

Northern Ireland Kidney Patients' Association



Newsletter

Autumn, 2020



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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.

NI COVID-TRANSPLANT STORY

By Aisling Courtney

At the end of 2019, we heard of a viral infection in an unknown province of China. But very few had any idea just how this particular coronavirus was going to change the world, change our worlds, in 2020.

By March the health service in NI was preparing for treating the huge numbers that were anticipated would be infected. Across the UK organ donation and transplantation dramatically reduced; almost every kidney transplant unit closed though some heart, lung, and liver transplants did take place. The Belfast City Hospital (BCH) was requisitioned as the Nightingale Hospital for NI, so the theatre suite was closed and the last kidney transplant took place in mid-March.



Of course, the need for life-transforming and life-saving transplant surgery did not disappear. And faced with kidneys that were being buried rather than transplanted, the transplant team began to think about a possible solution. No operation could take place in the Belfast City Hospital (BCH). Could we operate somewhere else? Emergency theatre provision was essential for non-COVID related disease, and for Belfast this was maintained in the Royal Victoria Hospital (RVH). This might be an option. However the transplant ward and staff were all in the BCH hospital (albeit relocated to a different level, with many of the nursing

staff deployed elsewhere and fewer beds – since the transplant programme was closed!). So where and how could we look after patients, even if we could do the operation? And if we could do the operation, and find somewhere to care for the patients, how could we ensure they could be safely followed-up? All out-patient facilities had closed, and what if they needed to have a second operation? It seemed improbable that these issues could be resolved. Improbable? Yes. Impossible? No.

In mid-April two kidney transplants were performed simultaneously in the RVH. This was the start of the new Royal Victoria Hospital Transplant Unit, which over the next 7.5 weeks became the busiest kidney transplant unit in the UK – carrying out a third of all the kidney transplants in the UK.

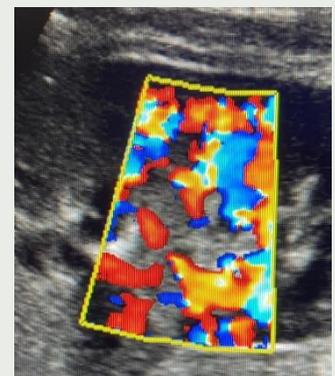
To achieve this number of transplants, 63 in this period, would have been incredible even in 'normal' circumstances. To do this in a hospital where there had never previously been a kidney transplant and in the midst of the exacting restrictions imposed by COVID-19 precautions was herculean. One transplant was even undertaken in the Ulster Independent Clinic, with the staff willingly going out of their way to facilitate this when there was no capacity in the RVH. In early June the programme returned to the BCH hospital, with the surgeons then operating exclusively at night or weekends. A brutal regimen, but one that each embraced as the alternative was to deny a patient a transplant.



On a practical level, the success of this 'story' depended on a massive number of staff (medical, surgical, nursing, laboratory, clerical, managerial) being willing to think innovatively, work differently, take on new roles, and most importantly work collaboratively together. The non-exhaustive list includes: the anaesthetic, theatre and recovery teams in RVH; the current and retired transplant theatre nursing sisters in BCH; the Burns Unit in the RVH (who at short notice, agreed to provide the immediate pre- and post-

operative care for all the transplant patients, even though none had any experience of this previously); the BCH transplant nurses (who went willingly to work in RVH to support the Burns Unit staff); and the staff in the transplant laboratory (who had additionally taken on much of the COVID testing for NI). The post-operative and outpatient care also had to be adapted to the 'new normal' with rapid discharge planning (essential to minimise time in hospital), and the typical numbers that could be seen at clinic were dramatically reduced, at the time when the volume of patients needing seen twice a week was increased 8-fold. The ward staff, pharmacists, and outpatient teams quickly developed innovative approaches and showed immense agility in changing practice, including working routinely at weekends that was essential to successful post-transplant care.

