

SUPP RT

AUTUMN 2021

Flying high for the IKA



AUTUMN

giveaway

5 X €80

GIFT CARDS FOR

peter mark

SEE PAGE 41

IRISH KIDNEY ASSOCIATION CLG

(Company Limited by Guarantee)

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

TELEPHONE: 0818-543639 (KIDNEY) OR 01-6205306 • WWW.IKA.IE

FOR ORGAN DONOR CARDS FREE TEXT DONOR TO 50050

CHARITY REGISTRATION NUMBER 20011260

Editorial...



In my last editorial in SUPPORT's summer issue, I began with the good news that the vaccination rollout had quickened pace and things looked very hopeful. However, in the words of Professor Kingston Mills, "The only certainty about this pandemic is the uncertainty". We know vaccination works and provides protection, but unfortunately, it is now very clear, that the level of protection provided is not as high for transplant and dialysis patients.

The Irish Kidney Association is working closely with the HSE to address this and it is very likely that a 3rd additional vaccination shot for vulnerable patients will happen before our Winter SUPPORT magazine issue. We advise people to continue to observe the safety guidelines and avoid crowded and poorly ventilated spaces. For more details see article on pages 4-5.

The rollout of the vaccination programme to 12-15 year olds which began in August was well very received amongst the families of youngsters returning to school in September with a very high uptake. One teenager happy to receive her vaccination was kidney transplant recipient Amber O'Rourke who is going into her second year at secondary school. You can read about her on pages 10-12.

I hope you will find it as uplifting as I did to read about

young transplant and dialysis children returning to national school with their photos provided by their proud parents. Pages 22-24.

Our holiday homes in Tramore, Tralee and Killarney have successfully re-opened and it gives us great pleasure to share photos of some families who availed of holidays (see page 50).

I had the tremendous pleasure of visiting the holiday homes for the first time since my appointment to the IKA and physically meeting branch committee members in Waterford, Cork, and Kerry. I really enjoyed my visits.

It is very inspiring to chat to such dedicated and committed volunteers who work so hard to make sure kidney patients enjoy their holidays. They are the heart and soul of the Association and I learned so much from them. They have excellent ideas which will help make our Association even better.

The Board has reviewed all the options for plans for the development of the IKA's Cork properties and decided that the most cost-effective way to proceed was to retain both houses located side by side and to create a two-bed apartment for commercial renting which will offset the costs of running the Cork Support Centre. Planning permission documents and detailed costings are now being

Contents...



FRONT COVER

Inspired by a kidney transplant colleague, Helen Milligan, Managing Director of GEM Oils in Cavan takes a giant tandem leap out of a plane for charity with skydive instructor Lukasz Kucharski

Photo: Gavin Brookfield

- 2 EDITORIAL
- 4 UPDATE ON VACCINATIONS
- 6 SNAP-SHOT OF A PERFECT HEALTH SERVICE
- 7 ANNUAL GENERAL MEETING
- 8 SUMMARY OF STRATEGIC PLAN 2021-2025
- 10 TRANSPLANT TEEN AMBER GETS GREEN LIGHT FOR VACCINATION
- 13 RENAL SUPPORT CENTRE
- 13 IKA CHRISTMAS CARDS
- 14 CHRONIC KIDNEY DISEASE AND HOME THERAPY OPTIONS
- 17 DAWN DAVIN, PHARMACIST, NATIONAL RENAL OFFICE
- 18 NOVICE CYCLIST TAKES ON 100KM CYCLE
- 20 VULNERABILITY
- 22 BACK TO SCHOOL
- 25 MEETING THE ACCOMMODATION NEEDS OF PEOPLE WITH DISABILITIES

prepared.

The Board realises that much of our accommodation is located in the South and Southeast and we need to develop additional supports in the West/North West. So, working with branches, this will be a priority for 2022. I plan to visit the West and Northwest and meet Branch Committee members before the end of the year.

We held our virtual national AGM on Saturday, September 4th. See page 7 for a report.



The Association's new strategy was discussed with members when the formal agenda of the AGM was finished. This new Strategic Plan, will make sure our support foundation is strong and secure, so that patients can safely enjoy the services we provide, and we can maintain the trust of our contributors. We also plan to improve and expand the services we provide. Full report on pages 8-9.

We held an online zoom session for members on July 5th where we looked at the ideal type of healthcare service for patients. See page 6.

On September 27th, our next online zoom session for members will look at home dialysis.

We have also worked closely with St. James' Hospital on their new smartphone app. This provides support for kidney patients. You can see the useful videos we developed on our website about our services and how kidney disease can affect mental health.

We had a meeting with the management of Beaumont Hospital to discuss the return of the Support Centre to our control since it was sequestered in March 2020 to make emergency provisions around COVID-19, (page 13).

Planning is also now well underway for the 2021 Service of Remembrance and Thanksgiving which will be held virtually for the second year in a row and filmed at Our Lady Queen of Peace Church, Merrion Road, Dublin. The date of transmission, yet to be advised, will be widely advertised soon.

We have several changes in staff. We bid farewell to Amanda Bissett in June as she moved on after over three years of loyal dedication to the organisation. We wish her well for the future. We welcomed Fiona Aherne as the new Patient Services Manager whose appointment notice features on page 52. We also welcomed a new temporary receptionist.

Given that a large proportion of

our community tends to be older, COVID-19 does have a bigger impact and we have heard of more deaths in this demographic. We offer our deepest condolences to all of you who have experienced the loss of loved ones recently.

Many of our more senior members are not online and may not be receiving our emails or taking part in our online forums. With Government services increasingly moving online, and the restrictions of COVID-19, such people are at a huge disadvantage. So we encourage you to get online using free help from Age Action Ireland. All you need is a smartphone. More information about this free service can be obtained from Age Action Tel. 01-4756989.

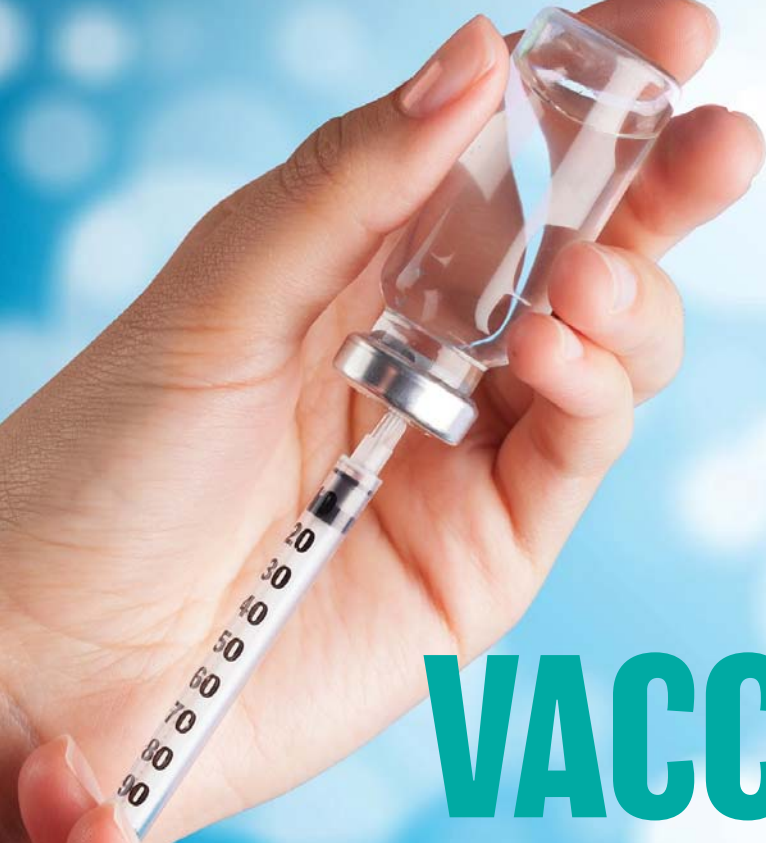
As you can see, there has been no summer lull here and we continue to work hard to support you our valued members.

We hope you enjoy reading this issue which is peppered with several hair-raising stories about children and adults shedding their tresses for charity and to raise awareness for organ donation. We are delighted that Peter Mark's sponsorship of giveaway prizes for 5 lucky winners will receive €80 gift cards to redeem against hairdressing services or product from any of their 69 stores salons nationwide. Best of luck! Stay Safe.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

26 VIRTUAL RUN FOR A LIFE
28 IRELAND LAGS BEHIND IN INTERNATIONAL BEST PRACTICE IN VASCULAR ACCESS FOR DIALYSIS PATIENTS
30 DUBLIN FAMILY'S SIX-IN-A-ROW TRANSPLANTS
32 FLYING HIGH FOR THE IKA
36 WHERE THERE'S A WILL...
38 TEENS CUT TRESSES FOR CHARITY
41 AUTUMN GIVEAWAY
41 AL AMYLOIDOSIS SUPPORT GROUP IRELAND
42 WATERFORD TRIO IN HEAD SHAVE FOR HUGH
43 TAX RELIEF ON MEDICAL EXPENSES INCURRED BY KIDNEY PATIENTS
44 THERE'S MORE TO FIBRE THAN YOU THINK!
46 LEADING FROM EXAMPLE
46 SPORTS UPDATE

48 EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION (EODD)
48 ANNUAL SERVICE OF REMEMBRANCE AND THANKSGIVING
49 BROTHERLY LOVE
50 HOLIDAYS RETURN
51 INTERNATIONAL WEBINAR ON PKD
51 TAXI TALES - 'ALFRED'
52 STUDY RECOMMENDS INTRODUCTION OF EXERCISE PROGRAMMES TO HAEMODIALYSIS UNITS
52 FIONA AHERNE, IKA PATIENT SERVICES MANAGER
53 TRIBUTE TO THE LATE VERA DWYER AND IAN O'DOHERTY
54 AROUND THE BRANCHES
63 MEMBERSHIP FORM
64 BRANCH SECRETARIES



UPDATE ON VACCINATIONS

**BY COLIN WHITE,
NATIONAL ADVOCACY
& PROJECTS MANAGER**

As I write, almost 90% of the national adult population is vaccinated and the programme to vaccinate 12-15 year olds is progressing. As we start September there have been new announcements that will impact our community directly.



TO SUMMARISE THE NEW INFORMATION:

- Transplant recipients and people on dialysis/an eGFR of less than 15 are listed amongst those who will shortly be invited to avail of a third vaccine shot
- The third vaccine shot will be an mRNA vaccine
- The third vaccine shot will be offered to people aged 12 and over in the clinically extremely vulnerable group
- NIAC announced the intention to give a third vaccine dose to the clinically extremely vulnerable and now the HSE is working on the plan to deliver on that intention. It is expected to be announced 'shortly.'

We recently had the opportunity to state the case for kidney patients and the immune-compromised to be prioritised for a third top-up shot in an interview on Newstalk radio. This was against the back-drop of the World Health Organisation (WHO) recommending that countries considering a booster shot for their general population should hold off whilst countries who have not started their vaccine programmes get an opportunity.

It was gratifying to hear our point being raised with a WHO official on the same radio show the following day and he clearly acknowledged the need for a top-up shot for people who are clinically extremely vulnerable (including transplant recipients and

people on dialysis) – separating them out from a national booster programme.

Ireland may have gotten off to a stuttering start in terms of the vaccination programme but now, when comparing ourselves to our European neighbours, we are second only to Malta in relation to percentage of the adult population vaccinated.

This is a positive foundation upon which to build but the journey is not yet over. The efficacy of the COVID-19 vaccines rates very highly when compared to some other vaccines but 90% coverage means that it works for 9 out of every 10 people in the general population. This means that 1 in 10 people are still vulnerable.

We are also hearing of 'breakthrough infection' which is when someone who is vaccinated still gets the virus. It has been noted in a number of research papers that the immune-compromised and those not mounting the typical immune response to the vaccines have been found to 'shed the virus' for longer than the average person and there is therefore an increased risk of the virus mutating. This public health argument helped to strengthen the case for prioritising these categories of patients for a third shot.

This can be very discouraging at first glance but we must look deeper. Rather than solely focusing on the rates of infection we need to also look at the outcomes. The vaccines are

having a significant impact in relation to reducing the severity of illness and the number of deaths.

Recent research in the UK, the US, France and other countries, now allows us to look at the impact of the vaccines specifically on the renal community.

There are a number of key observations to draw out from this research:

- COVID-19 vaccination offers the best available protection to clinically extremely vulnerable (CEV) kidney patients and should be recommended to all kidney patients.
- Some kidney patients may not have achieved full protection from vaccination with 2 doses of an approved vaccine.
- Extensive international data has confirmed that protection can be considerably improved amongst the clinically extremely vulnerable by receipt of a third mRNA vaccine dose.
- Whether vaccinated or not, people on dialysis and transplant recipients (as well as all others in the clinically extremely vulnerable group) should continue to:
 - Wear a face mask
 - Wash hands regularly
 - Avoid crowded indoor places
- Healthcare facilities should maintain a fully protective stance in dialysis units and there must be safe pathways for dialysis patients, transplant recipients and patients



Kidney transplant recipient Luke Herlihy (13) (right) and his brother Sam (12) from south county Dublin. They are among the 12-15 age group to have recently received the Pfizer BioNTech vaccine.

who are on or have recently received significant immunosuppression for autoimmune kidney disease. This must include the provision of COVID safe hospital transport for CEV kidney patients.

Society is 're-opening' and there is a general expectation that after such an extended period of restrictions that many of us will find re-engagement raises our anxiety levels. The general advice at this point is coming across as cautious re-engagement.

We are already seeing employers asking their staff to return to their place of work. If you feel uncomfortable about returning to your place of work, you are entitled

to ask your employer to carry out a risk assessment specific to your needs.

Equally, share any concerns with your consultant as they will know the specifics of your medical condition and will be able to advise accordingly.

We are not there yet but we are moving forward and there is research taking place internationally around how we can best live with the virus in the community. We will continue to monitor all this research, ask questions and share information. The answers to all our questions are not there yet but it is encouraging to note that evidence based advocacy is having an impact on government policy.



Kidney transplant recipient Aido O'Brien from Cork (13), getting his vaccination.



Sophie Cody (age 15) and her kidney donor mum Claire, from Skerries, Dublin. (Inset) Sophie displays her vaccine card.



Snap-shot of a perfect Health Service

At a July Zoom meeting of Branch Officers and members our CEO, Carol Moore, asked everyone to imagine that it is the year 2035, we have the 'perfect health service' and they are to describe it to someone who is newly diagnosed with End Stage Kidney Disease.

The purpose of the exercise was to get people to reflect on what is important to them in the health service from diagnosis to treatment and beyond. With a mix of patients who have been availing of renal services for a long time, those who have needed the service more recently and family members, we were confident that we would get a broad overview of the key issues.

Several breakout rooms were used so that participants could discuss in smaller groups and the groups then all came back together to share their thoughts. An overview of the discussions is below.

APPROACH TO HEALTHCARE

- A partnership approach to healthcare with the patient (and family if relevant) at the centre of everything and involved in shared decision-making.
- Healthcare professionals should recognise many patients have trauma as a result of the diagnosis and should provide "trauma responsive services" For example, Patients should not have to keep re-telling their stories
- In a crisis, there should be access to all diagnostic tools, immediately.
- Healthcare to be more proactive

**By
COLIN WHITE**

than reactive. More information on prevention of kidney disease is needed.

- There should be clear organised pathways to access all services not just healthcare. The concept of intersectionality was raised. This is where many factors combine to make it harder for people to manage their illness, e.g. fear of losing home due to inability to pay mortgage. Healthcare needs to consider all the factors affecting people's lives.
- Education of patients and medical professionals to ensure that any messaging or reporting of symptoms is properly understood by both parties. Ensure that it is personalised and appropriate to each individual patient.
- Empathy rather than paternalism will encourage patient engagement. Treat the person, not the patient.
- The provision of a medical card or Long-Term Illness card for all End Stage Kidney Disease patients. It is a life-long illness requiring life-long treatment.

MOVING THROUGH THE SYSTEM

- Equity of access to treatments no matter where people live in the country.
- Identify and make clear the care pathway from diagnosis through the various treatment options.
- Single point of contact – a case

manager who can facilitate the patient in understanding what is going on and help ensure joined up thinking if there are more than just renal issues being addressed.

- Advice on how to get the best out of clinic appointments and your relationship with your healthcare professional.
- Psychological support throughout the process as the journey through a life with ESKD has many peaks and troughs.
- Access to a structured advocacy service, if patients are unsure of their treatment choices or just want an objective explanation of their options.
- If attending the Emergency department, clearer protocols for treating patients needed.
- As part of highlighting the value of peer support, information about the services of the Irish Kidney Associations should be provided early on in the health journey. The wide array of IKA services complements services provided by medical professionals and such information about what is on offer to patients, and their families, should be shared throughout the health journey.

DIALYSIS

- Dialysis units need to be staffed adequately with the timing/provision of transport to be matched with people coming on and off machines.
- Greater promotion and explanation of the treatment types

Continued next page



AGM

Saturday 4th September 2021

The Annual General Meeting of the Irish Kidney Association CLG was held by virtual zoom on Saturday September 4th, 2021

The National Chairman, Colin Mackenzie, welcomed the members to the AGM. A minute's silence was observed for all deceased members and donor families.

There were apologies noted.

The quorum of 20 had been set for the AGM at the board meeting on the previous evening, Friday September 3rd. More than 70 people attended at least part of the meeting including staff.

The minutes for the 2020 meeting were read and adopted.

Eddie Flood, National Treasurer, read the 2020 Accounts report. The accounts show a deficit for the year of €361,000 in comparison to €422,000 in 2019. So, despite the fall in income, because the Board took action to reduce expenditure



the deficit was reduced by €61,000.

The full accounts can be found on the Association's website.

There were no queries on the accounts.

The Directors were given the authority to fix the remuneration of our auditors PKF O'Connor, Leddy & Holmes Limited.

The Chairman welcomed the members to the AGM and read his report to members. 2020 was a very challenging year for patients, healthcare professionals, staff and the Association. The Association had however shown considerable

flexibility in responding to these challenges and continued to support patients well.

Once the formal AGM was over, there was a short break. The CEO outlined the new strategy (see pages 8 to 9) and members then went into breakout groups to discuss how they could support the implementation of the new strategy. Members then returned to the main group and there was a very good discussion on the new strategy.

The strategy was very well received, with the general consensus being that it covered all the main issues of concerns to members. It was acknowledged the strategy was very detailed and set challenging targets and thanks were expressed to staff, the Board and all who participated in developing a very complete strategy.

Thanks to everybody that attended.

