

SUPP RT



SPRING 2022



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Editorial...



As I wrote previously, the only constant is this pandemic is uncertainty. Despite the concerns that the Irish Kidney Association and other patient organisations raised, the mask mandate was lifted and now we are seeing a higher level of cases again.

We continue to advocate for improved COVID-19 treatments for renal patients and you may have seen TV, radio and press coverage on this issue. One result of this campaigning is an official patient information leaflet from the HSE which is shown in this magazine, on page 14-15. We participated in a joint IPPOSI letter to key-decision makers requesting a meeting and setting out the key priorities to be addressed. Our press release can also be seen on our website.

An article on the latest COVID-19 treatments is included in this issue and we continue to advocate for clearer pathways for renal patients to these treatments (page 16).

In January, the Board reviewed the holding of face-to-face meetings and, at the time of writing, decided due to the risks involved, to continue with online meetings. While this is very disappointing, we do not want to put people at risk. Other charities, such as Diabetes Ireland, have decided not to have face-to-face meetings for the rest of the year, so the IKA Board will keep this issue under review.

We now face the uncertainty of the Ukrainian war, and our thoughts are with all those who have died or have been forced out of their homes. It's a very difficult situation, particularly for those patients on dialysis. We are playing

a small role in connecting European groups to help deliver a directory of key contacts for dialysis services and we are supporting the Cork Branch in helping one refugee family.

In happier news, our holiday homes in Tramore are reopening on April 30th. Tralee and Killarney homes remain open for bookings. See page 54-55 for more details.

On the Cork Support Centre, the disappointing response from Cork City Council was to request a further re-publishing of the planning permission notices. While we believe this was incorrect, after discussion, it was agreed that rather than challenge the decision, it would be quicker to simply re-publicise as requested by the Council.

We responded to a call by the Department of Health, requesting submissions for new health screening programmes. We called for screening for people at risk of kidney disease.

On World Kidney Day, we launched a major campaign on preventing and slowing down the progression of kidney disease by a simple blood and urine test. As so many of you are personally aware, the early stages of kidney disease have few warning signs. So, raising awareness of the need for screening is vital.

We were delighted to work with the HSE National Renal Office and Diabetes Ireland to make this significant public health contribution. You can read all about our work on this on page 4-8.

Another significant development is the launch of the Medication Sick

Contents...



FRONT COVER

Twins Amy and Harry (9) and their sister Isabel O'Brien (11) from Salthill, Galway (whose father Raymond is a kidney transplant recipient with diabetes) at a photocall to launch the IKA's 'We're Counting on You' campaign to mark World Kidney Day on March 10th.

Photo by Conor McCabe

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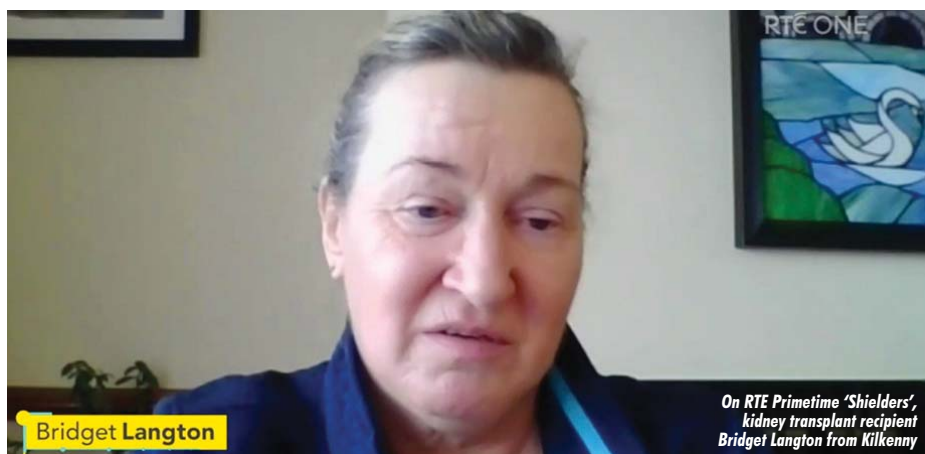
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Day Guidance pilot project in Tallaght University Hospital. This aims to guide patients and doctors on what medications to stop taking when they have diarrhoea or vomiting to prevent further kidney injury. Full details on page 17.

We are planning a further meeting with management in Beaumont Hospital to discuss arrangements for the Renal Support Centre which the hospital sequestered on the arrival of COVID-19 in Spring 2020.

The independent investigation into a transplant operation which was postponed due to the lack of an ICU bed in the Mater Hospital continues. A useful report, highlighting the difficulties of organ donation, was issued by the National Office for Clinical Audit (NOCA) and we will be following up on these recommendations during Organ Donor Awareness Week (ODAW), April 23rd-30th.

We are working hard on preparing for ODAW. Given the Ukrainian war, we believe it will be difficult to obtain our usual publicity, but please do watch RTÉ Nationwide during the week, as it is likely to

feature some very special people.

Due to the restrictions on physical meet-ups, we are asking Branch members to take photos of themselves outside public sites and buildings which will have been lit-up in green in support to the campaign and share them with us. More details on page 10-11.

We had two lively Branch forums, and these are invaluable for making sure we meet the needs of our members. We are also planning several member events, so, please make sure you are on our email list by emailing info@ika.ie. One such members event will be a webinar on the 'paired-exchange programme' which a Galway couple successfully underwent at Belfast City Hospital in early January. See page 32-34.

At National Board level, the results of the Directors hard work are now more obvious as a number of key policies have been approved by the Board. A survey of the skills needed at Board and Branch level is also underway.

The Board were also delighted to accept funding from Punchestown Kidney Research Fund (PKRF) which

will allow us to commence a new exciting formal peer support pilot project which will help more patients. For more details, please see 25.

The Board also decided, in the interests of member safety, to hold postal elections for all Branch Officer and National Director positions. We will be holding an online member session to let people know how they can make sure their voice is heard.

The IKA is a member led charity and to build on past successes we need strong membership involvement. So, please vote or even consider getting involved in the running of your local Branch if your life situation permits. You can find out more on page 30-31.

It is becoming more and more difficult to engage in society without digital skills. While it can seem difficult, once you have a smartphone it is possible to use the internet.

Free lessons are available from Age Action Ireland (call them on 01-4756989 to find out more).

Take the opportunity to learn how to engage with friends, family and wider society online. You can even take part in one of our members' Zoom sessions.

Our thoughts are with our long-serving holiday co-ordinator Deborah Cervi and her family. Her father Martin died suddenly and unexpectedly, whilst on holiday in Cyprus. May he rest in peace.

Finally, we want to know your views on *SUPPORT* Magazine and how we can make it better, see pages 35-38.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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WORLD KIDNEY DAY



WE'RE COUNTING ON YOU!

- Chronic Kidney Disease (CKD) affects 1 in 10 people.
- Often described as 'a silent illness hiding in plain sight', it usually develops slowly over time and can progress to total kidney failure.
- It is estimated that CKD will become the fifth leading cause of death globally by 2040.
- Early diagnosis of Chronic Kidney Disease (CKD) through screening is key to better health outcomes.

ALL it takes are simple blood and urine tests to check your kidney health



World Kidney Day which was celebrated on Thursday, March 10th 2022 aimed to bridge the knowledge gap to better kidney care. To mark **World Kidney Day**, the Irish Kidney Association (IKA), in association with the HSE's National Renal Office (NRO), launched an awareness campaign entitled **'We're Counting on You'** to highlight to the general public the importance of early screening for Chronic Kidney Disease (CKD), a condition characterised by a gradual loss of kidney function. Early stages can be asymptomatic. Disease progression occurs slowly over a period of time.

Diabetes Ireland supported the campaign to ensure that the core messaging about looking after your kidneys was heard in one of the most common at-risk groups, i.e., people living with diabetes.

The **'We're Counting on You'**

Chronic Kidney Disease affects 1 in 10 people



Could it be you?

message sought to reach beyond the people the IKA usually represents in its patients' advocacy role i.e., the five thousand people in Ireland living with End Stage Kidney Disease and their families and carers.

CKD significantly increases the risk of negative outcomes in people living with diabetes, cardiovascular

disease, and high blood pressure (hypertension), amongst other health conditions. The focus of the IKA's campaign is to highlight that it is possible to prevent or slow down the progression of kidney disease through lifestyle changes and medication and that it all starts with simple blood and urine tests that can be done through your GP to measure and monitor your kidney health.

The tagline message for the IKA's campaign was **'We're Counting on You'**. This represents the importance for the public to be proactive in managing their kidney health and that they are being 'counted on' to get a simple blood test and urine test which will reveal their kidney function 'numbers'. These 'numbers' represent how well the kidneys are functioning in filtering blood and removing waste from the body. If



By GWEN O'DONOGHUE

Right: Coming together to mark World Kidney Day were Prof. George Mellotte, Clinical Lead, Renal Services, National Renal Office, Carol Moore, Chief Executive, Irish Kidney Association, and Tess Clinch, Events and Marketing, Diabetes Ireland. Photo: Conor McCabe.

CKD is detected early enough, its progression, through the five stages of CKD, can be slowed down supporting better patient outcomes.

In order to help prevent or delay the progression of CKD, it is important to eat a healthy balanced diet, take regular physical activity and have a weight that is normal for your height. It is important for everyone in the high-risk groups for CKD to maintain these healthy lifestyle choices as taking these steps will help to control diabetes, blood pressure and cholesterol which will go a long way towards protecting the kidneys now and in the future.

A photocall was held to mark World Kidney Day with Prof. George Mellotte, National Clinical Lead of Renal Services, National Renal Office, Carol Moore, Chief Executive, IKA and Tess Clinch, Events and Marketing, Diabetes Ireland.

Also attending was teacher Rachel O'Hara, who is living in Dublin and a proud Mayo native. For close to eight years Rachel has been awaiting a combined kidney and pancreas transplant. Her health story is featured on Diabetes Ireland website diabetes.ie/rachels-story/

Just like Rachel, Raymond O'Brien from Galway continues to live with Type 1 Diabetes, but he has undergone a life-changing kidney transplant, thanks to his donor sister Denise.

Attending the photocall with Raymond were his wife Ethna and their three children Isabel (11) and twins Amy and Harry (9).

Carol Moore, the IKA's Chief Executive, explained the reasons for the 'Counting on You' campaign, "as there is no public health screening programme for kidney disease in Ireland, the IKA hopes that the 'Counting on You' awareness campaign to mark World Kidney Day will encourage the public to take action to look after their kidney health."

"We are pleased that the National Renal Office is endorsing the campaign and are delighted to be



working closely with Diabetes Ireland to highlight the importance of kidney health screening as diabetes is one of the main risk factors for chronic kidney disease".

In backing the IKA's campaign for kidney health screening Prof. Mellotte stated, "People with CKD are medically vulnerable to the effects of high blood pressure, diabetes and cardiovascular disease. It is important that people with CKD are identified so that they can seek the appropriate treatment in a timely manner".

In explaining why Diabetes Ireland was supporting the IKA in its campaign, Clair Naughton, Diabetes Nurse and Regional Development Officer with Diabetes Ireland said, "Diabetes Ireland welcomes the opportunity to highlight the importance of screening for CKD, a condition that can go undetected in the early stages as it doesn't cause symptoms.

"Diabetes, which affects in excess of 250,000 people in Ireland is one of the leading causes of CKD. Diabetes check-ups should include the routine monitoring of kidney function so that changes can be picked up early.

"It is easily done with routine kidney blood and urine tests. Diabetes Ireland is urging all people with diabetes to attend for their routine diabetes check-ups with their GP or diabetes team, to ask for a kidney function test, and ensure

that a discussion of kidney health becomes an integral part of check-ups".

Diabetes Ireland encourages patients to find out the results of the test and regularly discuss their kidney health with their doctor. Diabetes Ireland has adapted the CKD acronym to help remind people what to do, Check, Know, Discuss".

As well as the photocall, the IKA activities to mark World Kidney Day included a media campaign involving print and social media as well as radio advertising on the days around World Kidney Day.

The Smart Group, provided creative, design and print support to the IKA for the **'We're Counting on You'** campaign. An information leaflet and poster were produced and are available digitally to download from the IKA's website www.ika.ie/kidneyhealth

The IKA also hosted a free webinar which was open to the public on the evening of World Kidney Day, March 10th, which was led by Prof. George Mellotte.

Kidney transplant recipient, Raymond O'Brien who had taken part in the photocall the day before, and Juliette Duff, shared their very different health experiences.

The recorded webinar is now available to view on the IKA's website www.ika.ie/kidneyhealth

There was a strong emphasis on social media on World Kidney Day to

continued next page...

WORLD KIDNEY DAY contd...

reach the public who might not have considered their kidney health previously.

Media platforms employed included Instagram, Facebook, Twitter and LinkedIn with the theme **'We're Counting on You'** carrying through on a number of online videos. Some videos targeted the general public whilst others were specific to health care professionals.

The on-going success of the campaign is reliant on the valued support of healthcare professionals including GPs and Pharmacists. The Irish Pharmacy Union shared the campaign message on its digital and print platforms including inserting the campaign poster in the March issue of its magazine IPU Review which is circulated to every

pharmacy in Ireland. Several independent pharmacy chains with a wide geographical spread across the country, including Lloyds, CarePlus, Stay Well, Life, and All Care, also promoted the campaign to their customers and the poster was displayed on their instore digital screens and they shared videos on social media platforms.

Pharmacists have a key role to play in medication safety for patients. In cases where patients are being prescribed medications by more than one doctor, the pharmacist ensures that there are no unwanted drug interactions as they have an overview of all drugs being prescribed.

The collaboration between all the interest groups in supporting the campaign is an indicator of the importance of monitoring kidney health.



World Kidney Day is held annually on the second Thursday in March. It is a global awareness campaign aimed at raising awareness of the importance of our kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide.

WEBINAR - Kidney Health and Chronic Kidney Disease

The Irish Kidney Association (IKA) hosted a webinar on the evening of **World Kidney Day** entitled **'Kidney Health and Chronic Kidney Disease'**.

It included presentations by three guest speakers including Prof. George Mellotte, and kidney transplant recipients Juliette Duff and Raymond O'Brien. Juliette's kidney disease had developed to end stage kidney failure before it was diagnosed, whereas Raymond is a shining example of how early detection can make a real difference in significantly slowing down its progression.

The webinar was introduced by the IKA's Chief Executive Carol Moore, she then encouraged participants to complete a quick poll to determine the reasons for delegates tuning into the



webinar. This revealed an even spread of interest groups including healthcare professionals and students, people living with diabetes, high blood pressure, underlying illness, people diagnosed with chronic kidney disease, and some with end stage kidney disease.

PROF. GEORGE MELLOTTÉ, CONSULTANT NEPHROLOGIST, AND CLINICAL LEAD OF RENAL SERVICES AT THE HSE NATIONAL RENAL OFFICE

Prof. Mellotte gave a very informative half-hour presentation on the role of the kidneys, threats to kidney health and ways to protect them. He also spoke about ways to test for kidney disease. The key message to take away from it was reassurance in that through following medical advice and self-management it is possible to protect your kidneys and slow down the progression of chronic kidney disease. He encouraged people not to be afraid to get to know their kidney numbers as he asserted 'knowledge is power'. He spoke about diet and avoiding salt,

minimising alcohol intake, getting BMI under control, and also the importance of getting both blood pressure and protein urea checked regularly as these can provide early signs of trouble and allow for interventions which can slow down the progression of kidney disease. Getting either blood pressure or protein urea down will help, but getting both down, is key to seeing improvement.

Collectively the three guest speakers gave a clear message about the importance of getting

checked and being proactive in managing your health, following medical advice and this can have a positive impact on your health outcomes and quality of life.



Rachel O'Hora at the photocall with Prof. George Mellotte

RAYMOND O'BRIEN

Raymond O'Brien, a father of three from Salthill, Co. Galway, had been living with Type 1 Diabetes which was diagnosed in 1987 when he was 21-years-old. Regular check-ups for his diabetes led to the diagnosis of chronic kidney disease about fifteen years later.

He was advised that it would likely be only a year or two before he would progress to end stage kidney failure and commence dialysis treatment.

Under the care of Prof. Mellotte, he diligently followed his consultant's advice with priority given to his diet and getting his blood pressure down. By doing so he managed to delay end stage kidney disease for 15 years by which time his sister Denise was waiting in the wings to donate a kidney to him in 2017.

He described how he felt like a new man straight away after his kidney transplant. He said that if you follow the advice, doing the right things, 'it does work' summarising that it was 'early detection' that got him to this positive point in his life.



Raymond O'Brien and his wife Ethna with their children Isabel and Harry.



Juliette Duff

JULIETTE DUFF

Juliette Duff, a kidney transplant recipient, from Dublin's southside is now in her first year working as a junior doctor at Beaumont Hospital. Juliette was displaying signs of Chronic Kidney Disease including high blood pressure from the time she was in her Leaving Certificate exam year, but symptoms were being incorrectly attributed to stress of exams and 'white coat syndrome'.

She finished her exams and secured a place in medicine in UCD. By this time, she was enjoying college life and didn't want to think about her health. Her mother was still concerned about her and persuaded her to go back to the GP on New Year's Eve.

Her CKD remained undiagnosed until eventually an astute GP, on realising that Juliette's father had undergone two kidney transplants

many years before, concluded that there was a strong likelihood that Juliette had kidney disease. He asked her to do a urine test which quickly confirmed his suspicions were correct. She was sent straight to St. Vincent's Hospital where further tests were done, and they confirmed that Juliette was in end stage kidney failure and she soon began dialysis treatment.

Juliette described how it was a huge relief to finally get a diagnosis and how knowing made her feel so much better. She saw how good a quality of life her father could live post-transplant.

She began dialysis treatment a year later. Juliette has since had a successful kidney transplant.

Juliette reflected on how a simple urine test was all that was required to lead to her diagnosis.

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WORLD KIDNEY DAY contd...

WEBINAR CONCLUSION

A questions and answers session followed the three guest presentations which was facilitated by Colin White, the IKA's National Advocacy and Projects Manager. The questions revolved around how family can support a family member who has CKD, diet and alcohol, as well as the role of sports and an active lifestyle.

He explained how Transplant Team Ireland offers an outlet for people to engage with physical activity at their own level and how it is also a very positive peer support network that promotes the physical and emotional wellbeing of people on dialysis and transplant recipients, including kidney, heart, lung, liver, pancreas and bone marrow.

Concluding the webinar was Colin Mackenzie, the IKA's National Honorary Chairman, who Carol Moore described as 'a long-time champion and volunteer of the organisation'. He gave an uplifting appraisal of the event and he thanked everyone for attending.

A second online poll was taken at the very end of the webinar with positive feedback that 96% of people were very satisfied with the webinar event and the other 4% were somewhat satisfied.

The recorded webinar is available to view on the IKA's website www.ika.ie/kidneyhealth

UCC MARKS WORLD KIDNEY DAY

An information event on kidney disease was held at University College Cork, Brookfield Health Sciences Centre on **World Kidney Day**, March 10th.

The event was organised by third-year medical student Mark Vesey, who is Educational Officer for the Translational Medicine Society. Kidney transplant recipient Sheenagh MacDonagh, who is Secretary of the IKA Cork Branch, was a guest speaker at the event along with Dr Sarah Moran, Consultant Nephrologist at Cork University Hospital.

At the event Sheenagh, from Rochestown, in Cork, described her health experience and how her kidneys failed after she experienced severe pre-eclampsia in 1997 when her son was born 27 weeks into the pregnancy.

Her kidney function improved but didn't recover fully. Her condition was carefully managed for over a decade while all the time her kidney function gradually declined until the point when she needed to commence dialysis in 2008.

She tried two forms of peritoneal

dialysis treatment which she underwent in her home, her first CAPD dialysis which she underwent four times daily and then she was switched to APD, nightly dialysis treatment for 8-9 hours at a time.

Following four years of dialysis treatment she was called for a kidney transplant in Spring 2012.

Ten years on from her successful deceased donor kidney transplant Sheenagh is now a facilitator as part of the HSE's *Living Well Programme* providing guidance, counselling and support to other patients with chronic kidney failure.

Sheenagh also did an interview on Cork's 96FM radio and with the *Irish Examiner* and *Evening Echo* to mark **World Kidney Day**.



Sheenagh MacDonagh, Dr. Sarah Moran and Mark Vesey

FOR MORE INFORMATION

www.ika.ie/kidneyhealth • www.worldkidneyday.org • www.diabetes.ie

AstraZeneca provided an unrestricted grant to the Irish Kidney Association for its 'We're Counting on You' campaign to mark World Kidney Day.



Want to send Easter greetings to your friends and family in an eco-friendly way that also supports the Irish Kidney Association?

OUR E-CARD OPTION IS PERFECT FOR YOU!

After purchasing the e-Card from www.ika.ie/onlineshop it is yours to send to whomever you like. You can email it to your friends and family, or simply share on your social media pages.

Don't forget to tag us!

SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK



When you are a charity, your year is built around various 'set in stone' events. The dates themselves might change ever so slightly, but mostly the thinking behind ours goes a little something like:

"World Kidney Day and Organ Donor Awareness Week in Spring, which leads us into Run for A Life. Then the Transplant Games will be due. After that we better start thinking about the Service of Remembrance & Thanksgiving. Then there's Christmas to think about, we need to check Christmas card stock."

All these plans start to formulate, probably before January is even out. But what happens when the world comes screeching to a halt, and all the plans you rely on cannot go ahead?

In March 2020, our plans for **Organ Donor Awareness Week** were cancelled at the eleventh hour; our volunteers were called off and our staff were sent to work from their kitchen tables.

Soon afterwards, more events were cancelled including our much-anticipated hosting of the **European Transplant & Dialysis Sports Championships in Dublin** in August 2020. The annual **Run for A Life** family fun run and the **Annual Service of Remembrance and Thanksgiving** evolved into 'virtual' events. The disappointment was high, but we got through on the strong support from volunteers and fundraisers up and down the country who got creative with their events, taking things online.

We reassured ourselves with the thought that "next year will be bigger and better than ever". Unfortunately, that wasn't to be as March 2021 rolled around and we found ourselves in a lockdown that had

lasted even longer than the first one. With a little bit more notice this time, we ventured into the world of virtual campaigning for **Organ Donor Awareness Week** – we held our launch over Zoom, asked transplant recipients to send videos from all over the world and it even sparked some new ideas like asking City and County Councils to light-up public buildings in the colour green.

So, where does that leave us, and our dedicated volunteers, in 2022?

We aren't officially in any lockdown, but virus numbers are still high and our focus on protecting our volunteers hasn't changed since that first cancellation in 2020.

The word we are using is 'hybrid'. Whilst there will be a small launch, the event will be tightly controlled with just a small number of attendees, and we've been sure to pick a venue with plenty of outdoor space and room for social distancing.

To make sure everyone can still be part of the day, we are planning to stream the launch online for anyone who wants to watch it, so keep an eye on our social media pages for those details!

We are also asking City and County Councils to light-up public

buildings and sites in green again, and we would love if people could help us spread awareness by getting photos outside these buildings and sharing them online. We'll be publishing a full list of all the locations on the website soon (www.ika.ie/donorweek2022).

Don't forget to tag us and use the hashtags **#DonorWeek22** **#ShareYourWishes**.

Speaking of social media, share our posts, your own stories, details on how to get an organ donor card, and anything you can think of to promote awareness during the week.

Check if your local pharmacy has stock of organ donor cards and a poster and ask them to contact us if they would like some more. If you can think of somewhere impactful to put up our lovely **Organ Donor Awareness** poster, you can get a copy from our website and pop it up.

The louder we all shout, the more impact we will have!

Circumstances outside of our control continue to play a large role in dictating what we do, but we have been creative and can continue to do so if each of us does our bit.

Please contact me if I can help in any way at all!



@IrishKidneyAssociation



@IrishKidneyAs



@IrishKidneyA

ORGAN DONOR AWARENESS WEEK



Grateful transplant recipients from around the country are backing the Organ Donor Awareness Week 2022 campaign which will take place from 23-30 April and is organised by the Irish Kidney Association in association with the HSE's Organ Donation Transplant Ireland.

Featuring on the campaign poster are photos of 32 people from all walks of life and of all ages, who between them are enjoying over 410 years of extra life made possible by the families of deceased organ donors who gifted them organs including hearts, lungs, livers, kidneys, and pancreas.

This year's awareness campaign is built around the theme of **Share your wishes** about organ donation, **#ShareYourWishes**.

The key message is that members of the public can play their part in supporting organ donation for transplantation by ensuring that their families know their wishes. i.e., have the conversation.

The words **Share Your Wishes** represents the importance of discussion with loved ones about organ donation and sharing your wishes is the cornerstone of the campaign.

Many independent pharmacies and pharmacy chains have pledged their support for the campaign by agreeing to display the campaign poster on their digital screens or putting the printed version up in store. They are also taking countertop boxes of free organ donor cards which are accompanied by information fact files. Pharmacies are also leveraging their social media presence to get the message across about having the family conversation.

By GWEN O'DONOGHUE

The Irish Kidney Association (IKA) also provides their 'Digital Organ Donor Card' free to download from the App Store and the Google Playstore.

