



Service of Remembrance and Thanksgiving Supplement

PAGES 33-44

IRISH KIDNEY ASSOCIATION CLG

WINTER

10 X €50 GIFT CARDS FOR

DUNNES STORES SEE PAGE 9

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Editorial



Beannachtaí an tSéasúir

s I wrote previously, the only constant in this pandemic is uncertainty. A number of weeks ago, we had started developing guidance to help safely resume face-to-face meetings, to now pausing face to face meetings until a further review in January. This has also meant postponing my visit to branches in the North West.

As we go to print, cases of COVID-19 continue at a high level, the impact of the new Omicron variant is being debated and the situation looks daunting. But as you can see from our article on vaccinations (pages 10-11) so much has been achieved, that we must not lose hope. At this stage most kidney patients have received their third primary shot and research to date indicates it should improve the level of cover. In 2022, we expect to see further developments on medication which can actually treat COVID-19 symptoms.

We continue to work closely with the HSE, so if you have not yet been offered your top-up vaccination shot, please contact us.

In happier news, while our holiday homes in Tramore are now closed, bookings are still being accepted for the Tralee and Killarney homes through the winter. See page 48 for more details.

We are also progressing planning permission for our Support Centre development in Cork and expect a positive decision soon.

We held a very informative online session on home dialysis, and you can see a full report on Professor Mellotte's presentation together with three different patient stories on pages 54-56.

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We also recorded the 2021 Service of Remembrance and Thanksgiving which was broadcast on November 21st and the feedback has been very moving. You can read full details in the centre-pages supplement.

The front cover features kidney transplant recipient Ellie Collins. Ellie recently got her wish granted from the wonderful charity 'Make a Wish Ireland' who grant the wishes of children with life limiting disease. See the full story on pages 6-8.

We have had a further meeting with management in Beaumont Hospital to discuss Support Centre arrangements and staffing issues in the dialysis units. Unfortunately, the need for staff to isolate when they come into close contact with COVID-19 is leading to reduced staff to patients ratios and delays. Despite, their best efforts the number of transplant operations is very disappointing. You can see more details on pages 22-24.

We are delighted to report that former Westmeath inter-county footballer John Egan underwent a living donor kidney in November 2021 at Beaumont Hospital. You can read more about his uplifting story on pages 60-61.

We had the very disappointing news that a transplant operation had to be postponed due to the lack of an ICU bed in the Mater Hospital. This is so disturbing and disheartening not just for the patient and family, but for the donor family and all the healthcare professionals involved who continue to work under huge pressure, being forced to make very difficult decisions.



FRONT COVER

Kidney transplant recipient Ellie Collins, age 6, from Abbeyfeale, Co Limerick, promoting the IKA campaign encouraging people to light a candle at Christmas to honour organ donors. Photo by:

John Allen Photography

EDITORIAL

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Dialysis patient Lorna McSwiggan-Martin being interviewed on RTÉ TV News regarding ICU beds crisis.

The impact on our own community was also obvious as people remembered their own transplant stories and how grateful they are to their donors. We issued a press statement on this issue (available on the website) and contributed to many media reports. An independent investigation is now planned, and I am pleased to report that I have been asked to sit on the steering committee of this investigation. So, hopefully action will be taken to ensure we do not see this terrible situation reoccur again.

On November 29th, we had a lively Branch forum on the support needs of Branches, and in the New Year we are looking forward to progressing many of the excellent ideas we received.

At Board level, we have been working hard to see how we can strengthen the voice of the patient in our Association while meeting governance code requirements. We are very lucky to have directors who give their valuable time freely and who are so passionate and focused on patient needs. We will have more details on this work in the Spring edition of this magazine.

We also partnered with The Wheel's 'We Act' campaign which is working to improve public perception of charities and show just how much good, charities like the IKA do. Keep an eye out for their promotional activities as you may see images of IKA people in action. You can find out more a on the 'We Act' website https://www.weact.ie/

We have been working closely with the Irish Nephrology Society and now have two grant application submissions selected for full submission to the Health Research Board for funding. Developing our research expertise is an important part of our strategy. The new strategy document can be found on our website with printed paper copies sent to Branches. Members can receive a paper copy by phoning or emailing Donor House.

Our new Patient Services Manager, Fiona Aherne, and administrator Jesse Brien are settling in well. Together, they have produced a guide to social welfare entitlements. It is useful reading, if you want to make sure you are getting your full benefits. Sadly, we had to say goodbye to Simon Walsh, one of our Support Centre staff. Patricia and Frank will continue to answer the phone for accommodation requests. You can find full details of the opening hours over Christmas on page 9.

Once again, I would like to encourage anybody who is not currently accessing the internet to consider getting free lessons from Age Action Ireland (call them on 01-4756989 to find out more). Take the opportunity to learn how to engage with friends, family and wider society online.

Finally, I know many people who have lost loved ones will find this time of year very tough. For me personally, it will be my first Christmas without both my parents which will be difficult. I draw comfort though from being part of the IKA community. I am privileged to hear the inspirational stories of so many of you who deal with such adversity on a daily basis and continue to be gentle, kind and compassionate. I salute our healthcare professionals who are under such workload pressure but keep turning up and going the extra mile. The courage and compassion of the organ donors and their families who give so generously at a time of great personal tragedy continues to inspire.

Your attitude reminds me of one of the most moving books I've ever read called. *'Man's search for meaning'* by Victor Frankl, a concentration camp survivor. In it, he states:

"Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way." So, we may not be able to celebrate Christmas in the way we might wish. But we can choose how we can make the most of the Christmas break from daily routines.

We wish you all a Christmas that you can enjoy and hope you feel peace, solace, serenity and hope for 2022 and beyond.

Nollaig Shona agus Athbhliain faoi Mhaise Duit.

> CAROL MOORE CHIEF EXECUTIVE OFFICER

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A Christmas Message

from

The National Chairman



reetings to all members and friends of the IKA. On behalf of the Board of Directors and Staff, I wish you a happy, healthy and safe Christmas, as we near the end of a very challenging year for all of us.

The importance of the vaccines in controlling the spread of COVID-19 cannot be overemphasised.

In taking all advised precautions we have asked each other to make sacrifices and adjustments in our daily lives. Normal every day sociability and communication is curtailed. This is difficult – but right if we are to keep each other safe.

We are grateful to those working on the front line, facing this disease – medical and all hospital staff, and those working in public services and retail.

At this time of the year we are especially conscious of those living alone who may not have access to social media and Zoom, and for whom an offer of support or a visit is a lifeline.

Zoom has been essential for business and maintaining contacts, but has it's limitations.

We thank all who have generously supported us throughout the year.

The IKA objectives are clearly outlined in our recently launched Strategic Plan 2021 to 2025.

It clarifies who we are, our mission, vision and values which aim to support all patients and their families. The production of this document is the result of many meetings, discussions and consultations throughout the Association.

I want to pay tribute to Esther Behan who was responsible for designing this superbly produced document. The layout, colour and presentation reach the highest professional standards. Thank you Esther.

We are currently reducing our deficit, but have also expanded Patient Aid and are funding research that will benefit kidney patients.

We are getting professional advice on both fundraising and governance.

We welcome and look forward to the increased availability of the Tramore apartments in 2022, and thank the Waterford Branch for their work and dedication. Also, thanks to the Kerry Branch for their management of the beautiful holiday homes in Tralee and Killarney.

Due to the enthusiasm of our Cork subcommittee, we hope to see the opening of our Cork Support Centre before the end of next year.

Our Service of Remembrance and Thanksgiving changed due to COVID-19. The immediacy of being present at this gathering is not possible due to the pandemic, but Kairos and RTÉ have ensured that our Service can be viewed everywhere.

I thank members, Branch Officers and our Board of Directors for your support, and also our dedicated staff and CEO Carol Moore, our National Secretary, John Whelan and National Treasurer, Eddie Flood. Once again, I wish you a happy and peaceful Christmas and a bountiful New Year.

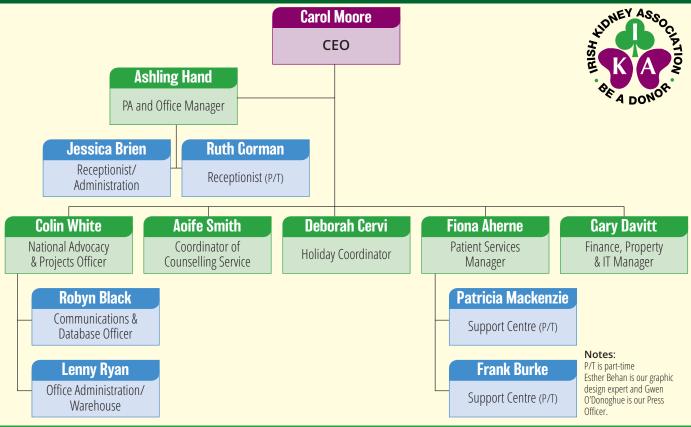
Season's Greetings



From top left and across: Carol, Ashling, Deborah, Jess, Colin, Robyn, Lenny, Ruth, Patricia, Gary, Fiona, Esther, Simon, Frank and Gwen.

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

IKA STAFF ORGANISATIONAL CHART



Ellie's dreams come through

By GWEN O'DONOGHUE

For many of us, the year 2021 will be remembered for the harsh impact of the global pandemic.

owever, for six-year-old Ellie Collins from Abbeyfeale in Co. Limerick, 2021 will be remembered as the year when all her dreams and wishes came through. Ellie's new and greatly improved 'normal' life began on the 14th June 2021 when she received a life changing kidney transplant thanks to her donor mother Jackie Enright.

Just three months after their living donor kidney transplant, Ellie re-joined her classmates in Senior Infants at Knocknasna N.S. in Abbeyfeale, while Jackie, a national schoolteacher, returned to Scoil Iosaf N.S. in Newcastle West.

Ellie and Jackie took part in a photocall at their home to highlight the Irish Kidney Association's campaign encouraging the public to light a candle this Christmas to honour all organ donors who saved or improved the lives of others.

In the summer of 2021, Ellie's wish for a garden playhouse was granted by Make a Wish Ireland. Two weeks after Ellie returned home from hospital following her successful transplant operation, she was overjoyed when the pink and blue playhouse she had wished for appeared in her back garden. Complete with swings, a see-saw, climbing frame and a slide, it was all made possible by Make A Wish Ireland. A photo of Ellie, in her new playhouse, featured in a Make A Wish Christmas appeal mailout campaign to raise funds for the charity to help bring happiness and hope to other sick children with life threatening medical conditions.

There was further excitement for Ellie, when she won a Tesco colouring competition for patients at Temple Street hospital. Children attending the hospital were invited to colour in an elephant and give it a name. Ellie decided to call the elephant in her entry after her namesake, 'Ellie'.



<image>

As she was the winner, a plush toy called 'Ellie the Elephant' was created and became available for sale in Tesco Stores in the lead up to Christmas.

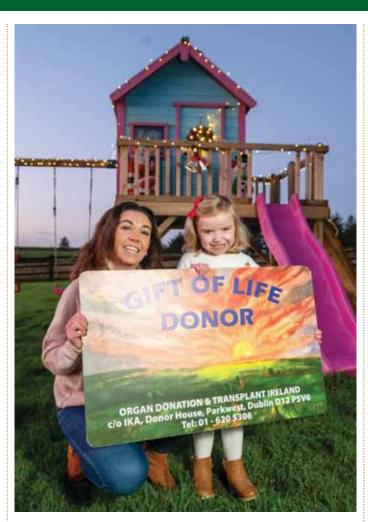
All proceeds from the sale of 'Ellie the Elephant' go to the Children's Health Foundation Temple Street, the charity which raises funds to provide world class care and to pioneer new treatments and cures for childhood illnesses.

And all these momentous events culminated in Ellie's 6th birthday celebration on December 16th, 2020, just eight sleeps before Santa's arrival and what would be her first ever traditional Christmas Day dinner without being fed through a peg and rigid dietary restrictions.

When Ellie was born in December 2015, she was diagnosed with Chronic Kidney Failure because of underdeveloped kidneys, a condition known as Bilateral Renal Dysplasia. She became a regular inpatient at Our Lady's Hospital for Sick Children in Crumlin right up until her life saving transplant which she underwent at Temple Street hospital after Jackie's donor kidney was retrieved at Beaumont Hospital.

Jackie described Ellie's health journey, "When I was pregnant with Ellie, a scan at 28 weeks revealed that there was only a small amount of amniotic fluid surrounding her. This was a huge worry for me and her father Joe.

Thankfully, Ellie was delivered to almost full term on December 16th. However, she had only one partial kidney, which was a third of a normal sized



baby's kidney. She was brought to Crumlin Hospital where she spent her first Christmas and many more times as an inpatient in the years that followed, up until her successful kidney transplant.

She commenced dialysis treatment when she was eight months old and this continued for almost five years. Every night myself or her father Joe would hook her up to a dialysis machine for ten and a half hours.

"Ellie had a difficult start in life, but she took it all with a smile on her face. We are extremely grateful to Make a Wish for granting her wish for a playhouse. The minute she saw it for the first time in our back garden her eyes lit up and she said it was



her best day ever. "For me, my best day ever was the day it was confirmed that I could be Ellie's kidney donor. Joe was also screened for living donation, but I was considered to be a more suitable match at the time.

WINTER 2

I feel very privileged to have been able to donate my kidney to Ellie and to see her thriving now.

"She had been PEG-fed with a tube to her stomach right up until the time of her transplant. Now she can enjoy lots of different foods and has developed a fondness for chocolate, Nutella and she loves McDonald's nuggets and fries.

Before her transplant she was not allowed to go swimming as she had to protect her dialysis catheter. She is now taking swimming lessons. On hot days in the summer, she loved to splash around in the paddling pool.

"We feel very fortunate. I know other children who are still waiting for suitable donors to be found and that is why it is so important that people talk about organ donation, get an organ donor card or have your decision displayed on your driving licence."

"The Irish Kidney Association has been there for us all through Ellie's health journey. They provide advocacy and support to kidney patients and their families. It was a comfort to know that they provide free overnight accommodation for families of patients travelling from the country to Dublin for hospital appointments. They are a wonderful resource for information, advice and peer support. We are delighted to have been asked to support them in reminding people at Christmas to light a candle in memory of organ donors.

continued next page

ELLIE'S DREAMS COME THROUGH cont'd...



"We have so many people to thank for helping us to get this far including Ellie's school for always remembering to keep in touch and to her classmates for sending her pictures and good wishes when she was in hospital: Scoil losaf where I teach, for their support and understanding from the time Ellie was born; Ellie's father loe who took on the role of Ellie's carer for the first year so that I could return to work and for being a rock of strength throughout; to Ellie's grandparents and our extended family for their unwavering support and helping to care for Ellie so that we both could return to work; and not forgetting our friends who were only ever just a phone call away; and to our whole community for their good wishes.

"Thanks to all the nursing, medical and support staff at

Crumlin Hospital, Ellie's second home, for the compassionate and excellent care she received there since birth. We extend our gratitude to the transplant teams at Beaumont Hospital and Temple Street for successfully guiding us through our transplant journey.

A special thanks also to Make a Wish for their tireless and important work they do in making dreams come through for sick children and for bringing tremendous joy to Ellie by granting her wish for a garden playhouse."

Jackie summed up an eventful 2021 saying "it has been a whirlwind year for Ellie. As we count our blessings, our thoughts are with all those children and adults who are waiting for transplants and all the organ donors who have given a second chance of life to others."

The Irish Kidney Association thanks Ellie and her mum, Jackie, for sharing their uplifting story which gives hope to others who are waiting for transplants particularly at a time when transplant activity globally has slowed down due to COVID-19. We extend our gratitude to Make a Wish Ireland for choosing Ellie's uplifting transplant story for their campaign and thereby increasing organ donor awareness. We encourage the public to come behind supporting Make a Wish and Tesco's 'Ellie the Elephant' initiative in raising funds to benefit patients at our Childrens' hospitals.



Light a candle at Christmas for people with organ failure and for organ donors and their families.



https://ika.ie/product/christmas-e-card-2021/

GIFT CARDS F DUNNES STORES

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DUNNE

This winter, **DUNNES STORES** is spreading some festive cheer to SUPPORT readers. Our friends over at Ireland's leading retailer have generously

sponsored a prize giveaway to the value of €500. Ten lucky readers who enter the prize

giveaway in our winter issue, will each receive a **DUNNES STORES** gift card worth €50 to use online or in any one of their 114 stores nationwide across all food, fashion and homeware departments.



In 1944, the late Ben Dunne founded his first store on Patrick Street in Cork City. Generations have enjoyed shopping at the **DUNNES STORES** chain which, to this day, continues to be a market leader while maintaining its Irish owned status. Ben Dunne's philosophy to offer 'Better Value' with a variety and quality products at affordable prices, proved to be a hugely successful business model. Today, DUNNES STORES employs close to 15,000 people and continues to offer quality, value and choice to its customers.

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

ACCOMMODATION TELEPHONE BOOKING HOURS 087-4169907



As hotels get busier (though this may change again with COVID-19 cases increasing), make sure to ring the Renal Support Centre staff, as soon as you receive your hospital appointment, so we have a better chance of making a room booking for you. Recently we had a situation where the Clayton Hotel was full.

ROUTINE APPOINTMENTS The accommodation phone line is now 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 goes to voicemail, just make sure you leave a message saying you need accommodation that night and we will do our very best to book you into a hotel room, liaising with Beaumont hospital staff as needed.

CHRISTMAS OPENING HOURS The phone will operate for emergency appointments only on



Christmas Eve, Christmas Day, St Stephen's day, New Year's Eve and New Year's day from 12pm to 4pm.

AUTUMN PRIZE GIVEAWAY WINNERS

Thank you to **PETER MARK** for generously sponsoring **5 x €80 gift cards** as a prize giveaway in the Autumn issue of SUPPORT.

The gift cards can be redeemed (online or in any of their 69 salons nationwide) against products and hairdressing services. Congratulations to the winners:

Eugene Ivers, Kiltimagh, Co. Mayo, Breda Leahy, Tipperary Town. Clodagh McHugh, Swellan Lr, Cavan, April Power, Borris, Co Carlow Fidelma Reilly, Redhills, Co. Cavan.



COVID-19 UPDATE

The pandemic has been going on for over 18 months and with the recent media focus on the environment and the COP26 conference in Glasgow, it is easy to become overwhelmed by all the data and doom and gloom that is endlessly being shared in the media.

In the end all the information can become a little meaningless. However, I will endeavour to highlight some key points and share some basic take away messages.

Before the vaccine programme began, the public was asked to play its part in the public health campaign by following some basic advice.

- Practice social distancing
- Wear a mask
- Cough and sneeze into our elbows
- Maintain regular hand hygiene These became second nature to us,

and we all hunkered down hoping that the scientists would come up with a vaccine that would keep us all safe, remove the anxiety and allow us all lead our lives to the full.

Transplant recipients were heard saying, *Welcome to our world'* in relation to the need for cautious engagement with society.

Twelve months ago, vaccines started to receive approval and there was a collective hope that 2021 would see us return to 'normal'. There was also talk of 'the new normal' where society would hopefully have learned from the pandemic experience, and we would 'build back better' as Joe Biden pronounced.

Whilst the vaccine roll-out got off to a stuttering start, we successfully lobbied for the prioritisation of people on dialysis and transplant recipients.

The vaccine programme developed, a more stable supply of vaccines was secured, and the nationwide network of vaccination centres worked incredibly efficiently to get us to the point where now over 90% of our adult population has received two doses of a vaccine.

It has not all been plain sailing. So many families have lost loved ones or experienced the isolation and fear of having a loved one in hospital and out of reach. People on dialysis, transplant recipients and their families have had to put so many aspects of their lives on hold and anxiety has been a very real issue for many.

So, where are we at now? There was a feeling across the world that the vaccine programme was going to be the *'silver bullet'* that would solve everything and allow us to live our lives unrestricted, but this has proven to be not the case.

This has led some to question the value of the vaccines. However, if we look at the statistics, we can clearly see the impact that the vaccine programme has had in the country. Looking at statistics shared by

the HSE;

- as of November 3rd, 92.7% of the adult population in the country had received two doses of vaccine whilst 94.1% had received at least one dose.
- of the 507 people admitted to an ICU between April 1st and October 30th, 2021, 326 were not vaccinated, 44 had one dose of a vaccine and 137 had two doses.
 Taking these two points together,

we can see;

- 27% of the cases admitted to ICU (137 out of 507) came from 90+% of the population (those with two doses of the vaccine)
- 64.3% of the cases admitted to ICU (326 out of 507) came from approximately 6% of the adult population (those not vaccinated)

It is clear that the vaccines are having an impact. The number of cases of severe illness and death has declined when compared to the number of people testing positive for COVID-19.

As the country has come out of



BY COLIN WHITE, NATIONAL ADVOCACY & PROJECTS MANAGER

the *'lock-down'* restrictions, people on dialysis and transplant recipients have been taking differing approaches to their re-engagement with society. It has become clear that the efficacy of the vaccines amongst the immune compromised is not as good as amongst the general public and as a consequence, the third primary dose was approved for this group.

The roll-out of this third shot is well under way. Different to the 'booster' campaign, the third primary dose is given to the immune compromised to bring them closer to the same level of immunity as the general population after two doses. The expectation is that there will be a fourth or booster shot for this group in future. Treating hospitals are either giving the vaccine directly to the immune compromised or, more frequently, people are getting an appointment to attend a vaccine centre, often closer to their home than their treating hospital.

With talk of a booster shot likely being offered to the whole population, where does this leave society at large and the immune compromised in particular?

The vaccines are not the 'silver bullet' we had all hoped BUT they are having a significantly positive impact in relation to the number of people succumbing to severe illness or death if they get the virus.

To quote the government website (www.gov.ie);

We will all need to take steps individually and collectively in our everyday lives to keep this risk under control, in particular by:



- acting fast, isolating and getting tested if we have symptoms
- wearing our face coverings where appropriate
- making sure that indoor spaces are well ventilated
- maintaining adequate social distancing whenever appropriate
- covering our coughs and sneezes and keeping our hands clean

With the change in season meaning that our lives are now lived more indoors, the point about ventilation is an important one. In advance of Christmas last year, we were advised to 'have a window open' if gathering as a family. In the last year we have seen a growing emphasis on good ventilation. With this year's Christmas just around the corner, let's all continue to be sensible, keep following the good advice above and be proactive in our own healthcare.

The Irish Kidney Association will continue to liaise with the National Renal Office, the HSE and international colleagues and contacts and when there is reliable information to share, we will be sure to share it.

If you have not yet received an appointment for your third primary dose of a COVID-19 vaccine, please contact **Colin White (colin@ika.ie or phone: 01-6205306)**.

If you have questions or observations to share, please also get in touch with me as we need your input to ensure that our advocacy is relevant and up-to-date. A night to remember

In our Summer 2021 issue of SUPPORT we invited our readers who are interested in sharing their experiences about their journey living with kidney disease to write a short story and send it to us to be considered for inclusion in a future issue.

We are delighted to publish the following article, written from by a Dublin woman, who wishes to remain anonymous, aptly titled 'A Night to Remember'.

