

SUPPORT



AUTUMN 2022



IRISH KIDNEY ASSOCIATION CLG

(Company Limited by Guarantee)

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CHARITY REGISTRATION NUMBER 20011260

Editorial



I open with the very sad news that Patricia Mackenzie, a much-loved staff member, volunteer and friend, died suddenly after a short illness in July. Many of you will have known Patricia from her wonderful work in the Beaumont Renal Support Centre. It gave great solace to us in Donor House, her family and friends, to see so many kind words of condolence. You can see a full tribute to Patricia on pages 12 to 13.

In happier news, after a competitive tendering process, a builder has been appointed and has started work on the new Cork Renal Support Centre. You will see photos on page 58.

We are now planning for the return of the Renal Support Centre at Beaumont Hospital to the Irish Kidney Association following it being sequestered when COVID-19 arrived. Notice has been given to the Hospital that we will be re-taking possession of the Centre in March 2023 after which refurbishment will be required.

Part of the building's roof will have to be removed to allow for new water tanks to be installed to resolve water quality and pressure issues. The project plan and costings are currently being developed and will be brought to the Board for approval in October. It is likely that significant additional expenditure will be required.

We will also be seeking your views on the Centre and on what it

should offer to patients and their families.

An article on the latest COVID-19 treatments can be found on page 34 and we continue to advocate for clearer pathways for renal patients for these treatments. We encourage everyone to get their booster vaccination and you can find out more on page 35. We also encourage those vulnerable to influenza to also get vaccinated for this.

The cost of living continues to drive increased demand for our services and cause high levels of stress for patients. The number of referrals to counselling has doubled since 2019 and the IKA's patient aid



expenditure has quadrupled in the six months to June 2022, compared to June 2021. This increase in demand means it is now taking three to four weeks to respond to requests for support.

The Board has now approved both an increase in the budget for patient aid and the appointment of two part-time assistants to help us to keep up with demand.

We have been active in the media requesting more supports for renal patients and will continue

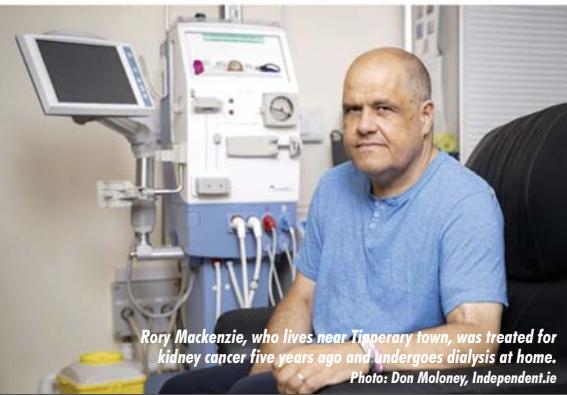
FRONT COVER

Midlands couple Briona Reynolds and Shane Hunter on their wedding day in August, two years after their living donor kidney transplant.

Photo: Moat Hill Photography

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'Our bill has already doubled' – father on home dialysis hits out over threat of electricity blackouts this winter



Rory Mackenzie, who lives near Tipperary Town, was treated for kidney cancer five years ago and undergoes dialysis at home.
Photo: Don Moloney, Independent.ie

to raise awareness of the impact of electricity costs. You can see our press release on our website.

If you have not changed energy supplier in the last year, it might be very worthwhile doing this now as cheaper prices are offered to new customers. We also encourage those who are eligible to register as a vulnerable customer to avoid energy supply cut-off for non-payment and a higher priority in the event of electricity outages. More details on pages 14-16.

The new Board has already met three times and are actively examining key areas from volunteer recruitment, compliance with the Charities Governance Code, and supports for Branches. The recruitment of a new national volunteer and organisation manager will help us to improve the supports we provide for Branches.

We recently held a Branch forum with many new officers and lots of good ideas and enthusiasm.

Congratulations to the sports team who travelled to Oxford in August and represented Ireland so

well. They also generated lots of publicity raising organ donor awareness.

We also continue to work to raise organ donor awareness in the media and recently covered two uplifting stories. There was lots of publicity around two friends, Ally and Roisin, both kidney transplant recipients, who started back to school (see page 8-10). Our cover story about Briona and Shane's nuptials, following their living donor kidney transplant, also generated widespread publicity along with transplant recipient John Egan who also got married this summer (see pages 18-19).

Our thanks to *Hot Press* magazine for supporting us by distributing promotional leaflets including organ donor cards to third level students in universities and colleges around the country during Fresher's Week.

We will be holding a free Zoom event on 'shared care in haemodialysis' for both patients and healthcare professionals which allows patients to take more control of their own care. Details on page 42.

Another exciting development is the award of a major grant from the HRCI/HRB Joint Funding Scheme towards research into 'patient reported outcomes' for patients with rare kidney diseases, referred to as Glomerular Disease (GD).

This research, which will be conducted in partnership with University Hospital Galway and the Irish Nephrology Society, will give a strong voice to GD patients. Patients

will be asked what is most important to them in terms of their treatment and this will guide future healthcare treatments (see pages 40-41).

The IKA's pre-recorded 37th Annual Service of Remembrance and Thanksgiving will be shown on RTE 1 at 11am on Sunday, October 30th.

Our community continues to do major work in fundraising including some cycling events which took place over the summer months. The Upperchurch Drombane Cycle has raised over €27,000 for the IKA (covered on pages 36-39) and another cycling event, Pedal the Peaks, which took place at the end of August has raised over €40,000 over the past number of years. (further details in our next edition).

Finally, our thanks to all the volunteers who applied for the Peer Supporter role. Such was the high standard of applications that we were unable to recruit all volunteers. So many applicants had great ideas and passion with the all-important qualities of empathy and kindness.

There is great interest in the Peer Support service, not just from patients but from healthcare professionals, and we are really looking forward to the training programme (see pages 32-33).

This can be a very stressful time for many people facing into a difficult winter. Please remember, that many of our 25 Branches have now restarted physical Branch meetings, and that support is available from your local Branch and from Donor House.

Stay Safe.

**CAROL MOORE
CHIEF EXECUTIVE OFFICER**

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MESSAGE FROM THE NEW NATIONAL HONORARY CHAIRPERSON

Eddie Flood

Dear Members and Friends

As a grateful kidney transplant recipient myself, it is a great honour for me to introduce myself to our readers as the new National Honorary Chairperson of the Irish Kidney Association, having previously held the role of National Honorary Treasurer.

I thank my lovely wife Jennifer and my four adult sons who supported and encouraged me in my decision to take up this role and its additional demands of my time while also continuing serving as the Westmeath Branch Chairperson.

I wholeheartedly commend our retired Chairperson Colin Mackenzie for demonstrating great leadership and wisdom over the past three years in guiding the Association through a very challenging time in its 44-year history. I have gained great insights and experience from both Colin and the former National Honorary Secretary John Whelan, who previously served as National Chairperson, and has now retired. Through working with these two men, we have forged lifelong friendships.

I extend my deepest sympathy to Colin and his family on the recent passing of his wife Patricia Mackenzie, a long-time friend and dedicated member of the Association, who served as Branch Secretary of the Dublin North Branch, and also co-managed the Renal Support Centre. Patricia always had a smile and kind word for everyone she met. Rest in Peace.

I look forward to working with the 25 members of the Board including the newly appointed fellow national officers, Marie Fowley, National Secretary, and Joan Gavan, National Treasurer. I also look forward to working closely with the IKA's CEO Carol Moore and the staff at Donor House, while championing and overseeing the wonderful work of the Irish Kidney Association, made possible by its valued grassroots membership of over 3,000 people, including volunteers from 25 Branches.

Recently I travelled to Cork and had the pleasure of meeting with members of the Cork Branch and our builder Pascal Falvey who is undertaking the renovation of the Cork Renal Support and Accommodation Centre. We look forward to the opening of this wonderful facility next year which will mirror the Support Centre in Dublin at Beaumont Hospital, and will serve patients from the South attending Cork University Hospital.

I am delighted to inform you of our Peer Support Programme, which is being rolled out in the coming months, generously funded by the Punchestown Kidney Research Fund.

Our patients' services, support and counselling, have met with unprecedented demand and we endeavour to continue to support patients as best as we can going forward.

The IKA's 37th Annual Service of Remembrance & Thanksgiving this year will be virtual, due to the continued presence of COVID-19. It will be pre-recorded at Newman University Church on St. Stephen's Green in Dublin and broadcast on RTÉ One on Sunday, October 30th at 11am. This is a very special occasion and I invite you to tune in, light a candle for donor families and transplant recipients.

As we are approaching Winter time, I urge everyone to avail of the booster programme that's available to stay healthy. As the energy crisis grips, I encourage those qualifying as 'vulnerable customers' to register with their energy providers.



Join the organ donor conversation

Cork University Hospital recently launched its “#7livesaved” organ donor public awareness campaign. The launch coincided with Ireland’s National Organ Donor Awareness Week. The aim of this campaign is to encourage people of all ages to have a conversation and share their wishes on organ donation with family and friends.

In Ireland, over 600 people are currently on transplant waiting lists and you are six times more likely to need an organ transplant for treatment of end-stage organ failure than becoming an organ donor.

Unfortunately patients die in Ireland each year while awaiting an organ transplant. There is a considerable shortage of organs available to ensure each patient on the transplant list gets an opportunity to live a long and improved quality of life.

The organ donation team in CUH includes Breda Doyle, Organ Donation Nurse Manager and Dr. Adrian Murphy, Clinical Lead in Organ Donation and Consultant in Emergency Medicine who work with the wider CUH team in ensuring organ donation is considered in

appropriate situations within the hospital.

With the support of the HSE’s Organ Donation and Transplant Ireland (ODTI), CUH are very proud to be leading a unique organ donation awareness campaign within the hospital. What makes this campaign different is its focus on both healthcare professionals and also the public. Healthcare staff play a vital role in ensuring organ donation is considered in end of life options for patients where medical treatment have failed to improve the outcome of the patient and there is no prospect of recovery. We remember those donors and their families who selflessly give so many people the precious and priceless ‘gift of life’.

The visual campaign includes transplant recipients images lending



their support for donation who were former or current patients, recipient colleagues who work as part of the healthcare team whom have benefitted from donation and members of staff who support organ donation through their work in the hospital. There are organ donation teams throughout the country supporting families and hospital teams to ensure organ donation is considered and raised with families where appropriate. This team consists of an Organ Donation Nurse Manager and a Clinical Lead in Organ Donation.

Together the organ donation team work with the extended healthcare team in providing support to families in difficult circumstances in considering organ donation and helping to ensure it is facilitated where possible.

Although there is a tendency to focus on donation rates and numbers and ultimately we would like to increase donation rates, we passionately agree with a donation specialist nurse Leanne McEvoy working in the Australian healthcare system in Austin Health when she stated: *“Success is not measured in terms of donation rate or consent rates but rather as the proportion of families who, at the end of the process, believed they had made the right decision for the family/loved one”*.





New Board is working hard on your behalf

The newly elected Irish Kidney Association (IKA) Board of 25 members has already met three times with its first face-to-face meeting taking place on Saturday, September 3rd from 9.30am to 3.30pm. All agreed it was delightful to meet in person for the first time in over two years.

As well as looking at finances, the board also considered a number of topics. Stuart Garland from Volunteer Ireland presented on *'Latest trends in Volunteering in Ireland'*. COVID-19 has had a major impact and we need to develop new ways of encouraging and retaining volunteers.

Unusually, the Association does not have a staff member who is dedicated full-time to supporting volunteers.

The Board also looked at how we can better support Branches which are a key part of our new strategy. They also discussed future Board development.

The Board is appointed by each individual Branch but Branches sometimes struggle to find volunteers and are either not represented or their Directors have to serve for longer periods. Under the Charities Governance Code, the Board must

comply with certain standards as follows:

- ▶ Complete a Skills audit and recruit to fill gaps identified (Standard 5.14)
- ▶ Have a charity trustee succession plan in place and maximise diversity (Standard 5.11)
- ▶ Term limits for Directors – with nine years in total suggested (Standard 5.5)

So, the Board has identified a need to strengthen the involvement of patients as volunteers in diverse and different ways while continuing to ensure we are connected as a national Association that facilitates exchange and solidarity with core values of kindness and compassion.

The Board agreed to recruit a new manager who will be dedicated to supporting volunteering in the

Association and ensure that we retain and strengthen our volunteer ethos, which is a core value of the Association.

This new role will have the following responsibilities

- Develop a volunteer strategy including a pipeline to ensure continuous supply, retention and development of volunteers at all levels/roles from grassroots to Board
- Strengthen IKA competency and capacity in volunteering at all levels from local Branches to Directors at Board level
- Make explicit the IKA values and culture for how business gets done and the necessary behaviours expected in all parts of the IKA
- Work with Branches to identify their volunteer and skills' needs and develop pathways to ensure more members can volunteer in a way that suits them
- Set up processes and tool kits to facilitate the recruitment and training of volunteers for the Branch network
- Working with Branches, to plan and deliver the annual volunteer conference
- Work with the Board to identify skills' needs for Board Directors and develop pathways to ensure all branches can nominate Directors with relevant skill sets.

This role will be advertised in the coming weeks.

What is the role of the Board?

Directors act as custodians and they have certain legal responsibilities under both the Companies Act and the Charities Act. A Director, one from each Branch, is elected by its Branch, but legally their priority must be to act in the best interests of the IKA, and its overarching role, and not their Branch.

The Board ensures every decision made and every action taken is to protect the IKA, stakeholders and founders, to ensure that the Association delivers its charitable purpose long into the future.

The Board and Management have different responsibilities as shown below:

BOARD

- Set strategy, direction, high level goals and policies – always looking towards future development of the IKA
- Approves annual budget and plan
- Directs and oversees management via CEO
- Oversees performance to ensure charitable purpose is delivered
- Ensures compliance with a range of legislation
- Ensures Charities Governance Code is adhered to

MANAGEMENT

- Runs the IKA in line with goals and direction set by the Board
- Implements the decisions of the Board
- Makes operational decisions and policies
- Keeps Board informed
- Be responsible to requests for additional information

The Board is like a music conductor – setting direction and ensuring a quality performance. If the conductor starts playing instruments, chaos results. Likewise, if the Board starts doing the work of staff, they lose focus on future direction and in ensuring management accountability.

Therefore, the Board is vital to protecting and securing the future of the IKA.

CONGRATULATIONS

Congratulations to 12-year-old Bernard Óg Keaney from Roundstone, Galway who had the honour of presenting the game ball to the referee for the throw-in at the epic AIB All-Ireland Senior Football Final on 24th July 2022. He represented his club Clifden Youth GAA.

Bernard Óg, a patient at the Children's University Hospital, Temple Street, underwent a kidney transplant when he was six years old.

Well done Bernard Óg and commiserations to your home county Galway who put in an incredible game against the victorious Kerry team.



Transplant friends celebrate first school day



Ally Whitston, Roisin Byrne and Doodles

A child's first day at school is an unforgettable milestone for most families. However, its significance is an even more memorable celebration for the family of Ally Whitston (age 4) from Greenhills, Dublin and her friend, Roisin, both having recently received kidney transplants. Ally began junior infants on August 31st and can now look forward to a brighter future, thanks to her father David, who donated a kidney to her in March this year. Waving goodbye to father and daughter, as they walked hand in hand to school, were three generations of their family.



Also sharing in the celebration was Ally's friend Roisin Byrne (age 6) from nearby Belgard, Tallaght, who underwent a kidney transplant, from her donor mother Christina, just three months before Ally's.

Roisin was reunited with her classmates in 1st Class having previously only spent 20 school days since she began school in 2020.

Ally's grandmother Anne Sweeney was delighted to play host to the life affirming gathering of the two families at her Greenhills home. Ally's parents, Michelle and David, Ally's two younger brothers Riley (age 2) and Rian (age 1), and the Byrne family including Roisin, her kidney donor mother Christina, aunt Myra O'Brien, grandmother Betty Byrne and Roisin's dog, Doodles all attended.

Coincidentally, Ally and Roisin have shared many of the same experiences and timelines. Living in the same area of Dublin, they were diagnosed with the same kidney condition, Congenital Nephrotic Syndrome, for which they spent much of their short lives in Crumlin Children's Hospital. They commenced dialysis treatment around the same time, and they received transplants from

a kidney donor parent within the space of three months.

Roisin was born two years before Ally on the same date in mid-September. For decades their grandparents have lived in two neighbouring estates in Greenhills, Dublin 12 where their gardens are back-to-back.

Ally had spent the entirety of her first five months of her life in Crumlin Children's Hospital with one of her failed kidneys being removed during this time. Up until her transplant in March she had been hooked up to a dialysis machine in her home every night for 13 hours.

Roisin's diagnosis of her kidney condition was revealed when she was two years old. Like Ally, Roisin's life revolved around sickness and regular hospital stays until her transformational transplant.

For 18 months Roisin underwent nightly dialysis at home for 14 hours until her mother Christina donated a kidney to her on December 13th, 2021.

Ally's mum Michelle Whitston said on her first day at school, "It's an emotional day for me. I used to think of the milestones like today's,



The Whitston family, parents David and Michelle, Ally and her brothers Riley (2) and Rian (1) and her mother Anne.

wondering how well Ally would be for them. It's wonderful that she can start school in good health without the restrictions of kidney failure, dialysis and related sickness holding her back.

"My husband David is our hero for transforming Ally's life. It's just fantastic to see Ally and Roisin, who shared such similar health battles, getting a fresh start thanks to their successful transplants."

"The staff at Crumlin and Temple Street have been amazing in Ally's care and Beaumont Hospital has been fantastic in supporting me through the process of living kidney donation. My parents Michael and Anne Sweeney, have been our rock, with their practical and emotional support. David's employers,

Microsoft, have been wonderful employers and so understanding, all along, of our situation and it's great that he could be with us to celebrate this wonderful occasion.

"David was discharged from Beaumont 5 days after his operation and I collected him and brought him to see Ally in Temple Street. It was very emotional when they were reunited as they had been apart for two weeks with Ally being taken into hospital a week before transplant in preparation for the operation.

"It was amazing to see how well she had improved and that her blood pressure had stabilised. She looked so well.

"She was allowed home two weeks after the operation and we haven't looked back since."

contd...

Transplant friends celebrate first school day contd...



Kidney donor David Whitston proudly stated, "I wouldn't have missed seeing Ally start her first day at school for the world. We are all so happy to have come to this point. A huge weight has been lifted. Donating a kidney was the least I could do. Michelle did all the hard work up until then caring for Ally, staying with her in

hospital for the first five months and all the visits and overnight stays afterwards, while also looking after our two boys who came along later."

Roisin's kidney donor mother Christina Byrne said, "I'd like to really thank the staff in the nephrology ward in Crumlin Hospital, they were like a second family to us. I'd also like to

Christina Byrne with her mum Betty and Roisin and her cousin Fiadh (4).



Ahead of Father's Day the Whitston family, David & Michelle with Riley, Ally and Rian.

thank the surgical medical and nursing staff at Temple Street for their excellent care of Roisin and Ally.

"Roisin spent most of her young life in hospital and only 20 days in school since she started two years ago. Reading inspiring stories about other children and adults who received transplants in the Irish Kidney Association's *SUPPORT* magazine and elsewhere kept me going over the past few years.

"These stories gave me hope that one day Roisin's day would eventually come. I never expected Roisin to be so well and healthy following her transplant. It has far surpassed my expectations. I feel like I've won the lotto. After all she's been through it's amazing to see her so well. It's a miracle. She'll be able to enjoy a normal happy childhood. She was really looking forward to going back to school and renewing friendships with children in her class."

Christine continued, "It was a hugely emotional time when I was separated from Roisin, while being operated on at Beaumont

Hospital, while Roisin, who I hadn't seen for a week, was in another hospital across the city, Temple Street, undergoing an operation to receive my kidney. But it was a great relief to know that my sister Myra was with her for all this time and she and her husband John O'Brien made a huge sacrifice cocooning with their two children for two weeks to ensure that she could be with Roisin."

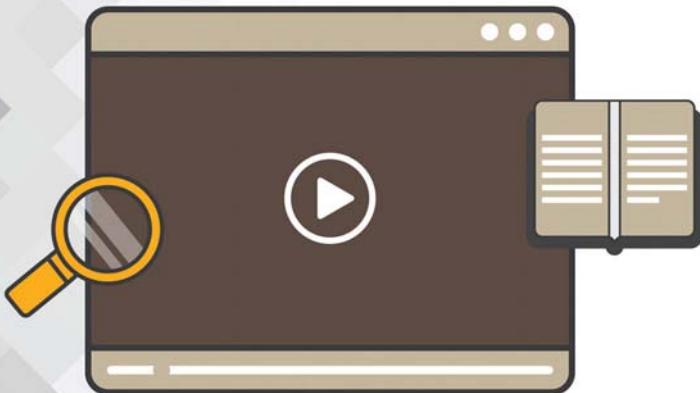
The girls' families shared their happy outcomes with national and local media to support the IKA in promoting the importance of organ donation and transplantation.

For them reading stories in *SUPPORT* and elsewhere about adults and children receiving transplants gave them hope when they were living with health struggles and uncertainty of what the future held. Their wish is that, in turn, by sharing their story of triumph over adversity, they can give hope to others who are in organ failure and demonstrate the truly transformational impact of successful transplantation.

SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK



BEWARE OF WHAT YOU SHARE ONLINE!

MINDFUL SHARING

We're now at the end of summer, and if you have a social media account you have likely spent the last few months being bombarded with images of summer holidays, barbecues, and first and last days of school. It's great to be able to keep up with friends and family so easily, but as technology develops and more of our daily lives are shared with others, there are a few reasons you should be mindful of what you post online.

One of the main things to remember is that nothing is private. No matter what your privacy settings, whatever you put out there has the potential to be shared further than your intended audience.

Something to be aware of is the type of information you are sharing that could be used by hackers. Two of the most common things people include in passwords are their birthdays and pet's names – if this information is readily available on your social media, make sure you are not using it in any passwords!

You should also try to avoid taking part in online trends where you

answer questions like your mother's maiden name or the first street you lived in – these are often security questions used to reset passwords.

Another big reason to keep an eye on your posts is that nowadays everything is searchable.

According to research conducted by cybersecurity company Kaspersky, more than a third of job seekers believe their prospects would be harmed if a potential employer had access to their posts – which is important, because 40% of employers admit to looking at someone's social media before offering them a job!

If you use your social media to voice your opinions, political beliefs or even to criticise a company, be aware that it could come back to haunt you one day. Remember – the internet is forever, and even if you have deleted something that doesn't mean there isn't still a copy of it somewhere.

There are many online concerns that are specific to the world of kidney and transplant patients especially. A common issue we are seeing more and more of, in recent times, is the risk to respecting anonymity of deceased organ donors and their grieving families in a country that is so small.

In the excitement of being called for a transplant and wishing to share the great news with friends and family on social media, the chances of such a post crossing the path of the donor family grows higher every year as social media algorithms grow smarter.

We are aware that the transplant teams are now asking people to keep this in mind when they are called for transplant.

Something else to consider is location information. Every summer we see reminders not to post that you are away from home on a holiday, but kidney patients should take this advice year-round.

If you have regular appointments and dialysis schedules, try to refrain from sharing the exact details online as this information could end up in the wrong hands; it is well known that burglars trawl social media looking for potential empty homes.

Social media is a great way for people to connect, especially when living with kidney disease, so don't be discouraged from using it. You can enjoy the benefits of having an online community at your fingertips but just be mindful of what and how much you share.

Patricia Mackenzie (née Doyle)

1949 - 2022

The Board of Directors, Staff and Members of the Irish Kidney Association (IKA) extend deepest sympathies to the outgoing National Honorary Chairman Colin Mackenzie and family on the sudden death of his beloved wife Patricia Mackenzie from Portmarnock, Co Dublin.

Patricia, who underwent a kidney transplant 14 years ago, was a much loved and respected colleague. All those who have used the IKA Renal Support Centre, which she co-managed, will remember Patricia for her warm welcome and her geniality. She also held the voluntary role of secretary for the IKA's Dublin North Branch for 16 years.

May her gentle soul Rest in Peace.



REMEMBERING Patricia

It takes great courage and strength to stand up to give an inspiring eulogy at the funeral of your wife whom you deeply loved and shared your life with for almost half a century. There was a standing ovation following the recently retired IKA national honorary Chairman Colin Mackenzie's tribute to his beloved wife Patricia who passed away following a short illness on 14th July 2022.

There was a huge outpouring of grief and shock amongst the Irish Kidney Association community on hearing of Patricia's death. A large congregation of mourners travelled from all over Ireland to St. Anne's Church in Portmarnock, County Dublin, to pay their respects and remember Patricia, a talented musician, wife, mother and grandmother, and advocate for kidney patients, whose kindness touched the hearts of so many.

Accustomed to public speaking, having honed his skill as a former assistant school principal and music teacher and author, Colin delivered the eulogy with great dignity and composure, laced with warmth and a sprinkling of humour, as he charted Patricia's accomplishments and talents, her early life and the life and interests they shared together.

Patricia was only about four years old when her parents discovered she was very musically talented. She had a natural musical ability, perfect pitch, and a wonderful memory for music. When playing accompaniments she only occasionally referred to the score, as she had already memorised it. She started with piano, and eventually got a Scholarship (more than one in fact) to the College of Music, and ended up studying with Dr. O'Reilly, who was the head of the piano section, and later playing piano duets with John O'Conor.

She became one of the first four Lindsay Singers, a well-known and very famous choir. If you remember the 70s and 80s you will be familiar with the Lindsay Singers. It culminated in 1969, when Patricia and her sister Mary, and their friend Sheila, represented Ireland in the Eurovision Song Contest, backing Muriel Day.

Apart from her love of music and singing, Patricia had amazing presentation and oration skills. Her reading at an annual Service of Remembrance and Thanksgiving was extraordinary, with many people in attendance commenting on it.

Colin and Patricia married just a few years after first meeting 49 years ago and became proud parents to Suzanne, Philip and Jennifer, and later grandparents to Emily, Ethan, Nina and Clodagh, whom Patricia adored.



Patricia and Colin Mackenzie

Patricia and Colin did everything together - children's music classes, shows, they wrote and arranged songs together, and worked tirelessly on behalf of the Irish Kidney Association. They both loved every moment of it.

Unfortunately, when Patricia was 50 years old, she got renal failure. She spent eight and a half years on dialysis, and anyone who knows anything about dialysis knows that is a very long time. But, eventually she received a transplant, and she was 14 years transplanted, and fortunately she had good health during that time.

During that period, she was given the chance to work in the Renal Support Centre at Beaumont Hospital where people visiting the hospital for treatment would stay. Patricia was a manager at the Centre.

If you want to know what the people who used the Centre thought of her, look up the Condolences Section of RIP.ie or tributes to her on Facebook. She was loved, and she loved the people who came to the Centre, and they refer to her as, 'Lovely Lady', 'friendly', 'caring', 'kind, supportive,' and that's exactly who she was.

Patricia was dedicated to IKA patients and knew every detail of the operation of the Renal Support Centre and begun detailing the work needed to reopen the Centre. She also looked at the requirements for the Cork Support Centre. Her knowledge of the needs of patients was invaluable.

We share in Colin's departing words at Patricia's funeral mass, "*Patricia, we miss you and we love you and we always will love you, and if you are not living with us, you are living in our hearts, forever*".

Electricity and Gas Suppliers

Your rights as a vulnerable customer

The Irish Kidney Association is doing our best to raise awareness around the impact of the energy crisis on kidney patients



As we face into an Winter of uncertainty in relation to energy costs and the reliability of supply, it is important that we are all aware of the supports available.

The information here is useful to all and of particular relevance to those who carry out their dialysis treatments at home.

You may not have heard of the Commission for Regulation of Utilities but their Electricity and Gas Suppliers' handbook 2019 is an important publication.

www.cru.ie/wp-content/uploads/2019/11/CRU19138-Electricity-and-Gas-Suppliers-Handbook-2019.pdf

The Supplier Handbook sets out obligations on electricity and gas suppliers under Condition 18 of the Electricity supply licence and Condition 21 of the Natural Gas Supply Licence. Electricity and gas suppliers are required to comply with these obligations when preparing terms and conditions of supply, Codes of Practice and Customer Charters and conducting their electricity and gas supply business. The obligations outlined in the handbook are not exhaustive but rather describe the minimum level of service that electricity and gas suppliers are required to adhere to in their dealings with energy customers.

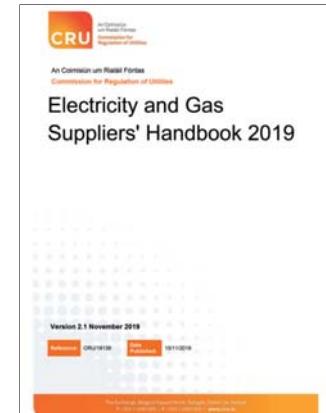
The Handbook contains a Code of Practice for Vulnerable Customers.

7.1 Definition of a Vulnerable Customer

7.1.1 A Vulnerable Customer is defined in legislation as a household customer who is:

- a. critically dependent on electrically powered equipment, which shall include but is not limited to life protecting devices, assistive technologies to support independent living and medical equipment, or
- b. particularly vulnerable to disconnection during winter months for reasons of advanced age or physical, sensory, intellectual or mental health. The definition of vulnerable customers provided above originates in the definition of vulnerable customers provided in the S.I. No. 463 of 2011. This piece of legislation places a set of obligations on suppliers in relation to the treatment of vulnerable customers.

7.1.2 For the purpose of this Code, a Vulnerable Customer is a customer who has self-registered on their supplier's register.



The key point here is that YOU must register as a Vulnerable Customer with your electricity and/or gas supplier.

7.2.3 Suppliers are required to adhere to the following rules when supplying Vulnerable Customers. These rules are legislative obligations set out in S.I. 463 of 2011.

- a. establish, maintain and regularly update a register ("Priority Services Register") of its customers who are vulnerable customers that are critically dependent on electrically powered equipment;
- b. establish, maintain and regularly update a register ("Special Services Register") of its customers who are vulnerable customers that are particularly vulnerable to natural gas or electricity disconnection during winter months;
- c. take reasonable steps to identify household customers who should be included on a Priority Services or Special Services Register;

- d. ensure that data contained on a Priority Services or Special Services Register is forwarded to the distribution system operator for inclusion on an industry register as appropriate;
- e. ensure that customers on a Priority Services Register are not disconnected or de-energised (power shut off) at any time for reasons of non-payment of bills;
- f. ensure that a customer on a Special Services Register shall not be disconnected or de-energised (power shut off) during the winter months for reasons of non-payment of bills;
- g. provide an annual report to the Commission on the measures it has taken under this Regulation.

If you qualify for Vulnerable customer status, make sure that you register with your supplier(s) and take the opportunity to speak with them to ensure that you are on the best tariff. Also, ensure that you understand their interpretation of the requirements outlined above and how they relate to your circumstances.

7.3.2 Suppliers are required to ensure that all registered Vulnerable Customers are on the most economic tariff available for their chosen payment method and billing format (i.e. not penalised due to remaining on a legacy tariff).

If you are on the priority register you cannot be disconnected for non-payment of bills at any time.

If you are on the special services register you cannot be disconnected for non-payment during the winter months.

SAVING MONEY

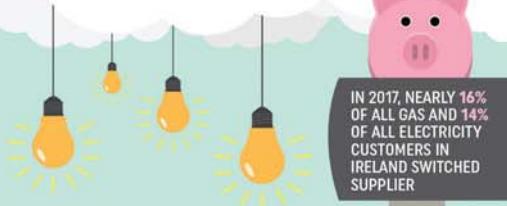
If you have not switched energy suppliers in the last year, you could save money by switching now. See <https://www.cru.ie/home/switching-supplier/> to find out the 4 easy steps to switching supplier.

If there is debt on your account of over €225, your current supplier will notify your new supplier of the debt by placing a debt flag on the account. The new supplier may reject the switch if there is a debt flag.

POWER TO THE PEOPLE

SWITCHING ENERGY SUPPLIER COULD **SAVE YOU MONEY!**

Follow this path to lower your energy bills...



IN 2017, NEARLY 16% OF ALL GAS AND 14% OF ALL ELECTRICITY CUSTOMERS IN IRELAND SWITCHED SUPPLIER

WHAT IS SWITCHING?

- LICENSED SUPPLIERS ARE **COMPETING** FOR NEW CUSTOMERS
- OFFERING **LOWER** ENERGY PRICES
- SWITCHING CAN **SAVE** CUSTOMERS UP TO €300 EACH YEAR



4 STEPS TO SWITCHING:

STEP 1 Find out...

- WHO YOUR SUPPLIER IS
- YOUR AVERAGE BILL
- HOW MUCH ELECTRICITY/GAS YOU USE
- WHEN YOUR CONTRACT FINISHES
- HOW YOU PAY



STEP 2 Renegotiate

- CONTACT YOUR SUPPLIER(S)
- ASK ABOUT DISCOUNTED OFFERS
- REMEMBER YOU ARE FREE TO MOVE SUPPLIER WITHOUT PENALTY IF YOU ARE NOT UNDER A TERM CONTRACT

IF YOU ARE NOT HAPPY WITH THEIR OFFER...

- LOOK AT OFFERS FROM OTHER SUPPLIERS
- PRICE COMPARISON WEBSITES ARE USEFUL AND CAN DO THE LEGWORK FOR YOU FOR FREE
- THEY CAN ALSO SWITCH SUPPLIERS ON YOUR BEHALF AT **NO COST** TO YOU

STEP 3 Shop around



STEP 4 Choose

- CHOOSE THE BEST OFFER THAT SUITS YOUR NEEDS
- CONFIRM YOUR NEW OFFER WITH NEW SUPPLIER(S)
- THEY WILL **INFORM** YOUR CURRENT SUPPLIER



Are you worried about energy costs?

In the IKA we are acutely aware of the impact that rising energy costs are having on many households. This significant rise will lead to challenges in meeting the costs of gas and electricity.

On February 10th, 2022, the Department of Finance announced two financial measures to support households.

1. an increase in the energy credit to €200 including VAT, to be paid in April 2022 to every household.
2. a lump sum payment of €125 on the fuel allowance was paid in March 2022 to social welfare recipients who are entitled to fuel allowance.

On your right is some good advice given by our colleagues in St. Vincent de Paul (SVP) for people who may be experiencing difficulty.

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

Engage

Get in touch with your energy supplier - they can work with you to find a solution if you are experiencing financial difficulties. Under the Energy Engage code, you will not face disconnection if you

- Are engaging to pay back arrears as part of a payment plan or have agreed to install a prepayment meter

Apply

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

Reach Out

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

Switch

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

Register

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

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



The Money Advice and Budgeting Service (MABS) is the State's money advice service, guiding people through money matters for 30 years.

FREE, CONFIDENTIAL AND INDEPENDENT

HOW MABS HELPS

MABS advisers provide advice on managing money and help people deal with a wide range of debts. The service is available for everyone, regardless of their financial circumstances.

Common types of client queries include, but are not limited to:

- Mortgage & Rent Arrears
- Credit Card Debt
- Personal Loan Debt
- Utility Arrears
- Legal Moneylenders
- Budgeting
- Income Maximisation
- Saving Tips
- Court Fines

Follow MABS info on...



ABOUT MABS

The advice is free and provided by qualified professionals, in more than 60 locations nationwide. Advice is also available online by chat on mabs.ie or call the national helpline. The service is non-judgemental, confidential and independent.

Call the national helpline on

0818 07 2000 Monday to Friday, 9am to 8pm

helpline@mabs.ie

mabs.ie for more information and to chat to an adviser online.



Funded and supported by the Citizens Information Board

Lorna's wedding favours

Lorna McSwiggan wasn't going to let a detail like her kidney failure get in the way of finally getting to nail down a day for her wedding, following three failed attempts hampered by COVID-19. The qualified nurse and mother of two, who undergoes hospital dialysis treatment twice a week, finally tied the knot with her American partner Richard Martin, on August 4th, 2022.

In the company of friends, their two children and both their families, including Richard's mother and siblings who travelled over from the States, the couple exchanged vows in the National Maritime Museum of Ireland, in Dun Laoghaire. Their wedding reception was held in the Killiney Castle Hotel.

Speaking about the happy event, Lorna, a native of Sandycove, said, "The day was amazing and such a whirlwind. It was our fourth attempt as we had to postpone three times due to COVID-19. It was fantastic to finally celebrate together with our family and friends from all around the world.

"We chose to donate to the Irish Kidney Association, in lieu of wedding favours, as it is such a worthwhile cause that is so close to our hearts and we felt it would be a nice thing to do on our wedding day."

In June 2019, Lorna's world was turned upside down when kidney failure led her to having to undergo a C-section to deliver her baby girl two months prematurely and Lorna commenced dialysis treatment



By GWEN O'DONOGHUE

directly afterwards. Lorna and Richard decided to call their tiny miracle baby who required CPR within moments of her birth, Nadia Rae Vale, or as they regularly refer to her as *Ray of Hope*. Lorna explained that they chose the name Nadia as it means Hope and the names Rae and Vale were chosen from her two grandmothers names Valerie and Rae.

Due to her kidney condition and the dangers of COVID-19 Lorna hasn't resumed working as a nurse which would involve long hours and is too strenuously demanding.

Lorna, has a condition called Alport Syndrome. She was accepted onto the transplant waiting list in March 2020 and several members of her family were tested for living



donation but none are suitable matches. She remains on the list in the hope of a transplant from a deceased donor.

Lorna said, "I am grateful for all that I have with a wonderful husband, supportive family and our children Nadia who is 3-years-old and Kai who is 13, their new home in Shankill which they purchased last year. We hope that I will receive a kidney transplant soon as I want to be able to see my children grow up. Like our daughter's name, organ donation offers a *Ray of Hope*".

The Irish Kidney Association extends its congratulations to Lorna and Richard and we hope that all their hopes for the future, including a transformational transplant, are realised.



*Briona Reynolds and Shane Hunter
Photo by Moat Hill Photography*

Kidney transplant newlyweds keeping it local!



By GWEN O'DONOGHUE

wanted to ensure that all their family and friends could be invited to share in the celebration of their happy event, grateful that Briona's health struggles, and three times weekly hospital dialysis, were behind her.

Briona said: "We had a wonderful wedding weekend and it was great to be surrounded by all the people we love. Everything has been going so well for us over the last two years, since Shane donated a kidney to me on June 22nd, 2020.

"Sometimes we forget the struggles we experienced. We still talk about how things were back then but it's always followed by how grateful we are for how much better things are now.

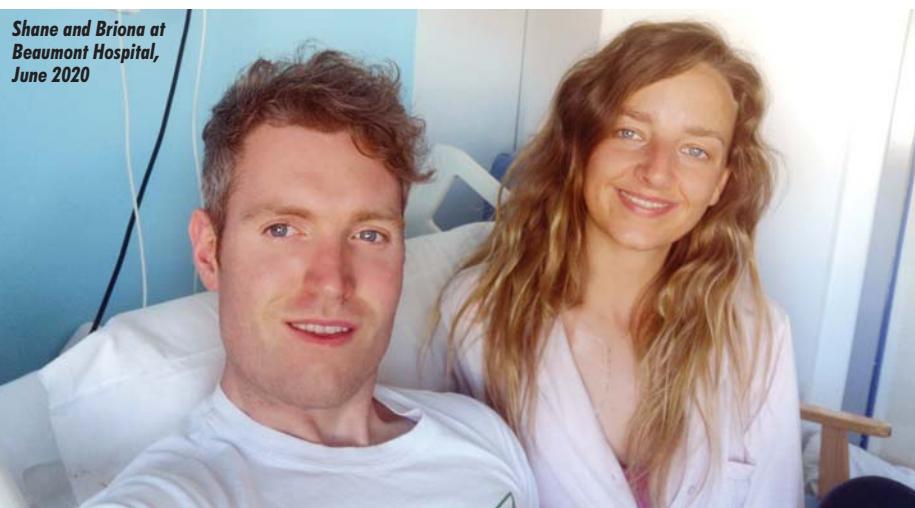
"When I think about then and now it's like two different lives, things now are so much more relaxed. We're currently renovating our house, planning little trips away and just enjoying life. We've both returned to work and life is great!"

Shane is now back to work at Tullamore Garda Station. Just a week before the transplant operation took place, Briona, completed her thesis for a master's in education, fulfilling her dream to become a secondary

A Midlands couple exchanged wedding vows over the August bank holiday weekend, grateful for their shared good health, made possible by the groom donating a kidney to his bride two years ago.

Like many other couples who faced delays with their wedding plans due to an unwelcome guest, COVID-19, Garda Shane Hunter (31) from Athlone, Co Westmeath and his

art teacher bride, Briona Reynolds (30), from across the county border in nearby Tubber, in Co Offaly, postponed their nuptials which were to take place last summer. They



school art teacher. Briona secured a teaching post at Mullingar Community College and has just returned to work there after the summer holidays.

Briona and Shane first met through an introduction by Briona's sister in 2009. Love blossomed and thanks to the gift of organ donation they share a unique bond as they now embark on married life together.

In describing their wedding Briona said, "the two-day wedding celebration was just amazing. We were very lucky as we had close to our original number of guests when we started planning four years ago.

"We were delighted when the day finally came, after previously being a casualty of COVID-19, as it should have taken place last year. Luckily all of our vendors were still available, including the venue and Simon Casey and his band who were excellent.

"Our wish was to keep things as local as we could throughout the wedding. We wanted it to be local and alternative. We got married in Mount Druid in Castletown Geoghegan, which is a wonderful venue, and the staff were so accommodating.

"On the second day we celebrated at our home with a marquee and music provided by Adrian Hiney from across the village in Tubber.

"After this we took a few days away and went down south just to relax. We are looking at honeymooning abroad at some point next year.

"While I'll be forever grateful to Shane for the 'gift of life' he has given me, I'd also like to thank his parents, Norman and Sharon Hunter, who now live in Dysart, Co Roscommon, as well as my mam and dad, Gina and Frank Reynolds for their loving support".

It was a case of third time lucky for the couple when their living donor kidney transplant went ahead in June 2020. Beaumont Hospital had suspended transplant operations before the country went into lockdown on March 27th, 2020 including Briona and Shane's operations, which were initially scheduled to take place on March 23rd.

