

Spring 2025

NEWSLETTER



NORTH EAST KIDNEY PATIENTS ASSOCIATION

NEKPA میں خوش آمدید جہاں سب کا استقبال ہے۔

NEKPA-তে স্বাগতম যেখানে সবাইকে স্বাগত জানানো হয়

NEKPA માં તમારું સ્વાગત છે જ્યાં દરેકનું સ્વાગત છે

NEKPA में आप का स्वागत है जहाँ सभी का स्वागत है

Witamy w NEKPA, gdzie każdy jest mile widziany

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NEKPA Committee

Topic	Contact	Phone No.
Transplant & Haemodialysis	Terry Oldfield	07503 919474
	Lyndsey Hoare	07789 465917
	Phil Pugh	07850 225279
Home Dialysis	Sarah Eales	07504 117082
	Brian Child	01833 660916
Peritoneal Dialysis	Terry Oldfield	07503 919474
	Lyndsey Hoare	07789 465917
Living Donor	Margaret Jackson	07791 272640
	Nasim Akhtar	07402 790779
	Alastair MacKenzie	07768 816304
Supporting a Renal Patient	Annie Oldfield	07460 874034
	Brian Child	01833 660916

Chairman's Welcome

Hello everyone,

Welcome to the Spring Newsletter.

A lot has been going on behind the scenes for the kidney charities'. Both the National Kidney Federation (NKF) and Kidney Care UK (KCUK) have launched national Peer Support groups and members of our committee will be 'Supporters' on these groups. I am pleased to confirm that all supporters will have received professional training before commencing their role. This is a significant improvement in the resources available to patients and carers in our area.

Looking forward to the coming months, NEKPA will be manning a stand in the Atrium of James Cook University Hospital, Middlesbrough on World Kidney Day (13th March). If you are in the hospital on that day do please drop by and have a chat, we would love to see you.

On 23rd of March a young supporter of NEKPA will be running in the Liverpool half-marathon on our behalf. Details of her involvement and a link to her sponsorship site are included in this newsletter.

The Renal Unit at James Cook is holding a 'Patient Education Day' on April 4th for patients approaching dialysis. These are very popular events and NEKPA is heavily involved as usual. We tend to get a lot of anxious patients who want to know what dialysis is really like. Hopefully we can help set their minds at rest.

April 5th is the Annual General Meeting of the NKF and I will be representing NEKPA. The NKF Executive Committee is elected at the AGM and I am standing for the role of Secretary. This will be my 7th year and by the rules of the NKF I will have to stand down at the end of the year, so we will need to find a new candidate next year if we wish to continue our involvement.

A handwritten signature in black ink, appearing to read 'B. M. Child', is displayed within a light grey rectangular box.

Brian Child, Chairman

Obituary - Marlene Cliff 1943 - 2024



In late 2024, Marlene Cliff unfortunately passed away after suffering cancer but we hope the fact that she lived **41 years with a kidney transplant** and her attitude to living life to the full will give reassurance to current transplantees and 'patients in waiting'.

Her son Andrew, has been kind enough to donate her funeral collection to NEKPA and this is when we learnt of her exceptional story.

Marlene's kidney problems started following the birth of her son Andrew, and she was put on a strict diet to control her salt and potassium intake. At the beginning of 1981, her doctor told her that she would be receiving dialysis within two years but it actually started 8 months later.

Symptoms had included backache, arms and legs pain, feeling tired and out of breath with high blood pressure. Her weight, due to the restricted diet, plummeted to six and a half stone. Marlene stated at that time that she was "petrified" of dialysis but once she received it, her blood pressure reduced significantly which in turn made her quite ill. However, dialysis soon became a part of normal life for Marlene until her transplant in January 1984.

All she knew of her donor was that she was from Sunderland and she used to write a letter every couple of years to say how grateful she was to be alive and seeing her son grown up.

Andrew has also related his experience of his mum's illness. He was aware of his mum's health problems as a teenager and he had to give up his bedroom which was refurbished as a "small hospital ward" which frightened him. His fear continued in that he would take every chance to get out of the house when his mum was undergoing dialysis.

cont/.....

