

In Touch

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

Welcome to the June 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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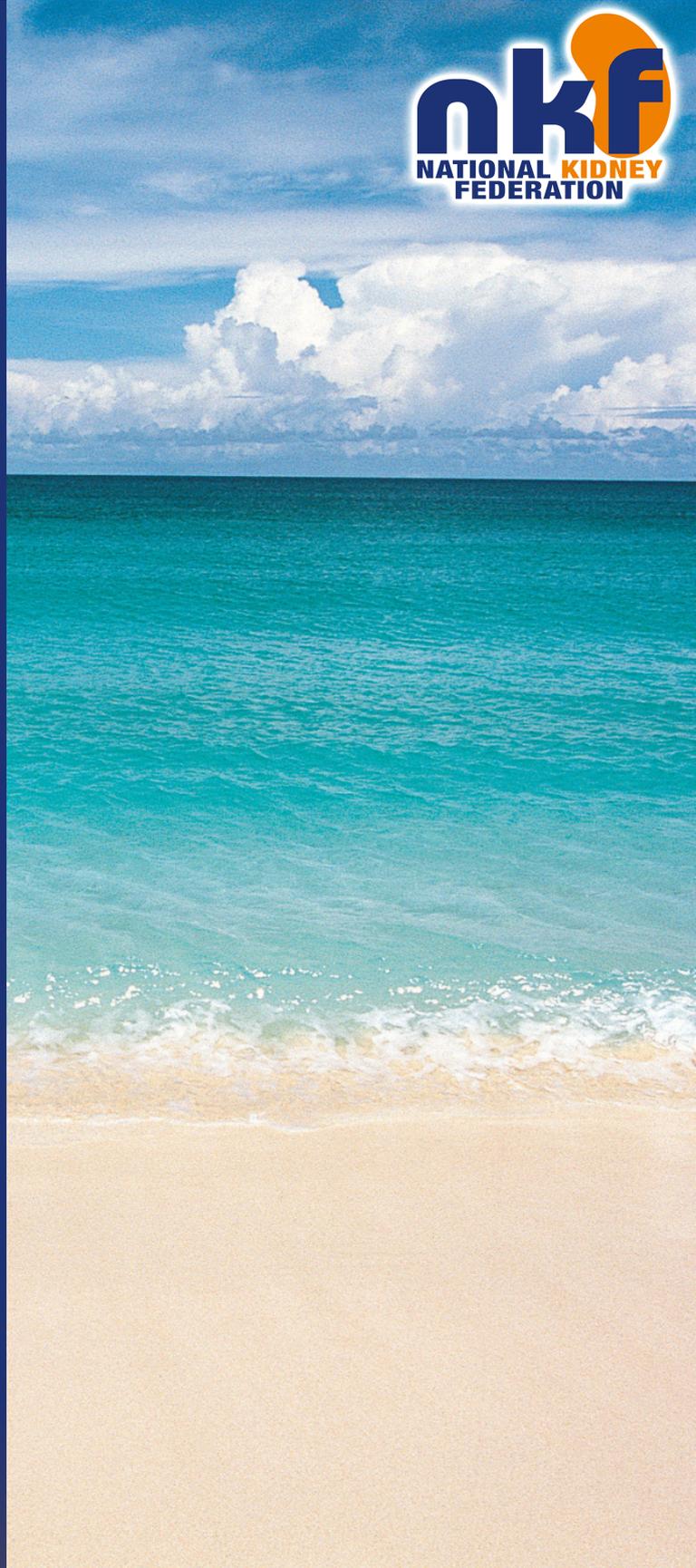
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If you have an article that you would like sharing in the next newsletter, please forward to Fiona Broomhead at fiona@kidney.org.uk by 5th July 2021.



Annual Patients' Event

Our annual patients' event will be taking place on Saturday 9th October.

This year's event is virtual and we will be joined by a host of engaging speakers, ranging from renal professionals to patients. The opportunity to network with each other will also be available.



