

KIDNEY NORTH EAST

October 2024

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



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President's Report

It has been another busy year for the South Tees Renal Team. The population is getting older and kidney disease is getting commoner - so we have more patients to look after. In October 2023 the total number of dialysis and transplant patients being looked after by the unit reached 1000 and is now almost 1030. This compares to 375 when I joined the team in March 1996!

To look after all these additional patients needs lots of additional staff and facilities. In 1996 we had two dialysis units , one at South Cleveland Hospital (now called James Cook University Hospital) and the other in Darlington. We now have 5 units, all of which are pretty full. In addition, our home dialysis team are doing a good job training people for home haemodialysis. This is a treatment that gives lots of flexibility to patients and allows them to take some control of their treatment. My experience has been that virtually everyone who has moved to home haemodialysis tells us how much better it is than dialysing in hospital or at one of our satellite units.

Although looking after lots of patients needs additional staff we have had some staffing problems this year. The first problem that we had to cope with was strikes. Thankfully from my point of view, none of the consultant kidney doctors went on strike. We did however have to cover for our junior doctors when they were taking action. This meant that we frequently had to cancel or rearrange clinics so that consultants could be doing ward duties and providing extra cover in the evening and overnight. Thankfully all of the hospital based strikes have ended but we now have the challenge of general practitioners taking industrial action. This could cause some difficulties over coming months.

cont/...

The second problem was that we had a shortage of consultant staff partly because of a combination of sickness, maternity leave and parental leave. In addition, Dr Abdelmahamoud has had a year away from the unit working in the Middle East and Dr Lim left us some months ago to move to a job in Scotland. At times this has left us very stretched. Some of my colleagues have been working really hard doing lots of on-call. They are tired out! We are now looking forward to the team getting back to a more normal size, with Dr Abdelmahamoud returning in late Autumn and 2 new consultants joining the team in November. One of the new consultants, Dr Tariq, has worked with us as a trainee so we know him well. The other, Dr Boshara, has just completed his training in the South West of England and is moving to this area with his wife and children. We look forward to welcoming them. We hope that these two new consultants are going to take leading roles in developing some parts of our service including trying to promote peritoneal dialysis.

Peritoneal dialysis has been an interesting challenge for us during the past year as we had delays in getting patients into theatre for insertion of Tenckhoff catheters. We were fortunate to get support from colleagues in Sunderland who have helped us with a number of patients. Thank you very much to them - it is always great when teams pull together to help each other out. We now have a few patients who are on peritoneal dialysis who had their dialysis catheters inserted by the Sunderland team and are doing very well.

In terms of personnel changes, I would like to mention and give thanks to Yvonne Taylor who was the ward manager of Ward 4 for many years. I am sure that some of you will remember her. She took partial retirement a few years ago since which time she has been working as a staff nurse on Ward 4. She is now retiring completely and will be spending more time walking in the Lake District. She has been a dedicated renal nurse for over 20 years. I wish her all the best in her retirement.

We are lucky to have many excellent renal nurses in the team who develop a great deal of expertise over the years. Sister Claire Milner is our Transplant Nurse Specialist. She has been working hard with colleagues around the region to develop pathways for assessment and management of potential kidney transplant patients.

Much of the work that she developed at James Cook has now been adopted across the region and Claire has been appointed as one of the co-leads for the Regional Transplant Group. Well done Claire!

It has not been a great summer although as I write this in mid September the sun is shining and it is warm. However we are now looking ahead to late autumn and winter with colder days and less light. It is therefore time to get our vaccines updated. I strongly recommend vaccination against flu and COVID as well as making sure that you have had a pneumococcal vaccine at some point in the last few years. Unfortunately COVID is still causing problems so for patients with kidney disease it is wise to continue with regular COVID vaccinations.

I will end by saying that this will probably be my last address to the group as President. It would be wonderful to see an increase in the number of active members of NEKPA in the future. In the meantime best wishes to everyone.

A handwritten signature in black ink, appearing to read 'David Reaich', with a long horizontal line extending from the end of the signature.

Dr David Reaich

Deputy Chief Medical Officer, JCUH

Chairman's Report

Hello everyone,

Welcome to our Autumn Newsletter. What about this weather?? Whatever happened to Global Warming? We must have upset someone very badly to deserve what we get - much more like a 'normal' British summer.....

