

SUPPORT



SUMMER 2023

SUMMER

giveaway

**FAMILY* MINI BREAK AT THE
CLAYTON HOTEL
DUBLIN AIRPORT
AND A FAMILY DAY PASS
TO DUBLIN ZOO**

SEE PAGE 45



**ORGAN DONOR AWARENESS
WEEK REPORT**

WORLD TRANSPLANT GAMES
€100 HARVEY NORMAN VOUCHER TO BE WON
– SEE PAGE 33

Editorial



Carol Moore, Chief Executive, IKA



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Welcome to our Summer issue of
SUPPORT.

It is hard to believe we are already half through the year. So much has happened since our last **SUPPORT** magazine issued.

We had a very enjoyable time at the **World Transplant Games** in Perth. The 14 members of Transplant Team Ireland embody the success of organ donation and were wonderful ambassadors for their country and their donors.

Over half the team travelling to the World Games were competing for the first time. Many new friendships were formed. I had the pleasure of meeting lots of inspirational people including an altruistic kidney donor.

The sports facilities were incredible and the Australians looked after us really well. Full report on pages 31-42.

When I returned from the Games it was straight into preparing for **Organ Donor Awareness Week**. It was heartening to see that community participation with the campaign is returning to pre-COVID-19 levels. It was great to see some Branches running events using our newly developed **Teacht le Chéile** event guidelines. See pages 4-13.

We have taken a significant step to address the delay by Beaumont Hospital in returning the Renal Support Centre to us as



per the Memorandum of Understanding. On May 31st, we issued a 'Notice of Termination and To Quit' to Beaumont Hospital, requesting the facility back by July 1st, 2023. We did so reluctantly, as we value our working relationship with the hospital.

We trust that this notice will prompt a timely response from Beaumont Hospital, allowing us to re-establish the facility for its intended purpose. We understand the impact on our members and appreciate your patience and support during this unusual period. Thank you for your continued support as we work towards resolving this situation.

* * * * *

There were some delays in the building work with progress slower than expected, in the new Support Centre in Cork and we now expect to see it open in the Autumn. Full report page 61.

Demand for our services continues to increase as the cost of living puts so much pressure on people and there is now more



FRONT COVER

Transplant (tx) recipients gathering for a photocall at St. Vincent's University Hospital to mark **Global Surgery Day**.
Seated: **Ciara O'Connor**, Tralee, Co Kerry (liver tx), **Rachel O'Hara**, Bohola, Co. Mayo (kidney and pancreas tx), and **Martin Malinowski**, Castleblayney, Co Monaghan (heart and liver tx).
Standing: **Gillian Curtis**, Portlaoise, Co Laois (heart tx), **Carol Moore**, CEO, IKA, and **Lisa Fitzgerald**, Dublin 24 (kidney tx).

Photo: **Conor McCabe**

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Renal Support Centre, Cork



awareness of the services we provide. If demand for the services continues to grow at current levels, we may need to look at more recruitment or else start operating a waiting list.

We held an Information Day for counsellors which received very positive feedback (see pages 52-53). A reflection of the esteem in which our free counselling service is held is that our National Coordinator of Counselling Services, Aoife Smith, has been selected for a regional award by the Irish Association of Counselling and Psychotherapy (IACP). These awards recognise an individual who has made a substantial contribution to the profession of counselling and psychotherapy.

We are fortunate to have staff of this calibre working with us who are so very dedicated to meeting the needs of patients. Some of these staff are themselves renal patients or have family who are renal patients and their lived experience really improves our understanding of the needs of patients and what we need to do to help.

You'll be able to access information about our team and learn more about their backgrounds and roles on our website <https://ika.ie/team/>

In common with many other charities, we are experiencing problems in retention and recruitment, due to lower pay scales and benefits in the sector. Our receptionist Jesse Brien has moved on and been replaced by Barbara Morris who brings considerable experience of working with patients.

Sarah Buchanan, a kidney patient, has joined us on a one-year contract to help get the Support Centres in Cork and Beaumont open.

We did recruit a Volunteer and Organisation Development Manager but disappointingly they resigned after just two weeks as they received a more attractive job offer elsewhere.

We hope to have employed a part-time fundraising contractor by late summer. This role is badly needed to support all the excellent work that our community is currently doing to raise funds.

BRITISH TRANSPLANT GAMES 2023

The British Transplant Games 2023 will be held in Coventry at the end of July.

We wish the Irish participants, which include five transplant children, and their travelling supporters, every success and an enjoyable experience.

The Human Tissue Bill was brought to the Health Committee in June and we had a face-to-face meeting with Department of Health officials. It is likely the Bill will come back to the Dáil in the Autumn with a view to passing all stages in the Oireachtas in the Autumn also. We will continue to advocate for changes. See article on pages 22-25.

There has been a terrific response of over 300 replies to our survey of patient experiences in the healthcare system. We would, however, like to hear more from patients who are on dialysis. If you have not yet had a chance to participate, or know of a member that is still to complete it, it is not too late to do so. Every survey counts.

Planning for the Service of Remembrance & Thanksgiving is well under way. This year, in order to ensure a pleasant experience for everyone, and estimate food requirements, we are asking people to register their interest in attending. See details on page 27.

Due to pressure on space, in this issue, we have held some articles over until the Autumn issue.

I hope you get to enjoy the Summer. If you are thinking about taking a holiday you might like to read our holiday section (pages 44-48).

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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Working together for Organ Donor Awareness Week

Organ Donor Awareness Week 2023, held from May 20 to May 27, marked significant milestones in organ donation and transplantation in Ireland, including the 60th anniversary of the first transplant, a kidney transplant.

Led by the Irish Kidney Association (IKA), in association with Organ Donation Transplant Ireland (ODTI), the week-long event aimed to raise awareness about the importance of organ donation and encourage people to share their organ donation decision with their families.

The campaign's message, 'DON'T LEAVE YOUR LOVED ONES IN DOUBT, #LeaveNoDoubt,' resonated with the public, thanks to the collective engagement of individuals including IKA volunteers, sponsors, patient advocacy groups, hospitals, the HSE and Department of Health, and other organisations invested in organ donation and

By **CWEN O'DONOGHUE**

transplantation.

A crucial factor in the success of this year's Organ Donor Awareness Week and other awareness campaigns is the willingness of individuals to publicly share their personal stories, related to organ failure, transplantation, and organ donation. Significant work goes on behind the scenes to identify personal stories that can attract media interest.

These stories play a significant role in raising awareness, educating the public, and fostering empathy towards the cause. By sharing their experiences, individuals provide real-life examples of how organ donation can profoundly impact and transform lives. Each story has the potential to inspire others and spark meaningful conversations about organ donation.

The media provides the platform to amplify these stories, thereby raising awareness and fostering a supportive environment for organ donation and transplantation.

The campaign's poster, featuring the theme 'Don't Leave Your Loved Ones in Doubt, #LeaveNoDoubt,' played a vital role in conveying a thought-provoking and unambiguous message. The deliberate and simplistic design, with large block capital letters in white on a purple background, captured the attention of the public. It emphasised the public's role in supporting organ donation by ensuring their families are aware of their decision regarding organ donation.

The poster, available in English, Irish, and Polish, can be displayed year-round, serving as a constant reminder of the importance of organ donation.

AN POST

One of the key supporters of the campaign was **An Post**, which significantly contributed significantly to raising awareness about organ donation. In its 350 largest and busiest post offices nationwide, newly designed organ donor card and fact-files were prominently displayed, ensuring that patrons had access to the necessary information.

Furthermore, in 295 of these post offices, the campaign poster featured prominently on digital advertising screens, leaving a lasting impression on visitors. An Post's commitment to spreading the message of organ donation to staff and within local communities played a crucial role in creating awareness.

Speaking about An Post's support of the campaign Lucy Murray, its CX & Marketing Director said, "We are delighted to support the Irish Kidney Association ahead of Organ Donor Awareness Week 2023. 'Don't leave your loved ones in doubt' is such an important message and we're helping to share this across communities in our network of Post Offices. Thousands of families across Ireland have benefited from the gift of organ donation and we want to play a part to grow this number by encouraging people to sign up and carry an Organ Donor Card."

Photos by **ANDRES POVEDA** and **CONOR McCABE**



Pictured at the announcement of An Post support for the Organ Donor Awareness Week campaign at St. Andrew's Street Post Office were: Susan Mulligan, a kidney transplant recipient, Carol Moore, CEO, IKA, and Lucy Murray, CX & Marketing Director, An Post.

Below:
Carol Moore, Chief Executive, Irish Kidney Association, Michael Cooper, Ratoath, Co Meath, who is both a bone marrow transplant recipient and a double lung transplant recipient; Susan Mulligan, who received a kidney transplant in 2019, a native of Castlereagh, Co Roscommon, now living in Kilcock, Co Kildare; Conor Nott, Retail Marketing Manager, An Post and Lucy Murray, CX & Marketing Director, An Post Retail.

continued next page





Senator Mark Daly; Christine Hegarty, Road Safety Authority; Dr. Catherine Motherway, ODTI; Carol Moore, IKA.

ROAD SAFETY AUTHORITY (RSA)

The Road Safety Authority (RSA) also joined forces with the IKA for a photocall, commemorating the 10th anniversary of the introduction of **Code 115**. Despite there not being any dedicated awareness campaign, around the introduction of Code 115, over 1.485 million individuals, or 46.3% of all drivers, indicated their willingness to be an organ donor on their driver's licence application, signifying the public's growing support for organ donation. Representing the Road Safety Authority at the national launch of the campaign was Christina Hegarty, Road Safety and Education Manager.

Sam Waide, CEO Road Safety Authority said: "The RSA are happy to support IKA in their 'Leave No Doubt' campaign. We hope that any individuals renewing their license or applying for a permit or licence for the first time will think to have a conversation with their loved ones, based on their personal preferences."

FAIR CITY

The popular soap opera *Fair City* incorporated a storyline centred around kidney failure, and its landing during Organ Donor Awareness Week 2023 was guided by the IKA.

The IKA's Colin White supported *Fair City* scriptwriters in their research, to ensure the storyline accurately reflects real life experience of kidney failure and dialysis. The campaign poster was prominently displayed in the background of some scenes, creating

additional exposure, and reaching a broad audience of 300,000 to 400,000 viewers per episode. The power of TV entertainment, combined with the campaign's message, helped to foster a greater understanding of organ failure and transplantation. See pages 14-15 for full report.

PHARMACIES

Many independent pharmacies and pharmacy chains including *CarePlus*, *Staywell*, and *Life Pharmacy*, showed their support for the campaign by displaying the poster on their digital screens and displayed countertop boxes containing organ donor cards instore. The Irish Pharmacy Union's magazine *IPU Review* promoted the campaign to its members in an article in the May issue of its magazine, which had a campaign poster inserted for pharmacies to display.

OTHER ACTIVITIES

The IKA's branch network was active in organising organ donor awareness

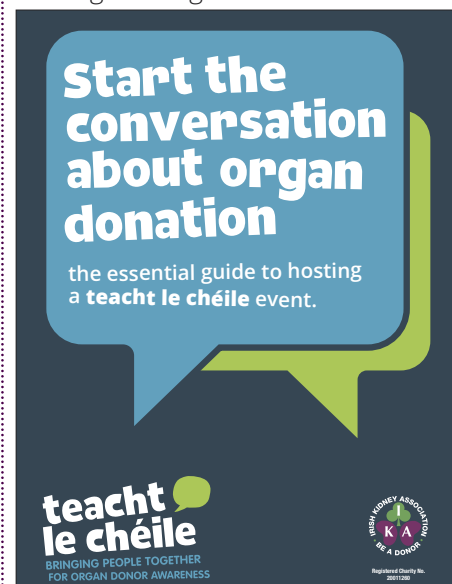


Life Pharmacy display.



CarePlus Pharmacy display.

events and in supplying and replenishing stocks of organ donor cards in various locations including retail outlets and workplaces. The IKA created a toolkit entitled '**Teacht le Chéile / Coming Together**' which guides people on how to organise and run events encouraging people to discuss organ donation, such as coffee mornings, picnics, and other social gatherings.



Aligning Organ Donor Awareness Week with other important events taking place at the same time, such as **European Public Health Week** and **Global Surgery Day** further enhanced its impact.

To mark **Global Surgery Day**, which took place on May 25th, the IKA held a photocall at St. Vincent's University Hospital, with transplant recipients and three transplant surgeons to celebrate the valued lifesaving work of transplant surgeons. You can read more about this on pages 18-20.

The Wheel, Ireland's national association of charities, community groups and social enterprises, supported the campaign by displaying the poster at their annual Summit Exhibition held at Croke Park and distributing organ donor cards with the card printed on their swag bags for delegates.

This year's shift



Eddie Flood at The Wheel Summit



Pictured left: Ireland AM presenters Muireann O'Connell and Tommy Bowe with (2nd from left) Naomi Dunleavy and (2nd from right) Dr. Catherine Motherway.



Clear Channel poster in Millfield Shopping Centre in Balbriggan.

in the timing of Organ Donor Awareness Week, moving it to the end of May instead of Spring, was influenced by Transplant Team Ireland's participation in the **World Transplant Games** in April. As part of its sports programme, the IKA coordinated Transplant Team Ireland's involvement at the Games which were held in Perth, Australia, and which also generated significant organ donor awareness and publicity.

On the penultimate day of Organ Donor Awareness Week, **Transplant Team Ireland** were guests of the Australian Ambassador to Ireland, Gary Gray, at the Australian embassy on St. Stephen's Green, Dublin.

You can read about this in the centre pullout/supplement with this issue.

MEDIA ACTIVITY

In a report generated through press monitoring company **RuePoint Media** who we use to monitor print and online media for published stories relevant to the work of the IKA, the publicity secured for Organ Donor Awareness Week in print media alone had an impressive reach of over 14.5 million people.

This extensive coverage not only increased awareness but also highlighted the importance of organ donation and transplantation in saving lives. The estimated value of this media support amounted to over €700,000.

This came just over a month after considerable media coverage on Transplant Team Ireland's participation at the World Transplant Games for which the media value, excluding radio and tv coverage was over €342,000 with a reach of over 8

million people. Concerns that media fatigue following the World Transplant Games might result in reduced coverage for Organ Donor Awareness Week, thankfully proved unwarranted.

Not included in these figures was the considerable amount of publicity secured through news and interviews on national and local radio and much of the coverage being shared online. Virgin Media's Ireland AM interviewed Naomi Dunleavy, the mother of organ donor Aaron Cantwell whose organs were donated when he passed away in 2022.

Joining her on the couch with presenters Muireann O'Connell and Tommy Bowe was Dr. Catherine Motherway, Clinical Lead, ODTI. Naomi was also interviewed by Ryan Tubridy on his **RTÉ Radio One** show.

Naomi and her husband David and son Adam organised a special **Ducky Deeds Swim Derby** at Aura in Navan which took place on the second day of Organ Donor Awareness Week and brought together donor families and transplant recipients. See pages 16-17.

Another TV interview took place on Virgin Media's **Tonight Show** with presenter Claire Brock who was joined by IKA's Chief Executive Carol



Michelle Geraghty and Carol Moore at Virgin Media.

Moore and kidney transplant recipient Michelle Geraghty.

Further awareness was generated through social media.

Looking at the two weeks around Organ Donor Awareness Week we saw significant increases in the reach on our social media platforms for the two-week period from May 13th-27th.

Facebook reach 38,732 (+133.7%)

Instagram reach 4,924 (+192.7%)

LinkedIn up 74.5%

Twitter reach 25,100 (+269%)

comparing months of April to May

Social Media hashtags for Organ Donor Awareness Week 2023 were **#LeaveNoDoubt** **#ShareYourWishes** and **#DonorWeek23** and people could tag the IKA when doing their own social media posts.

The success of Organ Donor Awareness Week 2023 was further bolstered by the generous support of free advertising from **The Irish Times** newspaper and **Clear Channel**, an outdoor poster advertising company. The commercial value of this combined sponsorship would have cost the IKA €45,500 (excluding VAT).

The Irish Times provided free advertising over three days of the campaign, significantly increasing the visibility of the message to its 286,000 daily readers.

Clear Channel played a crucial role in supporting the campaign and has done so for many years. This year they sponsored the cost of displaying posters on 30 digital sites at 20 shopping centres for two weeks surrounding the campaign period. This strategic placement ensured that the campaign's message reached a wide audience in high-footfall areas, maximising its impact.

National Launch of ORGAN DONOR AWARENESS WEEK



Front row: Prof. Emer Joyce, Transplant Cardiologist, Mater Hospital; Dr. Catherine Motherway, Clinical Lead, Organ Donation Transplant Ireland (ODTI); Robert McCutcheon, Chairman, Irish Heart & Lung Transplant Association; Minister for Health Stephen Donnelly; Philip Watt, CEO, CF Ireland; Carol Moore, Chief Executive, Irish Kidney Association (IKA); Senator Mark Daly. Back row: Prof. Jim Egan, Director, ODTI; Eddie Cassidy, Chairman, Irish Lung Fibrosis Association, (ILFA); Val Kennedy, ILFA, Gemma O'Dowd, ILFA and Christopher Nielson, Irish Liver Trust, Eddie Flood, National Honorary Chairman, IKA.

The national launch of Organ Donor Awareness Week, was held at the Mansion House in Dublin on May 16. Attending to officially launch the campaign was the Minister for Health, Stephen Donnelly T.D.

Greeting Minister Donnelly on his arrival and pinning the forget-me-not flower on his lapel, was kidney and pancreas transplant recipient Marie Fowley, from Sligo. The Minister and

guests were welcomed to the event by Eddie Flood, the National Honorary Chairman, IKA, himself a kidney transplant recipient.

Before the Minister's arrival attendees gathered for photos and interviews with the media in the Mansion House Garden.

Among those gathering were representatives of patient advocacy groups and the surgical, medical, and nursing profession as well as

Organ Donation Transplant Ireland.

Five transplant recipients representing Ireland's hospital transplant programmes including a heart, lung, liver, kidney, and kidney/pancreas, as well as a dialysis patient, and Naomi Dunleavy, the mother of an organ donor, all of whom would later share their stories at the live streamed launch, also gathered for photos and interviews outside in the garden.

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Marie Fowley pins the forget-me-not flower on Minister for Health Stephen Donnelly's lapel.



Transplant recipient Liam O'Connor (5) with Suzanne Kernan, Mairead Kinelough, and Prof. Atif Awan, CHI Temple Street hospital.



Kate Twohig



KATE TWOHIG, LIVER TRANSPLANT

Kate Twohig, a liver transplant recipient from Clonmel, shared her heartfelt story of battling autoimmune liver disease, Primary Sclerosing Cholangitis (PSC) and the life-changing impact of receiving a liver transplant.

After years of managing her illness with medication and check-ups, Kate's health took a turn for the worse, and she was placed on the transplant waiting list where she would remain for 23 months.

Faced with her mortality, she and her future husband Eoin embarked on a journey of embracing life, including getting married and channelling their shared musical talents into organising their first music festival in Clonmel.

With the support of a caring medical team at St. Vincent's University Hospital, Kate received her transplant in October 2022, seven months after her wedding, marking a turning point in her life.

Kate and her husband now plan for a future they once thought was out of reach and are currently planning their second music festival in Clonmel, 'When Next We Meet', which will be held at the end of July. www.whennextwemeet.ie

Newlyweds Kate Twohig and Eoin Hally.



Niall Whiteley



NIALL WHITELEY, HEART TRANSPLANT

Niall Whiteley, from Knavinstown, Co. Kildare, shared his heart transplant story. As he was adopted, he had no access to medical records indicating a family history of heart disease.

When he returned from a trip to India for work he became very unwell. He was diagnosed with Dilated Cardiomyopathy at Naas Hospital, by Consultant Dan O'Gorman, who referred him to cardiologist Vincent Maher at Tallaght Hospital.

After a course of medication he returned to good health which he enjoyed for several years. By 2017 he began to experience a slow decline in his health which had significantly escalated by 2019.

By the Autumn of the same year Niall and his family thought he was close to the end of life. The father of three collapsed and fractured his skull and was admitted to the Mater Hospital, where under the care of Prof Emer Joyce, he was placed on the Transplant Waiting List.

Just three days later, he received the call he had been waiting for – a donor heart was available.

Unfortunately, the first attempt was unsuccessful and the heart transplant operation did not proceed. Niall was put on a balloon pump which left him flat on his back and unable to move. Although this was very difficult and really tested his resolve he only had to wait a further three weeks until he underwent a successful heart transplant, leading to a slow, but well-managed recovery.

He expressed immense gratitude for the donor family who gave him the 'gift of life', allowing him to return to his work, coaching ladies football,

and his hobbies of fishing and shooting.

Niall praised the incredible work of medical and nursing staff in the healthcare system saying, "they don't get paid enough for all they do."

MICHELLE GERAGHTY, KIDNEY TRANSPLANT

Michelle Geraghty



Life with kidney disease can be a challenging rollercoaster ride, as described by Michelle Geraghty from Salthill, Galway, whose journey began with a diagnosis of Polycystic Kidney Disease (PKD) in 2000 after she developed septicaemia from a minor kidney infection.

Initially, following the diagnosis life returned to normal, and she enjoyed a successful career. However, by the time she was 34-years-old her kidney function declined, the impact of her kidney condition became more significant.

After Michelle's son Dylan was born, she had reached end-stage kidney failure.

By December 2020, Michelle had begun her dialysis treatment, Peritoneal dialysis, which became a routine for eight hours a night, seven nights a week. The search for a compatible donor proved difficult despite their being several willing living donors.

In August 2022, she received a call for a kidney transplant.

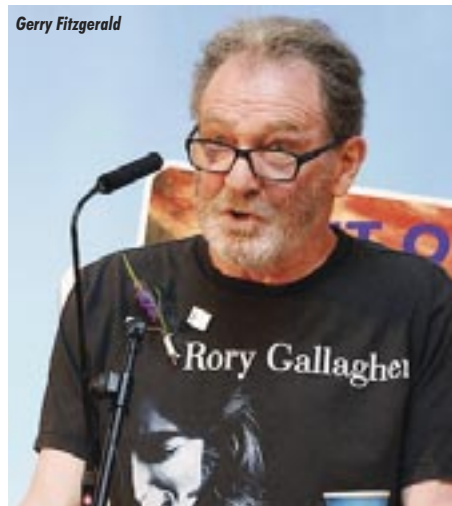
In her speech at the launch Michelle credited the selfless decision of the donor's family for making it possible for her 5-year-old son Dylan to finally have a healthy mother. She acknowledged the support she received from her husband Eoin, family, friends, medical teams in the Beaumont and Merlin Park Hospitals, and

continued next page

organisations like the IKA who, she said, played a crucial role throughout the journey.

You can read Michelle's article on overcoming obstacles around taking holidays as a kidney patient on pages 46-48.

GERRY FITZGERALD, SINGLE LUNG TRANSPLANT



Gerry Fitzgerald, from Tipperary Town, shared his gratitude to his donor for receiving a life-saving lung transplant in 2022.

Initially experiencing annual chest infections, Gerry didn't think much of it until his astute GP, Chris Ryan, suggested further investigation for possible Pulmonary Fibrosis.

Following tests, the diagnosis was confirmed, leaving Gerry with an incurable lung condition. He began medication and engaged in a physio and exercise program provided by the **Irish Lung Fibrosis Association** and the Mater Hospital. Despite his efforts, his lung function continued to decline. Consultant Lung Transplant Physician Michelle Murray informed him that he would need a lung transplant.

For two years, Gerry relied on 24-hour oxygen and faced significant physical limitations. Five false calls for potential donor lungs caused additional emotional stress and disappointment.

However, on the sixth call, Gerry finally received the life-saving single lung transplant during the winter of 2022. Since then, he has made remarkable progress, attending regular check-ups at the Mater Hospital, walking daily with his rescue dogs, staying active with an exercise bike and enjoying spending time with his family and partner Pip.



WILLIAM MILLS, COMBINED KIDNEY AND PANCREAS TRANSPLANT

William Mills, from Mallow, Co. Cork, shared his story of receiving a combined kidney and pancreas transplant in early 2022, at St. Vincent's University Hospital.

