

# SUPP



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SUMMER 2020



## IRISH KIDNEY ASSOCIATION CLG

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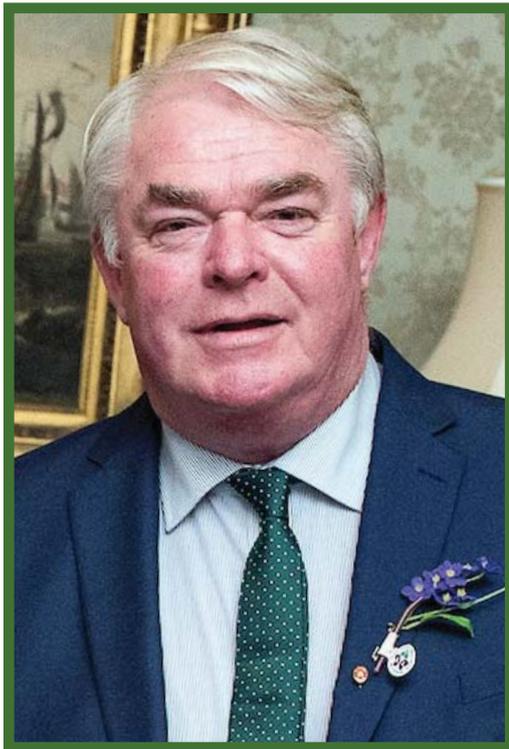
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# Editorial...

**W**e have come through four of the most difficult months that the Health Service has ever witnessed. 'Difficult' is the word that captures, most effectively, this period – difficult for all of us. The trouble now is how do we return to pre-COVID lives? The truth is that it probably will not ever happen to the level we would like. Relaxing from lockdown comes with many terms and conditions – yet to be proven and refined. Are we relaxing too quickly? – Probably! Everyone has endured mental health issues of one level or another and anxiety still abounds.



Some eastern haemodialysis centres were particularly impacted upon with almost 30 lives lost. Our sympathies go out to the families of these dialysis patients, along with the four kidney transplant patients who, tragically, also lost their fight with COVID-19.

Our medical professionals have only had six months to study, learn and discuss this new illness. Our Health Services and leaders did particularly well in the management of 'the unknown' illness and made some excellent and prudent early decisions. The National Renal Office was of immense help to us and adapted protocols as lessons were learned. A big 'thank you' is not enough and recognition for what was achieved and is being achieved remains a decision not yet decided upon.

The Association has been particularly busy. We are replacing our data management systems, a decision taken long before COVID so, with that in mind, we phoned all the patients on our membership list and followed up later with non-patients to ensure the data we had on file was correct and to see how they were all coping during COVID-19. We are now coming to the end of this 4,000 call project, which results in our preparedness for the changeover. The Staff are now returning to Donor House on a staggered basis. We will all mix our time between home and office for the coming weeks and some will remain cocooned.

The Board has put in more hours of meetings than ever before. Shortly, the results of long hours of work concerning the Strategic Plan, for the next five years, will be published. The Annual Accounts are at their final stages and our Annual Audit has also commenced. As a result of the Strategic Review and in order to comply with good governance we have recommended changes to our Constitution and, as members, you will be asked to vote on these changes at our AGM in late September.

Beaumont Hospital has requested keeping our Renal Support Centre for a while longer. Therefore, anyone requesting accommodation at the Centre is being offered the Clayton Hotel, adjacent to Dublin Airport, as an alternative. Visiting patients in hospital is still heavily restricted,

# Contents...



## FRONT COVER

*Michael O'Driscoll (left) and Gavin Downes (right) are pictured at the end of the gruelling 24-hour 888km Physical Endurance Challenge. They were met by John Moran (centre), who is celebrating 35 years transplanted.*

*See pages 12-13*

*Photo: Conor McCabe*

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fearing, as we all do, the 'second wave'.

'Dialysis away from base', as the National Renal Office has labelled holiday or work dialysis, is not on the cards anytime soon with the exception 'for compassionate reasons'. So, our holiday accommodation facilities will not be utilised this year. Similarly, we are unable to accept dialysis bookings abroad as patients will, most likely, not receive the medical clearance to travel.

Our sports programme has been particularly hit by COVID-19 and the first casualty was our hosting, in August, of the European Transplant and Dialysis Sports Championships in Dublin. Now the World Transplant Games in 2021 in Houston, Texas have also been cancelled. The 1st Transplant Soccer World Cup in Italy was also cancelled. I anticipate that these important events will only return when 'the vaccine' we all crave, is discovered.

Our 35th Service of Remembrance and Thanksgiving will now not be held in Mullingar in October, due to the pandemic. We are currently negotiating a TV proposal for an alternative type Service to be broadcast. This has yet to be finalised. Do please keep an eye out for an announcement on our website.

Online fundraising is the new reality and our staff has adapted very well and, whilst it is a team effort, I do wish to single out Robyn Black for her enthusiasm and impressive skills with modern technology. She has achieved so much in such a short time. Indeed, I am the one who calls her 'my millennial!'

I also want to single out three people and thank, Dr. Colm Magee, Consultant Nephrologist and Kidney Transplant Physician at Beaumont Hospital, Professor George Mellotte, National Clinical Lead of the National Renal Office and Consultant Nephrologist at St. James's and Tallaght Hospitals and Dr. Siobhan MacHale, Consultant Renal Transplant Psychiatrist, Beaumont Hospital.

They all, collectively, cooperated with our call for COVID-19 videos for our website [www.ika.ie](http://www.ika.ie)

They are still available to view and, indeed, are still very much relevant – more to come.

Our retired Computer Programmer and kidney transplant recipient, Adrian Hastings, sadly passed away in June, may he rest in peace. I wish to extend my own sympathy, IKA Staff and our Board's sympathies to Aido's family.

I am pleased to announce that we have secured planning permission for the development of the six ensuite bedroom Support Centre, situated beside Cork University Hospital. Studying of the design and specifications for the building are well underway. This is an ambitious project and the Cork Branch has been very patient and active fundraisers for the project.

On a personal note, I wish you all good health. I have enjoyed, enormously, serving the Association for the last twenty years. This is my last time editing our *SUPPORT* Magazine. Indeed, I was meant to slip away in May, but circumstances moved that date to the end of September. Similarly, Lorraine Costello, Patient Support Officer, who served the Association for nearly forty years, will be departing also.

I would like to take this opportunity, in my last *SUPPORT* to thank and compliment my staff for, over the years, putting up with many of my quirky ways! I would particularly like to acknowledge the loyalty, efficiency and daily patient support of Donor House's Office Manager and, indeed, my own Personal Assistant, Ashling Hand. I also received consistent help from three loyal contractors: Esther Behan, Gwen O'Donoghue and Colin Murray. Finally, I wish to pay tribute to the ten IKA Chairpersons with whom I worked and the many Board Members over the years.

Slán,



**MARK MURPHY**  
CHIEF EXECUTIVE

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# Transplant solutions needed if COVID-19 re-escalates



By CATHERINE REILLY

**The potential resurgence of COVID-19 cases should not necessarily halt kidney transplants, the Irish Kidney Association (IKA) CEO MARK MURPHY has urged.**

**D**uring the COVID-19 crisis, Beaumont Hospital in Dublin “paused” its kidney transplant programme, as did most centres in the UK. However, Northern Ireland’s kidney transplant programme reportedly cleared almost one-third of its waiting list following a short pause.

Mr Murphy said there must be a firm contingency arrangement to allow for the possibility of continuing kidney transplants in the event of a resurgence of COVID-19. He acknowledged that Northern Irish patients’ outcomes would need to be followed closely, but he expected these would be good.

The North’s programme had the major advantage of access to a designated ‘non-

COVID’ hospital to conduct transplants, noted Mr Murphy. Additionally, more donations became available to Northern Ireland as many UK centres paused their transplant lists.

On the suspension of the programme at Beaumont, Mr Murphy also acknowledged that the virus posed a serious risk to transplant patients. There had been a possibility of continuing kidney transplants in private hospitals under the State deal, but it is understood this was not taken up for safety reasons. These factors may have included lack of laminar air flow isolation beds, the *Medical Independent (MI)* understands.

More broadly, Mr Murphy reiterated his call for a second kidney transplanting hospital in the Irish health service, potentially in Cork University Hospital, St Vincent’s University Hospital, Dublin, or Belfast, in order to boost transplant numbers.

As previously reported in *MI*, the kidney transplant programme in Belfast City Hospital has extensively used extended donor criteria and donation after cardiac death (DCD) in recent years. Speaking to *MI* in 2019, Belfast transplant surgeon Mr Tim Brown said this had increased the risk profile of the programme but also boosted deceased donor transplant numbers with good outcomes. The programme is also a European leader in living donations.

Mr Murphy noted that



Beaumont’s programme has been undertaking a consent process with patients regarding potential acceptance of more ‘marginal’ donations. The HSE’s Organ Donation Transplant Ireland office has underlined that DCD, for example, requires enhanced resourcing and infrastructure.

The IKA CEO said Beaumont’s outcomes were good and it was around the top of the European list in this regard. He said the programme was “super safe” but some patients “mightn’t get their transplant where they would in another jurisdiction”.

He suggested that Beaumont could work alongside a second designated hospital operating a programme with a different risk profile, so that overall numbers could be increased.

Mr Murphy added that the three national transplant centres in Ireland also lacked ringfenced beds and this was hampering the capacity to deliver transplants. Mr Murphy’s understanding was the hospitals were now pushing for ringfenced transplant beds in the context of COVID-19.

Meanwhile, Mr Murphy said it was not yet clear how much extra pressure would be placed on dialysis services due to kidney injury acquired through COVID-19.

However, he said the slowdown in the transplant programme would put more pressure on dialysis units. Mr Murphy added that it would be prudent to unite the dialysis and renal transplant budgets to underline the huge financial and quality-of-life impact of prioritising transplant for eligible patients.

Mr Murphy said COVID-19 infection presented a major concern to dialysis and transplant patients.

According to statistics from the HSE National Renal Office, (*Ed. comment: at end of May*) 89 dialysis and 26 transplant patients had been diagnosed with COVID-19, with 31 deaths (27 haemodialysis and four transplant patients) in the cohort.

The renal office said the supply of surgical masks to haemodialysis patients – worn from when they were collected for their treatment until they returned home – helped reduce COVID-19 infection, alongside other measures.

*Reprinted courtesy Medical Independent*

# ADVANCE NOTICE OF THE IKA



# AGGM

The **ANNUAL GENERAL MEETING** of the  
**IRISH KIDNEY ASSOCIATION** will be held  
on **Saturday September 19th, 2020** at **2pm**  
at our Head Office at

**Donor House, Block 43A, Parkwest, Dublin 12, D12 P5V6.**

## COVID-19 IMPORTANT NOTE

Due to the current COVID-19 pandemic and restrictions on the movement of people, and in particular because all IKA patient members are highly vulnerable from COVID-19 the **Board of Directors** requests that members do not physically attend at the **AGM**.

The meeting will be conducted via Zoom. In due course you will be required to register for the **Zoom AGM**.

Members can propose **Motions** and **Resolutions** for the AGM which must be seconded by another member. They must arrive by post to Head Office or email to [ashling@ika.ie](mailto:ashling@ika.ie) by **Wednesday, August 19th** at **5pm**.

By **Monday, August 24th** Head Office will send, by post or email, the official **Notice of the AGM**, including the **Agenda, Motions, Resolutions** and **Proxy Voting Forms** to all members. The **IKA Accounts and Directors Report** will be available on the IKA website – [www.ika.ie](http://www.ika.ie) on **Monday, August 24th**.

All signed Proxy Voting Forms and questions on the Accounts must arrive by post or email to [ashling@ika.ie](mailto:ashling@ika.ie) by 5pm on **Friday, September 11th**.

We would prefer if you could be contacted by email. If we have your email address you will have received this advanced notice, otherwise please submit your email address to [ashling@ika.ie](mailto:ashling@ika.ie)

**THE AGM IS ONLY OPEN TO MEMBERS OF THE ASSOCIATION.**



Above:  
*Pictured at the Department of Renal Medicine in University Hospital Limerick are (from left) Prof Austin Stack, Consultant Kidney Specialist; Dr Liam Casserly, Lead Nephrologist; and Yvonne Crowe, Clinical Nurse Specialist.*

Photo courtesy of UL Hospitals Group.

# HOME DIALYSIS

## transforming lives of chronic kidney disease patients in Mid-West

**Home dialysis is transforming the lives of chronic kidney disease patients in the Mid-West, improving quality of life through efficient treatment modes and schedules that can be adapted to people's domestic and working lives, and reducing frequency of hospital visits for the patient.**

**A**t a time when some 85-90% of the 200-220 patients receiving dialysis treatment for chronic kidney failure are doing so 'in-centre' at University Hospital Limerick, making it one of Ireland's

busiest haemodialysis services, the hospital's Department of Renal Medicine team continues to promote home-based dialysis as the best option for patients requiring the treatment.

Dr Liam Casserly, Lead Nephrologist in the Department, who has cared for patients on dialysis treatments for the past 25 years, says: "Patients tell us that home treatments provide a quality of life that comes closest to their normal routines; whether that's going to the shop, going away for a weekend, having a holiday, or even sudden events like funerals,

these home therapies allow flexibility; they allow the patient to achieve their usual goals of life most easily.”

And during the Covid-19 pandemic, Dr Casserly explained, home dialysis therapies have been advantageous for patients: “The pandemic has brought great challenges for everyone, but unlike patients who have to come to the in-centre haemodialysis unit, patients who are doing the treatment at home have been safely able to isolate during the peak of the pandemic and over the past few months. This is just one example of the advantages of home therapies. While this isn’t a primary reason to choose it, it again demonstrates the flexibility patients have when they choose home therapies. It also brings new meaning to the phrase, ‘No place like home’.”

Yvonne Crowe, Clinical Nurse Specialist in the Department explains: “When we are talking to patients about potential therapies, we always promote dialysis at home,

because it keeps people more independent. It fits in with their lifestyles, their work, their social activities, and it enables them to travel as well. It gives them a lot more flexibility.”

Kidneys continuously cleanse approximately 180-litres of blood in the average human body every day, controlling blood pressure, and producing hormones that regulate haemoglobin levels and Vitamin D, as well as stimulating production of oxygen-carrying red blood cells.

These crucial functions are impaired by chronic kidney disease, which can be caused by four primary factors: diabetes, high blood pressure, nephritis (a condition of the immune system caused by a past infection or inflammation of the filters in the kidney), and inherited disease.

When the patient’s kidney function falls below 20%, patients attending the Department of Renal Medicine will be offered a number of dialysis options:

**Haemodialysis** is a 4-hr process undertaken either in hospital or at home three or four times weekly, by which

the patient’s blood is filtered and cleansed of toxins via an external machine.

**Peritoneal Dialysis** involves the permanent surgical insertion of a soft tube into the patient’s abdomen, through which dialysis fluid flows into the peritoneal membrane, drawing excess water and waste products from the blood in an ‘exchange’ process. This exchange process is undertaken either manually (Continuous Ambulatory Peritoneal Dialysis - **CAPD**) requiring dialysis fluid to be changed four times during the day, or automatically (Automated Peritoneal Dialysis - **APD**) using a machine at night while the patient sleeps.

Dialysis treatment in-centre is increasing all the time. Between 2014 and 2018, the number of in-centre treatments at UHL grew from 10,412 to 17,232. However, the logistical demands of hospital-based treatments on the average patient are formidable. In-centre haemodialysis treatment requires three weekly hospital visits (at least 150 visits per year) for

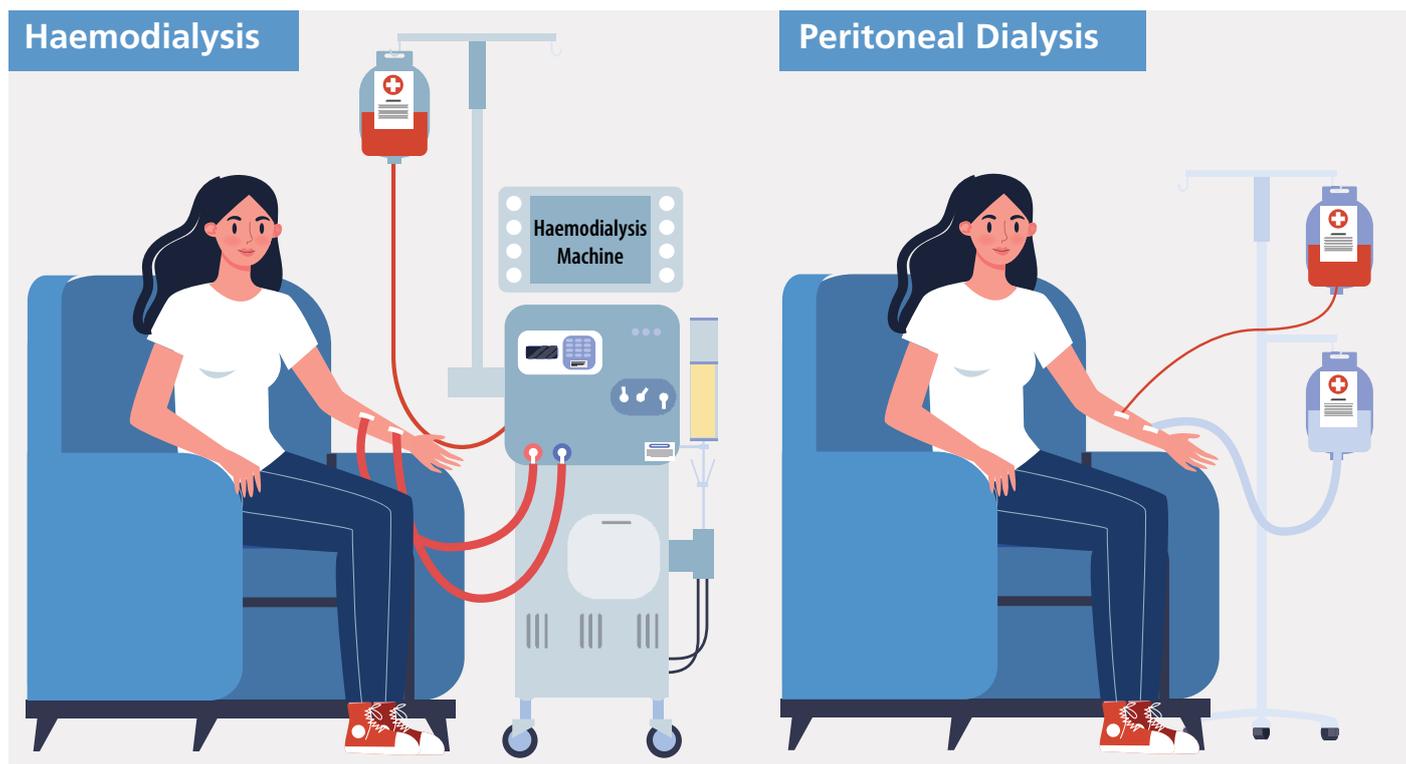
treatments lasting four hours per visit.