It's a true story about the night when her husband, who had been on dialysis for six years, was called for a kidney transplant.

We hope you enjoy reading it like we did, and that it might inspire you to share your story or poem which, in turn, might inspire others to do the same. t was a Tuesday in mid-March. The phone beside our bed was ringing me out of a deep sleep. As I fumbled around trying to find the phone in the dark, I looked at our oversized clock. It displayed 12.43am, but I knew it was really 12.37 as it was six minutes fast. I grunted a sleepy *"hello"*. As soon as I heard the melodious tones of the Transplant Coordinator Aileen, I knew immediately this was the call we had been waiting almost six years for. I was out of our bed in a flash.

"Hello Louise, do you know who this is?"

"I do Aileen, I do".

"Do you think you can make your way to the hospital within the hour." "I'm halfway out the door already Aileen. We'll be there." A frenetic scramble begins. Patrick flew into the shower to do a quick scrub. I threw his half-packed wheelie suitcase on the bed – it had been half-packed for five and a half years since Patrick was approved for a transplant. But I needed to throw in his phone charger, toothbrush and paste, list of meds, something to read, and a robe. Not a big deal as I could always bring up any missing items later, but it distracted me until he had showered and was ready to go.

By 1.00am, we were standing kerbside in front of our house waiting for the taxi. A three-quarter moon shone down casting shadows on our seemingly lifeless street. It was surreal just standing there in the still of the night, waiting patiently. Suddenly, a taxi races up the street but it passes by us and dumps a few latenight revellers at the corner. They were still having a good time but soon disappeared into an apartment nearby, a welcome distraction in a weird way.

The eerie quiet returns and for what seemed like an eternity (5 minutes) our taxi finally turns the corner but stops in front of the wrong house. I frantically wave from the middle of the road to make our presence known and then we were soon on our way. "Beaumont Hospital please" and I thought to myself 'make it snappy, no detours tonight please, no chatter please'.

We said not a word to each other the whole way, contemplating what the day may bring to both our lives. It was six years and a month to the day that Patrick was first diagnosed, out of the blue, with chronic kidney disease (CKD). For the first time in six years, we were full of hope and anticipation and, of course, a fair bit of anxiety and trepidation.

As Patrick paid the driver at the front doors of Beaumont Hospital, he revealed the purpose of our journey to the driver, *"Wish me well, I am hopefully getting a kidney transplant".*

We chuckled with anticipation as we ran down the hallowed halls of Beaumont, dragging the wheelie suitcase and my bag of diversions (the book I would never read and plenty of chocolate bars) to the elevators at the end of the long hall and up to the fourth floor. We knew where we had to go. Aileen had told us where to report to and how to get to the ward of that great Saint to the lepers, St. Damien -

which was to be home to Patrick for the next few days. A quick squirt of the sanitiser at the doors and in we went to hopefully make some history. It was 1.30am.

The nurse was waiting for us and ushered Patrick into a private room. At this point I realised it really, really, really, could be the day we had been waiting for. My doubts and fears dissipated. Patrick was indeed on the transplant list for real. For the next few hours, I became a witness to all the pre-op drills required for a transplant patient.

First order of business was to draw down about ten vials of Patrick's blood. This would probably be the most important deciding factor as to whether he was indeed a suitable candidate for the precious extraordinary gift he was about to receive.

Then the expected blood pressure monitoring and temperature taking exercises interspersed with 'interviews' by various medical staff to doublecheck his biographic and medical history details. At 8am, he was brought downstairs to the basement for a chest x-ray and we met the other candidate for a transplant that day (two kidneys, two transplants). While we were excited about the real possibility of a transplant happening, we also recognised that somewhere, an incredibly

generous family were simultaneously undergoing sadness and grief at losing a loved one.

By 9am, there was still no news about whether he had passed all tests nobody was saying anything. But then it was decided that because he had not been dialysed since Saturday, he would need to go down to their dialysis centre to endure one final process for removing waste and excess water from his blood. This seemed like a positive sign, and I took the opportunity to crawl into his hospital bed and grab a little shut eye.

When Patrick came back to the room, one of Beaumont's many talented transplant surgeons was waiting to brief him. The operation was now scheduled to begin at 2pm. But first he had to go into the shower with a special soap, and then 'put on this 'pinny'. We were both guardedly giddy now. It was happening.

I accompanied the nurses and aides as they wheeled him in the hospital bed (that would become his home for the next ten days), towards the large blue elevator doors that went down to the operating theatre. I was only allowed to accompany him to these doors. I had no words nor did he as we said goodbye. As I squeezed his hand, the only words I could muster were 'See you in a bit Babe'.

I was like being in a slowmotion dream sequence you see in a film.

Once the elevator doors swooshed shut, I was bereft. I had no idea what I would do for the next six hours which was how long the operation would take. Patrick's fate and future (and mine too) were now in the hands, literally, of the transplant team of surgeons, nurses and anaesthesiologist – the miracle workers! All was now dependent on the suitability of the donated kidney - the 'gift of life' from one generous family who will forever remain anonymous to us.

I went back to Patrick's bedless room and paced around anxiously. He would be tied up in the operating theatre and post op for at least six hours. I did not know what I should be doing. I was so tired at this point. From 1.30am, I had been keeping our son informed as he had taken on the role of Chief Communications Officer for keeping the rest of the family updated as events unfolded.

Then the eversupportive Aileen (Transplant Coordinator) came by - she had just missed Patrick. When I asked her if I would be allowed to watch the operation from the theatre gallery, she laughed out loud.

"Are you kidding? You watch too much TV. We're

continued next page...

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As my husband paid the driver at the front doors of Beaumont Hospital, he revealed the purpose of our journey to the driver. "Wish me well, I am hopefully getting a kidney transplant."

A NIGHT TO REMEMBER contd...

lucky to have enough light bulbs never mind a gallery in the operating theatre."

Sharing a good laugh with her at my thinking that the Beaumont operating theatre resembled a *Grey's Anatomy* TV set for some reason put me at ease.

Aileen then directed me to the Irish Kidney Association's Renal Support Centre right across the road where I could grab a cup of tea and a chat with one of the volunteers. This is where accommodation is provided by the IKA for relatives and family of transplant and other renal patients who have to travel up from the country.

The volunteer I met there had been in fact a transplanted patient himself 13 years prior. Telling me all about his experience reassured me no end. He then told me to go home for a few hours. I was of no use hanging around waiting and home was but a twenty minute taxi ride away.

A few hours later, after a nap and shower, I returned to Beaumont with my son and waited for Patrick to come out of the operating theatre.

Around 8pm Patrick was brought back to his room. There was shared exhilaration between the three of us. Even though Patrick was still a bit groggy, he was so, so happy. His 'plumbing' that hadn't worked in six long years worked instantly. Who would ever think you would get so much joy from peeing? We left him in peace and went home to make a million phone calls. It had happened

finally, and all indications were pointing to success.

Returning to the hospital early the next day, we three were still on a high. Of course, such euphoria makes sense. Patrick had been given a new lease on life.

Over the next few days, we met with all the posttransplant experts who advised us on what happens next. They explained the new regimen of meds, the importance of sunscreen, exercise and diet, and all the other postoperative recovery stuff that we needed to take onboard. I don't know how much information we absorbed at the time, but we would adhere to all their instructions. It would be a slow journey to recovery and normalcy but dialysis was history. Six years and Patrick's

number, the ultimate lifesaving lotto number, had been drawn.

What now? Four years later and we still are thanking our lucky 'stars'. Stars like the transplant team of surgeons, nurses and all medical staff in St. Damien's.

Stars like the transplant coordinators who guided us every step of the way on this journey.

Stars like the renal consultants and renal nurses who continue to monitor Patrick's status post-transplant.

But, above all, we are oh so grateful to the donor family, who in their grief and sadness, made a decision of immense generosity and kindness.

The writer and her family wish to remain anonymous. Names and some details have been changed.

Yes, I would like to make a regular donation by
STANDING ORDER.
STANDING ORDER REQUEST FORM
To: The Manager of
(Your bank's name and address) I/We hereby authorise you to set up a Standing Order on my/our account as specified below:
Signed:Date:
Address:
PLEASE CHARGE TO MY / OUR ACCOUNT: Name of Account:
IBAN: Bank Identifier Code - BIC: (These can be found, printed on your bank statement)
My regular
(Please tick as appropriate) to start on Date:/
AND CREDIT TO THE FOLLOWING ACCOUNT: Name of account: IRISH KIDNEY ASSOCIATION at Bank of Ireland, College Green, Dublin 2. IBAN NO.: IE06 BOFI 9000 1717 1934 35 SUP BIC NOW BOFILE2D 2 1
As long as you are a PAYE or self-employed tax payer, when you donate €250 or more in a year (€21 or more per month), the Revenue Commissioners will give Registration the Irish Kidney Association CLG an extra rebate of 45%. For example, if you gave €250 in one year, the IKA would gain an extra €112, at no extra cost to you.
Please post to: THE IRISH KIDNEY ASSOCIATION CLG, DONOR HOUSE, BLOCK 43A, PARKWEST, FREEPOST, DUBLIN, D12 P5V6 (PLEASE DO NOT POST TO YOUR BANK) CHARITY REG. NO. 20011260
THANK YOU FOR YOUR GENEROSITY

SOCIAL MEDIA &COMMUNICATION **THE COMPARISON TRAP**



Judging from her Facebook page, Jane has the perfect life – a great job, lots of friends and a picture-perfect home. She travels on fabulous holidays, is impeccably dressed and on Christmas Day her kids wake up to numerous gifts under the tree. Chances are, we all follow someone like this online. What is easy to forget is that what we see online is usually a carefully curated image of perfection, an illusion of what someone wants you to see.

There are many reasons why social media has been linked with increased anxiety and depressive symptoms, but increased social comparison is one of the most powerful. It is human nature to make comparisons; we do it in real life, and we do it online, but comparing ourselves can have a big effect on how we feel.

In some ways it can be helpful to motivate us to make positive changes in our lives. However, when comparison to others online begins to make you feel deficient and discouraged, it might be time to have a social media cleanse.

Here are some tips to make your social media a happier place:

1. TIME CHECK

A good place to start is by looking at how much time you are spending online. Most modern smartphones have a way to track your weekly screentime, and will break down how much time you have spent on each app. If you feel like social media is becoming a bit of a bad habit, you can set time limits on how much time you can use the apps for each day before your phone will warn you that time is about to run out, and remind you to close the app. You can also set downtime and bedtimes on your phone, which will silence notifications after a certain time.

2. CURATE

If you have been on social media for a long time, you might have friends or follow people that you are not close with anymore. Going through friends lists and unfollowing or unfriending people you don't want to see content



from anymore is a great way to curate your newsfeed, especially if what they post is having a negative impact on you. If you feel you can't outright unfriend someone because of work or friendship, you can always use tools (like 'Mute' on Twitter and Instagram or 'Unfollow' on Facebook) to stop seeing their posts whilst remaining friends – and they will never know.

3. REPORT AND BLOCK

This is an extreme measure but if someone posts something that you think is not appropriate, you can report their post. This is totally anonymous and the social media companies will review the post before they decide to remove it or not. You can also block people entirely which means you won't be able to see them, and they won't be able to see you – you won't even appear if they search for you.

4. TAKE A BREAK

Want to have a complete break from social media? You can delete the apps from your phone which makes it harder to check them. If you want to go even further, you can temporarily deactivate your accounts – you can do this indefinitely on Facebook and Instagram, but only for 30 days on Twitter before they will permanently delete your account. It can be hard to shut off the

comparison impulse completely but understanding what triggers you and how to mitigate it is a great place to start improving your experience online.

The Christmas period is often the worst for many people, with gift giving and festive experiences coming at you from all angles. If you've found yourself victim of the comparison trap at this time of year you are not alone – but taking some of the steps above could make all the difference to your own festive season.

@IrishKidneyAs

O @IrishKidneyA

@IrishKidneyAssociation

Kidney Disease

Enhancing support and care for people with kidney disease



By CATHERINE REILLY

CEO of the Irish Kidney Association **Carol Moore** speaks to **Catherine Reilly** about her first year at the helm and the pivotal issues affecting people with kidney disease.

nly 74 kidney transplants took place this year to the end of August. A lifechanging event for the individuals who received organs, it is nevertheless a trajectory that presents a cause for concern.

The potential for total kidney transplants to fall lower than last year (when 123 took place) is "very worrying", CEO of the Irish Kidney Association (IKA) Carol Moore told the *Medical Independent (MI).* At the time of this interview, the IKA was awaiting further information on the factors impacting this year's transplant activity to date. During 2020 the national kidney transplant programme at Beaumont Hospital, Dublin, was paused for approximately 10 weeks due to clinical and capacity factors associated with the COVID-19 pandemic.

IRISH KIDNEY ASSOCIATION

Transplant provision is among a number of key issues for Carol Moore, who was appointed IKA CEO in October 2020. Carol is a member of Chartered Accountants Ireland and has a strong background and interest in healthcare. She is a cofounder of LIFEWISE, an online alcohol harm reduction service, and was Governance Manager with Mental Health Ireland. Carol is also a co-founder of Dual Diagnosis Ireland.

The core function of the IKA, which is a registered charity, is supporting patients and their families affected by end-stage kidney disease (ESKD). In the coming years, it also intends becoming more active in promoting prevention of kidney disease.

The Association has 25 local branches and provides a wide range of information and resources on kidney disease, advocates for greater supports and service improvements, facilitates access to free counselling, provides free holiday accommodation in Ireland for dialysis and transplant

IKA SUPPORT WINTER 2021

patients, and operates a sports programme, among other activities. It plays a major role in organ donation awareness and runs a national annual awareness week.

In the past 18 months, its activities have been profoundly impacted and influenced by the COVID-19 pandemic. COVID-19 has posed a huge threat to people with chronic kidney disease, particularly those on dialysis and transplant recipients, due to a higher risk of serious illness and death.

Throughout the pandemic, the IKA has been active in advocating for kidney patients, including lobbying for vaccine reprioritisation of transplant and dialysis patients in the sequencing plan.

The HSE National Renal Office (NRO) and HSE Organ Donation and Transplant Ireland (ODTI) also supported a reprioritisation.

Carol noted: "It wasn't that we were trying to jump the queue, it was just that the clinical evidence was very clear that kidney patients and anyone who is immune suppressed are at such huge risk of this and we have seen a huge level of death in our community."

Chronic kidney disease patients (on dialysis, or eGFR<30ml/min) and transplant recipients are among the cohorts who should receive a third (mRNA) dose of the COVID-19 vaccine, according to the national immunisation advisory committee. This recommendation has been made in the context of people with immunocompromise associated with a suboptimal response to vaccines and is due to be implemented in the coming weeks.



The successful reprioritisation campaign reinforced Carol's views on the importance of collaboration for the IKA. Carol said she had been "surprised" there were only 10 full-time equivalent staff in the organisation given its high profile.

"So we have to collaborate. We are talking about a memorandum of understanding with the Irish Nephrology Society, we are working with Age Action Ireland, we have joined HRCI [Health Research Charities Ireland] and we work closely with IPPOSI [Irish Platform for Patient Organisations, Science and Industry] in terms of the vaccination campaign. So we will be doing a lot more of that."

SUPPORT

The pandemic has placed a considerable burden on the mental health of kidney patients. According to Carol: "We have seen situations where patients are refusing to go to dialysis because they are scared or because they are so tired of the whole burden of care and we have even seen patients develop agoraphobia." She said kidney patients should have direct access to mental healthcare through their renal centre.

The development of a peer support programme is among 18 core objectives in a new fiveyear strategy the IKA has developed in consultation with members and stakeholders. The Association already facilitates "a lot of informal peer support" and intends to formally train patients to become peer support workers, with a view to them eventually becoming employees in renal units. The Association hopes to attain funding from the National Lottery to establish a pilot initiative.

Carol said that wider social determinants have a major impact on health. "Kidney patients don't automatically get a medical card," she noted. "With housing costs so high, money has become a real issue for many of our patients."

I of the wholePeople's livingIKA SUPPORT WINTER 2021

arrangements and accommodation can impede access to home dialysis, which the IKA wants to become much more accessible. According to 2020 NRO statistics, there were 2,014 patients attending in-centre/ contract haemodialysis, with just 58 patients accessing home haemodialysis and 238 peritoneal dialysis.

While some financial support is available for patients on home dialysis, the Association is seeking a much more comprehensive approach. It also advocates more ongoing care support for home dialysis patients.

Systemic problems in the health system are limiting the development of home dialysis provision. According to Carol, incentre dialysis is funded out of the hospital budget as a Hospital Inpatient Enquiry (HIPE) activity. However, once patients move to home dialysis, the hospital budget is reduced (even though the hospital continues to provide care) and this acts as a disincentive for hospitals to encourage home dialysis.

"This is why Sláintecare is so important as it calls for regional structures thus removing the budget barriers between hospital and community-based care," she said. Another difficulty facing patients is accessing 'out of area' dialysis for holidays in Ireland, due to lack of capacity.

TRANSPLANT

At the end of 2020, some 519 people were on the kidney transplant waiting list, compared to 509 in 2019 and 462 in 2018. Even pre-pandemic, Ireland was significantly short of performing a *Continued next page...*

Enhancing support and care for people with kidney disease contd...

long-held target of 250 kidney transplants per annum. In 2019 the fiveyear average was 167.

Carol said she believed "what gets measured, gets managed, gets done". However, comprehensive information was lacking on the various stages of the donation process (eg, whether donation was requested, medical suitability of potential donors, consent rates, etc).

While the Association has previously posited a second transplanting hospital, Carol considered that this should not be an initial priority. There is a need to maintain a certain amount of operations at a centre to ensure surgeons' skillset, noted Carol, who also referred to the level of transplantation during 2021.

"What we need to do is ringfence transplant activity," she said. "It is happening in an acute hospital, so is it a problem that we don't have ICU beds? Is it a problem that we don't have theatre capacity? Is it clear to everybody that beds are ringfenced?" Medical recruitment issues must also be addressed, she

added.

The Irish health service has been slow to develop real-time information systems, observed Carol. She said there was no core funding for a system of surveillance and measurement to track activity and clinical outcomes in dialysis centres, for example.

"You can get best-inclass treatment in one centre, and then in another, you don't get it. And we are not measuring that on a routine, systematic basis. That is why our costs are so high because we are not identifying poor practice and actually dealing with it on a routine systematic basis...There is a real lack of information. What is needed is a team in the NRO and ODTI that are dedicated to data analytics..."

She underlined that "investing more into organ donor awareness and systems that are tracking and measuring performance will save money".

LEGISLATION

The long-awaited Human Tissue Bill is due to be published this year. Under the Bill, it is planned to introduce an 'opt-out register' whereby people who do not wish to be considered as potential organ donors can record their wishes. People who do not sign the register would be deemed potential donors, but the consent of families would still be required.

The IKA considers that an 'opt-in' option should also be included to ensure the public's engagement with organ donation can continue to be active, rather than passive.

Having a legal framework for organ donation is "important", said Carol. However, she said the legislation needs to be supported by better infrastructure and a greater number of specialist healthcare professionals facilitating donation to significantly enhance transplant access.

Carol also told *MI* she was concerned about the "current environment" of COVID-deniers and antivaxxers and the potential for such elements to manipulate public opinion around an opt-out register. "In England, when they did the 'Share your Wishes' campaign when they were introducing their opt-out register on top of their optin register, a number of the right-wing groups got hold of it and were giving out messages like 'the government is going to steal your organs', so we need to be very careful about that." The IKA has raised the matter at a public awareness group established by ODTI.

The Association also wants behavioural scientists to be engaged to examine the draft legislation, according to Carol.

FINANCES

The pandemic has impacted the fundraising activities of the IKA. Last year it spent over €400,000 on organ donor awareness activities, which have a large population reach. ODTI contributes €180,000 per annum towards the Association's awareness activities, although there is no annual funding agreement.

This funding is never guaranteed and is paid in arrears, which is an "unsatisfactory" situation, said Carol.

There are increasing financial demands on charities for more services and in regard to ensuring good governance, she noted. While the IKA is fortunate to have legacy funding, the current situation of an annual deficit cannot continue forever, she said.

The organisation will be working on developing its fundraising strategy, stated the CEO, who remarked upon the "impressive" loyalty and commitment that people have shown towards the organisation.

© Courtesy of Medical Independent



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Shane's quest to scale the Beara heights

our years after donating a kidney to his young son, Shane Herlihy, from Sandycove, County Dublin, undertook a gruelling adventure race in West Cork as a fundraiser for the Irish Kidney Association which raised €2,256.

Shane completed the first time, one-day adventure race, called *Quest 12 Beara*, at the end of August 2021, covering 152km of the unchartered territory of the Beara Penninsula.

Not for the faint-hearted, it included cycling 108km with a climb of 1,813 meters on top of trail running 40.7km with 1,370 metres of climbing. Shane, undaunted from a hamstring strain he received just weeks before, pushed through the pain of covering the unforgiving terrain.

Shane, also an avid skier, holds the honour of being the first and only member of Transplant Team Ireland to win a medal, gold, at the Winter World Transplant Games held in Banff, Canada in 2020, in the Giant Slalom Skiing event. In 2018, Shane won a silver medal at his first World Winter Transplant Games in 2018, held in Anzere, Switzerland, just nine months after he donated a kidney to his, then, 10-year-old son Luke in April 2017.

Following the successful kidney transplant Shane and Luke shared



By GWEN O'DONOGHUE

their uplifting story in the media increasing organ donor awareness by participating in radio and tv interviews and generating publicity in print media also. At the time Shane professed how fortunate he believed he was to be a suitable kidney match for living donation to his son while so many others in organ failure wait in hope to find a suitable donor.

Caroline, Shane's wife, and their sons Luke (13), Sam (12) and Alex (11) were able to track his progress with live GPS tracking throughout the day as he completed the challenge in an impressive time of 12 hours and 20 minutes.

Shane described his challenge in a post on his Just Giving Fundraising page saying, "Made it through the whole 152km in 12:20! The cycle had some of the toughest sections I have ever done, 16% gradient climbs, blind corners at bottom of descents and all single car width!"

Later he added, "I enjoyed the challenge, albeit it very physically demanding, but the amazing scenery helped me push through. It is nice to be able to do something I enjoy while at the same time raising funds for the Irish Kidney Association to help them in their work supporting kidney patients and in increasing organ donor awareness".

Coping with Chronic Illness COVID-19 and Christmas



By AOIFE SMITH

t is hard to believe we are entering our second Christmas holiday season of COVID-19. We are all a little worn out from doing our best to navigate and manage our way safely through this pandemic.

For many of you living with a chronic illness, behind the classic Hallmark movie depictions of family gatherings, traditional recipes, and sparkling lights, the holiday season can also mean the pressure of increased activity, commitments, responsibilities, and financial strains bringing with it a heightened sense of anxiety and stress.

Combining that with the spiking of COVID-19 cases in recent weeks and rising hospital admissions who would blame any of you if you were left feeling overwhelmed rather than excited for the upcoming season?

So how does one manage a chronic illness, COVID-19 and Christmas? I thought it might be no harm to mention some pointers to help you enjoy the holiday season.

