

SUPPORT



AUTUMN 2020

The first virtual
35th Annual
Service of Remembrance
and **Thanksgiving**
will be broadcast on
RTÉ One television and
RTÉ Radio One Extra (LW252)
on **Sunday 15th November**
at **11.00am**



IRISH KIDNEY ASSOCIATION CLG

(Company Limited by Guarantee)

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

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FOR ORGAN DONOR CARDS FREE TEXT DONOR TO 50050

CHARITY REGISTRATION NUMBER 20011260

Some initial thoughts on entering my new role



I feel extremely honoured to be appointed as your new CEO. Many years ago, a family member experienced kidney failure and we benefited from the services of the Irish Kidney Association (IKA), so I have had a particular interest in the work of the IKA since that time.

Thanks to my predecessor Mark Murphy, (full tribute page 30-33) I join a high-profile organisation which has consistently had much more influence than its size would suggest in supporting patients with end stage kidney disease and their families. This is due to the excellent staff and the huge number of committed, energetic and passionate volunteers.

On my first day, I participated in the recording of the Service of Remembrance and Thanksgiving for TV in Newman Church. This was a marvellous introduction into the real heart of the IKA. It was an exceptionally moving and emotional experience. You can read the full report on page 5-7. Not many people are privileged to have the benefit of such a meaningful first day in a new role.

We live in an incredibly challenging time. COVID-19 has impacted both our physical and mental health. People with kidney disease are particularly affected. From previous experience of patients who are medically compromised, I can fully understand the challenges faced by kidney patients when suddenly having to adapt from living a somewhat normal life to having to accept further vulnerability and restrictions.

However, the best minds in the world are working on solutions, but it is likely we will still have to live with this virus for some time. It will also continue to impact our activities as a patient-centred organisation. For example, our Support Centre continues to be sequestered by Beaumont Hospital, (refer to article on page 9).

Of most concern is the fact that organ transplant figures are disappointing – particularly, when we see the progress being made in Northern Ireland where two thirds of the waiting list has been cleared – albeit under a different and unique structure than we have here.

We are also faced with increasingly onerous regulations, which also have a cost. However, it is right that we be both transparent and accountable to our members and to the people who so generously donate their time and money. Not only must we continue to be of assistance to our community, but also the positive impacts and results of our activities must be seen. Our Board, which is representative of all our Branches, has a key role to play in this regard.

We must make sure that we are focussing on the needs and priorities of people with kidney disease and ensure that we understand what these needs really are. We must remember the needs of those patients on long-term dialysis and some of those patients whose specific health circumstances prevent them from hope of an organ transplant. We have to ask ourselves where our major priorities lie: should they be in improved healthcare, easier access to home dialysis and increasing organ donation, or are better Government disability supports, patient aid, mental health services or supports to return to work more pressing priorities? I look forward to working with you to hear your views.

Our new Strategy Plan is nearing finalisation. It will have a strong focus on delivering high quality services to both Members and Branches at a reasonable cost. The world of information technology and digital health presents many opportunities for us to help our members more effectively. While this will initially require more expenditure, it will ultimately enable us to reduce the annual income deficit, while improving services in the longer term.

IKA people work closely with healthcare professionals. Often, we have filled a gap in

healthcare systems by providing resources and information. While we will continue to collaborate closely with all health care professionals, we also need to maintain our independence and become an even stronger advocate and effective campaigning organisation for our members. We will work closely with Irish and International organisations working to improve the lives of those with kidney disease.

We are already faced with many healthcare issues. These range from ensuring that we minimise the impact of COVID-19 on our renal community to advocating for an increase in the number of transplant operations. From coping with the effect of the eventual enactment of the proposed Human Tissue Bill and the development of Sláintecare to advocating for the automatic setting up of dedicated renal hospital wards once patient numbers reach a certain level at an individual hospital.

So, there are plenty of challenges, but we are very fortunate to have an active community, and, thanks to our extremely generous benefactors and branch fundraising, we also have the capacity and potential to make the IKA an even stronger and more effective organisation.

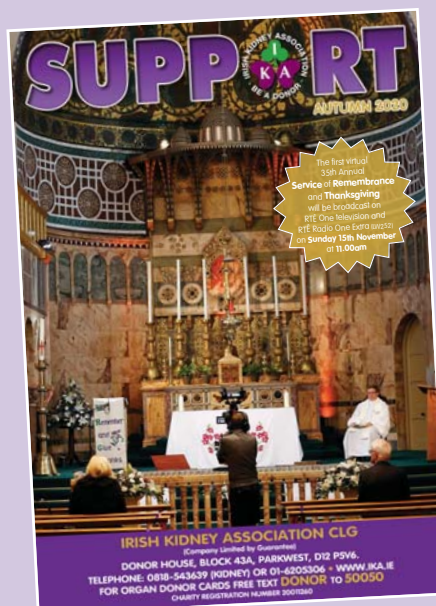
Once we update the Strategy Plan, with your input and after Board approval, we will be arranging a special launch event to tell you about our new strategy.

I am excited to be in my new position as CEO of this significant organisation, and I am confident that by working together we can make an even bigger difference to the lives of those affected by kidney disease.

I could not finish without acknowledging, once again, our heartfelt gratitude, appreciation and thanks to our donors and donor families. It is only their exceptional generosity, often in times of great personal tragedy, which continues to make the ongoing life-saving work of organ transplantation possible. This is truly the 'gift of life'.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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FRONT COVER

Donor mother Sallyanne Clarke, Prof. Jim Egan, ODTI, and Revd. Gary Chamberland filmed by cameraman Seamus Callagy of Kairos Communications at Newman University Church, Dublin 2 for the pre-recorded Irish Kidney Association's 35th Annual Service of Remembrance and Thanksgiving for broadcast on RTÉ One and RTÉ Radio 1 Extra on Sunday, 15th November at 11am.

Photo: Conor McCabe

THE IRISH KIDNEY ASSOCIATION APPOINTS

Carol Moore

as new Chief Executive Officer



Carol Moore and Colin Mackenzie. Photo: Conor McCabe Photography

CAROL'S CREDENTIALS...

Carol Moore brings to the Irish Kidney Association (IKA) her considerable experience in healthcare, education, telecoms, and not-for-profit organisations delivering community services.

Carol is a fellow member of Chartered Accountants Ireland with over 30 years' experience working in the private and public sectors in management consultancy roles.

She holds a Masters in Psychology, post-graduate qualifications in social science, education and psychometrics and she is a qualified mediator.

Just before taking up her new role with the IKA she was a co-founder of LIFEWISE, an online alcohol harm reduction service as well as Governance Manager with Mental Health Ireland, the national Mental Health Organisation with member branches all around the country.

She is also a co-founder of the registered charity Dual Diagnosis Ireland, the organisation for people who have the co-occurring disorder of both mental health issues and substance abuse.

Carol also helped co-found Mental Health Reform, the leading national coalition of mental health care in Ireland which has over 70 member organisations. She was a non-executive director with CORU, the state agency regulator for multiple health and social care which promotes high standards among health and social care professionals.

Carol lives in Rathfarnham, Co Dublin with Caitriona, the youngest of two daughters, who works in fundraising for Movember, the global men's mental health charity. Her eldest daughter Sarah works as a Speech and Language Therapist in New Zealand.

Carol strongly believes in social justice and compassion for people experiencing hardship and with her broad wealth of knowledge and experience we look forward to having her at the helm guiding our Association through these challenging times.

On behalf of all involved with the IKA, it is my pleasure and privilege to welcome our new Chief Executive Officer, Carol Moore.

Carol, as a Chartered Accountant with a Masters in Psychology, among other qualifications, and a former CEO brings with her a wealth of administrative experience, especially suited to the current needs of our Association. We look forward to working with Carol through this challenging period, and are confident that present difficulties in communications, due to the current pandemic, can be overcome.

Carol's already apparent dedication to the welfare of patients and carers, together with new approaches and supported by our dedicated staff gives us great optimism for the future.

Carol, on behalf of myself and the Board and Staff, I offer you our support as we continue our endeavours to improve the welfare of all kidney patients.

COLIN MACKENZIE
Hon. Nat. Chairman



The Irish Kidney Association's first virtual and

35th Annual Service of Remembrance and Thanksgiving



will be broadcast on

RTÉ One television and RTÉ Radio 1 Extra (LW252)

on *Sunday, 15th November, 2020* at *11.00am* (GMT)

and available to view on RTÉ Player www.rte.ie/player and on www.ika.ie

Previously recorded at

Newman University Church, Dublin 2

by *Kairos Communications*

*During the broadcast you will be invited to participate in the
Service of Light ceremony by lighting a candle in memory of
organ donors who have given the precious 'gift of life' to others.*

PRESIDENT, CLERGY, CELEBRITY & TRANSPLANT COMMUNITY UNITE FOR TELEVISED EVENT HONOURING ORGAN DONORS

First Virtual

35th Annual Service of Remembrance and Thanksgiving

People from all walks of life and beliefs, united in their wish to honour organ donors, are encouraged to come together for the Irish Kidney Association's 35th Annual Service of Remembrance and Thanksgiving which will be broadcast on RTÉ on Sunday, 15th November 2020 at 11am. This will be the first time for the inter-denominational Service to go virtual, transitioning from a previously large in-church congregation of 2000+ to a broadcast production by Kairos Communications which will feature on RTÉ One and RTÉ Radio One Extra (LW252). It will also be available to view on RTÉ Player (www.rte.ie/player) and on www.ika.ie

The IKA promises a truly special and poignant Service for people of all beliefs which is laced with beautiful music and symbolic processions, readings and messages from the President of Ireland and two Archbishops, and other celebrated members of society, who are all invested in acknowledging deceased donors and their legacy, the 'gift of life'. This Service is a mixture of sadness and joy for the families of organ donors and transplant recipients alike. For many donor families this unique annual Service has become an anniversary to both remember their loved ones, and for transplant recipients, the opportunity to honour and give thanks for the wonderful 'gift of life' they have received.

The IKA is asking the public to actively participate in this year's Service, especially during the very symbolic Service of Light ceremony, when it is hoped that, in households the length and breadth of the country and beyond, a

candle will be lit in memory of deceased donors who gave the 'gift of life'. The Service will be led by two members of the successful Transplant Team Ireland, liver transplant recipient Deirdre Faul and Team Captain Harry Ward, a kidney transplant recipient.

The 'Book of Remembrance', a 'Roll of Honour', has been an integral part of the Service since its inception with the names of organ and tissue donors carefully inscribed by calligrapher Annette Daly from Glenageary, Co Dublin for the past 35 years who also features.

This year's Service includes a special message from the President of Ireland, Michael D. Higgins, Patron of the IKA, which pays homage to deceased organ donors and their families. Grateful transplant recipients including heart, lung, liver and kidney, and members of deceased organ donor families, have been filmed carrying out various symbolic roles for the pre-recorded Service.

The inter-church Service was recorded at Newman University Church, Dublin 2, in October with celebrant Rev. Gary Chamberland and Archbishop Michael Jackson delivering



Fr. Finbarr Treacy working on camera shots

the Homily. Archbishop Diarmuid Martin shares a Reflection. Music at the Church is directed by Steven Warner, Associate Director, Newman University Church and involves the widely revered cantor Dr. Sharon Lyons and music by the Vocare Ensemble.

There is a special inclusion from the 'Circle of Life' Commemorative Garden for organ donors in Salthill, Galway with Eleanor Shanley singing accompanied by classical guitarist John Feeley. They are watched on by the Garden's creators, Martina and Denis Goggin, the parents of a deceased donor, and some grateful transplant recipients.

Among those filmed at Newman University Church, is Sallyanne Clarke, the mother of deceased donor Andrew who was baptised in the same church. Sallyanne and her husband Derry run the Michelin star L'Ecrivain Restaurant in Dublin. Alan Finnegan, delivers a testimony about the profound impact of the passing of his late brother, deceased donor Paul, the chef, who famously prepared a meal for Michelle Obama and her daughters when she visited the family pub in Dalkey, Co. Dublin.

Senator David Norris, who underwent a liver transplant, recites Seamus Heaney's poem, *'The Miracle'*, at Newman University Church. Majella O'Donnell, whose mother had experienced temporary kidney failure, sends a message of encouragement from her home in Donegal. Members of the medical profession Dilly Little, Transplant Surgeon and Surgical Director of the National Kidney Transplant Service and Professor Jim Egan, a lung physician who is the Director of the HSE's Organ Donation Transplant Ireland, also feature.

Speaking in advance of the Service, IKA Hon National Chairman, Colin Mackenzie, explained, "This Service embraces people from all walks of life and all beliefs including humanists. It is a hugely important event on the annual calendar for many donor families and transplant recipients as well as for the wider community, including donor and transplant coordinators and medical, surgical and nursing staff. We are confident that our first virtual Service provides a worthy and fitting replacement to the traditional church event that has been taking place since 1986. We sincerely hope that people from home and abroad will tune in to RTÉ at 11am on



Sunday, 15th November to watch the Service, which was filmed in the magnificent setting of Newman University Church and at other locations, amid COVID-19 restrictions."

Producer Fr. Finbarr Treacy, from Kairos Communications and Steven Warner, Associate Director at Newman Church, worked closely with the IKA's Liturgy committee, who were involved in its planning and content and they include:- Colin Mackenzie, IKA Honorary National Chairman (Dublin), Lorraine Costello, Patient Support Officer (Dublin), Gwen O'Donoghue, IKA PRO, Board members Valerie Brady (Meath), Joan Gavan (Tipperary), Monica Finn (Roscommon) and Pat May (Carlow). The flowers which adorn the church altar were arranged by Una Whelan (IKA Dublin East+Wicklow).

The concept for this Service

evolved from a grieving organ donor mother who contacted the IKA in their first office in Monkstown, Co. Dublin. The mother expressed her distress and sadness that her son's organ donation had never been acknowledged. At the time there was no system in place at the Old Jervis Street Hospital to acknowledge and thank organ donors and their families. In consultation with the then newly appointed National Transplant Coordinator, Phyllis Cunningham, it was decided that a Service be held to publicly acknowledge and recognise the courageous generosity of organ donors and their families. The inaugural Service, in 1986, had an attendance of 300 people in St Mary's Church, Haddington Road, Ballsbridge. Since then, the numbers have increased annually with an attendance of over 2000 people now attending from all over Ireland.



Transplant Surgeon Dilly Little being recorded by Ita Callaghan at the monument for organ donors at Beaumont Hospital by production company Kairos Communications for the virtual Service of Remembrance and Thanksgiving

EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION (EODD)



*'The one bright light
in a very dark time'*

This year the European Day for Organ Donation and Transplantation (EODD) was held on Saturday 10th October.

The aim of the day is to promote awareness of organ donation in Europe. It is an opportunity to honour all organ donors and their families and to thank transplantation professionals throughout Europe whose hard work helps to save lives and improve the quality of life of many people.

There is a specific focus on the importance of making one's own wishes on organ donation known to families and next of kin. The day is also an opportunity to pay tribute to all the deceased and living donors who have helped severely ill patients to regain a normal life.

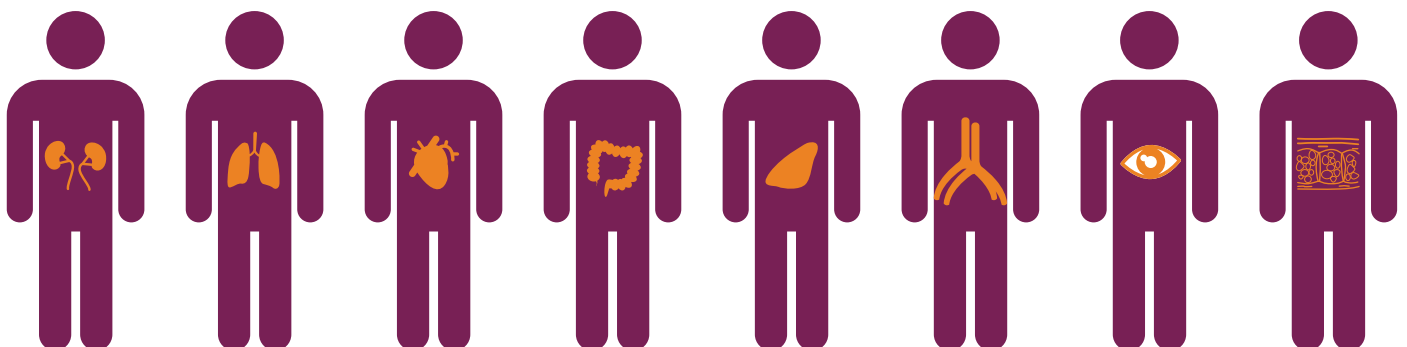
In Ireland, the Organ Donor Card has been the national 'Call to Action' since it was first introduced by the Irish Kidney Association over 40 years ago. The card continues to be the public prompt to encourage the family conversation – this is why it has the space for the next of kin signature. We took this into account when developing our Digital Organ Donor Card App in that the sharing of your wishes with family and friends is at its core.

Whilst our European neighbours have organ donor cards, they also have a

centralised database where the public can register their wish to be an organ donor – unlike in Ireland. In 2015 Wales introduced a Soft Opt-Out system which necessitated the addition of a 'No' option to their national registry. Any successful public awareness campaign needs a clear 'call to action' that gives the public the opportunity to engage and respond and having a YES/NO Registry allows for this.

Last year in Ireland, 274 organ transplants were carried out. 153 kidney transplants were performed at the National Renal Transplant Service at Beaumont Hospital, 25 of which were living donor transplants. 66 liver transplants occurred at the National Liver Transplant Service at St Vincent's University Hospital, and 38 lung transplants and 15 heart transplants took place in the National Heart Lung Transplant Service at the Mater Misericordiae University Hospital.

Organ donors are at the centre of the success that is transplantation. Whilst we are all aware of the need for organs, we must also look at organ donation from the donor's perspective. It is the potential to leave a legacy to your family. Many donor families have described the donation as 'the one bright light in a very dark time.'



RENAL SUPPORT CENTRE

will continue to be used by Beaumont Hospital until October 2021

As members know in the early days of the pandemic, Beaumont Hospital officially sequestered (legally took over) the Irish Kidney Association's Renal Support Centre at Beaumont for use during this COVID pandemic.

I visited this wonderful centre and talked online to the Support Centre staff. I can really appreciate the enormity of the temporary loss of the Centre. It is not just a roof over people's heads, away from a sterile hospital environment, but a place of comfort, safety and warmth. It is a place where patients and their families can relax together, have a cuppa, cook their own meals, talk to staff who are also patients, and also chat to other families experiencing the same struggles. Strong and lasting relationships are formed there. This "peer support", as the professionals call it, is a vital part of the IKA community and the Support Centre is our crown jewel. This COVID pandemic has broken many of these connections, but hopefully only temporarily.

The IKA have had considerable discussions with Beaumont Hospital Management on their very urgent ongoing requirement for the Centre. The IKA Board itself debated this issue at length.

