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AUTUMN 2023



AUTUMN

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Editorial



Carol Moore, Chief Executive, IKA



Irish Kidney Association CLG

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Welcome to our Autumn issue of **SUPPORT**.

While there was a normal seasonal dip in uptake of some of our services during the Summer, demand continues to increase as the cost of living puts so much pressure on those affected by kidney disease including our members. We continue to raise awareness of the services we provide to members, patients and their families.

I, and the Chair, Eddie Flood, had a meeting with the interim Beaumont Hospital CEO, David Sweeney, who has confirmed, on behalf of the hospital, their intention to plan for the return of the Renal Support Centre (RSC) to us. This is very positive news. The issue has consumed considerable Board and Management time and is a top priority.

We can now look forward to beginning the process of re-establishing the RSC for the purpose for which it was originally intended and hope to establish a clear definite timeline with Beaumont for the return of the Centre in the near future.

We are acutely conscious of the needs of our patients, and the impact the unavailability of the facility has had on you during this time. We are also very aware of the patience and forbearance you and your families have displayed throughout this challenging

period.

I would like to extend my appreciation to you, and to also request that you continue to extend your support to us as we work to resolve this situation as soon as possible.

In the meantime, I would also ask you to direct any media enquiries you may receive from journalists on this issue directly to the CEO, Carol Moore.

I am pleased to write that building work is now nearing completion in the Support Centre in Cork. A big thank you and well done to all those involved.

Reflecting the fact, that patients from the wider Munster area will use the Centre, it will now be known as the Munster Support Centre. Full report page 17.

The six joint seminars between the IKA and B. Braun, focusing on different topics concluded during the autumn and the feedback from the participants was excellent. Full report on page 40.

We are delighted to report on further important partnerships we have agreed, which will really help patients with their daily lives.

Thanks to the support of James Tracy and the PuncHESTOWN Kidney Research Fund, (PKRF), Kidney Beam, an online physiotherapy led exercise programme for kidney patients, is being made available free of charge to kidney patients.

We know physical exercise is so important to our wellbeing, with



CHARITY REGISTRATION NO. 20011260

FRONT COVER

Jessica Stone and her husband Michael and daughter Ellie on the first day of school for Zack, a milestone made possible by the father to son living donor kidney transplant he received last year.

Photo: John Allen

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expressions like “move it, or lose it” well known. This means unless we move our body and joints regularly, we lose mobility. Exercise is also very helpful for supporting good mental health.

We are holding an online Zoom session on October 5th to tell you more about this important service and we really hope as many of you as possible will attend. It does not matter what level of fitness you have as the programme is designed for your individual needs. Full details on page 31.

Another new very valuable partnership is with the National Concert Hall which will provide a fun music programme where no previous experience is needed.

Two important milestones have been achieved. Firstly, we will have our first formal programme for young people and secondly our first formal programme in music. More details on page 30.

We hope you enjoy reading our cover story on pages 4-6 about a family's joy as their young boy began school in September, having undergone a kidney transplant last year thanks to his donor father.

In common with many other charities, we continue to experience staffing shortages. We are now recruiting for two part-time receptionists as well as a

Volunteer Manager and Organisation Development Manager.

A part-time fundraising contractor, Sinead McDonald, has started working with us, to help guide, support and increase our income through fundraising and other means.

One of Sinead's first engagements with the IKA was helping out at our information stand at the Fleadh Cheoil, a huge organ donor awareness opportunity with close to half a million people attending the festival. See page 14-15.



Sinead McDonald (right) having fun with some patrons at the Fleadh Cheoil.

You can read the touching story, on pages 10-13, of a young man with renal failure who left a lasting legacy through a generous bequest to the IKA. If you're interested in leaving a meaningful gift in your will please visit our website to learn more, <https://ika.ie/leave-a-gift-in-your-will/>

It is likely the Human Tissue Bill will come back to the Dáil shortly with a view to passing all stages in the Oireachtas in the Autumn.

The Department of Health has responded to our proposed changes. The Irish Kidney Association will continue to advocate for changes to improve the legislative landscape for organ donation and transplantation across the country.

One proposed amendment, in particular, is the conducting and reporting of an annual potential donor audit on a statutory basis (report pages 8-9).

Finally, planning for the Service of Remembrance and Thanksgiving in Mullingar is nearly complete. This year, to ensure a pleasant experience for everyone, and reduce food waste at the reception afterwards, we are asking people to register their interest in attending. See details on page 7.

Always in our thoughts is our gratitude to the families who, in their darkest moments, selflessly donate their loved ones organs to give the 'gift of life' to others.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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Family celebrates first school day for transplant son

The first day of school is a milestone that carries emotions for every family, but for one family in Cork, this day held particular significance. Jessica Stone was filled with joy as she watched her five-year-old son Zack, walk hand in hand with his older sister Ellie (7) and their father Michael, whom Zack had received a donor kidney from less than a year before. That milestone event on Tuesday, August 29th, 2023 symbolised a journey of resilience and hope, for a cross-cultural family, who had chosen Ireland as their home, more than a decade ago.

By GWEN O'DONOGHUE

Photos by JOHN ALLEN

Zack with kidney donor dad Michael.



The journey to this moment had been far from smooth. Zack's mother, Jessica Stone, originally from East Sussex in England, reflected on the significance of the short half mile walk they took from their home to the school, Mallow CNS. Jessica described the challenges they had faced since Zack's birth. "Soon after his arrival, he fell seriously ill and had to be urgently transferred from Cork University Hospital to Temple Street Hospital. He was diagnosed with Acute Renal Failure, with one Multicystic Dysplastic Kidney and Renal Dysplasia, conditions which meant his kidneys hadn't developed properly and a kidney transplant was inevitable. This marked the beginning of a series of hospital stays and medical challenges, turning Temple Street Hospital into a second home for Zack".

For Michael, a native of Strasbourg, France, he described how "seeing my son start school is a testament to our family's

journey for the past five years. Zack had spent fifteen months on nightly dialysis at home, a routine that often came with complications. Through it all Zack was a great little patient. Zack has shown us what bravery truly means. Those nights on dialysis were tough for him but this was his normality. Today, seeing him walk to school gives us a sense of great pride".

For parents Jessica and Michael, after Zack was born the situation was doubly demanding. They balanced the needs of their then two-year-old daughter Ellie while constantly commuting between their home in Mallow and hospital in Dublin. Family support was limited due to their distant homes in the UK and France, but everyone pulled together to support Zack, with Jessica's mum travelling from the UK frequently to support the family. Despite this, both parents managed to navigate their professional lives with the

understanding support of their employer, an international tech company, where they had met eleven years prior. Jessica took maternity and carer's leave before returning to work, and then followed Michael's extended carer's leave for two years, allowing them to share the responsibility of caring for Zack and his sister Ellie.

The day of the transplant, which occurred on 3rd October 2022, remains etched in their memories. Jessica vividly recalled the anxiety of waiting at Temple Street Hospital while her husband Michael underwent surgery to donate his kidney across the city at Beaumont Hospital. Both surgeries were successful, marking a turning point in their journey. Jessica said, "I'll never forget that day. Waiting for news about both Michael and Zack felt



Baby Zack.

like the longest day of my life, but seeing them now, it was all worth it".

When asked about his decision to donate his

kidney, a pragmatic Michael declared, "It was a natural step as a parent, a way of providing for my family. I view it not as a

grand gesture, but as an extension of my role. Zack can now begin a new chapter of education, fun, and making new friends at school. He no longer has a restricted diet and it's wonderful to watch him grow and take up new hobbies like swimming and football which he really loves. He now has a chance to enjoy a normal childhood."

Both Michael and Jessica emphasised their respect for the medical staff who cared for Zack, acknowledging their compassion in challenging circumstances. They expressed gratitude to the healthcare system for saving Zack's life. The family had also found support in the Irish Kidney Association, and wished to thank the charity for helping them by providing overnight accommodation in Dublin and helping other families in similar

continued next page

Reunited: Michael visiting Zack after transplant.



Zack leaving hospital after transplant.

DONOR FATHER CELEBRATES FIRST SCHOOL DAY FOR TRANSPLANT SON cont'd...



Michael in Zack's bedroom on the first night his dialysis machine was set up at home.



Zack playing doctor with his sister Ellie.



Dressed up after his transplant.



Ellie and Zack.



Proud parents Michael and Jessica with Ellie and Zack.

situations who have to travel from the country to Dublin hospitals for care.

Jessica concluded, "Our journey is a testament to the power of hope that transplantation gives. And it is our hope that by sharing our story, we can inspire others to consider organ donation. It is truly life changing".

Michael added, "Transplantation isn't a cure, but it is an amazing treatment that gives us a new sense of normality. It's about quality of life, about giving hope where it is needed most".

The IKA would like to thank Jessica and Michael for sharing Zack's first day at school story. Their positive organ donor awareness story was covered in national and local newspapers and on Virgin Media News with interviews on three radio stations.



**BOOK
YOUR PLACE
NOW!**

38th Annual Service of Remembrance and Thanksgiving

at the

Cathedral of Christ the King

*Bishops Gate Street, Commons, Mullingar,
Co. Westmeath, N91 EF82*

on

Saturday, October 14th, 2023

at 2.00pm

(We ask that all attendees be seated by 1.50pm).



The Service will be followed by a light lunch. In order to ensure a pleasant experience for everyone, and to reduce food waste, we are asking people to register their interest in attending in advance and let us know if there are specific dietary requirements.

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

PLEASE BOOK EARLY!

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

The Service will be recorded, for broadcast on RTÉ One TV and RTÉ Radio 1 Extra on Sunday, November 5th at 11.00am.



In light of the expected large attendance, we respectfully request that if you are experiencing any respiratory or COVID-related symptoms, you refrain from attending the Service. This measure is aimed at safeguarding the health of all attendees, many of whom have compromised immune systems. Your understanding is greatly appreciated.



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

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

Directions are available on our website.

Potential Donor Audit



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



Organ Donation Transplant Ireland (ODTI) asked the National Office of Clinical Audit (NOCA) to look at the need for, and the value of, a Potential Donor Audit and produce a report. The report was launched on September 7th following a pilot study conducted in just six hospitals over a three-month period, November 2022 to February 2023, coordinated by organ donor nurse managers working at the coalface of organ donation.

WHAT IS A POTENTIAL DONOR AUDIT AND WHY IS IT RELEVANT?

It is about looking at the number of people who died in the right circumstances to be potential organ donors, to see how many of these became actual organ donors, and then to understand why some of the potential donors did not become actual donors – perhaps there was a medical reason, an issue with hospital capacity, not getting family consent, etc.

It is important to understand that only approximately 1– 2% of people die in the right

circumstances to be a potential organ donor. This is why it is so important to understand how well the system is working and be able to identify where to focus efforts to improve outcomes and inform best practice.

When we think about organ donation, we naturally think about those who are on the transplant pool and the transformative impact that a new organ can have on their lives, the lives of those around them and society at large. We also think about the sense of appreciation that is there for every organ

donor and their families.

Martina Goggin was a Public and Patient Interest Representative on the working group that produced the NOCA report. Martina and her husband Denis agreed to donate the organs of their son, Éamonn, in 2006. Many of you will know Martina and Denis who are responsible for the creation of the 'Circle of Life' Garden in Salthill, Galway.

Martina wrote in the report, "When our son died, following a road crash, my husband and I would have been devastated if we had not



NOCA National Office of
Clinical Audit

10 out of 23 potential organ donations did not happen for a variety of reasons, from best practice not being followed to lack of family consent.

been given the opportunity to donate his organs. The comfort and consolation we felt in knowing that our son performed the noblest act of generosity by giving the gift of life to others is like a light that continues to shine, even on the darkest days”.

The Irish Kidney Association (IKA) has been calling for an annual clinical audit of organ donation practices for many years and applauds the commitment of ODTI to the advancement of best practice in the delivery of organ donation and transplantation in Ireland. The last time such an audit was conducted in Ireland was in 2008.

However, whilst the commitment to an Annual Potential Donor Audit is commendable and the work of NOCA is excellent, the IKA would like to see the inclusion of the Audit in the Human Tissue Bill which is expected to be transposed into law later this year. In this way it would put it on a statutory footing and ensure that its future delivery is not at risk of changing budgets or possible future recruitment freezes.

In focusing on ensuring that every person who is approaching the end of life in ICU and ED is offered

the possibility of becoming an organ donor, where this is appropriate, the NOCA report rightly shines a light on the need to ensure that the organ donation decision of every potential donor is followed through.

To reinforce this focus, the IKA would like to see the inclusion of an ‘opt-in’ register to run alongside the ‘opt-out’ register proposed in the Human Tissue Bill, as is the case in the UK. This dual register is operated in the UK.

During the launch of the NOCA report, when talking about an opt-in organ donor register, Michael O’Leary (Medical Director of the New South Wales Organ and Tissue Donation Service) described it as being ‘incredibly powerful’ in achieving family consent.

As with the Human Tissue Bill that is currently working its way through the Dáil, there is a need for public education around organ donation, how it works, and the value of it to the individuals and wider society. If we are to fulfil the aim of the Potential Donor Audit (PDA), there is a need to bring organ donation into education so that organ donation becomes a natural part of end-of-life care.

The Irish Kidney Association (IKA) has been calling for an annual clinical audit of organ donation practices for many years and applauds the commitment of ODTI to the advancement of best practice in the delivery of organ donation and transplantation in Ireland.

RESEARCH – YOUR HELP MATTERS

Can you help improve services for kidney patients?

As regular readers will know, the Irish Kidney Association (IKA) is active in ‘research’, partnering with the HSE and Healthcare Professionals on many projects.

Our current research study with the National Renal Office (NRO) and the RCSI (Royal College of Surgeons in Ireland), on understanding the experiences of patients in the healthcare system, already has over 800 replies and the information you are providing is very valuable and will help improve services.

A new research grant has just been awarded to the University of Galway, to find out about the burden of kidney disease, using information obtained from the kidney treatment system (EMED).

We are excited to provide the patient voice into this research to ensure that patients benefit from it.

We are currently setting up a group of 10 to 12 patients who will meet online, two to three times a year. There will be one optional face to face celebratory event, and travel expenses will be paid for that event.

Patients will read documents before meetings and then provide their thoughts at the meetings. These thoughts will then feed into the main steering group.

No previous experience is needed as training will be provided and it is patients lived experience of kidney disease which is most valuable.

So, if interested please email: research@ika.ie telling us a little about yourself (a paragraph is fine) as we want to ensure the group has a mix of people with different experiences and is representative of our community,

Once we receive your email, we will tell you more about the project before you decide whether you want to take part.

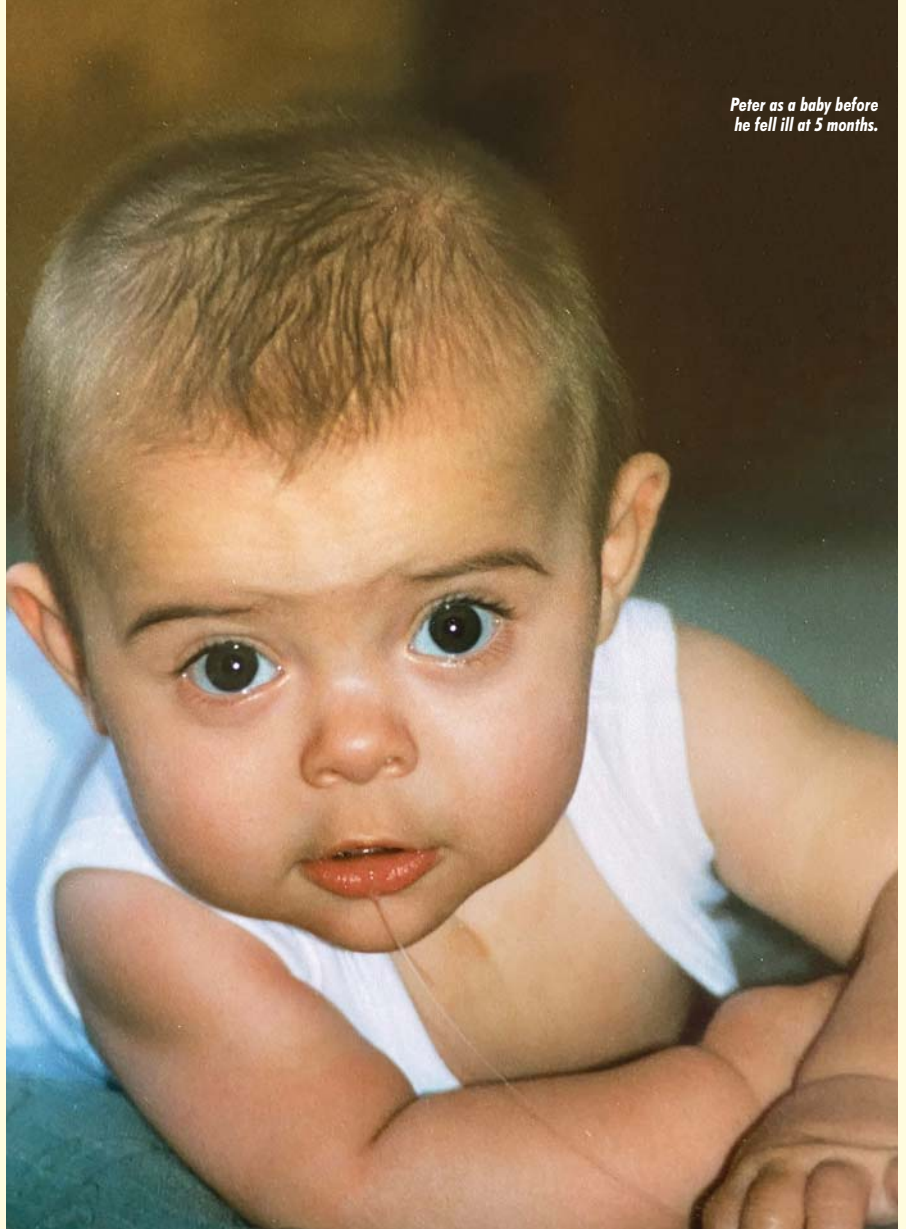
CAROL MOORE, CEO



'Push it for Peeps'



By PAT & GERRI CURRAN



Peter as a baby before he fell ill at 5 months.

