

SUPP RT



WINTER 2023



WINTER

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AND

2 X €50 TESCO

GIFT CARDS

SEE PAGE 28

Editorial



Carol Moore, Chief Executive, IKA



Irish Kidney Association CLG

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Welcome to our Winter issue of *SUPPORT*.

We hope you all are staying dry and warm after the very hot spell in September, which changed to wet and very stormy weather.

There have been a number of very momentous achievements in the Association's history since our last *SUPPORT* magazine.

First of all, the construction and fit-out of the Munster Support Centre is finally complete. Patients and families from the Munster region attending Cork University Hospital, can now avail of the comfortable facilities of this home away from home. Residential overnight

accommodation will also be phased in over the month of December. This new Centre reflects years of hard work by so many people and is a reflection of the energy and passion of the Irish Kidney Association (IKA) community.

So, many thanks to you all, and we hope if you are in Cork, you will take the opportunity to drop in for a cup of tea or coffee during opening hours. You can see the full article on page 6-9 which also covers the

memorable prelaunch showing to Munster Branch Officers and Cork members.

Secondly, thanks to Fine Gael spokesperson on Health, Colm Burke, T.D., we hosted our very first information event for TDs and Senators in the AV room in the Oireachtas, Leinster House. This was very much a team event with presentations from a wide range of healthcare professionals. We also invited



Munster Support Centre

representatives from the Healthcare Community, such as dietitians and physiotherapists.

We covered a wide range of issues, from the need for screening for kidney disease, to the Human Tissue Bill, to the postcode lottery that operates for patients in terms of the services that are provided, for example, differences in whether car parking is reimbursed, clinical approach, and access to blankets. The lack of holiday dialysis spaces was also highlighted.



FRONT COVER

Outside the IKA Munster Renal Support Centre are, front: Jennifer Barry, Support Centre Supervisor; Sally Nagle and Colette Hawe, Support Centre Officers and Sarah Buchanan, Support Centre Implementation Manager; back: Pat O'Sullivan, IKA Cork Branch and Board member and Fiona Aherne, Patient Support Manager.

Photo: John Allen

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CHARITY REGISTRATION NO. 20011260

A patient told her moving story. Before the speakers session, a team from St. James's Hospital provided blood pressure testing. The event which was extensively promoted on social media was very well received. It has greatly enhanced our reputation with both politicians and healthcare professionals.

Full details on page 12-14.

The presentation slides used were circulated to Branch officials and can also be requested from info@ika.ie

We met with the Minister for Health, Stephen Donnelly, T.D., and his officials, on the Human Tissue Bill, at the Department of Health. While they did not accept all our proposed amendments, they agreed to bring in two new amendments based on our recommendations.

The first amendment provides for a statutory review of the **Opt-Out** register three years after the commencement of the Act, and the second allows for a representative of a deceased organ donor to be on the independent panel to be set up under the Act.

The Bill will now be brought before the Seanad and it is expected to pass before Christmas (see pages 16-17).

While Beaumont Hospital has agreed, in principle, to the return of the Renal Support Centre, at the time of writing, we have not



yet received a date for its return. We have initiated legal proceeding against Beaumont Hospital.

We did so very reluctantly, but felt we had no alternative. The legal route will bring the outcome we want, but as you will appreciate the wheels of the judicial process can turn very slowly.

I want to thank you all for your support and patience during this time, and again to reassure you that the Board and I are doing everything in our power to resolve this situation as quickly as possible.

I would encourage any of you to write to me directly with any questions you may have on this issue.

In this edition, you will see a wide range of articles covering our

very special Service of Remembrance and Thanksgiving, which was our first face-to-face Service in four years due to COVID-19 (see pages 31-42).

This edition also covers the online event we held on Kidney Beam, which provides free access to physiotherapist led exercises, along with feedback from a patient using our Peer Support service.

There are also some heartwarming stories shared by kidney patient families and the family of a deceased donor child.

Our condolences to staff member Ruth Gorman, whose mother Betty passed away recently.

At this seasonal time, we remember patients and their families who are burdened with their illness. We particularly think of, and are immensely grateful to, the families, in their darkest moments, who so generously donate their loved ones organs to help give others the 'gift of life'.

For these families and so many other people whose loved ones have passed away, Christmas will never be the same again. You are in our thoughts.

Nollaig Shona agus Athbhliain faoi Mhaise Daoibh.



**CAROL MOORE
CHIEF EXECUTIVE OFFICER**

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A Christmas Message

from the

National Chairperson



As we celebrate this festive season, we can reflect on the journey we've shared throughout the past year. We returned to in-person gatherings following the challenges posed by COVID-19 for the previous three years.

I was honoured to perform the role of narrator at the **Service of Remembrance & Thanksgiving** on October 14th, this year, which was attended by close to 1,400 people. It was held in my local town of Mullingar, in the magnificent Cathedral of Christ the King. For the previous three years the Service was virtual and broadcast on RTÉ One. It was a very unique and moving Service as many organ donor families and grateful transplant recipients came together once again. As the event was recorded by Kairos it was wonderful that members of the congregation, and those who were not able to travel, could watch it on RTÉ One a month later.

Some other high notes during the year were the successful **Organ Donor Awareness Week** campaign, our session in **Leinster House** advocating for patients and highlighting issues they face, the **Human Tissue Bill** being passed in the Dáil and its progression to the Seanad.

There continues to be a huge demand for the IKA's counselling service and the end of the year marks the first-year anniversary of the introduction of the **Peer Support Programme** which has been a huge success.

A highlight came at the end of the year with the opening of the **Munster Support Centre** adjacent to Cork University Hospital. This wonderful home from home for patients travelling from Munster took years to realise. There are a number of people who worked tirelessly to ensure its doors opened to patients in December and we thank them, and all those people and organisations for their support and fundraising to help make this dream come through.

I wish to thank our Board members, Branch members, and all volunteers who continued to support us over the past year as we faced some challenges. To all those who supported fundraisers for our charity I thank you also.

It is disappointing that we had to issue legal proceedings for the return of our Renal Support Centre at Beaumont Hospital, which was sequestered on the arrival of COVID-19. We understand the value this Centre serves to patients and their families visiting Beaumont especially those travelling long distances. We will continue to push for this Centre to be returned. We will also continue to advocate for better conditions for patients with many dialysis centres at capacity, some outdated, and other issues affecting some around travel, carparking, holiday dialysis and more.

To our invaluable volunteers in our Branches, we thank you for your tireless efforts. You make a significant difference. Your dedication embodies the true spirit of the season, and we are grateful for your commitment to helping patients. You are the backbone of our organisation.

To the dedicated staff at Donor House, thank you for your hard work and professionalism. Your behind-the-scenes efforts ensure that our projects and services run smoothly and effectively.

So to everyone, the Board and my fellow Officers, staff, our Branch volunteers, organisations, and individuals who have supported us I wish you all a happy and healthy Christmas and peaceful New Year.

Nollaig Shona.

EDDIE FLOOD

Front row: Sinead, Lisa, Carol, Deborah.
 2nd row: Colin, Edina.
 3rd row: Aoife, Robyn, Margaret.
 4th row: Ashling, Caroline, Jacqueline
 Back row: Gary.
 Missing from photo: Lenny, Sarah, Fiona, Gwen.



From all of us!

We wish each and every one of you a safe and healthy Christmas and happy New Year

Christmas Opening Hours

DONOR HOUSE
 (IKA Main Office)
 Ph: **01 620 5306**

Mon - Fri:
 9.30am - 5.30pm

CLOSED
23rd December
 until
2nd January, 2024

ACCOMMODATION BOOKINGS – Ph: 01 690 8887

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

OPENING HOURS

Clayton Hotel
 Mon - Fri: 9.30am - 5.30pm

For emergency bookings:
 Mon - Fri: 7.00pm - 10.00pm
 Sat - Sun and
 Mon/Tues **25th-26th Dec.**
 and Mon **1st Jan.**
 12.00pm - 4.00pm

Munster Support Centre
 Drop-in

Mon - Fri: 9.30am - 6.00pm

Phone lines open:

Mon - Fri: 9.30am - 8.00pm

For emergency bookings:

Sat - Sun and

Mon/Tues **25th-26th Dec.**

and Mon **1st Jan.** 12.00pm - 4.00pm



MUNSTER SUPPORT CENTRE

‘Home away from home’ for kidney patients



Sunday, 26th November, 2023 marked a proud day for the Irish Kidney Association (IKA) when an exclusive pre-view event of its highly anticipated development, the **Munster Support Centre**, was held. Located at the end of a cul-de-sac on **Wilton Avenue** in Cork city, conveniently just 200 metres from Cork University Hospital (CUH), it was an opportunity for members of the Munster IKA Branches to view the Centre before it commenced operation in December.

The Centre has been designed to offer a warm, comfortable, and welcoming ‘home away from home’ environment for kidney patients and their family members and carers attending CUH. It also offers a drop-in social hub where patients can seek downtime away from a clinical hospital environment with free tea/coffee and refreshments for patients and their families. It offers free overnight accommodation for kidney patients and their accompanying family

By GWEN O'DONOGHUE

members and carers who travel from throughout Munster for hospital appointments and in-patient stays at CUH.

First mooted in 2014, the first sod for the re-development of two adjoining houses at 11 to 12 Wilton Avenue was turned on August 15th, 2022. Full planning permission was granted by Cork City Council.

The management of Cork University Hospital, where the care of

600 renal patients is managed, has been fully supportive of the project which is on its doorstep.

The Centre includes six well designed ensuite bedrooms two of which are wheelchair accessible, an open plan sitting, kitchen and TV lounge, two quiet rooms, and a large back garden for patrons to enjoy outdoor space, and six off-street parking spaces. It is conveniently located at the end of a cul-de-sac beside a pedestrian access to the hospital.





The Centre employs three trained support staff who will take bookings and offer a warm and friendly welcome to visitors. All three staff are from Cork and each one of their personal lives have been touched by kidney disease. They include Centre Supervisor **Jennifer Barry**, and Centre officers **Collette Hawe** and **Sally Nagle**. **Fiona Aherne**, the Patient Support Manager, who is based in Donor House in Dublin, is responsible for overseeing the operation of the Centre.

Sarah Buchanan, a kidney transplant recipient, and volunteer peer supporter was recruited in early 2023 for the role of Implementation Manager. She has been credited for doing a stellar job in ensuring the Centre was delivered in as timely fashion as was possible, liaising with contractors, neighbours, the hospital, and for her great taste when selecting furniture and fittings.

Sarah was supported in this role by Cork IKA Board member **Pat O'Sullivan** who passionately volunteered considerable time, both onsite and offsite, to help drive the project to fruition. Cork Branch Secretary **Sheena McDonagh** dedicated many hours of her time freely to the Centre, particularly in the lead up to its opening.

Finance and Property Manager **Gary Davitt** kept a firm control of costs. He also worked hard on relationships with the many contractors, supporting value for money when making design decisions, and ensuring speedy same day payments to contractors when needed.

Outside the Centre, a 12ft Christmas tree and garlands over the doors, themed in IKA brand colours, which was organised by the Cork IKA Branch, created a warm and welcoming atmosphere over the festive season.

Collette Hawe, Fiona Aherne, Jennifer Barry, Sally Nagle, Sarah Buchanan and Carol Moore.



The Munster Renal Support Centre is open Monday to Friday, with special arrangements in place for patients families' requiring accommodation at weekends, during public holidays, and outside its normal working hours.

The first preview of the Centre's facilities was given to Irish Kidney Association (IKA) Branch representatives from the five Munster counties within its 25-Branch network. It was an opportunity to acknowledge the Branch representatives, all volunteers, who were a key part of the driving force behind the IKA's mission to establish this early anticipated Centre and who are integral to its future success.

The occasion allowed them to personally explore the newly built Centre and see first-hand the beneficial effects it will have on kidney patients who visit CUH. Afterward, they could go back to their Branches and share information about the free Centre and convenience it provides.

Carol Moore, Chief Executive, IKA said at the pre-view event, "This is a proud and historic day for the Irish Kidney Association, Cork, Munster and all 25 Branches of the Association. What was once an aspiration has now materialised into a significant achievement and it reflects what the IKA is all about which is providing support and friendship.

continued next page...

The O'Sheas Wesley and Frances with Kate (15) and James (9).





The Egan family – Parents Mary and Tadg with Éabha (18), Leah (15) and Ben (11)



Frances Moynihan, Waterford IKA with Sinead McDonald, IKA Fundraising Manager.



Cork Branch members: seated, Donal O'Flynn and Pat O'Sullivan. Standing, Hugh Nolan, Helen O'Sullivan, Helen O'Flynn, Denis Hyland, Liz Hyland, Wilson O'Sullivan and Ray Scanlan.



Pat O'Sullivan, Jennifer Barry, Fiona Aherne, Sarah Buchanan, Carol Moore, Sinead McDonald and Theresa Looney.



Quiet room

"This Centre will help our community to meet and connect. It is very special to be here in this wonderful Centre today and witness the best of what we can achieve.

"Our thanks to all involved for their dedicated support, including the generosity and commitment of numerous people who

volunteered their time, fundraised, and sought sponsorships to bring this ambitious vision to life.

"In December, the doors will open to kidney patients, marking the beginning of a new era in the IKA's provision of patient centred care.

"Today we celebrate the initial phase of our commitment to providing





Cork representatives: Pat O'Sullivan, Sheena McDonagh, Bishop of Cork and Ross Fintan Gavin, Bernard Cronin, Julianna Crowley (Chaplain CUH), Denis Hyland.



Tipperary Branch representatives Mary Adamson, Joan Gavan and Ann Hackett.



Cork Branch representatives Michael Kiely and Elsie Dineen, founding member.

a supportive *'home away from home'* space for renal patients, helping to ease the burden for patients who often experience difficult health circumstances.

While the IKA's primary focus during this period is to ensure a seamless and comforting experience for its guests, we are excited to involve IKA Munster branch representatives here today from Clare, Cork, Kerry, Tipperary, and Waterford, who so generously volunteer for our charity organisation on behalf of patients from the region. We extend our gratitude also to the 20 other branches and Directors on the Board of our Association for their support for his important project.

"The involvement of these dedicated volunteers emphasises the collaborative effort of the

community to create a place of solace and care for kidney patients in need. Their contributions have been invaluable in shaping our facilities and services to cater to the unique needs of our guests.

"We extend our heartfelt gratitude to everyone who contributed to the success of this Centre. Your collective support has been instrumental in getting us to this point. As we move forward, the ongoing running and day-to-day operations of the Centre rely on continued support.

"We look forward to holding an official opening of the Centre in early Summer 2024. We welcome representatives and members of all 25 Branches to visit this wonderful Centre. For those wishing to drop in to view the Centre a warm welcome will be extended, however, out of

respect for the privacy of patients and families using the Centre, intending visitors are encouraged to contact the Centre staff in advance, to make an appointment."

Special mention was made to the initial property steering committee for the project which included volunteers, Eddie Flood (Chair) Frances and Joe Moynihan, Michael Kiely, Joe Higgins, and Pat O'Sullivan.

A steering committee has been set up to oversee the future of the Centre with stalwart IKA volunteers and representatives from the Cork IKA Branch...Pat O'Sullivan and Denis Hyland, Kerry IKA Branch's Theresa Looney, along with Donor House staff including Fiona Aherne, Gary Davitt (Finance and Property Manager), Sarah Buchanan, and Jennifer Barry.

The local building contractor for the redevelopment was Paschal Falvey, and the project manager was Architect Peter Kavanagh.

All those at the pre-view event were delighted with the warmth and comfort of the Centre, and look forward to families from their Branches using it. As one person noted in the feedback..."How can you improve on perfection".

Directly after the pre-view event the annual Mass of Remembrance & Thanksgiving, which is organised by the Cork IKA Branch, was held in the Hospital chapel of Christ Our Saviour. Members of the Cork IKA Branch who attended the Mass were given the opportunity to view the Munster Support Centre afterwards.

To find out more about the Munster Support Centre visit <https://ika.ie/support-centre/>

For bookings phone 01-6908887 or Email: munstersupportcentre@ika.ie



Carol Moore (right) with Clara Branch representatives Martin, Sharon and Linda Fitzgerald.



Kerry Branch representatives Brigid Herbert, Elsie Moore, Treasurer, Debbie Templeton, Asst. Treasurer, Josephine Lawlor, Theresa Looney, Brendan Herbert, Chairman.

A Daughter's 'Gift of Life'



A heartwarming Christmas tale

A West Cork family's heartwarming story of love, sacrifice, and life's renewal captures the true spirit of Christmas. In July 2023, **Claire Quinn**, a 41-year-old married mother of two young children, who has completed three tours of duty overseas with the Defence Forces, performed the ultimate duty of service for her family, by donating a kidney to her father.

By GWEN O'DONOGHUE

This Christmas marks a celebration for three generations of a family who live in Kilbrittain, Co. Cork, symbolising a new chapter of health and gratitude for the 'gift of life'. Claire and Kevin share their story to encourage families when they come together for the festivities, to share their wishes about organ donation in the hope of saving more lives.

Drawing from her army background, her skills in planning and executing tasks came to the fore as she and her husband Gary Mollaghan, devised a meticulous plan to manage the care of her two young children, Anna (3) and Dara (2), intent that their routine remained undisturbed to prepare for donating a kidney to her father.

The family's journey began four and a half years ago when Kevin Quinn found himself back on dialysis after a kidney transplant that had given him over four decades of a good quality of life.

Kevin travelled to Cork University Hospital three times a week for dialysis for which he will be forever thankful and greatly appreciated the kindness and care of the staff in the Dialysis Unit, and his consultant Prof. Michael Clarkson.

Kevin has expressed his profound gratitude to his deceased donor for the precious 'gift of life' he received in 1977. He explained, "I was a young man and three years after the transplant I married my lovely wife Marian, we welcomed the arrival of our two wonderful daughters into to the world and enjoyed watching them grow up. Little did I know that our first born would later be the one who would give me the 'gift of life'. What she has done is amazing and it's a testament to her selfless character and the strong bond we have always shared."

Claire explained, "Dad and I have always been very close. From an early age I spent as much time as I could with him and loved helping on the farm during lambing season. My mother has always said about our father-daughter relationship that 'you both always know what each other is thinking'. But he would never expect me to

donate a kidney to him. I was just determined to do it if I could.

"We knew the risks involved and felt it was a very safe calculated risk worth taking in knowing that the outcome of a successful transplant would mean we could have dad with us for much longer. As dad had enjoyed such a good innings with his first transplant from a deceased donor, it also meant a lot to us that if a deceased donor kidney were to become available, that another patient and their family would be able to receive it.

"When dad went on dialysis I wanted to try and help him if I could. I was approaching my forties and while pregnant with my first child, I contacted Beaumont Hospital to enquire about donating a kidney. I was told I would have to wait until a year after my child was born to donate."

Navigating the challenges of her age and family planning, Claire and Gary welcomed two children in quick succession, strategically planning the kidney donation process around their needs.

Undeterred by the hurdles, Claire embarked on a screening process for living donation which took nine months with the first test taking place exactly a year to the day after her second child being born. With unwavering support from her family, including her husband and extended family Claire successfully passed the robust screening process and was deemed a suitable match.

There was meticulous planning prior to the transplant to ensure minimal disruption to her young children's routine, which had been of high priority for Claire and Gary.

The day of the transplant arrived in July 2023, and was marked by mixed emotions. Claire explained, "while I was excited by the prospect of a positive outcome for dad, we were both worried about each other getting through the surgery safely.

"Thankfully the transplant was a success, and I was so relieved to be told a few hours after my surgery that my father was doing well. I can't describe how wonderful it was to hear this news.

"Donating a kidney was never about me and to hear that he came through the operation successfully was such a comfort and relief. I was

Claire and Kevin Quinn at the Munster Support Centre.



discharged from the hospital just five days later and dad followed home three days later where he would receive the excellent loving care of my mother."

Today, the Quinn family is gearing up for a Christmas they never thought possible – a celebration unburdened by dialysis, screening, and transplant uncertainty.

Claire said, "Dad is now full of life and energy, he has regained his life, his appetite has been restored now that he is free from dietary restrictions of dialysis. This Christmas we will all enjoy Christmas dinner together. My dad will be able to eat everything that is served up.

"Christmas will mark a significant milestone as it will be the first Christmas since my children were born that they will celebrate with grandparents who are both in good

health, after a challenging few years for all of us!"

Claire, who has returned to work in Collins Barracks, expresses gratitude to everyone who played a role in this life-altering journey. From her immediate family and community support to the medical professionals who cared for her, the outpouring of kindness has been overwhelming.

