

# SUPPORT



SPRING 2024

# WE'RE BACK!



SPRING  
*giveaway*  
**10 X €50**  
GIFT CARDS FOR  
**DUNNES**  
STORES  
SEE PAGE 25

# Editorial



Carol Moore, Chief Executive, IKA



## Irish Kidney Association CLG

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Welcome to our Spring issue of *SUPPORT*.

Before we report on 2024 to date, it is worth noting the many achievements of 2023.

Our beautiful Munster Kidney Support Centre opened in December and was so well received. It is a wonderful achievement and reflects many years of hard work by the Board, staff and our passionate volunteers, particularly our Branch officers and volunteers in Cork. It shows what our community is about, providing high quality support in a friendly and compassionate manner. We can rightly be proud of this latest addition to the services the IKA provides.

Our new peer support service launched and in January 2024 it passed an independent third-party evaluation with flying colours. (see details on page 49).

We again increased the level of support we provide with counselling and patient aid reaching their highest ever levels. (For a summary of activity see page 13).

On February the 21st, the **Human Tissue Bill** passed the final stage and went to the President to be signed into law. We brought a group of people

to this historic occasion and completed a photoshoot and video with the Minister for Health, Stephen Donnelly.

It was an emotional occasion for all concerned particularly when Minister Donnelly entered the names of the transplant recipients who took part in the photoshoot into the Dáil record and formally thanked the Irish Kidney Association for our contribution.

Afterwards the Minister invited us to the Dáil visitors bar and bought refreshments. The esteem in which the Irish Kidney Association is held was very evident and augurs well for the future.

As the Human Tissue Act does not provide for an Opt in register, the Organ Donor Card will continue to be used as a communications aid and prompt for family discussion and awareness of their loved ones' wishes. You can read more about the new Act on pages 16-18.

In March, for the first time since COVID-19, our national fundraising collections returned, aligned with our kidney health awareness campaign to mark **World Kidney Day** on March 14th. It was lovely to see the huge enthusiasm from our branches' volunteers getting back out there and it was a pleasure for me to meet some



## FRONT COVER

IKA Board representatives and volunteers at the Aspect Hotel Park West, Dublin celebrating the return of a national fundraising drive after a four year hiatus due to COVID.

(Front, l-r): Liam Buttle, Wexford; Frances Moynihan, Waterford; Brian McHugh, Sligo; Cathriona Charles, Leitrim; Marie Fowley, Sligo. (Back): Joan Gavan, Tipperary; Elsie Moore, Kerry; Eddie Flood, Westmeath; Peter Kearney, Kildare; Pat O'Sullivan, Cork.

Photo Conor McCabe

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of the collectors. See photos on pages 10-11.

We are also building on the great work which Branches and individual members have been doing by providing more support to encourage conversations around organ donor awareness.

A new support guide called **“Teacht Le Chéile”** will be available and will be incorporated in the upcoming **Organ Donor Awareness Week (April 20th-27th)** campaign.

Despite our charity's limited budget resources, the combined support of our dedicated Branches and volunteers, together with the generosity of individuals impacted by organ failure sharing their stories, and the recent addition of our comprehensive *“Teach le Cheile”* toolkit guide for organising organ donor awareness activities, allow us to uphold our leadership role in advocating for organ donation across communities nationwide. See article on pages 26-28 for further details.

We are also proud to have been selected as one of the charities for the **Ring of Kerry Cycle** on July 6th. Find out how to get involved and support us, even if you are not a cyclist (see pages 32-37 for details).

Our Board has been working hard on safeguarding the future of our organisation. To allow this

Senator Mark Daly, Minister for Health Stephen Donnelly with John Brennan, heart transplant recipient and kidney patient, Ally Whitston, a kidney transplant recipient with her mother Michelle.



work to progress, elections have been deferred until 2025, and therefore there will be no elections this year. For an update on work to date, please see article on pages 14-15.

Inside you will also read some inspiring patient stories, kidney friendly Springtime recipes, and a variety of articles covering topics on research around barriers to exercise for dialysis patients. There is also a BT Young Scientists project by two Westmeath students on ethnic minorities and their awareness around organ donation; and lots of activities going on around the country are reported in ‘Around the Branches’.

We have planned a major patient **Information and Family Day** in University College Cork on June 29th. There will be information and awareness talks from healthcare professionals and fun activities for children and lots more. I look forward to seeing many of you there (see page 30).

Finally, our condolences to the families of beloved staff member Ruth Gorman, past Chairperson Joan Kerley and Isabel Terry, who passed away recently, see pages 45, 56 and 60.

Wishing you a happy Springtime.

**CAROL MOORE**  
**CHIEF EXECUTIVE OFFICER**

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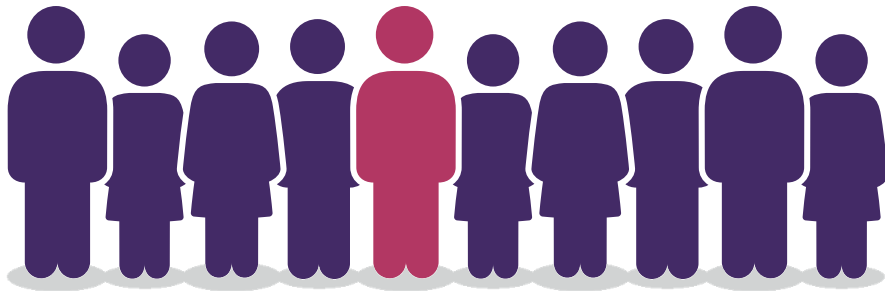
**72 BRANCH SECRETARIES**

# WORLD KIDNEY DAY

MARCH

14th  
THURSDAY

## 1 in 10 people have Chronic Kidney Disease (CKD)



The **Irish Kidney Association (IKA)** and the **HSE National Renal Office (NRO)** came together to raise awareness about Chronic Kidney Disease (CKD) on **World Kidney Day, March 14, 2024**. With statistics revealing that 1 in 10 people of the general population, and 1 in 7 people in Ireland over the age of 50, have Chronic Kidney Disease (CKD), the focus of the campaign is to urge individuals to take action and prioritise kidney health, especially given its close links to diabetes, hypertension (high blood pressure), and heart disease. Additionally, the **World Kidney Day 2024** campaign marks the return of the IKA's national fundraising campaign after a four-year hiatus due to the COVID-19 pandemic.

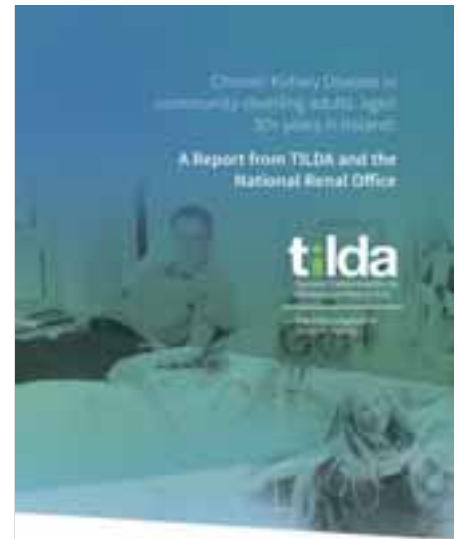
**E**arly detection is key to slowing down the progression of CKD. A simple blood or urine test can be the first step to check kidney health and identify if kidney disease exists. By catching CKD early, people can take proactive steps to manage their condition, slow down its progression, and possibly prevent further complications.

CKD is categorised into five stages of progression with Stage 5, the final stage, indicating End Stage Kidney Disease (ESKD) and the need for either dialysis or a transplant. Chronic Kidney Disease is often

By  
**GWEN O'DONOGHUE**

described as 'the silent illness hiding in plain sight' which develops over time and usually does not show any obvious symptoms until it progresses to kidney failure.

According to a recently published report by *The Irish Longitudinal Study on Ageing (TILDA)\** and the *HSE National Renal Office*, over 200,000 people in the over-fifty age group in Ireland have CKD. Also, there are more than 5,000 people diagnosed with end-stage kidney disease (ESKD,



also referred to as Stage 5 kidney disease), with over 2,400 patients currently undergoing dialysis treatment. These numbers highlight the urgent need for increased awareness and support for those affected by kidney disease.

CKD is not just a standalone isolated health condition; it is closely linked to hypertension, heart disease, and diabetes. Individuals with one or more of these conditions are at higher risk of developing CKD, and vice versa, and it is important for patients to be aware of these links.

It is also important for healthcare professionals to collaborate closely, ensuring that heightened awareness, treatments, and medications are coordinated to manage these interconnected health challenges effectively.

## FIVE STAGES OF KIDNEY DISEASE

STAGE 1

STAGE 2

STAGE 3

STAGE 4

STAGE 5

90%+

89-60%

59-30%

29-15%

<15%

Normal function if over 60% unless other signs present (e.g. Albumin in the urine)

Moderate to severe loss of function

Severe loss of function

Kidney failure need dialysis/treatment





Carol Moore, Chief Executive with kidney/pancreas transplant recipient Mary Murnagh. Photo: Conor McCabe.

This year marks a significant milestone as the IKA reinstates its national fundraising campaign after a hiatus due to the COVID-19 pandemic. Volunteers, many of whom are patients themselves, will be back in ALDI stores, and other locations across the country, distributing free organ donor cards and collecting vital funds to support patients in need, through the sale of the IKA's Forget-Me-Not flower emblems, which are also available to buy online from the **IKA Forget-Me-Not Virtual Garden**.

**DEDICATE A FLOWER TODAY**

<https://visufund.com/forget-me-not-garden>



IKA Forget-Me-Not Virtual Garden

Commenting on the campaign, **Carol Moore**, Chief Executive of the IKA stated, "Chronic Kidney Disease is a very real and prevalent issue affecting approximately 800 million people globally, including 500,000 people here in Ireland. The lack of knowledge about CKD and its relationship with the better-known high blood pressure, diabetes, and heart disease conditions needs to be addressed.

"According to the TILDA survey, 98% of people who had CKD were unaware they suffered from it. The results of the TILDA survey reinforce the IKA's call for CKD to be integrated into the HSE National

Chronic Disease Management Programme as a crucial step towards ensuring better health outcomes and reduced healthcare costs.

Through initiatives like **World Kidney Day**, the IKA wants to start a public conversation on the importance of early detection and collaborative care in managing CKD effectively.

"The IKA is delighted that **World Kidney Day 2024** will also mark the resumption of our much-needed national fundraising campaign after almost four years and we are grateful for the support of our dedicated volunteers, many of whom are family members of patients or patients themselves.

"Over the past four years, the demand for our charity's counselling services has doubled, while our charity had to forgo national fundraising. Despite this, the IKA has continued to support and advocate for kidney patients as well as managing national organ donor awareness events and promoting and distributing the organ donor card. Securing the support and generosity of the public is now more critical than ever to sustain the work our registered charity does.

*continued next page...*

\* Nowak N, Mellotte G, O'Halloran A, Kenny RA, Sexton D. *Chronic Kidney Disease in community-dwelling adults aged 50+ years in Ireland: A Report from TILDA and the NRO*, October 2023. Website: [www.tilda.ie](http://www.tilda.ie), [https://tilda.tcd.ie/publications/reports/pdf/Report\\_CKD.pdf](https://tilda.tcd.ie/publications/reports/pdf/Report_CKD.pdf)



Prof. George Mellotte. Photo: Conor McCabe.

Referring to the TILDA report, Prof. George Mellotte, Clinical Lead, National Renal Office added, "The TILDA report highlights that CKD is becoming more common in Ireland. This is consistent with Ireland's rapid demographic changes, highlighting the importance of action in primary and secondary care to raise awareness and to improve the outcomes for people living with CKD in Ireland.

"With the demands on the HSE to treat the growing number of people that are progressing to end-stage kidney disease each year requiring dialysis, (equal to building one new dialysis centre every year), it's clear that concerted efforts by the public and the HSE are needed to address this public health challenge. By raising awareness and supporting initiatives like **World Kidney Day**, we can make significant strides in improving outcomes for patients with kidney disease."

General Practitioners and pharmacies play a hugely significant role in patient care in our communities. The Irish Pharmacy Union and several pharmacy chains are supporting the IKA campaign around **World Kidney Day** and many pharmacies will be displaying the campaign poster on their digital screens.

The **World Kidney Day** campaign materials, including posters and digital resources, are available on the IKA's website.

For more information and to get involved, visit [www.ika.ie/kidneyhealth/](http://www.ika.ie/kidneyhealth/)

ALL it takes are simple blood and urine tests to check your kidney health



# What are the signs of CKD?

Most people do not have symptoms related to CKD. Symptoms may only be noticeable with more advanced kidney disease.







These can include:

 Nausea and/or vomiting	 Tiredness and weakness	 Muscle cramps	 Difficulty sleeping at night	 Urinating more or less
 Weight loss and weight gain and appetite loss	 Shortness of breath (due to a build-up of fluid in the lungs)	 Chest pain or irregular rhythm (due to a build-up of fluid around the lining of the heart)		
 Itchy, dry skin	 Feeling cold	 Swelling of feet or ankles	 Lack of concentration	 Headaches (due to high blood pressure)



# Who is at risk of developing CKD?

Anyone can get kidney disease, but some things can make it more likely to happen to certain people. **You are more at risk if you:**

 Have diabetes	 Have high blood pressure
 Have a family history of kidney disease	 Are over 50 years
 Are obese	 Have had acute kidney injury
 Long-term use of over-the-counter medications	 Have heart disease



## CASE STUDIES

# MARY MERNAGH

**M**ary Mernagh from Gorey, Co Wexford (age 40) was a Type 1 diabetic since she was eight years old. She was diagnosed with early-stage chronic kidney disease (CKD) in 2010 at age 26.

Mary managed her CKD through medication, and dietary changes, until 2019 when she started dialysis treatment, three times a week, initially at Waterford University Hospital and then at BBraun Wexford, which she underwent for three years before being called for her life-changing simultaneous kidney and pancreas transplant at St. Vincent's Hospital in the Spring of 2023.

While initially, she was anxious about her dialysis treatment, and particularly the needle insertion for her fistula, she overcame this and became empowered in her self-care, encouraged and supported by the staff at BBraun. Mary is now the poster girl for Self-Care and she created a poster which was displayed at BBraun Wexford.

In summing up her health journey and the impact of her simultaneous kidney and pancreas transplant Mary said, "My double transplant was truly transformational. It's not just about receiving two organs; it's about reclaiming my life, my independence, and my future. It has brought to an end the daily insulin injections I received since the age of eight, and then in recent years being tied to dialysis and the sickness and restrictions kidney failure brings.

"I am filled with immense gratitude to my donor, whose selfless gift has given me a second chance at life."



Sara Santi (left) and Mary Murnagh. Photo: Conor McCabe.

# SARA SANTI

**T**he journey with kidney disease for Sara Santi (26) began unexpectedly at the age of 19, soon after she moved to Ireland from her native Tuscany in Italy. Despite her diagnosis of stage 4 CKD, with only 20% kidney function, she remained resilient, fuelled by her love for horses.

She travelled throughout Europe working as a horse groom. Her consultant nephrologist Sean Leavey at Waterford Regional Hospital supported her passion, encouraging her to continue her equestrian pursuits while managing her care.

However, by 2020, Sara's condition worsened, necessitating dialysis, as she only had 10% kidney function. For one and a half years she underwent peritoneal dialysis at home, a treatment which she felt suited her lifestyle best. But unfortunately, the peritoneal dialysis failed, and it left her with no choice but to move to in-centre haemodialysis, initially in Waterford and then at Fresenius in Kilkenny, which she continued with for about 6 months before returning to peritoneal dialysis. Before she received her transplant her kidney function had reduced to just 1%.

This was a very dark time for Sara, but her horse *Dolly*, and IKA counselling, helped her through. In February 2023, she received the life-changing call for a kidney transplant.

Sara's post-transplant journey hasn't been without challenge. She

remains grateful to her medical teams' for their care, including the renal team at Waterford Regional Hospital, and especially her compassionate consultant, Dr. Ciara Magee, who Sara describes as 'extraordinary', and the rest of the team at Beaumont Hospital for her post-transplant care. Sara's message to fellow kidney patients is one of resilience and perseverance. A kidney disease diagnosis doesn't mean you can't go on living your life to the fullest for as long as possible. I enjoyed three years of total fulfilment, travelling Europe from the time I was first diagnosed and while on dialysis. Although it was a dark time for me, as a woman in my early twenties who suddenly had to face my new reality of end stage kidney disease, I could still work with my horses, and I credit them, and the counselling service, for getting me through".

Sara's story highlights the importance of early diagnosis, adherence to treatment, and maintaining positivity and not putting your life on pause despite the obstacles that illness can bring. As she continues her health journey, Sara's resilience serves as an inspiration to all facing similar challenges.

Sara is the secretary of the Kilkenny Branch of the IKA and lives in New Ross on the Kilkenny/ Wexford border. She is also an IKA Peer Support volunteer for kidney patients.

# WE'RE BACK!

Volunteer representatives from Branches across the country came together at the Aspect Hotel in Park West Dublin in early March, to kickstart the return of the Irish Kidney Association's first national fundraising drive, since the beginning of COVID-19, which was centred around **World Kidney Day, 14th March.**

Their positive energy and shared dedication are beautifully captured in these photos.



Frances Moynihan  
Waterford



Peter Heffernan  
Chloe Kinahan, Dublin North



Pat O'Sullivan  
Cork



Sara Santi  
Kilkenny



Elsie Moore, Debbie Templeton, Theresa Looney  
Kerry



Liam Buttle, Mary Mernagh  
Wexford





**Brian McHugh  
Marie Fowley  
Sligo**



**Jacqueline Burke, Nicola Coughlan  
Dublin East/Wicklow**



**Eddie Flood  
National Chairman  
Westmeath**



**Angela Kirwin  
Laois**



**Michelle Horan, Peter Kearney,  
Kildare**



**Karl Cronin  
Cavan/Monaghan**



**Cathriona Charles  
Leitrim**



**Joan Gavan  
Tipperary**





Jake & Eddie Kehoe, Wexford



Pat O'Sullivan, Mallow



Rachel O'Hora, Myriam Walsh, Frascati, Blackrock



Ron Grainger Blanchardstown



Ellen Walsh, Mallow



Clr. Martina O'Connor, Westside, Galway



Eoghan Daly Mallow



Christine Curley, Oranmore



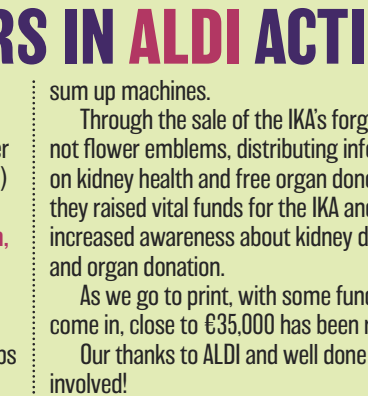
Sinead Ferris, Mallow



Sharon, Martin, Gerry Ennis



Michelle Geraghty Eoin Ryan, Westside Galway



Francis Hogan, Mary Adamson, Clonmel



Ken Horne, Mary Adamson, Eileen Murray, Clonmel



Simon Walsh, Colin Mackenzie, Bayside, Dublin



Carol Moore (IKA CEO), Jacqueline Burke, Sallynoggin, Dublin



Rhona Black Oranmore



Lenny Ryan, Girley Lugares, Ronald Condren, Belgard



Sisters Miriam Cremin, Angela Sherlock, Cora Doyle, Nutgrove Shopping Centre, Dublin

## IKA VOLUNTEERS IN ALDI ACTION

In a heartwarming display of solidarity and generosity of spirit, volunteers from Branches across the country came together to support the Irish Kidney Association (IKA) kidney health awareness campaign which marked **World Kidney Day** on **March 14th**, and to raise funds.

Over the following days, on March 16th and 17th, they located themselves at ALDI stores, donned in IKA volunteer collector bibs and equipped with collection buckets and

sum up machines.

Through the sale of the IKA's forget-me-not flower emblems, distributing information on kidney health and free organ donor cards, they raised vital funds for the IKA and also increased awareness about kidney disease and organ donation.

As we go to print, with some funds still to come in, close to €35,000 has been raised.

Our thanks to ALDI and well done to all involved!



# IKA VOLUNTEERS IN ALDI ACTION



*Jerry O'Sullivan and his son Adam, Mallow*



*Michelle Moran, Alceina O'Brien Athlery*



*Peadar O'hici, Michelle Geraghty Westside Galway*



*Carmel Fennessy and friend, Cahir*



*Margaret & Lisa O'Keeffe*



*Jennifer & Eddie Flood Kinnegad*



*Linda Brennan, Bridget Langton, Graigue, Co. Kilkenny*



*Anne O'Grady, Bridie Lennon Co. Kilkenny*



*Mary Rooney, Rodel Vergas Kilkenny City*



*Sharon Byrne, Bridget Langton, Graigue, Co. Kilkenny*



*Joyce Grainger Blanchardstown*



*Jacinta Roche, Enniscorthy*



*John & Patricia Wogan, Greystones*



*Walter Kent, Trinity Street, Wexford*



*Mary Ryan, Jean Murray Westside, Galway*



*Rita Ngolle, Madeliene Dempsey, Newlands Cross*



*Joseph, Sarah, Susie at Newlands Cross*



*Paddy & Marguerite Sneyd, Wachida Parvin, Lorna O'Leary*



*Gerry, Trudi and Laurence, The Square Tallaght*



*Rhona Black, Eoin Madden, Oranmore*



*Sheila Gregan, Orla Hogan, Nenagh*



*Sean Fawley, Geraldine McHugh, Sligo Town*





Dr Carol Traynor and team at Beaumont Hospital.



Midland Regional Hospital Tullamore staff Alice Curran and Ashling Stapleton.



Frances Moynihan Waterford IKA (right) at UHW with staff Cathriona Culleton and Fiona Tobin CNS CKD.



Kerry IKA branch members Brendan and Bridget with staff from University Hospital Kerry, Elaine, Ken, Lisa, Lisa and Brendan.



Dialysis patients at Cavan General Hospital: Patrick Field, Raymond Brady, Mel Maguire, Bernadette Holohan.



Ladies supporting World Kidney Day at Cavan General Hospital.



Sarah Buchanan at a Health Fair in Navan on International Women's Day



Stand at the Mater Hospital.



Bernie & Michael Dwyer E. Dublin/Wicklow Branch at the Lexicon Library, Dun Laoghaire



Paul Donohoe, Cavan/Monaghan branch with Hannah, Bride To Be from Armagh and her hens supporting World Kidney Day.



South Dublin displays at County Library, Tallaght

## MUNSTER KIDNEY SUPPORT CENTRE



World Kidney Day was celebrated at the IKA's new Munster Kidney Support Centre with nursing and medical staff, including Prof. Liam Plant from CUH, as well as IKA volunteers, calling in for a cuppa and a chat. Engaging conversations were had, fostering a sense of community and support for kidney health advocacy. Guests enjoyed delicious treats provided by the Centre's staff, Manager Jennifer and Sarah, and got a glimpse of the Centre's welcoming environment for its patrons.



Digital and print posters displays at Life and Care Plus pharmacies, Tullamore



Mellericks Pharmacy, Fermoy.