More patients are experiencing the benefits of opting for either peritoneal or haemodialysis treatment at home, and for a Department that has a finite number of haemodialysis machines.

Robert Swanton (74) from Pallaskenry, Co Limerick, lives an active retired life and found home-based CAPD peritoneal treatment the best ‘fit’ for his lifestyle. “My routine is four times a day, four to five hours between each session. I do the first treatment first thing in the morning, then at midday, then six o’clock-ish, and last thing at night. You don’t have to keep appointments every second day going into the hospital, and I’m more than happy with what I’m doing – it leaves me freer to plan my day, within reason, as I wish.”

Patrick Stapleton (73) is a driving instructor from Thurles, Co Tipperary, who has been diabetic since the age of 40. He opted for peritoneal dialysis when he figured out how to schedule

*contd next page →*





# SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK

## DIGITAL LIFE LESSONS

If you have ever spent any significant time in the IKA office, you might have heard some of the pet names coined for me by my lovely colleagues. 'The Millennial' and 'Google Ninja', (supposedly) able to fix any and every phone or laptop that goes awry and never without my own iPhone in hand, it's fair to say they're not inaccurate!

Every big moment at work and at home is captured, edited, and posted on varying forms of social media; I rarely ever have my nose out of my phone. Yet, during lockdown, I find myself barely able to reply to a text message, and feeling increasingly frustrated by the desire to do 'real' things.

Don't get me wrong, some things that have come out of the pandemic have been great. We have a weekly staff meeting on Zoom that, despite some shaky starts with the technology, has been brilliant. As an office, we have probably never been so up to speed on each other's daily tasks and projects. We spend upwards of two hours every Thursday chatting and for that time, it's almost easy to forget that we haven't physically seen each other for months.

We've ventured into virtual events like our 'Run For A Life', which I was especially delighted with. Over the three-and-a-bit weeks that we ran the campaign, we had 325 individual registrations and 92 family registrations. For an event that almost didn't happen at all and was our first foray into 'hosting' an event that wasn't physical, the numbers were exciting to see and we hope to keep the virtual aspect next year for those



who can't attend on the day of the run.

Our supporters have been more generous and creative than ever with their online fundraisers. As I write, two guys are completing an 888km endurance trial which I'm pretty sure is further than the sum of any distance I've ran, ever! If you are doing anything for us at all, please get in touch and send me photos and videos so we can cheer you on!

Some digital projects that had been waiting on the side-lines have also kicked off, such as upgrading our membership database and updating several pages on our website. I'm excited about both of these and they should provide lots of interesting work over the next few months.

But despite all of these good things, I'm longing for 'tea at three' in the office kitchen. I can't wait to

stomp in on a cold Monday morning grumbling about my bus being late, and don't even get me started about missing my friends and family back home in Scotland.

So if you're suffering from digital burnout and can't wait to see people in real life again, you're not alone! This Millennial has looked up from her laptop and is longing to get back out into the real world. As long as they have WiFi of course...!

I'd like to finish by adding that I know my issue fades in comparison to others. I'm fully aware that many of the people reading this will have been cocooning for months, or have lost a loved one to this horrible virus. I know the blessings I have and don't take any of them for granted. My thoughts are with anyone who has struggled during this time.

Stay safe everyone.

robyn@ika.ie  
@IrishKidneyAs (Twitter)

@IrishKidneyAssociation (Facebook)  
@irishkidneya (Instagram)



# Mental health during COVID-19

**MARK MURPHY, CEO, Irish Kidney Association invited DR SIOBHAN MacHALE, Consultant Renal Transplant Psychiatrist, Beaumont Hospital, to discuss looking after your mental health during the COVID-19 pandemic.**

**Q** There is a general feeling of anxiety and fear surrounding us right now because of the risk of COVID-19. What advice can you give to our patients experiencing these feelings?

**A** I think what is really important to understand is that these feelings are entirely normal. The COVID-19 situation is abnormal, but the feelings of anxiety and fear are normal appropriate responses with regard to how we manage stress. Stress is our body's evolutionary response to how we deal with change in our environment in an adaptive, helpful way. So it helps us to be able to respond to our environment, to think quicker, to be able to speed up our bodies, to get oxygen flowing into our lungs, to get our hearts beating faster, in order that we can get ready to fight or run away or deal with the danger in an effective way.

It is important to be aware that these are normal, common feelings in the population at the moment. The first phase of the COVID-19 psychological survey in Ireland has shown that 20% of people have significant anxiety, almost a quarter of all people are feeling low in mood or depressed, and in fact 40% of people are feeling very lonely at the moment.

So the question is how do we respond in a helpful, healthy way to deal with these challenges?

There are lots of things we can do to help ourselves and, in fact, I would commend Aoife Smith from the IKA and the IKA website which outlines a whole host of information that's very

helpful and available through the HSE and other services.

To summarise that advice, the first thing is the importance of having a daily routine, a structure each day. At a time like this, we can tend to lose our structure, our sleep and wake cycles, because each day blends into the next. But it is important to have a plan for each day, an aim for each day, doing things that are pleasurable and of interest to us as well as the routine tasks of day-to-day life.

It is important that we maintain our sleep cycles, eat well and healthily, and maintain a degree of physical fitness. I would encourage everyone to get outside their front door every day, for at least a couple of minutes.

Other things that are important relate to how we speak to each other and how we stay connected, especially at a time where we may be less able to have direct contact with relatives and friends. Have daily contact, either by phone or by emails, but also recognise the importance of talking to people about how we are feeling, rather than keeping that hidden.

Human beings need to share and put words on their feelings in order to be able to process them effectively.

Another good way of doing that is to write down how we are feeling, and to be able to reflect on that. All of these are good strategies for helping us to stay on top of how we are feeling, and how to reframe our experiences in a more helpful way, in terms of processes such as

'cocooning' and 'keeping safe', as 'reflective time', rather than phrases such as 'being imprisoned' or 'isolated'.

Additional strategies we can use include mindfulness and relaxation, and there are some very good websites in relation to that. One I could recommend is [Beaumont.ie/MARC](http://Beaumont.ie/MARC), the Beaumont Hospital Mindfulness and Relaxation Centre website. It's a free site that you can link in to and be taught about how to do straightforward mindfulness, breathing, relaxation strategies to help you deal with symptoms of anxiety and stress.

**Q** A number of patients under a psychiatrist's care are unable to attend appointments and feel they are struggling to cope in isolation. What advice would you give to these patients?

**A** I would emphasise the importance of recognising that, rather than separating our health into physical and mental health, combining these into a single health journey is important. Mental health and psychiatric illness relate to disorders affecting the brain as the main organ, compared with renal disease affecting the kidney as the main organ.

Of particular significance is that the brain is not a static unit, but responds to the environment, adapting to what is happening inside our body, as well as outside our body. Rates of psychiatric disorders such as anxiety and depression – which are very common in the general population –



are increased in patients with chronic health problems. For example, about a third of all patients on dialysis will, at some point, have an anxiety or depressive disorder.

So, in the same way as you would expect appropriate treatment for any high blood pressure or diabetic disorders, alongside your kidney journey, similarly you should have appropriate treatment for your anxiety or your depression, as well as treatment of your renal failure.

We have good evidence-based treatments for anxiety and depression now that are well tolerated, both talking treatments and medications.

Appropriate treatment for these will improve your overall health journey, including your renal journey outcomes, as well as your overall quality of life. So, I would encourage people with comorbid (co-occurring) psychiatric disorders to be confident about asking for help from your health caregiver, from your GP, from your renal doctor or from your team.

The second thing is if you are already on treatment or on medication, make sure that you are linked in with your mental health service. Most services are providing at least virtual clinics, or phone appointments and support. Make sure that you have your medication up-to-date and available for you in the pharmacy, and then engage in all the other self-care strategies that we previously discussed.

**Q The transplant programme has been stopped until further notice. This is frustrating for patients hoping to receive a kidney this year. How can they stay mentally positive at this time?**

**A** These are very understandable and appropriate concerns for patients who have kidney disease and are very concerned about the pathway ahead, balancing the risks of developing COVID-19 vs deferring the opportunity for transplantation.

Following transplantation, you are more vulnerable to COVID-19, when your immune system is going to be suppressed. What is important is that the transplant programme will be up

and running as soon as possible, and we are hoping that it will be started in a stepped way from the end of May.

We expect to move forward from there initially with patients who have good general health and fitness for transplantation, before moving on to patients who are at higher risk, and then finally on to live donor programme transplants because you are then in a situation where you have two people involved.

So, there is a clear pathway, with a timeline dependant on the changing environment in the healthcare service.

So, our initial level of anxiety in response to COVID-19 and the uncertainty of lockdown, is now moving on to a new area of worry where things are less clear.

How long will the next phase take? How safe will it be before we can reinstate the full programmes as we have had them before? These are all areas that are being negotiated, focusing on the patients' best interests and safety so that when you get your transplant, your outcome is as good as it can be and that you have that transplant for many years to come.

**Q Carers play an important role in the lives of patients. Generally, the carer is the person who leaves home for shopping or medications, with the attendant risk of them bringing the virus back with them. How would you recommend they manage their increased anxiety around this issue?**

**A** Carers are under tremendous amounts of stress at the moment for a whole range of reasons, including the general uncertainty around COVID-19; caring for vulnerable people at home and concerns about the risk of transmitting COVID-19 to that person; the increased physical demands on the carer in having to be the one to go out and interface with the world, doing the shopping etc, while their loved one is in quarantine or social isolation.

In addition to that there are financial worries, worries about employment, all of these add to the burden of stress for carers. In that context it is important to be open and supportive of your carer, to recognise if they're being a bit snappy or irritable. Rather than reacting to that, perhaps say; "You must be under a lot of pressure" or "I really appreciate all that you're trying to do at the moment."

Those small tokens of appreciation, being compassionate, not jumping into arguments, perhaps giving them a little bit of space, and then encouraging them to join you in self-care strategies around daily routine - all of these are important day-to-day ways of optimising how we all work as an enclosed unit together. Also know that these are valuable times where we can spend positive time together, enjoying that component as well.

**Q Are there any other suggestions you have to help our patients look after their mental health at this time?**

**A** I understand that our mental health is a part of our overall health journey, just as important as dealing with our kidneys, just as important as dealing with our blood pressure and our diabetes etc.

Use the helpful resources that are available on the IKA and HSE websites. There are community care supports, including volunteers, the GAA, An Post coming in to check on people. The IKA Counselling service is a tremendous support, providing free 1:1 counselling support throughout the country.

All of that social connectedness is out there to support the most vulnerable people in our society. Within that, know that this time will pass, know that we will move forward as a society and be aware of how well we are caring for each other at this time.

Since this interview took place the Transplant Programme did re-open, as hoped, by the end of May, and the Live Donor Programme in June - Ed.

Gavin and Michael are cheered on by family and friends as they complete their 888KM Physical Endurance Challenge.  
Photo: Conor McCabe



# Dublin duo battle harsh weather in...

# 888KM PHYSICAL ENDURANCE CHALLENGE

**B**attling through the heavy rain and wind on the weekend of June 27-28th two old school friends, Michael O'Driscoll (23) from Clontarf and Gavin Downes from Raheny (25), undertook a gruelling 24 hour 888 KM Physical Endurance Challenge to fundraise for the Irish Kidney Association and raise awareness for organ donation. They two men who play Gaelic sport together were motivated to undertake the gruelling challenge as a friend of theirs underwent a kidney transplant a few years ago.

The duo were also inspired by retired transplant surgeon David Hickey who showed up to support them on the first day of their challenge. David Hickey played football for Dublin with Michael's uncle Gay O'Driscoll in the '70s winning three All-Ireland's together. With donations still coming in the fundraiser has raised over €10,500 for the Irish Kidney Association.

The challenge involved each of the two men cycling 400km and running 44km over two days covering the three coastal locations of Clontarf, Sutton and Howth on Dublin's northside with 6am starts. Cycling over to meet them in Clontarf as they neared home was Transplant Team Ireland powerhouse John Moran (61) from Glasnevin who is celebrating 35 years since receiving his successful kidney transplant and who won three gold medals and two silver for cycling and running events at the World Transplant Games last year. Also showing up over the two days to support the lads were family and friends.

Michael and Gavin have both played hurling and football competitively with St. Vincent's GAA Club since early childhood. Having attended the same secondary school, Ardscoil Rís on Griffith Avenue, Gavin went on to graduate from St. Patrick's College in Drumcondra in addition to completing a professional master degree in primary education through Hibernia College to become a Primary School Teacher at Holy Trinity SNS in



Photo: Conor McCabe



*The lads take a well-earned rest at Michael's home after completing the challenge.*



*Gavin Downes (left) and Michael O'Driscoll (right), with Dublin GAA legend David Hickey.*

Donaghmede. Michael, a qualified personal trainer and fitness coach at Gravity Fitness in Raheny, graduated from Dublin City University with a BA degree in Human Development before going on to complete a postgraduate degree in Psychology at Trinity College Dublin.

According to Michael, "a close friend of ours underwent a kidney transplant a few years ago and having spoken with David Hickey who explained the impact of kidney disease on the lives of individuals and families and how their health can be transformed as a result of a life-changing kidney transplant, we decided we wanted to focus our passion for sport and fitness into supporting the IKA, which is obviously an extremely worthy charity which promotes organ donation.

"We were fortunate to meet David Hickey through my uncle Gay O'Driscoll, who was a previous teammate of his on the great Dublin football team of the '70s managed by the late Kevin Heffernan. David is obviously a highly respected former Gaelic football player and medical professional. David pioneered medical transplant operations in Ireland therefore, it was incredibly insightful to get his perspective on the importance of raising funds and awareness for organ donation. It is fantastic to have his support for our event.

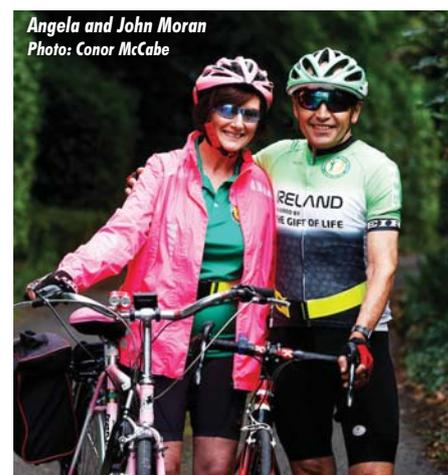
"It was a tough challenge. The heavy rainfall and strong winds made it far more difficult than we had expected. There were plenty of

demons fought but we got through the many obstacles, especially the harsh weather, that were thrown at us as we focused on the cause and why we were doing it.

We are very grateful to all who have kindly supported us with their generous donations and with donations still coming in we are delighted to have raised over €10,000 for the IKA. We hope that our Challenge will encourage others to open up conversations surrounding organ donation and the immeasurable gift it bestows to those in need. We also wish to convey a message which details the importance of engaging in physical exercise to maintain a healthy body and a healthy mind."

Gavin Downes, a 5th class teacher at Holy Trinity SNS in Donaghmede said after his challenge, "It was an extremely tough challenge we set ourselves but we enjoyed pushing

through the physical and mental challenge over the two days. It was a great feeling to complete it and have friends and family at the end line. All for a great cause! I'd like to thank Principal David Henry and the school and Hibernia College for their support with the fundraiser and in helping to raise awareness."



*Angela and John Moran  
Photo: Conor McCabe*



*Gavin and Michael are greeted by Colin White, IKA and John Moran. Photo: Conor McCabe*

Those wishing to make a donation to Michael and Gavin's 888km Physical Endurance Challenge can do so through the GoFundMe link <https://www.gofundme.com/f/888-km-physical-endurance-challenge-ika>

*“The greatest glory in living lies not in never falling but in rising every time we fall”*

– Nelson Mandela



By **AOIFE SMITH**

**E**veryday life can often be a challenge, a rollercoaster ride where we can encounter a series of obstacles and roadblocks. These challenges can be multiple and multidimensional, occurring unexpectedly at any point in our lives. I think it's fair to say that COVID-19 has certainly been a roadblock without any warning signs, a time of uncertainty and unpredictability. It has thrown up many and varied types of challenges for all of us over the last few months.

The full impact of this pandemic has yet to be seen but life has undoubtedly changed. For many, entering a hospital has a new added level of stress and having a phone consultation with a doctor has become the new norm. Familiar things are on hold, normal supports are not available and networks that we usually rely on are just out of reach.

During this time there has been a lot of talk on the news, social media, and advertisements all highlighting the potential impact COVID-19 may have on our mental health. Isolation, loneliness, depression, anxiety, grief in this very complicated situation are all very real and existing challenges.

Our ability to deal with these challenges and absorb the impact of such roadblocks is determined by our emotional resilience. This relates to our individual capacity to cope with the difficulties of life, the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress.

For years, it has been assumed that this ability was either inherited, a result of upbringing or a combination of both. It is now understood that learning and developing how to manage our emotional responses is achievable for each one of us.

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

**The Irish Kidney Association provides a FREE and confidential counselling service for those on treatment, their families and carers either through their counsellor based at Donor House or through a nationally registered locally based counsellor network.**

**If, as a person on treatment, family member or carer, you feel it would be of benefit to you to speak to a counsellor or if you would like a referral to a counsellor in your local area, please contact Aoife at Donor House.**



Dr Harry Barry, a GP and expert in Cognitive Behavioural Therapy, recently published his book *'Emotional Resilience: How to Safeguard your Mental Health'*, and in it, he suggests that the foundation of the

development of our emotional resilience is based on three concepts:

1. **Cognition** – the way we think
2. **Perception** – the way we analyse and evaluate things
3. **Action** – the way we react to it

He suggests that we can develop resilience further by recognising the fact that our thoughts influence our actions, acknowledging stress and being willing to cope with it effectively, being open to changes and being flexible while adapting to new situations, embracing the self by building self-compassion and empathy, and accepting the truth that by changing the way we react to stress, a lot of difference can be made. "It's like learning to drive a car, emotional resilience can be learnt and practiced until it becomes automatic," he says.

So, if you have gotten this far with me, you are probably thinking "but why is she writing about this?" It's because I realised that while the resilience of people throughout this pandemic is very evident, I see it at an

even higher level every day in the work that I do with people living with chronic health conditions, who live with 'uncertainty' and 'unpredictability'.

I see people learning to drive that car – learning to cope with a diagnosis, with complications, another surgery, side effects, setbacks. Most of the time they are completely unaware of how resilient they are and at a time of a major roadblock, like COVID-19, I feel it is important to highlight the strengths that I see in so many people living with chronic kidney disease.

I see them confronting their fears and anxieties, talking about their loss, dealing with their new reality head-on no matter how difficult it may be. I see them adapting to change quickly, acknowledging their limitations of energy, keeping things in perspective and doing their best to maintain a positive outlook.

They are being proactive in their healthcare, seeking out new challenges, actively cultivating purpose, as well as appreciating that 'purpose' doesn't have to be something magnificent but can be found in something as simple as a hobby, helping others or a commitment to a small act of service.