The event is free to attend and keep checking our website and social media for more details and information on how to register.

Job Vacancy - Communications and Marketing Officer

An exciting opportunity has arisen to join the NKF.

We are looking for an experienced communications and marketing officer to continue the growth of the charity.

You will raise awareness of the NKF's work and impact and you'll manage our social media channels, encouraging others to engage.

The role offers a great development opportunity for someone with an understanding of marketing principles, creative flair, knowledge of current marketing trends and a professional approach.

You can download the full job description and person specification [here](#).

To apply for this role, please send your CV and a covering letter explaining the reasons you should be considered for the role to nkf@kidney.org.uk.

Remember

If you add Gift Aid to your donations to us, please ensure that you have paid enough income tax and/or capital gains tax each year to cover the amount of Gift Aid that all charities and community amateur sports clubs claim on your donations in each tax year, otherwise you are responsible for paying the difference.

If your tax status, name or address changes or you wish to cancel your declaration, please let us know as soon as possible by calling **01909 544 999** or emailing **nkf@kidney.org.uk**.



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

Organ Donation: One Year On

Thank you to everyone who attended our webinar, celebrating the first anniversary of the organ donation law change in England. If you were not able to attend, you can watch a recording on our website.

Lord Jitesh Gadhia, NBTA ambassador, started proceedings before Millie Banerjee CBE, chair of NHSBT Board, introduced the webinar.

Dr Dale Gardiner, national clinical lead for organ donation, provided an update on how the law was being implemented in England, and how Covid-19 has affected it. Specialist nurse for organ donation Sibonokuhle Ngwenya gave her experience of being a specialist nurse and Alex Cullen, head of organ donation marketing at NHSBT, showed us the media coverage the law change had had, and also how the NHS's 'Leave them Certain' was being covered.

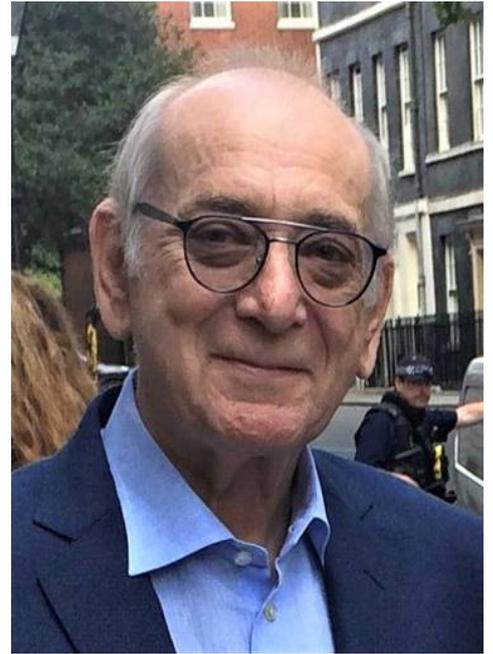
The honorary president of the NKF and NBTA, Kirit Modi, then chaired a panel discussion, which included the three speakers and Dr Adnan Sharif, consultant nephrologist at Queen Elizabeth Hospital, Birmingham, and Charles Kwaku-Odoi, chief officer at the Caribbean and African Health Network.

Kirit then showed a recent video to promote organ donation, which was produced by Veerayatan UK, Shrimad Rajchandra Mission Dharampur UK and Shishukunj with the support of Ragatip Music, before Lord Gadhia concluded the webinar.

[Watch the webinar](#)

David Myers receives British Empire Medal

The NKF is delighted that David Myers, chair of the Royal Free Organ Donation Committee and life-president of the Royal Free Hospital Kidney Patients' Association (RFHKPA) has been awarded the British Empire Medal in the Queen's 2021 Birthday Honours List for services to renal patients. David has made an enormous contribution to improve the lives of kidney patients over many years.