# Irish Kidney Association



## IKA ACTIVITY – 2023

### PATIENT SUPPORT



#### PATIENT AID

**461** Patient support requests

#### FINANCIAL AID

UP BY **8%**

#### COUNSELLING



**2,402**  
FREE HOURS

Referrals UP BY **14%**

#### NEW PEER SUPPORT

Service Launched

**35** Referrals



#### HOTEL ACCOMMODATION

**890** Overnight stays for **135** families



#### HOLIDAYS

**111** Families provided a 6-day week holiday

**201** Dialysis treatments organised abroad

### ORGAN DONOR AWARENESS

#### ORGAN DONOR AWARENESS WEEK

– MAY –



#### 38th ANNUAL SERVICE OF REMEMBRANCE AND THANKSGIVING

– OCTOBER –

Viewed by

**38,200** People with  
**1,400** attending



#### ROLL OF HONOUR FOR ORGAN DONORS

### ORGAN DONOR CARDS



**72,000**

DISTRIBUTED

**3,400** DONOR CARD APP DOWNLOADS

### EVENTS



#### FITNESS

**2** Virtual **2** In-person  
**14** Team members at World Transplant Games in Australia



#### HEALTHCARE

**18** Healthcare Professionals **8** Patient Online

#### MEETINGS

**5** National Branch Forums  
**27** Branch Meetings

### COMMUNICATIONS



**32,283**



**3,565**



**3,819**



**700**



#### Emails

**2,151**

to [info@ika.ie](mailto:info@ika.ie) UP BY **34%**

### PUBLICATIONS

**4** FREE

Quarterly **SUPPORT** Magazine



Circulation: **3,200** per issue

**7** FREE

Patient Information Books



**9,000** issued

**3,500** INFORMATION LEAFLETS CIRCULATED



Staff, Board members, and representative volunteers attended a meeting at the Aspect Hotel on March 2nd to discuss Future Proofing the IKA. From left Deirdre Markey, Marie Fowley, Joan Gavan, Liam Buttle, Frances Moynihan, Elsie Moore, Ashling Hand, Eddie Flood, Debbie Templeton, Carol Moore, Brian McHugh, Cathriona Charles, Sarah Buchanan, Peter Kearney, Pat O'Sullivan, Mary Mernagh, Theresa Looney and Tiberius Pereira.

By CAROL MOORE

# Future proofing the Irish Kidney Association

As one renowned Irish footballer wisely remarked, **“Fail to prepare, prepare to fail”** - Roy Keane

It is thanks to our energetic volunteers, Board and staff, the Irish Kidney Association is certainly no failure but a very successful, and highly regarded, organisation. From Board to Branch Officer, we are very fortunate to have individuals who have generously devoted substantial time, talents and energy at all levels of the organisation, to deliver vital patient services and supports. To ensure we continue our successful path of strong volunteer involvement, the Board is preparing for the future and looking at how the Board and Branches operate.

The environment we live in has become very complex. There are now strict regulations which all charities must comply with. These regulations place extra responsibilities on Board Directors and Branch Officers and a significant amount of their time is now taken up with governance, making these type of volunteer roles less attractive to new people.

People have less time and do not want to sit on committees, preferring to volunteer for specific activities which support patients directly. This

is one of the reasons why not all Branches are represented on the Board anymore. Many Branches do not have a full committee, with individual volunteers filling multiple

- ensure we continue to be the genuine effective voice of the patient
- ensure any governance changes strengthen this patient voice
- ensure our underlying core value of volunteerism remains central to our work.

Our planning for the future includes three special Board development days.

BOARD DEVELOPMENT DAYS		
<b>Review</b>	<b>Day 1, January 20th</b>	How should the board be constituted in the future?
<b>Design</b>	<b>Day 2, March 2nd</b>	How should Branches and membership be constituted in the future?
<b>Reflect on next steps</b>	<b>Day 3, May 18th</b>	Reflect on findings so far and develop proposals

Two of these development days have now been held. Ten additional people and four staff members attended the second workshop which looked at how branches operate, so a broad range of views

roles which can lead to volunteer burn out.

So, the Board is looking at these issues to:

was obtained. It was a very positive and enjoyable day with a wide range of different views expressed.

We heard how other organisations are adapting to change.





# Human Tissue Act 2024

## The History and the Future

The 'Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and Public Display) Act 2024' was enacted by the President of Ireland on February 28th, 2024 after being formally passed through the Houses of the Oireachtas in the Dáil on February 21st. The Act covers many areas including organ donation and transplantation.

Here we reflect on what has brought us this far and what to expect in the future.

The first kidney transplant to take place in Ireland happened in 1963. This was followed by the first heart transplant in 1985, the first pancreas transplant in 1992, the first liver transplant in 1993 and the first lung transplant to take place in Ireland was in 2005.

People also travelled to the UK for transplant operations and there continues to be strong links between the two jurisdictions with the paired kidney exchange programme, as well as all paediatric transplants, except for kidneys, happening in the UK.



By **COLIN WHITE**  
NATIONAL ADVOCACY  
& PROJECTS MANAGER



Colin White; Joan Gavan, Director; Eddie Flood (Chairman); Senator Mark Daly; Michelle and Ally Whitston; John Brennan; Minister for Health Stephen Donnelly; Carol Moore (CEO); Colin Mackenzie; Jacqueline Burke, Director; John Whelan.

One of the first actions of the Irish Kidney Association (IKA), when it was formed in 1978, was to introduce the Kidney Donor Card which subsequently became the Organ Donor Card we know today. The Association has been at the forefront in the promotion of organ donation for over 45 years and it has been no different in relation to advocating for legislation in the areas of organ donation and transplantation.

It was the introduction, in the early 1980s, of Cyclosporine as an immunosuppressant that truly opened up organ transplantation as it became more realistic to transplant organs other than just the kidney. There have been developments in immunosuppression over the years, with new medications and finer tuning of doses.

Legislating for organ donation for transplantation has been a work in progress for many years. Under past leadership of Board and staff there was a lot of groundwork done to influence the development of domestic and EU policy. Senator Mark Daly has been actively supporting the work of the IKA in this area since he first entered the Seanad in 2007. *The Human Body Organs and Human Tissue Bill 2008* lapsed with the dissolution of the Dáil and Seanad in 2011. Throughout the years, the IKA has brought its experience of promoting organ donation to bear on the debate as

well as its considerable understanding of what happens in other countries and, in many cases, how and why they made changes to how they operated.

After almost 8,000 organ transplants, the Human Tissue Act 2024 will, for the first time, provide a national legislative framework for operating organ donation and transplant services in Ireland, repealing the almost two centuries old Anatomy Act 1832.

### TRANSPLANTS IN IRELAND SINCE 1963

5,558		KIDNEY Transplants
439		HEART Transplants
1,359		LIVER Transplants
178		PANCREAS Transplants
364		LUNG Transplants

It has been encouraging to see cross-party support for the promotion of organ donation and transplantation services right through the legislative process. The IKA has been there every step of the way providing briefing documents to all parties, advocating for several amendments to improve the Bill, and ensuring that the perspectives of patients, donors and donor families were part of the conversation.

The work done by the Association in relation to the legislation has built its reputation as a partner in the future



development of services around organ donation and transplantation. This included organising an Oireachtas Briefing session in November last year as well as meetings with Department of Health officials and the Minister for Health Stephen Donnelly.

Whilst the Association did not get all that it wanted in relation to amendments, the Minister did agree an amendment that commits to a review of the **Opt-out Register** not later than three years after the commencement of the register. This will be important as it will put organ donation and transplantation on the political agenda again and allow for reflection on, and learnings from, the experiences of the three years.

At the frontline in promoting organ donation in the community, the IKA will play a key role in this review.

There are many aspects to the Human Tissue Act and they each need preparatory work (training, education, etc.) and infrastructure put in place **BEFORE** they can commence. So, nothing has changed yet in relation to practice in hospitals and the Opt-out Organ Donor Register has not yet been established. We are awaiting a timeline for the roll-out of the changes.

### WHAT CHANGES WILL THE HUMAN TISSUE ACT BRING?

**The introduction of non-directed Altruistic donation for the first time.**

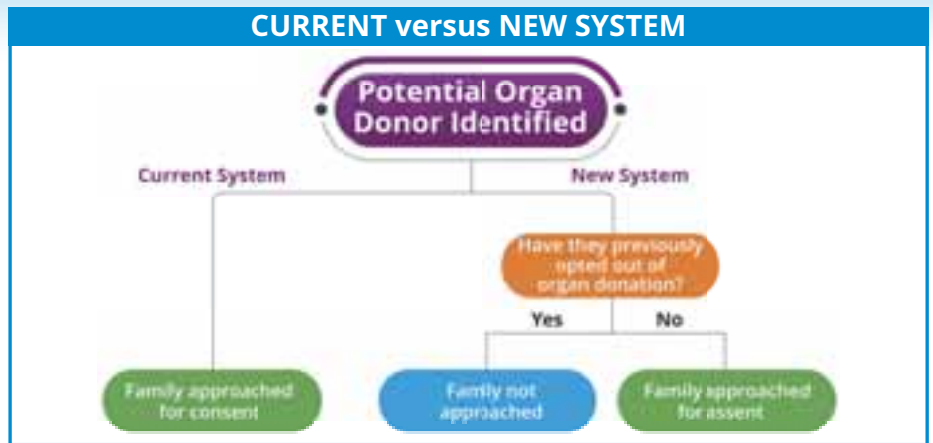
Altruistic kidney donation is where a member of the public steps forward to donate a kidney to the transplant pool and the recipient will be a stranger.

According to the Human Tissue Act, a non-directed altruistic donor may not direct or specify that his or her organ shall, or shall not, be donated to a person of a particular class or classes of persons.

To date, if someone wanted to donate a kidney to a stranger (altruistically) they had to go to Belfast or abroad to do so.

### The Introduction of an Opt-out Register and Presumed Consent

An official online register, an **Opt-Out register**, will be set up to record the details of those who choose not to be considered as a potential



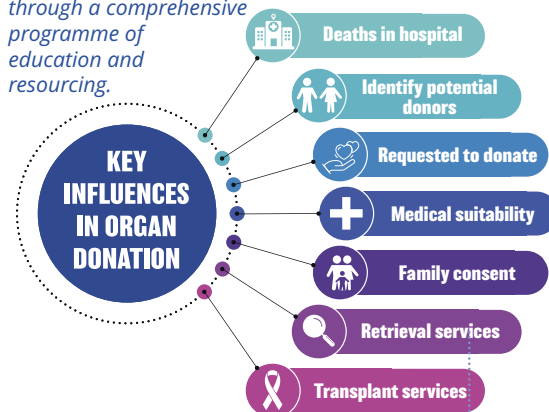
organ donor. The graphic above illustrates how this will change the approach for family approval.

Any person who does not Opt-Out on the online register will be considered a willing **potential** organ donor. It is important to note that:

- **Approximately only 1% of deaths annually are in the circumstances for organ donation to be possible.**
- **Organ donation will only go ahead if there is assent (consent) from the family.**

In relation to organ donation, the core message for the public remains; **'Don't leave your loved ones in doubt.'** Use the Organ Donor Card

*This graphic shows that there are many steps involved before transplantation can happen meaning that real change will only come through a comprehensive programme of education and resourcing.*



as an icebreaker to initiate a family discussion so that your organ donation decision is known.

### WHAT'S NEXT?

Passing the legislation by the President of Ireland on February 28th, 2024, is historic, but it is not the end of the story in relation to organ donation for transplantation. It is merely the end of a chapter. The next chapter will include the commencement of the relevant parts of the legislation, and it will need to include appropriate resourcing to ensure that the changes in the legislation are meaningful.

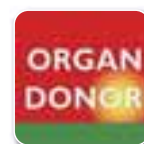
It was obviously pleasing to see the Minister for Health, Stephen Donnelly, make an announcement to coincide with the passing in the Dáil of the Bill committing to increased funding of €1.6 million in 2024 for organ donation and transplant services.

The Irish Kidney Association will continue to play its part which is built on our volunteers promoting organ donation at community level and will continue to include national campaigning and advocacy.

### REMINDERS OF YOUR WISH TO BE AN ORGAN DONOR



**ORGAN DONOR CARD**  
www.ika.ie



**DIGITAL ORGAN DONOR CARD APP**  
from the APPLE or ANDROID STORE



**1.45 million people** with **CODE 115**  
on **NDLs Drivers Licence** (Jan. 2013-Feb. 2023)



**MY PERSONAL WISHES AND CARE PLAN**

# A MOMENTOUS DAY

John Brennan, Senator Mark Daly, Stephen Donnelly, TD, Carol Moore, IKA CEO and Michelle Whitston and her daughter Ally.



On February 21st we made the trip to Dáil Éireann at the invitation of the Leas Ceann Comhairle, Seanad Éireann, Senator Mark Daly, to be present for the passing of the Human Tissue Bill, presented by the Minister for Health Stephen Donnelly.

The IKA was represented by National Chairman, Eddie Flood, past Chairmen Colin Mackenzie and John Whelan, Board Directors Jacqueline Burke, Joan Gavan and Chloe Kinahan (joined by her son Sam, who is a kidney transplant recipient, and her daughter Ally), our CEO, Carol Moore, and Colin White, the National Advocacy & Projects Manager and Gwen O'Donoghue, Media Relations. Also in attendance was Michelle Whitston with her daughter Ally (a kidney transplant recipient) from Dublin.

Prior to the Dáil session, we were joined by Minister Donnelly for photographs outside Leinster House. We were delighted to have John Brennan, a heart transplant recipient and dialysis patient from Co Louth, participate in these photos also.

We witnessed the presentation of the



Minister Donnelly with IKA representatives: Colin Mackenzie, past Chairman, Joan Gavan, National Board, Eddie Flood, National Chairman.

Bill from the Visitors' Gallery. The IKA was mentioned by both Government and Opposition speakers in the Dáil Chamber as were Sam Kinahan, John Brennan and Ally Whitston. They were observed in the gallery and visibly acknowledged by the Minister and the Leas Ceann Comhairle.

This was an historic day and a significant milestone for the IKA given our involvement in the promotion of organ donation and transplantation for over 45 years. The President of Ireland formerly enacted the Bill into Law, exactly one week later on 28th February, 2024.



TIME CAPSULE: History unfolds in black & white. Photo by Andres Poveda. All other photos by Conor McCabe

## LIVE UPDATES: Video and Tweets

Minister Donnelly tags IKA on passing of the Bill in the Dáil and posts video with IKA CEO Carol Moore. President of Ireland tweets passing of Human Tissue Act on 28th February.



John Brennan, heart transplant recipient and dialysis patient from Louth.



Michelle and Ally Whitston, a kidney transplant recipient from Dublin.



# You could earn over €290 per week TAX FREE

Government incentive to help meet a housing need and benefit homeowners and tenants, without affecting their social welfare payments or medical cards.

By FIONA AHERNE

## RENT A ROOM TAX RELIEF

Since December 2023 local authority tenants (previously known as council house tenants) can rent out a room in their home to a third-level student and earn up to €14,000 per year (€293.23 per week) from that rental income tax-free.

To read more about this, including how to qualify and exclusions visit <https://www.revenue.ie> and search for Rent-a-Room Relief.

## RENTAL INCOME AND YOUR SOCIAL WELFARE PAYMENTS

If you are getting a means-tested weekly social welfare payment, supplementary welfare allowance or working family payment, you can earn up to €293.23 per week (€14,000 per year) for renting out a



room in your home without it affecting your social welfare payment.

## SITUATIONS WHERE PAYMENT WILL BE AFFECTED:

In certain situations, rental income of less than €14,000 a year, for renting a room, will be considered and can affect your social welfare payment. This applies if you rent a room in your home:

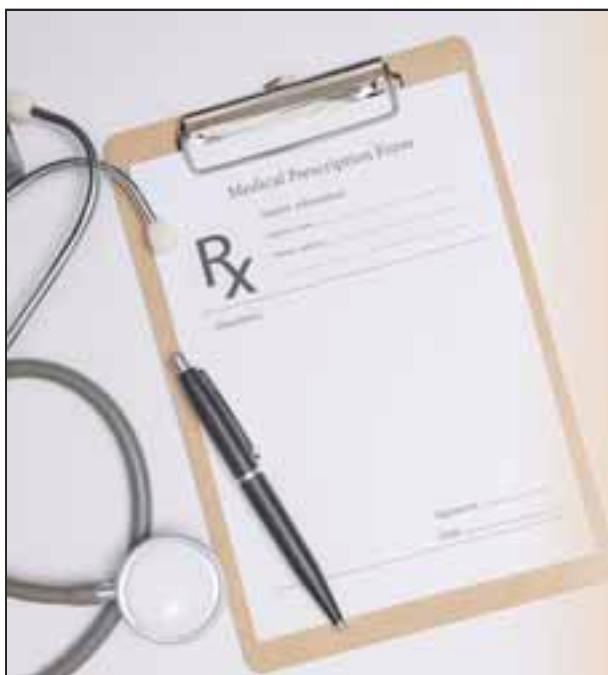
- As a short-term let. Short-term lets are stays that do not exceed 28 days in a row.
- To an employee.
- To an immediate family member such as your spouse, civil partner, or partner, your child, their spouse, your parent, step-parent and parent-in-law, siblings

(step-siblings and siblings-in-law), your grandparent or grandchild, your aunt/uncle and niece/nephew.

You do not have to own the property to qualify for rent-a-room relief. You could be a tenant and be sub-letting to someone else. In this case, you should check with your landlord that sub-letting is allowed.

## HOW TO APPLY

To claim rent-a-room relief you must record your rental income when making your tax return. You can complete and submit your tax return online on Revenues [myAccountService](#). Alternatively, you can contact your local tax office to request a hard copy of the form to complete.



## Change in Prescription Rules

The Minister for Health Stephen Donnelly has announced an extension of prescription validity from 6 to 12 months, effective from March 1st, 2024. This will mean that your prescription will be valid for longer periods and remove the need to visit doctors, dentists and other prescribers so often.

It also gives discretion to pharmacists to extend prescriptions for up to 12 months, allows patients longer prescription periods, and aims to reduce visits and ease primary care demand on doctors, dentists, and other prescribers.

This will reduce the cost for people who do not have medical cards or free GP visit cards as well as medical card holders.

Detailed information for patients, pharmacists, and prescribers on this change aims to improve access to healthcare healthcare accessibility and convenience for kidney patients and their families is available at

<https://www.citizensinformation.ie/en/health/drugs-and-medicines/prescribed-drugs-and-medicines/>

# RENTING OUT A ROOM

“I feel safer at night having someone else in the house”.



Nalaka rents a room in Caroline Gleeson's home. Photo: Alan Betson



By JESSICA DOYLE

Caroline Gleeson has rented out rooms in her Whitehall home for more than 20 years.

Caroline Gleeson spent most of her adult life travelling the world, seeking out new experiences, learning about other cultures and meeting new and interesting people. Since moving home to Ireland more than 20 years ago – “Fallen leaves always return to their roots,” she says – she continues to meet new people from far-flung lands by renting out rooms in her home in Whitehall, Dublin 9.

After an initial 10-year stint in Australia in her 20s, Gleeson lived in India for a year and passed through countries such as Germany, Austria, Greece, Turkey and Jordan (to

name a few) before spending two years in Malta and eventually settling in Italy for about 12 years, where she became fluent in the native tongue.

When Gleeson eventually returned to Ireland, her three-bedroom family home in Whitehall needed extensive upgrading, including the installation of central heating, double-glazed windows, a new kitchen and a new bathroom, and so renting out her two spare rooms “was the perfect solution”, she says.

Initially, she continued to work as a tour guide in Italy for a few months of the year, so having tenants to look after her house in

Dublin also allowed her to come and go with peace of mind.

A person can earn up to €14,000 a year, tax free, by renting out rooms in their main residence to long-term tenants (who stay for more than 28 days), and it does not affect social welfare payments the homeowner may receive. Given the housing crisis, there are plenty of students and professionals in need of rental accommodation so homeowners who do so are providing a much-needed service.

Having spent many years as an immigrant herself, Gleeson had no qualms about welcoming people from other

Jessica Doyle writes about property for *The Irish Times*



countries into her home. "From travelling around, I've seen people are just the same everywhere," she says.

"If you're married with a family, you want the same things; you want a roof over their head, you want food on the table and you want an education no matter where in the world you live."

One of Gleeson's first tenants, Olga from Russia, studied at a medical college in the city, and on her departure, left Gleeson's details with the college so students in search of accommodation could contact her. From then on, many of Gleeson's tenants have been student doctors staying for a year or two at a time.

"Most of my tenants have been married men with children and family at home, so they are mature and responsible," she says.

"My first tenant, who I hadn't met in advance, was a doctor from Egypt, and the most handsome man I have ever laid eyes on," says Gleeson. "That really gave the neighbours something to talk about."

Olga and her husband, Alex, later bought a house just up the road from Gleeson and they are still great friends, she says, and spend Christmas Eve and New Year's Eve together.

"It's not been rosy every time, though," Gleeson points out. "I've had a few problems along the way and I have had to ask people to leave," she says, citing issues such as people leaving the key in the front door or leaving the front door wide open.

Other notable tenants for Gleeson were a South Korean couple, a teacher and a police officer, who took leave for a year to study English in Dublin. Gleeson developed a great rapport with them and felt

## CAROLINE'S TIPS FOR RENTING OUT A ROOM IN YOUR HOME

1. Don't advertise on a rental or property website, you will be snowed under with responses. Instead, I suggest you contact a local college, school, hotel or hospital, or better yet, your local residents' association Facebook page.
2. When you meet your potential new tenant/housemate, clearly lay down the house rules. For example, some of my rules include: no overnight visitors, no showers after midnight (my bedroom is next to the bathroom) and maximum 5 minutes in the shower (I only have the one bathroom).
3. No candles burning in rooms – I added that one from experience.
4. Clean the bathroom and kitchen after use.
5. Share the housework equally. For example, you vacuum upstairs and I vacuum downstairs once a week.
6. Make sure your schedules are compatible. It's good to have the house to yourself when your tenant is working, and if they work nights, for example, you'd have to keep quiet during the day, which could be a burden.

comfortable enough to leave them to look after the house while she planned a dream trip to Africa to work in an elephant sanctuary.

Unfortunately, in 2020, COVID lockdowns put international travel to a halt and the couple's language school closed for in-person classes. Luckily for them, though, they found themselves living with an experienced English teacher, and Gleeson says she was delighted with the company and for the opportunity to teach them. She fears she would have felt extremely isolated without them at that time, she says.

The couple returned to South Korea when the borders reopened, and Gleeson decided not to get new tenants as she no longer needed the income with her house upgrades paid off, and she didn't want to risk being exposed to COVID having stayed it off for so long.

It was when lockdown eventually ended that Gleeson was contacted by Pradeep, a chef from Sri Lanka, who was working at a city hotel that had Gleeson's details on file for prospective tenants. She was still hesitant to have anyone else in the house, so along with her usual house rules, she added that the tenant would be required to entertain the house cat, Molly, for 20 minutes every evening. "I thought, that should do it. He won't want to come here," says Gleeson.

But Pradeep was not dissuaded and told her he'd love to take the room. "And he was the best tenant ever," Gleeson says; they had a great laugh together, and Pradeep would whip up Sri Lankan curries that would keep them fed for days.

Pradeep says he was keen to rent a room in a house as it would have been too expensive to rent an apartment and cover the bills on his own. "It was

my first time here and I didn't know anything about Ireland," he says. "Caroline was very kind and she was like a mother to me, she taught me everything and guided me."

Pradeep has now moved to Clare to work as he hopes his wife and two children will join him in Ireland, and the rent would be too expensive for the family to have their own place in Dublin.

Pradeep's brother-in-law, Nalaka, who is also a chef and from Sri Lanka, is Gleeson's current tenant and was happy to take Pradeep's room when he moved west.

Gleeson says that technology is not her area of expertise and she often calls on Nalaka to help her with computer problems, for example. It's also a huge benefit to have a live-in cat-sitter, she says.

As she gets older, Gleeson says it gives her comfort to know there will be someone around should she become ill. When she was briefly unwell last year, it was a "huge relief," she says, to have someone go to the pharmacy for her and bring her cups of tea.

