

# Northern Ireland Kidney Patients' Association



## Newsletter

Spring, 2021



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*NIKPA is a non – profit making charity that relies totally on donations to continue supporting kidney patients across Northern Ireland. We could not continue to offer our services to kidney patients, their families and carers without your kind generosity.*

*NIKPA wishes to say a HUGE THANK YOU for your ongoing support.*

### **Ways to support NIKPA**

Fundraise through ‘Just Giving’ - <https://www.justgiving.com/nikpa>.

Transfer directly or set up a standing order contact us directly for details.

Shop on Amazon using ‘Amazon Smile’

Click <https://smile.amazon.co.uk/> and select “Northern Ireland Kidney Patients Association” as your chosen charity.

## A MIRACLE DONOR

*The mother of a nine-year-old boy from Enniskillen, County Fermanagh, who is waiting for a kidney transplant says it is a miracle a donor has been found.*



That donor is a senior police officer, who discovered he was a suitable match after reading an appeal in a newspaper. Joshua Dolan has only one kidney functioning at 17% and must travel to Belfast three times a week for a four-hour dialysis session. Mary Dolan said the dialysis has left her son feeling very tired.

"He's been having a hard time these past couple of months. It's very heart-breaking for a mum to watch," she said. Police Service of Northern Ireland (PSNI) Ch Insp Graham Dodds read the family's appeal for a donor in the 'Impartial Reporter' newspaper, and discovered he was a suitable match. "What stood out for me was Joshua's story and despite very trying circumstances his happy smile and determination," he said. Graham had undergone tests to be a donor for a police colleague who was ill a number of years ago. His co-worker later recovered and no longer required a transplant. "I always had it in my mind that if something arose where I could help I will try," said Graham. "When I saw Joshua's appeal I just thought 'that's perfect for me, it's a local lad and if I can help I will'."

Graham said he was honoured and proud to be able to help Joshua. Ms Dolan said her son had always been interested in the police and the family has formed a strong bond with the chief inspector while talking to him online. "It's given him a buzz he's going to get a kidney from a police officer," she said. As well as donating a kidney, Graham has agreed to give Joshua his police whistle, a hat and a medallion when they finally get to meet in person after the operation.

"Whenever Joshua and I actually physically meet will be after he has my kidney inside him and that's when we'll be able to meet up in hospital and I think that will be fantastic," said the senior police officer.

"To me as a police officer my whole raison d'être is to help people and to protect life and to look after people.

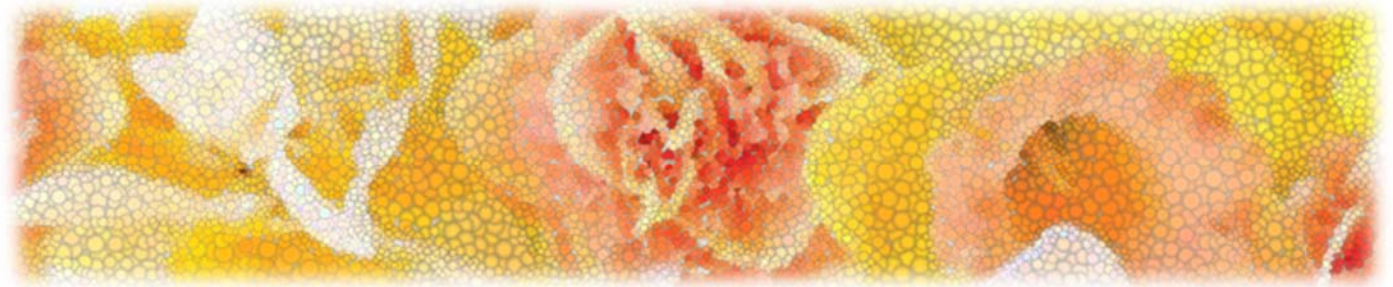
"I think that is something instilled in me to the core as a police officer of 23 years service, but as a human being, to me it's a natural thing to want to help someone." Graham is "honoured and proud" to be able to help Joshua. "My relatively small act of giving up an organ that I don't actually need will have a massive impact for his life and his family when it will have a fairly minor impact on mine," the policeman added. "You have three or four hours of surgery and a couple of months recovery period but once that's done you're back to normal."