MENTALLY PREPARING YOURSELF FOR THE HOLIDAYS

It can be helpful to manage the expectations you have of yourself at this time of year. Energy levels can be greatly impacted with the effects of chronic illness. The body uses energy differently, much of what was used for normal everyday activities is now being used to try to heal. The brain releases signals to encourage the body to rest more, in turn making you feel less able to do the things you normally would. Therefore, managing energy well enables you to make the most of what you want to do.

Focus on what's most meaningful to you. Is it family? Is it health? Is it slowing down? Getting more rest? Spend your time doing things that give you energy.

COMMUNICATE YOUR NEEDS

Once you figure out 'how' you would like to spend this Christmas and what you need to feel safe doing that, communicate your needs to your friends and family.

Aoife can be contacted at Donor House on 0818-543639 or 01-6205306 or by email: aoife@ika.ie Talk to them in advance about how you would like special events or gatherings to go. Let them know if you want people to call around to the house or if you would prefer to attend a gathering through zoom or video call.

If people call unexpectedly, focus on what you can control, have a box of disposable masks and hand sanitiser at the ready and don't feel embarrassed to ask them to use them.

If you attend gatherings, be mindful of the amount of time you spend at the gathering and set limits for yourself. This will help with your energy levels and minimise any risk of coming in contact with COVID-19.

It can be hard setting boundaries or limits around times or attendance. It may feel a little awkward or uncomfortable, especially when faced with comments like "You have to come it's Christmas!" or "Please just stay a little longer". While your friends and loved ones may be doing this out of love, remember that this is your health and your Christmas too.

Being clear about your needs can help make the holidays easier and happier for everyone.

LEARNING HOW TO RESPOND TO YOUR FEELINGS

If you find yourself getting stressed, overwhelmed, or anxious it can be difficult to acknowledge the feelings. Being aware of what you are feeling allows you to respond to them. If it is a feeling of anxiety and you don't recognise the symptoms within yourself then you don't know that you need to stop and work with it.

Everyone experiences anxiety differently. Physically it can feel like a racing heart, sweating, rapid breathing, disturbed sleep, tensed or weak muscles, loss of appetite, stomach churning, dry mouth or feeling dizzy.

Emotionally, it can look like excessive or undue worry, feelings of panic, loss of self-confidence, difficulties concentrating or irritability.

Any of these symptoms, individually or in combination, can be intense and alarming to experience, nevertheless it is important to remember that these feelings can be managed.

Learning how to name and validate the anxiety without judging

yourself can be effective. Being able to stop and say: "I'm anxious right now" allows you to look for the underlying core emotions, needs or conflicts you might be experiencing.

This awareness gives you the opportunity to change or take action, maybe walking away for a few minutes, getting some fresh air, taking some slow deep breaths or talking to a friend.

TAKE TIME FOR YOURSELF

Self-care is key to maintaining our mental health and at a time like this it is more important than ever.

Nevertheless, I know when living with a chronic illness it can be very tiring to hear "you need to take care" as it can feel like it's another thing you must do!

Try looking at self-care as taking time, each day, to do one thing you enjoy. Lose yourself a little in doing what you love, whether it's a walk in the park, cooking a healthy meal, watching your favourite programme, reading a good book or simply sitting listening to music. This will help lift your energy and give you a mental break from the hustle and bustle of this time of year!!

I would like to wish you all well over the Christmas, stay safe and be mindful of yourself and loved ones.

And most importantly, this year give yourself permission to do the holidays your way!

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.

Thank you to the Cork branch for the invitation to present at their recent Zoom branch meeting. Hopefully next year I might actually get to see some of you in person.



Thank you to everyone who took part in the virtual VHI Women's Mini Marathon on September 19th to help raise funds for the Irish Kidney Association. Well done to Angela Sherlock (pictured above right), a kidney transplant recipient and member of Transplant Team Ireland, from Greenhills, Dublin. Angela was joined by her sisters, Mary Cremin and Cora Doyle. They all completed the 10km distance and in the process raised €470 which will benefit kidney patients and their families. Thank you!

Looking back at 2020 ORGAN DONATION AND TRANSPLANTATION

By COLIN WHITE

The Newsletter Transplant is an annual report Produced by the European Committee of Organ Transplantation of the Council of Europe in conjunction with the Spanish Organizacion Nacional de Trasplantes (ONT),that shares information on donation and transplantation activities in member states of the Council of Europe – and beyond.

PERCENTAGE DECLINE IN NUMBER OF TRANSPLANTS CARRIED OUT Between 2019 and 2020						
	Kidney	Liver	Heart	Lungs	TOTAL	
EU	20.5%↓	12.5%↓	8.3%↓	18.5%↓	17.7% ↓	
Ireland	19.6%↓	43.9%↓	40.0%↓	57.9% ↓	30.7% ↓	

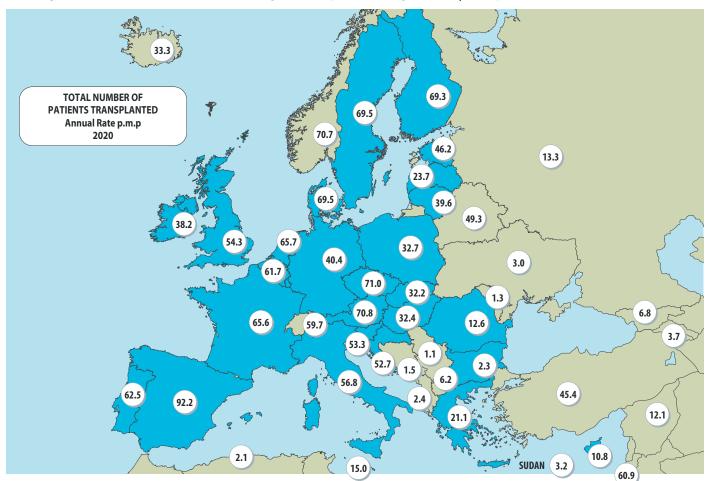
his report allows us to make some interesting comparisons with our European neighbours and also gives rise to some interesting questions. For example, if we look at the number of donors per million population, what lies beneath the figures for each country? What is the age profile of the population, how many ICU beds do they have per million population, etc.

Looking at the report, the negative

impact of COVID-19 is very evident.

It should be noted that the number of pancreas transplants in Ireland went up from 2 to 5 from 2019 to 2020. I have not included the pancreas in the table above as the Ireland numbers are too small for meaningful percentage change reporting.

The map below shows the total number of patients transplanted per million population (pmp) across Europe.



As mentioned previously, it is important to understand the context of figures reported. For example, we saw a phenomenal 101 kidney transplants carried out in 101 days in Northern Ireland in 2020. This was facilitated by the fact that they were able to carry on transplanting in a hospital that they managed to keep COVID-19 free. Also, at the time, the majority of the transplanting units in the UK were not functioning because of COVID-19 so Belfast got a disproportionate number of donor offers compared to normal.

The pandemic has perhaps offered us an opportunity to look at the resources that are allocated to organ donation and transplantation.

Reflecting on the impact of COVID-19, Prof. Jim Egan, Director of Organ Donation Transplant Ireland, wrote in the 2020 ODTI Annual Report:

The pressures on ICU capacity was substantial and the demands around organ donation underscored the ICU bed capacity infrastructure deficit, as highlighted by the Prospectus Report in 2011. Furthermore the provision of specialised transplant surgical services were under threat from unscheduled acute care in the 3 major acute hospitals providing transplant services.

Country	No. Transplant Centres	Average Population per Transplant Centre (Million)
Croatia	4	1.03
Spain	40	1.17
Netherlands	10	1.71
Germany	38	2.2
UK	24	2.83
Ireland	1	4.9

This underpins the need to ring fence national transplant programs to sustain them during waves of unexpected unscheduled care demands.

Referring to the **Newsletter Transplant,** we can calculate the average number of people served by each kidney transplant centre in the respective countries of the EU. With only one kidney transplant centre in Ireland it serves our total population of 4.9 million. Only three countries in the EU (Finland, Ireland and Romania) have more than 3 million people per kidney transplant centre.

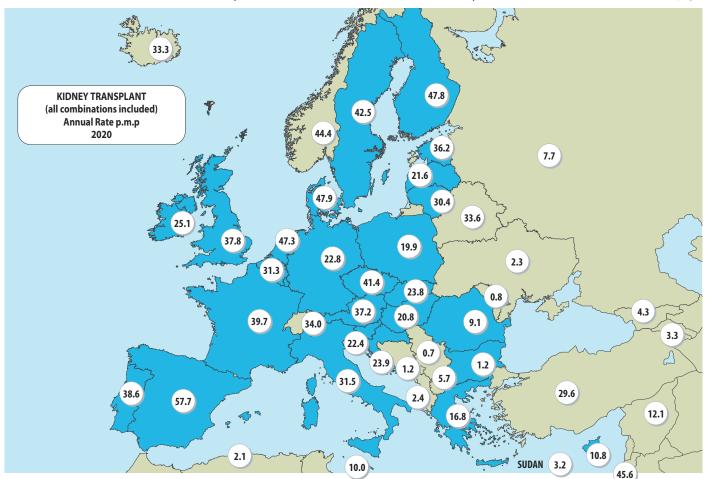
In the absence of detailed domestic data it is difficult to determine the relevance of this. Is Ireland at the lower end of the European table in terms of organ transplants per million population (see map on previous page) because of physical capacity issues, is it a staffing issue, are all potential organ donors being identified and followed through, is it a comparatively high level of family refusal when looking at our European neighbours?

As with most things in life, it is likely to be a combination of all of these factors, and more. To plan the way forward it is important to understand what underpins these headline statistics.

Looking at the map below we can see the rate of kidney transplantation (per million population) across Europe.

The team in Beaumont put in a robust COVID-19 secure pathway for kidney transplantation to recommence after a brief hiatus between March and May 2020. Their commitment is to be admired and is

continued next page...



ORGAN DONATION AND TRANSPLANTATION CONTINUED

	IRELAND	UK	SPAIN
Actual Deceased Organ Donors	63 (12.9 pmp)	1248 (18.4 pmp)	1777 (38.0 pmp)
Older than 60 years of age	10 (15.9%)	377 (30.2%)	957 (53.9%)
Donors after Circulatory Death	7 (11.1%)	434 (34.8%)	621 (35.0%)
Donors after Brain Stem Death	56 (88.9%)	814 (65.2%)	1156 (65.0%)

appreciated but one has to ask the question; do they have all the right supports in place to realise their potential for kidney transplantation, particularly living donor transplants?

The public conversation around organ donation and transplantation tends to focus on the shortage of organs available. We must not forget the need for sufficient infrastructure (ICU beds, staffing, testing and workup processes, etc.) to maximise the potential of organ donation for transplantation and deliver a safe world-class programme.

When reflecting on organ donation during the pandemic we have to acknowledge the thoughtfulness and generosity of spirit of those families who said yes

to donation at their time of loss despite the added emotional burden of the restrictions that came with the pandemic. Their legacy is the gift that truly keeps on giving.

The Council of Europe/ODQM *Newsletter Transplant* gives a very detailed breakdown of figures in relation to donation activity.

Taking out some of the

figures it is interesting to compare Ireland with our near neighbours, the UK, and the 'world leaders' in organ donation and transplantation, Spain.

We can see from the table above that both the UK and Spain have greater percentages of their donors in the over 60 years of age and the Donors after Circulatory Death categories. In medical circles, these groups are often referred to as 'expanded criteria donors', a generic term for organs that have the potential for transplantation but which do not meet one or more of the criteria for optimal donation.

It is pleasing to note that the team in Beaumont are looking at what is involved with expanded criteria donors including the need for fully



informed consent from patients who are listed for transplant.

In reading through the **Newsletter Transplant** it is important to take a fully rounded picture from all the data available. We can look at bottom line organ donation figures, bottom line transplant activity but we also need to look at what is happening with the waiting lists.

In the table below we get an indication of the level of activity pre-COVID-19 in 2019 and in the midst of the pandemic in 2020. Again we need to acknowledge the work involved in ensuring that transplant work-ups continued despite the pandemic AND the cyber attack.

In summary, the COVID-19 pandemic has had a hugely negative impact on organ donation and transplantation in Ireland as well as in our European neighbours. However, we cannot just dismiss this decline as one of the many 'costs of COVID-19' that the country has had to endure.

We need to learn from our European neighbours, embracing extended criteria donors for example. We need to learn from the pandemic that the fragility of our transplant service cannot be allowed to continue. We need to think outside the box as to how the transplant service in Ireland can be developed to ensure sufficient staffing and resourcing that can allow us to plan for moving forward rather than us fighting to remain standing still.

KIDNEY TRANSPLANT WAITING LIST IRELAND	2020	2019
Patients added to the Wait List (WL) for the first time in 2020	152	208
Total Number of patients ever active on the WL in 2020	661	670
Patients waiting for a transplant (only active candidates) on 31/12/2020	421	386
Patients on dialysis on 31/12/2020	2310	2196



THE PROVISIONAL DATES FOR ORGAN DONOR AWARENESS WEEK 2022 23rd-30th APRIL

We hope to confirm these provisional dates by January 2022. Watch out for updates on our social media and website:

www.ika.ie

UTILITIES PROVIDERS BY COLIN WHITE

Am I a Vulnerable Customer?

f you are on peritoneal dialysis or home haemodialysis you will know the importance of a reliable supply of electricity and water. The Commission for Regulation of Utilities has protections in place for 'vulnerable customers.' The information below is taken from their website.

For energy customers you could be classified as a vulnerable customer if you meet the following criteria:

- If you are critically dependent on electrically powered equipment. This includes (but is not limited to) life protecting devices, assistive technologies to support independent living and medical equipment, or
- If you are particularly vulnerable to disconnection during winter months for reasons of advanced age or physical, sensory, intellectual or mental health. For customers of Irish Water.

you could be classified as a vulnerable customer if you meet the following criteria:

- If you are critically dependent on water for your medical needs, or
- If for reasons that may include advanced age or physical, sensory, intellectual or mental health reasons, you require additional support communicating with, or receiving services from, Irish Water.

WHAT SHOULD I DO IF I'M A VULNERABLE **CUSTOMER?**

If you or a member of your household are a vulnerable customer, it is important to let your energy supplier and/or Irish Water know. Energy suppliers and Irish Water are required to establish, maintain and regularly update a register of vulnerable customers. They must also take reasonable steps to identify household customers who should be included. However, it is also up to you to let

them know if you are a vulnerable customer.

Energy suppliers and Irish Water are required to provide customers with a free and easy way to register as a vulnerable customer. You should contact your supplier to discuss how you can register as a vulnerable customer.

FROM IRISH WATER:

Irish Water runs a Priority Services Register for those who have a critical dependency on water as a result of their medical condition. We will contact (phone or text) these customers at least two days in advance of planned disruptions, and for unplanned interruptions that may last longer than four hours.

You can register via the link below:

www.water.ie/help/domestic-account/vulnerable-customers/register/

FROM ESB NETWORKS

We have a Vulnerable Customer Register based on information from all electricity suppliers to ensure we can look after these customers if a power outage occurs in their area.

Please contact your electricity supplier to get your name placed on this register. They will notify us and we will put your details on the Vulnerable Customer Register.

We will contact you at least three days before a planned outage by post or SMS text. This gives you time to make alternative arrangements if you need to, as some planned outages may last for a number of hours.

If there is serious damage to the electricity networks resulting in widespread faults, ESB Networks will provide additional communications specifically to those customers dependant on medical equipment.

The bottom line is that registering as a vulnerable customer is up to you. From personal experience, it is definitely worth doing as it actually does work. They do go the extra mile to keep you informed.

IKA SUPPORT WINTER 2021



In today's world Cancer is commonplace with debilitating effects. It not only attacks your physical health, but also takes hold of one's state of mind. Von Hippel Lindau (VHL) affects 1 in 36,000 people across the world, and I happen to be one of them.

By SANDRA COLLINS



A special graduation gift from Sandra's family

WARRIOR

y journey with VHL started in 1992, the year I lost my beautiful mother Patricia (Pat). She was just one year older than I am now when she died aged 42, and I had just turned 11.

Unbeknownst to us VHL had been raging through our genes for many years. My mam lost her mam, at a very young age, to kidney cancer and her brother to a brain tumour. Until my mother passed, we had no idea what was to come, the challenges, the losses, and the generational grief a disease like VHL would bring on us.

When I refer to Von Hippel Lindau, I like to call it my 'My Politician', because it makes decisions about my life without consulting me, never taking my opinion or plans into consideration before it strikes an attack on me or someone I love.

VHL is a genetic chronic tumour condition where those affected develop cancerous tumours on their kidneys, pancreas, brain, spine, and adrenal glands. This rare disease cruelly runs throughout my family.

My older sister Joanne had her first brain tumour at the young age of 18 and my other sister Edel had her first kidney tumour at 19-years-old. This series of traumatic experiences of VHL tumours was relentless with ongoing suffering from numerous brain, spine, kidney and adrenal tumours that would see them in and out of hospital until they passed away.

For the last eight to ten years of their lives, they relied on dialysis three or four times weekly in Tallaght University Hospital. I have harrowingly watched both my sisters suffer due to difficult surgeries, sometimes spending months in Intensive Care in Tallaght and Beaumont Hospitals. Sometimes even in the same hospital at the same time. Both my sisters will forever be the Ultimate Warriors living life to the full, lives they fought so hard for every day.

After my sister Edel passed in 2019, it forced me to face the grief and trauma I had witnessed from this horrible disease from a young age. My lived experience of VHL is a series of unfortunate events, that never seems to end.

Three days after I had major surgery to remove my right kidney, I was discussing end of life plans for my sister. She was in ICU, in the same hospital as me, and I organised her funeral from my hospital bed. It is another traumatic experience that will be ingrained in my memory and my heart forever.

After my mam passed, my sisters took on sole responsibility to look after me, to bring me up in a world that showed no mercy for our feelings, our security, and our support systems. They loved me unconditionally and my sisters were my whole world. We looked out for each other like no other could. There was an unbreakable bond filled with love, deep connection, and true understanding of our daily struggles. Watching the trauma and sufferings they both faced left scars in me that will never heal.

You see physical scars from VHL will heal, stitches will be removed, hair will grow back, but the psychological effects are etched deep in the mind and heart forever.

VHL has left devastating physical, financial and emotionally stress and trauma



Sandra (left) with her eldest sister Joanne (front) and Edel (right).

that comes with having such a complex rare genetic disease.

After my surgery and Edel's passing, my body and mind went into survival mode. I managed to keep it together for the next three months to finish a Masters in Community and Youth Work from Maynooth University. But as soon as I handed in a comprehensive research project on 'Youth work with young people with cancer' my body and mind decided it was time to take a break and get some emotional support.

The Irish Kidney Association's counselling services were instrumental in working with me to process all that had happened in my life and supported me to get back on track and start living again.

I soon went to work in Maynooth University with the Access Programme. I work to support students who are underrepresented in higher education for social transformative change.

In losing my sisters, I lost my support system, which left me extremely vulnerable in many ways.

In March of this year, I found myself with nowhere to live. I couldn't rent anywhere and having no immediate family, I had no choice but to go into homeless accommodation. Due to COVID-19, public services slowed down and it took almost six weeks to process my case.

I was in homeless accommodation at a time when COVID numbers were on the rise and I found myself again in a completely vulnerable position. Despite many calls to the HAP office from Tallaght Hospital, who coordinate my medical care, to explain the dangers of me being in homeless accommodation during a global pandemic, they did not care. I

"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles."

- Christopher Reeves



Sandra, working at Maynooth University, making Education accessible to communities underrepresented in higher education.

was in a system that did not see me or understand the complexity of my illness.

I am in a precarious situation. I will never get a mortgage as I can't get life insurance. I cannot go for promotion because it will raise my income level and I will no longer qualify for social housing.

My medical battle is still ongoing. Last year I had my adrenal gland removed due to a tumour and I also have tumours on my remaining kidney, pancreas, liver and ovaries. I will eventually end up on dialysis and become a diabetic. I'm 41 and if I live till I am 45 with my condition, I will have had the privilege of living a long life compared to others in my family.

But I push through every day like my sisters always did and live to the fullest. Some days are sad days, but a lot are funny, belly laughing days with people around me who love me dearly.

I have a great job where I get to do great things to make education equal for others and I love it. I have a caring extended family who support me through all life's challenges. My everyday life is about meaningful connections. I aim to show empathy instead of criticism, listen instead of talking over and reach out to people with meaningful words instead of a generic 'hello'.

I don't know the end to my story, but I am resilient, determined, and come from a long list of warriors, with the strongest of hearts.

I have realised through all the chaos that my VOICE is the greatest power I have. I speak up when I need change, I speak up if I need support and I encourage anyone to speak up if they want change.

Renal Care Centre in Portlaoise

The official opening of the Wellstone Midlands Renal Care Centre in Portlaoise took place on October 14th 2021, two years after it first opened its doors in October 2019.

ollowing a HSE tender process, which identified a need for a satellite haemodialysis facility in the area, B. Braun Avitum opened the Wellstone Midlands Renal Care Centre on a green field site. The facility is located just 1.2km from Portlaoise town centre and 2.6km from Portlaoise hospital.

The 800 m² state-of-the-art Satellite Renal Care Centre has capacity for 60 patients and up to 20 medical and ancillary staff. It has15 dialysis stations, three isolation units and three self-care stations. As part of its holistic patient care it also provides a dietitian and GP service.

To date, a total of 43 patients have been cared for at the Midlands Renal Care Centre where currently 28



Gerard Farrell (Clinical Manager), Keith Cullen, Mountrath & Portlaoise (former dialysis patient) cutting the ribbon and Fiona Duggan (Head of Ambulatory Care - B.Braun).



The renal care team at Wellstone midlands Renal Care Centre in the heart of Portlaoise. Denise Carmody (CNM 1), Libertine Tronso (nurse), Mary Handcock (nurse), Sabrina Ruth (PCT), Gerard Farrell (Clinical Manager), Nichola Lanigan (HCA), Carole Townsend Rebecca Maher (Admin Supervisor) and Dan Supangan (nurse).

people are receiving treatment. Keith Cullen, who was formerly a dialysis patient at the centre and has since received a kidney transplant at Beaumont Hospital, was given the honour of 'cutting the ribbon' at the official opening.

The €5 million satellite facility offers a significant reduction in travel time and cost for those currently travelling to Tullamore and South County Dublin for treatment. Dr Eoin Bergin, Consultant Nephrologist at Midlands Regional Hospital, who works closely with the clinic said, "This unit has opened in Portlaoise largely as a reflection of how busy we are in the midlands. Our cooperation with B.Braun in developing and operating the unit has been critical in maintaining the service we provide for our patients". Liam Ferguson, Regional Head Western Europe, B.Braun Avitum



Paul Challoner (Global Nurse Director, B.Braun), Liam Ferguson (Managing Director), Fiona Duggan (Head of Ambulatory Care, B.Braun) and Paul Mullaly (MD, B.Braun Ireland).



