



Supporting and working for
kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association

Newsletter

Winter 2022



Welcome to the 2022 Winter Newsletter.

WLKPA have had a busy, productive year. We continued to fund many kidney units to assist with patient comfort and wellbeing. Thank you to everyone who has made donations.

Infection Control at Hammersmith Hospital were happy for us to have a table to sell Christmas cards again; we had to wear face masks and use hand gel of course and we should all be following this advice through the winter period. This is a very positive move forward and we are enthusiastic that next year, hopefully, we will be able to see patients in person and resume our fundraising and awareness events.

Merry Christmas & a Happy and Healthy 2023 to you all.

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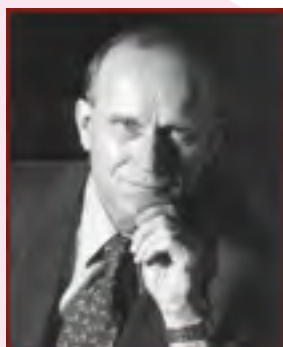
Kidney-Pancreas Transplantation: History, Success Stories And Future Prospects

– By Professor Vassilios Papalois, Consultant Transplant Surgeon,
Patron of the WLKPA

Type 1 diabetes is a most challenging illness that starts at a young age and has serious complications, kidney failure being one of the most common and debilitating ones.

A recently published article in the Lancet Diabetes and Endocrinology (Figures 1 and 2) paints most clearly the scale of the problem of Type 1 diabetes around the world which is anticipated to be 60-100% worse by 2040.

A simultaneous kidney-pancreas transplant is an operation that can treat both illnesses, diabetes and kidney failure, and change dramatically the lives of the patients. The first kidney-pancreas transplant in the world was performed in December of 1966 at the University of Minnesota by Richard Lillehei and William Kelly for a female patient who had diabetes and kidney failure, and no one wished to look after her in the long-term because of her very complex problems. The team of those two pioneer surgeons offered this revolutionary, at the time, operation that was very successful. The programme of pancreas transplantation at the



Professor David Sutherland, the pioneer of modern pancreatic transplantation and translational surgical research.

University of Minnesota and around the world was later developed by David Sutherland, (see picture inset) a truly remarkable clinician and academic and the father not only of modern pancreatic transplantation, but of modern translational (research that can be clinically applicable) surgical research. I had the great honour and privilege to be trained by him for 4 years before I started my work as a Consultant Surgeon initially at St. Mary's and later at the Hammersmith Hospital.

Since the first kidney-pancreas transplant in December of 1966, more than 50,000 diabetic patients

have received pancreas transplants in more than 200 centres around the world.

Our programme in West London has been one of the first and very successful ones. I remember most vividly the call I got from the team on Handfield Jones ward in March of 2001 that there was a potential young donor for a kidney and pancreas transplant for one of our diabetic patients on dialysis.

It was my first kidney-pancreas transplant as Consultant Surgeon and, thanks always to the great collaborative work of our multi-disciplinary transplant team, but also thanks to the courage and support of our patient and her family, it was a great success.

Here is her story in her own words 21+ years later:

Hello, my name is Bridgette. My story starts when at the age of 17, and on a pre-nursing college course, I was diagnosed with type 1 diabetes.

Over the years since then I suffered with all the major complications of diabetes including retinopathy, necrobiosis lipoidica (leg ulcers) and autonomic neuropathy. Following the birth of my second child I developed end stage renal failure and soon required daily dialysis. At this point I was constantly exhausted, spending most of each day in bed, I was unable to look after my family. There seemed to be no worthwhile future. While on dialysis I was lucky enough to join the kidney+pancreas transplant waiting list at Imperial College Healthcare Trust, and after some years I received the most important phone call of my life – a potential donor match had been identified! That same evening, I underwent surgery for a simultaneous pancreas and kidney transplant at St. Mary's Hospital in London. My life was almost instantly transformed. I could lead a normal life, I could be a wife and mother, and could spend time with friends. Seeing my children become adults was something I never believed was possible in my darker times while on dialysis. It was strange at first not to have to inject insulin four times a day, and I could eat and drink ...

