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SUMMER 2021



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Editorial...



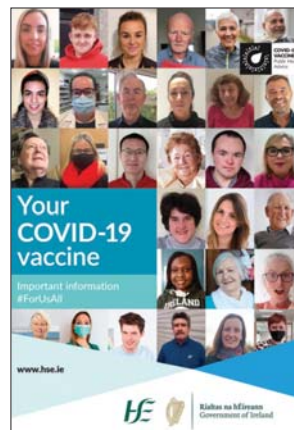
It is nice to begin an editorial with the good news that the vaccination rollout has quickened pace with nearly all of our community having received their first dose, and many have received their second. The happiness and relief are very obvious and almost palpable. The Irish Kidney Association (IKA) assisted the HSE to spread the good news with some of our community taking part in HSE vaccination advertising campaigns including a TV advert and information booklet which was distributed to every home nationwide.

The vaccination campaign was planned to reach huge volumes of people, which it achieved. However, not enough attention was spent on communication with patients, which did cause unnecessary anxiety. The IKA worked closely with the HSE to address this, and we dealt with many questions from patients. We also helped patients who had not been contacted to get vaccinations.

Some studies have questioned the effectiveness of the vaccine in immune compromised patients, and it is likely that booster shots will be required. In consultation with the National Renal Office (NRO) we advise people to continue to observe the safety guidelines. For more details see article on page 6-7.

We also discussed the return of holiday dialysis in Ireland with the NRO. Unfortunately, due to capacity issues in dialysis units, it is unlikely this will happen until later this Summer, when hopefully extra

funding for more staffing becomes available. We recognise the heavy work burden and stress on already very busy healthcare professionals as a result of COVID-19, and now they have the added issue of cyber hacking. It is disappointing for centre-based dialysis patients that they cannot go on holidays far away from their dialysis centres. Holidays are such an important part of wellbeing.



We are planning to re-open our holiday homes to transplant recipients and home dialysis patients and their families on July 1st, with extra cleaning to be undertaken and capacity restricted to keep guests safe from COVID-19.

There will be two apartments in Tramore available for 7-day holidays, and there will also be availability in

Tralee and Killarney for 5-day holidays. More details on page 15.

COVID-19 and the cyber hacking have had a major impact on health services, and this will continue. Much credit is due to the HSE who have successfully continued dialysis services and the transplant programme (albeit transplant figures in the year to date are lower than normal).

What both the pandemic and cyber hacking have shown, is the need to have a strong support foundation around delivery of services to patients. A useful metaphor is to think of people staying in a house (and compare it with patient services). If the house is well insulated it will keep people safe

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Dialysis mother Lorna McSwiggan and her daughter Nadia at their local beach in Sandycove, Dublin promoting Organ Donor Awareness Week. Story on page 4-5.

Photo: Conor McCabe

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and comfortable – (i.e. the support foundation). If the foundation of the house is crumbling eventually patients get hurt and services are affected.

The Association's new strategy will make sure our 'support foundation' (the house) is strong and secure, so that patients can safely enjoy the services we provide, and we can maintain the trust of our contributors.

At the moment the Board is focused on strengthening the 'house foundations' in order for us to have a firm base for improving and expanding our services. The Board has continued working to ensure that our organisation is compliant with the Charities' Governance Code and has also been taking part in an ongoing independent review of its own effectiveness as a board.

In light of COVID-19, the Board took the decision to defer branch AGMs until next year because many of our Branches cannot hold meetings effectively. Our national AGM will be held virtually on Saturday, 4th September (details will be advised).

We ran a successful virtual Organ Donor Awareness Week 2021, and you will find more details on page 10-13. Our continued heartfelt gratitude and appreciation goes to organ donors and donor families who are central to this life-saving awareness campaign.

We had another successful Zoom session for branch officers, where we looked at developing successful campaigns for improving patient services and the work and skills needed to do this. The Branches are now looking at what the priorities for campaigning should be. So make sure your local branch knows your views!

What is most important to you, our members? Is it automatic medical

cards for patients, easier access to and more supports for home dialysis, ways to expand our kidney transplant treatments, holiday dialysis or upgrading of dialysis units? You might let your local branch officers know your top priorities.

If your branch would like to try Zoom for holding meetings online, please contact Colin White, our National Advocacy & Projects Manager, who will be pleased to assist – colin@ika.ie

We also looked at developing a phone and Zoom peer support pilot programme.

As we go to print, we have just completed a member survey to explore the demand for patient services in Cork. A Board sub-committee is considering the options for the best use of the properties we have acquired, and we are also conducting a feasibility study on how to maximise the benefit of the properties.

Following on from these findings, the Board will be in a position to make a final decision as to the best way forward.

We have recently established an online shop on our website for branded face masks and t-shirts as well as the popular kidney diet appropriate 'Truly Tasty' cookbook. The quality face mask, *pictured above*, is tastefully branded with 'Organ Donation, Gift of Life' and the forget-me-not flower emblem on one side on



black fabric. Orders are already flying out for the popular unisex face mask, priced at €10 each including postage and packing. The face mask is of the highest quality and has a pocket for a disposable filter and, best of all, it is made in Ireland!

I am very conscious that many of our 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. To help address this, we have partnered with Age Action Ireland to provide up to six hours of free basic computer training and assistance in the use of smartphones for people over 55 years of age. All that you need to participate is a smartphone.

More information about this can be obtained from Age Action, **Phone: 01-4756989**.

Another volunteer group called GenerationTech, which offers free support to people 65 years of age and older who wish to seek advice on technical matters, can also be contacted on a helpline at **Phone: 01-9633288** which is open from 8am-8pm weekdays with a call back facility at weekends.

As you can see, we are very busy working on behalf of you, our members. Hopefully, we are now at the beginning of the end of the COVID-19 pandemic and, that soon, we can begin safely meeting face to face again.

We offer our deepest condolences to all of you who have experienced the loss of loved ones recently.

CAROL MOORE
CHIEF EXECUTIVE OFFICER

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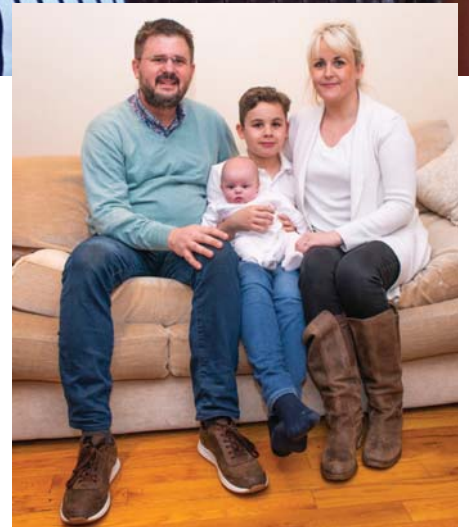
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By GWEN O'DONOGHUE



Lorna got to hold Nadia for the first time when she was a week old.

RAY OF HOPE FOR DIALYSIS MOTHER AWAITING TRANSPLANT



Springtime rays of sunshine graced our country during Organ Donor Awareness Week 2021 amid 5km travel restrictions as a result of COVID-19.

Earning front page position in the *Irish Times* was a photo of dialysis mother Lorna McSwiggan and her toddler daughter Nadia (then 21 months old) at their local Sandycove beach in Dublin.

Lorna (40), a nurse who has in the past worked at Crumlin Children's Hospital with kidney patient children, was herself catapulted into kidney failure halfway through her second pregnancy in 2019. Her two months premature baby was named Nadia Rae (meaning Ray of Hope).



Lorna, who like most other dialysis patients is in the extremely high-risk group for COVID-19, has been cocooning for over a year and half. Just after last Christmas, her husband Richard Martin and daughter Nadia tested positive for COVID-19, however luckily Lorna tested negative.

Lorna who has been on the waiting list for a kidney transplant since March 2020 says that 'organ donors offer a ray of hope' and she shared her story during Organ Donor Awareness Week 2021 which garnered a lot of publicity in national and local newspapers.

A month later she also did an interview on national radio station Newstalk which was shared on a network of local radio stations regarding the proposed amendment to legislation around the Human Tissue Bill in relation to consent around organ donation. While welcoming its introduction she

called for a register which will record not only people's wishes to Opt Out but also their wishes to Opt In, the latter offering the opportunity to confirm your willingness to donate and prompting conversation with family about your wishes.

In June 2019, Lorna's world was turned upside down when kidney failure led her to having to undergo a C-section to deliver her baby girl, Nadia. Nadia was born two months prematurely and weighed just 3 pounds 4 ounces. Within a minute of being born, Nadia required CPR and then was cared for in the Neonatal Unit at the National Maternity Hospital in Holles Street while Lorna was transferred to St. Vincent's Hospital for treatment where she remained for almost a week before she could be reunited with her new-born in the neonatal intensive care unit.

Baby Nadia then came home safely to her family a few weeks

later and has been thriving ever since.

Lorna, the proud mother of Nadia who is now 2-years-old and Kai who is 12-years-old, said, "Being able to live long enough to see my children grow up would be the greatest gift I could ever receive. Regrettably, none of my family, although willing, are suitable living kidney donors for me so I live in hope for a deceased donor kidney. Organ donors offer a ray of hope to me and others on transplant waiting lists and to our families also."

Lorna explained, "Nadia Rae Vale was the name that myself and Richard chose for our tiny new-born, our Ray of Hope. Nadia means Hope and Rae is the female version of Ray. Rae and Vale comes from her two grandmothers' names Valerie and Rae."

"I started dialysis treatment in June 2019 as I went into renal failure during pregnancy with Nadia. I have a renal condition called Alport Syndrome and I am the only known family member with this condition."

"Due to my kidney failure I am currently unable to return to my job nursing as I would find it impossible to tolerate with its long hours and the physical impact of my condition. The pandemic



“
Due to my kidney failure I am currently unable to return to my job nursing as I would find it impossible to tolerate with its long hours and the physical impact of my condition.

has also impacted on my ability to work as I am so high risk and I have been cocooning for over a year.

"I have been on the transplant waiting list since March 2020. Unfortunately, none of my family are suitable donors so I am relying on a deceased donor transplant to happen."

"I attend the Beacon Clinic for my three hourly dialysis treatments. I am so thankful to the care I have received from my Consultants Professor Watson, Professor Holian and the amazing dialysis

team at Beacon Renal.

I have a great support network including my family, my parents and

husband Richard and my best friend Dr. Carthage Carroll who has been a great support."

COVID-19 Tech Help



Generation Tech wants to ensure that everyone aged 65+ on the island of Ireland has access to technology. As the vaccine roll out continues we want to remind the public of our presence and to ensure that the public knows we will continue to provide our service after the pandemic.

WE HAVE A VOLUNTEER TECH HELPLINE FOR OLDER PEOPLE

- We will help anyone with an IT issue, as long as it is an a person aged 65 and over.
- We are a volunteer IT group offering over the phone help to resolve any IT or technical issues you might have.
- Tablets, phones, PCs, software, other hardware as well as Apps and communications.

HOW TO CONTACT US

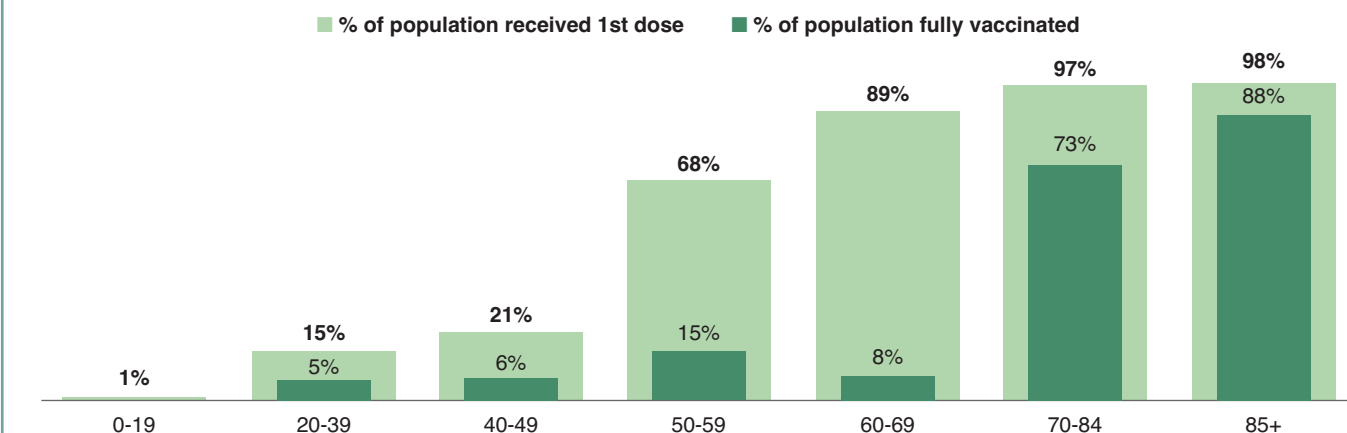
- Ring our contact number **01-9633288** and one of our volunteers will answer your call.
- Direct Message (DM) on our twitter handle **@Covid19_tech** – hashtag is **#TechHelpCovid19** and leave a brief explanation.
- **Facebook** page **Covid19TechHelp**.
- This is a completely **FREE** service. All time is donated by volunteers.
- No personal details such as access to bank details, cards etc. is required.
- Call distribution is random and all calls are recorded. The Twitter feed is also logged.



Ireland: % of age groups that have been vaccinated – As of 24th May 2021

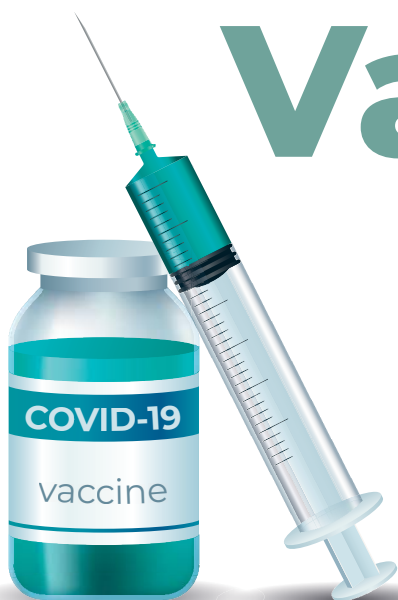
As of the 24th of May ~47 % of the adult population have received their 1st dose of the vaccine and ~17 % have been fully vaccinated. Note: Numbers exclude GP vaccinations from 14th of May.

Chart showing the % population vaccinated by age group



SOURCE: HSE

Vaccination UPDATE



Thankfully, the vaccine rollout has been able to carry on despite the cyber-attack on the HSE. From the graph above you can see that the uptake of the vaccines has been very high in the two older age categories. It is also interesting to see the uptake in the 60-69 year-olds as this is the first age category that used the online portal to book their appointments.

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

From a survey we carried out, contact with renal units and anecdotal reports received, it would appear that almost every renal patient (group 4 or group 7) who wanted the vaccine has received their first dose.

It is important to note that as the rollout continues to move down the age categories, it does not mean that those in older categories have 'missed' their opportunity. The programme is still open to everyone in the current advertised age category AND all those who are older. Equally, it is still open to people in group 4 and group 7 for their first dose. If you have not yet received your first dose, please contact me (email: colin@ika.ie).

Second doses for people who received the AstraZeneca vaccine are starting to happen and we shall soon see people who received the Pfizer-BioNTech or Moderna vaccines also being called for their second dose. We have been informed by the HSE that the place that organised your first dose will also organise your second dose. Appointment notices should arrive via phone calls or text messages.

The gap between the first and

second dose of AstraZeneca for ALL people has been confirmed at 12 weeks, at the time of writing – NPHET are reviewing the possibility of reducing the gap. The gap between the mRNA doses (Pfizer-BioNTech and Moderna) is currently 4 weeks. Some readers will have received a confirmed date for their second dose at the time of receiving their first dose whilst others will have been told that they will be contacted.

Based on the vaccine you received, you will know when you are due your second dose. If you have not received an appointment when you are approaching a few days before the due date, it is suggested that you contact HSE Live (tel. **1850-241850** or you can find them on Twitter). I have found them very prompt in replying to direct messages on Twitter both from the IKA account and my own personal account. Have your PPSN ready.

We have received a number of enquiries about the possibility of having an mRNA vaccine as your second dose if you had AstraZeneca as your first dose. We have conveyed this enquiry to the HSE, and the latest response is that the data is currently insufficient to prove the

value of doing this. However, research is ongoing and there may be a change of policy down the line.

As with the rollout of the first dose, we are happy to help if people are having problems getting an appointment for the second dose.

You may have heard about or read of the 'vaccine bonus' that opens up to people after their second dose of vaccine. The specifics are obviously dependent on the conditions at the time, but it currently refers to meeting up with other households and individuals.

However, it is important to realise that, like any vaccine, the efficacy of the COVID-19 vaccines is likely to be lower amongst those with compromised immune systems compared to the general population. That said, nephrologists and transplant physicians, both here and internationally, are advising their patients to take the vaccine when offered and to ensure that they receive both doses as there will be some protection. NPHET is currently considering whether follow-on booster shots may be required.

The current advice, both here and in other countries, is for people who are immune compromised to continue following the precautions of wearing a mask, washing hands and avoiding congested indoor venues.

It appears we are now at the beginning of the end of pandemic, the vaccine rollout has picked up pace and the early statistics coming out are showing that the vaccines are proving to be very effective in the general population. We will continue to share all the reliable information that we receive.

Please feel free to get in touch with your questions and experiences.

In a joint statement by the International Society for Heart and Lung Transplantation (ISHLT) and the American Society of Transplantation (AST) issued on June 2nd, on COVID-19 Vaccination in Solid Organ Transplant Recipients (SOT), it stated,

"we strongly caution against concluding that low antibody response rate to SARS-CoV-2, (COVID-19) vaccination will lead to reduced clinical effectiveness until more information is available. These results should not prompt or encourage vaccine hesitancy in SOT recipients". In the statement it concluded that "until more complete data is available, we urge continued adherence of all transplant recipients to protective measures including masking, and social distancing regardless of vaccination status."



Lana Devine,
Gearoid Wrafter and
Rebecca Osgood
Pic: Conor McCabe
Photography

A SECOND CALLING... FOR THREE TRANSPLANT TEENAGERS

After a year of trepidation, three kidney transplant teenagers came out of cocooning on Thursday, 8th April when they attended Beaumont Hospital for an unprecedented cause for celebration. The former patients at Temple Street Children's Hospital were among the first in the revised Group 4, classified as very high-risk, to receive their second and final 'shot in the arm' of the Pfizer/BioNTech vaccine, against COVID-19. They were photographed outside the Irish Kidney Association's Renal Support Centre at Beaumont Hospital. Their good news story garnered lots of coverage in national and local media.

With the changes in the vaccine rollout that were introduced in March, revised Group 4 was extended from 18-69 years to include 16 and 17-year-olds. With the Pfizer-BioNTech vaccine being the only one currently approved for 16 and 17-year-olds, the three teens were added to the group for vaccinations thereby allowing them to return to school.

First of the three to receive her second dose was Lana Devine (16) from Kells, Co. Meath who was accompanied by her parents, former

By GWEN O'DONOGHUE

Meath footballer Jody Devine and mother

Emer and two younger brothers Liam (13) and Joe (7).

Soon afterwards two other kidney transplant recipient teens were given their second dose of the vaccine and an increased level of reassurance.

Gearoid Wrafter (16) from Loughaun, Tullamore, Co Offaly travelled to Beaumont with his mother Theresa and sister Denise.

Also joining them was Rebecca Osgood Daly (17), whose kidney donor mother Bernie Osgood had driven her daughter to her hospital appointment from Ballinlough, Co Roscommon.

Their vaccines were given during the Easter school holidays. Gearoid received his kidney transplant in 2015 and is a 5th year student at Killina Secondary School. Rebecca, also a 5th year student, attends Ballyhaunis Community School in Mayo where her mother Bernie, who donated a kidney to her in 2010, is a teacher.

Lana, is a Transition Year student in Eureka Secondary School in Kells. She received her kidney transplant in 2008 when she was just 4-years-old following two years of nightly dialysis treatment as she was born with dysplastic kidneys.

TWO STEPS TO FREEDOM

By GWEN O'DONOGHUE

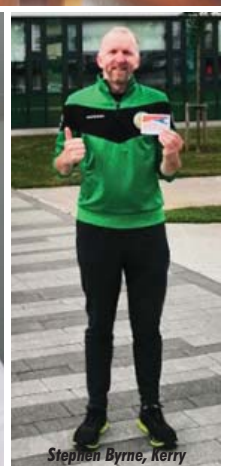
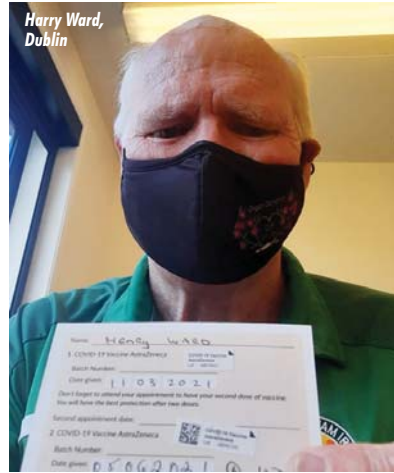
There was almost a palpable sense of relief and excitement for transplant recipients and dialysis patients as they made a return visit to vaccine centres around the country in early Summer 2021 for their second dose of a COVID-19 vaccine.

It was a momentous event back in March 2021 when the rollout for the first dose of the vaccines for this community categorised as 'very high risk' commenced as many had been hibernating for over a year. Most of this vulnerable group were allocated the AstraZeneca vaccine in two doses taken three months apart.

As the AstraZeneca vaccine was not licensed for the 16 and 17 year olds, who are also in the 'very high risk' group, these teens received the Pfizer BioNTech vaccine which had a shorter gap of less than a month between first and second doses. Almost all members of this vulnerable community have now received their second vaccine dose, with the prospect of a booster shot into the future.

They can finally breathe a sigh of relief and feel a little more protected against COVID-19 though knowing that face masks, hand washing and avoiding crowds are still best practice..

Pictured are transplant recipients and dialysis patients in celebratory mood after receiving their second COVID-19 vaccine dose.





Julie Sutcliffe, Wicklow



Angela Sherlock, Dublin



Elizabeth Ferry, Galway



Suzah Dalton, Dublin

– SUMMER – giveaway



5 x €100 vouchers
for Suncare and Skincare products at

Care+PLUS
PHARMACY

CarePlus Pharmacy is Ireland's fastest growing independent retail pharmacy group. Its first store was established in Cork in 2015 and now a **CarePlus Pharmacy** can be found in most key towns and counties around Ireland.