It is important to note that patients with COVID-19 disease are precluded from donating, so no organs are offered for transplantation from such patients. The temporary increase in availability of kidneys for NI patients, simply reflected the closure of other UK units to transplant because of the pandemic restrictions. It was anticipated that by opening in mid-April Belfast might have a 2-3 weeks head start. It turned out to be a 2-3 month period. Other units reopened one by one and by the final week in July when all were transplanting again, we had performed 101 deceased donor transplants in 101 days. Ordinarily we would expect 14 in that period.



Ultrasound scan of newly transplanted kidney

This was an unprecedented era for renal failure patients in NI. An extraordinary golden-transplant-COVID-cloud-lining. The transplant team, in its very broadest sense, were inspirational in its willingness and enthusiasm to adapt, innovate, and work exceptionally hard. In so doing it has serviced its people and fulfilled its purpose.

By Susan Mussen



My husband, Harry had his right kidney removed 14 years ago at the age of 54. When the cancer returned to the left kidney four years ago, it was our worst nightmare. After removal of the second kidney, Harry started his three dialysis sessions per week, initially in the B.C.H. Renal Unit then moving on to Knockbreda Haemodialysis Self-Care Unit.

Life was very different for us. Following a Renal diet and very strict fluid restrictions (500ml per day max) was not easy. Luckily I like cooking so I managed, with the help of all the cookery books the renal dietitians gave me, to create meals that were suitable for Harry. Going out for a meal was a rare treat! We also greatly missed going on holidays and just managed to get the odd night away, and then back in time for dialysis.

When, in the middle of lockdown we were woken on Thursday 31 April at 8 a.m. by Dr. Courtney to tell Harry they had a kidney for him, we were shocked beyond words. We'd been on the kidney sharing scheme, as I was not a match for Harry and due to lockdown getting a kidney was the last thing on our minds. Dr. Courtney told us to take 15 minutes to think about it and return her call. She explained the process and the precautions they were taking due to Covid so, as Harry had already had one unsuccessful trip to the Transplant Unit in November 2019, we felt it was a wonderful chance to get that much needed kidney. Dr. Courtney also told us that Harry was the 21st kidney transplant to take place during lockdown. (By the end of July, I believe it was in the 90's!) When I left Harry off at the door of The Tower Block about an hour later, I think we were both still in shock. It was an emotional farewell. Harry was transferred to the RVH where the surgery was going to take place. I put in a very long and worrying day, not helped by the fact that my son and daughter couldn't even be with me, due to the Covid restrictions. I was so upset thinking that I wasn't going to be able to be there for him during his time in hospital. The sheer relief when Mr Tim Brown so thoughtfully rang me at 9.30 p.m. to tell me, "Harry's operation couldn't have gone better and he's got a good kidney!" At about 11.30 p.m. the Nurse in the RVH recovery ward rang me to tell me he was doing well and even gave him the phone so he could say goodnight to me. This was so very kind and comforting.

The next day, Harry was transferred back to the Renal Ward in the City, which was very good news as this was the unit in which we had so much faith. Harry had a tough few days after his surgery and it was very difficult for the family not to be able to see for ourselves how he was doing. We spoke twice a day on the phone, and a few

times when I was feeling anxious about him, I rang the ward where I was always reassured that they were happy with his progress.

Exactly seven days later, I picked Harry up at the front door of the Hospital. I have to admit I was shocked when I saw him being wheeled out, wearing a mask and looking very pale! This was a tearful reunion. Although Harry was very weak when he got home he was in no pain, which was absolutely amazing.

Since then, I have driven him up and down to the hospital twice a week for his check-ups. I waited in the car as, due to Covid, I wasn't allowed to accompany him. These check-ups were so reassuring being told that the kidney was working well. They are now once a fortnight.

My daughter, Clare and son-in-law, Colin were so grateful to the Kidney Team for the amazing work they were doing during the Covid lockdown, that they felt they wanted to raise some money for N.I. Kidney Charities to thank them for their wonderful work. Colin had always wanted to run a marathon so he had the idea that he would run one. He had been running, in his district during lockdown, in order to keep fit. He planned his route and off he went. Below is a photo of him on his return with his two sons 26.3 miles later!

They put a Just Giving Page on the internet and due to the generosity of our family, friends and many others, managed to raise £4,650. We were so proud of Colin and Clare raising this amount.