Continued on next page



...whatever I liked for the first time in 20 years. Since the transplant my eyes problems and neuropathy have been fairly stable. After more than 21 years both of my transplanted organs are functioning extremely well and still enable me to lead a normal life doing all the things I love to do. Having the double transplant was the only decision I could ever have made, it gave me my life back.

There are many other success stories in our and other programmes in the UK. However, pancreas transplantation has most certainly not reached its full potential in the UK and around the world. Every year, almost half of the pancreases retrieved for transplantation are discarded and not transplanted depriving many patients from a life changing operation (Figure 3). This is because the pancreas is an organ that can be easily damaged during the retrieval and also there has been no objective way to assess and, even more, improve the condition of a pancreatic graft.

Over the last 10 years, this has been the area of work of my translational research team at Imperial College. We have managed to develop reliable methods for assessing and improving the condition of pancreatic grafts prior to transplantation by using machine perfusion in hypothermic and normothermic conditions. Those machines can circulate a preservation solution via the pancreatic graft (the same way blood circulates through the pancreas in the human body) and allows us to use many different methods for objectively assessing if an organ is suitable for transplantation, improve its condition and predict the transplant outcome. This pioneering research has led to many publications and has been recognised in the cover of scientific journals. We have now started the first clinical trials and thanks to a generous donation by the “Friends of the Hammersmith Hospital” Charity, we were able to purchase a new state of the art machine that will help us to advance our clinical trials.

We are hopeful that this ground-breaking experimental and clinical work will allow us to significantly increase the number of pancreas transplants and also improve their outcomes so that we can have many more success stories like the one of Bridgette.

Figure 1: Type 1 diabetes worldwide in 2021.

GA Gregory et al, Lancet Diabetes & Endocrinology, Vo110,15SUE 10, P741-760, OCTOBER 01, 2022

In 2021, there were about 8.4 million individuals worldwide with Type 1 diabetes.	In 2021 there were 0.5 million new cases diagnosed (median age of onset 29 years).
Of these: 1.5 million (18%) < 20 years 5.4 million (64%) 20-59 years 1.6 million (19%) >60 years or older	About 35 000 non-diagnosed individuals died within 12 months of symptomatic onset.

Figure 2: Type 1 diabetes worldwide in the next 20 years.

GA Gregory et al, Lancet Diabetes & Endocrinology, VOLUME 10, ISSUE 10, P741-760, OCTOBER 01, 2022

One fifth (1.8 million) of individuals with type 1 diabetes were in low-income and lower-middle-income countries.

