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SUMMER 2022

LATE SHOW

SUMMER

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Editorial...



An article on the latest COVID-19 treatments can be found on page 7-9 and we continue to advocate for clearer pathways for renal patients to these treatments.

The Board again reviewed the holding of face-to-face meetings in May and agreed those Branches wishing to hold face-to-face meetings can now do so subject to following safety precautions. You can find out more on page 11.

We worked long and hard to find a solution as to how Transplant Team Ireland could travel to Oxford for the European Championships with Irish Kidney Association (IKA) support. Unfortunately the current uncertainties regarding COVID-19 and the Irish medical and legal environment mean that this is not possible at the moment, as ultimately the IKA carries the legal responsibility and liability for any mishap or negative consequence that might occur in respect of the team's involvement in events. We cannot ignore medical and legal advice. We did however put in place an arrangement with the Championship organisers and have agreed that individuals from Ireland can register and participate as individuals in the Championships. More details on page 47.

In happier news, our holiday homes in Tramore are now open again. All those who applied for an IKA holiday break in Tralee, Killarney or Tramore should now have received notification of the result of their application. Unfortunately,

demand is much higher than supply, so many people will be disappointed.

Beaumont Hospital requested an extension of the use of the Renal Support Centre for a further year, and the Board has agreed to a further 6 month extension from October 2022.

Regarding the Cork Support Centre, we finally received planning permission, subject to minor amendments. A Project Manager has been appointed and we are currently seeking redevelopment quotes.



The IKA was honoured to receive an accolade from The Wheel, the national association of community and voluntary organisations, charities, and social enterprises. The certificate entitled 'The Dr. Mary Redmond Honorary Award' was given to the IKA 'in recognition, admiration and thanks for the



FRONT COVER

Ryan Tubridy with Late Late Show guests, Aine Cornally and her friend kidney transplant recipient Sheila Hanevy, who shared their inspiring story for Organ Donor Awareness Week.

Photo by Conor McCabe

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outstanding contribution made during the COVID-19 pandemic in 2020/21 in providing pandemic related care whilst also keep frontline services running’.

The independent investigation into a transplant operation which was postponed due to the lack of an ICU bed in the Mater Hospital is now nearing a conclusion.

We ran a very successful Organ Donor Awareness Week 2022 (ODAW) which received widespread media coverage. This was set against a backdrop of media attention, justifiably, on the war on Ukraine.

This SUPPORT’s cover story features two friends since infanthood, who shared their inspiring story with Ryan Tubridy, when he interviewed them on the RTÉ *Late Late Show* on the eve of the awareness campaign.

After 19 years of dialysis treatment for one of them, she finally received her long-awaited kidney transplant thanks to her friend and the paired exchange programme in Coventry. More details on pages 4-5.

You can also read more about the ODAW campaign on pages 32 to 43.

After a period of unprecedented change due to the COVID-19 global pandemic where society sacrificed so much to protect those we hold dear, we saw a first in the Association’s proud history – the hosting of postal branch elections. This required significant planning and organising, with the Board playing an active and decisive role.

We held an online event to

explain the process with a detailed procedures manual developed and with all details posted on our website.

Thanks to everybody who participated. What the results show is that we have plenty of work to do to encourage more member participation. The report of the AGM, which took place on Saturday, July 2nd, including the Election results, can be found on pages 10-11.

A number of members who have made a significant contribution to the Association’s success have retired. We would like to thank them for all they have done, without them the Association would not be as successful as it currently is.

In particular, I would like to thank Colin Mackenzie, retiring National Honorary Chairman (see his farewell message on page 6), and John Whelan, National Honorary Secretary, who were so supportive of me as a new CEO.

Congratulations to Eddie Flood, former National Honorary Treasurer, who has now taken up the role of National Honorary Chairman. I look forward to working with Eddie and also our newly appointed National Honorary Secretary Marie Fowley and National Honorary Treasurer Joan Gavan.

The Board also approved new policies for patient aid and counselling, and you can find out more on page 11.

I attended, and spoke at the annual conference of the Irish Nephrology Nurses Association, attending the pre-conference dinner as a guest. I also attended the

annual scientific meeting of the Irish Nephrology Society. Both groups made me feel very welcome and spoke highly of our Association.

It was very enjoyable chatting to such dedicated and passionate health care professionals who really care about their patients and want to improve services.

One such improvement is described on page 12-14 about a new very positive development in matching people on the transplant list who are sensitised. The key message is no matter how long you are waiting on the transplant list make sure your blood tests results are up to date.

Finally, we held a very lively and stimulating session with 40 participants who are interested in volunteering as peer supporters. The quality of questions from the participants and level of interest were both excellent, and this shows that when we provide a good structure for volunteers in an area they are passionate about, we can recruit new volunteers.

I really believe this new pilot service will have a major positive impact both for the Association and patients and their families. Full details on page 18-19.

Whatever your circumstances, I hope you are enjoying the summer and getting to spend some time outdoors while remembering to apply sunscreen.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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Best friends in kidney transplant chain swap on The LATE LATE SHOW

By
GWEN O'DONOGHUE



Westmeath natives **Sheila Hanevy** and **Aine Cornally** were interviewed on the **RTÉ Late Late Show** on the eve of **Organ Donor Awareness Week** when they shared their story of triumph over adversity with **Ryan Tubridy** and the nation.

After 19 years on dialysis Sheila Hanevy received a kidney transplant. Sheila and Aine shared their story on the *Late Late Show* to highlight the annual campaign and to give hope to people in organ failure who are languishing on waiting lists for a transplant.

Born four minutes apart in the same maternity hospital, an enduring friendship, spanning five decades, has been copper fastened as Aine came to the rescue of both Sheila and a stranger by donating a kidney in March 2019. This involved donor kidneys criss-crossing between London, Coventry and Scotland.

Sheila had been undergoing dialysis treatment for 19 years when eventually the hope of a lifeline, which Aine's husband Brian Wickham had discovered many years before, came through. This followed a successful first transplant years before that lasted 15 years.

Like some members of Sheila's family neither Aine nor Brian were suitable kidney donors for Sheila. Undeterred, Brian was inspired by a programme he saw on a UK TV channel about a paired exchange kidney swap. The programme showed how a willing donor and patient are entered into a programme to do a kidney swap in a chain of other people in the same situation.

Sheila enquired about the paired exchange kidney programme with Consultant Colm Magee at Beaumont Hospital who has been looking after her kidney care since she was a teen. He advised that Beaumont Hospital was in negotiations with the University Hospital of Coventry & Warwickshire in England about Irish patients entering the paired exchange programme. Sheila was one of the first Irish patients to go into that programme in 2011.

Brian and Sheila made a trip to Coventry and underwent tests after which it was confirmed they could be accepted onto the paired exchange programme.

But the road to Sheila's second transplant took 19 years, with Aine also going into the programme in the hope that she could be a donor. There was one failed attempt which was called off at the eleventh hour in



Aine and Sheila

January 2019. The chain was broken as Sheila got an infection.

The Westmeath natives who grew up in the village of Ballymore, near Moate, spent part of national school and all of secondary school together before sharing a flat in Dublin when they came to work there where they eventually settled.

Aine and Brian Wickham settled down in Rathmines and had three children, two girls, ages 17 and 24 and a boy aged 21. Sheila who lives in Maynooth was accompanied to the *Late Late Show* by her partner Pat Dunne and Aine's husband Brian was also an audience guest.

In March 2019 Aine donated a kidney to a stranger so that Sheila could also receive a kidney in return.

Sheila started dialysis treatment in 1983 when she was just 15-years-old. She described her health journey: "I was on the transplant list for 7 years and received a transplant that lasted for 15 years and I am very grateful to the family of the kidney donor who gave me this

transformational new lease of life.

"I went back on dialysis and I was on the transplant list for 19 years. I was one of the first patients to go into the paired exchange programme in 2011 in Coventry and I received a transplant in March 2019.

"My best friend from birth Aine donated a kidney to a stranger in London to enable me to get a successful kidney from an altruistic female donor from Scotland.

"Aine and I were born in the same hospital on the same day in 1968. She is 4 minutes older than me. We have grown up together and are still best friends to this day. She is like my sister and a very special person to give such a generous *gift of life*."

Aine, who works in Markets and Treasury at Bank of Ireland, said, "Sheila and myself are like sisters, she has a key to our house and our children grew up with her being around.

"We all watched her health deteriorate over the years but she is a formidable and determined lady and very seldom let her kidney failure get to her. Despite her failing kidneys she worked all the way through in Finance and never let any of her colleagues know when she was clocking off at 5pm that she was heading into hospital for dialysis treatment.

"We could all see her deteriorate over the years and it was heart-breaking to watch as when we used to go for walks she would have to link into my arm for support.

"She never travelled light and when she came to stay in our house, my kids would help her with her bags as she didn't have the strength to carry them into the house. But she was always good fun and never dwelled on her plight.

"It is such an honour to be able to donate a kidney so she could get one in return and I hope the kidney recipient of the one I donated is still doing well".

Aine explained to presenter Ryan Tubridy about helping to give her friend a new lease of life, "The real benefit is to see Sheila do the stuff we take for granted like going on holiday".

Sheila concluded the interview with an important message, "to anyone on dialysis, be patient because there is always hope!".



Late Late Show tweet

Farewell

Dear Members

It has been an honour to oversee the Irish Kidney Association (IKA) for the past three years. I became a National Officer, when I assumed the role of Treasurer, and later, National Honorary Chairman.

I have just completed five and a half years as a National Officer. A year was added to my tenure as Chairman, as the Board decided to postpone Elections for another year, due to difficulties created by the pandemic.

On the completion of my term of office as Chairman, I have also decided to step down from the Board, and not seek a nomination from my Branch. I wish to remain Chairman of the Dublin North Branch, and members have allowed me to remain in that position.

We have able and experienced Board members, who have been more than two years on the Board, and are therefore eligible to be National Officers.

There are many people, whose advice, support, and cooperation were essential to me, especially over the past three years. My thanks to my two fellow officers, Eddie Flood, National Honorary Treasurer, and John Whelan, National Honorary Secretary, whose wise and friendly support has been of great value to me.

I thank every member of the Board, for their trust and, I believe, wise decisions, always made in the interests of patients, and the welfare of the Association.

My thanks to staff for their cooperation, and awareness of members' needs.

My sincere gratitude to all members, carers, and supporters, who have contributed to the work of the Association. We welcome your interest, enthusiasm, and new ideas, so please keep in touch with your local Branch, if possible.

I wish my successor on the Board, Chloe Kinahan, every success. Many of you will remember her son little Sam Kinahan, who received a living donor transplant from his dad, Ivan, and is now a very happy and healthy schoolboy. Our good wishes to Chloe, Ivan, Ali, and Sam. I am confident that Chloe will bring a new energy and enthusiasm to the Board.

There is another very important, and often overlooked, role. No Branch Officer or Board Member works alone. Your family members, whether patient or carer, often make it possible, by their cooperation, for you to give your time to the IKA. My thanks to all of you, who help us to be more effective Board Members. For example, I could not have carried out the duties of the National Office without the support of my wife, Patricia (who many of you may know, looks after accommodation for patients staying in the Clayton Hotel), who received a transplant fourteen years ago, and understands, as only a patient can.

My sincere thanks to all the doctors, nurses, and all medical staff for your skill, attention to detail, and the great kindness you continue to show to all patients.

Finally, my thanks to our dedicated and innovative CEO, Carol Moore for all your hard work and vision.

To everyone, it has been a privilege to be your National Honorary Chairman. It has been interesting, challenging, inspiring, maddening, and fascinating, and often all of these in the same week!

We look forward to seeing the IKA grow, flourish, and become evermore meaningful, as we fulfil our aim to serve, advocate for, and support all renal patients.

With every good wish for the future to you all.



Colin Mackenzie

Former **National Honorary Chairman**

COVID-19 UPDATE

By COLIN WHITE
National Advocacy
& Projects Manager

NORMAL

NEW NORMAL

I am sure that there are some of you thinking, 'enough already, we are tired of COVID-19!' However, it is important to take the opportunity to reflect on 'the new normal' and how we can best navigate it whilst considering the current summer surge in COVID-19 cases that is built on the newer BA4 and BA5 Omicron variants.

The discussion has moved on from mandated requirements to personal and social responsibility. The concept of 'risk assessment' is entering into common usage. When deciding whether to engage in an activity we are being encouraged to measure the COVID-19 related risks of doing it against the psycho-social risks of not doing it whilst also considering ways that we can mitigate risk.

The HSE's most recent media campaign focused on raising public awareness of the vulnerability of some people in the community to the virus (particularly the immunocompromised) and the need to acknowledge it in general behaviour. This came out of the on-going consultations between the HSE and relevant patient organisations, including the IKA.

It is important that we are aware of our options so that we can make

informed decisions. The HSE piece that follows gives a good overview of the vaccine and treatment options currently available and the importance of engaging with your health team early.

Have you had your first booster (fourth dose), are you due your second booster (fifth dose)? Remember, the current guidance is four months between your fourth and fifth dose and also between testing positive for COVID-19 and your next booster. Wherever you are in the vaccine cycle there is the opportunity to book the next dose you are due. If in doubt, speak with your medical team.

The article in the link at the bottom of the page offers some interesting advice for navigating our 'new normal'.

Immunologist Professor Paul Moynagh has said the public should carry out a personal risk assessment

before attending social gatherings, or visiting elderly or vulnerable relatives.

GP Yvonne Williams added that different measures would be necessary if young people were gathering, compared to an event at which people would be mixing with someone who was vulnerable.

Speaking to RTÉ Radio's *Today with Claire Byrne* show, Prof Moynagh suggested that if people were going to mix with elderly or vulnerable people, they should do an antigen test.

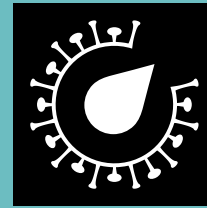
A personal risk assessment should also consider the ventilation of where they would be gathering, he added.

COVID-19 is not gone but we can live with it. Professor Moynagh's advice about personal risk assessments is important – do what you are comfortable doing but remember to look at the bigger picture beyond the COVID-19 risks.

It is worth noting that you can request free COVID-19 tests from the HSE:
www2.hse.ie/conditions/covid19/testing/get-tested/

www.breakingnews.ie/ireland/caution-urged-around-social-gatherings-as-covid-infections-rise-again-1322902.html

Living with COVID-19



**COVID-19
VACCINE**
Public Health
Advice

Advice for people at higher risk

People who have high-risk health conditions, or who have a weak immune system, are more at risk of serious illness if they get COVID-19. If this affects you, or someone close to you, you may feel concerned about COVID-19 as restrictions ease. Follow these steps to protect yourself and people around you.

- Stay up-to-date with all your COVID-19 vaccines.
- Take quick action if you have symptoms – stay at home and get a test.
- Know about COVID-19 treatments that could help you – visit www.hse.ie or ask a health professional for advice.
- Protect yourself day to day – wear a face mask, wash hands and let fresh air into your home.

What causes a weak immune system?

You may have a weak immune system because you have a health condition or you are getting treatment for a health condition.

Causes may include, but are not limited to:

- getting cancer treatment
- some treatments for autoimmune diseases, such as rheumatoid arthritis, lupus, multiple sclerosis (MS) and inflammatory bowel diseases
- living with HIV and not on effective treatment
- having an organ transplant or a bone-marrow transplant
- if you have a chronic kidney disease and are on dialysis or have an eGFR <30ml/min

If you are unsure if you have a weak immune system, you can speak to your GP or consultant.

You can find more information about having a weak immune system on www.hse.ie.

How many COVID-19 vaccine doses should I have received?

If you have a weak immune system, you should have received:

- your first round of COVID-19 vaccinations
- an additional dose of the vaccine
- a first and second booster dose

A second booster dose is now recommended for people with a weak immune system aged 12 and over, and all adults aged 65 and over. You can get your booster from participating GPs and pharmacies, or you can book a vaccination centre appointment on www.hse.ie.

Further information

You can read more about the vaccines or COVID-19 testing on www.hse.ie or call HSE Live on **1800 700 700**.

You can also talk to your GP, nurse, pharmacist or person who is vaccinating you.



Rialtas na hÉireann
Government of Ireland

If you are aged 12 and over and have a weak immune system you should have received the following COVID-19 vaccines:

First round of COVID-19 vaccination	This means dose 1 and dose 2 if you received the AstraZeneca, Moderna or Pfizer vaccine. This means a single dose if you received the Janssen vaccine.
Additional dose	If you had a weak immune system at the time of your first round of COVID-19 vaccinations, you should have been offered an additional dose to give you better protection. You would have received this additional dose 2 months after your last vaccine.
First booster dose	If you are aged 12 and over you should get a first booster dose at least 3 months after your additional dose.
Second booster dose	If you are aged 12 and over and have a weak immune system you should get a second booster at least 4 months after your first booster.
If you have had COVID-19 since your first booster, wait at least 4 months after you tested positive or from when your symptoms started before getting your second booster.	

Why do I need these additional doses and boosters?

Some people with a weak immune system may not respond to vaccines as well as others. Having a weak immune system puts you at higher risk of serious illness if you get COVID-19. Getting your second booster will give you more protection against this.

Act fast on symptoms of COVID-19

If you have a weak immune system and have symptoms of COVID-19, get a PCR test. Please don't delay when you notice any symptoms (cough, temperature, tiredness) – get a test straight away. As well as getting your test, make sure to stay at home, and self-isolate if you can.

This is important because new medicines are available to treat people with COVID-19 who are at the highest risk of becoming seriously ill. They work best when they are given in the early stage of the infection, usually in the first 5 days.

You will be advised by your GP or consultant if these medicines are for you. You can read more about COVID-19 treatments on www.hse.ie.

Keeping safer day to day

You may feel anxious about getting back to normal and wondering how to keep safe if you have a high-risk health condition. It may feel harder to take precautions and limit what you would like to do when other people are getting back to normal. However, the things you have been doing all along to protect your health still work to keep you safer.

- It is good to keep active and look after your general health. A healthy way of life improves your chance of recovery if you get COVID-19.
- Try to avoid crowded indoor spaces. If you have to be in a crowded space, wear a medical grade or respirator face mask. Respirator masks are often referred to as FFP2 masks.
- Always practice good hand hygiene.
- Continue to keep your distance where possible.
- If you see someone coughing or sneezing, move away if you can.

At home, make sure everyone you live with is vaccinated. Try to keep the number of people who come into your house to a small number of people you trust. People may need to visit you to see how you are, work in your home or provide healthcare.

Check that anyone who visits is well when they arrive. Ask them to clean their hands, to wear a medical grade or respirator mask and to keep some distance from you whenever possible.

It is important that you continue to use the healthcare services you need. It is OK to ask or remind healthcare workers about precautions. If you have an appointment with your GP or at a hospital or clinic, it is important to attend.

AGM and Board Elections



Eddie Flood, National Honorary Chairman



Marie Fowley, National Honorary Secretary



Joan Gavan, National Honorary Treasurer

On Saturday, 2nd July, the Annual General Meeting of the Irish Kidney Association was held via Zoom. 50 people logged in for the meeting and it was chaired by Colin Mackenzie, outgoing National Honorary Chairman of the Association. The outgoing National Honorary Secretary John

Whelan also attended.

An important feature of this year's meeting was the announcement of the new National Board, including the new National Honorary Chairman, National Honorary Secretary and National Honorary Treasurer. The new National officers of the Board are:

Hon. Chairman: Eddie Flood
Hon. Secretary: Marie Fowley
Hon. Treasurer: Joan Gavan

All three are long-time members of the Board. Eddie Flood is a kidney transplant recipient and is the Board member for Westmeath. He previously held the role of National Honorary Treasurer before being

IKA BRANCH OFFICIALS 2022

Branch	Chairperson	Secretary	Treasurer	Board Member
Carlow	Patricia May	Susan Tobin		Patricia May
Cavan/Monaghan		Karl Cronin		
Clare		Siobhan Mungovan	Gerard Moran	Sharon Fitzgerald
Cork	Denis Hyland	Sheena McDonagh	Bernard Cronin	Pat O'Sullivan
Donegal	Seamus McDermott			Jennifer McDermott
Dublin East/Wicklow	Bernie Dwyer	Rachel O'Hora	Catherine Foley	Jacqueline Burke
Dublin North	Colin Mackenzie	Colette Fox	Brian Carney	Chloe Kinahan
Dublin South	Gerry McKenna	Gerry McKenna	Paddy Sneyd	Liz O'Sullivan
Galway	Eoin Madden	Peadar Ó hIcí	Christine Curley	Eoin Madden
Kerry	Brendan Herbert	Theresa Looney	Elsie Moore	Elsie Moore
Kildare	Michelle Horan		Peter Kearney	Michelle Horan
Kilkenny	John Lacey	Anne O'Grady	Bridget Langton	Hugh Byrne
Laois	Dan Shiels	Sarine Browne	Hazel Case	Angela Kirwan
Leitrim	Annetha Kieran	Cathriona Charles	Frank Heslin	Cathriona Charles
Limerick	Sandra Earls	Shaun Faloon	Finola O'Brien	Pat O'Brien
Longford	John Opabola	Elaine Heslin	Carmel Donlon	Deirdre Heslin
Louth/Meath	Valerie Brady	Celine Tuite		Valerie Brady
Mayo	Maureen Bourke	Mairead Thomas	Catherine Gormally	
Offaly	Jerome Burke	Marjorie Stanley	Leona Mahon	Dermot Glynn
Roscommon	Vincent Finan	Maura Quigley	John Cormican	Maura Quigley
Sligo	Sean Fowley	Geraldine McHugh	Noreen Keane	Marie Fowley
Tipperary	Anne Hackett	Orla Hogan Ryan	Mary Adamson	Joan Gavan
Waterford	Raymond Halligan	Frances Moynihan	Vera Frisby	Frances Moynihan
Westmeath	Eddie Flood	Cathy Smyth	Valerie Galvin	Eddie Flood
Wexford	Pauline Atkinson	Walter Kent	Marie Kehoe	Liam Buttle

As you can see there are vacancies in branches which the new Board will be looking for solutions. The Association will be examining the process it uses to elect Directors to ensure our appointment processes comply with the Charities Governance Code. Minutes of the AGM will be available at a later date on the IKA website www.ika.ie

elected as National Honorary Chairman. Marie Fowley is a kidney and pancreas transplant recipient and is the Board member for Sligo. Joan Gavan is a living kidney donor and is the Board member for Tipperary.