The Quinns also extend their thanks to the Irish Kidney Association that provided free accommodation near the hospital for their family during the transplant and recovery period.

The Quinn's story serves as a reminder that the holiday season is not just about presents under the tree but the importance of family, health, and the profound 'gift of life'.

Claire, when she was 10-years-old, on the family farm with her father.





Prof. George Mellotte
and Colm Burke, TD



It was also the day that the Human Tissue Bill passed its final stage in the Dáil and went forward to the Seanad for scrutiny – you can read more about this on pages 16-17.

Special thanks go to **Colm Burke TD** (Cork North Central) for hosting the session in the AV Room.

Significant groundwork and planning went into

delivering what was a very successful event. Even before the day itself we were seeing the benefits of the initiative as our efforts to engage a broad spectrum of Healthcare Professionals were met with unequivocal enthusiasm. It is important that we build upon this collaboration to improve kidney healthcare for all.

Our briefing was limited to one hour and we all

November 8th, 2023 will go down in Irish Kidney Association history as an important day. It was when we delivered a briefing, open to TDs and Senators, on **Improving Kidney Patient Outcomes and Reducing Costs** in the AV Room in Leinster House.

know that there are a lot of issues in renal healthcare that need to be addressed, so there was need to limit the range of areas covered to make meaningful points.

Some of the areas covered were influenced by the fact that the Human Tissue Bill has been working its way through the Oireachtas and as such there were topics that would be of current interest to the intended audience.

It was recognised that areas not covered in the session remain important and that this briefing was intended to be the first of a number to come.

A stellar line-up of speakers was brought together for the session

and there was significant collaboration in advance to ensure that we maximised the time available to get across all the important points.

After welcome remarks and introductions from IKA Chairman, **Eddie Flood**, **Prof. George Mellotte** (Clinical Lead at the National Renal Office) opened the session by putting the current, and future demands in kidney healthcare, in context and highlighting the significant impact this often-overlooked disease is having, and will have, on public health (chronic kidney disease is expected to be the fifth leading cause of death internationally by 2040),



Eddie Flood

and financial resources.

Prof. Mellotte highlighted the HSE's Chronic Disease Management Programme and the need for chronic kidney disease (CKD) to be included as early diagnosis and management of CKD leads to better outcomes for patients and could significantly ease a growing financial burden on the health service.

On September 7th this year, the National Office of Clinical Audit (NOCA) launched its report on a pilot potential donor audit that was carried out in six hospitals. The report highlighted the central role that a comprehensive national annual Potential Donor Audit (PDA) could play in informing best practice, as well as giving focus to organ donor awareness campaigns.

We were delighted to have **Dr. Maria Kehoe** from NOCA presenting after Prof. Mellotte. She spoke about the pilot PDA, how it was developed by researching best practice in other countries, the findings of the pilot so far and the value that a national annual PDA would bring to the area of organ donation and transplantation.

The Irish Kidney Association (IKA) had lobbied for the inclusion of an annual PDA in the



Speakers at Leinster House: Lisa Fitzgerald, Prof. George Mellotte, Dr. Maria Kehoe, Dr. Brenda Griffin, Carol Moor and Eddie Flood.



At Leinster House taking blood pressure, the team from Tallaght and St James Hospital, Prof Donal Sexton, Consultant Nephrologist, Darran Rogan, HCA, Dr. Satish Jayawardene, Consultant Nephrologist and Dr. Brenda Griffin, Consultant Nephrologist and, seated, Colm Burke, T.D.

Human Tissue Bill to give its delivery legislative protection. Unfortunately, the Bill has not been amended but there have been verbal assurances that a potential donor audit is very much in future plans.

The transition from paediatric to adult services is a challenging time in all chronic illnesses. **Dr. Brenda Griffin** (Consultant Nephrologist at St James's Hospital and Tallaght University Hospital) brought the audience through the issues faced by young kidney patients on this journey.

She highlighted the need for a comprehensive wrap-around service to help young people better manage their health as they develop the independence and face

the challenges that come with adulthood.

Lisa Fitzgerald, a kidney transplant recipient, shared her kidney health journey and really brought home the importance of patients being fully engaged in their healthcare – kept fully informed and brought into the decision-making process.

You can read more

about Lisa's excellent talk on page 15.

Carol Moore, IKA CEO, took on the challenge of bringing all the strands together and highlighting the need for a strategic plan bringing together all aspects of kidney care. Whilst 'only' 1 in 1,000 of the population has End Stage Kidney Disease, requiring either dialysis or a transplant, approximately 1 in 7 of the over 55s in our population have Chronic Kidney Disease.

In our World Kidney Day campaigns of 2022 and 2023, we highlighted the fact that chronic kidney disease does not usually exist in isolation – diabetes and cardiovascular disease are just two of the complicating co-morbidities.

Carol made a point of raising current issues being faced by the kidney community as highlighted below in what was one of her slides.

Continued next page....

Unequal Treatment

- Long travel distances
- Travel costs for 3 to 4 visits per week
- Car parking charges
- Mask wearing by taxi drivers
- Provision of TVs and remotes
- Provision of blankets
- Provision of food
- Ageing dialysis units
- Choice of Dialysis options e.g. peritoneal, walking, shared care
- Access to social worker, physio, art therapy, etc...

Improving Kidney Patient Outcomes and Reducing Costs *continued...*

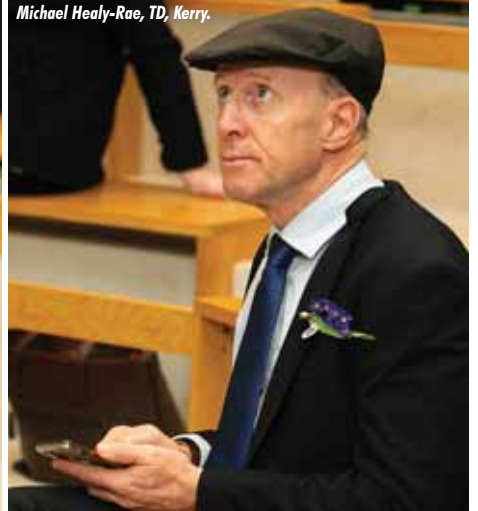
Danny Healy-Rae, TD, Kerry.



David Cullinane, TD, Waterford.



Michael Healy-Rae, TD, Kerry.



Senator Pauline O'Reilly, Galway West constituency getting her blood pressure taken at Leinster house by Darren Rogan, HCA, St. James's Hospital.



Senator Rose Conway Walsh, Mayo, having her blood pressure taken by Dr Brenda Griffin.



After Carol fielded some questions from TDs and Senators, that either she answered or addressed to the panel, IKA Chairman, Eddie Flood, concluded the session and it was very pleasing to note that all the work and collaboration in advance had paid off as the programme ran exactly

to schedule.

IKA staff and healthcare professionals left the session enthused that there had been an opportunity to put forward current issues and proposals for the future. It was felt to have been a constructive session as the goal was to offer proposals

on improving kidney patient outcomes whilst reducing costs.

A good foundation has been laid and it will give a solid base from which to build in 2024 and beyond.

We were delighted that we were also able to have representation from nursing, renal dietetics,

and physiotherapy in the audience.



Violet-Anne Wynne, TD, Independent, Clare; Marian Harkin, TD, Independent, Sligo-Leitrim.



Eoin Madden, a kidney transplant recipient from Kiltulla, Galway getting his blood pressure checked by Darren Rogan.



Having his blood pressure taken by Dr Brenda Griffin, was Leinster House Usher Paul Smith.



LISA'S STORY



Lisa Fitzgerald.

In her impactful presentation at Leinster House, **Lisa Fitzgerald** shared her health journey, before receiving a kidney transplant almost five years ago.

Lisa's first pregnancy uncovered underlying kidney issues when she developed pre-eclampsia. Her recovery became increasingly challenging, and it wasn't until a meeting with a consultant from St. Vincent's Hospital that she learned about her underlying condition.

She attended annual check-up appointments but was not given the impression that there was cause for concern. She was unaware of the risks of the progression of kidney disease, nor the steps she might take herself to manage her condition, including a kidney diet.

During her second pregnancy, six years ago, she confronted the

- A patient's perspective

medical system's shortcomings, expressing frustration at monthly appointments with a succession of different trainee doctors unfamiliar with her case. It was on this 'outspoken' occasion that she was with Consultant Nephrologist Dr. John Holian who took the situation in hand and shed light on her Stage 3 chronic kidney disease. This marked a pivotal moment in her beginning to understand her condition.

Her second pregnancy was categorised as 'high risk' and although a worrying time for her, she felt reassured that her pregnancy was being carefully monitored with good collaborative care between her nephrologist Dr. Holian and her obstetrician Prof Higgins. She gave up work in the best interests of her family including her unborn child who was born prematurely but was healthy, and this time Lisa was grateful to be awake for her baby's arrival.

However, complications a few days after the birth led to a life-threatening situation which left her in hospital for ten days away from her newborn. A further year of sickness ensued with uncertainty and struggle for her and her family.

Lisa spoke about the lack of guidance and support during this period, expressing the isolation she

felt. With sickness, continuous medication, and the demands of dialysis, her daily life became a relentless struggle.

Home dialysis brought relief but not without its challenges, and the preparation for the transplant list added emotional and logistical stress with additional expense in travel and parking fees for regular hospital appointments requiring her husband to take time off work for childcare.

Remarkably, a kidney transplant arrived after a short wait of just four months on the waiting list, thanks to a gift from a generous donor family. Describing herself as capable and strong she acknowledged the physical and emotional toll of kidney failure and dialysis, and extended empathy to others who might not be as forthright as her but were facing similar challenges.

In her poignant summation to the Leinster House gathering she asked how the people there would feel if it was a member of their family who was affected. She called for changes in healthcare, with the need for early education and pre-screening.

In her words, "*Knowledge is key, and change is needed,*" to ensure better outcomes for patients and that no one should have to navigate their journey alone.

The Human Tissue Bill

The **Human Tissue Bill** was passed by the Dáil on November 8th, 2023 and it went through its second stage in the Seanad on November 22nd. It is due back in the Seanad on the December 6th, 2023 and, all going to plan, it will be sent to the President for his signature before Christmas. Once he signs it, it becomes law, and we will change from calling it the Human Tissue Bill to calling it the Human Tissue Act.



Senator Mark Daly, Stephen Donnelly, TD, Carol Moore, IKA CEO and Colin White, IKA National Advocacy & Projects Manager.

By **COLIN WHITE**

NATIONAL ADVOCACY & PROJECTS MANAGER

This is an historic piece of legislation, and it is important to acknowledge the huge amount of work, on the part of many people over a long period of time, that has gone into making it a reality. The section on organ donation for transplantation is only part of a much bigger picture.

It is important to note that some Acts come into force immediately, while others are commenced on a later date by the relevant Minister. In can also be the case, (as is expected with this legislation) that not all parts will commence at the same time.

In the case of the Human Tissue Bill, a national public education and awareness campaign about the impact of the legislation on organ donation needs to be put in place before the changes in practice in that area come into force.

Getting the legislation passed is the end of one chapter and another one begins immediately for the Irish Kidney Association (IKA), with the focus moving to shaping and helping

to deliver the public education and awareness campaign around the new legislation.

It has been heartening to have the input of the IKA in the legislative process to date acknowledged both in the Dáil and the Seanad by many speakers. During his introductory comments in the Seanad on November 22nd, the Minister for Health, **Stephen Donnelly TD** said.



Stephen Donnelly, TD.

"Several amendments were introduced on Report Stage in the Dáil, all of which seek to ensure the legislation aligns with policy intent. Two amendments were made to Part 2 of the Bill, on organ donation and transplantation. I have provided for a review that will examine the impact of the opt-out register on organ donation and transplantation in Ireland, to be carried out three years after commencement of Part 2 of the Bill. A further amendment was made to this Part so that there may be two patient

advocates on the independent panel for organ donation, at least one of whom may be a patient donor advocate. *These amendments arose from my engagement with the Irish Kidney Association.*

I acknowledge the Irish Kidney Association's work and indeed the work of other civil society and patient advocacy groups in Ireland. We have engaged with them at length. The Leas-Chathaoirleach and I met with the Irish Kidney Association recently. Several of the amendments that were brought forward on Report Stage were consequent to that meeting and to various requests the association had made. I acknowledge that there has been constructive and positive engagement across the board between myself, Members of both Houses, my Department, the Irish Kidney Association, and the other fantastic groups that work in this space. I thank them for all their constructive input. We have updated the Bill and I have introduced amendments through the Stages to try to reflect what patients, families and their advocacy groups have been looking for."

It was noted by Senator Mark Daly during the second stage of the Bill in the Seanad that it is the first

piece of national legislation about organ donation and transplantation in the history of the State.

The Association has been following a policy of constructive engagement with the Oireachtas and the Department of Health, and will continue to do so, having welcomed the Bill, and acknowledged the Minister's dedication to its delivery.

BEHIND THE SCENES

During the legislative process, the Association provided briefing documents, grounded in years of research, to all members of the Oireachtas Committee on Health as well as the respective Health spokespersons for all the political parties.

We also attended a meeting of the Committee on Health and took the opportunity to discuss our proposed amendments with the members of the committee.

Following up on a meeting with Department of Health officials where we discussed the Association's proposed amendments to the Bill, the Association met with the Minister for Health, Stephen Donnelly, TD, on October 18th to discuss our 5 proposed amendments to the Human Tissue Bill. We must acknowledge the support of Senator Mark Daly in securing this meeting.

UPDATED ON THE PROPOSED AMENDMENTS

1. Organ Trafficking

The IKA proposed the inclusion of explicit wording in the Bill to outlaw all aspects of Human Trafficking relevant to the buying and selling of organs for transplantation – providing text from The Human Tissue (Authorisation) (Scotland) Act 2019 as an example of how to address the issue.

The Minister and his officials provided extracts from existing legislation indicating that our concerns are already suitably addressed.

2. Potential Donor Audit

The IKA proposed that provision for a Potential Donor Audit be included in the Bill to give a legislative guarantee that such an audit would be carried out, and published, annually and would not be subject to possible changes in priorities, funding, or



recruitment freezes.

Whilst it was accepted that the pilot Potential Donor Audit carried out by the National Office of Clinical Audit (NOCA), under instruction from Organ Donation Transplant Ireland (ODTI) is a valuable piece of work, it was argued that there was no need to legislate for it.

It was stated that there are plans to introduce an annual Potential Donor Audit and Donor House is currently following up, and putting pressure on, to ensure that it is delivered by the National Office of Clinical Audit.

3. Inclusion of a donor family representative on the Independent Panel

Given that it is accepted that there should be a patient representative on the panel, it seemed odd that there would not be a commitment to include a donor family representative. As noted above, an amendment was introduced to the Bill to address this.

4. Statutory Responsibility for Organ Donor Awareness

The IKA wanted the Bill to include the assignment of statutory responsibility for organ donor awareness – much in the same way as the Irish Blood Transfusion Service has statutory responsibility for the promotion of blood donation.

It leads to accountability, and the IKA feels that this will be particularly important with the anticipated significant increase in budget allocated for the promotion of organ donation and the impact of the new legislation.

The Department officials stated that the responsibility for organ donor awareness sits with the office of ODTI and they have control of the assigned budget. It should be noted that at the meeting of the Oireachtas Committee on Health (June 21st, 2023) that the Minister for Health stated, *"The HSE will roll out the programme. The Department needs to allocate a good chunk of funding. I also refer to the role of civil society. It will not just by the HSE. It will be bodies such as the Irish Kidney Association and other phenomenal patient representative groups, which will continue to play an important role."*

5. Inclusion of an Opt-in register as well as an Opt-out register.

The IKA's case for the inclusion of an **Opt-in** register to run alongside the **Opt-out** register planned for in the legislation has been well covered. The Minister, and his officials, listened to our arguments and reviewed the evidence that we had assembled and whilst he was not swayed, he did commit to the inclusion of an amendment allowing for a review 3 years after the commencement of the legislation.

Through its extensive work on the Human Tissue Bill, the IKA has shown itself to be, and has been acknowledged as, a worthy partner in the development of national policy. Following up on our success in the prioritisation of kidney patients in the roll out of the COVID-19 vaccination programme, this bodes well for future engagements with policy makers.

Soccer Legend Scores for Kidney Awareness!

Andy Cole at the Liam Miller Tribute Match in Pairc Uí Chaoimh in Cork on September 25th, 2018, between Celtic/Ireland legends and Manchester United legends. Photo: INPHO/Tommy Dickson.

By GWEN O'DONOHUE

When we learned that legendary footballer **Andy Cole**, who underwent a kidney transplant in 2017, was coming to Ireland in early November for an event in his honour, organised by Iconic Promotions, we saw an irresistible opportunity to capitalise on the moment, and raise awareness for kidney patients and organ donation.

Our thanks to at Iconic Promotions, organisers of 'A Night With Andy Cole' held on Friday, 3rd November in Portmarnock, Dublin, for kindly agreeing to our request to sponsor a prize giveaway on the IKA's social media of four tickets to the event. Their prize included early access to meet the football legend and be photographed with him.

The prizewinners, who each received two tickets to the event, were **James Reynolds** and **Chris Kelly**, both from Dublin and both kidney patients.

On the busy night Andy spoke to the winners about their health journeys while being photographed with them.

The IKA contacted the RTÉ *Late Late Show*, to advise them about Andy's visit, and asked if they would invite him onto the show to talk about his illustrious career, and the impact of his kidney failure and subsequent kidney transplant.

It transpired that the show's new presenter, Patrick Kielty, is a lifetime Manchester United supporter and fan of Andy's, and the interview was secured. The clash in timing of



James Reynolds and Andy Cole.



Chris Kelly and Andy Cole.

Andy's event taking place at the same time as the *Late Late Show* is broadcast was not a barrier as the TV interview was prerecorded earlier in the day.

The former English footballer holds the third position as the most accomplished striker in Premier League history, boasting an impressive 187 goals. Over his 20-year career, he played for twelve clubs, but his time at Manchester United stands out most, as he contributed to their historic treble in 1999, earning 15 international caps along the way. In the glory days of Man United, Andy Cole was part of the almighty football royalty, including David Beckham, Ryan Giggs, Dwight Yorke and Roy Keane.

However, in 2015, six years after retiring from playing football professionally, the elite athlete's world was turned upside down when he faced kidney failure. The diagnosis marked the beginning of a new, even more challenging chapter in his life.

He received a life-saving transplant from his nephew in 2017. His experience of transplantation and the challenges with mental health, following his kidney failure diagnosis, inspired him to set up the **Andy Cole Fund with Kidney Research UK** to assist others living with kidney disease.

The funds raised contribute to research on kidney disease and transplants, and finding the best methods to enhance the mental health and well-being of patients.

In his TV interview with Patrick Kiely he spoke about both the physical and mental toll of his kidney disease.



On the RTÉ Late Late Show host Patrick Kiely with Andy Cole.

"It's a hard daily chore just trying to stay on top of it mentally. It's six years ago I had a kidney transplant. It totally came out of the blue and it rocked my world, you know. It's difficult mentally, getting used to the medication is really, really tough. There's good days and bad days. There's days when I can't get out of bed.

"In 2017 my nephew donated his kidney to me. He said I will be honest with you I just can't stand to see you in this state anymore."

When asked by Patrick how bad things had got, Andy responded, "My kidney capacity was down to 7%. I was basically sleeping 14 to 15 hours in a day and getting up was a chore, walking was a chore, and I had gone up to something like 17 or 18 stone with all the water retention I was holding. So yeah, it was a difficult time at that time."

Patrick asked: "And what was worse, was it the physical illness or where your head goes, going through something like that," with Andy responding: "For me personally it was more in my head, knowing

that I played football. I'd been fit all my life and all of a sudden this has come about. It has changed my world, to be brutally honest, and then knowing that I have got to deal with whatever is in front with me.

"I don't think that they really explain to you what goes on when you have such a surgery. I remember the first time I sat down.

They said you have to have a transplant. I said okay, no problem. But then they said I had to take medication all my life. I said I can't do that, I can't take medication for the rest of my life. I play football if they give me a course of tablets for a week, I take two days, then I'm done."

When he talked about his Irish teammate and friend Roy Keane visiting him in hospital while recovering from his transplant operation and the nurse, asking Roy on arrival, not to make him laugh to protect the stitches, which were very tight in his stomach, Andy said, "Within about five minutes he had me rolling around, and I was in so much pain, but Roy being Roy he continued to make me laugh.

continued next page...



Andy Cole, during the warm-up, on the Pairc Ui Chaoimh pitch, Cork, for the Liam Miller Tribute match between Ireland/Celtic legends and Manchester United legends.