SNAP-SHOT OF A PERFECT HEALTH SERVICE *contd...*

available, especially the home therapies (peritoneal dialysis and home haemodialysis). Possible review of treatment options three months after starting, when the patient is more familiar with dialysis and the impact it is having on their health and daily routines.

- Supported home dialysis options are offered in the UK and the provision of such a supported service should be considered here too.

TRANSPLANTATION

- More transplant coordinators are needed to manage the system
- Greater emphasis on pre-emptive transplantation, altruistic

donation and living donation to reduce the waiting lists.

- Next of kin should not be permitted to over-rule the wishes of a potential donor.
- Transport to be provided for transplant recipients attending clinics immediately post-transplant. Patients are likely to have 'used up' all their favours whilst in hospital for the transplant (feeding the cat, looking after the children, etc.).
- Pre-habilitation and rehabilitation to be offered to all to help patients be physically ready for transplantation and also to recover post-transplant.
- A support network post-transplant as moving from

attending dialysis three times a week to quite quickly be attending clinics only 4 times a year can take quite an adjustment on the part of the patient.

The above list is by no means exhaustive but it was an interesting exercise that brought out what is important to people. With the variety of people attending the meeting it was felt that we got a good snapshot of all the key points.

There will be future member / branch engagement events and we encourage you to get involved so that we can ensure that the Association represents your views and meet the needs of its members.



Strategic Plan 2021-2025



STRATEGIC PLAN

2021 - 2025

Our Strategy is important because it sets out the future direction of the Irish Kidney Association (IKA), just as in the same way we would never start a journey without knowing our destination.

In order to develop this strategy, we surveyed our members to understand their needs and priorities. In specially convened meetings, we asked our staff, our members and our stakeholders what their priorities were. We discussed these findings also with our Branch Officers.

Where appropriate, we adjusted our strategy to take account of the impact of COVID-19. Our Board discussed and reviewed what our priorities should be.

We believe that this Strategy gives us the best possible chance to rise to the challenges and take advantage of the opportunities we meet.

We reviewed our mission statement and values and decided while the original mission and vision still held, we should also look at improving the provision of education and information to people who are or who may become affected by end-stage kidney disease (ESKD). Our mission, vision and values are described on the top right of this page.

Mission, Vision and Values



MISSION

To be the national patient-led organisation which supports, educates, and advocates for people living with or likely to be affected by end-stage kidney disease.



VISION

To bring about the best quality of life for those affected by end-stage kidney disease, with quality and equality in their care and treatment.



VALUES

The Irish Kidney Association is guided by these core principles, which underpin everything we do.



Our Environment 2021–2025

We live in an incredibly challenging time. COVID-19 has impacted both our physical and mental health and how we live our lives. People with kidney disease are particularly affected.

This has meant curtailing many of the IKA's activities such as the Renal Support Centre in Beaumont, Dublin, and a move to online activities. It has temporarily broken the strong bonds of face-to-face connection within our community. The number of transplant operations has declined as a result of COVID-19. As these operations are not only the best treatment for patients on dialysis, but are also the most cost-effective treatment, we need to prioritise advocacy for our community on this issue.

The new Human Tissue Bill will have a major



impact on organ donation in Ireland, putting organ donation on a proper statutory basis, and this will impact the organ donor card and our organ donor awareness campaigns and how we work with other stakeholders in this area.

The strategy has a strong focus on delivering a range of high-quality

services to both members and Branches within the IKA's financial means. Also, the world of information technology and digital health presents many opportunities for us to help our members more effectively.

We also aim to improve patients' ability to live well with ESKD, participate fully in their communities and

reduce the structural barriers which can hamper their ability to participate in society.

We are also faced with increasingly onerous regulations, which also have a cost. However, it is right that we are both transparent and accountable to our members and to the people who so generously donate their time and money.

Not only must we continue to be of assistance to our community, but the positive impacts and results of our activities must also be seen.

We wish to express our heartfelt gratitude, appreciation and thanks to organ donors, organ donor families, funders and all our supporters. Without you the Irish Kidney Association would not be in such a strong position to deliver this strategy.

Our Strategic Objectives

The objectives within these themes are summarised right and detailed in the full Strategy which can be found on the Association website www.ika.ie

These objectives and themes make up an overall picture of the IKA's strategic vision. They are not rigid; they are intended to be flexible. Objectives may contribute to several themes at once. This Strategy encompasses all of the complexity of the IKA and its work.

In the Strategy, for each objective, we explain why the objective is important, what are the key actions we will take and how we will measure success.

The Strategy charts an ambitious course for the Association, setting goals and objectives which will be challenging and exciting. Implementation is a shared responsibility between the Board, staff and the volunteers of the organisation.

The Board's role is to set the



Strategy and to review its implementation through reports from the CEO and staff.

The CEO will establish detailed annual plans setting out the approach to bringing the Strategy to life, implementing our plans and achieving our goals. All staff reporting to the CEO will be responsible for working towards those plans and implementing the Strategy, providing regular and detailed reports about progress to the Board.

The Strategy, combined with our operational plans, will form the roadmap for the organisation for the next four years, documenting the detail of how the Association will work towards realising all of these objectives.

We will report on progress in relation to each action in the Strategic Plan within our annual report, with a formal mid-term review of the Plan taking place in 2023.



By GWEN O'DONOGHUE

Transplant teen Amber gets green light for vaccination

A 13-year-old transplant teen, who received a donor kidney from her parents best friend, welcomed her shot in the arm of the Pfizer BioNTech vaccine for COVID-19, on August 20th as it paved the way for her to return to secondary school.

Amber O'Rourke from Brownhill Road in Carlow was nine-years-old when her parents Elaine and Billy O'Rourke's friend Anne Marie Byrne donated a kidney to her after secretly getting tested to determine if she was a suitable match.

Mother, daughter and donor friend marked the momentous event by visiting the magnificent Delta Sensory Gardens in Carlow on the same day that Amber received her vaccination at Clayton Medical Group in Carlow.

They were happy to let the Irish Kidney Association share their positive story which resulted in lots of coverage in

newspapers online and in print media while the trio also appeared on RTÉ TV News and Elaine and Amber spoke to Bryan Dobson on RTÉ Radio 1 news. They also featured on Virgin Media news.

It was only fitting then that Anne Marie, herself a mother of two, chaperoned Amber to receive her



Amber speaking to RTÉ

COVID-19 vaccine at Clayton Medical Group in Carlow. At the time Amber said she was looking forward to joining her friends in second year at Gaelcholáiste Cheatharlach having had to be extremely vigilant since Spring 2020 and cocooned all through summer school holidays away from her friends.

Amber's older siblings, Kelly (18) and Jordan (25), had already received their vaccines as well as her parents Elaine and Billy.

Amber, who is now taking lifelong immunosuppressant drugs to retain her transplanted kidney, is in the very high-risk group for COVID-19. When the HSE announced that the rollout of vaccines to the 12-15-year-old age category would commence on August 13th this came as a welcome relief to many concerned parents, but especially to Amber's family and other young transplant recipients in this age category.

Amber is no stranger to needles having first been thrown into poor health and medical intervention since the age of five when she suffered a stroke. Months of hospitalisation and rehabilitation away from home in Dublin followed as she learned to walk again and nightly twelve-hour long dialysis treatments up until her life-changing kidney transplant in August 2017.

She still has regular visits to Temple Street Children's Hospital who monitor her health. She made a timely visit to her consultant Dr. Atif Awan on Monday, August 30th before getting the 'all-clear' to return to school in early September.



Elaine O'Rourke, Amber and Anne Marie Byrne at the magnificent Delta Sensory Gardens in Carlow

Mother of two Anne Marie Byrne (44) from Graiguecullen, in Carlow, who comes from a family of 18 siblings said, "I feel privileged to have been able to donate a kidney to Amber four years ago and it's only fitting that I am with her and my friend, her mother, on the day she receives her vaccination to protect her against COVID-19."

Anne Marie, who works at Carlow IT, returned to work less than two

months after donating her kidney when her kidney retrieval operation was carried out by fellow Carlow native Transplant Surgeon Dilly Little at Beaumont Hospital.

Amber's mother Elaine said, "it is a relief that Amber is getting her vaccine which gives her more protection as she returns to school, although we and her school will ensure that she remains cautious as it is likely she has less immunity and that she will need a booster shot following her second shot."

"But for a teenager it's important for her emotional wellbeing that she can resume a normal childhood and be amongst her friends and this vaccine brings her one step closer to regaining normality."

"I would like to thank her school for the care and attention they have given to Amber's needs as well as all the nursing and medical staff at Temple Street Children's Hospital for their excellent care, and nurse Julia McGrath at the Clayton Group Medical Centre who administered the vaccine to Amber."

It goes without saying our heartfelt gratitude to Anne Marie who has brought us to this point. She has gone over and above what any friend might be expected to do

continued next page...



Amber receives her vaccination from nurse Julia McGrath



Anne Marie and Amber's 1st transplant anniversary.

since Amber's eventful health journey began."

Anne Marie said, "I'm delighted that Amber is getting her Pfizer vaccine which will give her family more peace of mind. I would encourage people not to be afraid to get tested for living kidney donation and to help make the public more aware of the plight of people with organ failure so that they will support organ donation."

Elaine advised that Anne Marie didn't hesitate to help Amber and tried to offer emotional and practical support to her as her daughter Amber had been blighted with poor health after suffering a stroke when she was just four-years-old and then progressed to nightly dialysis for five years right up until her kidney transplant.

Ahead of receiving her first dose,

Amber said, "I am happy to be getting the vaccine. Once I am fully vaccinated I look forward to being able to spend more time in the company of my friends."

When members of Amber's family were deeply disappointed with the news from Beaumont Hospital that they could not be tested for donation, Anne Marie was resolved to put herself forward for living donation as the uncertainty about a deceased donor kidney transplant becoming available continued to loom.

Anne Marie contacted Beaumont Hospital in January 2017, initially without telling Amber's family as she didn't want to offer false hope about her suitability to be a living donor.

When Anne Marie was advised that she could proceed into the screening process she was delighted to share the good news with Amber's family.

Anne Marie who has two children, Jack 22, and Noah 16, believed she was in a good position to donate one of her kidneys as she felt she was in good health and her children were not as dependent on her. She said that it might have been different if they had been younger.

When someone asked Anne Marie what if her own children might need a donor kidney one day, she expressed her confidence that in the unlikely event they would, there would be plenty of siblings and cousins in her own large family who would be willing to step forward.

In August 2018, the O'Rourke and Byrne families came together for a party to celebrate the 1st anniversary of the successful living kidney donor transplant.



Amber cutting her kidney 1st anniversary cake.

Carol Moore, Chief Executive, Irish Kidney Association, said, "While research coming through is showing that transplant recipients are less protected after vaccination than others, we welcome the recent government announcement that a third dose vaccine will be given to this cohort."

"COVID-19 has impacted on all our lives, but it's been a particularly anxious and lonely time for all transplant recipients and dialysis patients who are in the very high-risk category for COVID-19."

"Many have been cocooning since the first mention of the pandemic's arrival to our shores in late February 2020 and it is a huge concern for many that they may not be as protected as others with the vaccine. However, the vaccine offers hope and as the majority of the population becomes vaccinated it will become a safer environment for all of us allowing the more vulnerable, including schoolchildren like Amber in the high-risk group, to lead as normal a life as possible amongst their peers."

"We wish Amber a happy future and many years of successful transplantation. Her story is very inspirational and shows how one person can make a huge difference by becoming an organ donor."



RENAL SUPPORT CENTRE

Beaumont Hospital has requested that the IKA Renal Support Centre be retained by them until October 2022. Hospital personnel are of the belief that the country and, in particular, acute hospitals are in for a very difficult winter as COVID-19 cases continue to rise and there are concerns expressed by leading medical experts that Ireland is at risk of a bad flu outbreak this winter.

We recently completed a physical inspection of the Centre. It is obvious that Beaumont Hospital has made a considerable investment, spending approximately of €200,000 upgrading the Centre with several major works completed by them which included replacing water tanks, repair of flooding leaks, repair of collapsed roof section and repainting.

After careful consideration, the IKA Board has agreed to Beaumont's request on the basis, that:

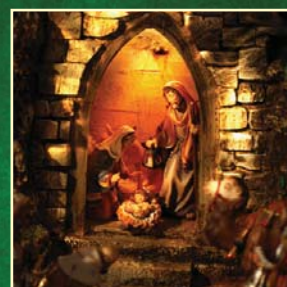
- Hospital visitor restrictions will continue to operate and therefore occupancy of the Centre would be less than 30% if returned to the IKA.
- The communal areas of the centre would have to remain closed, effectively cancelling the opportunity for people to socialise.
- The current arrangement which provides alternative accommodation at the nearby Clayton Hotel (paid by Beaumont Hospital) appears to be working well.
- Unlike Beaumont Hospital, the IKA does not have infection control expertise, and this will need to be put in place to safely re open the Centre.
- Taking the Renal Support Centre back at this point, would increase the IKA's deficit by €210,000.



- We do appreciate that the IKA's Renal Support Centre at Beaumont is the "jewel in our crown" and members may be disappointed with this news. We will continue to work towards developing the expertise that is

needed to safely re-open and run the Centre with the expectation of return of the Centre (subject to COVID-19 restrictions) to the Irish Kidney Association in October 2022.

12 Christmas Cards AND ENVELOPES



ASSORTED DESIGNS

Made in Ireland



€5

PER PACK OF 12
6 images x 2 of each

Plus Post & Packaging

The entire proceeds from the sale of these charity cards go to support the IKA's work for dialysis and transplanted patients in Ireland.

See IKA website www.ika.ie or phone: **01-6205306** for details
CHARITY REGISTRATION NUMBER 20011260

Chronic Kidney Disease and Home Therapy Options

By FIONA BYRNE, Head of Renal Care Ireland & Scotland (PD) in Baxter Healthcare Ltd

Kidneys are vital for your body. Well-functioning kidneys remove waste and excess fluids from your blood, keep important minerals in balance, and help regulate blood pressure, produce red blood cells and vitamin D. In other words, your kidneys make sure your body stays healthy and balanced.

Chronic Kidney Disease (CKD) is a condition in which your kidneys gradually lose their ability to help your body remove waste and fluid from your blood. When this happens, harmful waste and fluid begin to build up in your body, making you feel unwell and out of balance. Although CKD is not curable, treatment can help slow its progression, control symptoms and enable you to live a full life.

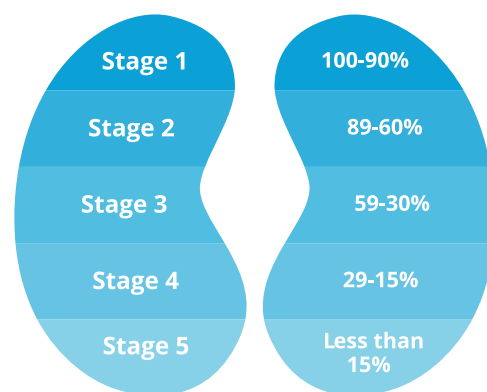
CKD has five different stages, ranging from stage 1 to stage 5. What stage you are in, depends on how well your kidneys are currently able to filter your blood.

At stage 4 of CKD there can be severe loss of your kidney function. This means you may notice symptoms of CKD and you should either be in treatment for your CKD or have discussed the options available with your clinician to prepare you for the event that kidney failure develops.

At stage 5 of CKD your kidneys have failed, this means you will likely notice symptoms of CKD and you will need to move forward with the treatment that you and your clinician have decided is right for you.

EXPLORING YOUR TREATMENT OPTIONS

Many people living with CKD are treated with dialysis at some point in their treatment journey, either at home or at a hospital. Dialysis is a process involving the removal of waste and extra fluid from your blood that your kidneys are no longer able to filter out. Dialysis filters your blood through a membrane which mimics a healthy kidney. During dialysis treatment, the small waste products in your blood flow through this membrane and into a fluid called dialysate,



Stages of Chronic Kidney Disease

% of Kidney Function (Both Kidneys)

ensuring the blood is cleaned of waste products.

This article will focus on the options available to you for Home Dialysis.

PERITONEAL DIALYSIS (PD) AT HOME

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

There are two forms of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD).



Continuous Ambulatory Peritoneal Dialysis (CAPD)

The basic treatment is the same for each, but the way exchanges are done, and the number of exchanges needed are different.

WHAT IS CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)?

CAPD is a type of PD that uses gravity, rather than a machine, to “exchange” your old dialysis solution for fresh solution. To do this, a bag of dialysis solution is connected to a tube that goes into your abdomen.

The exchange starts by placing the drain bag portion of the system on the floor and draining out the used solution in your peritoneal cavity (effluent).

The new solution bag is hung above your head on a coat stand or hook in the wall, and then gravity is used to pull the fresh solution into your abdomen.

Once this is completed, the system is disconnected from your catheter and you are free to move about until your next exchange.

Each of these **exchanges lasts about 20 minutes and is done 1 to 4 times per day**, depending on your dialysis requirements. Your clinicians will discuss **your medical and lifestyle needs** with you to determine **your individual dialysis prescription**.

WHAT IS AUTOMATED PERITONEAL DIALYSIS (APD)?

APD is a form of peritoneal dialysis (PD) that uses a machine called a cycler to perform dialysis exchanges. The cycler is programmed to give you the dialysis treatment by your clinician. Typically, an **APD programme lasts between 8 and 12 hours**, depending on your



Automated Peritoneal Dialysis (APD)

medical and lifestyle requirements, and is performed overnight, **giving you the freedom to carry on your normal activities during the day**. This may make it easier for you to continue working, studying, or socialising during the day.

Before each treatment, your APD cycler is set-up with tubing that connects it to 10-15 litres of clean dialysis solution. A cycler tube is then connected to your catheter.

The APD cycler is programmed to control the movement of clean dialysis solution into your abdomen by the machine. It drains the used dialysis solution from your body and replaces it with new solution at regular intervals throughout the therapy.

You will have to set-up the dialysis machine with fresh equipment and dialysis fluid every time you do your APD therapy. Since every patient needs a different amount of dialysis, your APD cycler's programme will be customised to your specific needs.

REMOTE PATIENT MANAGEMENT WITH APD

You and your clinician may consider using

Remote Patient Management to manage your APD treatments. Remote Patient Management allows your clinician to follow your treatment and ensure you are on the right track, which may increase your confidence about doing your treatment at home.

Almost anybody can perform PD with proper training. In most cases, training will be 2-5 days long depending on the type of PD therapy you chose. You will not have to perform at-home PD by yourself until you and your clinician feel you are ready.

