



Supporting and working for
kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

Summer 2021

SUMMER'S HERE

(SUN CREAM, HATS AND BBQS AT THE READY!)

It's lovely to wake up to blue sky and sunshine and to now be allowed out to enjoy it with family and friends (albeit with caution). Some of you may be finding it difficult to adjust after so long in lockdown or shielding. Even with two vaccines under your belts it is advisable to take care and we must remember the importance of adhering to "Hands-Face-Space". So when going out remember your Sun cream and Hat and also take your mask/face covering with you too.

Our summer issues are usually packed with details of our annual day trips but unfortunately we have to postpone them for another year. So for now we hope you can enjoy day trips of your own to some of the beautiful English coastal and countryside locations.

Contents

Pages 2-3

Peritoneal Dialysis (PD)
by Dr Richard Corbett &
Sr Sally Punzalan

Page 4-5

The OC Way
Charity Cycle Ride

Page 6-7

Virtual "Know Your
Dialysis" Seminar

Page 8-9

Kidney Care UK

Page 10-12

Soya and kidney disease
– is it good for me?

Page 13

West London Hospitals
Holiday Dialysis Trust
Sale of St Anne's

Page 14-15

Puzzle Corner

Page 16

Imperial College
Renal & Transplant Centre
Contact Numbers

Peritoneal Dialysis (PD)

by Dr Richard Corbett & Sr Sally Punzalan

Peritoneal dialysis (PD) continues, alongside Home Haemodialysis, to be one of the two great options available for people wanting to do their own dialysis at home. In particular PD can be the ideal dialysis option for the person who is starting dialysis due to problems with their own or a transplanted kidney. The Covid-19 pandemic has led many people starting dialysis to think more carefully about the benefits that come with home dialysis.



Bringing the service right to your doorstep

We are fortunate to work as part of a motivated Renal Home Therapies team that has expanded with the increasing demand from patients across North West London for home dialysis treatments. We now see each month between a quarter and a third of all patients starting dialysis, choosing PD. This means that there are now well over 200 people doing peritoneal dialysis at home. This number has increased dramatically from about 80 people five years ago and we hope it will continue to grow.

This is great news as it means that so many more people have the opportunity to choose a treatment that gives them flexibility in the timing and place of dialysis. PD is also a great way for people to be able to travel whilst doing dialysis, though for all of us this has been much harder in the last year given the lockdowns and the need for shielding!

We are delighted to celebrate Professor Edwina Brown. She has been a strong advocate for the benefits of PD for many

years within West London and became the President-Elect of the International Society for Peritoneal Dialysis this year. She remains very active clinically and continues to champion the importance of individualising dialysis care, as she has done across her long career.

What this means in practice is that alongside the person doing PD, we focus on individualising dialysis so that PD fits into their life rather than the other way round. This includes, supporting older people who may have otherwise struggled with doing PD at home or, with our surgeons who have an interest in PD (Frank Dor and Anand Muthusamy), pioneering the placement of longer dialysis catheters in the larger person who wants to do PD.

We look forward to being able to continue to offer PD to an increasing number of people wanting to do their own dialysis at home. If you are interested do speak with the team looking after you about whether PD may be an option for you.

The OC Way Charity Cycle Ride

Co. Westmeath native, Oliver Connell established Oliver Connell & Son Ltd in 1974, with his brother Pat joining him five years later. As partners in the business, and together with their sons, they grew the business into the significant construction company it is today.

Pat, Greg, James & Tom Connell are raising money for two charities, one of which is the "West London Kidney Patients' Association", a charity which is very close to their family as Oliver, the Founder of Oliver Connell & Son Ltd, sadly passed away last year, having suffered kidney disease for more than the last fifty years of his life.

Pat, his brother, donated his kidney for Oliver's first transplant and it lasted for almost forty years before

Oliver became unwell again. Oliver later went on to receive a second donor kidney.

They are also supporting "The Lighthouse Club", which is a well-known charity in the construction

industry. They are the only charity 100% dedicated to the physical, mental and financial wellbeing of construction workers and their families in the UK and Ireland.

Their mission is no construction worker or their family should feel alone in a crisis.