Roy Keane and Andy Cole prepare to enter the Pairc Ui Chaoimh pitch for the Liam Miller Tribute match between Ireland/Celtic legends and Manchester United legends.

Soccer Legend Scores for Kidney Awareness! contd...



Andy promoting organ donor awareness at 'A Night with Andy Cole'.

"I've always had a fantastic relationship with him, obviously as a captain, he was an unbelievable captain. I was fortunate to play with such a great player.

Away from the football pitch he always had great time for me. You could say we are a bit alike as well. I don't think I am as ferocious as he is. I like to speak my mind but not as much as he does."

During the interview the Irish Kidney Association website address was flashed on the TV screen for viewers to request organ donor cards.

The footballer's compelling interview on the national show garnered extensive coverage in both traditional media and across social platforms. This not only raised awareness about the mental and physical challenges faced by individuals experiencing kidney failure and the transformative effects of transplants but also significantly contributed to increasing awareness about organ donation.



DONATING A KIDNEY

Outcomes in an Irish National Centre After Transplant: Evaluation Study

DONATE STUDY

WE WANT TO HEAR YOUR VIEWS!

We are seeking individuals who have donated a kidney to a family member or close friend. We are interested in investigating post-donation health outcomes and to understand participants' experiences.

– A BRIEF ONLINE SURVEY –

This survey takes approximate **10-15 minutes**. The survey is **completely anonymous**.

If you have any questions please contact:

Dr Diane Gillan (Psychologist)
or **Dr Carol Traynor**
(Consultant Nephrologist
& Transplant Physician)

at **Beaumont Hospital**
at (01) 8092223

SIMPLY SCAN THIS
QR CODE WITH YOUR
PHONE CAMERA



Or copy and paste the URL below into your internet browser
https://nursingandmidwifery.fra1.qualtrics.com/jfe/form/SV_9oz49JQtVq1zC4e

Transplant & Dialysis Sport

By **COLIN WHITE**

NATIONAL ADVOCACY & PROJECTS MANAGER

2024 is around the corner and with it comes the promise of another year of sports, camaraderie, and the promotion of organ donor awareness. The key message about transplant and dialysis sport is that it is open to all to get involved.

Two of the international events on offer in 2024 are detailed below.

EUROPEAN TRANSPLANT SPORTS CHAMPIONSHIPS

This event will be held in Lisbon, Portugal from **July 21st-28th**. It is open to organ (kidney, liver, pancreas, heart, and lung) and bone marrow transplant recipients, and people on dialysis.

There is a meeting in Lisbon during the first week of December and it is expected that there will be further details available soon after that.

BRITISH TRANSPLANT GAMES

This event will be held in Nottingham from **August 1st-4th**. Thanks to our friends in Transplant Sport UK, Ireland can participate in the Games under the banner of the Dublin Transplant Adults and the Dublin Transplant Children's teams. Registration details normally become available in early February

CIVIC RECEPTION FOR TERESA SMYTH

On October 23rd, 2023, Galway County Council held a Civic Reception to acknowledge the fantastic achievements of a variety of different people. Included in the line up was our own Teresa Smyth (kidney transplant recipient) who made headlines for her participation in this year's World Transplant Games in Perth, Australia and the well-deserved silver medal she won in Darts. Representing the IKA Galway Branch at the event in support of Teresa's achievement was Eoin Madden.

Perth was Teresa's first World Transplant Games. She embraced



Teresa Smyth, centre right, with other award recipients and officials at a Civic Reception at Galway County Council.



Teresa Smyth, Eoin Madden.

the opportunity and typified the spirit of her teammates who represented Ireland on the international stage.

Teresa's daughter, and her family, live in Perth and were on hand to support throughout the week. Teresa was able to reciprocate the support as she stayed on in Perth to be with her daughter for the birth of her child.

Teresa returned home to Galway in June to great fanfare, with a motorcade and brass band!

AN INSPIRING GESTURE FROM RON GRAINGER

Ron got involved in transplant and dialysis sports in 2014 when he competed in his first European Championships and has not looked back since.

As one of the first World Transplant Games Federation Fit For Life ambassadors, Ron has been a role model to so many, both at home and abroad, as he has willingly shared his story to show the accessibility and benefits of sports for people on dialysis and organ and bone marrow transplant recipients.

Affectionately known as 'The Flying Doctor' by his teammates due to his achievements on the track, like a fine wine, at this year's World Transplant Games, Ron showed that he is getting better with age!

Not only did he win the 100m and 200m sprint, but he also broke the Games record in both events in the process!

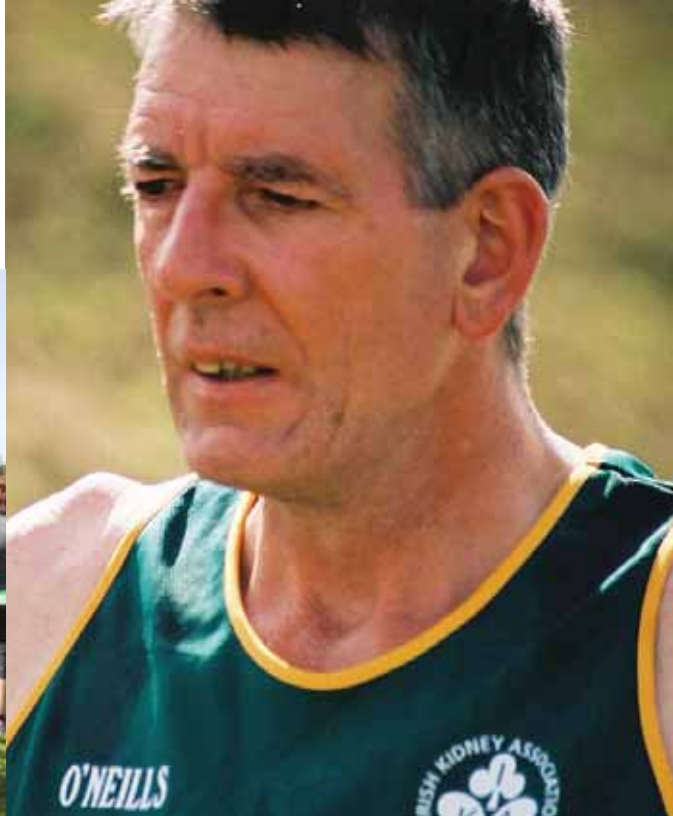
A few weeks ago, Ron made a beautifully framed presentation of his 2023 World Games athletics vest, along with one of his medals, to Tallaght University Hospital.

The gift was received by Prof. George Mellotte (Consultant Nephrologist). For Ron, it is a token

of his appreciation for all the care he has received from the nephrology team in Tallaght University Hospital and also to encourage those who feel unable to get fit and exercise that it is possible.



Ned Crowe



A FAMILY MAN, A FRIEND...

The ethos of Transplant Team Ireland has always been one of inclusion and sports for all, as the Irish Kidney Association (IKA) sees it as an important peer network as well as being a medium for the promotion of physical activity and sports.

It was with this in mind that Ned, Deirdre and their three boys, joined the Transplant Team Ireland family in 2006. At the time, Ned was on peritoneal dialysis.

Regular attendees at our team meet-ups in the ALSAA Sports Complex, next to Dublin airport, the family first travelled with the Ireland team to the 2006 European Transplant & Dialysis Games in Hungary.

In 2008, Ned and Deirdre made the national news as the first spousal living donation in the country with Deirdre donating a kidney to Ned. Happily, all went well for them both and they started a new chapter in their lives.

Coincidentally, the operation took place during Organ Donor Awareness Week that year and both Ned and Deirdre have been very actively involved in the promotion of organ donation ever since.

Ned and Deirdre embraced the 'extended family' ethos of the team,



and it was not long before they were watching out for, and supporting, new team members. Ned competed in badminton and on the track in the early days and was a regular doubles partner of team captain, Harry Ward.



Ned later went on to take up archery as an additional sport when competing at the British Transplant Games. Even though they did not travel to every international Games, Ned and Deirdre maintained their connection with the Transplant Team Ireland family throughout and could be relied upon for words of encouragement or congratulations to team members throughout.

With a great fondness for music and travel, Ned and Deirdre were able to enjoy life. Ned was well supported by his employer, Abbott Vascular in Clonmel, during his health journey and Deirdre trained as a nurse and went into dialysis nursing.

The Transplant Team Ireland family is a close-knit one. We get to celebrate many wonderful stories, but we also lose very dear friends such as Ned. It was a sad occasion attending Ned's funeral, but it was also an opportunity to show our support to his family and reflect on all the shared memories.

Whilst Ned is no longer with us, his life story will forever be a part of Transplant Team Ireland's history and Deirdre and their three sons will always be a part of the Transplant Team Ireland family.

- COLIN WHITE

Are you a Kidney BEAMer?



Kidney BEAM is an online service helping kidney patients take care of their physical and mental health. It offers you a way to improve your physical activity in your own home, in your own time and at your own level. It has a comprehensive library of videos demonstrating exercises from the very basic to longer and more challenging activities. There are also live online classes available.

Thanks to James Tracy and the **PUNCHESTOWN KIDNEY RESEARCH FUND (PKRF)** this service is open and **FREE** for all Chronic Kidney Disease patients and their families/carers in Ireland to use. Visit www.beamfeelgood.com/kidney-disease to find out more and register. Be sure to discuss the programme with your healthcare team.

At the beginning of October, the Irish Kidney Association hosted an introductory online meeting to explain more about the programme. You can watch it back here: <https://bit.ly/KidneyBeamIRL>.

It was pleasing to see one of the renal consultants from Beaumont highlighting the value of the **Kidney BEAM** programme at a patient education session in the hospital in October.



PUBLISHED RESEARCH

On November 13th this year, the results of the **Kidney BEAM Trial** were published in *The Lancet*. The full title of the paper is:

Evaluating the effect of a digital health intervention to enhance physical activity in people with chronic kidney disease (Kidney BEAM): a multicentre, randomised controlled trial in the UK.

"Our findings indicate that the **Kidney BEAM** intervention resulted in significant and clinically important effects of HRQoL (Health Related Quality of Life) when compared with usual care. Specifically, the **Kidney BEAM** intervention was effective for the primary outcome of mental health related quality of life and related secondary outcomes of physical function, symptom burden, social interaction, anxiety or depression, and patient activation."

WHY YOU SHOULD CONSIDER BEING A KIDNEY BEAMER

- The **Kidney BEAM** website has a video library with activities to suit all ages and abilities as well as access to live online classes and advice.
- The programme is being embraced by hospitals in Ireland.
- Research has been published showing the benefits available from engaging with the programme.

SUPPORT MAGAZINE AUTUMN PRIZE GIVEAWAY WINNERS

Thank you to **LANDMARK TECHNOLOGIES** for generously sponsoring **5 Amazon Fire Tablets** as a prize giveaway in the Autumn 2023 issue of *SUPPORT*. Congratulations to the winners:

Michael Enright, Ballylanders, Co Limerick; James Moore, Easkey, Co Sligo;
Darren Farrell, Crumlin, Dublin 12; Colette Fox, Donaghmede, Dublin 13;
Jackie Enright, Abbeyfeale, Co.Limerick

Family at Christmas

Christmas is my favourite time of year. I love the hustle and bustle, Christmas trees and sparkling fairy lights, I love the fire lighting, Christmas movies and making hot chocolate. My spirits lift naturally, and I look forward to spending time with loved ones, family, and friends.



By AOIFE SMITH
COORDINATOR OF
COUNSELLING SERVICES

From a young age we learn that Christmas is traditionally a time to celebrate, to enjoy the closeness of family and friends and to follow rituals that allow us to feel safe and secure in our connections. Unfortunately for many the reality doesn't match the harmonious dream we were told Christmas stands for. I'm very aware that Christmas can evoke many different emotions and that this very traditional view of spending time with family and friends can, for some, be a source of sadness instead of joy, and pain instead of happiness.

I hear people feeling overwhelmed, feeling pulled between different family members' expectations, feeling judged and having the feeling of being weighed down by a sense of

obligation to attend family gatherings.

I hear people dealing with strained family relationships whether that's with their family of origin, in-laws or within a blended family. I hear people dealing with isolation and I hear people dealing with grief after losing their loved ones.

Feelings of disappointment, sadness and anxiety can often dominate, making Christmas a very stressful rather than a joyful time.

So, what can we do to have a Christmas that is filled with more joy and less stress?

LET GO...

We don't get to choose our family and yet unlike any other relationship we are expected to find ways of making it work no matter what. The expectation that we 'should' be able to get along and have the perfect Christmas day, "because we are family," is very powerful in our tradition.

Sometimes, it is we, ourselves, who have to let go of this expectation.

Letting go of that need to have the perfect Christmas can allow us focus on whatever joy we do experience

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.

with family. We may not even notice the traditions that cause us some of the biggest stress, we do it because *"it has always been done like that."*

This year it might be useful to ask yourself *"if I didn't have to meet other peoples' expectations how would I like to spend My Christmas?,"* and maybe try including more of that!

ACCEPTANCE...

Accepting people for who they are can be hard, especially when their behaviour might cause an emotional reaction within us. Embracing the idea that we are not in control of what others do, or say, and that it's not our responsibility to change them, can be freeing.

The more we hold on to the hope that they might communicate better, share our opinions, understand our point of view, show love or respect, the more we sometimes set ourselves up for disappointment or heartache.

Being realistic and accepting relationships for what they are and accepting the differences in people, can lessen the impact the person has on you. Maintaining a healthy emotional distance might be what's needed to care for ourselves. You never know, practicing acceptance might bring a shift in a relationship in a way that surprises you.

LIMITS...

There are always limits to what we can tolerate, and setting clear and firm boundaries for our limits might be one of the most important things we can do to preserve relationships and our own energy to better enjoy Christmas.

Before Christmas it might be worthwhile asking yourself who are the people that cause you the most stress or what are the situations you find most draining? From there you can look at how you set boundaries for yourself.

Would it be helpful to set time limits on visits? Should conversations be restricted to certain topics? Would sitting beside certain relatives or friends help you to feel more comfortable?

What about an exit plan? Do you need to take your own car so you can leave when you are ready? Asking these questions and answering them gives an insight and understanding of what boundaries may need to be set in order to protect ourselves and leave ourselves feeling more relaxed.

ALLOW ROOM FOR GRIEF...

Christmas time can always bring

up memories of our loved ones who have passed. If you are grieving the loss of a family member, or friend, it may be helpful to accept that our emotional responses might be mixed and unpredictable at this time, and we might easily be triggered into bursts of emotions.

These are very normal reactions to loss. Understanding and allowing the space for this to happen acknowledges the person you loved, and you are missing. Memories of lost loved ones can live on in spirit within the traditions we use to celebrate Christmas.

ASK FOR SUPPORT...

We choose our friends ourselves. Our friends may form part of our close network who offer love and support. We may now consider them to be like family. Being proactive in reaching out to them for connection and support can break down the feelings of loneliness or disappointment and remind us that we are loved.

It is true that not everyone spends Christmas with family. Finding ways of making Christmas a more enjoyable experience is the aim and it is an aim I believe that is very achievable.



My hope for you all, however and with whomever you spend Christmas this year, is that you find your way to having the most relaxed and enjoyable time. Warmest and kindest wishes, Aoife x





Pictured (l-r): Ted's brother Paul Tobin, sister Sylvia O'Donovan (nee Tobin), Sabina and President Michael D Higgins holding a picture of Ted Tobin, Ted's niece Fiona O'Donovan, and sister Jean Keogh.



Ted Tobin

By GWEN O'DONOGHUE
and FIONA O'DONOVAN

Prior to becoming Ireland's first transplant recipient, 21-year-old **Ted Tobin**, an accomplished clarinet player from Crumlin in Dublin was gravely ill with end stage renal failure and given a bleak long-term prognosis. At that time, the medical staff considered transplantation, which had never been undertaken in this country before, to be a huge, but necessary, undertaking for any chance of Ted's survival.

Sixty years ago, organ transplantation was met with controversy and skepticism. Despite being perceived as unconventional at the time, it is crucial to acknowledge that patients grappling with chronic kidney disease had scarce treatment alternatives and survival chances minimal.

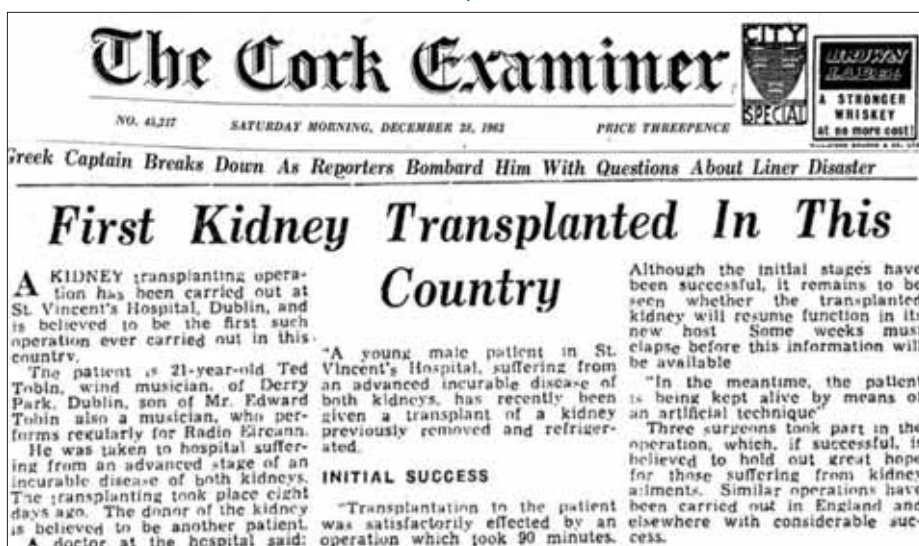
News of Ted's trailblazing

Remembering Ted's Trailblazing Transplant

On **December 19th, 1963**, a pioneering medical team from the old St. Vincent's Hospital on St. Stephen's Green in Dublin, together with a young Dublin man struggling with kidney failure, and a deceased donor, made medical history. It was on that landmark day, sixty years ago, that Ireland's first organ transplant, a kidney transplant, took place.

transplant sparked immense celebration, capturing the spotlight on the front pages of national newspapers, echoing the joyous occasion for the country.

The hospital released a press release over a week after the groundbreaking surgery disclosing that three surgeons took part in the operation. It stated, "A young male



First kidney transplanted in this country. Press cuttings courtesy of Irish Newspaper Archives.



The Tobin family at home in Dublin. Back row: Sylvia, Ted and Madeleine, RIP. Front, Paul, parents Eddie and Roseanne, and Jean.

patient in St. Vincent's Hospital, suffering from an advanced incurable disease of both kidneys, has recently been given a transplant of a kidney previously removed and refrigerated. Transplantation to the patient was satisfactorily affected by an operation which took ninety minutes. Although the initial stages have been successful, it remains to be seen whether the transplanted kidney will resume function in its new host. Some weeks must elapse before this information will be available. In the meantime, the patient is being kept alive by means of an artificial technique."

An unnamed doctor was referred to in the *Irish Press* newspaper (Saturday, December 28, 1963) declaring that the operation was a great new step forward in Irish surgery and held out tremendous hope for sufferers of kidney ailments.

Ted's parents Eddie and Roseanne expressed their appreciation to their son's donor's family, reportedly from the west of Ireland, for their selfless generosity and kindness. His donated kidney was a gift which gave renewed hope for himself and his family and the bright musical future that lay ahead for him.

Initially the transplant appeared to work, but complications and rejection set in. Sadly, Ted passed away two months later, on February 16th, 1964.

A press release issued by St. Vincent's Hospital stated: "The partial success and ultimate failure of this attempt emphasises both hope for the future and the difficulties involved".

The statement also added: "it was clear that the techniques in the operation gave hope to some other cases of otherwise irreversible kidney failure".

Ted's parents agreed to a postmortem to find out more about kidney failure which might help other kidney patients. Although the transplant was short lived, it helped advance medical knowledge and gave hope to both patients and the medical community about the possibilities of what ultimately could be achieved.

Throughout the course of six decades since then, dedicated medical professionals in Ireland have worked tirelessly to advance transplantation methods, making transplant surgery almost routine. Meanwhile, organ donors and donor families have continued to leave an indelible legacy of changing countless lives forever.

Ted's niece Fiona O'Donovan who underwent a kidney transplant in recent years, in the United States where she lives, said, "Ted, the courageous 21-year-old Dubliner, is an unsung hero who helped advance medical knowledge and inspired hope in many patients with end stage renal failure including myself and members of my family who ultimately followed in his footsteps."

Today close to 6,000 people in Ireland are enjoying extended life made possible by organ donors. Ted Tobin, along with his trailblazing transplant surgery team and donor, will be recorded in the annals of history, for initiating this profound legacy.