"I do feel safer at night having someone else in the house," she adds.

"Over the past few years, I have lost two very good friends who died alone in their home," she says. "This is a concern so I will continue to have a tenant. And if I do suddenly snuff it, at least I will not be eaten by the cat."

Gleeson says she would recommend to other people with empty rooms to do as she has done. "For the most part it has been a joy meeting and knowing many lovely young people from all over the world and making lasting friendships," she says.

*© Courtesy of The Irish Times.*

Morgan Lyons, Colette Hawe  
and baby Croía.



# Mother's Day

# *Little Miracle*



**M**other's Day on March 10th, was a particularly special one for a Cork woman whose journey from the depths of kidney disease diagnosis to the joy of motherhood culminated in a celebration of life, love, and the unwavering support and exceptional multidisciplinary care of medical teams at Cork University Hospital (CUH), and loved ones.

When Colette Hawe, 37, from Charleville in Cork, and her partner Morgan Lyons, welcomed their baby girl into the world, it marked a 'miracle' milestone in her journey with kidney disease.

Diagnosed with chronic kidney disease (CKD) at the age of twenty-four, Colette then faced nearly a decade of uncertainty and worry about her health and the chance of ever becoming a mother. However, her journey took a turn for the better in January 2020 when she underwent a kidney transplant, paving the way for her to pursue her dream of starting a family.

Just a fortnight before Mother's Day, at 34 weeks gestation, Colette gave birth to a beautiful fully developed baby girl, weighing in at 2 kilos (4.41 pounds). The proud parents named their little bundle Croía, an Irish name meaning 'little heart'.

The emotional event was made even more special by a special bedside visit from her Consultant Nephrologist, Prof. Liam Plant, who has been by Colette's side every step of the way since her kidney disease diagnosis. While initially, as a pre-term baby, she was for a brief time monitored in CUH's Neonatal ward, Croía soon thrived, and her medical care was stepped down. She joined her doting parents at home two weeks after her birth two days before, and just in time, for Mother's Day.

Prof. Plant, known for his exceptional patient care and commitment to the renal community, retired a few weeks later.

Baby Croía is the happy culmination of the last pregnancy of a renal patient he will have managed in close collaboration with the Obstetrics service at CUMH before his retirement.

Throughout his career he has

*Morgan, Colette and Croía with Richard and Angela Hawe.*



By  
**GWEN O'DONOGHUE**

contributed to the safe journey towards birth of more than 50 babies for kidney transplant patient mothers, as well as many other babies whose mothers had other degrees of kidney failure.

Colette praises Prof. Liam Plant for his invaluable guidance and support, in managing her illness with compassion and expertise and the multidisciplinary care of specialists from an array of specialities that worked together.

The Nephrology service's involvement extended beyond Prof. Plant, whose Consultant Nephrologist colleague Dr. Sarah Moran worked closely with Consultant Obstetrician Prof. Nóirín

Russell to ensure that Colette's pregnancy planning and transplant anti-rejection and insulin medication adjustments were safe and effective.

Colette shared, "Our baby is truly a miracle, and I am overwhelmed with gratitude. For a long time I faced uncertainty of ever being able to have a successful pregnancy with my kidney disease and not knowing if I would end up on dialysis and how long I'd be on the waiting list for a transplant.

"Prof. Plant diagnosed my CKD in 2014, following a referral from my GP to investigate if my two closely timed flare-ups with gout were kidney related. Since then, Prof. Plant has been more than a doctor to me; he has been a guardian angel. His retirement marks the end of an era, but I am forever grateful for his unwavering support.

"Croía now holds the title of being Prof. Plant's last kidney baby before he retired, and we are happy for her to have that special title!

"I also would like to acknowledge the truly outstanding care of so many others at CUH, including Consultant Nephrologist Dr. Sarah Moran, who helped manage my care throughout my pregnancy, Renal Nurse Phil O'Driscoll and the rest of the Renal team, Dr. Ora Kgosidialwa from the Endocrinology team who carefully guided me through my gestational diabetes,

*Prof. Liam Plant with baby Croía.*



*continued next page...*



**Consultant Nephrologist Dr. Sarah Moran, neonatal nurse Limya Rajan, Consultant Nephrologist Prof. Liam Plant, new parents Colette Hawe and father Morgan Lyons and their baby Croia, Consultant Obstetrician Prof. Nóirín Russell (back second from right), and Croia's proud grandparents Angela and Richard Hawe.**

my Consultant Obstetrician Prof. Nóirín Russell and her team at CUMH, and also all the wonderful midwives and nurses who took exceptional care of me in labour and then my caesarean section, and everyone involved in Croia's exceptional care in the neonatal who I consider to be angels.

"My family will be forever grateful to all who contributed to the safe arrival of our beautiful baby daughter."

Colette also expressed her heartfelt gratitude to the family of the deceased organ donor whose selfless gift made her transplant possible. "I am eternally grateful to the donor and their family for giving me a second chance at life and the opportunity to become a mother. They have left an incredible legacy with their 'gift of life' to me and my family and now the circle of life continues with Croia."

Colette added, "I want to give special mention to my amazing partner Morgan who has known me since before I was diagnosed with CKD and he has been a rock of support, and now I know he will be a wonderful father."

"My parents Richard and Angela Hawe, from Ballyhea, continue to be great loving parents to me and my

two brothers and they are now absolutely thrilled to be grandparents to Croia."

In addition to her medical team and loved ones, Colette said, "As we celebrate our little miracle of life, it's a good time to remember the important work the Irish Kidney Association does in raising awareness about kidney health and supporting thousands of patients like me."

Prof. Liam Plant said, "One of the

greatest privileges of my professional life has been to participate in the joyful event of mothers, with renal transplants, being able to have a baby. Few events more powerfully illustrate the remarkable gift that organ donation represents. All new babies are special, but few are as special as these. Their births are a testament to the amazing resilience of patients with kidney disease and their families".

When Colette permitted the IKA to share her uplifting story just in time for Mother's Day, in support of organ donor awareness, it sparked considerable media interest. It received coverage in both national and local newspapers, as well as online media platforms. Additionally, two local radio stations featured her story, and it also garnered significant attention on social media through widespread sharing.

Members who visited the new IKA Munster Kidney Support Centre might have met Colette there, as she is a part-time member of the Centre's three-person team. As she embarks on motherhood, a new and exciting chapter in her life with her partner Morgan and Croia, her Cork colleagues Jennifer and Sally, as well as the management and staff at Donor House, and board members, extend their best wishes for a lifetime filled with happiness and good health together.





## ACCOMMODATION BOOKINGS

**PH: 01 690 8887**

If you require overnight accommodation at the Clayton Hotel or Munster Kidney Support Centre please contact us on above number.

Clayton Hotel, Dublin



### PHONELINE OPENING HOURS FOR CLAYTON HOTEL, DUBLIN

Mon – Fri: 9.30am – 7.00pm

**For Emergency Bookings:**

Sat – Sun and Bank Holidays  
12.00pm – 4.00pm

*Please be sure to phone the IKA Renal Support Centre staff as soon as you know of your hospital appointment.*

Munster Kidney Support Centre



### OPENING HOURS

#### MUNSTER KIDNEY SUPPORT CENTRE, CORK

**Drop-in:**

Mon – Fri: 9.30am - 6.00pm

**Phone lines open:**

Mon – Fri: 9.30am – 7.00pm

**For emergency bookings:**

Sat - Sun and Bank Holidays  
12.00pm – 4.00pm



S P R I N G

*giveaway*

10 X €50

GIFT CARDS FOR  
**DUNNES**  
STORES

In the spirit of springtime generosity, the Irish Kidney Association (IKA) is delighted to announce an exciting giveaway for our readers of *SUPPORT* magazine by **DUNNES STORES - 10 x €50 gift cards**. Not only that, the significance of the support from **DUNNES STORES** with nationwide chain stores which enjoy a heavy-footfall of shoppers for food, homeware, and fashion, extends beyond their sponsorship of €500 in prizes. They will also be helping the IKA to raise awareness about organ donation. Through the valued support of **DUNNES STORES**, the IKA has found a new and important avenue to highlight the **ORGAN DONOR AWARENESS WEEK 20-27 APRIL** to the general public. For the awareness campaign organ donor cards in counter top boxes will be prominently displayed at customer services desks in some of its 118 stores in Ireland.



In 1944, the late Ben Dunne founded his first store on Patrick Street in Cork City. Generations have enjoyed shopping at the **DUNNES STORES** chain which, to this day, continues to be a market leader while maintaining its Irish owned status. Today, **DUNNES STORES** employs close to 15,000 people and continues to offer quality, value and choice to its customers.

To be in with a chance to win a **€50 gift card**, email: [robyn@ika.ie](mailto:robyn@ika.ie) with your name, address and phone number making sure to include the words '**DUNNES STORES**' in the subject line of your email. Ten winners will be selected at random on **Monday 15th April** and each will receive a **€50 gift card** which can be redeemed at [www.dunnesstores.com](http://www.dunnesstores.com) or in any store across the country. Good Luck! Winners' names will be included in the Summer issue of *SUPPORT*.

# ORGAN DONOR AWARENESS WEEK



At the 2023 national launch Minister for Health, Simon Donnelly, TD, with transplant recipient Liam O'Connor (left) and his twin brother Daniel.



## DON'T LEAVE YOUR LOVED ONES IN DOUBT.

#ShareYourWishes

## Coming together to save lives

As the days grow brighter with the arrival of springtime and a sense of optimism fills the air the stage is set for our upcoming **Organ Donor Awareness Week 2024** campaign from **April 20-27**.

The Irish Kidney Association (IKA) will once again lead the annual Organ Donor Awareness Week campaign, in association with Organ Donation Transplant Ireland. The campaign will be launched in Dublin on April 16th by the Minister for Health, Stephen Donnelly, TD.

The 2023 theme of Organ Donor Awareness Week, **Don't Leave Your**

By  
**CWEN O'DONOGHUE**

Loved Ones in Doubt! #LeaveNoDoubt and #ShareYourWishes, received widespread praise for its effectiveness and simplicity in conveying the importance of family conversation about organ donation. By sharing your wishes you leave no doubt. Due to its success, we are continuing with the same approach for this year's campaign.

The primary message emphasises that the public can contribute to organ donation for transplantation by ensuring their families are clear about their wishes regarding organ donation. This unambiguous

message is underpinned in the campaign tagline: 'Share Your Wishes'.

Additionally, the campaign poster, about Organ Donation, available in three languages (English, Irish, and Polish), includes a QR code which, when scanned, directs individuals to ways they can support organ donation on the IKA website.

Digital copies of the posters can be downloaded from our website.

[www.ika.ie/donorweek](http://www.ika.ie/donorweek)

Building on the successes of last year's organ donor awareness campaign and the long-awaited enactment of the **Human Tissue Bill** on February 28th this year, along with our charity's recent successful awareness activity for **World Kidney**



Day, we've been rejuvenated by the enthusiastic support of our dedicated volunteers and other supporters and partners.

This has further fuelled our collective sense of optimism and purpose as we prepare for the upcoming 2024 Organ Donor Awareness Week campaign.

It is important to acknowledge the outstanding dedication and value that our Branch volunteers can bring to the upcoming awareness campaign. By wearing the IKA forget-me-not flower emblem, (the symbol of transplantation), when out and about during the Organ Donor Awareness Week it brings further visibility to the campaign.

Transplant recipients wearing the IKA's new badges 'An Organ Donor Saved my Life' has proven to be a great conversation starter.

Having recently undertaken the IKA's national collection day in March, around World Kidney Day, the volunteers demonstrated remarkable dedication and enthusiasm in fundraising for the IKA while also distributing free organ donor cards.

and other community settings. This approach has proven to be an effective way to increase awareness, as it inspires people to support organ donation.

You can find this *Teacht Le Chéile* toolkit on our website [www.ika.ie/donorweek](http://www.ika.ie/donorweek)

If you or a family member are employed by large companies, many of which have a corporate social responsibility (CSR) policy, approaching them about organising an organ donor awareness activity can bring positive responses. Based on past experiences, we've found that companies welcome such initiatives. Having someone share their personal story can deeply resonate with employees and leave a lasting impact, and support for the cause.

As our volunteers step up and our Branches mobilise once again, our collective efforts gain momentum, fuelled by stories shared by those



Eddie Kehoe, Castlebridge, Co. Wexford with Liam O'Connor, Artane, Dublin at the launch of Organ Donor Awareness Week 2023, celebrating 40 years and 1 year of successful transplants.

touched by organ donation. These stories are inspiring and show real love and compassion.

But the collective support doesn't end there.

The media plays a vital role and we hope to secure their substantial support in both national and local outlets, as we have successfully done in previous years.

Social media platforms are immensely important for spreading the message far and wide, as their immediate and potential reach, when wisely used, can bring hugely positive awareness. *continued next page...*

## Start the conversation about organ donation

the essential guide to hosting a **teacht le chéile** event.

**teacht le chéile**  
BRINGING PEOPLE TOGETHER  
FOR ORGAN DONOR AWARENESS



We've developed a toolkit, *'Teacht le Chéile, Coming Together'*, a guide which is full of ideas and advice on organising events and activities that advocate for organ donation and transplantation.

The guide provides tips for hosting events like social gatherings, coffee mornings, picnics, and outdoor activities. It highlights the power of sharing personal experiences of organ donation at gatherings in workplaces, schools, sports clubs,



Announcing An Post's support were transplant recipients Finn O'Shea from Clonmel, the son of a postman, and Andy Kavanagh, a heart and kidney transplant recipient who works at the GPO.

An Post, at the heart of every community in Ireland, is supporting the campaign for a second year (report on pages 29-30). On a national level, the Irish Pharmacy Union, some pharmacy chains, Dunnes Stores, RTÉ soap *Fair City*, digital poster site company Clear Channel, Libraries Ireland, are just some of the organisations who are pledging their support towards the campaign. At local level in towns and villages around Ireland we anticipate there will be lots of activities taking place.

This extensive involvement from so many underscores an understanding of the importance of organ donor awareness in our communities, where so many of us have personal connections to the cause and many, including workplaces, consider it an important part of their social responsibility and active citizenship.

## ORGAN DONOR AWARENESS WEEK *continued...*

We run this Organ Donor Awareness Week campaign, in association with HSE's Organ Donation Transplant Ireland (ODTI). Other patient advocacy and support groups for liver, heart and lung patients, and our hospitals which run transplant programmes, health professional representatives including the Irish Nephrology Nurses Association (INNA) and Irish Nephrology Society (INS) also support the campaign.

A new support group representing patients who have experienced liver failure will officially launch on the first day of Organ Donor Awareness Week, a very timely alignment in support of the donor awareness campaign. We wish them every success. You will find out more about this new group in the Summer issue.

Another alignment will be for the celebration to commemorate organ donors on the campaign's final day, which we also look forward to sharing information about with you in the Summer issue.

It's heartening to see so many individuals and

## IKA ONLINE CALENDAR EVENTS

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/](http://www.ika.ie/whatson/yourevent/) and we can include it on our website calendar. We may be able to help promote it through our social media channels.

### Social media hashtags are

**#LeaveNoDoubt, #ShareYourWishes and #DonorWeek24**

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

**@IrishKidneyAs** on Twitter

**@IrishKidneyA** on Instagram

**@IrishKidneyAssociation** on Facebook.

organisations coming together for a cause that touches the lives of countless individuals.

**All of this collective surge of support from so many showcases solidarity in support of patients facing organ failure while acknowledging the monumental selflessness of organ donor families and appreciation for their profound life-saving legacy.**



### ONE ORGAN DONOR CAN SAVE SEVEN LIVES - ISN'T THAT REMARKABLE!

Organ Donation means that nearly 6,000 people around the country are currently enjoying the 'gift of life' after successful transplants for which their gratitude and that of their families to organ donors is immeasurable.

At any one time in Ireland there are close to 600 people active on waiting lists for organ transplants including heart, lung, liver, kidney,

and pancreas, and at least 500 of these are awaiting kidney transplants. It is because of 95 deceased organ donors last year and 30 living kidney donors, that 282 organ transplant operations were carried out in Ireland in 2023 (32 more transplants than in 2022). See report on page 42-44.

At the core of these statistics, we must never forget the families in communities across Ireland who are grieving the loss of their loved ones, who selflessly donated their organs. Due to their generosity, these families and entire communities are grateful for the patients whose lives were saved, leaving a legacy that will endure for generations to come.

We must also recognise the unwavering dedication of healthcare professionals, including nursing, medical, and surgical teams, alongside the indispensable roles of organ donor coordinators, organ donor nurses, transplant coordinators, and all the ancillary teams that collaborate tirelessly to facilitate organ donation and transplantation.



Watch out for this outdoor mobile digital display van displaying the campaign poster in Cork City and County during Organ Donor Awareness Week, kindly sponsored by dialysis patient and Cobh native Pádraig Feen of Big Pix Media.

We are all part of a vast community, interdependent on one another. Organ donation and organ failure can impact any one of us, underscoring our shared vulnerability and the importance of solidarity for this life-saving cause.

So now, let us all rally together to support those on transplant waiting lists, honour the selflessness of organ donors, and raise awareness about the vital

importance of organ donation and transplantation.

Together, let's sow the seeds of hope for a future where every patient in need of a transplant has the opportunity for a brighter tomorrow, and living organ donors and families of deceased organ donor families can take solace in knowing their selflessness has left a profound life-saving legacy.



# AN POST delivers ORGAN DONOR AWARENESS

In an initiative to promote public conversation about organ donation, AN POST is proudly supporting the Irish Kidney Association's national Organ Donor Awareness Week 2024 (20-27th April).

At the core of this collaboration is the commitment to raise awareness of organ donation within communities all over the country. The key message of the campaign is **DON'T LEAVE YOUR LOVED ONES IN DOUBT, #LEAVE NO DOUBT**. This simple message captures the vital importance of letting your loved ones know your wishes around organ donation.

AN POST's support will include the display of organ donor cards in countertop boxes and the campaign poster shown on large digital screens located across 350 of its bustling outlets, as well as through social media engagement.

Other post office outlets interested in displaying campaign materials can request printed posters and organ donor cards from An Post's Retail Marketing and Irish Kidney Association branch representatives can also approach



Carol Moore, IKA, transplant recipients Michael Cooper and Susan Mulligan, and An Post's Conor Nott and Lucy Murray, at the digital screen display in St. Andrew's Street Post Office last year.



Joan Flynn, CNS Renal, CHI Temple Street, postman Eoin O'Shea, his wife Lisa and their kidney transplant son Finn, and heart and kidney transplant recipient Andy Kavanagh, GPO, and Carol Moore, CEO, IKA. Back centre: Conor Nott, Retail Marketing Manager, An Post.

their local post offices to encourage their participation which is at the discretion of the individual post office's discretion. This strategic placement will serve as a constant reminder to the public about the value and impact of organ donation and encourage people to consider becoming donors.

The photos here showcase the remarkable success of organ donation with kidney transplant recipient Finn O'Shea, who will celebrate his 10th birthday on 22nd April during Organ Donor Awareness Week 2024.

Finn is the son of a postman Eoin O'Shea from Clonmel. Finn, a patient at CHI Temple Street, who was born with underdeveloped kidneys, underwent a kidney transplant in February 2023, bringing to an end young Finn's lifetime of sickness and the final two years of nightly dialysis treatment.

Also happy to take part in the photocall was Andy Kavanagh, a post clerk at the GPO, from Coolock, Dublin, who received the 'gift of life' twice – first a heart transplant 38 years ago and then 26 years later a kidney transplant.

Andy works at the parcel counter at the iconic and historic GPO on O'Connell Street, Dublin. Andy holds the record for the longest surviving successful heart transplant in Ireland which he received in 1986, following

a shock diagnosis that he had cardiomyopathy soon after suddenly becoming very ill. A heart donor saved him and allowed him to live a normal life.

In 2008, he encountered another health challenge, requiring dialysis treatment for kidney failure. Enduring sessions three times weekly, each lasting four hours, he grappled with sickness and chronic fatigue.

This continued for four years until he underwent a successful kidney transplant in 2012. He hasn't looked back since and is living a full and healthy life full of gratitude to his two donors. Andy is a major advocate for organ donation, and he played a big part in the 2019 Organ Donor Awareness Week campaign when AN POST issued a special Stamp and Andy featured in a promotional video sharing his successful transplant story which was filmed at the GPO while carrying out his daily work.

*Continued next page...*



Andy Kavanagh in 2019 promoting the special Stamp issued by An Post.



At the GPO kidney transplant recipient Finn and Andy Kavanagh, heart and kidney transplant recipient.

Also happy to support the photocall was Joan Flynn, CNS2, CHI Temple Street who oversaw Finn's care down through the years and expressed how delighted she was to see Finn's progress and to be able to be involved in the photocall along with Finn and his parents. Finn's mother Lisa said, "Finn's recovery post-transplant has been remarkable, and he can now enjoy a normal childhood. It's impossible to express our immense gratitude to the family of his deceased donor for their profound gift to ours."

"AN POST has shown great compassion in supporting us on Finn's health journey and allowing Eoin, who works as a postman in Clonmel, to take time off to care for Finn. A shout out to our local postmaster Dick Nugent. It's wonderful to see AN POST on such a nationwide level also supporting the organ donor awareness campaign which offers hopes to families like ours".

Representing AN POST at the photocall event was Conor Nott, Retail Marketing Manager, An Post who said, "Organ donation and transplantation impact communities countrywide. Many of us have a family member who has benefited from an organ transplant or know someone whose life has been touched by the selfless act of organ donation. By joining forces with the IKA, we aim to foster a culture of giving within our communities and highlight the profound impact individuals can make through this noble act."

"With our presence in the heart of communities nationwide, AN POST is uniquely positioned to spread the message of organ donor awareness. By using our network and engaging with customers, the initiative aims to spark conversations, dispel myths, and ultimately inspire more people to share their organ donation decision with their families."

In welcoming AN POST's support Carol Moore, CEO, IKA stated, "We're delighted to collaborate with AN POST on this campaign. It's dedication to community service aligns perfectly with our mission to advocate for patients and their families and save and enhance lives through organ donation. Together, we can make a crucial difference for this vital cause".

# Save THE Date

Saturday, June 29th

## Join the IKA for our 1st National Summer's Day of Health, Fun, and Community! University College Cork

Get ready for a day packed with informative talks, exciting activities, and chat with fellow patients and families! Here's what you can look forward to:

- ❖ **Expert Speakers:** Learn about a wide range of health topics from kidney care to getting the most out of your healthcare appointments.
- ❖ **Socialise & Support:** Chat with others facing similar challenges, share experiences, and build supportive relationships.
- ❖ **Fun Activities for Kids:** Keep the little ones entertained with face painting, a magician, and other fun activities!
- ❖ **Meet the Team:** Get to know our dedicated staff and volunteers from the Irish Kidney Association and learn more about the work we do from peer support, patient aid to exercise and sports.
- ❖ **Complimentary Refreshments available**
- ❖ **Campus Accommodation Available\*:** Make it a hassle-free experience by staying on the college campus where the event will be held.
- ❖ **Contribute and Sponsor:** If you have information or resources to enhance the event, or if you're interested in sponsoring prizes, food, beverages, or hand-outs, we'd love to hear from you!
- ❖ **Something to offer?** If you think you can help make the event even more special, email your suggestions to [volunteer@ika.ie](mailto:volunteer@ika.ie)



Stay tuned for more details on our social media channels. Don't miss this opportunity to gather knowledge, have fun, and strengthen our community!

*\*Fee payable to UCC and subject to availability.*



# Plan your holiday on dialysis

**Y**ou can travel abroad if you are living with chronic kidney disease. Most people need a break from time to time, and kidney patients are no exception! Holidays are a great way to reinforce the fact that you can still enjoy the good things in life, as a kidney patient, but you'll need to plan ahead to make sure you have a relaxing break stress free.

