

# SUPPORT



SPRING 2021



**IRISH KIDNEY ASSOCIATION CLG**

(Company Limited by Guarantee)

**DONOR HOUSE, BLOCK 43A, PARKWEST, D12 P5V6.**

**TELEPHONE: 0818-543639 (KIDNEY) OR 01-6205306 • [WWW.IKA.IE](http://WWW.IKA.IE)**

**FOR ORGAN DONOR CARDS FREE TEXT **DONOR** TO **50050****

**CHARITY REGISTRATION NUMBER 20011260**

**ORGAN  
DONOR  
AWARENESS  
WEEK**

**27th March  
3rd April**



# Editorial...



In the Winter issue of *SUPPORT*, my editorial began with thanking the Irish Kidney Association (IKA) community for its support on the death of my father. So, it seems surreal, to once again be thanking the IKA community for its support on the death of my mother who died in January. I took time away from work, as we cared for her at home until she died. The Staff and Officers covered for me and supported me, so that I could be with her. This greatly eased the burden of what was a very difficult time for me and my family.

Too often, families, including many in the IKA community, have experienced grief, made worse by the fact that they could not be with their loved ones who died alone in nursing homes. It shows how far, as a society, we have to go in valuing and respecting people's dignity and basic human rights.

It is a great comfort to me, that I work for an organisation which 'gets it' and understands how our loved ones must come first and that people deserve to be treated with dignity.

I received so many lovely messages of kindness and support, and for that I am most grateful.

My deepest condolences to so many of you, who have also experienced the death of a loved one in the last year and beyond. There have been too many untimely deaths. Once this pandemic is over, we will find some way to properly remember and pay our respects to all those who died and whose funerals we could not attend due to COVID-19.

When I returned to work, my focus went straight back into trying

to improve COVID-19 vaccinations priority for transplant and dialysis patients.

While it is a decision between patients and their healthcare professionals on whether to vaccinate, we wanted to ensure that patients had the choice. We liaised directly with healthcare professionals and joined with patient advocacy group IPPOSI and international colleagues.

Our Board sent a letter to the Minister for Health and key decision makers. We involved the media and facilitated people to share their stories which highlighted how our community had been disproportionately disadvantaged.

We developed parliamentary questions (PQs) for the Oireachtas. We hosted an online forum for Branches to give feedback. When it looked as if change was not going to happen, we set up an easy-to-use online tool so that patients could email their local TDs. Using this tool over 9,000 emails were sent to public representatives, and, working collectively, our concerns could no longer be ignored.

Priorities for the vaccination roll-out were changed, renal patients and all transplant recipients between the ages of 16 to 69 being moved up the priority list under the newly assigned Group 4.

In more good news, as we go to print, vaccinations for renal patients have commenced, albeit with a temporary pause for AstraZeneca – welcome news for many of our readers and their families who have been cocooning for over a year. You

# Contents...



## FRONT COVER

*Mother and daughter Claire (right) and Sophie Cody, who underwent a living donor kidney transplant last November, at their local Skerries beach promoting Mother's Day and organ donor awareness.*

Photo: Conor McCabe

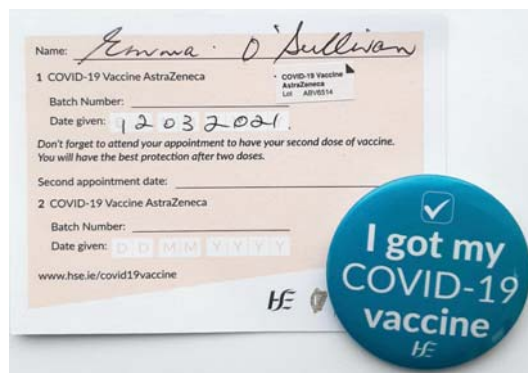
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can find more details in the article on page 4-7.

This successful result was based on the indisputable evidence we collated from Irish and international data which showed the increased risks for renal patients – dialysis and transplant.

Compiling reliable verified data, which strengthened our case for reprioritisation, takes considerable time and effort. Prioritising and communicating our key messages is a team effort, and securing media attention in a very busy world can be challenging. This detailed and time intensive work may not be very visible to you the members, whom we represent, but it is essential to making a successful case for better services for our community.

It also really helped that so many of you supported the campaign. It augurs well for the future, as we can build on these strengths and campaign for better services and supports once we agree with you, the members, what are the most important priorities for you.



Before this summer, we are planning an online members' session to understand, what is most important to you the members. Is it automatic medical cards, easier access to and more supports for home dialysis, ways to expand our kidney transplant treatments or upgrading of dialysis units? So, get your thinking caps on.

Our Board has also been working really hard, ensuring our organisation is compliant with the Charities Governance Code and also taking part in an independent review of the Board's effectiveness. We are very lucky to have so many committed and enthusiastic people who are prepared to give so much of their time and energy to the IKA, setting down a road map to ensure we are 'fit for purpose', remain successful in the future and that our members value our services.

Given the current pandemic conditions, it is difficult for many Branches to hold AGMs. The Board has considered the position and agreed AGMs may be deferred. So there will be no election of Branch officers or Board Directors this year. The National AGM will take place on the 4th of September.

You'll see the wide range of

activities that are going on as you read inside about World Kidney Day, plans for Organ Donor Awareness Week (27th March – 3rd April), a patient's experience of home dialysis, an individual's motivation to undertake fundraisers for the IKA, patient reviews of the new Dialyze clothing range, and branch notes. There is also a competition for gift vouchers for

renal-friendly ready meals and an update on organ donation and transplant statistics.

I am very conscious that many of our members are not online and may not be receiving our emails or taking part in our online forums. With Government services increasingly moving online, and the restrictions of COVID-19, such people are at a huge disadvantage. So, we have partnered with Age Action Ireland to provide up to six hours of free computer training, for people over 55 years. All you need is a smartphone. More details Page 31.

I could not finish without acknowledging, once again, our heartfelt gratitude and appreciation to organ donors and donor families. As we approach Organ Donor Awareness Week, their personal stories shared by donor families and transplant recipients reflect all that is good about people.

It has been my very real privilege to read about their experiences and understand their incredible strength, giving me and hopefully anybody who reads them inspiration and hope in a very challenging time.

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

**Accommodation Phone Number**

**087-4169907**

is **NOW** the way to make a booking in the **CLAYTON HOTEL DUBLIN AIRPORT** (which will be on the IKA account) through our Managers **Patricia, Frank or Simon.**

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# COVID-19 VACCINATION begins for kidney patients in GROUP 4



We have been working hard on your behalf, to improve the priority assigned to kidney patients for COVID-19 vaccination. Obviously, your decision to be vaccinated rests between you and your healthcare professionals.

This work includes liaising directly with healthcare professionals, international colleagues and politicians. We set up an easy-to-use online tool so that patients could email their local TDs. 9,142 emails have been sent and we have now ceased using the platform.

The prioritisation has been reviewed and the following gives an overview of the revised priorities for kidney patients.

## STOP PRESS

As we go to print, the AstraZeneca vaccination programme has just been temporarily paused.

We are planning an online information event which will be recorded and made available on our website. So visit our website for up-to-date information.

## KIDNEY PATIENTS: PRIORITY FOR VACCINATION

Criteria	Group 1	Group 3	Revised Group 4 Very high risk	Revised Group 5 High risk	Revised Group 7 High risk
Over 65 years and resident in long-term care	✓				
70 years and older		✓			
On dialysis and aged between 16-69 years			✓		
eGFR less than 15ml/min and aged between 16-69 years			✓		
eGFR less than 30ml/min and aged between 65-69 years				✓	
eGFR less than 30ml/min and aged between 16-64 years					✓
Have received transplant and aged between 16-69 years			✓		
Listed for transplant and aged between 16-69 years			✓		

Vaccinations have already started for people in group one and two (green columns) with these groups attending their GPs for vaccinations.

The very good news is that vaccinations are now being offered to people in the revised Group 4 (brown column).

## ARRANGEMENTS FOR REVISED GROUP 4

If you are in this Group 4, vaccinations are being organised by your hospital or dialysis unit, who will be in touch over the

next few weeks. For logistical reasons, in some cases the location may not be your hospital or clinic but may instead be in another public place such as a hotel.

People do not need to do anything, the HSE or your healthcare team will contact you when it is your turn to be vaccinated.

The HSE ask for your patience on this as it will take a number of weeks to identify, contact and arrange vaccinations for people who meet the criteria to be in this revised Group 4. Overall, there are 150,000 people in this Group 4.



**THE COVID-19 VACCINATION IS FREE. WHEN CONTACTED FOR YOUR VACCINATION APPOINTMENT, YOU WILL NEVER BE ASKED FOR PERSONAL BANK OR CREDIT CARD DETAILS.**

Different arrangements will apply for different allocation groups and these are being planned at the moment.

### WHICH VACCINE?

At this stage, the vaccine being given to Group 4 is AstraZeneca. The National Immunisation Advisory Committee (NIAC) has advised any of the approved vaccines are suitable for use for patients in this group and that the priority was to offer an effective vaccine as quickly as possible.

NIAC had also advised that it was preferable for kidney patients to get the mRNA vaccine if was available soon. The reason for this, was because NIAC considered that there was a better chance of a stronger immune response to the mRNA vaccine in kidney patients.

However, the HSE has looked into this and found that all the available deliveries of mRNA vaccine for the next few weeks are committed to the group of people aged 70 years and older. It would take weeks before there was mRNA vaccine available for kidney patients and it is safer to go ahead as soon as possible with the AstraZeneca vaccine. Vaccinations for kidney patients have now started.

Many of you will know that the first research study of the AstraZeneca vaccine showed protection of about 60%, however, further studies showed higher protection (above 80% in the most recent study), and all of the vaccines, which require two doses 12 weeks apart, provided excellent protection against severe disease.

The National Renal Office are recommending people take the AstraZeneca vaccine.

### SECOND DOSE OF VACCINATION

You will be contacted for the second vaccination, which will be due (per the manufacturer's instructions) 12 weeks after the first dose is given. The risk of being admitted to hospital with severe COVID-19 is reduced by 94%, 4 to 5 weeks after just one dose of the AstraZeneca vaccine.

### DO NOT GET COVID-19 VACCINE IF YOU:

- have had a severe allergic reaction to any of the ingredients in the vaccine, including polyethylene glycol (found in the Pfizer/BioNTech and Moderna vaccines) or polysorbate 80 (found in the AstraZeneca vaccine) – the vaccinator will ask you about any allergies you may have
- have had a severe allergic reaction to a previous dose of the vaccine
- currently have COVID-19 or symptoms of COVID-19 – wait until it has been 4 weeks since you first noticed symptoms, or you first tested positive
- have symptoms of COVID-19 – self-isolate (stay in your room) and phone your GP to get tested
- have a fever (temperature of 38°C or above) – wait until you feel better.

If you have had an immediate allergic reaction to any other vaccine or injectable therapy, you should talk to your doctor before getting your COVID-19 vaccine.

### REVISED GROUPS 5 AND 7

Planning for these groups is under way with further details on whether GPs or hospitals will deliver the vaccinations to come shortly.

For those patients falling into the eGFR groups (explained below) it is important you and your healthcare professionals know your eGFR, as this will ensure you obtain the correct priority.

GPs are currently giving the vaccine to Group 1 and 2. Many GPs have created a standby list in case people do not turn up for their appointments.

If you can travel to your GP within 30 minutes, let your GP know this and ask to be placed on their cancellation or standby list.

### WHAT IS eGFR?

eGFR - Estimated glomerular filtration rate is the best test to measure your level of kidney function and determine your stage of kidney disease. Your doctor can calculate it from the results of your blood creatinine test, your age, body size and gender.

The image below shows how eGFR is used to determine the stage of kidney disease.

*continued next page...*

			mg/mmol	mg/mmol	mg/mmol
GFR Stages	G1	Normal or high	> 90		
	G2	Mildly decreased	60-90		
	G3a	Mildly to moderately decreased	45-59		
	G3b	Moderately to severely decreased	30-44		
	G4	Severely decreased	15-29		
	G5	Kidney failure	<15		

## COVID-19 VACCINATIONS continued...

### 16 TO 17-YEAR-OLDS

Planning is underway to see how the Pfizer vaccine will be administered to this group. This is the only vaccine currently licensed for this group.

### UNDER 16-YEAR-OLDS

International clinical trials are under way to see how safe and effective these vaccines are for children.

### NOT IN ANY PRIORITY GROUP?

The NIAC has stated: *"This guidance will be subject to ongoing review as more evidence becomes available, about COVID-19 vaccines, their safety, efficacy, effectiveness, impact on virus transmission and population immunity, and as new vaccines are authorised by the European Medicines Agency (EMA) and become available in Ireland. Different weighting may need to be given to different values and priority of ranking as more evidence emerges."*

So, if you are not in any priority group yet, this may change in the future.

The speed at which researchers and healthcare professionals are working is inspiring. Expect further news and developments, with the situation constantly changing.

### MISLEADING INFORMATION

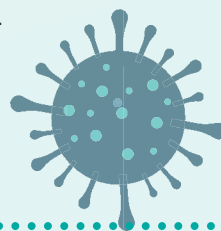
There is a significant amount of vaccination misinformation circulating, so we urge you to only consult reputable sources.

You might find the following sources useful:

- National Renal Office (<https://www.hse.ie/eng/about/who/cspd/ncps/renal/resources/>)
- HSE information on vaccination (<https://www2.hse.ie/covid-19-vaccine/>)
- The European Society for organ transplantation – COVID 19 vaccines studies [https://new.esot.org/the-covid-19-vaccine-studies/?fbclid=IwAR2qN0NYUJmmsil\\_gJXUiLKlIVCJ3HkPllmNPjQmno6ccPCIkblFV8ByeA](https://new.esot.org/the-covid-19-vaccine-studies/?fbclid=IwAR2qN0NYUJmmsil_gJXUiLKlIVCJ3HkPllmNPjQmno6ccPCIkblFV8ByeA)
- Transplant Australia webinar on vaccination (2nd half more relevant) [https://www.youtube.com/watch?v=gPjrHYTCi\\_Y](https://www.youtube.com/watch?v=gPjrHYTCi_Y)

### FUTURE UPDATES

We are working closely with the HSE to get answers to all your questions. To ensure we keep you updated, make sure you are on our email list.



For up-to-date information go to [www.hse.ie/covid19vaccinematerials](https://www.hse.ie/covid19vaccinematerials)

# COMING OUT OF HIBERNATION

After cocooning for over a year, there was almost a palpable sense of relief amongst the renal community when the COVID-19 vaccination rollout for many in Group 4 finally began in the second week in March.

Members of this 'very high risk' renal community, from all over the country, proudly posted photos of themselves receiving their long-awaited first vaccine dose on social media and WhatsApp groups.

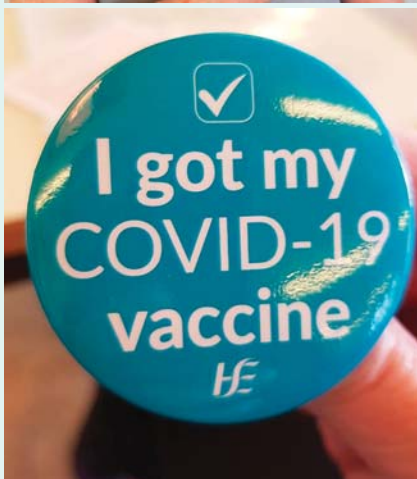
The programme for the AstraZeneca vaccine came to a sudden temporary halt, as a precautionary measure, due to inconclusive concerns reported around potential side effects.



John Moran, Dublin



Ned Crowe, Waterford with his wife, vaccination nurse Deirdre



Stephen Byrne, Kerry





# COMING OUT OF HIBERNATION



Phelim Pritchard, Cavan



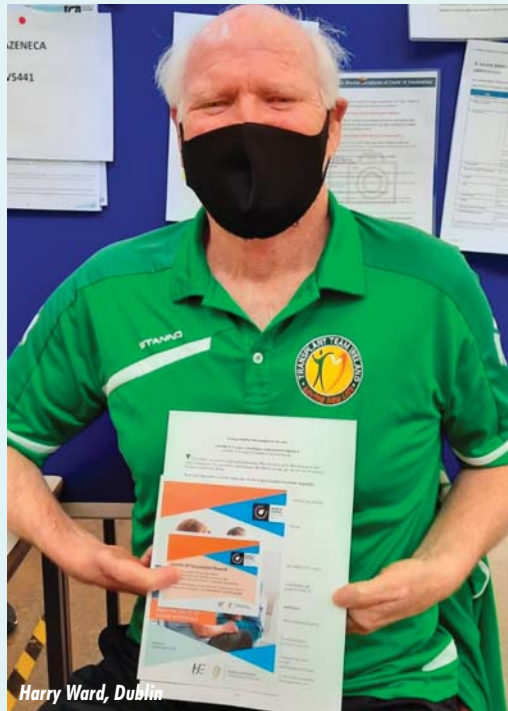
Emma O'Sullivan, Limerick



Eoin Hurley, Waterford



Betty Deering, Co. Offaly



Harry Ward, Dublin



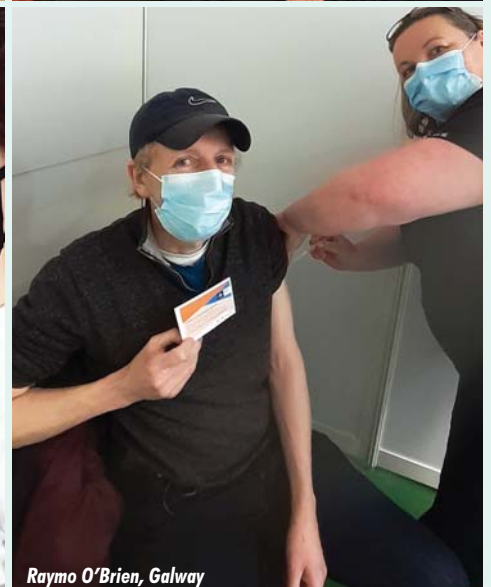
Oisín O'Gorman, Waterford



Denis Hyland, Cork



William O'Sullivan, Kildare



Raymo O'Brien, Galway



# ORGAN DONOR AWARENESS WEEK



*Angelina Ball,  
Actress and singer  
and aunt of a  
liver transplant recipient*

**The Irish Kidney Association (IKA) is pleased that the annual Organ Donor Awareness Week will proceed and take place from 27th March until 3rd April 2021.**

A year ago, the 2020 campaign was postponed and ultimately cancelled at short notice due to safety concerns when COVID-19 reached our shores. This impacted on our ability to have a physical presence 'on the ground' to promote organ donor awareness and the annual Awareness Week campaign. The necessity to social distance also hugely negatively impacted on our ability to raise funds during what is normally our flagship fundraising week. It was not safe for volunteer collectors, many in the high-risk category for COVID-19, to have a physical presence on the streets and in shopping centres in towns and villages around the country.

As COVID-19 still prevails a year later, and it looks like it will be around for some time, we have decided to proceed with an Organ Donor Awareness Week campaign this year but with most of our activities online. Being forced to move away from the traditional methods we previously employed, for the annual

campaign, made us find other exciting ways to run the campaign in a safe way some of which are outlined here.

The focus of all the IKA's organ donor awareness campaigns lies in emphasising the importance of discussion around organ donation i.e. have the conversation *#have the chat*. This year's campaign will be built around the theme *#Life is a Gift Pass it On* and *Share your wishes*. These feature on campaign materials including campaign posters. The campaign full colour posters are available in three languages, English,

Irish and Polish. We are embracing our heritage by including posters translated into Irish. The poster has also been produced in Polish to reach out to this large community. According to the last census in 2016 Poland is the largest non-Irish population in Ireland. All posters are available digitally and can be downloaded from the IKA's [www.ika.ie/donorweek2021](http://www.ika.ie/donorweek2021)

The words *#Life is a Gift, Pass it On* encapsulates the transient beauty of the 'gift of life' underpinned by the selfless generosity of human spirit. The importance of discussion with loved ones about organ donation and sharing your wishes is the cornerstone of campaign messages. This decision for families to donate a loved one's organs is made easier when they know they are honouring their wishes i.e. their wish to 'Pass it On'. Research indicates families are more likely to donate when they know they are following the wishes of their loved one.

Moving away this year from featuring a photo of a celebrity ambassador on the Awareness Week poster, this campaign poster carries the *Life is a Gift, Pass it On* theme and features photos of 32 grateful transplants recipients (including heart, lung, liver, kidney and pancreas). These people are enjoying over 400 years of extra life thanks to the gift of organ donation from deceased donors.

