

## Editorial





**Irish Kidney Association CLG** 

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Welcome to our Spring issue of SUPPORT.

efore we report on activity this year, it is worth noting the many achievements in the past year. There have been some really positive developments. We are now providing our highest ever level of patient support in the history of the Association, as you can read about on page 51.

We launched our new Peer Support Service for patients (page 50). This is a really exciting development and already patients are telling us how much it is helping them.

We also started to return to a different type of normality. We saw the number of transplant operations taking place moving back in the right direction although we have yet to return to the fiveyear pre-COVID average (see pages 42-43).

Sadly, in the past year, many of us lost loved ones and a huge loss to the IKA family was Patricia Mackenzie, who touched the hearts of so many in her work at the Renal Support Centre at Beaumont Hospital. You can read our tributes to other valued friends, including Angeline Cooke, one of the Cofounders of the Irish Kidney Association, who have passed away this year, page 58-59.

Speaking about the Renal Support Centre, building inspections have been performed and meetings with Beaumont Hospital management were held.

The reopening of the centre is a top priority for the IKA Board.

Work continues on the new Support Centre in Cork and we hope to see it open in June.

In our winter magazine, we asked readers to complete a survey to get your views on the needs of our community and ensure that we are working on your top priorities. We received some really interesting feedback and will report on this in the next edition of SUPPORT magazine.

Disappointingly, however, only one hundred responses were received, showing we have plenty of work to do to encourage our community to give us more feedback. We do love hearing from you, whether it is positive feedback such as compliments or perhaps something we need to improve on.

Demand for our services continues to increase as the cost of living puts increasing pressure on people. So, we are busy working in the backroom to make sure we continue to meet this demand. For example, we put in a new phone system to make it easier to transfer calls. This caused some temporary problems for people trying to contact us, for which we apologise to those affected.

The Human Tissue Bill was debated in the Dáil in January. We prepared a detailed submission, which was approved by the Board. It was good to see so many of our questions being raised and discussed in the Dáil.

We also had a discussion with senior people in the Minister for



#### FRONT COVER

**Prof. George Mellotte, Consultant Nephrologist** and Clinical Lead. **National Renal Office.** (right seated) with his patient Paul Owens, launching the **'Kidney Health and Heart Health** Go Hand in Hand' campaign to mark **World Kidney Day** Photo: Conor McCabe

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**CHARITY REGISTRATION NO. 20011260** 

Health's office and we did interviews on various local radio stations. It is very welcome to see this longawaited Bill progressing, although we have requested some amendments.

Copies of our submission have been sent to Branch Officers and can also be requested by emailing info@ika.ie. We will also be providing a user-friendly guide to the Bill and the IKA's position on it, which will be issued to all members.

To mark World Kidney Day, which was held on 9th March, we launched a campaign about the links between kidney and cardiac disease, a topic which all patients with kidney disease should be aware of. The ongoing awareness campaign is also directed at healthcare professionals.

We partnered with the National Renal Office, the Irish Heart Foundation, and Croí, for the campaign. Partnering with other organisations is a key part of our strategy, as by working together we can achieve more for patients. You can find out all about this campaign on pages 4 to 8.

We had another Branch forum recently and discussed a wide range of topics ranging from patient issues to World Kidney Day. A key item we need your help with is understanding the experiences of patients in the healthcare system, so we can campaign for improvements in this area, on your behalf, more effectively.

You can read about an upcoming research project which will be supported by the School of

Population Health (Department of Health Psychology) at the RCSI for which willing survey participants are being sought. See pages 16-17.

As many of you know from personal experience, kidney disease often has no symptoms. I have spoken to people who first found out they needed dialysis in the Hospital Emergency Department! Yet, it is very easy to screen for kidney disease with simple blood and urine tests.

So, it is a major step forward to see the publication of a HSE report which recommends the inclusion of Chronic Kidney Disease (CKD) in the management of chronic diseases in the general practise (GP) programmes.

The GP programme started in 2020, funding GPs for the very first time to manage chronic disease in the community and has been very successful. If CKD is included it will mean kidney disease will be identified much earlier and people will be able to take action to reduce the possibility of ending up on dialysis.

Now we have to make sure Government funding is put in place to make this very exciting development a reality.

We had a very interesting online session on infection control, treatments, and vaccination. We are also currently running a series of six online events in partnership with B. Braun covering everything from understanding kidney disease to nutrition and exercise. You can see details on page 18.

Finally, we have some inspirational stories in this issue, from the launch of the late Liz McCue's entertaining book, *Alfie's Escapades*, which she wrote while receiving dialysis treatment, (pages 44-45). There are two uplifting stories highlighting the unbreakable bond between mothers and their sons, and also about a father whose daughter came to his rescue by donating a kidney to him. We also hear from a nurse who himself has been undergoing peritoneal dialysis for three years.

We also share a Christmas miracle story celebrating two lives which were saved.

You will see on page 32 how 14 transplant recipients are donning their Irish jerseys to participate in the World Transplant Games in Perth in April. All these uplifting stories demonstrate the importance of organ donation for transplantation which only happens thanks to the selflessness of organ donors and their families.

On my parting note, we look forward to a successful Organ Donor Awareness Week campaign which will take place six weeks later than usual, from May 20th-27th.

We hope you will get involved in Organ Donor Awareness Week, by helping to spread awareness or organising events which we can post on our online events calendar. For more information visit www.ika.ie/donorweek.

Wishing you a happy Springtime.

CAROL MOORE CHIEF EXECUTIVE OFFICER

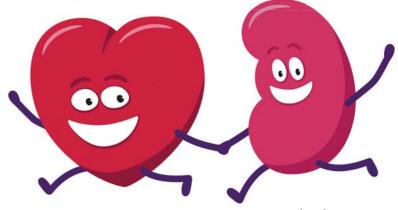
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# WORLD KIDNEY DAY



# Kidney health & Heart health go hand in hand



We are delighted to join forces with the National Renal Office (NRO), together with the Irish Heart Foundation and Croí Heart and Stroke Charity, to raise awareness about the close link between Heart Disease and Chronic Kidney Disease. This ongoing campaign was launched on **World Kidney Day**, which was celebrated on **Thursday**, **9th March 2023**, and included a free public webinar titled **'Kidney and Heart Health Go Hand in Hand'**. The campaign is aimed at both the heart and kidney patient community and the general public with a specific campaign also targeting healthcare professionals online.

eart health and kidney health are closely related, as the heart pumps oxygen-rich blood to all parts of the body including the kidneys, which in turn control blood pressure, and clean the blood (removing waste products). Chronic Kidney Disease (CKD) can cause heart disease and vice versa, making it important to understand the relationship between these two conditions and ways to reduce the risks associated with them.

Known as the 'hidden disease', 1 in 8 people have Chronic Kidney Disease (CKD), with many unaware they have it. While only 1 in 1,000 people will reach End Stage Kidney Disease (ESKD), for which the only treatment is conservative care (which focuses on treating the symptoms of kidney failure as they arise), dialysis or a kidney transplant, those with any of the five stages of CKD are at risk of developing heart disease.

Conservative estimates are that at least 50% of those with CKD Stages 4 or 5 have cardiac disease, and at least 50% of those with heart failure

have CKD.

Diabetes and High Blood Pressure are leading causes of both CKD and heart disease. Even without these conditions, CKD can increase the risk of heart problems, and heart disease can lead to kidney problems.

CKD is often associated with anaemia, which reduces the blood's ability to carry oxygen, putting extra strain on the heart.

To reduce the risk of both kidney disease and heart disease, it is important to follow a healthy diet, be physically active, and stay engaged with your own healthcare. Knowing your numbers, such as blood pressure, blood sugar, and weight, can help detect any changes that may indicate a problem.

Regular check-ups with your doctor, attending specialists' appointments when scheduled, and knowing when to seek urgent medical attention are also important.

Understanding your own medications and ensuring your doctor and pharmacist are aware of all of the medications you take to avoid side effects are also key.

Attending a photocall to announce the campaign at the Museum of Modern Literature in Ireland (MoLI) on St Stephen's Green, Dublin 2, was Prof. George Mellotte, National Clinical Lead, NRO, who said, "The National Renal Office is pleased to support the Irish Kidney Association in its efforts to raise awareness about this important issue. Our shared goal is to educate and empower individuals to take control of their health and to reduce the risk of chronic kidney disease and heart disease. We encourage everyone to participate in this important campaign and to join us in our efforts to improve kidney and heart health in Ireland".

50% OF PEOPLE WITH ADVANCED (STAGES 4 AND 5) CHRONIC KIDNEY DISEASE ARE LIKELY TO HAVE HEART DISEASE.

50% OF PEOPLE WITH HEART FAILURE ARE LIKELY TO HAVE CHRONIC KIDNEY DISEASE.

#### By CWEN O'DONOGHUE

Right: Maeve Frawley, Cardiovascular Nurse Specialist, Croí Heart & Stroke Charity; Carol Moore, Chief Executive, IKA; Prof George Mellotte, Clinical Lead, NRO, and Janis Morrissey, Director of Health Promotion, Irish Heart Foundation; (front left): Paul Owens, a heart patient who developed kidney failure.

Carol Moore, Chief Executive, Irish Kidney Association (IKA), said, "World Kidney Day on 9th March 2023 provided a platform for the IKA to raise awareness about the importance of kidney health and the close relationship with heart health.

"The IKA and the NRO invited all healthcare professionals, pharmacists and the general public to join them in marking the important occasion.

"By working together we can help to reduce the burden of chronic kidney disease and heart disease and improve the health of our communities".

Neil Johnson, CEO, Croí, the Heart & Stroke Charity, advised, "We were delighted to support World Kidney Day as an opportunity to highlight the significant interdependent relationship between our heart and the kidneys. Keeping our hearts healthy helps keep our kidneys healthy and vice versa.

Maintaining good cardiovascular health such as having a balanced and healthy diet, achieving healthy cholesterol and blood pressure levels, taking regular exercise, and having a healthy weight are all linked to a healthy heart and reduces the risk of kidney disease. It is important for people to know that heart health and kidney health are inextricably linked".

Janis Morrissey, Director of Health Promotion with the Irish Heart Foundation, said, "We are proud to partner with the Irish Kidney Association to highlight the close links between heart health and kidney health. By raising awareness together for World Kidney Day, we hope to encourage people with kidney disease or heart disease to talk to their doctor, know the risks they can control and take manageable steps to look after their health."

Several media outlets highlighted the campaign in radio interviews and in print.

The Irish Nephrology Society (INS) also highlighted the campaign on its website and its President Prof. Liam



Plant, did an interview with Cork's 96FM along with kidney transplant recipient Colette Hawe.

The IKA is delighted to have received the support of the Irish Pharmacy Union (IPU), and several pharmacy chains backed the campaign through promotion and display of materials.

The IPU promoted the campaign in the March issue of its magazine *IPU Review*, which has a circulation of just under 2,000, and each issue also had the campaign poster inserted which pharmacies could display in-store.

The pharmacy chains who also came behind the campaign, by

displaying posters on their digital screens and sharing on their social media, included Care Plus Pharmacy, Life Pharmacy, Staywell by United Drug, Hickey's, All Care, and Lloyds.

Further information on the IKA's campaign, including promotional materials (information leaflets, posters and videos) and a recording of the free webinar held on World Kidney Day (explained next page), can be found on the IKA website

#### www.ika.ie/kidneyhealth

The theme for World Kidney Day 2023 was 'Kidney Health For All, Preparing for the Unexpected, Supporting the Vulnerable!'
www.worldkidneyday.org

continued next page..



By working together we can help to reduce the burden of chronic kidney disease and heart disease and improve the health of our communities.

#### **WORLD KIDNEY DAY contd...**

#### WEBINAR

As part of the campaign, a free webinar, which was open to the public and hosted by the Irish Kidney Association (IKA), titled 'Kidney Health and Heart Health Go Hand in Hand', was held on the evening of World Kidney Day, March 9th March.

Carol Moore, the IKA's Chief Executive opened the webinar before introducing guest speakers Prof. George Mellotte and Maeve Frawley, Cardiovascular Nurse Specialist, Croí Heart & Stroke Charity.

Paul Owens, a heart patient who developed kidney disease later, also shared his story (you can read his story on the next page). The guest speakers presentations were followed by a questions and answers session afterwards.

Over one hundred people registered for the event. A poll for feedback from delegates revealed that over 95% would recommend the webinar to others. A video recording of the webinar can be seen on our website

www.ika.ie/kidneyhealth

# Consider holding SADMANS medication if patient is vomiting or has diarrhoea until they are well again

- S sulfonylureas, other secretagogues
- ACE inhibitors
- diuretics, direct renin inhibitor
- **M** metformin
- angiotensin receptor
- N nonsteroidal anti-inflammatory drugs
- SGLT2 inhibitors, or "flozins"

Patients should have individualised recommendations of what to do with these medications if unwell (are dehydrated with vomiting or diarrhoea) to avoid Acute Kidney Injury.

#### **FIVE STAGES OF KIDNEY DISEASE**

STAGE 1	STAGE 2	STAGE 3	STAGE 4	STAGE 5
90%+	89-60%	59-30%	29-15%	<15%
Normal functio		Moderate to	Severe loss	Kidney failure
unless other si (eg. Albumin in		severe loss of function	of function	need dialysis/treatment

# DATE FOR YOUR DIARY

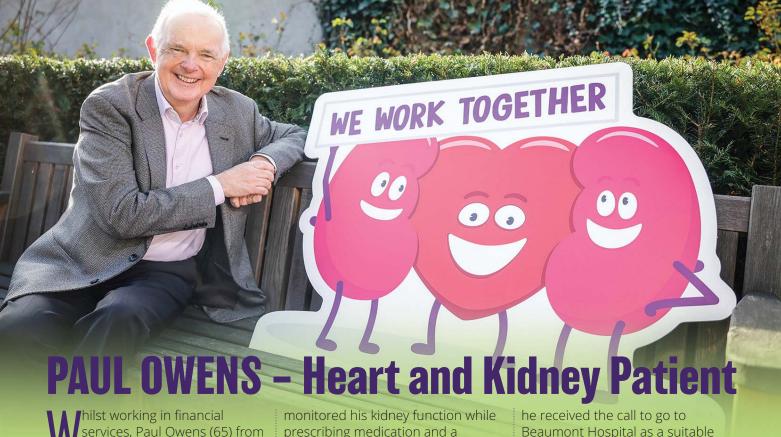


# **Irish Heart**Foundation

With a clear link between kidney health and heart health, keep your eye out for an upcoming **high blood pressure** public awareness campaign from the Irish Heart Foundation.

The campaign, launching in May, aims to increase awareness of high blood pressure and why it matters – including the risk of kidney disease – and encourage people to get their blood pressure checked.

It will include radio and online ads and be supported by posters, flyers and online health information on **irishheart.ie** 



services, Paul Owens (65) from Baldoyle, Co Dublin, underwent a routine corporate medical examination over fifteen years ago which revealed he had high blood pressure. The Bangor native was just 49-years-old, had no outward symptoms, and was unaware he had any health issues.

At the time Paul had a demanding job and was a father of two teenage children. Paul's own father was just a year younger than him, only 48-years-old, when he passed away following a heart attack in 1975.

Following the results of the medical exam, Paul visited his GP, Dr. Tony O'Connor (now retired) who referred him to a cardiologist, Prof. David Keane. Further examination revealed that Paul had some hardening of the arteries and he underwent a procedure to have a stent inserted

Paul carried on with life and didn't experience any further health problems as he continued to attend annual appointments with his cardiologist and was taking medication for his heart disease.

As heart disease can often lead to kidney disease, Prof. Keane decided to refer Paul to nephrologist Prof. George Mellotte who ordered a scan of Paul's kidneys. It was discovered that Paul's kidneys were smaller than normal and had underperforming renal function.

Paul continued to see Prof. Mellotte, every six months, who prescribing medication and a restricted diet to Paul for his chronic kidney disease. Paul complied with this regime with relative ease.

For over ten years Paul's quality of life remained normal while he attended regular GP appointments to monitor his blood pressure and kidney function in-between his appointments with Prof. Mellotte.

These appointments with his nephrologist became more frequent as Paul's kidney function deterioration began to gather pace.

It was in 2019 that Paul's kidney function had reached a low level and by late 2021 it had fallen below 10% function, making it necessary for him to commence dialysis treatment.

In November 2021, he started CAPD dialysis treatment, a form of home dialysis requiring dialysis exchanges 3 to 4 times daily. After two months on CAPD Paul moved to overnight peritoneal dialysis whereby the dialysis exchanges occurred automatically throughout the night while Paul was asleep. This meant that he was able to carry on with his daily life and normal routines.

Paul was able to function well through the day but be experienced tiredness and described how, by evening time, he might fall asleep in the chair.

Paul had prepared himself for the probability he would have to wait years for a donor kidney to become available. However, he was only waiting for six months when, in 2022, Beaumont Hospital as a suitable donor kidney had been identified.

Paul has expressed his profound gratitude to the family of his kidney donor for coming to his rescue by making the selfless decision to consent to organ donation. He said it is "because of their generosity and my kidney donor, I am no longer tied to dialysis treatment and the lifestyle and dietary restrictions it brings with it, and I can enjoy a good quality of

In describing his health journey Paul said, "I had a very quick recovery following my kidney transplant. I was surprised just how well I felt after the transplant as I didn't realise the impact on my energy levels beforehand. I feel I have cheated the potential harsh effects of the symptoms of my kidney and heart disease.

"I credit the early screening I received for both conditions for this positive outcome. My kidney donor has given me a lifeline which I am deeply grateful for. I want to thank my GP, as well as my cardiologist and nephrologist and of course the transplant team at Beaumont Hospital for their excellent care. Because of this coordinated effort, I feel I have been very lucky to experience the best possible health outcome and still be here enjoying life surrounded by my wonderfully supportive wife Geraldine and my now, grown-up children."

#### **WORLD KIDNEY DAY**

Staff from Beaumont Hospital celebrated World Kidney Day. Staff representing the Transplant, Urology and Nephrology (TUN) Directorate came together with an information stand and other activities to highlight their work in caring for kidney patients at every stage along their journey.





eaumont Hospital: Colm Fox, CNM 3; Prof. Conall O' Seaghdha, Consultant Nephrologist, Annette Butler, Directorate Nurse Manager; Ana Bica, Staff Nurse, Renal Day Ward.



 $\textbf{\textit{Beaumont Hospital: Team in Home the rapies supporting and empowering people self-manage their dialysis at home.}$ 

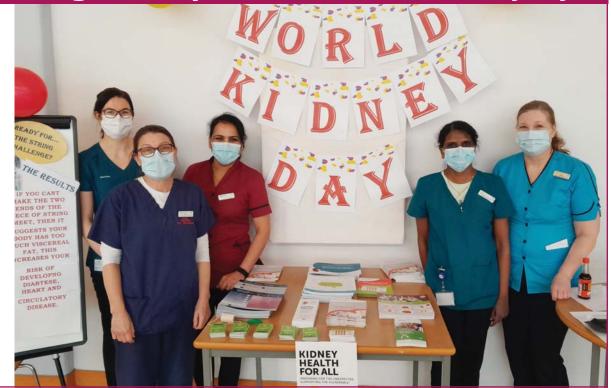








#### Midland Regional Hospital celebrates World Kidney Day



At the Midland Regional Hospital, Tullamore, on World Kidney Day were: Aisling Stapleton, Senior Renal Dietician; Maura Reilly, Vascular Access Nurse; Sani George, ANP (CKD); Karmaleena Thandavarayan, Clinical Facilitator; Maria Bergstrom, CNS (Renal Inpatient Co-Ordinator).

# Kidney transplant patients praise new Diet & Exercise programme at TUH

To mark World Kidney Day,

Tallaght University Hospital
(TUH) held an interactive
stand to raise awareness of
what people can do to prevent
kidney disease, or detect it at
an early stage.

On the same day the hospital celebrated a new programme, which is already bearing fruit, with lots of positive feedback from participants.



Tallaght University Hospital Ospidéal Ollscoile Thamhlachta

An Academic Partner of Trinity College Dublin

Idney transplant recipients have praised a transformational new lifestyle programme at Tallaght University Hospital (TUH). Those who attended the new diet and exercise classes at TUH say it not only improved their overall physical health, but also boosted their confidence.

The eight-week virtual classes took place online, twice per week, and included both an exercise element led by a physiotherapist and an education session led by a dietitian.