Noreen Galvin (CNM 3, Tullamore), Maria Raftery (CNS, B.Braun), Denise Carmody (CNM 1), Gerard Farrell (Clinical Manager), Jini Jacob (ANOP Tullamore) and Jomin Joykutty (CNM 2 Tullamore).

spoke at the official opening. He explained that "vision, determination and commitment had been shown to deliver a worldclass service for people living in Laois and surrounding areas" and that the service "puts the patients first". In acknowledging the contribution of the centre's staff who cared for patients through the pandemic he said, "thank you for your unyielding commitment to patient care in the face of untold adversity. When things were at their worst you were at your very best."

Fiona Duggan, Head of Ambulatory Care, B.Braun also thanked all staff who help deliver the service. She also said, "here, we have the capacity to treat up to 60 patients, delivering dialysis treatment in the heart of the communities of Portlaoise and surrounding areas. As a company we are very proud of our B.Braun Wellstone renal care centres and the service we can offer our patients".

B.Braun now has three Renal Care Centres in Ireland. Along with Wellstone Renal Care Centre, Portlaoise, it also has the long-established Wellstone Clinic Galway and Wellstone Wexford Renal Care Centre.

The B.Braun Group is one of the world's largest developers and manufacturers of Renal Care technology and consumables. B.Braun Avitum is a leading provider of Renal Care operating more than 350 centres around the world. B.Braun have over 64,000 employees in 64 countries.

ROLE MODELS FOR THE NEXT GENERATION OF RENAL NURSING

he Irish Kidney Association welcomes news of the HSE appointment of Jini Jacob and Sani George as the first Renal Advanced Nurse Practitioners (ANP) at the Midland Regional Hospital Tullamore's (MRHT) Renal Unit.

Jini and Sani, both from India, started working in the Hospital in April 2006 and contributed to the development and expansion of renal services at the hospital over the last 15 years. In that time the Hospital has increased from a six station

to a twenty-nine station Haemodialysis Unit.

Prior to their new roles, Sani was working as the Clinical Nurse Specialist (CNS) in Chronic Kidney Disease (CKD) whilst Jini was the Clinical Facilitator for the hospital's renal unit. Both completed their Masters in Nursing at Trinity College and also Nurse prescribing at the Royal College of

Surgeons as well as a higher diploma in renal nursing from Trinity College.

On a daily basis, both staff members incorporate their advanced academic and practical knowledge and critical thinking skills independently to manage the care of the renal dialysis patient group and Chronic Kidney Disease population in MRHT. They were also credited in 2008 as the first registered nurse prescribers within a renal dialysis unit in Ireland which gave them the additional authority to prescribe any medicine for patients.

The HSE reports that the role of Advanced Nurse Practice in Renal Nursing has had very positive patient outcomes within the chronic kidney disease and haemodialysis populations at MRHT. In carrying out their roles in caring for renal patients it is reported that Sani and Jini are achieving better anaemia management for iron deficiency, improved fluid management, and early detection of any potential infection. As part of their work the two nurses prepare patients for renal replacement therapy (dialysis, haemofiltration and transplant), allowing for pre-emptive transplant work up and pre-emptive vascular access work up.

Outlining the roles, Noreen Galvin, CNM 3 Renal Unit explained that Jini and Sani are "autonomous practitioners with a wealth of advanced specialist renal knowledge and critical thinking skills in providing optimal care to renal patients. They encourage new initiatives, promote change and development based on evidenced based research. They are



dedicated, hardworking, knowledgeable and an excellent asset to the renal team and their patient group. They provide on-going guidance and educational support to their patients, nurse colleagues and the many students who travel via the Renal Unit. They are role models for the next generation of Renal Nursing.

Noreen added that

she "would like to acknowledge the continuous and on-going expert professional clinical guidance provided to both Sani and Jini by Dr Eoin Bergin, Consultant Nephrologist at MRHT who also provided 500 hours of supervised clinical practice before their appointment as Renal AN's, the support and guidance of Louisea Burke, Director of Nursing, Dr Mary Doolan, Regional Nurse Practice and Development Planning Officer, Clare Foley Assistant Director of Nursing Practice Development Co-ordinator and the renal multidisciplinary team."

Jini Jacob and Sani George said, "We as a team could not have achieved this without the tremendous support of everyone from the Midland Regional Hospital Tullamore. Since arriving to Ireland we have been afforded many opportunities to learn, develop and transform the renal services available to our patients. We would like to thank everyone for their support and guidance and acknowledge our patients who inspire us every day".

Social welfare entitlements

By FIONA AHERNE IKA Patient Support Manager and JESSE BRIEN

We recognise that the stress of living with a chronic condition can often be made worse by the additional task of trawling through information to find out what social welfare payments you may be entitled to. We have put together a list of potential benefits and allowances you could be entitled to along with an overview of some conditions for eligibility. The list shows schemes for those living with illness, disability and/or in a caring role. It reflects the type of queries the renal community often have regarding accessing social welfare and includes recent increases to social welfare in Budget 2022.

SOME KEY TERMS WHEN READING ABOUT SOCIAL WELFARE ENTITLEMENTS

DSP: Department of Social Protection.

- **Intreo:** A service provided by the Department of Social Protection. Intreo is responsible for providing help around employment and income support. It provides services to both jobseekers and employers.
- **Means tested payments:** Income will be looked at to find out what amount of social assistance payment, if any, you may qualify for. The maximum income allowed can vary between social welfare payments. Certain types of income are not included during a means test.
- **Non-means tested payments:** Certain payments do not require a means test. Instead, they are calculated on the amount of social insurance credits you have paid in a given period of time.
- **Personal rate of payment:** The amount of social welfare payment for yourself.
- **Qualified Adult and Qualified Child:** Also called an adult or child dependant. You may be eligible for an extra amount for an adult or child you support. This is paid as an increase to your personal payment.

SWA (The Supplementary Welfare Allowance Scheme): This scheme consists of a basic payment, called Supplementary Welfare Allowance, and other financial amounts for certain expenses you may not be able to afford. This includes emergency situations. It is run by the Department of Social Protection's representative (formerly known as the Community Welfare Officer) in your local Intreo centre.

Habitual Residency: Means you have a proven close link to Ireland and are not living abroad for a long time. The term also conveys permanence – that a person has been in the Irish State for some time and intends to stay for the foreseeable future.

1. DISABILITY BENEFITS

These are a range of benefits allowance and pensions paid to people with an illness

Invalidity Pension is a weekly **non-means tested** payment available to people who cannot work due to **long-term illness or disability** and are covered by social insurance (PRSI). At 66, you transfer automatically to the State Pension (Contributory) at the full rate. Invalidity Pension is taxable.

The maximum personal weekly rate of Invalidity Pension will increase to €213.50 from January 2022.

ILLNESS BENEFIT

You may get Illness Benefit from the DSP if you cannot work due to your illness. This is a **nonmeans tested** payment and is paid for either a one- or two-year period depending on the number of social contributions you have paid. The rate of payment will depend on your average weekly gross earnings. The maximum rate of Illness Benefit from January 2022 will be €208 whilst the minimum will be €96.10.

DISABILITY ALLOWANCE

Disability Allowance (DA) is a **means-tested payment.** It is paid weekly to people with a disease or disability that has continued, or may be expected to continue, for at least one year. You may be eligible for DA from 16 years of age and if you are still in school. You must satisfy the habitual residence condition to receive this payment. The maximum personal rate of DA will be €208 per week from January 2022.

PARTIAL CAPACITY BENEFIT

Partial Capacity Benefit is a weekly **meanstested** social welfare scheme allowing you to return to work or self-employment and continue to receive a payment from the DSP once your doctor approves and you have received approval from the DSP. To qualify you must be in receipt of either Illness Benefit for at least 6 months or Invalidity Pension. The rate of payment fluctuates between €101.50 to €203 depending on the severity of the condition.

If you are moving from Invalidity Pension, your Partial Capacity Benefit will continue for a

maximum of 3 years (156 weeks). However, you can apply for PCB again. If you are moving from Illness Benefit, your Partial Capacity Benefit payment will continue to the end of your entitlement to Illness Benefit.

2. SUPPORT FOR CARERS CARER'S BENEFIT

Carer's Benefit is a **non-means** tested payment made to a person who leaves the workforce to care for a child or adult who needs full-time care and attention. To gualify for Carer's Benefit, you must have been employed for at least the last eight weeks in the previous 26-week period for a minimum of 16 hours per week or 32 hours per fortnight. These eight weeks do not have to be consecutive. You can work up to 18.5 hours per week earning a maximum net income of €332.50 and still receive carers benefit once you can prove the person you are caring for has adequate care whilst you are away. The maximum rate of Carer's Benefit is €225 from January 2022 which can be claimed for a total period of 104 weeks for each person being cared for. After 104 weeks you may apply for Carers Allowance.

CARERS ALLOWANCE

Carers Allowance is a **means tested payment** for people on low incomes who are looking after a person who needs support because of disability or illness. For those aged under 66 caring for one person the rate of pay is €224. This increases to €262 if the Carer is over 66 from January 2022. Whilst the conditions for eligibility for Carers Allowance are similar to Carer's Benefit there are some additional requirements including being habitually resident in the Irish State.

DOMICILIARY CARE ALLOWANCE

Domiciliary Care Allowance (DCA) is a **non-means tested payment** monthly payment for a child (under 16) with a severe disability. The DCA payment is based on the impact of the disability rather than the type of disability. The full rate of DCA is €309.50 whilst half rate is €154.80. Since 2017 all children eligible for DCA are entitled to receive a medical card.

CARERS SUPPORT GRANT

The Carer's Support Grant is an annual payment made to carers who get Carer's Allowance, Carer's Benefit or Domiciliary Care Allowance (DCA). The Carer's Support Grant is €1,700 for each person you are caring for. It is paid once each year, usually on the first Thursday in June.

3. MEDICAL SUPPORTS MEDICAL CARD VS DISCRETIONARY MEDICAL CARDS

Medical cards are **means-tested**. If your income is above the limit, you may still be able to get a medical card if your circumstances would result in financial hardship without one. This is sometimes called a discretionary medical card. The application process for the discretionary medical card is the same as for the means tested medical card, but you should also include information about your family's medical expenses in your application and supporting documentation from your medical team.

GP VISIT CARDS

If you are not eligible for a Medical Card you may be eligible for a GP visit card. A GP visit card allows you to visit a participating family doctor (GP) for free. Children aged up to 7 are now entitled to free GP care. If you are under 70 the HSE will conduct a means test to determine eligibility.

DRUGS PAYMENT SCHEME

The Drugs Payment Scheme is a monthly maximum payment of ≤ 110 for approved drugs, medicines and certain appliances for yourself or family per month as per Budget 2022. It means the maximum you will pay per month is ≤ 110 . To qualify you must be a resident in Ireland for at least one year.

4. HOUSEHOLD AND OTHER BENEFITS FUEL ALLOWANCE

A Fuel Allowance is a one per household style payment to help with the cost of heating your home during the winter. You can choose to get Fuel Allowance paid weekly or paid in 2 lump sums. The 2021-2022 Fuel Allowance season started on 27th September 2021. The allowance will be €33 per week for 28 weeks as per Budget 2022.

HEATING SUPPLEMENT

If you have additional heating needs due to a medical condition and satisfy a means test you may be eligible for an additional weekly supplement under the

IKA SUPPORT WINTER 2021

Supplementary Welfare Allowance.

You can read more about additional non-social welfare entitlements for patients receiving home dialysis on page 54.

TRAVEL PASS

If you are under 66 and have confirmed your identity through the SAFE registration process, you will get a Free Travel Card automatically if you are in receipt of:

- an Invalidity Pension;
- a Blind Pension;
- Disability Allowance;
- Carer's Allowance; or
- Widow or Widower's Pension and your spouse held a free travel pass.

5. HARDSHIP PAYMENTS Exceptional Needs

The Exceptional Needs Payment is a **means-tested** single payment to help meet essential, once-off, exceptional expenditure, which a person could not reasonably be expected to meet out of their weekly income. It is paid under the Supplementary Welfare Allowance Scheme. You may qualify if you need help with funeral costs and your income is low. Each case is decided upon by a representative of the DSP. Your sources of income will be examined in order to determine the rate of pay.

URGENT NEEDS PAYMENT

The Urgent Needs payment is an emergency, **means-tested** payment. It is also under the Supplementary Welfare Allowance Scheme. You may have to pay some or all of this back at a later date. The DSP will examine all of your sources of income. All of your property/capital except for your home will be considered to determine the rate of pay.

CONCLUSION

If you qualify for any social welfare payment you may also be entitled to further benefits.

You can get application forms and make further enquiries regarding other entitlements in a number of different places:

- Your local Intreo Centre;
- Your local social welfare branch office;
- Your local Citizen's Information office; or call Citizens Information at **0818 07 4000** and request a call back; or
- The government website www.gov.ie

SPORTS UPDATE 😿 Soont and Digitistics **BY COLIN WHITE**

t is a pleasure to be able to start this guarter's update with positive news! The plans for the 2022

European Transplant & **Dialysis Sports**

Championships to be held in Oxford, England (August 21st -28th) have been green lighted.

The European Championships are known for their friendliness and our team is known for its warm welcome so make 2022 the year that you join Transplant Team Ireland! Contact team manager (Colin White) on colin@ika.ie or phone 087 684 3644. The plans for Oxford look really exciting with the Games being based at Radley College (www.radley.org.uk) for accommodation, meals and many of the sports. The stunning Blenheim Palace will provide the backdrop for the cycling, the 5km run and the petanque.

The Opening Ceremony alone is reason enough to be part of the team! To quote the organisers; "There will be a parade of athletes on the afternoon of Sunday Aug 21st through central Oxford led by a band which will process to the historic Sheldonian Theatre, which is the venue for the Opening Ceremony. It is the ceremonial hall of Oxford University and was built in 1664 designed by Sir Christopher Wren who designed St Paul's Cathedral in London.

We plan a celebration of transplantation with an Oxford twist including a new song, commissioned dance routine, touch of Shakespeare and music to accompany the formal opening of the Games. Following the opening ceremony, we will return to Radley by pleasure boat with full bar and entertainment. Dinner will be in the Dining Hall at Radley."

An important element of Transplant Team Ireland is the inclusion of family and friends. Whether it is at one of our sessions in the ALSAA Sports Complex (yes, they will come back - watch our website and social media) or travelling away to events, family and friends are always welcome and an integral part of what we do. In the New Year, the Board of the Irish Kidney Association will be making a decision about the re-starting of all Association in-person activities, including the sports programme.

Check out www.transplantteamireland.ie.

You can read more details here: https://transplantsport.org.uk/european-transplant-and-dialysis-sports-games-2022/

KAREN JACKSON

ETDS

any of you will be aware of the passing of team member, and former team manager, Karen Jackson from Mulhuddart, Dublin. I first met Karen in 2004 on a very wet and windy day at the ALSAA Sports Complex next to Dublin airport. It was the National Transplant & Dialysis Games and Karen had convinced my wife, Chikoyo, to take part.

Chikoyo was participating in the IKA's back-to-work training scheme in Donor House at the time, a programme also coordinated by Karen. Having been on dialysis for a few years at this point, Chikoyo and I were unsure of her opportunities and limits. Karen was an immediate friend to Chikoyo in Donor House and always encouraged her to push her boundaries.

Thus, Chikoyo found herself going to the ALSAA Sports Complex to meet a bunch of strangers and take

on sports she had never tried. I was unable to attend the Games that day but I dropped in to pick Chikoyo up at the end and I met this 'Karen' I had being hearing all about. Warm, friendly and upbeat, Karen made a very strong first impression.

Little did I know at the time that Karen would be passing over the sports programme to me the following year. From the start, I found a programme that was focused on the people involved more than the sport they were doing. It was about a community of friends who supported and encouraged each other in all aspects of life. It was a wonderful ethos and I immediately knew that it was my responsibility to keep this at the centre of the sports programme.

In reflecting on her life, I think of all the individuals and families that Karen impacted over the years. Having 'been there and done that' in relation to dialysis and



transplantation, Karen brought empathy to her interactions and led by example through her own participation in transplant and dialysis sports.

Karen will remain in the heart of Transplant Team Ireland as an individual, as a team member and in her role in shaping the sports programme. Our thoughts are with her son Brandon, her partner David, her father Philip and their partners, and to a large circle of relatives and friends. RIP Karen.

The Irish Kidney Association's virtual and

36th Annual Service of Remembrance and Thanksgiving

> Mary Dillon, sister of an organ donor, holding the Book of Remembrance, a roll of honour for organ donors.

Recorded at

WATER STREETERS

Book of Remembrance

NET STATES IN STATES IN STATES

Our Lady Queen of Peace Church, Dublin 4



Colin White, Valerie Brady, Carol Moore, Joan Gavan, Very Rev. Fergus O'Connor, PP, Colin Mackenzie, Very Rev. Damian Canon O'Reilly, Patricia May and Fr. Finbarr Treacy

Service of Remembrance & Thanksgiving

housands of organ donor families and grateful transplant recipients from at home and abroad tuned in to watch the Irish Kidney Association's 36th Annual Service of

Remembrance & Thanksgiving. The pre-recorded interchurch Service was broadcast on the RTÉ News Channel* on Sunday, 21st November which coincided with World Day of Remembrance for Road Traffic Victims and the month of All Saints which is celebrated by Christians worldwide.

Four of the eight donor families who participated in the filming of the Service, which was recorded at Our Lady Queen of Peace Church in Dublin 4, were remembering their loved ones who became organ donors following fatal road traffic incidents.

The interdenominational Service, dialysis patient for over 20 y *Available to view on Saorview #21, Sky Ireland #521, Virgin Media Ireland #200, Eir #517

an occasion for both sadness and joy, included clergy, a humanist celebrant, as well as organ transplant recipients, families of organ donors and members of the medical profession involved in organ donation and

transplantation. Captivating music and song by cantor Dr. Sharon Lyons and the Pro-Nuova Music Group was interspersed between poignant symbolic processions and meaningful scripture, reflections and

gratitude, selflessness, and faith in humanity.

President of Ireland Michael D. Higgins sent a message which was read aloud by Colin White, National Advocacy & Projects Manager at the Irish Kidney Association whose wife Chikoyo has been a dialysis patient for over 20 years. In his message (which can be read in full on page 36) the President, who is patron to the Irish Kidney Association, proclaimed that "The act of organ donation is a reminder of the great advancements that have been achieved in medical science in recent times. It is also a reminder of the extraordinary spirit of humanity and human solidarity that exists within our society, and of the many people whose lives are guided by a fundamental instinct of compassion and care for others".

Grateful transplant recipients of deceased donor organs, including heart, lung, liver, kidney and

pancreas, were filmed carrying out symbolic roles at the prerecorded Service. A touching introduction to the Service was filmed at the scenic Garden of Reflection for organ donors and

Higgins organ donors a transplant recipients.



Leanne Rowlette

The garden is located at Doorly Park in Sligo where the Garavogue River and Lough Gill Lake meet, with the imposing mountains of Benbulben as a glorious backdrop.

Singing in the Garden was sixteenvear-old Leanne Rowlette, from Dromore West, in Sligo whose deceased donor mother Sally passed away eight years ago. Leanne gave a moving rendition of the multi-awardwinning song 'Jealous of the Angels'. She was watched on by her father Sean and her three younger siblings including her youngest sister, named Sally after her mother, who was just one day

old when her mother passed away following childbirth.

Filmed at the Sligo garden also was Marie Fowley, a kidney and pancreas transplant recipient and board member of the Irish Kidney Association (IKA), who introduced viewers to the beginning of the Service in Dublin.

The Service included contributions from the Catholic Archbishop of

Archbisho

Dublin, Dermot Farrell and Church of Ireland Archbishop of Dublin & Glendalough, Dr. Michael Jackson.

The Service was facilitated by Very Rev. Fr. Fergus O'Connor, P.P. Our Lady Queen of Peace. Chief Celebrant was the Very Rev. Damian O'Reilly who presided delivered a reading from the Holy Gospel according to John [15:9-12], "This is my Commandment: 'Love One another as I love you'.

Archbishop Dermot Farrell's

message was delivered on his behalf (via video link) by Very Rev. Gareth Byrne who gave a Reflection on the Gospel in which he said, "The ceremony we are participating in is a celebration of love, a celebration of the fact that we are loved by God and

loved by one another. We

recognise, today, the gift of life given us by the generosity of God, and the gift of life given again, a second time, to many of you participating, by the generosity of a donor". (Page 43.)

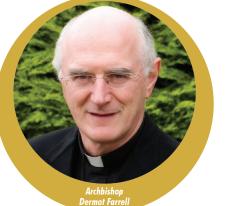
Verv Rev. Damian Canon O'Reilly

In Archbishop Michael Jackson's message he praised the IKA for its "well-honed instinct for sensitivity and compassion" stating that "countrywide there are tales of both joy and sorrow where the contribution of the Association has been deeply felt and deeply appreciated".

In thanking the IKA for its support role, Archbishop Jackson's letter also stated, "I wish to acknowledge the generosity and the selflessness of organ donors and their families, and the transformation that their thoughtfulness and their openness brings to transplant recipients and their families. The positive impact that such giving and receiving brings to our society is both incalculable and to be celebrated in remembrance and thanksgiving". (Page 42).

Representing the Humanist Association of Ireland was celebrant Emma Sides, whose cousin received a kidney transplant. She recited an Indian Poem, 'One Thought to Keep'. (Page 37).

Narrating throughout the Service was Colin Mackenzie, the national honorary chairman of the Irish







Service of Remembrance & Thanksgiving



Kidney Association, from Portmarnock. His wife, Patricia, received a kidney transplant fourteen years ago following eight years of dialysis treatment.

In his words of welcome Colin Mackenzie said, "You are welcome regardless of your faith and philosophy. Donors of all backgrounds have given the gift of life, and patients from all backgrounds have received the gift of life". He introduced members of deceased donor families and transplant recipients as they carried out their roles in symbolic processions, prayers, and reflections throughout the event.

In his closing address Colin Mackenzie thanked Cantor Dr. Sharon Lyons and the Pro-Nuova Music Group, stating that the 'music conveyed a depth of feeling and spirituality which took us beyond words'. The Pro-Nuova Music Group included Michael Crowley (vocals and guitar), Deirdre Doyle (piano) and John Magee (vocals).



UACHTARÁN NA hÉIREANN PRESIDENT OF IRELAND

MESSAGE FROM PRESIDENT MICHAEL D. HIGGINS

May I send my best wishes to all those attending this year's Service of Remembrance and Thanksgiving.

Once again, this annual event enables the gathering together of individuals and families linked by an extraordinary act of generosity. The act of organ donation is a reminder of the great advancements that have been achieved in medical science in recent times. It is also a reminder of the extraordinary spirit of humanity and human solidarity that exists within our society, and of the many people whose lives are guided by a fundamental instinct of compassion and care for others.

Many of those compassionate donors are in virtual attendance at this Service, alongside the very grateful recipients of the profound gift that is an organ transplant. Amongst you also are those remarkable family members who, at a time of great personal loss and distress, have so unselfishly responded to those in need by agreeing to donate a loved one's organs. May I thank you for that profound act of generosity.

Today, let us also remember the many people around the country who are anxiously awaiting an organ donation. I hope they will, in the future, become a part of this inspiring and very special congregation that is rooted in and connected by a profound sense of citizenship, empathy and care of others.