Please **DO NOT book a holiday or flights** before making arrangements for your dialysis treatment abroad. I'm seeing more and more patients, over the last 6 months, booking hotels and flights before securing holiday dialysis. This can add a lot of stress for the patient if dialysis isn't available for your chosen dates in a particular area.

We will do a thorough search of all hospitals in the area you are travelling to, but since the COVID-19 pandemic some hospitals have less capacity. We will do our best for an alternative option if your chosen location is not available. To avoid this stress please get in touch to arrange your dialysis treatment **before** you book your holiday.



**By DEBORAH CERVI**  
Holiday Co-ordinator



It is essential that you either contact a member of staff in your dialysis unit or you can submit an enquiry using **our online form** at <https://ika.ie/patient-holidays/> or contact Deborah in the IKA on 01-6205306 email: [deborah@ika.ie](mailto:deborah@ika.ie)

Patients need to give a **minimum of 8 weeks' notice** for holiday treatments abroad, as a lot of planning is required, so last minute bookings are not a realistic option.

## **DIALYSIS IN LOURDES - USING THE EUROPEAN HEALTH INSURANCE CARD (EHIC) IN FRANCE**

For any patients planning to travel to Lourdes, by themselves or with a pilgrimage, as of 2023 in some areas of France the EHIC may not fully cover the cost of dialysis for these patients. Lourdes is one of these areas. The EHIC will only cover 80% of your dialysis sessions so the patient must pay 20% which works out at €54.26 per dialysis session. This payment must be paid prior to the patients holiday departure date.

If you are an Irish citizen, Irish pensioner or an EU citizen living in Ireland you can apply for an EHIC:

- in person at your local health office
- online – [www.ehic.ie](http://www.ehic.ie)

It's free and there is no charge to apply. The card takes about 10 working days to process and will

be posted to your home address.

## **HOLIDAY HOMES**

Spring has arrived and the good news is the holiday season is upon us once again.

We will operate our three holiday locations this year on a 6-night basis (Saturday to Friday) to comply with COVID guidelines in our holiday homes. We remain committed to ensuring a safe environment for guests.

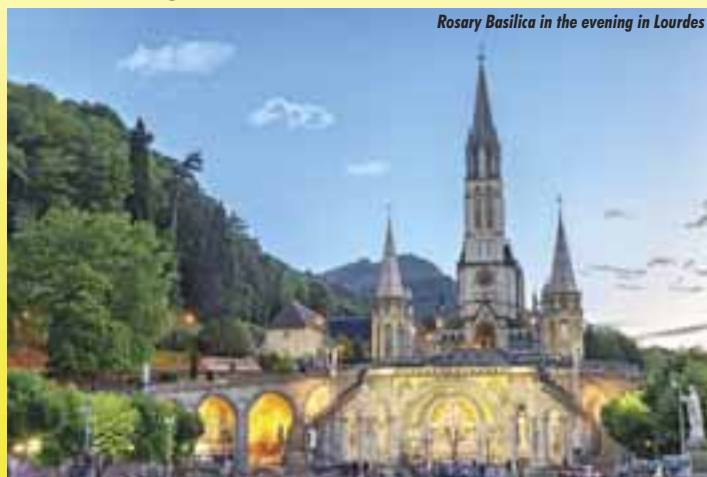
Priority will be given to first-time holiday applicants and to families with schoolgoing children during Summer school holidays.

The holiday application forms are available on our website at [www.ika.ie](http://www.ika.ie) under 'Our Services', then click on patient holiday <https://ika.ie/patient-holidays/>

Your local Branch Secretary, Haemodialysis units, PD Units and social worker also have forms, alternatively you can contact me by email at [deborah@ika.ie](mailto:deborah@ika.ie)

Take Care.

*Deborah Cervi*



# Peddalling for purpose



By GWEN O'DONOGHUE

## Four decades of the RING OF KERRY CYCLE

For over four decades, the **Ring of Kerry Cycle** has been a beacon of hope, raising funds and awareness for various causes, including the Irish Kidney Association.

The iconic annual cycling event, which attracts thousands of cyclists, takes place along one of the world's most renowned touring routes.

The Ring of Kerry Cycle takes in a 170km scenic circular route, starting and ending in the picturesque town of Killarney, taking in the beautiful scenery along the Wild Atlantic Way.

From humble beginnings, the **Ring of Kerry Cycle**, with the Irish Kidney Association (IKA) at its core from the outset, has blossomed into a monumental event. Along its journey it has raised over €19 million euro for 160 charity and voluntary community organisations.

As the IKA gears up to be one of the chosen charities to benefit from the 42nd year of this celebrated event, on 6th July, we can take a moment to reflect on its remarkable journey and the impact it has had on countless lives, including kidney patients and their families.



**SATURDAY 6TH JULY 2024**



# HOW IT ALL BEGAN

It all began in the early eighties when a small group of individuals, deeply moved by the plight of kidney patients in Kerry, decided to take action. In the absence of a dialysis centre in Kerry, patients in the county faced arduous long journeys to Cork for life-saving dialysis treatment. Wanting to offer support to these patients, a group of their family members and friends were motivated to come together to form the Kerry Branch of the IKA in 1982. Their primary focus was to establish a satellite dialysis unit in Tralee, Co Kerry, to alleviate the burden of long-distance travel for treatment.

Two individuals, in particular, stood out during those early meetings – **Denis Geaney** and **Theresa Looney**.

Denis and Theresa hatched a plan to have a group of Denis's friends cycle the Ring of Kerry to raise funds for the IKA. And so, the Ring of Kerry Cycle was born.

With sponsorship cards in hand, and the support of local

businesses and volunteers, and Theresa at the forefront, Denis and his cycling companions set off on their inaugural ride. What started as a local initiative soon gained momentum, with the community rallying behind the cause. Year after year, the event grew in scale and significance, attracting participants from across the country.

For the Kerry IKA Branch, despite facing challenges along the way, including a decade-long wait for support from the Southern Health Board, they remained resolute and finally achieved their goal and target amount required for a long-awaited dialysis centre to be established in Tralee.



Theresa Looney

The annual Ring of Kerry Cycle event continued to flourish, raising funds not only for kidney patients but also for various other charitable causes. Through the dedication of volunteers and the unwavering support of participants, the event became a symbol of hope as well as a major tourism draw for Kerry, and enticing

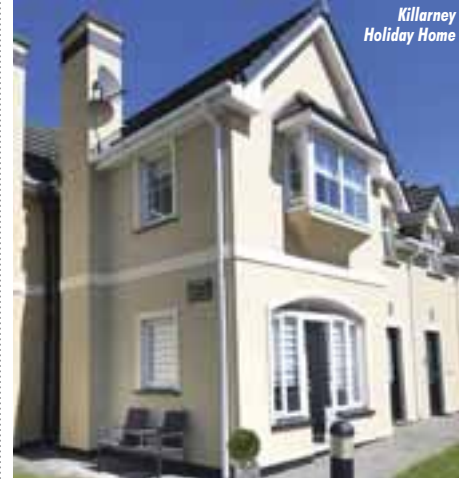
sportive for avid cyclists to enjoy.

Not resting on its laurels, the Kerry IKA Branch then set a new goal with the proceeds raised from the Cycles in later years to provide a holiday home in Tralee and then later in Killarney for kidney patients and their families.

The holiday homes continue to operate all year round and are managed by dedicated volunteers in Kerry who always offer patrons a warm welcome.



Denis Geaney. Photo: Kerry's Eye



Killarney Holiday Home

The impact of the Ring of Kerry Cycle for the IKA extends far beyond benefitting the people of Kerry providing free holiday accommodation for kidney patients nationwide and their families, and offering much needed respite, support and holiday dialysis for those who need it.

*continued next page*



Extract from 'The Kingdom' Newspaper, October 16th, 1984.



Some of the cyclists who participated in the 2016 Ring of Kerry Cycle. Photo: Valerie O'Sullivan



The Kerry Branch of the Irish Kidney Association are putting on their annual sponsored cycle of the Ring of Kerry on Saturday, July 27. Association secretary, Mary Theresa O'Donoghue, and chairman, James O'Donoghue, are pictured here presenting singles for those participating in Denis Geaney and Egan Neeson. The organisers also plan to collect in the towns of Kilmalee, Cahersiveen, Waterville, Tralee and Killarney as they travel the 132-mile route.



Theresa Looney (front centre) with a cheque to the IKA, proceeds from the 2011 Ring of Kerry Cycle.

# JOIN US ON OUR JOURNEY

Whether you're an avid cyclist or simply looking to make a difference, we invite you to support the Ring of Kerry Cycle. It offers opportunities for everyone to get involved, from participating in the physical event, to taking part virtually from the comfort of your own home.

Gather your friends, family, or colleagues and register today to be part of something truly special. Together, we can pedal towards a brighter future for kidney patients and their families.



IKA Munster Kidney Support Centre

## RING OF KERRY CYCLE - SATURDAY 6TH JULY 2024



### CAN'T MAKE THE EVENT?

### TAKE YOUR OWN VIRTUAL JOURNEY

- Get your spinning class, gym, school, local sports club, or office, involved and challenge yourselves to cycle 170km collectively. You can do it as part of a relay team or the full distance over several days or

weeks. Posters and leaflets are available as support materials, in print or digital format, to help spread awareness.

- Join our Virtual Stadium of support which is live on our website.

### LOTS OF REASONS TO CYCLE FOR THE IKA

- **Registration Discounts for Teams:** Sign up as a team of 5, or more, and receive exclusive discounts.
- **Prizes for Top Fundraisers:** Receive recognition for your fundraising efforts and stand a chance to win exciting prizes.
- **Dietary Advice:** Receive expert guidance from qualified dieticians to support your training and nutrition needs.
- **Join our fitness workshop** for advice on how to build up your fitness levels and develop a training schedule.
- **Join our cycling experts** for workshops on bicycle repairs and maintenance, and planning for the day of the event.

## TO REGISTER GO TO [ika.ie/ringofkerry](https://ika.ie/ringofkerry)

Your entry fee for the Cycle will go towards a fund which is split between all the nominated charities.

Our fundraising team will be happy to guide you on registering to take part in the event or linking in to the online platform **iDonate** to fundraise for the Irish Kidney Association (IKA).

You can phone **Lisa** or **Sinead** on **01-6205306** (available weekdays excl. Thurs) or email [fundraising@ika.ie](mailto:fundraising@ika.ie).

If you register via the link on the IKA Ring of Kerry page you will be asked if you would like to fundraise for a Tier Two charity of which there are six charities. Once you select 'Yes', you can choose to fundraise for the IKA.

Once you've signed up, you will be sent a link to set up an iDonate fundraising page, which you can share with your friends and family to get them to sponsor you! All the money you raise via your iDonate page will go to the IKA.

*Join us on the journey. Let's come together as a community to pedal towards a brighter tomorrow for kidney patients and their loved ones.*

 [ika.ie/ringofkerry](https://ika.ie/ringofkerry)

 [fundraising@ika.ie](mailto:fundraising@ika.ie)



## REGISTER FOR THE EVENT

Become our  
**TOP FUNDRAISER** to

**WIN**  
A hotel stay!

On the June 1st, 2024, the top fundraiser on **iDonate**, registered to cycle the event for the Irish Kidney Association, will **WIN a 2-night stay**, in a Killarney Hotel, for the days of the event.

To qualify to be entered into this Draw, you must have raised a minimum of €600 on your fundraising page.



## Join the excitement with a **Charity Raffle!**

Get ready to win incredible prizes in our charity Raffle. Organised by two volunteers from the IKA Kerry Branch, this Raffle is your chance to support the IKA while being in with a chance to win some amazing prizes, as can be seen in the ticket image above. Take a sneak peek at one of the prizes – an Original Painting, valued at €5,000, by celebrated Kerry artist Michael Flaherty. Tickets are only **€10 each!**



To buy tickets, simply contact the raffle organisers, **Theresa Looney** at ☎ **087-2059205** or **Irene Hurley** at ☎ **087-9478833** or ✉ **kerrybranchika@gmail.com**

Winners will be randomly selected on **Saturday, 6th July.**

Ticket sales, to over 18s only. Full terms and conditions are printed on the reverse side of the raffle ticket.



Support the Irish Kidney Association

## The Ring of Kerry Charity Cycle

Saturday July 6th 2024



### Why Choose the Irish Kidney Association?

- Registration Discounts for teams of 5 or more.
- Prizes for top fundraisers.
- Dietary advice from qualified Dietician.
- Expert workshops on exercise routines, repairs and supported cycles.

### Can't make the 6th of July? Take your own virtual journey!

- Get your spinning class involved.
- Get your gym on board.
- Share the course – Challenge your school or office to cycle 170km between you.
- Join our virtual stadium on our website.

For more information contact Sinead or Lisa  
E: Fundraising@ika.ie T: (+353) 01 620 5306

**Register  
Online**

[ika.ie/ringofkerry](http://ika.ie/ringofkerry)

**170KM**

circular route starting  
and ending in the  
beautiful town  
of Killarney

# MEET SOME OF OUR INSPIRATIONAL CYCLISTS GEARING UP FOR THE CYCLE ON **SATURDAY 6TH JULY 2024.**

## WOULD YOU LIKE TO BE A PART OF **TEAM IKA**

### Bryan Duignan



Bryan Duignan, aged 43, a triathlete living in Carlow with his family, received a kidney transplant in 2006. The Tipperary native said, "I was young when I received my transplant. It wasn't until later, when I got involved in Triathlons and then represented Transplant Team Ireland at the World Transplant Games in Perth last year, that I truly appreciated the depth of my health journey. "Reflecting on the Games experience, Bryan describes it as *"truly positive and unforgettable."*

Now the PRO in his local Carlow Triathlon Club, Bryan remarked, "I did my first triathlon in 2021 and haven't looked back; I was hooked! I love cycling, and I'm excited to participate in the iconic Ring of Kerry Cycle for the first time. Some of my club teammates will also be joining me, supporting my training, and helping with fundraising efforts for the Irish Kidney Association."

### Anna Pokojka



**Anna Pokojka**, a kidney transplant recipient and avid cyclist, will be very familiar with the route of the Ring of Kerry Cycle, not only because she took part in it once before in

2019, but also because it begins and ends in her hometown, Killarney.

Following her kidney transplant in 2017, Anna took up cycling to keep fit, and two years later she won a silver and bronze medal at the World Transplant Games 2019 in cycling events, while proudly representing Ireland as part of the successful Transplant Team Ireland team.

Anna moved from her native Poland



*Anna with cycling teammates Anthony Byrne and John Moran, before the World Transplant Games 2019.*

to Kerry in 2006 where she lives with her 19-year-old daughter Daria. Anna continues to prove that life post-transplant can be filled with fitness, energy and vitality. "Cycling is something I really enjoy doing," says Anna. "I am now looking forward to

challenging myself again by taking part in the Ring of Kerry Cycle in July and hope I can inspire others to select the IKA as the charity to benefit, as it does incredible work in providing support to kidney patients like me and their families."



## Martin Malinowski



In 2021, **Martin Malinowski** (32), originally from Poland but living in Monaghan for fifteen years, became the first person in Ireland to receive a combined heart and liver transplant at the Mater Hospital in Dublin.

"I started cycling after I got sick but before my transplant. Initially, the main goal of cycling was to improve my health and reduce the chances of surgery complications on the premise that better health equals better outcome. I believe that cycling played a big role in the success of my transplant and essentially became my main sport and hobby for hopefully many more years.

"I'm looking forward to taking part in the Ring of Kerry Cycle for the first time, and the months of training ahead, and I hope that with the support of others we can raise funds for the Irish Kidney Association which does great work in supporting patients, but also in promoting the critical need for organ donation which has saved people like me.

## WHY NOT SUPPORT THOSE PATIENTS WHO ARE NOT ABLE TO CYCLE THE EVENT



*Inspired by Francis Hogan's resilience, on his journey towards dialysis, some of his friends, and also members of two local cycling clubs...Upperchurch Drumbane CC (UDCC) and An Túr CC, have chosen to cycle for the Irish Kidney Association in the Ring of Kerry Cycle this summer.*

**F** Francis Hogan, (47), a father of five from Templemore, who, despite having just 25% kidney function at the time, completed a gruelling 24-hour, 600km long, cycling challenge from Mizen to Malin with six friends from his local cycling club UDCC in September 2022, and raised over €20,000 for the Irish Kidney Association.

Francis was diagnosed with a hereditary kidney condition in his early twenties, but his kidney function only started to deteriorate when he reached his forties. He is now in end-stage kidney failure and will be unable to participate in this year's cycling challenge as he prepares to start dialysis.

Francis, like Martin Malinowski, professes the mantra of staying active leads to better outcomes. He encourages those diagnosed with Chronic Kidney Disease not to let it define their lives, saying, "The journey doesn't mean you have to put your life on hold. Stay active for your overall physical and mental well-being."

# Living Kidney Donation

By COLIN WHITE, NATIONAL ADVOCACY & PROJECTS MANAGER



**Dr. Carol Traynor, Consultant Nephrologist and Transplant Physician, Beaumont Hospital.**

## THE PERSPECTIVE OF THE POTENTIAL KIDNEY DONOR

**If you have a family member or friend who needs a kidney transplant you may have heard of living kidney donation and you may be thinking about stepping forward to be tested to see if you are a suitable match, but would like some more information before you do so.**

**I recently had the pleasure of talking with DR. CAROL TRAYNOR (Consultant Nephrologist and Transplant Physician at Beaumont Hospital) about living kidney donation and below are some insights that she shared.**

## TO BE CONSIDERED A POTENTIAL KIDNEY DONOR

**P**otential living donors should ideally be older than 25 years of age and there is no strict upper age limit – transplant outcomes are generally better when the donor is a similar age to the recipient.

It should be noted that there are some medical conditions that preclude kidney donation such as diabetes. The Transplant Coordinators in Beaumont hospital are there to help and can run through a list of questions to check if there is any medical history that may rule you out.

The Beaumont website is also a good source of information.

[www.beaumont.ie/kidneycentre-becomingadonor](http://www.beaumont.ie/kidneycentre-becomingadonor)



All testing for potential living kidney donors is carried out in Beaumont hospital and most of it can be completed in one day. Several family members/friends may step forward for the initial blood tests to see if they are a suitable match. It is important to let your family member/friend know that you are putting yourself forward for testing.

Several factors, including age, and how well matched the kidney is, are considered before recommending who should come forward for the day assessment.

Normally, it takes approximately 3 weeks for the blood test results to come back to see if you are an immunological match. If you are, then you come for a day assessment where more blood tests and scans are done to ensure that it is safe for you to be a donor.

It is important to note that as a potential donor, you will be under the care of a different medical team than the one looking after your family member/friend and your visits to Beaumont will be separate. Your health will be the primary concern of your medical team.

There is a lot to consider when thinking about being a potential living kidney donor.

You may be planning to donate to a sibling, a parent or friend, but you have a family of your own to also





consider. You can reassure them that the evaluation process is very thorough to identify any issues that might make donation too risky for you. They will also have the opportunity to meet with the transplant team and ask any questions that they have.

There is a living donor reimbursement policy in place to address the issue of the costs incurred by donors participating in the Living Donor Programme in Ireland during the pre-operative and post-operative period.

The implementation of this policy is intended to minimise financial disincentives for potential living donors, with a view to ensuring the pool of living organ donors continues to expand.

More can be found out here: [www.hse.ie/eng/about/who/acute-hospitals-division/organ-donation-transplant-ireland/living-donor-programme/](http://www.hse.ie/eng/about/who/acute-hospitals-division/organ-donation-transplant-ireland/living-donor-programme/)

One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will hamper them in later life.

A healthy person can live a completely normal life with only one kidney; indeed, some people are born with only one kidney. If a kidney is removed, the remaining kidney increases slightly in size and capacity, and can carry on the function of two kidneys.

Studies have concluded that the risk of experiencing serious problems (such as kidney disease later in life) from donating a kidney is very low. There is sometimes a slight rise in blood pressure or increased loss of protein in the urine for the donor, but this does not usually impact on the donor's health in the long-term.

All living donors are offered lifelong follow-up including checks of blood pressure, a urine test and a blood test for kidney function.

A donor's stay in hospital is up to 5 days. He or she can expect to be out of bed the day after the operation and home in less than two weeks. The stitches are removed approximately 10 days post-surgery. The wound may remain sensitive for several weeks.

Typically, the donor will have to take 4-12 weeks off from work to

recuperate, depending on the individual and his or her occupation.

You can change your mind at any point in the process and no further tests are carried out. The hospital do not share any information about your testing with anybody. They will notify your GP if there are any medical issues that need to be followed up on.

Maintaining a healthy lifestyle after donation is important.

In 2022, twenty-two living kidney donors successfully reached the summit of Kilimanjaro in Tanzania to demonstrate that donating a kidney does not negatively affect the health or fitness of living kidney donors.



Living kidney donors climb Kilimanjaro

**THE PERSPECTIVE OF THE PERSON NEEDING A KIDNEY TRANSPLANT**  
**You may be wondering how to start the conversation about living kidney donation amongst your family/friends or you may have concerns about a loved one putting themselves forward to donate a kidney to you.**

If you are wondering about how to start the conversation, you can tell family/friends that your doctor has advised that you need a kidney transplant and that a living donor transplant is the best option in terms of minimising the waiting time, and living donor kidneys, on average, last longer than transplants from deceased donors.

You should both know that all potential donors undergo rigorous medical testing and psychological

evaluation and people will only go forward to donation if they are deemed to be in excellent health. If you, or they, want more information, you can contact the Irish Kidney Association and check out the Beaumont Kidney Centre website [www.beaumont.ie/kidneycentre](http://www.beaumont.ie/kidneycentre) and you can also ring the transplant coordinators in Beaumont hospital.

If your donor is not a match because of blood group or antibody reasons, then you can both enter the paired kidney exchange programme. This means your donor gives his/her kidney to a compatible recipient and another donor gives a kidney to you.

The donor and recipient details

are loaded into the UK Paired Kidney Exchange computer system to identify any potential matches. Unfortunately, not everyone is guaranteed a match this way and it can take a long time to find a match. If a match is found,

both donor operations usually happen at the same time.

If your first kidney transplant was from a deceased kidney donor, the advantages of having a living kidney donor include: getting a transplant sooner, spending less time on dialysis, and perhaps even avoiding dialysis altogether.

If you had a previous transplant, you may have antibodies that make finding a good match more difficult. Having a living donor who is related to you, increases the chance of finding a suitable match.

There is a series of books covering many aspects of the kidney disease journey. You can find them all here: [www.ika.ie/patient-guides](http://www.ika.ie/patient-guides) or order printed versions from Donor House.

Book 4 is specifically about living kidney donation. Often, speaking with someone who has donated their kidney can help shine a light on the experience.