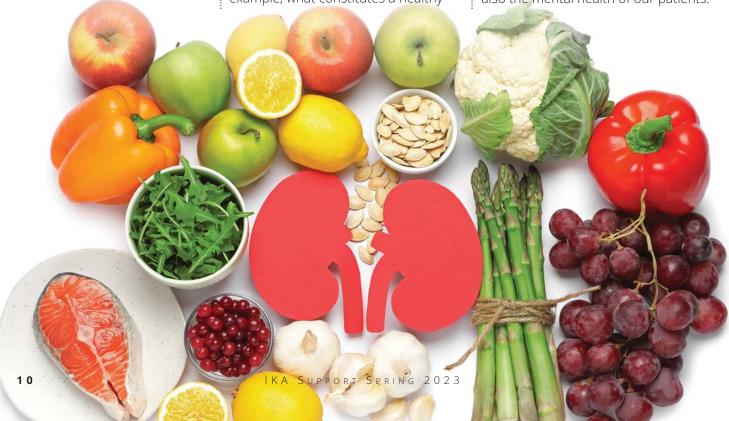
Oonagh Smith, Clinical Specialist Renal Dietitian at TUH said, "The healthy eating element of the programme took the form of a 15-20minute discussion at the start of each online session. As part of this, participants were encouraged to ask any nutrition-related questions, with a different topic discussed each time, for example, what constitutes a healthy diet for kidney disease, as well as menu planning and behaviour change techniques."

Cliona Barrett, Senior Renal Physiotherapist at TUH said, "The fitness classes comprised of both aerobic and strengthening exercises and took place virtually for 45 minutes, twice per week.

The exercise section was adapted to patients' home environment, where no equipment was required except for resistance bands for strengthening exercises. They worked to a moderate intensity level during the class."

Consultant Nephrologist Professor Peter Lavin who is also the lead Clinical Director at TUH said, "There are currently 5,000 adults and children requiring treatment by dialysis or kidney transplantation in Ireland. This is an increase of nearly 50% in 13 years.

"I want to compliment the renal team at TUH for introducing this important initiative. It is showing real benefits not just for the physical but also the mental health of our patients."



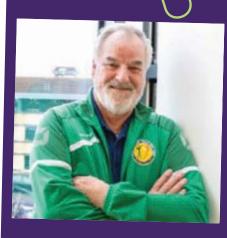
### Patients' feedback on the programme



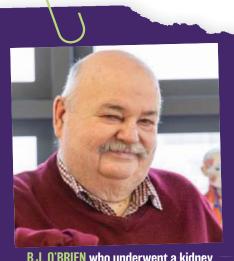
SARAH WILLIAMS who is 14 years post kidney transplant says the new programme came, "At a time when I needed it most for my physical and mental health. It has been great; the combination of exercise and nutrition is so important. I have even started sea swimming. I am more confident and the regular checks with the team in TUH, help keep me on my toes."



FRANCIS DAVIS underwent a kidney transplant 5 years ago. He said "I am feeling much better both physically and mentally and have more confidence since taking up the new diet and fitness programme for transplant patients at Tallaght University Hospital. The support from the team is so important and the programme gets you right back into proper habits. I am now walking and swimming and feel so much better now."



MICHAEL DWYER is 23 years post kidney transplant and is a member of Transplant Team Ireland. He has represented Ireland at World and European Transplant Games events. He said, "The diet and exercise programme for transplant patients run by Tallaght University Hospital was very important to me, not just physically but also to keep my head in order. I would encourage everyone to carry an organ donor card, on this World Kidney Day 2023."



B.J. O'BRIEN who underwent a kidney transplant over 12 years ago said, "The new diet and fitness programme for kidney transplant patients run by Tallaght University Hospital is smashing and I am sticking to it. This is the first time I have ever tried something like this. It is a challenge but the benefits are so worth it.

My vitals are improving."



KEITH ARMSTRONG who underwent a kidney transplant a year ago said, the new diet and fitness programme for kidney transplant patients at Tallaght University Hospital has been very important to him.

"I learnt all about keeping fit and healthy and can push myself a lot further now. I don't get so out of breath and am getting out more. I have taken up wheelchair rugby and have gone back to college."



Cork man who received a kidney transplant, thanks to his donor mother, had more reason than most to celebrate Mother's Day recently. Neil Coleman (30) who received a kidney donated by his mother Marion, agreed to support the Irish Kidney Association in increasing organ donor awareness by sharing their health story with the media for Mother's Day which was celebrated this year on Sunday, 19th March.

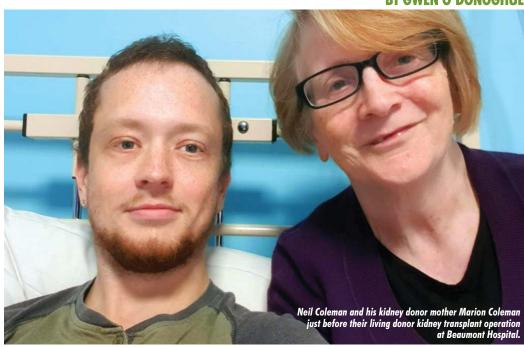
Their story was widely covered in national and local print media and they also did some radio interviews.

Neil from Charleville, Cork said, "To attempt to express my gratitude through words would be a disservice to the immeasurable gift my mam has given. I'm alive today due to her selfless donation and words will always fall short of how that really makes me feel. While my gratitude is, and always will be ever-present, I'll still take every opportunity I have to express it that much more to her."

Marion, a native of Churchtown in Dublin, is a grandmother of two, and was 62-years-old when she donated one of her kidneys to Neil, her youngest of three sons, on 13th September 2021.

Neil's shock diagnosis of kidney failure came in 2018, when he was 25. He had been struggling for years with tiredness and lack of concentration. He said, "While a group of family members and friends stepped forward wanting to donate a kidney to me, my mam was first in line".

The operation took place at Beaumont



Hospital and Neil had to stay in isolation for three months afterwards as the global pandemic prevailed.

Two days after the operation Neil and Marion, who were in separate rooms in a ward for isolating patients, reunited with a warm embrace.

Neil said, "It's not so much the embrace that has stuck with me but rather chatting to my mother while I was still bedridden and the immense feeling of relief that came with that experience – knowing that she was all right and everything went fine with both of our operations."

He added, "Waking up for the first time after the operation was as though I had come out of a horrible nightmare and all of a sudden every last worry had melted away. My thoughts were clear and deliberate, I could feel an alertness I had never realised I was missing in the first place. I felt like I was me again.

"My father Jimmy and I had to remind mam to take it easy for a while. Within two weeks of the operation the two of us were home in Charleville

and dad looked after us as did Sherlyn, my sister-in-law, who prepared meals for us for a few weeks after our operations.

"By week three mam felt she was back to normal and full of energy caring for me to ensure I made a full recovery. I struggled to overcome persistent infections which lasted six months but this minor physical setback did not take away from how much better I felt emotionally and physically.

"So, Mother's Day will not only be a treat for my mam. It will be the first Mother's Day in quite a few years where I feel I am fully myself and not a grumpy son, and I have her to thank for that."

It was in the hours following his brother's wedding celebrations that Neil describes how he experienced "a very sobering moment" with the sudden onset of "massive black bags under his eyes". Having had a kidney removed at the age of seven and some health issues related to food intolerance in his teens, he was immediately aware that the symptoms he was suddenly experiencing

were pointing towards kidney issues.

His self-diagnosis was confirmed after tests at Cork University Hospital.

Prior to the transplant operation, Marion was determined to lose weight and undertook a strict diet and exercise regime. In contrast, Neil struggled to gain weight as it had plummeted by 24kg to just 56kg by the time the transplant operation proceeded at Beaumont Hospital. However, thanks to his mother's continued love and support Neil developed a love of cooking as well as finding and making recipes that made what was "a cripplingly restrictive renal diet significantly more manageable".

Neil explained how this effort was made all the easier through the support his mother and father had given every step of the way.

Through Neil's insistence the three of them joined a gym and made further refinements to their individual diets. On most days, however, Neil said that he could confidently rely on his mother to help

continued next page..

## Thank you Mother contd...



in preparing special dietary restricted meals and nursing him back to health. Neil has now returned to a normal healthy weight of 70kg.

Neil described the contrast between how he was before and after the transplant, "I feel like a different person, I am no longer tired, suffering from exhaustion, and I can concentrate my mind. I am back studying Computer Science at UL and back training in the gym three to four times a week.

"Although my diet is complicated by the fact that I am allergic to both dairy and soy, my mother has been a powerhouse of support creating dietary friendly meals for me and helping to regain my health. I am looking forward to travelling to France with my girlfriend soon with her guiding me around Paris, her hometown. I am also planning a trip to Chicago to visit my oldest brother sometime within the next year."

When asked about the deed of donating to her youngest son, a pragmatic Marion replied, "I don't think I know anyone who wouldn't do this for their child. Once I heard that

Neil would need a transplant, there was no question, ever, that I would not be the one to put myself forward. I was delighted when it was confirmed that I was a kidney match.

"When I heard that the operation was a success I was on a high and in a state of euphoria. The fact that Neil was doing well carried me through my recovery which couldn't have gone any better. I was raring to go within a few weeks although I did my best to behave and follow medical orders to take it easy for six weeks."

Marion continued, "No one could have guessed how hard it would be emotionally on my husband Jimmy as he worried about both of us undergoing operations on the same day. He was not allowed to visit us due to visiting restrictions because of COVID but he could call to the hospital to get regular updates on our progress.

The Irish Kidney
Association was very good
to our family and provided
hotel accommodation
close to the hospital so
Jimmy could be nearby and
feel more connected to
us."

# Another special Mother's son

On St Patrick's Day another mother and son's uplifting living donor kidney transplant story was shared on RTÉ Radio One.

Presenter **Brenda Donohue** had visited **Andrew Ishmael** and his parents **Jenny** and **Scott** in their Athenry home to pre-record an interview for her show 'Like Family' which was aired on March 17th.

ndrew and Jenny underwent their living donor kidney transplant on January 30th this year. Andrew described the kidney donation by Jenny as a "beautiful and selfless act".

Andrew said, "I will always be thankful to her. She was able to give me life twice. I can feel her kidney in my torso and the reminder will always be there about what she did for me.

Andrew was diagnosed with IgA Nephropathy when he was sixteen years old. In the summer of 2021 his kidney function had dropped to a point where he had to commence dialysis treatment, initially hospital based haemodialysis and then he progressed to peritoneal dialysis at home.



Jenny, Scott and Andrew celebrating Scott's 60th birthday on 18th March.

While Andrew (Drew) and Jenny were at Beaumont Hospital for their transplant operations and recovery, Scott and other members of their family availed of accommodation provided by the Irish Kidney Association at the Clayton Hotel.

Just before leaving their Athenry home radio presenter Brenda commented that one thing that stood out was the family's sense of gratitude to the whole team at Beaumont Hospital for their wonderful care.

When asked about their recovery Jenny explained that she was almost back to her normal self although she had experienced some minor ups and downs following transplant.

For Andrew he encountered some setbacks in the weeks that followed the operation with some rejection but strong steroids and medical treatment overcame this. He is slowly getting back to normal.

Scott, a native of the USA, and his Irish wife Jenny set up the popular *Scotty's American Diner* on the Headford Road in Galway in 1991 and can proudly boast that they have served over 2 million burgers in 30 years.

In the interview Scott said he was so proud of Jenny and that he is Andrew's biggest fan. Jenny described her immense pride for her son who carried his illness with such bravery and positivity but watching him hook up to the dialysis machine was difficult for her.

"On the day I received the call from Beaumont Hospital to say I was a perfect match to donate a kidney to Drew, I was over the moon. It was like I had won the lottery."

Andrew is looking forward to when he has fully recovered and will be able to reopen his successful bakery 'Imperfect Bakery' in Salthill which he and his girlfriend Beth set up during COVID lockdown.



### RESEARCH PROJECT - PARTICIPANTS NEEDED



**CHEYENNE DOWNEY** 

The Irish Kidney Association (IKA) is a charity for renal patients led by renal patients. We know that every renal patient is an individual and you need personalised care depending on your symptoms and treatment. We hear individual stories from patients all the time, but an overall picture of people's experiences in the healthcare system is missing.

Neither we nor the HSE National Renal Office have an overview of people's experiences of the renal healthcare system which is essential for improving and campaigning for better services.

e know very little about your experiences of the healthcare system in Ireland and this makes it difficult to understand what matters most to you as you progress through your healthcare journey. We want to change this by finding out from patients in every centre in the country what is most important to you and your opinions on the services provided to

We hope to learn about aspects of your wellbeing that may not come up during hospital or clinic visits.

With the support of Dr Lisa Mellon's research team in the School of Population Health (Department of Health Psychology) at the Royal College of Surgeons in Ireland (RCSI), we want to learn more about your views, concerns and experiences of the Irish healthcare system.

Shortly after the surveys are completed, Dr Lisa Mellon and Cheyenne Downey (who both have deceased mothers that lived with kidney disease) will organise online and inperson focus group interviews to hear what patients have to say

directly.

We are working with the HSE National Renal Office to complete this research and we need patients from all over the country to take part in the study.

All the information you provide is totally confidential.

#### WHAT DOES THE STUDY INVOLVE?

The study has two parts. The first part (the survey) will help us to develop general statements and gain an overall picture of the patient experience. You can take part as follows:

1. A patient survey that can be completed



DR. LISA MELLON



online via Microsoft Forms, or a paper copy can be posted to you by the study research assistant, Chevenne Downey, if preferred. You can also tell us in the survey if you would like to take part in the focus groups.

2. Four months after the surveys are completed, the RCSI research team will hold in-person or online audio-recorded focus group interviews with renal patients. The

purpose of this is to look at the survey findings and get a deeper understanding of what are your top priorities for renal care in the future.

The survey is currently being reviewed by renal patients and an online link will be available on the IKA website and our social media.

#### WHO CAN TAKE PART?

1. A patient with end stage kidney disease,

- either on dialysis or transplanted, who is over 18-years-old.
- 2. For focus groups you must not be an inpatient in hospital at the time the focus group is taking place.

You can take part in the survey only, without taking part in the focus group and vice versa, or you can do both the survey and the focus group.

Any travel expenses of people attending the focus groups will be paid once you complete an expense form.

#### WHAT'S IN IT FOR ME?

We will be using the survey results to work with the HSE National Renal Office to help improve services. By taking part in the survey, you are helping not just us, but also healthcare professionals to understand what your priorities are and what improvements you want.

We cannot promise to make all the improvements you want straight away, but the report will help us to work towards improved care for everyone.

#### **CONTACT DETAILS**

If you meet the criteria and would be interested in taking part, please contact the study researcher, **Cheyenne Downey** at cheyennedowney@rcsi.ie

Phone: +353 (0) 86 030 2408



#### JPPORT THE WORK OF THE IKA

Yes, I would like to make a regular donation by STANDING ORDER

STANDING ORDER REQUEST FORM	
To: The Manager of	
(Your bank's name and address) I/We hereby authorise you to set up a Standing Order on my/our account as specified below: (Please print all inform	nation clearly)
Signed:Date:	
Address:Ph:	
PLEASE CHARGE TO MY / OUR ACCOUNT: Name of Account:	
IBAN: Bank Identifier Code - BIC: (These can be found, printed on your bank statement)	
My regular	
(Please tick as appropriate) to start on Date:/	
AND CREDIT TO THE FOLLOWING ACCOUNT:	JONEY ASSO
Name of account: IRISH KIDNEY ASSOCIATION at Bank of Ireland, College Green, Dublin 2.	A Hara
<b>IBAN NO.:</b> IE06 BOFI 9000 1717 1934 35 <b>BIC NO.:</b> BOFIIE2D	SEA DONOR
As long as you are a PAYE or self-employed tax payer, when you donate €250 or more in a year (€21 or more per month), the Revenue Commissioners will g	Ve Charity Registration

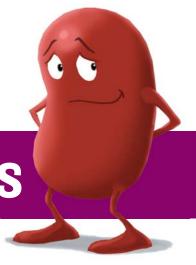
I the Irish Kidney Association CLG an extra rebate of 45%. For example, if you gave €250 in one year, the IKA would gain an extra €112, at no extra cost to you. №. 2001126.

Please post to: THE IRISH KIDNEY ASSOCIATION CLG, DONOR HOUSE, BLOCK 43A, PARKWEST, FREEPOST, DUBLIN, D12 P5V6 (PLEASE DO NOT POST TO YOUR BANK) **CHARITY REG. NO. 20011260** 

THANK YOU FOR YOUR GENEROSITY

# B BRAUN SHARING EXPERTISE

## Join our Webinar series



e are delighted to be chosen as charity partner by **B.Braun**, the organisation that provides dialysis in Portlaoise, Galway and Wexford. Part of this partnership is delivering a six-part webinar series all about kidney disease.

During these evening sessions from 6.30pm-7.30pm you can learn about Kidney Disease, Treatment Options including Shared Care, Medications, Diet and Exercise along with Counselling and how the IKA can support you. In the first session held on March 15th,

What is Kidney Disease?', Gerard Farrell, Clinic Manager, Wellstone Midlands Renal Care Centre, gave a very clear picture of kidney disease, how it affects us and what we can do about it.

Sarine Browne who is Secretary of the IKA Laois Branch told her story in a really powerful way. One key piece of advice she gave was, "Looking after the little things of our health really helps." She gave an example of going to the dentist on a regular basis.

The second in the webinar series was held on March 29th and Mairead Brennan, a Renal Nurse at the Wellstone Galway Renal Care Centre, gave an informative presentation on *Treatment Options'*. Imelda McGann from Galway outlined her positive experience and support she had when she decided to take ownership of her treatment on shared care.

The four remaining webinars in the series, which will each include a patient impact story and a guest speaker are:

#### **Medication Explained**

Date: April 12th

Presented by **Maria Raftery**, Clinical Nurse Specialist, Portlaoise. IP Shanahan, Chemist.

#### Renal Diet and Fluid Intake

Date: April 26th

Presented by **Ann-Marie Murray**, Renal Dietitian, Wellstone Wexford Renal Care Centre.

#### Importance of and opportunities for exercise

Date: May 10th

Presented by **Colin White**, National Advocacy and Projects Manager with the Irish Kidney Association.

#### Counselling and other supports available from the IKA

Date: May 31st

Presented by Aoife Smith,

Counselling Services at the Irish Kidney Association.

You can register for these FREE events on the IKA website events calendar at https://ika.ie/whats-on/

In order to protect patient privacy these sessions are not being recorded. With event satisfaction running at 100%, these free sessions are well worthwhile joining.

Brought to you in partnership with the IKA and B. Braun







s part of B.Braun's supports package in partnering with the Irish Kidney Association (IKA) as its charity partner for 2023, they organised a family fun day at Croagh Patrick with refreshments throughout the day.

A large turnout of B.Braun Ireland staff from all of its sites, together with their families, spent Sunday, March 26th, climbing Croagh Patrick on a beautiful sunny day. In the process they raised over €5,000 through online platform JustGiving for the IKA with some additional donations being made offline.

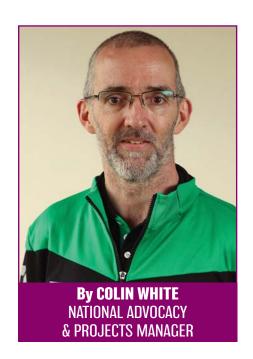
Joining them for the enjoyable day out was Mayo native, Dr. Lisa Mellon, a stalwart supporter of the IKA whose late mother Marie was a long-time dialysis patient.

On its JustGiving fundraising page B.Braun's chief organiser of the climb David Flannery stated, "Our goal at B.Braun is to support the IKA as much as possible throughout 2023. We aim to do this through fundraising, volunteering, and sharing our expertise where required."



# An Overview of Dialysis and Kidney Transplantation Statistics

2017-2022



The HSE's National Renal Office (NRO) and Organ Donation and Transplant Ireland (ODTI) produce annual reports that are available on the HSE website. These are useful as they allow us to reflect on the effectiveness of current practices, pose questions, and put forward proposals on the type of future developments needed.

In looking at the last 5 years, we have to take into account that the COVID-19 pandemic arrived in 2020. We were told that COVID-19 has an adverse impact on kidney function in many of the general population. How much of this was temporary (Acute Kidney Injury) and only required dialysis to allow people's kidneys to recover and how much was permanent (End Stage Kidney Disease) is not recorded in the reports being examined. Sadly, the pandemic also took its toll on the people already on dialysis or transplanted.

**TABLE 1: PEOPLE ON DIALYSIS** 

Numbers on Dialysis	2017	2018	2019	2020	2021	2022
Adults	2055	2108	2189	2292	2317	2450
Children	11	10	7	13	12	16
TOTAL	2066	2118	2196	2305	2329	2466

Numbers on Dialysis	2017	2018	2019	2020	2021	2022
In-Centre Haemodialysis	1813	1873	1933	2014	2026	2159
Home Haemodialysis	54	55	52	58	54	52
Peritoneal Dialysis	207	196	211	238	256	255

Numbers on in-Centre Haemodialysis	2017	2018	2019	2020	2021	2022
HSE	1296	1304	1325	1326	1339	1472
Contract	517	569	608	688	687	687

#### **GRAPH 1**

TOTAL NUMBER OF PEOPLE ON DIALYSIS 2466 2500 2400 2329 2305 2300 2196 2200 2118 2066 2100 2000 1900 1800 2017 2018 2019 2020 2021 2022

Graph 1 (opposite) shows the total number of people on dialysis as of 31 December from 2017 to 2022. In the space of 5 years, we have seen the total number of people on dialysis increase by 400 or 19.4%.