A major factor for the Board, was the fact that the



Centre **cannot** be operated in the current COVID pandemic environment. This is because the Centre was not built to conform to hospital level infection control standards. This means that any patient staying in the Centre would be at increased risk of infection. Additionally, the staff (who are also patients in a high-risk group) operating the Centre are also at increased risk of harm. As a responsible employer, we cannot expose our committed and valued staff to increased infection risks.

Beaumont Hospital is now paying the considerable cost

of bringing the Centre up to hospital infection control standards. They are also paying for patients to stay in a nearby hotel, the Clayton Hotel. So, when the Centre is returned to the IKA in October 2021, we then anticipate (subject to expert health advice) to be able to safely operate the Centre again, without incurring the considerable upgrade costs.

We really understand the fact that people will be upset by the temporary loss of the Centre, but we believe we had no other course of action in these very difficult circumstances.

The IKA Board is setting

up a sub-group to develop a plan for the return of the Centre and also the development of our Cork property and we will be bringing in various volunteer experts to consider how best to do this.

For patients who would normally have stayed in the Support Centre, alternative accommodation, which includes bed, breakfast and parking, has been arranged with the nearby Clayton hotel which can be accessed from the M50. Members should phone Patricia, Frank or Simon at 087-4169907 for bookings.

Carol Moore, CEO, IKA

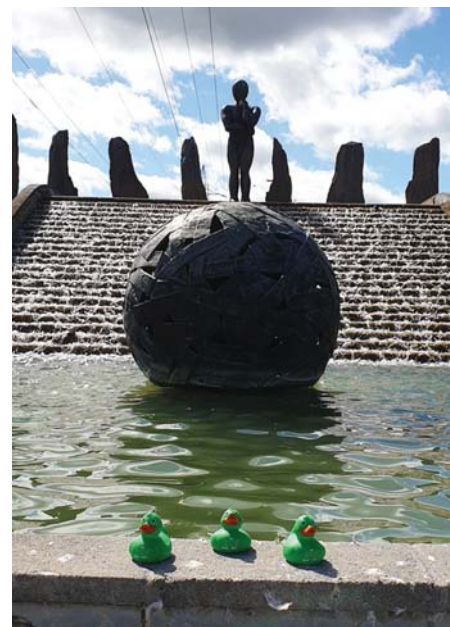
Ducks quack farewell to **ETDSC** which fell 'fowl' to pandemic



Were it not for COVID-19, Sunday, August 9th would have marked the final day of what would have been the largest international organ donor awareness event this year and held in Dublin – the 2020 European Transplant & Dialysis Sports Championships (ETDSC).

500 participants, including heart, lung, liver, kidney transplant recipients as well as dialysis patients and supporters, from 30 nations, would have been saying farewell to the week-long 11th ETDSC 2020. The Championships were due to begin on August 2nd and organised by the Irish Kidney Association (IKA) but had to be cancelled due to the pandemic.

To mark the cancelled Championships, which are a celebration of life through sport, two grateful Irish transplant recipients and members of Transplant Team Ireland were joined by a kidney donor father and his transplant son who enjoyed the fun and frolics of a virtual international Duck Race. The Duck Race, involving 30 green ducks, each with their nation's flag colours on their plastic plumage, was held at a





Harry Ward



Sam and Ivan Kinahan

water feature beside the IKA's head office at Donor House in Dublin's Park West.

A video of the event was shared online via YouTube with the 30 nations (link <https://youtu.be/cEBDcKAhZzU>). A Slovenian duck won convincingly followed by Germany in second place and Cyprus third while Ireland's duck bobbed along behind.

Team Ireland Captain Harry Ward, from Baldoyle, underwent a kidney transplant 13 years ago while newcomer to the team Simon Keegan from Dublin 1, who was on life support before undergoing a heart transplant two years ago observed with father and son Ivan and Sam

Kinahan (5) from Baldoyle.

Ivan who had returned to work since donating a kidney to Sam last June had taken this week off work for the Games and had planned to take part in a Donor Race for families of deceased organ donors and living donors.

Harry said, "we are sad that our Championships in Dublin this year were called off but, in the true spirit of the Irish team, we made sure that at least some fun was to be had. We hope one day again we can say a Céad Míle Fáilte welcome to Ireland. We should have been celebrating with competitors and supporters from all over Europe to Dublin this week for the 11th European Championships."



Simon Keegan



18th Birthday Fund



Katie and Matt McAlevey at their home the day after Katie's 18th birthday. (Photo by Andrew Spearman)

Marking an 18th birthday for many young women means glamping up for a big celebration and being gifted with an abundance of presents, part and parcel of what is expected for their coming of age. However, for a young Dundalk woman, who celebrated this milestone birthday amid pandemic restrictions, on Sunday 11th October, she had a different perspective.

Katie McAlevey from Drumcar said, "I am just grateful to be able to share my 18th with my family and especially my father whose quality of life has improved considerably since his kidney transplant last year. That's why, instead of getting presents, I want to help highlight organ donation and raise funds for the Irish Kidney Association through a Facebook fundraising platform." Katie's fundraiser has already raised over €1400 for the charity.

Dancing since she was three years old Katie is a world champion Irish dancing medallist. She is the oldest of three siblings and daughter of publican Matt and nurse Ciara McAlevey. Katie explained, "my father has had two kidney transplants in his lifetime. He received his first transplant when he was 30 years old before he married and it lasted eighteen years. That's the same length of time that I have been alive! His first transplant

was a success for a long time, and even though it eventually failed, my family are very grateful to his first kidney donor for giving him a lifeline and eighteen good years to enjoy life, get married, run a pub and have a family.

"His second transplant took place in May 2019 because of another selfless organ donor. Before this transplant, for six years he had to have dialysis and attend the Beacon in Drogheda three times a week for his treatment. For most of my teens my father has been struggling with his kidney failure and even though he managed to keep running the family pub in Castlebellingham, he had very little energy and poor quality of life. Even when he was having a difficult time, he always remained upbeat. With the little energy he had, he still made the effort to travel around with me and my sister as we competed in dancing competitions in different parts of the world while organising dialysis treatment wherever we would go. He also was on the sidelines to support my younger brother when he played football. He helped raise €4500 for the IKA through fundraisers he ran in the pub while he was on dialysis. I am proud of my father for the way he has lived with his kidney condition and I am also proud for the families of his kidney two donors.

"Our family would like to express

our appreciation to Jackie and the staff at the Beacon in Drogheda for taking such good care of my dad when he was receiving dialysis treatment and also to the transplant and nursing team at Beaumont Hospital who took care of him when he received his transplant.

"When he got his transplant last year, I could see the difference in him straight away, it was like night and day. He has a much better quality of life now. We are making the most of having him stay at home with us. He has much more energy now and his complexion looks so much healthier now also. Unfortunately, after COVID lockdown, he has had to close the business because of all the restrictions on pubs, as well as the fact that because he is a transplant patient and immune suppressed and must be extremely careful."

Katie and her sister Holly (16) are 6th and 5th year students respectively at St. Vincent's Secondary School in Dundalk. They are both world dancing champion medallists from the hugely successful dancing school Scoil Rince Mona Ni Rodaigh. Katie and Holly as solo dancers have been placed among the top-30 finalists from all over the world every year for almost a decade while also winning the coveted World Champion title as part of the 8-hand reel team. This year would have been their 10th year to take part in the World Dancing Championships which would have taken place in Ireland were it not for COVID-19. Katie and Holly's younger brother Mark (12) doesn't share his sisters' passion for Irish dancing, he is a keen footballer playing with his local club, Rock Celtic in Blackrock.

Katie who is now in her final year of school is undecided about whether she should pursue a career in nursing or as a primary school teacher when she leaves. However, she explains "the one thing I do know is that were it not for organ donation my father may not be here and I felt very fortunate to have him around to share with me in celebrating my birthday."

BILLION STEPS CHALLENGE

The **Billion Steps Challenge** is an opportunity for **everyone** (including family, friends and even nurses, doctors and hospital staff!) to get involved in a global programme that is aimed at encouraging people to be active and also to talk about organ donation.

You can find out more, and how to sign up here:

www.wtgf.org/Billion-steps-challenge

IT'S FREE AND OPEN TO EVERYONE!

The Challenge is taking place now and the collective goal is to reach a total of one billion steps between now and December 13th.

WHAT IS THE BILLION STEPS CHALLENGE?

- The Billion Steps Challenge aims to encourage everyone in the wider transplant community to take the first step towards a life of activity and movement.
- Regular exercise not only benefits physical health but also boosts mental well-being.
- We want to show the world that those living with a transplant are serious about their health and the precious gift they have been given. What better way than to walk a collective billion steps to the moon and back?
- The Billion Step Challenge invites everyone to sign up into small teams of between 2 and 5

people, with the aim of walking and exercising regularly and counting those steps to add to a collective total.

- We are partnering with **MoveSpring**, an online fitness platform which integrates with most fitness trackers, however manual entries will also be an option for those who do not have a fitness tracker.
- **All physical activities count and can be converted to steps with our Activity to Steps Converter guide. This means a cycle, swim or yoga class can all be easily converted to steps. Every step counts!**
- The challenge is open to everyone. Teams can be made up of many different combinations including, but not limited to, transplant recipients, medical professionals, living donors and donor families, friends, family, colleagues and neighbours.
- There is no age limit and no experience needed. It starts by taking the first step to a more active and healthy life.

WHAT'S IN IT FOR ME?

- A healthy lifestyle is important for everyone, but it is especially important after an organ transplant. Poor lifestyle habits can increase the risk of organ rejection.
- The Challenge is designed to motivate transplant recipients to get active. We also recognise the benefits for the entire transplant community.
- COVID-19 may have kept many of us apart with restrictions on social interactions and travel but this challenge allows us to come together as a community, promote organ donation and transplantation and get active.
- This challenge is part of the greater **Fit for Life!** initiative which is designed to help transplant recipients live full and active lives through ongoing physical activity and participation in organised sports.
- This challenge aims to motivate everyone in a fun and interactive way to exercise within their means, starting with some simple goals, such as walking around the block and building towards more ambitious goals.
- There is a great interactive chat facility in the App which opens up the opportunity to connect with others around the world!



Proudly supported by  NOVARTIS

Welcome to our Billion Steps Challenge for 2020

All great expeditions start with a single step...
Can we do One Billion?

The World Transplant Games Federation is committed to promoting sports and physical activity within the Transplant Community.

We invite you to join our ambitious goal to collectively walk **TO THE MOON & BACK** and create awareness for organ donation and transplantation...**10 WEEKS - ONE BILLION STEPS!!!**

Regular exercise not only benefits physical health but also boosts mental well-being.

Let's all encourage the worldwide transplant community to live full and active lives and celebrate what can be achieved with the ultimate gift...the gift of life.

The Billion Steps Challenge is open to anyone - transplant recipients, living donors, donor families, health professionals, friends, families and supporters.

The Challenge:

- 10 week challenge – 1 Billion Steps
- 5th October – 13th December 2020
- Create teams: min 2 / max 5 people
- All activities count - convert exercise to steps
- Free entry and everyone is welcome to join, no experience needed
- WTGF branded hoodies up for grabs throughout the challenge!
- Partnering with MoveSpring

How to Enter:

- Click the challenge link [HERE](#) to sign up
- Sign up as a new user with org code: WTGF20
- Follow the steps to create your MoveSpring account
- Connect a device or add manual entry
- You'll automatically be added to the challenge
- Create or join your team!
- Need help? MoveSpring user support – email help@movespring.com

**SIGN UP**

**SYNC DEVICES**

**CREATE TEAMS**

**GET STEPPING**

Let's get active, let's get moving and promote organ donation & transplantation

Together we can be Fit for Life!

Detailed information on the challenge, how to sign up, sync your devices, and create your teams can be found at the World Transplant Games Federation website www.wtgf.org/billion-steps-challenge

Contact colin@ika.ie if you have any questions.



To school or homeschool

That is the question... for transplant children

Pranathi with her
mother Anne Marie



RTÉ One TV News and children's TV news News2day, covered a story at the beginning of September on the dilemma and uncertainty around children who are health compromised returning to school.

Earlier in the year, the then Taoiseach Leo Varadkar announced the sudden closure of all schools from the 12th March which was to continue until the 29th March to help combat the spread of COVID-19.

However, as the prevalence of the virus continued to escalate, the government ruled that children should not return to school until after the Summer holidays. Pupils and parents tried to adapt to the new normal for learning, homeschooling, during the extended hiatus.

As schools re-opened in September RTE News, facilitated by the IKA,

featured two lively transplant recipient girls from Waterford, one a heart transplant recipient and an only child, who didn't return to school while the other girl, who had received a combined liver and kidney transplant, returned to school along with her two siblings.

Almost two months since their appearance on RTE we checked in on their progress just before schools' mid-term break.

Anne Marie Lally and her husband are both lecturers at Waterford IT. Anne Marie described how their daughter Pranathi O'Donovan, a heart

transplant child, has been getting on with her home schooling through her parents who are also working from home.

Anne Marie said, "Pranathi will be four years post heart transplant in the Spring (2021) and since her transplant she is doing amazingly well, full of energy, happiness and health. Pranathi's care is jointly managed by the Children's Heart Centre in Crumlin and Great Ormond Street, London. Throughout the COVID pandemic she has been very fortunate to have had the very best of medical advice as to how her family should keep her safe and reduce exposure to Coronavirus risk.

"Our family cocooned throughout the first lockdown and maintained only a very small number of interactions since then. In August as her parents we

were advised that, if possible, we should seek to homeschool her rather than returning to school as her immunosuppression regime would increase her risk of COVID infection should positive cases present within her school or social contacts.

"Pranathi is doing very well with her home-schooling routine. Each morning she has a zoom meeting with a Newtown Junior School liaison teacher and is working away on all the usual school subjects albeit remotely. She loves being able to go to the skate park for her 11 o'clock break and the biggest positive of homeschooling is that we have promised not to give homework!

"There is no doubt that arts and craft have been a super fun element of homeschooling and the good autumn weather

Lexi and sister Ali



Lexi with her mum Kim and dad Declan at the national launch of Organ Donor Awareness Week in 2017.



presented lots of opportunity for nature walks and outdoor learning. Pranathi recently had her annual flu jabs and we are all hoping that her next vaccine will be a COVID vaccine so that she'll be able to get back to school, family visits and lots of playtime with her friends."

Lexi Murphy (10) underwent a combined liver and kidney transplant in Birmingham in 2016. After much consultation between her parents, Kim and Declan, and her medical team and consideration to the complication of having two siblings who would be attending school, it was decided that Lexi should return to National school along with her younger sister Ali (6). It was also important that her older brother Dillon (15) returned to school as he is in 3rd year preparing for his Junior Cert. Kim who works as a hairdresser has to be very vigilant in ensuring that she doesn't carry the virus home.

On the RTÉ News feature Lexi displayed impressive flexibility with acrobatics on and off the trampoline at her home. In the almost two months since returning to school her mother Kim explained "Lexi continues to bounce around and is full of energy and she loves attending school. She has been keeping great, thank God. She was in Crumlin hospital this week for a routine check-up and a scope. Her doctors are

happy for her to continue going to school. Thankfully any of their young liver patients between Ireland and the UK that have tested positive for COVID-19 have recovered well. The school has been great in keeping me reassured that all public guidelines are being followed. Obviously, Lexi herself was already so used to the importance of good hand hygiene so she continues to be extremely happy to stay going to school."

Pranathi embarked on a 100km cycle challenge, starting on 30th July cycling a 10km distance on ten different days within a month. She raised an impressive €4500 for Ronald McDonald House where her parents had stayed to be near her when she became gravely ill with

heart failure four years previously.

On her online fundraising platform IDONATE she explained her motivation. "I was very lucky to get a wonderful donor heart three years ago and now that I'm able to cycle farther and

faster, I want to raise money for Ronald McDonald House so that all families with sick children can stay together and have a home away from home as long as they need it."

Well done Pranathi and Lexi!



Pranathi on completing her fundraiser for Ronald McDonald House.

Maintaining our **Mental Health** in Tough Times



By **AOIFE SMITH**

In my last article I wrote about and complimented the emotional resilience I see in so many of you who are living with the uncertainty and unpredictability that comes with a long-term health condition. The coping skills that are developed to deal with the difficulties of illness can really stand to us in challenging times.

However, I am also very aware that the prolonged situation of the COVID -19 pandemic is affecting all of us in various ways and with this a high level of stress may be experienced. People who previously coped well may now be less well able to cope. Some may newly develop a mental health condition. Those who previously had few experiences of anxiety may suffer an increase in number or intensity, and those already diagnosed, may see a worsening or a relapse of a previous condition.

The World Health Organisation (WHO) has reported an increased level of mental health conditions seen in several studies around the world due to the impact of COVID-19. Therefore, right now it is

vitaly important that we do what we can to manage our own mental health.

The WHO, HSE and Mental Health Ireland, have continually updated and circulated a vast amount of information online, to make resources widely available to anyone looking for support. One area that is greatly focused on is anxiety. I thought it might be useful to share some information that is presented around anxiety and how best we might manage it in these tough times.

WHAT IS ANXIETY?

Anxiety is one of the most common mental health problems presenting worldwide. However, anxiety is a normal, understandable response and its function is to increase a person's ability to respond to a threat.

Anxiety can keep us safe; it is our body's natural way to warn us when something doesn't feel right. It involves a type of fear usually associated with a perceived threat or something going wrong in the future.

Research has shown that severe or

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

ongoing threat can play a prominent role in the development of anxiety disorders. Persistent unpleasant feelings of uneasiness, apprehension and worry can be distressing and can have physical, behavioural and emotional effects.

WHAT DOES ANXIETY FEEL LIKE?

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

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

Any of these symptoms, individually or in combination, can affect the way we behave in any situation.

WHAT CAN WE DO...

These feelings can be intense and alarming to experience, nevertheless it is important to remember that these feelings can be managed. If you feel that you are worrying excessively, that it is interfering with everyday life and that it has become upsetting or difficult to control, it may be the right time to look for support.

Anxiety, like many other mental health conditions can be harder to treat if you wait, getting help early will really help to reduce the impact. Now more than ever is a 'good time to talk', it is highly likely that whoever you choose to talk to may be experiencing some of these feelings too. Talking it through with family, friends or colleagues may help you both feel supported.

How my physical activity is, how I eat and how I sleep, if unbalanced, have all been shown to affect mood and well-being negatively. So, it is important to check the basics.

A small increase in physical activity has been shown to trigger brain chemicals that improve our stress levels. Very sweet foods can cause an initial sugar rush which often can be followed by a sharp dip in blood sugar levels which can cause anxious feelings.

Caffeine is also known to increase anxiety levels, minimising your intake



control emotionally and physically. If COVID-19 has increased your anxiety feelings remember that you can help to manage them, remember what is in your control.

Mental Health Ireland produced a poster to help us to do just that - 'Focus on what you can control'.