He also remembered how as a family they travelled abroad with a portable dialysis machine in a shiny metal case which reminded him of James Bond films. He remembers his father getting very defensive with the Spanish security who wanted to push and press all the buttons.

Andrew can also remember taking the 'magic' call from the hospital stating they had a kidney available for her - a feeling that can be recognised by all kidney patients who have received the same phone call.

Marlene knew only too well how precious 'the gift of life' was and was determined to continue living it to the full, free of the illness which struck her in her 30's. She also played badminton in the Transplant Games.

We are very sorry that life has ended for Marlene but hope you can take inspiration from her story. We would like to extend our sincere thanks to Andrew for his kind donation of £325 and his help in compiling this obituary.



Andrew and his Mum, Marlene

Events & Fundraising

Emily Atkinson is running the Liverpool Half-Marathon for NEKPA



Emily with her parents at the caravan

On the 23rd March 2025, I will be running the Liverpool Half Marathon for North East Kidney Patients' Association in honour of her "amazing, brave dad".

After my dad's kidney transplant donated by his sister fifteen years ago, NEKPA took care of our family and arranged a trip away for us to help with dad's recovery and spend quality time together.

Since, dad has fought a heart attack, bowel perforation and multiple cancers. He has gone through surgeries, radiotherapy, chemotherapy but does it all with a smile on his face and never fails to make our day.

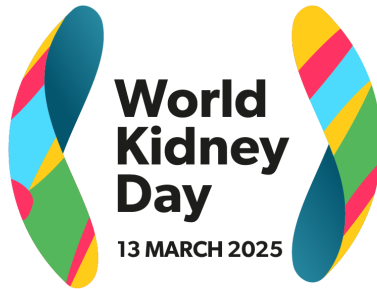
When I watched the Liverpool Half Marathon last year in March, I decided I wanted to challenge myself and run the half marathon in honour of him. As hard as it has been going from no running to weekly training, it could never be as tough as what my dad has faced. Thank you for reading and please share with your friends and family. Any donations are so greatly appreciated so that I can hopefully reach my fundraising target of £500 for an amazing association.

You can sponsor Emily by following the link below.

https://www.justgiving.com/crowdfunding/emily-atkinson-03?utm_term=MJAKPNygr

Our thanks go to Emily for choosing NEKPA as her charity and at time of going to print, she has so far raised £1,130!!

World Kidney Day - 13th March 2025



World Kidney Day is a global healthcare event celebrated on the 2nd Thursday in March every year since 2006, intending to bring together the patients suffering from kidney diseases and promote awareness of “amazing kidneys” by educating the people about their role in maintaining health

1 in 10 people worldwide suffers from some degree of chronic kidney disease, as it can develop at any age, and various risk factors can accelerate it.

World Kidney Day is a great chance to highlight that 7.2 million people in the UK have chronic kidney disease (CKD), so everyone is likely to know someone who is affected.

NEKPA will be hosting a stand in the South Atrium of the James Cook University Hospital, Marton Road, Middlesbrough from 10:00am — we would be absolutely delighted to meet you !

JCUH Renal Open Day - 4th April 2025

We are delighted to announce that this wonderful event is taking place in the David Kendrew Lecture Theatre at James Cook University Hospital on 4th April 2025.

It has been organised by Sister Claire Milner (Transplant Nurse Specialist) and there will be two sessions; 10am - 12am and 12am - 2pm with lunch provided.

Renal staff of all disciplines will be available to provide information and address any of your concerns and we (NEKPA) will be on hand to explain what we do, share our experiences and provide information leaflets.

This is always a very successful event and well worth attending. For those who do plan to attend, please can you let us know by email contact@nekpa.org.uk so we can give the organisers an idea of the number of patients who will be attending

Donations

NEKPA has been very fortunate to receive the following donations since our last Newsletter:

Funeral Collection for the late Marlene Cliff	£325
Xmas Donation—Andrew & Richard Child	£200
Darlington Dialysis Unit Xmas Raffle	£138
Anonymous Donations	£395

Please be ensured that **ALL** monies received by NEKPA are used to help patients and raising kidney awareness across the region. The charity itself is run by volunteers using their homes as the 'office' and 'meeting venue' so no overheads are incurred. Our audited accounts are published every year and if you wish to view a copy, please do not hesitate to contact me:

a.oldfield@nekpa.org.uk

Annie Oldfield
NEKPA Treasurer

New Regional Peer Support Schemes

New regional Peer Support Service to tackle fear and uncertainty of kidney treatments and care decisions



Meeting a long-held need to improve understanding and emotional wellbeing, the North East and Cumbria Renal Network (NENCRN of which NEKPA is a member) have partnered with the UK's leading kidney support charity Kidney Care UK to bring peer support to kidney patients and their families across the region.