To quote the Irish Kidney Association website: *"The Irish Kidney Association is an organisation of Kidney Patients and carers of Kidney Patients. It has 25 support Branches across the country."*

Each local Branch elects/selects three officers – Branch Chairman, Branch Secretary and Branch Treasurer – whose valued work is vital in ensuring a vibrant local grassroots support and representation.

Each local Branch also elects one of its members to the national Board of Directors for a 2-year term. The outgoing 25 Board members had held their office for 3 years because of the COVID-19 pandemic.

Much of the work of the Board of Directors goes unseen but is crucial to the successful delivery of services and supports.

We would like to welcome all our new officers and thank all Branch officers who have agreed to continue serving. Their contribution is very welcome and makes the IKA stronger and better. We would also like to thank all the volunteers who have retired from their roles, many after years of dedicated service. They will shortly receive an acknowledgement of their efforts in the post.



Physical Branch meetings

The Board has agreed that Branches who wish to hold physical meetings may do so. Each Branch should assess the risk of holding meetings and make their own decisions. Branch Officers should consider the following points:

- Hold meetings outdoors where possible. Many venues now have covered outdoor areas
- Review the local prevalence of COVID-19, as well as whether the number of cases is rising or falling, and inform Branch members about this information. This information can be found on the COVID-19 smartphone app or at <https://covid19ireland-geohive.hub.arcgis.com/>
- Ensure that everyone is vaccinated and boosted
- Ask people not to attend if they have any symptoms, even where they have a negative antigen test
- Ensuring proper building ventilation – for example keeping windows in meeting room open and using CO2 monitors. Some public buildings now have HEPA filters
- If meeting indoors, use N95 or FFP3 masks. Do not serve refreshments as this creates a higher risk
- Restrict the number of attendees at meeting and the duration of meeting
- Where possible, talk to local experts in infection control

Do you still need a printed copy of SUPPORT Magazine?

As print and postage costs increase we want to make sure we are not sending *SUPPORT* magazine to people who no longer wish or need to receive a printed copy. Or perhaps your family is receiving two copies of the magazine?

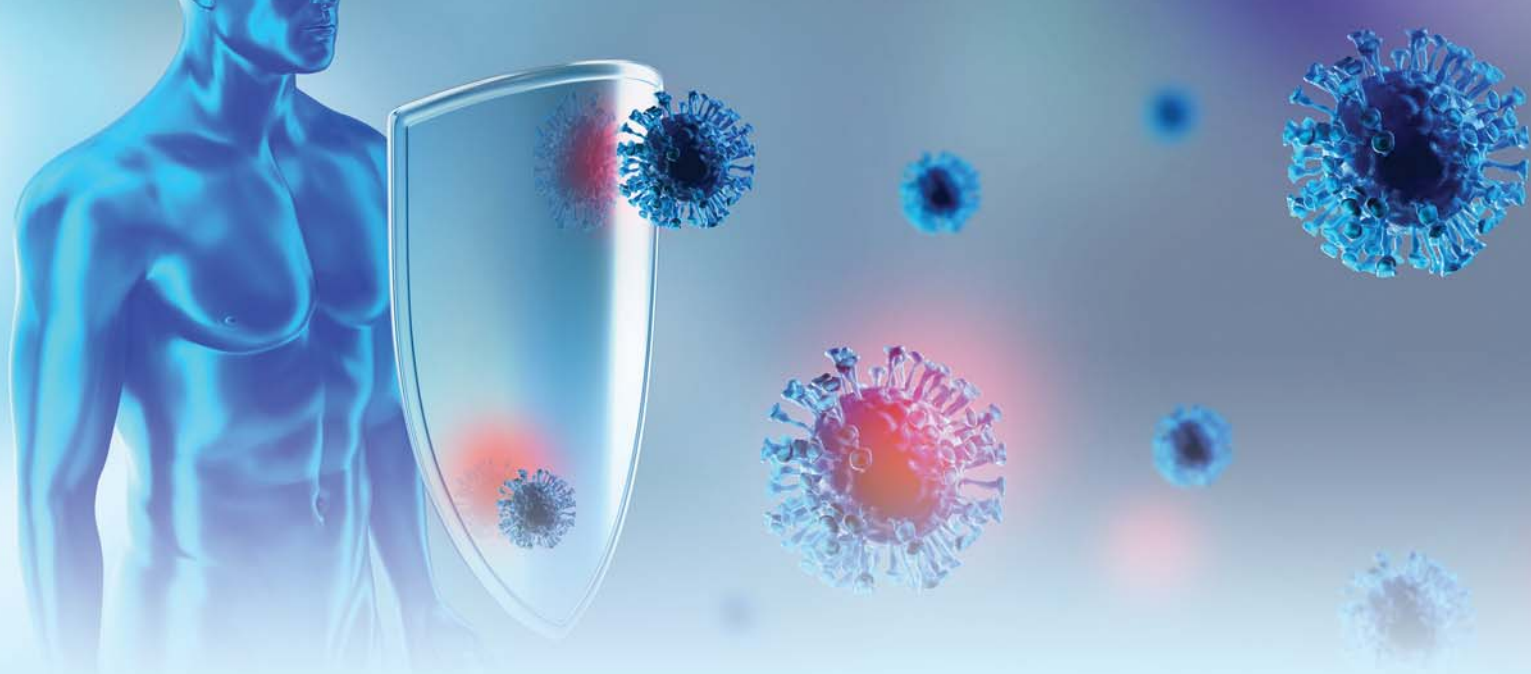
If this is you, please email info@ika.ie and let us know your contact details so we can stop sending you a printed copy. You can always download *SUPPORT* magazine at

www.ika.ie



Extra benefits for members

In line with the Charities Governance Code, the Board recently approved two new policies for our counselling and patient aid services. This means there is more transparency around the services we provide and what you can expect with a wider range of supports. We will also look for your regular feedback on our services so we can continue to improve them. Patients who are members will also receive extra benefits. So, if you are not a member why not join now. Membership form is on page 56.



Progress in Transplanting Highly Sensitised People



By **MARY KEOGAN**,
CONSULTANT IMMUNOLOGIST,
BEAUMONT HOSPITAL

Our immune system's main job is to protect us from infection. To do this, the immune system attacks any cells which do not look like our own cells. When the foreign cells are bacteria or viruses, this immune response helps us recover. Unfortunately, when we transplant a kidney from one person to another, the immune system of the person who receives the transplant recognises the kidney as foreign. The recipient's immune system can then attack the cells in the kidney, causing rejection. We can control certain types of rejection fairly well by using a combination of medicines which suppress the immune system.

All our cells have special proteins, called HLA (Human Leucocyte Antigens) molecules on their surface. Our immune systems use these HLA molecules like a barcode, to see if cells are self or foreign. There are thousands of different HLA molecules, and we inherit some from our mother, and some from our father.

When anyone is exposed to foreign HLA molecules very strong immune responses are made to foreign HLA molecules. Immune

reactions against foreign HLA molecules are the biggest immunological challenge in transplantation. There are other, non-HLA proteins which can also cause immune reactions and rejection.

When the immune system sees a foreign cell for the first time, it takes many days or weeks to make the cells and proteins to attack. The immune system makes memory cells, and remembers what it has seen before. So if you see the same foreign cells or bugs again, you make a

much stronger and faster immune response.

Immunosuppression medications are very good at preventing the initial immune response, but not so good at controlling the memory immune response.

The immune system attacks foreign cells using special proteins, called antibodies, and also special cells called T lymphocytes.

In the laboratory, we regularly measure antibodies to see what your immune system has reacted against. T cells are very hard to measure, and

are not measured routinely. We try to find a kidney for everyone to which their immune system has not made antibodies, to reduce the risk of rejection.

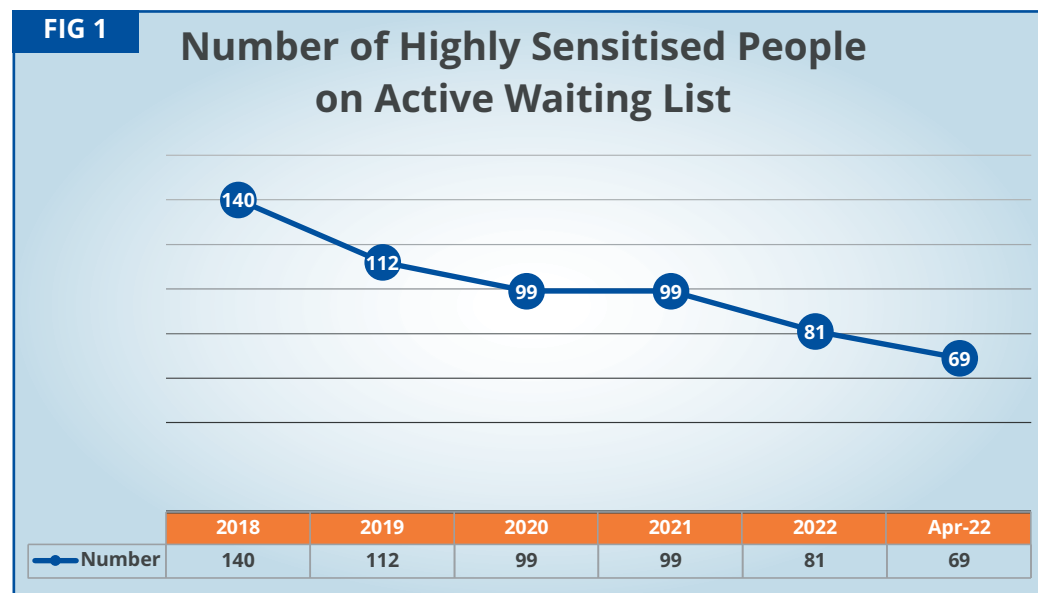
People who have been exposed to foreign HLA molecules usually make very strong immune reactions. This happens when another organ has previously been transplanted, following a transfusion, or during pregnancy. This is called "sensitisation".

As well as these classical sensitisation events, some people will make antibodies to HLA molecules following infection. The amount of antibodies following sensitisation can go up and down, however even when antibodies go down, the immune system still has memory cells, and can make a fast, strong reaction which will damage the kidney.

When people have made antibodies to more than 95% of the Irish population, we call them "highly-sensitised patients (HSPs)". It is much harder to find a suitable kidney for someone who is highly sensitised than for someone who has not made antibodies to many HLA molecules.

Usually highly-sensitised people wait much longer to be transplanted compared to others waiting for a transplant.

Over the last 20 years, several initiatives have been undertaken both in National Histocompatibility and Immunogenetics Service for Solid Organ Transplantation (NHISOT) at Beaumont Hospital and by the transplant team to try to increase the number of highly sensitised people who are safely transplanted.



The routes to transplantation which have been successful are living donor transplantation (either directly or through the kidney sharing scheme), and for deceased donor transplantation, the acceptable mismatch programme and the HLA incompatible programme.

Taken together, these measures are at last increasing the numbers of HSPs transplanted. The number of HSPs waiting has been halved (see Figure 1), and the average waiting time for transplantation has decreased by 8 months.

Living donor transplantation can be helpful to highly-sensitised people, as close relatives may share HLA molecules and therefore the kidney may look less foreign to the recipient's immune system. If the immunological risk is too high for direct living donation to proceed, another option is to enter the UK Kidney Sharing Scheme, which has led to successful transplantation for some highly-sensitised people.

For people who do not have a living donor, we have had an acceptable mismatch programme for almost a decade. This is a

system where with every donor, we search for any fully compatible highly-sensitised people.

However, most highly-sensitised people will never find a completely compatible kidney, against which they have never made any antibodies. We started a HLA-incompatible programme in late 2018 to improve transplant rates for highly-sensitised people.

This means that every time we have a suitable deceased donor, we run a programme to search for highly-sensitised people who have low levels of antibodies.

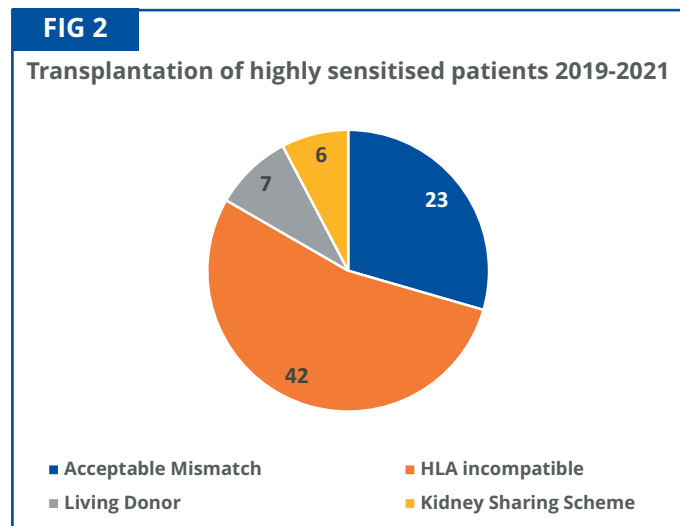
Senior scientists and consultants work on-call to review immunological risk to see if any highly-

sensitised people could be transplanted, often with extra immunosuppression. Only a small number of people can be reviewed, as it is very labour-intensive.

Almost 60 patients have been transplanted in this way to date.

Over half of all highly-sensitised people who have been transplanted, received a HLA incompatible transplant (Fig 2). As expected, because of immunological memory, there is a higher risk of rejection, with 10% of people having significant rejection to date.

All rejections were reversed however, and there have been no transplant failures, in this programme, due to rejection to date.



Continued next page...

All highly-sensitised people have additional testing performed on routine 3 monthly samples, to help us decide how likely each antibody is to cause severe rejection.

Highly-sensitised people are automatically enrolled. However, you can only be considered for a donor when your antibody testing has been performed within

REMEMBER

- To improve the chances of being transplanted, make sure that you send a blood sample to NHISSOT at Beaumont Hospital every 3 months
- If you have an infection, or another medical reason making you temporarily unfit for transplant, make sure you inform the transplant co-ordinators. This means that review will focus on people who are fit for transplant on a given day.

3 months.

We have noticed that some people, particularly when on peritoneal dialysis or home dialysis may not

always have antibody testing samples up to date. This means that opportunities may be lost, as you cannot be

considered for a HLA incompatible transplant if antibody results are not up to date.

CASTLEKNOCK COMMUNITY COLLEGE PROMOTES ORGAN DONATION

Fifth year students at Castleknock Community College, Dublin, supported Organ Donor Awareness Week with promotional activity in their school.

The LCVP students were facilitated by the school and their teacher Pamela Dunne, whose husband Ken Mulkerrins, from Lucan, underwent a lifesaving heart transplant in 2016. Ken's photo features on the top right hand side on the Organ Donor Awareness Week campaign poster, along with 31 other grateful transplant recipients.

The busy students set-up an information stand in the school and they also circulated around the school building distributing organ



donor cards, engaging in conversation about the importance of family conversation around organ donation and letting people know your wishes **#ShareYourWishes**

Speaking about the student's initiative, LCVP, Business and Maths teacher Pamela Dunne explained, "We

had watched the Orla Tinsley's *Warrior* documentary during Life Skills and the students took a great interest and had lots of questions.

"I shared my husband's Ken's heart transplant story with them and told them about my brother Joseph, who underwent a successful kidney transplant 21 years ago.

"I explained how well they both were doing and how transformative organ transplantation really is and how it is made possible by organ donation. The students really engaged with the topic and were highly motivated to play their part in increasing organ donor awareness."



The cost of MEDICATION

Whether you are on dialysis or are a transplant recipient, prescription and 'over the counter' medications play an important role in your daily life and recent studies have shown that there can be significant variation in costs for both.

Looking at prescription medication, new drugs are normally patent protected for a particular period of time to recognise the investment from the pharmaceutical company that developed them. This means that no other company can produce the same product for an agreed period.

When these drugs 'come off patent' the market then opens to other producers to copy the drugs and because they did not have to invest in their development they can afford to sell their products at significantly lower prices. These are known as 'generic' medicines.

In an article in *The Irish Times* on June 21st the author, (Dominic Coyle), referenced a report commissioned by Medicines for Ireland, the industry body for the generics sector. The article goes on to highlight the fact that when compared with the European average for generic usage which

stands at 70 per cent, Ireland is currently at 57 per cent (up from 33 per cent ten years ago).

Given the cheaper price of generics the argument is that if the government increased their usage there would be a saving to the State which can then be re-invested in other areas of healthcare.

Looking at the prices of medications charged by pharmacies, a recent study conducted by the Royal College of Surgeons and Trinity College Dublin has shown there is large variation in the price of prescription drugs in community pharmacies in Ireland. "This study's finding that chains are more expensive than independent pharmacies is in contrast to several studies in other contexts." *

Taking both these reports into account it is important to educate yourself about your options in relation to medications. Whether it is shopping around for the best price for products or discussing the appropriateness of using generic medication with your treating physician, we each have the potential to make a difference to the amount spent on medications annually.

Things to consider when it comes to the cost of medication:

Discretionary Medical Card

You may not qualify for a medical card based on the means test. But if you have medical expenses, you may qualify for a discretionary medical card. You can find out more here: www2.hse.ie/services/medical-cards/discretionary-medical-cards.html.

A discretionary medical card gives you the same services as a means-tested medical card.

Drug Payment Scheme

Under the Drugs Payment Scheme (DPS) an individual or family will pay no more than €80 each calendar month for

- approved prescribed drugs and medicines
- rental costs for a continuous positive airway pressure (CPAP) machine
- rental costs for oxygen

If you don't have a medical card and you pay more than €80 a month for any of these, you should apply.

You can find out more here: www2.hse.ie/services/drugs-payment-scheme/drugs-payment-scheme-card.html

* Source: www.sciencedirect.com/science/article/pii/S1551741122001577

By GWEN O'DONOGHUE

Mike Sheehy, a father of three, from Listowel, Co Kerry, donated one of his kidneys to his nephew Brian Sheehy (33) from Athea, Co Limerick, in August 2014. This was Brian's second transplant following almost three years of dialysis.

In August 2005, Brian's late brother Patrick was just 18-years-old when he became an organ donor, saving six lives, following a tragic road traffic collision. Brian was just sixteen and had been receiving dialysis treatment at the time of his brother's death.

It was bittersweet for Brian and his parents, Margaret and Richard, when a month later, in September 2005, Brian was called to Beaumont Hospital for his first kidney transplant, which was made possible by the decision of another grieving family of a deceased organ donor.

Fast forward to the 4th June this year, Brian and Sarah Reidy exchanged marriage vows in Sarah's parish church in Ardagh, Co Limerick. The couple were watched on by their parents, their extended family and friends including their daughter Kayla (age 11), Brian's kidney donor uncle Mike and his wife Rose and their three children, Laura (22) Mairead (18) and Rosie (16), and Brian's proud parents Margaret and Richard. A couple days later the happy couple flew out to Portugal on their honeymoon.

Brian explained, "I'm feeling on top of the world now and I have Mike to thank for it. The transplant has given me my life back. It allowed me to go back to work, save for a house with Sarah, plan ahead and play an active role in my daughter's life.

"The whole extended family attended our wedding celebration over the June bank holiday weekend and while we exchanged vows we had three candles lit, one each for Sarah and myself and one more candle to honour the deceased donor who gave me my life back as a teenager.

"A photo of my brother Patrick, who gave life to others in his death, was also on display at our wedding reception. And when the time came for after dinner speeches we raised



Wedding Gift of Life

A Limerick man, whose family made the decision to donate his brother's organs, celebrated his wedding nuptials over the June bank holiday weekend, watched on by his uncle who donated a kidney to him.

a glass for Mike for giving me a new lease of life making it possible for me to proceed with my wedding and planning for the future".

Mike explained, "Although I didn't see Brian frequently when he was a child, as I was busy raising my family in another county, I knew about his plight and I was happy to put myself forward to be screened to be a living donor along with some other members of the family. It was an honour to be able to donate a kidney to him and I want to thank my wife Rose for fully supporting me with this".

Brian was born in Melbourne and was diagnosed soon after his birth with Posterior Urethral Valve Syndrome which blocks the flow of urine and damages the kidneys. His family returned to Ireland when he was three and he spent much of his childhood and early teens in Crumlin Children's Hospital due to complications around his condition and the necessity to have one of his kidneys removed.

Brian met Sarah while studying for a Bachelor's Degree in Information Technology at Tralee Institute of Technology. The couple welcomed baby Kayla a few years later and following the kidney donation by his uncle Brian the couple went on to buy their own home together. Brian recently started a new job in Information Systems at Limerick City Council.

The IKA wishes the newlyweds continued good health and a lifetime of happiness together.



Brian with Sarah and a photo of his late brother Patrick



Brian and his uncle Mike in Beaumont Hospital when transplant surgeon David Hickey and Joe Brolly came to visit.



IKA planning formal Peer Support Service

In October 2022, the Irish Kidney Association will be launching its very first Peer Support programme. This will be building on the grassroots support that has been provided at a personal level by our Branch network for over 40 years.

Peer Support has been identified as one of the most valuable ways of meeting the psychosocial and practical needs of patients at all stages of their journey. The Irish Kidney Association is excited to pilot this programme amongst our members. It is an intervention that is very close to our hearts and it is fantastic to have witnessed such a considerable level of interest so far.

WHAT IS PEER SUPPORT?

Peer Support is based

By **JESSICA BRIEN, FIONA AHERNE & AOIFE SMITH**

on the belief that people can use their lived experience to encourage hope and provide support to those facing similar situations. Many of our members have an overwhelming amount of knowledge and insight from their own journeys through diagnosis and treatment for chronic kidney disease.

