

In Touch

Information from the National Kidney Federation. Supporting kidney patients, their friends & family.

Welcome to the May 2021 In Touch newsletter. Please feel free to share with your friends, family and colleagues. If you are receiving this newsletter from someone else and not the NKF, you can contact us and request to be added to our mailing list.

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If you have an article that you would like sharing in the next newsletter, please forward to Chris Albas-Martin at chris@kidney.org.uk by 2nd June 2021.



Organ Donation: One Year On

Join us for a free webinar on Thursday 20th May as we and the National Black, Asian, Mixed Race, and Minority Ethnic (BAME) Transplant Alliance (NBTA) look back on how organ donation has progressed since the law change.

May 20th 2021 marks exactly one year since the law around organ donation in England was changed. Under the current law, known as Max and Keira's Law, all adults agree to become organ donors when they die, unless they have made it known that they do not wish to donate.

We'll look at how the law is working in practice, how Covid-19 has affected its implementations and the impact on patients from BAME backgrounds.

The webinar will be chaired by Lord Jitesh Gadhia and Millie Banerjee CBE, Chair of NHSBT Board, will provide the introduction. Speakers include:

- Dr Dale Gardiner, National Clinical Lead for Organ Donation, NHSBT
- Alex Cullen, Head of Organ Donation Marketing, NHSBT
- Sibonokuhle 'Bonnie' Ngwenya, SNOD in the Northern Team

A panel discussion will be chaired by Kirit Modi, honorary president of the NKF and the NBTA, and panel members include Dr Adnan Sharif, consultant nephrologist at Queen Elizabeth Hospital, Birmingham; Charles Kwaku-Odoi, chief officer at the Caribbean and African Network; and the three speakers.

The webinar starts at 5:30pm and will end at 7:00pm and you can register for free [here](#).



Annual Patients' Event

We are pleased to announce that our annual patients' event will take place on Saturday 9th October.

This year's event will be virtual and will start at 10:00am and end at 2:00pm.

We have five confirmed speakers, ranging from renal professionals to patients, and a breakout room will be available for attendees to chat with each other.



The event is free-of-charge and details of speakers and how to register will be available in next month's In Touch.

Job Vacancy - Liaison Officer

The National Kidney Federation's Mission is to improve the quality of life of kidney patients and their families across the UK. The charity is a unique place to work because the NKF is the only national kidney charity run by kidney patients, for kidney patients.

Following the completion of our new strategy, the charity is embarking on an exciting new phase of growth. We are looking to recruit a new member of the team to commence the position of NKF Liaison Officer.

You will develop and maintain contact with all Kidney Patient Associations (KPAs) affiliated or not to the National Kidney Federation and you'll

help set up KPAs in areas where there is no KPA presence.

The ideal candidate will show empathy with kidney patients and the problems they face and have experience of stakeholder engagement.

A full job description and person specification can be downloaded **here** and more information on how to apply can be found at www.kidney.org.uk/nkf-job-vacancies.

Remember

If you have recently changed address, please contact us on **01909 544 999** or at nkf@kidney.org.uk so we can update our records.

Thanks!

Kidney Patient Support Pack

We have produced a brand new Patient Support Pack as a guide for new kidney patients starting their dialysis journey.

The pack is for patients who may be facing end-stage kidney failure to help with understanding kidney disease and dialysis and the treatment options available.

The new 60-page booklet is packed full of vital information, including: about the kidneys, fluid balance, anaemia, dialysis treatment choices and useful contact numbers. There are also sections to record your personal information, appointments and renal records.

Our Patient Support Pack has always been very well received by patients, carers and renal nurses and is available free-of-charge. To request a pack call the NKF Helpline on **0800 169 09 36** and talk to an adviser or email helpline@kidney.org.uk with your postal address.



Kidney Life

The summer edition of Kidney Life is now out!

This edition features regular columnist Dr Jeremy Crane, as well as a round-up of this year's KPA Day and information about the endovascular arteriovenous fistula (EndoAVF).

Keep an eye out for your copy dropping through the door.

