

SUPPORT



SPRING 2019

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ORGAN DONATION & TRANSPLANT IRELAND
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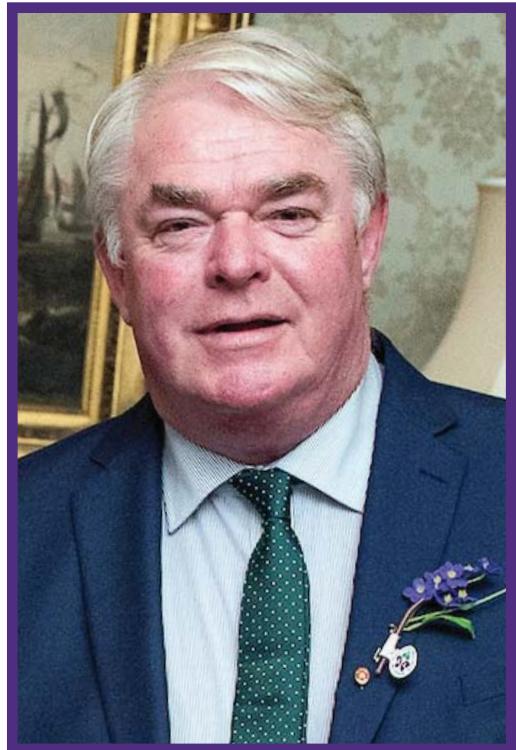
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Editorial...



Spring has arrived and you will have noticed, from the front cover of this edition of SUPPORT, that Ray D'Arcy has kindly responded to our request, for the second time, to be an Ambassador for the Irish Kidney Association's 2019 Organ Donor Awareness Week's campaign. He previously headed the campaigns in 1998 and 1999.

Fundraising is an essential part of the Association's past and future. 'Yes' we are in a position to expand our services and about a quarter of our annual expenditure is funded by the HSE. However, the remainder of the €1.75 million expenditure comes from fundraising and donations.

Currently, we are developing a six bedroom Renal Support House adjacent to the Cork University Hospital. Negotiations to provide a four to five station holiday dialysis centre in Tramore, Co. Waterford are advancing to accommodate up to sixteen local patients for year-long dialysis.

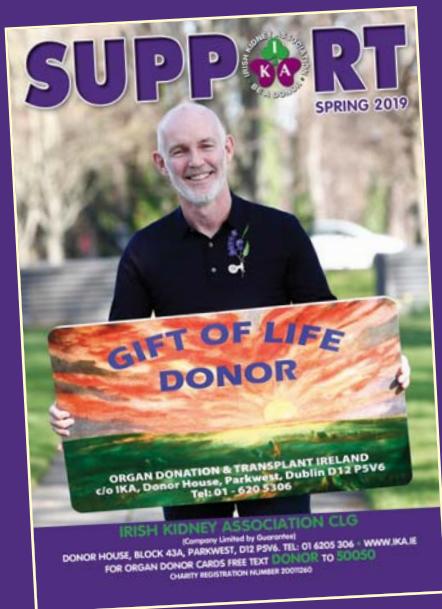
The new purchase of an additional holiday house in Killarney is ready for the season and, indeed, the Renal Support

Centre in Beaumont is currently undergoing a facelift (see page 31).



We have ambitions to provide an accommodation and holiday facility on the grounds of Merlin Park Hospital in Galway and, for the first time in many years, we are in a position to commit €250,000 to kidney research projects, over a five year period.

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*Photo:
Conor McCabe Photography.*

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All this growth will increase our annual budget and the ongoing fundraising, conducted by the branch members across the country, will keep us independent of the HSE. We are not a service provider charity to the HSE, however, they do contribute to some of our services.

Continuing to encourage organ donor cards directly into the hands of the public and, generating the discussion about organ donation within families, is more important than the fundraising conducted during the Organ Donor Awareness Week. Demonstrating the impact of organ transplantation on people's lives impacts well on the public at large. So, why not give your local IKA branch a call and offer them two hours of your time, helping out in your own community. Branch Secretaries' phone numbers are on page 63 of this SUPPORT.

At this time, every two years, the twenty five IKA branches elect their Officers and a National Board Member. Your local branch, which you are welcome to join at any time, will be having their AGM in April. If you wish to contribute and get involved in your local branch, do contact the Secretary from your area.

Like the IKA branches, the elections for the National Officers takes place at this time, and you, the members will have the chance to vote for the National offices of Chairman, Treasurer and Secretary of the whole organisation, if an election is required.

The AGM of the Association is taking place on June 29th in the Red Cow Moran Hotel, Dublin

(see page 41). This is where the election for National officers is concluded. We will plan talks in the coming weeks for the Patients Conference.

Enclosed in this SUPPORT you will find various statistics for 2018. Our headline is worth repeating here - 54% of Irish people, with failed kidneys, are treated by receiving a kidney transplant. We are one of about ten countries, worldwide, where the majority of patients are transplanted rather than remaining on dialysis. That is entirely due to the generosity of the public in donating organs at a sad and most difficult time and we sincerely thank them for this.

I was delighted that An Post decided to produce a stamp promoting organ donation and equally pleased that organ donor cards are now available in every post office in the country.

May I wish you all a successful Organ Donor Awareness Week and I hope our Spring weather will be benevolent to all our volunteers.

Thank you




MARK MURPHY

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IKA'S NEW AMBASSADOR FOR ORGAN DONOR AWARENESS

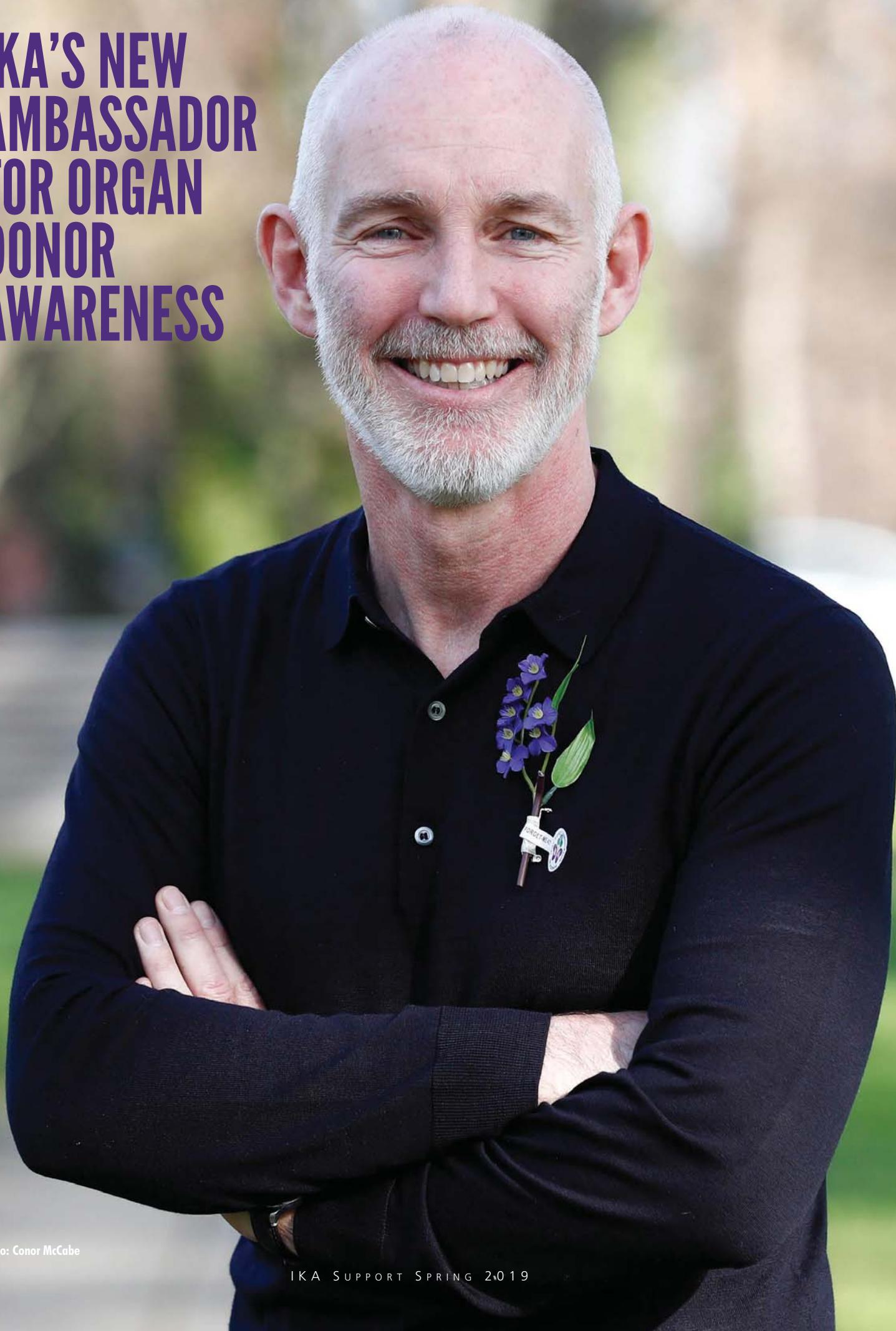


Photo: Conor McCabe

Ray D'Arcy

The Irish Kidney Association is delighted to announce that Ray D'Arcy has agreed to the voluntary role of ambassador for organ donor awareness 2019 taking up the baton from Claire Byrne who fronted last year's campaign. Ray, the popular RTÉ TV and radio broadcaster was also the ambassador for the campaign two decades ago. Since then he has continued to champion the life-saving cause on national airwaves.

He will front the 2019 Organ Donor Awareness Week campaign which will take place from March 30th until April 6th encouraging the public to support organ donation for transplantation by letting their loved ones know their wishes.

#Have the Chat

Ray will feature in radio advertising and posters as well as attending the national launch in the Mansion House Dublin on Tuesday, March 26th.

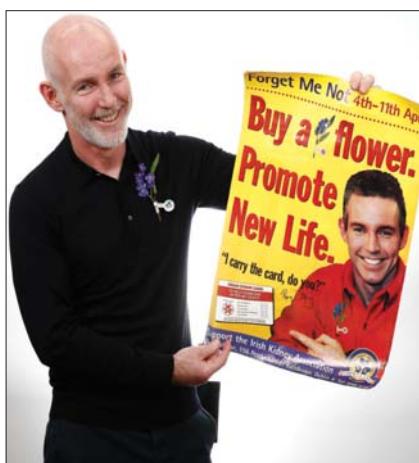
Ray said, "It's such an honour to be asked to be ambassador for this year's campaign. Organ donation is something that I feel very strongly about. Listening to people's stories down through the years about organ transplantation, dialysis and organ donation, sometimes heart-warming and at other times heart-wrenching, I honestly believe that there is no better gift in life than the gift of organ donation."

"I have heard from grieving families about the solace they have got from donating the organs of someone they have loved knowing that other individuals and families have benefited. The news of a person receiving a transplant affects the families involved and it ripples through communities around Ireland.

"I have also heard how people's lives have been transformed through organ transplantation and



Ray D'Arcy as IKA Ambassador with then Minister for Health Brian Cowan and some Forget-Me-Not children at the national launch of Organ Donor Awareness Week at Buswells Hotel in 1999.



Ray D'Arcy, 1998 and 2019 Ambassador

I commend the donors who have made this possible. There are approximately 550 people in Ireland awaiting an organ transplant and hopefully these people's lives will be saved through organ transplantation. I would encourage everyone to discuss organ donation

with their family members as I have done with mine. It doesn't have to be a long conversation, but it is such a vital and potentially life-saving one. The legacy of organ donation by selfless deceased donor families is profound."

Chief Executive of the Irish Kidney Association (IKA) Mark Murphy said, "It's wonderful to have Ray D'Arcy, who enjoys household name recognition, lending his support once again to the IKA twenty-one years after first fronting the annual campaign. Ray has always demonstrated great empathy for people touched by organ failure. To have such a popular figure representing the IKA, a charity organisation of patients and carers, carries with it huge impetus to the work we have undertaken advocating and caring for our patients."

"I HONESTLY BELIEVE THAT THERE IS NO BETTER GIFT IN LIFE THAN THE GIFT OF ORGAN DONATION."

ORGAN DONATION AND TRANSPLANTATION													
		2018	2017	2016	2015	2014	2013	2012	2011	2010	2009	10 year Total	10 year avg.
Deceased Donors		81	99	77	81	63	86	78	93	58	90	806	80.6
Transplantation from Deceased Donors	Kidneys	127	141	122	120	112	147	131	165	98	154	1317	131.7
	Liver	56	62	58	61	44	55	50	61	38	64	549	54.9
	Heart	18	16	15	16	18	11	10	6	3	11	124	12.4
	Lungs	28	36	35	36	31	32	14	8	4	5	229	22.9
	Pancreas	5	5	0	0	6	11	1	8	8	9	53	5.3
SUB-TOTAL		234	260	230	233	211	256	206	248	151	243	2272	227.2
Living kidney donors & transplants		40	51	50	33	40	38	32	27	23	18	352	35.2
All organ transplants TOTAL		274	311	280	266	251	294	238	275	174	261	2624	262.4
Living & deceased donor kidney Tx		167	192	172	153	152	185	163	192	121	172	1669	166.9

Organ Donation and Transplantation 2018

It was always going to be a difficult task to follow on from the record-breaking year for Organ Donation and Transplantation in 2017 as the uncertainty of availability of deceased organ donors always varies. In the last 10 years we have had extremes of low numbers in 2010 of 58 donors to the height, last year, of 99, a 70% swing. 2018 can only be described as an average year with 81 deceased organ donors, which is exactly the average number over the last 10 years.

By
MARK MURPHY

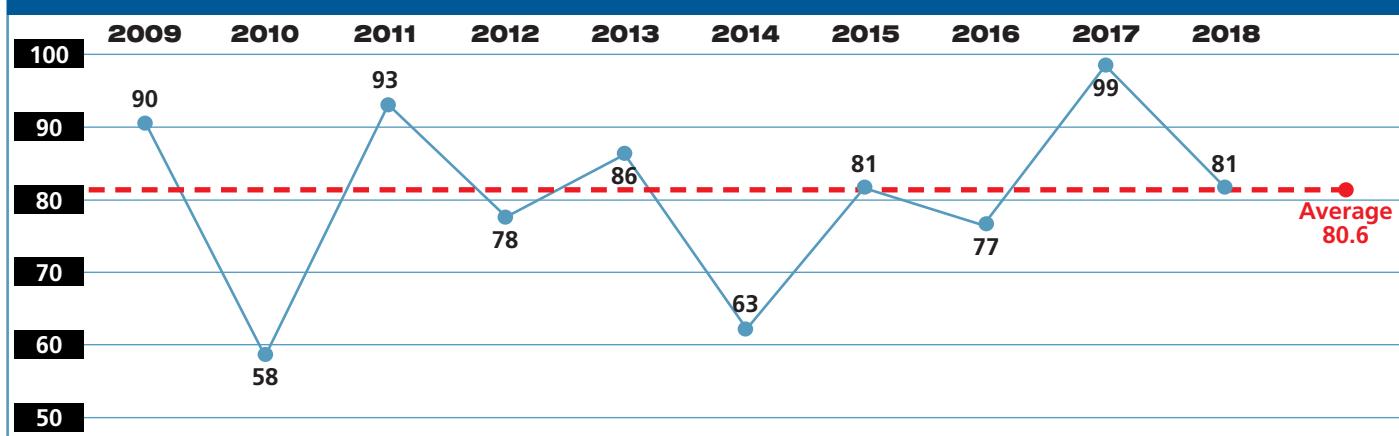
As a result there were no records broken in transplantation in 2018. And there were 26 less deceased organ transplants than 2017 when the record was set at 260.

Deceased donor transplantation of liver 56, heart 18, and lung at 28 were all slightly above the 10 year average. Kidney was 5 lower than the average and pancreas was the average at 5.

For the first time in 10 years the living donor kidney transplant numbers did not grow and dropped from 51 in 2017 to 40 in 2018. Surely it is now time for Ireland to follow our neighbours in the UK and start accepting the offers from the public as altruistic living donors.

The Department of Health would prefer to wait until the new Human Tissue Bill is passed, but up to 10 living kidney transplants are now being lost per annum, while we wait and wait. I know of no legal impediment preventing these

DECEASED ORGAN DONORS



generous living donors from giving a kidney to a stranger.

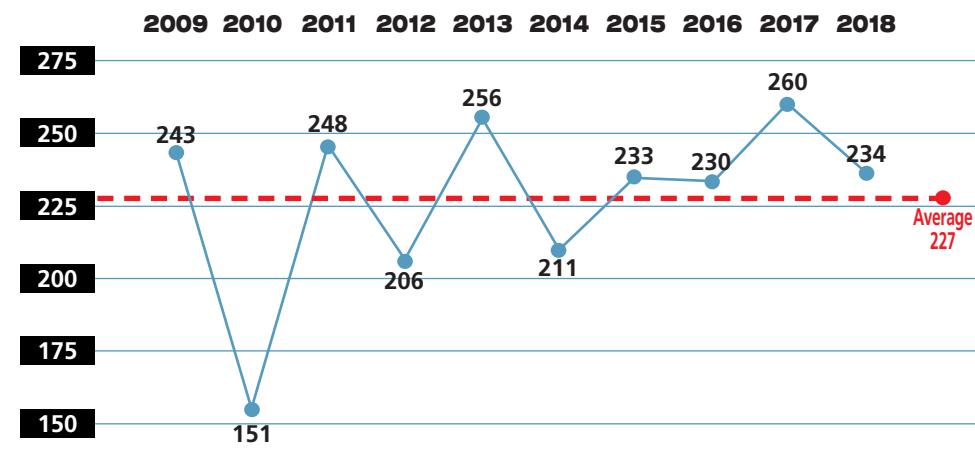
The 10 years of deceased organ donors graph has followed the trend of dropping and rising on each alternative year. So 2019 will be a year of greater numbers of deceased organ donors if the trend continues, please God. (See previous page).

