

In Touch

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

Welcome to the July 2022 In Touch newsletter. 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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Is there something you would like to share in the next newsletter?

Email sharney@kidney.org.uk by Monday 8th August 2022



NKF Virtual Annual Patients' Event

On Saturday 15th October 2022, we will be hosting our Annual Patients' Event!

Last year we lined up a variety of guests including professional and patient speakers and it proved a success.

This year, we are bringing back the event virtually, as you may be aware, we recently circulated a survey within our Kidney Life magazine, our supporters who replied to the survey preferred that we make the day an online event once again this year due to COVID-19.

We aim to bring this event back face to face again in 2023. Our programme for the day of the event can be found via the link below.

To register your FREE place to join the virtual event which will be held via Zoom, please visit our event web page [here](#).

NKF Webinar - Benefits for Kidney Patients

THE NKF
WEBINAR SERIES
CONTINUES...

Benefits for Kidney Patients

Learn more about welfare benefits, information about attendance allowance and carers, benefit regulations with the needs of haemodialysis and much more.



20th July 2022
at 5pm



Webinar via Zoom
FREE to register

REGISTER NOW

[www.kidney.org.uk/Event/
nkf-webinar-series](http://www.kidney.org.uk/Event/nkf-webinar-series)



01909 544999



nkf@kidney.org.uk



www.kidney.org.uk

British Transplant Games

Don't forget that we will be attending the 45th Westfield Health British Transplant Games this year! Taking place across the city of Leeds on 29th - 31st July 2022.

The Games are organised on behalf of Transplant Sport whose aim is to raise awareness of the need for organ donation, encourage transplant recipients to lead active lifestyles and show appreciation for, and remember, donors and their families.

The NKF will be having their very own stand and will be in attendance on Sunday 31st July 2022.

Who will be joining us? If you are taking part in the Games, let us know your story. Email in to sharney@kidney.org.uk.



NKF Home Dialysis Peer Support Service

Our national Home Dialysis Peer Support Service offers an opportunity for patients to have a one-to-one chat and share home dialysis queries, similar life experiences and lifestyle stories with trained home dialysis peer supporters.

Patients can be matched with a peer supporter who have experienced home dialysis themselves or are a carer of someone on home dialysis.

Covering the whole of the UK, our peers are available to give support over the phone, through Zoom and at some stage face-to-face discussions.

For help, advice or just some reassurance, you are very welcome to contact us via our NKF Freephone Helpline for more information on **0800 169 09 36** available from 9am to 5pm Monday to Friday.

For more information please visit our Home Dialysis Peer Support web page [here](#).

An advertisement for the NKF Home Dialysis Peer Support Service. The top part features the text 'NKF Home Dialysis Peer Support Service' in white on an orange circular background. To the right is a circular inset image of a young woman smiling and hugging an elderly woman. Below this, the text reads: 'Would you like to talk to someone who is or has been in the same situation as yourself? The NKF Peer Support Service is giving short-term practical, emotional and social support to people with kidney disease, their families or carers, surrounding home dialysis.' A horizontal line separates this from the next section, which is titled 'OUR NKF PEER SUPPORT SERVICE IS FOR:' followed by a bulleted list: '- People on home dialysis', '- People considering home dialysis', and '- Family and carers of people on or considering home dialysis'. At the bottom, it says 'For more details contact the NKF FREE Helpline 0800 169 09 36' and includes the NKF logo.

NKF KPA Members

Currently there are 49 Kidney Patient Associations (KPAs) that are the controlling council of the NKF. Please find the below details of the KPA's available or for more information please contact the NKF office via **01909 544 999** or email in to nkfadmin@kidney.org.uk.

Addenbrooke's KPA
Aintree KPA
Barts Renal Patients' Association
Bristol Area KPA
Bute Kidney Patients Support Group
Chesterfield KPA
Colchester KPA
Coventry & Warwickshire KPA
Doncaster and Bassetlaw Kidney Association
Dudley KPA
Exeter & District KPA
Friends of Derriford Hospital Kidney Unit
Gloucestershire Kidney Patients' Association
Guy's & St. Thomas' KPA
Heart of England KPA
Hope KPA
Humberside KPA
Ipswich & District Kidney Association
Isle of Wight KPA
Kent KPA
King's KPA
Leicestershire KPA
Lincolnshire KPA
Lister Area KPA
Manchester Royal Infirmary KPA
Manx KPA
North East KPA
Northamptonshire KPA
North Staffs & South Cheshire KPA
Nottingham and Notts KPA
Orkney KPA
Queen Elizabeth Hospital KPA
Royal Derby KPA
Royal Free Hospital KPA
Royal London Hospital KPA
Sheffield Area Kidney Association
Scottish Kidney Federation
Shropshire KPA
Six Counties KPA
South Eastern KPA

