

In Touch

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

Welcome to the January 2022 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.

In this Issue

Action Point

- 02 NKF Peer Support Service
- 02 All Party Parliamentary Kidney Group Update
- 03 Exeter & District Kidney Patient Association

News

- 04 Transplant Medication Videos Available
- 05 Do you want to join the NKF Committee?
- 05 KPA Day - Registration Now Open!
- 06 The NKF Webinar Series Continues
- 06 COVID-19 Updates
- 07 Making our NKF Website More Accessible

Patient Participation Opportunities

- 08 Protect-V Trial
- 08 Are You Living with a Functioning Kidney Transplant?
- 09 Focus Group: Do You Have 2 or More Long Term Health Conditions?
- 09 Living Well on Haemodialysis

NKF Helpline

- 10 Glomerulonephritis

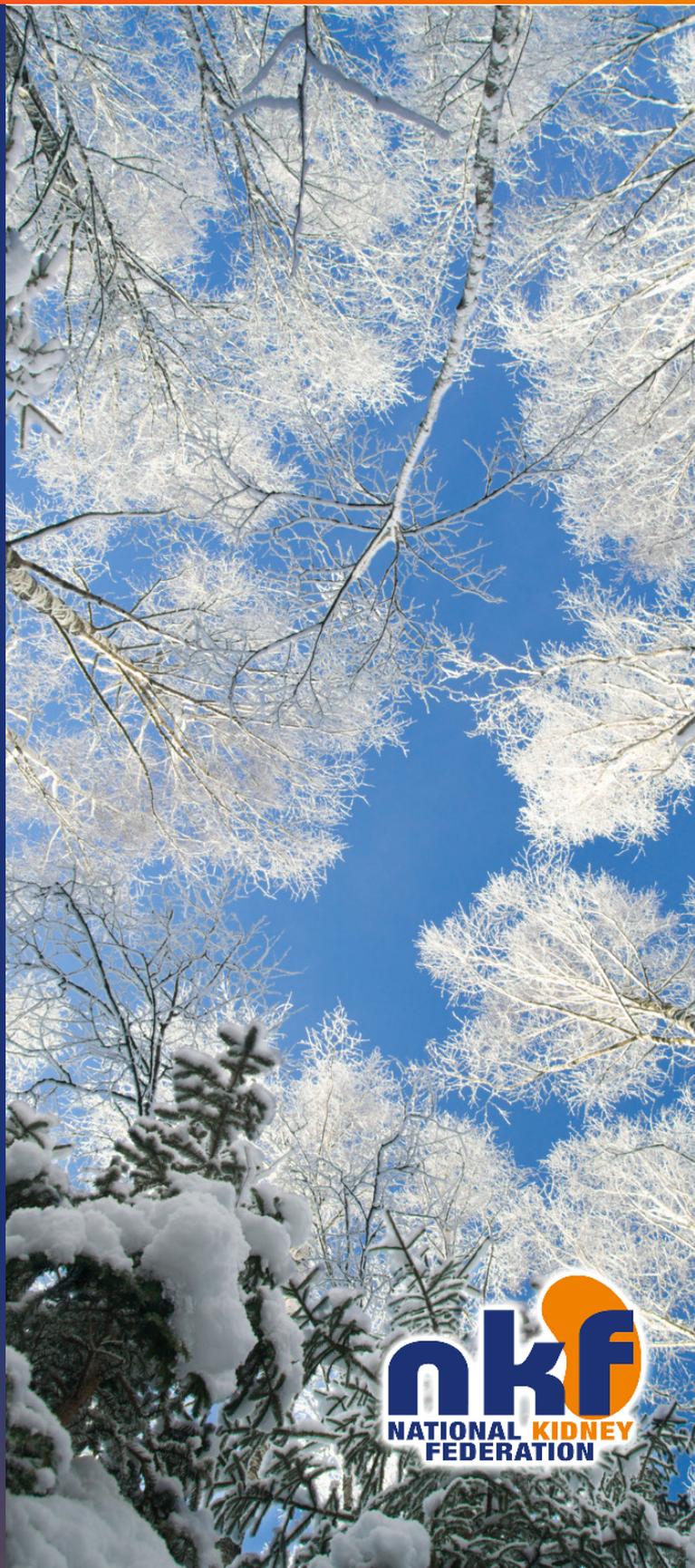
NKF Fundraising

- 11 Events
- 11 NKF Facemasks and Lanyards Available
- 11 NKF Calendar 2022 Available
- 12 Weather Lottery

