

KIDNEY NORTH EAST

Spring 2022

NEWSLETTER



NORTH EAST KIDNEY PATIENTS ASSOCIATION

Charity Commission No. 503164

For any enquiries, please email us at contact@nekpa.org.uk

Again, we would like to thank all the staff involved with hospitals, renal units, home care, GP surgeries, pharmacies, key support workers and others for their constant work and dedication, especially during this pandemic

We hope that you all have had your 3rd booster and possible 4th vaccination by now but if you are still waiting and termed 'vulnerable' , then please contact your GP surgery and let them know.

Chairman's Notes

Dear Members,

We are now into another new year but sometimes it seems like nothing has changed except the number of jabs we have had. If you are a dialysis or a transplant patient you should have had four jabs by the time you read this newsletter or at least have a date for the 4th.

You will see from the treasurer's report that we have sold our caravan. It was originally intended to benefit patients but of late members were not using it and financially we could not justify keeping it on a purely commercial basis. It was also proving increasingly difficult to get dialysis places at Scarborough or Bridlington for holiday patients.

So what will 2022 bring? Hopefully, greatly reduced Covid infections, and correspondingly fewer restrictions. It would be wonderful to make arrangements for holidays, and family get-togethers knowing we will be able to keep them.

As a charity we would hope to be able to restart fund raising events which would mean we would once again be in a position to help our members in time of need. We will also be able to take part in face-to-face events such as the pre-dialysis days run by the renal unit. Hopefully this should mean we will all have a happy and healthy new year. We did at least manage to run our Christmas raffles this year. Our thanks to all of you who took part.

Last but not least I would like to welcome new Committee Members, Catherine and Alastair MacKenzie. Catherine is a



transplant patient and Alastair is a 'live' donor.



Brian Child
Chairman

Alastair & Catherine McKenzie

Obituary - John McElhone

It is with great sadness that I report the death of John McElhone who was for many years a NEKPA Committee Executive. He served as Vice President for a number of years, and latterly as a Committee Member but unfortunately John had to resign due to increasing ill-health in late 2019.

John and his wife Marie were prominent members of our committee and attended all our events to promote NEKPA, always the first to arrive and the last to leave (much better than my attendance record). People like John are the backbone of small charities and their contribution greatly appreciated—he will be sorely missed by many.

Our deepest condolences go out to Marie and her family at this sad time.

Unfortunately John was not the only one of our members to have died in the last two years. We are aware of the death of at least 23 NEKPA members and would like to extend our sympathies and condolences to all those families and friends in these difficult times.



Brian Child
Chairman



Treasurer's Report

Well here we are in another year and I hope 2022 is better to you than the last 2 years have been though that might be wishful thinking as all the excess expenditure has to be recouped by the Government now.

In similar vein, it has been a difficult couple of years for NEKPA as we have had no opportunity to hold events, increase membership or fundraise.

Our current financials status is :

 CafCash Account	£1,000.00	Make a payment
Account: 00014314	Cleared balance: £1,000.00 [?]	Make a transfer
		View activity »
 CAF Gold Account	£11,493.93	Make a payment
Account: 00093352	Cleared balance: £11,493.93 [?]	Make a transfer
		View activity »

In 2017, NEKPA purchased a second-hand static caravan at Cayton Bay, nr Scarborough to provide cheaper holidays for members with the close proximity of dialysis units if needed.

Despite advertising where possible, we only had a couple of members use the facility over the 5yr period of ownership. To offset continued operating costs of approx. £8,000 per year, we made the caravan available to the general public but this also had limited take-up until the onset of Covid 19 in 2020. We managed to break even in 2021 due to demand for UK holidays but the years prior had all been a drain on NEKPA funds.

In November 2021, I presented a report to Committee detailing all the costs incurred since purchase with negative projections and consequently the decision was made by all to sell the caravan

In January 2022, we sold the static caravan to Parkdean Resorts.

General Expenditure:

Whilst income is at an all time low, we have significantly reduced costs, primarily with the digital version of our Newsletter which negates printing and postage costs at this time.

Grant Requests:

A grant request for a washing machine + fitting was approved by the Committee to a value of £310.