If you want to talk to a professional, many therapists, including myself, are now doing appointments by phone or conference call, in accordance with current guidelines and will resume normal service when it is safe to do so. You can continue to contact me here at the Irish Kidney Association and I will arrange it for you, or you can contact your GP to avail of the range of options they have available.

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

of it can help. Anxiety can cause sleep disturbances, but sleep disturbances can cause anxiety. It can be useful to use relaxation techniques such as meditation or mindfulness to help you prepare for sleep.

Breathing techniques are particularly beneficial when it comes to managing anxiety. It is well proven that simply breathing out for longer than you breathe in has a relaxing effect on your body. Try breathing in for a count of three and breathing out for a count of six to notice if there is a difference in how your body feels.

There are many YouTube videos, downloads and apps to guide you through these techniques if you are 'techie', or if not asking someone who is will help.

Often people describe an experience of anxiety as an 'anxiety attack' because they are left feeling out of

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.

Thank you to the Tipperary Branch for the invitation to join their Zoom Branch meeting. I look forward to the day that I get to meet you all in person!

I would also like to take this opportunity to wish Mark Murphy the very best in his recent retirement and to express heartfelt good wishes to Lorraine Costello on her pending retirement. It has been a pleasure to work with you both.

And to our new CEO, Carol Moore, the very best of luck in your new position. I am excited about the journey ahead!!

HELPFUL LINKS

- If you need urgent help, Samaritans can be contacted on **116 123** or email jo@samaritans.ie.
- <https://www.who.int/teams/mental-health-and-substance-use/covid-19>
- <https://www2.hse.ie/wellbeing/mental-health/covid-19/minding-your-mental-health-during-the-coronavirus-outbreak.html>
- <https://www.mentalhealthireland.ie/>
- <https://www.aware.ie/>
- Mindfulness apps such as Calm and Headspace.

with problem-solving attempts despite setbacks.**

This is a very academic way of saying that peer support comes out of an individual's own experiences of a situation similar to that of their peer.

For peer support to be truly impactful it clearly needs to be objective and rooted in fact but there also needs to be a relationship of trust and understanding between the peers to ensure that it is both appropriate and relevant. The supporter needs to be clear about the limits of their experience, knowledge and understanding and be very open about the importance of seeking confirmation and reassurance from medical professionals, and others, where necessary.

A question often asked by individuals who are due to start dialysis is which treatment type; haemodialysis or peritoneal dialysis is 'better.' An individual who has had a positive experience with peritoneal dialysis is obviously going to be able to talk more knowledgeably

about it and they are likely to speak of it in positive terms. However, as a good peer supporter they are going to address the question from the perspective of the person asking, rather than simply basing their response on their own experience and circumstances.

When it comes to peer support, how do you get to understand the other person's perspective whether you are giving or receiving the support? It comes down to empathy – having an understanding of the individual and what they are bringing to the discussion. Put simply, getting to know each other.

This is where our Branches come in. Offering a forum for peers to meet, get to know each other and discuss shared experiences, our Branches are our grassroots network. The added value that our Branches bring outside of simple friendship is the connection into support services, the contacts to follow up issues beyond an initial enquiry and the

security of an established like-minded community.

Traditionally, our Branches held face-to-face meetings on a regular basis. Now that our collective realities have changed we need to look at being innovative so that we remain relevant. Zoom has become one of the new means of communication and a number of our Branches are holding regular 'meetings.' The value of such contact can be immeasurable; an encouraging word, a new insight or a feeling that you are alone can be particularly informative and supportive in these isolating times.

We currently hear so much about contact tracing in the media. Let's put our own twist on it and consider tracing contacts at Branch level who can support each other. The facilitation of peer support does not only have to happen at a formal meeting. A 'virtual' coffee can help brighten up many

a day! Whether we are living under COVID-19 restrictions or not we can embrace the networking ability we have as a national organisation with roots in every county. Let us facilitate people getting in touch with each other in their own time whilst letting them know that the structures of the Association are there to offer support and services.

It's all about offering clear communication pathways to everyone living with, and affected by, end stage kidney disease and meeting their needs in the way that is most appropriate to them. There are always many questions but there are also many answers, some of which can come from within our own community. #StrongerTogether #TogetherApart

Please contact Colin White (colin@ika.ie) if you have thoughts and suggestions on this area.

* *Online peer support interventions for chronic conditions: a scoping review protocol.* Sarah Elizabeth Patricia Munce, BMJ Open 2017 Sept 24

** *Peer support within a healthcare context: a concept analysis.* Dennis CL, Int J Nurs Stud. 2003 Mar; 40(3):321-32.



Individuals who provide peer support offer three types of support based on experiential knowledge: emotional, informational and appraisal.



Life in Lockdown

Back at the end of January, I got home from hospital after my kidney transplant, which I received thanks to my wonderful donor mother Frances. In between watching everything on Netflix and indulging in all the things I desperately missed while on a renal diet (specifically jambons from the nearest deli counter and crisps – all of which I now only have in moderation before any dieticians give out to me), a countdown was on. While reading over all the recommendations that the hospital send you home with – avoiding any large gatherings, washing hands regularly and not allowing any visitors with coughs or colds for the first six to eight weeks post-transplant – I don't think anyone could have known how familiar it would all become.

By now it's so commonplace that masks and hand sanitiser join the 'phone, wallet, keys' checklist before leaving the house. But back then, I was looking forward to reaching the end of my post-transplant quarantine, meeting up with friends in the pub, maybe going on holiday later in the year and actually having the energy to be out and about, even just for a wander around a shopping centre. The last time I had been in a shopping centre before that point I was completely worn out after twenty minutes. This time I'd be doing laps of Liffey Valley and there'd be no stopping me!

Once I was free to go out and see people I was going to throw a new kidney party too. I hadn't ironed out any of the details by then, but I was



By **KARYN MOYNIHAN**
(October 2020)

considering making it a karaoke party so I could call it kidneyoke, a term that I was extremely pleased with. While I count myself very lucky that my operation went ahead when it did and without any issues, I couldn't help feeling a little hard done by when I reached the point that I could be out in the world again, only for it to coincide with Government announcements shutting the country down and initiating what would become lockdown.

At first, it wasn't so bad. I was still getting out for daily walks, and my partner Aengus and I got into jigsaws in a big way. I even started baking, which was extremely unlike me, as up until then my go-to creation was a banoffee pie, which is more a case of putting a series of things in the fridge and I had made it maybe twice in the

last ten years. However, emboldened by a successful attempt at peanut butter cookies I was suddenly churning out caramel slices and lemon drizzle cake like no man's business. I attribute this unexpected development to an extremely unsound theory involving the transfer of baking powers via my mother's kidney, considering she's a woman who can knock out an apple tart in her sleep and would have a tray of scones baked and in front of you before you knew what had happened. Of course, it could also have been down to quarantine boredom, but I like the magic kidney powers explanation better.

As the COVID case numbers rose, the situation grew ever more serious, and when people over 70 and the medically vulnerable were encouraged to cocoon, (a term we've all come to know and loathe), the daily walks had to go out the window. For those six weeks my exercise involved a steady amount of swearing at Joe Wicks while I huffed and puffed my way through his daily YouTube workouts, hating every minute of it. The fact that my dad is a kidney recipient too meant that he was also cocooning for that stretch of time, although in his case, living in gorgeous rural Waterford meant that he could do loops of the large garden or walk along the road for an hour and not meet a single other person, something I was highly jealous of when I couldn't go past my own front door in Dublin.

When some of the restrictions for cocooners were eventually lifted and we could go outside again, I completely lost the run of myself and demanded that my partner and I go for a 10k walk on the first day of the new guidelines. I had a great time striding around Phoenix Park, looking for deer and taking photos by the Papal Cross, but needless to say, 10k after six weeks of not being out walking at all was ridiculous and I could only stagger out for significantly shorter and more ache-filled walks for the rest of the week until I got back into the swing of things. By the end of June I was back on form and without doing any damage to myself, managed another 10k walk, this time for the IKA's virtual 'Run for a Life'. It's not quite the level of my auntie Noelle Conway, a seasoned marathoner who will be taking part in this year's KBC virtual Dublin Marathon and raising funds for the IKA on the 26th October,

Getting through this pandemic when you're medically vulnerable really does just mean having to adapt your routine over and over to make sure you feel as safe as possible.

but it was still pretty good going for me!

As case numbers fell and nationwide restrictions eased, things didn't really change all that much for me and I'm sure for many other 'at-risk' people too. My partner had the fortnightly solo food shop down to a fine art, we weren't going to the pub, to the cinema, or to friends' houses.

We've travelled out of Dublin three times since March, twice for weekend visits to see family in Sligo and then Waterford and a mid-week break in a fancy hotel in August to celebrate my parents' birthdays. It's looking increasingly likely that that may have been the extent of our travelling for this year, which is funny to think about compared to my boundless optimism in January, when I was hoping to go on a big holiday abroad later in the year, now that I'd have all this newfound energy thanks to my transplant.

There was even talk of a cruise, something unthinkable at this stage in the COVID game. Now the idea of a busy boat full of strangers not washing their hands every time they enter a room is enough to make me feel slightly panicked and like I need to coat myself in hand sanitiser. Not a particularly ideal way to spend a holiday, in fairness. Very slippery, I'd imagine.

For the last few months I've only really left the house for walks or for renal clinic appointments. My daily walks sometimes feel like an obstacle course, as in many cases it seems like people have abandoned the notion of keeping a two-metre distance from others, so while they might not be bothered anymore, it means a lot of jumping into wet grass for me in an effort to avoid them, or walking out on to the road when it's safe to do so. Sometimes I end up clocking up the kilometres earlier than usual from all the dodging and weaving I end up doing, and there are two local joggers in particular that have become my mortal enemies. Of course, as feuds go it's entirely one-sided as they're not aware of any of this, and since I started going out walking early in the mornings when the parks are quieter it's been less of an issue.

Getting through this pandemic when you're medically vulnerable really does just mean having to adapt your routine over and over to make sure you feel as safe as possible, i.e. no

joggers running past your shoulder on a completely wide open park path, but look, I'm getting off track. For all my giving out, I know that I'm lucky, I have a brilliant partner, and we live in our own house so we don't have to deal with precarious renting situations or housemates who don't care about any of the new measures we're all trying our best to live by.

We both work from home and enjoy each other's company, but it's still not exactly the 2020 I had in mind for myself. It's funny how the working week seems to go by so slowly and yet this year has just flown. When there isn't really anything to look forward to and all our time is being spent at home, the days can all blend into one really easily, so it's important to have something to distinguish the weekends. Even something small helps with this, in our case it's as small as buying a loaf of sourdough bread from a bakery around the corner on Saturdays and taking Sundays off from early-morning walks.

Now that the case numbers are on the rise again, and we're being urged to cut our contacts and stop socialising, I can't help but look around and wonder what else I could possibly do. At this stage, the only person I see is my partner, who I live with, and short of literally cutting him in half in a big box like a magician, my contacts can't be reduced any further.

The most exciting thing to have happened in the last few weeks was a five-minute walk to my GP's office to get a flu jab, and while the nurse there is a very nice woman, I'm pretty sure that doesn't count as socialising.



We've basically been living like it's Level 5 all this time, so it can get frustrating when you're being told over and over again to buckle down and abide by the public health recommendations, when 'at-risk' people have been doing this all along.

It's hard seeing reports of large gatherings, anti-mask rubbish and people not taking the public health measures seriously, and I know that every so often I and many others wonder if we're being paranoid eejits for sticking so strenuously to the advice. But we're not. We've been keeping ourselves and each other safe to the best of our abilities and we'll continue to do so until we get to the other side of this pandemic, whenever that may be. Maybe it's time to break out the jigsaws again. As long as I don't have to reacquaint myself with Joe Wicks and his smiley workouts I think it'll be okay.



Noelle Conway did the KBC Dublin Marathon to fundraise for the Waterford Branch of the IKA. She is a seasoned Marathon runner having many Dublin, Limerick and Waterford Marathons under her belt. Noelle was due to run the half marathon in Berlin with her husband Joe, in 2020. Unfortunately this did not go ahead due to COVID-19. Her connection to the IKA is through her sister Frances Moynihan. Frances donated a kidney to her own daughter Karyn in January 2020 and her husband Joe Moynihan received a kidney from his sister Mary Moynihan in April 2009. COVID-19 has curtailed many of the fundraising activities of the IKA in 2020.

EMERGENCY SURGERY TO SENIOR HURLING



Oisín O'Gorman, Lismore, in action against Darragh Lyons, Dungarvan during the Waterford County Senior Hurling Championship Group D match in Dungarvan, Waterford. Photo: Eóin Noonan/Sportsfile

Oisín O'Gorman's Inspirational Story

Four minutes into Lismore and Abbotside's Waterford hurling quarter-final at Fraher Field last month, commentator Kieran O'Connor brought the local knowledge.

It was the type of colour you want – but don't always get – from a native commentator; the garlic dip that sometimes comes with a takeaway pizza.

"The teenager strikes in the top corner," said O'Connor, "the man with just one kidney but he's playing as if he has more than two at this stage."

The statement threw up a couple of questions: Would having three kidneys really make you a better hurler? And, more importantly, why did Oisín O'Gorman, the scorer of the Lismore goal, have one kidney fewer than most of us?

Moments earlier, a long ball from the Lismore fullback line scaled the Abbotside defence and rolled down the other side into the possession of O'Gorman. He raced through on goal and batted the sliotar to the net, rolling away with his fist raised in celebration before remembering there

By PJ BROWNE
BALLS.IE

was another hour of defending from the front to be done.

The 19-year-old scored 1-5 in all, helping his side progress to the semi-final where they lost to the Ballygunner seven-in-a-row steamroller.

The answer to why Oisín has just one kidney is found 12 years ago in the week before the 2008 All-Ireland final. That game is a nightmare Waterford hurling fans will never forget. It was the day they met Kilkenny at their most monstrous and walked out of Croke Park on the end of a 23-point defeat.

For the O'Gorman family, the week was the beginning of a year-long ordeal which made matters on the pitch trivial.

"I was just out playing, came off the bike and the handlebar went into my stomach," Oisín O'Gorman tells *Balls*.

"It didn't go through the skin or anything but I knew that there was something wrong."

It took Oisín's parents, Jennifer and Kieran, some time before they realised the precariousness of their seven-year-old's situation.

"We were on the way to Waterford in the back of the ambulance and we were chatting away," says Kieran.

"I was on the phone still trying to organise tickets for the All-Ireland final on the Sunday, not thinking that it was serious, 'Ah, he's sore, he's after falling off his bike; he might have a broken rib or two but we'll get to Croke Park on Sunday.'"

"We didn't."

"He went into semi-unconsciousness; by the time we got to Ardkeen, he was knocked out. They said they'd have to bring him to theatre because there was the laceration in the kidney."

"Jennifer and myself were outside the operating theatre and the surgeon came out and said 'Look, I'm very sorry but we had to remove the kidney.'"

"We were upset but I said, 'Relax, now, he'll be fine, he has another one. Remember Seanie O'Leary from Cork that hurled against your father? He has only one kidney. He'll be fine."

Oisín with Kilkenny manager Brian Cody and players Henry Shefflin, centre, and Michael Kavanagh, left, during a visit to Our Lady's Hospital for Sick Children in Crumlin.
Photo: Pat Murphy/Sportfile



He'll manage away fine with one.'

"Jesus, 20 minutes later, the surgeon came out and said, 'I'm very sorry but Oisín only had one kidney; only one had developed from birth.' We didn't know prior to the accident."

As is tradition, on the day after their victory, the All-Ireland champions visited Crumlin Children's Hospital with the Liam MacCarthy Cup. There, Oisín – who had fallen asleep during the game (a small mercy) and was pumped full of drugs to numb the pain (of surgery, not Waterford's defeat) – met Kilkenny trio Brian Cody, Henry Shefflin and Michael Kavanagh. It's a meeting he vaguely remembers.

Oisín was not immediately placed on the transplant list. Having undergone surgery three times in four days, his body would not have been ready for an operation even if a viable organ had been available.

It was November before the possibility of a transplant was even discussed. Kieran and Jennifer decided they'd get tested to see if they were a match for their son.

Hitting the winner in an All-Ireland final – even if it ended Waterford's 60-plus year drought – would not compare to the moment which followed: Kieran was compatible.

Between the initial surgery and the transplant on June 23rd, Oisín was not

wrapped in cotton wool. He travelled to Dublin three times a week for dialysis – a process which replicates the function of the kidneys – but he continued to hurl. At one point, he had a dialysis appointment rearranged from midday to 8am so he could play in a match.

"When he was on dialysis, we were more careful of him than what we are now," says Kieran.

There was one night that they were playing an under-8 match and he got a little tap on the leg. Like all eight-year-olds, he went down looking for something.

It was either Matt Prendergast or James Shanahan who ran on with a bottle of water for him. Myself and his mother were there shouting, 'Don't give him water!' He was on fluid restriction with the dialysis. If he'd taken a cup of water, he'd have had to go straight to Temple Street.

Life wasn't easy for the O'Gormans when Oisín got sick. They had to take a break from work and caring for their younger son, Fionn, was outsourced to Kieran's parents and other family members. The help of Lismore primary school principal Seán Prendergast – one of the great hurling men of that part of Waterford – and Oisín's teacher Patricia Lonergan was invaluable at the time.

Kieran – who played at minor and

U21 level for Waterford in the early 90s – went back training with Lismore to keep his weight down ahead of the transplant. He played a couple of challenge games "because the lads were stuck" but that return ended when they got the surgery date.

"That was the end of the hurling from then to the transplant because a cut or an infection [could have caused a problem] – I was afraid to shave myself," says Kieran.

Initially, it appeared as though the surgery had gone well. Three days after the operation, Kieran – who had been recovering in Beaumont – was allowed to visit Oisín in Temple Street and a day later, Kieran was allowed home.

"Then on the Tuesday morning, at about seven o'clock," Kieran says, "Jennifer rang me to say that her father would collect me in half an hour and that I had to come to Dublin."

"I said, 'What's wrong?' She said, 'Oisín took a turn last night and got a seizure and had to be resuscitated.' It's a thing that can happen after transplants.

"That was on the Tuesday. The following Thursday he had to go back into theatre because the kidney was working but, as Dilly Little, the surgeon, said, 'Look, it's grand, we'll sort it. It's plumbing problems.'

EMERGENCY SURGERY TO SENIOR HURLING CONTD...

"My kidney was big on him and they were having difficulties connecting it to the bladder. The kidney was doing its job producing the urine but it was leaking into his system and he was getting infections."

"Then he had another operation on the Friday. It was up in the air for a week and a bit. Thankfully, he hasn't looked back since then."

"His consultant in Temple Street, Dr Atif Awan, should be canonised. He's a gentleman. Not just Oisín, he treats everyone like his own. He's a fantastic man and all the staff there, I couldn't speak highly enough of them."