Once you do go home, you will not be alone with your treatment – always remember your healthcare team is ready to support you at anytime and there are 24-hour Helplines if you run into difficulties with your cycler to help you troubleshoot any problems you may encounter.

PD may provide you more lifestyle flexibility than other types of dialysis. The equipment is portable, making it easier to perform treatment in other locations. PD does not require daily needles and is usually painless. It is also considered gentler on

your body than other types of dialysis, which may result in you feeling better after treatment.

It will take time to get used to the feeling of performing PD and you will need to follow certain precautions to avoid the risk of infection, which will be taught to you by your healthcare team.

You will also need storage in your home for the PD supplies and equipment and will have a catheter implanted in your abdomen for the duration of your therapy.

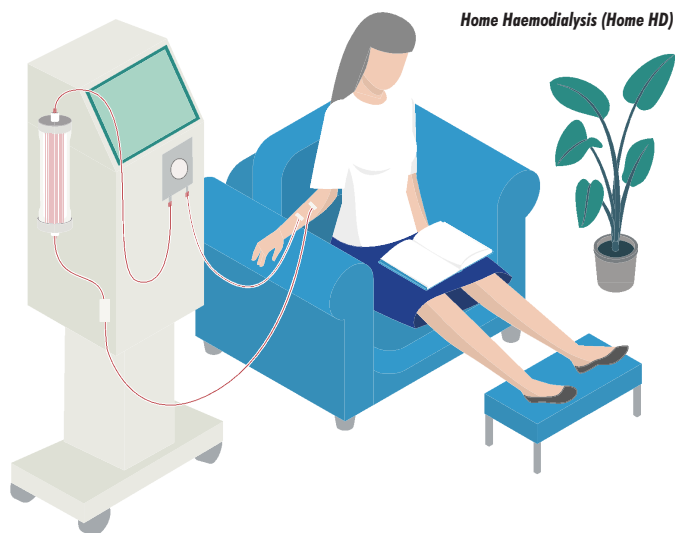
HOME HAEMODIALYSIS (HOME HD)

Haemodialysis (HD) is a type of dialysis that filters your blood outside your body using a machine and a dialyser, which is a manufactured filter that acts like an artificial kidney.

During haemodialysis (HD), the dialysis machine removes a small amount of your blood from your body through a needle or catheter. The dialyser then cleans your blood, removing waste, toxins, and excess fluid. Finally, your clean blood is returned to your body.

Haemodialysis (HD) can be done at home, giving

continued next page...



Home Haemodialysis (Home HD)

you the flexibility to adjust your treatment schedule around your daily activities.

Compared to in-centre haemodialysis (In-Centre HD), you may save the time you would have spent on transportation to the hospital or clinic and enjoy the convenience and comfort of your own space while completing therapy.

Despite these benefits, home haemodialysis (Home HD) does have some special considerations, and you should keep these in mind when discussing with your clinician whether Home HD is right for you.

If you perform Home HD, you will need space in your house for a haemodialysis (HD) machine, as well as your regular dialysis supplies.

You will need to have adjustments made to your plumbing and electrical systems to accommodate the water and electricity the dialysis machine uses during treatment. You should talk to your clinician about how to prepare yourself, mentally and physically, for this process.

Before you begin Home HD, you will need to complete the 4-6 weeks of training required to

perform treatment safely and successfully.

Before HD treatment starts, you will also need to have a surgical procedure that creates a dialysis access site under your skin called a fistula. This dialysis fistula lets unfiltered blood flow from your blood vessels through the dialysis machine and lets clean blood flow back into your blood vessels. Access to this fistula is created by inserting two needles into the blood vessels in the fistula. You will be shown how to insert needles into your fistula to perform your treatment.

Home HD may be the right treatment option for you if it is well-suited to your medical and physical condition, and lifestyle choices.

Home haemodialysis (Home HD) gives you the opportunity to enjoy the comfort and freedom that comes with performing dialysis in a space that feels familiar and safe, while having telephone access to professional help if you need it.

Doing your treatments at home may also increase your flexibility by allowing you to avoid frequent trips to the hospital or clinic.



Fistula

Find out if home Dialysis is an option for you?

"We believe all patients requiring dialysis, no matter where they live in Ireland, should automatically be offered a choice of in-centre or home-based therapy. Travelling to a centre, several times a week for treatment, places a heavy burden on patients and their families (as well as a significant budgetary burden on the HSE).

For many people, home-based dialysis, (whether home haemodialysis or peritoneal dialysis), with active support from trained professionals can make a huge positive difference to a

patients quality of life.

In some countries, patients who choose one of the home therapies are offered a direct allowance to cover the costs of managing their treatment at home. There is also a significant saving for the Exchequer in terms of the overall annual costs of treating all those receiving dialysis.

Additionally, home dialysis reduces the risk of infections such as COVID-19 – we are seeing increased interest in home dialysis since the start of the pandemic.

So, we are delighted to

announce **Professor George Mellotte**, National Clinical Lead, HSE National Renal Office and Consultant Nephrologist at St. James' and Tallaght University Hospitals, will join us online on **September 27th at 7pm** to outline the options for home dialysis.

We will also have two patients using home dialysis telling their stories and the pro's and con's of home dialysis for them. There will be a chance to ask questions.

Booking details to follow."

- Carol Moore

Dawn Davin

National Renal Office Pharmacist



Earlier this year, the National Renal Office appointed Dawn Davin as the National Renal Pharmacist.

Dawn's overarching interest lies in improving aspects of pharmacy and medicines management for patients with kidney disease. This includes patients with End Stage Kidney Disease, patients who are receiving dialysis, and patients living with a functioning transplant. Understanding how kidney disease impacts on a patient's health overall, and how this can be managed in relation to medicines, is an important part of addressing kidney patient care going forward. This includes how new medicines are managed and includes patient education and monitoring.

Dawn brings to the National Renal Pharmacist role an impressive resume and background in renal pharmacy. She graduated in 2003 as a pharmacist from Trinity College, Dublin, followed by an MSc in Hospital Pharmacy in 2005. She also has a qualification as a Pharmacist Independent Prescriber.

She is a Clinical Lecturer with the School of Pharmacy and Pharmaceutical Sciences at Trinity College, where she teaches students about various aspects of kidney disease.

For almost twenty years Dawn worked at Tallaght University Hospital

and for almost fifteen years, she has specialised in renal pharmacy taking part in many aspects of pharmacy research and ways to develop and improve areas of pharmacy practice for kidney patients.

Safe prescribing of medicines and reducing medicine related errors is a key focus of Dawn's work. This involves working with prescribing systems in both hospital and community settings and developing approaches to digital or IT advancements.

Dawn explains, "an example of how we can simplify how prescriptions are written for patients, including patients on dialysis, is that if prescriptions could be routinely transferred electronically from where they are written in hospitals, directly to a patient's pharmacy, it would be more convenient, reduce delays in getting medicines, and avoid issues such as lost paper prescriptions.

"It could also improve communication between hospitals and community pharmacies. While this is happening in some settings at the moment, many prescriptions are written as paper prescriptions at clinic appointments or in dialysis units.

"This is one area where I am trying

to improve the system for kidney patients.

"It has been very difficult for patients with kidney disease dealing with COVID-19 since the pandemic began and it has brought a lot of varied challenges for both patients and healthcare professionals.

Responding to the challenges is also providing opportunities to improve care, both in community and hospital settings, improving the overall patient experience."

Dawn outlines another example of the work she is involved with in finding ways to help patients manage their medicines safely and with confidence. She explains, "many kidney patients are prescribed a large number of medicines. Raising awareness of how to manage medicines on sick days is important.

"Partnering with patients to find the best ways to help them with issues that are of concern to them, such as what to do if they become unwell, is an important aspect of medication safety and self-management that I am working on.

"I am looking forward to working with and involving patients more and more in their care in the future through medicine and quality initiatives in pharmacy practice."

Tara O'Connell



A novice cyclist resolved to cycle a 100km distance in a charity fundraiser for the Irish Kidney Association (IKA) as a tribute to her late mother who passed away with multi-organ failure.

It took just five weeks preparation for a Dublin mother of three to complete the Challenge Cycle, on a borrowed bike, from Dublin to Wicklow and back on August 1st, 2021 raising organ donor awareness and €2,200 for the IKA.

Novice cyclist takes on 100km cycle

Breda Daniels O'Connell



The late Breda Daniels O'Connell from Dun Laoghaire, Dublin, passed away on January 11th, 2021 following six years of dialysis treatment and in her final weeks complications which led to a stroke and multi-organ failure.

Her daughter Tara O'Connell, who lives in Ballybrack, Dublin undertook the challenge cycle in memory of her mother who was also the grandmother of nineteen including

Tara's three children Evan (16), Bruce (7) and Jess (5).

Tara described her motivation on her challenge Go Fund Me page: "Our beautiful mam was taken at the young age of 67 was a devoted grandmother. She suffered for many years fighting for a kidney transplant. Unfortunately, a match could not be found, and she remained on dialysis as her health deteriorated."

Following her challenge cycle, Tara explained, "I received

great encouragement from my good friend, children and two brothers and two sisters and they all came behind me to support what I was doing.

"Before deciding to take on the challenge, I had never cycled on the open roads before and nor was I a runner. I took up fitness in a gym four years ago and it benefitted my health and feeling of wellbeing enormously. I had been going through a difficult time and was carrying some weight, but exercise transformed me and my mindset.

When COVID-19 arrived, it proved very difficult for my Mother. I had been living with her but had to move out with the children to avoid exposing her to potential harm as she was vulnerable as a dialysis patient and was travelling to Vincent's Hospital three times a week for treatment.

She had cooked Christmas dinner every year for the family but in the lead up to last Christmas she was too weak. She suffered a stroke weeks before she went into multi-organ failure fighting until the end.

"My family are grateful to the IKA who were supportive throughout her illness and especially for providing her with a holiday accommodation two years ago in one of their holiday homes in Kerry. It really lifted her spirits to be able



Zander, Jess, Bruce and Izar.

to get away with my sister and brother. It helped her greatly get over her disappointment that dialysis treatment prevented her from travelling to see my sister who lives in London.

"Everyone has been so generous and supportive since hearing about my challenge. I work as a hairstylist in Dalkey, and my clients were hugely supportive and so were my friends. Thanks to my friend for trusting me with her road bike."

In describing the day of her cycle Tara said, "I set out early on Sunday morning of the August bank holiday weekend. The weather was favourable to cycling on the way

down to the halfway point, at Jack White's Inn in Brittas Bay, but there was a strong wind on the way back and I found it gruelling pushing through it. My friend helped motivate me to keep going and it was lovely to be greeted by my family when I arrived back in the evening.

By completing it I have inspired other members of my family and some friends who have agreed to undertake the challenge next. It's our way of remembering my Mam while supporting the IKA in trying to raise awareness about other people who are suffering from organ failure.



Breda with her daughter Lisa, grandson Izar, son Andrew, granddaughter Rhea and grandson Zander



'In order to empathise with someone's experience you must be willing to believe them as they see it and not how you imagine their experience to be.'

Brene Brown

VULNERABILITY



By AOIFE SMITH

Throughout this pandemic there has been a lot of talk around patients who are in the 'vulnerable' category. There was information, guidelines, special times for shopping or days for activities. There were protests, arguments and lobbies all centred around vulnerable people, aiming to highlight the very real risk and danger they were exposed to if their loved ones and others did not follow the COVID-19 guidelines.

However, what I noticed from friends, family and patients in this category was that the very word '**Vulnerable**' caused, for many, a negative emotional reaction.

Feeling vulnerable is uncomfortable. Nobody wants to be vulnerable, yet in chronic illness it is a familiar feeling.

So, how did the constant reminders of how people with a chronic health condition were in the most 'vulnerable' category

impact our emotional wellbeing?

Recently, I listened to a very moving podcast by Jarlath Regan, '*An Irishman Abroad*', where he interviews his wife, Tina, who lives with a chronic health condition. They talk about what it was like for her to be in this category.

The interview was honest, open, and emotional. Their discussion inspired me to write this article as it really resonated with me, when I thought of so many of you living with chronic kidney disease who may be feeling the same way.

Jarlath is very familiar with the world of transplantation as he successfully donated a kidney to his older brother in 2017, and Tina, tells her story of how she was diagnosed at 14 years of age with a chronic health condition.

Tina had grown-up being sick and she tried her best to cope with her illness by having a strong positive mental attitude, using statements like 'I am powerful' and 'I am strong', to keep her going through the hospital appointments and treatments. She explains how she did not need or want to burden anyone

You can listen to Jarlath Regan's podcast at...

<https://podcasts.apple.com/ie/podcast/coronapod-tina-regan-tells-her-story/id683760002?i=1000528330812>

with her illness and just tried to get on with it the best she could.

Until of course the pandemic arrived, when she felt she had to let down her shield of power in her positive mental attitude and come out to the world as a person with an illness, in order for other people 'to cop on' and be careful around her.

After years of trying not to think of illness, telling herself she was not vulnerable and trying to live a 'normal' life, her illness was now in the spotlight. While there were many good wishes there was also curiosity, judgements and comments that left her feeling disempowered, humiliated and vulnerable.

She explains how she never felt more of a hassle, a burden to everyone in the world and even to her family and friends who loved her. She talks about how she felt shaken with the harsh reminder of her illness. She had not only to rely on herself to be hypervigilant when it came to hygiene, but also put her fate in the hands of everyone around her, which caused her a great deal of stress and anxiety.

What used to give her the power to stay strong was taken away from her with the constant reminders of the dangers of this virus to vulnerable people.

Tina spent most of her life 'just getting on' with her illness and I see that resilience and strength everyday with so many of you living with chronic kidney disease.

CKD patients often hide in plain sight due to the lack of external evidence or conventional signs of suffering, an invisible illness. The inconsistent and unreliable nature of CKD symptoms can cause confusion for family and friends, as they do not fit neatly into the idea of what a "sick person" should look like, which can mean that you may not receive the appropriate degree of compassion or empathy needed.

Comments such as "You don't look sick," while often intended as encouragement or a compliment, can carry unintended consequences. If you don't "look sick," the thinking goes, it must not be so; yet, the struggle with the realities of this condition are very real.

This can lead to a questioning of the validity of symptoms and feelings of inadequacy as you can be left

wondering whether you are overreacting or trying hard enough to manage the condition, and that is without the added stress, worry and fear that the pandemic has brought.

With the easing of restrictions and the numbers of new cases still high, I wanted to acknowledge that while getting back to normal for others may be welcomed, for those who fall into the vulnerable category, it could be adding a new depth to the feeling of 'vulnerability' and affect their emotional wellbeing. There still needs to be empathy, compassion, understanding and respect when it comes to COVID-19 guidelines.

According to Toni Bernhard J.D., writing on the subject of chronic pain and illness, "The kindest thing we can do for ourselves when people

disappoint us is to accept that disappointments are an inevitable part of life and then cultivate compassion for ourselves over any suffering we're experiencing as a result of [others'] lack of understanding about what it's like to live with invisible illness."

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

I look forward to hearing from you!



Jarlath and Tina Regan

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



Sofia Corey (7)



Sofia Corey on her way to school on the first day



Sofia with new puppy Bella



After many interruptions to the school calendar by COVID-19 since Spring 2020, there is now a higher level of confidence amongst parents, their children, and teachers, about their safety since schools re-opened in September.

Now that most of the population has been vaccinated, there is an even greater sense of relief for families with children in the very high-risk group for COVID-19 and also children who have vulnerable family members. They have been disproportionately affected by the pandemic having to be even more vigilant.

Sofia Corey (7), from Walkinstown, Dublin, who featured in our summer issue of *SUPPORT*, was one happy little girl to reunite with her school friends at St. Pius N.S. on September 1st after a two-year hiatus due to her kidney condition. She went straight into 1st class despite having skipped senior infants and much of junior infants due to complications around her kidney condition, and recovery from her transplant.

Sofia's mother Elaine McElroy explained about her only child, "We had a wonderful first day back to school. She was so happy as she put on her uniform and then said goodbye to her new pet dog Bella who joined our family a few months ago. Driving her to school on her first day back, it was also the first time I didn't have to worry about her getting sick in the back seat of the car and I could return to work without any real cause for concern knowing she was in safe hands and happy to be surrounded by her friends.

"Huge thanks are due to her school for facilitating her during her

sickness and especially to her teacher Ms. Goss who volunteered her time to give Sofia online lessons in the evenings which helped her keep up with her classmates and re-join them in September.

"I also want to thank all the staff at Crumlin Children's Hospital for their loving care of her since she was a baby. Sofia is now under the expert care of Temple Street Children's Hospital. She is now well enough to have her own baby to care for, her pet Bella. Were it not for her kidney donor she might not be in this happy place now".

Sofia was born a month prematurely and was diagnosed with the kidney condition called Congenital Nephrotic Syndrome when she was just seven-weeks-old. Up until her transplant last Christmas, Sofia, a patient at Our Lady's Hospital for Sick Children in Crumlin, had been undergoing nightly dialysis from the time she was two and a half years old.

Sophie O'Neill from Monaghan travelled a similar health journey as Sofia. Sophie is also seven-years-old and in 1st class at school. Sophie was born with the same kidney condition as Sofia, Congenital Nephrotic Syndrome, and both children spent a lot of time at Our Lady's Hospital for Sick Children together.

Sophie O'Neill spent the first nine months of her life as an inpatient in hospital and in this time her parents, Thomas and Martina O'Neill developed a great friendship



Sophie O'Neill (7)

with Sofia's family. Martina explains her daughter Sophie is a transplant success story and since her husband Thomas donated a kidney to their only child three years ago, she has been thriving.

Just a few years younger than Sophie and Sofia, and sharing the same kidney condition, is **Ally Whitston**, who celebrated her 4th birthday this September, the same month she was accepted onto the transplant waiting list.

Ally, from Naas, Co Kildare, has been undergoing nightly dialysis treatment since July 2020 and her father, David, is hoping to be assessed for living kidney donation soon. Spending so much time in and out of hospital Ally's parents also got to know Sophie and Sofia's parents and they all keep in touch.

Ally's mother, Michelle, explained that "it is a big step for us that Ally started at Barney's Preschool this September having held her back for a year because of her illness. She loves it. Ally spent six months of her life as an inpatient in Crumlin. After that she got to spend more time at home. She has done amazingly well so far and, please God, the next few months will go smoothly for her and that she will be safe and happy at preschool."

Dialysis patient **Tomás O'Dowd** (7) from the picturesque Dunquine, in Co Kerry opposite the Blasket Islands, returned to school at the end of August. Tomás who undergoes nightly dialysis, returned



Ally Whitston (4)



Tomás O'Dowd (7)

to 1st class in the small school he attends, Muiríoch National School in the West Kerry Gaeltacht. There are just six pupils in his class.