Similar to the Awareness Week

**ORGAN DONOR AWARENESS WEEK**  
SATURDAY 27TH MARCH – SATURDAY 3RD APRIL  
ALL OF THESE PEOPLE RECEIVED THE 'GIFT OF LIFE'

**#LIFE IS A GIFT PASS IT ON**

400+ YEARS OF EXTRA LIFE THANKS TO ORGAN DONATION

**Share your wishes**

Website: [www.ika.ie](http://www.ika.ie)  
Phone: 0818-543639

FOR ORGAN DONOR CARDS  
FREE TEXT  
DONOR TO 50050

**AN TSEACHTAIN FEASACHTA I LEITH DEONTÓIRÍ ORGÁN**  
DÉ SATHAIRN 27 MÁRTA – DÉ SATHAIRN 3 AIBREÁN  
BRONNADH AN BHEATHA AR NA DAOINE SEO AR FAD

**BRONNTANAS NA BEATHA CUIR AR AGHAIDH E**

NÍOS MÓ NA 400+ BLAÍN BHREISE DEN BHEATHA A BHUÍOCHAS LE DEONÚ ORGÁN

**Roinn do chuid mianta**

Website: [www.ika.ie](http://www.ika.ie)  
Phone: 0818-543639

LE CÉARTAI DEONTÓIRÍ ORGÁN A FHÁIL  
CUIR TEACS SAOR IN AISCE LÉIS AN  
BHFOCAL DONOR GO 50050

**TYDZIEŃ ŚWIADOMOŚCI DAWCÓW NARZĄDÓW**  
SOBOTA 27 MARCA – SOBOTA 3 KWIECIAŃ  
WSZYSCY CI LUDZIE OTRZYMALI 'DAR ŻYCIA'

**#ŻYCIE JEST DAREM PRZEKAZ JE DALEJ**

PONAD 400+ LAT ODDATKOWEGO ŻYCIA DZIĘKI ODDANIU NARZĄDÓW

**Podziel się swoimi życzeniami**

Website: [www.ika.ie](http://www.ika.ie)  
Phone: 0818-543639

W PRZYPADKU KART DAWCÓW  
NARZĄDÓW WYŚLI SMS O TREŚCI  
DONOR POD NUMER 50050



Tomas Caffrey (21), a liver transplant recipient



Kidney patient John Egan (30), a former Westmeath Senior footballer



dated poster, a generic poster is also available which can be used all year round. This includes an additional ten transplant recipients who, between them, are enjoying more than 520 years of extra life.



which celebrates organ donation, symbolising the hope organ donors provide to patients in need and their families. By lighting up public sites in green we are drawing attention to organ donation being an integral part of active citizenship and that we should have the family discussion about our organ donor wishes.

From dusk to dawn over 30 locations will be lit up in green, undoubtedly prompting much discussion around organ

donation.

We are encouraging lots of sharing of messages in support of organ donation on social media and will be prompting some of these through videos.

Well-known personalities and Irish diaspora from around the world, (including New Zealand, Malaysia, Australia, Canada, America, Europe and South Africa), who have been touched by organ donation, have come behind the videos of passing on the organ donor card.

The talented and widely acclaimed actress and singer Angeline Ball is lending her support to this initiative as it is a cause close to her heart. Her niece Saoirse Perry underwent a liver

transplant. Former ambassadors for organ donor awareness, who feature on the videos promoting *Life is a Gift*, Pass it On, include Vivienne Traynor, Mary Kennedy and Ray D'Arcy.

In social media posts promoting Organ Donor Awareness Week the following hashtags were

employed: #LifelsAGift,

#DonorWeek21 and tagging the Irish Kidney Association (@IrishKidneyAs on Twitter, @IrishKidneyA on Instagram & @IrishKidneyAssociation on Facebook).

We also encourage our members and the wider public to support the campaign by organising their own socially distanced awareness activities and challenges. As well as generating organ donor awareness, some of these might incorporate a fundraising aspect where funds can be channelled through online platforms such as Facebook or GoFundMe or asking people to donate directly to the IKA through its website platform [www.ika.ie/donorweek2021](http://www.ika.ie/donorweek2021)

Some people commenced a 21 Day Walking Challenge on World Kidney Day (11th March) which would conveniently conclude during Organ Donor Awareness Week. The beauty of the challenge is that you can chose to commence it at any time but commit to doing it on 21 consecutive days. While undertaking it we encourage people to post photos of their progress online whilst giving a mention to Organ Donor Awareness Week. More details on this Walking Challenge are on page 47.

The IKA is grateful to the Irish Pharmacy Union for distributing our awareness posters to 1,850 pharmacies around the country. The poster will also be a background star on the RTÉ *Faircity* set for some of the scenes output during Awareness Week. For three weeks' leading up to and including Organ Donor Awareness Week Adshel poster sites, located in 30 shopping centres around the country, displayed the campaign poster. A full list of sites is available on the IKA website.

The Mansion House, Dublin



# MAP OF HAEMODIALYSIS UNITS USED BY PATIENTS FROM THE REPUBLIC OF IRELAND AND DIALYSIS PATIENT NUMBERS AS OF 31/12/20





# CHRONIC DIALYSIS & TRANSPLANT PATIENTS - 31/12/20

Dialysis Facility	HAEMO	HOME DIALYSIS		TOTAL DIALYSIS	TRANSPLANT	TOTAL ESKD
ADULTS	HD	HHD	PD	PATIENTS	AT CLINIC	PATIENTS
Beaumont	169	20	54	243	782	1025
Mater	84		9	93	135	228
Fresenius Northern Cross	89			89		89
Beacon Drogheda	99			99		99
Cavan	63			63	19	82
St. Vincent's	72		6	78	170	248
Beacon Sandyford	112			112		112
Tallaght Hospital	106	4	57	167	339	506
Beacon Tallaght	102			102		102
Tullamore	97			97	65	162
B Braun Portlaoise	22			22		22
Cork	168	18	30	216	391	607
Waterford	116	2	33	151	186	337
Fresenius Kilkenny	61			61		61
B Braun Wexford	44			44		44
Tralee	56			56		56
Limerick	132	11	14	157	136	293
Fresenius Limerick	82			82		82
Galway	76	3	22	101	232	333
B Braun Galway	67			67		67
Castlebar	70			70		70
Letterkenny	60			60	77	137
Sligo	57			57	34	91
Northern Ireland	5			5		5
<b>ADULT TOTALS</b>	<b>2009</b>	<b>58</b>	<b>225</b>	<b>2292</b>	<b>2566</b>	<b>4858</b>
<b>CHILDREN</b> Temple St, Crumlin	<b>5</b>		<b>13</b>	<b>18</b>	<b>55</b>	<b>73</b>
<b>OVERALL TOTALS</b>	<b>2014</b>	<b>58</b>	<b>238</b>	<b>2310</b>	<b>2621</b>	<b>4931</b>

As of December 31st, 2020 there were 4,931 people with End Stage Kidney Disease (ESKD) registered in Ireland. With 53.2% of these living with a functioning kidney transplant, Ireland continues to be one of the few countries in Europe with over half of its ESKD population being treated with a functioning transplant.

The percentage of patients on home therapies (peritoneal dialysis and home haemodialysis) continues to remain comparatively low with a total of only 6% of the ESKD population being treated in this way. The COVID-19 pandemic has seen an increased interest in home therapies from patients and it is encouraging to hear that some of the

hospitals are working to increase their capacity to offer these treatments.

With one-third of centre-based dialysis being delivered by commercial providers, the HSE has to be careful not to lose sight of the need to have the capacity to offer home therapies. World Kidney Day in March had the theme 'Living Well with Kidney Disease' and this includes patients having the choice of the optimal form of treatment.

2020 was a unique year for so many reasons. We saw the number of people living with a functioning transplanted kidney actually drop. It may have only been by 4 but when we are used to seeing increases in the range of +/- 100, it is significant and a reminder that we need to re-double our efforts to promote

## IRISH DIALYSIS PATIENTS - 31/12/20

	Patients	%
<b>Centre Haemodialysis</b>	2014	87.2
<b>Home Haemodialysis</b>	58	2.5
<b>Peritoneal Dialysis</b>	238	10.3
<b>Total Dialysis Patients:</b>	<b>2310</b>	<b>100</b>

## IRISH ESKD PATIENTS - 31/12/20

	Patients	%	PMP
<b>Transplanted</b>	2621	53.2	527
<b>Centre Haemodialysis</b>	2014	40.8	405
<b>Peritoneal Dialysis</b>	238	4.8	48
<b>Home Haemodialysis</b>	58	1.2	12
<b>Total ESKD Patients:</b>	<b>4931</b>	<b>100</b>	<b>992</b>

PMP = Per Million of Population

Population 4,977,400

continued next page →

organ donation amongst the public whilst also advocating for increased resources to support greater rates of transplantation.

The number of patients with ESKD continues its inexorable climb as we reached 4,931. We are now looking at an incidence of recorded ESKD of 1-in-1000 of our national population or 0.1%. That may seem insignificant in the larger scheme of things but it means 'everything' for those affected by ESKD. It is noteworthy that the cost of treatment is disproportionate to the number of patients when looking at the overall health budget. Previous governments have realised that treatment with a transplanted kidney is significantly more cost-effective than treatment by dialysis. Investment in transplantation makes good sense as it is the gold medal standard of treatment for those suitable for transplant AND it is more cost efficient too.

Reflecting on the past decade we have seen significant growth in the provision of dialysis by the commercial providers with an increase of 104%. The dialysis population has gone up by 29% whilst the transplant population has gone up by 37%.

The real stand out observation from the last ten years is that whilst the population of our country increased by 11.4%, the number of people with ESKD increased by 33%. This can be partly attributed to improving rates of diagnosis but at the same time, it is a worrying trend. The health service needs to take this growth into account when developing renal services nationally and

looking at the bigger picture. There needs to be an understanding of the reasons behind the disproportionate growth in people with ESKD to understand how to address it.

Only 296 (12.81%) patients are on 'home therapies' across the country. I expect that more people will consider the options of peritoneal and home haemodialysis in the future, if they are deemed suitable, however the reality is that not everyone is.

Over half of all patients, 53.15% (2,621) are transplanted. I cannot emphasise enough how few countries there are with this high level of transplant versus dialysis patients. It is the pride of our renal services and making the transplant figure even better is a goal everyone aspires to.

The one-year changes show 60 extra haemodialysis patients and 97 more transplant patients at clinic. The ten-year comparisons which highlight the growth in

haemodialysis is absorbed mainly by the contracted satellite units which more than doubled in patients and, over the years, went from 5 to 9 new centres across the country. Home haemodialysis has hovered around 50 patients in recent years and peritoneal around 200 or so.

The overall growth of patients from 3,699 to 4,931 (33%) in the ten-years was expected and there is no reason to believe that the level of annual growth of 3.3% will not continue.

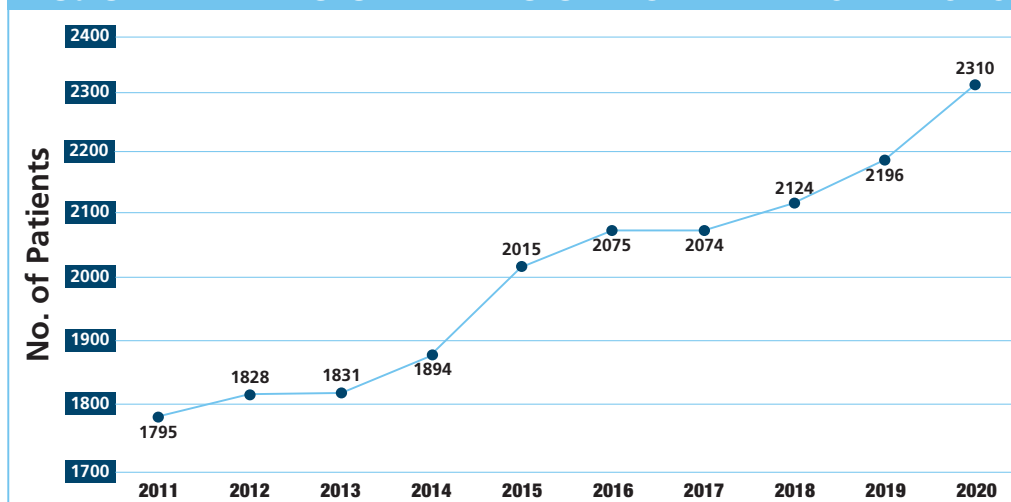
## ONE-YEAR COMPARISONS

TREATMENT	2020	2019	% CHANGE	PATIENTS
<b>CENTRE HAEMODIALYSIS</b>	<b>2014</b>	<b>1933</b>	<b>+4.2%</b>	<b>+81</b>
<b>PERITONEAL DIALYSIS</b>	<b>238</b>	<b>211</b>	<b>+12.8%</b>	<b>+27</b>
<b>HOME HAEMODIALYSIS</b>	<b>58</b>	<b>52</b>	<b>+11.5%</b>	<b>+6</b>
<b>TRANSPLANT</b>	<b>2621</b>	<b>2625</b>	<b>-0.15%</b>	<b>-4</b>
<b>ESKD TOTAL</b>	<b>4931</b>	<b>4821</b>	<b>+2.3%</b>	<b>+110</b>

## 10-YEAR COMPARISON RENAL ADULT PATIENTS BY TREATMENT TYPE

	2020	2010	CHANGE IN NO.	CHANGE IN %
<b>HSE Hospital Renal Unit</b>	<b>1205</b>	<b>1069</b>	<b>+136</b>	<b>+12.7</b>
<b>HSE Hospital Satellite Unit</b>	<b>126</b>	<b>144</b>	<b>-18</b>	<b>-12.5</b>
<b>Commercial Satellite Unit</b>	<b>678</b>	<b>332</b>	<b>+346</b>	<b>+104.2</b>
<b>Northern Ireland</b>	<b>5</b>	<b>9</b>	<b>-4</b>	<b>-44.4</b>
<b>Home Haemodialysis</b>	<b>58</b>	<b>11</b>	<b>+47</b>	<b>+427.3</b>
<b>Peritoneal Dialysis</b>	<b>238</b>	<b>206</b>	<b>+32</b>	<b>+15.5</b>
<b>All Dialysis</b>	<b>2310</b>	<b>1793</b>	<b>+517</b>	<b>+28.8</b>
<b>Transplant (Adult)</b>	<b>2621</b>	<b>1906</b>	<b>+715</b>	<b>+37.5</b>
<b>TOTAL ESKD PATIENTS</b>	<b>4931</b>	<b>3699</b>	<b>+1232</b>	<b>+33.3</b>
Population in Ireland	4,977,400	4,470,000	+507,400	+11.4%

## NO. OF PATIENTS ON DIALYSIS DECEMBER 2011-2020







# AGM

Given the current pandemic conditions, it is difficult for many Branches to hold AGMs. The Board has considered the position and outline the following arrangements:

1. Branches will defer their AGM until 2022.
2. There will be no election of Officers of branches or Board Directors.
3. Branches may replace Officers of branches and Directors who wish to stand down.
4. The existing Board and National Officers will remain in place for a further year.
5. This year's **National AGM** will take place on **Saturday, September 4th, 2021.**

**FURTHER DETAILS WILL BE SENT IN DUE COURSE**

## COVID-19 HAEMODIALYSIS TRANSPORT

The **Irish Kidney Association** is pleased to confirm the **30c per kilometre**, for self-management of your own transport from your home to your dialysis centre and return, is now available from the HSE.



For the duration of this COVID-19 outbreak, patients who access their own transport and opt to self-drive or engage a family member, friend or carer to bring them to their haemodialysis session, are reminded that they are eligible to claim a stipend from the HSE. They can claim **30c per kilometre** travelling directly to and from the Haemodialysis Parent Renal Unit or HSE Contracted Haemodialysis Unit **that is closest to their place of residence**. Each unit has procedures for reimbursement.

Eligible patients will receive a refund for the reasonable costs of taking their own transport to

attend their regular haemodialysis sessions only through their normal channels.

Taxi providers under HSE tender who are providing this service have confirmed that they are open for business as usual and have no issue with continuing to provide this service.

**Eligible journeys:** Reimbursement will be made for all patient journeys directly to and from regular haemodialysis sessions. On average this will be 6 journeys per week, based on patients attending for 3 times per week dialysis.

# THANK YOU MUM!

By GWEN O'DONOGHUE

**Mother's Day this year was extra special for a Dublin woman who donated a kidney to her ailing teen daughter just three months before.**

Just three months after their living donor kidney transplant, mother Claire Cody and her kidney recipient daughter Sophie (14) stepped out on their local strand in Skerries for a photo opportunity, organised by the Irish Kidney Association (IKA), to celebrate Mother's Day. The pair celebrated this special day by beginning a 21-Day Walking Challenge, in support of the IKA and organ donation, which they finished at the end of Organ Donor Awareness Week (27th March – 3rd April). [www.ika.ie/donorweek2021](http://www.ika.ie/donorweek2021)

When Sophie Cody kissed goodbye to her mother Claire, as the teen was admitted to Temple Street Children's Hospital on Wednesday November 25th, 2020, they both hoped that the next time they would see each other, Sophie would be successfully transplanted with her mum's donor kidney! It would be 17 days before mother and daughter would see each other again on December 12th and two more days before Sophie could return home.

On Monday morning, November 30th, 2020, Claire from Skerries, Dublin was wheeled down to the operating theatre in Beaumont Hospital, for the removal of one of her healthy kidneys by transplant surgeon Dilly Little. The retrieved kidney was then fast-tracked across the city to Temple Street Hospital, where surgeon Gordon Smith and his team were waiting to perform the transplant operation on Sophie.

Sophie's transplant ended 22 months of upheaval which began in February 2019, when she was suddenly catapulted into kidney failure and hospital dialysis treatment at Temple Street Hospital.

Her mother Claire described, "it has been an emotional journey for all our

Sophie with her dad Damian





family since Sophie's shock diagnosis two years ago. Our world was turned upside down and it took an emotional toll on Sophie as she was coming into her teenage years. Then COVID-19 came along and that compounded our anxiety levels. Sophie went to skin and bone and she was very pale but since her transplant she is putting on weight again and she looks really healthy now, with colour back in her cheeks and she has a positive outlook."

In the days that followed post-transplant, as visitors were restricted in both Beaumont and Temple Street Hospitals due to COVID-19, the mother and daughter remained in two different hospitals, eagerly waiting to be reunited with one another.

Claire explained, "it felt very surreal when I woke up from my operation. All I wanted was to see that Sophie was ok and to hug her but we had to settle for 'Facetime'. It was an emotional reunion for both of us when I finally got to visit her in Temple Street on the same day I was discharged from Beaumont, five days after my surgery and seventeen days after I last saw her, as she was admitted to Temple Street a few days prior to her operation.

For almost three weeks, Sophie was confined to her hospital room. Obviously, there was very valid safety reasons for this measure but for our 14-year-old, with all her renewed energy from the successful transplant, she felt isolated and was going 'doolally' as she longed for the day she could finally go home."

It was a particularly difficult time for Damian Cody also, not to be able to visit his wife and with limited visits allowed by Temple Street Hospital to see Sophie, both of them having undergone major surgery.

Damien left his wife at the doors of Beaumont Hospital the day before her operation and didn't get to see her again until 6 days later. He also was separated from his youngest daughter Amy (11).

Amy left the family home two weeks before the transplant operations to allow her other family members to cocoon safely. She stayed with her nanny, Claire's mother Eileen, so that Amy could continue to attend national school and ensure the safety of her family from COVID-19. The physically disconnected family of four kept in touch through phone calls and video.



Claire left hospital five days after donating her kidney. It was another 12 days before Sophie returned home, was reunited with her family and they could enjoy Christmas Day together, which was in stark contrast to December 25th, 2019 when Sophie was very unwell.

Relieved that the transplant was a success, Claire explained, "It is wonderful to have Sophie's health restored and she can now enjoy a new lease of life. I was aware that she could be waiting on the transplant list for a long time. I didn't want to see her struggle any longer, so I made the decision to put myself forward as a living donor. I was confident that I was physically fit enough to undergo the operation. I am healthy and go to the gym regularly and play tennis also.

"I was delighted when we finally got the results of tests that confirmed I was a suitable match. But COVID-19 temporarily halted the living donor screening process which was to begin in March, so we had to wait a few months before the programme restarted."

"Sophie's kidney failure came about very suddenly in February 2019 when she became almost fatally ill, as her blood pressure sky-rocketed. Up until then, it had not been known that her kidneys hadn't really developed since birth, and it is thought that this may have been because she was born nine weeks premature.

*continued next page...*

***"It is wonderful to have Sophie's health restored and she can now enjoy a new lease of life. I was aware that she could be waiting on the transplant list for a long time. I didn't want to see her struggle any longer, so I made the decision to put myself forward as a living donor."***



*Sophie with her younger sister Amy and their dog Freddy.*

"Sophie was put on haemodialysis treatment almost immediately. She was just entering her teenage years and her life was suddenly turned upside down. It was difficult for her and on the rest of her family too as we felt helpless. We learned to manage our lives around her illness and her regular hospital visits for dialysis treatment, which were sometimes as much as five days a week, for 4 hours at a time.

"It was tough on her as her diet and fluid intake were considerably restricted and the normal happy life she had been enjoying was altered dramatically. She still attended her school in Skerries Community College and was also schooled in Temple Street on her dialysis days.

Sophie said, "I am so grateful to have received the gift of a kidney from my mother and I feel so much better now. I can't wait for the restrictions and lockdown to be over so that we can celebrate properly with our friends and family. For Mother's Day, we will pamper mam, we will make the most of being together and my dad will cook for us."

Claire remarked, "We have both recovered well since our operations and are grateful that Sophie is back to good health. However, the challenge now is to keep her safe as she will be taking immune suppressants for the rest of her life.