I am glad to say Harry is doing very well and is enjoying being able to eat and drink freely, and it's a relief not to be on that Renal diet! Although life is not back to normal due to Covid, we know it will be one day.

Harry doesn't miss his dialysis three times a week but I know he misses his "second family" in Knockbreda Haemodialysis Unit for keeping him so well for 2 ½ years.

What can we say about the B.C.H. Renal Team?

First, it is a TEAM – from top to bottom. The way in which they turned the disaster of Covid into an opportunity to transplant so many N.I. patients is truly remarkable. It is a world-class team developed over many years on the experience of those visionaries who had the foresight to make Belfast the leading global, renal centre that it is today.

Thank you all, from the bottom of our hearts.



A LIVING DONOR STORY

By Mark Boyce

I had known Justin for quite some time before I became fully aware of the seriousness of his illness. Justin was never one to complain and it was only when I began to see first hand the full extent of the pain and torture my friend was suffering that I had my eyes opened to how poor a quality of life he actually had. I witnessed him missing out on seeing his boys growing up and enjoying his life with his family and as a new father myself I couldn't imagine this pain.

When his wife told me that there was a living donor programme that anyone could join it really was a "no brainer" for me, within a few weeks of the initial conversation with the living donor coordinators I had completed all of my tests and had been approved to be a living donor for Justin. We weren't a perfect blood match but we scored very highly with our genetic markers which was a real bonus. The funny thing is we had to prove our friendship before the donation could go ahead and after weeks of searching photo albums and phones for pictures of us together we could only manage to find three or four, there were plenty of pictures of my wife, Judith, and Justin and Justin's wife, Sharon and me, but very few of us two together or indeed all four of us together.

The surgery itself was very straightforward, the living donor programme was very professional from start to finish, it was an experience i am very glad that I went through and one which I will never forget, I made a very quick recovery post-surgery and was home within 3 days and back to work within the week. Justin took a little longer to recover but that's not surprising given the abuse his body had suffered over the years of his disease and also dialysis.

It is without doubt the most rewarding thing that I have ever done, to see the change in Justin's quality of life, to see him back working, training, holidaying with his family. It honestly gives me so much happiness and satisfaction that I was able to in some way contribute to that and give him his life back essentially. Since the surgery Justin and myself and our families have only got closer and we now just treat them as part of our family because that's just how it feels.

For anyone considering becoming a living donor I personally couldn't recommend it enough, it has been one of the most memorable events in my life and knowing that I have given a good friend a second shot at life is irreplaceable. I suppose my decision to become a donor was heavily influenced by upbringing where I was taught "do unto others as you would have them do unto you"



By Mary Heaney (Joe's Mum)



Joe with his dad

My son Joe aged 8 and a half years was one of the lucky ones to have had his second living donor kidney transplant on 7th July 2020 at the Royal Belfast Hospital for Sick Children thanks to the amazing effort of the Belfast Transplant team.

Joe was fortunate that both myself and his father were deemed a match for donating, and so never required dialysis. Joe received his first transplant 4 years ago in June '16 from myself and his second from his father Bryan in July this year. Two very different experiences for both Joe and his family.

Looking back transplant during Covid was quite a lonely experience, no visitors dropping in to wish him good luck, no hugs and kisses from his extended family, no grandparents coming to stay to provide vital support to mind his older siblings, cook dinners, offer a badly needed hug to his parents or help out in any

way they could. This time round we had to work as a tight family unit of 3 reduced from 5 with his brother and sister shipped off to family in Sligo for 3 weeks.

On the eve of the transplant a drive by drop off was performed at the City Hospital with Bryan heading off to prepare for his part with a wave and a promise to see us in a few days. Joe and myself checked into the Children's Hospital to a totally different experience from 4 years previously. We were met with a friendly smile behind every PPE mask but this time round there were lots of changes:

Confined to our room in Barbour ward, there was the dreaded Covid Test of which we were becoming accustomed too but still ran from, the dislike of PPE and wishing we could see everyone's face, Joe's long road

to theatre without his mother to hold his anxious hand, wipe away his tears of fear and give him a comforting kiss goodbye. Although this role was more than adequately performed by the wonderful play therapists. When he was feeling better there was no freedom to visit the playroom to relieve the boredom, no chatting with other patients or sneaky glimpses of his siblings in the hospital corridor during parent hand over time, this had to be done virtually with daily facetime calls and the constant reminding to wear a mask when leaving his room. This time round Joe had only the staff, his mother and endless boxes of Lego to entertain him and help fill his days, of which there were many as it was nearly 34 days before he finally got his official discharge papers.