What does this mean beyond the impact on the lives of the people involved? Providing dialysis for an additional 400 people needs additional facilities, staff and patient transport which is a significant draw on the HSE budget.

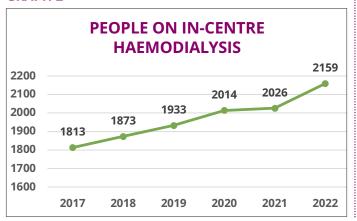
Equally, we must consider the role of preventative healthcare and education (see www.ika.ie/kidneyhealth) and how it can positively impact the rate of growth. The Irish Kidney Association is playing a strong role in this area as well, see pages 4-6 for details.

their dialysis in-centre and on peritoneal dialysis respectively across the 5-year period. A graph showing the number of people on home haemodialysis has not been included as you will see from Table 1 that the figure has remained consistent.

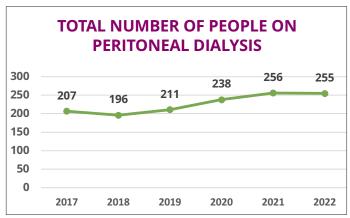
Graphs 2 and 3 show the number of people receiving

The growth in the number of people on peritoneal dialysis is noteworthy (21% from 2019 to 2021). Could this be a response to the pandemic, a planned development or both?

#### **GRAPH 2**



#### **GRAPH 3**



We are all aware how the dialysis units around the country are already running to capacity meaning that there is a need for existing units to grow and for new units to open in order to meet this ever-increasing demand. When planning for this, the HSE considers the geographical spread of people requiring dialysis and uses this to help inform where the required increased capacity should be located.

There is also the maintenance and development of existing facilities to consider. In recent times, Tallaght Hospital opened its new dialysis unit whilst the service in Sligo Hospital awaits a much-needed overhaul of facilities.

Table 2 (on next page) was drawn from the annual reports of the NRO and ODTI. We can see that in 2022, the number of people on dialysis increased by 137.

We can also see that there were 163 kidney transplants in the year and the number of people at year end 2022 with a functioning transplant increased by 26 when compared to in 2021.

However, the figures available do not indicate the number of new people starting dialysis for the first time in 2022, nor do we see the number of people on dialysis who died during the year, (137 is the number of extra people on dialysis compared with 2021).

We can neither see, nor calculate, how many people who had a functioning transplant at year end 2021 had to return to dialysis in 2022 nor how many of them died during that year.

continued next page...

#### **DIALYSIS AND KIDNEY TRANSPLANTATION STATISTICS 2017-2022** continued

#### TABLE 2:

	2017	2018	2019	2020	2021	2022
Number of people with a functioning kidney transplant	2459	2528	2625	2621	2656	2682
Annual increase/decrease in number of people with a functioning kidney transplant		69	97	-4	35	26

Total number of kidney transplants	192	167	153	123	139	163
Difference between total number of transplants and increase/decrease in number of people with a functioning kidney transplant		98	56	127	104	137

Total number of people on dialysis	2066	2118	2196	2305	2329	2466
Annual increase/decrease in number of people on dialysis		52	78	109	24	137

Successful advocacy for improvements in services and facilities relies on hard data at the core. We saw this in our successful advocacy for changes in the prioritisation of people on dialysis and transplant recipients in the provision of COVID-19 vaccines. We had clear statistics from other countries as well as Ireland. Part of the problem is that for much of 2022, the National Renal Office operated with a vacancy in this key Information Technology Role.

Access to a more complete set of statistics on dialysis and transplantation would empower the Irish Kidney Association (IKA) to advocate more effectively for changes and improvements in services and facilities for renal patients. The politics is simple, the collective patient voice can put the issues on the agenda for the policy makers.

The UK's NHS Blood and Transplant posts a comprehensive annual report on all aspects of organ donation and transplantation on its website as well as weekly and monthly updates throughout the year. This provides the data required to advocate for meaningful change and investment. The IKA is advocating for a similar level of data capture to be legislated for as part of the Human Tissue Bill to lay the groundwork for informed future planning and developments.

With a more in-depth understanding of the circumstances of people on dialysis (numbers starting dialysis annually, numbers returning to dialysis after a failed transplant and the number of people who are on 'long-term' dialysis, etc.) the IKA could work in partnership with the HSE to better tailor its services to support the patients and their families.

In good news, the IKA has been successful in a funding application to develop and administer a Patient Reported Experience Measure survey of all renal

patients. Working in partnership with the National Renal Office, this will go behind the headline numbers and measure the experience of patients and thus help inform future planning and developments with the focus on patients. See pages 16 and 17 for more details.

With the increase in availability of knowledge, patient-centred care can become a reality in healthcare if patients and patient advocates are treated as partners. In recent years, the European Society for Organ Transplantation (www.esot.org), an organisation for healthcare professionals involved in transplantation, established a patient engagement initiative under the banner of the European Transplant Patients Organisation so that patients and patient advocates can be a part of discussions about the planning for, and delivery of, patient care.

The collaboration between the National Renal Office and the IKA in the provision of patient education is an example of the positive outcomes of partnership in delivering patient-centred care. Equally, during the COVID-19 pandemic the HSE set up a network of patient organisations to facilitate the flow of information in both directions. Working together as partners improved outcomes for patients.

As a patient led organisation with 45 years' experience, the IKA is well placed to work as a partner with the HSE and advocate for developments that will have a very real impact on how healthcare is delivered and the quality of life of patients and their families.

As a bridge between patients and the health service, the IKA is a partner that facilitates the two-way flow of information to ensure an informed health service that is patient-centred. Strengthening this partnership can only benefit patients.

# UUCK

Ducky is a character I created to honour the memory of my youngest son Aaron Cantwell, a swim coach, an organ donor, and empath, with a big heart. I was inspired by Aaron's journal entry, which I found shortly after he passed away.



Not an Organ Donor?

"I'm going to be myself and be nice to everyone l can. Even if a small thing I do makes someone smile then I did a good job because everyone has their battles and if even for a few seconds they are happy it makes a difference."



#### By NAOMI DUNLEAVY

ucky is a kindness activist and an empath. He's able to see things from others perspective, by putting himself in their shoes and seeing a situation from others point of view, not just his.

#### **DUCKY DEED**

A Ducky Deed is a conscious act of kindness carried out with intent. It makes a difference to the recipient, by placing them in a better position than before the act. It's not random, it calls for careful consideration, and it's not easy either. It requires:

- 1. Self-compassion to accept ourselves as we are and know that we are more than enough to make a difference.
- 2. Motivation to look up from our devices and into the eyes of others.
- 3. Empathy to see the world from others' perspectives, not just our own.
- 4. Curiosity to ask others what they need, rather than what's convenient for us to do or give.
- 5. Courage to actually carry out the kind deed, no matter how hard.
- 6. Selflessness to do it 'without hoping for praise or recognition'.

#### **DUCKY'S GIFT OF LIFE SWIM DERBY**

Ducky Deed Derbies are races or contests that facilitate a shift in perspective (empathy), in a nonjudgemental environment.

Aaron Cantwell worked in Aura Leisure and his last act of kindness was organ donation. He was 20-years-old when he passed away and by donating his two kidneys, liver and heart, he saved four lives.

Ducky's 1st Derby is in association with both the Irish Kidney Association and Aura Leisure. It will take place on Sunday, 21st May during Organ Donor Awareness Week, with qualifiers taking place from the week commencing 8th May. Each member of the winning team will receive a prize of one year Aura Leisure Family Membership.

The relay swim will consist of mixed teams of organ transplant recipients, organ donor card holders, living donors and deceased donor family members. Its aim is to promote the importance of becoming an organ donor card holder and to give both recipients and donors the opportunity to participate in a shared social event.

For more information follow @duckydeed on Instagram or Facebook.

To register, email: duckydeed@gmail.com

each member of the winning team

Simply Freetext DONOR to 50050 to get an Organ Donor Card!



# The Late Late Show's 'Christmas Miracle'

The RTÉ Late Late Show covered an inspiring transplant story on its final show aired before Christmas 2022. It was a particularly timely reminder for families who were gathering for the festivities to discuss their wishes about organ donation.

ost Ryan Tubridy interviewed emergency nurse Lorna McSwiggan-Martin who described how, just five weeks after she received a kidney transplant, she saved the life of a five-year-old boy in the lead up to last Christmas. Ryan, who also interviewed the boy's parents, described it as 'a Christmas miracle'.

In a desperate plea to save his choking son Jack's life, Donegal (Dungloe) native Finian Gallagher ran next door to Lorna, in the hope that as she was an emergency nurse she could save him. The next door neighbours live in Shankill, on Dublin's southside.

In an emotional interview with the *Late Late Show* host Ryan Tubridy, Finian's wife Louise Gallagher described the almost fatal incident as 'the most traumatic time of our lives' and their gratitude to their neighbour Lorna who had 'carried

through' with the *gift of life* she had received from an organ donor by saving Jack's life.

When the almost fatal event was unfolding, Louise was at work in nearby Dun Laoghaire as her husband Finian was at home looking after Jack. With the help of Gardai who gave her a lift she arrived home just in time to see Jack revive with his heart beating again and in the ambulance.

Louise said Jack was "sitting up and crying and he looked horrific with no colour in his face". They sped off in the ambulance to Our Lady's Hospital for Sick Children in Crumlin.

Although Lorna had not been able to work for a couple years due to the impact of her kidney failure, her emergency nurse training immediately sent her into 'auto pilot'. Her first impulse on hearing that Jack was in trouble was

to call out to her husband Richard to phone an ambulance as she ran out of their house next door.

Lorna attempted the Heimlich Manoeuvre on Jack, who had choked on spaghetti, which proved unsuccessful.

She quickly progressed to administering CPR on the non-responsive child who had gone into cardiac arrest. A defibrillator, which the boy's father frantically retrieved from a nearby shop, could not help save his son who had, by then, no pulse and was non-conducive to shock therapy.

Lorna described how she used all the strength she had, while still recovering from her major transplant operation, to continue with CPR for a total of 9 to 10 minutes, by which time the paramedics arrived and took over by carrying him to the ambulance where he 'miraculously came back to life' and sat up.

It wasn't until then that Lorna began to realise the enormity of what had just happened and became emotional.

Jack was then transported to CHI Crumlin's Emergency Department, where Lorna had previously worked, and he underwent an examination and some tests which revealed that he had escaped completely unscathed from the traumatic incident.

Jack returned home two days later and his first visitor was Lorna. Louise described how Lorna and Jack "shared a big hug that will stay in my heart forever. He [Jack] didn't understand what that hug meant to our family".

On the first night she spent in Crumlin with Jack she sent a message to Lorna asking "how could I ever thank you? The person who had saved Lorna's life and had donated their organ to Lorna in effect had carried through and it had carried on to Jack."

Ryan Tubridy responded, "No donation – no recipient, no recipient – the worst. That is a remarkable circle of life and generosity and kindness and loving and obviously with respect to the donor's family. They should take some comfort to know that it was a remarkable donation all round."

In concluding the interview, Ryan announced that both families would

receive complimentary tickets to see the *Lion King* at the Bord Gais Energy Theatre

He then addressed the audience and viewers, "That story drives home the need for everyone out there to have a family conversation this Christmas about organ donation." See www.ika.ie

Sitting beside his parents in the Late Late Show's audience was a bright-eyed healthy Jack with his protective twin sister Izzy. Both were wearing their Christmas jumpers, a timely coincidence as the show aired on Down Syndrome Ireland's Christmas Jumper Day.

Their parents, Finian and Louise, and Lorna and her husband Richard Martin, wore Forget-Me-Not flowers, the Irish Kidney Association's emblem and symbol of transplantation, in a bid to remind viewers, when families gather for the festive season to share their wishes about organ donation.

When asked by Ryan Tubridy about whether the situation was very serious, Lorna explained that as an emergency nurse she rarely panics, however, in this circumstance, when the paramedics arrived her emotions took over given the severity.

She said in Jack's case, she was initially very worried about the outcome. While Finian and Louise are still in shock after the traumatic incident, they believe that were it not for Lorna's intervention combined with some kind of miracle Jack would not be with them today.

The experience prompted Richard and Finian to complete a training course in CPR and plan to share their knowledge of this life-saving intervention within their community.

Readers of *SUPPORT's* Autumn 2022 issue might recall about Lorna's nuptials in August 2022, while on dialysis awaiting a kidney transplant.

In describing the lead-up to her 'totally unexpected' kidney transplant Lorna said, "I had been on dialysis for three and a half years, so I was highly sensitised and it was difficult to find a match and I was expecting a longer wait than I got.

"I was absolutely delighted to have a phone call [to get a kidney match]. I am so grateful to my donor and their family and the Irish Kidney Association and all they have done for me. Life has changed so much, life is so much better. I'm not tired all the time and I have things to look forward to."



# ORGAN DONOR AWARENESS WEEK





rgan Donor Awareness
Week is happening from
May 20th-27th and it is our
annual opportunity to rally
together to shine the spotlight on
the important issues around organ
donation and transplantation.

The success of Organ Donor Awareness Week is rooted in our ability to get the key messaging out, at a local community level, as well as pitching at a national level. This is where each one of us can make a difference.

We all know people, we all have a reason why we are engaged with the Irish Kidney Association (IKA) so we all have a story to tell.

In sharing our respective personal stories it is important that each of them is rooted in the same basic facts so that we have consistency in

#### By COLIN WHITE and GWEN O'DONOGHUE

our messaging.

One organ donor can save seven lives! Organ donation means that over 5,000 people around the country are currently enjoying the 'gift of life' after successful transplants.

At any one time in Ireland there are between 550 and 600 people on waiting lists for organ transplants including heart, lung, liver, kidney and pancreas.

The positive impact of organ donation and transplantation on their lives, and the lives of their friends and families, is immeasurable, giving comfort to the organ donor families who have made it possible.

Organ Donor Awareness Week 2023 is organised by the IKA in association with the HSE's Organ Donation Transplant Ireland (ODTI). By having the week coincide with European Public Health Week it gives the opportunity to use existing structures within the HSE to amplify the messaging and frame the topic as a conversation that we should be having as a nation.

During Organ Donor Awareness Week, organ donor families and grateful transplant recipients from around the country are being asked to make their wishes known to loved ones about organ donation.

This year's Organ Donor
Awareness Week campaign is built
around the theme 'Don't Leave Your
Loved Ones in Doubt!'
#LeaveNoDoubt.

The key message is that members of the public can play their part in supporting organ donation for transplantation by ensuring that their families are not left in any doubt about their wishes around organ

donation. i.e., they 'have the conversation'.

Sharing your wishes when you are in good health makes it a less stressful decision for your family, in the event of them being approached about you being a potential organ donor.

The Minister for Health Stephen Donnelly will officially launch Organ Donor Awareness Week on Tuesday, 16th May.

Significant work is going on behind the scenes to identify personal stories that can attract media interest and thus put the topic in front of as many people as possible.

If you are interested in possibly sharing your story to inspire others in the context of promoting organ donation for transplantation, please fill in the form in this link **before** May 2nd - https://tinyurl.com/0DAW23.

The concept for this year's grassroots campaign to be run through our 25 Branches is

'Teacht le Chéile' / 'Coming Together'.

Optimistic for a successful campaign, we are encouraging our members and supporters to facilitate coffee mornings, picnics, walks, or any other social gathering where they can share their own stories and encourage others to think about organ donation, talk about organ donation and make a commitment to organ donation.

An event toolkit will be available from Donor House.

Many independent pharmacies and pharmacy chains will be showing their support for the campaign by displaying the campaign poster on their digital screens, or displaying the printed version prominently in their outlets.

They will also be displaying countertop boxes of free organ donor cards which are accompanied by information fact files and leveraging their social media presence to get the message across about having the family conversation.

Take the opportunity to check with your pharmacy whether they are joining the campaign.

We are delighted that An Post is supporting the campaign by displaying stocks of organ donor cards with fact-files in its top 350 busiest post offices which have the most footfall. An Post will also be

displaying the campaign poster on digital advertising screens in 295 of its top post offices.

Watch out for the campaign poster which may appear on the RTÉ Fair City set for some of the scenes shown during Organ Donor Awareness Week.

The poster will also be carried on outdoor advertising poster sites, sponsored by Clear Channel.

All campaign posters are available in English, Irish and Polish, and digital copies can be downloaded from the IKA's website www.ika.ie/donorweek

#### SOME FACTS AND FIGURES

At any one time in Ireland there are between 550 and 600 people active on waiting lists for organ transplants including heart, lung, liver, kidney, and pancreas.

250 organ transplant operations were carried out in Ireland in 2022 (44 more transplants than in 2021).

This activity last year, in very challenging times with COVID-19, could not have taken place but for the generosity of the families of 86 deceased donors and 33 living kidney donors.

In 2022, 51 liver transplants and 8 pancreas transplants took place at St. Vincent's Hospital, while 10 heart transplants and 18 lung transplants were carried out at the Mater Hospital.

Last year saw an increase in the number of kidney transplants taking place at Beaumont Hospital - 163 kidney transplants took place, of which 33 were from living kidney donors.

Supplies of organ donor cards, which are attached to newly designed Z-cards (fact files folded to credit card size), with updated information on organ donation and transplantation, will be available in counter-top boxes for display in 350 of An Post's busiest post offices, in pharmacies and other retail outlets, places of work, community centres, and other outlets.

Right: Organ Donor Z-Card cover

There are 2,466 patients in Ireland in end stage kidney failure undergoing dialysis treatment but only about one fifth of these are active on the transplant waiting list.

Individuals who wish to support organ donation by sharing their wishes with their loved ones are encouraged to keep the reminders of their decision available by carrying the organ donor card, permitting Code 115 to be included on their driver's licence, or having the 'digital organ donor card' App on their smartphone.

Organ Donor Cards can be requested by visiting the website www.ika.ie/get-a-donor-card or, phoning the IKA on Ph: 01-6205306 or FREE TEXT the word DONOR to 50050.

You can read the IKA's response to the Human Tissue Bill here: https://tinyurl.com/IKAHTB.

It is important that we capture all events/activities undertaken during Organ Donor Awareness Week so let us know your plans by completing the form in the link: www.ika.ie/whatson/yourevent/ and we can include it on our website calendar and help promote it through our social media channels.

Social media hashtags for Organ **Donor Awareness Week are:** #LeaveNoDoubt. #ShareYourWishes and #DonorWeek23

People can also tag the IKA when doing their own social media posts

@IrishKidneyAs on Twitter @IrishKidneyA on Instagram @IrishKidneyAssocation on Facebook.



# ACIDOSIS IN PATIENTS WITH CHRONIC KIDNEY DISEASE

By PROF. MUHAMMAD MACDI YAQOOB, Professor and Renal Consultant, Barts and the London Hospital, UK.

#### WHAT IS ACIDOSIS?

cidosis 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 a 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 tests as low bicarbonate

#### 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%.



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

#### 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, high BP, or diabetes, it is important to let your healthcare provider know immediately.

Article reprinted courtesy of **NKF** (National Kidney Federation), UK

levels.

### 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 leads 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 manifests 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.



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



#### **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 this 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 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 the severity of your kidney disease.





Digital literacy has become indispensable in almost every part of society. From applying for jobs to connecting with friends; being able to use technology safely, effectively and responsibly has become a vital skill.

igital education now starts at school for most children, but that doesn't account for the millions of people well-past school age who have not had the opportunity to learn, or others who don't have the resources to learn at

A recent report by Vodafone found that just over half (53%) of Irish adults are equipped with basic digital skills and over-65s are well below the EU average of 25% at just 19%, with the divide worsening for those in rural locations.

Additionally, a 2021 Digital Index report by Accenture (a global IT consultancy firm) found that whilst around 95% of Irish people used smartphones, computer use was

split according to socio-economic status.

Socio-economic status is a way of describing people based on their education, income, and type of job, usually described as low, medium, and high. People with a lower socioeconomic status usually have less access to financial, educational, and social resources than those with a higher socio-economic status evident in Accenture's study with only 39% of those in lower socioeconomic groups using computers daily, compared with 61% in higher groups.

The COVID-19 pandemic accelerated this divide as more companies took the opportunity to jump to online services.

