

# SUPP RT



WINTER 2022



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# Editorial



**W**e continue to be extremely busy with counselling referrals and patient aid referrals at an all-time high, leading to delays in processing requests. As approved by the Board, three new part-time staff have joined the team in Donor House. A big welcome to Jackie Moore (payments); Edina Csibi (patient aid referrals) and Margaret Doyle (Counselling). We are already seeing delays reducing referrals and these new staff will also help ensure continuity of service (in case of annual leave / sick leave) as each area will now have a manager and a part time staff member.

We have also recruited two new part-time staff for the Renal Support Centre at Beaumont hospital, in Dublin following the sad passing of Patricia Mackenzie, a much loved and respected manager there. A big welcome to Colette Hawe and Agnes Matthews.

An initial inspection has been performed on the Renal Support Centre on the grounds of Beaumont hospital to start establishing what building work is needed to re-open it. So far, we have identified that window replacement, insulation and plumbing, are among the issues to be addressed.

A detailed project plan for re-opening has been prepared to bring to the Board for approval in December 2022. Already, though it is obvious substantial money will be required to reopen the Centre. So, in this magazine on pages 25 to 26,

you will find a survey to help us to find out your views and ensure we are acting in accordance with your priorities. We would really appreciate it if you would complete the survey either online or you can simply cut out the survey in this magazine, complete it and return by Freepost to Donor House.

Since the last issue, I visited Roscommon, Leitrim, Sligo, Donegal and Galway branches. Thanks to the volunteers who took time to meet me. It is obvious there is plenty of enthusiasm and energy. Once we recruit the new National Volunteer and Organisation Development Manager in the new year, we will hopefully be able to help the Branches run more events and provide more supports to members.

We had a very interesting online session on Shared Haemodialysis Care which allows patients to take more control over their own care. You can see details on pages 18 to 21.

We had an online session with the sports team and the first physical event took place in ALSAA, near Dublin Airport on Sunday, November 26th. Nineteen people have registered to go to the World Transplant Games in Perth, Australia (April 15th-22nd) so we are pleased that we will be sending a team there which presents a valuable organ donor awareness opportunity to showcase the success of organ transplantation.

The timing of these Games impacts on dates for Organ Donor



## FRONT COVER

**Peer Supporters who have lived experience of kidney failure in festive spirit on their final day of training for the pilot programme to be rolled out in 2023.**

Photo:

Conor McCabe

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Awareness Week 2023. With Board approval Organ Donor Awareness Week will take place between May 20th to May 27th, 2023.

The Irish Kidney Association continues to participate as part of the ODTI public awareness group on organ donation which also includes representatives from the Department of Health. As I write, The Government Cabinet has approved the publication of the Human Tissues Bill. We have written to the Minister of Health welcoming the Cabinet's approval to publish the Bill but have also requested amendments.

We are hearing encouraging news that the number of kidney transplants has increased this year from the lower numbers previously experienced since the arrival of COVID-19.

The 37th Service of Remembrance and Thanksgiving was shown on RTÉ One at 11am on Sunday, October 30th and once again was very moving and dignified. I am delighted to inform you the Board has approved a physical service next year which will take place on Saturday, October 14th in central Ireland at the Cathedral of Christ the King in Mullingar.

Our community continues to carry out major work in fundraising, which you will read about throughout this issue. Sincere thanks to all of you, we could not continue the work we do without your support.

The Board considered at length action required on the vacant

dialysis unit in Tramore which has been subject to vandalism. It is very unlikely at this stage that the unit will ever be used to provide dialysis. So, bearing in mind the severe housing crisis, with much reluctance, the Board has decided the unit should be sold with the proceeds re-invested in holiday activities.

A particular highlight for me this year was meeting with our group of volunteer peer supporters at their first training session. These people are so passionate and enthusiastic with such a wide variety of experiences and great ideas. By the time you read this, the group will have completed their eight days of training and will be ready to start accepting requests for peer support. We are seeing huge interest in this which augurs well for the future of the IKA. Full details of this cover story are on pages 6, 7 and 13.

Another special highlight was meeting representatives of Garda Síochána and an army sergeant whose late brother was an organ donor. You can read more details on pages 47 to 49 and pages 56 to 57.

So, another year draws to a close. So much has happened with much of society operating as if COVID-19 does not exist and lost opportunities to make participation in society easier for people with chronic illnesses. We have the terrible war in Ukraine. This is a stressful time for many people, facing into a difficult winter worrying about paying utility bills, missing deceased loved ones, making often difficult decisions about healthcare treatments. Our

healthcare professionals are under such pressure, yet they continue to work so hard on our behalf very often in very difficult circumstances (The Sligo dialysis unit being just one example).

It is said when there is trouble or sadness, always look for the people helping, you can always find them. This is where the IKA community shines.

There are huge strengths in our community. Our volunteers work so passionately to help others in such a wide variety of different ways. From serving on a Branch or the Board, to a wide range of activities. Our staff also care so much about providing quality supports to patients and their families. Together we are making a real and positive difference to the lives of kidney patients.

So, this Christmas, we hope you manage to rest and relax, enjoy the break and feel some peace, solace and serenity.

*Nollaig Shona agus Athbhliain faoi Mhaise Duit.*

**CAROL MOORE**  
**CHIEF EXECUTIVE OFFICER**



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# A Christmas Message

from the

## National Chairperson



Greetings to all members and friends of the Irish Kidney Association.

Since my appointment in July to the role of National Honorary Chairperson we have been very busy and there has been a huge demand on our services. We have employed extra staff to help us to keep apace with this heightened demand and continue to develop our services. I wish them well.

Our twelve Peer Support volunteers have undergone training and are now ready and eager to get started. Through their lived experience they can support others who are facing similar journeys. Thanks to Counsellor Aoife Smith for developing this very worthwhile programme.

I am happy to report that the development of our Renal Support Centre in Cork is progressing nicely, and we expect that it will be completed by early Spring.

I visited our Renal Support Centre in Dublin in November to establish what work needs to be done to recommission it for our patients when we take back possession of it from Beaumont Hospital early next year.

We recorded our 37th Service of Remembrance & Thanksgiving which was broadcast on RTÉ on October 30th. It was an honour for me to carry out the role of narrator at this very special and poignant occasion. I would like to thank everyone who participated on the day in the pre-recorded Service and all those who tuned in to watch it. I look forward to welcoming you to my local town of Mullingar in central Ireland next October for the 38th Service. It will be held in the Cathedral of Christ the King which has ample room for the large congregation that we expect will attend.

I wish my fellow officers, the Board of Directors, staff, our members, and supporters, a peaceful, healthy and happy Christmas.

**EDDIE FLOOD**





*From all of us!*  
*We wish each and every one of you a healthy, safe and*  
*happy Christmas and New Year*

## Christmas Opening Hours

Donor House  
 (IKA Main Office)  
 01 620 5306

Mon - Fri: 9.30am - 5.30pm

**CLOSED:**  
 Monday 26<sup>th</sup> December until  
 Monday 2<sup>nd</sup> January

Re-opening Tuesday  
 3<sup>rd</sup> January

Hotel Accommodation  
**(New Phone Line)**  
**01 690 8887**

If you require a hotel room in the Clayton Hotel  
 this season please contact us.

Renal Support Team  
 Mon - Fri: 9.30am - 5.30pm

**Emergencies:**  
 Mon - Fri: 7.00pm - 10.00pm  
 Sat - Sun: 12.00pm - 4.00pm

December 26<sup>th</sup> & January 2<sup>nd</sup>:  
 12.00pm - 4.00pm



IKA SUPPORT





The Irish Kidney Association (IKA) has always aimed to create an environment where peer support can be provided. COVID-19 interrupted a lot of our everyday activities that allowed us to connect with family, friends and other supports. It also meant a lot of our branch meetings and events had to stop. During this time the Board started to look at different ways to connect to people and decided to pilot a new online service, so that no matter where a patient lived, they could reach out and get support, and hence the peer support programme was born.

Aoife Smith, the IKA's National Co-Ordinator of Counselling Services reports on progress.



*The Peer Supporters team with Eddie Flood, the IKA's National Honorary Chairperson (front right) are: Front row (L-R): Sara Santi, Angela Sherlock; Second row: Sheila Hanevy, Jackie Whitaker, Mary Adamson, Sandra Collins Third Row: IKA Coordinator of Counselling Services, Aoife Smith with Collette Hawe, and Sally Nagle. Back Row: Joan Dobbey and Project Manager & Trainer Patricia Bourke D' Souza, Tiberius Pereira, Sarah Buchanan, Agnes Matthews Missing from the photo is Rachel O'Hara who is recovering from her recent transplant operation. (Photo by Conor McCabe).*

# A new era dawns for Peer Support in the IKA

As 2022 draws to an end and the festive season is upon us, December encourages us to finish the year strongly and put in place preparations to start the new year successfully. This is certainly how I am feeling as the peer support training has just been completed and we are preparing to open the referral system for patients early in the new year.

The excitement for this new service within the IKA is tangible with everyone I meet, and it has been a fantastic journey to be able to work with such great people, who

come from all over Ireland, along the way.

The training for our 12 peer support volunteers covered a wide range of topics.

Our **Induction Day** opened with a presentation from Carol Moore, our CEO, who talked about the importance and the need for a service like this for kidney patients. She spoke of how, from her experience in past positions, peer support can not only transform lives and really have an impact on individual people's personal lives but can also help campaign for

change in the healthcare system.

Patricia Bourke D'Souza, our peer support consultant, trainer, and Somatic Trauma Therapist, explained the value of a peer support service, looked at why we train and gave an overview of what the upcoming training would cover for the peer support volunteers.

On **Day 2**, Martha Griffin, Chair of the Peer Support in Mental Health Programme in Dublin City University and a Peer Educator with the Recovery College and her colleague Sean Keating joined us. Martha and Sean explored the role



of a peer supporter and the practices and actions that are important in becoming a peer. They talked about sharing experiences, strategies, and stories of hope.

Encouraging people to take responsibility for their life and recovery but encouraging people without doing things for them. Providing people with relevant information that might be needed. Helping people to build social networks and supporting people to ensure that their human rights are respected. They discussed the values of peer support, what it is and what it is not and showed how peer support is based in mutuality and equality.

Baxter Healthcare covered **Day 3**. Enfy's Thomas and Patrick Jolomba gave the peer support volunteers an overview of kidney disease, the different dialysis options and looked at the various resources and tools that were available for patients through their website.

The overview of our *Living Well* programme was **Day 4**. Our volunteer leaders of the programme, Joan Gavan, Cathriona Charles and Sheena McDonagh were there on the day to share their experience, tips, tools, and insights in the value of this course for patients.

**Day 5** was everything IT, from online forms, to Zoom, to database systems. The kind of day that most would not look forward to. However, to ease the pain, we had our very own IT specialist, Robyn Black, present on the day who made it very easy to follow and learn.

**Day 6** was back to Patricia Bourke D'Souza, with an overview of Trauma Informed practice. She started the day with a quote from Stephen

Porges, an American psychologist, author, and neuroscientist who said,

*'If you want to improve the world, start by making people feel safer.'*

This really set up the theme for the day. She spoke of the importance of becoming aware that so many people we talk to daily may be carrying past traumas of which we are completely unaware.

Trauma is the response to a deeply distressing or disturbing event that overwhelms an individual. She spoke of how for most people who experience a trauma that they can recover, they can get support, manage their symptoms and do well, but for others it may continue to affect their everyday life. Patricia provided a very informative day looking at the foundations of trauma informed practice, highlighting to our peer supporters the potential of trauma in another person, understanding the language of trauma, and the link between trauma and the brain.

She also discussed the supports peers may have available to them that they can draw on for additional support.

Patricia also delivered **Day 7**, where she focused on empathy, vicarious trauma (where the person providing support may get traumatised by hearing about the trauma), compassion fatigue, burnout and the vital need for self-care in every supporting role.

Our last day was our closing session where we got to meet in person again, evaluate the training, map out our next steps and take the beautiful photo you see on the front cover. Edward Flood, our Chairperson, made an appearance with words of encouragement and to

thank the volunteers for their commitment.

Here in the IKA, we are very aware of the value of a peer support service and that is why we have put a high standard of training behind the scenes for our volunteers. We wanted to ensure they had what they needed to provide the best possible service.

I would like to thank everyone involved in the training for their invaluable input, effort, and work in bringing the service to a delivery starting point. A special thanks to Patricia, whose wealth of knowledge and experience carved the way in the development of the service and to PuncHESTOWN Kidney Research Fund (PKRF) who were our major funder for the Peer Support programme. (see page 13 for more details).

I also say a huge **thank you** to the new team of peer support volunteers who have given their commitment, given their time, and given their energy to make this service possible.

I want to reiterate something that Carol said on the first day of training as I think it is quite fitting again as I write this article. 'By being here you are building on the values of the IKA which is all about volunteerism and helping patients. You are inspiring us and showing the very best of human kindness. *We really appreciate it and I hope we can reciprocate by providing you with the supports you need so that together we can make the lives of all patients in Ireland who have end stage kidney disease better.*'

I look forward to the next step!

*Aoife*

## HOW CAN I CONTACT A PEER SUPPORTER?

To talk online with a Peer Supporter please complete the Request for Peer Support form. The form is available on our website or by contacting the Irish Kidney Association. Once received we will contact you to confirm that we have an accurate understanding of your needs, and the best times for you to talk to someone. We will then match you to a Peer Supporter and arrange for your online meetings.





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

# COVID-19 AND THE FLU

## “The Swiss cheese approach to protection makes most sense”









As COVID-19 has faded from the headlines it remains a risk for those who are immune compromised, including people who have Stage 4 Chronic Kidney Disease, people who are on dialysis and organ transplant recipients.

In the beginning of the vaccine roll-out we were all very clear where we were at on our respective ‘vaccine journeys’ but as this year has progressed, the journey seems to have stalled for many.

For some, it has been a case of confusion (very understandable) over how many doses they should have whilst for others, the talk of a ‘new’ vaccine coming out in the Autumn led them to pause their vaccine journey over the summer to wait for it. This bivalent vaccine (essentially, the original vaccine with an added component to address the Omicron variant) is now the one being offered.

Some decided to wait for the flu vaccine to start rolling out so that they could get both at the same time. The need to wait four months between a diagnosis of COVID-19 and getting another booster has also thrown some people whilst others have just grown tired of the journey.

Whether you have paused your vaccine journey, or are unsure of where you should be on your journey, check out the image below for guidance and know that it is possible to take up your journey again no matter where you are on it.

WHAT IS MY COVID-19 VACCINATION COURSE?					
<b>65s and older</b> 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen		<b>Booster dose</b> ✓	<b>Booster dose</b> ✓	<b>Booster dose</b> ✓
<b>50s to 64s</b> 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen		<b>Booster dose</b> ✓	<b>Booster dose</b> ✓	
<b>12s to 49s</b> (with certain long term medical conditions; residents of long-term care facilities; and healthcare workers) 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen		<b>Booster dose</b> ✓	<b>Booster dose</b> ✓	
<b>12s to 49s</b> 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen		<b>Booster dose</b> ✓		
<b>12s and older</b> (with a weak immune system) 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen	<b>Additional dose</b> ✓	<b>Booster dose</b> ✓	<b>Booster dose</b> ✓	<b>Booster dose</b> ✓
<b>Pregnancy</b> 	<b>1st round of vaccination</b> ✓ 2 doses OR single dose Janssen		<b>Booster dose</b> ✓	<b>Booster dose</b> ✓	
<b>Children 5 to 11s</b> 	<b>1st round of vaccination</b> ✓ 2 doses				
<b>Children 5 to 11s</b> (with a weak immune system) 	<b>1st round of vaccination</b> ✓ 2 doses	<b>Additional dose</b> ✓	<b>Booster dose</b> ✓		

HSE National Immunisation Office | August 2022



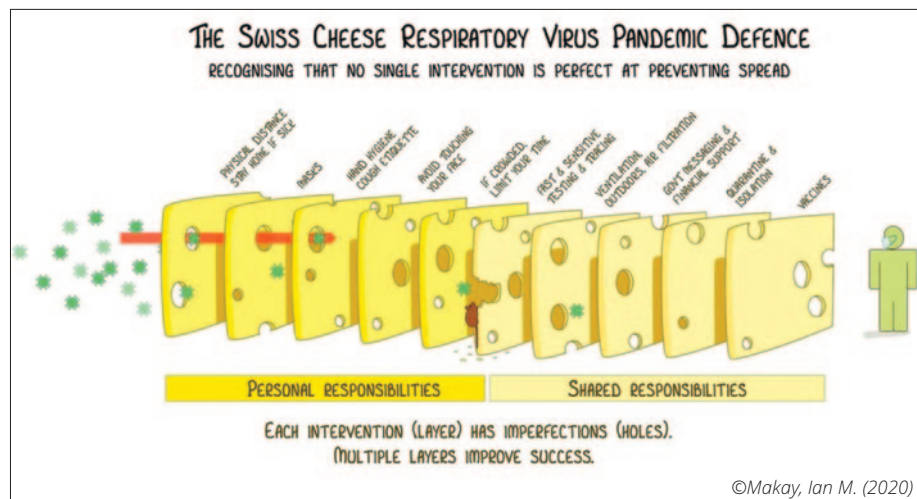


Now that the winter is here and our outdoor living of the summer has very much turned into indoor living, it is important to take stock and reflect on how best we can protect ourselves and our loved ones.

The Swiss cheese approach to protection makes most sense. There is no single step that we can take that will give us full protection. Instead, if we take a number of steps together we can minimise the risks.

The country has mostly moved on from the pandemic and the responsibility for protection against the COVID-19 virus has moved from societal to personal. We are all individuals and, as such, our perceptions of risk differ. As mentioned in the Autumn issue of this magazine, it is about balancing the risk of the virus and the risks of not engaging in activities that hold meaning in our respective lives.

During the pandemic we learned the value of regular handwashing and cough etiquette. As the festive season approaches, the shops are getting busier and invitations to social events may increase too. You



need to think ahead and decide your comfort zone. We cannot always control our environment but we can control what we do. Should you / could you wear a mask? Should you consider the ventilation before going? Is it worth considering when the quieter times may be in indoor public spaces?

#### HAVE YOU HAD YOUR FLU VACCINE?

Remember, it is free if you are a person at risk or if you are living with a person at risk.

[www2.hse.ie/conditions/flu/getting](http://www2.hse.ie/conditions/flu/getting)

#### -the-vaccine

Remember, if you are due a COVID-19 booster vaccine, you can get the flu vaccine at the same time.

You may be wondering where you can get your COVID-19 booster now that many of the centres have closed. This webpage [www2.hse.ie/screening-and-vaccinations/covid-19-vaccine/get-the-vaccine/](http://www2.hse.ie/screening-and-vaccinations/covid-19-vaccine/get-the-vaccine/) explains all.

As with all things medical, if you have questions, always consult your healthcare professional.



## WRITING TO YOUR DONOR FAMILY

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

From our experience the families of organ donors welcome and really appreciate this gesture. 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 a little 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 donor family through your local recipient co-ordinator who will then forward this on to ODTI. All correspondence is completely anonymous and identities are kept confidential.

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

Outlined below is some general information you may wish to include:

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

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

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

This may be the most difficult letter you will ever have 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.



# Looking back at 2021

## 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). It shares information on organ donation and transplantation activities in member states of the Council of Europe and beyond.

Before analysing the statistics, it is important to acknowledge the generosity of all organ donors and their families. Without them we would not have so many lives transformed and saved every year. The ripple effect of receiving an organ donation goes far beyond the recipient. It is the 'gift of life', the gift of time and the gift of more shared experiences.

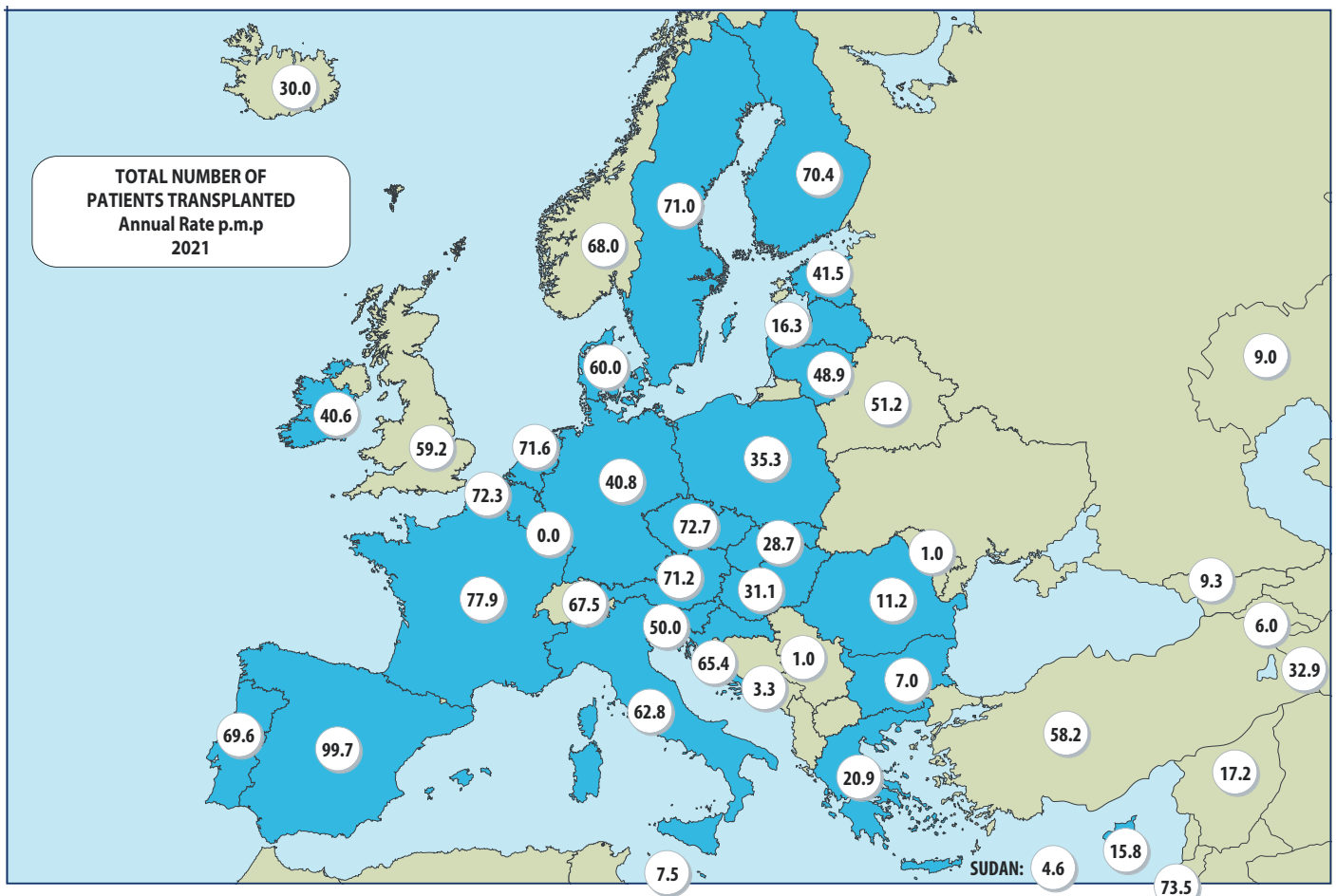
In looking back at 2021 I have chosen six European countries from the Newsletter to study as well as Ireland. I chose them based on their reputation and strength in particular areas as well as their comparative population sizes to see if there can be any lesson we can learn.