Peter at 10-years-old.



In celebration of **PETER 'PEEPS' CURRAN**, who faced relentless health battles in his short lifetime, his parents Pat and Gerri write about their son's legacy. Peter, who touched the hearts of many, passed away at the young age of 24 years. The young man bequeathed €10,000 to the Irish Kidney Association and, following his death, the charity which had helped him, also benefited from a successful 'Push it for Peeps' fundraiser organised by Peter's siblings. In his short lifetime, his father describes how Peter taught the true meaning of courage, resilience, and selflessness, and how his family and friends celebrate his life and legacy that continues to inspire.

We would like to share Peter's health journey with you and explain how, even when times were tough, he refused to give up hope.

Peter was lucky enough to have been born a perfectly healthy baby in the UK in 1997. However, at the age of five months, he developed intussusception, a condition where part of the intestine folds into another causing bowel obstruction. Unfortunately, his

initial care in hospital did not go to plan.

As with babies of this age they can deteriorate at an alarming rate. He became very unwell, required resuscitation on numerous occasions and intraosseous infusions due to

dehydration. We, his parents, witnessed things that we will never forget. After 24 hours he was recovered by an emergency team and transferred to Great Ormond Street Hospital (GOSH).

He spent several weeks in their intensive care unit; the team were continually fighting for his life. Battling with septicaemia, heart, liver and kidney issues, along with uncertainty surrounding his brain function, due to his multiple resuscitations.

Peter overcame all these challenges with the exception of his kidney issues. He lost both of his kidneys and was subsequently transferred to the renal ward in GOSH. He stayed there for a further three months.

Peter required many operations over the following twelve months to facilitate dialysis treatment.

He was selected for a transplant at the age of 18 months. Unfortunately, it was unsuccessful and the donor kidney had to be removed in an emergency operation.

Peter received a successful transplant at the age of 3. This freed him from the commute to London three times a week, with hours sitting at a dialysis machine.

A year after his successful transplant, we moved to Ireland and Peter came under the care of

Peter with his auntie Mary, one week after she gave him one of her kidneys at the IKA Renal Support Centre, Beaumont.



Temple Street Children's Hospital. Visits with the renal team were common, during which he made friends and had many admirers among the staff and other young patients.

At the age of 14, Peter was back on dialysis – a devastating blow and restriction for anyone, let alone a teenager. His week consisted of school for three days and commuting to Dublin, from our home in North Tipperary, for three

long days on dialysis. He handled this without complaint. We used to often talk about the people who cared for him, how they made each other laugh. It is strange to think that in such difficult and often painful times for Peter, we reminisced as though it was akin to his school days. We remembered them as happy days, which he made happen.

He received his third and final transplant after a year on this exhausting schedule. It was gifted to him by his Auntie Mary. This finally allowed him to enjoy freedom for the remainder of his life. Peter grabbed this opportunity with both hands and started experiencing the positive things in life, many of which we take for granted on a daily basis; college – to study so he could help those less fortunate than himself and to experience student life; holidays – travelling around Europe with the lads. When COVID-19 struck and they couldn't fly abroad, they decided to travel around rural Ireland in a camper van; moving out of home – getting his first apartment in Tralee and sharing it with his girlfriend; and most importantly, to remain in continuous contact with his friends, and to always be there for them.

However, as well as his physical challenges, Peter was aware of his mortality from a young age. Not a subject any young person should have to deal with, he handled it far

Continued next page...



Peter with his parents Gerri and Pat at his Graduation.



Peter with his nephew Matthew.

better than many of us could have. The fact that he understood that, during any of his regular visits to hospital, his results could show that he had deteriorated leading to a very restricted life on dialysis at best...or much worse, is testament to his fortitude. He never burdened any of his friends with this. He simply said it was routine.

In August 2021, he entered the care of the renal ward at University Hospital Limerick with a painful back.

Over the next three weeks Peter experienced huge levels of pain. He stopped communicating with many people because he didn't want to describe things to them, probably brushing it off and apologising when

he got out.

He was diagnosed with lymphoma. Treatment started immediately and sent many of his organs into shock. His blood started to become acidic, and dialysis was once again both his saviour, and his fear. For two weeks he was winning, his kidney function started to return.

But he was fighting cancer and the return of glandular fever. Infections came easily because his immune system was extremely reduced due to chemo.

On the night of Friday, September 24th, his breathing increased rapidly, his heart ran at 160. His body was fighting for oxygen and Peter was mentally and physically exhausted. He looked at us, his parents, and

said, "I want to be sedated". The team followed his wishes.

His final gift to his loved ones was him taking control of the situation and being sedated.

He passed peacefully with people who truly loved him holding his hands and talking to him.

We, as his family have always known how special he was. Since he left us, we have heard how he spread such kindness, support and inclusion in all the circles he moved in, be it school, college or friends from home...the list goes on. Many people have shared their stories with us on how he helped or impacted their lives, and this has been a real comfort to us, his family.

With all the mental and physical challenges thrown at Peter he should have been angry, bitter, less caring...the fact that he was never any of these makes him a truly remarkable young man.

He was always so appreciative towards the professionals that cared for him and for the volunteers that looked after the IKA Renal Support Centre at Beaumont Hospital.

We'd like to commend the team at Temple Street Hospital for their crucial support during his upbringing. Their care made them integral to his life, easing our concerns and anxieties greatly. We're thankful to this day.

Peter's siblings wanted to mark his passing with a simple tribute to him and organised "Push it for Peeps". This encouraged his friends and family to walk, run or push themselves on December, 26th 2021.

The event raised in excess of €10,500 via a GoFundMe page with proceeds going to the Irish Kidney Association.

Peter himself left a bequest of €10,000 to the Irish Kidney Association as thanks to those who help others.

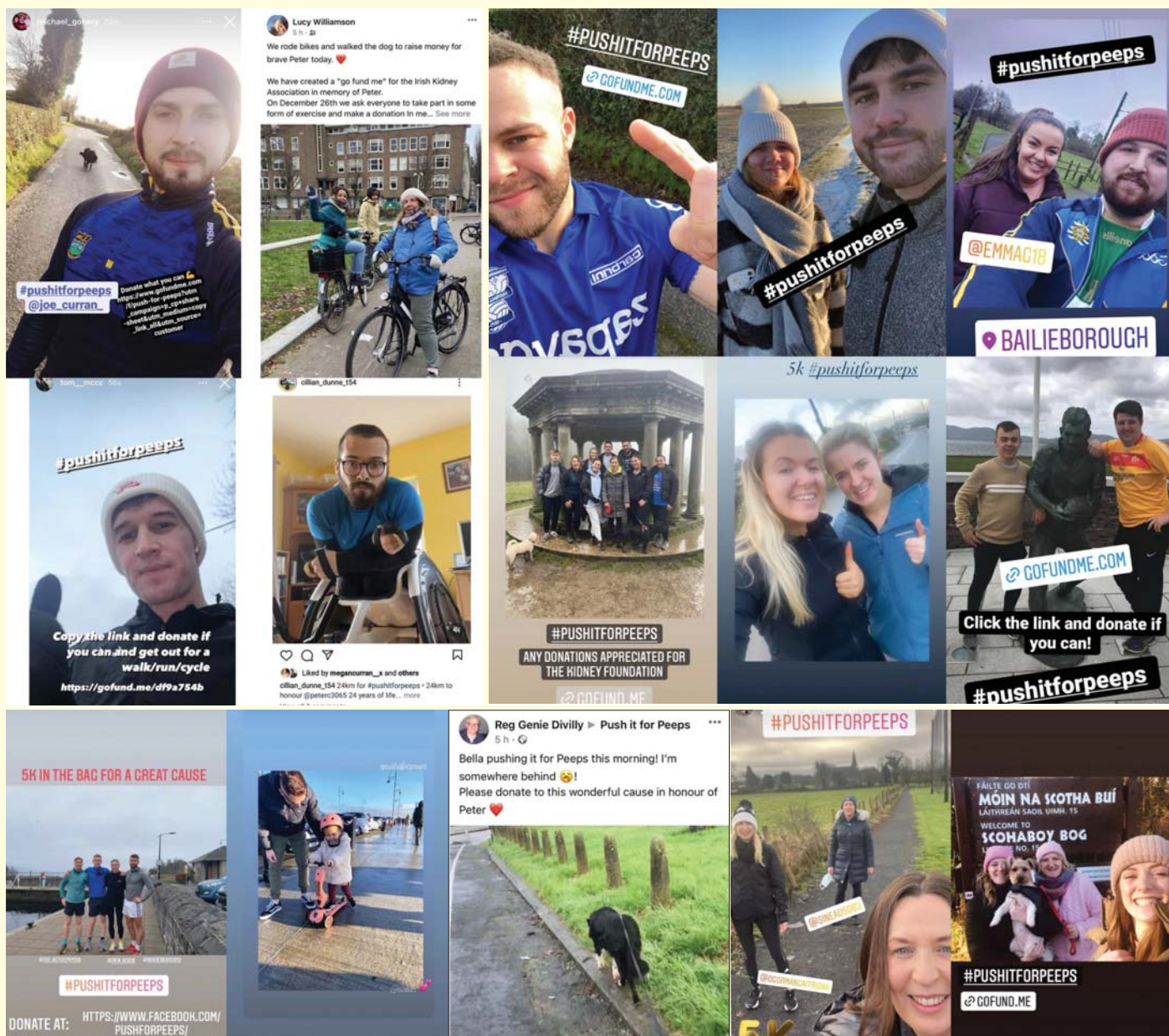
We, his family, are so very proud!

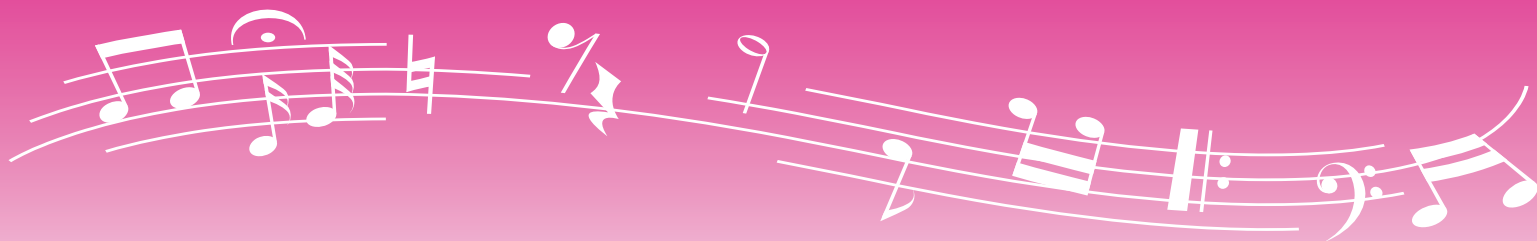
Remember his laugh, his smile, his generosity, his actions.
Remember him.



PUSH IT FOR PEEPS, a fundraiser for the IKA, held on December 26th, 2021, took place three months after Peter passed away in his memory. For the event participants were encouraged to walk, jog, run, or roll a wheelchair. A total of €10,555 was raised through donations to the GoFundMe online platform. Pictured at the event were members of Peter's family and friends who walked together, many wearing jerseys for Chelsea FC for which Peter was a passionate fan.

BACK (l-r): Joe Curran (Peter's twin), Pat Curran (father), Carol Roberts (great aunt), Aine Hogan (family friend), Gerri Curran (mother), and family friends Pat Hogan, Ali McSherry, Ailise Hogan, and Rachel Hill. **FRONT (l-r):** Megan Curran (Peter's sister) holding Pippa Cleary (Peter's niece and goddaughter), Matthew Cleary (nephew), Evie Curran (sister), David Cleary (Megan's partner) and their children Hannah and Sean Cleary.





Fleadh Cheoil na hEireann - The Homecoming Festival 2023



The Irish Kidney Association was pleased to be given the opportunity to be a charity participant for the Fleadh Cheoil na hEireann – The Homecoming festival 2023. From August 6th to 14th half a million people descended on Mullingar, my local midlands town, which hosted the festival for the second year in a row.

By **EDDIE FLOOD**, IKA NATIONAL CHAIRMAN

Mullingar town is also where Comhaltas was founded in 1951, in the same year the inaugural Fleadh Cheoil was held there. It is the world's largest annual celebration of Irish music, language, song and dance.

For nine days and nights, Mullingar was the centre for celebrating Irish

culture. As Chairperson of the Irish Kidney Association, it was with a sense of great pride and delight that our charity was part of it.

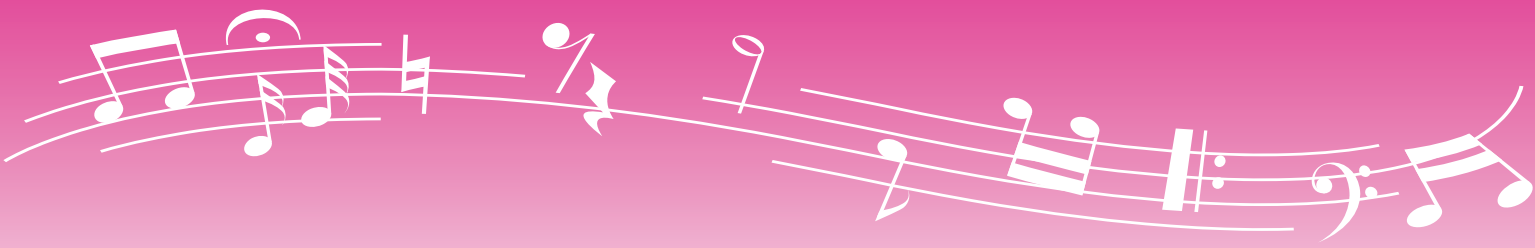
The event provided a fun yet important platform to raise awareness about the work we do in supporting kidney patients and promoting organ

donor awareness.

For the first three days the Comhaltas allowed us to set up 'Betty', our exhibition trailer, in the busy Town Park where there was a hive of activity, and then we relocated to Blackhall beside the gig rig which benefited from many more people passing-by.

Never before have I experienced such a





positive atmosphere quite like it and observe such a large gathering of musical and cultural talent including young performers.

In the middle of the Festival week I met with board members Joan Gavan and Cathriona Charles to enjoy a performance from Mullingar Choral Society. We had previously considered inviting them to participate in the upcoming Service of Remembrance & Thanksgiving at the Cathedral of Christ the King in Mullingar on October 14th. They did not disappoint and we were so impressed we wasted no time in booking them for the Service!

We had a great response to our organ donor awareness promotion, distributing over five thousand organ donor cards and also raising awareness about the work of our charity.

We chatted to people from all over the world, and many of them were transplant recipients.

Betty, our exhibition trailer, with all its colourful branding, offered an inviting sheltered space to meet and chat with the public.



However, it would not have been possible for us to cover the event without the help of our local volunteers including Joe Leogue, Marian Swaine, Una McCarthy, Frances Little, Eileen Dunican, Finian Farrell, Cathy and Gerard Smyth, Catherine O'Farrell, May Smyth, Lorraine Cahill, Vincent Evans, Edel and John Farrell, as well as Joan

Gavan who travelled from Tipperary, Cathriona Charles from Leitrim, and Sean and Marie Fowley from Sligo.

Staff member Robyn Black also helped out and Sinead McDonald, our new fundraising manager, went around the town capturing great photos with a fun Instagram frame prop featuring the words **#LeaveNoDoubt**,

delivering both novelty and a serious message all in one.

It was a tiring, long-week, but an unforgettable, rewarding and very enjoyable experience. We thank the Comhaltas organising committee for involving us and wish them continued success as the annual festival moves to Wexford town in 2024.



