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WINTER 2018



IRISH KIDNEY ASSOCIATION CLG

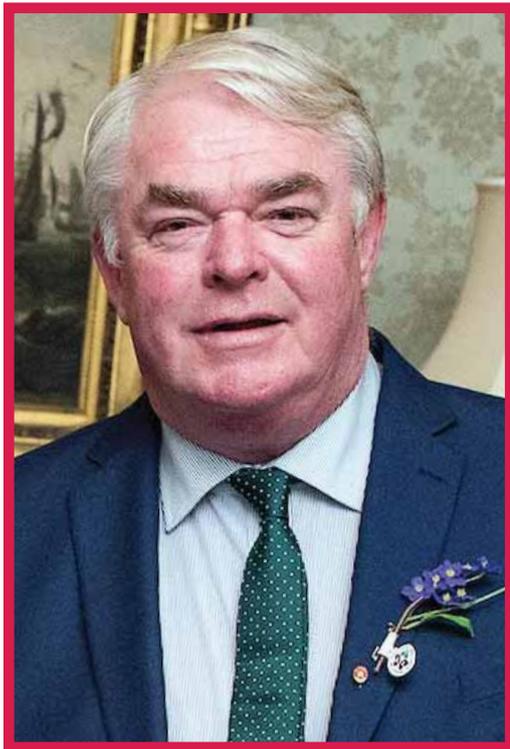
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CHARITY REGISTRATION NUMBER 20011260

Editorial...



2 018 marked our 40th year and the landmark was even more outstanding due to the remarkable bequest we received from Elizabeth O'Kelly almost a year ago. This has changed our outlook to the future and it is a pleasure working to increase the IKA's capacity to help more patients in a very practical way.

I want to thank and pay tribute to Professor Liam Plant for his enormous contribution to the National Renal Office and welcome his passing of the baton to Professor George Mellotte who now holds the position in the office of the HSE. We look forward to working together to further improve the choices and locations of future renal care in Ireland.



Liam Plant, George Mellotte

Contents...

Claire Byrne has been a wonderful Ambassador for the 2018 Organ Donor Awareness campaigns. She was particularly moved by her attendance at both the launch in March and the Service of Remembrance and Thanksgiving in October. The Christmas radio campaign, with her voice, completes her year of activity for the IKA - thank you very much Claire!



FRONT COVER

Broadcaster Claire Byrne took time out for a photoshoot with Sadhbh Browne (4), who awaits a liver transplant, from Mountbellew, County Galway, and her family, to highlight an important radio advertising awareness campaign, which encourages families and friends to discuss organ donation as they gather for the festive season.

Photo:
Conor McCabe Photography.

2 EDITORIAL

4 A CHRISTMAS MESSAGE FROM THE NATIONAL CHAIRMAN

5 ELIZABETH O'KELLY

6 A MESSAGE FROM THE PATIENT SUPPORT OFFICER

7 WRITING TO YOUR DONOR

8 STRESS

10 THE SECOND HAND OF THE CLOCK

12 'GIFT OF LIFE' AT CHRISTMAS

I was in attendance at a number of Branch social events in recent months and I would like to 'thank you' for the invitations and wonderful evenings that both myself and my wife Frances enjoyed immensely.

I would also like to thank the Branch members for their year-on-year support for their local patients. It is the local connection that can discover some individual patient difficulties which we can then try to resolve.

Dialysis transport is always local. We now have six areas within the HSE and each of them organise renal patients' transport in their own way. If you believe your transport could be organised differently – do say it to the nurse in charge of your Unit. If that does not resolve the issue, mention it to your Branch Officers or indeed, ourselves, in Donor House. We are currently seeking a national policy on renal transport and your input is essential.

Many more haemodialysis patient holidays are a long-standing goal of the Board of the IKA. 2019 will see the Killarney house as our third location for patient holidays, joining Tralee and Tramore.



2019

Organ Donor Awareness Week
March 30th - April 6th

The commencement of haemodialysis treatments at Tramore, Co. Waterford is again on our and the HSE's agenda. I cannot promise it for all of 2019 but perhaps at the latter end of the year we will have the treatments locally available for the four holiday apartments.

We have also rented an apartment in Portugal for the months of April, May, September and October. It is envisaged that those able to afford their own flights can avail of this. Further details on page 15 of this magazine. Do express your interest early to Deborah in Donor House.

There is a competition on page 24, to design a silver brooch to honour the 'living kidney donors' in our society. So I would like to ask you all to put your thinking creative heads on and come up with an uniquely Irish design.

May I wish you all a happy Christmas with your family and friends, and I hope the weather will be a little kinder than last year, to those of you travelling anywhere but, especially, the people attending their treatments and the staff across the country – dialysis, unfortunately, does not know it is Christmas!



MARK MURPHY

**14 YOU HAVE GOT TO BE
KIDNEY-ING ME!**

15 HAEMODIALYSIS HOLIDAYS

**16 PRESUMED CONSENT IS NOT THE
KEY FOR SUCCESS IN DECEASED
DONATION**

18 WORLD KIDNEY DAY

19 SOCIAL MEDIA & COMMUNICATION

**20 HEADFORD ORGAN DONOR
AWARENESS INITIATIVE**

**22 EATING WELL ON YOUR
HAEMODIALYSIS DAYS**

23 77 YEARS A-DREAMING

24 JEWELLERY DESIGN COMPETITION

24 SPORTS PROGRAMME 2019

**25 10TH EUROPEAN TRANSPLANT &
DIALYSIS SPORTS CHAMPOINSHIPS**

37 AROUND THE BRANCHES

63 MEMBERSHIP FORM

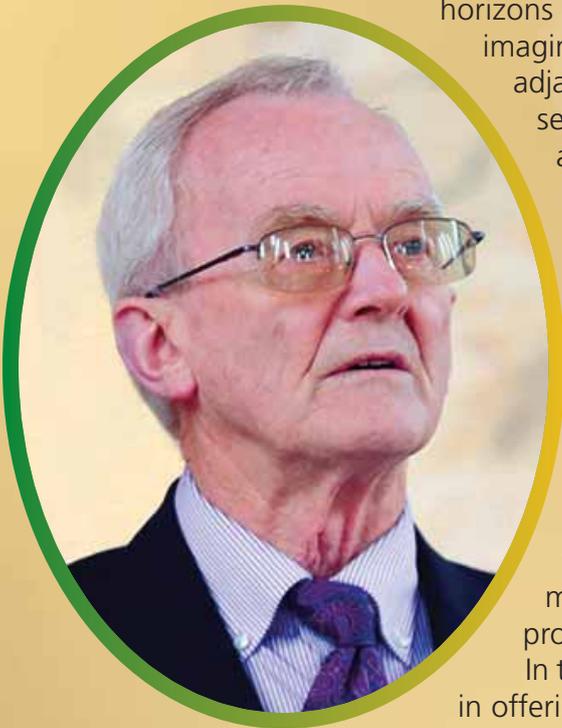
64 BRANCH SECRETARIES

A Christmas Message

from

The National Chairman

A It's hard to believe that a whole year has passed since I wrote my last Christmas message, and I am happy to confirm that it has been a very good year for your Association. At the beginning of the year we became aware that we were to benefit from an exceptionally generous legacy from the late Elizabeth O'Kelly. This has transformed our financial situation from being, in recent years, consistently in deficit, to enabling us to expand our horizons and to take on new projects which we could previously only imagine. Chief among these projects is the acquisition of a property adjacent to Cork University Hospital which we are in the process of setting up as a Support Centre for patients and their families attending CUH.



In the light of such a significant increase in our assets many might be tempted to say why do we have to continue fundraising. However, when considered in the context of the Association's annual expenditure of €1.7 million, we can get a better perspective. When substantial extra funds become available, we are given the opportunity to take on new capital projects. In this however, we must find the correct balance between expending money on capital projects and preserving funds for the ongoing maintenance of these projects and the further needs of the Association, and, to assist us in this, we are taking expert professional advice. We are also holding special meetings of the Board to decide on strategy in the light of such professional advice.

In the meantime, the day-to-day work of your Association continues in offering help and support to our members, and in this I would like to particularly acknowledge the ongoing dedication of our volunteers and the loyalty and professionalism of our staff. This ongoing work however still requires continuous funding, and it is to this that we look to the continuing generous help of our members and friends. Our fundraising activities serve two purposes, namely, to keep the work of the IKA before the public, and also to enable us to continue our work into the future. This has by no means become redundant as a result of our changed circumstances. In this regard we remain acutely conscious that local members of the IKA work tirelessly and consistently throughout the year and not just during Organ Donor Awareness Week. Again, we thank you all for this and urge you to continue your efforts during the coming year.

Finally, once again I would like to take this opportunity to send greetings and good wishes to our members and friends everywhere and to wish all our members and their families, our staff and friends, a happy and blessed Christmas and a successful and peaceful New Year.

JOHN WHELAN

Elizabeth O'Kelly



Through Elizabeth O'Kelly's thoughtfulness we can look forward to being able to deliver enhanced services to our members and the wider renal community. Her legacy will greatly ease the burden on those affected by renal illness for years to come. For this we express our deepest gratitude.

The Board of the Irish Kidney Association (IKA) would like to express its sincerest gratitude to the late Elizabeth O'Kelly for the largest single bequest in the 40 year history of the Association.

Whilst the continued efforts of our fundraisers will always remain vital for the support and services the IKA provides, her bequest will enable the Association to pursue new projects that have previously been out of reach and to fund further developments into renal disease and treatments. Her generosity will make a huge difference to those living with and affected by kidney disease in Ireland.

With the extremely generous bequest she has given us the opportunity to consider delivering projects that were previously aspirational. It is our responsibility to ensure that the benefits of her legacy will be felt by people living with, and affected by, kidney failure for many years to come.

The Association has always focused on the needs of patients. In the early days it was about raising funds to get dialysis units built and we introduced the 'kidney donor card' forty years ago (which subsequently has evolved into the 'organ donor card'). As the Association developed so has the range of services it could offer.

The Board of the IKA has been discussing how to make a real difference with the unprecedented opportunity afforded to us through this bequest. This has involved reviewing what we do now and what are the needs going forward.

During the economic downturn when funding, for all charities, fell dramatically our focus had to be on maintaining our existing services to the best of our ability. With approximately 75% of our funding coming from the public, the fundraising activities of our members and supporters have always been central in giving the Association the ability to deliver our range of on-going services.

With the continued support of our members and supporters in funding the delivery of existing services, the Association will be able to use the bequest to deliver on plans for new and enhanced services. For example, we have already purchased a house next to Cork University Hospital that we will convert to an accommodation facility for patients and family members when they have appointments or admissions – similar to the services currently provided through our Renal Support Centre in Dublin for people attending Beaumont Hospital.

We are also negotiating a position to deliver a dialysis unit next to our holiday facility in Tramore which, with HSE cooperation, will open up the opportunity for increased holiday dialysis. Most dialysis patients are totally restricted to their local dialysis treatment centre making it difficult for them to travel due to shortage of national dialysis capacity.

We have also agreed to financially support research through the Irish Nephrology Society – an aspect of the work of the Association that we have not been able to fund for a considerable period.

After 40 years the IKA has deep roots in the community across the country thanks to our Branch network and is very much respected as an advocate for patients and their families.