IKA SUPPORT WINTER 2023

ABOUT TED

Ted was one of five siblings brought up in Crumlin, Dublin by his parents Eddie and Roseanne Tobin. His father Eddie Tobin was known internationally as a brilliant five-string Banjo player and music teacher.

It was no wonder Ted's natural musical talent emerged from a young age and this was nurtured by his parents. Eddie was once visited by actor and comedian Billy Connolly who himself played the banjo.

Prior to his groundbreaking transplant, Ted was a student at the Municipal School of Music and had a scholarship awaiting him in London. He played the clarinet and won numerous musical accolades in his short lifetime.

Ted's youngest sibling, Paul, who lives on Dublin's southside, is also gifted with the 'music gene' as he is a talented pianist and double bass player. Paul performs with the Dublin Symphony Orchestra and the National Concert Hall's Blow the Dust Orchestra.

Paul, a retired lecturer in Electrical Engineering, still recalls when he was a young fellow helping his ailing brother.

Paul said; "Ted played with the popular Tommy O'Brien dance band. I remember how, when struggling with his illness he was very weak, I would accompany him to the bus he would take to perform at gigs at Clerys ballroom, I would carry his clarinet and other belongings and help him on board."

Continued next page...



Evening Herald November 8th, 1963, page 15. Ted (far left). Press cuttings courtesy of Irish Newspaper Archives.



Sisters Jean Keogh and Sylvia O'Donovan

Ted's sisters, Sylvia, and Jean, remember him with pride describing him as a lovely, unassuming young man with a great sense of humour, who was devoted to his music and his faith.

The two sisters attended the Irish Kidney Association's 38th Annual Service of Remembrance & Thanksgiving in October this year and took part in a symbolic procession, carrying a photo of Ted and a music book he had won.

In 2018, Ted's siblings had the honour of meeting the President of Ireland Michael D Higgins at a special reception at Áras an Uachtaráin to acknowledge the families and organisations who support organ donations.

President Higgins paid tribute to the Tobin family, in recognition of Ted's legacy.



Ted Tobin proudly holds the McCulloough Trophy he won for clarinet playing at the Dublin Feis Ceoil. Press cutting courtesy of Irish Newspaper Archives.



Writing to your DONOR FAMILY

A transplant recipient acknowledges their donor in their own special way. Sometimes transplant recipients make the decision to write to the donor family. This decision is a personal choice and you may have to re-write this letter a number of times before you feel it is right.

From our experience the families of organ donors welcome and really appreciate this token. It can be difficult to express your thanks when the donor family may still be grieving for the loss of their loved one. However, your letter can often provide them with some comfort, and consolation and help them cope somewhat better.

As a transplant recipient, you have the opportunity to write to the family of your donor through ODTI (Organ Donation Transplant Ireland) who facilitate written correspondence between recipients and donor families. You can also write to your family through your local recipient co-ordinator who will then forward this on to ODTI. All correspondence is completely anonymous and identities are kept confidential.

If you would like to write to the family of your donor, you may send a greeting/Mass card, note or letter. Please do not include any identifying details, i.e home town, phone number, etc. Do not seal the

envelope as the Organ Donor Co-ordinator will need to review your correspondence to ensure confidentiality. Outlined below is some general information you may wish to include:

- Your first name **only**
- Acknowledge the donor family's loss and thank them for their gift
- Interests and hobbies
- Marital status, family size, etc.
- How long you waited for your transplant and how it has improved your quality of life.

When sending your card/letter to the transplant co-ordinators, please enclose your name and date of transplant on a separate piece of paper so that the card can be forwarded to the appropriate family. Place your card/letter in an unsealed envelope. Then send both documents in a sealed envelope to:

**Organ Donor Co-ordinators,
Organ Donation Transplant Ireland (ODTI),
Ground Floor, Bridgewater House,
Bridgewater Business Centre,
Conyngham Road, Islandbridge,
Dublin 8, D08 T9NH**

This may be the most difficult letter you ever had to write, if we can provide any assistance in this process please do not hesitate to contact Fiona in the IKA or the Beaumont Hospital Transplant Coordinators or staff in ODTI.



WINTER giveaway

GIFT CARDS 3 x €150 All4One, 2 x €50 TESCO

Get ready to unwrap the magic of the season with our WINTER GIVEAWAY exclusively for SUPPORT readers. Five lucky competition entrants will win gift cards which will open doors to festive treats. From groceries to garb to gadgets, this holiday season let the joy of choice be your ultimate gift.

Three prize-winners will each receive a **€150 All4One gift card**, with thousands of choices of outlets on where to spend them. Also, thanks to our friends in **TESCO** there will be two prizes of a **€50 TESCO gift card** which can be spent online or in any one of their 166 stores nationwide, across all their departments including food & drink, lifestyle, homeware, electrical, stationery, toys, and fashion. Every little helps.

To be in with a chance to win, email robbyn@ika.ie with your name, address and phone number making sure to include **KIDNEY JOY** in the subject line of your email. The five winners will be selected at random. So go on, get your entry in, and you could be a winner! The closing date for receipt of entries is **Wednesday, 20th December 2023**.

SOCIAL MEDIA & COMMUNICATION

ILLUMINATE HOPE



By ROBYN BLACK



PURCHASE A LIGHT ON OUR VIRTUAL TREE OF HOPE

In the spirit of spreading joy, hope, and generosity, we invite you to participate in a unique and heartwarming initiative this holiday season. Imagine being able to contribute to the services of the Irish Kidney Association (IKA) while also creating a virtual spectacle of lights that symbolise the collective goodwill of a community. Welcome to our **Tree of Hope** campaign, where you can purchase a virtual light to illuminate our digital tree, with all proceeds going directly to support kidney patients.

In this digital age, we have the opportunity to make a real impact through innovative and meaningful ways. Our virtual tree allows you to purchase a light that will shine brightly in the online realm, representing your commitment to making a positive difference in the lives of others. Each light on the tree tells a story of compassion and solidarity, forming a beautiful tapestry of giving.

HOW IT WORKS

1. **Visit Our Tree of Hope website:** Navigate to our dedicated website where you can also explore the messages left on the virtual tree by others – www.ika.ie/hope
2. **Choose Your Light:** Select the light you'd like to purchase, and choose the colour you would like it to glow. Each light has a minimum donation of €10 but you can select more if you wish, allowing you the option to contribute more.
3. **Personalise Your Light:** Add a special message or dedication to your virtual light, making it a personalised gesture of kindness. Whether you're remembering a loved one, celebrating a milestone, wishing a patient improved health, or simply expressing goodwill, your message will be displayed alongside your illuminated light. You can even add a photograph!

SPREAD THE WORD: Share your participation in the **Tree of Hope**, with friends, family, and colleagues. Encourage them to join in this collective effort to brighten the lives of those in need. You can then send an email directly from your donation to let them read the message on your light!

THE IMPACT OF YOUR CONTRIBUTION

By purchasing a virtual light on our **Tree of Hope**, you are directly supporting the Irish Kidney Association and our vital initiatives. Your contribution could provide counselling for those who need it, fund advocacy campaigns, or offer essential resources to those facing challenging circumstances. Every light on the tree represents a beacon of hope and a step towards creating a better, more compassionate world.



Legacy Gifts and Wills: Crafting Your Timeless Impact

Have you ever thought of, or possibly considered, including a legacy gift in your will? Once family and friends have been looked after and all other important personal decisions have been made, deciding to include a legacy gift to a charity is a very special way to support a cause that matters to you in the future.

Legacy giving is a planned donation that designates a part of an individual's estate to a chosen charity. Large or small, every legacy is a generous gift of hope and trust in a better future.

We all know that having a will is very important for so many good reasons and we encourage you to take that first step in writing your will, by making an appointment with a solicitor. It is a private and personal decision.

We will never pressure you in any way and respect your right to change your mind at any time in the future. You don't need to tell us if you choose to leave a gift to us. You can find a solicitor near you at lawsociety.ie/find-a-solicitor

You can consult the Charities Regulator's website for the list of registered charities.

Should you choose the Irish Kidney Association, you will need the following information:

IKA INFORMATION

Full name of charity:
Irish Kidney Association

Registered address of charity:
Donor House, Block 43A,
Park West,
Dublin, D12 P5V6

CHY number:
No: 6327

Charity registration number:
20011260

Leaving a legacy to charity can offer many benefits beyond just the act of giving.

Here are some of the benefits:

- **Make a lasting impact:** Leaving a legacy gift to a charity provides the opportunity to make a lasting impact on society and support a cause you care about
- **Reduce taxes on your estate:** By leaving a gift to a charity, you can reduce the tax liability on your estate. In Ireland, approved bodies can claim tax relief for donations made to them by donors. The following donations to approved bodies qualify for tax relief: a minimum donation of €250 and a maximum donation of

€1,000,000 in any one year. Relief will be restricted to 10% of the donor's annual income if there is a connection between the donor and the approved body. An approved body may claim 31% tax relief on your donation.

- **Provide personal satisfaction:** Leaving a legacy gift to charity can provide personal satisfaction by knowing that you have helped make a difference in the world.
- **Enable long-term funding:** Legacies enable charities to plan long-term funding for their programmes, which can result in improved lives for people in need.

For more information visit our website:

www.ika.ie/leave-a-gift-in-your-will/

There we highlight and answer some frequently asked questions like: Will my gift be taxed?; What if I have already written my will?; and suggested wording for your will and more.

If you wish to speak in person with someone in our office, feel free to email info@ika.ie or call **01-6205306**.

We are always happy to talk to you. We are here to answer any questions you may have including leaving a gift, the IKA's work, how we manage our income and more importantly, how we would oversee your legacy in the future.

Last Will And Testament

OF

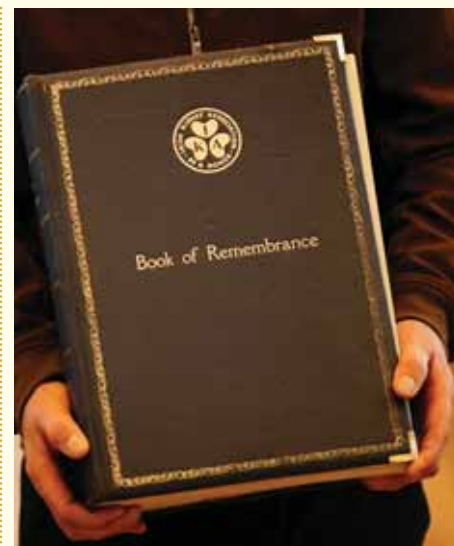


38th Annual Service of Remembrance and Thanksgiving



Cathedral of Christ the King
Mullingar, Co. Westmeath

38th Annual Service of Remembrance & Thanksgiving



For many donor families the unique Service serves as an anniversary to remember their loved ones, and allows transplant recipients the opportunity to honour and give thanks for the wonderful 'gift of life' they have received.

Individuals of all faiths, and non-religious including Humanist, came together to celebrate the 'gift of life'. During the special Service captivating music and song, were interspersed between poignant symbolic processions and meaningful scripture, reflections and expressions of gratitude, selflessness, and faith in humanity.

The **Transplant Team Ireland** sports team led the symbolic **Service of Light** ceremony by lighting candles, brought to the altar by the congregation. Handwritten names of deceased loved ones were received in baskets, held by two members of the team.

Following the Service, organ donor families viewed the name of their deceased loved ones inscribed in the **Book of Remembrance**, a roll of honour for organ donors.

A reception afterwards, in the neighbouring school, **Coláiste Mhuire**, provided another opportunity for the congregation, who had travelled the length and breadth of the country, to connect and share stories of their unique experiences, in a relaxed setting, while enjoying food organised by local caterer **David Smyth** and his very capable team, before making their journeys home.

School caretaker **Aidan Daly** was there, with his helpful and friendly disposition, to ensure the smooth running of the reception in two

Reigniting the Flame after three virtual years

On 14th October, 2023, the Irish Kidney Association's (IKA) **38th Annual Service of Remembrance & Thanksgiving**, returned to its in-person roots, after three years of virtual events, which were televised due to the COVID-19 pandemic. It was the first time since its inception, almost four decades ago, that the unique Service was held in the Midlands, and the second time only for it to be held outside of Dublin.

The event, dedicated to honouring

organ donors and allowing transplant recipients to express their gratitude, witnessed a strong turnout this year, with an estimated 1,300 people flocking to the magnificent **Christ the King Cathedral** in Mullingar. The large attendance reflected both the event's legacy and the pent-up longing for in-person interactions to pay homage to organ donors, and the desire to forge connections and convey gratitude was palpable.



different areas of the boys school.

The IKA's National Honorary Chairman, **Eddie Flood**, a kidney transplant recipient from Killucan in County Westmeath, performed the role of narrator at the Service with great aplomb. He played an active role in over half a year of careful planning leading up to the Service in his local town, as one of the six members of the **Organising Liturgy Committee**.

On the event day there was no scarcity of willing volunteers from the community of Mullingar and from Branches of the IKA who acted as stewards. The Cathedral staff were very accommodating, from the office staff to sacristans.

The two florists, **Jane Johnson** and **Una McCarthy**, made beautiful arrangements which adorned the altar.

Liturgy committee member **Ashling Hand**, who is also the Office Manager at Donor House, organised the production of the beautiful altar cloth and stoles for celebrants, which were tastefully embroidered with the forget-me-not flower.

The **Civil Defence** were on standby with paramedics and fortunately, didn't have to be called to action. The **Gardaí** were also dotted around the busy town, to direct traffic to numerous car parks all within a short walking distance from the cathedral.

At the Service Eddie Flood thanked the Catholic Bishop of Meath, Most Reverend Thomas Deenihan, Very Reverend Phil Gaffney and Chief Celebrant at the Service **Reverend Barry White**, for hosting the Service in the Cathedral, a magnificent masterpiece of divine



splendour. The IKA Chairman also thanked co-celebrant **Fr. Stan Deegan**, P.P. from his local parish, Killucan, as well as co-celebrant **Reverend Canon Alastair Graham**, Church of Ireland, **Evangelist Mario Martins** from Youth for Christ

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L-R: John Kelly, Joe Gavin, Johnny Gaye, Rosaleen Rabbeth, Catriona Williams, Bernie Gilleran, Martin McDonagh, Imelda Bardon, Rachel Raleigh.



Humanist Louise Burchall



Aoife Nally.



Choir members Ann Dunne and Marian Corbett.



Front: Choir members Christy Sheridan and Stephen Cummins.
Back: Brian Browne, Tony McNerney and Patrick Pilkington.

Ireland, and Louise Burchall, who represented the Humanist Association of Ireland.

In praising the music by uilleann piper Aoife Nally and the 50 strong members of Mullingar Musical Society, its musical director John White, and its organist Gerard Lillis, Eddie Flood said, "Your music beautifully enriched and reflected the solemnity and poignancy of this unique Service".

Eddie Flood also acknowledged, on behalf of the Organising Liturgy

Committee, all who contributed to the event including readers and those in processional roles, Transplant Team Ireland, volunteers, the Civil Defence and Gardai, staff at the IKA, members of the medical and nursing procession and Organ Donation Transplant Ireland (ODTI). ODTI distributed invitations to more than 3,500 families of organ donors.

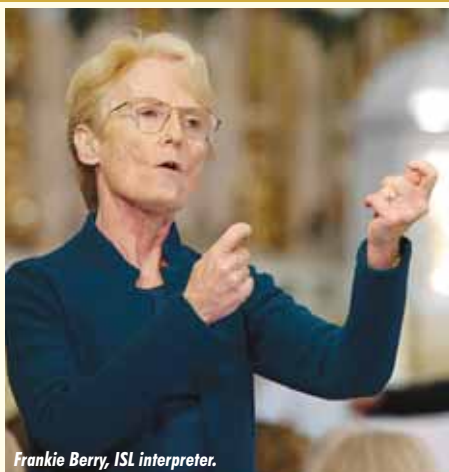
The reading from the Gospel according to Luke [10:25-37], which centres around the parable of the Good Samaritan, was read by Fr.

Stan Deegan. The Homily, which reflected the Gospel reading, was given by Reverend Barry White who said, "Today, as we remember the Good Samaritans among us, and those who have given the incredible gift of organ donation, we also honour those who received organs and their families, as well as the dedicated medical personnel who make these life-saving acts possible".

Ensuring inclusivity for the hearing impaired, the IKA engaged the



Mullingar Choral Society with conductor John White.



Frankie Berry, ISL interpreter.

services of **Frankie Berry**, an ISL interpreter, who communicated the Service through sign language.

Kairos Communications were present with camera men and a sound engineer to record the Service, which was later edited down to a 55-minute production, and was televised a few weeks later on RTÉ 1 and broadcast on RTÉ Radio One Extra on Sunday, 5th November.

The Kairos team included **Finbarr Tracey**, camera director, **Sebastian Pannakal**, location manager, **Adrian Cunningham**, sound engineer, camera operators **Seamus Callagy**, **John Fay**, **Gerard Doyle** and **Gini George**.

It is important to recognise the broader impact of the gathering for the Service. By bringing together the organ donation and transplant community for this event it is also contributing to a wider cause – raising awareness about organ donation for transplantation. The collective effort plays a significant role in fostering a culture of compassion and inspiring more individuals to consider the profound impact they can make through supporting organ donation.

When shared on the IKA's social



Dr. Catherine Motherway, ODTI.

media channels, 62,290 people were reached on **Facebook** with 2,845 followers engaging through likes, comments and shares.

35,600 tuned in to **RTÉ One** to watch the Service broadcast on Sunday, 5th November (12.59% of the available TV audience), 23,200 of the audience was from Dublin. A further 2,100 tuned in on **RTÉ One+1** an hour later. Afterwards, almost 400 people watched the Service on **YouTube**.

Ruepoint Media, a media monitoring company, recorded coverage about the Service in print media and online (national and local), which reached an audience of 4,611,867 readers.

The combined influence of the live annual event with its community involvement and its subsequent broadcast, along with engagement on social media, mainstream media, and platforms like TV and YouTube, while honouring organ donors, also created a compelling organ donor awareness initiative.

Taking part in symbolic processional and reading roles were courageous families of deceased organ donors, living kidney and liver donors and grateful transplant



Jean O'Reilly, organ donor coordinator, ODTI.

recipients of heart, lungs, liver, kidney, and pancreas, and a multi-organ transplant recipient mother.

Also participating were members of the wider organ donation and transplant community, including medical, surgical, and nursing staff.

Amongst the participants were **Dr. Catherine Motherway**, Clinical Lead, Organ Donation Transplant Ireland (ODTI) and organ donor coordinator **Jean O'Reilly**, (ODTI); Transplant Surgeon **Gordon Smyth** (Beaumont Hospital); **Laura Austin** and **Andrea Fitzmaurice**, transplant coordinators (Beaumont Hospital), and **Carmela Malapit**, a dialysis nurse at Midland Regional Hospital, Tullamore and wife of kidney transplant recipient Dante.

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Laura Austin, kidney transplant coordinator.



Cameraman Seamus Callagy.



Transplant Surgeon Gordon Smyth, Beaumont.



Carmela Malapit.



Jean Keogh and Sylvia O'Donovan with a photo of their late brother Ted.

The two sisters of **Ted Tobin**, a young man from Crumlin, Dublin, who made history when he became the first person to undergo a transplant in Ireland, which took place on 19th December 1963 (60 years ago), took part in an offertory procession. Ted's sister **Sylvia O'Donovan**, who lives in Abbeylax, Co. Laois, carried a photo of her late brother, an accomplished musician, to the altar, while sister **Jean Keogh**, from Enfield, Co. Meath, brought one of Ted's prized music books. Sylvia's daughter **Fiona** received a kidney transplant and Sylvia's late husband Michael passed away while waiting for one.

In the opening procession Army Sergeant **Lavinia Connell** from Athlone, whose late brother **John** was an organ donor eighteen years ago, following a fatal motorbike accident, carried the cross to the

altar. She was followed in the procession by **Leanne Walsh**, Tullamore, Co. Offaly, who carried a candle to the altar. Leanne's sister **Michelle Kavanagh**, a mother of two, became an organ donor in 2019. Also carrying a candle was **Declan Gorman**, Mullingar, who underwent a liver transplant in 2016.

Nine-year-old **Sam Kinahan** and his kidney donor father **Ivan**, from Baldoyle, Dublin, brought the medals they each won at the British Transplant Games this Summer, to the altar. Sam was one of five Irish transplant children, ranging in age from 8 to 16 years, who secured medals at the British Games this summer and his father Ivan, an accomplished runner, won a Silver medal in the 50m sprint event for living donors. The father and son duo received a round of applause from the supportive congregation.