Joe has taken all this in his stride although he did mention on one occasion during the early days in PICU that he “didn't sign up for this” but thanks to the fantastic and dedicated staff involved: from the skill of the consultants and surgeons to the friendly smiles of the domestic staff and all the important people in between, Joe has come through a stronger, hopefully healthier, more energetic little boy, who has a new found love for food especially a good Ribeye steak, as Joe has proudly reported “this is Definitely not a vegetarian kidney”. We owe a massive thank you to the incredible staff who work tirelessly, going over and beyond to give all the paediatric renal patients 110% to change their lives for the better especially during this unprecedented time.

FROM A DAD'S PERSPECTIVE

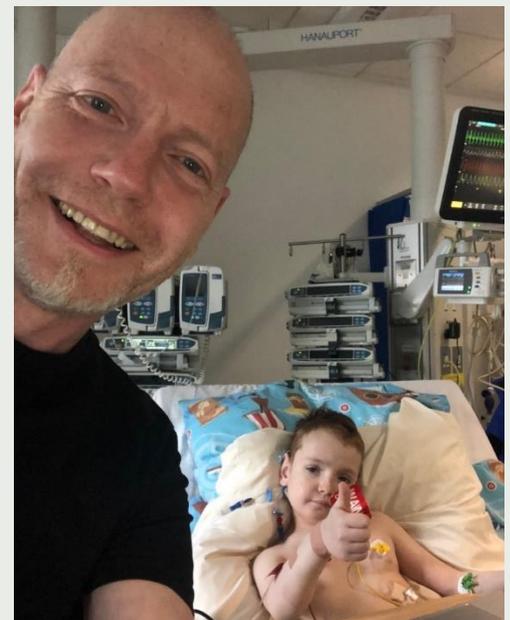
By Brian Heaney (Joe's Dad)

We were heading into this one slightly earlier than previously envisaged, approx 20 years too early in fact. My wife Mary had donated her Kidney 3 years ago to Joe & although all worked great at the start, a few complications meant that things started to deteriorate meaning we had to go for the 'back up'..... this time it was my turn.

When your on a waiting list, be it to receive a Kidney or in this case donate one, you never really know when it will happen, & when it does you never think it would happen so quickly. To be honest no time to deliberate is the best way to make decisions & get prepared. The initial tests had been carried out in the year previous so all the ground work was complete & ok to go. Joe & I are very similar in many ways so it didn't come to me as a surprise during the initial tests that we would be compatible, I took it for granted the Kidney would suit.

In fact we would laugh that my real job in life would be to keep Joes 'back-up' in storage, carry it around for him for a few years, keep it safe. Then some day down the line, when he's fallen off a mountain bike or come a cropper at an extreme sports event (something he's probably likely to do) he would give me a call “Dad ...you wouldn't give me a lend of that Kidney would you?” Sure enough I would rack up & do what all Dads do & help out their Kids when they need them.

In reality it wasn't quite like that. There was no cool Mountain bike accident after 20 years with his Mum's Kidney, no.... just a lad who needed sorted.



It was month 4 of Covid lockdown, July 7th. Things were starting to open up & get back to the 'new normal', but we remained in our family cocoon. My being from Tyrone & Mary from Sligo has always meant having to ask extended families to travel up & help out. This time support would be restricted & we would have to go it alone. We had done it before with Mary, so knew the format which made planning a lot easier. Joe's older brother & sister were shipped to Sligo & the family unit was down to an essential three.

Mary & Joe dropped me off at the City Hospital. No reason to pull in & park-up as they couldn't go in, "see yous on the other side" a few fist bumps & hugs & they headed off to the Royal. I made my way up to the 11th.