While the role of the HSE for renal patients encompasses the provision of treatment and care, the KA will continue in its aim to strive for the best outcomes for renal patients and their families by continuing to innovate and advocate on their behalf.

Through Elizabeth O'Kelly's thoughtfulness we can look forward to being able to deliver enhanced services to our members and the wider renal community. Her legacy will greatly ease the burden on those affected by renal illness for years to come. For this we express our deepest gratitude.

Message from IKA Patient Support Officer



Lorraine Costello



Lorraine Costello

It is difficult to believe that Christmas is almost on top of us. I do not know where the time has flown and I have been busy, since early November, making contact with all the countrywide hospitals and branches via the Christmas gift cheque scheme. All people involved put enormous careful consideration, thought and energy into identifying patients and their families who are most in need, and who will benefit

from receiving a Christmas gift cheque. Whilst it is a small amount it is that little bit extra that makes all the difference. It is an especially difficult time of year for families when Santa is eagerly expected and the feedback received from patients, indicates their sincere appreciation.

Illness continues to create enormous difficulty for families and, particularly so, when the patient is the family's bread earner. Coming to terms with a vastly reduced income stream is never easy. It is a privilege, for me, to be in a position to provide help, perhaps by paying utility bills, home central heating oil or, indeed, whatever financial pressure a family is currently encountering. I am aware that some patients find it extremely difficult to make a call seeking help. May I reassure those families, who are under stress, that their request will always be treated with the utmost confidence and I will do my best to endeavour to assist them.

As in previous years, I would like to respectfully remind you of the various channels which can be used to seek help:-

- Contact your local **Branch Officers**.
- Contact the **Senior Nurse** in your Unit.
- **Patient Care Coordinator/Hospital Social Worker** and of course, directly
- **Lorraine Costello, Patient Support Officer, Donor House**
Tel: 01-6205306 | Email: l.costello@ika.ie

I am frequently approached to write supporting letters for housing/re-housing applications/medical card appeals. I always attempt to convey the human side of renal failure, in my documentation, and especially also, to portray the daily courage required by both the patient and their family living with their illness. I derive enormous personal

satisfaction when I hear if their application has been successful. May I request that those, who were awarded housing/change of housing/grants, kindly let me know if they have been successful in their application and the timescale involved. It helps enormously to guide me regarding subsequent applications.

May I also encourage applicants to meticulously retain a copy of all documentation, at the time of posting as, frequently, original documents go missing and the patient then must retrace and duplicate all supporting information.

Each year sees an increased demand for patient aid and the Association continues to valiantly attempt to maintain services. As is frequently highlighted, patient aid is administered twelve months of the year and our 25 branch officers undertake this responsibility with great sensitivity and with strict confidentiality. The arrival of strict GDPR guidelines has made confidentiality even more an essential and important component when dealing with patient information.

I would now like to acknowledge and thank all the Patient Care Coordinators, Hospital Social Workers, Nursing Personnel and all those involved in the day-to-day care of our renal patients. Thanks to their vigilance, interest and support, patients' needs and concerns are discreetly and confidentially brought to my attention.

I especially wish to thank our IKA Branch Officers who, voluntarily, continue to advise me of their local members' needs. As is acknowledged by all, they are truly the backbone of the IKA.

This year we celebrated the fortieth year of the establishment of our Association. As the staff member with the longest service in Donor House, I have found myself looking down memory alley and, in the year of receiving the largest bequest in the history of the Association, it is important to remember and acknowledge just exactly how our Association was founded and has thrived since 1978.

Patricia Doherty, the first National Administrator/Chief Executive founded the Association on her kitchen table. A short while later, due to the support of the then Chief Executive of UVOH (Union of Voluntary Organisations for the Handicapped, Des Kenny, now known as DFI, Disability Federation Ireland) who believed passionately in Patricia's cause, went on to provide two small adjoining rooms in his offices in Eaton Square, Monkstown. From there we moved to Donor House, 156 Pembroke Road before



relocating to our current home, Donor House, Park West.

April, 1978 saw the inaugural meeting of the Association which was held in Jervis Street Hospital, chaired by Patricia and attended by several hundred renal patients and their families. And so the Irish Kidney Association was born, founded by patients, for patients, with the twin aims of improving the lot of dialysis patients and to promote kidney donation. At that time the only transplants carried out, infrequently, were kidney transplants. Indeed, the only aspect of our aims that has changed since is that we now promote all organ donation. An interesting fact to note is that Cork had their own Kidney Association but immediately joined the National Association. It is difficult to believe that at this time there were only three Dialysis Units

and the Association enthusiastically undertook to reverse this policy. The first branches of the Association were in the cities where there was a dialysis unit - Dublin, Cork and Galway. The structure of the Association developed democratically also, with local branches electing a representative to what was then, the National Executive, now the National Board and we now have 25 countrywide branches.

It is important to acknowledge and recognise that a Founder Member, Angeline Cooke, who attended the inaugural meeting, with her late husband Bernard RIP, is still actively involved in the Association. Please forgive me for not highlighting others who are equally deserving. It is a tribute to the Association that such dedication has been maintained for forty years. The IKA has always been proud of the fact that it has never

employed professional fundraisers. The euro that is donated is the euro that goes to directly assist the patient.

In closing may I pay tribute to the wonderful donor families, without whose generosity, so many would not be alive today. The 'Gift of Life' they selflessly conveyed, at a time of enormous loss and sadness must never be forgotten or overlooked. It is an honour to speak to and meet them at our annual Service of Remembrance and Thanksgiving. May I respectfully encourage transplant recipients to consider sending a remembrance note to the ODTI Team who will gladly send it on to the relevant donor family. We are all mindful that, at this festive time of year there sadly is an empty space at their own table.

Finally, may I wish all our members and readers a happy Christmas and a peaceful and healthy New Year.



Writing to your Donor Family

A transplant recipient acknowledges their donor in their own special way. Sometimes transplant recipients make the decision to write to the donor family. This decision is a personal choice and you may have to re-write this letter a number of times before you feel it is right.

From our experience the families of organ donors welcome and really appreciate this token. It can be difficult to express your thanks when the donor family may still be grieving for the loss of their loved one. However, your letter can often provide them with some comfort, and consolation and help them cope somewhat better.

As a transplant recipient, you have the opportunity to write to the family of your donor through ODTI (Organ Donation Transplant Ireland) who facilitate written correspondence between recipients and donor families. You can also write to your family through your local recipient co-ordinator who will then forward this on to ODTI. All correspondence is completely anonymous and identities are kept confidential.

If you would like to write to the family of your donor, you may send a greeting/Mass card, note or letter. Please do not include any identifying details, i.e home town, phone number, etc. Do not seal the envelope as the Organ Donor

Co-ordinator will need to review your correspondence to ensure confidentiality. Outlined below is some general information you may wish to include:

- Your first name **only**
- Acknowledge the donor family's loss and thank them for their gift
- Interests and hobbies
- Marital status, family size, etc.
- How long you waited for your transplant and how it has improved your quality of life.

When sending your card/letter to the transplant co-ordinators, please enclose your name and date of transplant on a separate piece of paper so that the card can be forwarded to the appropriate family. Place your card/letter in an unsealed envelope. Then send both documents in a sealed envelope:

**Organ Donor Co-ordinators,
Organ Donation Transplant Ireland (ODTI),
2nd Floor, Temple Theatre, Hardwicke Place, Temple
Street, Dublin 1 D01 X584**

This may be the most difficult letter you ever had to write, if we can provide any assistance in this process please do not hesitate to contact Lorraine in the IKA or the Beaumont Hospital Transplant Coordinators or staff in ODTI.



STRESS

You may remember the lyrics of a song with the title 'Love is all around us'. Change one word in the title and it would read 'Stress is all around us'. Isn't this the way it feels at times? Just think about it, we speak of relationship stress, exam stress, work stress, financial stress and so on. Over the summer amid the heatwave stress was mentioned frequently in relation to the farming community, livestock and on one occasion someone interviewed on the radio proclaimed that crops are stressed! In the course of another interview, in the space of two minutes, the interviewee used the word stress six times! Obviously, there is a lot of stress about! With the coming

of Christmas, with all its hopes and joys, we can experience an increase in our stress levels.

Have you noticed that some people seem to stress over one thing, which in the eyes of another is trivial as they would not see it as stressful at all! Yet stress is real. As with many things, stress can be good or bad. Stress that is good can galvanise and energise us into action. To illustrate with an example; recall a moment in your life when you really wanted something - like the job you always dreamed about. You would put a lot of effort into preparing for the interview, but this was not without its stress. Yet the stress can be used to your advantage as this type of stress energises and

sharpens the way you respond allowing you to perform at your best.

However, another type of stress can be negative, work against us and in some cases can lead to illness. In its negative form stress leaves us feeling unable to cope with a particular situation. We can feel overwhelmed, unable to act or articulate what we feel, thereby increasing the stress we feel. When this happens, we scramble and employ mechanisms we have used in the past to combat the level of stress we feel.

When we experience stress, we respond in three separate but related ways. One response is emotional, a second is somatic and the third is psychological.

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.

Emotionally, stress can provoke fear and anxiety as we feel unable to cope or fear being overwhelmed. Our somatic or body response includes a faster heart rate, muscle tension and a dry mouth. Psychologically we respond by employing defence mechanisms and coping strategies.

WHAT ARE SOME OF THE TOOLS IN MY 'EMOTIONAL TOOLBOX' THAT I CAN USE TO COMBAT STRESS?

What can be of great help and which can reduce our level of stress is awareness of the triggers in us that cause stress. If we know the triggers, we can create a space that will allow for time to employ healthy mechanisms which will help reduce the stress we are feeling.

Sometimes our thoughts, particularly if we feel stressed, can be predominantly negative rather than positive. This negative thinking will only add to our stress. Reviewing our thinking and taking a more positive stance can reduce the stress we feel.

Another mechanism we can employ is to structure our day. If our day is disorganised and chaotic it can exacerbate our stress levels. Putting some structure - without it becoming

too rigid - can contribute to lowering our stress levels.

Taking time out to relax is also helpful. Look for something that is enjoyable, for example, listening to music, yoga or meditation can relax us and lower our stress levels. They may also help create a space where we can think more positively, which also helps.

Taking exercise is another way we can reduce our stress levels. Again, it is about finding exercises that are enjoyable so that in doing them they do not add to stress but actively reduce it.

If none of these 'tools' work and your stress levels continue to be difficult to manage, it is important that you seek help, either through your doctor or through referral to a counsellor. Stress levels that are high and remain high are not good for us, either physically or mentally.

At Christmas time, which can be a magical time for many, be aware of your stress levels and particularly what triggers that stress. Take whatever measures you feel comfortable with to reduce your stress so that you can join in the enjoyment of the season.



By MIKE KELLY



May I wish all of you a very enjoyable and restful Christmas and may 2019 be a year of peace for you all



SELF MANAGEMENT PROGRAMME

The IKA has organised a number of successful self-management programmes in various branches. The programme runs one morning a week for six weeks, each session lasting two hours. Feedback from those who have participated in the programme is positive, commenting that they found it of help in their day to day living with their illness.

If there is any other branch or a cluster of branches that are interested in running a programme, please contact Mike at Donor House.

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



GUH Arts Trust Arts Assistant Bridget Cheasty with stars of the film Christy Reid and Dan Brennan



Artist Terrence Crowe and his wife Maureen

The Second Hand of the Clock

A poet, a raconteur, and two nurses escape the clinical confines of dialysis

A special film, made in collaboration with staff and patients at Galway University Hospital is now publicly available online.

