

# KIDNEY LIFE

The magazine of the National Kidney Federation



## ► THE TRANSPLANT PHONE CALL...

.....  
The kidney transplant journey.  
Part one of our three part series.



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## Welcome to the winter edition of Kidney Life

Hello,

**As we drift towards the season of glowing fires and cosy jumpers, it seems only fitting to turn to page 14 of this winter edition of Kidney Life and try out a delicious recipe from the Taste cookbook... all the wonderful recipes are written with kidney patients in mind.**

In this winter edition, we share with you the first in a three-part series of articles by consultant transplant and vascular surgeon Jeremy Crane, who discusses the transplant phone call and what to expect.

We share two heart-warming kidney patient stories. Robert (Bob) Price, reveals details of his forty years with home haemo-dialysis (page 06), and Andrew Lines describes his transplant journey full of hope, happiness and... Hamleys (page 16).

We recently enjoyed the NKF patients event 2021 and you can find out more about the event on page 04. And don't miss our gold star on the back page of the magazine, where you can remember a loved one and share your special message with us.

And if 2022 is the year you would like to tell your story, please get in touch, we would love to hear from you.

And finally, I wish you all a very happy and relaxing time over the festive period.

**Seasons greeting to you all!**

**Nichola Rumboll**  
Editor

# Seasons Greetings

from NKF Chief Executive, Andrea Brown

**As we draw to the end of another year and reflect on the last year and a half, it has certainly been challenging for us all.**

The NKF has helped and supported many thousands of patients during the pandemic and will continue to do so. Patient support is the heart of this charity, so if you need us, please get in touch.

We have made great strides with our new five-year strategy that we implemented at the beginning of this year, making us a stronger charity to improve the lives of patients.

We launched a national campaign to increase home dialysis and have set up the first national peer support service for this, which is going very well. We will provide an updated report on the campaign at the beginning of 2022.

We will be producing an impact report, so you can see in more detail, what we have done during 2021. We will circulate a copy of this to you all next year.

I would like to thank our staff, executive committee, volunteers, peer supporters and patients for all that you do to support the NKF. Without doing what you do, the NKF could not exist.

I hope you all have a lovely Christmas and a healthy and happy 2022.



**Best wishes**

Andrea



**HELPLINE 0800 169 09 36**

All **CALLS** to the **NKF Helpline** are **FREE** of charge

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**0800 169 09 36**



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-  @KidneyNKF
-  @NKF\_UK
-  @nkf.uk



**GET IN TOUCH**  
If you'd like to share your story, we want to hear from you.  
Please email the editor at:  
[kidneylife@kidney.org.uk](mailto:kidneylife@kidney.org.uk)



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### NKF OFFICERS

- Chairman Jim Higgins, Northants KPA
- Vice Chairman Brian Child – North East KPA
- Treasurer Michael Sinfield – Six Counties KPA
- Secretary George Palmer – Exeter & District KPA
- President Kirit Modi
- Patrons Lawrence Keogh and Nina Wadia

NKF officers and executive members do usually belong to a KPA, but offer their services to NKF as individuals. As such, NKF recognises that views expressed by its officers and executive members are expressed as individuals and do not necessarily represent the views of their KPA.



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Our Helpline is free of charge to call on 0800 169 09 36. The NKF runs the only UK Helpline dedicated to kidney patients, with over 200 unique and regularly updated information leaflets and two fully trained, experienced advisers providing a 5 day a week service to kidney patients, carers and healthcare professionals.

The NKF Helpline is open from 9am until 5pm Monday to Friday on 0800 169 09 36 e: [helpline@kidney.org.uk](mailto:helpline@kidney.org.uk)



If you want to raise funds for the NKF, plan an event, make a donation to the NKF or discuss leaving a legacy to the NKF please contact Pete Revell (NKF Head of Marketing and Fundraising).

T: 01263 722287  
E: [pete@kidney.org.uk](mailto:pete@kidney.org.uk)

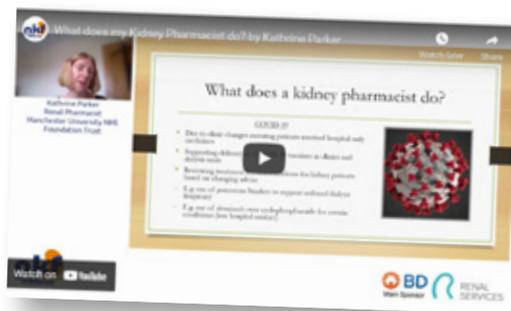


# Virtual Patients' Event 2021

On Saturday 09 October, this year's Annual Patients' Event took place and was an entirely virtual event. Kidney patients from across the UK joined, from the comfort of their home, to hear the speakers talk about a range of themes and discuss some of the challenges faced by kidney patients.



◀ Jim Higgins



**Jim Higgins**, NKF chair opened the event and gave a warm welcome to the speakers and everyone listening at home. He was followed by **Andrea Brown**, NKF chief executive, who reflected on the work of the charity over the past year and how NKF has supported kidney patients throughout the pandemic. Andrea shared a look at the NKF strategy 2021 – 2026 and talked about the charity's mission to improve the quality of life of kidney patients and their families across the UK.



Andrea Brown ▶



## Participants



▲ Lisa Burnapp



▲ Professor Jeremy Hughes



▲ Kathrine Parker



▲ James Gilbert



▲ Stephen Higgins



▲ Nicola Ward



▲ Andrew Cole

**Lisa Burnapp**, Associate Director for Living Donation and Transplantation at NHS Blood and Transport gave an informative talk about the UK living kidney sharing scheme, one of the largest kidney exchange programmes of its kind.

Next, **Professor Jeremy Hughes**, Chair of Trustees from Kidney Research UK, gave an update on the latest Covid-19 research and what this means for kidney patients, also the transforming treatments campaign and the aim to raise £3M for research.

**Kathrine Parker**, Renal Pharmacist at Manchester University NHS Foundation Trust spoke next to discuss the role of a kidney pharmacist and how they can help and support kidney patients. Katherine talked about a 3-year research project she started in 2020 that plans to inform a national guideline to help support kidney patients.