Peer Support helps those feeling lost and lonely, those who feel socially excluded or discriminated against, and individuals with low motivation. Self-care is of vital importance for kidney patients. The goal of Peer Support is to improve the experience of kidney patients and to enhance and build upon supports already in place.

The Irish Kidney Association aims to achieve this by using a local and national peer support network, both online and face-to-face.

The pilot will take place online (phone/Zoom). During the initial contact, the patient and/or their family will give us some details about themselves and where they are in their journey. This will enable us to better understand their needs and ultimately identify the correct support service for them. Some will benefit from counselling rather than peer support. On completion of this pilot, it is our expectation that the Peer Support programme will be identified as a key part of the IKA service provision. At that stage, we

intend to train more people and make the service more widely available.

Peer Support volunteers will have the opportunity to broaden their skill set and further refine their existing skills with the support and guidance of our highly experienced support team. Volunteers will engage in peer support training and will have the opportunity to work as part of a dynamic and passionate team. Volunteers will be trained in trauma-informed practice: understanding the symptoms and side effects is crucial, as well as managing how not to re-traumatise someone, to build a trusting partnership, and to help people to support, enhance and control their lives and mental health.

THE SELECTION PROCESS AND TRAINING

WHAT WE EXPECT FROM A PEER SUPPORT VOLUNTEER

- 10-15 individuals to take part in the pilot phase
- Safeguarding and Garda vetting
- A commitment to volunteer during the pilot for 4 hours per week. Provision for holidays will be made
- The induction training will take 6.5 days in total
- We want to encourage more volunteering and be a force for real change in the healthcare services
- Discretion and confidentiality

WHAT YOU CAN EXPECT FROM THE IKA

- Ongoing training on topics such as safeguarding and suicide prevention
- Professional supervision and team engagement
- Flexibility
- IKA certification on successful completion

QUALITIES NEEDED TO BE A PEER SUPPORT VOLUNTEER

- 1. Lived Experience:** We are looking for people who are living with end stage kidney disease (ESKD) or those who are a family member or carer of someone living with ESKD. Peer Support workers will build upon their own experience to enable them to further develop their ability to give support. Knowledge across different stages, treatment types and strategies that might prove helpful are considered valuable.
- 2. Personal Traits:** The ideal peer support worker will be non-judgemental, empathetic, patient, optimistic, and will commit with a level of flexibility that is very important when working with people engaging in peer support. Other admirable traits useful include integrity and the ability to observe discretion and confidentiality. There should be an openness to learning opportunities and a passion to deliver, whilst also understanding the importance of self-care and the balance between both.
- 3. Role Skills:** The role will require basic administration skills and the ability to understand the importance of policy.
- 4. Knowledge of the IKA and the role:** A full introduction to the policies and procedures will be provided.
- 5. Safeguarding:** Newly diagnosed people can be particularly vulnerable, and so being mindful of this and other sensitive issues is very important. Suicide prevention is also vital, and a HSE module will be made available.

SUMMARY

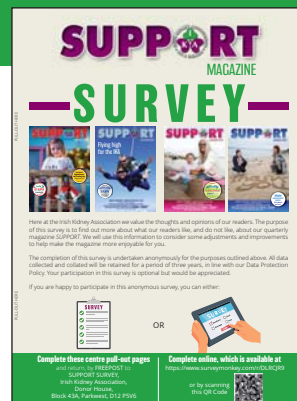
Those who are interested should complete an application form with some basic background information including hobbies, interests and motivations and any previous volunteering undertaken.

These details will enable us to match volunteers with those who share similar interests. The closing date for all applicants will be **Monday 25th July**. Selection will take place on **Friday, August 19th** with induction taking place in September and the formal service commencing in October.

Further information can be found on our website at www.ika.ie/peersupport/

SUPPORT SURVEY

An opportunity to reflect...



By COLIN WHITE & JESSICA BRIEN

We would like to thank everyone who took the time to respond to our readers' survey in the last edition of the magazine. It was very useful to get insights into the value of each of the topics covered and to understand what is relevant to a cross section of readers. The feedback will help inform future content decisions for the magazine and help ensure that it remains relevant to our membership.

Over half of the respondents were transplant recipients (54.55%), with 30% being people on dialysis and the remainder were family members or friends of renal patients.

A clear message was that people enjoy reading about the lived experience of others who are perhaps further down the treatment road than themselves. As one respondent put it; *"Your features on people's journeys through dialysis and transplant give hope to those on the transplant list."*

There is a clear interest in more practical information related to the lived experience of renal disease. For example, the renal diet and renal recipes featured prominently in responses with a desire for more recipes for day-to-day living.

You may have noticed in recent editions of the magazine that there has been more content provided by members. Whether it was short stories, sharing the lived experience of kidney disease or giving an account of a fundraising event, there is definitely an interest in seeing more such content, coming from members, in the magazine.

Some other interesting observations are;

- The most commonly used words to describe our magazine included 'reliable', 'useful' and 'informative'
- 45% of survey respondents rated our magazine as being of high quality, with a further 24.4% rating it of very high quality.
- The majority of respondents felt that they were less likely to read *SUPPORT* magazine if they received it by email rather than a physical hard copy.
- The majority of respondents were likely or very likely to recommend the magazine to a friend.

We look forward to working more closely with our membership and the wider renal community to ensure that the magazine remains relevant, interesting and useful to as wide an audience as possible.

For the love of Goss!



Catherine and Augustine

“Where there is love there is life’ - Mahatma Gandhi’s philosophical words resonate loudly for Dundalk man Augustine Goss and his wife of 37 years, Catherine, who donated a kidney to him on 26th April 2021.

Anyone who has had the fortune to meet with the affable couple will have found their obvious enduring love for each other and shared zest for life alluring. A year to the day of their transplant operations they shared their exuberance and joy for living with presenters Tommy Bowe and Muireann O’Connell on Virgin Media’s Ireland AM to highlight Organ Donor Awareness Week. Two days later they held a golf fundraiser which generated huge support which was, no doubt, influenced by the couple’s inspirational story and infectious positivity.



By GWEN O’DONOGHUE



Stella Hoey, Stephen Staunton, Augustine and Catherine Goss

Grateful that they can continue their journey in life together with renewed health, Augustine channelled his other love, golf, towards organising a hugely successful golf fundraiser in aid of the Irish Kidney Association (IKA). He organised it along with another transplant recipient, Stella Hoey, to mark the first anniversary of both their kidney transplants which they received a few days apart at Beaumont Hospital.

The sun came out for the hundreds of people, including eight transplant recipients, who turned up for the Golf event, held at Greenore Golf Club on the beautiful Cooley Peninsula in Co Louth on 29th April 2022. Not only did the event create organ donor awareness and included support from some internationally renowned sporting personalities, but it also raised in excess of €16,500 for the IKA.

The 4-ball scramble event attracted huge support with 45 teams taking part and more than 100 sponsors. Former Irish professional golfer Des Smyth showed up on the day. Pdraig Harrington donated a signed t-shirt which Augustine had framed and raffled a couple of weeks later.

The local Dundalk Football Club donated a jersey signed by all the team which was also raffled. Former soccer international player and Ireland manager Stephen Staunton, a Dundalk native, showed up to play with his brother David

and two others, and agreed to numerous requests for photos with other participants.

The cream of past and present ladies golfing talent also took part including Noeleen Quirke, Carol Wickham, Jackie Quinn and Phil O'Gorman.

Representing the IKA at the event was Gary Davitt who also enjoyed a round of golf.

Augustine and Catherine said that they are extremely grateful for the support from kidney transplant recipient Stella Hoey, a past secretary at Laytown & Bettystown Links Golf Club and her husband Stephen, the Club's greenkeeper, who worked tirelessly with them in organising the event.

The first time Augustine and Stella met was while in hospital a few days after Stella underwent a kidney transplant from a deceased donor and Augustine and Catherine were about to undergo a living donor kidney transplant. Augustine was anxious about his and Catherine's operations, and Stella, who was recovering well post-transplant helped put his mind at rest. Stella and Augustine forged a friendship following their kidney transplant experiences and they discovered they also shared a passion for golf.

Delighted with the successful outcomes of their operations, both couples wanted to shine a light on the importance of organ donation for transplantation, acknowledge the important and life-saving work done by the transplant and dialysis teams in Beaumont hospital and raise the profile of the services offered by the IKA whilst also raising funds to support their continued delivery.



Carol Wickham, Jackie Quinn, Augustine Goss, Catherine Goss, Des Smyth, Stella Hoey, Phil O'Gorman, Noeleen Quirke.



Augustine Goss, Stella Hoey, Bronagh Daly, Catherine Goss.

Augustine (age 65) had become very unwell in 2019 as he was heading towards kidney failure but under the care of Prof. Peter Conlon and staff at Beaumont Hospital, including dietitians, for whom he has great praise, he managed to stave off dialysis for some time meaning that he had to undergo dialysis at home (7 nights a week) for just 7 months.

Speaking after the golf event, Augustine said, "We are blown away by the level of goodwill and support we have received from so many, participants and sponsors, individuals and companies and also for the huge, combined efforts between Greenore and Laytown & Bettystown golf clubs.

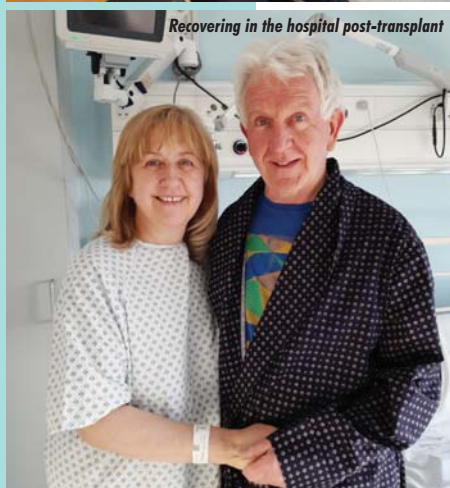
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Catherine & Augustine Goss, Stella & Stephen Hoey



Augustine and Catherine at the sponsorships' sign



Catherine and Augustine with their sons Liam (left), Pierce (right).

Thanks to all our friends who helped with the event on the day ensuring it ran smoothly.

When we hatched the event plan with Stella a year ago we could never have imagined just how generous and kind people could be. If it weren't for my hero Catherine, my kidney donor, and Stella's deceased donor, and the wonderful doctors, nurses and transplant surgeons for their exceptional care, we would not be enjoying our renewed health today".

"When I was diagnosed with kidney failure, it was a huge blow for me and I found it difficult on my mental health. The counselling service that the IKA provided played a big part in me accepting my condition and the challenges that it brought with it.

"I found it difficult to even accept the offer of a kidney from Catherine, who I first met 44 years ago and who became the mother to our two children, Liam and Pierce. I didn't

want to put her health at risk but counselling helped me accept my kidney failure and to accept Catherine's unconditional offer of support."

Colin White, National Advocacy and Projects Manager, IKA, who first met Gus and Catherine at a Beaumont nurse education day where they shared their story, said, "The IKA is delighted that the kidney donation and transplantation between Catherine and Augustine has been such a great success.

"Augustine and Catherine speak very positively about organ donation and transplantation and are great advocates for it. Their willingness to share their story to encourage the public to talk about organ donation and their wish to raise funds for the Irish Kidney Association to continue its promotion of organ donation and the provision of services and support to people living with, and affected by, end stage kidney disease is inspirational".



Augustine and Catherine with their sons Pierce and his girlfriend Aimee Hanlon and Liam and his girlfriend Denise Buckley.

A tribute to the late writer and pioneering feisty renal warrior

Liz McCue

For almost 20 years, Liz McCue was a patient on renal dialysis at University Hospital Waterford (UHW). It was here that she connected with Waterford Healing Arts Trust (WHAT), which supports patients through long hours on dialysis by providing opportunities to be creative: visual art, creative writing, music and photography.

Through the Arts Programme, Liz found her creative voice, and drew great sustenance from being involved in much of the work WHAT produced with patients and staff of the dialysis unit over the years.

This began in 2012 with the publication *All About Us*, featuring patients' stories and poems about their lives.

In 2013, Liz was one of three patients who collaborated with artist Philip Cullen on *Unfolding Time*, a collection of poems, short stories and photos.

In 2015 came *Tea Room Tales*, a beautiful leather-bound book into which patients and staff, led by Liz, could write their news, thoughts and reflections from the cosy tea room in the dialysis unit.

But it was in 2017 that Liz's dream came true, with the publication of *Thursday's Child*, her autobiography.

At the launch, Liz said "I aspired to be a writer of sorts from a young age. It was tough, but I kept going. Through the process, I have come to love and respect the feisty, confident, determined renal warrior that is now the new *Lizzybits*. I'm very grateful to everyone who helped me to make this happen".

Guest speaker Consultant Nephrologist at UHW, Dr Sean

The WHAT Arts Programme in Renal Dialysis is funded by the PuncHESTOWN Kidney Research Fund.

Copies of *Thursday's Child* are available from Waterford Healing Arts Trust, with proceeds going to the IKA and to WHAT. Please contact WHAT on 051-842664 / what@hse.ie



Leavey, described Liz as "a pioneer in the work she has done", adding "*Thursday's Child* is a memorable, courageous book which provides us with a chance to wonder in awe at the person who is Liz McCue...She displays an amazing kindness and generosity to others, and tells wonderful tales with wit and humour; with great honesty and understanding. A magnificent

achievement."

At the time of her passing, Liz was working on her next book, which she had begun during the pandemic.

With the consent of Liz's family, WHAT will publish this later in 2022. Liz was the beating heart of the WHAT Arts Programme in Renal Dialysis at UHW. Through her writing, her spirit will live on.

- MAEVE BUTLER (WHAT)



'Mission is Possible'
'The action starts with YOU'



By AOIFE SMITH

Men's Mental Health in Kidney Disease

Men's Health Awareness Week was held in June. Each year there is a theme, and this year was *'Mission is Possible'* and the call to men (and those who support the health of men) was *'The Actions starts with YOU'*.

The overall aims of the campaign were to heighten awareness of preventable health problems for males of all ages, support men and boys to engage in healthier lifestyle choices and to encourage early detection and treatment of health difficulties.

This campaign gave everyone from health professionals, sporting bodies, employers, community groups, the media to individuals, an opportunity to encourage men and boys to take better care of their health and to seek help or treatment at an early stage.

Research has widely shown that loss of health is a major contributing factor in

developing mental health problems such as anxiety and depression.

Our mental health plays a central role in how we experience and how we cope with a chronic illness. Women with a chronic illness are more likely to ask for help than men with the same illness and are also more likely to ask for that help sooner.

When it comes to kidney disease specifically some more recent studies show that while both males and females can suffer from either depression or anxiety, women with CKD are more likely to suffer from anxiety while men with CKD are more likely to suffer from depression.

So, I decided to take this opportunity and use this edition's article to talk about depression in males. I hope that this will encourage any of our male patients or male family members that may be suffering with their mental health to

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

reach out, if they can, for support.

Depression impacts millions of men of all ages and backgrounds, as well as those who care about them – spouses, partners, friends and family. Of course, it's normal for anyone to feel down, low or fed up from time to time. Dips in mood are an ordinary reaction to losses, setbacks, and disappointments in life and with a chronic illness this can be all too often.

Depression changes how we think, feel, and function. It can interfere with how we care for ourselves, and impact relationships, sleep, diet and overall enjoyment of life.

There are various types of depression, with respect to symptoms, but there are some typical signs of depression:

1. Feelings of hopelessness and helplessness.
2. Low energy.
3. Loss of interest in friends, activities, and things you used to enjoy.
4. Feeling more irritable, short-tempered, or aggressive than usual.
5. Consuming more alcohol, engaging in reckless behaviour, or self-medicating.
6. Feeling of restlessness and/or agitation.
7. Sleep patterns, weight or appetite changes.
8. Difficulty concentrating or find it hard to make decisions.
9. Difficulty controlling negative thoughts.

Unfortunately, depression in men often gets overlooked, as it can be masked by increased anger or alcohol/substance use.

Many men find it difficult to talk about their feelings. Men tend to focus more on the physical symptoms that often accompany male depression, such as back pain, headaches, difficulty sleeping, or sexual problems. These can all result in the underlying depression going untreated.

In kidney patients depression can be even more difficult to identify because key symptoms of depression like low energy, loss of weight or appetite and insomnia can be attributed to kidney disease itself.

Depression in kidney patients can be a serious health risk as it can lead to poorer health outcomes, increased hospitalisations, decreased quality of life and more.

Some typical feelings and experiences of depression in people with kidney disease include:

- Regular pain and difficulty sleeping
- Feeling that their life is in the hands of those who care for them and their disease
- Unwanted feelings of dependence on health care providers and the dialysis machine
- Feelings of powerlessness over the disease
- Feelings of lack of control over their schedule and lives
- Inability to stand up to social pressures at the expense of their own healthcare needs, such as not following a renal food and fluid plan when out with friends
- Feelings of hopelessness that there are only treatment options rather than a cure for kidney disease

Depression can be intense and unrelenting. For men living with

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

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

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

chronic kidney disease the risk of depression significantly increases.

If you feel you connect with several of the symptoms of depression or with several of the common experiences for kidney patients, it may be time to reach out for support.

And as I write that, I am very aware of how difficult and overwhelming reaching out might feel. I understand it can take courage to ask for help from a family member, friend or a professional and I know it takes time for any support plan that is put in place to have a positive effect. However, such plans can have a powerful effect on how we think and feel, supporting the process to overcome the symptoms of depression and regaining enjoyment in life.

So please don't try to 'tough it out' or 'man up', please open up and allow yourself to get the support that may be needed. Remember that the mission is possible, but the action starts with you.

Save THE Date

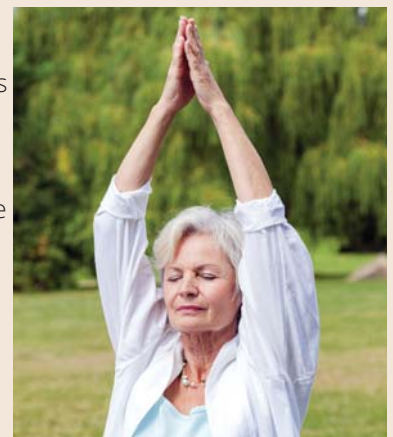
**Sunday, September 18th
from 8am to 7pm.**

"How to be our best self day"

Stuart Breen is a qualified fitness instructor, personal trainer and author as well as chief Tai Chi instructor with **Tai Chi Your Way**. He and his colleagues will run a series of free workshops on a range of complementary therapies from Tai Chi, meditation to reiki and yoga.

Workshops can be attended in person (Pearse Street, Dublin) or online. Workshops are free with a suggested donation of €10 per workshop. All donations from the workshop, which will take place on Sunday, September 18th, will go to the Irish Kidney Association.

For more details, please see www.ika.ie/bestselfday



S U M M E R G I V E A W A Y

WIN!

A **FAMILY* MINI BREAK** at the **4-STAR**



CLAYTON HOTEL
DUBLIN AIRPORT

WITH BREAKFAST AND DINNER



A **DAY PASS TO**

D U B L I N



FOR A FAMILY* OF FOUR

In this issue of *SUPPORT* we are offering one lucky reader the opportunity to win a fantastic one-night staycation for a family of four* including breakfast and dinner at the **CLAYTON HOTEL DUBLIN AIRPORT** and a **FAMILY DAY PASS** to **DUBLIN ZOO**. Thanks to our friends at **DUBLIN ZOO** for sponsoring the free **FAMILY DAY PASS**.

The hotel prize, kindly sponsored by the **CLAYTON HOTEL DUBLIN AIRPORT**, allows the winner to share their good fortune with three others (including one more adult and 2 children – under 12 years). The group can enjoy the luxurious 4-star hotel as their base for exploring the capital and a **FREE FAMILY DAY PASS** to **DUBLIN ZOO**. With over 1 million visitors a year, **DUBLIN ZOO** is officially Ireland's biggest family attraction located at the Phoenix Park, and not only does it offer a great day out for all, but also a journey of learning and discovery about the world's precious wildlife.

The **CLAYTON HOTEL DUBLIN AIRPORT** is located just a 15 minutes' drive away from Dublin city centre attractions and is the perfect base to explore nearby scenic seaside villages of Malahide and Howth.

Enjoy the comfort of unwinding in one of the **CLAYTON HOTEL DUBLIN AIRPORT'S** refurbished large bedrooms, its friendly customer service, and its multiple cuisine options from the hotel's award-winning Italian Restaurant or it's stunning bar, with free breakfast and dinner, and for the adults a complimentary bottle of wine. If the adults have any energy left after a busy day at **DUBLIN ZOO**, sightseeing or shopping, they can take turns enjoying free access to the hotel's fitness centre which is open 24/7.

To enter, simply email robyn@ika.ie with the subject line **Clayton Zoo Giveaway**, include your name, address and contact telephone number, and tell us who you would like to bring with you if you win. The winner will be picked on 31/07/2022 using a random number generator, numbers will be assigned chronologically to entries. By entering this competition, you agree to your name being published in the Autumn edition of *SUPPORT* magazine.

*Family of four is 2 adults and 2 children (under 12 years).

Hotel voucher is valid until July 2023 and booking is subject to availability.

Dublin Zoo voucher is valid for 5 years. The winner will receive a voucher code to pre-book their visit to Dublin Zoo online at www.dublinzoo.ie

Visit must be pre-booked at least one day before their chosen date.



SPRING PRIZE GIVEAWAY WINNERS

Thank you to **HOMESTORE + MORE** for generously sponsoring **10 x €50 gift cards** as a prize giveaway in the Spring issue of *SUPPORT*. Congratulations to the winners:

Tommy Byrne, Waterford; Carmel Casey, Cork; Shaun Faloon, Clare;
Collette Fox, Dublin; Caroline Greaney, Galway; Kieran Kenneally, Waterford;
Robert McCullagh, Dublin; Trudi Mulreany, Dublin; Rachel O'Hara, Dublin and
Chikoyo White, Dublin

HOLIDAYS

Tramore, Co. Waterford
Aerial view of the Metal
Man – a 3-metre tall
cast-metal figure of a
sailor pointing seawards.
According to local lore,
he is said to warn
seafarers away from
dangerous shallow waters.