Galway University Hospital's Arts Trust was awarded the 2017/18 artsandhealth.ie Documentation Bursary to work with filmmaker Tom Flanagan on a short documentary film about its Dialysis Arts Programme in Unit 7. Set against the changing seasons of Merlin Park University Hospital, the film is a moving account of how arts and health practice can enhance time on dialysis, told from nursing and patient perspectives.

Borrowing its title from a poem Christy Reid wrote, in response to clock watching on dialysis, *'The Second Hand of The Clock'* was

previewed at The Glass Factory, Galway Crystal on June 9th, 2018 and has screened at several conferences, and is now publicly available online at Ireland's national Arts and Health resource artsandhealth.ie.

To view the film visit <http://www.artsandhealth.ie/resource/videos/the-second-hand-of-the-clock/>

The Dialysis Arts Programme was established by GUH Arts Trust in 2012 with an Arts Council Project Award with the aim of enhancing patients' experience of dialysis treatment through participatory arts workshops. Participants find a more positive, productive use of their time in hospital, engaged in a way that distracts from worries and 'makes time fly'. Some have embarked on

significant creative projects which have redressed the balance of what they have had to give up in attending dialysis.

In the first year of the project, participants published the book *The Magician and the Swallow's Tale*, launched with an exhibition at Galway Arts Centre. Patient consultation also informed improvements to the dialysis waiting area which included a wallpaper and window blind designed by a participant during dialysis treatment.

Now in its sixth year, the arts programme thrives on the continuing enthusiasm and support of the renal team in Unit 7 and a special partnership grant from the Irish Kidney Association and Saolta University Health Care Group.



TD Hildegard Naughton, Galway City Arts Officer James Harrold, GUH Arts Trust Arts Director Margaret Flannery, and Cairde Othar na Gaillimhe and Saolta Patient Council member Mary Lane Heneghan



Unit 7 Ward Clerk and her family



Staff and patients of Unit 7 at a private screening of the film at The Glass Factory in June 2018.

**Photos by:
ANDREW DOWNES**



Unit 7 Health Care Assistant Helena Costello and her family



Artwork on view at Galway International Arts Festival



Christy Reid dancing with Nora Cummins



**Star of the film
Christy Reid with
Unit 7's Liz and Nora**

In 2016 participants exhibited at the National University of Ireland, Galway as part of Galway International Arts Festival and the film is their latest achievement in a long list of artistic accolades.

The Arts Trust would like to thank all the staff and patients of Unit 7 for their creativity and support in making

the film, particularly its stars Dan Brennan, Christy Reid, Ethna Gillespie and Jacinta Reade.

GUH Arts Trust looks forward to continued collaboration with our colleagues and partners and extends special thanks to the Galway branch of the IKA and Angeline Cooke for their generous donation to our

programme this year, raised through sales from Angeline's own art exhibition.

For more information on the Unit 7 Dialysis Arts Programme and the work of GUH Arts Trust or to screen the film at an event contact guhartstrust@hse.ie.



L-R Back row: Caoilin and Clidhna McElroy, IKA Ambassador Claire Byrne, and IKA National Chairman John Whelan. Front: Siofra, Donagh and Tadhg McElroy, Gillian and Aine.

Claire Byrne fronts campaign to discuss 'Gift of Life' at Christmas

Broadcaster Claire Byrne took time out for a photoshoot with kidney transplant recipient Tadhg McElroy (age 7) and Sadhbh Browne (age 4) who awaits a liver transplant and their families to highlight an important radio advertising awareness campaign, organised by the Irish Kidney Association, which encourages families and friends to discuss organ donation as they gather for the festive season.

Grateful for the 'gift of life' which they received in 2014, living kidney donor Clidhna Costello from Bray and her transplanted son Tadhg McElroy, along with his younger twin siblings Caoila and Donagh (2½ years), joined organ donor ambassador Claire Byrne for the festive photocall.



Sadhbh Browne, her parents Deirdre (left) and Patrick (right) with Claire Byrne and John Whelan

They were highlighting the campaign in support of the families of approximately 550 people who are currently on transplant waiting lists for hearts, lungs, liver, kidney and pancreas, including the children's grandmother Evelyn McElroy who has been undergoing dialysis treatment for over 4 years.

Four years old Sadhbh Browne from Galway has been on the transplant waiting list for a liver since July this year and she attended the photocall with her parents Deirdre and Patrick who are members of Children's Liver Disease Ireland (CLDI).

In the radio advert, which will be broadcast on national radio stations in the days leading up to and directly after Christmas Day, Claire Byrne explains that you are three times more likely to need an organ transplant nowadays than to be a deceased organ donor. She is encouraging families and friends to discuss organ donation over the festive season.

Claire, who lent her voice to the radio advertising campaign said, "Christmas, known as a time for giving is the ideal time to discuss the 'gift of life' that is organ donation and let your wishes be known when families and friends come together. I would urge families to talk to each other about organ donation and keep the reminders of their willingness to donate visible by carrying the organ donor card and permitting Code 115 to be included on their driver's licence. I am glad to have had that important discussion with my family."

"I feel humbled and privileged to have met organ donor families in my role as ambassador for organ donor awareness this year. I have witnessed the results of the profound legacy of donor families through the numerous truly grateful transplant recipients I have met whose lives were transformed and saved. One of the highlights of the year for me was learning that the IKA received over 8000 requests for organ donor cards in the week that followed the RTÉ TV documentary about the inspirational CF campaigner 'Orla Tinsley: The Warrior' and the discussion that followed on 'Claire Byrne Live'."

Patrick Browne explained, "Our beautiful and only child Sadhbh developed Biliary Atresia within 24 hours of her birth and has been under the wonderful care of Crumlin



Claire Byrne and Tadhg McElroy

Hospital since then.

Last Christmas she became very ill after her condition worsened and she developed Cholangitis causing her liver to fail. Myself, my wife Deirdre and other members of our family have already been screened for living liver donation but regrettably we are not suitable donors due to incompatible blood groups and other factors. Now as Sadhbh's condition worsens her only hope for survival is for her to receive a deceased donor liver transplant which would be carried out at King's Hospital in London, where all liver transplants are carried out on Irish pediatric patients. We hope that by highlighting our daughter's plight that the public will be moved to making an

informed decision about organ donation which will give hope to our family and other families who are relying on a grieving stranger family's selflessness to donate their loved ones organs."

Living kidney donor Clidhna Costello said, "We got lucky, so lucky, because I was a suitable donor for my son Tadhg! Other people aren't so fortunate, they may desperately want to give that gift to their child or loved one but may not be a suitable match. Their only hope and our only hope for my mother-in-law Evelyn, is that another family, at a time of complete devastation, is generous enough to think about others in need and consider organ donation."

Jennifer at her brother's wedding this year - she was one of the bridesmaids



In 2010 I developed Chronic Kidney Disease (CKD) and would at some point in the future, need a kidney transplant.

Some people living with Spina Bifida can often have a lot of kidney problems.

At that time my kidney function was at 35%. However, I was informed that this would decrease even further until I reached the stage known as End Stage Kidney Disease (ESKD).

As my kidney function began to decrease so too did my appetite. This was due to the toxins building up in my blood. As a result of this, I began to experience symptoms such as high blood pressure, fast heartbeat, nausea and vomiting, and itchy skin. This meant an increase in appointments for clinics and an increase in blood tests.

to remove the fluid that had built up on it. Fluid had also built up around my heart. It was at this point that I had to start dialysis.

My haemodialysis treatment began on January 24th, 2018. For the first few days I was on the machine for two hours each day to try to drain the fluid from my body. I also needed that time for my body to get used to being on the machine.

I now attend Dialysis Unit 1 which is one of the more modern dialysis units in the country. At present, dialysis is for 3 hours 30 minutes, 3 days a week

Since being diagnosed with CKD in 2010, I've experienced 'mixed feelings'. Of course I want a new kidney which, like most of the operations I have had up to this point, will again allow me to stay on this earth for a little longer and fulfil my

You have got to be Kidney-ing Me!

My name is Jenny Kerr. I am 32 years old and I live in Co Meath. I was born with a physical disability known as Spina Bifida. Due to having this disability, I am a wheelchair user. I also have a

condition called Hydrocephalus. Currently, I am waiting for a kidney transplant and travelling up and down to Beaumont Hospital 3 days a week to receive dialysis. Let me tell you about my journey to this point.

Jenny on dialysis



In 2016, I was told that my kidney function was below 20%. This was the point that I had reached ESKD. I would need a fistula inserted into my arm, to prepare me for haemodialysis.

Getting a fistula made was a complicated surgery for me because the veins in my lower arm were very small. I eventually got my fistula in my arm in October 2017.

In January of this year my kidney function dropped to 8%. I developed pneumonia on my left lung and had to have a chest drain inserted

hopes and dreams for my life.

Over the year, I have discovered, no matter whether you have a disability or are on dialysis and need a transplant of any kind, or both even, there are always ways to plan your life around hospital appointments and stays in hospital, so that you can be able to fulfil your hopes and dreams in your life.

For people who struggle with achieving this however, Beaumont Hospital provides great supports for not only patients on dialysis and who need a kidney transplant but



Jenny with her mam and friends at the Michael Buble concert in Croke Park, after a dialysis session.

also their families too.

When I first discovered I needed haemodialysis, I met with Beaumont's Patient Co-ordinator. I was given all the information I needed about how dialysis worked and what it would be like starting off.

Through that meeting, I got in contact with Beaumont Hospital's counsellor, who to this day, has helped me to keep focusing on living life to the full instead of worrying about how sick I may get while I wait for this kidney.

Across the road from the hospital, the IKA have provided accommodation, for patients on dialysis or who need a kidney transplant and their families, who may need to stay near to the hospital overnight or longer.

There is a kitchen for those who just want somewhere to have a cup of tea or a bite to eat. There are 13 bedrooms for patients and their families who have to make long journey's up and back regularly for dialysis or who have had a kidney transplant.

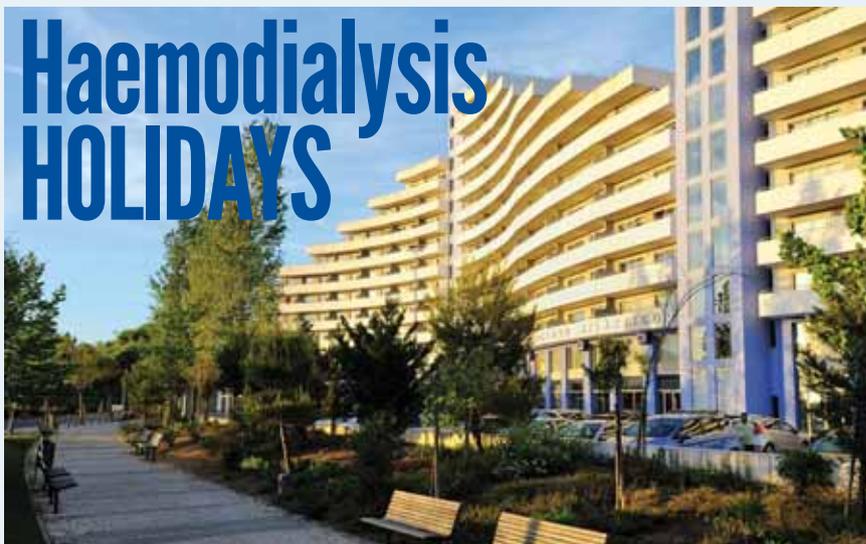
The IKA have also publishes a series of books with information on everything that patients and their families need to know about CKD and how to manage it, to transplants and dialysis.