The progress towards the EU's 'Digital Decade' ambition shows that while Ireland had one of the highest increases of adults in Europe equipped with the basic digital skills year-on-year, there is still a long way to go to meet the 2030 target of

With groups of people at risk of being left behind as society grows increasingly digital dependant, there has been a move to provide resources and education to help provide people with the tools and skills they need.

If you feel you could use some help with your digital skills, we have pulled together a list of some of these resources to help you get started.

♠ @IrishKidneyAssociation
♠ @IrishKidneyAs
♠ @IrishKidneyA
♠ irishkidneyassociation



#### **HI DIGITAL VODAFONE**

Vodafone Ireland Foundation announced the launch of face-to-face digital skills training classes for over 65-year-olds across the 26 counties. There will an investment of over €2 million over five years in the Hi Digital programme, and more than 26,273 sessions have been initiated by older people online to date.

A first of its kind, five-year initiative, Hi Digital was developed by Vodafone Ireland Foundation alongside charity partners, Active Retirement Ireland and ALONE. Topics include:

- understanding Smartphone features and essential online skills that help enhance daily life
- keeping in touch through WhatsApp and social media
- planning trips
- researching interests and hobbies
- online shopping
- entertainment
- education on online safety
   People can register for a
   free in-person class by calling
   1800 20 30 30 or visiting
   www.activeirl.ie/hidigital.

#### **AGE ACTION**

Age Action's *Getting Started Computer Training programme*delivers free training on computers, tablets and smartphones to people over the age of 55.

Since 2006 Age Action has trained more than 35,000 older people in 14 counties with the assistance of thousands of volunteer tutors.

The training takes place in small class groups and runs in libraries, community centres, schools, colleges, family resource centres, corporate offices, and housing complexes for older people.

Contact the relevant office for more information of *Getting Started Computer Training* in your area:



#### **eCOLLEGE**

eCollege is a government-funded online training facility. It provides a range of online learning courses, available any time. If you want to learn at your own pace, eCollege is perfect for you.

eCollege delivers online training courses in:

- information technology
- business
- project management
- graphic design
- software development
- basic computer skills

eCollege courses are **free** of charge, part-time, certified and always on-demand, so you can get started straightaway.

The courses could help you whether you are already doing a course and want to add to your learning, are unemployed or had your hours reduced, or simply want to improve your skills or learn new

ones.

The courses are designed to give you specific skills training, with certification, to help you get a job or improve your skills.

Visit **www.ecollege.ie** for more information.

#### NATIONAL ADULT LITERACY AGENCY

NALA provides **free** courses for adults in Computer Skills. There are no exams, but you will get a QQI qualification at the end and there are tutors to support you.

If you are not ready to learn online yet, they have tutors who can start teaching you over the phone too – normally they make one call a week for up to 30 minutes and keep working with you until you meet your goals.

Freephone: 1800 20 20 65 Text 'LEARN' to 50050 Learn online at www.learnwithnala.ie



AREA	PHONE	EMAIL
Dublin and Leinster	01 4756989	gettingstarted@ageaction.ie
Cork & Munster	021 2067399	gettingstartedcork@ageaction.ie
Galway, Connaught & Mid-West	091 527831	gettingstartedgalway@ageaction.ie



By COLIN WHITE NATIONAL ADVOCACY & PROJECTS MANAGER

At the time of going to press fourteen Irish transplant recipients were about to travel to Perth, Australia to participate in the 24th World Transplant Games (April 15th-21st). This follows a four-year gap as the previous biennial World Transplant Games planned for Houston, USA in 2021 had to be cancelled due to the global COVID-19 pandemic.



he Games are a celebration of life, an appreciation of organ donors, their families, and an opportunity to remember friends lost, since the Games were last held in Newcastle in 2019.

1,524 participants from 46 countries coming together to compete in 17 different sports disciplines provides a wonderful positive platform from which to encourage a public discourse about the importance and success of organ donation for transplantation. Each of the participants also stand as role

models for others who are newly diagnosed with organ failure or who are wondering what can be achieved post-transplant.

The simple act of getting on the plane to travel to the other side of the planet is a huge statement about the effectiveness of organ donation for transplantation. Our team brings together fourteen different personal stories and fourteen different personal goals.

Team member Ron Grainger captured the essence of the Games experience in an interview to camera



Signing their new team kit were members of Transplant Team Ireland who will be taking part in the World Transplant Games in Perth, from left Finbar O'Regan, Dublin 2, Mairead O'Mahony, Cork, and Bryan Duignan, Carlow.



Transplant Team Ireland triathletes Sheila Gregan (kidney recipient), Tipperary and Bryan Duignan (kidney recipient), Carlow cheered on by former Olympian triathlete Gavin Noble, Olympic Federation of Ireland.

on March 12th when the team received their official kit at ALSAA Sports Complex. He said; "If I win something, well and good. If I don't, what a joy just to be able to take part."

Guest speaker at the team gathering at ALSAA was former Olympian Triathlete Gavin Noble, the Olympic Federation of Ireland's Chef de Mission for the Paris 2024 Olympic Games.

He said, "Each and everyone of you are an inspiration as you are living your best life, honouring your donors and representing your country in sport. Sport brings people together as does organ donation."

You can follow the exploits of Transplant Team Ireland on the team Blog;

www.transplantteamireland.ie and on the team's various social media channels.

With this year's squad ranging in age from 36 to 75-years-old and including kidney, liver, and bone marrow transplant recipients, the team has experienced competitors and we also have people entering the world of transplant sport for the first time.

With sports ranging from skill-based events such as pétanque, darts and ten pin bowling to more physical sports such as athletics, golf and swimming, there's something for everyone.

Transplant Team Ireland is an extended 'family' that brings together transplant recipients, people on dialysis, their families and their friends. This year it has been great to see people from within the team step up in relation to seeking external support for the squad going to Perth and working on developing a plan for the growth of the team.

New team member, Finbar O'Regan, a liver transplant recipient, made contact with Health Services Staffs Credit Union (HSSCU) that led to them being kit sponsors for their first time.



Experienced team member, Pat O'Sullivan, reached out to Ryan Golf and they sponsored very appropriate headcovers for all woods and putters for the six Irish golfers competing in Perth. Former team doctor, Claire Kennedy, facilitated the sponsorship of sunscreen for the team from La Roche Posay.

Continued next page



Megan Clarke handing over sponsored La Roche Posay sunscreen to



#### WORLD TRANSPLANT GAMES 2023 CONTD.



You can read a full report on the team's participation at the World Transplant Games in the Summer issue of *SUPPORT*.

#### LOOKING BACK AND LOOKING FORWARD

big shout out to the transplant football team that travelled to Solihull in England in March to compete in their first tournament. The event was hosted by Transplant Sport UK and it brought together several transplant football teams from around the UK.

The squad that travelled represented a wider football team that has been training together for some time now. They were cheered on by travelling supporters and their active social media coverage and engagement with the public media ensured that family, friends and supporters could follow them and their core message about honouring their organ donors and promoting organ donation could reach a wide audience.

#### **BRITISH TRANSPLANT GAMES**

This year's British Transplant Games are on in Coventry from July 27th-30th. Registration is currently open

(www.britishtransplantgames.co.uk).

This is an opportunity for all interested transplant recipients to engage with transplant sports, meet your peers and be part of a wider movement that promotes the importance and success of organ donation for transplantation and the improved quality of life that can come with engaging in physical activity and being part of a team.





Our friends at **Top Oil** would like to spread some warmth amongst the renal community, by generously sponsoring a prize giveaway to the value of **€500** in this issue of *SUPPORT*.

Five lucky readers who enter the prize giveaway will each receive a €100 Top Oil gift voucher for Home Heating Oil.

**Top Oil** has a strong history of more than 200 years in the oil and energy industry, and is committed to providing its customers and retailers in Ireland with quality petrol and diesel fuel products. Today, its network includes more than 200 locations, 22 local depots, six motorway service area, and more than 200 Fuel Card locations.

Leveraging its network of nationwide service stations, and through a new partnership with the Children's Health Foundation, **Top Oil** was pleased to introduce its **Fuel the Care** programme across the country in 2022. The programme helps families travelling with children requiring medical care, by providing fuel gift vouchers to support travel costs between home and hospital.

Irving Oil, a Canadian-based company which operates **Top Oil** as well as the Irving Oil Whitegate Refinery in Co. Cork, celebrated its 20th year operating the **Fuel the Care** programme in North America last year. Since 2002, by partnering with hospitals in Atlantic Canada, Quebec and New England, Irving Oil has been able to help fuel the care for more than 80,000 families. Visit **www.top.ie** for further information.

To be in with a chance to win a €100 voucher for Home Heating Oil, email: robyn@ika.ie with your name, address and phone number, making sure to include Top Oil in the subject line of your email. Five winners will be selected at random. So go on, get your entry in, and you could be a winner! Closing date for receipt of entries is Monday 8th May, 2023.



n Monday April 3rd, the Midland Regional Hospital Tullamore donated thirty-five Dialysis machines, for humanitarian aid, to Turkey following recent earthquakes.

The donation including machines, all consumables and spare parts are being delivered as part of a coordinated response from the HSE Global Health Programme, Strategy and Research group. The machines, while nearing end of life, can still be put to good use by those in need.

John Adlington, Principal Clinical Engineering Technician at the Midland Regional Hospital Tullamore states, "The hospital has an ongoing medical device equipment replacement programme in line with manufacturers and HSE requirements and guidelines.

"The machines that are being donated have been in use within the renal dialysis departments for the last 10 years and have been fully maintained to a very high standard by the Clinical Engineering Technicians.

"It is good to know that they will continue to treat acute patients requiring dialysis." This is not the first time the hospital has donated equipment to improve global health, John continues, "In 2022, any medical device equipment that was no longer supported by the manufacturer, but was in good working order, was donated to the Equals Initiative which is an Irish-based collaboration between Royal College of Physicians of Ireland and the HSE that coordinates the distribution of donated

equipment to Zambia."

Catriona McDonald, General Manager, MRHT added, "The hospital is delighted to be able to support this important humanitarian aid initiative, and bridge the gap for those working in hospitals in Turkey under difficult circumstances, treating those most in need. I would like to acknowledge the work of our Clinical Engineering team for driving this worthwhile initiative."





# SUN HOLIDAYS

## The best places to go for sun, sea and sand, and most importantly excellent dialysis units.



In need of a sun holiday? It's time to top-up your vitamin D levels, dig out your swimwear and board a plane to one of these sunny destinations.

#### SPAIN

pain is always a popular destination for Irish holidaymakers but knowing exactly which resort to go to if you are on dialysis can be tricky. But fear not, we have some of the best Spanish dialysis units to recommend for a sun holiday. Whether it is time by the beach you crave, the chance to top up your tan safely, or simply a chance to just explore the wonderful sights, you'll find exactly what you need.

#### **COSTA DEL SOL**

The Costa del Sol is one of the most popular tourist destinations in the world. With such a wide range of facilities and attractions, there is something for everyone. Miles of sandy beaches and fantastic all year-round warm weather keeps tourists flocking back year after year to Torremolinos, Marbella, and Estepona.

#### **TORREMOLINOS**

Torremolinos is a modern city preserving the great charms of the Andalusian tradition. Here visitors enjoy more than 300 sunny days every year.

Diaverum Torremolinos is the nearby dialysis unit and its conveniently located within 15 minutes by car of popular local attractions such a Sea Life Benalmadena, Crocodile Park, and Parc de la Paloma. El Bajondillo beach is only a 15-minute walk from the dialysis unit.

EHIC is accepted for dialysis treatment but transport is not provided by the dialysis unit.

#### **ESTEPONA**

Estepona is an idyllic town surrounded by both the Mediterranean sea and mountains on the Costa del Sol in southern Spain. The white-walled town centre has many shops and picturesque squares.

Estepona is renowned for its beaches, which stretch along some 21 kilometres of coastline. It's a popular year-round holiday destination. Estepona has a micro-climate with over 325 days of sunshine per year.

There are plenty of restaurants and water sports facilities at Puerto Deportivo, plus a fishing port and the cove of Playa del Cristo.

The closest dialysis unit for patients holidaying there is *Diaverum Estepona* which is only 1.3km from the restaurant, pub and shop lined promenade of

EHIC is accepted but transport to and from the dialysis centre is the patient's responsibly.

### **MARBELLA**

Marbella is perfect for those looking for a sun-soaked holiday, with easy beach access and also a little added luxury. Whether you want a golf or spa resort holiday, Marbella has it all! So if you are looking to sample the Costa del Sol, Marbella is definitely the town for you to visit.

The dialysis unit is in *Hospital Quiron Marbella* with a prime seafront location, is situated next to Marbella's fishing port, providing a spectacular view of the Mediterranean Sea.

The EHIC is accepted for dialysis treatment, but like the other Costa del Sol resorts transport is not included.

# **BARCELONA**

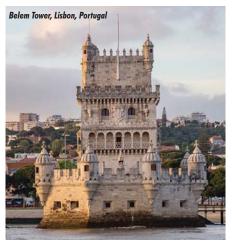
A sun holiday and city break in one trip! Barcelona is the second most populated and popular city to visit in Spain. The Catalonian capital, located in north eastern Spain, is a cosmopolitan Mediterranean city with a rich historic-artistic heritage.

If you are the kind of person that can lie in the sun, with shade and sun protection, for a day but after that you get bored, then why not consider a trip to somewhere like Barcelona. In Barcelona, you can choose between the pool, beach, shopping or incredible cultural sites such as the famous Gaudi Cathedral, Sagrada Familia.

There are five Diaverum dialysis units in Barcelona. *Diaverum Nephros* clinic is only 2 kilometres from Parque Güell. *Diaverum Center Virgen de Montserrat* is 12 minutes away from Barcelona's train station.

The Institute of Haemodialysis of Barcelona Dialysis unit is just 350 meters away from Camp Nou Stadium. Diaverum Emilio Rotellar Dialysis Centre is just 10 minutes away from Maragall metro station, and Diaverum Palau Dialysis Centre and 10 minutes away from Alfons X metro station.

All five dialysis units accept the EHIC but, like with other Spanish resorts, transport has to be arranged by the patient.



# **PORTUGAL**

# LISBON

Portugal's capital Lisbon is the perfect city for a short break that includes a chance to look around the bustling city and hit one of its beautiful beaches.

Lisbon is one of the oldest cities in the world. Lisbon is famously surrounded by seven hills, but you don't have to be super-fit to explore.

The city centre is level and easily walkable with beautiful tiled streets. Lisbon is about 15 miles from the sea which you can explore by trains, metro, trams and buses which are very cheap and efficient.

There are ten *NephroCare* clinics in and around Lisbon to choose from, all units accept the EHIC, but transport is not provided by the dialysis units.

### **ITALY**

### **ROME**

If you're a fan of ancient history, Rome is the perfect destination for you. The city combines ancient architecture, and plenty of history.

Whether you are in Rome for one day or one week be prepared to step into the world's biggest openair museum.



Rome offers countless historical sights. The Italian capital is regarded as one of the world's most beautiful ancient cities, and contains vast amounts of priceless works of art, palaces, museums, parks, churches, gardens, basilicas, temples, and theatres.

You will find it difficult to decide what to see first: the Vatican, the Trevi Fountain, St Peter's Square, Spanish Steps or the Colosseum.

If you are craving the beach, you can always take a train out of the city to visit the nearest beach and enjoy the best of both worlds!

Whether you spend your time sightseeing, or lazing in cafés watching the world go by, it will be your turn to feature in your very own Roman Holiday.

Diaverum Roma is the name of the dialysis unit in Rome and it's situated about 30 minutes' drive from the Vatican City.

EHIC is accepted at this dialysis unit but transport is the patient's own responsibility.

# **DUBAI**

A sun holiday in Dubai for year-round sunshine.

The weather in Dubai is warm all year round, and although it's probably a little uncomfortable in the height of summer, it is perfect if you are envisioning feeling a little winter sun on your bones.

October, December and February are all popular times to experience Dubai at its best, whether you want to shop, lay by the pool, visit the beach or trek through the desert.

Al Zahra Private Hospital Dubai (AZHD) is where the dialysis unit is located on Sheikh Zayed Road in Al Barsha which runs through the heart of the Emirates, along with the

Dubai World Trade Centre, Emirates Towers, Dubai Mall, Burj Khalifa and many more landmarks.

Dialysis costs around €230 per dialysis session and no transport is provided by the dialysis unit.

EHIC is **not** accepted in Dubai or in other countries outside of Europe.





y now we are well settled into the new year. I'm sure (if you are anything like me) at the beginning of the year there were New Year's resolutions made with genuine intent but by now the effort they require might be slowly dwindling.

I was thinking of one particular resolution I know a lot of people can make, but also know it can be the first one to go when life gets busy, and that's Self-Care. "I promise I will look after myself more this year, eat better, exercise, relax more, read more", but when stressors arrive self-care can easily drop in importance.

As we come into brighter evenings and think of spring cleaning, I thought it might be a good time to refocus, not just on the house, but on ourselves.

The World Health Organisation defines Self-Care as "the ability of individuals, families and communities to promote health, prevent disease, maintain health and to cope with illness and disability with or without the support of a healthcare provider".

According to this definition, self-care

includes everything related to staying physically healthy – including hygiene, nutrition, and seeking medical care when needed.

When I read this definition I get a little overwhelmed by the sense of responsibility it places on individuals and I am acutely aware of how off-putting it might be to those living with a chronic disease.

Self-Care is anything we can do to take care of ourselves so that we can stay not just physically well but mentally, emotionally, and spiritually well too. It is important to find a balance that allows us to address each area of self-care, but it is also important to know that picking one area to start on can positively affect other areas.

Physical Self-Care includes how well we are eating, how much sleep we are getting, how much physical activity we are doing, and how well we are caring for our physical needs.

Attending hospital appointments, taking medication as prescribed, and managing our health care needs are also part of good physical self-care.

Asking ourselves how well we are doing in these areas and making small changes may be a good place to start improving our own physical self-care.

Mental or Cognitive Self-Care involves doing things that help us stay mentally healthy. The way we think and things we say to ourselves or the things we do to fill our minds can greatly influence our psychological wellbeing.

Thank you to all who emailed or called to discuss the counselling service provided here at the Irish Kidney Association. Please continue to email me at <code>aoife@ika.ie</code>, with topics that might benefit you to read about. Your comments to me will be completely confidential, no names will be used, and no reference will be made to any person or any specific email. If there is a common theme in the requests, I will base the next article around that topic.

Mental Self-Care includes doing things that keep the mind sharp. Learning about things of interest, reading books, or keep watching movies that inspire, or doing puzzles, fuel the mind.

Practising self-compassion, acceptance and non-judgemental self-talk can help maintain a healthier inner dialogue and reduce stress.

Emotional Self-Care refers to becoming more aware of and identifying what we are feeling. Our emotions directly correlate to how we feel every day.

When we understand our emotions and know how to express them it allows us to channel those emotions in a way that benefits our overall wellness.

When living with a chronic illness, each day can bring a new set of emotions which may be challenging – emotions like anger, sadness, and fear. Whether you talk to a partner or close friend, attend counselling or set aside time for activities that help process these emotions, it can be of great value to incorporate emotional self-care into our lives.

Research shows that a lifestyle which includes religion or spirituality is generally a healthier lifestyle. Prayer, attending Mass and following religious beliefs, support and give comfort to many people.

However, looking after your spirit doesn't have to involve religion.



Spirituality means feeling more connected to our innermost self, the world around us and to a higher purpose. It can involve anything that helps to develop a deeper sense of meaning, understanding or connection in our life.

Meditation, practising gratitude, getting out in nature, and spending time doing things that fulfil us can all be ways to feeling more spiritually connected.

Self-care plans have been shown to have several important health benefits such as reducing anxiety, stress, and depression, improving resilience, energy and happiness, and overall becoming better equipped to handle the challenges.

Assessing which areas of life that may need some more attention, considering stressors and devising self-care strategies to help make small changes, may be a first step in creating that plan.

Self-care is a work in progress, it changes as we do, and when living with, or caring for someone with a chronic illness, we all know how easily situations can change.

So, when creating a self-care plan remember the aim is to help feel less stressed and not to add stress.

Self-care doesn't have to be overwhelming. Tailor it to your life and your needs, a plan or routine that is created by you, for you.





The Irish Kidney Association

# 38th Annual Service of Remembrance and Thanksgiving

for organ donors, transplant recipients, and their families, will be held at

Cathedral of Christ the King, Mullingar, Co Westmeath

on Saturday, 14th October, 2023

Further details in the Summer issue of SUPPORT and online.

# Shopping on a budget for a kidney friendly diet

With rising food and energy costs, many of us are feeling the pinch. Shopping for nutritious foods while keeping costs down can be challenging, especially for those following a renal (kidney) friendly diet.

We know that eating a healthy diet is an important part of looking after your kidney and overall health so this is not an area which should be compromised. By being organised and planning ahead, you can help keep the costs down.

