



Photo by Arnó Smit on Unsplash

We've had a very turbulent couple of years when the entire planet was grounded to a halt and it now seems that we are emerging from it just as the spring blossom appears on the trees and we are surrounded by budding shoots and new growth in the natural world around us.

The need to be careful still remains and it will be some time before we can say that we're finally over the pandemic. 2022 is however looking more hopeful. The WLKPA are aiming to be back and "firing on all cylinders" over the coming months as we resume our efforts to participate in all of the activities that we have missed over the past couple of years. Remember to stay up-to-date with news as it happens on our website, www.westlondonkpa.org.

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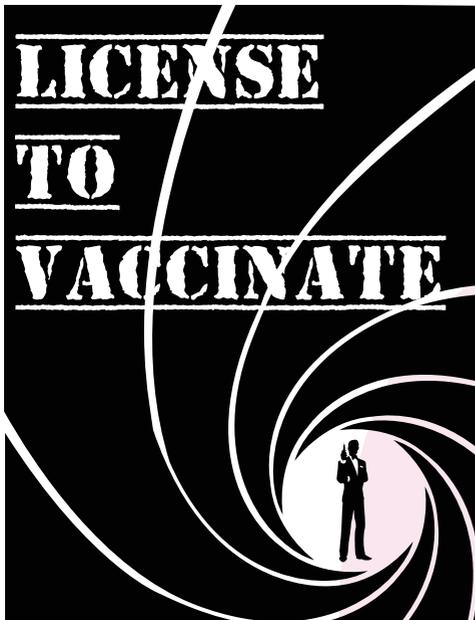
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Useful Numbers

If you have an
interesting article to
contribute for future
issues, get in touch.

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westlondonkpa.org

Summer Issue
editorial deadline
30th June 2022



“THE VACCINE ISN’T LICENSED!”
a fellow kidney patient gave me their reason for not getting vaccinated against Covid-19.

My heart sank when I heard this. As someone that has worked in the area of design/ branding/ licensing for a long time, I’m familiar with the traditional framework of licensing. As a driving license holder or a television license holder, most people ought to be familiar with the term “licensing”.

For those who may be less familiar with the term, read on!

- A TV Licence gives someone legal permission to install or use television receiving equipment to watch or record television programmes.
- A driving license allows a person to drive a car/ vehicle on the roads.
- A pharmaceutical license allows a company to manufacture a drug/ vaccine which has been developed by another company that owns the patent or other intellectual property rights of a particular drug.

Product Licensing and Authorisation are often confusingly used to mean the same thing.

It’s important to understand that all vaccines must go through a stringent process before it reaches your arm. A company marketing a product has a responsibility to do so in accordance with the law. A medicinal product placed on the UK market must have a marketing authorisation (MA). A marketing authorisation is only granted for a medicinal product which meets statutory standards of safety, quality and efficacy.

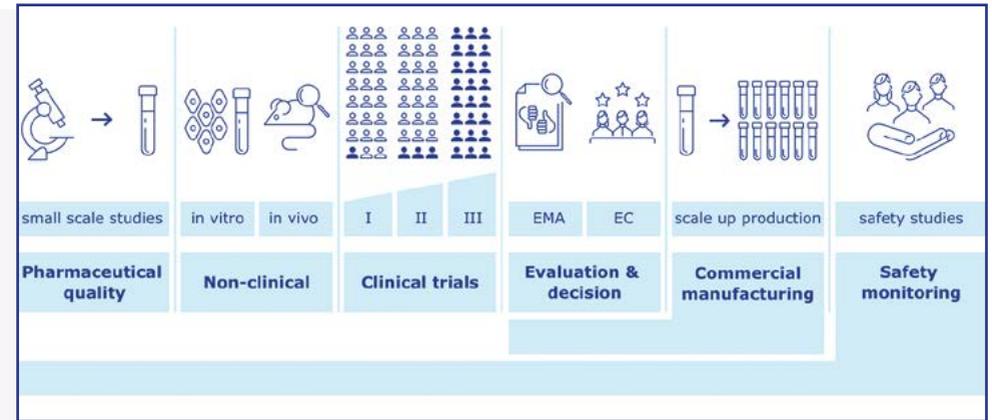


Diagram showing an overview of vaccine development and approval stages www.ema.europa.eu

A page on the BBC News website explains in detail the step-by-step development of the Covid vaccine as described by Prof Sarah Gilbert, the architect of the Oxford vaccine. Just go to www.bbc.co.uk/news/health-55041371 to read more.