Social Prescribing

- a holistic approach to healthcare

For many years, it has been recognised that the current medical system is flawed as it treats our bodies separately from our minds and ignores the link between the individual and the wider social and emotional contexts, in which our lives unfold and health or illness happen. A simple example, if I suffer from loneliness on a long-term basis, I am much more likely to become ill, yet doctors cannot prescribe for loneliness, they can only treat the symptoms of the illness.

This is how social prescribing came about. Social prescribing allows doctors to recommend activities that help people in their wider lives. When prescribed by a healthcare professional, these activities are usually free of charge to patients on a medical card. A social prescribing link worker can provide up to 8 one-to-one sessions to help the person take part in an activity.

The infographic below shows the types of activities that are available.

The information below is taken directly from the HSE website and it gives a useful insight into a service that it is developing.

WHO IS SOCIAL PRESCRIBING FOR?

Social prescribing is for adults over the age of 18 years, including (but not exclusively) people:

- with one or more long-term conditions
- who need support with their mental health
- who are lonely or isolated
- who are frequent GP/ED attendees and may benefit from other social supports outside of clinical services
- who have complex social needs which affect their health and wellbeing.

IS SOCIAL PRESCRIBING AVAILABLE NATIONALLY IN THE HSE?

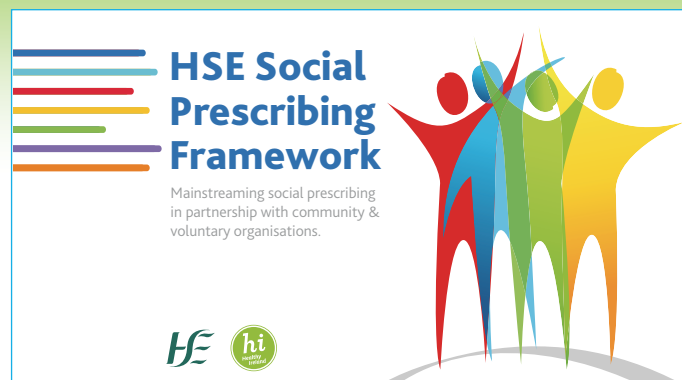
Social prescribing is a formal way of linking medical healthcare providers: GPs; Mental Health practitioners; Occupational Therapists (OTs); and Hospital Consultants, to community-based social supports that radically improve the health and wellbeing of people they are seeing, to such an extent that visits to GPs, where there is an active social prescribing project, can drop by up to 20%.

What is offered is often a complement to medical treatment, but on occasion it can replace a medical solution. A person is offered a 'social' prescription rather than a medical one. They are linked to a social prescribing link worker who expands out what would support their health and wellbeing through locally-based community programmes.



HSE-funded Social Prescribing services are now available in over 30 locations around the country. These services are delivered in partnership with community and voluntary organisations such as Family Resource Centres and Local Development Companies.

The HSE Social Prescribing Framework outlines how social prescribing can be mainstreamed and integrated within the HSE. One full-time social prescribing link worker per Community Healthcare Network or Sláintecare Healthy Communities site is proposed as part of the delivery model for social prescribing outlined in the HSE Social Prescribing Framework.



HOW CAN I GET A SOCIAL PRESCRIBING SERVICE?

To make a referral or to self-refer to a service contact your local social prescribing service directly. See <https://www.allirelandsocialprescribing.ie/services-map> for a list of social prescribing services and their contact details across the country.

SOURCES

www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/mental-health-and-wellbeing/social-prescribing/
www.hse.ie/eng/about/our-health-service/making-it-better/social-prescribing-better-than-a-tonic.html

IKA MUNSTER SUPPORT CENTRE



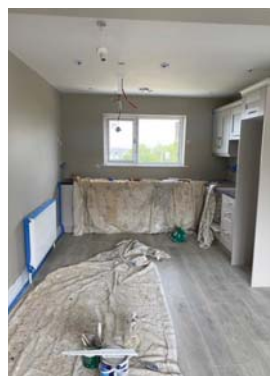
By SARAH BUCHANAN

The IKA Munster Support Centre in Wilton Avenue, Bishopstown, Cork, is reaching the final stages of its building development works, sparking a growing sense of anticipation for its opening.

Once completed, the Support Centre will serve as a vital resource, offering support, accommodation, and a sanctuary to renal patients and

their families from the broader Munster area who are attending Cork University Hospital (CUH), conveniently situated just 100 metres away.

Currently the landscaping and paving work are in full swing to ensure the Centre's exterior is finished.



Internally, all aspects of the project have been completed, with snag lists currently being completed.

Delivery of equipment and soft furnishings are due over the coming weeks.

The Support Centre recruitment process has been successfully

finalised, and the team is eagerly looking forward to opening the doors and extending a warm welcome to renal patients and their families.

As the building development phase nears its conclusion, the collective vision and tireless efforts of so very many people, are on the cusp of becoming a reality.

The imminent opening and operation of the Munster Support Centre marks the beginning of a new chapter within the Irish Kidney Association community, as the excitement continues to mount.





The Murphy family, Mahon, Lia and baby Calm, Jack, Síle, the late Sean and Bob (photo taken in 2015).

By SÍLE MURPHY

Counting our blessings: A Waterford family's story

In this article **SÍLE MURPHY** writes about family life living with genetic kidney disease which has affected many of her family.

Her husband Sean passed away in October 2022. His advocacy, lobbying, and fundraising efforts, for kidney patients began over four decades ago. Throughout his life he demonstrated an unwavering commitment to improving the quality of life for kidney patients which has left an enduring legacy. He was also the first to initiate a chain of life-enhancing kidney transplants within his own family as he donated a kidney to his then 10-year-old son, Bob, before it transpired over a decade later that he himself had kidney disease. Later it began to emerge that three of his four children shared the same genetic kidney condition.

Retired school principal Síle's article reflects that positivity and goodness can be derived from difficult situations through a shift in perspective, while being grateful for the support and assistance of so many people who have helped along the challenging journey.



A 1984 press cutting covering the father to son kidney transplant.

My late husband Sean, both a kidney donor and a kidney transplant recipient, declared many times that “without organ donation, transplantation and the dedicated renal medical teams over the last 40 years, my wife would be a widow today with only one surviving child and we would not have experienced the joy of having our six wonderful grandchildren”.

Sean became involved in the campaign to establish a dialysis unit in Waterford Regional Hospital when his four-year-old son, Bob, was diagnosed with renal failure in 1978.

By 1981, Bob had progressed to haemodialysis in Crumlin Children's Hospital three days a week. This entailed the arduous 250-mile round journey from their home in the Comeraghs, Co. Waterford by ambulance, leaving home at 6am and arriving back in Waterford between 7 and 8pm.

It wasn't all hardship though. Bob was entertained on his journeys with good humoured drivers, nurses and patients, and even stopping for chips in Kilcullen. He once arrived home with a white rabbit found on a building site in Crumlin which the nurses washed in the sluice room and put in a box for him. The rabbit was running about our house for years.

Bob was often taken out by student nurses in St. Mary's Hospital in the Phoenix Park for chips or to just see what was going on outside the hospital. St. Mary's was used as an overflow renal treatment for Jervis Street before Beaumont Hospital was built.



Parents Sean and Sile with children Jack, Lia, baby Mahon and Bob.

Bob's dad Sean was part of a committee which was formed to raise awareness of the necessity for a dialysis treatment unit in Waterford. They were told that as there were only three patients in the area requiring dialysis, the provision of a local dialysis facility was not feasible. Sean carried out some research and identified 11 patients from the South East who were relying on dialysis to survive.

After much lobbying of councillors and ministers and public meetings it was decided by the then Health Board to set in motion plans to provide dialysis in Waterford provided that a sum in the region of £400,000 could be raised.

Undaunted and with great determination to achieve this ambitious target, the committee set about raising public awareness of the situation and it was not long before fundraising efforts were underway all over the South East.

Huge support came from factory workers, particularly at Waterford

Crystal who generously agreed to have a small sum of money deducted from their weekly wages.

£130,000 was raised within the first year. The campaign gathered momentum and soon the local dialysis unit was a reality.

It opened in May 1983 in the old St. Brigid's unit in Ardkeen. Initially there were only 5 patients there, Bob being the fifth. It is marvellous to see that today there is a purpose-built dialysis unit catering for over 120 dialysis patients.

Sean had campaigned and fundraised tirelessly for this, and the result was a new lease of life for our young son.

Dialysis within easy reach of home offered improved quality of life for all those dialysis patients whose plight would otherwise have been further exasperated by having to travel long distances for their life-saving treatment. It was a wonderful outcome for patients and their families.

Another positive development ensued when it was suggested by Drs. Garrett Fitzgerald and Michael Carmody that it might be possible for Bob to have a living donor kidney transplant from a parent. Sean didn't hesitate in putting himself forward to be Bob's kidney donor and in April 1984 the father to son transplant operations were successfully carried out in Jervis Street Hospital.

Unfortunately, Sean became ill in 1995 and it was discovered that his remaining kidney was failing.

Then our eldest son Jack started to show signs of renal failure and because of new research it emerged that the family,



Bob receiving treatment at Crumlin Children's Hospital, 1983.

continued next page...



Sile and the late Sean Murphy.

including three of our four children, had a genetic condition known as Familial Membrano Proliferative Glomerular Nephritis. This was subsequently discovered to have affected our son Jack and daughter Lia, who also went on to have long years of dialysis followed by successful transplants.

Sean commenced home dialysis and during this time he continued to fundraise for the Irish Kidney Association (IKA) through his comedy double act, *Bachelors in Trouble*, with his friend Tony Coffey.

Along with being a great husband and father, Sean was also a keen historian and performing arts entertainer. Sean, Tony and other friends made a total of 30 comedy videos about a pair of bachelor brothers, living in the rural Ireland of the mid-20th century. The plots centred round their struggle to find a wife to help with the many farm jobs. Funds raised from launching the videos in hotels and pubs went to the local IKA branch. The duo also raised funds for many more charities and entertained at many charity functions.

Sean underwent a successful kidney transplant in 2003, thanks to a grieving family who generously allowed the organs of their deceased loved one to be donated.

This gave Sean nineteen years of a fulfilling life with his family which enabled him to continue with writing his local history books, giving talks on many subjects, and making the *Bachelors in Trouble* videos.

He enjoyed a great



CDs from just some of the 30 'Bachelor in Trouble' comedy plays.

relationship with the staff at the Waterford renal unit, including doctors Walker, Leavy, and Abernathy, who supported him right up to the time of his death on October 4th, 2022. Each Spring he gave his 'amusingly serious' account of his family's experiences as renal patients at the Mini Med School in Waterford Institute of Technology.

Today our family has been the recipients of seven transplants, five made possible by the generosity of the families of deceased donors and the original living donor father to son transplant between Sean and Bob, who in later years also received a kidney from his younger brother Mahon. Jack has had two transplants and our daughter Lia has given birth to two healthy children since her successful transplant in 2011.

An intensive research study into our family's genetic kidney condition is still ongoing and has been overseen by Professor Peter Conlon who, from his very early career, has been involved with our family, guiding, and advising during the many kidney crises which arose over



A scene from 'Bachelors in Trouble'.

the years.

In the 45 years of meeting and being treated by numerous doctors, nurses, administrators in practically every hospital in Dublin, our family has always been afforded top-class care and respect. There are no words to express our thanks adequately.

When the IKA Renal Support Centre was built in Beaumont, it became a home from home during the many anxious hospital stays. There is no doubt that the respite from the clinical hospital atmosphere aided hugely in the recovery and recuperation of the patients who have enjoyed the facility. Going on our experience, I'd go so far as to say that, in an ideal world, it should be a prescribed part of the kidney patient's treatment!

Throughout the years our family has experienced a profound rollercoaster of mixed emotions, encompassing moments of joy, hope, sadness, and trepidation. The emotional journey has been deeply intertwined with a recurring cycle of kidney failure, the demanding regimen of dialysis treatment, and the ultimate life enhancing kidney transplants.

Demonstrating great resilience, my husband and children have refused to let its hereditary medical condition define their lives and have maintained a steadfastly positive outlook, pursuing their ambitions with determination to live full and happy lives.

Our children's optimism and lived experience, shaped by Sean's positive example, has been fuelled by the invaluable gifts of life made possible by organ donation and transplantation.



Sean and Bob at the All-Ireland Hurling Final 2017 Waterford v Galway at Croke Park.



Hi all,

I know it's not been a great summer weatherwise but so many families enjoyed a break away in the IKA holiday homes in Waterford and Kerry.

Tramore holiday apartments will close at the end of September while our Kerry holiday homes, in Tralee and Killarney, are remaining open through the winter.

If you are interested in holidaying at one of our homes in Kerry over the coming months, please get in touch.

HOLIDAY DIALYSIS IN IRELAND

Unfortunately, it's still extremely difficult for patients who are attending in-centre haemodialysis treatment to travel within Ireland for a holiday due to dialysis units working at full capacity with no extra space to accept holiday patients.

TRAVELLING ABROAD

If you are thinking of a holiday abroad in 2024 or would like advice on destinations, you can now make an enquiry on our website <https://ika.ie/patient-holidays/> by clicking on patient holidays and complete our secure enquiry form or, alternatively, you can telephone me on 01-6205306.

Please remember to contact me to arrange dialysis treatment before you book your holiday. Dialysis units abroad now require a minimum of eight weeks' notice.

Deborah



An Amazon Fire Tablet

Thanks to **LANDMARK TECHNOLOGIES**, which supplies all of the Irish Kidney Association information technology needs, we can offer **FIVE LUCKY READERS** the chance to win an **AMAZON FIRE TABLET**.

The Amazon Fire Tablet is a small computer with 13 hours of battery life (lasting an entire dialysis session!) so you can watch your favourite TV programmes while also sending emails. With plenty of storage space at 32GB you can store photos and videos taken with its easy-to-use camera. Alexa is built-in so you can ask questions, play music, and shop online with just a few words. Up to 95% of its packaging is made from responsibly managed wood-fibre-based materials.

LANDMARK TECHNOLOGIES

LANDMARK TECHNOLOGIES is one of Ireland's leading IT Outsourcing and Cloud Service Providers providing a wide range of IT services including cyber security, cloud hosting, and equipment provision.

To enter simply email robyn@ika.ie with the subject line **AMAZON FIRE TABLET GIVEAWAY** including your name, address, and contact telephone number.

The five winners will be drawn after **9am on Monday, 16th October** using a random number generator. By entering this competition, you agree to your name being published in the Winter 2023 issue of **SUPPORT** magazine.

Kidney Diet Website – Recipe for Success

A specialised kidney (renal) diet is an essential part of the management of Chronic Kidney Disease (CKD). Chronic kidney disease leads to a build-up of waste products in the blood. This may cause symptoms including nausea, taste changes, loss of appetite and itchiness. It may also cause more serious complications such as fluid overload, which can cause breathlessness; or a high potassium level which can affect the rhythm of the heart.

The aim of the kidney diet is to provide sufficient nourishment whilst also controlling the build-up of waste products in the blood. People with CKD may need to restrict various elements of their diet including sodium, potassium or phosphorous. This is not a 'one size fits all' diet and people with the condition require assessment by a renal dietitian, and individualised dietary advice and support to help them understand what they can eat.

The diet can be challenging to follow, and those with CKD often struggle to inject variety into their daily diet. It requires planning and imagination to make the kidney diet more enjoyable but it can be difficult to know where to look for reliable information.

Mindful of the challenges a group of renal dietitians who are members of the Renal Interest group of the Irish Nutrition and Dietetic Institute developed the website

www.irishkidneydiet.ie for people with CKD and their families. The aim was to create a website to help people understand their condition better, help them explore new avenues with regard to cooking a kidney diet, and to improve the choice and variety of



food options available to them.

The website is a valuable tool for people with CKD, their families, carers and health professionals alike. It features recipes, meal plans, frequently asked questions, videos, seasonal information and practical tips and advice on all aspects of the kidney diet.

It has been well received, with over 2.5 million hits in 2022. The website has many followers on twitter including patient advocacy groups including the Irish Kidney Association (IKA), dietetic associations, nephrologists, dietitians and people with CKD.

It has featured in local and international newspapers, and HSE publications. It was also shortlisted for the Irish healthcare awards 2018 in two categories: 'Best use of information technology' and 'Patient Education/Lifestyle Project'.

With the support of the National Renal Office, a new suite of recipes has been developed. A number of these recipes are released each month and provide seasonal inspiration for special occasions. For example, in June our seasonal theme was 'summer garden party', with recipes such as *lime and chilli pitta crisps* and *sour cream and chive dip* making a debut.

Our Easter instalments saw the addition of mouth-watering recipes such as *lemon cheesecake* and *raspberry fruit fool with lemon shortbread biscuits*.

All recipes have undergone a full nutritional analysis by renal dietitians and guidance on allowances is provided, enabling people with CKD to choose appropriately.

Check out www.irishkidneydiet.ie and check out the 'latest recipes', released each month.