Beir Beannacht

/ minul D thegins

Michael D. Higgins Uachtarán na hÉireann President of Ireland



It was the second year in a row, for the event to be held virtually, due to safety concerns around the pandemic. Prior to COVID-19, the event has, in recent years, attracted a physical congregation of close to 2,000 people. The second virtual and 36th Annual Service of Remembrance and Thanksgiving, which was inaugurated in 1986 by the Irish Kidney Association, was pre-recorded by Kairos Communications who also recorded the previous year's event at a time when even greater COVID-19 restrictions prevailed.

Since its inception 36 years ago, the Service has become a hugely important event in the calendar of members of the organ donation and transplant community. Out of a collective strong will to meet this need, the Board of the IKA, decided that it was important to run a second virtual event as a safe and befitting alternative to Services which had gone before in paying homage to organ donors and their families who gave the 'gift of life' to others.

Several thousand households tuned in to watch the Service, on Sunday 21st November at 2.15pm. As well as receiving a large national audience, many of the Irish organ donor families who are living in more than thirty other countries worldwide, also tuned into watch the Service on RTÉ News Channel (which was available to view on Saorview #21, Sky Ireland #521, Virgin Media Ireland #200, Eir #517) or via the RTÉ News app or live and on catch-up on the RTÉ Player.

After the Service had aired it was posted on the Irish Kidney Association's website, where within the first week it had over 500 views. Content relating to the Service proved as popular as ever on the Irish Kidney Association social media channels. 82,700 people were reached across Facebook and there were 5574 engagements (likes, comments and shares) across Service posts. From the period following broadcast (21st until the 27th November) there was a 74% increase in Facebook reach, and a 23% increase on Instagram.

Organ Donor Card requests also saw an uplift, with a 43% increase in average weekly requests. Irish Kidney Association social media followers

Reflection

Narrated by E**mma Sides** Celebrant, Humanist Association of Ireland

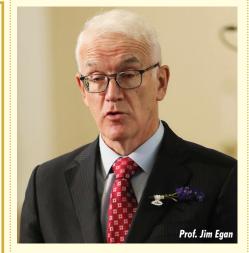
One Thought to Keep

I give you this one thought to keep. I am with you still. I do not sleep. I am a thousand winds that blow. I am the diamond glints on the snow. I am the sunlight on ripened grain. I am the gentle autumn rain. When you awaken in the morning's hush. I am the swift, uplifting rush Of quiet birds in circled flight. I am the soft stars that shine at night. Do not think of me as gone. I am with you still in each new dawn. Native American Poem were overwhelmingly positive in response to the Service, with comments flowing in about how much the annual event means to them and their families.

The confidential database for organ donor families is held by Organ Donation Transplant Ireland (ODTI) who posted invitations to view the Service to the thousands of families living in Ireland and hundreds more who are living abroad.



The two readings at the Service were delivered by ODTI Clinical Lead Dr. Catherine Motherway, an Intensive Care Consultant at University Hospital Limerick who works at the coal face of organ donation, and ODTI Director Prof. Jim Egan, a Consultant Lung Transplant Physician at the Mater Misericordiae University Hospital.



Other members of the medical profession who read reflections at the Service were Dr. Niamh Dolan, a Consultant Paediatric Nephrologist at Children's University Hospital, Temple Street and Aoife Coffey,

Reflection

Narrated by **Dr. Niamh Dolan** Consultant Paediatric Nephrologist Children's University Hospital Temple Street

I'm Free

If my parting has left a void Then fill it with remembered joy. A friendship shared, a laugh, a kiss, All the things I too will miss. Be not burdened with time of sorrow, I wish for you the sunshine of tomorrow. My life has been full, I savoured much, Good friends, good times, a love one touched. Perhaps my time seemed all too brief, Don't lengthen it now with undue grief. Lift up your heart and share with me, God wanted me now, He set me free.

Reflection

Narrated by **Aoife Coffey** Transplant Co-ordinator National Liver Transplant Service St. Vincent's University Hospital

Too Soon

This was a life That had hardly begun No time to find Your place in the sun No time to do All you could have done But we loved you enough for a lifetime. No time to enjoy The world and its wealth No time to take life Down off the shelf No time to sing The song of yourself Though you had enough love for a lifetime. Those who live long Endure sadness and tears But you'll never suffer The sorrowing years: No betrayal, no anger, No hatred, no fears, Just love - only love - in your lifetime.

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Service of Remembrance & Thanksgiving



Transplant Co-ordinator at the National Liver Transplant Service in St. Vincent's University Hospital, who has been involved in the transplant service there since its inception in 1992.

In the opening procession, bringing the Cross to the altar was Larry Moloney, a member of the historic Munster team of 1978 that beat the All Blacks at Thomond Park. Out of his decision to donate his beloved wife Rose's organs when she passed away in 2017, a new lease of life was given to three people.

The Book of the Gospel was brought to the altar by Patrick McGovern from Virginia, County Cavan who received a life saving liver transplant in the summer of 2020, during COVID-19 restrictions, at St. Vincent's University Hospital.



Two candles were brought to the altar by Jo and Steve O'Donovan from Ballymacoda, Cork whose only son Luke's organs were donated in 2016 after a tragic road death when he was just six years old. His parents in their sadness take solace in knowing that

four other people's lives were saved and improved through transplantation because of their 'hero'. They shared that "When people say he is an angel in heaven they (Jo and Steve) say that they can hear their son Luke, who loved superheroes say, 'angels are for girls and super heroes are for boys!'

FORGET-ME-NOTS

The family of another road traffic victim and organ donor were involved in the offertory procession bringing forget-me not-flower emblems, the IKA's symbol of transplantation, to the altar. The brown wood on the forget-me-not emblem has a bandage over the graft of the flower symbolising the transplanted life-giving organ.

Carrying baskets of forget-menots to the altar were recently bereaved Patrick Shanahan and his sister-in-law Mary Dillon. The late Siobhan Shanahan, née Brosnan, a native of Ballybunion, Co Kerry and late of Adare, Co Limerick, had worked as an Organ Donor Manager at University Hospital Limerick. In that capacity, she supported grieving families in their decision to be organ donors.

In April this year as Organ Donor Awareness Week came to a close, Siobhan was involved in a fatal road accident. Patrick, Siobhan's loving husband, agreed to fulfil his wife's wishes by donating her organs, saving four people's lives, and offering them one of the greatest gifts we can give to another.

Siobhan's zest for life was infectious and her mantra was to 'leave everyone and everything in a better place'.







Sarah and Pat Powell from Gurteen in Sligo honoured the wishes of their second youngest child of seven, Karen, to be an organ donor, when she passed away in 2015 in a road traffic incident. Sarah read a prayer of thanksgiving.

The final prayer of thanksgiving was read by grandmother Maureen Shiel from Kylebrack, Loughrea, Co Galway. Her 26-year-old son Barry passed away ten years ago, two days after a car accident. Maureen and her late husband Michael, who passed away earlier this year, courageously honoured Barry's wishes to be an organ donor.

Soon after the donation the family received anonymous letters from two transplant recipients who along with their families are benefiting from both of Barry's kidneys being donated. This continues to provide solace to Maureen and her five adult children.

BOOK OF REMEMBRANCE

The Book of Remembrance, a 'Roll of Honour', has been an integral part of the Service since its inception. The book contains the names of organ donors which have been carefully inscribed by Annette Daly, from Glenageary, Co Dublin, for the past 36 years.

Wearing yellow clothes at the Service as a tribute to the late 17-year-old Scarlett Donnellan of Tulla, Co Clare who loved the colour yellow, were her mother Kirsty and Scarlett's sister Freya (age 7) who carried the Book of Remembrance to the altar.

Attending the Service with them

was Kirsty's husband Kevin and their 3-yearold son Liam Donnellan. Liam who also wore yellow, was born just months after Scarlett passed away.

Another child taking part in a procession at the Service, on the second anniversary of his transplant, was nine-year-old Josh Harbourne from Raheen Close in Dublin 24. Josh was accompanied by kidney donor mother Karen Kelly in a gifts procession as he brought a collaboration of his two



favourite interests together - the LEGO model of Harry Potter's 'Hedwig the Owl' - to the altar.

continued. next page



Service of Remembrance & Thanksgiving

ORGAN DONOR CARD

The large organ donor card was carried to the altar by heart transplant recipient Aoife Farrell from Bray. She was joined in the procession by Crystal Gale Spollen, the mother of deceased organ donor child Nevaeh. Crystal is from Lucan, now living in Kinnegad, Co. Westmeath. 'Nevaeh' which means Heaven (and is the word Heaven spelt backwards) was just weeks away from her 10th birthday when she suffered a massive brain haemorrhage in 2014 and passed away a few days later.

Crystal and her husband Emmett made the selfless decision while grieving to donate five of Nevaeh's organs which forever changed the path of the lives of the transplant recipients and their families who received her gifts of life.

32-year-old Aoife Farrell was just 19-years-old when she received her first heart transplant and underwent her second heart transplant ten years later. In gratitude to her donors, she is embracing her gifts of life and sport and is a member of Transplant Team Ireland.

SERVICE OF LIGHT – LIGHT A CANDLE

In publicity leading up to the televised Service, viewers were encouraged to actively participate, while tuning in to the Service, particularly during the symbolic 'Service of Light' ceremony, by lighting a candle at home in memory of deceased donors. Leading the Service of Light ceremony were two members of Transplant Team Ireland.



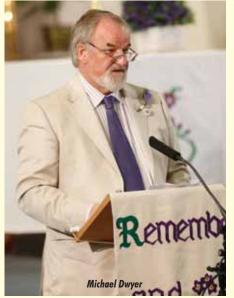
The team has enjoyed huge success competing in European and World Transplant Games events while showcasing the success of organ donation and honouring organ



donors. Sandra Doyle from Beaumont underwent two liver transplants, in 2003 and 2017, and her fellow Dubliner Team Captain Harry Ward from Baldoyle, received a life changing kidney transplant fourteen years ago which followed years of dialysis treatment. Sandra and Harry slowly and respectfully lit numerous candles which were laid out on tables in front of the altar representing organ donors.

The significance of the 'Service of Light' resonated with sound engineer Adrian Cunningham. When he observed it for the first time at the previous Service, recorded in 2020 at Newman Church, it inspired him to waive his professional fee and he did this again for a second time, this year.

2021 marked the 21st anniversary of Dubliner Michael Dwyer's kidney transplant. It was therefore very



appropriate that Michael, from Cabinteely, and who is a veteran member of Transplant Team Ireland, said a prayer of thanksgiving.

Another grateful transplant recipient filmed at the Service and who said the final Reflection was, the mother of two children, Elaine Kavanagh from Newbridge, who underwent a lifesaving lung transplant at the Mater Misercordiae Hospital in 2016.



Our Lord's Prayer was read 'as gaeilge' by Deirdre Lynch, who underwent a kidney transplant in 2003. A native of Kerry, Deirdre is now living and working as an Irish, German and Career guidance teacher in Blarney, Co Cork.

The magnificent flower arrangements which adorned the Altar were arranged by Una Whelan, from Bray, a member of the Dublin East/Wicklow IKA branch.





Her husband John Whelan is National Honorary Secretary of the Irish Kidney Association and a former National Honorary Chairman. Members of the Liturgy Committee included IKA board members Valerie Brady, from Meath, Joan Gavan, from Tipperary, Patricia May, from Carlow, and Colin Mackenzie, IKA Honorary National

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Service of Remembrance & Thanksgiving

Chairman, from Dublin. They were assisted by Colin White, IKA National Advocacy & Projects Manager, also from Dublin. Gwen O'Donoghue liaised with families involved in the recorded Service and also coordinated publicity around the event.

Fr. Finbarr Treacy from Kairos Communications worked closely with the Liturgy Committee in planning the Service. He was assisted in the production by Sebastian Pannackal. The camerawoman and men were Ita Callagy, Paschal Brookes, Gerry Doyle and John Fay.

Photographers Conor McCabe and Robbie Reynolds captured the participants at the Church while James Connolly took photos at the Garden of Reflection in his local Sligo town.

The Irish Kidney Association wishes to thank all who contributed to and watched the Service, and Roger Childs at RTÉ for scheduling the broadcasting of the Service on the RTÉ News Channel.

On behalf of the organ donation and transplant community, the Irish Kidney Association would like to acknowledge all organ donors and their families who are owed a huge debt of gratitude.



Church of Ireland United Dioceses of Dublin & Glendalough

Church of Ireland House Church Avenue Rathmines Dublin 6

The Most Reverend Dr Michael Jackson Archbishop of Dublin and Bishop of Glendalough Primate of Ireland and Metropolitan

6th October 2021

Tel: 00353 1 4125663 archbishop@dublin.anglican.org

First I must apologise for not being in a position to attend this Service of Remembrance and Thanksgiving in person. I am delighted however that words I had hoped to speak in person will be spoken by Canon Damian O'Reilly who is part of a hospital chaplaincy team. Such teams live out collaboration and commitment, ensuring that those in distress and in need in our hospitals are continually supported. None of us need reminding how difficult and distressing the past 18 months have been both for individuals and for our society. I have every confidence that the work of the Irish Kidney Association has continued compassionately and carefully throughout this time. The Association has a well-honed instinct for sensitivity and compassion. Countrywide there are tales of both joy and sorrow where the contribution of the association has been deeply felt and deeply appreciated. In thanking you for all you have done and all you will go on to do, I wish to acknowledge the generosity and the selflessness of organ donors and their families, and the transformation that their thoughtfulness and their openness brings to transplant recipients and their families. The positive impact that such giving and receiving brings to our society is both incalculable and to be celebrated in remembrance and thanksgiving.

The Most Reverend Dr Michael Jackson Archbishop of Dublin







Very Rev. Gareth Byrne

Vicar General, Moderator of the Dublin Diocesan Curia Catholic Church

I am very happy today, on behalf of Archbishop Dermot Farrell to offer this reflection on our chosen Gospel. This is my commandment: love one another as I love you'. We all recognise Christ's commandment to love our neighbour. He would lay down his life for his friends, for those he called neighbour, that is for all of us – so to love one another 'as he loves us' is no small thing.

Becoming aware of God's love in our life and that we remain always in God's love, every day, is life changing, transformative. It gives us a whole new way to look at life.

In a celebratory moment such as this, when we reconnect with God's love for us, and know that God is walking with us on our journey, our hearts fill up with joy: 'I have told you this,' Jesus says 'so that my joy might be in you and your joy might be complete.'

The ceremony we are participating in is a celebration of love, a celebration of the fact that we are loved by God and loved by one another. We recognise, today, the gift of life given us by the generosity of God, and the gift of life given again, a second time, to many of you participating, by the generosity of a donor.

Each year in this special way we give thanks and pray for those who have gone before us, but who in their going provided another person with a precious gift, given remarkably to someone they never knew. We remember and pray, also, for the families of these donors who at a time of great loss and sadness had the courage to reach out, recognising that there were others in need, and that there was a gift that could be given that would make a difference. We are celebrating, too, the generosity of those family members and friends who were able and willing to support a loved one by providing a living donation to them.

All who have given in this way are witnesses to love, joining with Jesus in proclaiming love: 'Love one another as I have loved you', says the Lord. That is what you remembered to do, and the effects of your love are all around us. You have laid down everything out of love - offering a gift that has transformed another person's life. Those who have received from this generosity, from this act of love, are filled with gratitude we know - and we are all filled with joy when we think on this.

There are still of course many questions in life, a journey to be lived in the time that we have, the ups and downs that all of us experience, days of sadness, days of joy, days battling unexpectedly with COVID-19 as we have learned, and its particular impact on this community.

To become aware that we are loved, however, to experience the thoughtfulness of another, is something special, always to be cherished. When you know that you are loved, you too can become a person who gives to others, who loves as you have been loved. As one writer puts it:

Always be the first to love, and be faithful to love, even if you get no answers. Be thankful and praise God, when you realise that you are loved. *(Rule of a Little Brother)*

HOW THE SERVICE BEGAN

he concept for the Service of Remembrance evolved from a grieving organ donor mother who contacted Lorraine **Costello (former Patient Support** Officer, now retired) at the Irish Kidney Association. The mother expressed her distress and sadness that her son's organ donation had not been acknowledged. At the time there was no system in place at the Old Jervis Street Hospital to acknowledge and thank organ donors and their families. In consultation with the then newly appointed National Transplant **Co-Ordinator**, Phyllis Cunningham, it was decided that a Service be held to publicly acknowledge and recognise the courageous generosity of organ donors and their families.

The inaugural Service, in 1986 had an attendance of 300 people in St. Mary's Church, Haddington Road, in Ballsbridge, Dublin 4. Since then, the numbers have increased annually with a congregation in recent years pre-COVID of close to 2,000 people from all over Ireland.



Service of Remembrance & Thanksgiving







Honouring Siobhan Brosnan



hen Siobhan Brosnan, Organ Donation Nurse Manager at University Hospital Limerick, died tragically in a car crash in Co. Limerick last April, her own organs were donated for transplantation, as were her wishes.

At a special and moving event held

at the 'Circle of Life' National Organ Donor

Commemorative Garden in Salthill, Galway, on Saturday, 9th October, Siobhan was remembered by her husband Patrick, family and colleagues from UHL and the ODTI (Organ Donation & Transplant Ireland). It was also an occasion when her dedication to her work at UHL, and particularly in the field of organ donation and transplantation, was acknowledged and honoured.

The 'Circle of Life' Garden is dedicated to organ donors and their families and Siobhan





Colleagues of Siobhan: Karen Healy, Organ Donation Nurse Manager (ODNM); Emma Corrigan, National Organ Procurement Service (NOPS), ODTI; Breda Doyle, ODNM, Brenda Poole, NOPS, ODTI; Nikki Phillips, ODNM; Bernie Nohilly, ODNM; Deirdre Coffey, (previously) ODNM and Pauline May, ODNM.

had visited the garden on a number of occasions and always spoke of its importance to donor families and recipients. Siobhan's colleagues at ODTI felt it was a fitting and appropriate place to commemorate Siobhan in a significant way by having a stone seat created there in her memory.

The inscription on the seat is a quotation from Mahatma Gandhi and very much reflects the ethos of those who work in the medical profession: *The best way to find yourself is to lose yourself in the service of others*?



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

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

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

If you would like to write to the family of your donor, you may send a greeting/Mass card, note or letter. Please do not include any identifying details, i.e home town, phone number, etc. Do not seal the envelope as the Organ Donor Co-ordinator will need to review your correspondence to ensure confidentiality. Outlined below is some general information you may wish to include:

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

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

Organ Donor Co-ordinators, Organ Donation Transplant Ireland (ODTI), 2nd Floor, Temple Theatre, Hardwicke Place, Temple Street, Dublin 1 D01 X584

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



By MICHELLE O'SHAUGHNESSY Consultant Nephrologist Cork University Hospital

Itchy skin (pruritus) and chronic kidney disease

Itchy skin (pruritus) is a common problem experienced by people with chronic kidney disease (CKD), especially those requiring dialysis. Medical terms used for this condition are "CKD-associated pruritus" and "uraemic pruritus". This article summarises what is known about it.

KEY TAKEAWAY POINTS:

- CKD-associated pruritus (itching) is very common, affecting approximately 50% of patients with CKD
- Patients with CKD-associated pruritus may experience a reduced quality of life, impaired sleep, or depression, because of severe itching
- Research into treatment strategies for pruritus is a high priority for patients and doctors, as current therapies lack strong evidence and don't always work

WHAT IS CKD-ASSOCIATED PRURITUS?

CKD-associated pruritus is defined as itchy skin due to kidney disease. Part of the challenge in diagnosing and treating this condition is the fact that it can present in different ways. In some patients, it can affect the entire body (generalised pruritus) whereas in others it is limited to certain body parts (localised pruritus), particularly the face, back, and arms. Even within the same person, the itch can fluctuate in severity over time: it is often worse at night time and can be made worse by conditions such as extremes of temperature, showering, or physical activity.

There is usually no associated rash, except for scratch marks (excoriations) left from vigourous scratching. Scratching can also result in the development of skin infections (eg. impetigo, cellulitis), ulcerations of the skin, or bumps (nodules) with overlying scabs (prurigo nodularis).

It is important to note that many other conditions can cause skin itching, and your doctor will usually screen for these other causes before concluding that you have CKD-associated pruritus. Tests might include blood tests to check your liver function, your thyroid function, and for the presence of any blood disorders.

Your doctor will also review your medication list and stop, or reduce the dose of, certain medications (eg. opiods like morphine) that can cause itching. If no other cause for the itch is identified, then a diagnosis of CKD-associated pruritus can be made.

HOW COMMON IS CKD-ASSOCIATED PRURITUS, AND WHY IS IT AN IMPORTANT PROBLEM?

Early descriptions of itchy skin in CKD reported that this problem affected almost all (86%) of patients receiving haemodialysis¹. With improvements in dialysis prescribing and technologies, this number is now closer to 55%, still far from optimal, and similar in patients receiving haemodialysis or peritoneal dialysis².

For example, a recent international study (the Dialysis Outcomes and Practice Patterns Study, DOPPS) of 6256 patients receiving haemodialysis, from 17 countries, reported that 37% of patients were at least moderately bothered by itching, while 18% were very much or extremely bothered by itching³.

In patients with CKD not yet on dialysis, the problem is slightly less common, with another international study performed by the DOPPS CKD group reporting moderate pruritus in 24% and severe to extreme pruritus in 11% of patients with stages 3, 4 or 5 CKD ie. an estimated glomerular filtration rate (eGFR) below 60ml/min/ 1.73m² but not yet on dialysis.

The prevalence was highest in stage 5 CKD i.e. those with an eGFR <15ml/min/1.73m²⁴.

However, itchy skin might be even more common than we think, as doctors often under-estimate how common a problem it is³, and patients might not report it to their doctor³.

While CKD-associated pruritus is typically considered a nuisance rather than a serious medical condition, several studies have shown that patients who experience CKD-associated pruritus are more likely to have poor-quality sleep and mood problems, which can negatively impact their quality of life³.

Some studies have also reported

that patients with CKD-associated pruritus have a higher mortality⁵, although it is not clear whether this finding is explained by itch being a marker of poorer underlying health, or whether it might directly affect survival.

WHAT CAUSES CKD-ASSOCIATED PRURITUS?

Many theories have been proposed to explain why CKDassociated pruritus occurs, although the truth is that nobody knows the exact cause and probably more than one mechanism is at play. Abnormalities in the levels of certain salts and hormones in the blood (e.g., high phosphorus or parathyroid hormone), and insufficient dialysis, were traditionally considered to be the major causes. However, a recent analysis found no association between itch and blood levels of phosphorus, calcium, or parathyroid hormone, or measures of dialysis efficiency².

It is thought that itch-inducing chemicals are released by skin, immune, and/or nerve cells and that these chemicals activate nerve fibres in the skin, which then send messages to the brain that are interpreted as itch.

The trigger for the release of these chemicals could be:

- The presence of toxins in the skin e.g., calcium, phosphorus, or other "uraemic" toxins
- Damage to nerves supplying the skin (peripheral neuropathy)
- Abnormal immune function, resulting in inflammation in the skin
- Abnormalities in the levels, or regulation, of natural (morphine-like) opiods

Treatments (see below) developed for managing CKD-associated pruritus typically aim to target one or more of these potential mechanisms.