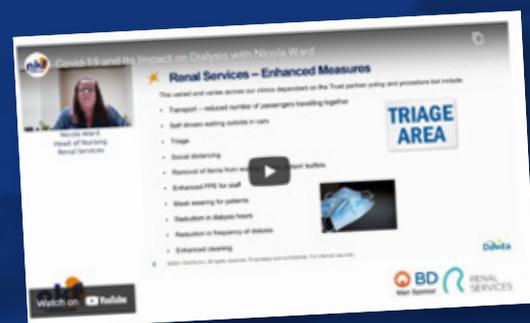
**James Gilbert** a consultant transplant and vascular access surgeon at Oxford University Hospitals spoke next to share a wealth of information (and images!) about endovascular fistula for haemodialysis.

**Stephen Higgins**, a dialysis patient, reflected on his kidney journey and how he was diagnosed with stage 4 kidney failure in 2016 and how he is currently on the transplant waiting list.

Ex-professional footballer and England player **Andrew Cole** chatted to Nina Nannar, ITV Arts Editor, to reflect on his experience of kidney disease. He looked back on the time he was diagnosed with kidney disease and talked about how he dealt with the impact of the diagnosis on his health and mental wellbeing. He also talked about having a kidney transplant and how important it is to look after your kidneys.

**Nicola Ward**, head of nursing for renal services spoke about Covid-19 and the impact on dialysis. She considered the choice of home therapy versus in-centre dialysis and the psychosocial impact of Covid-19 on kidney patients.

**The event was closed by Jim Higgins, who thanked everyone for joining this year's event.**



📺 We have uploaded a recording of the event, if you would like to watch a particular speakers presentation, or the whole event, please visit: [www.kidney.org.uk/Event/nkf-patients-event-2021](http://www.kidney.org.uk/Event/nkf-patients-event-2021)

Thank you to the event sponsors:



MAIN SPONSOR



# Forty years with home haemo-dialysis

By Bob Price

**Wednesday 13 May 1981, the date of my first dialysis. I'm surprised looking back that I returned for my second – it took three nurses and eight attempts to insert the needles. I came off after three hours, four kilos lighter, feeling woozy and my arm black and blue.**

Six months later, I began home dialysis, having managed to regularly insert the needles into a fistula in the wrist. Back then, dialysis sessions took five and a half hours, which I have continued to do at home.

In 1981, home dialysis was the norm and the Oxford unit covered 2.2 million people. It was understood that having haemodialysis at home enabled patients to live a more normal existence. The ethos of the whole kidney unit was geared for home treatment.

## Good fortune

Over the years, I have been incredibly fortunate. My first stroke of luck was an invitation to the dialysis nurses' Christmas party and to be seated next to Christine. We got to know each other and danced as well as two people that are 6'2" and 5'2" can. We have now been married for thirty-seven years. Our love has been tested along the way, most recently when Chris developed a chronic health condition and Covid-19 seriously affected our lives.

A year after commencing dialysis, I received a kidney transplant. After the operation my fistula clotted and I returned to surgery for a Scribner shunt while my kidney picked up. My kidney slept for five weeks and I was kept in isolation, leaving only for dialysis (patients in those days were strictly isolated until their kidney worked). Following a biopsy, my rejected kidney was removed causing my blood to be highly sensitised. This and a rare blood group made it my first and last graft.

Hollow fibre dialysers were introduced into Oxford a year later which could only be attached to the new small Cobe machine. For those of us using a flatbed (Kiil) dialyser and a Lucas machine, it was like parking my old Ford Prefect next to a gleaming E-Type. I had to have one!

My only option was to buy a new Cobe machine for £5k, so I declared my charity open. One of the first organisations I approached 'The Chesham Lions' happened to be looking for a project to fund. They organised the 1982 Christmas Santa float, driving and collecting from the streets of Chesham. The money raised, purchased two Cobe machines (one for another home patient) and a colour TV and Norton recliner for my cabin.

The Post Office, my employer at the time, generously gave me two days off during the week to learn how to dialyse at home. And in 1984, when Chris and I married, they allowed me to transfer to the Oxford Post Office and we set up home in Abingdon.

Chris and I moved three times in the first five years of marriage. Two moves involved a crane lifting our portacabin over our homes due to a lack of access. I have lost count of the number of times our technicians have dug us out of a hole over the years!

I can't stress how greatly Chris has contributed to my longevity. My temporary Scribner shunt lasted ten years. When a brachial fistula was created, my nerve in needling had vanished so to speed things up and to avoid errors, Chris took over needling.

In the early 1990's many patients, including myself, were managing life with haemoglobin of seven or under. I began regular blood transfusions when the miracle drug Erythropoietin (EPO) was introduced - it was a game-changer in the health of kidney patients.

## Six Counties KPA

We first visited a Kidney Patients Association (KPA) in 1984. During that meeting, at the Six Counties KPA (reflecting the number of counties the Oxford Dialysis Unit covered), I unexpectedly became Chair to avoid the group closing down. My first task was to introduce Dot Juggins, a former Oxford dialysis nurse, eager to open a holiday dialysis unit in St Ives, Cornwall. She asked the SCKPA to fund three machines costing £15k, giving Oxford patients priority booking. It was voted through and was a great success, dialysing patients from all over the country. Since then, it has been a great privilege to serve patients on the committee in one post or another.

And now.... I have a host of niggly medical ailments, or as Chris says 'war wounds', and holiday insurance takes far too long to obtain and costs an arm and a leg. We still enjoy holidays in Europe having visited and dialysed in over 14 countries, many of them more than once. With regret, children never came along, but we have both enjoyed teaching children at Sunday School in our local Church where our faith in God is strong.

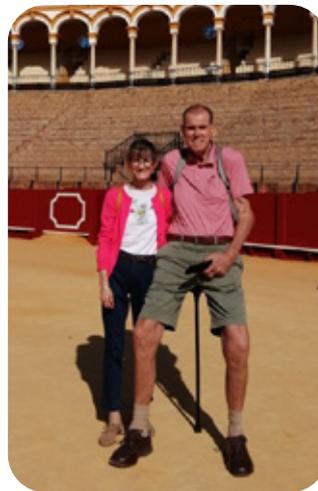
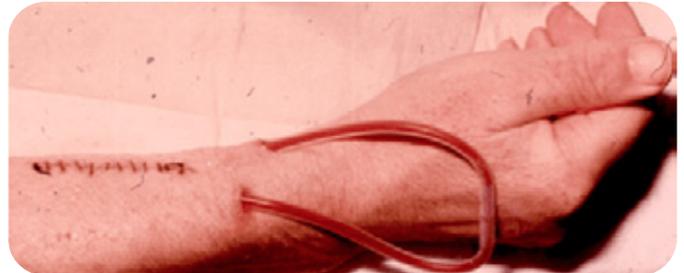
Although I have been fortunate, luck has a great deal to play... I am still on my first limb (left arm) for needling, I rarely feel unwell, and I have a first-class group of professional, accessible and skilled friends who care for me at the Oxford kidney unit.