The figures need to be viewed through the prism of the COVID-19 pandemic. Consequently, when looking at the tables for **Actual Deceased Donors** and the **Total Number of Kidney Transplants**, you will see that I took advantage of this Newsletter for 2021 which includes figures for 2019 and 2020 also to provide context.

*The following definitions will help your understanding of the tables and interpretations given in this article.*

### ACTUAL DECEASED DONOR

A deceased person from whom at least one organ was recovered for the purpose of transplantation.





## DONATION AFTER BRAINSTEM DEATH (DBD)

This is possible from patients whose death has been confirmed using neurological criteria (also known as brainstem death or brain death). This is the more commonly known form of organ donation where the person has been on a life support machine.

## DONATION AFTER CIRCULATORY DEATH (DCD)

Previously referred to as donation after cardiac death or non-heart-beating organ donation, it refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria.

## PER MILLION POPULATION (PMP)

Using Per Million Population (PMP) figures allow us to make meaningful comparisons between countries.

## EXPANDED CRITERIA DONORS

Due to the shortage of organs available for transplantation, efforts to increase the donor pool are being explored. For example, by accepting so-called 'expanded criteria donors'. These include older organ donors,

donors with complicating diseases and non-heart-beating donors.

A baseline figure when looking to compare organ donation and transplantation activity in different countries is the number of organ donors per million population (pmp).

In **Table 1** we can see that in 2019 Ireland's rate of donors pmp was sixth out of the seven countries. Four of the seven countries saw a decline of over 20% in their donors pmp in 2020 when compared to 2019. We can see that although Ireland's donors pmp figure slightly recovered between 2020 and 2021, it was marginal when compared with the other countries.

We should not look at these figures in isolation. We have to consider the age profile of each population, the number of intensive care beds pmp and the number of deaths pmp for example, and we also have to look at the stories behind the figures. However, the figures in **Table 1** do raise an obvious question – Two years into the pandemic, what have the other countries done differently to Ireland that has seen their numbers recover

at a faster rate?

In **Table 2** we can see the total number of kidney transplants per million population for 2019, 2020 and 2021.

Again, we see the other countries performing at a higher level than Ireland in 2019 (significantly higher in some cases). However, Ireland's decline and subsequent recovery between 2020 and 2021 compares more favourably in percentage terms.

If we now look behind the headline figures, there are some interesting observations to make. For example, looking at how countries have been using **expanded criteria donors**, (**Tables 3** and **4**), we can see how this is impacting on their rates of organ donation overall.

**Table 3** shows the number of donors per million population above the age of 60. Spain's 21.9 donors over the age of 60 pmp is notable when compared with the other countries and highlights that rates of organ donation are influenced by more than just consent from donors and their families.

*continued next page...*

**TABLE 1**

Actual Deceased Donors pmp with change compared to 2019 and shown as a percentage			
Country	2019	2020	2021
Ireland	17.7	12.9 -27.1%	13 -26.6%
UK	24.7	18.4 -25.5%	19.8 -19.8%
Norway	21.3	18.9 -11.3%	17.5 -17.8%
Croatia	32	25.4 -20.6%	29.5 -7.8%
Spain	49.6	38 -23.4%	40.8 -17.7%
Austria	23.4	23.7 +1.3%	20.2 -13.7%
Netherlands	15.1	14.9 -1.3%	15.9 +5.3%

**TABLE 2**

Total Kidney Transplants (Living and deceased donors) pmp with change compared to 2019, shown as a percentage			
Country	2019	2020	2021
Ireland	31.9	25.1 -21.3%	27.8 -12.9%
UK	54.5	37.8 -30.6%	42.8 -21.5%
Norway	47.8	44.4 -7.1%	42.0 -12.1%
Croatia	32.9	23.9 -27.4%	30.2 -8.2%
Spain	73.8	57.7 -21.8%	63.2 -14.4%
Austria	43.9	37.2 -15.3%	34.0 -22.6%
Netherlands	55.6	47.3 -14.9%	53.3 -4.1%

**TABLE 3**

Actual Deceased Donors (>60 years) pmp in 2021							
2021	Ireland	UK	Norway	Croatia	Spain	Austria	Netherlands
Actual deceased donors (>60 years) pmp	3.6	6.6	7.8	No record	21.9	8.4	6.8



# ORGAN DONATION AND TRANSPLANTATION CONTINUED

**TABLE 4**

Kidney Transplants from Donation after Circulatory Death (DCD) in 2021							
2021	Ireland	UK	Norway	Croatia	Spain	Austria	Netherlands
DCD Kidney Donor Transplants pmp	3.2	12.9	0.0	0.0	20.0	0.7	17.5
DCD donor kidney transplants as a percentage of all deceased donor kidney transplants	15.4%	40.2%	0.0%	0.0%	35.6%	2.3%	64.9%

**TABLE 5**

Living Kidney Donor Transplants per million population in 2021							
2021	Ireland	UK	Norway	Croatia	Spain	Austria	Netherlands
Living Kidney Donor transplants pmp	7	10.7	12.2	1.2	6.9	4.7	26.3
Living Kidney Donor transplants as a percentage of total kidney transplants	25.2%	25.1%	29.0%	4.0%	10.9%	13.7%	49.3%

In **Table 4** we can see how the different countries are engaging with donation after circulatory death with particular reference to subsequent kidney transplantation.

Ireland started working in this area in recent years and 15.4% is a significant share of the overall number of kidney transplants from deceased donors. The Netherlands is a world leader in its use of Donation after Circulatory Death and again we see Spain featuring prominently as well as significant numbers from the UK.

Living donor kidney transplantation has become an increasingly more interesting option for people as the surgery for the living donor has moved to primarily being 'keyhole' meaning that recovery can be quicker. Also, with the uncertainty of the waiting list for a deceased donation, a living donation can bring more certainty.

**Table 5** shows the level of living kidney donor transplants in the seven countries.

It is interesting to see that living kidney donation features so prominently in the Netherlands whereas it is not as significant in Spain.

Thus, we can see that headline figures that often make it into the media do not tell the whole story. It is important that we look beyond the headlines at the component parts that make up the bigger picture.

In looking at how we can improve the rates of transplantation in Ireland, we can learn from the experience of other countries. As mentioned earlier, we should not look at consent rates for organ donation as the only source of change. It is certainly an area to address but, the above examples show that there are other avenues to be considered also.

Spain has clearly focused on building up donation from people over the age of 60 years as well as donation after circulatory death whilst the Netherlands has focused on donation from people over the age of 60 and living donation and the UK has focused on donation after circulatory death and living donation.

With an eye to the impact of the COVID-19 pandemic, it is interesting to note that in 2021 the USA carried out more than 40,000 organ transplants – the first time to reach this milestone in the nation's history.

Also, in 2022, they reached another milestone, they carried out their 1 millionth transplant.

(Source: [www.UNOS.org](http://www.UNOS.org))

In relation to organ donation, the discourse on the impending Human Tissue Bill discussion has put the focus on consent. In looking at the experiences of some of our neighbours, as shown above, it is important that the HSE and the government looks at resourcing these other areas too.

Extra staffing adding additional beds, operating theatres and equipment in organ retrieval and transplantation services are all needed. As we saw in 2021, with the Mater Hospital incident when an organ donation was not used, all areas must be resourced properly to increase the number of organ transplant operations.



For further information, please see [http://www.ont.es/publicaciones/Documents/NEWSLETTER%20TRANSPLANT%202022\\_baja\\_def.pdf](http://www.ont.es/publicaciones/Documents/NEWSLETTER%20TRANSPLANT%202022_baja_def.pdf)



## Who is PKRF?

**T**he PuncHESTOWN Kidney Research Fund (PKRF) is a registered Irish charity. It was founded by Kilcullen kidney transplant recipient James Nolan who is also a proud member of Transplant Team Ireland.

Since its inception, the PKRF has provided a wide range of support activities for people living with kidney disease, raising some €1,590,000 to enable this.

The Fund has supported many initiatives including: the landmark project – a state-of-the-art renal unit in Temple Street Children's Hospital; contributed to the refurbishment of the dialysis unit at Sligo General Hospital; provided support to continuous research programmes; and sponsored trips to ski camps for younger kidney patients.

The key PKRF fundraiser event is the last race of the PuncHESTOWN National Hunt Racing Festival each year which is a charity sweepstake horse race where amateur riders raise sponsorship money as well as creating much needed organ donor awareness.

James Nolan rode in the first thirteen runnings of the race and this year will be the 32nd anniversary of the event which will be held on Saturday April 29th. The PKRF is pleased to be funding the majority of the costs of this new online pilot peer support service.

The IKA is delighted to be working with PKRF again to deliver on a key strategic theme which will increase the range of services we can offer patients and their families.

## WHAT OUR PEER SUPPORTER VOLUNTEERS HAVE TO SAY ABOUT THEIR EXPERIENCE SO FAR:

*"Being part of the peer support training has been amazing, Aoife and all the IKA team have put so much effort into selecting a wide range of training to help us in our peer support role. I have also made some incredible friends and connections with the other peer supporters, who all have such amazing stories of their own. I am so excited for the peer support pilot programme to get started as I feel this is something I would have greatly benefitted from when I was first diagnosed with kidney failure, to have had someone who could be a listening ear at a very uncertain time for me."*

**- Sally**

*"When I heard the IKA were setting up a peer support group, I jumped at the chance to become a peer support volunteer. For the role, we had training from different people. The training has been fantastic, not only am I learning from those running the course, but I am also learning from my fellow peer support volunteers. We may all have our own stories, but we have quite a few similarities. It made me realise we are not alone on our journeys. By talking and listening to one another we are helping one another."*

*I chose to become a peer support volunteer because I wish there had been something like this in place when I was starting off, as sometimes it's easier to talk to another patient. I would like, as a peer support volunteer, to give hope to others and that they have a positive experience along the way."*

**- Angela**

*"I applied to be a peer supporter because I believe it's important for anyone who has an illness to be able to talk to people who have similar experiences."*

*In the case of those with ESKD, we are well provided with professional care, but sometimes you just need to chat on a different level."*

**- ANONYMOUS**

*"As a renal patient from childhood, I have lots of experience of renal disease/transplant from a patient's perspective. I volunteered for the Peer Support Programme as I would like to give back to the renal community and help other patients in any way that I can."*

**- Sheila**

*"My personal reasons for becoming a peer-to-peer supporter are about ensuring that the individual and families gets the information, guidance, and support that will help them to navigate the many hurdles that can sometimes exist with any long-term health condition."*

*Personally, I am really excited about taking on this role, and working with people together to explore a positive outcome. I learned to be attentive, truly listen, have empathy, embrace diversity, be resourceful, and continue seeking knowledge and growth in the peer supporter role."*

**- Sandra**

*"I firmly believe that those of us who have experienced ESKD should help others who are learning or new to the diagnosis or situation...To give advice, motivation and encouragement. I am looking forward to giving my 40 years' experience with ESKD as a Peer Support Volunteer, and sharing my experiences in the hope others will benefit from it."*

**- Jackie**



# Community rallies to support local teen



At the cheque presentation to Rachel O'Hora and Michael Dwyer of the Dublin East Wicklow Branch were: Councillor Michael Fleming, Tony McMahon, the owner of Johnnie Fox's, John Roe, Rachel O'Hora, Gerry Mulvey and Michael Dwyer.

**The plight of 18-year-old Cillian Doyle, who was hurtled into a world of kidney failure and dialysis in November 2021, was the inspiration for the close-knit community Glencullen, in South County Dublin, to raise almost €10,000 for the Irish Kidney Association. The whole community demonstrated huge support for Cillian as he struggled with his shock diagnosis, and were uplifted when news came that Cillian received a life-changing kidney transplant in August 2022, which ended his tumultuous nine months of sickness, exhaustion and three times weekly dialysis treatment.**

By GWEN O'DONOGHUE

Cillian's uncle John Walsh, who felt helpless with Cillian's plight, decided to show his support by organising a fundraiser for the Irish Kidney Association (IKA) to shine a light on kidney disease and the importance of organ donation for transplantation.



Cillian with Mick Dwyer

In planning an event early in the year, a Walk/Run with Dublin Mountain Running Club, to be held in September 2022, John generated widespread awareness. This quickly built momentum and inspired others to organise events for the same worthy cause.

One of these other events included Glencullen's first ever Tractor Run which took place on the day after the Walk/Run in September.

Earlier in the year the local Stars of Erin organised a mountain climb to show its support to Cillian, a valued and talented footballer in its GAA Club.

Glencullen village and its picturesque rural townland is on the slopes of the Three Rock Mountain in South County Dublin. Glencullen, is often associated with a popular watering hole and meeting point, Johnnie Fox's pub, the highest pub in Ireland.

On Saturday September 24th and Sunday September 25th the community came together in support of two fundraising events for the IKA and afterwards they stopped by at Johnnie Fox's for refreshments and some platters of food kindly sponsored by the pub's owner Tony McMahon.

In late October, a large cheque for the proceeds of the Tractor Run, €5,100, was presented to members of the Dublin





Olive Doyle,  
Cillian's mum



André Mooney with his  
portrait of Dutch footballer  
Virgil van Dijk



Olive Doyle and Noel Ward

East & Wicklow branch of the IKA outside Johnnie Fox's.

Earlier in the year, on April 2nd, was when Stars of Erin undertook its fundraiser for the IKA to show its support for its valued member and talented footballer Cillian.

Inspired by the 'Climb with Charlie' initiative, as all over the country people were climbing peaks for charities, members of Stars of Erin organised a Mountain Climb in their own locality. The idea to rally support for this Mountain Climb was first mooted by Jason Sinclair, a member of the Stars of Erin club who felt compelled to highlight the plight of people with kidney disease like Cillian, and the work of the IKA. Starting out in Glencullen village, the group travelled through Glencullen Adventure Park and then up Three Rock Mountain.

Not wanting to be left out of this activity, Cillian, although going through dialysis treatment, took part in the climb with his whole family including his grandad Sean Walsh. A raffle was held by Stars of Erin which raised €2,080 which was presented on a later date to Mick Dwyer, representing the Dublin East & Wicklow IKA branch. €1,000 of this amount was generously donated by

local shop owner Des Kennedy at Centra, Stepaside.

In support of the cause also, locally based, and popular artist André Mooney, who was moved by Cillian's story, donated a large print of one of his works, a portrait of Dutch footballer Virgil van Dijk, which raised a further €460.

Dublin Mountain Running Club held a 5k and 10k Walk/Run on Saturday, September 22nd, the day before the Tractor Run. The Walk/Run event was spearheaded by Cillian's uncle John Walsh and Noel Ward, who both run with the club, and it raised €1,885 which was later presented to Bernie Dwyer, Chairperson of the IKA Dublin East & Wicklow Branch.

The successful Glencullen Tractor Run, held on Sunday, September 25th, was organised by local man Gerry Mulvey. Months before the event, Gerry, a vintage tractor enthusiast, resolved to do his bit in support of his friend Derek Doyle's son Cillian by organising the first ever Glencullen Tractor Run with a convoy of 65 tractors, vintage and new. Gerry and his own son Adam each took their tractors for a spin in the event.

Cillian's uncle John Walsh, who was responsible for kickstarting all the fundraising initiatives, along with Cillian's brother Sean, also drove tractors in the convoy. John, a sheep farmer, took his John

Deere out for a spin while Sean was given a loan of a tractor by John Murphy (fondly known as big John), a farmer from Bohernabreena.

Attending the Tractor Run with his son as spectators was Cian Pearson who gifted to Cillian a prize of a trip to the Bike Park Sicily in Italy which he won at the Irish Downhill Mountain Bike Series Round 3, held at Glencullen Adventure Park in September. Cillian, and his friend James Smith were delighted to travel to Italy in late October and to enjoy the 5-day trip to Bike Park Sicily and take in some sightseeing also.

Both the Tractor Run and the Dublin Mountain Running Club Walk/Run events were well

*continued next page...*



Cillian's uncle John Walsh, Dublin  
Mountain Running Club presenting  
a cheque to Branch Chairperson,  
Bernie Dwyer



## Community rallies to support local teen continued

supported and demonstrated the huge level of community spirit and goodwill for young Cillian as he recovered from his kidney transplant operation.

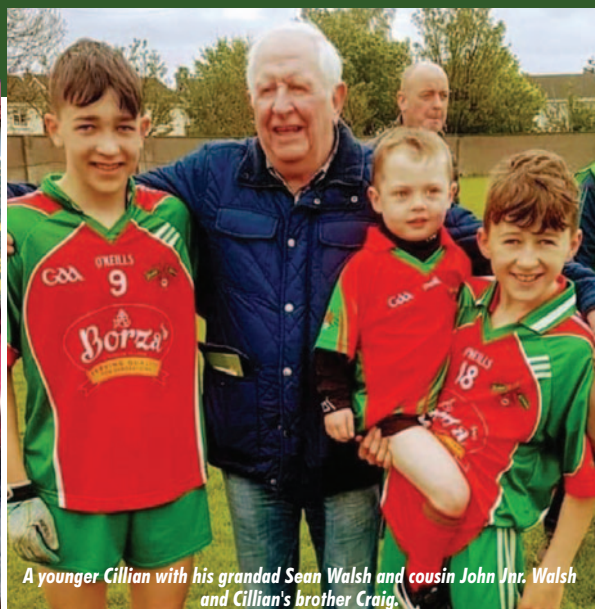
The Doyle's, are a well-known business family in Glencullen and Cillian's parents, Derek and Olive, run a Plant and Machinery business there.

Cillian's mother Olive said that she was overwhelmed with the level of support received from the community. In describing Cillian's rollercoaster past year, she said, "Prior to us receiving Cillian's shock diagnosis, he had been complaining about indigestion and we thought it was reflux. He has always been passionate about sport, any sport really, but enjoyed trial and mountain biking and football with the Stars of Erin. While playing in matches he would find himself coming off to get sick and going back on again when he got a chance to rest. Even with these interruptions to his game, he was performing really well and scoring goals for his team.

"It wasn't until one day last November that I had to take him home early from 5th year at school as he was feeling really unwell with indigestion and nausea. I brought him to



Noel Ward, Mick Dwyer and John Walsh outside Johnny Fox's



A younger Cillian with his grandad Sean Walsh and cousin John Jr. Walsh and Cillian's brother Craig.

our GP who initially thought he might have acid reflux but as a precautionary measure took blood samples. Within 24 hours the lab phoned to say that Cillian had to be taken to Vincent's Hospital immediately pointing to the likelihood of total renal failure. He was immediately taken under the care of Consultant Nephrologist Dr. John O'Regan who confirmed Cillian was in end stage kidney failure and had IgA Nephropathy. Within a matter of hours a line was inserted for dialysis and Cillian began his treatment the very next day. He continued to travel to Vincent's for his three times weekly treatment and then was transferred to the Beacon in Sandyford.

"While the dialysis treatment was keeping him alive he felt exhausted on

the days in-between it. He missed a lot of school and it halted his sports participation. It was such a shock for all of us. One day our seemingly fit and healthy son was suddenly beginning a new life of uncertainty, hospital dialysis treatment, and not knowing how long it might continue for until he might get an organ transplant.

"We feel fortunate that his wait for transplant wasn't long as he was only waiting for less than nine months. We are deeply grateful to the family of an organ donor who made it possible for Cillian to resume a normal life. Although he experienced kidney rejection initially and was very sick for the first few weeks post-operation, he is now thriving and at the beginning of November he returned to school.

"He has missed a lot of

school and is now in 6th year but I really don't worry about that. I am just grateful to have my son back to enjoying good health and being happy, as that is more important than anything else. He is easing his way back into sport taking the advice of Consultant Nephrologist Dr. John Holian whose parting words after Cillian's check-up post-transplant were, "Cillian get out and live your life, play sport within reason and get yourself a kidney belt. This advice and the prospect of being able to resume sport with his kidney protected by a belt, offers him, and us as a family, huge relief, encouragement and hope for a happy future."

Speaking about the community effort and compassion shown towards Cillian, Olive said, "we feel overwhelmed and will be forever grateful to



Gerry Mulvey



Cillian's cousin John Jr. on his dad John Walsh's tractor





the whole community of Glencullen that has rallied together to show their love and support from the time Cillian was diagnosed on November 24th, 2021. Even before the amazing fundraisers began people were dropping dinners to our door as we tried to shield Cillian and ourselves from COVID-19.

"I can honestly say that the goodwill and kindness that we have received from the whole of the Glencullen community and even those from outside who supported some of the fundraising events, helped keep Cillian and our family uplifted over a time of great upheaval.

"While we will never know who they are, the family of Cillian's donor kidney will be forever in our thoughts and we are deeply humbled to have received such a precious 'gift of life' from a stranger. We will be lighting a candle to remember Cillian's donor all through Christmas.

"The whole experience demonstrates the enormous goodwill that abounds which is life affirming."

Bernie Dwyer, Chairperson of IKA Dublin East & Wicklow Branch, from Cabinteely, said, "I would like to thank the Doyle family for allowing Cillian to be the focus and inspiration for the fundraisers, collectively raising close to €10,000 which goes directly to the IKA. This considerable contribution will help our registered charity continue its vital work in providing services and supports and advocacy for kidney patients, like Cillian and my husband Mick, and their families.

"Another really positive outcome from Glencullen's community effort is that it increased organ donor awareness. It is truly heartening and uplifting to see how the community rallied together for one of its own, and a shining example of humanity at its best. On behalf of the IKA I would like to thank every single person who played their part in supporting any of the events, through organisation, taking part, donations, and sponsorship.

"Finally, I would like to wish Cillian the very best as he starts his new journey in life and continued good health."



WINTER  
*giveaway*

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*Every little helps*

**'When times are tough, joy matters more than ever. We Stand For Joy'.**

These are the themes for **TESCO** Ireland's advertising campaign this Christmas.