By **PAULINE CONNOLLY**
SENIOR RENAL DIETITIAN, CAVAN GENERAL HOSPITAL
on behalf of the Renal Interest Group
of the Irish Nutrition and Dietetic Institute (INDI)

The website has also seen the addition of two new videos; *Salt Intake and Chronic Kidney Disease* and *Phosphate Control*. The Department of Renal Medicine, Cork University Hospital created both animated patient educational videos aiming to provide clear and concise explanations for both sodium and phosphorus restrictions.

The team behind this website are very aware that the kidney diet places challenging restrictions on

people with CKD and requires planning, imagination and practical ideas.

We hope www.irishkidneydiet.ie will continue to inspire, support and motivate the renal community to enjoy great tasting food while also meeting the goals of the kidney diet.

Check out www.irishkidneydiet.ie and see for yourself!

There is a direct link to irishkidneydiet.ie from the IKA website. www.ika.ie/medical-information/

Current website team: Pauline Connolly (Senior Renal Dietitian, Cavan General Hospital); Theresa Rennick (Dietetic Manager, Midland Regional Hospital, Tullamore); Bernice Moore (Senior Community Dietitian, Louth/Meath); Laura Brennan (Clinical Specialist Renal Dietitian, St James's Hospital, Dublin); Karolina Pawlak (Senior Renal Dietitian, Beacon Renal Drogheda) and Neasa Forde (Senior Renal Dietitian, Beaumont Hospital, Dublin).



LEMON CHEESECAKE

SERVES 8

Ingredients:

150g Digestive biscuits	4g zest of two lemons
50g unsalted butter	80g juice of two lemons
275ml cream	100g caster sugar
280g cream cheese	

Method:

Line the base of an 18cm spring cake tin with greaseproof paper.

Place the digestive biscuits in a blender until you get a breadcrumb like consistency. Melt the butter and then pour it into the digestive biscuits and blend together.

Spoon the biscuit base into the prepared tin and use the back of a spoon to smooth it flat.

Put the tin into the fridge to chill while you make the topping.

Whip the cream using a whisk or mixer, once the cream is whipped, add in the sugar, cream cheese, lemon juice and lemon zest and whisk together until you get a light fluffy texture.

Remove the baking tin from the fridge and spoon in the lemon mixture. Use the back of a spoon to smooth out the top.

Place the cheesecake in the fridge for at least 2 hours to set fully. Remove from the fridge 30 minutes before serving.

Per Portion this recipe provides:

¼ dairy exchange.
½ protein exchange (from the bread and cereals group).



RASPBERRY FRUIT FOOL

SERVES 4

Ingredients:

350g frozen raspberries (1 bag)
300ml double cream, whipped
40g caster sugar

Method:

Pour the frozen raspberries into a large bowl and sprinkle the caster sugar over them. Place in the fridge and allow to sit and thaw for up to 1 hour.

Whip the double cream whilst waiting for the raspberries to defrost.

Once defrosted, puree the raspberry and sugar mixture in a liquidiser or blender. Pass this mix through a sieve to remove the seeds. Discard the seeds.

Gently fold in the whipped cream. Divide into four dessert bowls. Serve immediately or chill for serving later.

Serving Suggestion: This raspberry fruit food is delicious when served with shortbread biscuits. A recipe for lemon short bread biscuits appear on the website.

Per Portion this recipe provides:

1 fruit exchange

SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK



AI Revolutionising kidney failure diagnosis The future of medical care

The field of healthcare is on the cusp of a revolutionary transformation, thanks to the rapid advancements in Artificial Intelligence (AI) technology. Among the many areas that stand to benefit from this progress, the diagnosis and treatment of kidney failure is poised for a significant leap forward. AI's ability to process vast amounts of data, recognise patterns, and make accurate predictions has the potential to revolutionise kidney failure diagnosis, leading to earlier detection, more precise risk assessment, and improved patient outcomes.

ENHANCING EARLY DETECTION

One of the major challenges in managing kidney failure is the difficulty in detecting it at an early stage. Often, symptoms manifest when the disease has already progressed significantly.

AI offers the promise of enhanced early detection through the analysis of various data sources. Machine learning algorithms can be trained on extensive datasets, including electronic health records, medical imaging scans, and genetic information, to identify subtle patterns and risk factors associated with kidney failure.

By analysing this data, AI models can generate predictive models that flag individuals at higher risk, enabling healthcare providers to intervene proactively and initiate early treatment, potentially preventing the progression of kidney failure.

PRECISION RISK ASSESSMENT

In addition to early detection, AI can provide precise risk assessment for individuals already diagnosed with kidney failure. By analysing a multitude of patient-specific factors such as medical history, laboratory results, vital signs, and lifestyle data,

AI algorithms can generate personalised risk profiles.

These profiles can predict the likelihood of disease progression, help identify complications, and guide clinicians in tailoring treatment plans to the specific needs of each patient.

AI's ability to analyse complex interactions among different variables allows for more accurate risk stratification, leading to improved patient care and better allocation of healthcare resources.

AUTOMATED DIAGNOSIS SUPPORT

AI can also play a crucial role in supporting healthcare professionals in diagnosing kidney failure. Machine learning algorithms can be trained to analyse medical images, such as ultrasounds, CT scans, and MRIs, to identify characteristic patterns and abnormalities associated with renal dysfunction.

AI-based image analysis systems can provide quick and accurate assessments, assisting radiologists and nephrologists in making faster and more informed diagnoses.

The integration of AI into medical imaging workflows not only enhances diagnostic accuracy but also improves efficiency, allowing for prompt treatment decisions and reduced patient waiting times.

CONTINUOUS MONITORING AND PERSONALISED TREATMENT

Traditionally, kidney failure patients undergo intermittent check-ups to monitor their condition. However, AI offers the potential for continuous monitoring, enabling real-time data analysis and timely intervention.

Wearable devices and remote sensors can collect data on vital signs, fluid balance, medication adherence, and other relevant parameters. AI algorithms can process this data and provide actionable insights to both patients and healthcare providers.

This continuous monitoring facilitates personalised treatment plans, as healthcare professionals can make adjustments based on

real-time data trends, leading to improved disease management and better patient outcomes.

CONCLUSION

The integration of AI technology into the diagnosis and management of kidney failure holds immense promise for the future of medical care. By leveraging AI's capabilities in data analysis, pattern recognition, and predictive modelling, healthcare providers can achieve early detection, precise risk assessment, and personalised treatment plans.

This transformative power of AI has the potential to significantly improve patient outcomes, optimise healthcare resource allocation, and enhance the overall efficiency of the healthcare system. As research and development in this field progress, we can look forward to a future where AI revolutionises kidney failure diagnosis, making a profound impact on the lives of millions of individuals worldwide.



THE REVEAL

Although my name is at the top of this article, I did not in fact write it. This article was generated in seconds by an AI tool called **ChatGPT** – all I did was give a simple instruction; *"Write a 500-word article on how AI could transform kidney disease diagnosis"*.

There is a lot of rumblings about how AI will take jobs away from people and how there is much to be feared from this new phase of technology. I wanted to explore it more myself and show that, not only can it be used to provide information at an astoundingly quick rate, but it holds promise for the future of many fields.

The idea that these intelligent systems could not only predict, but prevent kidney disease progression, is fascinating. So, whilst it may be fun to ask tools like ChatGPT to write poems and try to ask it trick questions, keep an eye on this exciting field as it progresses into more parts of our daily lives!

CAUTION

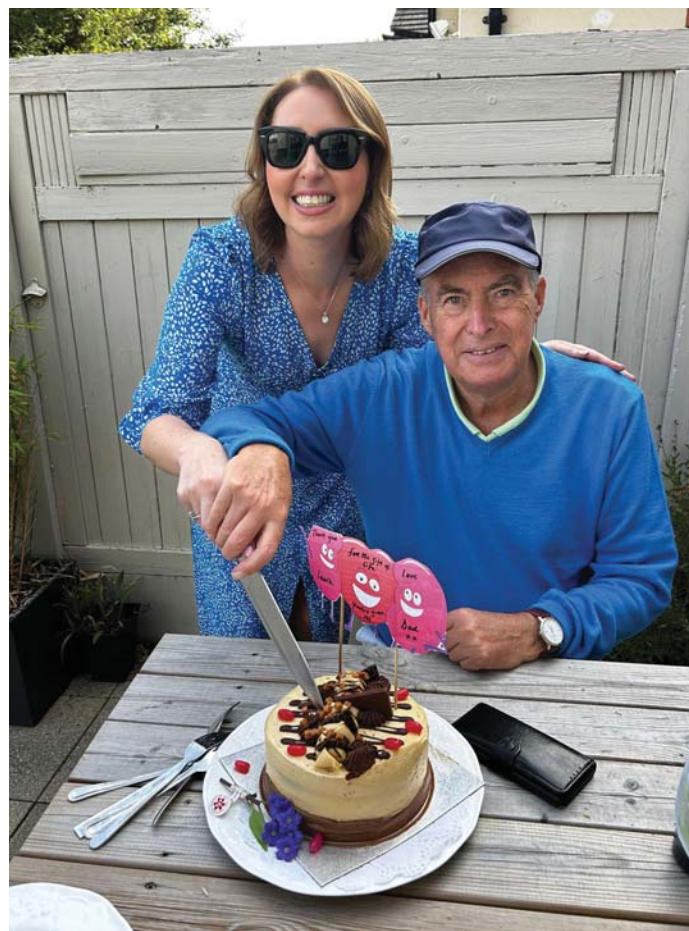
Using Artificial Intelligence (AI) and applications such as ChatGPT can simplify tasks and save time, but it's important to remember to keep your personal information safe. Staying informed about the terms and conditions of AI tools is essential to protect your privacy and the security of your personal information.



Friends run **HACKNEY HALF MARATHON**

In May this year a group of six Irish friends living in the UK ran in the Hackney Half Marathon in London and in the process raised €6,345 for the Irish Kidney Association (IKA).

The IKA is a charity close to their hearts as Howard Slattery, father to their friend and running participant John Slattery, was diagnosed with kidney disease last year. In June 2023, Howard's daughter, Laura Sargeant, successfully donated her kidney to him.



Above: Howard Slattery with his kidney donor daughter Laura Sargeant.



John, a native of Terenure, Dublin, explained, "Throughout the whole experience, our family has witnessed first-hand the importance of organ donation and continues to encourage everyone to consider being an organ donor and potentially save someone's life. The impact of such a selfless act is immeasurable and can truly make all the difference in the world for someone in organ failure".

"The IKA provides support for those with kidney disease in Ireland, as well as promoting organ donation and transplantation. Their work is vital in improving the lives of those affected by kidney disease, and the group were proud to be supporting the efforts of the IKA".

Pictured left: Sean Fenny, Niall Healy, Kevin O'Neill, Nick Moore, Sean Deane, John Slattery.

Waterford men go to **'HELL AND BACK'** for the Irish Kidney Association!

Dungarvan brothers Christy and Shane Power, along with friends Richie Hayes, Niall Butler and Paul Lennon, took on the ultimate challenge on June 10th, 2023 when they embarked on the **'HELL & BACK'** challenge. In doing so they fundraised for the IKA as a thank you for all the support Christy and Shane's mam got, and continues to get, from the Association as she undergoes dialysis in University Hospital Waterford.

'HELL & BACK' is Ireland's toughest physical and mental endurance challenge, specifically designed and created by award winning outdoor specialists, to push participants physical and mental boundaries to the limit. It is set in the magnificent Kilruddery Estate and the 8km course has stunning views of Dublin Bay.

The course combines infamous man-made obstacles with the natural terrain, including rivers, mountains, bogs and forests creating a uniquely terrifying challenge! The group endured an 8km run up the Sugarloaf mountains, with ice baths, obstacles, swamps, swimming in open water, water obstacles and electric shock obstacles, taking approximately two hours to complete.

They raised the impressive sum of €2,075 for the IKA, for which the charity is very thankful. All monies raised locally are used for patients in the local area.

If you or anyone you know is suffering with renal issues and would like to access information and supports please feel free to contact your local Branch or Donor House, contact details on the back page of this magazine.



(L-R): Richie Hayes, Christy Power, Niall Butler, Shane Power, Paul Lennon.

by **FRANCES MOYNIHAN**, Waterford IKA
Email: franceswaterfordika@gmail.com

Recognising the signs of DEPRESSION

As the dark evenings descend, some people find themselves going downhill into the depths of depression. Recently, the Irish Kidney Association (IKA) supported Irish research which showed that 35% of people with chronic kidney disease currently experience symptoms of depression.



DRINKING MORE THAN USUAL

Drinking alcohol more than usual can actually make depression worse. Initially, it numbs our feelings but then it comes back to bite us afterwards. So, if the signs on the picture on the left ring a bell with you, it might be worth considering reducing your alcohol drinking.

WHAT TO DO IF THIS IS YOU?

Well, the good news is recognising these symptoms is a really good start, because it's really easy to be depressed without knowing we're depressed. So being aware of the symptoms means we can take steps to help ourselves.

RECOGNISE WHAT WE CAN CONTROL

Understanding what we can and can't control is vital. So, we can't control having kidney disease, but we can control how we respond to it. We can take action, if we recognise any of the signs in the picture.

Chatting to a trusted friend about how we're feeling can help. If you feel you cannot talk to a friend because they do not fully understand what it is like to live with kidney disease, the IKA has a free online Peer Support Service and you can find out more at www.ika.ie/peersupport

If you live in an area with an active IKA Branch you might find attending Branch meetings helpful. Contact details for local Branches are on our website and at the back page of this magazine.

You can also contact **AWARE**, on its helpline at **1800-804848** which is open from 10am to 10pm, seven days a week.

OTHER SUPPORTS

If you don't like chatting, going for even a short walk every day, preferably in nature, can really help. If you feel you are not physically able for walking, then try out the online Kidney Beam which can help to get you fitter. More details on page 31.

One of the good things coming out of the COVID crisis, is better awareness of mental health. So, you're not alone, if you're feeling down help is available.

BY CAROL MOORE

Waiting for the Call

- *a patient's thoughts*

I was delighted to be added to the Kidney Transplant waiting list in November 2022. I packed my hospital bag, which has been sitting ever since in my bedroom, but I very rarely think about when I will get to use it.

I am well aware that the phone call could come within the next 24 hours, or that it could be a matter of years, so there's no point in keeping it at the front of my mind. When it comes it comes, and all I can do in the meantime is stay as active and healthy as possible.

However, while I don't give much thought to the transplant itself, I find myself acutely aware that

I and a total stranger are on a sort of "collision course". I regularly wonder who this person is, where they live, how old they are, and what family they have. And of course, the unavoidable questions which might seem insensitive – When will they die? How will they die? Will it be an expected, but nonetheless sad situation? Or will it be unexpected, sudden, possibly even tragic?

The only thing that I can know about this person whose death will give me a new life, is that they and their family, in the midst of great personal loss, will think of Organ Donation – the ultimate in selflessness, in giving.

As these musings fill my mind, I realise that I wish there was a way to thank this stranger before our very bittersweet "collision". So this prompted me to write the following little poem, which I dedicate to donors everywhere – past, present and future.

JOAN DOBBYN

I DON'T KNOW YOU

*I don't know you,
You don't know me,
But we have a shared
Trajectory.*

*Where are you now?
What do you do?
I would so love
To speak to you.*

*And thank you now
For what you'll give –
A part of you
So I can live.*

*The time will come
When we'll collide.
I'll get that call,
But...you'll have died.*

*I do not wish for you to die.
Your loved ones will be very sad...
Are you their Mum,
Their Son, their Dad?*

*But maybe it
Will help them grieve
To think of this
Great gift you leave.*

*I don't know you,
You don't know me,
But THANK YOU for
Your gift to me.*

CALLING YOUTH WITH

MUSIC IN MIND



Are you a young person with end stage kidney disease who would like to have fun exploring your musical ability?

The Irish Kidney Association is delighted to announce that we have been selected by the **National Concert Hall** for the **Music in Mind (MIM)** programme for children/adolescents and young adults.

The **MIM** programme, which has been made possible through the Government's **Creative Youth Nurture Fund**, will provide a series of **8 FUN WORKSHOPS (Singing or Drumming)** for children/adolescents/young adults in the **12-24 age range** who are living with End Stage Kidney Disease.

This programme, which will be **FREE** for participants, will start in early 2024. In advance of this we need to know how many people are interested, their ages, what days suit best, and which physical location(s) will suit people best.

No prior experience in singing or playing an instrument is needed.

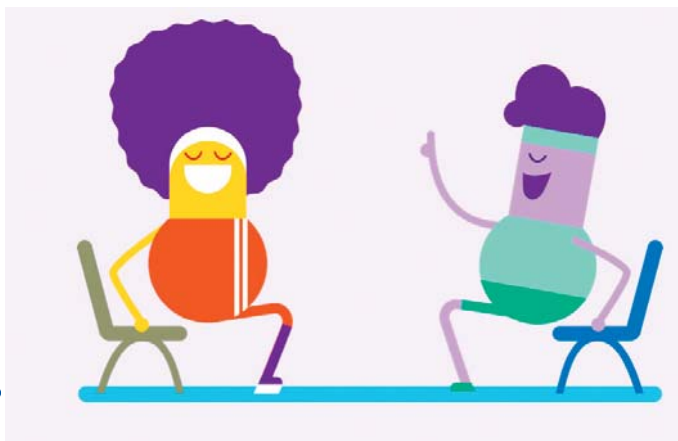
If interested, please complete the form at <https://ika.ie/music/>. Completing the form does not guarantee a place on the programme or commit you to participating in it. We will be in contact when details are finalised.