Adverts

- 12 Mesogeios
- 13 MyPelvicHealth iMEDicare
- 13 Lakeland Dialysis Limited

If you have an article that you would like sharing in the next newsletter, please forward to Sharney Warren at sharney@kidney.org.uk by Monday 7th February 2022.



Action Point

NKF Peer Support Service

Our NKF Peer Support Service is a free service aimed to support people who:

- Would like someone to talk to regarding the options of dialysis at home
- or have just started home dialysis and would like further support

For help, advice or just some reassurance, you are very welcome to contact us via our NKF Helpline for more information on **0800 169 09 36** available from 9am to 5pm Monday to Friday. For more information please visit our Peer Support web page [here](#).



"Dialysing at home was not an easy choice for us to make as a couple. The process can be very stressful from time to time. However, overall, I feel much better and a lot less tired than when I dialysed in a renal unit. My wife and I feel we have a lot more independence now, and a better understanding of dialysis management, giving us more control."

- Chris and Jenny Rolfe, NKF Peer Supporters

Contact the National Kidney Federation's FREE Helpline to speak to one of our trained home dialysis peer supporters based across the UK.

0800 169 09 36
www.kidney.org.uk

All Party Parliamentary Kidney Group (APPKG) Update

The next APPKG meeting will be taking place this month with APPKG Chairman and MP, Brendan Clarke-Smith.

Speakers attending the meeting will be discussing COVID-19 vaccine efficacy for kidney patients.

We will be having another meeting in May where we will be talking about home dialysis, followed by an autumn meeting about transplantation.



KPA of the Month

Continuing to explore the history of our Kidney Patient Associations (KPAs) by including a monthly feature dedicated to a specific region.

Exeter & District Kidney Patient Association

In this issue Exeter & District KPA Chair, George Palmer, discusses the history of their KPA.



The Exeter & District KPA was formed in 1970, making it one of the oldest KPAs in the country. Back then membership cost 15 shillings a year (75p) and there were 28 members. We now have a membership of around 350 – 400 and it's free. Our secretary, Jean Aplin, was not present at that first meeting but her husband Pete was. Jean did however become treasurer in 1972 and subsequently secretary in 1977. She has been the association's secretary ever since – although Pete sadly died in 1993.

In the early days, Jean remembers fundraising with volunteers including knitting bags, slippers etc and sewing together items from offcuts of shirt materials that were supplied by a patient who worked in a shirt factory. Since then we have been able to build up our reserves from other fundraising events, through people kindly leaving us legacies in their wills and through fundraising websites. These monies have been wisely invested over the years which means we have been able to assist patients in our area who suffer from all forms of kidney disease.

The “& District” in our name refers to the whole of Devon (excluding Plymouth) and most of Somerset. It is largely rural so that transport issues are of particular importance to our members. We like to think however that we have a good relationship with our local CCG and are therefore able to help sort out transport problems as quickly as possible. We have assisted in the rollout of the personal transport budget scheme, putting patients in charge rather than the NHS.

We have also entered into an agreement with Citizens Advice Exeter, whereby we fund an advisor to assist our members in all aspects of claiming benefits. This is a service tailored for renal patients and covers everything from initial advice through to completing application forms and arranging advocacy if required at appeal hearings.

We also use our funds to try and fill in the gaps missed by the NHS. This includes the purchase of TVs, hospital equipment and the funding of a specialist nurse for children and young adults, we also provide a quarterly newsletter, social functions, grants to members finding it difficult in making ends meet, subsidised trips to the pantomime etc.