By **DEBORAH CERVI**
Holiday Co-ordinator

Thinking of travelling abroad while on dialysis

Holidays in the IKA holiday homes are now in full swing with Tramore having re-opened in May and staying open until October this year while Killarney and Tralee are operating all year round.

Donor House has received hundreds of requests from patients who wish to avail of a holiday this year. The holiday homes are let free of charge on a 5 night basis (Saturday-Thursday). While we try to fulfil as many requests as possible, demand continues to exceed availability.

All three locations are now fully booked for the season. However, we have a waiting list in place for those families that could not be accommodated for the dates they have requested. If a cancellation occurs, we will steadily draw from our waiting list as we strive to accommodate as many requests as is possible this year.

I wish everyone an enjoyable summer and I hope that wherever you may travel, the summer brings lots of happiness and good memories to your life.

Deborah

If you are receiving haemodialysis and considering a holiday in foreign parts, you must make arrangements for your dialysis treatment well in advance as at least 8 weeks' notice is required.

First, speak to your dialysis nurse in your dialysis unit about your holiday plans, or you can contact me directly at Donor House, on **01-6205306**. Please **DO NOT** book your holiday until it is confirmed that we can access haemodialysis at your chosen location.

Patients should be up to date with their COVID-19 vaccines before travelling. Patients must be fully vaccinated against COVID-19 to receive dialysis whilst on holiday in another country. A copy of your vaccine certificate is required at the time of booking your dialysis treatment.

Dialysis units abroad require patients to have a PCR Test 48/72 hours prior to your flight departure.

You must have a valid European Health Insurance Card known as the EHIC. This card entitles you to free dialysis/health care in a public hospital in another EU or European Economic Area (EEA) state.

If you are an Irish citizen, Irish pensioner or an EU citizen living in Ireland, you can apply for an EHIC:

- in person at your local health office
- by post
- online – www.ehic.ie

There's no charge to apply for the free EHIC card and it will be posted to you in about 10 working days.

If you would like any advice on destinations or have any questions regarding holiday dialysis, or our holiday homes please get in touch with me or go to <https://ika.ie/patient-holidays/>



SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK

‘Influencers’



If you have any social media presence, you will probably be aware of so-called “influencers”. There are thousands of lifestyle, food, fitness, fashion and any other kind of influencer accounts covering a wide range of topics.

For some people, being an influencer is their entire job; they get paid by brands to promote products, or they get a percentage of the sale price when people buy a product using their ‘promo code’ which usually gets the customer a nice little discount too – a win-win for all involved! These types of accounts have their uses, but if you look hard enough there are also niche pockets of people online that can provide more than just product recommendations.

When you are living with a chronic illness, finding others who are experiencing the same things or who are on the same journey as you can help immensely. Curating your online community with people who support and inspire you is a great way to start making your own health journey

more positive. There are lots of them out there, and indeed some members of the IKA are very active and sharing interesting content on social media, but we’ve selected just a few ‘influencers’ to get you started:

JARLATH REGAN

Jarlath is a UK-based Irish comedian and blogger who donated a kidney to his brother in the USA in 2017. His hugely popular podcast ‘*Irishman Abroad*’ has covered the topic of organ donation several times, with guests including Health Minister (at the time) Simon Harris; fellow kidney donor and RTÉ reporter Vivienne Traynor; actress and kidney transplant recipient Lucy Davis best known from the BCC series *The Office*; and James Nolan, who received a

kidney from his sister in 1987 and has gone on to fundraise to support a broad range of projects through his Punchestown Kidney Research Fund (www.pkrf.ie).

[@Jarlath](#)
[@jarlathregan_irishmanabroad](#)
[@JarlathReganComedian](#)

DARREN CAWLEY

Darren is a kidney transplant patient who has used his kidney disease experience to become one of Ireland’s leading motivational speakers, using his knowledge and inspirational outlook to help others through their journeys to health.

[@darren_cawley](#)
[@darrencawleyspeaker](#)

ORLA TINSLEY

You may be aware of Orla from her ongoing advocacy work for Cystic Fibrosis patients, or her incredible 2018 documentary *Warrior* which documented her journey to double lung transplant.

[@IrishKidneyAssociation](#) [@IrishKidneyAs](#) [@IrishKidneyA](#)

Today, Orla uses her online presence to document her health journey and campaign for high-risk patients, as well as sharing her passion for writing.

[@orlatinsley](#)
[@orla_tinsley](#)

WORLD TRANSPLANT GAMES

The World Transplant Games Federation often share information about free fitness and wellness activities you can take part in through their Refit For Life programme. For example, they recently celebrated World Meditation Day with a free online 8-week mindfulness course.

[@WTGF1](#)
[@worldtransplantgames](#)
[@WorldTransplantGamesFederation](#)

KIDNEY CARE UK

Although a UK account, Kidney Care UK often shares inspirational patient stories and helpful information, such as tips for monitoring your fluid intake if you are on dialysis or renal diet friendly recipes.

[@kidneycareuk](#)
[@kidneycareuk](#)
[@kidneycareuk](#)

NATIONAL KIDNEY FOUNDATION

Another international account, this time American, the NKF is always sharing patient stories. The good part about these is that they will often tag the person featured in the story – if you are particularly inspired by someone, you can follow them directly!

[@nkf](#)
[@nationalkidneyfoundation](#)
[@nationalkidneyfoundation](#)

Note: As always with social media, don't take medical advice from anyone but your doctors, and be aware that accounts in different countries may post advice and information that isn't considered appropriate, best practice or accurate in Ireland.

Social media is great for connecting with a wider community such as people living with or affected by end stage kidney disease. However, when it comes to medical advice, your medical team are the ones who know you and your complete medical history. Make sure that you discuss any questions, ideas or advice received with them before considering any new course of action.

The internet has given us all unprecedented access to information and social media, in particular, has allowed us to connect with role models and others with similar interests.

In relation to living with a chronic illness this offers great potential for support and ideas and it is all about how we manage the resource – an 'expert patient' is one who works with their medical team.



How can I protect my privacy and security online?

- Putting a password or pin code on your electronic device is helpful.
- Use strong passwords (at least 15 characters, uppercase letters, lowercase letters, numbers) and change them regularly.
- Remember the personal information you put in your social networking profile may be used by scammers to guess your passwords so choose passwords not linked to public information.
- Do not share your email address or log on with any one else.
- If you are using a shared device at home we suggest you create a separate account and password for you only. Google "create a user account for (insert name of your device)" to find out how to do this.
- Log-off using the programme rather than closing the browser page.
- Avoid using public computers to access your personal information. If you do use a public computer, check to see if the service provider has any secure settings. Always remember to clear the history, close the web browser and log-out before you leave the terminal.
- Avoid using Wi-Fi hotspots for sensitive internet use. These are often open and unencrypted. A hacker may be able to break into your computer through a hotspot and potentially access your personal information.
- Use anti-virus protection, basic free versions are available.
- If you wish to take extra steps and can pay fees to protect your privacy, using paid secure emails such as *hushmail* and web browsers like *Tor*, provide extra security.

Are you worried about



A brief overview of how to qualify for debt relief and what the process involves.

The Insolvency Service of Ireland (ISI) has recently updated their guide on Debt Relief Notices.

The ISI is an independent statutory body whose objective is to restore bankrupt persons to financial stability.

A Debt Relief Notice (DRN) is a debt resolution for people who cannot afford to pay their personal debts. It allows for the write-off (cancellation) of qualifying debt up to €35,000 under a 3-year supervision period.

ARE YOU ELIGIBLE?

Qualifying Debts

You must have qualifying debts of up to €35,000 with a low disposable income or assets (an asset is anything you own) with no prospect of being able to pay off these debts in the next three years. You can qualify for a DRN if your debts are unsecured.

By FIONA AHERNE
Patient Support Manager

Example of unsecured debts include:

- Utility bill arrears (gas, electricity, phonenumber, etc.)
- Rent arrears
- Credit card debt
- Store card debt
- Bank overdrafts
- Unsecured loans

A mortgage is considered a secure loan and therefore **DOES NOT** qualify for a DRN.

Some other debts cannot be included in a DRN, these are considered excludable debts. Most types of excludable debts are those owed to the state. Some examples include:

- Taxes or levies such as Local property tax or VAT
- Money owed for a nursing home loan under the Fair Deal Scheme
- Money owed to the Department of Social Protection

Income

All income and assets will be taken into account, with the exception of

Child Benefit, to determine eligibility. You will only qualify for a DRN if, after deducting certain outgoings, you would be left with a total not exceeding €60 per month.

Two types of outgoing expenses are:

1. Payment to excludable debts.
2. Reasonable living expenses.

A detailed guide of what is considered reasonable is available on the ISI website www.isi.gov.ie

Assets

An Asset is something that is owned by you, including property, savings, equipment, etc.

The total value of your assets must be €1,500 or less. Here is an example of assets that are **not** taken into account.

- Essential household or employment equipment up to the value of €6,000
- Primary and secondary school items
- An adapted vehicle
- A motor vehicle up to value of €5,000

How does a Debt Relief Notice Work?

If you qualify for a DRN it will allow

for the write-off, of your qualifying debt up to €35,000.

Your financial situation will be supervised for 3 years. During this time if your financial situation changes you will be obliged to inform the agency.

During the supervision period your creditors (people you owe money to) will not be allowed to take any action against you for the recovery of debts covered in the DRN.

Debt Relief Certificate

At the end of the supervision period the DRN will cease. You will be discharged from the debts it covered. Your DRN will be removed from the register and you will receive a Debt Relief Certificate. The ISI will inform your creditors.

How to apply for a DRN?

You must apply through an Approved Intermediary (AI) such as MABS (Money Advice & Budgeting Service).

You must disclose details of your



financial affairs to the AI who will then advise you whether you meet the conditions for a DRN, the consequences, and any alternative options.

The AI will assist you to complete a Prescribed Financial Statement (PFS) and will process your application if:

1. You meet the eligibility conditions
2. The information in your PFS is complete and accurate.

How much does a DRN cost?

The ISI has waived its fees for DRN's until 31st December 2023.

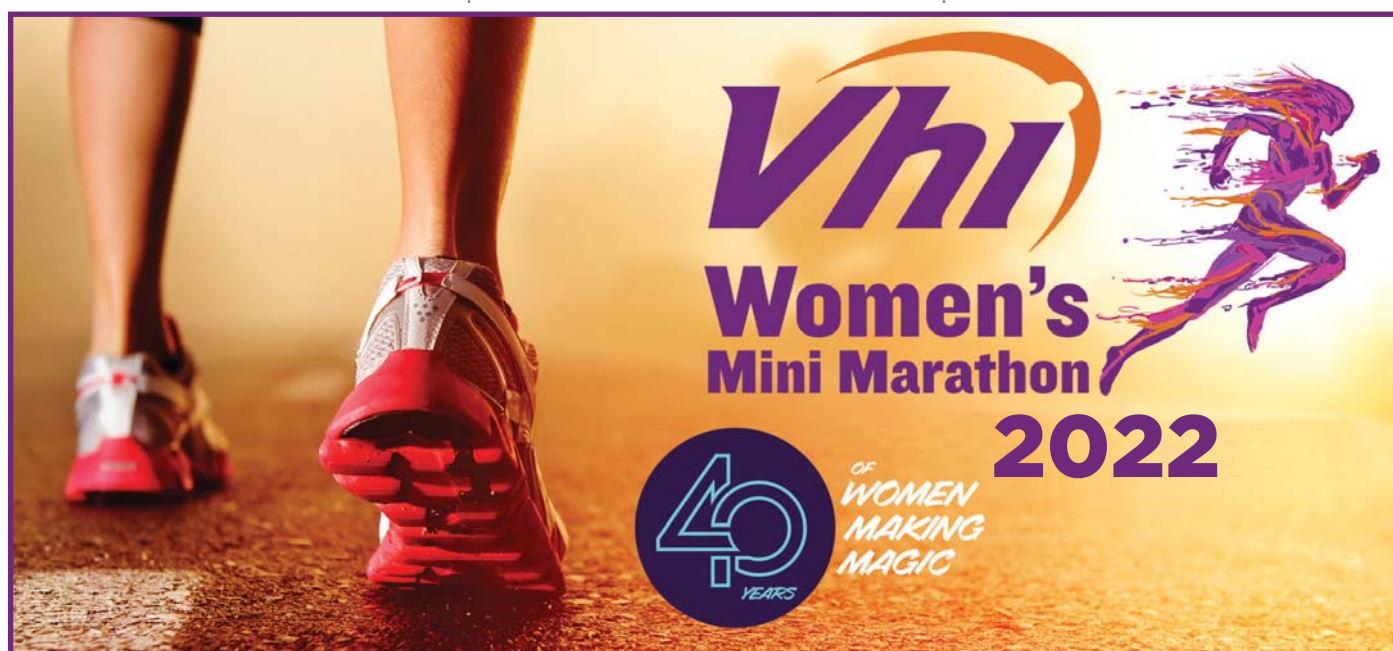
A Debt Resolution Notice can be given only once to an individual.

For more information, and to see alternative options to managing debt, please visit:

www.isi.gov.ie

www.mabs.ie

www.backontrack.ie



Celebrating 40 years, this year saw the VHI Women's Mini Marathon come back as an in-person event after a two-year COVID-19 enforced break. Given the popularity of the virtual version that was organised during the pandemic, the organisers also offered it as an option this year.

The Irish Kidney Association has a long history of supporters taking part in the event and their reasons are many and personal. This year

was no different.

We had Emma Noble and her friends taking part and raising funds for the Association. Dialysis nurse, Christine Murphy, also took part as she knows how people on dialysis really value the services of the Association. Niamh Walsh took part because her Dad is on dialysis and is awaiting a transplant.

Siobhán McNamara and her friends, Keara, Sarah and Ana took part in memory of their friend

Maureen Finn.

These are just a few representative examples of people who have taken part in the annual event and take the opportunity to raise funds for the IKA.

To all those who have taken part in the Women's Mini Marathon over the years, those who take part in other organised events and all those who set up their own challenges to raise funds for the IKA, we say **THANK YOU!**



Robert McCutcheon, Chairman, Irish Heart and Lung Transplant Association; Anne Marie O'Dowd, Chair of Research Committee, Cystinosis Ireland; Philip Watt, CEO, CF Ireland; Dr. Stephen Quinn, Administrative Officer, Blood & Organ Transplant Policy and Divisional Planning Unit, Department of Health; Prof Jim Egan, Director, ODTI; Carol Moore, CEO, Irish Kidney Association (IKA); Dr. Catherine Motherway, Clinical Lead, ODTI; Colin Mackenzie, Honorary National Chairman, IKA; Senator Mark Daly, Cathaoirleach, Seanad Éireann.

Organ Donor Awareness Week

APRIL 23rd – APRIL 30th 2022

After a two-year hiatus, there was an almost palpable sense of relief and optimism for its organisers, when a physical national launch of **Organ Donor Awareness Week 2022** returned to the prestigious Mansion House in Dublin 2, on Tuesday, 19th April.

This year's launch event, hosted by the Irish Kidney Association (IKA) was scaled down, with considerably fewer attendees invited than would have been the case in pre-pandemic days, and stringent safety measures were also put in place.

Carefully organised by the IKA in association with Organ Donation and Transplant Ireland (ODTI), the campaign was held a month later than usual and the launch got the go-ahead in the knowledge that the prevalence of COVID-19 cases in the general community had reduced greatly.

Key to the success of the

By GWEN O'DONOGHUE

campaign was the valued cooperation of people willing to publicly share their stories about the impact of organ failure, transplantation, and organ donation on their lives. It is these 'human interest' stories that resonate with the public so much more than just statistics.

These wonderful people had inspiring stories to tell so it was crucial that we had the support of national and local media, made use of online and social media, and engaged our wider membership, in highlighting them thus ensuring that the importance of organ donation was communicated far and wide.

The live-streamed launch event was hugely successful and achieved what it was intended to do, it gave the facts and told the stories and thus raised informed awareness for

organ donation and transplantation.

We use the services of Rue Point Media to monitor print and online media for published stories relevant to the work of the IKA. Doing a specific search on print and online media content generated directly related to Organ Donor Awareness Week 2022, according to Rue Point Media, the total value of the coverage comes in at approximately €825,000 with a reach of close to 16 million readers.

Every commercial local radio station highlighted the campaign with most covering interviews on their current affairs programmes while at least one local paper in every one of the 26 counties covered one article or more.

In the period between the launch date April 19th and May 1st a total of 1590 organ donor cards were requested via our Freetext service and the IKA's website.

There were an additional 838 downloads of our Digital Donor Card during this period. 228 boxes of 70 organ donor cards (almost 16,000 donor cards) were sent to pharmacy chains nationwide including Lloyds, CarePlus, StayWell, Uniphar, Hickeys, Life, Allcare, Total Health and Haven.

Social media hashtags for Organ Donor Awareness Week were:
#ShareYourWishes,
#DonorWeek22.

People could also tag the IKA when doing their own posts on various platforms: Twitter @IrishKidneyAs, Instagram @IrishKidneyA and Facebook @IrishKidneyAssociation.

Looking at the 10 days around Organ Donor Awareness Week we saw significant increases in the reach of our social media platforms when compared to the previous 10-day period.

- **Facebook** Reach: 85,598 (+305% increase on previous 10 days)
- **Twitter** Reach: 30,800 (+431% increase on previous 10 days)
- **Instagram** Reach: 4626 (+279% increase on previous 10 days)

Aided by the large media turnout, the beautiful Spring sunshine on the launch day facilitated outdoor interviews and photos in the Lord Mayor's beautiful front garden where flowers, including forget-me-nots, were in full bloom.

Attendees at the launch included



Sofia Corey, kidney transplant recipient in the Mansion House garden.

an organ donor family, six recipients of organ transplants including heart, lung, kidney, and liver, and also a person on dialysis, who all cooperated with media interviews with some giving presentations to the small gathering inside about their health experiences.

You can read more about these on pages 38-41.

Representatives of patient advocacy groups at the launch included Robert McCutcheon, Chairman, Irish Heart and Lung Transplant Association; Philip Watt, Chief Executive, Cystic Fibrosis Ireland; and Anne Marie O'Dowd,

Cystinosis Ireland; and the Irish Kidney Association's Honorary National Chairman Colin Mackenzie and Carol Moore, Chief Executive. Also attending were representatives from transplanting hospitals and Senator Mark Daly, Cathaoirleach of the Seanad, Dr. Stephen Quinn representing the Department of Health, and both Dr. Catherine Motherway and Prof. Jim Egan representing Organ Donation and Transplant Ireland (ODTI).

Representatives of two universities who were sharing the campaign on their respective campuses also attended.

continued next page



Saoirse Perry, Teaching Librarian Maynooth University and Mark Vesey, third year medical student at UCC and Education Officer, UCC Translational Medicine Society attending the national launch of Organ Donor Awareness Week at the Mansion House.



Attendees watch the Minister for Health Stephen Donnelly.

This year's campaign was held as the war in Ukraine raged on. The launch event attracted national media including news crews from Ireland's two national TV stations and this was the springboard for lots of further media coverage highlighting the lifesaving week-long awareness campaign which took place from 23-30 April.

As well as featuring on the evening news on RTÉ and Virgin Media on launch day, other traditional print and broadcast media highlights for the campaign included it being announced on the first day of the week, 23rd April, on Newstalk News and on numerous news stations around the country.

Print coverage included, front page in Ireland's largest national daily paper, several newspapers' health and lifestyle supplements including the cover story on some of these as well as the *Irish Independent's* *Seachtain* (Irish).

There were interviews on national and local radio stations' current affairs programmes. *The Irish Times* and *Irish Independent* gave



advertising space 'free gratis' on several occasions during the campaign. Every one of the national newspapers gave considerable coverage to the campaign.

The IKA was delighted to secure coverage on the RTÉ *Late Late Show* on the eve of the Week which proved pivotal in ensuring the awareness campaign reached a large national audience.



It covered an interview by host Ryan Tubridy with two inspirational women, one coming to the rescue of her lifelong friend who had been receiving dialysis for 19 years. They entered the paired exchange programme in the UK, and although it took several years to finally get a kidney match, they were eventually successful. The takeaway message for patients awaiting transplant was 'to never lose hope'. You can read about this cover story on page 4-5. Virgin Media's *Ireland AM* also covered an interview with husband and wife Augustine and Catherine Goss. See pages 20-22.

Another defining media event was when on Monday, 25th April, towards the beginning of the campaign, more than 220,000 people tuned in to watch RTÉ *Nationwide* which devoted a complete programme to organ donor awareness and the work of the IKA. See page 42-43 for story.

In a speech delivered via video to officially launch the 2022 campaign, the Minister for Health, Stephen Donnelly TD, announced that additional funding of over €1 million has been allocated to transplant services this year which he said would further develop the infrastructure and equipment needed to meet demands following the introduction of the 'opt-out' system for organ donation as part of the Human Tissue Bill.



Some national newspaper coverage on the launch.



One of the national health supplements cover stories.



One of the free adverts which were covered in the Irish Independent and Irish Times.

Chloe and Nicole Grier with a photo of their deceased mother Martina, an organ donor.



Dr. Catherine Motherway



He advised that the enactment of the Bill has been a priority for him and the government. Minister Donnelly, who was wearing a forget-me-not flower, also said, "I am grateful to the donors, their families, and all the staff who help make this life-saving gift to others possible. I am committed to further developing our organ donation and transplantation system and building on the progress we have achieved so far.

"It is important that we take this opportunity, during Organ Donor Awareness Week, to raise awareness of the life-saving role of organ donation, and the improvements in the quality of life it brings to recipients and their families."

Minister Donnelly gave a special mention to Chloe and Nicole Grier from Claremorris, Co Mayo who attended the launch and shared their poignant story about the sudden loss of their late mother who became an organ donor.