Annie Oldfield
Treasurer

NEKPA Committee

Chairman	Brian Child (<i>Home Dialysis</i>)	07730 922355
Vice Chairman	Phil Pugh (<i>Transplant</i>)	07850 225279
Secretary	Terry Oldfield (<i>Transplant</i>)	07503 919474
Treasurer & M'bership	Annie Oldfield	07460 874034
Committee Members	Lyndsey Hoare (<i>Transplant</i>)	07789 465917
	Margaret Jackson (<i>Living Donor</i>)	07791 272640
	Sarah Eales (<i>Home Dialysis</i>)	07504 117082
	Catherine MacKenzie (<i>2 x Transplant</i>)	01642 481216
	Alastair MacKenzie (<i>Living Donor</i>)	01642 481216

Please remember that there are no salaried or paid Committee Members
- all give their time and effort on a voluntary basis.

Patient Support

Restrictions imposed by Covid-19 are still in place so we, the NEKPA Committee, are still not in a position to be able to carry out our usual activities, e.g. fundraising, meeting patients, liaising with medical staff in how best to support their work.

We are, however, always available to help with non medical advice, information and support, our Facebook pages have regular updates and our website, www.nekpa.org.uk contains lots of useful information, links and contact details.

You can also email us at contact@nekpa.org.uk with any queries or requests for help or information.

**Stay safe everyone,
NEKPA Committee**

JCUH New Renal Day Unit Opening

James Cook University Hospital's aging Renal Day Unit has been transformed into a modern, purpose-built centre. Staff and patients at the Middlesbrough hospital announced ambitious plans to raise £500,000, with the support of Our Hospitals Charity, back in November 2020 to help develop a first-class facility to deliver kidney care.

Despite challenging times with COVID-19, their fundraising goal was exceeded and the old unit has now been replaced with an area where patients' needs can be met in one place. Those attending will now be greeted in a large welcoming waiting area and will have access to treatment rooms as well as a home dialysis training room.

David Reaich, Deputy Chief Medical Officer for South Tees Hospitals NHS Foundation Trust, said: "Thanks to the help of our patients, staff, Our Hospitals Charity and a number of local businesses, including Drive Motor Retail, we now have excellent facilities that will enable us to help the increasing amount of patients we're seeing." The unit was officially opened with a ribbon-cutting ceremony by patients Neal Waters and Sarah Eales (NEKPA Committee Member).

During the opening, Cheryl Burton (Service Manager) said: "It feels fabulous for all the team, patients and families to officially open the new unit. It's been a long journey and despite it being a challenging time for everyone the charitable funds team has been brilliant and we've managed to raise £540,000. We're all extremely grateful to our patients, staff and the community for helping us achieve this refurbishment."



Renal patients Neal Waters and Sarah Eales at the opening ceremony

**Live Life
Give Life**

Live Life Give Life are running a campaign on Transplant Heroes - this campaign is focussing on the people who help those having transplants. They are looking for nominations of your Transplant Heroes - be it a nurse, a cleaner, a favourite receptionist - if they helped you through your transplant you can nominate them!

Send us your nominations at georgia.wilding@livelifegivelife.org.uk with an explanation of who you're nominating and why!

Live Life Give Life is a national charity promoting organ donation & fundraising to support transplant research & education.

World Kidney Day



World Kidney Day 2022 – Kidney Health for All

World Kidney Day calls for everyone to not only be aware of the disease but to actively know what their own kidney health measures are.

It is a cause that involves all of us in the global kidney community — physicians, scientists, nurses, and other healthcare providers, patients, administrators, health-policy experts, government officials, nephrology organizations, and foundations.

We all need to be aware of how increased awareness of the importance of kidney health, amongst policymakers and opinion formers, can lead to major benefits both to patients and to healthcare budgets

How Much Do You Know About Kidney Health?

Take our quick fun-quiz and test your kidney health knowledge!

[Take the Kidney Quiz!](#)

Click the link above or go to

<https://www.worldkidneyday.org/facts/your-kidneys/>

Home Dialysis

HOME DIALYSIS

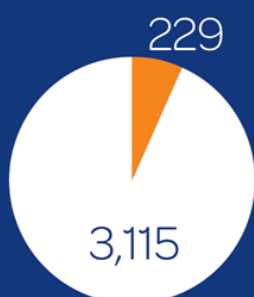


Hemodialysis is a treatment that replaces the work of your own kidneys to clear wastes and extra fluid from your blood.