I know being emotionally resilient doesn't mean that a person does not experience difficulties or that they don't have their bad days or bad weeks and that the road to emotional resilience usually involves a considerable amount of emotional distress.

It is inspiring to see how people can experience such distress without being consumed by it and how they are still willing to grow, to learn and to live well despite their illness. To all of you, who have allowed me to see the amazing, immeasurable resilience within you, 'thank you'.

Thank you to the **Cork and South Dublin** Branches for allowing me to join their Zoom Branch meetings. I look forward to the day that I get to meet you all in person!

'Thank you' to all who called or emailed the counselling services provided here at the IKA. Please continue to email me with topics that might benefit you to read about. Your comments to me will be completely confidential, no names will be used, and no reference will be made to any person or any specific email. If there is a common theme in the requests, I will base the next article around that topic.

I look forward to hearing from you!

Briona and Shane  
the night before surgery



# Garda donates kidney to ailing fiancée as transplant programme resumes

**It was a case of third time lucky when a 29 year-old midlands Garda came to the rescue to give the ultimate pre-wedding gift to his ailing fiancée, a soon-to-be qualified art teacher, when he donated a kidney to her on June 22nd. The couple are sharing their good news to offer hope to the hundreds of other families with loved ones in organ failure on transplant waiting lists as the kidney transplant programme has resumed at Beaumont Hospital following its suspension in March due to the COVID-19 pandemic.**

**F**ive years ago when beautiful Briona Reynolds (now age 28) discovered she had kidney disease she could never have known that her boyfriend, Shane Hunter, from Athlone, Co Westmeath, whom she met in 2009 after her sister's introduction would ultimately give her the 'gift of life'.

Briona no longer has to undergo three times weekly haemodialysis treatment at the Midlands Regional Hospital in Tullamore. The couple can now look forward to a bright future together as they are now recovering following their successful living donor transplant operations at the home they share in Briona's native Tubber

in Co Offaly. They are now turning their attention to planning their wedding in July 2021 at the nearby Mount Druid and Shane will return to working at Tullamore Garda Station soon.

Beaumont Hospital had already suspended transplant operations before the country went into lockdown on March 27th including Briona and Shane's operations, scheduled to take place on

Briona and Shane  
eight days post-surgery



One day post-surgery

March 23rd. This would be their second disappointment as a previous date for transplant, February 3rd, had also been cancelled due to safety concerns as a result of Shane's blood results showing irregularities at the time.

By February, Briona's kidney function had almost fully declined and she then had no option but to commence haemodialysis treatment in order to keep her alive. Briona's mother Gina Reynolds was also found to be a suitable living kidney donor match but Shane was determined that he should be the one to proceed.

Just a week before the transplant operation took place, Briona, completed her thesis for a Master's in education. Fulfilling her dream to become a secondary school art teacher is now edging closer.

Speaking from his home, eleven days post surgery, kidney donor Shane commented, "for the last number of years I've seen Briona struggle with the complications of having kidney failure and so, when I was given the opportunity to get tested for kidney donation, I was eager to help but also nervous that I might not be a match.

"Thankfully, here we are less than two weeks on from the transplant and both of us are doing great and recovering well. The successful transplant allows us to plan ahead and focus on what is coming, like our wedding next year.

"Throughout the whole process leading up to and at the time of our surgeries, including the disappointment around our two previous postponed surgeries, we always felt safe under the care of Beaumont Hospital. The confidence and support experienced was incredible and we were very lucky to have had an excellent team looking after us.

"Right now, we are just looking forward to getting back to a stage where we can go back to work, go on holidays and just get back to normal living."

Shane quipped, "Now my concern is what to get Briona for her birthday, it is hard to top a kidney!"

Briona explained, "since being diagnosed five years ago we watched as my kidney function decreased knowing there was nothing we could do other than trying to delay the inevitable through medication and



*Briona and Shane at Shane's Attestation Ceremony*

“  
Now my concern is what to get Briona for her birthday, it is hard to top a kidney!”

lifestyle and dietary changes. But as my kidney function continued to decline to a point where my treatment options were reduced to commencing hospital dialysis treatment or the hope of getting a kidney transplant. I was so grateful when both Shane and my Mam went forward to be tested to be living donors knowing that not everyone gets this opportunity and many are reliant on the uncertainty of a deceased donor kidney becoming available.

"Both our families were hopeful the living donor process would work out but at the same time concerned for Shane and my Mam.

"The past ten months have probably been the most challenging, waiting for test results, watching my

health decrease further and trying to complete my thesis while on dialysis.

"But after all the stress and disappointment when Shane and I finally checked into Beaumont Hospital the evening before our operations, it all felt worth it and that everything was going to work out. I honestly do not think it has fully sunk in yet that Shane has donated his kidney to me and I'll never know how to fully thank him but I am so grateful that we can finally move ahead with our lives.

"I'd like to thank Shane's parents, Norman and Sharon Hunter, who now live in Dysart, Co Roscommon and my Mam and Dad, Gina and Frank Reynolds for their loving support throughout my health journey."

#### **BRIONA AND SHANE'S STORY SHARING LEADS TO SURGE IN DONOR CARD REQUESTS**

Briona and Shane's uplifting story was covered on national and local media including interviews on RTE News and on 2FM's *Sound of the Nation* with Jennifer Zamparelli. They were also interviewed on their local radio stations and they were front page news in a national and local newspaper. The response to the 2FM interview alone, in which the public were encouraged to obtain an organ donor card, garnered more than 600 requests from the general public for organ donor cards mostly through the FREETEXT number and the remainder through the IKA's website.

One newspaper article about the couple's living donor kidney transplant story received a massive response reaching an audience of 7943 with over 1000 people clicking through to read the article and over 1000 reactions on the page.

As traditional and social media combined it served as the powerful conduit to share Briona and Shane's story and touched the hearts and minds of the general public thereby generating a very real response in support for organ donation through organ donor card requests.

# Aughrim 10km June Challenge

Julie Sutcliffe

## WICKLOW VILLAGERS RAISE FUNDS FOR IKA IN SUPPORT OF LOCAL MOTHER IN ORGAN FAILURE



Organiser Caoimhe Byrne (right) and sister Monica

Inspired by the plight of a local 42-year-old mother, Julie Sutcliffe, who has kidney failure, the community of Aughrim in County Wicklow rallied together to support a 10km June Challenge in aid of the Irish Kidney Association. Leading the charge was local Londis shopkeeper Caoimhe Byrne, who worked as an Intensive Care and Trauma Nurse when living in the United States and who saw first-hand the process of organ donation.

Caoimhe was delighted that the local Aughrim Athletics Club and Community Games and the twenty staff at her family shop enthusiastically came behind the Aughrim 10km June Challenge. The shop staff promoted organ donor awareness while at work by wearing IKA t-shirts and distributing donor cards during the month of June. Caoimhe and her parents, who she works alongside in the family business, vouched a €10 donation to the IKA for each member of staff who did the 10km run. With donations still coming in, the event has raised just under €1500 for the IKA.

While adult members of Aughrim Athletics Club & Community Games were encouraged to run or walk the

10km distance any time before the end of June, there was also an opportunity for children to get involved by walking or running a 2.5km distance to support fellow junior club member Jane Sutcliffe (age 6), the daughter of the dialysis mother Julie. Julie, together with three of her siblings and her father, have Polycystic Kidney Disease. One of her sisters, Susan, underwent a kidney transplant last summer just a few months before Julie started her twice weekly journeys to Dublin to receive her dialysis treatment at Tallaght Hospital.

Speaking about the Challenge organiser Caoimhe Byrne said, "We received huge support for this event through participation in the running event as well as through donations. It is wonderful that our staff and the community came behind it so enthusiastically. The Sutcliffe family are well thought of in the community and this is evident from the level of support and good wishes we received for the fundraiser. By walking or running while observing social distance for a good cause, this Challenge offered all those taking part, children and adults, a positive step towards emotional and physical well-being.

"Having worked as a nurse in the United States in Intensive Care and

Trauma I have seen first-hand how lives can be saved through organ donation while grieving families can take consolation from the legacy of their deceased loved one who can save the lives of many people in organ failure. We hope that through this fundraiser we have demonstrated solidarity in support of the Sutcliffe family while raising awareness about the plight of people with organ failure and the importance of organ donation for transplantation while raising vital funds for the IKA."



Jane Sutcliffe

Jane Sutcliffe (6) recorded a video to explain that her mother Julie was a dialysis patient and that organ donation is very important and this generated a lot of interest on social media.

Event organiser Caoimhe Byrne came together with her mum Teresa and her sisters and some members of the athletics club committee who completed the 10km challenge and recorded another video encouraging people to take part in the Aughrim 10km June Challenge which was also shared on social media (*see more details opposite page*).



Pamela O'Toole



Louis making a donation after he completed 2.5km walk



Kelly Power



Tara Lyons, Majella O'Shea, Aine Lally, Fiona Duffy, Rachael McGrane. In foreground Oisín Jordan.



Anne Marie Cullen Kenny, Catriona Doyle, Tina Byrne, Jasmine Doyle, Sheila Nolan



Teresa and Siobhan Byrne and Anna Shannon



Michael Duffy, Brett O'Sullivan



Ronan Sutcliffe with son Andy



Watch Jane Sutcliffe's video – <https://www.facebook.com/watch/?v=2603638936402193>  
 Watch Caoimhe Byrne's video – <https://www.facebook.com/watch/?v=285011259309824>  
 Donations for the Aughrim 10km June Challenge can still be made on Facebook byrneslondis or aughrimannacurracommunitygames



# ‘Who’s Zoomin Who?’

By  
**COLIN WHITE**

**W**ho gets the Aretha Franklin reference and who can guess the year? Zoom calls have really taken off during the pandemic with zooming happening at work and at play. Children have been taking to Zoom to connect with school and their friends. Extended families have become adept at setting up calls to keep in touch with those who cannot travel home and those who are cocooning.

Zoom, and similar platforms, have become the modus operandi for office and business meetings. We have a weekly staff meeting by Zoom and it has been great. It is an opportunity to connect with work colleagues at a higher level than can be achieved with a phone call as we get to maintain our bond as a collective.

Rather than ceasing its activities, our Board has become very proficient in their use of Zoom, holding regular meetings

and ensuring that business can continue as close to normal as possible. A growing number of our Branches are also embracing Zoom as a way of keeping in contact at a local level. The feedback has been extremely positive as it helps develop a sense of community with people checking in on each other.

It has been a strange time since that Leo Varadkar speech back in March. It has been a time of isolation, a time of uncertainty and a time of anxiety. However, technology has shown its value in keeping people connected.

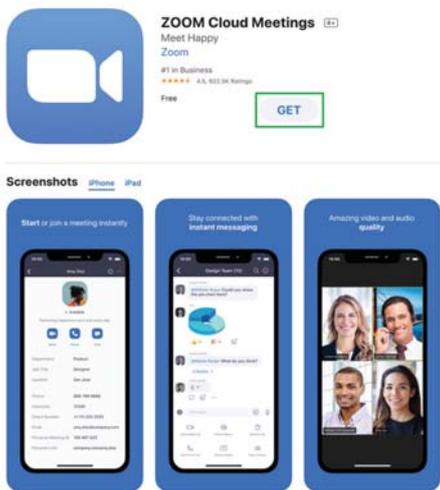
Opportunities for traditional socialising have been few and far between in recent months but people have been creative in their use of technology. We have people ‘meeting up’ for a coffee on Zoom or even going on Zoom dates! With a free option available, it is worth checking out Zoom or indeed looking at other platforms operating in the same space.

It’s **1985** by the way.



# A QUICK GUIDE TO ZOOM TELECONFERENCING

You do not have to have a Zoom account to join a Zoom meeting, but it will be an easier experience if you have downloaded the software/app beforehand. To do this, visit the website [www.zoom.us/download](http://www.zoom.us/download) and click download. On mobile or tablet, visit your App Store and download the Zoom app - it will look something like this:



When you receive an invitation to join a Zoom meeting, it will look something like this:

**Join Online:**  
<https://us02web.zoom.us/j/85293801943?pwd=L2x3NkxZbXVzUEExJQkdNOW5rTkFPUT093>

or

[www.zoom.us/join](http://www.zoom.us/join)  
 Meeting ID: 852 9382 1943  
 Password: 169043

**Dial in:**  
 01 653 3894

Meeting ID: 852 9380 1943  
 Password: 169040

You can see the instructions on how to join the meeting, including:  
**Join Online** - There are two links here. The first longer one is the direct entry link, and the second will take you to a generic login page, where you will be prompted to enter the **Meeting ID** and **Password**.  
 On a mobile or tablet device, you may be prompted to **'Open in App'**,

and on desktop or laptop you may be prompted to **'Open with Zoom Meetings'**. Click 'Yes' if you are given these options, and you will be taken to the meeting in the Zoom app that you previously downloaded.

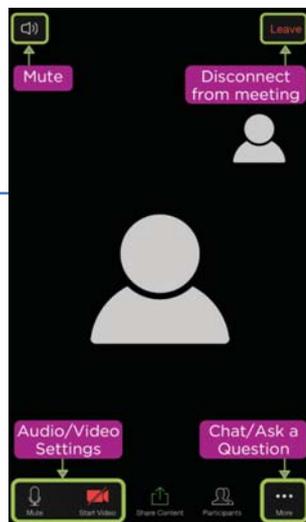
You may then be prompted to **Join Using Video** and **Join Using Audio** - give permission for these as they will allow others to see and hear you in the meeting.

**Dial In** - If you are unable to join using a camera device, you can dial in to all Zoom meetings. You will be taken through an automated service to enter the **Meeting ID** and **Password**.

Once you are in the meeting on a desktop or laptop, this will be your view:



Once you are in the meeting on a tablet or mobile, this will be your view:



The main controls on both types of device are fairly similar. They can be found on the bottom bar.

**MICROPHONE:** This controls you speaking to the meeting - you can tap to silence yourself (mute). On mobile phones you may be given the option to Join via Device Audio or Dial In. Joining via Device Audio is preferable.

**CAMERA:** This controls your video - you can tap the symbol to show yourself on video, or not. The following may be included in 'More' on mobile phone devices:

**CHAT:** This allows you to type a message to others in the group without speaking. You can use this to ask a question of your meeting host. They can reply using Chat as well.

**SHARE Screen:** This allows you to show documents on your screen for others to see.

**LEAVE Meeting.**

**VIEWS:** On the screen you may be given the option to change the display view to

**Speaker** (is the person talking visible on the screen with smaller thumbnail of previous speaker

**Thumbnail** (is the person talking plus small strip of up to 8 others in miniature

**Gallery** (view of up to 25 participants with active speaker highlighted). Not all devices allow this as space is limited, but if you can change between views you might find one you prefer.

**Volume:** Find out how to control the volume of the computer for the Zoom meeting.

## ZOOM ETIQUETTE

- Mute yourself if you are not speaking**, especially in large meetings and if you are not using headphones. Background noise can really interfere with the quality of a meeting, and if you are not using headphones the feedback from the audio you are hearing may cause issues too. Something as simple as shuffling papers can be picked up by sensitive microphones and the other meeting attendees will not thank you for it.
- Speaking of **headphones/earphones**, any with a microphone included will do. Many mobile phones come with free earphones included, but you can pick some up fairly cheap in most shops too. Not only will headphones improve what you can hear, they will make it easier for others to hear you.
- More lighting is better, but not behind you.** If you sit with a window or bright light behind you, you will appear as a silhouette on video.
- Join meetings on time**, if not slightly ahead of time to make sure your audio/video settings are working and fixing any issues will not impede on meeting time.
- Remember you are on camera!** There are plenty of incidences of people forgetting that everyone can see them - if you want to pick your nose, do it later!

# PROTECTING FROM SKIN CANCER FOLLOWING A TRANSPLANT

**P**atients who receive a renal transplant have an increased risk of developing skin cancer, and the skin cancer itself may be more aggressive due to immunosuppression associated with transplantation. Nonmelanoma skin cancer (NMSC), predominantly squamous cell carcinoma (SCC) and basal cell carcinoma (BCC), accounts for 90% of all skin cancers in transplant recipients. It is estimated following 10 years of immunosuppression 6.4% of patients will develop NMSC and 20 years post-transplantation, approximately 40-50% of caucasian recipients in Western countries will have developed at least one NMSC. The majority of these skin cancers occur on exposed body sites.

## NON-MELANOMA SKIN CANCER: SQUAMOUS CELL CARCINOMA

Squamous Cell Carcinomas account for over 1,000 cases of skin cancer annually in Ireland. SCC arise when UV radiation damages keratinocytes and have a scaly, rough texture, they can also be painful. They arise usually on the scalp, back of the hands and other sun exposed sites such as the lips.

## RISK FACTORS FOR SQUAMOUS CELL CARCINOMA

- Chronic UV exposure
- Fair skin type
- Being on immunosuppressive medication
- Smoking



Squamous cell carcinoma



By **PROF. ANNE-MARIE TOBIN, PhD FRCPI**  
CONSULTANT DERMATOLOGIST  
TALLAGHT UNIVERSITY HOSPITAL

Treatment for SCC requires wide local excision, in rare cases radiotherapy or chemotherapy may be required. Squamous cell can spread to lymph nodes and cause death therefore it is very important that patients do not ignore any new red lumps on their skin

Patients may develop numerous areas of rough red skin which are slightly scaly on the scalp, forehead and on the back of the hands. These are known as Actinic Keratosis and are not cancerous but a marker of sun damage to the skin cells. SCC are more likely to arise in these areas. Actinic keratoses are usually treated by freezing the damaged cells with



Actinic keratoses on the forehead

liquid nitrogen known as cryotherapy or killing the damaged cells with a chemotherapy cream called Efudix or Aldara.

## NON-MELANOMA SKIN CANCER: BASAL CELL CARCINOMA (BCC)

BCC form the bulk of non-melanoma skin cancer, with more than 10,000 diagnosed annually in Ireland. Basal carcinomas arise when deeper cells in the skin sustain genetic damage from chronic UV exposures. They tend to occur in sun-exposed sites usually on the face, arms and upper back as red bumps with a slightly shiny appearance or as an area of scarring.

There are three main types BCC, each of which has a different appearance:

- **Nodular:** Often appear on the face as a shiny, skin coloured lump with small blood vessels visible. May ulcerate or bleed.
- **Superficial:** Tend to occur on the chest, back and limbs. Usually appear as a red, scaly patch.
- **Morphoeic:** Usually scar-like, hard lumps in the skin. Tend to be more aggressive.



BCCs are usually painless and grow slowly over months to years. While they almost never spread to other



parts of the body, if untreated they can spread locally and cause damage to the skin and surrounding structures, such as the eyes, nose or ears.

### RISK FACTORS FOR BASAL CELL CARCINOMA

The most important risk factor for skin cancer is exposure to UV, usually from the sun. Frequent sunburns, sunburns in childhood, chronic sun exposure over many years (in work or recreational activities) and tanning salon use all increase the risk of basal cell carcinomas.

Fortunately, BCC are entirely treatable by surgical excision.