Outside of his police duties, Graham is an officer in the Royal Air Force Air Cadets and leads the Squadron in Omagh, as well as holding the role of Media Communications Officer for the Scotland and Northern Ireland Region. He is married to Nicola, and has two teenage sons, Ethan and Alexander. His family have been totally supportive of his decision to donate a kidney and have been fully involved in all the elements of the process. While the testing aspect of the process may put some people off, Graham explains that while it was detailed, it was not that unusual or difficult stating, "The one day testing at Belfast City Hospital was certainly very detailed and comprehensive. I had numerous blood tests, scans and checks to ensure I was fit to donate. Essentially it was an MOT on me and I was reassured by the lengths to which staff went to make sure I was fit to donate and that my kidney was suitable".

The donation process has also prompted many questions from family, friends and colleagues on the donation process. Questions have ranged from 'can you still drink alcohol' to 'will you always need medication after you donate'. Graham has been able to answer these questions ('Yes' and 'No'), as well as the others posed due to the excellent briefings provided by the living donor staff at BCH. Graham is an altruistic donor, having no relationship with his recipient, Joshua. This has led to people asking why he is undertaking the process when he has no links or obligation to do so. The answer, Graham states is easy, "To me, it's a simple answer in that helping another person is what you should do in all and any circumstances. In this case, I have a spare kidney and am in a position in life which allows me to donate. Its as simple as that" Post-surgery, Graham plans to relax and recover by catching up on some much delayed reading of the many historical books he has bought but not yet read due to the pressures of his policing role, family life and cadet duties. He also hopes to spend time walking in the Tyrone countryside to build up his strength during recovery.

It is hoped the operation to give Joshua his new kidney will be able to take place in May.

NIKPA wishes Joshua and Graham well in this unique gift which brings them both together.



## NIKPA WELCOMES NEW MEMBER TO THE RENAL ARTS GROUP

*By Fina Wurm*

Hi everyone, I'm Fina and it's a pleasure to meet the readers of the NIKPA Newsletter! I am a new member of the Renal Arts Group and wanted to introduce myself to you all.

I work in the field of psychology as a trainee cognitive behavioural therapist but originally, I was a classical musician! While I was studying an undergraduate degree in music, I undertook a work-placement at the Cork University Hospital, and this ultimately changed my life. During my time at the hospital, I created an arts-based intervention for paediatric patients and their families and saw the positive effects music had on the quality of life of my patients. This inspired me to make a career of researching the arts in healthcare and facilitating this as a therapist, so I moved to Belfast to do postgraduate study in psychology at Queens University.

I dove into the world of arts in healthcare in Belfast and volunteered as a dance therapist for adults with Parkinson's Disease and recently, joined the Renal Arts Group, a fantastic group that research how the arts can improve the quality of life for people living with kidney disease.

My eyes were opened to the world of those with kidney disease when I spoke with Susan Kee, a member of Kidney Research Fund Northern Ireland. I was lucky to have been chosen to speak at a conference on the topic of organ donation, a subject I cannot stress the importance of and interviewed Susan when writing my speech. Susan shared her family's story of her daughter's experience with kidney failure and her survival after receiving a kidney transplant from a live donor, her dad. While the story was harrowing and made me aware of the immense difficulties people and their families experience when living with kidney failure, it also highlighted the strength and resilience every person with kidney failure has within them. I shared Susan's story at the conference and would love to invite you to watch it, so I have included a link you can type into google that will bring you to the presentation.

When I am not working or volunteering, you will find me at the kitchen table hunched over my canvas painting or hammering the keys of my piano. I hope to those that have made it this far in my introduction that my love of the arts might encourage you to also engage with the arts, maybe by listening to your favourite music today!

Thank you so much for reading and thank you to NIKPA for inviting me to introduce myself to you all.

[https://www.ted.com/talks/fina\\_wurm\\_saving\\_lives\\_by\\_changing\\_the\\_default](https://www.ted.com/talks/fina_wurm_saving_lives_by_changing_the_default)



## FROM MALIN TO MIZEN – VIRTUALLY

*By Mairead Canavan*

From December 2020 to May 2021 28 members of staff from the renal unit undertook a 341 mile virtual walk from Malin head in Donegal to Mizen Head in Co. Cork. To date 5 have completed the walk and the rest are on target to meet the May deadline. Throughout we have walked through all weathers, rain sun snow and even a few storms in our mission to raise funds for the excellent work of our local charity NIKPA. Battling through the challenges of working through global pandemic (did I mention steps in work didn't count) our preservation and commitment has helped raise over £2300 to date.