Thankfully, the deceased donor transplants has managed to stay above the average of 227 over the last 4 years. (See opposite). Regrettably, due in no small part to the disappointing 2010 figure of only 151 transplants, it keeps the 10 years average down.

It is worth mentioning that in 2015 like 2018 we also had 81 deceased donors but 8 less transplants occurred largely due to the absence of pancreas transplants back then. It is good to see the service restored.

Beaumont Hospital has circulated letters to everyone on the deceased donor kidney transplant pool. It makes difficult reading for some people and the videos are well worth watching. Utilising the extra

DECEASED DONOR TRANSPLANTS



SUMMARY ACTIVITY FOR 2018 FROM THE NATIONAL KIDNEY TRANSPLANT SERVICE

Kidney only transplants from deceased donors	122
Combined Kidney Pancreas Transplants	5
Kidney Transplants from Living Donors	40
Total number of kidney transplants performed in Ireland	167
Kidneys Transplanted through UK Paired Kidney Exchange Program (PKE)	3
Patients transplanted from the Irish Kidney Transplant Waiting List	170

donors makes complete sense and informing everyone on the pool is the correct and proper thing to do. Your Nephrologists are there to answer all

your questions and I am certain the changes will lead to many more successful kidney transplants.

Jewellery Design Competition

Winners...

We were delighted to receive ten entries for our competition that featured in the last SUPPORT magazine.

There was a total of 18 designs from which to choose a winner. I am pleased to report that the winners of the first prize of €500 One4All vouchers are the

Schulte family from Clontarf, Co. Dublin. The two runners-up prizes go to Karl Cronin from Cavan and Sara Philpott also from Clontarf, Co. Dublin. Many thanks to all the artists for their thoughtful and creative designs. We are now going to involve some experts in the field to assist us deciding on a final brooch selection. *Editor*

Regina with her husband John and baby Dáithí



Transplant baby joy

If you don't believe in miracles, meet my son. His birth is my best news of recent times. It's a world away from the bad news that came before, of kidneys failing and dialysis starting and dialysis not going well.

He is my best news since my kidney transplant.

I know there was once a time – and it wasn't so long ago – when to have a transplant was miracle enough. To hope to have a successful pregnancy after that life-saving surgery would have been too much for medicine to handle. But expertise evolves and now the gift of renewed life from a donor can beget another brand new life in the form of a beautiful baby.

Dáithí is his name and together we flew through 36 weeks of an uneventful pregnancy before a few wonky blood results prompted the doctors to decide it was time he made his grand entrance.

Throughout those 36 weeks, I was never given a sense that my transplant was a problem. My obstetrician, Professor Fergal Malone, simply counted it as another circumstance to be taken into account. That came as a great comfort.



Dáithí

But I knew that on the other side of those nine months, there was the need for me to be okay, and that long after this baby was born, my relationship with my kidney would continue to be the single most important element of my body's story.

To that end, my renal team were central to everything that happened. There were weekly appointments with them. There were conversations over and back between the 'baby man' and the 'kidney woman'. At my fortnightly scans, the obstetrician would look closely at what was going on in the womb before directing the sonographer to give him a look at the transplanted organ too.

Eventually, when the medics agreed it was time, the consent form was presented and a date set for myself and my husband to meet our little man.

He emerged through an incision made along a section of my transplant scar and despite a diet of anti-rejection drugs and steroids on the inside, he weighed in at a healthy seven pounds and one ounce. Four months later, he continues to thrive and he delights us every day.

This is the latest twist in my transplant story. There would have been none of this joy without my donor. Every day I remind myself of that. From the big stuff – the wedding day, the career, the holidays of a lifetime – to the small stuff – eating chocolate and drinking buckets of coffee – all of it is possible only because on some family's darkest day, they made the decision to donate the organs of their loved one.

They gave me the chance to love my life again.

Now I have a baby to love too.

Education helps academic along transplant journey

Greg Foley, from Leopardstown, Dublin, is a chemical engineer who has over thirty years' experience of lecturing in Biotechnology in DCU. Diagnosed with cystic fibrosis at the age of six in 1969, he underwent a double lung transplant in December, 2002 in Newcastle, England.

In January 2011 he underwent a kidney transplant following a year on haemodialysis to treat kidney failure caused by the effects of anti-rejection medication. He believes the year on dialysis was one of most psychologically demanding of his life but he found it inspiring to watch older patients deal so well with the prospect of a lifetime on dialysis and no hope of transplant.

Although Greg was reasonably healthy as a child and young teenager, his lung function deteriorated significantly during his Leaving Cert year and during his time studying engineering in UCD. However, being very driven and ambitious, he persevered and earned a master's degree from Cornell University in 1986 and a PhD from UCD in 1993.

During his long lecturing career, his health gradually deteriorated and in the five years before his double-lung transplant he became more and more oxygen-dependent, culminating in requiring 24-hour oxygen supplementation in the months preceding his surgery. In that long, slow year on the waiting list he also required a BiPAP machine at night, a machine that ultimately kept him alive.

Greg says he has never allowed his CF to define him at least not in a conscious way. It was never about "beating CF" but



more about making a fulfilling life for himself, one where the CF was always in the background, and often in the foreground, but simply had to be dealt with sensibly. He never saw having CF as being a "battle" – to him having a chronic disease is far better described as a journey, one with lots of twists and turns, and quite a few setbacks.

Having support helps make the journey easier and

Greg would not have gotten through his lung transplant without the support of his wife, Julie.

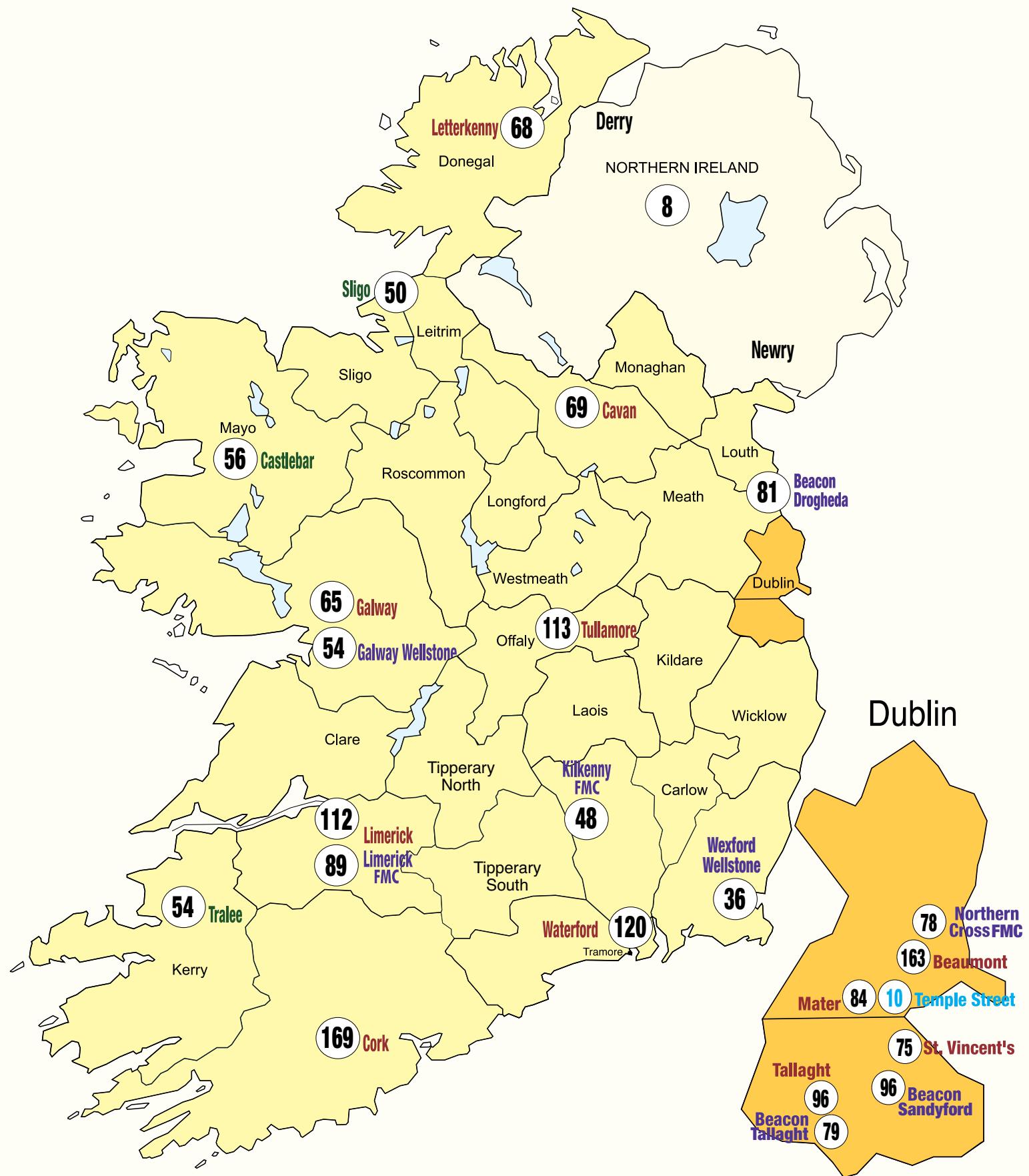
If anything defines Greg, it is his love of the academic life and his passion for education. It was this passion that helped him to endure some very tough years, especially in the 1990s. In a way, education saved his life.

Greg is obviously grateful to his deceased donors for his two transplants. He strongly believes that the best way to honour and thank organ donors and their families is to achieve something tangible with your life and to give something back, not just to the family of the donors, but to society as well.

While he is delighted with the transformational effects that transplantation has had on his life, he is very aware that both his lungs and his kidney have the potential to fail. This is something he is philosophical about and all he can do is be meticulous about taking his medication.

That's the only way he can maximise the time he will have with his son, Leo, who was born in 2008.

MAP OF HAEMODIALYSIS UNITS USED BY PATIENTS FROM THE REPUBLIC OF IRELAND AND DIALYSIS PATIENT NUMBERS AS OF 31/12/18



CHRONIC DIALYSIS & TRANSPLANT PATIENTS - 31/12/18

Dialysis Facility	HAEMO HD	HOME DIALYSIS HHD	PD	TOTAL DIALYSIS PATIENTS	TRANSPLANT AT CLINIC	TOTAL ESKD PATIENTS
ADULTS						
Beaumont	163	23	54	240	765	1005
Mater	84		5	89	118	207
FMC Northern Cross	78			78		78
Beacon Drogeda	81			81		81
Cavan	69			69	17	86
St. Vincent's	75		15	90	162	252
Beacon Sandyford	96			96		96
Tallaght Hospital	96	4	33	133	335	468
Beacon Tallaght	79			79		79
Tullamore	113			113	51	164
Cork	169	15	22	206	383	589
Waterford	120	3	29	152	168	320
FMC Kilkenny	48			48		48
Wellstone Wexford	36			36		36
Tralee	54			54		54
Limerick	112	6	20	138	120	258
FMC Limerick	89			89		89
Galway	65	4	12	81	176	257
Wellstone Galway	54			54		54
Castlebar	56			56	64	120
Letterkenny	68			68	73	141
Sligo	50			50	32	82
Northern Ireland	8			8		8
ADULT TOTALS	1863	55	190	2108	2464	4572
CHILDREN Temple St, Crumlin	10		6	16	64	80
OVERALL TOTALS	1873	55	196	2124	2528	4652

IRISH DIALYSIS PATIENTS - 31/12/18

	Patients	%
Centre Haemodialysis	1873	88.2
Home Haemodialysis	55	2.6
Peritoneal Dialysis	196	9.2
Total Dialysis Patients:	2124	100

The HSE's National Renal Office (NRO) has completed its census of patients at December 31st 2018 and thanks are due to Professor George Mellotte and Pat O'Connor for continuing to share the data with the Irish Kidney Association (IKA).

There are now 4652 people being treated for end stage kidney disease (ESKD) in the country. That is 958 per million of the population or one in 1044 people. Thankfully we are one of about 10 counties worldwide that have more patients treated by a kidney transplant 54.2% than are treated by dialysis 45.8%. The one year growth in patients is 2.6% or 119 people.

continued next page →

IRISH ESKD PATIENTS - 31/12/18

	Patients	%	PMP
Transplanted	2528	54.3	521
Haemodialysis	1873	40.3	386
Peritoneal Dialysis	196	4.2	40
Home Haemodialysis	55	1.2	11
Total ESKD Patients:	4652	100	958

PMP = Per Million of Population

Population 4,857,000

ESKD TREATMENT BY UNIT TYPE - 31/12/18

	HD	%	PD	Home HD	Transplanted	ESKD
HSE Hospital Renal Unit (11)	1134	60.6	190	55	2368	3747
HSE Hospital Satellite Unit (3)	160	8.5			96	256
Commercial Satellite Unit (8)	561	30.0				561
Northern Ireland NHS (3)	8	0.4				8
HSE Paediatric Renal Unit (2)	10	0.5	6		64	80
TOTALS	1873	100	196	55	2528	4652

ONE-YEAR COMPARISONS

TREATMENT	2018	2017	% CHANGE	PATIENTS
HAEMODIALYSIS	1873	1813	+3.3%	+60
PERITONEAL DIALYSIS	196	207	-5.3%	-11
HOME HAEMODIALYSIS	55	54	-2%	+1
TRANSPLANT	2528	2459	+2.8%	+69
ESKD TOTAL	4652	4533	+2.6%	+119

continued...

In centre haemodialysis patient numbers grew by 60 patients in the year or 3.3%. The numbers across the country vary but the outstanding growth in the Waterford area requires a mention. A year previously Waterford had 122 haemodialysis patients and 27 home therapy patients, a total of 149 in treatment. In January 2018 their satellite centre in Wexford commenced treatments. At December 31st, 2018 the new Wexford unit had 36 patients but Waterford now has 3 patients more than a year ago with 152 on haemodialysis and home therapies. Total including Wexford of 188 patients is 39 more than a year ago, 26% growth in one year. So the release of pressure expected by Waterford because of the opening of Wexford was short-lived.

The IKA has a holiday dialysis building in Tramore, County Waterford and we have offered the facility to the HSE provided that holiday dialysis is ring-fenced for our holidaymakers in our 4 apartments in Tramore. This could further alleviate the pressure on Waterford while satisfying a long held goal of the IKA in having dedicated holiday

dialysis centre in Tramore.

The amount of patients on peritoneal dialysis at 9.2% and home haemodialysis at 2.6% are both low figures by international standards. Not all patients are suitable for these alternatives and both require a personal commitment to dialyse alone and spare space in the home is a necessity. However the patient's choice to decide on these alternatives comes with other advantages, control of your own timing of dialysis and no travelling.

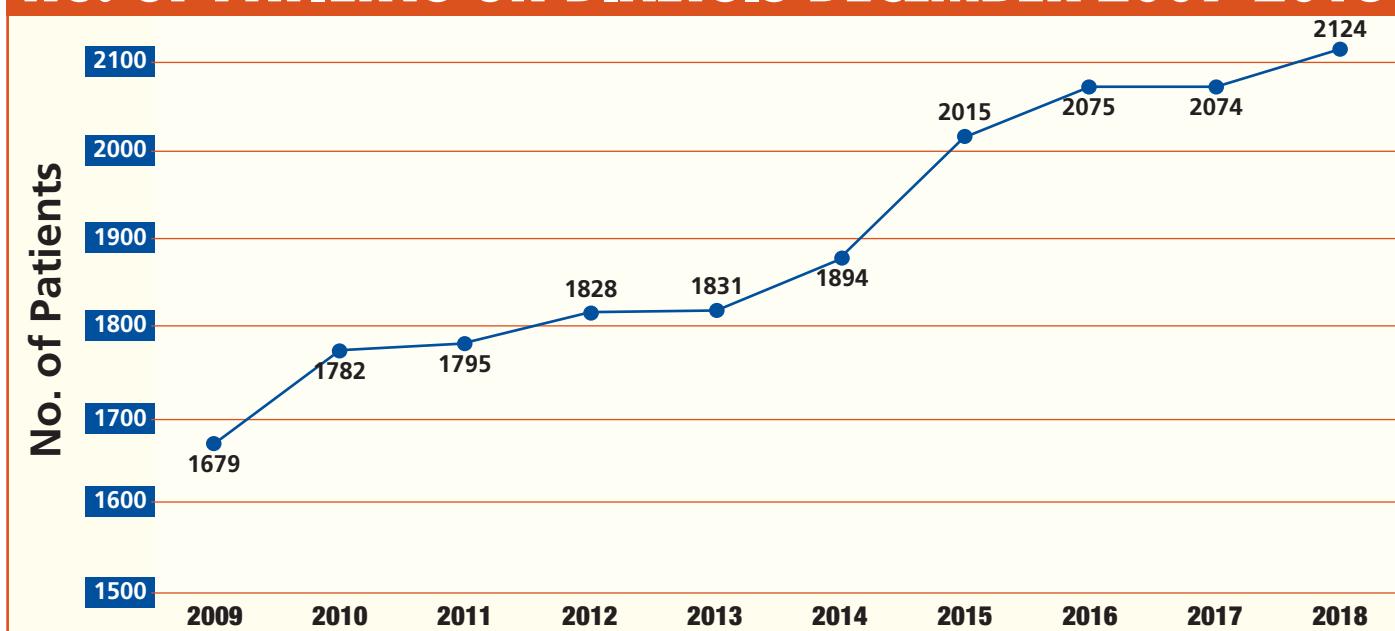
There are now 22 adult haemodialysis units in the State of which 8 are contracted units. The next to come on stream will be the Bbraun facility in Portlaoise. I am assured it will be treating patients in the fourth quarter of this year. That will be a relief to Tullamore, the fourth busiest unit in the country.

