

In Touch

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

Welcome to the July 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 NKF Annual Patients' Event
- 03 Covid-19 Guideline changes
- 05 National Institute for Health and Care Excellence Survey

Patient Participation Opportunities

- 06 Living with IgA Nephropathy (IgAN)?
- 07 Interview Study for Adults with cytomegalovirus (CMV) after transplant

Adverts

- 08 Lakeland Dialysis
- 09 Take a Break Magazine

NKF Helpline

- 10 "What is a fistula?" ,
"Caring for your fistula"

NKF Fundraising

- 13 Best Foot Forward Thank You
- 14 Lanyards

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 August 2021.



Annual Patients' Event

Join us for the 2021 Virtual NKF Patients' Event!

This year's event is entirely virtual, meaning you can enjoy the speakers from the comfort of your own home.

We have a range of engaging and informative patient and professional speakers lined up.

The day will start at 10:00am and finish at 2:00pm.

We have talks on: **'What does my kidney pharmacist do?'** from Katherine Parker,
'Kidney sharing scheme - NHS Blood and Transplant' from Lisa Burnapp, Clinical Lead Living Donation,
'Covid-19 and its impact on dialysis' from Nicola Ward, Head of Nursing, Renal Services, and more.

To see what's planned for the day and to book your free place click the link below, or contact us on **01909 544 999** or at **nkf@kidney.org.uk**.

<https://www.kidney.org.uk/Event/nkf-patients-event-2021>

Thank you to the event's sponsors, Becton, Dickinson and Company and Renal Services.



Covid-19 Guideline Changes

With the upcoming Covid-19 guidelines changing on Monday 19th July we know patients are very concerned about coronavirus (Covid-19).

The NKF are working with the National Renal Guidance Group for Covid-19. This is a group of specialist clinicians, partners and patient charities, who are providing the latest clinical and patient guidance.

There are things that everyone can do to keep safe out there:

- Wash your hands regularly
- Continue to wear face coverings
- Wear an NKF social distancing lanyard to show people that you are practicing social distancing
- Meet outside when possible
- If possible have your food shopping delivered

For more information please take a look at our website:

<https://www.kidney.org.uk/news/coronavirus-latest-information-and-advice>

The following information has been taken from the Gov.UK Website. For more information please take a look the Gov.UK website below.

<https://bit.ly/3yXC19G>

This guidance is for everyone in England who has been identified as clinically extremely vulnerable from coronavirus (COVID-19). This includes those people who have been identified by the NHS as being clinically extremely vulnerable and those identified through the COVID-19 population risk assessment. All of those identified have been added to the Shielded Patient List, and more information on the criteria used is available below. If you have been identified as being clinically extremely vulnerable, you will previously have received a letter from the NHS or from your GP telling you this. You may also have been advised to shield in the past.

As restrictions will be eased following the move to Step 4 of the roadmap, we will be advising clinically extremely vulnerable people, as a minimum, to follow the same guidance as everyone else. It is important that everyone adheres to this guidance.

However, as someone who is at a higher risk of becoming seriously ill if you were to catch COVID-19, you may wish to think particularly carefully about additional precautions you might wish to continue to take. Individuals may choose to limit the close contact they have with those they do not usually meet with in order to reduce the risk of catching or spreading COVID-19, particularly if they are clinically extremely vulnerable and when COVID-19 disease levels in the general community are high. It is important to respect and be considerate of those who may wish to take a more cautious approach as restrictions are lifted. We understand you may have concerns and wish to know how you can continue to take precautions to keep yourself safe.

Although the vast majority of the population, including the clinically extremely vulnerable, will be well protected by the vaccine, no vaccine is 100% effective and there is emerging evidence that suggests that some immunocompromised and immunosuppressed individuals may not respond as well to COVID-19 vaccines as others. However, all COVID-19 vaccines should offer some degree of protection. Therefore, it is really important that you have both your first and second dose of the coronavirus vaccine.

The above information has been taken from the Gov.UK Website.

Get involved - Uroshield for people with long-term indwelling catheters - user survey and organisation submission Brief introduction to the technology:

Uroshield is used to prevent catheter-associated urinary tract infections (CAUTI) in people with long-term indwelling catheters. The innovative aspects are that it uses surface acoustic wave technology to prevent the attachment of bacteria to the surface of catheters. The intended place in therapy would be as well as existing catheter products to help prevent infection in people with indwelling catheters.

There was a medtech innovation briefing published in 2019 on the technology when the potential patient benefits were said to be:

- Reduced blockages and catheter-associated urinary tract infections (CAUTIs)
- potentially resulting in better patient quality of life
- less pain and discomfort
- and fewer hospitalisations and acute settings visits

Find the survey here:

<https://nice.researchfeedback.net/MedtechPatientSurveyM-T476UroShield>

Patient Participation Opportunities

Living with IgA Nephropathy (IgAN)?

Online Survey – share your experiences and help other patients!

We would like to inform you about an online survey for patients diagnosed with Primary Immunoglobulin A Nephropathy (IgAN), also called IgA Nephropathy or Berger's disease.

The purpose of this survey is to obtain your opinions and insights as a person living with IgAN.

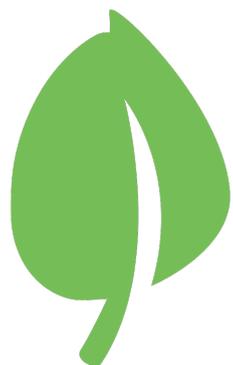
It should take about 3 to 5 minutes to complete.

Your responses are completely confidential. We will not collect any contact information from you, nor will we attempt to contact you in the future about your responses.

We thank you for your support and assistance as we strive to develop potential new medicines to treat Primary Immunoglobulin A Nephropathy (IgAN).