Diagnosed with Type 1 diabetes at the age of 15, William had to manage his health capably for nearly two decades. Despite facing challenges, including a decline in kidney function, he remained dedicated to his work and found support in the healthcare professionals at the Bons Hospital and diabetic nurses who played a crucial role in his care. As his kidney function worsened, William was put on the transplant waiting list.

Following the transplant, William encountered some setbacks but ultimately recovered fully and now feels better than ever before.

In his speech at the launch he expressed immense gratitude to his donor's family, who are in his thoughts every day, and appreciation to his family for their unwavering support as well as his employer SuperValu.

He also acknowledged the medical teams at the Bons Hospital, CUH, Beaumont Hospital, and St. Vincent's Hospital for their exceptional care and support. With his health restored he now has the opportunity to return to work and contribute to society.



Gerry Fitzgerald with his partner Pip.



NIAL KENNEDY, WAITING FOR A TRANSPLANT

Niall Kennedy, from Bunclody, Co. Wexford, shared his health journey as someone who has been living with chronic kidney failure and who has been awaiting a kidney transplant for over three years.

Diagnosed with polycystic kidney disease (PKD) in 2005, Niall's kidney function gradually declined despite his efforts to manage his health. In 2020, he joined the transplant waiting list and began peritoneal dialysis in February 2020, which he continues to do every night for 9 hours at a time.

While facing challenges and restrictions, Niall strives to live a full life, embracing his roles as a husband, father, son, nurse, and someone coping with chronic illness. The possibility of a kidney transplant represents freedom from dialysis and dietary restrictions, as well as the hope for a long and healthy life with his wife, to witness his three teenagers grow into men.

Niall acknowledged the profound impact of organ donation on donor families saying, "Having worked in Intensive Care Nursing I know the heart-breaking decisions that families make to donate their loved one's organs. But I also know how the life-changing gift of a kidney could utterly transform my life and that of my family."



Pancreas Transplant Coordinator Caroline Doyle, SVUH with William Mills.

Naomi Dunleavy



NAOMI DUNLEAVY, MOTHER OF ORGAN DONOR

In her speech, Naomi Dunleavy from Navan, Co Meath shared her family's organ donor story and the hope it has brought them. After the tragic loss of their 20-year-old son Aaron Cantwell, in 2022, Naomi and her husband David and their son Adam, made the selfless decision to honour his expressed wish and donated his organs.

Naomi spoke about the gratitude to the four organ recipients who now safeguard Aaron's organs.

Aaron was a popular swim coach and lifeguard. Inspired by the life he led and his legacy after his death, Aaron's family created 'Ducky,' a symbol of kindness activism, to promote conscious acts of kindness called "Ducky Deeds."

You can read about the first Ducky Deed, a relay swim Ducky Deed Derby, on pages 16-18.

Five-year-old twins **Liam and Daniel O'Connor** and their older sister Caoilinn (8) from Artane, Dublin, proved to be very popular with press photographers and their photos appeared in nearly all the national papers the following day. Liam

Three generations:
Moira and Edel O'Brien
and Laura Farrell.



underwent a kidney transplant from a deceased donor and they were joined by members of the team from CHI Temple Street who cared for him.

Another welcome attendee was **Edward Kehoe** from Castlebridge, Co. Wexford, who is enjoying the successful longevity of the deceased donor kidney transplant he received 40 years ago. You can read more about his story on pages 26-27.

Also attending were three generations of a Westmeath family. Grandmother Moira O'Brien donated a kidney to her daughter Edel over four decades ago, and just last year after the kidney transplant eventually failed, Edel's daughter Laura Farrell stepped up to donate a kidney to her. They were interviewed by Ray D'Arcy on his RTÉ 1 radio show during the campaign week and you can read about their story in a future issue of *SUPPORT*.

Representatives of patient advocacy groups at the launch included Robert McCutcheon,

Chairman, **Irish Heart and Lung Transplant Association**. Eddie Cassidy, Val Kennedy and Gemma O'Dowd represented the **Irish Lung Fibrosis Association**. Also attending was Philip Watt, **Cystic Fibrosis Ireland**, and Christopher Neilson, Irish Liver Trust.

When speaking at the launch, Minister Donnelly acknowledged the bravery of Naomi Dunleavy, the mother of a deceased organ donor who spoke before him. In his speech, the Minister said, "Organ donation is a gift of a second chance of life. Raising awareness about the importance of organ donation is a critical part of the great effort we must make so that more people get this second chance."

"I want to thank all of those involved: the transplant centres, ICU staff, organ donor nurse managers, Organ Donation and Transplant Ireland, and all of those who have

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Denise and
Patrick O'Connor
with Daniel, Liam
and Caoilinn.



Eddie Kehoe with his wife Marie.





Minister Donnelly with kidney transplant recipient Liam O'Connor (left) and his twin brother Daniel.

worked to raise awareness.

"This year has set a record for the number of organ donors in the first three months of a year with 81 transplants carried out. As Minister for Health, I am committed to increasing organ donation and transplantation rates in Ireland and to make organ donation 'the norm' where possible. Enactment of the Human Tissue Bill will be an important step to achieving this."

The IKA's Chief Executive **Carol Moore** spoke at the launch saying, "Organ donation is a great example of active citizenship, and the IKA is calling on everybody to take the opportunity of Organ Donor Awareness Week to share their organ donation decision."

Carol described how, "Patients on transplant waiting lists live in hope that organs will become available for them and a strong public show of support by requesting organ donor cards builds that hope. The uncertainty associated with waiting for an organ transplant is difficult as the future is unknown and there is

the knowledge that in order to be given the 'gift of life' another family will be grieving the loss of a loved one.

"The end of year figures for transplantation last year offer encouragement and hope to people on transplant waiting lists as there was an increase in transplant activity with 250 organ transplants taking place in 2022, 44 more transplants than in 2021.

Carol Moore also said, "We look forward to the Human Tissue Bill being transposed into law. It will allow for altruistic living kidney donation in Ireland, where the donor does not know the recipient. Currently such donors have to travel outside our jurisdiction to Northern Ireland or overseas in order to donate altruistically."



Dr. Catherine Motherway, Clinical Lead, ODTI, HSE also spoke at the national launch of the campaign and said, "Organ donation saves and transforms the lives of Ireland's transplant recipients. The 'gift of life' given by our donors, both living and deceased, is celebrated and cherished publicly every year during Organ Donation Awareness Week.

"This year will mark 60 years of Organ Donation and Transplantation in Ireland. Over the intervening years advances in transplant medicine and surgery have allowed us to offer hope to more patients suffering from the failure of a vital organ. At this time, we take a moment to reflect on how this would not be possible without the selfless generosity of our organ donors and their families.

"We remember the families of our deceased donors who, in the midst of grief and in the face of the sudden loss of a loved one find it in their hearts to think of others in need.

"Our living donors give of themselves freely to help a loved one. This week I would encourage everyone to let their families know their wishes. Have that conversation please. For bereaved families when the wishes of the donor are known it is an act of love to respect and honour that wish. It can bring comfort in a very dark and difficult time.

"For those of us who have the honour of caring for our donors and their families and who work to care for our transplant community we thank and honour all our donors."

ORGAN DONATION AND TRANSPLANTATION FIGURES

The figures presented at the national launch regarding organ donation and transplantation in Ireland further highlighted the ongoing need for increased organ donation rates.

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

250 organ transplant operations



Carol Moore.



ODTI Donor coordinators (DC) and Organ Donor Nurse Managers (ODNM): Elaine Pierce Kelly (DC); Eimear Dempsey (DC); Eimear Shields (DC); Jennifer Whelan (DC); Bernie Nohilly, ODNM, University Hospital Limerick; (standing): Orla Craddock, ODNM Ireland East Hospital Group; Gillian Shanahan, ODNM Saolta Hospital Group; Nikki Phillips, ODNM Dublin Midlands Hospital Group.

were carried out in Ireland in 2022 (44 more transplants than in 2021). This activity last year, in very challenging times with COVID-19, could not have taken place but for the generosity of the families of 86 deceased donors and 33 living kidney donors.

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

Last year, saw an increase in the number of kidney transplants taking place at Beaumont Hospital - 163 kidney transplants took place of which 33 were from Living Kidney Donors. There are 2,466 people in Ireland in end stage kidney failure undergoing dialysis treatment, but only approximately one fifth of these are on the transplant waiting list.

ORGAN DONATIONS AND TRANSPLANTS			
	2021	2022*	5 year Average 2015-2019
Deceased Donors	65	86	85
Kidney	104	130	128
Liver	35	51	61
Lungs	20	18	33
Heart	10	10	16
Pancreas	2	8	2
Total Deceased Donor Transplants	171	217	240
Living Donors	35	33	43
TOTAL TRANSPLANTS	206	250	283

*Excludes 8 UK paired exchange/desensitised transplants.

MILESTONES

Important milestones in organ donation and transplantation in Ireland were also highlighted during the campaign. These milestones commemorated significant achievements, such as the first transplant in Ireland 60 ago, the

introduction of the kidney donor card by the IKA 45 years ago, and the establishment of various transplantation programmes.

They serve as reminders of the progress made in organ donation and transplantation over the years.



Eddie Cassidy, Chairman, Irish Lung Fibrosis Association (ILFA); Gemma O'Dowd, ILFA, Robert McCutcheon, heart transplant, Chairman, Irish Heart and Lung Transplant Association (IHLTA); Irene Byrne, IHLTA, and Val Kennedy, lung transplant, ILFA.



Tomcy Baby, heart transplant clinical nurse specialist; Prof. Jim Egan, Director, ODTI; Niall Whiteley, heart transplant; Gerry Fitzgerald, lung transplant; Robert McCutcheon, heart transplant, IHLTA; Susan Towell, lung transplant, clinical nurse specialist; Val Kennedy, lung transplant, ILFA.

THE HISTORY OF ORGAN DONATION & TRANSPLANTATION IN IRELAND 1963 - 2023



60

YEARS AGO

Ireland's
first organ transplant
- a **kidney transplant**
at St. Vincent's Hospital (1963)



30

YEARS

of **liver transplantation**
at St. Vincent's Hospital
(1993)

51

YEARS AGO

Ireland's
first live
kidney transplant
at Jervis Street Hospital
(1972)



20

YEARS

of the
paediatric kidney
transplant programme
at CHI Temple Street,
Dublin (2003)



45

YEARS AGO

Organ Donor Card
introduced by the
Irish Kidney Association
(1978)



18

YEARS AGO

Ireland's **first lung transplant** at
the Mater University Hospital (2005)



38

YEARS AGO

Ireland's
first heart transplant
at the
Mater University Hospital
(1985)

15

YEARS

since **first spousal**
(**non-blood related**)
live transplant
at Beaumont Hospital
(2008)



31

YEARS

of
pancreas transplantation
(1992)



10

YEARS

1.45 million people
with **Code 115** on
NDLS Drivers Licence
(January 2013 - February 2023)

Joan is floored to learn she has kidney failure and risks dying without dialysis or a transplant.



FAIR CITY

Fair City first aired on RTÉ One on Monday, September 18th, 1989. The show introduced audiences to the ups and downs of people living in the fictional Northside Dublin town of Carrigstown.

By COLIN WHITE

Airing four episodes a week, all year round, with each episode averaging an audience of approximately 300,000 people, it has become an excellent platform to address serious topics like addiction, homelessness, mental illness and more recently, kidney failure. The Irish Kidney

Association (IKA) has enjoyed the support of *Fair City* for several years as its organ donor awareness posters and other merchandise were used as set dressing.

Regular viewers with a keen eye will have noticed campaign posters for organ donor awareness week on the *Fair City* sets including the community centre and doctor's surgery.

We were delighted when in late 2021 one of the show's researchers approached the IKA for advice on developing a possible plot line involving a character being diagnosed with kidney failure, going through dialysis, and facing an uncertain future.

Many emails and phone calls followed as the context around the possible storyline developed and we suggested that it would be very timely if it emerged



Joan's snared on her laptop and banned from working in the hospital.

during Organ Donor Awareness Week.

The show's researchers also contacted Beaumont Hospital to answer some of their queries in relation to possible storyline directions.

And so, it was actually during Organ Donor Awareness Week this year (May 20th-27th) that *Fair City* character, Joan Howley (played by Noni Stapleton), was diagnosed with End Stage Kidney Disease and the storyline has been developing since then.

Whilst TV Soaps are often obliged to telescope timelines and add drama to ensure that they keep their storylines interesting, it has been encouraging to see some of the realities of the patient journey already being covered and we look forward to seeing how the storyline continues to develop.

We have already seen Joan going through the



Joan pretends to accept Monika's advice to put her health first, but gets straight back on the horse.

initial shock of diagnosis, facing dialysis, finding out about the supports available (she is seen reading the IKA Peer Support leaflet for example) and the storyline is also covering the impact on family and friends and the emotional issues that can come up with living kidney donation.

The importance of good communication becomes clear as some members of

her family mistakenly believe Joan will die soon if she does not get a transplant.

The IKA's campaign poster '*Don't Leave Your Loved Ones in Doubt*' can be easily seen in the background in scenes at the *Fair City* Community Centre.

There is good basic public understanding of organ donation and transplantation. However, the same cannot be said about dialysis. Consequently, it is encouraging that a programme with a significant audience is taking the time to shine a light on it.

With approximately 2,500 people currently receiving dialysis every week, it is important that the wider public realises what is involved.



Campaign poster in the background.

We know from experience that it is sharing people's lived experiences that has the greatest resonance with the general public in relation to raising awareness of issues and we thank *Fair City* for bringing kidney failure, dialysis, organ donation and transplantation into the living rooms of so many people around the country.



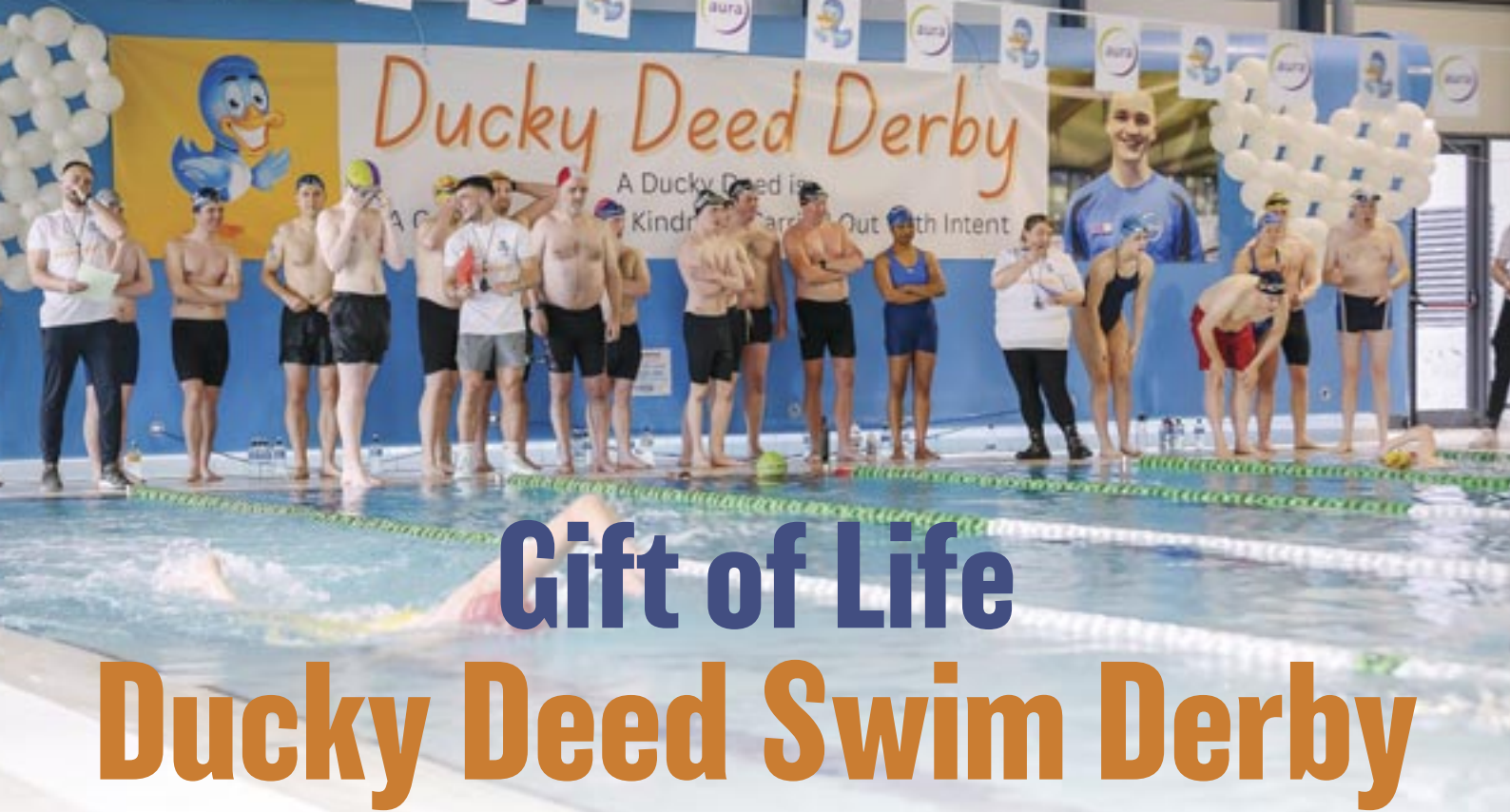
Joan reading an IKA leaflet.



Joan softens the blow to Dearbhla with news of a promising opportunity.



Joan warns Gareth she wants nothing from him.



Gift of Life Ducky Deed Swim Derby

The **Gift of Life Ducky Deed Swim Derby** took place at Aura Leisure Centre Navan on **Sunday 21st May** which marked Organ Donor Awareness Week and the life of the late **Aaron Cantwell**, a 20-year-old swim coach and lifeguard, who worked there.

Aaron's last act of kindness, which was Ducky's first Ducky Deed, was to save four lives through organ donation when he passed away in 2022.

The Ducky Derby event, which was supported by Aura, brought together organ donor families and transplant recipients, Aaron's parents Naomi and David and his older brother Adam, extended family, friends, and Aura work colleagues and patrons.

By **GWEN O'DONOGHUE**

Eddie Flood, the national honorary Chairman of the Irish Kidney Association (IKA), and a kidney transplant recipient from Killucan, Westmeath, spoke at the event. He acknowledging the bravery of the Dunleavy Cantwell family in staging such an inspirational and unique tribute to their late son Aaron, while raising organ donor awareness.

Swimming in the Ducky Derby swim was the IKA's very own Colin White, the national Advocacy and Projects Manager, who travelled from Balbriggan, Dublin to be part of the event. A few weeks beforehand Colin swam in a time trial qualifier which secured him a place at the Derby final.

Colin who is also the Team Manager of Transplant Team Ireland said: "It was an honour to be part of the special event and nice to get

experience as to what it was like to be a participant, rather than a supporter. I've now a renewed respect for all swimmers including those on Transplant Team Ireland!"

Patrick Sands and Mark Touhy were part of the winning swimming team. Patrick's son Mark Sands saved three lives through his organ donation in 2019. He was a UCD Computer science student on an exchange in Austin Texas when he passed away at 21 years of age in a road collision. His mum Ruth also swam in the Derby race.

Mark Touhy received his first kidney transplant in 2002 which gave him the opportunity to go to college, marry and become a father. He underwent a second kidney transplant in 2021 which he says allows him to look forward to watching his daughter grow up.

Kevin Feely, a triathlete, signed up to participate in the Derby as his 8-year-old cousin Callum Cooney has



Eddie Flood,
Colin White,
Peter Heffernan,
Tony Gavigan.



been on the waiting list for a kidney transplant for over a year.

Rosh Karvnaratne also participated in the Ducky Derby. His wife Louise's cousin, Jamie Gavin, made headlines in 1985 when he was 3-years-old by being the youngest heart and lung transplant recipient. A year later Princess Diana presented him with a 'Child of Courage' award.

Aaron's older brother Adam, also a swim coach at Aura, presented the overall winners of the Swim Derby with a trophy and a One Year Aura Leisure Family Membership, kindly sponsored by Aura. There was also a prize for the fastest male and female swimmer in the timed trials and they each received a voucher for two nights B&B at the Clayton Hotel Charlemont in Dublin.

Many organ donor families and transplant recipients showed up as spectators in support of the organ donor awareness event.

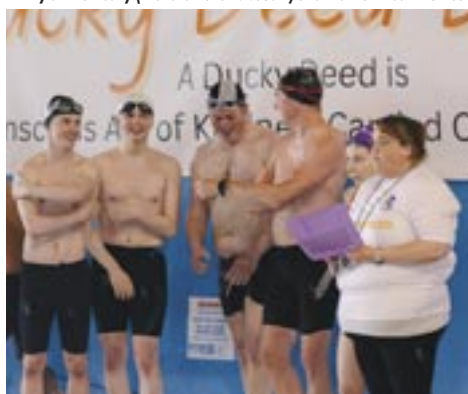
David Crosby from Kingscourt, Cavan attended with his wife Katie and two children who had taken swimming lessons with the late Aaron Cantwell. A few years after David underwent a lifesaving lung transplant, he caught COVID-19 which left him fighting for his life on a ventilator. While he survived, his kidney function did not recover and he is now receiving dialysis treatment and is on the waiting list for a kidney transplant.

Olivia Lynch, from Navan, the wife of late organ donor Séan Lynch, also attended. Olivia honoured Séan's expressed wish to be a donor, when he was involved in a fatal cycling accident. His donation went on to save five lives.

Janet O'Brien, whose son Luke passed away in 2017 when he was 20-years-old, saving five lives through organ donation, travelled from Dublin for the event.



Dylan Dunleavy (the late Aaron's cousin) and his mum Leah Dunleavy, Naomi Dunleavy, David and Adam Cantwell, and Ezra Dunleavy.



Dylan Dunleavy and Adam Cantwell (cousin and brother of Aaron).

Tony Gavigan, from Navan was also pleased to support the Gift of Life Ducky Deed Swim Derby just a month after he competed in the World Transplant Games in Perth Australia, where he won a silver medal in golf. Tony underwent a kidney transplant just a few years after his own son Kyle became an organ donor following his untimely death as a child.

Peter Heffernan, who underwent a kidney transplant but returned to kidney failure last year, presented a gold medal he had won at the 2015 World Transplant Games and his team t-shirt to Naomi's family.

Other transplant recipients who supported the event as spectators were Martina McGuire, a kidney transplant recipient, and Kate Twohig, a liver transplant recipient, who met the late Aaron's family at the launch of Organ Donor Awareness Week.

Also attending the Swim Derby

was Michael Cooper from Ratoath, Co Meath with his wife Joanne and son Mícheál. Michael underwent a bone marrow transplant, thanks to his donor brother, and some years later he found himself in lung failure and because of an organ donor his life was saved through a double lung transplant at the Mater Hospital.

Michael took part in a photocall with An Post to announce their support of the campaign by displaying posters and donor cards in their larger post offices.

In summing up the event Naomi Dunleavy said, "Ducky's first Ducky Deed Derby was such an amazing day. So many people came to honour Aaron and to support Organ Donor Awareness".

Sharing Peter Strople's quote in her Instagram post, Naomi wrote,

*'Legacy is not leaving something for people.
It's leaving something in people.'*



David Crosby, with his wife Katie and children.



Joanne and Michael Cooper with their son Mícheál.



(Back row:) Lisa Fitzgerald, Ciara O'Connor, Gillian Curtis, Martin Malinowski and Rachel O'Hara. (Front row): Prof. David Healy, Dr. Tom Gallagher and Dr. Emir Hoti.