These books and more information about the IKA are available on their website, www.ika.ie.

If you would like to learn more about transplants and dialysis, please visit www.beaumontfoundation.ie.

For more information on Spina Bifida and Hydrocephalus, please visit www.sbhi.ie

Haemodialysis HOLIDAYS



The IKA has secured accommodation in Oceano Atlântico, Portimão, Portugal (<https://en.oceanoatlantico.com.pt>) for haemodialysis patients holidays. The studio apartment, which has one double bedroom, can accommodate four people. It is self-catering apartment and transfers from Faro Airport will take an hour.

The apartment is secured for April, May, September and October 2019. If you would like to avail of a week in this free accommodation, please express your interest to Deborah, our Holiday Coordinator. Haemodialysis will have to be secured and booked separately. There is a Fresenius Haemodialysis Clinic, ten minutes walk from the apartment, which accepts the EHIC card for dialysis. Kindly note that you will have to fund your own flights and journey to the apartment. Priority will be given to those patients who have not travelled abroad previously and who, otherwise, would not be in a position to afford it.

Air Lingus offer flights from Dublin, Cork, Shannon and Belfast to Faro. Ryanair offer flights from Dublin, Cork, Kerry, Knock, Shannon and Belfast.

If you have never received dialysis treatment abroad it is essential that you talk to your nurses and doctors about undertaking a trip like this. The Fresenius Unit, if it is available, will not block-book spaces for anyone and will require a medical report from your unit - early! Irish patients have used this facility and it complies with the strict standards that your unit will insist upon. So, if you wish to consider a week in April or May it is necessary to commence the process now.

May I caution you to never book a flight before you secure your dialysis treatment. Deborah has vast experience of booking patients throughout the world but, particularly, in Europe. So if you wish to consider a different location - do speak to Deborah in Donor House, 01-6205306.

We expect to have our new Holiday house in Killarney ready for occupation by May 2019. The forms for Tralee and Tramore, along with Killarney, will be available at the end of January.



Presumed consent is not the key for success in deceased donation



Rosario Marazuela



Beatriz Domínguez-Gil

First published in
TransplantWorld, 2, 2018

Rosario Marazuela and Beatriz Domínguez-Gil discuss issues surrounding presumed consent for organ donation

Solid organ transplantation is the best and, frequently, the only therapeutic strategy available for patients with end-stage organ failure. According to the Global Observatory on Organ Donation and Transplantation, almost 136,000 solid organ transplants were performed worldwide in 2016¹. Although impressive at first sight, this activity barely covers 10% of the transplantation needs of patients. Shortage of organs is indeed the main obstacle that precludes the full expansion of transplantation therapies. As a result of shortage, thousands of patients die or endure a poor quality of life while waiting for an organ. Desperate patients in need of a transplant may look for solutions in the form of organ trafficking and transplant tourism, practices that violate fundamental human rights and erode the image of ethically sound transplant programmes. Transplant rates are also extremely unequal across countries, ranging from 0 to more than 110 patients transplanted per million population in Spain².

Although many factors can potentially explain this variable activity across jurisdictions, the type of consent system for posthumous donation has traditionally gathered a lot of attention. Some countries have put in place the so called opt-in or explicit consent system, whereby persons will only be considered deceased organ donors if they have specifically expressed their willingness to donate their organs or if their legal representatives authorise organ recovery. In countries with an opt-out or presumed consent policy, all persons are considered deceased organ donors unless they have expressed the opposite during their lifetime. Because, theoretically, presumed consent sets down a more favorable scenario to organ donation, several legal systems have moved on to this type of consent. Recent examples are those of Argentina, Colombia, Scotland or The Netherlands.

KEY FOR SUCCESS?

But is presumed consent really the key for success? Spain is a world leader in organ donation and has an opt-out system in place since 1979. However, we have never considered that this type of consent explains the Spanish success³. First, it was not until 1989 – ten years after the legislation was issued – that donation rates started to increase in our country following the implementation of the so-called “Spanish Model on Organ Donation and Transplantation⁴.” The presumed consent policy is not strictly enforced either, so the daily practice more closely resembles an opt-in system⁵. Donor coordinators must ensure that no opposition to organ donation has been recorded during the lifetime of potential deceased organ donors, through the Advanced Directive Registries and other means. An interview is always held with relatives of potential organ donors to assess if donation was

KIDNEY HEALTH

FOR EVERYONE EVERYWHERE



WHAT WE CALL FOR

This year, **World Kidney Day** sets out to raise awareness of the high and increasing burden of kidney diseases worldwide and the need for strategies for kidney diseases prevention and management.

Kidney Health for Everyone Everywhere calls for **universal health coverage (UHC) for prevention and early treatment of kidney disease.**

The ultimate goal of a UHC policy is to promote population health by ensuring universal, sustainable and equitable access to essential healthcare of high quality, protecting people from health impoverishment and improving equity in health across socioeconomic groups.

Specifically, WKD calls on everyone to advocate for concrete measures in every country to improve kidney care:

- Encourage and adopt healthy lifestyles (access to clean water, exercise, healthy diet, tobacco control). Many types of kidney diseases can be prevented, delayed and / or kept under control when appropriate prevention measures are in place.
- Make screening for kidney diseases a primary healthcare intervention including access to identification tools (e.g. urine and blood tests). Screening of high risk individuals and early diagnosis and treatment is cost effective to prevent or delay end-stage kidney diseases.
- Ensure kidney patients receive basic health services they need (e.g. blood pressure and cholesterol control, essential medications) to delay disease progression without suffering financial hardship.
- Call for transparent policies governing equitable and sustainable access to advanced health care services (e.g. dialysis and transplantation) and better financial protection (e.g. subsidies) as more resources become available.

Breaking down socioeconomic barriers and expanding access to comprehensive services in order to meet the needs of the population is essential to guarantee equitable kidney care and increase quality.

JOIN OUR CALL FOR KIDNEY HEALTH FOR EVERYONE EVERYWHERE!

[i] Organisation for Economic Co-operation and Development

KIDNEY DISEASE: THE BURDEN

850 MILLION PEOPLE WORLDWIDE are now estimated to have kidney diseases from various causes. **Chronic kidney diseases (CKD)** cause at least 2.4 million deaths per year and are now the 6th fastest growing cause of death.

Acute kidney injury (AKI), an important driver of CKD, affects over 13 million people worldwide and 85% of these cases are found in low and middle-income countries (LMICs). Around 1.7 people are estimated to die annually because of AKI.

Moreover, CKD and AKI are important contributors to increased morbidity and mortality from other diseases and risk factors including cardiovascular disease, diabetes, hypertension, obesity, as well as infections such as HIV, malaria, tuberculosis and hepatitis. Furthermore, CKD and AKI in children, not only lead to substantial morbidity and mortality during childhood but also result in medical issues beyond childhood.

CHALLENGES TO KIDNEY HEALTH: DISPARITIES & ACCESS

Despite the growing burden of kidney diseases worldwide, kidney health **disparity and inequity** are still widespread. CKD and AKI often arise from the social conditions in which people are born, grow, live, work and age including poverty, gender discrimination, lack of education, occupational

hazards and pollution among others.

Transplantation is considered the most cost-effective treatment of CKD. However, it has high set up costs with regards to infrastructure and requires highly specialised teams, availability of organ donors and cannot be done without dialysis backup. Physical and legal infrastructure requirements and cultural bias against organ donation often present barriers in many countries, making dialysis the default option.

However, while national policies and strategies for non-communicable diseases (NCDs) in general are present in many countries, specific policies directed toward screening, prevention and treatment of kidney diseases are often lacking. More than half (53%) of countries that have an overarching NCD strategy in place have no management guidelines or strategy for improving the care of people with CKD (either specifically or within a broader NCD strategy).

If you want to do something for WKD you should go to the website www.worldkidneyday.org and download the materials which are freely available and of high quality for printing. You will also see what people have done in passed years.



World Kidney Day is a joint initiative of



International Federation of Kidney Foundations

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SOCIAL MEDIA & COMMUNICATION



By **ROBYN BLACK**

Facebook or Twitter... take your pick. How many times a day do you visit these, or any other social networking site? And if you're not a user yourself, you probably know at least one person who never has their phone out of their hand, scrolling through endless pages of jokes, videos, memes, news and more. It's easy to point the finger at social media as being the cause of many of society's problems today, but can I give you a reason to argue that for us, social media is an invaluable tool?

I can give you 24,924 reasons. Or €24,924.76 to be exact. Since activating the fundraising tool on our Facebook page in March this year, that's the figure that has been raised. The incredible thing is that it requires little-to-no effort on our part, as people set up their own birthday fundraisers and click to donate without prompting. Simply by maintaining a presence on the site, our fundraisers have done a lot of the work for us!

But fundraising isn't the main thing that we use our pages for. With our network of branch pages, run by volunteers, we're spreading the word about organ donation. Our follower count is steadily rising, and thankfully our followers are as passionate about the cause as we are. I'm always on the lookout for the next way to convince people to become donors, and with an army of people liking, sharing and commenting on our content, we're already a step ahead of most marketers.

Looking forward to 2019, I want to build on our already strong platforms. Instagram is our smallest page in terms of followers, but one of our most reactive when it comes to engagement; as they say, a picture is worth a thousand words. The Instagram demographic is typically younger than that of other platforms, which makes it useful to promote the idea of organ donation to a generation which is already one of the most liberal

and open-minded. With talk of the Facebook-owned platform rolling out the fundraising tool, it could soon be another way to fundraise. Making this page bigger and better is top of the 'to do' list.

Another thing I want to focus on is video. It's estimated that 74% of all internet traffic is video-based, and that figure is only increasing. 90% of consumers say videos help them make buying decisions, and that they prefer to watch a video about a product than read about it. In fact, one digital marketing expert has estimated that 1 minute of video content is equal to around 1.8 million words. Maybe that seems a bit far-fetched, and technically we're not selling a product. But we are selling an idea, and the marketing principles are the same. Live videos on Facebook and Instagram could massively increase our engagement numbers, and in turn hopefully convince more people that organ

donation is the way forward.

Until then, I'm always here to help promote our events, answer the questions and requests we get daily, and share the odd funny video (Stayin' Alive on HD anyone?). So if you're having an event, or branch meet-up, or even if you come across an article or photo you think is worth sharing, drop me an email or tag the IKA page in it. Your events and thoughts and news are the content – I'm just the messenger.



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



Mick Connell, Pauline May, Angeline Cooke, Bernie Coyle, Owen Trill and Neil Fraser

HEADFORD

Organ Donor Awareness Initiative

A pilot organ donor awareness initiative in Headford, Co. Galway, the first of its kind in Ireland which aims to rally the support of a whole town, was launched on Saturday, December 1st.

The initiative entitled 'Headford Organ Donor Awareness Week' is the brainchild of Neil Fraser who was motivated to undertake the project following the death of his dear friend Aidan Hickey. The late Aidan RIP sadly passed away earlier this summer after a heart attack whilst he was waiting for a liver transplant.