In 2017 which was a very good year for kidney transplantation, there were 5 extra patients on dialysis at the end of the year and in 2018 with an average year for kidney transplantation there are 50 extra patients on dialysis of all types because of the 40 less transplants in 2018 compared to 2017.

5 YEAR COMPARISON ADULT HAEMODIALYSIS BY UNIT TYPE

	2018	2013	5 YEAR CHANGE	%
HSE Hospital Renal Unit (11)	1134	1010	+124	+12%
HSE Hospital Satellite Unit (3)	160	138	+22	+16%
Commercial Satellite Unit (8)	561	(5) 398	+163	+41%
Northern Ireland (3)	8	10	-2	-20%
Home Haemodialysis	55	44	+11	+25%
TOTAL	1918	1600	+318	+20%

NO. OF PATIENTS ON DIALYSIS DECEMBER 2009-2018

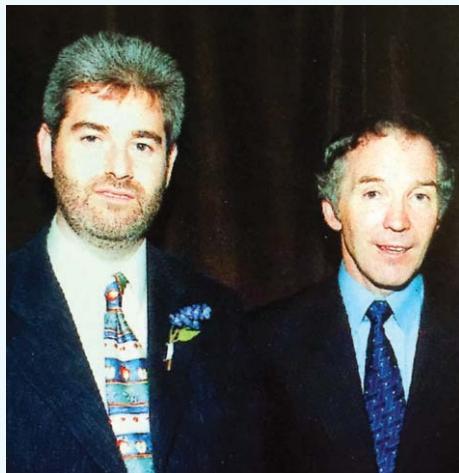


RETIRED PRISON OFFICER CELEBRATES...



Simon in the garden of the IKA's Renal Support Centre

25th Anniversary of Kidney Transplant



Simon is pictured with the then Governor of Mountjoy Prison, John Lonergan in 2001.



Simon with his wife Marcella on the night he was presented with his Long Service Medal in St. Patrick's Institution.

Dubliner Simon Walsh (53) retired from his job as a prison officer two years ago after 30 years' service and this year is celebrating the longevity of the successful kidney transplant which he underwent 25 years ago, in February 1994. Prior to his life-saving kidney transplant he had been undergoing haemodialysis treatment at Beaumont Hospital, three times a week, for close to two years. Simon worked at Mountjoy Prison, Loughan House and St. Patrick's Institution.

Soon after his transplant Simon wrote to the family of his deceased organ donor anonymously via the Transplant Coordinator and also on the first anniversary to express his gratitude.

In wishing to honour his deceased organ donor he was the instigator of two initiatives between the prison service and the Irish Kidney Association (IKA).

In 1992 he suggested the introduction of a Prison Officers pay deduction scheme through the Prison Credit Union for the IKA which then began and his prison officer colleagues have now raised over €250,000 for the charity.

The scheme continues to run since Simon's retirement.

Another was an approach to the then Governor of Mountjoy Prison, John Lonergan, with an idea which resulted in one of Mountjoy's work parties making benches and building a landscaped garden at the IKA Renal Support Centre, which is located on the grounds of Beaumont Hospital. The Renal Centre provides free accommodation to patients and their families who have to travel from the country for appointments and transplants.

Simon continues to enjoy good health and he now works part-time as an interviewer for Red C at Dublin Airport. He lives in Dublin and is married to Marcella and they have three children aged 18 and twins aged 14.

He is also a former Chairperson on the Dublin North branch of the IKA and continues to be involved by attending meetings and supporting other events. Like he has done for many years before he will volunteer during this year's annual Organ Donor Awareness Week 2019, distributing organ donor cards and selling the IKA's Forget-Me-Not flower emblems.

The Irish Kidney Association's position on...

GOVERNMENT'S PROPOSED OPT-OUT LEGISLATION

A misconception that is at the core of the opt-out debate is that a person has to have an organ donor card to be considered a potential organ donor. This is simply not true. Current practice is that **every time** a potential organ donor is identified in an ICU the family is approached and asked for consent for donation. If they say Yes then it goes ahead, if they say No, it does not.

Once this is understood it becomes very clear that introducing an opt-out system cannot increase the pool of potential donors as the families of **ALL** potential donors are already

approached under the current system. Therefore, the focus has to be on improving the consent rates from families.

The role of the donor card has always been to encourage a family discussion about organ donation. The space for the next of kin to sign is the way into what can be an uncomfortable conversation for families. The card does not have to be present for organ donation to be considered and is not actively sought when a potential donor is identified.

Looking at the Government's proposal, they are planning to introduce

'soft opt-out with family consent'. What this means in practical terms is that the public will be offered the opportunity to 'opt-out' should they not wish to be considered potential organ donors. Everyone else is then considered a potential organ donor.

Let's not forget, to be a potential organ donor one must be in an ICU on a life support machine when declared brain stem dead – this immediately narrows down the pool of potential donors significantly.

According to the government's proposal, the families of all potential organ donors **who have**

not signed the opt-out register will be approached for consent to donate. This is no different to current practice (as stated).

Looking at the current system and the government's proposed system, family consent is at the core of both. A family is much more likely to consent when they know the wishes of their loved one. By focusing on an opt-out policy the government would remove a clear call to action in terms of sharing wishes with family – 'if I do nothing I will be considered a potential donor' – The donor card would become obsolete.



22%

of families consent when **NO** Specialist Nurse is involved in the formal organ donation discussion with the family



52%

of families consent when **Specialist Nurse IS involved, and potential donor is NOT signed up to the Organ Donor Registry**



92%

of families consent when a **Specialist Nurse IS involved, and potential donor IS signed up to the Organ Donor Registry**

WITH SPECIALLY TRAINED NURSES, AND AN OFFICIAL RECORD OF CONSENT, DONOR RATES ARE SHOWN TO RISE SIGNIFICANTLY

*Statistics from Potential Donor Audit UK, 2017-2018





LOOKING AT THE UK POTENTIAL DONOR AUDIT REPORT FOR 1 APRIL 2017 – 31 MARCH 2018

When a patient was known to have registered an opt-in decision on the UK Organ Donor Register the overall consent/authorisation rate was 92% compared with 52% when the patient had not registered an opt-in decision, or their organ donor status was not known at the time of the approach to the family.

When a Special Nurse for Organ Donation (SN-OD) was present for the formal organ donation discussion with the family the overall consent/authorisation rate was 71% compared with 22% when a SN-OD was not present.

The message is clear, the use of an opt-in Organ Donor Register and the involvement of Specialist Nurses for Organ Donation improves consent rates

significantly compared to when they are not involved.

What is also evident is that an annual Potential Donor Audit would bring into focus the policies that are working and the areas that need additional input.

The organ donor card has been helpful in initiating the family conversation about organ donation ever since it was first introduced by the Irish Kidney Association (IKA) 40 years ago. However, it does not give a record of an individual's decision. This is why the IKA is proposing that rather than restricting itself to an opt-out registry the government should also have an opt-in registry and thus, for the first time, offer a record of an individual's decision which would be available to the families of potential donors. We would move from asking the family for a decision to asking the family to confirm the decision of their loved one.

The time of potential

donation is very traumatic for the family of the deceased. If they can be given the reassurance that their loved one had signed an organ donor registry they are more likely to give consent as evidenced by the figures given above from the potential donor audit in the UK.

In 2017 in Ireland there were 99 deceased donors whereas in 2018 there were 80 deceased donors – approximately a 20% decline on the face of it. However, the figures can be misleading as we should be looking at the conversion rate from potential donors to actual donors each year rather than comparing actual donors as the number of potential donors is going to be different every year.

Already, we are seeing some very negative commentary online about the government's proposal. It is all misinformed but it is how certain members of society choose to view the

topic and the debate is getting caught up in general anti-government sentiment. Rather than seeking to confuse the public, the IKA is seeking to bring clarity to the topic and keep it focused on basic principles that have been proven to work. In the Netherlands we are seeing a backlash against their opt-out policy as people are not happy about the presumption of consent which is implicit in how the policy is promoted.

The IKA has been at the forefront of promoting organ donation for over 40 years and the Board's position on the best way to improve rates of organ donation has always been based on comprehensive research and experience. Science and medicine continue to make fantastic breakthroughs but it would mean nothing without the thoughtful and selfless consideration of organ donors and their families.

Letter to the Editor of the Irish Times...

On Government's Proposed Opt-Out Legislation

Printed: 4th February 2019

Sir, – While the Irish Kidney Association (IKA) in principle wholeheartedly welcomes the upcoming legislation to replace the current 1832 Anatomy Act with the Human Tissue Bill 2019, it does have certain issues with aspects of the proposed legislation in relation to organ donation.

The “urgent” need to replace the Anatomy Act became necessary following Ireland’s examination of its own post-mortem practices following the UK revelations unearthing retention of children’s organs in Alder Hey and Bristol in the late 1990s.

As a consequence, in 2004 the UK replaced its legislation on post-mortem practices and created the Human Tissue Authority.

The then-Minister for Health Mary Harney received an Irish report from Dr Deirdre Madden on the same subject in December 2005. That report highlighted that “presumed consent” was a major part of the post-mortem problems in retaining children’s organs in Ireland’s past.

Some 14 years later, ironically, recommendations are being made to legislate for a “soft opt-out system” – or presumption of consent system for organ donation for transplantation – in Ireland because almost every other European country is doing so. However, the health services in all European countries do not practise presumption of consent, of either the hard or soft variety. Without next-of-kin consent they do not proceed to donation – no matter how protected they are by legislation. Presumption of consent is proven not to be a practical organ donation consent system at the coalface.

Because of our various statements in connection with this debate, many of which are totally misunderstood, one often hears the IKA portrayed as being somehow “against organ donation.” Nothing could be further from the truth.

Indeed, in the proposed legislation Ireland does not intend to practice soft or hard opt-out or presumption of consent either. If you pass the headlines of the legislation and read through the actual provisions you will see how this is so. The IKA is very happy about this. Its only difficulty with the legislation is the setting up of an Organ Donor Registry for those that do not want to donate their organs without the registry having a positive section where people would be able to record their positive wish to donate organs in the same registry. We strongly believe this is a huge lost opportunity to improve the positive chances of the next of kin’s consent to organ donation. If the wishes of the deceased potential donor are known via a positive registry, the next of kin are far more likely to carry out the donor’s recorded wishes. The facts speak for themselves as has been found in the UK experience.

The most recent UK National Potential Donor Audit showed that the rate of consent was 68.6 per cent when a specialist nurse for organ donation was involved in the approach to the family. This dropped to 27.5 per cent when they were not involved. When the specialist nurse was involved in the approach and the patient was known to be on the organ donor registry as positively consenting at the time of potential donation, the consent rate of the family was 92.6 per cent.

Ireland does not have a potential donor audit or the specialist nurses that the UK has, nor does it have a public donor registry. We need all of the above if we are serious about improving the Irish deceased organ donor rates.

Following the EU directive on organ donation and transplantation in 2012, we now have a new organ procurement service called Organ Donation Transplant Ireland (ODTI). We now have a valuable addition of six specialist nurse champions for organ donation, one in each of the six areas of the HSE. The ODTI staff are doing a tremendous service but with very limited resources.

We are advocating for an adjustment to a very small part of this legislation – it does have financial implications as do the other essential elements mentioned above.

All concerned want to maximise potential organ donor identification in Ireland and its subsequent conversion into actual organ donors, but the cheap option that successive Governments have recommended, will be, I am afraid, a complete waste of valuable time. The fear is that the public will react to soft opt-out legislation if they think that their consent is going to be presumed, and they will simply say no to organ donation in the proposed register, because they object to the presumption of their consent. This reaction has been shown to be evident in parts of the UK and in the Dutch registries. – Yours, etc,

MARK MURPHY,

Chief Executive,
Irish Kidney Association,
Donor House, Block 43A,
Park West, Dublin 12.

Since this letter was printed, the UK has published an updated report from their Potential Organ Donor Audit - see previous page.



(l-r): Narendar with his teammates Stephan Martinez, David White and Alannah Murphy who won first prize at the Hatch Lab Start-Up weekend in Gorey

Katta's Kidney Transplant Success

Narendar Katta (35) from Lower Gardiner Street in Dublin underwent a kidney transplant at Beaumont Hospital in July 2018. He was first diagnosed with kidney failure in 2013 and his condition was managed carefully through medication until his renal function declined to a point where he had to commence dialysis treatment at the Mater Hospital. He was then moved to another dialysis centre, Fresenius at Clare Hall, in Dublin. Narendar underwent the treatment for close to three years for three hours at a time on three days of the week. He found it very tough, was sometimes in pain and felt completely sapped of energy most of the time.

Narendar, along with a team of three others, won first prize at the Hatch Lab Start-Up weekend held in Gorey, Wexford on March 3rd, for their concept to create an app for learner drivers and routes to practice. Narendar, who secured a Masters in Business, is now a consultant in digital

and social media marketing and web design. He moved to Ireland from his native India twelve years ago.

Narendar explains that "the kidney transplant has improved my quality of life greatly and I have my donor to thank for this. I now have more energy to participate in things that I enjoy doing. I can eat what I want to which I couldn't do before whilst receiving treatment. I have full freedom and can be more spontaneous now as I don't have to plan around dialysis treatment.

I enjoy playing badminton as a way of keeping fit, and I am looking forward to joining Transplant Team Ireland to compete in Badminton at the European Transplant & Dialysis Sports Championships when they take place in Dublin next year."

Narendar is an enthusiastic member of the IKA and has volunteered with the North Dublin branch for fundraising and distributing donor cards whilst on dialysis last year during Organ Donor Awareness Week and, he will also be helping out, as a volunteer, this year for the campaign, however, this time, as a grateful transplant recipient. Narendar also volunteers as a fundraiser for the Irish Cancer Society.

I am very grateful to my donor's family for giving me this opportunity. I attended the Annual Service of Remembrance and Thanksgiving, in Drumcondra last October, as a way of honouring my donor and I sent a card expressing my great appreciation to their family through the Transplant Coordinator at Beaumont Hospital.

{ "The kidney transplant has improved my quality of life greatly and I have my donor to thank for this." }

WALLS



By MIKE KELLY

**Mike can be contacted
at Donor House on
01-6205306
or by email:
mike@ika.ie**

What is it about us humans and walls? From time and memorial, we seem to like to construct walls! The Chinese, over two and a half thousand years ago, began constructing, what is now known as, the Great Wall of China. It was a mammoth task, over twenty-one thousand kilometres long – half the length of the Equator. There were obviously a lot of people the Chinese wanted to keep out...or keep in!

This need to build walls continued down the centuries. In the 1960's the East Germans built a wall to separate East Berlin from West Berlin. That remained intact until 1989. The Israelis have built a wall to separate themselves from their Palestinian neighbours. And now, the President of the United States proposes building a wall from the Gulf of Mexico to the Pacific Ocean! Some of us really do like building walls!

Throughout history, it seems walls were built to serve a number of purposes, including to keep people out – usually perceived as threatening – and to protect and keep people in – usually to create a façade or image. However, as history shows, the problem with walls is that they don't always fulfil the task for which they are built.

OUR INTERNAL WALLS

It's a funny thing about walls but they seem to draw us to gaze at them. Just think of the number of tourists who visit the Great Wall of China each year and the Berlin Wall was the focus of many who visited Berlin. These are external walls, ones we can see with our own eyes. What about other walls, internal or psychological walls, that may be far harder to recognise and see. Are they there? Of course they are, we all have them, we, after all, have constructed them! Some walls are positive and necessary. We construct them to protect us thereby making us feel safe and secure. But not all walls are positive. Some we construct, rather than protect us, can act like a prison, keeping us confined, imprisoned and alone.

We build many internal walls. They may not be one long wall but made up of a series of short walls, just like the Great Wall of China. I will highlight two by way of example.

One of the walls we construct we use to keep others at a distance, 'outside'. Those outside, on the other side of the wall, are perceived as threatening.

One of the threats imagined is the difference between the way we see ourselves and how others see us. Behind our wall, our image of self is predominantly negative which will

inhibit our ability to relate to others. We hide behind our wall out of fear that others might see who we really are or more accurately how we perceive ourselves to be. The reality for all of us – and we know this, although accepting it is a different matter – is that we are a mixture, with our good points and not so good points. Our wall prevents us from holding these two parts of all of us in tension.

If we feel insecure or have been wounded, or deeply hurt we build a wall to protect ourselves. This can be a very solid wall, intended to keep people out. This wall can be very divisive, keeping others 'on the other side' but also leading us to believe we are secure behind our wall. What keeps this wall solidly in place is our sense of insecurity and our difficulty in trusting the other out of fear of being hurt again.

Contained behind this wall are our fears, worries and anxieties. Perhaps the day will come when we will have the courage to peep over our wall to see if anyone is there, with hand outstretched, to help us. Perhaps then, we, with the help of others, can begin to reduce the size of our wall which will allow us to engage in healthy relationships that enhance our life rather than diminish it, which is what happens if we remain ensconced behind our wall.

SOMETHING TO THINK ABOUT

Do not let the past become a prison. We cannot change what has happened to us, all we can change is the way we look at it. Our past provides a bank of information, we should not think of it as a web in which we are caught.



It is helpful to remember that change can only be made in the present. This means accepting and seeing clearly where we are now. This means accepting reality. We may not like it but if we pretend it does not exist, nothing can change.

We cannot predict the future. A wall we construct protects us from the uncertainty of the future. We do not know what the future holds, much of it is outside our control, yet we can let it control both our thinking and our actions.

Let us not forget that we are products of evolution, of our social and cultural upbringing and of our psychological conditioning. We do not

even begin to become free until we recognise this.

A FINAL THOUGHT

It was John Cleese who said that the degree to which we face reality is a sign or yardstick for positive mental health. There is a lot of truth in this. To face reality, painful though that may be at times, involves reconfiguring our walls, bringing them to a size that allows us to protect ourselves yet at the same time allows us to behave differently, to be inclusive rather than distant, to engage in a healthier way with new ideas or new relationships.