In explaining the theme for the annual campaign this year, IKA Chief

Executive Carol Moore, said, "The key message of the campaign is to *Share Your Wishes*. The traditional Organ Donor Card and the digital organ donor card app are there as an 'icebreaker' to get the organ donation conversation started. The card, or app, is a symbol of your wish to donate but is not a legal document nor are personal details recorded.

"Downloading the digital donor card App or requesting a donor card through the IKA website or having Code 115 on your driver's licence, is a prompt to assist the approach to family members to discuss organ donation wishes."

At the launch Carol Moore described how, "The ripple effect of active citizenship in your decision to say 'YES' to organ donation is an amazing legacy to gift to the recipients, their families, your own family, and society at large."

Speaking on behalf of Organ Donation and Transplant Ireland (ODTI) was its Clinical Lead, Dr. Catherine Motherway, who is a

Consultant in Intensive Care & Anaesthesia at Limerick University Hospital. Dr. Motherway began her speech with a summary of the history of organ transplantation in Ireland and she spoke about the profound act of generosity by organ donors and referred to her late colleague Siobhan Brosnan, an organ donor nurse manager whose organs were donated when she tragically died a year before.

Dr. Motherway said, "Organ Donor Awareness Week is a time when we honour and thank all donors both, living and deceased, who, by their actions, have given the 'gift of life' to others.

"Every year those of us who work in intensive care and transplantation are humbled by the generosity of our donors and their families. To our deceased donors and their families, in the midst of great sorrow, you find it in yourselves to think of others. Thank you!

"The generosity of organ donors is the bedrock of our transplant programmes. Organ donation saves and transforms the lives of our transplant recipients. This week, in particular, we encourage our community to speak to each other about their wishes around organ donation."

In her slide presentation, Carol Moore outlined the key factors that influence improvements in organ donation and transplantation levels.

She said "The success of organ donation relies on many factors. A culture of organ donation within the health service that is underpinned by suitably trained and resourced healthcare professionals is needed.

continued next page

Carol Moore, Chief Executive, IKA



Colin Mackenzie, National Chairman, IKA.



"Specialist organ retrieval and transplant professionals are also required as well as access to theatre space, recovery facilities and all the necessary infrastructure to carry out the lifesaving and life-transforming procedures.

"Promotion of organ donation for transplantation is obviously important but all these other elements need to be in place to ensure a successful service. The effective deployment of existing resources and planning for future developments of the organ donation and transplantation service needs to be underpinned by data. For example, there needs to be an understanding of the number of potential organ donors every year and what barriers, if any, are impacting on the conversion to successful transplantation. In that way, resources can be targeted to have the greatest impact.

"As the recent NOCA (National Office of Clinical Audit) Feasibility Study Report announced on 1st March 2022, *'If you cannot measure it,*

you cannot improve it.'"

In describing the impact of COVID-19 Carol Moore said, "Despite the unprecedented challenges which the pandemic has presented, organ transplants continued which is thanks to organ donors and their families and to the dedicated teams who facilitated transplant operations at Beaumont, Temple Street, St. Vincent's and the Mater Hospitals.

"There are just under six hundred people active on waiting lists for organ transplants including heart, lung, liver, kidney, and pancreas. There was a decline in the number of transplants over the past two years during COVID-19 across all the national transplant programmes.

"A total of 206 transplant operations were carried out in Ireland in 2021 which was 16 more than in 2020. This activity in challenging times could not have taken place but for the generosity of the families of 65 deceased donors and 35 living kidney donors."

In her presentation Carol Moore showed a slide with a table of figures

APPENDIX ONE: DONATIONS AND TRANSPLANT OPERATIONS

	2020	2021	5 year Average 2015-2019
Deceased Donors	63	65	85
Kidney	95	104	128
Liver	37	35	61
Lungs	16	20	33
Heart	9	10	16
Pancreas	5	2	2
Total Deceased Donor Transplants	162	171	240
Living Donors	28	35	43
TOTAL TRANSPLANTS	190	206	283

for donation and transplantation (as can be seen below left).

In his opening address Colin Mackenzie, National Honorary Chairman of the Irish Kidney Association paid tribute to organ donor families and asked attendees to observe a few moments of silence in memory of those people who passed on. He also saluted the medical profession for saving and keeping safe dialysis and transplant patients, and his sentiments were echoed by Carol Moore in her presentation also.

Green is the internationally recognised colour associated with organ donation for transplantation. Many city and county councils supported the campaign with over 50 public sites lit-up in green from dusk to dawn during Organ Donor Awareness Week. Sites are listed on the IKA website

www.ika.ie/donorweek2022



Clare County Council building lit in green for the campaign.

The Organ Donor Awareness Week poster was produced in English, Irish, and Polish. A digital copy is available to download from the IKA website. Featuring on the poster are photos of 32 people from all walks of life and all ages, who between them are enjoying over 400 years of extra life because families of deceased organ donors gifted their loved ones' organs including heart, lung, liver, kidney, and pancreas. Another poster is available with ten additional transplant recipients'



Polish and Irish versions of the poster at the Mansion House.

photos featured and can be downloaded (also with three language options) from the IKA website for display all year round.

The campaign poster was displayed on outdoor advertising sites in 30 shopping centres around the country for two weeks and this activity was sponsored by Clear Channel.



Poster in the background (right) of Faircity set

The poster made a cameo appearance on every episode of RTÉ *Faircity* that was broadcast during Awareness Week.

Many independent pharmacies and pharmacy chains supported the campaign by displaying the poster in-store and on their window digital screens. They also had countertop boxes of organ donor cards and they leveraged their social media presence to get the message across about having the family conversation about organ donation **#ShareYourWishes**.

Once again, this year, members of the IKA branch network came behind the campaign with many checking in with pharmacies to ensure they had adequate stocks of organ donor cards and displaying posters in some other public locations.

While restrained by safety concerns around the continued prevalence of COVID-19, many branches organised outdoor photos at local public buildings when they lit-up in green and shared in posts on social media.

Also invested in the lifesaving annual campaign being a success are the hundreds of people currently on waiting lists and their families hoping to be called for a transplant, as well as more than 5,000 people in Ireland who are enjoying extended life thanks to successful organ transplants.

As the biggest Organ Donor Awareness campaign of the year, Organ Donor Awareness Week takes a lot of planning, collaboration, and negotiation. It is a team effort which is underpinned by the selfless generosity of all organ donors (living and deceased) and their families who have gone before. They are a true example of active citizenship which we highlight through the campaign.

Allied activities that coincided with Organ Donor Awareness Week



Martin Malinowski from Co Monaghan is the first person in Ireland to receive a combined heart and liver transplant, thanks to organ donation. The 30-year-old underwent the highly complex dual organ transplant surgery before Christmas 2021 at the Mater Hospital and is now making great strides with his recovery. He is pictured here with his Consultants Dr Emer Joyce, Transplant Cardiologist at the Mater Hospital and Dr Zita Galvin, Transplant Hepatologist at St. Vincent's University Hospital (SVUH).

Photo: Julien Behal.

A joint announcement was fortuitously made during Awareness Week by the Mater Hospital and St. Vincent's University Hospital about the ground-breaking first combined liver and heart transplant to take place in Ireland, received by Co. Monaghan resident, and Polish native, Martin Malinowski. It generated further media coverage which further boosted the Organ Donor Awareness Week campaign.

Another timely awareness activity during the Week was when Cork University Hospital launched a pilot campaign. It included large posters of local transplant recipients, who were familiar faces in the hospital, dotted around the building and on elevator doors and carrying an important message with the hashtag **#7LivesSaved** to let the public know that anyone had the potential to donate up to seven organs on their death. It is hoped that this initiative will be rolled out to other hospitals around the country (following the personalised approach by including local transplant recipients).

In early 2020, pre COVID-19, Cavan General Hospital, piloted an organ donor awareness project, with organ donor awareness messages featured on elevator doors and inside.

The Knock Shrine hosted their annual organ donor awareness Mass to coincide with Organ Donor Awareness Week 2022, on Sunday 24th April. The Mass has become a special annual gathering for all organ recipients and their families, those waiting for transplants, their medical teams and carers, as well as for bereaved families who generously donated the organs of their deceased loved ones.

The lived experience of the 'Gift of Life'

A common thread to all the transplant recipients in their presentations at the launch was their profound gratitude for organ donors. Their presentations were recorded and are available to watch on YouTube which can be accessed on the IKA's website www.ika.ie/donorweek2022

The following is a summary of their inspiring stories.



Matthew McNeive

First up to the podium to share his health story at the launch of Organ Donor Awareness Week 2022 was 23-year-old **Matthew McNeive**, from Knock, Co Mayo. He explained that his journey with kidney disease began from infancy as he was born with Triad Syndrome. Numerous long journeys from Mayo to Dublin for hospital visits and stays ensued in his childhood. The kidney transplant that he received when he was 11-years-old from a deceased donor in 2010, which followed 9 months of nightly peritoneal dialysis treatment, gave him his childhood and teen years

back and he and his family are very grateful to the family of the organ donor that made this possible.

However, the transplant failed just before he began his third level studies. He returned to dialysis, this time haemodialysis treatment, over 4 years ago, which he now undergoes three to four times a week at Beaumont Hospital, the same hospital where he is gaining work experience for his course of study, Clinical Measurement Science.

Also attending the launch with Matthew was his mother, Bernadette McNeive.

Bernadette is a willing kidney donor but unsuitable match for Matthew (like his twin brother and other siblings who were tested), as he has a high level of antibodies following his transplant. He and Bernadette have entered the UK paired exchange programme, hoping to find a suitable cross way match with strangers.

The day after speaking at the national launch, Matthew was interviewed by Sean Moncrieff on Newstalk highlighting the campaign.

The second patient presentation was given by 42-year-old **Gillian Curtis**, a native of Athy and now living in Portlaoise, who underwent a heart transplant at the Mater



Gillian Curtis

Hospital in the summer of 2019 following two false calls.

At the launch she said that her brother Martin was just 18 years old when he passed away unexpectedly, from Sudden Adult Death Syndrome. Gillian received the devastating news while she was in hospital undergoing tests, following the discovery she had an enlarged heart.

She was allowed to leave the hospital for the funeral but on her return, she was fitted with an ICD (implanted cardiac defibrillator) for her heart condition Hypertrophic Cardiomyopathy.

Several years passed and she tried to lead as normal a life as possible and travelled extensively with her husband Nigel, but all the while her



James Dreeling, Matthew & Bernadette McNeive



Gillian Curtis (3rd from right) with her family, nephew Finn, mother Mary, husband Nigel, father John and sister Fiona.

health was failing. With the intention of just attending a check-up appointment at the Mater Hospital, at the beginning of the New Year in 2019, it was determined she would have to remain there on a machine, in the hope a transplant would come along. She was connected to a Ventricular Assist Device (VAD) machine with four tubes and during that time she was called for a heart transplant twice, but the operations didn't proceed. However, it was a case of third time lucky on that fateful day in the Summer of 2019 when her life was saved and transformed by a heart donor, to whom she expressed she will be forever grateful.

She said, "I owe it to my donor family, to live the best life I can, and to my brother who didn't get the chance I did. Life is so precious. Until my experience with my organ donor I never fully understood the importance. It is a 'gift of life'. I hope that my story can start the discussion with you and your family." Gillian said she now feels great and enjoys playing tennis, walking, and spending time with her family.

Attending the launch with Gillian was her husband Nigel, her parents John and Mary Behan, and her sister Fiona Redmond, and one of Fiona's two sons, Finn (11).

Gillian participated in several media interviews and a month later, to mark World Surgery Day, she did an interview with Pat Kenny on Newstalk, along with Mater Hospital Transplant Surgeon Aisling Kinsella.

Following a slide presentation by Carol Moore, the IKA's CEO, she invited **Dr. Christopher Neilson**, to share his personal health story about receiving a liver transplant. Christopher, a South African native, has been living in Punchestown, Co Kildare for two decades. In his earlier life in his native South Africa he worked as a trauma surgeon whilst being embroiled in political upheaval. He gave a very thought-provoking presentation at the launch having seen lives being saved and lost in his profession and its impact on patients and their families. No stranger to being a guest at the Mansion House, Christopher attended this venue in 2003 when the (then) Lord Mayor, Dermot Lacey, honoured him with an



Dr. Christopher Neilson, Amanda Doyle

award for the foundation he established in 1999 for tortured survivors.

Christopher underwent a liver transplant at St Vincent's University Hospital in April 2020, when the country was shaken with the arrival of COVID-19. He described how three to four years previously he was in 'a very dark place and slowly dying from my liver which failed desperately'. His quality of life was extremely poor, and he needed frequent hospital admissions. He couldn't eat or drink, due to constant nausea, and despite his extreme fatigue he lay awake at night in a confused state and suffered severe cramps. "I struggled to try to have hope, but I finally got the call one day". But as he waited for the transplant to proceed he described how in his mind as a Christian, "I thought about the person who had to lose their life for me. It was hard. I hoped they weren't in pain."

Describing how he responded to people who ask what it felt like after the transplant, he said, "My honest words were that I felt better than the day I was born. I pray for my donor and his family every day. I have been through many things in my life but this is the greatest thing that I have been a part of. I hope that the people of Ireland will open their hearts because that is what we need to save peoples lives. If we can do that the world will be a much better place."

Accompanying Christopher to the launch was his friend Amanda Doyle.

Grandmother **Mary McGarry**, who is living in Palmerstown, Dublin and a native of Co. Westmeath, underwent a single lung transplant in the Spring of 2018, on the seventh occasion she was called to the Mater Hospital for a transplant.

Mary's declining health story began in 2002 when she was diagnosed with Pulmonary Fibrosis, a condition involving the irreversible scarring of the lung, which, in her case, affected both lungs. Her diagnosis initially didn't impact hugely on her quality of life, and she was able to continue to work and go to the gym. However, by 2017 her health had deteriorated considerably following a bout of pneumonia and left her 24-hour oxygen dependent.

Mary described one of her biggest fears was that the oxygen tank would run out. She needed help to dress and get up the stairs. She also explained that when she was accepted onto the transplant waiting list, it was a bittersweet moment for her.

continued next page



Mary McGarry, Cara Nig Fhearraigh and baby Iarlaith

The lived experience of the 'Gift of Life' continued...

As she had been called on six occasions and the transplants didn't proceed, on the seventh occasion when she was about to have her dinner, and she received the call, she told her family to keep her dinner for her as she believed she'd soon be home again. But this time she woke up after the transplant in disbelief that she had survived the operation.

She described how the recovery was slow, but she gradually got back to living her life and was delighted to attend her daughter's small wedding and managed to get away for a few nights' pre-pandemic. She has a fear of COVID-19, she has been very cautious since its arrival. She is grateful to her donor for saving her and being able to enjoy the arrival of three grandchildren whom she cherishes.

Mary said she thanks God every day for her health, being there for her family and grandchildren, and enjoys simple things like just feeling her feet touch the floor when she wakes up every day. She has great praise for the staff at the Mater Hospital describing their care as 'outstanding'. I am forever grateful to my donor and have written to them through the transplant unit twice. It's a wonderful thing to give someone else a second chance. I think this is a wonderful week for awareness."

Attending the launch with Mary were her daughter Cara Nig Fhearraigh and one of her three grandchildren Iarlaith (6 months).

Representing the kidney pancreas transplant programme at St. Vincent's Hospital at the launch via a



video was **Siobhan Brady** from Ballinagh, Cavan. Siobhan was returning later on the day of the launch to Ireland from Dubrovnik where she spent her first holiday abroad since receiving her simultaneous pancreas and kidney transplant at St. Vincent's Hospital in 2020.

The patient who was to represent the kidney pancreas programme at the launch became unwell and Siobhan kindly allowed her video to be shared.

In her video presentation Siobhan explained that she had been a diabetic before catching E-Coli in 2012, while on a work trip to India, which had a detrimental impact on her physical health. It had an impact on her mental health also but she resolved to not let her illness define every aspect of her life. She said, "when I think about my donor and my donor family it is with an outpouring of gratitude, from the

very depths of my soul, and I can only hope that that sentiment reaches their hearts. I think of my dad and my donor hugging it out in heaven as I will at some stage". In summing up Siobhan said, "if you can leave the legacy of giving somebody a life back, who otherwise would have lost theirs, then regardless of anything else, that would have been a life well lived."

The final presentation of the day before the IKA Chairman Colin Mackenzie concluded the event was from 21-year-old Chloe Grier, the daughter of an organ donor. Chloe from Claremorris, Co Mayo, who is training to be a midwife, spoke about how she was just eleven years old when her mother Martina suffered a fatal, undetected brain aneurysm, ten years ago. Martina had an organ donor card. Chloe's father sat Chloe and her older sister Nicole, who was seventeen at the time, down to discuss organ donation. Although they had never discussed organ donation before, they immediately said 'Yes' as they wanted to honour their mother's wishes, which resulted in five lives being saved.

Chloe, in describing the comfort in receiving letters from the recipients of her mother's organs, said that one recipient's story stuck out more than others for the family, about an eight-year-old child in the UK who received her heart. Chloe said, "Ten years ago this girl's parents did not know if their daughter was going to survive and then they received a phone call that would change their lives forever.





Carol Traynor, Consultant Nephrologist, Beaumont Hospital, Laura Austin, Senior Transplant Coordinator, Beaumont Hospital, and Mairead Kinlough, CNM2 in Nephrology, Temple Street Children's University Hospital

She is 18 today and that's insane to think about. That somewhere out there these parents have got ten extra years with their daughter, who was only a few years younger than me when I lost my mother."

Chloe continued, "We feel incredibly proud. It's been really comforting to know such a positive thing can come out of our grief and that there are five families out there who think of our mum every day, even though they didn't know her. Over the years organ donation has been an immense comfort to me and my family and I am honoured to speak today, on behalf of my mother."

"I cannot describe how thankful I am for the letters and the cards that we receive every year (from transplant recipients). And although this time of grief and this loss is tragic and has impacted on our lives, irreversibly so, I will always look at this as a positive experience that has

changed my life for the better."

Attending the launch with Chloe was her older sister Nicole.

Two other transplant recipients turned up on launch day in support of the campaign.

Eight-year-old **Sofia Corey** from Walkinstown, in Dublin, practically stole all the limelight with her cuteness when she visited the Mansion House Garden. Sofia underwent a kidney transplant from a deceased donor, in December 2020, at Temple Street Children's Hospital.

Staying outdoors for the launch, Sofia was accompanied by her grandmother Joan McElroy, and proved very popular with the media, with their photos in various national newspapers the next day. They were photographed with Mairead Kinlough, CNM2 from Temple Street Hospital, who was part of the medical team who cared for her.

Another popular participant at the launch was twenty-nine-year-old **Saoirse Perry**, from Cabra in Dublin. Saoirse, who was born with Cystic Fibrosis, underwent a liver transplant in 2014 at St Vincent's Hospital. A former student at Maynooth University, where she now works as a Teaching and Learning Librarian, Saoirse was eager to support the campaign and highlight organ donor awareness activity on campus, and she also participated in media interviews.

Her photo is one of 32 transplant people on the campaign poster, and she received front page coverage on the Irish Independent's Irish

supplement Seachtain. Saoirse's mother Maria Perry, who is a sister of actress Angeline Ball, accompanied Saoirse to the event.

Also, eager to support the campaign on university campus, bringing organ donor awareness promotional materials back to Cork



Joan McElroy and her granddaughter Sofia Corey.



Saoirse Perry

with him was Mark Vesey, a 3rd year medical student at UCC from Abbeylax, Co Laois. Mark is the Education Officer at the Translational Medicine Society in UCC, and to mark World Kidney Day in March he organised a seminar at the university for students which was also open to the public.



A photo of Scarlett.



Kirsty (centre), mother to the late Scarlett, with some staff from St. Joseph's Secondary School.

RTÉ Nationwide

The RTÉ *Nationwide* programme dedicated to the Organ Donor Awareness Week campaign, which was broadcast on Monday 25th April, pulled in a national audience of 220,000. It had been planned months in advance and on 31st March they filmed a mother, Kirsty Donnellan, in Co. Clare who, along with family members and friends, were marking what would have been her late daughter Scarlett's 21st birthday. Scarlett passed away tragically a few years before and her organs were donated.

In recognition of Scarlett's love for everything yellow, this bright colour was worn by pupils in the local national school and by Scarlett's family and friends, in memory of her on her 21st birthday. Students in St. Joseph's Secondary School, that

Scarlett had attended, wore yellow ribbons made by the TY students, to mark her birthday and help raise organ donor awareness.

In St. Joseph's Secondary School Kirsty was filmed sharing Scarlett's

5th and 6th year students at St. Joseph's Secondary School in Tulla.



Scarlett's friends, Lauren, Laura, Rebecca and Chloe at the 'Gift of Life' memorial for organ donors in Ennis.

story when she spoke about the importance of organ donation with hundreds of students attentively listening.

Kirsty's family and a group of Scarlett's friends visited her grave on her birthday and then later they visited the 'Gift of Life' Memorial for organ donors in Ennis, where Clare Branch Chairperson Peggy Eustace along with IKA board representative and kidney transplant recipient, Sharon Fitzgerald, were interviewed. Some of Scarlett's school friends



Scarlett's brother Liam's preschool class at Bambinis made yellow hearts.



Scarlett's younger sister Freya (5th from right) with her classmates wearing something yellow to mark her 21st birthday.



Aoife and Darren Cawley with their sons Caoilan (3) and Iarlaith (5), Theresa Looney, Kerry IKA, Anne Cassin, Presenter Nationwide and David Downey, a kidney transplant recipient from Killarney.



Nationwide producer, Suzanne Butler Walsh with Theresa Looney, Kerry IKA Branch, outside Kerry holiday home.

were also interviewed. Our thanks to the cameraman Matt Kelly and producer Marian Malone for covering this segment with sensitivity.

A couple of weeks later *Nationwide* spent another day filming in Kerry. Presenter Anne Cassin, Producer Suzanne Butler Walsh and Brian Walsh, cameraman, spent time filming at the IKA's Kerry holiday homes in both Tralee and Killarney.