Our friends at **TESCO** Ireland would like to spread a little joy amongst the renal community by generously sponsoring a prize giveaway to the value of **€500** in this issue of *SUPPORT*. As **TESCO**'s well known slogan says **Every Little Helps!**

Ten lucky readers who enter the prize giveaway, will each receive a **TESCO gift card** worth **€50** to use online or in any one of their 162 stores nationwide, across all their departments including food & drink, lifestyle, homeware, electrical, stationery, toys, and fashion.

Celebrating 25 years in Ireland, **TESCO** Ireland employs over 13,000 people across the country. Supporting local suppliers is central to **TESCO** Ireland's business ethos as it sources from 500 Irish food and drink suppliers and supports over 13,000 farm families nationwide. Sustainability is important to **TESCO** Ireland's setting its own operations a target of net zero by 2035.

In 2021, six-year-old kidney transplant recipient Ellie Collins, from Limerick, was selected as the winner of a competition to illustrate a toy elephant which she called **'Ellie the Elephant'**. Her winning entry was developed by **TESCO** Ireland into a plush toy which was on sale in its stores with all proceeds going to the Children's Health Foundation, supporting sick children and their families. This year's winner's toy, **Monty the Monkey**, went on sale in **TESCO** stores on November 26th for €5.

To be in with a chance to win a **€50 gift card**, email [robyn@ika.ie](mailto:robyn@ika.ie) with your name, address and phone number making sure to include **TESCO JOY** in the subject line of your email. Ten winners will be selected at random. So go on, get your entry in, and you could be a winner! **Closing date for receipt of entries is Monday 9th January, 2022.**



# What is Shared Haemodialysis Care

On October 26th, 2022, the **IRISH KIDNEY ASSOCIATION** hosted a free talk on shared haemodialysis care which was held via Zoom. Our guest speaker, **TANIA BARNES**, is shared haemodialysis Care Strategy Director and Trainer with Kidney Care UK

Those attending learned the definition of shared haemodialysis care, the importance of a good relationship between nurses and their patients, the training involved, as well as the key benefits from shared haemodialysis dialysis care.



By **JESSICA BRIEN**



## WHAT IS SHARED HAEMODIALYSIS CARE?

**S**hared haemodialysis care (SHC) acts as the middle ground between obtaining renal care at home and in hospital. It involves patients contributing towards their care. This could be by doing something as small as weighing themselves, or as big as inserting the needle by themselves.

SHC gives patients the opportunity to exercise both choice and independence. Patients can experiment with their dialysis and consider what they are comfortable with and what they are not comfortable with.

Shared haemodialysis care allows patients to take control of their own treatment. It is about supporting and working *with* people, not *for* people.

## THE IMPORTANCE OF A GOOD RELATIONSHIP BETWEEN NURSES AND THEIR PATIENTS

Shared haemodialysis care involves the support of hospital staff. The trust staff and patients have in one another serves to increase patients' confidence. SHC is about bridging the gap between patients and staff. The goal is to teach for full patient independence. This facilitates and enables patients, encouraging them to be more active. It is still care, whether it is providing hands-on, teaching, or both.

Shared care is not about getting patients to perform the work of the staff. It is not about cost-saving or pushing patients into doing home dialysis. Some individuals do not like mixing their dialysis with their home life, or fear that the treatment will lead to further isolation. Shared

care does not involve forcing or coercing anyone into doing anything they are not comfortable doing. **The emphasis of shared care is on choice.**

SHC involves discovering what motivates people in order to understand why and how shared care could improve a patient's experience of haemodialysis. The extent of shared care is entirely up to the patient. It is a very flexible system. Everyone is motivated differently.

## WOULD YOU LIKE TO BECOME AN EQUAL PARTNER IN YOUR CARE?

### TRAINING

Training involves a two-day Nurse workshop which takes place online. The foundations of shared care are explored before nurses can develop plans for their team. There are network meetings every couple of

months for those who wish to be involved, giving them the opportunity to ask further questions.

Training occurs in small steps in order to develop patient confidence. It's a very nurturing experience for patients. It doesn't matter how long it takes each individual to learn. Help will always be there. There may be times when a patient does not feel like participating in their care, in which case the nurses will take over. Sometimes people take breaks and pick it up again when they feel better about it. This is all part of the process.

#### WHAT DOES A SHARED CARE UNIT LOOK LIKE?

In a successful shared care environment, there is support available from

- Managers and dedicated people involved.
- There are links for shared care for pre-haemodialysis and home haemodialysis available.
- There are regular conversations regarding health and a can-do attitude by all involved. Patients are involved as educators also.
- Peer work involves patients supporting one another.
- Networking is commonplace to improve and share the good practice.

#### WHAT WERE THE KEY FINDINGS OF A SHARED CARE STUDY?

1. People who are supported to take care of themselves have **better experiences and outcomes**, e.g., happiness, independence and the gaining of knowledge.
2. Many patients consider engaging in shared care for a number of reasons, such as: being motivated by seeing others participating in their own treatment, wishing to **understand** their own treatment, gaining an aspect of **control** over the situation, wanting the chance to dialyse at home, seeking **independence** or to occupy oneself rather than waiting for the nurses. Another incentive is the ability to needle one's own fistula when on holiday.
3. **Consistency** amongst staff is important for the success of shared care.
4. Considering patient's **different learning styles** is necessary. Some prefer step-by-step instructions whilst others prefer a physical demonstration.
5. It is important for patients to **be aware of their own limitations** without allowing this to hinder their progress. Slow and steady wins the race!
6. **Setting goals** between a patient and staff can improve **partnership, friendship and trust**.
7. **Job satisfaction** is a benefit for nurses as they see improvements in their patients following some encouragement.

## IN PRACTICE: THE EXPERIENCE OF NURSES AND PATIENTS

### DONNA PIKE

Donna has worked as a renal nurse in Derry for the last 14 years. Many of her patients felt a loss of control and a lack of independence upon starting dialysis. Some patients expressed feeling that hospital staff had taken over making decisions over their healthcare. Donna wanted to help her patients and attended a seminar about shared care. She noted several obstacles including staff resistance to change and time constraints. Donna attended the shared care course in 2017.



Donna Pike

Donna began SHC with one 36-year-old patient who was a mother of two. She had been on dialysis for six years. She was offered three kidneys but refused them. She did not see the benefits of not being on dialysis. Her patient was a quick learner and keen to gain new skills.

After a few months, she transformed into an independent patient, monitoring her own blood results and inserting her own fistula. She understood the connection between her diet and her blood results. There was great improvement in her phosphate levels, and her fluid levels dropped. She spoke as an equal to the nursing staff and was comfortable correcting them when necessary. She then started to take an interest in other patient's treatment and care. She began recruiting new

members. Donna was bursting with pride.

Following an issue with her fistula, the patient finally made the decision to get back on the transplant list. She got a call just two weeks later. She swears shared haemodialysis care saved her life. This experience encouraged Donna to keep helping her patients and suggesting they begin shared care. Donna now educates staff and students to prove this is a service that must be provided.

Donna has adapted her teaching methods to meet patients' needs. Donna strives to grow this in her unit, to develop upon development and support patients on their shared care journey.

### ALCEINA O'BRIEN

Alceina was diagnosed as diabetic 26 years ago and she has been on dialysis in the Wellstone Clinic in Galway for the last three years. She has been on the transplant list for a pancreas and kidney for the last four years. She attended Tania's programme on shared care.

Alceina was excited about this as she came from a medical background and felt like she was maintaining her career on the other side of the fence as a patient. She was a qualified midwife and previously worked with nursing students.

Gaining knowledge about her treatment took time. She got to know her own body and how she reacted to things. She learned what helped her the most. Alceina filled in a questionnaire before the programme, so she felt she was 'on the same page' and became engaged from the very first session. Alceina encourages other patients to give feedback as to what they like and what they don't.

Alceina believes whatever a patient wants to get out of their sessions is totally acceptable as the programme is

contd...



## WHAT IS SHARED HAEMODIALYSIS CARE? CONTINUED...

patient-led.

Alceina felt more comfortable speaking with her peers after attending the programme. Her goal was to take what she learned and reach out to other patients. "Sharing this knowledge can uplift other patients. Shared understanding is invaluable to the patient experience. It gives patients autonomy and a voice." Following her experience, Alceina hopes to pursue patient advocacy work in the future.

### EMER KENNY AND ANN MARIE LEONARD

Nurse Emer and dialysis patient Ann Marie shared their experience at St. Vincent's University Hospital. Although Emer is her nurse, she has said she views Ann Marie as both a friend and a colleague. Emer attended the course and began incorporating shared care in the dialysis unit last July.

Ann Marie was diagnosed with chronic kidney disease when she was thirteen years old. She has been dealing with her condition for over thirty years. She felt she had lost control. Her whole week revolved around dialysis, which resulted in low mood. Emer noticed this and suggested shared care. Ann Marie was hesitant at first but decided to try it. Ann Marie surprised herself with her abilities. She paid more attention to her fluid levels. Having a say in her treatment was really beneficial for Ann Marie. She has felt supported during this process, and more confident in herself. Ann Marie wants to encourage other patients to ask questions. She wants to remind patients they can do as much or as little as they want to.

### HOW DOES THIS DIRECTLY AFFECT THE PATIENT?

When working with nurses to do the various steps in the dialysis process, there is the development of a connection and better relationship with hospital



Tania Barnes

staff. This keeps patients active and stimulated. It enables patients to give back – they may want to help the nurses or feel they are doing something of use within the unit.

Patients may opt to begin shared care as they will become a part of a team, they will ultimately have more control over their own treatment, they will have a larger range of choices based on their understanding, while creating more options for themselves in the process. This may change the way a patient views their dialysis treatment.

### CONCLUSION

The vision for the future is that all people who receive dialysis at centres will have the choice and information to participate in aspects of their teaching. It may sound daunting doing something new, but it is worth giving it a go to see how they feel about it.

Shared care is valuable as it changes people's lives, empowering patients for the better. The emphasis of shared care is not on the tasks completed, but on the partnership developed between a patient and healthcare professionals.

Hospitals interested in contacting Tania Barnes about Share Care can contact her directly at the following email:

[tania.barnes@nhs.net](mailto:tania.barnes@nhs.net)

Further information and resources on how staff and patients are taught, and patient stories, can be found at <http://www.shareddialysis-care.org.uk>

You can watch the Irish Kidney association zoom event at <https://youtu.be/Tayomp6SHdQ>



Ann Marie Leonard and Nurse Emer Kenny

# SHARED HAEMODIALYSIS CARE?

At the recent webinar on Shared Haemodialysis Care one of its participants, **ANN MARIE LEONARD** from the Dublin South Branch, shared her personal experience. Here she gives a written account of her experience with Shared Haemodialysis Care.

**M**y name is Ann Marie Leonard. I am 45 years of age and I was diagnosed with SLE (LUPUS) in 1989 when I was 12 years old. In 1990 it attacked my kidneys, so I've had a lifetime of kidney deterioration. Throughout the years I've had snippets of conversations about dialysis (and transplant) but, in my mind, dialysis was always something in the future. But in 2020 that day arrived for me. In clinic my ANP nurse Emer Kenny sat with me and said 'Ann Marie it's time to start dialysis'. It came as a shock even though we had spoken about it previously. I was full of fear and worry about what the future would be like.

In July 2020 I started training for PD (Peritoneal Dialysis). I thought this would suit me best as I could still go about my daily life and just do my dialysis at home at night. In September I was fully trained and, as my catheter had been fitted previously, I was now ready to start. My PD nurse Rita came to my home and set me up for my first night. PD doesn't work for everyone and I soon found out it wasn't working for me!

So, in December 2020 I went to theatre and had a neckline fitted and was taken to the dialysis ward after recovery for my first haemodialysis (HD) session. Emer called to the ward to see me and I couldn't speak to her without crying. I was so upset about the unknown, the line hanging from my chest and being told not to get the line wet. How would I shower? I can't go swimming? I felt like I had finally lost all control over my life and felt so down and depressed.

Emer has become my rock throughout the years and always speaks to me straight and I can talk to her about anything. She sat with me and listened to all my concerns and worries and helped me find a way to overcome them, as she always does. Her famous line to me is 'Ann Marie you have to live'. She even found me a dressing to wear in the shower and when swimming.

Then one day as I'm sitting in

dialysis Emer comes in full of the joys of life....'Ann Marie how would you like to do Shared Haemodialysis Care' (i.e., participate in my own dialysis). Straight away I said 'NO'. I had watched the nurses in awe at how they had connected me to my machine and fixed any alarms during my treatment. I thought I'd never be able to do that!!

But after a bit of persuasion, I agreed to give it a try. There was no commitment so if I didn't like it I could stop at any time. I had nothing to lose!

The first day I arrived at my dialysis unit I had a feeling of excitement, nervousness and self-doubt, all at once. Emer met me in the waiting room and said 'let's do this' and then explained the eight steps to me.

## STEP 1: WEIGHING MYSELF

Emer explained why we weigh before and after treatment and why it's so important to stick to our fluid allowance. It was important to understand if I had weight gain from food or whether it was extra fluid.

## STEP 2: TAKING MY OWN BLOOD PRESSURE

Emer explained that my BP reading can affect how much fluid (UF GOAL) we would remove.

## STEP 3: HAND WASHING

Learning how to wash your hands properly. Your hands can never be too clean!

## STEP 4: OPENING YOUR PACK

I was shown each component and explained its purpose as well as the importance of keeping all components sterile.

## STEP 5: CONNECTING TO MACHINE

I learned all the different parts and compartments of the dialysis machine and how to connect the lines.

## STEP 6: DISCONNECTION

I learnt how to take myself off the machine.

## STEP 7: ALARMS

Learning about alarms and how to fix them and know when to call the nurse for assistance.

## STEP 8: LINING AND PRIMING

How to line your machine with the bloodlines and dialyser, and how to strip it after treatment and disinfect it.

Once trained up I found myself looking forward to coming to dialysis and my confidence slowly returned. There was one girl doing shared care before me and I found myself asking Emer how long it had taken her to learn the steps and be confident enough to be doing her treatment by herself, but Emer wouldn't tell me. Instead, she told me 'It's not a race and there is no time frame or pressure. Everyone moves at their own pace'. When the patient and nurses feel that the patient is competent and comfortable doing each step by themselves then the patient is ready. The patient can complete as many or as few of the steps as they wish to on any given dialysis day.

It is important to state that shared care is **NOT** about easing the workload of nurses or reducing staff. Instead, it's about giving the patient back some control and input into their own individual care as well as educating the patient on their treatment and letting them be involved as much, or as little as they wish. I still have days when I don't feel up to doing my treatment or might be feeling unwell and the nurses will take over straight away without hesitation.

I can't thank Emer Kenny enough for giving me this opportunity to take back control of my life and for all the guidance and support throughout the years. Also, I want to thank all the nurses in St Vincent's Hospital dialysis unit for their patience and support whilst training and for the care, they continue to give to me and dialysis patients each and every day. I also want to thank Tania Barnes from the UK who conducts so many training courses and training days for both patients and staff in shared haemodialysis care.

If you would like to contact Ann Marie or Emer for advice. Email [amoleonard77@hotmail.com](mailto:amoleonard77@hotmail.com) or [ekenny@svhg.ie](mailto:ekenny@svhg.ie)



Oral Health is an essential part of our overall health and wellbeing. It allows us to speak, smile, touch, chew, laugh, taste, and swallow and increases our self-esteem, and confidence.

Like kidney disease, oral diseases such as tooth decay and gum disease affect all age groups, both men and women.



By **ETAIN KETT, MPRII**  
Public Affairs &  
Communications Manager  
Dental Health Foundation

# Oral Health Kidney Health

**T**here is a lack of awareness of the seriousness of gum disease and the health problems associated with it. In fact, gum disease has even been described as a silent epidemic which effects eight out of ten people over the age of thirty-five.

There are two types of gum disease. The first type, gingivitis, causes redness and swelling of the gums. If this is neglected it may advance to the second, more serious type of gum disease, periodontal disease. This causes inflammation around the tooth with the gum pulling away from the teeth, leading to tooth loss. It is the sixth most prevalent health condition globally, and evidence suggests that it has associations with many non-transmittable diseases including kidney disease due to chronic inflammation.

Lifestyle choices that may increase the risk of severe periodontal disease are poor oral hygiene, a poor diet, smoking and not visiting the dentist for frequent check-ups.

One of the first symptoms of gum

disease that you may experience is bleeding gums, healthy gums don't bleed after brushing your teeth.

Recent research suggests that even a modest reduction in gum inflammation may benefit kidney function. Gingivitis can be reversed by removing plaque build-up on the teeth and below the gum line.

## 3 STEPS TOWARDS GOOD ORAL HEALTHCARE

- Brush your teeth twice a day for 2-3 minutes using a gentle circular motion. Use a soft/medium toothbrush and fluoride toothpaste 1450 parts per million (ppm) - spit it out after brushing, don't rinse with water as this only washes the protective fluoride off the teeth. Fluoride helps keep your teeth strong and mouth healthy. Replace toothbrushes about every three months, or sooner if the bristles are worn. A worn toothbrush won't do a good job of cleaning the teeth.
- Flossing between the teeth will help clear plaque and food debris from

between the teeth, preventing a build-up that can lead to tartar.

- The third essential step is visiting the dentist for regular check-ups, every 6-12 months. Your dental team can detect and treat cavities and gum disease before they become serious, and give a professional cleaning 'scale and polish' to scrape away any tartar. They will also give you advice on the best toothbrushing and flossing techniques. Always let your dentist know if you have kidney disease so that they can support you with optimal oral hygiene.

A side effect of many medications, including kidney medication is dry mouth which increases the risk of tooth decay. Be mindful not to suck sweets regularly e.g., mints, boiled sweets. Although this may give temporary relief it will cause severe tooth decay in the absence of saliva. Avoid fizzy drinks, sugary tea, and also sugar-free drinks, as their acid content may cause tooth erosion. Sipping water will help or chewing sugar free gum will offer relief.

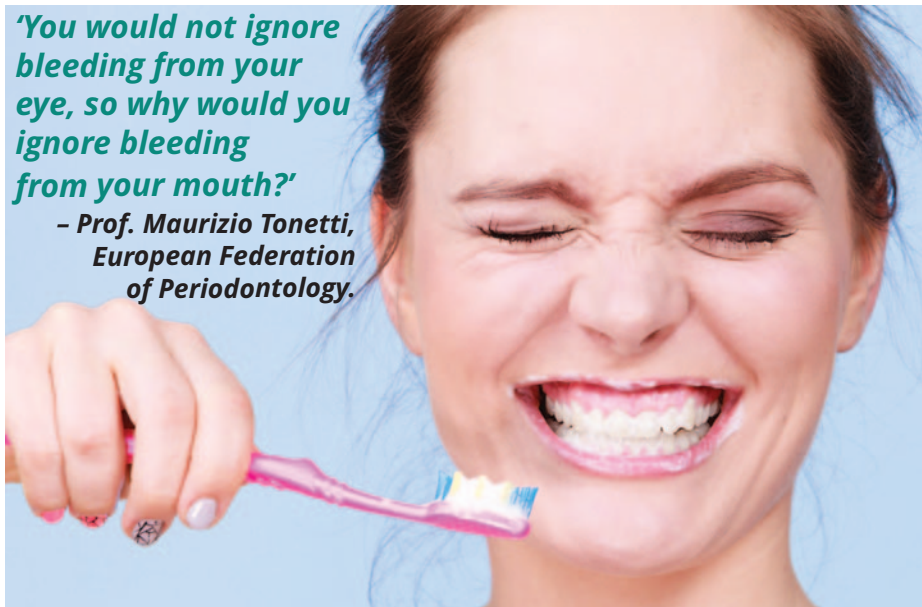
Kidney disease weakens the immune system, and you may be more prone to infections. Before you receive any dental treatment, make sure to give your dentist a list of your medicines, especially immunosuppressants, as these reduce your ability to fight infections. Your doctor may recommend antibiotics before starting treatment.

If you are on dialysis, schedule your dental treatments on the day after a dialysis treatment due to the risk of bleeding. Talk to your doctor and dentist for further advice.

Remember that gum disease is preventable, so keep brushing those pearly whites and improve your quality of life.

**'You would not ignore bleeding from your eye, so why would you ignore bleeding from your mouth?'**

**- Prof. Maurizio Tonetti,  
European Federation  
of Periodontology.**



**For further information on looking after your oral health please see [www.dentalhealth.ie](http://www.dentalhealth.ie)**



## SUPPORT THE WORK OF THE IKA

**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: *(Please print all information clearly)*

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_ Ph: \_\_\_\_\_

PLEASE CHARGE TO MY / OUR ACCOUNT: Name of Account: \_\_\_\_\_

IBAN:                      Bank Identifier Code - BIC:

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

My regular ☐ Monthly ☐ Quarterly ☐ Yearly DONATION of Amount € \_\_\_\_\_

*(Please tick as appropriate)*

to start on Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

#### AND CREDIT TO THE FOLLOWING ACCOUNT:

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

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

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



**Please post to: THE IRISH KIDNEY ASSOCIATION CLG, DONOR HOUSE, BLOCK 43A, PARKWEST, FREEPOST, DUBLIN, D12 P5V6**  
(PLEASE DO NOT POST TO YOUR BANK) CHARITY REG. NO. 20011260

## THANK YOU FOR YOUR GENEROSITY



# SOCIAL MEDIA & COMMUNICATION

## ONLINE UPDATES



By **ROBYN BLACK**

### A DATE FOR OUR DIARY

We are very lucky to benefit from having so many active and passionate supporters who regularly organise events in aid of the Irish Kidney Association (IKA). Our services rely on the goodwill and efforts of people who donate to us, and we always want to show our appreciation.

We have now created a form on our website so you can easily let us know if you are organising an event to support us – you can simply complete the form, telling us all the details, and we will then be able to get in touch with any assistance you might need. The earlier you let us know, the better prepared we can be to supply you with organ donor cards, posters, leaflets and more. We can also help you get in touch with your local Branch who are always delighted to help!

Another big benefit to letting us know about your event is that we can help you promote it – we will add it to our online calendar of events, and can share the details on our social media pages.

We have Facebook pages for almost all of our Branches, and over 30,000 followers on the main IKA page, so we are well placed to help spread the word!

To complete the form, visit: [www.ika.ie/whats-on/yourevent](http://www.ika.ie/whats-on/yourevent)

To view our online calendar of events, visit: [www.ika.ie/whats-on](http://www.ika.ie/whats-on)

### CHRISTMAS ECARDS

Left it too late to send Christmas cards this year, or simply trying to be more eco-friendly? We have the perfect solution for you! Our Christmas eCards are available in



both English and Irish versions, and will be emailed, for a donation amount of your choosing, directly to your chosen recipients. One donation allows you to send your card to multiple recipients. Visit our website to purchase yours today!

Visit [www.ika.ie/christmas-ecard](http://www.ika.ie/christmas-ecard) to buy yours.