All campaign posters are available in English, Irish and Polish. Digital copies can be downloaded from the IKA's website www.ika.ie/donorweek2022

The IKA is encouraging the wider public to show their support for the campaign by organising their own awareness activities and challenges while observing all appropriate COVID-19 safety measures. Whether it is getting organ donor cards to share with your family, giving an



information talk in your school, college, or place of work, it all makes a difference, and you can request Organ Donor Cards via the IKA's website.

Public buildings and sites around the country are lighting-up in green in support of the life-saving awareness campaign (sites are listed on) www.ika.ie/donorweek2022

Green is the internationally recognised colour which celebrates organ donation for transplantation.

Last year over 70 sites, including a castle, cathedral, Church, a bridge, a spire, the Convention Centre and the Mansion House in Dublin, and other public buildings around the country, were lit-up in green for the duration of the week-long campaign demonstrating nationwide solidarity in support of organ donation.

City and county councils are supporting the campaign as are the hundreds of people currently waiting in hope for a call for a transplant and many more as well. There are more than 5,000 people in Ireland who have successful functioning transplanted organs.

Whilst many things have been put on pause during the COVID-19 pandemic, the need for organ donation and transplantation continues.

Despite the unprecedented challenges which the pandemic has presented, organ transplant

City Hall Cork, one of the sites to be lit-up in green – the internationally recognised colour which celebrates organ donation and transplantation



operations continued which is thanks to organ donors and their families and also the dedicated transplant teams in our transplanting hospitals, Beaumont, St. Vincent's, The Mater, and Temple Street.

There was a fall in the number of transplants over the past two years across all the national transplant programmes during COVID-19.

206 transplant operations were carried out in Ireland in 2021 (16 more transplants than in 2020). This activity, in very challenging times, could not have taken place but for the generosity of 65 deceased donors and 35 living kidney donors.

Carol Moore, Chief Executive, IKA said, "Two years ago, the 2020 Organ Donor Awareness Week campaign was postponed and ultimately cancelled at short notice when COVID-19 reached our shores.

"Last year the pandemic was still with us. This impacted on the IKA's ability to promote organ donor awareness 'on the ground' and the overall annual Awareness Week campaign.

"With COVID-19 still lingering, we have had to adapt awareness campaigns and while government restrictions have lifted, many people at high-risk of infection, including immune suppressed transplant recipients and vulnerable patients in organ failure, continue to observe caution and double down on their safety measures".

Carol Moore explained, "We greatly value the role of pharmacists in helping to spread the message about the importance of organ donation by displaying the campaign poster and carrying stocks of organ donor cards. Patients on transplant waiting lists live in hope that organs will become available to them and a strong public show of support by requesting organ donor cards builds that hope.

"The uncertainty associated with

waiting for an organ transplant is difficult as the future is unknown and there is the knowledge that in order to be given the 'Gift of Life' another family will be grieving the loss of a loved one.

"We also welcome the support of County Councils. By lighting-up public sites in green we are drawing attention to organ donation being an integral part of active citizenship on the part of the public. From dusk to dawn, public sites all over the country will be lit-up in green, undoubtedly prompting much discussion around organ donation.

"The IKA welcomes the recent National Office of Clinical Audit (NOCA) recommendation for the introduction of an annual national database for organ donation in intensive care units (ICUs). The report notes the datasets of existing national audits fail to identify all missed opportunities for organ donation and fail to empower the relevant Organ Donor personnel with the necessary information to drive improvement."

Social media hashtags for Organ

Donor Awareness Week are:

#ShareYourWishes and

#DonorWeek22. People can also tag the IKA when doing their own posts (@IrishKidneyAs on Twitter, @IrishKidneyA on Instagram and @IrishKidneyAssociation on Facebook).



Minister for Health Stephen Donnelly at the 2021 campaign virtual launch.

The Minister for Health has been invited to officially launch the campaign which will be held a few days in advance of the Week. The launch will have a much smaller attendance than in previous years but will be live streamed making it possible for a much larger online audience.

The campaign poster will also appear on the RTÉ *Faircity* set for some of the scenes output during Awareness Week and the poster will be carried on some outdoor poster sites also thanks to the generosity of Clear Channel. Watch out for a full programme feature on RTÉ *Nationwide* during the Awareness Week.



We are looking for people from across the country with newsworthy health stories to share as part of our media campaigns to highlight the work of the Irish Kidney Association and increase organ donor awareness.

If you would like to share your experience of organ failure, dialysis or an organ transplant, or if you are in the process of living donation or have donated a kidney

or part of your liver to a family member or friend, or your family has made the selfless decision to donate a loved one's organs, we'd love to hear from you.

If your story has been widely shared in the media before, it may still be of interest if there is an update on a significant life event since then, such as: a milestone anniversary; getting called for a transplant; a family event such as childbirth; marriage or becoming a parent; or an achievement such as an academic, sporting or career event.

We will never share any of your details or your story without contacting you for permission.

We will also provide support to help you tell your story.

So, if you would like to promote the work of the Irish Kidney Association as well as raising organ donor awareness we'd love to hear from you. You can complete the application form on our website

www.ika/donorweek2022

Jack raises the bar in Five-a-side fundraiser



Sixty-four people including family, friends and supporters donned their football boots while many more turned up at St. Finbarr's GAA to support the event from the side-lines held on February 27th, 2022.

After the successful event, the group returned to Jack's father's bar, Mok's bar, on the Bandon Road, Cork for refreshments and a singalong as one of Jack's friends brought along his guitar for the social gathering.

A box full of organ donor cards was emptied by the end of the night with everyone, who didn't already have one, taking one home with them.

Jack who has since turned 20, is the eldest of three siblings. He described his health journey, "I was just eight-years-old when I was diagnosed with the kidney

condition, 'Idiopathic focal segmental glomerulosclerosis (FSGS)', which was thought to have stemmed from a streptococcal (throat) infection. At the time I had to stay in Temple Street Children's Hospital for three months before being allowed to return home.

"My kidney condition was stabilised and I really didn't have any major concerns for several years as Temple Street kept a close eye on my kidney function until I was 16-years of age. My care was then transferred to Cork University Hospital. By then my kidney condition was starting to deteriorate and my consultant Prof. Liam Plant took me under his wing and is still looking after my care. My kidney function before Covid was 20% but it dipped to 12% in the New Year, although it has improved a little in the past few weeks.

Cork student Jack Ellis, who will require a kidney transplant in the near future, decided to put his best foot forward by organising a five-a-side fundraiser in aid of the Irish Kidney Association (IKA).

A total of €7,732 was raised for the IKA by the 19-year-old first year UCC Arts student.



Jack with his parents Don and Tara Ellis.



Jack Ellis, Tront centre, and some of the 64 participants at the Five-A-Side Soccer Fundraiser.

By GWEN O'DONOGHUE

However, it is only a matter of time before my kidney function dips below 10% by which time I will need dialysis treatment or a kidney transplant. Several family members and a friend have said they would be happy to get tested to see if they are suitable to donate one of their kidneys to me."

In explaining why he decided to do the fundraiser, Jack said, "I have always loved sport and play rugby, Gaelic and soccer. I have been lucky that my health has remained fairly good despite my kidney condition so that I could continue to enjoy playing sport".

"Now that I am coming closer to needing a transplant, I wanted to do something positive to raise awareness for organ donation while supporting the Irish Kidney Association which is the charity which helps kidney patients and their families. A Five-A-Side Soccer Tournament seemed like a good way to raise a lot of funds while doing something healthy and fun that everyone could enjoy. My father and mother were very supportive of the idea and my father promoted the event in his pub and many of his regulars decided to take part, and so did he. The weather was great on the

day and 64 people taking part with lots of others cheering on from the sidelines."

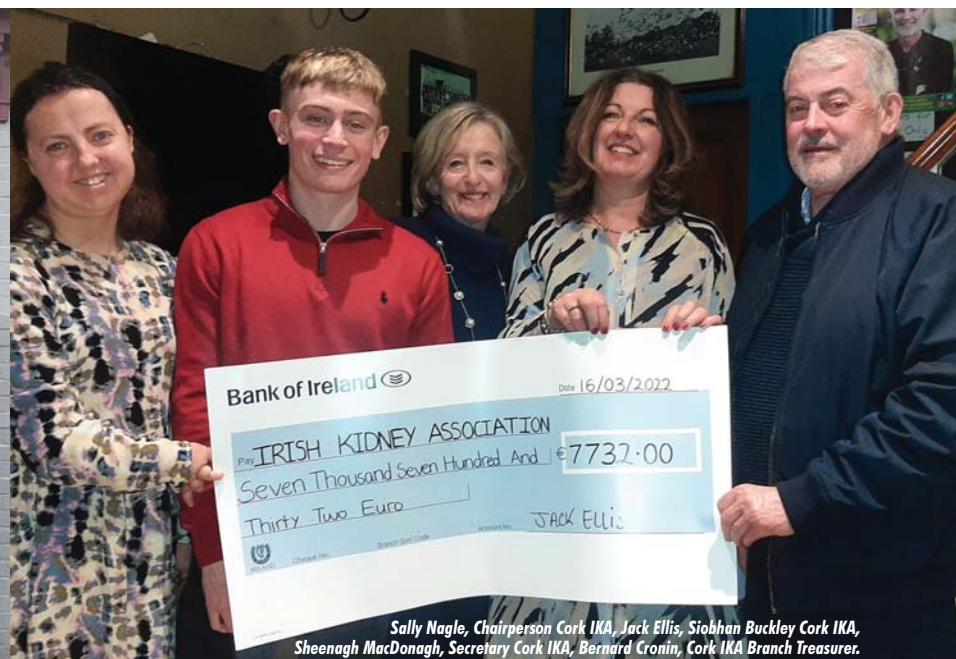
"I'd like to thank everyone who supported the event, from past school friends at the Christian Brothers College, students at UCC, friends and family and customers at Mok's. I'm proud that with their help we raised so much for the Irish Kidney Association as well as raising organ donor awareness. By letting people know my kidney condition, I hope that it has encouraged people to talk more to their friends and family about organ donation and carry an organ donor card. I feel

lucky that my parents, a friend, an aunt and an uncle, are willing to donate a kidney to me when the time comes. But if they are not suitable I, like many others waiting for transplants, might have to rely on a stranger to help me."

A presentation night was held in March at Mok's bar with Jack's parents Don and Tara there to proudly watch their son present a large cheque for €7,732 to members of the Cork branch of the Irish Kidney Association including Sally Nagle, Branch Chairperson, Sheenagh MacDonagh, branch Secretary, and Bernard Cronin, Branch Treasurer.



Jack and his friend Mark Callanan outside Mok's dressed up for their Debs in November 2021.



Sally Nagle, Chairperson Cork IKA, Jack Ellis, Stobhan Buckley Cork IKA, Sheenagh MacDonagh, Secretary Cork IKA, Bernard Cronin, Cork IKA Branch Treasurer.

PATIENT INFORMATION LEAFLET

Information for people at the highest risk from COVID-19

Everyone should be doing what they can to protect themselves and others from the COVID virus by following the public health guidance.

There are no longer Government regulations that say everyone has to wear a mask in places such as shops and public transport or keep social or keep to other restrictions. But everyone is still recommended to wear a mask on public transport and people at highest risk are still recommended to take steps to help keep safe.

You can find information on the conditions that put someone at high risk at the following link <https://bit.ly/3t0O7if>

Many people, especially people with conditions that put them at high risk, are feeling anxious about getting back to normal and wondering how to keep safe. It is harder now to take precautions and limit what you would like to do when other people are getting back to normal but the things you have been doing all along to protect your

health can still work to keep you safe as the country and people around you move towards a normal way of living.

It is good to keep active and look after your general health. A healthy way of life improves your chance of recovery if you get COVID-19.

Remember if your immune system does not work very well (if you are immunocompromised) you need an extra dose of vaccine. That fourth dose is your 'booster' dose.

Some other things you can do to keep risk of infection with COVID-19, influenza and other infections as low as possible are:

- Try to avoid crowded indoor spaces. If you have to be in a crowded space, wear a medical grade or respirator face mask. Respirator masks are often referred to as FFP2 masks
- Always practice hand hygiene
- Continue to social distance where possible
- If you see someone coughing or sneezing, move away if you can

SAFETY AT HOME

There is almost no chance of you catching COVID-19 at home if people who are infectious with COVID-19 do not come to your home. It is usually not practical for people in a family household to avoid contact with each other at home. If everyone in the household is vaccinated (including booster) and careful when out of the house, that helps to keep you safe.

Try to keep the number of people who come into your house to visit, work or provide healthcare, to people you can trust to have practiced safety measures. Then you can feel safe at home and you can relax there.

Check that anyone who comes to the house is well when they arrive (no symptoms of COVID-19). Ask them to clean their hands when they arrive, to wear a medical grade or respirator mask and to keep some distance from you whenever possible.

It is important that you continue to use the healthcare services you

Masking - The Issue

By COLIN WHITE, National Advocacy & Projects Manager

It is March 23rd and COVID-19 numbers both in and out of the hospital system have been on the rise. There is a new variant of Omicron that is being viewed as more infectious than the original Omicron with some commentators likening its level of infectivity to measles.

In many public settings the level of mask wearing has declined significantly. The WHO has announced that several European countries, including Ireland have lifted restrictions too 'brutally.'

The current reality is that we all have to take responsibility for our own health and well-being. We need to get the balance between avoiding risk whilst living life.

This is where mask wearing (and hand washing and avoiding crowded situations when possible) is key. The latest advice for those who are at increased risk from COVID-19 is to wear the FFP2 masks (see image right). These, when worn correctly, have been shown to offer more protection to the wearer than surgical or cloth masks.





COVID-19 VACCINE

Public Health
Advice

need. It is OK to ask or remind healthcare workers about precautions.

You can tell people who provide services to you that you need to be extra careful to avoid COVID-19. They will usually try to fit you in at a quiet time and be extra careful when providing you with the service.

If you have an appointment with your GP or at a hospital or clinic it is important to attend.

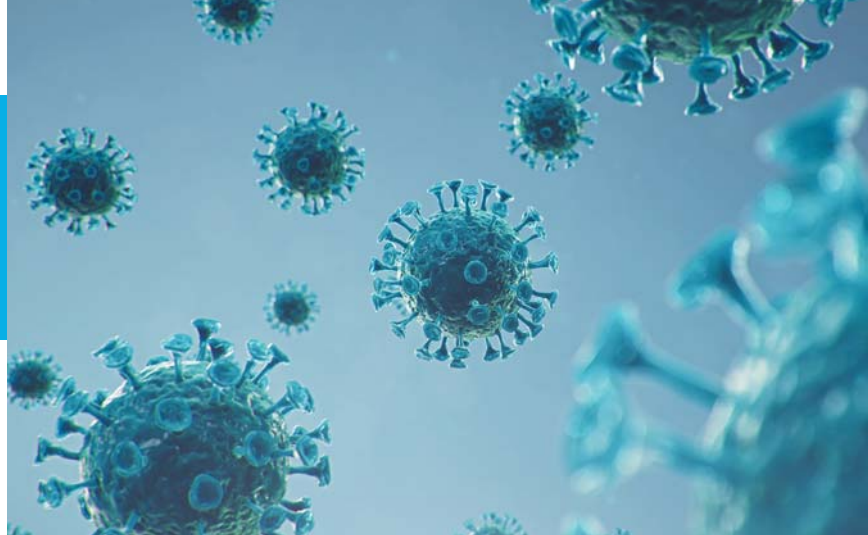
NEW MEDICATION

Some new medicines are becoming available for early treatment of some people with COVID-19. Most people who catch COVID-19 don't need these early treatments. The early treatment is important for some immunocompromised people and for some people who have not taken the vaccine.

Early treatment needs to start within 5 days of COVID-19 symptoms starting. People who might benefit from these treatments need to contact their doctor early. Sotrovimab is one of these treatments for early COVID-19 and is now in use in Ireland.

If you are immunocompromised or if you have not had the vaccine and you get symptoms that might be COVID-19 call your GP or other doctor who is seeing you regularly. They will be able to tell you if you might benefit from this early treatment.

Reproduced courtesy of the HSE



KEEP IN TOUCH

Talking on the phone or by video link is safe and is a good way to keep in touch. Stay in touch with friends and family. If you need help for any reason, there are a number of places you can go for help including:

- HSE Safeguarding and Protection Teams (<https://www.hse.ie/eng/services/list/4/olderpeople/elderabuse/protect-yourself/safeguardprotectionteams.html>)
- SAGE (1850-719400 from 8 in the morning until 10 at night) www.sageadvocacy.ie
- ALONE (0818-222024 from 8 in the morning until 8 at night) www.alone.ie
- The HSE Confidential Recipient is at 1890-100014.
- Alzheimer Society of Ireland 1800-341341 (www.alzheimer.ie).
- If you need medical assistance call your GP or in an emergency call 112 or 999
- Family Carers Ireland 1800-240724. (<https://www.familycarers.ie/media/1986/familycarers-ireland-emergency-plan.pdf>).

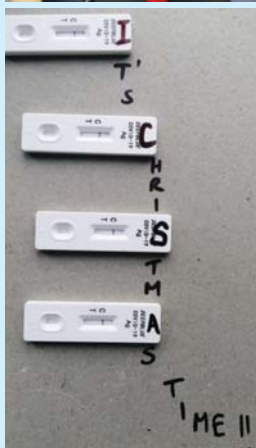
If you attend a dialysis unit you should be offered FFP2 masks to wear during your treatment. If this is not the case please be sure to ask for that mask type as it is the agreed protocol.

The Irish Kidney Association continues to collaborate with other health-related charities in lobbying for the ready availability of FFP2 masks, as well as ask clear pathways to treatment in the event of getting the virus. If you think that you may have COVID-19, get an antigen test, and if it is positive, contact your kidney team to arrange a PCR test, as prompt treatment can be key to better outcomes.

U12s AND SIBLINGS GETTING 1ST VACCINE



Right: Sam Kinahan (a kidney transplant recipient) and his sister Ali, from Dublin and below left, their family's positive antigen tests at Christmas 2021



Harry Ward, Dublin

ADULT BOOSTER VACCINATIONS



Ned & his nurse wife Deirdre Crowe (Tipperary)



Pat O'Sullivan, Cork



COVID-19 UPDATE

As I write, we are almost a month since the lifting of many of the COVID-19 restrictions. Mask wearing on public transport and in healthcare settings has now become an advisory rather than mandatory.

Ancedotally, some feedback received has indicated that the number of people wearing masks in shops, etc., has fallen precipitously since February 28th.

The number of cases in hospital has climbed significantly and the numbers in ICU have moved between 45 and 55 on any particular day.

This all adds up to uncertainty and anxiety for those who are medically vulnerable and their families. The return to the workplace and the general increase in community interactions has seen the combined number of confirmed cases (PCR) and registered positive Antigen tests rise to over 20,000 cases per day.

We each have a different attitude to risk but we can all carry out the same simple basics and mitigate the COVID-19 related risks. The advice is to keep the focus on the basics of wearing your mask, washing your hands and avoiding crowded indoor settings.

It's about controlling the daily variables that you can and making an informed decision in relation to mixing with others.

Have you had your fourth ('booster') vaccine dose? All those considered medically vulnerable to the COVID-19 virus were offered two doses of vaccine initially. It was then viewed that a third ('additional') dose was needed for this group as their

general immune response was less than that in the general population. This means that the 'booster' dose for the medically vulnerable is a fourth dose whilst the third dose for the general population is their 'booster' dose.

The 'additional' dose and the 'booster' dose are both an mRNA vaccine (Pfizer-BioNtech or Moderna). You qualify for the fourth 'booster' dose 3 months after your third dose or 3 months after recovering from a COVID-19 infection. It is important to note that you must book your fourth dose yourself, an appointment will not be sent to you. You may receive a text message and/or a phone call making you aware that you are due your fourth dose.

Whilst the fourth dose is not guaranteed full protection, it has been shown to increase the potential protection offered in the medical vulnerable group. Even though there are cases of COVID-19 amongst those who are fully vaccinated, the severity of the illness is usually diminished by virtue of being vaccinated.

If you have any concerns related to the vaccines, please be sure to discuss them with your medical team.

If you are anxious about returning to the workplace, you are entitled to ask your employer for a risk

assessment in relation to your presence in the workplace.

The consistent message from all patient representative organisations involved with people who are medically vulnerable to the COVID-19 virus, both here and in the UK, is that we are asking the relevant authorities, employers and the general public not to forget those around them as we get used to a life without mandated restrictions.

There are new treatments being introduced to help treat people who have the COVID-19 virus but the key to their success is that, if appropriate, they need to be prescribed within 5 days of the first symptoms of COVID-19.

It is therefore important to understand the pathway to treatment. For example, requesting a PCR test from your medical team or your GP after a positive Antigen test, and immediately informing your medical team in the event of a positive PCR test.

COVID-19 may be slipping down the news agenda but it does not mean that it is no longer with us. Be proactive in looking after your own health – take the simple measures that can make a difference. Ensure that you are fully vaccinated – ask your medical team if you have any concerns. Ensure that you follow-up on any possible COVID-19 symptoms promptly as it may improve your treatment options.

The country is learning to live with COVID-19, it may be an anxious time. Be sure to seek advice/support from reliable sources if you are unsure.

Medication Sick Day Guidance Pilot

The National Renal Office (NRO), in conjunction with Tallaght University Hospital (TUH) and GP practices are piloting an initiative around 'Medication Sick Day Guidance' for patients with kidney disease.

The NRO has liaised with Consultant Nephrologists, GPs, Renal Pharmacists and Renal Nurses to produce a pilot 'Medication Sick Day Guidance Patient Information Leaflet'. This includes a 'Plan for my Medicines' which will be individualised to the patient and their specific medications. Community Pharmacists are also being asked for their feedback during the pilot.

When patients with kidney disease get ill, they tend to get more sick than the average patient. This is particularly relevant if they are losing a lot of fluid such as in illnesses that cause diarrhoea or vomiting. If patients are taking particular medications, these can aggravate the illness and cause additional kidney damage. Therefore, many doctors and pharmacists give advice regarding holding certain medications. This is known as 'medication sick day guidance'.



By **DAWN DAVIN**
National Renal Office Pharmacist

However, practical experience has taught us that it can be confusing for patients to decide which medications should be stopped, when and why these medications should be stopped and when they should be restarted.

The purpose of the pilot is to see how well the guidance that we have drawn up works, and, what changes are necessary to make it better. We need to understand if there are any difficulties around this project.

HOW CAN PATIENTS CONTRIBUTE TO THE PILOT?

This is a wonderful opportunity for patients to contribute to their care. During the pilot, the NRO is inviting feedback from patients.

Patient feedback is a central and highly valued aspect of the pilot and will help to guide information going forward on how patients manage medications when they are sick.

Patients in Tallaght University Hospital and related GP practices who take part in the pilot will be given a feedback form to complete.

We would encourage any patient taking part in the pilot to complete the feedback form and return it to the collection point as directed by your doctor or healthcare professional. All feedback is being collected anonymously.

All other patients can send comments on the patient information leaflet shown below to nro@hse.ie

Once the pilot phase is complete and feedback is incorporated from patients, doctors, pharmacists, and nurses, the patient information leaflet will be rolled out to all patients.

Medication Sick Day Guidance

PATIENT INFORMATION LEAFLET

This leaflet is about what you should do about taking certain medicines that are prescribed for you if you become unwell and dehydrated.

This information is called "Sick Day Guidance"

Dehydration is the loss of fluid from your body due to illness such as vomiting, diarrhoea and fever (high temperature, sweats, shaking). Generally, more than two episodes of vomiting or diarrhoea can lead to dehydration. In this case you should follow the advice in this leaflet.

Signs of mild to moderate dehydration:

- Unusual sleepiness or tiredness
- Dizziness or light headedness
- Passing less urine
- Dry, sticky mouth
- Dry, cool skin
- Headache

Signs of severe dehydration:

- Passing little or no urine
- Confusion + Irritability
- Low blood pressure
- Very dry/cool skin
- Rapid breathing
- Extreme thirst
- Sunken eyes
- Dry mouth
- Headache

What should you do with your medicines when you are unwell/dehydrated?

- Hold or temporarily stop** any medicines listed on the reverse side of this page. This is to prevent side effects of the medicines or kidney problems. Your healthcare professional will explain which medicines are to be held.
- Do not stop any other medicines unless specifically advised to by your doctor.
- If you have diabetes, check your blood sugars regularly.
- If you are using insulin, you may need to adjust the dose. If your blood sugars are too high or too low, contact your doctor.
- Restart** the medicines again when you are feeling better (usually after 24-48 hours of eating and drinking normally). When you restart your medicines, take them as prescribed for you. Do not take any missed doses.

When to contact a doctor?

- Signs of severe dehydration include: extreme thirst, dry mouth, headache, sunken eyes, dry/cool skin, confusion +/- irritability, low blood pressure, rapid breathing, passing very little urine.
- Not passing urine for more than 12 hours.
- Vomiting or unable to eat or drink.
- Ongoing diarrhoea (more than 24 hours)
- Raised blood sugars if you have diabetes.
- If you do not feel better after 3 days, or, if you become very unwell at any time, contact your doctor for advice.