The Irish Kidney Association is delighted to partner with **CarePlus Pharmacy**, to remind our readers, especially transplant recipients, of the importance of sun protection, not just in summer but all year round.

Transplant recipients need to be particularly careful of the sun as they are at a significantly higher risk of developing skin cancer than the general population because of the medication they take.

Sun protection starts with regular use of protective clothing, seeking shade, and for additional protection, the daily frequent application of sunscreen to exposed areas.

Sun Protection Factor (SPF) 50+ is recommended. It is important to use a sunscreen that protects against UVA and UVB rays. These sunscreens are usually branded 'broad spectrum'. Sunscreen should be applied 20-30 minutes before going outside, and should be reapplied every 2 hours.

Reapply SPF after exercising, swimming, sweating or towel drying. Even 'water-resistant' sunscreens need to be reapplied.

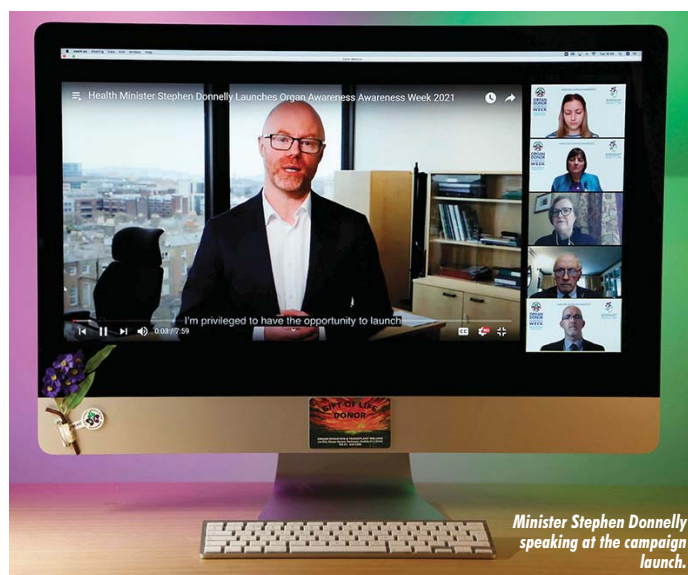
For more information see: <https://irishskin.ie/sun-protection-for-organ-transplant-recipients/>

5 lucky readers will each receive a €100 voucher for suncare and skincare products which can be used at any CarePlus Pharmacy.

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 **CarePlus Sun Protect** in the subject line of your email. 5 winners will be selected at random and will each receive a €100 voucher which can be used at any **CarePlus Pharmacy** branch nationwide – www.careplus.ie

**Offer applies to suncare and skincare products only and does not include prescriptions, medicines, baby food, vouchers, gift cards and in-store services.*

Reflecting on First Virtual ORGAN DONOR AWARENESS WEEK



Minister Stephen Donnelly speaking at the campaign launch.



'An Irishman Abroad' podcaster Jarlath Regan

The Irish Kidney Association's foray into its first ever VIRTUAL Organ Donor

Awareness Week campaign this year proved successful with lots of publicity generated in print media and online and engagement by the public. The campaign has had almost three decades long of tradition of being held every year in Spring, but last year it had to be cancelled with just a few weeks' notice. This unprecedented cancellation was in response to the global pandemic which took all of us off guard and most of us, non-front-line workers, retreated to our homes as fears about the virus engulfed the world.

Since the onset of COVID-19, transplant activity in our hospitals has slowed down while people continued to wait for 'the call'. This can be seen in the table of figures at the end of this article (on page 13).

The IKA decided that despite the challenges which still prevail with COVID-19, that it was vital, this year, to continue

By GWEN O'DONOGHUE

highlighting the importance organ donor awareness to the public at large while following government restrictions and not jeopardising the safety of our members. The 'mostly' virtual Organ Donor Awareness Week 2021 campaign was held, amid travel restrictions, from 27th March to 3rd April.

It has to be acknowledged that without the support of volunteers in the community, the business sector's sponsorship and the media's cooperation, it would not have been possible to run the campaign successfully.

People from a broad section of the community came on board with great enthusiasm to support the campaign. Social media Influencers shared posts about the campaign and our own community kept busy liking and sharing stories from our various digital platforms.

Celebrities supporting the campaign included actress and singer Angeline Ball, whose niece Saoirse is a

liver transplant recipient, as well as comedian and 'An Irishman Abroad' blogger Jarlath Regan, who donated a kidney to his brother.

Previous organ donor awareness ambassadors for the IKA, including kidney donor Vivienne Traynor, Mary Kennedy and Ray D'Arcy, all willingly lent their support to the campaign. Ray D'Arcy also covered an interview to highlight the campaign on his RTE1 radio show and so also did his fellow RTE presenter Jennifer Zamparelli, who, like Ray, regularly covers organ donation on her 2FM show.

Celebrities took part in a chain of videos passing on the donor card with the message 'Life is a Gift, Pass it On'. The videos were shared widely. This concept of passing on the donor card started with Irish diaspora from five continents around the world on St. Patrick's Day with an end clip flagging our Organ Donor Awareness Week campaign and how to get a donor card.

The 'Pass it on' concept was also translated into an Irish language version with Mary Kennedy and grateful transplant recipients or their family members speaking 'as gaeilge'.

Jarlath Regan's podcast covered three inspiring interviews including one with Vivienne Traynor, who like him is a living kidney donor, and also with James Nolan, the prolific champion butcher, transplant recipient and founder of the successful Punchestown Kidney Research Fund.

It was a particularly major coup that Jarlath could attract Lucy Davis, the star of internationally renowned TV Hit series 'The Office' and daughter of British comedian Jasper Carrott, to do a candid and first ever public interview about her experience with kidney failure and receiving a donor kidney from her mother Hazel in 1997.

The Minister for Health Stephen Donnelly sent his address by video for our first ever virtual launch of Organ Donor Awareness Week 2021 which was held on Tuesday, 23rd March.



IKA CEO Carol Moore,
performed the role of
master of ceremonies
at the online launch



**Sallyanne and
Derry Clarke**



Ian O'Doherty
heart patient

Joining in to watch the launch online were IKA members and media as well as many others invested in the organ donation and transplantation journey, from the various transplant teams as well as other patient advocacy groups. Technical difficulties prevented some people being able to watch the live launch online but, fortunately, they could watch back the recorded launch soon afterwards via our website.

Dr. Catherine Motherway, Clinical Lead, Organ Donation Transplant Ireland (ODTI) spoke of her experience working at the coalface as an intensivist and Head of ICU at University Hospital Limerick. She spoke of how humbling it is to support families in the decision-making process around donating a loved one's organs.

While applauding the work of the IKA and others in the promotion of organ donation, as well as honouring organ donors, Minister Donnelly gave special mention to Sallyanne and Derry Clarke for lending their support to the campaign launch by sharing their experience about their decision to honour their late son Andrew's wish to be an organ donor.

Minister Donnelly announced €75 million funding to support improvements in organ donation and transplantation services while saying he was looking

forward to the enactment of the current Human Tissue Bill in relation to Opt-Out consent for organ donation.

In his recorded speech, the Minister also said, "With the continued successful rollout of the vaccination programme there are better days ahead for all of us. If all of us share our intentions with our families to pass on the 'gift of life', there will be better days ahead for those waiting for organ transplants also."

Carol Moore, the Chief Executive of the IKA performed the role of master of ceremonies at the online launch and while outlining the campaign, she also welcomed the Minister's announcement about additional funding.

Referring to the profound generosity of the families of organ donors, the IKA's national honorary chairman Colin Mackenzie stated that "If we ever lose faith in humanity, just think of organ donor families." He also thanked those who

work in delivering the organ donation and transplantation process, and he offered his condolences to all the people who have lost loved ones during COVID-19. He explained how in these times it has been very difficult for dialysis patients and transplant recipients who are extremely vulnerable to COVID-19 infection.

People who received heart, lung, liver, kidney, and pancreas transplants shared their experiences through pre-recorded interviews for the online launch. Each of them echoed the same underlying sentiment, their profound gratitude for the 'gift of life' they had received.

They included Tomas Caffrey, a 21-year-old student from Tipperary who received a liver transplant, Denise Geoghegan from Laois who received a heart transplant, Siobhan Brady who underwent a combined kidney and pancreas transplant and her fellow

Cavan native Stephen Smith who finally received a lung transplant after being called eight times previously.

Recently qualified junior doctor Juliette Duff spoke about her kidney failure and the transplant which she received while studying medicine.

These inspirational people have written personal accounts of their health stories which are featured in this issue on pages 16-25.

A particularly poignant moment of the launch was a pre-recorded video of 46-year-old Limerick man, Ian O'Doherty, (pictured below) who spoke from his bed in the CCU at the Mater Hospital where he explained how he has been an in-patient since July 2020 and that he has received two calls for donor hearts., neither of which happened. Ian and his family including his 19-year-old daughter Ava, desperately hope for the 'gift of life' before time

continued next page



Ian in his hospital bed in CCU at the Mater Hospital



Ian with his daughter Ava



Deborah Cervi at Swords Castle



Minister Stephen Donnelly, wearing the forget-me-not on TV News



Dr. Colm Henry wearing the forget-me-not on TV



Dr. Ronan Glynn wearing the forget-me-not on TV

runs out.

In our Spring issue of *SUPPORT* we reported that over 30 public sites would be 'lighting up in green' from dusk to dawn in support of Organ Donor Awareness Week, as green is the internationally recognised colour which celebrates organ donation. By the time the organ donor awareness campaign week came around almost every County Council came on board.

In the end, a total of 91 public sites were 'lit up in green' for the campaign's week-long duration. Sites included Dublin's Convention Centre, the Mansion House, public libraries, town squares, a bridge, church, a monument, and lots of council town halls around the country.

This visually impactful initiative, which was the brainchild of the IKA's holiday coordinator, Deborah Cervi, captured the imagination of people, prompting conversation amongst the general public. It offered our network of branch volunteers and county councils an opportunity to hold socially distanced photocalls in the evenings which were covered by local

newspapers, and on social media and thereby generated even more awareness and goodwill for a life-saving cause and was a welcome distraction from COVID-19.

A new design approach was taken with the campaign posters as they featured photos of 32 grateful transplants, of all ages and all walks of life, who collectively are enjoying over 400 years of extended life thanks to their gift of life from deceased donors – a powerful message about the success of organ donation! The Campaign Week poster was adapted and another version, for display, all year round, features 42 people who also received deceased donor transplants and are enjoying over 520 years of extended life (and can be seen on the back cover of

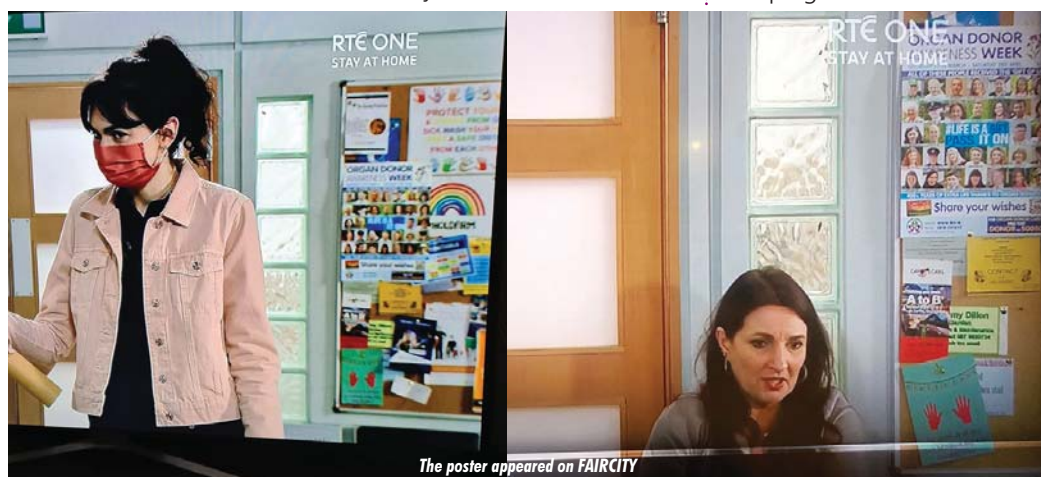


Poster on display at Milford Shopping Centre (this issue).

The posters were distributed by the Irish Pharmacy Union who circulated them to over 1850 pharmacies for display during Awareness Week and all year round and our branches sought out public locations to display them locally. The Irish and Polish

language versions of the posters were well received. Clear Channel also sponsored the display of posters in over 30 shopping centres around the country while some local and national newspapers also featured the poster free of charge. The poster also made a cameo appearance on several days during Awareness Week on the set of RTE's long-running TV series *FAIRCITY*.

At televised media briefings on COVID-19, Dr. Ronan Glynn, the Deputy Chief Medical Officer and Dr. Colm Henry, Chief Clinical Officer, HSE could be seen wearing the IKA's forget-me-not flowers and Minister Stephen Donnelly was also seen on TV News wearing the distinctive emblem in support of the campaign.



The poster appeared on FAIRCITY

Many other people responded to a callout on our social media to share their health stories for organ donor awareness and they engaged in media interviews which were broadcast on radio and could be read in local and national papers. Publicly sharing personal health stories is the cornerstone of the success of awareness campaigns as it has been proven that hearing about and reading about real life experiences with organ failure and/or transplantation is what resonate with the public prompting the all-important awareness and discussion about organ donation.

For those people whose stories were not covered this time round, we hope to engage with you for future organ donor awareness campaigns.

Former Westmeath senior footballer John Egan's successful sporting career was cut short due to his kidney disease and he recorded a video which was shared on our social media.

Since then he has commenced home dialysis and despite recently learning that two members of his family have been tested and are not suitable living donors he remains

optimistic that a suitable donor might come along before he exchanges wedding vows with his fiancée Traci next year. They were forced to cancel their wedding celebration last year due to COVID-19. You can read more about John on pages 42-44.

A family with hereditary kidney disease supported the campaign and featured in a video for the *Irish Independent* and *Sunday World* online. This was shared on our social media and garnered a lot of interest as two sisters Emma O'Connor and Louise Cowman were involved in a living donor kidney transplant.

In the video they discussed how four generations of their family were affected by Polycystic Kidney Disease and a cousin of theirs underwent a kidney transplant in Sweden just a few days before Awareness Week.

During Awareness Week another transplant counsellor attended the wedding of her daughter who works as a nurse in the transplant unit at Beaumont Hospital.

Many other health stories were shared in papers and on radio stations around the country inspiring the public

to respond with numerous downloads of our digital organ donor card app as well as requests for donor cards to be posted, all of which will generate more conversations about the importance of organ donation.

Stories were shared about milestone kidney transplant anniversaries of people, some of whom are celebrating more than four decades of successful transplantation.

An uplifting story about sisters, who underwent a living donor kidney transplant in December 2020, proved timely for Mother's Day which took place two weeks before Organ Donor Awareness Week and appeared on the front page of national newspaper the *Irish Examiner*.

As the campaign week came to a close, 7-year-old Sofia Corey could enjoy her first ever Easter egg thanks to the deceased donor transplant she received just before Christmas 2020 (see page 32-33).

A photo of a nurse, Lorna McSwiggan, who went into renal failure on her second pregnancy with her toddler daughter, featured on the front page of Ireland's

national paper of record *The Irish Times* during the campaign Week. Lorna's story is covered on page 4-5.

While fundraising for the campaign is vital for the continuance of the work which the IKA does in advocating for and offering support to kidney patients and their families, the only focus of this year's virtual Organ Donor Awareness Week was to keep the importance organ donation and saving lives at the forefront of people's minds and hearts.

We hope that later this year when we are all living in a safer environment which is more protected from COVID-19, that there will be a resurgence of activity and fundraising. While we successfully learned how to quickly adapt to the challenges of the pandemic and moved our activity to online, we look forward with optimism to working with our branch officers, our members and supporters, and delivering a successful non-virtual Organ Donor Awareness Week campaign in 2022.

Campaign materials including a video of the online launch are available on www.ika.ie/donorweek2021

ORGAN DONATION AND TRANSPLANTATION ACTIVITY - 10 YEAR COMPARISONS

		2020	2019	2018	2017	2016	2015	2014	2013	2012	2011	10 year Total	10 year avg.
Deceased Donors		62	85	81	99	77	81	63	86	78	93	805	80.5
Transplantation from Deceased Donors	Kidney	95	128	127	141	122	120	112	147	131	165	1288	128.8
	Liver	37	66	56	62	58	61	44	55	50	61	550	55.0
	Heart	9	15	18	16	15	16	18	11	10	6	134	13.4
	Lung	16	38	28	36	35	36	31	32	14	8	274	27.4
	Pancreas	5	2	5	5	0	0	6	11	1	8	43	4.3
SUB-TOTAL		162	249	234	260	230	233	211	256	206	248	2289	228.9
Living kidney donors & transplants		28	25	40	51	50	33	40	38	32	27	364	36.4
All organ transplants TOTAL		190	274	274	311	280	266	251	294	238	275	2653	265.3
Living & deceased donor kidney Tx		123	153	167	192	172	153	152	185	163	192	1652	165.2

Light-up in green initiative

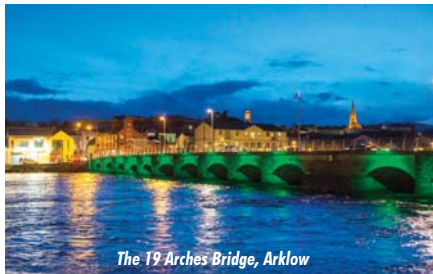
Almost every County Council demonstrated solidarity in support of Organ Donor Awareness Week with 91 public sites throughout the country 'Lit Up In Green' from dawn to dusk for the campaign's week-long duration. Sites included Dublin's Convention Centre, the Mansion House, public libraries, a town square, a bridge, church, monuments, and town halls and other public buildings around the country. The initiative captured the imagination of the general public prompting conversation about the life-saving gift of organ donation.



Municipal District Office, Carrick-on-Suir



Tullamore Town Square



The 19 Arches Bridge, Arklow



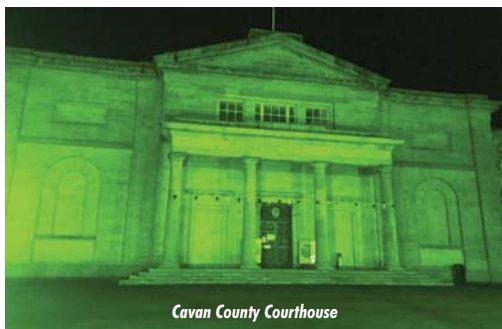
Swords Castle, Dublin



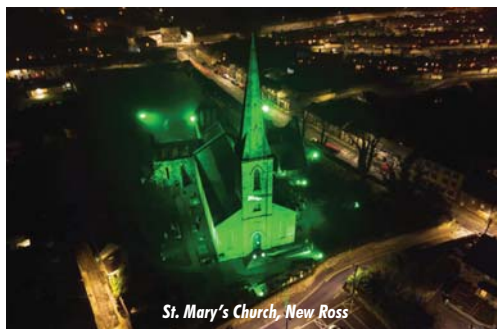
Clare County Council



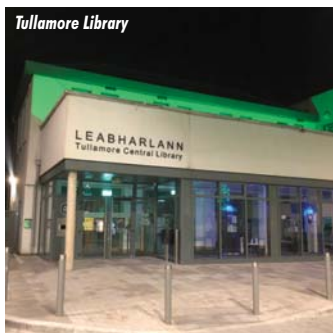
Bray Town Hall



Cavan County Courthouse



St. Mary's Church, New Ross



Tullamore Library



City Hall Cork



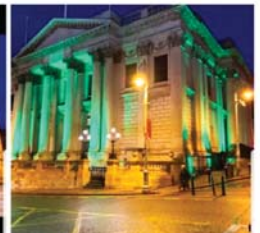
The Mansion House, Dublin



City Hall Dublin

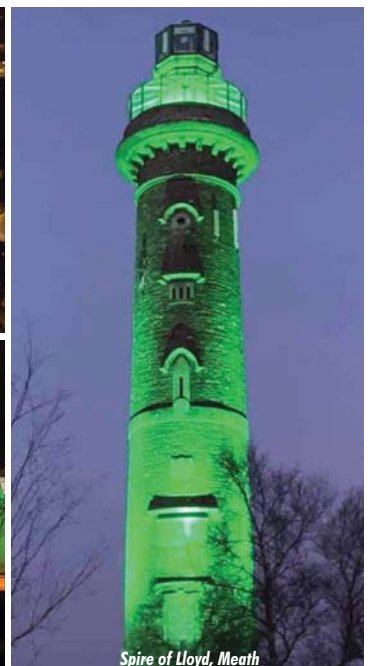
19h · 🌐

We are delighted to be lit up green this week in support of organ donor awareness week @irishkidneya #LifelsAGift #Donorweek21 #organdonorssavelives #organdonation #lifeisprecious #irishkidneyassociation



ORGAN DONOR
AWARENESS WEEK
2021
27TH MARCH - 3RD
APRIL

How well does City Hall look?



Spire of Lloyd, Meath



Tramore Holiday Homes



HOLIDAY HOMES RE-OPENING 2021



We could all benefit from a nice holiday after the months and months of daunting lockdowns and restrictions. Holidays are good for our general wellbeing and our mental health and it is nice to have something to look forward to. We have been working hard in the background to safely re-open our holiday homes this year, and we are delighted to announce holidays for Transplant and Peritoneal patients will happen this year. We will start to welcome patients from the 1st July onwards to the Kerry and Tramore holiday homes.

Dialysis patients are also accepted, if they can travel back to their home dialysis unit for dialysis treatment e.g. a haemodialysis patient attending Cork University Hospital (CUH) for dialysis treatment holidaying in Tralee, Co Kerry could travel back to their dialysis centre at CUH for treatment.

Unfortunately, dialysis provision away from base will not resume until possibly late summer, depending on advice from NIAC for haemodialysis patients. We appreciate how disappointing this will be for patients.

The National Renal Office (NRO) has made an application for additional funding to facilitate away from centre holiday dialysis. We will continue to discuss this with the NRO.

We will operate our holiday locations this year on a 5 and 7-night basis (Saturday to Thursday and Saturday to Saturday) as we implement longer cleaning routines and comply with COVID-19 guidelines.

Enhanced sanitation procedures and new practises have been implemented for the safety of guests. We will continue to monitor all developments relating to COVID-19 and remain committed to ensuring a safe environment for guests.

We also request that guests adhere to COVID-19 guidelines and this will be a condition of booking. There will also be a number of other changes so, therefore, please read the booking form very carefully. For example, towels will not be provided.



Tralee Holiday Home

Priority will be given to first time holiday applicants and to families with schoolgoing children during Summer school holidays.