The OC Way Charity Cycle

Ride will take place on Saturday 3rd July 2021. 24 cyclists will cycle 90 miles from Trinity College, Oxford to Addenbrooke's Hospital, Cambridge

Oliver Connell 1945-2020



An event poster for "The OC Way Oxford to Cambridge Charity Cycle Ride" on Saturday 3rd July 2021. The poster features a stylized map of the route from Oxford to Cambridge, passing through London, Brighton, Southampton, Bristol, Cardiff, Birmingham, and Nottingham. It includes contact information for Tom Connell and Denise Hogan, and logos for the Lighthouse Club and West London Kidney Patients' Association. The text "Raising money for the Lighthouse Club and West London Kidney Patients' Association" is prominently displayed at the bottom.

A white line-art illustration of a cyclist riding a bicycle, set against a purple background with colorful confetti and streamers. The cyclist is in a dynamic, forward-leaning position, pedaling the bike.

A huge THANK YOU to Oliver Connell & Son Ltd, all those taking part in the cycle ride and those who are supporting the fund-raising event with their generous donations.

Virtual “Know Your Dialysis” Seminar

By Kim Pryde –

CNS Renal for Imperial College Advanced Kidney Care Team

If anyone had told me last January 2020, on my return from what was to be my last trip abroad for a long time, that I would become an expert in Zoom meetings, Teams meetings, sharing my screen, etc., I would not have believed them.

I am the type of person, and my Kidney Care colleagues will attest to this, that if I am asked to cut and paste anything I still reach for the scissors. We have all, in a very short space of time, had to adjust to a new way of working and communicating with each other.

Previously, pre-Covid, my Kidney Care colleagues and I would invite patients and family members to seminar rooms at various locations to teach people about their dialysis options. We were able to show the equipment, take them to a dialysis unit, and discuss the treatment options face to face.

Post Covid, the Kidney Care team had to quickly figure out how we were going to reach our patients and teach them about their dialysis options in a socially distant way.

We had help and guidance in setting up the seminars from a technology point of view. We had to use Microsoft Teams because it was the virtual system approved

by The Imperial College Trust. We all learned the system together as time went on.

We had to carefully collect slides that did not have copyright status and all the slides had to be approved of by the Imperial College Communications Department.

We decided together as a team what we would say, how it should be presented and even practiced a bit before we went live.

The technology was very new to us, but also new to many of our patients. Many of the patients have managed to embrace technology, often with the help of children and grandchildren.

We created a slide to show at the beginning of each presentation demonstrating how to use the “mute” button, how to get our attention if they wanted to ask a question, asking everyone to be “screen ready” and to make sure their background was appropriate.

The kidney care nurses take turns putting on the seminars in teams of two. One nurse introduces the seminar, goes through the guidance and talks about Peritoneal Dialysis. The second nurse handles the Haemodialysis and Shared Care Dialysis.

We give time for questions at intervals between topics.

Anyone familiar with these online chats know that there is a “Group Chat” option. The nurse who is not presenting keeps an eye on the Group Chat column and answers any questions written in by patients and family members as the seminar goes along.

While virtual seminars are no substitute for face to face contact they do, for many, make it much easier to keep in touch with their clinicians. For patients with mobility issues, or no readily available transport, virtual appointments and information seminars are ideal.

Our dialysis seminars have been well attended. More people have been able to attend these on-line seminars than the face to face seminars. The size of the room

no longer limits the numbers of people we can invite.

We have had lots of positive feedback so far. People have said the seminars are clear, well organised and helpful.

Initially we did have a few complaints as people had trouble with the technology, but as people have become more familiar with their devices problems are limited.

While we miss seeing our patients face to face, we have to admit that the virtual pre-dialysis seminars have made it possible to continue our education program and to reach more people than we otherwise might have. All it takes is an email from one of our team with the link to the Teams seminar and the date and time.

Virtual meetings, seminars and WhatsApp video calls, have become a part of everyday life for many of us.

What incredibly good fortune that at such a time in history this technology is available to us.

For information about the dates and times of and links for the next online seminar please email kimpryde@nhs.net



Kidney Care UK

We believe that no-one should face kidney disease alone. For over 40 years we have been committed to improving kidney care services and helping everyone affected by kidney disease. We give you our total support to ensure you can live your life to the full, providing practical advice, emotional support, and financial assistance.