Plan my medicines

Type of Medicine & reason for use	Prescribed Medicine	Trade Name
S Sulphonylureas (blood sugar control)		
A ACE inhibitors (blood pressure control)		
D Diuretics (water tablet to control fluid)		
M Metformin (blood sugar control)		
A Angiotensin Receptor Blockers (ARB) or Alikiren (blood pressure control)		
N Non-steroidal anti-inflammatory drugs (NSAIDs) (reduce pain and inflammation)		
S SGLT2 inhibitors (manage diabetes, kidney and heart function)		
Other		

Name of combination Products or Diuretics

Patient Guidance

This document is to be:

- Reviewed monthly by pharmacist or whenever there are any changes to the medications.
- Brought to GP appointments and outpatient clinic visits for review by healthcare professionals.

Over the counter medicines

Check with your pharmacist before taking any over the counter medicines if you are feeling unwell

Blister Packs

If your medicines are in blister packs, ask your pharmacist to help you identify which medicines to hold

Insulin

If you are using insulin, check with your doctor what you should do while you are feeling unwell

Contact your doctor if you experience any of above

Patient Notes:

PILOT V1 | 2022

GIFT OF LIFE DONOR

ORGAN DONATION & TRANSPLANT IRELAND
c/o IKA, Donor House, Parkwest, Dublin D12 P5V6
Tel: 01 - 620 5306

FOR DONOR CARDS

FREETEXT

DONOR to 50050

MAP OF HAEMODIALYSIS UNITS USED BY PATIENTS FROM THE REPUBLIC OF IRELAND AND DIALYSIS PATIENT NUMBERS AS OF 31/12/21



CHRONIC DIALYSIS & TRANSPLANT PATIENTS - 31/12/21

Dialysis Facility ADULTS	HAEMO HD	HOME DIALYSIS HHD	PD	TOTAL DIALYSIS PATIENTS	TRANSPLANT AT CLINIC	TOTAL ESKD PATIENTS
Beaumont	158	19	49	226	783	1009
Mater	95		13	108	139	247
Fresenius Northern Cross	91			91		91
Beacon Drogheda	99			99		99
Cavan	69			69	20	89
St. Vincent's	80		18	98	169	267
Beacon Sandyford	107			107		107
St. James' Hospital	1			1	6	7
Tallaght Hospital	133	5	60	198	337	535
Beacon Tallaght	92			92		92
Tullamore	89			89	69	158
B Braun Portlaoise	29			29		29
Cork	161	13	25	199	407	606
Waterford	108	2	35	145	193	338
Fresenius Kilkenny	57			57		57
B Braun Wexford	51			51		51
Tralee	51			51		51
Limerick	135	10	20	165	141	306
Fresenius Limerick	88			88		88
Galway	75	5	24	104	236	340
B Braun Galway	64			64		64
Castlebar	67			67		67
Letterkenny	58			58	73	131
Sligo	59			59	33	92
Northern Ireland	2			2		2
ADULT TOTALS	2019	54	244	2317	2606	4923
CHILDREN Temple St, Crumlin	7		12	19	50	69
OVERALL TOTALS	2026	54	256	2336	2656	4992

When talking about dialysis and transplantation, statistics can often be viewed as being very 'dry' as they do not reflect the stories of the people behind them. However, it is important that we understand the numbers and what they represent.

Table 1 indicates the number of people on each mode of dialysis from 2017 – 2021. The figures are taken from the annual reports from the National Renal Office that take a snapshot of the service on December 31st each year.

What do these 5-year figures tell us? We can obviously see that the total number of people on dialysis is going up every year. It is interesting to note that the number of people on home haemodialysis has apparently remained static during this time. It may be that the people who typically are on home haemodialysis are more likely to get transplanted because of their health status.

For planning the future of dialysis provision in the country it is important to understand the reasons behind the numbers and how they are changing. For example, how much of the increase in the number of people on peritoneal dialysis is down to increased interest coming from patients and how much is to do with a change in capacity to offer peritoneal dialysis as an option?

Table 2 (below) indicates the percentage changes from 2017 to 2021.

Dialysis is provided by primary hospitals, satellite units and commercial providers.

TABLE 1				
In-Centre Dialysis	In-Centre HD	HHD	PD	TOTAL
2017	1805	54	196	2055
2018	1863	55	190	2108
2019	1925	52	204	2181
2020	2009	58	225	2292
2021	2019	54	244	2317

Table 3 indicates the number of people receiving in-centre haemodialysis from the different providers whilst Table 4 (next page) shows the percentage change from 2017 to 2021.

The commercial providers operate on HSE contracts and are all under the supervision of a dialysis hospital.

continued next page →

TABLE 3		
In-Centre Dialysis	Hospital & Satellite Units	Commercial Providers
2017	1288	517
2018	1294	569
2019	1325	590
2020	1326	683
2021	1339	680

TABLE 2				
In-Centre Dialysis	In-Centre HD	HHD	PD	TOTAL
% Change from 2017-2021	+11.9%	No change	+24.5%	+12.7%

continued...

Looking at Table 1, on the face of it, there were 262 additional people receiving dialysis in 2021 compared to 2017. However, we also need to take into account the number of kidney transplants that took place over the same period.

Looking at the annual reports from Organ Donation Transplant Ireland we can see that the total number of kidney transplants carried out between 2017 and 2021 is 774. A certain number of those procedures will have been pre-emptive transplants (where a patient gets a kidney transplant before starting dialysis) but the vast majority will have taken people off dialysis.

Also, unfortunately, a number of people on dialysis die each year. Therefore, the actual number of 'new' people starting dialysis between 2017 and 2021 was clearly more than 262.

The National Renal Office statistics show us the total number of people with End Stage Kidney Disease (people being treated by dialysis plus people being treated by transplant). We can see how this number has changed over this period (2017-2021) in Table 5.

The total number of people with End Stage Kidney Disease grew by 480 or 10.8% from 2017 to 2021. Unfortunately, as with dialysis, a number of transplant recipients die each year. Therefore, the actual number of new people diagnosed with End Stage Kidney Disease in this period was more than 480.

Table 6 brings together statistics from the National Renal Office and Organ Donation Transplant Ireland to build a more rounded picture of activity in the renal sector but there is information these figures do not give.

- When looking at 'starters' on dialysis each year, how many are starting for the first time and how many are returning to dialysis after a transplant?
- What is the median time on dialysis of those currently receiving dialysis treatment and how is it trending?
- How is the age profile of the dialysis community trending?
- What is the appetite amongst people on dialysis to change from hospital or centre-based treatment to home treatment and what is the capacity to meet this demand?

TABLE 4		
In-Centre Dialysis	Hospital & Satellite Units	Commerical Providers
% Change from 2017-2021	+4.5%	+25.9%

TABLE 5			
Year	Total number on dialysis	Total with a functioning transplant	Total ESKD population
2017	2055	2388	4443
2018	2108	2464	4572
2019	2181	2566	4747
2020	2292	2566	4853
2021	2317	2606	4923

- Is there equity of access to treatment options across the country?
- What are the average travel times to dialysis for people attending each unit and is there a business case for the opening of dialysis units in new locations to reduce journey time (and cost)?

These are only some of the issues that the National Renal Office has to manage when planning for the future of dialysis provision in Ireland. It is a complex and expensive service to deliver and it is important that the patient voice is heard in the planning process so that service provision reflects need as effectively as possible.

If we look at some dialysis units individually (see Table 7 below) we can see what, on the face of it, are some significant changes in the numbers being treated by in-centre haemodialysis.

Once again, it is important to look for the story behind the numbers. For example, the opening of the dialysis unit in Wexford will have had an impact on the number of patients attending Waterford. Equally, the new unit in Portlaoise will have impacted on the numbers attending Tullamore.

An interesting metric that is not reflected in the statistics is the lack of holiday or 'out-of-centre' dialysis capacity nationally. It remains easier to find holiday dialysis in Spain or Portugal, which is great for a sun holiday, but if someone wishes to visit family members or friends or go on a holiday, in Ireland, in a location far from their dialysis unit, they cannot access dialysis nearby and therefore have to limit their time away.

TABLE 6						
Year	People on dialysis	Change	People with a functioning transplant	Change	No of kidney transplants	Transplant recipients deceased or returned to dialysis
2017	2055		2388		192	
2018	2108	+53	2464	+76	167	91
2019	2181	+73	2566	+102	153	51
2020	2292	+111	2566	+0	123	123
2021	2317	+25	2606	+40	139	99

TABLE 7			
In-Centre Dialysis	2017	2021	Change
University Hospital Limerick	93	135	+45%
Tallaght Hospital (Trinity Health Kidney Centre)	104	133	+27.9%
Midlands Regional Hospital Tullamore	111	89	-19.8%
University Hospital Waterford	122	108	-11.5%

Rebranded Baxter 'Living with CKD' website

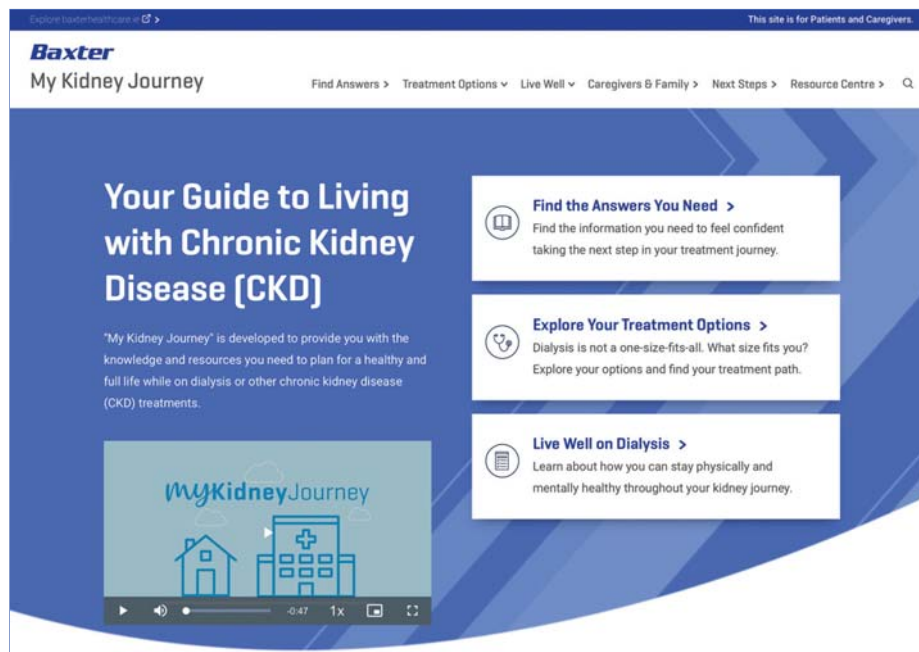
<https://mykidneyjourney.baxterhealthcare.ie>

Baxter has just launched a rebranded Irish education website, *Living With Chronic Kidney Disease*. This website offers plenty of information about chronic kidney disease. The language is clear, simple, and concise, and covers many issues. This makes it easy to read, so it doesn't overwhelm the reader.

There are also short videos (under a minute long) detailing the written topics. These are helpful as they could be easier to understand for those who struggle with reading and those who simply do not want to face the words on paper.

USEFUL SUGGESTIONS

The website gives a good overview of symptoms of chronic kidney disease as well as a detailed list of potential causes. Additionally, each stage of chronic kidney disease is listed, with all potential treatment options explored. Aside from the medical aspects of the site, it also deals with the emotional trauma of



diagnosis. The site offers advice on keeping well during diagnosis. Different people react differently to bad news and have different ways of coping. There are several helpful suggestions: from coping with emotions, to talking about your

condition, to intimacy, to exercising and travelling as well as diet.

ADVICE FOR FAMILY AND SELF-CARE

The site not only provides advice for patients, but it also contains information about caring for someone on dialysis and how to care for yourself. Everyone in the family is affected by end stage kidney disease.

END-STAGE KIDNEY DIAGNOSIS

A serious diagnosis can affect an entire household – physically, emotionally, mentally, and spiritually. When dealing with such difficult emotions and life changes, it is hard to

remember what questions to ask, and what information to retain. There are pages which offer several questions to ask a doctor or other health professional. There is also a page that offers PDF documents of various useful topics such as:

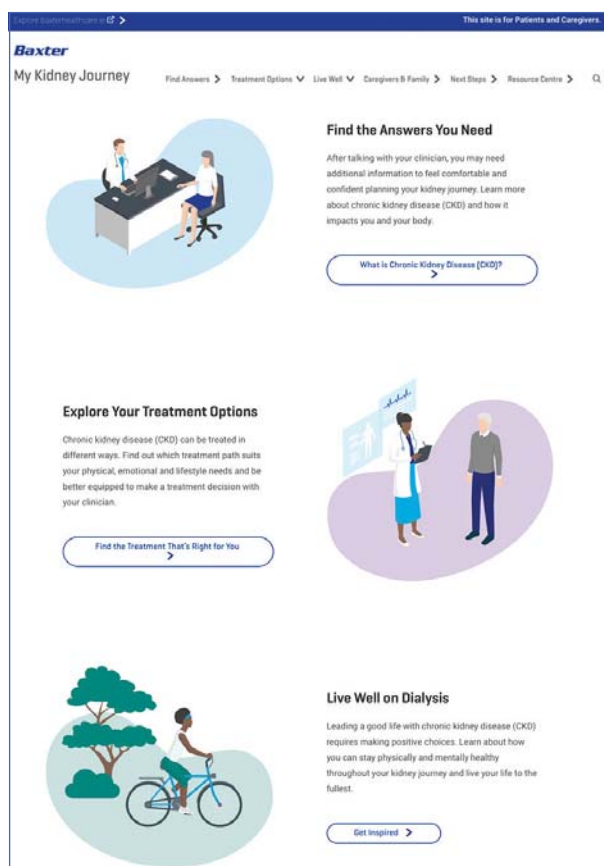
- Understanding Treatment Options
- Haemodialysis
- My Kidney Journey
- Peritoneal Dialysis
- Comparison of Dialysis Types
- A Mini Guide to Chronic Kidney Disease Terminology, and many more

CONCLUSION/SUMMARY

I found the website extremely useful as someone who is only just becoming familiar with the concept of kidney disease. It offers invaluable insights and suggestions not just to kidney patients but also to their family and friends, and any person looking for more information about the disease. It was very easy to read as well as thought-provoking.

It was shortlisted for two prizes in the HealthTec Ireland Innovation Awards.

It is likely a lot of patients and families will find this website useful.



Finnegan's joy at second transplant

Donegal man Ronan Finnegan woke to the sound of a phone ringing one early morning in September last year. He instinctively knew in that instant that it was Beaumont Hospital in Dublin calling him for his second life-changing kidney transplant. He describes how five other people were also called for a kidney transplant in the days around his life-changing operation.

By GWEN O'DONOGHUE

Ronan Finnegan



Bernie and Ronan



Ronan from Falcarragh was just 18-years-old when he received his first kidney transplant in October 1992. The transformational transplant which followed just three months of dialysis remained successful for over two decades through adulthood. Twenty nine years later, thanks to the generosity of another family of a deceased organ donor, he underwent his second kidney transplant in September 2021 which followed four years of dialysis treatment. Three of those years were spent traveling to Altnagelvin hospital in Derry for four hour treatment sessions, three times a week. In the final year leading up to his second transplant, the burden of travel to his treatment was lessened when he attended dialysis in Letterkenny University Hospital.

Christmas 2021 was an extra special one for Ronan as the previous four had been spent on dialysis. Following his first transplant in 1992, Ronan was discharged from hospital on Christmas Eve, just in time to enjoy his first traditional Christmas Day dinner having previously been restricted all through his young life with dietary and fluid restrictions.

Ronan's first transplant brought him into adulthood and paved the way for a normal life, being able to work, enjoying holidays in Ireland and the UK and supporting his local GAA club. He proclaims his love for his fiancée Bernie, whom he met six years ago, and who he says has been 'his rock' and supported him when his first transplant eventually failed and he returned to dialysis treatment. Ronan's return to dialysis and being placed back on a transplant waiting list did not deter the couple from planning for the future. The couple got engaged to be married in 2020 but resolved not to set a wedding date until the worldwide pandemic retreated.

Ronan describes how that fateful day in September last year changed his life for the better. "The transplant has changed my life. I had very little energy before it came along and the years of dialysis were taking their toll on me physically but I always remained positive. Looking back now, following my successful transplant, I didn't realise just how sick and tired I was feeling while on dialysis. Sickness was my normal for the past four to five years.

"The pandemic has been difficult for everyone but dialysis patients have had to be extremely careful not to catch it as they have higher mortality rates if they get infected. I've been working since I was sixteen years of age but had to stop when COVID arrived. I found it very isolating although my fiancée Bernie has been 'a rock of support'. She and her daughter Maria and sons

Michael and Darach have been a wonderful support and I love them dearly. I have always been a very positive person throughout my life but the transplant has given me a new spring in my step. I feel very happy and healthy.

"The good news of my transplant spread quickly through the whole community of Falcarragh and beyond and brought the conversation around organ donation into focus. As five other people got called to Beaumont Hospital for transplants in



the days around when I was there for my operation I would suspect that five other communities were also celebrating the gift of organ donation at that time and this was all made possible by the selfless generosity of other families, who in grief, consented to have their loved ones organs donated."

To demonstrate his family's profound gratitude for the 'gift of life' he received, Ronan said, "We will have a Mass said to honour my two kidney donors. I would like to send a

letter anonymously to the family of my organ donor but it's difficult to put my gratitude into words so it might take me a while longer to process my thoughts. I was young when I received my first transplant and it gave me close to 25 years of good health until my body began to reject it. I feel enormous gratitude to the two donor families who gave me the 'gift of life' and who have got me to this point. Without them I might not be here today planning for the future and hopefully a wedding!"

Ronan has high praise for health professionals who have cared for him. "The care I have received from medical, surgical and nursing teams including dialysis staff has been excellent. Huge credit and respect is due to them for their professionalism and diligent care despite the high pressures they have been working under, particularly during the pandemic. I owe my life to them and my donors. I want to thank everyone who has supported me throughout my dialysis and transplant journey especially Bernie, Maria, Darach and Michael, my mum Margaret and the rest of my family and friends. The Irish Kidney Association has helped me on my journey also and we are extremely grateful to them for providing accommodation for Bernie

and Maria in Dublin to be near me when I was called to Beaumont hospital for my transplant".

Ronan summed the reason for sharing his health experience, "I hope that people who read my story will be encouraged to consider other people on transplant waiting lists and that they let their families know their decision around organ donation and then take the next step by carrying an organ donor card or ticking the box on their drivers licence application form."

“

The good news of my transplant spread quickly through the whole community of Falcarragh and beyond, and brought the conversation around organ donation into focus. ”

Interested in volunteering as a...



PEER SUPPORTER?

By CAROL MOORE

Since its foundation in 1978, the Irish Kidney Association has dedicated itself to meeting the needs of renal patients, their families and carers, living with and affected by end stage kidney disease (ESKD). This has included the provision of support services such as the Renal Support Centre which has been in operation since 2000 and our Branch volunteers providing face to face support in their local communities. As one person said:

"Being part of the IKA has meant a lot to me, it feels like a family watching over you; many a joke over the years have been shared back and forth between us".

With the COVID-19 pandemic, much of this very valuable face-to-face support had to stop. So, while waiting for the

restrictions to ease an independent review was commissioned. This review confirmed both the existence of an informal peer support service throughout the Irish Kidney Association (IKA) and the need to develop and implement a more formal peer support service.

In response to this and recognising the vital supporting role offered by peers, the IKA has worked hard to plan for, and develop, the foundation towards the implementation of a formal pilot peer support service.

The long-term vision is to have a community of fully trained peer supporters around the country, in every dialysis unit and every renal centre.

The initial pilot, which

has been made possible through a grant received from PKRF, (see opposite) will work in addition to the existing supports provided by branches. It is a very first step and will be totally online.

We are delighted to announce that the **recruitment and selection process towards the implementation of the pilot will commence at the end of May 2022.**

Peers who have either direct lived experience of end stage kidney disease (ESKD) or who are a family member or carer of someone with ESKD will be invited to submit a short expression of interest for consideration for the peer volunteer role.

Following a review of submissions, shortlisted applicants will be invited to attend for an informal

online interview.

The 15 volunteers, who will be selected to participate in the pilot, will be supported and upskilled through a series of online training workshops. Ongoing support will be provided.

Peer Support Volunteers generally find that using their experience of living with ESKD to help someone else with ESKD is very rewarding.

In advance of the recruitment and selection process, the IKA will host an online information session on **Monday, May 23rd**. This event will offer people an opportunity to hear about the service, what it will involve, and will provide an opportunity for questions about the role and the service.

Event Registration details will be published on the website from April 1st.



Who is PKRF?

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

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

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

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

James Nolan rode in the first thirteen runnings of the race and this year will be the 31st anniversary of the event which will be held on Saturday April 30th, the final day of Organ Donor Awareness Week 2022.

The PKRF is pleased to be funding the majority of the costs of this new online pilot peer support service.

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

SPRING Giveaway

10 X €50 GIFT CARDS FOR

home store + more

This spring, our friends at Home Store + More have generously sponsored a prize giveaway and are offering readers the chance to win one of 10 x €50 gift cards to shop in-store. A 100% Irish established and owned company, Home Store + More has 22 stores nationwide, serving local communities across the country. They pride themselves on offering you the widest range and best value when it comes to homeware!

Home Store + More wants to help you create a happy home. Whether you're cooking up a storm in the kitchen, decorating your living room, adding some style to your bedroom or simply cleaning and organising any clutter throughout your home, Home Store + More provides exceptional quality at unbeatable prices. Friendly store colleagues will welcome you when you visit and provide their expert advice across all departments.

To be in with a chance to win a €50 gift card, email robyn@ika.ie with your name, address and phone number making sure to include the words 'Home Store + More' in the subject line of your email. Ten lucky winners will be selected at random and each will receive a €50 gift card which can be redeemed in any of Home Store + More 22 stores. Good Luck!

Winners' names will be announced in the Summer issue of SUPPORT.

A 'Good Enough' Recipient?

Sometimes,
I compare
myself to
other patients.



By **HOLLY LOUGHTON**

Thanks to my level of charity involvement and the wonders of social media, I am pretty well-connected to a large number of other renal patients, all in different situations and with different experiences. Some are “much worse” than me. They have stories, from a health perspective, a personal one, or in many cases both, that I cannot imagine having lived through.

As the first anniversary of my transplant approached, I thought of a conversation I had with a friend while I was in hospital directly after surgery. I was still feeling pretty rough, but was in a good enough frame of mind to start to think about being discharged and to consider what I might want to do with this new, healthier life that awaited me.

I'd seen the news articles that pop up every so often, featuring very accomplished transplant recipients. In many cases, they've recovered from near-death experiences and gone on to climb mountains, run marathons,

fundraise thousands of pounds and achieve all kinds of exceptional things.


They do this simply because they can, and because they want to show their donor families how incredibly grateful they are and how fully they're using the life-changing gift they've been given.

And then there's me.

Where do I fit? Was I really “sick enough” before my transplant? Am I “lively enough” after it?

I was diagnosed in my mid-twenties, so I never had to deal with this illness during my childhood. I also managed to finish university before I became unwell. My family are largely supportive, with the time, resources and knowledge to back me up in virtually everything I do. These are huge advantages.

Because the early treatment I had was so effective, I was pretty symptom-free. That doesn't mean I wasn't sick, there were days when even the zombie apocalypse couldn't have got me out of bed, let alone out of the house, but, compared to what



because my “bad day” could be another patient’s goal, guilty because I can work, when so many other patients can’t, guilty because of how quickly I got a transplant, when I know how long others have waited.

Sometimes I even feel guilty that I got the call at all. Because I did, somebody else didn’t. What would they have done with that chance?

I know so much of this is illogical. I understand how organ donation works. I know I didn’t “cheat”, and that if I hadn’t been the sickest potential recipient at the time, I would not have got this kidney, but still, over a year down the line, I’m still trying to get my head around it all.

Back to the list my friend and I made after my transplant. It was never a “reverse bucket list” of sorts, but it was a collection of things I felt like I should do now I was “healthy”. As if I had to prove how much my life had changed for the better. This list, and the things on it, seemed hugely symbolic and vitally important.

Eighteen months later, I can’t remember what most of them were. I think that says a lot.

In the last year, I feel like I’ve done “everything and nothing”.

It’s not as if I’ve done nothing at all. I was eventually able to accept the job I was offered the day before my transplant, and although I’ve since moved on from there I now work full-time in a variety of different roles in the wider kidney and chronic illness community, as well as continuing to speak and write, with sometimes painful levels of honesty, about my personal experience of kidney disease and transplantation. I do these things because they matter.

But there are no marathons here, no mountains being climbed or fortunes being raised. That’s not who I was before I got sick, and it isn’t who I am now.

Ultimately, this has to be ok. I have to get into a frame of mind where who I am, and what I do, is Enough. I have to stop feeling like I need to “be more” or “do more”, as if these things are required as some kind of proof of how ill I was, how life-changing my transplant is, and a yardstick with which to measure my worth and gratitude.