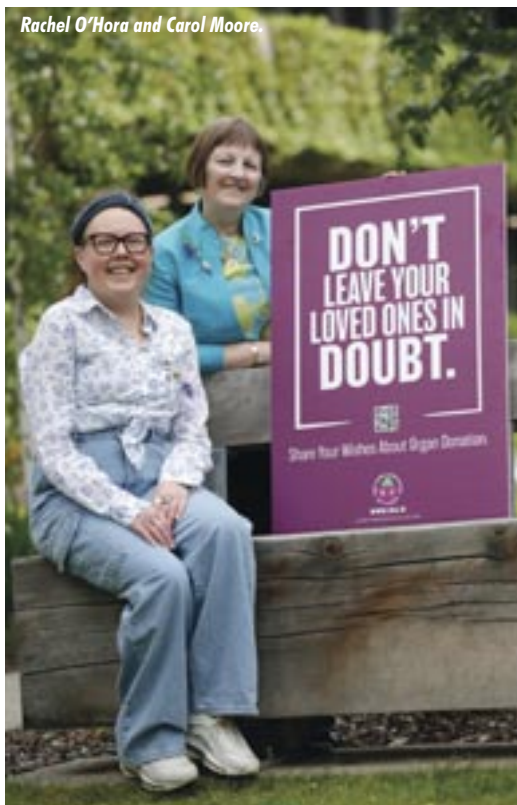
Transplant surgeons celebrated on GLOBAL SURGERY DAY

Global Surgery Day on Thursday, 25th May, coincided with Organ Donor Awareness Week (20-27 May). To celebrate the contribution of transplant surgeons and their valued life-saving role, the Irish Kidney Association decided to mark Global Surgery Day with an event bringing together transplant surgeons and transplant recipients.

The event was held at St Vincent's University Hospital (SVUH), in Dublin 4, with the valued cooperation of Jennie Cotter, the hospital's Corporate Communications Manager.

It was also supported by Organ Donation Transplant Ireland and the Irish Heart and Lung Transplant Association.

Rachel O'Hara and Carol Moore.



Transplant surgeons who took part in the photocall were Dr. Emir Hoti, Consultant Surgeon Liver Transplantation, HPB & Pancreatic Surgery; Dr. Tom Gallagher, General Surgery, HPB and Liver Transplant Surgeon, St. Vincent's University Hospital (SVUH); and Prof. David Healy, Cardiothoracic Surgeon (heart & lung transplant surgeon), at The Mater Hospital and SVUH.

They were joined by transplant recipients whose lives have been saved and transformed through the transplants they have received.

They included two people who underwent their transplants at SVUH including 27-year-old Ciara O'Connor from Tralee who received a

liver transplant in March this year, and **Rachel O'Hora** (40), from Bohola, Co. Mayo and now living in Blackrock, Co Dublin, who underwent a combined pancreas and kidney transplant in St. Vincent's University Hospital (SVUH) in 2022, **Lisa Fitzgerald** (42) from Kiltipper, Dublin 24, is a former dialysis patient at SVUH, who underwent a kidney transplant in February 2019 at Beaumont Hospital. **Martin Malinowski** (31) who was the first person in Ireland to undergo a heart and liver transplant in 2021 at The Mater Hospital. Martin travelled from his home in Castleblayney, Co Monaghan for the event.

His double transplant involved a multidisciplinary team from both the Mater Hospital and St. Vincent's Hospital as he was transplanted with a heart first and, directly afterwards, the liver transplant team from SVUH brought their expertise and equipment to The Mater to transplant Martin with a donor liver.

Attending also was **Gillian Curtis** (43) from Portlaoise (and a native of Athy) who underwent a heart transplant at the Mater Hospital in 2019, which followed two false calls for donor hearts.

Dr. Catherine Motherway, Clinical Lead, Organ Donation Transplant Ireland said, "Global Surgery Day happens each year on May 25th! This year in Ireland it coincides with Organ Donor Awareness Week. As we celebrate 60 years of Organ Donation and Transplant in Ireland, we recall it is nearly 69 years since the world's first successful kidney transplant!

"In that time enormous advances have been made in transplant medicine, surgical techniques, immunology, tissue typing, peri-operative and critical care, leading to much improved outcomes for our transplant community!

"Our surgeons and their teams have been instrumental in driving, developing, and advocating for our National Transplant Programmes. They deliver a 24/7 service with excellent outcomes for our transplant patients and ensure that our donors and their families' decision to donate and give the Gift



Prof. David Healy, Martin Malinowski, Dr. Emir Hoti, Ciara O'Connor and Dr. Tom Gallagher.

of Life is honoured."

Carol Moore, Chief Executive of the Irish Kidney Association said, "Notwithstanding the invaluable contribution of all the medical and nursing staff involved in organ donation and transplantation, made possible by organ donors, it is important that we take time to celebrate the skilled work and dedication of transplant surgeons who work so hard, on behalf of patients, when called at any hour of the day or night to carry out transplant operations.

"It really is encouraging to see how far medical advances have come for transplantation over the years. Families of transplant recipients, up and down the country, are grateful that their loved ones are living longer."

Speaking at the event **Dr. Emir Hoti**, said, "At St. Vincent's University Hospital, we perform a range of complex surgeries annually including 100 – 110 pancreatic resections, 160 liver resections, 50 – 60 liver transplants, 6 – 8 pancreas transplants and 40 – 50 major robotic resections.

"Global Surgery Day is a powerful reminder of the transformative impact surgical interventions have on individuals and communities worldwide. Through collaboration and innovation, we can bridge the gaps in healthcare access and make life-saving surgical care more accessible to those in need.

"As surgeons, we have a

responsibility to not only provide exemplary surgical care but also to share our knowledge and experiences, empowering the next generation of medical professionals. By joining forces, we can drive positive change and shape the future of surgical care for the better."

Dr. Tom Gallagher said, "On Global Surgery Day, we are reminded that ensuring access to high quality timely surgical care is a core tenet of any healthcare system. This of course is equally applicable in our national liver transplant, pancreas transplant, and hepatobiliary cancer programs here in SVUH.

"Our ability to provide the safest, most effective and timely service to our patients, however, is only possible through a strong multi-disciplinary team throughout the hospital and in our wider network. Improving access and outcomes for this incredibly resilient group of patients is what drives us as a team on a daily basis."

Robert McCutcheon, Chairman of the Irish Heart & Lung Transplant Association said: "As we celebrate Global Surgery Day on Thursday 25th May, which coincides this year with Organ Donor Awareness Week, it is appropriate that I, as Chairman of the Irish Heart and Lung Transplant Association and a heart transplant recipient, take this opportunity to recognise the skill, expertise and commitment of our cardiothoracic surgeons and the entire transplant teams."

continued next page...



"Before my transplant, I faced numerous health challenges and the daily struggles of managing a chronic

"I encourage everyone to reflect on the incredible impact they can make by registering as organ donors and discussing their wishes with their families."

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



You can also make a donation on our website: <https://ika.ie/make-a-contribution/>



AGM



Colin Mackenzie, past IKA National Chairman (third from left) with IKA staff Deborah Cervi, Aoife Smith, Colin White, Lisa Fitzgerald and Margaret Doyle.

On Saturday June 24th, the first face-to-face **Annual General Meeting (AGM)** since the pandemic, was held in the Louis Fitzgerald Hotel in Dublin. It was a nice return to normality and great to see old friends in person again. In total 40 people attended with 26 watching online.

The meeting was opened by National Honorary Chairperson Eddie Flood who welcomed everyone and held a moment's silence for all deceased members and donor families.

The minutes of the 2022 AGM were read out by National Secretary, Marie Fowley and were then approved.

The National Treasurer Joan Gavan presented the Treasurer's

report from the Audited Accounts which were approved.

The Directors were authorised to appoint the Auditors and fix the Auditors remuneration.

The Chairperson then presented the Chairperson's report which was drawn from the full Directors' report in the audited Accounts.

Thanks were expressed to those officers who had resigned since the last election.

The formal AGM then ended.

After the formal AGM, the CEO, Carol Moore, gave an update on the Human Tissue Bill.

Following the presentation members enjoyed a light lunch with plenty of stimulating conversation.

A recording of the AGM is available at www.ika.ie/videos



Una Whelan, Colin Mackenzie and John Whelan.



Carol Moore, IKA CEO.



Chief Executive Carol Moore (standing) with IKA National Officers and the Board.



The Human Tissue Bill



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

The Irish Kidney Association (IKA) has been actively engaged in the debate around the sections of the Bill that deal with organ donation and transplantation. In January 2023, the Association prepared a detailed submission for the government and all the party spokespersons for Health. It was pleasing to see that the submission was referenced heavily by all sides in the debate in the Dáil.

The IKA is 45-years-old this year. One of the Association's first actions was the introduction of the Kidney Donor Card which subsequently became the Organ Donor Card that we know today. That's 45 years at the coalface of promoting organ donation to the public. That's 45 years of understanding the need for, and impact of, organ donation for transplantation.

With its 38th annual Service of Remembrance and Thanksgiving happening later this year, the Association acknowledges the

The **Human Tissue Bill** has been a subject of discussion for quite some time now. It is encouraging to be able to report that the Bill is progressing through the Oireachtas. In January 2023 it passed through the second stage with debate in the Dáil chamber. In June 2023 the Bill moved to the Expert Committee stage where there was discussion around proposed amendments.

importance of organ donors and their families in the circle of life that gives us organ transplantation.

This history means that our input to the debate around the Human Tissue Bill is rooted in experience and built on the network of long understood sources and contacts built up over time.

The motivation to increase organ donation for transplantation is clear in relation to the impact that it has on the life of transplant recipients, their

families and society at large, and the solace that it gives to the donor families.

There is also a financial motivation. Using figures received in response to a Parliamentary Question, it can be shown that treating one person for 15 years by kidney transplantation can save €1.6 million, compared to treating them by dialysis for the same period.

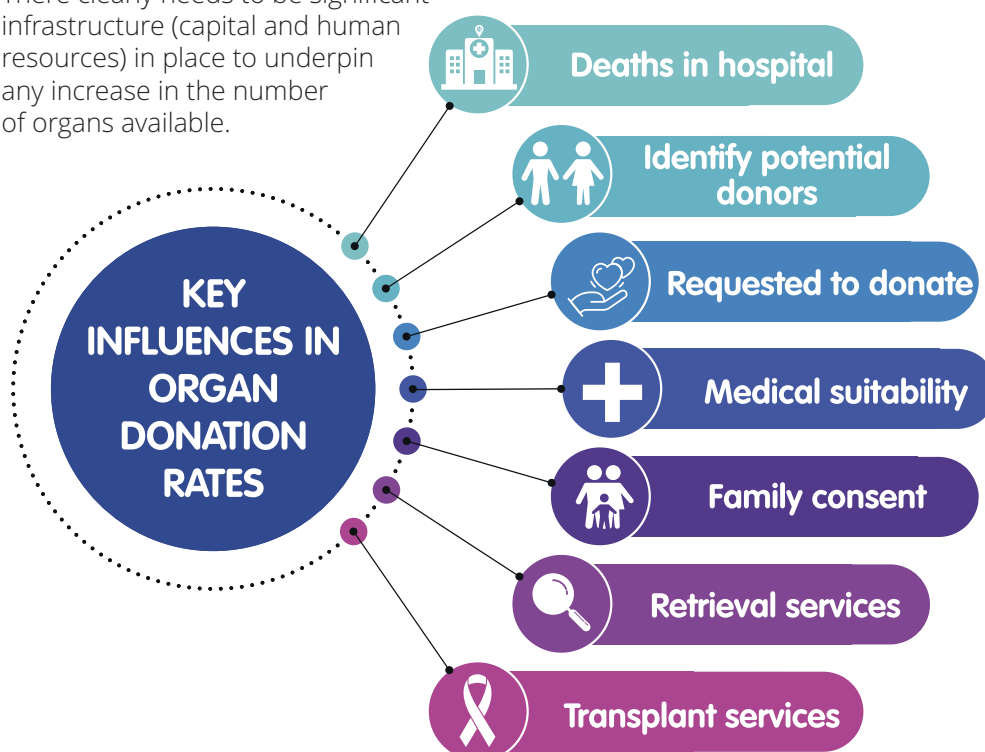
In advance of the Committee Stage of the Bill in June 2023, significant time was invested by the IKA in preparing an

evidenced based submission that gives context to the Bill, proposes six amendments, and highlights several areas that will need clarification for both the public and the health service when promoting the changes that the Bill will bring about.

When discussing any change, it is important to understand where you are, the goals of the proposed change, and the reality of any external examples used.

UNDERSTANDING THE DONATION AND TRANSPLANTATION PROCESS

The key message here is that consent is part of an overall picture. There clearly needs to be significant infrastructure (capital and human resources) in place to underpin any increase in the number of organs available.



Under the current system in Ireland, the families of potential donors are approached for consent for organ donation. If the potential donor had an organ donor card, recorded **Code 115** on their driving licence, or recorded their decision in their Advance Healthcare Directive (Think Ahead), it makes the decision for the family a little easier as they will have proof of their loved one's organ donation decision.

Although the current system is referred to as **'Opt-in'** you **do not** need to have an organ donor card or have Code 115 on your driving licence for consent to donate to be sought from your family.

The system that is proposed under the new legislation is referred to as **'Opt-out'**. Everyone will be considered a willing donor unless they have opted-out, by registering their decision not to donate their organs on what will be a newly created register.

Looking more specifically at consent and how it is currently sought, compared to the system proposed under the Human Tissue Bill (see image next page) we can see that family consent remains pivotal under the new system and, therefore, any awareness campaign needs to focus on sharing the organ donation decision with family at the centre of their call to action.

LOOKING TO OUR NEIGHBOURS

Wales was the first country of the United Kingdom to introduce **Opt-out** legislation which was implemented in December 2015.

Scotland, England and most recently, Northern Ireland have all since introduced **Opt-out** legislation and are all now implementing it.

REMINDERS OF YOUR DECISION TO BE AN ORGAN DONOR



ORGAN DONOR CARD
FREETEXT **DONOR** to **50050**



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




DIGITAL ORGAN DONOR CARD APP
from the APPLE or ANDROID STORE



MY PERSONAL WISHES AND CARE PLAN
(Advanced Healthcare Directive)


TAKEN FROM THE NHS ONLINE ORGAN DONOR REGISTER

<https://www.organdonation.nhs.uk/register-your-decision/>




Register to donate
Choose this option if you would like to donate some or all of your organs and tissues.

DONATE
Register a decision to donate




Register not to donate
Choose this option to record a decision not to donate your organs and tissues.

DO NOT DONATE
Register a decision not to donate (opt out)



Amend your registration
Choose this option to update your existing registration or donation preferences.

AMEND
Amend your registration



Withdraw your registration
Choose this option to remove your existing registration from the register. This will leave no recorded organ donation decision for you.

WITHDRAW
Withdraw your registration

ARE WE COMPARING LIKE WITH LIKE?

It has been argued that the proposed legislation will mean that Ireland will simply be following the example of Wales, Scotland, England and Northern Ireland who all now have opt-out legislation.

This is not the case.

When looking to the legislation introduced in the UK it needs to be noted that they have had an **Opt-in register** in place since 1994 and, from a practical perspective, their legislation introduced

an **Opt-out register** that runs alongside the existing **Opt-in register**. This allows them to have **'Record your wishes'** as their call to action in relation to organ donation.

Continued next page...

The Human Tissue Bill contd...

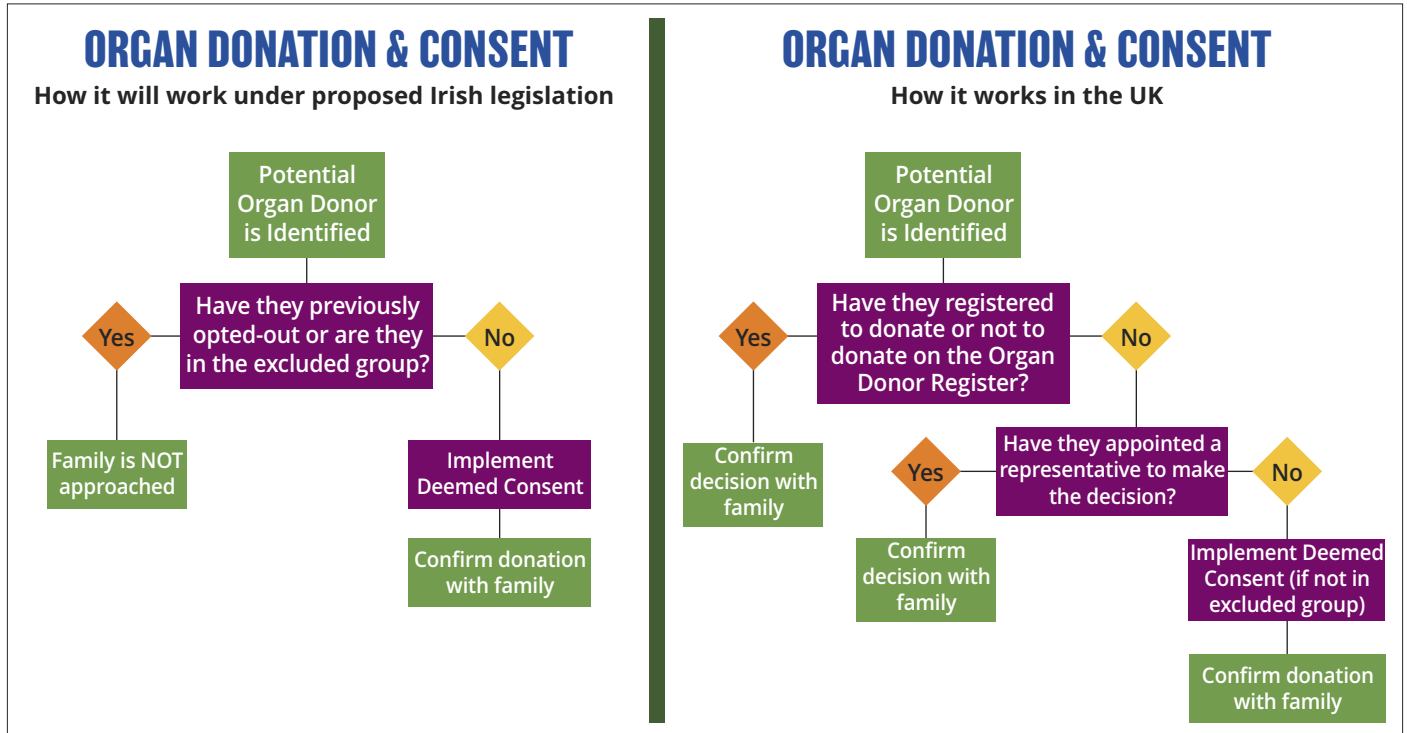
In Ireland, we do not have an existing register.

The Organ Donor Card, its digital equivalent, noting your organ donation decision on your driving licence (Code 115) and more recently the opportunity to record your organ donation decision via an Advanced Healthcare Directive are the only current means for recording your

organ donation decision.

There is no central database of information kept.

The image below compares the system being proposed by the legislation currently passing through the Oireachtas and the system in the UK



Looking at a recent report from the UK, 57.5% of their organ donors had 'opted-in' on the Organ Donor Register meaning that 'deemed consent' did not apply as the family could be told that their loved one had

recorded their decision to donate.

Again, looking to the UK statistics that are publicly available, one can see the impact on families of knowing the organ donation decision of their loved one.



29.8%

of families consent when **NO** Specialist Nurse is involved in the formal organ donation discussion with the family



57.5%

of families consent when Specialist Nurse **IS** involved, and potential donor is **NOT** signed up to the Organ Donor Registry



93.9%

of families consent when a Specialist Nurse **IS** involved, and potential donor **IS** signed up to the Organ Donor Registry

WITH SPECIALLY TRAINED NURSES, AND AN OFFICIAL RECORD OF CONSENT, DONOR RATES ARE SHOWN TO RISE SIGNIFICANTLY

*Statistics from Potential Donor Audit UK, 2018-2019



THE IKA'S PROPOSED AMENDMENTS TO THE BILL

1. POTENTIAL DONOR AUDIT

If you have made it this far in this article, you will have noticed that the UK have significant statistics available around organ donation and transplantation. A key annual report they publish is their Potential Donor Audit.

The Potential Donor Audit aims to provide an up-to-date assessment of the potential for solid organ donation from Intensive Care Units (ICUs) throughout the UK.

The audit identifies the number of patients who could be deceased heart beating or non-heart beating solid organ donors and helps to establish the obstacles to donation.

The only national potential donor audit in Ireland was carried out in 2009. The National Office for Clinical Audit is currently carrying out a pilot audit with results expected in September 2023.

The IKA is asking that provision for a detailed **annual** potential donor audit be included in the Human Tissue Bill to ensure transparency and allow for informed, and therefore, focused improvements in future. "What gets measured gets managed."

2. INCLUSION OF AN OPT-IN REGISTER

As was seen above, the Human Tissue Bill is proposing to introduce an Opt-out register only, whereas the UK's recent introduction of Opt-out

legislation added an Opt-out register to work alongside their existing Opt-in register.

The IKA is proposing that the legislation be amended to include an Opt-in register as well as the proposed Opt-out register. This will ensure that those who want to record their organ donation decision for their family's future reference can do so.

It will also ensure that the headline public messaging around the change in legislation can be simplified to a focus on asking the people to record their organ donation decision.

Noting that 1.45 million people have already proactively indicated their decision to be an organ donor through their application for a driving licence, without any awareness campaign, it is evident that there is strong support for organ donation in the country.

ADDITIONAL AMENDMENTS:

There are four other areas where the IKA would like to see covered by the legislation:

3. REQUIRED REQUEST

Hospitals must have a policy in place requiring all families of suitable donors to be asked to give consent for their loved one's organs to be used for transplantation.

The IKA believes that it is important that the families of every suitable donor be given the opportunity to consent to organ donation and it is also a way of

giving structure to best practice and maximise the number of actual organs transplanted.

4. INCLUSION OF A DONOR FAMILY REPRESENTATIVE ON THE INDEPENDENT PANEL

It is important that the perspective of donor families is considered by the Service as those who have been through organ donation are the best advocates for organ donation.

5. PUT ORGAN DONOR AWARENESS ON A STATUTORY FOOTING

Clarification is needed about which authority or entity has the statutory legal responsibility for organ donor awareness as this does not appear to be currently assigned, nor is it referenced in the legislation.

Other countries have set up organisations specifically focused on organ donation awareness within public health and have specific websites devoted solely to organ donation.

For example, Northern Ireland has established Organ Donation NI under their Public Health Agency. Its remit is the promotion of Organ Donation to the public. www.organdonationni.info They have a Regional Organ Donation Promotion Manager employed, whereas there is no such position in Ireland.

It is notable that the functions of the Irish Blood Transfusion Service are set out in Statutory Instrument

No. 78 of 1965 and Statutory Instrument No. 209 of 1998 and include; To make any necessary provision for publicity in relation to the service.

6. TRAFFICKING

There is need for greater clarification in the provisions in the Bill aimed at preventing the commercialisation of organs (organ trafficking), advertising or brokering in human organs.

The offer of organs for sale is sadly very real. It is usually brokers who facilitate the transaction with the 'donors' generally coming from less well-off backgrounds.

The Scottish have made a clear provision dealing with trafficking in their organ donation legislation.

We have looked at the benefit of organ donation for transplantation to the transplant recipients and to the donor families.

We have looked at the financial benefit to the State that comes from treating renal failure by transplant rather than dialysis.

We must now use the opportunity of this legislation to maximise the opportunities for organ donation and transplantation.

The Irish Kidney Association is working with the HSE through Organ Donation and Transplant Ireland, as well as the Oireachtas Committee on Health, and the Department of Health, and will continue to advocate for best practice.

For Organ Donor Cards Freetext **DONOR to 50050**

Trailblazer Eddie's 40 years of transplant success

A Wexford man who is celebrating the successful longevity of a kidney transplant he received from a deceased donor, and who fought for justice in a landmark case for seafarers, attended the national launch of Organ Donor Awareness Week 2023.

Forty years ago, Eddie Kehoe underwent a life-changing kidney transplant that not only saved his life but also led to a significant change in British Transport law for seafarers requiring kidney transplants. This landmark case began with Eddie's struggle to regain his livelihood as a ship's steward with Sealink Stena on the Rosslare to Fishguard line.

In 1974, Eddie, from Rosslare, had started working for Sealink Stena, but a few years later, he was diagnosed with kidney failure. When he received a kidney transplant, he faced an unexpected obstacle. Despite being declared fit for work by medical experts in both Britain and Ireland, a Department of Transport Medical Officer, bound by regulations at the time, could not give

Eddie a medical cert which prevented him from returning to permanent employment.