# **REDUCING FOOD WASTE**

staggering one-third of all food purchased in Ireland ends up in the bin, costing the average household €700 annually (data from the Environmental Protection Agency).

# **TOP TIPS FOR REDUCING FOOD WASTE**

- Plan your meals for the week ahead.
   Start by checking what you have in the fridge and cupboards so you don't buy what you don't need.
- Check use by dates and plan to use items with shorter dates first.
- Make a list and stick to it.
- Don't shop when you're hungry.
- Try to keep to one main shop a week.
   If you need to shop for a few items during the week, don't bring a trolley/basket you may be tempted to fill it!
- Batch cook, make larger quantities of one meal and freeze for days when you're short on time or don't feel like cooking.
- Cook the main meal at home as much

- as possible and keep eating out for special occasions.
- Bring a packed lunch to work/school/ college. You have control over what's in it and it'll be much cheaper that going to canteen as well as avoiding the queue!
- Choose supermarket own brands instead of big branded products. These may be located on lower shelves. Compare cost per gram of food, where this information is displayed, to check you are getting the best value for money.
- No need to buy organic foods, these are more expensive but no more nutritious than non-organic foods.
- Be careful with special offers. These are only good value if you need them, if not, walk on by.
- Store food correctly so that it lasts longer. Keep dried foods like pasta, flour, cereals in airtight containers. Clean out your fridge regularly to help protect your food from harmful bacteria.

# **CHILLI CON CARNE**

# Serves 4

# **Ingredients:**

400g minced beef

1 onion, finely chopped

1 clove garlic

1/2 beef stock cube ( zero/very low salt stock cube)

1/2 pint/150ml water

1 dessertspoon flour

1 teaspoon chilli powder

½ tin chopped tomatoes

400g kidney beans (drained weight, almost 2 tins)

### Method:

Chop the onion and garlic. Dissolve beef stock cube in ¼ pint/150ml boiling water.

Put minced beef in a dry frying pan. There is sufficient fat in minc

pan. There is sufficient fat in mince for frying. Cook for 20-25 minutes over a low heat until well browned,



stirring all the time.

Add onion and garlic to the pan and cook for 2-3 minutes. Sprinkle on the flour and chilli powder and cook for 1-2 minutes, stirring all the time.

Add beef stock, and tinned tomatoes. Bring to the boil. Add kidney beans to the mince. Simmer for 20 minutes.

Serve with a portion of wholegrain rice to increase the fibre content.

Per portion, this recipe provides 4 protein exchanges (3 meat and 1 vegetarian) and 1 portion of vegetables.

Recipe adapted from 101 Square Meals with permission from Limerick Money Advice & Budgeting Service

FOOD	TIPS
BREAD, PASTA, CEREALS, POTATOES	Choose foods from this group for each meal.  If on a potassium restriction, use pasta/rice frequently as alternative to potatoes Remember to boil potatoes to reduce potassium content, rather than steaming/baking.  Supermarket own brands for cereals, pasta and rice will be cheaper. Porridge is good value for money and doesn't contain any additives.
FRUIT AND VEG	Choose fresh fruit and vegetables in season. Be mindful of suitable choices if you are on potassium restriction. Supermarkets usually have special offers weekly which can be good value.  Frozen vegetables can be a great option.
MILK, CHEESE AND YOGHURT	Remember your dairy allowance if on a phosphorous restriction. Mozzarella, cottage and cream cheese, are good options. Avoid processed cheese. Check use by dates and choose those with longer dates.
MEAT, FISH, EGGS, PEAS, BEANS	Avoid processed meats such as sausages, rashers, bacon, packet meats. These contain additives which can increase phosphorous levels in the blood. Cooking fresh meats such as chicken, turkey, beef, lamb, and using leftovers for sandwiches/salads, etc. works out cheaper than relying on processed meats and is better for your kidneys.  Avoid smoked meat/fish.  Cheaper cuts of meat are just as nutritious as more expensive cuts.  Stews/casseroles are a good way to cook cheaper cuts of meat. Cooking extra when you have the oven on and freezing saves time and money.  Tinned fish like salmon (avoid the bones), tuna (tinned in water) are good, inexpensive alternatives to fresh fish. Use in sandwiches, salads or pasta/rice dishes. These are great options for lunches.  Eggs are nutritious and inexpensive.  Pulses such as frozen peas, chickpeas and red kidney beans canned in water and drained, can be suitable on the renal diet. Substituting some of the meat in stews, casseroles, curries, or chilli (see recipe on opposite page), can help reduce the cost of a meal, while increasing its nutritional value. Talk to your renal dietitical about including pulses in your diet.
FATS AND OILS	Rapeseed, sunflower and olive oils contain heart healthy fats. Try supermarket own brands. Use sparingly. If you use a plant stanol/sterol based spread, which are quite expensive, talk to your dietitian who should be able to advise if these are recommended for you.
FOODS AND DRINKS HIGH IN FAT, SUGAR AND SALT	Cakes, biscuits, chocolate, pastries, crisps, and minerals, contribute little nutritional value and should be taken in small amounts only. Avoid cola drinks which are high in phosphorous. If you are on a potassium restriction, avoid crisp chocolate and any cakes/biscuits containing dried fruit, chocolate or nuts.
ALCOHOL	Alcohol can contribute significantly to the weekly shopping bill as well as using upart of your fluid allowance, for those who are on a fluid restriction.

By **CELENE SANDS** 

SENIOR RENAL DIETITION, MAYO UNIVERSITY HOSPITAL on behalf of the Renal Interest Group of the Irish Nutrition and Dietetic Institute (INDI)





# We have been talking about the COVID-19 'pandemic' for what feels like an eternity. Let's remind ourselves of the definition of a pandemic.

pandemic is an outbreak of an infectious disease that occurs over a wide geographical area and that is of high prevalence. A pandemic generally affects a significant proportion of the world's population, usually over the course of several months. Pandemics are known to cause widespread disruption, illness and hardship, as we have witnessed through the COVID-19 pandemic.

You may have heard talk that COVID-19 is now moving from its pandemic phase to become 'endemic'.

An **endemic** means a disease is spreading in a community at the normal or expected level. A pandemic begins to shift to an endemic once the disease becomes more stable and manageable. It's not that the virus has gone away or that there won't be occasional outbreaks, it just becomes less intrusive in daily life.

While the borders between a pandemic and endemic are not defined, there are indications that COVID-19 is moving to an endemic. The overall spread of the virus has slowed as people continue to get vaccinated and/or build up natural

immunity.

That is an overview of the situation for the general population. It was clear during the pandemic that the longer people struggled with the virus, the greater the potential there was for variants to develop.

With the introduction of treatment options and a better immune response, symptoms are less severe and there are fewer overall cases and hospitalisations, making health care systems less stressed.

As an indication of the effectiveness of the vaccines and treatments, their introduction, was accompanied by a decline in the rate of variants developing.

By definition, people who are immune compromised are at greater risk from viruses than the general population. Equally, given that vaccines are aimed at triggering an immune response to protect against viruses, they are never going to be as effective in the vulnerable population as they will be amongst the wider community.

Should we therefore now be highlighting the need to factor in people with compromised immunity when developing new treatments and vaccines for COVID-19 and other viruses?

At the end of March you will have heard about the closing of COVID-19 testing centres. The public narrative is now very much about winding down the 'emergency' and managing COVID-19 in the community in the same way that we manage the 'flu.

In a recent meeting with the HSE, the Irish Kidney Association highlighted the fact that whilst it makes sense to focus the public messaging around the needs of the



An **endemic** means a disease is spreading in a community at the normal or expected level. A pandemic begins to shift to an endemic once the disease becomes more stable and manageable.



many, it is important that the communities who remain vulnerable to COVID-19 not be overlooked.

Given the changes in services/policies around COVID-19 that will continue coming, we requested that a briefing document on advice and the treatment pathways for those who are medically vulnerable should be issued via patient organisations to ensure that this critical information does not get lost in the general public noise around the winding down of COVID-19 services.

We also raised the issue about vulnerable patients often having to access hospital services via the Emergency Department and all the anxieties that come with this.

Whilst NPHET has not yet issued a decision on future booster vaccines, it is thought likely that there will be one offered for people who are medically vulnerable, possibly late Spring/Summer and another in Autumn/Winter.

We have suggested to the HSE that they consider making any future vaccines available in dialysis units for their patients to avoid unnecessary additional visits to healthcare settings.

No matter where you are on your vaccine journey, there is no doubt that there is a lot of 'advice' out there in relation to the effectiveness and possible side effects of the vaccines on offer. When reflecting on such 'advice', consider its source and whether it can be corroborated from other sources.

As always, it is important that you discuss any questions/concerns you have with your renal team.

In the meantime, it is about personal responsibility and managing the variables in your life that can be managed. General public health messaging is relevant here look after your overall physical and mental health whilst also accounting for the risks of COVID-19.

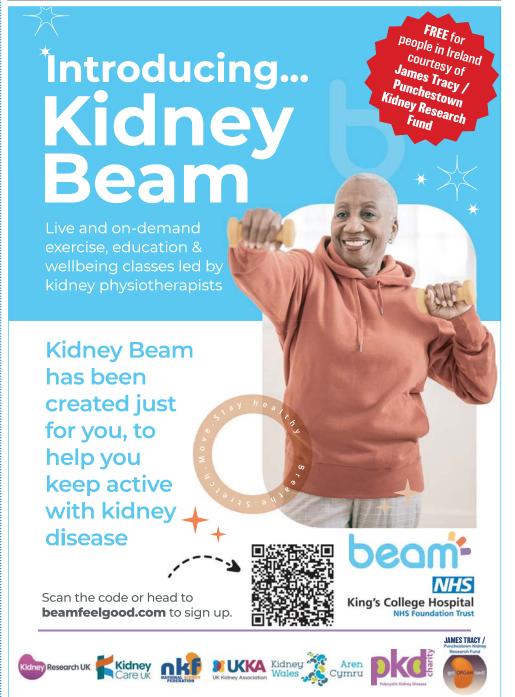


# ORGAN DONOR AWARENESS WEEK

Saturday 20th - Saturday 27th May 2023

For more information see pages 26-27 and keep an eye on the website for updates. www.ika.ie/donorweek







aterford Healing Arts Trust (WHAT) hosted the launch of Alfie's Escapades, the second book by former renal dialysis patient Liz McCue, on Tuesday, 6th December, 2022 to mark the first anniversary of Liz's passing. The launch took place in WHAT at University Hospital Waterford and was attended by members of Liz's family, friends, staff from the Renal Dialysis Unit at University Hospital Waterford (UHW), and the WHAT team. Alfie's Escapades, was officially launched by Consultant Nephrologist Dr. Sean Leavey and is a wonderful collection of stories from the point of view of Liz's beloved Jack Russell.



Alfie is a small dog with a big heart. Always on the lookout for a chance to romance his Sheila-dog neighbour next door, he also keeps a loving eye on his Momma. Why does she have to go to hospital so often? What does she do in there? And who is Mabel?

Following the success of her autobiography *Thursday's Child*, author and renal dialysis patient Liz McCue's imagination takes flight in this collection of stories from her beloved Jack Russell. Light-hearted and fun, Alfie's observations also offer a rare insight to the daily life of a feisty renal warrior, gently reminding us that life is for living, to the full.

For almost 20 years, Liz McCue was a patient of renal dialysis at UHW. It was here that she connected with Waterford Healing Arts Trust (WHAT), which supports patients through long hours on dialysis by providing opportunities to be creative: visual art, creative writing, music and photography.

Through the Arts Programme, which is funded by the Punchestown Kidney Research Fund, Liz found her creative voice, and drew great sustenance from being involved in

much of the work WHAT produced with patients and staff of the dialysis unit over the years, including *All About Us, Unfolding Time, Tea Room Tales,* and her magnum opus, *'Thursday's Child'.* 

Speaking at the launch of *Alfie's Escapades*, Dr. Sean Leavey said "Tonight we are honouring Liz and celebrating her last work. Liz was an incredibly feisty, resilient woman. Early along the way in her dialysis journey, through her artistic mentors in WHAT, she discovered her writing muse and she had the tenacity and courage to let it take flight and lead her wherever it might.

"Alfie's Escapades is a light-hearted read, but through the stories, Liz tells her journey with chronic kidney disease over the couple of years of her life through COVID.

"It's a powerful message, and an opportunity for her as a person to tell us what those two years were like as a renal patient. There's a great warmth jumping off the pages, and a lovely turn of phrase."

He went on to say "Liz always had a smile, twinkling eyes...She could illuminate a room, and I think anyone who wants to have a template for approaching life or challenges could



really do no better than read the Introduction to *Alfie's Escapades...*it's full of very positive, very clear advice.

"Liz was always about what she needed to do to make things happen, and then doing them. Not sitting back. In her own words she 'oozed ambition and purpose' and she exhorts all of us to find purpose, saying we must 'go with our own flow, and do the very best we can, before life slips by."

In addition to Dr Leavey, the other guest speakers at the launch of *Alfie's Escapades* were Jane Cullen, Clinical Nurse Manager (CNM) of the Renal Dialysis Unit at UHW, Brenda Ronan, retired CNM of the Renal Dialysis Unit, WHAT artist Philip Cullen, musician and retired dialysis nurse Mary Prendergast, who paid a beautiful musical tribute to Liz, and Claire Meaney and Maeve Butler, Director and Assistant Director of WHAT.

Waterford Healing Arts
Trust (WHAT) brings arts
experiences to the bedsides
of patients at University
Hospital Waterford and other
healthcare settings. WHAT
believes that the arts
contribute to the wellbeing
and vitality of society and that
engaging with the arts
stimulates our sense of
identity and creativity.

See www.waterfordhealingarts.com
Core funded by the Arts
Council, WHAT also supports
the development of arts and
health in Ireland and
manages the national website
www.artsandhealth.ie

# **BOOK REVIEW**

# Alfie's Escapades

Stories from a mischievous Jack Russell and his Feisty Renal Warrior

At only eighty-three pages in length, Alfie's Escapades: Stories from a mischievous Jack Russell and his Feisty Renal Warrior offers a quick and pleasant read.

The heart-warming novel includes photographs of the key characters, Alfie and Liz as they embark on their journey of renal failure, and all the highs and lows associated with it. This is a book that leaves the reader feeling hopeful.

Author Liz McCue uses a series of beautiful and creative images to make her points. The

book is written from the perspective of Liz's dog, Alfie, as he thinks about the human condition and what it means to be a dialysis patient in Ireland in the current of the COVID-19 pandemic.

# **ABOUT THE AUTHOR?**

The late Liz McCue was an Irish author, known for her autobiography *Thursday's Child. Alfie's Escapades* was first published in 2022 by the Waterford Healing Arts Trust. The publication of this book was made possible by financial support from the Arts Council and the Punchestown Kidney Research Fund. Liz

passed away unexpectedly in December 2021. This book honours her memory.



### WHY IS THIS BOOK RECOMMENDED FOR KIDNEY PATIENTS?

This short text is an animal lover's dream, filled with delightfully humorous Irish wit and heart-warming tales that tell a story of resilience and overcoming life's obstacles, something which kidney patients, in particular, can certainly relate to.

This book is also suitable for young readers and offers comfort to those who regularly attend dialysis treatments and suffered through the pandemic whilst trying to look after their health. This acknowledges the impact that COVID-19 had on kidney patients. It is very important for people to see themselves portrayed, whether it be in books of fiction or non-fiction, or in this case, a healthy lashing of both. The book explores the home dynamic of families living with illness, whilst also invoking a nostalgic sense of Irishness and what it means to be Irish in today's landscape.

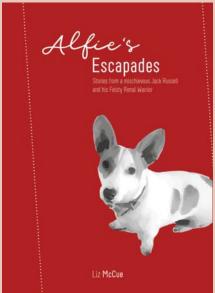
In conclusion, I would certainly recommend this unique read in which both Liz McCue and Alfie's personality truly shines through.

My story goes to show whatever we need or want to achieve can be done by using our magnificent imagination, by feeding it good thoughts of a positive nature and watering these thoughts. (14)

# WHERE TO GET THIS BOOK?

You can purchase this book for €10 at *The Book Centre* in their stores located in Waterford, Wexford, Kilkenny and Naas, or online via their website www.thebookcentre.ie

Alfie's Escapades is also available at the Post Office in Kilmacthomas, Co. Waterford and from Waterford Healing Arts Trust, www.waterfordhealingarts.com



My two chronic comics

depend on me to care for

them unconditionally. (46)

BY **JESSICA BRIEN** 

IRISH KIDNEY ASSOCIATION



Dialysis patient **Niall Kennedy** is a respiratory nurse who has been on the transplant waiting list for a kidney since January 2020. The oldest of a family of five, he was born and raised in Co. Roscommon. He now lives near Bunclody in Co. Wexford with his wife Helen and three sons ages 18, 15 and 14.

He was diagnosed with kidney disease in 2005 and has been receiving dialysis treatment since January 2020.

Here he shares his health story and how he manages his working and family life around home dialysis.

### **BACKGROUND**

aving lost my father to a brain aneurysm when I was just 10 years old, I went on to finish secondary school, and trained to be a nurse. I have worked primarily in Intensive Care and on medical wards and now work as a Respiratory Nurse Specialist.

While working in Intensive Care I saw first-hand the devastation of families when faced with the tragedy of their loved ones being kept alive on life support when hope of recovery was gone. I also witnessed their bravery and selflessness in considering others through organ donation.

In the nineties one of my sisters was diagnosed with Autosomal Dominant Polycystic Kidney Disease (ADPKD). Despite my years working as a nurse, I had never heard of this genetic condition.

Following a quick internet search, I soon discovered that it is the most common genetic cause of kidney disease in Ireland. However, the disease develops very slowly and varies from person to person, and symptoms usually do not develop

until middle age.

Cysts slowly form and grow in both kidneys over time making the kidneys bigger and eventually reducing kidney function to the point of requiring dialysis treatment. For some people with the condition dialysis may be required by the time they are in their fifties while others can keep reasonable kidney function well into their seventies.

The fact that my sister had ADPKD meant that I and my three other siblings each had a 50% chance of having the condition. However, as I felt very well for a long time, I reckoned that I would probably be okay, so I opted to not get tested for the condition.

When I noticed the occasional high blood pressure reading while demonstrating blood pressure monitors in my line of work, I chose to ignore it. My other three siblings didn't seem to be affected and I hoped that I would be lucky too.

## **MY DIAGNOSIS**

It was only in 2005, when I had a medical for a new job and my blood pressure was 'through the roof', I knew I had to bite the bullet and see a kidney specialist.

While I knew instinctively what the diagnosis would be, it was still a shock when Professor Keogh diagnosed me with ADPKD. At that stage my kidney function was close to normal, my renal bloods were only slightly raised and the only obvious symptom I had was high blood pressure.

I had to have a CT scan as there was a link between ADPKD and increased risk of cerebral aneurysm. This was especially worrying as my father had passed away from a brain haemorrhage caused by an aneurysm when I was 10 years old.

Thankfully my brain scan results showed I was okay.

### **MANAGEMENT**

The years moved on and I learned to live with my condition. In the meantime, life continued at work, with marriage and building a house and making a home together took over. Our first child was born the year before I was diagnosed, and we went on to have two more children.

Raising three boys filled much of our time and occasionally I would worry that I could have passed on the ADPKD gene to some or all of them. However, I hoped then, and still do, that if they have issues in the future, medical science might have progressed to minimise the impact.

I saw my Renal Consultant, Professor Wall, in Tallaght Hospital on a yearly basis and my blood pressure was controlled with medication. I had my blood values monitored and I took steps to improve my lifestyle, watched what I ate, and got fitter.

# **MY CONDITION'S DETERIORATION**

However, the kidney cysts continued to grow, enlarging and decimating my kidney function, turning them to something resembling Swiss cheese. By early 2019 my kidney function had reduced to the point that my consultant started to discuss going on the transplant list and options for dialysis treatment in the interim.

My sister had been through all of this before me and had received a kidney transplant, so, I thought I had a realistic idea of what to expect. However, my journey took a sudden turn just a few months later when I developed excruciating pain in my left kidney.



I was diagnosed with a ruptured kidney cyst. But there was a chance that I could have something more serious in the kidney and so my medical team recommended that one of my two poorly functioning kidneys be surgically removed.

# **MY DIALYSIS JOURNEY**

Prior to the surgery to remove my left kidney, I had a central line tube inserted in a vein under my collar bone in preparation for haemodialysis treatment.

However, after recovering from the surgery I managed to limp along for another three months without dialysis. But I could only put off the inevitable for so long. I had previously agreed with my renal consultant that, when the time came, I would do peritoneal dialysis (PD) from home, rather than attending the hospital for haemodialysis (HD). I had the central line removed and a PD catheter was inserted surgically in my stomach.