Tomás's parents, Amanda and Denis O'Dowd, hope that he will receive a life-changing transplant soon as his father Denis is going through the living donor screening process.

Like Tomás, who has graced the front cover of *SUPPORT* magazine, the Winter 2020 issue, so also has **Sam Kinahan** (7) from Baldoyle, Co. Dublin made it to front cover news and not only in a previous issue of *SUPPORT*.

Two years ago, Sam made national headlines and national front-page news when he started national school after successfully undergoing a living donor kidney transplant from his donor father Ivan just a few months before, in June 2019.



Ali (10) and Sam Kinahan (7)

Prior to his transplant, Sam had been receiving dialysis treatment from the time he was just four and half months old.

Now in 1st class, Sam received a big hug from his big sister Ali (10) at the front door of their house as they left for their first day of the new term at St Laurence's School in Baldoyle.



Josh Harborne (9)

Nine-year-old **Josh Harborne** was happy to return to school and commence 3rd class at St. Anne's Primary School in Tallaght, Dublin. In October 2019, Josh and his mother, Karen Kelly, successfully underwent a living donor kidney transplant. Earlier that year Karen and Josh took part in the Irish Kidney Association's Run for a Life at Corkagh Park. Prior to Josh's transplant he received six months of peritoneal dialysis treatment.

Molly Fitzgerald Kiersey (10) from Waterford city underwent a kidney transplant in 2018 when she was seven-years-old, and which followed eight months of dialysis treatment. Her



Molly Fitzgerald Kiersey (10)



Molly with Hugo the pony.

mum, Donna, described how Molly is doing really well now, "she celebrated her first Holy Communion last September and this September she was delighted to be able to reunite with her friends in 4th class at Our Lady of Good Counsel Girls School. Molly loves attending horse riding lessons and has developed a special bond with Hugo the pony bringing him his favourite treat of polo mints every time she goes. Molly's father Brendan is also enjoying a successful kidney transplant and we are deeply grateful to the families of their deceased donors who gave them a new lease of life".

Now six-years-old and recently commenced Senior Infants at St. Mary's N.S. in Drogheda, **Ella Hewitt** was just four when she underwent a kidney transplant in July 2019 thanks to her donor mum Samantha O'Reilly. The transplant brought to an end to the 19 months of dialysis treatment which Ella had to

undergo, and which followed 15 months of chemotherapy for Wilms tumour. She and her adoring protective older brother Jacob (8) who is in 3rd class were happy to pose for a photo on their first day back to school, taken by their proud mother Samantha.

Attending 4th class at his local Scoil Chualann in Bray is ten-years-old **Tadhg McElroy** and his twin siblings Caoila and Donagh (5) who are excited as they are just beginning school in junior infants class. Their mum, Clíodhna Costello, gave birth to the twins just two years after donating one of her kidneys to Tadhg in 2014. Prior to the transplant operation, Tadhg, a patient at Temple Street Hospital, had been receiving dialysis treatment from the time he was six-months-old and was just two and a half years old, when he received his transplant.

The bravery and resilience of all these children and their parents is awe inspiring as all were unwittingly hurtled into the world of kidney failure and with children's hospitals



Jacob Hewitt (8), 3rd class and Ella Hewitt (6), senior infants.



Tadhg McElroy (10) with his younger twin siblings Caoila and Donagh (5).

becoming their second home.

We commend them and also the nursing and medical profession for their unstinting care in bringing the children along to the point where they can return to school allowing them to be playful children having fun in the company of other children. All the parents of these children will attest to the compassion and understanding of school management and staff in helping to smooth their path in their return to school mindful of their additional safety and emotional needs.

Our best wishes to all children who are still receiving dialysis, like Tomás and Ally, or who will soon commence this treatment. Many of these children attend the hospital schools in Temple Street and Crumlin which provide an invaluable service. We share with parents in expressing our gratitude to all the hospital tutors and play therapists for their dedication and care they bestow on the children and for supporting the children's developmental and educational needs.

The IKA extends its heartfelt good wishes to Sofia, Sophie, Ally, Tomás, Sam, Josh, Molly, Ella, and Tadhg, and all the other children and teens who have suffered organ failure, for a thoroughly enjoyable and safe school year in the company of their friends. Although their life journey is just beginning their parents should be bursting with pride!



Meeting the accommodation needs of people with disabilities

The Citizens Information Board (CIB) and Disability Federation of Ireland (DFI) are carrying out a study on the housing and accommodation needs of people with disabilities.

It is hoped that the findings and recommendations from this research will inform the next National Housing Strategy for People with a Disability, which is currently being reviewed by the Housing Agency.

The Irish Kidney Association was asked to contribute to the study and we submitted the following responses to their questions:

What in your view are the main barriers to providing housing with supports to enable people with a disability live independently in the community?

A central information point is not apparent. What's available, what

needs to be considered, etc. It can feel like needing to know what questions to ask. It can leave one feeling quite vulnerable when seeking appropriate accommodation or getting adaptations done.

What are the main factors impacting on the move from congregated settings?

Availability of suitable housing is obviously a stumbling block. Also, changing the culture of how needs are met takes time – congregated settings are quite structured and therefore more easily managed than a supported living service where there are a lot more blurred lines and opportunities for things to 'go wrong.' It's about putting appropriate background structures in place to support greater independence. Keeping the focus on the individual, what they want and what is practical

is very easy to say but not always easy to deliver. However, looking at the bigger picture, properly resourced supported living can lead to a better quality of life for the individuals involved and can also relieve pressure on hospitals and nursing homes.

A focus of the National Housing Strategy for People with a Disability 2011-2016 was on Local Authorities and the HSE working together to provide person-centred approaches to the delivery of housing options and supports.

Has this worked? What, if any, additional measures need to be put in place to improve this?

In limited experience in this area it seems that the individual / their family can be left to navigate the system for themselves. If one is neither assertive nor well versed in the ways of the HSE / Local Authorities, this can lead to people feeling hopeless and ending up in difficulties when it does not have to be the case.

What in your view needs to be prioritised in the new Housing Strategy for People with a Disability?

Adapting existing housing for people who develop a physical disability is under-supported with the 'squeezed middle', as always, receiving minimal support to engage in what can be very expensive work. There is a need for joined up thinking in that additional supports in this area could allow for an increase in independent living which would save money over a relatively short period of time when compared with nursing home/hospital care.



VIRTUAL Run for a life, ie

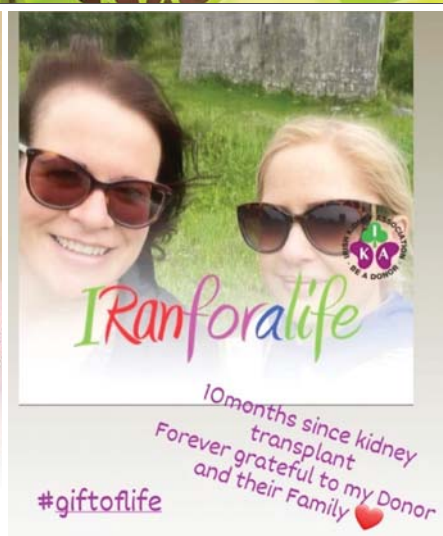
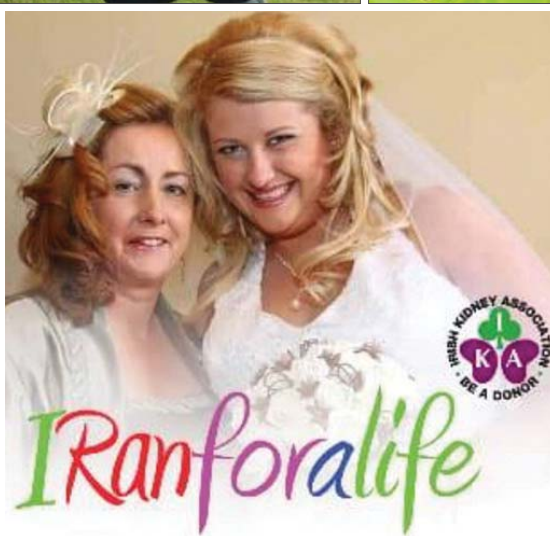


This year's Run for a Life had to go virtual again because of COVID-19. We would like to thank the 258 people who signed up to do 2.5km, 5km or 10km in their own locality. We also had a couple of our Branches organising COVID safe events where people gathered on the same day in the name of our Run for a Life challenge.

The Run has always been about promoting the message of organ donor awareness and, importantly, it has also been about community. Our in-person events in previous years brought people together from around the country in Corkagh Park in Dublin and it was always a wonderful opportunity to catch-up with people whilst enjoying a walk, jog or a run.

Prior to the pandemic we had often discussed the possibility of growing the Run for a Life concept outside of the confines of meeting up in Corkagh Park. The pandemic obliged us to move on this idea. By going virtual and also having our Branches embracing the opportunity to consider a local offering we have now opened the door to expanding our reach in future years.

As you know, the IKA is passionate about peer-support and we are also passionate about encouraging physical activity. The Run for a Life allows for us to bring both these passions together. We have seen friendships formed through our Corkagh Park event and we will be spreading



our reach, and friendship opportunities, further afield as we go forward.

The beauty of the Run for a Life is that it offers a range of distances making it open to a wide range of ages and abilities and the fact that we encourage walking, jogging and running it, opens it into a great family event that does not emphasise competition.

At the Corkagh Park event everyone gets a medal, including the family dog in some cases!

We look forward to Run for a Life 2022 being a bigger event so that we build our network and collectively send out a strong message about the importance and success of organ donation for transplantation.



Ireland lags behind in international best practice in Vascular Access for dialysis patients



By **PROF. AUSTIN STACK**

A new University of Limerick study has found that the treatment used in the majority of Irish kidney failure patients may lead to higher rates of hospitalisation and death.

The research carried out by a team at University of Limerick School of Medicine found high rates of central venous catheter dependency in Irish patients undergoing haemodialysis, which the researchers believe may lead to worse clinical outcomes than those in other countries.



Patients who develop kidney failure are hugely dependent on their 'lifeline' connection between the dialysis machine and the patient's blood vessels. This connection is usually in the form of an arteriovenous fistula (AVF), a surgical connection between a vein and artery in the patient's blood vessels, or a large central venous catheter (CVC), which is an artificial plastic tube inserted into a large vein in the body (usually a neck vein).

The new national study by the UL researchers, published in the journal *Kidney360*, found extremely low rates of AVF placement with correspondingly high rates of CVC use in dialysis patients, which may predispose patients to higher rates of hospitalisation and death.

The research shows that Irish patients who started dialysis were more likely to be using a catheter than a fistula (77% versus 23%) for

treatment, and that the percentage of patients with a functioning fistula varied substantially across major centres in Ireland. The proportion of patients using a fistula only increased modestly at the end of the first year on dialysis.

International studies have proven that countries that adopt a policy of using a fistula in preference to a catheter have better clinical outcomes for their patients than those who do not.

"When catheters are used for haemodialysis, they predispose patients to higher rates of infection, clotting problems, hospitalisations and even death," explained Professor Austin Stack, Foundation Chair of Medicine at the School and Consultant Nephrologist at University Hospital Limerick, who was a senior author of the study.

"As a result national clinical programmes and professional

Evolution of Vascular Access among Incident patients during the first year on Haemodialysis: A National Cohort Study

Kidney360

Cohort

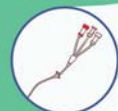
Data from the Irish National Kidney Disease Clinical Patient Management System

Adult patients who started haemodialysis from 1st January 2015 to 31st December 2016 and were on treatment for at least 90 days

N=610

Day 90

Fistula Use 23%



Catheter use 77%

Conversion from Catheters to Fistulas



varied significantly and substantially across dialysis centres



was significantly lower for older patients (57% lower for patients age > 77 years)



was significantly higher for larger patients

Day 360

Fistula Use 41%



Catheter use 59%

Conclusion:

The presence of a functioning Fistula is extremely low (23%) among new haemodialysis patients in Ireland with a high dependency on Catheters (77%). Conversion rates from a Catheter to Fistula in the first year are low in general and vary by age, body size and by dialysis centre. Ireland lags behind international best practice in Vascular Access for haemodialysis.

Wael F. Hussein, Gasim Ahmed, Leonard D. Browne, William D. Plant and Austin G. Stack. Evolution of Vascular Access Use among Incident Patients during the First Year on Hemodialysis: A National Cohort Study has been published in Kidney360. See more here: <https://kidney360.asnjournals.org/content/2/6/955>



Scoil an Leighis School of Medicine

societies have advocated for the use of fistulas in preference to catheters for most patients who start haemodialysis.

"The results of this new national study highlight that Ireland lags behind international best practice in the achievement of fistula rates for patients treated with haemodialysis.

"The low rates of fistula use and high rates of catheter dependency at the start of dialysis are very concerning and need to be tackled at a national level as they may be predisposing patients to higher rates of infection and hospitalisation," added Professor Stack.

The study, funded by the Health Research Board (HRB), looked at 610 patients initiating haemodialysis in Ireland between January 1, 2015 and December 31, 2016, with a follow-up one year later.

The research team noted that at the three-month mark after the onset of dialysis, only 23% of patients were using a fistula, while the remaining 77% were dependent on a catheter. These results fall well short of international benchmarks where other countries have reported much higher rates of fistula use at the start of dialysis (56% in Germany and 53% in the UK).

The researchers also noted significant variation in the percentage of patients using fistulas across major dialysis centres in Ireland, ranging from a low of 9% in one to 37% in another. These variations in prevalence were not accounted for by differences in patients' age or general clinical health. This would suggest that factors other than those that were patient-related are responsible for the extremely low use of AVF in the Irish health system, according to the research team.

At the end of the one-year follow-up, the percentage of patients with a functioning fistula had increased only modestly to 41% with the remainder using an artificial catheter for dialysis. Again, there remained substantial variation in the rates of fistula versus catheters in use across centres of dialysis provision in Ireland.

The study reveals a need for a detailed investigation of why fistula rates are so low in Ireland compared to other European countries, according to Dr Wael Hussein, lead author.

"Our analysis suggests that factors relating to the organisation and planning of vascular access – i.e.

those operating outside the patient domain – at the individual centres were responsible for the observed poor results," he explained.

"These factors might include the resourcing of the current national haemodialysis programme with dedicated vascular surgical support and access to theatre time, recruitment of vascular nurse specialists similar to international centres of excellence, and high level coordination of the vascular access pathway with quality metrics to ensure timely implementation," Dr Hussein added.

With over 500 new patients in Ireland developing kidney failure and requiring dialysis each year, and in excess of 2,000 patients undergoing treatment on the haemodialysis programme annually, Professor Stack said that the "national programme for dialysis needs to be resourced and empowered to deliver for our patients".

The IKA will be discussing these results with Professor Austin Stack and Professor George Mellotte, National Renal Office.

We will also have an article in the winter *SUPPORT* magazine about the pros and cons of fistulas versus catheters.

The full study can be found at this link...

<https://kidney360.asnjournals.org/content/2/6/955>



Emma O'Connor, her son Callum (14) and Emma's kidney recipient sister Louise Cowman and her twins Aoife and Andrew (12) with pet dog Amber.
Photo by Lisa Trainer

By
GWEN O'DONOGHUE



Brendan McCarthy

Dublin family's six-in-a-row transplants

It has been five years since Dundalk based hairdresser Emma O'Connor underwent keyhole surgery in Belfast City Hospital to donate a kidney to her ailing sister Louise Cowman, who lives in Marino in Dublin.

Louise had suffered pre-eclampsia and then renal failure following the birth of twins twelve years ago.

In March this year, the sisters' cousin Brendan McCarthy's life was transformed when he underwent a deceased donor kidney transplant, in Sweden, where he lives. It was a fortuitous and timely coincidence for the family that the 'gift of life' which Brendan received took place on the first day of Organ Donor Awareness Week 2021 and the same week that Louise's twins celebrated their 12th birthday.

Three days after Brendan's successful transplant operation, another happy event took place back in Ireland when Brendan's niece, a nurse who works in the transplant unit at Beaumont Hospital, exchanged wedding vows watched on by her father Noel and her mother Anne who, five years ago, also received a kidney transplant.

Sisters Emma and Louise's father,

Joe Fitzpatrick, underwent a kidney transplant in Beaumont Hospital in Dublin 14 years ago.

Several members of Emma and Louise's family have been affected by a hereditary kidney condition called Polycystic Kidney Disease (PKD). Six of the family have received kidney transplants including their father, an uncle, aunt and two cousins and all from deceased donors with the exception of Louise's living donor kidney transplant from her sister.

The family consider themselves fortunate to live in times of medical advances and are grateful that because of organ donation so many of them have been given a second chance of life.

Kidney recipient sister Louise explained, "Previous generations were not so lucky, the condition was undiagnosed or unknown. Dialysis as a

form of treatment only became available about half a century ago. My great grandmother Bridie Reinhart buried eight of her children who we now suspect carried the same PKD condition as us."

Five years ago, mother of two Emma O'Connor (46), gave her sister Louise Cowman the ultimate gift, a donor kidney. Fortunately for Emma, she was not born with PKD, a hereditary condition that usually remains dormant until those who have it reach middle age.

Kidney donor Emma, who works for Peter Mark in Dundalk, has two children now 15 and 17-year-old. Emma said, "I could donate my kidney to my sister Louise five years ago as I am fortunate not to have PKD. Louise had suffered pre-eclampsia with her twins, and this sped up the progression of her kidney disease and she was struggling. Our father Joe Fitzpatrick, who still lives in our native Poppintree in Dublin, had a kidney transplant 14 years ago from a deceased donor and some of my aunts, an uncle and cousins had organ transplants too.

"In fact, my cousin Brendan McCarthy, who is living in Sweden, underwent a kidney transplant at Karolinska University Hospital in Stockholm on March 27th, the first day of Organ Donor Awareness Week this year. It was the icing on the cake, when three days later, his sister Anne Downes who lives in Prosperous, Co Kildare and who received a transplant 5 years ago, attended the wedding of her daughter Fiona. Fiona is a nurse and works in the transplant unit at Beaumont Hospital. Brendan and Anne's mother Teresa received a life-saving transplant which gave them over 20 years with her before she passed away five years ago. My father's brother Jim, since deceased, received a transplant when he was in his thirties.

"We are a very lucky family and because of organ donation everyone is well and in good health. It was a very easy decision to donate my kidney to Louise. She had young twins with their whole lives ahead of them and needed a strong, well mammy. It was on St. Stephen's Day in 2014 that I decided I wanted to be a kidney donor to Louise. I had seen



Anne Downes and her newly married daughter Fiona.