"Sophie is in the extremely high-risk category for COVID-19, as the rollout

of vaccines currently lists her among the very last in line, in 15th place, to receive a vaccine. Part of this is because the vaccine has not been tested on young teenagers.

"We are so grateful to the medical, nursing staff and transplant teams at both Temple Street and Beaumont and our transplant surgeons Gordon Smyth and Dilly Little and, to the staff in Michael's C Ward in Temple Street who cared for Sophie when she was receiving dialysis.

"A big 'thank you' to John our taxi driver, who ferried Sophie to and from the hospital, and also to Paddy Cox of Dialyze Clothing, who sent Sophie a big hamper just before she went to hospital for her transplant.

"I'd also like to thank our extended family for their loving care throughout and to our friends and neighbours who sent us messages of support.

"Our thanks also to Sophie's teachers and the principal at Skerries Community School for supporting her. We also would like to acknowledge how supportive the staff at Brady's pharmacy in Skerries have been for Sophie's medication needs.

"I was lucky to be a suitable donor to Sophie but there are many other children and adults who don't have the opportunity for a living donor, and they remain on transplant waiting lists. Two years ago, we had no idea that Sophie would experience organ failure and that's why I would encourage people to consider organ



donation as you never know if, someday, a member of your family will find themselves in the same situation that we suddenly did!

"We are delighted to support the IKA. It's really important that Sophie learns to empower herself to look after her kidney health and get the best out of her life as a kidney transplant patient. Now that her diet and fluid intake is no longer restricted, she is embracing a healthy diet and taking her life-long anti-rejection drugs. She is participating in her Zoom classes with Skerries Community College as she prepares for her Junior Cert, keeping up a social life with her pals online and we both take regular exercise together walking our pet dog Freddie."



# END STAGE KIDNEY DISEASE and MENTAL HEALTH BRIDGING THE GAP

Recently I was contacted by Clodagh Cogley of St. Vincent's Hospital to ask if I was interested in supporting research for patients with end stage kidney disease and mental health difficulties. Naturally, I said 'yes', and felt encouraged for our patients that this research is being done. Previous research suggests that individuals with mental health difficulties often find it more difficult to access quality healthcare.

This study will help to understand the factors impacting the quality of life and mental health of kidney patients in Ireland, including measures such as pain, fatigue, social support, and the effect of kidney disease on individuals' daily lives. This research will also help to determine the link between mental health difficulties and how often individuals follow healthcare providers' treatment recommendations (treatment adherence).

Clodagh has put a patient expert panel in place to guide her research and will work alongside Dr John Holian, Consultant Nephrologist at St. Vincent's Hospital, and his renal team, to engage with patients. The research will be supervised by Prof Paul D'Alton, Consultant Psychologist at St Vincent's Hospital, who has completed several funded research projects,

Clodagh Cogley



published several book chapters and peer-reviewed journal articles, and played a key role in shaping the 2017-2027 National Cancer Strategy, ensuring that the psychological needs of cancer patients are explicitly addressed in the strategy.

There have been several research projects done in this area but very few here in Ireland. I felt it was really important to give our renal patients an opportunity to be involved in this research and space for their voices to be heard. This research will gather information on what helps and hinders access to kidney care for individuals, so improvements in future care and supports can be made.

The Irish Kidney Association fully supports this research project being led

by Clodagh, as part of a research PhD in University College Dublin and would encourage you, if you meet the criteria below, to get in contact with Clodagh.

Clodagh would like to hear the perspectives of individuals with mental health difficulties, their family members, and healthcare providers.

## WHAT DOES THE STUDY INVOLVE?

A one-hour long conversation with Clodagh, the lead researcher, via zoom. In this conversation you will discuss the factors that impact access to quality kidney care for individuals with mental health difficulties.

## DO YOU MEET THE FOLLOWING CRITERIA?

1. Do you have kidney disease and have you received a diagnosis of a mental health difficulty in the past?

**OR**

2. Do you have a close family member with kidney disease and a mental health difficulty?

**OR**

3. Are you a healthcare professional or allied healthcare professional with experience working with kidney disease patients?

If you meet any of the above criteria and would be interested in hearing more about the research, please contact Clodagh at

[clodagh.cogley@ucd.ie](mailto:clodagh.cogley@ucd.ie)

# *“Believe that a further shore is reachable from here.”*

SEAMUS HEANEY



By AOIFE SMITH

This time last year I wrote an article about understanding loss and grief. I never mentioned ‘COVID-19’. I wrote the article from a chronic illness perspective without any true appreciation or comprehension of the year that was about to unfold in front of us. We now approach the marking of a full year of official lockdowns and we enter a phase of ‘Living with COVID-19’ plans, variants, vaccines and safe reopenings. We continue to dig deep into our emotional resilience and manage our anxieties. But how do we manage the new wave of conflicts that COVID-19 has brought when quite frankly our tanks are on empty?

With less energy and prolonged states of stress, differences may have started to surface in our beliefs and ideas about COVID-19 and adherence to imposed government guidelines. This can easily become a source of conflict within family, or with friends and colleagues. Like any conflict, it can cause a great deal of pain and add to an already very stressful situation.

It is helpful to find ways to manage our emotions and use a collaborative approach to look for a middle ground. It is important when we are trying to resolve conflict that we pay attention to how we communicate both verbally, (what we say) and non-verbally, (through our body language, our facial expressions, our eye contact, and our posture).

It is also important to pay attention to how we listen, asking questions for more information, clarifying what we think and checking that we understand what the other person is feeling.

In my work I often use a very straightforward well-known psychology technique to help look for a resolution, *‘The Perspective Triangle Strategy’*.

The Perspective Triangle Strategy uses the concept of a triangle to separate the different points of view within a conflict. Each point of the triangle is a step that represents a perspective because within any conversation between people there are at least three perspectives.

**1st Perspective – Self:** This is what is going on from your own perspective. It is what you are seeing, hearing, feeling, and thinking during an interaction with another person. It is the conversation from which we usually operate, as it is our own default world view, made up of our experiences, values, beliefs and ideas.

**2nd Perspective – Other:** This is the point of view of the other person. It is what they are seeing, hearing, feeling, and thinking during a conversation with you. From this position we try to understand the



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world from their point of view.

**3rd Perspective – Observer:** This is the point of view of an impartial observer. What I mean by that is of someone who has nothing invested in the outcome but who is interested in both parties and how they interact. From this perspective they can see with clarity what is going on between people. The pattern of conversation is obvious to them because they are outside of the problem.

These perspectives can be very different, and it can be difficult to separate or untangle these at the best of times, never mind when living with a chronic illness and being stuck in the middle of a pandemic. This strategy asks us to break the conflict down into steps:

**Step 1:** Consider your own perspective and reflect on why you are feeling upset about the situation. Essentially this asks you to become self-aware and honest with yourself about how you are really feeling.

**Step 2:** Consider the perspective of the other person, putting yourself in

their shoes and reflecting on why you think they are feeling upset. This step requires you to suspend your own perspective and widen your understanding with empathy for what that other person may be feeling.

**Step 3:** Imagine you are an observer of the conflict and ask yourself what you see in your own behaviour and perspective. And what are the differences you notice, in your opinion, by considering the other person's perspective and by being the observer?

Using these three different steps allows you to get to the necessary emotional detachment and provides valuable insights that can help you find a resolution to your conflict.

In times like these, with so many environmental stressors on top of everyday struggles, conflict may be something we may not be able to avoid or control when it arises.

Peace within our family, friends and colleagues provides a sense of reassurance and well-being with those we hold dear.

When conflict arises it threatens

that sense of security. We may not be able to avoid it, but we can arm ourselves with skills that help us find resolutions and restore peace. Awareness breeds change and change breeds action. That action begins with you, from within you.

Thank you to all who called or emailed the counselling services provided here at the IKA. Please continue to email me 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.

I look forward to hearing from you!

I received a great response to the Christmas Giveaway of the book **'How to be Our Best Self in Times of Crisis'**.

Congratulations to all of you who got in touch and received a copy of the book.

# RAISING THE BAR

FOR ORGAN DONATION AND FUNDS FOR IKA



By GWEN O'DONOGHUE

**A Galway barrister raised the bar for organ donation when she gave a kidney to her younger brother, in August 2017, when he needed a kidney donor. While they were both undergoing their living donor kidney transplant at Beaumont Hospital, their brother, Mr David O'Brien, a Consultant Neurosurgeon, was operating in the adjoining theatre.**

**T**uesday August 22nd, 2017 was the day that changed everything for living kidney donor recipient Raymond O'Brien, a carpenter/joiner who lives near the Salthill prom with his wife Ethna and their three children, Isabel (10) and twins Harry and Amy (8). It was the day Raymo received a donor kidney from his sister Denise Waldron. It brought to an end his declining kidney function which was diagnosed fifteen years previously.

Denise, a barrister who also lives

nearby in Salthill, said that "giving a kidney to my brother Raymond, changed all of our lives for the better."

Raymo had just turned twenty when he became a type 1 diabetic which resulted in having lots of eye laser treatment, two eye operations and other diabetic related complications.

In 2002 he was diagnosed with kidney disease. Within fifteen years of treatment he reached end stage kidney failure and was just about to commence dialysis when Denise came to the rescue and gave him one of her healthy kidneys.

Denise, who recently became a grandmother to baby Ayra, said, "I felt privileged to be able to help my younger brother Raymo as he was struggling with his health while trying to raise three young children with Ethna. My two daughters, Hilary and Laura, are grown-up and I discussed the donation with them and got their seal of approval.

"An amusing and unexpected outcome of the transplant operations was that at the time I was going through the menopause and some of my menopausal hormones remained on the donating kidney which had a strange effect on Raymo! For a few weeks after the operation he was getting hot flushes and kicking off the blankets as he was overheating at night. Ethna and I found this hilarious. We joked that he is now more in



Denise with grandson Ayra.





*Ethna and Raymond with children Amy, Isabel and Harry.*

touch with his feminine side and has a better understanding of what women have to go through."

"The transplant team at Beaumont were wonderful throughout and I never felt pressured to proceed. There was rigorous testing including counselling and the team had me well prepared. They facilitated the transplant taking place in August while I was off work as the courts were on summer recess.

"The surgeons were amazing. I was wheeled down to theatre first and transplant surgeon Mr Gordon Smyth removed my kidney and Ms Dilly Little transplanted the kidney into Raymo. The transplant was a success. The aftercare in Beaumont was excellent. The transplant unit is brand new and state-of-the-art, with an amazing team of doctors and nurses.

"I was well enough to be discharged from hospital after five days and Raymo after ten. I was back to work within 6 weeks and have never looked back. Raymo is looking and feeling much better and I have more energy now than ever, probably because I don't take my good health for granted and try to lead a healthy lifestyle most of the time. I swim in the sea all year round and have been doing so since I donated my kidney to Raymo in 2017. I have regular check-ups with my GP Dr. Barbara O'Beirne and my nephrologist Dr. David Lappin and they take really good care of me.

"The Irish Kidney Association (IKA) supported us along the way and the charity is a cause close to our hearts. This January for my birthday, I decided

to do a small fundraiser on Facebook for the charity. I was taken aback by the generosity of friends and family, as a total of €1,527 was raised. We are delighted to be able to share our story to help the IKA raise awareness about the importance of organ donation."

In describing his health journey Raymo explained, "At that time there was no full-time nephrologist based in Galway. From 2002 until 2017 Ethna and I travelled to Dublin to meet Consultant Nephrologist Prof. George Mellotte at St James and Tallaght Hospitals. Prof. Mellotte, who is also from the West of Ireland, is an excellent, caring consultant and a true professional.

"Ethna attended many of my appointments with me and even when

Galway got its own nephrologists we stayed attending Prof Mellotte in Dublin.

"Following the advice of Prof. Mellotte and the equally respected diabetic consultant Prof. Tim O'Brien at UCHG in Galway I kept active, adhering to my diabetic and renal diets, taking medication, and monitoring my blood pressure. I felt fortunate to be under both Professors' excellent care.

"When first diagnosed with kidney disease in 2002, it was forecast that I would be on dialysis within two years but actually held off for 15 years before a transplant was needed. The way in which I managed my condition played a huge part in delaying its progression.

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*Brothers and sister...Raymond, Paul, Denise and David.*





Raymond and Denise at the 'Circle of Life' garden in Salthill, Galway.



Raymond, Ethna, Harry, Amy and Isabel.

"Managing and having good blood pressure control is the key according to Prof Mellotte, who also lectures to his peers and medical students using me as a case study. Prof O'Brien in Galway oversaw the diabetic side of things and arranged for me to be put on an insulin pump for better control, but we always knew someday a transplant would be needed.

"However, in the last year or two before my transplant, my kidney function and health deteriorated. My energy levels went down and I needed to rest a lot. It was now time to either get a kidney or start dialysis, which had been avoided thus far."

Raymo said, "Ethna offered to donate a kidney straight away but was told that they wouldn't even test her because of having three young children. I was fortunate to also have two brothers and a sister who were all willing to donate a kidney to me. Denise, when tested, was a perfect match and a transplant was arranged for August 2017.

"A year before my operation, Dr Ruth Smith, the wife of a good friend of mine, underwent a donor process as she received a kidney from her colleague doctor Noel Howard. This was great news and gave us lots of encouragement.

"We are so grateful to my sister Denise, my hero. Our family of five cannot thank her enough. She is an amazing woman. The only way we can show how grateful we are is to look after the kidney she gifted to me.

"I can't forget to mention Ms Dilly Little who performed the transplant on me. I could not have been in better hands. Ms Little, the transplant coordinators and all the staff in Beaumont were fantastic. Who would of thought that just a couple of hours after the operation I was up and about walking the corridor of the hospital even though I was on crutches at the time!!

"The IKA's Renal Support Centre is a wonderful facility with free accommodation for patients and their families. It is so conveniently based beside Beaumont Hospital. We were fortunate and feel very grateful that Ethna and Denise's daughter Hilary could stay there while myself and Denise were undergoing our operations. Having the centre on the grounds of the hospital, walking distance away from your loved one, is a God's send.

"I'm incredibly grateful to all of my friends and family who have helped and supported us over the years, but especially my wife Ethna, who through

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***"We are so grateful to my sister Denise, my hero. Our family of five cannot thank her enough. She is an amazing woman."***

thick and thin has always been there for me.

"Lastly, it's hard to explain or express the gratitude that I have to my big sister for giving me a new lease of life. I have lots of energy now to do things, especially with my kids which I couldn't have done previously. Anyone who would go for surgery while being perfectly healthy must be special. Denise, 'thank you' from the bottom of all of our hearts.

"I tell everyone that Irish people are renowned for giving to charities, money and time is great but if you want to really help someone with a chance of a new lease of life, get an organ donor card today and share your wishes with your family."



# thanks a million

**W**e never cease to be blown away by the generosity of people who make donations to the IKA. On our website, we have a comment facility where people can leave a message for us, and every day there are messages left by people who are donating in memory of loved ones, letting us know about their fundraiser and sometimes they donate with no comment at all.

There is no time that the messages are more heart-warming than at Christmas. Over Christmas and New Year, we received so many lovely comments that we wanted to share some of them with you.

Some names and details have been removed for privacy.

These are just some of the many messages we received and we want to thank everyone for their kind

By  
**ROBYN BLACK**

words. So many people donated in lieu of Christmas

Cards and gifts, took part in 'Give-mas', and one even donated to celebrate a kidney recipient family member's festive wedding!

After a long hard year in 2020, these were the uplifting messages we needed to hear.

We would also like to say thanks a million to anyone who has contributed to us, at any time, leaving a message or not. Your donations help support renal patients and their families all over Ireland, and without them we wouldn't be able to do any of it.

A final thanks goes to the tireless volunteers who work so hard around our Branches, because they are the foundation that our reputation is built on and that is something that money can't buy.

“

This Christmas instead of sending Christmas cards to my family members and friends I decided I wanted to give a little donation to the Irish Kidney Association to help other people with kidney disease. My mother sadly fought it for 12 years and lost her battle and now my father and sister have it too. However, early this year before COVID-19 took over the world my big sister had a kidney transplant and I'm so grateful – she is doing great.

My mother may not be at our table on Christmas day but she will be in our hearts.

“

We would like to make this Christmas donation, in lieu of presents and on behalf of our mother. The family have a long history of engagement with the Irish Kidney Association and many of mammy's siblings have received kidney transplants over the decades. We keep all donors, recipients and their families in our thoughts at this time of the year and wish to thank the IKA for all their hard work supporting this worthy cause.

“

I was on kidney dialysis from February to June 2020. I managed to come off dialysis but I am appreciative of the work done by IKA. I also know what patients go through and the excellent care and attention provided by the renal nurses. I am forever in their debt.

“

As a token of gratitude for your support, I am not sending Christmas cards this year and will donate the cost of the cards and postage instead to the IKA. Merry Christmas to you all and many thanks for your continued support.

“

My mother was a dialysis patient, she passed away in May 2020. She went on a couple of holidays with the Irish Kidney Association and attended the events when held locally. I would like to thank you for all the good work you do.

“

My sister is alive because of the work you do.  
THANK YOU!!

“

My niece had a transplant operation in recent months. I would like to donate to this Association as a recognition of the great work done by all involved. Have a happy and healthy Christmas and all the best in 2021.

# VITAMIN D

## The role of Vitamin D for CKD patients and its impact on COVID-19



**PROF. JOE EUSTACE**  
Director  
HRB Clinical Research Facility  
Cork and Nephrologist CUH

There has been a lot of discussion recently about the role of Vitamin D, not only for bone health but for boosting the immune system, and its potential to fight against COVID-19. Many people in Ireland have Vitamin D deficiency. We invited experts **PROF JOE EUSTACE**, Nephrologist and **IRENE CRONIN**, Renal Dietitian who have gathered considerable data from research and studies into the role of Vitamin D to share their knowledge with our readers. They caution that while optimum levels of Vitamin D have indisputable health benefits particularly for bone health, studies so far, about its role in boosting immunity and safeguarding against COVID-19 infection, are inconclusive.

**V**itamin D is a fat-soluble vitamin that plays an essential role in the body. It plays a vital role in maintaining normal healthy bones.

### NATURAL SOURCES: DIETARY AND ULTRA VIOLET B LIGHT (SUNLIGHT)

There are few foods that are naturally rich in Vitamin D, the best sources being oily fish, such as sardines and salmon, and eggs. However, a wide range of additional foods are now available with added Vitamin D, including, milk, yogurts, spreads, breakfast cereals and bread. Despite this, dietary vitamin D intake in Irish adults is generally low, and by itself is usually inadequate to maintain an optimal level.



**IRENE CRONIN**  
Clinical Specialist Renal Dietitian  
Cork University Hospital

Our skin is able to produce Vitamin D but to do so needs Ultra Violet B light exposure from sunshine. In Ireland the intensity of sunlight is inadequate over the winter months to facilitate this, while given the risk of skin cancer, the necessary use of sun block limits the body's ability to produce Vitamin D during the summer. As a result many people in Ireland are at risk of Vitamin D deficiency, especially those who are older, have darker skin or who are overweight, and therefore benefit from taking supplements.

In considering the benefits of taking Vitamin D supplements, it is important to distinguish at least 3 distinct purposes for which Vitamin D preparations are potentially used in medicine.

### 1. Treating Vitamin D deficiency.

Standard over-the-counter Vitamin D supplements are used in the general population or in patients who have mild or moderate pre or post-transplant Chronic Kidney Disease (CKD) in order to avoid below-normal Vitamin D levels. There is undisputed certainty that an absolute deficiency of Vitamin D is harmful to bone; in children it causes rickets and in adults, osteomalacia.

As measuring Vitamin D levels is difficult and expensive and as routine over-the-counter Vitamin D supplements – when taken in the recommended doses – are very safe, many high-risk groups, such as CKD patients are advised to take supplements







without measuring or following their actual level. The Department of Health recommends that those aged 65 years or older, take a daily Vitamin D supplement.

## 2. Vitamin D as a therapy in advanced CKD.

In order to function, Vitamin D needs to be **'activated'**, a step that takes place in healthy kidney tissue. People who have advanced kidney disease need to use special formulations of Vitamin D, as the standard over-the-counter preparations won't work in the absence of adequate kidney function. These modified formulations, for use in patients with CKD, require a prescription and work even in the absence of any kidney function.

In patients with CKD we also use higher doses of these agents in order to control parathyroid hormone (PTH) levels. There are now several different forms of 'modified' Vitamin D supplements available which differ slightly in their effects.

Some investigators have suggested that there may be advantages to giving 'standard' Vitamin D supplements, as used in the general population, to patients with stage 5 CKD in addition to the pharmacological doses of the **'activated'** Vitamin D discussed previously; however, the benefits of this approach are unproven. What is clear is that the usual standard over-the-counter Vitamin D supplements are not by themselves sufficient in the vast majority of patients with advanced kidney failure, or on dialysis.

Transplant recipients should be careful to use appropriate sunscreen and use a Vitamin D supplement to maintain their Vitamin D levels; with a well-functioning transplant this can usually be a standard over-the-counter Vitamin D preparation.

## 3. 'General Health' benefits of Vitamin D.

Vitamin D is associated with a wide range of highly varied processes within the body, including influencing immunological and inflammatory conditions. This has given rise to the possibility that using Vitamin D supplementation to achieve above normal Vitamin D levels might exert additional therapeutic benefits.