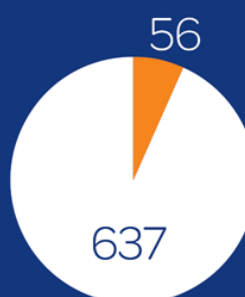
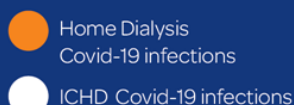


Dialysis can be done at home where the patient is responsible for his own treatment

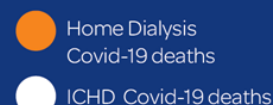
A requirement for home hemodialysis is that you and/or your care partner can pass the training and learn to place your needles.



15% of ICHD patients contracted Covid-19 compared to 5.3% of home dialysis patients



3.1% of ICHD patients died from Covid-19 compared to 1.3% of home dialysis patients*



INCREASING HOME DIALYSIS IN THE CONTEXT OF COVID-19 IN THE UK

A 28 page report has been published by NKF which outline the many benefits of home dialysis to Covid 19.

<https://www.kidney.org.uk/home-dialysis-campaign#Report>

Copy the link above and place in your web browser and you will be able to download the report

Home Dialysis Training

Dialysis patients to benefit from ground-breaking technology

State-of-the-Art technology which aims to enable patients receiving dialysis at home to have their treatment monitored remotely is to be evaluated across the Tees Valley.

The innovation piloted by South Tees' renal team and partners at Teesside University, the What Works Centre for Wellbeing and Alio Medical aims to give patients and their caregivers the ability to monitor key treatment measurements at home without the need for invasive blood tests or hospital visits. The novel project won funding through Q Lab UK; a Health Foundation and NHSX collaboration which aims to explore how to build trust and confidence in technology enabled remote monitoring to help develop digital capabilities in the National Health Service. Along with three other Q Lab teams across the UK, the partners will explore barriers and enablers to the uptake of such technologies at home, by patients and their care providers.



Dr Jonathan Murray, consultant nephrologist, patient Elizabeth Fraser and home dialysis sisters Karen Coaker and Sarah Dunn

The same technology may in the future also benefit people with other chronic health conditions, such as diabetes, heart failure and chronic kidney disease.

Jonathan Murray, South Tees' renal consultant, said: "Our goal has always been to help develop technologies which can enable patients to have their health monitored remotely, including at home. "This would empower patients and

provide autonomy by effectively enabling them to monitor their health and treatment around their daily activities, rather than vice versa. "As the Alio Monitoring System is developing, we recognise it is imperative that we understand which factors matter to patients and would influence their use of such technology at home and this project with Q Lab UK will help us to achieve this." John S. Young, professor of translational healthcare at the National Horizons Centre at Teesside University, said: "This project has the potential to make a massive difference to patients' lives. The ultimate aim is to enable patients to track their potassium levels and other important measurements regularly at home. This could save lives by facilitating timely treatment of abnormal blood results; if potassium levels are too high or too low, this can be fatal." The first phase of the project will see staff and patients working together to explore how they can build trust and confidence in the technology, and identify barriers to implementation. The second phase hopes to utilise experience and learning from the first phase to inform and support wider roll out of the technology, once the technology has completed final

New Renal Unit in North Yorkshire

Friarage Hospital RU, Northallerton

A new renal unit has officially opened its doors at the Friarage.

The unit, funded by the Friends of the Friarage, has space to dialyse up to ten patients at one time, reducing the need for people to travel to Middlesbrough or Darlington for dialysis.

Dr David Reaich, Deputy Chief Medical Officer, said it was fantastic to now have a dialysis centre at the Friarage. "We are very excited to be able to provide this service to our patients from Northallerton, Thirsk and the surrounding areas who currently have to travel quite a long way for their dialysis, three times a week," he added. "It is a huge step forward for those patients and will really help to improve their quality of life."

The unit was officially opened with a ribbon-cutting ceremony by Ian Macdonald who has been a renal patient with South Tees for nearly 50 years.