Motivational speaker and kidney transplant recipient Darren Cawley from Mayo was interviewed by Anne while holidaying in the Killarney home with his wife Aoife and their two children. He spoke very eloquently about his many years on dialysis and receiving two transplants and how he is embracing life since. He exuded positivity and viewers were left in no doubt about his gratitude to his donors.

Dr. Catherine Motherway, who is Clinical Lead for ODTI travelled from Limerick to the IKA's Killarney holiday

home to be interviewed by Anne Cassin. She gave an informative overview of the awareness week campaign and organ donation and transplantation in Ireland.

Also interviewed for the programme was Kerry holiday home co-ordinator, Theresa Looney, who has been advocating for kidney patients for almost four decades and played a pivotal role in getting the first dialysis centre established in Tralee. On achieving this, she, along with other volunteers fundraised for the provision of a holiday home in Tralee for kidney patients and their families to enjoy and in more recent years she spearheaded the purchase of a second holiday home in Killarney.

Sisters Bernie and Maggie Quinn from Ashbourne, who underwent a living donor kidney transplant in 2017, were enjoying a holiday in the IKA's holiday home in Tralee with family and friends and they also spoke on camera about their

successful health experience.

Following the programme, the IKA received lots of very positive feedback. Praise was sent in an email message to the IKA from Martina Goggin whose late son Eamonn was a deceased organ donor. After the tragic loss of their son, Martina and her husband, Denis, were the driving force behind the creation of the national commemorative garden for organ donors called, 'Circle of Life', located in Salthill, Galway.

In Martina's email to IKA chief executive, Carol Moore, she said, "Just want to say congratulations to you, and to all involved in the Organ Donor Awareness Week promotion campaign. It has been so comprehensive, with this evening's Nationwide programme capturing the full human side of organ donation, and powerful in getting the organ donation message across. Well done to all, and I'm sure it will have a big impact on reinforcing the important message that organ donation is truly "a gift of life".



Bernie and Maggie Quinn with Anne Cassin, with cameraman Brian Walsh.



Darren Cawley and Anne Cassin.



Protein and Fibre in the Renal Diet

The world of food and nutrition research is ever-developing. New and exciting research has changed what we now know about how certain foods act in the body. You do not absorb as much phosphate and potassium from certain foods as previously thought.

This means that, for those following a kidney diet, there are now more foods to choose from with important health benefits.

As they say, variety really is the spice of life, and having more choice in what you eat makes food much more exciting.

Let's take a closer look at these changes and what it means for you and your health.

Swap a portion of this...	For a portion of this...
25g/1oz cooked meat/poultry/fish	Pulses: 100g/4oz drained chickpeas, butter beans or kidney beans or 125g/5oz peas or 100g/4oz homemade hummus
25g/1oz cooked meat/poultry/fish	Nuts: 25g/1oz of unsalted peanuts/peanut butter or 40g unsalted cashews/cashew butter*
1 slice (25g/1oz) sandwich meat	1 egg or 2 egg whites (egg whites are a great choice for someone on a phosphate restriction)
White sliced pan/bagel/pitta pocket	Wholegrain sliced pan/bagel/pitta pocket
White pasta or rice	Wholegrain pasta or wholegrain rice
White crackers	Wholegrain crackers/oatcakes

*Avoid eating more than one portion of nuts/nut butter a day.

*Avoid eating more than 2 portions of pulses OR 1 portion of pulses and 1 portion of nuts a day

80% of Irish adults do not eat enough fibre. Fibre plays many important roles in our health and in preventing disease. Regular fibre intake helps to prevent constipation, along with exercise and adequate fluid intake (if you are on fluid restriction it is still important not to exceed your fluid allowance).

For people with diabetes, fibre can improve blood sugar levels. Fibre can help you feel fuller for longer which can be helpful for people who are trying to maintain a healthy weight. A very exciting area of research is the beneficial effect fibre-rich foods have on our gut health.

Higher fibre diets are associated with a lower risk of developing type 2 diabetes, stroke, heart disease and bowel cancer. As you can see, the health benefits of including wholegrain products and vegetarian protein sources are endless!

Swapping animal protein sources for

vegetarian protein sources is not only good for your health, it is also good for the environment. Reducing meat intake can significantly reduce our greenhouse gas emissions.

It also reduces the amount of land lost through deforestation and water used for farming. Small changes really can make a big and lasting difference.

Having meat free meals during the week is a great way to try your hand at new recipes and increase your intake of vegetarian protein sources at the same time. Another idea is to try a mix of protein sources, for example chickpea and chicken together in a dish.

Snacks are an easy way of trying new protein options – unsalted peanut butter on oatcakes or homemade hummus on wholegrain crackers are a great choice. Try out our easy and delicious recipes for Cauliflower, Chickpea and Cashew curry, and No-Tomato Veggie Chili.

By **SALLY HOULIHAN**
and **MARY HORAN**
Tallaght University Hospital



CAULIFLOWER, CHICKPEA AND CASHEW CURRY

– Serves 4

Ingredients:

550g cauliflower, divided into small florets – boiled in unsalted water and drained
1 tablespoon (22g) vegetable oil

1 small onion (60g), finely chopped

1 clove garlic (6g)

160g unsalted cashew nuts

2 heaped teaspoons (10g) garam masala

400g chickpeas total drained weight (slightly less than 2 tins)

2 tablespoons (30g) mango chutney

1 tablespoon (15ml) lemon juice

1 tablespoon (8g) fresh coriander leaves, chopped

Basmati rice or brown rice to serve

Method:

Boil the cauliflower florets in a large pan of water for 5 minutes or until tender.

Meanwhile, heat the oil in a large pan and fry the onion over a medium heat until softened. Stir in the garlic, garam masala and cashew nuts and fry gently for a couple of minutes. Add 500 ml water. Bring to the boil and simmer for 20 minutes. Meanwhile, boil the rice in unsalted water.



Add the boiled cauliflower, chickpeas, mango chutney and lemon juice to the curry mixture and cook for 5 minutes or until heated through. Serve with the rice, or with pitta bread, chapattis or other bread. *One serving of this dish contains 1 portion vegetable and 2 protein exchanges.*

NO-TOMATO VEGGIE CHILI

– Serves 4

Ingredients:

1 teaspoon (3g) ground cumin

1 teaspoon (3g) ground coriander

1 teaspoon (3g) smoked paprika

1 teaspoons (3g) chili powder

1 teaspoon (1g) dried oregano

1 small onion (60g), diced

2 cloves garlic (12g), minced

1 tablespoon (22g) vegetable oil

500ml low salt vegetable stock (try

kallo very low salt stock cube or knorr zero salt stock cube)

100g pepper, diced

2 diced carrots (60g),

boiled and drained

3 small stalks of diced

celery (100g), boiled

and drained

400g (drained weight)

kidney beans (slightly less than 2 tins)

500g frozen/fresh peas

Brown rice or basmati rice to serve

Method:

Before starting to cook, prepare all the ingredients: Drain and rinse the beans, measure the spices and chop all the vegetables. Set aside.

Heat a large pot over medium heat with the vegetable oil. Add the onion and fry until translucent and slightly browned. Add the minced garlic and peppers. Stir to evenly distribute. Add the spice mixture and toast until the spices are strongly aromatic, about 1 minute.

Pour in the vegetable stock. Add the vegetables and the beans. Cover the pot, and bring to a boil over medium-high heat. Once boiling, remove the lid, reduce heat to medium-low, and let simmer for 15 minutes, then serve.

One serving of this dish contains 1 portion vegetable and 2 protein exchanges.



Punchestown Charity Race

The Punchestown Kidney Research Fund has been organising the Punchestown Charity Race at the annual National Hunt Racing Festival annually since 1990 with the exception of the COVID-19 interruption. The charity is the brainchild of kidney transplant recipient, James Nolan, and over the years it has raised over €1.6 million and they invested these funds in projects that improve the quality of life for patients on dialysis, projects that establish ways to maximise the life span of the transplanted kidney and identify projects that examine the causes that lead to renal failure.

James began dialysis in 1986 and in 1987 his sister, Catherine, donated a kidney to him. The PKRF is his way of 'giving back.' James rode in the race for the first 13 years and rode *Nero's Dancer* to victory in 2002.

The Charity Race is the PKRF's primary fundraiser each year and as a mark of its success, it continues to

be significantly over-subscribed annually. There are 25 slots in the race and they are open to amateurs who are required to pass fitness and competency tests before being cleared to ride. The must also raise a minimum of €1,500 for the charity.

It is a serious commitment that is asked of each participant but the opportunity to ride at the National Hunt Racing Festival is an attractive one. 30,000+ spectators make for an amazing back-drop to a real bucket-list experience.

Observing the parade ring as the horses, and their riders, get ready for the race highlights what is very special about this event. The jockeys have many family members there and everyone is buzzing. Some of the jockeys look like they were born to do this whilst others look 'a little tense' as they await the excitement to come!

On return to the parade ring, the sense of elation and camaraderie is fantastic and with members of Transplant Team Ireland on site too, the message about the importance of having the organ donation conversation is not lost on all who are watching. James works hard to get this message out and seeing him being interviewed for television on the day is a regular occurrence.

The Charity Race has attracted some very high profile alumni of the racing world with Jessica Harrington, Tommy Carberry and Robert Hall, to name but a few, and the great *Moscow Flyer* took to the starting line too.

The PKRF has supported many and varied projects over the years including;

- €150,000 donated to open a new renal unit at Temple Street Children's Hospital in Dublin
- €100,000 committed to support two kidney related research projects under the guidance of the Irish Nephrology Society
- €20,000 committed to continue Art Therapy programmes for Dialysis Patients in Tallaght & Waterford Dialysis Units.

The charity has also been a long-time supporter of Transplant Team Ireland, sponsoring two to three participants to attend the European Transplant & Dialysis Sports Championships or the World Transplant Games each year.

As covered in our last edition of *SUPPORT*, the most recent commitment has been €65,000 provided to fund the Irish Kidney Association's Patient to Patient mentoring support pilot programme.

James Nolan is one of those people you remember meeting. From his firm handshake when he looks you in the eye to his constant thoughtfulness, his warm heart shines through. Along with his wife Emma, and his son Andrew James, he is a very popular member of Transplant Team Ireland both within the team and on the international stage. As a very successful award-winning butcher he continues to take the time to make a difference for the renal community in Ireland.



Leona Hughes with
Andrew James
Nolan



SPORTS UPDATE

By COLIN WHITE

Like so many other walks of life, COVID-19 brought the in-person activities of our sports programme to an abrupt halt in March 2020. The momentum of the programme had been building at the time as we were busy planning the hosting of the European Transplant & Dialysis Sports Championships in August that year.

Our previous hosting of the event in 2010 brought in many newcomers to our sports programme and the public profile of transplant and dialysis sport took a giant step forward. The hosting of the 2020 Championships was to take the programme to a new level in terms of participation and profile in sporting circles and again shine a light on organ donation.

In the build up to the 2019 World Transplant Games we had received coaching / in-kind support from National Governing Bodies such as Swim Ireland, Athletics Ireland and others. The fact that we were to be hosting the Europeans the following year helped develop the interest in supporting the niche area of transplant and dialysis sport.

Whilst the in-person activity of the sports programme has not been happening, the team's online activity has remained vibrant as we all went through the rollercoaster of emotions driven by COVID-19 and its variants. People shared information from around the country as the mysteries of the pandemic unfolded and, crucially, everyone rallied round to support each other.

We had team Zoom calls that allowed people to at least see each other, if only in two dimensions and the World Transplant Games

Federation introduced a number of virtual events, including its very successful Billion Steps Challenge.

A very pleasant surprise over the last two years has been the number of new people who made contact and asked to join the team as they sought out the camaraderie of people on a similar health journey and looked to the future and the opportunity to have the goals of future events to motivated them to keep physically active and engaged in sport.

COVID-19 has remained the unwanted 'guest' across the globe for far too long. Societies have been moving back towards 'normal' in recent months but COVID-19 has been showing a stubborn side as witnessed by the current summer surge we are experiencing. This has impacted on the involvement of Transplant Team Ireland in this year's European Transplant & Dialysis Sports Championships to be held in Oxford in August.

Having sought medical and legal advice in relation to the risks associated with participation in the Championships it was decided that the IKA would not be entering a team. Whilst it was accepted that individuals can make decisions in relation to their own risk, the Association had to think of the bigger picture in relation to the potential collective risk that would come with the participation of Transplant Team Ireland (the Association's sports programme).

The decision was made in the context of all IKA activities with no in-person activities having started back. It was obviously a huge disappointment to the regulars who

always go to the Championships, as well as the significant number of newcomers who were hoping to have their introduction to the international transplant and dialysis sports community just 'across the water' in England.

Based on the good name and reputation of our team, as built up by all the team members who have travelled to European and World events in the past, the European Transplant & Dialysis Sport Federation and the Local Organising Committee in Oxford agreed that if individuals from Ireland wanted to participate in the Championships they would be welcome to do so.

It is important that we do not let the hiatus in our sports programme, brought about by the pandemic, derail us in our ambitions to build on our strong community, to be always welcoming to newcomers, to take on the responsibility of being role models to others and ensure that we embrace the opportunity to showcase the importance and success of organ donation for transplantation, whilst keeping organ donors and their families to the forefront of our thoughts.

In previous years when writing about our sports programme, I borrowed a phrase from Barack Obama; **"Yes we Can!"** to describe the attitude of members of our sports team. Now let me borrow a phrase from the current US President, Joe Biden; **"Build back better!"** With a commitment to work together to ensure that the appropriate structures are in place to allow for the sports programme to develop, our **'family'** can, and will, grow bigger and stronger.

VIRTUAL Runforalife.ie

Hundreds of people from around the country donned their running shoes in support of the Irish Kidney Association's third virtual **Run for a Life** which was held between May 21st and 28th. Individuals and groups set out their own plans on where, when and how far they would walk, jog or run, with a choice of distances, 2.5km, 5km or 10km. Some eager people took part on more than one day.

This year a **7x7 Challenge** was introduced to the **Run for a Life** event to shine a light on the profound life-affirming act of organ donation and that **1 Organ Donor can Save 7 Lives**.

People were encouraged to share photos of themselves taking part, on their social media and with the IKA.

To promote the **Run for a Life** event in advance, a photocall was held at the scenic Burgess Park in Athlone, on the banks of the River Shannon, with four grateful transplant recipients (heart, lung, liver and kidney) together with their families and friends.

Helping to promote the event was nine-year-old Caeden Geoghegan with his mother **Denise Geoghegan** (41) from Mountmellick, Co Laois who, following two false calls, received her lifesaving heart transplant at the Mater Hospital, in Dublin in 2020.

Denise's friends Karen Ravenhill from Tullamore, Co Offaly and Claire Gillespie from Lecarrow, Co Roscommon showed up for the photocall and they, along with another friend ran the 10km distance for **Run for a Life**.

Also attending the photocall was 22-year-old liver transplant recipient **Tomas Caffrey** from Holycross, in Co Tipperary, who has just completed his 3rd level education at the Institute of Technology in Athlone where he now works.

Like Denise, Tomas also underwent his transplant in 2020 during the global pandemic, in the liver transplant unit at St. Vincent's University Hospital.

Two other grateful transplant recipients happy to support the photocall, flanked by their families,

By **GWEN O'DONOGHUE**

Photocall photos by
DEE ORGAN

were kidney transplant recipients **Phelim O'Neill** from Roscommon and **Cathy Smyth** from Coosan, Athlone, Co Westmeath who both underwent their transplants at Beaumont Hospital.

Phelim, formerly a goalkeeper with Clann na nGael and who also played for Roscommon, was accompanied to the photocall by his wife Tracy and their two-and-a-half-year-old twins Cára and Ken. Following his kidney transplant 26 years ago, Phelim got to know Tracy, who worked at the pharmacy where he collected his anti-rejection medication.

Phelim said, "I'm supporting the Irish Kidney Association's Run for a Life because I got a good run at life thanks to my donor. I think of my donor every day. For the past 26 years, every year, on my birthday in January, I remember my donor who gave me the 'gift of life' on the day of my 22nd birthday.

Since then I have enjoyed good health, I met and got married to Tracy and we are now blessed with twins. I'm still passionate about GAA and although not playing for my club Clann na nGael anymore I enjoy coaching underage. I was delighted that the club came behind an initiative to promote organ donation on training jerseys and I ensured that my twins got theirs also."

Cathy Smyth, who is the secretary of the Westmeath Branch



Karen Ravenhill and Claire Gillespie.



Phelim O'Neill
with his wife Tracy
and their twins
Cára and Ken.



Denise & Caeden Geoghegan, Tomas Caffrey, Tomas Caffrey, Cathy Smyth, Donnacha & Ger Harrison and Phelim O'Neill.

of the IKA is enjoying the successful kidney transplant she received eight years ago (also from a deceased donor).

Cathy suffered kidney failure after the birth of her son Donnacha ten years ago. Cathy's husband Ger Harrison and Donnacha joined her at the photocall.

Speaking in advance of **Run for a Life**, Colin White, National Advocacy & Projects Manager for the IKA said, "The **Run for a Life** event is a fun way for people of all ages and levels of fitness to come together (virtually) in solidarity around the need to raise awareness of the importance, and success, of organ donation for transplantation. It is also about raising funds to support the work we do.

Waiting for a transplant is an uncertain time and events like this

are about letting those on the transplant pool, and their families, know that they are not alone. Every person who gets an organ donor card and shares their wishes with their family is giving hope to those who are waiting for 'the call'.

We encouraged people from all around Ireland and beyond to take part in this fun and life affirming event and to post their photos on social media, using **#RFAL2022**.

We hope that next year it will be safe for us to return to staging an in-person event, like we did before COVID-19, where everyone can gather together at one location to take part in this celebration of life".

To heighten awareness that one organ donor can save seven lives, the Run for a Life 7x7 Challenge offered a discounted registration rate of €7 per person for groups of 7 and a free t-shirt for everyone who

got sponsorship of €7 or more each from seven people.

Individuals could register for €10 or for €25 for a family of four and those wishing to fundraise were encouraged to invite donations through the Just Giving platform www.justgiving.com/campaign/IKA7x7Challenge2022

The IKA is grateful to everyone – individuals, families, friends and larger groups – who supported **Run for a Life** by taking part or through sponsorship.

Eoghan Rua Ladies Football Club in Sligo organised its own fundraiser to mark the Run for a Life 2.5 km event with over 100 men, women and children turning up to the beautiful Enniscrone beach to participate.

They raised €754 which was gratefully accepted by the Sligo Branch of the IKA. You can read more about their event on page 58.

Stephen Lyness did the run, in memory of his late father, Jerome, a kidney transplant recipient, who had taken part in the fun run with his family and a large group of runners from Navan, when the event was held in Corkagh Park in 2019, prior to his untimely passing.

Stephen is pictured left after taking part, this year.



Aine Phelan and Gwen O'Donoghue.



Bridget and her husband
Richard with some of the
young villagers of Simanjira

By BRIDGET LANGTON



OUT OF AFRICA

Since her kidney transplant 26 years ago a Kilkenny woman has embraced life's experiences and enjoyed travelling extensively around the world.

On her travels she fell in love with a village in Africa and has set her sights on returning there again next year, to see her dream realised, to build a water well to benefit 6000 villagers, their livestock and crops. She shares her life affirming story here.

Hello everyone, my name is Bridget Langton and I come from Graiguenamanagh, Co Kilkenny. Unfortunately, like so many I too experienced renal failure, then haemodialysis but, thankfully, after a time I had a very successful kidney transplant.

I first experienced renal failure in 1989 during my pregnancy when I began to feel very unwell. My blood pressure went sky high and I was also retaining excess fluid.

What a shock it was to be told my kidneys were not working.

From the time my daughter Renée was born, I began attending Consultant nephrologist John Donohoe, in the Mater Hospital in Dublin, who carefully monitored my renal function.

In 1994 it was decided

that I should commence home dialysis treatment but, as can sometimes happen, it did not work for me after two trials.

In August 1994 I underwent a Gore-Tex Graft which was inserted in my arm so that I could begin haemodialysis treatment. As many of us know, the routine of attending in-hospital treatment, three times weekly, can be gruelling.

In October 1995, I received that magical call – a donor kidney was found for me!

In hospital, ready to be wheeled down to the operating theatre, Transplant Surgeon David Hickey said to me, 'I will see you in 30 minutes'.

Unfortunately, I experienced an acute anxiety attack and the transplant operation was cancelled.

After that crushing event I spiralled into a state of

depression. I had literally given up life as I thought I would never see my daughter grow up. However, this bleak time came to pass, when in May 1996, I received a second call from Beaumont Hospital for a transplant, which gave me a new lease of life.

From that day to the present I have had an absolutely wonderful life! Words can never express my gratitude to my donor for giving me their kidney. I have seen my daughter grow up, graduate from college, get married and now I am a very proud Gran.

In 1999 I returned to college and completed the course that I had wanted to do. I then returned to work.

In 2006 my husband and I decided to open and run our own Bed and Breakfast, Killvarra B&B, in our unique town. Running



2019

Dubai 2018



Bridget cradling her grandson Tadhg

the B&B allows me to meet and speak to people from across the world which I really enjoy.

I too enjoy travelling and visited many countries and continents around the world.

The place I most enjoy travelling to is Tanzania in East Africa. I highly

recommend people, if on dialysis or transplanted, to try to travel as much as you can and make the most of life.

Before travelling speak to your consultant for a health assessment as I always do before I arrange plans. The Irish Kidney Association has always been so helpful with advice too. I always take care when travelling, being mindful of my health. I recommend all to wear a face mask on transport and in busy crowded areas.

Also due to my transplant I am very careful in any of my travels, even in Ireland, to always wear the highest sun factor. Insect repellent is also

essential on exposed skin as an insect bite can lead to an infection.

I have travelled to Tanzania five times with my husband, Richard. After visiting Simanjiro, a very rural area, on our first visit in 2014 and seeing the standard of life there, without even the most basic need for easy access to clean drinking water, I began doing some charity work to raise funds for the people of the village.