Helen Nugent from Sutton, Dublin has attended the Service every year since her 29-year-old brother **Brendan Tyrrell's** organs were donated in 1987 following a road



Ivan and Sam Kinahan.



Sergeant Lavinia Connell.



Leanne Walsh and Declan Gorman.



Helen Nugent.



Kate Hynes.

accident, while **Gerard** and **Margaret Reidy** from Loughill West, Limerick have attended since their daughter **Miriam** passed away in 1997, when she was just 18-years-old, from a brain aneurysm.

Other parents of deceased organ



Gerard Reidy.



Michael Kerrigan

whose son **Cormac** died earlier this year after a cardiac arrest and would have celebrated his 18th birthday on the same week as the Service; and **Eddie Burns** from Macroom, Co Cork whose baby son **Harvey** died in a car collision seventeen years ago.



Eddie Burns.

donors who had reading or processional roles at the Service included: **Kate Hynes**, Thomastown, Kilkenny, remembering her son **Jonathan** who was just 22-years-old when he passed away, in 2012, with a brain haemorrhage; **Kevin Fitzpatrick**, Collinstown, Co. Westmeath whose beloved son **Darren** was 19-years-old when he passed away, under tragic circumstances in 2018; **Éilis Carlin**, Cloghan, Donegal, whose much loved son **Tony** was 25 when he passed away tragically in 2019; **Michael Kerrigan**, Muff, Co. Donegal,



Kevin Fitzpatrick.



Éilis Carlin.

Sisters **Lauren** and **Niamh Davis**, Athy, Co. Kildare, whose mother **Ashling** was a deceased organ donor, following a fatal brain haemorrhage in 2017, carried a large donor card to the altar.



Niamh and Lauren Davis.

Reading a prayer of thanksgiving for living donors was kidney transplant recipient and former Westmeath footballer **John Egan**, from Athlone, whose father-in-law donated a kidney to him in November 2021. John has since got married and recently become a proud father.

continued. next page



John Egan.



Sinead Lowndes



Laura Farrell, Moira O'Brien and Edel O'Brien Farrell

Reading a prayer of thanksgiving for members of the medical, surgical and nursing profession who work in organ donation and transplantation, was **Sinead Lowndes**, Dublin 15, who underwent multiple organ transplants including a liver, pancreas, bowel and part colon, and abdominal wall transplant in the UK in 2019.

Edel O'Brien Farrell, a well-known business woman in Mullingar, underwent two living donor kidney transplants. Edel's mother **Moira O'Brien** donated a kidney to her 45 years ago when she was just a child. This transplant eventually failed after four decades of successful longevity, and last year Edel's daughter **Laura Farrell** stepped up to donate a kidney to her mother. The three generations brought baskets of the IKA's emblem, the forget-me-not flower, the symbol of transplantation, to the altar.

Frances Little, Mullingar, who had been undergoing dialysis for 16 years before she underwent her life-changing transplant last year, also took part in the offertory procession carrying the IKA's SUPPORT magazine.



Frances Little.



*Sheila Gregan and John Moran
Transplant Team Ireland.*

SERVICE OF LIGHT

Transplant Team Ireland who took part in the Service of Light candle ceremony and included members of the transplant soccer team **John Brennan**, a heart transplant recipient from Tallanstown, Co. Louth; Dubliners **Jack Bentley**, a double lung transplant recipient from Lusk, and **Jayson Flynn**, a liver transplant recipient from Ballyfermot.

Other transplant athletes, who have participated in World or European Transplant Games, who took part in the candle ceremony included: **Aodhagan Cullen**, a kidney/pancreas transplant recipient from Loughduff, Cavan; and twelve kidney transplant recipients including: **Michelle Reinhardt McCabe**, Smithboro, Monaghan; **Sheila Gregan**, Nenagh, Tipperary;

*Front: John Brennan, Michelle Reinhardt McCabe.
Back: Finian Farrell, John McAleer,
Aodhagan Cullen, Harry Ward.*





Transplant Team Ireland members Pat O'Sullivan and Peter Heffernan lighting candles for the congregation.



Michelle Reinhardt McCabe, John Brennan, John Moran and Sheila Gregan.



Lenny Ryan

Teresa Smyth, Dunmore/ Williamstown, Galway; Finian Farrell, Mullingar, Westmeath; Patrick O'Sullivan, Mallow, Co. Cork; John McAleer, Antrim; Rose D'Alton, Cavan; and Dubliners, Team Captain Harry Ward (Baldoye), Ron Grainger (Castleknock), John Moran (Glasnevin), Peter Heffernan (Skerries), and



The Lowndes family, Sinead, Stuart and daughter Paige (age 5).

Lenny Ryan (Tallaght).

Condolences were offered by the IKA's Chairman Eddie Flood, just before the Service began, to the team and the family of **Edward (Ned) Crowe** from Tipperary, a past member of the team, who passed away unexpectedly just two days before the Service.

continued. next page

A Candle

Narrated by
Louise Burchall
Humanist Association
of Ireland

*A candle's but a simple thing
It starts with just a piece of string
But dipped and dipped with patient hand
It gathers wax upon the strand
Until complete and snowy white
It gives at last a lovely light.
Life seems so like that bit of string
Each deed we do a simple thing
Yet day by day if on life's strand
We work with patient heart and hand
It gathers joy, makes dark days bright
And gives at last a lovely light.*

SERVICE OF REMEMBRANCE & THANKSGIVING CONTD....

The IKA Liturgy Committee, who were involved in the organisation and planning of the event, comprised: Board members Cathriona Charles, (Leitrim), Joan Gavan (Tipperary); and National Chairman, Eddie Flood, (Westmeath); and also Ashling Hand (Dublin), Gwen O'Donoghue (Offaly), and Olive Cummins (Dublin).



The Liturgy Committee: (l-r) Olive Cummins, Ashling Hand, Cathriona Charles, Eddie Flood, Joan Gavan and Gwen O'Donoghue.



Sister Teresa Smyth and Geraldine Fahy, Galway.



Jason Hassett, Tipperary, his partner Sergeant Lavinia Connell, Athlone, (inset holding a photo of her deceased organ donor brother John), her parents Marie & Jerry Connell and son John.



Ciaran, Gerard and Margaret Reidy with Fr. Michael O'Connor, OMI Darndale-Belcamp, Dublin.



The Fitzpatrick family, Mullingar, Eric, his father Kevin and Kevin's mother Helen and his brother Frank and Kevin's son Sean.



IKA Branch representatives, Marie Fowley, Sligo; Francis Moynihan, Waterford; Ellen Flanagan, Kerry.



From Donegal: Aidan McGarry, Geraldine Clare, Fiona and Michael Kerrigan and Paul McGill.

How the Service of Remembrance & Thanksgiving began

The concept for the **Service of Remembrance & Thanksgiving** evolved when a grieving mother contacted **Lorraine Costello**, the Patient Support Officer at the Irish Kidney Association expressing her distress and sadness that her son's organ donation had not been acknowledged. At the time there was no system in place at the Old Jervis Street Hospital to acknowledge and thank organ donors and their families.

Lorraine Costello consulted with Phyllis Cunningham, the National Transplant Coordinator (both ladies are now retired), and it was decided that a Service would be held to publicly acknowledge and recognise the courageous generosity of organ donors and their families.

The inaugural Service, in 1986, had an attendance of 300 people in St. Mary's Church, Haddington Road, Ballsbridge, Dublin 4, and it has been organised by the IKA each year since then. The numbers have increased annually with a congregation in recent years, pre-pandemic, at Corpus Christi Church, Drumcondra, Dublin 9, close to 2000 people from all over Ireland and beyond.

The same calligrapher, **Annette Daly**, has been entering the names of organ donors in the Book of Remembrance since it was first introduced. Her continuous involvement provides a consistent and personal touch to each entry, making the act of inscription deeply meaningful and respectful.



Sinead McDonald, IKA, with John Boyce and his kidney donor daughter Trish.



Gerard and Deborah Burns, Cork.



Transplant Team members Finian Farrell and Aodhagan Cullen.



Rosemary Scally, Kilbeggan and Phil Coghlan, Mullingar, members of Mullingar Choral Society.



David Smyth Catering staff at Coláiste Mhuire: Emer Duignan, Michael Leonard, Miriam Canning, Kathleen Keegan, Ella Carroll, Cian Colgan, Ann Moran, Tracy Glynn Cully.



IKA Staff Members: Sinead McDonald, Sarah Buchanan, Aoife Smith, Colin White, Lisa Fitzgerald, Margaret Doyle, Jacqueline Moore and Deborah Cervi.



Nikki Philips, Dublin Midlands Hospital Group, Breda Doyle, South/South West Hospital Group, Karen Healy, RCSI Hospital Group, Gillian Shanahan, Saolta Hospital Group, Bernie Nohilly, University Hospital Limerick, and Dr. Catherine Motherway, Clinical Lead, ODTI.



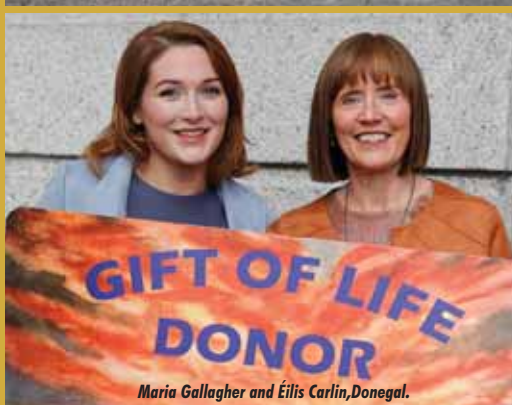
Laura Austin and Andrea Fitzmaurice, transplant coordinators, Beaumont Hospital, Kathleen Tyrrell, Jean O'Reilly and Dr. Catherine Motherway, ODTI, Carmela Malapit, Dialysis Nurse, Midland Regional Hospital, Tullamore.



The Kinahan family from Baldoyle, Ali, Sam, Ivan and Chloe.



Kate Hynes, Kilkenny, Helen Nugent, Dublin, Éilis Carlin, Donegal, John Egan, Athlone and Carmela Malapit, Co Offaly.



Maria Gallagher and Éilis Carlin, Donegal.



Leanne Walsh, Tullamore with her husband Dermot and children Jayden, Emma and Alex.

Aoife Smith

Receives prestigious Dublin Regional Award

Congratulations to **Aoife Smith**, the Irish Kidney Association Coordinator of Counselling Services, who was honoured with the Dublin Regional Award at the **Irish Association for Counselling and Psychotherapy (IACP) 8th Annual Conference**, which took place on 21st October, 2023 at the Royal Marine Hotel in Dún Laoghaire, Co Dublin.



Speaking regarding this year's awards, IACP Chief Executive Officer Lisa Molloy stated, "I would like to congratulate **Aoife Smith**, our Dublin Regional Award honouree, for her passion and positive approach to promoting the benefits of counselling and psychotherapy within her region and beyond. Aoife does outstanding work at the Irish Kidney Association (IKA) supporting patients, where she is a full-time counselling co-ordinator.

"Ms. Smith is a fully accredited humanistic integrative psychotherapist, working in private practice since 2008. She was also a specialist care representative in the healthcare industry for 20 years, during this time gaining invaluable experience working in chronic illness in the form of diabetes, respiratory diseases and pain management.

"These combined careers have given her a wide range of knowledge both medically and therapeutically, allowing her to fully support patients through her role at the IKA. Aoife brings to her clients and patients a professionalism that encapsulates warmth, generosity and a profound interest in the betterment of their

lives. Her commitment to this work is ongoing and of immense importance."

Following the award presentation, Aoife, from Blessington, Co Wicklow, commented, "I am very grateful and honoured to receive this award and I want to thank the IACP and the Dublin Regional Committee. As a therapist you really don't look for reward, you do the work because you want to support others, you want to give back, you want to build and create better services that are more accessible for clients – services that really meet their needs.

"I work with the Irish Kidney Association, and we provide counselling for kidney patients, their families and carers, as we recognise the impact of chronic illness on the household, not just on the patient. We aim to give as much support as we can to try to make a difference in

journeys that can be long and very challenging.

"To be recognised for the work that I do is really special. This award acknowledges the tremendous effort of every person I have ever had the honour to sit with and their commitment to change and growth, and for every person that has supported me on my own journey and for all the incredible therapists with whom I work. I am very thankful to be able to do the work that I do."

Carol Moore, Chief Executive, IKA, said, "The IKA is extremely proud of Aoife's accomplishments and greatly value her being part of our team, and her contribution to our organisation, dedicated to supporting the emotional well-being of renal patients and their families and driving the successful Peer Support volunteer programme which was established a year ago."

To be recognised for the work that I do is really special.



Manchester United mascot, Finn O'Shea, age 9, from Clonmel, Tipperary walks out with Tom Heaton of Manchester United before the pre-season friendly match between Manchester United and Athletic Bilbao at the Aviva Stadium in Dublin.
Photo by David Fitzgerald/Sportsfile

Nine-year-old **Finn O'Shea**, from Clonmel, experienced not one, but two unexpected life-altering surprises and blessings in 2023. The year came to a close on a high note for the **O'Shea family** with a very special Christmas, the first time in ten years away from the shackles of Finn's kidney disease, thanks to a life-changing transplant.

The O'Sheas share their story to support the Irish Kidney Association in raising awareness about organ donation.

By **GWEN O'DONOGHUE**

The Mighty Finn

The first momentous event came in February 2023, when, after young Finn's lifetime of sickness, he was called to CHI Temple Street for a kidney transplant. The successful transplant, made possible by a selfless donor family, marked a turning point in Finn's health, allowing him to embrace life and engage in activities and his passion for sport.

Six months after Finn's transplant he was overjoyed to be invited to walk out on the pitch, as mascot, with his Manchester United football heroes, when they played Athletic Bilbao at the Aviva Stadium in August.

Up until his transplant it had been a very difficult time for Finn and his parents, Eoin and Lisa, and older brother Rian (age 18) whose lives revolved around the uncertainties of his condition.

His mother Lisa outlined Finn's challenging health journey, "Finn was diagnosed, when he was six weeks old, with underdeveloped kidneys. His childhood has been marked with frequent



The O'Sheas at the Aviva Stadium. Rian, Finn, Eoin and Lisa.

hospital visits to Temple Street with plenty of overnight stays there and numerous medical challenges.

"He missed out on so much of a normal early childhood and lengthy absences from school and spending time with kids of his own age. Even though he couldn't enjoy playing, he loved supporting his dream team Manchester United on TV and has enjoyed watching hurling and football.

"For over two years, up until his transplant, he was connected to a dialysis machine throughout the night for ten hours at a time, for six nights out of seven nights every week.

"He struggled to keep food down and regular sickness and tiredness was the norm. A kidney donor has literally changed his life.

"His recovery post-transplant has been remarkable. He is now back at school enjoying spending time with his friends.

"There was huge excitement when he was given the opportunity to be mascot for his team, Manchester United, when they played in Ireland in August. It was a day he will never forget.

"His bedroom was once like a hospital with his



Finn O'Shea shakes hands with Athletic Bilbao players before the pre-season friendly match between Manchester United and Athletic Bilbao at the Aviva Stadium in Dublin. Photo by David Fitzgerald/Sportsfile



Finn with his older brother Rian.



dialysis machine and supplies for his nightly dialysis treatment, but now it is decorated with photos of his sporting heroes.

"When I think back on the challenging times, Finn's older brother Rian's support and understanding was unwavering. Hospital appointments and

prolonged absences from home became a routine part of our lives.

"When Finn was called for his transplant, Rian just got on with the task of sitting his mock Leaving Cert exams while the family rallied around his younger brother. Seeing my older son stay strong and selfless during tough

times makes me proud of him and really shows how resilient he was through the challenging times when Finn's illness demanded much of our attention and time. It makes you aware of the silent sacrifices made by the siblings of sick children.

"But the ultimate selfless sacrifice is that which organ donor families make to help families like ours and we will never forget their 'gift of life'."

"Eoin and myself are so grateful to the doctors and nurses at Temple Street who cared for him so well, and our incredible families for their unwavering support. To the Irish Kidney Association for supporting us and families like ours, and to the Make a Wish Foundation for making Finn's dream to be a mascot with the Manchester United team come through."



Eat Mindfully and Happy Christmas



IT'S CHRISTMAS!...A time of festive cheer and gatherings with family and friends. Along with this comes a varied selection of good food and drink. While following a renal diet be mindful of what you eat and drink. Know your own dietary guidelines – what to take freely and what to be careful of!

Be aware of the foods and fluids with higher potassium, phosphate, salt and fluid content. This will help control your blood levels. If you are not mindful this could result in high blood pressure, high potassium

levels, longer dialysis sessions, extra dialysis days (to control blood levels and remove fluid) and possible hospital admission.

Planning and preparation is key to every event: *Fail to prepare, prepare to fail!!* See the suggested Christmas menu below.

The traditional dinner for many at this time is Turkey and Ham (with stuffing). Have more turkey than ham, due to the salt content of ham. Steep the ham in water and boil it to remove excess salt.

The suggested Sage and Onion

stuffing recipe, along with low salt gravy, will help to avoid excess salt intake.

Be aware of your fluid allowance. Remember the obvious and not so obvious sources of fluid. Less obvious sources include jelly, ice cream, ice pops and custard.

If planning to have a festive drink consider spirits and mixers such as ginger ale and lemonade.

If you are unsure about your renal dietary guidelines please do speak with the Renal Dietitian and the Renal team.

'Eating the right foods makes you feel good from the inside out!'

Suggested Christmas Day Menu

STARTER

Melon
Carrot sticks with Cream Cheese
Egg Mayonnaise

MAIN COURSE

Roast Turkey and Ham* with Sage and Onion Stuffing or Roast Beef
Low Salt Gravy
Roast Potatoes* / Creamed Potatoes*
Vegetables* – Carrots, Brussel Sprouts,
Cranberry Sauce (small amount)

DESSERT

Trifle
Cheesecake
Jelly and Ice Cream

*Speak with your Dietitian about suitable cooking methods and refer to the Irish Kidney Diet website. If you have Diabetes you could choose sugar free jelly, sweeteners, low sugar and low fat varieties.

Check out www.irishkidneydiet.ie for more recipes and advice!

ROAST CROWN OF TURKEY WITH SAGE & ONION STUFFING

Ingredients:

Ready-prepared Turkey Crown, 4.5kg (10lb)

Butter, room temperature, 75g (3 oz)

1 garlic clove, crushed

Finely grated zest of 1 orange

Fresh flat leaf parsley, chopped -

1 level tbsp

Fresh thyme, chopped - 1 level tsp

For the Stuffing

Butter - 75g (3oz)

1 small onion, diced

Fresh sage, chopped -- 1 level tsp

Fresh white breadcrumbs - 175g (6oz)

Freshly ground black pepper - pinch (¼ level tsp)

Method:

Preheat the oven to 190°C/375°F/ Gas 5.

To make the stuffing, heat a frying pan and melt the butter. Add the onion and sage and cook for a few minutes, until softened but not coloured. Stir in the breadcrumbs, mixing well to combine. Season with freshly ground black pepper.

Wrap the stuffing in buttered tinfoil and mould into a large sausage shape.

This can be cooked in the oven for 25-30 minutes.

Next, prepare the Turkey Crown.

Cream the butter in a bowl until very soft and then add the crushed garlic, orange rind, parsley and thyme. Beat well, until thoroughly blended.



Gently loosen the neck flap away from the breast and pack the flavoured butter right under the skin - this is best done using gloves on your hands. Rub well into the flesh of the turkey, then re-cover the skin and secure with a small skewer.

Place the turkey crown in the oven and calculate your time. You should allow 20 minutes per 450g (1lb) plus 20 minutes, so a joint this size should take 3 hours and 40 minutes. Cover loosely with the foil and remove this about 40 minutes before the end of cooking time.

The turkey crown will cook much quicker than a whole turkey, so

make sure to keep basting.

To check if the turkey is cooked, pierce a fine skewer into the chest part of the crown - the juices should run clear.

When cooked, cover with foil to rest and keep warm.

To serve, carve the turkey crown into slices and arrange 125g (5 oz) on warmed plates with the cooked stuffing.

Per portion

This dish provides 5 protein exchanges.

Reproduced with kind permission from Recipe book.

LOW SALT GRAVY

Prep Time: 10 minutes Cook Time: 10 minutes

Ingredients:

Meat juices

Gravy browning - (a product that will add colour and flavour)

Cornflour

Herbs, spices, onions - for flavouring

Method:

Allow the meat juices to cool and skim off the fat. Thicken with cornflour. Add gravy browning until the gravy is the colour you want. Add flavourings as you wish.