That isn’t how life works.

other people have gone through, I feel like I have had a very easy ride.

I was assessed for transplantation with a pre-emptive transplant being the goal. While nobody could guarantee that this would happen, I knew that thanks to my age, ethnicity and otherwise excellent health, I had fairly good odds of receiving a transplant within a reasonably short timeframe. While this didn’t take away my anxiety over what was happening to me, it certainly made me aware that I was in a very good position compared to many other patients.

Even though I didn’t end up getting a pre-emptive transplant, I was still extremely lucky that beyond the initial adjustment period, I was never seriously ill on dialysis.

I was healthy enough to apply for and be offered, a new full-time job just two months after starting PD. The same day I got my job offer I also got my transplant call. You couldn’t make it up.

Uncanny circumstances aside, I often feel enormously guilty. Guilty

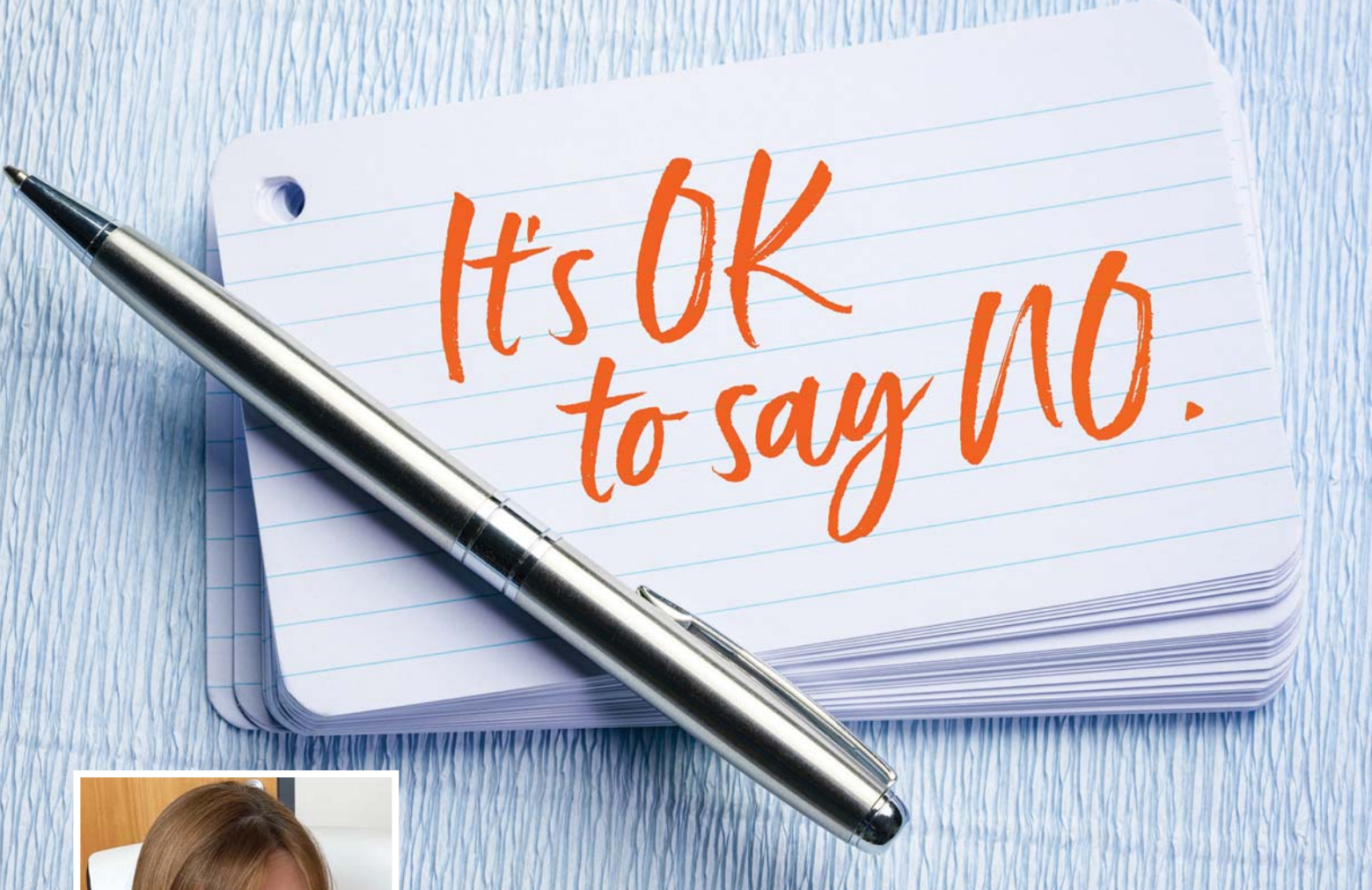
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*Thanks to **Holly Loughton** for giving us permission to republish this blog post. Holly diagnosed with kidney disease in her early 20s and since receiving a kidney transplant, from a deceased donor in 2016, she has been involved in a wide range of projects to ensure the lived experience of people with kidney disease is acknowledged and valued by healthcare providers and other relevant organisations.*

Alongside speaking and writing, Holly is the co-founder of Young Adult Kidney Group; the Patient Involvement Facilitator for KPIN (Kidney Patient Involvement Network) and an ambassador for ESOT (European Society of Transplantation).

Her blog can be found at www.secondhand-life.com and you can follow her on Twitter and Instagram @HollyMLoughton.

”



It's OK
to say NO.



By AOIFE SMITH

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

Covid-19 has had a severe impact on mental health throughout the pandemic. It has resulted in increased levels of depression, anxiety, stress and sadness. 1 in 4 people in Ireland have reported a significant deterioration in their mental health, whilst 1 in 5 cited a decline in their general health.

When the restrictions were imposed there was a need for a period of both mental and physical adjustments to our everyday lives. We gave ourselves time and showed understanding towards these very new and difficult challenges that we faced.

Gradually many of us got comfortable in lockdown, felt safe in our bubble. But now that the restrictions have been lifted as quickly as they were enforced, a new set of anxieties and fears have started to surface as the world gets back to 'normal'.

It makes me wonder have we shown ourselves the same kindness and given ourselves the same space and time we might need as we readjust?

ADVOCATE FOR YOUR COVID-19 COMFORT LEVELS

Part of navigating COVID-19 anxiety and adjusting to the re-opening process is paying attention to our emotions and

validating them, understanding what we might see as a COVID comfort level. So, whether that's wearing of masks, attending family gatherings, or doing antigen tests before a visit, it's important to understand what it is that makes you feel comfortable and to do only what feels right for you.

Show yourself a level of patience, kindness, and compassion by advocating for your own COVID comfort levels to be met by friends and family.

INSIDE OUR CONTROL

The pandemic may have taught many that we have less control than we initially thought, but that doesn't mean that we have zero-control. As we manage any social anxiety during re-opening, it is helpful to determine what's in our control and what's out of our control.

It can be hard to let go of things outside of our control, but we do have the ability to choose where to focus our energy and attention.

If we focus on concerns outside our control, we risk increasing our stress or anxiety levels. By choosing to focus on what is within our control, we move to a more proactive and productive space.

The first step in solving almost any problem is asking 'what can I control?'.

TAKE ONE DAY AT A TIME...

The lockdown hit our communities quickly and furiously. This doesn't mean we must exit as quickly. Think about where you must go and who you need to see.

Ask others you know about where they have been and whom they have seen. This may help you find your COVID comfort level.

...TAKE IT SLOWLY AND START SMALL!

For instance, this could be meeting a friend outdoors for a coffee or attending a family gathering but limiting your time there.

It may be your essential visit to the shops, which are now likely to be busier. Consider the quieter times such as early in the morning or late in the day.

Whatever your outing, attempt to take a compassionate, non-judgemental look at your emotions and any anxieties that arise during it.

Over time, you may find that although your anxiety is coming from a very real place, your response to it doesn't have to be debilitating.

Take your re-entry at your pace. Your health is your priority.

If you feel you are still unable to manage the anxiety or fears, you can always contact our counselling services.

You can contact me by phone or email. Your doctor, nurse or carer can make a referral also.

We require a brief history so that we can contact and arrange an appropriate counsellor.

Donor House is an option, and if this is not suitable you will be referred locally.

In the countryside, the referrer will be given a counsellor's name and contact details. Online counselling is also available.

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

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

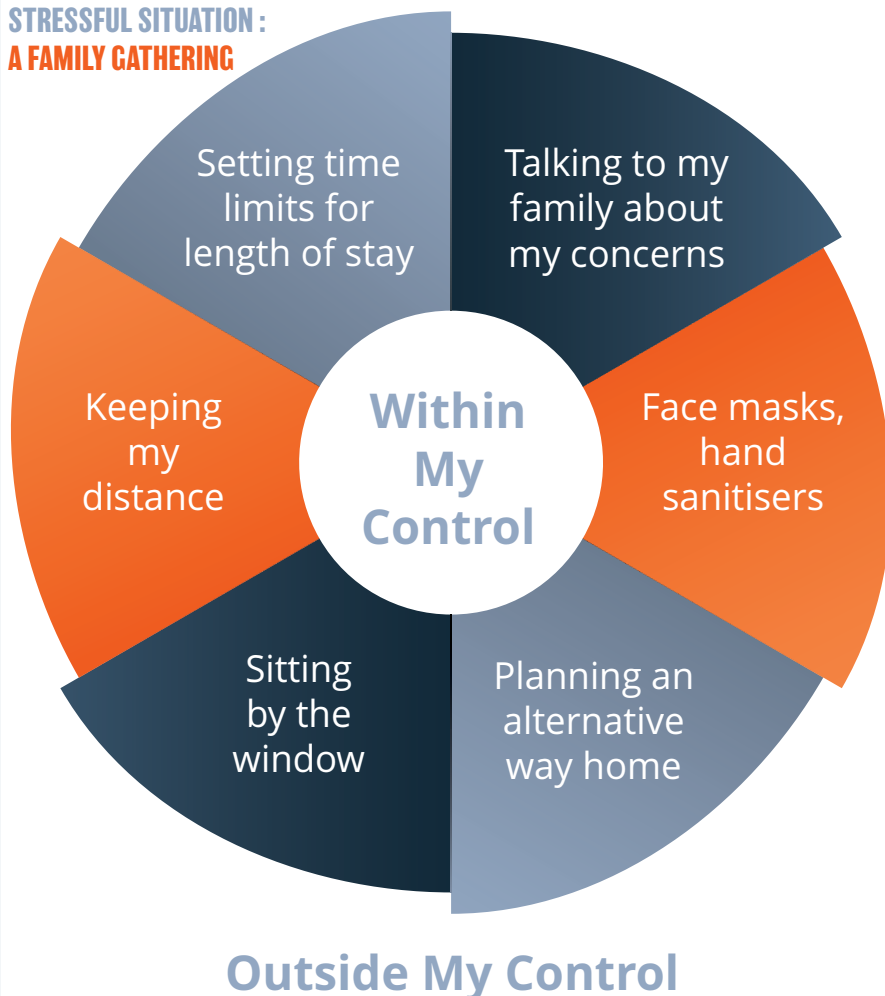
Your comments to me will be completely confidential, no names will be used, and no reference will be made to any person or any specific email. If there is a common theme in the requests, I will base the next article around that topic.

CONTROL CIRCLE

A useful tool for stress management is the control circle, which can have a powerful positive impact on stress levels.

On the top of a piece of paper write down the situation that is causing you stress. Then draw a circle. Inside the circle write all the worries and stresses within your control. Outside of the circle, write all the worries and stresses outside your control.

STRESSFUL SITUATION : A FAMILY GATHERING



What other people
choose to do?

Unexpected
guest numbers

This tool shows a way to explore how to gain more control when we feel like we have none and can highlight where we may have more power than we thought.

NEW APPOINTMENT

We are pleased to announce that following the Irish Kidney Association's nomination, the Minister for Health Stephen Donnelly T.D., has appointed **Aoife Smith** to the Consultative Council on Hepatitis C. This appointment came into effect from March 8th, 2022 and will continue until March 7th, 2025.

Aoife is the co-ordinator of counselling services at the Irish Kidney Association (IKA). She is a fully accredited humanistic integrative psychotherapist, and previous to her IKA role she had worked in private practice since 2008. She was also a specialist care representative in the healthcare industry for twenty years, during this time she gained invaluable experience working in chronic illness in the form of diabetes, respiratory diseases, and pain management.

The Consultative Council on Hepatitis C is a statutory body set up by the Minister for Health to advise and make recommendations on all aspects of Hepatitis C in relation to those who were infected through administration within the State of blood and blood products.

Play your part in the IKA's future

At the time of writing, the Board of Directors recognises that COVID-19 is still prevalent in the community. In order to protect our patient group and avoid the health risks associated with bringing members together for in-person voting at the respective Branch AGMs, and to ensure that we meet our statutory obligations, the Board of the Irish Kidney Association has opted to run postal elections in 2022.

POSTAL VOTING

Postal voting is a new process for the Irish Kidney Association. However, the Board and senior management of the organisation want to assure all members who have the entitlement to vote, that time and effort will be invested to ensure that this process is clear and transparent and produces a result that is a true reflection of the voting membership's wishes.

WHO CAN NOMINATE OR VOTE?

According to our Constitution

- All renal patients who are members can nominate and shall have one vote
- All ordinary members of at least 3-year standing can nominate and shall have one vote
- Associate members shall not be entitled to vote
- The instrument appointing a proxy shall be in writing under the hand of the appointer or his/her attorney duly authorised in writing.

All members who are eligible to vote will receive a nomination paper first and then a ballot paper. Both of these will be sent by post and will need to be returned to Donor House, in the prepaid envelope enclosed, by the date specified on the paper.

WHAT ROLES ARE AVAILABLE?

Under our Constitution, all roles become vacant at each election. Elections are held every two years. There are three Officer roles at individual Branch level: (Chairperson, Secretary and Treasurer) and each Branch can appoint one National Director to the National Board.

So, in total there are four roles to be filled.

WHY SHOULD I GET INVOLVED?

Research has shown that as well as benefitting the community, volunteering also benefits the person volunteering. Benefits can include:

- Giving something back to your community or society
- Gaining new skills and knowledge and enhancing existing skills
- Meeting new people with similar interests
- Gaining valuable experience – often with a view to gaining employment
- Feeling connected to your community
- Making a difference in someone's life
- Having fun with like-minded people

The IKA has recently adopted a new exciting strategy and needs more



volunteers to make sure we build on past successes and deliver even more for our community into the future.

WHAT IS THE PROCESS?

AM I ELIGIBLE TO VOTE

– Examples

Abel: "I am a renal patient and have been a member of the Irish Kidney Association for 2 years...can I vote?"

Yes. In line with our Constitution, Votes of Members (S32), all renal patients shall have one vote.

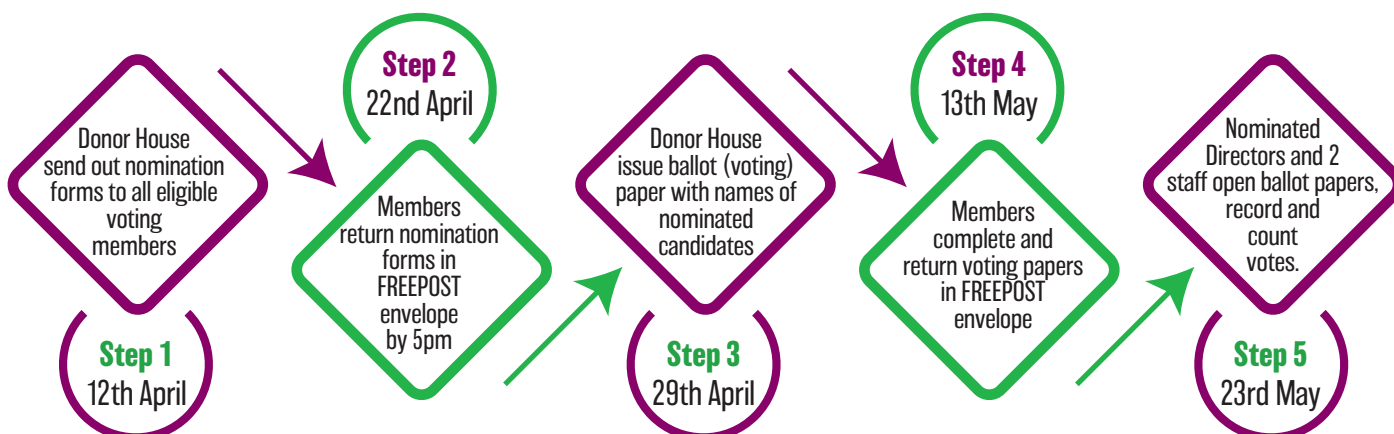
Marie: "I am a carer for an end-stage renal disease patient, and member for the last 4 years, can I vote?"

Yes. As a person who is directly affected by end-stage renal disease and a person who supports the cause and objectives of the Association (4 (b)), as an ordinary member for more than three years you are entitled to vote.

Luca: "I am an Associate Member, can I vote?"

No. In line with our Constitution, Votes of Members, Associate Members shall not be entitled to vote.

Key Election Phases



Claire: "Hi, I'm 16 and would like to become a member of the Irish Kidney Association, can I vote when I do?"

No. Our Constitution states that membership of the Association shall be open to people who are over 18 years of age (S4).

Matthew: "Hi, I am visually impaired and cannot complete my own ballot paper, what do I do?"

Yes Matthew, you can still vote. You can appoint a proxy, who can vote on your behalf.

Aleni: "Hi, I became a non-patient member in 2021, am I eligible to vote?"

No Aleni, under our Constitution you will not be eligible to vote until 2024.

How do I nominate an individual for a role

The nomination paper will have four boxes. Each box will have the role being nominated for, i.e., National Director; Branch Chairperson; Branch Secretary; Branch Treasurer.

If you wish to nominate an individual for a role you write their name into the relevant box. Please write **one name only** in each box.

Permission of the nominee must be obtained. If you do not have direct contact details for your nominee, please contact your local Branch Secretary or Donor House who will assist you.

Can I nominate myself?

Yes. If you wish to nominate yourself for a role(s), you can certainly do so. Please remember that you can only nominate one individual for each role.

Can I nominate myself for more than one role?

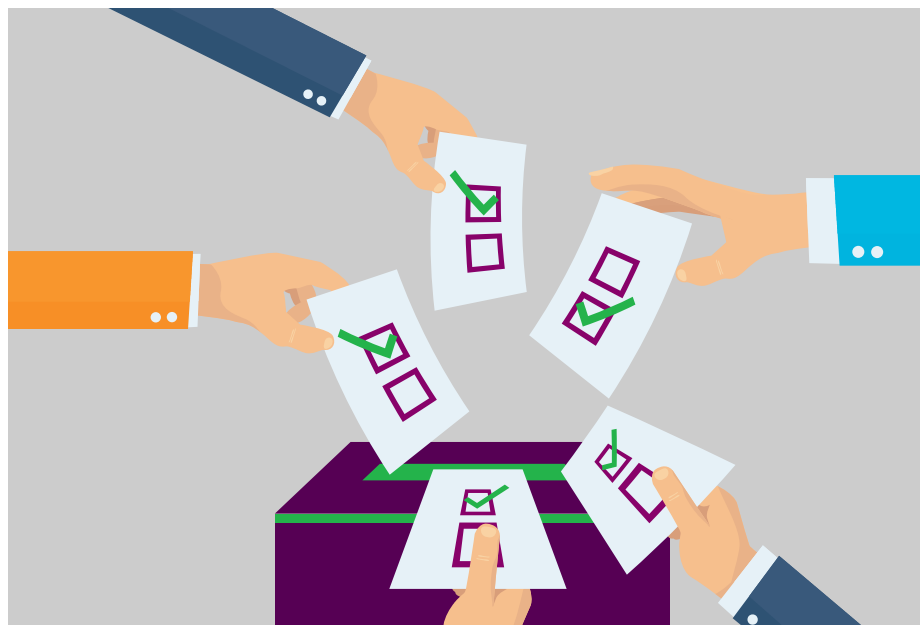
Yes. Providing only one name appears in each of the boxes.

How many nominations do I need to get before my name appears on the ballot paper?

We do not anticipate multiple nominations for each role, so all individuals receiving at least one correctly completed nomination will be included on the ballot paper.

If I am not aware that I have been nominated, will I be contacted in advance of seeing my name on a ballot paper?

A person cannot be nominated without their agreement. You will be contacted by the person nominating you to accept the nomination.



Will I have to pay for postage?

No. All nomination papers and ballot papers will be sent with a prepaid envelope with a return address of Donor House.

I put two names on one box in error, will this cause my vote to be discounted?

Yes. For this role only as it does not comply with the voting rules of one name per role. If you nominated only one individual for each of the other three roles, then these will be counted and deemed valid.

I didn't vote for all four roles – is this okay?

Where you chose not to vote for a particular role, this will be deemed to be an invalid vote. Your votes for the other three remaining positions, if you nominated one individual only per role (as per the voting rules), will be deemed valid and be counted.

How secure will my nomination or vote be?

Similar protocols will be adopted for both returned nomination forms and ballot papers. Once received, all will be date stamped and stored in a locked safe. Nomination forms and ballot papers will be opened, counted and recorded by two members of IKA staff. Directors from

the Board will act as independent observers for the counting of ballot papers. Four counts of the ballot papers will take place.

Nomination and Ballot papers will be kept in a safe for 2 months in case of a post-election query. Thereafter they will be destroyed by our Confidential Shredding Company.

Will there be training?

- (i) All newly appointed Branch Officers and Directors will receive induction training in the early weeks of their appointments. They will receive notification of these dates once appointed.
- (ii) In addition, the Irish Kidney Association believes in the importance of ongoing personal development so we would envisage access to training will increase for all Officers and Directors over time.
- (iii) It is our intention to provide Board mentors for new Directors where we can for the first 6-12 months.

Appointments to the National Officer roles (National Chairperson, National Treasurer and National Secretary) will take place at the next Board meeting after the National AGM takes place.

The IKA is an organisation for patients and their families which is led by patients and their families. It is important for future success in helping patients and families that this continues. We need you to vote and consider getting more involved if your life situation allows this.

The most up to date guidance is available on the IKA's website:
www.ika.ie/elections2022

Galway couple kick-off New Year in cross-border kidney transplant swap

By GWEN O'DONOGHUE



Michelle and Eoin Madden

A Galway couple is celebrating a successful cross border four-way kidney transplant swap which took place on January 4th, 2022. Eoin Madden from Kiltullagh in County Galway is now enjoying a newly transplanted kidney which he received from a stranger in the UK as his wife Michelle (Shelly) Tooher, has recovered from donating one of her kidneys in a process known as 'paired-exchange'.

The carefully orchestrated event, which involved operations in two hospitals, in Northern Ireland and England, was facilitated through cooperation between the HSE Treatment Abroad Fund, the UK's National Health Service, the ODTI, Beaumont Hospital and Belfast City Hospital.

There was also impromptu support from two members of the Police Service of Northern Ireland who came to the rescue as the couple's car gave trouble enroute to Belfast City Hospital the day before the scheduled operations.

Eoin and his wife Michelle are the first Irish couple this year to go through the UK Living Kidney Shared Scheme.

On January 4th, Michelle, the mother of three, underwent an operation to have one of her healthy kidneys removed at Belfast City Hospital paving the way for Eoin to receive a kidney from a UK-based living donor later that day.

Michelle was not a suitable match for Eoin who had been receiving dialysis

treatment for over five years following two previous kidney transplants. This had led to a build-up of antibodies, reducing his chances of finding another suitable donor.

Michelle's kidney was then flown to a hospital in the South of England to be transplanted into an awaiting patient. Later that day, Michelle's extraordinary deed was reciprocated, as her husband, Eoin, received a lifeline through a healthy donor kidney which was retrieved in England and flown over as 'special cargo' to be transplanted into him.

Michelle, now weighing in a little

lighter minus one kidney, returned home within a few days of the operation while Eoin remained in Belfast for a few days longer as the newly transplanted kidney, from an unidentified stranger in the UK, settled in.

Two months prior to the life-changing transplant, Eoin, while shopping for Halloween decorations at his local Homestore + More at Wellpark, was overjoyed to receive a phonecall confirming that a suitable donor kidney match had been found for him through the UK Living Kidney Paired Scheme and a suitable recipient was



Michelle with PSNI Off Aaron Chambers, Matthew Millen outside Belfast City Hospital

identified to receive a donated kidney from his wife Shelly.

Home Store + More is pleased to sponsor a prize giveaway in this *SUPPORT*, in recognition of the good news Eoin received while shopping in one of their stores. (Page 25).

The operations were scheduled to take place just before Christmas, on December 16th, but a last-minute hitch after travelling to Belfast City Hospital arose. Just after his wife Michelle was ready to be wheeled down to theatre to have her kidney removed, the intended UK recipient had become unwell and the operation could not proceed. All parties were stood down and a revised date of January 4th was set.

The couple returned home to cocoon, once again, away from the threat of the escalating cases of COVID-19, with their three children, ages 3, 7 and 10. Michelle and Eoin had taken a couple of months extended leave from their places of work, and their two older children were also taken out of national school at the beginning of December to cocoon.