David said: "I have been working on behalf of my fellow kidney patients for over 20 years and promoting organ donation and in particular living kidney donation for many years. I feel very grateful to be awarded this honour but it would not have happened without the incredible care and treatment I have had from the Royal Free renal team and this incredible NHS system which has given me additional years to live my life; to share that with my wife, Martha, and be able to summon up the strength to carry on with my work.

"I have always said, whatever I do for kidney patients, I can never pay back what I have received from the Royal Free.

"I feel that I will be accepting this honour on behalf of everyone who has cared for me at the Royal Free, all my colleagues at the RFHKPA and Royal Free Organ Donation Committee."

Kirit Modi, honorary president of the NKF, said: "Our congratulations go to David on being recognised nationally for his incredible work in being a most effective champion for kidney patients. David has been a great supporter of the NKF and it has been my honour to work with him on innovative projects, addressing issues facing BAME patients over a number of years. David continues to help improve the lives of kidney patients and the NKF is very proud of his achievements.

"Our best wishes to David and Martha for the future."

Help Us, Help You

NHS England and NHS Improvement has launched the next phase of the latest 'Help Us, Help You' campaign which focuses on the NHS 111 service as a new way to access A&E.

If you have an urgent but not life-threatening medical need, make sure you contact NHS 111 first, rather than going straight to A&E. If you do need urgent care, then NHS 111 can now book you in to be seen quickly and safely in A&E. As well as this, NHS 111 is also able to direct you to or book an appointment at urgent treatment centres, GP surgeries, pharmacies, emergency dental services and walk-in clinics.

Contacting 111 first will help the NHS to keep you safe by maintaining social distancing and ensure that you receive the right care in the right place, in a more timely and safe way.

If you or your loved one have a life-threatening illness or injury, then you should always use 999 and if you do arrive at A&E without contacting NHS 111, you will still receive medical care, with emergency treatments prioritised.

If you have hearing loss, are deaf or have difficulties communicating, you can also access NHS 111 by telephone on **18001 111** and British Sign Language (BSL) users can use the NHS 111 BSL interpreter service via nhs.uk/111.

Just think 111 first. When you think you need A&E, contact NHS 111 by phone or online.

For more information about how to use the NHS 111 service including information in BSL, easy read, large print and audio, visit nhs.uk/111.



NHS

If you are ill or hurt and need help fast, but it is not a 999 emergency, use NHS 111

Go to 111.nhs.uk or call 111



EasyRead version



How to contact NHS 111 first

If you need medical help or advice contact 111 first.



You can contact NHS 111:

- online at 111.nhs.uk



- by phone on 111



The people at NHS 111 are trained to help you, like a nurse, doctor or even a dentist.



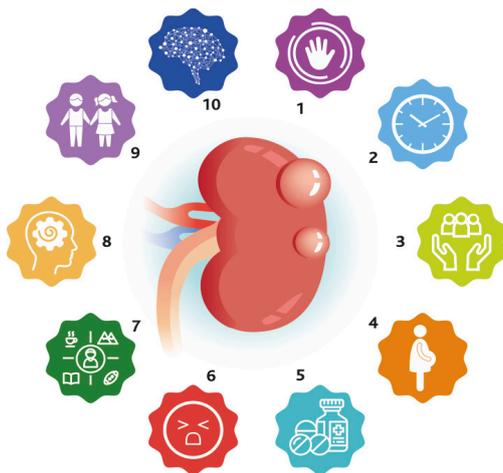
ADPKD Research Priorities

The PKD Charity has finalised 10 research priorities which they hope will improve the lives of people with autosomal dominant polycystic kidney disease (ADPKD).

To find the top 10 priorities, they funded a research Priority Setting Partnership (PSP), overseen by a steering group which included people living with and affected by ADPKD, healthcare professionals and the James Lind Alliance.