"He said to Oisín around the middle of September or the start of October that he could go back to school. Oisín said, 'There's no point in me going to school.' Atif said, 'Why?' Oisín said, 'You told me that I can't play hurling. You don't understand, if I can't play hurling, there's no point in me going to school'."

Determined that he wasn't going to be forced into retirement aged eight, Oisín did not settle for the doctor's conclusion. As the transplanted kidney had been placed in his belly, and so did not have the protection usually provided by the ribs, external armour was required.

"We went into Dublin," says Oisín, "into a shop and we bought a kickboxing vest – a big, bulky vest. We had to go up and show Atif and make sure it was A1 with him."

It was, and from there, Oisín's sporting career was on an upward curve. He has competed for Ireland at the World Transplant Games, winning gold medals, and played at Minor level for Waterford in 2018.

"It was a dream come through really after being so sick and thinking that you'd never play again," says Oisín. As you get older you begin to become more thankful. You appreciate it more because you realise everything that he (Kieran) went through.

"I remember he put a lot of work into getting the weight down. When I look back at it, it's phenomenal what happened. I wouldn't be here without him."

Though he had some understandable concerns about



12-year-old Oisín (right) with his parents Jennifer and Kieran and younger brother Fionn, before flying to the 2013 World Transplant Games in South Africa. Photo: Conor McCabe Photography

playing a team sport in the middle of a pandemic, this year was Oisín's second hurling at Senior level for Lismore.

The one-inch thick vest which he wore through the early years is gone, replaced by the lightweight EvoShield, a solution Kieran spent hours searching the internet for and eventually discovered was being sold by a man in Offaly. Oisín has never received a blow to the vulnerable area but is confident the guard, which is moulded to his body shape, offers protection which makes worrying pointless. The teenager also continues to take anti-rejection medication morning and night.

"I wouldn't say that I get any special treatment because of the kidney," Oisín says of his Lismore teammates. We'd all look after each other when we're out there.

"I got wicked sick last year from tonsillitis – I pick stuff up easily. I came back training too soon and they could all see that I wasn't right."

"A few of them went to management and said, 'He's not right. Bring him home.' Little stuff like that, they'd always look out for you. Management told me to take a week and get myself right. I took the week and I was back right as rain."

Neither does he receive any special

treatment from his father.

"It's always nice to see young fellas progressing," says Kieran. "When it's your own fella playing Senior hurling, you would be even prouder."

"I'm good to give him praise. I'd be his biggest critic as well. I remember the first game they played against Fourmilewater, he came out and won a good ball, turned and put it wide. Everyone on the bank was saying, 'Oh, hard luck, Oisín.' I said, 'Ah, the fuckin' eejit.' That was my point of view. I'd be his biggest critic but I'd be his biggest fan as well."

"The message to get across is to look at what can be achieved through organ donation. Oisín was lucky that I was a match. Some people can be years on a waiting list."

"I'd like to encourage everyone to carry a donor card. I brought 100 of them up to the GAA field in Lismore one day. All the lads took them and hopefully they're still carrying them."

"Oisín's success story is that he never looked back from it. It just goes to prove that you can lead a normal life after and that you can achieve on the sporting field, academically, or whatever you choose to do. The opportunity is there thanks to people being donors."

Oisín and his younger brother Fionn were featured on RTÉ News on 11th September, the day the first round of CAO offers for third level places were finally released. This followed a turbulent and uncertain year for Leaving Cert students all around the country following schools' closure in March due to COVID-19. The sports mad duo, were filmed at the local pitch with their hurleys in hand and were relieved to have each received an offer to study Arts together at Mary Immaculate College in Limerick, bringing them one step closer to realising their shared wish to become schoolteachers. As Oisín had missed a lot of time at school due to his kidney failure, he stayed a year longer to catch-up, joining his brother Fionn's class at Blackwater Community School. Oisín said, "It was tough trying to do the online classes and I suppose the fear of the unknown and what was going to happen, but we got through it!" In 2013 Oisín represented Ireland as part of Transplant Team Ireland at the World Transplant Games in Durban, South Africa where he won a gold medal for badminton and a bronze for the long-jump event, watched on by his parents and brother who travelled out to support him.



SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK

THERE'S AN APP FOR THAT!

If I try hard enough, I can just about remember a time where ordering a takeaway meant finding the menu in a drawer somewhere, speaking to an actual human being on the phone and then waiting for it to be delivered; definitely not able to track its progress from oven, to car, to my front door. These days, there's an app for just about everything you can imagine. Almost every single facet of life can be managed from the palm of your hand. Of course, technology is only great when it actually works and some things are just better done in person – but overall, I'm a big fan! There are millions of Apps available (over 2.2 million actually); below I've curated a selection of apps that you might find useful, entertaining or even – whisper it – life-changing. Some of these I use every day myself, some are highly recommended and some are just for fun. I've tried to keep them as cost free as possible, but bear in mind that some might only have free trials and then move onto a subscription, or have a paid-for Pro version to which you can upgrade.

ENTERTAINMENT & LIFESTYLE



TED (iOS & Android, free) – Free access to over 2000 inspirational and informative 'TED talks'. Speakers range from Bill Gates to Jamie Oliver, and topics include 'How to Spot A Liar' and 'What Are Those Floaty Things In Your Eye?' There's definitely something for everyone here!



Coursera (iOS & Android, free) – Access to thousands of free and paid online courses by some of the world's top universities and companies, including Yale, Google and IBM. You can even earn real qualifications and certificates.



DuoLingo (iOS & Android, free) – Learn a language! There's a choice of over 30 (including Irish if anyone wants to brush up!) and you can choose your starting level. Currently I am trying my best at Scots Gaelic.



Shazam (iOS & Android, free) – Ever hear a song and drive yourself crazy trying to remember who sang it? Shazam listens to songs and tells you all the details (and then lets you add to Spotify or Apple music).



Stocard (iOS & Android, free) – Have a wallet full of loyalty cards? This app lets you store them all virtually. It also sends you monthly publications from stores so you can see all the deals without picking up the magazines in store.



Family Organiser by Picniic (iOS & Android, Free) – Create a family account, add all your members and it lets everyone edit shopping lists, 'to do' lists and a family calendar. You can even send a 'Last Call' alert to everyone from the shopping list when you are heading out to the shops.

HEALTH & WELLBEING



Calm (iOS & Android, free trial) – Try Calm free for one week, but then it is on a monthly or annual subscription basis. Choose from soothing sounds and music, daily guided mindfulness sessions or Sleep Stories (some read by famous voices like Cillian Murphy or Matthew McConaughey). The ultimate app if you need to relax or sleep better!



StepsApp Pedometer (iOS & Android, free) – Many phones already have a built-in step counter, but

StepsApp has a beautiful user-friendly interface and allows you to set goals or look back over the months or years at a glance. They also support wheelchair users and have VoiceOver for people with vision impairment.



One You Couch to 5K (iOS & Android, free) – There are two versions of this on some App stores - look for the free one made by Public Health England. Choose your trainer (celeb voices include comedian Sarah Millican) and take it week by week. The programme is 9 weeks, but you can repeat weeks if you feel like you need a bit more time.



MySugr - Diabetes Tracker Log (iOS & Android, free) – Featured by *Forbes* magazine and *The Washington Post*. Track your sugar level readings easily, with weekly/monthly/annual reports you can share with your doctor. You can upgrade to a Pro version for a cost, but the basic app is just fine.



Medisafe Pill Reminder (iOS & Android, free) – Set up your virtual Pill Box! Set reminders to take your medication, alerts for when you need a refill, doctor's appointment reminders and more. GDPR compliant so your information is never shared with anyone else.



MyFitnessPal (iOS & Android, free) – Another app you can pay for a subscription, but the free version is more than enough. Mostly used for weight loss, this app is handy to enter your daily meals and drinks so you can track your macro intake (carbs, protein, sugars). A built-in barcode scanner lets you scan food packaging to save you the hard work.

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@irishkidneya (Instagram)

TRANSPLANT LADIES HAVE IT ALL SEWN-UP



Seamstress Cathriona Charles from Mohill, Co Leitrim marked the 30th anniversary of her kidney transplant in August, while in her neighbouring county Cavan, Rose Dalton marked the 20th anniversary of her transplant in September. Both were making masks for their communities in the fight against COVID-19. The two women had planned to represent Ireland in the ETDSC along with over 500 participants from more than 25 countries.

Both mothers, grateful to their deceased donors, put their time to good use while cocooning as part of a vulnerable group during the pandemic and between them have made over 1000 reusable fabric face masks helping others and the environment!

Cathriona, married to Charles Beirne, attributes her deceased kidney donor to making it possible to give life to her two adult children, Rebecca who is 29-year-old and Neill who is 27. She has been a fervent advocate for organ donation and has been a Board member and Branch Secretary of the Irish Kidney Association for over a decade.

Cathriona said, "I started dialysis treatment when I was 16-years-old and had my transplant when I was 19. Were it not for my donor I would not have been able to give life to my two children and see them grow up. I am so grateful to my donor for the last 30 years of good health and for my two children and to be able to volunteer with the IKA to promote organ donation so that others might be as lucky as I am. I joined Transplant Team Ireland when Dublin hosted the 2010 Championships and am disappointed that the games, which were to return here this year, were not able to proceed. It was nice to be able to give something back to my community, while cocooning, and being part of a small group of four from the Mohill Family Resource Centre, who have



Undeterred by the cancellation of the 2020 European Transplant & Dialysis Sports Championships (ETDSC), which were to take place in Dublin in August, two kidney transplant recipients, who share a combined 50 years of successful transplantation, put their time to good use while cocooning as part of a high risk group, by sewing masks for healthcare professionals and others during the COVID-19 pandemic.

Left: Cathriona Charles with Joe Duffy in 2012, at the launch of Organ Donor Awareness Week.



made and distributed over 1500 masks, free of charge for the community."

Rose enjoys making patchwork quilts in her spare time outside working as an administrator for BT and being a caring wife and mother to her husband Chris and their 25-year-old son Christopher. When Rose experienced kidney failure over two decades ago, she underwent hospital dialysis treatment for just

under two years.

Grateful for the new lease of life she was given in the millennium year she joined Transplant Team Ireland and took part in the World Transplant Games in Canada in 2005. In the lead up to the games she set up a fundraiser, the 'Mullahoran Annual Walk' for the IKA and the dialysis unit at Cavan Hospital, which has become an annual event and has to date raised over €165,000.



Rose explained, "During the COVID-19 pandemic I joined a group 'Masks for All Ireland Sewists against COVID-19'. We have been making masks for healthcare professionals and vulnerable people. Although I have continued to work from home for my employer, making masks has helped me greatly. This is my way of giving something back and I will be forever grateful to my donor for giving me these last 20 healthy years."



SUPPORT THE WORK OF THE IKA

**Yes, I would like to make a regular donation by
STANDING ORDER.**



STANDING ORDER REQUEST FORM

To: The Manager of _____
(Your bank's name and address)

I/We hereby authorise you to set up a Standing Order on my/our account as specified below:

Signed: _____ Date: _____

Address: _____

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

IBAN: Bank Identifier Code - BIC:

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

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

(Please tick as appropriate)

to start on Date: / /

AND CREDIT TO THE FOLLOWING ACCOUNT:

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


IBAN NO.: IE06 BOFI 9000 1717 1934 35 BIC NO.: BOFIIE2D

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



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

THANK YOU FOR YOUR GENEROSITY



“An **APPLE** a day keeps the doctor away”

Fruit and vegetables provide essential antioxidants, vitamins and minerals, including vitamin C for a strong immune system and help with blood pressure control. They are also an excellent source of fibre, which helps maintain a healthy gut and gut bacteria (microbiome), maintain a healthy weight and lowers your risk of diabetes, heart disease and some types of cancer. Over 80% of us in Ireland don't eat enough fibre. Like everyone else, kidney patients should be eating fruit and vegetables every day. Variety is key: eat the colours of the rainbow!

Choosing fruits and vegetables that are in season and locally grown is better for the environment and for our wallets. Frozen can be just as nutritious as fresh, so you can always freeze any excess for later or you can buy frozen fruit and vegetables. Tinned fruit is always in season and

particularly handy to have in your store cupboard during the current pandemic. Choose fruit tinned in its own juices and drain juice or syrup from tinned fruit before eating.

See the table below for the fruits and vegetables in season in October.

SEE THE TABLE BELOW FOR THE FRUITS AND VEGETABLES IN SEASON IN OCTOBER.

Fruit	1 portion is...	Vegetables	1 portion is...
Strawberry	8 small strawberries	Cauliflower	4 dstspn boiled (100g)
Raspberry	25 raspberries (100g)	Carrot	4 dstspn boiled (100g)
Apple	1 apple	Cabbage	4 dstspn boiled (100g)
Bramley apples	100g stewed	Brussel sprouts	x5 boiled (50g)
Tinned fruit cocktail	170g	Kale	4 dstspn boiled (100g)
Tinned pineapple	200g	Celeriac	2 dstspn boiled (50g)
Tinned pears	200g	Marrow	6 dstspn boiled (150g)
Tinned peaches	100g	Parsnip	2 dstspn boiled (50g)
Tinned mandarins	200g	Onion	6 dstspn boiled (150g)
Tinned strawberries	200g	Broccoli	4 dstspn boiled (100g)
Salad	1 portion is...	Leeks	4 dstspn boiled (100g)
Tomato	1 small tomato (65g)	Celery	2 dstspn boiled (50g)
Peppers	4 dstspn raw (100g)	Herbs - try the following herbs which are also in season to flavour your meals instead of using salt; thyme, chives and parsley.	
Radish	2 dstspn raw (50g)		
Spring onions	2 dstspn raw (50g)		

BUT WHAT ABOUT THE POTASSIUM IN FRUIT AND VEGETABLES?

Healthy kidneys can control the amount of potassium in your body. When your kidneys are not working properly, the amount of potassium in your body can rise too high. This is dangerous, as it may affect your heart muscles and the heartbeat. Depending on the stage of your kidney disease you may need to limit the amount of fruit and vegetables you eat because they are rich in potassium. If you are unsure as to whether you need to follow a low potassium diet, please check with your doctor or dietitian.

If you are on a low potassium diet, you may have been advised to limit your fruit and vegetable intake to two portions of each per day. The table on the previous page shows what one portion is equal to. To reduce the potassium content of vegetables you should boil them and throw away the water rather than steaming, stir frying or roasting them.

If you are following a low potassium diet you should also avoid the high potassium fruits and vegetables altogether. Those that are in season now which should be avoided are rhubarb, beetroot and mushrooms.

HOW CAN I GET ENOUGH FIBRE FROM FRUITS AND VEGETABLES IF I HAVE TO LIMIT MY INTAKE?

If you have to limit the amount of fruit and vegetables you eat you can choose the ones that are higher in fibre to help if you are prone to constipation. The fruits and vegetables in season which are higher in fibre are raspberries, apples, cauliflower, carrots, parsnips and broccoli. Tinned pears are also higher in fibre. You can talk to your dietitian about other fruits and vegetables that are higher in fibre and the suitability of other high fibre foods to eat.

Here are some simple ways to get more fruit and vegetables into your diet but remember to keep within your daily allowance of fruit and

By
MARTINA O'SULLIVAN
Tallaght University Hospital
on behalf of the



vegetables if you have been advised to.

- Add chopped fruit, berries to your breakfast cereal
- Add lettuce, tomato, cucumber, peppers, grated carrot to your sandwich
- Include vegetables or salad with your lunch or dinner
- Try to eat one portion of fruit or vegetable with each meal
- Have a piece of fruit for dessert

PORK STEAK WITH APPLES AND MUSTARD

Serves 4

Recipe adapted with thanks from Kidney Kitchen, Kidney Care UK

Ingredients

- 4 pork steaks (140g each)
- 1 level tbsp olive oil
- 1 medium eating apple (approx. 100g)
- 1 onion, halved & sliced (approx. 100g)
- 100ml water (For additional flavour you could add a stock cube to the water, ask your dietitian for a suitable stock cube choice)
- 2 tsp wholegrain mustard
- 50g butter
- 2 level tsp dried sage
- 400g potatoes (approx. 4 medium sized)
- 300g cabbage boiled & drained weight (approx. ½ medium head)
- 600g swede boiled & drained weight (approx. 1 swede)
- Black pepper to season

Method

Peel the potatoes and cut into thin slices. Bring to the boil, using four times as much water as potatoes. When cooked, drain off water, leave to stand with the lid on.

Peel and cut the swede into 2.5cm chunks. Put in a large saucepan and fill with enough water to cover. Cover with a lid and bring to a boil then reduce heat and simmer for 20 minutes, or until the swede is soft. Drain and discard the water, leave to stand with the lid on.

Meanwhile, rub the pork steaks with a little oil and season with pepper to taste. Heat a large frying pan and fry the pork for 2 minutes on each side until golden brown. Transfer to a plate to rest.

Core the apple and cut into eight segments. Peel and slice the onion. Adding a little more oil to the pan, fry the



apples, onions and sage for 5 minutes or until the apples have softened.

Pour the water over the mixture and spoon in the mustard, then return the pork to the pan and simmer for 10 minutes until the sauce has reduced by about a third and pork is cooked through.

While the pork is cooking, finely slice and add the cabbage to a saucepan of water and boil for 10-15 minutes until cooked, then drain and discard the water.

Remove the lid on the swede, mash until smooth. Season with pepper and cook for a further 1-2 minutes.

Remove the lid on the potatoes, mash until smooth.

Serve the pork mixture with the mashed potato, mashed swede and boiled savoy cabbage.



A TRIBUTE TO OUR RETIRING CHIEF EXECUTIVE

Mark Murphy

Wednesday 30th September marked the end of an era for the Irish Kidney Association (IKA) as our long-standing Chief Executive Mark Murphy retired. Below is a short tribute, written by one of Mark's good friends, member since 1988, and now Board Member VALERIE BRADY.

When you think back at the year 2000 you may find yourself wondering, what happened in that millennium year, what was going on in the world?

2000, or Y2K as it was more commonly known, was the year Destiny's Child dominated the music charts, the Millennium Dome opened, the world was obsessed with Brad and Jen, you used a floppy disc to back up your data, there was a holy hour on a Sunday between 2pm and 4pm, where pubs were forced to close and the IKA appointed a new Chief Executive (CE).

As is so often in life, not everything stands the test of time. All of the above are now either obsolete or gone, with the exception of one. For two decades now Mark Murphy has been the CE of the IKA steering the Association through buoyant and difficult times alike. Throughout his illustrious career Mark has overseen and driven the transformation of the Association to where it is today, raising the profile of the IKA and promoting organ donation.

Given the task of paying tribute to a long-standing CE is an extremely difficult one, but an honour nonetheless. Where do you begin and what do you include? In a career like Mark's it is impossible to cover everything that he has achieved down through the years. From Editor of the *SUPPORT* Magazine, advocate, lobbyist, statistician, problem-solver, event planner to taxi driver, the list is endless.