### MELANOMA SKIN CANCER

Transplant patients also have a slightly elevated risk of developing melanoma. Melanoma can arise on any body site. They tend to occur more commonly on the back in men and the lower legs in women. A melanoma may arise in *a new or an existing mole which changes* in size, colour, outline or shape and the ACBDE rule is a good metric for assessing change.

- be **A**symmetrical
- have an irregular **B**order
- have multiple **C**olours
- have a **D**iameter greater than 6mm
- **E**volve, enlarge or change

Another good rule of thumb is the 'Ugly Duckling Rule'. A person's 'normal' moles tend to look alike, resembling each other in shape, colour and size. Check any mole that is different from the others, the so called 'ugly duckling'.

More rarely melanomas can arise as a *new red bump* in the skin known as an amelanotic melanoma.



### RISK FACTORS FOR DEVELOPING MELANOMA SKIN CANCER

The main risk factors for developing melanoma are:

- Occasional, intense sun exposure
- sunburn, particularly during childhood
- Sunbed use
- A previous melanoma or other non-melanoma skin cancer
- Multiple large or unusual moles
- Immunosuppression
- Many moles (of different sizes, shapes and colours)
- A fair complexion: pale skin, blue eyes, red/blonde hair, freckles
- A family history of melanoma

### TREATMENT OF MELANOMA

Fortunately, if melanoma is detected early it is entirely treatable by surgical excision.

It is important that patients who have received a kidney transplant know to keep an eye on their skin and to present without delay to their doctor with any new red lesions, a scarred area that won't heal or a changing mole. Transplant recipients should also be linked in with a dermatology service for skin surveillance.

### PROTECTING YOUR SKIN FROM THE SUN

As highlighted in each of the skin cancers above UV radiation from the

sun causes structural DNA damage to the skin increasing the risk of skin cells to undergo malignant change, hence it is vital that transplant recipients protect their skin from the sun. In recognition of the increased risk in 2018, the HSE re-imbursed SPF 50 for transplant patients with a medical card\*.

Below are the the simple SunSmart code messages are the **5 S's**:

1. **Slip** on clothing that covers your skin, such as long sleeves, collared t-shirts
2. **Slop** on sunscreen on exposed areas, using factor 50+ all year round
3. **Slap** on a wide-brimmed hat
4. **Seek shade** – especially if outdoors between 11am and 3pm
5. **Slide** on sunglasses to protect your eyes.

Sunscreen should be applied liberally and evenly 15-30 minutes before sun exposure to allow it time to dry, and again shortly after going outdoors to ensure that all areas are covered. Reapply frequently, at least every two hours and after perspiring, sport, swimming, or friction (such as towel drying).

Covering up with clothing which has a tight-enough weave (if you hold up to light and can see light through it it will not protect) is the most hassle-free method, so long-sleeved t-shirts and trousers, hence sunscreen needs only to be applied to hands and face. The same is true of wearing a hat especially in men who have hair thinning.

There are excellent resources for patients on the Irish Skin Foundation website [www.irishskin.ie](http://www.irishskin.ie), including a nurse-led helpline and also the Irish Cancer Society [www.cancer.ie](http://www.cancer.ie)

**\*EDITORIAL COMMENT:** Only people who have had organ transplants and who are medical card holders may access sunscreens for free, and then only through the Discretionary Hardship Arrangements (which involves a community pharmacist taking certain details and filling in a form). While overall the move to make sunscreen available, for free, to some transplant recipients is a positive one, the move does not go far enough and should have been extended to all organ transplant patients. For transplant patients without a medical card, who access their treatments through the Drug Payment Scheme (DPS), the HSE's Medicine Management Programme has concluded that, "as high quality products can be purchased at low cost in many pharmacies and supermarkets," DPS patients can afford to buy sunscreen themselves – Disappointing and short-sighted.

GAA FOOTBALLER'S

# 100KM RUNNING CHALLENGE

IN MEMORY OF  
ORGAN DONOR  
FATHER, RAISES  
OVER €8,000  
FOR THE IKA

Brothers Aidan and Stephen Carroll



The late Paddy Carroll  
after running a  
Dublin City Marathon

**A** Dublin club footballer was sixteen years of age when his late father became an organ donor saving three lives after the 53-year-old suffered a fatal brain haemorrhage. To honour the memory of his father and to raise organ donor awareness Aidan Carroll (now 21) from Bayside in Dublin 13, with the help of his family, organised a successful fundraiser for the Irish Kidney Association, the **100k May Challenge**, which raised €8,402.

Paddy, a father of three and seemingly fit and healthy and a regular marathon runner, collapsed in early March 2015 while he was erecting a goal net at a pitch in St. Anne's Park. Aidan's team Naomh Barróg was about to play a match against rival club St. Vincent's. Paddy who coached Aidan's gaelic football team was a huge Dublin supporter and was highly regarded in GAA circles. As a mark of respect, when Tyrone

played Dublin in Croke Park a few days after Paddy Carroll passed away, a minute's silence was observed for the much-loved stalwart during half-time.

Almost 100 family members, friends and supporters, many of them who played with Naomh Barróg where Aidan is now in the senior squad, each committed to run a total of 100km over the month of May in Paddy's memory while fundraising for the IKA and sharing their involvement on their social media to highlight the importance of organ donation.

Aidan, a DIT business student, said of the successful fundraiser, "When I heard that the IKA was forced to cancel or postpone the Organ Donor Awareness Week 2020, which was to take place in April, as a result of the Covid-19 pandemic, I was determined to step-up and do something myself to raise awareness.

It doesn't seem like five years ago since my father died, and I think about him a lot and also



Aidan and Stephen Carroll with their late father Paddy

wanted to do something in his memory whilst observing social distancing. My father ran numerous marathons including New York and Barcelona and therefore a running event seemed like an obvious way to tie-in with this.

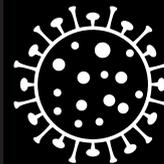
My family are proud of him and take great consolation in knowing that as he was an organ donor he saved three people's lives. After his death we were deeply moved to receive letters from the families of his grateful organ recipients who are now enjoying a new lease of life. The letters are anonymous and were passed on by the organ donor coordinator, but they mean so much to us as it gives us comfort to know they are doing well because of our father.

We attended the IKA's Service of Remembrance and Thanksgiving, which takes place at Corpus Christi Church in Drumcondra every October, and is attended by hundreds of families like ours who also made the important decision to donate a family member's organs. The Service will take place again this year in October, but it will be in a different form. For the first time, as a result of the pandemic, it will be a Virtual Service and my family will be watching it online.

"My mother, brother and sister and our extended family would like to thank all the people who took part or supported the Challenge in any way and to Naomh Barróg and the GAA county board for honouring my father's memory.

We would also like to thank the staff at Beaumont Hospital who cared for my father while he was on life support and for the sensitivity they demonstrated at his end of life and in guiding us through the organ donation process."

## SURVEY ON THE...



Coronavirus  
**COVID-19**  
Public Health  
Advice

# Impact of COVID-19

**We would like to invite you to participate in our study about the experiences, concerns and support needs of people on dialysis and kidney transplant recipients who have been cocooning due to COVID-19.**

**Interim results can be found on centre pages (27-30)**

### WHO CAN TAKE PART?

Any transplant recipient/person on dialysis aged 18 years and over, living in Ireland, who has been advised or has chosen to cocoon due to COVID-19 can take part. We are equally interested in the views of people who decided to cocoon and those who did not (or who started cocooning and then gave it up).

### HOW LONG WILL COMPLETION TAKE?

Completion of this survey should not take longer than 20 minutes.

### DO I HAVE TO TAKE PART?

No. It is entirely up to you whether you choose to take part, or not.

### IS MY PARTICIPATION ANONYMOUS AND CONFIDENTIAL?

You do not have to provide your name or contact details in order to complete the survey.

The information you give us will be kept confidential within the project team. We will store it on a password protected computer and will not sell it.

### CAN I WITHDRAW MY DATA FROM THE STUDY AT A LATER DATE?

As the survey is completed anonymously, we cannot withdraw your data once you have entered it. **Please note** that partially completed surveys may also be used.

### WHAT WILL HAPPEN TO THE DATA?

We will share the results of the survey widely, with health professionals and policy makers. We hope that this will help them to improve support for patients who are 'cocooning' and their families, now and in the future.

Once the survey has finished, the data will be stored on a password-protected computer at Donor House.

### ARE THERE ANY RISKS INVOLVED?

There are no risks to your health and personal safety from taking part in this study. You are free to omit any questions you do not feel comfortable answering.

If you would like to receive a copy of the survey results please be sure to include your email address at the end of the survey.

### WHO CAN I CONTACT IF I HAVE ANY QUERIES?

The research is being conducted by the Irish Kidney Association. You can contact the project coordinator; Colin White ([colin@ika.ie](mailto:colin@ika.ie))

To take part please visit [www.ika.ie/survey](http://www.ika.ie/survey)

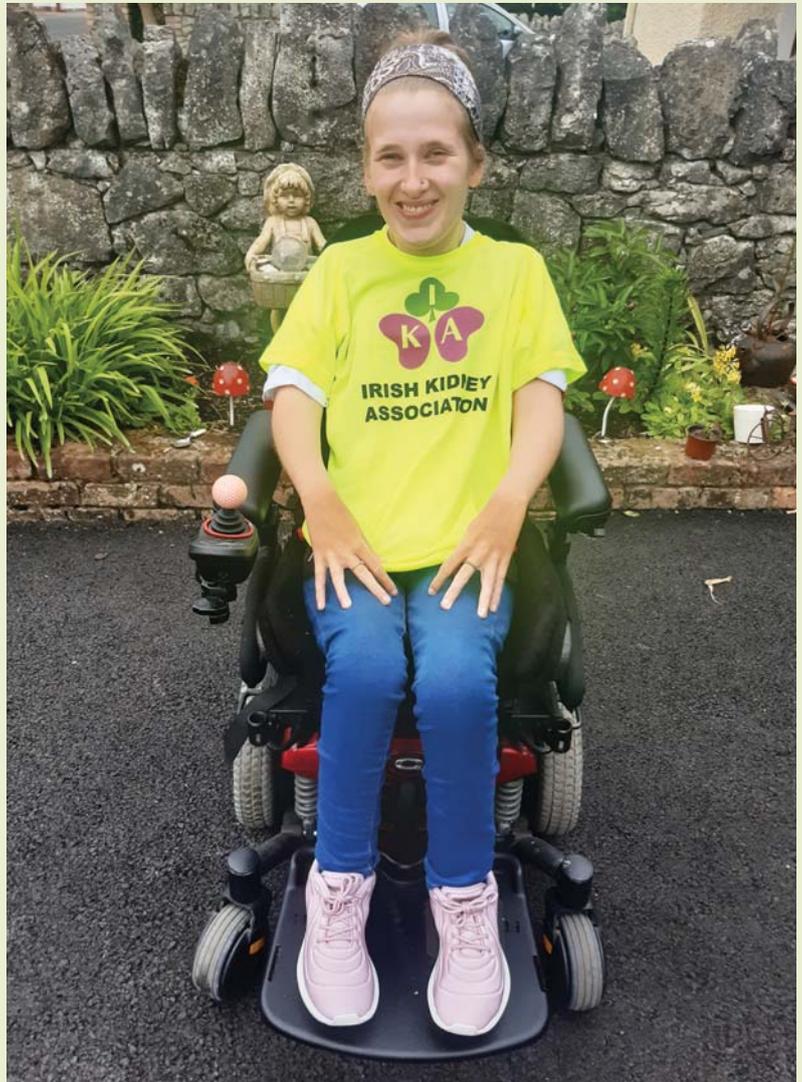
# Sarah fundraises nearly €5,000 on a virtual journey

**A** 21-year-old woman from Askeaton, Limerick who has Cerebral Palsy has raised just under €5,000 for the Irish Kidney Association by travelling on her motomed for 58kms, to represent the same distance to and from Limerick county's Gaelic Grounds Páirc na nGael. Sarah O'Sullivan, a full-time wheelchair user, decided to undertake the virtual journey over seven days during the Covid-19 lockdown in March to raise organ donor awareness.

Sarah's inspiration for undertaking the challenge was to honour the memory of her late cousin Jack Walsh who was 19-years-old when he died tragically in Spain two years ago and saved four lives through organ donation. She also paid tribute to her late grandfather, Bobby Walsh, who passed away before she was born, and who underwent a kidney transplant in 1986.

Sarah was overwhelmed that her initial fundraising target of €200 was far surpassed when a much greater total of €4,970 was raised via the JustGiving online platform through donations from her family, friends and supporters in her community who, enthusiastically, came behind the life-saving cause.

Sarah's mother Bríd said, "Sarah is passionate about sport including hurling and football and is a Munster rugby fan. Our family's support for organ donation and the IKA goes back decades as my late father had a kidney transplant. Gaelic Grounds seemed like



the obvious location for Sarah to choose for her virtual journey during lockdown and the IKA was the obvious charity for whom to fundraise for.

"I am one of five siblings and we have a very close extended family and we all carry donor cards and all the children were brought up knowing that we supported organ donation. When they became teenagers, they opted to carry donor cards including their late cousin Jack.

Sarah had a huge grá for her cousin Jack and they were the same age when he died. We all miss him terribly, but we take heart in knowing that he saved the lives of four other people through organ donation. We are all very proud of what Sarah has done in Jack and her grandfather's memory."

*Left: Jamie, Sarah, Liam Og, Brid and Liam O'Sullivan celebrating at the end of Sarah's fundraiser with the Limerick flag as well as Irish flag raised in the background for frontline staff during the Covid-19 lockdown.*



# INTERIM REPORT ON THE IMPACT OF COVID-19 SURVEY

We shared a survey via our website and our social media channels to get a flavour of the impact of the COVID-19 pandemic on renal patients (people on dialysis and transplant recipients). It is quite a broad-based survey and we would like to thank all those who have already taken the time to respond. This Report is an interim result and we would encourage those who have not participated in the survey to go online at [www.ika.ie/survey](http://www.ika.ie/survey) – we would love to hear from more patients, especially those on dialysis. The more respondents we have the stronger the argument created by the survey results.

## BREAKDOWN OF RESPONDENTS BY TREATMENT TYPE

You will see that the majority of respondents were transplant recipients. We decided to look at the responses of people on all dialysis treatment types and transplant recipients to see what learning points, if any, emerge.

## ANSWERS SPECIFIC TO PEOPLE ON DIALYSIS

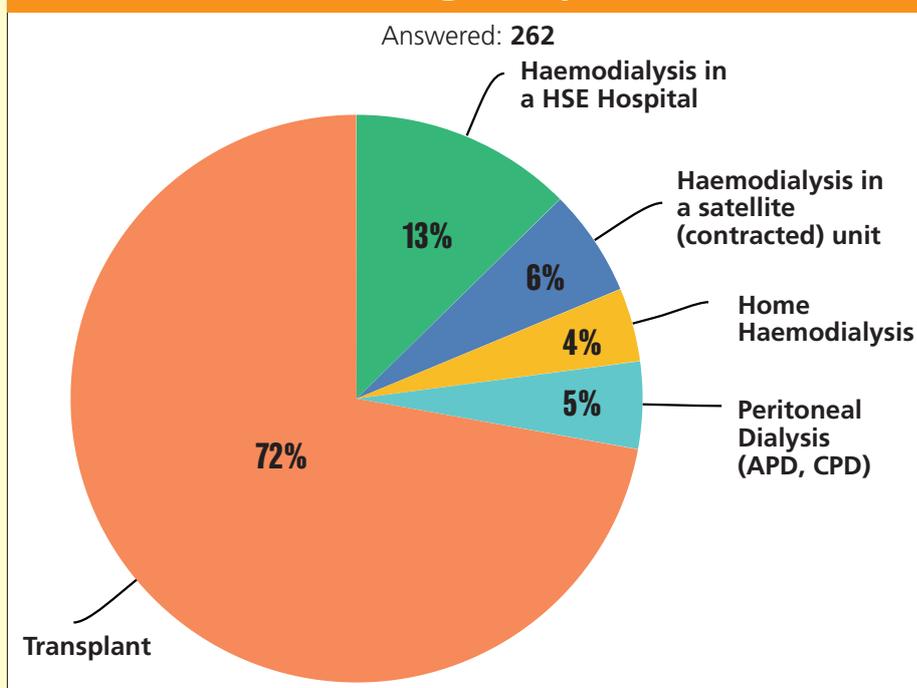
The first number of questions were specific to people on dialysis and the findings were interesting. 46% of respondents experienced a change to their transport arrangements to help ensure social distancing on the journey to and from dialysis.

49% of all respondents used some form of HSE provided transport whilst 51% managed their own transport with 36% of all respondents availing of the 30c per km managed by the dialysis unit.

The vast majority of respondents maintained their normal dialysis schedule with only 12% experiencing changes. Whilst understanding that people travelling to dialysis cannot completely cocoon it was noteworthy that 12% or approximately 1-in-8 of the respondents did not abide by the principles of cocooning at home.

**Q2**

Please describe your current treatment for end stage kidney disease.



## COMPARING RESPONSES FROM PEOPLE ON DIALYSIS WITH TRANSPLANT RECIPIENTS

It is interesting to note that 17% of dialysis respondents and 20% of transplant respondents made their decision to cocoon based on advice from their respective medical teams with the vast majority basing their decisions on information available in the media or on their own initiative.