“

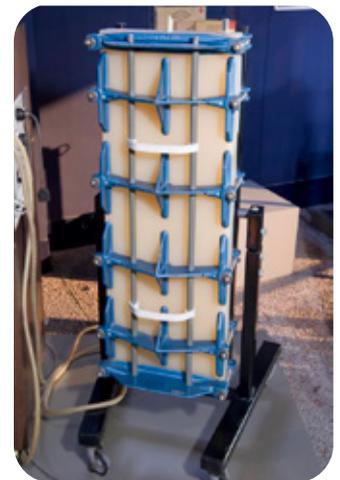
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”

Bob's Scribner shunt ▼



◀ Bob & Chris on one of their many holidays since dialysis started, this time at a Seville Bull-Ring



Kiil dialyser ▶



▲ Bob & Chris in Innsbruck



## PART ONE of a kidney transplant journey

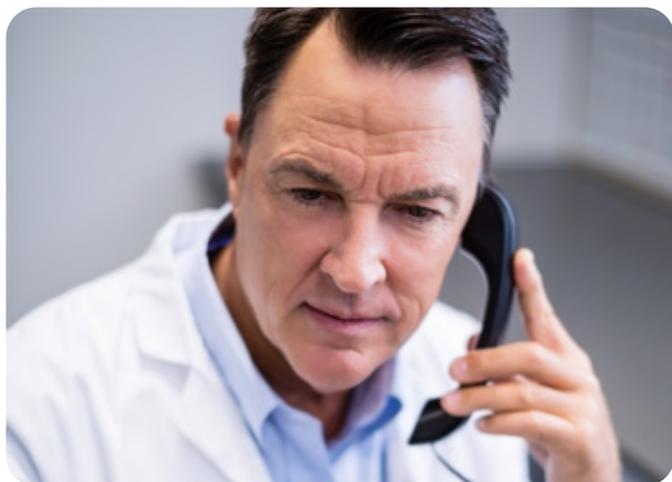
# THE TRANSPLANT PHONE CALL: WHAT TO EXPECT

By Jeremy Crane

**Deciding to go on the kidney transplant list is a life-changing step. The next challenge? No one can say when the call will come. Here's what to expect when it does.**

**It is not easy being on the waiting list for a kidney transplant. However, in some ways, it is a positive step. Being on the list means your local transplant surgeon and physician feel you would benefit from having a transplant. So, when my patients tell me they are 'putting their life on hold' whilst they wait for the call, I don't feel it is the best way forward, particularly from a mental health perspective.**

It is very difficult to say when you are going to get that all-important call to tell you a transplant is available. The statistics from NHS Blood and Transplant (NHSBT) reveal the average wait times are 2 to 3 years. The time spent waiting is valuable years of life. Some people get the call in a much shorter time, some wait many years. There are lots of reasons why waiting times differ so much. In general, those that don't wait as long often have a common blood group (e.g. AB) and tissue-type, and fewer antibodies in their blood. Children and young people under the age of 18 tend to wait less than adults. Those waiting from a Black, Asian and minority ethnic background tend to wait longer. Also, there is waiting time variation between UK transplant units.



## Keep your phone turned on!

Once you are on the list, the most important point to make is that your phone should always be on. The call can come at any time, so it is vital you are contactable day and night. Make sure your local unit has your mobile and home phone number, also a number for your next of kin.

When the call comes, it can be at any time - night or day. It generally means that you are considered to be the best match on the waiting list for that particular kidney at that time. The call is made by a member of the transplant on-call team. You will be asked if there are any new major medical issues that your local centre might not know about. If there isn't, you will be asked to come to the transplant unit as soon as you're able. In some circumstances, the urgency is a little less with quite some time (12 to 24 hours) before the transplant takes place. But sometimes time really is of the essence and the transplant might take place within a few hours.

Occasionally the phone call might be a conversation about your willingness to accept a certain transplant, for example, if the kidney is deemed not to be ideal. This will be a conversation with the transplant professional who will give you all the information you need. Certain characteristics about the donor can be shared with you, including the age range (decade), male or female, type of death and whether the donor had any illnesses or diseases that might affect the long-term outcome of the transplant.

▶ **Jeremy Crane MD FRCS (vasc)**

*Consultant transplant and vascular surgeon  
at the Hammersmith Hospital West London*



Once the kidney arrives in the transplant unit, the transplant surgeon will 'bench' the kidney. This benchwork involves reconstructing the blood supply of the kidney, removing all the fat and other tissue from it, and making sure there is no damage and it is in good shape to be transplanted. If there are significant issues with the kidney at benching, the surgeon will discuss these with you. At this point, your surgeon will go through a consent process to make sure that you are willing to move forward with the operation and you understand the risks and complications involved. We hope that this wouldn't be the first time you've heard about these, and they would have been discussed with you in your clinic appointments. Once all the above has happened, and a theatre slot is available (sometimes this might not be the case and there can be a delay whilst other more urgent operations finish), you will be wheeled down to theatre.

## Don't panic

After the phone call, stay focused on arriving at the hospital safely. In your overnight bag, pack some essentials, and include a phone charger, nightclothes, underwear, slippers, toiletries and other necessities. Bring all your current medication and don't eat or drink anything.

Once you arrive there will be lots of blood tests, x-rays and often, a fair bit of waiting around. One important blood test is a 'cross match' between yours and the donor's blood - if there is no cross-reactivity, it is deemed negative. We typically expect it to be negative, but occasionally if there are immunological issues, it might be positive (although this does not happen often). The anaesthetist will also see you. It is not uncommon for the transplant to not work out. The most common reason is due to the donor being from a 'donation after circulatory death', where the retrieval of the organs does not always take place. The transplant surgeon will keep you in the loop.