I had the full work-up for transplant which entailed almost every test known to medicine. If nothing else I was going to be the 'healthiest' sick person around. I went to Beaumont Hospital and met the renal transplant team and got accepted onto the hallowed list.

We discussed the possibility of receiving a kidney from a living donor within my family but I knew that option had been explored by my sister and, for one reason or another, no suitable donor was

found for her. I would have to wait for a suitable kidney match from a generous deceased donor and that could take anything from three months to an average of three to four years.

A few weeks later, once I had completed my training for peritoneal dialysis, with the wonderful Home Therapies nurses in Tallaght Hospital, I joined the small number of approximately 250 people in Ireland doing PD at home. For me, this entails connecting to a machine for nine hours every night which heats and pumps over 10 litres of special fluid in and out of my abdomen.

The PD machine is about the size of a large suitcase that sits at the foot of my bed. It is supplied by Baxter who also deliver the fluids, tubing, and connections necessary for home therapy. I get a pallet full of stock delivered every month that takes up a corner of our bedroom as well as some space in a spare room.

For me, this is a gentler form of dialysis than haemodialysis. It allows me to work full-time and gives me autonomy over my own care. It isn't without its drawbacks of course and, despite my nursing training, I have had abdominal infections (peritonitis) on two occasions. On one of these occasions the infection was so severe that I was hospitalised twice in three weeks.

It was further complicated by a fungal infection which required surgical removal of the PD catheter

continued next page

# Life as a Nurse on Dialysis contd...



and a six-month spell of attending the hospital three times a week for haemodialysis treatment. Personally, I found the time on haemodialysis to be the hardest of my life, spending over eighteen hours a week on therapy or travelling to and from the hospital for the treatment. I felt exhausted trying to balance work and family life, not to mention lack of autonomy and dealing with a whole new regime with less control over my treatment.

Luckily, I was able to return to PD at home and chalk the previous hospital-based haemodialysis down to experience.

I should point out that every

dialysis patient has a different experience. While peritoneal works best for me, some patients prefer, and are more suited to, haemodialysis.

### **FAMILY LIFE**

Being on PD at home means that when I am not at work I can have more time to spend time with my family, watching our boys grow and develop into fine young men. They know all about my condition and understand that our lives have been a bit disrupted.

We haven't had a foreign holiday over the past three years as to do so would mean coming off the transplant list. It is possible to go abroad while on PD, with a bit of organisation, but we have made the decision not to go as our priority is for me to get a transplant.

We have been on holidays in Ireland, taking all the PD equipment with us in a second car.

The Irish Kidney Association (IKA) provides holiday homes in Ireland for kidney patients, but we haven't availed of these in the last few years. We have applied to the IKA to be considered for one this summer. An advantage of this is that once I bring my peritoneal dialysis machine, Baxter will supply the fluids and other equipment to the holiday home, reducing the need to take a second car.

# COVID-19

COVID-19 came along in March 2020, one month after I commenced PD. I switched from working in the frontline care of people with respiratory disease (and now COVID!) to being told I was highly vulnerable and had to work from home. With the support of my HSE managers and colleagues I developed my role and continued to work full-time, interacting with people with respiratory diseases, such as COPD and asthma, through the use of technology such as video calls and virtual clinics.

Now that COVID is retreating and I am fully vaccinated with six vaccine doses, I have recently returned to meeting my patients face-to-face.

The most significant impact of COVID-19 for dialysis patients was not just the fear of being told we were in the higher risk category, but that it reduced the number of transplant operations taking place in

# 1 2 3 OFF AND OFF AND

# ACCOMMODATION TELEPHONE BOOKING HOURS 01-6908887

As hotels can be very busy, be sure to ring the Renal Support Centre staff as soon as you know of your hospital appointment. The earlier the better, so we have a greater chance in securing accommodation. We have had some cases where the Clayton Hotel, Swords, Dublin has been full.

# **ROUTINE APPOINTMENTS**

The accommodation phone line is open: Monday to Friday 9:30am to 5:30pm.

# **EMERGENCY APPOINTMENTS**

For unplanned appointments, emergency visits or even the very welcome call for a transplant, the phone line will be open on an emergency basis only from Monday to Friday: 7pm to 10pm. Saturday, Sunday and Bank holidays: 12pm to 4pm.

If the phone is unanswered you will be greeted by a voicemail. Please be sure to leave a message about urgent accommodation you require. We will do our very best to accommodate you in a hotel and will liaise with Beaumont Hospital staff, when needed.

Ireland and elsewhere resulting in longer average waiting times for transplants.

The challenge for me now is to keep well and healthy enough to remain on the transplant waiting list.

# A TYPICAL DAY

I work full-time, so I am up at 7am every morning for a 35-minute commute. Between work and dialysis is the usual hectic family life, including cooking dinners, bringing the boys to football and hurling training, walking the dog and trying to stay on top of things.

Bedtime must be earlier than normal to allow for nine hours of dialysis but that gives me time to relax.

Regular dialysis keeps my blood on an even keel while I work to self-manage my condition through diet, exercise and keeping a positive mental attitude. I take between 14 and 18 tablets every day to keep me well and I give myself an injection every three weeks to maintain my blood count.

My diet is quite restrictive, but I have adjusted well to it. I am lucky that, unlike many dialysis patients, I don't have to strictly limit my fluid intake but there are certain drinks that I can't have

The renal dietitians have created a personalised plan for me so I know exactly what I can and can't eat or drink.

# **PSYCHOLOGICAL IMPACT**

People with end stage kidney disease, and especially people on dialysis, can have higher levels of depression and anxiety.

Being on the transplant list gives me hope of better days to come, even though I have no idea when to expect "the call". I have the mobile phone fully charged and it never gets switched to mute. I find I jump and think "is this it?" whenever an unknown caller rings my phone.

The thought of what being called for a transplant might entail can cause a certain level of trepidation. I know that for me to have a transplant, my donor's family will be grieving the loss of a loved one.

Being a transplant recipient will have its own physical and psychological challenges, but I have had time to consider them and know that I will get the support I need from my family, the renal team, and the IKA.

# WHAT A TRANSPLANT WOULD MEAN TO ME

I am grateful to my family for their loving support and all the medical and nursing staff, dietitians, and everyone involved in my care. I feel fortunate that dialysis is working well for me.

A successful transplant will give me freedom from dialysis, more energy, and a longer healthy life. It will give me confidence that I can enjoy my sons grow into men with lives and families of their own.

I look forward to being able to eat freely without having to measure portions, calculate protein values, and looking at labels for added phosphate. I also look forward to my wife Helen and I growing older gracefully together and taking trips abroad well into future retirement.

I live in hope for a kidney transplant for which my family will be eternally grateful to a selfless donor who will restore my health and greatly improve my quality of life.



# **CONGRATULATIONS**

ongratulations to **Patrick Eustace** who is enjoying the successful longevity of the kidney transplant he received 25 years ago when he was just twelve years old. He participated in some media interviews in January which included one on RTÉ *Drivetime* along with Dr. Catherine Motherway, Clinical Lead, Organ Donation Transplant Ireland.

Patrick, a native of Ennis, Co Clare, is the son of long-standing Clare IKA branch stalwart members, Peggy and Val Eustace. Patrick was born with renal dysplasia, a disease in which at least one kidney fails to develop properly when a baby is growing in the womb. Under the care of Crumlin Children's Hospital, his condition deteriorated considerably by the age of 12. Fortunately, he was only on dialysis for six months before receiving a deceased donor kidney transplant facilitated by retired transplant surgeon David Hickey.

The transplant enabled Patrick to live a healthy life without being tethered to a dialysis machine, having had opportunities to travel abroad that wouldn't have been feasible otherwise. Patrick is now happily married to Áine Doherty and they live in Ballinderreen, County Galway with two beautiful children Méabh and her baby brother Darragh.

Patrick, remains extremely grateful to his donor family for their selfless decision and sends a gesture of appreciation anonymously to the organ donor family every year.

He said, "It's very important that as recipients we honour the decision that donor families make – it's made in a very difficult time and space for them."



# **PEER SUPPORT UPDATE**

he Irish Kidney
Association is
delighted to inform
you that its Peer
Support Service is now
open. We are taking selfreferrals and referrals from
your renal teams at your
request.

This Peer Support Service, based on the belief that people can use their lived experience to encourage hope and provide support to others facing a similar situation, is up and running.

Patricia Bourke D'Souza, our Peer Support Consultant Trainer, and I have been busy with hospital meetings and we are planning more.

We have met with full renal teams to make them aware of the new service which is now available for their patients. We have shown them the work that has been done to create this service, the training that the peer support volunteers have received and let them know how and where to make referrals.

We have had a tremendous response from the teams at these meetings. I feel their openness to have us in to the hospitals and their engagement during the meetings really showed the need for this service to be available within our renal community.

Our Peer Support Service is intended to complement the care and education given by your renal team.

The Peer Support



# A New Year A New Service

Service is available to all patients living with end stage kidney disease, their families and carers. Peer Support can provide you with many benefits, including:

- Being able to talk to someone who has had to cope with similar experiences;
- Someone who understands the challenges you are facing;
- Sharing of information;

• Learning from practical experiences.

If you, or someone you know, feel you or they could benefit from this service please complete the Peer Support request form which is available on our website:

www.ika.ie/peersupport/ or contact the Irish Kidney Association.

Once we receive your request, we will contact you to confirm we have an accurate understanding of

your needs and the best time for you to talk to someone. You will then be matched with one of our Peer Support volunteers and your online support will be arranged.

I'm looking forward to hearing from you!

The Irish Kidney Association wishes to acknowledge the support of **Punchestown Kidney Research Fund (PKRF)**, the major funder for the provision of the Peer Support programme.

WINTER PRIZE
GIVEAWAY
WINNERS

Thank you to **TESCO** for generously sponsoring **10 x €50 gift cards** as a prize giveaway in the Winter 2022 issue of *SUPPORT. Congratulations to the winners:* 

Mary Adamson, Tipperary; Kieran O'Mahony, Kerry; Finola O'Brien, Limerick; Kelly Concannon, Galway; Oliver Ennis, Dublin 4; Aoife Owens, Dublin 14; Marion Young, Kilkenny; Janice Johnston, Dublin 13; Vincent Harbourne, Dublin 16; Philip Duane, Wicklow.



# Irish Kidney Association



# IKA ACTI **- 2022**

# PATIENT SUPPORT



# **PATIENT AID**

Patient support requests

# **FINANCIAL AID**

UP BY **98%** 

# COUNSELLING



**FREE HOURS** 

Counselling referrals up by 40%

# **NEW PEER SUPPORT**

Service Launched



# HOTEL ACCOMMODATION

Overnight stays for 135 families



# **HOLIDAYS**

Families provided a 6-day week holiday

Dialysis treatments organised abroad

# **ORGAN DONOR AWARENESS** ORGAN DONOR **AWARENESS WEEK**

– APRIL –



# 37th ANNUAL SERVICE OF REMEMBRANCE AND THANKSGIVING

- OCTOBER -

Viewed on TV by

People



# **ROLL OF HONOUR**

FOR ORGAN DONORS

# **ORGAN DONOR CARDS**



DISTRIBUTED

**DONOR CARD** DOWNLOADS

# **EVENTS**



Virtual

In-person



# HEALTHCARE

Healthcare Professionals 1 Online

Patient

# **MEETINGS**

**National** Branch Forums

Branch Meetings

# COMMUNICATIONS

31,181

3,443

3.514



**Emails** 1,600

to info@ika.ie UP BY 143%

# **PUBLICATIONS**

**Quarterly** SUPPORT Magazine









Patient Information Books



**1.900** issued

n December 1st, 2022, Wexford native Trish Boyce donated a kidney to her father John Boyce (age 69), bringing an end to his two and a half years of haemodialysis treatment at the renal care unit at Waterford University Hospital and Wellstone Renal Care, Wexford.

John, a grandfather of two, and retired seaman who worked for Stena Line Ferries for over 43 years, on the Rosslare-Fishguard route, made a quick recovery as the new kidney started working almost immediately. He returned to his home in Rosslare Harbour, which he shares with his wife Bridgie, just a week after his operation.

Trish, who lives nearby, bounced back after her operation and was home from hospital four days after her surgery.

Trish describes how donating a kidney to her father, "a ship and maritime fanatic", is "the best thing I have ever done and a privilege to have been able to help give Dad a new lease of life.

"The transplanted kidney worked for him immediately and he looked so much better when I got to see him the following day after our operations. The colour had returned to his cheeks and his eyes were brighter. It was an added bonus for him when recovering in Beaumont Hospital to be given a room with a window from which he could partially see Dublin Port.

"For me, to hear my twelve-year-old nephew, Joe, say to me when he phoned me the day after the operation, 'Thank you for giving Grandad his new kidney', was so rewarding as it reminded me just how organ donation is a gift to the whole family and not just the patient. Dad is delighted that his three times weekly dialysis treatments and its side effects, like extreme tiredness, sickness, and dietary restrictions, are now in the past and he looks forward to getting back to one of his old pastimes of



# Seafarer sails through kidney transplant from donor daughter

# By GWEN O'DONOGHUE

enjoying his walks along the scenic coastline of Rosslare Harbour."

Both Trish and her brother Sean, who works as a Captain with Stena Line in Dublin, were screened for suitability for living donation and Trish describes how delighted she was to have been found to be a suitable match.

Trish said, "From the moment it was revealed that I would be his kidney donor, I have received huge support and continue to receive it from my mother Bridgie, my brother Sean, my whole extended family, friends and also my employers, Hidden Hearing, who have been very understanding and supportive throughout. I work there as a Clinic Coordinator for the last thirteen years and looked forward to returning there early in the New Year.

"My father is the Chairman of the local Maritime Heritage Centre in Rosslare Harbour and his friends there have been very good to him also and wished him a speedy recovery."

Both John and Trish have high praise for all the surgeons, doctors, nurses, and staff at Beaumont Hospital where they had their surgeries. "We were looked after in such a professional and caring way and the whole team in Beaumont are just fantastic".

John said, "there are no words to describe my gratitude to my daughter Trish for her generous kidney donation which has transformed me and given me renewed health. My wife, family and friends have been a rock of support throughout my kidney failure journey.

"I'd like to thank the medical and nursing staff at Waterford Regional Hospital and Wellstone in Wexford, who cared for me so well when I was receiving dialysis treatment. Our family are also grateful to the Irish Kidney Association for its support and for their work they do in helping kidney patients and their families and promoting organ donation and the organ donor card. The 'gift of life' is the most important and special one of all".

John and Trish shared their story on RTÉ Radio One with presenter Miriam O'Callaghan on Sunday, January 22nd, generating great organ donor awareness. You can listen to the podcast by logging on to www.rte.ie/radio/radio1/clips/22200661/

# Truck and tractor run raises €45,000 for kidney charities

he Irish Kidney Association (IKA) is delighted be one of the three charities to benefit from a very successful Truck and Tractor Run, held in Longford on December 27th, 2022 which raised over €55,000. Both the IKA and the Cavan/Monaghan Dialysis Patient Comfort Fund received €22,500 each while the balance of €8,500 was presented to another very worthy cause, the suicide awareness and support charity, SOSAD.

A cheque presentation night was held on March 4th, 2023 at Creegans Pub in Bunlahy, Co Longford, with monies presented to representatives from the three charities who outlined how the greatly welcomed funds would benefit the provision of the causes they represented.

It was fitting on the night that the popular local man Myles Reilly carried out the roll of Master of Ceremonies as he himself is a dialysis patient attending Cavan General Hospital, and he appreciates first-hand how it will benefit two of the charities both of which represent kidney patients.

For a number of years, the committee for Longford's Finest Truck and Tractor Run has organised fundraisers which, to date, have raised in excess of €200,000 for various worthy charities.

The original idea for these events stemmed from Norman Hall of Hall Transport, who has been at the forefront of these events.



The organising committee decided that after a five-year break, with COVID-19 in between, to reconvene and stage an event at Christmas time.

The December 27th fundraiser involved truck and tractor competitions held in Mastertech Business Park, with the run and impressive large convoy then travelled on to Creegans, Bulaghy via Mostrim and Granard.

An auction on the same evening raised over €15,000 with a huge crowd turning out for an enjoyable night of entertainment by the *Midlanders*, and *Night Fever*.

In a comment on behalf of the Committee it stated, "we would like to sincerely thank everyone who supported the event either by attendance or donations.

A special thank you to the Garda Siochana for their help on the day in traffic management assisting all our stewards. We greatly appreciated all your help. Thanks also to Longford's singer-songwriter Declan Nerney who popped in to sing a few songs, and to the catering vans who attended on the day.

Thank you to the tenants and management in Mastertech who facilitated us for the assembly and competitions, and to members of Colmcille Vintage club for their participation in the event".

For further details on how the monies will be spent contact Ashling Hand, at the IKA head office in Dublin or Jackie Larkin, the Cavan Dialysis Unit Manager.

The IKA would like to congratulate the organising committee for staging such a successful event and express its sincere gratitude to everyone who participated and contributed to the fundraiser which will greatly benefit patients.







# Benefits and Taxes 2023

# **Working Family Payment**

Number of children	Weekly income threshold	Number of children	Weekly income threshold
1 child	591	5 children	1,010
2 children	692	6 children	1,126
3 children	793	7 children	1,262
4 children	884	8 children	1,358

Working Family Payment is 60% of the difference between your net family income and the income threshold that applies to your family.

# Accommodation Recognition Payment (ARP)

The Accommodation Recognition Payment (ARP) is a tax-free payment of €800 per month for each property used to provide accommodation to refugees from Ukraine. Accommodation must be provided for at least 6 months. ARP is not paid if there is a rental agreement in place. It is not included in the means test for grants or payments from the DSP or other public bodies.

# Childcare supports

The Early Childhood Care and Education Scheme (ECCE) provides 3 hours of paid care and education per day to children who are at least 2 years and 8 months before 1 September and not older than 5 years and 6 months on or before 30 June of the programme year.

The National Childcare Scheme (NCS) provides childcare subsidies for children from 6 months (24 weeks) up to 15 years (children aged 15 do not qualify). There are two subsidies:

- Universal subsidy for children above the age of 6 months. It is not means-tested.
- Income-assessed subsidy is based on parental income.

More information and a subsidy calculator is available on ncs.gov.ie. For both the ECCE and NCS, children must be attending a childcare provider registered with Tusla.

# **Back to School Clothing and Footwear Allowance**

Rate for each child aged 4–11 years on 30 September 2022.	260.00 (once-off payment)
Rate for each child aged 12–17 years on 30 September 2022. It is also paid to qualified children aged 18–22 in second-level education.	385.00 (once-off payment)
Weekly income thresholds	
Number of dependent children	Income limit
1 child	642
2 children	692
3 children	742
4 children	792
Each additional child	50

260.00

### Student Grant Scheme

The means-tested Student Grant Scheme for third-level students includes a maintenance **grant** to help with living costs and a **fee grant** to help with the Student Contribution and the tuition fees of students who do not qualify for the Free Fees Scheme

# Extra payments

Over 80 Increase	10.00 weekly	
Living Alone Increase	22.00 weekly	
Island Increase	20.00 weekly	
Widowed or Surviving Civil Partner Grant	8,000 (once-off payment)	
Fuel Allowance	33.00 weekly	
Telephone Support Allowance Paid to people getting Living Alone Increase together with Fuel Allowance.	2.50 weekly	
Increase for a Qualified Child	Full rate	Half rate
Child under 12	42.00	21.00
Child 12 or over	50.00	25.00

### Treatment Benefit Scheme

Provides dental, optical and aural benefits including free dental and optical examinations. Other treatments and aids covered by the scheme are subject to a maximum amount, for example, the cost of non-surgical hair replacement (due to illness).