Dry skin (xerosis) is also often a contributing factor, and one that should not be overlooked.

HOW CAN CKD-ASSOCIATED PRURITUS BE TREATED?

Your doctor will first ensure that you are assessed for underlying treatable or reversible causes of itching, including:

• Examining you for a skin rash or a IKA SUPPORT WINTER 2021

primary skin disorder

- Screening for medical conditions, other than kidney disease, that can cause itchy skin
- Ensuring that blood levels of phosphorus, calcium, parathyroid hormone, and iron are within an acceptable range; and
- Ensuring you are getting enough dialysis (if you are on dialysis) Where possible, you should also make some simple changes to your lifestyle, including:
- Avoiding or minimising situations that trigger your itch (e.g., temperature fluctuations)
- Avoiding harsh washing detergents, soaps, and scented toiletries
- Patting rather than rubbing your skin after bathing or showering
- Wearing loose clothing made from natural fabrics (e.g., cotton)
- Liberal use (2-4 times per day) of emollient creams to keep your skin well-moisturised.
 Moisturisers containing aloe vera, camphor, or menthol are effective for some patients.

If the itch persists despite these measures, then several additional treatments have been evaluated, mostly in small studies and with varying success rates. Because of the poor quality of most of these studies, it has been impossible to develop evidence-based treatment guidelines for CKD-associated pruritus, and so treatment largely relies on a 'trial and error' approach.

Among the available treatment options, the strongest evidence supports:

- Medicines (e.g., gabapentin or pregabalin) used to treat peripheral neuropathy (damage to nerves supplying the skin), although only in very low doses as patients with reduced kidney function are more prone to sideeffects like dizziness and sleepiness⁶
- Creams containing capsaicin, which is derived from capsicum chilli peppers⁷
- Gamma-linolenic acid (evening primrose oil), either as a cream or tablet⁸
- Ultraviolet-B phototherapy (light therapy), provided by a dermatologist⁹
- Medications (e.g., nalfurafine and Continued next page....

Itchy skin (pruritus) and chronic kidney disease out'd.

difelikefalin, not widely available) that manipulate opioid (morphine-like) chemicals involved in transmitting nerve impulses¹⁰ Antihistamines and steroid creams are often prescribed but, while effective for other causes of itch (e.g., allergic skin rashes), they are not usually helpful for CKD-associated pruritus.

HOW CAN I FIND OUT MORE?

If you are troubled by itchy skin, you should talk with your doctor and clinical team about this.

You can also find reliable information, written for patients, at the below websites.

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Kerry Holiday Homes remain open all year

Our Holiday Homes in Killarney and Tralee will remain open all year round. Our thanks to the wonderful volunteers in the Kerry branch for making this possible. There are so many places to visit in Kerry in the winter months. You might like a walk in Killarney National Park, drive the Ring of Kerry, visit Dingle and take in other stunning sights including Ireland's highest mountain, Carrauntoohil. If you are interested in taking a short break away to Kerry this winter, please get in touch with us.

TRAMORE HOLIDAY HOMES

The Tramore holiday season has now come to a close for this year, and I'm delighted to say it was a huge success. We did wonder early in the year if we should open considering we are still amid Covid, but the Waterford Branch were committed to ensuring a safe environment for guests. We are so glad that so many patients and their families got to have some normality back in their lives by enjoying a well-deserved holiday.

SUMMER BOOKINGS OPEN IN FEBRUARY 2022

Please remember to apply early for the 2022 Summer holiday season due to an expected high demand for our Tramore and Kerry holiday homes. The season will be upon us before we know it! The applications for bookings for the Summer season will open in early February 2022 and application forms will be available on our website at **www.ika.ie** under 'Our Services' and then click on 'Patient holidays' https://ika.ie/patientholidays/

Your local branch secretary, social workers and your dialysis unit also will have forms, or alternatively you can contact me by email at deborah@ika.ie

THINKING OF GOING ON HOLIDAYS ABROAD

If you are a dialysis patient and thinking of planning a holiday abroad, and would like advice or



assistance in organising holiday dialysis, please contact me at Donor House on 01 6205306 or via email at deborah@ika.ie

Please **do not** book your holiday until dialysis abroad is secured in your chosen destination. Dialysis is a priority and needs to be booked before you book your flights and accommodation.

Dialysis units abroad require as much notice as possible with a minimum of 6-8 weeks prior to a holiday commencing. This gives me and your dialysis unit adequate time to process your paperwork.

I would like to wish everyone a very happy and healthy Christmas and best wishes for 2022.



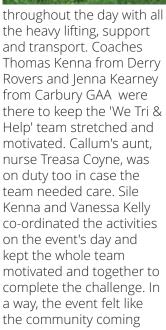
Teen's triathlon tribute to late great-grandfather

Four Kildare teenagers raised over €8,000 for the Irish Kidney Association (IKA) through a triathlon fundraiser to honour the memory of one of the team's great-grandfather who had been a dialysis patient at the Midlands Regional Hospital in Tullamore.

n Sunday 29th August, teenagers Callum Kenna, Joe Cassidy, Leah McKeon and Megan Kilduff, from Ticknevin, Carbury, Co Kildare, set off on their first ever triathlon supported by friends, family and community. Earlier in the summer, Callum (age 14), had decided to raise funds for the IKA to honour the memory of his greatgrandfather Sennan 'Saney' Daly, a kidney patient, who had passed away in May 2021. Callum's three friends came on board without hesitation to do a triathlon and devised a route for the event starting out in Ticknevin and crossing over the county border into Edenderry in Co. Offaly.

A week before the event, Callum's uncle Barry Kenna, set up the teenager's GoFundMe platform for the challenge which they had aptly named 'We Tri & Help'. The four friends had aimed to raise around €500 for the charity the IKA. However, to everyone's surprise, within an hour of the fundraising platform going live they had already raised nearly €1,000. By the time the triathlon day came around, their fundraising had surpassed €6,000.

Callum's proud uncle Barry explained, "We could never have anticipated the amazing response the event would receive. People turned out with vans to carry the bikes and kayaks to chaperone the swimmers through the first part of the triathlon. People were all too happy to volunteer their time to help the team. Declan and Ger McKeon were on hand



back together after a long COVID hiatus". Just before the event began, Callum spoke about how his motivation and dedication for taking up the triathlon challenge was to honour the memory of his great-grandfather 'Saney' as he and his three teammates released balloons to the skies. They started the Triathlon with the swim with team member Leah McKeown gliding under Hartley Bridge, followed by the rest of the team, with what seemed like the whole of

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L-R: Joe Cassidy, Callum Kenna and his great-grandmother Nancy Daly (Saney's widow), Ann McKeon and her granddaughter Leah McKeon and Megan Kilduff. IKA SUPPORT WINTER 2021

on from the canal banks. As they jumped on their bikes Tommy Kenna led them out towards Edenderry for the second leg. They cycled down the tunnel road to reach the last part of their triathlon. Their legs a little tired, they mustered up their strength and they stayed together all the way to the beautiful finish line handmade by Sophia and Bella Kenna.

To celebrate they all went back to Cushling House together for a barbecue, beers for the adults and bouncing castles. It was a great day for the whole community and a total of \in 8,065 was raised for the IKA.

Within a week of their challenge, the four teenagers returned to Oaklands Community College and St Mary's Secondary School Edenderry to commence 2nd year. Collectively they commented, "We would like to thank everyone who helped us turn this idea into a reality and for making it such a memorable day. On behalf of Nancy, Saney and family we'd also like to thank Dr. Maurice Carroll, Edenderry Medical Centre. Maria Bergstrom and all the nursing staff in Tullamore Renal Unit led by the very kind and caring Dr. Eoin Bergin. Their care and kindness made the passing of Saney, a wonderful father, grandfather, greatgrandfather and friend, bearable. Words can never express our gratitude to them. Also, we'd like to thank the Irish Kidney Association for all the great work they do. 'We Tri & Help' those who helped us."

Tips to help you safely enjoy the festive season whilst following a renal diet

which the festive season just around the corner there is no better time to start planning ahead to ensure that you can enjoy eating with your family during the festive period. It is important to remember that many of the traditional favourite foods often contain too much potassium, salt or phosphorous for those on a renal diet. But do not despair there are lots of traditional foods that you can still safely enjoy.

An excellent first step for planning for your diet for the festive period would be to make a list of all the kidney friendly foods you **ENJOY** and know you **CAN** have. Keeping a selection of the more kidney friendly treats at home will also make it easier to stick to your diet. The **irishkidneydiet.ie** website and the **Truly Tasty** cookery book have many recipe ideas to help prepare kidney friendly dishes that all the family can enjoy.

Remember you can always ask your kidney (Renal) dietitian about these or to help you to plan your meals over the Christmas period.

Let's look at foods suitable for Christmas dinner, treats to enjoy and which foods to continue to take caution with or avoid altogether.

MEAT/ POULTRY/ FISH

Foods to enjoy: Roasted fresh meat: i.e. turkey, chicken, duck, beef,

veal, lamb, pork, unsmoked fish, i.e. salmon, plaice, cod, haddock and calamari.

Caution/Avoid: Ham, pâté, prebasted frozen turkey.

POTATOES

Foods to enjoy: If you are on a potassium restriction you will need to peel and boil your potatoes as per your dietitian's advice. These lower potassium potatoes can then be used to make roast potatoes or homemade croquettes. It is important to keep to your recommended daily portion of potatoes.

Avoid: Chips, roast potatoes/potato products if not boiled prior to roasting or frying.

Remember: Rice, pasta, noodles, couscous or breads can be taken instead of, or with a smaller portion of potatoes with main meals to lower the overall potassium content of your meal.

VEGETABLES

If you have been advised to restrict your potassium intake you will need to continue to limit your vegetable and fruit intake and avoid types which have a lot of potassium.

Vegetables to enjoy include brussel sprouts, cabbage, turnips, carrots, or parsnips. Boil prior to roasting or adding to dishes to reduce potassium content. **Avoid:** peas, baked beans, sweet corn, mushrooms and spinach if you have been advised to restrict your potassium intake.

ACCOMPANIMENTS

Foods to enjoy: Stuffing made from breadcrumbs, margarine, fried onions and herbs are suitable.

Avoid: Recipes that contain apricots, dried fruit, nuts or potato as this would increase the amount of potassium in the stuffing.

Suitable sauces include homemade low salt gravy, cranberry sauce, mint sauce, apple sauce, white sauce, onion sauce and mustard sauce.

CHRISTMAS TREATS

Cakes/desserts: Trifle, meringues, pavlova, cream cake or gateau, lemon meringue pie, cream buns, doughnuts, plain pastries and bakewell tart can be eaten as alternatives to Christmas cake and pudding.

If you have diabetes or are trying to lose weight, please consult your diet sheet or your kidney dietitian for suitable suggestions.

Alcohol: Remember your fluid allowance. Spirits such as whiskey, brandy, gin and vodka are suitable in moderation. Use mixers such as lemonade and water not fruit juices.

If you have diabetes use diet or no added sugar mixers. All other alcohol

contains some potassium.

Savoury snacks: Most are high in salt and potassium. Unsalted popcorn, cream crackers, breadsticks and corn snacks e.g. tortilla chips are suitable alternatives.

Chocolate/Sweets: Be cautious with chocolate over the holidays as it is high in both phosphate and potassium.

Suitable alternatives include: Mint sweets, boiled fruit sweets, marshmallows, starburst and jelly.

If you have diabetes discuss

suitable choices with your dietitian. **Biscuits:** Most are fine, but avoid options containing chocolate and dried fruit if you have been advised to restrict your potassium intake.

If you have diabetes check your diet sheet or speak with your

dietitian for suitable suggestions.

Remember:

- Don't add salt to your foods
- Don't forget to take your phosphate binders
- Keep within your fluid allowance
- Portion control is still recommended within the foods to enjoy list as well as discussing your Christmas menu with your dietitian.

Hopefully these suggestions will help you create enjoyable holiday dinners this season that also will let you stay on course with your renal diet.

As a final word, remember, *moderation* is the key.

By SINEAD DUIGNAN (SENIOR RENAL DIETITIAN) Midland Regional Hospital Tullamore

on behalf of the Renal Interest Group of the



ROAST CROWN OF TURKEY WITH SAGE AND ONION STUFFING

Ingredients – Serves 8

Ready-prepared Turkey Crown – 4.5kg (10lb) Butter, at room temperature – 75g (3 oz) 1 garlic clove, crushed Finely grated zest of 1 orange Fresh flat leaf parsley, chopped – 1 level tbsp Fresh thyme, chopped – 1 level tsp

For the Stuffing

Butter – 75g (3oz) 1 small onion, diced Fresh sage, chopped – 1 level tsp fresh white breadcrumbs – 175g (6oz) Freshly ground black pepper – pinch (¼ level tsp)

Instructions

Preheat the oven to 190°C / 375°F / gas 5. To make the stuffing, heat a frying pan and melt the butter. Add the onion and sage and cook for a few minutes, until softened but not coloured. Stir in the breadcrumbs, mixing well to combine. Season with freshly ground black pepper. Wrap the stuffing in buttered tinfoil and mould into a large sausage shape.

This can be cooked in the oven for 25–30 minutes. Next, prepare the turkey crown.

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

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

Place the turkey crown in the oven and calculate your time. You should allow 20 minutes per 450g (1lb) plus 20 minutes, so a joint this size should take 3 hours and 40 minutes.



Cover loosely with foil and remove this about 40 minutes before the end of cooking time.

The turkey crown will cook much quicker than a whole turkey, so make sure to keep basting.

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

When cooked, cover with foil to rest and keep warm. To serve, carve the turkey crown into slices and

arrange 125g (5 oz) on warmed plates with the cooked stuffing.

Per portion this dish provides 5 protein exchanges. Check your daily allowances to see if you have enough remaining for this dish.

> Reproduced with kind permission from 'Truly Tasty' Recipe book.

CASE STUDY

Enjoying independent living while on Home Dialysis

Independence has been crucial while managing kidney disease during COVID-19, and it's all thanks to technology.

County Clare native DERMOT HAYES outlines his kidney disease journey and emphasises the importance of maximising your quality of life through homedialysis. ermot Hayes was diagnosed with kidney disease in 2016 at age 62 when he was taken to hospital with complaints of low energy and redness in his face. It was discovered that his kidney function was at 20%.

Dermot, who lives in Ennis, Co. Clare with his wife, his two daughters and their dog, leads an active life and volunteers with various organisations both locally and nationally and hosts a weekly radio show. He doesn't drink or smoke, and looked after his diet, so had never realised he had any issues with his kidneys.

His healthcare professional team, led by Professor Stack in University Limerick Hospital, recognised that Dermot was experiencing kidney failure. He was immediately put on medication and intensive treatment, with dedicated monitoring and was looked after "exceptionally well". Dermot spent two weeks in hospital then was moved to out-patient treatment.

Dermot is unsure of the cause of his kidney disease as he maintains a generally healthy lifestyle. Over the years he has regularly attended his doctor due to his Ankylosing Spondylitis, he has had two hip procedures, but his kidneys were never found to be a problem until then.

Despite treatment and monitoring, by 2020 Dermot's kidney function had reduced to 20% and he was advised to start thinking about dialysis treatment. He attended an information evening in University Hospital Limerick along with other patients and was presented with potential dialysis options that he could choose from. Dermot decided that athome peritoneal dialysis was his preference as it would give him the



freedom to maintain his busy life volunteering and spending time with family.

Following this decision, Dermot had his catheter fitted in hospital to facilitate his home dialysis treatment. He completed a week of training in University Hospital Limerick, with the Home Therapy Nurses, which he found fantastic, where he learned how to use the machine correctly. The home-dialysis machine was set up in his home, and fluid is delivered every two weeks. He uses his machine at night while he sleeps, as it works on an 8-hour cycle, and he can choose when he goes to bed rather than having to stick to a specific time of day if he was attending hospital for dialysis. The machine is linked to the hospital unit so his medical team can monitor his machine readings remotely each day. Professor Stack's team has different types of healthcare professionals such as the nurse specialists and dietitians, and they keep in close contact so that his readings are correctly monitored.

Before starting dialysis, Dermot worried about whether it would work for him and if he would be able to function and live his life as he wanted to. He works with people who have disabilities and it was very important to him that he continue leading an active lifestyle. The home dialysis and connected technology has helped Dermot to feel confident in his treatment and to maintain his independence, he lives the best quality of life possible and it is "all thanks to this technology".

His wife and daughters are a great support to him, one of his daughters is training to be a nurse so he is in good hands at home.

While Dermot still visits the hospital fortnightly to have his bloods taken, he is grateful he no longer has to attend for dialysis treatment, which he recalls made him feel "drained" and tired. He was always worrying about contracting Covid-19 during his visits to hospital, despite the best efforts of the amazing staff there to make him feel comfortable and reassured. He feels he has much more energy and is livelier on home dialysis. He is better both physically and mentally as he feels safer at home. He feels good when he wakes in the morning and can go for his daily walk and spend time on his hobbies and community work. His energy can sometimes dip a bit as the day goes on, so he regularly takes an afternoon nap to keep good care of his energy and watches his diet.

Most of all, Dermot enjoys being in control of his treatment and the independence that home dialysis affords him. He can decide what time he wants his dialysis and it doesn't interrupt his day to day activity. The ability to travel is also important to him and he went on his first trip with his machine this summer. It is a small machine that he can set up anywhere and doesn't cause any interruption to the holiday. Any equipment needed for the dialysis can be delivered to Dermot while he's away. Home dialysis gives him the best quality of life and he is extremely grateful for the team in University Hospital Limerick and the technology that has helped him to enjoy independent living.



'SHE' is the final in a series of four short stories, 'Taxi Tales' written by the late Alexander Ager, formerly a member of our Dublin South IKA branch. The short stories are inspired by his experiences while travelling by taxi to and from dialysis and give a snap shot of the simple humanity of the friendships and the characters we meet.

'SHE'

They sent me for an 'evaluation' they said, as if I were an old piece of furniture of uncertain heritage. "We are sending you to a clinic out of town for a few days, just to get you well again."

The when turned out to be immediately after my next dialysis.

I was ready, unaware that there was a clinic over there, a way out of Dublin, an area that I had never previously visited.

Feeling my usual post-dialysis self and resigned to the hearsay of 'At least an hour each way!' and 'No parking anywhere near there!'

I viewed my ride with interest and accepted the invitation to sit up front with the driver, their way of getting to know their new ride, and for me to get to know my first female taxi driver.

Not at all like the guys, who one could consider collectively as the 'lads'. She was a charmer, could have been my daughter, full of caring humour, a font of raunchy stories mainly from the female perspective.

Tales of men in general, ex-husbands (plural) in particular, new found friends, the considerate gentle loves of yesterday, the loveable lads of last night, all becoming the rogues and bounders, only fit to be thrown out by lunch time, leaving her 'Lady Shave' clogged with bristles, and the toilet seat – well we won't go there.

"What are your plans for this evening?" I asked laughing, she always made me laugh.

"Clubbing, need to find another husband. Sooner rather than later."

Once my evaluation was completed, I reverted to my usual dialysis routine and my daily allocated cabbies to and from home.

They don't make me laugh like 'She' did.



The Irish Kidney Association's Webinar on...

'IS HOME DIALYSIS AN OPTION FOR YOU?'

n Monday, September 27th, the Irish Kidney Association (IKA) hosted its first in a series of information evening webinars for its members. 'Is Home Dialysis an Option for You?' explored the options available for home dialysis.

The webinar commenced with IKA Chief Executive Carol Moore, introducing Prof. George Mellotte who is the National Clinical Lead for Renal Services at the National Renal Office and Clinical Director of Nephrology in Tallaght University Hospital and St. James's Hospital.

At the event three patients, all active members of society and in different age groups, gave presentations on their personal experience of home dialysis and its different forms - home-haemodialysis, Continuous Ambulatory Peritoneal Dialysis (CAPD), and Automated Peritoneal Dialysis (APD).

BY JESSE BRIEN & GWEN O'DONOGHUE

In his presentation Prof. Mellotte outlined the following:-

- Both home and incentre dialysis have an important role depending on individual patients needs.
- Patients should discuss different forms of dialysis with their nephrologist. It may be possible to change their dialysis treatment options to best suit their clinical and lifestyle needs, and to review changing needs.
- The number of patients availing of home dialysis has increased four-fold in the past 25 years and this trend has accelerated since the arrival of the COVID-19 pandemic.
 - The progression to dialysis treatment usually begins once



kidney patients experience symptoms such as nausea, itching, weight loss and high potassium. Common practice is that dosages for patients new to dialysis treatment are gradually built-up.

- Likely clinical barriers to patients commencing home dialysis include staffing ratios and lack of financial incentive.
- Practical barriers for patients include lack of space for equipment and supplies in homes, lack of confidence and ability to manage selfcare and infection control.

WHAT TYPE OF WATER SYSTEM IS NEEDED FOR HOME DIALYSIS?

Prof. Mellotte explained that Baxter, the equipment company, usually provide testers to check the microbiological purity of water. Reverse Osmosis (RO) is a water filter needed to ensure water used in dialysis is of a high enough quality. This is very efficient at taking away all the toxic waste. It checks for any unusual contaminants. Sometimes in rural areas, the local water schemes are not as good as others and extra filters are required to ultrapurify the water. In these instances, the chlorine levels are checked each day.

PATIENTS ON HOME DIALYSIS Prioritised by Irish Water And Electric Ireland

Prof. Mellotte informed the group that when receiving home dialysis, patients can get themselves added to a priority list with both *Irish Water* and *Electric Ireland*. This is strongly recommended as they will notify patients of any outages in advance. If patients have issues with their electricity or water supply, they will be prioritised.

TAX RELIEF ON ELECTRICITY BILLS

Carol Moore advised that patients on homedialysis can apply for tax relief on their electricity bills, telephone use and laundry but this is not applicable to those who do not pay tax. An article on how to claim tax back is available on page 43 of the Autumn 2021 issue of the IKA's *SUPPORT* magazine which can be found on the IKA's website **www.ika.ie** (see link opposite page).

Colin White, the IKA's National Advocacy and Projects Manager, delivered an update on vaccinations against COVID-19 for the immunocompromised referring to the third vaccine as a third primary shot rather than a 'booster shot' which had started to be rolled out around the country. See pages 10-11.

Three patients described their experiences of different forms of home-dialysis.

TYPES OF DIALYSIS

Haemodialysis is a **3-4 hour process** undertaken either in hospital or at home **3-4 times weekly.** The patient's blood is filtered and cleansed of toxins via an external machine.

There are two main types of **Peritoneal Dialysis (PD).** This involves the permanent surgical insertion of a soft tube into the patient's abdomen, through which dialysis fluid flows into the peritoneal membrane, drawing excess water and waste products from the blood in an 'exchange' process.

The first type of Peritoneal Dialysis (PD) is known as **Continuous Ambulatory Peritoneal Dialysis (CAPD).** In this form of PD, patients have fluid in their abdomen **24 hours a day.** At the end of each period of dialysis, patients must change the dialysis fluid themselves. This exchange process is undertaken manually. Dialysis fluid must be changed four times every 24 hours.