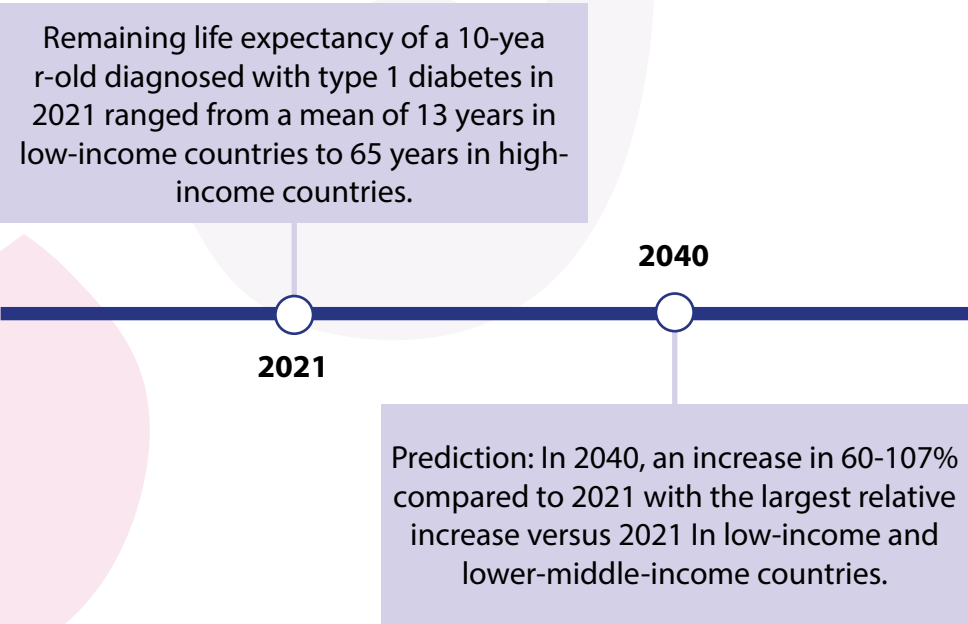
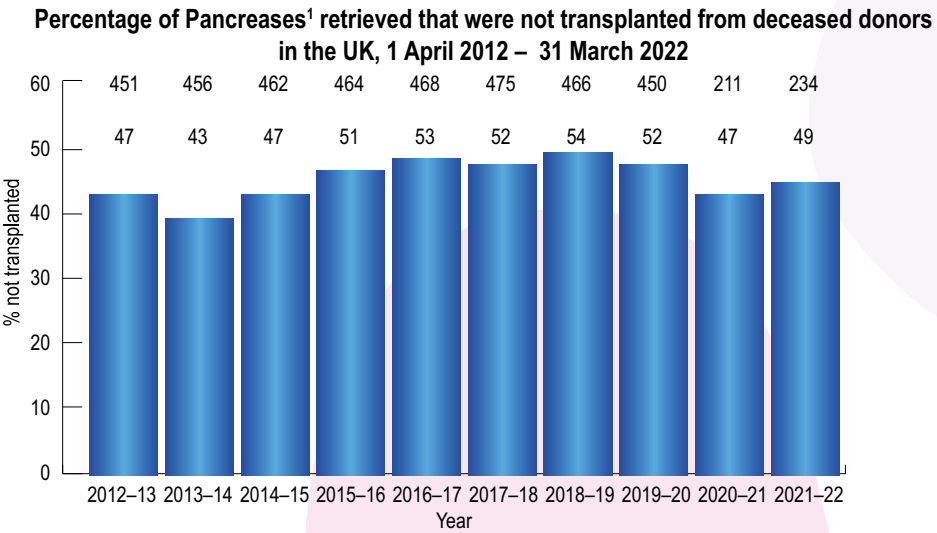




Figure 3: Every year in the UK, ~ 50% of the pancreases retrieved are not transplanted depriving patients from a live saving operation-data from NHS BT.



Source: Transplant activity in the UK, 2021-2022, NHS Blood and Transplant



Take part in our interview project!

We want to talk to you about your needs, experiences receiving support and your thoughts about online emotional support programmes.

Our goal is to create a support programme for family members, partners and friends of people living with a kidney condition.

Are you
a family
member,
partner or
friend of
someone
living with
a kidney
condition?

To participate you need to:

- Be 18 years old or older
- Live in the UK
- Be a family member, friend or partner of someone with a kidney condition who is also at least 18 years old



If you are interested in participating or want more information contact Chelsea:

- e-mail c.coumoundouros@exeter.ac.uk
or
- scan the QR code to create a draft email



The interview will take place at a time convenient for you over the telephone or using a video-call programme (for example, Microsoft Teams or Zoom).

The interview will last around 45-60 minutes.

Thank you!





Burst Water Pipe Disrupts Dialysis Services At Watford Dialysis Unit. *By Head Nurse Merlin Peter*

A major water pipe supplying water to the dialysis unit burst, causing total disruption to dialysis services in September 2022. It was only after a few months of taking charge as the Head Nurse of Watford.

The Renal Unit team experienced this worst-ever water leak affecting the dialysis unit due to a massive sinkhole outside the Watford General Hospital. As a result, the Unit had to close entirely with immediate effect, leaving us with no time to plan or prepare for a major relocation of the patients for their life-saving treatment.

This incident was challenging for our entire team to come together with immediate plans to create dialysis arrangements for our 105 dialysis patients to have their life-saving treatment delivered safely and effectively. However, we managed to allocate all our patients to other satellite units, such as Brent, Ealing, Hayes, St Charles, and Northwick Park, without compromising their dialysis care. Our nursing team travelled to Northwick Park and St. Charles units to support the care of our Watford patient group.