### OUR TEAM

We recently added a new page to our website featuring our staff team. We speak to so many people every day, but it might be useful for you to put a face to a name – now you can do just that with our new headshots (or mugshots as Patient Support Manager Fiona called them!). We've also added a little biography for each of us, so you can read more about what we do every day.

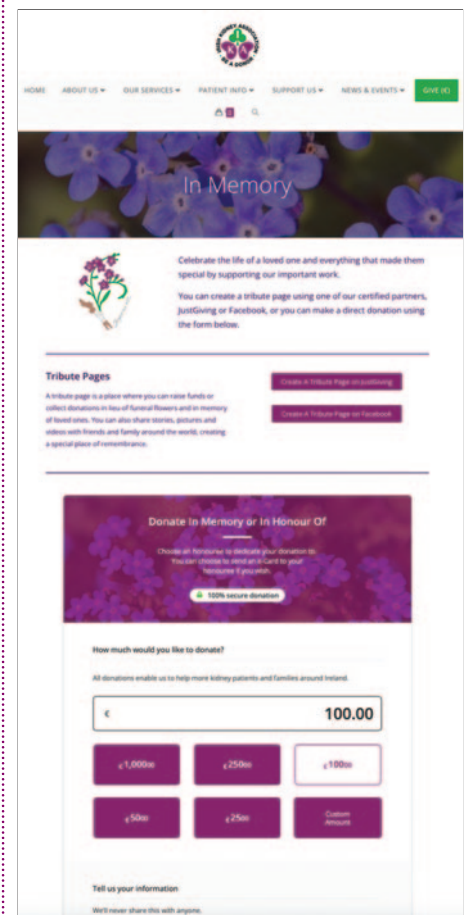
Visit [www.ika.ie/team](http://www.ika.ie/team) to view.

### IN MEMORY/IN HONOUR DONATIONS

We've upgraded our donation options on the website, so now you can leave donations, specifically in memory or to honour someone. Our new online form will also allow you to notify someone of your donation by email, making it easier to donate for someone's birthday, special anniversary or other occasion, or in lieu of funeral flowers.

Visit [www.ika.ie/in-memory](http://www.ika.ie/in-memory) to view.

We have been working hard to upgrade our website. Please visit it at [www.ika.ie](http://www.ika.ie) in the months ahead as we continue to add more information in various sections.



@IrishKidneyAssociation



@IrishKidneyAs



@IrishKidneyA

# IKA SERVICES SURVEY

Here at the Irish Kidney Association (IKA), we value the opinions of our members. The purpose of this survey is to find out more about what services our members use and what services they would like to see prioritised. You can find more information on this survey and fill it out online at [www.ika.ie/survey](http://www.ika.ie/survey).

Your completion of this **anonymous** survey is **optional** but would be appreciated. We encourage family members who may have used or interacted with our services to also participate in this survey. All data collected and collated

will be retained for a period of three years, in line with our Data Protection Policy.

The closing date for receipt of the completed survey is **Monday, 16th January, 2023**. Please return addressed to: **FREEPOST, IKA Services Survey, Irish Kidney Association, Donor House, Block 43A, Park West, D12 P5V6**.

You can also complete this survey online which can be accessed on our website [www.ika.ie/survey](http://www.ika.ie/survey) or scan the QR code here



1. What is your gender?  
☐ Male                      ☐ Female                      ☐ Other (please specify)
2. What is your age?  
☐ 18 to 24                      ☐ 25 to 34                      ☐ 35 to 44                      ☐ 45 to 54  
☐ 55 to 64                      ☐ 65 to 74                      ☐ 75 to 84                      ☐ 85 or older
3. Which county do you live in?
4. Which of the following best describes you?  
☐ Transplant Patient                      ☐ Dialysis Patient  
☐ Kidney Disease Patient (*not on dialysis or transplanted*)                      ☐ Carer or friend of a patient  
☐ Family member of a patient                      ☐ Healthcare Professional  
☐ Kidney donor                      ☐ Other (please specify)
5. Which hospital do you attend for your kidney clinic appointment?

Which services, if any, have you benefitted from that are provided by the IKA in the last 5 years?  
Please answer YES or NO to each of the following questions.

- |  | YES                   | NO                    |
|--|-----------------------|-----------------------|
| 6. Patient Financial Aid?  | <input type="radio"/> | <input type="radio"/> |
| 7. Counselling?  | <input type="radio"/> | <input type="radio"/> |
| 8. Holiday Homes?  | <input type="radio"/> | <input type="radio"/> |
| 9. Holiday dialysis abroad?  | <input type="radio"/> | <input type="radio"/> |
| 10. Accommodation at the IKA Renal Support Centre at Beaumont Hospital? ( <i>Before April 2020</i> )                               | <input type="radio"/> | <input type="radio"/> |
| 11. Accommodation funded by Beaumont Hospital in the Clayton Hotel, Dublin Airport or at other hotels? ( <i>After April 2020</i> ) | <input type="radio"/> | <input type="radio"/> |
| 12. Branch meetings or support from branch volunteers?   | <input type="radio"/> | <input type="radio"/> |
| 13. Advocacy or advice e.g. help with a medical card?  | <input type="radio"/> | <input type="radio"/> |
| 14. Sports programme?  | <input type="radio"/> | <input type="radio"/> |
| 15. Living Life Well training course? ( <i>6 training sessions on pain management etc.</i> )                                       | <input type="radio"/> | <input type="radio"/> |
| 16. SUPPORT Magazine?  | <input type="radio"/> | <input type="radio"/> |

17. If you answered **YES** to Question 10 about staying in the IKA Renal Support Centre at Beaumont Hospital, how would you rate the quality of your most recent stay?  
☐ Very low quality                      ☐ Low quality                      ☐ Neither high nor low quality  
☐ High quality                      ☐ Very high quality



# IKA SERVICES SURVEY



18. Please tell us more about your rating of the IKA Renal Support Centre.

19. If you answered **YES** to Question 11 about staying in accommodation funded by Beaumont Hospital in the Clayton Hotel, Dublin Airport or at other hotels, how would you rate the quality of your most recent stay?

- ☐ Very low quality
 ☐ Low quality
 ☐ Neither high nor low quality
 ☐ High quality
 ☐ Very high quality

20. Please tell us more about your rating of the Hotel accommodation (*Clayton Hotel or other*).

21. If you could choose between staying in the Renal Support Centre and the hotel accommodation provided what would you choose?

- ☐ Renal Support Centre
 ☐ Hotel

22. Please tell us more about your answer.

23. Given the current cost of living crisis and the increased demand for the IKA services, how would you like to see IKA funds being prioritised in 2023? *Please rank the activities below from 1 to 13, where 1 is the activity you most want prioritised and 13 is of least importance to you.*

- ☐ Patient support/financial aid
- ☐ Counselling
- ☐ Peer Support (*new service – patients trained to help other patients*)
- ☐ Holidays, including holiday home improvements and new holiday homes
- ☐ Dialysis for holidays abroad
- ☐ Refurbishment and reopening of Renal Support Centre at Beaumont Hospital. Cease accommodation arrangements provided by Beaumont Hospital, at the Clayton Hotel Dublin airport, the Hilton and other hotels
- ☐ Promoting Organ Donor Awareness
- ☐ Living Life Well Programme
- ☐ SUPPORT Magazine, 4 issues a year
- ☐ Branch meetings and branch volunteer support
- ☐ Sports programme
- ☐ Advocacy or Advice e.g. help with a medical card
- ☐ Annual Service of Remembrance & Thanksgiving

24. Do you have any other comments, questions, or suggestions?



# HOLIDAYS



By **DEBORAH CERVI**  
Holiday Co-ordinator

I know that it can be difficult to turn our attention to booking holidays for the year ahead, while it's cold outside, with dark dreary winter nights. However, it will be holiday time again before we know it.

We will have our application forms for 2023 holidays ready from 1st February, 2023. Forms will be available on our website under patient holidays where you can fill out our secure application form or visit <https://ika.ie/patient-holidays/> or alternatively you can ask your dialysis nurse in your local dialysis unit for an application form.

Accommodation is allocated based on:

- The number of years since a family has had a holiday in Ireland or abroad (applies to all holidays and not just holidays in IKA holiday properties)
- Priority is given to families with schoolgoing children during summer school holidays
- Families in extreme hardship (recent deaths, special needs).

There is a huge demand for holidays each year which far exceeds the availability. So please remember to apply early if you are looking for a

holiday break in July/August which are the most requested months for our holiday homes. Please return your application form to Donor House by February 28th.

Tramore holiday apartments will open for holidaymakers from April to October in 2023.

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

## THANK YOU

We would like to thank all our patients who took the time to complete our holiday home comment cards. We were overwhelmed with the lovely responses from patients about the pleasant experiences they had in our holiday homes.

We have taken on board recommendations on how we can improve each home and are working on some of your suggestions. Your satisfaction drives us to do better and improve our services for everyone.

## HOLIDAY DIALYSIS IN IRELAND

Unfortunately, haemodialysis patients still cannot travel for holidays within most of Ireland due to dialysis units working at full capacity with no extra space to accept a holiday patient.

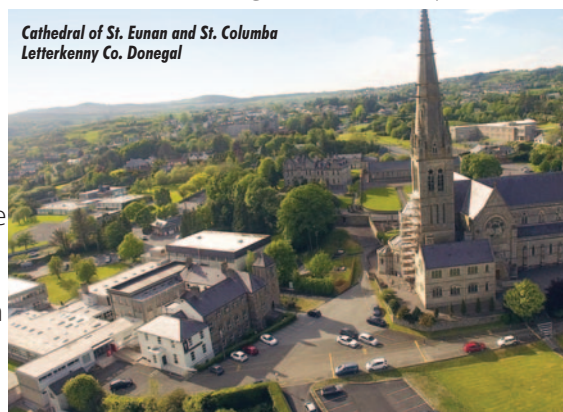
However, if you are looking for a holiday or short break in the Northwest of Ireland, Altnagelvin Area Hospital, located on the



outskirts of Derry, is the main hospital in Northern Ireland for the Northwest and it has some space available to accept holiday haemodialysis patients. It is on the main route from Derry to Belfast and ideal if you want to base yourself in areas like Letterkenny, Buncrana and Ballybofey.

At Altnagelvin Area Hospital

Cathedral of St. Eunan and St. Columba  
Letterkenny Co. Donegal



holiday dialysis is covered by the EHIC. Transport is not provided by the hospital so you must arrange your own to and from the hospital.

If you are thinking of a possible break to the Northwest, please get in touch and I will be happy to check availability for you.

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

*Deborah*



# Pedal the Peaks raises almost €40k for the IKA

Over 300 cyclists and their supporters from all over Ireland turned out for the Pat Colgan Pedal the Peaks Challenge on Sunday, August 28th. The event raised €12,000 which was shared equally between two worthy charities, the Offaly Hospice Foundation and the Offaly Branch of the Irish Kidney Association (IKA). Since 2016, the annual event has raised close to €40,000 for the IKA.



By GWEN O'DONOGHUE

This year the popular annual sportive, which has been running for over two decades, offered cyclists a choice of four different challenge routes from the Tullamore Harriers Athletics Club to the magnificent Slieve Bloom Mountains, taking in picturesque countryside and villages in Laois and Offaly. Open to people of all abilities, the more experienced cyclists could

choose the 4 Peaks Ultimate Challenge 125km route or the 2 Peaks Challenge 95km. Individual and tandem cyclists could challenge themselves to shorter distances with less elevation skirting around the mountains by taking part in either the Base of the Blooms 85km or Kinnitty Village 50km.

The Challenge was the culmination of months of preparation by Tullamore Cycling and Touring Club

(TCTC), whose focus is to stage an enjoyable and successful event, raise funds for charity, while continuing to honour the memory of the late Pat Colgan, a deceased former member of the cycling club who was the inspiration for the creation of the annual Challenge following a fatal cycling accident in 1998.

Two cheque presentations for €6,000 were made by Dermot Milner, Chairman of the

TCTC to the Offaly Hospice and the IKA Offaly Branch at the Tullamore Court Hotel on Wednesday, November 2nd. Gratefully accepting the proceeds on behalf of the IKA Offaly Branch was Tullamore local Dermot Glynn, a kidney transplant recipient and member of the Branch.

At the cheque presentation Dermot said, "On behalf of the Offaly and its Branch Chairman Jerome Burke, who could







not be here tonight due to illness, I wish to express our heartfelt gratitude to the TCTC and all the sponsors and supporters of the Pat Colgan Pedal the Peaks Challenge for shining a light on the work of the IKA. We are truly grateful to the Cycling Club for the considerable sum of close to €40,000 that it has raised since 2016 for the IKA through Pedal the Peaks and this greatly assists the IKA in providing vital support to benefit kidney patients in Offaly and beyond."

It was in 2015 when Dermot Glynn first brought the idea to Donagh McArdle, the then PRO of the TCTC, to direct some of its fundraising for the Pat Colgan Pedal the Peaks Challenge to the IKA's

Offaly Branch. Every year since then, the TCTC has continued to choose the IKA's Offaly branch as one of the charities to benefit from the proceeds. Sinéad Molloy, PRO for TCTC explained, "Since we first collaborated with the IKA Offaly branch, its members have always been 100% behind supporting the event, and catering for the cyclists in Kinnitty village when they stop for refreshments and marshalling in Kinnitty to ensure safety for all. Each year when our Club runs our Spinathon in the Bridge Shopping Centre in the weeks before Pedal the Peaks, to both advertise the event and raise money, the IKA volunteers always show us great support at this. They are so motivated,

have a fantastic support system in their group, and there is great teamwork in the well-established partnership of TCTC and Offaly IKA.

"Tullamore Cycling and Touring Club is fortunate to have such great support from the cycling community and locally from the people of Tullamore to run this event so successfully since it began over two decades ago. Cyclists from near and far travel to support the event, which caters for people of every ability and of all ages. Local businesses and companies generously support the event through sponsorship, which covers the significant expense in running an event like this. This means that 100% of

proceeds can be given directly to the charities we are working with, as was the case this year."

Dermot Milner, TCTC Chairperson said, "The Pat Colgan Pedal the Peaks Cycle Challenge has been running for over twenty years and is synonymous in raising money for local charities and local causes. It is wonderful to be able to remember and pay tribute to the late Pat Colgan in this way, while also raising money for local charities."

Dermot added, "The IKA Offaly Branch was one of the first charities that TCTC worked with and fundraised for. Our members have seen first-hand the gratitude and support that we receive from Offaly IKA."

*continued...*





## Pedal the Peaks raises almost 40k for the IKA contd...

Working with them, including their Branch Chairman Jerome Burke, himself a transplant recipient, to plan and prepare for the Pat Colgan Pedal the Peaks each year, has always been such a positive experience. Dermot Glynn and the team of IKA volunteers have supported us in the tea stop in Kinnitty each year, and provided the most delicious spread of refreshments, and a warm welcome for all the cyclists from the IKA committee on the event day.

"Everyone from the Offaly IKA is so appreciative and supportive of our efforts to fundraise for the cause. Kidney and other organ failure could affect any of us, or any of our family members at any time. Most of us know someone within our community who has been touched by organ failure or the gift of organ donation and transplantation.

"We admire the great support Offaly IKA shows to these people and their families. We are delighted and proud to have played a part in contributing to the Offaly IKA over the years, as we know they do fantastic work in our community, and how worthy a cause it is."

Sending his best wishes to all who were involved in making the event a success, Jerome Burke, the Chairman of the IKA Offaly Branch said, "I'd like to acknowledge the support of all those involved in the fundraising *Spinathon*, which was held as a prelude to the Challenge two weeks beforehand.

"I would also like to thank members of the



*At the Spinathon fundraiser in the Bridge Centre were members of Tullamore Cycling and Touring Club and IKA Offaly Branch.*

Tullamore Cycling and Touring Club for taking part including Dermot Milner and Martina Martin and also volunteer members of the IKA Offaly Branch who manned the information stand, in particular, Dermot Glynn and his daughter Maureen, Treasurer Leona Mahon and Kay Dunne.

Our thanks to the management of the Bridge Centre for hosting the Spinathon event and its patrons who interacted with us and so generously contributed to the fundraiser with many picking up an organ donor card also.

"On the day of the challenge members of the IKA Offaly Branch provided a welcome stopover for weary cyclists, with food

and refreshments at the community hall in Kinnitty village managed by caterer Jackie Masfield Hall. Special thanks to our branch members Dina Mangan Tricia Steinegger, Linda Buckley and team leader Mary Young as well as Marjorie Stanley, Carol Stanley and Leona Mahon for helping out."

In summing up the IKA's Offaly Chairman Jerome Burke said, "our heartfelt thanks to An Garda Síochána, the Civil Defence, motorcycle outriders, photographers and the stewards and the community of Kinnitty for providing such a fabulous Community Centre at our disposal and members and friends for the IKA Offaly Branch who began their day at 8am and who fed

each participant until 3pm in the afternoon. The Branch could not have had a better group of people, where there was great banter and craic despite the hard work.

"Great praise must also go to Tullamore Harriers, for the outstanding facilities and also to the providers of the wonderful barbecue in the afternoon which was enjoyed by all where everyone was in good spirits following the day's events.

"Finally, we wish to thank the TCTC organisers, riders, volunteers, sponsors, and to everybody who gave up their time to help others and so deservedly succeeded in achieving an outstanding day."



*At the cheque presentation to the IKA Offaly Branch: (l-r): Martina Martin, Eddie Scully, and Dermot Milner, Tullamore Cycling and Touring Club; with Leona Mahon, Treasurer, IKA Offaly Branch and Dermot Glynn, IKA Offaly Branch.*



*The Irish Kidney Association's third virtual and  
37th Annual Service  
of Remembrance and Thanksgiving*



Recorded at  
*Newman University Church, Dublin 2*





## Service of Remembrance & Thanksgiving

**T**he Irish Kidney Association's third virtual and 37th Annual Service of Remembrance & Thanksgiving inter-faith Service was pre-recorded by Kairos Communications at Newman University Church, St. Stephen's Green, Dublin 2 (in September). It was broadcast on RTÉ One and RTÉ Radio 1 Extra (LW252) on Sunday, 30th October at 11am. Thousands of organ donor families and grateful transplant recipients tuned in at home and abroad to watch the Service.

The public were actively encouraged to participate in this year's virtual Service, including the symbolic **Service of Light** ceremony by lighting a candle at home in memory of deceased donors who gave the '**gift of life**' and to also give thanks to living donors.

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

Prior to the global pandemic, the annual event attracted a physical congregation of close to 2,000 people. For the past three years the Service has been pre-recorded with a small gathering of participants due to safety issues around COVID-19, particularly for transplant recipients and other vulnerable people. It is hoped that it will be safe to return to a physical Service in 2023, which will be open for all to attend.

After this year's virtual Service was broadcast on Sunday, 30th October there was an uplift in the average number of organ donor card requests and digital downloads of the donor e-card.

41,500 tuned in to watch the Service broadcast on RTÉ 1 TV at 11am. Others listened to the broadcast on RTÉ Radio One Extra (LW252).

A further 520 watched the Service from over 20 countries spread across the globe on RTÉ Player on the same day with others watching on RTÉ Player in the days that followed.

Of those watching on RTÉ Player on the day of the broadcast, a total of 408 were in Ireland, and a further

68 in the UK, with the remainder from other countries including: Spain; United States; Australia; Canada; Germany; Italy; New Zealand, Belgium; Czech Republic; Finland; Croatia; Luxembourg; Netherlands; Portugal; Saudi Arabia; and South Africa and nine watched from 'unspecified' countries.

When shared on the IKA's social media channels, a further 26,600 people were reached on Facebook with 3,349 followers engaging through *likes*, *comments* and *shares*.

In the days that followed the Service broadcast (30th October – 4th November) there was a 60.2% increase in the IKA's Facebook reach and a 15.7% increase on Instagram.

Twelve families of deceased organ donors participated in the filming of this year's 'virtual' Service, to remember their loved ones who became organ donors following their untimely deaths. Nine grateful transplant recipients who received different deceased donor organs (including heart, lung, liver, kidney, and pancreas) also took part. They included a five-year-old twin boy who received a kidney





Organ Donor Coordinators, ODTI:  
Brenda Poole, Jean O'Reilly,  
Dominic Lozanes, Emma Corrigan,  
Emer Shields and Lynn Martin.



Rebecca Maher

transplant this year, a lung transplant grandmother in her late 60s, and a mother in her mid-forties who has received the 'gift of life' three times in her lifetime, and another mother who is enjoying the successful longevity of a kidney transplant she received 32 years ago.

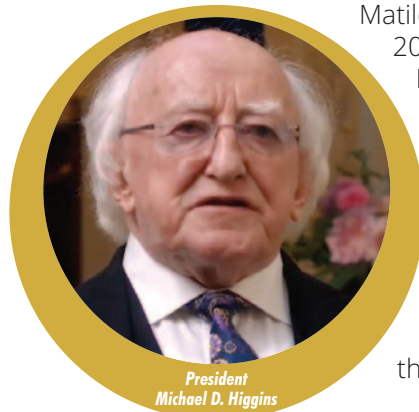
The Service, an occasion for both sadness and joy, included clergy, humanists, as well as organ transplant recipients, organ donor families, and the medical profession involved in organ donation and transplantation.

Music and song were interspersed between poignant symbolic processions and meaningful scripture, reflections and expressions of gratitude, selflessness, and faith in humanity.

Since its inception 37 years ago, the Service has become a hugely important event on the calendar of members of the organ donation and transplant community. The confidential database for organ donor families is held by Organ Donation Transplant Ireland (ODTI). The invitation cards, which are sent to organ donor families, are designed and printed by the Irish Kidney Association and are then delivered to Kathleen Tyrrell at the ODTI who coordinates their distribution to thousands of organ donor families nationwide and to those who are living in other parts of the world. Attending the Service were six ODTI organ donor coordinators who provide support to organ donor families including Brenda Poole, Jean O'Reilly, Dominic Lozanes, Emma Corrigan, Emer Shields and Lynn Martin.

The **Book of Remembrance**, a 'Roll of Honour', has been an integral part of the Service since its inception with the names of organ and tissue donors carefully inscribed by calligrapher Annette Daly from Glenageary, Co Dublin for the past 37 years.

A letter by **President of Ireland Michael D. Higgins**, who is patron to the Irish Kidney Association, was read aloud at the Service by **Rebecca Maher**, from Castleknock, Dublin, the mother of deceased organ donor infant



President  
Michael D. Higgins

Matilda Quinn who passed away in 2015. In an extract from the President's message, Rebecca read, "I join you all in expressing my support and thanksgiving for the great gift of organ transplantation, which has transformed and enriched so many lives – allowing new possibilities and new opportunities for recipients and their loved ones".