Don't use stock cubes or gravy mixes.

Use gravy sparingly and include as part of your fluid allowance.



By **BRIEGE O'KANE**

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

INDI  **RENAL**
Irish Nutrition +
Dietetic Institute

Neighbours journey of Loss and Triumph

Fourteen years ago my family was blessed by the incredible generosity of an organ donor. My mother received a lung transplant. It saved her life and in a way mine too.

By EAVAN MURRAY

I will tell my daughter all about my mum. How special she was. How kind she was. How wise and brave and strong she was. And how she lived her life with grace.

Anyone awaiting a transplant needs those qualities. And my friend and neighbour Matthew McNeive who has been waiting many years for a kidney transplant has the very same inner steel.

Matthew grew up two doors from my family in Knock, Co Mayo. He received his first transplant within a few days of mammy. It was a remarkable coincidence. He was eleven and Mammy was nearly sixty. And they were firm friends.

Matthew was in the womb when doctors discovered complications due to a blockage in his bladder, which destroyed one kidney and damaged the other. He was just eleven when he ended up on dialysis in 2009, which was carefully managed by his mother Bernadette for five days a week, twelve hours at a time.

When he got the call for a kidney transplant nine months later, thanks to the generosity of a deceased donor he is profoundly grateful to – his life dramatically changed. Matthew recalls,

“From then, there was no dialysis and I could eat whatever I wanted. Which was amazing for an 11-year-old. I got to live fully.

“The next years including all of secondary school were brilliant, but, unfortunately the week I was due to start college, the kidney failed again.

“I was quite young when I was on dialysis initially, and I think all sick children are carried along by their mothers and I certainly was.

“My mother is fantastic. But it has been very hard on her. It's tough enough on two parents but she was on her own after my dad died when we were young. She looked after me and raised my brothers and kept down a job. She is amazing.



A lot of patients I meet are very down in the dumps and sad. That is so understandable. But I hope someone will see me and see that you can live a good life.



I loved her desperately and, had I lost her then, when I was still a young woman who needed her, I think the grief would have broken me. We got an extra 13 years and I am grateful for every day we shared.

She got to see me get married and to know and love my son. When she died in October 2022, I was four months pregnant. So, she never met my daughter. Passing ships. But I feel the three of us are connected in a way I can't explain.

Eavan on her wedding day with her mother Jacinta Murray.



"I was 20 the next time I had to begin dialysis so I was a lot more aware of what was involved. It meant no swimming, no long holidays unless you get dialysis abroad which is a bit of a pain. And then, when my kidney function went down, my diet became very, very strict.

"I can only have one litre of fluid a day and that includes coffee. If I want a coffee it can just be one. There are no potatoes, no tomatoes, no avocados and only two portions of fruit a day, no phosphates, no dairy, and then it's just tablets, tablets, tablets. But it's like having a shower every day, it becomes part of your daily routine."

What Matthew (now aged 25) has managed to achieve while undergoing dialysis every week for five years is nothing short of amazing. He recently graduated with first-class honours from TU Dublin in Clinical Measurement Science.

Matthew now works full-time as a Cardiac Physiologist at the Beacon Hospital in Sandyford.

"A lot of patients I meet are very down in the dumps and sad. That is so understandable. But I hope someone will see me and see that you can live a good life. I went to college and I'm holding down a job and I'm living my life as much as I can.

At Matthew's conferring, James, Matthew, Bernadette and Michael McNeive (Matthew's twin).



Matthew McNeive and his mother Bernadette from Knock at the launch of Organ Donor Awareness Week 2022.

"It was always very important to me to honour my original donor and their family by getting as much as I could out of life. I hope that anyone who has been diagnosed with kidney failure or renal disease knows that it doesn't always have to be life-altering and, for many, they can have a normal life. You can hold down a job and go to college.

"A lot of people maybe didn't expect me to work or go to college but that wouldn't be my mindset at all. I think it would be worse to be sitting at home everyday dwelling on your problems. Dialysis is not a life sentence, it just changes the routine of your life but it doesn't have to dominate your existence. You can live a full life. People say to me sometimes, they think I am brave, but I'm not really. I was born with these problems so I knew no different. I had no

other choice.

"My two brothers including my twin Michael were in college too and I wasn't going to let them get ahead of me," he laughs. "It was tough but I never at any point thought about giving up. I always thought every day I was getting closer and edging ahead. I knew when I qualified it would all fall right for me and it has. Keep going. Keep working and keep your mind alive and busy. That is so important for your mental health."

Matthew has a small request that people make their wishes around organ donation known to their families when they are home this Christmas.

"If, donating your organs to somebody else when you die so they carry on living is something you want to do, please just let your family know."

RENAL GENETICS

HISTORY

If you studied biology in school, you may remember **Gregor Mendel** and his work on 'recessive' and 'dominant' genes and the role they play in determining certain characteristics of offspring.

The big breakthrough in genetics came when the **Human Genome Project** was completed in 2003. This international scientific genetics project generated the first sequence of the human genome – providing fundamental information about the human blueprint, which has since accelerated the study of human biology and improved the practice of medicine. In September 2001 the cost of sequencing per genome was over \$95 million, last year, it was \$525 which has made it a lot more accessible to frontline medicine.



Prof. Peter Conlon.

By COLIN WHITE, NATIONAL ADVOCACY & PROJECTS MANAGER

I recently had the pleasure of sitting down with **Prof. Peter Conlon** in Beaumont Hospital, to discuss the role of genetics in kidney disease, and the work of the Renal Genetics Clinic in the hospital.

Over one third of people in Ireland who develop kidney disease will have another family member affected by kidney disease. Genetics plays an important role in the development of kidney disease.

THE IRISH KIDNEY GENE PROJECT

This was set up in 2014 to explore the links between inheritance and kidney disease. It is a collaboration

between the Department of Renal Medicine at Beaumont Hospital and Department of Human Genetics at The Royal College of Surgeons.

AIMS OF THE PROJECT

- To study the genetic causes of kidney disease
- To create a national database of patients affected by genetic kidney disease
- To operate a clinical renal genetics clinic, in Beaumont Hospital, providing diagnosis and genetic counselling
- To identify new genes in families affected by kidney disease.

POLYCYSTIC KIDNEY DISEASE

When we talk of kidney disease with a genetic origin, invariably, Polycystic Kidney Disease (PKD) is mentioned as it is one of the most widely known.

Approximately 85% of patients with PKD have what is known as PKD1 and, on average, this group is likely to experience kidney failure in their mid-fifties.

The remaining 15% of PKD patients have PKD2 and they may experience cysts on their kidneys but will likely not develop kidney failure. Gene testing allows healthcare professionals to predict the probable outcomes.



Prof. Peter Conlon with colleagues from the Renal Genetics Clinic in Beaumont Hospital.

Prof. Conlon has always been interested in the causes of kidney failure. With improvements in dialysis and the success of transplantation in treating kidney failure, there has been an increase in the number of people with a genetic cause of kidney disease having families of their own and this has led to the problem gene being passed on.

This highlights the importance of providing clinical support as well as carrying out research to better serve the patient community.

It is thought that ongoing research in genetics will, in the future, allow for 'personalised medicine', predicting disease development, and influencing decisions about lifestyle choices and tailoring treatment to an individual.

RENAL GENETICS CLINIC IN BEAUMONT

Prof. Conlon and his team at the clinic are interested in people with a family history of kidney disease amongst others. They operate a renal genetics clinic twice a month to help diagnose and manage those with hereditary kidney disease.

They are happy to see patients and family affected by kidney disease. His advice is that if this affects you, please ask your GP or nephrologist to send them a referral.

This is very much an evolving science with some genetic causes of kidney failure simply identified as a Variant of Uncertain Significance. However, Prof Conlon explained the value of engaging with the clinic and supporting research projects as there may be opportunities to re-examine data at a later date as science progresses.

There are now some treatment options for specific genetic causes of kidney disease – highlighting the value of engaging with the Renal Genetics Clinic. For example, The Food and Drug Administration (FDA) in the US granted Jynarque an orphan* drug designation in April 2012, for the treatment of autosomal dominant polycystic kidney disease.

Whilst there is not a treatment in every case, getting a correct diagnosis can help cut out some options and avoid potentially toxic treatments that are not going to work.

Normal practice is that when you are seen at the renal genetics clinic, a treatment plan is developed and you return to your own nephrologist who will continue to have responsibility for your care.

The renal genetic clinic is working towards having its own genetic counsellor to provide support to individuals and families in areas such as family planning and living donation.

FAMILY PLANNING

If you are considering starting a family, you should discuss it with your nephrologist. Genetic testing allows for predictive testing for family planning.

LIVING DONATION

If you have a genetic cause of your kidney failure, it is important that any family members offering to be potential living donors are evaluated at the genetic clinic to

ensure that they are not at risk of kidney failure themselves.

TESTING OFFSPRING

Prof. Conlon suggested that if a child is healthy with controlled blood pressure and good bloods, there is no need for gene testing. As they are entering adulthood is a better time to consider testing.

THE VALUE OF TESTING

Some of the genetic causes of kidney disease can cause other health issues so finding the presence of certain genes can help inform the overall management of the patient's health.

RESEARCH

We often think of our nephrologists as only being responsible for looking after the health of people with kidney disease. This opportunity to talk with Prof. Conlon has provided a timely reminder that not only do our nephrologists look after us, they are also involved in research of their own and keeping up to date with research done by others to ensure that they give their patients the best.

The Professor told me that there are some interesting new developments in the pipeline in relation to treatments for certain causes of kidney disease.

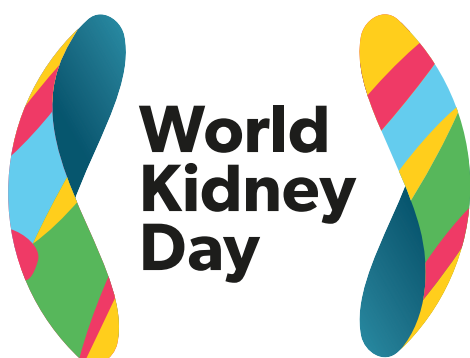
Thank you to Prof. Conlon for taking the time to talk about the role of genetics in kidney disease.

RESOURCES

www.beaumont.ie/kidneycentre-about-us-irishkidneygeneproject
www.pkdccharity.org.uk

www.alportsyndrome.org

* Orphan Drug status is granted to medicines which are considered vital in the treatment, prevention or diagnosis of life-threatening or chronically debilitating diseases, but are not commercially viable to produce because the disease is 'rare'.



World Kidney Day 2024

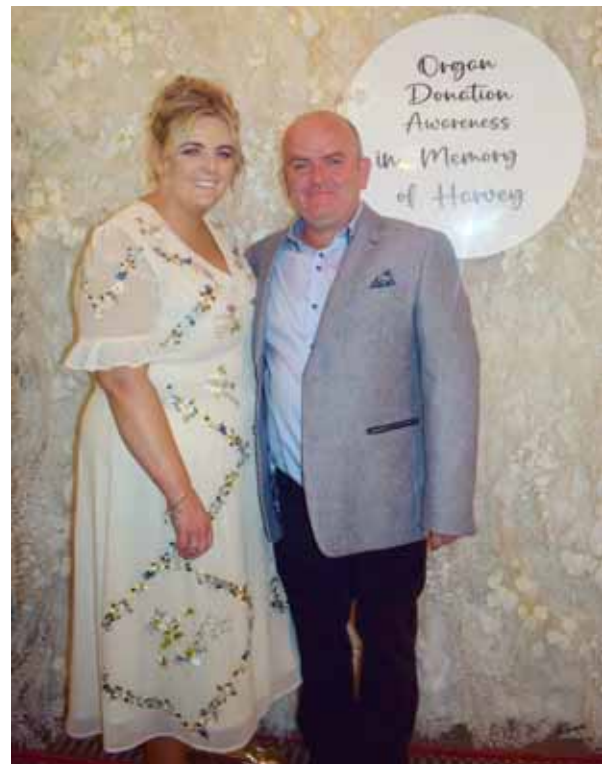
will be on

March 14th

It is an annual global campaign aimed at raising awareness of the importance of our kidneys.

The **Irish Kidney Association** uses the day to raise awareness about risk factors, preventive behaviours, and awareness about how to live with chronic kidney disease.

REMEMBERING HARVEY



Parents **Eddie and Deborah Burns** from Macroom, Co Cork, organised a charity fundraising event, to celebrate the life of their deceased organ donor baby son, on what would have been his 18th birthday.

Over €30,000 was raised with proceeds, divided equally, going to the **Irish Kidney Association** and the **Strangeboat Foundation**.

By **CWEN O'DONOGHUE**

Deborah Burns, miraculously survived the serious head-on collision that tragically took her baby son Harvey's life when he was just nine and a half months old, and while she was being cared for in hospital, her husband Eddie had to make the profoundly selfless decision to donate their son's organs.

To mark Harvey's milestone birthday on September 17th, 2023,

the family organised a 4-course gala dinner, which was held the night before, at the Castle Hotel in Macroom with entertainment provided by the very popular band *'Bog the Donkey'*.

A bumper prize draw with sponsored prizes including hotel weekends and other luxury items, generated additional funds.

In presenting cheques for the proceeds raised, to Eddie Flood the

National Honorary Chairman of the Irish Kidney Association (IKA) and Martina and Denis Goggin, founders of the Strangeboat Foundation, Deborah explained how significantly important it was for her and her family.

Deborah expressed her gratitude to everyone who contributed and made Harvey's 18th birthday celebration a resounding success.

She said, "our family was deeply

moved by the unwavering support of friends and the entire community of Macroom, to commemorate Harvey's life. The support we received for the Gala Night was incredible and we could have filled the function room four times over but for its capacity being limited to just 160 people.

"On the night organ donor coordinator Eimear Shields and her colleague Kathleen Tyrrell from Organ Donation Transplant Ireland gave a talk, inspiring everyone there, to go home and discuss organ donation with their loved ones.

"Our focus with the event was to increase organ donor awareness and encourage more people to carry organ donor cards and I think we achieved that.

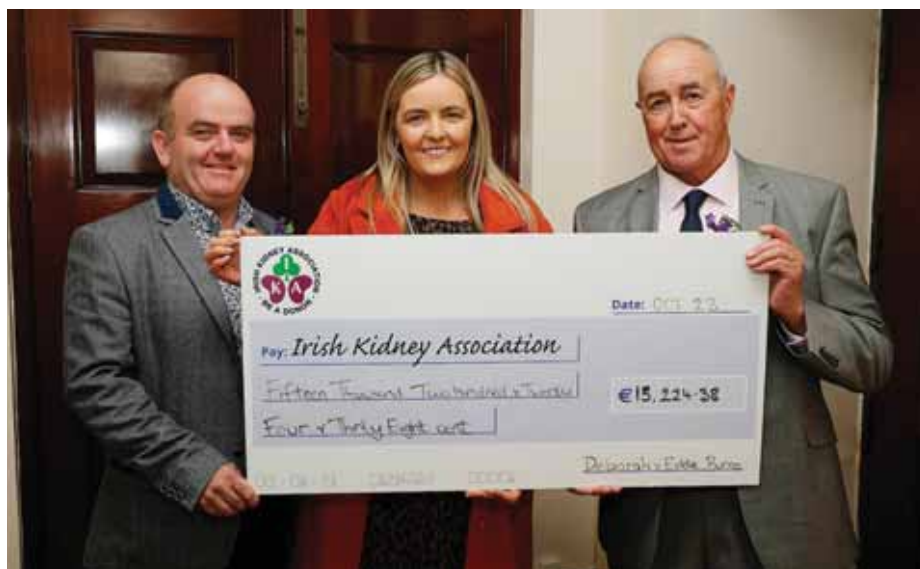
"The fundraiser, which exceeded all our expectations with more than €30,400 raised, is a testament to the collective compassion of the community. It is fitting that the funds are divided equally between two worthy charities, both dedicated to promoting organ donation and transplantation, ensuring that Harvey's legacy contributes to honouring organ donors and saving and improving the lives of others."

Thanking Deborah and Eddie on behalf of the IKA on receiving a cheque for €15,224.38, it's chairman Eddie Flood said, "As a kidney transplant recipient myself, I am humbled by your bravery and selflessness in continuing to help others following Harvey's organ donation. Through your generosity and the support of your community, Harvey's memory lives on, and his legacy of giving the 'gift of life' endures.

"Celebrating his birthday served as a beautiful tribute to his life cut short, but never forgotten, and is a reminder of the importance of organ donation in transforming tragedy into hope and giving life to others.

"We thank you and greatly value the funds you have raised for the IKA which helps us to continue to offer support to patients who have suffered organ failure and to promote the organ donor card."

Speaking on behalf of Strange Boat Donor Foundation, Denis Goggin said how much he, and his wife Martina, appreciated the extraordinary generous donation to



Eddie and Deborah Burns presenting a cheque to Eddie Flood, Chairman, IKA.



their Charity and to the 'Circle of Life' garden, and thanked the Burns family, their friends, and the local community of Macroom, for their remarkable support of the fundraising event.

"This support", he said, "is a testament to the courage of families who overcome the adversity of losing a loved one and be inspired by their memory to reach out so generously to society and to the cause of organ donation and transplantation".

Eddie and Deborah Burns were

among over 1,300 people who attended the IKA's 38th annual Service of Remembrance & Thanksgiving in Mullingar Cathedral on 14th October, where families of organ donors and transplant recipients came together to honour organ donors and celebrate the 'gift of life'.

At the Service Eddie participated in an offertory procession and both Eddie and Deborah participated in a symbolic Service of Light candle lighting ceremony remembering organ donors.

Our focus with the event was to increase organ donor awareness and encourage more people to carry organ donor cards, and I think we achieved that.



PLAY YOUR PART

Empower people to play an active role in their care

Motivated by his own personal journey after being diagnosed with kidney disease and undergoing a subsequent kidney transplant at Beaumont Hospital in 2017, **Tiberius Pereira**, has emerged as a passionate supporter of Health Literacy. Tiberius is now Patient Advocate for Patients for Patients Safety Ireland and a Peer Supporter with the Irish Kidney Association.

In this article he emphasises the importance of individuals taking charge of educating themselves about their health condition and self care, highlighting the key questions patients should ask of health professionals, to empower themselves in the process.



By **TIBERIUS PEREIRA**

When I was first diagnosed with kidney disease, I learned that seeking answers to some key questions about my health enabled me to absorb the essential information about my condition and the options available. The approach enabled me to gain control and be well-informed about my health condition.

As I continued on my health journey, it was extremely helpful and reassuring to have the specific kidney-related education resources from the Irish Kidney Association's website www.ika.ie under 'Patient Info' offering:

- Patient Guide books: clear explanations of the most important topics relevant to me
- Kidney Health

webinars and seminars delivered in partnership with Beaumont Hospital

- YouTube videos
- Counselling services
- Practical information

My kidney transplant in 2017 gave me a new lease of life. The Irish Kidney Association (IKA) resources are still available to help me to continue to manage my health. I am now a volunteer Peer Supporter with the IKA supporting other kidney patients.

I am also a Patient Advocate with Patients for Patient Safety Ireland (PFPSI) which was formed under a World Health Organisation programme ten years ago. We are a group of volunteers who have been working in a spirit of partnership and

collaboration with Irish health care for over ten years to elevate the voice of patients at every opportunity.

PFPSI is launching a major new initiative in recognition of the increasingly crucial role patients, families and caregivers play in the safety of health care. PFPSI is calling on our Government to implement a joined-up approach to health literacy in health care, education, and community settings, including through schools from an early age to empower people to engage and be active partners in their own care. This approach will produce better health outcomes, improve patient safety, and lead to a more efficient health service.

HEALTH LITERACY

Health literacy is defined as the ability to find, read, understand, and use health care information. This includes how to access and navigate the health care system. Health literacy is in effect, the corner stone of how people get the most out of health care information. This includes accessing our own health information and understanding how to understand and use it for our own benefit. Many of us rely on our health care professionals to also be our teachers when it comes to understanding health matters, without that input the health literacy of our population would be much lower.

Research by the National Adult Literacy Agency (NALA), confirmed by international studies, shows that patients who understand health information are:

- better informed about their health,
- have more effective consultations with their health care provider,
- are better informed about the medicines they are prescribed and
- have improved health outcomes.

According to NALA and confirmed by international reports from the World Health Organisation and others, when patients are treated as partners in their care and are enabled to be active partners in their own care, significant gains are made in safety, patient satisfaction and health outcomes. A health service with empowered and engaged patients is a safer and more effective service.