Your regional Advocacy Officer is available to support and represent you, your families, and carers. We can help you with a range of issues relating to kidney disease including treatment options, welfare and benefits, emotional support, and dialysis away from base. As you would

expect the advocacy service is sensitive, compassionate, and completely confidential. We will work with you one-to-one and if necessary, we can arrange further support offered by Kidney Care UK including our telephone counselling service and financial grants programme. Financial support is available to those on a low income and can help to pay for household items, travel expenses and towards training courses.

The opportunity to take a break with family can make a huge difference to your physical and emotional wellbeing but can too often feel out of reach either practically or financially. If you are

on dialysis and looking to take a break in the UK in the future, we fund the Kidney Care UK Dialysis Freedom service, which can help you plan and organise your dialysis away from base. We can also offer grants to help cover the cost of a respite break or contribute to a family holiday in the UK or overseas. This will be subject to any government travel restrictions.

We continue to work collaboratively with a number of KPAs, through our Hospital Grants Programme to improve patient outcomes by funding improvements to local kidney services.

We provide grants for staff posts, projects, and equipment, as well as invest in major renal projects. Some examples of how we are doing this include jointly funding a Youth Worker at Southampton Children's Hospital, with the Wessex KPA. Providing a small financial grant to the North Staffordshire KPA to help them set up their new website and supporting the Tayside KPA to fund a caravan in Scotland that can be used by kidney patients and their

families to enjoy a short break. If you think we can support your KPA with a project, please get in touch.

As part of our work improving care services, we actively support the Kidney PREM, which stands for Patient Reported Experience Measure. This anonymous annual survey is undertaken in partnership with the Renal Association and it is used nationally to look at how care is provided and promote the sharing of best practice. Locally the results help your renal unit

The opportunity to take a break with family can make a huge difference to your physical and emotional wellbeing...

understand how their patients really feel about their care, highlights what's

working well and identifies the areas where improvements could be made. Our Advocacy team will be looking closely at the results in their regions and supporting units, KPAs and patients to come together and improve services. If you would like to read more about this year's kidney PREM, go to www.kidneycareuk.org/prem

For an advocacy referral, financial help, or support with any other issues, call us on 01420 541424.

Soya and kidney disease – is it good for me?

With the rise of vegan foods in supermarket aisles, soya foods are becoming more popular. But what is the hype really about?

What is soya?

Soya is similar to beans and pulses –however, it has a different taste and less carbs and has more high-quality protein than chickpeas, beans and lentils, whilst also having more fat than other beans. This fat is mostly polyunsaturated, a heart-healthy type of fat, that can help lower cholesterol.



Can you eat soya if you have kidney disease?

Soya foods are high in protein, which can be a concern if you have chronic kidney disease and are not on dialysis. However, animal protein (such as red meat, chicken, fish) is very different to plant protein (such as soya), and there is some evidence that soya products may be beneficial at any stage of kidney disease.

What about phosphate and potassium?

Soya is also safe if you have been advised to limit the potassium and phosphate in your diet. Tofu (condensed soya milk) is about 4 times lower in potassium than beef, and soya milk is lower in potassium and phosphate compared to cow's milk. The phosphate from plant foods is poorly absorbed compared to the phosphate from dairy and meats, so swapping to soya milk could be a way to help control your phosphate.

How else can soya be beneficial?

For muscle building:

Soya is just as efficient as animal protein in building muscle and may be a better choice than meat as it may have a smaller effect on creatinine levels – an important marker of kidney disease.

In the menopause:

Soya contains isoflavones, oestrogen-like compounds that can have a similar effect to oestrogen and can therefore dampen some effects of the menopause, like hot flushes.

But is it safe?

Yes! The stigma around soya comes from old animal studies saying soya was not safe to eat for people who have had or are at risk of breast cancer – however, recent human studies now oppose this.

What about the environment?

Compared to dairy milk, soya drinks have a lower carbon footprint. Producing one 200ml glass of soya milk will require 1/3 of the land required by cow's milk, and 1/10 of the water, making it more environmentally friendly.



How can I add more soya into my diet?

Here are some tips on how to add more soya into your diet:

Soya milk: Add 250ml of soya milk in cereal or porridge, tea, coffee and in cooking. Soya drinks are the only plant-based milks that are considered equivalent to dairy, as most are fortified with calcium, vitamin D and vitamin B12.