This was their second



John & Traci outside Glasson Lakehouse Hotel.

disappointment as a previous date for transplant, February 3rd, had also been cancelled due to safety concerns as Shane's blood results showed irregularities at the time.

By February 2020, Briona's kidney function had almost fully declined and she then had no option but to commence haemodialysis treatment to keep her alive.

Briona's mother Gina Reynolds was also found to be a suitable living kidney donor match but Shane was determined that he should be the one to proceed.

Shane shared, "We had a great wedding. It is so rewarding and gives me great joy to see Briona so well and that we are both happy and healthy and can look forward to what the future will bring."

By coincidence, Shane has known another living donor kidney transplant recipient, John Egan from Athlone, since they attended secondary school in Athlone.

Following John's transplant last year which was thanks to his future father-in-law, the former Westmeath footballer also got married this summer to his beautiful bride Traci.

John and Traci's Brennan's wedding was held on June 5th. The happy couple exchanged vows in St. Mary's Church, Athlone and their reception was held at the beautiful and newly refurbished Glasson Lakehouse Hotel.

The Irish Kidney Association wishes both couples a lifetime of good health and happiness together.

TRAUMA



By AOIFE SMITH

Aoife can be contacted at
Donor House on 0818-543639 or 01-6205306 or by email: aoife@ika.ie

Trauma in places we go to get better

Recently I was talking to a close friend about her experience of waiting in an A & E department on a Saturday night. Unfortunately for her the wait turned into Sunday before she was seen by a doctor. She wasn't upset with the doctors or the nurses and she could see the extreme pressure they were under and respected how they could handle such brutal situations. She did, however, express how she felt traumatised after the experience.

She witnessed patients arriving injured and bloody, arguments and shouting from some patients as they hurled abuse at staff for the waiting times, the repeated asking from a stranger, who made her feel fearful, for a smoke. She felt a heightened sense of fear, her body rigid and defensive, all the while feeling her own vulnerability in her illness.

Her use of language, 'traumatised', got me thinking of trauma and the trauma we can suffer in places we go to get better.

When we say the word 'Trauma' most of us will think of some horrific human experience such as a war, natural disasters, car accidents or some ongoing effects of childhood trauma like abuse, family violence or addiction.

However, trauma is defined as 'an emotional response to a terrible event'.

A terrible event is described as one in which someone is exposed to actual or threatened death, serious injury or violation.

Exposure means directly experiencing the traumatic event, witnessing the event, learning of a trauma happening to a close family member or friend or being repeatedly exposed to the details of a traumatic event.

So, when we break down the

definition like this and think of what people may go through in a medical setting it makes it much more realistic to accept that trauma can occur in these settings.

Medical trauma is defined as a set of psychological (emotional) and physiological (bodily) responses to pain, injury, medical procedures and frightening treatment experiences.

Research shows there are some common experiences that have a higher association with developing medical trauma such as: heart attacks and strokes, difficult childbirth, stays in intensive care units, cancer treatments, health complications as a child, surgery, poor treatment, and dialysis.

Medical trauma can affect anyone and for many different reasons, but it is subjective. It is the individual's response to their medical diagnosis, treatment, procedure, injury, or negligence. It can often be missed as many patients suffer in silence.

We are socialised to endure medical treatments and there can be an expectation that we will 'just deal with it'. We get asked about pain scores or medication side effects but not about the fear or worry we might be experiencing.

The successful treatment of the medical condition doesn't necessarily mean that the mental health issues related to the trauma will end. Just like any other trauma, trauma experienced as a result of medical procedures, illness and hospital stays can have lasting effects, such as the development of anxiety and depression.

We know that most people who experience a trauma can recover,

they can get support, process the trauma, manage their symptoms and do well, but some may go on to develop persistent traumatic stress reactions after the trauma. A person may show symptoms of this as:

- Fear of medical settings or medical staff
- Significant distress, sweating, pain, feeling sick or discomfort, when confronted with reminders of medical trauma, including medical appointments
- Persistent intrusive thoughts or memories of aspects of the medical event
- Disruptions in treatment adherence due to trauma related avoidance
- Irritability or emotional numbing.
If this feels familiar or you think you may be experiencing the effect of trauma, know that you are not alone. Recognise that this kind of trauma is real and it is worthy of being acknowledged and this requires support in the healing process.

Part of trauma is lack of, or loss of control, and it can be helpful to find ways to take some personal power back. For some that might be gathering information, asking questions, asking doctors to explain procedures or medications so that you have a better understanding of what's going on and for others that might be communicating with your medical team about what you are experiencing.

Name your medical trauma and explain how you would prefer to be treated by medical professionals in order to prevent any further trauma.

In fearful situations, it might help

Thank you to all who emailed or called to discuss the counselling service provided here at the IKA.

Please continue to email me at aoife@ika.ie, with topics that might benefit you to read about.

Your comments to me will be completely confidential, no names will be used, and no reference will be made to any person or any specific email. If there is a common theme in the requests, I will base the next article around that topic.

to bring a supportive friend or family member to the medical setting who can help soothe any fears or help remind you of any questions you may want answered.

As with other types of traumas, there is also a vast amount of research to show that engaging in counselling can significantly help people experiencing trauma.

Counselling does not have to be complicated, simply having a space to talk can result in some well needed emotional relief. As trauma is experienced in body and mind, therapy will encourage you to explore both of these areas. Therapists can draw on several evidence-based techniques such as trauma focused cognitive behavioural therapy, mindfulness based cognitive therapy, somatic therapy (taking a body-based approach to healing trauma), and narrative therapy, to support your healing. I understand that this might not be an easy or linear process but getting support can help you move forward from trauma.



Annual Service of Remembrance & Thanksgiving

**Due to precautions around COVID-19 the
37th Annual**

**Service of Remembrance and Thanksgiving
will be virtual for the third year in a row.
The pre-recorded Service,
will be broadcast on RTÉ One and Radio 1 Extra
on Sunday, 30th October, 2022 at 11am and will
be available to watch later on**

www.ika.ie



Progressing a potential donor audit in Ireland



By CATHERINE REILLY

The Irish Kidney Association has advocated for an organ donor audit process for many years. We are pleased to share this article, from the **Medical Independent**, about progress in this area.

In 2008, the Australian government announced a major national reform programme for organ donation that involved several elements.

"As a government-led initiative in healthcare, this is one of the most impressive I have ever seen," Assoc Prof Michael O'Leary, State Medical Director of the New South Wales Organ and Tissue Donation Service, told the *Medical Independent* (*MI*).

Assoc Prof O'Leary spoke at a recent seminar in Dublin organised by the National Office of Clinical Audit (NOCA) and attended by organ donation

personnel.

In March, NOCA published the Potential Donor Audit Feasibility Study Report, which was commissioned by HSE Organ Donation and Transplant Ireland (ODTI). It recommended the development of a potential donor audit starting with implementation in one hospital in each of the six Hospital Groups and expanding to all acute hospitals, including paediatric hospitals, as organ donation nurse manager resources increase.

According to the report, evidence from other countries indicated that a

potential donor audit was a key driver of improvement in organ donation rates. It noted the rate of organ donation in Ireland was 18 per million population (PMP) compared to 25 PMP in the UK and over 45 PMP in Spain.

INCREASE

Assoc Prof O'Leary said the Australian potential donor audit was an important element of the national reform programme, which received significant financial investment from government. The programme involved appointment of specialist

Pictured top of page (l-r): Marina Cronin, Head of Quality and Development, National Office of Clinical Audit (NOCA); John Walsh, Chief Operations Officer, Organ Donation and Transplant Ireland (ODTI); Assoc Prof Michael O'Leary, State Medical Director, New South Wales Organ and Tissue Donation Service; Eimear Shields, Donor Coordinator, ODTI; Hilary Barry, Quality Manager, ODTI; Breda Doyle, Organ Donation Nurse Manager, South/South West Hospital Group; Dara Kelly, System Administration Manager, ODTI; Nikki Phillips, Organ Donation Nurse Manager, Dublin Midlands Hospital Group; Karen Healy, Organ Donation Nurse Manager, RCSI Hospital Group; Gillian Shanahan, Organ Donation Nurse Manager, Saolta University Health Care Group; Dr Alan Gaffney, Clinical Lead in Organ Donation, RCSI Hospital Group and Clinical Lead, Potential Donor Audit; Collette Tully, Executive Director, NOCA; and Dr Maria Kehoe, Postdoctoral Researcher, NOCA.

organ donation nurses and doctors covering 81 hospitals across Australia, development of a national authority for organ donation, and enhancements to organ donation retrieval services.

Between 2009 and 2019, the number of donors increased by 122 per cent. The number of donors PMP rose from 9.8 (which was "really poor on the world stage", acknowledged Assoc Prof O'Leary) to just over 20 in 2019.

Assoc Prof O'Leary said it was difficult to specify the impact of the audit as it was part of a larger programme. "But I don't think any of that would have been possible without an audit," he told *MI*.

The audit was "a very important part of the approach within the hospitals", he continued.

"The idea back then was that we needed a way of determining the potentiality for donation so we know how many potential donors we might be able to get with best practice, and then to look at missed opportunities. So, it is a classical audit system where you measure and then you have some form of feedback to the people who are involved in the management of the patients, and through that, you hope processes will be put in place that lead to practice change; that leads to an increase in the number of donors."

"So, that is what we did. The initial way the audit worked back then, in the early stages, was principally focused on donor identification, missed opportunities and how they could be identified and how processes could be put in place to change that."

**Assoc Prof Michael O'Leary
and Dr Alan Gaffney**



Originally there was some scepticism about the extent of missed donation opportunities.

Assoc Prof O'Leary told *MI*: "As an intensive care specialist I believed we had no problem with donor identification in Australia, especially in the brain-dead pool. I thought there is no way we are missing brain-dead donors and we are probably doing nearly as good as we can...and I was proven completely wrong, we weren't, and the increase in donors in that period was pretty much equally made up of brain-dead donors as DCD [donation after circulatory death] donors...There was a really significant increase in brain-dead donors."

Doctors may be resistant to change without the presence of hard data, according to Assoc Prof O'Leary.

Australia also has an 'opt-in' system and 36 per cent of the eligible population have registered as donors, according to 2021 data. Consent rates are substantially higher where a person has registered as a donor and/or their family are aware of their wishes.

IRISH AUDIT

Dr Alan Gaffney, Clinical Lead for the NOCA Potential Donor Audit, told *MI* that the Irish audit has moved to the development phase, which involves it being deployed in one hospital in six of the Hospital Groups. It is anticipated that this phase will continue until May 2023. The findings from the Potential Donor Audit Development Study will then be presented to the September meeting of the NOCA governance board for endorsement and publication.

Dr Gaffney, who is also Clinical Lead in Organ Donation at RCSI Hospital Group, said the appointment of specialist organ donation staff in hospitals is proven to boost donation rates.

Currently, there are six clinical leads in organ donation and nine organ donation nurse manager posts (five nurse manager posts are filled with four in the recruitment process, according to the HSE). There are four additional nurse manager posts planned under the HSE National Service Plan 2022.

The ultimate aim is to have an organ donation

nurse specialist in every acute hospital.

"Yes, that is the idea," said Dr Gaffney. "Again, in principle, if you have organ donation personnel in the units, on the ground, working with those ICUs, and they are trained well and they have got an audit, that is the most likely [way] to increase organ donation rates – at least that is the evidence from around the world."

The forward to NOCA's Potential Donor Audit Feasibility Study Report was authored by Dr Beatriz Domínguez-Gil, Director General of Spain's Organización Nacional de Trasplantes – a world leader in the area. She stated that the key to improving deceased organ donation rates was "the exquisite management of a multidisciplinary process of high complexity – the deceased donation pathway". This entailed appointment of the "right professionals, providing them with appropriate guidance and continuous training, and assessing performance".

Dr Domínguez-Gil cautioned of "magic bullets", such as

Continued next page...

PROCESSING A POTENTIAL DONOR AUDIT IN IRELAND continued...

promotional campaigns or reforming the existing legislation towards an 'opt-out' system, noting that these measures had never been proven to result in "sustained improvements in organ donation".

Asked if it was a concern that this message was being lost with the Government's focus on opt-out legislation, Dr Gaffney said: "I think so, yes. There is good and bad [in regard to the proposed legislation]."

From a political point of view, changing legislation is something that politicians can do, so that can increase the visibility of organ donation within a country and that itself can have the side-effect of hopefully improving the community attitude towards organ donation, although there is nothing to suggest that that is not really high in Ireland...

"There is a huge community acceptance of organ donation within the country already, which is great."

However, he said it is vital that the complex processes relating to organ donation in hospitals and the interaction with families are carried out in a "meticulous fashion".

"We feel that having the right people in the ICUs to

make sure that that happens and to be able to then measure and complete that feedback loop and make sure that what should be happening is happening, is the key."

Dr Gaffney indicated that no definitive statements can be made on the number of donation opportunities in Ireland that may be missed until the necessary data is collected and analysed.

"What we are doing at the moment is comparing our donation rate per million of population to the rest of the world, and we are making an assumption that it could be better. If we make that assumption that it could be better, then by definition there are missed opportunities unless we can prove that there aren't – and the only way to prove that there aren't is to go out and do an audit, so to find out how many people are dying in circumstances where organ donation could be a possibility and how many of those [families] are we actually approaching and how many are actually going through that process."

While Ireland has a low rate of DCD donation, Dr Gaffney highlighted that such donations have now been facilitated in several

hospitals nationally, whereas previously they only took place in Dublin centres. He confirmed that it is planned the Irish audit will include potential DCD donations. Most countries, he noted, focus on optimising donation after brain death in the first instance.

"If you get that right, that is a good measure of how well the system is working. Once you have a very well-functioning system for donation after brain death, then donation after circulatory death is something that can certainly add to that...Our view in the country at the moment is we should optimise the number of donations after brain death and then once that is in place, then start expanding the donation after circulatory death numbers."

Dr Gaffney acknowledged that ICU capacity impacts on organ donation rates. However, he was encouraged by Government commitments to enhance capacity following the onset of the pandemic.

PUBLIC AND PATIENT INTEREST

After NOCA's recent seminar, a steering committee was formed with key stakeholders

including public and patient interest (PPI) representatives for the potential donor audit. PPI representative Martina Goggin founded the Strange Boat Donor Foundation with her husband Denis after the death of their son, Éamonn, to help support other organ donor families (further details can be found at www.organdonation.ie).

She commented: "As the parent of an organ donor I feel it is most important that potential donors always be identified, and their families given the opportunity of considering organ donation by being spoken to by an appropriately trained organ donation specialist.

"Although I was very aware of organ donation, at a time of such overwhelming anguish when our son was on life support, if we had not been approached and asked about donating our son's organs, quite possibly we would not have thought of it. How disappointing and devastating that would be knowing the comfort organ donation gives and the ongoing benefit to a donor family."

© Courtesy of Medical Independent

ACCOMMODATION TELEPHONE BOOKING HOURS

087-4169907

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

ROUTINE APPOINTMENTS

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

EMERGENCY APPOINTMENTS

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

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

HOLIDAYS

Port in Barcelona, Spain
during the evening.

By DEBORAH CERVI
Holiday Co-ordinator

HOLIDAY DIALYSIS ABROAD

The Irish Kidney Association facilitates arrangements for holiday dialysis (dialysis away from home) for kidney patients. We aim to provide patients with knowledge and advice in helping make arrangements that will help make their holiday stress free.

After the restrictions of the pandemic, this year has seen dialysis patients begin travelling overseas again. We have had people travel as far afield as India, with several patients travelling to units in Greece, Czech Republic, Dubai, France and Romania. I have listed below the most popular holiday destinations patients travelled to in 2022.

SPAIN

Spain with its flamenco, paella and Mediterranean beaches, has long been a favourite destination for Irish tourists, with the most popular regions being the Costa del Sol, Costa Blanca and Costa Brava, as well as some of the major cities.

Dialysis units accept the EHIC (European Health Insurance Card) in the following regions:

Torremolinos
Torre Del Mar
Estepona
Malaga
Alicante
Elche

Murcia
Barcelona
Pineda del Mar
Valencia
Benidorm
Torrevieja

CANARY ISLANDS

Canary Islands, with its year-round subtropical climate, is the ideal choice for both winter and summer holidays with dialysis units in three regions all accepting the EHIC.

Lanzarote **Gran Canaria** **Tenerife**

ALGAE (PORTUGAL)

The Algarve has everything; beautiful beaches, world-class golf courses and superb cuisine.

There are three possible areas to dialyse whilst on holiday, these units accept the EHIC and provide a free ambulance transport service to and from treatment.

Faro Portimao Tavira

The post-COVID surge in travel saw the dialysis units in The Algarve overwhelmed with holiday requests and, along with a surge in local patients in Portugal contracting COVID-19, this meant that not all patients were able to holiday in Portugal this year, despite the best efforts of the units on the ground.

Over the last few months some units abroad, mainly in areas of Spain, are having staff shortages due to COVID-19 and some patients' holidays were cancelled because of this.

We are continuing to monitor the situation in these areas and hopefully, no more patients will be affected. I would advise patients to

not book your holiday until we know we can secure dialysis in your chosen destination.

Patients must be vaccinated for COVID-19 in order to receive dialysis in a unit abroad and must have a minimum of three doses with some dialysis units requiring four doses.

If you would like any advice on destinations or assistance in booking a holiday abroad, you can contact me at 01-6205306 or by email deborah@ika.ie

IT IS NOW EVEN EASIER TO ASK ABOUT HOLIDAY DIALYSIS ABROAD

We have been working hard to make it easier for you to book dialysis abroad. So, now you can make an enquiry about your dialysis abroad any time of the day or night.

Simply go to our website and click on holidays and then fill out our secure enquiry form, or visit <https://ika.ie/patient-holidays/>

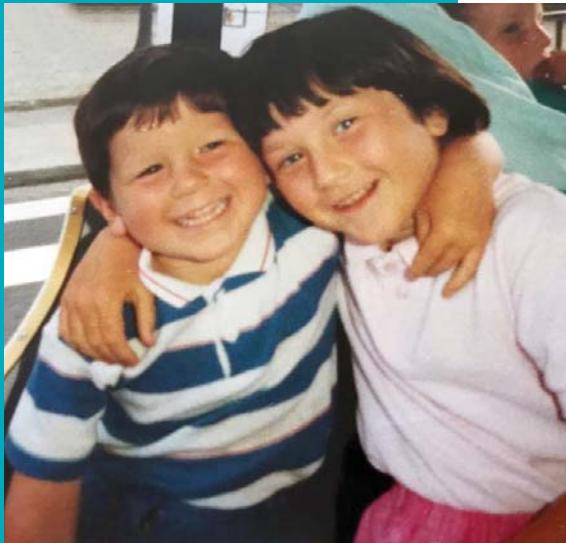
I will then be in touch.

Now, if you are looking at holidays at midnight on Friday you do not have to wait until Monday morning to make that enquiry.

Remember, please contact me about arranging your dialysis abroad BEFORE booking your holiday.

Due to extra COVID-19 paperwork requirements we need at least eight weeks' notice.

Deborah



Siblings Niamh Ann Dolan and her brother Paul who later became her kidney donor.

On hearing his older sister Niamh Kelly would need a kidney transplant, without hesitation Paul Dolan stepped forward determined that he would be the one to come to her rescue.

On July 5th, 2021, Paul got to fulfill his wish when he donated a kidney to Niamh.



Niamh Kelly on her wedding day, with her kidney donor brother Paul.

Siblings in ‘awesome’ kidney transplant success

By GWEN O'DONOGHUE

The natives of Lecarrow, in County Roscommon, where their parents Marion and Michael still live, underwent the living donor kidney transplant in Beaumont Hospital. Niamh who lives in Ballyhaunis, Co Mayo with her husband Alan, cocooned from COVID-19 for nine months while recovering from her operation before returning to teaching at St. Paul's Boys National School in Castlerea, after the Easter school holidays this year.

Her donor brother Paul, a father of two, who lives in Knocklyon in Dublin, was eager to get back to work in the Central Bank of Ireland and returned within two months of the living donation.

Niamh was just seventeen years old when she was diagnosed with Cystinuria, a rare condition in which stones made from an amino acid called cysteine, form in the kidney,

ureter, and bladder. She had been struggling for a couple of years before and found that when exercising and playing camogie, with her club St. Dominics, she experienced really severe pains in her abdomen.

Niamh underwent numerous operations and lots of shockwave

lithotripsy.

In 2011, her left kidney was removed. Under the direction of a renal dietitian she was put on a strict renal diet with low salt and potassium intake. She was told at the time to expect to be on dialysis within a year or two.

She followed medical and dietary advice to the letter and maintained a very healthy and active lifestyle. She believes that this is the reason why she managed to slow down the progression to dialysis.

By 2019 she was feeling very unwell and exhausted. Three days before her wedding, her consultant said that she would have to begin dialysis soon. She didn't want to entertain the idea and continued to struggle on until January 2020 when she was assessed for suitability for the transplant list which she was subsequently entered on to.

By March 2020, just as COVID-19 took hold, she had commenced Peritoneal Dialysis in her home which she had been trained up for in the months before.