### ***Ramblers you might know ...***



Along the way we learned a lot about ourselves; our limits and how we were able to push past these to make the journey some in record time! Throughout we helped each other along with the support of a WhatsApp group which also resulted in bringing out the competitive side of some of us! We couldn't have completed the walk without the help and support of each other and our families who made the walk possible! The just giving page will stay open until the middle of June, so please continue to donate to this very worthy cause. This challenge has had a positive impact on staff well-being and has aided us in getting through some of the most difficult times of our careers. Staff have enjoyed this fund raising event and we are now wondering what we will do for our next team building challenge and helping charities along the way.

## A GIFT I WAS DELIGHTED TO GIVE

*By Brenda Doran*

My name is Brenda and I work as a care worker in the community for the NHS. I am married with three of a family. In my pass time one of my hobbies is running which I enjoy at least twice a week.

Life was normal for our family until October 2019, when my youngest brother Brian who was 34 years of age, was suddenly sent to A&E, by his GP, with kidney failure with a function of 12. Brian was admitted to hospital and was eventually started on dialysis which continued for 3 days a week. His consultant told him, almost immediately that he would need a kidney transplant and he should give the information leaflets, which he had received, to family and friends.

Without any hesitation myself and our five other siblings along with six of Brian's friends made our appointments to have a blood test done in the renal department of the Ulster Hospital Dundonald. This was to determine if there were any matches and if there weren't any matches Brian would have to be placed on to the waiting list for a kidney which could have meant a few years if he was lucky.

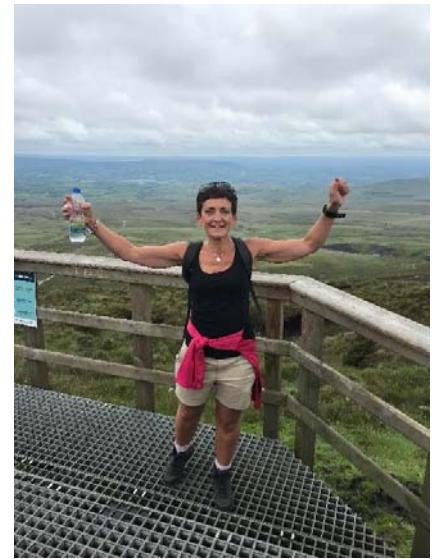
It was of course a shock to find out that my brother was so poorly and was in need of a kidney transplant. And I am ashamed to say that, for me, these sort of things only ever happened on "ER" or "Casualty".

I was contacted in January 2020 by Erin, who became my donor co-ordinator. She informed me that I was a perfect match and asked if I was still willing to donate. I didn't have to think twice about it. I cried with relief for Brian. He was going to get better and wouldn't have to rely on a machine three times a week to keep him alive and he could have his life back again.

People in general were in awe of me doing this and wished me all the best although a small few I think found it hard to understand why I would put myself under such a high-risk operation. To be honest the only thing I thought of was that I had something that I didn't need and my youngest brother desperately needed to keep him alive and there was no way in this world would I have ever denied him this.

I opted for the one-day assessment rather than having my tests done over a few days. These tests were done in the BCH. I met my Erin for the first time and it was great to finally meet her. She really was such a great support and guide through it all, she was always able to answer any questions and queries I had and believe me, I had lots. I had numerous blood tests and scans done that day and I was finally told after a few weeks that I was in perfect health and it would be my left kidney which I would be donating.

My husband, two sons and my daughter were a great support to both Brian and myself. They simply understood what I needed to do to save their uncle. Never once did I feel nervous or have second thoughts, my aim was to get Brian better and that we were in exceptionally good hands and had every faith in the renal consultants and their team at the BCH.



Brian and I both attended a meeting with a counsellor to talk to both of us together to go over exactly what would happen before and after the transplant and also to see how we were coping mentally etc. Over time we also met our surgeons and consultants. They really are in my eyes, “our angels”.

Now with all that behind us we only had to wait on a date. We were aiming for end of March 2020. However, Covid-19 put it all on hold.

Eventually on the 1st of September 2020, “transplant day” arrived. It all went according to plan, the surgeons and their team and were very pleased with procedure.

I had to spend a few nights in the hospital after the procedure, I was then able to go home where I could fully recover. After 3-4 weeks I was able to go out walking/running, 6 weeks post operation I completed my first 5k run, I was delighted with myself.