Louise was very sick all through Christmas Day and she had just been told that she would need to commence dialysis as her kidney function was extremely low.

We both had seen how much our dad had benefited from a kidney transplant and I knew that a transplant would make a huge difference to her quality of life. After Christmas I phoned Beaumont Hospital and asked if I could be tested for organ donation. It was the best decision I have ever made to proceed with the living donor kidney process and it completely changed my outlook on life. We were a perfect match but still there were certain medical issues which would make the operations more complicated. So, we travelled to Belfast City Hospital for our living donor kidney transplant which was carried out by Consultant Transplant



Emma and sister Louise with kidney transplant father Joe.

Surgeon Tim Browne and another excellent surgeon and supporting team. After the transplant Louise joked with me that she helped me lose 2kg by taking one of my kidneys. I had a really fast recovery from my operation and was able to return home within a couple days. It felt like a blessing that I had helped my sister but also had five more weeks to spend at home with my children before returning to work. I can't thank my employers Peter Mark enough for being so accommodating in allowing me to take time off work."

Louise, who works with the City of Dublin ETB on the quality assurance of apprenticeships and further education courses, said, "I am so grateful to Emma for giving me the chance to live a full life again and my children feel grateful also as they can remember me when I was sick and had little energy.

My twins Andrew and Aoife who turned 12-years-old during Organ Donor Awareness Week were only five when I went on the transplant waiting list. Our whole family feel very lucky that so many of us have been given a second chance through organ donation and transplantation.

Louise explained, "After my transplant I said it was like winning the lotto. It just completely transformed everything. I went from being really sick with young children and now I feel so good it's like I had never been sick. I returned to work and was able to begin coaching my daughters GAA team. My transplant has had such a transformational effect on my life and it's completely down to Emma who I am so grateful to. Of course, we have to acknowledge all the people that supported us to enable the kidney donation to go ahead including our employers, Emma's husband and family who looked after her children, as well as the surgical medical and nursing staff who cared for us in Beaumont and in Belfast.

"Families of living and deceased donors make huge sacrifices. So many members of our family are living proof of the legacy of the selfless act of organ donation. That's why we are supporting the IKA in helping to raise awareness about the importance of organ donation."


Flying high for the IKA

Two times kidney transplant recipient Hugo McCaffrey recalls that the woman who he inspired to jump out of a plane was just a baby in a pram when he first set eyes on her.

By
GWEN
O'DONOGHUE



Helen Milligan with tandem skydive instructor Lukasz Kucharski.



Over the forty years he worked at Gem Oils in Cavan until his retirement in December 2019, Hugo McCaffrey had become an endearing friend and employee in the Milligan's family business. Helen Milligan, Managing Director, describes Hugo as "a dependable, loyal and kind colleague and everyone at GEM would describe Hugo as an inspiration as he carried his journey with kidney disease so bravely".

Hugo was Helen's motivation to undertake a skydive and raise funds for the Irish Kidney Association (IKA) through a Just Giving Fundraising page <https://www.justgiving.com/fundraising/helen-milligan3>. Over €9,000 was raised between the online fundraising and other donations.

Her tandem skydive with Lukasz Kucharski took place on Monday, August 23rd, 2021, at the Irish Parachute Club in Clonbullogue, Co Offaly.

On her fundraising page it states, "Helen's interest in fundraising for the IKA is as a tribute to a Gem Oils colleague who has suffered with long term kidney ailments.

This has led to dialysis and two

transplants. Throughout, his attitude has been an inspiration to his colleagues and friends – he has often been the one making them smile! Using her profile and network to support a fundraising effort, Helen has decided to jump out of a perfectly good aeroplane while it is still in the air! Anyone who knows her well will understand this will be a major challenge! Helen will fund the cost of the jump herself so all contributions will go directly to this very worthy cause."

Helen is a keen advocate for organ donation, carrying a donor card since she first became aware of Hugo's plight. She said, "Seeing first-hand how the 'gift of life' has saved and improved Hugo's life has cemented my simple decision to carry a donor card and my deepest respect for organ donors."

Hugo, who has undergone two kidney transplants, was in his twenties when he started working at Gem Oils in Cavan. He attended his doctor in Clones in 1982

complaining about a bad pain in his back. This led to a diagnosis, at the Old Jervis Street

Hospital in Dublin, that he had advanced stage polycystic kidney disease. Fortunately, his three siblings were spared the hereditary condition.

This shock diagnosis came just a few months after he married the love of his life, Delia. The couple would soon become stalwart members and fundraisers for the Cavan/Monaghan branch of the IKA.

Contd....



Photos by
GAVIN
BROOKFIELD

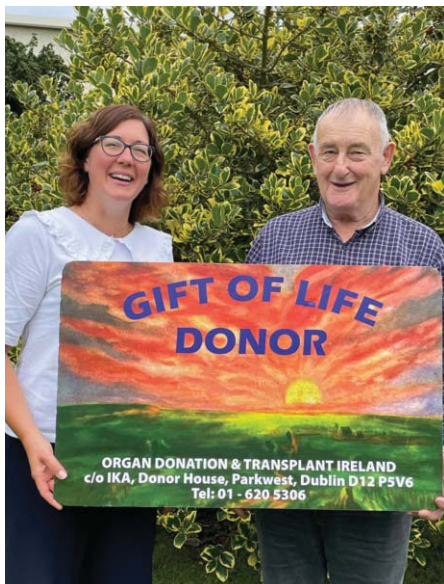
FLYING HIGH FOR THE IKA contd...



Delia and Hugh McCaffrey on their wedding day.

Delia herself did a skydive, in the late 80s, along with branch member Vinny McEntee, to help raise funds for the establishment of a dialysis unit in Cavan. This dream for a local dialysis treatment facility to ease the burden on travel for treatment for patients, became a reality and this was thanks to Delia and Hugo along with other dedicated local branch members who organised lots of fundraisers.

It wasn't until 1990 that Hugo could no longer stave off dialysis treatment. In July that year, he began



Helen Milligan and Hugo McCaffrey



Helen and Hugo in the hangar before her skydive.

his three times weekly trips to Beaumont Hospital for his treatment.

It was a relief for him and Delia that exactly one year later, in July 1991, that he was called for his first transplant. When describing this he said, "I feel huge gratitude to my donor for this transplant which lasted 13 years until it eventually failed.

"I had to return to dialysis treatment again but this time round the unit was up and running in Cavan General Hospital and I could manage my three times weekly dialysis around my work. My employers Gem Oils were very accommodating and understanding as my treatment continued for a few years.

"In 2006, another stranger family came to my rescue as they donated a loved one's kidney to me, and it continues to be a success. In my final years working in Gem Oils, I undertook less physically demanding work for Helen who, like her father, Alec, had been a good employer and friend to me.

"I am humbled that Helen says I was the inspiration for her to do this fundraiser and it's wonderful that with the money it raises that the IKA can help other people with kidney disease while promoting organ donation.

"I would like to formally thank her from the bottom of my heart and also thank my wife Delia who has been my constant support. I'd also like to thank my two kidney donors who have given me the chance to enjoy a full and healthy life."

Helen had been trying to get her skydive 'off the ground' since April last year. Its first deferral was due to the arrival of COVID-19 and other obstacles, including Hugo undergoing an operation and also unfavourable weather conditions hampered it going ahead.

Eventually, a beautiful sunny day on Monday, August 23rd provided the ideal weather conditions for Helen's skydive to proceed. Hugo and Delia, eager to support Helen, made the trip from Cavan to Clonbullogue to witness Helen take her giant leap for charity.





By ROBYN BLACK

Where there's a Will...

Best Will in the World Week, a campaign promoted by Mylegacy.ie to highlight the importance of leaving a legacy to a charity in your Will and Testament and show the difference that such a gift can make, will take place from 21st – 25th, October. During Best Will in the World Week, solicitors across the country will offer consultations for a fee of €50. People interested in making their will, or updating an existing will, are asked to consider leaving a gift to their favourite charity once loved ones have been taken care of.

A recent study showed that despite people's best intentions, almost two out of three adults do not have a Will and Testament or any legal estate planning for after their death. Some of the most common reasons given for this were that they had not gotten around to it, or that they did not know how to start.

In our experience, writing a Will and Testament and having the organ donation conversation often falls into the same bracket of "uncomfortable conversations", and "not wanting to tempt fate". However, it has also been our experience in both cases that proper planning and being clear about your wishes can take away a lot of the avoidable stress, work and worry for your loved ones at a difficult time and can allow your final legacy make a real difference in the lives of others.

Any type of gift left to a charity, big or small, can make a huge difference.

Many will remember that the Irish Kidney Association (IKA) received a significant bequest a few years ago which has allowed us to put some big plans in motion such as developing a Support Centre in Cork. Equally, the smaller bequests that we receive more regularly help us to provide the services that our members rely upon on a daily basis and are just as important when it comes to supporting the Association.

If this is something you would be interested in learning more about, we have set out some basic information below on how to leave the Association a gift in your Will and Testament.

TYPES OF GIFT

You are generally able to leave three types of gift to a charity; specific, pecuniary and residuary. These are outlined on following page.

• SPECIFIC

A gift of a specific item such as jewellery or stocks.

• PECUNIARY

A gift of a specific or fixed sum of money.

• RESIDUARY

What is left of your estate, known as the residuary estate or residue, after payment of debts, expenses and deduction of gifts you have made to family and friends.

WILL MY GIFT BE TAXED?

The IKA has been granted tax-exempt status by the Irish Revenue Commissioners, which means that gifts made in a Will are exempt from inheritance tax - i.e., we will receive the gift in full.

SPECIFIC REQUESTS FOR USE OF A GIFT

As with any donation made to the IKA, we will always endeavour to honour your specific wishes of where the money should be spent. You can make this legally binding within your Will, but this can become complicated if

for some reason we are not able to meet the requirements specified. A more flexible way of doing this is to include a 'Letter of Wishes' – this is not a legal document but allows you to express your hopes for how the gift will be used, which we would always try our best to honour.

WHAT INFORMATION WILL YOU NEED TO LEAVE A GIFT TO THE IKA IN YOUR WILL?

Making a gift to a charity is relatively simple. You need to get the name, address and the Registered Charity Number of the charity you wish to give to and decide what gift you wish to make.

Our details are shown below.

WHAT IF I HAVE ALREADY WRITTEN MY WILL?

You don't have to redo the whole thing, don't worry! You can simply use an addition, known as a codicil, to make small and simple amendments to your existing Will (although you can only have five codicils in place before it is

IMPORTANT NOTE

If you intend to be an organ donor, should you meet an untimely death and circumstances allow for you to be an organ donor, please let your next-of-kin know and do not rely on leaving this information in your Will. In almost every case, by the time your Will is read you will already have passed away and it will be too late to be an organ donor.

recommended that you make a new Will).

Any legacy you leave to the IKA is a pledge to support us in the many years to come, and we will always be grateful for it. If you do decide to include our charity in your Will, we'd love for you to let us know. Drop us a letter, email or give us a call so we can thank you properly and answer any questions you might have.

More information is available online from the Citizen's Information Office – www.citizeninformation.ie or from mylegacy.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:

Signed: _____ Date: _____

Address: _____

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

IBAN: Bank Identifier Code - BIC:

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

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

(Please tick as appropriate)

to start on Date: ____ / ____ / ____

AND CREDIT TO THE FOLLOWING ACCOUNT:

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

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

Tweens cut tresses for charity

By GWEN O'DONOGHUE

Summer 2021 saw three youngsters bravely donate their hair which was grown throughout the pandemic for charities including the Rapunzel Foundation and the Irish Kidney Association (IKA).



Emily with her grandad Denis Connaughton

The tweens, two girls and a boy, ages 11, 12 and 13, from Roscommon, Dublin and Donegal, chose the IKA to benefit from the fundraisers which they ran alongside their 'mane' events inspired by family members with kidney disease. They each surrendered over 14 inches in length of their hair to the Rapunzel Foundation, which supports and helps provide wigs for people suffering hair loss due to Alopecia and other illness. They raised a combined total of €3,435 for the IKA and a further €1,500 was raised from one of the events for Diabetes Ireland and the Irish Cancer Society.

EMILY JONES from Whitehall in Dublin 9 chose her 12th birthday party as the occasion at which she would have her locks cut off. The celebratory event took place under a gazebo in her back garden on a rainy Saturday on July 3rd.

Hairdresser Sarah Nugent donated her services for the event as she cut away sixteen and a half inches of Emily's hair which was divided into seven plaits.

They were watched on by Emily's mother Jillian, her older brother Jack (13), sister Hannah (15), cousins and four of her friends as well as her grandfather Denis Connaughton.

Denis underwent a kidney transplant in January 2020 and is enjoying a new lease of life since then. He hopes to compete as part of Transplant Team Ireland when it is safe for competitions to resume.

Emily raised over €800 for the IKA from cash donations with sponsorship cards. She also ran the fundraiser through the Facebook platform for Diabetes Ireland and the Irish Cancer Society which raised an additional €1500.

She decided to divide the proceeds equally for the two charities choosing for €750 to go to Diabetes Ireland as her brother Jack has Type 1 diabetes and the remainder to the Irish Cancer Society as a family friend is undergoing treatment for cancer.

Emily said, "COVID-19 meant my hair was getting longer and there were no hairdressers open. My friend Katie had donated her hair last year and I thought it would be a lovely thing to do for sick children needing wigs. I wanted to raise money for charities that have helped my family.

"I'm loving my new shorter hair and have recently had fun dying it blue and black". Emily is enjoying her new look and commenced secondary school in September at Clonturk Community College in Whitehall.





As hairdressing services were closed during much of the pandemic it gave **CONNOR WALSH** from Buncrana, an opportunity to explore his curiosity on just how long his hair would grow. It was his Nana, Irene McEleney who suggested that as he had decided that he would get it cut on his 13th birthday, the 26th May, he should do it for charity. Connor held a fundraiser which raised €2,101 for the IKA.

Connor's mum Aileen, a midwife, who works in Letterkenny University Hospital, donated a kidney four years ago to his grandad Seamus after he was diagnosed with Stage 5 kidney failure. Connor's namesake barber, Connor Grant, kindly volunteered his services for free and cut two braids of more than 14 inches of the teen's hair.

Explaining his reason for choosing the IKA as the charity to benefit Connor said, "it is because the money will go to the IKA to help people who have kidney problems and because they supported both



my mother and my grandfather Seamus who underwent a living donor kidney transplant".

The teenager attends secondary school at Scoil Mhuire Buncrana.

continued next page...

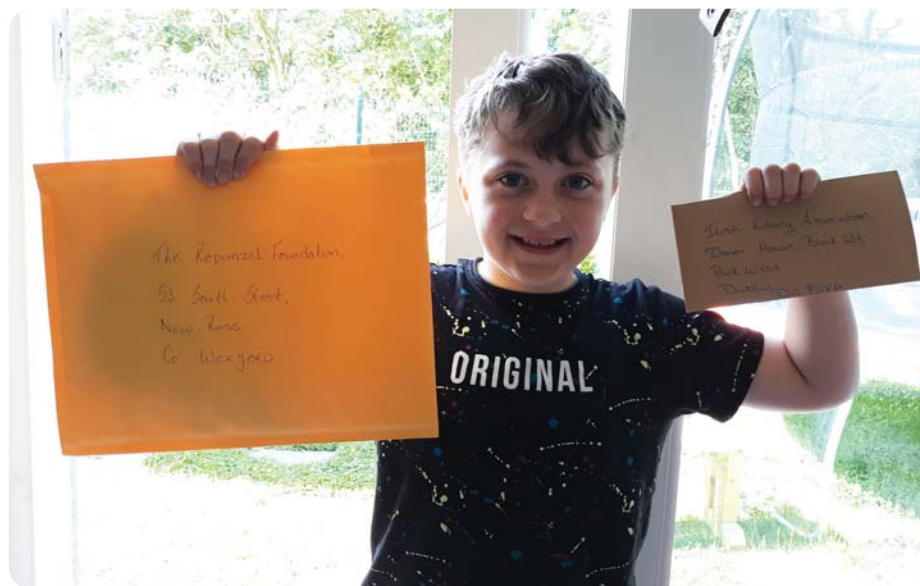
ACCOMMODATION PHONE NUMBER

087-4169907

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



Tweens cut tresses for charity *continued*



LEXI SHEEDY (11) from Boyle, Co Roscommon and her older brother Colin (17) knew from an early age what kidney disease was. The siblings helped their mother, Nicola Coles, as she struggled with the effects of Polycystic Kidney Disease.

Thanks to the 'gift of life' from a stranger, Nicola received a kidney transplant in September 2019 which she says has improved her quality of life considerably.

Lexi, who started in 6th class at Scoil na Naingéal Naofa this September took the brave step of getting her tresses cut on June 24th.

Lexi said, "I wanted to raise money for the charity that helped my mother when she was sick and that is why I chose the IKA. I would like to thank hairdresser Phillippa Breheny who cut my hair for free at her lovely salon. She tied my hair into one

large ponytail before cutting it into a braid measuring 14 inches long.

I'd also like to thank everyone who supported the fundraiser and because of their generosity €535 was raised for the IKA.

Since my mother received her transplant, she can now do things she would not have been able to do when she was sick. We are very grateful that a kidney donor gave her a new lease of life. She has improved greatly and doesn't have to have dialysis every night. When she was sick there were times when I had to help her dress herself as she was so weak. Now she has much more energy. We enjoy going for long walks together with our dog Ellie.

I am happy to have been able to donate my hair to the Rapunzel Foundation and to know that I can help others."



“

Commenting on the youngsters' fundraisers Carol Moore, Chief Executive, IKA said,

"The future looks bright for our country as Emily, Lexi and Connor exude the wonderful spirit of generosity, goodwill, gratitude, empathy, and social conscience which is so common among our young people now. We thank them for raising funds for the IKA to help us to deliver our services in supporting kidney patients and their families while also promoting organ donation."

”

AUTUMN

giveaway

5 X €80

GIFT CARDS FOR

peter mark
CELEBRATING 60 YEARS

Redeemable against products and hairdressing services.*

Our crowning glory, HAIR, which may have been neglected since the arrival of COVID-19, is a coincidental theme running through several stories in this issue of *SUPPORT*.

We hope you enjoy reading about people, young teenagers and slightly older, volunteering to get their hair cut or shaved to fundraise for charities and to raise awareness for organ donation. As well as hairdressers donating their services for free for these fundraisers, you will also read about a hairdresser at Peter Mark in Dundalk who went one step further and donated one of her kidneys to her sister (see page 30).