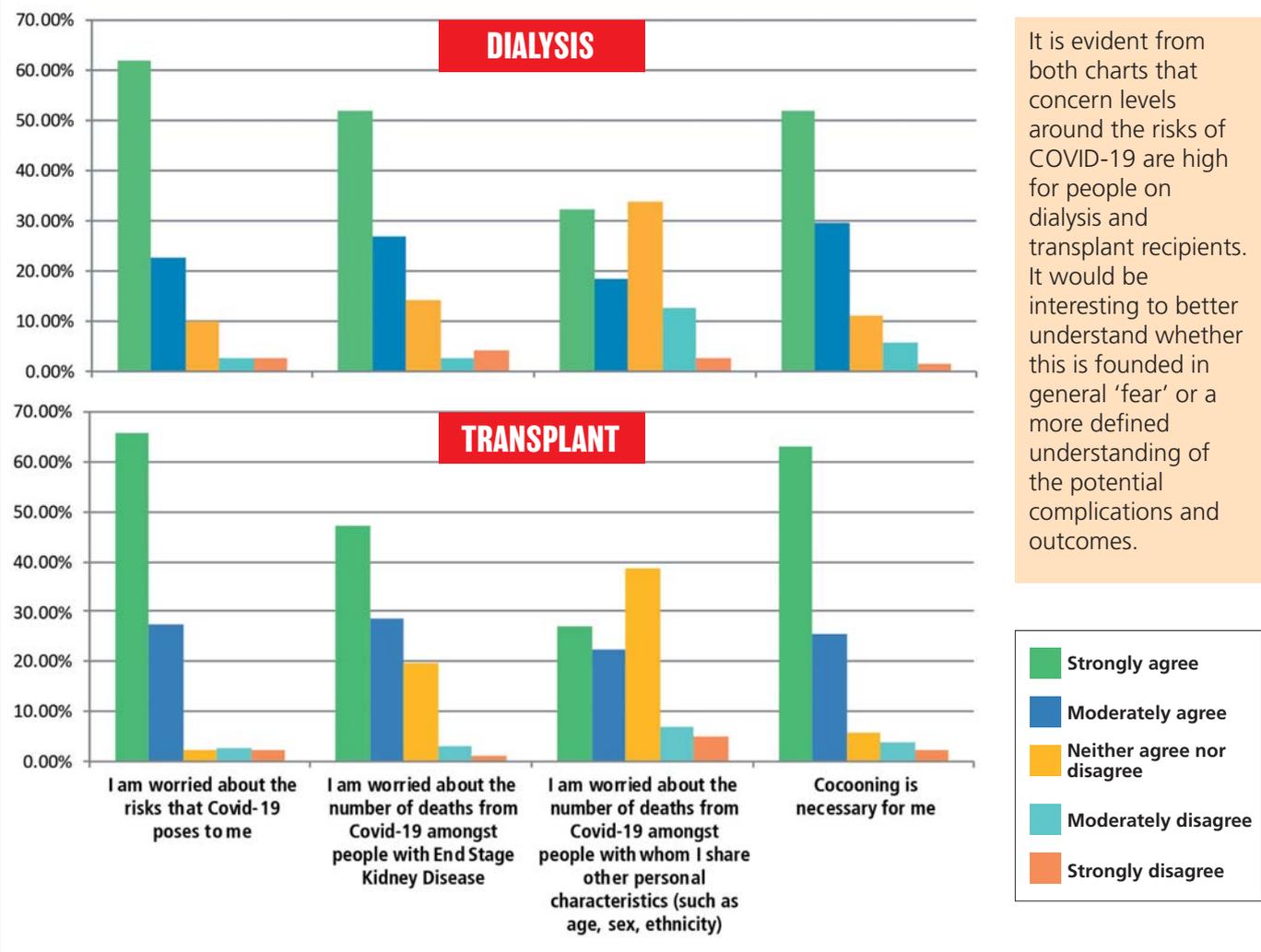
The restrictions that have come with cocooning have proven to be varied in their challenges. For both transplant recipients and people on dialysis, not

leaving home and not attending family gatherings have proven either moderately difficult or extremely difficult for over 50% of respondents.

The activities at home where a significant number of people have not 'strictly' cocooned are, eating alone and using separate crockery, etc. – with the activities felt to be difficult to manage or socially important not to change.

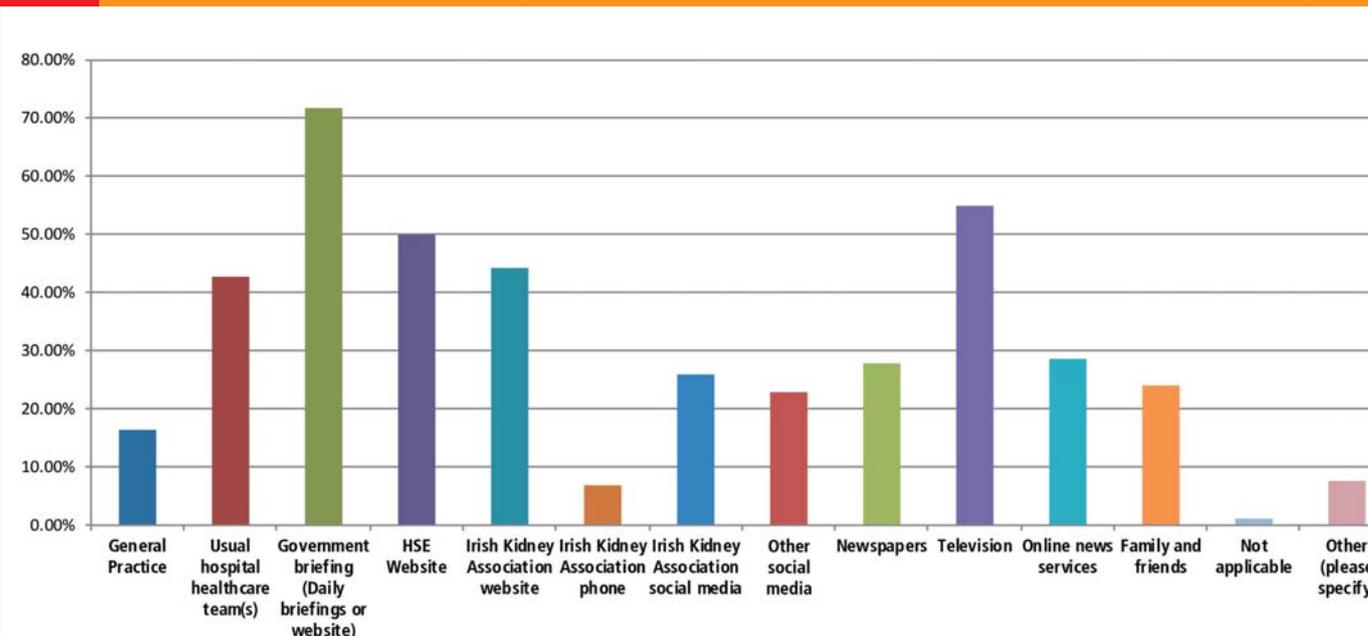
**Q18**

**To what extent do you agree with the following statements?**



**Q20**

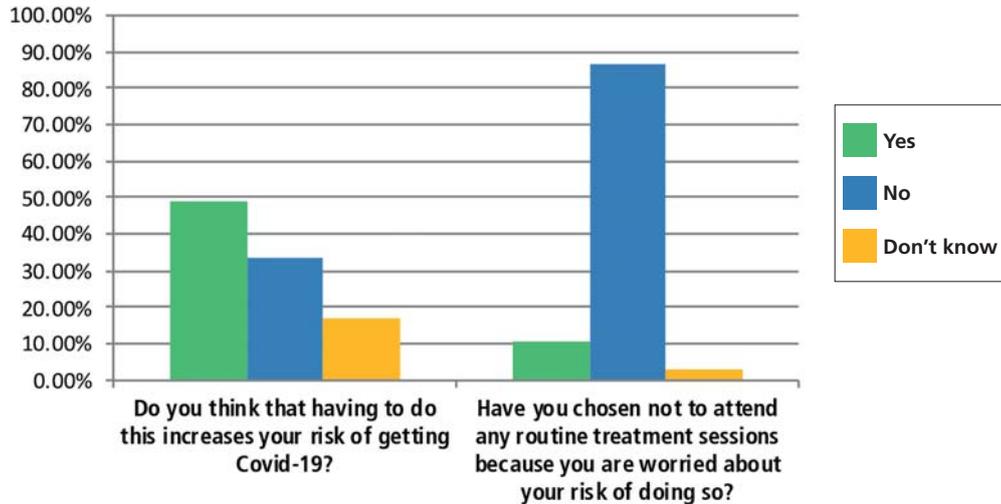
**From what sources have you received information about COVID-19 and cocooning?**



The responses show the value of the government briefings and the HSE website when it comes to being informed about the Covid-19. It would be expected that people on dialysis are more likely to get information from their medical team as the majority are attending their unit three times a week.

**Q35/36**

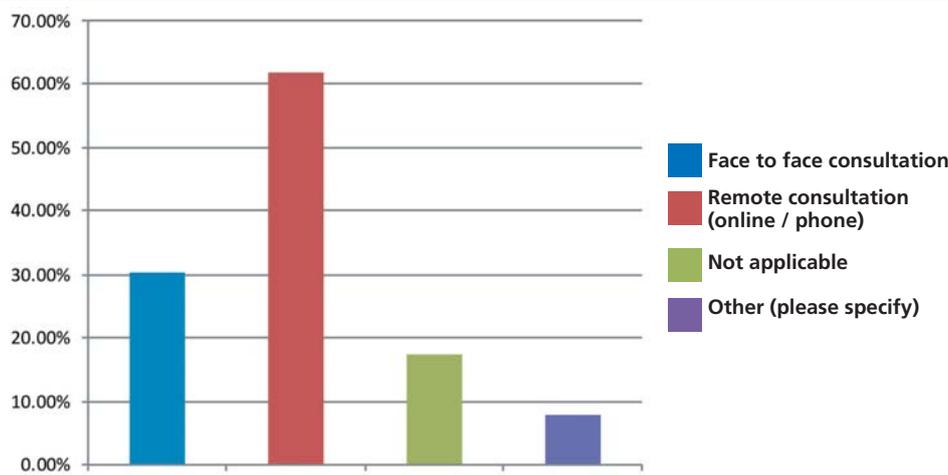
**80% that need to leave home in order to receive dialysis or to have bloods taken answered these questions**



It is important to note the significant number of respondents who felt that the nature of their treatment put them at increased risk in relation to the virus. It makes sense given that it involves leaving the safety of home.

**Q37/38**

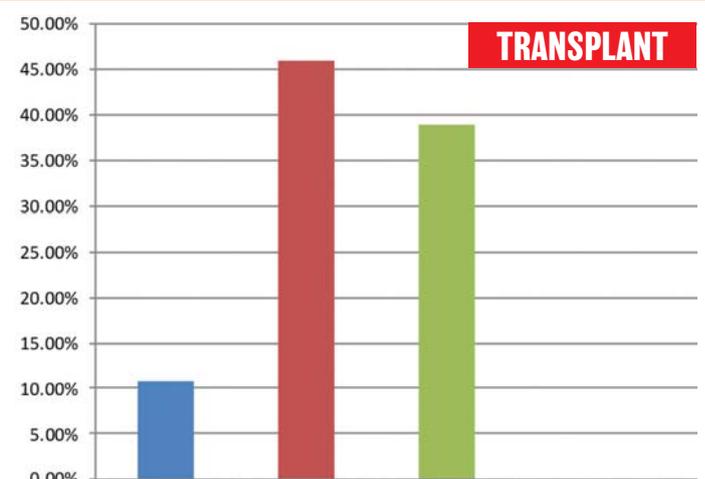
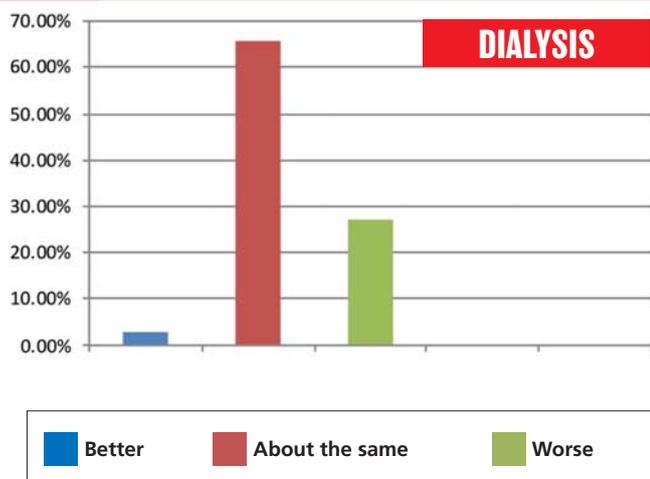
**73% that had a consultation with their health care team while concooning answered how these were conducted**



A significant number of consultations by phone. It will be interesting to see if this is a legacy of the pandemic and will we see it happen into the future. Is it something that patients want? Are there lost opportunities from face to face contacts – patient demeanour, visual review for issues such as skin cancers, etc.

**Q47**

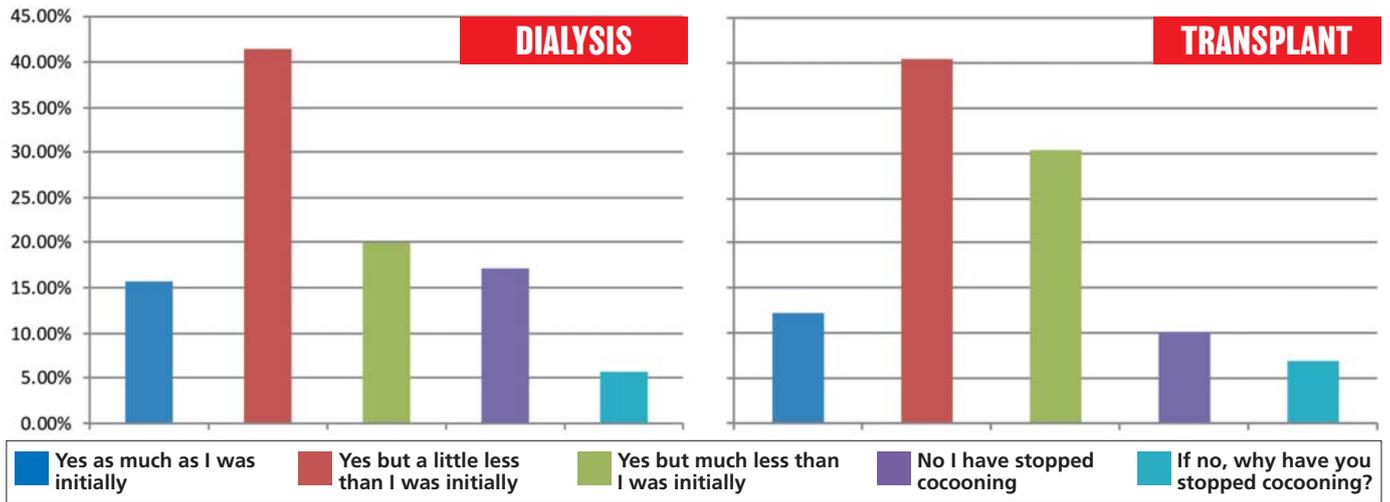
**How does your mood during concooning compare to how it was before?**



An interesting question about the mood of respondents. Analysing it has to be tempered with the fact that responses may have been impacted by a person's mood on the day. That said, there is a significant number of responses in both groups indicating a worsening of mood. This will need to be watched to see if there is a long term legacy that needs to be managed / supported. The responses from both groups to the question about support give some insight.

**Q49**

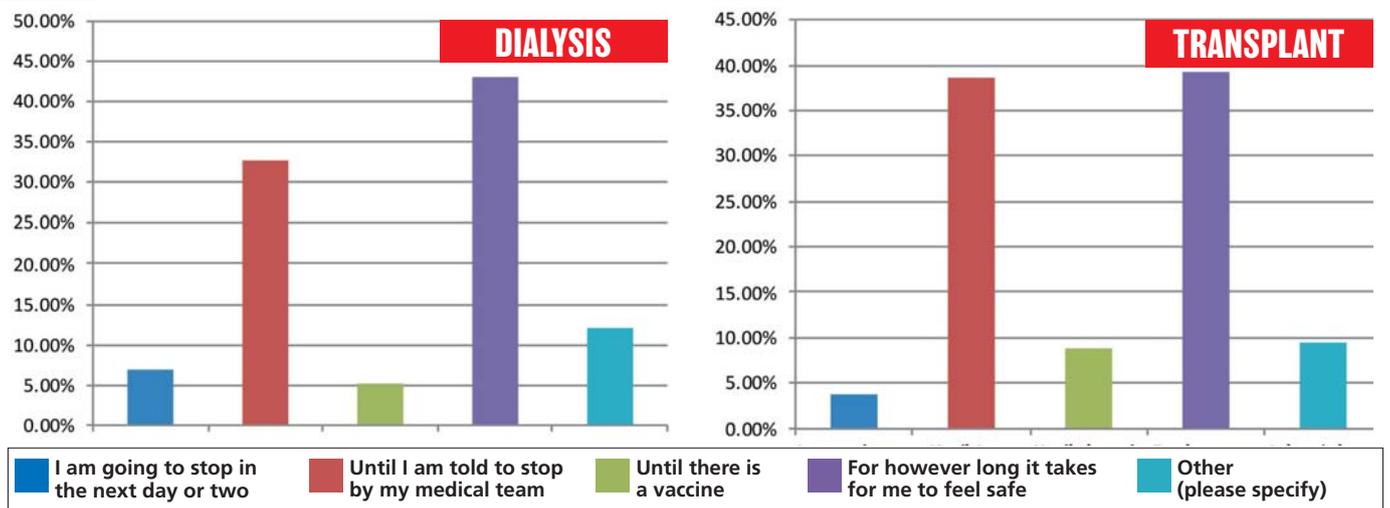
**With restrictions being relaxed, are you still cocooning?**



We can see in the responses to Q49 and Q50 that whilst people have been stepping back a little from cocooning that there is still a notable level of caution.

**Q50**

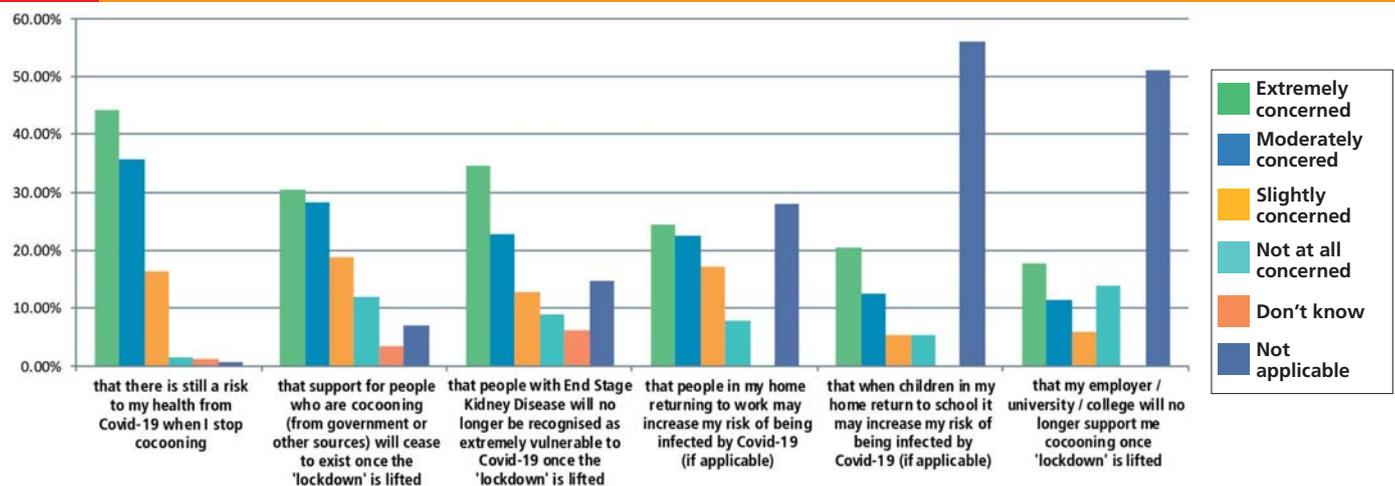
**If you are still cocooning, how long are you going to continue to do so?**



Both dialysis and transplant have a similar caution and the significant numbers, over 30%, are going to wait until told to stop cocooning from the medical team and about 40% are saying they will cocoon for as long as it takes to feel safe.