It has now been 8 months since the transplant, I am now in training in preparation for a half marathon to raise money and awareness for NIKPA. Brian is doing so well and if I’m totally honest I do get a little emotional at times when I see how well he’s doing. I feel so lucky and privileged that I was able to help my brother and give him his life back again.

## SUPPORT NIKPA AT BELFAST CITY MARATHON – SEPTEMBER 19<sup>TH</sup>, 2021

The **Belfast City Marathon** offers everyone the opportunity to join us and make a difference. As part of NIKPA you are supporting kidney patients and their families throughout Northern Ireland. So if you are up for a challenge, you and your friends can take part in a Team Relay, 8 Mile Walk, 5k Fun Run or the Full Marathon. As you can see there is something for all fitness levels. You are guaranteed a great day out and a chance for your family and friends to get together and spread awareness, whilst supporting a great cause.



### **How to enter**

Signing up is easy, just head to [www.belfastcitymarathon.com](http://www.belfastcitymarathon.com) and register your place.

### **Just Giving**

Raise funds and awareness for NIKPA with our JustGiving link: [www.justgiving.com/nikpa](http://www.justgiving.com/nikpa)

### **Fundraising Pack**

To receive your fundraising pack including; sponsorship form and NIKPA T-shirt, get in touch with us via: [nikidneypatients@gmail.com](mailto:nikidneypatients@gmail.com) or contact us on Facebook - @NIKidneyPatients

Many thanks from NIKPA. Your support is greatly appreciated.



## ORGAN DONATION IN NORTHERN IRELAND

By Catherine McKeown, Organ Donation Promotion Manager

### AN OPT-OUT SYSTEM

On 11 December 2020, Health Minister Robin Swann launched a public consultation on the introduction of a soft opt-out system for organ donation in Northern Ireland. The purpose of the consultation was to seek the public's views on how to introduce a soft opt-out system, as this would require new legislation to change from the current opt-in system to one in which people can choose to 'opt out'.

The consultation ran for 10 weeks and there was extensive engagement with a range of audiences across Northern Ireland to ensure as many people as possible had opportunity to respond. The consultation received just under 2,000 submissions from individuals and organisations, which was described by the Health Minister as 'tremendously encouraging'.

The views received will help inform the proposed change to legislation which will more accurately reflect the support that exists for organ donation in Northern Ireland. Latest figures show that 90% of the population supports organ donation but only 49% have recorded this decision on the NHS Organ Donor Register.

The responses will inform the development of a draft Bill for consideration by the Northern Ireland Assembly. Once consultation analysis is completed in the weeks ahead, the first step will be to secure the approval of the Executive to introduce the draft Bill. Subject to the views of the Assembly and Health Committee this process should take us up to summer 2022.

In November 2020, the Public Health Agency (PHA) surveyed the general population in Northern Ireland to gain insight into current views about organ donation, donation behaviours, intentions and attitudes. This is the fifth population-wide survey conducted by PHA with a focus on organ donation since 2013. It provides the ability to track changes in the public's perceptions about aspects of organ donation over time.



Public Health Agency Omnibus Survey 2020

Results from the November survey were very encouraging with figures on an upward trend, indicating increasing positive attitudes towards organ donation and good general awareness of the Organ Donor Register (ODR), and understanding of the organ donation system. Key findings are highlighted below:

- Support for organ donation was up to 90%, from 84% in 2013, that's 9 out of 10 people
- The need to discuss our wishes was up to 93%, from 78% in 2013
- 4 out of 5 people were aware of the ODR

- 53% (of this survey) had registered on the ODR with a further 39% very/fairly likely or unsure, and only 8% saying they would be unlikely to or wouldn't register
- 86% of those registered had done so 'to help others'
- 3 in 5 (60%) said they had talked to family about their organ donation decision (up from 38% in 2013)
- However, when asked about the donation decision of others, only 2 in 5 (44%) knew the donation decision of their partner
- This indicates that there is good discussion of our own donation decision but lesser awareness of others' decision, so a two-way conversation is very important
- 66% felt their family would know their decision (up from 43% in 2013)
- 74% felt that their family would agree with their decision (up from 55% in 2013)

Most recent NHS Blood and Transplant figures for ODR registrations for Northern Ireland show that 49% of people are now registered. Contrasted with the 90% of people who support organ donation, this illustrates the gap between intention and action. To close this gap is a key objective for promotion going forward and awareness and education will focus on two important and linked actions: 1. Sign the Register and 2. Share your decision.