If Kidney Life is not posted to you, you can read it online at www.kidney.org.uk/kidney-life.

If you'd like to receive a copy through the post, please email your name and address to nkf@kidney.org.uk.



How kidney patients reported their experience of care in 2020

The Patient Reported Experience Measure (PREM) 2020 annual report is now available. Results show that, despite the Covid-19 pandemic, patients still rated their experience of care highly; demonstrating the hard work kidney teams throughout the UK have done to support their patients.

Nearly 10,000 kidney patients took part online during October - November 2020, in the midst of the Covid-19 pandemic.

The key top performing themes of experience remain similar national to previous years (privacy and dignity, access to the renal team and patient information), and remarkably despite all the challenges of Covid, patient overall experience remained high for most responders in 2020. Some of the additional headline findings from this year's report include:

- Patient reported experience of support and sharing decisions about your care fell in 2020.
- Patient scores for support fell among chronic kidney disease (CKD), peritoneal dialysis, home haemodialysis and transplant patients compared to 2019.
- Patient experience of sharing decisions about your care was lowest in those receiving in-centre or in-satellite haemodialysis.
- Patient reported experience of transport improved for in-centre and in-satellite haemodialysis patients in 2020.
- The experience of patients living with CKD but not receiving renal replacement therapy notably decreased in 2020 compared to 2019 particularly for overall experience, support and how the team treats you.

[Read the full results](#)

New dialysis away from base guidance

With Covid-19 infections decreasing across the UK, the National Kidney Federation, along with other kidney charities, has published new guidance to help dialysis units safely welcome patients.

Dialysis units are weighing up whether to re-open to dialysis away from base (DAFB) patients. Any dialysis patients who wish to travel during this period should talk with their renal team as patients receiving dialysis remain clinically extremely vulnerable to Covid-19 and transmission has occurred in dialysis units. The guidance only applies if shielding or local lockdown is not in place in base or destination units.

What the new guidance says:

1. Assess risk based on the current incidence of Covid-19 in the base unit/locality and the designated unit/locality for DAFB.
2. Ensure that there is a documented discussion between the clinical staff at the base unit and the DAFB centre for shared awareness of Covid-19 infections in the base unit or receiving service. Ensure that the patient is aware in advance of the local protocols that they will need to follow.
3. Those wishing to have holiday dialysis should have received two doses of the Covid-19 vaccine, separated by at least three weeks before travelling. Travel should ideally be at least two weeks after the second dose to build up an immune response. However, if a patient has refused vaccination or been unable to be vaccinated, this should not exclude them from being considered for DAFB.
4. Patients should have a negative PCR Covid-19 swab 3-5 days before travel.
5. On return to the base unit, patients should dialyse in isolation for two weeks, and have Covid-19 tests as per unit protocol. The base unit should consider its capacity to isolate patients on return from holiday whilst planning the timing of patients' holidays.
6. Patients should not travel if they are a close contact (within 2m distance for at least 15 minutes) of any individual with Covid-19 infection, including other patients on the dialysis unit, within the preceding 14 days. Or been advised to self-isolate for any reason.
7. Patients should not travel if they have symptoms of Covid-19 or are awaiting a Covid-19 PCR test result.
8. Patients should not travel if they have planned surgery within 14 days after the proposed holiday return date as they will be asked to self-isolate for 14 days before the operation.
9. Patients should follow the local guidance for high-risk prevalence, in the DAFB locality. This guidance is likely to vary with time and between areas.
10. Advise patients to take out travel insurance before making any booking due to the risk of sudden cancellations. Check what is covered by travel insurance in the event of an infection with Covid-19 just before or during the holiday.

Read the full statement and guidance

Kidney Beam

Want to look after your wellbeing?

It's time to try Kidney Beam, a new, free online platform for all kidney patients, offering movement, fitness, physical and emotional wellbeing sessions, designed especially for people living with kidney disease.

A team of kidney experts led by Sharlene Greenwood from King's College Hospital have developed the platform so that it is specially tailored for kidney patients. Kidney Beam has a choice of live and on-demand classes led by NHS kidney professionals and other qualified instructors, some who are themselves living with kidney disease.