Here are the PKD Charity's top 10 research priorities:

1. What treatments can be developed that slow or prevent progression of ADPKD and improve patients' quality of life?
2. Which people with ADPKD would benefit from early treatment and how can doctors identify them?
3. What are the best ways to organise the care of people with ADPKD to improve their outcomes?
4. What effect does pregnancy have on women with ADPKD including their pregnancy health, kidney function, and liver cysts?
5. What are the benefits and harms of drugs that can be used for the management of ADPKD including polycystic liver disease (PLD)?
6. For people with ADPKD experiencing pain, what treatments work best to reduce this pain?
7. What changes to lifestyle, exercise and/or diet (including amount of water drank) benefit people with ADPKD and polycystic liver disease (PLD)?
8. When people are newly diagnosed with ADPKD, how does this affect them psychologically and what impact does it have on their life? What information and support would help people at this time?
9. What are the benefits and harms of screening for and diagnosing ADPKD in children and young people (up to 18 years) at risk of having inherited this condition?
10. What causes enlarged blood vessels (aneurysms) in some people with ADPKD and what is the most effective way to screen for and treat aneurysms?



Read the ADPKD research priorities report for more detail on each of these priorities and how the PKD Charity arrived at the top 10.

NHS Digital to begin sharing GP data

From September 1st, GP practices across the UK will start sharing patient data. The data held in the GP medical records of patients is used every day to support health and care planning and research in England, helping to find better treatments and improve patient outcomes.

The new General Practice Data for Planning and

Research (GPDPR) will reduce burden on GP practices, allowing doctors and other staff to focus on patient care. NHS Digital has engaged with the British Medical Association (BMA), Royal College of GPs (RCGP) and the National Data Guardian (NDG) to ensure the relevant safeguards are in place for patients and GP practices.

What data will be shared

Data may be shared from GP medical records about:

- Diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental and sexual health
- Data on sex, ethnicity and sexual orientation
- Data about staff who have treated patients

What data will not be shared

- Name and address (except for postcode, protected in a unique code form)
- Written notes, such as the details of conversations with doctors and nurses
- Images, letters and documents
- Coded data that is not needed due to its age - for example medication, referral and appointment data that is over 10 years old
- Coded data that GPs are not permitted to share by law - for example certain codes about IVF treatments, and certain information about gender re-assignment

How do I opt-out?

Type 1 opt-out

A type 1 opt-out is where you can tell your GP practice you do not want your confidential patient information held in your GP medical record to be used for purposes other than your individual care. This opt-out request can only be recorded by your GP practice.

If you do not want your data to be shared with NHS Digital, you need to return this form to your GP practice by **Wednesday 23rd June**. You can send the form by post or email to your GP practice or call 0300 303 5678 for a form to be sent to you.

National Data Opt-out

If you don't want your confidential patient information to be shared by NHS Digital for purposes except your own care - either GP data, or other data such as hospital data - you can register a National Data Opt-out.

You can find out more about and register a National Data Opt-out or change your choice here, or by calling 0300 303 5678.

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**.

Are you a woman living with kidney disease?

All women aged 18-50, residing in the UK are eligible to take part in this UK-wide study, learning more about women's experiences of kidney disease and decisions about having children, or not.

The Wales Kidney Research Unit want to hear about your views and experiences even if you have decided not to have children, or have opted for another pathway such as adoption or surrogacy.

The findings will help them develop new shared decision making tools to help better support women with the sometimes complicated and emotional decisions they may need to make about having children.



To take part head to cardiff.onlinesurveys.ac.uk/ckd-engage.

Type 2 diabetes and chronic kidney patients study

Global Patients are running a study to learn more about the experiences of patients with diabetic/chronic kidney disease and type 2 diabetes in the UK.

The study consists of a telephone interview (up to 60 mins) and you will receive £100 for your time.

If you or anyone you know is interested, please contact miriam@global-patients.com.

More information about the study can be found at www.global-patients.com/gp0499a-type-2-diabetes-and-chronic-kidney-patients-uk/.



GET INVOLVED

Tips to keeping cool in hot weather

We all look forward to the warm days of summer, but sometimes those days can get a bit too warm! When you are on dialysis, drinking more is not the best way to stay cool.