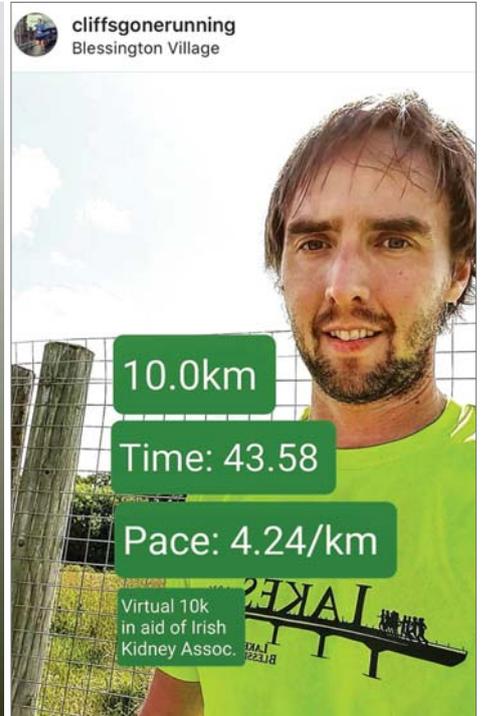
**Q52**

**How concerned are you about the following?**



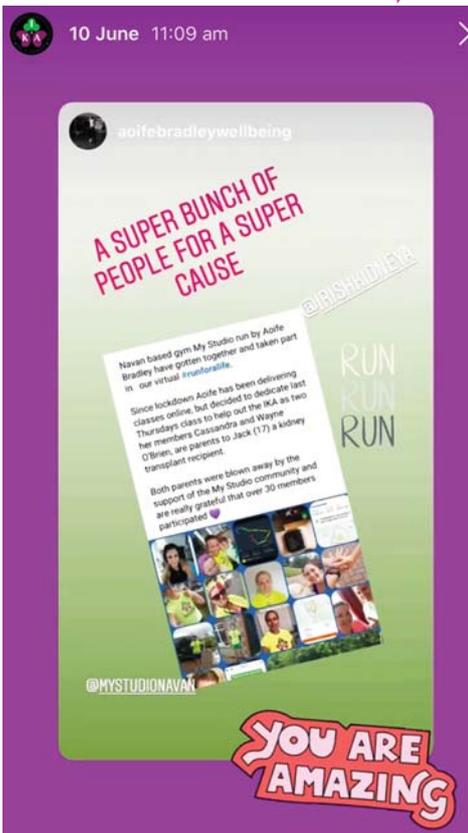
The overall sentiment from the survey is that people are concerned about their future health but also finding some aspects of cocooning challenging from a mental health perspective as well as a financial imperative.

**In conclusion, it is probably fair to say that participants in the survey are concerned about their health yet keen to re-engage with society and underpinning it all is a desire for reliable information specific to their needs. To paraphrase one respondent, we are forgotten when it comes to the cocooners as the focus has always been on the over 70s.**



VIRTUAL

# Runforalife.ie





Sisters Julie Sutcliffe and Susan Mulligan



Susan Mulligan, a kidney transplant recipient came out of cocooning to meet her sister Julie Sutcliffe, a dialysis patient, over the June Bank Holiday weekend at the Phoenix Park Dublin to highlight the Irish Kidney Association's Virtual 'Run for a Life' which celebrates organ donation. Julie was the inspiration behind the Aughrim 10km June Challenge (see page 18).



Sam Kinahan

Our 12th annual 'Run for a Life' took on a new form this year after the COVID-19 lockdown made it impossible to host our usual day in Corkagh Park. Not to be deterred, we instead ventured into the world of virtual events and invited people to donate €10 and then run, walk or jog the distance in their own areas. Starting on Friday May 29th and ending on Sunday June 21st, there were just over three weeks for people to take part. We were blessed with some fantastic weather in that period which made it all the more inviting to get involved – and get involved people did!

In their usual enthusiastic style, our supporters were more than happy to pull on their runners and head out in the name of Organ Donation Awareness. Every week we saw registration numbers grow and were tagged in hundreds of photos on social media as people joined in and shared their own stories or why they were inspired to get involved.

We were also delighted to receive numerous videos of support. Our Ambassador for Organ Donation Ray D'Arcy sent us a video urging people to sign up, as did lead singer Bee from the band *Chasing Abbey*. A very popular video of support was sent by Sam Kinahan (6) and his big sister Ali (9), who celebrated Father's Day with a 5km walk almost exactly a year after Sam received a kidney from his dad Ivan.

As always Transplant Team Ireland were on hand to show us how it's done, with several team members producing great times for the leader board! Team Manager Colin and team doctor Obi joined in on the fun too, inspired by the zest for life that the Team always brings to a challenge.

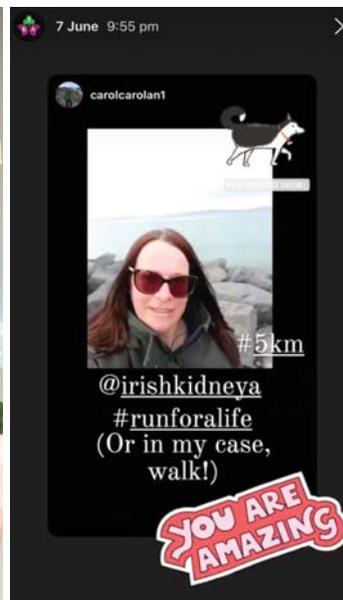
As restrictions began to ease over the course of the event, a couple of our branches were able to host 'socially distant' versions of the Run.

The Kilkenny Branch enjoyed a walk on the River Barrow, whilst the IKA's Renal Gaignamanagh, whilst the IKA's Renal

Counsellor, Aoife Smith, organised a full-day event in Blessington, Co. Wicklow. Supported by Tracey Flahive, mother of organ donor Conor who saved three lives when he passed away in 2008, Aoife's day had 115 participants and raised €1491.

In just over three weeks, we had registrations from not just all over Ireland, but also all over the world – people signed up to take part from the UK, Australia, South Africa and more! In the end, we had 417 online registrations (325 individuals and 92 families) and an additional 28 signed up on the day with Aoife – a fantastic result for an event that almost didn't happen!

We hope to be back in the park next year, but keep a virtual element so that those spread across the globe or who cannot make it on the day can still join in. Thank you to everyone who took part in our first ever Virtual 'Run for a Life' and helped us to make it a success whilst promoting the important message of organ donation!





# BLESSINGTON

# Runforalife.ie

*Pamela O'Connor, Laura Dignam, Lenny Ryan, Aoife Smith, Tracey Blanchfield*



*Aoife Smith, Saoirse Smith, Lenny Ryan, Amanda Bissett*

*Aaron Byrne, Craig Derham*



*Niamh Crawl*



*Roisin Glennan, Elaine Ash*



*The Walsh Family supporting their Mum, Mrs Walsh who received kidney two years ago*



*Tracey Blanchfield's family – Tracey donated her 9-year-old son Conor's heart and kidneys in 2008*



The Rigney sisters



Max Clifford & Louise Gilligan (husband & wife) with brother Rob Gilligan who ran in memory of their uncle who was a transplant recipient



Tracey Blanchfield with her sister and niece



Carol & Michael Kelly



Mark Derham  
Aoife Smith



Pamela O'Connor, Laura Dignam



Aoife Smith with brother Ian and partner Rojina



Aoife Smith  
Amanda Bissett



Derham family



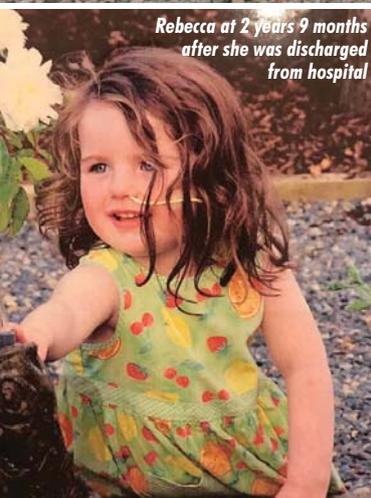
Dedan Shine, Niamh Croul (winner of Women overall 10km Run)



Rebecca and Lauren are pictured with Ryan Tubridy at the IKA launch of Organ Donor Awareness Week in 2010. Pic: Justin Mac Innes / mip.ie

# Rebecca's 10th kidney transplant anniversary

Written by 16-year-old Rebecca Osgood-Daly from Ballinlough, Co. Roscommon as she marked the 10th anniversary of her living donor kidney transplant which took place on 27th July 2010. Rebecca has just completed Transition Year (TY) at Ballyhaunis Community School where her kidney donor mother Bernie is a secondary school teacher. Throughout her teens Rebecca, along with her mother Bernie, have been active in advocating for organ donation. They have given several media interviews and school and other public talks to increase organ donor awareness and demonstrate how Rebecca is a shining example of how organ transplantation transforms lives.



Rebecca at 2 years 9 months after she was discharged from hospital



Rebecca and her sister Lauren



Bernie and Rebecca Osgood-Daly with presenters on RTE Two Tube when she was 12 years old in 2016

I can't really remember much before the transplant operation. Just a woman over my bed and she placed a Disney Princess activity book next to my arm. I can't recall what she looked like, so I was probably feeling the effects of the anaesthetic. It seemed to me that this woman was comforting me, in her way telling me that I'll be ok and that I have no need to worry anymore.

In 2008 I was six-years-old when I went on dialysis, both at home and in Temple Street Children's Hospital. I wasn't able to leave my room from 8pm to 8am and the dialysis would keep me awake at night.

I wasn't able to do what most kids my age mainly took for granted like eating normally, to swim carefree and staying up late for the *Late Late Toy Show*. I would miss one day of school each week in order to go to Temple Street.

My mom told me that as a young child I found it difficult to talk to people, so I didn't have many friends and had a hard time making new ones. This was because I spent so much time in

hospital!

From what I remember during the time around my transplant and the next three and a half weeks of recovery at Temple Street, the nurses and doctors who took care of me were really kind especially my play specialist Olive and Doctor Atif and they played games with me while I was confined to my bed as I wasn't able to walk.

At the time of my transplant my dad stayed with me in Temple Street while my mom, who had given me her kidney, stayed in Beaumont Hospital where she underwent her operation.

Afterwards I enjoyed being allowed to try some new foods for the first time such as chips, pizza and Pringles. Although the first food I wanted to try – sushi, was unavailable. I decided on sardines instead which I liked.

Loads of people including my classmates, my family and my parent's co-workers gave me gifts. Each day I felt my strength coming back as I learned how to walk again.

On the day I was ready to leave hospital it also

happened to be my 7th birthday, so all of the nurses and patients in the ward came into my room with a special birthday cake and sang happy birthday. I remember that special time fondly.

Ten years later, I am confined to my house due to COVID-19. It reminds me of my days on dialysis, but the difference today is that people all around the world are going through this isolation with me.

I am forever grateful to my mother and happy that my transplant continues to be a success ten years on. By sharing my story, I hope that I can inspire others to think about organ donation and how a transplant can help people like me.



*Bernie and Ian Day and their daughters Rebecca and Lauren are pictured with Ryan Tubridy at the IKA launch of Organ Donor Awareness Week in 2010.*

*Pic: Justin Mac Innes / mip.ie*



## Alexander's Dialysis Routine

**Alexander is a 78-year-old haemodialysis patient in Tallaght Hospital. He is dyslexic but he wrote a book for children called *The Golden Puppy*, available through Amazon.**

**In his earlier life he travelled around the world which may sound like fun, but he missed Ireland and his family. He had booked a one week holiday in Portugal, but COVID-19 arrived the day before he was to travel and all flights were cancelled. He is now wheelchair dependent and an avid reader.**

**Mis-spellings are intentional.**

**D**ialysis is a word I was unable to spell for many months. I had the same problem with 'Protoneel?', but that is behind me now. I have my bedroom back and the mean jokes of my living with Baxter are now behind me. Dislecia is another word I have problems with, and now my new word is Homodialisis which now controls my life.

For most people a week is Monday through Friday with a weekend for fun and family, I remember them well, almost with affection. Now with my homodialisis set for Monday, Wednesday and Friday, I wake up at quarter past five, a light breakfast, ten pills from the box marked breakfast, a bathroom all for myself, dress as directed by my all loving wife, mind you without her I would still be running around barefooted due to a hip op' that went wrong.

And then the wait, by the ever-patient taxi driver, or by me mostly ready for the scheduled six thirty pick-up - a habit I had to get used to when I was number one of four, then the journey took up to forty minutes, with the return trip occasionally exceeding an hour!

And now, with the new rules and regulations, it's almost like having a limo all for myself, with a journey time of just fifteen minutes.

And then, my three days on dialysis and four days for me were changed.

I am now on dialysis four mornings a week, my Saturday stolen away, my weekend sleep in, our early morning cup of tea, relaxed family breakfast come lunch, all gone!

My four dialisisis days have evolved into wake up at a quarter past five, dress, breakfast, teeth, and that routine that seems to ensure privacy, the removal of the access dressings, yes both, the In one and the Out one. The

prepping of the bathroom worktop, the laying out of the ELMA, the cream, with an amazingly complex 'see through' plasters. Sharing the cream over the In and Out areas that disfigure my arm I am finally masked up and ready for the taxi.

Yes, there are the positive aspects, there is a TV over each bed which leads, to some amusement, for the rush to get the Zapper, while I ask the tallest of the nursing team to turn my TV off. The idea being that I can read, until they turn off the lights that is. Now I have a new idea, in fact I am now spoilt for choice, Podcasts, music to suit all tastes, and audio books. Mind you, with a good audio book, the dimmed lights and the soft footed nurses one has the tendency to nod off, one gets woken by the blood pressure routine, some times every fifteen minutes, but one is barely aware as one is trying to catch up on the story. And finally wake up time. Bandages fly, nurses in control instruct us to sit up, shoes on, dissy? Yes or no! Get weighed, good bye. And I'm still wondering which way is up as I am dropped into my wheelchair, pausing to grab my obglitry sandwich, I am rushed down to the taxi, ramp down, strapped down, and still in a daze delivered home to eat the sandwich with its bold instruction to Eat Within Two Hours or Destroy!

After such a morning I stagger up the stairs and collapse into my bed for at least two hours, and finally with luck fit enough to be with my family, the wife working from home, my son, if not at work, commandeering the TV with some overloud game.

Luckily, it's sunny outside, and that is where you will find me, with a cup of tea, ten pills, and a book.

Stay safe and watch your diat.

**ALEXANDER AGER, Email: alexander.ager@gmail.com**

# Coachford community raises €17,000

*Coachford community celebrates life of deceased kidney patient clocking up 858 running kilometers*

**Community spirit shone brightly in Coachford, County Cork when celebrating the life of a local mother who passed away with organ failure during Covid-19 lockdown which raised just under €17,000 for the Irish Kidney Association.**



*Declan and Sandra Murphy.*

**A**s a mark of respect to the family of the late Sandra Murphy, over 90 people donned their running shoes to undertake individual runs and collectively clock up a distance of 858 kilometres. The runners included students and teachers from Coachford College who play hurling and football with Ahabullogue and some other GAA Clubs as well as soccer players from Coachford AFC.

Sandra was mother to 2nd and 6th year students Eric and Mark, and wife to their father, local Centra store owner Declan Murphy. Sadly, Sandra passed away on 18th March 2020 due to health complications arising from kidney disease. Popular students Mark and Eric are both talented Gaelic and soccer players with Aghabullogue GAA as well as Coachford AFC. Their fellow students and teachers and their sports clubs' players and supporters came together, while staying apart, to honour Sandra's memory as Covid 19 restrictions prohibited them from attending her funeral.



*Above and right: The Murphy family.*

The two running events were promoted on the school's, GAA and soccer club's social media. Donations to the Coachford College's event raised €1,020 while Coachford AFC's event accumulated €15,683 through the Just Giving platform.

While raising organ donor awareness the first running event, which had a GAA twist, took place over three days in May and involved students and teachers at Coachford College running and clocking up an impressive 400 kilometres. An uplifting video was compiled by Coachford College's teacher Shane Creed who features in it along with brothers Mark and Eric Murphy. The footage also features 60 other individual players representing clubs from 12 localities pucking a sliotar or kicking a ball and symbolically passing on the baton ball to the next person to take up the running challenge. A link to the video is [https://youtu.be/9zoA\\_HZskRY](https://youtu.be/9zoA_HZskRY)

Cousins Luke and Billy Casey at Coachford AFC, who are friends of Mark Murphy, set a target for club players, past and present, to run 300 kilometres between them representing the distance to the



national kidney transplant centre in Dublin at Beaumont Hospital.

Coachford AFC's Kenneth Hogan, who works in Dublin, did the final leg of the virtual route in the capital city by stopping off at the Aviva Stadium on the way. Kenneth's brother, John Hogan, undertook his 10k run in Wales taking in the Principality Stadium, Cardiff while Dhani Merrick did his run in Toronto, where he now lives and works taking in the iconic Scotia Bank Arena and the Rogers Centre on his route.

Other diaspora also supported the event through donations. In the end more than 30 club soccer players, past and present, covered a distance of 458 kilometres in ten hours on Saturday 30th May which raised close to €16,000.

Coachford AFC's treasurer Peter O'Riordan said, "the death of



**Mark Murphy after completing his 10km run in memory of his late mother Sandra.**

Sandra had a deep impact on all the members of our club who felt fortunate to have known her. She was a great supporter of the club and was always on the sidelines cheering on her sons Eric and Mark. Her passing away during lockdown, prohibiting funeral gatherings, presented us with a challenge as we really wanted to find a way to pay our respects to her husband Declan, a coach and past player and her sons who play for the club. It was wonderful to be able to find a way to do this and we could never have anticipated the level of support it achieved from our club, Coachford's village community and its diaspora while increasing organ donor awareness."

Declan Murphy, said, "I was humbled and deeply grateful to the people of Coachford and the wider community for their profound expression of support to our family on Sandra's passing. They found a wonderful way to celebrate her life, while raising funds for the Irish Kidney Association and increasing awareness around organ donation. Sandra had been undergoing dialysis treatment for polycystic kidney disease. She underwent an operation to have one kidney removed. We were disappointed last year when the living donor kidney transplant operation, at Beaumont Hospital, which Sandra



**John Hogan outside the Principality Stadium in Cardiff.**

and one of her close friends were to undergo, was halted at the eleventh hour. This was as a result of an unforeseen medical issue arising just before Sandra was to be wheeled down to theatre for surgery. Following this Sandra's health continued to worsen causing her liver function to be severely compromised. Most of her final year leading up to her passing away in March was spent as a patient at the renal unit at Cork University Hospital. We are grateful to Consultant Dr. Eva Long and her team at CUH for their professionalism and care. We would also like to thank the nursing and medical staff who cared for her during the time she spent at St. Vincent's University Hospital in Dublin and Beaumont



**Kenneth Hogan outside the Aviva Stadium in Dublin.**



**Dhani Merrick outside the Scotiabank Arena in Toronto.**

Hospital. Part of Sandra's wonderful legacy is that in the celebration of her life after death our community has raised funds which will go to the Irish Kidney Association to help other kidney patients like her. My family takes consolation from this."