# Payments for people with disabilities

Daymand	Maximum personal rate (weekly)		
Payment	Claimant	Qualified adult	
Invalidity Pension (PRSI-based)	225.50	161.10	
Illness Benefit (PRSI-based) Reduced rate paid if your average weekly earnings in 2021 were less than €300.	220.00	146.00	
Disability Allowance (means-tested)	220.00	146.00	
Blind Pension (means-tested)	220.00	146.00	
Disablement Benefit (PRSI-based)	251.00	n/a	
Injury Benefit (PRSI-based)	220.00	146.00	
Blind Welfare Allowance (HSE)	66.70	n/a	

# Payments for carers and guardians

Davimont	Maximum personal rate (weekly)	
Payment	Caring for 1	Caring for 2 or more
Carer's Benefit (PRSI-based)	237.00 355.50	
Carer's Allowance (means-tested) Carer under 66 Carer 66 and over	236.00 354.00 274.00 411.00	
A half-rate Carer's Allowance may be paid with an existing social welfare payment.		
Domiciliary Care Allowance	330.00 per month	
Guardian's Payment	203.00	
Carer's Support Grant	1,850 annually per person cared for	
	Child under 12	Child 12 and over
Foster Care Allowance (Tusla)	325.00	352.00

# Payments for widow/ers and surviving civil partners

Payment	Maximum personal rate (weekly)	
Widow's/Widower's/Surviving Civil Partner's	Under 66	66 and over
Pension (Contributory) (PRSI-based)	225.50	265.30

Your rate may be reduced, depending on your (or your late spouse's or civil partner's) PRSI

Widow's/Widower's/Surviving Civil Partner's Pension (Non-Contributory) (means-tested)	220.00

# Extra payments

Over 80 Increase	10.00 weekly	
Living Alone Increase	22.00 weekly	
Island Increase	20.00 weekly	
Widowed or Surviving Civil Partner Grant	8,000 (once-off payment)	
Fuel Allowance	33.00 weekly	
Telephone Support Allowance Paid to people getting Living Alone Increase together with Fuel Allowance.	2.50 weekly	
Increase for a Qualified Child	Full rate	Half rate
Child under 12	42.00	21.00
Child 12 or over	50.00	25.00

### Treatment Benefit Scheme

Provides dental, optical and aural benefits including free dental and optical examinations. Other treatments and aids covered by the scheme are subject to a maximum amount, for example, the cost of non-surgical hair replacement (due to illness).

# Additional Needs Payment

The Additional Needs Payment is paid under the Supplementary Welfare Allowance Scheme. It can help with an essential expense that you cannot pay out of your weekly income. It can also be paid after an emergency event such as a fire or flood.

Every week our patient support team answers queries regarding social welfare benefits our members may be entitled to. Based on the themes of those calls we have gathered the following most up to date information on benefits as implemented by the Government in Budget 2023. If you require further information please visit Citizens Information, contact details below or scan the QR code.

Tax credits		
Personal circumstances		Credit
Employee (PAYE)		1,775
Earned Income The Earned Income Credit applies to self-employed people. The credit available is the lower of €1,775 or 20% of your qualifying earned income. If you have income that qualifies for the Earned Income Credit and the Employee (PAYE) Credit, the combined tax credits cannot be more than €1,775.		1,775
Single person		1,775
Married couple/civil partnership		3,550
Single person child carer		1,650
Home carer		1,700
Blind person (single)		1,650
Blind persons (married couple/civil partners, bo	oth blind)	3,300
Widowed/surviving civil partner (bereaved in 2023)		3,550
Widowed/surviving civil partner (no dependent children), bereaved before 2023		2,315
Widowed Parent Tax Credit		
Bereaved in 2022		3,600
Bereaved in 2021		3,150
Bereaved in 2020		2,700
Bereaved in 2019		2,250
Bereaved in 2018		1,800
Other credits		
Rent Tax Credit	Single	500
Maximum amounts (20% of rent up to limit). Available 2022-2025. For 2023 rent, can claim credit during year.	Married couple/ civil partners	1,000
Incapacitated Child Tax Credit		3,300
Fisher Tax Credit		1,270
	Single	245
Age Tax Credit	Married couple/ civil partners	490

lax reliefs and exemption limits		
<b>Rent-a-room scheme</b> The exemption limit for rooms rented out in a principal private ro	esidence is €14,000.	
Allowance for employing a carer  Maximum allowance at your highest rate of tax  75,000		
Medical expenses relief		
Qualifying health expenses	20%	
Nursing home fees Your highest rat		
Age exemption limits		

Housing		
Housing Assistance Payment (HAP)		
Rental Accommodation Scheme (RAS)	Differential rent, based on household income	
Local authority housing		
Rent Supplement	Single	Couple
Minimum personal contribution towards rent	30.00	40.00

# **Remote Working Relief**

Married/civil partner (65 or over)

Single/widowed/surviving civil partner (65 or over)

Tax relief is available at your marginal tax rate for electricity, heating and internet costs for days working from home. The relief applies to 30% of qualifying costs.

All figures in tables are in euro (€).

Rates may be subject to change. For current rates check citizensinformation.ie.



# Find out more with the QR code.

Point the camera on your smartphone at the black-and-white OR code to go to citizensinformation.ie

Medica	l card <i>i</i>	/GP \	isit card

People under age 70	Weekly income limit (gross earnings less PRSI, USC and income tax)				
Single person living alone	Medical card	GP visit card			
Aged under 66	184.00	304.00			
Aged 66 and over	201.50	333.00			
Single person living with family					
Aged under 66	164.00	271.00			
Aged 66 and over	173.50	286.00			
Couples/one-parent families					
Aged under 66	266.50	441.00			
Aged 66 and over	298.00	492.00			
Additional allowance for each dependent child					
First two children under age 16	38.00	57.00			
Third and subsequent child under age 16	41.00	61.50			
First two children aged 16 and over	39.00	58.50			
Third and subsequent child aged 16 and over	42.50	64.00			
In full-time third-level education and not grant-aided	78.00	117.00			

Additional allowances include rent/mortgage expenses, childcare costs, maintenance paid, nursing home or home care costs, travel costs to work (actual cost of public transport or mileage at  $\in$ 0.30 per mile/ $\in$ 0.18 per km). Hardship cases are assessed individually.

Children with Domiciliary Care Allowance, or who have cancer, are eligible for a medical card. People aged 16–25, and dependent on a parent with a means-tested medical card, qualify.

### GP visit card without a means test

All children under 6, people getting Carer's Allowance or Benefit, and people aged over 70. The GP visit card may be extended to other groups in 2023.

### People over age 70

Medical card weekly income limit is €550/€1,050 for a single person/couple. There is a savings disregard of €36,000/€72,000. The GP visit card is available to everyone aged over 70 without a means test.

### Prescription charges

Medical card holders pay €1.50 per prescription item, with a monthly cap of €15 per person or family. If over age 70, the charge is €1 per item, up to €10 per month.

# **HSE** schemes

### **Drugs Payment Scheme**

Non-medical card holders pay a maximum of  ${\in}80$  a month for prescribed drugs, medicines and certain appliances.

# Nursing Homes Support Scheme (Fair Deal)

Your contribution to the cost of care is 80% of your assessable income and 7.5% of the value of your assets per annum. If you own your home and are renting it out, you pay only 40% of this rental income towards nursing home care and keep 60% of the rental income. Your home must be your principal residence.

# Hospital charges

Emergency department charge (if not referred by a GP) Charge does not apply to COVID-19 patients	100
Injury unit charge (if not referred by a GP)	75

### In-patient charge for public patients

Maximum of €800 in 12-month period 80 per day

Medical card holders are not liable for these charges. Since September 2022, there are no public hospital in-patient fees for children aged under 16. Public hospital in-patient fees for adults are due to be abolished in April 2023.

# Citizens Information C

LOG ON www.citizensinformation.ie

**CALL** 0818 07 4000 Mon to Fri, 9am-8pm DROP IN locations nationwide

18.000

36.000





# BY FIONA AHERNE PATIENT SUPPORT MANAGER

ith energy costs continuing to be a source of anxiety for many we would like to give you an update on the Fully Funded Energy Upgrades scheme (formerly Warmer Homes scheme).

The scheme which is provided by the Sustainable Energy Authority of Ireland (SEAI) provides free home energy upgrades to qualifying homeowners who get certain social welfare payments. The scheme prioritises the oldest and least energy efficient homes.

You can apply for the free upgrades if you've already had work done under the scheme, but your home would benefit from further upgrades. To access the scheme again you must meet the qualifying criteria.

### **QUALIFYING CRITERIA**

- You must own your home and be living in it
- Your home must have been built and occupied before 2006
- Your home must have a BER of C,D,E,F or G – if you don't have a BER cert the SEAI will arrange for a free BER cert for you
- You must be getting one of the following social welfare payments:
  - Fuel Allowance as part of the National Fuel Scheme
  - Working Family Payment
  - Iobseeker's Allowance for over 6 months and have a child aged under 7
  - Disability Allowance for over 6 months and have a child aged under 7
  - Domiciliary Care Allowance
  - One Parent Family Payment
  - Carer's Allowance and you must live with the person you care for.

# **HOW DOES THE SCHEME WORK?**

There are **four** steps to this process:

1. Apply for the scheme, ensuring

# WORRIED ABOUT BILLS - Take Action

Here are some things that can help if you are concerned about your energy or other bills.

**Engage** 

Get in touch with your energy supplier - they can work with you to find a solution if you are experiencing financial difficulties. Under the Energy Engage code, you will not face disconnection if you are engaging to pay back arrears as part of a payment plan or have agreed to install a prepayment meter.

**Apply** 

You may be able to receive an Exceptional Needs Payment from your local Social Welfare office if you satisfy the means test. This applies to prepayment customers too.

**Reach Out** Reach out to advice services like MABS who can help you with budgeting and debt advice, including related to energy costs. See www.mabs.ie or call 0818 07 2000.

**Switch** 

Switching supplier may help you get a cheaper deal. Check out www.cru.ie/home/switching-supplier/ for more information.

Register

If you are registered as a vulnerable customer on age or health grounds, your supplier will not disconnect you in winter\*, but you must have notified them of this.

\*If you are critically dependent on electrically powered equipment, you will be protected throughout the year.

If you are struggling with energy costs, reach out to your supplier and support services, like SVP and MABS, who will help you come up with a plan.

that you meet the qualifying criteria above.

- 2. Have an SEAI surveyor check your home is suitable for the works and recommend upgrades.
- 3. Get the works done by an appointed SEAI contractor.
- 4. Get the works assessed by the SEAI once the works are completed. This will include a new BER assessment and may involve a quality inspection.

# **HOW DO I APPLY?**

If you meet the qualifying criteria, you should complete the application form. You can download it from the SEAI website, or ask SEAI to post it to you. Contact details are below.

You need to provide evidence that you qualify for the scheme. If you qualify for the scheme because you are getting Carers Allowance, you must complete the Carers Allowance Confirmation Form.

If you are getting one of the other qualifying payments, the Department IKA SUPPORT SPRING 2023

of Social Protection will need to complete the relevant section of the application form.

Full details of the information needed are on the application form. You can email or post the completed form and supporting documents to SEAI. The process from application to completion of works usually takes between 18 and 24 months, though this may vary.

# **HOW MUCH DOES IT COST?**

You will not be charged for work done if you qualify for this scheme.

NOTE: If you do not qualify for the Fully Funded Energy Upgrades scheme there are part-funded SEAI grants available to homeowners and landlords which, once approved, can be claimed after work is carried out.

Contact SEAI to request an application form or further details.

Locall: 1800 250 204 Homepage: www.seai.ie Email: warmerhomes@seai.ie



# **IRISH KIDNEY ASSOCIATION CLG**

(Company Limited By Guarantee)

# MEMBERSHIP APPLICATION FORM



# **BLOCK CAPITAL LETTERS PLEASE:**

Mr. Mrs. Ms. FIRST NAME:						
SURNAME:						
ADDRESS:						
POSTCODE: TEL:	MOBIL	E:				
EMAIL:						
We record this information in line with the Constitution of the IKA. a member of the Association.	You must be	e 18 years of	age to become			
Please indicate if any of the following apply to you: PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED	YES	NO				
		Do not	wish to disclose			
Do you wish to receive our quarterly 'SUPPORT' magazine by Please tick 'No' if your household is already receiving it		YES	□ NO			
		YES	NO			
Can we correspond with you for notices of Annual General Meeting of the Association and Annual Director's Report by	Email?	YES	NO			
Would you like to receive information on activities from your local IKA branch which entails us giving them the data from this form?	YES	□ NO				
Would you like to receive information on the IKA Transplant & Dialysis Sports and Fitness which is based in Head Office?		YES	□ NO			
By signing this form you agree to become a member of the Association and you subscribe to the Constitution of the Association (copy available on request or on the IKA website – www.ika.ie)						
I subscribe to (sign up and accept) the Constitution of the Irish Kidney Guarantee).	Association	CLG (Compan	y Limited by			
SIGNATURE:	TF.					

# Angeline Cooke - ATRIBUTE

he Board, Officers and Members of the Irish Kidney Association (IKA) were deeply saddened to hear the news of the sudden passing of Angeline Cooke, from Maunsells Road, Galway, on 31st March 2023. Our deepest sympathies to her family and friends.

A founding member of the Association,
Angeline underwent a kidney transplant in 1996. She enjoyed the successful longevity of this transplant for over 25 years before returning to dialysis treatment. Her gratitude to her deceased kidney donor was immense.

Angeline, together with her late husband Bernard, who passed away in 2012, committed their voluntary lives' work to the Irish Kidney Association's Galway branch's kidney patients. Totally devoted to each other, they were founder members when the Association was established in 1978. As a united couple they were determined that, under their guidance, dialysis and transplant patients would receive the best treatment and facilities that were possible.

Angeline and Bernard understood the importance of improved facilities, be it hospital equipment, haemodialysis transport arrangements, respite holidays, patient aid, and much more. They both dedicated themselves to achieve these goals by becoming unrelenting major fundraisers.

After Bernard's passing, Angeline continued to pledge her support to the Association and be an active member with the local Branch, and unless on the rare occasion when she was sick, she never missed a Branch meeting right up until her death.

She will be remembered fondly by nursing and medical staff who cared for her at University Hospital Galway.

She always had praise for the care she received from dialysis staff in Unit 7.

Polite and soft spoken, the former dedicated schoolteacher was not afraid to speak up when she saw injustice, and

when she saw injustice, and her insight and experience was of huge benefit to

the Board's policy
making. Her efforts
helped create a culture
of kindness and always
acting in the best
interests of patients
which the IKA
continues to benefit
from to this day.

Angeline had a passion for music and was a gifted painter. Her watercolours were often publicly exhibited and are proudly hung in many homes. She encouraged dialysis patients

to take up art.

Angeline spoke fondly of her brother-in-law Frank and his wife Eithne who lived nearby and their daughter Vicky who were a

She also kept in regular contact through Whats App with her late sister's daughter, Vicky and grandniece Deborah who live in Switzerland.

constant support to her.

Angeline's cousin Marie, from Clonmel, also underwent organ transplant, a liver transplant over seventeen years ago.

She was always grateful to her wonderful neighbours and in particular Anne who stopped by regularly.

The IKA has lost one of its 'greats' and she will live long in the minds and hearts of all who had the privilege to know her!'

The beautiful blessing, 'On the death of the Beloved' from the book 'Benedictus' by John O'Donoghue, was read aloud at Bernard's funeral and it is now fitting that we offer it as a tribute to Angeline as she reunites with him in an eternal place of peaceful rest.

LORRAINE COSTELLO

Though we need to weep your loss,
You dwell in the safe place in our hearts
Where no storm or night or pain can reach you.
May you continue to inspire us:
To enter each day with a generous heart,
To serve the call of courage and love
Until we see your beautiful face again
In that land where there is no more separation,
Where all tears will be wiped from our mind,
And where we will never lose you again.

# ATRIBUTE TO Bernadette Munnelly

t is with a deep sense of sadness that the Irish Kidney Association (IKA) extends its sympathy to the Munnelly family and a large circle of close friends of former Board member Bernadette Munnelly from Ballina, Co. Mayo.

Bernadette passed away on 22nd March, 2023 while on holiday in Lanzarote. She was repatriated to Ballina, Co Mayo. Two weeks after her passing her funeral Mass was celebrated at St Muredach's Cathedral. Ballina. She was laid to rest in

Crossmolina cemetery.

Her loss will be hugely felt by so many, particularly those in the IKA. Bernadette was a deeply spiritual person whose faith and kindness was evident throughout her life. Her courage in dealing with renal failure was inspirational. Her gratitude to her two kidney donors was reflected in every conversation. She truly understood that her restoration to good health also meant a tragedy for the families of her donors.

Bernadette was an integral member of the IKA's Liturgy Committee. Her input and commitment to the annual

> Service of Remembrance and Thanksgiving was legendary. She was a perfectionist in any

responsibility she undertook. She designed and organised the inclusion of the embroidered forget-me-not symbol into the annual Service on ushers' sashes, clergy's stoles, and on all the dressings for lecterns and the altar.

She recognised the importance of the Service as a means of acknowledging the generosity of organ donors, together with the gratitude of all transplant recipients.

Bernadette's love of travel reflected her enthusiasm for life, always cheerful with a radiant smile which was legendary.

She will be greatly missed. May she rest in peace.

Lorraine Costello

Retired IKA Patient Support Officer



# ATRIBUTE TO

# **Greg Foley**

he Irish Kidney Association would like to express its sincere condolences to the family, friends, colleagues and students, of the late Greg Foley. The Dublin father of one, who had Cystic Fibrosis, underwent a lung transplant twenty years ago and a kidney transplant in 2011 before returning to dialysis treatment last year.

The highly regarded DCU lecturer was a very active and effective campaigner on organ donation and in a recent article in The Irish Times he called out the prevalence of "woolly thinking" around consent for organ donation complex issues.

He epitomised the courage and gratitude of transplant recipients who raise awareness of organ donor transplantation and live their lives in the best way possible.

He will be sorely missed. May he rest in peace.



Hello one and all.

We are well into the New Year and I hope you managed to keep to your resolutions into Spring.

It seems a long time since the last edition of the *SUPPORT* magazine. The Cork Branch has been very active in the last few months.

# **ANNUAL MASS OF REMEMBRANCE**

Thankfully, we were all back live and in-person for our annual Mass in November. It was great to see such a large turnout given that some of you are still reluctant, and – understandably so, to still mix in large groups and crowds as COVID-19 has not yet fully retreated.

It was a beautiful ceremony as usual, celebrated by Fr Pierce Cormac, Head Chaplain, at Cork University Hospital. He is such a humble man.

# CORK

# By PATRICK O'SULLIVAN







# **Cork Annual Mass of Remembrance**

























# **SUPPORT CENTRE. CORK**

Work has continued on the house and at the time of writing the plastering work was finished on both upper levels and work had commenced downstairs.

This will now allow the carpenters, electricians and plumbers to start second fixing upstairs – fitting radiators, finishing bathrooms, hanging doors, installing light fittings and fixtures. etc.

Tiles have been chosen throughout the house and apartment and the colour scheme for each room chosen. The next process now will involve choosing kitchens, wardrobes and general furniture, for the project.

So, hopefully towards the end of April we will see some of these actions progressing.

# **STUDENT TALKS**

Sheena McDonagh and Pat O'Sullivan spent a day with fourth year pharmacy students in UCC. The students had just finished a workshop about Transplant and Dialysis patients and wanted to learn more by hearing from actual patients and their experiences.

It was a welcome opportunity for them. Their lecturers will be contacting the Branch, in the future, requesting for volunteers to talk to

# CORK

them again.

Hugh Nolan and Pat O'Sullivan spoke to students in Nagle Rice Secondary School in Doneraile. Again, it was another opportunity to speak to students and spread the word and increase organ donor awareness.

Speaking at these events is a great way to spread organ donor awareness. It really is just about telling your health story and your journey through your illness.

### **VOLUNTEERS**

From time to time the officers in the Branch will be looking for volunteers to help promote Organ Donor Awareness at various events. This usually consists of manning a desk for an hour or two, handing out organ donor cards and maybe talking about their own personal health experiences.

Volunteers can be from families and patients alike.

If you would like to volunteer for future events, please contact the Branch Secretary at

secretarycork.ika@gmail.com or Ph: 086-2755754.

This mobile is also the number for our WhatsApp group. If you would like to be kept up to date with all the goings on in the Branch, please text this number to be included.

### **GOLF CLASSIC**

Our annual Golf Classic will take place, as usual, in Mitchelstown Golf Club on Friday, June 2nd. The tee times are now available and bookings can be made through the usual channels. We hope to see as many of you as we can on the day.

Volunteers are always welcome to help out on the day, as days like this demand a lot of manpower. Help



can involve simply manning a desk and taking the names of the competitors or just selling some raffle tickets.

We are always looking for prizes for the event, so, if you would like to donate a prize for the raffle or sponsor a prize for the golf itself this support is always welcome.

The format continues to be the same with teams of three at €150 per team. Teams can be of any gender or mixed. Prizes on the day will be for Longest Drive Mens and Ladies, and Nearest the Pin Mens and Ladies.

# WORLD TRANSPLANT GAMES, PERTH, AUSTRALIA

There will be four transplant patients from Cork participating at this year's World Transplant Games including Michael Kiely (golf and Petanque), Hugh Nolan (golf), Mairead O'Mahony (athletics), Pat O'Sullivan (golf, Petanque and athletics).



# CORK

We would like to wish them and the rest of the 14 strong Irish team the very best of luck. By competing in the Games they are honouring their donors and their donor's families. For most competitors at the Games they would never have considered competing for their country while they were going through their own particular illness journey, but, thanks to the 'gift of life', and the wonderful generosity of their donor, they now can.