Two days after his successful transplant operations, Eoin shared the good news on his social media describing how he felt like 'A New Man' since receiving his kidney transplant, his third, a lifeline that he and his wife Michelle, who he affectionately refers to as 'Shelly', had almost given up on.

Before entering the paired-exchange programme in the UK, Eoin was advised that as his two previous transplants in 2001 and 2008 which he received from deceased donors had led to a build-up of antibodies, the prospect of him finding a suitable kidney was one-in-a-million.

Eoin explained, "after Shelly was screened by Beaumont Hospital for suitability to donate one of her kidneys to me, we received the disappointing news that she was not a suitable match for me.

"It was then that a consultant at Beaumont, Dr. Colm Magee, suggested that we enter the paired-exchange programme in the UK which, with a larger pool of donors, might result in a suitable match, although, with my antibody build-up there were no guarantees.

"The scheme offers four cycles in



Michelle and Eoin post-transplant

a year to find a suitable match. We feel blessed that on the very first cycle we were entered into a suitable match was found for me, while Shelly was found to be a suitable match for a patient in the UK. We hit the jackpot first time!

"Organ donation really is the 'gift of life'. My life has been extended now because of three donors. I will always be mindful of the selfless families of two deceased donors who gave me many extra years of better health and allowing me to enjoy wonderful experiences including getting married to my beautiful wife who, as well as giving me three beautiful children, has now become a hero kidney donor.

"We are so grateful to all the people who helped us on my health journey. There are so many people to thank. Firstly, the amazing team at Belfast City Hospital who do incredible work and filled us with confidence that we were in safe hands under their expert care. They really have a world-class team there.

"In 2020 in the early stages of COVID, as other transplanting

hospitals' programmes temporarily paused in the UK, Belfast City hospital performed a record breaking 101 transplants in 101 days, and in doing so they significantly reduced their kidney transplant waiting lists."

Keen to acknowledge the goodwill that both Eoin and Michelle experienced, Eoin said, "We will never forget the kindness we received from PSNI Officers Aaron Chambers and Matthew Millen who came to our rescue when we experienced car trouble on our way to Belfast City Hospital and they drove us the rest of the way there.

"We would like to thank Beaumont Hospital and the HSE for facilitating the process, the consultants and dialysis team at Merlin Park in Galway who have cared for me for over two decades, and the Irish Kidney Association (IKA) who have also been a huge support for many years. We are grateful for the goodwill we have received from our friends, neighbours, work colleagues and the whole community of Kiltullagh".

Continued next page

“Organ donation really is the ‘gift of life’. My life has been extended now because of three donors.”

Before saying goodbye to her husband to make her journey home to Galway, when she was discharged from hospital, Michelle said, "It has been an incredible experience and we are both so relieved Eoin's transplant was a success. We feel so uplifted with all the good wishes and support we have received from so many people."

"Both Eoin's family and my family have been unwavering in their continued support and have given so freely of their time to us and are caring for our children as we recover from our surgeries. Our children can now, for the first time, see their father in a new light enjoying renewed health away from the restrictions of dialysis."

In the weeks following their operations, Eoin and Shelly did media interviews with BBC Radio Ulster, RTÉ Radio One's Claire Byrne show and Galway Bay FM and their uplifting story was also covered in several national and local newspapers also.

Eoin will participate in a webinar

on the paired-exchange programme, along with Dr. Colm Magee, which the IKA is hosting in early May and which will be publicised on the IKA's social media and website.

In congratulating the happy couple on their successful transplant, Carol Moore, Chief Executive of the IKA, said, "We are delighted for Eoin and Michelle. This is a wonderful example of how successful cross-border cooperation through the HSE treatment abroad scheme can be. Our thanks to the HSE Treatment abroad office, the ODTI, the NHS and Beaumont Hospital who worked so hard to put this agreement in place."

"Beaumont Hospital continues to be our national kidney transplanting hospital and despite challenging times during the pandemic it carried out 137 kidney transplants in 2021 of which 35 were from living donors. However, for certain patients on the kidney transplant waiting list in Ireland, who are unlikely to be matched with a suitable donor, the UK Kidney Paired Exchange Scheme



Eoin post-transplant

offers great hope.

"Last year two other Irish pairs were successful through the scheme, there was just one in 2020 while pre-pandemic, three such paired-exchange transplants for Irish patients took place in 2019. There are currently ten other Irish pairs (donor and kidney patient) enrolled in the programme, six managed through Coventry and four in Belfast who receive financial support from the HSE's Treatment Abroad Scheme."



AGM

VIA ZOOM

Due to ongoing pandemic conditions,
the national

Annual General Meeting

of the

Irish Kidney Association

will be held online via ZOOM on

Saturday, July 2nd, 2022

You will be required to register in advance to attend the ZOOM AGM.

In due course details for registration to attend the meeting will be posted on

www.ika.ie



THE AGM IS ONLY OPEN TO MEMBERS OF THE ASSOCIATION

SURVEY



If you are happy to participate in this anonymous survey, you can either:





SUPPORT MAGAZINE SURVEY 2022

1. What is your gender?

- ☐ Male ☐ Female ☐ Other

2. What is your age?

- ☐ 18 to 24 ☐ 25 to 34 ☐ 35 to 44 ☐ 45 to 54
☐ 55 to 64 ☐ 65 to 74 ☐ 75 or older

3. How long have you been a reader of SUPPORT Magazine?

- ☐ Less than 6 months ☐ 6 months to 1 year
☐ 1 - 5 years ☐ 5 or more years

4. What type of reader are you?

- ☐ Transplant Patient ☐ Dialysis Patient
☐ Kidney Disease Patient (*not on dialysis or transplanted*)
☐ Family member, carer or friend of a patient ☐ Healthcare Professional
☐ Other (*please specify*)

5. What county do you live in?

6. What is your view of the topics in SUPPORT Magazine?

Please rate whether there is too much or too little on each topic below?

	Too little	Just right	Too much
Cover Story	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Editorial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 Vaccinations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
COVID-19 General	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sports Update	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Stories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Media and Information Technology Advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Holiday Updates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 6 cont.

	Too little	Just right	Too much
Healthcare Activity, e.g. Transplants & Dialysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical Consultant Advice on Topics, e.g. Itchy Skin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Welfare Entitlements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recipes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Competitions/Giveaways	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Around the Branches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book Reviews	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)			

7. What kind of articles would you like to see more of in SUPPORT Magazine?

8. Which of the following topics would you like to read about in SUPPORT Magazine's dietitian article? Please choose your top 5.

- | | | |
|---|--|-------------------------------------|
| <input type="radio"/> Salt | <input type="radio"/> Fluid | <input type="radio"/> Phosphate |
| <input type="radio"/> Potassium | <input type="radio"/> Vitamin D | <input type="radio"/> Gout and diet |
| <input type="radio"/> Eating Well Post Transplant | <input type="radio"/> Maintaining a healthy weight | |
| <input type="radio"/> Kidney Stones and Diet | <input type="radio"/> Diet and Gut Health | |

9. Would you like to see more nutrition articles on any of the following?

(✓Tick one or more boxes if Yes)

- ☐ Patients writing an article with their dietitian
☐ Recipes
☐ Current nutrition research in the area of kidney conditions

10. A short animated video on 'Salt and Chronic Kidney Disease' is on the IKA website – have you viewed it?

- ☐ Yes ☐ No

11. If you have viewed the video, would you like further videos on 'Salt and Chronic Kidney Disease' to be put on the IKA website?

- ☐ Yes ☐ No

12. Which of the following words would you use to describe *SUPPORT* Magazine?

Select all that apply.

- | | | | |
|--------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| <input type="radio"/> Reliable | <input type="radio"/> Useful | <input type="radio"/> Interesting | <input type="radio"/> Informative |
| <input type="radio"/> Boring | <input type="radio"/> Impractical | <input type="radio"/> Ineffective | <input type="radio"/> Unreliable |

13. How would you rate the quality of *SUPPORT* Magazine (e.g production and content quality)?

- | | | | | |
|-----------------------|-----------------------|---------------------------------|-----------------------|-----------------------|
| Very low
quality | Low
quality | Neither high nor
low quality | High
quality | Very high
quality |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

14. Overall, how satisfied are you with *SUPPORT* Magazine?

- | | | | | |
|-----------------------|--------------------------|---------------------------------------|-----------------------|-----------------------|
| Very
dissatisfied | Somewhat
dissatisfied | Neither satisfied
nor dissatisfied | Somewhat
satisfied | Very
satisfied |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

15. Would you be more or less likely to read *SUPPORT* Magazine if you received it by email, instead of a paper copy?

- | | | |
|-----------------------|-----------------------|-----------------------|
| Less Likely | No Change | More Likely |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

16. What do you as a reader think we are doing well here at *SUPPORT* Magazine?

17. What do you as a reader think we could improve on here at *SUPPORT* Magazine?

18. How likely is it that you would recommend *SUPPORT* Magazine to a friend or colleague?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all likely | Unlikely | Neutral | Likely | Extremely Likely |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

19. Do you have any other comments, questions, or concerns?

PULL-OUT HERE

PULL-OUT HERE



The greatness within

In 2016, David Crosby from Kingscourt, Co. Cavan underwent a double lung transplant as a result of a devastating lung condition, which claimed the lives of three of his four siblings.

His sister Regina was just 7-months-old, and his brother Paul was only two when they passed away, while his brother Ciaran fought bravely for eleven years before his death.

The father of three's inspirational story caught the attention of former President of Ireland Mary McAleese. In her TV series *'All Walks of Life'* David remembered his late siblings' and his parents' fortitude in their grief.

The former Meath minor footballer described how, within weeks after his 40th birthday, he would also be struck down with lung disease that had evaded him for four decades but left him fighting for his life. The lung condition IPF (idiopathic pulmonary fibrosis) causes incurable scarring of the lungs.

David recounted the feeling of devastation for him and his devoted wife Katie, after receiving a false call for a transplant as the donor's lungs were not

viable, and thinking his final chance of survival had passed him by. Two weeks later, he received another call for a double lung transplant, which on this occasion went ahead, and saved his life.

David's profound gratitude to his donor and wish to honour his deceased siblings spurred his determination to embrace the second chance of life he had been gifted.

With his renewed health, he resolved to share his story as widely as possible to promote organ donation. Since his transplant he has given several inspiring talks and numerous media interviews to increase organ donor awareness.

Just eight months after his transplant operation,

David had progressed from being at death's door to completing a five-mile run.

21-months post-transplant David, together with thirteen friends, completed the New York Marathon.

It was after this notable personal feat, that he resolved to make it his goal to become the first double lung transplant recipient in the world to complete the Super Six Marathon Majors.

Now halfway there, he has completed the Berlin Marathon in September 2018 and the London Marathon in 2019. His ambitions to complete the other three marathon locations, Tokyo, Boston and Chicago, were hampered with the arrival of the global pandemic.

In late summer of 2020, David experienced another disappointing blow when he was diagnosed with acute lung rejection. He received steroid treatment but this wasn't effective in slowing down the rejection.

He then underwent ten

weeks of TLI radiation. This treatment was successful in halting rejection but unfortunately David's lung function had declined from 90% post-transplant to 52%. David's reduced lung capacity heightened his fears of catching COVID-19 but when he received his vaccination shots it gave him a sense of relief and protection.

However, in August 2021, David and his family's worst fears were realised when he had caught COVID-19 which brought him back to the Mater Hospital, where he received his transplant four years before, to fight for survival for a second time.

David is now learning to adjust to the aftermath of his almost fatal COVID-19 infection which led to acute kidney failure and dialysis treatment which he undergoes three times a week.

His story of triumph over adversity continues...

Continued next page...

THE GREATNESS WITHIN

By DAVID CROSBY

Here David gives his account on how COVID-19 wreaked havoc on his body and mind, his road towards recovery, while learning how to adjust to being on dialysis, a consequence of the infection.

David is half way through the 'Super Six Marathon Majors' challenge.



In August 2021, I picked up COVID-19. I hoped it wouldn't be too serious and with my good level of fitness that I would be strong enough to fight it.

I went up to the Mater Hospital for an assessment and they decided to keep me in for observation. My temperature was continually spiking and on some days my breathing became laboured, but I still thought this would be the worst of it. Some days were worse than others.

A week after being admitted I thought I was improving and was texting some of my friends about a big championship game my local club was in. Little did I realise that two days later I would be put into a medically induced coma. I got

severely worse, and my stats were all going in the wrong direction.

The doctors were very concerned and called my family up as they thought I was facing death.

I had to say my goodbyes to my children and tell them how proud I was of them and knowing that this might be my last conversation to have with them. It was extremely hard having these conversations with my wife Katie and our children and with the rest of my family especially after all that we had gone through over the years. All we have fought to overcome; it all came down to this.

There were no other treatment options left and they were putting me on a ventilator to buy me extra time. The next 12 to 24 hours were critical but hopes were fading for a

positive outcome.

I remained extremely critical, but stable initially, and the doctors took me off my immune suppressant drugs in the hope that my natural immune system and the vaccine would give me a better chance to overcome COVID-19. I had some really dark and scary days while on the ventilator.

My family including my children were called in for a second time to say their goodbyes, by then I was in multi organ failure. The doctors were extremely concerned. Thankfully, I remained stable for the next 48 hours and started to show slight progress in a positive direction. Over the following two weeks I recovered enough for the doctors to consider taking me off the ventilator.

I put my faith in the doctors that were looking after me in the Mater Hospital. I don't remember much of this time or the weeks that followed.

When I was brought back round from the coma I didn't know where I was as I felt so disorientated. I thought I was in London or Belfast. I couldn't speak properly, nor could I move my arms or legs as I had lost 15kg weight which was mostly muscle loss.

It was very hard for me to comprehend what I had been through. I felt I should be able to pick up where I left off and go home and take the football teams I've been training out onto the pitch, because I thought there was nothing wrong with me. It took me a while to get my head around all of this. As you can imagine I had a lot to think about with my lung transplant, being back on oxygen, the weight loss, and no strength.

Unfortunately, my kidneys failed while on the ventilator and initially I was on dialysis 24/7 and then it was reduced to three times a week after a number of weeks.

This was a whole new unknown area for me and many of you reading this will know more about it.

At the beginning I found it hard to accept this setback and understand the process of dialysis.

COVID-19 took a huge toll on me both mentally and physically. I had to adapt to a new daily routine in my



David was selected to bring the tricolour through the parade at the New York Marathon with his friend and pharmacist David McNally.

life and understand how important dialysis is as part of it.

It took a while for me to build-up my strength as I had to learn to walk again and talk again but at least I had a chance.

I went through some very bad days in hospital trying to figure out what had happened to me, but I knew from my previous experience of my lung transplant that the only way to get through something like this is to figure it out, work with what I can do, and not fight it. I followed doctors advice and slowly recovered.

Every little step forward was a step closer to getting out of the hospital.

All that I could focus on was getting home to my family, looking out my own window and enjoying the comforts of being in my own home.

After a lot of pain, despair and frustration, over a period of nine weeks and three days, I finally got to leave the Mater Hospital. I will never ever forget that important day of departure because there had been times that I thought I might never leave there or even survive.

I did fight, I did gain weight and I did figure out the dialysis. I did my rehab every day, I took my medications on schedule, and I continue to follow my renal diet strictly.

To say that I have so much



David Crosby with his wife Katie and children at Áras an Uachtaráin on St. Patrick's Day in 2018 with President Michael D. Higgins and Sabina Higgins.

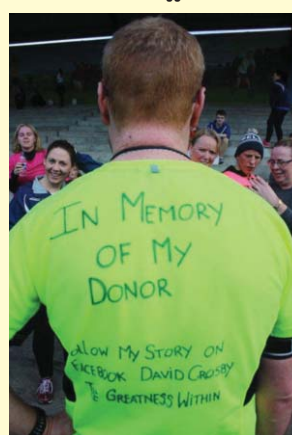
appreciation for the nurses and staff in the Mater Hospital is an understatement. They were not only amazing to me, but to my family also. They kept in constant communication with them as visiting was restricted. They checked in with my wife to make sure she was coping and minding herself.

I am home now and recovering and I am attending dialysis treatment at Cavan General where staff are so good and supportive to me.

I get picked up in a taxi three mornings a week at 6.30am and dropped home by midday. Things are going pretty well considering all that has been thrown at me.

Fighting COVID-19 has definitely been one of the hardest things I've been through in my life, but life is worth fighting for.

I still have a dream of picking up



my Super Six Marathons' medal and I'm not going to give up on getting it. I'm halfway there towards my goal with three marathons left to do.

Hopefully, with the strength and fight that I have inside I will complete them. I am doing this, not for my sake, but to honour my donor, to remember my late brothers and sister,

and for my family who have been by my side every step of the way.

My family, including my wife Katie and children, have gone through such a difficult time. The important role that the family of a patient plays in supporting them, is not acknowledged enough, but not by me!

Trust me when I say that I do!

Thank you for reading my story which I hope helps make people understand just how important organ donation and the 'gift of life' and good health is.



David and his wife Katie in Berlin





Myth Busting Home Dialysis

We know that the thought of starting a home dialysis therapy can seem daunting and there are a lot of myths surrounding it. This article is designed to clarify any concerns or misconceptions you and your family may have about choosing Peritoneal Dialysis (PD) or Home Haemodialysis (HHD).



By ANNA HOLLINGSWORTH
PD Senior Product Manager
Baxter Healthcare

PD

Peritoneal Dialysis (PD) cleans your blood while a dialysis solution is in the peritoneal cavity, using the lining of your abdomen (peritoneal membrane) as a filter. Because of this, it can be performed **at home, at work, or while travelling**, either by yourself or with the support of a care giver. You can perform PD during the day or while you are sleep, **giving you the flexibility to plan** your dialysis treatments around your daily schedule.

HHD

Haemodialysis (HD) is a type of dialysis that filters your blood outside your body using a machine and a dialyser, which is a manufactured filter that acts like an artificial kidney. During HD, the dialysis machine removes a small amount of your blood from your body through a needle or catheter, into a continuous circuit. The dialyser then cleans your blood, removing waste, toxins, and excess fluid. Finally, your clean blood is returned to your body. HD can be done at home (HHD) **giving you the flexibility** to adjust your treatment schedule around your daily activities.



“There is no support for me at home if things go wrong”

FALSE!

During training, home dialysis nurses teach a person everything they need to know to self-care independently and to problem solve. Your nursing team keeps in regular contact with you to discuss your therapy. Help is as close as a telephone call with a 24 hour/7 day a week helpline to support you. If you choose PD your dialysis machine sends therapy data to your hospital every day so your clinical team can review and make changes if necessary.



Home dialysis is too complicated, I'll never be able to learn to do it myself!

FALSE!

Currently in Ireland there are people on home dialysis ranging from young babies to some over the age of eighty. Training is individualised to each person. You will not have to perform dialysis at home by yourself until you and your Healthcare Team feel you are ready and even after this, remember you will not be alone with your treatment. There are no age limitations to perform PD or HHD.



“I cannot do HHD because I could not put a needle in my arm”.

FALSE!

Self-needling can seem to be the most stressful part of the HHD therapy. However once a person learns to self-needle, they will tell you that they would prefer to do this themselves rather than have anyone else do it! During training self-needling is taught and it's not difficult to learn. PD does not require any needles.



“I will be forgotten at home”

FALSE!

If you choose to do home dialysis you will never be forgotten. Speak to your renal nurses about what their routine is for contacting home patients. In some cases, home dialysis nurses will visit you at home. Others will phone you to see how you are doing. You will also be seen regularly by your renal doctor and perhaps your GP. If you

choose to do PD, remote patient monitoring in your machine sends daily therapy data to your hospital. Your clinical team will review this data and will call you if there is anything to discuss.



“I live in a rented house I can't do home dialysis”

FALSE!

Living in a rented house doesn't exclude you from doing home dialysis. If you choose PD you will not need to make any modifications to your home. If you choose HHD, you will need to ask permission from the landlord for the homecare supplier to install electrics and plumbing. Many landlords in Ireland have had no issues with people making these minimal modifications although some may require this to be reversed if you decide to move house, but this will be supported by your homecare supplier.



“I need a lot of room in my house to do home dialysis”

FALSE!

Home dialysis can be successful even in small homes. It is true that you will need room to store your dialysis supplies, however, suppliers can provide weekly, fortnightly, or monthly deliveries to suit your lifestyle. You do not need a totally separate room to perform your dialysis. Depending on the type of PD you choose, it can be performed in your bedroom at night while you sleep or any suitable room in your house during the day. Some people who have chosen HHD perform this in their living room or it can also be done during the night whilst you sleep. Your home dialysis nurse can advise you on this.



“Patients on dialysis can no longer travel”

FALSE!

You can continue to travel when you are on dialysis, but it takes some planning! If you are on PD, dialysis suppliers provide a Travel Club which will arrange to ship your supplies to your destination. Most PD machines are portable and come with a travel case. If you are on HHD, your clinical

continued next page





Myth Busting Home Dialysis_{continued}

team can arrange dialysis sessions in certain hospitals abroad. Some people on PD and HHD have even had dialysis on cruise ships sailing around the Caribbean!

8

MYTH

"Home dialysis patients don't have the time or energy to work"

FALSE!

Many people who are on home dialysis continue to work, go to school or college and are active members of their community. Home dialysis provides flexibility allowing you to continue to work if you choose to and live a full and active lifestyle.

9

MYTH

"Dialysis patients have no say in their treatment"

FALSE!

As a patient you have a great deal of control over your treatment choice. Choosing the right treatment for you should be a shared activity with you, your family and your kidney doctor. Shared Decision Making is patient engagement and empowerment in

the clinical consultation allowing you to choose suitable treatments for your clinical condition, lifestyle, and social circumstances. If you choose home dialysis you will be trained to be proficient in self-caring at home giving you the freedom and flexibility with your dialysis schedule whilst always being supported remotely by your clinical team.

10

MYTH

"Home Therapies are very time consuming"

FALSE!

As you are self-caring at home you have more freedom and flexibility with your dialysis schedule. If you choose Automated Peritoneal Dialysis (APD) your machine will perform your dialysis whilst you sleep at night leaving your days free. Continuous Ambulatory Peritoneal Dialysis (CAPD) takes place up to four times during the day with each of these exchanges lasting only 20 minutes. If you are on Home Haemodialysis (HHD) you may choose to have your dialysis at night whilst you sleep, this is known as Nocturnal dialysis. Or you may prefer to do short daily dialysis for a few hours at a time.

If you require further information on dialysis treatment choices and kidney health please visit: <https://mykidneyjourney.baxterhealthcare.ie>

If you get any side effects from home therapies, talk to your doctor, pharmacist or nurse.

Reporting forms and information can be found at www.hpra.ie/homepage/about-us/report-an-issue

**ACCOMMODATION TELEPHONE
BOOKING HOURS**
087-4169907



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

ROUTINE APPOINTMENTS

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

EMERGENCY APPOINTMENTS

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

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

WINTER PRIZE GIVEAWAY WINNERS

Thank you to **DUNNES STORES** for generously sponsoring **10 x €50 gift cards** as a prize giveaway in the Winter issue of *SUPPORT*.

Congratulations to the winners:

Jackie Enright, Co. Limerick

Harry Ward, Co. Dublin

John Lacey, Co. Kilkenny

Aine Hayes, Co. Waterford

Caroline Horgan, Co. Tipperary

Eloise Cryan, Co. Tipperary

Colette Stephens, Co. Galway

Mary O'Rourke, Co. Louth

Eileen O'Driscoll, Co. Cork

Ann Nolan, Co. Longford



Are you worried about energy costs?

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

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

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

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

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

Engage

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

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

Apply

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

Reach Out

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

Switch

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

Register

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

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



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

FREE, CONFIDENTIAL AND INDEPENDENT

HOW MABS HELPS

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

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

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

Follow MABS info on...



ABOUT MABS

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

Call the national helpline on



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



helpline@mabs.ie



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



Funded and supported by the Citizens Information Board

SPORTS UPDATE

By COLIN WHITE

It's time to be ACTIVE

The weather is improving and the days are getting longer so the opportunities to shake off the winter cobwebs and perhaps address the 'COVID curves' are becoming more frequent.

Upping your level of physical activity may involve working on waking up a garden after its winter slumber, scheduling regular walks into your weekly diary or re-engaging with your favourite sport(s).

As we all know, but it is no harm reminding ourselves, if you have not being active for some time, make sure you build up your level of exertion in stages. There is nothing more discouraging that re-engaging with regular physical activity and getting overtired or getting an injury.

We also have to remember that we are all getting older so some of our bodies may not be up to the rigours we may have put it through in the past. If you are making a conscious effort to re-introduce regular physical activity into your day or you are looking to up your amount of physical activity, it can always help to have a training

'buddy' as you can motivate each other and celebrate new achievements together.



TENPIN BOWLING

The World Transplant Games Federation has established a Virtual Tenpin Bowling competition that is an opportunity to engage with the wider transplant community internationally.

The rules of tenpin bowling are very straightforward and whilst some will want to compete, the event is open to all to participate.

You can involve your family in the competition too. The flyer below gives all the details.