South East Scotland KPA
Southport Kidney Fund
St Helier and Surrey KPA
Tyneside KPA
United Norwich KPA
Wessex KPA
West London KPA
West Riding KPA
Ysbyty Gwynedd KPA



We are proud as the NKF to support Kidney Patient Associations and to be a patient voice across the UK

If you are a Kidney Patient Association that would like to become an NKF member please email: nkf@kidney.org.uk

Friends of Derriford KPA

The “Friends of Derriford Hospital Kidney Unit” Kidney Patient Association, was formed by a group of patients, their families and the renal team, they registered as a Charitable Association in 1986. Initially it was formed to raise money to help buy equipment for the renal wards, working alongside “Plymouth And Cornwall Kidney Dialysis and Transplant Association” who raised funds to support kidney patients with financial difficulties, until their closure in 2005.

In 2015 with the retirement of many of the original board members, the KPA hit a lull in activity, and lost contact with patients including those who had registered for KPA membership. This wasn't helped by the implementation of the General Data Protection Regulation (GDPR) in 2018. Fundraising did continue with limited activity, thanks to the efforts of 4 individuals who remained on the board.

In 2018, new members joined the board of trustees, Pamela Perry, now Chair and Charleen Sepede, Treasurer. A relaunch of the KPA was planned for April 2019 in the form of a Craft fair and fun day, which worked to raise awareness and funds. With the relaunch came a new governing document, which expanded the KPA's charitable objectives to incorporate those previously offered by PACKDATA. Although our objectives prevent the charity from subsidizing the NHS, equipment can still be provided for the wards where there will be a clear benefit to the health and wellbeing of patients. The KPA provide patients and their families with moral support and peer support. Providing information on employment and disability rights, and details of organisations that can provide more in-depth help and support where appropriate. We offer a Patient Advocacy Service, hardship grants and loans on a case by case basis, and peer support drop-in coffee mornings to give patients and families the chance to meet with others living life with renal disease or injury.

The board has been working towards raising the KPA profile with the patients to raise its membership numbers, although this has proven to be a challenge. With the outbreak of Covid-19, the Board had no option but to suspend activity between March 2020 and July 2021. We meet periodically with the management team of Derriford Hospital Kidney Unit to discuss patient issues, NKF campaigns and how to improve the patient experience. In March this year we did a mailshot, primarily to CKD patients and transplant patients. We provided the renal unit with patient packs with a letter of introduction, a patient leaflet and a membership form, which they kindly addressed and posted out to avoid any issues with GDPR. Packs were also provided to the Heamodialysis units and the CKD team to pass out to patients.

The Board is made up of 7 members,
(Below from the left)

Chair

Treasurer

Secretary

Volunteer Coordinator

Media and communications Officer

Health and Safety Officer

Trustee

Pamela Perry

Charleen Sepede

Lyn Jarvis

Maureen Wakerell

Ann Demaine

Andy Demaine

Ian Jarvis



There is provision for 13 committee members, and unlimited provision for volunteers to help with fundraising, as well as organizing and helping to facilitate social events and fundraisers. Our membership is growing slowly. We now have a 4 monthly patient magazine, and a website to make us more accessible, along with banners and a dedicated email and telephone number on which we can be contacted.

With the calming of the pandemic, we are looking forward to planning social activities for patients and family members, along with fundraisers and charitable activities. With the opening up of wards again we will be visiting patients in hospital and whilst on dialysis, asking them where they would like to see change. We look forward to greater integration with the renal unit and working with them in partnership to promote patient and community wellbeing. Working forward we are looking to improve patient mental health, especially with the fallout of lockdown and the pandemic, and the ongoing impact it has on the lives of the immunocompromised.

We cover the area of West Devon and East Cornwall, although we do accept kidney patients from anywhere in Cornwall as there is currently no KPA covering the other parts of the region.