The 67-year-old from Great Ayton, who has had four kidney transplants, said it was a privilege to be one of the first patients to see the new unit. "I've been connected to the renal unit for 49 years all together," he said. "I started dialysis at North Ormesby Hospital in 1972, I was one of the



Ian Macdonald and his wife Sue Macdonald with renal unit manager Faye Brown

first patients to go for dialysis at what was then known as South Cleveland Hospital, I dialysed at home for ten years and I am now one of the first to see the unit at the Friarage. "The renal team are tremendous; the nurses are fantastic and they're always really supportive. This small unit is ideal for patients like me."

In total the Friends of the Friarage donated £300,000 for the unit's development work and purchase of equipment. Liaison trustee for the Friends of the Friarage Donna Jermyn said: "The dialysis unit is a terrific development for the Friarage and the local population. The Friends have been delighted to support this and I'm sure we'll continue to take an active interest." During the opening Cheryl Burton, service manager for renal, thanked the Friends for supporting the unit. "On behalf of the trust, our renal team and our patients I would like to say a huge thank you to the Friends of the Friarage and to all of their supporters. You have raised an amazing amount of money for us without which we couldn't have opened this unit. This will make a huge difference to our patients."

Survey for Care Partners

Are you helping someone who has a kidney condition?

We are designing a support programme for people who help someone with a kidney condition. What would you want in a programme like this? Tell us in our online survey!

What do we mean by “helping someone with a kidney condition”? It could mean something like...

Helping with their medical care or talking with their care team

Helping around the house like cooking or cleaning

Listening to them if they are worried or stressed



If you are interested in participating please use the QR code or this link to go to our survey!



https://exetercles.eu.qualtrics.com/jfe/form/SV_725d9rMSoarmOr4

Need more information? Contact Chelsea at:
c.coumoundouros@exeter.ac.uk



Who can participate? Anyone who is...

- At least 18 years old
- Living in the UK
- Helping someone with a kidney condition who is also at least 18 years old

You can be connected to the person with a kidney condition in any way – they could be your family member, friend, neighbour or colleague.

The survey will take around 15-20 minutes to complete.

Thank you!

Survey link: https://exetercles.eu.qualtrics.com/jfe/form/SV_725d9rMSoarmOr4

The 'end of Covid-19 regulations' for renal patients?



is fervently working to clarify issues regarding this topic and recently wrote to every MP to outline some of the things which will be needed to protect and support people with kidney disease at this time and as we move into the weeks and months ahead.

On Monday 21 February, the Prime Minister is expected to publish a 'plan for living with Covid-19' in England and he has indicated this may include bringing forward the end of Covid-19 self-isolation rules to later in February. Kidney Care UK has raised our concerns about the ending of restrictions directly with MPs and policy makers and we know that many of you have also written to your MPs to share your views.

NKF have now joined with 17 other health charities to set out the '5 key tests' the Prime Minister's plan must pass to ensure it supports those most at risk from Covid-19 now, and in the future. We know many people want to get back to normal, not least people at highest risk from Covid-19 who have been among those most acutely affected by the pandemic, but the risk will not simply disappear for people who are immunosuppressed and Government policy must prioritise supporting them to manage this risk.

The five tests are:

- Directly address the concerns of people at highest risk and commit to improve communication with them.
- Smooth, timely access to Covid-19 treatments.
- Lateral flow tests remain free.
- Improve employment protection and support.
- Set out a plan for the use of preventative Covid-19 treatments and prioritise further research into treatments and vaccines.

Fiona Loud from Kidney Care UK said "We are worried about the government's plans to remove Covid-19 self-isolation rules. We urge the government to show some commitment to 500,000 immunosuppressed people by sharing their plans, and the evidence for this decision. Abandoning all measures without preventative treatments, free lateral flow tests, and a duty not to expose immunosuppressed people to Covid unnecessarily risks making us into second class citizens. Despite Omicron being a milder illness for the general population, there remains uncertainty about future variants, further impact on higher risk groups; with a record of really poor communication this will make things harder and increase anxiety for people with kidney disease who have already spent two years under Covid-19 stress."

Kidney Care UK, as part of the charity coalition, is sending a briefing to all MPs which set out the five key tests and explain why they are so important. It highlights that people who are immunosuppressed may be less well protected by the vaccine and are also at highest risk of severe illness with Covid.

continued/.....