Dialysis patients will be pleased to hear that NHS England has issued new guidelines to all Trusts that should ensure that all dialysis patients are either provided with free transport or proper reimbursement for private transport. This has been a very contentious issue for some patients who have not received any money towards mileage or parking regardless of the costs. Hopefully, all home dialysis patients are receiving full reimbursement of their costs now. Please let us know if you are not?

Now that the General Elections are out of the way, the *All Party Parliamentary Kidney Goup* (APPKG) can be reformed and that process has started. We certainly have lots of new faces that we can approach. We will keep you updated of who comprises the group. Remember, your local MP, regardless of party affiliation, can be a member providing they don't hold a ministerial position.

As usual in Autumn, the *Patient Reported Experience Measures* (PREM) Survey will take place. When you read this Newsletter, the survey will be in full swing. It is open to all patients whatever stage of kidney disease they are at and I would encourage you all to take part. The survey is completely 'on-line' this year so you can even sit at home and complete it. Please contact NEKPA if you don't have access to the internet - remember, if you don't report problems, they don't get fixed.

In this issue, we have an article by Karen Coaker (Senior Home Dialysis Nurse) outlining the work of her team.

cont/...

Due to this work, Regional Home Dialysis patient numbers have doubled since Covid when home treatment was shown to be much safer than in-centre dialysis.

It will soon be time for our *Annual General Meeting (AGM)*. As I am now 80 years of age, it was my intention to retire as Chairman. However, I have been persuaded to serve for another year but this will definitely be my last. This highlights one of the Committee problems in that we are all getting older and we desperately need an injection of new people and ideas. The AGM is the ideal time for members to consider joining the NEKPA Committee and help ensure its future.

The past year.....

It has been a quiet year for NEKPA with what seems like little contact with James Cook University Hospital Renal Department although there are signs that this is starting to improve. We are well represented on the *North East, North Cumbria Renal Operating Network (NENCRON)* where most of the decision making seems to take place. I remain on the *National Kidney Federation (NKF)* Executive for another year where activity seems to be ramping up with much greater involvement with the NHS which should be to everyone's advantage. NEKPA are also building much better relationships with Kidney Care UK regional staff.

Our success this year has been our involvement in the Patient Information Day which was a resounding success.

Before I finish, I would like to thank all our Committee Members for their continued effort they put into maintaining the running of NEKPA and to the personal support they have given me.

A handwritten signature in black ink, reading "B. M. Child". The signature is written in a cursive, flowing style.

Brian Child, Chairman

Treasurer's Report

Once again, there has been very little financial activity this year. As reported last year, our income is still depleted since Covid and we receive very little in the way of donations or legacies. This is curtailing our funded activities. NEKPA has had to take a harder look at Grant Applications this year and many have been referred to *Kidney Care UK* (KCUK) who have much greater funds and resources for checking criteria than this small charity. We are working on developing stronger links with KCUK to enable grants being sanctioned where and when they are needed.

Income for the year totalled £1,504 partly due to the surprise of £430 from Darlington Dialysis Unit who held their own 2023 Xmas raffle and donated the proceeds to NEKPA. Our thanks go to staff and patients for their kindness.

Expenditure for the year totalled £2,073 comprising printing costs and back office expenses.

The above figure includes Printing expenses which are £439 year to date. This figure is lower than previous years. We get many requests from JCUH to pay for printing of their information booklets and this year we had to refuse these requests. However, due to this need and our own, the Committee made the decision to purchase a laser printer which has the capacity to print smaller items in bulk. We have reduced considerable expense with the increased adoption of computer based technologies. As you will have noted, our Newsletter is now issued via email which has saved £1,500 per edition. Our 'Welcome' letters are printed in-house and delivered by email saving £300 per year but there are still some patients who find technology adoption hard though this is mainly the elderly. If you need help, please contact me or any other Committee Member listed on Page 3 of this Newsletter.

cont/...

This was factored into the Committee decision to purchase the printer as we still need 'hard' copies of our Newsletter to be left in Dialysis Centres across the region.

Our website is continually updated and we now welcome viewers in differing languages—our small contribution to acknowledging the diversity of members and kidney patients in general.

We had significant expense £497 in relation to income with the attendance at various national events by our Chairman. It is invaluable to our charity that we are represented and kept abreast of new activity which is then relayed to yourselves via this Newsletter and the website.

NEKPA funded the purchase of 'Fistula Wristbands' for JCUH Renal Vascular Dept at a cost of £205.

At time of writing, the audited accounts have not yet been received from the accountants but should you wish to view them later, please contact me.