'Voyages are accomplished inwardly, and the most hazardous ones, needless to say, are made without moving from the spot.'

– HENRY MILLER

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

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



The Mulligan family at Paula's twins christening last August. (Back, l-r): Michael and Breege, Lynda, Pamela and Mikki. Front: Julie, Susan, Paula and nieces and nephews.



Susan Mulligan (right) with housemate Anne-Marie Breen at Darkness into Light



Susan Mulligan

Life goes on for family with PKD

Susan Mulligan, originally from Castlerea, Co. Roscommon, now living in Islandbridge in Dublin, was diagnosed with Polycystic Kidney Disease (PKD) when she was in college after she sustained a sports injury. For over two and a half years she has been undergoing haemodialysis treatment at the Beacon in Tallaght.

Four out of six siblings in Susan's family have been diagnosed with PKD which is a progressive illness which can remain dormant for decades. Their father, Michael Mulligan, now aged 70, underwent a deceased donor kidney transplant 14 years ago. His transplant continues to be successful as he

enjoys his senior years with his wife Breege in their native Castlerea, Co. Roscommon.

Following Susan's diagnosis she managed to stave off dialysis treatment for over a decade as her condition was carefully monitored and treated through medication as well as lifestyle and dietary changes.

Three of Susan's sisters, Pamela, Julie and Paula, live in Wicklow less than 15 minutes drive from one another (in Aughrim, Avoca and Arklow). Their three husbands had been friends since before marriage. Susan's sister Julie, who lives in Aughrim in Wicklow, went into end stage kidney failure following the birth of her son two years ago.

Julie's declining kidney function is being carefully monitored and she may need to commence dialysis treatment soon and is awaiting her appointment to visit the renal team at Beaumont Hospital for referral onto the transplant waiting pool.

Pamela and Julie completed their PKD tests for a medical report which was required for their mortgage applications. Fortunately for Pamela, who lives in Arklow with her husband Neil and three sons, her tests came back negative for PKD. However, another sister, Paula, who lives in Avoca and was diagnosed with the disease, had experienced a temporary dip in kidney function after the birth of her twin boys last year but her kidney function has since improved and her condition hasn't progressed.

The oldest sister in the Mulligan family, Lynda, also has received a PKD diagnosis but she continues to enjoy good health while living in Rahen, Co. Offaly with her husband Nicky. The youngest member of the family and only brother, Mikki Mulligan, lives



Three sisters...Julie, Paula and Pamela who are all living in Wicklow.

in Canada and has not been tested yet for PKD.

Susan and her family are grateful to the family of their father's deceased donor transplant and are eager to share their story to support the annual

Organ Donor Awareness Week which aims to raise awareness about organ failure and encourage the public to support organ donation for transplantation and tell their next of kin their wishes.



SUPPORT THE WORK OF THE IKA

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



STANDING ORDER REQUEST FORM

To: The Manager of _____

(Your bank's name and address)

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

Signed: _____

Date: _____

Address: _____

PLEASE CHARGE TO MY / OUR ACCOUNT:

Name of Account: _____

IBAN:

Bank Identifier Code - BIC:

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

My regular

Monthly

Quarterly

Yearly

DONATION of Amount € _____

(Please tick as appropriate)

to start on Date: _____ / _____ / _____

AND CREDIT TO THE FOLLOWING ACCOUNT:

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

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

BIC NO.: **BOFIIE2D**

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

Please post to: **THE IRISH KIDNEY ASSOCIATION CLG, DONOR HOUSE, BLOCK 43A, PARKWEST, FREEPOST, DUBLIN, D12 PSV6**
(PLEASE DO NOT POST TO YOUR BANK)

CHARITY REG. NO. 20011260



THANK YOU FOR YOUR GENEROSITY

Spring into action

RENAL DIET TIPS THIS SEASON

Spring is a great time to press the reset button, recharge and kick start a healthier lifestyle. Use these 5 top tips to make some positive changes this Spring – your kidneys will thank you!

1. REDUCE SALT IN FAVOUR OF HERBS AND SPICES

Many people in Ireland consume too much salt. Salt is found naturally in many foods but up to 20% of salt consumption¹ comes from adding salt to our food and up to 70% can come from manufactured and processed food¹. A high salt intake can increase blood pressure, increase thirst, contribute to fluid retention and put pressure on your heart and kidneys.

Choose from the array of herbs and spices below to season and flavour your food the healthy way.

HERB	SUITABLE DISH
Rosemary	Lamb
Thyme, coriander, fennel, rosemary	Fish
Garlic, tarragon,	Chicken
Mint	Pork
Pepper	Potatoes, vegetables

Avoid salt substitutes (e.g. Lo-Salt, So Low) as these are high in potassium

2. FRUIT AND VEGETABLES

Spring is a great time of year to avail of fresh fruit and vegetables. Fruit and vegetables are a great source of many vitamins and minerals. However, many patients with chronic kidney disease are required to limit their intake of fruit and vegetable as they contain potassium and sometimes phosphate. But don't let this put you off – there are plenty of fruit and vegetables for you to enjoy, just make sure you stick within your allowance. As a general rule, most people on a renal diet can take 2 portions of the fruit and 2 portions of the vegetables listed below, each day. However, this can vary so discuss with your doctor or dietitian what is suitable for you.

EXAMPLES OF VEGETABLES TO HAVE

Portion
Carrots (boiled)
Cauliflower (boiled)
Broccoli (boiled)
Green Beans (boiled)

EXAMPLES OF FRUIT TO HAVE

Portion
Apples
Blackberries
Raspberries
Melon
Mandarin
Peach
Kiwi
Plums

Top Tip: Don't forget to drain the juice or syrup from tinned fruit before eating it!

FRUIT & VEGETABLES YOU MAY NEED TO AVOID DUE TO HIGH POTASSIUM CONTENT

FRUIT	VEGETABLES
Banana	Peas
Rhubarb	Beans
Dried fruit	Sweet corn
Dried Apricots	Avocado
Cakes or biscuits that contain dried fruit	Spinach

It is very important not to go over your daily allowance of fruit and vegetables if you have been advised to limit your potassium. Speak with your dietitian or doctor if you are unsure of how much you can have.



By NEASA FORDE
& EIMEAR KELLEHER
Beaumont Hospital
on behalf of the
Renal Interest Group of the Irish
Nutrition & Dietetic Institute.

3. SWAP OUT THE CHOCOLATE EGGS!

Easter is a big part of Spring and with Easter comes chocolate Easter eggs. Unfortunately, chocolate is high in potassium and phosphate, so it is not suitable if you have been advised to follow a renal diet. For a sweet treat why not opt for more suitable choices such as jellies*, marshmallows*, ice-pops* – or try our Berry Dessert below.

*may not be suitable if you are overweight or watching the sugar in your diet

MIXED BERRY CRUMBLE

Serves: 4

Prep Time: 10 min

Cook Time: 50 mins

Ingredients:

200g Raspberries
200g Blackberries
75g Plain flour
50g Rolled Oats
50g Brown sugar
50g Hard unsalted butter
½ tsp. Ground Cinnamon



Method:

1. Preheat the oven to 190°C / Gas mark 5.
2. Place the raspberries and blackcurrants in a small ovenproof pie dish and sprinkle with 25g of the sugar.
3. In a separate bowl mix the flour, oats, cinnamon and the remaining sugar together.
4. Cut up the butter or margarine into small pieces. Using your fingers rub the butter into the mixture until it forms a crumble consistency.
5. Sprinkle the crumble mixture evenly over the fruit.
6. Bake for 40-50 minutes, until the crumble is golden brown and the fruit juices are bubbling up at the side.

Per serving this dessert contains: 1 portion of fruit. Check your diet sheet to see what your daily allowances are and to see if you have enough fruit allowances left for this dish.

4. PREPARATION IS KEY FOR KIDNEYS!

Even with our best intentions, plans can sometimes fall to the wayside when life gets hectic. This can sometimes lead to us making unsuitable dietary choices simply because we aren't prepared.

Taking the time to prepare can save you a lot of hassle and stress in the long run and can help ensure that you are make healthy lifestyle choices.



- Make a list! Spend 30 minutes each week writing up a weekly meal plan and shopping list. Why not bring a notepad with you next time you have dialysis or when you are taking the bus.
- Batch cook. Make meals in advance and freeze them to use on another day. This means you will have suitable meals at the ready on those days when you are run off your feet.
- Get the family involved. When planning meals, get ideas from everyone else in the household and ask them to help with the preparation and cooking. Kids will love this and it will make meal times all the more enjoyable.
- Avoid shopping when hungry. We've all been in that situation when the hunger pangs hit as we walk down the confectionary aisle. Have a snack before shopping to help avoid impulsive food purchases. It will also help save on your shopping bill!

TOP TIPS:

Stock up on food storage containers of all shapes and sizes!

Check out <http://www.irishkidneydiet.ie/adapting-recipes/> for tips on adapting recipes to the renal diet

5. PUT A SPRING IN YOUR STEP!

Walking can be great for the body and the mind. However, only 41% of Irish adults get enough exercise each week². If you feel well and your medical team have given you the go ahead, why not grab a friend and get out and about walking this Spring. Not only will it help you to get your step count up but you can also enjoy all the new flowers this season brings. Even better, walking is free and if you find you don't have time in the day, even going for a few short ten minute walks during the day will benefit you!

Check out this useful website to find out your nearest walk ways and trails. <https://www.irishtrails.ie/>

Always discuss any increase to your physical activity level with your doctor.

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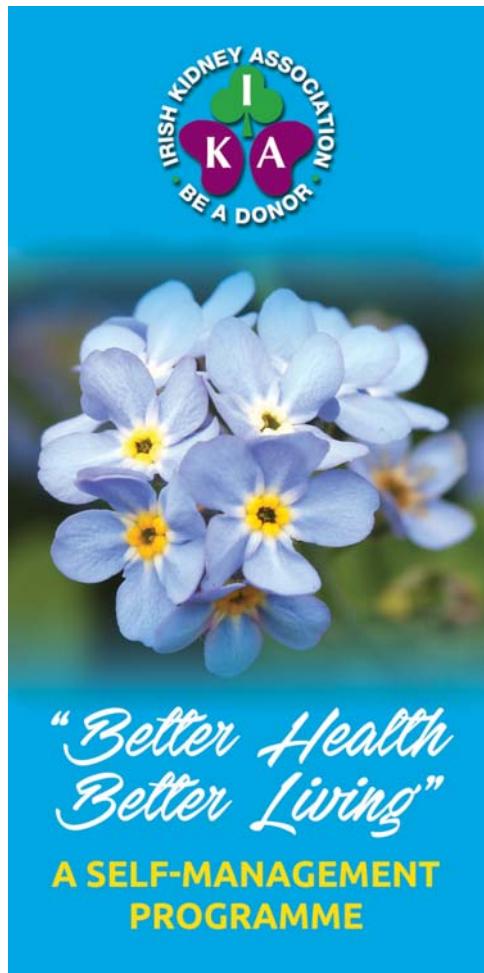
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Patients helping patients towards wellness

Sheena McDonagh, from Rochestown, Cork (51) and a native of Kilmallock, Co. Limerick, underwent a kidney transplant during Spring 2012 following four years of dialysis treatment. Since receiving her transplant she says, "I have enjoyed good health which is thanks to a deceased donor and I am working on keeping myself and my kidney well."

Sheena advocates for wellness and took part in an Irish Kidney Association Chronic Disease self-management course. She has just completed training with Beaumont Hospital as a facilitator on 'Better Health Better Living', for renal patients, their families, carers and friends.



Sheena and three other facilitators will be running these courses in Cork (away from a hospital setting) for patients, carers and friends. She said, "Patients have to manage their condition every day. Most time spent dealing with our health is not in a doctor's surgery or hospital, but how we live our lives affects our long-term health and quality of life. We want to choose to be active managers of our health, in both short and long term. Our role' as facilitators' is to help people to develop skills to manage their own on-going health conditions and to live a happier and healthier life."

Sheena advises that if anyone from the greater Cork area is interested in attending this course which is approx 2½ hours a week over 6 weeks, and which is free of charge, they can contact the Cork branch of the IKA, Siobhan Buckley (facilitator) 086-1621539 or email: secretarycork.ika@gmail.com

In 1997 Sheena's kidneys failed after severe pre-eclampsia when her son Daire was born at 27 weeks weighing in at 2lbs. Her kidney function came back but never recovered fully. Daire was kept in a neo-natal unit for two months before Sheena could bring him home. He is now 21 years old. Sheena also adopted a daughter from China called Mei who is now 16. She would like to let other people know that she is living proof that "Having chronic kidney disease isn't necessarily an obstacle to adoption depending on your personal health status and other circumstances."

Sheena's kidney condition was carefully managed for over a decade while all the time her kidney function gradually declined until the point when she needed to commence dialysis in 2008. She tried two forms of dialysis treatment which she

underwent in her home peritoneal dialysis first, which she underwent 4 times daily. Then she was switched to nightly dialysis treatment for 8-9 hours at a time.

Sheena explained, "While I am grateful that dialysis treatment was keeping me alive. I know different people have different experiences of it, while some are more positive than others, for me my energy levels were low and I was constantly tired, I couldn't plan, I didn't know how sick I might get and, if I was fortunate to get a transplant, how well I would feel afterwards. Another aspect was that I always had to plan ahead for everything working around my dialysis schedule. There were diet and fluid restrictions. My illness controlled how I led my life. The medical and nursing staff did their best to care for me and my family were very supportive.

"After having my transplant, I felt like a new person. I got my zest for life back. I could exercise which is something I couldn't do for years. All the 'brain fog' which I had while I was on dialysis cleared, the difference was like night and day. I appreciate everything so much now. Life is more spontaneous. Holidays had to be planned very carefully while I was on dialysis. Anything could go wrong. But now I am looking forward to going to Florida in June. I was able to hop on a plane in January and have taken several flights and holidays since my transplant.

"My transplant transformed my life in a very positive way and it was all because of my donor. I sent a letter to my donor family through the Transplant Coordinator expressing my immense gratitude for giving me a second chance at life!"

I have enjoyed good health which is thanks to a deceased donor and I am working on keeping myself and my kidney well.



VHI Women's Mini Marathon Sunday 2nd June 2019 at 2.00p.m.

Are you taking part in this year's VHI Women's Mini Marathon?

Please consider getting sponsored to participate on behalf of the **IRISH KIDNEY ASSOCIATION**

ENTER ONLINE AT
www.vhiwomensminimarathon.ie

CONTACT DEBORAH@IKA.IE FOR SPONSOR CARDS, T-SHIRTS, ETC.

Closing date for entries Friday 17th May, 2019
or when maximum number of entries is reached

IRISH KIDNEY ASSOCIATION
KA
BE A DONOR

Time to Move



Transplantoux, an organisation based in Leuven, Belgium, hosted their second annual Symposium, focused on promoting the value of physical activity pre- and post-transplant. The event brought together representatives of a wide variety of areas of medicine that are involved in the overall care and rehabilitation of people pre- and post-transplant.

After engaging with the organisers, it was agreed that the European Transplant & Dialysis Sports Federation (ETDSF) would deliver one of the keynote presentations over the two-day event. I was delighted to co-deliver a presentation with the President of the ETDSF, Judit Berente.

We focused on the important role that international organisations, such as the ETDSF and the World Transplant Games Federation (WTGF), and domestic organisations, such as the Irish Kidney Association (IKA) play when it comes to providing a vehicle for people pre- and post-transplant to engage in organised, and fun,

physical activity. We highlighted the importance of the social role in encouraging people to remain engaged in regular physical activity.

The Symposium offered a wonderful forum for the sharing of ideas and practices and allowed for all players to better understand how the bigger picture comes together. It was a great opportunity to get the message across that 'patients' do not only need to be the subjects of research, they can be partners in research too.

It is evident that there is growing interest in the importance of physical activity in maintaining, and improving, the overall health of people pre- and post-transplant. Organisations, such as our own, are well placed to play a role in determining and facilitating this important development.

It is particularly pleasing that the WTGF has broadened its horizon to look beyond competitive sport. The recent launch of its 'Refit for Life' programme is a great step forward in supporting those who are recently post-transplant and are looking to 'rehabilitate' so that they can get back to an active lifestyle.



By
COLIN WHITE



A World Transplant Games Federation Initiative

A Rehabilitation Program For Transplant Recipients

Would you like to get active post your transplant?

Would you like to improve the function of your whole body?

Would you like to enjoy a greater quality of life?

The Refit for Life! rehabilitation program is here to help you take those first steps....

The World Transplant Games Federation launches Refit for Life!, a 6 month online rehabilitation program aimed to help new transplant recipients take the first steps to get active and start enjoying an increased quality of life!

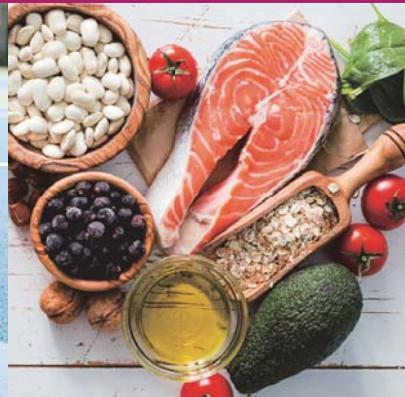
The Program includes:

- Progressive exercise programs
- Nutrition guidelines
- Mental wellbeing advice
- Assessment and Tracking tools

Start the program now!

Visit www.wtgf.org/refitforlife
for more information

Refit Reinspired Refocused





PARAMEDIC celebrates TRANSPLANT



Jason with his daughter

In December 1999, when living in New York, a young man Jason McKenna (20), from Clontibret, County Monaghan received a shock diagnosis from a doctor that his kidneys had failed and that it was vital that he would commence dialysis immediately.