Please note: Holiday grants are no longer automatically paid whilst on holiday. Financial support may be available from our Patient Support Manager, email: fiona@ika.ie or speak to your local branch.

The holiday application forms are available on our website at www.ika.ie by clicking on the tab at the top of the page titled 'Our Services' and then 'Patient holidays'. Link below.

Your local branch secretary and your PD Unit also have forms or alternatively you can contact me by email at deborah@ika.ie

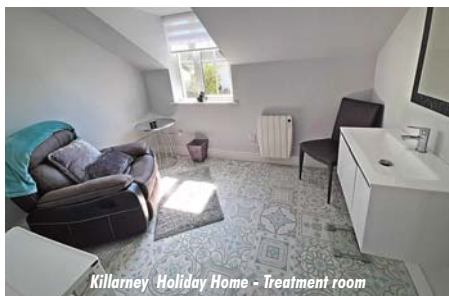
We will be ensuring an enjoyable holiday experience amid the restrictions that prevail.

Have a lovely summer. Stay safe and take care.

Deborah Cervi
Holiday Coordinator



Killarney Holiday Home



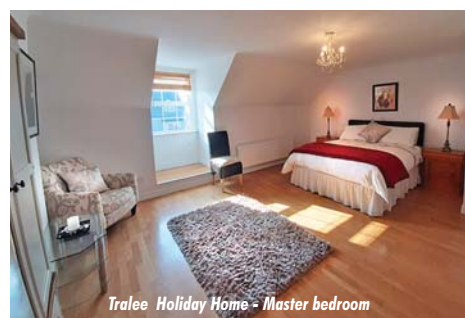
Killarney Holiday Home - Treatment room



Killarney Holiday Home - Kitchen



Tralee Holiday Home - Sittingroom



Tralee Holiday Home - Master bedroom

ONLINE LINK: www.ika.ie/patient-holidays/



Denise with son Caeden (8)

Life begins at 40 for heart transplant mum

It was in January 2020, I went to my GP as I had swollen legs and stomach and I was finding it very hard to breathe. He sent me to A&E in Portlaoise Hospital. From there I was sent to St James in Dublin for an Angiogram and it was then that I was told I had severe heart failure, Cardiomyopathy and I would most likely need a heart transplant. My world was turned upside down. To say I was shocked would be an understatement. I was never aware I had any heart issues although it was in our family history.

I was then transferred to the Mater Hospital where they confirmed that I would need a heart transplant and that I would have to undergo a series of necessary tests to identify my suitability to go on a waiting list for a heart transplant.

It was somewhat ironic that it was on February 14th, Valentine's Day that I was put on the transplant waiting list for a heart, and that very night I

received my first call for a new heart.

It turned out to be a false call as I was not a suitable match for this heart. I was not really too upset about this news as it had all happened so quickly and I still needed time to get my head around all of this situation that I had suddenly found myself in, and I still had to explain this difficult news to my sons.

So, then started my long wait in hospital. In total I was an inpatient in the Mater Hospital for eight long and difficult months. As my heart was only functioning at 10% this is where I had to stay in the knowledge that the only way I could ever leave was if I got a donor heart.

I found this all so difficult and I missed my kids so much. But in the early stages they could visit me regularly. Then the restrictions around COVID-19 hit and I was not allowed visits anymore, except from my husband Emmett.

This is when my world started to fall

apart and the only contact I had with the outside world was through Facetime. The hardest part was knowing that my kids needed me and there was nothing I could do about it.

It was a really tough time for my husband Emmet as he visited me every single day and then went home to care for the boys while trying to hide the huge stress he was under from all of us.

The staff in the critical care unit in the Mater Hospital were amazing. I really thought of them as my family. They went over and above to help me in anyway that they could and I will be forever grateful for the love and support they showed me, despite that at times I was not the easiest of patients (which they had to put up with) while I was in that ward for half a year.

The hardest part for me was when the second call for a transplant came, and I got told that it wasn't a match again. It was totally devastating for me



and my family. All that I wanted was to be home with my kids but it wasn't to be this time. My mind went through a rollercoaster of emotions.

It was a case of third time lucky for me. Finally, when I got my next call, the third, I don't know how, but I knew that this time the donor heart was meant for me and when it was confirmed the transplant was going ahead this time I was over the moon but scared also.

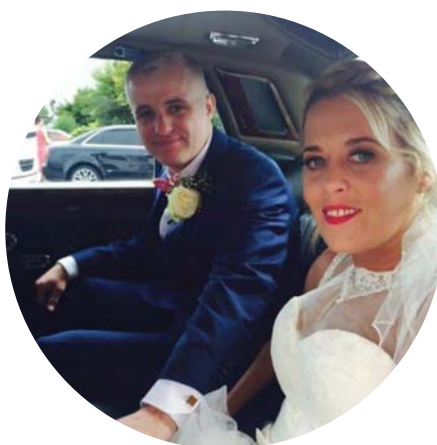
My husband Emmet was with me all that day and until I was wheeled into the operating theatre. I could see by his face he was terrified for me and so was I but I focused on the prospect of me being able to be home again with my kids, family and friends, and that took away the fear for me.

The operation took over six hours

and I woke up about three hours later totally delighted with the new life a stranger had given to me.

After four weeks I finally went home to my husband and kids. If my brush with death has taught me anything, it is that life is for living, and that is what I intend on doing. Life begins at 40, and never more so than for me as I'm 40 now with my new donor heart. I'm caring for my three sons and husband, walking every other day with my dog Max and enjoying the simple things in life and am grateful for every breath of fresh air I take.

Everybody needs to understand how important organ donation is and what better gift can you ever give anybody but the 'gift of life'!! To my organ donor family I cannot thank you enough and will be forever grateful for the new life you have given to not just



me but for my family also.

We would never have got through any of this without the help from my family and my in-laws. To my friends who witnessed my despair and saw me cry, you helped me more than you will ever know.

The love and support shown to us from the people in the town I live in, from my two younger son's schools, St. Patrick's Boys National School and Coláiste Íosagáin, was really overwhelming and I will be eternally grateful to each and everyone of you.

Lastly, to everyone in the Mater Hospital, from kitchen staff to the nursing and medical staff to the transplant team and surgeons who performed my life-saving operation, I thank you from the bottom of my donor's heart.



AGM

Given the current pandemic conditions, it is difficult for many Branches to hold AGMs. The Board has considered the position and outline the following arrangements:

1. Branches will defer their AGM until 2022.
2. There will be no election of Officers of branches or Board Directors this year.
3. Branches may replace Officers of branches and Directors who wish to stand down.
4. The existing Board and National Officers will remain in place for a further year.
5. This year's **National AGM** will take place virtually on **Saturday, September 4th, 2021**. Further details will be advised in due course.



Tipperary student receives liver transplant

I am Tomas Caffrey. I am 21-years-old and I received a liver transplant in 2020. When I was 17, I was suffering badly with stomach pain in 5th year in school. I thought it may have been because of a bad diet so I let it go for a while.

After a month or two of putting up with it I decided that I should see someone about it. I talked to my mam and we went to my GP Dr Elaine Joyce. She was not happy with what she saw, and she set up an appointment in Clonmel hospital in Tipperary. Dr Claire O'Leary was my doctor there. She was brilliant. Soon after I had a colonoscopy, we discovered that I had Ulcerative Colitis. I did not really mind all that much, I was just glad to know what the issue was.

After a while Dr O'Leary seemed to think there was something more as I had told about my itchiness. She scheduled a liver biopsy for me in July 2017. After finding out the results of the biopsy I was diagnosed with Primary Sclerosing Cholangitis (PSC).

PSC is a chronic liver disease, and it causes problems in the bile ducts which eventually can cause serious problems for the liver, in some cases people need transplants – I was one of them! It was a bit of a shock to hear but as a 17-year-old lad it did not get me down much. I had no real flare-ups from the PSC and apart from itchiness and a lack of energy I felt like I could carry on like anyone else my age.

I always had good support from my friends in school who were always there for me. When I was coming to the end of my Leaving Cert year, I began to see some effects from the PSC.

In April of 2018 I started noticing the whites of my eyes changing to yellow followed by my skin. I went to Clonmel hospital, but it was clear after blood results that I should be transferred to the wonderful St. Brigid's ward in St. Vincent's University Hospital in Dublin. I had very bad jaundice and spent around a month in hospital.

When I spent time in hospital, I never allowed it to get the better of me. Positivity is key when going through something like this. I always walked around the ward and would go down to the shop without a bother. I would then see people who may not be able to get out of their bed and I felt I had no right to let myself get down about my condition because there was always someone worse off than me.

Near the end of 2018 is when I started to see a problem again. In the run-up to Christmas I could see my jaundice was coming back, and I knew I had to go to



(L-R): Saoirse Caffrey, Tom Caffrey, Tomas, Jane Ryan and Oscar Caffrey (front).

Dublin. It was clear that there was an issue, and I was admitted.

The jaundice showed no signs of going away and after talks of possibly getting a stent it was decided that I would need a biliary drain. I initially thought the worst but after the situation was explained it seemed like the best option.

I had a drain fitted on 11th January 2019, this helped drain my liver and so the jaundice slowly went. They told me that this might only last a little while but, hopefully, it would help long-term. I never was ashamed of having a tube coming out of me. In those situations you must be confident. I took pride in my drain and I would never be shy about talking about it. A few days later I was put on the liver transplant list and that started the big waiting game.

The drain was not always the most convenient, but I dealt with it. I had appointments every six weeks in radiology to get my drain changed. I got used to it after a while and it just became normal. The drain kept me out of hospital apart from when I got the chickenpox.

In February 2020, my mam got the call from St. Vincent's Hospital just after 6 in the morning. I was in Athlone at College and my mam was in Tipperary, but we were organised that if this happened my mam's cousin, who lives in Athlone, would collect me and meet her at the hospital.

We all got there with no problems and I had to have bloods done and then we were waiting for a little while. We were then told that the liver was not viable. It did not dishearten

me too much as I knew that my doctors had my best interest at heart, and they were going to find me the perfect match.

When COVID-19 began in March 2020 we joked at home about how handy it would be if we got the call during lockdown as it would mean that I could get everything done while the world is at a stop. Then on the morning in early June the call came.

We were always prepared for this moment. I never allowed myself to get my hopes up as I knew that the liver may not work out. We headed for Dublin that morning.

As expected, I had lot of scans and tests to do. It was a long day but the longer it went the better I felt about the chance of this working out. I can honestly say the entire day I never felt nervous, only pure excitement. I knew this was my new beginning and I was ecstatic.

At close to midnight it was finally time to head to surgery. As I went down, I could not believe it was all actually happening. I walked into the operating room and I knew that this was it, it was going to happen, and all the hard work was done and time to leave it to the professionals. My operation started at 12.40am and finished at 6.10 am – so much quicker than they thought it would take.

The first couple of days are very hazy. When I left ICU it began to get harder. I knew it would get worse before it got easier. I was in a good bit of pain which was expected but on day five I began to see the light at the end of the tunnel. I started to feel like myself again. I was making conversation and even started getting up a small bit. I was hesitant to start getting out of bed, but I knew it was my best chance of recovering quickly.

After ten days I was fit enough to go home. I could not believe how quick it was. I was feeling great and looking forward to getting back to my own bed. I had very little complications in the weeks after. I had ascites, which is an abnormal build-up of fluid in the abdomen, and we travelled back up to Dublin and they sorted me out and I



Tomas evening after he had his transplant that morning.

was able to go back home that day. Things began to get better and better as the weeks went on.

I am now nearly a year post-transplant and I truly feel like a new man. I have so much more energy in everyday life. Before the transplant I used to spend my night up because of the most horrendous itch and I would be drained of energy every day but from the minute I woke up from my transplant my itch was gone and over the weeks after my transplant my energy started to improve.

It has changed my life for the better and it's all thanks to the amazing people in St. Vincent's hospital and Clonmel hospital. I had a heavy few years but I also had some of the best years of my life.

If I could give any piece of advice for anyone who is going through something like this, it would be to not let it take over your life and see the brighter side to life.

I will be grateful every day to my donor.



Tomas (10) at training

HOPE AND LOVE = ORGAN DONATION

SIOBHAN'S STORY KIDNEY & PANCREAS TRANSPLANT



Siobhan and Miley

My name is Siobhan Brady, I am 38-years-old, from Cavan, and I work as a project manager for an health insurance company. Last summer I received a simultaneous pancreas/kidney transplant in St. Vincent's University Hospital.

I am, well I guess I was, up until the time of my transplant a diabetic. In 2012 I got an E. Coli infection, which was during some travel to India for work. E. Coli can be a lethal infection and it had a detrimental effect on me physically and, to a somewhat lesser degree, mentally. I spent most of a year to 18 months in and out of

hospitals, firstly in Cavan until I was transferred to the Mater Hospital. I developed sepsis on two occasions, the second being the lowest point of the illness. I spent a week in ICU in Cavan General Hospital and at the early stage it looked like I quite likely wouldn't make it through.

Shortly afterwards I was transferred to the Mater Hospital and to the care of Prof O'Meara and the renal team there. It was a long road, but I eventually got back on my feet thanks to my parents, and especially my mother who really helped nurse me back to health, and my family and friends. It was a difficult period for

everyone, and it was so hard on my mam and dad and my family to watch me waste away to nothing. I still get emotional when I think about what they went through. I really think it was easier for me to deal with as I was in it. It's hard for your family and friends to watch on and be unable to help especially in the really low points.

Thankfully, I got back on my feet and eventually returned to a more normal life. I continued to attend the renal clinic in the Mater which have dealt with the prolonged aftermath of the infection since then. Anyone who has diabetes knows how difficult it can be to control blood sugars with even a common cold and as such the complications from the infection began to appear with the onset of kidney failure, which was diagnosed around 2014 and many other associated problems.

By 2017 I needed to start dialysis and I chose to try peritoneal which is a form home dialysis treatment.

I would say there was a certain element of relief when I was told that the day had come for me to commence dialysis treatment. When you have organ failure and, in my case kidney failure, your body is slowly poisoning itself on day-to-day basis. It's like someone giving you very small doses of arsenic, not enough to kill you outright but just enough to make you feel like you are. I was constantly sick, nausea, vomiting, bowel problems, fatigued, just unwell.

With starting dialysis, I really felt a positive impact quite quickly, while I wasn't perfect it was a massive improvement and there were even days in the first year or so of treatment where I genuinely felt okay.

Peritoneal dialysis is an amazing option as it allowed me to maintain a somewhat normal life. I continued working full-time, maintained a social life and managed to stay active, however it has its cons as does everything. The treatment can become less effective with time, you are

responsible for your own infection control and the dialysis machine, which I lovingly named Des, can be noisy. If treatment is not going so well it can cause a lot of disruption to sleep.

After around a year and half on dialysis its effectiveness started to deteriorate, and I began to really struggle with the impact. I can't begin to explain the chronic fatigue, the constant sickness, so much so that I almost couldn't eat or keep anything down, the drain of carrying a few litres of extra fluid in your body, the swollen feet and legs, the cold that permeates your bones, the loss of interest in aspects of life because you just don't have the energy.

Coping with an illness is difficult but throw in the realities of life, work, family responsibilities, trying to maintain friendships, even everyday tasks that you don't normally think about become a mammoth task.

The 18 months prior to transplant were particularly difficult for me and my family, my dad was diagnosed with a form of pre-leukaemia and he passed away in Jan 2020. Caring for a sick loved one where there is little to no hope is devastating. The stress of this and the guilt I felt over not being able to do as much as I felt I should was heart breaking.

Coupled with my dialysis which was not going so well, trying to maintain some sort of diabetes control, working full-time and a run in with a car whilst crossing a street in the estate brought me to a point where something had to give. Work was abandoned for a few months. COVID-19 on top and a surgery to replace the dialysis tube and a bout of hospital based

haemodialysis took its toll mentally and physically.

It sounds like a tale of woe, but it isn't. While living with organ failure is hard, there is hope. I always felt that while one area of my life wasn't exactly easy that didn't have to have an impact on every part of my life. I think



there is always joy to be found in life you just have to accept the hardships and try and make peace with them. Maybe that was easier for me as I had already faced my own mortality and that's finality.

There was a hope of a better, no, an easier life with kidney failure and that's where the importance of organ donation lies. I never would wish to go through any of my illness over again, but I wouldn't change it. It has given me far more than it has taken away.

When I talk about my transplant journey, I tend to use two words a lot, 'hope' and 'love' and to me that's what organ donation stands for. Over the course of my journey, I have been blessed with my family and close friends who have been by my side all through this. The number of Mass

cards and well wishes and phone calls to the house has been unbelievable.

There is so much sincerity and goodness in the world and organ donation is just another manifestation of that. When I think about my donor and my donor family, I feel an outpouring of love

and gratitude from the depths of my soul. I can only hope that some of the sentiment reaches their own hearts and that maybe my dad and my donor have embraced in heaven as I would wish to.

People often ask me how life after transplant compares and it is so difficult to try and explain how many aspects of my life have changed for the better. To try and capture it I think I would say I can breathe again, I can live again, and I can hope and dream again. I'm able to do things I haven't had the energy or interest in for many years.

My love of reading is back. I am amazed when I am out with the dog and can run and play with him. Even everyday tasks, cleaning windows, hoovering, ironing no longer feel like I'm facing

Everest.

Dialysis is a thing of the past; I no longer have tubes hanging out of me from all angles. If I want to take a bath I can. I'm not hooked to a dialysis machine for 8 or 10 hours a night. There are no fluid restrictions, no diet restrictions and amazingly no insulin. I'm no longer having to constantly worry about sugar control which was so difficult with dialysis and possibly having to face further diabetic complications or worse still a hypo I'd never wake up from.

All of this is only possible because of organ donation. The team in the Mater, Prof O'Meara and all the doctors, the renal nurses, Elaine, Millie and all the girls in the renal day unit have been my life-support and continue to be. Mr Gallagher and the teams in St. Vincent's and Beaumont Hospitals made it possible. The transplant coordinators in St. Vincent's Hospital are phenomenal.

My family and friends are my rock, I will be forever grateful for all they have done. But ultimately, I wouldn't be here if it wasn't for organ donation and my donor and my donor's family.

I would beg anyone who isn't an organ donor to carry an organ donor card. Even more importantly have the conversation with your loved ones, let them know how important it is to you and more importantly what it means to people like me. Death is a tragic thing, we all have to face it. I have faced it and will again but if you can leave the legacy of giving a life back to someone who would otherwise lose theirs, regardless of anything else, it will have been a life well lived!

9th call gives breath of fresh air to STEPHEN



My name is Stephen Smith and I'm 42-years-old and from Cavan. I received a double lung transplant in the Mater Hospital in November 2013, due to a condition called Alpha-1 Antitrypsin Deficiency. Alpha-1 is a genetic condition that can affect the lungs and the liver. It is commonly referred to as genetic emphysema. 1 in 25 Irish people are carriers for Alpha-1, making it the second most common genetic lung disease after Cystic Fibrosis. My lungs were like an 80-year-old smoker's lungs despite having never touched a cigarette in my life.

I was 25 when I was diagnosed and was fit and healthy and an avid Gaelic player for my local team Drumalee. Prof. McElvaney from Beaumont Hospital first diagnosed my condition. The diagnosis was at least an answer as to why my lung function had declined so much but it also meant that I had to give up playing Gaelic with my club and the only thing that would give me back some quality of life was a double lung transplant.

I was struggling to walk short distances or climb stairs at that point and, also, suffering frequent chest infections. It was also around that time I met Rachel who would eventually



become my wife so I was acutely aware that I would be bringing her into all my health issues. She never questioned it though, despite knowing all the potential consequences of my illness, and has been my rock throughout all of it. I know how lucky I am to have her by my side throughout it all because there have been some very dark days.

We got married shortly after I was put on oxygen 24-hours a day, so I knew she was the one! It never phased her and never saw me as my

illness just as Stephen. Without her and my amazing family I don't think I could have got through it all.

The transplant when it was proposed was a scary thought, but I knew it would be a gift considering the prognosis wasn't good. It was a gift that I sometimes doubted I would ever get after eight false alarms over three and a half years on the transplant waiting list.

Those false alarms were very tough mentally to process, because my health had begun to deteriorate, where the simplest things like taking a shower and drying afterwards became a mammoth task, but I tried to stay positive and believe that my time would come.

I had also been told that I would need to give up work, restrict my social interactions for fear of infection, much like people are today in COVID times. Before I gave up work, I used to transport dialysis patients to treatment, so I knew all about transplantation and the importance of organ donation.

Eventually my transplant call came in 2013 and while I was initially nervous about the surgery, I kept thinking about the family who'd chosen to donate their loved one's organs and how they were incredibly selfless to do that in the most

difficult time.

I have first-hand experience of that process as 2 years before my transplant, my own Auntie Kathleen donated her organs and while it was extremely upsetting for her children and our family to lose her, she saved 3 lives that night the decision was made. That comforts their family somewhat knowing that even in death their mother was the fountain of generosity and compassion that she'd been in life.

My transplant proceeded and it was all down to my amazing surgeon and her team, Dr. Donna Eaton, that thankfully I came through the operation without any complications. I vividly remember the doctor asking me how I felt once they removed the breathing tube and answering, "This feels awesome". It was so amazing to be able to breathe properly for the first time in many years. It is something we take for granted in life and, really, it's one of the basics of human life.

First thing you do when you're born is take a big breath or let out a cry and everyone knows you're fine. I was very lucky and was home from the Mater and back in my own bed, 15 days post-transplant. Having me home again was a huge relief to my wife and my family.

It doesn't matter how old you are, your parents will always worry about you and mine were no exception. I'm very close to my family and knew well the relief, having me through one of the biggest operations you can have gave them. It can be very stressful for them as well as you when you're waiting so they were delighted after it was all over.

After the transplant, the recovery went well, and I took things very easy initially and followed the doctors guidelines rigidly to give myself the best chance. Being able to do very simple things again like have a shower without oxygen or climbing the stairs in my house to play a game of pool, made me realise just what I'd been missing out while I was waiting on my transplant.

I was able to go back to full-time employment after about 6 months and that was a great feeling knowing that I'd be out and about again meeting people and having a chat.

I also started going back to playing football casually with a few friends and was even able to participate in a charity Gaelic match as well. I was also



able to travel to New York with Rachel as well as to represent Ireland in the Transplant Games in Finland in 2016 and I proudly brought home 3 medals.

A lot of the praise for allowing me to live a normal life again would have to go to the doctors and nurses who cared for me. Respiratory Consultant Prof McElvaney of Beaumont Hospital, who diagnosed me with the condition. My thanks also to the team in the Mater Hospital led by Prof Jim Egan, the transplant co-ordinators who called me on nine occasions, including eight false calls, the ninth which came just in time to save my life, Zita, Vivienne and Alexia, the team in my local hospital led by Prof James Hayes and his respiratory team, Bernie, Rita and Claire, who kept me so well while

I was waiting on my transplant.