Soya yoghurt: Have with cereal, honey and fruit as an alternative to dairy yogurt.

Firm tofu: Fry 100g of firm tofu per person with spices like paprika, cumin and lemon juice – cube it up and serve over some fried rice or noodles instead of chicken or pork.



Continued on next page

Silken tofu: Puree some silken tofu and use it as a base for creamy soups and sauces, like a vegetarian mac and cheese with tofu and basil pesto, or for creamy desserts and pies, like dairy free or vegan cheesecakes.

Soya “meats”: Why not choose soya mince, burgers or sausages for a “Meat-Free Monday” meal? Swap beef mince for soya mince in a Shepherd’s pie or homemade Bolognese sauce, add soya protein sausages to a Sunday roast, bring some soya patties to a barbeque.

There is no need to dramatically change your diet but aiming to replace even one or two meat or dairy products with soya foods every week could bring some health benefits. So why not give it a go?

**Have you had a TRANSPLANT for AT LEAST 6 months?
Or do you provide support to someone with a transplant?**

WELLBEING AND LIFESTYLE IN TRANSPLANTATION

RESEARCH STUDY

You will receive a £20 Thank You voucher.



**Join a discussion group
to share your experiences
of life post transplant**

**If interested in taking part
or curious to know more,
please contact Lina on:**

Tel: 020 3313 3947



Email: I.johansson@imperial.ac.uk

West London Hospitals Holiday Dialysis Trust Sale of St Anne’s – By Dr Peter Hill

The West London Hospitals Holiday Dialysis Trust has been providing holiday accommodation at the former convent, St Anne’s in Emsworth for over 30 years. The COVID pandemic has caused so many changes for all of us. No one has been able to travel to St Anne’s throughout 2020 and 2021 is looking similar. With departure of the dialysis staff during 2019, the financial viability of providing holiday dialysis at St Anne’s has become increasingly questionable. Following extensive discussion the trustees of the WLHDT decided to sell the house in St Anne’s.

This is not the end of the trust by any stretch. Providing holiday dialysis for patients receiving treatment in West London is very much the mission of this charity and we will be consulting with all over the coming months to decide how to continue offering holiday dialysis away from centre.

It is with a heavy heart that St Anne’s has been sold but I think with this, there are great opportunities to provide a patient focused future for the charity that will allow many more patients to receive dialysis away from home and facilitate travel once more.