As an illegal alien in the States, working on building sites with friends, he could not afford the medical care there and took the next available flight home. His room-mates and many of his friends from the Irish community rallied behind him and arranged for his ticket for a flight he had booked for three weeks later to be brought forward, and for him to be met at the airport with a wheelchair.

A concerned flight stewardess who had heard about the young man's plight decided not to tell the pilot until they were half way across the Atlantic Ocean as she feared that if she told him earlier, he might not allow him to travel.

When the plane touched down on Irish soil, Jason was rushed to Accident and Emergency at Beaumont Hospital where he was connected to a dialysis machine within hours of arriving.

He spent almost three weeks in Dublin and, by coincidence, was discharged on the same day he had originally booked his flight to come home for the millennium New Year.

He then became a dialysis patient at Cavan General Hospital where he underwent haemodialysis 3 times a week, for nine months, until one day in 2000 he received the anxiously awaited call from Beaumont Hospital advising that a deceased donor kidney had become available.

“This year I celebrate the 13th anniversary of my successful transplant. I hope there are many more anniversaries to come.”

Unfortunately, the transplant was not successful and failed almost straight away. Complications around this event left Jason in a critical condition and it was thought that he might not pull through.

Obviously, this was very disappointing for Jason and his family as it cast uncertainty on his health. Jason was also disappointed for the family of his deceased donor as their selfless gift, while grieving, didn't lead to a successful transplant.

His health settled down and Jason went back on dialysis for another five and a half years. As a man in his twenties he tried to maintain as normal a life as possible within the restrictions that his condition brought. He found it difficult, at times, watching his friends being able to travel abroad and do things that he was not able to do.

By 2005 his family members had started the process of being considered for living donation, and initially, he was hesitant. Eventually he came around to the idea but in January 2006 he hit another health setback and ended up back in hospital. It was soon after this that he was called again as a donor kidney became available. He was successfully transplanted in April 2006.

Jason's interest in pre-hospital care was sparked in 2005 by a friend of his who had an interest in pursuing it as a career. Jason went along with his friend to participate in a First Responder Course for a week, and during this time, he arranged to have his dialysis in Beaumont instead of at his usual treatment centre in Cavan General Hospital.

Jason then went on to do other courses, including the Emergency Medical Technician (EMT) in 2007, before securing a position on the Paramedic training programme in 2011.

Having worked as a Paramedic for several years he continued his studies in the University of Limerick and then on to University College Dublin where he completed the Advanced Paramedic programme in 2018. Coincidentally, one of his jobs was working with Lifeline Ambulance Service which transports transplant teams and coordinators around the country. He has also brought patients to Dublin for heart and lung transplants and he is currently employed by the National Ambulance Service.

Sadly, as part of his job he has also been called out to fatal road traffic accidents.

In expressing his gratitude to his donor Jason, who is now 40 years old, said, “Organ donation can mean different things to different people. As a transplant recipient, to me organ donation means an extended and normal life and being able to enjoy things that people take for granted. It also means the freedom to travel, to feel healthy and to make decisions without the constraints that constant medical care apply.

“Without my transplant I could not have the life that everyone takes as the norm, nor would I have been able to pursue my career in pre-hospital care and commit to the level of education I have achieved.

“I would not have the energy that my 4-year-old daughter expects from me and it's her energy that reminds me every day how life-changing, and how life-saving organ donation really is.

This year I celebrate the 13th anniversary of my successful transplant. I hope there are many more anniversaries to come.”

Know your Hospital...

THE FOLLOWING CODES ARE NOW BEING USED WIDELY BY HEALTH SERVICE PROFESSIONALS:

ACRONYMS	HOSPITAL NAME
BGH	Bantry General Hospital
BH	Beaumont Hospital
CGH	Cavan General Hospital
CHB	Connolly Hospital, Blanchardstown
CNOH	Cappagh National Orthopaedic Hospital
CUH	Cork University Hospital
CUHTS	Children's University Hospital, Temple Street
CWIUH	Coombe Women and Infants University Hospital
LCH	Louth County Hospital, Dundalk
LUH	Letterkenny University Hospital
MALL	Mallow General Hospital
MAYO	Mayo General Hospital
MMUH	Mater Misericordiae Hospital
MPUH	Merlin Park University Hospital
MRHM	MRH Mullingar (Longford/Westmeath General Hospital)
MRHP	MRH Portlaoise General Hospital
MRHT	MRH Tullamore General Hospital
MUHC	Mercy University Hospital Cork
MWRHE	Mid West Regional Hospital, Ennis
MWRHN	Mid West Regional Hospital, Nenagh
NCHT	National Children's Hospital, Tallaght
NGH	Naas General Hospital
NMH	National Maternity Hospital Holles St.
OLCHC	Our Lady's Children's Hospital, Crumlin
OLHN	Our Lady's Hospital Navan
OLOL	Our Lady of Lourdes Drogheda
PHB	Portiuncula Hospital, Ballinasloe, Co. Galway
RCH	Roscommon University Hospital
RHD	Rotunda Hospital
RVEEH	Royal Victoria Eye & Ear Hospital
SCH	St. Columcille's, Loughlinstown
SGH	Sligo University Hospital
SIVUH	South Infirmary Victoria University Cork
SJH	St. James' Hospital
SJL	St. John's Hospital Limerick
SLH	St. Luke's Hospital
SLK	St. Luke's General Hospital Carlow/Kilkenny
SMH	St. Michael's Hospital, Dun Laoghaire
STGH	South Tipperary General Hospital Clonmel
SVUH	St. Vincent's University Hospital
TUH	Tallaght University Hospital
UHG	University Hospital Galway
UHK	University Hospital Kerry (Tralee)
UHL	University Hospital Limerick
UHW	University Hospital Waterford
WGH	Wexford General Hospital



HOLIDAY ACCOMMODATION FOR KIDNEY PATIENTS AND THEIR FAMILIES



The Irish Kidney Association has three self-catering accommodation locations in Ireland...Tramore, Co. Waterford, Tralee, Co. Kerry and Killarney, Co. Kerry for peritoneal dialysis (**PD**), haemodialysis (**HD**) and kidney transplant patients (**TX**).

We operate all locations on a one week holiday basis from May to October.

In **TRAMORE** we have 4 apartments

Apartment 1&2 – Double bedroom, twin bedroom and sofa bed in living room – maximum 6 people.
Apartment 3&4 – twin bedroom and sofa bed in living room – maximum 4 people.

In **TRALEE** we have one

2 storey detached 4-bedroom house
for 1 patient and family
– maximum 8 people.

In **KILLARNEY** we have one 2 storey terraced

2-bedroom house for 1 patient and family
– maximum 4 people. The house is 25 minutes from
Kerry General Hospital. Not suitable for wheelchair users
as sleeping accommodation is upstairs.

More detailed information on each location will be forwarded to the attending holiday patient when dates are offered to them. A holiday support allowance of €150.00 is awarded to each patient on the holiday.

Please circle the start date of your 2 preferences below for Tramore, Tralee or Killarney.

If you are free to travel anytime please tick here

TRAMORE APARTMENTS – PD & TX					
MAY	JUNE	JULY	AUG	SEP	OCT
Sat	Sat	Sat	Sat	Sat	Sat
4	1	6	3	7	5
11	8	13	10	14	12
18	15	20	17	21	19
25	22	27	24	28	26
	29		31		

TRALEE HOUSE – HD						
MAY	JUNE	JULY	AUG	SEP	OCT	
Sun	Sun	Sun	Sun	Sun	Sun	
5	2	7	4	1	6	
12	9	14	11	8	13	
19	16	21	18	15	20	
26	23	28	25	22	27	
	30			29		

KILLARNEY HOUSE – PD, TX & HD					
MAY	JUNE	JULY	AUG	SEP	OCT
Sun	Sun	Sun	Sun	Sun	Sun
5	2	7	4	1	6
12	9	14	11	8	13
19	16	21	18	15	20
26	23	28	25	22	27
	30			29	

Have you enjoyed an IKA Holiday in Tramore or Tralee before

Yes

No

Name of patient: _____

Address: _____

Patient Phone No.: _____

Treating Hospital or Clinic: _____

Currently treated by: ✓ the box

HD PD TX

If you or your accompanying people have any special needs please bring them to our attention, e.g. visually impaired, wheelchair, commode, etc.

Tralee Holiday Home



Please give the names, age and relationship to patient of accompanying people

NAME:	AGE:	RELATIONSHIP

All completed forms to be returned to
deborah@ika.ie or by post to **Deborah Cervi**
 Irish Kidney Association,
 Freepost, Donor House, Block 43a,
 Park West, Dublin 12 P5V6.
 Tel: 01-6205306.

I understand my information will be kept on file for the duration of my holiday and deleted upon my return.



Killarney Holiday Home

Renal Support Centre Facelift

The Renal Support Centre in Beaumont Hospital is currently undergoing a facelift. The first job to be completed was the re-furnishing and decoration of the popular living room. This was greatly assisted by the team from Astellas, who kindly volunteered to undertake the work in both the living room and the painting of the kitchen.

What followed next was the addition of four extra car-parking spaces. The ten original bedrooms are also all acquiring fitted furniture and fixed bedside lighting. The lobby round room has been closed off by the addition of a new door and window. This will permit the return of a quiet public space for individuals and families when the need arises.

This week we removed and replaced the wheelchair ramp and steps at the front of the entrance and replaced them with a gradual slope from the door to the carpark. The garden patio is looking well after being power cleaned and re-grouted.

We will proceed to add raised flower beds in the patio area and the exterior of the building will be repainted. The kitchen is likely to be our next target.

It was necessary to take a number of rooms out of service while the work was going on. There is a further month's work left in order to complete the refurbishments. May I extend thanks to those of you for tolerating disappointments when we had no rooms available. I am sure you will enjoy the improvements when the Centre settles down after the works are completed.



Creative MEGAN Thanks PLAY SPECIALIST

Megan modelling her make-up art



My name is Megan Carter and I live in Dublin. When I was three-years-old my parents were told that my kidneys were failing.

Growing up I had many operations to try and fix my renal problems but nothing worked.

When I was eleven-years-old I was put on the transplant list. It was only four weeks later that my parents got the important call from the Transplant Coordinator that they had found a match.

I remember being scared and not fully understanding what was going to happen but I went into the hospital hopeful that I would come out to be like everyone else my age.

Sadly, only eight hours after the transplant it went into rejection with my whole body fighting to reject the kidney. I was in hospital for one month recovering and in that time I experienced so much anger and betrayal but my loving parents were there to try to console and support me.

But that's when Olive came into my life.

Olive was a Play Specialist in Temple Street Hospital and she became my best friend during many hard times. I was used to being poked and prodded but it was a sense of relief when Olive came to me, with a box of art supplies. I strongly believe that if it wasn't for Olive I wouldn't be doing what I love now – drawing and doing make-up.

My mental health really took a toll on me while I was recovering and it was very comforting to have someone there who wasn't only present to try to help me get better but to also bring out my creative side and to distract me from everything that was going on with my physical health.



Megan modelling her make-up art



Olive wasn't just a Play Specialist, she was my friend.

I spent three long years on dialysis and during this time I looked forward to seeing Olive and drawing alongside her while I was waiting for my transplant.

In 2013 when I was only thirteen-years-old I was put on a trial to be the first person under 18, in both the UK and Ireland, to receive a kidney transplant from someone who wasn't a kidney donor match (due to my 100% antibodies build-up as a result of my failed transplant). My dad had stepped up to be my donor.

I had to fly to London to undergo several treatments over a week to remove the antibodies from my body. It was called desensitisation.

I feel very lucky that it worked!

I flew back to London again later in the year to receive my

kidney transplant from my dad on April Fool's Day!

I will always have some antibodies and I will always be high risk with bumps in the road but I'm so grateful and lucky to have received this life-changing transplant and for it to have worked.

I spent three months recovering in London and the Play Specialists there kept my spirits up by drawing with me, and as wonderful as they were, they were no Olive!

This year I will be five years post-transplant and I am about to start a make-up course. I'll be able to take my art skills from my hospital bed into the real world.

To Olive, all the medical and nursing staff and my parents who cared for me along the way I will be forever grateful.



{ I strongly believe that if it wasn't for Olive I wouldn't be doing what I love now – drawing and doing make-up. }

TRANSPLANT
SPORT



the Westfield Health
**BRITISH
TRANSPLANT
GAMES**
Newport 2019

BE PART OF THE GAMES

N E W
P O R T
2 0 1 9

britishtransplantgames.co.uk

The IKA will be
sending an Adult & Junior
team to the games.
Contact: Colin in Donor House
for more information
if you are interested.

NEWPORT

25
JULY
28

SOUTH WALES



Llywodraeth Cymru
Welsh Government



ANTHONY
NOLAN

saving the lives
of people with
blood cancer



NEWPORT LIVE
CASNEWYDD FYW





Runforalife.ie

2.5km, 5km or 10km

A FUNRAISING DAY FOR ALL THE FAMILY

Saturday, 25th May - 2.00pm

CORKAGH PARK, CLONDALKIN, DUBLIN



WALK

JOG

RUN

TO REGISTER LOG ON TO:

www.runforalife.ie

**LIGHT SNACKS
AVAILABLE
AFTERWARDS**

REGISTRATION

ADULT: €20.00

CHILD: €10.00

FAMILY: €45.00

(up to 2 adults and 4 children)



Or contact:

Colin in Donor House

Tel: 01-6205306

Email: colin@ika.ie

CHARITY REGISTRATION NO. 20011260

All finishers
will receive
a medal

**T-Shirts will
be available
on the day
for €5.00**



More details will be posted on the IKA's Facebook page and the IKA website: www.ika.ie

Mother's pride as late

Son saves lives



My name is Tracey and I am the proud mother of two children. My beautiful daughter Kayleigh will soon turn 25 and my handsome son Conor is forever 9 years old. He died a few days before his birthday in February, 2008 and was buried on what should have been his 10th birthday. This is his story...

When Conor was born, it was a huge shock to discover that he had Hydrocephalus (a condition in which fluid accumulates around the brain, enlarging the head and sometimes causing brain damage) and a unilateral cleft lip and palate. The nurses were anxious that I bonded with him. They need not have worried - I loved him from the first minute I saw him!

I soon learned that the prognosis for his future was grim. Doctors agreed that even if he lived for longer than 24 hours, the damage to his brain was so severe that he would never walk, talk, or even smile. Conor proceeded to prove them all wrong and together we started out on a long road of surgeries, at Beaumont and Temple Street Children's Hospital, first to release the fluid around his brain and

then later to repair the cleft in his lip and palate.

Despite all of this, Conor grew into an amazingly happy, friendly little boy. He did walk, he did talk and he never stopped smiling!

Conor, Kayleigh and I lived a happy life in Blessington, Co. Wicklow. He started his schooling



Tracey and Conor

at a special school in Tallaght but soon moved to St. Mary's National School in Blessington where I worked – and still work – as a special needs assistant.

As Conor grew, we had regular trips to Temple St.

mainly for outpatient appointments... and so it was to Temple Street that Conor was taken when he and I were involved in a car accident in February 2008.

His injuries were catastrophic and he never regained consciousness. When I was taken to him after the accident, I knew without being told that he was gone. He was still breathing because he was on a life-support machine, but his light, his spirit, his soul had gone...and so, when organ donation was mentioned I didn't even hesitate.

Conor had gone but his body was left behind, so why would



Kayleigh and Conor

we not try to squeeze even an ounce of positivity and meaning out of his death?

In February 2008 Conor donated his heart and kidneys and saved the lives of three people. I received three incredibly moving letters of thanks in the months following his death and they still pick me up, on the bad days.

Conor would have celebrated his 21st birthday in February this year. Kayleigh and I have never

gotten over the Conor sized hole left in our lives, but we carry him with us in our hearts - safe, warm and always smiling.

In the 11 years since his death, his organ donation has been a great source of comfort to me as a mother.

Every October we go to Corpus Christi in Drumcondra for the IKA Service of Remembrance & Thanksgiving and we reflect on the amazing gift that organ donation is, for



Conor

donors and recipients alike. This gathering is a hugely significant part of our year now, as important as birthdays or Christmas.

I am forever grateful to the IKA for honouring my boy and all of the other

organ donors and recipients in such a special way.

Even on the darkest days, there is a chink of light in knowing that Conor's death has saved three lives. I am the proudest mother in all of Ireland.

New Stamp for Organ Donation

**Be an Organ Donor
Save Lives**

- Get a donor card.
- Sign it.
- Tell your next of kin.

Find out more about our stamps at irishstamps.ie
To learn about being an organ donor, visit hse.ie/organ-donation

POST

An Post has launched a postage stamp to promote Organ Donation. The Minister for Health, Simon Harris, was present on March 21st to unveil the new stamp, at the GPO in O'Connell Street, Dublin.

The symbolism of a sand timer, in the shape of two hearts, is very clever and with the sand running out, it gives a sense of urgency.

On the right side of the top of the stamp there is a symbol of a mobile phone. This can be scanned by a special app (CEE App) available free in App stores. In this case it leads you to the ODTI website.

As a follow-on, An Post's 950 post offices have received organ donor cards for their customers. Hopefully, this addition to the donor cards' availability to the public will continue long into the future.



EUDONORGAN SOCIAL AWARENESS EVENT



'Why Organ Donation Matters to Us All'

The EUDONORGAN social awareness event "Why Organ Donation Matters to Us All" was held on February 18th at the European Parliament in Brussels.

The EUDONORGAN project is a European level programme aimed at increasing rates of organ donation across the continent. The focus is on two main actions: training and social awareness. Both activities are oriented to healthcare professionals and other relevant players such as patients and patient support groups; representatives of public and governmental agencies, representatives of health institutions, opinion leaders and the media.

Organ Donation and Transplant Ireland staff and our own National Projects Manager, Colin White, previously engaged with the training phase of the programme.