The other type of Peritoneal Dialysis is known as **Automated Peritoneal Dialysis (APD)** whereby a machine changes the dialysis fluid for the person, usually at night while a patient sleeps.



Michelle's Experience

Home Haemodialysis

Michelle Horan, (early 50s) from Athy, Kildare, has been undergoing dialysis treatment for the past eight years having previously undergone two kidney transplants. She was in her early twenties when she started dialysis.

Her first transplant lasted three years while her second kidney remained successfully transplanted for twenty years and during this time Michelle gave birth to a son.

When faced with dialysis once again eight years ago, she initially resisted home dialysis. She didn't feel confident that she would be able to operate the dialysis machines on her own. After a few months she approached the home dialysis team who eased her concerns. Her training took roughly six weeks in Beaumont Hospital.

Baxter rigged up the home haemodialysis machine in her bedroom connecting the water and the sewage supply. They also set up a separate electricity supply which meant that if her electricity failed at home, her treatment would remain unaffected.

A nurse assisted her at home for the first three days of her dialysis. The nurses visited every so often after that for checkups. She resolved that home haemodialysis was easier than travelling from her home in Athy for ninety minutes to Beaumont Hospital three times a week.

Michelle expressed how she felt safer undergoing her treatment in the safety of her own home by being less exposed to the possibility of COVID-19 infection. Baxter visit every month to change the water, check water samples and to ensure the dialysis machine is working properly. One disadvantage Michelle highlighted was the additional electricity cost as a result of extra usage due to her treatment. Her homehaemodialysis requires five and a half hours supply of electricity every second day, which results in higher bills.

Michelle also pointed out that additional storage space is required for equipment and supplies although Baxter provides a shelving unit for this purpose.



Mary's Experience Continuous Ambulatory Peritoneal Dialysis (CAPD)

Ary Stewart is 72-years-old from Tallaght, Dublin 24 and works as a counsellor. Married to John, she has four sons and seven grandchildren. She has been receiving dialysis treatment for over two and a half years.

In September 2018, she was diagnosed with endstage kidney failure as a result of vasculitis.

She ended up on emergency haemodialysis. In August 2019, she began peritoneal dialysis at home but alternated between a combination of hospital haemodialysis and peritoneal dialysis for a short period.

She found the prospect of dialysis at home overwhelming. However, she said the training and support from the renal team in Tallaght Hospital was excellent. In struggling to get to grips with the breadth of information, Mary decided the best approach for her would be to pretend she was doing it all for someone that she loved rather than for herself.

By November 2019, having completed hospital haemodialysis treatment, she was offered the chance to go on the night-time Automated Peritoneal Dialysis (APD) machine at home. She could instantly enjoy the benefit of her

https://ika.ie/wpcontent/uploads/2021/09/IKA_SUPPORT_AUTUMN-2021_WEB.pdf

'IS HOME DIALYSIS AN OPTION FOR YOU?' CONT'D

days being freed up and she found this liberating.

Unfortunately, this was short-lived as soon after Mary's sister was diagnosed with terminal cancer and Mary moved in with her. During this time, she reverted to daily dialysis manual exchanges (CAPD). Sadly, her sister passed away in April 2020.

Mary reverted to the night-time dialysis machine (APD), but she found it difficult to sleep with the noise of the machine.

As a result of COVID-19, Mary was considered very high-risk, and it was suggested that she cocoon. She decided to revert to the four times a day dialysis manual exchange regime of CAPD. Mary finds this method of treatment works best for her needs and she finds it easy to manage now and it fits in with her family and work life.

When visiting her family and friends, she brings her supplies with her. She was able to enjoy a holiday in Ireland provided by the Irish Kidney Association in one of its holiday homes.

In highlighting why peritoneal dialysis works best for her, Mary said that it is flexible, comfortable, and private. She said she uses the time spent while undergoing treatment to read, meditate, chat, listen to music and podcasts, and watch television.

Mary remains hopeful that she will get a kidney transplant soon.



Michael's Experience Automated Peritoneal Dialysis (APD)

ichael Stapleton is 38-years-old and lives in Donabate, Co. Dublin. He has been on automated peritoneal dialysis for over two years. He chose this form of treatment based on medical advice that it would best suit his needs as he is relatively young and fit and enjoys sport. He praised the excellent training he received to prepare him to self-mange his nightly treatment at home.

In November 2019, he underwent a procedure to have a catheter inserted which took forty minutes. He recovered quickly, playing golf three or four days later.

He commenced dialysis

in December 2020. A nurse from Beaumont Hospital came to his house and walked him through setting up the machine. The option of nightly dialysis for eight hours at a time gave him a lot of independence. While there is sound from the machine which initially took him some time him to adjust to, it soon became background noise to him.

Michael gets a delivery of supplies once a month from Baxter which he says requires a large storage area. Michael finds his treatment quite manageable.

The machine is portable and allows him to travel. Together the equipment weighs 26-27 kilogrammes, but any complications that arise can be overcome with careful planning.

When arranging travel, there is a necessity to notify the airline in advance. Last February, Michael enjoyed a skiing trip. He contacted Baxter four weeks in advance and all of his supplies were delivered to the hotel in Austria. He has completed several trips around Ireland, taking his equipment with him.

A negative to his treatment is that there is a huge amount of cardboard and plastic waste which he describes as 'phenomenal' but it can be recycled.

Michael also explained that there has been an increase in his electricity bills. He explained that his general health while on APD is really good. He lives a good quality life and looks after himself.

He explained that while he suffered some discomfort with drain pain and leg pain initially, it went away quickly. His body grew accustomed to the procedure. Michael said that he is content with his choice of APD dialysis treatment.



The Irish Kidney Association is delighted to report that just a few weeks after sharing his dialysis experience on this webinar, Michael was called for a kidney transplant. We extend our best wishes to Michael and his family as he recovers while we also express our gratitude in acknowledging the selflessness of his kidney donor.

As the session concluded, Carol Moore invited attendees to complete a quick online poll on the prevalence of itchy skin amongst dialysis patients. The majority signalled that it was an issue for them. As a result of this important feedback on itchy skin, the Irish Kidney Association invited Consultant Nephrologist at Cork University Hospital Michelle O'Shaughnessy to write about this topic (see pages 46-48)

The YouTube video of the webinar can be viewed on the IKA's website www.ika.ie

Husband's tribute to late wife Claire Bardon-Maher

t is with a deep sense of sadness that I record the passing of my dear wife Claire Bardon-Maher on August 22nd last.

It was in the early noughties I first met Claire: she won four medals at the European Transplant & Dialysis Games and I interviewed her as part of my weekly work for Westmeath Topic Newspaper where I was in the early years of my journalism career. That bright, bubbly, gregarious personality that enriched so many lives over the years was very obvious from the first time we met.

She was modest and played down the achievement. When one considers that in 2000 she underwent

life-changing surgery, over approximately six hours to have a double transplant (kidney and pancreas), to go to Hungary and participate in the Games two years later was a noteworthy achievement.

I thought of the medals in the days following her passing and felt it appropriate that they be included in the gifts at the start of Claire's funeral Mass.

Claire enjoyed travel, reading, music, singing, dancing, swimming, films, comedy, soaps and shopping (especially in Penneys), just some of a long list of favourite hobbies. Claire loved animals and nature and a visit to the zoo was a regular part of a holiday abroad. She especially loved dogs and cats. She packed so much into her short life and no sooner was a holiday over than she would begin planning the next one.

Claire was an avid GAA enthusiast and proud supporter of her local teams St. Loman's for football and Clonakill for hurling, and Westmeath in everything! Her favourite counties in the GAA world were Kilkenny in hurling and Tyrone and Kerry in football. Sport was a huge part of her life as she followed Liverpool FC in soccer, horse racing, darts and rugby.

Aside from all that, Claire was a busy and active person. In recent years she worked at the Department of Education, Athlone. Illness never held her back.

She was actively involved in the Westmeath Branch of the IKA, serving as Secretary of the Branch and always participated in the annual Organ Donor Awareness Week.

Claire was ever-present during my many years in local sports journalism. Indeed, when the late Westmeath GAA Chairman Seamus Ó Faoláin passed a few weeks earlier than Claire, I could well recall him welcoming us both into the press box in Cusack Park and wishing us every blessing. It's amazing now to think that both are gone and I shed a little private tear when I returned for the first time since Claire's passing. I know



they will both be there in spirit any time I'm assigned to cover a match at the great venue.

When I consider that Claire and I were in London seventeen days before her passing, pursuing a new treatment option, I am extremely relieved and grateful for her beautiful passing at the Midland Regional Hospital, Mullingar and that we got to be with her in her final hours.

Claire's transplant surgeon, and Dublin GAA football legend, Dr. David Hickey sent a lovely message, noting how Claire's positive attitude always lit up the place when she was in for appointments or check-ups. She lived every moment of her life and was an

example to us all, he noted. Claire always respected and appreciated how lucky she was to receive a transplant and Dr. Colm Magee referred to her as a model patient. Even on her last day, she enquired about her kidney function. It is remarkable that her new organs never failed despite the onset of cancer.

To everyone who helped in any way, through calls, texts, cards, letters, words of support, many thanks. My heartfelt gratitude to the GAA community, to my neighbours and supportive colleagues, local and national scribes, and all those who attended Claire's funeral and on the evening before.

I thank Claire's wonderful family including her mum Patricia, brothers Patrick and Martin, and nieces Nicola, Sarah, Laura and Michelle who have been an absolute rock of support, as have my own family, especially Fiona and Ken. It's simply not going to be possible to thank everyone, but please accept this note as a token of my appreciation.

No words can thank the Irish Kidney Association, especially Eddie Flood and Patricia and staff in the Renal Support Centre. The truly outstanding work of staff at St Claire's Ward, Beaumont must be acknowledged; Dr. Colm Magee, Prof. Liam Grogan and their respective teams are absolutely remarkable people. Thanks to the Irish Cancer Society also. A special word of thanks to Claire's wonderful GP, Dr Liam Dalton, his colleagues and staff at the Mullingar Medical Centre.

Typical of Claire that she made new friends during her long year in Beaumont Hospital and then briefly in St James's Hospital. It was the same during her final few days at Mullingar Hospital, where she smiled and acknowledged the great work of the brilliant staff.

Claire was a fighter to the end: spirited, courageous, friendly, loving and kind. That is her epitaph. Go méadaí Dia thú.

DAMIEN MAHER

THE MERITS OF Fistulas versus Catheters

To perform haemodialysis, a means of access must be created. An access is a site from which blood can be safely removed and returned to your body. The access site is often referred to as your 'lifeline'. There are two main types of haemodialysis access - arteriovenous fistula and central venous catheters.

PERMANENT ACCESS OPTIONS

Arteriovenous Fistula

The *arteriovenous* or AV fistula is a type of access, involving a direct connection between an artery and a vein. This connection is made underneath the skin with a surgical procedure that will only require a short stay in hospital. The connection between a vein and artery allows for adequate blood flow during dialysis. This increased blood flow leads to larger and stronger veins and makes repeated needle insertions easier. Fistulas are the preferred vascular access for longterm haemodialysis patients because they last longer than any other access and are less prone to infection and clotting.

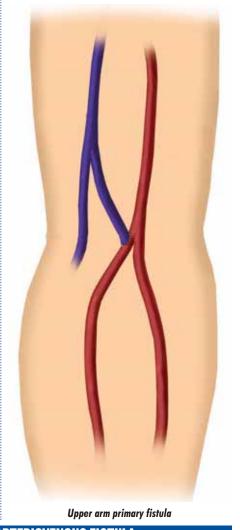
fistula. It is preferred that the fistula be placed on the 'non-dominant' arm or the arm that you do not use as frequently.

8-12 weeks is usually needed to allow the fistula to properly develop, although it may take longer in some cases. Once the fistula has developed, you are ready to commence haemodialysis treatment.

A nurse will insert two needles into the fistula, one for withdrawing blood from the body and the other to return dialysed or filtered blood to the body.

Not everyone is suitable for an AV fistula. It can be difficult to create in some patients due to small veins and other medical conditions.

Your surgeon may order a test to show the blood flow in your arms, to determine if you are suitable for a fistula.



vein Addatery

The fistula is usually placed in the forearm. AV fistulas may also be placed in the upper arm, if a previous AV fistula has failed or if the arteries or veins in the forearm are unsuitable for the creation of a

PROS AND CONS OF AN ARTERIOVENOUS FISTULA CONS

Visible on the forearm

fistula matures

removed

May take time to develop

May require temporary access while

May bleed after dialysis needles are

Some fistulas may fail to mature

- Best overall dialysis performance
- Considered the best vascular access
- Less chance of infection than other types of access
- Tend to last many years

PROS

- Predictable performance
 - lictable performance

RISKS WITH AN AV FISTULA

Not every fistula will work first time. The success rate when creating a fistula is about 70%. Some patients have to come back to have a new fistula made a second or third time.

Occasionally, when a fistula is made it takes too much blood from the hand, resulting in what's called 'steal syndrome'. If this happens, it may require that the fistula be reversed and another access created for dialysis.

Occasionally, a fistula will clot and it will not be possible to use for dialysis until addressed by your Unit. Sometimes it may be necessary for the surgeon to remove the clot to ensure your access functions again.

Care for Fistulas

The following information is important to remember in order to ensure your fistula stays working for the longest time possible.

- Do not wear constrictive clothing or watch straps on the fistula arm.
- Avoid trauma to the fistula arm, such as cuts and abrasions.
- Do not allow anyone to take blood samples, blood pressure readings or insert an IV cannula (drip) into vour fistula arm.
- Avoid dehydration. This may occur if you lose excessive amounts of fluid (for example, if you develop diarrhoea or are unwell and unable to drink your fluid allowance).
- Maintain a high standard of hygiene. It is preferable to have a daily shower. Before and after your dialysis treatment, your fistula arm must be washed well up to the elbow with Hibiscrub (pink solution), which is located at all sinks within the dialysis unit.
- Should you develop any signs of infection such as redness, swelling, pain, tenderness or discharge from your fistula, contact your dialysis unit immediately.
- You will be shown how to assess your fistula. A healthy AV fistula has a bruit (a rumbling sound that you can hear), a thrill (a rumbling sensation that you can feel) and good blood flow rate.
- Do not sleep with your access arm under your head or body.
- Do not lift heavy objects or put pressure on your access arm.
- Learn how to properly hold the



A patient receives dialysis treatment using an anteriovenous fistula

gauze after the dialysis needles are removed. If your fistula starts bleeding when you are not at your Unit, apply pressure to the fistula site until bleeding stops and contact your unit immediately.

• To ensure safety, during your dialysis treatment, your fistula should be in view of nursing staff at all times.

TEMPORARY ACCESS

A dialysis catheter is a flexible, hollow tube which allows blood to flow in and out of your body. They are most commonly used as a temporary access for up to three weeks. This is often undertaken when a patient first needs dialysis immediately and is waiting for a fistula to mature.

They are also used when a permanent access fails and a patient is too unstable to delay treatment.

After a catheter has been placed, needle insertion is not necessary to receive haemodialysis treatment, dialysis lines are directly connected onto the catheter.

CARE OF YOUR DIALYSIS LINE

Protecting your dialysis access is

PROS AND CON

crucial to you. The following tips will help you care for your catheter.

- The dialysis staff will change your line dressing at the end of each dialysis session.
- Most daily activities are not affected by having a dialysis line. However, you should avoid swimming and contact sports.
- Take extreme care when dressing and undressing to avoid pulling accidentally on your catheter.
- If you have a bath, do not allow the dialysis catheter or dressing to come into contact with the bath water.
- If you have been taught how to dress your own exit site by dialysis staff, then you may take a shower and redress the line as shown.

IMPORTANT POINTS TO REMEMBER AFTER INSERTION OF YOUR DIALYSIS LINE

When you are discharged home from hospital you will be given an emergency pack containing:

- Blue dialysis clamps
- Gauze dressings
- Spare dressings

Please keep this pack with you at all times. In the unlikely event that

continued on page 70

PRUS AND CUNS OF A DIALYSIS CATHETER				
PROS	CONS			
 Dialysis can be performed 	 Not ideal as permanent access 			
immediately	 May cause narrowed central veins 			
 Easy removal and replacement 	• Higher infection rates than a fistula			
 Avoids needle insertion for each 	• Blood flow may not be sufficient to			
treatment	complete your dialysis treatment			

Kidney transplant for former footballer

Former Westmeath inter-county footballer John Egan said he will be 'forever grateful' to his future father-in-law and friend, for donating a kidney to him on November 8th, 2021. John described the transplant as 'life-changing' saying that he had 'not felt as good in years'! He posted his delight with an announcement on Twitter two days after the successful transplant operation, which was widely shared and garnered a lot of media attention including interviews with local and national newspapers, radio and TV. He was joined by Dr. Colm Magee, Consultant Neprhologist, at Beaumont Hospital for an interview via Skype on Virgin Media's Ireland AM.



<image>

By GWEN O'DONOGHUE

ohn and his fiancée Traci can now look forward to planning their nuptials which they hope they can celebrate in 2022.

In Spring 2021, John shared his story in media about the impact of his kidney condition, IGA Nephropathy, during the virtual Organ Donor Awareness Week 2021, to support the Irish Kidney Association in raising awareness about the plight of people with organ failure. Soon afterwards he commenced nightly peritoneal dialysis treatment while he continued to work by day.

His dialysis treatment continued for over five months until his transformational transplant, while all the time some family members and friends were being screened for suitability to donate a kidney to him. However, it was Ollie, who proved to be the most suitable kidney donor match for John.

John was diagnosed with IGA Nephropathy as a teenager.

IKA SUPPORT WINTER 2021

Despite John's declining kidney function, he enjoyed a very impressive football career with Westmeath and his local Athlone GAA. However, by 2018 his kidney function had reduced to a point where it was impacting on his ability to play and then a knee injury led to his decision to retire from inter-county sport. He continued to be involved with his local Athlone GAA Club. John's plight and organ donation became a cause close to the hearts of all involved with the Club.

Just two weeks after the successful living donor kidney transplant operations at Beaumont Hospital, John had begun easing his way back to working in IT, remotely from his Athlone home, while his kidney donor, Ollie Young returned to working remotely in finance from his home in Coosan, Athlone.

It was timely that on the same week following John's transplant, that Athlone GAA Club, in association with Marsh Nissan Athlone/Tullamore and The Sheraton Athlone Hotel, launched a Car Draw Fundraiser for the Club with €1 from every ticket sale to be donated to the Irish Kidney Association.

Eddie Flood, the Irish Kidney Association's National Honorary Treasurer and member of the Westmeath branch, attended the launch which was held at the Athlone Sheraton Hotel.

Eddie, himself a kidney transplant recipient, expressed his gratitude to the organisers for choosing the Irish Kidney Association as the charity to benefit from a portion of the proceeds. He said, "In doing so it is shining a light on our charity's role in supporting kidney patients and their families and raising awareness around the importance of organ donation. I wish John and Ollie a speedy recovery so that John can now more confidently plan ahead, including for his nuptials with his fiancée Traci."

Speaking at the Car Draw launch, John Connellan, PRO, Athlone GAA said, "We encourage the whole town of Athlone to get behind this fundraiser to help make it a success raising funds for the Club while also recognising the great work of the Irish Kidney Association by directing a portion of the ticket sale proceeds to the charity. We can't wait to see someone drive away in this gorgeous car, or, jet off to somewhere exotic like New York, or, Sydney."

The car draw, which will take place



on St. Patrick's Day 2022, will see one lucky person drive away in a brand-new Nissan Juke Enigma courtesy of Marsh Nissan. Other prizes include 40,000 Marriott Bonvoy Points (equates to approximately €1,000 towards accommodation) redeemable at any Marriott Bonvoy Hotel worldwide together with €500 towards flights.

There is also an early bird draw

for all ticket buyers who purchase a ticket before January 7th, 2022, where the winner will receive a 2-night midweek break in the Galway Bay Hotel.

Tickets are priced at €20 for one and €50 for a book of three and are available online at

www.marshnissan.ie and www.athlonegaaclub.com and from Club Members.





MARSH



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Welcome to our Winter edition of *SUPPORT*.

We hope that all our members are keeping well and staying safe. It was a relatively quiet time for the Branch regarding meetings, etc. Vera and Eddie Frisby being the busiest of us with the visitors to the Tramore Apartments. Thanks to them for their continued work with the patients and their families holidaying in Tramore.

On Saturday, September 18th, 2021, Waterford Branch IKA was invited to be part of the County Waterford Blackface Sheep Breeders Association Champion Show and Auction. The day started at 8am with judging of all rams, and culminated in the picking of a Show Champion. The super sunny morning was not lost on competitors, animals and spectators alike. Sunglasses were the order of the day.

Once the judging was completed the auction began at around 11am. This was the interesting part of the day for the Branch as four ewes, kindly donated by members of the Association, were to be auctioned with the proceeds going to the local



Donated ewe in the auction ring

WATERFORD By VERA FRISBY & FRANCES MOYNIHAN



The Newtown Fundraising Committee (NFC), Kilmacthomas presented a cheque for €2,500 to the IKA Waterford branch, proceeds of money raised from a virtual walk, (L-R): Ann Power, NFC, Ray Halligan, IKA, Mary and John Bagge and Martin McNamara (NFC).



Mattie Fahey, representing the Co Waterford Blackface Sheep Breeders Association and Frances Moynihan, IKA Waterford Branch Secretary.

branch. Ray Halligan, Branch Chairperson, Vera Frisby, Branch Treasurer, Frances Moynihan, Branch Secretary and Branch member Seán Murphy, were all in attendance to lend support. We also had our display stand on view and distributed organ donor cards and had some interesting conversations with competitors and spectators.

The auction, with donations on the day, raised almost €800. We are most appreciative of the Association for choosing us as the beneficiaries of the auction and wish them all the best in their future endeavours.

Our next big fundraiser took place on December 1st, when Joe Conway, a brother-in-law of Branch Secretary Frances Moynihan, got his lovely locks of hair and considerably long beard shaved off. This was a

IKA SUPPORT WINTER 2021

culmination of growth since March 2020! Well done Joe. Full report and pictures in next edition.

We are postponing meetings until after Christmas when we hope we can meet 'in person'.

Our condolences to any member who may have lost a loved one over the past few months.

We extend Christmas greetings to Sr. Jane and all the staff at the Renal Dialysis Unit, University Hospital Waterford. Thank you' for the wonderful care and support you give all patients, throughout the year. It is greatly appreciated.

In the meantime, it remains for us to wish all our Branch members a peaceful and safe Christmas.

Nollaig shona agus athbhliain faoi mhaise daoibh go léir.



Season's greetings to all Dublin North members and fellow members and friends of the Irish Kidney Association. A number of you have been in hospital. We hope you are all doing well and staying safe.

CONDOLENCES

Christmas is a time for remembering. A time to look back to valued members of Dublin North Branch.

At our recent gathering we stood silently as we remembered Mai Kearns who passed away on September 29th, 2020. Mai and her husband Paddy were regular attendees at past meetings in the Renal Support Centre in Beaumont. Mai is greatly missed by Paddy, her son Martin, daughter Ann, five grandchildren and her sisters. Rest in peace Mai.