We can be contacted by email on fodhku.general@gmail.com, by telephone on **07307 170 787** for further information or to obtain a membership form. Alternatively you can contact Friends of Derriford KPA through our web page, fodhkukpa.org.



Lincolnshire KPA Need Your Help!

The Lincolnshire Kidney Patients Association, who have been a registered Charity since 2003, support all renal patients including pre dialysis, dialysis, transplant and conservative care patients, and are currently looking for new committee members.

You do not need to be a patient but some renal connection would be preferable.

A meeting will be held to discuss any interest on Wednesday 20th July at 7.00 pm.

For details of venue and more information please contact our NKF Helpline Advisor Linda Pickering on **0800 169 09 36**.



A Simple Update to Our Privacy Policy

We have recently updated our privacy policy to reflect how long we keep your personal data. You can read the revised privacy policy in full, on our website [here](#).



NKF Accessibility Tool: How To Use

Join Pete Revell, Head of Marketing and Fundraising at the NKF in learning all about the NKF Website's Accessibility Tool!

This tool makes the NKF website super easy to use whether you are dyslexic, partially sighted or even if English isn't your first language!

To view our brand new video on how to use the website accessibility tool please visit our YouTube channel [here](#) and don't forget to subscribe!



Donation and Transplantation for Wales

A new plan has been released which will aim to build on the improvements in donation and transplantation in Wales 2022-2026. The plan covers both living and deceased donations of both tissue and organs for adults and children.

The plan developed by the Wales Transplantation Advisory Group (in collaboration with key delivery partners and stakeholders) complements the UK Organ Donation and Transplantation 2030: Meeting the Need strategy and supports its objectives.

Within the plan it recognises the pressures within the NHS and the need to provide services differently due to the COVID-19 pandemic, as well as the plan to tackle the reduction in the number of organ donors and the increase in the transplant waiting list due to the pandemic.

The plan focuses on actions which will or are likely to:

- increase organ and tissue transplantation
- reduce inequalities and improve access to transplantation for patients
- improve outcomes from transplantation

For more information, please visit the NKF website [here](#).

COVID Updates

To find the latest COVID-19 guidance and updates for kidney patients please [visit our website](#). We regularly update our COVID-19 web page in response to any further announcements or developments.



Keeping An Eye on Renal Research

Our friends at Kidney Research UK are sharing information with us on their latest research developments.

A new research hub dedicated to the study of Alport syndrome has been launched at the University of Manchester.

The Stoneygate and Kidney Research UK Alport Research Hub was created thanks to £2.55 million investment from Stoneygate Trust in partnership with Kidney Research UK.

As well as centres across the UK, the Hub will provide a virtual collaborative centre for international research. The programme is kicking off with two research projects

one looking at the possibility of gene therapy for Alport syndrome; the other searching for new, more sensitive, biomarkers for disease progression in blood and urine.

Sandra Currie, Chief Executive of the charity, said: “The work undertaken at the Hub will be crucial to advancing outcomes for patients of this rare genetic disease. As a leading research charity, it is really exciting to be at the forefront of this new way of conducting research – bringing together a wealth of facilities and expertise – which we hope will become the gold standard in future research proposals.”



The Heat Is On...

With the temperature continuing to climb to new records, we wanted to share some tips on how to stay safe in the sun.

- Use plastic ice cubes or frozen grapes to keep your drinks cool without adding any extra fluid if you're on dialysis.
- Make sure you cover up in the sun.
- Wear sunscreen!
- Spend time in the shade when the sun is at it's strongest.
- Make sure you know the difference between heatstroke and heat exhaustion.
- Avoid alcohol and fizzy drinks.

For more tips on keeping cool in hot weather take a look at:

- [The NKF Helpline Information page](#)
- [The NHS website](#)

For more information about Heatstroke vs Heat Exhaustion take a look at our [social media post](#) on Instagram we made for #SunAwarenessWeek and give us a follow!



Patient Participation Opportunities

Are You A Family Member, Partner or Friend of Someone with a Kidney Condition?

A support programme is being designed for family members, partners and friends of people living with a kidney condition. What would you want in a programme like this? Tell us in the below online survey!

Who can participate? Anyone who is...

At least 18 years old, living in the UK, a family member, partner or friend of someone living with a kidney condition who is also at least 18 years old. The survey will take around 15-20 minutes to complete.