From the moment I entered the Kidney unit I was made welcome. The staff were brilliant & my donor co-ordinator guided me through & answered any questions. It took me a while to change into pyjamas & get into bed as it was mid-week, late afternoon, I'm feeling great, why am I getting into bed in a Hospital? It took a while to acclimatise & settle into the role. Mary & Joe were over in the Royal. A face-time confirmed they were fine. I had been in Mary's position three years previous. This time its a role reversal I'm in the City, they are in the Royal.

The procedure was first thing the next morning. I woke up feeling slightly sore but fine. All went well, so it was just a case of waiting to see how Joe get's on while recuperating at my sister's.

Recovery for Joe was slow for the first few weeks. Everyone put it down to him getting a Tyrone Kidney, knowing that its going to be 'thran' & not going to do what you want it to do. Give it time & it will come around & sure enough thankfully thats what happened.

The whole experience has been life changing, especially for Joe. He's a different man with so much energy, & a zest for life. The only concern now that I have is, if he puts all this new energy into mountain biking, an extreme sport, has an accident & possibly damages the Tyrone Kidney..... who's he going to call?

TRANSPLANTATION – A NEW NURSE'S PERSPECTIVE

By Jill Lennon

In April of 2020 I had the privilege of being present for the surgery of a kidney transplant whilst all the Covid restrictions in hospitals throughout the UK were in place.

I was amazed and totally inspired by the organization and co-ordination that was involved prior to the actual surgery of transplant, and how smoothly the events unfolded to give a patient on dialysis a new chance of 'normal life.' A total of 101 of these transplants were performed by the team in as many days.



It was emotional also thinking of the family of the donor, who through their grief knew that the donation of a kidney would give someone else this amazing gift.

The skill of the surgeons involved and indeed the whole team is incredible, and their passion and total dedication is way beyond the call of duty. This experience is something that will never leave me and I am in total awe of the team!

By Catherine McKeown

Catherine McKeown commenced her role as Organ Donation Promotion Manager for Northern Ireland in July. She is based at the Public Health Agency in Linenhall Street, Belfast. Below she tells us about the role:

I am delighted to now be in post as the regional Organ Donation Promotion Manager. It has been a difficult and strange few months for all of us, but moving jobs in the middle of a pandemic has been particularly interesting.



Having seen the role advertised at the start of the year, it really stood out to me and I was immediately motivated to apply. The processing of the post took a bit longer than normal given the additional pressures the pandemic brought to recruitment within health and social care, but I was delighted to start the role in July.

Having worked solidly from home since lockdown in March, adjusting to a new role, workplace, and only being able to 'virtually' meet new work colleagues, took a bit of getting used to!

The main focus of my role is to work between the Department of Health and the PHA to advance Organ Donation in Northern Ireland. A key part of this will be the development of co-ordinated communications paired with creating strong strategic partnerships.

My first few weeks were focused on meeting all the partners in the organ donation family, the Trusts and the organ donation charities, and I would certainly describe it as a family. The level of support, enthusiasm, and dedication has been overwhelming.

It would be fair to say I have hit the ground running as the first big initiative of Organ Donation Week came around very quickly at the start of September. An amazing amount of content and coverage was achieved across the week to help promote awareness of organ donation and to get conversations started. I was able to secure support from other key partners such as all the Local Councils as well as establishing valuable contacts in the local emergency services and the prison service, further and higher education providers, and a number of other organisations to promote organ donation to staff via internal channels, and where possible on social channels.

I have really enjoyed my first two months as I particularly enjoy working on campaigns and initiatives, as well as stakeholder development. I'm now looking forward to establishing a rolling annual plan for more sustained promotion of organ donation and to capitalise on a range of new opportunities.



Having worked in Marketing and Communications for 20 years, I bring a range of knowledge and experience to this post. I started my career in the advertising industry managing marketing communications for a range of public and private sector organisations. This provided me with excellent experience in a range of industry sectors, however I knew that I would particularly enjoy putting my skills to use in sectors that would enhance opportunities to improve or 'make a difference' to individuals health, wellbeing or education. Most recently I worked as Marketing Communications Manager for Ulster University where campaigns and communications were central to the role across a wide range of initiatives internally and externally. Prior to that, I worked within the Communications team at Sport Northern Ireland where I was responsible for the promotion of sport and physical activity at all levels with a heavy emphasis on partner working across sporting bodies, local councils, Government departments and other organisations.