Kidney Research UK helped establish the activity and have recently extended their funding. "We're really pleased the charity has been able to continue to support patients at a time when access to traditional services has become so difficult," said Sandra Currie, chief executive of Kidney Research UK. "We are also funding research which we hope will mean the platform is commissioned by the NHS offering security for the service beyond 2021."

Suitable for anyone with kidney disease

Kidney Beam has broad appeal - it's aimed at anyone over 16, of any ability, any kidney condition, and at any stage of kidney disease. Family and carers can join too.

All classes have a fitness rating so users can choose the right one for them. At the beginning and end of the live classes, people can chat to each other and the instructors, building new friendships can help motivation.

Helping people through lockdown and beyond

Sharlene Greenwood is a consultant physiotherapist in renal and exercise rehabilitation at King's College Hospital and leads the team that has brought the project together:



"During lockdown I became increasingly worried about my patients with kidney disease who were shielding at home," she explains. "There were real concerns about physical and mental wellbeing, and many patients reported missing coming to our renal rehab classes that we offer at King's College Hospital, and having that interaction with people. Kidney Beam is an excellent opportunity to bring something novel and exciting to the kidney community at a time when it is most needed."

User recommended

Angela Watt appreciates Kidney Beam as both a kidney patient and a former renal nurse.

"I know I will be needing either dialysis or a transplant soon," she said: "I need to lose weight to get on the transplant list - my consultant set me a target and I'm two-thirds of the way there, largely thanks to using Beam.

"It's been a godsend over the winter because I've still been able to exercise even though I haven't been able to go out because of shielding, isolating or the weather.

"And because I'm doing it in my own home, I don't have to worry about comparing myself to those who might be more experienced or fitter.

"I love the fact that there are a range of classes and for different levels and abilities. In the Get Started programme you can do them seated or standing - one of the instructors is always seated, it's so helpful.

"If you can't make the live class you can follow it on demand, so it's easy to fit into your everyday

life. And the best bit is it's free - no guilt about paying a subscription that you don't use as much as you should!

"It's been a really important, supportive community of people, especially during the last lockdown. We chat at the end of each class, comparing notes on vaccinations and all sorts. A godsend."



Give it a try

Beam have developed a dedicated programme for beginners, or for those looking to get back into exercise. The Get Started series is the perfect place for beginners to start to develop all-round strength, cardiovascular fitness, and improve posture and co-ordination, which will support you to enjoy your favourite activities this spring. This series is led by Jules from King's College Hospital Renal Rehab team. Jules eases you into the classes step-by-step, offering gentle progressions with each session.

Head over to Beam to sign up and join the Get Started Programme [here](#).

To find out more and get signed up, visit: beamfeelgood.com.



Dialysis Centre
Established
1995

KC Holiday Dialysis Centre (Bournemouth)

This friendly, family run unit is situated about 100 yards from the beautiful sandy beaches of Bournemouth with the town centre approximately 2 miles away

The unit's facilities offer the following:

- Open all year round.
- Free treatment to NHS patients.
- Direct online booking so patients can check availability and book at a pace that suits them.
- Choose between morning and afternoon sessions.
- Help provided with your booking every step of the way.
- Can recommend accommodation depending on your needs.
- Providing a caring, professional and friendly service for over 25 years. Making your stay with us as comfortable as possible.
- Refreshments while on treatment.



**For further
information
telephone**

01202 422311

www.kcdialysis.com
admin@kcdialysis.com

Not sure where to stay?

Let us take the stress out of searching, please ask us for a list of local accommodation suggestions. We can help you find the right place for you.

Did you know?

Bookings can be placed up to 12 months in advance to help secure your preferred dates and times.

35 Southwood Avenue, Southbourne, Bournemouth, Dorset BH6 3QB

Patient Participation Opportunities

Volunteers needed to help with research study

Dr Anna Winterbottom and her team are developing a booklet to help kidney health professionals gain a better understanding of and talk to people with kidney disease about their wishes at the end of their life.