Those people really care about their patients and we're incredibly lucky to have access to the type of care I received from them.

Finally, it is due to the generosity of one donor and the strength of their family to carry out their wishes, I'm here today. There is no doubt in my mind that I wouldn't be here now without them.

I've lived another seven years and counting, and I've made so many memories in that time. Good and bad I was here to experience it and support my family when they've needed me. People who make the choice to donate, in the event of the unthinkable happening to them, are selfless, amazing people. I can only hope my donor family get some comfort knowing their loved one has helped me.

Of course, it will never bring their loved ones back to them, but it might shine a little light in an incredibly dark time for them all. I can imagine their recipients are eternally grateful. I know I will never express in a thousand lifetimes the gratitude I have to my donor and their family.

My favourite quote is "The greatest hero I never knew is an organ donor who saved my life". It's so true, they're my hero and they always will be.

So, I would encourage anyone to carry a donor card or have the chat with their next-of-kin. You've no idea how it could change someone's life like mine was changed. Some day you could be somebody's hero.



ANNUAL SERVICE OF REMEMBRANCE AND THANKSGIVING

The 36th Annual Service of Remembrance and Thanksgiving will, for the second year in a row, be held virtually due to continued concerns around large gatherings amid COVID-19. The virtual Service will be held later this year and will be available for all to view online. More details to follow in the Autumn issue of *SUPPORT*.

Junior Doc Juliette thanks donors

My name is Juliette Duff and I am a 26-year-old junior doctor from Dublin. Three years ago, just before my 23rd birthday, I received a kidney transplant that completely changed my life. I can still remember the gorgeous June evening. I had picked up my brother from work and as we got out of the car my Dad was running towards me. I was thinking of climbing up the stairs and getting onto my dialysis machine, as by that stage I was getting quite sick and feeling more unwell with each passing week. But my Dad had tears in his eyes and said, "We need to get to Beaumont. Quickly".

I was diagnosed with Chronic Kidney Disease in January 2014 while in my first year of science at UCD. I had hypertension during a visit to the GP during 6th year. I was so young and healthy that we all agreed it was a combination of Leaving Cert stress and

white coat syndrome.

But the Leaving Cert came and went and still I wasn't myself, I had heart palpitations, fatigue and I caught every respiratory infection doing the rounds which was very unusual for me. My Mum had that sixth sense that mothers do and on New Year's Eve 2013 she insisted I go to the GP.

When I mentioned my Dad had two kidney transplants, the first when he was 23, just 4 years older than I was at the time, the GP suspected this could be history repeating itself.

During this time I repeated my HPAT and took up a place in medicine. I had seen my Dad go through dialysis and his second transplant when I was 7. He was a massive inspiration and an example of perseverance, and he would be so embarrassed of me saying that!

I started my medical degree and within a few months of that I started peritoneal dialysis. This involved 9

hours on my dialysis machine at home each night via a tube in my abdomen and during the day I would carry 1-2 litres of fluid in my 'tummy' to dialyse throughout the day.

I had spinal surgery for scoliosis when I was 16 so this put a huge strain on my back and was quite uncomfortable. The dialysis machine would wake me up usually every 1½-2 hours at night. However, I was happy to do dialysis as at this point it made me feel a bit better. Family members were getting tested during this time to see if they could be a potential donor for me, however none of them were suitable. It was incredible to think that they would do that for me, I was really moved by it and felt so lucky.

I began to get sicker. My legs were so swollen and my whole body felt restless and uncomfortable all the time. I struggled a lot with anaemia, I often felt faint and couldn't stand for very long. It made college very



Juliette with her Dad Manus



Juliette and her Mum Nora

difficult. It's actually quite hard to think back on it as I didn't realise how bad it was at the time.

I was 22 and didn't want to miss out. My friends were wonderful and always looked out for me and subtly adjusted the pace so that I could be involved. It was the summer before my second last year of my degree and I knew at that point I was struggling. It felt like something needed to give but I didn't want to give up my dream career. I was about to start training in the hospital and I didn't know how I would have enough time to dialyse at night with the long days. I struggled with just a flight of stairs. That's when I got the phone call.

I cannot put into words what the 'gift of life' means to me and my family but I will try my best.

It took so much worry off my parents' shoulders and meant my brother got his big sister back. I got to graduate last May, I could go on holidays, I could return to my swimming which is my favourite hobby. For two and a half years when I couldn't sleep on dialysis or when it all felt too much, I imagined my first length of the swimming pool after the transplant.

I could eat anything I wanted, including my three favourites again, chips, cheese and chocolate. I could stay out late with friends or family and go to college balls and make up for the experiences I had missed out on.

I went from wishing I could do a flight of stairs, to climbing Croagh Patrick. I no longer felt sick and uncomfortable and that alone was enough. While I was sick it felt like I was on the outside of something looking in. When I got the call it felt like the whole world had been handed to me.



Juliette's virtual graduation in May



Juliette on the day after her transplant



Juliette with boyfriend Adam Muldowney when she climbed Croagh Patrick on New Year's Eve 2019

It wasn't the first time my family were blessed to receive the 'gift of life' from an organ donor. Before I was born my Dad received a lifesaving kidney transplant, and again when I was 7. For the third time, my family was given the 'gift of life'. Somewhere in Ireland, in a moment of immense pain and sadness, a family decided to help us without even knowing us. They didn't care who I was, only that I needed help and perhaps they could provide it.

Having lost my own wonderful Dad last September, I am amazed that despite their pain they took a moment to ease mine.

We are such a generous country and everyone I speak to is genuinely interested in becoming an organ donor so it is incredibly important that we all discuss it. Right now, there are so many people holding on to the hope that they get the call and it's up to all of us to help them.

It is so exhausting to hold onto that hope as you get sicker, so please, if you want to be a donor and give someone the 'gift of life', tell your loved ones, tell them you carry an organ donor card and download the app on your phone.

Thank you so much to my family for their constant support, my friends who were always there for me, and the staff in Beaumont and St. Vincent's hospital for the wonderful care I continue to receive.

Most importantly, 'thank you' to my donor up in heaven and to their family. Thank you to both of my Dad's donors and their families who gave me years of happy memories with him. I think of my donor and their family every day. I wish I could give them a hug and tell them that I will never forget what they have done for me.



UNIVERSITY OF
BIRMINGHAM

Coventry
University



UCC

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh



TEAM

TRANSPLANT EDUCATION & ACTIVITY MOVEMENT

Foreword

The Irish Kidney Association is excited to be part of this new research initiative. It brings us together with academics who have the skill set, and motivation, to make a difference. Evidence based research can really make a difference when advocating for the development or introduction of a service.

The fact that TEAM brings together researchers from both Ireland and the UK is very positive as it broadens the perspectives that are brought to bear on the work. With the Irish Kidney Association's strong membership base and its sports programme that connects us with so many of our peers internationally, we are in an excellent position to advise on and support research in the area of the health and well-being of people living with and affected by end stage kidney disease.

It should be acknowledged that the researchers have been putting in significant hours of their own time in getting this work off the ground as there is currently no funding in place. We are fortunate to be working with such committed people.

The receipt of an organ transplant is for many a second chance at life and a significant gift. While there is much research that informs us about the physiological aspects of living well with transplantations, there is far less work aimed at understanding the psychological and social elements that impact on this journey. This is also true for those individuals that are awaiting the chance for this life altering

gift; those undergoing dialysis treatment or with a condition that means they can't receive a transplant.

These are some of the goals of our new group; the Transplant Education & Activity Movement (TEAM). TEAM aims to research these psychosocial variables that impact on the health and well-being of transplant recipients and other members of this community (i.e. those on dialysis, family members, transplant games coaches).

TEAM intends to be a growing research network and is interdisciplinary in nature with the current membership comprising educationalists, psychologists, sports scientists and therapists and those working in the areas of advocacy and outreach in transplant health, wellbeing and research. We hope this community will grow in time and we aim to build a European and worldwide research and education community of practice.

PATIENTS' SURVEY

Our first step in the journey is to gather some initial data so that we might begin refining the areas of focus for our future activities.

We are currently conducting a large-scale survey study and we are seeking any and all renal transplant recipients, those waiting for transplants, individuals with CKD or any other members of the community that suffer with any kidney related illnesses.

The survey consists of a number of questions on areas such as motivation, general wellbeing, social engagement and so on. It should take approximately 30-40 minutes and the data will be so valuable to our work and the future activities we have planned aimed at improving knowledge and support in these areas.

Please consider helping us out by taking the online survey (if eligible) and share widely within your networks. Once you click on the link you will be given some more information about the study.

SURVEY LINK
<https://forms.office.com/r/mvJsURGAei>



Introducing the TEAM Research Network Members



Dr Thomas Delahunty
(B. Ed, PG Dip. Psych, PhD,
CPsychol)
Chair of TEAM

Tom is a Lecturer in the Department of Education and Social Justice in the School of Education at the University of Birmingham and Visiting Lecturer in the School of Education at University College Cork.

His primary research interests are in the areas of cognitive representation and conceptualisation in human reasoning, presage variables in STEM learning processes, and gender.

Tom is the current Chair of TEAM and is himself a transplant recipient, having been diagnosed with CKD in 2012 and receiving his transplant in 2016.

This "second chance" has allowed him to fully pursue his academic career and he sees this project as his duty to give back to the community for this gift.

He is committed to applying his psychological, educational and research expertise to enhancing quality of life among this unique global community of people



Dr Joseph A. Moynihan
(BA, HDE, MA, GDGC,
CIS, PhD)
Researcher

Joe is a Lecturer in the School of Education in University College Cork (UCC), Ireland. He is the Director of the Educational Leadership Post-Graduate Programme.

Joe is also a lecturer/tutor in Initial and Graduate Teacher Education where he specialises in Educational Leadership and Management.

Joe also supervises research students at Masters and PhD level at the university.

To further broaden and deepen his knowledge in the field of coaching, Joe is currently undertaking a two year M.Sc. in Personal & Management Coaching at UCC that he completes in June 2021.

Joe was diagnosed with polycystic kidney disease (PKD) in 1993. He was fortunate to have a life-changing transplant in 2009 while serving as Principal of a large school in Co. Waterford at the time.

He received this 'gift of life' from his sister Mary through the living donor programme at Beaumont Hospital in Dublin.

His wife Frances donated her kidney to their daughter Karyn in 2020.



Sheila Leddington Wright
MSc, BSc(Hons), PGCert,
Grad.Dip. Phys. SFHEA, MSST
Researcher

Sheila is a member of the Chartered Society of Physiotherapy and an honorary member of the Society of Sports Therapy.

She worked as a therapist within sport for over 30 years before moving into academia. She worked as an associate professor until 2020 and is currently an honorary teaching fellow at Coventry University.

Over the last decade she has championed the development of the research base related to transplant sport.

Sheila has worked with transplant athletes since 2009 attending British, European and World Transplant games and was awarded the Peter Griffin award for services to Transplant Sport UK in 2018.

She has a track record of presenting her research at National and International conferences including her work within transplant athletes.



Thomas Hames
(BSc, MSc, MSST, FHEA)
Researcher

Thomas is a member of the Society of Sports Therapists and the Course lead of the BSc Sports & Exercise Therapy program at Coventry University, UK.

As a clinician, Thomas has worked with Coventry Bears RLFC, Rugby Lions RFC, West Bromwich Albion FC, and Peterborough United FC.

Since joining Coventry University, Thomas has also taught on the BSc Physiotherapy and MSc Strength & Conditioning programmes, while also continuing to work in an applied capacity with National 2 Hinkley RFC.

In 2017, Thomas provided clinical support for Transplant Sport event and is now part of the medical support team for the British Transplant Team having attended the 2017 and 2019 World Transplant Games.

In support of the athletes, Thomas is currently undertaking Transplant Sport research and a PhD entitled 'The Athletic Implications of a Life Saving Allograft on the Body'.

continued next page →

Introducing the TEAM Research Network Members contd...



Dr Niamh O'Brien
(B.Ed., M.Ed., PGD, PhD.)

Researcher

Dr Niamh O'Brien is currently a lecturer in the B.Ed. Sports Studies and Physical Education Programme, in the School of Education, at University College Cork (UCC), Ireland.

Niamh's key subjects in education include; health, health promotion, inclusion, disability and pedagogy and sports medicine.

Her research investigates the constructs of wellbeing and positive mental health and its relationship with physical activity.

The foundation of Niamh's work stems from a health promotion perspective and therefore, her research aims to take a salutogenic approach to wellbeing through discovering and educating members of society on the methods and strategies that aid us to protect mental health and promote life-long flourishing and health.



Colin White
(BSc Soc., PGCE)

Facilitator

Colin has been working for the Irish Kidney Association (IKA) for 16 years and his current role is as the National Advocacy and Projects Manager.

As manager of Transplant Team Ireland he has seen that domestic and international programmes of sport for people pre and post-transplant have a positive impact on the quality of life of participants as well as the obvious physical benefits.

He has spoken on this topic at international medical conferences and is currently Treasurer of the World Transplant Games Federation and Secretary of the European Transplant & Dialysis Sports Federation.

Inspired by his wife who is 20 years on dialysis, Colin is passionate about working to enhance the quality of life of people living with and affected by organ failure.



'TIM' is the second in a series of four short stories, 'Taxi Tales' written by 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. The first in the series entitled 'Early' featured in the Spring issue of SUPPORT. Sadly, Alexander passed away in April 2021. May he Rest in Peace.

'TIM'

Timothy, or Tim as his chums called him, is a likeable, chatty person, prone to stop talking mid-sentence resulting from triggers and abstract thoughts. It was a warm sunny day, traffic, not too bad, conversation easy and from his curiosity born question 'Your only boy?' I was sent into a reflective mood. After seventy odd years a man tends to reflect on 'what might have been'. A mystical place of disastrous relationships and remote possibilities.

Tim long ago caught the eye of Sheila, the tea lady, who always ensured that there was a cup of tea and a spare packet of sandwiches, in excess of requirements, for when he rolled me into the reception area.

My question to Tim, 'Do you have a boy?' provoked an even longer pause and I regretted asking such a personal question, and then just as I was about to comment on the number of houses coming on to the market in our part of town, he started talking.

'Yes, four, plus a girl. She is a handful. The youngest and misses her mother'. After a few moments manoeuvring through a busy roundabout, he continued. 'My wife and I had to divorce'. Another thoughtful silence. 'The boys are all grown up now and probably give little thought to their sister. The girl is something else. She is from my second wife. And she needs her and misses, naturally, the advice and role model that she presented prior to her passing away'.

I now understand Tim better with his moods, and also Sheila's interest in such a sensitive cabby.

SPRING PRIZE GIVEAWAY WINNERS

Thank you to Geraldine and the team at Meals4Health (Ph: 091-354000/085-8719384) for their generous gift of a €25 voucher each, including the first order delivery costs, for ten lucky readers of SUPPORT. They kindly donated these for our prize giveaway competition in our Spring issue.

THE WINNERS WERE: Mary Adamson, Tipperary; Tom Crowley, Kildare; Ita Schuttke, Dublin; Michelle Moran, Galway; Carmel Moran; James Brady, Meath; Jennifer Tuohy, Clare, Jack Cuniffe, Westmeath; Celine Tuite, Meath; Karley Rodriguez Torres, Dublin

www.meals4health.ie





GETTING MORTGAGE PROTECTION OR LIFE INSURANCE FOR KIDNEY PATIENTS

– A BROKER'S PERSPECTIVE –

By
NICK MCGOWAN
DIRECTOR

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**If you need some
advice, Nick is
available to help.**

Tel: **057 93 20836**
Email: **nick@lion.ie**

LET'S START BY LOOKING AT LIFE INSURANCE IF YOU HAVE CHRONIC KIDNEY DISEASE (CKD)

If you have CKD, the main factor the insurers concern themselves with is your Estimated Glomerular Filtration Rate (eGFR). Your eGFR shows your level of kidney function and determines your stage of kidney disease.

Generally, it isn't easy to get cover if your eGFR is under 45. Regrettably, if it's below 30, all of the insurers will decline to offer cover.

Insurers also need to check if there is a history of proteinuria or hypertension (high blood pressure). The presence of either will make it more difficult to get cover.

Finally, the insurers like to see a period of eGFR stability. If there are spikes, they may postpone making a decision until your eGFR levels off.

If the insurers can offer cover, they will load (increase) your premium. The increase can be multiples (e.g. 2.5 times the normal price) or per €1000 worth of cover (e.g. €10 extra per €1000 worth of cover).

NOW, LET'S LOOK AT LIFE INSURANCE SPECIFICALLY IN RELATION TO A GENETICALLY INHERITED DISORDER SUCH AS POLYCYSTIC KIDNEY DISEASE (PKD)

Symptoms of PKD usually begin between 30 and 40 years of age. If a parent has PKD, then a child has an approximate 50% chance of developing the disease. Over time, the chances of developing it decrease substantially. As you get older with no sign of the hereditary disease, the insurer assumes that you won't develop it, so they underwrite

more leniently. Therefore, it's easier (and cheaper) to get cover for someone diagnosed with PKD who is in their 30s compared to someone in their 20s.

If one of your parents has PKD and you haven't had a screening, it's going to be impossible to get cover.

There is a genetic test for the disease, but please be aware that you do not have to disclose the results of a genetic test to the insurers. Under the Disability Act 2005, insurers cannot take either a positive or a negative genetic test into consideration.

If you have PKD, your premium will be around three times the standard price. If your parent has PKD but you don't, your loading/increase will depend on your age when you apply. The younger you are, the higher your premium.

IS THERE ANYTHING YOU CAN DO TO IMPROVE YOUR CHANCES OF GETTING COVER IF YOU HAVE KIDNEY ISSUES?

1. Be proactive in managing your condition. Work with your GP and follow-up on treatments and advice given to you.
2. Life insurance underwriters view regular check-ups with your GP in a positive light.
3. Use an experienced broker who deals with all five major insurers (Aviva, Irish Life, New Ireland, Royal London and Zurich Life). All the insurers are not the same when it comes to kidney disease. Some are more understanding than others.

EDITOR'S NOTE

Sometimes, lenders will agree to a mortgage protection (life insurance) 'waiver' where an applicant can show that he/she has been declined cover by three Life Insurance Companies. However, this is entirely at the discretion of the mortgage provider.

If you would like the Irish Kidney Association to prioritise investigation into improving access to life assurance for people with kidney disease, please let your branch officials know or email Colin White, our National Advocacy & Projects Manager, email: colin@ika.ie



By GWEN O'DONOGHUE

Daughter's tribute to late dialysis father

A Galway family were left bereft last Christmas in the midst of COVID-19 as their loved one, a dialysis patient, passed away with heart complications. Only 25 people could attend church for his funeral mass amid government restrictions. His grieving family would now like to celebrate his life which he led with 'such dignity' by sharing his story, and support the Irish Kidney Association, in raising organ donor awareness.



The late Martin Henderson



Jenny Henderson

The late Martin Henderson, from Ballyforan (on the Galway and Roscommon border) and a native of Cavan, who was a loving husband to Frances, a father of three and a grandfather of five, passed away at the age of 67, on 16th December 2020.

Martin was a self-employed barber. His daughter Jenny (25) followed in her late father's footsteps qualifying as a hairdresser, and she is now the young mother of two sons Ryan (5) and baby Timothy. Jenny explained, "from the time I was a young child, I was aware of the kidneys and their importance. I was just 7-years-old when dad started receiving dialysis treatment. He had Polycystic Kidney Disease (PKD), a hereditary kidney condition which some of his brothers and sisters also had. It is thought that

his own mother might also have had undiagnosed PKD as she died in her early forties following a stroke on Christmas Day. My father, the youngest of eleven siblings, was just 6-years-old when she died.

"For my dad, and like many people who have PKD, his kidney condition didn't start to impact his health until he was in his forties. I understand that for some living with the disease it doesn't progress until later in life. One of my brothers also has the condition, but fortunately he is enjoying good health.

"Dad was 50 when he progressed to end stage renal failure and he then began receiving haemodialysis treatment at Merlin Park Hospital in Galway, three times a week which continued for two years until in 2005 he received a kidney transplant.



***Martin's grandchildren, who live in Australia...
Lachlan, Finn and baby Patrick.***

I remember how his illness prior to his transplant affected his energy levels and how my mother and he would carefully have to plan family events and trips away. We were fortunate to have been able to enjoy some holidays abroad when he could arrange dialysis treatment away.

"I was 9 when dad received a kidney transplant. At the time there was a huge sense of relief and happiness for our family as well as gratitude to the kidney donor. The transplant gave my father a good quality of life for ten years until it started to fail. By then he was also experiencing other health issues including heart complications and he no longer had the strength or energy levels to continue working. My mother became his carer about five years ago and they were a great support to each other. In 2017, dad returned to the all too familiar, three times weekly, trips by HSE taxi to Merlin Park for his dialysis treatment, the same regular journey he had made for two years before his transplant.

"At the end of last year, I felt helpless when my father became extremely ill and ended up in hospital. My feeling of helplessness and desperation became even greater when he ended up being gravely ill in ICU on 3rd December. The medical and nursing staff did their best for him, and my family prayed for his recovery. There was nothing else we could do but hope he would make a recovery, which he briefly showed signs of doing, before deteriorating further, and it was his heart that finally gave up on him.



Martin with his sister Joan on their Confirmation day.

"While he was in ICU, I realised there was one thing that I could do amid all the uncertainty, and that was to try to help other people like dad, who had kidney failure by setting up a Facebook fundraising page in aid of the Irish Kidney Association (IKA). A few hundred euros was raised in the week before he passed away. At his funeral we asked that people who wished to make donations, if desired, could make them to the IKA. I hope in the future to pick up where I left off by supporting, once again, the IKA who provide help to kidney patients and their families. By sharing our father's story, we can honour his memory and celebrate his life and the way he carried his illness so bravely, without complaint and with such great dignity. We also hope that by sharing his story we can pay tribute to, and raise awareness for, all those other patients who have organ failure and their



Frances and Martin Henderson on their wedding day.

families who are affected also. We also remember and express our gratitude to the deceased kidney donor of my father's transplant which gave us years more precious time with him.

"Our family would like to thank all the medical and nursing staff in the dialysis unit and ICU at Merlin Park who showed huge compassion and provided great care to my father. We would also like to express our gratitude to friends, neighbours and the whole community who sent cards and messages of support and sympathy."



Frances, Martin and Jenny Henderson.