Ironically, Eddie had made an excellent recovery and was in great health after the transplant. Nevertheless, he was denied the opportunity to be allowed to work.

Determined to fight for justice, Eddie appealed the decision with the support of the Irish Kidney

Association (IKA) and the National Union of Seamen (NUS).

Armed with compelling medical opinions in his favour, Eddie's case was brought before the British Government. The General Secretary of the NUS criticised the decision, stating that it disregarded practical and human considerations, making it clearly unreasonable and unjust.

During this time, Eddie's success in winning two silver medals at the World Transplant Games in Amsterdam, a testament to his physical fitness, further

bolstered his fight for justice.

The Sunday Independent covered his achievements, and the national newspaper article was discussed in the House of Lords. Ultimately, common sense prevailed, and the decision was overturned.

Eddie not only secured his right to retaining his livelihood but his case also paved the way for safe tenure for future transplant recipients working at sea.

Today, Eddie, now 64-years-old and living in Castlebridge, Wexford, is enjoying 40 years of successful kidney transplantation. He changed job 29 years ago and has been working with the Environmental Protection Agency since then.

The kidney transplant, from a deceased donor, took place in March 1983, a year after Eddie married his sweetheart, Marie. In the span of twelve months, he got married, experienced kidney failure,



*Kidney transplant recipients
Eddie Kehoe and
Liam O'Connor.*



Eddie and his family at the IKA's Run for a Life in 2015 – Eddie, Marie, Cathline, Amy and Jake Kehoe.

and began regular dialysis treatment at Dublin's Old Meath Hospital.

His transplant took place at the old Jervis Street Hospital.

Eddie and Marie had three biological children. Over the years, Eddie and Marie fostered numerous other children. One of these children, whom they have fostered since she was 12-months-old is now 17 and holds a special place in all the family's hearts and enjoys being an essential part of their loving family.

Eddie reflects on the profound impact his deceased donor had on his life. He vividly remembers receiving a phone call at 2am from Jervis Street Hospital, summoning him to Dublin for the transplant. Accompanied by his father-in-law and wife Marie, Eddie arrived at the hospital in the early hours of the morning. His life-changing transplant took place at 4pm.

Expressing his gratitude, Eddie mentions that he still thinks of his deceased donor almost every day.

He shares a heartwarming connection with a fellow kidney recipient from Castlepollard, whom he had known from their dialysis treatment days at the old Meath Hospital. Coincidentally, they

received their transplants just a day apart and spent their recovery time together at Jervis Street Hospital. They exchanged Christmas cards for several years afterward.

Eddie explained that within 18 months of his kidney transplant he had returned to playing football in the Wexford Premier league for his native Rosslare Rangers. Some years later he took up hurling as he hadn't played it as a child, and played for St. Mary's, Rosslare Harbour.

Two years after his first World Transplant Games in Amsterdam, he attended the biennial World Transplant Games when they were held in Innsbruck, Austria and he also competed in the World Transplant Games when they were held in Singapore and Budapest.

He also captained the Irish team when the World Games were held in Nancy, France in 2003.

Eddie's last time to participate in transplant sport was in 2010 when Dublin played host to the European Transplant & Dialysis Sports Championships. Eddie explains that life and work has got in the way of him competing since then but he is happy to be busy and be able to live a full and healthy life made possible by his donor!

Book your place for the Annual

Service of Remembrance & Thanksgiving

The Irish Kidney Association's **38th Annual Service of Remembrance & Thanksgiving** for organ donors will be held on **Saturday, 14th October at 2.00pm** in the **Cathedral of Christ the King**, Bishop's Gate Street, Commons, Mullingar, Co. Westmeath, **N91 EF82**.

The Service will be followed by a light lunch.

In order to ensure a pleasant experience for everyone, and to reduce food waste, we are asking people to register their interest in attending and let us know if there are specific dietary requirements.

So, please register your attendance, either online using the link at **www.ika.ie/service2023**, or you can email: **info@ika.ie** or phone **Donor House, Ph: 01-6205306**.

The Cathedral can accommodate 1800 people. As this will be the first time in four years, that we are holding a physical Service, demand is likely to be high for places. So, **PLEASE BOOK EARLY!**

Mullingar railway station is a five-minute walk from the Cathedral and there are a range of bus services, depending on where you are travelling from.

The parking capacity in the Cathedral is 220 cars and Coláiste Mhuire, College Street, Commons, which is adjacent to the Cathedral, can accommodate 100.

Directions will be available on our website closer to the time.



Focusing on the positive – a nurses' perspective

INTRODUCTION

Healthcare in Ireland is represented in the media in very negative terms. Words like “crisis” and “overcrowding” feature in almost every health-related news story. There are very valid reasons for this; our healthcare system is under strain and change and improvement are needed in many areas.

However, at any given moment, in any healthcare setting, no matter how difficult or upsetting the circumstances are, there are hundreds of positives – small things and big things that can go overlooked because of the human tendency to focus on the negative, and for bad things to stand out and loom large in our minds.

Whilst it is important to accept that there are problems and to continuously strive for improvement where it is needed, it is equally important to occasionally take a moment to focus on some of the under-represented positive aspects of nursing in Ireland today.

The nurses of the renal department in the Mater Misericordiae Hospital Dublin were asked to share some of the more positive aspects of their roles. This reflection was done with respectful acknowledgment of the patients' perspectives, their complex situations, the challenges they face, the difficulties involved in living with a lifelong condition and the many variables at play at any given time.

The intention is not to overlook or diminish problems, but to see the overall picture and recognise that it is a privilege to be involved in caring for others, even in challenging circumstances.

The renal nurses identified seven key things that make them experience the happier side of life as a healthcare worker.

NEWS OF A KIDNEY TRANSPLANT

Dialysis nurses get to know their patients very well. Most of these patients attend their dialysis units three times a week for treatment, and dialysis is needed on an ongoing basis until the patient receives a kidney transplant.

The phone call to inform the dialysis unit staff that a particular patient won't be coming for dialysis anymore because they were called for transplant is an especially joyful one. Everyone in the vicinity of the call will notice the cheerful, happy tone of the call and anticipate that there is good news to share.

Throughout the day the word will spread to other healthcare workers in the team, and each in turn will react with happiness and delight as the good news ripples out.

Transplant has its own challenges, but overall it signifies a new phase for the patient, where they will likely have more freedom and an improved quality of life. The nurses expressed genuine happiness for the patients who get transplanted.

KIND GESTURES

These often come from grateful patients in the form of chocolates, biscuits and sweets. The endless generosity of patients is overwhelming at times, particularly at Christmas, and is not taken for granted.

The kindness of staff members to one another was also highlighted as a source of happiness in the workplace. There were many examples of this; supportive words, a well-timed cup of tea, even a quick back rub!

A story that stood out was that of a student nurse who arrived at morning handover

on the renal ward one day and noticed some food items laid out at two of the places at the table. She discovered that her preceptor's two friends would be finishing the night shift and the preceptor had bought them their favourite snacks to cheer them up after a long night. The student noted how this act affected the whole atmosphere of the handover and lifted everyone's spirits.

HELPING A SICK PERSON FEEL WELL AGAIN

Healthcare is not straightforward and there is not always a perfect solution, but sometimes it happens that someone arrives to hospital very unwell, and later after a period of treatment they leave feeling well again.

The renal nurses expressed particular satisfaction around this, revealing the emotion they experience when they see someone walking out of the hospital ward in their own clothes, no longer in their



By **OONAGH GOOD**
NEPHROLOGY CNS
MATER MISERICORDIAE HOSPITAL
DUBLIN

hospital gown or pyjamas, no longer a patient but back with their families and feeling strong again.

TEAMWORK

When teamwork goes well it is a very satisfying feeling for all involved. In the acute hospital setting situations can escalate quickly. At times immediate action is required and there is not always time for explanation or discussion.

The renal nurses spoke about the reassuring feeling of seeing their colleagues arrive at their side in numbers whenever they have had to raise the alarm about an emergency situation.

Teamwork in healthcare is also necessary on a multidisciplinary level. Many of the renal patients have co-morbidities that require interaction between different departments, and renal care itself requires the input of dietitians, physiotherapists, podiatrists, psychologists and social workers, as well as doctors, nurses and healthcare assistants.

It was noted how additions to the team over the years have led to improved patient care and that this has contributed to increased job satisfaction for the renal nurses.

The wider hospital staff were acknowledged by the nurses as well – porters, cleaners and canteen staff whose work makes a positive impact on a daily basis.

CAREER MILESTONES

The old-fashioned notion of nursing as a vocation has changed. Nurses see themselves (and expect to be seen) as trained professionals who provide expert care based on specialist knowledge.

Nurses are well-decorated academically at both undergraduate and postgraduate level and are frequently involved in continuous



Rochelle Santos (CNS), Elaine Mannix (ANP), Aine Griffin (CNS), Toni Bodie, Oonagh Good (CNS) and Sheila Mae Janoras (Staff Nurse).

professional development and lifelong-learning in a practical and theoretical sense.

In the world of contemporary nursing there is an expectation that nurses undertake postgraduate academic studies whilst also working full-time. This is a challenge in itself, and many of the nurses who do this also have busy lives to manage outside of the workplace.

While it is a difficult balancing act, it is also very rewarding. With this in mind it was not surprising to hear that many of the positive stories reported by the renal nurses were happy stories of graduations, promotions and career progression.

BABIES!

For those with chronic kidney disease, planning and growing a family is complicated. During the time when the patient is on dialysis pregnancy is not advised.

After transplant however, it becomes a possibility again, but close management and expert care are required.

In the Mater the nursing side of this expertise is provided by the advanced nurse practitioner for post-renal transplant patients. Over the years she has helped numerous families welcome tiny new members into their homes, including three sets of twins!

It is amazing to think that a

transplanted woman carrying twins will, at a certain stage, potentially have seven kidneys inside her body (her own two native kidneys, her transplanted kidney, and the two kidneys of each of the twins). The human body can do remarkable things!

CHARACTERS

This was widely agreed to be one of the best parts of the job! Nursing involves meeting all sort of colourful characters from all walks of life.

The renal nurses described encounters with eccentrics, sweethearts, divils, lovable rogues, not-so-lovable rogues, and everything in-between.

It is possible to find humour in unlikely places...

Patient: What is a dialysis patient's favourite song from *The Sound of Music*?

Nurse: I don't know.

Patient [singing]: 🎵How do you solve a problem like urea! 🎵

CONCLUSION

Nursing is not easy but, as with any job, it is important to take the rough with the smooth.

This is a tiny snapshot of some of the positive aspects of working as a renal nurse. It was carried out as an informal reflection by nurses in order to better appreciate the work they do and the impact that it has.

This was widely agreed to be one of the best parts of the job!
Nursing involves meeting all sort of colourful characters
from all walks of life.

Taste of Summer

Embrace the flavours of summer with these kidney - friendly diet, easy to prepare, recipes for tasty beef burgers and refreshing chicken salad, for all to enjoy.

BEEF BURGERS

Serves 4

Ingredients:

450g (18oz) lean minced beef.
1 small (60g / 2 ½ oz) onion finely chopped.
½ tsp dried mixed herbs.
¼ tsp black pepper.
1 medium egg, beaten.



Method:

Mix together the minced beef, onion, mixed herbs, black pepper and beaten egg.

Divide the mixture into 4 equal portions and shape them into round flat cakes.

Grill for about 10 minutes on each side, pressing occasionally to extract any liquid.

Per portion this dish provides 3½ protein exchanges (allowances).

Check your daily allowances to see if you have enough remaining for this dish.

Total nutritional analysis per portion	238 kcal	23g protein	16g fat	0.2g salt	7mmol 274mg Potassium	6 mmol/ 187mg Phosphate	0.5g Carbohydrate	0.3g sugars
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CHICKEN SALAD WITH YOGHURT AND MINT DRESSING Serves 2



Ingredients:

2 medium (125g / 5oz each) skinless chicken breasts.
1 stick (25g / 1oz) celery, sliced.
5 red / green seedless grapes, sliced in half.
2 x tinned pineapple rings (canned in juice), drained and chopped.

Yoghurt Mint Dressing

1 ½ heaped tbsp low fat mayonnaise.
125g (5oz) carton low fat natural yoghurt.
Juice of ½ lemon.
1 level tsp honey.
¼ tsp white pepper.
2 tsps finely chopped fresh mint.

Method:

Place chicken into a pot of boiling water and simmer for 30 minutes or until the chicken is cooked through.

Drain and allow to cool to room temperature.

Chop the chicken into 1 inch pieces and place into a bowl with the sliced celery, grapes and pineapple pieces.

To make the yoghurt mint dressing, put all ingredients in a bowl and whisk to combine.

Add to the chicken and vegetable mixture, refrigerate until ready to eat.

Per portion this dish provides 4½ protein exchanges (allowances), ½ dairy exchange, ¼ portion of fruit and ¼ portions of vegetables. Check your daily allowances to see if you have enough remaining for this dish.

Total nutritional analysis per portion	383 kcal	35g protein	11g fat	0.9g salt	12mmol 456.5mg Potassium	9 mmol/ 281mg Phosphate	16g Carbohydrate	15g sugars
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Recipes reproduced with kind permission of www.irishkidneydiet.ie

PERTH, AUSTRALIA

The team on Matagarup Bridge.



Supporters at the Opening Ceremony.

2023

WORLD TRANSPLANT GAMES

15TH – 21ST APRIL

We are family...



By **COLIN WHITE**
TEAM MANAGER

This year's World Transplant Games in Perth, Australia was the first since 2019 as the pandemic led to the cancellation of the 2021 event that was planned for Houston in the USA. Consequently, it had a feel of a real family reunion as old friendships were renewed and new ones made.

There was also an opportunity to remember friends we

have lost in the period since 2019, with too many taken too soon by the COVID-19 pandemic.

The Ireland team was made up of 14 competitors, 7 of whom had competed for Ireland before and 7 for whom it was all a new experience.

The team which included bone marrow, kidney and liver transplant recipients, brought home an impressive haul of 17 medals including 7 Gold, 6 Silver and 4 Bronze. Nine of the fourteen transplant recipients came away with medals and all fourteen members displayed great sportsmanship and camaraderie while honouring their donors.

What was very notable this year was the number of Australian-based family members who took the opportunity to join the team, as supporters, during our time in Perth.

Our team gathered in Perth via many and diverse routes but as soon as we were together, the traditional Irish team spirit was evident with everyone open and keen to share the experiences together.

As you will read elsewhere, the opening ceremony was an amazing experience. Thinking about the guard of honour from all the supporters as the athletes paraded into the stadium still raises the hairs on the back of my neck! The Irish did themselves proud cheering on our team.

Seeing transplant recipients, their families and friends gather from 46 countries around the globe was a reminder, if one was needed, that organ donation is truly the 'Gift of Life'. For many, travelling to Australia was a once in a lifetime opportunity and everyone was conscious that it was because of organ donors and donor families that we were all able to gather there and celebrate life through sport.

We enjoyed the traditional parade of nations around the inside of the stadium. Parading behind your national flag, at an international event, never gets boring! The last group to enter the stadium was the living donors and donor families who had come to not only support the Games but to compete in some of the events too. The huge outpouring of emotion from all the gathered teams was palpable and testimony to the good that there is in the world.

It was a busy week, but it was a GREAT week. Perth is beautifully situated and easy to navigate, and the weather was delightful too. Although our team was smaller than previous Games, our numbers were swollen by our local supporters, so we did not go unnoticed! It was evident that being Irish in Perth is a good thing as we were warmly welcomed wherever we went.

The 5km road race and a public 5km event were held in a beautiful park in Perth. Having them as the first event was an inspired decision as it was our first opportunity to meet many of the other teams so it set a wonderful atmosphere that was to continue through the week.

Whilst we may not have had a World Games for four years, the standards had not fallen. The level of competition was extremely impressive and the number of Games records broken was notable too – including our own Ron Grainger breaking his age category record in both the 100m (16.09 seconds) and 200m (33.97 seconds) track events. Did I mention that Ron is in the 70-79 years age category!?



This year saw the first full triathlon at a World Games. The fact that there was sufficient demand for such an event is testament to the impact of organ donation for transplantation. It was particularly pleasing to have two of our team members, Sheila Gregan and Bryan Duignan, taking part in the event!

Our golfers, once again, did themselves proud. A fantastic haul of medals across both singles and pairs events. Our golfers are a vibrant group who meet up around the country and are always looking for newcomers to join them!



Tony Gavigan, Pat O'Sullivan, Hugh Nolan, Nick Heather, Ron Grainger and Mike Kiely.

I particularly like the fact that the World Transplant Games and the European Transplant and Dialysis Sports Championships (which take place on alternate years) are open to all ages, and they offer a range of physical and skill-based sports such that there really is something for everyone. I also like the fact that honest effort is all that is expected of competitors – it is about being the best that YOU can be at that time.

Our 2023 World Games experience was wrapped up nicely with an invitation to the Australian Embassy in Dublin to join the ambassador in celebrating a successful and memorable trip. Report on pages 40-41.

Ahead of their departure for the games, Transplant Team Ireland were delighted with the wave of goodwill and encouragement they received from both individuals and organisations. Notable figures like rugby legends Paul O'Connell and Mack Hansen, as well as prominent political figures including Taoiseach Leo Varadkar and Australian Ambassador to Ireland Gary Gray, took the time to record heartfelt video messages extending their best wishes to the team.

The outpouring of support has not been limited to these individuals alone, as the Olympic Federation of Ireland actively championed the team through social media and a motivational talk by Gavin Noble, the Olympic Federation's Chef de Mission for the Paris 2024 Olympic Games.

Goodwill and support towards the team also came in the form of sponsorship. La Roche Posay generously sponsored sunscreen for

the team, facilitated by Consultant Nephrologist Claire Kennedy. Ryan Golf sponsored some head covers for woods and putters for the golfers while the team kit was sponsored by the HSCU Credit Union.

As the Games came to a close, the Irish Kidney Association selected four members of Transplant Team Ireland for special recognition awards and they were each presented with a certificate and a €100 voucher, generously sponsored by Harvey Norman.

In recognition of two members of the team for leading by example and looking out for other members on the team, the Ladies Leadership Award was presented to Sheila Gregan and Pat O'Sullivan received the Men's Leadership Award.

Tony Gartland received an award in celebration of the 30th anniversary of his liver transplant. Tony was the first person to undergo a liver transplant in Ireland at St. Vincent's Hospital and has competed in almost every World Transplant Games event since then.



Ambassador Gary Gray

Newcomer to the team Finbar O'Regan, also a liver transplant recipient, received the Team Ambassador Award as he embraced every opportunity to network with people from all over the world seizing the opportunity his donor had given him to be part of the celebration of life.

Next year's European Transplant & Dialysis Sports Championships are considerably closer to home with Lisbon scheduled to be the host. The 2025 World Transplant Games will be in Dresden in Germany.

We are always looking to grow our Transplant Team Ireland family and new members are welcome throughout the year. If you would like to find out more, contact teammanager@transplantteamireland.ie



Sheila Gregan



Pat O'Sullivan



Tony Gartland



Finbar O'Regan

COMPETITION

WIN A €100

Harvey Norman® VOUCHER

To celebrate the success of **Transplant Team Ireland** at the World Transplant Games, **Harvey Norman** is giving away a **€100 voucher** to one lucky reader, which can be used at any of its 18 stores in Ireland. The international electrical, computer and furniture company, which originated in Australia, has 290 stores worldwide.

To enter just answer the following question:
In which city will the 2025 World Transplant Summer Games be held?

Send your answer with your name, address and phone number, with 'Harvey Norman' in the subject line, by email to colin@ika.ie by **July 31st, 2023**. The winner will be selected randomly and will be announced in the Autumn issue of **SUPPORT**.

THE GAMES THAT REUNITED FRIENDS AND FAMILY



Matagarup Bridge

PAT O'SULLIVAN gives a day-by-day account of Transplant Team Ireland's adventures at the World Transplant Games.

Qatar, Emirates, Qantas and British Airways, all carried the Irish competitors to the Southern hemisphere in April, to compete in the **World Transplant Games** in Perth. Some went out early to catch-up with family whilst others stayed on to see what Australia and New Zealand had to offer. We travelled from Cork, Carlow, Kildare, Tipperary, Limerick, Galway, Meath, Westmeath, Wicklow and Dublin, to represent our country and our donors at the biennial Games.

Thursday April 13th: Mairead O'Mahony and myself met in the railway station in Mallow to commence our journey to Perth. On arrival at Dublin Airport we met up with fellow team members; Tony Gartland, Ron Grainger, Teresa Smyth, Finbar (Finny) O'Regan and No. 1 supporter Joyce Grainger. Finny was lucky to make the flight as he had slept in the taxi to the airport and was also found by Teresa asleep in the food court area before we checked in!

We were last to leave Ireland, John Loftus was flying that day on a different airline so it was nice for some to see 'The Bullet' before take-off. Qatar Airways are the number one airline in the world for customer experience and our journey from Dublin to Perth, via a quick layover in Doha, went very smoothly. Finny slept for most of the flight.

Friday April 14th: We arrived at Perth international airport; it had been just over 24 hours since we had left Mallow. We have all seen the TV programme *Border Security*. Passengers were warned before arrival to declare anything they think they should declare. I had some Barrys Tea Bags and Cadburys Creme Eggs which I declared.

After Passport control, I was directed to Customs where I saw a sign to say Channel 7 TV were there filming for *Border Security*! Lucky for me, they kept the cameras off. I put my bag on the desk and was greeted by a customs officer with a thick Tipperary accent. "If you have tea bags in the bag," he said, "I'll bate you with my hurley for declaring them." We laughed and after being inspected by a member of the Dept of Agriculture, I was on my way, tea bags and Creme Eggs in tow.

Our hotel was the Mantra on Hay in Central Perth. When we arrived the rest of the team had gathered in the lobby. I was greeted by my son Patrick who is now living in Perth with his girlfriend Lenoa. The family reunions were in full flow.

Tony Gavigan had already been in New Zealand to catch-up with his son and get some golf tips, Michael

Kiely had also arrived early and was catching-up with family in Perth.

Limerick native John Loftus was staying with his son. Nick Heather, a Dublin native, had travelled over from his home in Melbourne and was joined in Perth by his mother and other family members and friends.

Teresa had been met at the airport by her daughter Rachael. Bernie Cox met her niece Emma, and her family, who had travelled over from Sydney – Emma also happens to be team manager Colin White's sister.

Sheila Grogan was joined by her daughter and niece. Mairead O'Mahony was joined by her friend Caice, and Ron Grainger and his wife Joyce had friends join up with the team later in the week. It really was a week of reunions.

Saturday April 15th: Registration Day. Our hotel was very central and registration was in the local town hall which was only down the road and there were plenty of smiling volunteers to greet us on arrival. We all had to do a COVID test before registration with results sent to the Team Manager, Colin White, and lucky for Team Ireland we were all clear.

With bags of goodies collected it was off to the golf course for some practice. Tony Gavigan's golf clubs had eventually made it across the Tasman Sea. Some enthusiastic team members were even going for runs and stretching their legs.

Finny, Teresa and Bernadette went to Petanque practice. It was at this stage Finny started collecting telephone numbers and photos with

his fellow competitors. By the end of the games Finny had built-up a fair collection of pen pals to keep in touch with!

Finny would sleep for Ireland and if medals were handed out for sleeping Finny would have come home with more medals than the rest of the team put together!

It was around this time that a certain Hannah Duignan started becoming the star of the team. Hannah, (4), was the life and soul and had a laugh and a smile for all the team members. Together with her brothers Alex and Dara, they created a lot of fun.

We all went out for a team dinner that evening. Perth is a very small city and very easy to get around, locals had told us that if you had not been in Perth in the last five years you would not recognise it when you would return.

Sunday April 16th: 5K road race day. We had four competitors in the race, Mairead O'Mahony, Tony Gartland, Sheila Grogan and Bryan Duignan. We all gathered in Kings Park overlooking the city for the race.

There was a Donor 5k happening at the same time.



Hannah Duignan

Mairead O'Mahony won our first medal of the Games and it was great to get things off to such a great start with a podium finish for one of our competitors.