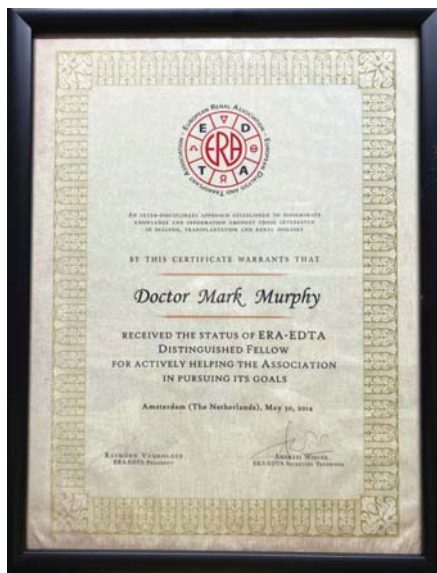
Mark's journey with renal disease began long before his appointment as CE. He had almost first-hand experience when he found himself in the position of supporting, and caring for someone with renal failure.

His first wife Bernadette sadly lost her battle with renal failure and subsequently passed away. This had a profound effect on Mark and influenced by this experience, Mark remained a member of the Association and later joined the National Executive Committee.

During his time on the Executive Committee he realised the need for all members to have an input into the Association. Upon his appointment as CE he brought about the changes required to ensure that all branches would have representation at the table.

As many of you will know, Mark is not the shy type, and this has meant his voice has been heard loudly, both nationally and internationally. As a respected advocate and contributor, he has until recently, held the position of President of the European Kidney Patients' Federation. He is the only non-medic on the National Organ Donation and Transplantation Advisory Group and he has held positions on the governing councils of both the European Transplant and Dialysis Sports Federation and the World Transplant Games Federation, to name but a few.

His collaboration with various European and International organisations has given Mark a vast knowledge base and the ability to analyse and dissect often complex data and figures. Often times he has been mistaken for a medical professional such is the depth of his knowledge. In fact, proudly displayed on his office wall was a certificate which was issued in 2014 titling him, 'Doctor Mark Murphy', and stating that he was awarded the status of



Lorraine Costello and Mark Murphy in the early 90s at the Service of Remembrance & Thanksgiving at St. Mary's Church, Haddington Road, Dublin

Distinguished Fellow of the European Renal Association/European Dialysis and Transplant Association ERA/EDTA for actively helping the Association in pursuing its goals.

Through his work at an international level he built up the credibility of the IKA at a domestic level, and this has been instrumental in ensuring that the voice of the patients has been represented, at decision-making level, within the government and the HSE for many years.

Since taking office Mark has

- Overseen the sale of the offices in Ballsbridge to the establishment of the head office 'Donor House' now currently in Park West.
- Grown the organisation to provide services for patients, otherwise not available to them e.g. our nationwide counselling.
- Advocated for a 'living donor' programme.
- Secured government funding for the payment of expenses for those taking part in the living donor programme and the paired exchange.
- Persistently advocated for Organ Donation for Transplantation including legislation around consent and continuing to fight for a dual Yes/No Registry.
- Successfully lobbied EU legislators for amendments to the EU Directive on Organ Donation and Transplantation.
- In collaboration with the Laois, Offaly and Westmeath branches purchased and located a temporary Dialysis Unit at Tullamore Hospital.
- Alongside the Cork branch secured

the purchase of a property in Cork city for future use as the organisation's second renal support centre.

- Lobbied for the inclusion of an organ donor symbol on both the public services card and new format driving license and was successful in achieving the latter. To date, over 1 million people have consented to have code 115 printed on their driving license.
 - Campaigned for better services for patients i.e. transport, dialysis, overall physical and emotional well-being of patients.
 - Overseen the development of a very successful sports programme for dialysis patients as well as transplant recipients (all organs) under the umbrella of Transplant Team Ireland.
- All of the above does not include the work that goes into the day-to-day running of the Association.

continued....

“Mark is not the shy type, and this has meant his voice has been heard loudly, both nationally and internationally.”

Mark Murphy contd...

More recently, Mark has guided the Association through the current COVID-19 pandemic, delaying his retirement to ensure there was a steady hand steering the ship. We thank him for his continuing care and thought for the patients during these turbulent times.

We are sure there are many with a fond story or memory to tell about Mark. Some may remember the banter had at an undisclosed location, others may remember hearing a talk and the impact it had on them at that moment in time. Many will know the friendly ear that listened and the sound advice given by him.

We will be forever indebted for Mark's vision and commitment to the Association, always ready to go to battle for the patients. After two decades as our CE, Mark Murphy leaves a long and impactful legacy not only on the IKA but on the wider dialysis and organ transplant community.

We wish Mark and Frances well as they embark on a new chapter in their lives together.



Mark with Joe Duffy.



Mark puts the Forget-Me-Not flower on Health Minister Dr. James Reilly's lapel at the National launch of Organ Donor Awareness Week in 2014.



Minister for Health Simon Harris with Mark Murphy at the national launch of Organ Donor Awareness Week 2017



Albert Groenewoud, Astellas Europe and Mark

Message from Hon. National Chairman COLIN MACKENZIE



Colin Mackenzie

As we read of Mark's retirement, it is important to remember the enormous contribution he has made to the Renal Community. His affable and approachable demeanor concealed an unparalleled dedication to the welfare of kidney patients. This dedication was born from his own loss of a loved one due to renal failure.

Since his appointment, over 20 years ago, as Chief Executive, Mark has established a reputation both nationally and internationally as a powerful advocate for renal patients.

Anyone who has heard Mark speak at length without notes or references soon realises that he has an unparalleled knowledge of his subject.

The good reputation and nationwide awareness of the IKA is due in no small measure to his commitment.

Mark, we wish you well in your retirement secure in the knowledge that you have laid the foundations for the further development and influence of the Irish Kidney Association.

On my own behalf I thank you for your friendly and knowledgeable support during my time as National Treasurer and National Chairman.

On behalf of Members, Branch Officers, Board and Staff, and all involved with the IKA, I wish yourself and Frances a long and happy retirement.



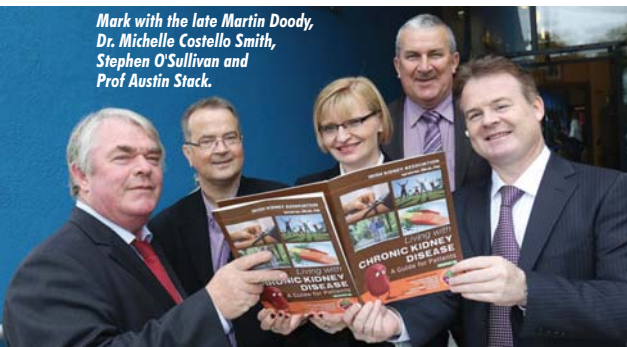
Mark Murphy CEO, IKA with Mary Kennedy and Tim Browne, Transplant Surgeon, Belfast City Hospital at the national launch of Organ Donor Awareness Week 2015.



Minister for Health Leo Varadkar and Mark at the launch of Organ Donor Awareness Week 2015.



Mark Murphy with President Mary McAleese and Bernard Loty at the 9th European Day for Organ Donation & Transplantation in October 2007.



Mark with the late Martin Doody, Dr. Michelle Costello Smith, Stephen O'Sullivan and Prof Austin Stack.



Presentation by the IKA officers Eddie Flood, Colin Mackenzie and John Whelan to retiring CEO Mark Murphy



Message from SENATOR MARK DALY

I'm the Cathaoirleach of the Seanad and it was really due to Mark Murphy the CEO of the Irish Kidney Association that I got this far because he nominated me when I was no hoper outsider in 2007 and I worked with him since. In fact, we were responsible for recalling the senate from its summer holidays many moons ago and it was with Mark's assistance and as a result of that that we had more people employed in the organ donor system and Mark has been responsible for the saving of many lives as a result of his work as the CEO.

And now Mark has to learn the lesson of how to spend time without spending money. I wish him all the best in his retirement.

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← Tweet

Congratulations to retiring CEO of the @IrishKidneyAs Mark Murphy (on the left) when I was a no hoper 1st timer candidate in '07 he backed me. We worked together since. Famously recalling Senate for 1st time ever from recess 2013

[irishtimes.com/news/politics/...](https://www.irishtimes.com/news/politics/...)



6:57 PM · Oct 2, 2020 from Kerry, Ireland · Twitter for iPhone

1 Retweet 14 Likes



Transplant recipients Layla Henderson and Michaela Delany and Lee Moroney, Tallaght 'Person of the Year' with the three Daves...Fitzpatrick, Callaghan and O'Callaghan.

3 DAVES RUN VIRTUAL BOSTON MARATHON IN DUBLIN

Three Tallaght Athletics Club runners, Dave O'Callaghan, Dave Fitzpatrick, and Dave Callaghan, set themselves an ambitious challenge when they ran this year's Boston Marathon on home soil on Sunday, 13th September. They undertook the challenge in support of several Club members who have loved ones affected by organ failure, including two children, and to raise organ donor awareness and funds for the Irish Kidney Association through their GoFundMe page <https://gf.me/u/yrjdn2>

In warm and windy weather conditions, the namesake trio, who jokingly call themselves Dave AC, set out on their challenge from Tallaght AC clubhouse on Sunday morning at 8am aiming to finish in under 3-hour 10 minutes, the Boston Marathon qualifier time. While two of the men were delighted to comfortably smash the time, with 3 hr



Just before their early morning virtual Boston Marathon Run at Tallaght AC Dave Callaghan, Dave Fitzpatrick and Dave O'Callaghan.



Dave Callaghan, his mother Pauline with her grandchild Layla whom she donated a kidney to in 2014.

40 sec (Dave C) and 3 hr 5 mins (Dave O'C) times, an injured Dave Fitzpatrick had to pull out of the race six miles before the finish.

This is the first year in its 124-year history that the Boston Marathon has gone 'virtual' due to COVID-19.



Kidney donor mother Liz and recipient daughter Michaela Delany at Tallaght AC supporting the 3 Daves Boston Marathon virtual Run.

Virtual running works exactly the same as any other type of running but the difference is that the entered race can be run from any location.

The three Daves and other members of their Club have supported the Irish Kidney Association (IKA) annual 'Run for a Life' at Corkagh Park previously as several runners in Tallaght AC have family members touched by organ failure and transplantation. At this year's fun run, which also went 'virtual', the trio secured the top three positions for their times over the 5km distance.

In November 2014, Dave Callaghan's mother Pauline from Old Bawn, Tallaght, flew across the world to Australia to donate a kidney to her then three-year-old granddaughter Layla Henderson. Layla, her twin sister, and her parents are now back living in Dublin. The Henderson family left a message for the trio on the GoFundMe page "Best of luck for Sunday guys! The support for the IKA is a deeply personal one for us and like thousands of other families in Ireland, managing chronic kidney disease will continue to impact our little girl and our whole family, forever. To us, you are 3 heroes out there on Sunday."

The three Daves also run with Dermot Delany whose daughter Michaela (20) has undergone two kidney transplants, the first when she was just 2-years-old from a deceased donor and the second from her living donor mother Liz in September 2016. Michaela, a Media Studies student, helped with the promotion of the



The 3 Daves in Seville in 2019, where they qualified for the Boston Marathon. (L-R) Dave Callaghan, Dave O'Callaghan and Dave Fitzpatrick.

men's challenge and was there to cheer them on when they crossed the finish line.

Speaking after the race, the youngest Dave, Dave Callaghan, whose twin niece Layla underwent a kidney transplant said, "we were delighted to see club supporters turn out at the start early this morning and at the finish point. The warm and windy conditions weren't ideal but we enjoyed it all the same. Overall we are very happy with our times. I finished in 3 hours 40 seconds and Dave O'Callaghan just a few minutes after me. It was unfortunate that Dave Fitz had to pull out 20 miles into the race as he was doing really well up until



Dave Callaghan after completing his 3 hour marathon flanked by his wife Laura and his kidney transplant niece Layla Henderson (left), her twin sister Maddie-Rose and cousin Jack Dunne.

that point. We are delighted that in doing this we can help shine a light on the importance of organ donation and raise money for the IKA." Speaking in advance of the run Dave Fitzpatrick who is a coach at Tallaght A.C. explained, "In February 2019, the three of us ran a marathon in Seville, Spain and achieved times good enough to qualify us for the 2020 Boston Marathon, normally held on Patriot's Day in April. Obviously COVID-19 meant this year's event was cancelled and a virtual event was planned for September instead. We aimed to run the marathon in around three hours each as this time is considered a decent benchmark for marathon runners and annual statistics show that only 1% of all marathon finishers get below the 3 hour barrier. We knew our goal would be tough to achieve particularly in a virtual event where a large field of competitive runners and supportive crowd are missing. The three of us were delighted to take part and for the generous support we received raising over €4,300 for the IKA. One hundred per cent of the funds raised will go directly to the IKA. When not challenging themselves physically, the dynamic trio work in demanding jobs. Dave Callaghan, the youngest (aka Young Dave) holds an Honours Degree in Business Management and works for Paddy Power Betfair. Dave O'Callaghan is a director of a successful software company and David Fitzpatrick is an Associate Professor in Biology at Maynooth University.

Carlow's gals around the globe running for the IKA

Sarah May proudly showing off her participant medal after completing the virtual VHI Women's Mini Marathon



Pictured in July 2019 before Monna Mullins moved to Australia were: (L-R): Monna Mullins, Eva Balfe, Sarah May (back centre) Maeve Howe and Lauren Stewart.



Lauren Stewart



Maeve Howe

Five young Irish ladies donned their running shoes, in three different time zones across the globe, on Saturday, 10th October for the virtual VHI Women's Mini Marathon.

They were undertaking the challenge to demonstrate solidarity in support of a cause very close to the heart of one of the friends, Sarah May, which was to raise organ donor awareness and funds for the Irish Kidney Association (IKA). The friends synchronised their watches to undertake the run at the same time from their locations in Abu Dhabi, Melbourne, Kildare and Carlow.

They have raised almost €2,000 through their Just Giving fundraising platform – <https://www.justgiving.com/fundraising/sara-h-may19>

Wearing their bright yellow running t-shirts with IKA branding, Sarah May and Lauren Stewart, both from Brownshill, Carlow, set out running their 10km distance on home turf. In their neighbouring county of Kildare, friend Maeve Howe sported the same bright IKA t-shirt when pounding the roads in her native Athy. Running for the cause in 'the land down under' was Monna Mullins, also from Brownshill, who is working as a nurse in Melbourne while her friend Eva Balfe, jogged along under the warm sunshine in the Emirates capital of



Sarah with her mum Pat May

Abu Dhabi where she lives and works as a teacher.

Four of the friends had been classmates since they were children attending Bennekerry National School in Carlow and continuing together right through Secondary Level at St. Leo's College.

Sarah May who works in Human Resources for a Dublin based software company has been working remotely since COVID-19 lockdown. Sarah was just 16-years-old when her father Paul, who was Advertising Manager with the Carlow Nationalist newspaper, passed away in 2008. Three decades previously, the father of two, had received a diagnosis of end stage kidney disease progressing to dialysis treatment in 1984 when he and Sarah's mother Pat joined the Carlow branch of the IKA and became active members as they found the organisation very supportive. Pat was elected to the National Board in 2001 and she became National Secretary in 2007 before taking up the two-year tenure of National Honorary Chairman in 2009.

No doubt influenced by her late father and her mother, Sarah has also aligned herself closely to the IKA and has taken a week out every summer, with this year being the exception, to travel as Team Writer with Transplant Team Ireland, when they compete at World and European Transplant Games events on alternate years. She is a very popular member of the Team's panel and carries out the demanding role reporting team members' results, their successes and sharing their inspirational stories, which she carries out with great aplomb, while helping to spread awareness about the success of organ donation.

Sarah said, "I was delighted my friends supported me by running in the first ever virtual VHI Women's Mini Marathon which was to take place earlier this year. A huge positive is that because it is virtual it can be done anywhere in the world. It is a fun way to connect with my faraway and closer to home friends whilst supporting the IKA which does great work in advocating for kidney patients and their families, together with promoting the organ donor card. I would like to thank all those people who supported the fundraiser and hope they will also consider organ donation and let their friends and family know their wishes."

Celebrating 17th Anniversary of second transplant



Angela Sherlock with her sister Miriam Cremin

Angela Sherlock from Greenhills, Dublin, was just 8-years-old when she learnt that she had kidney disease. Then began her health journey which was to result in two kidney transplants. Seventeen years after her second transplant she took part in the virtual VHI Women's Mini Marathon with her sister Miriam and raised €400 for the Irish Kidney Association in the process.

Angela explained, "I was sixteen years old when I started dialysis treatment. At the time it was difficult for me, I was a teenager in secondary school trying to fit in. I was on dialysis for a year until I got my first transplant in 1991 which was successful. It gave me a normal life into my early twenties until it eventually failed after five years when I returned to dialysis. My wait for my second transplant was much longer, seven years. I remember clearly that it was the June holiday weekend in 2003 as the Women's mini-marathon was taking place that I was called for my transplant. I was so grateful and relieved to get this long-awaited call which gave me a completely new lease of life. I felt very lucky to be given a lifeline for the second time.

So, this year, I marked the seventeenth anniversary of my transplant by doing the virtual Women's Mini Marathon close to home in Marley Park. I thought of my donor as I did it along with my younger sister Miriam. She has been a pillar of strength to me as have the rest of my family down through the years.

It is because of my donors and their families I am living a full and healthy life. I will be forever grateful to them. I am proud to have represented my country at the European and World Transplant Games and have made lifelong friends with other team members who, like me, will always be grateful to our donors who have made it possible for us to be here today.

“It is because of my donors and their families I am living a full and healthy life.”

TEARS OF DELIGHT FOR LAUREN

Young transplant woman who has endured over 80 operations completes Women's Mini Marathon



A young woman who has endured over 80 operations in her short lifetime sobbed tears of delight with her mother after completing the VHI virtual Women's Mini Marathon in just over two hours using her baby brother's pushchair as her walking aid. Her determination to prove that she could complete the challenge was also driven on by her wish to honour her deceased kidney donor and mark the 10th anniversary of her successful kidney transplant and raise organ donor awareness and funds for the Irish Kidney Association.

Lauren Devoy Carroll (23), from Cabra, Dublin who was born with a chromosome disorder causing her to be visually, hearing and physically impaired, underwent a kidney transplant when she was twelve and a half years old following nearly three years of dialysis treatment at Temple



Lauren pushing brother Pascal

Street Hospital. The young woman whose mother describes as being "forever upbeat, bright and exuding positivity, while overcoming a battery of health challenges throughout her short life."