Check out these ideas which might work for you to help keep you cool:

- Try freezing berries or grapes for a cold, refreshing snack
- Sip your beverages slowly. Sipping will let you savour the liquid longer
- Use small cups or glasses for your beverages
- Freeze your water in an ice cube tray
- Wet and freeze washcloths to put on your neck to keep you cool
- Place a bowl of ice in front of a fan to help cool the air
- Go somewhere with air conditioning - e.g. a restaurant, shopping centre, community centre or cinema
- To help control your thirst, limit the amount of salty foods you eat
- Try drinking cold liquids instead of hot ones
- Snack on low-potassium vegetables and fruits that are ice cold, like chilled sliced pears, apples, grapes or strawberries
- Wear a hat when you have to go out in the sun
- Wear loose and light cotton clothing

If you are transplanted

The anti-rejection drugs you take to prevent your body from rejecting your kidney transplant do so by suppressing your immune system. Your immune system is designed to fight infection but it also detects and destroys cells that can become cancerous. This means that your drugs can increase the chances of getting some sorts of cancers, including skin cancer. Sun and transplant drugs are a bad combination.

Staying out in the sun

- Do not get sunburn
- Do not "try to get a tan"
- Never use a sunbed

Using sun cream is essential. The effectiveness of sun cream is rated by an SPF (sun protective factor) number. The number indicates how long you can stay in the sun before your skin burns. For example, if your skin would normally burn after 10 minutes, an SPF of 15 means that you can stay in the sun fifteen times longer before burning than if you had not applied sun cream. Because some transplant medication makes the skin extra sensitive to the sun, all transplant patients are advised to use an SPF factor of 50.

Other simple ways to avoid exposure to the harmful rays of the sun:

- Protect your skin with suitable clothing. Clothing offers the advantages of even, non-sticky protection that you don't have to remember to reapply
- Wear a hat, preferably one with a brim
- Wear long sleeves rather than short sleeves

Even in the shade you are prone to sun damage.

Check your skin regularly

- Once a month look closely at your skin. Use a mirror to look at your back, or get someone else to help you
- You may notice a variety of spots, we all have them. Most are not serious
- If one spot looks different from the others or you have concerns that it is growing, speak to your doctor about it. Discuss it when you next attend a transplant clinic or contact your GP

Skin infections

A fungal infection is common for patients. Look out for pale or dark patches or rather liverish-looking spots. It is easily treated so contact your health professional.

Warts

Common warts are often seen in transplant patients but take longer to disappear due to the reduced immune system. Early treatment is worthwhile, but if in doubt seek medical advice.

Moles

These are easily recognisable and could be potentially dangerous. If in doubt seek medical advice.

Should you have any doubts about your skin condition, please consult healthcare professionals immediately.

The NKF cannot accept responsibility for the information provided. The above is guidance only. Patients are advised to seek further information from their doctors.



NKF Fundraising

Best Foot Forward

Thank you to everyone who is taking part in our Best Foot Forward challenge, we have seen a record amount of sign ups to the event and also seen sponsorship flooding in from very generous supporters. Thank you to everyone involved and please keep the steps and fundraising going.

This year's campaign has been a phenomenal success, with fundraisers so far raising over £15,000! There's still time to support our challengers, and read why they are taking part in Best Foot Forward at

www.justgiving.com/campaign/Bestfootforwardforkidneypatients.



Ben Nevis



Good luck to Stephanie and Milly who will be climbing Ben Nevis this Saturday for us - to date they have raised over £3,000. If you would like to take part in our September Ben Nevis weekend, please go to www.kidney.org.uk/Event/ben-nevis-weekend2021.

Garden Party

On Saturday 10th and Sunday 11th July the beautiful gardens of the Grange in Northwold, Norfolk, will be open to the public for a garden party and art exhibition.

Singer-songwriter Richard Digance will not only be showing off his artwork, but entertaining as well. Admission is free with donations to the NKF - we would love to see you there!



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 GY51.