To participate or learn more click this link: https://exetercles.eu.qualtrics.com/jfe/form/SV_725d9rMSoarmOr4

If you want more information, please email the lead researcher, Chelsea Coumoundouros at c.coumoundouros@exeter.ac.uk

Living with CKD

We are investigating the mental health needs of people living with chronic kidney disease (CKD) and their experiences accessing treatment to support these needs.

If you are an adult in the UK living with KCD stage 3b+, receiving dialysis, or a kidney transplant recipient, you can take part in the questionnaire.

The questionnaire should take 15-20 minutes to complete, and your responses will contribute to an MSc research project, as part of a broader project funded by Kidney Research UK.

For more info and to take part: tinyurl.com/moodmapsCKD

If you have any questions about your participation, please contact: joseph.chilcot@kcl.ac.uk.

Type 2 Diabetes and CKD

Do you have type 2 diabetes with Chronic Kidney Disease (CKD), or do you care for someone who does? Cognitant are on a mission to improve the health information that patients and their families receive to help them manage and live with their conditions.

We are holding two focus groups looking at how people with diabetes and CKD could be supported more effectively. We'd like to understand the difficulties of living with diabetes and CKD, whether people feel like they are supported enough to be able to self-care, and how support materials (such as leaflets, videos and online information) could be improved.

You can make a difference by providing your thoughts!

We'll be running the two sessions online on Microsoft Teams in the coming months. Please note, you (or the person you care for) must have been diagnosed with both type 2 diabetes and CKD to be eligible to take part.

If you are interested in taking part, please contact the research team by emailing: jake.sykes@cognitant.com.

Anaemia and Kidney Failure

What is Anaemia?

Anaemia occurs when there are not enough red blood cells to carry oxygen from the lungs to places where it's needed. Anaemia, which is always secondary to some other disorder, can be caused by blood loss, blood destruction or, commonly in kidney patients, impaired blood production.

Why does it happen to patients with Kidney Disease?

Damaged kidneys are unable to produce enough of the hormone erythropoietin, which stimulates the bone marrow to produce red blood cells. Within these cells' oxygen is carried around the body by a protein called haemoglobin.

A damaged kidney leads to impaired production of erythropoietin which leads to reduced number of red blood cells which leads to anaemia.

How do I know if I am Anaemic?

Common symptoms are loss of energy and shortness of breath. Someone may also become irritable and frustrated at the difficulty experienced in doing daily tasks.

How can Anaemia be treated?

Blood tests should be performed to measure the level of iron in the blood, and also two vitamins important in the production of red blood cells (vitamin B12 and folic acid). If there is a deficiency of any of these, supplements can be given. Immediate treatment of anaemia requires blood transfusions. Adding red blood cells to the body's low stocks gives a better oxygen-carrying capacity and hence improves the Anaemia.

What will these drugs do for me?

By increasing your haemoglobin level, these drugs will correct the symptoms of anaemia. Your energy levels and appetite should improve.

Who can benefit?

These drugs can be prescribed for haemodialysis, peritoneal dialysis and pre-dialysis patients and for those with a failing transplant who are anaemic.

How are these drugs given?

These drugs are given by injection, usually one, two or three times each week dependent upon the type of drug prescribed and the medical instruction given.

How much will I need?

Your dose will be calculated according to your weight and adjusted to achieve a steady rise in haemoglobin level.

How quickly will the treatment work?

These drugs will start to work immediately, but it could be a few weeks before your haemoglobin level rises to the point where you begin to feel better.

Will the treatment affect my dialysis and drug treatment?

With a greater red blood cell concentration, you may need to increase heparin during haemodialysis.

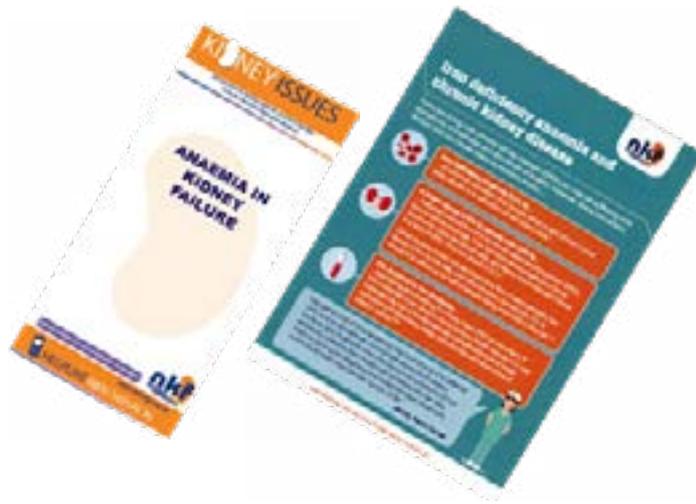
What about iron supplements?