Lauren's mother Gillian Devoy explained, "Lauren has had so many operations since she was a baby that I have lost count, but I estimate the figure is now as much as 86. I am so proud of her and we both sobbed with tears of joy when I walked beside her as she completed the mini marathon pushing my son Pascal along, and using his buggy as a support as she would otherwise have had to use her wheelchair. Since her transplant ten years ago Lauren has taken part in the annual IKA 'Run for

a Life' fun run in her wheelchair completing the 2.5km distance in over an hour. She was overjoyed to be able to complete the more than four times longer 10.39km distance for the mini marathon without her wheelchair in two hours and 25 minutes. She now has a mini marathon finisher's medal which has pride of place in the house and will always be a treasured souvenir of her huge achievement and a memory from COVID-19."

Gillian who has two younger children, Hazel (3) and Pascal (10 months) continued, "I was very young when I had Lauren. She was my first born and I loved her the moment I saw her. I did not know prior to her birth that she had a chromosome disorder. She was taken to intensive



Lauren proudly displays her medal beside her mother Gillian



Lauren Devoy Carroll, her mum Gillian and baby Hazel Quinn (18-months-old) Cabra, Dublin at the 2019 'Run for a Life'

care almost immediately and within a few months I was told that her chances of survival hung in the balance. Yet she fought through it all and is here with us today. She is really a little miracle. She is a really bright intelligent young woman who has faced so many challenges and she still has such a positive attitude to life and always has a smile on her face. Despite all her setbacks and missing a lot of school she managed to get honours in most subjects both in her

Junior Cert and Leaving Certificate which she did through Irish and has a great aptitude for languages including French, Spanish and Irish.

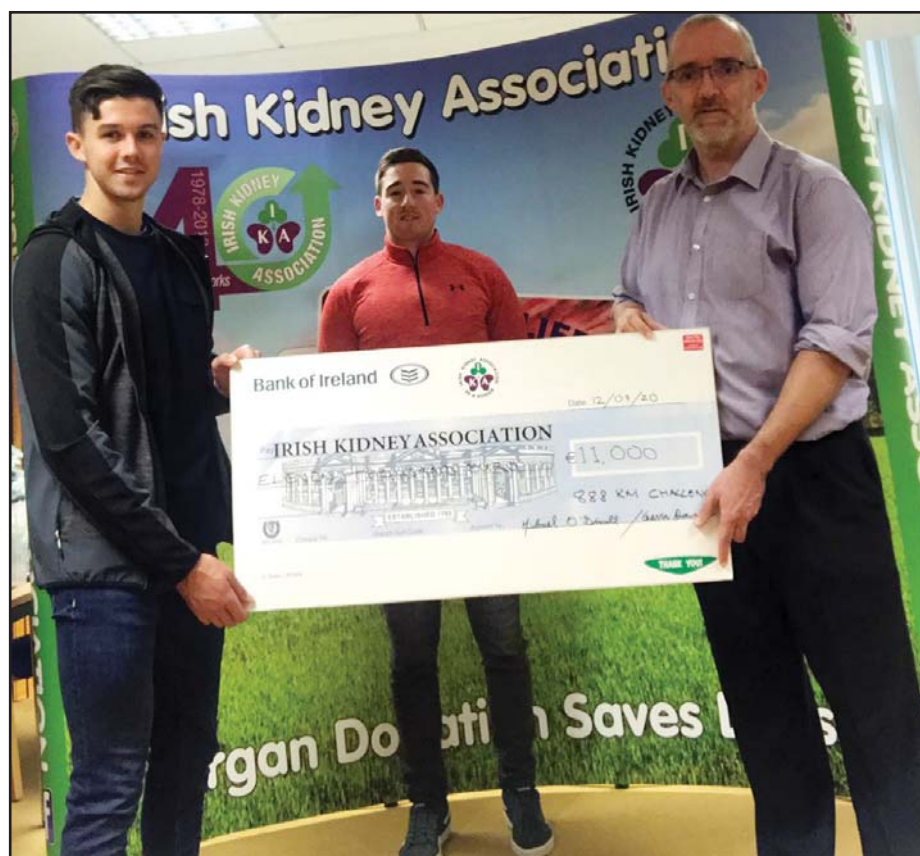
Unfortunately though, going to college has presented so many challenges, because of her physical disabilities and the absence of SNA's at third level, that she hasn't been able to progress to third level or get employment.

Lauren said, "My mother had suggested that I do the marathon over

ten days trying just a kilometre a day but, when I got started pushing Pascal along in his buggy, I just wanted to keep going and only stopped for a water break. My kidney donor was on my mind when I was doing it. I feel so happy that I did it all in one go. My family and friends have encouraged me and supported me. It's great that I have raised money for the IKA which can hopefully go to helping other people like me who have kidney failure.



Well done to Lisa Keogh from Firhouse, Dublin who completed the virtual VHI Mini Marathon. Lisa's son Sean underwent a kidney transplant in 2008 when he was 10-years-old. Sean's father Fintan, whom Lisa is featured with in this photo, has taken part in ten marathons including this year's KBC Dublin City Marathon which marked his 50th birthday and in six of his marathons he raised funds for Temple Street hospital where their son Sean attended as he was born with displastic kidneys.



Two old schoolfriends from Dublin successfully completed an 888KM Physical Endurance Challenge within 24 hours at the end of June raising a substantial €11,000 for the Irish Kidney Association. Their challenge involved cycling and running clocking up a total of 888KM and covered the three picturesque seaside locations of Clontarf, Howth and Sutton on Dublin's northside. The duo, Michael O'Driscoll (left) and Gavin Downes (centre) visited Donor House for the cheque presentation to Colin White National Projects Manager, IKA.

POOCHES UNITE WITH RORY'S STORIES FOR FUNDRAISER



Rory O'Connor (Rory's Stories), Misty (aka Denis Irwin), Murphy (aka Roy Keane), Suzanne Murphy and Jim Hallinan.

A retired Garda with kidney failure was the inspiration for his neighbourhood friend, Suzanne Murphy Beattie, to undertake a fundraiser to mark her 50th birthday. She did it to increase organ donor awareness and raised over €3000 to support the Irish Kidney Association.

Dog lover Suzanne, from Ashbourne, Co. Meath wanted to make her milestone birthday in September an unforgettable one to support all those people waiting for transplants including her friend and ex-Garda Jim Hallinan (70) who undergoes dialysis treatment.

Jim received the shock diagnosis of kidney failure sixteen years ago after watching a TV ad about prostate cancer encouraging men to go and get a health check.

Popular social media funny man and author Rory O'Connor, aka Rory's

Stories, also from Ashbourne, showed up for a photo opportunity with Jim and Suzanne on her farm to support her fundraiser and to highlight the important cause. Also taking part in the photos were Suzanne's cherished dogs fondly known as Denis Irwin and Roy Keane.

Rory said, "When I heard from Suzanne about her motivation for her fundraiser I didn't hesitate when I agreed to try and help her raise awareness for it. If I can help shine a light on the cause so that more people will think about organ donation and



Jim in his younger years at work in the Garda Command and Control.

sign up for donor cards then I'm delighted to be involved."

Former Garda Jim Hallinan and Suzanne got to know one another when they met while she was out walking her dogs. Like most of the neighbourhood Jim was amused by the pet's alias names Roy Keane and Denis Irwin which Suzanne explains reflect the pooches' personalities. Her Schnoodle Murphy goes by the alias Roy Keane and Misty, a Shih Tzu, is more commonly known as Denis Irwin and this causes great amusement within her neighbourhood. Renowned caricature artist Niall O'Loughlin captured Suzanne and her two pooches to help highlight her birthday fundraiser.

It was on one of the outdoor encounters with Jim, a father of four and grandfather of nine, that he told Suzanne about his kidney failure and his three times weekly trips to Dublin's Northern Cross for dialysis treatment while he remained on a transplant waiting list for a donor kidney.

Suzanne is no stranger to fundraising and reflecting her love of dogs and her willingness to support those in need, she previously held a birthday fundraiser last year, and successfully raised €2055 for Autism Assistance Dogs.

Suzanne's fundraiser was run through the IKA's Facebook. To encourage donations she also secured



Jim Hallinan and his wife Jean flanked by family including his children and grandchildren.

prizes as further incentive for anyone who donated to her Facebook fundraiser and they were entered into a draw for prizes sponsored by local businesses which included a hotel stay and vouchers from local restaurants, a garden centre, supermarket, hairdressers and golf club as well as a family ticket to Tayto Park.

Explaining her motivation a very enthusiastic Suzanne said, "Jim walks by my house everyday and is such a gentleman and he always stops to chat. During the first lockdown we got to know each other a lot better and he told me he is having dialysis three times a week and is on the waiting list for a transplant.

That was the motivation for me to do a birthday fundraiser as I wanted to do something to try to help Jim and raise awareness about people like him waiting for kidney transplants and other organs also.

I chose the IKA as they do fantastic work in supporting kidney patients and their families and they also promote and distribute the organ donor card in Ireland. When doing my research I learned that there are nearly 5000 kidney patients in Ireland. Almost 2200 of them are undergoing dialysis treatment and about 500 of them are on transplant waiting lists for a kidney and a further hundred approximate people are waiting for heart, lungs, liver or pancreas

transplants.

I was also surprised to learn that many people who end up in hospital with Coronavirus suffer kidney failure and require dialysis treatment."

Jim asserted, "Suzanne is a really positive outgoing and fun person with a good heart. I really appreciated her doing the fundraiser for the IKA which advocates for people like me who are in renal failure.

In explaining his health story Jim said, "a TV advert which I watched about sixteen years ago, which encouraged men to get their prostate checked, led me to my GP who undertook various tests and one led to the shock diagnosis for myself and my wife Jean that I was progressing towards kidney failure. Fortunately, it was caught early, and I was able to manage my condition and slow down its progression for over a decade with medical supervision and lifestyle and dietary changes.

Three years ago my kidney function declined to a point that I had to commence dialysis treatment and

around the same time I was entered on to the transplant waiting list where I remain until a suitable donor kidney becomes available. I currently undergo four hourly dialysis treatment three times a week. Fortunately, the dialysis is working well for me.

I have always enjoyed sport including soccer and golf. While in the force, I worked in Command and Control at Harcourt Square and I enjoyed being part of the Garda Gaelic football team in the 70s. In later years I took up indoor soccer to keep fit which I played with my garda mates. I continue to enjoy playing golf and have regular outings at my local club in Ashbourne which is good for the mind and body.

I also enjoy spending time with my grandchildren who all live nearby although now being in the high-risk group for COVID-19, I have to be careful when with them and when in the company of others also."

€3300 in total was raised by Suzanne through her online platform and other donations.

"If I can help shine a light on the cause so that more people will think about organ donation and sign up for donor cards then I'm delighted to be involved."



Saturday 10th October was European Day for Organ Donation & Transplantation and to mark the event, a Kildare woman who is now 'bursting with energy' following a transformational kidney transplant in February 2020 just before COVID-19 lockdown, donned her running shoes for the virtual VHI Women's Mini Marathon, to raise funds for the Irish Kidney Association (IKA) through the Just Giving online platform, raising almost €2,000.



Sarah proudly displays her medal

JASPER

the rookie kidney

and the

FORGOTTEN BAG

Sarah ran the 10km distance, in a very impressive time, in her native Naas, wearing a bright yellow IKA t-shirt, powered by her new kidney, donated by the family of a deceased donor, and which she affectionately calls 'Jasper'.

Sarah, who has a rare autoimmune disorder, continued to work as a florist throughout her illness and although it had become more and more difficult, as her kidney failure progressed, she managed to continue working right up until her transplant. Sarah describes how her failing kidney function had reduced her energy levels to a point where, at the end of her working day, she only had enough energy to crawl up the stairs in her home which she shares with her partner Ronan.





Sarah's forgotten bag!

Prior to that fateful night in February, the 34-year-old was in bed and just a few hours into her 9 hour nightly dialysis treatment, when at 2am she received a phone call from the transplant coordinator at Beaumont Hospital telling her to come to Dublin immediately for a kidney transplant. She had a special bag packed and tucked away in her wardrobe for several months before, in anticipation of this important phone call. However, when the call actually came, she forgot to bring the bag with her. She said, "In my haste to get to the hospital and with the flurry of emotions I was experiencing including excitement mixed with the sad thought that some other family had lost a loved one, I forgot to bring my bag with me."

Eight months later Sarah set about unpacking the same bag she never got to use which she found tucked away at the back of her wardrobe.

Sarah said, "Since my transplant my life has been completely transformed.



Sarah a few hours before her transplant operation.

I'm bursting with energy now. I've gone from feeling total exhaustion and only being able to crawl up the stairs, to walking, then running, painting and decorating, gardening, enjoying a little socialising with my friends and, basically, experiencing a hugely improved quality of life. One of the strangest things I found after my transplant was getting used to seeing my dialysis machine beside my bed, which had become more like a relic to my past, as I no longer had to hook up to it every night for 9 hours at a time. After being discharged from hospital post-transplant, I gradually built up my fitness levels, firstly walking for 2km with a cane once a day, then

progressing to doing it twice a day, and later dispensing with the walking aid and gradually being able to run.

"I loved my job as a florist, but it was very physically demanding and, working in cold temperatures, did not suit my condition. No matter how many layers of clothes I wore I could not keep warm. Since my transplant I have been lucky to secure employment as a civil servant which is less physically strenuous. I can work remotely from my home and stay safe as transplant recipients are among the high-risk category for COVID-19. I've come so far since receiving my transplant and I have my donor to thank for it.

"I decided to run the virtual VHI Women's Mini Marathon on its final day, to honour my donor and to mark 'European Day for Organ Donation & Transplantation' which was celebrated across Europe on Saturday 10th October. I'm delighted with the support I have received from family and friends and to have raised almost €2,000 for the IKA. It is such a deserving charity that advocates for kidney patients and their families, and also promotes the organ donor card. I hope that I can help raise awareness about the importance of organ donation and, hopefully, shine a light on all those people like me who experience organ failure and the hugely important and selfless gift of organ donation."

ROSCOMMON LADIES RAISE €1300 FOR THE IKA IN VIRTUAL MINI MARATHON

Five Roscommon friends have raised €1300 for the IKA by taking part in the virtual VHI Women's Mini Marathon. Supporting Sarah Naughton, who was taking part to honour the memory of her late mother Ann, who had kidney failure and who passed away earlier in the year, were Kathleen Rowntree, Erica Power, Bernie Sharkey and Lisa Rowntree.

The ladies walked the 10km distance around their home town of Castlerea along with Sarah, from Williamstown, taking in some beautiful nature walks through the demesne along the way. Their impressive fundraising total amount of €1300 for completing the challenge was from a combined €515 through the IKA's Facebook fundraising platform and the other €785 was raised from donations from family and friends with sponsorship cards.



Kathleen Rowntree, Erica Power, Bernie Sharkey, Lisa Rowntree (Castlerea) and Sarah Naughton, Williamstown

Speaking after the event, Lisa Rowntree, whose brother is engaged to her friend Sarah said, "taking part in the mini marathon together, while observing social distancing, was really enjoyable for all of us and we are delighted to have been able to raise funds for the IKA which supported Sarah's late mother and her family.

We would like to sincerely thank everyone who donated and supported us so generously in these particularly hard times."



BAKER RAISES DOUGH FOR CHARITY

Two Dublin brothers working in partnership in a recent start-up bakery business and whose father underwent a kidney transplant supported the Irish Kidney Association (IKA) to raise awareness for organ donation.

Pictured above: Peter Heffernan, Ashley Earnest, Jack Bentley, Patricia Carthy (Cian's mum), Pearce Carthy Heffernan, Jade Earnest, Cian Carty Heffernan and Conal O'Brien.

A young Dublin man, motivated by both his father and a close school friend's arduous health journeys towards kidney and lung transplants, was inspired to emulate a challenge undertaken by David Goggins, a retired US navy seal, in support of the Irish Kidney Association and to raise organ donor awareness.

On Sunday, 30th August, Cian Carty Heffernan (24), who recently started up a bakery business in Dublin's seaside village Skerries with his older brother Pearce, began his 4 x 4 x 48 Challenge. The Challenge involved running 4 miles every 4 hours within 48 hours, a total of 48 miles in 48 hours.

Cian's inspiration to complete the challenge and raise organ donor awareness came from his first-hand experience since he was a boy of seeing his father Peter Heffernan endure kidney failure, as well as his old school and university friend Jack Bentley (25) struggle with Cystic Fibrosis. Both Peter and Jack are now enjoying renewed life as a result of organ transplantation and are embracing sport as members of Transplant Team Ireland.

Cian, a former DCU student, and his older brother Pearce (27), an accomplished pastry chef, found themselves out of work after lockdown. In May, Cian and Pearce, who previously, worked with the two-star Michelin restaurant 'The Greenhouse' and

other popular eateries, established 'The Rock Bakery'. Their business offers freshly baked produce for delivery business which operates out of the kitchen of 'The Potager' restaurant in Skerries. The brothers pledged to donate delivery charges for their customers' freshly baked orders to the fundraiser which raised €3,055 through the Challenge's GoFundMe page.

Cian and Pearce were young when their father Peter Heffernan was diagnosed with kidney failure in 2005 and they were involved in his care helping him set up his dialysis machine tubes at home for his daily life-saving treatment until he was called for a deceased donor kidney transplant at Beaumont Hospital in 2011. Cian's friend Jack, underwent a double lung transplant at the Mater Hospital last year.

Cian's 4x4x48 Challenge commenced from The Square in Skerries on Sunday evening, 30th August at 8pm. His twelve 4 mile runs brought him through, and around the beautiful Skerries seaside village, with some taking in the park at Ardgillen Castle. On Tuesday evening, 1st September at around 8.30pm, tired from his 48-hour Challenge, Cian reached his final destination, Bob's Casino on Skerries South where he was greeted by his mother, Peter and Jack.

Cian explained, "I always liked challenging myself to new feats. I wanted to run 1000km

this year and I have over 800km covered so far. So I wanted to push myself a bit more by doing this Challenge for the IKA and organ donor awareness. I find that keeping myself healthy and fit is great in every way, physically and mentally. From being a kid when my dad was on dialysis and he did not have the energy to kick a ball and fast forward to him winning medals at the Transplant Games, showed me how important your health is!"

"I was only ten or eleven-years-old when my father started to become unwell but one of the ways my brother and myself felt we could help him and support my mother Patricia was by setting up his home dialysis machine and ensuring that everything was safe and sterile for his daily treatment. This routine continued into my mid-teens until he finally got called for a kidney transplant nine years ago.

Our family is hugely grateful to the donor family for this life-saving gift. My awareness of the plight of people, like my father, who also had other types of organ failure was heightened when I commenced secondary school at Skerries Community College and became friends with my classmate Jack Bentley who experienced regular bouts of sickness and was often absent due to his cystic fibrosis.

I have remained friends with Jack since both of us went on to third level at DCU. Jack's life has been transformed since his double lung



Cian Carty Heffernan with his father Peter Heffernan in the garden of their family home at The Square, Skerries

transplant last year and it's wonderful that he has now joined the recently established transplant soccer team as part of Transplant Team Ireland which I am proud to say my father has been an athlete on since 2013.