We all have friends and loved ones who have been impacted by the pandemic in one way or another. It is no secret that conflicting information, ignorance, misinformation, fake news and conspiracy theories have been abound in the media and society over the past two years, more so than ever. Whether we choose to get vaccinated or not is a personal choice. It’s imperative that we make these decisions after gathering as much information as we can about the benefits and risks.

Please make sure that when carrying out your own investigations that you ask the correct questions in order to get the correct answer. For me, the question of whether the Covid vaccine is “licensed” or not is not important. I want the peace of mind of knowing that the vaccine going in to my arm is safe and has come directly from the company that created it not by a third party that has paid a huge sum of money for a license to potentially make, distribute and sell it for profit.

For those of you who are still unsure whether it is safe or not to have the vaccine, you can view the government’s decisions on authorisations of vaccines and other drugs at the following link; www.gov.uk/health-and-social-care/pharmacy

**Important message from Hammersmith Renal Clinic
DON'T FORGET TO REMEMBER...**

THAT...

**YOU MUST REMEMBER TO ATTEND
YOUR CLINIC APPOINTMENT.**

Arriving for your appointment 5 minutes early is recommended.
Arriving earlier doesn't guarantee that you will be seen earlier.
Not arriving at all is a cause for concern.

THAT...

**RELATIVES ARE NOT ALLOWED TO ACCOMPANY
PATIENTS IN TO THE CLINIC AREA.**

To maintain social distancing, unless agreed with staff,
only the patient is permitted to enter the clinic area.

THAT...

**IF YOU KNOW THAT YOU HAVE COVID-19,
DO NOT ATTEND THE CLINIC**

Attending clinic is important but NOT if you have Covid-19.
Call the clinic instead and get advice on what to do.

THAT...

**YOU MUST ENSURE THAT YOU HAVE ENOUGH
MEDICATION AT HOME AT ALL TIMES**

At least a month's supply of medication must be kept at home.
Don't wait until you have almost run out to request for more.

How to re-order your medicines

Most of your medicines will be prescribed by your GP and dispensed by your community pharmacy.

There are some specialist medicines that you may need to take that the GP cannot prescribe and your kidney team will prescribe these.

You must never run out of any of your medicines.

Before you attend clinic

Make a list of all your medicines including the dose you take.

Bring the list of medicines to clinic with you.

Calculate how long the supplies of each medicine will last at your current dosage, in particular the specialist medicines that your kidney team will prescribe.

How to re-order your GP medicines

You should never have less than one-week's supply of these medicines at home.

Your GP surgery will be able to tell you how they organise requests for repeat prescriptions – please confirm this with them.

As a general rule, you must request repeat prescriptions from your GP surgery at least 2 working days in advance.

If the kidney clinic start a new medicine or change the dose of a medicine which is normally prescribed by the GP you must take a copy of the outpatient prescription to the GP surgery to ensure they continue the medicine.

How to re-order the specialist medicines from your kidney team

A pharmacy home delivery company or the outpatient pharmacy at the hospital you attend will provide the specialist medicines prescribed by your kidney team.

You must never have less than one-month's supply of these medicines at home

Not doing so may mean you will have to attend the hospital to collect an outpatient prescription for an emergency supply dispensed by the hospital outpatient pharmacy.

You must be registered with the home delivery company before they can deliver medicines to you.

If you have not been registered and would like to receive your specialist medicines via home delivery please let the clinic staff know.

Always know how much stock of each specialist medicine you have at home and ask the doctor, nurse or pharmacist you see in your kidney clinic to write a prescription when you need one.

Requests cannot be made via telephone or email outside of your clinic appointments – you must remember to ask for the prescription during clinic appointments.

During your clinic appointment

Ask the doctor, nurse or pharmacist you see the following two questions:

1. WHEN will my next clinic appointment be?

If you **do not** have enough of your specialist kidney medicines to last until your next appointment then ask your doctor for a new prescription. Even if you have 3 months supply at home but your next appointment is not for another 3 months ask your doctor for a new prescription.

Continued on next page

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2. Have any of my doses changed?