During this time family members were waiting in the wings to be assessed for a living donation. In fact, from the time Paul had heard that his only sister would eventually need a transplant, he was determined that he would be tested and hoped that he would be the one to donate to her.

And so, on July 5th, 2021, the father of two, fulfilled his wish.

The living donor transplant was a complete success, much to the relief of the whole family. This included Niamh's husband Alan, and

One simple thing you can do to reduce harm caused by medication errors



By SHEILA MCCONNELL, Patients for Patient Safety Ireland



Patients for Patient Safety Ireland

Patients for Patient Safety Ireland and the HSE have issued an important call to action for patients, families and caregivers – **Keep a Medications List**.

The group is also calling on healthcare professionals, including pharmacists, to encourage their patients/service users to keep the medication list as this greatly improves the flow of information both ways.

Unsafe medication practices and medication errors are a leading cause of avoidable harm in healthcare across the world. This is a huge burden of harm. Therefore, "Medication Safety" has been selected by the World Health Organisation (WHO) as the theme for **World Patient Safety Day, September 17th, 2022**.

H IQA estimates that "...one medication error occurs per hospital patient per day, equating to three million medication errors in Irish hospitals per year". The report does not include medication errors in other healthcare settings.

"This is a simple yet powerful step that can improve patient safety", said

Information for people who take medicines and their families

My Medicines List

KNOW
CHECK
ASK

Before you take it...

KNOW
your medicines and keep a list
CHECK
that you are using the right medicine the right way
ASK
your healthcare professional if you're unsure

Before you take it...

KNOW
your medicines and keep a list
CHECK
that you are using the right medicine the right way
ASK
your healthcare professional if you're unsure

World Health Organization | Irish Pharmacy Union | ICPO | HSE | National Patient Safety Agency | www.safermeds.ie

| |
|-------------------------|
| My pharmacy's name |
| Phone number |
| My family doctor's name |
| Phone number |
| Emergency contact name |
| Phone number |

Bernie O'Reilly of Patients for Patient Safety Ireland. "Research from the WHO and the HSE confirms that empowered patients who know and understand their medications, dosage, frequency, etc., can greatly reduce the number of adverse events arising from medication errors. Sharing this simple message across Ireland could make a real difference to addressing medication safety in our country – and can save lives."

This self-compiled list should include all medicinal products patients are currently taking: prescription and over the counter medications, vitamins, supplements,

and alternative medicines, and all relevant details of dose and frequency.

The list is then used by the patient to share with healthcare professionals at appointments or whenever they are asked about their medications. It can also be used to ask for clarity on any medication questions or unexpected symptoms of concern for the patient.

You should not presume that healthcare professionals have this information, and a list is easier than relying on memory alone. Keeping a hard copy or a photo on a smart phone are both good ways to make sure it is always to hand.

Templates of the list below are also available in pharmacies and healthcare facilities, can be downloaded from <https://www.hse.ie/eng/about/who/nqpsd/patient-safety-programme/medication-safety/my-medicines-list-jan-2020.pdf> or by scanning the QR code opposite.



This document belongs to the person named above. If taking a copy, return the original to the person.

The objectives of

The objectives of **WORLD PATIENT SAFETY DAY 2022** are:

1. Raise global awareness of medication related harm.
 2. Engage key stakeholders in the efforts to prevent medication errors and reduce harm.
 3. Empower patients and families to be actively involved in safe use of medication.
 4. Scale up implementation of the WHO Global Patient Safety Challenge; Medication Without Harm.

Promotional posters and leaflets are available for healthcare providers to display in areas frequented by patients/service users and the general public. Healthcare professionals should also provide patients with a form to enable patients to make their medication list. Forms can be printed on the reverse of appointment letters and other communications.

Medication safety is in the interest of everyone. Patients for Patient Safety Members believe we all have a responsibility to play a part in reducing the burden of medication harm.

If you are interested in joining Patients for Patient Safety Ireland and use your experience as a patient or care-giver to improve patient safety visit:

<https://patientsforpatientsafety.ie/contact-us/>



RTÉ News ELAINE LORIGAN McSWEENEY

HOME DIALYSIS – ENERGY CRISIS

Home dialysis patient **Elaine Lorigan McSweeney** joined with **Carol Moore**, the IKA's Chief Executive, for an interview on RTÉ Six One News on August 30th, about the impact of the energy crisis for home dialysis patients.

Also supporting the IKA, through media interviews, in calling for additional measures for home dialysis patients were Rory Mackenzie from Tipperary and Karen Corbett from Swords, Dublin.

Lorraine Cooney from Donegal called the Joe Duffy RTÉ Radio 1 Show describing the harsh impact on her family as her young son Callum undergoes nightly dialysis.

Autumnal Treats

Autumn time brings a wonderful harvest of Irish seasonal food produce. In preparation for Halloween, the gardeners and farmers harvest their crops of pumpkins and squashes; while the apple trees are laden with fruit and our country ditches are bursting with juicy blackberries.

Choosing local produce not only ensures the freshest of foods which taste best and are at their nutritious best but also helps the environment by reducing the carbon footprint of our food supply.

In October look out for local apples, broccoli, brussel sprouts, cabbage, carrots, cauliflower, kale, leeks and many more Irish grown vegetables.

Another advantage of including fresh fruit and vegetables every day is the extremely low/zero salt content in comparison with processed snacks. Increasing fruit and veg intake and avoiding salty foods is recommended if you have high blood pressure.

If your renal dietitian or doctor has

recommended you follow a low potassium diet, you can still enjoy 2 servings of fruit and 2 servings of vegetables every day, and your dietitian will provide you with an information sheet on how much fruit /veg equals 1 serving.

This article will focus on pumpkin, apple and blackberries and their nutritional benefits. The recipes using these ingredients are suitable for anyone following a renal diet.

PUMPKINS

We are all familiar with the use of pumpkins at Halloween to create Jack O'Lanterns, but the nutritional benefits of pumpkin flesh should not be forgotten. It's packed full of vitamins and minerals, particularly vitamin C and beta-carotene which our bodies convert into vitamin A.

Vitamin A is best known for its role in eyesight and also has a number of other important health benefits including maintaining healthy teeth, skeletal and soft tissues. However, taking a vitamin A supplement is not recommended if you have chronic

kidney disease so it is best to get it from your food.

Vitamin C promotes healing, helps the body absorb iron and is important for skin, bones and other tissues. A healthy balanced diet should provide your body with all the vitamin C that it needs. It is important not to take a high dose vitamin C supplement if you have chronic kidney disease. Check with your dietitian or doctor before taking any multivitamins.

Pumpkin also contains fibre which plays an important role in the digestive process and helps maintain a healthy gut and bowel function.

Pumpkin can be roasted in wedges, used in baking cakes or muffins, used in soups, curries and stews.

If you are on a low potassium diet, check with your dietitian about cooking methods and portion sizes.

This delicious recipe for spiced carrot and pumpkin soup can be made with the pumpkin flesh. Adding spices like cumin, coriander and chilli create a wonderfully warming dish.

further 5 minutes, stirring occasionally.

Add the carrots and pumpkin to the pot and cover with the water. Reduce the heat to a simmer and let the contents simmer gently for 45-50 minutes, until the vegetables are completely soft.

Remove from the heat and blitz the contents of the pot with a handheld blender (or use a food processor). Add in the Parmesan cheese and cream and season with black pepper to taste.

Ladle into warmed bowls to serve.

Per portion, this dish provides 2 portions of vegetables and 1 dairy exchange.

If you are on a fluid restriction, remember to count this soup as part of your daily fluid intake.

SPICED CARROT AND PUMPKIN SOUP

Serves 6

Ingredients:

50g (2oz) butter
240g (8 ½ oz) Spanish onion, finely diced
3 garlic cloves
¼ red chilli, (4g) seeded and chopped
A pinch (¼ level tsp) ground cumin
1 level tsp ground coriander
1 level tsp fresh thyme, chopped finely
135g (4½ oz) leek, sliced
225g (8oz) carrot, peeled and chopped
200g (7 oz) pumpkin flesh, seeded and chopped
900ml (1½ pint) water
80g (3oz) Parmesan, made with pasteurized milk, freshly grated
100 ml (3½ fl oz) cream
A pinch (¼ level tsp) freshly ground black pepper



Method:

Place a large casserole pot or deep pot on a medium heat and melt the butter. Add the onion, garlic, chilli, spices and thyme to the pan. Reduce the heat and cover the pan with a lid to allow the vegetables to sweat for 5 minutes without browning. Then remove the lid, add the leek and cook for a

(Reprinted with Truly Tasty, page 175)



BLACKBERRIES

Blackberries are a great source of fibre, vitamins C and E and folic acid.

Vitamin E plays an important role in the immune system

Folic acid is a B vitamin that is essential for helping the body make healthy new cells.

Blackberries can be eaten raw, stewed or baked, and can be also used to make jam, jelly and chutney.

If you are gathering them in the countryside, you can wash them, put on a baking sheet and place in the freezer. Once they are frozen, you can transfer them to freezer bags and store them in the freezer for up to 6 months.

If you are on a potassium restricted diet approximately 20 small raw blackberries (100g) count as 1 serving of fruit.

APPLES

There are many varieties of Irish apples including eating apples and cooking apples. Apples are a useful snack between meals and can also be used to make a delicious dessert by baking, stewing or used in pies, flans or crumbles. Apples contain fibre and vitamin C.

If you are on a potassium restricted diet, 1 average sized apple counts as 1 serving of fruit.

This seasonable fruit crumble is an easy way to enjoy the blackberry and apple harvest this Autumn

APPLE & BLACKBERRY CRUMBLE

Serves 5-6

Ingredients:

200 g plain flour
100 g butter
50g brown sugar
1tbsp rolled oats
3 cooking apples
125g black berries fresh or frozen
4tbsp brown sugar
Set the oven to GM6 200°C 400°F.

Grease the inside of an ovenproof dish with butter.

Rub the butter into the flour and stir in the 50g brown sugar and oats.

Peel, core and slice the apples.

Mix the apple slices with the berries and 4 tbsp of brown sugar.

Arrange them in the greased ovenproof dish.

Sprinkle over the crumble mix leaving the surface rough. Bake for 30-35 minutes until the top bits darken.

Per portion, this dessert provides 1 serving fruit.

Recipe used, with permission from, Cork University Hospital, Renal Recipe Resource



By **IRENE CRONIN**
Clinical Specialist Renal Dietitian
CORK UNIVERSITY HOSPITAL
on behalf of the
Renal Interest Group
of

INDI 
Irish Nutrition +
Dietetic Institute
Renal



PEER SUPPORT UPDATE

By AOIFE SMITH

I am delighted to be giving you all an update on the peer support programme, which is well and truly progressing steadily. Support networks are crucial to improving the experience of being a kidney patient.

Our aim is to enhance and facilitate peer support networks because we know that sometimes the best support is simply speaking with someone who has been there and experienced it. That said, it

is a very exciting time here in the Irish Kidney Association to be part of developing such an important service for our patients.

We had an online information evening on the May 23rd, as well as an article in the last *SUPPORT* magazine to outline our vision for the service.

These helped to inform everyone interested of what we were planning for the service, as well as setting out the clear requirements and

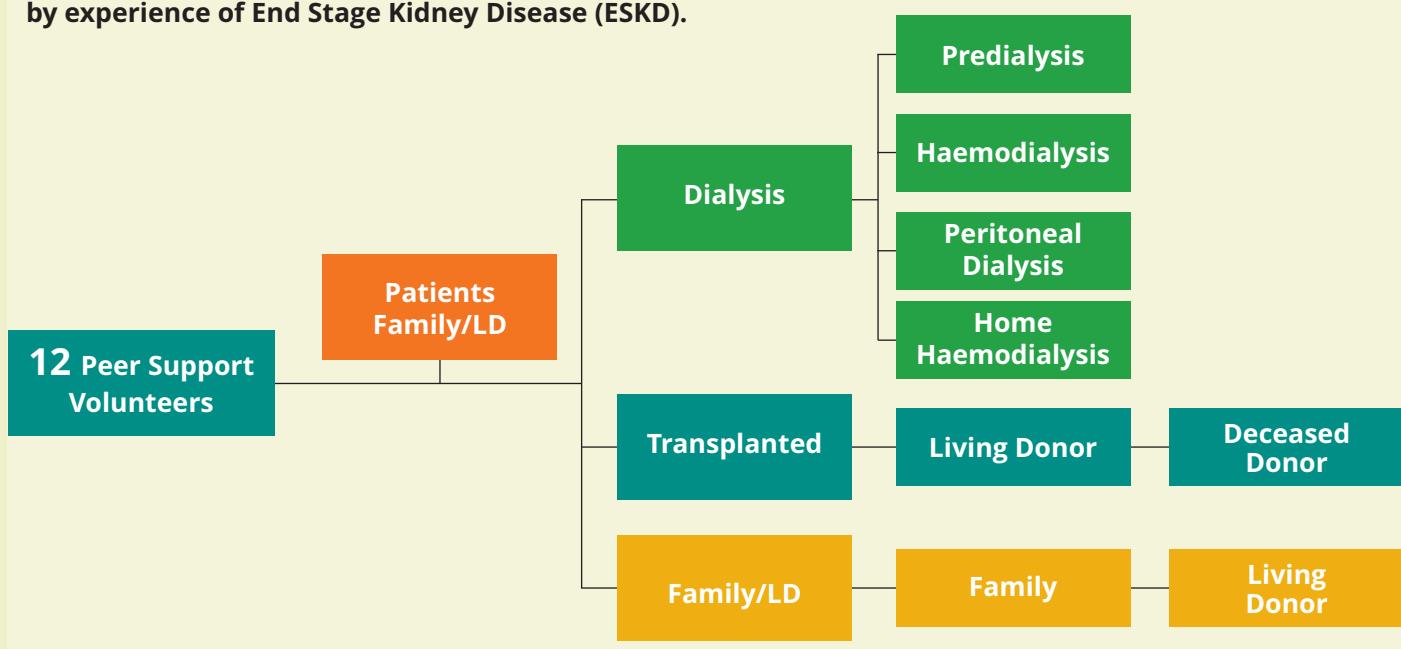
commitment needed to be a peer support volunteer. The information evening was very well attended, with lots of thought-provoking questions and discussions.

After the event we uploaded the expression of interest form to our website. This allowed anyone who wanted to come forward to be a peer support volunteer to make an application. We had a tremendous response from the expression of interest.

The passion and drive for the service was evident with the very high standard and volume of applicants.

While setting up the pilot programme we looked at the service requirements we believed would have the most potential to meet the expected need within our renal community. From the applicants we did a shortlisting process and unfortunately had to turn down some very good applicants on this occasion.

Estimated proportion of Peer Support Volunteers needed by experience of End Stage Kidney Disease (ESKD).



When we looked at the service requirements of volunteers needed, we then moved on to meet further criteria such as CKD stage, hospitals, geographical spread, gender, diversity, self-care and skills required to be a peer supporter to select applicants for interviews.

The interviews took place over a two-week period, which we just wrapped up and are under consideration. Thank you to all who attended for interview.

NEXT STEPS

From here we will be notifying successful applicants before moving on to the training. The training will be held on Zoom for the most part and it will be a full week of training. A lot of time and effort has gone into the training schedule for the successful peer supporters. We understand how important this role is for both volunteers and peers. We want to support our volunteers as much as we can during their commitment to the role.

The training for the successful volunteers will be held in October. Once completed we will begin to place peer support volunteers with patients.

The peer support sessions will focus on building and enhancing people's confidence to manage their illness. The Peer Support Volunteer will support peers as they explore and develop skills and strategies to help manage and maintain wellbeing as they adjust to living with kidney disease.

If you feel you would like to be matched with a peer support volunteer, please do not hesitate to contact me at: aoife@ika.ie

We want all patients to know they are not alone!

Family enjoys SUMMER GIVEAWAY PRIZE



Moira and Joe Cashin and their daughter Catriona Cashin and her children Amelia and Eddie Kearns (ages 2 and 1)



Congratulations to grandmother Moira Cashin from Mooncoin, Co Kilkenny, the winner of our Summer Giveaway prize, sponsored by the Clayton Hotel and Dublin Zoo.

Moira and her husband Joe along with their daughter Catriona and their grandchildren Amelia (age 2) and Eddie (age 1) enjoyed Moira's prize of a family mini break with an overnight stay, breakfast and evening meal at the 4-star Clayton Hotel Dublin Airport and a family day pass to Dublin Zoo.

Moira, who underwent a kidney transplant in 2011, said of their experience, "We had a most enjoyable time at The Clayton Hotel and Dublin Zoo. The evening meal at the hotel's Italian restaurant was delicious, and we were given the best of attention at all times by staff. The hotel even wrote off the cost of our parking fees, as we had to bring two cars to carry the two pushchairs for the children. Thanks to the staff of the hotel for having us stay. We would love to go back sometime next year."

"Our day at the Zoo was great, the weather was very warm. The kids loved the Zoo, we took our time walking around and stopping for snacks along the way, and I made my wish in the Wishing Chair with Amelia."

"Our thanks to the IKA for organising the prize, and the Clayton Hotel and Dublin Zoo for giving us a wonderful family experience creating memories to treasure."

COVID-19 UPDATE

COVID-19 no longer dominates the media and its visual presence in the community has very much diminished to aging signage in supermarkets and other areas of social interaction. Mask wearing is the exception, outside of medical settings, and the general public is now more worried about the spiralling energy costs and general price inflation.

In the early days of the pandemic, I remember hearing, 'welcome to our world' from some people living with a compromised immune system. Their point being that they have to live with medical vulnerability every day whether there is a pandemic or not.

The pandemic has provided a learning opportunity for the public at large about the importance and impact of sensible hygiene from a personal perspective and at a societal level too. In the interests of public health, it is hoped that we will all maintain good habits formed during the restrictions of the pandemic.

As the pandemic unfolded, we saw COVID-19 precautions change from being government mandated to government advised to personal responsibility. We were told about the importance of mental health when society re-opened. The need to make risk-based judgement calls in relation to our own interaction with society; to balance safety in relation to the virus with mental well-being in relation to the benefits of re-engagement with the activities that bring us happiness. This has been our reality in recent months.

We are now heading into the autumn, the weather is changing and we are spending more time indoors. The summer holidays are over and we are faced with the impending realities of spiralling energy costs and general price inflation. Many families are currently facing the costs of the return

to school. There is the budget next month and we have only one bank holiday weekend between now and Christmas.

Throw a possible resurgence of COVID-19 into the mix and we can likely expect a less than enthusiastic public response to any possible reintroduction of restrictions whether they be advised or mandated.

This brings us back to the importance of personal responsibility, the importance of also keeping family and friends informed of the risks to people with compromised immunity and the importance of also talking with your place of work, education or other points of regular community interaction if and when there is a resurgence of the virus.

It's about the environment around you – what was referred to as 'your bubble' prior to the re-opening of society. Depending on the status of the pandemic, appropriate mask wearing, regular hand-washing, and physical distancing can make a difference.

The importance of appropriate ventilation should not be overlooked either. Keeping up to date with your own vaccine boosters and encouraging family and friends to do likewise is also important.

You should make immediate contact with your renal team if you test positive for COVID-19 to discuss what treatments are suitable for you.

VACCINES

The community of people living with compromised immunity looked on in hope as the vaccine roll-out began last year and the Irish Kidney Association played its role in ensuring prioritisation for this group.

Reports are indicating that whilst not everyone who is immune compromised is showing a measurable immune response at each round of the vaccine, each time there are additional people showing a response.

As a person with compromised immunity, it is important to note that your initial treatment was two doses of vaccine. Your third dose was a 'top-up' dose. Your **fourth dose is your FIRST BOOSTER** and your **fifth dose IS YOUR SECOND BOOSTER**.

Wherever you are on the cycle of vaccinations, you can book in your next dose bearing in mind that you should leave 4 months between doses and 4 months if you have had COVID-19.

Remember, if you have any questions about the vaccines in relation to your current treatment (by dialysis or a functioning transplanted organ), please speak with your consultant or their team.

FROM THE HSE

COVID-19 and booster updates

People in the following groups who haven't had a second booster vaccine can now boost their protection:

- People aged 50 and older
- People aged 12 or over with a long-term health condition like diabetes, asthma or heart disease. Please find the lists of health conditions at <https://www2.hse.ie/conditions/covid19/people-at-higher-risk/overview/#conditions-that-put-you-at-higher-risk>
- Healthcare workers
- Anyone who is at least 16 weeks pregnant. If you're pregnant and you haven't had a first booster, you can get this at any stage of your pregnancy.

Your next COVID-19 vaccine will help protect you from serious illness in the months ahead. This is because protection from previous vaccines or from COVID-19 infection, decreases over time.

If you've had COVID-19 recently, wait 4 months before booking your vaccine appointment.

Vaccines are also available from participating GPs and pharmacies.

For more up to date information, or to book an appointment in a HSE vaccination centre, visit hse.ie or call our team in HSE Live on **1800 700 700**.

COVID-19 VACCINE RESOURCES

The HSE produces and regularly updates resources for the COVID-19 vaccine. You can visit the COVID-19 vaccine materials page for the latest leaflets and booklets including information on boosters and vaccines for children – <https://www.hse.ie/eng/services/covid-19-resources-and-translations/covid-19-vaccine-materials/>



LOOKING BACK AND LOOKING FORWARD...