The good news is that we received ample support and leadership from the hierarchies, especially the Dialysis Lead Nurse, Helen Watts, Renal consultants (Dr Rishana and Dr Hill), the transport team, technicians and Head nurses of other satellite units throughout the relocation. Although the patient and staff reallocation went smoothly, one of our major challenges was patient transport allocation to different departments.

Although it was a chaotic experience for all staff and patients, we are proud that our team worked together and made everything possible to deliver dialysis treatment for our 105 patients. In addition, our nursing team received extended support from all the nursing staff from other satellite units where our patients were allocated for their dialysis sessions.

Many thanks to all those staff members who supported and worked collaboratively and demonstrated the trust of the values to support our patient journey.

Cost Of Living Support And Benefits



The recent Autumn Statement produced by the UK government seems to have hit the nation with confusion and uncertainty. There is help out there for most households. **KidneycareUK** have a section on their website with lots of information on the different sources of help you may be entitled to. Go to www.kidneycareuk.org/get-support/cost-living-hub/cost-living-support-and-benefits for further information. If your household qualifies, you could receive up to £650 Cost of Living Payment.

Here is a list of the different support packages available:

- Cost of Living Payment
- Pensioner Cost of Living Payment
- Cold Weather Payment
- Warm Home Discount Scheme
- Disability Cost of Living Payment
- Energy Bills Support Scheme
- Gas and electricity bill help
- Phone and broadband bill help
- Water bills help

You can also email KidneyCare UK at info@kidneycareuk.org or call them on 01420 541424.



The National Kidney Federation (NKF) also provides support on a variety of issues affecting kidney patients. The NKF can be contacted Monday to Friday 9.00am – 5.00pm on 0800 169 09 36 or email them at helpline@kidney.org.uk.



Don't let your kidneys spoil your holidays! A kidney friendly holiday season

— by *Costanza Stocchi*

While it might feel like summer was just a couple of weeks ago, the year went by quickly and we're back knee-deep in the holiday period.

No matter what you celebrate, December's a time for festivities, indulgences and delicious food and drinks. After all, food is more than just fuel: it is a social activity, a reunion, sharing and experimenting in the kitchen.



Having kidney disease means you might feel like you have to miss out on all of this, and the advice you received on what you should or shouldn't eat can often be overcomplicated. Try focusing on a couple of things only: potassium, fluid, and salt. Being mindful of these three elements in your food will help you enjoy the holidays safely and avoid overthinking what you are eating.

General tips for managing potassium and fluids:

- be sensible and eat high potassium foods in small quantities, trying to be a little stricter in the days before a big celebration;
- spread your fluids throughout the day – avoid drinking too much at mealtimes, try to be conscious of alcohol and remember that gravy and sauces also count as fluid!
- If you are drinking alcohol, beware of potassium! Spirits are often lower in potassium and fluid than pints or large glasses of wine.
- try to avoid very salty foods (crisps, pork scratchings, bacon, or even stock cubes and soy sauce) – instead flavour your foods with lemon juice, vinegar and fresh herbs to enhance their natural flavours.



If you have had a transplant in the last year, be especially careful of risk of infection from foods and make sure to store, prepare and cook your food safely – avoid rare meats or raw fish as well as unpasteurised and blue cheeses!

Check your fridge's temperature ahead of packing it full of leftovers and make sure this is no higher than 5°C, and only eat leftovers the day after preparing them.

How can I put a festive menu together?

Kidney Care UK has put together a mix of Christmas or festive recipes that are low in potassium, phosphate and usually low in salt: you can find these online at <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/kidney-kitchen/recipes/> or by asking the dietitian at your dialysis unit or in clinic. You can have a full festive dinner with all the trimmings just by making a few swaps in your ingredients and being mindful of drinks and desserts.