Please note that for children under 18 years, we kindly request that a parent/guardian confirms their attendance at the venue each week of the programme.

The closing date for receipt of applications is SEPTEMBER 30th, 2023.



Kidney Beam



Kidney Beam is an online service helping kidney patients take care of their physical and mental health. It offers a way to improve your physical activity in your own home.

Designed just for kidney patients, it is a collaboration between King's College Hospital NHS Trust and Beam, a digital exercise, education and well-being platform for people with chronic health conditions.

Thanks to James Tracy and the PuncHESTOWN Kidney Research Fund (www.PKRF.ie), kidney patients in Ireland can now avail of this service for free.

The Irish Kidney Association is facilitating an introductory online session for those interested in finding out more, on **Thursday, October 5th at 6.30pm**. You can register at www.ika.ie/kidneybeam.

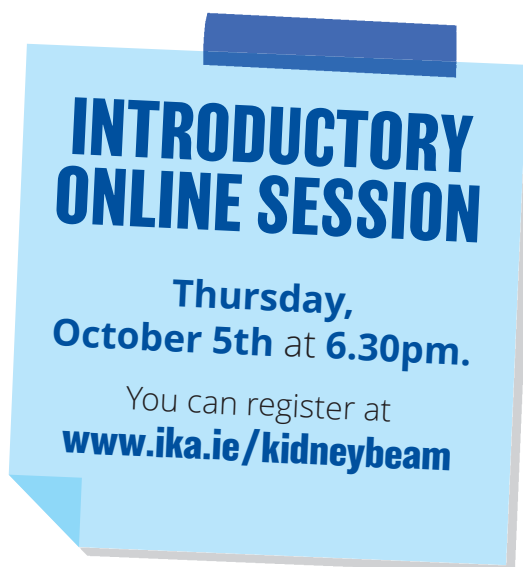
Keeping active and doing exercise can be especially hard when you are living with a health condition and the symptoms, treatments and pressures that come with it as well as coping with all the trials and tribulations of daily life.

The digital delivery of this programme through Kidney Beam allows people to participate without having to leave the house and on a schedule that works best for them.

Dr Sharlene Greenwood, Consultant Physiotherapist for King's College Hospital NHS Trust and clinical lead for Kidney Beam said: "Our research is showing that the platform has

proved to be a lifeline to people during the COVID-19 pandemic, and we can confidently predict it will continue to be, even in more normal times".

To find out more online, visit www.beamfeelgood.com and select the 'Kidney Disease' tab on the home page.



beam

JAMES TRACY /
PuncHESTOWN Kidney
Research Fund



NHS

King's College Hospital
NHS Foundation Trust

SUPPORT MAGAZINE SUMMER PRIZE WINNERS

SEAN LUCEY, Mitchelstown, Co. Cork was the winner of the
CLAYTON HOTEL and **DUBLIN ZOO COMPETITION**.

PETER DALY, Kilmihil, Co. Clare was the winner of the **HARVEY NORMAN COMPETITION**.

Thank you to our sponsors.



*Sara-Jane Tracy with Helena at
Punchestown House, Co. Kildare.
Photo: Damien Eagers*

Rugby Hooker supports Kidney Beam

Prompted by the unexpected kidney failure diagnosis of his sister **Sara-Jane**, a talented showjumper, **James Tracy** resolved to raise funds to help kidney patients like his sister. James, the recently retired Leinster and Ireland rugby hooker, whose successful sporting career was cut short last year due to injury, directed the proceeds he raised in support of Punctestown Kidney Research Fund (PKRF) in bringing the **UK's Kidney Beam** project to renal patients in Ireland.

By
GWEN O'DONOGHUE



James Tracy in action in the Heineken Champions Cup Round 1 Montpellier vs. Leinster. Photo: INPHO, Dave Winter.



James Tracy. Photo: INPHO, Ryan Byrne.

“Today is a day
of reflection and
gratitude”.

The joint project between himself and the Punctestown Kidney Research Fund (PKRF), the charity which is led by James Nolan, provides an online physiotherapy led exercise programme for kidney patients which is now available free of charge to kidney patients here in Ireland.

From Kildare, both men who share a deep interest in equestrian sport, also have a family connection. James Nolan's kidney donor sister, Catherine, is married to a relation of James Tracy. Having first met at a family wedding years ago, the two men were brought together again as James Tracy, who at the time was still playing rugby, decided to channel his energies into supporting James Nolan in offering the Kidney Beam project here.

Tracy was capped six times by his country between 2016 and 2017, scoring one try, in addition to representing his province, Leinster, 141 times. In December last year he announced his retirement following a sports injury to his neck which he sustained in April that year saying, “Today is a day of reflection and gratitude”.

Just two months before he sustained the sports injury that would end his rugby career, Tracy undertook the gruelling February Freezbury Challenge which raised over €23,000, later donated to the Kidney Beam project.

The challenge involved submerging himself in the cold Irish sea, which required he also dunk his head, building the duration of one minute incrementally each day until

contd...



Photo: Damien Eagers

he reached 28 minutes on the final day of February.

Tracy had support from some rugby teammates while taking his fundraising dips, including Ryan Baird, Dan Leavy, Ferg McFadden, Scott Penny, Josh Murphy and James Lowe.

At the time of the Challenge Tracy said, "I have done a few days on my own, but it's really been an eye-opener of how lucky I am to have friends, family and teammates who are all reaching out to me...it'll all help raise awareness".

Having set a target of €5,000 to raise, Tracy did not expect the overwhelming support for his fundraiser with more than four and a half times more raised.

Tracy's passion for helping patients in need began in 2015 when his beautiful sister Sarah-Jane, who was at the height of her successful showjumping career, was diagnosed with Multiple Sclerosis (MS). The condition affects the motor, sensory and cognitive function, for which there is no known cure.

She was just 28-years-old at the time. Sara-Jane who had qualified as a barrister but continued her showjumping career, described the shock diagnosis, "When I got the news, I thought for a brief moment that my life was over. It felt like all my dreams, and everything I'd worked for throughout my twenties, had come to nothing".

Her condition quickly took hold

and brought her to a point where she could hardly walk and could barely hold a pen to sign her name.

She explained, "I was devastated to be told I couldn't ride competitively anymore because it would not be safe, given all my symptoms. And that's the moment I thought my life was over. Without horses, it wasn't worth living. So, I decided, No, I will prove them all wrong".

Sarah-Jane began to train really hard and sought help from Brian Murray, a strength and performance expert, whom she credits for helping to transform her life.

There was lots of mental and physical conditioning, rehab, and physio, which gradually brought her back to a point where she could walk properly again. By April 2016 she had returned to competitive showjumping, not an easy undertaking as she had to learn how to literally get back on the horse again, and hold her balance, and force her body and mind to relearn all her horse-riding skills.

She describes her uncle, showjumper Edward Doyle, as her

"I was devastated to be told I couldn't ride competitively anymore because it would not be safe, given all my symptoms. And that's the moment I thought my life was over."

guardian angel for his patience and support in helping her to reach this goal. Sara-Jane's medication proved effective in sending her MS condition into remission. She and her brother James became active campaigners and ambassadors for MS Ireland.

Another health blow came when her Anti-GBM disease caused her kidneys to fail, a consequence of the medication she was on to keep her MS symptoms at bay. She remains grateful that it continues to work.

However, the medication wreaked havoc on her kidneys. She was hurtled into a world of dialysis travelling from her family home in Kill, Co Kildare to St. Vincent's Hospital in Dublin three times a week for treatment.

Several family members were screened for living donation but were crushed that none were suitable. Then another guardian angel came to her rescue in the form of another uncle, Alex Tracy, who secretly got tested at Beaumont Hospital before the hospital phoned Sara-Jane with the good news that a suitable living donor was found.

The successful living donor kidney transplant operations were carried out at Beaumont Hospital on 4th November, 2021 bringing to an end five years of dialysis treatment for Sara-Jane and setting her on a path of renewed freedom.

Sara-Jane said, "Words can never convey my gratitude to my uncle Alex without whom I might not be here today, and to his wife and young family in supporting his incredible decision to donate a kidney to me.



"Thank you to my parents and siblings for their love and unwavering support throughout my health journey since been diagnosed with MS and then kidney failure.

"My thanks also to all the renal team, my surgeons, my nephrologist, all the amazing nurses and staff from the national kidney transplant unit at Beaumont, and everyone on the transplant ward who were superheroes and beyond amazing. They saved my life better than I could have dreamed of.

"I commend the work of charities including MS Ireland, PKRF and the Irish Kidney Association for advocating and supporting patients like me and their families. Organ donation has helped to transform my life and has saved so many others."

Sara-Jane's brother James, explained about his motivation for getting involved with Kidney Beam, "As a family, we couldn't be prouder of Sara-Jane. She has shown incredible resilience in the face of not one, but two serious health challenges – battling both MS and kidney disease. While these conditions remain a part of her life, she relentlessly pursues her passion for horses and showjumping, serving as an inspiration to all of us with her remarkable achievements".

James continued, "Sport, especially rugby, has always held a special place in my heart and within our

Photo: Damien Eagers



extended family. Witnessing a loved one cope with the daily trials of dialysis and the limitations it imposes is a powerful reminder of the importance of supporting causes that encourage physical activity and emotional wellbeing for kidney patients.

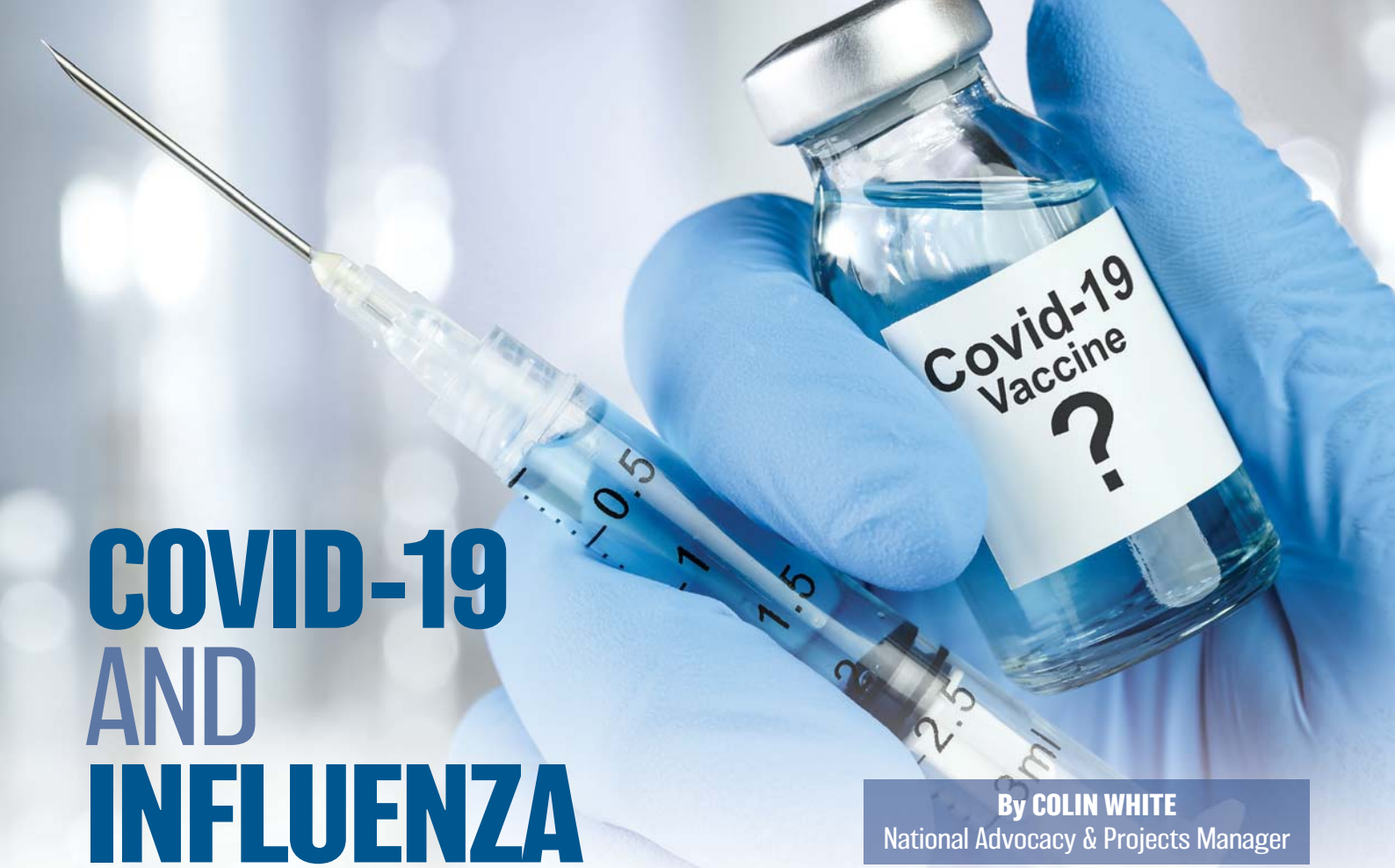
"I consider it both fitting and an honour to contribute to such a cause through Kidney Beam, as it aligns with my personal values and the values we hold dear as a family."

Despite an abrupt end to his successful sporting career James Tracy has risen above adversity with remarkable resilience. He continues to channel his energy into supporting charities helping people with MS and kidney disease and, like his sister Sara-Jane, is a shining example of strength and compassion in the face of adversity.



I consider it both fitting and an honour to contribute to such a cause through Kidney Beam, as it aligns with my personal values and the values we hold dear as a family.





COVID-19 AND INFLUENZA

By **COLIN WHITE**
National Advocacy & Projects Manager

“Protect Yourself. Protect Others”.

The HSE’s Autumn Winter Vaccination Programme starts on October 2nd, 2023 with the rollout of the **FREE** flu vaccine and COVID-19 Autumn booster to recommended groups. Both vaccines will be available from participating GPs and pharmacists and can be given at the same time.

To see what vaccines are recommended for you, visit www.hse.ie, call **HSELive** on **1800-700700** or talk to a participating GP or Pharmacy.

Dr Aparna Keegan, Consultant in Public Health Medicine, HSE National Immunisation Office, said, “This winter both the flu and COVID-19 viruses are expected to circulate. It is very important that all those who are invited, get both their free flu vaccine and COVID-19 booster vaccines. Flu and COVID-19 are caused by different viruses but both can cause serious illness. The flu vaccine does not protect against COVID-19. That is why it is important that if you have had a COVID-19 vaccine you should still get your free flu vaccine”.

Anecdotally, we are hearing mixed views from members in relation to whether they intend to get the next booster. The current public medical advice is that unless there is a specific contraindication to getting the vaccine, people should go ahead. As with all issues related to your health, it is important that you keep your

renal team up to date with your vaccine status. If you have any questions about taking the vaccine, you should raise them with your medical team.

The practical advice we got during the pandemic about being aware of your surroundings remains relevant. Think about your hand hygiene, physical distancing, mask wearing, ventilation when you are indoors or in crowded places.

It is up to each of us to take responsibility for ourselves. It is about finding that balance where you are conscious of minimising the risk of exposure to COVID-19 and the flu virus, but you are also living your best life.





Expansion of GP Visit Card Scheme

The Minister for Health, Stephen Donnelly, recently announced more people can now apply for free GP care. This includes people between the ages of 8 and 69 who currently pay for private GP visits, and they might now be eligible for this free service following means testing if they meet certain income and other criteria.

Children under 8 and people aged 70 and over are automatically eligible for a GP visit card.

In addition to income, the means testing also considers personal and family circumstances, various types of income (like social welfare, wages, pensions, etc.), and allowable expenses (like rent, childcare, etc.).

The means test assessment is unique to each person or family, depending on their specific circumstances, income, and expenses.

From **November 13th, 2023** the income thresholds to be eligible for free GP care will increase:

- The Weekly Base Eligibility Threshold for a **single person living alone** will increase to €418.



- The Weekly Base Eligibility Threshold for a **single person living with family** will increase to €373.
- The Weekly Base Eligibility Threshold for a **couple with or without dependent(s)** will increase to €607. For a couple with dependents a weekly

allowance per dependent is added to the threshold.

- Similarly, the Weekly Base Eligibility Threshold for a **one parent family** will increase to €607.

During a means test assessment an allowance is added to the threshold for dependents:

- €57.00 for first and second child aged under 16
- €61.50 for third and more children aged under 16
- €58.50 for first and second child aged 16 or over who are financially dependent
- €64.00 for third and more children aged 16 or over who are financially dependent
- €117.00 for all children aged 16 or over who are financially dependent, in third level education and not grant aided.