Given the fact that public health experts did not have a template in place for managing the COVID-19 pandemic, the learning curve continues. It was initially about trying to understand how the virus spread and how to care for those infected with it. The focus then moved on to the development of vaccines.

Research now continues into more improved vaccines that can tackle the range of variants of COVID-19 that has developed. In all of this, it is important to understand that the **primary role of any vaccine is to reduce mortality and hospitalisations from serious illness** – it is unrealistic to expect 100% protection.

Post-exposure treatments such as Sotrovimab and Paxlovid have been developed and are available whilst new ones are in the pipeline. However, there have been questions about the efficacy of Sotrovimab in treating some of the newer variants of the virus (the FDA in the US removed authorisation for its use in May this year for this reason).

Paxlovid has been contraindicated by the HSE for people with an eGFR <30 and research is showing drug interaction related adverse reactions for transplant recipients.

Research is also taking place into pre-exposure treatments. It is felt that such preventative treatments may be most beneficial for people who have not produced antibodies in response to vaccination.

Evusheld is possibly the most discussed such treatment on social media. Some countries, including the UK, have given conditional approval for its use. However, in August this year, a spokesperson for the UK Department of Health and Social Care said, "Following a robust review of the available data, our clinical experts advise there is currently insufficient data on the duration of protection offered by Evusheld in relation to the Omicron variant and the government will not be procuring any doses at this time".

There is a need to keep the focus on researching treatments (preventative and post-infection) for people with compromised immunity not only in relation to COVID-19 but other viruses too. Some research papers have shown that the inability of a person with compromised immunity to fight off an infection can increase the opportunities for variants to develop.

This pandemic spurred the rapid development of existing research into the mRNA platform as a means of delivering treatments. There is a need to support this momentum in innovative research. We do not know when the next pandemic is coming or what it will be. COVID-19 has cost the global economy dearly and that is before we consider the emotional and mental health impact.

We must learn from this pandemic and improve – to quote Thomas Jefferson, "the measure of society is how it treats the weakest members".

The Magnificent Seven

Seven magnificent Tipperary men fought their best fight against 'brutal' weather conditions, which showed them no mercy, to complete a 600km cycle charity challenge, within 24 hours, from Mizen Head to Malin Head, and all with a half hour to spare!

As well as a great personal physical endurance achievement, they raised the considerable sum of €27,300 for the Tipperary Branch of the Irish Kidney Association (IKA).

Setting out from Mizen Head at Ireland's most southerly point on Saturday, June 25th at 3pm they could never have imagined how their resolve would have been tested by consistent rain and wind all the way, until they wheeled up, weather beaten but victorious, at Malin Head at the tip of Donegal at 2.30pm on Sunday.

It was with great pride that the challenge team leader, Francis Hogan, himself a kidney patient, and some other members of the Upperchurch Drombane Cycling Club, met with members of the Tipperary branch of the IKA, in early September, to present them with a cheque from their fundraiser.

Accepting the cheque on behalf of the IKA in Liberty Square, Thurles, was its newly-elected National Honorary Treasurer and Tipperary woman, Joan Gavan, from Donohil, along with Tipperary IKA Branch Officers.

Joan said: "It is a great honour for me, in my new role, to be here today with our Tipperary Branch members Orla Hogan, Ann Hackett



At the cheque presentation, Mark Ely, David Donovan, Danny Lawlor, Francis Hogan, David Russell, Michael Cahill and IKA representatives Ann Hackett, Mary Adamson, Orla Hogan and Joan Gavan.

At the end of their long journey, Malin Head locals John Hegarty (a kidney patient), his wife Mary and their four children (foreground), with the triumphant cyclists and other members of the greeting party at the end of the journey.

By: GWEN O'DONOGHUE



and Mary Adamson, and to meet such an inspirational group of people from my native county.

"These seven men showed great fortitude and determination by completing such a gruelling long distance challenge in very harsh weather conditions and all for the sake of raising considerable funds, which will benefit kidney patients and their families, as well as increasing organ donation. We thank you and your families for their encouragement, Upperchurch Drombane Cycling Club for so passionately coming behind the event, your essential and dedicated backroom travelling

continued next page



THE MAGNIFICENT SEVEN

continued



Launching the event in Liberty Square, Thurles on June 1st, the seven challenge participants from UDCC (l-r); James Tobin, Urlingford, Co Kilkenny; Pat Heffernan, Moyglass, Fethard; David Donovan, Thurles; Seamus Duggan, Templemore; Francis Hogan, Templemore; David Russell, Thurles; and Jamie Donovan, Thurles.

team, and all your supporters and generous sponsors for making such a successful event.

"On behalf of the IKA I want to thank you wholeheartedly for your significant contribution. Wishing you all good health".

Months of preparation and intensive training went into the 24-hour 600km challenge, which included 4000 meters of elevation, for the seven members of Tipperary's Upperchurch Drombane Cycling Club. Their goal was to raise as much money as possible for the Tipperary Branch of the IKA. By the time they crossed the finish line, the seven cyclists, one of them a kidney patient, had raised over €16,000 for the charity. A further €11,000 plus was gathered later from sponsors and others who had pledged to support the event.

The seven men and their travelling supporting team were greeted, when arriving to a wet and blustery Malin Head, by a welcoming party of family, friends including local dialysis patient John Hegarty (36) with his wife Mary and their four young children, Ella (age 7), Erin (4), Ada (3) and Ronan (1). For nearly 8 years, John has been making a two hour round trip, three times a week, to Letterkenny for life-saving haemodialysis treatment.

Challenge cyclist and kidney patient Francis Hogan, age 45, said, "the weather was brutal and we really were losing faith on being able to complete the challenge. While we felt fit for the challenge, we never envisaged the weather being so harsh from the time we set out, right through the night and into Sunday afternoon.

"We pushed the hardest that any

of us have ever done before. We couldn't have done it without our supporters and the team that travelled by van guiding us along with words of encouragement and making sure we were fed and watered and had numerous changes of clothes.

"Supporters dotted along the long route on countryroads, and in towns and villages, provided a welcome boost to our resolve also.

"Our stop in Birdhill was a 'Godsend' with supporters setting up a marquee and heaters for us with warm food and refreshments. It felt like a 5-star hotel and gave us time to re-energise and to focus on our goal. Knowing that donations kept pouring in from so many generous supporters, individuals and companies, this goodwill spurred us on.

Attendees at the launch in Liberty Square



Cyclist Francis Hogan chatting to Orla Hogan, Tipperary IKA

"Now that the journey is over, we are proud of our massive achievement, made possible by everyone that came behind us, and in particular our club Upperchurch Drombane. As part of our recovery, we relaxed in the leisure centre at the Red Castle Hotel, on the Inishowen Peninsula and later that night having a nice meal, along with family, friends and supporters".

Taking part in the Mizen 2 Malin Challenge were David Russell, an award-winning young farmer from Thurles, as well as father and son David and Jamie Donovan, also from Thurles, along with building contractor Seamus Duggan, from Templemore, farmer Pat Heffernan from Moyglass, Fethard, James Tobin, an Actuary, who lives in Urlingford, Co Kilkenny, (on the Tipperary border), and self-employed kidney patient Francis Hogan from Templemore.

Cyclist Francis Hogan, a father of five children, was diagnosed with Polycystic Kidney Disease (PKD), a hereditary condition, when he was in his early twenties. Through careful medical intervention, medication and healthy lifestyle choices, including dietary and fitness, he has slowed down the progression of his disease and he now has 25% kidney function.

Francis is a strong advocate for fitness in aiding a person's physical and emotional wellbeing. In 2001 Francis's late father Gus, who also shared the same hereditary kidney condition, passed away in hospital, at the young age of 49, with heart failure, just a day after undergoing a kidney transplant.

Orla Hogan, the Secretary of the Tipperary Branch of the IKA said, "We have huge admiration and appreciation to Upperchurch Drombane Cycling Club and these seven men who are truly magnificent for undertaking this gruelling challenge, which was made all the more difficult by unrelenting bad weather, to support the work of the IKA and in the process raising organ donor awareness. We thank them and everyone who was involved in supporting their mighty effort."

Orla's four kidney transplants came as a result of her hereditary kidney condition, Bidel Vardot Syndrome. She underwent two living donor kidney transplants, one from her mother Nora in 1991 and following two deceased donor kidney transplants which each lasted four years, her most recent successful and longest surviving transplant, took place in 2008 with a kidney donated by her younger brother Cathal Hogan.

Orla comes from a well-known sporting family in Tipperary. Her father Séamus Hogan played hurling for Tipperary when they won the all-Ireland final in 1971.



Challenge cyclist Francis Hogan (centre) with John Cleary (left), who is currently receiving dialysis treatment, and Liam Cleary (right) who recently underwent a kidney transplant.



Three of the Mizen 2 Malin UDCC cyclists (l-r): James Tobin, Pat Heffernan and David Donovan.



Kidney donor Nora Hogan with her daughter Orla, Secretary of IKA Tipperary Branch.

The Irish Kidney Association (IKA) is delighted to have been awarded a major grant from the HRCI/HRB Joint Funding Scheme towards research into ‘patient reported outcomes’ for patients with rare kidney diseases, referred to as Glomerular Disease (GD) (also known as Glomerulonephritis, Nephritis or Nephrotic Syndrome). This research, which is being conducted in partnership with University Hospital Galway and the Irish Nephrology Society (INS), will give ‘a strong voice to GD patients’ which will meaningfully guide future care towards ‘better clinical outcomes and quality of life’.



**By Dr. LISA MELLON
Health Psychology lecturer,
RCSI University of Medicine and
Health Sciences**

AND



**By Dr. MICHELLE O'SHAUGHNESSY
Consultant Nephrologist
University Hospital Galway**

IKA awarded major research grant

Speaking about the HRCI grant announcement, Carol Moore, IKA Chief Executive said, “this matched fund grant by the HRCI of up to €100,000 is greatly welcome as it will provide our registered charity, for the first time, the opportunity to conduct high quality peer reviewed research, introducing measurements which put patient reported experience centre stage. By giving a strong voice to patients, the research results will help guide future care towards better clinical outcomes and quality of life for patients with Glomerular Disease.

“I wish to extend our huge gratitude to ex Board director Dr. Lisa Mellon for leading from start to finish on this grant process. The success in this application for the Research Project being awarded to the IKA can be credited to months of detailed preparation coordinated by Lisa, a health psychologist, whose late mother Marie was a long-time dialysis patient.

“Thanks are also due to former National Chairperson Colin Mackenzie and current Board Director Elsie Moore for their dedication and considerable voluntary time they put into reading and ranking applications. This grant application and successful award could not have been achieved without this considerable volunteer help.

“We believe that achieving a better understanding of what matters to patients (known as patient reported outcomes) will enhance the clinical care of patients with Glomerular Disease and the development and evaluation of therapies that meaningfully improve patients’ daily lives. It will also potentially help patients with other kidney diseases as many of the findings may be common across different types of

kidney disease”.

Patient-Reported Outcomes are poorly studied in Glomerular Diseases (GD), yet recent evidence* suggests that they are as, if not more, important to patients with GD than traditional clinical measurements. This innovative and internationally collaborative research, with strong patient and public involvement, is strongly aligned with the strategic aims of the IKA and the INS.

The IKA wishes to acknowledge the support of the INS who worked closely with us to develop and publicise the call for research proposals and participated in the ranking and evaluation of proposals. Unfortunately, we could only submit one proposal for funding to the HRB/HRCI despite the quality of proposals.

The IKA is partnering with the INS for this important study and the research will be undertaken by a team at University Hospital Galway. The overall aim of the research is to develop and validate an instrument for measuring ‘Patient Reported Outcomes’ that are deemed important and relevant by patients with GD. As a secondary aim, the research study will evaluate whether participation in the IKA’s ‘Living Well’ peer-led chronic disease self-management programme improves health related quality of life in patients with GD.

The research will be led by Consultant Nephrologist Dr. Michelle O’Shaughnessy who has recently migrated from Cork University Hospital to University Hospital Galway. Dr O’Shaughnessy will now work alongside a research team at University Hospital Galway on the project.

The ‘Patient Reported Outcomes - Glomerular Disease’ (PRO-GD) study



will have three phases:

1. The research team will consult with Irish patients with GD to develop a new PRO questionnaire (PRO-GD) that is relevant and acceptable to Irish patients. These patients will also help co-design advertising and recruitment strategies for the study.
2. Irish patients with GD will be invited to complete the PRO-GD questionnaire to confirm that using this questionnaire in patients with GD is valid and reliable.
3. Some patients will then complete the '*Living Well*' programme. A follow-up PRO-GD questionnaire responses will be compared between those who do versus those who don't complete this programme, to evaluate the

impact of the programme on HRQOL.

The research team aims to advertise the study, and seek patient participation, in the early part of 2023.

The IKA expects this research to:

- Increase awareness amongst patients, their families, their clinicians, and wider society, of the effect that GD can have on patient wellbeing
- Develop a new PRO-GD questionnaire that can be applied in diverse clinical and research settings e.g. more comprehensive reporting of drug treatment effects to support shared treatment decision-making; and
- Determine whether completing the '*Living Well*' programme improves HRQOL in patients with GD.

WHAT IS THE JOINT FUNDING SCHEME

The Joint Funding Scheme, which Health Research Charities Ireland (HRCI) runs in partnership with the Health Research Board (HRB), offers the opportunity to HRCI members, like the Irish Kidney Association, to secure matched funds from the HRB to support research of importance to their communities. It also helps charities to fund research according to international best practice in research governance.

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active in health, medical and social care research, together representing over 1 million people in Ireland.

Through support and advocacy, it represents their joint interests, to achieve its vision of improved lives through a united community of health research charities.

It also runs the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland.

www.hrci.ie



WHAT ARE GLOMERULAR DISEASES?

Glomerular Diseases (GDs) - also called Glomerulonephritis, Nephritis or Nephrotic Syndrome - are rare kidney diseases that damage kidney filters (glomeruli) and can result in kidney failure, hospitalisation, and death.

GDs are the third leading cause of kidney failure worldwide. GDs also affect health-related quality of life (HRQOL), including reduced ability to participate in normal life, fear or anxiety about the future, low mood, or eroded confidence.

The patient reported experience approach to research of the impact of their GD and medications will provide an instrument to help understand and meet patients' needs.

FOOTNOTE: Clinical research in patients with GD mainly focuses on surrogate laboratory outcomes such as kidney function and proteinuria, or clinical outcomes such as kidney failure and death. However, these measures often poorly associate with patient perceptions of their illness. In response, PROs (i.e. direct reports from patients about how they feel or function, without amendment or interpretation by a clinician or researcher) are increasingly incorporated in clinical and research practice as quantitative assessments of the patient voice. However, obtaining a better understanding of the impact that GDs, and their treatments, can have on patients with GD has been hampered by the absence of a PRO instrument specific to the needs of patients with GD.

* In one U.S. study of 766 patients receiving outpatient chemotherapy for advanced cancer, regular reporting of PROs by patients to their treatment team resulted in better HRQOL and fewer hospitalisations compared to usual care. Incorporating PRO measurement into clinical care can also guide medical decision-making e.g., medication adjustments, lifestyle modifications, and timely specialist referrals. PRO instruments can also ensure clinical trials comparing treatments provide a more relevant evidence base that better informs shared decision-making between doctors and patients. Finally, disease-specific PROs can increase measurement sensitivity and the likelihood of detecting treatment benefits when they exist. In light of these and other data, the National Institutes of Health (NIH) and Food and Drug Administration (FDA) in the U.S. urge clinicians and researchers to examine PROs in medical decision-making, research, and clinical trials.

Shared Haemodialysis Care

Can it help you?

Receiving dialysis treatment means there is a long intense relationship with the medical system. Most other chronic health illness conditions do not involve visiting a healthcare facility, three to four times a week for hours at a time.

Patients have expressed their feeling a loss of control over their bodies and of constant waiting around for other people to do things for them. Waiting for the taxi to come, waiting for a nurse for the next step of the procedure and then waiting again for the nurse to come and take them off the machine. Patients can feel a real loss of power and control over their own lives, and this is what academic authors refer to as a 'lack of agency'.

Recognising the impact of this on patients' mental health, a new approach of shared haemodialysis care is now recommended in the UK. This recommends that shared haemodialysis care is offered to all patients. Shared haemodialysis care allows patients to take more control of their own care, in a way that suits them.

The extent of Shared Care can be as much or as little as the patient desires.

It can be small tasks like taking your own blood pressure or weight, to taking full control and doing dialysis at home. Some patients use Shared Care as a way of finding out if home dialysis is suitable for them.

However, participating in Shared Care does not mean the patient is expected to transfer to home dialysis eventually. Participating in Shared Care means the patient becomes more of a partner in their own care, even when that care continues in a centre.

The patient is trained to do the tasks they wish to do, and on the days when they feel too ill to do these tasks they can ask staff to take over.

Studies on Shared Care show that allowing patients to have a more active role in their own care leads to improvements in their physical and mental health. From being a passive person who patiently waits for "things to be done to them" they become an active player in their own care. Patients become more involved in decisions about their own care and develop a greater understanding of how to manage their own care. They can identify problems



with treatment and potential health complications more quickly.

In some dialysis units in Ireland, staff have been trained to provide Shared Care as listed in the blue box below.

In St. Vincent's in Dublin some patients are actually

now practicing shared care.

The Irish Kidney Association will be hosting an event where patients can find out more about Shared Care haemodialysis from leading UK and Irish experts and Irish patients. Please see details below to register for this **free** event.

SHARED HAEMODIALYSIS CARE

Zoom event on Wednesday, 26th October

The Irish Kidney Association is delighted to announce it is hosting a **Zoom event** on **Wednesday, October 26th at 7pm** on Shared Haemodialysis Care.

We will have Shared Haemodialysis Care Strategy Director and Trainer, **Tania Barnes** from Kidney Care UK, presenting together with healthcare professionals **Donna Pike** from the Altnagelvin Unit, Western Trust HSCNI in Derry, and **Emer Kenny** from St Vincent's University Hospital, Dublin. There will also be two patients sharing their experience.

A questions and answers session will be included.

This **FREE** event is open to both healthcare professionals and patients. You can register here at <https://ika.ie/event/shared-haemodialysis-care/>

AREAS WHERE STAFF HAVE BEEN TRAINED IN SHARED HAEMODIALYSIS CARE

Limerick
Wexford
Portlaoise

Galway Wellstone
Dublin St. Vincent's
Letterkenny*

* Staff currently being trained

Yvonne rejoices that her *Health is her Wealth*

Kidney transplant recipient Yvonne Cullen from Ballinteer, Dublin 16 is enjoying the benefits of the kidney transplant which she underwent in December 2016 proclaiming that her newfound '*health is her wealth*'.

After giving birth to her son Josh, at the Coombe Maternity Hospital eighteen years ago, she was referred to nephrologist Dr. Catherine Wall in Tallaght University Hospital.

Yvonne initially didn't realise the implications of the sudden medical intervention to monitor her health post-pregnancy and she explained, "I had no prior knowledge that my kidneys were failing and even when I began to be monitored by medics, I didn't fully realise that my kidney function might be deteriorating and how that would affect me in the future. It came as a shock to me when I was told that in time I would need a kidney transplant.

"As no other members of our family suffered from kidney disease it was suspected that mine might have stemmed from an infection which I picked up as a child. It was thought that it could have been triggered as far back as when I was a newborn when I caught pneumonia. I remember having several kidney infections as a child but these were not attributed to anything in particular. I was prescribed antibiotics to fight them off, and carried on with life.

"I was lucky to be put in the safe hands of Dr. Catherine Wall and for several years, through medication and lifestyle changes, I got to stay away from dialysis for many years. I changed



jobs and then made the decision to be a stay-at-home mam looking after my son Josh while also childminding other people's children. However, as my kidney disease progressed it became more of a struggle to continue as I was tired all the time.

"Despite this obvious decline in my health, it still came as a blow to me when, in late 2015, Dr. Wall told me that I would have to start dialysis and that it was now time for me to go on the transplant waiting list for a donor kidney.

"So, in June 2016 I had commenced receiving a form of home dialysis, which involved undergoing treatment, four times throughout the day, and then later I transferred over to a nightly dialysis hooking up to a machine which filtered toxins out of my blood for ten hours each night.

"By this time I was reduced to 'skin and bone', a size 6, and exhausted all the time. This was upsetting for me as I was concerned for my future, and, as a single mum, raising my son Josh, who was just eleven or twelve years old at the time.

"The Irish Kidney Association was very good to me offering advice and support and were a shoulder to lean on as I didn't want to overburden my family and Josh with my

concerns. I was facing years of waiting for a kidney transplant and some of my family were willing to donate to me but they were not suitable donors for me.

"I feel absolutely blessed to have been called to Beaumont Hospital for a kidney transplant, in December, from a stranger which changed my life. Although my recovery took a few weeks I was home in time for Christmas eve 2016, much to the joy of my son Josh and the rest of our family. I am so grateful for the 'gift of life' I have been given and I have written to the family of the organ donor anonymously through the organ donor co-ordinator at Beaumont Hospital to thank them.