Find the survey below:

<https://bit.ly/3qUPbkY>



ClinLife

Interview Study for Adults with cytomegalovirus (CMV) after transplant

Adelphi Values, a health research organization that works with pharmaceutical companies to assess the impact of health conditions and their treatments on peoples' lives, is conducting a study exploring the burden of cytomegalovirus (CMV) and its treatment on transplant recipients. CMV infection is common in post-transplant patients and can lead to various medical problems such as increased graft failure and mortality.

Sometimes CMV lasts for a long time even if being treated with medicine, or it comes back after you and your doctors think it has gone away.

Adelphi Values is looking to speak with adults 18 years of age or older who are recipients of a solid organ transplant (SOT) or an allogenic hematopoietic stem cell transplant (HSCT) within the past five years, and have experienced CMV infection that lasted for over two weeks despite treatment, or CMV infection that came back after being treated successfully in the past.

Adelphi Values invites those who have experienced this type of CMV to participate in a telephone interview. Participation in the study will consist of a brief interviewer administered questionnaire and a one-on-one 60-minute telephone interview to discuss your experience with CMV infection, its treatment, and its impact on your life. You will receive £75 for completing the 60-minute interview.

During this study, no medication will be given or tested. Your inclusion in the interviews will not replace or affect any care or assistance you are currently receiving or may receive in the future. Your name and contact information will not be shared with anyone and will remain confidential.

If you wish to participate, or have any questions, please contact Adelphi Values and reference study number TK8701A:

Samantha Power (Samantha.power@adelphivalues.com)

Thank you for your consideration.



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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

TAKE A BREAK MAGAZINE

Have you donated a kidney to a friend or received one of theirs?

If so Take a Break Magazine, the UK's best-selling women's magazine, would like to hear from you.

We're looking to profile people in the lead-up to our Britain's Best Friends competition.



Do please drop us a line if this sounds like you, it just involves a short phone interview. Anyone who has their story published will have it read back to them before they go to print to check they are happy with it first.

You must also be willing to be named and pictured in the magazine.

Everyone featured will also be entered into the Britain's Best Friends competition.

Just email tab.jean@bauermedia.co.uk

Closing date for entries is 31 August 2021.

The winners will be treated to a FREE make-over to be featured in the magazine.

“What is a fistula?”

Fistulas for dialysis are made usually at the wrist but can be made at the forearm or elbow. The more powerful blood flow from the artery flows into the vein causing the vein to stretch, enlarge and become stronger.

Once the veins become enlarged and stronger, dialysis needles can be put into the vein and used for dialysis. Before the needles are put in, you will be asked by the nurse if you would prefer a local anaesthetic injection to numb the area around where the needles will be placed. The needles are taken out at the end of the dialysis treatment.

“Caring for your fistula”

After your fistula operation, you may experience some swelling, pain and /or numbness in your hand. These symptoms do disappear but do continue in some patients. If you notice your hand is getting colder, or there is increased pain or numbness please contact your renal dialysis unit.

Check the buzzing (called bruit- pronounced brew-ee) on your fistula each day. If this buzzing stops, notify the renal unit as soon as possible.

There are a number of things you can do to protect your fistula. We often call your fistula your “lifeline” because it is so important in enabling good dialysis.

Do not allow your blood pressure to be recorded from the arm your fistula is in.

Do not allow staff to take blood samples from your fistula: it is for haemodialysis needles only.

Do not wear tight restrictive clothing on your fistula arm. Avoid tight straps such as wrist watches or jewellery on your fistula arm as this can constrict blood vessels.

Do not carry heavy shopping bags on your fistula arm.

After dialysis, keep the dressing pads on for at least 8 – 12 hours, to ensure the holes are healed over. If you have a dirty job or you are in the garden - make sure the needle sites are covered.

Try not to scratch your fistula or do anything which can cause an injury to it. If you suffer from itching, let your doctor know so that medication can be considered to relieve the itching.

Do not pick at the fistula - it can become infected and this can cause the fistula to stop working.

Try to avoid sleeping with your head resting on your fistula arm

If you notice any changes in your fistula or hand – such as change in size, redness, swelling or numbness, please notify your renal unit.

Remember to check your fistula daily - your renal team will show you how to check for a pulse or a vibration through your fistula (called a thrill) or a sound called (called a bruit).

If you can't feel it, you must contact your renal unit as soon as possible.

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.

The Helpline has a leaflet called “Care of your Fistula”, if you would like to receive this please contact the Helpline on: **0800 169 0936** or e-mail: **helpline@kidney.org.uk**

Introduction to haemodialysis leaflet

<https://www.kidney.org.uk/introduction-to-haemodialysis>

Home Dialysis the advantages leaflet

<https://www.kidney.org.uk/home-dialysis-the-advantages>

Dialysis line insertion leaflet

<https://www.kidney.org.uk/dialysis-line-insertion>

NKF Home Dialysis Resource Centre website page

<https://www.kidney.org.uk/Pages/Category/home-dialysis>

NKF Helpline

Monday to Friday 9am to 5pm

Phone: **0800 169 0936**

E-mail: **helpline@kidney.org.uk**



NKF Fundraising

Best Foot forward For Kidney Patients

A massive thank you to everyone that took part in last month's step challenge, it turned out to be our best ever fundraising event to date – the most people to sign up for an event and the most money raised totaling around £30,000!

We had some amazing stories of why people were taking part and some of these people will feature in our next edition of our Kidney Life magazine.



Thank you once again for your fantastic support.

THANK
YOU

Follow us on social



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.

Social Distancing Lanyards £1



With COVID-19 lockdown rules being relaxed even more, let people know you want social distancing, plus the hook can hold a hand sanitiser.

Click the link below to buy one!

WWW.KIDNEY.ORG.UK/SHOP