Your body needs enough iron to support the extra red blood cells produced by the treatment. So, if your iron level is low, you will need supplements, either by tablet or by injection.

Will I need more tests?

When you begin taking an erythropoietic agent, your weight, blood pressure and haemoglobin levels will be monitored and the dose adjusted if necessary. You will still need all your usual blood tests.

The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.



To request our full information leaflet about **Anaemia in Kidney Failure** or our leaflet **Iron Deficiency Anaemia and CKD** or to receive our full list of patient information leaflet titles, information packs, dialysis patient cards, kidney transplant patient cards or patient support packs please contact the NKF Helpline on **0800 169 0936** Mon to Fri 9am to 5pm or e-mail helpline@kidney.org.uk



The NKF Helpline has a series of leaflets written by Jeremy Crane MD FRCS who is a Consultant Transplant and Vascular Surgeon at Hammersmith Hospital West London. The series of leaflets takes you through a patient's whole transplant journey. There are three leaflets in this series starting with the "The Telephone Call: What to Expect, followed by The Transplant Procedure: What to Expect and finally After my Kidney Transplant: What to Expect."

To request any of the leaflets in this series, please contact the NKF Freephone Helpline on **0800 169 0936** or email us at helpline@kidney.org.uk.

NKF Fundraising

NKF Best Foot Forward Challenge

The NKF Best Foot Forward Challenge took place last month, this is the second year of this event and thank you so much to everyone that took part!

We have seen some amazing fundraising and also fantastic stories on why people have walked or ran the 60,000 steps. We are still collecting the money in but its already the biggest fundraiser of 2022. Once again a big thank you to all that took part. The challenge will return next June so be sure to pop it in your calendar as a reminder!



London Landmarks

Registration fee: £50.00

Sponsorship £500.00



The London Landmarks Half Marathon is a closed road, central London run and is the only half marathon to go through both the City of London and City of Westminster.

The event is not your average half marathon! From cultural landmarks and heritage to the city's quirky and hidden secrets, runner get to explore the capital on a route like no other!

The 2022 event started on Pall Mall, finished by Downing Street and had fabulous views of London's most iconic landmarks including Big Ben, St Paul's Cathedral, Nelson's Column, the Gherkin, the Shard, the Tower of London and the London Eye.

To register please [visit here](#) or contact Pete Revell at pete@kidney.org.uk.

Do You Shop Online?



If yes, then you could help raise money for the National Kidney Federation by simply adding Easyfundraising as an add-on to your internet browser. Easyfundraising turns your everyday online shopping into FREE donations when you use them to shop with over 6,000 retailers such as Sainsburys, Tesco, eBay, John Lewis & Partners, Argos, ASOS, Tui, and Booking.com to mention but a few.

Please note: You have to shop via the retailers website and not using their applications. Retailers then make a small donation to say 'thank you' and Easyfundraising gives those free funds to the cause.

Please register using this [link](#) and click sign up. Plus, once you've signed up and raised £5 in donations, Easyfundraising will give us an extra £5 donation! There's no catch or hidden charges and the National Kidney Federation will be really grateful for your donations.



Are you due to receive the Cost Of Living Payment?



Our friendly advisors are ready when you are to talk in confidence.

With the cost of living still increasing some of our customers may struggle to afford essentials.

We are here to help, with up to £230 off your water bill.

If you're in receipt of any of the following benefits you could be eligible for financial help:

- Pension Credit
- Income-based Jobseeker's Allowance (JSA)
- Income Support
- Income-related Employment and Support Allowance (ESA)
- Child Tax Credit
- Working Tax Credit
- Universal Credit
- Housing Benefit
- Council Tax Reduction/Support

SAVE UP TO
£230



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0800 052 0145

Visit us online for more information
[dwrcymru.com/HelpWithBills](https://www.dwrcymru.com/HelpWithBills)



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countries



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collaboration with Kidney
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-  Book for you or for others

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"I love it and will be back, such a good place."
CF 2021

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