"All the medical and nursing staff who have cared for me from the time I gave birth at the Coombe, to Tallaght Hospital and then Beaumont where I had my transplant operation, have been wonderful. My family have been amazing also including my father Billy Cullen who has looked after Josh so well when we lived with him for a few years in Churchtown, and he continued to keep a close eye on us when we moved to Ballinteer.

"My life has been completely transformed and I am making the most of it. I have put my weight back on and I am delighted to have recently been able to go back to work in catering. I have taken part in a few Women's mini marathons since the transplant and with one of these I raised funds for the IKA. I enjoyed a holiday in Majorca with family in Spring this year, which was my first time abroad in 17 years.

"My health is my wealth and I have my donor to thank for it."





Transplant Team Ireland members supporting Paralympian, Mary Fitzgerald, in promoting the 20x20 message in 2019: Orla Hogan, Rachel Eagleton, Sheila Grogan, Mary Fitzgerald, Marie O'Connor, Deirdre Faul and Anna Pokojska.

"Take inspiration from them"

Like so many other walks of life, COVID-19 brought the in-person activities of our sports programme to an abrupt halt in March 2020. The momentum of the programme had been building at the time as we were busy planning the hosting of the European Transplant & Dialysis Sports Championships in August that year.

You may remember the 20x20 national campaign that started in 2018 with the goal to create a measurable cultural shift in our national perception of women's sport.

The tagline for the campaign was; **"If she can't see it, she can't be it."** The idea being that we need to celebrate our role models and make them visible so that they can inspire others.

Our sports programme has had this concept as one of its pillars since its inception. Following a sports-for-all philosophy, the programme has encouraged people of all ages and abilities to come together to enjoy

By COLIN WHITE

sport and the camaraderie it brings. In so doing, one of the goals is that the wider transplant and dialysis community will have role models with whom they can relate.

Whether it is an experienced sports person wondering about engaging in sport after starting dialysis or a transplant recipient unsure of their physical ability but looking for a healthy past-time, the people who engage in transplant and dialysis sports offer inspiration and reassurance by their example and, most importantly, they offer a warm welcome and friendship to others interested in getting involved.

In recent years, the value of a healthy lifestyle that includes regular physical activity / sport for people who are on dialysis or post-transplant has been gaining significance in medical circles with an increasing interest in research in the area. The fact that the oldest age

category at the World Transplant Games has been increased from 60+ years to 80+ years in the last decade is also indicative of the quality of life that can be achieved with regular physical activity / sport.

We have had many people represent Ireland on the international stage at the European Transplant & Dialysis Sports Championships and the World Transplant Games with newcomers every time getting to experience the buzz of celebrating their health, representing their country and, in the case of transplant recipients, representing their donor.

Sports on offer range from the physically focused such as athletics, swimming and racquet sports, to the more skill-based ones such as darts, ten-pin bowling and petanque.

Ireland has shown prowess across a wide variety of the sports on offer. John Moran, a kidney recipient, won his first transplant sport medal in cycling in 1987 and he has continued to triumph at every game since, in

both cycling and track and field events. Liver recipient, Charlie Ryan won his first European darts title in Wurzburg, Germany in 2008 and he has defended and retained his title every two years since.

In 2018, Chikoyo White won the best overall female competitor (dialysis) award at the European Championships in Sardinia and in the most recent Europeans, Marie O'Connor was awarded best overall female competitor (transplant).

Ireland is also known for its friendliness and spirit of fair play. This is in the DNA of the teams that have represented

the country year after year. Our team members are fantastic ambassadors at international events and great role models and friends domestically.

International events such as the European Championships and the World Games give a platform to showcase the value of a positive life attitude.

The people who put themselves forward for these events are not only challenging themselves to be the best that they can be in their chosen events, they are also role models. Take inspiration from them to be the best YOU can be in everything you do!



Recruitment for the team going to the World Transplant Games in Perth, Australia next April (15th-21st) will begin shortly.

A Zoom webinar will be held on Monday October 10th to discuss participation in the games.

Please get in touch with Colin White if you are interested at Ph: 01-6205306 or email: colin@ika.ie
You can also refer to the Games website at www.worldtransplantgames.org

It was with great sadness that we learned about the passing of Paul Prendergast, a veteran member of Transplant Team Ireland, from Ballymun, Dublin, on August 30th, 2022.



Paul represented Ireland at numerous World and European Games events since his kidney transplant 23 years ago from which he gathered a haul of medals for his sports events – Swimming, Petanque, Darts and Ten-Pin Bowling. Paul, always grateful to his kidney donor was a much loved and valued member of the team's family. Always remembering his organ donor, he participated in numerous media activities to highlight the success of organ donation.

Married to Rose his childhood sweetheart, who was just 17 when they wed, they always travelled together to the Games and they also always had a large welcoming party on their arrival back into Dublin airport when returning home with the team. The devoted couple were married for 55 years and reared 13 children.

Our deepest condolences to his wife Rose, their children, grandchildren and great grandchildren. Paul's three surviving siblings, and extended family. May he Rest in Peace.

– GWEN O'DONOGHUE



Congratulations

Congratulations to Colin White, the IKA's National Advocacy and Projects Manager on his recent appointment to the role of Honorary President of the European Transplant and Dialysis Sports Federation (ETDSF). Colin who is also the Transplant Team Ireland manager, previously served as Secretary of the ETDSF.

Married to Chikoyo, a dialysis patient, Colin is passionate about the positive social impact of sport and has spent the past 25 years actively promoting organ donation and exercise pre and post-transplant.

His impressive CV also boasts the role of Honorary Treasurer of the World Transplant Games Federation.



Outgoing President Judith Berente from Hungary, passing on the baton of Presidency to Colin White.

The Adventurous Ten

Hiking Kilimanjaro for charity

DAY 2: In the Moorlands on way from Rainforest to Shira Camp 1.
(L-R): Joanne Langton, Veronica Horan, Seamus Lyons, Colleen Nolan, Roisin Nolan, Daithi Horan, Meadbh Hurst, Ruairi Mensink, Ciarán O'Sullivan. Front: Doireann Langan.





By: **GWEN O'DONOGHUE**

*At the Summit:
Back row, Ruairi, Veronica,
Ciarán, Colleen. Front: Joanne, Roisin,
Doireann and Daithí.*



Ten young men and women from six Irish counties discovered their shared love for hiking, which brought them together during COVID-19, and decided to channel this passion into raising funds for charity and encouraging others to take up hiking.

They have called their initiative GET UP THAT HILL (GUTH) and it has grown in momentum over its two-year history, with funds raised from different hikes going to several charities.

In August 7th-13th this year, as part of the Get Up that Hill 2022 fundraiser, ten friends tested their physical and mental endurance to the limit, as they undertook their ultimate hike, by scaling 5,895 meters of Kilimanjaro, the tallest free standing mountain in the world and one of the Seven Summits.

Self-funding the cost of their trip, one hundred per cent of the funds raised from individual supporters, their employers, and sponsors, goes to three charities: the Irish Motor Neurone Disease Association (IMNDA), Save Elders Tanzania; and the Irish Kidney Association (IKA). With funds still coming in since their expedition in August, to date over €11,000 has been raised through their online GoFundMe platform – see link below.

The ten college graduates who are all in employment include: 23-year-old Veronica Horan, from Ferns, Co Wexford who is the youngest in the group; and fellow Wexford woman Colleen Nolan,

from Drinagh; 26-year-olds and two of the eldest members in the group, Joanne Langton from Stradbally, Co Laois and Maedbh Hurst from Ballinasloe; Maedbh's fellow Galwegian Roisin Nolan from Furbogh; Daithí Horan from Athy, Co Kildare; three West Corkmen including Ruairi Mensink, from Allihies, Ciarán O'Sullivan, from Castletownbere, and Seamus Lyons from Eyeries; and Doireann Langan from Athlone, Co Westmeath who shares a house in Dublin with Maedbh and Seamus.

Corkman Ciarán O'Sullivan, who works in Operations for Australian Tech company Galaxy, explained, "Seamus, Ruairi and myself went to the same school together, Beara Community School. Through networking and our college connections there are now ten of us who together, hiked Kilimanjaro and have forged friendships for life. It was a phenomenal experience and unforgettable personal achievement for

continued next page

<https://www.gofundme.com/f/get-up-that-hill-2022>



Setting out from Dublin airport: Back row: Daithí, Veronica, Colleen, Meadbh, Seamus and Ruairí.
Front: Roisin, Doireann, Ciarán and Joanne.

each and every one of us.

"It took us seven days and six nights to complete and in that time we hiked through rainforest, moorland, and the daily changes in temperature of alpine desert from extreme heat to freezing cold.

"The scenery was spectacular and different every single day and the terrain and altitude changes brought different challenges including headaches, muscle pain and difficulty breathing.

"Fortunately, we had recruited four local guides who could help us prepare and navigate through the terrain and, when our resolve began to falter, we gave each other encouragement to push through, motivated by our pledge to help three deserving causes.

"We took the time away from our workplaces as annual holiday leave and self-financed our trip determined that every cent raised went into the fundraising pot".

Describing how the global pandemic brought the group together, Galway woman Roisin Nolan and Joanne Langton from Laois agreed, "Serendipity is a word we would use to

“

It took us seven days and six nights to complete and in that time we hiked through rainforest, moorland, and the daily changes in temperature of alpine desert from extreme heat to freezing cold.



Rising sunrise as group approached the Summit.



View of Uhuru Peak from Basecamp.

describe how our group was formed. Despite COVID-19, having different professional backgrounds, from pharmacists to accountants, and coming from all different corners of the country, from the sunny southeast, to the Midlands, over to the wild Atlantic West, and West Cork, chance brought us together! Even though it was fate that united us, it was our common interest in hiking that was the glue that kept us together!"

Daithí Horan from Athy, who works as a Design Engineer with Boeing, outlined why the Irish Kidney Association, would benefit from the group's fundraiser.

"The group was unanimous in agreeing to support the IKA as one of the three charities to benefit. My mother Michelle and Veronica's father Ben Horan, who lives in Ferns, both have kidney failure and are undergoing dialysis treatment. We are deeply grateful for the support our parents have received from the IKA which does amazing work in advocating for kidney patients and promoting the organ donor card".

To honour the memory of young Galway woman Maedbh Hurst's grandmother Betty O'Hare, who passed away with Motor Neurone Disease before Maedbh was born, the IMNDA was chosen to receive some of the fundraising proceeds. This charity delivers support to over 400 families suffering with MND around Ireland today.

Wanting to give back to the African country hosting the ten hikers monumental expedition, they set about identifying a worthy charity in Tanzania.

Group member and Wexford woman Colleen Nolan contacted her old friend, Precious, who is a native of Tanzania and



*The group with their guides
Josh (left), Kennedy (front right) and Harun (right).
(Fourth guide Eiezer is not pictured)*

asked if she could recommend any local charities there. Precious's cousin Sarah had set up a charity there called Save Elders Tanzania to support senior citizens.

Colleen, a regulatory professional with LEO Pharma, explained, "We decided to select Save Elders Tanzania to benefit from our fundraising after researching the work they do and realising how much older people in Tanzania lack support when compared to Ireland. They now have 60 volunteers who regularly meet up to help improve the lives of older people in Tanzania. The day after our expedition, we enjoyed the hospitality of six of the charity's volunteers including its founding member Sarah."

Before returning to work, the entire group enjoyed a five-day safari, taking in Tarangire and Serengeti National Parks, while also having the opportunity to drive into the phenomenal Ngorongoro Crater. They also saw many impressive animals in their natural

habitat and were especially fortunate to see all members of the Big 5, the lion, leopard, rhino, elephant and African buffalo.

Ciarán, Seamus and Meadbh had less time than others in the group before they returned to work but spent three days visiting Arusha before flying home. Seven of the group went on to have a one-week holiday in Zanzibar.

In summing up the Kilimanjaro experience, Doireann Langan from Athlone, Co Westmeath, who works as a pharmacist said, "we are all so grateful to everyone who have supported us and contributed to our fundraising which we hope will help two very worthy Irish charities who help patients and their families here in Ireland while also giving something back to Tanzania, a magnificent country which has given us memories we will treasure for a lifetime. A special mention is due to *Expect In Africa Safari*, the Tanzania-based company, which looked after us throughout our hike and safari, they were outstanding!"

The group's Instagram page @getupthathill2022 includes photos of the groups endeavours.





By GWEN O'DONOCHUE

Members of the Roarty family with representatives of The Dunlewey Celtic football club and representatives of the Donegal IKA Branch.

Young Roycee's Legacy

On Saturday, August 27th, Dunlewey Celtic presented a cheque for €6,090 to the Donegal branch of the Irish Kidney Association (IKA). This considerable sum was just part of over €10,000 which has been raised to date for the charity and to honour the memory of a young man who had tragically passed away in 2019.

The Donegal branch supports families and patients from Donegal whether their needs may be within the county or if they must attend hospital elsewhere in the country.

A total of €6,290 was raised following a football tournament held in Dunlewey on Sunday July 31st in memory of Mícheál 'Roycee' Roarty who tragically passed away in 2019, when he was 24-years-old, when three other young men also lost their lives – John Harley, Shaun Harkin, and Daniel Scott.

Mícheál himself was a renal patient since he was 18-years-old. The Donegal branch of the IKA are a charity that are held close to the hearts of Mícheál's family when they provided supports to them in their time of need, and in particular Mícheál's parents Martin and Maire Roarty.

Dunlewey Celtic decided to run a similar fundraiser in the summer of 2019 in Mícheál's memory but, unfortunately, they were unable to organise anything until this summer with the easing of COVID-19 restrictions.

The Club decided that it would run an annual event to remember Mícheál in the community, and to

raise funds for the Donegal branch of the IKA given its ties to the family.

They decided upon a football match initially, which brought huge interest with a vast amount of people wanting to play in the match. This reflected how many people Mícheál touched in his short life.

This year they decided to expand and have a mini football tournament of four teams. The teams were made up of former teammates, friends and family of Mícheál.

They played two semi-finals and a final, with the perpetual cup going to the winners. The cup was kindly sponsored by Roarty's Shop and Garage in Dunlewey, of whom Mícheál was a former employee.

The weather forecast for the weekend did not look promising, but on the Sunday Mícheál was certainly looking over them all as the sun shone as brightly as his smile used to.

Mícheál's family had a lovely tribute at their home, which is on the way to the pitch, where the jersey

Mícheál Roarty, RIP



Mícheál wore whilst playing for Dunlewey was displayed at the front of the house, bearing the number 4. The number 4 was retired by the club following Mícheál's passing.

A GoFundMe page was set up to take donations for the event, which enabled people from all corners of the world to donate, including some of Mícheál's close friends located in Australia.

The event was a huge success with over €1,800 being raised on the day alone. People's generosity was reflected as the donations kept rolling in from people who knew Mícheál. At the end a total of €6,090 was raised.

On September 7th an email was received by the Club from the ESB stating that they would like to sponsor a further €200 for the cause, bringing the total amount raised to €6,290.

This is the second event held in Mícheál's memory, and in total over €10,000 has been raised for the Donegal branch of the IKA in his name.

The football club, Mícheál's family, and representatives from the Donegal branch of the IKA, wish to acknowledge their gratitude to everyone who donated to the cause, and to McGeady's Bar, Dunlewey who hosted the presentation both after the tournament, and on the night of the presentation of the cheque to Siobhán McCafferty Bates and George Bates of the Donegal Branch of the IKA.

Such generosity will go a long way towards helping people in need of the vital services provided by the IKA.

Go raibh maith agaibh.

"How to be our best self" Wellbeing Day

A very enjoyable and interesting day was had by all who attended the "How to be your best self" wellbeing day in St Andrew's Resource centre in Dublin.

A wide range of workshops, talks and mediations were held between 8am to 6pm.

These covered a range of complementary therapies from mediations, chi kung, green therapy, the secret of ageless aging, mental health in senior citizens, to yoga and a children's workshop.

There was even a session on maintaining kidney health.

Aoife Smith, the IKA's National Counselling Co-ordinator attended, participating in the sessions and was on hand to answer a range of questions from participants.

All the sessions were livestreamed and recorded and can be seen at <https://www.facebook.com/taichiyourway/> for a limited time.

Thanks to Stuart Breen and his team of volunteers who organised the speakers and logistics, covering all the costs out of their own pockets.

Stuart is a qualified fitness instructor, personal trainer and author as well as chief Tai Chi instructor with Tai Chi Your Way.

The event raised over €2,000 for the Irish Kidney Association.

So why not take a look the videos and let us know what you think.

If there is enough interest, we will look at whether we, in the IKA, can organise providing these types of events in the future.



Stuart Breen, Aoife Smith and Tom Gunning



Artists Geraldine and Kamila.



TWO JOURNEYS

The American Tourist

INTRODUCTION

In 1984 Ron Walsh's daughter, Laura, was born in the US. She was soon diagnosed to have tiny, deformed kidneys and was not expected to live more than a few weeks. Even though there was very little kidney tissue, Laura, with medication and diet, survived.

In this article, Irish descendant Ron charts how his daughter's kidney failure would influence their life journey in their native Wisconsin. His second journey took Ron and his wife on a European cruise with one of the highlights being a visit to Donor House, the IKA's head office, in Dublin.

By RONALD J. WALSH, KIDNEY DONOR



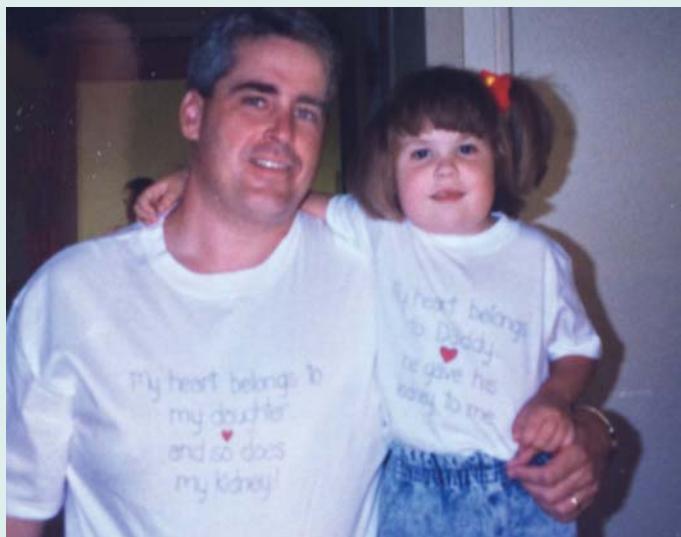
On July 3rd, 1991, at age six, Laura underwent transplant surgery at the University of Minnesota in Minneapolis, Minnesota USA. Her kidney transplant surgeon was the famous Dr. John Nagarian, who had performed the first paediatric liver transplant. Ron, her father, was the living donor for Laura.

Laura's road has been bumpy. She has had at least two major rejection episodes which were successfully treated. She almost succumbed to a serious illness caused by a virus that ran rampant due to being immuno-suppressed. She survived again from illness that was thought to be unsurvivable. She has been a source of pride for her strength and grit. Her life has continued to be difficult but rewarding.

She is presently in stage four renal failure and will likely need another transplant. Through all the difficulties we remind her, and ourselves, that Laura enjoys life and is fortunate to be alive to face the challenges ahead.

Ron, with his wife Sue, their son Ryan (his wife Tracy and son Evan) have been active with Laura in the National Kidney Foundation of Wisconsin. They have attended several NKF events. They attended the 2000, 2002, 2004, 2006, 2008 and 2010 US Transplant Games at Disney World, Louisville, Minneapolis, Pittsburgh, and Madison, WI.

The Walsh's donate monthly to the NKF of Wisconsin because, as Dr. Walsh states, "The National Kidney Foundation has provided life-saving interventions for countless individuals and families over the years, at the most vulnerable times of their lives. The work they do is inspirational. I'm proud to be associated with this wonderful group of people."



JOURNEY TWO

THE IRISH KIDNEY ASSOCIATION (IKA) IN DUBLIN

In 2008 my family participated in the US Transplant Games for Team Wisconsin. The Games were held in Pittsburgh, Pennsylvania. It was there that I met the representatives from the IKA. We had a brief discussion about Ireland and the US and, if I recall correctly, we had a brief discussion of kidney transplantation in Ireland as well as the journey that my daughter, Laura, and I had with our own journey. I have always wanted to visit Ireland for many reasons. Among the reasons were that I had heard that the people were friendly and that my own family came from Ireland in the mid-1800s.

When my wife and I planned our cruise of the British Isles, in January of 2020 for August of 2020, I wanted to be ready. The first thing I ordered was a pair of lightweight hiking shoes. The second thing? A *Peaky Blinders* type newsboy hat. I bought this because I'd read that one sure way to look like an American Tourist was to wear a baseball cap; of which I have many. I did not want to look like a typical American tourist.

After having our cruise cancelled in 2020 and again in 2021, we were excited when it looked like a go, for August of 2022. The first thing I noticed in Southampton, and then in Guernsey, Cork and Dublin, was that no one was wearing the flat style hat, but I saw many baseball caps.

For me, the highlight of our trip was our brief stay in Dublin where my wife and I had the chance to stop at the IKA and meet a few of the staff members in Donor House. What a great group of people! They were

very welcoming, and we had a nice conversation about transplantation.