Insights from this and other research findings will help shape forward plans and messaging for the promotion of organ donation in Northern Ireland.

## SCHOOL RESOURCES

While the aim of promoting organ donation is to do so as widely as possible, it is also useful to identify key audiences for tailored resources. Once such audience is our young people, who are often described as vehicles for change in our society.

With this in mind, a working group has been created to develop schools resources to educate and inform young people. The group is working on the development of resources to cover the entire education journey from primary to post-primary and onwards to 16+. Resources will be tailored appropriately to each age group and the aim is to ensure young people are educated on all aspects of organ donation to allow them to normalise conversations, and to make informed choices.



The working group is made up of teachers, all of whom have had personal experience of organ donation and whose passion and dedication for the project is very inspiring. Everyone involved is very excited about the project and we look forward to updating on developments in due course.

## WELCOMING NEW RENAL OUTPATIENT'S SISTER

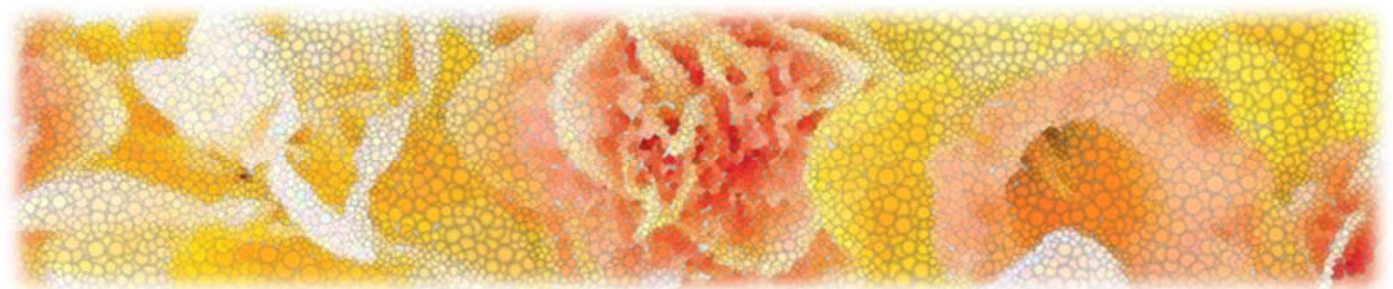
*By Theresa Bigmore, Renal Outpatient's Sister*

My name is Theresa Bigmore, I have worked in the Nephrology department of the BHSC for the last 23 years. Most of my time was spent in the haemodialysis ward where I developed my passion for renal nursing. From I was a young child I always wanted to be a nurse having been inspired into the career by Nurse Nancy in the Twinkle magazine who cared for all her dolls, teddy bears and stuffed animals. I completed my nurse training in the BCH and it was here I gained my first permanent post after qualifying. I did venture to Addenbrookes in Cambridge after qualifying, but I was too much of a home bird and was delighted to quickly return to home soil.

Working in Renal has always been special to me, I love how it has afforded me the opportunity to build up lasting relationships with the patient's getting to know them and their families, as they return as service users for many years. Many of the patients I have known since I started in Renal, and it is so encouraging to see them doing so well. Last October I moved to the Renal Outpatient's as Sister of the Department, in the midst of a global pandemic. The Outpatient's traditionally has been a very busy department with a small number of staff, who were all very welcoming. Covid-19 has brought many changes to the department and my main focus was ensuring the safety of both patients and staff while maintaining a high standard of excellence. The clinic deals with many ward attenders on a daily basis alongside routine transplant and General nephrology clinics, to name but a few. With the reduction in face to face clinics new ways of working were adopted, including virtual clinics and telephone clinics. Staff have been very adaptable and willing to change to ensure we continue to deliver an excellent service to our patients.

Outside of work I enjoy spending time with my family, I have 3 teenage children, a new puppy and a husband. Last spring we purchased a motorhome and I look forward to restrictions being lifted and getting away for the weekends again. We love to head off to the coast and enjoy walking in the countryside.

I am so grateful for having spent my time in nursing working alongside the most wonderful staff and patients. Renal nursing for me has always had a 'family feel' to it, and family is everything to me.



## 40 YEARS A RENAL NURSE: SISTER LINDA HANNA

*By Linda Hanna*

I first joined the renal team as a newly qualified staff nurse in 1981 and I retired last year...can't believe that its almost 40 years ago! I decided to apply for nursing after completing a secretarial course and realising this was not for me (although for a friend of mine it most certainly was her forte – you know who you are!). I decided to apply and was thrilled to be accepted for training at Belfast City Hospital School of Nursing in 1977.