*In your overnight bag, pack some essentials, and include a phone charger, nightclothes, underwear, slippers, toiletries and other necessities.*



## Next time:

The operation and what to expect afterwards is another important piece to share with you. We will cover this in the next edition of Kidney Life.

**Keep in touch**

@JeremyCraneMD

[www.transplantandvascular.com](http://www.transplantandvascular.com)





# CHRISTMAS DRAW



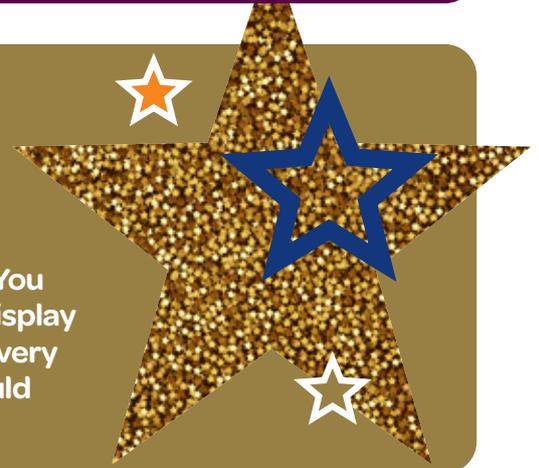
**You could win £1,500 with our annual Christmas draw!**

The draw will take place on Wednesday 8th December and all tickets must be returned to us by Friday 3rd December. Thank you to everyone that has taken part and good luck... one lucky person will be £1,500 better off this Christmas!

## GOLD STAR

Remember a loved one and share your special message on an NKF Christmas star.

On the back cover of this magazine, you will find the gold star. You can write a message or decorate the star and send it to us to display on the NKF Christmas tree at our head office. We will display every star we receive, but if you would like to add a donation, we would appreciate it very much.



## CHRISTMAS CARDS

Do you still need to buy your Christmas cards?

The NKF have a fantastic range of cards, gift wrap, money wallets and not forgetting the 2022 NKF calendar! Check out the full range here:

[www.kidney.org.uk/shop](http://www.kidney.org.uk/shop)

FROM  
**99p**

## FUNDRAISING

**Could you take on a challenge in 2022?**

As restrictions ease and people feel more confident going out, the NKF would love you to take part in one of our exciting fundraising events.

Fancy a parachute jump, walk, run or you can organise your own bespoke fundraiser. For information and help please visit:

[www.kidney.org.uk](http://www.kidney.org.uk) or email [pete@kidney.org.uk](mailto:pete@kidney.org.uk)

# A GIANT THANK YOU!

**You have helped to support us when we needed it the most!**

As we come to the end of the year, we would like to thank everyone that has donated or fundraised to support the NKF. It has been a difficult few years, but our wonderful NKF supporters have pulled out all the stops...

## THANK YOU!



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Established  
1995

## KC Holiday Dialysis Centre (Bournemouth)



*This friendly, family run unit is situated about 100 yards from the beautiful sandy beaches of Bournemouth with the town centre approximately 2 miles away*

The unit's facilities offer the following:

- Open all year round.
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- Direct online booking so patients can check availability and book at a pace that suits them.
- Choose between morning and afternoon sessions.
- Help provided with your booking every step of the way.
- Can recommend accommodation depending on your needs.
- Providing a caring, professional and friendly service for over 25 years. Making your stay with us as comfortable as possible.
- Refreshments while on treatment.

### Not sure where to stay?

Let us take the stress out of searching, please ask us for a list of local accommodation suggestions. We can help you find the right place for you.

### Did you know?

Bookings can be placed up to 12 months in advance to help secure your preferred dates and times.

**For further information telephone**

**01202 422311**

[www.kcdialysis.com](http://www.kcdialysis.com)

[admin@kcdialysis.com](mailto:admin@kcdialysis.com)

35 Southwood Avenue, Southbourne, Bournemouth, Dorset BH6 3QB

# NKF HOME DIALYSIS PEER SUPPORT SERVICE



**WOULD YOU LIKE SOMEONE TO  
TALK TO AND EXPLORE THE OPTION  
OF DIALYSIS AT HOME?**

**Speak to one of our trained  
home dialysis peer supporters  
based across the UK.**

**Giving short-term practical, emotional and social support  
to people with kidney disease, their families or carers.**

**For more details contact the  
National Kidney Federation FREE Helpline  
0800 169 09 36**

**[www.kidney.org.uk](http://www.kidney.org.uk)**

# Meet the team



▲ Linda with helpline colleague Steve

**We are delighted to introduce Linda Pickering, our new Helpline Advisor. Linda joined the NKF Helpline team in October 2021 and has a long history of working with and supporting the NKF. Here's more about Linda...**

Linda's husband was a renal patient diagnosed in 1996.

Linda got involved with the Friends of Lincolnshire Kidney Patients (LKPA) and

in 2003 along with the late Stuart Denby they gained charity status and became members of the National Kidney Federation (NKF). Linda served as chair and then secretary of the LKPA, and went on to serve on the executive committee of the NKF. She was involved with Leicester General Hospital in one of the first Department of Health Learning Sets and took a keen interest in the Optimal Renal Care pilot study with the Lincolnshire Primary Care Trust (PCT).

A family move to Yorkshire saw her resign from the LKPA and made it difficult to attend executive meetings and so she reluctantly resigned from the NKF executive committee. Linda joined the Humberside Kidney Patient Association (KPA) run by the late Rosemary Barlow. In 2011, Linda spotted an article in the winter edition of Kidney Life magazine - the advocacy service was expanding and needed someone to cover the North East, Yorkshire and the Humber. Linda applied and successfully secured the role.

She joined the NKF advocacy service in March 2012 and went on to support patients in the North East, Yorkshire and the Humber regions as well as attending area network and NHS England meetings.