One of these additional effects, which has garnered substantial interest recently, has been the ability of Vitamin D to support the immune system and potentially help to avoid or reduce the severity of COVID-19 infection. To date, it is unconfirmed that the administration of higher dose Vitamin D, for these reasons, has any actual additional benefit, provided that sub-normal Vitamin D levels are avoided.

In many situations in biology, adequate levels of a substance may be necessary for health, but above normal levels are not associated with any additional benefits.

## WHY IS IT SO DIFFICULT TO ESTABLISH WHETHER HIGHER DOSES OF VITAMIN D EXERT ADDITIONAL 'GENERAL HEALTH' BENEFITS?

To understand this, it is important to remember that, across the population, Vitamin D levels are associated with a good dietary intake and with sunlight exposure. People who are sick and unwell typically don't have hearty appetites and spend less time outside and will, on average, have lower Vitamin D levels than healthy subjects; this means that, in the absence of taking supplements, the Vitamin D level provides an overall surrogate measure for several healthy behaviours.

If you measure Vitamin D levels in a group of patients who are chronically ill and not taking supplements, their Vitamin D level will tend to be low, not because low Vitamin D levels caused their illness but because having become ill, they developed poor appetites and spent less time outside.

However, these low levels are the consequence of the illness's impact on their behaviour rather than the cause of the illness itself.

*contd. next page...*



## VITAMIN D *contd...*

Furthermore, as people in poor general health are likely to be at higher risk for severe COVID-19 infection, you would also expect to see an association between lower Vitamin D levels and the occurrence and severity of infection, again not because the Vitamin D deficiency directly causes this, but because chronic poor health is independently and separately associated with both a tendency for lower Vitamin D levels and with COVID-19 risk.

Any simple observational study which therefore measures Vitamin D levels and examines peoples'

outcomes is very likely to see an association with worse outcomes with lower Vitamin D levels. To establish an actual benefit of giving Vitamin D in this situation, you would need to know a lot of information about the study participants' overall health. Realistically this is almost impossible to do in simple observational studies, but this limitation has not stopped a vast literature of such observational studies from being published and widely commented on.

Instead, to rigorously establish such a beneficial effect, of Vitamin D with infection risk or other health outcomes, it is necessary to conduct large-scale randomised trials

comparing the outcomes in people who are randomly allocated to take additional Vitamin D with those who aren't.

There are at least two such trials, examining the potential effect of Vitamin D on COVID-19 infection, which are currently in development and will hopefully help clarify this issue.

A number of smaller trials have examined the preventative effect of Vitamin D with regard to other viral infections, however, results have been inconsistent and non-conclusive, but they do, in general, support benefit in patients who have below normal Vitamin D levels.

## IN SUMMARY..

- Normal Vitamin D levels are critical for bone health and potentially have other health benefits.
- Standard over-the-counter supplements require adequate kidney function in order to activate them. This also applies to recipients of a well-functioning kidney transplant in order for them to maintain optimum Vitamin D levels, as they protect their skin from sun exposure. For patients with advanced CKD, modified Vitamin D agents are required through a prescription which will work even in the absence of kidney function. Modified preparations are used to treat or prevent some of the complications of kidney failure, such as a high Parathyroid hormone (PTH) level.
- Many studies have shown an association between high Vitamin D level and good general health and reduced risk of infection, including for COVID-19.

Unfortunately, many, if not all, of these associations may be coincidental in nature. It makes every sense to avoid having a sub-normal Vitamin D level, as this is definitely bad for your bones, regardless of any other problem that it may cause.

However, there is no current good evidence from appropriate high-quality clinical trials that taking extra Vitamin D supplements, in order to achieve higher than normal levels of Vitamin D, has any specific benefit in treating or preventing COVID-19 or other infections.

- Patients with CKD should remember to take any Vitamin D supplement or other forms of 'activated' Vitamin D medications that are prescribed to them by their doctor in the recommended dose and if they have any concerns or questions to discuss them with your doctor.

# *Tribute to...* Marie Mellon



The death on January 23rd, 2021 of Marie Mellon, Chairperson of the Mayo IKA branch and long-standing member of the IKA, came with great shock and sadness to everyone that knew her.

Marie battled with kidney failure for forty years, beginning in her early twenties. She experienced all of the challenges that kidney failure can bring, including six years on peritoneal dialysis in the UK, two failed transplants, many, many hospital admissions and eighteen years on haemodialysis, under the excellent care of the staff in the Castlebar dialysis unit.

Marie's attitude to life was inspirational, and she was admired by many for her positivity, her courage, her sense of humour, her smile, and her care for others.

One person hit the nail on the head recently when they described her as a role model for resilience – despite all of the challenges and hard days, she always looked forward to the future, made the most of every opportunity and really did live her life as fully as she could.

She fought her illness with such dignity, and didn't let it define her life. A great source of pride for her was that

she stayed working as a clerical officer in Mayo University Hospital right up until COVID-19 made her step back from her work.

She was so interested in people, and was always a strong voice for the patients of Mayo. Every year for the past twenty-seven years she orchestrated the fundraising initiatives for Organ Donor Awareness Week, Church gate collections on the streets of Swinford, and stood fundraising, even on days when her health was poor.

She had fond memories of her time with Team Ireland at the European Transplant and Dialysis Games in Slovenia in 2004 – to her delight she brought home a few medals, and new friends for life.

She will be deeply missed by her husband Terry, her daughter Lisa, her wider family, her friends and the Mayo IKA branch.

The knowledge that she touched the lives of so many is of great support to her family, and they hope her legacy of resilience, positivity and determination, when living with kidney failure, will live on.

May she rest in peace.



# TAXI TALES

By ALEXANDER AGER

## 'EARLY'

He was a popular taxi driver, known as Early, because that is what he always was. He was a friendly guy who puts himself out, who rolls you out through your front gate, straps you in to your seat, folds up the wheelchair like a piece of origami, and moves on for the next 'Ride'.

That was before Covid, then there may have been up to five of us crammed into his taxi van, but now, with just one Ride at a time, he still manages to get his allocation of us Rides in on time and is always early for when we are released from the bloodthirsty jaws of our allocated dialysis machine.

Early is always sensitive of our post-dialysis moods, aware of our unsteady hands, taking one's front door key and ushering us into our, for many, oft empty homes, ensuring that we acknowledge his question 'OK?' as he hands back the key.

Early was a raconteur, a human storybook, reflecting his varied career from suit and tie, to pan European truck driver – where hitch-hikers were welcomed for their company and their far-fetched stories.

It was the health of his wife that brought him back to Dublin. We, as concerned Rides monitored his journey through to widowhood, his loneliness, and eventually us being allocated to another Cabby for our rides to and from our ever-thirsting dialysis machines.

The other day I phoned for a taxi to take me to a major shopping centre, and the driver turned out to be Early. It transpires that he and our ward's rotund tea lady became close, as against just chums, or just Rides as were most of the people he came into contact with. But Early, in his own discreet way, became a couple, with her handing her house over to her child, and Early sharing his with her.

An unlikely couple, but well matched, and each with their own story to tell.

## PRIZE GIVEAWAY

Thank you to Sarah and the team at THE VIRGIN MARY, ALCOHOL-FREE BAR on Capel Street, Dublin 1, Tel: 086-2458392. for their generous Alcohol-free starter kit which they kindly donated for the prize giveaway competition in our Winter edition of SUPPORT. Our winners were Karl Cronin and Briege O'Kane.

[www.virginmarybar.com](http://www.virginmarybar.com)

# HEAVEN SENT



Brother Darragh, Cillian and father Mark Dunne with Poppy, the family dog

Inspired by his grandmother Mary Rooney who underwent her second kidney transplant last September, 16-year-old Cillian Dunne from Kilkenny undertook a gruelling 4x4x48 Challenge in March 2021 and in the process raised €1380 for the Irish Kidney Association.



Darragh, grandmother Mary Rooney, Cillian

Cillian explained, "It was in September 2012 and just one month after my grandfather passed away, my granny received a call from Beaumont Hospital to inform her that there was a potential kidney donor match. We all felt it was grandad's heavenly gift to her. This was her second kidney transplant, she received her first transplant fifteen years ago.

She is a fantastic woman and has made a great recovery and has regained her strength. After seeing everything she had gone through and the support she received from the local Kilkenny branch of the IKA I decided to take on this personal challenge and raise funds for the charity.

"My challenge was to do the 4x4x48 which is to run 4 miles every 4 hours for 48 hours. The challenge was tough but was well worth it and I had great support from family and friends who ran some of the twelve by 4 mile distances with me. I ran late at night and the 4am runs were by far the hardest but I pushed through determined to finish what I had started.

"I have been running with Gowran Athletics Club, Kilkenny since I was 7-years-old. Running is not only my passion but it plays a massive part in my life. Although I had no races or competitive events to look forward to I was still training hard. I thought this challenge would be a great opportunity to work towards and put my training to good use.

"I'm very determined when it comes to running so doing this challenge was, of course, tough but very enjoyable and my motivation came from all the generous people who were donating, supporting and helping out.

"Overall, the challenge was a success and the money we raised was exceptional and far more than I first expected."

# SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK



## KNOW YOUR AUDIENCE

When you work in a role like mine, a lot of your day revolves around numbers. To be honest, maths was never my strong suit and I much preferred English, which is why I went on to study Media & Journalism – but here we are!

On an average day the numbers spinning around my head include our social reach, how many interactions we have had, when our best performing posts were shared and much more. It may be of interest to a lot of you that I can tell a lot more about our audience than you might think.

Thanks to the wonders of social tracking, Google Analytics and more, I have a fairly good idea of who I'm speaking to when I post updates on our website and social media. I thought I'd break some of it down for you all and explain a couple of reasons why this information is so valuable to us.



### SOCIAL MEDIA

We have an audience of 30,177 on Facebook. 79% of these followers are female, and only 21% are male. Our largest audience is made up of people aged 35-44, followed by those 45-54. This contrasts with our audience of 2,667 people on Instagram, which is still predominantly female but with the 25-34-year-olds as our biggest demographic.

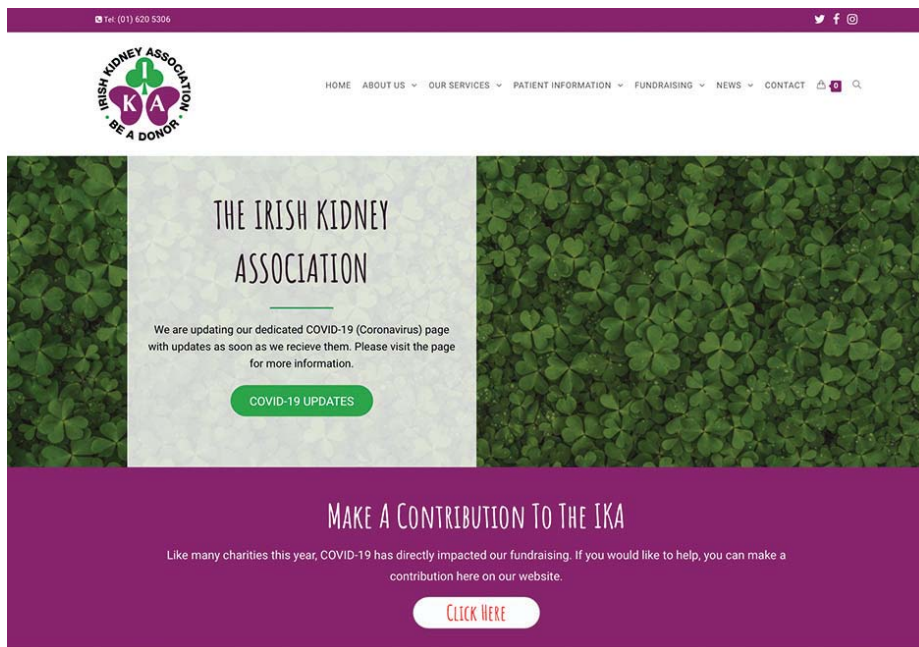
### Why does this matter to us?

- We can target specific campaigns to specific people. If we want to reach a younger cohort with the message we are pushing, Instagram is the place to do it.
- Whilst (according to Facebook) men are the biggest Facebook users worldwide, women create 70% of all fundraisers on the platform – as we have a predominantly female audience, this might explain why Facebook is our biggest online fundraising platform!

### WEBSITE

On our website, it will come as no surprise to most that the majority of our visitors (90%, in fact) are using mobile phones! Last month, most of them were using Apple devices – but this changes frequently to Android devices, so the old Apple vs Android argument won't be settled by us!





Over 16,000 people visited our website in February, viewing over 25,000 pages between them – an incredible number! The majority of these people came to us through a link on Facebook (4,058), followed by those directly typing our link into their search bar (3,360), following a link on Instagram (3,179) and then people who found us on Google (1,415).

Happily, our most popular page last month (February) was the Donor Card Application Form. Almost everything that followed this was in relation to the COVID-19 vaccine in some way – we have been posting regular updates for our members online.



### Why are these statistics important?

- If we know how most people are visiting the website, we can make it the best experience possible. When you create a webpage, you must make it 'responsive' – i.e., optimised for mobile viewing. These statistics show this is extra important for us.
- Knowing that most people come to our website through Facebook reminds us to post all of our updates to the platform – people may rely on this to make them aware of updates.

### SALESFORCE

We recently adopted a new system in-house at the IKA called Salesforce. I've been heavily involved in the implementation, and for a data geek like me, it has been supremely satisfying!

Salesforce manages our membership, so we can easily see details whilst being able to email large groups directly from the platform, as well as pull detailed lists on our members themselves.

You might be interested to know that we have 3,722 members – of these, 2,233 are patients themselves.

Our largest Branch membership is Cork, followed by Dublin North, Dublin South, Louth/Meath and then Galway (although there is not much difference in size between them at all!).

2,885 people are subscribed to this very magazine, whilst our email list regularly has an open rate of over 55%; that is how many people who receive the email actually open it. An average email open rate would be between 15-25% – we are doing well!

### Why are these statistics important?

- Comparing the number of renal patients, we know there are in Ireland at the moment, with how many patient members we have, we can see that we might need to make sure that all of the services we provide are more widely known – something we are working on.
- The number of people who open our emails is important. It shows how many people find our emails useful and helps make the information we send more valuable.

I hope you found all of this as interesting as I do – numbers may not be the most exciting thing in the world, but I do think you need to know your audience to best be able to serve them. Hopefully with all the information we have at our fingertips, we will continue to do that!



# POSITIVE STEPS TO NAVIGATE YOUR WELLBEING THROUGH COVID-19



The way we live has changed in every way due to COVID-19. As with all of life's challenges it's important to keep mentally and physically well with a healthy lifestyle. Here we list some simple steps to help you along this journey.

## STAY CONNECTED WITH OTHERS

Maintaining healthy relationships is important for mental wellbeing. Think about ways to stay in touch with family and friends. Send your An Post free postcards to a family member or friend. Make the most of technology – video-chat apps like Skype and FaceTime. Video call a friend or family member while enjoying a meal. This might help to maintain regular meals and give a sense of social dining.

## TALK ABOUT YOUR WORRIES

It is normal to feel worried, scared or helpless about the current situation. If you cannot speak with someone you know avail of the services and programmes available through the IKA (<https://ika.ie/counselling>). If your mood has affected your appetite please get in touch with your dietitian for support. A reduced appetite or poor nutrition will affect your energy levels and overall health.

## DO THINGS YOU ENJOY

Focus on your favourite hobby, if it is something you can do at home. Or, start a new hobby like cooking, reading, writing, crosswords, jigsaws, baking or painting.

Check out [www.irishkidneydiet.ie](http://www.irishkidneydiet.ie) for some tasty recipes, this is the perfect time to get inventive in the kitchen, ditch the salt and

discover new flavours.

Check out this new information video about how to reduce your salt intake <https://slide.incareview.com/salt-intake/>

## BE KIND TO YOURSELF AND YOUR BODY

We are in the middle of extremely difficult circumstances – a balanced diet can help us feel good and provide our bodies with all the nutrients we need. Think about what you can add to your diet in terms of having a variety of foods and drinks.

## PLAN AHEAD

Take time to plan your meals and write a shopping list. Planning ahead will help you organise what you need when shopping, and remove the stress of having to think of what to have each mealtime.

## KEEP A REGULAR MEAL PLAN

Keeping up regular mealtimes may help to add some normality and encourage you to eat balanced meals instead of grazing on whatever you have in the cupboards. Cooking in bulk will reduce the need to cook.

## SLEEP WELL AND STAY ACTIVE

Diet, keeping active, sleeping well and taking some time out for yourself are all important for helping us to cope in these difficult times. This can help with worries and feeling down. Examples include soaking in a warm bath, listening to music or practicing mindfulness.





By **ANN-MARIE MURRAY**  
(Registered Dietitian) B.Braun Wexford & Portlaoise  
and **ALEX KILKELLY**  
(Registered Dietitian) Galway University Hospital  
on behalf of the  
Renal Interest Group of the



## HIGH FIBRE BROWN SODA BREAD

(Used with permission from Renal Interest Group recipe book 2020)

### Makes 15 thin slices

#### Ingredients

400g coarse wholemeal flour  
1 tbsp brown sugar  
A pinch (¼ level teaspoon) salt  
1 level tsp bread soda, sieved  
1 tbsp vegetable oil, plus extra for greasing  
300mls milk  
125g natural yoghurt  
1 x 900g (2lb) loaf tin

#### Method

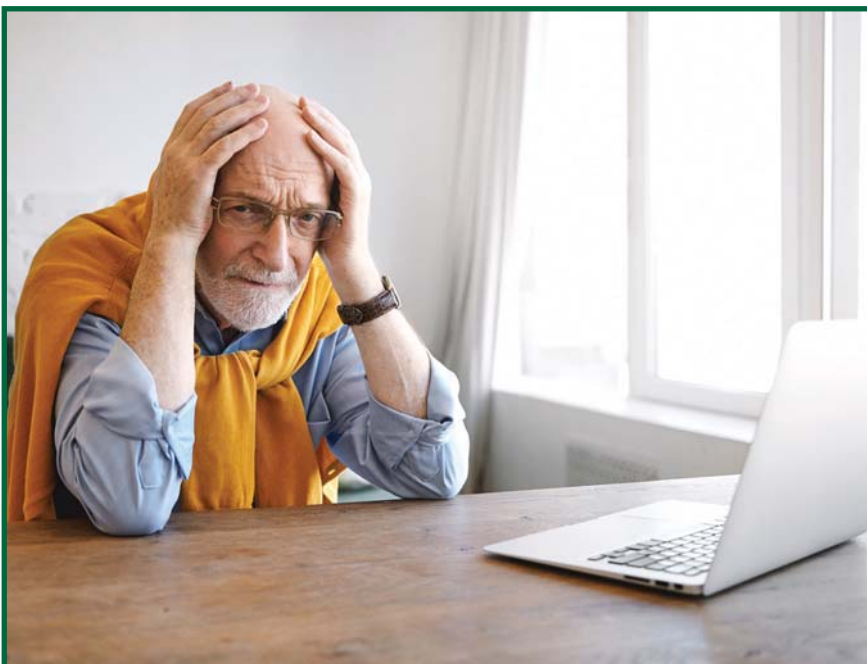
Preheat oven to 200°C/400°F/Gas 6.  
Grease a 900g (2lb) loaf tin.

Put wholemeal flour, sugar, salt and bread soda into a mixing bowl and mix well together. Make a well in the centre and add the oil, milk and yoghurt and stir until well blended. The mixture will be quite wet.

Transfer to the prepared tin, make a cut down the centre and bake for 45 minutes. To check if the bread is fully baked, tap the loaf on the base. If it is done it will make a hollow sound.

Wrap in a clean tea towel and allow to cool. The bread cuts better if left until the next day.

**Each thin slice of bread has the equivalent of 30mls milk. This needs to be taken from your daily allowance of 200mls.**



# OVER 55 AND FEELING LEFT OUT ONLINE?

**D**o you think smartphones and laptops are for young people? Well, one of Ireland's oldest 'silver surfers' was 95-years-young, and wrote about his life, online, until he passed away.

So, if you have a smartphone or tablet, but feel you're not getting the most out of it, free help is available. **Age Action** have developed the **Keep In Touch (KIT)** in response to COVID-19. This remote national learning initiative helps older people improve their digital literacy skills, so they are more connected, informed and supported specifically during periods of social distancing.

They are offering five hours tutoring, by phone, to anyone who feels that they need support with using their smartphone, smart device or laptop. Covering topics like how to set up an email, how to download an app, and how to use video to see your loved ones, learners will be matched with a volunteer tutor who will cover the topics the learner chooses, at their pace. They will also send learners a 40-page learning booklet with lots of smart images to help with tutoring sessions.

Please ring **01-4756989** if you would like further information and the Age Action team will get in touch.

Or you can fill out a form electronically at

<https://www.ageaction.ie/getting-started-kit-remote-training-sign>

The video tutorials were broadcast in 2020 by RTÉ on the *Today with Maura and Dáithí* programme and they are now available to view on the Age Action YouTube Channel...