By GWEN O'DONOGHUE



Pics: Conor McCabe Photography

Seven-year-old SOFIA COREY, from Walkinstown in Dublin, who has been cocooning for over a year, got to taste her first ever Easter egg this year as Organ Donor Awareness Week came to a close. Sofia has been a kidney patient from the time she was a newborn and due to the diet restrictions of her illness she was denied chocolate. That all changed and her penchant for chocolate developed quickly, after she received a life-changing transplant during Christmas week 2020. Her parents Elaine McElroy and Daniel Corey shared their only child Sofia's health story to help raise organ donor awareness.

Sofia's Egg-travaganza

Sofia was born a month prematurely and was diagnosed with the kidney condition called Congenital Nephrotic Syndrome when she was just seven weeks old. She became a patient at Our Lady's Hospital for Sick Children in Crumlin and

underwent an operation to have one of her kidneys removed when she was six months old. When she was two and half years old her parents were trained up to give her nightly dialysis treatment, which she underwent at home for twelve hours at a



time. This continued for over four years until she was called for her kidney transplant last Christmas.

Sofia's mum Elaine McElroy explained, "Because of COVID-19 and as a dialysis patient and now a transplant patient in the high-risk category, she has been cocooning for over a year away from her school friends. It's great that Spring has arrived as she can now enjoy more time outside in the back garden where she loves to play in her playhouse.

"We are so grateful to the kidney donor for finally giving Sofia a chance of a normal childhood. Both myself and Sofia's father were extremely disappointed to learn that neither of us were suitable kidney donors as we had always assumed that one of us would be. Sofia had to reach 12kg in weight and 90cm in length in order to be accepted onto the transplant waiting list. She needed to be big enough to be able to receive a donor kidney. She was five-years-old before she reached the required size. Then Daniel and I began the screening process for living donation which turned out to be unsuccessful. We can never thank the donor family enough who transformed Sofia's life.

"We hope that by this September Sofia can be reunited with her school friends when she starts first class, who she hasn't seen for over a year because she has been cocooning with



Sofia Corey with her gran Joan McElroy and mother Elaine.

just me and her dad. She can now look forward to a normal childhood and like most kids she has developed a fondness for chocolate. This was her first Easter to enjoy Easter eggs, just like her friends. She is totally free from dialysis now and we are starting to see her appetite improve and she is much more active now. She no longer has diet and fluid restrictions. The fluid restrictions were very tough

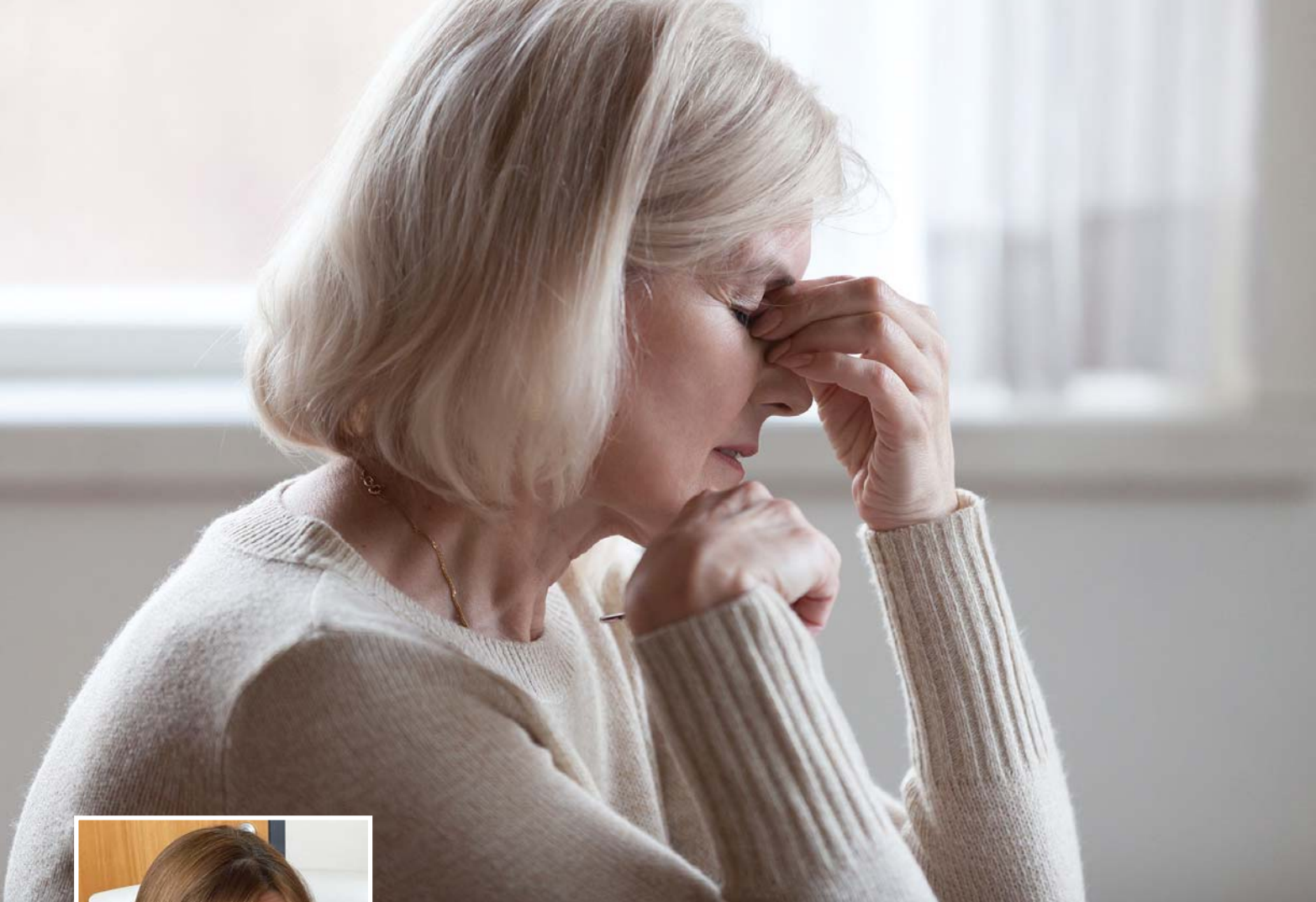
for her particularly in the summer months when she was confined to just 200mls of water which we would have to make up in ice cubes to try to prolong her enjoyment when she was thirsty. She liked to suck on a damp sponge. Her life revolved around nightly dialysis before and lots of sickness and hospital visits but since her transplant she hasn't had any setbacks. She was so excited to have to go into hospital on Good Friday to finally have the dialysis line removed from her chest. She can't wait to go swimming as she has never done this before. We are going to buy her a paddling pool for the sunny weather, something she has never been able to enjoy before when she had a dialysis line.

"I would urge everyone to try to understand the importance of organ donation. A donor has given Sofia a chance to have a normal childhood. Our family will never be able to describe how grateful we are for this."



At six months a week after she had an operation to have one of her kidneys removed.





By AOIFE SMITH

As we start to emerge from beneath the veil of COVID-19, I can almost feel the shift in energy from people. Life is starting to resume for many, shops are open, roads are busier, and people are out!! For others, the easing of restrictions brings with it a new sense of anxiety about leaving the safety of the bubbles they have created. This is a very understandable feeling after such a long stretch of uncertainty and fear.

DISEASE VS. ILLNESS

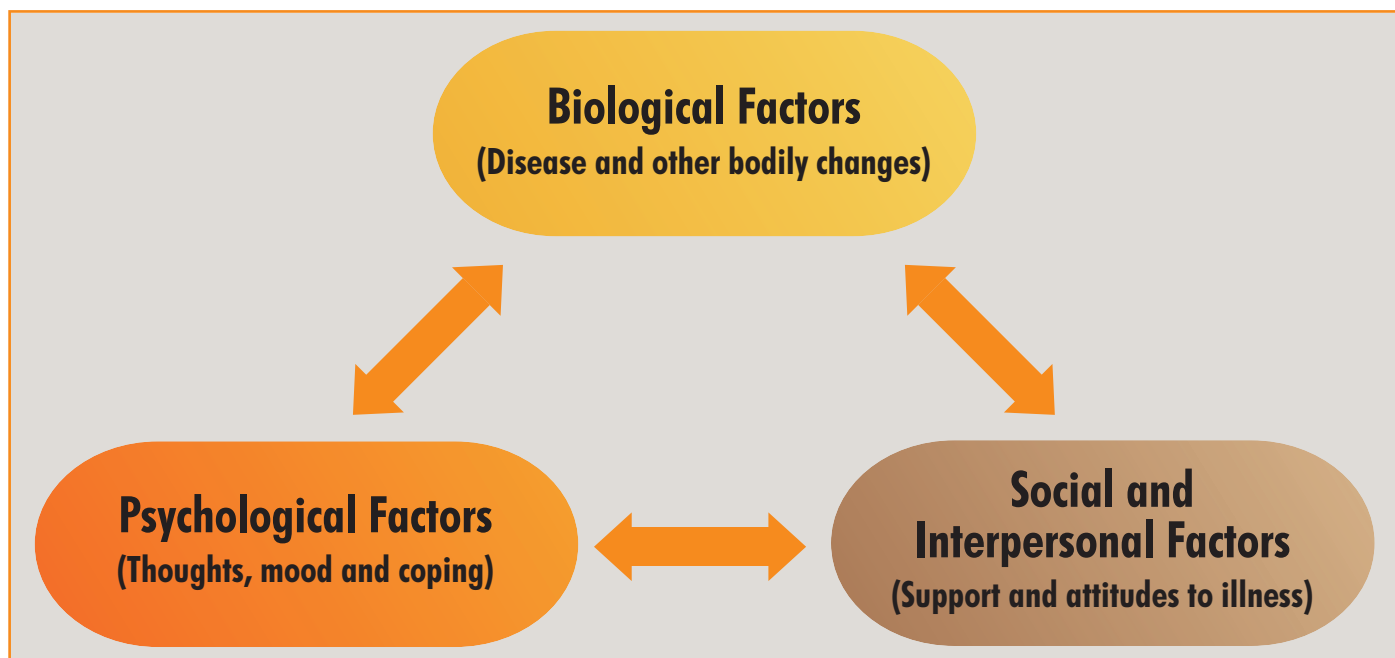
When you live with a chronic illness uncertainty and fear can be familiar feelings. I am often asked how best to cope with these feelings and how to feel more empowered living with chronic kidney disease. When I am, I try to explore what it means for a patient 'to be empowered' and what is happening to make them feel disempowered. Some feel they have lost their voice, they no longer feel heard or seen as a person. Somehow, they have lost a sense of control over their bodies and their lives. They become 'Chronic Kidney Disease' instead of say 'Alan', who is a father, son, brother, uncle, and friend who lives with chronic kidney disease.

What patients have found helpful, and I thought might be useful to share, is the work of Frankie Campling and Prof Michael Sharpe in their book, *'Living with long-term illness - the facts'*. They look at illness from 'the integrated or bio-psycho-social approach'. Now that may sound complicated, but it is actually quite straightforward and when discussed with patients it often opens up a new

perspective on their illness and offers new ways to feel empowered in their own healthcare.

Firstly, to help understand this approach it is important to look at the distinction between two words: disease and illness. From a medical perspective **disease** deals with pathology, the change in your body, which is what doctors are trained to identify and manage. This change could be due to infection, degeneration of tissue, injury/trauma, toxic exposure, development of cancer, diabetes etc. On the other hand, **illness** refers to your experience of having that disease. It describes your symptoms, your feelings, or reactions to it and what you can or cannot do. It is your own subjective experience of the disease. What is of interest to a patient is the impact it may be having on their functioning, relationships, and social interactions.

These words are commonly used interchangeably in healthcare circles, and they are clearly related and usually do occur together. Most of the time, a disease will be accompanied by illness and



a decrease in feelings of illness can indicate the passing of a disease. However, it is worth noting that you can have one without the other, it is not uncommon for a person to have a disease but have no experience of illness. People can have something like high blood pressure or even kidney disease, and not know it. People with the very same disease can typically suffer very different degrees of illness.

Understanding this can help to view illness from a broader perspective. This opens up the idea that there are other factors contributing to illness separately from the disease. *Campling & Sharpe* break these factors down into biological, psychological, and social and interpersonal categories.

Biological (or physical) factors that cause you to feel unwell include the identified disease i.e. chronic kidney disease, and the changes in how well your body functions because of the identified disease.

Psychological factors include your thinking, your emotions, and what behaviours you use to cope with your illness. All long-term illnesses affect how people think, how they feel emotionally and how they behave, which can then influence their feelings of being well or unwell.

Social and Interpersonal factors include the way we interact with other people and how they respond to us. What others say and do, and how much support we get or do not get, influences how we feel. Wider social factors, such as generally accepted views about certain illnesses, can also change the illness experience.

Campling & Sharpe say by considering all the relevant factors and not just the changes in your body that enable a doctor to diagnose a **disease** helps you understand what else may be adding to the feelings of **illness**.

It may appear to be a bad thing that so many factors other than the disease can make you feel unwell, but the reverse is actually true. This approach helps identify all the factors that could make you feel ill, but it also suggests that these things affect each other e.g. a positive attitude (social and interpersonal factor) to coping with the illness may enable you to stay more active, this in turn can improve how you are thinking and feeling (psychological factor) and make your body stronger (biological factor).

This means that even if the disease is chronic, awareness around the interaction of the different factors may help you think about which factors are relevant or important to your illness and where making small changes could help you take back a sense of empowerment!!

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!

"LIVING WELL" PROGRAMME

The IKA has organised a number of successful online self-management programmes. The programme runs one morning a week for six weeks, each session lasting two and a half hours.



Feedback from those who have participated in the programme is very positive. If you are interested in participating on the course, please get in touch with me.

Aoife

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



Here comes the Summer!

The summer is here, and although Irish weather can be a little unpredictable, barbecues and meals out with friends and family are definitely set to soar in popularity this year. It's time to dust off the barbecue and dig out the glad rags! With this in mind, we have put together some helpful tips and recipes to help you enjoy these occasions while still keeping to your kidney diet.

It is exciting to see restaurants opening again, but for many it has been a long time since they have gone out for a meal. A little bit of preparation can go a long way. If you have been prescribed phosphate

binders, put spares in your wallet, bag or car so you won't be caught without. Think about what you are choosing to eat during the day to make sure you keep enough allowances of protein, dairy, fruit and vegetables for your meal. Looking at the menu online in advance will help you plan your meal choices. If you are still unsure, call ahead to discuss any requests you have with the restaurant. Cut out the template to bring with you; this has some tips to help you choose the most kidney friendly options.

A barbecue is a tasty way to cook and adds great flavour to meat, fish

and vegetables. Cooking from scratch is a simple way to keep track of the ingredients in your food. Choosing fresh meats, for example steak, ribs or chicken rather than packaged meats such as sausages is a simple way to avoid salt and phosphate additives.

If you are attending a barbecue, as a guest, why not bring a dish for you and others to try as well. The website www.irishkidneydiet.ie has recipes for burgers, tandoori chicken bites, and a marinade to add to the menu. Why not try your hand at our mouth-watering recipe for marinated chicken, couscous and roasted vegetables? Enjoy!

TOP TIPS FOR EATING OUT

- Don't be afraid to ask for more detail on how the meal is cooked or request a particular ingredient to be left out – you may be able to ask for less added salt or salty additions (e.g. soy sauce).
- Choose dishes with a small amount of sauce/dressing, or ask for it on the side to control how much is added.
- Drink sugar free fizzy drinks, squash, ginger ale, mineral water, or tap water.
- Enjoy an after dinner tea instead of coffee.
- If you are having an alcoholic beverage, choose spirits in small amounts in place of wine, beer, cider, or liqueurs. Discuss alcohol with your doctor or dietitian.
- For dessert enjoy flan, cheesecake, plain sponge with fruit, a crepe, or apple sponge/tart. Avoid desserts with dried fruit, chocolate, banana or rhubarb.

IF YOU ARE ON A POTASSIUM RESTRICTION

- Ask to swap high potassium vegetables for low potassium alternatives – for example swap beetroot, mushroom or avocado for red/yellow/green pepper, aubergine or spring onions.
- Choose rice, noodles, pasta, boiled potato or mashed potato instead of chips/potato products like croquettes or waffles – if you are having potato have ½ of your allowance of potatoes as they will not be double boiled.
- Avoid soups as they can be high in potassium and salt – choose a solid starter such as garlic bread, a small salad, or chicken wings.

IF YOU ARE ON A FLUID RESTRICTION

- Finish your drink before the glass is refilled to monitor your fluid intake.
- Hot, spicy or salty foods may increase your thirst.

IF YOU ARE ON A PHOSPHATE RESTRICTION OR DAIRY ALLOWANCE

- Include white sauces in your dairy allowance.
- Choose cream with your dessert – if you are having ice cream as part of it count it in your dairy allowance.
- Avoid desserts containing nuts.
- Choose other sugar free fizzy drinks instead of cola drinks.

By
SALLY HOULIHAN
and
SUZANNE BENSON
(Renal Dietitians)
Tallaght University Hospital

on behalf of the



COUSCOUS SALAD WITH LEMONS AND HERBS

Serves 6

Ingredients

450g couscous (plain white)
45mls of Olive oil (4tbsp)
Juice of 1 lemon/1 lime
(45mls)
500mls boiling water
½ teaspoon black pepper
15g chopped mint/
coriander or parsley
(approx. 4tbsp)

Place the couscous in a large bowl, add the olive oil and lemon juice and mix well to coat all the grains. Pour in the boiling water and place a plate on top, allow to sit for about 10mins (until all the water is absorbed). Use a fork to fluff the grains and add the chopped herbs of choice.

BBQ VEGETABLES

Serves 6

40g red pepper
200g courgette
300g aubergine
90g bunch spring
onions/ scallions
(approx. 10 pieces)
33mls olive oil (3tbsp)
4g dried mixed herbs
(4 tps)
½ tsp black pepper

Cut up the pepper in 4-5 pieces (similar size), Slice the aubergine and courgette lengthways.

Add these to a large bowl with the olive oil, mixed herbs and a good pinch of pepper. Mix well with clean hands.

Add to the BBQ, grill for 4 mins each side, keeping an eye on the process!

MARINATED CHICKEN

Serves 6

600g chicken pieces
(breast or leg) (in total)

45mls oil (3tbsp)
30mls balsamic/ wine
vinegar (approx. 2 tbsp)
3 cloves garlic - chopped
(approx. 28g)
½ tsp of black pepper
7.6g chopped parsley and
thyme (approx. 2 tbsp)
30g of brown sugar
(2 tbsp)

Add the marinade ingredients in a large bowl and mix well. Add the chicken pieces and make sure they are well coated.

Marinate for 15 mins to 2 hours depending on how strong you want the marinade to be.

Cook for approx. 10 mins on each side until well cooked, turning often while cooking.

Per portion this dish provided;

2 portions of vegetables
No dairy
4.5 protein exchanges
3 portions cereals/grains



We encourage our SUPPORT readers to share their stories about their journey living with kidney disease which might help and inspire others.

Almost every other day we get a call from a member who would like to know if someone else has experienced what they are going through. Although everyone experiences things in different ways, reading about someone else's might offer comfort to and greatly benefit others who could be living through a similar situation.

If people sharing stories would prefer not to be recognised we can assure you that anonymity can be retained. Please be aware that while we greatly welcome all submissions we may not cover each and every one of them.

Your story might be about being newly diagnosed, starting dialysis treatment, what it is like to be on long-term dialysis or to have received a transplant, how your health status impacts on your daily life and relationships with family and others, planning for a family, fertility and adoption, achievements or milestones, your physical and emotional self-management, your experience around buying a house or accessing mortgage or life cover, having to make adaptations to your home, applying for a medical card or accessing other benefits.

We would welcome good quality photos to accompany your story.

Your experience might benefit and inspire our SUPPORT readers. Please send your written submission to us for consideration and photos by email to robbyn@ika.ie or Phone: 01-6205306.



Next steps forward for renal services

*COVID-19 has impacted the entire healthcare system, but renal services and patients have faced a particularly tumultuous year. Clinical Lead for Renal Services **Prof George Mellotte** speaks to **Catherine Reilly** about the impact of the pandemic and priorities for 2021 and beyond.*



By **CATHERINE REILLY**

The COVID-19 pandemic has further underscored the need for increased access to home dialysis therapies, a longstanding priority for the HSE National Renal Office (NRO), according to the Clinical Lead for Renal Services Prof George Mellotte. End-of-year figures for 2020 show an additional 34 patients accessed home therapies compared with the end of 2019 (an extra six home haemodialysis and 27 peritoneal dialysis patients).

The NRO described the rise in provision as substantial, equating to an extra 9,000 treatments during the year. At the end of 2020, there were a total of 58 patients on home haemodialysis and 238 on peritoneal dialysis.

Nevertheless, these figures were dwarfed by the numbers receiving in-centre haemodialysis, which also

rose last year (2,014 at the end of 2020, up from 1,933 in 2019).

"At the moment around 12 per cent of people are on home therapies and 88 per cent are on hospital-based therapies. The goal of the NRO is to get that up to 20 per cent of people on home therapies," outlined Prof Mellotte, a Consultant Nephrologist at Tallaght University Hospital and St James's Hospital, Dublin.



Prof. George Mellotte

He told the *Medical Independent (MI)* it is vital to inform and educate patients about home therapies at an early stage.

"I think there's a need for increased nursing support to these patients," continued Prof Mellotte, who noted there were "relatively few" nurses assigned to home therapy provision. "We need pre-dialysis nurses [and] we need home therapy care nurses to provide that support to these patients. That is one of the barriers

and we have been talking to the HSE about increasing the supports to these patients. Because most people will agree it is a better quality-of-life if you can do it, but you need training."

Prof Mellotte said most people "do not want to go back into the hospital" after commencing home-based treatment, as it provides them with more freedom and flexibility, as well as reducing infection risks. Of note, as of 19 March 2021, there had been no COVID-19-related deaths in patients on home therapies.

Greater provision of home therapies is also cost-saving for the healthcare system. But as Prof Mellotte acknowledged, patients can be out of pocket for costs, such as electricity, "and we should look at incentivising home therapies."

According to the Irish Kidney Association (IKA), patients on home therapies are entitled to claim back some incurred expenses against taxes, but there may not be a taxpayer in the household (the average age of a person starting dialysis is over 60). Prof Mellotte referred to models in some other countries, such as Australia, that involve a grant to cover expenses associated with training, electricity, etc.

"I do think we should look at models that other countries have for

incentivising home therapies." A proposal has been developed by the NRO and is under active discussion, he confirmed.

