

In Touch

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

Welcome to the April 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.

Action Point

- 02 Job Vacancy - Social Media and Office Administrator
- 02 KPA Zoom Meetings
- 03 NKF Patients' Event

NKF Information

- 03 NKF & KPIN Webinar
- 04 NKF KPA Day 2021
- 04 Home Dialysis Peer Support Group
- 05 Sir Lenny Henry's Open Letter
- 05 Ramadan and the Covid-19 Vaccine
- 06 JCVI Vaccination Recommendations
- 07 Utilities Help

Patient Participation Opportunities

- 08 Itchy Skin Survey
- 09 CVDPREVENT Research Study

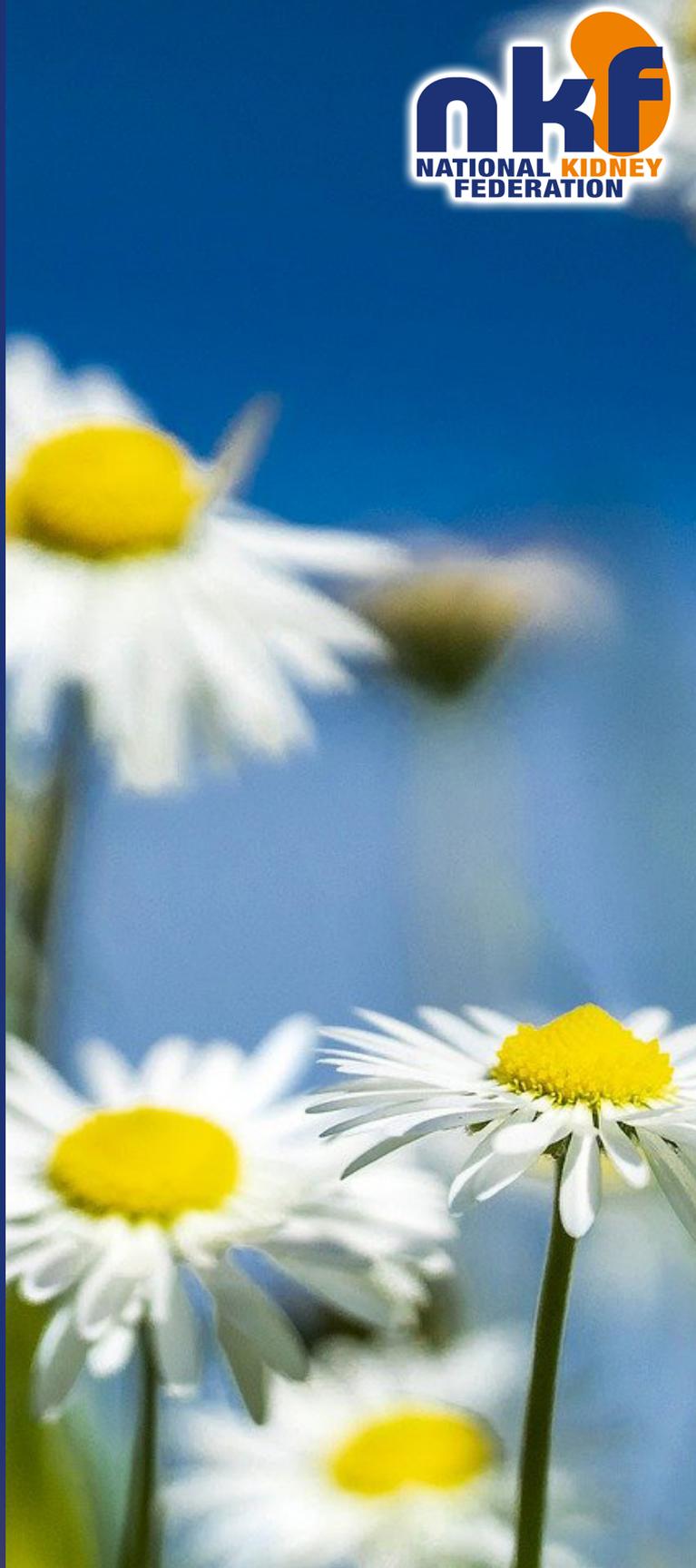
NKF Helpline

- 10 Mouth Care in Renal Failure

NKF Fundraising

- 11 Spring Draw and Water Challenge
- 12 Captain Tom's Fundraising

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 3rd May 2021.