Next year's European Transplant & Dialysis Sports Championships are planned for Lisbon in Portugal. These Games are also open to dialysis patients and we would like to encourage even more people from Cork to participate at these Games.

With a diverse range of sports on

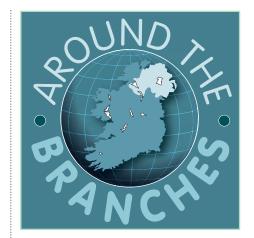
offer, there is something for everyone, no matter what your sporting prowess and ability is.

### **CALLING ALL THESPIANS!!**

The Cork Shakespearean Company will be celebrating its 100-year anniversary in 2024. As part of their anniversary celebrations, they are planning a special production of some of William Shakespeare's best known plays, the proceeds of which will go to Irish charities, including the Irish Kidney Association.

If anyone is interested in taking part, either in acting or production, please contact the Cork Branch Secretary.

You don't necessarily have to be living in the Cork area. All patients, family and friends are welcome to take part.



Enjoy your summer. Updates on Organ Donor Awareness activity will be posted when details are available. Remember you can keep up to date with all our news and information through our Social Media channels and our WhatsApp group.

Thank you from the Officers of the Cork Branch.

# DUBLIN NORTH BY COLETTE FOX

I hope that everyone is keeping well and enjoying springtime.

It has been relatively quiet for Dublin North recently, but busy times are ahead.

We would like to extend our best wishes to Ron Grainger from Castleknock and the other 13 members of Transplant Team Ireland who will represent Ireland at the World Transplant Games in Perth in April.

Our best wishes also to Dave Bennett and the PKRF for a successful event at Punchestown Races on Saturday, 29th April.

# **GET YOUR TICKET FOR A STAR STUDDED NIGHT**

The talented crooner Red Hurley has been a long-time supporter of the Irish Kidney Association. His support stemmed from his friendship with IKA Dublin North Branch member Ann Burke from Portmarnock. For many years he has been bringing together a crop of talented entertainers for events to raise funds for the Irish Kidney Association.

Once again he has assembled an impressive line-up of nationally renowned artists for a special night of entertainment which will be held

at the Grand Hotel in Malahide on Thursday, 13th July.

Red Hurley will be joined by Mary Byrne, Linda Martin, Eugene McCarthy, Ronan Collins, showband brother and sister duo Keith and Lorraine McDonald.

Doors open at 7pm and the star studded show starts at 8pm.

Tickets are €30. There will also be a Bumper Raffle.

For tickets contact the Dublin North Branch members Colette on Phone: 086-2870174 and Ann on 087-1352775.

# LEITRIM BY CATHRIONA CHARLES



Eileen Gibbons from Leitrim Village received her transplant late last year, after a number of years on dialysis. In thanks for this, Eileen displayed our large donor card and a collection bucket at a community coffee morning in the local community centre. A total of €1,440 was raised which Eileen donated to our Branch. Thank you Eileen, Seamus and all her friends and neighbours. Lots of donor cards were also distributed on the day.

The Leitrim Branch hopes to hold a meeting during April. This will be our first meeting post-COVID and we'd love to see a good turnout.

# OUND PANCY

# Find us on: facebook.



# **FAMILY FUN DAY**

A fun family day was held in B Braun dialysis unit in Wexford in December. Staff members, patients and their families attended.

There was music and song and plenty of renal friendly food served up on the day.

Wexford Branch Chairperson Pauline Atkinson, Secretary Walter Kent, and Board member Liam Buttle all attended. IKA Christmas cards were on sale. A big 'thank you' to Carol Ann and her team for organising the event.

# **HAPPY BIRTHDAY**

Bridget Boyce celebrated a special birthday recently and asked for donations for IKA in lieu of presents. Thank you Bridget for an amazing amount of €770.

# WEXFORD

# By MARIA DONLON







### **CHRISTMAS SWIM**

Thank you to Liam Buttle who braved the elements on Christmas day and took part in the annual Christmas swim and collected €468.50.

## **CONGRATULATIONS**

Trish Boyce recently gave her dad John the very special gift of a kidney.

Congratulations to Trish and John, we wish them both good health and happiness and thank them for

highlighting Organ Donor Awareness during their interviews on local and national radio and with newspapers.

You can read their story on page 52.

## **SYMPATHIES**

We extend our deepest sympathy to the Barnes and Curtis families who have suffered recent bereavements.

# DONEGAL

# By JENNIFER McDERMOTT



Hello from the Donegal Branch.

We are so happy to have had our first face to face meeting since the arrival of COVID-19. We met in January and it was really lovely to get together for a chat and a coffee at long last.

Our Chairperson Seamy McDermott presented a cheque for €2,500 to the Renal Dialysis Unit recently. This was from a sponsored cycle he did from Mizen to Malin.

On January 21st, a cheque was presented to the Donegal Branch by friends of the late Tony Carlin, who organised an event in his memory.

The Tony Carlin Memorial Pool Competition raised €3,662. Tony tragically passed away four years ago and as he carried a donor card his organs were transplanted to four recipients.







Tony's mother Eilis, along with his brother Ronan were there for the presentation. On behalf of the Irish Kidney Association, Patricia Callaghan, Donegal Branch Secretary thanked Eilis, Ronan and Tony's friends for their generous donation.

John Quinn and Frankie Devine from Glenties donated Christmas presents for the patients in the Renal Dialysis Unit of University Hospital Letterkenny. A big 'thank you' to the Biddy Devine Dialysis Fund.

Our thanks also to Jeanette Longwill who presented gifts, on behalf of her family, to the Dialysis Unit, in memory of their brother Stephen Doherty, Buncrana.



Seamy McDermott gave a talk to the students of Finn Valley College in Stranorlar, on the occasion of World Kidney Day, about the importance of a healthy heart and kidneys.

Teacher Ms. Garry facilitated the talk which was positive and informative and afterwards Seamy participated in a questions and answers session with the students. It was a very successful day.

The Donegal Branch is hoping to hold an interdenominational Service in Letterkenny in the near future, for which a date will be advised later.

Best wishes from Donegal.



Greetings to all our members and friends from Dublin East & Wicklow. Spring has been many things to our Branch this year.

The first thing that comes to mind was the wonderful news that our Branch Secretary Rachel O'Hora is recovering well from her recent combined kidney/pancreas transplant which took place in St. Vincent's University Hospital in late November.

This was wonderful long-awaited news for Rachel and her family and we wish her good health and freedom that the transplant will give her in the future.

As we are approaching Organ Donor Awareness Week, we of course think of our donors and are so thankful for that wonderful 'gift of life' they gave to others.

We would like to wish our long time Treasurer, Catherine Foley, a speedy recovery after her unfortunate fall on the ice back in December.

Hope you are out and about again soon, Catherine!

# **PEER SUPPORT**

We would like to congratulate Joan Dobbin who has become one of the new Peer Support volunteers for the Irish Kidney Association.

This is a valuable service which will connect patients, and will offer huge support to those starting out on a kidney health journey.

Good luck Joan.

# **CONDOLENCES**

Our Branch send our sincere condolences to Jacqueline Burke and family on the sudden passing of Jacqueline's beloved husband Martin, who sadly passed away on St. Patrick's Day.

The Branch have fond memories

# **DUBLIN EAST & WICKLOW**

# By BERNIE DWYER









# **DUBLIN EAST & WICKLOW**





of Martin at Branch meetings. May he rest in peace.

Many of you will be sad to hear of the recent passing of Tadgh O'Connell of Delgany. We send our sincere sympathy to his wife Lucy and his daughters and family.

May he rest in Peace.

### **CHRISTMAS LUNCH**

It really does seem like ages ago since we were delighted to get together for our Christmas Lunch on the December 10th in The Powerscourt Arms Country House in Enniskerry.

It was lovely to catch-up with members who we hadn't seen for a couple of years due to COVID-19.

Everyone was in good spirits and we

enjoyed a nice lunch with a raffle for lovely prizes (some kindly donated by members) and a lovely Christmas Hamper.

Hope you enjoy seeing the photos and I'm sorry I didn't get everyone included in them!

Please keep in touch with your Branch and let us know how we can help. If you are not receiving our emails etc., please let us know.

Looking forward to a lovely year and a successful Organ Donor Awareness Week at the end of May.

Finally, very best wishes to Transplant Team Ireland as they travel all the way to Perth in Australia for the World Transplant Games in April to represent Ireland and ultimately honour their donors.

# KILKENNY BY SARA SANTI



Front row seated: Owen Hanrahan, Lizzie Fogarty, Anne Brennan, Seamus Carrigan; Middle row: Bridget Langton, Mary Rooney, Johnny Lacey, Arlene Carrigan, Mary Lacey; Back row: Ger Kelly, Mary Fogerty, Emma Rooney, Mary Kelly, Richard Langton, Sara Santi and Eric Holland.

Sara Santi is now the new Branch Secretary having replaced Anne O'Grady. We are deeply grateful to Anne for her dedication to this role, and for serving the Branch so well over the past number of years.

As Spring is upon us we hope you are looking forward to the rest of the year ahead

On January 15th, members from the Kilkenny Branch attended a belated Christmas lunch. It was lovely getting together to meet and speak to people face to face for the first time in three years.

The lunch was lovely and it was wonderful to be able to enjoy

sharing stories and laughs.

Anne Brennan celebrated her 30th kidney transplant anniversary in January. How incredibly successful her transplant has been. Sending Anne our warmest congratulations.

We are looking forward to having our first Branch meeting this year in April. Members will receive either notification through an email or by post.

We look forward to welcoming new members to our Branch. Also, persons not yet registered with the IKA please feel free to come along to our meeting and consider joining our Branch. You can share your stories and ideas with us.

Looking forward to catching-up with you all soon.

The Kilkenny Branch Officers are always available to take calls. If you need their support please do not hesitate to contact any one of them.

John Lacey, Chairperson, 085-1328255 Hugh Byrne, Board Member, 086-8938800 Bridget Langton, Treasurer, 086-1202918 Sara Santi, Secretary, 089-4299894



# Find us on: facebook®

# **DRAW BRINGS CHEER FOR PATIENTS**

Our Branch brought Christmas cheer to the dialysis unit at Sligo University Hospital with free draws and prizes for all patients. There was also a draw for staff members.

Prizes consisted of hampers, turkeys, vouchers, cosmetic sets, boxes of biscuits, and lots more.

Branch members visited the dialysis unit five times over three days so as to take in all shifts.

In feedback afterwards patients and staff said they were delighted with the draws which brought joy to the unit after a difficult year.

They praised the work of our Committee in shopping for the prizes, wrapping them and organising the draw.

Sligo Branch thanks Des and Martha in Cosgrove's Centra, Maugheraboy for sponsoring a number of the prizes.



# SLIGO

# By BRIAN McHUGH



Dialysis patient Mairead McHugh holds one of the prizes, pictured with Marie Fowley, IKA National Honorary Secretary, Geraldine McHugh, Secretary Sligo Branch (Mairead's mother), Irene Ekpechue, Brian McHugh, PRO Sligo Branch (Mairead's father), and Sean Fowley, Chairman Sligo branch.



Brian McHugh, Sean Fowley, Dialysis nurse Cherryll McCaul, Geraldine McHugh and Marie Fowley.



Pictured at Cosgrove's Centra, Maugheraboy were Eileen Nolan, Sligo Branch member, Sean Fowley, Sinead Nolan, Alicia Sutor representing Cosgrove's Centra, Marie Fowley, National Honorary Secretary, IKA, Noreen Keane, Treasurer, Sligo Branch. Cosgrove's kindly sponsored a number of arizes.

# **SLIGO**



Treasure hunt organiser Jim Doyle makes the presentation to Branch Secretary Geraldine McHugh. They are both Ransboro residents and are pictured at Coolera Drama Centra.

## **IKA WINS IN CAR TREASURE HUNT**

The annual Ransboro St. Stephen's Day Car Treasure Hunt raised a fantastic €1,600 for the Irish Kidney Association (IKA) Sligo Branch.

As always, it was a most enjoyable community event, with much friendly banter afterwards among the participants about the location of clues and who 'nearly' got the correct answers!

Thanks to Jim Doyle for all his work in organising the event and in doing so raising funds for Sligo Branch IKA.

Also thanks to Coolera Dramatic Society for sponsoring the prizes and to all treasure hunters who took part.

Your support for the IKA and renal patients is much appreciated.

The prize winners were: 1st - Joe Murphy, 2nd - Philip Hunter, 3rd - joint winners, Kate Harte and Stephen Devaney.

# WHEEL COMES FULL CIRCLE AT FASHION SHOP

When Dympna Mannion generously donated the takings of her closing down sale at the Style Emporium fashion shop on Saturday, March 5th, to the IKA it was a case of closing a circle for her.

Shortly after the opening of her shop in the mid-80s, Dympna recognised the plight of kidney patients in Sligo, who up to then had to travel to Dublin or Galway for dialysis three days a week.

This moved her to contact the founders of the Sligo Branch to offer



Pictured at the Style Emporium were (I-r): Dympna Mannion, Teresa Davey, Sean Fowley, Ita Leyden, Noreen Keane, Aoife Dolan and Marie Fowley.

to help raise funds to provide dialysis facilities at Sligo General Hospital.

She met two founders of the then newly-formed Sligo Branch, Teresa Davey and the late Angeline McKinney, to offer her support to them. Together they ran a number of successful fashion shows in the Sligo Park Hotel for the new Branch.

Dympna was loud in her praise of her co-organisers. "Teresa Davey and Angeline McKinney were stalwarts. They were pioneers, visionaries, leading champions."

She said that now nearly 40 years on, the wheel has come the full circle. "I'm coming to the end of my career and again helping raise money for kidney patients."

Members of the IKA Sligo Branch were present in the shop on the closing down day, distributing organ donor cards and other IKA material.

# **BOOK GENERATES FUND FOR IKA**

Sales from a book published by a local newspaper has generated funds for the IKA.

The funds donation was from the sales of a book produced by the *Sligo Weekender* newspaper. The book, entitled *The Best of the Sligo Weekender Volume Two,* contains many of the stories that appeared in the paper in 2021.

The book was dedicated to Tara McHugh who passed away in June 2021.



Dympna Mannion, Style Emporium with Teresa Davey and Eileen Long.

Volume Three of the book is now on sale. Thanks to the *Sligo Weekender* for their generous donation to our Branch.



Jonathan Costello (right) makes the donation, on behalf of the Sligo Weekender to Sean Fowley (left) and Brian McHugh, Tara's father and Sligo Branch PRO.



# **DONATION FROM MOYLOUGH CONCRETE**

Thanks to Michael McHugh for obtaining a donation to our Branch from Moylough Concrete Products.

A kidney transplanted patient, Michael is a past Chairman of the Branch and former Board member.

While no longer involved, he is a loyal supporter and friend of the IKA.

Thanks also to Moylough Concrete Products.



Deirdre Caheny and Ger O'Carroll of Arrotek Medical make the presentation to Sligo Branch Treasurer Noreen Keane and Branch Chairman, Sean Fowley.

### ARROTEK MEDICAL SUPPORTS RENAL PATIENTS

Medical device design consultancy firm Arrotek has again made a generous donation to our Branch for the support of renal patients.

The Finisklin based company, which specialises in the design and manufacture of minimally invasive medical devices, has been a valued supporter of the IKA over a number of years.

Making the cheque presentation Ger O'Carroll, Director of Arrotek Medical said, "We are pleased to support the local Branch the Irish Kidney Association. We are aware of

# SLIGO CONTD.



Michael McHugh presents a cheque to Sligo Branch Treasurer Noreen Keane (centre) and IKA National Honorary Secretary, Marie Fowley.

the great work you do in helping patients affected by kidney disease and their families."

Sean Fowley, Chairman of the Sligo Branch, thanked Arrotek Medical for their ongoing assistance. He said, "It greatly helps our Branch in the support of kidney patients in the Sligo region".

# **PUSH FOR NEW RENAL UNIT CONTINUES**

The Branch is continuing with our push for a new renal unit at Sligo

University Hospital.

Chairman Sean Fowley, Secretary Geraldine McHugh and IKA National Honorary Secretary Marie Fowley, met with hospital management on February 2nd.

The Branch members were informed that the hospital management had made an application for funding for a Design Team to advance the plans to the next stage which is to select a location and compile a blueprint for the unit.

Application for funding for the Design Team was submitted.

Meanwhile, at a Branch meeting it was agreed that the Secretary Geraldine McHugh would write to George Mellotte, Clinical Lead of the National Renal Office, HSE, requesting him to use his influence to expedite the project.

At time of *SUPPORT* going to press a reply is awaited.

### **UPCOMING EVENTS**

Please keep an eye on our Sligo IKA Facebook and Twitter pages for events coming up over spring and summer.

# KERRY

# By THERESA LOONEY

Hello from Kerry.

Firstly, I would like to thank Myles McMorrow from Templemore, who together with friends held a Darts competition on New Year's Day and raised €2,000 for the Kerry Holiday homes.

Unfortunately Myles wasn't well enough to attend the cheque presentation on the night and we wish him well in his recovery. We very much appreciate the huge effort they made and hope we see Myles visit Kerry again before long.

I would also like to acknowledge receiving €1,410, proceeds of a Santa Run, organised by the staff in Astellas Ireland in Killorglin.

In particular, I'd like to thank Gina Halliday for all her fundraising efforts over the years whilst she was based at the Killorglin plant.

We wish her well in her new position.

We have an upcoming fundraiser organised by Lough Lein Anglers Association in Killarney. They are holding a Wet-Fly Charity Competition on Sunday, April 23rd, to help towards the costs of running the Holiday homes in Tralee and Killarney.

There will be a draw for many prizes to support the event. Cards costing €10 are available from the Branch and your support would be very much appreciated.

We are sprucing up the holiday homes at present, in anticipation of hosting many patients and their families in the coming months, who are lucky enough to be offered a holiday and we can guarantee them a céad míle fáilte.

# WESTMEATH

# By CATHY SMYTH



Cathy Smyth, John Egan, Eddie Flood and Miriam Murphy.

Our thanks to Athlone IT recruitment agency Solas IT Recruitment which has raised €10,000 in donations to support the work of the Irish Kidney Association (IKA).

With offices in Athlone and Dublin, the agency chose the IKA as the beneficiary to celebrate the successful living donor kidney transplant of their employee John Egan, an executive recruitment consultant, just over a year ago.

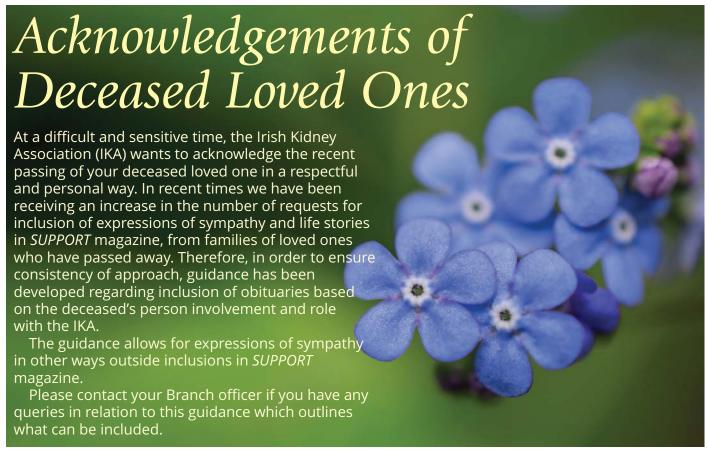
John, a former Westmeath County footballer, and his work colleagues, and some of his clients, joined in the fundraising challenge to raise



€10,000 by walking 123 kilometers in a month, the same distance from their workplace in Athlone to their Dublin office.

A cheque presentation was held at the Sheraton Hotel in Athlone on February 21st.

Gratefully accepting the cheque for €10,000, on behalf of the IKA, was National Honorary Chairman Eddie Flood and Cathy Smyth, the Secretary of the Westmeath IKA Branch. Presenting the cheque was John Egan and Miriam Murphy, the Operations Director of Solas IT Recruitment who said, "This fundraising challenge was a personal one for us. John is a key member of our team and he has handled the last few years like a champion."





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Telephone: 01-6205306 | Email: info@ika.ie | www.ika.ie

Renal Support Centre, Beaumont Hospital, Dublin D09 Y5R3 - SEQUESTERED

Telephone: 01-6908887 | Email: renalcentre@ika.ie



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# DUBLIN EAST + WICKLOW

# **Bernie Dwyer**

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# KILDARE

# Michelle Horan

Farishta Tonlegee, Athy Co. Kildare R14 RE69

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# **LONGFORD**

# **Elaine Heslin**

Augharickard Shroid, Longford Co. Longford N39 D2P2

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# **SLIGO**

# **Geraldine McHugh**

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# CAVAN/MONAGHAN

# **Karl Cronin**

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# LOUTH/MEATH

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# **LAOIS**

# **Sarine Browne**

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