'Why Organ Donation Matters to us all' was the third social awareness event organised within the project. It was hosted in the European Parliament in Brussels and was attended by 120 healthcare professionals and other relevant stakeholders coming from 33 countries.

Mark Murphy attended representing the European Kidney Patients Federation. Colin White was there representing the European Transplant & Dialysis Sports Federation, the World Transplant Games Federation and as someone who had completed the EUDONORGAN training programme.

Robyn Black, our Digital Media Coordinator, was there representing the Irish Kidney Association given that an important element of the day addressed the role of social media in promoting organ donor awareness.

It is encouraging to be part of a progressive, multi-disciplinary



approach to the promotion of organ donation. There is a growing understanding amongst the medical fraternity of the value that patients and patient advocates bring to the table. We got to hear some powerful testimonies from people on the day that could not but motivate the audience.



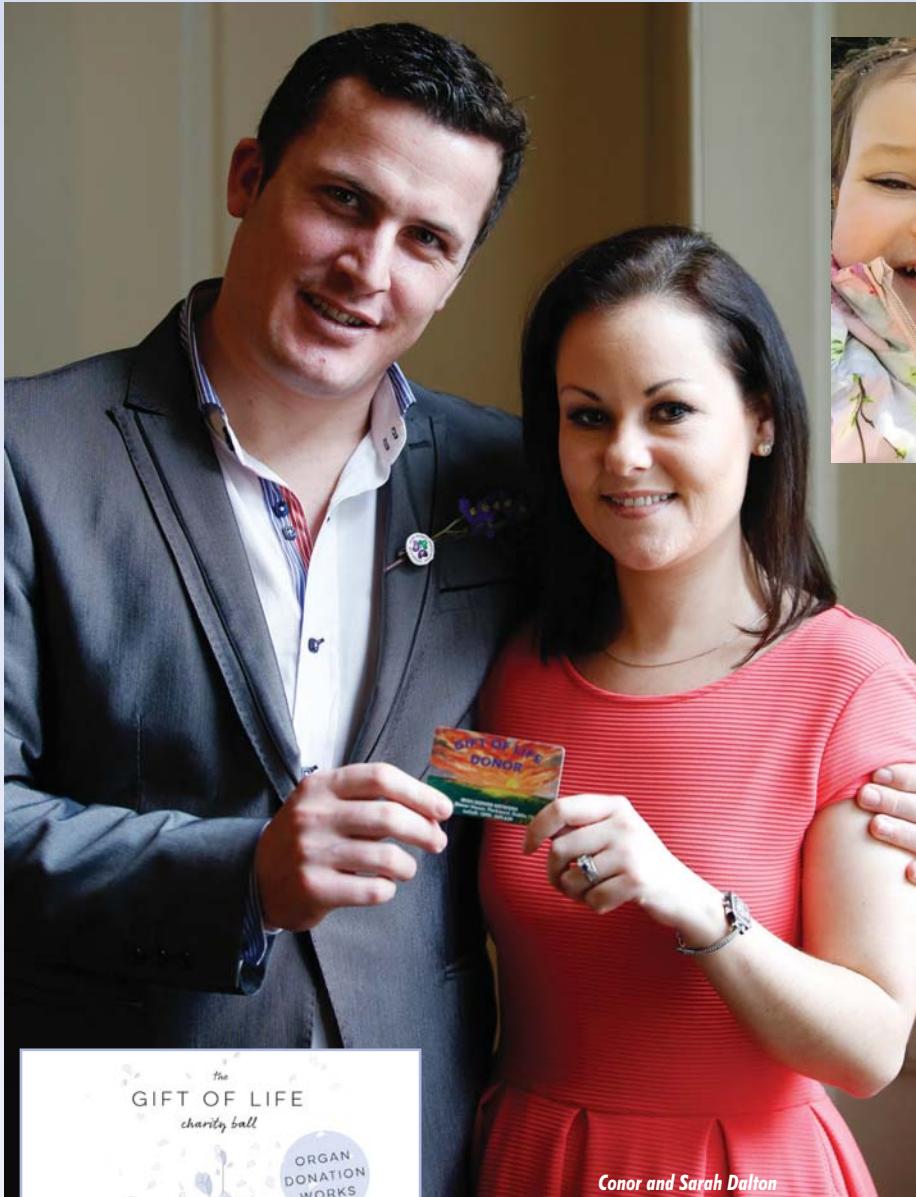
Colin White



Robyn Black

The value of an event such as this is the opportunity to keep up-to-date with best practice in other countries and to develop contacts across Europe who may be useful in advocating for new approaches or services in Ireland.

Giving back for GIFT OF LIFE



Anabelle, Sarah and Conor

Like my first transplant, the second transplant gave me my life back which enabled me to live normally again. I am now healthy, able to work and also the proud mother to a beautiful daughter Anabelle.

I am fully aware of what it means to be a kidney transplant patient in Ireland and want to give back to the Irish Kidney Association (IKA) which offers support, comfort and advice to patients and families.

This is why I am organising the Gift of Life Charity Ball in aid of the IKA to help raise funds and awareness for this wonderful organisation as well as increasing awareness about the life-saving legacy of organ donation.

The Gift of Life Charity Ball will be a Black Tie event and will take place at the luxurious Castleknock Hotel on Dublin's northside on Friday, 27th September 2019.

The event will commence with a drinks reception at 7pm followed by a sumptuous three course meal at 8pm and live entertainment.

For further information and tickets contact giftoflifecharity@gmail.com and tickets are also available on www.eventbrite.ie

the GIFT OF LIFE charity ball

ORGAN
DONATION
WORKS

27 SEPTEMBER 2019
7.30 drinks reception
8.00 three course dinner
live entertainment

Castleknock Hotel, Dublin 15

Tickets for this black tie event available on www.eventbrite.ie
Contact giftoflifecharity@gmail.com for other payment options and donations

IN AID OF
IRISH KIDNEY ASSOCIATION

My name is Sarah Dalton and I have had two kidney transplants. I received my first transplant when I was seventeen years old from a deceased donor. My second transplant was from a live donor, my husband Conor in 2013, two years after we were married. I was on home dialysis every day for a year, however, my health deteriorated quickly during this time.

SOCIAL MEDIA & COMMUNICATION



By ROBYN BLACK

Charity Campaigns in the Social Age

As we approach Organ Donor Awareness Week 2019 – and my first at the helm of the IKA's social media – I've found it valuable to look at how the right social media strategy can impact a campaign. Almost everybody uses social networks; they're as much a part of how we communicate with one another as real-world conversations. You can engage and inform in much more effective ways than before, which is very good news when it comes to charities.

As with many other things, the best way to understand the impact that you can have is to look at the examples set by others.

One of the most successful examples in this case is the Ice Bucket Challenge, a campaign coordinated by the ALS Association. You'd find it hard to come by someone who didn't take part in, or at least hear of the challenge – it left everyone from Bill Gates to George W. Bush shivering and drenched, before nominating their friends to do the same.

The premise was simple, as the best viral campaigns often are. It encouraged and rewarded audience



participation, it had a hashtag/tagline that was easy to remember, and it made use of rich media (i.e. video) which is known to increase success rates by up to 30%.

Dismissed by some at the time as 'slacktivism' – where

something appears to 'do good' whilst actually achieving very little – in only one month the challenge raised more than €104 million – money which actually led to a breakthrough in ALS research.

robyn@ika.ie
@IrishKidneyAs (Twitter)
@IrishKidneyAssociation (Facebook)
@irishkidneya (Instagram)

Of course, such a successful campaign is hard to replicate. More often than not, these viral campaigns are the result of luck more than planning – catching the eye of a celebrity, or campaigning in reaction to a disaster of some sort are always guaranteed some level of success. When it comes to Organ Donor Awareness Week we are lucky to have a strong network of supporters who are ready and willing to spread our message, which gives us a head start.

So how can you help? Engage! Share posts, encourage your friends to do the same and make it clear what you're campaigning for. Use hashtags, tag the IKA's pages and if you have some great photos or videos you think we'd love to see, let me know.

We all know the saying; if you throw enough mud at the wall, some of it will stick. In this case, if you throw enough Donor Cards at people, someone is bound to get the message – and that's good enough for me!

Some hashtags you might find useful for Organ Donor Awareness Week 2019:
#DonorWeek2019
#ShareToSaveALife

NOTICE OF THE IKA



AGM

The Annual General Meeting of the Irish Kidney Association CLG will be held in the **RED COW MORAN HOTEL DUBLIN, NAAS ROAD, DUBLIN 22**, on **Saturday June 29th** at **2.00pm**

Members can propose Motions and Resolutions for the AGM, which must also be seconded by another member. These **SIGNED** Motions and Resolutions must arrive, by post, at Head Office, by **WEDNESDAY, MAY 22nd, 2019**.

By **MONDAY, JUNE 3rd, 2019** Donor House will send, by post, Notice of the AGM, including the Agenda, Election of Officers, Motions, Resolutions and Proxy Voting Forms to all members. These will also be sent electronically to members who have given us their email address. The accounts will be available from the IKA website on **MONDAY, JUNE 3rd, 2019**

All **SIGNED** Proxy Voting Forms and questions on the Accounts, must arrive, by post, to **Donor House** by 5pm on **FRIDAY, JUNE 21st, 2019**.

THE AGM IS ONLY OPEN TO MEMBERS OF THE ASSOCIATION.

PATIENT CONFERENCE JUNE 29th, 2019

The **Patient Conference** will commence at **11.00am**, before the AGM of the Irish Kidney Association CLG, in the **Red Cow Moran Hotel, Naas Road, Dublin 22**.

The Programme for the Conference will be published on our website and sent to the branches, in plenty of time for you to make your decision to attend. Patients, carers and healthcare professionals are all welcome. You do not have to be a member of the Association to attend the Conference. Numbers will be limited so we would kindly ask you to register your intention to attend, which will include lunch between **1.00-2.00pm**.

There will be a place on the website to register for the Patient Conference but if you would prefer communication by post please make your interest known to Ashling at Donor House, **01-6205306**.

• AROUND THE BRANCHES •



Peter Shortall, Castlebridge, Wexford, a kidney transplant recipient, celebrated his 80th birthday recently. He requested donations to the Dialysis Unit at UHW, in lieu of presents. Peter presents a cheque for €1,395 to Sister Margaret and Sister Brenda at the Dialysis Unit. Happy birthday Peter and congratulations!

The annual Christmas swim took place on Christmas day in Ballinsker. €300 was collected and many thanks to all who took part and braved the elements including our chairman Liam Buttle.

The launch of the Wexford Credit Union 5k Night Run took place on the Quay front in Wexford town on Thursday, January 24th. Members of the Wexford branch and The High Meadows Community Centre Hub, who are the two beneficiaries this year, were in attendance together with the main sponsors Wexford Credit Union.

Almost 500 people took part in the 5k Night Run on Thursday February



Members of Wexford IKA branch, Wexford Credit Union, High Meadows Community Centre Hub at the launch of the 5k Night Run.



Busy day in the registration tent on Thursday February 28th, getting ready for the 5k Night Run

28th. It started with a party atmosphere on the Quay. The Mayor of Wexford, Tony Dempsey, gave the starting signal while David Kelly kept the music going

The organiser David Martin thanked all the generous sponsors, the organisations who helped out with traffic and the stewards who gave

their time on the night.

B Braun Wellstone, Renal Care Centre, Wexford is now opened one year and has completed 4,000 dialysis treatments during its first year in Wexford. The centre now operates 6 days a week caring for 40 patients who previously had to travel to Waterford and Dublin.



A big hello to our members and family and friends in west and east Wicklow and east Dublin. Hopefully we have all arrived safely from a long Winter into the beauty and promise of Spring.

As always we think of our members coping with ill health or anxiously waiting for a much needed transplant, and hope you get good news very soon.

Gloria Proby invited our branch to attend a presentation of a cheque for €600 from the very kind people of the Gorey Bridge Club. John Whelan, National Chairman, travelled down to receive the cheque, on behalf of the branch. A big 'thank you' to one and all.

The Rotary Club of Sligo presented a cheque for €2,300 to the IKA and John, as National Chairperson accepted the cheque.

On March 5th, John and Una Whelan, Catherine Foley and Michael Dwyer participated in the annual Health Fair in St. Vincents Hospital, answering questions and distributing books, leaflets and donor cards - a very worthwhile event.

On March 19th our branch gave a presentation in Bray Library about Organ Donation.

As we head towards Organ Donor Awareness Week, a very important

DUBLIN EAST & WICKLOW

By BERNIE DWYER



John Whelan accepting a cheque for €600 from Gorey Bridge Club.



Noeleen Cleary, Una Whelan, Joan Dobbyn, Catherine Foley, Michael Dwyer at our last branch support meeting in St. Anne's Resource Centre, Shankill.

and busy time in all the branches, we earnestly appeal for volunteers. Please can you give one or two hours to help us, if so, do contact 086-1673467.

We particularly need people from West Wicklow to become involved and as we have four Aldi stores to

man in Bray, Sallinsoggin, Sandyford and Frascati on March 30th, all help would be greatly appreciated.

As we start a new year with Ray D'Arcy as our new Ambassador, we wish you all a very happy and healthy Easter.

DUBLIN SOUTH BY LENNY RYAN

The most recent meeting of the Dublin South branch was held on March 13th, in Donor House. We will have our Organ Donor Awareness Week collection and distribution of organ donor cards in The Square Shopping Centre in Tallaght on Saturday March 30th. If enough volunteers come forward we could also avail of the Aldi Belgard invitation on the same day.

We hope to have a presence in Tallaght University Hospital on Tuesday April 2nd, all day.

If you are reading these notes in time and would like

to volunteer for 2 hours on either dates please give me a call on 087-2328342.

The AGM of the South Dublin Branch is taking place on Wednesday April 10th in the Plaza Hotel, Belgard Road, Tallaght, Dublin 24 at 8pm.

Mike Kelly, the IKA Renal Counsellor in Head Office, is the guest speaker. I hope there will be a good attendance. Elections for branch Officers and Board member will be taking place at this meeting.



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SLIGO IKA BRANCH

The Irish Kidney Association Sligo branch wishes to thank the Inner Wheel Club and Rotary Club of Sligo for their generosity in hosting a recent fundraiser in the Radisson Hotel Sligo. All proceeds from the lunch, auction and raffle went to the Sligo IKA branch.

The large attendance enjoyed a delicious four-course lunch in The Benbulben Suite, followed by a fabulous display by the McMorrow troupe of young dancers.

Chairperson of Inner Wheel Sligo, Mary Horan and President of Rotary Club of Sligo, Una Dunne Shannon welcomed the guests.

The IKA National Chairperson John Whelan outlined the great work of the organisation in supporting kidney patients and their families. John received a new kidney eleven years ago.

IKA board member and Sligo branch vice-chairperson Marie Fowley, Hazelwood, told her personal moving story of receiving a kidney and pancreas transplant eight years ago.

Both speakers stressed the necessity for people to carry organ donor cards and to have the 'donation' conversation with their families.

There was a generous response to the auction with George Draper putting several items donated by local businesses 'under the hammer'.

ORGAN DONOR AWARENESS WEEK

Several activities are taking place in Sligo to mark Organ Donor Awareness Week. The main fundraising event is on Saturday, April 6th, when there will be collections all around Sligo town's

SLIGO

By BRIAN McHUGH



(L-R): Geraldine McHugh, Secretary Sligo IKA, John Whelan, IKA National Chairman, Una Dunne Shannon, President, Sligo Rotary Club, Mary Hogan, Chairperson, Inner Wheel Sligo, Mayor Rosaleen O'Grady, Martina Brennan, kidney recipient, Ita Leydon, Sligo IKA, Marie Fowley, Vice-Chair, Sligo IKA and Sean Fowley, Chairman, Sligo IKA.

main streets. Any volunteers available to help would be most welcome.

Other activities include:

Saturday, March 30th, collection at Aldi store, Cranmore.

Tuesday, April 2nd, Information desk in Tesco Arcade, O'Connell St.

Thursday, April 4th, Information desk in Quayside shopping centre.

Friday, April 5th, collections in Ballymote and Collooney.

There are other activities in the pipeline, details of which were not available at time of this magazine going to press.

The local launch of the week took place on March 19th. The launch was performed by Mayor of Sligo, Rosaleen O'Grady, who is a founding member of the Sligo branch.

Cllr. O'Grady did the honours at the IKA Garden of Reflection at Doorly Park, followed by a mayoral reception in the Mayor's parlour in City Hall.

The Sligo branch are looking forward to a successful Organ Donor Awareness Week after two local dialysis patients having received kidney transplants in 2018.

DIARY DATE

The IKA Sligo branch AGM is on Tuesday, April 16th at 8pm in the Glasshouse Hotel. New members welcome.

SOCIAL MEDIA

The Sligo branch has a new Twitter page. Check it out at @IkaSligo. This is in addition to our popular Facebook page.



Dancers from the McMorrow Dance School who put on a display at the event.



ORGAN DONOR AWARENESS WEEK

Organ Donor Awareness Week takes place from March 30th March to April 6th. We appeal to our members, their families and friends, to help promote the Donor Card during this week. The promotion of the card, together with the sale of merchandise and 'Forget-Me-Not' emblems takes place at various locations around the county including Kilrush, Ennis, Shannon and Killaloe on selected days during the week. The campaign highlights the need for organ donation. Your assistance will be greatly appreciated as the funds collected go to the IKA's many projects in support of renal patients. Please ring Mary Abbott at 085-1245874 or Peggy Eustace at 087-9392148 to choose a location close to you.

WEST CLARE WALK

The Clare Branch 'West Clare Walk' will take place in Kilrush on the May Bank holiday Sunday, May 5th at 3pm. The route will be the same as last year,

CLARE

By MICHAEL MESCALL



Mark Murphy, IKA CEO, Carmel McCormack, Martin Keogh and Vincent O'Halloran at the Clare branch Christmas social.

commencing at The Square in Kilrush, heading out the N67 Ferry Road along the Wild Atlantic Way towards Aylvaroo and returning to Kilrush via Cappagh situated on the coast. Splendid views of the island's Loop Head and Kerry are to be observed on route.