Action Point

Job Vacancy - Social Media and Office Administrator

An exciting opportunity has arisen to join the growing communications and marketing team at the NKF. We are looking to recruit a new member of the team to commence a new position as Social Media and Office Administrator.

You will act as the main administrator on all NKF social media accounts and you'll provide administration support for fundraising and charity events. The ideal candidate will have proven administrative

experience and experience of working in the charity sector.

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

The closing date for applications is Friday 30th April.

KPA Zoom Meetings

Sadly, due to the pandemic, many KPAs have not been able to meet since March 2020. However, if you are a member of a KPA and would like to meet virtually with other members of your KPA, you can do so for free using the NKF's Zoom account.

We can set-up and host a virtual KPA committee meeting on your behalf, and any other meetings you wish to hold.

Zoom is very user-friendly and simple to operate.

If you would like us to set-up a meeting for you, please contact Donna Blizard at donna@kidney.org.uk or on **01909 544 999**.



Save the date!

This year's Patients' Event will take place on Saturday 9th October.

More details of the event will be published in the next issue of In Touch.



NKF Information

NKF & KPIN Webinar

Thank you to everyone who attended our joint webinar with the Kidney Patient Involvement Network (KPIN) on Thursday 8th April.

The webinar explored the roles of both the NKF and KPIN in supporting kidney patients, and delved into how KPIN can support NKF KPA activities through its membership experiences and resources.

KPIN is a network of kidney organisations, charities and individuals who are committed to quality patients and public involvement and engagement (PPI/E). They work together on initiatives to improve standards and develop patient leaders of the future.

The NKF was represented by its chairman Jim Higgins; Andrea Brown, chief executive; and Sarita Khurana, chair of West London KPA.

The webinar will be available to view on our website in due course.



Kidney Patient
INVOLVEMENT NETWORK

NKF KPA Day

NKF's first virtual KPA Day on Saturday 27th March was a great success, with lots of people attending and many KPAs represented. We would like to thank all for attending and contributing towards the business of the NKF.

The executive committee was elected for the next year. Details of the new executive committee can be found at www.kidney.org.uk/whos-who. The first meeting of the new committee will be held on Saturday 17th April. The past year had been very good for the NKF, it has a new ambitious strategy and development plan. The Home Dialysis Campaign is underway along with the setting up of the home dialysis peer support group. NKF will be monitoring the progress of

these.

Paul Cockwell, consultant nephrologist at University Hospitals Birmingham, spoke about the impact Covid-19 has had on the dialysis world and Rommel Ramanan, chair of the NHSBT Kidney Advisory Group, gave an informative talk on the impact Covid-19 has had on kidney donation and transplantation and he also provided an update on the new strategy for organ donation and transplantation.

If you were unable to attend on the day, you can watch the two speakers at www.kidney.org.uk/kpa-day.



Home Dialysis Peer Support Group

Are you on home dialysis?

Would you like to join our peer support group to help others who are starting home dialysis?

Following our national campaign on home dialysis, we have launched a new peer support group for people on home dialysis and we would love more volunteers to join our already fantastic team.

If you would like to get involved, please contact nkf@kidney.org.uk or **01909 544 999**.

Sir Lenny Henry urges black Britons to take Covid-19 vaccine

Sir Lenny Henry has written an open letter to encourage black Britons to take the Covid-19 vaccine. The letter has been signed by some of the most high-profile names in the UK.

Sir Lenny's letter, supported by the NHS, has also been turned into a powerful short film, directed by BAFTA Award winner Amma Asante, which features Sir Lenny alongside Adrian Lester, David Harewood, Naomie Ackie, Rt Rev Rose Hudson Wilkin, Bishop of Dover and Adjoa Andoh.

Sir Lenny Henry said: "I felt it was important to do my bit and so I wrote this letter to black Britain asking people to not get left behind, to not continue to be disproportionately impacted and to trust the facts from our doctors, professors and scientists, not just in the UK but across the world, including the Caribbean and Africa.

"I hear and understand the concerns which people of all backgrounds are wrestling with, but which are particularly concerning in black communities. I want people to be safe, I don't want people to die or end up in hospital because of Covid-19. So I'm saying, when your turn comes, take the jab."

You can view the video at www.kidney.org.uk/news/sir-lenny-henrys-covid-letter.

Ramadan and the Covid-19 Vaccine

Ramadan Mubarak to all our supporters celebrating.