The campaign was launched in the Anglers' Rest Hotel in Headford, Co. Galway. Aidan's family, including widow Siobhan Camplisson, daughter Laura and sons James and Cian, were guests of honour at the launch which had a large attendance of individuals and community representatives including schools, businesses, voluntary groups, sporting clubs and societies.

Guest speaker Pauline May, Saolta University Health Care Group, explained her role as a donor coordinator and the organ donation process.

Pauline explained the Saolta group



Headford Organ Donor Awareness Initiative attendees

of hospitals stretch from Donegal to Galway. She spoke about her work in the hospitals, training doctors and nurses in developing their skills in dealing with families and patients at end of life stage, and how to approach families to consider donation. So far, this year, she said that 10 donors came from her group of hospitals.

Peadar O'hici represented the IKA. Peadar, a retired school Principal, shared his personal experience of waiting for a kidney transplant and his fortune in receiving the 'gift of life'

thanks to a deceased organ donor. On the evening Aidan's daughter, Laura, gave a CPR demonstration.

Key organiser, Neil Fraser said, "When I first muted the concept of a Headford Organ Donor Awareness Week with Aidan's family and then members and organisations in the community, it was warmly and enthusiastically received. Aidan was a much loved and respected pillar in the community and in rugby circles as an accomplished former rugby player and then a passionate rugby coach. His



Cian Complisson (3rd on right) with Corrib Rugby Club Senior panel's Joe Walsh, Charlie O'Sullivan, John McHugh, Kevin Reilly, Cathal Reddington and Chris Kiely



Laura Hickey giving CPR training



Peadar O hici, Principal Mary and Pauline May at Presentation College Headford



Siobhan Camplisson (Aidan's widow)

tragic death, whilst awaiting a liver transplant, had a profound impact on many of those who were blessed to know him. By being the first town to undertake this project, we hope that the pilot ultimately flies and that other towns will be inspired to also host organ donor awareness initiatives next year and beyond and perhaps tie them in with, and create, even greater impetus for the IKA's national Organ Donor Awareness Week, which will run from March 29th until April 6th in 2019."

We were delighted that our doctors' surgeries and four local pharmacies, the Credit Union and some businesses and organisations, agreed to share the message of organ donation during the Week by prominently displaying organ donor cards for distribution.

On the Monday following the launch both Pauline and Peadar spoke to over 230 students in Presentation College, Headford on organ donation and transplantation. They spoke to the senior students and classes were divided into small groups. These talks took over three hours and the Principal and staff and, of course the students, were very supportive and appreciative of their talks.

Colin White, IKA National Projects Manager said, "we commend Neil and the Hickey family on this undertaking and wish them and their community every success. The pilot project is particularly timely at the beginning of December just before families gather for the festive season and they can take the opportunity to discuss their wishes around organ donation".

Written by members of
**RENAL INTEREST GROUP
OF THE IRISH NUTRITION
& DIETETIC INSTITUTE**



EATING WELL ON YOUR HAEMODIALYSIS DAYS

Research has shown that some people don't eat enough on dialysis days as they can often miss a main meal and have a very long period of time when they are away from home. During your dialysis session your protein requirements increase and you lose protein in the fluid that is removed during the procedure. You need to eat enough protein containing foods to keep your muscles strong, repair tissue and fight infection.

It is recommended that you try to eat foods that contain protein during your dialysis session, such as meat, fish, chicken or eggs. Some patients cannot tolerate eating while on the dialysis machine. Your doctor, nurse or dietitian will advise you regarding this and will arrange for you to have something to eat either before, or after, if you cannot tolerate food during dialysis.

WHAT SHOULD I EAT DURING HAEMODIALYSIS?

During haemodialysis we would encourage you to have a nutritious sandwich to ensure you get enough protein that day. The best options for fillings include;

- Turkey
- Beef
- Chicken
- Chicken and stuffing
- Tuna mayonnaise
- Egg mayonnaise

Avoid processed meats with phosphate additives.

Sandwiches can be made on white, brown or granary bread and can include a small amount of salad.

To add some extra flavour to your sandwich, talk to your dietitian about suitable sauces, for example cranberry sauce and horseradish sauce.

Please remember to bring your phosphate binders with you to dialysis, to take with your sandwich.

Fluid intake should be restricted to one small cup of tea or water per dialysis session to ensure that adequate fluid is removed during your treatment.



IS IT SAFE TO EAT HIGH POTASSIUM SNACKS ON DIALYSIS (eg chocolate or crisps)?

No, it is not safe as the potassium contained in the snack may not be removed from your blood during that particular dialysis session.

If you have any questions or queries, please ask your Dietitian.



Front: Mary Butler, TD, Jack Kelly and Claire Meaney, Acting Arts Director, WHAT; (standing, l-r): Maeve Butler, Acting Assistant Arts Director, WHAT, Dr Elizabeth Abernethy, Consultant Nephrologist, UHW, Brenda Ronan, Clinical Nurse Manager, Renal Dialysis Unit, UHW and Boyer Phelan, artist with WHAT.

77 Years A-Dreaming

Recollections and Reflections on a Wonderful Life

The memoir of renal dialysis patient and amateur historian Jack Kelly was described as “an invaluable reference to life in Portlaw” and “a valuable insight into the social history of Ireland” by Mary Butler, TD, as she officially launched *77 Years A-Dreaming: Recollections and Reflections on a Wonderful Life* at Waterford Healing Arts Trust (WHAT), University Hospital Waterford (UHW) in November. The book is available to purchase at WHAT and The Book Centre, Waterford. Further details are available from www.waterfordhealingarts.com or phone: 051-842664.

Jack Kelly has spent the last year writing and crafting *77 Years A-Dreaming*, his voyage of discovery through his countless memories and stories, reflecting a life lived to the full. From his childhood in Portlaw to the heady days in London in the swinging 60s and 70s and back home to Portlaw in his later years coping with unexpected illness.

WHAT is Ireland’s leading arts and health organisation. Established in 1993,



Jack and family pictured at the launch

WHAT brings arts experiences to the bedsides of patients at UHW and other healthcare settings. WHAT has been running an arts programme in the renal dialysis unit of UHW since 2007, supported by the Punctestown Kidney Research Fund. WHAT believes that the

arts contribute to the wellbeing and vitality of society and that engaging with the arts stimulates the participant’s sense of identity and creativity. WHAT also supports the development of arts and health in Ireland and manages the national website www.artsandhealth.ie

Jewellery Design Competition

The IKA wish to acknowledge all 'living donors' for their selfless gift to their relatives or friends. With this in mind we are asking you to design a silver brooch which would suit this purpose. If you wish to submit a sketch of your idea, please do so and a team from both Beaumont Hospital and the Association, will adjudicate and select the winning proposal. The photographs below of some other designs, hopefully, will inspire you to produce an Irish design for this project. **The winner will receive a 'ONE FOR ALL' gift voucher for €500 and there will be two runner-up prizes of €100 gift vouchers.**



**Send your sketches, marked 'JEWELLERY DESIGN COMPETITION' to:
Donor House, Block 43A, Park West, Dublin D12 P5V6 by January 31st 2019**

SPORTS PROGRAMME 2019

ALSAA Sports Complex - www.alsaa.ie



SUNDAY JANUARY 13TH: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Bowling

SUNDAY FEBRUARY 3RD: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Darts / Bowling

SUNDAY MARCH 3RD: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Table Tennis / Bowling

FRIDAY APRIL 5TH-7TH:

5 NATIONS GOLF TOURNAMENT (Edinburgh)

SUNDAY APRIL 14TH: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Squash / Bowling

SUNDAY MAY 5TH: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Tennis / Bowling

SUNDAY JUNE 2ND: (11.00am – 3.30pm)

ALSAA Sports Complex
Sports Hall / Swimming / Track / Bowling

SUNDAY JULY 7TH:

TEAM KIT DAY – WORLD GAMES

WEDNESDAY JULY 24TH – MONDAY 29TH

BRITISH TRANSPLANT GAMES

Newport, Wales

SATURDAY AUGUST 17TH - SATURDAY AUGUST 24TH

WORLD TRANSPLANT GAMES

Newcastle, England

**There's a lot on offer in 2019
and newcomers are always welcome.
Contact Colin White in Donor House
(colin@ika.ie / 01 620 5306) for more details.**



10th European

TRANSPLANT AND DIALYSIS SPORTS CHAMPIONSHIPS



17-24
JUNE 2018

Cagliari, Sardinia



*Aoife Murray,
Rachel Eagleton*



*Sheila Gregan,
Orla Hogan,
Peter Heffernan,
Deirdre Faul*



Keiran Murray Vojta Koudelka, Simon Perkin



Charlie Ryan



Verina Borrisova



Paul Prendergast, Stephen Byrne

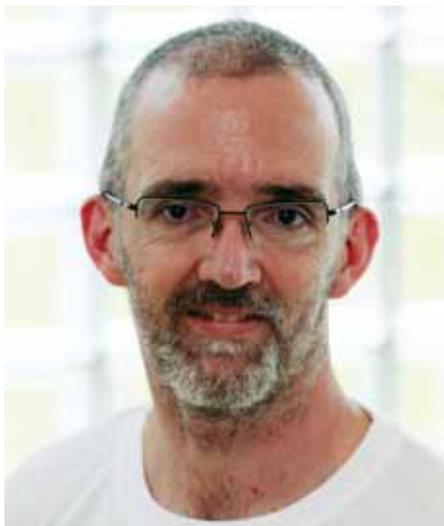


Finian O'Farrell, Emma O'Sullivan



Ron Grainger, Kieran Murray, Pat O'Sullivan, James Nolan

“Each and **EVERY MEMBER** of our **TEAM**, competitors and supporters alike, **BRINGS SOMETHING SPECIAL** to our team”



By **COLIN WHITE**
TEAM MANAGER

Email: colin@ika.ie
www.transplantteamireland.ie



Mark Murphy, Colin Mackenzie

This year's European Transplant & Dialysis Sports Championships were hosted by Forum Sport Italia in Cagliari, Sardinia from June 17th-24th. With 25 countries participating, including teams from Bosnia & Hercegovina, Kazakhstan and Russia, it was a great cultural melting pot as well as a celebration of life through sport.

With the Championships open to people on dialysis and transplant recipients the event brought together a great diversity of people. Everyone there understood the importance of taking a proactive role in their own healthcare and the power of regular physical activity/sport to make a real difference in the quality of life experienced.

The Championships offer the opportunity to set a personal goal. A transplant recipient may wish to use participation in the event as a motivation to return to a sport they love or to take on sports that they were not able to consider prior to

transplant. A person on dialysis may be active on a transplant pool or hoping to be listed and they use their participation in the event as a motivation to be as healthy as they can be or they may simply enjoy the opportunity of continued involvement in organised sport.

A word often used to describe the Championships is, 'friendly'. Whether old rivalries are renewed or new rivals are revealed, there is always respect and with that the opportunity for

friendship. Our team epitomises this aspect of the Championships. The natural affability and positive outlook from every member of the team is truly infectious.

I have said of previous Championships/Games that it is the thousands of 'moments' that make up the overall experience and this year was no different. The common denominator in all these 'moments' is the taking of joy in life – a deeply held appreciation for the value of good health.