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# Service of Remembrance & Thanksgiving

*Cantor Dr. Sharon Lyons*



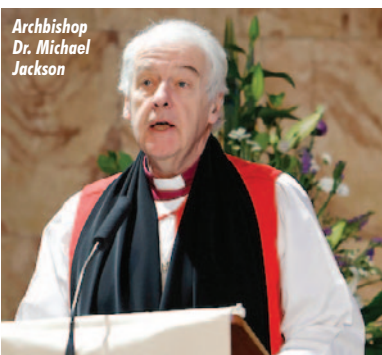
*Musical Director Dominique Cunningham*

Church of Ireland Archbishop of Dublin & Glendalough **Dr. Michael Jackson** gave the Homily and **Rev. John Kelly** read the Gospel on behalf of the **Catholic Archbishop of Dublin Dermot Farrell**. Chief Celebrant was **Rev. Gary Chamberland**, Newman University Church.

Revered soprano **Dr. Sharon Lyons** fulfilled the role of Cantor with her beautiful singing supported by talented Musical Director **Dominique Cunningham** who directed members of the Newman University Church choir, the **Vocare Ensemble**. Music accompaniment was provided by organist **Joseph Bradley**, harpist **Teresa O'Donnell** and violinist **Claire Kirner**.

The first and second readings at the Service were delivered by **Ms. Dilly Little**, Surgical Director, National Kidney Transplant Programme, Beaumont Hospital, and Consultant Paediatric Nephrologist **Prof. Atif Awan**,

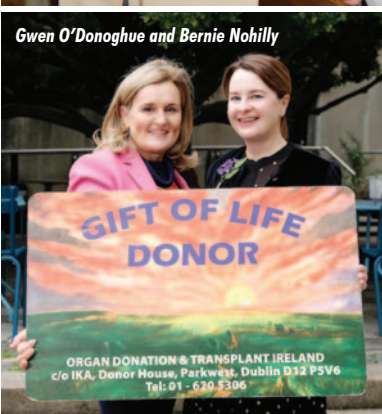
CHI Temple Street. Other members of the medical profession taking part were **Bernie Nohilly**, an organ donation nurse, and **Prof. Jim Egan**, Director, Organ Donation Transplant Ireland (ODTI) and Consultant Respiratory & Transplant Physician at The Mater Misericordiae University Hospital.



*Archbishop Dr. Michael Jackson*



*Rev. John Kelly*



*Gwen O'Donoghue and Bernie Nohilly*



*Harpist Teresa O'Donnell*



*Violinist Claire Kirner*



*Ms Dilly Little*



*Prof. Atif Awan, Mairéad Kinlough and Prof. Jim Egan*





Aoife Murray



James Reynolds



Eddie Flood

Narrating throughout the Service was kidney transplant recipient **Eddie Flood**, the newly appointed national honorary chairman of the Irish Kidney Association, from Killucan, Co Westmeath.

As a prelude to the Church Service, Kairos Communications filmed two mothers from Kilkenny on a beautiful sunny day in September in the picturesque Graiguenamanagh village (see page 40). Both mothers shared their different stories on organ donation, as **Deirdre Roche Doherty** spoke about her gratitude for receiving transplants on three occasions over three decades, while **Yvonne Cassidy**, spoke about honouring her late husband, Sergeant Pat Cassidy's wishes to be an organ donor, and that her son **Cian Cassidy** is following in his military footsteps.

The filming then moved to Dublin showing Yvonne's son, **Cadet Cian Cassidy** at Newman University Church, in full army uniform, leading the opening procession at the Service by carrying a cross to the altar.

### SERVICE OF LIGHT

As an introduction to the symbolic Service of Light where candles were lit for organ donors, **Nicole Grier**

### A Candle

Narrated by **Nicole Grier**  
Daughter of an organ donor

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



Nicole Grier

from Claremorris, Co Mayo, read aloud the poem '**A Candle**' by Helen Custer. Nicole was just 17 years old when her late mother Martina became an organ donor ten years ago following a brain aneurysm. Martina had carried an organ donor card. Knowing her wishes, Nicole, her younger sister Chloe and their father unanimously agreed to organ donation resulting in five lives being saved.

Leading this year's **Service of Light** ceremony and lighting one hundred

candles in memory of organ donors, were two members of the successful **Transplant Team Ireland** sports team who have represented Ireland at World and European Transplant Games – Dubliners **Aoife Murray** and **James Reynolds**.

Aoife (35) from Clonsilla, in Dublin and now living in the West of Ireland, was diagnosed with Auto Immune Hepatitis when she was just twelve years old. She received a liver transplant at St. Vincent's University Hospital in October 2015. She attended Crumlin Hospital until she was eighteen. Her health began to decline by the time she was twenty-five years old when she required several hospital admissions. Three years later, at the age of twenty-eight, she was accepted onto the transplant waiting list in February 2015 and for most of that her up until her transplant which took place eight months later she was hospitalised as she had become extremely ill.

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Yvonne Cassidy and  
Cadet Cian Cassidy



# Service of Remembrance & Thanksgiving

James Reynolds, also 35, from Tallaght, now living in Blanchardstown, Dublin, is grateful for the kidney transplant he received in 2009 at Beaumont Hospital when he was 22 years old which allowed him to resume a normal life, gain employment, get married and become a father to Dylan (now 6). Although James recently returned to dialysis treatment and is awaiting another transplant, he fully appreciates the 13 years of renewed health which he enjoyed in adulthood made possible by a deceased organ donor.



An uplifting part of the Service saw five-year-old kidney transplant recipient **Liam O'Connor** from Artane, in Dublin and his twin brother **Daniel** bringing their favourite toy wrestlers to the altar. Accompanying the twins in the gifts procession was their father Patrick. Watching on was their mother Denise and sister Caoilinn (age 7) as well as Prof Atif Awan and Mairead Kinlough, a CNM3 who cared for him at CHI Temple Street.

Just six months beforehand, Liam's young life was transformed by a kidney transplant which he received from a deceased organ donor. Born with Bilateral Renal Dysplasia, Liam spent the first two years of his life in and out of Temple Street with 40 hospital admissions in that time. Prior to his kidney transplant he had been undergoing dialysis treatment for over two years.

Taking part in a procession carrying the **Book of Remembrance**, was **Paul Millett**, from Pimlico, London. Paul's late partner of 25 years, Nora O'Gorman Miller, a native of



Rossmore, Co Tipperary, passed away three years ago following a catastrophic brain haemorrhage.

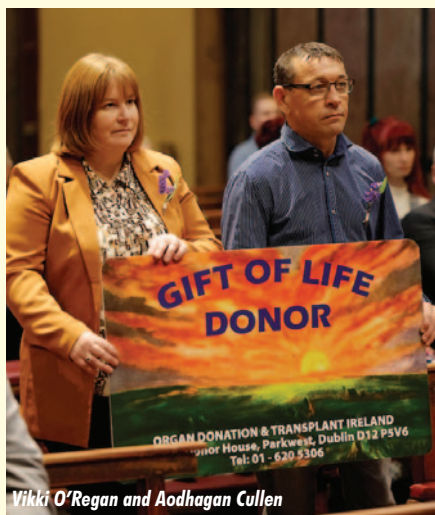
Her donated organs included her kidneys, lungs, and liver. Paul flew over from London for the Service which he attended with the late Nora's brother Eddie O'Gorman and his wife Anne.

Another symbolic procession included a large Organ Donor Card carried to the altar by **Vikki O'Regan** (nee McConkey) from Knockamish East, Tralee, Co Kerry and **Aodhagan Cullen** from Loughduff, Cavan.

Vikki O'Regan's late sister Gayle, the youngest in a family of five children, was just 40 years old when she passed away following a cycling accident in 2015. Four of Gayle's organs were donated including her two kidneys, liver and lungs and her heart valves were also donated.

Attending with Vikki was her father Pat McConkey and her sister Jenny Freytag, who travelled over from Germany, where she now lives.

A diabetic since he was four



years old, Aodhagan Cullen was hooked up to his dialysis machine when he received a call from St. Vincent's Hospital to undergo a combined kidney/pancreas transplant in 2017. The life-changing transplant followed seven years of waiting on the transplant list and transformed Aodhagan's quality of life as he no longer was insulin dependent or had to undergo dialysis.

Bringing baskets of **Forget-Me-Not** flower emblems, the Irish Kidney Association's symbol of transplantation, to the altar were **Rosie Buckley** from Clara, Co Offaly, and **Mary McGarry** from Palmerstown, Dublin.



Rosie Buckley's late partner of 30 years, Paddy Johnson was just 59 when he passed away in early 2021. Rosie and his adult children take great pride in knowing that by honouring his wishes to be an organ donor that he helped three other people as his kidneys and liver were donated. Accompanying Rosie to the Service were the late Paddy's son Pajo Johnson and his sister Nora Bracken.

Grandmother **Mary McGarry** underwent a single lung transplant in 2018, on the seventh occasion that she was called for a transplant at the Mater Hospital. Diagnosed with Pulmonary Fibrosis, a condition causing the irreversible scarring of the lungs, she was 24-hour oxygen supply dependent in the lead-up to her transplant which followed the disappointment of six false calls. Mary attended the Service of Remembrance with her husband John.





Martin Malinowski

Also filmed in an entry procession at the Service was **Martin Malinowski**, from Castleblaney, Monaghan and **Michelle Butler** from Stradbally, Co Waterford, as each brought a candle to the altar.

Martin Malinowski (a Polish native) made ground-breaking history as he is the first person in Ireland to undergo a highly complex combined liver and heart transplant at the Mater Hospital in 2021. Michelle Butler donated her husband Brendan's (Ben) organs when he passed away at the beginning of 2022 at the age of 45 following a brain haemorrhage. Michelle and her late husband had discussed his wish to be an organ donor.



Michelle Butler

At the Service **Cathriona Charles** from Mohill, Co Leitrim, a member of the Liturgy Committee, read Our Lord's Prayer 'as gaeilge'. Cathriona is enjoying the successful longevity of a kidney transplant she received from a deceased organ donor 32 years ago. Cathriona is the

Secretary of the Leitrim Branch of the Irish Kidney Association and is also on the National Board of the IKA.

**Carol Moore**, the Chief Executive of the Irish Kidney Association, read the words of reflection stepping in for Humanist Emma Sides who had to cancel at late notice due to a personal emergency which detained her.



Carol Moore

Reading a reflection at the Service was **Olivia Lynch**, from Navan, Co Meath. Olivia's late husband Sean was only 34 when he died while cycling in a race in Wexford in 2019. They had been a couple for eleven years and had planned to wed in 2020. Sean carried his organ donor card and had discussed his wishes around organ donation with Olivia. She describes Sean, whom she wed while he was in ICU before the organ donation, "he lived as an earth angel, and he had a big heart'. I am immensely proud that he saved five people's lives through organ donation". Supporting Olivia at the Service was Geraldine Conroy, a close family friend and Sean's former employer.



Cathriona Charles



Olivia Lynch

The mother of an organ donor **Janet O'Brien** from Tallaght, Dublin read the first reflection. Her oldest son Luke was only 20 when he suffered a fatal brain trauma following an unprovoked assault in 2017. In her heartbreak, when asked about organ donation, her immediate thoughts were that she didn't want any other mother to have to go through her feeling of devastation and that if she could help ease someone else's suffering that would give her and her family comfort.



Janet O'Brien

The family takes consolation from Luke's donation which led to one child receiving a kidney transplant, two adults receiving organ transplants and Luke's heart valves going to a 10-day old baby and young man.

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# Service of Remembrance & Thanksgiving



*Erin and Catherine Power*

Carrying the Book of the Gospel to the altar in the opening procession was **Catherine Power** from Hollyfort, Gorey, Co Wexford and her daughter Erin who travelled over from the UK to join her mother at the Service. Catherine's son (and Erin's brother) Finlay passed away in 2021 following a car driver's error which resulted in a collision with Finlay who was riding his motorbike. Finlay had received a full driver's licence just three weeks before.

A non-drinker and non-smoker, Finlay worked with the Civil Defence, was a blood donor, and carried an organ donor card and had code 115 on his driver's licence. In his life Finlay demonstrated a deep sense of civil mindedness. This was carried through in his death when his family honoured his wishes to be an organ donor, Finlay's heart, liver and two kidneys were donated.

Reading a prayer of the faithful was **Marie Monaghan**, the sister of a deceased organ donor. Marie is a native of Headford, Co Galway and is now living in Blanchardstown, Co Dublin with her husband Edward Carey and their two children, Shane (8) and Emma (6). Marie has attended or tuned in, since COVID-19, to watch the Service each year with her parents Michael and Marian, since her brother Kenneth became an organ donor, six years ago, at the young age of 34 following a brain haemorrhage.

Five of Kenneth's organs were donated, and the family takes great comfort in knowing that in their loss



*Sebastian Pannackal, Kairos*

he has helped others. They have received anonymous letters from some of the transplant recipients which gives them great solace.

**Fr. Finbarr Treacy**, Producer at Kairos Communications, worked closely in planning the Service with the Liturgy Committee which included Irish Kidney Association (IKA) board members **Valerie Brady**, from Navan, Meath who also had the role of floor manager; **Joan Gavan**, from Donohill, Tipperary, and **Cathriona Charles**, from Mohill, Co Leitrim. Organising the staging of the event were IKA Chief Executive, **Carol Moore** and staff members **Ashling Hand** from Lucan, Dublin, and **Colin White** from Ballbriggan, Dublin, as well as **Gwen O'Donoghue**, from Tullamore, who coordinated the event's promotion and participants' liaison.



*Marie Monaghan*

It was the third year in a row, for the Service to be held virtually and pre-recorded by Kairos Communications, due to safety concerns for immune compromised transplant recipients and others



*Liturgy Committee: Joan Gavan, Carol Moore, Valerie Brady, Eddie Flood and Cathriona Charles*





Cameraman Oliver Carmody, Kairos



Cameraman Paschal Brooks, Kairos



vulnerable to COVID-19.

The sound engineer was **Adrian Cunningham** and his sound assistant is **Emma Nolan** and cameramen were **Sebastian Pannackal**, **Ollie Carmody** and **Paschal Brooks**.

The beautiful flowers which adorned the altar were arranged by **Una Whelan**, wife of kidney transplant recipient and former national honorary chairman **John Whelan** from Bray, Co Wicklow.



Flowers by Una Whelan

## Reflection

Narrated by **Janet O'Brien**

Mother to the late Luke,  
an organ donor

### I Am Not Gone

*I am not gone, I remain here beside you,  
Just in a different form,  
Look for me in your heart,  
And there you will find me,  
In our love which forever lives on,  
In those moments when you feel alone,  
Look for me in your thoughts,  
And there you will find me,  
In sweet memories that burn strong,  
Every time a tear,  
Forms in your beautiful eyes,  
Look up to the heavens,  
And there you will see me  
Smiling down from God's glorious skies.*

## Reflection

Narrated by **Carol Moore**

Chief Executive,  
Irish Kidney Association

### Gates of Prayers

*In the Rising Sun and in its going down,  
In the blowing of the wind  
and in the chill of winter,  
In the opening of the buds and in the  
rebirth of Spring,  
In the blueness of the sky and in the  
warmth of Summer,  
In the rustling of leaves and in the  
beauty of Autumn,  
In the beginning of the year  
and when it ends,  
When we are weary and in need of  
strength,  
When we are lost and sick of heart,  
When we have joys we yearn to share,  
So long as we live, they too shall live,  
for they are now a part of us.*

## Reflection

Narrated by **Olivia Lynch**

Wife to the late Sean, an organ donor

### 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 loved ones touch.  
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.*



# Graiguenamanagh

For the introduction to the **37th Annual Service of Remembrance & Thanksgiving**, the **Irish Kidney Association** arranged for Kairos Communications to travel to Kilkenny on **Saturday, 17th September** to film two mothers who shared their inspiring stories about organ donation and transplantation.

The picturesque Graiguenamanagh village was the backdrop for the filming and the weather didn't disappoint as it was a beautiful sunny day.

Also in attendance were members of the Kilkenny branch of the Irish Kidney Association including its secretary Anne O'Grady, chairperson John Lacey and his wife Mary, and treasurer Bridget Langton.

**D**eirdre Roche Doherty was filmed in her back garden of the family home with the imposing Brandon Hill in the background. Now in her forties and a married mother of two girls, she described the sequence of events resulting in her receiving organ transplants from three donors.

Born with cystic fibrosis, Deirdre described how in her late teens, her own heart was donated to someone else as she underwent a lifesaving combined heart and lung transplant



*The Doherty family. Parents Deirdre and Brian, with Ruth and Abi.*



*The Doherty and Cassidy families with members of the Kilkenny IKA branch (4th from right) Bridget Langton, John and Mary Lacey and Anne O'Grady.*



*Yvonne Cassidy holding a picture of her late husband Pat and their son Cian as a child.*



*Rachel, Yvonne and Jessica Cassidy*



*Cadet Cian Cassidy with his mum Yvonne*

in the UK in 1996. Sadly, her sister, Orla, who also had CF, passed away when she was just 14 years of age while waiting for a lung transplant at Great Ormond Street Hospital.

In 2009 Deirdre underwent a kidney transplant, just months before she wed Brian Doherty. She went on to give birth to two daughters, Ruth who is now 11 and Abi who is 9.

Deirdre required a second kidney transplant which she underwent in 2017.

Deirdre expressed her deep gratitude to her donors and for making it possible to train to be a teacher, get married and enjoy being a mother to her two beautiful daughters.

Wife of a deceased organ donor, **Yvonne Cassidy**, who lives in Paulstown, in Kilkenny, was filmed on the banks of the River Barrow in Graigueanamanagh and her two adult daughters Rachel and Jessica were there to support her. She spoke about how her husband, **Sergeant Pat Cassidy** had carried an organ

donor card and that by honouring his wishes, when he died nine years ago, he helped three other people through organ donation.

Both Yvonne and Pat came from military backgrounds as both of their fathers were in the Army. Their son, Cian, was only 15 years old when Pat passed away and he is now following in his father and grandfathers' footsteps as he is a Cadet at the Curragh and expects

to be fully commissioned next year. It was a fitting tribute to his late father, that, in the opening procession of the Service, Cian was dressed in full army uniform, as he carried the cross to the altar at the Service of Remembrance, watched on by his proud mother Yvonne.



*Cameraman Gerard Doyle with Yvonne Cassidy and Fr. Finbarr Treacy, Kairos*





Vikki O'Regan, Pat McConkey, Jenny Freytag and Lynn Martin.



Paul Millett,  
Emma Corrigan,  
Eddie and Anne O'Gorman



Chloe and Nicole Grier



Amy and Aoife Murray



Cadet Cian Cassidy



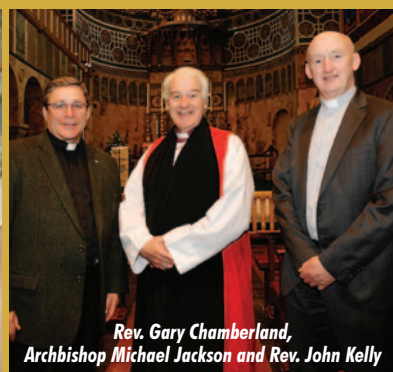
Denise & Patrick O'Connor with  
Daniel, Caoilinn and Liam



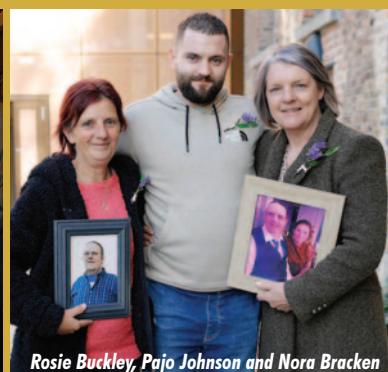
James and Samantha Reynolds



Back: Marian Michael and Marie Monaghan  
Front: Shane, Edward and Emma Carey



Rev. Gary Chamberland,  
Archbishop Michael Jackson and Rev. John Kelly



Rosie Buckley, Pajo Johnson and Nora Bracken



Mary and John McGarry



Margie and Janet O'Brien and Deirdre Byrne



Brenda Poole and Michelle Butler



Rebecca Maher and Emma Corrigan

## How the Service of Remembrance & Thanksgiving began

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

Lorraine Costello consulted with Phyllis Cunningham, the National Transplant Coordinator (both ladies are now

retired), and it was decided that a Service be held to publicly acknowledge and recognise the courageous generosity of organ donors and their families.

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



The World Kidney Day Joint Steering Committee has declared 2023 to be the year of

# KIDNEY HEALTH FOR ALL

World  
Kidney Day  
**THURSDAY**  
9th March  
2023

**PREPARING FOR THE UNEXPECTED,  
SUPPORTING THE VULNERABLE!**

The 2023 campaign will focus on raising awareness about kidney disease.



**#worldkidneyday #kidneyhealthforall**  
**[www.worldkidneyday.org](http://www.worldkidneyday.org)**

World Kidney Day is a joint  **ISN**  **IFKF-WKA** initiative





By LISA FITZGERALD

My journey with kidney dialysis began soon after my second child was born in 2017. It was after the birth of my first child, five years before that, I learned I had had a chronic kidney condition. I was referred onto the nephrology department in St Vincent's University Hospital where I was monitored with routine appointments right up until I became pregnant with my second child. They advised me of the risks, but no one could have predicted how rapidly my kidneys were going to fail once my baby girl was born in 2017. Two months after her arrival my nephrologist advised me that my kidneys wouldn't last for the remainder of the year. In September 2018 I started my dialysis journey.

It was a difficult time as I had a young family including a 10-month-old baby. After the initial shock diagnosis of what was to come, I gradually became accustomed to the challenges of my new reality. Having experienced different types of dialysis treatment, taking the time myself to research what is involved, as well as the support of my husband, family and healthcare professionals, I have learned how to manage my condition and care for my physical and emotional wellbeing. I'd like to share some of what I have learned from the short time of five months which I had spent on dialysis prior to being called for a successful kidney transplant in February 2019. I hope that this will help others who are new to dialysis.



# What happens now that I must begin DIALYSIS?

**W**hen you hear for the first time that you are now at a point where dialysis is on the cards for you, it can be very overwhelming. Having mixed emotions is certainly normal.

Your nephrologist and/or the team will organise an appointment for you to meet with a dialysis nurse to go through the whole process of dialysis or answer any questions you have.

There are two types of dialysis treatment available, and both offer variations. It is important that you discuss each of these with your medical team and bring the needs of your lifestyle (work, family, travel, etc.) into the decision-making process when it comes to choosing the best treatment for you.