This year Ramadan falls within the largest vaccination drive in British history and two leading Muslim figures working in the NHS have joined other medical leaders and Islamic scholars in saying that Ramadan should not stop anyone from getting the Covid-19 vaccination.

The British Islamic Medical Association, an affiliate of the Muslim Council of Britain, has issued [specific advice](#), recommending the vaccine and insisting it is OK to have during Ramadan as it is not nutritional, nor does it contain any animal or foetal products. Full ingredient lists are published by the Medicines and Healthcare products Regulatory Agency (MHRA): [AstraZeneca](#), [Pfizer/BioNTech](#), [Moderna](#).

JCVI recommends that adults living with adults who are immunosuppressed should be prioritised for the Covid-19 vaccine

The Joint Committee on Vaccination and Immunisation (JCVI) has advised the government to prioritise people for the Covid-19 vaccine who are over 16 and living with adults who have weakened immune systems, such as those with blood cancer, HIV or those on immunosuppressive treatment including chemotherapy.

There is growing evidence that the Covid-19 vaccines may reduce the chance of someone who has been vaccinated passing the virus on. Given this emerging evidence, the JCVI advises that those over 16 years of age who live with severely immunosuppressed adults are offered the Covid-19 vaccination alongside priority group 6. This will help limit the spread of the virus to immunosuppressed adults.

Professor Wei Shen Lim, chair of Covid-19 immunisation, the Joint Committee on Vaccination and Immunisation commented: "The vaccination programme has so far seen high vaccine uptake and very encouraging results on infection rates, hospitalisations and mortality. Yet we know that the vaccine isn't as effective in those who are immunosuppressed. Our latest advice will help reduce the risk of infection in those who may not be able to fully benefit from being vaccinated themselves."

Household contacts considered as a priority would be those over 16 who share living accommodation with adults who are immunosuppressed. The JCVI does not currently advise vaccination of household contacts of immunosuppressed adults who are themselves children.



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

**For further
information
telephone**

01202 422311

www.kcdialysis.com

admin@kcdialysis.com

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.



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

Get help from your utilities with priority services

We all rely on water and electricity every day. If anything goes wrong, it can seriously affect our medical plans and ability to operate a sterile environment for any home dialysis treatment.

Utilities work hard to ensure they provide essential services to their customers and are dedicated to keeping you safe, warm and independent in your home. To ensure that your energy and water providers can provide this extra support, we wanted to tell you about the priority services register and how it can support those with chronic kidney disease (CKD).

What is the Priority Services Register?

The Priority Services Register (PSR) helps utility companies look after customers who have additional communication, access or safety needs. It helps them tailor their services to support households who may need extra help, and is free to join. For example, if you are a carer for someone or you are someone who is medically dependent on water or you live with a critical illness you'll be contacted to check you're OK and see how utilities can help you.

By registering, your utilities can offer you support including:

- Alternative water supplies if yours goes off
- Alternative heating and cooking facilities if your gas goes off
- A dedicated number and specialist team to support you and your family during a power cut
- Keeping you safe on the doorstep with the use of passwords and identification badges
- Priority support in the event of an emergency, for example a severe weather incident
- You can sign-up for large print letters and bills or have them sent to an alternative contact

The best way to register for priority services with your providers is to visit their website and sign-up, or to find out who your providers are, enter your postcode on [Energy Networks](#) for electricity and on [WaterUK](#) for water.



Patient Participation Opportunities

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

CVDprevent Research Study

The NHS Benchmarking Network (with the support of the Patients' Association) are engaging with patients, carers and families in the CVDPREVENT Audit. They are seeking participants for a patient panel to guide and influence their involvement.

As part of this work, the Patients' Association will be hosting a series of patient panel meetings virtually (using Zoom, although dial in facilities by phone will be available, with the cost of calls reimbursed, to enable anyone without a computer to take part). The purpose of these meetings is to get patients' feedback

If you have recent or ongoing experience of any of the following, they are keen to hear from you:

- Atrial fibrillation (irregular heart beat)
- High blood pressure
- High cholesterol
- Diabetes
- Non-diabetic hyperglycemia
- Chronic kidney disease
- Cardiovascular disease

If you would like to take part, please complete this registration form:

www.surveymonkey.co.uk/r/KXDDQ5T. In order to ensure a wide geographical spread and all of the above conditions, recruitment and selection will include a short telephone conversation. Places are limited so if they receive large numbers of applications, they may not be able to include everyone but they will do their best to do so. No personal information will be retained following the selection process, in-line with GDPR.

on the development of the audit outputs to ensure they are suitable for a range of audiences.