# Spring Delights

## Tasty Recipes for the Season

Indulge in the flavours of spring with our tender **ROAST LAMB** recipe, designed with renal health in mind. And for a delicious dessert, savour the vibrant burst of berries in our kidney-friendly **MIXED BERRY PIE!**



### Roast Lamb

**Prep:** 30 minutes • **Cook:** 1 hour 30 minutes • **Serves:** 4

#### INGREDIENTS

1.5kg boneless leg of lamb (95g of cooked lamb per person)  
 Small bunch of rosemary, in small sprigs, divided into 2 halves  
 1 clove garlic, peeled and sliced  
 1 onion, sliced  
 4 medium potatoes (approx. 500g), peeled and cut into four  
 2 tablespoons olive oil  
 250g swede, peeled and chopped into chunks  
 40g unsalted butter  
 250g spring greens, shredded or 250g carrots peeled and chopped  
 Cracked black pepper

#### TO SERVE

15g plain flour  
 25ml low-salt lamb stock  
 Mint sauce

- Pre-heat the oven to 200°C/180°C fan/ gas mark 6. Make incisions into the lamb at an angle to a depth of about 5cm. Stuff one half of the rosemary sprigs and all the slices of garlic into the incisions. Put onion slices into the bottom of the roasting tin and sit the lamb on top. Season with black pepper and rub over a little of the olive oil. Place in the oven for 20 minutes, then lower the oven to 180°C/ 160°C fan/ gas mark 4, and cook for another 20 minutes per 500g (for a 1.5kg joint – 1 hour), depending on how you like your meat cooked.
- Put the potatoes into a pan of cold water and bring it to the boil. Cook until soft, then drain in a colander. Shake the potatoes to rough the edges up a little. Cover with a tea towel to trap any remaining steam.
- Heat another roasting tin with olive oil in the oven for 5 minutes, then remove and add the par-boiled potatoes, turning them to coat in oil. Add the remaining rosemary and return to the oven for 45 minutes.
- Add the swede to a saucepan of cold water and boil until soft, then drain and return the swede to the pan. Add the unsalted butter and black pepper to taste and mash, then keep warm until serving. 10 minutes before serving, add the shredded spring greens or chopped carrots to a saucepan of water and boil until cooked. Once cooked through, drain and discard the water.
- Remove the lamb from the oven, take out of the roasting tray and drain any juices back into the tray. Set the lamb to one side and allow to rest for 15 minutes. Put the roasting tray over a low heat on the hob and stir in the flour. Cook until the juices have absorbed. Add the stock slowly, stirring until it thickens to make the gravy. Strain.
- Serve your lamb, potatoes and vegetables on warm plates, pour the gravy over the top and serve with the mint sauce.

#### NUTRITION

✓	Low phosphate	✓	High protein
✓	Low potassium	✓	Low salt
30g	Carbohydrate	506Kcal	Energy
X	Low fat (less than 3g/100g)		

- Nutrition values are calculated per serving
- Kidney diet guidelines vary for each individual
- Consult your dietitian or doctor for the specific diet that is right for you



# Mixed Berry Tarts

Prep: 10 minutes • Cook: 12 minutes • Serves: 4



NUTRITION	
✓	Low phosphate
✓	Low potassium
✓	Low protein
✓	Low salt
23g	Carbohydrate
170Kcal	Energy

- Nutrition values are calculated per serving
- Kidney diet guidelines vary for each individual
- Consult your dietitian or doctor for the specific diet that is right for you

**Vegetarian Friendly**

A simple summer dessert with low potassium berries.

## INGREDIENTS

110g puff pastry

20g icing sugar

110g low fat fromage frais

350g fresh mixed berries – we've used 150g blueberries, 100g strawberries (halved or quartered depending on size), 50g cherries (de-stoned and cut in half) and 50g blackberries. Using frozen berries may be cheaper. Defrost and drain any juice before using.



Preheat the oven to 200°C/gas mark 6. Line a baking tray with greaseproof paper. Divide the puff pastry into four equal five inch by five inch squares and place them onto the baking tray.



With a sharp knife, score about five millimetres inside the edge of each pastry square. Place the tray of pastry squares into oven and cook for 12 minutes, until they are slightly risen and golden. Remove from the oven and allow them to cool.



In a large bowl, beat the icing sugar into the fromage frais with a spoon.



Push down on the centre of the pastry cases to make room for the filling. Divide the icing sugar and fromage frais mixture between the tarts, top with the berries and dust the tarts with icing sugar to serve.



# The importance of Data

By  
COLIN WHITE

*Before we look at these statistics related to organ donation and transplantation, it's essential to approach these numbers with empathy, remembering that each number represents a person with a unique story, as well as the loved ones who stand beside them.*

The 'Gift of Life' has a profound impact on the lives of recipients and their families. It can also be seen as a legacy to your own family – they will mourn your passing but can take solace in the fact that your Gift means that others can live on.

Pearson's Law states...

*"When performance is measured, performance improves. When performance is measured and reported back, the rate of improvement accelerates."*

Simply restated, Pearson's Law says that tracking results matters, and that reporting results to someone else makes a bigger difference. This is very relevant in the field of organ donation and transplantation.

For example, the aim of a **potential donor audit** is to ensure that every person who is approaching the end of life in an Intensive Care Unit (ICU) or Emergency Department (ED) is offered the possibility of becoming an organ donor, where this is appropriate.

The Pilot Potential Donor Audit report published by the National Office of Clinical Audit in September last year looked at six hospitals and provided information which acknowledges the work of ICU personnel and specialist organ donation personnel (ODP) in participating hospitals. It also identified some potential missed opportunities for organ donation by looking at medical eligibility.

Arising out of the pilot, there has been a commitment from Government

to deliver a national annual Potential Donor Audit. This is a huge step forward as the data gathered every year will inform practice in the hospital setting and help identify areas of need in relation to public organ donor awareness.

Looking outside of Ireland, it is noteworthy that in the United States of America, there were more than 16,000 deceased organ donors in 2023, a new annual record and a continuation of a 13-year annual-record trend.

Spain carried out more organ transplants than ever before in 2023, conducting a total of 5,851 such procedures, a 9% jump from 2022.

Looking at figures for Ireland, Table 1 below shows the number of donors and the number of transplants over the last six calendar years.

With 252 deceased organ transplants carried out in 2023 in Ireland, the progress from 'the COVID-19 years' is evident, but it needs to be borne in mind that the 7-year average number of deceased organ transplants (2009-2015) was 251, so, we are now just back to pre-COVID-19 levels.

When we look at the number of living kidney donor transplants we are not reaching the 50+ that has been a goal for over a decade now (see NODTO Business plan 2013). We share some insights into living kidney donation from the perspectives of people thinking about stepping forward for a family member or

TABLE 1		2018	2019	2020	2021	2022	2023
Deceased Donors		81	85	63	65	86	95
Transplantation from Deceased Donors	Kidney	127	128	95	104	130	161
	Liver	56	66	37	35	51	54
	Lung(s)	28	38	16	20	18	24
	Heart	18	15	9	10	10	7
	Pancreas	5	2	5	8	8	6
TOTAL		234	249	162	217	217	252
Living kidney transplants		40	25	28	35	33	30





friend, and from the perspective of people awaiting a transplant (see page 38-39).

Another reliable source of statistics is the annual report (**Newsletter Transplant**) produced under the auspices of the **European Directorate for the Quality of Medicine and Health Care** and it covers organ donation and transplantation activity in countries around the world.

The most recent Newsletter Transplant covers 2022. This document gives us the opportunity to put activity in Ireland in the context of what is happening in other countries.

From the Newsletter, it can be seen that there were 27,952 organ transplants carried out in the European Union in 2022. This works out at 62.8 transplants per million population. Ireland carried out 250 organ transplants in 2022 and this works out as approximately 50 per million population.

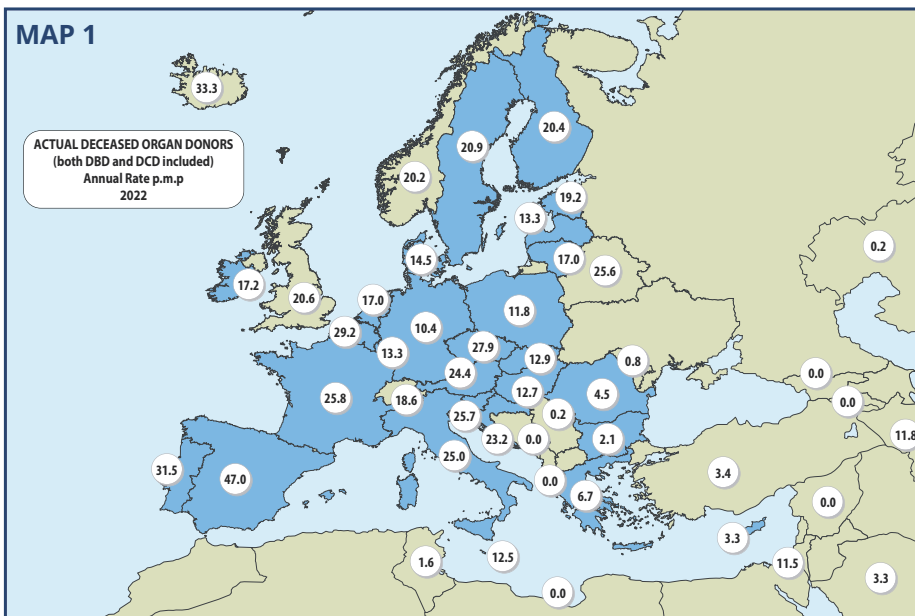
**MAP 1** shows the number of deceased organ donors per million population. You can see a significant variation across the map. Spain clearly stands out as the leader. In our previous review of last year's Newsletter Transplant, we pointed out that Spain's willingness to consider older organ donors is a significant reason for the level of their activity.

**MAP 2** shows the total rates of kidney transplantation per million population across Europe for 2022. We must be careful in not drawing over-simplistic conclusions from the figures.

If we go back to the first map, showing deceased organ donors per million population (pmp), we can see that Ireland (17.2) and the Netherlands (17) have achieved comparable rates, yet in Map 2 we see that the Netherlands recorded 58.6 kidney transplants pmp compared to Ireland's 32.6 kidney transplants pmp.

The fact that Ireland had a rate of 6.6 living kidney donor transplants pmp whilst the Netherlands had 30.0 living kidney donor transplants pmp explains much of the difference. See **MAP 3**.

The point is that in striving to improve rates of transplantation,



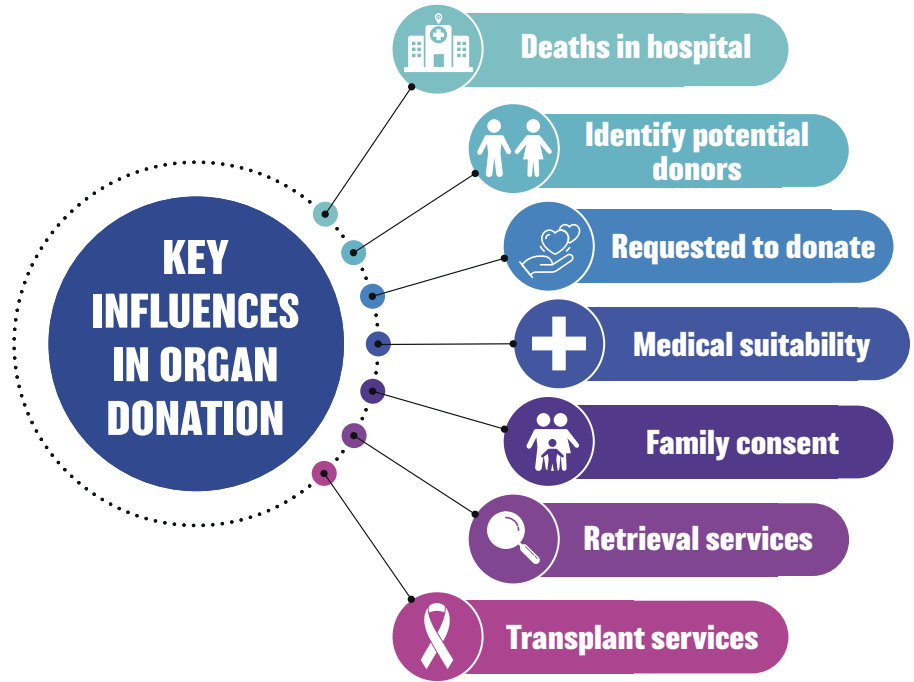
# ORGAN DONATION AND TRANSPLANTATION CONTINUED

2015, 36 lung transplants were carried out. On the face of it, one would think that there must have been a significant increase in the number of organ donors whereas the reality is that there were 90 deceased organ donors in 2009 and 81 in 2015.

The graphic opposite, is useful here. We can see that we must take many factors into account when measuring activity and learning from results.

Every organ donation and every organ transplant are something to behold. It is a reflection of active citizenship, a mark of the expertise of our healthcare professionals and an indication of what can be achieved when the necessary resources are in place. Looking at our own numbers and looking at activity in other countries allows us to benchmark and to learn.

The fact that we now have a **Human Tissue Act 2024** (we are awaiting on the commencement of the relevant sections that will impact

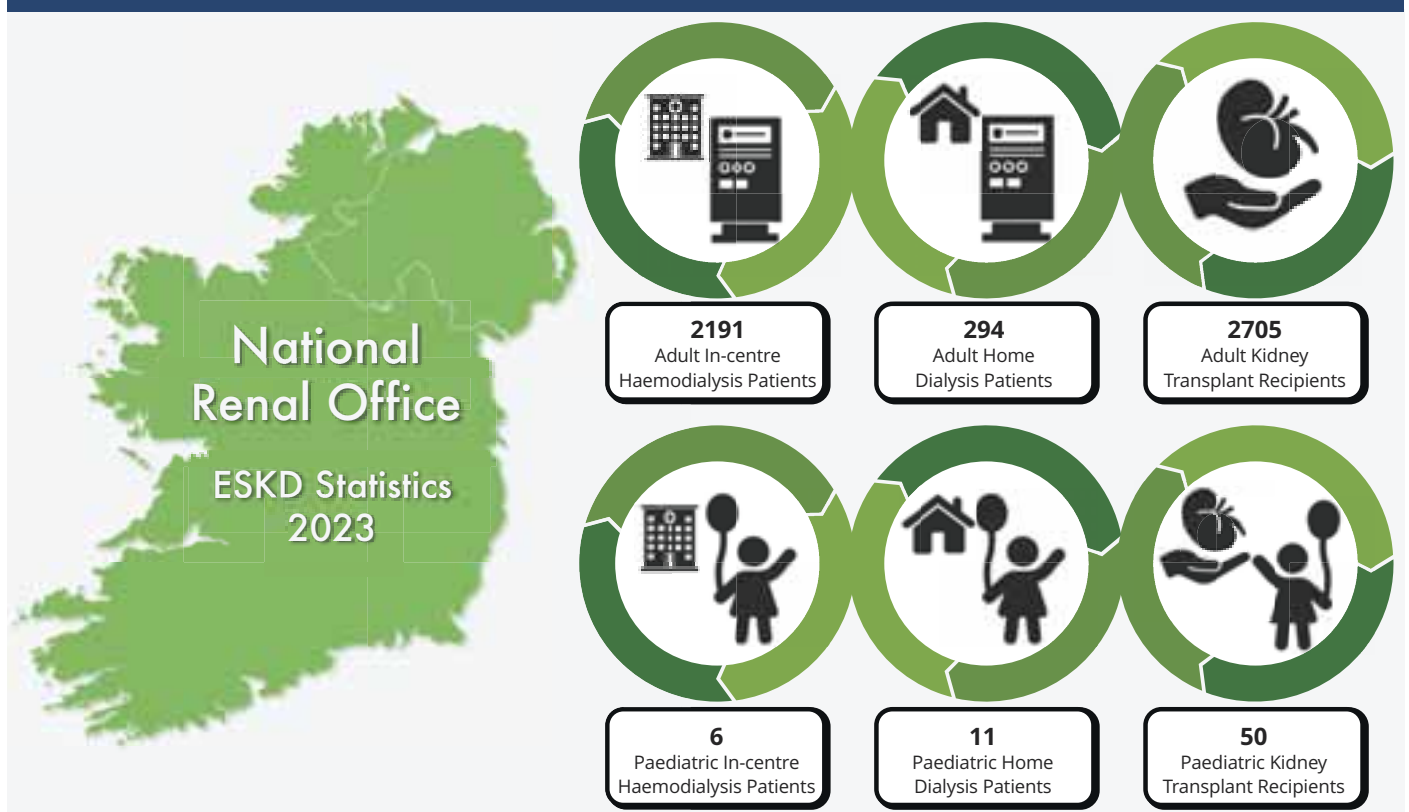


organ donation and transplantation) is a step forward. The legislative process has been an opportunity for key decision makers to reflect on what we have and what we need. We must now push forward to ensure that the required

infrastructure is put in place to ensure that aspirations can become reality.

The numbers will measure our progress, but it is the transformation of people's lives that will truly reflect the impact.

## DIALYSIS AND KIDNEY TRANSPLANT STATISTICS 2023



There are more than 5,000 people diagnosed with end-stage kidney disease (ESKD) which is also referred to as Stage 5 kidney disease), who are being treated with dialysis or transplant, with nearly 2,500 patients currently undergoing dialysis treatment. The HSE National Renal Office 2023 figures can be seen in the illustration above, which is courtesy of Dr. Sinead Stoneman.



# REMEMBERING RUTH GORMAN

**W**e were deeply saddened when we learned that Ruth Gorman (nee Bradley), a friend, and staff member at Donor House, passed away on February 26th, 2024.

Ruth, a kidney transplant recipient, was recently predeceased by her parents Betty and Jim three months apart in late 2023.

From Dublin, Ruth would be known to many of our members as the voice at the end of the phone, as our long-time receptionist. She joined the team in 2005 as part of a back-to-work scheme for kidney patients, and was loved by her colleagues at Donor House for her wicked sense of humour and ability to intelligently beat any of them in a debate.

Ruth was known for her remarkable memory and IT skills. She was also an avid reader. Her warm and empathetic nature made her a trusted presence at work, and as receptionist she believed in the power of a voice.

She demonstrated immense courage and resilience in coping with kidney disease but also other health issues. Despite battling illness, she never complained and showed incredible patience during hospital stays.

Whilst on extended sick leave she continued to actively engage



with her colleagues, staying abreast of the organisation's work and current affairs. She advocated passionately against cruelty to animals and for the rights of the disabled and wheelchair users. She was a truly formidable woman with a lively wit and sense of fun...

Outside of work, Ruth's happy spirit shone through in her close bond with her husband Alan, enjoying laughter and fun together. A colleague knew how much Ruth wanted to attend the RTÉ Late Late Show and asked the then presenter Ryan Tubridy for tickets. Ryan, a former ambassador for the IKA, had met Ruth at an event and was photographed with her. Much to Ruth's delight, Ryan came through, granting her two audience tickets for the show.

The staff and Board of the Irish Kidney Association pass on their deepest condolences to her husband Alan, her brothers, and wider family and friends.

*Ar dheis Dé go raibh a hanam.*



*Ruth on her wedding day in September 2006*



*Ruth with Ryan Tubridy at the launch of Organ Donor Awareness Week in March 2008.*

# Celebrating Two Women's Longest Transplants in Ireland

Two remarkable women in Ireland, living on opposite sides of the country, celebrate 50 and 45 years since their kidney transplants, notably emerging as the longest surviving functioning transplant recipients in the country, for both living and deceased donation. Both in their seventies, they've triumphed over cancer while their donor kidneys continue to function well.

Their stories underscore the progress in medical science and the impact of organ donation, honoured by surprise visits from fellow recipients.

This success also credits the dedicated medical teams who cared for them over five decades.

By GWEN O'DONOGHUE

In acknowledgement of their extraordinary stories the Irish Kidney Association (IKA) arranged for surprise visits by fellow transplant recipients to their homes in Dublin and Galway to present the ladies with bouquets of flowers, further honouring their remarkable resilience and inspiring others on similar paths.

Dubliner Grandmother Christine Kelly, (73), was the second person in Ireland to undergo a living donor kidney transplant. March 1st, 2024 marked the 50th anniversary of the transplant surgeries Christine and her donor sister Mary underwent at the old Jervis Street Hospital in 1974. Christine, who lives on Griffith Avenue on Dublin's northside, was 23-years-old when she and her sister Mary (25) underwent their surgeries.



The late Mary Curley (47), 3 years before she passed away.

Both mothers had young children at the time, Christine with 7-month-old and 1-year-old daughters and Mary with a 2-year-old daughter.



Christine Kelly (right) received a special visit from young fellow transplant recipient Sam Kinahan to present her with flowers from the IKA.

The need for Christine's transplant arose when her only kidney ruptured on the birth of her second child. The sisters transplant operations took place on the second anniversary of Christine and her husband Martin's wedding. The national newspapers at the time published this remarkable occasion and Mary is quoted in the article "I never thought about courage, or sacrifice, or things like that. I thought about my sister having to spend the rest of her life living on a machine. It was a very easy decision to make and I think anyone would have done the same". Sadly, Mary passed away in the year 2000 from cancer.

To mark the milestone transplant anniversary, Christine's family organised a surprise party for her with 40 family members attending including the late Mary's husband Owen and her adult daughters Aisling, Vanessa and Lisa.

The following week, on March 6th, Beaumont hospital staff welcomed Christine to a celebratory event in her honour at their kidney clinic.

Braving heavy snowfall on March 1st, determined to meet Christine for the first time on the exact day of the transplant anniversary, was nine-year-old kidney transplant recipient, Sam Kinahan from Baldoye and his mother Chloe, bringing flowers as a gift from the IKA. With infectious enthusiasm, Sam asked Christine to compare scars. She enjoyed the light-hearted moment and happily obliged.

Over 200 kilometres away on the opposite side of the country in Ballylee, Co Galway, Bernie Glynn's story was unfolding, marking a milestone of its own.

Forty-five years ago, on March 2nd, 1979, Bernie received the precious gift of a deceased donor kidney transplant at Jervis Street, the same hospital where Christine Kelly underwent her's five years before. Bernie's donor kidney came from an 18-year-old girl from the UK.



Celebration at Beaumont Hospital. Christine and family members with Prof. Peter Conlon. (L-R): Sinead, Lauren, Vanessa, Christine, Prof Peter Conlon, Lisa, Fiona and Joshua.



Making a surprise visit to Bernie's home to present her with flowers, on behalf of the IKA, to mark her milestone 45th transplant anniversary was **Ruth McGann from New Inn, Galway** who underwent a transplant from her living donor brother Gary McGann ten years ago.

Bernie (76), a retired nurse, and native of Kilmanagh, Co. Kilkenny, had been living in Dublin and was newly wed to Albert when she experienced organ failure. As Bernie reflected on the 45th anniversary of this life-altering surgery, which brought to an end three years of dialysis treatment, she remembered with profound gratitude and appreciation to her young donor, a lifeline that has sustained her 45 years.

She also remembered her beloved husband Albert, who passed away 5 years ago. She recalls what a wonderful husband he was as they were only newly weds when her kidney disease took hold.

*"We were not long married when I got sick. Albert trained with me on how to manage my dialysis treatment which I received three times a week for five hours at a time in our cottage in Dublin 7. Back then dialysis machines were enormous.*

*"My dialysis treatment didn't work well for me, I was very sick and weak, barely able to walk, and had to give up my phlebotomy job at Cappagh Hospital. Despite the seriousness of my condition, when my consultant Dr. Carmody told me I would need a transplant I was in disbelief. Not knowing anyone who ever had a transplant, it really didn't occur to me that it might be a possibility, it seemed like science fiction back then.*

*"I was 31 when I got called for the transplant. It was the turning point in my life and I haven't looked back since. Nine months after my transplant I got my old job back at the Cappagh Hospital where I worked until I retired at 60 and then in 2008 myself and Albert moved back to live in Albert's native Galway.*

*"Although we weren't blessed with children my transplant allowed us to enjoy a fulfilling and happy life together until Albert passed away in 2019. It was only recently that I had one major health setback when I had to have a lobectomy for cancer in 2018. But I recovered very quickly and so also did my donor kidney which is*

*Bernie Glynn, whose deceased kidney donor was just 18-years-old when she passed away 45 years ago.*



*still going strong."*

Soon after they wed, Albert's devotion to his ailing wife Bernie was the inspiration for him, along with a few other people touched by kidney failure, to establish a kidney patients' support group, the Irish Kidney Association. It was inaugurated in 1978, and in the same year it introduced the kidney donor card which has evolved into the multi organ donor card.