IN-CENTRE PATIENTS

In-centre haemodialysis patients have faced a disproportionate risk of COVID-19 infection associated with their medical vulnerabilities and need to attend dialysis units three times a week. Internationally, mortality rates of over 20 per cent have been reported in this cohort following infection. A study at Beaumont Hospital's Department of Nephrology, which reported data from the early weeks of the pandemic (mid-March to mid-May 2020), provided a stark insight into the level of threat for end-stage kidney disease (ESKD) patients.

In the study period, 20 out of 296 haemodialysis patients at the hospital and two satellite units were infected with SARS-CoV-2, of whom 10 (50 per cent) died. The high mortality rate was largely driven by an early nosocomial outbreak and underlying frailty, with 11 cases described as hospital-acquired, according to the paper published in the *Irish Medical Journal*.

On 7 April 2020, the NRO instituted a surgical mask-wearing policy for dialysis patients and healthcare workers for the duration of



dialysis sessions. Later that month, the NRO recommended patients should not eat on dialysis. This guidance contributed to significant reductions in COVID-19 infections in dialysis patients, stated Prof Mellotte.

He said there was a period of almost four months where there were no infections in dialysis units, following the initial wave.

I do think we should look at models that other countries have for incentivising home therapies

Prof Mellotte confirmed it was the prerogative of hospital management to implement NRO guidance. However, he maintained the HSE was fully supportive and it funded provision of surgical masks and thermometers for patients attending dialysis units nationally. He added that HSE National Director of Acute Operations Mr Liam

Woods authorised a self-drive stipend "so patients didn't have to take taxis, which I think made a big difference because a family member could drive someone in and there wasn't risk of exposure in taxis". There were also additional isolation spaces established to facilitate COVID-19-positive patients in continuing their dialysis treatment.

From the beginning of the pandemic to 19 March 2021, some 369 ESKD patients had acquired COVID-19 infection. This comprised 271 haemodialysis patients, 14 peritoneal dialysis patients, and 84 renal transplant patients. Sadly, there were 76 COVID-related deaths, 64 of which were in-centre haemodialysis patients and 12 renal transplant patients.

TRANSPLANTS

Last year, the growth in patients receiving in-centre

dialysis was double the average increase recorded over the past 10 years, representing an additional 13,000 haemodialysis treatments. This rise was associated with reduced transplant activity and the sequelae of COVID-19 infection.

"There was a pause on the renal transplant service for a while during the summer; that is re-established, but activity has been a little bit lower than usual for a number of complex medical reasons," stated Prof Mellotte. Some 123 kidney transplants took place in 2020, compared to a five-year average of 167 as of 2019.

"Those people who did not get a transplant had to be kept alive on dialysis, therefore the number of people on dialysis increased quite significantly during the year," outlined Prof Mellotte. In addition, there is a cohort of people who

now require long-term dialysis following severe COVID-19 infection, as well as people with pre-existing chronic kidney disease who suffered further kidney damage following infection, leading to a requirement for dialysis. All of these factors point to a considerable onward challenge for renal and transplant services.

Even pre-pandemic, Ireland's rate of kidney transplantation was average compared with European counterparts, which had prompted the IKA to call for a second transplanting hospital to supplement the programme at Beaumont.

When asked by *MI*, Prof Mellotte said he was not an advocate of a second transplanting hospital. He believed one kidney transplanting hospital was sufficient for a population of just under five million. "I am not sure it would be a good idea to dilute the clinical

Continued next page....

Next steps forward for renal services contd...

expertise that there is in Beaumont to a second unit," he said, describing the outcomes at Beaumont as "excellent".

Instead, Prof Mellotte said he would prefer "looking at initiatives such as protected inpatient spaces, protected theatres" to increase the number of transplants at Beaumont. He also cited promotion of living donation as among the priorities of the NRO.

The kidney transplant waiting list data, published annually by HSE Organ Donation and Transplant Ireland, has remained steadfastly within a particular range: 509 patients were listed in 2019 (208 newly listed; eight fatalities during the year); 462 in 2018 (178 newly listed; 17 fatalities); and 482 in 2017 (200 newly listed; 15 fatalities). However, Prof Mellotte said there was no

'cap' on the pool deemed eligible for kidney transplantation.

Eligibility is also assessed regularly, he added. "You could be medically fit one year and a couple of years later, because of other illnesses, you are no longer medically fit. Each patient who goes on the transplant list has been assessed as medically fit for transplantation."

Meanwhile, the NRO has been developing a model of care for chronic kidney disease, a programme of work disrupted by COVID-19. The NRO is aiming to launch the model of care in the second half of this year.

Prof Mellotte is keen to promote "preventative nephrology". He highlighted the importance of early blood pressure checks and getting GPs to look for renal failure and kidney disease at an early stage. Early

treatment has been shown to slow the progression of kidney disease, particularly in high-risk groups, such as people with diabetes and hypertension.

In addition, as certain treatments and interventions can be detrimental to people with chronic kidney disease (eg, analgesic medications and contrast dyes for diagnostic procedures), it is important to raise awareness of such issues in healthcare settings.

"So informing primary and secondary care providers to be more conscious of the impact of these treatments on chronic kidney disease progression is something that is a longer term aim."

VACCINATION

When **MI** spoke to Prof Mellotte in late March, COVID-19 vaccination had been rolled out to most frontline healthcare workers. It had also commenced for the “vast

majority" of dialysis patients and in a "substantial" number of transplant patients. At that time, patients with severe renal failure who were not yet on dialysis were "not quite as easy to identify".

The NRO has strongly lobbied for a reprioritisation of ESKD patients in the original draft vaccination sequencing plan, due to their high medical vulnerability. It is hoped vaccination will considerably lessen risks of infection for renal patients, reduce incidence of kidney damage associated with COVID-19, and allow for increased transplantation compared to 2020. It has been a very trying 13 months for renal patients and staff, Prof Mellotte confirmed.

"I want to thank all staff in dialysis units and home therapies for the excellent care they have given our patients during the pandemic," he emphasised.

Reprinted courtesy Medical Independent



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



A RETURN TO SPORT?

By **COLIN WHITE**

The COVID-19 pandemic has had a huge impact on organised transplant and dialysis sports. We were due to host the European Transplant & Dialysis Sports Championships last year in August. Plans had been going well with a significant number of newcomers joining our team when we had to make the decision to cancel. As I write this on May 28th, Transplant Team Ireland should have been in Houston, Texas for the start of the World Transplant Games. Numerous national Games and other single sport events have been cancelled including the inaugural World Transplant Games Federation Soccer World Cup.

What will it take for organised transplant and dialysis sports events to return? A successful and safe event is not just about having a safe environment at the time of the competition. The planning for an event such as the European Transplant & Dialysis Sports Championships starts a long way out as you have to lock in an accommodation provider, sports venues, transport and plenty more before you even open registration for the event. You have to have the confidence that you will be able to raise significant funds to underpin the hosting costs. Will dialysis services be able to accept incoming participants for the event? Will there be additional requirements because of COVID-19? There are so many questions.

A future transplant and dialysis sports event has to also look at the impact of the pandemic on the funding available to the visiting teams and the individuals involved. Will flights be available, what will they cost and will government funding be available for



those teams that rely on it for their participation? We don't yet know the full financial impact of the lockdown on national economies and individual pockets of prospective participants.

Oxford, England is due to host the next European Transplant & Dialysis Sports Championships in 2022. The event is still on the calendar but the Local Organising Committee will need to revisit all its plans to take into account the new circumstances post COVID-19.

Perth, Australia is already working hard on plans for the 2023 World Transplant Games. Having missed the 2021 World Transplant Games, the hope is that the international transplant community will gather in huge numbers in Perth to celebrate the 'gift of life'.

What about our domestic programme? Given that the majority of people on dialysis and transplant recipients are yet to receive their second vaccine it is too early for us to re-open the programme yet. However, we have an active WhatsApp group and an opportunity to meet up on Zoom once a month. It has been very pleasing to see the number of people who have joined the Transplant Team Ireland family in the last 15 months despite the pandemic and us not meeting up.

When it is felt that it is safe to gather again we will have organised sessions so that we can meet in person, enjoy the camaraderie and the added motivation to keep active

and keep healthy. In the meantime, some of you may be planning to re-engage with physical activity or sport at an individual level. Please remember than if you have not been too active during lockdown, take it easy when you return to sport to avoid injury.

There are some exciting virtual events being planned in the coming months by the World Transplant Games Federation and Transplant Sport in the UK. These will be opportunities for you to engage with the wider transplant sport family while remaining safe.

If you would like to be kept up-to-date about these events and any other plans for our Transplant Team Ireland get in contact with me, Colin White (colin@ika.ie) and ask me to add you to the team's WhatsApp group.

You can also follow our team blog; www.transplantteamireland.ie and you can find us on social media too.

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.**

Phone lines open from 8am-11pm.



John's inter-county sporting career kicked to touch!

At the end, relief trumped disappointment for John Egan. It is not an emotion any inter-county footballer should feel but instead of crossing the finishing line on his own terms, he felt its sharp impact as it hurtled towards him.

At O'Connor Park, Tullamore, on May 28, 2018, Egan knew his game was up and that a very different one was about to begin.

From the minute the ball was thrown in for Westmeath's Leinster SFC quarter-final against Laois, he felt he was treading water.

"I remember being on the ball a few times during the game and I did not have the energy or the power in my legs to go at full tilt that would be required at that level," he recalls.

"I was getting on the ball at times in the first half and I knew inside my head there was nothing I could do with it.

By **MICHAEL CLIFFORD**

"I was not able to keep up with the other players and these were guys that I knew I was at the same level as I was, but I just could not do it.

"I remember thinking, 'I am out of my depth here'.

"I actually got injured at the end of the first half and I had to come off early in the second half and instead of being disappointed I was actually relieved," he admits.

His eight-year career as a county player limped on for two more weeks until Westmeath's summer lights were turned out in a first-round qualifier defeat to Armagh when Egan was back in the starting team despite not being able to train in the lead-up as a result of a knee injury.

In hindsight, he regrets not telling manager Colin Kelly that he wasn't right. Instead he played but finished out the game on the bench,

knowing – this time – there was no way back.

"I had the exact same feeling in that game as I had against Laois and about five minutes into the second half, I had to come off after getting a terrible cramp in my calf.

"I knew in that moment I had played my last game for Westmeath regardless."

That day had been coming for 13 years but, even so, the end still felt brutishly sudden.

The first time he knew something was wrong was as a 15-year-old when, after taking a knock in a football match, he passed blood.

He was subsequently diagnosed with IgA nephropathy, also known as Berger's disease which, in layman's terms, causes inflammation that damages kidney tissues.

The bottom line is an unpalatable one – it is incurable and, ultimately, leads to kidney failure.

It is a reality that 30-year-old Egan has endured for half his life, although he has never allowed the condition to limit his outlook or ambitions.

Once his body adjusted to the medications, he thrived. That was especially true on the football pitch where he played Minor and Under-21 for Westmeath before graduating to the Senior ranks and coming off the bench in Westmeath's thrilling 2015 Leinster SFC semi-final win over Meath.

Through it all, he hardly gave it a second thought until Dr Gerry Flynn conducted his regular preseason medical examination of the Westmeath team in 2018 and everything changed.

"I had always made them aware I had a kidney problem so they knew that and when the results came back, they indicated that I was heading towards end-stage kidney disease.

"It was a big shock because I would have been going through these tests and getting bloods in previous years and nothing significant ever showed up, but between the tests in 2017 and the tests in 2018 there was just a significant drop in the kidney function that alerted everyone.

"But while that was a big shock to me, prior to that I had started talking to people about the symptoms of chronic kidney disease and I noticed, looking back, it had had an effect on me the previous year.

"I was always fit but I would have been cramping up a lot in games and early on in games as well.

"I would always have hydrated and managed that side of things very well but I would still be cramping after 40 or 45 minutes of games, even club games and that was all due to the effects of chronic kidney disease."

By that stage his kidney function had dropped to 30% – three years on, it now registers at nine per cent.

These days, the battle is no longer getting through 70 minutes but battling the crippling fatigue.

A recruitment consultant by profession, with Dublin-based Solas IT, his schedule is work, rest and then rest some more.

"You are just so tired and then when your working day is done, you just slump back. You don't have the energy to try and get out for fresh air or get a walk in for 20 minutes," he remarks.

"There was a phase where I was

trying to get back into more exercise in terms of running 5k but you would lose sleep at night because your body would be cramping after it. On a daily basis now it is just work and rest if possible."

Outside of tiredness, on bad days he feels generally unwell with cramping, swelling and gout all being symptoms while he tries to manage strict diet and fluid restrictions.

But he has already started out on the road to what he hopes will lead him back to a full and healthy life.

Recently, he travelled to Beaumont Hospital to meet with a team of medics and, inside the next fortnight, he should be formally placed on the transplant list.

Like everything else, COVID-19 has impacted deeply. Last year, organ transplants in Ireland dropped from 274 to 190, a 30 per cent reduction.

Outside of that, it has also put the brakes on the medical interventions for those trying to manage end-stage kidney disease, particularly with a greater demand for home-based treatments such as peritoneal dialysis.

"I am waiting for a date for surgery in Tallaght to get a catheter in for my dialysis which I can do at home which will be great.

"It will give me a lot more freedom than going to the hospital three or four times a week. It is very similar to the one you do in the hospital, the

haemodialysis, your blood is basically filtered out of you through a washing machine and put back in, whereas the one I will be getting at home will be through the lining of the stomach where you essentially put in cleaning fluid and you take the dirty stuff out of the stomach and you do that for eight hours through the night.

"It will take a bit of getting used to but it is probably something that is going to keep me healthy as long as possible so I am glad to be able to do it at the same time."

While getting on the transplant list will represent a huge step forward, it does not come with a definite set of dates and boxes to be ticked off.

"If it is a deceased donor it can unfortunately be a bit of a lottery, from one to four years but if I get a friend or a family member that is a good match for me, it can be anything from six months.

"I have spoken to people who have got a live donor and had it within six months. If I could get that or even within 12 months it would be unbelievable, so you just keep your fingers crossed."

He has good reason to do so. This winter, he is due to marry Traci Brennan, his girlfriend since he was 15.

Had COVID-19 not intervened last year, they would have been married by now but, faced with the health crisis



John Egan celebrates scoring his side's first goal during the Leinster GAA Football Senior Championship Quarter-Final match between Westmeath and Offaly at TEG Cusack Park in Mullingar, Co. Westmeath. Pic: Piaras Ó Midheach/Sportsfile



John with his fiancée Traci

restrictions, the couple decided to postpone their big day, which was set to take place in St Brigid's Church, Drum last December.

"We managed to get the same date, December 18, for this year as well, so that was great but we still don't know about restrictions, numbers and now on top of that the dialysis as well, so we will see how it goes when the time comes.

"I half thought back then I would be in a position to get on the list and get a transplant by now or even before now but unfortunately that has not been possible.

"We will have to see how I take to dialysis now and see how it impacts my lifestyle.

"Traci has been great. She has been with me for as long as I have been sick as well so she has been there from the start and all I want for her is to enjoy the build-up, enjoy the day and not to be worried about me.

"I mean if it had to be a case where I had to leave the wedding early to go up to the room and start dialysis. That is something that you would never imagine on your wedding day.

"We will eventually go with what is right for both of us. It could be a case I could be on the list and I could have a potential donor and you could get a call at any time and you have to take that call. 'There are all those things to consider and if you have it before the wedding, will you have recovered in time for it?

"There are so many things that are up in the air.

"The biggest grief I have with the whole process is not being sick, because I accept the cards I have been

dealt, but it is the unknown and not being able to put a timeline on things that is the most difficult part of it all," continues Egan. It would help if the organ donation message was absorbed by wider society, but it remains slow in getting through.

The transplant list he is about to join is a long one. In March, there were 415 patients on the Beaumont Hospital Kidney Centre transplant list, with just 16 transplants having taken place in the first two months of the year.

Deceased donors remain the primary supplier of organs – and just one of those 16 operations this year involved a living donor – underlying the importance of the wider public signing up to organ donation.

That lack of awareness among the wider population of their opportunity to transform the lives of ill people is a constant source of frustration for Egan.

"It is just a case of having that conversation with your loved ones and family," he insists.

"It is something that is so simple to do and yet could have such a huge impact on somebody's life.

"In Ireland, people these days live their lives at 100 miles an hour and you don't think about anything unless it affects you personally.

"My family and friends never thought they would be in a position where they might have to give a loved one a kidney or that an organ donation might come into their lives.

"It is just a case of having that conversation, picking up the phone to somebody, having that conversation at the dinner table because becoming an organ donor is so simple. You can do it in two minutes so it is a conversation every household in the country should have."

As for football, not playing has left a schism that has not been completely filled by his current role as a member of the Athlone management team, but he has gained perspective through his current circumstances.



John (right) with his family (from left): sister Niamh, father John Joe, sister Dee and mother Noeleen.

"When you retire due to health reasons, you look at things a lot differently.

"I am still involved with Athlone but it is tough to be on the management side when part of you still expects to be playing.

"And in a way it makes the time I had playing probably more precious.

"Not being able to do it has left a huge void in my life. From playing football four or five times a week and being with your friends, you can look back now having gone through this experience.

"It is such a big thing to say that you played for your county and I got to do it for 10 or 11 years.

"We were unfortunate in the era that we were in. If it was another time we could have won a Leinster. We got to an U21 Leinster final, where we lost to Dublin, which we could have won.

"The core of that team would feed into our senior team but that Dublin U21 team would also provide the core of this Dublin senior team with the likes of James McCarthy, Jonny Cooper but they just went on to a different level after that.

"But more than anything there are lads I played U14, U15 with Westmeath and with Athlone who I continued to play with all the way up until I retired.

"I am grateful for that time and I had some good days, too."

The hope is that his best are yet to come.

**Reprinted courtesy of
Daily Mail Extra.ie**

Since this article was written John has commenced home dialysis treatment which is working well for him. Two family members put themselves forward to be screened for living donation but unfortunately were unsuitable donor matches. John has had other offers from people willing to donate a kidney and he remains optimistic that he will receive a transplant. He and his fiancée Traci had planned to wed last year, but cancelled their nuptials when COVID-19 came along, have decided to postpone their wedding until 2022.

WORLD KIDNEY DAY

at

B | BRAUN

Wellstone Wexford

STEP CHALLENGE

The theme for World Kidney Day 2021 was 'Living Well with Kidney Disease' to promote wellbeing.

At the BBraun Wellstone Wexford Renal Care Centre we decided that it was a great opportunity to encourage physical activity amongst the patients, and with this in mind the patients embarked on a step challenge for the month of March. Each participant was provided with a pedometer and a record sheet to motivate them to track and increase their daily steps.

Over the month of March collectively they walked an amazing 3270 kilometres which is the equivalent of walking the length of Ireland's coastline. It was a great achievement for everyone involved. The youngest participant was seventeen years of age and the eldest was eighty nine years old. 72% of the participants were over fifty five years of age. Feedback from the participants demonstrated that 83% of them

increased their daily steps throughout the challenge, with a 38% increase in the number of steps between week one and week four of the challenge.

The word cloud presented below captures the positive impact that the participants voiced both during, and on completion of the step challenge.

Physical activity is known to increase muscle strength, improve sleep patterns and overall quality of life amongst people with kidney disease. The simple act of walking can have a big impact on both one's mental and physical health.



AnnMarie Murray, Renal Dietitian, BBraun and Dr Elizabeth Abernethy, Consultant Nephrologist.



Janet Cooney, Healthcare Assistant, Debbie MacDonald, Clinic Manager and Janice Savage, Staff Nurse.

Tracking your steps can be a great tool to motivate yourself daily.

As our participants have proven, one does not need to be of a certain age or a fitness fanatic to reap the benefits of daily physical activity. Walking incurs no cost, it can be done at any time, and most importantly it can be done at your own individual pace.



Ben Kelly, our youngest participant (17) and Ben Bailey, our eldest participant (89).

SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK



FIGHTING THE ONLINE FRAUDSTERS

Getting online can make your life easier in many ways; you can keep up with the latest news, keep in touch with family and find the answer to almost any question you can think of. It is how many of us shop and bank without leaving our homes - something that became even more essential this past year. But, as highlighted by the recent HSE IT systems hack, it can also come with risks. There are unfortunately people out there who use any opportunity they can to wreak havoc on unsuspecting internet users, usually in the name of defrauding money from them. Thankfully, there are a few small steps you can take to protect yourself as much as possible.

PASSWORDS

It can be frustrating when you set up a new account and the website insists on you including a capital letter, number, Egyptian hieroglyph and a small limerick as your password (only kidding, but sometimes it feels like that)! As annoying and hard to remember these passwords can be, they are designed to protect your online accounts and that is the first step to online safety.

You should always aim to include a combination of upper and lower case letters, numbers and symbols, and make it at least 12 characters long. Try not to use the same password across several different accounts.

A newer thing on many websites and especially in online banking is Two-Factor Authentication. This is your friend! Once set up, whenever you try to log into an

account it will send a separate text or email to you with a code that you can enter to verify that it is indeed you accessing the account.

A final tip is to look out for different ways fraudsters might try to get password-cracking information from you. A big example here are social media chains that ask you to "combine the first street you lived on with your mother's maiden name to get your stage name". The information you provide here is usually the information required for security questions to reset account passwords.

WEBSITES

When you are on a website, you might never have paid much attention to the address bar before. But a big indicator of security is right there.

All website addresses begin with HTTP, but you will notice most big companies are HTTPS. The S stands for Secure – meaning that the website is encrypted and less open to the information being hacked by a third party. This is especially important when shopping online – if you enter your credit card details on an HTTP website, this could be intercepted by people you really don't want having access to that information. An easy way to spot if the website you are visiting is an HTTPS website is that there will be a little padlock symbol in the address bar to indicate the Secure status.

On the subject of credit cards, when buying online it is a good idea to use one if you can. Many credit cards like Visa and Mastercard have insurance protection included against fraud, theft and damage to your purchase.

EMAILS AND MESSAGING

Emails are probably the main way that people will have experienced scammers before. Most of us will have received at least one email that is not what it seems. If you receive an email that seems suspicious or that you were not expecting to receive (even from a friend), make sure your guard is up.

- Check the actual email address, not just the name that appears. You can do this by clicking on the person or company name. The name might say 'Bank of Ireland Account Management' but when you look at the email that sent it, it could be 'BigJoe2071@gmail.com' – definitely not legit.



- Don't trust that emails or messages sent from the accounts of your real friends are safe. If you get an email from a friend that is out of character, is urging you to 'Click this link' or is asking for a loan of money etc., you are better to give that person a call to make sure it was indeed them that sent it. They may have been hacked or downloaded a virus that tries to spread by contacting unsuspecting friends.
- Look out for spelling mistakes or inconsistencies in emails from companies. Scammers do their best to mimic the real branding and logos of companies, but it's rarely ever perfect.
- Most banks would never email you to verify your information. Accounts like Netflix or Amazon

may send you emails about password resets etc., but if you did not request such a thing then you should be suspicious. If in doubt, try to call your bank or the company before proceeding.