<https://www.youtube.com/playlist?list=PL8wnDFoSYolqDfSS3KzAuTfCihCcmY2BR>



# The forgotten youth

**G**alway Leaving Cert student Lauren Melia from Oughterard (near Tuam) wrote to the IKA in January 2021 about her plight as a Leaving Cert student and dialysis patient. She expressed her additional anxiety around the lack of priority in the COVID-19 vaccine rollout for people like her as well as the confusion for students preparing for the state exams on how they would proceed.

Her letter, printed opposite, outlines her frustration which she also expressed in letters she wrote to the Minister for Health Stephen Donnelly and Minister for Education Norma Foley as well as five local TDs.

As well as being interviewed about her campaign on three local radio stations, Lauren was also interviewed by RTÉ News when it was announced that those in Cohort 7 were to be moved up to Group 4 and the age group was expanded to 16-69 years.

Three other brave young warriors campaigning for vaccine reprioritisation and who made national headlines included dialysis patient Matthew McNeive (21), from Knock, Co Mayo, a student in Clinical Measurement Science, and also kidney transplant recipients Rebecca Osgood (17) from Ballinlough, Co Roscommon and Jack O'Brien (18) from Navan, Co Meath. At the time of going to press with this issue, we are pleased to advise that three of these courageous campaigners have now received their first COVID-19 vaccination and we hope that Jack will receive his soon.

Matthew McNeive. Pic: Keith Heneghan



Rebecca Osgood Daly





# Lauren's Plea

## A LETTER BY LAUREN MELIA

### JANUARY 2021

I am a 19-year-old Leaving Cert student from Galway living with chronic kidney failure since August of 2019. I have been a renal patient for all my life.

When I was born my parents knew that I would have kidney problems. My kidney function kept getting worse as the years passed. At the age of six I started peritoneal dialysis at home. This involved having to do it every night for eight to ten hours at first, however, as the years went on it became less effective so my time on the dialysis machine increased to 12 hours. I spent three years on peritoneal dialysis, and along with this I had many hospital check-ups during this time as a patient at Temple Street Children's Hospital.

My worst memory was only being able to drink 400mls of fluid each day. As a 6-year-old I didn't understand why I had to do this, but I was assured that it would help me if I stuck to it. Thankfully, in late February 2012, at approximately 2.30am I got the call for a kidney transplant. Being rushed to Beaumont Hospital from Galway during the night was not easy and not really knowing what lay ahead was frightening for me. However, this kidney transplant was a success and my body accepted it. I enjoyed eight great full and healthy years with it and it brought me from childhood to my teenage years.

It gave me the opportunity to enjoy my full Transition Year at school, take holidays abroad and best of all not be tied to

dialysis treatment.

Unfortunately, in August 2019 my bloods started to show signs of kidney failure. My creatinine levels started to increase, my blood pressure was on the rise and fluid started to build up around my body. All the signs of kidney failure were showing but to have this reality confirmed was heartbreaking. Even worse, all I could think of was that I was heading into 5th year at school in the knowledge that I would shortly be commencing dialysis once again. The second time around was a lot harder for me. I have been receiving haemodialysis treatment in hospital 3 times a week for 3 hours, initially at Merlin Park, but since December 2019 I have been attending treatment at the Wellstone Clinic in Galway.

This reality is not easy as an 18-year-old but it is part of my life so I get on with it. Also, knowing that I had to start dialysis as I entered my last two years in school was both annoying and frustrating. I knew I would miss a lot of school with it, meaning I'd miss a lot of school work. In Leaving Cert now, I'm still playing catch-up.

Then, to add to this, COVID-19 came into our lives. For me, this meant I had to cocoon as I am classified as 'very high risk' of COVID-19 and in the same risk group as over 70s. So for me, I didn't know when I could return to school or, indeed, if I could return to school. As a Leaving Cert student the anxiety around this important exam is enormous, but throwing

Lauren Melia  
Pic: Joe O' Shaughnessy,  
Connacht Tribune



COVID-19, dialysis and appointments into the mix, makes everything even more stressful and worrying.

It is vital for me to receive this vaccine as soon as I can, which should be sooner, rather than later. If I do, this means I can attend school with my classmates in my last year of school. It's not the same sitting at home looking at a screen while my peers and friends can all see each other in person.

Worrying figures reveal that 25% of renal patients who contacted COVID-19 died. This scares me so much! This anxiety over when I and many other renal patients can get the vaccine is growing and this adds to my stress levels in the middle of studying for the Leaving Cert – stress I don't need.

I am appealing to the Minister for Health, Stephen Donnelly, that re-prioritisation of the vaccine

roll-out needs to happen now!! I also want to say to the Minister for Education, Norma Foley, that as a Leaving Cert student I am speaking on behalf of many more students when I say that clarity around the exams, which we are expected to take in less than 130 days, needs to be given to us now!

As a patient it is difficult to hear about the uncertainty around both the vaccines and my Leaving Cert. Clarity and choice, of continuous assessment and sitting the Leaving Cert, should be given now! We have missed 40% of our course. The teachers are doing fantastic work online but it's not the same at all. For me to get back to school, when all my classmates do at St Paul's Secondary School, I will have to have received the vaccine!

**LAUREN**

# Artist and renal dialysis patient **KATE QUINN** creates beautiful art for University Hospital Waterford



Kate Quinn's 'Colours Through Nature' series at UHW.

**A**rtist and renal dialysis patient Kate Quinn has created stunning artworks which have transformed areas of University Hospital Waterford (UHW), bringing beauty into clinical spaces and lifting the spirits of patients and staff. Commissioned by Waterford Healing Arts Trust (WHAT), Kate's photographic artworks have been installed in the hospital's mammography room, brightened up a busy basement corridor and she has also published her first collection of photographs.

A long-term dialysis patient, Kate has worked closely with artist Philip Cullen, developing her photographic eye over the last five years through the WHAT arts programme in the Renal Dialysis Unit of UHW. The programme, which has been running for 14 years with funding from the PuncHESTOWN Kidney Research Fund (PKRF), has supported Kate to be



Kate Quinn with Claire Meaney (Director of Waterford Healing Arts Trust) and Brenda Ronan, Clinical Nurse Manager (retired), Renal Dialysis Unit at UHW.

trained and mentored by Philip in the essentials of photography, progressing to portraiture and film-making.

To date, most of Kate's work has been strongly influenced by nature. Her first book of photographs, published by WHAT in 2016, was aptly

titled *Nature's Whispers*, while her biggest commission to date, creating images for large format light boxes to brighten up a busy basement corridor at UHW, is called *Colours through Nature*. Kate explains "Colours are the smiles of nature. I see strength in





people that they don't always see. I create art to hold a mirror up to them so they can see how beautiful they are within. I want to say to people 'blossom like a flower'. Nature connects us in a beautiful way."

Philip Cullen describes what it's like working with this remarkable person: "Kate Quinn has a fierce determination to make art. From my first meeting with her in the dialysis unit at UHW, I knew that I was dealing with a force of nature. She is passionate in her desire to produce and what she wants to say in her work, to be creatively independent and to express her love for nature." Philip goes on to say "Kate creates photographs by setting up scenes. There is an implied narrative in much of her work which demands reflection. I really admire Kate's determination and passion. She also loves to write poetry and she has worked with Red Lead, a film-making group I am involved in, where she documented our process and used her creative skills to create compelling make-up and costume for one of the actors in the film *Darkness & Despair*. One of Kate's images was also used in another film we made entitled *The Silent Injury*."

Claire Meaney, Director of WHAT, explains the impact of Kate's work in

UHW: "After Kate successfully completed a beautiful piece for the mammography room, we commissioned a bigger project to brighten up a dark basement corridor at the hospital. This corridor leads to the MRI Suite and the Department of Psychiatry. It was a huge undertaking, but Kate's stunning work, which she has called *Colours through Nature*, has transformed what was quite a gloomy, uninspiring space, and lifted the spirits of staff and patients who frequent this area. In fact, this is the route in to the hospital wards from the staff car park for a huge number of people, many of whom have commented on how Kate's work brightens their outlook at the start of their shift."

Jane Cullen, Clinical Nurse Manager of the Renal Dialysis Unit at UHW, is full of admiration for Kate's achievements: "It has been extraordinary to see Kate's talent blossom over the last five years and to witness her becoming an artist and fulfilling her potential. We feel very proud of her."

We're very fortunate to have the WHAT Arts Programme in our unit, which has supported Kate and many more of our patients to be creative and to realise their talents. It is so beneficial to patients' wellbeing, giving them a positive focus beyond the confines of their treatment. We are very grateful to the PKRF for their financial support of this fantastic programme."



Clinical Placement Co-ordinators Nora Flynn and Trish Gardiner enjoying 'Colours Through Nature' by Kate Quinn.



#### ABOUT WATERFORD HEALING ARTS TRUST (WHAT)

WHAT brings arts experiences to the bedsides of patients at UHW and other healthcare settings and has been in operation at the hospital since 1993. WHAT believes that the arts contribute to the well-being and vitality of society and that engaging with the arts stimulates our sense of identity and creativity. The aims of the WHAT Arts Programme in Renal Dialysis at UHW are to provide patients with the opportunity to participate in art making and to develop artistic skills, to work with a trained artist, to provide a high quality experience and to lift their spirits, support motivation and reduce anxiety during treatment. An independent evaluation of the Arts Programme in Renal Dialysis was carried out in 2018 with overwhelmingly positive feedback from patients, their family members and staff.

A summary of this evaluation is available at

<http://www.waterfordhealingarts.com/independent-evaluation-of-what-arts-programme-in-renal-dialysis/>

The WHAT Arts Programme at UHW is funded by the Punchestown Kidney Research Fund.

Further info from [www.waterfordhealingarts.com](http://www.waterfordhealingarts.com)



*Amanda and Frances*

By GWEN O'DONOGHUE

# CORK SISTERS DOING IT FOR THEMSELVES

As twin in Dubai raises €5,160 for the IKA

A Cork mother, whose sister donated a kidney to her in December 2020, was reunited with her family just in time for Christmas Day. Celebrating her successful kidney transplant with her were her identical twin daughters who had both completed quarantines following their return home from Dubai two weeks previously. In November one of her daughters undertook a 100km running challenge in sunny Dubai, to raise organ donor awareness for patients, like her mother, with organ failure and in the process, she also raised €5,160 for the Irish Kidney Association (IKA).

On 11th December 2020, identical twin sisters Julie and Edel Coyne from Youghal in Cork, both primary school teachers who took a career break to work and teach at the same school in Dubai, flew home in anticipation of their aunt giving their mother 'the best Christmas present of all time', a kidney transplant. Their mother Amanda received a kidney from her two years younger sister Frances (Fra).

The successful living donor kidney transplant, which took place on 14th December at Beaumont Hospital in Dublin, brought an end to Amanda's kidney function decline which started 28 years previously. Pre-eclampsia, in the pregnancy of her twin daughters, left Amanda in a coma for a month after childbirth, while her husband Tony looked after two newborn babies and his 2-year-old, now 30-year-old son, Joe. At the time, Amanda made a full recovery although her kidney function was compromised, and she required temporary dialysis treatment for 18 months until her kidney function was revived. Years of careful self-management and medical and dietary management allowed Amanda to lead a relatively normal family life and to stave off dialysis treatment for nearly three decades, until October last year when she only had 5% function in her kidneys.

Speaking about the transplant Amanda's daughter Julie said, "It was wonderful to be home for Christmas



to witness first-hand how well mum was looking and recovering post-transplant. Unfortunately, COVID-19 restrictions prevented our family from visiting Beaumont Hospital. Fra returned home from hospital after five days, but we still haven't been able to meet her in person to thank her for restoring mum's health, but we have chatted on video calls and although she is sore, she is doing very well."

Fra works as a carer in St. Raphael's Centre, Youghal, where management and staff were very accommodating to her for the living donor process. She is the kindest and most generous person I know. She instantly came forward to be considered as an organ donor for mum and thankfully her kidney was a great match. Fra has always played a big part in our lives attending our family events down through the years including when we won many sporting events and graduated as teachers. She gave mum and our family the best Christmas present of all time and we will be forever grateful."

In acknowledging the supportive role of her dad Tony, Julie said, "My dad has been mum's rock since day one. As you can imagine, it cannot have been easy for dad to be landed with two newborn babies and a toddler at home with the stress and worry of having his wife in hospital in a coma for a month. Ever since then, mum has fully embraced life and has been devoted to her family. Mum's favourite quote and one in which she says regularly is "YOLO"—**You Only Live Once**. And it is so true! She has been a constant support to us all. She has always taken pride in her appearance and if she was struggling with her health she never complained. In fact, most people that know her would not have been aware of her failing health. Dad has gone 'above and beyond' to ensure mum's wellbeing and safety especially in current times as it is vital that mum is not exposed to COVID-19 as she recovers."

Speaking from her home, newly transplanted Amanda said, "I feel great already and recovery is going well for me and for my sister Frances. It is impossible to put into words how much I appreciate what she has done for me and how she has always been a constant pillar of support. Our family would like to express our immense gratitude to the wonderful



Twin sisters Edel and Julie after completing the Sketchers Run in Dubai.

*It was wonderful to be home for Christmas to witness first-hand how well mum was looking and recovering post-transplant.*

nursing and medical staff at Cork University Hospital who have been amazing in caring for me, especially my nurse Abina and Consultant Michael Clarkson, as well as all the renal nurses in the Home Therapy Unit. Dietitian Irene has also played an instrumental part in keeping me as well as possible down through the years."

Both Amanda and Frances would also like to give a special mention of thanks to Ms. Dilly Little and Mr. Gordon Smyth and their team of experts for their skills and excellent care they received in Beaumont, with Amanda saying, "we will be forever grateful to you all."

Amanda added, "The IKA does fantastic work in supporting patients in kidney failure and we are delighted that Julie's fundraising challenge for the Association was such a success. Julie initially set a target of €1,000 to

raise over the whole month of November which she surpassed in the first week. In total Julie raised €5,160 for the IKA and it has also helped to increase organ donor awareness."

Julie finished by saying, "I really would like to thank everyone for being so generous in supporting this fundraiser. Yes, I would have always been into sports, but I would never have classified myself as a runner and I really wanted to pick something to challenge myself. So, not only was this support a huge boost for me throughout my challenge, but mum and Fra also received such heart-warming messages of support and goodwill from the Facebook fundraising platform which was a fantastic motivation for them both as they faced their transplant operations. It was the most enjoyable 30-day challenge, and I would definitely consider doing it again."



Frances, Amanda, Julie presenting Sally Nagle, Cork IKA branch with the cheque





# AWARD-WINNING NUTRITIOUS FOOD DELIVERED DIRECT TO YOUR DOOR

**M**eals4Health, is an award-winning social enterprise company which supplies nutritious and dietary specific, including renal, ready-to-eat meals nationwide. The Galway based company is giving ten lucky readers of SUPPORT a chance to each win a €25 voucher.

Geraldine Ryan, Manager at explains, "Meals4Health prepares fresh, tasty, affordable food and

delivers direct to your home. Meals are packed in ovenable and microwaveable containers and are suitable for home freezing. Recipes have been developed by our professional chefs and dietitian to meet specific nutritional needs.

"Meals can be created for your medically related dietary requirements or texture modified diet.

"Meals4Health provides specific nutritional support for people living

with chronic illness or recovering from illness, surgery or to carers who simply find it difficult to shop and cook for loved ones.

"The team at Meals4Health understand when you have chronic kidney disease, eating well is an important part of keeping yourself well. Many diet restrictions can make it challenging to maintain a well-balanced diet making it difficult to know what to eat to maintain a



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"Our main courses cost €6.50, soups and desserts cost €2 each and

♥ WELLNESS MEAL RANGE ♥ HEALTHCARE MEAL RANGE ♥ FORTIFIED MEAL RANGE

Meals4Health was recently awarded 'Social Enterprise of the Year' at the Charity Impact Awards which recognised entrepreneurial spirit and the invaluable contribution provided to its customers. [\\*4/5 you can consult your local dietitian](#)

## THANK YOU FOR YOUR GENEROSITY

The Guyett family, Christmas 2020  
Eddie, Averyl, Martina, Karl



# Woman welcomes new kidney 'Alice in Wonderland'

**A Westmeath woman has affectionately called her newly transplanted kidney, which she received in November last year, 'Alice'. Three other members of her family have also received kidney transplants due to their shared hereditary kidney condition, PKD (Polycystic Kidney Disease).**

**M**artina Guyett, a Claregalway native, who has made Rochfordbridge in Co Westmeath her home for the past twenty years, had been taken by surprise in November 2020 when at 2.48am one morning, she was woken from her sleep with a call from Beaumont Hospital to come up for her transplant kidney. Martina's husband Eddie had delivered her to the hospital's entrance by 4:20am! Restrictions on hospital visitors due to COVID-19 prevented him from going any further.

**By  
GWEN O'DONOGHUE**

While there she made friends with whom she calls her kidney transplant twin, Niall O'Grady, who received a kidney from the same deceased donor.

The HSE employee was well used to the journey to Dublin as for fifteen months she had been attending St. Vincent's University Hospital for haemodialysis treatment twice a week. Martina describes how she has now adopted 'Alice', the name she has given to her new

kidney after 'Alice in Wonderland', who has taken over the role of her failing kidneys, which she referred to as 'Thelma and Louise', liking them to the characters in the movie who were ready to drive off a cliff! While these humorous names might seem somewhat flippant, Martina describes her immense gratitude for her kidney donor and encourages people to follow the Irish Kidney Association's advice on discussing organ donation, when they would normally gather together during the festive season, and to take



the next step to get a donor card or choose code 115 to feature on their drivers licence.

Last year on seeing Martina's plight, a close friend, Emer Evans, stepped up to be her kidney donor and proved to be a suitable match. Delays due to COVID-19 prevented this from going ahead as planned.

Martina who will turn 52-years-old in April is mother to Averyl and Karl. She explained that since receiving her transplant, "I am over the moon, I feel on top of the world. The brain fog I had while on dialysis is gone and an unexpected consequence is that my eyesight has also improved since my transplant and it is all thanks to my donor. I had no idea how unwell I was until my kidney transplant showed me how well I could be.

"I was diagnosed with PKD when I was 13-years-old. I learned a lot from watching how my own mother managed her illness and was aware of the risks involved. I knew that managing my blood

pressure and staying healthy and fit was key to me staving off dialysis for as long as possible. I tried to walk 5km every day and adhered to medical advice as much as possible. I worked at Regional Hospital Mullingar for almost 16 years, 4 years in the lab where I learned to monitor my kidney function and could see they were gradually coming to end stage. My late mother's illness did not develop until she approached her fifties, just like me. She had two transplants and passed away at the age of 66 from cancer. My late uncle's condition also didn't progress until he was middle aged, and he had one transplant.

However, my brother was only 28 when he received a kidney transplant, which thankfully is working still."

As well as thanking her kidney donor, Martina, who works with Intellectual Disabilities Residential Services, has expressed her gratitude to former colleagues in the Regional Hospital Mullingar who had been a huge support to her



**Niall O'Grady and Martina Guyett, recipients of kidneys from the same deceased donor.**



**Martina leaving Beaumont Hospital after her transplant**

all through her illness, to all her family and friends and especially Emer for her willingness to donate a kidney. She also thanked "everyone at St. Vincent's Hospital including staff who looked after me and all the dialysis patients who became my friends. To all the staff at St Damien's Ward and Day Care in Beaumont Hospital, my transplant surgeon Mr Smyth and my consultant Dr Magee. The Irish Kidney Association has been a huge support to my family over the years and I want to help them spread the important message about

organ donation - *Have the Chat!*"

Within a couple of weeks of her transplant Martina did a lively interview with comedian presenter Jennifer Zamparelli, on RTÉ's 2FM which led to a significant number of requests from the public via the Irish Kidney Association's Freetext number for 219 organ donor cards and a further 23 digital donor cards downloaded from the Donor Card App.

Martina ran a fundraiser in December on Facebook for the Irish Kidney Association which raised €2676.



# IRISH KIDNEY GENE PROJECT (IKGP)

## KIDNEY DISEASE Running in the Family – AN OVERVIEW –



By **PROF PETER CONLON**  
CONSULTANT NEPHROLOGIST,  
BEAUMONT HOSPITAL



**DR ELHUSSEIN ELHASSAN**  
RESEARCH REGISTRAR, NEPHROLOGY  
DEPARTMENT, BEAUMONT HOSPITAL

### INTRODUCTION

**Normally your kidneys – two bean-shaped organs located in your lower back – filter out excess toxic and waste substances and fluid from the blood, among other various functions. These functions are precisely controlled, so your body would function properly. When you have kidney disease, your kidneys are no longer able to carry on their job effectively and wastes can build-up changing the chemistry of your body causing some symptoms that you can feel, and others that you don't.**

**W**hile kidneys might be affected with different medical conditions, like diabetes, high blood pressure or kidney stones for instance, there are many different kidney diseases that run in families. These are thus labelled as 'Inherited'. Doctors have long known that some families have more members with kidney disease than others, and often patients and doctors do not know the cause of an inherited kidney disease in their family.

Our studies have shown that between one in 5 and one in 3 causes of kidney failure can be inherited. Nowadays, very sophisticated testing of patients' genes can be done to help identify the gene that causes their kidney diseases. Often times the kidney disease is caused by an abnormal gene or 'mutation' in patients' genes. These tests can now be done on a blood, spit or biopsy sample.