It was nice communicating with Ashling Hand, the Office Manager through email and to personally meet a few of the other IKA staff: Jessica Brien, receptionist, Colin White, National Advocacy and Projects Officer and Aoife Smith, the Coordinator of Counselling Service.

When I told them the story of my *Peaky Blinders* hat, I mentioned that no one seemed to wear them anymore. Colin said, "Sure, people still wear them," to which Jessica replied, "Yes, I see the old guys still wearing them." Ouch! Our visit to the office was brief but it was still the highlight of the entire trip for me.

As I reflected on our visit to Ireland, especially the IKA folks in Dublin, it became obvious that my initial instinct about the Irish people was correct; they are very friendly people. I would say of the IKA, the same as I have said about our own

National Kidney Foundation, "The Irish Kidney Association provides life-saving interventions for countless individuals and families at the most vulnerable times of their lives. The work they do is inspirational. I'm proud to be associated with this wonderful group of people."

JOURNEY ONE

KIDNEY DONOR AND RECIPIENT

When I met Colin White at the IKA office, he asked that I share the experience that I'd had with my kidney donation to my daughter, Laura. Thus, this description of our first big journey, which continues.

It was when Laura was 5 years old that we knew her transplant would be within one year. At that time the option of living donation was presented to my wife Sue, and me. We decided it would be me who donated. From that point on, and for

continued next page



Colin White, Aoife Smith, Ron Walsh and Jessica Brien at Donor House.

TWO JOURNEYS continued

the next year, I became very focused and driven to maintain good health until the time came. As living donors know, a donor can be rejected at any time up until the time of surgery because of health issues or problems with blood and tissue compatibility. When you make the decision to donate, the last thing you want is to be denied the opportunity to donate.

As we came closer to transplant day, I assumed people knew about Laura's health and our donation decision. The decision to donate, and the donation itself, provides a very keen and personal sense of pride. The kind of pride you have when you know you are doing something for someone else for no other reason but love. Certainly, this pride is not bravado. I've never gone out of my way to promote or brag in any way about my decision to donate. I've always felt that doing so would cheapen the emotional and psychological benefits of

donation.

Laura's transplant was in July of 1991 while I was on summer vacation from my job with the Spooner, Wisconsin School District as a guidance counsellor. When I returned to work after summer vacation I was still focused on Laura's health since she had undergone some rejection and serious illness from complications. I was surprised when I was seated in our cafeteria on one of our opening in-service days with about 150 other staff members, when our superintendent, Mr. Jim Kling, welcomed all of us back to school. He told the staff, "As most of us spent our summers doing the things we do to refresh for another school year, Ron Walsh spent his summer in and out of the hospital with his daughter, Laura, to whom he donated a kidney." It is the only time I've ever received a standing ovation and I was deeply touched.

A local reporter in Spooner asked me soon after Laura's

My message to my Irish friends, especially those of you facing transplantation and/or donation, is simple and brief: "Enjoy life as you take on the challenges ahead. Support your family and do what you can to support the IKA that supports so many other people like us".

Our thanks to HOT PRESS MAGAZINE

for highlighting organ donation in over 30 third level colleges and universities around Ireland, by including 7000 postcards containing an Organ Donor Card, which can be cut-out and signed, and information on the Donor Card App, which students can download onto their smartphones.

The postcards were distributed to students during *Freshers Week* as part of the *Hot Press College Campus Roadshow*.

OHOT PRESS

GIVE THE GIFT OF LIFE



Scan to put an Organ Donor Card App on your smart phone

Please share your wishes with your family

To obtain plastic Organ Donor Cards Freetext **DONOR to 50050**



Sue and Ron on the ship after Dublin.

transplant why I decided to donate. I told him, "You go through life, and you don't do everything right, and then an opportunity like this comes along". My donation is the most powerfully good thing I have done in my life. I certainly do not want to brag about it, but I am proud and honoured to have had the opportunity to give the 'gift of life'.



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.**

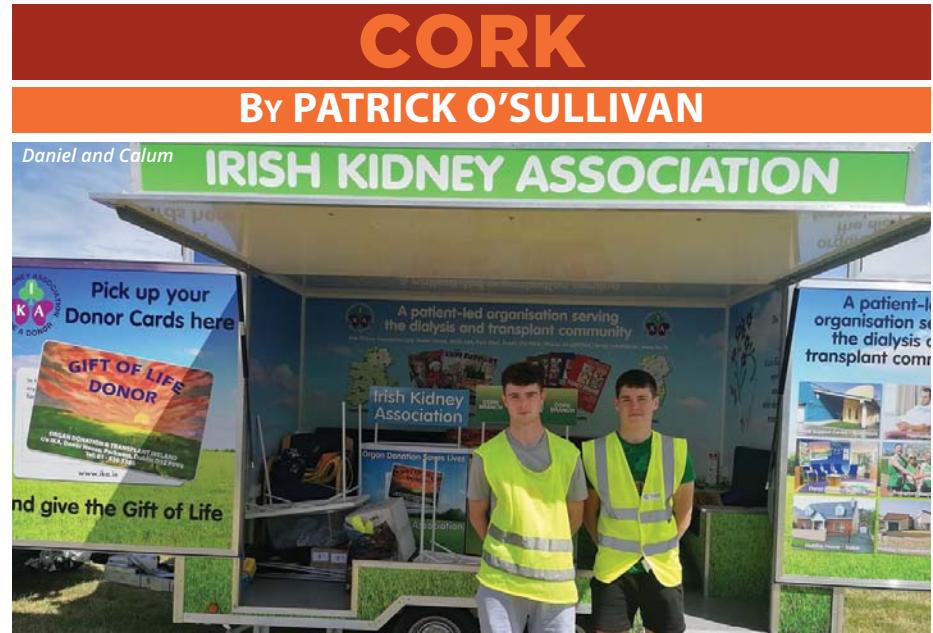


Hello one and all, and I hope all of you had an enjoyable summer. We hope you all applied plenty of sun protection and took on plenty of liquids during the unusually long dry and hot spell we had. It seems a long time since the last edition of SUPPORT magazine and as usual the Cork Branch has been very active in the last few months.

CORK SUMMER SHOW

The Branch was delighted to be invited to take part in this year's Cork Summer Show at the Munster Agricultural Grounds. It was the IKA's first chance to showcase the mobile display unit at the Show and a big 'thank you' to the volunteers who turned up for the 2-day event, promoting organ donor awareness to the massive crowds that turned up.

The Taoiseach Micheál Martin stopped by and had a great chat with us. He listened to our concerns on local and national issues. We also had Miss Cork, Saoirse O'Shaughnessy, stop by to add a bit of glamour to the day. She promised to include Organ Donation in any promotions she will be doing in her



role as Miss Cork in the lead up to the Miss Ireland competition.

SUMMER BBQ

We had a great turnout at our first get-together in three years, where we held a barbecue at the Anglers Rest in Cork. It was great to catch-up, once again, with old friends and welcome some new ones to the fold. Holding events like this is never easy and great credit should go to the Branch Officers for putting the event together and making sure it was a safe and enjoyable day for all.

During the course of the day a presentation was made to outgoing Board Member, Michael Kiely, by Chairman, Denis Hyland and Branch Secretary, Sheena McDonagh, to thank him for his service on the Board and to the Branch.

CORK SUPPORT CENTRE

The development of an IKA Support Centre for Cork University Hospital was first suggested in 2014.

Thanks to the generous bequest of the late Elizabeth O'Kelly, the Board of the IKA was able to make it a reality. In 2017, 11 Wilton Avenue was acquired and shortly after that the adjoining 12 Wilton Avenue was also purchased to give patients and families, in the Munster area, this much needed Centre.

The Cork branch has played an important role in fundraising and helping push the project forward.

Work began on the Centre on August 15th this year. A dedicated web page has been set up on <https://ika.ie/cork> where you can follow the progress of this project, and of course we will post regularly through our Branch social media channels, Facebook and Instagram.

The web page also has a donation link and if you would like to contribute to the future running and building costs you can do so on the page. Thanks to Robyn in Donor House for her work on the web page.



Denis Hyland & Micheál Martin



Denis Hyland, Saoirse O'Shaughnessy & Pat O'Sullivan



Frances O'Shea & Sheena McDonagh



Sally Nagle with her nieces Lailly and Natalie

CORK SUMMER BBQ



Colette and her mother Angela



Helen & Donal



Sheena, Liz, Joe, Veronica



The Rices & The Murphys



Ready to be fed



Rosarie



Elsie



The Fentons



Patrick & Leona



The Hyland family



Presentation to Michael Kiely (left) from Denis Hyland and Sheena McDonagh



Nurses Abina and Mike



Tom & Joan



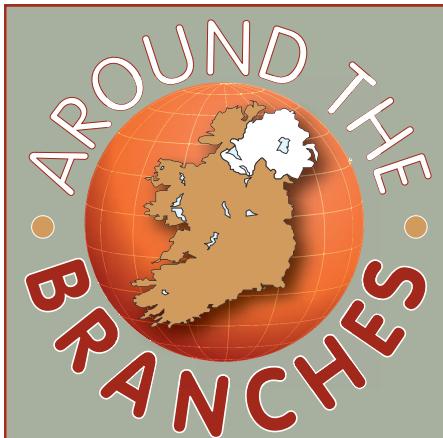
Wesley & Frances



Isabel & Sally



John & Mary



The house will consist of 6 ensuite bedrooms, an open plan sitting, dining and kitchen area. It will also have a self-contained two bedroom apartment with its own kitchen and bathroom, which will be rented out to raise income for the Centre's running costs. A dedicated recreational room will also be available where families and patients can sit and relax. There will be a large garden out the back to enjoy the outdoor spaces. Anyone that will be in clinic will be able to see the Centre by looking out the window from the consultants' rooms.

VOLUNTEERS

From time to time the officers in the Branch will be looking for volunteers in helping to promote organ donor awareness at various events. This usually consist of manning a desk for an hour or two, handing out donor cards and maybe talking about their own personal experience to help the promotion. Volunteers can be from families and patients alike.

If you would like to volunteer for future events, please contact the Secretary at secretarycork.ika@gmail.com or 086-2755754. This mobile is also the number for our WhatsApp group. If you would like to be kept up to date with all the goings on in the Branch.



Old garden



Eddie Flood, (IKA National Chairman), Dr. Michael Clarkson (Nephrologist CUH) and Abina Harrington (SNR CUH).



Pascal & James Falvey (Falvey Construction), Eddie Flood (IKA National Chairman), Sheena McDonagh (Secretary, Cork IKA Branch), Pat O'Sullivan (IKA Board Member), Denis Hyland (Chairman Cork IKA Branch), Bernard Cronin (Treasurer, Cork IKA Branch) and Dr. Michael Clarkson (Nephrologist, CUH).



Garden cleared



Good foundations



Rear of property

DUBLIN EAST & WICKLOW

By RACHEL O'HORA



From left: John Whelan, Bernie Dwyer, Rachel O'Hora and Jacqueline Burke.

Hello and welcome to all our members in the Dublin East and Wicklow branch. We hope you all had a wonderful summer. Our Branch activities resumed after the summer break.

CONDOLENCES

Our Branch sends our sincerest condolences to former National Board Member Colin Mackenzie, on the passing of his beloved wife Patricia. Members of the Dublin North branch, both Colin and Patricia, have dedicated themselves to the IKA and particularly to the IKA Renal Support Centre in Beaumont. Patricia's calm and gentle presence will be much missed in the Support Centre.

Ar dheis Dé go raibh a hanam dílis.

BRANCH OFFICERS ELECTIONS

Following the retirement of our former Chairperson and Board Member, John Whelan, there have been some new appointments to our committee.

Chairperson: Bernie Dwyer
Secretary: Rachel O'Hora
Treasurer: Catherine Foley
Board Member: Jacqueline Burke

We wish John well in his retirement and best wishes to our new committee members. See our Facebook (Dublin East and Wicklow IKA Branch) and Instagram

(@east_dublin_wicklow_IKA) accounts for introductions to our new committee.

PRESENTATION TO JOHN WHELAN

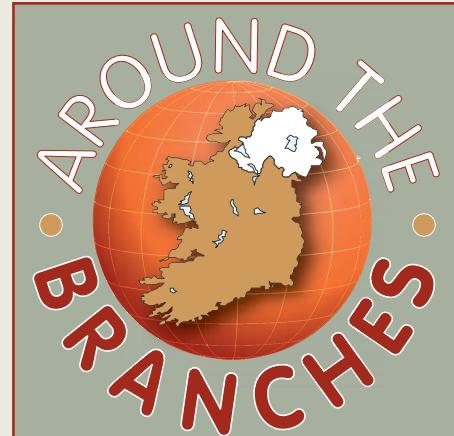
The committee met in July in Café du Journal in Monkstown, which has a lovely outdoor seating area with a canopy. Over teas and coffees we thanked John Whelan for his service and dedication to our Branch over the years and presented him with wine and a 'thank you' card. I'm sure you'll join with us in wishing John a long and happy retirement. We thank him for all he has done for our Branch, as well as the wider IKA community.

KILMACANOUE HORSE SHOW

Kilmacanogue Horse Show took place on Saturday, July 23rd and was a resounding success. There were horses and ponies of all sizes, a huge variety of dogs, and all sorts of other interesting events. We were lucky that the Show Committee decided to continue their association with their local branch of the IKA and a presentation will take place later in September.

CHARITY CYCLE

Congratulations and a massive 'thank you' to Declan Mulhall, who completed a 175km cycle, in July, in aid of the IKA. We look forward to the presentation of the cheque from



John Whelan being presented with his parting gift.

Declan in September and will have pictures in the next edition of SUPPORT.

CHARITY RUN/WALK

The Dublin Mountain Running Club is holding a 5k/10k Run/Walk at 9am on Saturday, September 24th in support of a young man, Cillian Doyle, who is currently undergoing dialysis treatment. Best wishes to all taking part. Funds raised are for the IKA.

RESUMPTION OF MEETINGS

We urge all our members to attend Branch meetings, which will continue to take place via Zoom for the moment. We will notify members when we intend to meet again face-to-face, once we have determined a venue and time schedule that is convenient.



It has been a busy season for the Waterford Branch as the Tramore Holiday apartments were back in full operation. There has been lots of very positive feedback from visitors and most benefiting from the lovely weather in the sunny southeast as it lived up to its name!

We wish to acknowledge the work of Cathy Keoghan as she welcomes visitors to the apartments, on behalf of the Branch, and for keeping a keen eye on the general upkeep of same. We also thank the cleaning staff who work to maintain the apartments in the best possible condition for our visitors. Thanks also to caretaker Andy Smith for his continued good work in keeping the exterior looking so well and for carrying out the odd jobs needed inside also.

Continued good wishes to Vera Frisby from Tramore for a steady recovery from her recent illness.

A sincere 'thank you' to Pat Connors and Chopper Organ who

WATERFORD

By FRANCES MOYNIHAN

Noelle Conway and Marie Moore



raised €1,800 in a head dye and shave in Bridgie Terries at The Pike, Dungarvan in January 2022.

Fundraising continued throughout the summer. Our very successful 8-a-side Soccer tournament organised by Chairperson Ray Halligan, along with the Newtown Fundraising Committee, has raised very valuable funds.

Saint Declan's Way is a 115km pilgrim walking route linking Cashel in Co Tipperary with Ardmore in Co Waterford. It follows the route that

Declan took when going to Cashel to meet Saint Patrick in the fifth century.

Noelle Conway and her friend Marie Moore completed the walk over four days in July and highlighted organ donor awareness along the way.

To all those who have lost family members recently, we extend our deepest sympathies, especially the family of Patricia Mackenzie, Dublin, RIP.

WEXFORD

By MARIA DONLON

Hugh and Dorothy Byrne celebrated their 25th wedding anniversary with a party for family and friends in Kiltealy recently and very generously raised €1,000 for the IKA.

Our recent Zoom meeting saw our newly elected Branch Officers taking charge.

Chairperson: Pauline Atkinson
Secretary: Walter Kent
Treasurer: Marie Kehoe
Board member: Liam Buttle

We wish them all well in their new positions for the coming year.

Please try to join in on our Zoom meetings and follow us on our Facebook page.



Find us on:
facebook®



Hugh and Dorothy Byrne presented the cheque for €1,000 to Walter Kent and Liam Buttle, Wexford Branch.

IKA SUPPORT AUTUMN 2022

WATERFORD 8-A-SIDE SOCCER FUNDRAISER

All photos are courtesy of
JOE CASHIN



On Saturday, July 2nd, in St Joseph's AFC grounds in Williamstown, Waterford, our IKA team of extended Halligan family, which included our Chairperson Ray Halligan, once again took on St. Joseph's team in our annual soccer match. What started as a very wet windy day, fortunately saw the rain stop at 4pm, in time for kick-off (and no statues to the Infant de Prague needed!).

The IKA team put up a valiant fight in a very entertaining game of 30 minutes a side. They scored 8 goals

on the day but the winner's trophy went to St. Joseph's AFC team who proved to be the more skilled.

We wish to thank our sponsors...Joe Moynihan Engineering, Stradbally for the perpetual plaque and trophies, Dooley's Hotel for the catering, Ballybeg Stores for refreshments for the teams, and Munster Furniture for a kind donation. Not only did St. Joseph's provide the winning team, they also very generously presented our Honorary Secretary Frances



Moynihan with a donation.

All monies raised in the Waterford Branch are used for patients in our county. As COVID-19 has greatly impacted on fundraising opportunities over the past two years, we were delighted to get the chance again, to generate awareness of the Branch.

If you know of anyone affected by kidney disease who would like to connect with us please feel free to email Frances at franceswaterfordika@gmail.com





Find us on:
facebook.®

WHITE FAMILY JUMP IN BLUE SKIES

After several months of delays the call to jump came for members of a Sligo family who had been waiting for the right weather conditions to do a charity skydive for the IKA and North West Hospice.

Collooney natives Nikita, Ian, Chris and Katelyn White, took the high jump on August 12th when the perfect day arrived for their skydive.

They did the jump in memory of deceased family members, Granda Mick (Michael White), a dialysis patient who passed away on May 20th last year, and Nana and Granda Michael and Margaret Philomena McKeon who died some years ago.

They had already raised the funds for the two organisations. They presented a cheque for €1,226 to the IKA Sligo Branch earlier this year.

BRANCH MEETS HOSPITAL MANAGEMENT

The need for a new dialysis unit and the creation of additional facilities in the short-term were discussed at a meeting between representatives of IKA Sligo branch

SLIGO

By BRIAN McHUGH

Nikita White



Katelyn White



Ian White



Chris White



and hospital management on June 15th.

Renal medical staff also attended. Sligo branch IKA were represented by Branch Chairman Sean Fowley and Secretary Geraldine McHugh.

All in attendance were in agreement that a substantially larger unit is required, with additional staff, to meet the ever increasing numbers of patients requiring dialysis.

SLIGO

Hospital management outlined plans for short-term measures to create additional dialysis stations while approval is awaited from national level for the longer term project.

It was agreed to hold another meeting when plans are further developed.

Our Branch has had a series of communications with the Minister for Health and health officials over the past two years, in which we have been pushing for adequate dialysis and renal facilities at the hospital.

The latest letter from the Minister's Private Secretary to the Sligo Branch stated that Sligo University Hospital and HSE Estates are working on completing an accommodation schedule for dialysis services at the hospital to cater for current and future demands.

It said that when the accommodation schedule is finalised

Saolta University Health Care Group plans to submit a request to HSE Estates to secure funding for the appointment of a design team to formally "scope out" the project.

Sligo IKA branch will continue to campaign at all levels for improved dialysis services.



CONGRATULATIONS

Congratulations to our

vice-Chairperson
Marie Fowley on
her recent
appointment as IKA
National Honorary Secretary. A
resident of Hazelwood, Marie is a
kidney and pancreas transplantee.

Also best wishes to Eddie Flood,
Westmeath Branch on his
appointment as National Honorary
Chairperson and to Joan Gavan
(Tipperary) on becoming National
Honorary Treasurer.

SYMPATHIES

One of our longest serving members, Helen Sproule, passed away on July 29th.



Helen, of Bella, Collooney, was a kidney transplant recipient and had been an active member of our Branch for more than 20 years.

An ardent fundraiser for the IKA, one of her favourite activities was baking for our cake sales and helping to man the annual sale stall at Sligo University Hospital.

One day later, July 30th, the death occurred of Mary Dolan, Kiltclogher, Co. Leitrim, mother of our Branch member Aoife Dolan.

More recently, our former Branch member Frank Keaney, Urlar, Drumcliffe, passed away on September 1st.

Sympathy to the families and friends of the deceased. RIP.

TIPPERARY

By ORLA HOGAN

We hope that everyone had a lovely summer.

We wish to pass on our sympathy to Colin Mackenzie on the passing of Patricia. We all got to know Patricia in the Support Centre in Beaumont, and the care and attention that she gave to everyone in Tipperary was excellent.

Members of our Branch were delighted to attend a cheque presentation by Francis Hogan, and members of the Upperchurch Drombane Cycling Club at Liberty Square, Thurles, in early September.

They raised an incredible €27,300. Well done to all involved (see page 36-39 for the full story.)

Congratulations to Joan Gavan on been elected as National Honorary Treasurer.

Thanks to Doireann Donovan on organising a golf classic which raised €630.