My father has represented Ireland in swimming events where he has successfully medalled at each World and European Transplant sports event he has taken part in since then. Over the years I have seen my father enjoy the camaraderie and support of members of the transplant team who have all faced their own organ failure battles and are now enjoying their gifts of life."

Cian continued, "Unfortunately the

IKA were forced to cancel several of its major fundraising and organ donor awareness events this year due to the pandemic including Organ Donor Awareness Week in April and it's hosting of the European Transplant & Dialysis Sports Championships which was to be held in Dublin at the beginning of August.

"The IKA has supported our family and therefore I wanted to play my part by helping raise vital funds through my Challenge so that it can continue supporting patients and families with kidney disease whilst also promoting organ donation as well as running the successful transplant sports programme."

DIALYSIS MAN ON RTE'S PRIMETIME



Father of three, Eoin Madden (IKA Galway branch Chairman), who is on dialysis waiting for his second kidney transplant was among patients who featured on RTE's Primetime 'The Waiting Game' on 24th September, about the impact of COVID-19 on hospital procedures. A link to the clip is below.

<https://www.rte.ie/news/player/2020/0924/11238738-prime-time/>



SLIGO IKA CAMPAIGNS FOR NEW DIALYSIS UNIT

The Sligo IKA branch is currently lobbying for a new renal dialysis unit at Sligo University Hospital.

The current unit opened in May 2005 when it catered for 30 patients – the same facility now has 59 patients with more arriving almost weekly.

Sligo is now the oldest dialysis unit in the country with no plans to modernise it.

In January of this year a delegation from our branch met with hospital management where some short-term requirements were addressed.

The hospital management were receptive to our requests for improvements. They undertook to deal with some of the issues raised where funds allowed but others were deemed not to be 'doable' for

SLIGO

By BRIAN McHUGH



Members of the Sligo branch display the cheque from Sharon's Walk at the IKA Garden of Reflection at Doorly Park. Seated: Eileen Nolan and Geraldine McHugh. Standing: Tommy Nolan, Sean Fowley, Marie Fowley.



Organisers of the Sharon's Walk with Sligo IKA members.

financial reasons.

However at the meeting branch members were greatly perturbed to learn that there are no plans for a new dialysis unit or renal clinic in Sligo. It's not even in a 10-year plan.

This is most disappointing and worrying with the ever-increasing number of dialysis patients that will require additional space and the current shortcomings of the unit and clinic area.

Another concern is that there is no proper waiting room for patients attending renal clinics. They must sit in a narrow corridor connecting the hospital to the next-door hospice.

Overall the current situation is most unsatisfactory for both patients and the excellent staff who care for them.

A new modern unit, with sufficient space for the existing and future needs of patients, is now required.

The Sligo branch has recently voiced their concerns and that of the patients to the Minister for Health, the top officials in the Saolta University Health Care Group and to local politicians.

We aim to maintain this campaign with the short-term aim of, as a first step, having the new facilities for kidney patients inserted in the plans for the development of the hospital.

DETERMINED SUPPORTERS WALK ALONE FOR IKA

You'll Never Walk Alone is famous as the anthem of Liverpool FC.

But several generous individuals from North Leitrim and Sligo did just that this summer. And many of the more energetic among them ran alone.

By doing so they raised €3,580 for Sligo branch IKA and also commemorated a young local girl who died seven years ago.

Each year residents of Newtownmanor, on the Leitrim/Sligo border, hold an annual memorial Fun run/walk in memory of Sharon Loughlin, a popular local girl who passed away unexpectedly at the age of 24 in September 2013.

For their efforts they get generous sponsorship from neighbours and friends and donate the funds to a local charity. This year they decided to give the proceeds to Sligo branch IKA.

However, like in many situations in 2020, they came up against a major obstacle – they could not organise their event while maintaining social distancing.

Not to be outdone, the organisers came up with an alternative plan – they asked participants to choose a time and place of their own to do their 5K/8K fun, run or walk, between Sunday 5th July and Sunday 2nd August.

And they met with a great response when many answered the call, to the extent that they raised €3,580 for local kidney patients in the region. Donation collectors for the event were Pat Dolan, Geraldine Loughlin, Maggie McLoughlin and Anne Dolan.

The organisers presented the cheque to members of the IKA (Sligo Branch) on Sunday September 20, outside Newtownmanor Hall.

Sean Fowley (branch chairperson), Marie Fowley and Eileen Nolan gratefully received the cheque.

They said all monies will be used for the benefit of kidney patients within the local counties, who attend Sligo University Hospital for treatment.

The Sligo branch thanks all who made the effort in difficult circumstances and gave so generously. Well done to all concerned.



At the presentation of the IKA cheque outside the door of the Renal Dialysis unit, front L-R, Geraldine McHugh, IKA Sligo branch secretary, Ann G. Hayes, Sligo University Hospital, Sean Fowley, IKA Sligo branch chairman. Back row, dialysis nurse Julie Fox, Marie Fowley, IKA Sligo branch vice-chairperson, Emer Melvin, Dialysis Unit Clinical Nurse Manager.

SLIGO IKA HELPS BRING ART TO DIALYSIS PATIENTS

The Sligo branch recently made a donation of €3000 towards an arts initiative that aims to boost the well-being of renal dialysis patients at Sligo University Hospital.

As part of his Artist-in-Residence role in the hospital, local artist Andy Parsons has been working with patients in the dialysis unit.

The Artist-in-Residence initiative is a unique arts and health partnership between The Model Art Gallery in Sligo and the hospital.

Accepting the cheque, on behalf of the Renal Dialysis unit in the hospital, Ann Hayes said: "I wish to extend my sincere gratitude to the IKA for the donation of €3000 for the Artist-in-Residence initiative. This wonderful donation will continue to support the initiative and benefit the well-being of renal dialysis patients".

The cheque was presented to Sean Fowley, chairman of the Sligo branch and Geraldine McHugh, branch secretary.

The presentation was due to take place last April but it was held over until mid-October because of the virus restrictions.

WELCOME CAROL

Congratulations to Carol Moore on her recent appointment as CEO of the IKA. Carol takes over from Mark Murphy who retired after 20 years loyal service to the Association.

Meanwhile, sympathy to Carol on the recent death of her dad.

SYMPATHY

Sympathy also to the family of Frank Dolan, Kiltyclogher, Co. Leitrim who passed away in July.

Frank was a patient of the Dialysis Unit at Sligo University Hospital for a number of years and earlier was an employee of the North Western Health Board.

SERVICE OF REMEMBRANCE AND THANKSGIVING ON TV

The Annual Service of Remembrance and Thanksgiving will be a virtual event this year, due to the current COVID-19 restrictions.

It will be televised on RTÉ One and RTÉ Radio 1 Extra (LW252) on Sunday, November 15 at 11am. In previous years the event attracted large crowds.

WELCOME BACK

Welcome back to Deirdre Melvin as she returned recently to her role as Clinical Nurse Manager of the Sligo dialysis unit after being off on leave.

Thanks to nurse Julie Fox for filling in during Emer's absence when she took good care of the patients.

DOMHNALL RETIRES

Good luck to Domhnall McLoughlin on his recent retirement as Assistant General Manager of Sligo University Hospital.

Welcome to Georgina Kilcoyne who succeeds Domhnall in the role.



SLIGO OPEN AIR MEETING

Sligo branch IKA members held an open air socially distanced meeting at their 'Garden of Reflection' in mid-September.

Pictured are members during the meeting and having a chat afterwards.

Meanwhile, branch chairman Sean Fowley wishes to thank Seamus Cummins, among the others, who helped maintain the garden over the summer.

SLIGO

By BRIAN McHUGH





CONDOLENCES

Our profound sympathy to our member Fiona Lavin and family on the passing of their father Jimmy Lavin in early September. May he rest in peace.

MARK MURPHY

Our best wishes for a happy and fruitful retirement go to Mark who retired as Chief Executive on September 30th.

Under Mark's creative and innovative guidance the IKA has grown in numbers and stature over the years to become a powerful and influential advocate for patients.

Mark, we wish yourself and Frances many years of happy retirement and hopefully and eventually some travel.

And 'thank you' for all the times you came to speak to us in Dublin North.

DUBLIN NORTH

By PATRICIA MACKENZIE

WELCOME

We welcome our new Chief Executive Officer Carol Moore, and we extend sympathy to her on the recent death of her father, RIP. Carol comes to us with a wide experience of working as a CEO and administrator.

Carol is especially looking forward to meeting Branch members, as well as Board and Staff.

Our good wishes and support to Carol in her new role.

GOOD NEWS

Congratulations to Deirdre and Peter Moore, who became grandparents recently, on the arrival of baby Jack, Peter.

SUPPORT CENTRE

As members already know, Beaumont Hospital has sequestered the Renal Transplant Support Centre at Beaumont, and it will be used by the hospital for consultations for the next year. Alternative accommodation for patients who would have normally stayed in the Support Centre, has been arranged with the nearby Clayton Hotel which includes bed and breakfast and parking, and can be accessed from the M50.

Members should phone Patricia,

Frank or Simon at 087-4169907 to book the Clayton.

BRANCH MEETINGS

Due to COVID-19, further branch meetings will take place on Zoom and details will be made available.

SERVICE OF REMEMBRANCE & THANKSGIVING

This year due to restrictions we are all familiar with, our Service of Remembrance & Thanksgiving could not take place.

A special pre-recorded tribute service has been specially made for the IKA by Kairos, and will be broadcast on RTÉ One and RTÉ Radio 1 Extra (LW252) on Sunday, November 15 at 11am.

We believe that nothing can replace our live Service of Remembrance & Thanksgiving – but we feel that this will be a moving tribute to those who gave the 'Gift of Life'.

TO ALL

Our thoughts are with any members who are hospitalised, or coping with the current restrictions at home.

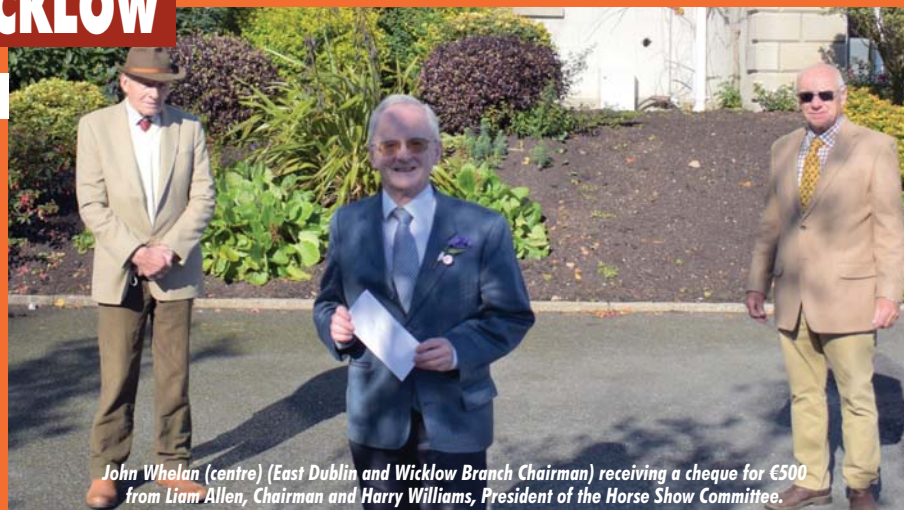
We pay tribute to the dedication and courage of doctors, nurses, and all staff involved in the care and protection of patients at this difficult time.

DUBLIN EAST & WICKLOW

By BERNIE DWYER

One of the big annual events in our calendar has customarily been the Kilmacanogue Horse Show from which the IKA has greatly benefited in July every year. Following the Show, the Committee traditionally hold a reception to distribute the proceeds among local charities. For many years now our Association has been nominated as one of the charity partners in this wonderful community show which does so much to help local charities and showcase their work in the community. Our branch members have participated year by year in helping with the stewarding at the Show itself, and our Branch has usually been rewarded with a very generous cheque.

This year however, due to



John Whelan (centre) (East Dublin and Wicklow Branch Chairman) receiving a cheque for €500 from Liam Allen, Chairman and Harry Williams, President of the Horse Show Committee.

COVID-19 restrictions, it was of course impossible to hold the Show in its usual format. However, the Show Committee decided that 'the show must go on', and so they devised a 'virtual' show, in which participants were invited to enter online. This proved very successful, and at the end

of September there was an open-air presentation, again in line with social distancing, at which cheques were presented to fourteen local charities, including Bray Lakers, Purple House Bray Cancer Support, and Wicklow Hospice, and also the Irish Kidney Association.



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Members of the branch continue to keep in touch through our regular Zoom Meetings. We have all been cocooning now since March, so the meetings have become an important way of keeping in touch. Just by being able to talk to others in similar circumstances is a comfort. Liz O'Sullivan keeps us informed of activities at Board level.

Marguerite Sneyd circulated her book *'From Analysis to Dialysis and Beyond'* to members who have enjoyed the read. One of our members has written a review which you can see on the right.

Thanks to Evelyn Leon and John Christian for joining our meetings from California and Germany respectfully. It is always interesting to hear about the experiences of Irish patients who are now living abroad.

We plan to continue with our Zoom meetings even after we get back to normal to facilitate those who are unable to meet with us in The Plaza Hotel.

AN APPRECIATION OF THE DIALYSIS STAFF IN TALLAGHT HOSPITAL

After so many years undergoing dialysis, it is thought that we knew everybody on our ward. Though, on consideration, the ward is running 7 days a week, optimising the 14 beds over 3 cycles per day. That equates to $14 \times 3 \times 7 = 294$ per week, or $\pm 1,100$ dialysis per month!

And when we move over to the new dialysis wing with its (rumoured) 35 beds, that could equal $35 \times 3 = 105$ per day, or $\pm 2,900$ dialysis per

DUBLIN SOUTH

By **JOHN SEMPLE**

month.

To us, recognising you, the nursing teams, the strong personalities, the leaders, the nurses established, and the new staff from the Osborne Ward, plus the helpers that always seem to be there when needed – and they seem to be able for everything.

We try reading your name tags, if

they are the correct way up, there, or even back-to-front.

To all of you, a heartfelt 'thank you', for treating each one of us as individuals, and with such gentle care. You really are appreciated, not only by us, but also our families and friends, and at home.

FROM ANALYSIS TO DIALYSIS AND BEYOND – A REVIEW –

We are not just kidney patients, we are failing kidneys, replaced kidneys, donor kidneys, happy new kidneys. We pass through our dialysis ward, some for a short time, others – to the end of our lives. Yet, for the dialysis staff who care for us every week, to really understand us we need to open up to those dedicated to our well-being.

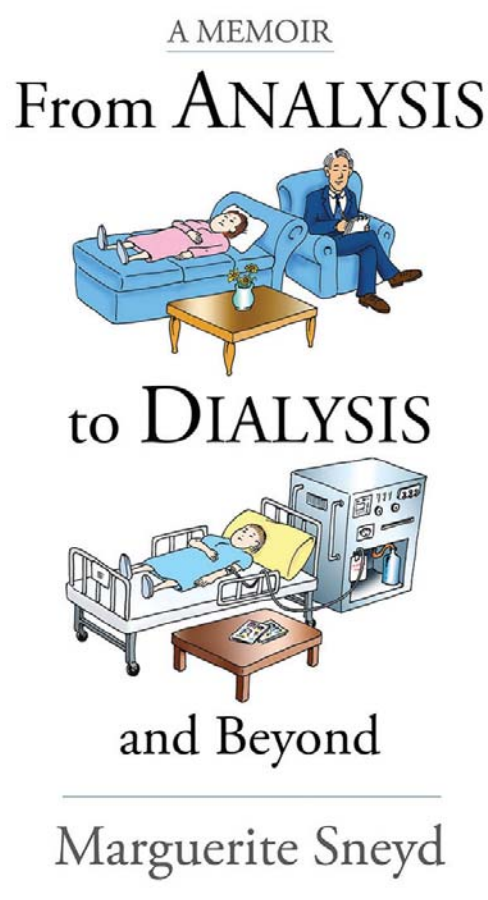
We do indulge in casual conversation, new house, job, car, baby, but we are mostly quite private patients, yet a remarkable book has been written by one of our Dublin South branch members, Marguerite Sneyd, which really illustrates the life of a long-term patient who is, even now, still under the watchful care of our godlike professors.

But, returning to our opening up to our wards team, Marguerite has opened up like a flower, from the very first visit to the clinic with its initial prognosis, through to the various treatments, and now a happy healthy beyond.

It details the numerous stages of her life, the husband and her children, and how dialysis has impacted not only her life, but that of the family too. She comes across as a typical Dublin girl, with its growing up issues, how the family has given her the support and strength through hospital and dialysis. But, to my mind, it gives an insight into just one of the lives we, as patients, experience.

Yes, I would recommend that our ward teams read it but, also, we as patients who are passing through life just as Marguerite Sneyd is now. It is a revealing insight for our new caring teams for whom Dublin is still viewed through the windows of their nurse's home.

Copies of the book are available by phoning Head Office, Donor House at 01-6205306. Price €10.00 (including postage). Proceeds from books bought through Donor House are donated to the IKA.





Hello to all from the Offaly branch. I hope everyone around the country is keeping as well as possible during these difficult times.

BEST WISHES

On behalf of the Offaly branch I would like to wish Mark Murphy all the best on his retirement as CEO of our Association. We would like to thank him for all the help he has given our branch, through the years, and in particular for his efforts with the original dialysis unit in Tullamore.

FUNDRAISING

Thank you to Ashley Touhey and her workmates that nominated the IKA, as a recipient from their charity collection of €800, which was matched by their employers' Grant Thornton for a total of €1600. Ashley nominated the IKA as her mother Ann Marie Glynn has received a kidney transplant.

Thanks to Siobhan Groome's daughter Hannah, who held a tea party in memory of her grandmother

OFFALY

By DERMOT GLYNN



Paul Reape, Morgan Byrne, Dermot Glynn and Leona Mahon Secretary Offaly IKA. Missing from Picture Roisin Galvin.

Margaret Groome, that has passed away recently. It is very kind of Hannah to think of others during this difficult time. Hannah raised €220.

One of our members, Pearl Lawrence, spoke about the IKA and organ donation at a Harvest Festival in the Church of Ireland Church in Tyrrellspass. The congregation very kindly donated €170. Thank you to everyone and well done Pearl!

Finally, our friends at Tullamore Touring and Cycling Club, who have contributed greatly to the Offaly branch through their annual 'Pat Colgan Pedal the Peaks Challenge', did not forget us even though the event had to be cancelled this year –

they presented us with a cheque for €250.

To all of the above we thank you for remembering us in what is proving to be a very difficult time for all charitable organisations during this pandemic. Your thoughtfulness is very much appreciated.

GET WELL WISHES

On behalf of all of our members, I would like to wish our Chairman Jerome Burke, continued 'get well' wishes during his current illness. Hopefully, in the not too distant future, he will return to full health and be back at the fore of our branch.