The Branch Committee, under the Chairmanship of Vincent O'Halloran, raise funds for IKA projects to benefit both Clare and countrywide patients. The Committee look forward to you joining them for the event and afterwards at Teach Ceoil for refreshments.

Sponsorship cards will be available shortly from Vincent O'Halloran, 086-0854834; Geraldine Grace, 087-9716814; Carmel McCormack,

086-1500657 or Peggy Eustace on 087-9392148. The event is now in its 21st year and has proved highly popular with the walkers who come from far and near over the years .

CONGRATULATIONS

The Branch wishes to take this opportunity of congratulating Aimy Moynihan on her recent kidney transplant and wish her good health and happiness.

FUNDRAISING

A recent pub quiz in Doolin, organised by Ciaran Fitzgerald raised €402. This money will go towards IKA projects and patient care . The branch wishes to thank Ciaran for his work in raising these funds.



Mark Murphy, IKA CEO, Fidelma Begley, Clare branch, Michael Begley, Cathaoirleach Clare Co. Council, Gerry Moran, Clare branch Treasurer and Peggy Eustace, Chairperson, Clare branch at the Clare branch Christmas social.



Deputy Lord Mayor, Cllr. Thomas Moloney and Sinead McGrath, main organiser, are pictured with this year's participating dancers



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Hello to all our members' families', patients and our loyal readers.

YOUR BRANCH NEEDS YOU

A Branch is only as strong and as good as its members. Even though our membership has grown in the last number of years that strong growth has weakened lately. We are asking members, who are attending clinic, to talk to the person beside them and ask if they are familiar with the Irish Kidney Association and what is available to them. We will have a welcome pack to give out to them once contact is made with them.

WELLBEING AND HAPPINESS COURSE

Our newly qualified instructors for the Wellbeing course will commence

CORK

By PAT O'SULLIVAN

their first course on April 11th at 6.30pm. They are still looking for participants and if you are interested please contact the Secretary on 086-2755754 or via email on secretarycork.ika@gmail.com. See special notice inside this magazine inviting you to attend.

SUPPORT CENTRE, BISOPSTOWN, CORK

Plans for the Support Centre are still progressing. We will publish photos of the house as soon as the renovations start and issue regular updates through our Facebook page and our WhatsApp group.

SUPPORT MEETINGS

Our support meetings continue to grow with more and more member participation. Our February speaker, Fiona Byrne, a dietitian from the Renal Department in CUH, spoke of the importance of diet. The talk was so successful that Fiona intends to come back to do a second talk for us because there were so many questions on the night.

Our March meeting, the last one for the outgoing Officers, was attended by a very good crowd despite the horrendous weather conditions on the night. IKA CEO Mark Murphy and National Chairman John Whelan both attended and gave members an update on some national

issues. Mark advised the group that patients on the Transplant Waiting List would receive a letter from Beaumont hospital about new changes to the Kidney Transplant Waiting Pool.

FUNDRAISERS 2019

In April we are holding a Broadway show in the Rochestown Park Hotel. All the dancers know their dance partners after a very successful launch in City Hall Cork, hosted by the Deputy Lord Mayor. All the money raised on the night will go towards the renovation of the Support Centre and its upkeep. Training for the dancers has started and we are all looking forward to the big performance on April 13th.

Anybody interested in attending the event should contact Veronica at 086-1999862. The show includes two kidney transplant patients, family members of transplant recipients and nurses and staff from the CUH.

On June 14th we will be holding our now annual Golf Classic in Mitchelstown Golf Club. The Classic is going from strength to strength but, in order for it to grow even more, we need your help. We need all our members to help get sponsors and teams for the day.

More details of both events will be posted to each individual member of the branch.

A huge thanks to the Drinagh Tractor Run and the 4C Bandon ladies' group who had fundraisers recently for the branch and for the house. The Bandon 4C ladies would like their contribution to go towards buying tables and chairs for the house.

ORGAN DONOR AWARENESS WEEK

Once again, this year, volunteers will be able to collect at Aldi on Saturday April 6th.

Our launch night will take place in the Rochestown Park Hotel Cork on Thursday March 28th at 6.30pm. All members and families are invited to attend and if you think you can still help during Organ Donor Awareness Week do please let us know.

ANNUAL GENERAL MEETING

Our Annual General Meeting takes place in the Rochestown Park Hotel on April 9th at 8pm. It is an election year so if you are interested in running for Chairperson, Secretary, Treasurer or Board member please let the Secretary know before the night.

DATES FOR YOUR DIARY

Organ Donor Awareness Week Cork Launch

March 28th, Rochestown Park Hotel 6.30pm.

Organ Donor Awareness Week

March 30th to April 6th.

AGM

(Election of Officers)

April 9th, 8pm

Rochestown Park Hotel.

Broadway Musical Night

13th April, 8pm

Rochestown Park Hotel.

Support Meeting,

May 7th, 8pm

Rochestown Park Hotel.



Isabel Terry, Miriam Hayes, Veronika Higgins, Cllr. Thomas Moloney, Francie Higgins, Pat O'Sullivan, Joe Higgins, Tipperary Rose, Celine O'Shea and Sinead McGrath are pictured with dancers from the Joan Denise Moriarty School of Dance



Mike Kiely, Cork IKA Branch receives cheque from the Drinagh Tractor Run Committee (l-r): Martin Lordan, Robert Ellis, Mike Kiely, Brid Young, Con O'Donoghue and Tim Hurley.



Attendees at the March Support meetings



Attendees at the February Support meetings



Welcome to the Spring edition of *SUPPORT* and a belated happy New Year to all.

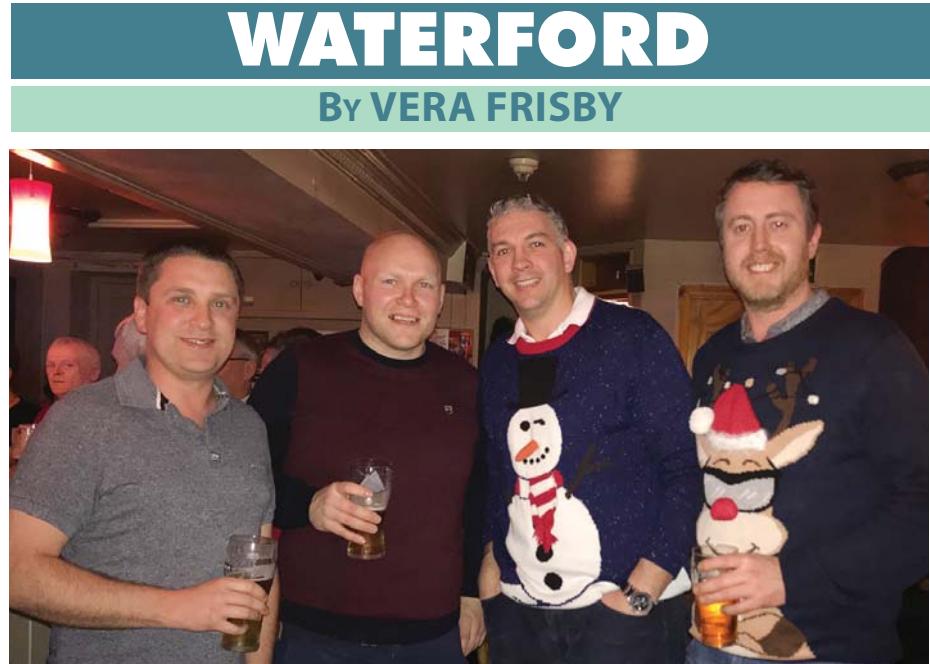
ORGAN DONOR AWARENESS WEEK

Organ Donor Awareness Week, possibly our busiest week of the year is almost upon us. We have many local supermarkets booked for collections during this week, in the City and County. We would be very grateful if you, your families or friends, could help us out during this week. One or two hours would be greatly appreciated.

We always need volunteers. If you have a few hours to spare, please contact Patsy, 087-9647231 or Vera, 086-8372442.

FUNDRAISING

Joe and Frances Moynihan organised a 'bag pack' at Dunnes Store, Dungarvan and raised the sum



of €2,109. 'Thank you' to everyone who helped over the two days, and all who supported the collection.

Alan Daly raised the sum of €305 at his premises Bridgie Terries, Dungarvan. 'Thank you' Alan and to everyone who contributed to this collection.

Thank you also to Eddie Sullivan, Paddy and Eileen Long for organising the 'Christmas Jumper Night' in December last and raised the sum of €830. 'Thank you' to Sean Power and all the staff at The Forge Inn, Portlaw, for all their help and kindness and to everyone who gave 'spot prizes' and those who supported the night.

Tristan Ungapen, a dialysis patient,

made beautiful Christmas decorations and sold them to the patients and staff at University Hospital Waterford and raised the sum of €85 for our branch. 'Thank you' Tristan and to everyone who bought the decorations.

Sean Murphy and all at Crotty's Inn, Leamybrien, raised the sum of €400 for our branch and we thank them.

Lenihan's Bar, Newtown, Kilmacthomas, held a weekend of music, fun and craic. The Committee also organised a BBQ and a Tea-Party. The funds raised were distributed between three charities including IKA Waterford branch. 'Thank you' to the Committee members, including our



WATERFORD

By VERA FRISBY

GALWAY

By PEADAR Ó HICI



branch Chairman, Ray Halligan, everyone involved in organising the events, those who gave sponsorship and all our supporters.

Frances Moynihan, Waterford Board member, with her sister Geraldine Noonan, brother-in-law Michael Treacy and niece Eimear Noonan Treacy (all from Mullingar) recently walked the final part of the Camino Portuguese in Spain. They wore the IKA tee-shirts during the walk to highlight organ donation. They were very visible along the route and were referred to as 'the Kidney Group' by others on the walk. It initiated conversations re organ donation along the way. They covered 170km in total, over 7 days, and were very happy to reach the Cathedral in Santiago for the finish. A very worthwhile, if tiring experience.

We would like to congratulate Paul Palmer, from Ballyouskill, who travelled the 32 counties on his vintage 1955 Ferguson 20 tractor, to raise awareness of organ donation for transplantation. He stopped in Dungarvan for a few hours and received great support.

BRANCH MEETINGS

We would love to see more patients, family members and friends at our branch meetings, all are very welcome. Our meetings are held on a Tuesday evening at The Cheshire Homes, St. John's Hill, Waterford at 7.30pm, every five weeks. Contact Vera for date of next meeting on 086-8372442.

On Thursday, March 21st the Galway Branch will launch our Organ Donor Awareness Week in the Menlo Park Hotel at 7.30pm. Dr Niamh Kieran, Nephrologist, Merlin Park University Hospital and Pauline May, Coordinating Nurse with Saolta Group of Hospitals, will be guest speakers. Both of these ladies would be well-known to patients and recipients in this region and they will speak about their work and especially about advances and improvements in the treatment and services for organ patients. Refreshments will be provided after the meeting.

On Sunday, March 24th we have organised our Annual Thanksgiving Mass for organ donors and their families. Mass will be at 12.30pm and refreshments will be available in Flannery's Hotel afterwards.

The Church is just off the Renmore Road, entrance across from the Bon Secure Hospital and the hotel is 5 minutes walk from the Church with lots of parking.

The following Saturday, March 30th the Branch has organised city collections. Lots of volunteers are needed and we use the Western Hotel,

Prospect Hill, as the distribution centre where volunteers can collect their boxes and supplies for the day.

Collection points will be allocated and boxes can be returned afterwards to the hotel. Collection points are spread around the city and in some stores. We wish to thank the Management of the stores for again giving us permission to collect at the entrances of the shops. We should mention that ALDI has granted blanket permission to us to collect at all of their stores not only in Galway but throughout the entire country. Mile buíochas dóibh.

Pauline May, Coordinating Nurse will have an information stand in the entrance foyer of University College Hospital on Tuesday April 2nd.

The AGM will be held on April 25th at 7.30pm in Menlo Park Hotel. We ask for a good attendance and would like to hear new ideas from you.

Our next Branch meeting is planned for May 16th at 7.30pm in Anno Santo Hotel, Threadneedle Road Salthill.

If any of our readers is willing to participate in the activities of the Galway branch please contact Peadar at 087-6536521.

CAVAN/MONAGHAN

KARL CRONIN

RETIREMENT

During the summer, we saw the end of an era as Sr. Marie Leddy-Sheridan retired as Clinical Nurse Manager of the Renal Dialysis Unit in Cavan General Hospital. Marie is widely known throughout our community and was instrumental in setting up the unit in Cavan in the early 1990's.

Marie managed a top-class dialysis service, through her dedicated staff in Cavan, and was a huge support and friend to all the patients and families who passed through the unit. She worked very closely with the IKA and our branch, sourcing support for patients wherever needed and organising holidays for both local patients and visiting patients every year.

Marie will be missed in our dialysis unit and on behalf of all our patients, families and branch members, we wish

her the very best for the future.

We would also like to acknowledge and thank the staff of the Cavan Renal Dialysis Unit for their continued support and care to all our patients, your work and commitment is very much appreciated.

BRANCH MEETINGS

If you would like to receive notification about branch meetings, please contact the IKA to ensure you are registered to receive branch mail.

BRANCH SECRETARY

The Cavan / Monaghan branch are seeking expressions of interest for the role of Acting Branch Secretary until the next Annual General Meeting.

Anyone interested in becoming Acting Secretary of the branch should contact Karl Cronin on (086) 851 3173.



CHRISTMAS CELEBRATIONS

On Tuesday, December 11th we had our Annual Christmas Dinner in the Skylon Hotel, Drumcondra. A great night was had by all. We had a wonderful meal followed by the usual few words. We also did a Kris Kindle plus a monster raffle and this was followed by a sing song led by Ron Grainger on his guitar. Ron also accompanied guest Red Hurley who gave us a beautiful interpretation of 'Silent Night'. A wonderful evening was enjoyed by all.

FIRST MEETING

Our first meeting of 2019 took place on Monday January 28th when our guest for the evening was Colin White who gave us a fascinating talk, not only about sporting activities but

DUBLIN NORTH

By PATRICIA MACKENZIE



Colin White and Sarah Dalton at the first Monday January meeting.



gave an international overview of renal affairs. The evening concluded with a lively question and answer session with Colin.

With the addition of tea and chat, none of us noticed that we had one of our longest meetings ever.

BRANCH AGM

The Dublin North branch AGM will take place on Monday April 8th at 7.30 pm in the Renal Support Centre, Beaumont when our speaker will be our member Tony Byrne who will talk about his transplant journey and interest in photography.

Please members do attend this

meeting as this is an Election year.

THANK YOU

We thank ALL our speakers who enlivened our meetings since last September. These included National Chairman John Whelan, CEO Mark Murphy, Deirdre and Peter Moore and IKA National Projects Manager Colin White. Thank you for your time and support.

ORGAN DONOR AWARENESS WEEK 2019

Good Luck to all for Organ Donor Awareness Week. We hope for a spell of warm weather and that the sun shines brightly for our efforts.



Dublin North Christmas Dinner - December 11th



Dublin North branch Christmas Party - December 9th





ORGAN DONOR AWARENESS WEEK

Organ Donation Awareness Week is almost upon us. We will be distributing organ donor cards, selling the 'Forget-Me-Not' flowers and other merchandise throughout Co. Longford during the week. As always we rely on your continued support and welcome any new volunteers that may be available to help out during this week.

ANNUAL GENERAL MEETING

Please note we will be holding our AGM in April. We will confirm the date and venue to members nearer

LONGFORD

By SUSAN MARTIN



the time. We would love to see some new faces attending this year's meeting to show their support and share some new ideas with the existing Committee.

FUNDRAISING

We would like to sincerely thank

Alan Ganley, along with his family and friends who, again this year kindly donated the proceeds of their 5th Annual Autojumble & Classic Car Show to our branch.

The event was held in the Old Army Barracks in Longford on February 24th February.



ROSCOMMON

By MAURA QUIGLEY

The members of Roscommon IKA would like to extend their sincere thanks to St. Michael's GAA Club (North Roscommon) who donated the sum of €500 from the proceeds of the Connacht Final preview fundraiser held in the Bush Hotel, Carrick on Shannon last June.

The presentation was made to the branch last November and was attended by Maura Quigley, Secretary and John Cormican, Treasurer.

At the recent meeting of the branch the upcoming Organ Donor Awareness Week was discussed. The branch will be out on the streets and shopping centres on Friday, April 5th, distributing organ donor cards and selling 'Forget-Me-Not' flowers, brooches, pens and shopping trolley discs. The Committee would



welcome volunteers to assist. If you are interested in helping

out, please contact the Secretary at 086-8969670.



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Our new Holiday Respite House in Killarney, which will deliver a home away from home for renal patients and their families, is undergoing a total makeover. The house, which was a shell, is being given a complete makeover with the wonderful help and support of many volunteers and businesses. We hope to have this very exciting project fully complete very shortly.

NEW SUPPORT GROUP

A new patient support group has been set up by Colm Clifford and Siobhain Crowley, both transplant recipients. They believe that an illness faced alone can be overwhelming at times so they want to reach out and encourage patients to take the first step to come and attend a Support Group Meeting.

These meetings are held on the second Thursday of each month. For further details contact Colm, 086-1999169 or Siobhain, 087-2510568.

ASTELLAS 2019 CALENDAR

On November 28th Astellas Pharmaceutical invited us to a presentation evening for the prizewinners from the local schools who participated in the annual calendar art competition. Winning paintings were published in a beautiful calendar and are now on sale for €5 each. All the the proceeds will be donated to the Kerry branch.

On the evening a special presentation was made to two local little girls namely Clodagh O'Shea, who received a kidney from her dad Tim, and Isobel Sweeney who received part of her dads liver. Both girls are doing great, thank God.