After a quick lunch and a change into our gear it was on the bus and off to the **Opening Ceremony**. The ceremony was being broadcast live, so all at home were advised to tune in. Despite the time difference it was great to see how many had tuned in.

We gathered by the Swan River and walked across the Matagarup Bridge to the OPTUS stadium. It was some sight as all the athletes were held on the bridge at the same time to attempt a record for the number of people on the bridge at the one time.

Just before we arrived at the stadium we were greeted by all our families and friends waving tricolours. Finny was like Joe Biden who was visiting Ireland at the same time, shaking hands and posing for photos with all the supporters.

Entering the stadium was a wonderful experience, standing behind the tricolour as we were announced and taking up our place in the stand was a hair standing on the back of the neck job.

Continued next page



Bryan proudly carrying the Irish flag in the parade of nations at the Opening Ceremony.



Bernie Cox, her niece Emma, her husband Dave and their children Chloe and Lucy, and Emma's brother, Team Manager Colin White.



Team and supporters.



Bernie Cox at Petanque.

Monday April 17th: The Games begin in earnest. Finny O'Regan, Bernie Cox and Teresa Smyth compete in the Petanque Singles at the Subiaco Petanque Club.

The golfers headed to Wembley Golf Course for pairs golf. More meeting up with old friends from previous Games and making some new ones. The course was in wonderful condition and the green keeper must have thought he was preparing the course for the Masters as the greens were fast, and pins were in tricky positions.

It is a tree lined course and was very tight.

At the end of the round we all gathered for the medal ceremony. Nick Heather and Mike Kiely were called out as bronze medal winners for Category 1, Hugh Nolan and myself the gold winners, with Ron Grainger and Tony Gavigan the bronze medal winners for Category 4 and that's when the controversy started.



Sheila Grogan in the far lane.

The gold winners were called out, a team from Great Britain, this team then announced to the organisers that they were not in Category 4 but should have been in Category 1.

After what seemed to be an eternity, the officials announced that Mike and Nick had been relegated to fourth place in Category 1 and Ron and Tony were promoted to silver. This put a dampener on our celebrations, as with only 6 golfers on the team we had been celebrating all six winning medals.

We left Wembley totally disconsolate; it was like none of us had won, we all felt so sorry for the two boys.

Tuesday April 18th: Sheila was in the pool, Finny, Pat, Teresa and Bernie in the Petanque doubles and Tony Gartland was competing in singles Ten Pin Bowling.

Sheila came 6th in the 100m breaststroke. Pat and Finny were embroiled in controversy at the Petanque over a very technical rule, while Teresa and Bernie proved to be formidable opponents in their games.

No medals today but we did have the Cultural evening to look forward to. Some took the opportunity to go to the beach, I don't think any of us had ever had the opportunity to spend time on a beach in April before.

To say Finny was the star of the Cultural evening would be an understatement. Dressed completely from head to foot in green and shamrock it seemed that everyone at the event was looking for a selfie with him and of course he obliged, whilst adding to his collection of telephone numbers.

The event was brilliant with great music, food, drink and craic. The bus journey back to the hotel had the Irish in full voice keeping the other travellers entertained with songs and jokes.



Sheila, Teresa and Finny at the Cultural Night.

Wednesday April 19th: Another full day of events with Sheila in the pool, Finny on the tennis court embodying his inner John McEnroe, the golfers were back out in Wembley for single play and, Teresa and John Loftus were competing in darts.

Teresa who had cajoled every visitor to her house for months before the Games to play her in a game of darts in her kitchen proved that practice does pay off as she collected a silver medal.

The golfers were back on the podium as well. Hugh with gold, silver for Nick and bronze for Ron. As a golf team we were punching well above our weight. We were all delighted for Nick getting his medal after the disappointment on Monday.



Sheila Grogan in the nearest lane.

The team were now really starting to gel together. The jet lag was wearing off, nights were starting to get longer and the hotel lobby was now like an Irish bar.

Other teams looked on in envy as they passed through looking at the fun and craic that we were having. Hannah as usual was centre of attention keeping us all entertained.

Team meetings were fun, lots of joking and taking the proverbial micky out of each other.

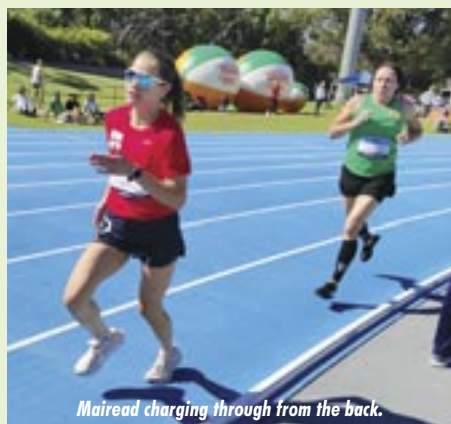
Thursday April 19th: Athletics Day.

The day that I had really been looking forward to! In the 100m race for the males over 70 we had two competitors, Ron 'The Flying Doctor' and John 'The Bullet'. As I warmed up with Ron, I could see the determination and that competitiveness build up in him.

John was adding to our medal tally by claiming bronze in the Ball Throw in another part of the stadium.

All three of us met up near the start line. These two had never competed against each other before and both had dominated this event at various previous Transplant Games. I stood behind as they lined up for the start of the race. Both looked fit and raring to go, I only wished that I was further up the track to see the race unfold.

The gun went off and they both started well out of the blocks and then disaster struck as John pulled a calf muscle 30 metres into the race forcing him out. Ron continued to the end and struck gold with a new world record for his age category.



Mairead charging through from the back.

Mairead O'Mahony was slowly becoming the queen of the team. Mairead was competing in the 1500m Race and the Shot Putt that day. Mairead threw a Personal Best of 8.96m in the shot putt to claim gold and followed that up with a



At the starting line for the 5k race.



Bryan Duignan

Tony Gartland

bronze medal in the 1500m.

In the men's race walk Tony Gartland, in tough walking conditions with the track temperature at 33°, claimed a bronze medal. Meanwhile Bernie, Teresa and Finny were also finishing up their games. Bernie was competing in Lawn Bowls, Finny and Teresa playing Table Tennis. Teresa as usual had her own fan club cheering her on.

Friday April 20th: Last day of competition.

Ron was back out on the track for the 200m, Mairead was competing in the 800m race and the Javelin. Bryan and Sheila were out at Champion Lakes competing in the Triathlon.

Conditions at the lakes were tough, the lake for the swim had a swell, the cycling consisted of two laps on a tough course and the run was also two laps around the lake.

A good crowd of Irish supporters congregated at the change-over area to cheer Bryan and Sheila on as they came by. Both seemed to be going well. Bryan discovered after he finished his race that he had completed a lap too many in the cycle thus taking him out of medal contention.

Back to the track just in time to watch Ron compete in his 200m. With the temperature in the mid-30s, once again Ron powered through the field to take another gold medal and another world record. His awkward finish over the line may not have got

him maximum points in any diving competition but the 200m he sprinted before ensured his place in the history books.

Mairead struck gold again in the 800m. Her last event was the Javelin. When she got to the Javelin area, as her reputation as a fierce competitor preceded her, the rest of her competitors suggested to her that she had won enough medals and asked if she could give the rest of them a chance to win something!

After the first three rounds Mairead was in fourth place but after a quick inspiring coaching session from Colin's brother-in-law Dave, an athletics coach, Mairead improved her position to 2nd place securing another silver medal, and bringing her tally to five medals for the Games and just surpassing Ron's four.

After a quick trip back to the hotel and clothes change it was off to the closing Gala Dinner, in Aussie style it was a BBQ! Plenty to do at the BBQ including petting snakes, some even had the nerve to wear the snake as a necklace.

The night finished off with one of our by now famous last night parties. It was time to let the hair down and relax. There was even time for a maths grind as Bryan's son Alex (14) got some tutoring from Hugh's nephew, maths teacher Eoghan.

For some of us it was also time to start getting ready to head home but for others their adventures were just beginning.

Hugh and Eoghan were heading east to Melbourne and Sydney, then to New Zealand and San Francisco, Michael Kiely and his wife Mary were undertaking a similar trip. Ron and Joyce were also heading east to meet up with old friends while Sheila was heading to Sydney to spend time with her daughter and niece. Teresa was staying on with her daughter Rachael who, shortly after we left, gave birth to baby Ruby.

Saturday April 21st: Time to check out of the hotel and we were all going our separate ways. For me it was time to spend the final few hours with my son Patrick, he had been great company all week and an even better taxi driver to half the team.

Continued next page

THE GAMES THAT REUNITED FRIENDS AND FAMILY CONTD...

Others had last minute shopping to do and to say goodbye to all the new friends they had met.

It was a long trip home, both legs of our flights were longer going home than going out. Sleep on the first leg of the journey was not an issue, so much so that I missed the food. Another quick layover in Doha and we were back in Dublin for a fantastic homecoming welcome.

Plenty of hugs and kisses from family members and team members who had not made the trip.

There was also instant fame as we appeared on both the RTÉ Six One news and the Nine O'Clock news.



Presenter Martin King on the couch with Mairead, Bryan and Pat.

Our journey was still not complete. A week later we were invited on to Virgin Media Ireland AM to discuss the Games. Bryan and myself got a quick word in after Mairead had finished.



At Virgin Media studios Bryan, Mairead and Pat with programme researcher Ollie Dingley, a former Olympian diver.



The Echo Chief Sub-Editor Rory Noonan making a presentation to Mairead O'Mahony with The Echo Women in Sport award for winning five medals at the World Transplant Games. Picture Dan Linehan

A supporter's view



A personal account by LARA DILLON who travelled to the Games with team member Bryan Duignan and their children Dara, Alex and Hannah.

The decision for Bryan to participate in the World Transplant Games for the first time came initially from a member of our club, Carlow Triathlon Club, suggesting that he give it a go, and learning that triathlon would be in the Games for the first time that year felt like the perfect time to start.

Bryan made contact with Team Manager Colin White and that was it. The brief really was to do more than one sport and really get involved with it all. We were 'Team Bryan' from day one. Little did we know that very soon we would be welcomed in with open arms to Team Ireland and become part of the extraordinary family they are.

It was an amazing experience as a supporter from start to finish. Seeing the changes in people as a consequence of being given the 'Gift of Life' and the amount of appreciation and respect every person from every country represented had for their donor and donor family was very uplifting.

It really was a celebration of life, something those of us who have not had such struggles may take for granted. I am passionate about organ donation from being Bryan's partner but even more so now from having seen the life it gives to people all over the world from our World Transplant Games experience.

It didn't matter where people came, in any sport or event. Everybody that participated was a winner. A winner in living life to its fullest potential thanks to the most generous gift of organ donation.

We are proud to be supporters and family for Transplant Team Ireland and look forward to many years of celebrating the 'Gift of Life' at all future Games, wherever they take place around the globe.



17 MEDALS
7 GOLD
6 SILVER
4 BRONZE

TRANSPLANT TEAM IRELAND – MEDAL TABLE

9 of the 14 transplant recipients came away with medals and all fourteen members displayed great sportsmanship and camaraderie while honouring their donors.

NAME	EVENT	MEDAL	NAME	EVENT	MEDAL
Mairead O'Mahony	800m race	Gold	Hugh Nolan	Golf Singles	Gold
	Shot Putt	Gold		Golf Pairs (Pat O'Sullivan)	Gold
	Javelin	Silver	Pat O'Sullivan	Golf Pairs (Hugh Nolan)	Gold
	5km race	Silver		Golf Singles	Silver
	1500m race	Bronze	Tony Cavigan	Golf Pairs (Ron Grainger)	Silver
Ron Grainger	100m race (WR 16.09)	Gold		Darts	Silver
	200m race (WR 33.97)	Gold	Teresa Smyth	5000m Race Walk	Bronze
	Golf Pairs (Tony Cavigan)	Silver		Ball Throw	Bronze
	Golf Singles	Bronze	John Loftus		



THE FULL IRISH TEAM

TEAM PERTH (Back): John Loftus, Mairead O'Mahony, Pat O'Sullivan, Tony Gartland, Hugh Nolan, Bryan Duignan, Tony Gavigan.
 (Front): Bernadette Cox, Finbar O'Regan, Teresa Smyth, Sheila Gegan and Ron Grainger. Missing from pic: Nick Heather and Michael Kiely.

NAME	TRANSPLANT	COUNTY	NAME	TRANSPLANT	COUNTY
Bryan Duignan	kidney	Carlow	Tony Cavigan	kidney	Longford
Michael Kiely	kidney	Cork	Sheila Gegan	kidney	Tipperary
Pat O'Sullivan	kidney	Cork	Ron Grainger	kidney	Dublin
Hugh Nolan	kidney	Cork	Finbar O'Regan	liver	Dublin
Mairead O'Mahony	bone marrow	Cork	Nick Heather	bone marrow	Australia
Teresa Smyth	kidney	Galway	Tony Gartland	liver	Wicklow
Bernadette Cox	kidney	Kildare			
John Loftus	kidney	Limerick	Colin White	TEAM MANAGER	Dublin



Promoting Organ Donor Awareness, Ambassador Gray (centre) with members of the team and supporters outside the Australian Embassy.

TRANSPLANT TEAM IRELAND ARE GUESTS OF AUSTRALIAN AMBASSADOR



By
GWEN O'DONOGHUE

Australian Ambassador to Ireland **Gary Gray** hosted a special reception to honour **Transplant Team Ireland**, following their participation at the **World Transplant Games** in his native city, Perth. The event was held at the **Australian Embassy on St. Stephen's Green, Dublin 2 on Friday, May 26th**, to mark **Organ Donor Awareness Week**.

At the event, Ambassador Gray highlighted Ireland's special links with Australia and the team's route, at the opening ceremony, to the stadium over Matagarup Bridge, emphasising the

significance of acknowledging the Indigenous population.

In outlining the mistreatment of the Aboriginal people by settlers he said, "The only head of state on the face of this earth to apologise to Aboriginal people for their treatment during settlement is the Irish Head of State. The Irish State remains the only State on the face of the earth that has acknowledged that, and did so in our parliament. They did it in October of 2017. So, the nature of that relationship to us is a very important one."



Lara Dillon, Bryan Duignan



Harry Ward, Ambassador Gray, Dr. Claire Kennedy, Joyce and Ron Grainger, Colin White.



Tony Gavigan, Lorraine Coburn.



Ambassador Gray, Mairead O'Mahony, Sean Hosford, Chief Executive HSSCU (team kit sponsors), and Colin White.



Robyn Black, IKA and James O'Donoghue, Events Officer, Australian Embassy.



IKA Chairman Eddie Flood, Ambassador Gray, Team Manager Colin White.



Eoghan, Hugh, Ambassador Gray, Mairead, her daughter Isabella, and Pat.

Ambassador Gray congratulated the team on its success at the Games. He expressed gratitude to them for promoting organ donation and connecting with the Irish community in Australia.

The team proudly wore their team kit and showcased their medals at the Ambassador's event. They presented the Ambassador with a framed team jersey as a token of appreciation.

Colin White, the Team Manager, thanked Ambassador Gray for the warm hospitality and spoke about their fantastic time in Australia, where they had the opportunity to reconnect with family members.

The event was attended by family members, representatives from the Irish Kidney Association, former Team Doctor Claire Kennedy, and the team kit sponsors, the Health Services Staff Credit Union (HSSCU).

The team was delighted to meet Tim Lion, at the reception. Tim, an Australian native, is now living in Glenageary, Dublin with his Irish wife Ruth and their children.

Tim underwent a lifesaving liver transplant at St. Vincent's University Hospital in August 2022, and hopes to join the team for future Transplant Games events.



Ruth and Tim Lion with Ron Grainger.



The backroom team...Gwen, Colin and Robyn with (second from left) Ambassador Gray and the framed jersey he was presented with.



Photos by **GARETH CHANEY**

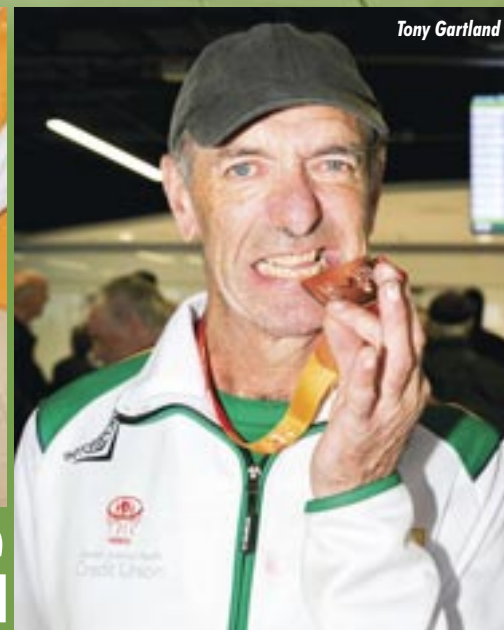
Team's homecoming reception at Dublin Airport.



Mairead O'Mahony



Finny O'Regan



Tony Gartland

THE HOMECOMING



Centre, Mairead O'Mahony's daughter Isabella (11) with her cousins and flanked by other welcoming supporters.



Bernie Cox



Pat O'Sullivan with his daughter Carol and wife Helen.



IRISH KIDNEY ASSOCIATION CLG
 Donor House, Block 43A,
 Park West, Dublin D12 P5V6
 Tel: 01-6205306
 Email: info@ika.ie | Web: www.ika.ie
 CHARITY REGISTRATION NO. 20011260



James Nolan and his son Andrew James (2nd from left) with the PKRF Charity Race jockeys. Photo by Healy Racing.

PKRF CHARITY RACE

One of the big attractions each year, at the Punchestown Racing Festival, is the **Punchestown Kidney Research Fund (PKRF) Charity Race**. The PKRF has been organising the Charity Race, at the annual National Hunt Racing Festival, annually since 1990, with the exception of the COVID-19 interruption.

The charity is the brainchild of kidney transplant recipient, **James Nolan**, and over the years it has raised over €1.7 million. PKRF invests these funds in projects that improve the quality of life for patients on dialysis, projects that establish ways to maximise the life span of the transplanted kidney, and identify projects that examine the causes that lead to renal failure. A recent project was the commitment of €65,000 for the IKA's Patient to Patient Peer Support pilot programme.

James Nolan began dialysis in 1986 and in 1987 his sister, Catherine, donated a kidney to him. The PKRF is his way of 'giving back'. James rode in the race for the first 13 years and rode *Nero's Dancer* to victory in 2002.

The Charity Race is the PKRF's primary fundraiser each year and as a mark of its success, it continues to be significantly over-subscribed annually.

At this year's race 71 amateur jockeys applied for 25 places to take part in the final race of the Punchestown Festival held on 29th April. The jockeys are required to pass fitness and competency tests before being cleared to ride.

They must also raise a minimum of €1,500 for the charity. It's a serious commitment for participants but the opportunity to ride at the National Festival is an attractive one.

30,000+ spectators make for an amazing back-drop to a real bucket list experience. Observing the parade ring as the horses and their riders get ready for the race highlights what is very special about this event. The jockeys have many family members there and everyone is buzzing with excitement. Some of the jockeys look like they were born to do this whilst others look 'a little tense' for what lies ahead.

It proved to be a home town affair with Kilcullen jockeys filling the first and second places. Local favourite **Paul Bell**, who has won two Kildare County Football Championship medals with Kilcullen, won on board *Stuzzikini* for Gordon Elliot. A fast finishing **Sinead Smullen** finished second on Jessica Harrington's *Jungle Cove* with Triona Burbidge, third, on *Diamondinthemud* for Nigel Slevin. The majority of the 33,000 people in the record breaking crowd stayed on in the glorious sunshine to create an

unbelievable atmosphere and cheer all the 25 amateur jockeys home.

On returning to the parade ring, the sense of elation and camaraderie is fantastic and with members of Transplant Team Ireland and the Irish Kidney Association (IKA) on site too, the message about the importance of having the organ donation conversation is forefront.

Race organiser James Nolan was delighted that all the Jockeys came home safely and thanked all the owners and trainers who had kindly entered horses in the Charity Race, as well as the Dream Team at Punchestown for helping the PKRF in every possible way to make the Charity Race happen.

The Charity Race has attracted some very high-profile alumni of the racing world with Jessica Harrington, Tommy Carberry and Robert Hall, to name but a few, and the great *Moscow Flyer* took to the starting line too.

As a very successful award-winning butcher and businessman in Kilcullen, James continues to devote much of his time to make a difference for the renal community in Ireland.

JOCKEYS VISIT TALLAGHT UNIVERSITY HOSPITAL

As part of their **PKRF Charity Race** experience, jockeys visited **Vartry Dialysis Unit at Tallaght University Hospital**, which has benefited from funding from PKRF, for the arts and health programme for patients undergoing dialysis.

The jockeys were given a guided tour of the hospital by Renal Consultant Prof Catherine Wall, Arts Officer, Ali Baker Kerrigan, and Artist in Residence Lucia Barnes.

Pictured from left are: PKRF Charity Race jockeys Aoiife Kiernan, Eimear Smullen, Cliona Costello, Katie McManmon and Sinead Smullen, with kidney dialysis patient Paul.

Photo: TUH Medical Photography & Illustration



Thinking about a holiday abroad...

...while on dialysis

There has been high demand for the Irish Kidney Association (IKA) holiday centres in Tramore, Tralee and Killarney throughout Summer and into the Autumn.

For dialysis patients wishing to holiday in other countries, the IKA provides a service of arranging dialysis treatment abroad.

Please contact us about arranging dialysis abroad **BEFORE** booking your holiday. Please give at least **6-8 weeks'** notice as the IKA's holiday booking service is extremely busy.

HOW DO I BOOK DIALYSIS ABROAD?

- Please **DO NOT** book a holiday or flights before making arrangements for your dialysis treatment abroad.
- Your first port of call should be either to 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
- Patients need to give **at least 6-8 weeks'** notice for dialysis treatments abroad.



By **DEBORAH CERVI**
Holiday Co-ordinator

WHAT INFORMATION DO I NEED TO PROVIDE TO THE IKA OR MY DIALYSIS UNIT?

The basic information required to book a patient's holiday abroad request is the following:

- Patient's name.
- Holiday location.
- Desired dialysis dates.
- The IKA will also need information on where you usually attend dialysis in Ireland, so we can contact them and start the booking process for your holiday.

WHAT DOCUMENTATION DO I NEED TO PROVIDE?

The following documentation is required from your dialysis unit

abroad in order to confirm the dialysis sessions:

- Completed medical and dialysis application form.
- Up to date blood test results of Hepatitis B, Hepatitis C, MRSA and HIV (the test results must be dated no more than 4 weeks before the departure date).
- A letter from your consultant stating you are fit to travel.
- EHIC – European Health Insurance Card (formerly known as the E111).
- If travelling outside Europe your EHIC is of no use, therefore, you must pay for dialysis treatments outside the EHIC card area.
- Official COVID-19 Certificate.

IS IT SAFE TO DIALYSIS IN ANOTHER COUNTRY?

- We offer our patients consistently high standards in any of the worldwide dialysis clinics. We assess them yearly, making sure they meet the same standards as here in Ireland.

WILL I BOOK MY FLIGHTS/ACCOMMODATION BEFORE MY DIALYSIS IS CONFIRMED?

- It is best to wait until you have received a dialysis booking

Holiday Application Forms are available on www.ika.ie/patient-holidays

confirmation from our co-ordinator before confirming flights or putting a deposit on your holiday. We will do a thorough search of all hospitals in the area you are travelling to. Since the COVID-19 pandemic some hospitals have less capacity. We will do our best for alternative options if your chosen location is not available.

- You will need to give the IKA at least 6-8 weeks' notice for your holiday treatment abroad.

HOW DO YOU GET MY MEDICAL INFORMATION TO BOOK MY HOLIDAY DIALYSIS?

Once you give consent on the application form, this allows us to safely communicate all your paperwork from one hospital to another. We have years of experience, and all your information is kept confidential.

DO I NEED TO ARRANGE MY OWN TRANSPORT TO AND FROM DIALYSIS ABROAD?