As with all charities, we would really appreciate some help with fundraising—there is so much more we could do. If you feel this could be something you could do, please make contact. Your involvement can be as little or as much as you wish.

A handwritten signature in black ink, appearing to read 'Annie Oldfield', with a stylized star-like symbol above the first few letters.

Annie Oldfield
Treasurer

NEKPA Committee Nomination Form



North East Kidney Patients Association

Charity No: 503164

Registered Office: The Renal Unit, The James Cook University Hospital
Marton Road, MIDDLESBROUGH TS4 3BW

www.nekpa.org.uk

ANNUAL GENERAL MEETING 2024

Dear Member,

The Annual General Meeting of the North East Kidney Patients Association will take place via ZOOM on 29th October 2024 from 7pm

Agenda:

- | | |
|--|----------------------------------|
| 1. Welcome by President/Chairman | 6. Election of Officers |
| 2. Apologies | 7. Election of Committee Members |
| 3. Minutes from AGM held on 10.10.2023 | 8. Any Other Business |
| 4. President's Report | 9. Date and Time of Next Meeting |
| 5. Chairman's Report | |

Please complete the reply slip below confirming your attendance and nomination/s for Officers and Committee Members and return to

Terry Oldfield (Secretary), 19, Roundhill Road, Hurworth on Tees, DL2 2ED

or complete the form on our website www.nekpa.org.uk and it will be sent via email. Those who indicate that they wish to attend will be sent full details of how to access the meeting via ZOOM.

Yours sincerely

Chairman

I will/will not join (please indicate) the virtual AGM meeting online via ZOOM on 22nd October 2020

Name		
Address:		
Email:		
I wish to nominate:	Name of Candidate	Nominated Position
	Proposer	Seconder
	Date	Date

Please ensure that the person nominated has agreed to their nomination.

NEKPA is affiliated to the National Kidney Federation
(NKF) President: Dr David Reaich

2023 AGM Minutes

Should you wish to read last year's AGM Minutes,
please follow the link below

<https://www.nekpa.org.uk/2023-AGM-Minutes/>

NEKPA Committee News

Activity by Nasim Akhtar

Promoting Organ Donation in the BAME Community – Sunday, 2 June

Dr. Ahmed, Nephrologist, South Tyneside and Sunderland NHS Foundation Trust and I visited the Gurdwara in Sunderland to raise awareness and promote organ donation within the *Black, Asian and Minority Ethnic* (BAME) community. Our goal is to increase organ donation rates in these communities, as patients from BAME backgrounds often face longer wait times for transplants.

Approximately 70 people attended the event, where Dr. Saeed delivered an insightful talk on the current state of organ donation in the UK. I followed by sharing my personal experience as a kidney donor to my son, which resonated deeply with many in the audience. We were warmly invited to join the community for lunch, and several individuals approached us with questions about the organ donation process, showing genuine interest in learning more

Kidney Bridges Walk, Newcastle – Sunday, 16 June 2024

My son, Azam, and I proudly took part in the 6.4-mile Kidney Bridges Walk across the famous Newcastle bridges, passing some of the city's most iconic landmarks to raise funds for Kidney Research.

We decided to join this walk as a celebration of our health, following my kidney donation to Azam in January 2022. Before his diagnosis, weekend walks, rain or shine, were a regular part of our lives, so being able to walk together on this sunny day felt very special. The event was lively and uplifting, with music setting the tone at both the start and finish lines. What made the day even more meaningful was realising we are part of a larger community of families navigating kidney-related challenges. It was a powerful reminder that we're not alone. A heartfelt thank you to all our friends and family who generously donated to support this cause..

Home Dialysis Overview—Karen Coaker

Editor's Note: Karen Coaker is the Home Dialysis Specialist Nurse & Team Leader at James Cook University Hospital, Middlesbrough

I would like to update you all on what has been happening in our Home Dialysis Team over the last year and I am pleased to inform you that we have had a very busy year.

First piece of good news, four of our home patients have had a transplant and are doing extremely well

Our training room has been a great success as it gives patients the opportunity to dialyse independently for a couple of weeks before going home but knowing that we are close at hand if any problems occur this has given patients a safe transition from hospital to home.

We have twenty-one patients on home dialysis and six training so we are keeping very busy with training and supporting our current patients with regular home visits.

As a multidisciplinary team we meet once a month to discuss all our home patients blood results and wellbeing this gives us an opportunity to all update on each patient

A typical day for the home dialysis team starts with a quick handover at 7am, patients who are training or shared/self-care will come into the unit early to set up their machine. Monday Wednesday and Friday are our busiest training days. We have six patients training at present who will hopefully transfer home in the next couple of months.