It is suitably fitting, therefore, that we have teamed up with multi-award-winning Irish brand **Peter Mark** which has very generously sponsored a prize giveaway for some lucky readers.

Founded in 1961, **Peter Mark** has become synonymous with excellence in hairdressing for over 60 years. With 69 salons all over Ireland, they have produced international award-winning hairstylists through their unique 4-year training system and brought that same world-class styling to each of their salons.

Peter Mark is giving away **5 X €80 gift cards**, redeemable against products, hairdressing services or gift cards, which can be used for its online shop (www.petermark.ie) or in person at any of their salons located nationwide. More good news is that the gift cards are transferrable and are valid for five years.

To be in with a chance to win, email: colin@ika.ie with your name, address and phone number, making sure to include the words **PETER MARK** in the subject line of your email. 5 winners will be selected at random and each will receive an €80 gift card.

**Offer applies to products and hairdressing services.*



AL Amyloidosis Support Group Ireland

Amyloid light chain amyloidosis is a "protein misfolding disorder."

It causes organs and tissues, including the heart, kidney, skin, stomach, small and large intestines, nerves and liver, to thicken and eventually lose function. It's a Systemic disease and currently there is no cure for AL Amyloidosis.

With the help of The Irish Kidney Association, the Irish Heart Foundation and the Irish Cancer Society a new support group will be set up this Autumn. It will provide patients, family members, caregivers of those affected with AL Amyloidosis help and support in dealing with this rare disease.

The new group will hold Support Group Meetings online so patients or those affected with AL Amyloidosis can attend from the comfort of their own surroundings.

There will also be meetings with Clinicians, with question and answer sessions, as well as the core Patient Support Group.

A new website and social media pages will be set-up for the new AL Amyloidosis Support Group Ireland. If you or anybody you know is affected by AL Amyloidosis please get the word out there of the new up and coming support group.

In the meantime while the group is been set-up, if you would like any information please contact alamyloidosisireland@gmail.com or call 087-8379542.



Frances Moynihan, Liz Roche, Business Systems Manager, RelateCare, Jason Power, Vera Frisby, Hugh Magee, Ali Tamgumus, Ian Gourlay and Angela Magee. Photo: Joe Cashin



Hugh Magee

Waterford Trio in Head Shave for Hugh

In an act of kindness and solidarity and in support of a kidney patient, the RelateCare Continuous Improvement Team have gone bald and shaved their heads, to raise funds for the Irish Kidney Association (IKA).

The chosen charity is not without meaning as our colleague of 11 years, Hugh Magee, has been receiving incredible support from the IKA this past few years as he bravely deals with ongoing kidney failure, daily dialysis treatment and the difficult wait for a transplant. Hugh's wife Angela, who has been supporting him through all this, is also a long-term employee of RelateCare and its team wished to do something to offer their support in such a trying time.

It is a testament to the care and fondness for Hugh and Angela within both the RelateCare and Rigneydolphin companies that this idea came to life. It was thanks to the creative imaginations of RelateCare's Continuous Improvement team, made up of Ian Gourlay, Jason Power and Ali Tamgumus, who were willing to shave their heads!

In terms of Hugh's own situation, this past year and the pandemic has made things increasingly difficult for a number of reasons.

Hugh told us, "In 2007 I was diagnosed with a hereditary Polycystic kidney disease, causing my kidneys to enlarge and lose function over time. My kidney function has reduced greatly over the last number of years leading me to needing life-saving treatment of dialysis in 2020. Dialysis treatment does the work my kidneys can't do. I attend dialysis three days a week for four-hour sessions, which can be

very tiring on the body afterwards. Being so ill at times has led to other illnesses where I have had to spend weeks away from home in hospital."

All of this was then further complicated when Hugh also contracted COVID-19 during one of his inpatient stays. This has meant that Hugh's place on the transplant list was temporarily paused while his other illness was treated.

"It's been very difficult dealing with this during the pandemic, but I have had amazing support from my wife Angela, my family, the IKA, my employer and friends. I currently write a weekly blog on Facebook called "My Funky Kidneys" about my journey where I discuss my highs and lows. This has been a great avenue for me to share my journey and possibly help anyone else who is, or could be, going through the same journey as I am."

Hugh expressed his deepest gratitude to the RelateCare and Rigneydolphin teams for their efforts

in the head-shaving fundraiser: "The IKA fundraising programme has been impacted during the pandemic and limited due to current restrictions. The head shave fundraiser was a fantastic idea, and I am honoured this was done on my behalf for a charity very close to my heart. It really means a lot to me and thank you all!"

In support of Hugh, RelateCare made a donation to the IKA to aid in its mission to help people who are in need.

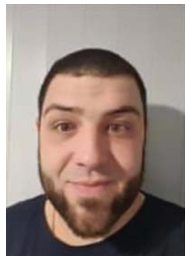
If you'd like to follow Hugh's stories, please check out his blog My Funky Kidneys, <https://www.facebook.com/groups/1712238778916073/?ref=share> where Hugh writes about his experience and journey!

The Waterford Branch wishes to acknowledge that the head shave event raised €500 in-house, with an additional €234 raised on Hugh's Facebook page and a further contribution of €200 from the company. Almost €1,000 was raised. A big 'thank you' from the Waterford Branch.

BEFORE

AFTER

Ali Tamgumus



Jason Power



Ian Gourlay



TAX

RELIEF

By GARY DAVITT

Tax relief on medical expenses incurred by kidney patients

In the interests of making the tax system more user friendly the Revenue no longer requires a Med 1 form to be completed. Instead, taxpayers looking to reclaim tax on medical expenses do so by completing an income tax return.

This can be accessed online through "my account" on www.revenue.ie and involves the following steps:

- Click on "review your tax" link in PAYE services
- Request a statement of liability
- Click on "complete Income tax return"
- In the "tax credits and reliefs" page select "health and health expenses"
- Complete and submit the form

Qualifying health expenses to the extent that they are not covered by health insurance can be claimed at the standard rate of 20%. The following are considered to be qualifying:

- Doctor and consultant services
- Drugs and medicines
- Physiotherapy or similar treatment which includes chiropractor, osteopath or bone setter.
- Special diet expenses for diabetics

To qualify the health care must be carried out or advised by a registered practitioner such as a doctor or dentist. Relief is not allowed for routine dental care or eye tests.

In addition, the following reliefs apply to kidney patients:

- Travel for dialysis. Travelling to and from hospital for dialysis can be claimed at €0.29 per mile or €0.17 per kilometre. This allowance does not apply where a claim has already been made from the HSE
- Home dialysis where the patient uses an APD or haemodialysis machine at home. Here relief is allowed up to €1,900 for electricity, €1,945 for laundry and protective clothing and €310 for telephone
- Chronic Ambulatory Peritoneal Dialysis (CAPD) where the patient has treatment at home without the use of an APD machine. Here relief is allowed up to €1,505 for electricity and €310 for telephone

Relief can be claimed for past qualifying expenditure going back four years.

A full list of all allowances and reliefs can be found at www.revenue.ie or by contacting Gary at Email: gary@ika.ie or go to <https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/health-expenses/index.aspx>



There's more to FIBRE than you think!

WHAT IS DIETARY FIBRE?

Fibre is found in plant foods and is a necessary part of a healthy diet. It is also known as roughage or bulk.

TYPES OF FIBRE

Fibre can be divided into two main types: **soluble** and **insoluble**.

Soluble fibre dissolves in water and absorbs fluid as it passes through the digestive system. It slows down digestion, keeping you fuller longer as well as creating softer stools.

Insoluble fibre does not dissolve in water. It passes through our digestive system in close to its original form. It promotes the movement of food through the digestive system and increases stool bulk. In this way it can be of benefit to those who struggle with constipation or irregular bowel movements.

Plants have varying amounts of each type of fibre. This is one of the reasons to include a wide range of plant foods in your diet.

WHERE DO YOU GET YOUR FIBRE?

The best sources of fibre are fruits, vegetables, beans*, peas*, nuts* and seeds.

In general, the least-processed foods are those that provide the most fibre. It is important to include a variety of sources every day.

Remember to keep to your daily allowance of fruit, vegetables, beans, peas and nuts. Check with your dietitian if you are unsure of your allowance.

**Beans, peas and nuts are higher in potassium, phosphate and protein. Speak with your dietitian for further guidance.*

Tips to increase your fibre intake:

- Eat all your daily allowance of allowed fruits and vegetables.
- For snacks try fruit or vegetable sticks.
- Choose a high fibre breakfast cereal e.g. wholewheat biscuit cereal or porridge. Why not add some fresh fruit for extra fibre.
- Replace white rice, bread, and pasta with brown rice and whole grain products.
- Add beans and peas, from your protein allowance, to your meals. They taste great in stews, stir fries, curries, soups and salads.
- Keep a supply of frozen vegetables so you are never without.
- Eat whole fruits instead of

drinking fruit juices.

If you are planning on increasing your fibre intake, it is a good idea to do so gradually. It is also important to drink fluids (within your fluid restriction, if any) and to be physically active.

REAP THE BENEFITS

Although fibre is probably best known for its ability to prevent or relieve constipation, it does more than just keep you "regular."

HEALTHIER GUT

We are increasingly learning about how important it is to have the right balance of gut bacteria – or a healthy microbiome. The gut bacteria use fibre for fuel. In turn they produce short-chain fatty acids which have been linked with improved immunity¹ and decreased systemic inflammation². Our large intestine also uses these fatty acids to keep healthy. A healthy gut means improved digestion and absorption of nutrients.

LOWER BLOOD CHOLESTEROL

There is good evidence that fibre reduces blood cholesterol levels³. When blood cholesterol levels are

high, arteries can get clogged up with build-up of fat. This can make them narrow and lead to an increased risk of heart disease. It is thought that some soluble fibres lower blood cholesterol by binding to it and our body excretes it in the stool.

STABILISE BLOOD SUGARS

Fibre can improve blood sugar control. Eating a diet high in fibre slows sugar absorption from the small intestine into the blood. This reduces the possibility of a big spike in blood sugar levels which puts strain on your pancreas and if diabetic, requires more insulin to control.

HOW MUCH FIBRE DO WE NEED?

Adults need at least 25g of fibre per day for good health. Over 80% of

us in Ireland don't reach this recommendation!

THE BOTTOM LINE

Fibre plays a key role in helping maintain our overall health and wellbeing. It boasts lots of health benefits, and high fibre foods are also high in vitamins, minerals, and other healthful nutrients. Variety is key and helps our body reap all the benefits!

1. Schley, P.D. & Field, C. (2002). *Immune-enhancing effects of dietary fibres and prebiotics*. The British Journal of Nutrition.
2. North CJ, Venter CS, Jerling JC. (2009). *The effects of dietary fibre on C-reactive protein, an inflammation marker predicting cardiovascular disease*. Eur J Clin Nutr.
3. Reynolds A et al. (2019). *Carbohydrate quality and human health: a series of systematic reviews and meta-analyses*. Lancet.

By **KAROLINA PAWLAK**

(Senior Dietitian)

BEACON RENAL DROGHEDA

on behalf of the Renal Interest Group of the



5 FOOD SWAPS TO BOOST YOUR FIBRE INTAKE

35g Puffed Rice Cereal

Fibre Content
1.8g



2 wholewheat cereal biscuits

Fibre Content
3.9g



White bread slice

Fibre Content
0.9g



Wholegrain bread slice

Fibre Content
2.6g



15g Jam spread

Fibre Content
0.0g



1 medium apple

Fibre Content
4.3g



130g white pasta

Fibre Content
3.3g



130g wholewheat pasta

Fibre Content
10g



Plain yogurt

Fibre Content
0g



Yogurt with 50g raspberries

Fibre Content
3.3g





LEADING FROM EXAMPLE

Our National Advocacy and Projects Manager, Colin White, was re-elected to the Board of Trustees of the World Transplant Games Federation (WTGF) for another 4-year term at the recent virtual General Assembly of all the member countries.

Colin was first elected to the Board of the WTGF in 2009 and has been an active member since. Colin joined the staff of the Irish Kidney Association in 2005 to take on the development of our sports programme and that was his first year to be the Ireland team manager at the biennial World Transplant Games.

Following his re-election to the Board, Colin was also re-elected as Treasurer of the Federation by his Board colleagues, a role that he has had since 2015.

Colin's professional achievements at an international level in transplant and dialysis sports are rooted in the reputation of every Ireland team that has ever participated in World and European competitions. Ireland's teams have always been known for their team spirit, their sense of fair play and their sense of fun and this is recognised on the international stage.

Since its inception, the promotion of organ donation for transplantation has been at the core of our sports programme. The team celebrates honest effort rather than competition results with everyone at every age and every ability feeling an equally valued member of the 'family'. As always, the family is open to new members throughout the year. Contact teammanager@transplantteamireland.ie for more details.



SPORTS UPDATE

As you will have read elsewhere in the magazine, the HSE has committed to a third vaccine jab for people who are clinically extremely vulnerable to the COVID-19 virus (including people on dialysis and transplant recipients). The roll-out of this is expected to start imminently. This is in response to research showing that the protection provided by the first two doses of a vaccine has not been adequate for many in this cohort.

As with all of the Association's activities that involve bringing people on dialysis and transplant recipients together in person, our sports programme's normal meet-ups have been put on hold for a long time now. This is not to say that sport or physical activity is put on hold – individuals are encouraged to keep active as part of their overall personal health management.

Whilst the goalposts for the re-start of the sports programme seem to be moving all the time it is in response to the ever-changing situation in relation to COVID-19 including increased levels of the virus in the community, the Delta variant and the efficacy of the vaccines.

The world response to the pandemic has been organic rather than pre-planned – we have been learning as we go along as it is an unprecedented situation.

We are looking forward to re-starting the programme as soon as it is deemed appropriate and safe to do so – it has been too long since we have been able to meet in person.

We are encouraged by the fact that the organisers of the 2023 World Transplant Games in Perth

are working at full pace to deliver an excellent event in April that year. Equally, we are waiting to hear from the European Transplant & Dialysis Sports Federation about the 2022 European Transplant & Dialysis Sports Championships that were planned for Oxford, England.

It is also exciting to report that the World Transplant Games Federation currently has two virtual activities that are open to all – transplant recipients, family, friends, donor families, medical professionals and anyone connected with the wider community.



Currently running is the first outing of the **Virtual Golf Challenge**. It is open to all golfers offering you the opportunity to play on your own home course. The third year of the **Billion Steps Challenge** starts this month too. The beauty of the Billion Steps Challenge is that you set your own goal. You are not competing against anyone, you are contributing to a collective international effort aiming to achieve a total of two billion steps together in 10 weeks this year.

Last year's Challenge was a huge success and a very popular element of it was the opportunity to connect with people all over the world.

More details about the Virtual Golf Challenge at...
<https://wtgf.org/the-first-world-transplant-virtual-golf-challenge-is-tees-off/>



fit for life

BILLION STEPS CHALLENGE



Proudly supported by  NOVARTIS

The World Transplant Games Federation
invites you to join the **Billion Steps Challenge 2021**

Join our global transplant community and **STEP your way to better health**,
raise organ donation awareness and celebrate those **Powered by the Gift of life**.

20 September – 28 November 2021

10 weeks • 2 BILLION STEPS • Free Entry



SIGN UP



SYNC DEVICES



CREATE TEAMS



GET STEPPING

EVERYONE IS WELCOME!

Transplant recipients, living donors, donor families,
health professionals, care givers, friends, family,
colleagues and supporters!

JOIN US!

- Get moving and increase your daily step count
- Make friends from around the world
- Stand a chance to win lucky draw prizes
- Unlock Teddy Bears for transplant youth

Let's **STEP UP** to the Challenge,
Let's **STEP IN** to greater wellbeing,
Let's **STEP OUT** and get moving!
Let's get **Fit for Life!**

MoveSpring



For more information, visit <https://wtgf.org/billion-steps-challenge/>



www.wtgf.org



[WorldTransplantGamesFederation](https://www.facebook.com/WorldTransplantGamesFederation)



[WTGF1](https://twitter.com/WTGF1)



[worldtransplantgames](https://www.instagram.com/worldtransplantgames)

STEP your way 2 better health

10 weeks to reach 2 billion steps

20th September – 28th November 2021

EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION (EODD)



The European Day for Organ Donation and Transplantation (EODD) is held to raise awareness of the importance of organ, tissue and cell donation as a way to improve and save lives.

SATURDAY, OCTOBER 9TH

The mission of the EDQM/Council of Europe is to **set quality, safety and ethical standards for organ, tissue and cell donation and transplantation for health professionals.**

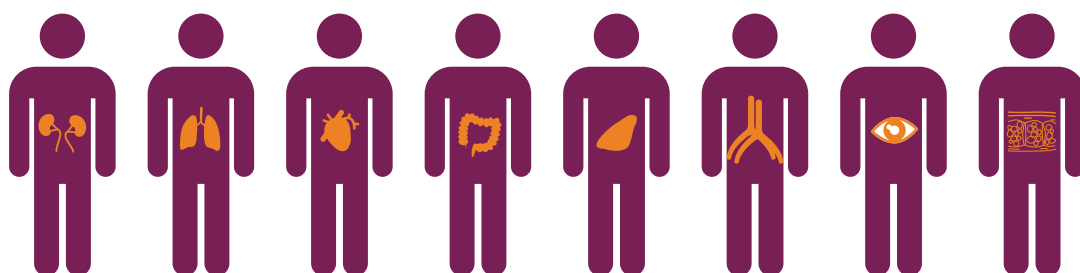
By organising the EODD in a different country every year, the EDQM (European Directorate for the Quality of Medicines and Healthcare) seeks not only to encourage public debate and reflection on this topic, but also to invite the medical community and policy makers across Europe to reflect on the importance of this life-saving therapy.

Above all, the EODD should be seen as an occasion to honour all organ donors and

their families and to thank transplantation professionals, whose hard work helps to save lives and improve many people's quality of life.

Taking into account the COVID-19 pandemic affecting all countries worldwide and the continuing uncertainty related to the organisation of major public events until the end of the year, the EDQM has decided to **celebrate EODD 2021 online.** Poland will be the hosting country for EODD 2021 which will be celebrated on Saturday, October 9th. More information will be provided as it becomes available on the IKA's website and social media and on the EDQM website.

<https://www.edqm.eu/en/meet-george-european-day-organ-donation-and-transplantation-eodd>



36th Annual Service of Remembrance and Thanksgiving

As with 2020, our 36th Annual Service of Remembrance and Thanksgiving will be 'virtual' again this year to respect the current COVID-19 restrictions. We are working with Kairos Communications again to ensure a professional production.