If the dose has increased then you may need to order more of your specialist kidney medicines in which case ask the doctor to give you a new home delivery prescription or outpatient prescription.

If you have enough medicine then wait until your next appointment and repeat the steps outlined above.

Contact numbers

1. **Alcura helpline: 0800 9800 686 or 01604 433 500**
– (Select option 1)

Call this number with any queries or if you do not receive your delivery or to re-arrange your delivery.

2. **Polarspeed helpline: 0800 7833 178 or 0800 0564 956**
– (Select option 1)

Call this number with any queries or if you do not receive your delivery or to re-arrange your delivery.

When the home delivery company call to arrange your delivery, they will be required as part of the Data Protection Act to ask a security question which may be your date of birth or full address or the password you have set up.

3. **Hammersmith hospital homecare team: 0203 313 1020**

Call this number if you need to update any information with the kidney pharmacy team.

British Transplant Games Summer 2022 – Leeds

After a two year hiatus since the last British Transplant Games (BTG) held in Newport, Wales in 2019, the annual games are set to return this summer in the host city of Leeds. Fancy coming along?

Team Hammersmith are on the search for new sporting talent this year as they prepare to head to Leeds this summer for the Transplant Games. The team had an impressive medal haul at the previous games in Newport, three years ago and are determined to do just as well (if not better) this year.

2019 was the first BTG for many among the team and friendships were made with one another and with fellow transplant patients from across Britain. All ages and abilities are welcome whether you're a seasoned pro or a total novice. Visit the WLKPA website

gallery to get a glimpse of the action and fun we had in 2019.

Registration deadline is 22nd May so you'd better get your skates on. Details on next page.



Take a look at the events on offer:

Adult Celebration Event
Adult Short Tennis
Adult Social Event
Adult Swimming
Adults 6 a side football
Archery
Badminton
Basketball
Children's Ball Throw
Children's Swimming
Childrens 5 a side football
Childrens Celebration Event
Childrens Cycling
Childrens Social Event
Cycling
Darts
Donor Run
Golf
Golf Practice
Indoor Bowls
Mini Marathon
Mini Tennis
Netball
Obstacle Course
Snooker
Sport Stacking
Sportshall Athletics
Squash
Table Tennis
Ten Pin Bowling
Tennis
Track & Field
Under 5's Archery & Long Jump
Volleyball
Walk



Are you a transplant recipient or a donor?

Are you interested in joining Team Hammersmith at the British Transplant Games?

There will be a variety of sporting events for all abilities and ages

Leeds 2022

From Thursday 28th July – Sunday 31st July 2022

Sponsored by:



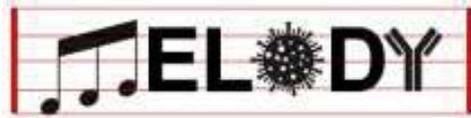
Contact us for further details:

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MELODY Research Study



The MELODY (Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people) study will use home blood finger prick antibody testing to improve our understanding of responses to COVID-19 vaccination in individuals who are receiving immunosuppression.

The research study is being run by doctors and researchers at Imperial College London, in collaboration with several NHS and academic partners. The MELODY study will target three groups of individuals: those with solid organ transplants, those with

some types of blood cancer, and those with autoimmune disease. It will employ home blood finger prick antibody tests to measure the proportion of patients who develop antibodies to their third dose of a COVID vaccine. It will then utilise linked NHS data to determine if antibody responses correlate with protection from subsequent disease and hospitalisation during a 6 month follow up period. The study will provide valuable information on vaccine efficacy in clinically vulnerable patients and will inform future recommendations for the use of protective strategies and novel therapies in individuals receiving immunosuppression.

If you wish to participate, please visit www.melodystudy.org

Covid-19 guidance

With restrictions being lifted you may be feeling anxious and want some guidance. We recommend you go to the Kidney Care UK website where you will find useful Covid-19 guidance which is continually updated, so please keep checking for the latest developments. www.kidneycareuk.org/coronavirus



FILL IN THIS CRISS CROSS PUZZLE WITH THE NINE WORDS LISTED BELOW

Some boxes have been filled in to help you

BLOSSOM	FLOWER	RAINBOW
BUDDING	GROWING	TULIP
BUTTERFLY	LAMB	UMBRELLA



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
West Middlesex Hospital	020 8321 2543

**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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