From the beginning of May, anyone affected by late-stage kidney disease can speak to the Peer Support Champion in their renal unit or call Kidney Care UK to be put in touch with a trained volunteer who has gone through a similar situation and can offer information, comfort and hope.

Deniz Hasan, Peer Support & Volunteering Manager for Kidney Care UK says, *"It's so exciting to be able to bring this valued support to people in the North East and Cumbria. We know from great feedback what a difference it's made to people in the London area. Not just the service users, but our volunteers tell us how much they get from being able to help others."*

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The Peer Support service will be available across the region from the beginning of May for anyone affected by late-stage kidney disease, including families and potential donors. Please look out for further information - particularly about volunteering as a peer supporter – over the coming weeks.

“The chance to actually talk about things properly in ‘non-doctor speak’ was so rewarding and was extremely helpful.” - Home Dialysis Patient.

About Peer Support

Peer support has been established as an important tool in improving outcomes for patients. The opportunity to speak with someone else who’s been through what you are facing is a source of information, comfort and hope. Particularly when patients are embarking on a new treatment, to speak to someone who shares tips about what they take from home to make their dialysis more comfortable, for example, or things they do to protect their fistula, really prepares patients for meeting the challenges with a positive approach.

In a novel approach tested across the London area, Kidney Care UK has partnered with the North East and Cumbria Renal Network create a sustainable service specifically for kidney patients and their carers across the region. The Kidney Care UK peer support team liaise with designated ‘champions’ from the health care teams in renal units to promote peer support and to identify and support volunteers.

Peer support volunteers undergo a short training programme and receive ongoing support from the Kidney Care UK team. When someone in similar circumstances to their experience requests a chat, the volunteer is contacted by the Peer Support coordinator, and if they are happy to help, provided contact details. They typically speak once or twice to the patient (or carer) and keep in close contact with the Peer Support coordinator to flag any issues.

One service user sums up their experience: *“Martin was truly an excellent listener, and we got on very well. He asked me to tell him a bit about me and my situation and we went from there. I didn’t take notes as I just needed to talk and Martin empathised with me. He was able to explain in more personal detail how the home haemodialysis works and what the drawbacks and positive parts were to it. What was especially important to me was having someone non-judgemental and understanding of what worries me. The chance to actually talk about things properly in “non-Doctor Speak” was so rewarding and was extremely helpful. We will hopefully catch up again mid March which I think will be of great benefit to me on my journey and it is a great comfort to have someone as good as Martin who listened to me.”*

National Kidney Federation Peer Support Service



The poster features the NKF logo at the top left, with the text 'We're here for you!' and 'NEW National Peer Support Service' in large, bold letters. A quote from a person with kidney disease is presented in a speech bubble. A circular inset shows two people talking on the phone. A QR code is provided for scanning, with a list of topics for support. A photograph of hands being held is also included. The bottom section contains contact information for the helpline and email, along with NKF registered charity numbers.

nkf
NATIONAL KIDNEY
FEDERATION

We're here for you!
NEW National Peer Support Service

*"Being thrown into this new world with kidney disease, the **peer support service** has been there for me and my family as a helping hand."*

Would you like to talk to someone with lived-experience about...

-  Caring for somebody with kidney disease
-  CKD & Diabetes
-  Dialysis
-  Transplantation
-  Wanting to donate

Our **Peer Support Service** is a safe space where people can connect with our 'peers' to converse about lived experiences and are there to support you. This might be over the phone, online, or in person.