For most destinations you will need to make your own arrangements to/from the hospital for your dialysis times. Destinations that do offer transport will be in touch directly with you prior to your arrival and will discuss pick up times with you.

DO I NEED TO LET THE TRANSPLANT TEAM KNOW I AM TRAVELLING ABROAD ON HOLIDAYS?

Yes, if you are on the waiting list for a transplant, you should let the team know that you will be abroad. This will 'pause' you on the list whilst you are away, as you wouldn't be available to receive the transplant should a suitable donor become available. Remember to let them know as soon as you return.

ARE THERE PROTOCOLS IN PLACE SINCE COVID-19?

All hospitals have taken extra precautions since the COVID-19 pandemic to ensure everyone is kept as safe as possible. There are a few further tests required before travelling, such as a PCR test, which must be taken 72 hours prior to your flight departure. We will be sure to inform you of what is required before you travel.

So, if you are thinking about holidaying abroad and would welcome our advice and support, please get in contact and we will be pleased to help.

SUMMER GIVEAWAY




A **FAMILY* MINI BREAK** at the **4-STAR**



WITH BREAKFAST AND DINNER

&

A **FAMILY PASS TO**

DUBLIN



In this issue of *SUPPORT* we are offering one lucky reader the opportunity to win a fantastic one-night staycation for a family of four* including breakfast and dinner at the **CLAYTON HOTEL DUBLIN AIRPORT** and a **FAMILY DAY PASS** to **DUBLIN ZOO****. Thanks to our friends at **DUBLIN ZOO** for sponsoring the free **FAMILY DAY PASS**.

The hotel prize, kindly sponsored by the **CLAYTON HOTEL DUBLIN AIRPORT**, allows the winner to share their good fortune with three others (including one more adult and 2 children – under 12 years). The group can enjoy the luxurious 4-star hotel as their base for exploring the capital and a **FREE FAMILY DAY PASS** to **DUBLIN ZOO**. With over 1 million visitors a year, **DUBLIN ZOO** is officially Ireland's biggest family attraction located at the Phoenix Park, and not only does it offer a great day out for all, but also a journey of learning and discovery about the world's precious wildlife.

The **CLAYTON HOTEL DUBLIN AIRPORT** is located just a 15 minutes' drive away from Dublin city centre attractions and is the perfect base to explore nearby scenic seaside villages of Malahide and Howth.

Enjoy the comfort of unwinding in one of the **CLAYTON HOTEL DUBLIN AIRPORT'S** refurbished large bedrooms, its friendly customer service, and its multiple cuisine options from the hotel's award-winning Italian Restaurant or it's stunning bar, with free breakfast and dinner, and for the adults a complimentary bottle of wine. If the adults have any energy left after a busy day at **DUBLIN ZOO**, sightseeing or shopping, they can take turns enjoying free access to the hotel's fitness centre which is open 24/7.

To enter, simply email robyn@ika.ie with the subject line **Clayton Zoo Giveaway**, include your name, address and contact telephone number, and tell us who you would like to bring with you if you win. The winner will be picked on 31/07/2023 using a random number generator, numbers will be assigned chronologically to entries. By entering this competition, you agree to your name being published in the Autumn 2023 issue of *SUPPORT* magazine.

**Family of four is 2 adults and 2 children (under 12 years).
Hotel voucher is valid until July 2024 and booking is subject to availability.
**Dublin Zoo pass is for 2 adults and 4 children and is valid for 5 years.
The winner will receive a voucher code to pre-book their visit to Dublin Zoo online at www.dublinzoo.ie
Zoo visit **must** be pre-booked at least one day before their chosen date.
The two prizes can be redeemed separately, at different times.*



Get ready for Summer

Taking a holiday can be a wonderful experience for kidney patients, providing a much-needed break from the routine of medical treatments and offering an opportunity to relax and rejuvenate. MICHELLE GERAGHTY, who has first-hand experience of travelling as a kidney patient, with her husband and child, shares valuable insights and practical advice to fellow patients who wish to embark on a holiday, whether in Ireland or abroad.

By **MICHELLE GERAGHTY**

Michelle, Eoin and Dylan.



Summer is here! But what does the summer hold if you're a person living with end-stage kidney failure, going through dialysis or navigating life with a new kidney and all the medication and side effects that goes with it.

What are your options for respite; for the opportunity to relax and enjoy a break, potentially for the first time in years? And what supports are out there to assist?

I'm Michelle. I have Polycystic Kidney Disease (PKD) and was living with kidney failure for five years (two on peritoneal dialysis) until I was blessed with the 'gift of life' in August 2022.

Whatever stage you're at on this rollercoaster, you must navigate life slightly differently to everyone else. There are more

obstacles, hurdles and mountains to climb, both physical and mental. So, the idea of going on a holiday or taking a break might seem like one challenge too far. Ironically though, you might need this break now, more than any other time in your life.

Here are a few ways my family got some respite throughout my kidney journey.

TRAVELLING IN IRELAND ON PERITONEAL DIALYSIS

When your peritoneal dialysis machine and supplies arrive for the first time, it's overwhelming! And the thought of travelling on top of everything else seems impossible.

But once you're used to your routine and managing your supplies, it's not a huge jump to pack up the machine in its hard travel

case, make a list of the supplies needed and hit the road.

Of course it all takes up a lot of space, both physically and mentally! But taking a minibreak makes it all worth it.

Here are a few tips that helped me out.

- 1. Create a dialysis checklist** listing everything you need and bring extras in case there is an issue. For me, that included an extra box of fluid as over the years I had a few incidents with leaking bags.
- 2. Check the layout of the room** in advance so you're prepared. Is there a table or counter for the machine and supplies? Is it close to a socket or do you need to bring an extension cord? Is it close enough

to the bathroom? Over the years I found hotels were very accommodating and in some cases, moved me to a different room for a smooth treatment.

- 3. Research the hotel car park.** Is there a lift from the basement car park? Do they have luggage trolleys? If travelling alone, is there someone who can help with the boxes of fluid, etc.
- 4. Check where the closest hospital with a Renal Unit is located,** in case of emergency and have emergency phone numbers at the ready including Baxter's support number and your machine number.
- 5. Remember that manual treatments are also an option** if travelling with the machine is an issue.

If you're planning to take a longer break, where up to 14 boxes of fluid or more might be required, you might rule out a break simply because getting all the supplies into the car would be impossible.

This is where your dialysis team and Baxter can help! With enough notice, we were able to coordinate with Baxter to have 2 weeks of fluid delivered to my parents' house across the country so we could have an extended stay. Baxter deliver around the country, so, as long as they have time to work out the logistics, they're incredibly accommodating.

If you're unsure where to start, speak to your dialysis team who will no doubt have navigated the process before (huge thanks to my team at Beaumont Hospital for their help!).

It's also worth remembering that the Irish Kidney Association (IKA) has holiday homes in Ireland where kidney patients and their families can take a much-needed break. And again, with enough notice, Baxter can assist with the delivery of supplies.

You can find more information on the IKA website at [ika.ie/patient-holidays](https://www.ika.ie/patient-holidays).

TRAVELLING ABROAD ON PERITONEAL DIALYSIS

Our family decided to take our son to Spain during the summer of 2021 while I was still on peritoneal dialysis. As with staycations, we were surprised how straightforward it was to arrange for delivery of our Baxter supplies to Spain. Not only were the boxes of fluid waiting for us at our hotel upon arrival, but they were actually already in our room (that was probably

thanks to the wonderful hotel staff who we had notified in advance).

We did have to bring a suitcase with all our other supplies (cassettes, tubing, caps, connectors, sanitising materials, etc.) but that was very manageable.

At this stage I had moved home to Galway so huge shout out to the dialysis nurses at Merlin Park Hospital who arranged everything with Baxter. They're all legends.

Travelling abroad with the dialysis machine took a little extra administrative work but it wasn't difficult. Aer Lingus (and, I imagine, all airlines) has a 'Special Assistance Request' process on their website. We had to provide information about our machine (including the battery) which Baxter had given us in an information document, along with some other information but it was relatively straightforward.

As the machine is a medical device, it was free to bring on-board which was a relief. We may have also been entitled to check-in our suitcase of supplies free of charge, but we decided to spread our supplies out between our three suitcases in case one of them got lost, so we didn't try to claim that.

We weren't allowed bring the machine on board because a) there was no room for it and b) the battery couldn't be



Dialysis Fluid Delivered to our Room in Spain.



Travel Case Baxter Dialysis Machine in Airport

removed. Knowing it needed to go in the hold, I made large 'Fragile - Medical Device' stickers and put them on the machine's travel case.

I also checked it in through the oversized luggage desk so that we could explain the importance of the case to staff.

We had no issue travelling to Spain. We did experience a bit of a delay checking in for our return flight as the lady on the desk wasn't familiar with the process and insisted we remove the battery which wasn't an option of course!

In the end, everything was fine but I would allow extra time for check-in to prepare for these kinds of delays.

TRAVELLING ON HAEMODIALYSIS

If you are a haemodialysis patient your renal team and the IKA can also assist you in planning a trip in Ireland or abroad, to facilitate in-centre HD sessions in a reputable clinic while you're away.

So, if that's something you're considering, speak to your team or contact the IKA who can help make the necessary

arrangements. Again, this web page is a good place to start – [ika.ie/patient-holidays](https://www.ika.ie/patient-holidays)

PERITONEAL DIALYSIS AND VAN LIFE

If you're looking for a challenge (as if kidney failure isn't challenging enough!), there's no need to limit yourself to traditional holiday accommodation options. Due to the pandemic, more than anything else, I found myself doing my peritoneal dialysis treatments in our motorhome.

We had invested in a second-hand campervan in 2020 after my husband took voluntary redundancy to look after our son while we all isolated. At that point, I was in end-stage kidney failure but hadn't started dialysis yet. The van allowed us to visit family and friends and get some respite away from home during isolation. It kept us sane and we made the most wonderful memories.

But when I started peritoneal dialysis in December 2020, there was a fear that our new-found freedom would be limited

continued next page...

GET READY FOR SUMMER CONTINUED

once again, especially since campsites were closed and we'd need significant power in the van to run the dialysis machine. But after some research, my husband found an inverter and leisure batteries that allowed me to do two nights' treatment on the road, powered only by the van!

We were lucky to have space in the shower for the machine and we took great care to clean and sanitise the area before connecting. It was a game changer and allowed us to live a 'normal' life, during a pandemic, while on life-saving treatment, which I never imagined would be possible.



Dialysis machine in the campervan shower.

While I know dialysing in a campervan may not be an option for everyone, I mention it to demonstrate that your travelling options aren't entirely limited, just because you're on dialysis.

For example, camping or glamping are still options on peritoneal dialysis (whether on the machine or doing manual treatments), if you are confident you can keep the area clean and sanitised, which is of course crucial. If in doubt, please speak to your renal team!

I'd like to take a moment to thank my incredible husband for helping to facilitate all the trips above. The campervan trips, in particular, saved our sanity during a tough period and I'm so grateful for all the

work he put into each and every trip and keeping our van on the road.

TOO FATIGUED TO TRAVEL?

While dialysis might seem to be the biggest obstacle to travel during your kidney journey, I'm aware that there are days that getting out of bed is difficult, let alone packing up and going on holiday!

Again though, there are accommodations that you can avail of that can open the doors to travelling, even if your energy levels are low.

Here are some that helped me travel with chronic fatigue:

1. Avail of any special assistance facilities at airports.

This wasn't something I needed to avail of but there's absolutely no shame in requesting a cart or wheelchair to help you get to your gate. I know from experience that asking for special assistance while I looked completely healthy was difficult. But when I did, it made the world of difference and I realised that no one thought anything of it but me!

2. Check to see if you can avail of any special passes at tourist attractions:

Six months after transplant, we fulfilled a dream of taking our son (then 5) to Disneyland Paris. While my kidney health was perfect and I was building up my fitness, after 5 years of illness and inactivity, long days on my feet walking around Disney and standing in line all day was never going to be an option.

I didn't have a disability so I didn't qualify for the Priority Card to skip



Michelle, Eoin and Dylan.

queues. But then I learned about the Disney Easy Access Card, especially for those with chronic illnesses. With this pass, we got a timeslot to come back to each ride, allowing me to rest or have lunch and avoid standing for long periods. It's always worth looking into, even if you're just on a day trip in Ireland. In general, people tend to do their best to help.

3. Look into mobility aids: Until we went to Disneyland Paris, I never considered hiring an electric mobility scooter. But walking 15-20km a day at Disney for 4 days was never on the cards. I wouldn't have been able to manage a wheelchair myself and since my husband would have had to focus his attention on our 5-year-old, he wouldn't have been able to wheel me around. In the end, my travel agent recommended a mobility scooter rental company that delivers to the hotel.

Disneyland is massive, so it made all the difference to have assistance travelling from the hotel to the Park and from one Land to another within the Park. It allowed me to retain the energy I had

for the rides themselves and to enjoy the Park with my family.

It had a basket to help me carry water and supplies and I always had a seat, including while watching the parades. The bonus was I could spin my tired son back to the hotel on my lap in the evenings! I'd be lying if I didn't say I was a little self-conscious at first, especially because I didn't look sick and often bounced up out of the seat to go on a ride. But I quickly realised no one else cared and I know I wouldn't have lasted more than a day without it.

So, wherever you are, if something like a mobility scooter would mean the difference between taking a trip or not, I recommend looking into it.

Whatever breaks you decide to take this summer, whether at home or abroad, for a day or a fortnight, I hope these tips help make your trip more manageable and enjoyable!

And don't forget to wear your sunscreen!

I've shared more details on my travel experiences with kidney disease on Instagram and TikTok at [@chellelife1](#) – feel free to message me with any questions.



By FIONA AHERNE

GP VISIT CARDS – What are they?

GP VISIT CARDS are a type of card that allow individuals to visit a participating family doctor for **FREE**. These cards are particularly useful for those who are not eligible for a Medical Card but still need access to affordable healthcare.

You are advised to check with your GP before applying for a Medical or GP Visit Card to ensure they participate in the scheme and will keep you as a patient in the event you are granted either card.

WHAT DO THEY COVER

The GP Visit Card covers charges such as the GP out-of-hours service and blood tests for diagnosis or monitoring of a condition.

ELIGIBILITY

The eligibility criteria for obtaining a GP Visit Card varies depending on the age and circumstances of the individual:

1. Carer's Benefit or Carer's Allowance recipients at full or half-rate **are** eligible for a GP Visit Card.
2. Individuals aged over 70 **are** eligible for a GP Visit Card without an income test.
3. For individuals under 70, eligibility is means tested, meaning their income is assessed by the HSE during the application process.
4. Starting from August 11, 2023, children up to the age of 8 are also entitled to a GP Visit Card.

In Budget 2023, it was announced that the income limit for the GP Visit Card would be increased to include people on, or below, the median income in 2023. **The income limits for the GP Visit Card are higher than those for the Medical Card.**

The income limits for the GP Visit Card depend on various categories, including age, marital status, and the number of children. The limits take into account allowances for children, dependents over 16 in full-time non-grant aided third-level education, and certain expenses such as childcare costs, rent, mortgage payments, and more.

HOW TO APPLY

- **To apply for a GP Visit Card**, individuals aged under 70 use the same application process as for a Medical Card. The application assesses both entitlements. Online applications can be made on **medicalcard.ie**, or you can download the application form for the GP Visit Card and Medical Card.
- For individuals aged 70 and over, registration for the GP Visit Card can be done online at **gpvisitcard.ie**, by downloading the registration form, or by calling **0818-224478**.
- If you are over 70 and have a dependant under 70, you can apply for GP Visit Cards for both of you using the standard Medical Card/GP Visit Card application form and including details of your income.

APPEALS

If your application for a GP Visit Card is refused, you have the right to request a review of the decision. Further appeals can be made to the Appeals Office of your HSE Area.

REVIEWS

- It's important to note that the entitlement to a GP Visit Card is reviewed periodically, as circumstances may change. Failure to return the review form may result in the non-renewal of the card. During the COVID-19 pandemic, GP Visit Cards that were due to expire between March and August 2020 were automatically extended for up to one year.
- If your income exceeds the limit for a Medical Card or GP Visit Card, you may still qualify for a Discretionary Card if your medical expenses would cause financial hardship and are used for a specific timeframe.
- The application process for a Discretionary Cards is the same but you should also provide information about your family's medical expenses e.g. receipts for prescribed medicines, receipts/bills for GP, consultants or other healthcare professionals, purchase or rent of medical equipment.

GP VISIT CARD – WEEKLY INCOME LIMIT (GROSS LESS TAX, USC AND PRSI)

Category	Aged under 66	Aged 66-69	Category	Aged under 66	Aged 66-69
Single person living alone	€304	€333	Allowance for each of first 2 children aged over 16 (with no income)	€58.50	€58.50
Single person living with family	€271	€286	Allowance for 3rd and for each subsequent child over 16 (with no income)	€64	€64
Married or cohabiting couple (or lone parent with dependent children)	€441	€492	Each dependant over 16 years in full-time non-grant aided third-level	€117	€117
Allowance for each of first 2 children aged under 16	€57	€57			
Allowance for 3rd and for each subsequent child under 16	€61.50	€61.50			

First steps in getting support for your mental health

Summer days and warm weather can really help to lift a person's mood. Studies have shown, when we are exposed to sunlight, our body produces less melatonin - a hormone that causes sleepiness and lethargy. This helps you to feel more energised and increases the production of serotonin, reducing anxiety and improving feelings of happiness.

However, this may not be true for everyone and there are some of you who may find the brighter, sunnier, longer days can leave you feeling quite the opposite. Even on the sunniest of days living with a chronic health condition can feel challenging.



By AOIFE SMITH
COORDINATOR OF
COUNSELLING SERVICES

Over the last two years the Irish Kidney Association (IKA) was involved in research by Dr Clodagh Cogley from St. Vincent's Hospital that looked at the mental health of chronic kidney disease patients in Ireland. The research was recently published and showed that 50% of renal patients had current significant anxiety symptoms and 35.4% had current significant depressive symptoms.

When we look at research done by Kidney Research UK it shows 67% of renal patients experience symptoms of depression, 68% of patients not being offered any mental health support and 36% of patients not being able to look after their physical health because of their mental health.

These findings are concerning and really highlight how important it is to

have the right supports available for patients because, living with chronic renal failure demands a lot of commitment and responsibility from a person: hospital appointments, bloods, weight, fluid and food restrictions, medications, transplant, post-transplant care, the list goes on.

The decision to reach out and ask for support is not always an easy one. I am often asked, *"Sure what difference can talking to someone for an hour a week make?"*

However, counselling can offer a safe space, an outlet, somewhere a person can say whatever they need to say without being judged, explore their own feelings, talk without hurting someone else's feelings, where they can be honest with themselves about how they are doing and not feel like they are putting additional worry or stress on loved ones.

It is a place where a person can discover new ways of coping, make changes and develop new skills which can make the difference that is needed to cope better with their illness.

If you were to avail of the counselling service here in the IKA, which is

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 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.

available **free of charge** to all those living with, or affected by end stage kidney disease, their family or carers, you would be assigned a fully accredited counsellor/

psychotherapist from our panel of counsellors that work with the IKA nationally.

All our counsellors have an understanding of kidney failure and have built-up experience from working with patients. You would be given their details and asked to contact them directly to make an appointment that best suits you both. From there the relationship is totally confidential between you and your counsellor.

When you see a counsellor for the first time you may feel a bit nervous or anxious, and this is a natural response to an unfamiliar situation.

This feeling should lessen as you build a relationship. Most counsellors will suggest starting with six sessions to allow time for a therapeutic relationship to develop between you both. The more you experience a sense of respect, trust, and safety the more you may feel you can talk about your challenges.

How long the process takes is impossible to answer. It really depends on the individual and what they want to explore. However, counselling is more short-term, and it may focus on specific or current challenges.

Psychotherapy is more long-term and is useful for anyone who would like to explore life experiences or traumas on a deeper level.

I think one of the most important parts of counselling is finding the right counsellor for you. We work closely with counsellors to make sure they are sensitive to your concerns.

When we are assigning counsellors, we do our best, with the information we have, to match you to a suitable counsellor.

Some useful questions to ask yourself after the first sessions might be:

- Did you feel the counsellor listened and understood your concerns?
- Did you feel the counsellor respected you?
- Did you feel the counsellor saw you as an equal and did not patronise you?
- Did the counsellor seem like a real person or were they playing a role?
- Was the counsellor passive (simply listening) or active (asking questions) in the session? What do you like better?
- Does it seem like the counsellor will be open to hearing about all your feelings, including being frustrated or angry with the counsellor?
- Do you feel the counsellor will not judge you if you talk about your problems?
- Did the counsellor have a positive outlook on life?
- Did you feel safe expressing your thoughts, concerns, and feelings?

If your answer to these questions is mainly **'NO'**, I would encourage you to get back in touch with the service so we can discuss if they are the right counsellor for you.

We understand counselling can be challenging, and we are aware it is your own unique journey. We want you to know if you do take that first step by making a call or sending us an email, that we are here to support you.



A tribute to...

SUSAN TOBIN

It was with great sadness that we learned of the death of **Susan Tobin** on April 28th. Susan, from Rathvilly, Co. Carlow and late of Rathfarnham, Co. Dublin, died at the Waterford Hospice after a very short illness.

She joined the Irish Kidney Association when she started dialysis and was delighted to receive a transplant some years later.

She served as the Carlow IKA Branch Secretary for the last number of years, a role she fulfilled with great enthusiasm.

Susan was also very involved in the local St. Vincent de Paul. Susan was a wonderful caring and friendly person, both in the Carlow Branch and in her local community.

She will be greatly missed by all who knew her.

We extend our deepest sympathy to her family, to Enrico, and to all her friends.

— PAT MAY



SPRING PRIZE GIVEAWAY WINNERS

Thank you to **TOP OIL** for generously sponsoring 5 x 100 Vouchers as a prize giveaway in the Spring 2023 issue of SUPPORT.

Congratulations to the winners:

Neethu Paul, Co. Galway

Tony O'Gorman, Co. Kerry

Robert McCullagh, Co. Dublin

Mary Egan, Co. Cork

Fidelma Reilly, Co. Cavan.



In May we had our first post-COVID Renal Educational Day for our panel of counsellors and psychotherapists, who work nationally with patients on behalf of the Irish Kidney Association (IKA).

The purpose of the day was to keep our panel informed and up-to-date with what you, as a patient, might be experiencing while living with chronic kidney disease (CKD).

THERAPIST RENAL EDUCATIONAL DAY

Our day opened with a presentation from **Carol Moore**, our CEO, who after outlining the agenda for the day, presented on some of the difficulties faced by charities in today's environment. She spoke about how the counselling service fits into the overall IKA strategic plan in providing meaningful supports for patients, their families and carers and highlighted the need for, and importance of, having easy and efficient access to these services available for patients.

Emer Kenny, an Advance Nurse Practitioner in Nephrology Home Care and Self Care Therapies in Tallaght University Hospital was up next.

Emer has extensive experience in CKD and with Shared Care therapies. We were delighted that she took the time from her day to share some of her knowledge.

Emer presented to our panel a short overview of chronic kidney disease, the different classifications of kidney disease stages and the symptoms that might be experienced before she went on to discuss the different options that patients have when deciding which type of dialysis might be more suitable for them.

Alison Larkin has been the Renal Counsellor in Beaumont Hospital since June 2017. She supports patients and

Alison Larkin



Aoife Smith and Emer Kenny



Laura Austin



their family members from diagnosis right throughout their journey. Her knowledge and experience allowed her to convey very clearly the different psychological impacts kidney disease might have on a person.

She talked about life assumptions, how we never plan to get sick and we assume we will always be healthy. Then when we lose our health it can evoke feelings of vulnerability, uncertainty, loss of confidence and trust in one's body.

She went on to talk about the grief response in illness and the psychological support that is available for patients. She highlighted some important support websites which the panel could find useful for patient information.

Just before we took a break for lunch, **Laura Austin**, a Clinical Nurse Manager in transplant coordination since 2015, took the panel through

the journey of a Transplant Patient. She is a highly experienced and motivated CNM3 with extensive expertise in Transplant Coordination.

She provides education on both kidney transplantation and living donation to potential recipients, potential donors and family members involved in the process.