This year we are actively looking at a complete revamp of our website, upgrade of our IT systems, and aim to build up our social media presence. We are also looking at increasing our ability to make more financial grants available for patients in need.

George Palmer
Exeter & District KPA Chair

Transplant Medication

Our NKF website now includes videos that have been created by the Leicester Kidney Pharmacy Team and a group of kidney patients.

Their aim is to help people with a kidney transplant, their families and carers understand medicines better. The videos are for information only and not a substitute for medical advice.

If you think you may have an issue with your health, please see your GP or specialist doctor straight away.

Videos include:

- Medicines after a kidney transplant
- Getting supplies of your anti-rejection medicine
- Tacrolimus after a kidney transplant
- Mycophenolate after a kidney transplant
- Prednisolone after a kidney transplant
- Co-trimoxazole after a kidney transplant
- Valganciclovir after a kidney transplant
- Sirolimus after a kidney transplant
- Azathioprine after a kidney transplant
- Ciclosporin after a kidney transplant



To view the videos on display via our website, please visit our web page [here](#).

Do You Want to Join the NKF Executive Committee?

The NKF has a strong and active Executive Committee.

Executive members are the Trustees of the NKF.

We are looking for an Executive Committee, which is representative of the diversity within our society including:

- A good independent judgement
- A willingness to speak your mind
- The ability to work effectively as a member of a team and can contribute actively to the board of trustees role in setting an overall policy for the NKF



There are up to six meetings per year - all expenses paid.

Completed nomination forms for the executive committee must be received by Friday 25th February 2022.

If you would like to discuss the role of an executive member please do not hesitate to contact Kirit Modi, Hon President by email: kiritmodi1@hotmail.com, or call the NKF on: **01909 544999.**

KPA Day - Registration Now Open!

Registration is now open for this year's KPA day. This event will be held virtually on Saturday 9th April starting at 10.00am and coming to a close at 1pm.

Speakers for the day will be from the Renal Services Transformation Programme (RSTP) NKF honorary president, Kirit Modi and NKF Helpline Advisor, Stephen Emmerson giving an update on the NKF home dialysis campaign and the home dialysis peer support service.

During the morning our AGM will be held and executive committee members will be elected. In the final hour the council meeting will be held.

To register your place please visit [here](#) or email nkf@kidney.org.uk or call us on **01909 544999, you will be sent the link to join once you have registered.**

The NKF Webinar Series Continues

NKF 2022 WEBINAR SERIES HELP, I NEED SOMEBODY, HELP

Wednesday 26th January 5pm

RELATING TO YOUR HEALTH CONDITION ARE YOU STRUGGLING WITH YOUR THOUGHTS, FEELINGS, MOODS, RELATIONSHIPS OR WORK COMMITMENTS?

Sharon Byrne Renal Counsellor, and Chair of the Renal Psychological Therapist Group (RPT) will provide top tips for your mental wellbeing.

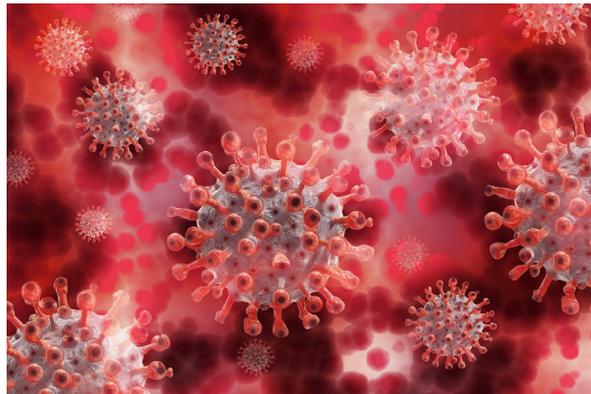
A live Q&A will also be available.

FREE ENTRY



If you're interested and would like more information on what will be discussed at the online webinar, or if you would like to register your free place to attend online, [visit our web page](#).

COVID-19 Updates



For generalised COVID-19 government guidance, we regularly update our webpage in response to any further announcements or developments.

For guidance on COVID-19 and vaccination advice please visit our COVID-19 information page [here](#).