Teacher Shane Creed, Coachford College explained the motivation for the fundraiser, "we were all deeply saddened with the death of Eric and Mark's mother Sandra. It was a particularly challenging time for her sons and indeed all of the students during the pandemic which brought much anxiety and uncertainty. I know the whole community's thoughts and prayers are with the Murphy family. We wish Mark every success with his Leaving Certificate results and look forward to seeing Eric back at school in September.

The format of the fundraiser allowed us to demonstrate our sympathies to the Murphy family while observing social distancing and guidelines and doing something positive. By engaging in events, which were both physically and mentally uplifting for all the students and teachers, we were also able, with the valued support of Aghabullogue GAA Club and Coachford AFC, to honour Sandra's memory and help raise awareness about the plight of people with organ failure while raising vital funds for the IKA."

# It's heating up...

## TIPS TO MANAGE FLUID INTAKE DURING SUMMER DAYS

By

**JEAN MURPHY**

and

**BARBARA GILLMAN**

REGISTERED DIETITIANS

MATER MISERICORDIAE

UNIVERSITY HOSPITAL

and

**GRACY NASRALLA**

HUMAN NUTRITION STUDENT

UNIVERSITY COLLEGE DUBLIN



**F**luid is one of the key parts of the diet in the management of kidney disease. With kidney disease you may not be able to get rid of enough fluid from your body. You may need to measure your fluid intake and keep to a daily fluid allowance to help manage your blood pressure, and swelling of your ankles.

Managing your fluid intake may help limit damage to your heart and help prevent breathlessness. We are all unique and fluid allowances vary with the amount of remaining kidney function, type of dialysis, if any, and other medical conditions you may have. If you are unsure if you need to change your fluid intake or are unsure of your daily fluid allowance ask your dietitian, doctor or nurse.

A fluid allowance is one of the most difficult dietary restrictions to follow and it can be more challenging when the Irish summer makes an appearance. Below are some key points and tips to help stick to your fluid allowance during the hot weather.

### KEY POINTS TO REMEMBER WHEN MONITORING FLUID INTAKE:

- Each morning measure out your fluid allowance and put this in a jug or bottle in the fridge. Every time you have a drink or add fluid to food pour the same amount out of the jug/bottle in the fridge. You will then see how you are using your fluid allowance.
- Remember to count all foods that are fluid at room temperature in your fluid intake. This includes gravy, jelly, yogurt, ice cream and ice cubes.
- Use the traffic light guidance system found on many food packaging to avoid foods high in salt. Choose the foods that are low in salt, green in colour.

With all this to help manage your fluid intake all that is left to do is enjoy the summer while it lasts!

### TASTY TIP:

Experiment with different flavoured sugar-free cordial and use the 20-40ml ice-pop moulds available in the supermarket.

# Tips to help manage thirst while on a fluid restriction

Avoid eating salty and very spicy foods as they will make you thirsty and make it difficult to limit your fluids.



Measure a small cup or glass. Measure the volume and work out how many you can drink in a day.



Fluid with medications can often be forgotten. Aim to keep fluid with medications to a total of 200 ml or less where possible.



Sucking on an ice cube can be refreshing and last longer than a sip of water. For extra taste try ice-pops or homemade ice lollies.



If your mouth feels fresh, it won't feel as dry. Brush your teeth or use a chilled mouthwash regularly.



A portion of juicy fruit within your fruit allowance can be used to refresh your mouth.



Sugar free chewing gum, strong mints or a handful of boiled sweets can help relieve thirst.



There are pharmaceutical gels and sprays available which can help manage your dry mouth. Contact your kidney dietitian, doctor or nurse to add them to your prescription



If you have diabetes and your blood sugars are high, this will make you very thirsty. Talk to your dietitian, doctor or nurse to see what you can do to improve your levels.





# Finds new ways to continue creative activity during Covid-19 restrictions



A high quality visual art resource pack was created by Waterford Healing Arts Trust (WHAT) for Renal Dialysis patients at University Hospital Waterford during the Covid-19 restrictions. Created by artist Caroline Schofield and WHAT, this pack was kindly funded by Viforpharma.

**W**aterford Healing Arts Trust (WHAT), which has been running an arts programme in the Renal Dialysis Unit of University Hospital Waterford for 14 years with funding from the Punchestown Kidney Research Fund (PKRF), found new ways to continue their creative work with dialysis patients during the Covid-19 period, supporting patients to make art, write and enjoy live music.

## VISUAL ART AND WRITING

Artist Philip Cullen works with patients in the Renal Dialysis Unit, supporting them in whatever artistic endeavour they are interested in...art, writing and music. When the Covid-19 restrictions came in, Philip quickly adapted his practice and began working online, using the Zoom platform and email, and over the phone with his patients, supporting them to continue creating paintings and writing.

Caroline Schofield, a professional artist trained and experienced in working with WHAT in healthcare

settings, devised a new art pack to support patients to create art independently. Entitled 'In Your Own Time', this high quality resource pack includes art materials, images of paintings from the UHW art collection and information about each artist, along with some prompts to support patients to make their own art. 100 packs were created so that every patient in renal dialysis has the opportunity to create art. This new initiative was made possible with the generous support of Viforpharma, who particularly wanted to support patients during the Covid-19 period.

## LIVE MUSIC

WHAT has run a successful live music programme in the Renal Dialysis Unit and on the wards of UHW for many years. Entitled 'Healing Sounds on the Wards', musicians who are trained to work in healthcare settings bring live music to the bedside, lifting people's spirits and transforming the atmosphere in the ward or unit. With the Covid-19 restrictions, these sessions had to be put on hold, but since late May the musicians have been returning to the hospital to perform music sessions outdoors. 'Healing Sounds Outdoors' sees the five musicians performing outside the windows of the Renal Dialysis Unit, and other outdoor locations around the hospital grounds, where patients and staff can enjoy summer tunes at a safe distance.



*Brenda Ronan, Clinical Nurse Manager of the Renal Dialysis Unit at University Hospital Waterford welcomes the musicians from Waterford Healing Arts Trust for a Healing Sounds Outdoors live music session for dialysis patients.*



*Musicians from the Healing Sounds team at Waterford Healing Arts Trust perform outside the Renal Dialysis Unit at University Hospital Waterford. (l-r) Alan Browne, Michelle Haberlin, Liam Merriman, Eoin O Meachair and Liam Kavanagh.*

Brenda Ronan, Clinical Nurse Manager of the Unit, is full of praise for all of these initiatives: "This has been a particularly difficult time for our patients who have been cocooning with extremely limited interaction with the outside world, family and friends. Being able to continue to create their own art and to write poetry, stories and memoirs has been hugely beneficial for their well-being and has helped them through this very challenging time. In the last month, it has been wonderful to hear live music coming in through the windows and to see the musicians playing for our patients – it gives everyone a tremendous lift and raises all our spirits. We are so grateful to WHAT for finding new ways to continue to support our patients, and to PKRF and Viforpharma for their financial support."

### ABOUT WATERFORD HEALING ARTS TRUST (WHAT)

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

A summary of this evaluation is available at <http://www.waterfordhealingarts.com/independent-evaluation-of-what-arts-programme-in-renal-dialysis/>

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

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



# Extra special Father's Day



**F**ather's day this year was extra special for dad Ivan Kinahan as it marked just over one year since he donated a kidney to son Sam (6). Sam had been on dialysis since he was 4 months old and family life has changed dramatically since the transplant.

Ivan said he has never regretted it and would encourage people to consider organ donation.

Mum Chloe said, "life has transformed hugely. Sam used to attend hospital three times a week for three hours, every single week whether it was Christmas time, birthdays, you name it. You can't take time off from dialysis.

"Since getting the kidney, these visits have slowed down considerably and we are now at a point where we only attend for review once every 6 weeks. In 2018, he attended Temple Street 159 times, in 2019 he attended 105 times and up to June this year, he has attended 9 times! It is amazing.

"Before the transplant Sam was unable to have a bath or go swimming because of his dialysis line. Chloe said, "he started swimming lessons in February and loved the water but unfortunately COVID-19 curtailed that

By **ELAINE KEOGH**  
Photos by: **CIARA WILKINSON**

for a short time. We can't wait to get him back swimming.

"His diet had been extremely limited but now at family meal time, which includes daughter Ali (9), she said, "it's a joy to watch him eat and inhale the smells of foods he never had."

Father's Day last year was earlier, on June 16th June, it was June 21st this year. Chloe said, "last year Ivan was just home from hospital and really feeling the effects of a major surgery and still quite unwell. The first 9 or 10 days post-transplant for Sam were quite challenging also.

"This year, we will be able to savour the day and the amazing life-saving gift that Ivan has given to Sam."

Ivan said, "I felt both lucky to have been such a close match and also privileged to be able to help him in a way I could only have dreamed to be possible in the early days of his diagnosis.

"It was always my hope to be able to help Sam in this way, but at times it seemed such a long way off. Even though the early days after transplant were tough, I've never regretted it for a second and would urge anyone considering organ donation to embrace the gift we all have within us," he added.

Sam was diagnosed with a rare kidney condition called Posterior Urethral Valve when Chloe was pregnant with him.

The family, from Baldoyle, Dublin, say, "you would be surprised what you can deal with when you have to. Sam's illness was diagnosed while I was pregnant and he started dialysis at 4-months-old and here we are nearly 7 years later still getting through it with a smile."

She said that many people do not realise that a transplant is not a cure but another form of treatment.

"Our family life has changed so much in the last 12 months but we know Sam may need another kidney or more as he grows and we want to urge as many people as possible to have that difficult conversation with their families about what their wishes would be regarding organ donation. Register for an organ donor card."

They have praised the support from the Irish Kidney Association (IKA) and took part in the Virtual 'Run for a Life' for the Association last month.

"We completed it on the last day, on Father's Day in a tribute to Ivan but to all donors, both living and deceased who selflessly save lives every day.

"The IKA is an incredible charity, we have made many friends and had amazing support from them, they really empower patients and their families to deal with a very serious illness in very practical and emotional ways. We would be lost without our friends in the IKA," Chloe added.

## SMEDIAS AWARDS 2020

# SPORTS WRITER OF THE YEAR



*Ronan Coughlan (right) and his classmate Ivan Smyth who represented UL at last year's Student Media Awards at The Aviva Stadium, Dublin.*

Congratulations to student journalist Ronan Coughlan (25) for winning the **National Student Media Awards 'Sports Writer of the Year'** for 2020, sponsored by the *Irish Daily Mirror*. The National Student Media Awards (SMEDIAS) are highly coveted and are considered to be the Oscars for student journalists across the island.

Ronan is a third year student in Journalism at the University of Limerick and has undergone two kidney transplants. He attended Temple Street Children's Hospital since he was a young child before his care as a young adult was transferred to Limerick University Hospital where he undergoes three times weekly haemodialysis treatment.

In 2014, Ronan's mother Deirdre donated her kidney to her son at Guy's Hospital in London, which enabled him to live three years dialysis free, a 'Gift of Life' which gave Ronan the springboard into third level education.

Now in 2020, Ronan hopes to commence home haemodialysis after extensive training under the guidance of Dr Liam Casserly and his team.

This is the second year in a row for Ronan to be nominated for this prestigious sports journalism award. Being nominated for the award last year also, while only in his second year of third level is a remarkable achievement and highly unusual.

Ronan was also nominated in a second category in 2019 under 'Best Radio Programme Arts & Features' for a Sports show he produced alongside his good friend and colleague Ivan Smyth.

Ronan has honed his craft and is a regular contributor to online sports news platform *Sporting Limerick* and *The Limerick Post* newspaper. He hopes to study a Masters in Journalism in 2021.

We wish Ronan a wonderful career in sports journalism and look forward to reading his report in a future edition of *SUPPORT*.



# Regaining your FITNESS



By COLIN WHITE

If you are like me, you may have become a little less active during the pandemic. For me, it was the change in routine that was my downfall. I used to go swimming on the way to the office every day and this obviously came to a halt when swimming pools closed and working from home became the new normal.

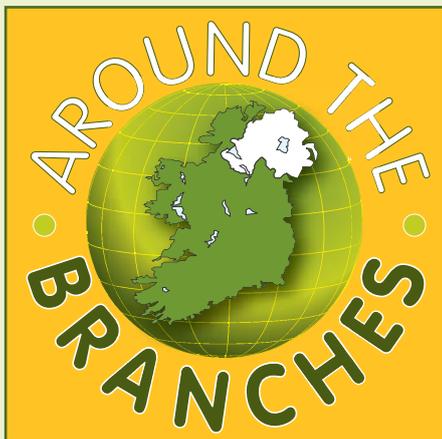
The first few weeks was all about adapting to new circumstances and developing a new routine with the focus being on remaining at home, as per government advice. My wife is on home haemodialysis so the importance of cocooning and avoiding unnecessary contact with others was not lost on me.

As the new routine settled I realised that I was missing something, I was not getting my regular exercise. My body was feeling it and starting to show it too! I decided to start walking in the early mornings to avoid meeting others and start regaining fitness. The Association's virtual 'Run for a Life' was a great motivator – to be part of something bigger...

I knew that I would have to temper my expectations and adjust my goals but more importantly I knew that it would be important to enjoy it. I am fortunate that we live in a seaside town so getting up early to enjoy the sights was an incentive. However, the recent change in weather has made heading out a little less attractive...I invested in a cross-trainer for the rainy days and I am determined that it will not become a glorified clothes horse!

I have found that, with a return to more frequent physical activity, I am feeling better both physically and mentally. I miss exercising some days and that's okay. Importantly, I am looking forward to what I will be doing.

It is all about doing what YOU can do and enjoying it! It is amazing how, with a little creativity, you do simple exercises in the home. You do not need to go to the gym, go for a walk, work in the garden, just remember to include a bit of physical activity in your daily routine and you will surprise yourself with how much better you can feel!



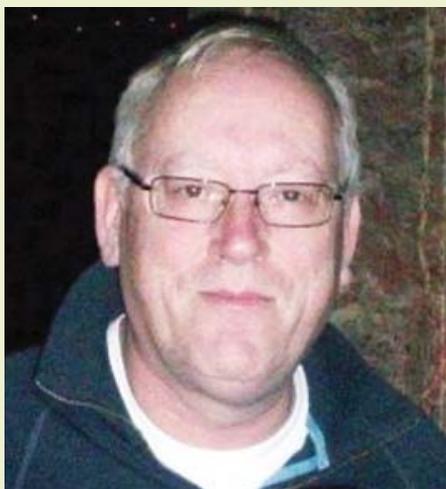
Greetings to all members of Dublin North. We hope that you have been keeping well over the past few months in these strange times.

### BRANCH MEETINGS

It is with great regret that we cannot avail of the Renal Support Centre for our monthly meetings.

Social Distancing and preserving the health of our members make it impossible even if the building had not been sequestered.

We look forward to the day we can meet again. Perhaps there is a solution we have yet to find to this problem.



*Adrian Hastings*

### ADRIAN HASTINGS RIP

It was with deep regret that we heard of the passing of recently retired staff member Adrian Hastings.

Ado, as he was known to his fellow workers was our former 'Computer Man' in Donor House. Anyone who visited there was sure to receive a friendly greeting from Ado.

Adrian was a transplanted patient, but additional health problems led to his retirement.

We extend our deepest sympathy to Adrian's family and friends.

Ar dheis Dé go raibh a anam.

# DUBLIN NORTH

By PATRICIA MACKENZIE



*Support Centre Staff as they are about to leave the sequestered premises on 14th March 2020. Simon Walsh, Patricia Mackenzie and Frank Burke.*

### A SMALL TRIBUTE

In Dublin North we are very conscious of the presence of Beaumont Hospital and the work undertaken by our dedicated doctors and nurses during and after lockdown.

Young men and women, some with young families, were willing to risk their own lives in the service of others. It is still so important to avoid the spread of COVID-19 not only to preserve our own health, but to respect the work and dedication of all

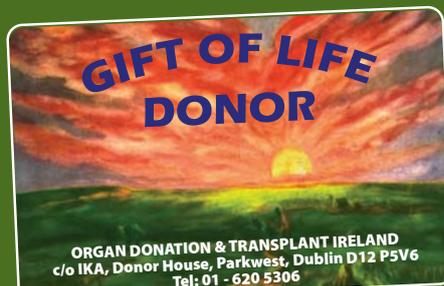
medical and hospital staff: the cleaners, porters, maintenance workers, kitchen staff and security staff, administration workers, ambulance personnel and taxi drivers and all whose dedication made a difference and saved lives.

Their courage and dedication makes us all proud.

We must continue to play our part.

In the meantime we look forward to better times as we strive to find a solution to current difficulties.

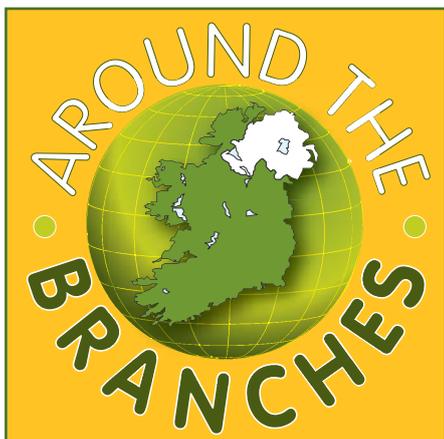
## FOR DONOR CARDS



## FREETEXT

## DONOR

## to 50050



### VIRTUAL 'RUN FOR A LIFE'

The Kilkenny Branch would sincerely like to thank all our patients, members, carers, their families and friends who got active on Sunday 21st June for the IKA's virtual 'Run for a Life' walk. It took place along the peaceful riverside 7km walk from Graiguenamanagh to St. Mullins and from Graiguenamanagh to Clashganny. A special 'thank you' to Cllr Peter 'Chap' Cleere, who met the group in Graiguenamanagh. He spoke of the great work being done for organ donor awareness. The success of the event was attributed to all parties involved on the day. The total sum raised was €664.15.

Members of The NoreValley Walking group also raised €135 by doing a social distancing walk in Woodstock Gardens, Inistoige, Co. Kilkenny on the day. A big 'thank you' to their commitment.

# KILKENNY

By ANN O'GRADY



We are grateful to Edward Hayden who advertised the walk on The Saturday Show, KCLR 96 FM. Edward invited John Lacey, Chairperson to speak to him about the walk before it took place.

In the words of our member Hugh Byrne: "Lovely day out and a good attendance, well done one and all, here's to 2021."

Arlene Corrigan (former Secretary): "Thanks to all for organising a great morning, weather was good and everyone in good spirits."

Finally many thanks to everybody who donated online at [www.ika.ie](http://www.ika.ie).

### ORGAN DONOR AWARENESS WEEK

The purpose of the walk was to raise awareness for Organ Donor Awareness Week 2020 campaign which was due to be held from 28th March – 4th April. The focus on the day was to promote awareness of the need for organ donation by distributing organ donor cards and 'Forget-Me-Not' flowers. We are very grateful to all who supported us and who continue to do so.