FUEL ALLOWANCE

The Fuel Allowance rate is now €33 per week. It was increased in Budget 2022 from €28 a week. The first lump sum of €462 should be paid in the last week of September 2023. The second fuel allowance lump sum of €462 (14 weeks at €33 per week) will be paid in early January 2024.

For more information on means testing GP Visit Cards and to apply online visit
hse.ie/GPVisitCards



Writing — the Best Medicine!



By DR. TONY LYONS

Retired lecturer and author **Dr. Tony Lyons**, who became a haemodialysis patient in 2017, shares his experience with **SUPPORT** readers on how he immersed himself in writing as a much-needed escape from the routine of dialysis treatment. He encourages other patients in renal failure to embrace their interests and hobbies which will provide physical, mental, and emotional benefits that contribute to a fulfilling life beyond dialysis.

My name is Tony, and I am a retired lecturer in Education History. Five years after my retirement from this role at Mary Immaculate College in Limerick, in December 2017, I became a dialysis patient at University Hospital, Limerick. While initially this health setback cast an unwelcome shadow in the enjoyment of my retirement, I was determined not to let it define me. Instead, I saw it as an opportunity to immerse myself in scholarly activities and writing, which turned out to be quite therapeutic for me.

During this period of transition to a life on dialysis, I decided to pick up where I had left off in my scholarly pursuits from years before. Despite the challenges of my health, I managed to maintain a busy schedule. In 2019, I published my first book, a culmination of my research and dedication to history. This achievement spurred me on, and I continued to work diligently on my writing projects.

As of 2023, I am proud to say that I have already published a third book. It has been a gratifying experience to see my work out in the world, inspiring others with my passion for history and scholarship. But I'm not stopping there. Later this year, I have another book set to be published, and I'm excited to share my new discoveries and insights with readers.

Dialysis is a wonderful catalyst! I enjoy history, especially the history of education, not only in Ireland, but in Britain and the Continent. Writing about such matters drags me away from the tedium of dialysis, and it gives me something to look forward to on the day after each treatment session. Preoccupation with a healthy hobby can be, very often, the best medicine. I feel that all dialysis patients should try to avail of every opportunity to dwell on some of their interests; you will not know how good it feels until you try; men's sheds are a case in point; meeting friends or family or a hobby, card games during the winter months or attending evening classes, could be another occupation to while away the long dark evenings.

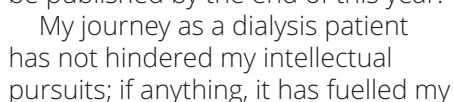
The spark for my interest in History was ignited in national school. While in St. Michael's College, Listowel, Co. Kerry, I was lucky to have encountered John Molyneaux, one of a small number of secondary teachers in the country who prepared students in Medieval History for the Leaving Certificate. 'Junior' Molyneaux had a very amiable method of recounting a story which brought history to life. He was called 'Junior' because another teacher of the same name was 'Senior', and he taught Latin. The school is still there, and thriving, but, alas, the classics, Latin and Greek, are no more.



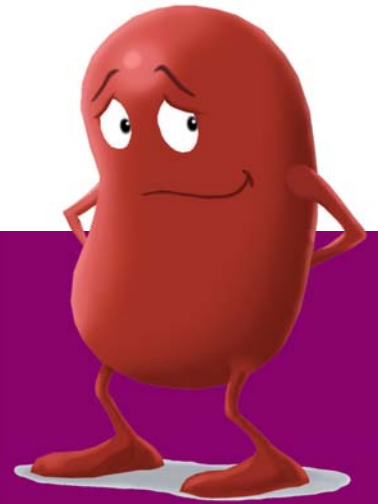
Writing has become a source of strength and joy for me, and I am grateful for the support and encouragement I have received along the way.



Upcoming is my book on Irish politician Sir Thomas Wyse from Waterford. Also in the pipeline is a



Thank you for taking the time to read a little bit about me and my journey.



Over 200 attendees at joint IKA and B. Braun information sessions

In chronic illness we often come across the phrase, “Nothing about us, without us”. In other words, patients should be a partner in their healthcare.

A diagnosis of End Stage Kidney Disease can be very overwhelming. Even the name itself can be scary. You are likely to be entering a whole new world with its own language and the prospect of regular hospital visits.

You might wonder how you can be a partner in your own healthcare or even wonder why you should be when there are healthcare professionals to look after you.

If we need our kitchen at home re-modelled, most of us do not

have the skill set to do it ourselves so we look for a professional and we sit with them to discuss the outcome we want, we may even do part of the manual preparation work before they start.

It is similar when it comes to healthcare. The majority of us do not have the skill set to manage the medical side of kidney failure so we look to a professional (nephrologist) and we should be sitting with them to discuss our goals, what they will do and what we can do ourselves.

During the Spring, the Irish Kidney Association and B. Braun collaborated on a series of webinars sharing insights into living with kidney disease.

The 6 one-hour sessions covered a variety of topics with the aim of educating people and giving them the confidence to be more involved in their healthcare.

The sessions were led by healthcare professionals identified by B. Braun and staff from the Irish Kidney Association.

The sessions looked at kidney disease and its impact, the treatment options, and the role of medication and diet and, also the role of physical activity and the importance of looking after your mental health.

The idea was to look at the illness, its treatment, and how to live with it. During the talks there were patients who shared their experience.

Peer support and networking can be so important in helping us to come to terms with a change in our health status and/or our circumstances.

The sessions were well attended, and the feedback was very positive.

If you would like to see the Irish Kidney Association facilitate sessions on any other topics, please email colin@ika.ie so that we can ensure that future sessions are addressing the topics that are important to you.



What is high blood pressure?

What is high blood pressure?

Blood pressure is the amount of work your heart must do to pump blood around the body. It is measured as two numbers – the higher number is the pressure as your heart beats and the lower number is the pressure as it rests between beats. A

normal blood pressure is about 120 over 80. If you are diagnosed with high blood pressure, your blood pressure is consistently higher than it should be.

What are the dangers of high blood pressure?

If left untreated, high blood pressure can lead to serious conditions such as

heart attack, stroke, heart failure, kidney failure or dementia.

What are the symptoms of high blood pressure?

High blood pressure usually does not have any symptoms. Only a blood pressure check with a healthcare professional will tell you if you have it.

When and where to check your blood pressure

If you are over 30, have your blood pressure checked once every 5 years at your GP or local pharmacy. Your GP will assess your overall risk of heart disease and stroke and may advise more frequent blood pressure checks if needed. If your blood pressure is high, it will be checked regularly.

How to control blood pressure

The good news is that, once diagnosed, high blood pressure is easily treated. There are many ways to control blood pressure before damage is done. Some people may need medications. The following steps can also help:

- Eating a diet high in fruit and vegetables and low in processed foods
- Cutting down salt
- Keeping cholesterol under control
- Drinking less alcohol
- Being active – at least 30 minutes of moderate intensity activity 5 days a week
- Keeping a healthy weight and waist size
- Quitting smoking

For more information about blood pressure and how to manage it, visit

irishheart.ie
Tel: 01-6685001



Irish Heart Foundation

The National Stroke & Heart Charity



High blood pressure can silently damage your heart and other organs

Get yours checked at your GP or local pharmacy

**BEFORE
DAMAGE
IS DONE**

Angela's Story

My story began at the age of eight when I started experiencing constant headaches and high blood pressure. Between ages eight and fifteen, I had numerous hospital stays and surgeries, making the hospital feel like a second home.

Dialysis began at sixteen (CAPD), and at seventeen, I received my first transplant in 1991. It gave me back a good quality of life but rejected after five years. Back on dialysis again, I spent seven years on CAPD, APD, and haemodialysis.

One miraculous night in 2003, while living in an apartment in a basement which had no phone signal, my phone miraculously started to ring. It was a call from a donor coordinator at Beaumont Hospital about a potential kidney match, and I was to make my way to the hospital.

That call was meant to be as it came at exactly the right time. Immediately afterwards when I tried to phone my parents to share the news with them the phone signal dropped again and prevented me from doing so.

I underwent my second kidney transplant which remains successful

to this day.

The transplant changed my life; I became a member of Transplant Team Ireland and I travelled the world competing in both European and World Transplant Games events which I really enjoyed and it gave me a lifetime of treasured memories.

I have had many different jobs over the years. As time went on, I realised that I didn't need to win medals, or have a great job, or even climb Everest (the kinds of things I felt I should be doing), to show my gratitude to my donor.

As time went on, I've realised that living my best life is the best way to honour both of my kidney donors and their families. These days, everyday activities remind me of them. Now when I walk the dog or meet someone for coffee, these are the moments I remember my donors.

Although, it has not all been plain sailing – I have struggled with my mental health at times but at all times, good and bad, I cherish life.

Earlier this year, to mark the 20th anniversary of my second transplant, I completed the women's mini-marathon with my sister Miriam.

Along the way, I met others with



Angela (right) and her sister Miriam after the Mini-Marathon.

their own stories, but my donors were my heroes at the finish line.

I was delighted to have been recruited and trained as one of the Irish Kidney Association's Peer Supporter volunteers. I hope that in this role I can help others who are navigating through their own kidney transplant journeys.

I'd like to thank my family, Tallaght Hospital staff, and the Irish Kidney Association for their support. To those on a similar journey, I encourage you to explore the IKA website www.ika.ie and use the services available.

Lastly, my deepest gratitude goes to my two donors and their families. Without them, my story wouldn't be the same. **Organ donation works – have the conversation!**

ANGELA SHERLOCK

ACCOMMODATION TELEPHONE BOOKING HOURS 01- 6908887

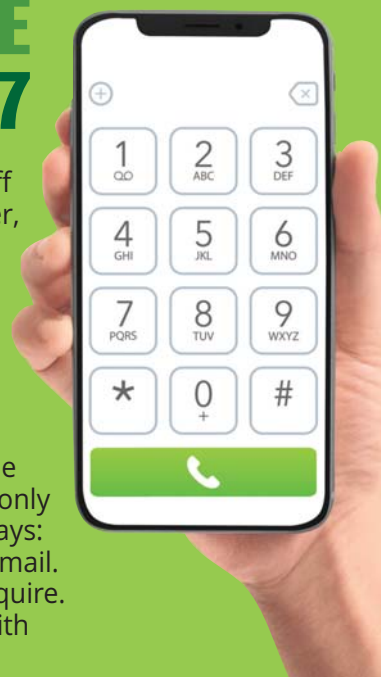
As hotels can be very busy, be sure to ring the Renal Support Centre staff as soon as you know of your hospital appointment. The earlier the better, so we have a greater chance in securing accommodation. We have had some cases where the Clayton Hotel, Swords, Dublin has been full.

ROUTINE APPOINTMENTS

The accommodation phone line is open: Mon. to Fri. 9.30am to 5.30pm.

EMERGENCY APPOINTMENTS

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





Black Bush Golf Club Lady Captain's Charity Day



Linda McGee, Hazel Conroy and the organising charity Committee behind the day.



Colin White accepting a cheque for €6,067 from the Lady Captain Hazel Conroy.

Lady Captain, Hazel Conroy, very kindly chose the Irish Kidney Association (IKA) as the beneficiary of her charity day at Black Bush Golf Club in Dunshaughlin on August 8th. The Club has a good relationship with the IKA having previously agreed to host the golf competition for the 2020 European Transplant & Dialysis Sports Championships (which had to be cancelled due to the pandemic).

The Club also supported training opportunities for the Ireland team in the build-up to the event.

The relationship does not end there. One of the ladies very involved

in delivering the charity day, Linda McGee, was also very involved (with her husband Brian) in the delivery of the 2010 European Transplant & Dialysis Games in Dublin.

Ron Grainger, and his wife Joyce, who are members of Transplant Team Ireland are also members of Black Bush Golf Club and they were very obliging in their support of the day too.

The weather was great on the day of the event and there was a great buzz about the Club as regular members and visitors from other golf clubs showed up to participate.

There was a real appreciation for the work of the IKA and interest in finding out more about how organ donation works.

The course fees on the day plus a very successful raffle resulted in a total of €6,067 being raised for the IKA.

The British Transplant Games are organised annually by Transplant Sport UK (TSUK) with the event moving around the country. This year saw the Games return to the city of Coventry, having last been held there in 2009. TSUK very kindly invites participants from Ireland to join them in what is a fantastic celebration of life through sport.

Ireland has had representatives at the Games since 2008 and this year, transplant recipients and people on dialysis from across the country, and their families, organised themselves to participate in Coventry.

With the biggest Irish team ever going to the Games, there was an Adult team and a Children's team with participants entered in sports ranging from Darts to Cycling, Swimming and Track and Field to Obstacle course and Table Tennis and many more. It was also the first time for Ireland to have a football team competing at the Games.



Chloe Kinahan

CHLOE KINAHAN, a Trustee of the Irish Kidney Association, and parent to one of the five children who took part on the Children's Team at the British Transplant Games and shares her family's experience of attending.



British Transplant Games

I'm Chloe and I'm married to Ivan and together we have two great kids, Ali (12) and Sam (9). Sam was born with a congenital defect resulting in him being born in end stage renal failure. At four months old, he started peritoneal dialysis and moved to haemodialysis at age three. At age five, his dad, Ivan gave him the greatest gift there is, the 'Gift of Life', by way of a kidney transplant. Sam has been thriving since and is currently a happy and healthy boy.

When our neighbour and team captain, Harry Ward, suggested we join the team and come to the British Transplant Games, we checked with Sam first and he jumped at the chance to meet other kids with similar stories to his and be part of the Children's Team. Sam loves reading, telly and movies. Sam is not sporty so at times we questioned what we were doing bringing him to the British Transplant Games – a sporting event.

For Sam, a very competitive streak came out while at the Games which we hadn't foreseen. There had been some success on day one with three of the five Irish kids winning medals in the table tennis and this ignited a fire in Sam. We reassured him that it was all about taking part and this being his first Games, he was amongst the youngest

and smallest in his age category.

At each event, he slowly realised that all the adoring crowds were cheering for him and other competitors like him, regardless of where medals were secured. We giggled at the 0-5 year category competing in their events and marvelled at some tiny transplant recipients whose lives had been saved by generous donors.

The Irish children's team, which was managed by one of the children's parents Aoife O'Gorman, all stayed in the same hotel and to say there was high jinks is an understatement. Sam's teammates included liver transplant recipients Tara Madigan (Limerick), Laura McDowell (Dublin), and Sadhbh Browne (Galway) and kidney transplant recipient Tadhg McElroy (Bray, Wicklow).

For our daughter Ali, one of the most positive outcomes for her was the opportunity to meet the siblings of organ recipients, in particular, those of our own small Irish children's team. She had a ball hanging out with kids with a similar experience to her, being passed from pillar to post when the 'ill' sibling's needs took over.

I had no idea what the British Transplant Games would entail for me before we went. Like my son, I'm not sporty at all, and I wasn't relishing the



The adult and children's teams.



Chloe, Ivan, Sam and Ali Kinahan.

thought of four days of non-stop sporting action. I just knew I wanted to build a community around myself and my family with those that have a common experience of illness and recovery.

For me it was also a chance to honour all organ donors. Like so many attending and so many reading this, I am in awe of the incredible generosity of those who chose to make a very difficult decision at the hardest time in their lives.

I wanted to revel in the success (or participation) of those that have already fought one of the hardest fights imaginable and my goodness, what a humbling experience it was! I found myself teary eyed on many occasions meeting and chatting with so many donor and recipient families.

For my husband Ivan, who has quite a few national sporting achievements to his name, including representing Ireland at the World Masters in Lyon in 2015 in middle distance Athletics, he had a different view of the Games.

He had a list of post-transplant goals he wanted to achieve, to get back running being the first goal, and go to another international sporting event and represent his country being another.

He had booked time off work to volunteer at the European Transplant Sports Championships which were due to be held in Ireland in the summer of 2020 but were called off due to the arrival of COVID-19. So, after four years of waiting, Ivan, as a living organ donor participant, was taking this event pretty seriously – pounding the roads and the track for months in readiness for the 5km and the 100m sprint, along with the ball throw and the obstacle race.

Ivan was desperate to pull on the green singlet again and represent Ireland but also to push himself and maybe win a medal for Ireland and for Sam.

And represent he did, bringing home silver for Ireland against an English dad who had also donated his kidney to his son. During the medal ceremony, the heavens opened and we laughed at the two young recipient children of these two heroic dads complaining about the weather, blissfully unaware of how emotional



Tadhg McElroy, Sam Kinahan and Sadhbh Browne.



Tara Madigan.



Laura McDowell.



Children's tug-of-war.



Laura McDowell and Tara Madigan (both liver transplant recipients). Laura won gold in the 13-15 years age category and Tara won in the 16-18 years age category.

it was for both to stand on the podium after such a challenging few years.