As with every successful team, there is a dedicated backroom team and we are fortunate to have a great set up. Our new team doctor, Heather gunning, took to it like a duck to water! She slotted in immediately and became an integral part of the team. Sarah May once again joined us to ensure that all the stories got out there via our Blog and social media and also through Gwen O'Donoghue who kept the domestic media up-to-date with all of the team's exploits. The ultimate compliment to Sarah is the fact that other teams want her on their team too as they see her commitment (always underpinned with a sense of fun!).

It was great to have Colin Mackenzie from the board of the IKA with us this year. He was a great supporter and the team embraced his friendship. He had the opportunity to share his experiences with the board of the IKA upon his return which is hugely important as our sports programme would not be the success it is without the support of the Board. Our CEO, Mark Murphy, is our team 'fixer.' If we need to get someone from A to B then Mark is there. If we need to find something locally that an individual or the team needs then Mark is there. Most importantly, if we need to get our doctor to a team member or get a team member to the hospital, Mark is there.

contd...



Judith Berente, Teemu Lakkasuo, Colin White, Chikoyo White, Paolo Trudu



Our captain, Harry Ward, has a heart of gold and his quick wit also keeps us all amused. I treasure his counsel – I know that I will always get honest advice from Harry and I know that it will always be given in the best interests of our team.

Each and every member of our team; competitors and supporters alike, brings something special to our team and they make our team what it is. I always let ‘newbies’ know that there is a certain responsibility that comes with being part of our team and there are so many benefits too.

The Gala Dinner was a great conclusion to the week as it was an opportunity to reflect on a week of great experiences and look forward to meeting friends again at the World Transplant Games in Newcastle/Gateshead next year. Seeing the juniors and the over 70’s getting special recognition is an inspiring aspect of the Gala Dinner – we can all learn a lot from their fortitude.

On a personal note, I was exceptionally happy to have my wife, Chikoyo, on the team for her fifth European Championships. Seeing what being part of the team means to her and seeing her perform to her best was a joy to behold. The memories from this year’s Championships will be particularly special as Chikoyo won the overall prize for best female athlete in the dialysis category. She is in her 18th year on dialysis and her determined

outlook and ‘can do’ attitude are a shining example to us all.

I was also humbled to be re-elected to the Presidential Committee of the European Federation and I will continue to serve as Secretary for another 4 years.

I was delighted to have the opportunity at the Gala Dinner to deliver a presentation about our plans for the 2020 European Transplant & Dialysis Sports Championships that we will be hosting in Dublin from August 9th-16th. There is great enthusiasm for our hosting of the Championships with many of the participants from across Europe remembering the success of the last time we hosted in 2010. If you can help with the planning (sourcing volunteers, funding, support, etc.), please contact me (colin@ika.ie).

Sign up for next year’s World Transplant Games in Newcastle/Gateshead or the European Championships in Dublin in 2020. Join a very wonderful team. Be a part of these special events and let yourself, your family and your friends know that YES YOU CAN! Let others coming to terms with organ failure see that ANYONE CAN overcome. Let the public know that the organ donation conversation CAN transform lives!

Whatever your motivation, I promise that if you sign up with Transplant Team Ireland you will thank yourself in future!



***Whatever your motivation,
I promise that if you sign
up with Transplant Team
Ireland you will thank
yourself in future!***

“ONE for ALL and ALL for ONE”

Merry Christmas to one and all.

This year's European Transplant and Dialysis Sports Championships were a great success for Transplant Team Ireland - bringing home a lots of medals as well as many happy memories of old friendships and plenty of new ones.

I would like, on behalf of myself, our team members, and our fabulous supporters, to say a massive 'thank you' and well done to Colin for once again organising every little detail of our trip. Also, a massive shout out to our hard working support team of Mark, Heather and Sarah and of course not forgetting our own Gwen.

This year we had the pleasure of Colin MacKenzie (current IKA Honorary Treasurer), as a supporter - we hope he enjoyed the Championships and could see how we honour our donors and their families through sport.

The Championships were a great success and our thanks has also to go to the Local Organising Committee for a wonderful event. Every year it amazes me how, as a team, we all

bond together - one big happy family where everyone looks out for one and other throughout the week of the Championships, and beyond.

The support from the Irish team, that is given freely to all, is welcome at every venue. Perhaps the same



By **HARRY WARD**
Team Captain



Harry Ward at the Opening Ceremony

cannot be said for the quality of our singing of 'Do a run Ron, Ron' in support of our team-mate Ron Grainger! Lol. It's all good team spirit and a lot of fun!

I want to thank all my team mates and our wonderful supporters for all the help in every which way no matter how small or big - if you were asked it was done. That is what makes Transplant Team Ireland work as the musketeers would say - One for all and all for one! I am looking forward to seeing our old team members and many new team members in the ALSAA Sports Complex for our Training Sessions in the New Year. Thank you and a happy, healthy New Year to all.



10TH EUROPEAN

TRANSPLANT

DIALYSIS

SPORTS CHAMPIONSHIPS

TRANSPLANT TEAM IRELAND - MEDAL TABLE -

NAME	EVENT	MEDAL	NAME	EVENT	MEDAL
Verina Borissova	10-pin bowling Singles	Bronze	Aoife Murray	10-pin bowling Singles	Silver
Verina Borissova	Petanque Singles	Bronze	Aoife Murray	Petanque Doubles	Bronze
Verina Borissova	Darts Singles	Gold	Aoife Murray	Petanque Singles	Silver
			Aoife Murray	Tennis Singles	Bronze
Rachel Eagleton	Tennis Singles	Silver	Kieran Murray	Golf Singles	Gold
Finian Farrell	Petanque Doubles	Silver	Kieran Murray	Mini-Marathon 5km	Bronze
Deirdre Faul	Swimming 50m Freestyle	Gold	Kieran Murray	Track & Field 800m	Bronze
Deirdre Faul	Swimming 100m Freestyle	Gold	Kieran Murray	Track & Field 1500m	Silver
Deirdre Faul	Swimming 50m Breast Stroke	Gold	James Nolan	Golf Singles	Silver
Deirdre Faul	Swimming 100m Breast Stroke	Silver	Marie O'Connor	Darts Triples	Bronze
Deirdre Faul	Swimming 400m Freestyle	Silver	Marie O'Connor	Golf Singles	Gold
Ronald Grainger	Golf Singles	Gold	Marie O'Connor	Petanque Singles	Bronze
Ronald Grainger	Track & Field 100m	Gold	Marie O'Connor	Track & Field 100m	Silver
Ronald Grainger	Track & Field 200m	Gold	Emma O'Sullivan	Mini-Marathon 5km	Bronze
Sheila Gregan	Cycling 20km Road Race	Gold	Emma O'Sullivan	Track & Field 200m	Bronze
Sheila Gregan	Mini-Marathon 5km	Silver	Patrick O'Sullivan	Track & Field Long Jump	Bronze
Sheila Gregan	Swimming 50m Freestyle	Silver	Patrick O'Sullivan	Track & Field 100m	Bronze
Peter Heffernan	Swimming 400m Freestyle	Bronze	Patrick O'Sullivan	Track & Field 200m	Bronze
Peter Heffernan	Swimming 50m Freestyle	Bronze	Paul Prendergast	Darts Triples	Bronze
Peter Heffernan	Swimming 100m Freestyle	Silver	Charlie Ryan	Darts Singles	Gold
Orla Hogan	10-pin bowling Singles	Bronze	Charlie Ryan	Petanque Doubles	Silver
Orla Hogan	Swimming 50m Freestyle	Bronze	Charlie Ryan	Petanque Singles	Silver
Orla Hogan	Track & Field 3km Power Walk	Silver	Leonard Ryan	10-pin bowling Singles	Bronze
Mike Keohane	Track & Field Discus	Silver	Leonard Ryan	Petanque Singles	Silver
Mike Keohane	Track & Field Shot Put	Bronze	Harry Ward	Darts Triples	Bronze
Mike Keohane	Track & Field 5km Power Walk	Bronze	Chikoyo White	10-pin bowling Singles	Silver
John McAleer	Golf Singles	Silver	Chikoyo White	Petanque Doubles	Bronze
John McAleer	Petanque Singles	Bronze	Chikoyo White	Petanque Singles	Silver

**CHIKOYO WHITE WON BEST OVERALL FEMALE AWARD
IN THE DIALYSIS CATEGORY**

MEDAL TABLE - 55 MEDALS

**Gold
11**

**Silver
20**

**Bronze
24**



Sheila Gregan



John McAleer, Lenny Ryan



Pat O'Sullivan



Deirdre Faul



Mike Keohane



THE FULL IRISH TEAM WAS:

NAME	COUNTY	NAME	COUNTY
Verina Borrisova	Dublin	Kieran Murray	Donegal
Stephen Byrne	Kerry	James Nolan	Kildare
Rachel Eagleton	Meath	Marie O'Connor	Clare
Finian Farrell	Westmeath	Emma O'Sullivan	Kilkenny/Limerick
Deirdre Faul	Dublin	Patrick O'Sullivan	Cork
Ron Grainger	Dublin	Paul Prendergast	Dublin
Sheila Gregan	Tipperary	Charlie Ryan	Cork
Peter Heffernan	Dublin	Leonard Ryan	Dublin
Orla Hogan	Tipperary	Harry Ward (Captain)	Dublin
Mike Keohane	Cork	Linda Waters	Roscommon
John McAleer	Antrim	Chikoyo White	Dublin
Aoife Murray	Dublin		

“I decided to put back on my RUNNING SHOES and return to the TRANSPLANT TEAM IRELAND FAMILY”

Having been away from the Games for nearly 8 years I decided to put back on my running shoes and return to the Transplant Team Ireland family.

It all began in July 2017 when I started doing the Couch to 5k to get my fitness levels up again. I started to enjoy training again and that's when it hit me that I missed taking part in competitive sport.

I decided to tell Colin White (our Team Manager) that I was coming back on board for the European Games in Sardinia.

I started training 4-5 days a week and it felt great to get stuck back into it again. I felt a lot healthier. As 5k was a new event for me I took part in a few 5k's to get my endurance levels up.

We arrived in Sardinia on Saturday night June 16th. My first event was on



By **EMMA O'SULLIVAN**

Monday morning, the 5k mini-marathon. When I was running I realised how much I had missed taking part in the Games. I missed the atmosphere and the comraderie not



Emma O'Sullivan, Rachel Eagleton

only within Team Ireland but with all the European teams, we are like one big family. Even though we are competitive, at the end of the day we have all been through the same experience and we all support each other along the way.

Thinking back over the week of the Games I realised how I loved being part of the team and the experience of taking part in competitive sport again. It was great to meet old friends and to also make new ones along the way. I brought home 2 bronze medals over the week, the first in the 5k mini-marathon and second in the 200m sprint.

Participating is a great experience and a great way to represent your donor family. I would like to thank them for giving me a second chance and also it is great to be able to represent your country, not everyone can say that they have represented their country at European and World level.

This year I was joined by my husband John, son Ewan (4) and my parents-in-law, this made going back to the Games even more special as my son got to see his mammy compete on the European stage for the first time.

I would encourage anyone reading this, who has had a transplant or on dialysis, to come and join the team for the 2019 World Transplant Games in Newcastle/Gateshead or the 2020 European Transplant and Dialysis Games which are being held in Dublin.