Importantly, genetic discoveries have allowed medical teams to identify the cause of inherited diseases, including kidney conditions, for families in whom the cause was mysteriously unknown.

More than 200 genetic diseases are currently known to directly or indirectly affect the kidneys. Inherited kidney conditions range from relatively common conditions to very rare syndromes.

### HOW IS THE KIDNEY DISEASE INHERITED?

It is important to know which relatives have kidney disease, including brothers, sisters, and parents – but also grandparents, aunts, uncles, and cousins. Whenever possible, it is of a particular importance to go back as far as possible in the family tree to identify affected and unaffected individuals. From this information, an inheritance pattern can be determined. It is also important to realise that inherited kidney disease can manifest at any stage in life from new born babies to older people in their 60s or sometimes 70s.

We often describe different patterns of inheritance including what we call Dominant inheritance, Recessive inheritance or Sex linked – please refer to table (1).



**TABLE (1): COMMON GENETIC PATTERNS OF INHERITANCE**

Mode of Inheritance	Autosomal Dominant (AD)	Autosomal Recessive (AR)	X-Linked (XL) Recessive (Sex chromosome)
<b>Required No. Copies of gene fault</b>	<ul style="list-style-type: none"><li>One copy is required</li><li>Occurs in every generation</li></ul>	<ul style="list-style-type: none"><li>Two copies are required</li><li>Not typically seen in every generation</li></ul>	<ul style="list-style-type: none"><li>One Copy in XL-dominant, or</li><li>Two copies in XL-recessive (more common)</li></ul>
<b>Family History</b>	<ul style="list-style-type: none"><li>Usually positive</li><li>Patients would have an affected parent</li></ul>	<ul style="list-style-type: none"><li>Usually unremarkable</li><li>Both parents of an affected patient are carriers</li></ul>	<ul style="list-style-type: none"><li>Affected males often present in each generation</li></ul>
<b>Affected patients (M:F)</b>	<ul style="list-style-type: none"><li>Males and females are equally affected</li></ul>	<ul style="list-style-type: none"><li>Males and females are equally affected</li></ul>	<ul style="list-style-type: none"><li>Males are more frequently affected</li><li>Affected males often present in each generation</li></ul>
<b>Examples</b>	<ul style="list-style-type: none"><li>Autosomal dominant PKD (ADPKD)</li><li>Autosomal dominant tubulointerstitial kidney diseases (ADTKD)</li></ul>	<ul style="list-style-type: none"><li>Nephronophthisis.</li><li>Renal tubulopathy e.g. Gitelman and Bartter Syndromes</li></ul>	<ul style="list-style-type: none"><li>Alport Syndrome</li><li>Lowe Syndrome and Dent disease</li></ul>

Autosomal dominant is one of these inheritance patterns, where symptoms and signs of the disease occur when there is only one faulty (mutated) copy of a gene. Children of an affected individual usually have a 50:50 chance of inheriting the disease. For autosomal dominant diseases, there are usually many affected family members, with commonly (but not always) at least one parent and child affected.

Examples for kidney conditions of autosomal dominant inheritance are autosomal dominant polycystic kidney disease (ADPKD), the most common inherited kidney illness, and hereditary Interstitial kidney disease.

On the other hand, the affected individual with autosomal recessive inheritance conditions must have two faulty copies of the gene, one from each parent. Thus, in autosomal recessive disorders, both parents are usually unaffected carriers, and one or more children may be affected.

In autosomal recessive disorders, there are many less affected individuals in the family – usually patients' children are less likely to be affected. Gitelman and Bartter syndromes represent examples for autosomal recessive kidney tubular defects.

X-linked disorders involve genes that are on the sex chromosome X, named X-linked inheritance pattern. Females have two X chromosomes, and men have one X chromosome.

Thus, men have only one copy of genes that are on the X chromosome. For this reason, individuals with X-linked disease will affect men predominantly, and women will usually be unaffected carriers. In some X-linked diseases, women may be mildly affected.

Alport Syndrome is the second most prevalent inherited kidney disease and most commonly follows X-linked inheritance pattern.

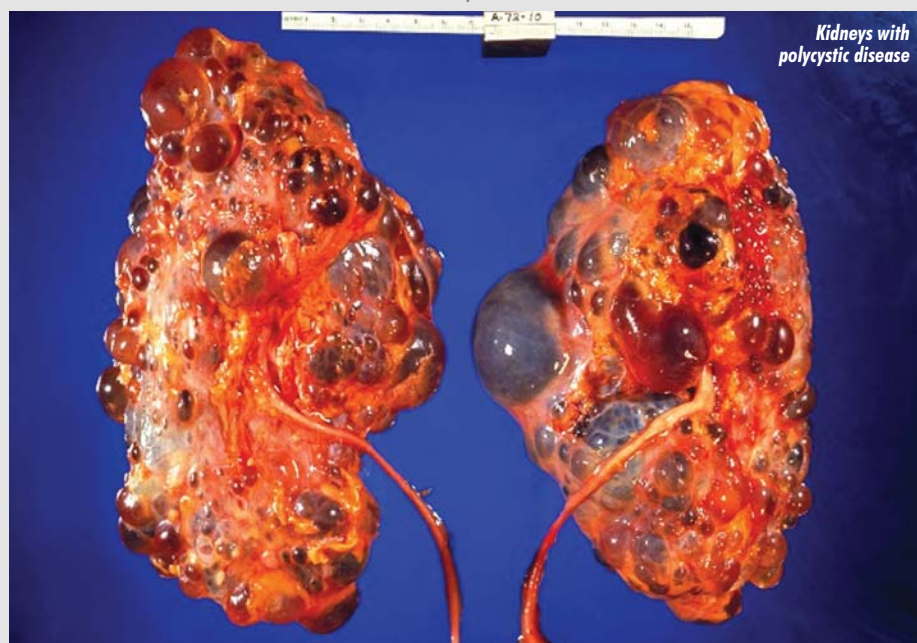
### VARIATION OF SYMPTOMS OF INHERITED KIDNEY DISEASE

While some inherited conditions are associated with only mild symptoms, severe health problems can be the

initial presenting story. Common symptoms associated with inherited kidney disease include hearing or vision problems, gout, anaemia, and a solitary kidney or problems with kidney drainage. These can be clues to diagnosis. Therefore, to diagnose and treat these conditions, special expertise is needed to address the special issues that arise in adults with genetically-determined kidney disease.

A team of medical professionals which include, but not limited to, would be a nephrologist with specific expertise in genetics, geneticists, other specialists in genetics including specialised nurses and pathology experts.

*continued next page...*



## WHAT SHOULD YOU DO IF YOU KNOW YOUR FAMILY HAS AN INHERITED KIDNEY DISEASE?

A good first step is to classify the conditions as described above and put together a family tree that lists affected individuals and ages that they needed dialysis or a kidney transplant. It is useful to talk personally to as many family members as possible with the condition. Who is their doctor? What diagnoses were they given? and when you go to your kidney doctor, make sure to bring as much information as possible and make sure to tell your doctor about your family history.

## SHOULD I GET GENETIC TESTING FOR KIDNEY DISEASE?

It is important to realise that in fact most kidney diseases are not genetic. However, if you have a strong family history of kidney disease with parents, brothers and sisters or cousins affected with kidney disease, it is not unreasonable to get tested.

Also, people often want to know if they have an inherited form of kidney disease before they have a family or donate a kidney. If patients have other things wrong with them besides just kidney disease, like eye or hearing trouble, genetic testing can be useful.

It is generally not necessary for people with polycystic kidney disease to have genetic testing as the diagnosis is usually obvious. There are some circumstances where genetic

testing may be useful; for example, if you have no family history or are planning to have a family and want to see if there is something you can do to ensure that your children might not have polycystic kidneys.

If you want to have genetic testing for kidney disease, you should discuss this with your nephrologist, but do bring as much information about your family history as possible as this is very useful.

Genetic testing generally involved a blood or spit test that is analysed in the laboratory. Because these tests are difficult to perform, it may take 6 to 12 months to get a result.

## IRISH KIDNEY GENE PROJECT (IKGP)

Since 2014, the Irish Kidney Gene Project (IKGP) has been exploring the links between genes and kidney disease. It is a collaboration between the Department of Renal Medicine at Beaumont Hospital and the Department of Human Genetics at The Royal College of Surgeons.

Through the Inherited Kidney Disease Clinic, Beaumont Hospital offers a range of genetic tests to identify and understand the nature of the inherited kidney diseases for patients and their families.

Additionally, we provide education, counselling and working with patients and families to navigate their available options for both genetic testing and treatment, and if available clinical trials of experimental therapies. We collaborate closely with our patients'

referring physicians to coordinate treatment planning and follow-up care.

Furthermore, with a goal to understand the nature of Polycystic Kidney Diseases (PKDs) in Ireland, Beaumont Hospital is undertaking research to help understanding the genes that cause PKDs and why patients get kidney failure.

The Research involves a ten-minute telephone conversation in which a kidney doctor from Beaumont Hospital will call you and talk to you about your kidney condition and a brief family history. We will then send you, by post, a patient information sheet and consent form and a DNA spit tube in which we will ask you to give us a spit sample. We will also use this sample to study your DNA. With your permission we will also review your medical records.

.....

If you are interested in helping us with this project, please email [irishkidneygeneproject@beaumont.ie](mailto:irishkidneygeneproject@beaumont.ie) and we will contact you back at a convenient time.

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**TABLE (2): EXAMPLE OF INHERITED KIDNEY DISEASES**

1. Polycystic kidney diseases (PKDs): Autosomal dominant PKD (ADPKD) and Autosomal Recessive PKD (ARPKD).
2. Collagen-related kidney diseases including Alport Syndromes (AS) and thin basement membrane disease.
3. *MUC1*, *UMOD*, and *HNF1B* – related Autosomal dominant tubulointerstitial kidney diseases (ADTKD), formerly known as medullary cystic kidney diseases (MCKDs).
4. Nephronophthisis.
5. Renal tubulopathy e.g. Gitelman and Bartter Syndromes.
6. Steroid-resistant nephrotic syndrome / Focal segmental glomerulosclerosis (FSGS).
7. Congenital anomalies of the kidney and urinary tract (CAKUT).
8. Familial glomerulopathies e.g. Atypical haemolytic uremic syndromes (aHUS)/ C3 glomerulopathy (C3G) and IgA nephropathy (IgAN).
9. Kidney stones of inherited conditions: Lowe Syndrome, Dent disease, cystinuria, and primary hyperoxaluria.
11. Fabry Disease.



# DIALYSIS keeps you going HOME HAEMODIALYSIS lets you live again

**Home dialysis therapy is the 'Rolls Royce' of dialysis allowing patients to receive treatment in their own home at a time that suits themselves.**

**While there are disadvantages, for example, the space needed, sterile environment etc, in times of pandemic it clearly has enormous advantages as patient PADRAIG MALONEY outlines in this article.**

**C**OVID-19 has been unprecedented in its impact on everybody. None more so than dialysis patients. Visits to the dialysis centres are difficult at the best of times but during a pandemic it can be fraught with huge stress and anxiety.

Step forward home haemodialysis – having your own machine in your own home has proven to be a blessing during COVID-19. It means not having to travel to the dialysis centre, no waiting for your slot to come up, or sharing a ward with other patients.

Having a machine in your house means that you can manage dialysis around your life not the other way around, and that includes your work life. I carry out my dialysis during the night, which means that, although being connected for longer the machine runs at a lower rate which is much kinder to my heart and gives better clearance. In an average week, I dialysis about twice the volume of blood as hospital-based dialysis patients. Over time this has had a beneficial effect to my overall health. While my dietician will not thank me for saying it, your diet can be that little bit less restricted, meaning you can get better nutrition.

While life will never be normal when you are on dialysis, family life is more like normal with home dialysis as



*Padraig Maloney*

you won't have to miss out on your children's school plays, the GAA matches or the dance lessons. With a home machine you can now fit in your dialysis around your daily routine, switch days, time of day or night. The machine is sitting there waiting for you, rather than the other way around.

Home dialysis is not for everybody, you must needle yourself, but once you have overcome this fear learning to use the machine is straight forward enough.

The training and monthly support from the Home Therapies Unit in Beaumont is excellent, any concerns you have can be answered with a quick call to the team. And thanks to the Punchestown Kidney Research Fund for funding the training machines.

One of the key things to feeling well on dialysis is control of your fluid levels, carrying too much fluid and you feel bloated or too little and you feel faint with low blood pressure. Over time you will develop a sense of what your optimum dry weight is as

its so easy to control.

The machine I have has been incredibly reliable, it is well engineered and I've never had a serious breakdown. In the rare event that there is an issue your training will kick in and you will be able to return any fluid in the circuit manually. Baxters have engineers on call 24 hours per day should you need to get an issue resolved.

Probably the biggest hurdle for me to overcome was needling myself, it goes against every basic instinct to stick a needle in yourself. In time it becomes second nature, and nobody is going to be more careful when needling yourself than you are. So much so that I can't remember the last time I had an issue with a vein.

In my 13 years on dialysis I have never been more grateful for having a machine at home than I now during COVID-19. While waiting for that illusive call the flexibility, convenience, control and improved health benefits together with the reduced risk of exposure far outweigh initial concerns around managing your own care.

# FATHER HELPS SON RISE TO THE CHALLENGE



By  
**GWEN O'DONOGHUE**

Inspired by his kidney transplant father, Cian Carty Heffernan (24) decided to support the Irish Kidney Association (IKA) and mark **World Kidney Day**, ([www.ika.ie/kidneyday21](http://www.ika.ie/kidneyday21)) on Thursday 11th March 2021, by completing a 4x4x48 Challenge in his native Skerries, Co Dublin which he began two days previously. Peter Heffernan, who this year celebrates the 10th anniversary of his transplant, joined his son for a 200-metre swim in the cold Irish sea after Cian had completed one of his 4 mile runs which he undertook every four hours over the two days.

Six months previously, in September 2020, Cian successfully completed his first 4x4x48 Challenge, raising over €3,200 for the IKA and emulating the same challenge, which former US Navy Seal David Goggins undertook. However, the second time around

Cian decided to go one step further. He added extra physical activity after some of his 4-mile runs. On his first and final run he did a 200-metre swim in the cold sea. He also did push-ups and increased his calorie intake to burn an additional 5000 calories.

Cian finished his Challenge at North Beach, Skerries after 12 midday on 11th March – World Kidney Day and this time raised over €2,000 for the IKA.

As a young boy, Cian saw his father suffer with kidney failure. This was Cian's inspiration to complete the challenge. Peter is now enjoying renewed life as a result of organ transplantation and is enjoying sport as a member of Transplant Team Ireland.

Before he set out on the 4x4x48 Challenge, Cian said, "I am delighted to be able to support the work of the IKA and to help highlight World Kidney Day 2021. I like to set at least



one major physical challenge for myself every year and my events have become more challenging down through the years.

I would encourage others to take up the Irish Kidney Association's 21 Day Walking Challenge. Like me, no matter how big or small the Challenge is, and once you are setting a realistic goal based on your personal ability, I can guarantee it will bring a positive outcome improving both your physical and mental wellness".

Cian's father Peter was diagnosed with kidney failure in 2005. He was called for a deceased donor kidney transplant at Beaumont Hospital in 2011.

Cian explained: "Our family is hugely grateful to the donor family for this life-giving gift. My father has represented Ireland in swimming events where he has won medals at each World and European Transplant Game that he participated in.

It was nice that he could join me for one of my swims as part of my challenge.

Over the years I have seen my father enjoy the camaraderie and support of members of the transplant team, who have all faced their own organ failure battles, and are now enjoying their 'gifts of life'.

"The IKA has supported our family and therefore I want to play my part by helping raise vital funds through my own 4x4x48 Challenge. This will help the IKA to continue supporting patients and families with kidney disease while also promoting organ donation and running the successful transplant sports programme."



# 21 DAY WALKING CHALLENGE

To celebrate the theme of



11 March 2021

**LIVING WELL  
WITH  
KIDNEY DISEASE**

**THE IRISH KIDNEY  
ASSOCIATION**

*invites you to sign up for*

**GET  
IRELAND  
WALKING**

**21 DAY WALKING  
CHALLENGE**

To find out more visit

[www.ika.ie/kidneyday21](http://www.ika.ie/kidneyday21)

Text **KIDNEY** to **50300** to donate **€4.00**

Text costs €4.00. Irish Kidney Association will receive a minimum of €3.60.  
Service Provider: LIKECHARITY. Helpline: 076 6805278.



Website: [www.ika.ie](http://www.ika.ie)  
Phone: **01-6203506**

CHARITY REGISTRATION NO. 20011260



**INS** Irish  
Nephrology  
Society



**T**hey say old habits die hard, but the same can be said for good habits. It takes 21 days to form a habit – make it a good one for your physical and emotional wellbeing by taking up a 21 Day Walking Challenge.

To celebrate the theme of *World Kidney Day, 'Living Well With Kidney Disease'*, the Irish Kidney Association joined forces with the Irish Nephrology Society and Get Ireland Walking inviting our members to take part in a 21 Day Walking Challenge! Many chose to commence their walk on World Kidney Day, 11th March, and walk their way into Organ Donor Awareness Week (27th March–3rd April). However, you can commence the Challenge any time over the months ahead!

For the 21 Day Walking Challenge participants are encouraged to aim to walk for at least 30 minutes each day or can build up to 30 minutes or more by being active for at least 10 minutes in the early days. There is a free Get Ireland Walking app to track your challenge (or download a record card). We invite those taking part in the 21 Day Walking Challenge to let their local IKA branch know as participants can be entered into a prize draw to win IKA branded facemasks.

At the end of the Challenge, participants should be able to see improvement and many will want to keep it up and see how much they can improve further in the months ahead!

Visit the Get Ireland Walking website for lots more information, tips on motivation and to find out why walking is so good for you.

[www.getirelandwalking.ie/21daychallenge/](http://www.getirelandwalking.ie/21daychallenge/)

You should always consult with a healthcare professional before participating in any fitness challenge or making major lifestyle changes.

# DIALIZE CLOTHING

In the Winter edition of *SUPPORT* we shared the story of Dialize Clothing (as seen on the *Late Late Show*). Paddy Cox, a dialysis patient, and his wife Rachel set up their company to offer an IV accessible clothing brand with the aim of making a stylish yet discreet garment for dialysis, chemotherapy, diabetics and all IV or PICC line treatments. We shared a call-out for people back then, to try out the product and let us know how they got on. Their reviews are below.

Since appearing on the *Late Late Show* last year he was invited back again in March, along with other fledgling businesses who grew during the pandemic, where he announced a new line of clothing including the full zip hoodie (Venifer).



## REVIEWER 1

Gender: Female  
Age: 70-79 years  
Time on dialysis: 2 years  
Access: Permcath

I was delighted to hear that there was a garment to wear for dialysis.

### FABRIC: 5/5

I give a 5 as it has a nice silky feel to it and it is easy to keep clean and is of a very good quality. The warmth of the garment is particularly good because of the type of lining which also deserves a 5.

### FIT: 3/5

The fit of the garment obviously depends on the size you buy. I have an XL size but I found that the sleeves were way too long and I have to roll them up, so I give a 3 for fit. I found that the pocket for the phone was too small, mine is a normal size Samsung Galaxy so it would be good to make the pocket a bit larger.

### STYLE/APPEARANCE

Excellent, particularly the colours range.

### EASE OF ACCESS: 5/5

The nurses found that the strong shoulder fasteners were excellent for holding the cables firmly in place while on dialysis. It was easy to put on a dressing because of the zip on the shoulder giving plenty of room for this.

### CARE OF THE GARMENT: 5/5

The garment washes very well and holds its shape, it doesn't need much ironing as it doesn't wrinkle. You would need three tops in total to wear for your appointments, to ensure good infection control.

### FASHION

The tops could be worn outside of dialysis, as the design and the colour range make it very suitable and it doesn't look like a medical uniform when worn outside of dialysis.

Several patients and staff have commented on the top and remarked on how smart it looked and I have recommended it to several of the patients.

Overall, it is an excellent garment for what it was designed for and well worth the price.

**Total Score: 18 marks out of 20.**



## REVIEWER 2

Gender: Male  
Age: 40-49 years  
Time on dialysis: 5½ years  
Access: Permcath, left

### GARMENT: 5/5

The quality of the fabric is good, it is warm and the fit is comfortable.

### EASE OF ACCESS: 3/5

Easy to view the site, easy to connect but nurses mentioned that it was a little tight for changing dressing – perhaps increase the length of the zip or change the alignment of zips?

### PRACTICAL: 5/5

The garment holds its shape well and is easy to iron.

### SUGGESTION

Produce a lighter summer version.

**Total Score: 13 marks out of 15.**





## REVIEWER 3

Gender: Female  
 Age: 50-59 years  
 Time on dialysis: 4 years  
 Access: Fistula on lower left arm

### OVERALL COMFORT: 4/5

Quality fabric and well stitched. Make sure you get a size that fits.

### STYLE: 4/5

A nice and sporty look. Scope for introducing brighter colours as well.