Our Liturgy Committee is busy working on the planning of the ecumenical Service which will be filmed in early October in Our Lady Queen of Peace Church on Merrion Road, Dublin 4.

The Service will be broadcast at a later date with details advertised in good time on our website and social media.



Leonard and Pat Fleming



BROTHERLY LOVE

This year marks the 42nd anniversary of a living donor kidney transplant between brothers Leonard and Pat Fleming from Athy, Co Kildare. Their sister, Michelle Horan, an active member of the Kildare branch, has been receiving dialysis treatment for eight years following two kidney transplants which she received from deceased donors.

Landscape gardener Leonard Fleming, who owns Fleming's Garden Centre in Athy, was just 10-years-old when his older brother Pat, who was 22 at the time, donated a kidney to him. The transplant operations took place on February 27th, 1979.

Six weeks later, Leonard and Pat's happy successful transplant event was tinged with sadness when their sister Theresa, who was receiving dialysis treatment, passed away at the age of 20 from her kidney disease. The family bereavement was just a few weeks before Pat's wedding.

The brothers have remained close and their homes are beside each other just a few miles outside Athy town.

Since donating one of his kidneys to Leonard, Pat pursued a career as a secondary school teacher, got married, had two children and is now a proud grandfather. He teaches Business Studies at Coláiste Eoin in Hacketstown, Carlow.

The brothers' sister, Michelle, who also lives nearby, shares the same genetic kidney disease Medullary Sponge Kidney (MSK) as Leonard and their late sister Theresa. Michelle was in her early twenties when she started dialysis. She has since undergone two kidney transplants, the first which lasted for three years but with the second transplant she enjoyed an additional 20 years away from dialysis before returning to dialysis treatment, which she has

By GWEN O'DONOGHUE



Taken just a couple months after their transplant operations, Pat on his wedding day with his kidney recipient, Leonard (10) and their brother Mitchell.

been undergoing at home for almost eight years now, as she remains on a waiting list in the hope for her third kidney transplant.

Michelle, who is in her early fifties, worked as a Special Needs Assistant up until the arrival COVID-19. She said, "Pat and Leonard are living proof of the successful longevity of living donor kidney transplantation. I feel fortunate to be close to them as well as being grateful to the two deceased donors who got me to this point in my life. My donors made it possible for me to become a mother to a healthy son David who is now 24-years-old."

Michelle Horan



Holidays return

By **DEBORAH CERVI**

This year we are delighted to have finally been able to re-open doors to our holiday homes in Kerry and Waterford. Holidays at the three holiday locations could not be availed of last year due to safety concerns around the pandemic causing additional pent-up demand for them this year.

A holiday is a pause, a rest, and time to recharge. A holiday is an opportunity to get away from your day-to-day life, away from work, from stress and something to look forward to, holidays can leave us with a suitcase of life-long happy memories.

Patients and families have been enjoying their much-needed break away and there has been lots of positive feedback from patients and families who have enjoyed a vacation in the IKA Holiday Homes.

I would like to thank both the Kerry and Waterford Branches who have done tremendous work to open our holiday homes safely. We could not have opened this year without their hard work and

dedication. Their volunteer work is greatly appreciated.

We will continue to monitor all developments relating to COVID-19 and remain committed to ensuring a safe environment for guests.

We look forward to welcoming more patients and families over the next few months. We hope that by facilitating these holidays for deserving families that they can make life-long treasured memories.

Although our holiday centres are fully booked for this year, enquiries for next year can be made by contacting deborah@ika.ie for an application form to be sent to you in early 2022.



Paul McCarthy from Cork with his wife Patricia and daughter Molly at the Killarney, Co. Kerry house.



Ray Halligan, Waterford Branch Chairman with Ann Marie Leonard from Dublin and her partner John Gaynor.



Owen Hanrahan from Kilkenny with his wife Therese and three sons, Matthew, Paul and James with Brendan Herbert, Kerry Branch Chairman.

PKD September
18/2021
European
Patient Day

Event hosted and delivered by

PKD International  

zoom

INTERNATIONAL WEBINAR ON PKD

**FREE for patients, family members,
carers and healthcare professionals
interested in learning more about
ADPKD (autosomal dominant polycystic
kidney disease).**

The first ever **European PKD Patients Day** will be held on Saturday, **18th September**. To mark this inaugural event, a free ZOOM webinar will be held on the same day, organised by PKD International, a global network of patient organisations created to fight all forms of autosomal dominant polycystic kidney disease.

Mike Kelly, Psychological Consultant at the European Dialysis and Transplant Renal Nurses Association, who previously worked as Counsellor at the IKA's Donor House, will be among an impressive line-up of international speakers at the event which will run from **9.45am until 16.45pm**.

Topics covered around PKD disease will include genetic testing, pain, research, nutrition, organ donation and transplantation in Europe, COVID-19, mental health as well as ADPKD in children.

IKA board member and secretary of the Leitrim branch **Cathriona Charles**, herself a kidney transplant recipient, is the Irish representative on the event's organisational committee.



**REGISTER IN ADVANCE
for the online webinar which is FREE!**

**To register and see the full programme
of speakers and an outline of topics to be
covered please visit
www.pkdinternational.org**

**SUMMER PRIZE
GIVEAWAY
WINNERS**

Thank you to the team at **CarePlus Pharmacy (www.careplus.ie)** for their very generous gift of a 5 x €100 vouchers for Suncare and Skincare products to be used at one of their Pharmacies.

THE WINNERS WERE:

Rebecca Loftus, Co. Waterford; Helena Cleary, Co. Sligo; Celine Tuite Co. Meath; Alison Barrett, Dublin 11 and Niamh Ann Dolan, Co. Mayo.



'ALFRED' is the third in a series of four short stories, 'Taxi Tales' written by the late Alexander Ager, formerly a member of our Dublin South IKA branch. The short stories are inspired by his experiences while travelling by taxi to and from dialysis and give a snap shot of the simple humanity of the friendships and the characters we meet.

'ALFRED'

Alf, or Fred, dependent on who is talking, is about my son's age and a regular driver for those of us that are dependent on tightly scheduled hospital visits to keep us in reasonable health. Some of his rides found him rather quiet, but one day when I was having issues with my mobile phone, I discovered that he and I had a common interest, namely in today's overly complicated technology. Being one of his four rides, ferried to and from the hospital, I ended up sitting up-front next to Alfred and discovered, in him, a character that I could never have imagined.

When his son married, he made his house over to him, as being a widower, he only needed a room for himself and was happy to fall into the daily routine of his daughter-in-law. There was another side to Alfred that I noticed through the odd bits and pieces that he purchased for a 'friend', a friend, who on looking at her photo, turned out to be an attractive middle-aged widow living in Africa, his holiday destination every Summer and Easter, ticket prices permitting.

"We chat a couple of times a week," he commented showing me another photo on his new mobile phone of a homely buxom late thirties, early forties woman with a warm welcoming smile.

"I send her a parcel every month or so. When she says that she likes some item that she cannot get locally, then, when I see it, I buy it, nothing expensive mind you, any biggish items I bring over with me in the summer."

I admitted to being a little sceptical. Regular visits? Goodie bags? Plus overseas phone calls? But all Alfred wanted was an undemanding friend, his new mobile phone, and his next ticket to visit someone who mattered to him.

Alfred moved on last Autumn looking after other rides. Strangely I still miss him and his fascinating selection of bits and pieces for Africa.



Study recommends introduction of exercise programmes to haemodialysis units in Ireland

(A collaborative study between the Department of Renal Medicine and Department of Physiotherapy at Cork University Hospital)

Structured, physiotherapy-led, intra-dialytic exercise can be safely and effectively introduced to Irish haemodialysis units, a study has found.

Intra-dialytic exercise was associated with many clinical benefits but it has not been widely adopted in routine practice, researchers noted in the February edition of the *Irish Medical Journal*, Vol 114, No. 2, P261.

"Exercise training is known to be beneficial for adult patients with chronic kidney disease," they wrote.

"There is a growing body of evidence that providing a structured exercise programme to haemodialysis patients during their routine dialysis treatment has significant benefits, including increased exercise tolerance, improved mobility and functional status, improved muscle strength and improved quality of life."

These programmes were also associated, they said, with improvements in blood pressure control, arterial stiffness and small solute clearance.

During their study, an intra-dialytic exercise programme was piloted to investigate patient adherence and early clinical benefits in an Irish haemodialysis cohort.

The primary outcome of the 8-week exercise programme was patient adherence.

Secondary outcomes included

physical functionality, quality of life and dialysis adequacy.

Physical functionality was assessed by hand-grip strength, the sit-to-stand test and the Duke Activity Status Index (DASI). Patients partook in 45-minute exercise classes twice-weekly, which included resistance training and aerobic training.

Six patients took part in the study.

The mean age of the participants was 58.2 years, with a mean dialysis vintage of 24.3 months.

Adherence was high, with five of the participants completing more than 75 per cent of the sessions.

The results showed there was a significant increase in physical functionality, as measured by the sit-to-stand test, from a mean of 21.1 (in 1 minute) to 27.3 (in 1 minute) following the programme.

There was no significant change noted in the other secondary outcomes, while no safety concerns were encountered.

Dr. Frank Ward and his fellow study associates at CUH said the findings of the pilot study were consistent with international findings.

"More widespread introduction and expansion of such programmes across the national chain of dialysis units would be expected to result in significant clinical benefits for patients and potentially significant cost savings for healthcare providers," they wrote.

© Reprinted courtesy of Irish Medical Times.

IKA SUPPORT AUTUMN 2021

IKA welcomes Fiona



The Irish Kidney Association is pleased to announce the appointment of **Fiona Aherne** as **Patient Services Manager**.

Fiona brings to the new role a wealth of experience.

Fiona qualified as a social care worker 15-years-ago and has worked in the charitable sector ever since. She began her career in Crosscare's crisis intervention homeless services working with children in Dublin city centre and then within Crosscare's many homeless services.

Later she moved to the patient organisation DEBRA Ireland where she advocated on behalf of those living with Epidermolysis Bullosa. These varied roles have exposed Fiona to the needs of those most marginalised in society whilst equipping her with the skills to assist in meeting those needs.

Fiona stated, "my previous roles as a social care worker and advocacy manager have strengthened my ability to advocate on behalf of those I support. I believe in an inclusive society where everyone gets the same opportunities as one another regardless of the cards they are dealt in life."

"I have never underestimated the power of listening and have worked hard to refine my skills in the areas of support, empowerment, and advocacy over the course of my career. I believe in the power of people and the patient voice in particular."

Fiona lives in her native Dublin with her husband Darren and her two children Cian and Olivia.

Tribute to... Vera Dwyer

This summer, we bade a sad farewell to great grandmother and Guinness Book of World Records holder Vera Dwyer from Ballinafad, County Sligo, following a short illness. A long-time friend of the Irish Kidney Association and passionate advocate for organ donation until the end, Vera leaves behind an indelible impression for her tenacity of spirit in how she embraced the second chance at life she was given 33 years ago.

Diagnosed with Idiopathic Pulmonary Fibrosis when she was a young mother of four, she underwent a life-saving single lung transplant in Harefield Hospital in England in 1988 having been given just days to live. The longevity of the successful single lung transplant secured her a place in the Guinness Book of World Records which made international headlines. In 2009, Vera underwent a kidney transplant and hip replacement surgery in 2018.

Her daughter Linda Kiernan explained, "we miss her greatly, but we take comfort and pride in all that she has done and for her positivity and the resilience she showed no matter what life threw at her. She was a devoted mother, grandmother, and great grandmother.

She was passionate about organ donation and transplantation. It was only in March this year just after her 80th birthday and coming out of hospital following a



Vera with her Guinness Book of World Records award in 2014.

bout of Sepsis she was delighted to be asked and agreed to support our local GAA club, Eastern Harps, health club initiative which promoted organ donation, along with the brother of a young woman whose organs were donated.

"To her children, she was just our mammy, but when she passed, we were surprised and deeply touched when we became more aware of how many people's lives she had touched with her kindness and positivity. She prayed for her donors every single day and they were prayed for at her funeral mass. The 'gift of life' was treasured by her, and the role of

organ donors and their families was always in her thoughts. Promoting the generosity of spirit in organ donation is her legacy and it is what she would have wanted to be remembered for."

Towards the beginning of this year, when asked by the Irish Kidney Association for her photo to be included along with other transplant recipients in an organ donor awareness campaign poster, she happily obliged.

Predeceased by her husband Michael in 2014, Vera is survived by her two sisters, her devoted four children, their families including her treasured eight grandchildren, three great grandchildren and extended family. May she Rest in Peace.

Tribute to... Ian O'Doherty



It was with great sadness, that we learned of the passing of heart patient Ian O'Doherty on July 6th, 2021, just three months after supporting the Organ Donor Awareness Week campaign. Ian, from Castletroy, County Limerick, passed away before his 47th birthday. He had been an inpatient in the Mater Hospital, for almost a year waiting for a donor heart.

Whilst bravely battling with heart failure as his hopes for a heart transplant diminished, and with two false calls, Ian selflessly shared his plight in a moving video for the launch of the awareness campaign, with the loving support of his daughter Ava and her mother Helen. Sadly, one year after he began his lonely isolation in a Critical Care ward, in the weeks before his passing he was taken off the transplant waiting list as he would not have been strong enough to undergo an operation.

Weeks before his passing he was interviewed by the *Sunday Independent* and the article generated huge organ donor awareness and a surge in requests for donor cards.

Our thoughts are with Ava, Helen and his family and we hope they can take comfort in his legacy that by sharing his story about his broken heart he touched the hearts of so many others while increasing organ donor awareness. May he Rest in Peace.



Welcome to our Autumn edition of *SUPPORT*.

RESPIRE CENTRE

Our holiday apartments, at Tramore, re-opened in July and will run until October. Due to COVID-19 restrictions we are using two apartments each week this year. The patients and their families, who have received a holiday, so far are very happy with this arrangement and the feedback has been excellent. We wish everyone a safe and enjoyable holiday.

FUNDRAISING

A 9-a-side football fundraiser was held on Saturday, June 26th, 2021 in St. Joseph's FC to raise much needed funds for our Waterford Branch. The event was organised by the Branch Honorary Chairman Ray Halligan. It is worth noting that St. Joseph's FC is the oldest football club in Ireland and Ray, having played there as a youth was looking forward to checking if he was as agile a player as he was when last on the pitch!

The IKA team was a selection of over 40s, 50s and 60s and included Ray himself as well as a group of younger lads including Ray's son Harry. The result was 4-3 to St. Joseph's in spite of the valiant efforts of the IKA team. Ray is convinced that but for the 'dodgy' decisions by the referee the IKA team could have won!!!!

Well done to St. Joseph's over 35s on their win.

An enjoyable afternoon was had and the cause is very worthy as all

WATERFORD

By VERA FRISBY



Ray Halligan, Harry Halligan, Sean Reilly, and Cormac Reilly.



Brendan Halligan, Ian Stenson, Aaron Stenson and Henry Halligan.



money raised locally is used locally. St Joseph's made a very kind donation of €200 and €465 was raised in total. On behalf of the Waterford Branch IKA we wish to

thank the following sponsors, for what we hope will become an annual event: Dooley's Hotel, St. Joseph's FC, Ballybeg Stores and Mike Brosnin, Ballymountain.

IKA SUPPORT AUTUMN 2021



St. Joseph's team 24th Division.

Newtown Fundraising Committee is organising a Virtual 5K Run/Walk. The proceeds will be divided between Down Syndrome Ireland and IKA Waterford branch. We would like to thank the Newtown Fundraising Committee for continuing to support the work of our branch.

CONDOLENCES

We would like to take this opportunity to remember all patients, members and friends who died recently, may they

rest in peace.

We hope to have our next branch meeting, towards the end of September, at the holiday apartments in Tramore. If you would like to join us, please contact: Frances Moynihan – Ph: 087-2411549 or email:

franceswaterfordika@gmail.com

We send every good wish to all our branch members, volunteers, patients, families and friends, especially those in hospital. Stay safe and take care of each other.



Christy Hannigan, Chairman of St. Joseph's FC presents Vera Frisby, Treasurer Waterford IKA Branch with a cheque for €200 from St. Joseph's FC, proceeds from a friendly fundraiser with the Waterford IKA.



The Waterford IKA team.



Find us on:
facebook®

PATIENT REPRESENTATIVE ON RENAL UNIT PLANNING TEAM

The Department of Health and the management of Sligo University Hospital have both agreed to have a member of our Branch join the Project Team working on plans for a new dialysis unit at the hospital.

The Minister for Health, Stephen Donnelly, had earlier confirmed to us that a Project Team has been set-up with key stakeholders to progress plans for a new unit.

We welcomed this development and requested that a member of our Branch should join the Project Team to represent the patients.

In letters of reply a spokesperson for the Minister, and also hospital manager Grainne McCann, both stated that they are supportive of the inclusion of a patient

representative onto the Project Team when the capital project is approved and moving to design stage.

We in the Sligo branch welcome this progress and will continue to monitor developments on behalf of patients.

SLIGO MAN LIAM PEDALS FOR IKA

Sligo man Liam O'Rourke recently completed a sponsored cycle from Malin Head to Mizen Head which raised €2,770 for the IKA. Liam, who is 26 and from Geevagh, is a nurse in the Mater Hospital. He was among a group of seven nurses

who did the 630km cycle over five days in aid of various charities. Liam said: "I chose to support the IKA as I have seen first-hand the fantastic work they do." Fellow Geevagh man Billy Kelly received a kidney transplant in 2017.

GAA €5,000 CHEQUE

It's almost 8,000km from Sligo to Mount Everest. But a GAA club from South Sligo bridged the gap earlier this year in an initiative to help kidney patients and promote organ donation.

Coolaney/Mullinabreena GAA Club members 'conquered Everest'

Liam O'Rourke



At the cheque presentation, Marie Fowley (IKA Board member), Conor McCormack, Enda Kivlehan (Coolaney/Mullinabreena), Sean Fowley (IKA Sligo Branch Chairman), Alan Duggan (Coolaney/Mullinabreena) and Geraldine McHugh (IKA Sligo Branch Secretary)

without leaving their own local area. They climbed the nearby historic Knocknashee Hill 100 times within 12 hours, more than matching the height of Earth's highest mountain.

In doing so they raised €5,000 for the Sligo Branch. Club players and officials gathered at their new Nace O'Dowd Pitch on August 17th to present the large cheque to members of our branch.

Clubmen Enda Kivlehan and Shane O'Brien, with the help of fellow players and club members, organised the climb while adhering to COVID-19 restrictions by going up the hill in pods of three.