KERRY

By THERESA LOONEY



Stephen Byrne, Connie Brosnan, Kerry branch Chairman, Patricia Quane, Vice President and General Manager of Astellas Pharmaceutical Company, Rhona Goggins-Quirke and Isobel Sweeney.

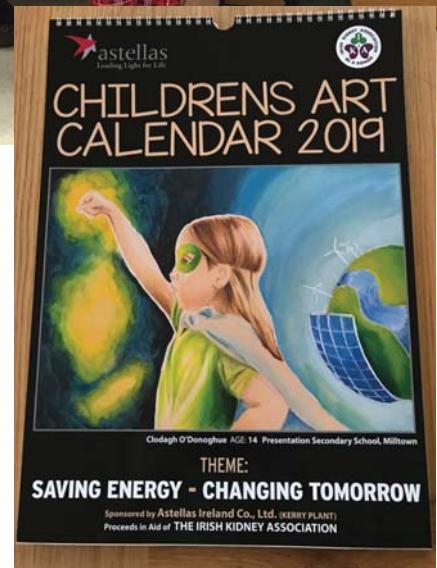
Your support in buying one of these calendars would be much appreciated and cost only €5. Calendars available from the secretary.

CHRISTMAS PARTY

Our Annual Christmas party was yet again a resounding success with over 180 adults and 60 children in attendance. After a superb lunch Mr. and Mrs Claus, together with Mr. Giggles, made it an afternoon to remember especially for the children.

Kathleen McCann, dialysis patient, together with her sister Marian entertained us with their lovely singing.

As usual our two youngest patients...Thomas O'Dowd (5) from Dunquin and Cianan Walsh (2) from Waterville were inspirational with their good humour.



A huge 'thank you' to those who donated spot prizes, bought Christmas cards and calendars. It was a great afternoon of networking and making new friends.

Congratulations to Joe Buckley from Faha, Killarney, on his recent transplant and, thankfully, he is doing very well. The family are ever so grateful for the use of the Renal Support Centre in Beaumont.

Kerry Christmas Party





The Leitrim branch launched Organ Donor Awareness Week (ODAW) in Gurn's Milestone Bar, Manorhamilton, on Friday March 1st. The launch took place at a Table Quiz organised by Leitrim Tourism Network (LTN) in aid of our branch.

LTN, which promotes, markets and sells Leitrim as a tourist destination, to domestic and international visitors, is the Leitrim branch Organ Donor Awareness Week ambassadors for 2019.



Felim Gurn (LTN), Cathriona Charles (IKA), Nuala McNulty (LTN), Annetha Kieran (IKA), Frank Heslin, (IKA), Wilfred van Wing (LTN), Mary McCormick (LTN), Carin van Wing (LTN), Helen Hay (LTN).

Branch members are currently getting ready for the week and will be collecting at various locations throughout the county on March 30th, April 4th and April 6th.

Meanwhile, in other branch news, we held our annual Service of Remembrance and Thanksgiving at the Bush Hotel, Carrick-on-Shannon on Sunday, November 18th.

The Ecumenical Service, which was concelebrated by Rev. Fr. Brendan O'Sullivan and Rev. Linda Frost

Pictured left:
*Mark Murphy, CEO, IKA with Leitrim branch members
Annetha Kieran (Chairperson), Frank Heslin, (Treasurer)
and Cathriona Charles (Secretary).*

remembered and honoured deceased and living organ donors and their families. The well-attended Service also offered transplant recipients an opportunity to pay thanks to their donors and their families.

On the night, the Leitrim branch marked the occasion of the IKA's 40th anniversary with a cake, which was served up with post Service refreshments.

The branch's Annual General Meeting will take place in the Bush Hotel, Carrick-on-Shannon, on Tuesday, April 9th at 8.00pm. All members are welcome and are encouraged to attend.

LIMERICK By MADELEINE DONAGHY

As Spring arrives it finds the branch very busy preparing for Organ Donor Awareness Week. We have secured two major shopping outlets ...Castletroy Shopping Centre and Aldi Ireland are also supporting the branch on Saturday, March 30th. The branch needs as much help as possible and would be very grateful if you could spare some time to help at these centres. Please contact Mary on 087-9612133.

A big 'thank you' to Askeaton/Ballysteen youth club for the donation of €2135.

The members of the club arranged fundraisers in memory of their friend and fellow member Jack Walsh, aged 19 years, who died



Tony Walsh, Mary Downes, Sandra Walsh, Claire McMahon and Siobhan Brosnan are pictured at the Askeaton Youth Club cheque presentation.

tragically in Spain last year. Jack's family donated his organs. Jack had ticked the box on his provisional driving licence to signify his wish to donate. Jack's family said that this

had helped them to make the very difficult decision to donate his organs.

Following on from this the youth club are making organ donation one of their goals.

The Branch will hold its AGM on Thursday, April 18th, 2019 at 7.30pm in the Good Shepherd Day Centre, New Road, Pennywell,

Limerick City.

Please contact Mary on 087-9612133 if you would like to help the branch in any way as we need as much help as possible.

LEITRIM

By ANNETHA KIERAN



Felim Gurn (LTN), Cathriona Charles (IKA), Nuala McNulty (LTN), Annetha Kieran (IKA), Frank Heslin, (IKA), Wilfred van Wing (LTN), Mary McCormick (LTN), Carin van Wing (LTN), Helen Hay (LTN).

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Pictured left:
*Mark Murphy, CEO, IKA with Leitrim branch members
Annetha Kieran (Chairperson), Frank Heslin, (Treasurer)
and Cathriona Charles (Secretary).*



We hope everyone is well in the county? We are all busy getting ready for Organ Donor Awareness Week.

We are holding our AGM in Thurles on Tuesday, April 16th at 8pm in The Anner Hotel. Colin White, IKA National Projects Manager, will give a presentation on the night and all are welcome.

Sophie Hogan and Orla Sheridan, two Transition Year students from St. Mary's Secondary School, Nenagh, have produced a book on Tipperary – which is written for children aged 5-10 years. The book is to help teach them about the history and facilities of Tipperary, in a fun way. It is priced at €5 with profits going to the IKA.

Their Green Isle Company is now through to the County Final of the Mini-Business Competition, to be held on March 28th, in LIT, Thurles.

Sophie's mam is a kidney recipient and it is wonderful that they thought of the IKA.

TIPPERARY

By ORLA HOGAN RYAN



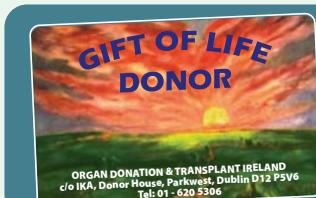
1st prize winners at the IKA Mixed 4 Person Open Scramble at Nenagh Golf Club are pictured with Andrew Warren, Captain, Billy Gaffney, Conor Tierney, David King, Michael Tierney and Seamus Hogan, IKA



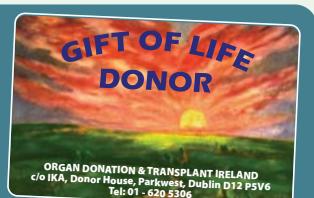
2nd prize winners



Orla Hogan Ryan and Michael relaxing at the prizegiving



For Donor Cards Freetext
DONOR to 50050





DONEGAL

By SIOBHÁN BATES



Hello everyone, from a very wet and cold March day in Donegal.

We are currently organising our Organ Donor Awareness Week and Church Gate Collections here in Donegal. By now everyone will have been notified by post, if not please do contact me and I will gladly accommodate you with whatever is needed for your area. All Aldi stores are to be covered in Donegal on March 30th. We have six Donegal stores to cover, Dungloe, Letterkenny (2), Donegal town, Buncrana and Ballybofey. Church gate collections will be held on April 20th and 21st.

Thanks to you all the branch continues to be very busy. We enjoy being out and about, meeting and greeting you all. We are truly grateful to anyone and everyone that has recently contributed to the Donegal Branch by way of fundraising or donations.

Thank you also to the Tullamore branch for inviting us to your Service of Thanksgiving in December. It was a beautiful occasion and enjoyed by all.

Recently we met with Bríd Gallagher from Killybegs who unfortunately lost her beloved son

Mary Whoriskey from the Whoriskey's Christmas Lights Display in Kerrykeel presenting a cheque for €4,000 to George and Siobhan Bates from the IKA Donegal branch, part of the proceeds from this year's event. Also included at the presentation in the Swilly Mulroy Credit Union office in Kerrykeel were James Sandilands, Cathy and Ollie Whoriskey, James Boyle, Mia McAteer and Michael Whoriskey. Photo Tirconaill Tribune, Milford, Donegal.

John in an accident, and through all the sadness, decided to contribute monies instead of flowers to the Donegal Branch. She has a lovely family friend, Patrick, who is currently receiving dialysis.

Helen McGinley, from Kerrykeel, works in McGinleys bar. She organises Helen's Bonus Ball draw which is run on an ongoing basis until the sum of €1,000 is raised for a local charity. I am delighted to report that we were chosen as the benefactor for this amount.

A massive 'thank you' to Marine Harvest in Fanad, Co. Donegal, for doing a fantastic 5k run for the IKA, in support of the IKA Renal Support Centre in Beaumont. This has greatly assisted the facilities' upgrading.

Marie McGrory, who donated a kidney to her daughter Jodie, and whose husband works for Marine Harvest, enjoyed the facilities at the Support Centre. They were most grateful for its existence for their family while they both recovered in Beaumont Hospital. €6,000 was donated for upgrading which is ongoing in the Centre. We look forward to viewing the changes.

A massive big 'thank you again' to Michael and Mary Whoriskey, the famous Christmas lights couple, who chose us again as one of their chosen charities for the Christmas lights spectacular. Other charities involved were St Vincent de Paul, Rathmullen. €4,000 were received by the Donegal Branch and St Vincent, Rathmullen



Marie and Jodie McGrory. Photo Tirconaill Tribune, Milford, Donegal.



Bernie Gallagher and Maurice Kelly. Photo Tirconaill Tribune, Milford, Donegal.

received €2,100, an amazing amount! Well done Michael and Mary and everyone who donated to the cause.

We were invited to Moville to meet with the lovely Bernie and Kevin McLaughlin, who lost their beloved son, Anthony. Anthony worked in Gillen's Shop, Main Street, Moville. He was highly thought of and loved as he was a great character and a respected member of staff. He is sadly missed. It was decided to organise a fundraiser collection in his memory. We were delighted to be presented with a cheque for €1,158. 'Thank you' for making us feel so welcome and all who contributed to this collection. I am told the fundraising is not over yet...Well done to all.

Thank you also to all at the IKA Renal Support centre, Beaumont for all they undertake to accommodate renal patients from Donegal.

'Hello' to all staff and patients at the Dialysis unit and Renal clinics in Letterkenny. It continues to be such a busy place but somehow they all still manage to keep a smile on everyone's faces.

Congratulations and continued good health to all who have received a transplant recently. Also may I convey our condolences from all of the Donegal branch to those grieving or whom have lost a loved one recently. I personally would especially like to reach out to the family of our dearest pal, Philomena Doherty, from Cullaff, who lost her courageous battle with life. She was an inspiration



Staff of Gillens of Moville shop, presenting a cheque to Siobhán Bates, IKA Donegal Chairperson, proceeds of fundraiser in memory of Anthony McGinley.

to us all and her family. Rest safely in peace.

The date for our branch AGM will be published soon. The Committee and Board member will be elected on the night. If you feel you can give time to your local branch, do feel free to please put your name forward. Everyone is welcome.

A dance and draw, in aid of the IKA, will be held on Friday June 14th. Music will be by Johnny Brady and supporting acts.

The event is being organised by Dale Hutchinson and will be held at the Inishowen Gateway Hotel, Buncrana. Doors will open at 9.30pm with dancing from 10pm-1am. Prizes will include hotel breaks, TV, various vouchers and much more.

Tickets are available from Dale on 087-9010774 or from the hotel on 074-9361144.

Other fundraisers are also in the pipeline so our next issue of SUPPORT will have more up-to-date information.

Please note if anyone has anything of interest to share with the branch, do join us on our Facebook page, Donegal IKA branch. Also if you have any bulletins or photos you would like to be included in SUPPORT, please let us know.

Take care and the best of luck to everyone with Organ Donor Awareness Week and the Church Gate collections. Slán.



Helen McGinley, Kerryke, presenting the Donegal branch with cheque for €1000, proceeds from Bonus Ball Draw

QUALITY OF LIFE DONEGAL

FREE Self Management Programme

1 Day a Week for 2½ Hours for 6 weeks

Starting Friday 3rd May, 11am-1.30pm
in Finn Valley FRC

For anyone (over 18) with a long-term health condition: Diabetes, Heart Disease, COPD, Depression, Arthritis, Pain, Parkinson's Disease, MS...Or if you are a carer for someone with a long-term health condition.

Learn how to manage the symptoms of your condition better – pain, fatigue and difficult emotions.

Learn new skills such as setting goals, relaxation and communication.

Meet new people, solve problems and make decisions.

FOR MORE INFORMATION and to REGISTER FOR THE PROGRAMME
CONTACT: FINN VALLEY 074 -9131245 or HELEN 087-3964307



The Mayo branch would like to put a call out to our members to please come forward and get involved in local meetings and in fundraising efforts for Organ Donor Awareness Week 2019. Please contact our secretary, Maureen Bourke, or Chairperson, Marie Mellon, if you are available during the week for local fundraising efforts.

Every year we have our Mayo Mass of Remembrance and Christmas get-together in November in the Fr Peyton Centre in Attymass. This is a lovely opportunity to meet and catch up, and to remember all the patients who have passed away over the year.

This centre is in a beautiful setting which enhances the occasion greatly.



MAYO

By LISA MELLON

KILDARE

By ELAINE MAGUIRE

A big hello from all in the Kildare branch and I hope everybody is making the most of Spring!

We have been busy with our regular meetings and we are glad to be welcoming newcomers and the increase in our attendees.

Our last meeting on February 4th was particularly interesting as we had, in attendance, Dr Conor Woods, Consultant in Endocrinology in Naas Hospital.

He gave a presentation to the group with some very interesting facts and then opened it up to the floor, where we could ask questions on a general and personal basis. It was very exciting to hear the progress being made in research and the advancement in medicine. One of the side effects for a diabetes tablet has seen improvement in kidney function for people with kidney disease!

We are busy organising Organ Donor Awareness Week and we had a very exciting event in Newbridge on March 24th.

The whole day was dedicated to specialists in various disciplines surrounding kidney disease. It took place in the Town Hall with a large marquee outside.

There was a Nephrologist, Podiatrist, Endocrinologist, Blood Pressure specialist and a Transplant Coordinator, to mention but a few.

We will have a detailed report in the next *SUPPORT* magazine.



Students, St. Gerald's DLS College with Lisa and Maria Mellon



We have had a busy couple of months in Mayo in terms of fundraising and education.

Students of St Gerald's DLS College in Castlebar chose organ donation as a project topic and invited Marie and Lisa Mellon to come and talk to them about organ donation and life on dialysis. On the day, the students were so enthusiastic and informed on the subject, it was such a pleasure to be there.

Tadhg Buckley, EPS Ballyhaunis, presented Maureen Bourke, branch secretary, and her granddaughter with a cheque for €1000. The presentation was made in memory of Bridann



Halpin, whose husband Brian was employed in EPS.

Melissa Hogan, owner of Curiosity charity shop, Westport, and Colin Mulchrone presented Maureen Bourke with a cheque for €500.



Colin Mulchrone, Maureen Bourke, Melissa Hogan



Tadhg Buckley and his granddaughter present Maureen Bourke with the cheque for €1000.



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 YES NO

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 YES NO

of the Association and Annual Director's Report by Email?

Would you like to receive information on activities from your local YES NO

IKA branch which entails us giving them the data from this form?

Would you like to receive information on the IKA Transplant & Dialysis YES NO

Sports and Fitness which is based in Head Office?

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

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

SIGNATURE: _____ DATE: _____

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



IKA DIRECTORY

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

Tel: 01-6205306 | Email: info@ika.ie | www.ika.ie

Renal Support Centre, Beaumont Hospital, Dublin D09 Y5R3

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Most of the IKA funding comes from you – the public

WE RELY ON YOUR GENEROSITY

The **Irish Kidney Association**, a charity for kidney patients and their carers, is fully compliant with the Voluntary Code of Fundraising practice and no commission is paid to any of our volunteer fundraisers or staff.

We provide all our services **FREE** to patients, including financial support, counselling, dialysis holiday co-ordination, sports and fitness programmes, advocacy, patient guides and quarterly magazine.

We are developing a 6 bed Support Centre, next to the campus in Cork University Hospital. We are providing a holiday dialysis centre in Tramore, Co. Waterford. An extra holiday house in Killarney has opened to cope with the demands of our holiday house in Tralee. The 20 year old 13 bed Support Centre in Beaumont Hospital is being upgraded and €250,000 has been pledged to kidney research projects.

We engage with the general public nationally for organ donor awareness campaigns via all modern social media sources, including TV, radio and press.



We employ 15 full and part-time staff to provide these services. Our Board Members are all volunteers elected by each of the IKA 25 branches.

JOHN WHELAN
IKA National Chairman

THE COMPLETE
2017 AUDITED
ACCOUNTS
ARE AVAILABLE
ONLINE AT
www.ika.ie

Our expenditure in 2017 was as follows:

Patient aid, respite, counselling	€930,412
Donor card and awareness	€396,491
Support Centre (Beaumont)	€125,067
Dialysis unit, equipment and research	€18,240
Fundraising	€86,329
Governance	€201,806
TOTAL	€1,758.345

Irish Kidney Association CLG, Donor House, Block 43A, Park West, D12 P5V6.

Telephone: 01-6205306 | Email: info@ika.ie

CHARITY REGISTRATION NO. 20011260