We are asking MPs to write to the Prime Minister emphasising our asks and raise questions challenging the Prime Minister on how the Government is planning to support immunocompromised individuals. Current Government advice to immunosuppressed patients is:

- ensure you have had all of the vaccines you are eligible to receive, including your booster
- continue to follow any condition-specific advice you may have been given by your specialist
- work from home if you can. If you cannot work from home, speak to your employer about what temporary arrangements they can make to reduce your risk
- wait until 14 days after another person's most recent dose of a COVID-19 vaccine before being in close contact with them
- avoid enclosed crowded spaces
- practice social distancing if that feels right for you and your friends
- ventilate your home by opening windows and doors to let fresh air in
- ask friends and family to take a rapid lateral flow antigen test before visiting you
- ask home visitors to wear face coverings
- wash your hands regularly and avoid touching your face.

Had a side effect to your medication?

Yellow Card | Coronavirus (COVID-19)

The Medicines and Healthcare products Regulatory Agency (MHRA) is the UK government agency, which aims to protect the public's health. It does this by making sure medicines and medical devices work and are acceptably safe. When any possible problem is found, the MHRA takes prompt action to protect the public and reduce risk

If you have, a symptom, which you think, may be a side effect of your medicine:

1. Check the patient information leaflet supplied with the medicine. This lists the known side effects, and advises you what to do.
2. Ask your doctor, pharmacist or nurse for advice.
3. You can report the side effect yourself via the Yellow Card Scheme, especially if it is not mentioned in the patient information leaflet. Always talk to your doctor, pharmacist or nurse if you have any symptom that worries you.

For more information about the MHRA:

www.yellowcard.mhra.gov.uk/information

Please report suspected side effects to medicines, vaccines, medical device and test kit incidents used in coronavirus testing and treatment to the Medicines and Healthcare products Regulatory Agency to ensure safe and effective use

<https://coronavirus-yellowcard.mhra.gov.uk/>

NEKPA GRANTS

Grants And How To Apply

We can make grants available for those of our members who are in the unfortunate position to be unable to provide essential items for themselves.

Should you wish to apply, please contact Annie Oldfield on 07460 874034 or by email a.oldfield@nekpa.org.uk

Your application will then be discussed by the NEKPA Committee and you will be informed of the outcome.

Since our last newsletter, we were able to approve a grant for a washing machine and installation

One the main purposes of NEKPA is to help our members at a time of need. As a charity, we are able to give grants to patients from the funds we have raised by various mean. In the past, we have purchased various good and services that patients have needed but not been able to afford.

The level of grant have been able to offer has varied over time and has been mainly determined by the fund we have available at the time. Lately, it has been circ. £300 but in the light of the 'cost of living' inflation, we haved decided to raise this figure to £350 per claim. We regret that this can't be higher as funds have decline during the Covid 19 epidemic and loss of fundraising opportunities.

NEKPA has never given cash grants or help towards household bills and we will not be doing so going forward. Should this be the case, or your need be significantly greater than the above, please contact Kidney Care UK Advocacy Officer for NE Region (Jo Bates on 01420 541424 of info@kidneycareuk.org) who may be able to help further.

Fundraising

Christmas 2021 Raffles

A huge thank you to the Regional Dialysis Units of Middlesbrough, Darlington, North Ormesby and Stockton for allowing NEKPA to hold a Xmas Raffle to help increase funds.

The following are the amounts raised and prizes winners where available.

Stockton £297

Darlington;	£283	Hamper	John Stamworth
		Teddy bear	Henry Hair
		Chocolate selection	Michael Peach
		Wine	Nikitas Maikos
		Cosmetics	Fiona Lowe

North Ormesby: £176

James Cook UK: £137.50

A total of **£893.50** was raise for which we than all those who bought tickets.

A donation of **£250** was als received from Mr B Childs (Chairman) in lieu of Christmas presents for his adult sons.

Renal Diet Recipe



Chicken or Vegetarian Curry

This curry is a great low potassium option, and when served with wholemeal rice rather than white rice will be high in fibre. You may want to add some extra vegetables to ensure you get your 5aday, such as green beans (you can even get these frozen). To turn this dish into a vegetarian option simply use a 400g tin of chickpeas to replace the chicken and enjoy. Remember both chicken and chickpeas contain phosphate so if you are prescribed a binder ensure you take as directed with this dish.