VIRTUAL TENPIN BOWLING CHALLENGE

You are invited to join the

WORLD TRANSPLANT VIRTUAL TENPIN CHALLENGE

Join your fellow bowlers in this fun and challenging sport, flex your bowling skills for the next Summer Games in Perth 2023, or just get out and have some fun with family and friends.

ABOUT THE CHALLENGE:

- The Challenge will run from 15 March – 15 May 2022
- Open to everyone: Transplant Recipients and all Community Supporters
- \$10 per registration
- Registration stays open for the entire duration of the challenge
- Take part in our fun challenges and win some prizes
- Medal Pins awarded to winners in each category

CATEGORIES:

INDIVIDUAL

- Transplant Recipients – Male & Female
- Transplant Community Supporters – Male & Female
- Age categories will be determined by the number of entries

PAIRS

- Register as a single entry & email WTGF who you are partnering with
- Both partners need to have registered
- All pairs can be mixed (any category, any gender, any age)

HOW TO PARTICIPATE:

- Register for the Challenge [HERE](#) in your category
- Take a picture of yourself playing to submit with your score
- Submit your verified scores online (printed copy or photo of your on-screen score)
- Play as many sessions as you like during the challenge & submit multiple scores
- Your best scores will override all previous scores

SCORING:

- Bi-weekly Leaderboards will be distributed on social media and on the WTGF website
- At the end of the challenge, the highest combined score in one bowling session (3 consecutive scores) in each category is the winner

For more information and to register - visit www.wtgf.org/tenpin

FORMAT:

- The challenge is a **THREE GAMES SERIES** for both individuals and pairs (you must bowl three consecutive games in one session at the same bowling alley) and submit your scores for all 3 games at once

AVERAGES CHALLENGE:

- Submit a minimum of 3 different bowling sessions scores to qualify for this competition
- Each bowling session must still include 3 consecutive scores
- Applicable to individuals only

World Transplant Games Federation

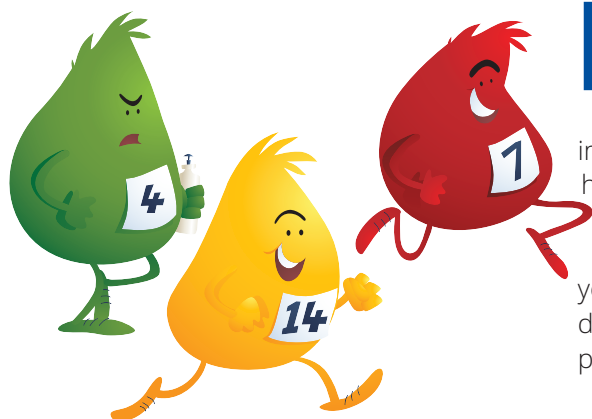
www.wtgf.org/tenpin

WTGF1
worldtransplantgames
worldtransplantgames

LET'S BOWL - EVERY STRIKE IS A VICTORY!

Runforalife

WE ARE VIRTUAL AGAIN FOR 2022!



Between **Saturday, 21st** and **Sunday, 29th May** we invite you to Walk, Jog or Run 2.5km, 5km or 10km in your local area to support the Irish Kidney Association's third virtual Run for a Life.

Raise funds for the Irish Kidney Association and awareness of the importance of organ donation. Challenge yourself and friends, and have fun taking part. As the event will run over eight days you can enter as many times as you like by registering each time!

There's a registration fee (adult €10, child €5, family of 4 €25) and you can select to be included on a leaderboard for your chosen distance via a link you will get when you register. You can also share photos of your endeavours on social media – using **#runforalife**

To order an IKA t-shirt and register visit www.ika.ie/runforalife

The European Championships are held every second year and the World Transplant Games are held in the alternate years.

These are the primary events for our sports programme each year.

The events are one of the key organ donor awareness activities of the Irish Kidney Association (IKA) each year as our involvement on the international stage gives us the opportunity to showcase the importance and success of organ donation for transplantation.

An exciting side of the European Championships is the opportunity for people on dialysis to travel to, and take part in, an international week-long event where haemodialysis is provided by our hosts.

It's an opportunity to be part of a diverse and very positively minded group of people who enjoy sport.

If you are competitive, there will be plenty of competition from the 20+ countries that will be there and if you are more interested in



camaraderie there will be plenty of opportunities for that both within our team and with other teams too.

The ethos of our team has always been one of participating to the best of one's ability. Your finishing position is secondary from the team perspective. Set your own goals, give 100% commitment and the team will support you.

There is a great range of sports from the skill-based ones like darts, tenpin bowling and petanque (French boules) to the more physical ones like badminton, cycling and

swimming.

With competition based on age categories (ten-year-age bands) you will be alongside your peers.

At the time of writing, the Board of the IKA are reviewing the safety of sending a team to the European Championships.

When the IKA re-starts its in-person activities we will be re-starting our open sessions in the ALSAA Sports Complex next to Dublin airport (www.alsaa.ie).

- By COLIN WHITE

If you would like to find out more you can check out:

www.etsdf.org

www.transplantsport.org.uk/european-transplant-and-dialysis-sports-games-2022

www.transplantteamireland.ie

BY GWEN O'DONOGHUE

Mark and Michelle
Moore with sons
Noah and Ollie



Olivia's Hair Studio in Baltinglass, Co Wicklow held a successful organ donor awareness and charity event. It raised over €5,100 for the Irish Kidney Association (IKA), which was thanks to the extraordinary support and generosity of the local community.

Salon proprietor Olivia Donegan and her staff were motivated to provide free hair blow dry services as part of their 'Give All Day' charity last, to demonstrate their support for staff hairdresser Michelle Moore and her husband Mark who is a dialysis patient.

Olivia said, "The staff at Olivia's Hair Studio were delighted with the success of the 'Give All Day' event which we organised to show support for our valued member of staff Michelle Moore and her husband Mark who undergoes dialysis treatment.

"They are a lovely couple with two young sons. We felt that the best way to show our empathy was to do a fundraiser for the IKA, the charity which provides support to patients like Mark who have kidney failure.

"What started out as an idea for an event where our

COMMUNITY
gives all day for
**ORGAN
DONOR**
AWARENESS

staff would donate their services by offering free blow dries for a day, with donations in lieu going to the IKA, grew into something much bigger!

"We were positively overwhelmed with the support and goodwill of the whole community of Baltinglass, including individuals and businesses alike."

Michelle said, "I can't thank my colleagues enough and the whole community for their incredible support. So many people called in on the day to get their hair blow dried and I loved being able to soak up the atmosphere while chatting to punters as they left happy with their crowning glory but not before donating to the cause."

"Mark and I were so uplifted to observe the goodwill and kind heartedness of everyone who came behind what turned out to be a hugely positive and fun event enjoyed by all ages within the community."

"Not only did the event raise funds for charity, the IKA, but it also heightened awareness of why organ donation is so important for people with kidney or other organ failure. Lots of people picked up organ donor cards on the event day which were prominently displayed in the salon, a pharmacy and other local businesses."

Michelle continued, "I was full of pride and gratitude when the team at Olivia's gathered to present Michael Dwyer from the Dublin East/Wicklow branch of the IKA, himself a kidney transplant recipient, with a presentation cheque for a grand total of €5,152.75".

Michelle explained, "My husband Mark was

At the cheque presentation were: (L-R): Rebecca Donegan; Olivia Donegan (salon owner); Michelle Moore; Kayleigh Corcoran; Ciara Lawlor and Bernie Kelly.



diagnosed with polycystic kidney disease when he was 11-years-old. It had been picked up by chance when he was admitted to hospital for something else.

"His late father had been receiving dialysis before he passed away at the young age of 61."

"Mark who is 34-years-old has been undergoing dialysis treatment for over a year. He had been travelling to hospital three times a week for haemodialysis treatment and he found it very difficult, and it left him feeling very tired."

"However, in recent months he has been receiving peritoneal dialysis at home which he undergoes for eight hours throughout the night, every night. This has been working extremely well for him, he has fewer side effects with it, and he was able to return to work in February 2022. His employers, Pfizer, have been very supportive throughout his illness."

He was accepted onto the transplant waiting list in January this year. We remain hopeful that he will receive a call soon which

will pave the way for a better quality of life and renewed health for him so he can enjoy a normal family life with myself and our two children, Ollie who is one and half years-old and Noah who is three and a half".

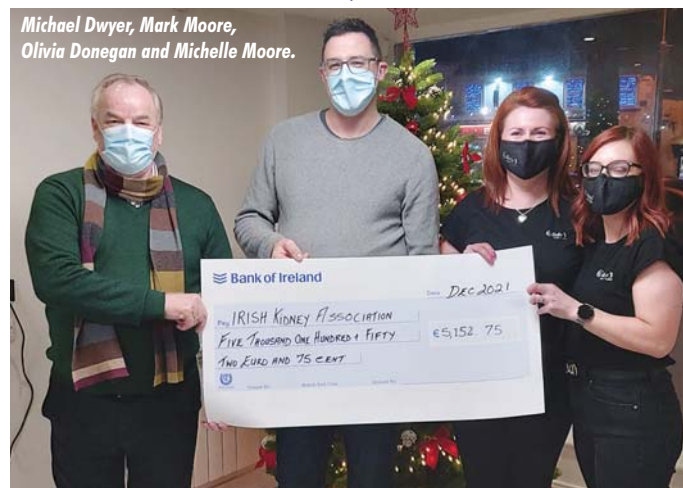
Michelle concluded by acknowledging the huge level of community support for the 'Give All Day' event saying, "I want to thank everyone who helped set-up and plan the day."

"We are truly grateful for the support we received from the community including Armadillo Grind for donating all their takings and bringing their van right to our salon door, Hangry For Hotdogs for their vouchers, The Green

Lemon for their delicious bakes, Bia Blasta for the soup and dinner for the staff, Germaines for cocktails and bar food for the staff on Friday night, Picture Perfect Crafts Ireland for supplying the fabulous balloon arch at our door and sweet packs also, Horans, Pattersons, Baltinglass Credit Union, Baltinglass Pharmacy, Burkes newsagents, and the staff from Quinn's, and not forgetting all the individuals who showed up on the day to support the cause and those who donated generously for their blow dries and other goodies."

"Mark and I feel privileged to be part of such a wonderfully supportive community".

Michael Dwyer, Mark Moore, Olivia Donegan and Michelle Moore.





eat less
SALT!

Kidney Diet Resources Available Online

2021 saw the production of two new information resources, for people affected by chronic kidney disease, on the topics of salt and phosphate.

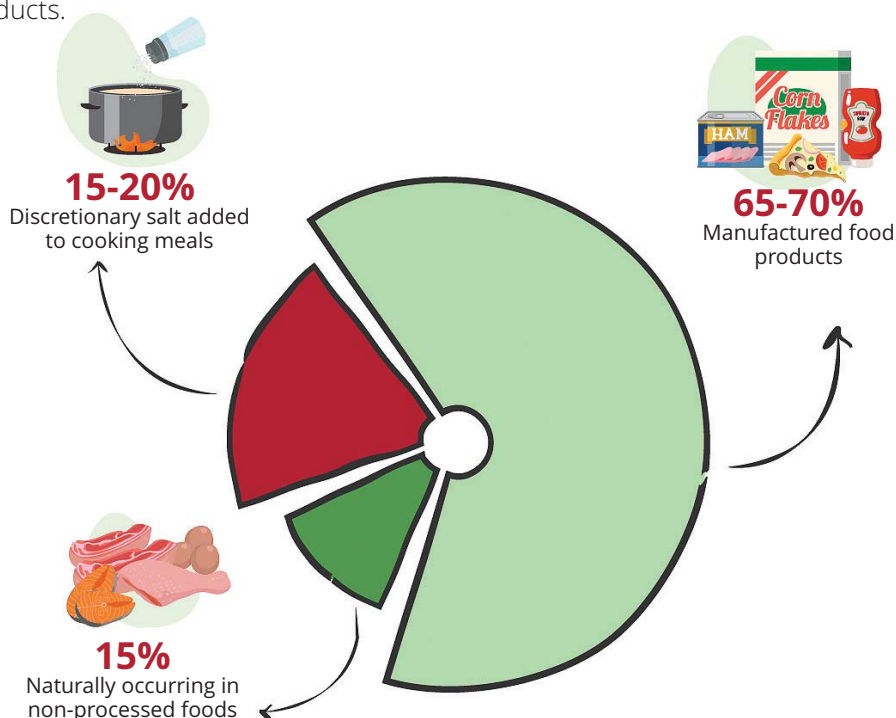
SALT VIDEO

In January 2021 a short animated video on how to follow a reduced salt diet to delay progression of chronic kidney disease was launched. This project was the result of a collaboration between the renal multidisciplinary team in Cork University Hospital, representatives from the Cork branch of the IKA and the Health Innovation Hub Ireland (HIHI).

The video explains how reducing salt intake can help in the management of blood pressure and reduce the amount of protein in the urine. Improving these can help to slow down the progression of chronic kidney disease.

HOW TO REDUCE SALT IN YOUR DIET

The video shows that most of our dietary salt comes from manufactured food products.



By **IRENE CRONIN**
(CLINICAL SPECIALIST RENAL
DIETITIAN)
Cork University Hospital
on behalf of the Renal Interest

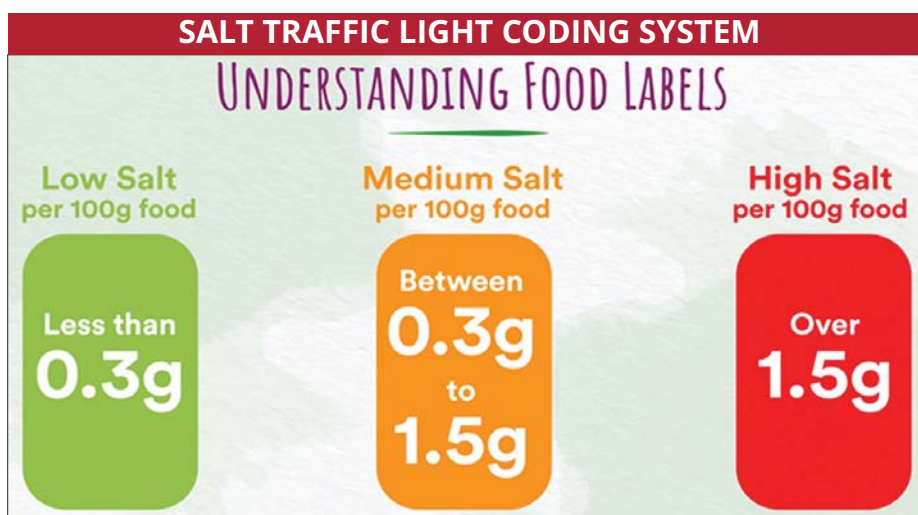
INDI
Irish Nutrition +
Dietetic Institute
Renal

The video also explains how to check a food nutrition label to see if the product is low, medium or high in salt using the **traffic light food coding system**.

So mostly choosing brands with a green or orange circle for salt on the front of the packaging is the best way to reduce the daily intake of salt.

Our IKA representative Sheena McDonagh, was central to ensuring that the information provided was practical and straight forward. Additionally a focus group of IKA Cork branch members reviewed the video and gave valuable feedback.

The salt video was endorsed by the Renal Dietitians Interest Group of the Irish Nutrition and Dietetic Institute (INDI) and is available to view on www.irishkidneydiet.ie and on the IKA website.



It can also be seen on the Cork University Hospital website at <https://slide.incareview.com/salt-intake/> where in addition to the salt video, there is a salt checking app which shows whether commonly

eaten foods are low, medium or high in salt.

While the video was developed for people with early chronic kidney disease, it is helpful for anyone advised to follow a reduced salt diet.

PHOSPHATE [PO₄³⁻] VIDEO

In summer 2021, the CUH renal department, along with the Charity Office in Cork University Hospital, granted funding to the renal dietitians to produce a second video on the topic of **'How to follow a low phosphate diet'**. This was a collaboration between the renal dietitians in CUH, a national team of renal dietitians representing the Renal Interest Group, INDI (including Beaumont Hospital, University of Limerick, Mater Misericordiae University Hospital, Tallaght University Hospital, Beacon Renal Drogheda) and patient representative Frances O'Shea from the IKA Cork Branch.

Once again the IKA was instrumental in supporting the project and ensuring the final product was clear and informative.

A low phosphate diet is recommended in advanced chronic kidney disease when blood phosphate levels are high over several blood results.

The dietary information for the video was taken from the new renal

diet sheet **'Eating Well for your Kidneys'**, launched by the Renal Interest Group, INDI in 2020.

If you are unsure whether you need to follow a low phosphate diet, ask your renal consultant or renal dietitian.

If you have been advised to follow a low phosphate diet, this video outlines the 4 steps to take.

The video focuses on step 3. The food industry commonly uses phosphate additives to improve the texture and appearance of foods. This type of phosphate is easily absorbed into the blood. It is important to check food labels and if the ingredients contain the word phosphate, check different brands and choose the brand that doesn't contain the phosphate additive. Check also for the ingredients lecithin and ribonucleotides which are also phosphate additives.

Some E Numbers are phosphate additives (see list opposite). It is important to avoid products that contain any of these E Numbers.

The video is available to view on the Cork University Hospital YouTube channel

(<https://www.youtube.com/watch?v=qB6O0G66wKI>) or ask your renal dietitian for it. It will soon be available to view on www.irishkidneydiet.ie

Feedback for both videos has been very positive. It is hoped that future funding will result in the production of further education videos on topics which people following a diet for their kidneys or post-kidney transplant identify as being of help.

Further information on a kidney friendly diet can be found on www.irishkidneydiet.ie

PHOSPHATE E NUMBERS

E322	E101(II)
E338-341	E1410
E343	E1412-1414
E450-452	E1442
E442	E541
E626-635	



Family's memories treasured

By
GWEN O'DONOGHUE



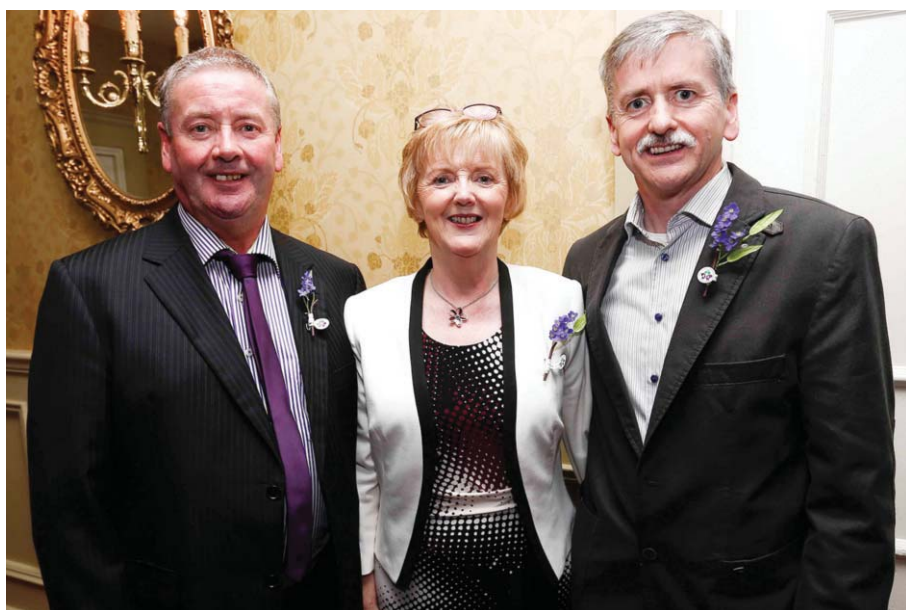
Pauric and Liam Brehon, prior to their transplant operations, make headline news in 1985.



Pauric and Siobhan on their wedding day in 1986.



Siobhan and Pauric at their 35th wedding anniversary celebration in 2021.



Pauric Brehon (Currae, Roscommon), his sister Ann Nolan (Lanesboro, Longford) and kidney donor brother Liam Brehon (Weston, Lucan, Dublin).

It was thirty-eight years ago when two brothers in a large Roscommon family of nine siblings underwent a living donor kidney transplant. Pauric Brehon is still enjoying good health and the successful longevity of the donor kidney he received from his youngest brother Liam who was just 22-years-old at the time. Liam who is now 60-years-old is also in good health.

The family dedicate this article to Pauric's son Cormac who passed away in late 2021 as they treasure one of his notable achievements as a child, a prize-winning essay about his father's health journey!

Pauric and Liam's successful living donor kidney transplant operations took place at the old Jervis Street Hospital in Dublin on July 17th, 1984. This momentous event followed a frustrating delay for the brothers with the temporary closure of the kidney transplant programme.

The two brothers did media interviews, including with RTÉ TV's *Today Tonight*, about the uncertainty of when their transplant operations would proceed. Pauric had previously received two kidney transplants from deceased donors, a year apart, but unfortunately, he suffered rejection with both donor kidneys. This created a high build-up of antibodies greatly reducing the prospect of a successful outcome if another deceased donor kidney was found.

Fortunately, the hiatus was short-lived, the transplant programme resumed paving the way for the Brehon brothers' living donor kidney transplant to proceed.

Pauric, the second youngest in the family of eight surviving brothers and one sister, had been diagnosed with kidney disease when he was 15-years-old. His condition quickly progressed to end stage kidney failure.

Following two unsuccessful kidney transplants from deceased donors, his youngest brother Liam came to the rescue. While Pauric's other siblings were disappointed that they were not suitable kidney donors for their ailing brother, Liam was waiting in the wings until he came of age and was deemed to be a perfect match.

Their sister Ann Nolan, a nurse with GP service Midoc, who is living in Lanesborough, County Longford with her husband Paddy, recounts the impact of Pauric's health journey on the family including his late son Cormac.

Ann remembers her brother Pauric's health struggles and his joy when he married his childhood sweetheart Siobhan Cattigan in

1986, two years post-transplant.

Well before they wed in the early eighties, the couple's desire to support other patients in kidney failure drove them to helping establish the Roscommon branch of the Irish Kidney Association.

They welcomed their son Cormac into the world in 1991. Ann describes her late nephew Cormac as being 'a miracle baby' due to the many years his parents longed for his arrival.

Four years after coming to the rescue of his brother, kidney donor Liam married Peig Donnelly, also from Roscommon, in 1989. Since then, they have lived in Dublin. They were blessed with one son, Niall, who is now 30.

Cormac was to be Siobhan and Pauric's only child, but tragedy visited last year when he passed away suddenly at the young age of 29.

While heartbroken, his parents treasure the memories of Cormac's childhood including him winning a prize for his written account of his father's struggle with kidney disease and the joy of his successful transplant.

Ann describes how Cormac's parents were bursting with pride when, at the age of eleven and in 5th class, they travelled with him to Boyle, in Roscommon to witness Cormac receive his accolade for winning the 'Junior Writer of the Year' title by the *Roscommon Herald*.

His winning essay 'Your Health Is Your Wealth' was written by Cormac while in the classroom, without any coaching from his family, as he wrote about what he had heard about the trials and tribulations of his father's kidney failure journey. It demonstrated that despite his young years, Cormac was a good listener and had a deep awareness and understanding of the impact of kidney and organ failure.

His empathy shone through in his essay as he remembered the two deceased donors who "had to lose their lives in order to donate their kidneys. Also, no money could compensate their families for their loss".

In his writing he displayed a deep sense of gratitude for his father's 'gift a life' and also a sense of humour as his essay concluded "My Dad's Health is my Wealth because only for my uncle I may not have been born and what a sorry place the world would be without me. The moral of the story is Health really is ones Wealth".

You can read Cormac's unedited story here.



The late Cormac Brehon, RIP



Cormac with his award for 'Junior Writer of the Year'

HEALTH IS WEALTH

This is a true story

By CORMAC BREHON

When my father was born, he was the second youngest of seven brothers (one who died around three months after he was born) and one sister. He went to Curraghroe N.S. which is closed down now. He played in backs for the school team. He went to secondary school in Lanesboro, but he got very sick. His brother told his teachers he was very sick. He had kidney problems.

His friends knew he would not be coming back to school after visiting several times and the teachers, staff and Principal knew it as well. After a few years he was back on his feet. But his problems weren't over yet. Dad started to get worse but this time it was a lot worse than before, almost fatal. His kidneys got worse. He spent some weeks in hospital in Dublin. The doctors explained to him and Beatrice and Pat, his parents, what lay ahead for dad. They told him that his kidneys no longer functioned properly, and he would have to go on dialysis three times weekly to cleanse out his blood.

This meant he had to travel to Dublin three times weekly just to keep his body alive. After some time, he was put on a transplant waiting list. So, he had to be patient and wait for the call. This came unexpectedly in the middle of the night in March 1980 when Gardai called to the house and said a kidney was available in Jervis St Hospital and to get there as soon as possible, which he did, but alas it was not to be. Dad rejected the kidney after two weeks, so it was back to dialysis again. Life carried on until July 1982 and Dad got the call again. But as before Dad rejected the kidney again. Things were not looking good for Dad. His family had all been tested to see if they were suitable to donate a kidney, but the news was not good on that front. His youngest brother had not been tested but he decided nothing ventured nothing gained. His brother's test proved that he was an identical match for Dad. It was up to his brother to decide whether or not to donate the kidney as there is a risk to every operation, but his brother decided he could give Dad the 'gift of life'.