### PRACTICAL: 3/5

The location of my fistula means that the full arm is exposed and the sleeve can get in the way. Suggest having the facility to open the sleeve from the cuff to the arm-pit. Worth considering replacing the knitted cuffs with tapered ends (possibly highlighted with coloured piping).

A lighter version for summer might be a good idea.

### CARE OF THE GARMENT: 5/5

The top cleaned very well after a bleed. It has maintained its shape, dries easily and does not need ironing.

**Total Score: 16 marks out of 20.**

NEW: Full zip hoodie - Venifer



## REVIEWER 4

Gender: Male  
 Age: 19 years  
 Time on dialysis: 18 months  
 Access: PD catheter port at torso

### COMFORT: 4/5

The slimness of the fit was great. It was a good neat fit and not overly big.

### STYLE: 3/5

I like the slim fit but would prefer the design on some of the other Dialize Clothing half zip tops that come without the shoulder tabs.

The hardware (zips, etc) is good quality, and it is washing really well. I would like to see a reverse of the run of the zip on the sleeves.

Would also love to see some tone-on-tone cammo print or tone-on-tone plains for school wear etc.

Overall quality is super, and it is washing really well.

### PRACTICAL APPLICATION: 4/5

When I first received the top I assumed it was for HD patients only, then I discovered the port access hidden cleverly in the front pocket.

I would have loved this for when I was on PD as it would have made accessing the port much easier.

I've only dropped one point because I thought the sleeve zip could be easier to use.

### CARE OF THE GARMENT: 5/5

It washes like a dream mum says, with no ironing necessary apparently.

### OVERALL

I was very happy with the innovation and look forward to seeing the evolution of the design.

As it stands, in the colourway I'm reviewing, I wouldn't wear it outside of its functional use. With its slim form and functionality in a different colour and without the shoulder tabs would be my preference. Great new product – I will follow the progress of the brand.

**Total Score: 16 marks out of 20.**



## REVIEWER 5

Gender: Female  
 Age: 50-59 years  
 Time on dialysis: Currently 9 years on home haemodialysis  
 Access: Graft left upper arm

Finding the right clothes to wear to dialysis, both at home and travelling to dialysis has always posed a problem, especially to females.

### OVERALL COMFORT: 4/5

The top is really warm and comfy. The fabric is soft and fleecy on the inside and the long sleeves keep my arms warm while on dialysis. I always get really cold and am constantly looking for blankets, so that has certainly eliminated that problem.

As regards the fit it is a little big for me. When I adjust the strings it helps though the sleeves are a little long. I ordered the small size but I am very petite so maybe an extra small could be produced?

Overall, I am satisfied.

### STYLE: 5/5

I really love the style. I chose the grey colour and it is very fashionable. I had seen a man going to dialysis one day wearing a top and it had 'Dialysis Clothing' in very big lettering splashed across the back. I thought to myself I would never wear that outside!! However I was really pleased to see my top had very small lettering for the logo over the pocket and I am proud to wear it on my walks and am proud to wear it as a normal tracksuit top. The colour also goes well with bottoms. It is of excellent quality.

### PRACTICAL: 5/5

It is very easy to slip my arm out so I can needle, change dressings etc. I am glad of the other zip accesses as I often need to get lines put in and this was a headache for me anytime I had to travel to the unit as I had to always think about what I was wearing. Even with my graft arm I had to wear short sleeves, but now my arms are kept warm with the long sleeves. The pockets are also really handy.

### CARE OF THE GARMENT: 4½

It is easy to wash and holds its shape. The material makes it iron free.

**Total Score: 18½ out of 20**

A big 'thank you' to our reviewers for taking the time to share their insights. If you would like to find out more about Dialize Clothing you can check out their website: [www.dializeclothing.com](http://www.dializeclothing.com).

# Cork woman opens up about her second life-saving kidney transplant

Sally Nagle who underwent her second kidney transplant in November 2020 pictured at her home in Montenotte, Cork.  
Picture: Dan Linehan



By CHRIS DUNNE, EchoLive.ie

At the age of 29, Cork woman **SALLY NAGLE** has undergone not just one, but two life-saving kidney transplants in 2008 and 2020.



**LETTER FROM THE PRESIDENT**  
Sally received a letter from the President of Ireland Michael D Higgins, in recognition of her contribution to the IKA as the Cork IKA Branch Chairperson, and for advancing the cause of organ donation by sharing her inspiring story and her fundraising efforts.

Gratitude is something we have become more familiar with in recent times, acknowledging all that is good in our lives.

"Saying thank-you is very important," says Sally Nagle, 29, who has two brothers and three sisters.

Sally, from Montenotte, was given the chance to live a full, happy and active life because of a life-changing gift of an organ donation – not once, but twice.

"I've had an underlying condition since birth," says Sally.

"The condition, idiopathic multicentric ostolysis, is so rare, I am the only case known in Ireland or in the UK. It's the breakdown of the brine in hands and feet, and hard tissue forms instead of bone.

"At a very young age I couldn't crawl, I used my elbows. I was very sore and cried a lot. I was five years old when I received a diagnosis from the UK."

How did the condition impact Sally's life?

"I couldn't walk very far, I'd get tired, and I had difficulty opening jars for instance. In later life, in my teens, there was a possibility I'd suffer kidney failure."

Sally was in third year at school when she had to go on dialysis treatment for two years.

"I didn't like the idea of that," says Sally.

"In third and fourth year at school there were a lot of trips planned. I didn't want to miss out."

Two years after commencing dialysis, Sally underwent her first kidney transplant.

"You are on tenterhooks

waiting for the phone to ring," says Sally.

That vital call changes the lives of people every year. In 2019 there were 153 kidney transplants carried out in Ireland.

"Getting that call is life-changing," says Sally.

"You never know when it will come. You keep your phone on constantly and you will it to ring with news of a prospective donor."

Life for Sally back then was a rollercoaster of ups and downs. Her future relied on someone somewhere to restore her life to a semblance of normality.

"I was on dialysis for 12 and a half hours at home every night," says Sally.

"I'd often have to go in late to school in the morning. Dialysis is draining."

Was her teenage social life non-existent?



"I did go out and see my pals," says Sally.

"But I couldn't do things like other teenagers, like go on sleepovers to my friend's houses."

Did she get fed-up while her life was on hold?

"I'd be generally an optimistic person," says Sally. "But I'm only human and I'd have my bad days. As time went on, I used to think, I'm ready for a transplant now."

Sally, being a member of the Baha'i religious community, had faith and she had hope.

Finally the call came. Sally was elated.

"It was such a nice surprise."

Time was of the essence.

"We rushed up to Beaumont Hospital in Dublin," says Sally.

Everything went well with the kidney transplant. She got a reprieve for 11 years.

"My life changed drastically for the better after my kidney transplant," says Sally.

"From having low energy, I had loads of energy. The strict dietary and fluid restrictions were gone. The dialysis was gone."

Sally enjoyed a new-found freedom.

"I didn't have to think about what I had to do every day all the time. Now I had choice," says Sally.

"I could engage with life like I never could before."

Sally broke free of the restraints that ill-health had caused her.

"I was able to go on holidays!"

She was also able to indulge herself in her passion.

"I did the 12 week Ballymaloe cooking course. I loved it! Cooking is a life-skill that is really useful."

She found a niche for herself.

"I love the whole industry and I enjoyed selling my home-made soups and

other products at the country market. I found my niche."

She explored other opportunities.

"I went back to college. When I was working in event management I was very interested in social media and marketing. For a time, I enjoyed minding young children."

Enjoying a new lease of life and embracing life, Sally kept the prospective life-span of her new kidney at the back of her mind.

"We are informed that the kidney is possibly not a 'forever' kidney," says Sally.

Sally did all the right things to promote the longevity of her donated kidney gifted to her from a deceased donor.

"You take the tablets and you look after yourself."

Sally was devastated when she suffered kidney failure again.

"There weren't any real symptoms," says Sally. "I felt a bit unwell."

She felt she couldn't

face the prospect of undergoing dialysis treatment again and the anguish of waiting for another suitable match for another kidney transplant.

"I waited as long as possible," says Sally.

"I was slow to go back on dialysis treatment. This time round I was older so I decided to get haemodialysis treatment three days a week for three hours a week in CUH. Also I associated being at home with enjoyment. The medical team at CUH were amazing."

The treatment took its toll on Sally's system.

"I couldn't plan anything else on those days," says Sally.

"I was very tired. If I'd planned to do things, I had to plan days in advance. That's just the way it was."

Having family support was always on hand.

"My parents and extended family were always there for me, offering their support. I have to thank them so much for that."

Sally's aunt made an incredible gesture.

"She offered to be tested as a possible match as a living kidney donor," says Sally.

"Going through all the tests and taking time out was an unbelievable gesture on her part. We have a great bond."

"The first time she was 'worked up' for the process, it was delayed due to COVID-19. We were on schedule for surgery in May. The second time in July that I was to undergo the living donor transplant, there were too many anti-bodies present for the operation to go ahead. It was a massive blow."

"You have yourself built up for it. The transplant was to go ahead on the Monday. On the Friday before I was

*continued next page*



**Sally, with her parents Ken and Sabina Nagle outside Beaumont Hospital on the day she was going home.**

*My life changed drastically for the better after my kidney transplant. From having low energy, I had loads of energy. The strict dietary and fluid restrictions were gone. The dialysis was gone.*

## Cork woman opens up about her second life-saving kidney transplant contd...

told I'd have to wait another eight weeks to check if the anti-body count had reduced in order for the operation to proceed."

In August, it was determined that the anti-body blood count was still too high. Sally was looking at another six months to get her life back.

"I was back on the list again. My chance of a new lease of life had been snatched away."

Then she got that all-important, life-changing call back again.

"Out of the blue I got a call advising me that a deceased donor had become available," says Sally.

She had to leave home in 20 minutes and make her way to Beaumont.

Sally's faith and trust paid off.

"I had prayed everything

would be all good and that this was meant to be," says Sally.

"I recovered well and was Zooming and on WhatsApp almost straight away after surgery!"

Sally realises that her salvation could be the result of a tragedy for another family who loses someone somewhere.

"I will always have a special connection with my donors," says Sally.

"I send a thank you card to them via the hospital every year. It is so important to acknowledge the wonderful gift they gave me.

"Every day I remember the freedom I now have and the new opportunities that are within my grasp."

Sally makes the most of her precious gift.

"I don't sweat the small stuff. I enjoy the little things



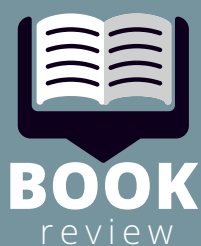
*Sally on the day she was leaving Beaumont Hospital, seven days after her transplant, with Dr. Colm Magee and Transplant Surgeon Dr. Ponnusamy Mohan*

in life and I look to the future," says Sally.

"I like to think that the families of the deceased donors get some solace from knowing they gave another the 'gift of life'.

Those families made a difficult choice at a difficult time. It is really important to remember those donors and their families. They have done so much good."

*Reprinted courtesy of EchoLive.ie*



**BOOK**  
review

**Title:** *From Analysis to Dialysis and Beyond*

**Author:** Marguerite Sneyd

**Published:** 2020

In her book entitled '*From Analysis to Dialysis and Beyond*', Marguerite Sneyd, a South Dublin IKA Branch member, offers readers an honest and open account of her personal journey through her own physical and mental health difficulties. She talks from her heart about her early childhood, growing up in Dublin, getting married and the joys of having her two sons.

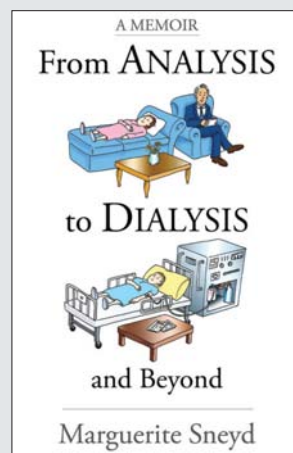
Interwoven in her journey are the losses and hardships of life that began to take a toll on her mental health. This book gives an insight to one patient's experience with various medical issues, doctors, and medications before going on to describe the shock of being diagnosed with kidney failure, the impact dialysis had on her life, her journey to transplant and now a happy healthy beyond.

I admire Marguerite for sharing her story with others.

Reading it might give hope and understanding to those of you who are also on the difficult journey of kidney failure and Marguerite's sense of humour might also raise a smile or two.

Part of her warm hearted nature is her wish to donate the proceeds of the sale of this publication to the Dialysis Units in Tallaght and Beaumont Hospitals.

Copies of the book are available by phoning Head Office, Donor House at 01-6205306. Price €10.00 (including postage).

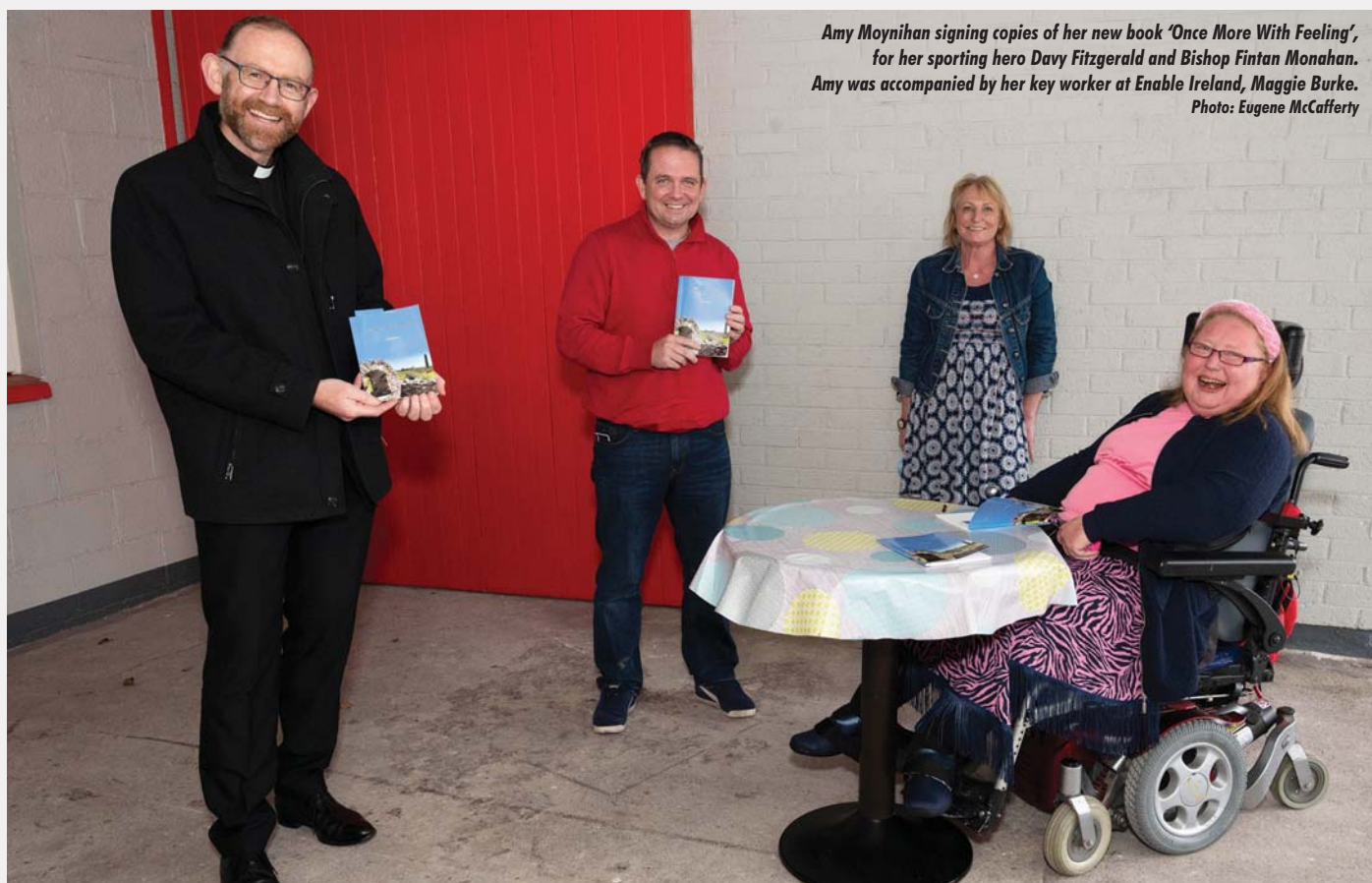


By  
**AOIFE SMITH**



# 'Once More with Feeling'

Amy Moynihan signing copies of her new book 'Once More With Feeling', for her sporting hero Davy Fitzgerald and Bishop Fintan Monahan. Amy was accompanied by her key worker at Enable Ireland, Maggie Burke. Photo: Eugene McCafferty



**An 'inspirational' woman with Cerebral Palsy received widescale acclaim for her book about her seven year dialysis journey. While writing her book, which also includes poetry, she got the call for a kidney transplant and the last chapter is dedicated to this positive outcome. Amy has pledged a donation from the proceeds of the book to the Irish Kidney Association who she credits for supporting her during her treatment.**

**The editor of the *Clare Champion* DAN DANAHER wrote the following review article (abridged).**

Former Clare hurling custodian and manager, Davy Fitzgerald (who attended a book launch) has described a new book produced by a Kilrush woman for kidney patients as 'inspirational'.

'Once More with Feeling' is a warts and all account of Amy Moynihan's dialysis journey interspersed with dietary information, poetry and uplifting messages.

Davy said he was proud to be associated with the beautiful production of her book.

"It shows inspiration, hope, courage and a reaching out to help others on their journey of life," he said.

Bishop of Killaloe, Fintan Monahan, described the publication as "heart-warming and inspirational. It gives an account of the courage and bravery of an outstanding woman who has lived with Cerebral Palsy and renal failure for years.

It is a testimony to faith, belief in oneself and the triumph of the human spirit. I recommend it highly as a book that will lift your heart," he stated.

The aim of the new book is to give dietary tips, practical support and help to kidney patients. With very little written information available to newly diagnosed renal patients, Amy has produced a very useful guide to navigate the difficulties around food choices, food products and

meal planning.

The 41-year-old, who was born with Cerebral Palsy, lives with Enable Ireland in a supported house on the Quin Road, Ennis and goes home to Kilrush at the weekends. Seven years ago, when Amy was diagnosed with end stage kidney failure she found there wasn't a lot of information to assist dialysis patients.

Before the book was completed, she got the all-important call for a new kidney and had a successful five-hour transplant operation at Beaumont Hospital in January 2019 after a seven-year wait.

'Once More with Feeling', which was published by Real Print in Ennis is available in Ennis Bookshop, Pen 2 Paper newsagent Kilrush and G Beauty Kilrush.





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*Ger O'Connell, Director at Arrotek with Marie Fowley, Sligo IKA branch*

### MEDICAL DEVICE FIRM SUPPORTS KIDNEY PATIENTS

The Sligo branch wishes to thank Arrotek Ltd for their recent generous donation.

The Finisklin based firm has been a strong and valued supporter of the IKA over a number of years.

Their latest donation took place just before Christmas, after the winter edition of *SUPPORT* magazine went to press.

Speaking at the cheque presentation Ger O'Carroll, Director of Arrotek said: "The company has again this year donated to the Irish Kidney Association.

"It does vital work supporting patients affected by end-stage kidney disease, as well as their families. It is a disease that can affect anyone, and the impact can be significant.

"Supporting organisations like the IKA is more important than ever as 2020 comes to an end, given their

## SLIGO

By BRIAN McHUGH



*At the draw, IKA members with nurses in the Dialysis Unit.*

## Centra Cosgrove's • Maugheraboy



*IKA members with some of the prizes outside Cosgrove's Centra Maugheraboy*

fundraising efforts have been curtailed this year. At Arrotek, we are proud to offer our support with this donation.

Chairman of the Sligo branch Sean Fowley thanked Arrotek for their generous donation. He said: "Your support is greatly appreciated by the members of our branch and by the many kidney patients in the Sligo region."

Arrotek is a medical device design consultancy specialising in the design and manufacture of minimally invasive medical devices.

### FREE DRAW HELD IN DIALYSIS UNIT

While Christmas seems like a long way back now, our festive treat for patients took place after the Winter *SUPPORT* magazine went to press.

For our 2020 event the branch held

a draw for patients in the dialysis unit in Sligo University Hospital.

Members of the branch visited the unit to hold the free draw with seasonal prizes for patients and staff. The members made three trips to the unit to cover all the dialysis shifts. There was also a draw for staff of the unit. A total of 25 winners received prizes.

The draw was in lieu of the IKA annual Christmas dinner that had to be cancelled for obvious reasons.

Prizes included large hampers, turkey and ham, food vouchers and tins of biscuits.

Thanks to Cosgroves Centra, Maugheraboy, for supporting the draw and to IKA branch committee member Eileen Nolan for organising the prizes.





Denise (right) with daughters Leona and Katie and partner Derek.



IKA Sligo branch Treasurer David Bereen (left) with the Howley family and IKA Sligo branch Chairman Sean Fowley (right)

### FAMILY WALKS FOR MUM AND IKA

On the day that her late mum would have been celebrating her birthday, a Sligo woman and her family started a fundraising memorial walk in aid of the IKA.

Denise Howley, Ballymote bid farewell to her mother Breda when she passed away suddenly on New Year's Eve 2019. The late Breda lost a kidney 12 years ago.