## HAEMODIALYSIS

This is the most common type of dialysis offered in Ireland. The haemodialysis machine cleans the blood and removes toxins and excess fluids. The majority of people on haemodialysis receive their treatment three times a week (usually on a

Monday – Wednesday – Friday or a Tuesday – Thursday – Saturday cycle) in a hospital dialysis unit or a commercial dialysis unit (under the medical supervision of your hospital-based nephrologist). Each treatment lasts approximately 3½ - 4 hours.

A relatively small but growing number of people are embracing the opportunity to manage their own haemodialysis treatments at home. Training and on-going support are provided.

## PERITONEAL DIALYSIS

This type of dialysis is carried out in the home. Peritoneal dialysis involves the use of the peritoneal membrane, as a filter, to remove waste products from the body and to correct body fluid and biochemistry. This is achieved by inserting a catheter (Tenckhoff) into the peritoneal cavity by way of a minor operation. About 15cm of the catheter remains outside of the body, providing a means for attaching a bag of special dialysis fluid (dialysate). The dialysate fluid and the peritoneum work together to remove

waste and excess fluid from your body. Peritoneal dialysis exchanges can be performed by the patient themselves during the daytime (Continuous Ambulatory Peritoneal Dialysis) or by a small machine at night while you sleep (Automated Peritoneal Dialysis).

The Irish Kidney Association, in conjunction with Beaumont Hospital, has produced a series of booklets to cover many aspects of the kidney journey. You can read the booklet on dialysis at: <https://tinyurl.com/ikadialysis>.

If you wish to do further research of your own, look to websites of kidney patient organisations in other countries for guidance on their resources to ensure that you are getting reliable and up to date information (for example [www.kidneycareuk.org](http://www.kidneycareuk.org)).

Your journey through dialysis will be easier if you can educate yourself about the impact of dialysis on your body. You can learn the 'life hacks' for managing the restrictions and symptoms that can come with dialysis treatment

Some people like to wait and speak with their doctor directly, but there is so much to learn, the time you have with your doctor probably won't be enough time to go through it all. That is why it helps to speak with a dialysis nurse.

**In my case I chose peritoneal dialysis**, as this suited me to be at home so that I could be with my young family. I had the line fitted in September but as it takes a few

sessions to be trained, and my kidneys were failing rapidly I had a temporary line fitted for haemodialysis. I only experienced this for approx. 3 weeks, but got a good understanding of what is involved. After a few sessions I felt so much better with more energy. I went by taxi to the hospital early mornings 3 times a week for approx. 3 hours of treatment and the more I did this, it seemed manageable and that I could start having a 'normal' daily life.

Once I was fully trained on peritoneal dialysis, I very quickly felt confident in doing this. I felt more in control and less like a patient. I was able to plan my day around dialysis. Yes, at times it was slightly frustrating that I had to come back to the house for my treatment and going out for the whole day was not an option anymore. But I was thankful overall that this process was making me feel so much better than before when I was in end stage kidney failure prior to treatment.

I was very lucky to get a call from Beaumont Hospital in February 2019 to say they had a match for me, and I was going to be transplanted. I was not expecting to be on dialysis for just five months, as I know many people are years dialysing while waiting on a match. But I suppose you never know when someone will go above and beyond to selflessly be a donor and it becomes your time to receive their precious gift to you, the 'gift of life'.

### **In deciding on which form of dialysis treatment was best for me:**

- I found it helpful to have my questions noted on my phone for when I was going to meet with my dialysis nurse. I asked for my husband's input also, as being on dialysis was going to affect us both
- I found the dialysis nurse not only extremely knowledgeable, but understanding and informative too. She made it sound not too 'alien' and reassured me about how much better I would feel once I started treatment
- I felt I could choose which type of dialysis treatment I wanted to go on, because I was given information about all the options
- There is a lot of information to take in from when you first learn about dialysis, but I was able to contact the dialysis nurse at any time with questions. I felt she was my help and guide before, during and after dialysis. It was important to me that we were able to speak openly and honestly about things
- I was brought around the haemodialysis unit in the hospital to see how it works and what the machines are like
- I was shown some of the tubes and bags that are used for peritoneal dialysis as well as the machine used

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# What happens now that I must begin **DIALYSIS?** continued



for automated peritoneal dialysis.

## THINGS I HAVE LEARNT SINCE BEING ON DIALYSIS:

### PERITONEAL DIALYSIS

- The risk of infection is an issue, but the training is good, and it is possible to minimise the risk
- It's important to keep in regular contact with your dialysis team, particularly in the early days, so that you can learn to identify possible problems early and avoid unnecessary trips to the Emergency Department
- When the dialysis fluid is dwelling in your peritoneal cavity you can feel, and look, bloated. You may need to take this into account when deciding what to wear
- You need to understand the volume of supplies that will be delivered to your house and have a plan for their storage. You also need to consider where you are going to carry out your treatment
- Baxter, who currently have the contract for supplies for peritoneal dialysis, offer an efficient and professional service
- After you get the hang of things you can really start to feel better in yourself, having more energy/appetite, etc.
- Good hygiene is key and so very important
- A lot of the above doesn't last too long, and you can get on with your

day-to-day life. It becomes your 'norm' and you manage your day around the times you dialyse

- I had a 10-month-old baby when I started on peritoneal dialysis, so it really can be managed.

### HAEMODIALYSIS

- Many of the taxi drivers who bring you to and from your dialysis unit are well informed about dialysis
- I found all the nurses so kind and friendly. Any questions I asked they were always happy to answer
- At the start it all felt a bit unusual but then it becomes the 'norm' and you get used to going to the dialysis centre 3 times a week, the weigh-ins, being hooked up to the machine to dialyse
- Unable to shower when lines are first put in (I had a temporary line) so I found this difficult not being able to shower and wash my hair. Treating yourself to a blow dry, or have friends or family wash your hair was strange at first but I chose to have clean hair and put

my pride aside!

- Having my temporary line put in for haemodialysis was a quick procedure, compared to the peritoneal dialysis line. It is positioned from the neck and down to your chest. At first, I was worried how I would wear clothing but managed, and large plasters that the hospital supply helped disguise it
- Bring a blanket/cosy cardigan or jumper as the hospital unit is always well ventilated and can get chilly. Although nurses will provide



blankets it is always nice to have your own comforts

- Bring a book/Kindle/iPad to make the time pass. You will be there for approximately 3-4 hours
- Earphones were my luxury as I was able to immerse myself in my book, movie or a podcast whilst dialysing
- One of the plus sides of haemodialysis is that once you have had your 3-4 hour session you can go about your day as normal and not think about it until you are back again the next time.

## IN CONCLUSION

The treatment burden of dialysis can be significant, whether you are on haemodialysis or peritoneal dialysis. However, it is manageable. It is your body, listen to it and take responsibility for it.

Embrace the professional input of your medical team and remember, you don't have to wait until an appointment to ask a question! If you have family/friends around you, educate them and discuss how they can support you.

Take advantage of the services and peer network offered by the Irish Kidney Association. They are there to support you on your renal journey.

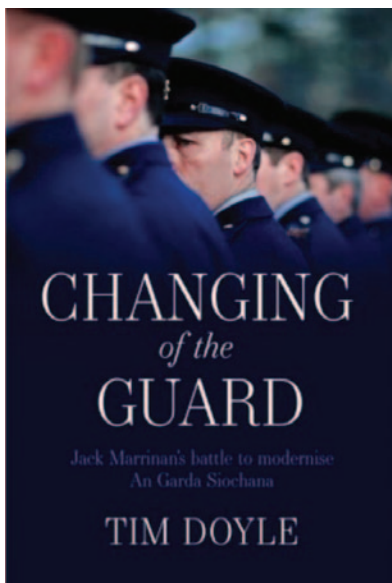
# ‘Proud day’ as retired Garda’s book raises €10,000

By GWEN O'DONOGHUE



Carol Moore, CEO, IKA (centre) with (l-r) George Maybury, AGSI; Christy Lonergan, GSRMA; Agnes and Tim Doyle (author); Damien McCarthy, GRA; and Superintendent Pat Ryan, AGS

**W**riting *Changing of the Guard* was how retired Garda Inspector Tim Doyle resolved to overcome the shock of his kidney failure diagnosis and an uncertain future. Available in hardback, *Changing of the Guard*, which is published by Currach Books, gives a snapshot into the period from the 1950s to the 1980s, a time of great turmoil and upheaval in the Garda Síochána and two central figures who played a pivotal role in its modernisation. The author Tim Doyle, a Kerry native, has directed all of the proceeds from the sale of the book to the Irish Kidney Association (IKA).



On 2<sup>nd</sup> December 2022, the Centenary year of the Garda Síochána, Tim and his wife Agnes, as well as Damien McCarthy from the Garda Representative Association (GRA), George Maybury from the Association of Garda Sergeants and Inspectors (AGSI), Pat Ryan, Association of Garda Superintendents (AGS), and Christy Lonergan from the Garda Retired Members Association (GSRMA), visited the Irish Kidney Association's head office in Park West, Dublin. Tim presented a signed copy of his book and a cheque for €10,000, the proceeds of the sale of his book in its first year, to Carol Moore, the

Chief Executive of the Irish Kidney Association.

## CHEQUE PRESENTATION TO THE IRISH KIDNEY ASSOCIATION

At the cheque presentation to the Irish Kidney Association, author Tim Doyle said, "It is especially noteworthy that on the Garda Centenary year when we honour over 40,000 members who took an oath to protect and serve all people it is more than appropriate that we reach out and support the lifesaving efforts of the Irish Kidney Association"

"It is my way of giving something back for all the wonderful care and support I received while I was struggling with kidney failure. I hope that the message people can take

**"It is my way of giving something back"**



# “it’s a proud day for me, my family, my Garda comrades and all generations of gardai”

from my story is that even in pain and struggles, positivity can emerge and manifest itself.”

“In my case I turned towards writing which helped me navigate my way through my illness. I feel blessed for the wonderful love and support I received from my wife and family and the outstanding care I received from health professionals. I hope that I can inspire others who are struggling with organ failure, to realise that there is always hope, and regardless

entertaining read for all people interested in the operation of Irish society -not just Gardai and their families. It charts the change from a conservative, oppressive, stifling culture to a more open and respectful environment. The bravery and courage of a few visionary leaders who put their own careers on the line is inspiring and the book shows the wide range of skills and tactics needed to successfully introduce change. A very useful read

that is being done, the challenges that you face, and those challenges might be somewhat easier to overcome with the proceeds of this great book. Because it’s never lost on us from the stories we hear, the trouble that comes to one’s door in terms of their health, stories of dialysis and transplant, and where the Irish Kidney Association has been there from day one”. It’s an honour and a privilege for me to be here as a member of An Garda Síochana, to play some small role in the good work Tim is doing with his book, helping not only in his career in the guards but in his retirement, continuing to serve his community and protect the importance of the preservation of life by donating the proceeds of his book to the Irish Kidney Association.”

While congratulating Tim, **Christy Lonergan**, representing the Garda Síochana Retired Members Association (GSRMA), spoke of some of the influential Gardai covered in the book whom he had known. “I met **Michael Conway** who was secretary of the garda medical aid and **Jack Marrinan** who was secretary of the Garda Representative Association, and not forgetting **Jim Cuffe** at the time who was the secretary of the Garda Benevolent Trust Fund. Those were three great guys from my point of view, because they were the guys that brought those three organisations up from where they were to a new plain, and I will be very grateful to them for all my time”.

**George Maybury**, representing the Association of Garda Sergeants & Inspectors (AGSI), spoke about the similarities between the Irish Kidney Association and the Gardai. “It’s all about managing relationships right across the board, it’s all about caring for people, being there for people... you learn so much about society, you learn to deal with people in the most difficult, sad circumstances”.

Detective Superintendent **Pat Ryan**, National Executive for the Association of Garda Superintendents said, “Tim is truly inspirational, and the association of garda superintendents are delighted to support him, and indeed the Irish Kidney Association.”



At the cheque presentation (centre), Carol Moore, Chief Executive of the Irish Kidney Association with Agnes and Tim Doyle, the author of *Changing of the Guard*

of where the journey brings you, you should focus your energy on pursuing a personal goal and being your best self. It is amazing how human nature can find fresh cause for optimism as hope springs eternal.”

Concluding his speech at the cheque handover, Tim said, “In our centenary year it’s a proud day for me, my family, my Garda comrades and all generations of gardai to be able to hand over a cheque to the Irish Kidney Association which does wonderful work in supporting kidney patients”.

Thanking Tim for his generous donation, the Irish Kidney Association’s Chief Executive, **Carol Moore**, said, “*Changing of the Guard* is a highly informative and

for anybody aspiring to change Irish social norms and wishing to advocate for others, like the Irish Kidney Association does for its patients. Given the vital role in Irish society of An Garda Síochana, we in the Irish Kidney Association are delighted to be receiving the royalties from this important book which is a record not just of Jack Marrinan’s life of service but a history of an important time in An Garda Síochana. The funds will help us carry out the work we do in supporting other kidney patients like the book’s author Tim Doyle”.

Garda **Damien McCarthy** of the Garda Representative Association (GRA) said, “I consider it a great honour to be invited here to the Irish Kidney Association’s headquarters today... we know first hand the work

## ABOUT THE BOOK - CHANGING OF THE GUARD

Available in hardback, *Changing of the Guard*, gives a snapshot into the period from the 1950s to the 1980s, a time of great turmoil and upheaval in the Garda Síochána. It charts the careers of two inspirational and transformational Clare gardai who joined in the early 1950s; **Jack Marrinan and Michael Conway**. The book is laced with comments by both men who were interviewed by author Tim Doyle. In the 1960s, Marrinan sacrificed his career and was sacked. Having been reinstated he refused promotion and secured a Garda representative body (GRB) independent of other ranks. In 1978 the GRB tripled in number and became the Garda Representative Association (GRA). Jack Marrinan remained as General Secretary until his retirement in 1989. During his tenure the Garda representation evolved into a skilful and powerful negotiating body. Nearly all the advantages enjoyed by present day gardaí are built on the foundations he established. He passed away in 2015.

Garda Michael Conway was wages clerk in the Garda Depot. Michael Conway, now 92 years old, is quoted in *Changing of the Guard* describing how "The welfare of Gardai and their families had been talked about for years. In the late 1950s I took over the Garda Medical Aid. All I had was a table a chair and typewriter. I brought medical claims home to sort them out. The widows and children of deceased gardai were destitute, depending on handouts from St. Vincent de Paul. I helped set up the Garda Group Assurance Scheme".

In the 1960s, Michael teamed up with Jack Marrinan. They rejuvenated the Garda Benevolent Society which had been set up in 1936. This gave subvention and grants to the survivors of deceased members and annual grants to orphaned children.

*Changing of the Guard* is available in hardback from most good bookstores around Ireland and can also be ordered online from its publishers Currach Books [www.currachbooks.com](http://www.currachbooks.com)

## ABOUT THE AUTHOR - TIM DOYLE

The self-described 'delinquent who came from humble beginnings in Dunloe, the Black Valley and Mid Kerry,' Tim played football for his county with the greats of the time and was gently encouraged to join the Guards which he referred to as 'The Job', by a retired sergeant.

Having become a garda in 1966 Tim began his career in Dublin where he remained throughout his 37 years' service. En-route to New York's Gaelic Park he met Laois born Agnes McCarthy and 'discovered a place in his heart he didn't know existed'. They set up home in Clontarf and have four children and seven grandchildren.



Tim served as a Garda, Sergeant, and Inspector and spent the last seven years of service as head of security in Dail Éireann. Having lived a healthy life, always being physically fit, and a non-smoker and non-drinker, he was blindsided while in early retirement to be diagnosed with end stage kidney failure. He had to learn and adapt to undergoing dialysis treatment and the restrictions it brings including lifestyle and dietary. This new reality took its toll on Tim's emotional wellbeing for a time. Having kept a diary for much of his life, he had written two books on his career; *Peaks and Valleys* 1997 and *Get up them Steps* 2003, with proceeds donated to charity.

Despite the ever-increasing

limitations imposed on his lifestyle Tim adapted implicitly to the expertise of the Mater Hospital's Renal Staff. He began to write what he describes as his 'best book to date'. It was a 'road never travelled' but he was never alone with the company of numerous colleagues who served with him during the almost totally unrecorded, hugely transformational, and traumatic decades of 1950s to 1990s.



Ever grateful for the transplant he received five years ago, Tim has dedicated the book, *Changing of the Guard*, to the family of his kidney donor and the healthcare professionals who cared for him as well as the numerous Garda colleagues who responded with encouragement and support during the writing process. The majority of these were in retirement, but expressed delight that their story was being written by one of their own. For Tim, he says the process of writing it proved hugely therapeutic. In September 2021, *Changing of the Guard* was published by Currach Books.



**"The welfare of Gardai and their families had been talked about for years."**





**By AOIFE SMITH**

**To start I would like to wish you all a very Happy Christmas and peaceful 2023. As I have said before, I am a fan of Christmas. I do enjoy the time I get to spend with family and friends, the Christmas hustle and bustle, Christmas trees, fairy lights and the joy that it all can bring.**

**A**s I write this, I am very much aware of how Christmas can also be hard and challenging for some. I am not thinking about the financial pressures of Christmas, I am thinking of all of you who live with a chronic illness every day of the year.

Our bodies don't get a memo to take a break from illness because it's Christmas, it doesn't matter the day, you still must take medications, get to hospital appointments, turn up for dialysis or feel the physical effects that illness has on our bodies. Even in illness, Christmas still brings with it an expectation that we should be happy, and that expectation, whether it's from others or ourselves, only adds to the challenge of it all.

Our health and our happiness are intertwined. I don't know how many times I have heard people say *'Your health is your wealth'*, meaning that our health is the real wealth in life because it gives us the freedom to enjoy our life the way we choose.

But that certainly does not mean that people living with an illness cannot be happy. There are many ways of thinking of happiness. We can sometimes think of it as a continued way of being, that we should always feel in a happy state or that it is something we seek to find, associated with something out there in

the future, far from where we actually are.

"I will be happy when I get the new job, new car, new house or new kidney." These can be unrealistic expectations that we put on ourselves and lead us to miss out on the happiness of the here and now.

In general happiness is understood as the positive feeling we get from the pleasurable activities in which we take part in our daily life. It is an emotional state characterised by feelings of joy, satisfaction, contentment, and fulfilment. Because happiness tends to be such a broadly defined term, psychologists typically use the term 'subjective wellbeing' when they talk about this emotional state. I like this term because it reflects the individual's overall personal feelings about their own life and shows that happiness is subjective, it is what you personally experience it to be.

This said, there are thought to be two key types of happiness, which date back to a Greek philosopher, Aristotle, who made a distinction between two different kinds of happiness:

**Hedonia:** happiness derived from pleasure and which is often associated with doing what feels good, self-care, fulfilling desires, experiencing enjoyment, and feeling a sense of

# Moments of Happiness

They asked her...

*What is real happiness?*

She answered...

*'Happiness is not fulfilling every pleasure or getting every outcome you desire'.*

*'Happiness is being able to enjoy life with a peaceful mind that is not constantly craving more. It is the inner peace that comes with embracing change'.*

satisfaction.

**Eudaimonia:** the type of happiness which is derived from seeking virtue and meaning. It comprises a feeling that your life has meaning, value and purpose and it is rather associated with more fulfilling responsibilities, investing in lifetime goals, concern for the welfare of others, and living up to personal ideals.

Hedonia and Eudaimonia are more commonly known today in psychology as pleasure and meaning. Psychologists have recently also added in a component that relates to engagement. These are feelings of commitment and participation in different areas of life.

These different components can all play an important role in our overall

experience of happiness but the value of each one is highly subjective in how you view it to be. Some activities may be both pleasurable and meaningful while others skew one way or the other as we all experience happiness in different kinds of ways. Joy, excitement, satisfaction, gratitude, hope and contentment are all examples of positive emotions that increase our happiness. Happiness is an overall sense of experiencing more positive emotions than negative ones. By becoming more in tune with ourselves when we are experiencing these positive emotions we get a greater overall feeling of happiness in our lives. These activities can be anything from watching your favourite

tv show, volunteering for a cause you believe in, to watching your grandchild's beam of excitement waiting in line for a hot chocolate, or the laugh you shared with the taximan this morning on the way to dialysis. Happiness is not a goal you can simply reach and be done with. It is a constant pursuit that requires continual nurturing and sustenance.

Every person has unique life experiences and therefore unique experiences of happiness.

Have a lovely Christmas and I hope you all notice the happy moments!!



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](mailto: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.



**ORGAN DONOR AWARENESS  
WEEK 2023**

**20th - 27th May**

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





# COST OF LIVING SUPPORTS

**O**n the 27<sup>th</sup> September, the Minister for Finance Paschal Donohoe and Minister for Public Expenditure and Reform Michael McGrath announced Budget 2023.

Here is a summary of the Costs of Living Supports (Information courtesy of Citizens Information).

## OCTOBER 2022

Most people getting a weekly social welfare payment received a once-off payment of an extra week also called a 'double week' (minimum payment €20) as a cost-of-living support. It was paid the week starting 17<sup>th</sup> October 2022. The Department of Social Protection has a list of payments that qualify for the double week.

## NOVEMBER 2022

- Double Child Benefit payment
- Once-off payment of €200 to people getting the Living Alone Increase
- Once-off payment of €400 to people getting the Fuel Allowance
- Once-off payment of €500 to people getting the Working Family Payment
- Once-off payment of €500 to people getting Disability

Allowance, Invalidity Pension, Blind Pension and carers who qualify for the Carer's Support Grant. You will get one €500 payment only, even if you qualify for more than one of these payments or you are caring for more than one person.

People getting Partial Capacity Benefit will **not** get the once-off payment of €500.

The double Child Benefit payment was paid on 1<sup>st</sup> November, 2022. The once-off payments were paid the week starting 14<sup>th</sup> November 2022. The once-off Carer's Support Grant was paid on Thursday, 24<sup>th</sup> November, 2022.

## SOCIAL WELFARE WEEKLY PAYMENTS

The maximum rate of all weekly social welfare payments will increase by €12 with proportional increases for qualified adults and people on reduced rates of payment (January 2023).

## CHRISTMAS BONUS

A Christmas Bonus of 100% was paid in early December 2022 to people getting a long-term social welfare payment (minimum payment €20).

## CHILD BENEFIT

A once-off double Child Benefit

payment was paid (November 2022). This means an extra €140 per child was paid in November.

## FUEL ALLOWANCE

People getting Fuel Allowance received a once-off payment of €400 (November 2022).

The Fuel Allowance income threshold has increased from €120 to €200 above the applicable State Pension (Contributory) rate for people aged under 70 (January 2023).



People aged 70 and over can qualify for Fuel Allowance as long as their weekly means (which includes

their State Pension) is not above €500 per week for a single person and €1,000 per week for a couple (January 2023).