Personally, I enjoy all things fitness, in particular outdoor sports such as hillwalking with my dog (both of us preferring the more gentle climbs now!) and snowboarding.

I count myself very lucky to have taken up this role and look forward to continuing to work with so many passionate, supportive and enthusiastic individuals and organisations.

A Kaleidoscope of NIKPA Butterflies

In 2010, it was decided to change the NIKPA logo from a red shield to a Blue Butterfly with a red kidney in the lower right wing lobe to reflect the goals and objectives of NIKPA.

The Butterfly symbolises Life and encourages patients whether on dialysis or transplanted to spread their wings and show the world their true colours.

NIKPA aims to support the Northern Ireland renal patients and families to Live Life as much as possible.

THE BADGES ...

GENERIC BLUE AND RED NIKPA BUTTERFLY BADGE

The first badge created is the generic NIKPA Blue and Red Butterfly which everyone can wear to support NIKPA. The design comes from the first original red and blue donor card with the NIKPA Butterfly being cut out of it to reflect a primary objective of NIKPA being the promotion of organ donation, the Gift of Life.



THE NIKPA "LIVE DONOR" GOLDEN BADGE

This NIKPA "LIVE DONOR" Golden badge was created to reflect NIKPA's admiration and gratitude to the Live Kidney Donors who give the Gift of Life.

This is presented to the Live Donor a couple of weeks after donation.



THE NIKPA SILVER MERIT BADGE

The NIKPA SILVER MERIT BADGE was created to acknowledge people who do something extra special for NIKPA.



THE NIKPA COVID 19 ACKNOWLEDGEMENT BADGE

This is a NIKPA SILVER BUTTERFLYBADGE given to every renal staff member in Northern Ireland to acknowledge their courage and compassion during the COVID 19 pandemic.

NIKPA wished to acknowledge the amazing courage, dedication and compassion of all the renal staff throughout Northern Ireland during the COVID 19 pandemic.

Every member of renal staff stepped up to ensure all the renal patients could continue dialysis during COVID in as safe an environment as possible.

It truly was a wonderful team effort and displayed the commitment of all the staff for their patients.

It was also decided to accompany the badge with a beautifully written poem by Jean Michelo, a transplant recipient, expressing the gratitude felt by all the renal patients. During Organ Donation week in September nearly 900 silver badges and poems were delivered to the eight dialysis centres in Northern Ireland.

THE NIKPA TRANSPLANT RECIPIENT BUTTERFLY BADGE

This is the latest badge to be created and will be distributed later in the year.

It is designed to acknowledge the strength of transplant recipients and also thank all donors, live and deceased.

Purple is the colour of the FORGET-ME-NOT flower with a golden rim to symbolise and thank all the donors.



During September 2020, NIKPA Committee members have delivered silver NIKPA butterfly badges to the staff of all the renal units to thank them for their dedication, hard work and extraordinary care through the Covid-19 crisis. This beautiful poem was written Jean Michelo to accompany the badges.



For You

A poem by Jean Michelo

*You've always been on the front line.
That didn't really change.
Winter, summer, spring, or fall
You have been there for us all.
You've always been on the front line
And when it mattered most
In darkness and uncertainty
You never left your post.
You stood your ground
Deeper courage found
To take the enemy on
In hand to hand combat, night and day, keeping the silent foe at bay.
With all your heart, body, soul, mind and might;
You did this,