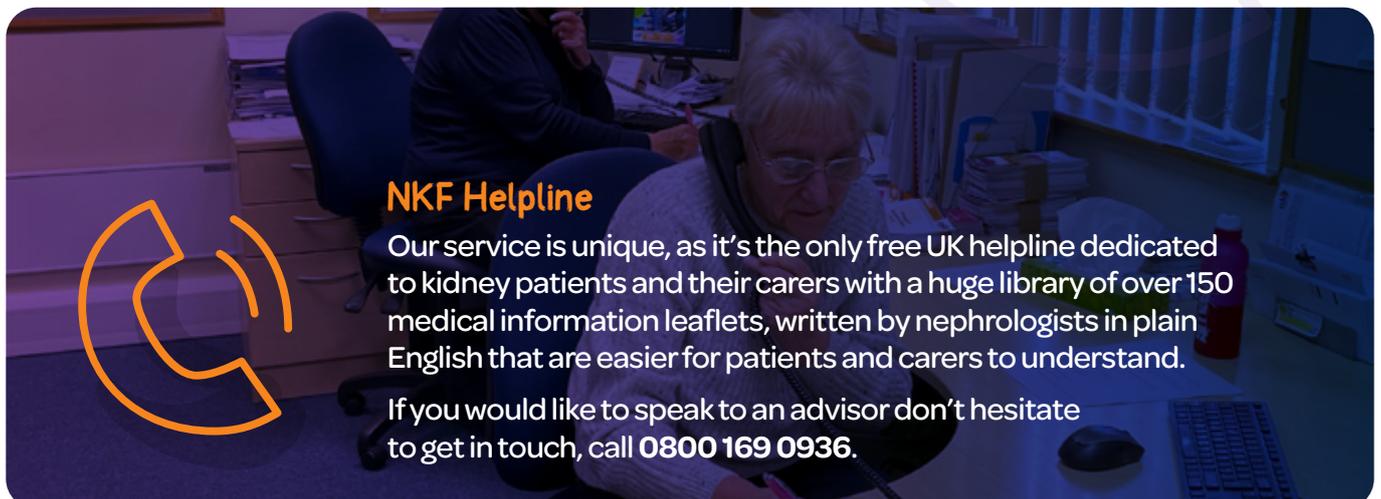
During Covid-19 Linda decided to move closer to her family in Lincoln. Her husband had sadly passed away in 2017, so she moved to the Newark area, not far from the NKF offices at Shireoaks. Linda had always kept in touch with the NKF and when the role became available, she applied for the position of helpline advisor and has now come full circle back to the NKF. She is very much looking forward to her new role.

In her spare time, Linda can be found at the gym and the swimming pool, when she is not looking after her three grandchildren.

**Welcome to the team, Linda!**



**HELPLINE**  
**0800 169 09 36**



## NKF Helpline

Our service is unique, as it's the only free UK helpline dedicated to kidney patients and their carers with a huge library of over 150 medical information leaflets, written by nephrologists in plain English that are easier for patients and carers to understand.

If you would like to speak to an advisor don't hesitate to get in touch, call **0800 169 0936**.

# Little Gem Prawn Cocktail Wraps

*Vibrant and flavoursome snack*

LITE  
BITES

*Everyone loves a prawn cocktail and these tasty little bites make a great lunchtime alternative. Very simple and very tasty, they're low in fat – just make sure you don't add too much Worcestershire sauce as combined with the bread and prawns, it will turn this into a dish high in salt.*

**Ready in about 10 minutes**

**Serves 2**

## Ingredients

- ½ lemon, zested and juiced
- 75g 0% fat Greek yoghurt
- 1 tbsp tomato puree
- ½ tsp Worcestershire sauce
- ¼ tsp smoked paprika, plus a pinch
- 150g cooked king prawns
- Freshly ground black pepper
- 1 head little gem lettuce, leaves separated
- 1 slice wholemeal toast, diced
- 1 tbsp finely chopped red onion

## Method

1. Zest the lemon and set aside.
2. Tip the Greek yoghurt, tomato puree, Worcestershire sauce, smoked paprika and lemon juice into a bowl and mix well.
3. Add the prawns and black pepper and mix until just coated in the sauce.
4. Divide the lettuce leaves between serving plates, then spoon the prawn mixture over the top.
5. Scatter the diced toast, red onion, lemon zest and a pinch of paprika over the top. Serve immediately or transfer to a sealable container and place in the fridge.

Can be kept for 3 days in the fridge.

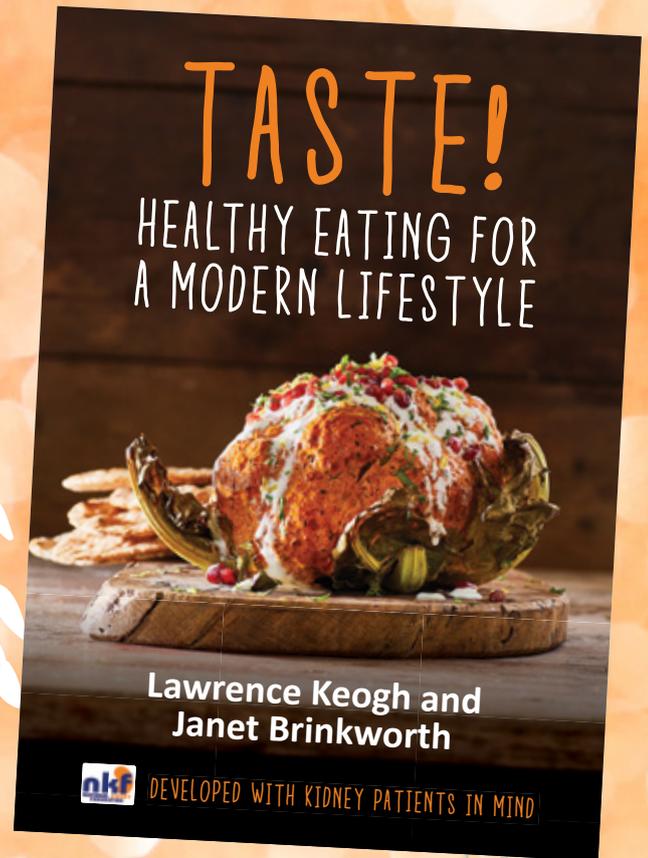


The NKF is proud to have this wonderful and inspiring cookbook that is suitable for kidney patients and their families.