Emma O'Sullivan with her husband John, her son Ewan and her husband's parents



Orla Hogan, Sheila Gregan and supporters



Ron and Joyce Grainger



*Aoife Murray,
Rachel Egleton*



Paul Prendergast, Harry Ward and Marie O'Connor with their friends from Germany



Marie O'Connor



Aoife Murray with a friend from Italy



Charlie Ryan



Orla Hogan



Rachel Egleton, Stephen Byrne



Lenny Ryan with fellow medallists after the Petanque



Harry Ward with a friend from Slovenia



Rachel Eagleton, Ivett Jakab



Colin White and
WTGF President Chris Thomas



Emma O'Sullivan, Harry Ward, Stephen Byrne



Mike & Dee Keohane



Charlie Ryan, Deirdre Faul, Aoife Murray, Mike Keohane



Marie O'Connor, John McAleer, Sarah May



Back: Charlie Ryan, Heather Gunning, Paul Prendergast
Front: Stephen Byrne, Chikoyo White, Orla Hogan



Emma O'Sullivan



Aoife Murray and fellow competitor from Italy



Kieran Murray



Claudio Mendes, Stephen Byrne



By
FINIAN FARRELL

“The **FRIENDSHIPS** I have made with fellow **ATHLETES** from here and across Europe will **STAY WITH ME forever**”

September 2015, not a major month in anybody’s memory but for me it will live forever as it was during this month that I decided to travel to ALSSA, one Sunday morning, to have a look at what Transplant Team Ireland was all about. My wife Tina had been onto me a few times after reading the *SUPPORT* magazines from the IKA, and seeing the articles about the Games that had taken place over the year. Whilst she was shopping with the kids in Liffey Valley, I said right here goes and off I went.

I walked in the door at ALSSA and in the foyer were Harry Ward and Colin White. Both introduced themselves and immediately put me at ease. I later found out that Harry is the Team Captain and Colin the Team Manager as well as the European Transplant and Dialysis Sports Federation Secretary.

They then brought me into the hall where there were a number of other people getting ready to enjoy some Badminton. Straight away they all came over and welcomed me into the fold.

I have played a number of sports over the years before I became sick but I have never felt as welcome anywhere as much as that day in Dublin. One of the first things to hit me was that I realised that everybody there had been through some major health issues themselves but that it wasn’t impeding them doing some sports to their own levels.

Another thing that really stood out was the family feel that came to me was very strong. To meet a strange group of people and to feel at home immediately helped me immensely along this journey.

Over the next few months at the training sessions I was encouraged to take part in the European Transplant & Dialysis Sports Championships (ETDSC) in Finland in 2016. I must admit that I was very hesitant at doing this but as there were also a number of other first-timers attending ALSSA, we all decided to jump in and go for it.

It has been one of the best decisions I have ever made as to go away with this amazing group of people and represent my country is just brilliant. No matter how many times anybody else had been at any Games, they were brilliant at just encouraging myself and the other ‘newbies’ throughout our first journey. Since then I have taken part in the British Games in Scotland in 2017 and the ETDSC this year in Cagliari.

If there is anybody who is anyway hesitant at joining up with this group, I must reiterate that there is absolutely nothing to fear as we are just one big group of friendly people who love to play some sports and meet up with like-minded persons from other countries who have all had health problems themselves but put them to one side to enjoy sports.

The friendships I have made with fellow athletes from here and across Europe will stay with me forever.



Charlie Ryan, Finian Farrell, Harry Ward, Paul Prendergast



Rachel Eagleton, Michael Dwyer



Back: Harry Ward, Lenny Ryan, Colin White, Chikoyo White, Heather Gunning, Front: Ron Grainger, Aoife Murray, Verina Borrisova



Aoife Murray and her mother Mags



James Nolan, Chikoyo White, Verina Borrisova



Orla Hogan, Sheila Gregan



Pat O'Sullivan, Mike Keohane, Charlie Ryan



Sophie, Grace and Chole Murray



Chikoyo and Colin White with Noel and Siobhan White



IRISH KIDNEY ASSOCIATION CLG

Donor House, Block 43A,
Park West, Dublin D12 P5V6
Tel: 01-6205306
Email: info@ika.ie
Web: www.ika.ie
Charity Registration No. 20011260



Kieron Murray, John McAleer, Heather Gunning



DUBLIN EAST & WICKLOW

By BERNIE DWYER

CHRISTMAS PARTY

The Dublin East + Wicklow branch had their annual Christmas lunch on Sunday December 9th in Ocean Bar & Grill Bray.

A total of forty five people attended including the Chief Executive Mark Murphy and his wife Frances whom we were delighted to have amongst us.

True to form we were served a beautiful 4-course meal by the friendly and accommodating staff in Ocean.

John Whelan our Branch Chairman and Mark Murphy spoke briefly of the work of the IKA and the continuing need for on-going support and participation from members during fundraising events so as to enable the IKA provide the necessary financial aid for patients.

A raffle followed which was met with both excitement and humorous rivalry amongst the group in anticipation as to who was going to be a lucky winner. A special thanks to Una Whelan and Mick Dwyer for their part in playing Santa Clause...!

The occasion was enjoyed by everyone providing an opportunity for members to meet up, enjoy gorgeous food and good conversation.

R.I.P

On behalf of the members and my fellow officers we would like to offer our deepest sympathies to one of our newest members Michael Long, whose wife Mary passed away in October, and also remembering all members who passed away during the year. May they Rest In Peace.

CHRISTMAS WISHES

John, Catherine and I would like to take this opportunity to thank all of our members, their families and friends, who generously gave of their time to help us throughout the year,



Gloria Proby, Ann Rountree, Joan Dobbyn



Philip and Marian Duane



Robert Litzer, John O'Connor



Denise and Caroline Cotter



Adam Sadleir and Eamon Kehoe



Patricia Delahanty, Frances Murphy, Michael Dwyer



Bridie Doyle, Mary Duffy, Noeleen Cleary

especially during Organ Donor Awareness Week. Your dedication and support is very much appreciated. To those of you who are feeling ill, either at home or in hospital, at this

time, we hope that you will be well enough to partake in the festivities. Wishing you all a very Happy Christmas and a happy and healthier New Year.



LONGFORD IKA BRANCH

CHRISTMAS PARTY

We held our annual Christmas party in the Longford Arms Hotel on Sunday, December 2nd. We had a really enjoyable day with a beautiful meal and great atmosphere. It was lovely to see a large turnout again this year and, in particular our kidney patients and donor families.

Thank you to all who donated spot prizes for our raffle and well done to all the winners.

THANK YOU

Thank you once again to all our volunteers who help out at our Annual Church gate collections throughout county Longford and during Organ Donor Awareness Week. Your continued support is greatly appreciated.



John Harte and his wife Maura handing over the cheque to Bernadette Wall and Elaine Heslin.

LONGFORD

By **SUSAN MARTIN**



We also wish to thank all those who generously donated to the IKA during 2018 and those individuals and groups that considered the Longford Branch of the IKA for the proceeds of their fundraising events during 2018.

In particular, we would like to thank Edre Mills and John Harte of the Lakeland Vintage Club who held a tractor run on October 14th - they kindly donated the proceeds to our branch.

CONDOLENCES

Our branch Committee extend their deepest sympathy to the family of the

late Peter Kinlan, Rathmore, Aughnaccliffe, Longford who sadly passed away on June 24th. May he Rest in Peace.

CHRISTMAS GREETINGS

Finally, I would like to take this opportunity to wish all our members and readers a very healthy, happy and peaceful Christmas and a prosperous 2019. We would also like to send Christmas wishes and much gratitude to all the staff in the Renal Dialysis Units and in Beaumont Hospital for all the care they gave our patients during 2018.



Longford branch Christmas Party





IKA LIMERICK

PATIENT INFORMATION EVENING

On Wednesday, November 7th a Patient Information Evening entitled *Chronic Kidney Disease: The Lived Experience* was held at The Auditorium, CERC Building, University Hospital, Limerick from 6pm to 9pm.

The Auditorium is now located on the site of the previous Home Dialysis Unit. This is a prefabricated building just adjacent to the main hospital and dialysis unit. Many anecdotes of days spent training in that unit, before starting home dialysis, were recalled and a lovely social evening followed.

There were questions on chronic kidney disease - what is it and how does it affect me? What treatments are available and how can it be fitted into a patient's lifestyle and information regarding the different types of treatments which are available. The aim was to provide practical, patient-focused information about all aspects of different types of dialysis. Four patients spoke of their personal experience of each treatment including: in-centre haemodialysis, home haemodialysis and peritoneal dialysis.

The staff were available to give demonstrations of equipment and answer any questions.

Consultant Nephrologist, Dr. Liam Casserly, hosted a question and answer session to round off the evening. Light refreshments were served.

The evening was facilitated by Brid Collins and Yvonne Crowe, Renal Nurse Co-ordinators and we would like to thank them both for the invitation to the evening.

LIMERICK

By MADELEINE DONAGHY





CHRISTMAS LUNCH

On Sunday December 2nd the Limerick Branch held its Annual Christmas lunch. The South Court Hotel, Raheen, Limerick was once again the venue. The response from patients and families was more than we anticipated, and a wonderful party followed.

We would like to thank the staff at the hotel who provided first-class service and the meal was thoroughly enjoyed by all.

This year we asked everybody to participate in a Secret Santa and this exceeded our expectations. Thank you to all the patients and their families who attended and who all arrived



bearing wonderful gifts. There was more than enough to go around and a free raffle afterwards ensured everybody went home with a Christmas gift. 'Thank you' to all who attended and made the day the wonderful success that it was, this year.

Jim Keane from the *Night Owls*, ably assisted by Christopher Downes, provided the music and the atmosphere in the room was wonderful.

The Limerick Branch would like to wish you all a Merry Christmas and a Happy and Healthy New Year.





GALWAY

By PEADAR Ó HICI

The Galway Branch organised a Party to celebrate the retirement of Anna Maguire, Renal Nurse Counsellor in Merlin Park Hospital, Galway and also to celebrate 40 years of the Irish Kidney Association. We held it in the Menlo Park Hotel on Saturday October 20th. The party was attended by many of her past renal patients and also a big cohort of her former nursing colleagues.

Anna came to us from Belfast in 1997, moving with her husband, two sons and their pet dog! In Merlin Park she gave 20 years of dedicated service to the renal patients until she retired in December 2017. During that time our lives were touched by her kindness, compassion, warmth and professional guidance. This writer first met her on my first pre-dialysis visits and was guided to which type of dialysis I could comfortably operate. In her role as Renal Nurse Coordinator she provided all the information and counselling that eased the patient and their family into adjusting to a new and unfamiliar life on dialysis.

Working in the Dialysis Unit 7 and the Outpatients Unit 1 she followed our progress right through transplantation and after, with interest and care. After my three monthly visit to Outpatients' Clinic I waited in anticipation to get a message from Anna indicating the latest report on my present medical position and any change needed in level of medication.

Anna was also an enthusiastic and helpful member of the IKA. At the party our branch presented her with an engraved plaque on which were the words of a song/poem first sung at the 50th Anniversary Celebrations of Christian Bernard's first heart transplant on November 30th 1967, in the Groot Schuur Hospital in Capetown, South Africa. The song is



called *Unselfish Act of Love*. The words epitomise the work Anna did during her long nursing life.

Thank you Anna and we wish you a long, happy and healthy retirement and many days walking with your dog.