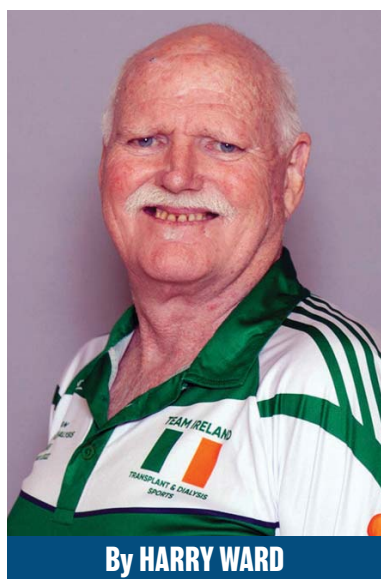
As a group, this was the largest Irish team that had ever gone to the British Transplant Games and the kids made the effort to go and cheer at the adults team events and likewise the adults attended many of the kids events. There was fantastic camaraderie amongst the team and I can't wait to replicate it in 2024. I'd urge anyone who wants

to participate in transplant sports to get in touch – it was life-changing and life enhancing for me.

On our last night, we sat to discuss what we'd need to bring for 2024 and our shopping list so far comprises glitter tattoos, green hairspray, Ireland flags, and tutus and costumes, for the Donor Race.

Next year the Games will be held in Nottingham from 1st-4th August. See you there!

HAVE THE CONVERSATION - SAY 'YES' TO ORGAN DONATION



By HARRY WARD

There was very much a sense of family amongst the thirty-four Transplant Sport Ireland athletes (26 adults, 5 junior athletes and 3 living donors) who participated, along with over 1,000 other athletes, at the British Transplant Games in Coventry, UK at the end of July.

I had the pleasure of being Team Manager and was so very proud as Team Ireland won a staggering 15 gold, 10 silver and 21 bronze medals, making it the largest and most successful Irish team ever to compete in these championships.

Of special note this year, was Team Ireland's first ever Soccer team, which won a bronze medal.

Irish athletes also competed in cycling, swimming, and track & field events such as athletics, long jump, high jump, shotput, javelin, discus, and darts.

These athletes were the recipients of a mixture of heart, liver, bone marrow, lung and kidney transplants, as well as

two dialysis patients. I am also very proud to have led this unique Team as it consisted of adult athletes, junior athletes and competing live donors!

The highlight of the Games for Team Ireland was meeting the woman whose daughter had donated her liver to Irish athlete Tara Madigan. This was a moment that powerfully proves that *Organ Donation Works* and it certainly resonated with all of us present.

Many thanks to all the athletes and their families who support us, to the media team of Dee and Mick, James Nolan and the PuncHESTOWN Kidney Research Fund, Aoife O'Gorman for coordinating the junior team's participation, but most of all to our donors and donor families who are forever in our thoughts.

The team has one simple request to everyone – please consider carrying an Organ Donor Card, *Have the conversation – Say 'YES' to Organ Donation.*



ETDSF

European Transplant and Dialysis Sports Federation

EUROPEAN TRANSPLANT CHAMPIONSHIPS

Lisbon, Portugal – 21st - 28th July, 2024

LET'S GO!

The European Transplant and Dialysis Sports Championships (ETDSF) and the European Heart & Lung Transplant Championships (EHLTC) have been two regular fixtures on the transplant and dialysis sports calendar for many years.

In a very positive development, in 2024, the two Championships are going to come together to be held in **Lisbon, Portugal**

under the banner of the

European Transplant Sports Championships from July 21st – 28th.



Offering a wide variety of sports, as well as an opportunity to meet your peers from across Europe, this event will be a true celebration of the 'Gift of Life' through sport, as well as being a significant

international platform for the promotion of organ donation for transplantation.

Open to people on dialysis, as well as organ and bone marrow transplant recipients, the Championships offer an enticing goal to aim for next summer.

Whether your sport is Petanque, darts or ten-pin bowling, golf, swimming, or athletics, and many more, there will be something for everyone.

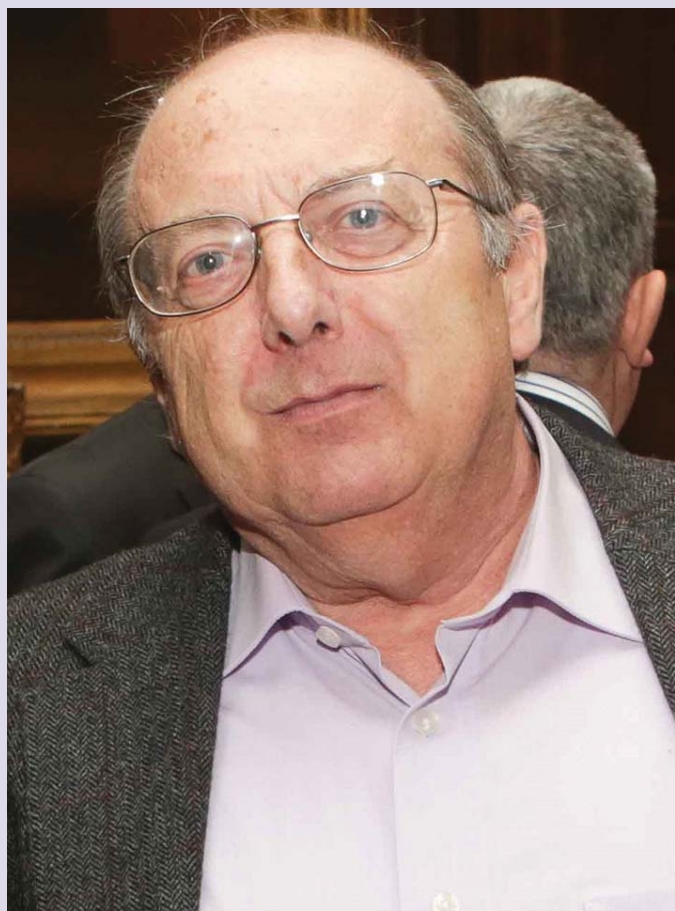
The two Federations (ETDSF and EHLTC) are working closely together with the Local Organising Committee in Lisbon, and they plan to release more details soon.

You can keep up to date if you follow the **Transplant Team Ireland** website and social media activity.

COLIN WHITE



A tribute to CYRIL KELLY



It was with great sadness that we learned that Cyril Kelly passed away on August 18th, 2023, having retired as Irish Kidney Association's Financial Manager just three years ago.

A transplant recipient and long-time servant for three decades to the Association, Cyril's dedication and genuine commitment to the wider renal community was known and appreciated by all. His gentle demeanour and sense of humour ensured that he was much loved by all his colleagues in Donor House. As many a Branch Treasurer throughout the country will attest, Cyril was always there supporting them and offering encouragement.

The staff and Board of the Irish Kidney Association offer their deepest condolences to his wife, Mary, and his son Paul. Ar dheis Dé go raibh a anam.



WHEN NEXT WE MEET

Alternative Irish Music Festival

Our thanks to **When Next We Meet** festival organisers and musically talented Kate Twohig, a liver transplant recipient, and her husband Eoin, for promoting organ donor awareness at the festival held in Clonmel on July 22nd and 23rd.

This was the second year for the outdoor alternative Irish Music Festival which was set in the idyllic



grounds of Raheen House Hotel. Over the two nights, award nominated Irish artists and local

emerging acts intertwined with an audience of close to 500 providing for an intimate unique gathering.

Kate Twohig and her husband Eoin Hally.



FEEDBACK SURVEY

- A small sample of your views

In December 2022, through **SUPPORT** magazine and social media, we asked for your views on what is important to you about the Irish Kidney Association (IKA) and the services and supports it offers.

The results were based on 92 respondents scoring 13 priorities rating them in order of importance.

There was a small number of respondents, in terms of the IKA's total membership, and some respondents may not have used a specific service. It is also worth noting that some IKA services were interrupted by COVID-19. The survey still offers a valuable anecdotal glimpse into what the majority might prioritise, based on the responses received from those who did participate.

This will assist the IKA in its planning for the future.

FINDINGS

This is a very brief overview on the information returned by a disappointingly low 2.5% of the total membership. There was a higher response from transplant recipients (57.5% of respondents) than dialysis patients (16.3% of respondents). In future surveys we will have to consider how to increase the response rate so that we encourage more response participation particularly from dialysis patients.

While there was no overall rating of the IKA services, the majority of the comments about the IKA were positive. It was encouraging to see that we are directing so much of our efforts to those services patients value most e.g. Patient Aid and Counselling.

The preliminary ratings confirmed the challenge facing our branches with much work needed to support,

grow, and promote branches to patients. We also need to do more to create awareness about the Sports programme, promote its proven physical and emotional benefits, and encourage participation.

In another study which is ongoing on Patient Experiences in the Healthcare system, we are

collecting additional information about patient perceptions of the IKA and with 800 responses to date this will further assist us in tailoring our services to the renal community. You can read more about this other study on page 9.

CAROL MOORE

RESPONSE RATE:

Total Number of Respondents:	92
% of total membership:	2.5%

NUMBER OF RESPONDENTS

Numbers or Respondents based Nationwide:	66 (72% of respondents)
Numbers based in Dublin:	26 (28% of respondents)

PROFILE OF THE 92 RESPONDENTS

	Number	% of Respondents
Carer or Friend of Patient	1	1.1%
Dialysis Patient	15	16.3%
Family Member of a Patient	8	8.7%
Kidney Disease Patient (not on dialysis or transplanted)	9	9.8%
Kidney Donor	3	3.3%
Other / incomplete answer	3	3.3%
Transplant Patient	53	57.5%

THE TOP FOUR PRIORITIES WERE:

Patient Support / Financial Aid
Counselling
Promoting organ donor awareness
Re-opening of the Renal Support Centre at Beaumont

RESPONDENTS PLACED LESS IMPORTANCE ON:

Annual Service of Remembrance & Thanksgiving
Sports Programmes
Branch meetings and Branch volunteer support
SUPPORT Magazine

People could also offer additional comments which revealed there was a clear preference for the Renal Support Centre at Beaumont, compared to the provision of Dublin hotel accommodation.



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



Find us on:
facebook®

Deirdre Cleary, one of our members, together with family, friends and staff from B. Braun Wexford, presented the Wexford Branch with a cheque for €3,698.50, the proceeds from a cycle they completed on June 24th.

The Ballycogley Players put on a play in the Opera House Wexford on June 23rd with the proceeds of €550 going to the Wexford Branch. The play entitled 'The Red Iron' was attended by our Chairperson Pauline and Secretary Walter and proved to be a very enjoyable night. Trish Boyce, who is a member of the Ballycogley Players, donated one of her kidneys to her dad John in December 2022.

We had the IKA exhibition trailer at the Bannow & Rathangan Agricultural Show in Killag on Thursday, July 13th. It was a very successful day with a huge amount of organ donor cards and information leaflets given out on the day. Many thanks to Liam for getting the unit on site and to Walter, Eddie, Philip, Catherine and Dora, who helped out during the day. €550 in donations to the IKA were received on the day.

WEXFORD

By MARIA DONLON



Cheque presentation to Wexford Branch for €3,698.50, proceeds from a charity cycle in June.
(l-r): Janice Savage, Walter Kent, Deirdre Cleary, Mary Coyne, Pauline Atkinson and Eddie Kehoe.



Ballycogley Players Drama Group presented a cheque for €550 to the Wexford Branch, proceeds from their performance of 'The Red Iron'.
(Back, l-r): Paddy McGuire, Colm Doyle, Sean Carthy, Edward Kehoe, Mag Cloney, Pauline Atkinson, Annette Dunphy. (Front, l-r): Bridget Boyce, Walter Kent, Trish Boyce and John Boyce.

We held our Mass of Remembrance in Clonard Church, Wexford on Friday, July 21st, the first time for it to be held since the arrival of COVID-19. There was a great turnout on the night. Special thanks to Fr. Billy Caulfield who officiated on the night and to the Rathangan Church choir who added to the

occasion with their lovely singing.

We lost three of our valued members who passed away recently, John Ashdown, Kathryn Kelleher, and Noel Dunne.

We extend our sympathy to their families and our thoughts and prayers are with them at this sad time.

CLARE By PEGGY EUSTACE

HOLIDAYS

Hello to all who are receiving dialysis treatment and all transplants recipients. We do hope you had an enjoyable summer. There is some availability for the remainder of the year in the Kerry holiday homes. Fill in the application form to book online, or alternatively contact Deborah at Donor House on 01-6205306.

SERVICE OF REMEMBRANCE & THANKSGIVING

The IKA annual Service of Remembrance & Thanksgiving will be held at 2pm on October 14th in the

Cathedral of Christ the King, Mullingar, Co Westmeath. This year people are asked to register their interest in attending, details on <https://ika.ie/service2023/>

SYMPATHY

The Clare Branch extends its sincere sympathy to the family of the late Cyril Kelly who passed away recently. He was such a kind and gentle person. During his time as Financial Manager at Donor House, Cyril gave great assistance to our Branch Treasurers.

May his gentle soul rest in peace.

GALWAY

By PEADAR O HICI



Peadar O hici, Secretary, Galway IKA, Anthony Hoban and his helper.



Paul Leufer, Tuam Cycling Club (TCC) Treasurer, Mike Gilligan, TCC member and dialysis patient and Peadar O hici.

On Sunday, August 6th, the community of Woodford, in south east Galway, organised a fund raising 'Tractor Run'. Over 100 tractors from vintage models to latest Agricultural models, plus over 40 vintage cars traversed 20 kilometers of rural south east Galway. The community, under the direction of Anthony Hoban, have been fundraising for a number of years for different charities. This year they choose the IKA as a charity partner.

It was a spectacular sight to observe the convoy sneak through the narrow country road. After the run the community returned to Woodford where the ladies had organised a monster barbecue. Music and singing carried on into the early hours of the bank holiday Monday. At first count over €8,000 had been raised.

Tuam Cycling Club donated €3,000 to IKA, proceeds from a charity cycle. The club also donated €3,000 to Tuam Cancer Care. Tuam Cycling Club member Mike Gilligan undergoes dialysis treatment and won a silver medal at the European Transplant & Dialysis Sports Championships in Oxford in 2022.

During Organ Awareness Week, held at the end of May, the Galway Branch shared an information desk in the reception area of University College Hospital, Galway, with medical staff who were promoting the 'Memory Box' project, developed by the nursing staff aimed at relatives of deceased patients.

It was a very successful day and doctors, nurses and visitors visited the stand and took some literature and exchanged views on the importance of both the awareness campaign and the memory box project.

When Teresa Smyth returned to her home town, Williamstown, from the World Transplant Games held in Perth, Australia, with her silver medal, she was met on the outskirts of the town by relatives and friends and marched into Williamstown, led by the Castlerea Brass and Reed Band.

A stage had been erected there where various local dignitaries greeted her. The Galway IKA was represented by Peadar O hici who spoke about organ donation and distributed IKA leaflets and forget-me-not flower emblems to the gathering.



Gillian Shanahan (right), the new Organ Donor Coordinator in the Saolta Group with hospital staff and Martina Goggin (second from left). Martina donated her son's organs when he died.

It was a great opportunity to promote organ donation and Teresa also spoke about the life-changing successful kidney transplant she received 21 years ago.



Welcome home gathering for Teresa Smyth.





Hello and welcome to all our members in the Dublin East and Wicklow Branch. We hope you all are keeping well, and enjoyed the summer and were pleasantly surprised after the unseasonal weather to finally enjoy some sunshine with an Indian summer in early September!

KILMACANOGUE HORSE SHOW

Again, for its 51st year, Kilmacanogue Horse Show which took place on Saturday, July 22nd and was a resounding success. The weather stayed dry, except for one small shower fairly late on. Like last year, there were horses and ponies of all sizes, a huge variety of dogs, and all sorts of other interesting events. We were grateful that the Show committee decided to continue their association with their local Branch of the IKA.

A presentation will take place later in the year.

CHARITY RUN/WALK

The Dublin Mountain Running Club is holding a 19k trail run and a 5k Fun Run/Walk at 9am on Saturday, November 25th with some of the proceeds going to the IKA, inspired by young local man, Cillian Doyle, who over a year ago was undergoing dialysis treatment, but thankfully underwent a successful transplant in August 2022. Best wishes to all taking part in the event.

CHARITY TRACTOR RUN

Again this year, Glencullen local, Ger Mulvey, will hold another tractor run in Glencullen on Sunday, September 24th, in support of Cillian Doyle with proceeds to the IKA.

All are welcome.

DUBLIN EAST & WICKLOW

By RACHEL O'HORA



Rachel O'Hora and Jacqueline Burke.



Caroline and Stephen Cotter.



Caroline Cotter and Charlotte Mooney.



Eamon Kehoe.



Michael Dwyer.



Michael Dobbey.

BRANCH MEETINGS

We urge all our members to attend Branch meetings, the next of which will take place on Tuesday, October 3rd, in St Anne's Resource Centre in Shankill at 7.30pm.

CONDOLENCES

The Dublin East and Wicklow

IKA SUPPORT AUTUMN 2023

Branch would like to extend its sympathies to the family and friends of Cyril Kelly, retired Financial Manager of the IKA, who sadly passed away in August. Many of our members, and particularly past committee members, remember Cyril with great fondness.

Ar dheis Dé go raibh a anam dílis.