Making Our Website More Accessible

As an NKF supporter, many of you will be familiar with our website which has over the years become a hub for the renal community. Viewed by many patients, carers, renal professionals, doctors and nurses worldwide every year for support and advice.

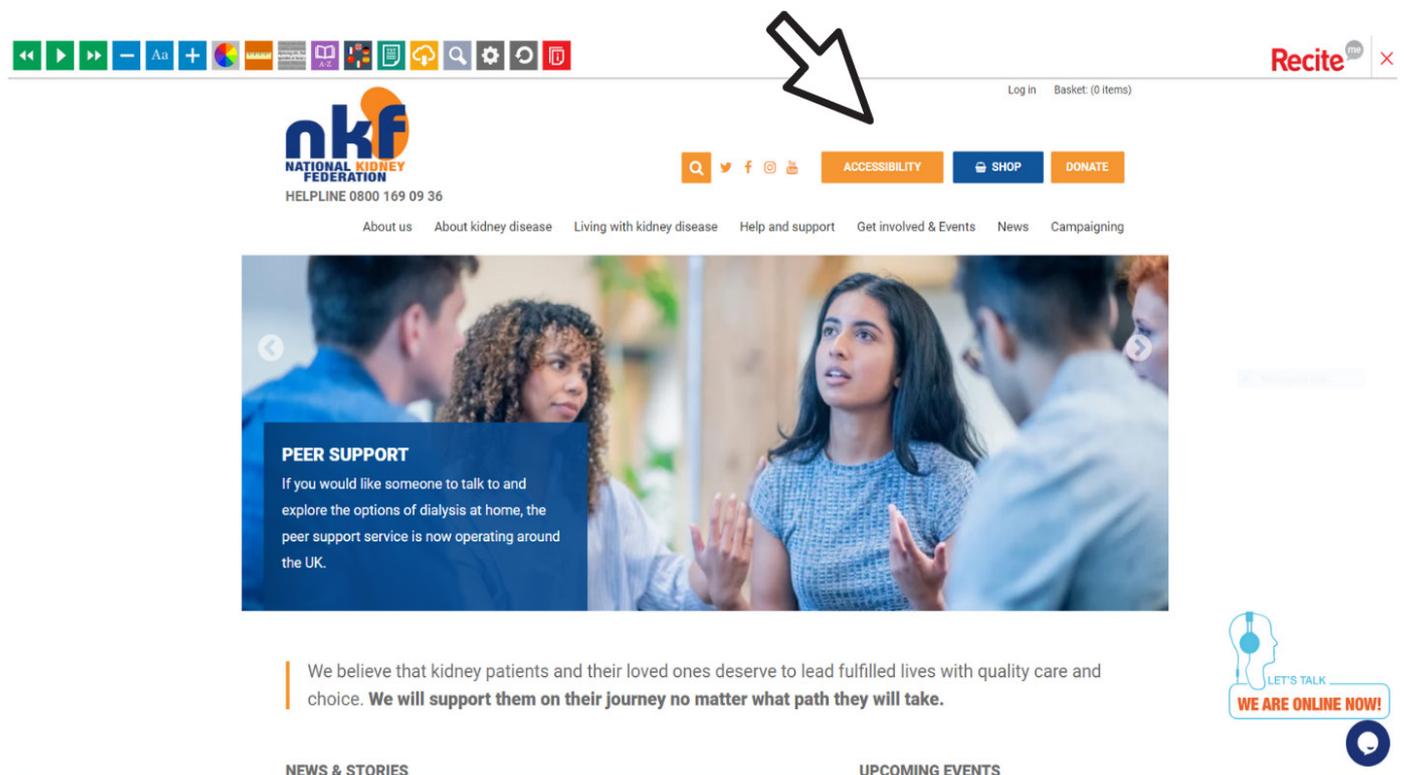
This year we wanted to make our website even more accessible with an accessibility assistive toolbar which enables you to customise the site in a way that works best for you.