Bernie shared, *"I am filled with gratitude to the family of my donor for their selfless generosity knowing my donor was just 18-years-old when she passed. It must have been heartbreaking for them to lose her. She and they are always in my thoughts.*

*"There were so many great medical and nursing people who looked after me all those years ago including Dr. Carmody and my transplant surgeon Mr. Hanson, both of whom have passed away.*

*"I want to thank Prof Peter Conlon and the team at Beaumont Hospital where I attended my bi-annual clinics until I moved to Galway. I am now under the excellent care of Prof. Reddan in Galway. The IKA, who through their wonderful work in supporting kidney patients and their families, continue to honour my late husband Albert's vision."*

**Back in Dublin, on March 6th, a celebration for Christine Kelly's 50th transplant anniversary was held in Beaumont Hospital** which has been responsible for Christine's care since 1987 when the old Jervis St Hospital moved to Beaumont.

Speaking at this event was Christine's Consultant Nephrologist Prof. Peter Conlon, Lead Clinical Director, Beaumont Hospital, who said, "We were delighted to welcome Christine and her family to the clinic to celebrate 50 years since her

successful kidney transplant.

Christine's story demonstrates the success of organ transplantation and gives hope to all patients with kidney failure.

"Christine, with thanks to the generosity of her sister Mary in 1974, has lived successfully with her transplant and enjoyed a good quality of life. This is a momentous occasion for Christine, her family and Beaumont and Jervis St Hospitals. Her story underpins the importance of organ donation in saving lives."

Accompanying Christine to the Beaumont Hospital event were her daughters Sinead and Fiona, along with her grandchildren Lauren, Joshua and Sam, and her nieces, (Mary's daughters) Vanessa and Lisa.

Sinead, filled with pride said, "Mam has been such an incredible woman, defying the odds time and again. When her kidney failed after childbirth, it was tough juggling dialysis with a newborn and me as a toddler. But Aunt Mary, herself a mother of a toddler, stepped up by donating a kidney to her. Mam then faced breast cancer, sharing the same BRCA1 gene, which Mary sadly succumbed to in 2000.

"Then twelve years ago mam had heart surgery and just three years ago, she underwent treatment for bowel cancer and once again pulled through. Her resilience, positivity and joy for life is inspiring and even more remarkable is that her transplant kidney, which is 76 years old, has survived all the health battles and remains to this day fully functioning and fighting fit."

***Christine and Bernie's transplant success stories of resilience and gratitude inspire those facing organ failure and their families, while comforting donors' families, knowing their legacy endures in others.***

# THE POWER OF LANGUAGE and POSITIVE SELF-TALK



**By AOIFE SMITH**  
COORDINATOR OF  
COUNSELLING SERVICES

**H**ave you ever thought about the power of language, the power of the words we use? Have you ever thought about the words you use to describe yourself when someone asks how you are or how you are feeling? Do you answer the same, regardless of how you are actually feeling? “Grand”, “Not Bad”, “Good”.

When you answer is it about your physical health or is it about your emotional wellbeing? Or is it both? Are you hoping that the other person notices the underlying truth from the answer you give, or from the tone in your voice?

Our voice and the words we use are the primary and most powerful tools we have for expressing our thoughts, feelings, and beliefs. Speaking, writing, and reading are a part of everyday life.

Words serve as a means of communication and of expression. A single word, even without a complete phrase or sentence, can have a profound impact on us, on individuals or even groups of people.

Consider simple words like “No”, “Stop”, “Go”, “Forgive”, “Peace” or “Love”, these words are simple, yet they possess tremendous power and may affect our actions. There is no doubt words are powerful, and they can be at their greatest power within our own mind!

We all have an internal dialogue; it is a normal cognitive function. Out of all the messages we receive throughout our day, we hear our own self talk and thoughts the most. How we speak to ourselves and the words we use can be incredibly helpful and positive or incredibly critical and negative.

Research has shown that positive self-talk can positively impact our mental health, help us feel more motivated and optimistic, better able to manage stress, reduce anxiety and cope with emotions.

Research has also shown that negative self-talk can adversely impact our mental health, increase anxiety,

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 [aoife@ika.ie](mailto:aoife@ika.ie) 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.



lower our self-esteem and confidence, and predict depressive episodes.

That said, all too often we find it difficult to speak positively to ourselves and find we can speak to ourselves in ways we would not take from another person.

When we are living with a chronic health condition it can be extremely easy to get caught up in a cycle of repetitive negative thinking.

### SO, HOW CAN WE SPEAK TO OURSELVES IN A MORE POSITIVE WAY?

Firstly, I think we must become aware that we are thinking negatively or speaking negatively to ourselves before we can change it. Some people find it helpful to write down some examples of their negative self-talk and then re-write it with positive self-talk.

Let me give you an example.

If you can, take a few minutes to think of the following statements and before you read on, try to get a sense of what feelings you would associate with them:

- This is hard
- This machine is ruining my life
- I should be better, I should be stronger, I should be happier
- I must go to this appointment... or hospital... or work...

**What kind of feelings came up for you?** When I stop and think of these statements I get a feeling of dread, hopelessness, and even pressure.

Now, let's look at these statements if I change one word in each:

- This is challenging
- This machine is saving my life
- I could be better, I could be stronger, I could be happier
- I get to go to this appointment.. or hospital... or work...

**What kind of feelings come up for you with these statements?** Is there more hope, more compassion, or less pressure simply by choosing to change one word?

Choice is another point I will make around the power of language.

Sometimes we get so familiar with the negative self-talk we barely notice we are doing it. It can be helpful to remember that there is choice in the

way we think, and we can challenge old habits or old ways of thinking.

We get, with a little practice, to change our internal dialogue. As we become more aware of our own self talk, we may also become more aware of the language of others. Whether it is about us or around us it may also have an impact on us. We can choose to challenge this negative talk.

A further key factor to consider in the way we think of, or speak to ourselves, is how to address ourselves, which has been shown to really matter. Positive self-talk can have a greater effect when we use the second-person pronoun 'you' or your own name rather than the first-person pronoun 'I'. This can help regulate feelings and thoughts. Reflect on this one statement from above, where I use this strategy and see if it changes how you feel about it even further. 'Aoife, you get to go to work'.

For me, I feel more empowered with the use of my name. When our self-talk becomes more positive, so does our thinking and our feelings. The choice is ours.

## IKA PEER SUPPORT SERVICE REACHES A NEW PHASE

**Our Peer Support Service has just completed a 12-month pilot phase and we are delighted to say we have now moved the service to mainstream. An independent evaluation took place from late November to late December 2023.**

**The evaluation presents the findings from a process and impact evaluation of the Peer Support Service delivered by the Irish Kidney Association (IKA).**

The overall evaluation was very positive. We had words like 'Empowering', 'Excellent', 'Welcoming' and 'Comforting' used by peers to describe their engagement with the service. There were comments that highlighted the importance of the processes involved in running the service, "I really was matched with the right person: they really met my needs...the whole experience was 100% for me", and comments which emphasised the impact the service had for our patients, "My peer just said something that has just given me **hope**".

Our team of Peer Support Volunteers, Patricia Bourke D'Souza (Peer Support Project Manager), myself and all

here in the IKA supporting the service, got a great sense of achievement when we read a comment from the independent evaluator: *"Through review of documentation and interviews it is clear that huge effort and passion has gone into developing the service"*, because, this as a team, we feel is very true!

If you, or someone you know, carer or family member, 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/](http://www.ika.ie/peersupport/) or contact the IKA. Once received we will contact you and confirm that we have an accurate understanding of your needs, and the best times



for you to talk to someone. We will then match you to Peer Supporter and arrange for your online meetings to begin.

We look forward to hearing from you.

**Aoife**

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 Service.

# Celebrating 40<sup>TH</sup> ANNIVERSARY

## of Dialysis in Waterford: 1983-2023

On December 11th and 12th, a significant milestone was celebrated at the dialysis unit of University Hospital Waterford (UHW) as it marked 40 years of providing vital dialysis services to the community. This event was made possible by the support of the Irish Kidney Association (IKA) Branches from Tipperary, Wexford and Kilkenny working with the host county Waterford Branch IKA.

The roots of this story trace back to 1981 when 11 patients from Waterford City and County were receiving life-saving dialysis in St. Mary's Hospital in the Phoenix Park and Jervis Street, Dublin.

The catalyst for change came from the late Seán Murphy, a Waterford father of a young child among those patients. He passionately lobbied councillors, Ministers, and the Health Service Executive (HSE), initiating plans to establish a dialysis unit in Waterford.

The agreement to proceed was contingent on raising £400,000, equivalent to €1.3 million today. Undeterred, a committee was formed to raise awareness and



Dr. Frank Walker retired nephrologist UHW, Dr. Elizabeth Abernathy, Dr. Catherine Browne, Dr. Frank Kelly, Dr. Seán Leavey, Nephrologists in UHW

### By FRANCES MOYNIHAN

funds, garnering substantial support from local Trade Unions and particularly from Waterford Crystal factory workers.

In the first year, £130,000 was raised, and in May 1983, the dialysis unit opened in St. Bridget's unit in Ardkeen.

Today, over 108 patients from Waterford and surrounding counties are cared for in the UHW unit by a dedicated team under the guidance of Jane Cullen, CNM. Additionally, 45 patients engage in home dialysis with support from the Renal Therapies Unit on the hospital's top

floor, overseen by Mary O'Grady, CNM, and her compassionate team.

To mark this remarkable milestone, the Waterford Branch IKA organised a gathering for staff, both past and present, on December 11th, 2023, along with a special event for patients over the two days of December 11th and 12th.

A welcome address was given by Ray Halligan, Chairperson Waterford Branch IKA, thanking the organiser Frances Moynihan, Treasurer of the Waterford Branch IKA, ably-assisted by her husband Joe. Ray expressed how he was especially grateful to the staff for the wonderful care they give to patients.

A special renal-friendly cake was



Ray Halligan, Nora Delahunty, UHW



Jane Cullen, CNM







Walter Kent, Ray Halligan



Gathering of staff members past and present with invited guests



Frances & Joe Moynihan and Margaret Moran, UHW



Síle Murphy with the original plaque from dialysis unit in 1983 and Frances Moynihan



Marion Young, Bridget Langton, Frances Moynihan



Dr. Seán Leavey UHW, Brenda Ronan, retired CNM dialysis unit UHW, Moira Cashin, and Ray Halligan

cut, having been provided by dedicated Waterford Branch volunteer Marion Young. A free raffle was conducted during the six dialysis sessions, featuring 4 x €40 Dunnes Stores vouchers and small gift packs for the remaining patients, thoughtfully assembled by Julie Anne, the Manager at McCauley's Pharmacy in Dungarvan, and her efficient team, within a tight timeframe of two days.

The raffle was also extended to patients on home dialysis, with Mary O'Grady and Frances Moynihan, overseeing the proceedings in the Home Therapies Unit.

The collaborative support from

the Kilkenny, Wexford, and Tipperary Branches of the IKA, all of whom have patients at UHW, was deeply appreciated.

Walter Kent, Wexford Branch Secretary and Bridget Langton, Kilkenny Branch Treasurer, were present to assist with some of the raffles over the two days.

Notably, Nora Delahunty, who has dedicated 40 years of service to UHW dialysis patients, was recognised for her outstanding contributions and was presented with a hamper by Chairperson Ray Halligan. She remains a friendly and caring presence to all who visit the unit.

Special guests included Bob Murphy, the fifth patient in the unit in 1983, accompanied by his mother, Síle Murphy. Bob's late father, Seán

Murphy, played a pivotal role in advocating for the unit in 1981.

The Waterford Branch IKA extends sincere gratitude to the staff in both units for embracing the idea of a celebration and for their warm hospitality over the two days.

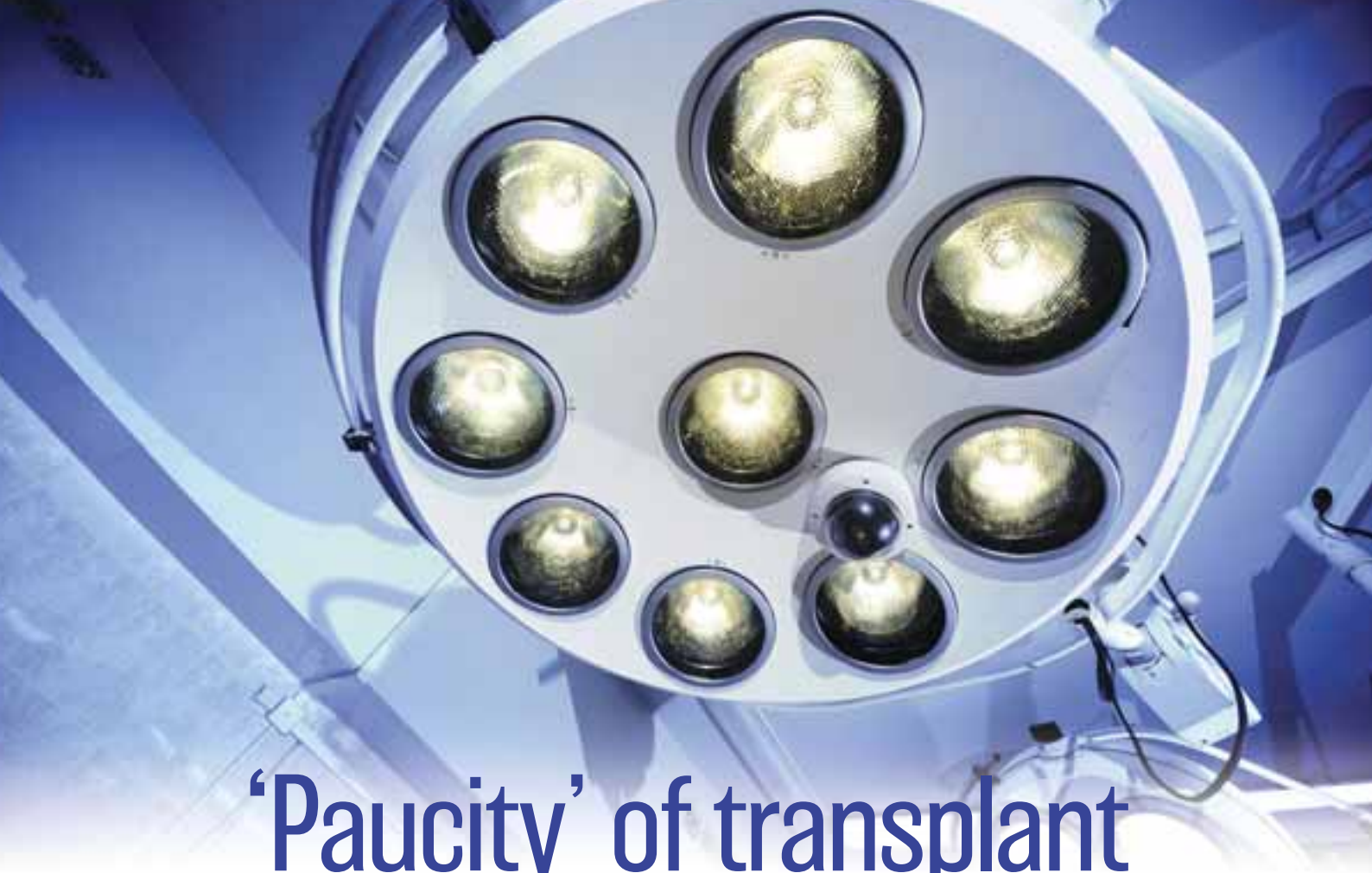
Looking towards the future, the Waterford Branch anticipates continued collaboration with other IKA Branches for the betterment of patient care.

If you or anyone in your family is living with renal disease and would like to access further supports and services, please contact your local IKA Branch or IKA Donor House at [info@ika.ie](mailto:info@ika.ie)



Nurses on the dialysis unit Margaret Walsh, Christina, Rekha and patient Moira Cashin





# ‘Paucity’ of transplant infrastructure leaves services ‘vulnerable to failure’



By CATHERINE REILLY

A “demand capacity mismatch” has left transplant services “vulnerable to service provision failure” in surge periods, a HSE review found.

**A** “demand capacity mismatch” has left transplant services “vulnerable to service provision failure” in surge periods, a HSE review found.

The internal review, finalised in December 2022, referenced a “paucity” of dedicated infrastructure and specialist staff for provision of complex care to these patients who have unique care requirements due to immunosuppression and

multiple co-morbidities. It said the capacity issues were also causing staff recruitment and retention difficulties.

The review, obtained under Freedom of Information law, was commissioned after the cancellation of an organ transplant at the Mater Misericordiae University Hospital, Dublin, in late 2021. The transplant was cancelled due to lack of critical care capacity following a surge in

COVID-19 cases. This matter was examined in a separate serious incident report.

According to the wider review, the requirements for transplant services and patients had not been formally mapped-out, costed, or future-adjusted, and the governance for these services was “splintered”.

Executive powers rested entirely with Hospital Groups and transplantation had to



compete with other service requirements. The clinical prioritisation of unscheduled care over all other services resulted in resources funded for transplantation being redirected.

There was also “limited information” available to manage the transplant process and drive performance improvement.

The review noted organ retrieval predominantly occurred out-of-hours because the donor hospital usually did not have emergency theatre space to accommodate retrieval during normal working hours.

“The restrictions of cold ischaemia time determine the timing of implantation; this all forces the whole process ‘out-of-hours’. When organs for donation are made available to the transplant centre the next day, [this impacts] elective surgery lists.”

Capacity shortfalls relating to protected beds, specialist staff, theatre access, and critical care were raised in the review.

In regard to renal transplant at Beaumont Hospital, Dublin, for example, it was noted deceased donor transplantation (which usually involves two transplants per donor) competed for access to the emergency theatre.

As Beaumont was the site of the national neurosurgical centre and

had an expanding catchment population, the demand for access to this theatre was “overwhelming”.

“To access the theatre with two transplants, which can occupy the theatre for between six to 10 hours at any given time, [would mean] other emergency cases are deferred. Transplant surgeons have to frequently ‘negotiate’ with other colleagues as to which emergency is most pressing or can the transplant surgery be delayed to allow life or limb saving surgery to proceed instead. This has led to prolonged cold ischaemia times of over 20 hours in approximately 20 kidney transplants last year, which in turn, contributes to [the risk of] delayed graft function.”

At the Mater, general cardiac and thoracic cases competed for finite resources with the lung and heart transplant service as well as general emergency and acute cases. This meant that cardiac and thoracic, including cancer, cases were regularly cancelled

when a transplant was being carried out, either due to lack of theatre provision or ward/ICU beds.

In common with the other programmes, the liver and pancreas transplant programmes at St Vincent’s University Hospital in Dublin competed for the same resources required for other emergency and urgent care cases.

Liver transplants took place in the same theatre as scheduled hepatopancreaticobiliary (HPB) cases so transplantation between Monday and Friday typically resulted in cancellation of two major HPB cases. Pancreas transplants usually occurred in one of the other gastrointestinal surgery theatres, again displacing scheduled (usually cancer) cases.

According to the review, increasing capacity so that patients with different urgent care needs are not competing for the same resources is fundamental to providing a consistent, quality-assured service.

“Transplantation is a highly effective therapy for complex patients with very acute healthcare needs. The relative scarcity of organs and the loss of individuals whilst on transplant waiting lists confers an urgency to this therapy that needs to be taken into consideration by the Government, the Department of Health, the HSE, and the hospital system when resourcing and implementing this service.”

Among the review recommendations was a formal strategy to quantify the requirements for transplantation services and an increase in critical care capacity to meet the requirements for all patients.

A HSE spokesperson said it is developing a strategy for organ donation and transplant services to deliver required outputs for the next 10 years.

The strategy is at final draft stage and will be presented to the HSE executive management team in early 2024.

© Courtesy of Medical Independent

“  
At the Mater, general cardiac and thoracic cases competed for finite resources with the lung and heart transplant service as well as general and acute cases.  
”

## SUPPORT MAGAZINE WINTER PRIZE GIVEAWAY WINNERS

Congratulations to the winners of the Prize Giveaway in the Winter 2023 issue of *SUPPORT*

**Naveen Philip, Lucan, Co. Dublin, Marion Dolan, Lecarrow, Co. Roscommon and Fred Carroll, Cootehill Road, Cavan** each won a **€150 ONE-4-ALL voucher**.  
**Cecile McInerney, Sutton, Dublin 13 and Helen Kennedy, Bunclody, Co. Wexford** each won a **€50 Tesco voucher**.



# ORGAN DONATION

## Breaking the boundaries

For many patients in need of a transplant the best match will come from a donor from the same ethnic background.

If you are Black, Asian or belong to a minority ethnic group, your decision to become an organ donor could increase the chances of someone from the same ethnic background finding a suitable match. You could even save someone's life.

According to a 2023 report\* from the UK Blood and Transplantation Service (NHSBT), agreement from families for organ donation to go ahead has fallen over the last few years and it is still much lower for potential donors of an ethnic minority. Overall consent rates were 39% for Black, Asian and other Minority Ethnic donors in the previous year, compared to 70% for white potential donors, (compared to 71% and 40% respectively last year) and families saying 'no' remains one of the main reasons for organ donation not going ahead.

The main reasons families from ethnic minority backgrounds gave for declining consent/authorisation for organ donation were that they felt it was against their religious or cultural beliefs or they were unsure whether the patient would have agreed to donation. Survey results of ethnic minority groups show that not knowing enough about organ donation is also a major barrier to organ donation.

\*NHSBT Annual Report on Ethnicity Differences in Organ Donation and Transplantation Report for 2022/2023 (1 April 2018 - 31 March 2023).

Two 16-year-olds, **AYULLEY AMENTORGE** and **LAUREN ROCAN**, students at **St. Joseph's secondary school in Co. Westmeath**, chose to address the issues around ethnic minorities and their views on organ donation, with their entry in the 2023 BT Young Scientist competition and they have kindly allowed us to share their findings.



By **LAUREN ROCAN** and **AYULLEY AMENTORGE**

We participated in the BT Young Scientist competition in early January 2023. The project that we did was titled *Organ Donation, Breaking the Boundaries*. We thought of this project in the hope that it would

bring light to and broaden people's knowledge on a profoundly serious issue. This issue being the awareness and shortage of organ donations within ethnic minority groups.

Our project aim was to find out how ethnicity and culture influences people's decisions in relation to organ donation and transplants.

Here in Ireland, we experienced a record year of organ donations in 2017. There was an increase of 29% of deceased organ donations and an 11% increase of transplantations compared to 2016. In 2018 a total of 231 transplants were completed from 80 donors. There has been a tremendous increase in these past years, but there is still a demand for organ donation with very little contribution and



participation from ethnic minority groups.

Although there is no available comprehensive research done in Ireland when it comes to awareness and participation levels of minority ethnic groups in Ireland, there has been a lot of research done in the western world in general when it comes to this issue.

Studies have shown that there is a pronounced shortage of organ donations among minority groups. This is mainly due to, among others, cultural, ethical and/or religious beliefs. On the other hand, however, available research evidence has pointed out the fact that ethnic minority groups are more likely to need an organ transplant as they are more predisposed to high blood pressure, diabetes, and heart disease.

Ethnicity matters when it comes to organ transplants because it is important that the match to the organs share the same ethnic background as someone you are more likely to have the same blood and tissue types with. Therefore, your body is more likely to accept the organ without any significant issues.

We created a survey and distributed it around our area. We then interviewed a few people from different walks of life; our main goal was to gain opinions and attitudes of people of ethnic backgrounds, here in our community. We also asked them to share it with their family members so we would be able to get a wide range of different age groups.