If anyone is interested in home dialysis please see our guide that we use to help you decide if it would be the treatment of choice for you and your partner/ caregiver

HOME HAEMODIALYSIS

A GUIDE FOR PATIENTS AND FAMILIES

Home haemodialysis is a safe and effective way to treat your kidney disease.

Home dialysis has many benefits:

- You can decide when and how to dialyze.
- You can be more independent and in control of your life.
- You will feel better and have better blood results.
- Puts you in control of your treatment.

You will learn about home haemodialysis from your dialysis team:

- We will help you learn how dialysis works.
- How to use the dialysis machine
- How to respond to alarms and problem solve
- How to stay safe at home

The training takes 8 weeks or more. During your training, we will give you lots of information and support. When you are ready to begin treatment at home, we will continue to support you. We will work closely together through home visits.

Karen Coaker

BEING ACCEPTED ONTO THE HOME HAEMODIALYSIS PROGRAMME

Before you start training, you and the Home Dialysis Team must decide if the Home Haemodialysis Programme is right for you.

Here are the questions we will consider:

Are you able to do this?

- You will be considered for training, even if you have physical, visual, or hearing problems.
- You may choose a partner (caregiver) to train with you.
- The home dialysis team can stop your training if we feel that your disability makes it unsafe for you to have home dialysis.

Is your home suitable for home dialysis?

- You will need a dedicated clean area to have your dialysis in, an electrical outlet, an easily accessed water source and a plumbing system for draining away wastewater. You will also need space to store the supplies which include the dialysis fluid, needles, and cleaning products. These need to be kept in a dry area away from damp or direct heat.
- The renal technician and nurse specialist will check your home to make sure it is suitable to install the dialysis equipment and supplies.
- The owner or landlord of your home must agree to have a dialysis system installed in your home.

Once your training is underway, we will arrange for a company called CES who specialise in home HD room conversions to come and install all the required equipment.

Financial support towards the cost of electricity and water that is needed for home dialysis. You may also be able to apply for a reduction in council tax and you and your partner may be eligible for attendance allowance.

HOME HAEMODIALYSIS PROGRAM EXPECTATIONS

The average training period is 8 weeks or more. Your training may be shorter or longer, depending on your needs.

Training sessions are Monday, Wednesday, and Fridays, from 7.30am to 11.30am or 1.30pm until 5.30pm

Your responsibilities during training

- ⇒ You must attend each training session. If a caregiver is required, he or she must also attend each training session.
- ⇒ During training, nurses will check your skills, we must be sure that you can do all the tasks of haemodialysis correctly.
- ⇒ You may need further training if you or your caregiver are not following instructions or doing tasks correctly, or there are concerns about infection or safety.
- ⇒ Training can be stopped at any time if program expectations are not being met, or you choose to stop training.
- ⇒ When you are ready to go home, you will spend at least a week dialyzing on your own, in a room separate from the main unit.
- ⇒ When you finish training one of the home dialysis nurses will stay with you for your first few sessions or until you feel confident to be left this can be arranged with yourself and your nurse.

Kidney Care UK—NE Regional Team

Last month, we introduced Adele Brown who is now representing Tyneside and Sunderland. We would now like to introduce Natalie Duffy

Hi, I'm Natalie Duffy from Kidney Care UK. I am the Patient Support and Advocacy Officer covering the Tees Valley.



I can help people living with chronic kidney disease, and their family members, by providing reliable information and support across various topics relating to chronic kidney disease including treatment, employment, benefits, housing and emotional support and can help them to access services and benefits that they may be entitled to. I can meet patients and their families by a telephone appointment and assess their needs

I can signpost patients and close family members to Kidney Care UK's Counselling Service so they can speak to our specially

trained Renal Counsellors. Kidney Care UK can provide grants for things like household appliances and holidays and I can help patients to apply for one of Kidney Care UK's Grants. At Kidney Care UK we have our own Money and Energy Advice Team and through identifying the individual's needs I can make a referral to this specialist team.

To contact Kidney Care UK you can;

Call us on **0808 801 00 00** (Monday to Friday, 9am to 5pm)

Email us at support@kidneycareuk.org

Events

Kidney Care UK events

October Dog Walking Challenge

1 OCT - 31 OCT 2024

09:00 - 18:00



Share



Our October Dog Walking Challenge is back! 🐾

Walk 32.5 miles across the month of October for the 3.25 million people in the UK living with stages 3-5 chronic kidney disease (CKD). It's the ulti-mutt way to show your support and raise awareness for those affected by kidney disease!