Whatever your query, contact the NKF Peer Support Service, call our Freephone Helpline **0800 169 09 36** from 08:30am – 5:00pm Monday to Thursday and Friday 08:30am – 12:30pm or email **helpline@kidney.org.uk**.

NKF Registered Charity Numbers: England and Wales - 1106735 Scotland - SC049431 Company Number: 527349

Our New Peer Support Service for Those Affected by Kidney Disease

Our National Peer Support Service is a safe space where people can connect with our 'peers' to converse about lived experiences. They are there to support you, whether over the phone, online, or in person.

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Our free Peer Support Service is for...

- Individuals who have kidney disease
- Family members, partners or carers of somebody with kidney disease

The UK-wide national service offers an opportunity for individuals to have a one-to-one chat with a fully trained peer supporter who may have similar life experiences and lifestyle stories. Whatever the experience or query you may have surrounding kidney disease, we can connect you with one of our peer supporters.

Examples of topics you may need support on:

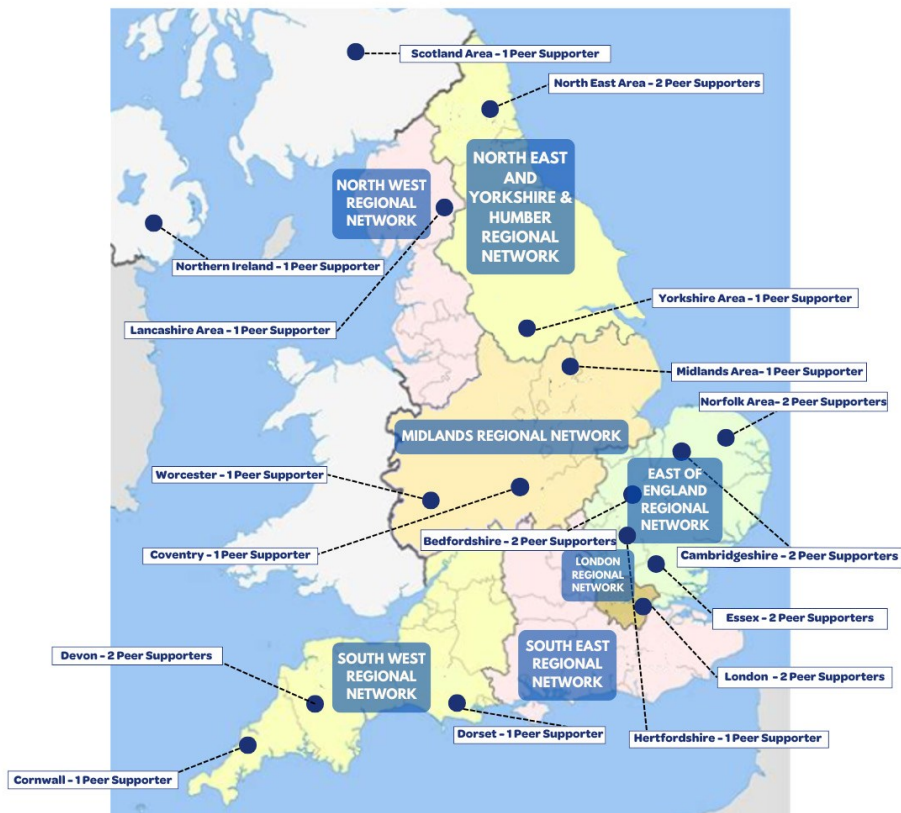
- Chronic Kidney Disease
- Caring for somebody with kidney disease
- CKD & Diabetes
- Dialysis
- Transplantation
- Wishing to donate

All of our peer supporters are fully trained and DBS checked and are between the ages of 20-80 years old.

They possess a wide range of experiences including:

- Shared care
- Peritoneal Dialysis
- Haemodialysis
- Home Haemodialysis
- Nocturnal Haemodialysis
- Balancing employment while on home dialysis
- Studying while on home dialysis
- Managing home dialysis with a young family
- Travelling while on home dialysis
- Dealing with Chronic Kidney Disease and Diabetes
- Preparing to give or receive a transplant
- Post-transplant
- Experiencing transplant rejection
- Receiving a kidney from a living donor
- Receiving a kidney from a deceased

Where Our Peer Supporters Are Located...