Dad and his brother appeared on Today Tonight to highlight the problems of kidney patients. The operation went ahead, and all was successful and eighteen years down the line I am here to tell Dad's story. My Dad is very grateful to the first two donors who had to lose their lives in order to donate their kidneys. Also, no money could compensate their families for their loss.

As my Dad says, if I won the Lotto in the morning My Health is still my Wealth. My Dad's Health is my Wealth because only for my uncle I may not have been born and what a sorry place the world would be without me.

The moral of the story is Health really is ones Wealth.



Kerry IKA volunteers Brendan Herbert (left) and Elsie Moore (right) at the Tralee holiday home welcoming Killaloe family Nuala Conway and Denis Costello and their children Jayden (13) a dialysis patient, and twins Denis and Isabella (4).

By DEBORAH CERVI, Holiday Co-ordinator

Holiday Homes

Spring has arrived and the good news is the holiday season is upon us once again. Several families enjoyed our holiday homes in Tralee and Killarney which remained open throughout the winter. Our local volunteers in Kerry and Waterford are looking forward to welcoming more people to the centres in the months ahead as holiday bookings at the Tramore centre re-commence on April 30th.

We will operate these locations again this year on a 5-night basis (Saturday to Thursday) to implement cleaning and comply with COVID-19 guidelines in our holiday homes. We will continue to monitor all developments relating to COVID-19 and remain committed to ensuring a safe environment for guests.

Whilst COVID-19 guidelines have relaxed, we ask you to continue to comply with public health advice to protect yourself and the medically vulnerable and to maintain social distancing and hand sanitation guidelines.

Priority will be given to first-time holiday applicants and to families

with schoolgoing children during Summer school holidays.

The holiday application forms are available on our website at www.ika.ie under 'Our Services' then click on 'patient holidays'. <https://ika.ie/patient-holidays/> also your local Branch Secretary, your PD Unit and social worker also have form. Alternatively, you can contact me by email at deborah@ika.ie

HOLIDAYS ABROAD

If you are thinking of a holiday abroad, your first port of call should be either to contact a member of staff in your dialysis unit or you can contact me directly at Donor House. Please **DO NOT** book your holiday until you are sure that we will be able to access haemodialysis in your chosen location.

Dialysis units abroad require as

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

Any patients, who would like advice or assistance in organising holiday dialysis abroad, can contact me at Donor House on 01-6205306.

Stay safe and take care.

Deborah





By GWEN O'DONOGHUE

The Irish Kidney Association's holiday homes in Tralee and Killarney, which are available free of charge to kidney patients and their families, opened throughout winter including Christmas. All credit is due to our volunteers from the Kerry branch of the Irish Kidney Association for managing the properties, ensuring the houses are fully cleaned and sanitised on each changeover and that families receive a warm friendly welcome.

A family from Killaloe in Co Clare were delighted to be able to avail of a Christmas break away to Tralee with their 13-year-old dialysis son and 4-year-old twin siblings.

Teenager Jayden has a rare form of Nephrotic Syndrome. He has had eleven operations in his lifetime including open heart surgery as a baby. He has been in and out of hospital for most of his life and for years twice weekly visits to Limerick hospital while also travelling up and down to Our Lady's Hospital for Sick Children in Crumlin from time to time.

He had one of his kidneys removed in 2017 which for about a year and a half saw his health improve but it went downhill again and eventually he commenced peritoneal dialysis. In February this year he had his second kidney removed and suffered complications which required a month-long hospital stay before being allowed to return home. He continues his peritoneal dialysis which he now undergoes for eleven hours at a time, seven nights a week.

Two of Jayden's uncles (Nuala's brothers) were ruled out for living donation during the screening process, and for one of the men it was revealed he had early stage kidney disease which he was unaware of. The family see it as a blessing that through screening for living donation, his kidney disease was detected and can now be managed. Jayden's step father Denis is currently going through the screening process for living donation and the family is hoping for positive news back from Beaumont Hospital about this soon.

Jayden's mum Nuala Conway said that: "most of the time Jayden sees the bright side in everything and that he is a great child". She said they were delighted to be able to avail of a holiday away in the beautiful spacious Tralee holiday home all decked out with Christmas decorations. Nuala also said that it was lovely to receive a warm welcome from IKA volunteers Brendan Herbert and Elsie Moore.

BRAVEMAN

Ben Kelly

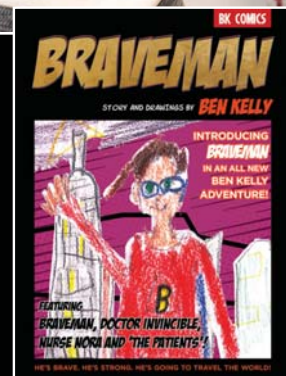


Braveman, the first comic book by young Wexford author and renal dialysis patient Ben Kelly, was officially launched at B. Braun Wellstone Wexford Renal Care Centre last November. Featuring characters such as Doctor Invincible, Nurse Nora and The Patients, *Braveman* was created by Ben through the Waterford Healing Arts Trust (WHAT) Arts Programme in Renal Dialysis at University Hospital Waterford and supported by staff at the B. Braun Wellstone Wexford Renal Care Centre.

The idea for the comic book was encouraged by Philip Cullen at WHAT to give Ben, a huge Marvel fan, a voice through his comic as he underwent the transition from Temple Street Hospital, where he had been a long-time patient, to adult dialysis services.

With Ben's vivid imagination and mischievous sense of humour, in *Braveman* he has created a superhero who is both inspirational and entertaining, while offering the reader a rare glimpse into the challenges and camaraderie of life on dialysis.

To request a copy of *Braveman* you can contact Waterford Healing Arts Trust (051) 842664 or what@hse.ie



Offaly family counts its blessings

By GWEN O'DONOGHUE



Phil and Jerome Molloy with baby Saoirse Cordial

Three sisters from County Offaly with a hereditary kidney condition called Polycystic Kidney Disease (PKD) are enjoying the benefit of successful transplantation thanks to the gift of organ donation. One of the three sisters has undergone two kidney transplants. Two of their cousins are also enjoying renewed health as a result of their successful transplants.

The families acknowledge that this would not be possible but for the selfless decision of six families who, at a time of grief, donated their loved one's organs.

Phil Molloy (65), from Kinnitty, said she was given a lifeline in August 2020, during COVID-19, when she received a call from Beaumont Hospital in the middle of the night to undergo a kidney transplant following three and half years of dialysis treatment. Exactly a year to the day later, there was cause for more celebration for Phil and her husband Jerome when, they became grandparents for the first time to baby Saoirse Cordial.

Phil managed to stave off dialysis treatment until five years ago. It was not long after her sister, Josie McGill (who lives in Laois) came off dialysis at the Midlands Regional Hospital in Tullamore after being called for a successful transplant, that Phil commenced her dialysis treatment there. Their sister Brigid Flaherty has undergone two transplants, one which lasted ten years and the second eleven years ago which is still going strong.

Sadly, in December 2020, Phil's other sister Mary Murphy passed away just over two years after her other sister Veronica Harrington passed away. They were predeceased by their sister Madge who was a dialysis patient and passed away ten years ago.

Phil, a native of Clareen, was born into a family of 12 children including 5 boys and 7 girls. She explained six of the siblings, the girls only, were blighted with the hereditary kidney condition, Polycystic Kidney Disease (PKD). Phil's youngest sister Bernie Carroll (from Kinnitty) was fortunate not to have PKD which is a disease which causes numerous cysts to grow on the kidneys causing damage to kidney function which can lead to kidney failure.

Phil described how when her brothers and sisters were children, the hereditary condition wasn't known. Her father John Murphy passed away at the young age of 43, following years of suffering with kidney failure. Phil's parents had her christened 'Philomena', after the name of the hospital ward, St. Philomena's, where her father spent a lot of time as a patient.

Phil's cousins, Michael Coughlan, who is a neighbour of Phil's (in Kinnitty), and his brother Christy Coughlan who lives in Clareen, are enjoying good health following their kidney transplants.

Phil described the transformational effects of her transplant and counts her blessings. She said, "Just before my transplant I really believed I was at 'death's door'. I had no energy left in me and I felt unwell all the time. The tiredness was crippling. My kidney donor has given me a lifeline and I can't begin to explain the difference to how I feel now compared to when I was on dialysis waiting for a transplant.

"The staff at Tullamore hospital were great. I received great care from the nursing and medical staff including my consultant Dr Bergin who helped me manage my condition and slow down the progression of my kidney failure for as long as possible.

"The transplant has changed me for the better in so many ways, both in my physical health and mentally. I now embrace my new lease of life and because of it I can play an active part in my granddaughter Saoirse's life.

"While many of my extended family have been blighted with PKD I thank my blessings that both of my daughters, Pamela and Mary, do not have the disease.

"Sadly, some members of our family have passed away due to complications around the disease while others have lost their battles to cancer. However, our whole 'extended' family will always be grateful to the organ donors who have given so many of us a second chance to enjoy extended life through kidney transplantation."



Sisters Bernie, Brigid, Phil and Josie

The transplant has changed me for the better in so many ways, both in my physical health and mentally.



SUPPORT THE WORK OF THE IKA

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STANDING ORDER REQUEST FORM

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I/We hereby authorise you to set up a Standing Order on my/our account as specified below: *(Please print all information clearly)*

Signed: _____ Date: _____

Address: _____ Ph: _____

PLEASE CHARGE TO MY / OUR ACCOUNT: Name of Account: _____

IBAN: Bank Identifier Code - BIC:

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

My regular ☐ Monthly ☐ Quarterly ☐ Yearly DONATION of Amount € _____

(Please tick as appropriate)

to start on Date: ____ / ____ / ____

AND CREDIT TO THE FOLLOWING ACCOUNT:

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

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

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



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

THANK YOU FOR YOUR GENEROSITY

Long and winding road

You've heard it said before that
"Life can turn on a dime".
And so it did for us one day
in February 2012.

The writer and her family wish to remain anonymous. Names and some details have been changed. The same writer's story, 'It Happened One Night', appeared in the winter 2021 issue of SUPPORT.

It was lashing rain in Dublin City Centre when Patrick picked me up from work. The Dublin International Film Festival was on and we had booked into Cineworld to see an Irish film about three brothers who drive across Ireland in search of their dying father's watch.

As we drove around Parnell Square looking for a parking spot, I asked him how his doctor's appointment had gone. He casually mentioned that he had been diagnosed with End Stage Kidney Disease. Preoccupied with getting to the cinema on time, it did not register with me immediately, although I did pick up on the words 'End Stage'.

As we finally settled into our seats in the cinema, I asked him "What does 'End Stage' mean exactly? In hushed tones he tells me his

creatinine levels which had been slightly above normal over the past couple of years had increased dramatically since he was last tested, two months prior, and he would have to start dialysis immediately. From his tone, I could tell that he himself was finding it hard to comprehend this diagnosis.

By this point, the film had started and I would spend the next 90 minutes pondering what this 'out of the blue' diagnosis actually meant.

By the end of the film, I still had not processed the seriousness of what he was telling me. It's almost like I couldn't bring myself to believe that whatever he had was that bad and that he would have to start dialysis 'immediately'.

This was unfamiliar territory to me. End Stage Kidney Disease and dialysis! I remember the woman next door to where I grew up had to

go into hospital three times a week for dialysis to get her blood cleaned somehow. That's how my mother explained it to me back then. And to be perfectly honest, I didn't really want to know. It was a time before the great leaps in modern medicine that we now know and take for granted.

So, first thing the following week Patrick went into James' Hospital for some preliminary tests. My son Jake and I accompanied him in the hopes we would get to talk to the Consultant about what this was all about. A diagnosis was all we had at this point and we wanted more information.

'Rocking up to the hospital and expecting we could just speak to the Nephrologist Consultant was not how it works', we were soon told in no uncertain terms. However, we were not going to leave without some answers. So we did manage to ambush the Consultant on his rounds and get some answers.

Yes, I'll admit it was a bit obnoxious, but there was no alternative meeting suggested to meet with Patrick and his family to explain what lay ahead for Patrick. We were a family in shock relying on Dr. Google – not the best source of information when you don't even know what questions to ask.

When the ambushed Consultant saw how confused and anxious we all were, he was very gracious and answered all our questions matter-of-factly. No bullshit.

Jake asked our prepared questions as I scribbled the answers and a perplexed Patrick listened quietly.

Jake: How exactly did Patrick get this kidney disease? What caused it?

Consultant: IgA Nephropathy.

Jake: What does that mean exactly?

Consultant: IgA Nephropathy is a disease that occurs when an antibody called immunoglobulin A (IgA) builds up in your kidneys. It usually progresses slowly over many years, but the course of the disease can vary from person to person. In

Patrick's case, it progressed quite quickly – his creatine levels increased dramatically in two months from 200 to over 1000. Patrick's kidneys were now inflamed. His kidneys were close to not functioning at all in a matter of days.

Jake: So, what caused it to progress so quickly? He's been very healthy up to now.

Consultant: (shrugs). We don't know. Genes, a previous infection. We just don't know.

Jake: Is there a treatment?

Consultant: Yes. The only treatment for end-stage kidney failure is a kidney transplant. Which means getting on the Transplant List and waiting for a suitable match.

Jake: So what's he to do while he waits?

Consultant: He really only has one choice. Dialysis. Or die.

Jake: Can one of us donate a kidney right now?

Consultant: Well not right now. But theoretically, yes, you are all potential donors. There is a whole screening process. Something to be discussed once he gets on the Transplant List. Meanwhile he has to start dialysis.

Jake: How often is dialysis?

Consultant: Depends on which route he decides to take. There's peritoneal dialysis or haemodialysis.

Jake: What's the difference?

Consultant: Peritoneal dialysis is performed at home by the patient, typically 4 times a day. Haemodialysis is performed in-clinic typically 3 times a week.

Jake: How long can patients survive on dialysis?

Consultant: Like everything kidney disease-related, it can vary. But your father will hopefully get on the Transplant List. It may take a couple of years, but it will happen.

Jake: What are the side effects of dialysis?

Consultant: Fatigue mainly, but also the patient can no longer pass urine normally.

Jake: Anything else we should know now?

Consultant: Yes, Patrick will have to adhere to a very strict diet, no food with salt, avoid potassium which means no potatoes unless you boil them three times.

Look, I know it's a lot of information to take in. Go home. There are more tests to do. We are on it.

There were a few more questions

related to matching kidney donors, blood types, and living versus deceased donors. We thanked the Consultant and apologised for our intrusion into his rounds. But now we knew a bit more about what lay ahead for Patrick. And, naturally, we had all come away from that meeting with one thing on our minds. And that was the the best possible outcome which was to get a transplant. The possibility of getting a transplant. Would Patrick qualify? He was 58. He would undergo a lot of tests to prove he was a strong enough candidate to go on the Transplant List.

Fair play to the Consultant – he expedited all the required tests, as there were many that had to pass muster with the Beaumont Transplant Team. Getting on the Transplant List was not a given and would not be decided overnight.

The very next week Patrick started on dialysis. Initially he took the peritoneal dialysis route.

A tube (catheter) was surgically inserted into his abdomen where the lining of his abdomen (called the peritoneum), acts as a filter and removes waste products from his blood. After a short period of time, the fluid with the filtered waste products flows out of his abdomen and is discarded.

The peritoneal nurses were absolutely amazing...angels from on high...providing guidance every step of the way. Pretty straight-forward process when he got the hang of it. And being able to do this from the comfort of home allowed a more normal lifestyle, more flexibility, and more independence for Patrick. We called it *'the new normal'*. And it did work wonderfully for several weeks.

TWO MONTHS LATER

Unfortunately, it didn't work for Patrick in the end. An infection in the incision point, necessitated very strong antibiotics and this time a day surgery operation to insert another catheter. And then another. Three infections altogether, the last one was so bad, I had to rush him to A&E where he waited on a trolley overnight in a hospital corridor of bright lights, banging doors, and constant echoing noises until a bed was found for him the next day.

Only when you actually witness what it's like to see a helpless loved

one on a trolley in such circumstances, do you realise how spirit crushing this experience is for any ill patient and you wonder what war zone you are living in.

But that's a story for another day.

Only that the A&E nurses are so caring and doing everything in their power to make the best of a very bad situation, is one able to maintain a modicum of faith, not in the system, but in the staff who deal with the onslaught day after day.

Despite best efforts, it was decided that after three unsuccessful surgeries and as many infections, Patrick would need to switch to haemodialysis.

It was a bit of a transition to this type of dialysis because he now had to get himself to Beacon Renal Sandyford three times a week, each session three and a half hours.

Hitched up to a haemodialysis machine, blood is slowly pumped and sent through what's called a dialyser which works like a kidney and filters out waste and fluid. The cleaned blood is sent back through a second needle in the arm.

Another period of adjustment. Another *'new normal'*.

But then in August, five months after the initial diagnosis, we were called into Beaumont to meet with the Transplant Coordinators and the legendary Dr. David Hickey, regarding Patrick's bid to be put on the Transplant list.

Fingers and toes all crossed. Patrick had indeed been approved for a transplant. This was a very happy moment for us because now there was a light at the end of the tunnel. And even more optimistically, we were told he would probably have a transplant in 2 to 3 years, from a deceased donor, based on his blood type.

We turned to each other and agreed, yes, he can do that. 2-3 years is not so long.

He had just begun haemodialysis and although it was not exactly fun, it was keeping him alive. Yes, 2-3 years is not so long. And sure, a living donor was still a possibility.

Less than a month after he started the haemodialysis Patrick began to experience a loss of balance 'out of the blue'.

Severe vertigo that didn't seem to want to go away. He couldn't walk without clinging to me or a wall.

He was now dependent on taxis to get him to and from the dialysis clinic.

Added to the stress of vertigo, our son's wedding had been planned and booked long before the CKD diagnosis for a month later. And to make it more challenging for Patrick, it was a destination wedding in America. Of course, Patrick wanted to attend his son's wedding.

Patrick was still getting used to the haemodialysis on home turf so the idea of finding a dialysis centre Stateside was a huge concern. Plus, the vertigo was really putting him off getting on an aeroplane for seven hours.

But that's where the Irish Kidney Association came to the rescue. Their holiday coordinator Deborah organised a dialysis centre within striking distance of the wedding festivities.

Medication alleviated some of the vertigo effects and Patrick was able to deliver a witty and memorable toast to the bride and groom and even managed a dance or two with me at the wedding reception (albeit I was leading and holding him up).

Attending the wedding proved a turning point for Patrick in this, so far, tumultuous year. He realised that he could work around dialysis to pursue normal activities.

Meanwhile, several family members had come forward as possible donors.

God bless them all. But none were deemed suitable donor candidates due to minor but evidently significant health issues as well as geography (some reside in the USA).

Then there's me. I was in very good health and the Transplant Coordinators went to bat for me, but I was rejected due to a history of kidney stones, not being a blood relative, and age. So, back to square one, Patrick would just have to wait for an anonymous 'deceased donation'.

THE 'NEW NORMAL' (YEARS 2 - 5)

The first year was tough alright. But the 'new normal' had become an acceptable routine such that Patrick applied and was accepted into a third level course in Film Studies as a mature student. Due to his 3-day

dialysis schedule, the university kindly gave him some leeway in not attending lectures that took place on Tuesdays.

Patrick thrived and became a student leader, actively collaborating on scripts and class productions, and delivering a 100-page Thesis to receive a Master's degree.

The lectures and assignments definitely distracted him from the dialysis routine, and kept him busy and engaged in a satisfying way.

During this stretch, we were blessed with the birth of first one granddaughter, and then another a year later. We became those annoying grandparents who think their grandchildren are the smartest, loveliest human beings to have ever graced this planet.

But I'll tell you, it definitely brightens up Patrick's life. He is crazy about these two kids. And they fill both our lives with joy and wonderment.

As I watch Patrick get himself to dialysis three mornings a week, I wonder when his number will come up.

I monitored the transplant statistics reported in the IKA magazine and note the downward trend in yearly transplants from 2012-2015. I learn that one issue is a shortage of transplant surgeons.

I was discouraged. I wrote letters to various TDs and Ministers urging them to allocate more funding in order to recruit suitably qualified kidney transplant surgeons in order to return to 2011 levels.

They get it. The cost of keeping each transplant candidate on dialysis is upwards of €70,000 per annum versus the cost of the once-off transplant operation.

The situation greatly improved, and there was something very consoling when you review the statistics and see how many transplant candidates received the 'gift of life' in a given year. Each transplant makes you feel hopeful that your loved one has moved up a notch on the list.

YEAR 6 - PATIENCE IS MORE THAN A VIRTUE

Patience is not the ability to wait, but the ability to keep a good attitude while waiting.

– Joyce Meyer

By then it seemed like we had been waiting for the call for centuries.

We kept the mobiles handy and on loud wherever we went, except when we went to the cinema or theatre. In those situations, we did turn the phones off but advised our son exactly where we were sitting in case 'the call' came through to him (he's one of the contacts we had given the Transplant Coordinator in case she can't reach either of us).

I made one more pitch to the Transplant Coordinator to be re-considered as a donor. I submitted my latest blood tests, as well as a recent screening record to support my request. She made the case for me to the Transplant Team, but again it was rejected.

We'd just have to wait...They promised that the call would come.

And then it finally did come. On the October Bank Holiday weekend in 2017, we got the call in the middle of the night. Our son who had been on call to drive us to Beaumont happened to be away that weekend. So we called a taxi and arrive at Beaumont only to find the front doors locked.

We headed to Beaumont A&E who directed us to Damien's Ward and the waiting nurse placed Patrick in one of those curtained cubicles. Many tests and interviews with various personnel took place. We were so excited. Patrick's day had finally come. And then around 8:30 in the morning, one of the Transplant Surgeons came in. He was about to burst our bubble. I could see the genuine sorrow on his face as he delivered the news. The deceased donor's kidney was not as healthy as anticipated. He kindly explained that it wouldn't be worth putting Patrick through this operation only for the kidney to be rejected in the very short-term.

Despite our disappointment, the Consultant promised us that it wouldn't be long now, that Patrick was up there on the list. This gave us great comfort and we left Beaumont, not dejected, but quietly optimistic. We considered it a dry run for when 'the call' would come.

It wasn't too long after when Patrick did get that life-giving call.

It happened one night...in March 2018.



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



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DUBLIN WOMAN RUNS MARATHON

A Dublin woman ran a marathon in Leitrim raising €2,771.21 for Sligo IKA. It sounds like a tale of three counties. But in fact it is the story of a woman's fond memory of a deceased friend and her determination to fundraise for a cause that her late friend held in esteem.

Kinlough native Grainne Kelly passed away suddenly in Sligo University Hospital on January 5th last year. The North Leitrim woman was a kidney dialysis patient and had been on the transplant list for a number of years.

Her close friend, Dublin woman Cassandra Connolly, was greatly saddened at Grainne's sudden death.

The Tallaght resident said: "I had never lost someone I was so close to and I didn't know how to deal with that". She said Grainne always spoke



SLIGO

By **BRIAN McHUGH**



Cassandra Connolly presents a cheque for €2,771.21 to Branch Chairman Sean Fowley (left) and Branch PRO Brian McHugh.

very highly of the Irish Kidney Association for everything they did for her during her treatment.

This prompted Cassandra to bravely decide to run her first marathon, in memory of her friend, and raise funds for the IKA.

In early January of this year Cassandra presented a cheque for €2,771.21 to the IKA Sligo Branch – the proceeds from the run.

While organising the marathon, Cassandra set up a GoFundMe page. Commenting on the page she said: "Running a marathon will be nothing compared to the struggles she had with her health.

"I wanted to do something that would be mentally and physically gruelling because the pain of running this marathon could never come close to what Grainne went through.

"Grainne was never one to complain much to others, and was such a special and amazing person".

On Saturday September 25th she donned her running shoes and embarked on her marathon to remember her friend in a special

way. She had never run a marathon before and only took up running the previous Christmas. Her friend Stephen Martin ran it with her and helped her get through it.

Grainne said: "We started at Grainne's house in Kinlough and covered 42.3kms over Leitrim, Sligo and Donegal, taking in the

cliffs of Mullaghmore around the halfway point and then back to the starting point".

Speaking at the cheque presentation IKA Sligo Branch Chairman Sean Fowley thanked Cassandra for her determination in running the marathon in memory of Grainne and for her donation to the Branch.

IKA Board member Marie Fowley said: "We are impressed with your understanding of the incredible difficult journey of dialysis patients".

THANKS TO ARROTEK

The final function for our Branch last year, just before Christmas, was a pleasant one – the presentation of a cheque for €1,000 from Arrotek Medical Limited.

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

BOOK DONATION GOING TO IKA

The publishers of a Sligo book, currently available in local bookshops, will make a donation from sales to the IKA.

The book, entitled *The Best of the Sligo Weekender*, consists of stories about Sligo people that were published in the *Sligo Weekender* newspaper last year.

The paper is making the donation to our Sligo branch in memory of the late Tara McHugh who passed away in June last year, aged 39.



PRIZES FOR ALL!

There was 'one for everyone in the audience' as our Branch held free Christmas draws for dialysis patients in Sligo University Hospital.

Every patient got a prize and there was also a draw for the staff who go above and beyond the call of duty for those they care for.