TIPPERARY

By MARY ADAMSON



Anne Hogan, Margaret Dodd, Bridie Corkery and Una Spillane supported the IKA Cahir Golf Classic.



Sheila Gregan receiving cheque for €7,000, proceeds of the IKA Golf Classic, from Martin Slattery, Captain Nenagh Golf Club and James Dodd, IKA.

The Tipperary Branch has resumed meetings since September following the summer recess, and we hope to see more of you now that we are back face to face again.



Pictured at the Clonmel Show, in July were: Ann Nolan and Mary Adamson.

Congratulations to our Branch Chairperson, Ann Hackett, following her recent kidney transplant. We wish her every success and good health.



Pictured at the Clonmel Show, in July were: Mary Adamson and Joan Gavan.

Despite the inclement weather the Branch were busy fundraising.

A successful golf classic was held at Cahir Park Golf Club, in aid of the IKA and the Irish Wheelchair Association (IWA). Many thanks to Paul Adamson and Vera O'Dwyer for organising. Vera's daughter Lorraine is on dialysis as well as a member of the IWA.

Nenagh also ran their annual golf classic with very successful fundraising. Many thanks to James Dodd for his long-standing valued dedication to fundraising for the IKA, and to all the sponsors, donors and supporters.

We had a stand at the Clonmel Agricultural Show on July 2nd and used the occasion to promote organ donor awareness and distributed close to 500 organ donor cards.

Looking forward to seeing our members in person soon.



Pictured at the Cahir Golf Classic (front) Lorraine O'Dwyer (IKA and IWA), Vera O'Dwyer (IKA and IWA), winners overall Michael Condon, John Darmody and Mary Adamson IKA.



Winning ladies team at IKA Golf event: Mary O'Sullivan, Nollaig O'Grady, Carmel Vekins and Patsy Daly.



SUMMER BBQ

Our summertime barbeque took place on Sunday, August 20th. The weather was very kind to us, and we were able to wander outside in the lovely grounds of The Vienna Woods Hotel.

Along with a great turnout from our patient cohort, we were also joined by renal specialist nurses from CUH and IKA Donor House support staff Fiona and Sarah.

Some new patient members joined us and lively chats were had!

Thanks to the Vienna Woods Hotel who put on a lovely spread for us.

SUPPORT CENTRE, CORK

Work is continuing on the new Support Centre adjacent to CUH. The project is nearing completion,

CORK

By SHEENA McDONAGH



and we can't wait for the final unveiling.

The Support Centre will be a great addition to the overall care of patients travelling from all parts of Munster and we anticipate that its use will be of benefit to all renal patients.

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



Sitting: Angela Hawe, Colette Hawe, Frances O'Shea, Wesley O'Shea, Sally Nagle, Jackie Whittaker. Standing: Graham Whittaker, Sheena McDonagh, Bernard Cronin.

CORK SERVICE OF REMEMBRANCE

We are in the middle of organising the Annual Mass of Remembrance, to be held in Cork in November.

Details will be available soon.

Photos courtesy of DENIS HYLAND



Helen O'Sullivan, Pat O'Sullivan, Wesley O'Shea, Matt McAuliffe, Celine McAuliffe.



Pat Rice, Alison Rice, Racquel Hegarty and her husband Michael.



Fiona Hanlon, Liz Hyland, Alex Hanlon and Adam and Lucy Hanlon.

CORK

CONTINUED



Rosarie and Daniel White.



Donal and Michele Fenton.



Ashleigh, Helen and Sarah Faughnan.



Morgan Lyons and Colette Hawe.

LEITRIM

By CATHRIONA CHARLES



Frank Heslin is joined by TV personality Katherine Lynch (left and above), at our stall in Mohill Show.



Katherine Lynch.

We attended two local agriculture shows and a harvest festival where we talked to people about our stories and organ donation in general, distributed donor cards and other merchandise.

We also had a collection bucket for the IKA and people were very generous.

The Branch meeting will be held in Duigans of Drumsna on Friday, September, 29th at 7pm. We look forward to seeing everyone after the summer break.



Cathriona Charles and Charles Beirne at the Ballinamore Show.



Cathriona Charles at the Lough Rynn Harvest Festival.



Annetha Kieran is joined by the Reidys from Limerick, whose daughter Miriam became an organ donor, when she passed away in 1997. The Reidy family attends the Annual Service of Remembrance & Thanksgiving every year and are looking forward to attending the upcoming event in Mullingar on October 14th.



Hello all, I hope everyone is feeling well and happy that we finally got some late summer sunshine.

On Sunday, July 2nd, the Kilkenny Branch arranged to hold a Summer Fun Day for people at different stages of kidney failure, including pre-dialysis and dialysis, as well as successful transplant recipients, their family members, friends and neighbours. It was a lovely event for all ages as the sun was shining outside under our umbrellas and there was music, face painting and a slice of pizza and a cuppa to enjoy, with lots of friendly conversation. We raised €1,245, of which an outstanding figure was given in sponsorship.

On July 30th, the Branch held a very belated AGM where the new Committee were elected.

Our new Branch Chairperson, Owen Hanrahan, just recently achieved his dream which was motorcycling through Germany, Austria, Slovenia and Italy, for two weeks. He also celebrated his 45th birthday with his incredible friends



Owen Hanrahan

KILKENNY

By SARA SANTI



and marked the upcoming fourth anniversary of his kidney transplant.

Owen, after being diagnosed with renal failure when he was 36-years-old, spent four years on dialysis until he received his call for a transplant.

He said: "Before my transplant, four years ago, I was barely living". Owen shared that he cannot express how grateful he is to his donors family as he now is enjoying working, and spending time with his family, including his three sons, as they grow up. The transplant also allows him to be well enough to be a supportive husband to his wife Therese who was his rock through his very tough years of ill health.

He also expressed his gratitude to the incredible wonderful professional staff in Dublin, Waterford and Kilkenny, that care for people with renal failure from day-to-day. The gift transplant recipients



receive from the selfless donors has a profound impact on them and their grateful families. We wish Owen continued good health.

The Branch is holding its next meeting in a few weeks' time and is looking forward to catching up with everyone again and also welcomes newcomers.

All members will receive an email with the date, time and venue of meetings well in advance. The email will include contact details for Branch representatives who are happy to offer advice and support.



WATERFORD

By FRANCES MOYNIHAN



Members of the Newtown/Kilmacthomas Fundraising Committee presenting a cheque to Ray Halligan, Chairperson, Waterford IKA branch. (l-r): Mary Bagge, Ray Halligan, Anne Power, John Joe Bagge and Martin McNamara. Photo: Joe Cashin

We are nearing the end of a very successful holiday season in the Tramore Apartments. Although the weather may not have been the kindest for some of it, all visitors were happy to have a holiday in Tramore and enjoy the South East coast.

Huge thanks to Cathy Keoghan who meets and greets our guests on arrival and is on hand if issues arise. We also extend thanks to Emma, Dickie and Andy, for their work at the

apartments on our behalf.

We have had a busy summer with some very successful fundraisers held locally in aid of the Association.

The Newtown Fundraising committee has again chosen us, along with Downs Syndrome Ireland, to be the beneficiaries of their fundraising events and presented our Branch Chairperson, Ray Halligan, with a cheque for €3,000 in Lenihan's Bar, Newtown, Kilmacthomas recently.



Ray Halligan thanked the Fundraising Committee for their donation. Photo: Joe Cashin

DONEGAL

By PATRICIA CALLAGHAN

The Donegal Branch has been very quiet over the summer with a lot of members on holiday.

For Organ Donor Awareness Week, which was held at the end of May, the Branch held a coffee morning in Ballybofey, organised by Board Member Jennifer McDermott and her husband Seamie, the Branch Chairman. The event was very enjoyable and well attended.

We also had an Information Stand at SuperValu, Donegal



Town. Many thanks to Marie Brogan and Patricia Callaghan who handed out donor cards and answered many queries on the day.

Cathal and Kathleen McGee, who have been great supporters of the IKA, raised €1,120 during the summer and we thank them very much.

We are hoping to hold a memorial service in Letterkenny in the coming months – details to follow.

A Branch meeting was held on Tuesday, September 12th in the Station House Hotel, Letterkenny.

Wishing you all the best from the Donegal Branch.

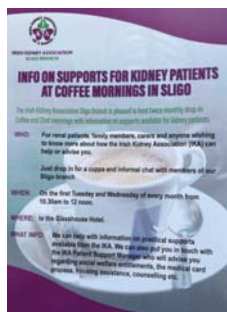


Cathal & Kathleen McGee with Board Member Jennifer McDermott (centre).



INVITATION TO INFORMATION MORNINGS

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



Branch members will be in the Glasshouse Hotel on the first Tuesday and Wednesday of every month from 10.30am to 12noon with information on supports available for all kidney patients. We started back on September 5th and 6th after the summer break.

All renal patients, family members, carers, and anyone wishing to know more about how the Irish Kidney Association can help or advise you, are invited.

The information mornings are for all patients or family members regardless of where they are at on their kidney disease journey.

You may have just been diagnosed with kidney disease and would like to talk to people who have been down that road? Or possibly you have been on dialysis for years and waiting for that transplant call? Perhaps you are one of the lucky ones who have already got a transplant? Either way Sligo Branch members will be there for you.

We can help with information on practical supports available from the IKA. We can also put you in touch with the IKA Patient Support Manager, who will advise you regarding Social Welfare entitlements, the medical card process, housing assistance, counselling, etc.

SLIGO

By BRIAN McHUGH



Branch members in the Glasshouse Hotel, organising the Information Mornings.

Just drop in to the Glasshouse Hotel for a cuppa and informal chat.

FEASIBILITY STUDY NEXT UP IN BID FOR NEW UNIT

Over recent months our Branch has been continuing to push for a new Renal Unit at Sligo University Hospital.

The current unit opened in May 2005 when it catered for 30 patients – the facility now has more than 70 patients.

Sligo is now the oldest dialysis unit in the country that has not been modernised. Overcrowding is a problem and it lacks other facilities for patients and medical staff.

Another concern is that there is no proper waiting room for patients attending renal clinics. They must sit in a corridor connecting the hospital to the hospice next door.

Following a request for an update on progress with the unit, hospital management informed our Branch that the project has received what is termed initiation approval.

Their next step is to get funding for a feasibility study. The study will examine possible locations for the unit. When completed the study will form part of a submission for capital approval.

Earlier this year Chairman Sean Fowley, Secretary Geraldine McHugh, and Director Marie Fowley, met with hospital management on

the issue.

Also in correspondence for the unit several letters have been exchanged, between our Branch Secretary and the Minister for Health, the Saolta Hospital Group and Sligo University Hospital management.

We have found that there are several preliminary stages to the procurement for a project like this and each of them seems to take a long time. If we find a way to help expedite the process we will do so.

GARDEN GETS A FACELIFT

In August our Garden of Reflection at Doorly Park received a complete overhaul.

The work was funded through a welcome donation from Moylough Concrete for the maintenance of the garden. The work was carried out by local gardener Gerry Devins.

With the overhaul completed, the ongoing routine garden upkeep will be done by our volunteer members. Eileen Nolan.



Cheque presented to Sligo IKA Branch by Michael McHugh, on behalf of Moylough Concrete, for the overhaul of the garden.

SLIGO CONTINUED



Branch Chairman Sean Fowley presents a cheque to gardener Gerry Devins for his work. Also in picture are Branch members Marie Fowley, Geraldine McHugh and Eileen Nolan.



Tommy Banks, Phoenix Bridge Club, father of Orla Banks, with Niamh Banks, presenting a cheque for €2,000, proceeds of the event, to Geraldine McHugh, Secretary, Sligo IKA Branch.



FUNDRAISING IN MEMORY OF LATE DOCTOR

Funds raised by the Bridge playing community of County Sligo, in memory of the late Doctor Orla Banks, were presented to the Irish Kidney Association Sligo Branch. The Bridge players held a charity fundraising game in remembrance of the 31-year-old doctor of Kestrel Drive, Kevinsfort, who passed away after a short illness last year at Sligo University Hospital. The young doctor had worked in the paediatric department at the hospital. The Bridge game held in the Southern Hotel raised €2,200.

NEW MEMBERS INVITED

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

Acknowledgements of Deceased Loved Ones

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

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

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





Greetings from Dublin North. We hope you all had a great summer and that you are enjoying the good weather at the moment.

We would like to congratulate all who competed in the British Transplant Games, held in Coventry this summer, especially North Dubliners Harry Ward, Peter Heffernan, and Ivan Kinahan and Sam Kinahan. Well done to you all.

We had a great night in the Grand Hotel in July with talented crooner and long-time IKA supporter Red Hurley, who, once again, lined up a host of other impressive guest

DUBLIN NORTH

By COLETTE FOX



Red Hurley, Ann Burke, Colin Mackenzie and Colette Fox.

performers along with himself, to provide an hugely enjoyable fundraising night, in aid of the IKA. There were some great raffle prizes for lucky prizewinners.

Colette Fox, Colin Mackenzie, Ann Burke, Red Hurley and Tony Byrne

met up in the Grand Hotel to receive our cheque for money raised. Thanks to Tony Byrne for all the photos.

We are back at our meetings at the end of September. All are welcome to come along.



(l-r): Martin Cahill, Teresa Byrne, Chloe Kinahan, Ann Burke, Colette Fox, Tess Burke, Harry Ward and Narender Katta.



Dublin North Red Hurley & Guests Fundraiser





BIRTHDAY CELEBRATIONS IN MONAGHAN

On Saturday, July 8th, there was a double celebration in Paddy Lynch's pub, Lisnalong, Co. Monaghan as Eugene Mooney turned 50 and his daughter, Kaitlyn, turned 18. The father and daughter duo asked their family and friends to donate to the IKA, in lieu of presents, and a whopping €2,000 was raised for the Cavan/Monaghan Branch.

Eugene received a very successful kidney transplant 18 years ago in 2005, after spending 3 years on dialysis in Cavan General Hospital. Three weeks later, as Eugene was adapting to life with a new kidney, he and his wife Veronica welcomed baby Kaitlyn into the world.

Eugene describes getting his new kidney, becoming a new dad and getting married within 12 months, as a whirlwind of a year, and says it's hard to believe that was all 18 years ago now. Eugene and Veronica's son

CAVAN/MONAGHAN

By KARL CRONIN



Jack Mooney, Kaitlyn Mooney, Eugene Mooney and Karl Cronin.

Jack was born in 2015 to complete the family of four.

Kaitlyn commenced peritoneal dialysis in March of this year and is currently on the waiting list for a kidney transplant. She has adapted very well to peritoneal dialysis and hopes that a new kidney will come along in the near future and be as successful as her dad's transplant was. We wish to thank Eugene and Kaitlyn and the Mooney family – for supporting the work of the IKA.

MULLAHORAN WALK

The 17th Annual Mullahoran Walk was held on Sunday, April 30th, 2023. To date the annual event has raised over €203,000 divided out

between nineteen worthy charities including the IKA and the Cavan Dialysis Unit.

A total of €11,800 was raised from this year's event with proceeds going to the Cavan Dialysis Unit and Ronald McDonald House at Crumlin Hospital, both receiving €5,650 each, and an additional €500 was given to Transplant Team Ireland.



Cheque presentation to Cavan Dialysis Unit.



Taking part in the Mullahoran Walk... (l-r): Fiona Reilly, Mary Sullivan, Rose Dalton and Grainne Lovett.

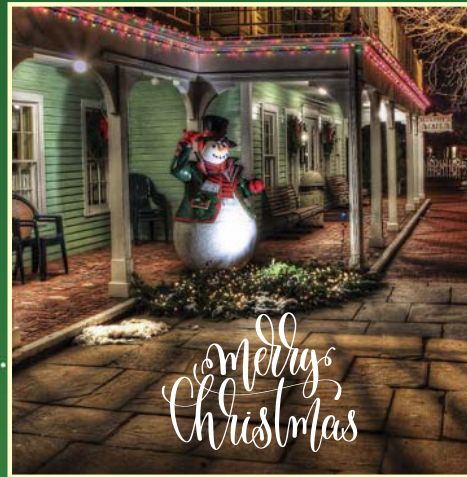
Do you have an upcoming event or fundraiser?

We would be delighted to add it to the events calendar on our website – just email robyn@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 Winter edition of SUPPORT is 20th November, 2023.

12 Christmas Cards AND ENVELOPES



**ASSORTED
DESIGNS**

*Made in
Ireland*

The entire proceeds from the sale of these charity cards go to support the IKA's work for dialysis and transplanted patients in Ireland.

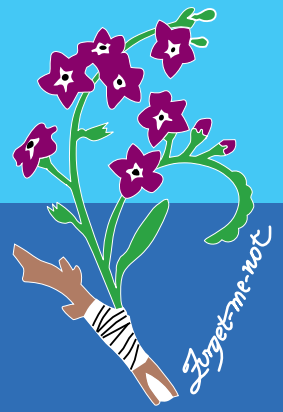


See IKA website www.ika.ie
or phone: **01-6205306** for details





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