To summarise, it's important to remember that even people who think they know everything can get caught out by the sophisticated methods fraudsters use. If you think you might have been a victim of online scams, tell someone, call your bank, or report it to the police if necessary. There's loads of support out there and you shouldn't feel ashamed to ask for it. There are also free courses available to make you feel more confident online – Age Action Ireland has a 'Getting Started' programme for people over 55 that has trained over 35,000 people!



@IrishKidneyAssociation



@IrishKidneyAs



@IrishKidneyA

HSE HACK ADVICE

After the HSE IT systems were hacked, some private medical information was leaked online. Fraudsters are taking advantage of this by contacting members of the public through phone calls and texts, purporting to be from the HSE or Department of Health to try to obtain financial and personal information in an effort to defraud them.

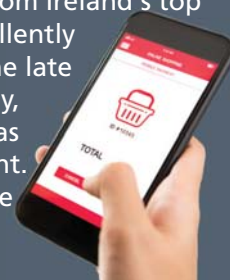
Regardless of how much personal information the caller appears to have already about you, do not give any confidential information (including banking details) over the phone to anyone saying they are from the HSE, the Department of Health or any other organisation. Report any such approaches to the Gardai.

You may find it helpful to note the medical numbers you normally receive calls from. The first three digits in the number of the hospital that looks after your care will probably be familiar to you.

For example, many HSE numbers start with an Area Code (e.g., 01 if Dublin) then the first three digits of the phone number are 635. Tallaght Hospital numbers often start with Area Code 01, and then the first three digits of the phone number are 414. You can also check phone numbers by searching on the internet.

Online Shop

The IKA has a small online shop which includes a small quality offering of tastefully designed facemasks as well as t-shirts that are ideal for fundraising events and the highly recommended Truly Tasty cookbook, which features over 100 renal friendly tasty recipes from Ireland's top chefs and excellently compiled by the late Valerie Twomey, who herself was a kidney patient. You can browse our selection by visiting...



www.ika.ie/onlineshop

NORA ENJOYS 40 YEARS WITH BROTHER'S DONOR KIDNEY



By GWEN O'DONOGHUE



Above: Nora and daughter Michelle.

Right: Nora with her kidney donor brother Martin

A west Waterford mother has happily resigned herself to postponing a milestone celebration, which was due to take place in May this year, until after the threat of COVID-19 subsides. This year marks the 40th anniversary of Nora Walsh's kidney transplant and the 10th anniversary of overcoming her battle with breast cancer. Nora (55) from Lismore shared her positive story during Organ Donor Awareness Week.

Nora is enjoying the successful longevity of the donor kidney, which she received in May 1981 from her

older brother Martin, when she was 15-years-old. The transplant took place at the Old Jervis Street Hospital in Dublin under transplant surgeon Sean Hanson.

When Nora and Martin's living donor transplant story made headlines in the *Cork Examiner* newspaper forty years ago, Nora was pictured with her parents (since deceased), Muriel and Jack Walsh, a cobbler from Lismore, Waterford.

Nora's transplant brought to an end her struggles with kidney failure as a teen, and twice weekly journeys for haemodialysis treatment from her family home in Lismore to Cork University Hospital. Her lifeline transplant took place when she was in Intermediate Certificate (Junior Cert) at school and while she missed the opportunity to sit the exams the first time round she returned to school the following year to finish them.

Page 16 Cork Examiner, Wednesday, December 30, 1981

Nora's new lease of life

By JOHN MURPHY

UNFLINCHING COURAGE and a huge slice of "brotherly love", made Christmas 1981 the happiest festive season 16-year-old Nora Walsh has ever had.

The moving story of Nora, daughter of Jackie and Muriel Walsh, New Street, Lismore, and one of a very closely knit family of 14, goes back almost two years to St. Valentine's Day 1980 when she was admitted to the Regional Hospital in Cork for tests. The results confirmed the family's worst fears — both Nora's kidneys were diseased and failing rapidly.

Six months of frequent illness, pain, and mental anguish followed until October 1980 when the inevitable decision was taken. Nora was destined to spend ten hours a week on a kidney machine, necessitating twice weekly journeys to and from Cork's Regional Hospital.

But through it all a courageous young girl never once allowed her spirits to flag. She was in fact, in the words of her proud parents, "the bravest girl one would ever meet". Words that have been echoed and re-echoed in her native town ever since.

While the kidney machine treatment undoubtedly brought some measure of relief to Nora, her highest hopes of recovery rested with the members of her own family. And no fewer than eleven of them, her father, six brothers and four sisters all offered themselves as kidney donors.

Three of the eleven were subsequently deemed to be "suitable donors", and after a "round the table" family conference it was decided that 27-year-old

Martin Walsh, a staff officer with Waterford County Council, would be the one to give his for the lifesaving kidney she so desperately needed.

May 18th last was D-Day for Nora and Martin, and the story had the happiest of endings when the major five-hour operation at Dublin's Jervis Street Hospital proved to be 100% successful.

It meant of course that Nora had to miss out on the Intermediate Certificate examination which followed a few weeks later, but she is now back at school at Lismore's Presentation Convent and looking forward to taking the examination next June.

Now having resumed all her former activities, Nora is enjoying life to the full. Martin, back at his post with the County Council, is feeling no ill effects whatever following the operation.

"I feel super" was Nora's comment to me when I spoke with her at her New Street home. She was loud in her praise of Surgeon Hanson who performed the operation at Jervis Street Hospital, and of Dr. Murnaghan and the staff of Cork's Regional Hospital. Weekly hospital check-ups have now become monthly ones, but as the road to complete recovery is swallowed up, these will become even less and less frequent.

The final words we left with a delighted Mr. and Mrs. Walsh. "Very few people would have been as brave as Nora has been through all of this. She is now reaping the rewards, and thanks to her own bravery and that of Martin, she can look forward to living a full and active life."

On this eve of New Year's Eve we all raise our glasses to that.

Picture shows Nora flanked by her parents.



Fortunately, none of Nora's 13 siblings experienced kidney failure and it is thought that Nora's condition was a consequence of an almost fatal dose of the measles, which she had suffered as a child. At only 4-years-old, Nora had to learn how to walk again as part of her recovery. Although Nora's brother Martin, a Waterford County Council employee (since retired), went forward to be a living kidney donor, the rest of the family were also willing to donate.

Nora said: "Life was difficult as a teen with kidney failure, as I was unable to socialise with friends or take part in any family activity. I was constantly tired, weak and sick. Every day was a struggle but I got through it with the love and support of my family.

Coming from a large family of fourteen I was blessed that my brother was a match and gladly donated his kidney to me. This transplant has made it possible for me to live a normal and full life. It allowed me to work and enjoy family holidays. Most of all I feel blessed to have become a mother to my daughter Michelle, who is celebrating her wedding next year.

I would like to thank Dr. Clarkson and all the staff at Cork University Hospital for taking care of me. I encourage people to share their wishes about organ donation with their family and make this an open discussion in every home. You can become an organ donor by having your wishes noted on your driving licence or by carrying an organ donor card. Organ donation saves lives and I am living proof of that."

PEDALING THROUGH DIALYSIS

By
GWEN O'DONOGHUE

Wicklow man Tom Miley from Laragh, Co. Wicklow suddenly found himself in multi-organ failure three years ago as a result of a sepsis infection which left him fighting for his life in hospital. The retired branch manager of AXA Insurance in Bray explained, "It was three months before I could leave hospital and return home to my wife. I spent 6 weeks in ICU until most of my organs' function was restored. However, my kidneys were irreparably damaged leaving me with dialysis dependency to keep me alive as I hope that a suitable kidney donor will change my life."

After leaving hospital, Tom who is now in his early 60s, underwent three times weekly dialysis treatment at St Vincent's University Hospital. He now undergoes dialysis treatment at the Beacon in Sandyford. He drives the 45 minutes to attend three times a week, and undergoes a three and a half hour treatment session.

When medics considered Tom to be well enough to go on the transplant waiting list, his brother came forward for screening to be a suitable donor. The rigorous process took about a year but, unfortunately, some final health screening tests deemed him to be unsuitable for kidney donation.

Tom, an avid cyclist, was always very fit prior to his setback three years ago. He enjoyed trips abroad cycling for the Irish Hospice in France and Spain. Just a few weeks before he succumbed to sepsis, he had enjoyed a cycling tour for the Irish Hospice in Portugal. He also loved to travel with his wife Mary.



Tom and Mary

Gradually he has tried to build back his fitness levels and during COVID-19 and lockdowns he manages to cycle within the 5km limit restrictions and protects himself from contact with other people as he otherwise cocoons with Mary. In the very high risk group for COVID-19, Tom is now delighted to be fully vaccinated having received his first dose of the AstraZeneca vaccine in March and his second in June.

Tom has recently joined Transplant Team Ireland and when the Transplant Games return post-pandemic his events will include badminton, golf and cycling.

Tom said, "I would encourage everyone to support organ donation. Organ failure can knock on anyone's door unexpectedly and for me it came out of nowhere. My world was suddenly turned upside down. While I am grateful to be still alive and dialysis is working well for me, a transplant would make a huge difference to my quality of life. I would have much more energy, less sickness and tiredness, no restrictions on diet or fluid intake, which are all consequences of my kidney failure." "With a transplant I would have much more freedom with my time to do the things I used to enjoy doing including travel. Also organ failure didn't just change my life, it also changed my wife Mary's. She has been my rock of support and prioritised my healthcare over herself.

"I hope that by sharing my story others will consider being organ donors. In death they might save or improve the quality of life for the families of patients in organ failure waiting for a heart, lung, liver or kidney transplant."

'LOOP THE LOOP'

Goes global for beloved Sandy

By GILLIAN WHOOLEY



Eric, Sandra's brother Hugh, Mark



Angela (Sandra's sister-in-law) and Sandra's nephews Sam and Adam



Sandra's friend Ann and sister-in-law Lisa



My beautiful sister Sandra Murphy (Sandy) passed away with complications arising from her kidney disease on 18th March 2020, at the beginning of the first lockdown. Her friends and I agreed that on Sandy's first anniversary we would organise a walk and a get together to celebrate her life while raising funds for the Irish Kidney Association.

Of course, we had big plans of a weekend away to do some incredible scenic loop...we had no concept then of how COVID-19 would continue to restrict our lives and our movements an entire year later.

I sat around with some friends a couple of weeks before St. Patrick's Day this year trying to come up with a fundraiser to honour Sandy's memory while still keeping within Level 5 restrictions. We decided on walking 100km in relay and then it was just a matter of where. The wonderfully creative Edel O'Brien came up with the idea of 100 rounds of the Model Village, Sandra's childhood home. And **Loop the Loop** was born out of this.

We looped the loop of the Model Village in relay fashion on a gloriously sunny St. Patrick's Day. We started at 9.30am to 5.30pm, all of us resplendent in our IKA t-shirts. Thank you to Robyn who went above and

beyond to get the t-shirts to us on time.

This relay was done 2 by 2 in each direction and allowed everyone taking part to stay within their bubble.

I wanted this to be a global event so all friends and family could join in no matter where in the world (or outside the 5km lockdown) they were.

So, I sent out invitations to all friends and family to take part and requested a selfie be taken while walking.

I had planned on keeping count of the number of kilometres walked but lost count because so many people wanted to take part.

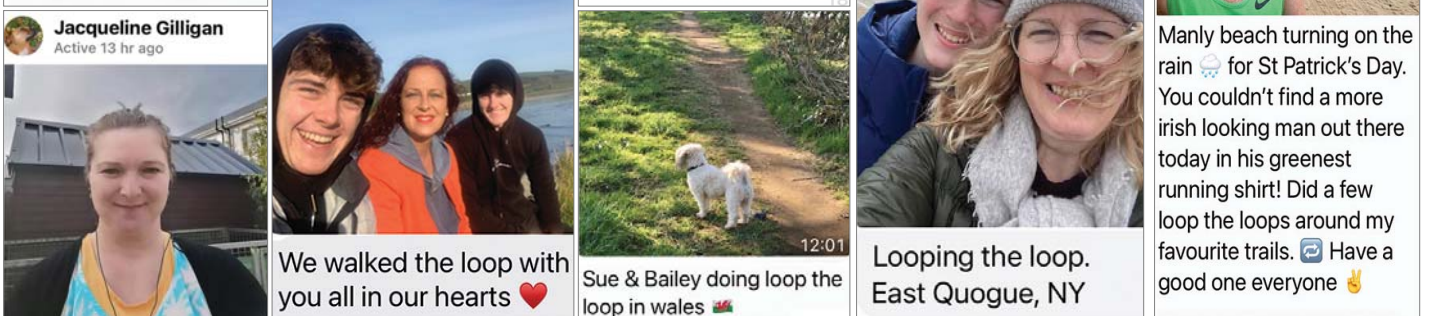
Loops were looped in Melbourne, Sydney, New Zealand, Berlin, New York, Kentucky, Montreal, Wales,

Lancashire and lots and lots of loops around all of Cork. It meant that all over the world Sandy was being thought about and that made me feel that I was truly honouring her memory. She certainly deserved nothing less.

A total of €6500 was raised for the IKA.

Sandra was vivacious, full of life and fun and laughter. And that was exactly what the day was all about. Nothing made Sandra happier than connecting with the people she loved. At a time when we were all hungry for connection we managed to connect all around the world, because of one person, our beautiful beloved Sandra.







Greetings all

Hope you and your families are safe and well and that you get to enjoy the summer months ahead and any good weather that comes. No doubt, the long-anticipated vaccine has reached most of you one way or another. As we still meander through with COVID-19, we are seeing light at the end of the tunnel so that bring hope for us all.



Joe Grace and Noretta Clifford at the Limerick Vaccine Centre in March 2021.

Although our monthly meetings have not been taking place, our support is still available, so feel free to call or text 087-6243367/ 087-9392148, email: ikaclare@gmail.com or MESSAGE us on Clare IKA facebook page.

ORGAN DONOR AWARENESS WEEK 2021

ODAW 2021 was once again quite different in 2021 where none of the usual fundraising/ awareness on street campaigns could take place. However, Clare IKA, just like all other local branches, endeavored to promote Clare IKA locally in the best and safest way possible.

We wish to thank kidney transplant

CLARE

By NORETTA CLIFFORD



Kerry walkers, Marian Cronin and Elaine Clifford taking part in the Walk on Reenroe Beach, Ballinskelligs.



Noirlin Fitzgerald and her daughter Nainsi walking the scenic Cliffs of Moher in support of Clare IKA

recipient Eoghan O'Neill who highlighted the need for organ donation as he shared his personal story to the *Clare Champion* reporter Dan Danaher. Kidney recipient and Clare Board member Sharon Fitzgerald spoke wonderfully to Gavin Grace on local radio CFM, along with IKA CEO Carol Moore, to promote the organ donor card while again highlighting the need for organ donation.

We also thank donor family member Kirsty Donnellan who shared her personal story on the *Clare Champion* about donating her beloved daughter Scarlett's organs following her sad passing.

We thank the Clare County Council whose offices were lit up in green for the week in honour of organ donation as well as the local media for highlighting Organ Donor Awareness Week for the Clare branch of the IKA.

We are grateful to the *Clare Champion* and to Clare FM for the excellent coverage they always provide



Sinead McGoldrick, Doc Dalton and Luke Dalton taking part in the walk in Toronto, Canada.



Michael Mescall accompanied on his Clare IKA walk!!

to Clare IKA in promoting Organ Donor Awareness Week.

Finally we wish to thank all our members for the continued support in fundraising and raising awareness for organ donation.

'GIFT OF LIFE' MEMORIAL

We also take this opportunity to remind you of the 'Gift of Life' Memorial, in the centre of Ennis town.

WEST CLARE WALK FUNDRAISER

The annual Clare IKA West Clare Walk has been running for 21 years. The 7.5km walk usually takes place on the Sunday of the May bank holiday. The usual route started in Kilrush and followed the N67 Ferry/Moneypoint national road, through Cappagh and along the Wild Atlantic Way. Views of Shannon estuary, Scattery and Hog Islands, Loop Head Peninsula and even Kerry can be seen along the route. It has always proven to be a most memorable and enjoyable event.

Proceeds from the walks over the years have gone to many wonderful IKA projects and initiatives for the benefit of all renal patients in Clare county and beyond.

Unfortunately, the West Clare Walk could not take place last year in 2020 but rather than letting COVID-19 restrictions get in the way again in 2021, Clare IKA hosted a virtual event so that anyone could take part, no matter where in the world they were. We had runners as far away as Canada and walkers from Kerry taking part, as well as participants from all corners of Co. Clare. We all got moving while supporting Clare IKA.

Donations were gathered through an online fundraiser, as well as offline donations, for a total of €1,351. We are very thankful for all the donations provided and raising this wonderful amount of money for Clare IKA.

We look forward to hosting this special event with us altogether physically next year, but for now we wish to thank you all for your participation in the virtual event this year and in doing so helping Clare IKA

continue its support to all renal patients

KIRSTY DONNELLAN FUNDRAISER

Thank you to Co. Clare mother, Kirsty Donnellan, who for the last two years has raised awareness for organ donation and the 'gift of life', in memory of her daughter Scarlett Belle Marie Feeley, throughout the month of what she fondly calls 'yellow March'. Scarlett's birthday month was March and her favourite colour was yellow, the brightest colour in the spectrum. Kirsty's message of positivity and hope, while raising vital funds for the IKA is inspiring. Well done Kirsty for supporting the work of the IKA and for raising much needed funds.

THANKS TO THE HOSPITAL DIALYSIS TEAMS

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 past 15 months of this COVID-19 pandemic. What a fantastic bunch of frontline staff!

CONDOLENCES

We share with the Limerick branch and many other IKA members in expressing our deepest sympathy to the family of Siobhan Brosnan RIP, on her untimely passing in March. Siobhan was the ODTI Organ Donor



Coordinator for the Mid-west, based at UHL. She will be remembered for her great dedication to her job and indeed the Irish Kidney Association. We also extend our deepest sympathy to her husband and family and to all her colleagues in the ODTI and UHL. You are in our thoughts and prayers at this time.

FINAL THOUGHTS

The vital work of promoting organ donation and supporting patients continues albeit behind closed doors. The IKA has risen to the challenges of the COVID-19 health crisis and is willing to assist in anyway it can.

We urge you all to continue to follow the HSE and government advice, staying as healthy and as safe as possible.

DUBLIN SOUTH

By JOHN SEMPLE

Many thanks to Carol Moore for joining our Zoom meeting in April. She outlined to us the Association's strategy of focusing on patient care and involving branches in discussions and policy formation. Campaigning and advocacy will play a major role in our activities. Peer support is another area Carol would like to develop in the future, and she hopes to launch a pilot scheme and will be looking for volunteers.

Although we were unable to hold our annual collection for Organ Donor Awareness Week 2021, the branch received donations of €600. Many thanks to Michael O'Brien for his efforts in this regard.

Liz O'Sullivan, Adrian Talpa and I attended the Branch Officer meeting on May 17th which was attended by thirty IKA members from around the country. We were very impressed with the presentation by Carol and Colin White. We enjoyed the discussion

sessions and hearing from members of other branches.

It is with great sadness that we learnt of the passing of our friend and colleague Alexander Ager, RIP. An active member of this branch he

served as Treasurer for a time. Alex contributed several articles for *SUPPORT* which were written with great wit as can be seen on page 28.

We offer our deepest sympathy to his wife Olive and son Theo.

We continue with our monthly meetings. Our schedule of meetings over the next few months is July 15th and August 11th. If you

would like to receive the link to any of these meetings, you can contact me at jsemple@outlook.ie. We are always very happy to meet new people at this very informal structure. Hopefully, we will be able to meet face-to-face before the year is out.

We wish all our members a very happy and safe summer.



Paddy Sneyd on Sorrel Hill in the middle of a three hour walk as part of the Run For A Life campaign with Blessington Lake/Reservoir in the background.

WEXFORD

By MARIE DONLON

Congratulations to Annie Bolger, one of our most loyal and hardworking members for many years who celebrated her 90th birthday recently.

A cheque was presented to Chairman Liam Buttle for €4,000, proceeds from the Wexford Credit Union Annual 5K Night Run which took place virtually this year from February 4th to 7th.

Thank you to all who took part.

We remember with great sadness those who passed away recently, Hori English and Kathleen O'Reilly whose late husband Brian was Chairman of the Wexford Branch in the early years.

Our thoughts and prayers are with their families at this sad time.



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Patrick Butler, a native of New Ross now living in Graiguecullen, Carlow set himself a challenge during March and fundraised for the IKA. Below is the letter he sent to me and I think it is an inspiring story. Patrick also raised the considerable sum of €5,363.23.

CHRISTMAS JUMPER FUNDRAISER

Susan McLoughlin of Little Stars Child Care, Quinnagh, Carlow held a Christmas Jumper day at her crèche and raised €500. Susan holds a fundraiser every Christmas and this year she decided to donate to the IKA. Susan's dad Con O'Neill is receiving dialysis treatment in the Beacon, Sandyford. Thank you Susan we really

CARLOW

By PAT MAY



Susan McLoughlin presenting a cheque to Pat May, Carlow Branch

appreciate your contribution at this difficult time.

CHRISTMAS DECORATIONS

Jimmy Farrell, Daybreak Shop, Graiguecullen sold Christmas decorations, which were made by his sister Margaret Brennan, and despite a late start made €90 for the IKA. Jimmy's brother Pa, who lives in Craughwell in Galway, received a

kidney transplant in the late 90s and is doing well.

Thank you Jimmy and Margaret for thinking of the IKA at this time.

CONDOLENCES

We extend our deepest sympathies to the families and friends of the following members who passed away this year...

Ellen Keogh, Bagenalstown, Imelda Hutton, Carlow Town, James Brogan, Carlow Town and George Ramsbottom, Graiguecullen.

Ar dheis Dé go raibh a n-anamacha.

LEITRIM

By CATHRIONA CHARLES



Charles Beirne, Cathriona Charles and Frank Heslin at Leitrim County Council buildings lit up in green.

Leitrim Branch is very quiet at the moment. We hope that you are all keeping well and enjoying your summer. Don't forget your sunscreen!

Some of our members met up in Carrick during Organ Donor Awareness Week to view the buildings which were lit in green for organ donor awareness.

Stay safe everyone.



Charles Beirne, Margaret Charles and Frank Heslin outside The Bush Hotel.

Hi Pat,
I hope that you are well.