If you are looking for healthy eating ideas that are enjoyable and tasty, you can buy the cookbook here:

[www.kidney.org.uk/shop/nkf-cook-book](http://www.kidney.org.uk/shop/nkf-cook-book)

# A great FESTIVE GIFT idea!



## TASTE!

by Chef Lawrence Keogh  
and Janet Brinkworth



Order online at:  
[www.kidney.org.uk/  
shop](http://www.kidney.org.uk/shop)

# My story of hope, happiness and Hamleys

by Andrew Lines



**I was born in the Suffolk town of Halesworth in the 1950s, the fourth son of George and Myrtle Lines. During my early years, I was a very sickly child.**

**In 1962, aged eight years old, I underwent an exploratory operation at Ipswich Hospital to investigate my ill health. I discovered my right kidney had not functioned since birth and that my left kidney was working, but not normally. In medical terms, I had end-stage renal failure secondary to dysplastic kidneys and ureteric reflux. During the operation, the kidney that wasn't working was removed, leaving me with only a poorly functioning kidney.**

In those days there were no scans and the only way to find out what was going on was to 'open up and take a look', leaving large scars in the process. I missed two years of primary school, and remember sitting my eleven plus not having a clue what it was, let alone knowing anything about the subjects.

My health improved as I got older and aged 15, I got a job at a supermarket in the nearest town of Halesworth. A year later, I played cricket for the village of Walberswick - cycling the eight miles there and back before and after the match! I was offered a job at an outfitters in Halesworth, a job that I loved, mainly because of the wonderful character who owned it. I learned to drive, bought a mini car, and moved to another outfitters in Saxmundham. Around that time my friends and I set up a disco, which we took incredibly seriously. The mini proved useful for driving the three of us (plus equipment) to venues. This occasionally meant removing the seats and using the speakers to sit on. Yes, I am serious!

Aged 21, I moved to South East London to attend college and I met my future wife, a Welsh girl called Cheryl. It became obvious that my health was beginning to fail and after a year at college, Cheryl and I decided to leave.

It had been indoctrinated into me that nothing could be done about my health, but Cheryl did not believe it. She was optimistic about my future and that gave me confidence. So, I moved into a flat in Charlton and got a job at Hamleys toy shop on Regent Street.

Soon after, blood appeared in my urine, and my GP arranged tests. The next day, I was surprised to find my amazing GP hammering on the door of my flat having arranged for me to go straight to Guys Hospital, even offering a lift!

Tests confirmed my remaining kidney was failing and one year later, in March 1979, it packed up altogether. Richard, the third of my three brothers, immediately offered to be tested for compatibility. In preparation for dialysis, the surgeons operated to create a fistula and I was put on dialysis. In those days dialysis meant seven hours at a time, three days a week. I travelled into London for my treatment with the commuters, including Cheryl, travelling to her job in The Strand. It was hard, I wanted to be commuting to work too.

My kidney was removed in April 1979 and it proved worse than the actual transplant. A vigilant young doctor spotted (whilst putting the lights out and checking each bed) that I was slipping into a diabetic coma. My now fiancée Cheryl arrived the next day and was greeted by patients excitedly telling her that they thought I was 'a goner' during the night and to discover I had turned an unbecoming shade of green.

“

*I hope that my story gives hope to others.*

”

Andrew, Cheryl & Richard  
(on the right) on the day of  
their wedding in 1980.



Finally, on 21 May 1979, the big day arrived. My brother Richard was wheeled to theatre and one of his kidneys was removed. I went next, to receive the precious organ. When I came round, I immediately felt better. My breathing was better and I felt stronger and had more energy.

My mother and all my siblings came to visit me at Guy's. Richard was already there, Arthur came from Peterborough, Edwin from Wiltshire and my sister Kathleen from Suffolk. It was the first time we had been reunited in 22 years.

As each day passed I felt stronger, bolstered by Cher visiting me every day. Two weeks after the transplant, I returned home. I resumed work at Hamleys in September and spent the next 30 years working there in various roles ranging from supervisor, to concession manager, to consultant.

Andy & Cheryl at nearby Southwold



Cher & I got married in her home village in South Wales in April 1980. Richard was of course best man... in every way possible! We flew to Sicily for our honeymoon and life was, and still is, good.

Since that miraculous day, I have led a normal life. I have travelled to some amazing countries that I never thought possible. I've played cricket for several teams (including the Hamleys cricket team, of course!) and I've been selected to stand for council twice and served a four-year term as a school governor. In 2003, Cher and I moved to Beccles in East Suffolk and I continued the daily commute to Hamleys for three and a half years.

It is now 42 years since my transplant and everything is stable - amazing considering Richard's kidney was only a 50/50 match. Richard too has stayed healthy. And my message? I would like to stress that anything is possible and not to give up. To quote John Lennon, "Everything will be okay in the end. If it's not okay, it's not the end."

### A note from Cheryl:

I put the success of Andy's health down to his positive attitude and zest for life. He has never thought 'why me?' and his illnesses never stop him from living life to the full. Andy has always insisted on working and I have the utmost respect for him. He has a cheeky, mischievous sense of humour and a special gift of making everyone laugh. Even after knowing and loving him for 45 years, he still catches me out with his dry humour. He regales friends and family with the most wonderful and hilarious stories of his days at Hamleys. He is kind, an animal lover and has a beautiful singing voice... I am simply very proud of him.

# Acidosis in patients with chronic kidney disease

by Professor MM Yaqoob

## What is acidosis?

Acidosis means that the amount of acid in the body is greater than normal due to chronic kidney disease or kidney failure. Normally acid is produced in the body as by product of food metabolism but usually kidneys get rid of them and keep acid levels in tight control. Too much acid in the body fluids means that kidneys are either not getting rid of it adequately or the body is producing too much acid due to consumption of high animal based protein diet. It shows in blood test as low bicarbonate levels.

## What causes acidosis?

Healthy kidneys, apart from many other jobs, keep acid levels in balance by excreting them in urine. Acidosis is caused by a build-up of these acids in the body fluids including blood. This happens usually when kidney function drops below 45%.

## What are the signs and symptoms?

Mild acidosis usually does not cause any symptoms and is detected only by blood tests. Moderate to severe forms of acidosis can cause these symptoms but none are specific.