TIPPERARY

By ORLA HOGAN RYAN

I hope that everyone is staying safe and well in these strange times. In the branch we are continuing with our zoom meetings. If you would like to join please do contact me. During our last meeting Aoife Smith, IKA Co-ordinator of Counselling Services joined us and was very informative. Thank you Aoife.

Nenagh Golf club had a fundraiser for the branch. We are so thankful to them for hosting this and we also thank James Dodd for organising it.

We wish to pass on our condolences to the Jonas family.

To Mark Murphy, our recently retired CEO, and Lorraine Costello, Patient Support Officer, we wish you both well in your retirement.

Congratulations to Paul Hackett and Lizzy Hayashida on your engagement.

WEXFORD

By MARIE DONLON

A cheque for €2,500 was presented to the Wexford branch recently by Michael O'Neill on behalf of 'Touched By Suicide'. A very generous donation and very much appreciated.

Many thanks to Debbie McDonald and her team from Bbraun Wellstone who celebrated World Kidney Day 2020, and organised a walk in Johnstown Castle on Sunday 8th March. Donations totalling €272.50 received on the day were presented to the Wexford Branch.

We fondly remember, with great sadness, those who passed away recently. Eugene Buttle, Graham Barnes, Seamus Carton, Philomena Ronan, Nicholas Morris and Rita Smith. Our thoughts and prayers are with their families at this very sad time.



TRIBUTE TO MARY O'SHEA

It was with great sadness that we learnt of the passing of our dear friend Mary O'Shea, Beaufort, Killarney. Mary passed away on September 17th after a long illness bravely borne. I first met Mary and her family when her husband Peter started dialysis.

Peter was very lucky to receive a kidney and pancreas transplant a few years later and they both became actively involved in the activities of the Kerry branch. Mary was our 'go to' person and advisor when it came to anything to do with catering. She had worked in the hospitality sector some years earlier. She dealt with the thousands of cyclists who needed

refreshments during the many Ring of Kerry charity cycles which raised thousands of euros for the IKA.

There was always a queue for Mary's homebaking. Even our Branch meetings became a social event as we looked forward to her culinary skills.

Mary and Peter travelled to Lourdes on a few occasions, and her faith and sense of fun will live on in my memory. She was a great listener and always saw the positive in everything, despite the health challenges she faced. Over the years Mary and Peter would look forward to the many overnight trips that we organised for patients, and no better woman to be last to leave the bar when a good 'sing song' was in flow.

Mary was so grateful for the new lease of life Peter enjoyed

KERRY

By THERESA LOONEY



Mary O'Shea

post-transplant. She was one of the most dependable volunteers during Organ Donor Awareness Week and was full of enthusiasm. She covered all the shops and chemists in her native Beaufort and Killorglin area. She understood first-hand the importance of spreading the

message of organ donation and was eternally grateful to Peter's donor.

Her passing leaves a huge void in our Branch but we are sure that Con Brosnan, Tom Fleming and many more past patients had a great welcome for her in her heavenly home. We extend our deepest sympathy to her husband Peter, daughters Sarah, Michelle and Maria, her son Michael, son-in-law Cian and Michelles' partner Joe, extended family and friends.

She may be gone but will never be forgotten.

CLODAGH'S STORY



Tim and Clodagh O'Shea

Huge congratulations to Clodagh O'Shea, Killorglin, who recently received her first Holy Communion.

In 2015, two weeks after Clodagh's fifth birthday, she was diagnosed with chronic kidney disease. Clodagh was transferred from University Hospital Kerry to Crumlin Children's Hospital where her condition deteriorated rapidly. Several months were spent in hospital and Clodagh returned home to Kerry to begin life on home dialysis.

This consisted of Clodagh being attached to a home dialysis machine for twelve and a half hours each evening, 7 days a week. Because of her poor appetite and deteriorating health, a feeder peg had to be inserted in her stomach so she could be peg fed. It was also used to administer her medication during the day.

Many visits to Crumlin followed where Clodagh was monitored before she was well enough to be considered for transplantation.

In April 2016, Clodagh and her parents went to Beaumont Hospital to meet Ms Dilly Little to discuss a transplant for Clodagh. Thankfully, her dad Tim, was a suitable match but before he could be considered for donation the doctors advised him that he would have to lose a considerable amount of weight.

Tim returned to Kerry and hit the ground running to achieve this. In August 2016, he was accepted as Clodagh's donor. The transplant took place on October 17th, 2016 and huge thanks to everyone who supported the family and made this dream come true.

Today, thankfully, Clodagh is leading a life like any other 10-year-old.





GREETINGS

As we continue navigating the uncharted waters of COVID-19, I hope that you and your families all stay safe and well. The last few months have undoubtedly been tough on us all. Things are different in lockdown but we will find our way through, together. Keep connected, one day at a time.

As you are by now aware, the Clare branch of the Irish Kidney Association 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 and the West Clare walk are but a few events that were cancelled and, now adding to this list, is the Christmas Social. Unfortunately, this is the way it will need to remain for another while.

Fundraising online is always an option and we encourage anyone with any ideas to create your own online/virtual fundraisers in order to ensure the IKA's vital services can remain for those who require it.

Our support is always available, so feel free to call or text **0876243367/087-9392148**, E: ikaclare@gmail.com or Message us on **Clare IKA facebook page**.

COMMEMORATIVE MEMORIAL FOR ORGAN DONORS AND THEIR FAMILIES

As you may be aware, Clare branch IKA committee members have been working with IKA Headquarters, Clare County Council, designers and construction contractors to erect a commemorative memorial in Ennis, in grateful appreciation of all organ donors and their families, whose generous gift restores the lives of so many through transplantation. These plans are progressing, and we hope to

CLARE

By NORETTA CLIFFORD



be able to reveal more about this in the coming months.

HELLO AND GOODBYE

As we say goodbye to former CEO Mark Murphy, Clare IKA would like to wish him a huge congratulations on his retirement and an even bigger 'thanks' for his many years of Service to the IKA.

We say hello and welcome to Carol Moore, the new CEO. We also extend our sympathy to her on the recent death of her father, RIP. Clare IKA looks forward to working with you

THANKS TO THE HOSPITAL TEAMS

Once again, Clare IKA members, transplant recipients and 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. We appreciate all you have done and continue to do during these challenging times.

WEDDING BELLS

Congratulations to IKA Clare branch member Aishling McCormack from Kilrush and Mark Linehan from Mallow Co Cork, who recently married in the Star of the Sea Church, Quilty, Co Clare, pictured above with their family members from Clare and Cork.

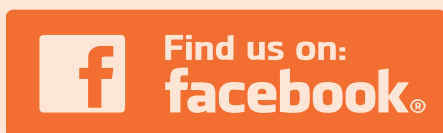
DEEPEST SYMPATHY

We extend our sincere sympathy to Imelda, Eamon and Kayleigh McGann on the recent passing of Imelda's mother Celine McHugh, RIP.

FOR DONOR CARDS



FREETEXT DONOR to 50050



ZOOM MEETINGS

Back in March when we last held our branch meeting none of us could have predicted how our lives would change and how we would have to adapt to new ways of dealing with things in our everyday lives.

And adapt we did, our Branch Committee decided we would join the trend and keep in touch by having Zoom meetings. We then extended this idea to hold our monthly branch meeting via Zoom.

We held our first meeting on Wednesday May 13th, which was hugely successful. Following on from this success we have held monthly meetings, with a variety of different guest speakers, covering a range of topics including living with COVID-19 as vulnerable patients, cocooning, flu vaccinations to mention but a few, with contributions from Professor Liam Plant, Counsellor Aoife Smith, Donor House, and Teresa O'Neill, Renal Nurse CUH.

It was great to be able to see and speak to our members and welcome some new faces.

While Zoom is a fantastic way to keep in touch it will not replace the human interaction of our monthly

CORK

By MARY HURLEY/SALLY NAGLE/SHEENA McDONAGH



March Support meeting when we could meet 'physically'!

meetings which we all miss, especially the after meeting chat over a cuppa.

Please God we will all get through this and we will be able to get together again soon. Our Support meeting will continue through Zoom on the first Tuesday of every month at 8pm. We are open to suggestions on what speakers we could invite to join us.

We would like to express our thanks and gratitude to the staff in our hospitals for their fantastic work during these difficult times.

Stay safe everyone.

NEW CHIEF EXECUTIVE OFFICER

On behalf of the Cork Branch we would like to wish Mark Murphy the very best wishes on his retirement and to thank him for his huge contribution to the Irish Kidney Association. We would also like to take this opportunity to welcome our new CEO Carol Moore and we extend our sympathy to her on the recent loss of her father, RIP. We wish her the best in her new position and look forward to working with her in the future.

ONLINE FUNDRAISERS

ENDLESS POSSIBILITY SONG FUNDRAISER

During the first lockdown I was feeling sad that Organ Donor Awareness Week could not go ahead, as I know how important it is to all affected by kidney disease. This week would be the biggest yearly fundraiser and promoter of organ donation and I could see the loss to all the patients

was so big.

I had co-written a song called *Endless Possibilities* with Limerick musician Mike O'Donovan in 2018, and also recorded a cover of a song called 'Don't Worry About Me' by Frances but never really released it as a music video. So one day I got onto my creative cousin and asked would he put together two videos that could be used as a GoFundMe page.

To my surprise the GoFundMe page and music videos raised over €2,300 for the Cork IKA branch. I was delighted to raise funds and create more awareness of the importance of being an organ donor and having the conversation with your families.

BIRTHDAY FUNDRAISER

A huge 'thank you' goes to our local member Colette Hawe who has raised the phenomenal amount of €3500 (split between the future



Colette Hawe



Colette Hawe, post-transplant

Cork Support House and the current Beaumont Renal Support Centre). Colette, from Ballyhea, Charleville, is a powerhouse of positivity and new-found energy. Her kidney transplant, in early 2020, has afforded her a new lease of life after 10 years of ill health due to renal issues.

However, she wasn't idle during those years, attaining a degree in Social Care in 2017 whilst also subsequently working in social care for a time.

Her 34th birthday this year was definitely a time to celebrate, but Colette selflessly asked for donations to the IKA in lieu of a birthday present. Colette set up a birthday charity initiative on Facebook where people were able to donate online.

Post-transplant Colette has been recovering at home, with the support of her boyfriend Morgan and her cute ball of fluff dog Freddie. Her parents, who live close by, couldn't be more proud of Colette, and the strength and determination that she continues to show in her recovery.

Colette would also like to give a huge shout out to Prof. Liam Plant and his team in CUH, and the transplant team in Beaumont Hospital.



Colette Hawe as a bridesmaid for her friend last November

CAVAN/MONAGHAN

By KARL CRONIN

RETIREMENT WISHES

The Cavan/Monaghan Branch wish to extend our congratulations and best wishes to Mark Murphy and Lorraine Costello on their retirement from the IKA. They have both worked tirelessly, on behalf of patients and their families, offering much needed support whenever needed and advocating on their behalf for decades. We thank them for their hard work and dedication and wish them, and their families, the very best of health and happiness for the future.

We would also like to extend a warm welcome to our new CEO, Carol Moore and sympathise with her on the recent death of her father, RIP.

KILLINKERE GFC

During the summer, Killinkere GFC promoted organ donation awareness on their Facebook page, encouraging their followers to have that conversation with their families and consent to becoming an organ donor. The post was shared over 130 times from their page and it is very encouraging to see this message being put out there by such a large football club. We are asking other football and sports clubs in the area, to promote organ donation on their social media platforms, so that the message reaches as many people as possible.

Thank you to all in Killinkere GFC for your support.



HOSPITAL LIFT DECALS

Our lift decals in Cavan General Hospital (featured in the Spring edition of *SUPPORT*) continue to generate interest and a lot of positive feedback from the public. If your local hospital would be interested in following this initiative, please do not hesitate to contact us for more details.





Find us on:
facebook®

Welcome to the Autumn edition of *SUPPORT*.

Our Facebook page is extremely popular with all our followers. This allows us to promote all events organised by our branch and publish photos of those events. Please follow us on Facebook Waterford branch.

If you would like us to communicate with you via email, please let us have your email address.

We would like to wish our new Chief Executive, Carol Moore, a warm welcome on behalf of the members of our branch and we extend our sympathy to her on the recent loss of her father, RIP. We look forward to meeting Carol over the next few months.

We would also like to take this opportunity to wish Mark Murphy, retired Chief Executive, good health and a happy retirement. It was a pleasure to work with Mark for the past twenty years. 'Thank you', Mark, for all your work on behalf of renal patients.

We also wish Lorraine Costello, Patient Support Officer, good health and a happy retirement. Lorraine served the Association for nearly forty years. We thank Lorraine for her help and kindness on behalf of renal patients.

The Respite Centre at Tramore is looking very well with new windows and front doors (see photo above) The outside walls and attic were insulated and seem to be highly effective. We hope to have the apartments painted inside and outside early next year.

We look forward to reopening next summer and welcoming patients and their families to Tramore once again.

Sr. Brenda retired from the Dialysis

WATERFORD

By VERA FRISBY

Respite Centre, Tramore



Unit at Waterford Regional Hospital in September. We wish Brenda good health and a happy retirement. On behalf of all patients at the Renal Unit and members of IKA Waterford branch, we would like to thank Brenda for her kindness and help over the years.

Noelle Conway, from Dungarvan, competed in the virtual Dublin City Marathon on Saturday, October 24th. Noelle is a seasoned Marathon runner and is doing the Virtual Marathon this year to raise funds for our Branch.

Noelle is sister of Frances Moynihan, IKA National Board Member and honorary Secretary of our Waterford branch.

Frances donated a kidney to her

daughter Karyn in January 2020 and her husband Joe received a kidney from his sister Mary Moynihan in April 2009.

We would like to thank Noelle for completing this Marathon and raising vital funds for our branch and 'thank you' to everyone who sponsored Noelle, your support is very much appreciated.

We are continuing with our Branch meetings via Zoom. If you would like to join us for our virtual meetings, please contact Frances Moynihan with your email address and phone number. Her number is 087-2411549, E: francesmoynihan19@gmail.com

Stay safe, look after yourselves and each other.

LIMERICK

To celebrate her milestone 60th birthday on June 7th, instead of receiving presents Aine Geraghty, from Limerick, asked her family to support the Irish Kidney Association which has become a cause close to her heart. Her husband David was soon to commence dialysis treatment.

Three generations of the Geraghty family took part in the IKA's virtual 'Run for a Life' by walking, jogging or running. David and Aine's daughter Fiona Geraghty said, "My dad has kidney disease and is just about to start his dialysis journey. Your Association has supported our family since his diagnosis. Through social media we have seen the great work that the Association does in helping us and other families and patients and for that we can't thank you enough. Keep up the amazing work that you do."



David and Aine Geraghty with grandchildren Harry (4) and Aoibheann (7), daughter Fiona and son Ian and his partner Ashling



Hello everyone from lockdown in Donegal.

Strange times for sure. Here's hoping everyone is doing good. We are really missing our branch meetings and seeing you all but please God those times will return. During this time we have heard of the loss of so many people.

We extend our deepest sympathies to our dear friend and past Committee member and Board member, Danny Breslin. Danny was an amazing man to have on board, he taught me so much. Danny was honest and very witty. His love and support for the renal patients in Donegal and the Renal Support Centre at Beaumont was outstanding. He will be sorely missed by his loving wife Mary, their 6 sons and extended family. Rest easy dear Danny and thanks for all you have done.

Condolences also to our dear friend, Eileen McFadden and daughters Yvonne and Donna and



Siobhán Bates presenting hand sanitisers for use by the renal dialysis patients.

DONEGAL

By SIOBHÁN BATES



A huge 'thank you' to Pixelili Fabric Company, Downings Co. Donegal, for donating beautifully made bamboo masks for the Renal Unit Letterkenny. The Unit was nominated by Shauna McClafferty, Beach Hotel, Downings. Pictured are Louise Kelly, Renal Nurse Manager accepting the donation from Siobhán Bates.

extended family on the death of Danny McFadden. Danny was a long-standing loyal member of the branch for over 30 years. Danny was from Falcarragh and served on our branch committee and worked so hard right up until his passing. Donations, in lieu of flowers, were made to the Donegal Branch and €710 was received. The PCC School in Falcarragh donated €140. Thank you for the amazing donation and rest in peace Danny.

Condolences to everyone who lost a loved one. It seems it is a lot harder to deal with given the strange and difficult times we are in. I also lost my beautiful dad Tommy McCafferty on July 6th. Thank God it was not COVID related and, therefore, able to hold his wake at his home (which is so popular in Donegal). We held a lovely funeral mass. I wish to thank all of you who

sent me cards and letters, if only I could thank you individually. It is much appreciated at this difficult time.

Blessings to all who recently received transplants and many more healthy years to you all.

The Donegal branch was happy to donate over €500 worth of hand sanitiser to our renal patients attending the dialysis centre at Letterkenny Hospital. We also assisted the purchase of packs of remote controls/earphones and shoulder bags which were needed for patients during lockdown.

The Renal Support Centre is sorely missed by Donegal and all patients nationwide. Alternative accommodation is available in the Clayton Hotel and we are grateful for this. We are looking forward to an update in the *SUPPORT* Magazine.

Good luck to Mark Murphy and Lorraine Costello on their retirements. It was a pleasure to work with you both and 'thank you' for all your hard work for the good of the renal patients in Ireland.

To all the frontline workers who are keeping the show on the road, and all members and IKA staff working from home, we salute you.

Keep well everyone, keep in touch and contact myself or any of the Committee at any time.



George Bates, Donegal branch PRO presenting welcome packs to the Letterkenny Hospital Dialysis Unit.



IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

MEMBERSHIP APPLICATION FORM



BLOCK CAPITAL LETTERS PLEASE:

Mr. ☐ Mrs. ☐ Ms. ☐ FIRST NAME: _____

SURNAME: _____

ADDRESS: _____

POSTCODE: TEL: _____ MOBILE: _____

EMAIL:

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

Please indicate if any of the following apply to you:

PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED

☐ YES ☐ NO

☐ Do not wish to disclose

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

Post? ☐ YES ☐ NO

Or Email? ☐ YES ☐ NO

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

Email? ☐ YES ☐ NO

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

☐ YES ☐ NO

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

☐ YES ☐ NO

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

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

SIGNATURE: _____ DATE: _____

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



IKA DIRECTORY



Irish Kidney Association CLG, Donor House, Block 43a, Parkwest, Dublin D12 P5V6

Tel: 0818-543639 (KIDNEY) or 01-6205306 | Email: info@ika.ie | www.ika.ie

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

Emergency Mobile Number: 087-4169907 | Email: renalcentre@ika.ie

LOCAL BRANCH SECRETARIES

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Phone:
087-6635910

DUBLIN EAST + WICKLOW

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Phone:
086-1673467

KILDARE

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CHARITY REGISTRATION NUMBER 20011260