Sign up today!



Why take part? The Choctober Challenge offers a unique way to step into a family member or friend's shoes affected by kidney disease, even if it is just for a short time. All of our supporter's efforts will not only highlight the importance of kidney health but also contribute to our vital patient support services and campaign work for kidney patients.

www.kidneyorg.uk

Patient Information Leaflets

There are a whole range of leaflets relating to CKD available from the National Kidney Federation (NKF). Some of the recent additions are

***Employers Guide to CKD,
Renal Patients and Alcohol
What are Statins?***

The full list of what is available is on the NKF website but also NEKPA supplies them to the Renal and Dialysis Units where you will find a good selection.

Should you have a problem with obtaining what you need we will be able to help so get in touch at contact@nekpa.org.uk

NKF Helpline and Helpline Information and leaflets



NKF Helpline

We run the only free to call UK Helpline dedicated to kidney patients with two fully trained, experienced advisers providing a 5 day per week service to kidney patients, carers and healthcare professionals and renal units.

The NKF Helpline 0800 169 09 36 is open from:

Monday – Thursday 08:30 am – 5:00 pm

Friday 08:30 am – 12:30 pm

The NKF Helpline is also the UK's largest provider of kidney-related medical information leaflets with a library of over 200 titles written by nephrologists in simple language for patients and carers.

The NKF Helpline can provide information about [chronic kidney disease \(CKD\)](#), [dialysis](#), [transplantation](#), [living donation](#) as well as [benefits information](#), [dietary advice](#) and [holiday information](#).

2024 PREM Survey

Kidney Patient Reported Experience Measure (PREM)

Every year the Kidney PREM collects the views of kidney patients across the UK to build a national picture of renal care experiences. Find out more about PREM, how the results are reported and how to take part in this year's survey.

This year's kidney Patient Reported Experience Measure (PREM) is open from Monday 16 September until Monday 11 November 2024.

How can the PREM survey benefit me?

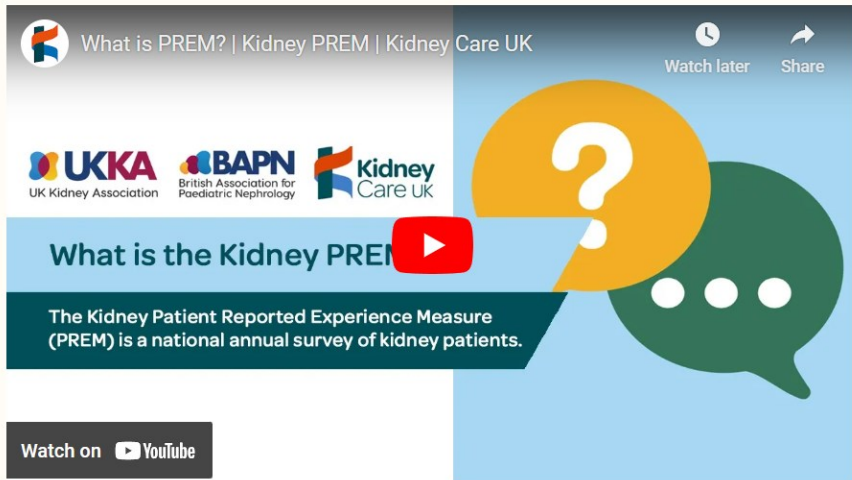
The survey can benefit you by helping you to anonymously share your praises and concerns about the main areas of your care with your unit. This helps your kidney team to understand how you and the other kidney patients they care for feel about your experience of care.

By taking part, you help your unit, other health care professionals, and kidney charities to get a national picture of people's experience. We can use this to identify where changes need to be made, and units can see how they are performing against other units, to make sure they aren't falling behind.

Am I eligible to take part?

Am I eligible to take part?

If you are over the age of 16 and living with chronic kidney disease (CKD) you can take part. This includes those attending a UK hospital renal unit or satellite unit but not yet on renal replacement therapy and anyone who has received a kidney transplant. The survey is available in English, Welsh, Urdu and Gujarati.



Click anywhere on the above image to watch the video on YouTube

Great News for Haemo Dialysis Patients

Some of you will have experienced the effects of inaccurate needling such as excessive pain and bleeding, blown fistula etc.