On her recovery back then Breda decided to become an organ donor and at her request her organs were donated when she passed. She had worked in Baxter Healthcare, Castlebar.

Spurred on by her mum's desire to donate the 'gift of life' to others, Denise decided to honour her. On February 1st this year, which would have been Breda's birthday, she and her family started daily fundraising walks with the money raised going to the IKA.

In the cold and often wet days of February, Denise, together with her daughters Leona and Katie, and her partner Derek Duffy walked a total of 100 miles within their local area. They raised €1,400 for the IKA.

Denise said: "The IKA was always close to my mum's heart so we took on the 100-mile challenge in her memory, starting on her birthday."

### €20,000 DONATION AIDS COMFORT FOR PATIENTS

Patients and staff of the Renal Dialysis Unit at Sligo University Hospital (SUH) wish to thank James Nolan and his team at the PuncHESTOWN Kidney Research Fund (PKRF) for their generous donation of €20,000.

With the money donated they



purchased two hospital beds, four mattresses and five haemodialysis chairs. This will further enhance the comfort of patients attending the dialysis unit.

They also put together a goody bag for all patients which included a range of Elave skincare products, aromatherapy hand sanitisers, tissues and sugar-free sweets.

James Nolan suffered renal problems from birth. In 1986, at the age of 19, he went on dialysis in the Meath Hospital, Dublin. In 1987 James received a kidney transplant from his sister Catherine.

### CONGRATULATIONS

Congratulations to Marie Fowley who recently celebrated 10 years of her double transplant.

Marie, from Hazelwood in Sligo is our Vice-Chairperson and Board member. She received a kidney and pancreas in a 13-hour surgery in early 2011.

Now, as she enjoys good health, she says she thinks of her donor everyday. "That donor gave me the

'gift of life', something I will be forever grateful for," Marie said.

We, her colleagues in the Sligo branch are proud of her contribution to the Association and her unstinting work for patients.

### EIOIN'S ONLINE GIG FOR IKA

Thanks to local entertainer Eoin Troy for doing a three-hour livestream for the IKA on Saturday night February 27th.

During his gig 19 viewers donated a total of €333.

The event was hosted on the McLynn's Bar Facebook page as part of the Sligo Level 5 Lock-Ins series. It was sponsored by The White Hag Brewing Co., Ballymote.

Eoin told viewers that the IKA is a cause close to his heart.

### SYMPATHY

We were all saddened at the passing of Hughie Costello on January 27. A dialysis patient, Hughie had been a dedicated member of our branch. Condolences to his partner Caroline, children Katelyn and Morgan and his extended family, RIP.

Condolences also to the family and friends of Grainne Kelly of Kinlough who passed away on January 5th, RIP.

Grainne was a good friend of our branch and was very well liked by all in the dialysis unit of SUH where she was a patient over a number of years.

We also express sympathy to the family of John Sheridan, Dromore West who passed away on December 16th, RIP.

John was a dialysis patient at SUH for a number of years. As well as being a patient himself, he showed his concern for other patients and their families by supporting the IKA.



Find us on:  
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## 2021 - A HOPEFUL YEAR

*Hello to you all!*

On behalf of the branch we wish all our renal patients, transplant recipients, their families, the medical and nursing staff of the Renal units, branch members and volunteers agus ár gcairde go léir san IKA a happy, safe and peaceful 2021. We look forward to moving on from all things COVID!

Our support is always available, so feel free to Call or Text 087-6243367/ 087-9392148, Email: [ikaclare@gmail.com](mailto:ikaclare@gmail.com), or Message us on Clare IKA Facebook page. Stay safe and well.

## FUNDRAISERS

We encourage you all to keep up the fundraising initiatives. We urge anyone with any ideas to create your own online/virtual fundraisers in order to ensure the IKA vital services can remain for those who require it. We are very grateful for any support in these trying times. Some of the 2020's ventures are outlined below and we hope others will follow:



Pat Danagher, Kilrush decorated his house with Christmas lights to raise funds for the Clare branch of the IKA. We thank Pat and all who supported his fundraiser which raised €1572. It was a wonderful sentiment to lift our spirits at Christmas time while raising amazing amounts of funds.

Also 'thank you' to kidney transplant recipient Amy Moynihan, Kilrush for her donation from the sale of her book 'Once More with Feeling' to the branch. The book outlines Amy's dialysis journey interspersed with dietary information, poetry and uplifting messages. Her wonderful story can be read in this month's *SUPPORT* magazine. Well done Amy on such a massive achievement of writing a book and raising much needed funds for the IKA.

We also like to thank, once again, Reah Higgins and her husband Aaron Higgins. Aaron received a kidney transplant, in January 2017, after many years of being ill and on dialysis. Reah was the live donor for his transplant and both them and their

two boys, Fionn and Stephen are grateful every day for this life-changing event. This fantastic family, who have journeyed the ups and downs of illness and kidney transplantation, decided to share their emotional story through a beautiful collection of music and poetry on their CD 'A New Dawn' and in doing so, raise funds for Clare IKA. A total of €540, was generously donated to the branch.

To mark 4 years since that testing, yet successful transplant journey, Reah also composed the delightful poem below – that perhaps some of our live donor readers and live donor recipients can particularly relate to.

*And as they wheeled me down  
To infinitely remove this part of me  
I felt no loss, just a willing  
That my lock would fit your key.*

*It slotted in with ease  
Determined, robust, secure  
And you gained a new lease of  
strength  
To be yourself once more and soar.*

*I do not yearn for nor miss it  
It was something I did not need  
Yet perhaps in gifting it to you  
I unlocked something for me too  
indeed.*

*Now we both step into our own  
Back where we each belong  
A force to be reckoned with  
Together or individually,  
we've never been so strong.*

– Reenie, Jan 2021

# LOUTH/MEATH

By CELINE TUITE

Hi to all our Branch members. We hope you're all keeping well during these strange times.

We would like to extend a warm welcome to Carol Moore and wish her well in her role as CEO. We would also like to wish Mark Murphy and Lorraine Costello well in their retirement and thank them for their service over the years.

Our deepest sympathies to Deirdre Lyness and family on the sad loss of her husband Jerome. Jerome was a

participant in the Transplant Games in Newcastle in 2019 and did the Branch proud by winning a gold and silver medal. May Jerome rest in peace. Also sympathies to Deirdre and family on the death of Deirdre's father Kieran, RIP.

Our sympathies also to Marian McMullan on the death of her brother Tony and sister-in-law Helen, sister of the late Terry McMullan. Sympathies also to all branch members who have lost loved ones.

If anyone in our Branch needs support please do not hesitate to contact Valerie Brady at 086-3186757, Email: [ur\\_pal\\_val@hotmail.com](mailto:ur_pal_val@hotmail.com); Ann McGivney at 087-2976876, Email: [mcgivney.la@gmail.com](mailto:mcgivney.la@gmail.com) or Celine Tuite at 086-1572088, Email: [celine.tuite@gmail.com](mailto:celine.tuite@gmail.com)

We wish all our Branch members well and look forward to when we can meet again.





(L-R): Irish Kidney Association Clare branch Chairperson Peggy Eustace, IKA Clare branch Treasurer Gerry Moran, Michael Fitzgibbons, Fitzgibbons Contractors, Clare Branch Secretary Noretta Clifford, Sarah Keogh, Fitzgibbons Builders and Carl Hale, Clare County Council.

## Sympathies

Our sympathy to the family of Aisling O'Reilly, Killaloe. As a Clare IKA branch member and loyal volunteer, Aisling helped to promote the organ donor card and was always willing to help with our fundraising initiatives. May she rest in peace.

Our sympathy also to the family of Clare IKA member John Monaghan, Cloughleigh, Ennis, who passed away recently. May he rest in peace.

## CLARE IKA 'GIFT OF LIFE' MEMORIAL

To mark 30 years in existence, the Clare IKA Branch commissioned a 'Gift of Life' memorial in the centre of Ennis town, providing a focus for our recognition of organ donors and their families who made the gift of life possible. Clare IKA are now delighted to be able to announce that the memorial is now complete.

It was our intention to have organ donor families, transplant recipients and branch members attend an official opening but unfortunately due to COVID-19 restrictions this was not possible. However, a small gathering was held to mark the occasion with words from Peggy Eustace, our branch Chairperson and Noretta Clifford, Secretary and transplant recipient herself. Present also was Gerry Moran, Clare IKA Treasurer, Carl Hale from Clare County Council and Michael Fitzgibbons and Sara Keogh from Fitzgibbon Contractors Ltd.

Denis Goggin designed the memorial centrepiece stone which is situated in an enclosed reflective area surrounded by shrubbery and boulders. The centrepiece features hands – the symbol of giving of new life and the Forget-Me-Not as no organ donor will ever be forgotten. Denis and his wife Martina, a donor



family themselves, were instrumental in setting up the beautiful Circle of Life Commemorative Garden in Salthill, Galway. Clare County Council kindly provided the site and helped with overall memorial grounds design. Michael Fitzgibbons Contractors constructed and put it altogether.

Life is the most amazing gift of all. Over the years, hundreds of lives are saved through organ donation. Our organ donors and their families are always upmost on our minds for the great gift they have given to those who were so ill. In donating the organs of those they loved, they have saved many lives through transplantation. We are forever grateful for the precious gift our recipients have been given.

The memorial grounds will encompass three themes:

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

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

**Remembrance:** Transplant recipients greatly cherish the memory of their organ donors and this memorial will also serve as a place for recipients to visit, remember and give thanks for the precious gift they have received

The 'Gift of Life' memorial was funded by the IKA in recognition of the kindness and generosity of organ donors and their families. There were a number of others involved too and Clare IKA Branch would like to express heartfelt thanks to all involved. In particular, we wish to thank Clare County Council for providing the grounds for the memorial. Thank you to John Corry, Tommy Scott, Carl Hale and the members of the memorial committee in Clare County Council. Thanks also to Niall Coonan, Stephan McTiernan and all the Fitzgibbons contractors' team who worked on this memorial project.

Finally, we would like to thank all those people from across the transplant and organ donor communities for supporting us to provide a memorial that will increase the knowledge and understanding of the need for organ donation.

Hopefully, later on in 2021 when restrictions are lifted, we will have a bigger and more official opening but in the meantime we hope you get a chance to visit the memorial grounds to reflect, recognise and remember the 'gift of life'.





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Members have been keeping in touch via our monthly Zoom meetings which are held on the second Wednesday of every month. Our meetings start at 7.30pm and usually last about an hour. If you would like to join any of our meetings, please contact me at 086-3416864 and I will send you the link. Our AGM will be held on May 12th.

Our sympathies are extended to our CEO Carol Moore on the passing of her mother only a few short months after she lost her father. May they rest in peace.

Liz O'Sullivan, Alexander Ager and John Semple took part in the Forum on February 12th to discuss the campaign for vaccinations of kidney patients. I am glad to report that many of our branch members took part in the lobbying of TDs by writing about their personal experiences of life with kidney disease.

## DUBLIN SOUTH

By JOHN SEMPLE



John Semple was interviewed by the *Tallaght Echo* which you can view on the IKA's Facebook page. We are all delighted to have been moved up the list for vaccines. Congratulations to everyone in the IKA for a remarkably successful campaign.

We are all looking forward to the

summer months when we will have received our vaccines and are able to get out and about a bit more without the fear of getting COVID-19.



Our condolences to the family of Terry Mangan, from Templeogue, who passed away in March 2021. Terry received the 'gift of life' in 1996 when he became unwell and required a heart transplant. Since then he became a fierce advocate for organ donation.

He was involved in the foundation of the Irish Heart and Lung Association and The European Heart and Lung Foundation where he held the position of Chairman.

Terry was a long time friend of the Irish Kidney Association.

A gentleman, he will be greatly missed by all who have had the good fortune to have known him. May he rest in peace.

## WATERFORD

By VERA FRISBY

Welcome to the Spring edition of *SUPPORT*. We hope our magazine will help to brighten your day after what has been a very strange year for us all.

Noelle Conway from Dungarvan competed in the Dublin City Virtual Marathon on October 24th 2020. The final figure raised by Noelle is €4,000.00. 'Thank you' Noelle for raising this magnificent amount of money for our branch.

### CONDOLENCES

We send our deepest sympathy to

Eileen Long on the death of her niece Pamela Mansfield; Eddie Sullivan on the death of his sister Eilis Faulkner and Tommy Byrne on the death of his sister Kitty Begley. May they rest in Peace.

We would like to take this opportunity to remember all our recently deceased members and friends. We send our deepest sympathy to their families.

### GOOD WISHES

We would like to send good wishes



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to all our branch members and volunteers, especially all those in hospital at this time. Stay safe and hopefully 2021 will be a better year for us all.

### BRANCH MEETINGS

We are continuing with our branch meetings via Zoom. Our next meeting will be in March 2021. If you would like to join us for our virtual meetings, please contact: Frances Moynihan, Phone: 087-2411549 or email: [francesmoynihan19@gmail.com](mailto:francesmoynihan19@gmail.com)



# OFFALY

By DERMOT GLYNN



## GREETINGS

I hope that everyone is staying safe and well in these very difficult times. The branch held our first zoom meetings on February 24th. This proved very successful amongst our members, it was a great way of getting in touch with each other again. If you would like to join in our next Zoom meeting please get in touch with our Secretary on email: leona.mcdonald1@gmail.com

## CONDOLENCES

Our sympathies to Lucy Smith and her family on the passing of her daughter Marion Feehan and especially to her husband Jude and their sons Max and Deema.

Condolences also to Ann

McDermott and her family on the recent passing of her brother John Hoey and her sister Chris Cleary and to Barry La Cumber and his family on the recent passing of his wife Patricia. May they rest in Peace

## FUNDRAISING

Fundraising has proven difficult during these times but this did not stop Seir Kieran's Community Group in Clareen, Birr. They organised a walk and raised €1050. 'Thank you' very much to all who helped, this is very much appreciated in these difficult times for fundraising.

## THANK YOU

On behalf of all our members I would like to take this opportunity to

thank all the doctors, nurses and all the staff in the dialysis unit in Tullamore for looking after our patients during these very difficult times.

## GET WELL WISHES

To any of our members who are sick or unwell at present we hope you get well soon, in particular our chairman Jerome. To anyone struggling during this lockdown, hopefully, in the near future we will all be vaccinated which will lead to better times for all of us in the not too distant future. Stay well and stay strong.

Join our next Zoom meeting and keep in touch.



# WEXFORD

By MARIE DONLON

William Whelan and Bree Vintage Club organised a virtual 'Rev it Up challenge in December and raised €3,252 for the Wexford Branch. 'Thank you' to all involved in the challenge.

One of our great supporters and fundraisers, Kathleen Tomkins, organised a fundraiser, on our behalf, among her family and friends and raised €2,121.74.

Wexford Credit Union Annual 5k Night Run in aid of IKA took place virtually this year from 4th to 7th February. We want to thank all who took part.

We remember with great sadness those who passed away recently, Paddy Conroy, Jo O'Brien, Mary Ryan and Michelle Brady. Our thoughts and prayers are with their families at this sad time.



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# TIPPERARY

By ORLA HOGAN RYAN

We hope that you are all staying safe and well in Tipperary.

We want to pass our sympathy to Doreen Donovan and family on the death of Sean. Sean was one of the founder members of the Tipperary branch and was dedicated to our Association.

We missed catching up with more of our members for our get-together at Christmas. Unfortunately, due to the pandemic it had to be cancelled. We are, for now, catching-up with members, through our support meetings, via Zoom. It is going very well.



We extend our sympathies to Carol Moore, our Chief Executive Officer, on the recent death of her mum, RIP.

Jim Flynn, Captain Nenagh Golf Club, presented James Dodd, Nenagh (left) with the proceeds of a recent IKA scramble.

A sum of €4760 was raised. The organisers extend a grateful thanks to the golfers and main sponsors ABP.



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*Eileen Phelan*

## FAREWELL AND 'THANK YOU' TO EILEEN PHELAN

The Home Therapies Units loss is someone else's gain as Eileen Phelan, Home Haemodialysis Nurse Manager has announced that she is moving onto pastures new. She has been appointed Accounts Manager for Baxter Healthcare South, and will be commencing her new role there at the end of March.

Eileen was head of CUH dialysis unit from 2005 until 2011, when unforeseen circumstances curtailed her attempt to live out her hippy dream of life on a houseboat in Brighton, and she took on the task of rolling out the Home Haemodialysis

# CORK

By SALLY NAGLE



*Eileen, pictured with colleagues at the September 2018 'Gift of Life' Ball, in Cork, organised by Sally Nagle.*

programme in CUH.

Over the last 10 years Eileen has showed immense kindness and dedication to her patients. She has guided people through extremely challenging times and has said that it was a privilege to be in a position to do so.

Like us all, Eileen and her husband Brian have found the last year tough, not being able to see their son Dave, who lives in Brighton with his wife Alice and young family. However, they are able to 'Zoom' in on her granddaughters disco nights, footballer and chef-in-training Eva (8) and sparkly princess Lily (6) which does make it easier.

We wish Eileen successful times ahead.

saw lots of new faces join for the first time and of course many old faces too.

We are working hard to try make the Zoom meetings as informative and helpful as possible. Although Zoom is not the same as meeting physically, it definitely has its benefits, with people being able to join from the outskirts of Cork and further afield. It also allows us to be able to invite speakers that may not live in Cork.

We are so lucky to be able to continue building our little community and it has been a great support to so many on their journey with kidney disease, whether they are only beginning their journey or they have been on that journey for many years. Be assured that if you are new to the meetings you will be welcomed and supported with open arms.

If you would like to join our monthly support meetings please contact us by email: [secretarycork.ika@gmail.com](mailto:secretarycork.ika@gmail.com) or call/text the Branch Secretary on 086-2755754.

## ZOOM SUPPORT MEETINGS



Our Zoom support meetings are going from strength to strength, supporting people through these challenging times. The first meeting of 2021 took place in January, where we

## DATES FOR SUPPORT MEETINGS:

All meetings start at 8pm.

**Tuesday April 6th**

**Tuesday May 4th**

**Tuesday June 1st**

– This will be our Branch AGM (Election year).



# DONEGAL

By SIOBHÁN BATES



*Donegal branch delivering Christmas presents for our Renal Dialysis patients at Letterkenny hospital.*

Hi to everyone from Donegal. Here's hoping this finds you all well and keeping as safe as one can be.

Our Donegal Committee continues to work behind the scenes and we are here to help with anything that may require our attention.

The Branch has not been publicly active with meetings or socialising due to Covid-19. We are all isolating and practising social distancing and trying to stay safe. Hopefully, we can all return to normality soon. The Donegal Branch officers – Kieran, Patricia, George and Siobhán take this opportunity to wish you all well.

We wish our recent transplant patients good health and would like to thank the donor families for their 'gift of life'.

Our condolences to Neil McBride, his children and family from Lifford on the passing of Caroline Caz McBride. May her young beautiful soul be at peace. Caz it was a pleasure to know you, RIP.

Our condolences also to the McGonigle family from Clonmany, on the sad passing of Roseanne. She was a fantastic fundraiser and very loyal friend of the branch for many years. May her gentle soul rest in peace.

Condolences also to Lucy and the Boyce family on the very sad passing of our great Ambassador and friend Hugo Boyce. A legend of a man. Mr. Clonmany to all who knew Hugo from running the famous Clonmany festival

here in County Donegal. He was also our longest kidney transplant recipient in Donegal (32 years). I would need a many hours to share with you all Hugos achievements and kind deeds. Rest easy Hugo – we will all miss you so much.

To all of you out there who have lost loved ones recently it is an awful big void. May their gentle souls rest in peace.

Thank you to all our frontline workers in jobs from A to Z, keeping us all safe. We salute you all.

We would like to thank Hillary Irwin, Donegal town, for her recent donation to the branch and also Cahal and Kathleen McGee, Newtoncunningham for their donation to the branch of €100 from their local Credit Union

All donations are so gratefully accepted especially in these hard times.

Our annual Organ Donor Awareness Week and Churchgate collections cannot be carried out due to the Covid-19 pandemic lockdown.

The branch AGM will take place in April 2021 – date to be announced. If you are interested in taking up a position please get in touch. It is always good to see new faces.

Take care folks and hopefully, we can all meet and greet again soon.



## DUBLIN NORTH

By PATRICIA MACKENZIE

Welcome Springtime and greetings to all Dublin North members.

We hope this finds you well and looking forward to the longer evenings.

We had another successful Zoom Meeting. It was nice to see some members, if only on a screen.

We wish to pay special tribute to all the medical people and staff who care for us in spite of the lockdown.

Stay well and roll on the vaccines.

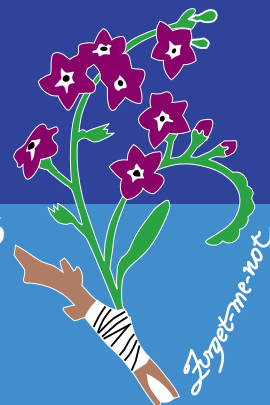


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Renal Support Centre, Beaumont Hospital, Dublin D09 Y5R3 - SEQUESTERED

Emergency Mobile Number: 087-4169907 | Email: [renalcentre@ika.ie](mailto:renalcentre@ika.ie)

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