Furthermore, the EU



Health Literacy Survey (2021) showed that 43% of people in Ireland have 'limited' health literacy. This has great implications for the health service and practitioners and makes health literacy a key issue to delivering a quality service with patient safety as a core goal.

When a person is ill, they may not be in the state of mind to absorb information about their condition. PFPSI therefore

believes that health literacy is a life skill that should be taught through mainstream education, in our primary and secondary schools, during those early formative years. Timely health education has the potential to give people autonomy, to help them avoid some of the pitfalls and habits that ultimately lead to poor health. This coupled with health literacy would surely benefit society by creating informed people who become conscious consumers and wiser users of health care services.

Health care professionals often work in extremely

BRAN

4 QUESTIONS TO ASK MY HEALTH PROVIDER TO MAKE BETTER DECISIONS TOGETHER.

- | | |
|-----------------|---------------|
| 1. What are the | Benefits? |
| 2. What are the | Risks? |
| 3. What are the | Alternatives? |
| 4. What if I do | Nothing? |

stressful environments. Under pressure of a huge workload it can be hard to remember that there is an imbalance of power between health care professionals and the patient. This can have a range of negative effects on patients' experience of care. Empowered patients with the knowledge, skills, and confidence to engage with health care professionals will enable patient understanding and improved collaboration – leading to fewer patient visits and better outcomes.

Through health literacy patients can learn to help themselves thus take some of the burden off the health care services.

Two literacy programmes **BRAN** from Choosing Wisely UK, and **Ask Me 3** from the Institute for Health Care Improvement provide key questions as tools to assist in making better decisions and communication for patients and their families towards understanding their health conditions and becoming more active and knowledgeable in self-care.

ASKME3

Every time you talk with a health care provider
ASK THESE 3 QUESTIONS

1

What is my main problem?

When to ask questions

You can ask questions when:

- You see a doctor, nurse, pharmacist, or other health care provider.
- You prepare for a medical test or procedure.
- You get your medication.

2

What do I need to do?

What if I ask and still don't understand?

- Let your health care provider know if you still don't understand what you need.
- You might say, "This is new to me. Will you please explain that to me one more time?"
- Don't feel rushed or embarrassed if you don't understand something. Ask your health care provider again.

3

Why is it important for me to do this?

Who needs to ask 3?

Everyone wants help with health information. You are not alone if you find information about your health or care confusing at times. Asking questions helps you understand how to stay well or to get better.



Ask Me3
Good Questions
for Your Good Health

To learn more, visit ihi.org/AskMe3

Patients for Patient Safety Ireland (PFPSI) welcomes new members who can add fresh perspectives and a new energy to the group.
Contact info@patientsforpatientsafety.ie for more information.

A stellar inaugural year with widespread acclaim

It's hard to believe that we are approaching the first year anniversary of the opening of our **Peer Support Service**. For me this year has just seemed to disappear, but what an unbelievable year we have had in peer support.

The Peer Support Service opened in January 2023 and over the last eleven months we did our best to inform patients and their families that the service is now available.

We had meetings with consultants, doctors, nurses, and social workers, we attended conferences, spoke at conferences, Branch meetings and events, we put out social media posts, posters and leaflets in clinics and units around the country, all to ensure that you and your family know you can reach out and get support from other patients.

We all know that some of the best support we get is simply speaking to someone that has 'been there' and experienced it!

I won't lie, we had a few teething problems. When running on online service, technology can get the better of you and there were days that it certainly did. Thankfully, the problems were ironed out

Fiona Loud, Pisana Ferrari, Aoife Smith and Borislava Ananieva at the ESOT 2023 Congress, Athens.



By AOIFE SMITH
COORDINATOR OF COUNSELLING SERVICES

early in the year and the service is now running smoothly and going from strength to strength.

So much so, our service is really getting noticed. We have had colleagues, interested in setting up Peer Support Services, contact us from other Irish charities, Northern Ireland and even from doctors as far away as Australia to discuss our programme.

I was invited to speak on the panel of a workshop at the European Society of Organ Transplantation (ESOT) 2023 Congress in Athens. ESOT has been dedicated to the pursuit of excellence in organ transplantation for over 40 years. It is the umbrella organisation under which transplant

activities are structured and streamlined in Europe and worldwide.

It was a real honour to be asked to speak and it was because of our Peer Support Service.

The workshop was entitled '*Living your life after transplantation. Patient-centred approach and peer support network*'. The workshop acknowledged that the period following transplantation can bring many physical, emotional, and social challenges that transplant recipients need to navigate.

To discuss and address these challenges ESOT invited representatives from patient societies and associations, patient advocates, transplant professionals and allied

healthcare professionals to gather at the European Society for Organ Transplantation-European Transplant Patient Organisations (ESOT-ETPO).

The purpose of the workshop was to learn from the different voices in attendance and explore the power of a patient-centric approach and peer support networks in enhancing life after transplantation.

Panel discussion speakers included **Fiona Loud** (Kidney Care UK), **Pisana Ferrari** (patient advocate, Italy), **Peter Carstedt** (More Organ Donation, Sweden), and **Borislava Ananieva** (European Patients' Forum Youth Group, Belgium),

emphasising the value of patient support groups at both national and international level.

With a room full of attendees, I spoke about how the need for peer support services was first and foremost expressed by patients. They really wanted to talk to someone with lived experience of what they were going through.

I spoke about the establishment of the service and the importance of laying down a strong foundation, putting in the groundwork before the service opened, from planning documents, service needs, to recruitment and training, promotion of the service and ongoing support for the peer support volunteers in place.

This was all to ensure that the service that was in the process of being built was strong and supported for both the peers providing the support and for the peers that were going to engage with the support.

The fact that I was asked to attend this international conference to talk about the Peer Support Service highlights the interest and importance of having these supports. We are actually one of the first European countries to have a one-to-one peer support service available, so, we are leading the way.

The Irish Kidney Association couldn't have gotten here without **Patricia Bourke D'Souza**, our Peer Support Project Manager. Her guidance and commitment to the service has been unwavering. And of course, our peer support volunteers without whom the service wouldn't be what it is today.

This team are the pioneers of the IKA Peer Support Service and at the end of this first year, Patricia and I want to thank each one of you personally for your time, energy, and commitment to the service. It has been a real pleasure working with you all and very rewarding for us.

If you, or someone you know, feel you or they could benefit from this service please complete the Peer Support request form which is available on our website: www.ika.ie/peersupport/ or contact the Irish Kidney Association.

We look forward to hearing from you.

The Irish Kidney Association
gratefully acknowledges the support of
Punchestown Kidney Research Fund (PKRF),
the major funder for the provision of the
Peer Support programme.

Vanessa's experience

of our Peer Support Service

My name is **Vanessa Garrioch** and I am a 65-year-old woman living in Greystones, Co. Wicklow since 2008.

In 2013, my GP sent me for a routine blood test and following on from that test I was referred to the Nephrology Department of St. Vincent's Hospital for further investigation. This resulted in a diagnosis of chronic kidney disease and marked the beginning of my journey through renal failure.

At the time of my diagnosis, my kidney function was at 35% and I was told I would not need to go on dialysis for quite a while, all going well. Although I felt daunted by my diagnosis, I welcomed this re-assurance from my renal team and that helped to reduce my fear and anxiety around, and about my condition, and I could get on with my life. At present, my kidney function is at 8%.

In 2022, my fiancé, who was one of my main avenues of support, passed away, leaving me feeling alone on this journey. I felt I had not just lost a life partner but one of the only people who understood my condition and how it affected me, not just physically but emotionally and mentally.

Feeling a bit lost in my illness, I heard about the services of the Irish Kidney Association (IKA), while at one of my regular check-ups in St. Vincent's. One of the services they provide is a Peer Support Programme and I felt this might be an avenue for me to connect with someone living with, or having lived with symptoms/effects similar to, or the same as mine. While people can listen to you talk about what you are going through, they can never fully understand it, so for me to have a medium to talk to someone with a lived experience, like mine, was a wonderful opportunity. I made an application to the programme and was contacted quickly by the IKA team to discuss it.

Through a screening process, I was linked with one of the volunteer Peer Supporters who had been trained to work with people like myself, looking for encouragement and guidance on our renal journey. I found my supporter to be warm and friendly, patient and understanding of my situation, and happy to share the space provided through the IKA, to help me in any way she could through her own experience.

Through our sharing over the six sessions of Peer Support, I believe I have learned more about my condition and how I can manage it better in some ways. I have been on the transplant list since February 2023 and I am more confident that I can continue to do the best I can to remain as healthy as possible and stay hopeful that I will receive the call that all renal patients are waiting for.

For me the Peer Support Programme was an enjoyable, educational and informative experience and I would recommend it to any patient considering being a part of it.

KIDNEY TRANSPLANT RECIPIENTS

Do you struggle to take your immunosuppressant medications?
TELL US HOW WE CAN HELP!



By **CHEYENNE DOWNEY**

Research Assistant,
Department of Health Psychology

STUDY OVERVIEW AND AIM

The Health Psychology Research Team at Royal College of Surgeons Ireland (RCSI) want to hear from kidney transplant recipients who struggle or have previously struggled to take their immunosuppressant medications. By sharing your difficulties, we hope to identify the personal barriers you face around taking your immunosuppressants, to develop effective strategies that can **HELP YOU** and **OTHER TRANSPLANT RECIPIENTS** to take their post-transplant medications as recommended by healthcare professionals.

WHAT DOES THE STUDY INVOLVE?

The study involves engaging in a **once-off** and **confidential** audio-recorded 30-minute semi-structured interview with the study research assistant, Cheyenne Downey. You have the option of participating online via MS Teams or in person at the IKA Donor House, 43A Park West, Co. Dublin D12 P5V6.

Your data will be pseudonymised (i.e. will ensure you are not recognised) and your name will not be included in any academic publications derived from this research.

DO YOU MEET THE FOLLOWING CRITERIA?

- Adult, aged 18 years or over
- Recipient of a kidney transplant from a deceased or living donor
- Are a minimum of 6 months post-transplant
- Receive prescribed immunosuppressive medications
- Struggle to take your immunosuppressants either currently or in the past

WHAT DO YOU GET FOR TAKING PART?

After your semi-structured interview is complete, you will receive a €50 One4All voucher, in line with the Health Research Charities Ireland Guidelines. For in-person interviews, participants will be given the voucher immediately following participation. For online participants, a voucher will be posted to you.

CONTACT DETAILS

If you meet the above criteria and would be interested in taking part, please contact the study researcher,

Cheyenne Downey

✉ cheyennedowney@rcsi.ie

☎ +353 (0)86 030 2408

TRAVELLING ABROAD



Hi all,

For many patients who are on dialysis the ability to travel is important to their self-esteem and lifestyle. Working patients may need to attend business meetings or conferences. Older patients may have dreamed of travelling during their retirement. A family event such as a wedding, graduation or family reunion may require travel away, or maybe just a family holiday to relax and unwind because everyone deserves a fulfilling life.

- 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, E: deborah@ika.ie
- Patients need to give at least a minimum of 8 weeks' notice for holiday treatments abroad.



By **DEBORAH CERVI**
Holiday Co-ordinator

IKA HOLIDAY HOMES

Applications for patient holidays at our holiday centres in Tramore and Kerry in 2024 will open on February 1st. Application Forms will be available on our website under patient holidays where you can fill out our secure application form or visit <https://ika.ie/patient-holidays/>, or

alternatively you can ask your dialysis nurse in your local dialysis unit for an application form. You can also contact Donor House on 01-6205306, Email: deborah@ika.ie to request an application form.

Please remember to apply early. There is a huge demand for holidays each year, that far exceeds the supply, preference is given to first time holidaymakers.

Tramore holiday apartments will open from April to October in 2024.

Kerry holiday homes are remaining open through the winter. If you are interested in one of our homes in Kerry over the coming months, please get in touch.

I would like to wish all of you a happy and healthy Christmas and New Year.

Deborah

IKA SUPPORT WINTER 2023

Interested in becoming a
**Living Well
Programme
tutor?**



The **Living Well programme** is a six-session programme for people living with kidney disease. It can help people to develop the skills they need to become an active self-manager of their illnesses and live a happier and healthier life.

Topics covered include:

- Managing pain, fatigue and difficult emotions
- Nutrition and exercise methods
- Communicating effectively with your family and team
- Problem solving and decision making
- How to set manageable goals
- Managing your medications.

The programme is delivered by patients who have been fully trained to help others. The programme is currently delivered online but it is planned to provide physical courses again in the future.

So, if you would like to use your experience to help others and are interested in becoming a tutor, please email: peersupport@ika.ie to receive more details.

TAKING CARE OF YOU

Winter is here and we need to look after ourselves. In a recent letter to patient organisations, the HSE Chief Clinical Officer, Colm Henry, gives a very timely message about the importance of getting vaccinated".

"It is important that everyone, especially people living with long-term health conditions, older people and anyone who is at greater risk of infection to act now and seek to protect themselves by getting their vaccines."

If you have any concerns or questions about vaccines, please talk with your nephrology team.

As we learned during the pandemic, looking after ourselves is about more than vaccinations.



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

There is a growing number of lifestyle resources specific to people with kidney disease that can help you in living your best life.

- **Renal diet** – The Renal Interest Group of the Irish Nutrition & Dietetic Institute provides regular recipes for the *SUPPORT* magazine, and they also run the website www.irishkidneydiet.ie. Check out their seasonal recipes on pages 46-47.
- **Physical Activity** – Kidney BEAM is an online service helping kidney patients take care of their physical and mental health that is now

available free of charge to renal patients and their families in Ireland. Check out page 23 to find out more.

- **Mental Health** – When living with a chronic illness we can sometimes focus on our physical health and forget about our mental health. Read Aoife's article on pages 24-25 and check out www.ika.ie/counselling for more information on the supports available from the Irish Kidney Association.

Are you playing your part in taking care of you?



SUPPORT THE WORK OF THE IKA

Yes, I would like to make a regular donation by **STANDING ORDER**.
THANK YOU FOR YOUR GENEROSITY

STANDING ORDER REQUEST FORM

To: The Manager of _____
(Your bank's name and address)

I/We hereby authorise you to set up a Standing Order on my/our account as specified below: (Please print all information clearly)

Signed: _____ Date: _____

Address: _____ Ph: _____

PLEASE CHARGE TO MY / OUR ACCOUNT: Name of Account: _____

IBAN: Bank Identifier Code - BIC:

(These can be found, printed on your bank statement)

My regular ☐ Monthly ☐ Quarterly ☐ Yearly DONATION of Amount € _____

(Please tick as appropriate)

to start on Date: ____ / ____ / ____

AND CREDIT TO THE FOLLOWING ACCOUNT:

Name of account: **IRISH KIDNEY ASSOCIATION** at Bank of Ireland, College Green, Dublin 2.

IBAN NO.: IE06 BOFI 9000 1717 1934 35 BIC NO.: BOFIE2D

As long as you are a PAYE or self-employed tax payer, when you donate €250 or more in a year (€21 or more per month), the Revenue Commissioners will give the Irish Kidney Association CLG an extra rebate of 45%. For example, if you gave €250 in one year, the IKA would gain an extra €112, at no extra cost to you.



Please post to: **THE IRISH KIDNEY ASSOCIATION CLG, DONOR HOUSE, BLOCK 43A, PARKWEST, FREEPOST, DUBLIN, D12 P5V6**
(Please do not post to your bank)

CHARITY REG. NO. 20011260



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.**

CHARITY REGISTRATION NO. 20011260



MALIN TO MIZEN CYCLE

The Kilkenny Branch is deeply thankful to all the amazing cyclists that completed their Malin to Mizen tour and fundraised over €3,000 for the Branch and all our members!

On the first week of September the two organisers Declan Blanchfield and Nigel Hanrahan, along with 14 other brave cyclists, completed a Malin to Mizen cycle covering an amazing 900km in seven days!

The cyclists had a fantastic week of good weather, great views, and lots of peddaling to complete this amazing achievement!

We the Branch are in awe of their great feat and so grateful for the total of €3,380 raised. Well done, and a big thanks to everyone involved!

SEASON'S GREETINGS

At the time of this magazine going to print, the Kilkenny Branch committee was planning a Christmas lunch get-together for all of its members. We send our best wishes to everyone for a wonderful and joyful Holiday Season!

Special thoughts go to all the extraordinary hospital staff that are, and will be looking after us, working hard throughout the festivities. We are truly grateful and thankful for everything you do!

Happy holidays and happy New Year!

KILKENNY

By SARA SANTI

Malin to Mizen cyclists.



Cheque presentation to Kilkenny IKA branch members by the Malin to Mizen cycling group.

CONDOLENCES – Owen Hanrahan

It was with great sadness, on May 20th this year, that we learned of the passing of our good friend and fellow dialysis patient Lizzy (Elizabeth) Fogarty after undergoing surgery. Lizzy was the light of her family and friends, always had that big smile and a fantastic welcome and chat with whomever she would meet.

Often when we met Lizzy, even when she was very ill or in a lot of discomfort, she would always have a warm smile and plenty of banter, and for me that was something only

Lizzy could manage.

Lizzy was always the life of our meetings and get-togethers for the Kilkenny Branch.

We in the Kilkenny Branch would like to express our deepest condolences to Lizzy's family and friends, and to thank all the great professionals that cared for her in both the Kilkenny and Waterford dialysis units.



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).

SUPPORT DEADLINE

The deadline for submission of Branch notes for the **SPRING** edition of **SUPPORT** is **11th March 2024**.

GALWAY

By MICHELLE GERAGHTY



Photos courtesy Murt Fahy.

The Galway Branch would like to extend its congratulations to all involved in the maintenance and upkeep of the 'Circle of Life' Garden, located in the Quincentennial Park in Salthill, Galway, which was awarded the Green Flag award from An Taisce this year. The Green Flag Award is the international quality benchmark for the public green space sector.

The 'Circle of Life', National Organ Donor Commemorative Garden was opened by the Strange Boat Donor Foundation awareness group, which was founded by Martina Goggin and her husband Denis in 2014. It was inspired by the loss of their son Éamonn in a car accident in 2006 who then became an organ donor.

The garden is dedicated to all organ donors and their families and is a very special place of commemoration and thanksgiving for both families of organ donors and organ recipients across Galway and beyond.

Martina Goggin was joined by the



Mayor of Galway, Eddie Hoare, the Deputy Mayor, Donal Lyons and the hardworking park staff and volunteers for the raising of the Green Flag on November 1st.

The Galway Branch wishes to extend its heartfelt appreciation to the Goggins and all involved for their unwavering commitment and tireless efforts in making the 'Circle of Life' Garden such a special place for the people of Galway.

For more information please visit <http://www.organdonation.ie/circleoflife/garden.html>



DUBLIN NORTH

By COLETTE FOX

Greetings from Dublin North. Hope you are all keeping well.

It has been quiet for us. We returned to our meetings in September with a great speaker, Sarah Buchannan, the IKA's Support Centre Implementation Manager. Thank you Sarah, it was a very informative meeting.

At our October Branch meeting our speaker was Alison Larkin, Renal Counsellor/Psychotherapist at Beaumont Hospital. Once again a very informative meeting, with lots of engagement and questions put forward. Our thanks to Alison also.

At time of writing this article we were planning the Branch meeting for November and a Christmas meet-up in December.

We at the Dublin North Branch would like to wish you all a very Happy Christmas and New Year.



Anthony Hoban and some of his team presenting a cheque, for €13,060 to the Secretary of Galway IKA, the proceeds from their Charity Tractor Run, held last August.



In October, Mary and Peadar O'hlci made a presentation to third year nurse students in University College Galway, on living with a transplant. Mary spoke about the role of a partner when the other person is on dialysis, and how she adapted to life the changes brought about. Peadar gave an account of how he coped with dialysis and the great change in his life after transplantation.



Greetings from Kerry in advance of the festive season.

HOLIDAY HOMES

Great to see so many patients and families still availing of a break, in the holiday homes in Tralee and Killarney. We were delighted to host so many families throughout the year and we have met some wonderful, inspirational people.

Anybody interested in shorter breaks over the winter months, please contact Deborah at Donor House.

MUNSTER SUPPORT CENTRE

We are delighted that the new Munster Support Centre, adjacent to Cork University Hospital, is now open. This is a wonderful facility for patients and their families travelling to CUH. The Kerry Branch plans to hold fundraising events in 2024 to support this worthwhile project.

FUNDRAISER

A huge 'thank you' to the staff of Astellas Pharmaceutical company in

KERRY

By THERESA LOONEY

Presentation to Mary Marley, (l-r): Bridget Herbert, Ellen Flanagan, Brendan Herbert, Chairman, Mary Marley and Theresa Looney, Secretary, Kerry Branch.



Killorglin, who raised €2,065 through a fun ball run.