Disablement Benefit and half-rate Carer's Allowance will be disregarded in the means test for Fuel Allowance (January 2023).

#### LIVING ALONE INCREASE

People in receipt of a Living Alone Increase got a once-off payment of €200 (in November 2022).

If you receive Fuel Allowance and Living Alone Increase, you get both once-off payments.

#### PAYMENTS TO FAMILIES

People getting the Working Family Payment received a once-off payment of €500 (in November 2022).

The **Working Family Payment** income limits will increase by €40 across all family sizes (in January 2023).

#### DISABILITY AND ILLNESS PAYMENTS

People getting Disability Allowance, Invalidity Pension or Blind Pension received a once-off payment of €500 (November 2022).

People getting Disability Allowance and Blind Pension will be able to earn up to €165 from work without affecting their payment. This is an increase of €25 on the previous threshold of €140 (in January 2023).

#### CARERS

Carers who qualify for the Carer's Support Grant received a once-off payment of €500 (in November 2022).

Domiciliary Care Allowance (DCA) will increase by €20.50 from €309.50 to €330 (January 2023). DCA will be available for babies who remain in an acute hospital after birth for a period of 6 months (in January 2023).

# World Transplant Games



**W**e are now only four months away from the 24th World Transplant Games which will be held in **Perth, Australia** from April 15th-22nd. The first gathering of transplant recipients from across the globe since 2019 will see 60+ countries represented in 13 different sports. The World Transplant Games is a veritable festival of sports and culture to promote the importance of sport post-transplant and the value of organ donation for transplantation.

We are currently actively recruiting for the Ireland team. With competition based on ten year age categories and with 80+ years being the oldest category, you are never too old to get involved. With sports ranging from athletic, cycling, golf, and swimming to lawn bowls, darts and ten pin bowling, and with many other sports in between, there is definitely something for you!

If you would like to find out more about the Games you can check out the website [www.worldtransplantgames.org](http://www.worldtransplantgames.org) If you want to find out more about Transplant Team Ireland, check out [www.transplantteamireland.ie](http://www.transplantteamireland.ie) and drop an email to [teammanager@transplantteamireland.ie](mailto:teammanager@transplantteamireland.ie) if you have any questions about the trip such as fundraising, planning, medical paper-work, level of competition, etc.

All competitors are required to get

medically signed off by their transplant physician as being up to the trip and taking on their chosen sports. From a team perspective, the ethos has always been about 100% effort. Whether that gets you across the line in first place or your goal is simply to finish your event in the best time you can, that is very much up to you. It is about encouraging people to be active and engaged at a level at which they are comfortable.

Transplant Team Ireland has a great reputation at the World Games for our team spirit, our sense of fair play and our have-a-go attitude. Whether you are into physical sports or prefer the more skill based one, there's a 'you' shaped space in the team waiting!

The plan is to meet up in the ALSAA Sports Complex (next to Dublin airport; [www.alsaa.ie](http://www.alsaa.ie)) on a Sunday in January, February, and March in advance of departure. A great opportunity to meet others and enjoy camaraderie!

We have a team WhatsApp group and if you would like to join it just drop an email to [teammanager@transplantteamireland.ie](mailto:teammanager@transplantteamireland.ie)

Get in touch, ask some questions, and see if it is for you – you know it's the right thing to do!

- By Colin White



**Please join us for a Zoom meeting on Monday, January 23rd at 7.00pm about the Sports Programme, including the World Transplant Games. It will be advertised through our social media channels and to register you can contact [teammanager@transplantteamireland.ie](mailto:teammanager@transplantteamireland.ie)**



# Parkrun - A place for everyone

By COLIN WHITE



**D**o you enjoy walking, jogging or running? Are you looking for motivation to get/keep active at your own pace?

Parkruns are free, weekly, community events taking place all around the country. Bring a family member or friend. They also offer an opportunity to make friends there.

Saturday morning events are 5km and take place in parks and open spaces. On Sunday mornings, there are 2km junior parkruns for children aged four to 14.



The Parkrun movement is a positive, welcoming and inclusive experience where there is no time limit and no one finishes last. Everyone is welcome to come along, whether you walk, jog, run, volunteer or spectate.

Registration is completely free and only needs to be done once,



whether you intend to walk, jog, run, volunteer, or do a combination of all these things! Simply complete the registration form, ([www.parkrun.ie/register](http://www.parkrun.ie/register)), print your barcode, and head down to your local event.

With 134 events around the country to choose from, there should be one near you! Check out the Parkrun map on [www.parkrun.ie/events](http://www.parkrun.ie/events). Once you are registered you can get involved in ANY Parkrun anywhere in the world – all you have to do is bring your barcode. With more than 2,000 locations spread across 23 countries, there's no excuse to miss out even when you are travelling outside of Ireland!

There are so many reasons to take part! Whether you walk, jog, run, volunteer or spectate, you can learn new skills and enhance your health

and happiness in the great outdoors whilst making new friends, feeling part of your local community and improving your fitness and overall wellbeing.

You may also like to look at [www.sanctuaryrunners.ie](http://www.sanctuaryrunners.ie). According to their website, "at latest count we have 30 groups and over 4,000 members. Also we work with the Parkrun movement and our Sanctuary Runners can be found at 5k runs every Saturday morning where we also volunteer. And through it all our core values maintain – Solidarity, Friendship and Respect. Our aim now is to expand across Ireland but also to grow our movement internationally."

If you would like to share your Parkrun experiences and a photo (optional) in the next magazine, please email your write up and some photos to [Colin@ika.ie](mailto:Colin@ika.ie)



# Traditional Mince Pies



Using apple and less dried fruit makes this a great festive treat that is low potassium, low phosphate and low salt.

## Ingredients

### Homemade mincemeat

1 large Bramley apple  
25g low fat margarine  
50g glace cherries  
50g dark soft brown sugar  
1 teaspoon mixed spice  
100g mixed fruit peel  
1 tablespoon brandy or rum

### Pastry

225g plain flour  
150g butter  
2 tablespoons caster sugar  
1 egg  
3 tablespoons cold water



Make the pastry. Sift the flour and rub in the butter using your fingertips until the mixture resembles coarse breadcrumbs. Stir in the sugar. Separate the egg and mix the egg yolk with the water and add to the dry ingredients to form a smooth dough.



Wrap the dough in cling film and chill in the fridge for 30 minutes. Meanwhile, grate the apple and roughly chop the cherries then combine all the homemade mincemeat ingredients in a bowl and stir well.



On a lightly floured surface roll out half the pastry to 3mm thick. Using a 7.5-9cm fluted cutter, stamp out 12 circles of pastry. Gently press into a greased patty tin. Then cut out 12 smaller circles using the rest of the pastry and a 6cm cutter.

## VEGETARIAN

Prep: 45 mins Serves: 12  
Cook: 20 mins



Drop a teaspoon of mincemeat into each round, brush the edges with water and then stick the lids on top, pressing together to seal.



Brush the tops with egg white and make a small hole in the top for any air to escape.



Bake at 190°C/gas mark 5 for about 20 minutes. Leave in the tin for 5 minutes then transfer to a wire rack.

**This is a simple recipe to make homemade mincemeat for traditional mince pies. To save time you can buy ready rolled shortcrust pastry. For a fruit tart alternative, try using the pastry recipe and filling with jam in place of mincemeat.**

## NUTRITION

✓	Low phosphate	✓	Low protein
✓	Low potassium	✓	Low salt
27.0g	Carbohydrate	246.0Kcal	Energy
✓	Low fat	✓	Vegetarian

- Nutrition values are calculated per serving
- Kidney diet guidelines vary for each individual
- Consult your dietitian or doctor for the specific diet that is right for you

Reprinted courtesy of **Kidney Care UK** - ([www.kidneykitchen.org](http://www.kidneykitchen.org))





Jason Hassett  
and Lavinia Connell

# Army couple conquer KILIMANJARO

By GWEN O'DONOGHUE

**T**he couple's self-funded expedition was to honour the memory of Lavinia's late brother John, whose organs were donated after his untimely passing seventeen years ago. In doing the 5,895 metres climb, their goal was to increase organ donor awareness and to raise funds for the Irish Kidney Association (IKA). Weeks after the climb, Lavinia presented a cheque for €4396.50, the proceeds raised, to Carol Moore, IKA Chief Executive at the IKA's head office.

Lavinia, from Athlone, works in the Medical Corps at Custume Barracks Athlone, and Jason, from Tipperary, is a Company Sergeant in the Transport Corps at The Curragh. They are both experienced with physical endurance and roughing it outdoors. However, never before had they scaled the magnificent Mount Kilimanjaro venturing through four climatic zones from rainforest to moorlands, alpine desert, and in their final climb, the arctic region, and all within seven days.



The late John Connell

While army training helped Sergeant Lavinia Connell along with her partner, Company Sergeant Jason Hassett, to climb the world's tallest freestanding mountain, Mount Kilimanjaro in October, its altitude presented some unwelcome challenges in the final hours of ascent.

Lavinia managed to overcome the altitude sickness which tested her resolve, and left her temporarily blind in one eye, in the final hours of her ascent. Lavinia described it as an 'emotional moment' on reaching the summit at Uhuru Peak in Tanzania when she placed a photo of her late brother John, an organ donor, along with a forget-me-not flower, the Irish Kidney Association's emblem.







Lavinia



Jason and Lavinia

The couple are now back to work. Lavinia spoke about their unforgettable experience, "Kilimanjaro was the most amazing experience. Fitness wise it was no problem at all to us, due to our army training everything was easily done. However, the altitude sickness is unpredictable as to who will get it, and although I did everything advised to avoid it, like taking medication and staying hydrated, on summit night I got all the symptoms and I lost sight in my right eye. That seven hour summit was very tough. Thankfully my sight has fully returned."

"I honestly believe that

my brother John was by my side that night because all of the odds were stacked against me. Placing John's picture and the forget-me-not flower on the top of Kilimanjaro was such an emotional moment and it will remain with me forever."

Lavinia added, "My partner Jason was a wonderful support who was by my side throughout the challenge. We had local guides, organised through travel company Earth's Edge, who helped us navigate the territory of Mount Kilimanjaro. It was such an amazing twelve-day expedition which included seven days on Kilimanjaro mountain.

Before they set out on their expedition, Lavinia said, "I hope that by doing this climb we can increase organ donor awareness encouraging more people to carry the organ donor card while also raising funds for the IKA. I cannot speak highly enough of the organ donor coordinator that supported our family and gave us the reassurance we needed at a very difficult time after John's tragic accident.

In a Facebook post Lavinia, a mother of one, explained how just two weeks before her brother John's passing that her mother, Marie Connell, had overheard her son discussing with his cousin

his wish to be an organ donor in the event of his untimely death.

John was only 24 years old when he was in a motorbike accident which left him on life support for a week before he succumbed to his injuries. Amid their devastating grief, his family honoured his wishes, and the lives of five people were saved and improved by organ transplantation.

The Connells received word through the organ donor coordinator that the recipient of John's heart was the same age as him. In their sadness, it gives the family comfort to know that their hero John's heart is still beating in someone else and that man now has a wife and children.

Lavinia stated on her Facebook fundraising page, "We are doing the climb in memory of my brother John to raise awareness of organ donation and the importance of carrying a donor card".

In signing off her post Lavinia poignantly said, "Kilimanjaro will be the closest I will get to you while on this earth John".



Lavinia Connell, Jason Hassett at their cheque presentation to Carol Moore, Chief Executive, Irish Kidney Association.



# Friends raise €4k for the IKA in Dublin Marathon

Two Microsoft employees, Fintan Keogh and Dessie Murphy, who took part in the Dublin City Marathon on October 30th have raised close to €4,000 for the Irish Kidney Association.



A cause close to their hearts, Fintan's son Sean (age 24) is enjoying the successful longevity of the kidney transplant he received when he was just ten years old. Fintan from Firhouse in Dublin is an avid runner. He is grateful to the family of the deceased kidney donor who gave his son renewed good health and quality of life. He decided in advance of this year's marathon to fundraise for the Irish Kidney Association and rally the support of his Microsoft colleagues and friends to contribute while also raising awareness for organ donation for transplantation. Dessie Murphy, Fintan's friend and colleague at Microsoft in Grange Castle, Dublin, resolved to support Fintan by running in the marathon with him.

This was Fintan's 14th marathon and he said his goal has always been to just be able to cross the finish line which he succeeded in completing in 4 hours 27 minutes. Dessie Murphy, also from Firhouse, faced a bigger challenge to complete it, as he had sustained an injury in advance of race day. While the men ran together for the first 16 miles in their bright yellow IKA t-shirts, Dessie asked Fintan to run ahead of him as he wasn't sure he'd make it as he struggled with his injury. But he pushed through the pain and completed the 26.2 miles distance in a very respectable time of 4 hours and 40 minutes.

*By Gwen O'Donoghue*



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



Roger Hanratty (son to Seamus), Colin White and James Bannigan.

## Seamus Hanratty Poker Memorial raises €1,500 for IKA

This year's Seamus Hanratty Poker Memorial chose the Irish Kidney Association as its charity to support. Held on November 25th, they raised €1,500. Colin White, the IKA's National Advocacy and Projects Manager, was delighted to pay a visit to Ballybay in Monaghan on 5th December to meet locals Roger Hanratty (son of Seamus) outside Roger's Barber Shop and James Brannigan, for a cheque presentation.



# IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

## MEMBERSHIP APPLICATION FORM



BLOCK CAPITAL LETTERS PLEASE:

Mr. ☐ Mrs. ☐ Ms. ☐ FIRST NAME: \_\_\_\_\_

SURNAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

POSTCODE:  TEL: \_\_\_\_\_ MOBILE: \_\_\_\_\_

EMAIL:

We record this information in line with the Constitution of the IKA. You must be 18 years of age to become a member of the Association.

Please indicate if any of the following apply to you:

PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED

☐

YES

☐

NO

☐

Do not wish to disclose

Do you wish to receive our quarterly 'SUPPORT' magazine by  
Please tick 'No' if your household is already receiving it

Post?

☐

YES

☐

NO

Or Email?

☐

YES

☐

NO

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

Email?

☐

YES

☐

NO

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

☐

YES

☐

NO

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

☐

YES

☐

NO

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

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

SIGNATURE: \_\_\_\_\_ DATE: \_\_\_\_\_

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



# IKA Renal Support Centre, Cork

By Pat O'Sullivan

**W**ork is continuing at good pace in the IKA's in Cork Renal Support Centre. Work began on the Centre on 15th August this year. The builder has completed most of his construction work and the plumbers and electricians are now on site completing their first fix.

Windows and doors were fitted on 18th November, making the building weather tight. Professor Liam Plant was on site recently to view the ongoing works and was very pleased at the progress so far.

Within just a few hundred meters walking distance from Cork University Hospital, the Support Centre will consist of six ensuite bedrooms, an open plan dining and kitchen area. It will have a self-contained two-bedroom apartment with its own kitchen and bathroom.

A dedicated recreational room will also be available for families and

patients where they can sit and relax. There will be limited off street parking and a landscaped garden at the back for patrons to enjoy the outdoor space.

Attention is now turning to the interior of the house. The selection of kitchens, wardrobes, beds, and other interiors, are currently being considered.

As we go to press, so far €955,000 has been spent on the project including €910k on the purchase of the two neighbouring houses. €167,000 has been spent on fees in relation to planning, fire certificate applications and building development work so far.

The Cork IKA branch has played a very important role in fundraising and helping to push the project forward and so far the branch has raised €107,000. Our thanks to all who have so generously contributed man hours or financially to this.

Our thanks to Cathal Nolan of HSF Health Plan Ireland Saturday Hospital Fund who visited Donor House in November to present a cheque for €12,000 to Gary Davitt,

the IKA's Finance Property and IT Manager, for the Renal Support Centre in Cork.

It is expected that the official opening of the centre, by a dignitary (to be confirmed), will take place in early summer 2023. Patients will be utilising the centre in advance of this. Before its opening to service users, an Open Day is planned for a weekend day, for our members and patrons who will have an opportunity to view its facilities

If any of our members are interested in helping with sponsorship for anything to do with the house or know a company or individual that would like to support the Centre, please contact the branch secretary at: [secretarycork.ika@gmail.com](mailto:secretarycork.ika@gmail.com) or call 086 2755754.

A dedicated web page has been set up on <https://ika.ie/cork> where you can follow the progress of this project. The web page has a donation link and if you would like to contribute to the future development and running costs you can do so on the page.



Gary Davitt, IKA, receiving a cheque from Cathal Nolan, Saturday Hospital Fund



Prof. Liam Plant and Pat O'Sullivan



Upstairs bedroom





# CORK

By PATRICK O'SULLIVAN



Branch members receiving the cheque for €9,150.

## CORK LADIES MINI MARATHON

Over 70 people, family and friends of Frances O'Shea, came together in September and took part in this year's Cork Echo Women's Mini Marathon and a fantastic day was had by all.

The somewhat boisterous and colourful group raised an amazing €9,150 on the day which will go towards the refurbishment of the local Support Centre.

In addition to raising funds for this Centre, a key aim was to support Frances and all those waiting on organ transplants, as well as raising awareness for organ donation.

Special thanks go to Happy Feet running club, the parents of St Joseph's Mardyke N.S. and all those family and friends who played their part in such a special day.

## CASTLEMARTYR GOLF RESORT

The Cork Branch was invited by Liz Moloney, the Lady Captain in Castlemartyr Golf Club to the club for three days to promote Organ Donor Awareness and to raise funds for the Cork Support Centre.

Amanda Coyne, who is a member of the club and had brought great

honour to the club with her Golden exploits at this year's European Transplant & Dialysis Sports Championships was the main organiser of the three-day promotion. The weather was not kind to us over the first two days with wind and rain causing havoc on the golf course and restricting numbers that turned up. Thanks to all the members of the Branch, and to the ladies of the club who volunteered to man our information desk for three days.

## JOHNSON & JOHNSON

Members of the Branch were



Sheena McDonagh (right) and Liz Moloney, Lady Captain, Castlemartyr Golf Resort.



Jacinta and Tony Coyne



Sheena McDonagh and Amanda Coyne



The O'Shea family



## BRANCH MEETING

On November 1st, our branch held its first face-to-face meeting since the beginning of the pandemic. The meeting was held in the Rochestown Park Hotel. It was great to see so many faces again and to discuss Branch issues. A presentation was made to the members on the progress of the Support Centre in Cork with photos



invited to participate in the Johnson & Johnson DePuy family fun day in Ringaskiddy. Unfortunately, inclement weather made an appearance, but it definitely didn't dampen the spirits of family and friends who attended the event. Many chats were had, and it was definitely an enjoyable day out and a great opportunity to promote Organ Donor Awareness.





of the current progress and detailed drawings of the layout. An update report on the development is on page 60.

### VOLUNTEERS

From time to time the officers in the Branch will be looking for volunteers in helping to promote Organ Donor Awareness at various events. This usually consist of manning a desk for an hour or two,

handing out donor cards and maybe talking about their own personal experience. Volunteers can be from families and patients alike. If you would like to volunteer for future events, please contact the Secretary at [secretarycork.ika@gmail.com](mailto:secretarycork.ika@gmail.com) or 086-2755754. This mobile number is also the number for our WhatsApp group. If you would like to be kept up to date with all that is going on in the Branch text this number to be included.

### ANNUAL MASS

At the time of going to print our Annual Mass was about to take place so a full report and photos will be in the Spring Issue of this Magazine.

### BRANCH DETAILS

**Chairperson:** Denis Hyland  
**Treasurer:** Bernard Cronin  
**Board Member:** Pat O'Sullivan  
**Secretary:** Sheena McDonagh

### CONTACT DETAILS FOR THE BRANCH

Tel: 086-2755754

Email: [secretarycorkika@gmail.com](mailto:secretarycorkika@gmail.com)

You can also find us on Facebook under Cork Branch of the Irish Kidney Association and on Instagram [@ikacorkbranch](https://www.instagram.com/ikacorkbranch).

Our WhatsApp group is also a great way of keeping up to date with happenings in the branch and if you want to be included, please text the secretary's number above.

### UPCOMING EVENT

**Support meeting,  
February 7th – we will  
advise on the venue  
through our usual  
channels.**

## GALWAY

By PEADAR O'HICI

### LOURDES PILGRIMAGE

Last May the Galway Lourdes Pilgrimage Group decided to disband due to lack of new volunteers coming forward to help the association.

Also they felt that after 25 years they no longer had the energy to run the pilgrimage as it involves many meetings, fund raising, checking passports, etc., it was opportune to disband.

Under Charities' various legislations they divided their surplus funds among six voluntary

organisations in Galway. Galway IKA was one of the nominated groups which received a very generous donation of €4,000 at a function where representatives of the other recipient organisations were present.

On the 3rd of November our CEO Carol Moore met with the members of the IKA Galway Branch. She gave an overview of the work to date and exchanged ideas and views from the Galway branch. Eoin Madden unveiled a new publicity poster pictured on the right.



Eoin Madden, Peter Greaney, Carol Moore, Peadar O'Hici and Chris Curley.



Galway Committee with Galway Lourdes Pilgrimage group

# TIPPERARY

By ORLA HOGAN RYAN

## SEASONS GREETINGS

We hope that all our members have a good Christmas and enjoy it all.

## BRANCH NEWS

Mary Adamson, a branch member, is now a peer support volunteer and will be working actively in the role online in the New Year.

## FUNDRAISING

The Nenagh branch of the IKA held a 4-person scramble at Nenagh Golf Club from the 2nd-4th September.

James Dodd organised a golf fundraising event in Nenagh Golf Club and raised over €7,300. A great time was had by all.



Michael Fitzsimmons receives a cheque for €7,335 from the IKA Scramble from Liam Hogan (Captain, Nenagh Golf Club) with Michael Manning, Helen Leo and James Dodd



From left: Michael Fitzsimmons, Fergal Madden, Liam Hogan, Michael Manning, Helen Leo, Niall Sherlock and James Dodd



# LIMERICK

By SHAUN FALOOON

## FUNDRAISING

A table quiz fundraising night for the Irish Kidney Association was held at O'Driscolls Bar, Corbally in November. Over 60 people attended and €750 was raised.

## CKD INFORMATION EVENING

The Branch supported a semi-annual Pre Dialysis information evening held by the Renal Department of the UHL Regional Hospital Limerick on 19th November. Three dialysis patients shared their stories of their health

journeys. Shaun Faloon, the Limerick IKA Secretary gave a short presentation on the role of the IKA and its services. Renal Nurse Yvonne Crowe and Dr Liam Casserly, Lead Clinical Nephrologist, presented on the impacts of Chronic Kidney Disease and treatments available.