The Coolaney/Mullinabreena Club, along with their neighbours in Saint Nathy's Ladies Football Club, have been strong supporters of organ donation over a number of years. Both Clubs display the organ donation message on their jerseys.

The Clubs took up the cause after 4-year old Ríoghnán Flanagan, son of St. Nathy's Etna Flanagan and her husband Connor, passed away in 2015 with a heart ailment before a suitable transplant donor was found.

The cheque presentation event was organised by Enda Kivlehan of the Coolaney/Mullinabreena club and Sligo IKA branch secretary Geraldine McHugh.

Branch chairman Sean Fowley thanked the club members for their generous donation and distributed organ donor cards to players.

DEATH OF TARA MCHUGH



In happier times, Tara near her home at the promenade in Strandhill.

This piece is on a personal level. In the summer *SUPPORT* magazine we sent get-well wishes to our daughter Tara McHugh who was then a patient in St. Vincent's Hospital, Dublin.

Unfortunately, it was not to be. Tara passed away in Sligo University Hospital on June 26th at the age of 39. She had spent most of April and May there, before being transferred to St. Vincent's University Hospital.

Tara had a kidney transplant in Beaumont Hospital in 2018. The illness that caused her death was not kidney related.

Her mother Geraldine and I thank the Irish Kidney Association for their loyal support. This support extended all along the journey from when she went on dialysis in 2016 right up to when the Chairman of the Sligo branch Sean Fowley helped carry her coffin on the day of her funeral.

Meanwhile, at time of writing, Tara's younger sister Mairead is due to go on dialysis within the coming weeks.

SYMPATHIES

Three dialysis patients at Sligo University Hospital passed away within a week of each other at the end of July.

John Clarke of Ardnaglass, Ballymote died peacefully, at the hospital on July 25th. His funeral Mass was in the Church of the Immaculate Conception, Ballymote with burial afterwards at St. Nathy's cemetery, Collooney.

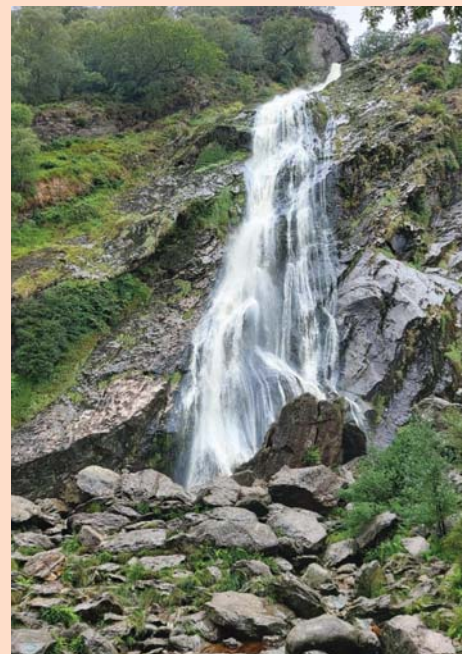
Andy Mulligan, Cortober, Carrick-on-Shannon, passed away at Sligo University Hospital on July 31st. Andy's funeral Mass was in St. Michael's Church, Drumlilion. Burial was afterwards in Drumlilion cemetery.

Margaret Kane, Culfadda, Ballymote, passed away at Ballymote Community Nursing Unit on August 1st. Her funeral Mass was held in Culfadda Church followed by burial in Knockbrack Cemetery. We in the Sligo IKA branch send sympathy to the families and friends of all three departed. They are sadly missed by the patients and staff in the dialysis unit. RIP.

IKA SUPPORT AUTUMN 2021

DUBLIN EAST & WICKLOW

By BERNIE DWYER



As Autumn has arrived we still hope for further lifting of restrictions and an end to this virus as the Delta variant gives us extra concerns. We all should be well and truly vaccinated by now and hope as many as possible enjoyed a holiday of sorts.

To those in the Branch, who were able to avail of one of the IKA holiday homes in Tralee, Tramore or Killarney, we hope you enjoyed these lovely venues, especially the newly-refurbished Tramore. 'Thank you' to the volunteers who keep them safe for our vulnerable visitors – we really appreciate your hard work.

It has been a quiet Summer in the Branch and as always we invite members to engage with us sharing any concerns or ideas. We are always happy to hear from you and welcome new members who would like to join in our next Zoom meeting which will be notified on our Facebook page, or by email.

The Kilmacanogue Horse Show took place on a wet Saturday, August 14th, with no public attendance. A few volunteers from our branch, who felt safe to do so, attended and we wished the events Committee well. Next year will be their 50th Anniversary so hopefully it will be a more exciting year.

Sending best wishes to you all in East Dublin and Wicklow.



Find us on:
facebook®

Greetings once again to all our patients, their families, kind carers and members.

A number of successful Branch Zoom meetings have been held to date and we aim to continue with them once monthly. Each meeting provides us with an opportunity for members to chat and support each other as we continue to embrace these challenging COVID-19 times. Hopefully we will be able to meet face-to-face towards the end of the year.

RUN FOR A LIFE VIRTUAL WALK

To tie in with the IKA's second virtual Run for a Life, the Kilkenny Branch also ran it's second successful virtual walk through Silaire Wood Loop Boardwalk and Riverbank Walk, Graignamanagh. Instead of the usual fundraising and awareness events which the branch would run pre-COVID-19, the local

KILKENNY

By ANNE O'GRADY



Hugh Byrne, Anne O'Grady Bridie Lennon, Cllr. Peter (Chap) Cleere and Johnny Lasey.

fundraising Walk, which was in compliance with COVID-19 guidelines, was successfully completed.

A special 'thank you' to our member, Daniel O'Connell who set up the GoFund me page.

The total amount of €2,500 was raised through the online fund, as well as offline donations on the day and following the event.

We are thankful for the donations received and for raising this wonderful amount of money for the Kilkenny Branch.

We would also like to thank Councillor Peter Chap Cleere who welcomed everybody on the day and got us started on the walk. Thanks also to Edward Hayden, Ireland AM, KCLR96fm Saturday Show presenter

KCLR and *The Kilkenny People* for the excellent coverage they all provide in promoting Organ Donor Awareness.

We are also truly grateful to everybody who has contributed to the Kilkenny Branch, in anyway, by fundraising or donations.

The Kilkenny Branch Officers support is always available. Contact details are as follows:

John Lacey, Chairperson

Ph: 085-1328255

Hugh Byrne, Board Member

Ph: 086- 8938800

Therese Hanrahan, Treasurer

Ph: 087-7796428

Anne O'Grady, Secretary

Ph: 087-9232190

Bridie Lennon, Asst. Secretary

Ph: 085-7051076



Kilkenny IKA Soliare Wood Walk.

LIMERICK

By MARY DOWNES



Katie Coughlan (Club Child Welfare Officer), Louise O'Callaghan (Club Secretary), Pat O'Brien (IKA) and John Gorman (Mary's brother).

Running Therapy is a group which acknowledges the power of running and shines a light on the positive outcomes of being active. One of the Club members John Gorman's sister Mary passed away in February 2021. She had availed of the services of the IKA so the Club decided to set up a fundraiser in her name to honour her.

Members of the club did a run, walk or activity of their choice and donated to the fundraiser in Mary's name. A total of €410 was raised by the Club, and this was passed over to the IKA in June.

On behalf of the Limerick Branch we would like to express our sincere thanks to all who took part in this fundraiser.

CONGRATULATIONS

Congratulations to Richard and Marina McEvoy on the birth of their baby Róisín, who was born on February 11th this year. Richard who underwent a transplant in December 2016 is a member of the Limerick branch and is always willing to give a hand when needed.

SYMPATHIES

The Limerick branch said goodbye to a very loyal and long-standing member and two special friends in the last few months.

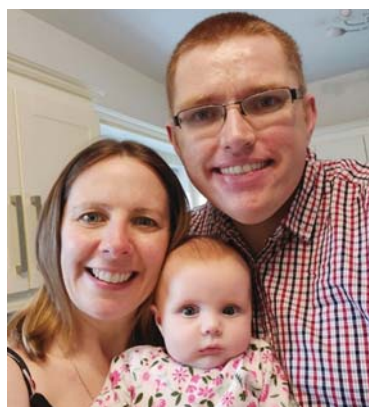
Mary O'Gorman had been a

member of the IKA for as long as we can remember. Mary is a lady we will remember for her kindness, dedication, and friendship. She never missed a meeting, thanks to her friend Evelyn Byrnes, who drove her to the meetings and events of the IKA, which she appreciated. 'Thank you' Evelyn.

Mary will be remembered with fondness and friendship, for her contribution to the Limerick Branch, for her sale of pens and Christmas cards over the years.

The late Jim Keane was an entertainer and musician and a good friend to the Limerick Branch. He provided the entertainment and music for our Christmas lunch over the years. He catered for everyone's taste and made the lunch a day to remember.

We send our sincere condolences to Mary and Jim's families and friends. Go dtuga Día dídean na bhflaitheas dóibh.



Marina, Richard and baby Róisín.

CORK

By SALLY NAGLE

SUMMER BREAK

Since we finished in June for Summer break it has been quiet in the Cork Branch. The committee and all members have been having a well-deserved break over the Summer months.

Lots of us were able to get out more and enjoy some of the sunny weather and meet with family and friends, many who had not been seen in over a year due to COVID-19. Some took the opportunity, over the Summer, to take up walking or other activities while others were able to enjoy and explore other parts of Ireland.

SUPPORT MEETINGS

We are all looking forward to meeting old and new faces when we restart our monthly support meetings in September. The Cork Branch/Committee are always looking for suggestions on how to improve, or make our monthly meetings as informative and supportive as possible. Please get in touch, at any time, with suggestions you may have. We are also looking for suggestions for guest speakers you would like to see at the support meetings.

DUBLIN NORTH

By PATRICIA MACKENZIE

Greetings to all members of Dublin North.

Just hoping that everyone was able to enjoy some of the really nice warm days during July and August.

It gives us a lift when the sun shines. Now, as the days are growing shorter we look to the Autumn and upcoming events.

The September meeting of Dublin North Branch will be on Zoom on Monday, September 20th at 7.30pm. As part of our opening meeting, we will have the pleasure of welcoming our new Patient Aid Manager, Fiona Aherne, who is also Manager of the Renal Support Centre. Fiona will speak to us about her work and say hello to everyone.

The Service of Remembrance and Thanksgiving will be recorded and the date of transmission, yet to be advised, will be widely advertised soon.

We have just been informed of a piece of good news. Beaumont Hospital has agreed, that when restrictions are eased, the Dublin North Branch will be allocated a room in the Hospital for our meetings, while the Renal Support Centre is unavailable. This will not happen soon, but it is something to look forward to. We hope to see you at our next Zoom gathering. Meanwhile stay safe and well until we meet again.



We hope that all throughout the Branch are keeping well and that people were able to get out and about over the Summer months.

Ann Hackett and family organised a socially-distanced Bog Walk in Two-Mile-Borris. We would like to thank Ann and her family for organising this, and also the community for coming out on the day. It was a lovely sunny day on Sunday, June 13th. Great chats were had, all socially-distanced or people wore masks. The walk raised €2,850 on the day.

We will be starting our Zoom meetings this Autumn – anybody who would like to join can contact me.



TIPPERARY

By ORLA HOGAN RYAN



Event organisers Ann Hackett (centre and to her right) with her daughter and son Aine and Paul





Hello to everyone from Kerry.

It is with great pleasure, after weeks of preparation, that we safely opened the doors of our holiday homes to patients. It is wonderful to be able to offer this great free service to those who need it most, and to see the joy that it brings to families is so rewarding.

We would like to thank Anne O'Donnell from Tralee, daughter of our Chairman Brendan Herbert, for her huge fundraising efforts recently. Anne took up the challenge of swimming across the bay from Derrymore to Fenit to raise funds for the IKA.

KERRY

By THERESA LOONEY



Anne O'Donnell back on dry land after completing her swim from Derrymore to Fenit as a fundraiser for the IKA Kerry Branch. L-R: Daphne Marinho, Brendan Herbert, Brian O'Donnell, Sean O'Donnell, Bridget Herbert, Killian O'Donnell, John Herbert and Debra Marinho at the finish of the Across The Bay Challenge swim. Photo by Dermot Crean, TraleeToday.ie

We were delighted to be at the finish when she came ashore.

Well done Anne.

We look forward to getting back

on track in the near future and having some more fundraising events.

CLARE

By NORETTA CLIFFORD

GREETINGS

As we continue navigating though the COVID-19 pandemic, I hope that you and your families are all safe and well and that most, if not all, of you have received your COVID-19 vaccinations at this point.

Unfortunately, our Branch has had none of our usual events to report about for this Autumn edition of *SUPPORT* – the monthly support meetings, the annual Mass of Remembrance & Thanksgiving in Ennis Cathedral and Church gate collections, are, but a few events that were cancelled.

Unfortunately, this is the way it will need to be until it is safe to resume such activities.

We did have some fundraising events take place through the

Summer such as the virtual West Clare Walk and these online fundraising events have been a wonderful means by which to ensure the IKA vital services can remain for those who require them.

We encourage anyone with any ideas to create your own online/virtual fundraisers.

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 Clare IKA Facebook page.

THANKS TO THE HOSPITAL TEAMS

Once again, Clare IKA members, transplant recipients and dialysis patients would like to thank all the nursing and medical staff at the hospitals where they attend, for

their help and assistance during the COVID-19 lockdown. We appreciate all you have done, and continue to do, during these challenging times.

SYMPATHIES

The Clare branch extend its sincere sympathy to Colman Hughes and family on the recent sad passing of Margaret, late of Feakle. Margaret was a great supporter of the Branch and always helped out with our fundraising activities. We also extend our sympathy to Mary Young and Bernie O'Brien of the Offaly and Clare branches, and extended families, on the passing of their brother Michael, late of Kilkee.

May their gentle souls rest in peace.



FOR DONOR CARDS

FREETEXT DONOR to 50050



IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

MEMBERSHIP APPLICATION FORM



BLOCK CAPITAL LETTERS PLEASE:

Mr. ☐ Mrs. ☐ Ms. ☐ FIRST NAME: _____

SURNAME: _____

ADDRESS: _____

POSTCODE: TEL: _____ MOBILE: _____

EMAIL:

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

Please indicate if any of the following apply to you:

PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED

☐ YES

☐ NO

☐ Do not wish to disclose

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

Post? ☐ YES

☐ NO

Or Email? ☐ YES

☐ NO

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

Email? ☐ YES

☐ NO

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

☐ YES

☐ NO

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

☐ YES

☐ NO

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

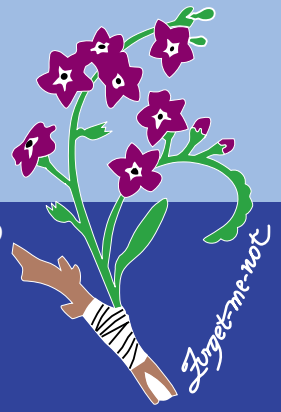
I subscribe to (sign up and accept) the Constitution of the Irish Kidney Association CLG (Company Limited by Guarantee).

SIGNATURE: _____ DATE: _____

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



IKA DIRECTORY



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

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

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

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

LOCAL BRANCH SECRETARIES

CARLOW

Susan Tobin
6 Woodgrove Ave,
Rathvily,
Co. Carlow

Tel:
087-6635910

DUBLIN EAST + WICKLOW

Bernie Dwyer
40 Granville Road,
Cabinteely,
Co. Dublin

Tel:
086-1673467

KILDARE

Michelle Horan
Farishta,
Tonlegee, Athy,
Co. Kildare

Tel:
085-7131478

LONGFORD

Elaine Heslin
Augharickard,
Shroid, Longford,
Co. Longford.

Tel:
087-9444515

SLIGO

Geraldine McHugh
Knocknahur,
Co. Sligo.

Tel:
086-8142002

CAVAN/MONAGHAN

Karl Cronin
13 Landsdowne
Manor, Swellan
Lower, Co. Cavan

Tel:
086-8513173

DUBLIN NORTH

Patricia Mackenzie
49 Martello Court,
Portmarnock,
Co. Dublin.

Tel:
087-9576808

KILKENNY

Ann O'Grady
4 Black Church Sq.,
Inistoige,
Co. Kilkenny.

Tel:
087-9232190

LOUTH/MEATH

Celine Tuite
Proudstown, Skryne,
Tara, Co. Meath

Tel:
046-9025585
086-1572088

TIPPERARY

Orla Hogan-Ryan
17 Hawthorns,
Nenagh
Co. Tipperary.

Tel:
087-2806068

CLARE

Noretta Clifford
Ballylannidy,
Shanaway Road,
Ennis, Co. Clare.

Phone
087-6243367

DUBLIN SOUTH

Lenny Ryan
36 Tymonville Grove,
Tallaght,
Dublin 24

Tel:
01-6205306

LAOIS

Sarine Browne
Coolglass House,
Coolglass, Wolfhill,
Co. Laois.

Tel:
087-4177731

MAYO

Maureen Bourke
St. Anthony's,
Carrowcushlaun,
Ballina, Co. Mayo.

Tel:
087-6604133

WATERFORD

Frances Moynihan
Lackendarra,
Ballinamult
(via Clonmel),
Co. Waterford

Tel:
087-2411549

CORK

Phone
086-2755754

Email:
secretarycork.ika@gmail.com

GALWAY

Peadar Ó hIcí
Rannoch,
Bearna,
Galway

Tel:
087-6536521

LEITRIM

Cathriona Charles
Gortfadda,
Mohill,
Co. Leitrim.

Tel:
087-9768637

OFFALY

Leona Mahon
Ballintaggart,
Mountbolus,
Tullamore, Co. Offaly

Email:
leona.mcdonald1@gmail.com

WESTMEATH

Cathy Smyth
The Beeches,
Coosan, Athlone,
Co. Westmeath.

Tel:
086-8049487

DONEGAL

Patricia Callaghan
Finabannes,
Donegal Town,
Co. Donegal

Phone
086-6073339

KERRY

Theresa Looney
Inch, Kilcummin,
Killarney,
Co. Kerry.

Tel:
087-2059205

LIMERICK

Shaun Faloon
2 Gort Na Mblath
Tulla Road
Ennis, Co. Clare

Tel:
087-1948679

ROSCOMMON

Maura Quigley
Creedy,
Roscommon,
Co. Roscommon.

Tel:
086-8969670

WEXFORD

Dora Kent
Newtown, Ramsgrange,
New Ross,
Co. Wexford.

Tel:
086-3745788