The new easy to use tool has a unique range of features which include:

- Text to speech functionality with 35 text to speech voices
- Fully customisable styling features: font type, text size and colour options
- Reading aids: ruler, screen mask, dictionary, text only mode, magnifying glass
- Translation tool with over 100 languages
- And many other features!

The features are available across all devices, giving everyone the opportunity to use the internet how they prefer providing an inclusive experience for all.

All you have to do to is visit our website www.kidney.org.uk and select in the top right corner the orange 'Accessibility' button. This will then activate the accessibility assistive toolbar at the top of the page for you to select any tool you may need for assistance. Why not give it a try? It's completely free to use!



Patient Participation Opportunities

Protect-V Trial

Royal Free London Hospital are inviting kidney patients to take part in a research trial. The PROTECT-V trial enrolls patients on dialysis or receiving immunosuppressive medications. The focus of this trial is on prevention of disease, rather than treatment once disease occurs. This will be measured by comparing if COVID-19 develops in people who take the trial treatment against those who receive a placebo (“dummy”) treatment.

The drug to be tested in the trial is niclosamide, a common safe drug that has been used in tablet form for tapeworm infections for decades. Preliminary research has shown it may also help protect against COVID-19 infection. However, niclosamide tablets are poorly absorbed from the gut into the bloodstream. Therefore, in this trial, niclosamide will be administered by a nasal spray directly to the lining of the nose, which is where the virus that causes COVID-19 infection usually first takes hold. This formulation of the drug is unlicensed, but has been shown to be safe and well tolerated in a study of healthy volunteers. In the trial, participants will receive a total daily dose of niclosamide through a nasal spray.

Participating in this trial is completely voluntary. If you decide to participate you will be asked to sign an Informed consent form, but you will be free to change your mind and leave the trial at any time without giving a reason. If you choose not to participate or to leave the trial, your future medical treatment and normal standard treatment will not be affected in any way.

For further information on this trial please contact Ellie Damian - Research Nurse:

Tel: 020 7472 6491

Email: rf.renalresearch@nhs.net

Are you living with a functioning kidney transplant?

We're running an anonymous online survey to find out how you think and feel about yourself

Prize draw to win a £10 gift voucher

If you'd like to take part, please go to: leicester.onlinesurveys.ac.uk/perceive or contact Rebecca Linnett on rjl48@le.ac.uk

Participants need to be 18+ and living in the UK

FOCUS GROUP

- Do you have 2 or more long-term health conditions?
- Planning a pregnancy / pregnant in the last 5 years?
 - Shape future research design – your opinion matters
 - 1.5 to 2 hours group discussion online, £25 voucher
 - Options to bring partner / family / carer along
 - Contact: s.i.lee@bham.ac.uk



What health & care outcomes should be reported in all studies of pregnant women and birthing people with multiple health conditions?

Living Well on Haemodialysis

Researchers at the University of Derby and the University of Nottingham are looking for people to take part in a trial of newly developed online materials designed to help people live well on dialysis.

The materials consist of a structured programme of online films based on an approach called 'Acceptance and Commitment Therapy' (ACT). ACT is used to help people in difficult, stressful situations cope better with the challenges they face and identify the things in life they value most, to take actions to improve their quality of life. The study will involve completing questionnaires before and after the trial, and there will also be a focus group to discuss and explore participants' experiences.

Participants will be required to spend an hour each week for four-weeks, watching short online videos and practising the associated activities and exercises as well as taking part in a focus group afterwards. Participants who complete all stages of the trial will receive a £30 Amazon voucher as a gesture of appreciation for their time and effort.

To take part, participants must be over 18, have received in-centre haemodialysis for at least 90 days in the last two years (even if presently on home haemodialysis), be able to converse in English, have good internet access and be able to commit to a four-week programme.

Recruitment is now open and closes 1st November 2021 to 31st March 2022. For more information visit [here](#) or email the research team renalresearch@derby.ac.uk.

Glomerulonephritis



What is glomerulonephritis?

Glomerulonephritis is the name for a family of diseases which affect the kidney. Glomerulo- refers to the glomeruli, or the tiny filters in the kidney, and nephritis means inflammation in the kidney.