for US.*

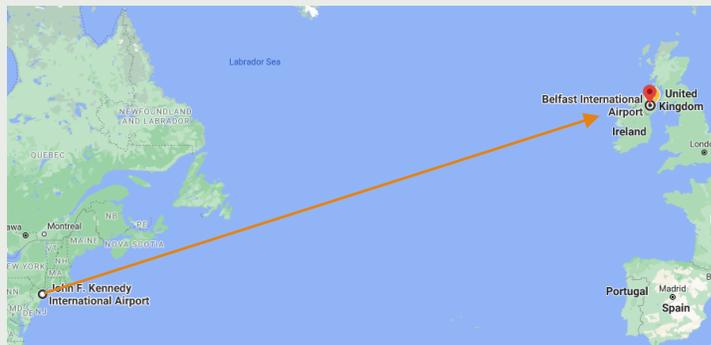


Jean Michelo
Vice Chair of
Northern Ireland Kidney Patients' Association

Patty Gilbert(NIKPA Co-Chair) talks with Anne McAfee

Sr Samantha Jennings had been asked by NIKPA if any dialysis patient at the City Hospital Unit might be willing to contribute to this Newsletter. She put me in touch with Anne and told me that not only did Anne volunteer to be interviewed, she had quite a story to tell.

Over 20 years Anne had no cause to attend a doctor until, in 2013 she was admitted to hospital in New York with acute appendicitis and was also told she was very severely anaemic. Additional tests uncovered the cause of Anne's significant level of weariness. She had renal disease necessitating dialysis. At home her father and brother were very anxious to get Anne back to Northern Ireland to enable the family to 'keep an eye' on her. Anne however had lived a very independent life, looking after children and often organising the whole household enabling it to run smoothly. She thrived on this way of life, living in New York and enjoying the activities of an energetic city. She insisted she didn't need an eye being kept on her!



Change did come in an all too dramatic form when, in December 2014 Anne was on the up escalators in a New York train station when she experienced a stroke. With no other travellers behind to break her fall she landed at the bottom of the escalator and the next thing she recalled was waking up in hospital.

This time her father and brother would not take 'no' for an answer. When she was well enough to travel her father made special arrangements to return Anne home to NI. She was taken straight from the aircraft to Antrim Area Hospital.



Anne McAfee

With her condition eventually stabilised Anne has been on haemodialysis three times weekly, initially at Antrim and for the past 3 years in the City Hospital after she moved house closer to Belfast.

Anne acknowledges she had hoped to receive a kidney transplant. This is no longer part of her treatment plan due to other complicating medical conditions. The early months of 2020 were particularly difficult as she emotionally wrestled with the reality that she would be dependent upon dialysis for the rest of her life. Anne describes the news as, 'A huge blow. I'm only 57. There was a sense of losing hope, though I had to accept it. I'm a tough cookie and I enjoy life too much to give up.'

2020 had another shock for Anne when she contracted Covid 19. She recalls thinking, 'I'm a goner' when her condition deteriorated and she was admitted to Level 11 of the City hospital. On day 7 she felt particularly low. With no visitors coming into the hospital Anne called her 'level headed' nephew who 'talked some sense into me and gave me encouragement to keep going one day at a time.' This conversation together with the inspirational care of all the staff enabled Anne to hold on to her fighting spirit.

Anne commented several times during our conversation how much she appreciated her medical care, 'We don't talk enough about how wonderful they are up there on level 11. Even the man who brought round our tea lifted the mood of patients. From the moment of testing the staff were very clear with me what was happening at each step. They should be on the TV and have books written about them they are a phenomenal team'

After three weeks Anne was discharged home though wasn't yet finished with the hospital. The next day, feeling unwell she was readmitted this time with a bleeding ulcer. This complication has now been resolved.

Throughout all of this Anne's dialysis continued. She considers that dialysis has altered her focus. 'Its made me take responsibility for myself. 'I'm committed to show up for dialysis three days a week, Monday, Wednesday and Friday. I owe it to the great people caring for me in the Unit and my brother and sister in law at home.'

Asked what motivates her to keep going Anne described moving house in recent weeks and being able to sit in the sun surrounded by beauty. 'I live for moments like that and I still have plans for life'

At 21 Anne was engaged to man who died in tragic circumstances. She recalls how angry she felt at the time and this in part contributed to her leaving for America making decisions for herself, seeking independence.