They would like to interview people about issues that are important to them about **end-of-life-care**.

They would like to talk to people who are:

- Aged 70+ and receive haemodialysis or peritoneal dialysis
- Receiving conservative management treatment
- Family members who care for someone with kidney disease
- Bereaved family members of someone who had kidney disease

Interviews will last about 60 minutes and take place at a location that is convenient to you (via Zoom, telephone, face-to-face).

For more information, contact Anna Winterbottom at anna@winterbottom.co.uk or on **07981 689 434**.

This study is being funded by Kidney Care UK and the British Renal Society and is in partnership with Hospice UK.



GET INVOLVED

Do you suffer from itchy skin?

ImpRoving the Reporting of ITch using AccerleromeTErs in kidney patients (IRRITATE)

One in three people with kidney disease are bothered by itchy skin, but many do not discuss this with their care team. Itchy skin can lead to sleeping problems. Researchers and students from the University of Manchester are looking into this problem. They want to know if wearable devices (or 'accelerometers'; see picture) can help with assessing sleeping problems in people with kidney disease who suffer from itch.

The research involves wearing an accelerometer on your non-dominant wrist for seven nights to record your movement, filling in a daily sleep and itch diary, and completing an online questionnaire. Once you have completed your data collection period, you will receive a shopping voucher to thank you for your contribution.



We are looking for people with kidney disease who:

- Are 18 years or older
- Are under the care of a kidney doctor
- Are currently bothered by moderate to severe itching
- Have their own email address

You cannot participate if you:

- Have been diagnosed with a sleep disorder, skin condition, Parkinson's disease or restless leg syndrome.
- Have taken sleep medication or other drugs with a sedative effect in the past four weeks.

If you are interested in taking part, please contact the research team by emailing or calling Dr Sabine van der Veer (sabine.vanderveer@manchester.ac.uk, phone: **0161 3067 767).**

You can also find more information about the study here:

www.herc.ac.uk/research_project/irit-a/



The University of Manchester

FSGS Study

Market research agency Gillian Kenny Associates are looking for patients with focal and segmental glomerulosclerosis (FSGS) or caregivers/parents of children aged 8-17 with FSGS to take part in a 75-minute phone call in return for a £45 Amazon voucher.

If you would like to take part in the study, please contact Sophie Wyatt at sophiewyatt@gilliankenny.com by **Wednesday 26th May**.



Have a great holiday in the stunning Lake District and let Lakeland Dialysis cater for all your haemodialysis needs in a relaxed and professional atmosphere.

Situated in the Western Lake District, adjacent to the market town of Cockermouth we have been specialists in holiday dialysis since 2004.

Regulated by the Care Quality Commission we pride ourselves in offering: personal and professional care, individual appointment times, disabled parking and ground floor access.



Treatment costs are met by the NHS



For a booking enquiry or more information please contact David on **01900 822 888** e-mail info@lakelanddialysis.co.uk or look at our website www.lakelanddialysis.co.uk where you can access patient recommended accommodation as well as details of our own 4-6 berth static caravan which is situated on a quiet local park and available to book for patients visiting the clinic.

Lakeland Dialysis Ltd. Unit 7E, Lakeland Business Park, Lamplugh Road, Cockermouth, Cumbria CA13 0QT

Cholesterol and kidney disease

Cholesterol is a fatty substance, one of several different types of fat in the body. It has several important functions and is carried around the blood. If blood vessels are damaged, cholesterol can be deposited, eventually causing narrowing to the blood vessels. This is more likely to occur if the blood level of cholesterol is high.

Does the cholesterol matter if I have kidney disease?

People with kidney disease are more likely to have problems with narrowings in their blood vessels than otherwise healthy people, so cholesterol is very important. This applies even with minor abnormalities in the kidneys, when there is chronic kidney disease.

Problems with blood vessels in people with kidney disease may differ slightly from those in people with normal kidneys, because abnormalities with the minerals calcium and phosphate, and in vitamin D, may contribute to blood vessel disease. However, cholesterol remains an important factor.