As a student nurse, I worked in a Urology ward in the old Belfast City Hospital. This was where I first had contact with renal patients. I found the patients to be very aware of their illness and treatments, which brought major limitations to their lifestyle. One night-duty shift, I had to make a delivery to the old Renal Unit, now long gone. Staff were locked in as a kidney transplant was in progress. My curiosity was raised when a nurse opened the door to me dressed in theatre gown, mask and hat, as to just what transplantation involved. At this point, I knew what area I would like to specialise in and was delighted get a staff nurse post in the renal unit. I completed the renal nursing course and gained experience throughout the renal unit in dialysis and transplantation. I loved the variety of treatments and the high standard of care provided to patients.

I was excited to join this team of highly skilled, experienced, and immensely caring staff, which created a sense of family for patients.

I have met many patients and families over the years, and all have had to make huge adjustments to their lives when coping with their diagnosis and treatments. Thankfully, there have been many changes that have brought improved care for patients with Chronic Kidney Disease (CKD).

Dialysis used to only be available at the Belfast City Hospital, patients had to travel long journeys from all over NI, and spend 8-10hrs on dialysis before beginning their journey home again. Patients were frequently unwell during dialysis, as the solution used in the early days was very harsh, causing headaches, hypotension, and vomiting. Blood leaks were also very common with lines splitting and the pumps kept turning therefore blood sprayed everyone. You had to be very observant of your patients, and act very quickly in response to stop pumps and clamp lines! Thankfully, as new equipment became available all of these issues were resolved.

Today, we have six dialysis centres throughout NI allowing patients local access to treatment. Advances in equipment and treatments brought shorter hours spread throughout the week, allowing better management of waste and fluid removal. The solution used today provides a much-improved treatment, without the severe side effects of the past. Shared care and Home therapies allow patients to be fully involved in their treatments. Home therapy nurse specialists today can support treatments at home remotely.

Anaemia used to be managed without Epo or Iron, and could only be treated with a blood transfusion providing only a short-term fix. Most patients had to get by with Hb levels of 50g/l, and would not qualify for a



blood transfusion until it fell lower. Many patients received well over 100 units of blood over their years on dialysis.

Today we routinely treat renal anaemia if appropriate with Iron and Epo therapies once the blood count is below 100g/l. These treatments have truly transformed patients' lives.

Transplantation in the Belfast City Hospital has always been highly regarded in the world of renal with the work of Professor Molly McGeown and the 'Belfast Recipe' for immunosuppression medication following kidney transplant. Strict isolation of patients was the routine. Side rooms were prepared for the patient's post-transplant recovery with everything including the newspapers being sterilised, or so we thought at the time, through a sterilising unit. Patients were isolated and relatives sat in the 'dirty corridor' chatting through a screened window. Research and understanding has changed how we do things today.

Transplantation in Belfast remains renowned, providing a first-class Living Donor and Transplant Programme. It aims to achieve pre-emptive transplantation where possible, and avoid dialysis for those patients who are suitable for transplant surgery. Early assessment and planning helps patients move towards timely transplantation.

Renal Patient Education Service is 30yrs old this year! I had the opportunity to establish this service with the support of Dr C Doherty and Miss Maureen McKinney. It aims to help patients understand how their illness would affect their lives, and prepare them for dialysis and transplant. One to one education sessions are provided, and information is tailored to suit the individual. Nurse specialists sensitively support patients and families to consider treatment options, which include Living Donor Transplantation, Home Haemodialysis or Peritoneal Dialysis, Hospital Haemodialysis and Conservative Kidney Management. Today pre-emptive transplantation and home therapies are encouraged. Over the last year, the team has been able to adjust to provide virtual education where possible.

Renal Low Clearance Clinic is a multidisciplinary clinic led by Dr Joanne Shields. A nurse specialist co-ordinates this clinic, and provides a nurse-led review clinic for patients who have progressing CKD. The clinic provides a co-ordinated treatment plan aiming for pre-emptive transplant or planned start to dialysis with access ready to use. This clinic is a 'one-stop shop' model, which brings together transplant assessment, access mapping, home therapy options, supportive care, anaemia management, and health assessment. It supports patients through these assessments in 2-3 visits to clinic, and for some, on to dialysis, transplant, or conservative care.