The transitions of life have proved difficult to manage. Thus, the impact of becoming dependent upon a dialysis machine with no prospect of a transplant prompted Anne to turn to meditation to find peace of mind. At a time she had a line in her neck and felt like an alien and ugly. The dialysis was to her, akin to 'dracula' taking her blood. Combating these thoughts Anne sought to rationalise and take ownership of her thinking, 'this machine is keeping me alive.' To bolster her understanding of dialysis Anne read and researched the topic and continues to avail of opportunities to ask questions should something new confront her.

If in a position to talk with someone just commencing dialysis Anne's advice is clear;

'Get educated about the process and get onboard with what you can do to keep yourself well. The more responsible you are the smother everything runs. When you feel low, don't be afraid to ask for help, that's the big issue for me as I was so independent and it was very hard recognising I needed help from my family.'

In conclusion, Anne adds, 'None of us knew what we were getting into with Covid 19. Everyone was a little scared. I was scared but handed it over to staff as I wasn't able to care for myself. I want them to know how much that meant to me to be able to hand it over to them.'

By Anna Wilson



The Renal Arts Group is a collaboration between patients, carers, clinicians, academics and artists to develop a programme of research with the ultimate aim of improving the physical and psychological quality of life of those living with kidney disease.

In 2016 the Renal Arts Group (RAG) was established at Queen's University Belfast (QUB) following a suggestion by members of NIKPA with an interest in arts-based

activities. The group is co-chaired by Dr Helen Noble, a nephrology nurse and Reader at QUB and William Johnston, the Northern Ireland Advocate for Kidney Care UK. It was formed to highlight the effects of living with kidney disease through the medium of art and to promote kidney transplantation. RAG is undertaking a number of activities to promote the benefits of the arts and support renal patients.

Script Development Project

The group received funding from the Arts Council of Northern Ireland to develop William Johnston's script for 'The Starman, The Superhero and The Wizards'. William began writing poetry and plays during his dialysis sessions, and found writing helped express his feelings and communicate better with healthcare staff, as well as being a productive and enjoyable way to pass the time spent on dialysis. William has been developing his script under the mentorship of award-winning playwright and producer Shannon Yee, which will culminate in a performance of the play in a theatre space with professional actors.



As part of this project we have been able to offer a series of scriptwriting workshops, facilitated by Shannon, to members of the renal community. The workshops offer the opportunity to develop script-writing skills, and also open up the conversation around organ donation, chronic illness, life on dialysis, life post-transplant, and how creative writing and the arts can be beneficial to the individual's journey. If you are interested in taking part in the workshops please email anna.wilson@qub.ac.uk.

Guidance for Volunteer-led Arts Interventions

Dr Helen Noble, in collaboration with Claire Carswell, Anna Wilson, and the Northern Health and Social Care Trust, have been awarded funding by the Economic and Social Research Council to draw up guidelines for future implementation of volunteer-led arts interventions in renal units. The guidelines are based on Claire's PhD studentship, which saw the successful development and implementation of an arts-based intervention for patients during their haemodialysis treatment.

The guidelines are being informed by a series of online meetings and workshops with NHSCT staff, patients and artists and will be disseminated across Northern Ireland and through national arts and health organisations.

Online Arts Activities

Dr Helen Noble and Anna Wilson have been awarded additional funding by the ESRC to develop a series of online arts-based activities that will build upon the work of RAG. As we are unable to run in-person events and workshops due to the ongoing pandemic, the online activities will provide an introduction to a range of art forms that we hope patients will find engaging and enjoyable. The arts activities will be:

- Printmaking with Ruth Osborne
- Drawing with Claire Carswell
- Creative writing with Shannon Yee
- Music with Ian Walsh.

The arts activities will run once a month beginning in October. You can keep up to date about all our projects by visiting our website www.qub.ac.uk/sites/renal-arts-group or by following us on our social media channels.

www.twitter.com/RenalArtsGroup

www.facebook.com/renalartsgroupqub

www.instagram.com/renalartsgroupqub

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.

NIKPA, c/o Dialysis Unit, Belfast City Hospital, Lisburn Road, Belfast BT9 7AB - email: info@nikpa.org, HMRC Charities Ref. No: NI00338, Northern Ireland Charity number: NIC104608