missed visiting your local pub, take a virtual tour around a Fuller's pub (beverages not included!)

www.whatsonstage.com/london-theatre/news/stage-shows-musicals-opera-free-stream-online_51198.html

Watch your choice of Stage shows, musicals and opera from the comfort of your own home now for free. For those who fancy a bit of the arts.

www.viking.tv

Viking TV is a very nice website brought to you by the holiday company. It showcases the entire spectrum of culture focusing on the Nordic and Scandinavian regions.

<https://artsandculture.google.com/project/360-videos>

Google brings to life culture from around the world in an interactive way. There is so much to explore with 3D virtual imagery of art galleries, museums and much, much more...

www.britishmuseum.org

The British Museum is home to an array of artefacts from diverse cultures spanning two million years.

www.nationalgallery.org.uk/visiting/virtual-tours%20

The National Gallery has an enormous collection of art by the most renowned artists. Take a virtual tour of its many rooms.

www.english-heritage.org.uk/visit/places/stonehenge/things-to-do

English Heritage are responsible for the preservation of historic landmarks. The mysterious Stonehenge site is just one of the places you can explore in 3D.

www.futurelearn.com/courses/rome?utm_source=fl_blog&utm_medium=organic&utm_campaign=covid_content

Rome: A Virtual Tour of the Ancient City. Brought to you by the University of Reading, this is a free course that will expand your knowledge of the Romans and their way of life.

www.youtube.com/watch?v=VL0TG_nCqzE&feature=youtu.be%20

Sit down with a bowl of popcorn and watch the magnificent Cirque du Soleil perform their show – Alegria.

www.eyerevolution.co.uk/aircraft

Won the lottery and can't decide which aircraft to buy? Go on a virtual tour of some of the best aircraft on the market.

www.footballstadiums360.com

Go on a virtual 360° tour of ten European football stadiums. With facts and stats. Equip yourself with knowledge that will impress family and friends (when you meet them!)



The law around organ donation in England has changed

Organ donation remains your choice
visit organdonation.nhs.uk

Renal Counselling & Social Support Service during Coronavirus crisis

The Imperial College Healthcare Trust Renal Counselling & Social support service are very mindful of the difficult and challenging time that our renal patients are now facing amid the Coronavirus crisis.

We are continuing to support our patients, families and carers through telephone counselling and telephone social support service.

You can be referred either by a member of the Renal team, or by self-referral.

Contact Details:

Counselling Service

Beverley Mealor –
Lead Renal Counsellor
Email: beverley.mealor@nhs.net
Tel: 0203 3136620

Sheila Goddard –
Renal Counsellor
Email: sheila.goddard@nhs.net
Tel: 0203 3135341

Social Support Service

Michelle Delon –
Social Support Worker
Email: michelle.delon1@nhs.net
Tel: 0203 3136619

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	0203 31336627
Brent Renal Unit, Central Middlesex Hospital, Renal Unit	0208 4532017
Charing Cross Hospital , Renal Dialysis Unit, 1 South	0203 31336627 / 0203 3111034
Ealing Hospital, Renal Unit	0208 9675737
Hammersmith Hospital , Renal Home Therapies (HD)	0203 3136649
Hammersmith Hospital , Renal Home Therapies (PD)	0203 3136647 / 0203 3136665
Hammersmith Hospital , Renal Out-Patients' Clinic – Currently joined with St Mary's Hospital, Renal Unit	020 8383 4247
Hayes Renal Unit	0203 7048450 / 0203 7048444
Renal Dietitian, Nutrition & Dietetics	0203 3111034
Northwick Park Hospital, Renal Unit	0208 8693245
Pam Sasso Unit (PIU), Hammersmith Hospital	0203 3136682
St Mary's Hospital, Renal Unit – Currently closed. Joined with Hammersmith Hospital, Renal Out-Patients' Clinic	020 8383 4247
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
West Middlesex Hospital	0208 321 2543

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

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www.facebook.com/WLKPA