Our findings were quite interesting, 54% of our participants were unfamiliar with organ donation



**Micheál Martin, Tánaiste, Minister for Foreign Affairs and Minister for Defence with Ayulley Amentorge and Lauren Rocan.**

and when asked if they would ever consider donating their own organs, 64% said 'no'. The last two questions of our survey were 'would you be open to learning more about this topic', and 'do you think this should be taught in schools'. 76% of people are open to learning more, and 72% believe it should be taught in school.

To conclude, there needs to be more awareness around this topic. Many a time, when most people from an ethnic background hear the words organ donation, they instantly relate it to the negative possibility of death. Therefore, they are reluctant to talk about this because death is considered a bad thing.

How can we get people to see that organ donation is a positive thing, that it could save someone's life and is also a beautiful gift?

We suggest an intense information and education campaign around organ donation among ethnic communities in Ireland and it should be a section in the SPHE course in secondary schools, and it should be a topic advertised all year round.

Thank you for reading!



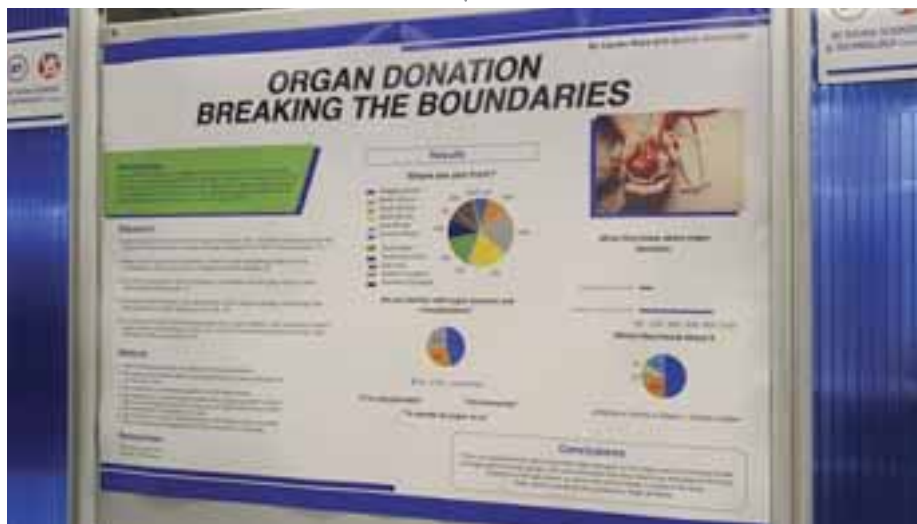
Well done to Adrian Cummins, the Chief Executive of the Restaurant Association of Ireland for raising awareness about kidney disease. A dialysis patient himself, Adrian did an indepth interview with the *Sunday Independent* recently and also spoke candidly to Miriam O'Callaghan on her radio show about living with kidney failure while continuing to work in his demanding role in representing and lobbying for the restaurant industry.

## QUIZ TIME

Get ready to test your wit with a brief mental workout as quizmaster **Paul Donohoe**, from Leitrim, invites our readers to tackle the following ten questions (answers below).

1. In what year did the Astronauts first walk on the moon.
2. In what European City will the 2024 Summer Olympics be held.
3. Who is the Leader of Irish Political Party The Social Democrats.
4. What long running popular TV Soap Opera was first broadcast on February 19th 1985.
5. Name the act that will represent Ireland at Eurovision in Malmö, Sweden on May 7th.
6. A "Knot" is the collective noun for group of what amphibian.
7. What player recently succeeded Jonathan Sexton as Captain of the Ireland Rugby Team.
8. Name the model of Volkswagen car celebrating 50 years of production in 2024.
9. Muck & Dizzy are characters in what animated TV show.
10. Complete the old proverb "A stitch in time..."

QUIZ ANSWERS  
1. 1969 (July 20th); 2. Paris; 3. Holly Cairns; 4. Eastenders; 5. Bambi Thug; 6. Toad; 7. Peter O'Mahoney; 8. Golf; 9. Bob the Builder; 10. Saves Nine.



# A TRIBUTE TO *Joan Kerley-Martin*



With sincere condolences, we commemorate the life and invaluable contributions of our esteemed former National Honorary Chairman, Joan Kerley-Martin, who passed away on 30th January, 2024. Our sympathies to her husband John, family, friends and colleagues.

From Dundalk, she served as National Honorary Chairman from November 1999 – November 2001. She was widely respected for the passion and dedication she brought to the Irish Kidney Association (IKA) representing the kidney community at national level, but also her long-standing servitude to her local community as she served on the Louth/Meath Branch as Secretary and Treasurer and then as a Branch representative on the national board over many years.

She is also remembered fondly as a gifted secondary school teacher by her past pupils and colleagues at St. Vincent's Secondary School Dundalk of which Joan herself was a past pupil.

As a kidney transplant recipient herself, Joan brought a unique

perspective to her role, understanding firsthand the challenges faced by those affected by renal disease. Her personal journey fuelled her commitment to advocating for kidney patients and increasing organ donor awareness.

Her ability to connect with the kidney community helped elevate our cause as she offered comfort and reassurance to patients and families navigating kidney health challenges.

She leaves behind a lasting impression on all who had the privilege of knowing her, cherished for her warmth, sensitivity, and great sense of humour.

Though she may have passed, her legacy endures and her spirit lives on in the lives she touched and the lasting impact of her contributions.

As Joan concluded an article she wrote in an issue of *SUPPORT* magazine in 2001, during her term as IKA Chairman, she described her life experience saying,

"Life is full of surprises. Kidney disease was a surprise for me but look where it has led me. If it has taught me anything it is to live life and love life and use the time and talents I have the best way I can.

"Being Chairman of the IKA is part of that for me. It enables me to turn the experience of illness into something positive." In summing up Joan wrote, "At the moment I am reading a beautiful book called 'Life Lessons' by Elisabeth Kubler-Ross. Her words echo how I feel:

"You don't get another life like this one. You will never again play this role and experience this life as it's been given to you. You will never experience the earth with all its wonders in this time again. Don't wait for one last look at the ocean, the sky, the stars, or a loved one. Go look now".

*Rest in Peace Joan.*

**Below: Joan Kerley-Martin at the Annual Service of Remembrance, held at St Mary's Catholic Church, Haddington Road in October 2000.**





# Barriers to Exercise for Dialysis Patients



Ciarán Williams

Last year, as part of an MSc in Sport and Exercise Science and Medicine final year project, Ciarán Williams carried out a 'Survey of Dialysis Patients in Ireland looking at Barriers to Exercise and the encouragement and education received from healthcare staff'.

Ciarán kindly agreed to our sharing an overview of his findings.

Research indicates that chronic kidney disease patients, particularly dialysis patients, could benefit from regular exercise and physical activity. Despite this, they are less active compared to the general population.

Fatigue was the leading barrier to exercise that patients reported.

Peritoneal dialysis patients were more likely to be physically active compared to haemodialysis patients.

More respondents did not agree that they had been educated on the benefits of exercise by healthcare staff, compared to those that agreed.

100% of respondents confirmed that they had reduced physical activity levels after commencing dialysis treatment.

Exercise has become known as a non-pharmacological intervention for Chronic Kidney Disease (CKD), with such interventions as short as 12 weeks bringing clinical benefits. Studies have also seen a decline in health within non-exercising control groups, indicating that physical activity can play a role in prevention as well as improvement. Benefits can also be seen in hypertensive patients (who have high blood pressure), one of the leading comorbidities (additional health issues) among patients with CKD.

As patients with CKD can sometimes require dialysis for the duration of their lives, exercise can offer a low-risk method of maintaining health and quality of life.

Only three studies reported a lack of motivation as a barrier to exercise, while healthcare providers have suggested this as a leading barrier, in addition to disinterest and being incapable of exercise.

When assessing barriers to exercise, it is important to note that international research suggests greater adherence to exercise programmes for those conducting intradialytic exercise (exercising whilst on dialysis), versus those completing at-home programmes

(where exercise is carried out at any setting outside their dialysis setting which can be at home, outdoors or in a gym). Contrary to this, however, patients state a preference for engaging with exercise in their home environment rather than intradialytic settings.

Additional research into the level of exercise promotion and education for dialysis patients in Ireland is needed. For example, it would be important to establish whether healthcare staff have access to the necessary resources to provide clear exercise guidelines to their patients. Research into intradialytic exercise during haemodialysis has brought about similar concerns in international research as to whether existing staff at dialysis centres have the capacity or willingness to add monitoring exercise to their role, as the need for additionally trained personnel may be required.

Since Ciarán carried out his study, the **Kidney BEAM programme** has been introduced, free to use in Ireland, thanks to the support of **James Tracy** and the **Punchestown Kidney Research Fund**.

This online service was created to help people living with kidney disease manage their physical and emotional wellbeing. The programme has been extremely well received amongst patients and Healthcare Professionals (HCPs) with it appearing on the agenda in a variety of patient and HCP education settings.

Published in the *Lancet* (November 2023), the Kidney BEAM trial evaluated the clinical effect of a 12-week physical activity digital health intervention on health-related quality of life. The findings were that the Kidney BEAM physical activity platform is an effective digital health intervention to improve mental health-related quality of life in patients with chronic kidney disease.\*

You can register with Kidney BEAM here: [www.beamfeelgood.com/kidney-disease](http://www.beamfeelgood.com/kidney-disease)

\* [www.thelancet.com/journals/landig/article/PIIS2589-7500\(23\)00204-2/fulltext](http://www.thelancet.com/journals/landig/article/PIIS2589-7500(23)00204-2/fulltext)

By **COLIN WHITE**  
NATIONAL ADVOCACY & PROJECTS MANAGER

As previously reported, at an online meeting on January 29th, a new entity, **Transplant Sport Ireland**, is being established to take over the delivery of a national transplant and dialysis sports programme and take on the management of national teams at international events.

Whilst this considerable work, which is being undertaken by volunteers from within the existing sports programme, is on-going, registration for the European Transplant Sports Championships (open to people on dialysis as well as organ and bone marrow transplant recipients) and the British Transplant Games has opened.

**EVENTS' WEBSITES:**

**European Transplant Sports Championships, Lisbon, Portugal (21-28 July) [www.eu-tsc.org](http://www.eu-tsc.org)**

**British Transplant Games Nottingham. 1-4 August [www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)**

If you have queries about representing Ireland at either or both of these events, please contact [transplantsportireland@gmail.com](mailto:transplantsportireland@gmail.com).

## 12TH WORLD TRANSPLANT WINTER GAMES



Shane, Alex, Sam and Luke Herlihy celebrating their medals.

The **Winter Games** were held in Bormio, Italy from March 3rd-8th. Games veteran, and kidney transplant recipient, Luke Herlihy from Sandycove, Dublin, represented Ireland on the slopes, alongside his kidney donor Dad, Shane, and his brothers Sam and Alex (who all competed in the donor family category).

Between them, they won two gold, three silver and four bronze medals! A fantastic haul for a small team.

Ireland (aka The Herlihys!) finished second on the medals table in the Donor Category and 18th on the medals table in the Transplant Category.

Word has it that they were 'adopted' by the team from the USA

and there were plenty of compliments about their skiing and their attitude.

A huge well done and thank you to the Herlihys for flying the flag for Ireland at the Games.



Alex, Shane and Sam

## TRISH'S DIP A DAY

Trish Boyce from Rosslare Harbour, Co Wexford donated a kidney to her father, John Boyce on December 1st, 2022, ending John's dialysis treatment which he underwent for two and half years.

To mark the first anniversary of the successful living donor kidney transplant, Trish decided to raise funds for the Irish Kidney Association and St. Damian's Ward in Beaumont Hospital. She did this by taking on the challenge of dipping every day in the month of December in the chilly Irish Sea at Rosslare Harbour.

Trish was delighted to be joined on every daily dip by her good friend, Celine Treacy. Trish declared, "it was an enjoyable and fun way to raise funds for two very special causes. We also had the support of several other people who braved the elements by dipping in the sea during the month of December and we were thrilled that an old friend of my dad's, Eddie Kehoe, joined me and my family and friends on the final dip at Rosslare Harbour Beach on Sunday, 31st December. Eddie also had a kidney transplant, from a deceased donor, which took place 41 years ago. The two friends, who had worked on the Sealink and Stena Line ferries together, on the Rosslare to Fishguard route, embody the remarkable success of organ donation and transplantation." Trish quipped, "Perhaps their transplant success is fuelled by the breeze of their past maritime journeys and good Wexford air".

Trish said, "I was delighted that our December Dip raised a total of €4,220 and I'd like to express my sincere thanks and gratitude to all those who supported the challenge fundraiser for both the Irish Kidney Association and St. Damian's Ward at Beaumont Hospital, both of which provide wonderful care and support to kidney patients".



Friends Celine and Trish





# Edmondstown Golf Club PUTTS its support behind Tallaght Dialysis Unit



The Edmondstown Golf Club, Rathfarnham, Dublin 2023 Captain's Charity Day selected Tallaght University Hospital Foundation (TUHF) as its charity for the event. Funds raised were specifically for use by Tallaght University Hospital (TUH) dialysis unit.

Club members and friends raised a phenomenal €27,427 and subsequently, a further €4,662 has been pledged giving a total of €32,089. The money raised will be used to purchase specialised leg trainers for use by dialysis patients while receiving haemodialysis in TUH.

In 2021, TUH introduced Ireland's first-ever exercise programme for dialysis patients,



led by physiotherapists. It incorporates aerobic and resistance training, primarily utilising the MotoMed Layson Leg Trainer.

The successful fundraiser will allow the dialysis unit to add more leg trainers to their programme and thus open the benefits of exercise to more of their patients.

**PICTURED ABOVE:**

*At the cheque presentation at Tallaght Hospital are (l-r): Captain Pat Conway, Sarah Benson TUHF, Prof. George Mellotte, Captain Bernie Beirne, and members of the physiotherapy team at TUH.*

**LEFT:**

*Captain Pat Conway, Captain Bernie Beirne and Consultant Nephrologist Prof. George Mellotte, at Edmondstown Golf Club, Rathfarnham, Dublin at the Charity Day function.*



### VOLUNTEER COLLECTIONS

The Cork Branch saw a burst of energy as volunteers mobilised to mark the IKA's campaign around World Kidney Day selling Forget-Me-Not flowers, distributing organ donor cards, and raising awareness about kidney health at various Aldi stores around Cork city and county.

Thanks to Pat O'Sullivan who coordinated the volunteers and locations brilliantly, and our volunteers, who manned information stands and generously donated their time. (Photos on pages 8-9).

Their enthusiasm and commitment made a significant impact, and we extend our heartfelt gratitude to all who participated.

### MUNSTER KIDNEY SUPPORT CENTRE MARKS WORLD KIDNEY DAY

We also express our gratitude to all our supporters and nursing and medical staff from CUH hospital who took the time to drop in to the IKA Munster Kidney Support Centre for a cuppa to mark World Kidney Day.

It was particularly nice that Prof. Liam Plant dropped in. It was a nice opportunity to enjoy chatting with him before his imminent retirement.

Special thanks to Jennifer and Sally for their warm welcome and for the delicious spread of cakes laid on for all to enjoy.

The event was filled with lively conversations, friendly exchanges, and a sense of community spirit. It was a wonderful gathering that brought people together to raise awareness and support each other in promoting kidney health.

### BABY JOY

Congratulations to transplant recipient Colette Hawe and Morgan Lyons on the safe arrival of their baby Croía (story on page 22-24).

## CORK



### ANGLESBORO TRACTOR RUN

Our thanks to Anglesboro Vintage Club for donating €3210.10 to the IKA, the proceeds of their very successful Car and Tractor Run held on December 27th.

Anglesboro Vintage Club members are pictured with Cork IKA's Noreen O'Halloran and Mike Kiely (5th and 4th from right).

### IN SYMPATHY

Our deepest sympathies go out to all our members who have experienced the loss of a loved one. During these difficult times of bereavement, please know that our thoughts and support are with you.

In memory of our dear friend Isabel Terry, who passed away last year, we share a heartfelt tribute written by Pat O'Sullivan.

## TRIBUTE TO ISABEL TERRY



On October 12th, 2023, we lost a true friend of the Cork Branch and a wonderful promoter of organ donation.

Isabel Terry, from Bishopstown, Cork, had been waiting 15 years for a call that could change her life. She suffered from pulmonary atresia, a birth defect of the pulmonary valve in the heart. Prior to her transplant Isabel had to use bottled oxygen 24 hours a day.

In 2003, she was first assessed as needing a heart transplant while she was in the care of the Mater Hospital in Dublin. However, she suffered heartbreak after receiving five unsuccessful transplant calls between 2003 and 2009.

In 2009, her condition had worsened to the point where she needed to get both a heart and double lung transplant.

Finally, in 2017 Isabel got the call that she had waited so long to get. She travelled by private jet to Newcastle in England and underwent a high-risk surgery spending nearly two months in intensive care. She survived multiple complications including a stroke, a cardiac arrest, and kidney failure.

Isabel had been writing about her journey of being on the transplant list on her Facebook blog, *Life on the List*, with the hope of inspiring other people in the same position, as well as raising awareness about the importance of organ donation and carrying organ donor cards.

She has been remembered as an absolute 'warrior woman' by many, and an 'inspiration in facing her health challenges'. She has been described as 'a person of great courage, strength and determination'.

She was a true warrior for promoting organ donation. One person wrote, "Isabel was the personification of courage and inspiration. Despite her health challenges, I was always struck by her zest for life and by her willingness to advocate so publicly and eloquently for organ donation – work I am sure has helped save many lives. To all of Isabel's family and her friends at this sad time, I can't believe she has gone and I am so sorry for your loss. Isabel was a beautiful and courageous brave girl who always had a great smile and loved a laugh and her fashion. She inspired me to become a donor."

To Isabel's husband Philip and her mother Deirdre, on behalf of the Branch and the Association we send on our deepest sympathies. To her closest friends, Sally, Lynda, and Annie, she is looking down on all of you keeping you safe. *Suaimhneas síoraí dá hanam uasal.*



# KILKENNY

By SARA SANTI



*Kilkenny Branch members in festive spirit at their Christmas lunch.*

The IKA Kilkenney Branch wants to thank all its members who attended the Christmas lunch. It was wonderful seeing you all there and being able to share in those friendly festive moments.

Our thanks to Paddy Cox of **Dialyze Clothing** who generously donated one of his company's products, cozy blankets, to patients in the dialysis unit in Kilkenney.

Paddy, having been a dialysis patient prior to his kidney transplant, understands the needs of patients. His clothing brand, Dialyze Clothing, which includes stylish clothing with discreet access for dialysis patients and any patients requiring PICC or IV line treatment, extends also to warm

blankets tailored specifically with patients in mind, providing them with a source of comfort during their challenging journey.

Thank you Paddy for your thoughtfulness and generosity.

I want to take a moment to thank everyone who thought of our Branch for wonderful and generous donations – please know that you have helped those who needed it the most.

Lastly, a heartfelt thank you has to go to our amazing Treasurer



*At the Christmas party, Justin, Sally and baby Conor Smith.*

Bridget and our Chairperson Owen, who sadly are stepping down from their voluntary positions.

Bridget and Owen have played a key role in all that this Branch has managed to achieve in the last year. We wish them well.

We hope that the Kilkenney Branch will keep moving forward with more engagement and more members, hopefully there will be more to come, and we look forward to seeing you all soon!



*Paddy Cox, Dialyze Clothing (centre) with Sara Santi and Owen Hanrahan.*

# KERRY

By THERESA LOONEY

*Greetings from the Kingdom!*

We recently held our first Branch meeting of the year and it was wonderful to see new faces getting involved with our Branch going forward, particularly to our newly transplanted Killarney patient, Paul O'Shea with his wife Maria – it's great to have you both on board.

The meeting was very productive with lots of new ideas for fundraising and creating awareness. We were delighted to accept a cheque from the Murhill family, from Killarney, who held a memorial walk, in January, in memory of Hugh Murhill, to mark the 4th anniversary of his passing. A heartfelt thank you to his wife Susan, and his children Jemma, John, Kaylyn, and Hugh Daniel, for organising the event.

We participated in the St Patrick's Day Parade, the theme this year for Killarney was 'Queen Victoria'. We had a beautiful float organised in keeping with the era, what better place to raise organ donor awareness, watch this space for photos.



*The Murhill family with Theresa Looney (second from left)*

The biggest fundraising event for this year is the annual Ring of Kerry Cycle. We are delighted to have been chosen as one of their Tier 2 charities. This is a huge event and we have lots of exciting plans, including a brilliant draw with the main prize of a week's holiday in a Villa in Spain. More details on the cycle for the IKA can be found on page 32-37 and on [www.ika.ie/ringofkerry](http://www.ika.ie/ringofkerry)

We are looking forward to everyone's support in the year ahead.



### NEW RENAL UNIT

Details have emerged about the new renal unit being planned for Sligo University Hospital.



It is envisaged that the unit will have 20 dialysis stations as well as additional inpatient, outpatient and home-based services and associated admin and staff welfare facilities. The current unit has 12 dialysis stations in a cramped space and there is insufficient areas for clinic patients and staff.

The planned basics for the unit are revealed in a reply to a Parliamentary Question raised by Sligo-Leitrim Independent TD, Marian Harkin.

In a letter to the TD, hospital General Manager Grainne McCann said the HSE had been requested to reply directly to the Dáil member.

The letter from Ms. McCann also said that approval to initiate the capital funding application process has been received. And funding has been made available to prepare a comprehensive feasibility study for the project.

The feasibility study is underway and after stakeholder engagement it is expected to be complete in the second quarter of 2024.

When finalised the study will form the basis for a full capital submission which, when approved, will facilitate the projects inclusion on the HSE Capital Plan.

The letter concludes by saying that the project will then proceed through the stages of the Capital Works Management Framework subject of funding.

The reply to Marian Harkin's question confirms what we have outlined here previously in

# SLIGO

By BRIAN McHUGH



*Cheque for funds raised by the run/walk are presented to Geraldine McHugh (right) Secretary Sligo IKA Branch by Catherine Foley, Mary Banks and Thelma Banks.*



*Tommy and June Banks, parents of the late Orla.*



### SUPPORT magazine:

Many preliminary stages must be gone through on the way to the delivery of the new unit. These stages are ongoing but progress is very slow. Our Branch will continue to try to expedite the process in any way we can.

Further on the political front, following the recent visit of the Minister for Health Stephen Donnelly to the hospital, local TD Frank Feighan made representations to the Minister using background information supplied by our Branch. A response to Deputy Feighan's intervention is expected shortly.

### FUN RUN DELIVERS

A run and walk organised by a group of local women delivered one of the biggest donations to IKA Sligo

Branch in recent times.

The Killennummery Women's Group 5k fun run and walk raised a huge €5,851 for the benefit of kidney patients and their families.

The event was in memory of Doctor Orla Banks of Kevinsfort, Sligo, who passed away after a short illness at Sligo University Hospital in November 2022. The 31-year-old doctor had worked in the paediatric department at the hospital.

Several winners took home prizes, donated by the organising ladies, along with numerous spot prizes gifted by businesses in the area.

All present enjoyed refreshments served in Killennummery Community Centre which was also the venue for registrations.

Orla's parents Tommy and June Banks attended the walk as did



members of our Sligo Branch.

Afterwards June Banks thanked all who supported the event in any way.

Sligo Branch Chairman Sean Fowley thanked Killenumbery Women's Group and Thelma Banks for choosing the IKA as the beneficiary charity this year.

### TREASURE HUNT WINS FOR IKA



*Jim congratulates treasure hunt winner Ann Marie Keane.*

Thanks to Jim Doyle who raised €1,250 for our Branch in the Ransboro St Stephen's Day Car Treasure Hunt which he organises annually. Thanks to all treasure hunters and sponsors Coolera Dramatic Society.