My mother passed away in 2012 from complications due to dialysis and kidney failure. After nine years of dialysis, both in the hospital and at home, her body could do no more. She was the most amazing woman and I miss her dearly.

This year I had my own kidney issues and was also diagnosed with diabetes. This triggered a 'change your life' response in me. If I had a chance to stay healthy I wanted to do so.

As it happened this coincided with World Kidney Day and donor month here in Ireland, so for the month of March I pledged to walk 10,000 steps a day for the IKA. Lockdown rules meant I could only go 5km from my home but I created over a dozen walks that helped me hit my daily target.

At the same time I reached out to my followers on TikTok and pledged that I would post daily videos of the Irish countryside for any donations that were made to my fundraiser. Over the course of the month we raised €5,500 and I hit every target every day.

It was a pleasure to do something for the IKA, who, when my mother was ill were always available to support us. I also lost 3 stone in weight and my blood sugar is now normal again. So it was a wonderful event all round.



Pat Butler, with IKA t-shirt, presented a cheque for €5,363 to Pat May.

WATERFORD

By VERA FRISBY



Blaa Giveaways presented a cheque to the Waterford branch, from left: Ray Halligan, Vera Frisby (Waterford branch) and Jenna Lee and Paul Leonard (Blaa Giveaways). Photo: Joe Evans.

Welcome to the Summer edition of **SUPPORT**.

RESPIRE CENTRE

The renovations at our holiday apartments, in Tramore, are now complete and they are looking very well. The holidays will commence in July and run until October this year. We look forward to welcoming our patients and their families to 'the sunny south east'.

We wish you a safe and enjoyable holiday.

FUNDRAISING

Blaa Giveaways, Waterford, selected the IKA for its raffle in March 2021, and presented a cheque for €2,650 to our branch. We would like to thank Paul Leonard and his team for this very generous donation.

RelateCare Continuous

Improvement Team, Rigneydolphins Group, Waterford, shaved their heads and raised almost €1,000 for our branch (full story to follow in next issue). We would like to thank everyone involved and all who supported this event for raising this magnificent amount of money for our branch.

Thank you to everyone who participated in the 21-day walking challenge – IKA branded masks are on the way!

CONDOLENCES

We were incredibly sad to hear of the death of Nigel Pim and send our deepest sympathy to his dad Alan, his wife Jeni, daughter



Jordan, son Robert, family and friends. Nigel was a great supporter of our branch especially during Organ Donor Awareness Week.

We send our deepest sympathy to the family of the late Patrick Davin. Patrick was Chairman of our branch for many years and worked tirelessly on behalf of all patients. His sparkling personality and genuine warmth exuded and all who encountered him felt better after meeting him. May he rest in peace.

We would like to take this opportunity to remember all patients, members and friends who died recently. May they rest in peace.

We send every good wish to all our branch members, volunteers, patients, families and friends, especially all those in hospital. Stay safe and enjoy the summer, hopefully we will have plenty of sunshine.

Our next branch meeting, via Zoom, will be on Monday June 28th. If you would like to join us for our virtual meetings, please contact: Frances Moynihan, Ph: 087 2411549 or email: franceswaterfordika@gmail.com

OFFALY By DERMOT GLYNN

Hello to all the members of the Offaly branch. I hope that everyone and their family and friends are keeping well in these uncertain times and don't forget we are still available for support if you need it. If you wish to contact me you can do so on 089-4480390.

MEETINGS

While we have not had a meeting recently we will hold a meeting of some type soon by Zoom, if we have to. Hopefully the government will give us some guidelines that may allow us to have some form of meeting indoors in the near future.

FUNDRAISING

We would like to thank Fintan Clooney for donating his prize that he won at Easter, in O'Sullivan's, Kilcormac. He had a raffle and donated the proceeds of €140 to the IKA.

A big 'thank you' to Tullamore Touring and Cycling Club who are currently undertaking an Around the World 4 Times in 80 Days cycling challenge. They have included us, once again, as one of their benefactors and we are very grateful to them as they have been great supporters of the Offaly branch for the last number of years.





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Christian Bernard's youngest son and Peadar O hici in Cape Town.



Fruited Schuur Hospital Cape Town.



Peadar at the Memorial Stone in Cape Town

GALWAY

By PEADAR Ó HICI

We in the Galway branch have been no different from all other branches in not been able to have face-to-face branch meetings since March 2020. We have had two Zoom meetings to see how people are coping but it is difficult, even with Zoom, to get all together due to work commitments. On the other hand it has been a good and enlightening experience to participate in the Zoom meetings organised by Donor House, both to see and hear from other branch officers and Donor House about their experiences and plans after COVID-19. So well done to Donor House for their initiative.

NURSE PROMOTION

We wish to extend our congratulations to Pauline May, who has recently been appointed, within the Saolta Group Hospitals, to the position of Assistant Director of Nursing in Practice Development in Galway University Hospital. Her work will be impacting on undergraduate nursing in the hospitals as well as auditing and influencing standards of nursing care for patients.



Pauline May

Over the past six years Pauline was Director of Organ Donation in the Saolta Group which covers all the hospitals from Donegal to Galway. She was often the first person to meet families in Intensive Care Units and broach the possibility of organ donation from their loved ones. She also trained doctors and nurses in skills needed to apply at these trying moments in relatives lives.

Her successor will be appointed by Saolta management shortly. We wish Pauline every success in her new position and thank her, once again, for being available to us in the Galway branch to speak at meetings.

HOSPITAL CLINICS AND DIALYSIS UNITS

All during this difficult time both Merlin Park and Wellstone Clinic operated as usual. Appointments were well managed and the care of all patients was impeccable. Thank you all nurses, doctors and clerical staff for your professional approach to your duties at all times.

HOLIDAY HOMES

Looking at the spread of IKA holiday homes it seems that an unintentional spread of these homes exist. Perhaps next time round the North West could be looked at if the opportunity arises to locate/purchase a property in that area.

DONOR MEMORIALS

Those of our readers who have visited the wonderful 'Circle of Life' Commemorative Garden in Salthill, Galway developed by Martina and Denis Goggin will have seen the perpendicular carved stone there remembering the donors and families of donors. These have been replicated in a number of places in Ireland, Ennis last year, Belfast before that and in various cities around the world.

They all came from the Goggin Workshop in Galway, carved by Ray Flaherty. On November 30th 2017, I had the pleasure and honour of being at the unveiling of one in the grounds of the Groote Schuur Hospital in Cape Town, South Africa. That day, 50 years previously, Christian Bernard performed the first human heart transplant. My wife and myself were on holidays in Cape Town and Denis and Martina Goggin asked us to represent them at the unveiling ceremony.

It was a magnificent ceremony which we gladly agreed to. Members of the South African Airforce opened the proceedings with a 'fly past' and wove the shape of a heart in the sky. Of course there is always a price to pay for an honour like we received and I spoke to the attendance about Ireland and reminded them that this engraved stone had travelled 10,000 kilometers from Galway.

During the course of the reception we met the youngest son of Christian Bernard and also met a grandson of our doctor Noel Browne who was on a three-month assignment there.

The hospital has over 300 beds and carries out all types of transplants. The original hospital is now a museum displaying the theatres where the original transplant occurred. There is also a residence for medical personnel.

The name Groote Schuur means big/large store and was built by Dutch traders to store their spices, tobacco and any other exotic herbs collected in the East.

DUBLIN NORTH

By PATRICIA MACKENZIE

Summer greetings to all.

VACCINATIONS

A gradual sense of relief is spreading as members receive their vaccinations. Anecdotal evidence is encouraging as those who experience post vaccination symptoms (which is not everyone) appear to quickly recover. The roll-out continues.

BRANCH NEWS

There will be no branch AGM's this year, but a National AGM will be held in September.

Some branches have held zoom meetings which have been very successful. Webinars run for branches by Donor House have elicited a very positive response.

We were very happy recently to welcome our CEO Carol Moore as our guest speaker. Carol gave us a very informative and detailed presentation outlining our current strategy and future development.

A lively discussion followed to

which all present contributed.

FACE MASKS

The new face mask featuring the Forget-me-not flower is now on sale online at €10, or contact Donor House at 01-6205306.

THANK YOU

Our heartfelt thanks go to all donor families. Your 'gift of life' cannot be adequately expressed in words.

To those in hospital and unable to receive visitors, we say – stay strong – we will eventually get back on track. Our thanks to all medical staff who took care of us in spite of COVID-19.

HOLIDAYS

There is a limited amount of accommodation available in our holiday homes which are opening up again in July. If you are fortunate enough to get a holiday we hope you have a lovely time.

CONDOLENCES

It is with deep regret and sadness



that we received news of the loss of our valued member Stephen Brady RIP.

He will be fondly remembered by many members of Dublin North.

Our deepest sympathy to his wife Orla and family. May he rest in peace.

We also remember all who suffered bereavements during the pandemic whether due directly to COVID-19, or lost loved ones for whatever reason. We offer you our deepest sympathy at this difficult time.

WISHING

We wish you a happy and healthy break after all the restrictions. Stay safe and well and enjoy the best of the Summer.

KILKENNY

By ANNE O'GRADY

FIND US ON FACEBOOK

Summer greetings to all the Kilkenny branch members. We held a couple of successful branch Zoom meetings to date and will continue once monthly.

It was lovely to chat on each occasion and support our members through these challenging times and as members receive their vaccination. Also, it is an opportunity to welcome new members.

We would like to pay a special 'thank you' to one of our members Mary Rooney. Her grandson Cillian Dunne completed a 4x4x48 Challenge for the IKA in March, fundraising €1364. Congratulations Cillian.

Our gratitude is extended to Kilkenny County Council for supporting the light-up in green initiative with 18 public sites lit up, from dawn to dusk, around the county.

As a follow on from the IKA's virtual Run for a Life which took place in early June, the Kilkenny branch, in compliance with COVID-19 guidelines, has organised a virtual walk which will be held in Graignamanagh on 27th June at 11am and has set up a GoFundMe platform for donations <https://gofund.me/dce952ec>

Seamus Carrigan has decided to step down from his role as Board Member, Kilkenny branch. We would especially like to thank Seamus for his dedication and commitment to this role for the last number of years. Hugh Byrne has now been elected to the role. Best of luck Hugh on behalf of everyone.

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

The Kilkenny branch officers contact details are as follows:

John Lacey, Chairperson 085-1328255

Hugh Byrne, Board Member 086-8938800

Therese Hanrahan, Treasurer 087-7796428

Anne O'Grady, Secretary 087-9232190

Bridie Lennon, Assistant Secretary 085-7051076



Seamus and Arlene Carrigan with Johnny and Mary Lacey.



Bridie Lennon and Anne O'Grady with Johnny and Mary Lacey.



Anne O'Grady, Bridie Lennon, Johnny and Mary Lacey and Seamus Carrigan



Hello to you all from Donegal. I hope this finds everyone in a happier and more upbeat place.

Thank God a light has emerged at the end of a long journey for all of us during the COVID-19 situation.

We have not been as active as we would normally have been as Organ Donor Awareness Week and our Church gate collections could not take place. There have been no meetings to socialise with each other, and no AGM but hopefully, things will start to return to normal in the near future.

I have called in on a few renal patients and it was lovely to see them.

On a sadder note we lost some people. Lucy Boyce, the wife of the late Hugo Boyce (whom passed 5 weeks prior) to Lucy. Both were long-time members of Donegal branch and were the leaning posts for me when I came on board 25 years ago. God rest them both.

Another gentle man and great friend to myself and George, and great supporter of the Donegal branch, was the lovely Patsy Doherty, husband of Maisy, from Moville. Patsy's family donated €347.50 in lieu of flowers. Thank you Majella, it was lovely meeting you for the handing

DONEGAL

By SIOBHÁN BATES



Nicola Doherty-Porter presented the cheque for €9,774 to George Bates, Donegal branch PRO. Also pictured are Denise, dad Jim and granddaughters Robyn and Emily.

over of the donations. Rest in peace Patsy, we'll miss you.

We were also sorry to hear of the passing of Conal Melly, Killybegs, husband of long-time member Mary, a prior Chairperson/Treasurer and Board member of the Donegal branch. Rest in peace Conal.

Thank you to all those who continue to support the branch with donations. Rest in peace Manus O'Donnell, Ballahaderg, Letterkenny. Manus's family donated monies €170, in lieu of flowers, to our branch. We offer our sincere condolences. It was nice to meet with Josephine for the handing over of the donation.

We also pass on our condolences to Neil and Sharon Gallagher, Buncrana (prior Secretary to Donegal branch) on the sad passing of Neil's brother Tommy.

Heartfelt condolences to all who have lost loved ones.

Thank you to Cahal Sheridan, C&M Embroidery, for his kind donation of €150. C&M Embroidery supply the branch with the shoulder bags all our renal patients are gifted. These shoulder bags help when travelling to their dialysis therapy to hold their remotes and headphones, etc.

Thank you Ellen Carlin for your donation of €20. Much appreciated.

Well what can I say about Nicola Doherty-Porter, Clonmany/Buncrana. A massive 'Bualadh Bos'. Well done to you and your wee helpers who took on a walking challenge during lockdown, in memory of your beautiful mother Patricia Doherty, RIP (nee Patsy Gillespie). I spoke with Nicola while she was in the planning stage and we delivered t-shirts to Buncrana. Patricia Callaghan, our



Cahal Sheridan, C&M Embroidery presents George Bates with a cheque for €150.



Dialysis nurse specialist Shona Doherty-Maloney, accepting 100 new bags from George Bates, donated from the Donegal branch for renal patients receiving dialysis at Letterkenny Dialysis Unit.

branch secretary also organised t-shirts from Donor House. Nicola exceeded well over her expectations by reaching a target of over €12,000, yes €12,000!! With grateful appreciation €9,774 was donated to the Donegal branch thru the GoFundMe page with monies going straight to IKA funding. The dialysis unit at Letterkenny General Hospital, Letterkenny received the remainder to help for the comfort, care and needs of the renal patients while attending dialysis.

Accompanying this most generous donation also to Donegal branch, was another €220. It was presented to us by Nicola's sister Denise, and their gentleman of a dad Jim and Patricia's granddaughters, Robyn and Emily, in lieu of flowers from Patricia's untimely passing in August 2019.

Thank you to all of you for such kindness and loyalty to the branch.

Our Renal Support Centre is so very badly missed by many. Hopefully, we will soon have it back when lockdown and COVID-19 has finally passed.

Thanks to the Renal Support Centre staff who always are so accommodating when they have enquiries regarding accommodation for Donegal renal patients, travelling to Dublin for clinic and renal procedures.

Big congratulations to the newly transplanted patients, and years of good health and happiness to you all. And thank you to the families who made the decision to donate.

Thanks to all nurses, doctors, clerical staff, all dialysis and transplant staff in clinics and in our hospitals. They are all doing their very best to keep us all happy and upbeat during these troubled times.

Anyone who ever wants any mention or anything posted on the branch notes for future *SUPPORT* magazines, let me know. You can email them to me (thebatesfamily@eircom.net) and we will get your announcements sorted. From myself Siobhán Bates (Chairperson), George Bates, (PRO), Kieran Murray (Treasurer and Board member) and Patricia Callaghan (Secretary) we take this opportunity to wish you all a beautiful Summer 2021 and hope to see you all soon. Till we meet again. Slán.

DUBLIN EAST & WICKLOW

By BERNIE DWYER

Greetings to you all in East Dublin and Wicklow. As we are hopefully reaching a return to some normality and a bit of freedom again we look forward to Summer and meeting with family and friends we may not have seen in a while.

Most renal patients will hopefully be fully vaccinated by the end of July, but remember as Wicklow is such a beautiful county and attracts many visitors we need to still take precautions for our safety.

We had a very quiet Organ Donor Awareness Week this year and thanks to Donor House for all your work encouraging virtual events and promoting awareness on the various social media pages.

We had some lovely photos of buildings turning green for a week including two in Bray.

As we approached Run for a Life in June we encouraged our members to take part and share some photos including some along our seafront in Dun Laoghaire, Bray and Wicklow and of other individual walks or runs.

We wish our chairperson John Whelan a speedy recovery during his present stay in hospital and indeed all of our members who are experiencing bad health at this time.

Don't forget your Association is there for you always with information and counselling.

Thanks to all who took part in our Zoom meetings and to Carol for joining us for one of them.

Please consider joining our next one, no travel involved!!

Wishing you all a happy, healthy and safe Summer.

LOUTH/MEATH



Caoimhe (middle) with her sister Eimear (left) and mother Kathleen (right).



The fundraiser mascot - Beautiful Belle!

Caoimhe Murphy and her family took part and completed walks throughout the month of May as a fundraiser on behalf of her uncle (Seán Mulligan). Seán raises money for the IKA every year. He has benefitted from the services provided by the IKA for many years and always wants to give back by fundraising.

Caoimhe would like to thank Catriona Callaghan of 'The Bunnery' bakery and everyone who kindly supported and donated to her fundraiser this year! Catriona raised €1,400 and in total a sum of €4,190 was raised.

Each day throughout the month of May they completed walks and Caoimhe would upload pictures of their route to her social media accounts allowing people to follow the link and donate.

Thank you Caoimhe.



Caoimhe, Belle and her mother Kathleen in the local forestry during one of their walks



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SLIGO BRANCH SEEKS VOICE ON TEAM PLANNING NEW DIALYSIS UNIT

We in the Sligo IKA branch are continuing our campaign for the provision of a new Dialysis Unit at Sligo University Hospital.

In the most recent development the Minister for Health, Stephen Donnelly, informed us by letter that a Project Team has been set up with key stakeholders from the Sligo Renal Dialysis Unit.

In the letter to our secretary dated May 5th, the Minister said that a schedule of accommodation will be drawn up and signed off on by the Project Team.

In a letter of reply, we welcomed

SLIGO

By **BRIAN McHUGH**

Volunteers who took part in the daily swim at Lissadell.



The prize was donated to us by a family member of a transplant patient.

The draw was based around numbers coming up in the Irish lotto draw with the winner being the entrant with the bonus number.

COLD DAILY DIP RAISES FUNDS FOR IKA

Four brave North Sligo ladies took to the cold seawaters at Lissadell beach every day during Organ Donor Awareness Week.

They raised more than €3000 for the IKA through a Go Fund Me page and other donations.

At all times they remained socially distanced and kept within the restrictions.

Thanks to the volunteer swimmers and all who donated.

SYMPATHY ON RECENT DEATHS

Our branch sends sympathy to the family of two renal patients who died in May.

Charles (Charlie) Elliott of Hillcrest Park, Strandhill, and formerly of Ballincar, passed away on May 15th at Sligo University Hospital.

His funeral mass was in Patrick's Church, Strandhill with burial afterwards in Scarden cemetery.

Less than a week later, Ella Flynn of Jink's Avenue, Sligo town passed away at the hospital.

Ella's funeral mass was celebrated in the Cathedral of the Immaculate Conception followed by burial in Sligo Cemetery.

May they both rest in peace.

this development. We requested that a member of our branch should join the Project Team to represent the patients who will be the exclusive users of the proposed new facility.

We made a similar request to Tony Canavan, CEO of the Saolta Hospitals Group in Galway.

The current dialysis unit opened in May 2005 when it catered for 30 patients – the same facility now has more than 60 patients with more arriving almost weekly.

Sligo is now the oldest dialysis unit in the country that has not been updated.

GET WELL WISHES

Get well wishes to Tara McHugh, St. Vincent's Hospital, Dublin.

Tara, who is a kidney recipient, spent most of April and May in hospital in Sligo.

Her current illness is not kidney related.

XBOX WINNER ON BONUS NUMBER

We recently ran an online fundraising draw with the prize of an Xbox Series X Console.

Congrats to the winner Sinead Spain, from Dublin.



THANK YOU AND GOODBYE

We would like to take this opportunity to thank Mary Hurley for all her hard work as Cork branch Treasurer over the last two years, as well as being amazing help on the Committee. Thanks for giving up your time. We look forward to seeing you at monthly support meetings and drawing on your help when we are back to having events physically. We wish you all the best going forward and many thanks again for everything.

We would also like to take the opportunity to welcome Bernard Cronin to the Committee as Treasurer from the end of June, for the next year. We wish you all the best in your new voluntary role for the Cork branch.

Sheena McDonagh (Secretary) Sally Nagle (Chairperson) with Mary Hurley.

THANK YOU TO SMA PARISH

Yet again, the SMA Parish, Wilton, has very kindly and generously donated their monthly charity collection for April and May to the Cork Support Centre development fund.

We would like to thank Fr Michael O'Leary, the sacristan Chris, and the

parishioners of St Joseph's Church, Wilton for their very generous donation of €1,000. They can be assured that their contribution will be put to great use. It is wonderful to have the support and interest of the local community in what is going to be a wonderful asset to renal patients and their families when visiting CUH.

CORK

By SALLY NAGLE and SHEENA McDONAGH



Mary Hurley and daughter Emma.

CAVAN/MONAGHAN

By KARL CRONIN

COVID VACCINATION ROLL-OUT SCHEME

The branch wish to convey its appreciation to the IKA for their representations, on behalf of all patients, to ensure we were reprioritised under the national COVID-19 vaccination roll-out scheme. The initiative to email local TDs was very well planned and communicated, and very effective. We hope all patients are well on the way to being fully vaccinated at this stage and that we can enjoy a summer with some sense of normality.

CAVAN RENAL DIALYSIS UNIT – DOUZE POINTS!

The renal dialysis unit in Cavan recently benefitted from a novel fundraiser organised by the staff in Sheridan Insurances based in Cavan town. They

decided to arrange a 'Eurovision Sweep' among the staff with each member of the team randomly assigned a country taking part in Eurovision 2021.

Audrey Jameson, one of the Life and Pension Advisors in Sheridan Insurances, was assigned Italy and ultimately claimed the €100 winnings. Audrey very kindly donated her winnings to the Cavan renal dialysis unit as a token of her appreciation as she herself has had a positive personal experience with the unit and the IKA.

Even though Ireland didn't have much success at this year's Eurovision Song Contest, the Cavan renal dialysis unit certainly came out with douze points!

TIPPERARY

By ORLA HOGAN RYAN

We hope all our members are safe and well and have received their vaccine(s).

We wish to pass on our sympathy to all the families in our branch who have lost loved ones recently.

We had a social distance walk on Sunday 13th June in Two Mile Borris, Thurles in aid of the IKA. All were welcome. Further details will appear in the next issue of *SUPPORT*.

We are hoping to have a social distance outdoor gathering in the summer - details to be announced.



Orla Hogan (right) with her two nieces Rosie and Peigi Murphy and her mother Nora Murphy.



IRISH KIDNEY ASSOCIATION CLG

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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



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

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