Our ambition is to provide a water well for the Simanjiro village which will supply clean drinking water for over 6,000 people as well as their livestock and crops sown there.

We realise that there are many worthy causes out

there but if you would like to help support this one through a donation, no matter how small, please contact me on my mobile 086-1202918.

We plan to return to Simanjiro next year and witness our dream for a water well become a reality in providing a lifesaving system for the villagers.

After all of the experiences I have been through, it has reinforced my conviction that life is for living! So get out there folks, enjoy your life, travel and gain new experiences, and make the most of the time you get to spend with those closest to you.

If anyone would like to talk to me anytime, I am always open for a chat.



February 2019



Bridget and her husband Richard with her daughter Renée on her wedding day in July 2018

Remembering Celia

By GWEN O'DONOGHUE

Celia Farrell, a retired nurse, passed away after a fall outside her Clonee home in August 2013 just hours before going out for a meal to celebrate her 39th wedding anniversary. Her husband Noel, on knowing that Celia had a signed organ donor card for many years, honoured her wishes to be an organ donor. The organ donation helped three other people as her kidneys were transplanted into two people and another stranger received a liver transplant.

Two and a half years later, Celia's cousin Michael Byrne from Ballyhaunis, Co Mayo, underwent a kidney transplant in February 2016 following dialysis treatment.

Noel treasures a gift he received from one of the transplant recipients, sent anonymously via the transplant coordinators' office. The framed photo of silver birds was accompanied by a card which explained the birds represented the treasured freedom that the transplant had given the transplant recipient.

Noel, a retired accountant who grew up and attended school in Tullamore, Co Offaly until 1970 explained, "we were both doing work around our house, a bungalow in Clonee in August 2013. I had finished mowing the lawn and was coming back towards the house when I found Celia lifeless on the ground.

"She had fallen off a ladder when she was almost finished clearing out a gutter. She suffered a brain trauma. She was a retired nurse and liked to keep busy and active and always cleaned the gutters out once a year around August even though I had often asked her why she didn't get someone in to do the job.

"After her fall an ambulance brought her to Blanchardstown Hospital but it was clear that she wasn't going to recover. When medics asked me would I consider organ donation I knew instantly that I had to say yes as that was her



*The late Celia Farrell,
an organ donor*

expressed wish and I knew she had always had an organ donor card.

"It's a decision I don't regret and although I miss her and think of her every day it brings comfort to know that I had honoured her wishes and as she had worked as a nurse all her life, until her retirement, she would have wanted to help others through organ donation.

"Celia and myself met at the National Ballroom in Dublin over four decades before and we clicked immediately and love quickly blossomed. I was working in Dublin as a trainee accountant and she was training to be a midwife in the Rotunda and in later years she nursed in Cappagh Hospital.

"We got married in the Old Church in her native Knock in Co Mayo and spent 39 happy years together.

"When she died I didn't want to continue living in the same big

house and a few years later in 2017 I bought a smaller house in another part of Dunboyne.

"It was while I was moving house that I found her old organ donor card. I brought the donor card to the annual Service of Remembrance and Thanksgiving in 2018 for organ donors, which is organised by the Irish Kidney Association (IKA). It was at this Service I met TV presenter Claire Byrne as she was an ambassador for the IKA that year and we were photographed together holding the old donor card.

"Organ Donation continues to be very important for me. Recently I phoned the IKA and requested a box of organ donor cards to put in my local church around the time of Confirmations. Most of the box was emptied and I just have a few left.

"I have some great memories of Celia and we marked our 25th



anniversary with a trip to the West Coast of America. Two years later for our 27th anniversary we went to New York, which is a trip I will never forget, as we had just left our hotel and hopped onto a coach to see the twin towers when we had to make a detour as we were told there had

been an incident at the towers. It was nine eleven, a day I will never forget.

"Celia worked hard as a nurse all her life. She was part of a team that were responsible for getting the first automated decontamination unit in Cappagh Hospital.

The Irish Kidney Association wishes to acknowledge Noel for his selflessness in both honouring his beloved wife Celia's wishes to be an organ donor and also for allowing us to share their story during Organ Donor Awareness Week 2022.

ANNUAL SERVICE OF REMEMBRANCE



Due to COVID-19 precautions the 37th Annual Service of Remembrance and Thanksgiving will be virtual for the third year in a row.

The pre-recorded Service, will be broadcast on RTÉ One and Radio 1 Extra on Sunday, 30th October, 2022 at 11am and will be available to watch later on www.ika.ie



SUPPORT THE WORK OF THE IKA

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

STANDING ORDER REQUEST FORM

To: The Manager of_____

(Your bank's name and address)

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

Signed: _____ Date: _____

Address: _____ Ph: _____

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

IBAN:

 Bank Identifier Code - BIC:

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

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

(Please tick as appropriate)

to start on Date:_____/_____/_____

AND CREDIT TO THE FOLLOWING ACCOUNT:

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

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

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

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

THANK YOU FOR YOUR GENEROSITY



Annual Golf Classic Mitchelstown

By PAT O'SULLIVAN

The Cork Branch of the Irish Kidney Association held its annual Golf Classic in Mitchelstown on June 3rd. We were delighted with the response that we got, from the number of teams that were entered on the day, our timesheet was full from 09.30 to 17.50 hours, and the sponsors that contributed to the event, both for the main prizes and the raffle that was held at the end of the evening.

For a change we were blessed with the weather and all teams came home dry at the end of their rounds. Thanks to all the volunteers who assisted us on the day because without their help it would not have been possible for the day to run as smoothly as it did. They helped with checking in teams, selling raffle tickets, collecting money for each team, and manning our fun hole on the 11th.

A special mention to a few: Amanda Coyne and Joe Higgins who did trojan work on securing some fantastic prizes for the competitors; Siobhan Buckley, Sheena McDonagh, Helen O'Sullivan and Mary Hurley ensured that nobody escaped without buying a raffle ticket; Hugh Nolan and Ray Scanlan had the hard task of dealing with each of the cards from competitors when they finished playing; John Hurley manned the 11th; Mick O'Shea for learning pretty quickly how to calculate the playing handicaps for each of the competitors having never been in that position before; and our photographer Denis Hyland who showed us amateurs how a photo should be taken.

The members of the organising committee responsible for pulling the event together were Jennifer Hurley, Michael Kiely, Hugh Nolan, Pat O'Sullivan and Ray Scanlan.

This year, as for every year in the recent past since the purchase of the Support Centre near Cork University Hospital, the proceeds of the event



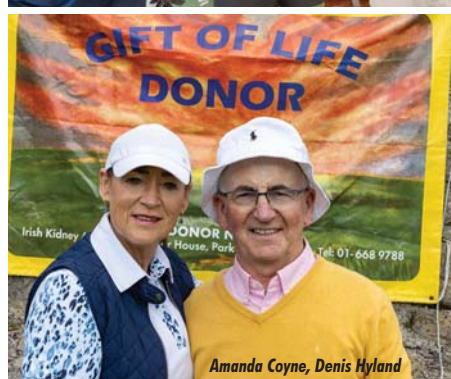
Jack Singleton, Longest Drive for Gents



Alan Copps, Decie Copps, Colman Sheehan, 2nd Overall.



Display of Sponsors on the way to the First Tee Box.



Amanda Coyne, Denis Hyland



Trish Landers, Amanda Coyne, Tony Coyne, winners of the mixed prize.



Competitors waiting to tee off on the first.



Branch Secretary
Sheena McDonagh with
Cork Branch members,
Dermot O'Connell and
Siobhan Buckley.



Siobhan O Herlihy, S Burke, D O Sullivan.



Tony Coyne posing on
the first Tee.



Hugh Nolan, Pat O'Sullivan, Sheena McDonagh, Amanda Coyne, Siobhan Buckley, Mick O'Shea, Denis Hyland.



Hugh Nolan, Tadgh Henan, Eoghan Daly, Patrick O'Sullivan

go towards the renovation and the future upkeep of the Centre. At the time of going to press we are still calculating the exact amount that was raised and we will update you on the final tally in the next edition of *SUPPORT*.

The winners on the day came in with the last card of the day with a fantastic score of 65pts. Apologies for not including their photograph due to technical issues! Congratulations to Michael Beston, Annette Beston and J. Moran on a fantastic score. You would feel sorry for the team – Alan Copps, Deccie Copps and Colie Scanlan – who had been in first place from early in the day until late on Friday night and must have had an acceptance speech

prepared.

We will start preparations for next year's event again shortly.

If you would like to get involved in helping in any way just let any officer of the branch know even if it's in some small way, like getting a tee box sponsor, or a prize sponsor from your local shop or business in your area. We will also be looking for volunteers to help out for a few hours.

Hopefully by the time the event comes around again we will have welcomed our first families and patients into what looks likely to be a wonderful facility, and not just for the people of Cork and Munster but hopefully also a place for families and patients from all over the country to enjoy.

The Winners on the day were;

- 1st M Beston, A Beston, J Moran, 65pts
- 2nd A Copps, D Copps, C Scanlan, 63pts
- 3rd D Walsh, J Roche, M O'Grady, 59pts
- Gross T Heenan, C Collins, H Nolan
- 4th S O'Herlihy, S Burke, D O'Sullivan, 58pts
- 5th N Jones, P Morrissey, R Davern, 57pts
- 6th D Magner, E O'Neill, M Kelleher, 56pts B9
- 7th E Roche, N Roche, S Collins, 56pts
- 8th M English, L Gamble, N Griffey, 55pts
- Ladies N Collins, Y Barrett, M Perry, 48 pts
- Mixed T Coyne, A Coyne, T Landers, 53pts
- Non GUI N Brennock, S McCarthy, D Daly
- Non GUI S O'Brien, J Tipper, J Healy
- Longest Drive Men Jack Singleton
- Longest Drive Ladies C Collins
- Nearest the Pin Gents Daithi Sexton
- Nearest the Pin Ladies Trish Landers



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.

Tribute to Angela McKinney

To set up a new branch of the Irish Kidney Association, and to help found another one in a neighbouring county, was a big achievement. And then to go on to play a leading role in a campaign for the provision of a local dialysis unit was an amazing feat.

That is the legacy that our Sligo Branch founder **Angela McKinney** left behind when she passed away on April 6th of this year.

Angela's inspiration to form the Sligo Branch was sparked by her involvement with her brother Joe O'Rourke in helping him in setting up a branch in Donegal.

Joe moved from the family home in Thomas Street in Sligo to Donegal around 1970 where he established a successful business. However, some years later his son developed kidney disease. After experiencing the difficulties his son and other renal patients faced, he decided to set-up a branch of the IKA in Donegal for their support.

As a woman who was always prepared to give of herself to help others, Angela frequently travelled to Donegal to assist her brother Joe in getting the new Branch up and running.

Soon she recognised the need for a similar Branch in Sligo and got to work in organising one. Her endeavours were soon recognised by others who shared her vision.

One of those was the now Sligo Councillor Rosaleen O'Grady who joined Angela in the setting up of the Branch. Then a nurse, Rosaleen had returned home to Sligo after having worked in the renal unit of Jervis Street Hospital in Dublin.

Rosaleen recalled the early days of the branch. She said: "We used to meet where Angela then lived in Temple Street after Mass in the nearby cathedral. She led out on setting up the Branch and inspired others to join in her good work. She was a very decisive woman who treated everyone with respect and was highly regarded by the many who knew her," said Rosaleen, who still remains a strong supporter of our Branch.



On right, Angela McKinney with fellow members of the first Sligo IKA branch Teresa Davey (left) and Rosaleen O'Grady (centre). They were pictured at our IKA Garden of Reflection Doorly Park in September 2016.



A plaque on the wall of the Sligo dialysis unit in honour of Angela McKinney, erected in 2011

Angela spent twenty-five years campaigning for the provision of an integral dialysis unit at Sligo General Hospital, which eventually opened in 2005. Some months later she was acknowledged for her achievements by being named County Sligo Person of the Year.

As well as being the founder of the Sligo Branch, Angela was the first Sligo member on the National Board of the IKA.

Paying tribute to her, the current Chairman of the Sligo Branch Sean Fowley said, "Angela McKinney set the bar very high for others to follow. We, the members of the organisation, must strive to have her legacy live on in supporting renal patients. In her voluntary work with the Branch in its early years, Angela was acutely aware of the supports required by renal patients and tirelessly endeavoured to meet those needs".

As well as her work with the IKA, Angela found time to give to other local organisations. Along with her late husband Liam, she was very involved in amateur drama circles. A spokesperson for Everyman Productions Sligo recalled that she and Liam were very active with the drama group in their formative years saying, "Although Angela never received plaudits on stage, she had played a pivotal role in so many other ways, and for that, we will be forever grateful and always hold her in great esteem".

Also paying tribute the Hawk's Well Theatre said: "The McKinney family played a central part in Sligo's theatre scene for many years and Angela's presence at the theatre will be missed. She has been a generous and loyal friend to the theatre throughout her life."

The Sligo Musical Society for which Angela had held the role of President for a time, paid tribute saying: "Her loyalty and generosity to us never faltered and for many years Angela was our front of house manager - meeting and greeting audiences at every performance. She kept meticulous financial records. She loved the banter and had a great sense of fun".

Members of the Sligo IKA branch formed a guard of honour at Angela's funeral at Saint Anne's church.

May she rest in peace.



NEW DIALYSIS UNIT

The preparatory process leading up to the delivery of a new dialysis unit at Sligo University Hospital is continuing. This was confirmed in a letter to our Branch Secretary, from the office of the Minister for Health, after we requested an update on the project.

The letter from the Minister's Private Secretary, Fiona Conroy, stated that Sligo University Hospital and HSE Estates are working on completing the accommodation schedule for dialysis services at the hospital, to cater for current and future demands for the service.

It continued: "Once the accommodation schedule is finalised, Saolta University Health Care Group plan to submit a request to HSE Estates to secure funding for the appointment of a design team to formally scope out the project".

The letter is the latest in a series of communications with the Minister and health officials over the past two years in which our Branch has been pushing for adequate dialysis and renal facilities at the hospital.



SLIGO

By BRIAN McHUGH



Nikita White of Collooney with family members presents a cheque for €1,226, from the proceeds of their sponsored Skydive to Sligo IKA. Pictured accepting the cheque, branch secretary Geraldine McHugh and branch members Noreen Keane (left) and Eileen Nolan (right).



RUN FOR A LIFE ON ENNISCRONE BEACH

Eoghan Rua Ladies Football Club in West Sligo raised €754 in their IKA 'Run for a Life' event on May 21st. Thanks to the more than 100 players, family members and friends who took to the sands at Enniscrone beach.

Eoghan Rua vice-Chairman and Team Manager Patrick Cleary said the IKA is a cause close to members of the club's hearts as two people connected to the club received kidney transplants within the past five years.

He said: "We would like to thank everyone who came out and supported us on the beach. It's great to see everyone coming together for such a worthy cause and shows just how brilliant a club we are".



Branch members on a recent tidy up of our Garden of Reflection at Doorly Park



Pictured is Garda Tony Lavin along with Brian McHugh, Eileen Nolan, Geraldine McHugh and Sinead Nolan.



Sligo City Hall lit-up in green. Pictured are Noreen Keane, Sean Fowley, Eileen Nolan and Marie Fowley.

ORGAN DONOR AWARENESS WEEK

Sligo Garda Station and Sligo City Hall were lit-up in green, in support of Organ Donor Awareness Week. Representatives of the Sligo branch attended photocalls at both locations to help raise organ donor awareness.

SYMPATHIES

Sympathy to the family of dialysis patient and retired nurse Sheila Gallagher, Collooney, Sligo who passed away on April 28th. Her funeral mass was in Collooney Church followed by burial in St Nathy's Cemetery.

May she rest in peace.



Helena (mum) Alannah (12) Caoimhe (10) Leigha (15) Éabha (17) and dad Pat.

Seventeen year old Eabhá Cleary, a sixth year student who attends Jesus and Mary Secondary School Enniscrone wrote a poem about the gift of life for Organ Donor Awareness Week, which was timely

IKA SUPPORT SUMMER 2022



Éabha and her dad Pat.

for Poetry Day Ireland 2022 on Thursday April 28th. She drew her inspiration from her father Pat Cleary's plight with kidney failure and the life-changing kidney transplant he received over five years ago.

A Dream
 While we didn't even know each other
 You still felt the need
 To give a special gift away
 Even when you'd leave.

 Your gift to me is everything
 Everything I dreamed
 For part of me came back alive
 The day you gave me life.

 We'll share a special bond
 One no one else will see
 For part of you lives on in me
 One no one else believes.

 Your gift to me is everything
 Everything I dreamed
 I know I've very lucky
 Not everyone achieves.

 So become an organ donor
 Sign the donor card
 Share your wishes loud and clear
 For your gift is one of the greatest
 One no one will believe.

Éabha Cleary



FLYING HIGH WITH OVER €10K RAISED FOR THE IKA

The Autumn 2021 edition of *SUPPORT* featured an article 'Flying High for the IKA' which told the story of Helen Milligan, Managing Director of GEM Oils in Cavan, doing a skydive, which raised a hefty €10,272 for the IKA. Helen chose the IKA as the beneficiary in recognition of Hugo McCaffrey's 40 years of service with the company up until his retirement in December 2019.

CAVAN/MONAGHAN

By KARL CRONIN

Helen Milligan, Hugo McCaffrey and Karl Cronin outside the GEM Oils head office in Cavan.



Hugo is a two-time kidney transplant recipient and he is enjoying his retirement now after a long and happy career with Gem Oils.

On behalf of the IKA, we express our gratitude to Helen and all at GEM Oils for their support and wish Hugo many more years of health and happiness in his retirement.



Helen Milligan presents a cheque for €10,272 to Karl Cronin, Cavan / Monaghan IKA Branch, with some of the team from GEM Oils and Hugo McCaffrey (centre).

WATERFORD

RESPIRE CENTRE

Our holiday homes in Tramore are open and ready for our guests this Summer season. All apartments are accommodating guests from Saturday to Thursday weekly. We look forward to you seeing, and experiencing, the best of the 'sunny South East' over the Summer months.

FUNDRAISING

Fundraising continues on a more muted level than previous years and we thank the Newtown Fundraising Committee for their continued support.

We wish our Chairman, Ray Halligan the best of luck as his fundraising 7-a-side soccer team go into action again at the end of June and hope they emulate the success of last year! No pressure Ray! Thank you to Joe Moynihan Engineering, Durrow,

Co. Waterford for kindly sponsoring the trophies and a perpetual plaque.

CONDOLENCES

To the families of members who have passed away, we offer our heartfelt sympathies at this time.

BEST WISHES

On behalf of the Branch members we wish our long-standing volunteer and Honorary Treasurer, Vera Frisby, best wishes for a speedy recovery.

Vera is known to many of you who have visited the apartments in Tramore as she would be there to greet you at some stage in your visit.

Wishing all our members a safe and enjoyable Summer season.

Summer greetings and good wishes to all our patients/members and their families

Zoom meetings will continue, once monthly, until we are allowed to meet again face-to-face. We trust everyone is keeping well and staying safe.

Meetings provide us with a forum to hear about updates from Donor House, chat and support our patients and members, and also, an opportunity to welcome new members.

A very special 'thank you' to Carol Moore CEO, IKA, who joined our Zoom meeting on May 24th. Carol's presence at our Zoom meeting provided an opportunity for Carol to discuss a number of topics, especially the Strategic Plan (2021-2025) and for patients/members to ask questions.



'RUN FOR A LIFE' FUNDRAISER WALK

As part of the IKA's third virtual 'Run For A Life' Sara Santi, IKA member and patient, designed the poster for the Kilkenney Branch for an open air walk held in picturesque Graiguenamanagh on Sunday, June 26th at 12 noon, in compliance with COVID-19 guidelines.

SYMPATHIES

We extend our sympathy to the family of the late Tim Comerford, Meadow Way, Kilkenney who sadly passed away on April 28th. May he Rest in Peace.

Kilkenny County Hall



ORGAN DONOR AWARENESS WEEK

For Organ Donor Awareness Week, John Lacey, Chairperson, Kilkenney Branch had his photo taken receiving his 5th COVID-19 vaccine from William Mulhall, Pharmacist, O'Shea's Pharmacy, Market Yard, Kilkenney.

Thank you to Kilkenney County Council who committed to lighting-up the following public sites for Organ Donor Awareness Week: Kilkenney County Hall, John's Bridge, Kilkenney, St. Canice's Cathedral and The Tholsel, City Hall.

CONGRATULATIONS

Congratulations to Paddy Cox, from Castlecomer, one of our patients who recently received a kidney transplant. We wish him continued good health and success with his unique clothing business for

dialysis and other patients, Dialize Clothing, which he started up during the beginning of lockdown, and since then it has continued to grow from strength to strength.

THANK YOU

We are truly grateful to everybody who has contributed to the Kilkenney Branch by way of fundraising or donations. Although our face-to-face meetings have not yet resumed, our support is always available, so feel free to call or text the Kilkenney Branch Officers:

John Lacey, Chairperson,
085-1328255

Hugh Byrne, Board Member,
086-8938800

Therese Hanrahan, Treasurer,
087-7796428

Anne O'Grady, Secretary,
087-9232190



John Lacey, Chairperson of the Kilkenney Branch, receiving his 5th COVID-19 vaccine and record of vaccination, from William Mulhall, Pharmacist at O'Shea's Pharmacy, Kilkenney.





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Greetings!

Hello to all our members. We hope everyone is doing well and looking forward to a nice summer ahead.

Although our in-person meetings have not resumed yet, our support is always available, so feel free to call or text 087-6243367/087-9392148 or email: ikaclare@gmail.com, or message us on the Clare IKA Facebook page.

CONGRATULATIONS

The IKA Clare Branch extends heartiest congratulations to our Secretary, and kidney transplant recipient, Noretta Clifford and her husband Shane McGoldrick, on the safe arrival of their beautiful twin girls Éabha and Croía in February.



Noretta Clifford and her little girls pay a visit to the 'Gift of Life' Memorial in Ennis.