### MEDICAL DEVICE FIRM - ARROTEK



*Deirdre Caheny and Ger O'Carroll of Arrotek Medical make the presentation to Sligo Branch Chairman Sean Fowley.*

Finisklin based Medical device design consultancy firm Arrotek has again come up trumps with a generous donation to our Branch for the support of renal patients.

The 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.

### JOIN OUR BRANCH

Our Branch invites new members to help with our voluntary work, on behalf of kidney patients in Sligo. If you are available to help out in any way please contact the Chairman Sean Fowley on 087-6211817 or Secretary Geraldine McHugh 086-8142002.

# WEXFORD

By MARIA DONLON

*34 brave people who took part in the annual Christmas day swim in Ballinesker Beach*



A group of 34 people braved the elements on Christmas day for the annual swim at Ballinesker Beach and collected €925 for the IKA. Trish Boyce completed her 'Dip a Day in December Challenge' on December 31st and presented a cheque to the Wexford Branch, on January 24th for €2,155. Trish collected a total of €4,200 and also presented a cheque to St

Damiens Ward, Beaumont Hospital.

Thank you to Trish and her friend Celine Tracey who both braved the elements every day to complete the challenge.

The Wexford Credit Union annual 5k night run took place on February 8th. Almost 400 people took part on a very wet and windy night. On the day of the launch in January, Wexford Branch received a cheque for €4,055 from High Meadows Community Hub, the proceeds from the 2022/2023 night run.

Ann O'Hara organised a fundraiser in Eurospar, Bunclody on February 16th which raised a total of €1,303 on the day. The winner of the €100 Eurospar shopping



*Walter Kent and Eddie Kehoe, IKA, with members of Wexford Credit Union and High Meadows Community Hub launching the annual 5k night run*

voucher was Martha Willis. Thank you to Ann and to Eurospar, Bunclody, and to all who helped out during the day.

Our thanks also to Kiltealy Community group who donated all proceeds of their St. Patrick's Day parade to the IKA.

We offer our sincere sympathy to our members John Murphy, Ray Doyle, Rosemary Rochford and Conor Kinsella who all suffered bereavements recently.



*Ann O'Hara and Aggie McHale collecting at Eurospar Bunclody*



*Trish Boyce presenting a cheque to Wexford Branch IKA, proceeds from her recent fundraiser 'Dip a day in December'. Back (l-r): Maria Donlon, Eddie Kehoe, John Boyce. Front (l-r): Walter Kent, Celine Tracey, Trish Boyce, Liam Buttle.*



# TIPPERARY

By MARY ADAMSON



Paul & Mary Adamson and Paul O'Dwyer

## WINTER GATHERING

The Tipperary Branch had a lovely get together in December in the Anner Hotel, Thurles. Our officers spoke about their journeys and experiences as patients. Mary Adamson introduced the peer support volunteer service to members and Joan Gavan spoke about the Living Wellness programme.

## CHRISTMAS CONCERT FUNDRAISER

The Templemore Parish Group performed a Concert at Christmas which was an outstanding success. The music was uplifting and thoroughly enjoyed by a huge crowd in the local Church. They divided the proceeds raised between three charities one of which was the IKA. They donated €5,000 which was accepted on behalf of the IKA by Anne Hackett (Tipperary IKA Chairperson). She thanked the folk group for this generous donation and in particular Cora Fogarty whose



Cora Fogarty ( Templemore Folk Group) Anne Hackett ( IKA Tipperary) and Frank Fogarty (kidney transplant recipient).



Members at our recent meeting in Thurles.



Legendary cyclist Sean Kelly and Francis Hogan.

husband Frank received a kidney transplant two years ago.

## THANK YOU

Congratulations to the Duggan brothers and team who cycled 100 miles around the Slieve Bloom mountains last August to mark 100 years of construction. They raised the grand total of €30,000 which was equally divided between three charities including the IKA, for which we are truly grateful. Legendary cyclist 'The King' Sean Kelly cycled the event along with IKA branch member Francis Hogan.

## ORLA OVERCOMING CHALLENGES

We would like to send our very best wishes to Orla Hogan (Branch Secretary). In her lifetime she has undergone four kidney transplants, two from deceased donors and the other two living donor kidney transplants were from her mother and brother.

A popular member of Transplant Team Ireland she has proudly represented Ireland at World Transplant Games and European Transplant Games which she has medalled at. While the donor kidney, which she received from her brother Cathal in 2008 is functioning well, she has experienced other health challenges recently including surgery

in late 2023 for partial amputation of a limb. She has displayed remarkable bravery and positivity throughout.

As a valued member of Nenagh Masters Swimming Club for years, the Club organised a Swimathon event in Orla's honour at Nenagh Leisure Centre on 10th March. Showing extraordinary

resilience, she participated in the event despite her recent surgery. Orla is a trooper who always has a smile on her face and is an inspiration to all of us.

## SYMPATHIES

Our deepest sympathies to Deirdre Crowe and family on the recent bereavement of Ned, beloved husband and dad. Ned was an active member of the IKA and will be greatly missed. Thanks to the family and friends for donations to the IKA following their bereavement.

## RECENT TRANSPLANT

Our best wishes to Daniel O'Connell in his recovery post-transplant.

## BRANCH MEETING

The Branch held a meeting in the Anner Hotel, Thurles on Tuesday February 20th. It was great to see so many faces again and the informal chats and sharing experiences starting up again.

The Tipperary Branch were at ALDI stores on March 16th to promote kidney health awareness for World Kidney Day and fundraise through the sale of the IKA forget-me-not flower emblems. ALDI store locations included Clonmel, Cahir, Thurles, Nenagh, Roscrea and Tipperary.



# GALWAY

By Eoin Madden



Organ Donation Nurse Manager with the Saolta Group, Gillian Shanahan joined the Galway Branch to share her experiences liaising with and supporting donor families during difficult times. Gillian is pictured on the left with committee members Eoin Madden, Michelle Geraghty, Bernie Coyne and Peadar O'Hici.

## BRANCH MEETING IN NEW VENUE

On February 19th, we held our first meeting for some outside of the city. It was held in the impressive Oranmore Community Centre. It was a lively meeting, with some new members, made all the more lively by the sound of Line Dancing coming from downstairs!

Tribute was paid to staff in Donor House who helped one member with holidays recently and another who was provided support.

The meeting began with a minute's silence for Peter Greaney, may he rest in peace. Our events won't be the same without Peter's organisational efforts and sense of humour.

Our March meeting was also held in the same venue and was all about preparation for World Kidney Day.

We were excited to welcome Rhona Black who was transplanted recently and Alceina O'Brien who came to our recent meeting straight from her dialysis session.

## PLANET PAYMENTS



Eoin Madden and Alma Murray

Eoin Madden's employer Planet Payments, a multinational software company who specialise in currency conversion and tourist tax refunds, held a St. Patrick's Day fundraiser in their Galway office. Staff were provided a full Irish breakfast, including vegan options, Tayto sandwiches and even Guinness Zero!

It was all organised by the wonderful Alma Murray, HR Leader

for Planet in Ireland. Alma's granny, Teresa Forde RIP, was well-known by those attending BBraun Dialysis Unit in Galway. Teresa was on dialysis for nearly 14 years but kept a very positive attitude throughout.

Thanks to Alma, money raised by Planet employees, throughout March, as part of their Raising and Giving Month, will be shared by the IKA and three other charities.

## BERNADETTE GLYNN



Ruth McGann and Bernadette Glynn.

On March 2nd, Bernadette Glynn celebrated the 45th anniversary of her kidney transplant. Bernadette currently holds the record for having the longest surviving cadaver donor kidney in Ireland. Bernadette's kidney function remains excellent 45 years later.

Many members will know that Bernadette's late husband, Albert, was a founding member of the IKA, in Dublin.

Ruth McGann presented Bernadette with a bouquet of flowers to celebrate the milestone transplant anniversary, at Bernadette's home in Peterswell.

## NEXT MEETING

Hope to see you all soon at our next Galway Branch meeting in Fionntarlann, Westside on April 15th at 7.30pm.



Pictured at our branch meeting is Michelle Moran, Alceina O'Brien, Rhona Black, Peadar O'Hici, Peter Conboy, Christine Curley and Eoin Madden.



# DUBLIN NORTH

By CHLOE KINAHAN & COLIN MACKENZIE



Charlotte Frisby, Captain Ward Frisby, Lady Captain Phil Moran, Lisa Fitzgerald (IKA), Brian Carney, North Dublin Branch Treasurer and Eddie Frisby (husband to Vera, retired branch member of the IKA and who also managed the Tramore Waterford Homes for many years).

## HUMAN TISSUE BILL

On February 21st we made the trip to Dáil Eireann at the invitation of Senator Mark Daly, to be present for the passing of the Human Tissue Bill, presented by the Minister of Health Stephen Donnelly.

Dublin North was represented by Colin Mackenzie, the former national honorary Chairman and Board Member Chloe Kinahan with her children, Ali and Sam (a kidney transplant recipient). The IKA was mentioned by both Government and Opposition in the Dáil Chamber as was Sam Kinahan and another transplant recipient child, Ally Whitston who attended with her mother Michelle. Both children were observed in the gallery and visibly acknowledged by the Minister and the Leas Ceann Comhairle.

## THANK YOU COLETTE

We are very grateful to Colette Fox who stepped in as Secretary of Dublin North at a difficult time for us. She has now retired from the position, but we shall miss her efficiency, diligence and friendly support over the past couple of years. Colette's late husband Stephen (RIP) was a valued member of Dublin North, and we wish Colette and her daughter Sarah, every good wish for the future.

## CHRISTINE'S 50TH KIDNEY ANNIVERSARY

On a snowy afternoon on Friday, 1st March, Chloe and Sam Kinahan had the fortune of visiting Christine Kelly and her family. The duo visited on behalf of the IKA to acknowledge the 50th anniversary of Christine's successful kidney transplant, a gift she received from her late sister Mary. Sam and Christine compared scars and swapped stories from their kidney journeys and Sam



Chloe and Sam Kinahan with Christine Kelly

presented Christine with flowers to acknowledge the event, the second ever living donor transplant in Ireland which took place in 1974.

Sam also brought flowers for the family of Christine's late sister Mary to remember her and her generous gift. Chloe said the meeting gave her such hope for the future as Sam moves towards the 5th anniversary of his successful transplant, a gift he received from his dad Ivan in 2019.

## AN EVENING WITH RED HURLEY

Dublin North are pleased to present this event. After expenses all proceeds will go to the IKA. By the time you read this, tickets will have gone on sale.

*An Evening with Red Hurley* and guests will include Eugene McCarthy and singers, the Malahide Golf Club Choir directed by Philip Mackenzie, and the Music of Patricia Mackenzie, performed by Colin and Philip and Bryan Hoey.

## BRANCH MEETINGS

After a great Christmas event in the Skylon Hotel, where we were serenaded by our Branch member Ron Grainger, who kindly brought his guitar for what is now a tradition in the North Dublin Branch, we have resumed the Branch meetings.

Branch meetings are typically held on the last Monday of the month in Baldoyle. All newcomers are welcome – for more information, please email [dublinnorthika@gmail.com](mailto:dublinnorthika@gmail.com)

## ST. MARGARET'S GOLF CLUB

The IKA was delighted to be chosen by St Margaret's Golf and Country Club for their charity of choice for 2024.

Transplant recipients Lisa Fitzgerald, a joint Fundraising Manager at the IKA, and Brian Carney, from the IKA's North Dublin Branch and a member of St. Margaret's Golf Club, attended a Captains' Day event on March 9th where they shared their health experiences and spoke about the services the IKA offers.

The IKA expresses its gratitude to Captain Ward Frisby and Lady Captain Phil Horan, staff and members of St. Margaret's for their valuable support.



# DUBLIN NORTH CHRISTMAS PARTY PHOTOS BY ANTHONY BYRNE







Hello and welcome to all our members in the Dublin East and Wicklow Branch. It feels like spring has finally sprung, and we hope that everyone is keeping well.

### CHARITY TRACTOR RUN

For the second time, Glencullen local, Ger Mulvey held a tractor run in Glencullen on Sunday, 24th September in aid of the IKA. The event raised an incredible €3,125 for our Branch and he presented a cheque to our Chairperson Bernie Dwyer and her husband Michael outside Johnnie Fox's Pub.

We were delighted to receive such a generous donation, once again, from the tractor enthusiasts and community! Well done Ger!

### THANK YOU PRIZE SPONSORS

We had promised our Christmas Lunch raffle prize sponsors an acknowledgement which was unfortunately missed out on in the Winter edition of *SUPPORT*.

Prizes were graciously donated by

## DUBLIN EAST & WICKLOW

By RACHEL O'HORA



Bernie Dwyer (centre) with Ger Mulvey, (third from left) presenting a cheque for proceeds from the tractor run to Michael Dwyer.

Haven Pharmacy, Killiney; Total Health, Johnstown Road; McCartan's Pharmacy, Shankill; Peter Mark, Killiney SC; Tierney Gifts, Dun Laoghaire; Twomey's SuperValu, Deansgrange; The Enniskerry Inn, and Teach O'Hora, Co. Mayo.

Thanks to the sponsors of the prizes which were very much appreciated by the winners!

### WORLD KIDNEY DAY

Our Branch had numerous fundraising and information events between March 13th-17th to mark World Kidney Day.

We had an information stand in St Vincent's Hospital for their Annual Staff Health Fair on Wednesday 12th March.

We were delighted to have been invited back this year after a very

successful attendance at it last year.

On Thursday, March 14th, which was World Kidney Day, the Lexicon Library kindly gave us space to fundraise and share information about the awareness campaign.

On Saturday March 16th we were located at three Aldi Stores where we sold Forget-Me-Not flower emblems and disseminated information about chronic kidney disease, dialysis and transplant. Our aim was to increase awareness of kidney health to a wide variety of people!

### CONDOLENCES

The Dublin East and Wicklow Branch would like to extend our heartfelt sympathies to long-standing member, and very enthusiastic fundraiser, Gloria Proby on the sad death of her beloved husband Allen, RIP.

Our sympathies are also extended to their children Jenny, Jonathan, David and Christopher, along with their treasured grandchildren.

We would also like to express our sympathies to the family and friends of Ruth Gorman, former receptionist at the IKA, who sadly passed away in February. Many of our members, and particularly past committee members, remember Ruth with great fondness.

Ar dheis Dé go raibh a n-anamneacha dílis.



Allen Proby

## Acknowledgements of Deceased Loved Ones

At a difficult and sensitive time, the Irish Kidney Association (IKA) wants to acknowledge the recent passing of your deceased loved one in a respectful and personal way. We receive requests for inclusion of expressions of sympathy and life stories in *SUPPORT* magazine, from families of loved ones who have passed away. To ensure consistency of approach, guidance has been developed regarding inclusion of obituaries based on the deceased's person involvement and role with the IKA. The guidance allows for expressions of sympathy in other ways outside inclusions in *SUPPORT* magazine.

Please contact your Branch officer if you have any queries in relation to this guidance which outlines what can be included.



# DUBLIN SOUTH

By GERRY McKENNA

## BRANCH MEETING

Dublin South Branch had our first Branch meeting of the New Year at Rua Red Arts Centre in Tallaght on March 5th last. It was very well attended, and many members expressed how happy they were to be able to meet face to face again. After covering a diverse range of IKA services in the agenda we discussed upcoming plans for our Branch.

Recent Branch activity included events around World Kidney Day, made possible by our volunteers who gave so generously of their time over three days, in Tallaght Library, The Square, Tallaght and Aldi stores in south Dublin.

## VOLUNTEERS NEEDED

We are seeking volunteers to promote Organ Donor Awareness Week, to distribute organ donor cards and other materials at various

locations in South Dublin. If you wish to volunteer or can suggest a good location for this activity, then please contact Gerry, details below.

Last year we had great help from members at Nutgrove and The Square S.C. The IKA provides tremendous support to all of us patients, families and carers, and we should do our best to help promote their work and to increase the awareness of the ongoing need for Organ Donors. Please help us if you can!

## COFFEE MORNINGS/WALKS

We will be organising Coffee mornings and walking activities over the coming months in different parks around the South Dublin area.

## FOLLOW US

Details on all of the above will be on our Dublin South IKA Facebook



page and WhatsApp community <https://m.facebook.com/SouthDublinIKA/>

Like to join our WhatsApp group to be kept up to date on upcoming activities? Please contact Gerry on

☎ 086-0268223 or ✉ [ika.dublinsouthbranch@gmail.com](mailto:ika.dublinsouthbranch@gmail.com)

## BRANCH MEETINGS

Our Next Branch meetings are planned for: Wed April 3rd, Thurs May 2nd, Tues June 4th and Wed July 3rd, see Facebook and WhatsApp for details.

# CAVAN/MONAGHAN

By KARL CRONIN



Enjoying the Christmas event James Fitzsimons and Zeny Lasoria.

We had a lively Christmas dinner for patients at Cavan Renal Dialysis Unit and thanks to all who attended our recently Branch meeting.

The 18th Annual Mullahoran Sponsored Walk / Run will take place this year on Easter Sunday, 31st March. This 8.5 mile route brings you through the Cavan countryside from Ballinagh to the Hideaway pub in Mullahoran where a warm welcome awaits all participants.

The IKA has been a long-standing beneficiary of this walk, along with other charities since its inception and to date, over €203,000 has been raised for 19 very worthy organisations.

Follow Mullahoran Annual Sponsored Walk/Run on Facebook for updates and we would love to see as many as possible join us on the day.

Pictured right: At the Christmas dinner Mel Maguire and Siobhan McGreal



Pictured at a Cavan/Monaghan Branch meeting recently were (front l-r): Joy Kennedy, Hunter Smyth, Yvonne Smith, Aodhagan Cullen, Karl Cronin, Secretary/Treasurer and Paul Donohoe, Chairman. (back l-r): Rose Dalton, Adrienne Donohoe, Mairead McMeel, Delia McCaffrey and Hugh McCaffrey.



We had a busy December in 2023 as we marked 40 years of dialysis in University Hospital Waterford (UHW)

Touching up and a few remedial works are getting underway in the Riverstown Holiday Apartments, Tramore in preparation for our Summer visitors. We were delighted with the responses to visitor experiences last year and hope to work on improving further as the year progresses. We look forward to welcoming you all again for the 2024 season.

We had been on a break from Branch meetings since November and resumed on March 12th with the first Branch meeting of 2024 at St. John's Pastoral Centre, John's Hill.

We covered a short agenda which was followed by tea, cakes, and a chat. We would love to see some new volunteers this year. So if you can spare 6-8 hours over the year to help out, do come and join us.

There were some very successful fundraisers in 2023, two of which involved the DC Marathon 2023 with Ailish O'Keeffe from Clonmel, raising €5,310. Also, Noelle Conway from Dungarvan and her walking buddy Marie Moore completed the Dublin City Marathon 2023 raising €1,017 for the Waterford Branch.



Marie Moore, Noelle Conway

We continue to express sincere thanks and gratitude to members, volunteers and the general public for their on-going support of the work we do for patients and their families in the area.

Please feel free to contact me if you need any further information on accessing supports and services available through the IKA at [franceswaterfordika@gmail.com](mailto:franceswaterfordika@gmail.com)

# WATERFORD

By FRANCES MOYNIHAN

*I had the pleasure of meeting Ailish O'Keeffe, a remarkable young woman, recently when she called to my home to present me with a cheque for a sizeable sum of €5,310 for the Waterford Branch IKA. Truly a lady with a determined mindset Ailish wanted to honour her beloved friend Kate Quinn, a young woman who passed away in February 2023, by taking on the Dublin City Marathon 2023 for the first time, and raising funds for the IKA.*

*The following are Ailish's own words explaining her reasons for taking on her first truly 'marathon' event.*

"February 15th marked Kate's first anniversary. The past 12 months have proved to be nothing short of a rollercoaster of emotions. To give you a short back story, I first got to know Kate through a mutual friend. Although I can't recall our first introduction, from that point on we continued to get to know each other.

"We continued to meet up for cinema trips, lunches, or nights out, and our relationship continued to grow, and over time I realised I was beyond blessed to get to call Kate my friend.

"I have such fond memories of her. Kate always had a defiant smile and that is one thing I always admired most about her. She never let being unwell dictate how she lived her life. She never took a day for granted and she was a true inspiration to me.

"That is one thing I will take from Kate's passing, that life is truly a gift and try to find some



Ailish O'Keeffe and Frances Moynihan

goodness in each day. Although I towered above Kate in stature, it was her I always looked up to.

"I wanted to do something in Kate's honour and in June 2023 I took on my biggest challenge to date. I chose to run the Dublin City Marathon. While doing so I wanted to raise funds for the IKA, a cause very close to my heart.

"I was completely blown away with the support throughout my training from both my family and friends and the generosity from the people of my hometown Clonmel. While I was training I was approached by people asking me what I was training for. It gave me an opportunity to keep Kate's memory alive as well as spread the importance of organ donation – I think we all assume it will never happen us or anyone we know until the time comes.

"I hope to continue to spread awareness of the importance of organ donation, along with the work done by the IKA and share the message 'Become an organ donor and give the gift of life'.

"I am delighted to say the total raised and donated to the IKA was €5,310".

## SUPPORT DEADLINE

The deadline for submission of Branch notes and high resolution photos for the **SUMMER** edition of **SUPPORT** is **25th June, 2024.**





# IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

## MEMBERSHIP APPLICATION FORM



BLOCK CAPITAL LETTERS PLEASE:

Mr.  Mrs.  Ms.  FIRST NAME: \_\_\_\_\_

SURNAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

POSTCODE:        TEL: \_\_\_\_\_ MOBILE: \_\_\_\_\_

EMAIL:

We record this information in line with the Constitution of the IKA. You must be 18 years of age to become a member of the Association.

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 Post?  YES  NO  
 Please tick 'No' if your household is already receiving it Or Email?  YES  NO

Can we correspond with you for notices of Annual General Meeting Email?  YES  NO  
 of the Association and Annual Director's Report by

Would you like to receive information on activities from your local  YES  NO  
 IKA branch which entails us giving them the data from this form?

Would you like to receive information on the IKA Transplant & Dialysis  YES  NO  
 Sports and Fitness which is based in Head Office?

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](http://www.ika.ie))

I subscribe to (sign up and accept) the Constitution of the Irish Kidney Association CLG (Company Limited by Guarantee).

SIGNATURE: \_\_\_\_\_ DATE: \_\_\_\_\_



# IKA DIRECTORY



IRISH KIDNEY ASSOCIATION CLG, Donor House, Block 43a, Parkwest, Dublin D12 P5V6

Telephone: 01-6205306 | Email: [info@ika.ie](mailto:info@ika.ie) | [www.ika.ie](http://www.ika.ie)

RENAL SUPPORT CENTRE, Beaumont Hospital, Dublin D09 Y5R3 - SEQUESTERED

Telephone: 01-6908887 | Email: [renalcentre@ika.ie](mailto:renalcentre@ika.ie)

MUNSTER SUPPORT CENTRE, Glenflesk, Wilton Avenue, Bishopstown, Cork T12 X6XP

Telephone: 01-6908887 | Email: [munstersupportcentre@ika.ie](mailto:munstersupportcentre@ika.ie)

## LOCAL BRANCH SECRETARIES

### CARLOW

In transition.

Tel:  
01-6205306

### DUBLIN EAST + WICKLOW

Rachel O'Hora

2 Tobernea Terrace  
Blackrock  
Co. Dublin A94 V6F8  
Tel: 085-1528436  
[ika.dublineastwicklow@gmail.com](mailto:ika.dublineastwicklow@gmail.com)

### KILDARE

Michelle Horan

Farishta  
Tonlegee, Athy  
Co. Kildare  
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