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:

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E: info@mesogeios.gr
W: www.mesogeios.gr



Renal Recipe



Chunky vegetable and pasta soup

Prep: 10 minutes • Cook: 45 minutes • Serves: 2



Ingredients

1 teaspoon vegetable or olive oil
1 small onion, peeled and roughly chopped
200g frozen casserole vegetables
1 dessertspoon tomato puree
1 small pepper, any colour, deseeded and roughly chopped
200g cannellini beans, rinsed and drained
1 teaspoon dried mixed herbs
1 low-salt vegetable stock cube made up with 500 ml boiling water
Black pepper
100g dried pasta – any shape

To serve

2 small crusty rolls (we used a 60g roll)

Nutritional info

Low phosphate ✓
Low potassium ✓
Low protein X
Low salt ✓
Low fat ✓
Cost per portion (October 2022) 99p
Carbohydrate 94g
Energy in kJ 486

- 1 Heat the oil in a pan and cook onions until soft. Boil frozen vegetables in a pan of boiling water for 5 minutes, drain. Add tomato puree, chopped pepper and boiled vegetables into pan with onions. Cook for 5 minutes until lightly browned.
- 2 Add in beans and cook for 2 minutes. Stir in the stock along with the herbs and black pepper. Bring to a simmer, then reduce the heat and cook on a low simmer for 20 minutes.
- 3 Add the pasta to the pan and simmer for 15 minutes, or until the pasta is cooked.
- 4 Ladle into 2 bowls and serve with the crusty rolls.

APRIL
 BLOSSOM
 BREEZE
 BUD
 BULBS
 BUNNY
 BUTTERFLY
 CHICK
 DAFFODIL
 EASTER
 EGGS
 GRASS
 GREEN
 HATCH
 JUNE
 MARCH
 MAY
 NEST
 PUDDLE
 RAINBOW
 ROBIN
 SEASON
 SHOWERS
 SUNSHINE
 THAW
 TULIP
 UMBRELLA



DIRECTIONS: Find and circle the vocabulary words in the grid. Look for them in all directions including backwards and diagonally.

F	T	L	Y	T	O	I	B	R	J	K	V	S	B	G	M	U	M	M
A	A	E	J	F	D	L	O	F	U	M	S	O	T	A	F	V	Z	H
U	L	H	P	U	D	D	L	E	P	A	E	E	Y	S	D	T	B	E
S	B	L	U	B	Q	L	F	R	R	Z	T	G	Y	T	H	A	W	U
L	X	Z	B	U	N	N	Y	G	K	Q	B	W	G	F	R	Q	X	M
W	M	S	H	O	W	E	R	S	G	B	L	O	S	S	O	M	C	B
P	W	U	M	P	N	V	A	R	Q	T	G	E	F	G	D	X	Z	R
F	T	N	K	A	K	H	V	H	E	K	P	B	R	E	T	S	A	E
G	E	S	W	O	R	O	B	I	N	C	O	F	R	J	M	P	J	L
M	Y	H	M	L	Y	C	L	L	J	I	Z	B	H	E	D	U	Z	L
N	N	I	Q	Q	I	U	H	I	T	H	R	U	T	Z	E	T	W	A
L	E	N	U	H	S	X	Z	D	U	C	Z	T	P	S	N	Z	Q	A
R	Y	E	Y	Y	N	N	M	O	L	H	N	T	Z	B	E	X	E	F
O	A	U	R	I	U	O	D	F	I	G	E	E	H	G	A	N	Q	T
W	P	I	J	G	G	K	S	F	P	P	J	R	J	I	A	S	A	M
K	R	J	N	Z	B	E	X	A	Y	B	C	F	J	H	A	T	C	H
B	I	S	U	B	U	X	M	D	E	B	F	L	Y	W	M	B	B	H
X	L	M	B	N	O	A	C	T	J	S	U	Y	H	B	H	G	Y	F
X	X	I	J	W	E	W	R	D	V	E	D	D	K	A	A	W	H	M



If you have any suggestions, would like to write an article or a story of your kidney illness journey, please send to t.oldfield@nekpa.org.uk for inclusion in our next Newsletter.