- Starters: try making some brie or cream cheese and cranberry filo parcels, or some homemade mini sausage rolls along with a small cheese and pear salad.
- Mains can be a delicious roast turkey, or a steak and ale pie – just try to hold back on the salt and stuffing, and limit the amount of gravy you have with this. Instead, try and flavour your vegetable sides with different herbs and spices, for example some marsala wine roasted carrots or a small amount of balsamic Brussel sprouts. Don't forget to boil these first!
- Be smart with your desserts – if you are likely to have quite a few sweet treats in a row, bring some rice pudding to a dinner party, or a homemade apple or pear crumble. Limit your mince pies and other fruity desserts to one daily to keep your potassium safe.

Remember – being careful with a few ingredients should not ruin your holidays. Work on finding swaps you might like, spend time experimenting and cooking with your loved ones while embracing the slower pace and letting go of the past year.



Renal Counselling & Social Support Team

The Renal Counselling & Social Support Team at Imperial College Healthcare Trust are continuing to offer counselling and social support.

We look forward to offering our continued support and assistance to all our patients.

As the nights draw in over the winter period and the weather becomes colder many people notice, with the change in season, that mood may be affected and low mood can be experienced by some at this time. Meditation can be of benefit to help with low mood and anxiety.

Here is a simple meditation that you may like to try:

Unclench your jaw

Unknit your brow. Soften.

Lower your shoulders,

Breathe in deeply for four, hold...and out for 6.

Feel your body in contact with whatever is supporting you.

Stretch

Winter Challenge: Can you do this once a day for a month?

Sheila has recently completed a sponsored walk along Hadrian's Wall for the Charity "[Climbing Out](#)".

Congratulations Sheila!

Stepping out provides fully funded activity courses and single walking days aimed at rebuilding confidence, self-esteem and motivation in adults after trauma or a diagnosis of a life changing illness. New dates have been released including a women's only programme. They work with adults with numerous conditions including adults who have renal failure as well as people who work with the NHS and whose health have been effected by the work they do. It is a great organisation. If you join one of their programmes, do let us have any feedback about your experiences – as well as pictures!

And Finally

What do the following text messages have in common?

GOV.UK Click here to apply for the Energy Support Scheme https://energysupport	AMAZON: Your Amazon Prime has been cancelled due to a failed payment attempt. To reactivate your prime Account visit: https://Amazon-reschedule
NHS.NET: You have been in close contact with a person who has contracted the Omricon Variant. Please order a test kit via https://nhs.co.uk/test-kit	British Airways 2022 Black Friday Giveaway. 5000 free round trip flights to Europe. https://shortlinks.uk/015749

The correct answer is that they are all scams. Scam text / Whatsapp messages are clever and are designed to look like they come from real companies. They can sell your information or use any bank account information to hack into your bank account. Never click on a link in a text message but go directly to the main company (preferably on a different device) or call the company on their main number to check. Never provide your bank details via a text message.

If you are unsure if a text message is real, talk about it to your family or your renal community before responding.



Season's greetings from the Renal Counselling and Social Support Team

From l-r: Beverley Mealor, Sheila Goddard, Michelle Delon



Changes at Northwick Park Hospital Dialysis Unit



This year we said farewell to Debbie Haynes our Ward manager. Debbie joined the unit over 25 years ago and has been a well-loved member of our team since then. We all wish her every success in her new venture in the country side (she is not sure where just yet!).

April Arribas was sucessfully appointed & been in post since June, she is doing a sterling job! We have had a challenging year with regards to recruitment but have now welcomed 13 new staff in to our fabulous team and all have come with amazing life and dialysis skills.

We are delighted to say we now have a newly refurbished staff room; this makes such a difference for the team during their rest breaks. This was funded by generous donations to the unit and was several years in the planning.

For 2023 I hope we can bring new things to the unit, we are hoping to start some patient focused activities to pass the time away during dialysis sessions. We have spoken to some of our patient group for ideas - so far we have card crafting, crochet and painting so get your orders in for Christmas scarves in 2023!

We would like to wish our KPA team, our patients and their friends & families all the best as the festive season approaches and best wishes for the New Year.



Christmas Criss-Cross Puzzle

Fill in the criss-cross puzzle with the numbered items of festive paraphernalia.





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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