A total of 12 hampers and 12 turkeys along with several other prizes were presented to the winners during the five draws held in the dialysis unit by our Branch members.

Thanks to Cosgroves Centra, Maugheraboy, for supporting the draw for the hampers and turkeys.

Thanks also to our neighbouring Leitrim IKA branch for their contribution to the draw and to the nursing staff for their assistance.

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

FAMILY TAKE TO THE SKIES

Members of a Sligo family are planning to take to the skies to raise funds for the Sligo Branch of the IKA and North West Hospice.

Collooney natives Nikita, Ian, Chris and Katelyn White have organised a charity skydive for the two local organisations.

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

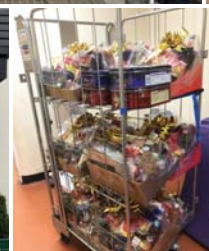
The skydive was due to take place in January but had to be postponed due to thick cloud. It was once again postponed in March due to one of the trio catching COVID-19. At the time of going to press the rescheduled date for the skydive has yet to be confirmed.

All donations will be split 50/50 between the Sligo Branch and the North West Hospice.

Nikita White said: "It is hard to put into words what both of these charities have done, not only for us but for several other families in Ireland at some point".

And she urged everyone to carry an organ donor card.

The family members have set up a



GoFundMe page ahead of their skydive.

PARKING ISSUES IMPROVED

In the winter issue of *SUPPORT* magazine we reported on a number of parking issues that we had taken up with Sligo University Hospital management on behalf of patients.

These problems have since been addressed. A parking control barrier, at the entrance to the renal unit, that had been out of action for some months, has been replaced.

And a shuttle bus service operating between the main carpark and the hospital entrance has made life easier for all attending the facility.

COVER YOUR FLOOR FOR IKA

Excellent value is promised at a fundraising carpet sale and floor coverings in aid of the IKA Sligo branch.

The sale, being organised in conjunction with a local carpet store, will be held on April 9th and 10th at the former Davey's filling station on Lower Pearse Road.

Final details are being worked out at time of going to press. Keep an eye on our Facebook and Twitter pages as well as local media for updates.

PLANS FOR NEW UNIT

Our branch is awaiting a reply from the Minister for Health Stephen Donnelly to a request for an update on plans for a new renal dialysis unit at Sligo University Hospital.

We had a number of communications from the Minister and the HSE last year confirming that plans are at an early stage.

Hospital management and a

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

We sought an update on the progression of plans last month. We have also arranged for a question on the update to be tabled at this month's Regional Health Forum meeting in Galway.

Meanwhile, the number of patients requiring dialysis at the current inadequate unit is increasing weekly.

ORGAN DONOR AWARENESS WEEK

At time of going to press the Sligo Branch is working on plans to mark Organ Donor Awareness Week which runs from April 23rd to 30th.

In the run-up to the week we would be delighted to hear from patients or their families of any impactful renal health stories to share as part of the campaign to increase organ donor awareness. Obviously, we will never share any of your details or your story without your permission.

If you have a positive kidney health story to tell please contact myself, Brian McHugh (PRO) at brianmchugh100@gmail.com or any of our branch members.

For updates on activities during Organ Donor Awareness Week see our Sligo IKA Facebook and Twitter pages and also local media.

SYMPATHY

Sympathy is extended to Bernadette Melly and the Melly family on the death of her sister-in-law Joan Gibney Melly of Ballina and late of Convent Rd., Claremorris.



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On behalf of the branch, we wish 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 2022. We look forward to moving on from all things COVID!

Although our in-person meetings have not yet resumed, our support is always available, so feel free to Call or Text 087-6243367/087-9392148; Email: ikaclare@gmail.com, or message us on the Clare IKA Facebook page.

CONGRATULATIONS

Congratulations to Clare branch member Aisling McCormack and her husband Mark on the birth of their little girl Sophie.

FUNDRAISER

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 times.

We thank Alan O'Reilly and the O'Reilly family, of Killaloe, who organised a fundraiser for the Clare branch, in memory of their much loved family member Aisling O'Reilly. The late Aisling, who passed away in December 2020, was a highly regarded member of the Clare branch who, over the years volunteered for many of our organ donor awareness campaigns and fundraising activities. This fundraiser was held at Queally's SuperValu

CLARE

By NORETTA CLIFFORD

store in Killaloe and raised a massive €1,560. We are thankful to everyone who contributed so generously to the Association.

SYMPATHIES

We extend our sympathy to the families of the late Joseph McCarthy, Shannon, and John Hassett, Quin, who passed away recently. Both Joseph and John were members of the Clare branch and volunteered for many of our branch activities over the years. We also extend our sympathy to branch members Joe and Geraldine Grace on the death of Geraldine's mother, the late Delia Murphy, and to Vincent and Ann O'Halloran on the passing of Vincent's brother, the late PJ O'Halloran. May their gentle souls Rest In Peace.

HOLIDAY HOME

With the IKA self-catering accommodation in Killarney, Kerry open for the Winter 2021/2022 season (December 21-April 22), for peritoneal dialysis (PD) and kidney transplant recipients (TX), we were delighted to hear that many of you have availed of these facilities during COVID and whilst there they got to enjoy the delights and pleasures Killarney and Tralee had to offer. We encourage many more Clare IKA patients to book your stay in Killarney or Tralee or indeed Tramore, Co Waterford. Contact Deborah at Donor House on 01-6205306; Email Deborah@ika.ie or apply through the IKA website link on <https://ika.ie/holiday-application/>

Well done to both the Kerry and Waterford branches for the tremendous work they have done with keeping the holidays facilities open during COVID. Your work is truly appreciated by the holiday makers.

ORGAN DONOR AWARENESS WEEK

Organ Donor Awareness Week takes place this year from 23-30th April. We are always on the lookout for new volunteers to ensure safe and enjoyable events or tell their kidney journey stories in local media etc. Therefore we appeal to our

members, their families and friends, to help out and promote organ donor awareness during this week. If there is an opportunity in your workplace or local shops and schools to promote organ donor awareness, then this would be greatly appreciated.

The campaign highlights the need for organ donation and encourages people to 'Have the Conversation'.

Please contact Noretta Clifford, 087-6243367 or Peggy Eustace, 087-9392148 if you can help out in anyway.

WEST CLARE WALK

The annual IKA West Clare walk takes place on the Bank Holiday weekend in May. For the last two years we have not held an in-person event due to COVID and with these uncertain times, it is unknown whether it will go ahead in 2022.

If an in-person event cannot take place, we hope to hold a virtual event as we did in 2021. Keep an eye out on the Facebook page and other communication means for any further updates on this event.

WEXFORD

By MARIE DONLON

The Wexford Credit Union 5k Night Run took place on Thursday, March 3rd with all proceeds going to IKA Wexford Branch and High Meadows Youth Hub. There was a great turnout on the night with almost 350 people taking part.

We would like to thank all the kind sponsors and also the many volunteers who turned out to help on the night.

We will be continuing our online meetings for some time yet and it would be great if more of you could join us.

Please continue to follow us on our Facebook page.



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KILKENNY

By ANNE O'GRADY



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Spring Greetings to all our patients, members, their families and supportive carers.

ZOOM MEETINGS

The Kilkenny Branch have held monthly Branch Zoom meetings and will continue until we are allowed to meet face-to-face.

Each meeting provides us with an opportunity to discuss any feedback from Donor Hous, the Board and Branch Forum meetings and also a chance to catch-up with each other.

We look forward to meeting face-to-face in future.

Our last meeting was held on March 22nd at 7pm. Thanks to Ashling Hand for setting up the codes and relevant details.

SOUTH EAST VIKING ORIENTEERS

On Sunday January 9th, the South East Viking Orienteers, led by Andrew Cox, held a very successful event at Castlecomer Discovery Park.

Donations on the day were in



Nigel Pim, RIP

memory of Nigel Pim, on his first anniversary. Nigel passed away in January 2021.

The event was very well supported and the €1,100 raised has been shared equally between the Waterford and Kilkenny Branches of the Irish Kidney Association.

On behalf of all our patients, a sincere 'thank you' to Andrew and his organising committee.

We are truly grateful to everybody who has contributed to the Kilkenny Branch in any way through fundraising or donations.



Event at Castlecomer Discovery Park

The Kilkenny Branch Officers support is always available. Contact details are:

John Lacey, Chairperson, 085-1328255

Hugh Byrne, Board Member, 086-8938800

Therese Hanrahan, Treasurer, 087-7796428

Anne O'Grady, Secretary, 087-9232190

Bridie Lennon, Assistant Secretary, 085-7051076

CAVAN/MONAGHAN

By KARL CRONIN

RETIREMENT WISHES

The branch extends their very best wishes to Susan McKenna, Renal Clinical Nurse Specialist, as she retires from the Renal Unit in Cavan General Hospital in May. Susan has been a huge supporter of the work of the IKA and has led many initiatives in the hospital such as selling Christmas cards, organising information stands for World Kidney Day and Organ Donor Awareness Week, introducing IV fistula identity bands for patients and more recently, co-ordinating the organ donor awareness decals on the visitor lifts in Cavan General Hospital.

Susan also produced 'Conservative Care of Kidney Failure' which is the 7th book in the series of patient information books available from the IKA and is available at ika.ie/patient-guides.

We wish Susan many years of good health and happiness in her retirement and thank her for all her support down through the years.



Susan McKenna



World Kidney Day was celebrated on March 10th with an information stand in the lobby at Cavan General Hospital. Pictured are Dr. Vladimir Stoyanov, Consultant Nephrologist, Aishling Sheils, Senior Renal Dietitian, Pauline Connolly, Senior Renal Dietitian and Donna Johnson, Home Therapies Clinical Nurse Specialist.



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University Hospital Waterford organised a display table for World Kidney Day in the in the hospital's foyer. Pictured is Vera Frisby, IKA, and Margaret Moran, Clinical Nurse Specialist, Nephrology Department.

Welcome to our spring edition of *SUPPORT*. Greetings to all our members. We hope everyone is keeping well and staying safe.

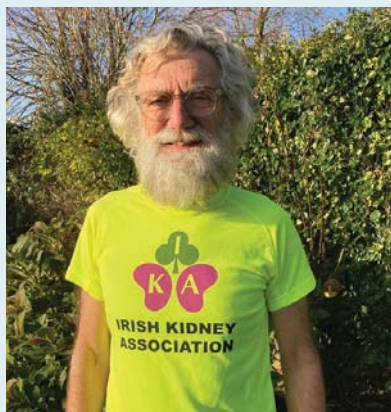
CONDOLENCES

We would like to extend our sincere condolences to those families who have lost loved ones recently. We were deeply saddened at the death of our friend and devoted volunteer Paddy Long, who passed away at University Hospital Waterford after a short illness. Paddy was a great supporter of our Branch and will be especially remembered for his involvement in the IKA Annual 10K Walk in Portlaoise. He will be greatly missed by all our members and friends. We extend our sincere sympathy to his wife Eileen, his family and friends.

We also remember the late Liz McCue, Tom Wall, Alice Melay, Michael Daly and David O'Brien – may their gentle souls rest in peace.

WATERFORD

By VERA FRISBY & FRANCES MOYNIHAN



Above: Jackie Ahearn, Frances Moynihan, Joe Conway, Noelle Conway and Sandra Dee.

Top left: Joe Conway before his haircut.

Bottom left: Noelle and Jackie get to work on Joe's locks.

FUNDRAISING

The Coffee morning in Portlaoise, organised by Eileen Long, raised the magnificent sum of €660. Our sincere thanks to Eileen and everyone who supported this event, for our branch.

Newtown Fundraising Committee organised a virtual 5K Run/Walk and raised the sum of €2,500. We thank the committee members who organised this event and all who supported it.

South East Viking Orienteers raised the sum of €1,100, in memory of the late Nigel Pim, RIP. This amount was divided between IKA Kilkenny and Waterford Branches. Our thanks to South East Viking Orienteers and everyone who supported this event.

LOSING THE LOCKDOWN LOCKS

On December 1st 2021 Joe Conway lost his lockdown locks as a fundraiser for the Waterford Branch of IKA. Joe is a brother-in-law of Frances Moynihan, Branch Secretary. He had not visited his barber since March 2020 when COVID lockdown restrictions began and so possessed quite the head of hair and beard as a result!

His barber, Jackie Ahearn of Classic Gents, Mitchell St., Dungarvan, volunteered her services and premises on the day. Joe's wife Noelle, also lent a helping hand.

Donation buckets and donor cards were displayed in Classic Gents and Dungarvan Golf Club in advance of the day. Thank you to all who supported us. The venture raised €2,465.80 in total with most of the donations given through Facebook. Our thanks are extended to Joe, Jackie and all who donated.

HOLIDAYS

Our Holiday apartments, Tramore, will reopen on April 30th for the summer season. The application forms are available on our website www.ika.ie/holiday-application/

BRANCH MEETINGS

We send every good wish to all our branch members, volunteers, patients and friends.

We are continuing with our Branch meetings via Zoom. If you would like to join us for our virtual meetings, please contact: Frances Moynihan, Tel: 087-2411549 or email: francesmoynihan19@gmail.com

DUBLIN NORTH

By PATRICIA MACKENZIE

Hello everyone

As I write this there are signs of Spring in the air, and even the smallest break in the weather brings sun-seekers to the coast of North Dublin.

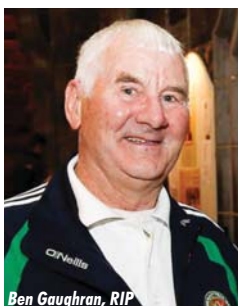
BEN GAUGHAN RIP

It is with great sadness that we announce the passing of our valued member, Ben Gaughran, peacefully in Beaumont Hospital on February 20th.

Ben, also a former member of Transplant Team Ireland, was a regular attender at our meetings, especially when they were in the Renal Support Centre.

His gentle presence, good humour and lively conversation enhanced every meeting he attended.

Our deepest sympathy to Pauline and family. At our recent meeting we observed a moments silence for



Ben. We shall miss his friendship and support for a very long time.



CLAIRE BURKE RIP

We also announce, with great sadness, the loss of our lovely member Claire Burke, who passed away in Beaumont Hospital after a long illness which Claire bore with great courage and dignity, always bright and cheerful.

She loved life and had many memorable days shared with family and friends.

She also loved music and being part of the charitable events organised by her mum, Ann, for the IKA, not least the concerts featuring Red Hurley, a close family friend.

She will be greatly missed by her loving parents, Éamonn and Ann, her dear brothers, Conor, Fergus and Ciarán and family. Also friends and neighbours in Portmarnock and



her friends in the CRC and Beaumont Hospital Kidney Unit.

In tribute to Claire, Red Hurley provided beautiful music for this sad occasion.

May her gentle soul rest in peace.

BRANCH MEETINGS

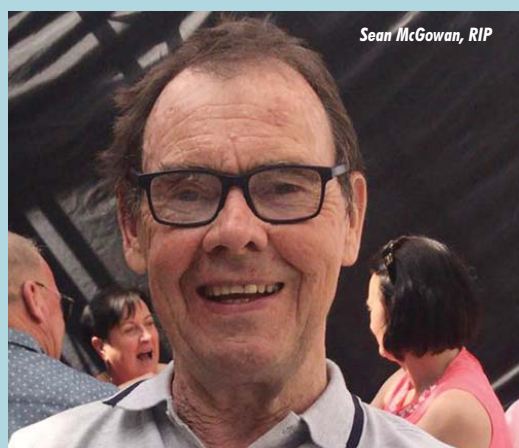
Our regular meetings, still on Zoom are well attended by a small, but faithful band of members.

Our next Zoom Branch Meeting will be held on April 4th at 7.30pm.

OUR WISH

We hope you all continue to stay safe and well, and hopefully enjoy the warmer weather.

LEITRIM



Sean McGowan, from Dromod, lost his final battle and passed away peacefully, in October 2021, surrounded by his family.

The positive impact left on the world by Sean is immense. He will be remembered fondly by all for his trojan like resilience and amazing sense of humour no matter what was thrown his way.

His kindness and generosity will forever be remembered through the deeds he has done, and the memories created. RIP.

DUBLIN SOUTH

*Covid's brought us many troubles, a list of unwanted ills
But in our little branch it helped us with our rusty IT skills
When we were socially distanced, said John, to dispel our gloom
"Sure we'll still meet monthly anyhow - we'll do it via Zoom!"*

*So reminders zealously were sent by email and WhatsApp
Two things as common nowadays as turning on a tap
And every month our little band tunes in to say "How do?"
Discuss things urological, as kidney patients do.*

*If sound and picture both are right, we share our bits of news
Discuss, advise and sometimes share our own distinctive views
There sometimes is a little glitch to make us all feel sad
When we all hear the plaintive cry, "Me signal's very bad".*

*But the commonest thing you'll ever hear,
Of that there's no dispute
Is "Sorry dear, we cannot hear.
Have you got yourself on mute??"*

By PADDY SNYED



GENEROSITY OF THE PEOPLE OF CORK

For the past few weeks we have all seen the horrendous scenes in Ukraine 🇺🇦 and so many have been affected by seeing people having to leave their homes, leaving most or all their belongings behind with many kids and wives having to say goodbye to their fathers and husbands. Sometimes seeing all the negative news can really get us down about the world we live in but it can also make us pull together in support.

Over the past few weeks I have seen first-hand how people really do want to offer support in any way they can and they will come together in times of crisis to help others. I was contacted by a friend and fellow transplant patient about a family that was coming to Cork from Ukraine and they needed accommodation and the husband also needed dialysis. I contacted Prof. Liam Plant to arrange dialysis and, of course without hesitation, he had the dialysis treatment organised for when the patient arrived in Ireland.

I was overwhelmed when I put out an urgent post on our Cork Instagram and Facebook to see if anyone would have accommodation for the family. I got so many offers of rooms in homes and to provide food, etc., for the family. I even had messages of people about to sell houses but they were willing to delay the process so that the Ukrainian family could use it. This uplifted me so much, and I felt even more proud than ever to be Irish, that I had to share this story for this Support magazine. It's so easy to always see what people are not doing but less frequently do we hear about a community coming together in just a few days to help others.

I hope you might find this story



heartening, even just a little. Thanks so much to every person for the outpouring of support and offers. And a big 'thank you' to Prof. Liam Plant, the Irish Kidney Association and all in Cork, for your help. – SN

KILDORRERY GAA 24-HOUR SPINATHON

On Friday, February 18th, Kildorrery GAA held a 24-hour Spinathon to raise funds for the GAA club, as well as awareness and funds for the IKA. The Spinathon was organised by the football and hurling teams, under the watchful eye of William Fuohy. This is not the first time Kildorrery GAA has raised funds for the IKA. Both players and

management have family members affected by kidney disease and transplantation.

As part of the Spinathon, there were three bikes with a changeover each hour. Team players, ex-players and management all got involved. There was also a constant flow of well-wishers calling into the local sports hall to wish them well throughout the 24 hours.

At the time of writing there was over €7,600 raised. We would like to thank Kildorrery GAA and the players for raising much needed awareness of organ donation and for the time and effort involved in this fundraiser. – NOH

DUBLIN EAST & WICKLOW

By BERNIE DWYER



Don Hannon at the stone in Cloon Curtlestown Woods.

As we are well into 2022 now and beginning to enjoy longer days we hope we can put the past two years behind us, albeit with continuing precautions for the vulnerable in our community. It is still out there!

CONDOLENCES



Kay Lynch, RIP

We were very sad to hear of the death of Kay Lynch on January 3rd this year. A wonderful and hard-working member of the Dublin East & Wicklow Branch for many years.

Kay was the very supportive wife of our former Board Member John Lynch, RIP.

I found her to be a very kind and gentle person who was always willing to help at fundraising events, even when she was not feeling well herself.

I know that many members have fond memories of Kay and John and we send our sincere condolences to her daughters Caroline and Maria and her beloved grandchildren and extended family.

May her gentle soul rest in peace. We also send condolences to

Branch Treasurer Catherine Foley whose mother Marie passed away in December 2021, as well as to Vanessa Garrioch whose partner John passed away suddenly on March 4th. May they rest in peace.

ZOOM MEETINGS

We have had just one meeting, so far this year, in February, and hope to have our next one on April 12th. Taking part in our meetings will give you a chance to meet other members, hear their stories and share your own stories and ideas.

FORTHCOMING EVENTS

The wonderful community of Glencullen, high up beside Johnny Fox's pub, are going to run some events this year to raise awareness



and funds for the IKA.

Their GAA club Stars of Erin will be doing a climb shortly and we will share details on our Facebook page. They are also having a fun run/walk on Saturday, September 24th with Dublin Mountain Running Club. Details will follow. They are doing all this in support of 17-year-old Stars member and dialysis patient Cillian Doyle. Well done to you all.

You may remember back in 2018 that Don Hannon from Sandyford, and now living in Wicklow, ran 1,000km from The Giants Causeway to Castletownbere to raise awareness of organ donation after he had donated part of his liver to his sister Therese.

Don sent me this picture of a stone in Cloon Curtlestown Woods and thought it was worth sharing.

We send our best wishes as always to those who are unwell or in hospital at this time and as we approach Organ Donor Awareness Week we look forward to hearing about many more transplant stories and a successful media campaign.

GALWAY

The Galway branch sends its best wishes to Eoin Madden and his wife Michelle who underwent a successful paired exchange kidney transplant early in the new year.

Peadar O'hici, Secretary of this branch did an interview 'as gaeilge' on TG4 Nuacht on February 22nd about the IKA's statement about the removal of the mask mandate.

On World Kidney Day, 10th March, Peadar, a kidney transplant recipient, collected a very generous donation of €4,000 from Athenry based healthcare company LifeWave. Employees at LifeWave, a US company that makes wellness patches, held their fundraiser for the Irish Kidney Association before Christmas.



DONEGAL

By SIOBHÁN BATES



Worshipful Brothers Joseph D'Arcy and Paul Govier, presenting a cheque to Siobhán Bates, Donegal IKA Branch.

Greetings and virtual hugs from Donegal. I hope this finds you all well and looking forward to getting out and about again.

Due to COVID, our Branch was not as active or as busy as normal. Hopefully, meetings will be resuming soon, but ONLY if an interest is shown to continue with them. We would also welcome 'new blood' to help with new ideas for fundraising and/or becoming newly elected Committee members.

The Donegal branch offers condolences to all who have lost loved ones recently, especially our good friend JP Bradley, from Carndonagh. JP was a true and dedicated friend and volunteer to the Branch.

Our appreciation goes to the Bradley family for the donation of €1000, proceeds donated to our Branch, in lieu of flowers, from JP's funeral.

Condolences also to our good friend Maisey Doherty from Moville, who lost her beloved daughter Kathleen. Sadly, Maisey had just lost her husband Patsy a few short months before.

We were also sorry to hear of the sad passing of Sean McGowan and extend our condolences to his family.

May they all Rest in Peace.

We were invited to Ballyshannon, by Joseph D'Arcy and Paul Govie (Worshipful Brothers) for the presentation of a cheque for €900,

from the local Freemasons, Masonic Lodge No. 287. This was in memory of Grainne Kelly (Joseph's partner) from Kinlough.

Great to see that the Kerry branch has extended the deadline for holidaying in the Kingdom. We were blessed to receive a few days at the end of September and what a welcome we received and what a house! We had an amazing break and it certainly recharged the batteries. Many thanks to Deborah and Fiona at Donor House and of course, Teresa Looney and team from the Kerry branch. It was amazing. It would be great to have the same facility in Donegal to accommodate people from other counties to holiday in our beautiful Donegal.

Congratulations to all those recently transplanted, may you all continue to have many happy healthy years.

Massive apologies to anyone who had a delay in receiving their receipts for their fundraising efforts. Our Branch



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Treasurer had technical difficulties which resulted in the delay. Hopefully, all should now have received their receipts, however, if not, please contact a member of the Branch Committee.

'Thank you' to all staff at Donor House and the Renal Support Centre for being so accommodating to our Donegal patients who still have to attend Dublin hospitals for their renal appointments. To have you at the other end of the phone gives that added bit of security for those nervous of travelling to Dublin.

Hello to everyone in our Dialysis Units, our taxi drivers, our brilliant nurses, doctors and all the medical staff and our wonderful HSE workers, who all help to make our kidney journeys easier.



Joe and Damien presenting a Samsung TV from Dry Arch Complex Mace/Taxaco Service Station to Eddie Cassidy and Caroline Mc Closkey from the kidney dialysis unit in the Letterkenny Hospital.



IKA DIRECTORY



Irish Kidney Association CLG, Donor House, Block 43a, Parkwest, Dublin D12 P5V6

Tel: 0818-543639 (KIDNEY) or 01-6205306 | Email: info@ika.ie | www.ika.ie

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

Emergency Mobile Number: 087-4169907 | Email: renalcentre@ika.ie

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ROSCOMMON

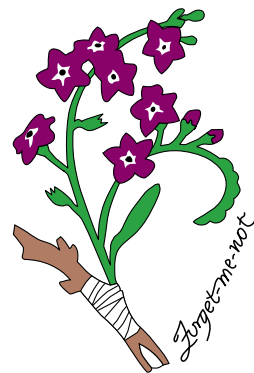
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