- Deep and rapid breathing rate to wash out acids by heavy and rapid breathing. Patients usually describe their symptoms as shortness of breath
- Fast heartbeat which patients describe as palpitations – particularly on minimal exercise
- Headache and or confusion
- Fatigue and lack of energy due to muscle weakness
- Vomiting and or feeling sick (nausea)
- Loss of appetite
- Bone pains

If you experience any of these, and you are known to have kidney disease or high BP or diabetes it is important to let your healthcare provider know immediately.



“Mild acidosis usually does not cause any symptoms and is detected only by blood tests.”



Healthy kidneys, apart from many other jobs, keep acid levels in balance by excreting them in urine.



## What are the complications of acidosis in kidney disease or kidney failure?

- **Increased bone loss (osteoporosis):** Acidosis can cause bone loss in your body. This predisposes patients to a higher risk of fractures in important bones like your hips or spine on minimal trauma.
- **Progression of kidney disease:** Acidosis is one of the known factors in the progression of severity of kidney failure. It is believed that untreated acidosis causes excessive scarring in the kidneys which eventually lead to their demise requiring dialysis or transplantation.
- **Malnutrition:** Albumin is an important protein in the body produced by liver that helps in the normal function of blood vessels and prevention of excessive fluids in wrong places like ankle, joints and lung. Acidosis causes excessive breakdown of albumin resulting in low levels of albumin in blood, a sign of malnutrition in chronic kidney failure.
- **Muscle loss:** Acidosis can also cause breakdown of muscle proteins which leads to muscle loss and manifest clinically as muscle wasting.
- **Endocrine disorders:** Acidosis interferes with the normal functioning of Insulin, a hormone produced to control blood sugar levels. Inability to function properly patients develop a phenomenon called resistance to insulin. If left untreated for too long or not corrected in time, this can lead to diabetes.

## How is it treated?

**Bicarbonate:** Bicarbonate (a form of carbon dioxide) also called alkali (opposite of acid) is produced in the body to prevent build-up of acids instantly before the kidney gets rid of the acids. However, in patients with kidney disease, acids stay in the blood instead of being excreted by kidneys in the urine. This results in constantly low bicarbonate levels in the blood which is a sign of acidosis. Healthy kidneys help keep your bicarbonate levels in balance. Low bicarbonate levels (less than 24 mmol/l) can also cause your kidney disease to get worse. A small number of studies have shown that treatment with sodium bicarbonate or sodium citrate pills can help keep kidney disease from getting worse in addition to improvement of muscle and bone function and quality of life. Sodium bicarbonate or sodium citrate pills should not be used unless a healthcare provider recommends it. If you experience side effects or are unable to take the prescribed dose of Sodium bicarbonate, discuss with your healthcare provider.

**Diet:** Certain types of food items such as red meat and eggs increase the production of acids. On the contrary vegetables and fruits produce less acids and also have high alkali content. Kidney dietitians can show you how to safely increase the right type and amounts of fruits and vegetables in your diet based on severity of kidney disease.

*Article submitted by Muhammad Magdi Yaqoob, Professor and Renal Consultant, Barts and The London Hospital.*

# The Getting It Right First Time national report on renal medicine has now been published

**The Getting It Right First Time (GIRFT) report on renal medicine by Dr Graham Lipkin and Dr William McKane, joint GIRFT clinical leads for renal medicine, has now been published and is available to view online.**

**GIRFT is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.**

The recommendations set out in the GIRFT report on renal medicine are based on Dr Lipkin and Dr McKane's visits to all 52 adult renal centres in England, in addition to detailed benchmarked data analysis and audits.

The report noted examples of excellence in every kidney centre they visited, but also highlighted unwarranted variation and opportunities for improvement.

**The recommendations in the GIRFT report include:**

- Improved access to transplantation
- Establishing regional renal networks to support levelling up access to kidney transplantation
- Remote and virtual outpatients
- Increasing rates of home dialysis therapies in large and smaller renal units to suitable patients

Central to these recommendations is putting patient experience at the centre of service design, and embedding quality improvement across the whole multi-professional team.

- To find out more and to read the GIRFT report in full, please visit: <https://www.kidney.org.uk/news/national-renal-girft-report-now-available>



Dr Graham Lipkin 



Dr William McKane 

# THIS WINTER WE NEED YOUR SUPPORT

The National Kidney Federation (NKF) relies entirely on your support and donations to continue its vital work supporting kidney patients and their families.

**A regular donation from you will help support every kidney patient in the UK**

- £20** Helps us with printing and postage costs to distribute our free of charge Helpline leaflets
- £10** Helps towards our campaigning to increase patients on home dialysis
- £5** Helps us make Government changes in Parliament
- £2** Covers the cost of your Kidney Life magazine

## WAYS TO DONATE:



### Donate by phone

You can call us on **0800 169 0936** for a chat and to make a donation.



### Donate online

Or visit [www.kidney.org.uk/donate](http://www.kidney.org.uk/donate)

**By Post** I wish to make a donation to the NKF by: **One-off card payment**  **Cheque**  **Direct Debit**



I would like to donate a **one-off**  **regular monthly**  payment of: **£5**  **£7.50**  **£10**  **Other** (specify)

**NB: Please complete in all cases** ➤ **My name:**

➤ **Address:**

**Contact Tel No:**

### Payment by Debit or Credit Card

Name on card:

Visa  Mastercard  Other:

Card No:

CVV / Security Number:  Expiry Date:



### Direct Debit Instructions (NB: please complete your name / address in the above boxes)

Name and full postal address of your bank:

Name of Account holder:

Bank Sort Code:  My Account No:

Signature:  Date:

Preferred collection day:



### Please send to:

**National Kidney Federation**  
The Point, Coach Road, Shireoaks,  
Worksop, S81 8BW

➤ **I enclose a Cheque\***:  \*Please make cheques payable to: National Kidney Federation

If you are a UK taxpayer your donation will be worth 25% more at no extra cost to you.

*giftaid it*

Yes – I am a UK taxpayer and would like to Gift Aid my donations now and in future. I understand I must pay enough income tax and/or capital gains tax each tax year to cover the amount of Gift Aid that all charities and community amateur sports clubs claim on my donations in that tax year, and I am responsible for paying any difference. I will inform you if my tax status, name or address change or if I wish to cancel my Gift Aid declaration.

# PUZZLES

Puzzles are a great way to keep your mind active and improve concentration, they're also a fun way to pass a little bit of time. Enjoy!