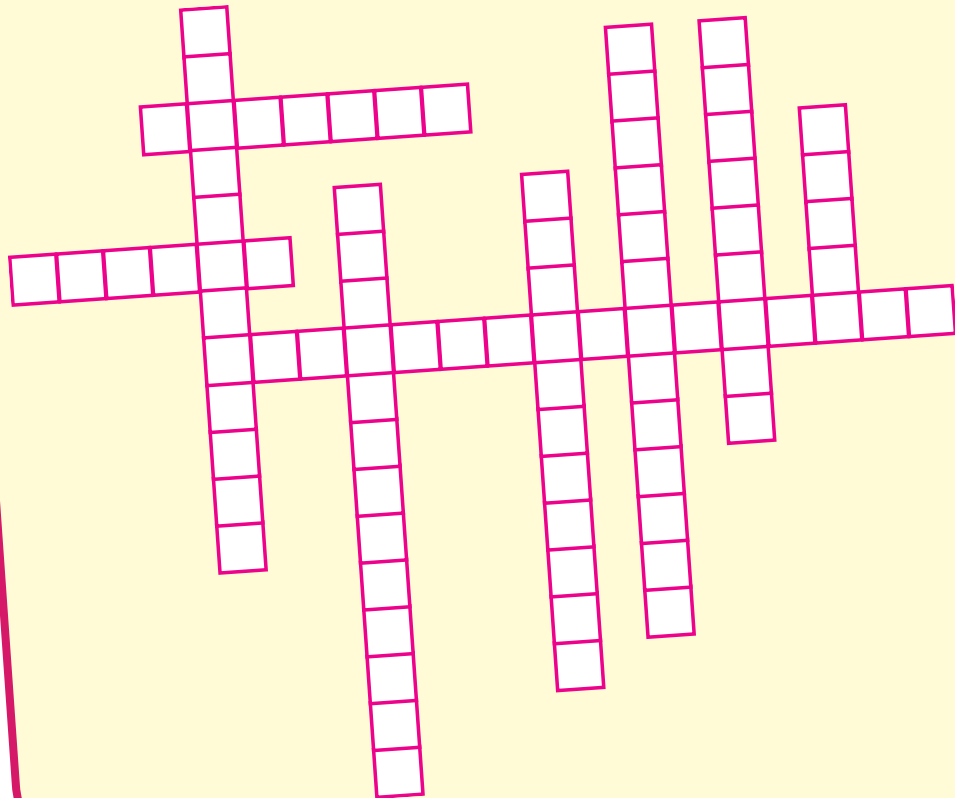


Dialysis Criss Cross Puzzle

Can you fill in the Criss-Cross puzzle by filling in the boxes?

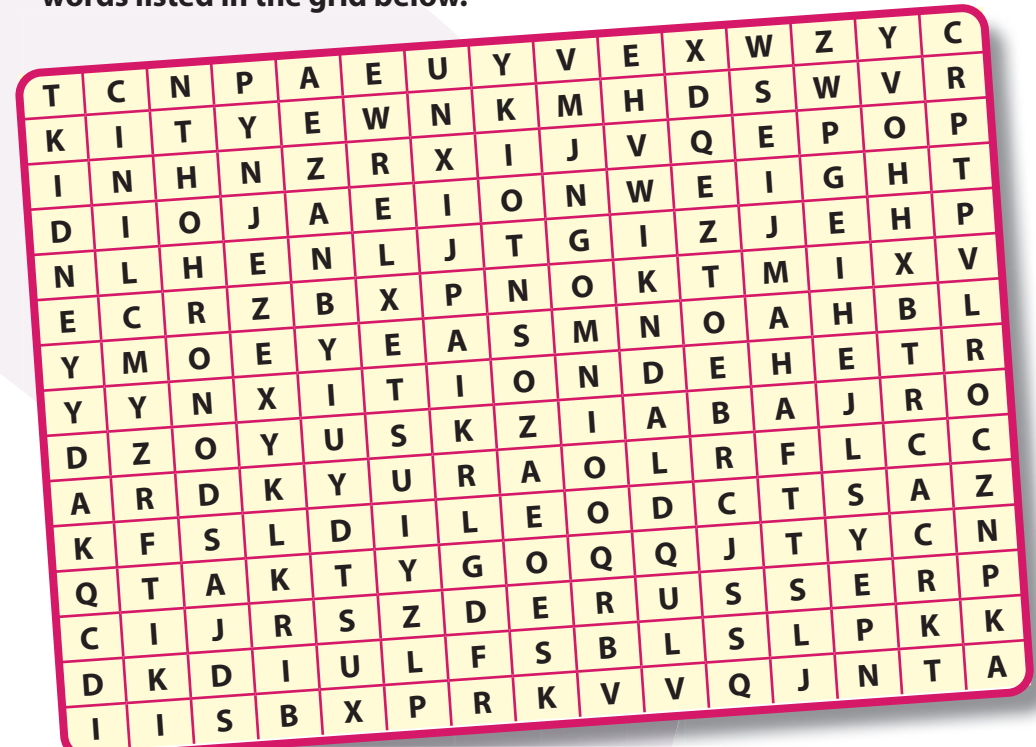
Clue: You may have had dialysis here.

(Answers can be found on the back page.)

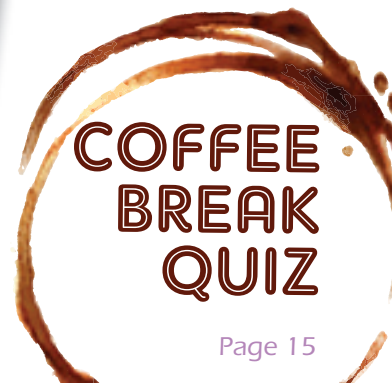


Renal Wordsearch

See how quickly you can find the twelve words listed in the grid below.



| | | | |
|--------------|--|----------|--|
| BLOOD | | CLINIC | |
| CREATININE | | DIALYSIS | |
| DONOR | | FLUID | |
| HEMODIALYSIS | | KIDNEY | |
| PERITONEAL | | PRESSURE | |
| TRANSPLANT | | WEIGHT | |



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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