It's been wonderful to see how treatment options and care over the years has continued to develop and improve for patients.

The past year was not exactly the retirement year I had hoped for but I have much to be thankful for and have enjoyed more time with my family particularly my 3yr old grandson. I also had a new experience of helping my daughter with a litter of 8 puppies... I think a baby is easier!

I continue to work a couple of days with the low clearance clinic, which I enjoy. Like everyone, I'm looking forward with hope to something more normal in the next few months. To meet up with family and friends and to enjoy our daughter's wedding day would be a great start!

By William Johnston

THE BIG FIGHT



*Ladies and gentlemen, welcome to the highlight of the night  
Introducing in the Blue Corner, WJ fighting for his life  
Introducing in the Red Corner, Chronic Kidney Disease (CKD)  
Hoping to make WJ beg for mercy bent double to his knees*

*CKD throws the first punch with daily fluid restriction  
WJ resists and adheres with whole hearted conviction  
CKD comes back with restrictions on favourite foods  
WJ just laughs as he knows this can only do him good*

*WJ refuses to buckle and is determined not to be beat  
He goes swimming, stays fit, CKD begins to feel the heat  
But CKD attacks WJs mental strength to grind him into the ground  
Those promised compatible donors are no longer to be found*

*Wounded and stunned WJ searches for new tactics from his corner  
Home dialysis programme is introduced and WJ begins to feel so much stronger  
CKD failed to realise that new technology will allow WJ to constantly attack  
No matter what CKD throws, the resilient WJ will keep on bouncing back*

*“So bring it on, CKD” you hear WJ proudly shout  
“Do your very worst as you will never knock me out”  
“I am one patient who will never live in fear”  
“As I am determined to keep fighting CKD for many more a year”*

Covid 19 arrived in the UK 2020. Nobody knew much about him, only that he originated from the Far East with the goal of world domination and nobody or country would be safe or stand in his way. I had just turned 54 years old and celebrated the 7th anniversary of my Big Fight victory over CKD. Life was OK and I had my championship belt securely fastened around my waist. I had spent the last five years training, supporting and assisting other renal fighters pre and post their Big Fights with CKD. I say life was OK, however post Big Fight presented new challenges which I had not perceived or been prepared for.

There were new mental challenges of managing expectations of how much winning my battle with CKD was truly going to transform my life. I had won a battle, but the war is ever present for the body and mind. I had knowledge and experienced first-hand the effects of the medications especially the steroids – the moon face, weight gain, hair loss etc however I had not anticipated the psychological side effects of the steroids taken to preserve my new kidney, bequeathing mood swings, depression and anxiety. Consequently, I stopped physical training, put weight on and started eating and drinking things that I had been deprived for so many years previously whilst training for my Big Fight against CKD. Unfortunately, with no fluid or diet restriction, I returned to the bad habits of a new normalized lifestyle. Therefore, in 2020 when this new challenger appeared from nowhere, I was neither psychologically or physically ready for this new gauntlet thrown down by Covid 19 who made it clear he did not only want to take my belt but most definitely also my life.

My confidence shattered and under the instruction of the UK renal management team, I reluctantly retired to hide at home until Covid could be fully understood and new tactics developed to hopefully beat him. This was devastating as I was no longer able to visit my renal fighters at their training centres where I could give advice and support. I felt I had deserted them at their time of need. My job satisfaction stemmed from supporting my fellow renal fighters but for this to be forbidden affected my overall feeling of well-being and mental health. I felt I was failing my renal fighters, my wife, my family, my work colleagues, my dogs because I no longer had the freedom, appetite or strength to confront this new challenger.

To this date, Covid is still undefeated toying with the nation's physical and mental health. Over 17 years on dialysis, I had always been use to fighting any challengers which came my way, but it is hard to fight an invisible enemy which moves like lightening and has no respect for the Queensbury rules. Covid is sneaky and cowardly and goes after the oldest, weakest and most vulnerable fighters first. I tick every box for Covid. I am the ideal opponent for him to fight. A middle-aged man, overweight, immune system severely compromised due to seventeen years of fighting CKD. But I am trapped at home with no access to physical fitness resources which only breeds psychological stress and drains my ability to fight. CKD has softened me up for Covid. Covid relishes playing mind games and is a master at psychological warfare. Doubt and fear are his principle weapons. In addition, and most worrying, he has now bought his brother and sisters to the UK who too are eager to fight and destroy all those who stand in their way.