What are the glomeruli, or filters, in the kidney?

Each kidney has about 1 million filters, each about the size of a pinhead. The glomerulus consists of a small ball of tiny blood vessels inside a bag, and the bag has a drainage tube running out of it.

What are the symptoms of glomerulonephritis?

Most commonly there are no symptoms, in other words someone with glomerulonephritis feels completely well. The only sign of damage to the glomeruli may be small amounts of blood or protein that have passed through the damaged filters into the urine, and can only be detected when tests are performed by a doctor or nurse.

How is glomerulonephritis diagnosed?

Doctors consider glomerulonephritis in anyone with kidney disease, but problems such as infection are more common. If glomerulonephritis is suspected, some blood tests will be performed to look for abnormal antibodies in the blood. However, it is not possible to make an accurate diagnosis.

What is the treatment for glomerulonephritis?

Treatment varies according to the type of glomerulonephritis. Some types of glomerulonephritis will respond to treatment that reduces the action of the immune system, but other types are very difficult to treat. Many treatments, because they attack the whole immune system and not just the abnormal part, can cause serious side effects.

What are the complications of glomerulonephritis?

Pain - Most patients with glomerulonephritis do not get pain over the kidneys, but in a few cases it can be severe.

Disease in other internal organs - In many patients, glomerulonephritis affects only the kidneys. However, in some cases, the immune system that damages the kidneys can also affect other parts of the body.

High blood pressure - This is a common complication of glomerulonephritis, because the kidneys control the level of blood pressure in the body.

For a full list of patient information leaflets from the NKF Helpline with over 150 titles available please contact them on **0800 169 0936** or e-mail helpline@kidney.org.uk.

NKF Fundraising

Events

As the new year is off to a start, you may be thinking of setting yourself a brand new challenge... why not take a look at some of the upcoming fundraising events that are available on our website?

Events include local running events such as 5k or 10k runs, inflatable events, treks including the Northern Lights and the Great Wall of China and much more!

[View NKF events page here](#)



NKF Facemasks and Lanyards Available

Our NKF black facemasks are made of soft cotton, very comfortable to wear, and have a small NKF logo and the best bit is - they are **only £1.50 each plus postage!**

We also have in stock social distancing lanyards at **£1.00 each plus postage.**

To order facemasks or our social distancing lanyards please visit [here](#) or call 01909 544999 where you can place your order and we can take payment by card.



The NKF Calendar 2022 *Limited Stock*

Our NKF 2022 calendar is still in stock at a reduced price of just £1.00!

Including twelve photos of locations from across the UK and space to write your reminders.

Order yours today [here](#) via the online shop or call 01909 544999 where you can place your order and we can take payment by card.



2022
CALENDAR



December 2022	
1	17
2	18
3	19
4	20
5	21
6	22
7	23
8	24
9	25
10	26
11	27
12	28
13	29
14	30
15	31
16	

Weather Lottery

Take part in our NKF Weather Lottery, it's only £1.00 per week!

How it works

The lottery results are calculated using the temperatures from selected destinations around Europe on a particular day each week.

Players are assigned 6 numbers when registering, that are then checked against the last 6 digits of temperatures in Fahrenheit that are published in the Daily Mail on the day of the draw.

By signing up you can win cash prizes whilst supporting the NKF, so we can continue our vital work with kidney patients, families and carers in the UK.

Interested in signing up? Visit our [web page](#) to see more on the Weather Lottery.

The background of the advertisement shows a couple walking on a beach at sunset. The woman is wearing a light-colored top and jeans, and the man is wearing a light-colored shirt and trousers. They are both smiling and looking at each other. The ocean waves are visible in the background.

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📍 Chalkida (Evia Island-Central Greece) 📍 Serres (North Greece) 📍 Thessaloniki (Pylaia, Evosmos)

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

Follow us on social media






The NKF – the largest Kidney Patient Charity in the UK
A FEDERATION OF MORE THAN FIFTY PATIENT CHARITIES, SUPPORTING KIDNEY PATIENTS & CARERS

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