CLARE

By PEGGY EUSTACE & NORETTA CLIFFORD



Bill and Pat Dale present the cheque for €250 to Gerry Moran (centre).

We are delighted to hear mother and babies are doing very well. Their brother Séimí is delighted with his two new baby sisters. Welcome to the world little ones.

FUNDRAISERS

We thank, once again, IKA Clare Branch friends Bill and Pat Dale, who recently presented our Treasurer, Gerry Moran, with a cheque for €250, the proceeds of their table top and car boot sales in the UK. As they now retire we extend our best wishes and a very big 'thank you' to them for their time and effort in multiple fundraising events, over the

years, for the Branch. We also thank their many friends in the UK who supported these fundraisers.

Another long-time friend and fundraiser for the Clare Branch, Gerardine Quinlivan, also recently raised €350. Therefore, we extend another sincere 'thank you' to her for her time and effort, and indeed those that supported her.

Many thanks also to Joe Hodgins of Architectural Facades, Grangemore, Tynagh, Loughrea, Co Galway who presented the Branch with a cheque for €300. Sincere thanks also to him.

ENNIS 'GIFT OF LIFE' MEMORIAL

The 'Gift of Life' memorial, located in Ennis, pays tribute to organ donors and their families who have made the 'gift of life' possible, recipients of transplants, and those waiting for a transplant.

The memorial grounds encompass three themes:

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

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

Remembrance: where all donors can be remembered with love.

Recently, new plaques with the following messages were added to the back of the memorial stone and the surrounding boulders. These enhance the message of thanksgiving and organ donation.

CLARE



'A Legacy of love'; 'Míle Buíochas'; and 'Organ Donation – The greatest gift, truly cherished by transplant recipients'.

We greatly appreciate the work that the members of Ennis Tidy Towns have carried out, on our behalf, at the Memorial to organ donors in Ennis. As our patients and many of our members are mainly in the vulnerable and older age group, Ennis Tidy Towns committee has offered to keep a watchful eye for the upkeep of the memorial. The memorial is a tribute to the generosity of our organ donors and helps to raise organ donor awareness.

MEDIA HIGHLIGHTS

We thank Tulla based Kirsty Donnellan, whose young daughter Scarlett was an organ donor. RTÉ's *Nationwide* visited Clare recently where they interviewed Kirsty to promote organ donation and to remember Scarlett on what would have been Scarlett's 21st birthday.

The programme showed Kirsty speaking with Transition Year students at St Joseph's Secondary School, in Tulla, on organ donation. She spoke fondly of her wonderful daughter and the 'gift of life' that her daughter bestowed onto others through organ donation.

Following this, *Nationwide* featured Kirsty and Scarlett's friends on a visit to our memorial to organ donors in Ennis, where she met with IKA Clare Branch Board Member Sharon Fitzgerald, Treasurer Gerry Moran and Chairperson Peggy Eustace.

It was a truly beautiful tribute to Scarlett while highlighting the all-important organ donation. Thank you to a brave and wonderful

woman, Kirsty, for all your campaigning.

Many thanks to dialysis patient Geraldine Frost whose story featured on the *Clare Champion* during organ donor awareness week.

Thank you to Professor Austin Stack, University Hospital Limerick, and kidney transplant recipient Patrick Eustace for their interviews on Clare FM to mark World Kidney Day.

Thanks also to Nuala Conway from Killaloe in Co. Clare, who also spoke on Clare FM during Organ Donor Awareness Week, about her family's Christmas break away to the IKA holiday home in Tralee.

Her 13-year-old son Jayden recently underwent a kidney transplant, thanks to his kidney donor stepdad Denis. We wish them both a quick recovery.

She said they were delighted to be able to avail of a holiday away in the beautiful spacious Tralee holiday

home, all decked out with Christmas decorations. Nuala also thanked the wonderful volunteers who make it all happen.

SYMPATHIES

We extend our sincere sympathy to the family of the late Mannix Berry who passed away recently. As a Branch member Mannix always gave generously of his time to help with our organ donor awareness campaigns and assisted with our Church Gate collections. His family kindly requested donations to the Irish Kidney Association.

We also extend our sympathy to Deborah Cervi at Donor House and all the Lynch family, on the sudden passing of her dad Martin.

May their gentle souls rest in peace.



Gerry Moran and Peggy Eustace at the 'Gift of Life' Memorial.



Peggy Eustace, Clare Branch IKA being filmed at the 'Gift of Life' Memorial in Ennis by Matt and Marian for RTÉ Nationwide.



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On May 4th, National Honorary Treasurer Eddie Flood represented IKA Westmeath at a Car Draw, run by Athlone GAA Club. Westmeath IKA was a beneficiary of this draw and has received a donation of €5,500, a percentage of the proceeds.

Many thanks to Athlone GAA for this very generous donation.

Congratulations to Athlone GAA Club member and former player, John Egan, who underwent a living donor kidney transplant last year, on his recent nuptials to his bride Traci, over the June Bank holiday weekend. We wish them good health and a lifetime of happiness together.

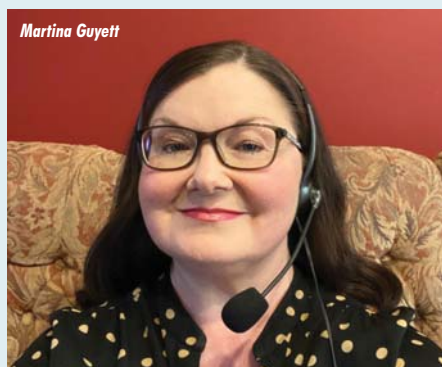
Organ transplant recipients from Westmeath were part of the launch of the IKA's annual 'Run for a Life' event. See page 22-23.

Well done to kidney transplant recipient Martina Guyett from



Eddie Flood (centre) prepares to draw the winning ticket.

Martina Guyett



Rochfordbridge in Westmeath, for being invited back, for a second year in a row, as a guest speaker on her health experience at a nephrology lecture for UCD final year medical students, which was held at St. Vincent's Hospital on April 20th this year.

Last year the event was held via

Zoom and this year it was in-person.

Martina also did an interview on Newstalk radio station, in relation to the announcement about the removal of masks mandate for air travel and concerns by patients in the high risk group for COVID-19.

No stranger to being on national radio, Martina won a prize of a mobile phone on the 2FM Zamparelli Show for telling her story in a competition for listeners to share their story about their 'best phone call ever'.

On June 6th, she phoned in to tell her story about the call she received to come for a kidney transplant and it was the outright winner. She said 'it was a great opportunity to promote organ donation'.

LEITRIM

By CATHRIONA CHARLES



Staff and young people in Leitrim Outreach with Cathriona Charles and Frank Heslin.

Our Branch gave two organ donation awareness talks, one for Leitrim Outreach and another in Mohill Community College. It's great to see the interest the young people have in this topic and hopefully they'll continue to spread the word **#havethechat**

Enjoy your summer everyone and remember to apply the sunscreen.

Below: TY students from Mohill Community College with Annetha Keirnan and Cathriona Charles.

The Branch Officers will remain the same for the following term:

Chairperson: Annetha Kiernan
Treasurer: Frank Heslin
Branch Secretary: Cathriona Charles
Board member: Cathriona Charles

Hopefully the next couple of years will be easier than the last few.



DUBLIN NORTH

By PATRICIA MACKENZIE

Greetings all.

We hope that everyone is keeping well as we move into the Summertime.

The AGM of the Dublin North Branch took place on Monday, 30th May 2022 on Zoom.

North Dublin Branch Chairman Colin Mackenzie is stepping down, after 3 years, from the role of National Honorary Chairman, and he is also stepping down as a member of the National Board after serving for 11 years.

The New Dublin North Branch election results, all of which were unopposed, are as follows:

Chairperson: Colin Mackenzie

Treasurer: Brian Carney

Branch Secretary: Colette Fox

Board Member: Chloe Kinahan

We extend our best wishes to Colin, Brian, Colette and Chloe in their roles.

CONDOLENCES

We extend our sincere condolences to all those who have lost loved ones since our entry in the previous issue of *SUPPORT*.

We acknowledge the passing of Angela McKinney, ex-Board Member and founding member of the Sligo Branch.

Our sympathies are extended to Deborah Cervi at Donor House, and her family, on the sudden passing of her dear father Martin Lynch.

We extend our sympathies to the members of Dublin South Branch on the loss of their Chairman, John Semple, and to his family also.

May they all rest in peace.



Amy, her sister Sophie and mum Claire Cody.

FUNDRAISER

A fundraiser took place recently at Skerries Tennis Club which raised nearly €600 for the IKA. Our thanks to the organisers Claire Cody and her kidney transplant recipient daughter Sophie. Well done to you both.

FAREWELL

I was appointed Branch Secretary in April 2006, while on dialysis. Sixteen years later and transplanted fourteen years, I would like to express my thanks to my donor, my donor's family, medical staff, Beaumont Hospital, Dublin North Branch members, and my family, for all the support I received during all these years.

In my role as Branch Secretary I reported on everything from fundraising, garden parties, tours in earlier years, branch meetings, bereavements, visiting speakers,



concerts, recent transplants, visiting consultants' talks, renal counsellor talks, living kidney donor families stories, sporting trips and achievements, any other news. I have had a great time.

When I became Secretary way back, I resolved that there would always be an entry from Dublin North in *SUPPORT*, because as a patient myself, I know how we love to turn to our Branch section for the latest local news and information.

I kept my word 99 per cent of the time!

I am delighted to pass on the baton to Colette Fox, an enthusiastic member of Dublin North who takes over the role of Secretary. I'm confident that she will look after you all very well. Colette, wishing you the best for the future from your outgoing Secretary.

My thanks to Donor House staff, especially Ashling and Esther, Dublin North members, and to various committees, for all the continued support over the years.

Thank you everyone and have a happy summertime.

Take care.

Patricia



Participants in Skerries Tennis Club fundraiser for the IKA



Debbie McDonald and her team at Wellstone Dialysis Unit in Wexford organised an afternoon walk for patients, staff and families in Johnstown Castle on Sunday, May 15th.

It was a very enjoyable afternoon and refreshments were available for all in the café after the walk.

A total of €500 was raised on the day for the Wexford Branch.

Please continue to follow us on our Facebook page.

WEXFORD

By MARIA DONLON



A great turn out from patients and staff from Wellstone Dialysis Unit Wexford for a walk in Johnstown Castle.



CORK

By SALLY NAGLE

Over the last few months in the Cork branch we have continued our monthly support meetings and had our last one for the summer in early June. We will be back in September and looking forward to seeing old and new faces again.

On June 18th-19th we had a stand at the Cork Summer Show and we were delighted to be able to have this opportunity to spread awareness around the importance of organ donation for transplantation.

We wish all our Branch members, patients and their families a wonderful summer, and look forward to seeing you all in September.



Meeting the Lord Mayor of Cork City, Colm Kelleher, are members of the Cork Branch, to promote Organ Donor Awareness Week at The City Hall.

If anyone needs to contact us over the summer please feel free and we will help you as best we can. **Ph: 086-2755754 or email: secretarycork.ika@gmail.com**

DUBLIN EAST & WICKLOW

By BERNIE DWYER



From left: Jason Sinclair, Martin Geraghty winner of the Virgil van Dijk print presented by artist André Mooney.

Hello and welcome to our members and readers from East Dublin and the Garden of Ireland.

CONDOLENCES

Our Branch sends our sincere condolences to holiday coordinator at Donor House, Deborah Cervi and her family, on the recent sudden passing of her beloved father Martin Lynch. May he Rest in Peace.

FORTHCOMING EVENTS

Looking towards the Summer months we have some news and stories to share...some pending. After the elections by postal voting we are happy to announce that we will have some new faces on our Committee and look forward to a new start and fresh ideas in the Autumn.

As always we urge members to join our Zoom meetings and look forward to our first face-to-face again.

Please watch our Facebook page 'Dublin East and Wicklow IKA Branch' for news of Declan Mulhall, who is doing a 175 km cycle in July for the IKA.

As mentioned previously in the Spring issue, at 9am on September 24th, the Dublin Mountain Running Club is holding a 5km, 10km run/walk in support of 17-year-old dialysis patient Cillian Doyle. Funds raised are for the IKA.

Our friends in The Kilmacanogue Horse Show will return with a full show on July 23rd. If anyone would

like to be involved as a volunteer steward, please contact us for this very popular event.

Our thanks to André Mooney for kindly donating a brilliant 'Virgil van Dijk' print to a recent Stars of Eireann GAA Club, for a Walk with Stars fundraiser. Our thanks to Stars of Eireann who were inspired by club member 17-year-old Cillian Doyle, who is receiving dialysis treatment, to direct its fundraising for the Irish Kidney Association

OTHER NEWS

A couple of members attended the Punchestown Charity Race on Saturday April 30th. Well done to organiser James Nolan. Some of the funds raised will help future projects for renal patients through the IKA.

And finally, Michael Dwyer teamed up with Tony Gavigan, a transplant



Mick Dwyer and Tony Gavigan.

patient from Meath, to take part in the Mitchelstown Golf Classic 2022 to raise funds for the Cork Renal Support Centre. The duo didn't win any prizes but they really enjoyed the day. Well done to all involved.

Finally, we never forget our members who are waiting for a transplant or who may be ill or in hospital. We are there for you so keep in touch and find out how the IKA can help.

We hope you have a good Summer and remember to use loads of factor 50.

Some renal/transplant guests at Punchestown Charity Race with James Nolan (extreme right).





On Thursday, June 23rd, a plaque was unveiled at the 'Circle of Life' Commemorative Garden for organ donors in Salthill. The plaque was dedicated to the many volunteers throughout Ireland, and particularly in Galway, who led the promotion of organ donation since 1978.

Those present at the event included founders of the garden Martina and Denis Goggin, members of the IKA Galway Branch including founding IKA Galway Branch member Angeline Cooke, and some volunteers who have been involved in the ongoing maintenance of the garden.

On Sunday, March 15th, 2020, the staff and patients of the B Braun Wellstone clinic organised a fundraising walk along the promenade in Salthill. This was the last day before the nation shut down due to COVID-19 and it was also one of the wildest days with wind, rain and high seas. Thank you to all who dared undertake the walk.

Funds raised were stored in a safe and after restrictions were eased Wellstone released the cheque and presented it to the IKA Galway

GALWAY

By PEADAR Ó HICÍ



Denis & Martina Goggin, creators of the 'Circle of Life' Garden with members of the Galway Branch of the Irish Kidney Association: Bernie Coyne, Angeline Cooke, Peadar Ó hÍcí and Chris Curley. Photo courtesy of Joe Shaughnessy, Connacht/City Tribune.

branch representative Eoin Madden and Peadar Ó hÍcí.

The management and staff of a company, LifeWave, in Athenry, Co Galway selected the IKA as the recipient of €4,000, raised in their Christmas Charity Fundraising project. LifeWave is a US company producing wellness patches, employing over 120 people and is a growing presence there. It is planning to increase production there. The Galway IKA is very grateful for the donation received.

Trish Griffin organised a family fun day in the village of Menlo, Co. Galway before Christmas 2021 which raised €4,058 for the IKA.

The event was to honour the memory of toddler Tess Lawless who sadly passed away with kidney complications at the age of 14



Trish Griffin (left), Benny Lawless with son Billy, Peadar Ó hÍcí, Paddy Duggan and Nicola Lawless.

months, and her parents Benny and Nicola Lawless nominated the IKA as the charity to benefit from the proceeds raised.

Paddy Duggan played a pivotal role as Santa Claus during the festive event.

Thanks to the Lawless family and all the people of Menlo who supported the event and helped out on the day.



Staff from B Braun Wellstone, Galway presenting a cheque for €3,000 to Eoin Madden, Chairperson of Galway Branch (right) and Peadar Ó hÍcí (left).



The management and staff of LifeWave presenting the cheque for €4,000 to Eoin Madden and Peadar Ó hÍcí.

GALWAY



Andrew Ishmael presented a cheque for €11,018 to the Galway IKA branch.
Pictured are: Peadar Ó hÍcí, Andrew's mum Jenny and girlfriend Beth, Andrew (centre), Eoin Madden and Chris Curley.

Andrew Ishmael, is a 27-year-old dialysis patient attending Merlin Park Galway for his treatment. In recent months he raised over €11,000 for the IKA, from a variety of activities such as walks, runs, cake sales, etc.

Our thanks to the Silke and Ishmael families and his girlfriend Beth Hanna for all the effort they have put into helping Andrew with this magnificent achievement in fundraising.

It was particularly thoughtful of 8-year-old Finn McNamara from Monivea in Co. Galway, who donated the considerable sum of €2,060, the money he received from family and friends for his Holy Communion, to the Galway IKA branch.

Finn's granddad is on dialysis and the young boy wished to support the work of the IKA and help patients like his granddad back to full health.

Watched on by his parents Sinead and Robert and his sister Inis, Finn, a pupil at Monivea National School, was presented with a certificate in recognition of his generous deed.



Finn with his certificate.



Sinead, Inis, Robert and Finn McNamara with Peadar Ó hÍcí and Eoin Madden.

DUBLIN SOUTH

By PATRICK SNYED

John Semple, Chairman of the South Dublin Branch passed away on May 26th, aged 68 years.

Here are just some of the postings to our WhatsApp page which indicate the high regard in which he was held by the members of the Branch.

Hi all, it is with deep sadness I have to inform you John Semple passed away this morning. I'm heartbroken. B

Really sad news – I still can't believe it – John was really great – at our meetings he always gave time to everyone and was kind and sympathetic to all – he will be hugely missed. May he rest in peace. M

Very sorry to hear this news. John was a lovely guy indeed and made time for everyone despite his own health challenges. So sad that he is no longer with us. May he rest in peace. G

I'm so sorry to hear that. I never knew him but heard you speak fondly of him at the last meeting. May he RIP. T

So sorry to hear that. John was some fighter. RIP. P

So very sorry to hear that sad news. I remember John from meetings pre-COVID-19 and he was always so helpful and enthusiastic about all events in the IKA.

May he rest in peace. N

What a sad day. Very shocking news. John is a huge loss to us all – a fine man who was encouraging, caring and thoughtful. Sincere sympathy to Margaret his wife and extended family. May you rest in peace John. L

Below is from the IKA Facebook page -

Everyone at the Irish Kidney Association would like to express our sincere sympathies to the family and friends of our Dublin South IKA Branch Chairperson, John Semple, who has passed away. We are very appreciative for his contributions to the organisation over the years. May he rest in peace.



LIMERICK

By SHAUN FALOON



Limerick Renal Team with Dr. Austen Stack.

The Limerick Branch supported a Patient Information Evening on *Chronic Kidney Disease, The Lived Experience*. This was organised by the Renal Team at the University Hospital Limerick and held at The Auditorium, The Clinical Education and Research Centre (CERC), University Hospital Limerick on Wednesday, June 1st.

The presentation provided practical, patient-focused

information about all aspects of different types of dialysis. Speakers discussed their personal experience of each treatment, including in-centre haemodialysis, home haemodialysis, and peritoneal dialysis.

There was an excellent turnout of 45, and the opportunity to mingle afterwards, with refreshments, and to ask questions of the team regarding treatment types.



Peritoneal Dialysis display by Renal Nurse Orla.



Clinical Renal Nurse Fiona Brouder and Dr Casserly (right) with some participants.



OFFALY

Some public sites in Offaly were lit-up in Green in support of the Organ Donor Awareness Week campaign, including O'Connor Square, The Library and the Town Hall in Tullamore.

Pictured at O'Connor Square, from left, Nora Bracken holding a photo of her deceased organ donor brother, the late Paddy Johnson from Clara; the late Paddy's partner Rosie Buckley from Clara; Jerome Molloy, Kinnitty, with his wife Phil Molloy, a kidney transplant recipient; members of the Offaly branch of the Irish Kidney Association, Mary Young from Mountbolus and Dermot Glynn, a kidney transplant recipient, Tullamore; and Cllr. Anthony McCormack, Cathaoirleach, Tullamore Town Council.





I hope you are all well and enjoying the summer. For those of our Branch members who have had a difficult time recently, we hope that by the end of the summer, there will be a positive improvement.

On Wednesday, June 1st at 6.30pm, in Thurles, Co Tipperary, it was my pleasure to meet seven cycling buddies from Upperchurch Drumbane Cycling Club, when we gathered at Liberty Square in Thurles to launch their Mizen2Malin Ultra Cycle Challenge, with proceeds going to the Tipperary IKA Branch.

The 600km distance cycle left Mizen Head in Cork on Saturday, June 25th and finished up 24 hours later at Malin Head in Donegal on Sunday June 26th.

Chief organiser of the event, and one of the seven cyclists, is Francis Hogan from Templemore. Francis has Polycystic Kidney Disease. With 25% kidney function he advocates for physical activity and its importance in helping to slow down the progression of kidney disease. At the time of going to press the cyclists far exceeded their initial

TIPPERARY

By ORLA HOGAN RYAN



Seven cyclists at the Mizen2Malin launch with family members and Orla Hogan (back centre), Tipperary IKA branch.

fundraising target of €7000 with funds still coming in on their online fundraising platform www.justgiving.com/fundraising/francishogan-549-hogan

There will be a full feature on the cycle in the Autumn issue of *SUPPORT*.

We are delighted to hear that the planning permission has been approved for the Support Centre in Cork, which will benefit patients from Munster and beyond.

We are looking forward to getting together outdoors for an assembly shortly, and meeting our members after a long time without seeing each other in person.

We encourage readers to keep abreast with news on the IKA's website and its social media.



Orla Hogan Ryan who has undergone 4 transplants, two from deceased donors, visited the 'Circle of Life' Commemorative Garden for organ donors in Salthill. She is pictured (left) at the garden with Sinead McKieran.

ACCOMMODATION TELEPHONE BOOKING HOURS

087-4169907



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

ROUTINE APPOINTMENTS

The accommodation phone line is now open: Mon. to Frid. 9:30am to 5:30pm.

EMERGENCY APPOINTMENTS

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

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



IKA DIRECTORY



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

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

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

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

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LAOIS

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