Table quiz night at O'Driscolls Bar



Participants at the Information Evening on 'Chronic Kidney Disease, A Lived Experience'

Also in attendance was Majella Corkery, Director of Nursing UHL Hospital, Anne Enright, Director of Gastro and Renal Departments, and Prof. Austin Stack.

## SEASONS GREETINGS

Wishing all our members an enjoyable festive season and best wishes for the New Year.





### SERVICE OF REMEMBRANCE & THANKSGIVING

We thank the Irish Kidney Association (IKA) Liturgy Committee and all at Donor House for the beautiful Service of Remembrance & Thanksgiving which they organised for organ donors, their families and the transplant community, which was broadcast by RTÉ 1 on Sunday, October 30th last. For all who have received the precious gift of a transplant, the service is truly special.

### WELCOME

Should any donor families, transplant recipients or IKA members, be planning an upcoming visit to Clare you are welcome to pay a visit to the Clare Branch IKA's memorial to organ donors at Friars Walk carpark in Ennis.

### 32-PEAK CHALLENGE

Emily Mason of Scariff and Roisin Boland (nee Treacy) from East Clare are completing a 32-peak challenge in aid of the IKA. Climbing the highest peak in each county in 2022, Emily said "all are welcome" to join them for their final climb of Moylussa, the highest peak in Clare, on Wednesday, December 28th at 11am. There will be tea/coffee and



Roisin Boland and Emily Mason.

## CLARE



Theresa Looney and Peggy Eustace

sandwiches for all in the hall in Ogonnolloe nearby from 2pm. They have raised just over €6,500 to date and have been "blown away" by the support they have received.

Emily's mum Maureen had a kidney transplant in 2010 and the IKA was an amazing support to her and her family. They will be forever grateful to the donor family and the IKA.

If you would like to donate you can do so via their Go Fund Me page, Emily and Roisin 32-Peak Challenge <https://gofund.me/9d3c765c>

### KILLARNEY HOLIDAY APARTMENT

On a recent visit to Killarney, Val and Peggy Eustace met up with Theresa Looney of the Kerry Branch IKA, who gave them the grand tour of the IKA holiday house in Killarney, which is truly amazing. The Clare Branch highly recommend that Clare transplant recipients and dialysis patients apply for a holiday in either Tralee or Killarney as both houses are open all year round, thanks to wonderful volunteers in the Kerry

Branch. Peggy thanked all in the Branch for the tremendous work they carry out at the Kerry holiday homes, all in a voluntary capacity. You can apply for a holiday in either Tralee or Killarney via the IKA website or contact the holiday coordinator, Deborah at Donor House. Thanks Theresa for coming to meet with us and for the cupán tae and apple tart we enjoyed while on



Val and Peggy Eustace

our visit to Kerry.

### THANKS

The Branch wish to thank Noretta Clifford for her assistance during the year especially in keeping our Facebook page updated, and also to Peggy Eustace for her continued assistance, advice and support.

### SYMPATHY

We extend our sincere sympathy to the families of the late Mannix Berry, Barefield, Ann Cooney, Tulla and Tom Whelan, Kilkee, who sadly passed away recently. The late Mannix, Ann and Tom were active members of the Clare Branch where they were always willing to help promote the organ donor card and fundraise for the association. Each of them will be greatly missed.

We also extend our sympathy to the former IKA National Honorary Chairman Colin Mackenzie on the sad passing of his dear wife Patricia. She will be greatly missed and fondly remembered by all who knew her through her work at the IKA Renal Support Centre. Patricia always had a kind word of encouragement for all that she met there.

May their gentle souls rest in peace.

### SEASONS GREETINGS

On behalf of the Clare Branch we wish our renal patients, transplant recipients, their families, the medical and nursing staff of the renal units, Branch members and volunteers, agus ar cairde go leir san IKA Nollaig Shona agus an bhliain nua iontach.

Enjoy the festivities.

# CAVAN/MONAGHAN

By KARL CRONIN



*Pictured (l-r): Ann McEneaney LCGB, Richard and Aine Conlon, IKA Cavan/Monaghan, and Ann Corrigan, LCGB at the presentation.*

## DONATION

The Cavan / Monaghan Branch were the grateful recipients of a cheque for €500 from the Lisdoonan Community Bingo Group on November 22nd at Lisdoonan Community Hall.

## CONDOLENCES

We extend our deepest sympathies to one of our longest

serving branch members, Mairead McMeel, on the recent untimely passing of her husband Noel.

May he rest in peace.

## MERRY CHRISTMAS

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



## BRANCH COMMITTEE

The Cavan / Monaghan Branch had its first in-person meeting in a number of years on October 24th in Cootehill.

A new Branch Committee was formed as follows:

**Chairperson:** Paul Donohoe  
**Secretary:** Richard Conlon  
**Treasurer:** Karl Cronin  
**Social Media:** Joy Kennedy

It was great to get together again to catchup, offer peer support and meet new members. If you are interested in attending our Branch meetings going forward, please let us know. Contact details for the branch are listed on the back page of this magazine.

# Acknowledgements of Deceased Loved Ones

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

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

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







Hello to everyone from Dublin North.

It has been a busy time for us since the last issue of *SUPPORT* magazine.

We have now returned to meeting face to face which has gone well so far.

## DUBLIN NORTH

By COLLETTE FOX

### FUNDRAISER

We had our fundraiser on September 29th in the Hilton Hotel at Dublin airport, which was organised by our Branch stalwart Ann Burke. Our heartfelt thanks to Ann for organising the annual event and for her ongoing sterling work for the Branch.

We are indebted to Ann's friend, singer Red Hurley, who has been a long-time supporter of the Irish Kidney Association's Dublin North Branch.

He was responsible for drafting in an impressive line-up of other popular singers and entertainers for the event including Mary Byrne, Linda Martin, Sil Fox, Eugene McCarthy, Ronan Collins and the

Sugar Cubes.

On the night there was a raffle with plenty of great prizes to be won. A beautiful tribute was made to remember two sadly missed friends of the Dublin North Branch who sadly passed away earlier this year, Ann Burke's daughter Claire and Patricia Mackenzie.

It was an enjoyable and successful night and the considerable sum of €4,007 was raised.

### CHRISTMAS MEET-UP

We had our Christmas meet-up at the Malahide Garden Centre on November 19th and a good time was had by all.

Dublin North Branch would like to wish you all a happy and healthy Christmas and New Year.

## CARLOW

By PAT MAY



### JJ CONNOLLY MEMORIAL

The Connolly family from Tullow held their annual fundraiser and memorial event in memory of their son JJ Connolly. Having to take a break as a result of COVID-19, they had held this event every year previously, since the death of JJ in 2014. This year's event was even more successful than before raising a total of €7,344. The money was divided between three charities, Cairdeas, Parkville Rangers, and the Irish Kidney Association.

After a Table Quiz in Dalton's Bar in Tullow, Jacinta and Gerry Connolly were photographed presenting a cheque for the proceeds raised.

### CHRISTMAS DECORATIONS

Jimmy Farrell, once again, sold Christmas decorations in his shop Daybreak in Graiguecullen and raised €100 for the Irish Kidney Association.

Jimmy's brother is a kidney transplant recipient and lives in Craughwell in Galway. I would like to take this opportunity to wish all our members a happy and healthy Christmas.

## WEXFORD

By MARIA DONLON

We held our first face to face branch meeting since Covid in the Talbot

Hotel, Wexford on Tuesday October 18th. The general feeling was it was good to get back to some kind of normality and there was a good turnout.

All were welcomed by our new branch Chairperson Pauline Atkinson.

We extend sympathy to the Donlon, Fisher and Holden families who all suffered recent bereavements.

Please continue to follow us on Facebook and we would of course love to see more of you at our meetings.



Find us on:  
**facebook®**



## IKA Christmas eCard

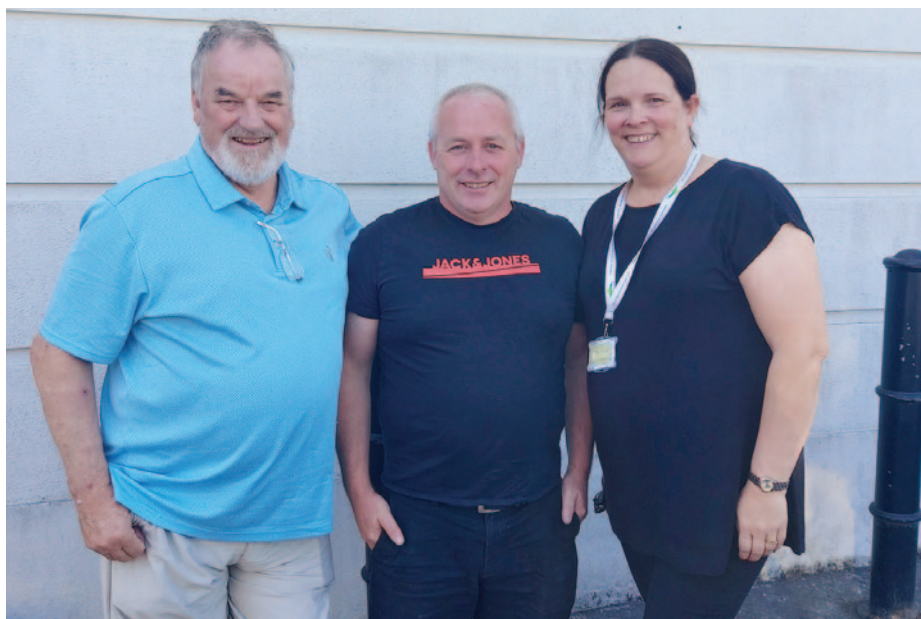
Looking for an eco-friendly option, or left it too late to send Christmas Cards this year?

Our eCard option is perfect for you, and is available in both English and Irish versions! For a minimum donation of €10 to the IKA, you can email a card to as many recipients as you wish.

Visit [www.ika.ie/christmas-ecard/](http://www.ika.ie/christmas-ecard/) for more information and to purchase yours.

# DUBLIN EAST & WICKLOW

By RACHEL O'HORA



Mick Dwyer, Declan Mulhall and his wife Sharon Mulhall who undergoes dialysis.

Hello again to all our members in the Dublin East and Wicklow branch. We hope you all are keeping well, and staying warm as the weather gets colder.

## SOCIAL MEDIA

Please follow us on social media for updates in between issues of *SUPPORT*. We have accounts on Facebook and Instagram; our Facebook (Dublin East and Wicklow IKA Branch) and Instagram (@east\_dublin\_wicklow\_IKA)

## KILMACANOGUE HORSE SHOW

The Kilmacanogue Horse Show took place on Saturday, July 23rd and was a resounding success. There were horses and ponies of all sizes, a huge variety of dogs, and all sorts of other interesting events.

We were lucky enough that the Show Committee decided to continue their association with their local branch of the IKA.

They presented us with a cheque for €1,000 in September. We are looking forward to attending the show again next summer!

## CHARITY CYCLE

Thank you to Declan Mulhall, who completed a 175km Ring of Kerry cycle in July, in aid of the IKA. Declan's wife Sharon undergoes dialysis treatment.

Declan presented Branch



Chairperson Bernie Dwyer with a cheque for €1,081 which was an amazing sum raised from his charity cycle!

## GLENCULLEN FUNDRAISING

The Glencullen community has been hard at work raising funds in support of a local young man, Cillian Doyle, who had a kidney transplant



in August. The community has raised close to €10,000 for the IKA. Well done to all involved!

You can read all about the fundraising events and wonderful community spirit on page 14 to 17.

## RESUMPTION OF MEETINGS

We urge all our members to attend Branch meetings, which have returned to being in-person. Our October meeting took place in St Anne's Resource Centre in Shankill and we decided to hold our November meeting in Roundwood Parish Hall.

Our next meeting will be in February. We don't meet in December as we will have our Branch members Christmas lunch, and the early nights in January make travelling treacherous for some of our members who have to traverse the Wicklow mountains.

If you are unable to attend in person, but still wish to be included by participating online, please let Rachel know on 085-1528436 and she will send you a Zoom link.

## CHRISTMAS LUNCH

Our Branch's Christmas lunch will be held in the Powerscourt Arms Hotel in Enniskerry on Saturday, December 10th. Please keep an eye on your mailboxes (both real and virtual!) for details and information on how to R.S.V.P.

We hope to have lots of lovely photos from this event in the Spring issue of *SUPPORT* magazine!

## DO YOU HAVE AN UPCOMING EVENT OR FUNDRAISER?

We would be delighted to add it to the events calendar on our website - just email [robbyn@ika.ie](mailto:robbyn@ika.ie) with the details (including what type of event it is, where, when it will be held, ticket and price information).





On behalf of the Branch executive and active members of the IKA Waterford Branch we wish to extend seasons greetings to all our members. It has been a busy summer season with all four apartments open in Tramore with visitors enjoying the best of the sunny South East.

We had numerous fundraising activities during the year generating funds for patients in the area.

We wish to extend heartfelt sympathies to those who have lost a loved one in 2022. We wish to acknowledge the passing of Seán Murphy a long-term member of the Branch along with many family members. Seán was a tremendous supporter of our Branch. He fundraised for many years during Organ Donor Awareness Week and also throughout the year in the guise of Jack Coffey in *Bachelors in Trouble*, well known to all and sundry in the county. Ni bheidh a leithéad ann arís.

### HALLOWEEN AT BRIDGIE TERRIES - HOLY MOLY!

A fundraising activity in Bridgie Terries, over the Halloween period, raised a whopping €1,305 for the IKA Waterford Branch. Patrons were extremely generous with their donations. We wish to thank Martin Carroll, Alan Daly and all the staff who facilitated this fundraiser for a very worthy charity. All funds raised locally are used to support patients in the area.

Our thanks to the staff members who got into the 'spirit' of the season and dressed up on the night.

If you, or anyone you know, is affected by kidney disease please feel free to contact [franceswaterfordika@gmail.com](mailto:franceswaterfordika@gmail.com) for further information.

## WATERFORD

By FRANCES MOYNIHAN

Frances Moynihan, Hon. Secretary Waterford Branch IKA, Martin Carroll, Manager Bridgie Terries, Maria Hickey presents the cheque, along with staff members Emma Norris and Emma Conroy.



Emma Norris, Mikey Veale, James Gough in the costume

### LIAM AND THE PIGGY BANK - ARE THE STARS OF THIS STORY!

On November 5th I had the pleasure, along with my husband Joe Moynihan, of visiting the Tubbritt family in Larchville, Waterford City. Our mission being to meet up with young Liam Tubbritt, age 4, who had saved his pocket money in his piggy bank. Liam loves drawing and did many sketches while we were there and is a fan of superheroes with a big poster of Buzz Lightyear on display!

Liam is donating his piggy bank savings to the IKA Waterford Branch. Liam's dad Bill, received a kidney and pancreas transplant in 2014. Liam is very grateful to the donor



Pictured are members of the Newtown /Kilmacthomas (Co. Waterford) Fundraising committee presenting a cheque for €4,000 to Ray Halligan, Chairperson IKA Waterford Branch. (L-R) Mary Bagge, Ray Halligan, Anne Power, John Joe Bagge and Martin McNamara. The money was raised through several successful fundraising events during the year.





Arasee Goinden Tubbritt, Liam Tubbritt, Frances Moynihan, Hon. Branch Secretary

family for helping to make his daddy so much better and all in the IKA who supported his family at the time.

Liam's piggy bank contained a whopping €98! What a lovely act by such a young boy showing such kindness and generosity. Truly an inspiration for the younger generation. Thank you Liam on behalf of all in the Waterford Branch. Thank you also to his mum, Arasee, and his dad Bill who treated us to true Irish hospitality on the day.

If you or anyone you know is suffering from kidney disease please feel free to contact Frances at [franceswaterfordika@gmail.com](mailto:franceswaterfordika@gmail.com)

**This is an item that Arasee wrote a few years back for National Kidney Month:**

**October!!!** It's a significant month for our family and me. My beloved Husband was born in October. He was given a second chance of life when he had his double transplants in October, 7 years ago!! And here we are, we became parents for the first time, to our precious son Liam, born the 7th of October.

I heartily thank his Donor and the Family, thanks to them, today we have a Family and I have my husband by my side, healthy and happy.

Our family thanks all the Kidney Donors, their families and all the lovely members of the IKA for everything they've done and they are still doing for everyone in need of their help. It's a great organisation. A great cause to raise awareness.

To my husband - We are a strong family who will stand hand in hand by your side, support you and love you with all our hearts.

**Be positive, Stay Determined, Raise kidney Disease awareness and wear green. ♥**

## DONEGAL

By **PATRICIA CALLAGHAN**

*Hello from the Donegal Branch.*

We are very grateful for the generous donations which we have received recently which include €50 from Clonleigh Co-Op, Newtowncunningham, and €100 each from The One Stop Shop in Newtowncunningham and also Lifford Credit Union.

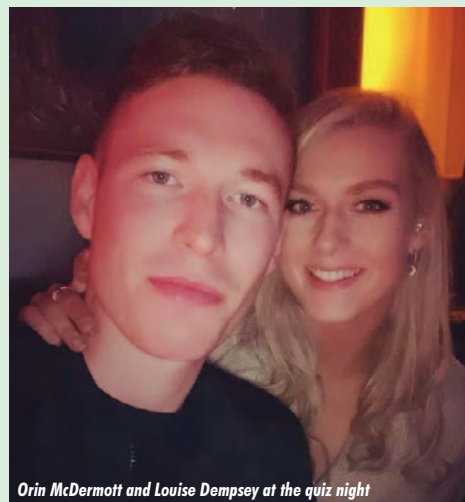
A very successful quiz night was held in the Ballybofey & Stranorlar Golf Club where a total of €460 was raised. We wish to thank everyone who supported this event.

We are planning to reschedule the Branch meeting, which was cancelled in November, to Tuesday, January 10th, 2023. This will be confirmed by email or post to all members.

On behalf of the Donegal Branch, we would like to wish you all a very happy Christmas and a healthy New Year.



Seamus McDermott, Kathleen and Cathal McGee



Orin McDermott and Louise Dempsey at the quiz night



Paul Kelly and Paul McDermott

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



Promoting organ donation - Jennifer and Seamus McDermott





## BRANCH GATHERINGS

We are still meeting on Zoom – usually once per month with the hopes of getting back to some face to face gatherings / events during 2023. If you would like to know the details of our upcoming meet-ups in 2023, please text Gerry on 086-0268223 and we will be happy to include you on the next meeting notifications. All are welcome to attend, patients and patient support/family.

## CONGRATULATIONS

Our congratulations are sent to Bernie Hopper who recently received a kidney transplant and has been recovering well. We wish her a long kidney life and the best of good health going forward.

Also, we congratulate Adrian Talpa who recently celebrated his first anniversary of successful kidney transplantation. We wish Adrian continued good health in the future.



Adrian, celebrating his one year anniversary with his mum Elizabeth.

## CONDOLENCES

Our condolences are sent to all Branch members who have lost loved ones in the recent past.

# DUBLIN SOUTH

By GERRY McKENNA



Gerry and Liz McKenna at the 'Circle of Life' garden in Salthill, Galway



## CIRCLE OF LIFE

On a recent trip to Galway, we visited the 'Circle of Life' garden in Salthill, Galway. We had both been made aware of this wonderful place from speaking to others who had been there and from reading about it at various times over the years. However, neither of us realised just how beautiful a place it is, until we walked inside.

Despite the busy road in front of the promenade, we found the garden to be very quiet and tranquil and the hum of the traffic seems to melt away after entering the garden.

Walking around inside it is apparent that this is indeed a special place of thanksgiving and commemoration of the 'gift of life'. It reminds us of the many organ donors there have been over the years in Ireland and the amazing 'gift of life' they have given to so many. It was a very pleasant visit and one of the highlights of our trip to Galway.

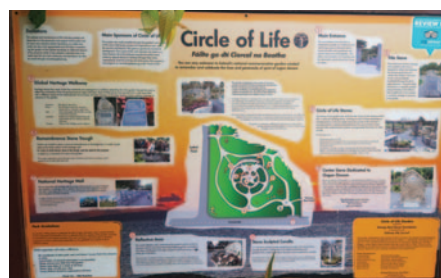
As we were about to leave, we received a text from one of our branch members, Bernie to share the great news that she had finally received a kidney transplant and



was recovering well in hospital. This made our visit to the 'Circle of Life' garden even more special.

We would thoroughly recommend a visit, to spend some time in this beautiful sanctuary, the next time you have occasion to visit Galway.

Well done to everyone who was involved with creating the garden and those maintaining it over the years.



More details and pictures of the garden can be found here: <http://www.organdonation.ie/circleoflife/garden.html>





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### IKA CEO VISITS BRANCH AND DIALYSIS UNIT

Members of our Branch welcomed Irish Kidney Association CEO Carol Moore to Sligo in November.

Carol updated us on the ongoing work she and the Directors are engaged in at national level on behalf of patients.

She informed members of the progress being made to have the IKA Renal Support Centre at Beaumont Hospital returned for use by patients and their families.

Beaumont Hospital sequestered the Centre in March 2020 for use during the COVID-19 epidemic.

Carol congratulated members of our Branch on all our work for the benefit of patients.

Branch members present informed the CEO of the various activities we are working on, particularly on our ongoing campaign for a new renal dialysis unit at Sligo University Hospital.

Carol promised her continued full support and the backing of her Directors for this campaign and our other activities.

We were delighted that after the meeting with her she visited the renal dialysis unit at Sligo University Hospital together with our Branch

## SLIGO

By BRIAN McHUGH



*Sligo Branch members with CEO Carol Moore (third from left) during her recent visit to Sligo.*

Chairman Sean Fowley and Treasurer Noreen Keane.

Carol spoke to dialysis patients and staff in the unit.

Afterwards she said the visit reinforced her view that a new unit was urgently needed.

Meanwhile our Branch Secretary has again written to the Minister for Health and to hospital management seeking an update on the progress with the provision of a new unit and we are awaiting a reply.

In correspondence some months ago we were promised an update before the end of the year.

### LATE ANITA BURKE

At our recent Branch meeting we passed a motion of sympathy to the family, friends and work colleagues of Sligo renal nurse Anita Burke who passed away on October 30th.

The late Anita will be greatly missed by all the patients she cared for in the renal dialysis unit at Sligo University Hospital.

### CHRISTMAS WISHES

Our Branch Chairman Sean



*Carol Moore with Branch Chairman Sean Fowley when Carol visited the Sligo Dialysis Unit. In the background at the entrance to the unit is a photo and plaque dedicated to our Sligo Branch founder, the late Angela McKinney.*

Fowley and Branch members send Christmas wishes and a happy New Year to all renal / dialysis unit patients and staff.

Also season's greetings to all our supporters in Sligo and further afield.



**FOR DONOR CARDS**  
**FREETEXT DONOR**  
**to 50050**





# IKA DIRECTORY



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