The patient panel will comprise of 35 patients from the different parts of England. The meetings will be held in July and October 2021 and February 2022 (dates are on the registration form). An £80 Amazon voucher will be offered in recognition of your time and **places are limited.**



Good mouth care in established renal failure

The NKF Helpline has a twelve-page information leaflet about good mouth care in established renal failure.

Good mouth care is essential for patients with established renal failure, helping to keep the mouth free of dental decay (caries) and gum disease (gingivitis) and lessening the discomfort associated with mouth dryness (xerostomia).

If you or someone you know has kidney disease, don't neglect your dental health. Kidney disease is associated with many dental health complications, including increased risk of periodontal disease, tooth loss and inflammation of the salivary glands, so it's important to maintain a consistent oral health routine, including regular dental visits.

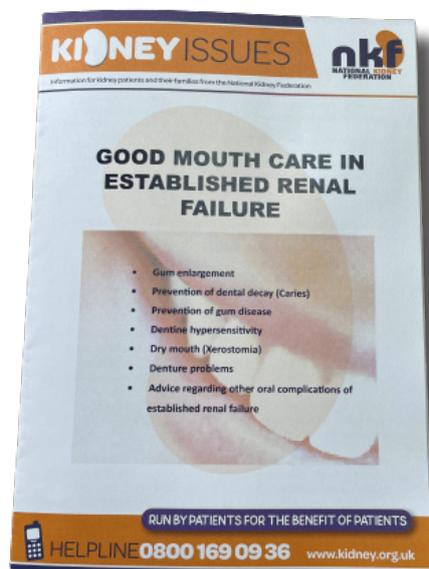
In addition, kidney disease can cause chronic bad breath because diseased kidneys can't remove urea from the blood, and it breaks down to form ammonia, which creates an unpleasant smell.

People with kidney disease should schedule dental visits for days that immediately follow a dialysis day.

The information in this leaflet provides an outline of the mouth care that individuals with established renal failure can themselves undertake.

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.



NKF Fundraising

Spring Draw

Thank you to everyone who has taken part in the NKF Spring Draw! It's not too late to sign-up and be in with a chance of winning £1,000.

All tickets need to be sent in by Friday 30th April, with the draw taking place on Wednesday 5th May.



Water Challenge 2021

Good luck to this year's Water Challenge participants. You've all done brilliantly so far! If you would like to join the challenge, email nkf@kidney.org.uk with your name and address. You can also support our fundraisers and set-up your own fundraising page at www.justgiving.com/campaign/water2021.

Fundraising Events

As restrictions are starting to be relaxed we would love you to take part in one of our many events - please visit www.kidney.org.uk to see our selection. If you fancy taking part in an organised run anywhere in the UK, we can secure your place!

For more details of events or fundraising in general, please contact Pete on **01263 722 287** or email pete@kidney.org.uk.

Are you going out?

With some people venturing out for the first time this year, don't forget that we are selling face masks and social distancing lanyards. To get yours, head to www.kidney.org.uk/shop. Hurry, while stocks last!



Captain Tom 100

We're proud to be part of [#CaptainTom100](#) to celebrate the life and legacy of Captain Sir Tom Moore.

Captain Tom 100 offers our supporters, of all ages and abilities, the opportunity to raise crucial funds for the NKF, while at the same time celebrating Captain Tom's generosity of spirit, the hope and joy he brought to millions, and his sense of fun.

All you need to do is dream up a Captain Tom 100 challenge based around the number 100 and do it at any time and anywhere over Captain Tom's birthday weekend - starting on Friday 30th April through to Bank Holiday Monday 3rd May.

The challenge could be walking 100 steps or running 100 metres, scoring 100 goals, baking 100 cakes, climbing 100 stairs, hopping 100 laps of the garden, building 100 sandcastles, writing a 100-word poem, flipping 100 pancakes - anything at all, inside or out.

Once you have chosen your challenge, you can fundraise or donate to us, and share your 100 on social media, using [#CaptainTom100](#).

More information can be found at captaintom100.com.



Follow us on social media



If you wish to unsubscribe from In Touch, please email nkf@kidney.org.uk.



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.