To help prevent these problems, the Renal Network have purchased four VSCAN Air Hand Held Ultrasound devices for the North East and Cumbria with one of them now in use at the James Cook University Hospital.

Point of Care Ultrasound (POCUS) training was led by Dr James Andrews and Dr James Rudman of Sunderland Royal Hospital who are seen handing over the device to Sandi Mathews, Vascular Nurse.



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/>



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

Renal Recipe



Sausage meatball pasta bake

Prep: 10 minutes • Cook: 40 minutes • Serves: 4



Ingredients

300g pasta shapes of your choice
400g sausages
1 leek, chopped
1 pepper, chopped
1 small courgette, chopped
1 tin (400g) of chopped tomatoes
1 garlic clove, crushed
20g mozzarella, grated
1 teaspoon dried Italian herbs
1 teaspoon olive oil

Nutritional info

Low phosphate ✓
Low potassium ✓
Carbohydrate 78g
Low protein X
Low salt ✓
Cost per portion (October 2023) £1.24
Energy in kcal 639

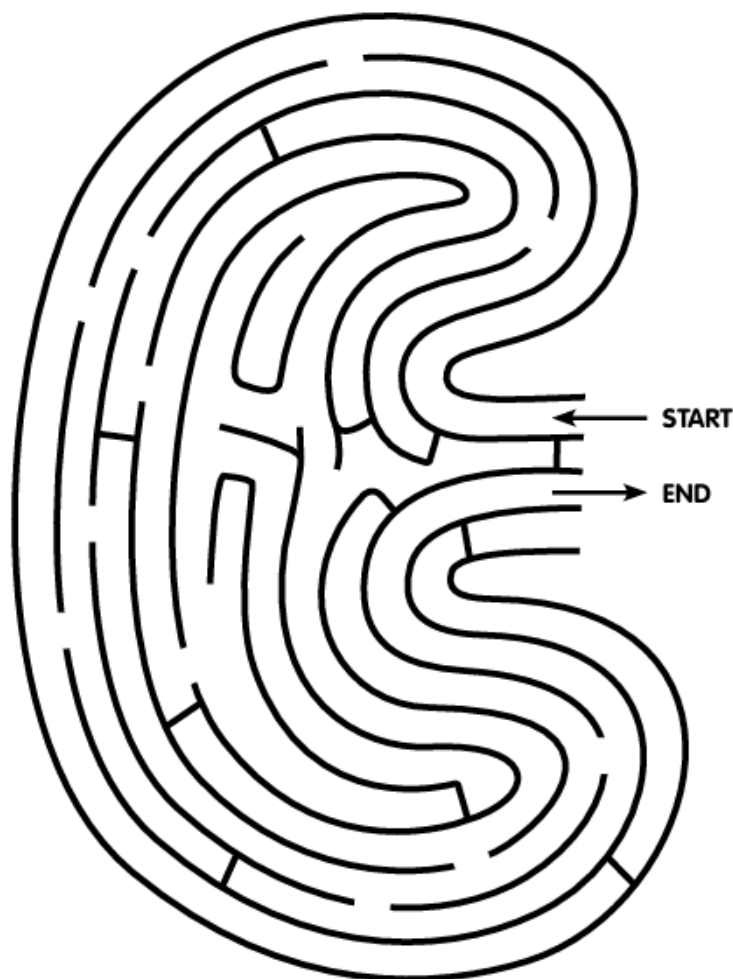
- 1 Cook your pasta as instructed, drain and set to one side. Take your sausages, remove the skin and discard. Break each sausage into four and roll into balls.
- 2 Preheat the oven to 180°C / 160°C fan / gas mark 4. Heat the olive oil in a large frying pan and sauté the leeks, pepper and courgette for 2 minutes and then add the sausage balls and cook for 5 more minutes.
- 3 Add the tin of chopped tomatoes to the pan, then fill the empty tomato tin with hot water and add in with the garlic and cook for a further 5 minutes.
- 4 Tip the cooked pasta into the pan with sausage and vegetables, then mix thoroughly.
- 5 Pour the mix into an oven-proof dish.
- 6 Sprinkle with mozzarella and Italian herbs and cook in the oven for 20 minutes. Remove when bubbling and golden and serve in 4 bowls.

www.kidneykitchen.org

Click the image to open the web page for a larger view

THE A-MAZE-ING KIDNEY!

Go in the start of the kidney-shaped maze and see if you can find your way to the end!





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.