### ANNUAL GENERAL MEETING & BRANCH MEETINGS

The Kilkenny Branch anticipate

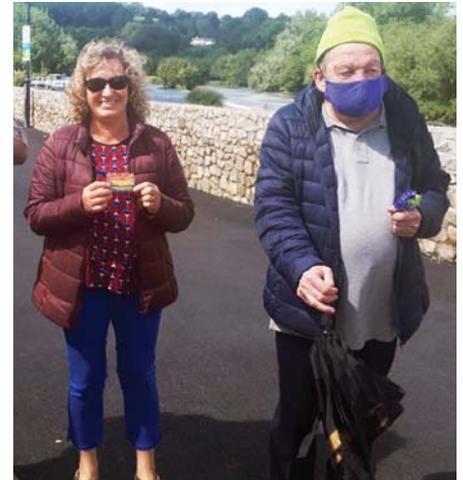
hosting the AGM in compliance with Covid-19 regulations if feasible. Similarly our Branch Meetings. If you would like to receive correspondence about the Branch Meetings you can contact the IKA to ensure you are registered.

### FUNDRAISING

The Branch will endeavour to fundraise in 2020 in compliance with Covid-19 rules and regulations.

Finally, we are truly grateful to everybody who has contributed to the Kilkenny Branch by way of fundraising or donations.





**KILKENNY BRANCH OFFICERS** can be contacted as follows if you would like to help our Kilkenny Branch:

**John Lacey**, Chairperson, Ph: 085-1328255,  
**Seamus Carrigan**, Board Member. Ph: 085-7683179  
**Therese Hanrahan**, Treasurer, Ph: 087-7796428  
**Anne O'Grady**, Secretary, Ph: 087-9232190  
**Bridie Lennon**, Assistant Secretary, Ph: 085-7051076

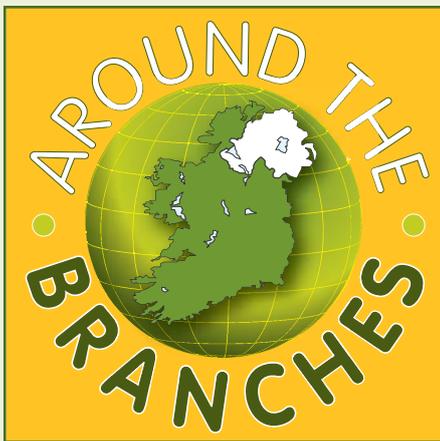
# DIALIZE CLOTHING



**DIALIZE CLOTHING** is a brand specialising in treatment friendly clothing designed by patients for patients. Paddy Cox, a patient himself realised how difficult it is when it comes to what to wear on dialysis days. The jacket is a hoody type with half zips, inner arm zip openings and chest openings for easy access for lines and fistulas doing away with the daily struggle of taking garments off or feeling cold on the dialysis machine. There are hidden pockets for insulin pump, medication and urinary catheters.

Their website is up and running and features a new treatment backpack that is bacteria friendly and also their thermal blanket. Coming soon is their brand new Dialize half zip, sure to turn heads with its unique design, new colour scheme, added comfort for patients to wear regardless of treatment days.

Check out their website [www.dializeclothing.com](http://www.dializeclothing.com)



Greetings in uncertain times.

Hope this finds you and your families all safe and well as we move through these strange times. The last few months have undoubtedly been bizarre, to say the least, as we all try to deal with Covid-19 Coronavirus in the best ways we can.

Over the past few months, opportunities to meet and greet have come and gone but we have not forgotten about you, our members. Our support is still available, so feel free to Call or Text **087-6243367/087-9392148**, Email: **ikaclare@gmail.com**, or Message us on Clare IKA facebook page.

#### **CHURCH GATE COLLECTIONS, WEST CLARE WALK AND OTHER FUNDRAISERS**

As you are by now aware, the Clare branch of the IKA unfortunately has had to cancel all our social and fundraising gatherings since mid-March and for the foreseeable future. Our monthly support meetings, the annual Mass of Remembrance & Thanksgiving in Ennis Cathedral were cancelled as well as all other upcoming Clare IKA scheduled events throughout the Summer/Autumn months. While all church gate collections are now postponed, on the first weekend of March, before the lockdown, IKA Clare church gate collection in Ennis Cathedral went ahead raising a mighty €2000. We sincerely thank the people of Ennis and surrounding areas who gave so generously and indeed all the volunteers who helped out over the weekend.

Another annual and staple event in the Clare branch diary is the IKA West Clare Walk which usually takes place on the May bank holiday weekend. Had it not been cancelled this year, it would have been 22 years running! We look forward to hosting this and

# CLARE

By NORETTA CLIFFORD



**Celbridge GAA Over 35's Gents 'Elite' football team – L-R: Back row: Aidan Burke, Tom Phelan, Sean Carthy; middle row: John Regan, Mark Cribben, Enda Gilchrist; front row: Tommy Stack and Mick Murray.**

other fundraising events in safer times. However, some people did get out for their own fundraising walks and none other than Gérardine Quinlivan and her son Evan, Clonlara, who raised €325 for Clare IKA in the process. Gérardine "thanked the Clare branch for the great work they do on behalf of renal patients." They presented the cheque to Gérardine's brother and IKA Clare Branch member John Mason. 'Thank you' Evan and Gérardine.



**Evan and Gérardine Quinlivan of Clonlara present a cheque for €325 proceeds of their recent walks to Gérardine's brother and IKA Clare branch member John Mason.**

I would like to take this opportunity to thank everyone who offered to volunteer at cancelled or postponed fundraising events already this year. No doubt your time and assistance will be required again in the near future.

Monica and Jackie Hickey and their family, Kilmaley, held a fundraiser also just before the lockdown, on Feb 29th in aid of Kidney Research UK. A night of fun with music, dancing and entertainment was enjoyed by all who attended at the Woodstock Hotel in Ennis. Also wonderful prizes were kindly donated and raffled off. Everyone was a winner. The Hickey family members, some of whom have inherited a genetic kidney condition, were overwhelmed by the generosity and warmth shown by those who attended. Well done to the Hickey family. In addition, Jackie set up a 'Gofundme' page to which €1026 was donated to the IKA. We sincerely thank the Hickey family, their friends and neighbours for their support.

Most of us will be all familiar with Prof. Austin Stack, Professor of Medicine at UL and Consultant Nephrologist at University Hospital Limerick who has been caring for Clare, Limerick and Tipperary renal patients throughout his esteemed medical career. We acknowledge his brother, Tommy Stack, along with his team mates and friends of Celbridge GAA who took part in a charity event running 15,954km and raising over €18,000 in the month of May for 5

# DUBLIN SOUTH

By JOHN SEMPLE



*Marguerite and Paddy Sneyd*

charities who benefited equally including the IKA. The 4 other charities were: Pieta House, AsIAm, One Day: Lesotho and National Breast Cancer Research. 'Thank you' Tommy and all at Celbridge GAA. And thanks to Prof Stack for highlighting the event to us at Clare IKA.

## **IKA BOARD MEMBER**

We would like to wish our new Board member, Sharon Fitzgerald, the very best in her role representing the Clare branch at IKA National Board meetings, normally held at Donor House but virtually in more recent times. Sharon kindly agreed to take up the role in May 2020. She is a long-time member of our branch and is herself a kidney transplant recipient. She will be a great advocate for Clare IKA renal patients.

We would also like to say a very big 'Thank you' to Tipperary Board Member, Joan Gavan.

Joan kindly stepped in and assisted the Clare branch of IKA at board level while we awaited the replacement of Peggy Eustace who retired as Board member for Clare IKA late last year. Peggy is still the active Chairperson for Clare IKA – thanks Peggy!

## **ENNIS OUTREACH RENAL CLINIC**

Prof. Austin Stack continued to hold his renal clinic at Ennis Hospital throughout the Covid-19 crisis. Patients were delighted that this service was maintained and we wish to thank Prof Stack and all involved to ensure this continued to operate.

## **HOSPITAL DIALYSIS TEAMS**

Clare IKA members, transplant recipients and, in particular, dialysis patients would like to thank all the nursing and medical staff at the hospitals where they attend, for their help and assistance during the Covid-19 lockdown. What a fantastic bunch of frontline staff!

## **CONDOLENCES**

Clare branch would like to convey our deepest sympathy to Geraldine and Joe Grace on the recent passing of Geraldine's father Kieran Murphy, RIP.

Our deepest sympathy to the family of Con Brosnan, RIP, on his untimely passing in March. Con was a long-standing chairperson of the Kerry Branch IKA and will be remembered for his great dedication to the IKA. We also extend our deepest sympathy to former transplant surgeon at Beaumont Hospital Mr David Hickey and his son on the recent tragic loss of their much loved wife and mother. You are in our thoughts and prayers at this time.

## **FINAL THOUGHTS**

The vital work of promoting organ donation and supporting patients continues albeit behind closed doors. The IKA has risen to the challenges of the Covid-19 health crisis and is willing to assist in anyway it can. We urge you all to continue to follow the HSE and government advice, staying as healthy and as safe as possible.

Members of Dublin South Branch have been keeping in touch on a regular basis through Zoom Conferencing. We have been finding the forum a good alternative until we get back to our regular meetings in the Plaza Hotel. Some members who were unable to attend our normal meetings have joined in the Zoom Conference. One of our former members who is now living in California, was able to join us on one evening, lending an international flavour to the proceedings!

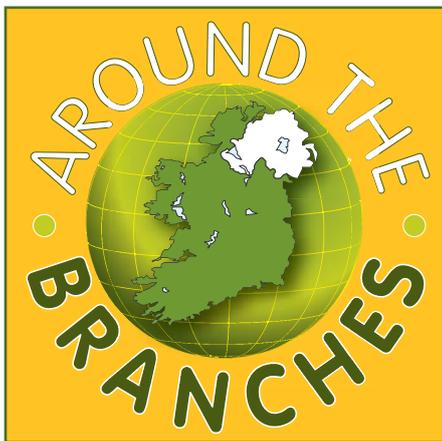
I would like to thank Aoife Smith, Renal Counsellor at IKA Donor House for joining one of our Zoom meetings recently. She was most interesting and helpful in suggesting ways of avoiding stress during these strange times. Aoife encouraged members to contact her should they need to talk.

Lots of our members have got behind 'Run for a Life' following Lenny Ryan's good example and I would like to thank those who have donated and encouraged their friends and family to also take part.

One of our members, Marguerite Sneyd, has written a memoir and will donate the proceeds from sales of the book to the Renal Units in Tallaght and Beaumont Hospitals and the IKA. As with so many other things, the pandemic has delayed the publication and launch of the book. Further news will follow.

I would urge members who have not already done so to forward me their email addresses so we can keep you informed of branch activities. You can send your details to [ikasouthdublin@gmail.com](mailto:ikasouthdublin@gmail.com).

I would like to wish all our members of Dublin South Branch an enjoyable and healthy Summer.



Welcome to the summer edition of SUPPORT.

We hope you are all keeping well and looking after yourselves. We are all living in a new way, spending lots more time in our homes and exploring our local areas, during this time of Covid-19.

We would like to say a special 'thank you' to all staff at the Dialysis Unit, Renal Home Therapies Unit and Clinics, University Hospital Waterford, for the excellent care they gave all patients during this difficult time of the Covid-19 pandemic. The Unit is very busy at the moment with a number of new patients starting dialysis and we wish them well. We also thank Waterford Healing Arts Trust at UHW who continually explore new ways and develop existing models to engage people in arts experiences in healthcare settings (see article on page 42-43).

The Renal Home Therapies Unit is currently being refurbished and the work should be finished in 5-6 weeks. The IKA has given €30,000 funding to make this project happen. This refurbishment will allow for a plumbed designated space for Home Haemodialysis training. Currently, there are two spaces to train/review peritoneal dialysis patients. Once refurbishment is complete they will have four spaces (including one isolation space/procedure room). The Home Therapies programme at UHW has increased 106% in 5 years (mostly due to the increased uptake in peritoneal dialysis as renal replacement therapy). The expansion/refurbishment will allow for the renal home therapies programme

# WATERFORD

By VERA FRISBY



*Bridget Norris, a dialysis patient at UHW who is recovering from a hip fracture is pictured with some staff members. Bridget made face masks and donated them to the patients in the Unit.*



*Jack Molloy, Manager, Azzurri Sport, Waterford, placing 200 face masks into Sr. Brenda's car, for patients at the Dialysis Unit, UHW.*

to further expand and develop.

Azzurri Sport, Waterford donated 200 face masks to the Dialysis Unit, UHW. We would like to thank Jack Molloy, Manager, Azzurri Sport for this very generous donation, it is much appreciated.

Unfortunately our Respite Centre at Tramore will remain closed for this summer due to Covid-19. Work has commenced on upgrading the four apartments, and hopefully, we will be open for the summer of 2021 when we look forward to welcoming

patients and their families to Tramore once again.

Since our last Branch meeting in March we have had to look at a different way of communicating with our members and conducting Branch Meetings.

We have successfully held Zoom meetings in May and June. It has provided a great opportunity to meet up in the virtual world and check in on our active volunteers. We expect to continue with Branch meetings via Zoom.



John O'Shea and Derek Frisby, Tramore, finishing their 10k 'Run for a Life'.



Joe & Frances Moynihan completing their 10k walk as part of the 'Run for a Life' fundraiser on Father's Day, June 21st.

If you are interested in joining our meetings contact [franceswaterfordika@gmail.com](mailto:franceswaterfordika@gmail.com)  
Our next Zoom Branch meeting will

be on Monday July 13th at 7.30pm and lasts for 1 hour approx. We look forward to meeting up with all then. New members are most welcome.

We send our sincere sympathy to the families of all our patients who have died over the past few months. May they rest in Peace.

## DUBLIN EAST & WICKLOW

By BERNIE DWYER

Hello to you all in these very unusual and sad times. Because so many of us have been cocooning there is unfortunately very little to report. So many events have been cancelled and, rightfully so, under the circumstances, and all we can do is keep in touch and hope for this to end soon.

On June 21st our IKA Counsellor Aoife Smith raised a fantastic €1,491.05 by organising a socially distanced 'Run for a Life' in Blessington. It was lovely to see this event in west Wicklow and well done to all who took part and helped including Lenny Ryan.

John, Catherine and I send best wishes to all our members and hope we can resume meetings again in the future when it is safe to do so. Please keep safe.



## SLIGO

By BRIAN McHUGH

The first meeting of the Sligo IKA branch after the lockdown was held on June 29, where social distancing was observed.

Plans were discussed for activities over the summer and into autumn.

A minute's silence was observed for the late John Coen, father of former Sligo branch secretary Geraldine Jenkins, who passed away on June 20th. RIP.

Sympathy was also expressed to the family of Joseph Gilmartin, Cartron Estate, Sligo who died unexpectedly at his home in April. Joseph had been a dialysis patient in Sligo University Hospital for a number of years. RIP.

Find us on:  
**facebook**<sup>®</sup>  
SLIGO IKA BRANCH

## TIPPERARY

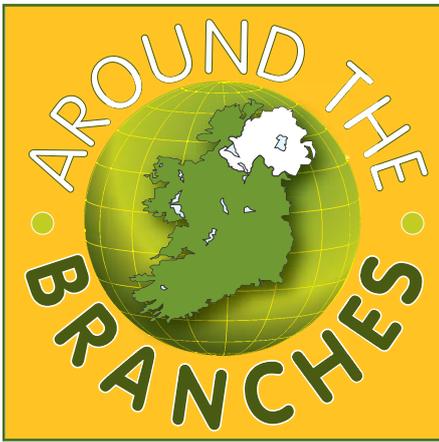
By ORLA HOGAN RYAN

I hope that everyone is well and safe in the county during these strange times of lockdown – a least the sun shone and is still shining for all cocooning. The gardens are all looking great.

There has been no meeting in the county but we have got into Zoom and had our chats there. This technology has been great for keeping in touch with one and all.

This year the 'Run for a Life' went virtual. Sheila Gregan and myself participated. Well done to all who took part.

We hope that all continue to stay well and safe.



### ZOOM SUPPORT MEETINGS

Due to people cocooning a lot of meetings and many fundraising efforts have had to be cancelled because of COVID-19. During a Committee Branch meeting in Cork we felt that at this difficult time for many, staying connected was important and that is when we decided to set up a Zoom support meeting to allow people catch-up and also express any concerns.

People really liked being able to meet even though, of course, missing meeting physically. We met once on Zoom at the start of May where we had a very good meeting with Aoife Smith, the IKA National Counsellor, explaining the service and how we can look after our mental health and we also had Treasa O'Neil, Renal Nurse to talk about how the weekly Clinic was working in Cork University Hospital.

Two weeks later Professor Liam Plant, from CUH, was kind enough to explain more about COVID-19 and how it affects people with



Sheena McDonagh.



Niamh, Oisin, Leonard and Sarah Moran, Killarney.



Sarah, Leonard and Oisin Moran, Killarney.

# CORK

By SALLY NAGLE



Leonard McCarthy, Ballinlough with Hannah and James. They just completed their 'Run for a Life', with Hannah and James on their bikes.

kidney disease.

These evenings on Zoom were both of great support to our members. We don't normally meet over the summer but look forward to meeting again in September – whether on Zoom or physically – it is unsure at this time.

### ENDLESS POSSIBILITY FUNDRAISER

The Endless Possibilities Fundraiser was set up by myself, Sally Nagle, as I wanted to raise money and awareness of organ donation as due to COVID-19 we were unable to have Organ Donor Awareness Week. The week is normally the biggest event for people affected by kidney disease.

I recorded two songs in Manor Studios in Cobh, Co. Cork back in 2018. One was an original song co-written with Mike O'Donovan, a songwriting friend from Limerick. It was called *Endless Possibilities*.

The other was a cover called *Don't Worry About Me* by Frances.

I have set up a GoFundMe page that has already raised €2300 for the Irish Kidney Association. If you would like to donate just go to GoFundMe and look for Endless Possibilities for the Irish Kidney Association.

### VIRTUAL 'RUN FOR A LIFE'

Many people in Cork City and County took part in the virtual 'Run for a Life' in their local areas. The daily couple of kilometres, around the local roads, were a great stress reliever and anxiety reducer during lockdown. Local members and friends were more than willing to jump at the chance to take part in the virtual online challenge.

Whilst our times and distances may not have put us in an elite athlete category, the challenge was a great boost, and also felt like a contribution to the IKA fundraising and awareness effort since our annual Organ Donor Awareness Week was cancelled.



# IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

## MEMBERSHIP APPLICATION FORM



**BLOCK CAPITAL LETTERS PLEASE:**

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

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

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

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

EMAIL:

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

Please indicate if any of the following apply to you:

PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED  YES  NO  
 Do not wish to disclose

Do you wish to receive our quarterly 'SUPPORT' magazine by  YES  NO  
*Please tick 'No' if your household is already receiving it* Post?  
 Or Email?  YES  NO

Can we correspond with you for notices of Annual General Meeting of the Association and Annual Director's Report by  YES  NO  
 Email?

Would you like to receive information on activities from your local IKA branch which entails us giving them the data from this form?  YES  NO

Would you like to receive information on the IKA Transplant & Dialysis Sports and Fitness which is based in Head Office?  YES  NO

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

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

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



# IKA DIRECTORY



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

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

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