If you would like further information about cholesterol and kidney disease, the NKF Helpline has an information leaflet which explains more about how you can help keep your blood vessels normal, what causes high cholesterol, cholesterol levels, diet for reducing cholesterol and what drugs are used to reduce your cholesterol. If you would like to receive this booklet, please contact the Helpline on freephone number **0800 169 09 36** or at helpline@kidney.org.uk.

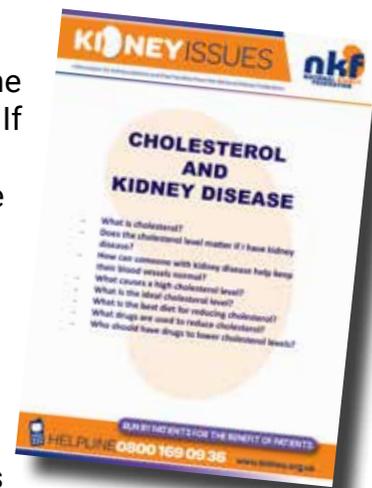
The Helpline is open Monday-Friday, 9am to 5pm.

The NKF Helpline has a vast library of information leaflets which you may also find useful. Below are a few of the other titles we have in leaflet form:

- Diabetes and the kidney
- Urinary infections
- Anaemia
- The emotional impact of CKD
- Kidney biopsy
- Kidney cysts
- Small or single kidney

To request a full list of our titles or to order any leaflets, please contact the Helpline,

As well as medical information, our advisers Pauline and Stephen can provide assistance with travel insurance, benefits advice or information about the renal diet.



NKF Fundraising

Spring Draw

Thank you to everyone who took part in our spring draw, the draw took place on Wednesday 5th May and the lucky winners are:

- 1st - £1,000 - Mr Higgins
- 2nd - £500 - Mrs Paterson
- 3rd - £250 - Mr McNicol
- 4th - £50 - Ms Mealing
- 5th - £50 - Ms Keary
- 6th - £50 - Mrs McNabb
- 7th - £50 - Mr Garrod
- 8th - £50 - Mrs Niazi



Water Challenge

Thank you to everyone who took part in this year's Water Challenge and for the past month given up tea, coffee, fizz and alcohol. To date we have raised over £6,793, which is fantastic! Congratulations to Richard Palmer, who raised the most sponsorship with an incredible £2,740. He has earned himself a spa day for two, courtesy of [spabreaks.com](https://www.spabreaks.com).



If you do have sponsor money to pay in, please use bank transfer and account details can be found by emailing pete@kidney.org.uk.



Best Foot Forward for Kidney Patients

This June we want you to walk or run 60,000 steps to raise money for kidney patients. The 60,000 steps represents the 30,000 people in the UK on dialysis and the 30,000 people who have received a transplant. The step challenge can be conquered over the whole month, over a week or if you really want, in a day!

To register and receive a fundraising pack, visit www.kidney.org.uk/best-foot-forward.

**Put your Best
Foot Forward for
kidney patients**



Walk **60,000 steps**
this June and raise
vital funds for
kidney patients



This June, put your Best Foot Forward and walk or run 60,000 steps to support people living with kidney disease.

- **Increase fitness**
- **Burn calories**
- **Make your heart healthier**
- **Improve your mental health**

To register please email: nkf@kidney.org.uk with your name and address and we will send you a fundraising pack.

National Kidney Federation

Registered Office: The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW
Telephone: 01909 544 999 • Email: nkf@kidney.org.uk • Helpline: 0800 169 09 36 • Website: www.kidney.org.uk
Registrations: Registered in England & Wales Charity Number: 1106735, Scottish Charity Number: SC049431, Company Number: 5272349
Give as You Earn contributions number: CAF GY511

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The NKF – the largest Kidney Patient Charity in the UK

A FEDERATION OF MORE THAN FIFTY PATIENT CHARITIES, SUPPORTING KIDNEY PATIENTS & CARERS

Registered Office: The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

Registrations: Registered in England & Wales, Charity Number: 1106735, Scottish Charity Number: SC049431.

Company Number: 5272349. Give as You Earn contributions number: CAF GY511.