So, even if I avoid Covid 19, there will always be one of his brothers and sisters hiding secretly to attack me when I am least prepared. I am angry and scared because if Covid does achieve his wish of confronting me, in

all probabilities, I will end up in a hospital ICU fighting to breathe through a ventilator where CKD will joyfully unite with Covid to finally be victorious over me and take my life away.

The UK management are hoping the new tactic of a vaccine will assist in fighting Covid and build my immune system back up. Even if this new tactic is successful and Covid is at least controlled, it is re-discovering the nation's strength, resilience and confidence again which will be the new challenges.

*Is this indeed just ONE FIGHT TOO MANY? What do you think? Nope! No! Absolutely not!*

Covid you under-estimate the fighting qualities of renal warriors.

All you have done is really annoy me or to put it crudely – f\*\*ked me off!

I am more determined than ever to fight you, your brothers, sisters and CKD for as long as it takes.

You will get weaker as I get stronger.

“So Covid, Bring it all on, you hear me proudly shout

Do your very best as you will never knock me out”

Life is precious. My life is precious.

I will always fight for my right to live.

Covid, you may have won the first few rounds, but be ready for a storm of retaliation as I will be victorious and I will retain my belt and I will be the winner AGAIN!

## THANK YOU TO NIKPA

*By Michael Deery, Dialysis Co-ordinator, Renal Unit, Altnagelvin Hospital*

At Christmas NIKPA provides funds to each of Northern Ireland's Dialysis Units to be used for the benefit of patients. Unable to use these funds at the time Altnagelvin held an Easter Raffle.



The hampers are very much appreciated by patients and their families and the winners above are Bridget Harkin, George O Hagan, Andrew Smallwood and Teresa Harkin



By Ryan Arthur



My name is Ryan Arthur. I am 25 years old and from Carrickfergus. On the 12th March 2021 I took on a challenge to raise funds for NIKPA. The challenge was to run 4 miles, every 4 hours, for 48 hours. This is the equivalent of 2 marathons in 2 days. David Goggins, a Navy seal and ultramarathon runner and triathlete, made this challenge famous. The 4x4x48 challenge is a test of resilience, endurance and willpower. Because you have to put in 4 miles every 4 hours, you can't get quality sleep making the challenge tough. I expected the 2am and 6am runs to be the most difficult!

My aim in completing this challenge was to raise money and awareness for NIKPA. I am completing this in memory of my late Granda Sam.

My Granda had diabetes and was on dialysis for 11 years. Through his illness, he ended up having multiple limb amputations and he had to adapt to a new way of living. As you could imagine this had both a physical and mental toll on him. He attended dialysis 3-4 times per week, until he passed away in July 2017. Despite all the hurdles he faced through his illness, he took them in his stride and I always looked up to him for this. Throughout his journey he was looked after so well by the staff in the Belfast City Hospital renal unit. The staff were incredible. The patients spend a lot of time in these centres and the staff almost turn into their extended family.



This year, more than ever, I felt it was the right time for me to take on this fundraising event. Due to COVID a lot of fundraising events have been unable to take place and therefore charities have had more difficulty raising the vital funds that they require.

NIKPA is a charity I hold dear to my heart as it provides vital support to kidney patients in Northern Ireland. The people involved in the running of this charity are inspirational and give their time voluntarily. What they do makes such a difference to kidney patients and their families. As NIKPA is entirely funded through donations I wanted to do what I could to raise money to contribute toward a worthy charity so that they can continue to provide the support that they do.

I knew this challenge would be tough both physically and mentally for me to complete. However my Granda was the driving force for me to complete this challenge even when the legs got sore and the tiredness set in. So far, I have raised over £3000 which I am delighted with. I want to say a massive thank you to everyone who has donated!

NIKPA very much appreciates the practical support of La Roche-Posay in donating samples of suncream for NIKPA 'Welcome bags'. We hope to be able to provide newly transplanted patients with a bag of gifts which might prove useful in their process of recovery.

In the meantime, just a little reminder to everyone, 'Don't forget to apply sun protection before going outdoors, even if the day is overcast'



Northern Ireland Kidney Patients' Association is a charitable voluntary organisation, dedicated to the support of Northern Ireland's kidney patients, their families and carers. Our association, which has almost 400 members, is self-funding and run by kidney patients, their relatives and friends.

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