CAVAN/MONAGHAN

By KARL CRONIN

Our Branch met via Zoom at the beginning of the summer in an effort to resurrect Branch meetings and activities after a prolonged period of inactivity. Unfortunately, there was very low attendance so it was agreed to defer until the autumn.

If you are based in the Cavan / Monaghan area and want to join Branch meetings, meet fellow IKA family members and keep up to date with the services provided through the IKA, please text your name and number to me on (086) 8513173 and I will ensure you are included in our mailing list.

PATRICIA MACKENZIE, RIP

We were very saddened to hear about the passing of a dear friend to many of us, Patricia Mackenzie.

Patricia welcomed callers to the Renal Support Centre with a smile and a friendly chat and always had a kind word for everyone. Her support to patients and families alike was invaluable. Patricia will be fondly remembered and sadly missed.

We extend our sympathies to Colin, the Mackenzie family and her friends in the North Dublin Branch at this sad time.

May Patricia's kind and gentle soul rest in peace.

LIMERICK

By SHAUN FALOON

The Limerick Branch would like to express their condolences to the Kelly family on the passing of Ger Kelly, late of Weston in Limerick. Ger was a member of the Limerick Branch and was always ready to help. He will be sadly missed. May he Rest in Peace.

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).



Enda Egan driving the tractor which pulled the float

It all began on St. Patrick's Day 1994. The Egan family, from Fivealley, and the Young family from Mountbolus in County Offaly, built a float based on the theme 'Dialysis' which they entered in the St. Patrick's Day Parade. The objective of the fun initiative was to convey an important message by creating awareness about the Irish Kidney Association (IKA) and haemodialysis treatment for patients.

Both families enjoyed presenting the float on the day and were delighted when they were rewarded for their efforts as they won first place in the category for 'most original float'.

Back then, there was no



Eimear Egan

OFFALY

BY MARY YOUNG

'Reflecting on the Past'



Catherine Young (assuming the role of dialysis patient), and playing the part of medical staff Carol Young, Eimear Egan, Pat Egan and Anne Marie Egan.

haemodialysis unit in the Midlands and patients had to travel to Dublin, Galway, and Cavan for dialysis treatment. The number of patients travelling for dialysis from the Midlands, including counties Longford, Laois, Offaly, and Westmeath, continued to increase.

Three people were instrumental in successfully lobbying for the establishment of a dialysis centre in the midlands. The three main campaigners included Renal Nurse Noreen Galvin, the Irish Kidney Association's then Chief Executive Mark Murphy, and local kidney patient, the late Richie Young, who later served as Honorary Treasurer and then as National Chairman of the IKA.

February 7th 2005 marked the ground-breaking first day for midlands patients to begin receiving their haemodialysis treatment, at a temporary dialysis unit located on the grounds of the Midlands Regional Hospital in Tullamore. The purchase of the temporary building was a collaboration between the IKA's Laois, Offaly, and Westmeath branches. The establishment of the haemodialysis unit was developed in close cooperation between the Midlands Regional Hospital Tullamore and the IKA. The IKA

provided the physical infrastructure of the temporary portable building. The hospital determined its location on its grounds and managed its staffing and ongoing management to provide haemodialysis treatment for 12 patients per day, operating from Monday to Saturday. Two years later, in May 2007, a new hospital building was opened, which included a state-of-the-art dialysis centre.

Since then, the dialysis centre has increased from a six station to a twenty-nine station Haemodialysis Unit, providing acute dialysis treatment within the ICU/CCU and the Nephrology in-patient medical ward.

In October 2019, it became the parent site for a new contracted haemodialysis unit located in Portlaoise, further reducing travel for midlands patients.

We've come a long way since March 17th, 1994!



OFFALY

By DERMOT GLYNN

The newly appointed Branch Officers for Offaly for the following term are as follows:

Chairperson: Jerome Burke
Treasurer: Leona McDonald
Secretary: Marjorie Stanley
Board Member: Dermot Glynn

BRANCH MEETINGS

Thankfully our face to face Branch meetings resumed again on September 17th in the Tullamore Court Hotel. All members new and old were welcome to attend. Current government guidelines and protocol were followed in relation to COVID-19.

FUNDRAISING

We would like to thank Marie Smart from Portarlington for her recent very generous donation. Thank you for your continued support.

A big 'thank you' to the Tullamore Touring and Cycling Club who nominated us, once again, as one of their chosen charities for the Pedal the Peaks Challenge.

There will be more information in the next issue of *SUPPORT* in relation to this event.

CONDOLENCES

On behalf of the branch we would like to extend our sincere sympathy to the family of our former member Betty McNamee, RIP. It was with great sadness that we received the news of her passing. Betty will be remembered for her beautiful knitting of such a variety of dolls. There are many a house which have more than one of her creations today. Betty and her predeceased husband Eamonn, a kidney recipient, added so much life to the branch. They are sadly missed.

We would also like to extend our sympathy to the family of Mary Bergin of Portarlington, RIP, who passed away recently. Mary was a very dedicated volunteer collector in Portarlington for the IKA for many years.

We express our condolences to Colin Mackenzie, former national Chairman of the IKA, on the death of his wife Patricia. Rest in Peace.



Visiting the IKA's mobile display stand at the Tullamore Agricultural Show, one of his first engagements as the newly appointed National Honorary Chairman, was Eddie Flood from Westmeath (second from right) with (left) Dermot Glynn, Board member/Offaly Branch IKA, a visiting Show patron, and Angela Kirwan, Board member/Laois Branch IKA.

Patricia was the ever-friendly face to many a member and their families staying at the Support Centre in Beaumont.

Our sympathies are also extended to Deborah Cervi at Donor House and her family on the passing of her father Martin Lynch. RIP

GET WELL WISHES

From everyone at the branch we would like to send our best wishes, for a speedy recovery, to former CEO Mark Murphy.

THANK YOU

A big 'thank you' to Mary Young who has stepped down from her position as Branch Treasurer. Mary has been deeply involved with the

Branch for several years and carried on the legacy of her late husband Richard, a former Branch officer and National Honorary Chairman, who passed away in 2009. We're all very grateful for the time and commitment Mary has shown to our Branch. We would like to offer our best wishes to her in her retirement from the role of Branch Officer. However, many who know Mary will understand that she will still remain very active in the background, as could be seen by her efforts recently when she organised food for 350 cyclists in the Pedal the Peaks fundraiser. Once again, our thanks to Mary for everything she has done for our Branch.

FOR DONOR CARDS



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Anne Lacey & Bridie Lennon at the Run for a Life Walk in Graiguenamanagh.

Autumn greetings to everyone, especially our patients, members, and their families.

On August 23rd, the IKA Kilkenny Branch, in compliance with the Board and COVID-19 guidelines, returned to holding a physical Branch meeting. It was terrific to meet everyone who attended on the evening.

We thanked Therese Hanrahan who stepped down as Branch Treasurer and welcomed Bridget Langton as our new Treasurer.

We now look forward to our next physical Branch meeting which is due to be held on October 11th at 7pm, in compliance with safety



Above: Some participants after the Run for a Life walk with Kilkenny branch Chairman John Lacey and Treasurer Bridget Langton.

Below: Sharon Byrne & Andrea Neill

guidelines.

Branch meetings were held monthly via Zoom before our last in-person meeting. The meetings provide a forum to update patients and members regarding IKA activities and forthcoming events.

RUN FOR A LIFE FUNDRAISING WALK

The Summer 2022 edition of SUPPORT featured a beautiful poster for our third local Run For A Life walk, which was designed by Sari Santi, an IKA member.

On Sunday, June 26th, participants turned out for the event and enjoyed the walk through the Silaire Wood, National Forest in the picturesque Graiguenamanagh.

The Kilkenny Branch would like to express its gratitude to all who took part in the enjoyable event which raised €656 and to those who donated online also.

A special 'thank you' to Edward



Hayden, a regular contributor on Virgin Media's Ireland AM and presenter of the KCLR96 FM who facilitated an interview with Bridget Langton, Branch Treasurer, on his Saturday radio show to promote the event in advance.

We are always truly grateful to everybody who has contributed to the Kilkenny Branch in any way, by volunteering, fundraising or through donations. Thank you!

The Kilkenny Branch Officers, who are always happy to offer support and take your call, are:

John Lacey, Chairperson ☎ 085-1328255
Hugh Byrne, Board Member ☎ 086-8938800

Bridget Langton, Treasurer ☎ 086-1202918
Anne O'Grady, Secretary ☎ 087-9232190



Deirdre Doherty, husband Brian and daughter Ruth with Martina and Keira McEvoy.



John Lacey, Noreen Hennessy, Dan O'Connell, Deirdre Roche Doherty, Hugh Byrne and John Joe Gahan.

LONGFORD

By SUSAN MARTIN

CHURCH GATE COLLECTION

We were delighted to see the return of the Annual Church Gate collection throughout County Longford this August.

Thank You' to all our volunteers who helped out – your time and efforts are greatly appreciated and 'thank you' also to all who supported our collections.

RETIREMENT WISHES

The Branch extends their very best wishes to both Bernadette Wall, former Chairperson, and Peter Connolly, former Treasurer of the Longford Branch IKA.

Both Bernadette and Peter have been involved for over 20 years. They have dedicated so much of their time and energy organising the annual events each year. As well as co-ordinating the smooth running of local fundraisers and have always been available to offer support to both patients and families locally.

Thank you for all your help and support throughout the years in County Longford. You will both be truly missed from the committee.

We would like to welcome on board, and wish our new Branch Chairperson, John Opabola and new Treasurer, Carmel Dolan, all the best in their new roles.

CONDOLENCES

Our Branch sends sympathy to the families and friends of kidney patients and branch members from County Longford who passed away over the past two years. In



particular, we remember Sylvester Heslin, the late husband of our Branch Secretary, Elaine, who sadly passed away in August 2021.

May he Rest in Peace.

FUNDRAISING

Our heartfelt thanks go to all the people who have fundraised for the Longford branch of the IKA in recent times. We would like to thank Kieran Woods, Paddy Dowd and Fergus Darcy for their ongoing support.

We would also like to thank The Longford Men's Shed and also The Sainsbury Family – Bryonny Bee's Truck & Tractor Run, to name a few. We really appreciate all your efforts and financial support.

GET WELL WISHES

We would like to send our best wishes to Jillian McNulty, the Longford Cystic Fibrosis campaigner who recently underwent a successful kidney transplant in Beaumont Hospital, after been on a waiting list



for a transplant for the past few years.

Not long after her transplant operation, she shared her recovery progress expressing her gratitude to the family of her donor on social media where she highlighted the Freetext number and IKA website address for people who wished to obtain organ donor cards.

Her transplant story was covered in newspapers and on broadcast media and included a very inspiring interview with Ray D'Arcy on RTE Radio 1.

Wishing Jillian continued good health and success for the future.





Greetings to you all. I hope you all had a great summer.

CONDOLENCES

We were deeply saddened to lose our wonderful, kind and lovely Patricia Mackenzie, when she passed away unexpectedly, soon after she retired from the role of Branch Secretary, which she carried out in an exemplary fashion for 16 years. I had taken up Patricia's role as Branch Secretary just weeks before she passed away. It will be difficult to do as good a job as she did, but I will try my best.

Patricia was always there to help each and everyone of us in the Branch, and beyond, including families who visited the Renal Support Centre which she co-managed.

Patricia was like a mother to the kidney patient community. Having gone through the experience of kidney failure herself and undergoing several years of dialysis treatment, followed by a kidney transplant, which took place 14 years ago. Patricia demonstrated a



Patricia Mackenzie RIP

DUBLIN NORTH

By COLETTE FOX

great understanding and huge empathy when interacting with kidney patients, their families as well as gratitude to donor families.

She was an enormous support to me after I lost my husband. We will all miss her so much. On behalf of all the Branch members, I would like to express our deepest sympathies to her husband Colin and his family.

May Patricia's
gentle and kind soul
rest in peace.

We also lost another great member to Dublin North Branch, Paul Prendergast, who was also a much loved member of Transplant Team Ireland which will s

We would like to send our

We would like to send our condolences to his wife Rose and their very large family. Rest in Peace Paul.

BRANCH MEETING

Our second last Branch meeting was held in May, via Zoom. It is great that we can now return to meeting face-to-face.

Thanks to the kind assistance from Sheena in Beaumont Hospital, for arranging the venue for our recent Branch meeting. It was held at the Education Centre, Room 8, at Beaumont Hospital on Monday, September 19th at 7.30pm.

FUNDRAISING CONCERT

Ann Burke, has for several years, done trojan work in organising a concert to raise funds for the Dublin IKA Dublin North Branch, drafting in the support of her good friend, singer Red Hurley, who has provided his wonderful singing talent 'free gratis'



Enquiries and tickets

Tess Robinson · 086 857 6190

We are extremely grateful to Red Hurley for being such an ongoing valued supporter of the IKA.

On Thursday, September 29th, he will sing at the concert event at which he has also secured the 'free gratis' support of other wonderful entertainers, also of national acclaim, including Linda Martin, Mary Byrne, Ronan Collins, Sil Fox, the Sugar Cubes, amongst others.

The event, which promises a great night of entertainment and will include a bumper prize draw, will be held at the Hilton Dublin Airport starting at 8pm (doors open at 7pm).

Thank you Ann for your very valued hard work in organising the event and to all the artists providing the entertainment, as well as sponsors of prizes and supporters.

Enquires for tickets to:
Ann Burke on **087-1352775**
and **Tess Robinson** on
086-8576190
which cost €27.50.

DONEGAL

By PATRICIA CALLAGHAN

Hello to everyone from the Donegal Branch. Over the past few months we have been very fortunate to have some wonderful people doing great things to raise money for the IKA and also for the Renal Unit at Letterkenny University Hospital (LUH).

Kathleen and Cathal McGee have raised an amazing €1610. This fantastic couple have supported the IKA for a number of years and we sincerely thank them.

The new Chairperson of the Donegal Branch, Seamy McDermott, along with Dean Harron, completed

Dean Harron with Jennifer and Seamy McDermott



andanda Mizen to Malin Cycle Challenge in aid of the Renal Unit in Letterkenny University Hospital. Seamy is 20 years transplanted and Dean's father is receiving dialysis treatment in LUH three times per week.

Seamy has undertaken a number of fundraising events this year to mark the 20th Anniversary of his kidney transplant.

His first challenge was a 20km run in the lovely coastal town of Bundoran in March. A very successful quiz was held in the Ballybofey/Stranorlar Golf Club. It was very well supported and €963 was raised. Businesses from far and wide sponsored the prizes.

Seamy started a Gofundme page for the cycle from Mizen to Malin. He wanted to make it tough to remind himself of the tough decision his donor family made 20 years ago. So far he has raised €1665. The last challenge, a swim with the Gartan Outdoor Swimmers from Marble Hill to Downings, aptly named 20/20 swim, 20 swimmers for 20 years transplanted. Arthur McMahon,



Kathleen and Cathal McGee with Jennifer McDermott

Donegal Oil/Maple Filling Stations is also taking part and is the main sponsor. This fantastic event took place on September 17th.

The Incoming Committee would like to thank the Outgoing Committee for all their hard work over the past years and wish them well for the future.

A Branch meeting will be held in the Radisson Hotel, Letterkenny on October 11th at 8pm. We look forward to seeing you all again, its nice to be back after COVID-19.

If you would like to attend please text or call Patricia on 086-6073339 so we can get an idea of numbers. Thank you and we hope to see you soon.

Chairperson: Seamy McDermott
Board Member: Jennifer McDermott
Secretary: Patricia Callaghan

DONEGAL

By SIOBHAN BATES

FUNDRAISERS

County Council staff held a staff lottery during COVID-19 with the Donegal IKA Branch being chosen as one of the charities to benefit.

Council staff member Neil



George accepting the prize from Leonard Watson, proprietor of Watson Menswear.

Gallagher's wife Sharon had received a combined kidney and pancreas transplant for which they will always be grateful for.

Our thanks to Neil and his colleagues who collected €350 which was presented to our Branch.

Celebrating ten years in business Watson Menswear in Letterkenny sponsored a competition on local radio with a prize fund of €2500 spread over five days.

The winner who guessed the correct song each day could nominate a charity of their choice which would receive €500.

George Bates, a winner on one of the five days nominated the Donegal Branch of the IKA as his chosen



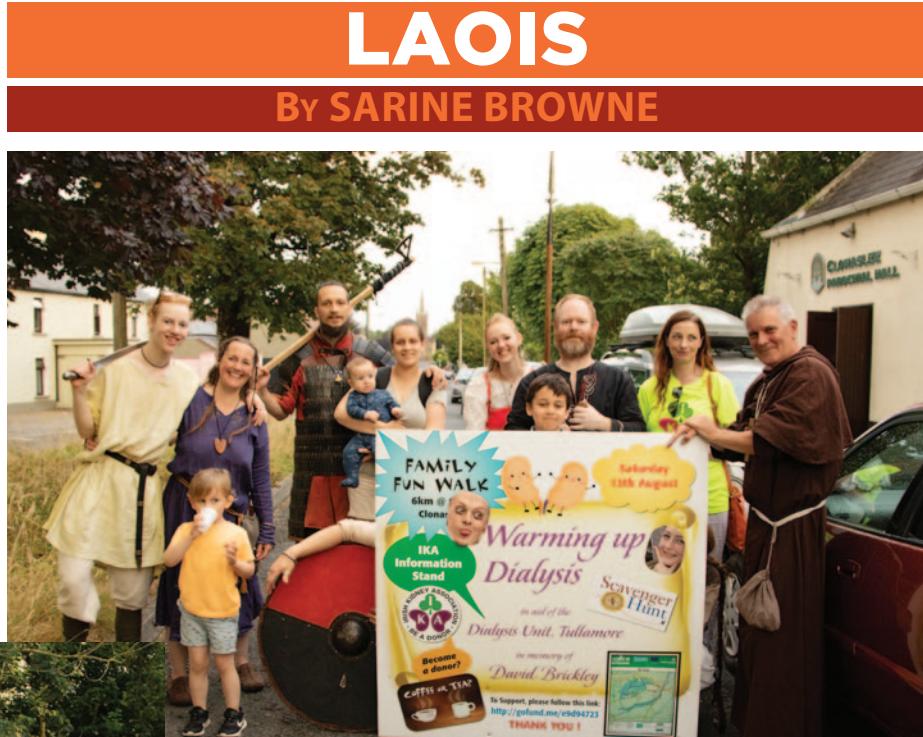
Neil and Sharon Gallagher (right) presenting Siobhán and George Bates with monies from Buncrana Council in-house lotto.

charity to receive €500.

On Saturday, August 27th, Dunlewey Celtic presented a cheque for €6,090 to the Donegal branch of the IKA following a football tournament in Dunlewey on Sunday, July 31st, which was held in memory of club member Michael Roarty, who was a 24-year-old renal patient who died tragically with three others in 2019. You can read more about this on page 50-51.



There was a super turn out in Clonaslee Co. Laois on Saturday August 13th, to attend a sponsored walk in memory of the late David Brinkley.



The walk was organised by David's family and Tullamore hospital, to generate funds for a blanket warming machine for dialysis patients in the hospital. The IKA Laois Branch was delighted to have an information stand at the event, which was visited by young and old. The weather was wonderful and

there was an amazing spread of tea, sandwiches and cakes afterwards in Clonaslee Parish Hall.

The walk was also attended by local viking re-enactment group The Golden Ravens. So far, the family has raised over €12,000 for the machine, with a target of €15,000.

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.



LAOIS

By SARINE BROWNE



ika DIRECTORY

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Renal Support Centre, Beaumont Hospital, Dublin D09 Y5R3 - SEQUESTERED

Emergency Mobile Number: 087-4169907 | Email: renalcentre@ika.ie



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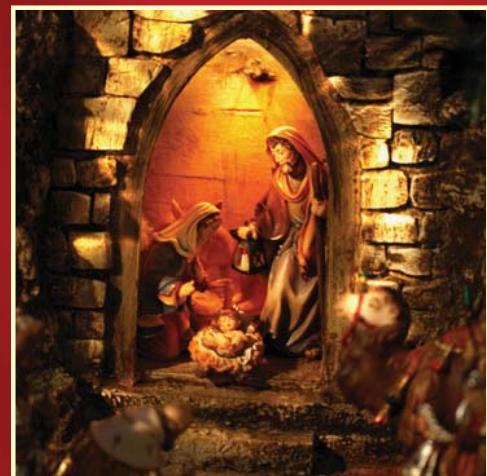
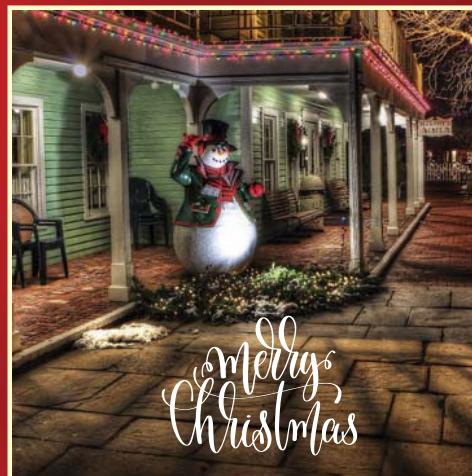
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