We were saddened to hear of the passing of Karen Jackson from Mulhuddart who passed away on September 20th. I remember Karen well when she dropped into the Support Centre to say hello and she always had a smile and friendly

DUBLIN NORTH BY PATRICIA MACKENZIE

words. Our sympathies to her family. May she rest in peace.

Sadly, more recently Frank Burke's brother Christy passed away. Frank works in the Renal Support Centre. Our condolences to Frank and all his family. May Christy rest in peace.

ZOOM BRANCH MEETING

It is always a pleasure to meet new staff and hear about their work and valuable insights. At our September Zoom meeting Fiona Aherne, Patient Services Manager, spoke to us about her career and wide experience in the 'not-for-profit sector', and outlined the valuable work she has begun as a new Manager with the Irish Kidney Association. A lively question and answer discussion followed, and we thank Fiona for her time speaking to us, and her energising contribution to our meeting.

On October 18th we welcomed our visiting speaker, Alison Larkin, Renal Counsellor, Beaumont Hospital. Due to current restrictions our meeting took place on Zoom, but in spite of that we enjoyed a fascinating and inspiring talk from Alison, who also stayed to discuss and answer questions. Alison reminded us that she is available to speak to patients and can be contacted at Beaumont Hospital. Thank you Alison for your time and support to our members.

IKA SUPPORT WINTER 2021

THANK YOU

A big 'thank you' to the children of Foxhill Estate, neighbours of our North Dublin member, Frank Burke.

They gave their time to visit houses in the area to raise funds for the IKA. They collected a total of €90. Our thanks to Frank and his neighbours children. Well done!

SERVICE OF REMEMBRANCE AND THANKSGIVING

Colin Mackenzie, the National Honourary Chairman and member of the Dublin north branch, carried out his role as narrator at the 36th Service of Remembrance and Thanksgiving with great aplomb. You can read all about the Service in this issue's centre page supplement.

CHRISTMAS PHOTOSHOOT

We recently met at the Garden House, Mabestown for a Christmas photoshoot with the kind permission of the Garden House management. We were able to have our pictures taken for this magazine among the stunning Christmas displays.

CHRISTMAS WISHES

Our thanks to all who look after renal patients during difficult times. It is greatly appreciated.

To Branch Members, Officers, Board and IKA staff, we wish you a safe and enjoyable Christmas and a brighter 2022.



Catherine and Brian O'Hare





Patricia Mackenzie, Ron Grainger, Colette Fox



Find us on: facebook

SERVICE OF REMEMBRANCE

The IKA's Service of Remembrance and Thanksgiving, which was broadcast on Sunday November 21st, opened with an introduction from our Garden of Reflection at Doorly Park in Sligo.

Speaking from the garden our branch vice-Chairperson and Board Member Marie Fowley welcomed thousands of organ donor families and transplant recipients viewing at home and abroad.

At the garden, Dromore West singer Leanne Rowlette performed a song in honour of her late mother Sally, whose organs were donated after her death at the age of 36. The song is entitled *Jealous of the Angels*'.

After the TV camera focus on the garden and some of Sligo's main scenic attractions, attention then switched to the main part of the interfaith service at Our Lady Queen of Peace Church, Dublin.

There was further Sligo involvement in the Church service when Sarah Powell from Gurteen read a prayer of Thanksgiving. Sarah is the mother of deceased organ donor Karen. When a student at GMIT, Karen passed away after an accident on the N17 between Claremorris and Knock in 2015.

The entire service was broadcast on the RTÉ News Channel. Our branch members have received much favourable feedback from those who watched it.

It is still available to view on RTÉ Player and also on the IKA website at www.ika.ie

The Sligo segment of the ceremony was recorded by Ita Callagy of Rosses Point, working for **6 4**

SLIGO By BRIAN McHUGH



Sligo branch members with The Rowlette family (centre) at the filming of the Service of Remembrance.

Kairos Communications. Ita is a niece of our branch member Ita McMorrow. See more comprehensive coverage on the Service on pages 33-44.

PRIZES ON WAY FOR PATIENTS

At the time of going to press our branch members are busy organising our free Christmas draw for patients.

This is the second year that, due to the pandemic, we have held a free draw in place of a patients Christmas party.

This year we will have even more valuable prizes to be won, thanks to the help of our neighbouring Leitrim branch. Several patients attending the dialysis unit in Sligo are Leitrim residents.

Draws will be held in the dialysis unit for all patient shifts. There will also be a draw for the staff of the unit. Draws will be held in mid-December.

HOSPITAL PARKING PROBLEMS

We have been working with Sligo University Hospital management over recent weeks regarding a number of issues concerning parking for patients.

Firstly, a number of patients told us that since the start of building works at the hospital they had to walk the long way from the main carpark to the renal door entrance, often in rain.

We wrote to hospital IKA Support Winter 2021 management about the problem. They got back to us with the good news that they were preparing to provide a free shuttle bus from the main carpark.

This is now up and running satisfactorily.

In their press release announcing the bus, hospital management acknowledged the IKA Sligo input to the provision of the new service.

More recently patients contacted us about the small Renal carpark being used by contractors vans and vehicles belonging to other workers. This problem arose after a barrier which controlled entry to the Renal carpark was removed.

We again emailed hospital management. In reply they told us that the barrier will soon be replaced. Hopefully by the time this magazine comes out, the barrier will be back in place.

NEW RENAL UNIT PLANS

Separately, moves are at a very early stage towards preparation of plans for a new renal dialysis unit at the hospital.

Hospital management and a spokesperson for the Minister for Health have both confirmed to our branch that they are supportive of having an IKA member as a patient representative on the Project team for the new unit when the capital project is approved and moving to design stage.

DEATH OF IKA ACTIVIST

All in our branch were deeply saddened at the death of our colleague and friend Tommy Nolan. He passed away in Sligo University Hospital on October 9th after a short illness. Tommy was always willing and eager to help with any of our branch activities over many years. A natural horticulturist, he took a keen interest in our Garden of Reflection at Doorly Park and was always available when needed to help maintain it and keep it looking well.

His bereaved wife Eileen has also been a very active **The** member of our branch over several years. Their son James got a kidney transplant 27 years ago.

Tommy will be greatly missed by all our members and by his many friends in the Sligo community. We send our sympathy to Eileen and the Nolan family.



The late Tommy Nolan helps replace a rope around our Garden of Reflection in March this year.

CONDOLENCES

We send sympathy to the family of dialysis patient James Wilson of Cartron Point, Sligo and formerly Belmullet, Co. Mayo who died on October 8th. Also at our last branch meeting members expressed sympathy to our treasurer David Berreen on the death of his aunt Kathleen Shields.

Sympathy was also expressed to myself (Brian McHugh) on the recent deaths of my mother Margaret McHugh and my uncle James Roche.

CONGRATS MICHAEL

Congratulations to our former branch Chairman Michael McHugh who in November celebrated 13 years since his kidney transplant. Michael guided our branch through nine years in the chair.

CHRISTMAS WISHES

Our branch Chairman Sean Fowley and members send Christmas wishes and a happy New Year to all renal unit patients, staff and to all our supporters.

We hope that circumstances will allow us return to more of our normal activities in 2022 after almost two years of being constrained by the pandemic.

BY BERNIE DWYER

DUBLIN EAST & WICKLOW

Greetings and best wishes to our patient, family and carer members in Dublin & East Wicklow. As we are now in the dark days of Winter we look forward to Christmas and a levelling off of the infection rates of COVID-19. We must all keep our guard up and stay safe as we hope to enjoy time with family and friends.

CONDOLENCES

We remember Johnny Cleary from Shankill who passed away on September 16th. We send our condolences to Noleen and family. Long-time member Don Litster passed away on November 24th and we also send condolences to his wife Maura, son Robert and other family members. May they rest in peace.

GET WELL WISHES

Get well wishes to Rachel Ní Ódhra who has had quite a spell in hospital recently. May you continue to make a speedy recovery and grow stronger each day.

We also send best wishes to our Chairperson John Whelan as he recovers from recent surgery.

To all patients in hospital or recovering at home we hope you feel better soon and enjoy a Happy Christmas.

ZOOM MEETINGS

We had two Zoom meetings since our last edition. We were delighted to have IKA Patient Services Manager, Fiona Aherne, as our speaker on October 12th. Those who participated found her very interesting and informative.

Our last meeting held on November 23rd encouraged discussion about what members would like from meetings and any ideas they may have. We hope those who did participate found them beneficial.



John Whelan pictured receiving a donation from the Kilmacanogue Horse Show President, Liam Allen and Show Chairman, Harry Williams.

KILMACANOGUE HORSE SHOW

In October, John Whelan attended a presentation in Powerscourt by the Kilmacanogue Horse Show committee. We were delighted to receive a cheque for €1,000 from them for which we are extremely grateful considering the restrictions again this year.

SERVICE OF REMEMBRANCE

At the recent very special Service of Remembrance Aoife Farrell, a double heart transplant recipient and member of Transplant Team Ireland, from Bray, and Michael Dwyer, branch member and also a member of Transplant Team Ireland, were honoured to take part. The beautiful flowers were arranged by Una Whelan, member and wife of our Chairperson John Whelan.

We wish you all a very safe and happy Christmas and look forward to a, hopefully, positive New Year.



GREETINGS

As we bring 2021 to an end, we look back at what has been a challenging yet successful year. Perhaps there are more challenges ahead but we are all looking forward to 2022 with a renewed hope and resilience!

Don't forget, our support is always available, so feel free to call or text 087-6243367/087-9392148 or email: ikaclare@gmail.com, or message us on Clare IKA Facebook page.

Also, we encourage you all to keep up the fundraising initiatives. We urge anyone with any ideas to create your own online/virtual fundraisers in order to ensure the IKA vital services can remain for those who require it. We are very grateful for any support in these trying times. Thank you.

CONGRATULATIONS

Congratulations to branch treasurer Gerry Moran and his wife Martina on the recent arrival of their two grandchildren Grace and Thomas. Congrats also to Carmel McCormack on the arrival of her granddaughter Sophie. Best wishes to all.

FUNDRAISER

A massive 'thank you' to Mary O'Shea, mother to the late Clare IKA member Aisling O' Reilly who died last December 2020. Aisling was a great supporter of the Clare IKA, helping where she could. Mary raised a fabulous €400 selling all sorts of items at the Tuamgraney Car Boot Sale. All proceeds from the sale were kindly donated to the IKA

CLARE By NORETTA CLIFFORD

Clare branch, in memory of her beloved daughter.

SERVICE OF REMEMBRANCE & THANKSGIVING

Clare IKA wish to thank the IKA Liturgy Committee and all at Donor House for their role in preparing the recent Virtual Service of Remembrance and Thanksgiving Service – It was truly special. Many of us, forever grateful, lit candles to honour and remember our organ donors and their families.

A special mention to Co. Clare participant Kirsty Donnellan and her daughter Freya who carried the Book of Remembrance to the altar during the Service. Kirsty's daughter, Scarlett, who passed away unexpectedly in 2015, is now forever honoured in the Book of Remembrance. We thank Kirsty and her family for their bravery, kindness and generosity for sharing Scarlett's memory and spreading the word about organ donation. Kirsty also has raised funds over the past few years since Scarlett's passing for the IKA with her 'Yellow March' fundraiser.

Kirsty also recently spoke with Alan Morrissey, Clare FM about Scarlett, organ donation, fundraising and the 'delight and honour' to be asked to partake in the Service this year.

ENNIS 'GIFT OF LIFE' MEMORIAL

A reminder to all of the 'Gift of Life' memorial, located in Ennis, which pays tribute to organ donors



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and their families who have made the gift of life possible, recipients of transplants, and those waiting for a transplant. The memorial grounds encompass three themes:

Reflection: a place of reflection and contemplation for all those who have been touched by or support organ donation.

Recognition: where the kind and generous 'gift of life' can be recognised.

Remembrance: where all donors can be remembered with love.

Recently, Limerick branch IKA member, Mary Downes, visited the Garden and in her own words "found it such a peaceful and tranquil place and the simplicity added to the peace".

Thank you Mary for the kind words and the photo that you sent.

SYMPATHY

We extend our sincere sympathy to Mary Neylon and her family on the recent sad loss of their loved one Patrick J. Neylon, late of Miltown Malbay. PJ was an avid footballer with his native parish in his younger days. In 1985 and 1990 he went on to be a selector with the St. Joseph's Miltown Malbay football team that won the championship on both occasions.

His son Michael took up the realm and managed the team in later years. Michael followed in his father's footsteps when the team went on to win further championships. PJ loved to while away the hours spent on haemodialysis at UHL watching a good game of football or hurling. He was a great supporter of the IKA West Clare Walk and loved to travel to Kilrush to see the walk taking place. May his gentle soul rest in peace.

CHRISTMAS GREETINGS

On behalf of the branch we wish all our renal patients, transplant recipients, their families, the medical and nursing staff of the renal units, branch members and volunteers agus ár gcairde go léir san IKA, Nollag Shona agus an bhliain nua iontach. Enjoy the festivities.

By DERMOT GLYNN



Fiona Claffey, Dermot Milner TCTC, Dermot Glynn, Offaly IKA and Paul Reape TCTC.

The Offaly Branch of the IKA would like to wish all our patients, members' carers, volunteers and all the staff in the Tullamore Renal Unit a very Happy Christmas and Peaceful New Year.

TRANSPLANTS

Some good news on transplants within the Offaly branch.

June 21st is the longest day of the year and it was a happy one for Alison Leahy from Cadamstown. She received a kidney from her aunt and godmother Martina Leahy Troy. Congratulations and wishing you both good health in the future.

Phil Molloy of Kinnitty received a kidney transplant on August 20th, 2020 and exactly a year later her granddaughter was born. Saoirse Cordial was recently christened and Phil was delighted to be able to take part in the occasion.

FUNDRAISING

A big 'thank you' to the Tullamore Cycling and Touring Club (TCTC) who presented us with a cheque for €1500 following their 'Pat Colgan and Around the World four times in eighty days' cycling challenge. We are very fortunate to have the TCTC who support us on an annual basis. Hopefully we will all be able to meet up in Kinnitty next year.

Thank you to Joan and Ellie from Edenderry for their shop box contribution of €385.



Transplant recipient Kevin Galvin's aunt Bridget, who passed away in January 2021, bequeathed the sum of €20,000 to

the IKA Offaly branch. On behalf of our members we thank the late Bridget, from Cloneyhurke, Portarlington, Co. Offaly, for her generosity.

CONGRATULATIONS

lini Jacob and Sani George have been appointed as the first Renal Advanced Nurse Practitioners (ANP) at the Midland Regional Hospital, Tullamore Renal Unit. This can only be of benefit to all attending the Renal Unit.

Both ladies will be well-known to all patients in the renal unit in



Tullamore for their kindness and dedication. Well done to both of you. You can read more about their appointments on page 29.

GET WELL WISHES

To all our members that may be unwell at this time of year we wish get well soon and better health for Christmas and New Year.

On behalf of our branch Chairman Jerome Burke, I would like to express his sincere thanks to the doctors, nurses and staff for the exceptional care he has received during a recent stay in the oncology unit in Tullamore.

CONDOLENCES

We would like to take this opportunity to remember all our deceased family members and friends who have passed and more recently Mary Murphy of Clareen. Our sympathy to Mary's brother, sisters, the Murphy family and partner Paudge Mulhare. May she rest in peace.

Condolences to our Treasurer Mary Young and to her sisters Margaret Lambe, Bernie O'Brien and Patricia Steinegger on the passing of their brother Michael Neylor, RIP.

Stay safe and take care of one another.

Nollaig Shona Daoibh.







Lizzy Hayashida and Paul Hackett at their wedding in Portugal.

We hope that everyone in the county is keeping safe and well and that you enjoy the festive season as the new year rolls in.

James Dodd organised a succesful Golf Scramble at Nenagh Golf Club recently. Many people turned out for what was a very enjoyable event, held over a weekend, and which raised a total of €4,915 for the Irish Kidney Association. 'Thank you' James for your valued work!

TIPPERARY By ORLA HOGAN RYAN



At the prizegiving ceremony following the IKA Golf Scramble at Nenagh Golf Club are: Sean Minoque, Golf Club President; James Dodd (IKA), Ray Hurley, Dom O'Brien, Eamonn O'Brien, Sean McLoughlin, Captain and Michael Fitzsimons (IKA).

Ann Hackett, another active branch member, attended the wedding of her son in Portugal recently. Paul Hackett who received a kidney tansplant in 2017, wed Californian native Lizzy Hayashida who is now living and working in Dublin. Congratulations to the newlyweds.

Congratulations also to long serving and valued branch members Mary and Paul Adamson on their son Sean graduating from the University of Limerick with a bachelor's degree. We wish Sean, who is now working in London, a happy and successful future.



Paul and Mary Adamson with son Sean.

By KARL CRONIN

KILLANEY VINTAGE CLUB ANNUAL TRACTOR RUN

The annual Killaney Vintage Club Tractor Run took place on Sunday, October 31st with this year's proceeds kindly donated to the IKA Cavan/Monaghan Branch and the local Spina Bifida Association. The proceeds of the fundraiser were presented to both organisations in the Shirley Arms Hotel, Carrickmacross on Saturday November 27th.

This year saw over 70 tractors take part in the tractor run, as well as 20 vintage cars and a number of vintage motorcycles.

The branch wish to convey their sincere appreciation to the organisers, Delia and Niall Russell, for their support of the work of the IKA and wish all in Killaney Vintage Club a very happy Christmas and continued success into 2022.

CHRISTMAS GREETINGS



Delia & Niall Russell present a cheque for €2,075 to Karl Cronin, Cavan/Monaghan IKA Branch Secretar proceeds of the Killaney Vintage Club Annual Tractor Run.

We wish all our members, their families and all the medical staff in the Cavan Renal Dialysis Unit, a very happy Christmas and a happy and peaceful New Year.

WEXFORD By MARIE DONLON



Ben Kelly with his family, dad Pat, mum Veronica and sister Mya.

Ben Kelly from Gorey, who is on dialysis in Wexford, officially launched his comic *Braveman* at BBraun Wellstone Wexford Renal Care Centre on Friday, November 5th. The comic was created by Ben, in conjunction with Waterford Healing Arts Trust (WHAT).

Congratulations to Ben on his great achievement and thank you to

Patrick Brown for taking the photographs.

Kathleen Tomkins, again this year, organised a raffle/collection among family and friends and raised €3,020. Kathleen has done this every year without fail for the last number of years and we thank her and her family for all their hard work and dedication in fundraising for the



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Wexford Branch. It is very much appreciated.

We also want to thank Sulzer Ireland Wexford who donated their 'Split the Pot' collection of \in 313 to the Irish Kidney Association.

We wish all our members a very happy and safe Christmas and please God we can all resume our meetings in the New Year.



Ben with Dora Kent, IKA Wexford branch.

Ben with Claire Meaney, WHAT.



Ben in a dialysis room with Nurse Carolann Flynn

Ben with Catherine Nunan & Debbie MacDonald, BBraun Wellstone Wexford Renal Care Centre.

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We hope you are keeping well and safe, and getting ready for the festive period ahead. We wanted to take this opportunity to give you a small update on what has been happening in the Cork Branch over the last few months.

We have continued our monthly support meetings on Zoom and it has been a great way for people to stay connected during these strange and challenging times. It has been a place for people to express concerns and share experiences to help others. We have been able to have a variety of speakers such as Professor Liam Plant, IKA counsellor Aoife Smith, and talks on the renal

CORK By SALLY NAGLE

diet, skin protection from the sun, and so much more.

CORK BRANCH REMEMBRANCE AND THANKSGIVING MASS

Our Annual Mass of Remembrance and Thanksgiving took place last Sunday the 28th November. It was only attended by a small group of people who were organising and taking part in the Mass itself, for others it was live streamed. The Mass was a time to remember and thank organ donors, both deceased and living and their families for giving the gift of life to so many people. We would like to thank all the readers and gift givers for being part of the Mass.

If you would like to see the Mass you will find it on the IKA website ika.ie or on the Cork branch Facebook and Instagram page.

MONTHLY SUPPORT MEETING DATES

Winter/Spring branch support meetings will be held at 8pm on February 1st; March 1st and April 5th.

KERRY By THERESA LOONEY

Greetings from Kerry for the festive c

season. It was wonderful to be able to host so many families in our holiday homes this year and great news that they are to remain open over the Winter months. The break is so beneficial to so many of our kidney patients and their families. The

feedback we receive is extremely positive. Thanks to Glenross Caravan Park

Thanks to Glenross Caravan Park and Kenmare Golf Club for their recent donations. We would also like to take this opportunity to thank all those who made individual donations in memory of loved ones throughout the year. Without these valuable donations, it would not be possible to carry on the work we do.

We would like to extend our sincere condolences to those families who have lost loved ones recently. And we'd especially like to remember our dear friend and devoted volunteer for the Branch, Larri Templeton. Larri gave his time and help with so much enthusiasm and for this he will forever be remembered. Our sincere condolences to his dear wife Debbie and family. May he rest in peace.

We would like to take this opportunity to wish each and every one of you a very Happy Christmas and good health for 2022.



FOR DONOR CARDS FREETEXT DONOR to 50050

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THE MERITS OF FISTULAS VERSUS CATHETERS continued from page 59

the catheter becomes damaged or leaks, lie flat with your legs elevated. Place the blue clamp from the emergency pack above the leak as close to your exit site as possible and contact the unit immediately.

Remember – keep sharp objects such as razors or scissors away from your catheter.

In the unlikely event of your dialysis **catheter falling out**, lie flat with your legs elevated, place gauze or a clean towel over the area and apply pressure for at least 5 minutes or until the bleeding has stopped. **Contact the unit immediately**.

Never open the clamps or sealing caps between treatments.

If you feel or observe fever, chills, redness, swelling, pain at exit site or, feel generally unwell, **contact the unit immediately**, as you may have a catheter infection that will need to be treated.

LONG TERM RISKS OF CATHETERS

Catheters can cause a number of long-term risks including infection. Catheters that have been in place for a long time, may cause narrowing or blockage of the central veins in the body, interfere with the functioning of a fistula or cause swelling of an arm or the face. This is called central venous stenosis. If this occurs, it may be necessary to have a new line inserted.

Poor flow – Catheters may develop a small clot, at the tip, causing poor flow of blood in the line. This can lead to inadequate dialysis and result in you feeling poorly.

In rare cases, catheters that are in place for a long time can become embedded, making their removal very difficult.

Reprinted from Beaumont Hospital's Haemodialysis and Peritoneal Dialysis – A Guide for Patients.



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Mr. Mrs. Ms. FIRST NAME:							
SURNAME:							
ADDRESS:							
POSTCODE:	MOBIL	MOBILE:					
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 t wish to disclose				
Do you wish to receive our quarterly 'SUPPORT' magazine by Please tick 'No' if your household is already receiving it	Post? Or Email?	YES	NO 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				
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I subscribe to (sign up and accept) the Constitution of the Irish Kidney Association CLG (Company Limited by

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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.

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