## WINTER WORD SEARCH

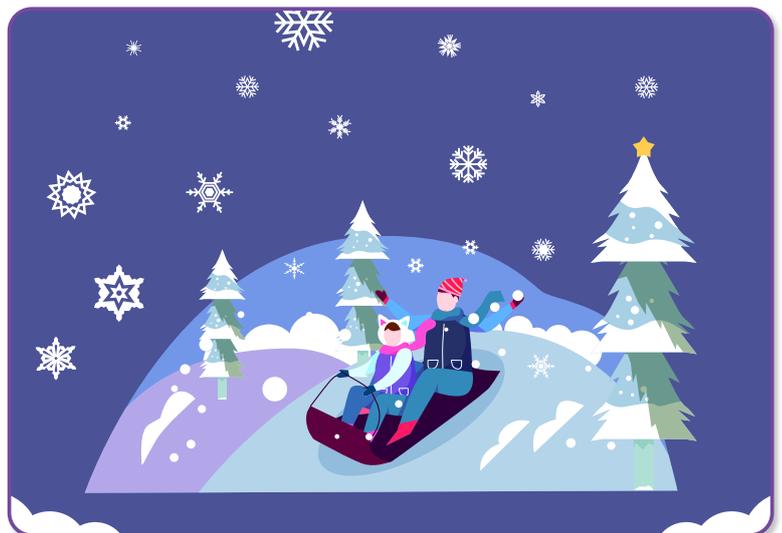
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- FESTIVE
- CRACKER
- BAUBLE
- LOG FIRE
- PUDDING
- TURKEY
- REINDEER
- PRESENTS
- TINSEL
- SNOWMAN
- SCARF
- MERRY
- JINGLE
- GOOSE



# SPOT THE DIFFERENCE

CAN YOU FIND THE TEN DIFFERENCES BETWEEN THESE TWO WINTER SCENES?



# The IGNAZ Trial

## Have you or someone you know been diagnosed with IgA Nephropathy (IgAN)?

If so, you may be interested in a clinical trial with an innovative treatment option for IgAN that diminishes the unwanted auto-antibodies responsible for the development of the condition.

To find out more, please email your contact details to:

**MorphosysCTHotline@druginfo.com**

and provide the country, city/town and postcode of your location, along with your telephone number and email address.

Your details will be forwarded to a study site close to your home, and you will be contacted to discuss your eligibility to participate in the trial.



**morphosys**

Engineering the Medicines of Tomorrow

## REDUCE INFECTION RISK IN DIALYSIS

## CATH DRY™

PROVIDED BY PATIENT CHOICE

**Cath Dry is a nephrologist-designed waterproof catheter dressing that reduces infection risk - and is now available on NHS prescription.**

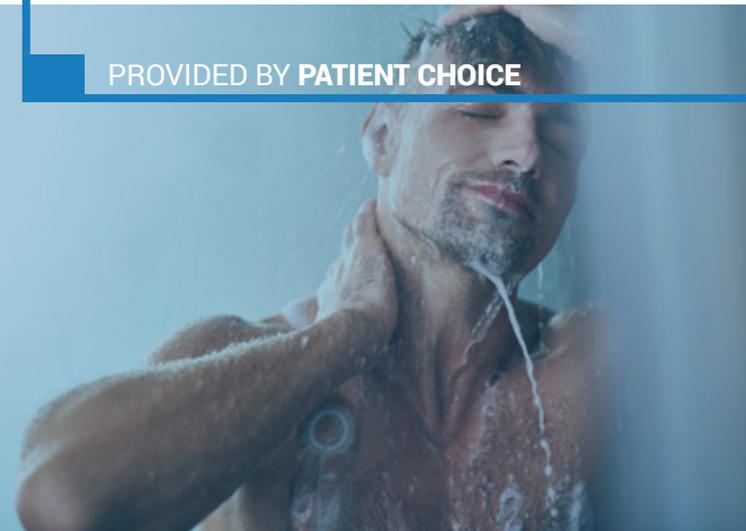
It is the only dressing available that can be worn for up to 3 days between treatments. Each dressing allows unlimited showering and provides up to 20 minutes of safe swimming.

**Cath Dry is proven to reduce infection risk at the catheter site and features a colour-changing moisture warning.**



- For Haemodialysis and Peritoneal.
- Sterile and bacteriostatic.
- Shower and swim-proof
- Apply between dialysis sessions.
- Hypoallergenic and Latex-free.
- Suitable for paediatric patients.
- No other dressing required.

Switching to Cath Dry can also save the NHS money. Ask your clinician or nurse about Cath Dry or request a sample online.



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**NHS**  
 Providing NHS services

For further information, sample requests and orders please visit our website [www.cathdry.direct](http://www.cathdry.direct)



This Christmas, remember a loved one you have lost by writing a message on the star, for us to hang proudly on our Christmas tree

Our Shining **STAR** at Christmas



If you can, please send us a donation with your star so that we can help to give Kidney patients a brighter future

Please send to:  
National Kidney Federation  
The Point, Coach Road,  
Shireoaks, Worksop, S81 8BW

Cut me out and send me to the NKF



I wish to make a donation to the NKF by: One-off card payment  Cheque  Direct Debit

I would like to donate a one-off  regular monthly  payment of: £5  £7.50  £10  Other (specify)

NB: Please complete in all cases

My name:

Address:

Payment by Debit or Credit Card

Name on card:

Visa  Mastercard  Other:

Card No:

CVV / Security Number:  Expiry Date:

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**Direct Debit Instructions** (NB: please complete your name / address in the above boxes)

Name of Account holder:

Bank Sort Code:  My Account No:

Signature:  Date:

Preferred collection day:

Name and full postal address of your bank:

Postcode:

I enclose a Cheque\*:  \*Please make cheques payable to: National Kidney Federation



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Yes - I am a UK taxpayer and would like to Gift Aid my donations now and in future. I understand I must pay enough income tax and/or capital gains tax each year to cover the amount of Gift Aid that all charities and community amateur sports clubs claim on my donations in that tax year, and I am responsible for paying any difference. I will inform you if my tax status, name or address change or if I wish to cancel my Gift Aid declaration.

Many thanks and best wishes for Christmas and the New Year from all at the NKF

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