She gave the panel a real insight into the facts about kidney transplant, the advantages and disadvantages. She discussed all that was involved for a patient during the work-up process before they were placed in the transplant pool, as well as what happens while a patient is waiting in the pool to be matched.

She spoke about the process involved for both a deceased donor and live kidney donor transplantation. She acknowledged how difficult the decision can be for families to donate their deceased loved one's organs.

She is the voice many patients are waiting to hear and remember forever, as her voice can be one that calls to say that a patient has been matched. It was great to hear from her on the day.

At this point we took questions and feedback from our panel to our speakers. There was a great discussion and feedback between our counsellors and the presenters. It really showed the interest and the learning that was taking place that morning.

We had a quick bite to eat before

we changed the focus from the patient to the counsellors and psychotherapists themselves.

Patricia Bourke D'Souza, a Somatic Trauma Therapist, Supervisor, Consultant, and Trainer of Trauma Informed Practice, working from Ireland to Australia to Singapore, training therapists and healthcare professionals in Trauma took to the podium.

Patricia provided a very informative presentation on the foundations of safer trauma informed practice, understanding the guiding principles of trauma informed practice, the language of trauma and highlighting the indicators of trauma recovery.

Patricia's presentation really inspired a deep discussion among the panel and she still managed to add in some very clear messages about the importance of self-care as a counsellor.

After a great line of guest speakers, I did a short presentation about the recent changes in the IKA counselling policy, practices and procedures when working with clients on the IKA's behalf. The housekeeping had to be done!!

Here in the IKA, we are very aware of the value of a counselling service and that is why we are committed to having days like this for our counsellors and psychotherapists.

All of the counsellors and psychotherapists we work with are fully accredited with the professional associations of counselling in Ireland, but days like this one give us the opportunity to support them and to ensure they have the information they need from the IKA to provide the best possible service.

I would like to thank everyone who attended the educational day for their engagement and enthusiasm on the day and for the continued work they provide for our patients.

A special thanks to all our speakers that made it possible to provide such a great day.

WEBSITES ALISON LARKIN MENTIONED ON THE DAY:

www.beaumont.ie/marc – Mindfulness & Relaxation Centre (MARC)

www.beaumont.ie/renalunit

www.ika.ie

www.nkf.co.uk

www.lhatedialysis.com

www.nkf@kidneys.org

www.nipka.org

www.getselfhelp.co.uk www.helpguide.org.



ACCOMMODATION TELEPHONE BOOKING HOURS 01- 6908887

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

ROUTINE APPOINTMENTS

The accommodation phone line is open: Monday to Friday 9.30am to 5.30pm.

EMERGENCY APPOINTMENTS

For unplanned appointments, emergency visits or even the very welcome call for a transplant, the phone line will be open on an emergency basis only from Monday to Friday: 7pm to 10pm. Saturday, Sunday and Bank holidays: 12pm to 4pm. If the phone is unanswered you will be greeted by a voicemail. Please be sure to leave a message about urgent accommodation you require. We will do our very best to accommodate you in a hotel and will liaise with Beaumont Hospital staff, when needed.

It was an extra special Father's Day, this year, for Joe Kelly whose 18-year-old daughter Ali is now enjoying renewed health and freedom from dialysis, made possible by the kidney he donated to her on Independence Day, July 4th, 2022.

By GWEN O'DONOGHUE

With her new lease at life from her kidney failure which blighted most of her teens, Ali Kelly from Newport, Co Tipperary, had more reason than most to celebrate the first transplant anniversary with her doting father, Joe Kelly, on Father's Day.

It was a case of third time lucky for the father and daughter as on two occasions previously the scheduled transplant operations at Beaumont Hospital were deferred at the eleventh hour.

On the first two occasions, just two weeks apart, when Joe was prepped and ready to be wheeled down to the operating theatre, Ali's unsatisfactory blood results led to the operations being cancelled.

Six weeks after their second disappointment, Joe and Ali's re-scheduled operations led to a momentarily happy outcome. As this time Ali's haemoglobin levels were positive, making way for the living donor retrieval and kidney transplant operations which proceeded on July 4th, 2022.

Ali and her parents Joe and Virginia, both north Limerick natives, celebrated Father's Day together with a special meal. Now that Ali is independent of her gruelling dialysis treatment the family spent the first transplant anniversary on holiday in sunny Spain, their first holiday



THANK YOU DAD

abroad in years.

The youngest of four children, Ali was born with a hereditary kidney condition, Polycystic Kidney Disease, which causes cysts to the kidney. She spent much of her early years at Crumlin Children's hospital and was tube-fed until the time she was 4-years-old when, following a year of nightly dialysis, she underwent her first kidney transplant. The transplant was made possible by a deceased donor which allowed Ali to enjoy a normal childhood and early teens.

It wasn't until Ali was 14-years-old that her kidney transplant began to fail causing her to return to dialysis treatment at the age of 15 which continued for two and a half years.

Initially the dialysis treatment involved Ali being hooked up to a dialysis machine at home every night for 14 hours. After almost two years she progressed to hospital-based haemodialysis treatment. By then

she was a patient at Temple Steet Children's Hospital and had to travel there four days a week, to undergo five hours of dialysis treatment, which also involved a four and a half hour round trip.

This time, finding a suitable kidney donor for Ali was complicated by the high antibody levels from her previous transplant and a blood transfusion. Joe didn't hesitate to put himself forward to be screened as a potential living kidney donor.

In describing his delight that the transplant has been a success, Joe said, "It is life-changing for all of us. It's so rewarding for our family to see Ali enjoying good health and getting her life back. There was no sacrifice on my part. It was awful to watch her struggle and donating my 'spare' kidney to her was the easiest decision to make.

"I bounced back within weeks of the operation, and I am overjoyed to

see how well she is doing now. She is flying! Before, while the dialysis treatment had kept her alive and she seldom complained, it took its toll on not just her physical health, but her mental health too. It was difficult to see her missing out on spending time with her peers, making new friends, and it was very disruptive to her education."

Joe explained, "It was also very disruptive for the whole family. When a family member is sick it affects everyone. Ali's mother Virginia did the lion's share of caring for her since she was born.

"Virginia brought her to Dublin on three weekdays for her treatment, while I continued working, and I brought Ali on Saturdays. We had little family time and it was mentally draining on all of us. When COVID-19 arrived, Ali was more vulnerable to the impact of the virus. It caused even further isolation and absence from school and time away from friends. The whole family had to be very vigilant in trying to avoid bringing COVID into the home.

"She has missed out on a big chunk of her teens and has decided not to return to secondary school. She is now ready to enter the workforce and is considering her options. She is very resilient and we are all very proud of her and enjoy watching her grow into a young independent woman with her whole life ahead of her."

We have had a good support network of family and friends to help, and the medical profession have been outstanding in their care of Ali. Beaumont Hospital's transplant team have been exceptional also. The Irish Kidney Association has also offered great support and advice.

With a new spring in her step Ali said, "I feel great now. I have loads of energy. Before my transplant I was so weak and could barely walk from one room to another without being out of breath. I can now leave the

house without feeling exhausted. My diet and fluid are not restricted anymore and I can really enjoy my food now.

"I no longer have tubes attached to my body and I am not feeling as self-conscious. It's great that I can wear whatever clothes I want now, not having to consider my weight fluctuating or experiencing bloating. I have always had an interest in fashion and beauty and now that I am well enough I am looking into a career as a beauty technician."

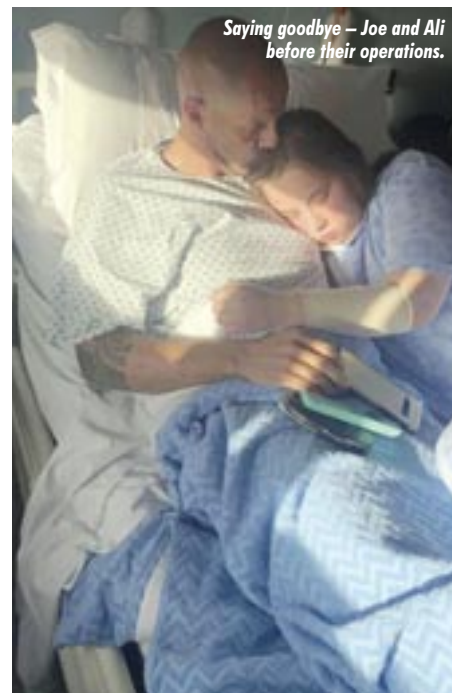
Ali continued, "Celebrating Father's Day this year was extra special for me and my dad. It's hard to find the words to express my gratitude to him for giving me my life back but I know he understands how grateful I am.

"Donating a kidney to me was the best gift I could ever have hoped for. I love him with all my heart and my mother also. They have always put my needs before theirs. I'd like to thank my whole family, my twin brothers, my sister Jody and my two nanas, who have always been there for me and to my friends who stuck with me especially to Kelsie, my 'go to' friend who is a great listener and support.

"I'd also like to say thanks to all the medical and nursing teams in the three hospitals that looked after me so well down through the years."

Remembering her first organ donor, Ali said, "Although I was only 4-years-old when I got my first transplant, now that I am older I can appreciate what my kidney donor and their family did for me, and they will always be in my thoughts, as I enjoyed 10 years of good health as a child."

"Life is good for me now and I intend to make the most of the chances that have been given to me. I hope that by sharing my story that people will understand how important organ donation is."



Life is good for me now and I intend to make the most of the chances that have been given to me. I hope that by sharing my story that people will understand how important organ donation is.



On Haemodialysis? ...Then, you need to 'THINK BEFORE YOU DRINK!'

Fluid balance is essential in order to ensure that our bodies are neither dehydrated (too dry) nor overhydrated (fluid overloaded). Healthy kidneys play an important role in maintaining good fluid balance. This enables the heart to circulate blood to all body parts.

If you are on haemodialysis it is important to know what your dry weight is. This is your normal weight without extra fluid on your body. **Your dry weight is actually your target weight after dialysis.** At the end of dialysis, if your weight is above your dry weight, then you are at risk of becoming fluid overloaded before your next dialysis session.

In the early days after starting haemodialysis you may still pass urine, but with time, for many, the amount of urine produced decreases.

If your kidneys are not able to clear enough urine from your body, you must limit your fluid intake in order to prevent fluid overload.

SIGNS OF FLUID OVERLOAD

- Heavier than your dry weight at end of dialysis
- Gaining too much weight between dialysis sessions
- Distended neck veins
- Swelling – feet, ankles, around eyes, face, hands
- Stiff joints
- Stomach bloating–feeling full
- Difficulty breathing
- Heart problems – high blood pressure, fast pulse.



TIPS TO PREVENT FLUID OVERLOAD AND MANAGE YOUR FLUID RESTRICTION:

1. Get to know how much urine you pass by measuring your total urine output in a 24-hour period. Your dialysis unit can give you instructions on how to do this.

2. Your dialysis team can then advise you on the amount of liquids that is safe for you to drink. This is known as your *daily fluid allowance*.
3. Calculate how much fluid you drink in one day
4. Check that you are not drinking more than has been recommended for you.

DIFFERENT CUPS HOLD DIFFERENT AMOUNTS OF FLUID

- How many mls does your cup hold? You can use a measuring jug to find out how much your cup or glass holds.
- It is recommended to drink only from a small cup or a small glass.



AVOID FLUID OVERLOAD

1. **Track your fluid intake.** Some people use a jug or glass with the mls marked to help them see how much fluid they are consuming.
2. **Keep a journal** of the volume (mls) of every liquid you have daily.



3. If you pass urine: **Know** your daily urine volume.
4. **Know** how much is (the volume) of your daily fluid allowance.
5. **Plan** how you will keep to your safe limit.
6. **Manage your thirst**
 - Suck an ice cube
 - Chew gum
 - Suck a hard sweet, or a mint
 - Use a mouthwash to rinse your mouth
 - Sip your drinks slowly
 - Drink from a smaller cup
 - Drink only two thirds of what's in your cup
 - Avoid foods with over 1.5g salt per 100g as these can increase thirst.
7. **Follow the guidelines** given to you by your Renal Dietitian.



8. Make sure you are **extra careful at weekends**.
9. If you have **diabetes**, maintain **good blood glucose control**.
10. **Talk with your dialysis team** about adjusting your dialysis treatments. Longer, or more frequent, dialysis treatments can remove extra fluid.

AND REMEMBER

- Some foods are moist and you may need to be aware of the fluid in these (e.g. jelly, porridge, yogurt, gravy, stewed apple).
- Milk counts as part of your fluids.
- Porridge or cornflakes need less milk than Weetabix.
- Alcoholic drinks count as fluids.

ENJOY THE WEEKEND

Weekends are particularly challenging because of longer spells between dialysis sessions. While others are planning their social life those on haemodialysis must become even more disciplined. This can take its toll mentally, and emotionally, so I encourage you to

include other pleasures in your weekend.

For example:

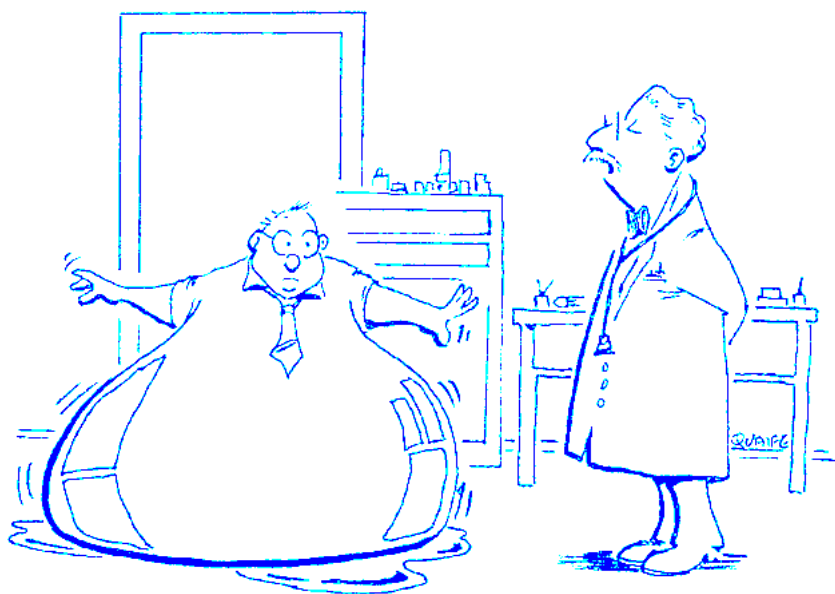
- Attend a sporting event or exercise/dance class.
- Arrange an outdoor hike or walk with friend or family member.
- Go to the cinema.
- Play with your pet.
- Play music, sing, join a choir.
- Phone a friend.
- Become creative – draw, colour, paint or write.
- Start a new hobby – what do you love to do?



There is ALWAYS something YOU can do to help yourself – If you don't know what it is, then talk to your renal dietitian.

The Renal Dietitian can help you to improve your fluid balance and you will feel better both on and off dialysis.

Hope you enjoy a happy and healthy summer!



*Your tests reveal that
you are retaining fluids!*

PLEASE NOTE:

This article only applies to individuals with end stage renal disease on haemodialysis, and, who are at risk of fluid overload. If you have other forms of kidney disease, (such as earlier stage renal disease, kidney stones, post-transplant) your renal team can guide you on appropriate fluid intake.

The past, the present, and the future of nephrology

The Irish Nephrology Society's (INS) **Annual Scientific Meeting 2023**, which took place in the Glenroyal Hotel, Maynooth, Co Kildare on 12-13 May, featured a notable line-up of national and international speakers, researchers, and experts.

The two-day event examined the wide spectrum of renal disease that affects patients across the lifespan. INS President **Prof Liam Plant** welcomed attendees after what he termed the “prequel” of the meeting. This included several insightful presentations and an accredited pre-course in point-of-care ultrasound (POCUS) for NCHDs, delivered by the INS POCUS faculty and **Dr Saeed Ahmed**, Consultant Interventional Nephrologist and General Medicine Physician, UK.

Primary themes throughout the meeting included education and scientific research; the value of patient registries; evidence-based medicine; and future developments in the field of nephrology, as well as a heavy emphasis on the patient journey.



Prof David Wheeler, Professor of Kidney Medicine, University College London, UK, gave a presentation that encompassed all of these major themes, which was titled: *‘High impact clinical trials in nephrology.’*

Comparing the evidence-based approach to an eminence-based one, he recalled a time in his career when he was reprimanded for prescribing beta blockers to a heart failure patient, and reflected on how “clinical trials have changed practice in nephrology”.

Emphasising the importance of asking questions, Prof Wheeler revisited several practice-changing studies, and commented that cultural changes are still required

By DENISE DOHERTY, MEDICAL INDEPENDENT

to fully integrate trials into practice.

Also noting that clinical trials have become “complicated and expensive”, he advocated for “simplified, pragmatic designs” that allow more questions to be addressed in “real-life settings”.

He also promoted the randomisation of groups of patients, instead of individuals, and the use of patient registries in simplifying designs. Telling attendees how he would like to see a change in the current guideline process, and referencing the ‘pop-up’ guidelines that evolved and changed as data became available during the COVID-19 pandemic, Prof Wheeler explained

how he hoped for a move towards a similar guideline process for nephrology in future.

A wide array of recent, ongoing, and planned trials and innovations were discussed throughout the meeting. The potential to monitor donor-derived cell-free DNA after kidney transplant to identify signs of rejection at a very early stage was presented on by **Prof Sam Kant**, Assistant Professor of Medicine in the Division of Nephrology and Comprehensive Transplant Centre, Johns Hopkins Hospital, Baltimore, US.

Attendees also heard from **Dr Susan McGrath**, who discussed ‘Ultrafiltration management

with sorbent-based automated wearable artificial kidney peritoneal dialysis prescriptions in a pig model’; **Mr Kane Collins**, who presented on ‘The utility of donor polygenic risks scores in predicting long term graft function’; and **Dr Elhoussein Elhassan**, who talked about the Irish kidney gene project, and ‘Novel dominant ALG5 variant in Irish families with late-onset autosomal dominant polycystic kidney disease and atypical tubulointerstitial changes’.

Dr Vicki Sandys, post-CSCT Renal Fellow at Beaumont Hospital, Dublin, presented on ‘Artificial intelligence empowered dry weight management’, outlining the development of a

machine-learning algorithm to make predictions that could potentially be used to guide ultrafiltration and interdialytic weight gain goals. The model is currently awaiting external validation, with plans for randomised controlled trials in future.

Dr Sandys described the myriad ongoing challenges in assessing fluid status, in establishing an accurate dry weight, and maintaining balance between volume overload and depletion during her talk.

Highlighting that currently, there is “no gold standard for dry weight assessment”, and that ultrafiltration goals are often determined by the nurse, she outlined the weak evidence supporting the routine practices of blood volume monitoring and body composition monitoring. She also presented evidence from clinical trials indicating that the majority of patients are volume-depleted and receiving excessive ultrafiltration, before explaining how the technology could help clinicians to overcome these challenges in future.

Prof George Mellotte, HSE National Clinical Lead for Renal Services, also looked into the past and future of renal services. He provided a National Renal Office update, beginning with an overview of the annual changes in end-stage kidney disease (ESKD) treatment modalities since 2009, followed by changes in patterns during the COVID-19 pandemic.

He commended the high levels of patient protection seen within nephrology services during the pandemic, before discussing the

decrease in kidney transplants during the same period. Increased prevalence of ESKD, higher demands for renal replacement therapy, the economic consequences of that increased demand, and an urgent need to upgrade parent renal units featured heavily throughout the update.

Prof Mellotte noted a “good uptake in home therapies” in several regions, and told attendees how more patients want these therapies, before acknowledging a major deficit in outreach support services in many areas across the country.

Commenting on the future, Prof Mellotte outlined the extra €25 million funding renal services received in the HSE National Service Plan 2022, and described how expanding dialysis capacity in parent hospital renal units through clinical governance and developing home dialysis services are priorities to support the 30 per cent growth in dialysis activity.

Planned advances in renal palliative care services and an expansion of multidisciplinary team members to include more psychologists, dietitians, specialist nurses, and other clinicians were also discussed.

“Two-hundred-and-twelve whole-time equivalent new posts have been approved, with 50 filled to date,” he explained, before finishing with an overview of plans to extend the HSE structured chronic disease management programme to include chronic kidney disease (CKD) as a specified disease, and to finalise a model of care for the management of early CKD.

A tribute to... **JEROME BURKE**

For over twenty years, Jerome Burke enjoyed good health, following a successful double kidney and pancreas transplant. In his own words – voiced many times, “*I remember and pray for my donor every day*”. He also appreciated and thanked his transplant surgeon Dr. David Hickey for his professionalism, kindness, and growing friendship.



Unfortunately, in the final three years of his life, Jerome, who resided in Portarlinton, Co Offaly, experienced ill health, resulting in many hospital admissions. He suffered without complaint, always a fighter and would bounce back again and again. However, in the early hours of Pentecost, Sunday morning (May 28th, 2023), Jerome lost that fight and sadly passed away peacefully.

He will be forever loved, and his loss will be greatly felt by many – his family, and friends, none more than his lifelong friend and dedicated carer Kay Dunne. We in the Irish Kidney Association (IKA) extend our heartfelt sympathy to Kay, her daughters Caroline and Margaret, and their families and also to Jerome’s brother Francis and his partner Anne, his brother Liam and wife Eileen.

Jerome loved and devoted all his energy to the care of transplant and dialysis patients. This was his passion. His passing leaves a huge void in the Offaly IKA Branch. He was Branch Chairman for twenty years, serving eight of those on the National Board.

Togetherness and enjoyment for patients and their families was very important to Jerome, as he organised Christmas lunches, music and dance events, trips to Leinster House, and many more. In this, he was helped by our wonderful volunteers. Our annual Branch Mass of Remembrance and Thanksgiving, which was amazingly prepared by Jerome, and celebrated by Fr. Joe Gallagher, was a blessing for all of us.

Of course, fundraising and awareness played a huge role e.g. concerts, night at the Greyhound track, and many others. These were all guided by Jerome with the help of the Branch member volunteers.

A highlight of Jerome’s term as Chairman was an invitation to Patricia Doherty, IKA Founder and its first Chief Executive, along with Mark Murphy, former Chief Executive and his wife Frances, to attend the 30th Anniversary celebrations for the Offaly Branch. Their presence was the pride and joy of the wonderful occasion.

Jerome, the world of nature and seasons join with the presence of eternal life. Rest well good and faithful servant.

MARY YOUNG, Offaly IKA Branch



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
Please tick 'No' if your household is already receiving it

Post? ☐ YES

☐ NO

Or Email? ☐ YES

☐ NO

Can we correspond with you for notices of Annual General Meeting
of the Association and Annual Director's Report by

Email? ☐ YES

☐ NO

Would you like to receive information on activities from your local
IKA branch which entails us giving them the data from this form?

☐ YES

☐ NO

Would you like to receive information on the IKA Transplant & Dialysis
Sports and Fitness which is based in Head Office?

☐ YES

☐ NO

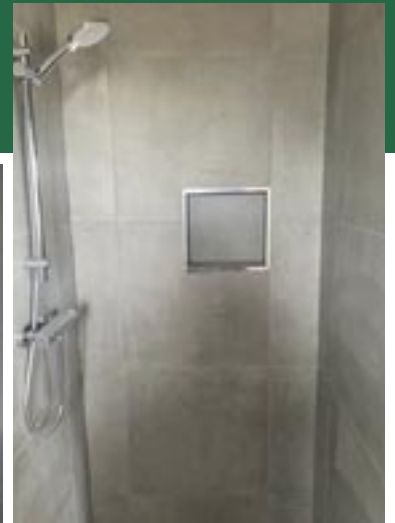
By signing this form you agree to become a member of the Association and you subscribe to the Constitution of the Association (copy available on request or on the IKA website – www.ika.ie)

I subscribe to (sign up and accept) the Constitution of the Irish Kidney Association CLG (Company Limited by Guarantee).

SIGNATURE: _____ DATE: _____

Please return the completed signed form to the
Irish Kidney Association CLG, (Freepost), Donor House, Block 43A, Park West, D12 P5V6.
There is NO SUBSCRIPTION charge.