Serves 4

- 450g chicken in 2.5 cm cubes
OR 400g tin of chickpeas
- 2 tbsp cooking oil
- 1 medium onion
- ½ tsp powdered ginger
- 300ml of chicken or vegetable stock
- 2 tbsp mango chutney
- 1 tsp soft dark brown sugar
- 150 ml cream

Seasoning

- 55g plain flour (use less if making with Chickpeas e.g. 25g)
- 1 tsp paprika
- 1 tsp cayenne pepper (less if you are not keen on a hot curry or omit completely)
- 1 tsp chilli powder
- 1 tbsp turmeric
- 1 tbsp hot curry powder (use mild if you prefer)
- 1 tsp ground coriander
- 1 tsp ground cumin

Preparation method

1. Combine the seasoning ingredients together in a bowl and then add the chicken or chickpeas to coat.
2. Heat the oil in a large heavy-based saucepan, then add the chicken or chickpeas and cook until sealed.
3. Add the onion and ginger and cook for a further 1-2 minutes.
4. Add the stock, chutney, sugar and bring to the boil. Cover and simmer for 15 minutes
5. Stir in cream and heat through, taking care not to boil the sauce.
6. Serve with boiled rice, ideally brown rice and some vegetables.

Dialysis Abroad

If you are planning a holiday or travelling for work or pleasure, the first thing to do is speak to your kidney team so that they can help plan your treatment while you are away.

Try to give them as much notice as possible - ideally at least 4 weeks for travel within the UK and 3 months for travel abroad.

Travel insurance is vital. Most standard policies do not cover chronic kidney disease and it is likely that your insurance costs will be higher than someone who does not have a long-term health condition. You may need a letter from your kidney team confirming that you / your child are well enough to travel.

You will need to let the **transplant coordinators** at your unit know that you are going abroad so that they can temporarily remove you / your child from the list until you return. You will not lose any time points while you are off the list

For further information: https://www.kidneycareuk.org/documents/175/Dialysis_away_from_home.pdf



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

National Kidney Federation KPA Day

Last year, the NKF events that were open to KPA members had to be held via internet streaming platforms due to Covid restrictions.

This year is starting in a similar manner with the KPA Day which includes the Annual General Meeting scheduled for 9th April (see NKF website for details) has already been consigned to a virtual format.

If you would like to take part in the AGM, the details of how to join are on the NKF website <https://www.kidney.org.uk/kpa-day>

The prospects for the Annual Conference, due to be held in October, don't look any more promising for 'face to face' and even if it were, it is doubtful that many vulnerable kidney patients would have sufficient confidence to attend.

World Kidney Day as mentioned earlier in this Newsletter is also likely to be 'virtual' events. NKF are planning to launch their report on progress with Home Dialysis Implementation on the that day.

Many of you will remember Linda Pickering who was the local 'advocate' for Kidney Care UK. Linda is now working for NKF as part of the Helpline team. We are certain her first hand knowledge of the affects of kidney disease will be invaluable in her new role.

Linda can be contacted on 0800 169 09 36 or helpline@kidney.org.uk.



Contact Us

INSPIRE, MOTIVATE & COMMUNICATE

ADVERTISE WITH US

If you would like to
advertise in our
next edition please
get in touch

Would you like to feature in our Kidney North East magazine?

Do you have a story or experience with renal disease that you wish to share with other readers?

Do you have advice or tips that renal patients may benefit from? If so, please get in touch with us.

PATIENT REPS WANTED

We are looking for patient representatives from each Dialysis Unit, either patient or staff. Anyone interested should contact Brian Child, Chairman on 07730 922355 or email contact@nekpa.org.uk

NEW FACEBOOK GROUP

In line with furthering NEKPA objectives for patient support, a new Facebook Group has been created where it is hoped you will share any concerns, questions or advice. Please join!

[NEKPA RENAL PATIENT GROUP](#)

North East Kidney Patients Association
The Renal Unit,
The James Cook University Hospital
Marton Road
Middlesbrough,
TS4 3BW (Registered Office)

Email: contact@nekpa.org.uk

Tel: 07730 922355 Tel: 074608 74034

Email: t.oldfield@nekpa.org.uk



March 2022