Little Cian Walsh, from Waterville, was the special guest on the day to set the balls off. We hope Cian will receive a successful kidney transplant in the future.



Cian Walsh

CONDOLENCES

The Kerry Branch would like to offer their condolences to families of patients and members whose loved ones have recently passed away. May they Rest in Peace.

CONGRATULATIONS

On a brighter note, we would like to congratulate Kerry patients who have recently received transplants, and for those waiting, we hope the call will come soon.

Congratulations to Elaine Dennehy, Renal Nurse Specialist at Kerry University Hospital, who received a Patient Care Award at a ceremony hosted by the hospital.

This was an award richly deserved for the wonderful care, compassion and dedication which Elaine extends to renal patients in her care.

Also, huge congratulations to Mary Marley, Nurse Manager of the Dialysis unit in Kerry University Hospital, who recently retired after being at the helm for many years.

Mary managed the unit since it first opened in 1995 and did a wonderful job looking after so many Kerry patients. She also extended a warm welcome to haemodialysis patients from around the country who were holidaying in Kerry.

At Mary's retirement party, our Branch Chairman, Brendan Herbert, made a presentation to her, as a thank you from the Branch and patients.

WEXFORD

By MARIA DONLON



Walter Kent, Pauline Atkinson, Eddie Kehoe, Liam Buttle and Marie Donlon, celebrating with Eddie, 40 years transplanted.

It is a year since Trish Boyce donated her kidney to her dad John, and to mark the anniversary Trish is doing 'Dip A DAY IN December' with all proceeds going to IKA and St Damians Ward, Beaumont Hospital. We wish her well with her fundraiser and best wishes to her and Dad John on their special anniversary.

Congratulations to Eddie Kehoe who celebrated 40 years transplanted earlier this year.

We lost one of our valued members recently, Thomas Cooney. We extend our sympathy to his family and our thoughts and prayers are with them at this sad time.



Eddie Kehoe cutting his cake to mark 40 years transplanted.

WATERFORD

By FRANCES MOYNIHAN



Frances Moynihan, Branch Treasurer, accepting a cheque for €1,800 from Colm Drummy, Comeragh Motor Club, proceeds from the annual Maurice Lenihan Memorial Run. Also in the photo are Ray Halligan, Branch Chairperson, Joe Moynihan, Branch member, his granddaughter Aria and members of the Maurice Lenihan Memorial Run fundraising committee.



Frances Moynihan, Waterford Branch Treasurer, Michael Browne, Sean Lennon, Colette Veale, Jason Dee, Máiread Coffey, Lia Murphy, Bob Murphy, Tony Coffey presenting on behalf of Kilrossanty Juvenile GAA, Ray Halligan, Sheila Murphy, Pat Whyte.



Ray Halligan, Chairperson Waterford Branch is seen being interviewed by reporter Kyle Butler, WLRFM.



Protestors standing in front of containers which occupy the space where dialysis parking was.
Photos Joe Cashin

Our Branch continues to be busy with fundraising activities including Vintage Car and Tractor Runs and Dublin City Marathon runners (photos in next edition). We are very grateful for the support of the Waterford community in all these events.

Our Treasurer, Vera Frisby, has retired from her role and we wish Vera all the best. We express our thanks for all she has done for the Branch at local level, as a member of the National Executive, and, last but not least, the stalwart work undertaken both by Vera and her husband Eddie at the Riverstown Holiday apartments.

PARKING ISSUES AT UHW

There has been no resolution to the ongoing parking issues for renal patients in University Hospital Waterford, despite the intervention of local public representatives, patients and the Branch Executive. We would hope for some resolution for the New Year as patients continue to experience difficulties in getting any space on the UHW campus and in some instances have to walk a considerable distance back to their cars after treatment. Truly a shocking situation for our patients.

BRANCH MEETINGS

We held our final Branch meeting



for 2023 on November 28th in St. John's Pastoral Centre, John's Hill.

We would be delighted to see some new members when we will resume meetings in the New Year. Perhaps make it a New Year's resolution to join us? We meet five times yearly and request, where possible that individuals make a commitment to join in fundraising activities for 8-10 hours each year.

SEASON'S GREETINGS

We wish all patients and families in Waterford, a peaceful Christmas, and for those on the waiting list for a transplant, we hope 2024 will prove to be your lucky year.



The Leitrim Branch wishes you all a Happy Christmas and a happy and healthy New Year.



NEW RENAL UNIT A PRIORITY



The need for a new renal unit at Sligo University Hospital continues to be a priority for the Branch. We have active lines of communication with the Department of Health, the Saolta Hospital Group and Sligo University Hospital management on the issue.

As reported in the autumn issue of *SUPPORT* there are several preliminary stages to the delivery of the project. These are ongoing but by their nature they take a long time and progress is very slow.

In the meantime, the hospital's General Manager, Grainne McCann, has written to dialysis patients outlining short-term measures being taken to relieve the space problem in the dialysis unit.

In her letter she said the capacity of the unit is inadequate. *"Over the past number of years the capacity of our renal dialysis unit is challenged in meeting the needs of our service users and we project that we will continue to need greater capacity in our unit, to accommodate the number of people requiring dialysis in the future".*

She informed patients that a modular building is being constructed in the courtyard area outside the unit. *"This will enable us to move some of our non-clinical areas out of the current renal unit which, in turn, will facilitate us expanding the clinical area and creating four new treatment stations".*

She went on to apologise to patients in advance for any inconvenience caused by the works. At time of writing, groundwork for the modular building is underway. Ms McCann informed our Branch of the plan before she wrote to patients.

SLIGO

By BRIAN McHUGH

WOMEN WALK FOR IKA

A group of ladies based on the Sligo/Leitrim border organised a 5k walk/run, in aid of the IKA, on November 26th.

We are grateful to the Killennumery Women's Group for choosing us as their recipient charity for this year's annual event which was in memory of Dr. Orla Banks.

Dr. Banks passed away, after a short illness last year at Sligo University Hospital, aged 31. The young doctor had worked in the paediatric department at the hospital.

There will be more on the walk / run event in the next issue of *SUPPORT*.

SUPPORTERS ATTEND OPEN MEETING

Our Branch hosted an open meeting for supporters and friends on November 8th. Patients, their family members, carers, friends or acquaintances of patients, were invited to the informal meeting in the Glasshouse Hotel.

On the night we outlined the range of services which the IKA provides to kidney patients and their families.

Some of those attending expressed an interest in becoming members and we gave them membership forms to complete.

INFORMATION MORNINGS

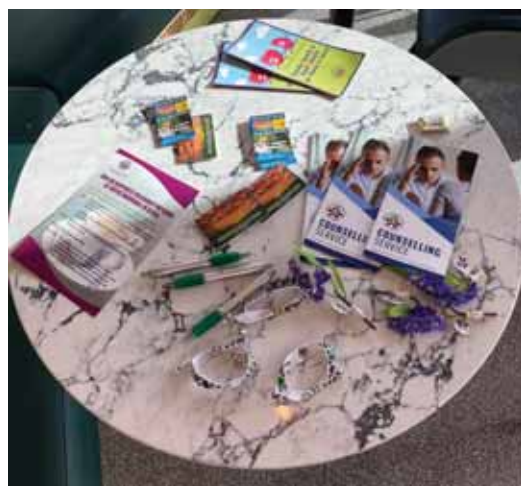
Our Branch is continuing with our twice monthly drop-in Coffee and Chat mornings with information on supports available for kidney patients.

Since earlier this year we have been holding them in the Glasshouse Hotel on the first Tuesday and Wednesday of every month from 10.30am to 12 noon.

All renal patients, family members, carers, and anyone wishing to know about supports available from the IKA are invited.

The information mornings are for all patients or family members, regardless of which part of their kidney disease journey they are on.

Having spoken to patients at these sessions, we are now



Part of the display at one of the Information mornings.

exploring ways of further improving this service in the New Year. Keep an eye on our Facebook and 'X' pages for news of any changes.

For updates please see our noticeboard in Sligo University Hospital located in the corridor to the left of the entrance into the dialysis unit.

OTHER MATTERS

CHRISTMAS TREATS: At time of writing, the IKA Sligo Branch is making plans for this year's 'Christmas treats' for patients. We try to bring some festive cheer to all who endure dialysis three times weekly. Last year we held free draws, visiting the dialysis unit five times over three days, with prizes for all shifts. We hope you enjoy our 2023 offering.

NEW MEMBERS: Our Branch invites new members to help with our voluntary work on behalf of kidney patients in Sligo. If you are available to help out in any way please contact:

Chairman: **Sean Fowley**
on Phone: **087-6211817** or
Secretary: **Geraldine McHugh**
Phone: **086-8142002**.

NOTICEBOARD: Our New Year's resolution is to regularly update the Branch noticeboard in Sligo University Hospital. It is located in the renal clinic area, in the corridor to the left of the door into the dialysis unit. Keep an eye on it for updates of activities.

OFFALY

By MARY YOUNG

CONCERT FUNDRAISER

A concert was held in 'Gracelands' Bar & Lounge, in Kilcormac, to raise funds for two charities, the Offaly IKA Branch and Midland United Powerchair Football Club. We are so grateful to Helen Clarke, her daughter Mary and Mary's partner Liam who worked tirelessly, along with their wonderful staff, to make the event such a success.

We also thank the various artists, led by Paddy and Michael Buckley and the Dunican sisters, who entertained the crowd at both the concert fundraiser and on the cheque presentation night.

A cheque for €2,600 was presented to each charity.

PEDAL THE PEAKS

The annual Pedal the Peaks Pat Colgan Challenge organised by the Tullamore Cycling & Touring Club



Dermot Glynn (centre) Offaly IKA, at the cheque presentation for Pedal the Peaks with members of the Tullamore Cycling Club.

takes place every August. Club cyclists cover many miles across the Slieve Bloom Mountains raising funds for charities in the process. Though bad weather prevailed throughout this year's event the cyclists weathered the storm.

We extend our thanks to Dermot Milner and Martina Martin and all the members of the cycling club and community who supported the event.

A cheque presentation was made to our branch representative Dermot Glynn.

MEMORIAL FOR JEROME BURKE

On Sunday, December 3rd a memorial Mass was held to honour the late Jerome Burke, in recognition of his dedicated service to the IKA and, in particular, the Offaly Branch for more than twenty years. The Mass was followed by light refreshments and friendly chat.

SEASON'S GREETINGS

We in the Offaly Branch send our very best wishes to all of the IKA members and their families for a peaceful Christmas.



Back row: Richard Young, Noel Troy, Mike Donagher, Helen Clarke, Catherine Donagher.
Front row: Tom Donagher, Conor Troy, Sean Donagher.



Mary Clarke, Richard Young, Mary Young, Jackie Masfield Hall, Helen Clarke.

Acknowledgements of Deceased Loved Ones

At a difficult and sensitive time, the Irish Kidney Association (IKA) wants to acknowledge the recent passing of your deceased loved one in a respectful and personal way. We receive requests for inclusion of expressions of sympathy and life stories in SUPPORT magazine, from families of loved ones who have passed away. To ensure consistency of approach, guidance has been developed regarding inclusion of obituaries based on the deceased's person involvement and role with the IKA.

The guidance allows for expressions of sympathy in other ways outside inclusions in SUPPORT magazine.

Please contact your Branch officer if you have any queries in relation to this guidance which outlines what can be included.



BRANCH MEETINGS

The Cavan / Monaghan Branch held meetings recently in the Cavan Crystal Hotel (Cavan) and the Westenra Hotel (Monaghan). It was great to see new faces coming along and getting involved in the Branch.

If you are interested in attending our Branch meetings going forward, please let us know.

SERVICE OF REMEMBRANCE & THANKSGIVING

Our branch was well-represented at the Annual Service of Remembrance & Thanksgiving at Mullingar Cathedral in October. Well done to its organisers – it was a very fitting tribute to organ donors

CAVAN/MONAGHAN

By KARL CRONIN



Laura, Geraldine and Eddie Askin present Paul Donohoe, Cavan/Monaghan Branch, with €5,000, raised by family and friends of the late Gary Askin.

and their families.

TABLE QUIZ

The branch hosted a very successful table quiz on Friday, 10th November in the Creighton Hotel, Clones. There were 15 tables in a hotly contested quiz and Quizmaster Paul Donohoe certainly put everyone to the test. Thank you to all who supported the

event, sponsored raffle prizes, and to all who helped on the night.

MERRY CHRISTMAS

We wish all our members, their families, and all the patients and medical staff, in the Cavan Dialysis Unit a very Happy Christmas and a Happy and Peaceful New Year.



Joy Kennedy, PRO, Paul Donohoe, Chairperson and Karl Cronin, Treasurer & Acting Secretary.



Table Quiz

DUBLIN EAST & WICKLOW

By RACHEL O'HORA



DUBLIN MOUNTAIN RUNNING CLUB (DMRC)

held a trail run in Glencullen on Saturday, 25th November in support of the Irish Kidney Association.

With two trails of 19km and 5km, they catered to entrants of a wide variety of trail running experience.

It was a fantastic event and great to get such continued support from the Glencullen community.

We are very grateful to DMRC and its members who have fundraised for us on several occasions thus far.

Their social media pages have lots of pictures and video footage from the event and they always welcome new members if the challenge appeals!

DONEGAL

By PATRICIA CALLAGHAN

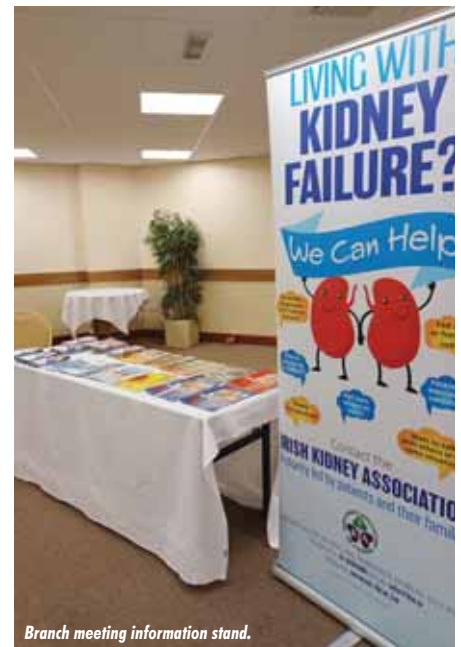


A cheque presentation for €3219.60 was made to the Donegal IKA Branch at McGeedys Bar on October 28th, the proceeds raised by Dunlewey Celtic Club fundraiser, in memory of Michéal 'Royce' Roarty who tragically passed away in 2019. Over the past three years almost €15,000 has been raised for the IKA in Michéal's memory.

The Donegal Branch had an information stand at a recent Branch meeting with books and posters available for members to take with them, which was well received.

Members are distributing these around their doctors' surgeries, and feedback from this is very positive.

Our Chairman Seamy has been in touch with the renal unit in



Branch meeting information stand.

Letterkenny Hospital and the renal nurses are very supportive of our Branch. Future planning is in place already, for next year, including having our Service of Remembrance.

Seamy also completed the Finn Valley remembrance 10k for his kidney donor, which was a great event.

We remember all our donors and donor families especially at this time of year.

We had a Branch meeting on November 21st in the Station House Hotel in Letterkenny and, as always at our meetings, we had a lot of positive discussions on the night. If anybody is interested in attending any of our meetings please contact our Branch Secretary Patricia Callaghan on 086-6073339. We would like to wish all our members and friends a very happy Christmas.



Seamy McDermott.



Noel McGeever and Seamy McDermott.

GER MULVEY TRACTOR RUN/CONDOLENCES

We would like to express our sincere condolences to Ger Mulvey and his family on the sudden death of his son Gavin who passed away on November 4th, less than two weeks after taking part in the Glencullen tractor run, in aid of the Irish Kidney Association, organised by his father Ger.

Our deepest sympathies to the Mulvey family on their loss. May Gavin rest in peace.

Held on October 24th, this was the second year for the tractor run to take place, with proceeds going to the IKA. Close to €3,000 was raised this year.





SERVICE OF REMEMBRANCE & THANKSGIVING

This year's Service was held at the beautiful Cathedral of Christ the King in Mullingar which was an ideal location. Having spoken to many donor families on the day they all said the Service was very special, while many mentioned that they were glad to see the Service being held outside of Dublin.

Many thanks to all those on the IKA Liturgy Committee and all at Donor House for organising this very special Service. For all who have received the precious gift of a transplant, the Service is truly special.

50TH BIRTHDAY CELEBRATIONS

The Clare Branch send their congratulations to Eleanor McLoughlin, from Killaloe, who recently celebrated her 50th birthday in the Killaloe Spa Hotel.

Eleanor, who is vision impaired, received a kidney pancreas transplant seventeen years ago, having endured three years on haemodialysis at UHL where she received wonderful care from the nephrologists and staff.

Eleanor is truly grateful to her donor and the donor family for this precious gift. She always remembers her donor and sends a thank you card and letter to her donor family

CLARE

By PEGGY EUSTACE



(L-R): Mary O'Loughlin, Monica Moloney, Carol Hanley, Eleanor McLoughlin and her mother Margaret enjoying Eleanor's 50th birthday celebrations at the Killaloe Spa Hotel.

each year, to let them how she is doing.

It's the gift that changed her life as she continues to have a positive outlook. Eleanor and her friend Monica Moloney took part in the IKA West Clare Walk for many years raising much needed funds for the Association.

THANK YOU

Thanks to the Branch members in Kerry and Waterford for giving a very warm welcome throughout the year to all home dialysis patients, transplant recipients, and their families at the IKA holidays homes in Tramore, Tralee and Killarney. We greatly appreciate the wonderful work that you do.

SYMPATHIES

We extend our sincere sympathy to the families of the late Jimmy Moroney, Ennis; Sean Moloney, Kildysart; and Alice Donnelly, Lissycasey. May their gentle souls rest in peace.



Peggy Eustace with Eoin Madden from the Galway Branch met following the Service of Remembrance & Thanksgiving in Mullingar.

SEASON'S GREETINGS

Christmas wishes to our renal patients, transplant recipients, their families, the medical and nursing staff of the renal units, Branch members, volunteers, all at Donor House, agus ar cairde go leir san IKA. Nollaig Shona agus bhliain nua iontach. Enjoy the festivities.



ORGAN DONOR AWARENESS WEEK 2024

will take place from

20th – 27th APRIL

If you are organising an activity to mark this campaign, or have an inspiring personal story about organ failure, organ donation, or transplantation, that you'd like us to share with the media, (which hasn't been widely publicised before) please get in contact by phoning Donor House or send an email to info@ika.ie

We hope you are all enjoying the unseasonal pleasant winter weather we have been having.

ANNUAL MASS

On Sunday, November 26th we held our annual Mass again back in its traditional home of the Chapel in Cork University Hospital. This year we were honoured to have the Bishop of Cork and Ross, Fintan Gavin, celebrate the Mass with us.

We were delighted to see the large congregation returning to the church as due to COVID restrictions over the last few years, it had been a long time since we had all got together in person.



The Cashmans with Bishop Gavin



Amanda, Tony, Ray, Maria, Maria.



Juliana, Denis, Sheena, Pat

The Curaheen Choir provided the songs and the music on the day. A special thanks to all that helped put the Mass together and to those who brought up gifts and said prayers.

As usual light refreshments were served in the Fastnet Restaurant afterwards.

MUNSTER SUPPORT CENTRE

For those of you that attended our annual Mass and visited the Munster Support Centre afterwards, you will have seen the progress that has been made. The Centre opens to patients and families in December. Photos and information about the Centre can be seen on pages 6-9 in this edition of *SUPPORT*.

Anyone going to clinic is welcome to drop in and see the Centre, you might even get a cuppa. It is located just a couple minutes' walk away from the hospital entrance at 12 Wilton Avenue, Bishopstown, Cork, T12 DRP8.

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 tel. 086-2755754.

BRANCH MEETINGS

Our monthly Branch meetings are for you, the members, but they have not been well attended since COVID. If they are not supported and attendances continue to be low, we need to know from you, the members, what you would like the Branch to do.

We plan to hold a meeting on the first Tuesday in February. If there is a particular speaker or subject you wish to talk about please advise the Branch through the Branch mobile number or through the WhatsApp group.

We have a very active WhatsApp group and if you wish to keep up to date with the Branch news. Please ask to join the group through the number above.

A tribute to the late **Isabel Terry**, RIP, will feature in the Spring 2024 issue.

Thank you from the Officers of the Cork Branch.



Too much for James!



Bishop Gavin with the O'Sullivan family.



Pat, Allison, Matt, Celine



Renal Nurses Theresa and Phil.



Hugh, Eoghan, Bishop Gavin, Siobhan



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