PROJECT WORK CONTINUES IN CORK



By
PAT O'SULLIVAN



The **Renal Support Centre** on Wilton Avenue in Cork, which is currently undergoing renovation, is expected to be operational in the Autumn. Located just 100 metres away from Cork University Hospital, the building project, which commenced in August 2022, involves converting two neighbouring 4-bedroom semi-detached houses into a 6 ensuite bedroom centre with an additional self-contained apartment and at least six off-street parking spaces.



The construction work is mostly complete, with the amalgamation of the houses finished and the centre taking shape. Plumbing, electrical, and plastering work has been finished, and kitchens have been fitted in both the main house and the apartment. The final stages which are now underway include completing tiling in the downstairs bathrooms, selecting furniture and fittings, and painting the walls and ceilings. Outside work has also begun, including constructing new perimeter



walls and paving for parking. The garden area has been cleared and will be landscaped, featuring a large patio area with seating and a kidney-shaped design in the middle and all garden footpaths will lead to a paved area.

The Renal Support Centre will provide a refuge for people from Munster and South Leinster who need regular visits to a hospital and will offer overnight accommodation, training facilities, a quiet room for counselling services and reading.

A dedicated website for the project is <https://www.ika.ie/cork/>



Fiona Aherne,
Pat O'Sullivan,
Sarah Buchanan





Wexford Independent TD Verona Murphy met with our Branch Secretary, Walter Kent (right) and Board Member Liam Buttle, to highlight Organ Donor Awareness Week

The Wexford Branch welcomed IKA CEO, Carol Moore, to our meeting on 10th May, in the Talbot Hotel. Carol addressed the very well attended event and updated all on the important issue of the Beaumont Renal Support Centre. Light refreshments were served.

Deirdre Cleary, one of our members, together with family, friends and staff from BBraun Wexford, cycled from Ballymitto to Wexford on 24th June to raise funds for the IKA. Well done to all involved.

The Wexford Branch is holding a Mass of Remembrance in Clonard Church, Wexford on Friday 21st July at 8pm.

All are welcome.

WEXFORD

By MARIA DONLON



Deirdre Cleary, friends and BBraun staff at the fundraising cycle on 24th Jun.



More support during Organ Donor Awareness Week as our branch chairperson Pauline Atkinson met with Wheelocks Fruit Farm (left) and Kellys Pharmacy (both Enniscorthy) to spread the word about the campaign message.

DUBLIN NORTH

By COLETTE FOX

Hello to everyone from Dublin North. Hope you are all enjoying the good weather.

We would like to congratulate the 14 members of Transplant Team Ireland on their success at the World Transplant Games in Perth.

Best of luck to Dublin north members Chloe and Ivan Kinahan's son, Sam, who will be competing in the British Transplant Games in Coventry Games in July.

Finally, all of us at Dublin North hope you enjoy the rest of the summer break.

CLARE

By PEGGY EUSTACE

Peggy Eustace, Marie Fowley



Emily Mason and her mother Maureen Mason along with Roisin Boland (nee Treacy) promoting the organ donor for Organ Donor Awareness Week.

Hello to all receiving dialysis treatment and all transplant recipients. I hope that at least some of you got to avail of a holiday at one of the Irish Kidney Association's holidays venues, located in Tramore in the sunny south east or perhaps in the Vale of Tralee or indeed in beautiful Killarney.

WALK

Many thanks to Gerardine Quinlivan who raised €300 in a recent fundraising walk for the Clare IKA Branch.

FUNDRAISER

The Clare branch are very grateful to Emily Mason of Scariff and her friend Roisin Boland from Tuamgraney who completed their

32-peak challenge, climbing the highest mountain in each county.

The duo had a celebratory hike on December 6th, 2022 when they climbed Moylussa in Ogonnelloe, Co Clare for a second time, with more than 70 family and friends, after raising almost €9,000 for the IKA, nine times more than the initial target.

Emily whose mother Maureen Mason is a kidney transplant recipient said, "I always wanted to give something back to the IKA because they were very good to my mother."

Many thanks to both ladies for their support to the Association. We thank Maureen whose journey on dialysis to receiving the gift of a kidney transplant was highlighted by



reporter Dan Danaher of the *Clare Champion* newspaper during Organ Donor Awareness Week.

CONGRATULATIONS

We send our congratulations to Patrick and Áine Eustace on the birth of their baby boy Darragh, in November, a little brother for Méabh. Welcome to the world little one. Patrick underwent his kidney transplant 25 years ago.

SYMPATHIES

We extend our sincere sympathy to our former Branch Secretary Noretta Clifford, on the recent passing of her mother Mary Clifford, late of Cahersiveen, Co. Kerry and also her father-in-law Seamus McGoldrick of Sligo.

Sympathy also goes to the families of Ann Cooney, late of Tulla, Co Clare, Jerome Burke, Co Offaly, and Angeline Cooke, Galway, all of whom were outstanding members of their local IKA Branches. May their gentle souls rest in peace.

CAVAN/MONAGHAN By PAUL DONOHUE



Ciara Leddy, CNM, Jacqueline Larkin, Manager Cavan Dialysis Unit, Paul Donohoe, Chairman, Cavan/Monaghan Branch, dialysis patient Colm Chambers.



Phelim Pritchard, kidney transplant recipient and Adrienne Donohoe.



Olivia McCormick CNM, Paul Donohoe, Colm Chambers and Saline Moynagh, Dialysis Nurse.

Our Branch would like to thank everyone who visited our stand at Cavan General Hospital during Organ Donor Awareness Week, including the patients, their family members, hospital staff and nurses at the dialysis unit.

Our thanks to Colm Chambers, a dialysis patient and all those who helped at the stand. Colm shared his

health story during awareness week and was featured in local media and in the *Farming Independent* also.

We would be delighted to offer help and assistance to patients and their families and encourage people to get in contact with our Branch.

Paul Donohoe, Chairman,
Karl Cronin, Treasurer/Acting Sec

Ph: 083-8577890
Ph: 086-8513173



Hello and welcome to all members! I hope everyone is enjoying the lovely weather we've been having so far this summer, and that everyone is well stocked up on Factor 50!

HEALTH FAIR IN ST VINCENT'S HOSPITAL

St Vincent's held a Health Fair on Wednesday, 3rd May, hosting various charities and community groups, alongside representatives from many of their hospital departments. The Branch was represented by myself and Bernie and Michael Dwyer.

Most attendees were healthcare workers and it was interesting for us to see what interested them, as most of our interactions are with patients and family.

They were very focused in the details of treatment, transplant and medications. It was a very interesting day and we also learned a lot from visiting other stands.

BRANCH AGM

Our Branch AGM was held on Wednesday, 10th May, in St Anne's Resource Centre, Shankill. It was lovely to see some returning members at their first face-to-face meeting since the start of the pandemic.

ORGAN DONOR AWARENESS WEEK

Organ Donor Awareness Week took place a little later than usual this year, occurring 20th – 27th May. With the focus on raising awareness, many pharmacies were approached to take posters and organ donor cards to get the campaign message of 'Leave No Doubt' out to as many people as possible.

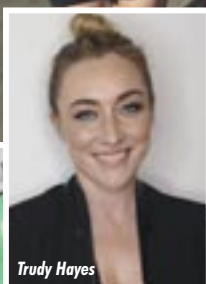
Also, as Global Surgery Day fell during ODAW, I was invited to attend a photocall in St Vincent's Hospital with other transplant recipients and

DUBLIN EAST & WICKLOW

By RACHEL O'HORA



Holding balloons (centre), Trudy Hayes with members of Irish Mountain Cardio.



Trudy Hayes



Trudy Hayes, Mick Dwyer.

10th anniversary of her kidney transplant by running from Shankill to Tallaght Stadium across the mountains. The celebrity hairstylist, and founder of successful beauty app *Raven* who runs with trail running club, Irish Mountain Cardio, was among a large group of close to 50 runners who undertook the gruelling trail on the last day of Organ Donor Awareness Week.

Branch representatives Bernie and Mick Dwyer showed up in a display of support for Trudy and the group headed out on her run. She chose to promote the IKA as she herself had a kidney transplant, 10 years ago, thanks to her kidney donor mother.

In support of Organ Donor Awareness Week Trudy also did an interview for the *Irish Independent* and *Herald's* health pages as well as an interview on Newstalk.

What a wonderful ambassador she is for organ donation and transplantation!

three surgeons, one of whom performed my transplant last year.

It was so nice to meet other transplantees who had received organs, thanks to the selflessness of their donors and their families. It was also great to be able to acknowledge the skilled work of the countless surgeons all over the world. You can read more about Global Surgery Day on page 18-20.

It was a busy week for me, as I was also invited to tell my story on RTÉ *Drivetime* on 26th May. If you would like to listen to it and cannot find it online, I can WhatsApp a recording to you. I also shared my story to a journalist from Dublin Live, which was published online on Sunday, 28th May.

On Saturday, 27th May, local woman Trudy Hayes marked the

SUMMER SOCIAL



Rachel O'Hora, Patricia Delahunty.

DUBLIN EAST & WICKLOW



Vanessa Garrioch, Nichola Coughlan.



Jacqueline Burke, John Whelan.

Our Branch held our first Summer Social in three years, on Tuesday, 27th June in The Burnaby in Greystones. A lovely evening of chats and refreshments ensued, and many attendees expressed their enjoyment of the evening to Branch officers afterwards.

We look forward to welcoming new and returning members to our monthly meetings in the autumn.

Have a safe and enjoyable summer everyone!



John Wogan, Michael Dwyer, Eamonn Keogh, Bernie Dwyer.

TIPPERARY

By OLIVE BYRNE



Templemore school raised €500.

We hope you are all enjoying the Summer. Congratulations to Sheila Gregan, our Branch member from Nenagh, on taking part in the World Transplant Games in Perth.

Congratulations to our current Treasurer, Mary Adamson, on her recent transplant through the paired exchange in Coventry.

Mary's niece Fiona Nolan donated a kidney, her kidney went to a child and Mary received a kidney from an altruistic donor.

Mary and Fiona are seen on the right of this page, at Fiona's sister's wedding. Wishing them both many years of good health.

Mary Adamson was with Clonmel CBS, 5th and 6th classes, who raised €1,000 for the IKA by having a cake sale. Templemore school also had a cake sale and raised €500.



Mary Adamson with CBS Clonmel 5th and 6th class who raised €1000 for IKA. Mary recently retired from teaching at the school.



Mary Adamson and her niece Fiona Nolan are pictured at Fiona's sister's wedding.



Ann Hackett, Joan Gavan

Cahir Park Golf club held a Golf Classic on June 23rd, in aid of the Irish Kidney Association and the Irish Wheelchair Association.

Well done to all involved.

Well done also to Ann Hackett and Joan Gavan (left), who were out and about in Thurles creating awareness during Organ Donor Awareness Week.



ORGAN DONOR AWARENESS WEEK (ODAW)

With help from Branch members we got quite a lot of this year's campaign posters with the message *Don't leave your loved ones in doubt* placed in Shopping Centres (The Square SC, Supervalu Walkinstown, Tuthills Clondalkin, Citywest SC, to name a few), and various other notice boards around South Dublin in the days leading up to ODAW.

A number of our Branch members and family turned out to support the promotion of Organ Donor Awareness Week at our stands in The Square Shopping Centre in Tallaght and at Nutgrove Shopping Centre in Rathfarnham on Friday May 26th and Saturday, 27th May. There was no fundraising, as requested by Donor House, but many organ donor cards were passed out to potential organ donors.

There is clearly a lot of enthusiasm for the cause of organ donation and many people enthused that they were already 'signed up' by having an Organ Donor Card or having the Code 115 on their driver's licence.

We encouraged everyone we engaged with to 'Have the Conversation' and spread the word amongst their family. We met many people with their own stories to tell on how Chronic Kidney Disease has affected their families, leading to dialysis and transplant.

Thanks to all the volunteers who generously gave their time to support our efforts, namely Bernie, Trudi, Ronan, Richard, Brid, Robert, Marie, Liz and Gerry.

ODAW MERCHANDISE

Prior to Organ Donor Awareness Week a number of our Branch members volunteered to remove old

DUBLIN SOUTH

By GERRY McKENNA



Bernie Hopper, Richard Quinn, Trudi Mulreaney and Gerry McKenna at Nutgrove SC during ODAW.



Gerry McKenna, Liz O'Sullivan and Ronan McMahon at The Square SC for ODAW.

labelling from Donor House stocks of shopping cart tokens, Forget-Me-Not flowers and pins, to reflect the change in the IKA's contact details. Well done and thanks to Trudi, Bernie, Cecile, Brid, Liz, Adrian and Elizabeth, for helping out here.

CONDOLENCES

Our condolences are sent to all Branch members who have lost loved ones in the recent past. In particular we wish to express our condolences to Lenny Ryan, whose father Mick, recently passed away. Mick was known to many in the branch and amongst many members of Transplant Team Ireland. He was heavily involved in helping with the European Transplant Games when they were held in Dublin in 2010.

Rest in Peace Mick. We are all sorry for your loss Lenny.



Mick Ryan

IN MEMORIAM - JOHN SEMPLE

We wish to remember at this time our former Branch Chairperson, John Semple, who passed away on May 26th, 2022. As we promoted Organ Donor Awareness Week in The Square, John was not far from our thoughts, a year to the day after he passed.

He was always concerned with how everyone else was doing despite having his own health challenges to deal with. We remember him with great fondness.

Some of our Branch members attended the one-year anniversary Mass for him before going to The Square for ODAW promotion. Condolences to John's wife Margaret and his siblings and families.



John Semple

MEET-UPS

We plan to meet up outdoors over this Summer in some of the beautiful parks we have in South Dublin for a walk and a coffee afterwards.

CONTACT OUR BRANCH

Follow us on Facebook at:

<https://facebook.com/SouthDublinIKA/> for details of upcoming events and meetings.

Email: IKA.Dublinsouthbranch@gmail.com

If you wish to join our Branch group meetings, or need patient support please contact Gerry on 086-0268223. Dublin South members are also welcome to join our WhatsApp group.

WATERFORD

By FRANCES MOYNIHAN



Helpers at the coffee morning, Mary, Patricia, Rosaleen, Martina, Ann, Rachel and Edel.

We are delighted to welcome patients and families to the Riverstown Apartments in Tramore again this Summer. Thank you to Cathy Keoghan and her team Emma and Dickie for their continued work on our behalf. It is greatly appreciated. Families have enjoyed lots of sunshine thus far so hopefully it continues for the rest of the Summer season.

Fundraising and raising awareness of organ donation continue to be brought to the fore with fundraising events in the area. Ray Halligan, Catriona Culleton, Lorraine Grant and Marion Young were busy with promoting our cause and engaging in fundraising in the Lisduggan Shopping Centre on June 3rd and the SuperValu Hyper on July 7th and 8th in association with the Newtown Fundraising Committee.

A big fundraiser organised by the Mitchell family in Carrick-on-Suir, to celebrate the successful living donor transplant of Michael Mitchell, receiving a donation of a kidney from his aunt Laurena, was an outstanding success with in excess of €18,000 raised.

Monies from the successful fundraiser were to be given to the Healing Arts programme in University Hospital Waterford (UHW), the dialysis unit in UHW, and the Waterford Branch IKA.

Branch meetings are paused over the Summer and we hope to recommence again in September 2023. We would love to see some new volunteers getting active in the Branch, something to consider over

the next few months. Generally, we meet every two months and would look for your active participation in fundraising activities for 8 hours approx. in the year.

We continue to wish the best of health to all our members and visitors to the Tramore apartments.



Bridget Mitchell, Frances Moynihan, Thomas Galvin, Eddie Sullivan, Ray Halligan, Dr Elizabeth Abernethy, Joe Moynihan, Michael Mitchell, Laurena Mitchell and Linda Power.



Laurena Mitchell and her nephew Michael Mitchell



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. In recent times we have been receiving an increase in the number of requests for inclusion of expressions of sympathy and life stories in *SUPPORT* magazine, from families of loved ones who have passed away. Therefore, in order 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.



We hope you are all having a great summer and have enjoyed some of the great weather we have been having.

ANNUAL SERVICE OF REMEMBRANCE

The national annual Service of Remembrance & Thanksgiving will take place this year in Mullingar on 14th October. As usual all patients and family members are invited. This year people are asked to register their interest in attending, details can be found on page 27 of this magazine.

WORLD TRANSPLANT GAMES, PERTH 2023

Cork was represented by four athletes at this year's Games which took place in Perth, Australia in April. Mike Kiely, Hugh Nolan, Mairead O'Mahony and Pat O'Sullivan all donned the green jersey at the games. Mairead was the standout athlete at the Games for the Irish team, coming home to Berrings with five medals. She dominated her events on the track and on the road.

Hugh Nolan, having earlier in the week won gold in the team golf event with Pat O'Sullivan, also won gold in the golf singles with a fantastic score playing off +3.

SUPPORT CENTRE, CORK

At the time of writing, work on the Support Centre has slowed up considerably. Having hoped to be into the house by early summer it now looks like completion of the centre will not be until late summer or early autumn.

There will be an Open Day for all patients and families as soon as work is complete and before the centre starts operating. Details of this Open Day will be provided through our usual channels. It will be a ticket invite only to allow us to control numbers on the day with time slots allocated for the viewing.

CORK

By PATRICK O'SULLIVAN



Sheena and Siobhan



Sarah and guests



Miss Cork with volunteers



Wesley, Shiela, Prof Liam Plant, Frances

VOLUNTEERS

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

Volunteers can be from families and patients alike. If you would like to volunteer for future events, please contact the Branch Secretary email: secretarycork.ika@gmail.com or Ph: 086-2755754. This mobile number is also the number for our WhatsApp group.

If you would like to be kept up to date with all the goings on in the branch text this number to be included.

GOLF CLASSIC

Our Golf Classic took place again this year in Mitchelstown Golf Club on June 2nd. We had 47 teams play on the day. For a change we were blessed with good weather and keeping the players hydrated and refreshed with sunscreen was a full-time job on the day.

As usual, events like this would not be possible without the help of

our volunteers on the day. Members and their families came out in strength to help out.

CORK SUMMER SHOW

The Branch had a display stand, again this year, at the annual Cork Summer Show. This is a two-day event which again required lots of volunteers to help out and man the stand. It is a great opportunity to promote Organ Donor Awareness with huge crowds coming to the event throughout the two days.

Lots of visitors stopped at the stand to share some of their stories on family members and friends who had received a transplant or were going through dialysis at the moment.

SUMMER BBQ

Our annual BBQ will take place, again this year, on August 13th at 5.30pm in the Vienna Woods Hotel in Cork. This will be a ticket only event as numbers will be limited. Tickets and price information will be available from the Secretary of the Branch.



Cork Golf Classic, Mitchelstown Golf Club



Ethna Birmingham team



Scanlon team



Brosnan Pharmacy team



Munster Bovine team



Magnier team



Magnier team 2



Mallow Credit Union team



Maschal Falvey team



PTSB Patrick Street team



Pat Ryan Bancourt team



PTSB Mitchelstown team



Paudie O'Toole team



Tadhg Egan team



Sponsorship signs



The Gallery team



Mike Crotty team



Millers team



Samco team



Irish Rail team



John O'Callaghan team



John Sexton team



Liam Walsh team



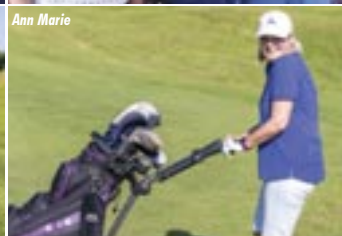
Frank O'Flynn team



Gerry Murray team



Albert Lynch team



Ann Marie



Smiling before the game



The Leitrim Branch were busy during ODAW23 with an information morning in Mohill and information stands in Carrick on Shannon, Manorhamilton and Ballinamore.

A big 'thank you' to everyone who hosted us, everyone who helped out, and all the lovely people who came up to chat with us.

We had our AGM on June 9th and plan to get back to regular meetings in September.

We hope everyone enjoys their summer and remembers to use sun protection.

LEITRIM

By CATHRIONA CHARLES



OFFALY

By MARJORIE STANLEY

LATE JEROME BURKE

It is with great sorrow that we report the death of our Chairman, Jerome Burke who passed away on Sunday, 28th May. We wish to extend our deepest sympathy to his brothers Francis and Liam and the Burke family.

We also send our condolences to Jerome's carer and friend Kay Dunne and her family. Jerome and Kay travelled the length and breadth of Ireland to represent the Offaly Branch.

Jerome was a native of Tralee, Co Kerry and a member of the Offaly Branch for many years. He served as our Branch Chairman for 20 years and he also served on the Board of the IKA for 10 years.

A tribute to Jerome is included in this edition of *SUPPORT* on page 59.

BRANCH MEETINGS

The Branch met five times since September 2022 in the Tullamore Court Hotel. Branch meetings will resume in September and members will be notified of the date and venue. We are always happy to welcome new members to the branch and to branch meetings.

RECENT TRANSPLANTS

Two Branch members received kidney transplants so far this year. We extend our good wishes to Maureen Bergin, who received a kidney from her brother-in-law Tony Woods, and to Maria Williams who received a kidney from a deceased donor. We hope both Maureen and Maria will enjoy many years of good health with their new kidneys.

We also extend our good wishes

to Tony and thank him for his very kind gesture of a 'gift of life' to Maureen.

SYMPATHY

We wish to extend our deepest sympathy to the family of James Lowry, Ferbane, who passed away, suddenly, in February. Sympathy is also extended to any other Branch members who suffered bereavements during the year.

PEDAL THE PEAKS CYCLE

The Tullamore Cycle and Touring Club has, once again, kindly offered to include the IKA Offaly Branch as a beneficiary of the annual Pat Colgan Pedal the Peaks Challenge on Sunday, 28th August.

This will be the seventh year that the Branch has benefitted from the cycle. The Offaly Branch will provide refreshments for the cyclists in Kinnitty Community Centre on the Sunday morning.

DO YOU HAVE AN UPCOMING EVENT OR FUNDRAISER?

We would be delighted to add it to the events calendar on our website - just email robbyn@ika.ie with the details (including what type of event it is, where, when it will be held, ticket and price information).

SLIGO



Speaker Fiona Aherne, Patient Support Manager, IKA.



*Sean Fowley,
Sligo Branch Chairperson*

There was a good turnout at the Irish Kidney Association (IKA) Sligo Branch Patient Support Information Evening in the Glasshouse Hotel on Thursday, 27th May.

We were happy to welcome speaker, Fiona Aherne, Patient Support Manager with the IKA.

Fiona spoke about various supports including social welfare entitlements, housing assistance and practical supports available from the IKA.



DONOR HOUSE

The Irish Kidney Association recently held an engaging webinar on fundraising, led by Niall O'Sullivan, which saw active participation from our Branches. and the recording circulated to all Branch Officers.

The session, conducted in late June, provided practical tips and sharing of information between Branches for our members who wish to engage in fundraising.

This webinar marked the start of an ongoing series on fundraising, and we are pleased to announce the upcoming sessions, scheduled for Wednesday, 13th September and Wednesday, 20th September, both at 7pm.

Further details, including registration information, has been circulated. If you wish to receive this again, please email:

info@ika.ie

By supporting Branch officers in learning and sharing ideas we can grow our income faster.

We would like to express our condolences to our valued member of our team **Lenny Ryan** on the recent passing of his father Michael. Rest in peace Michael.

The deadline for submission of branch notes for the **Autumn** edition of **SUPPORT** is **4th September** and for the **Winter** edition is **20th November, 2023.**

LOUTH/MEATH



Sarah Buchanan, IKA accepting a cheque from Gerard Lennon and other members of the Louth Abbey Vintage Club.

Our thanks to Gerard Lennon, a long-standing member of the Irish Kidney Association (IKA) who, along with fellow members of the Louth Abbey Vintage Club, organised a successful fundraiser over the June Bank Holiday weekend, with raffles and a horse racing night. Gerard, presented Sarah Buchanan, IKA, with a cheque from the proceeds raised, amounting to a €5,140.

A big 'thank you' also to sponsors and those that bought horses, gave donations and came along to the race night.



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