We had, as a special guest, Dr Brendan Duffy and his wife Anne. Dr Duffy was the Consultant with a special interest in renal medicine at Merlin Park for 30 years from 1973 until his retirement in 2002.

Before coming to Merlin Hospital he

studied nephrology in the USA where haemodialysis was still at an experimental stage.

Over his 30 years span, Dr Duffy oversaw huge changes and developments in renal treatment.

He was President of the Galway branch IKA, took great interest in the development of the Association and contributed to many talks and seminars. So thank you Dr Duffy for your 30 years of dedicated service to renal patients in the West.

Anna Maguire's Retirement Party





Find us on:
facebook®

CLARE IKA BRANCH



The Clare branch extends their congratulations to Stella McDonagh and Garry Davis (dialysis patient) who were recently married in Liscannor Church, Co Clare.

EILEEN O'HALLORAN MEMORIAL SCHOOL QUIZ

Teach Ceoil Kilrush was the venue for the IKA Eileen O'Halloran Memorial School quiz in October. Clohane beg N.S. took first place with Ennis National N.S. taking second and third place. We thank the schools that participated, and, thanks to all for travelling to Kilrush to support the pupils.

Thanks to Ann and Vincent O'Halloran, Kathleen Lynch, Chloe Cahill, Carmel McCormack, Val Eustace and Branch Secretary Michael Mescall for their assistance that afternoon, and of course thank you to our quiz mistress Ann Hayes.

CHRISTMAS SOCIAL

Our Christmas social was held on December 2nd at the Old Ground Hotel in Ennis. Guests were the

CLARE

By PEGGY EUSTACE



Imelda McGann, New Quay, Anna Maguire and Clare branch Chairperson Peggy Eustace at a recent function held by the Galway branch IKA.

Cathaoirleach of Clare County Council Michael Begley and his wife Fidelma, Fr Martin Shanahan, and CEO of the Irish Kidney Association Mark Murphy and his wife Frances. Brid Collins and Fiona Keane from the Renal Department at UHL also attended.

The chairperson extended a warm welcome to the renal patients, transplant recipients, their carers, branch members and our many loyal volunteers. She went on to highlight that this year marked the 40th anniversary of the IKA and mentioned the main aims of the Association. Formed in 1978 by patients for patients, she said the Association endeavours to improve conditions and treatment options for patients living with and effected by end stage renal disease.

In those early days in order to survive many Clare patients had to endure the long journey to the former Jervis Street Hospital in Dublin for their dialysis treatment. Due to the involvement of the Association, along with the now HSE, 40 years on we have seen great advances in treatment options and dialysis centres become available for our patients much closer to home.

She thanked the branch members and volunteers for their support throughout the year with promoting organ donor awareness while also supporting our various fundraising initiatives.

Transplant recipients were invited to

light a candle, over the Christmas period, in memory of their donor.

Thanks was extended to the medical and nursing staff in the renal units who, due to their commitment and dedication, have enhanced the lives of the patients.

Following a beautiful meal all enjoyed an evening of great music and dancing.

RETIREMENT

On behalf of the Clare branch of the IKA, Imelda McGann from the Burren, made a presentation to Renal Nurse Counsellor Anna Maguire, who recently retired from Merlin Park. Anna was thanked for the exceptional care she gave to the Clare renal patients and transplant recipients and all whom she cared for in her twenty years in the clinic. She was wished a long, happy and healthy retirement.

SYMPATHY

We extend our deepest sympathy to branch member Ann O'Halloran and extended family on the recent death of her sister Mai. May she rest in peace.

CHRISTMAS GREETINGS

I would like to take this opportunity to wish our renal patients, their families, branch members, volunteers, the medical staff at UHL and Fresenius Unit Limerick, B Braun Wellstone Unit and Unit 7, Merlin Park, Galway a very happy Christmas.



The festive season came early for the members of the Wexford Branch who attended our Christmas Party in the Riverbank House Hotel, Wexford on Saturday November 24th. Over 120 people turned up on the night including more than 40 transplant and dialysis patients.

Chairman Liam Buttle and Annie Bolger who is one of the longest serving members of the Wexford Branch cut a special cake to mark the 40th Anniversary of the IKA. The Wexford Branch was founded 38 years ago.

The branch was honoured to have Debbie McDonald, Clinic Manager, B.Braun Wellstone, Renal Care Centre, Wexford and some of her team joined us on the night. Mark Murphy, from Donor House, was also in attendance with his wife Frances. The music was supplied by *Theresa and the Stars* and a good night was had by all.

On Sunday, December 2nd, Debbie McDonald and her team organised a family afternoon at B.Braun Wellstone providing tips and treats for the renal diet for the Christmas season. It was a lovely afternoon and attended by many of the patients and their families.



A lovely display of the wonderful treats available at the Christmas Cooking event which took place in the Wellstone Wexford Renal Care Centre.

WEXFORD

By MARIA DONLON



Chairman Liam Buttle and Annie Bolger cut the cake at Wexford Christmas Party to celebrate 40th Anniversary of IKA.



The team from Wellstone Wexford Renal Care Centre



Eddie Kehoe, Marie Donlon, Mark Murphy, Dora Kent, Liam Buttle, Annette Foley at the branch Christmas Party.

The branch would like to thank everyone who helped with fundraising events during the year and wish everyone a very happy and healthy Christmas and peaceful New Year.



Wexford branch Christmas Party





Seasons greetings to you all from the Offaly branch. On Sunday, December 9th we gathered for our Annual Mass of Remembrance and Christmas lunch in the Tullamore Court Hotel. Once again it was very well supported by our dialysis and transplanted patients, families, friends, South Offaly Ploughing and the Tullamore Cycling Club. The Mass was celebrated by Fr. Joe Gallagher P.P. and Tom Kennedy performed the music for the Mass.

This was followed by a wonderful meal. The Buckley family, Kilcormac, provided the music as we danced away for the evening. Santa took time out of his busy schedule to drop in and visit our youngest members.

The Branch Chairman, Officers and Members were delighted to have the company of the founder of the Irish Kidney Association, Patricia Doherty, who attended with her daughter Jill at our Mass of Remembrance. It was very special to have her present and we thank her, most sincerely, for travelling to our special 30th celebration's founding of our branch.

CONDOLENCES

We extend our condolences to the families of Andrew and Kathleen Boland, Clara Road, Tullamore; Mary Bracken, Kilcormac and Sr. Pius

OFFALY

By KEVIN GALVIN

Patricia Doherty (back row, middle) with her daughter Jill and members of the Offaly branch.



Clarke, Mercy Convent, Tullamore who was a branch member and founding member of the Offaly branch. Our thoughts and prayers are with their families. Ar dheis Dé go raibh a anam dílis.

TULLAMORE CYCLING AND TOURING CLUB (TCTC)

On November 30th the Committee of the TCTC presented a cheque for €7680 to members of the branch following their annual Pedal the Peaks Challenge. A huge 'thank you' to all involved.

GET WELL

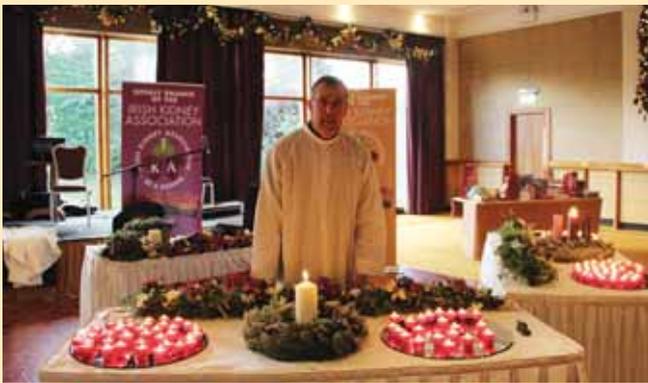
Get well wishes are extended to all who are sick and unwell at this time – we wish you a speedy recovery.

MEETINGS

Our next Support meeting will be held on February 21st, 2019 in the Tullamore Court Hotel at 8pm Sharp. Refreshments served and everyone is welcome.



Jacinta Condon, Liam Mulhall, Louise Galvin, Jerome Burke, Roisin Daly, Kay Dunne, Leona Mahon and Michael McConighey at the presentation of the cheque from the TCTC.





TIPPERARY

By ORLA RYAN

Our branch had its 35th year celebration in the Horse & Jockey Hotel, Thurles on November 10th at 8pm. We had people attend on the night who were at the first meeting all those years ago, and thanks to them, the branch is still going strong. Some of those who attended from that meeting were Doreen Donovan, Miriam Bryan and Willie and Joan Gavan.

Joan was MC on the night and did a fabulous job. She welcomed everybody to this wonderful occasion and thanked all for coming to the night.

Mark and Frances Murphy, John and Una Whelan, Colm and Patricia Mckenzie and Valerie Brady and her dad also attended.

We thank them all for travelling to our celebration in Tipperary.

Mark Murphy had produced a slideshow of pictures of the Tipperary branch, over the last 35 years, which was very nice to watch. It was good to see how the branch has evolved. We saw many old faces in those pictures.

Our chairperson, Ann Nolan, welcomed everyone and was delighted to see so many people from all over the county at our celebration. She gave a lovely talk about our branch.

John Whelan presented an informative speech on the current running of the Irish Kidney Association. Marie Fowley, from Sligo, (originally from Clonmel, Co. Tipperary) gave us a very animated insight from dialysis to transplant and how transplantation makes such a difference. She is a kidney and pancreas recipient.

A great night was had by all and there was plenty of time to meet old friends and make new ones on the night.



Liam Martin and Gordon Salte, President of the Simmental Society, presented a cheque for €5,500 to the IKA. They raised this money at the Ploughing Championship in Tullamore, as a result of a raffle for a heifer that Liam raised himself. It was a fantastic

amount of money. Liam spoke about how his son gave him his kidney and how he is forever grateful.

We would like to thank the hotel for the lovely food and the great service and thank you Olive for all your help with the balloons and the cake.

TIPPERARY BRANCH 35TH YEAR CELEBRATIONS





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

"Once you choose hope, anything is possible".



Valerie Twomey, RIP

The above quote is taken from the recipe book of the late Valerie Twomey, RIP. To anyone that ever had contact with Val or anyone she had contact with this just about summed her up. The quote may not be her own but no words could be so aptly put together to describe one person.

Val passed away on November 30th after a tremendous battle with life. The turnout at Val's funeral said it all about the woman. Members of Transplant Team Ireland from all over the country, the kids she coached at Crosshaven Tennis Club and the wider community of Crosshaven. Val's book *Truly Tasty* is a must-read for all renal patients, with contributions from the

CORK

By PAT O'SULLIVAN

WELL BEING AND HAPPINESS COURSE



Colm Clifford, Peter Pardoe, Harry Ward



Dermot O'Connell, Peter and Harry



Kitty Rice, Peter and Harry



Mary Egan, Peter and Harry

top chefs in the country. The book has gone on to be a huge success for renal patients all over Europe.

Ar dheis Dé go raibh a hanam dílis.

WELL BEING AND HAPPINESS COURSE

Our participants completed their course in November. Some of our graduates moved on to a teaching course in Malahide, Co. Dublin after that. They are anxious to give a course as soon as possible and are hoping to do so in the Spring. If you would like to participate in the course please contact the secretary.

Congratulations to Mary, Sheena, Marliese and Siobhan for volunteering to do this course and congratulations on your success.

ANNUAL MASS OF REMEMBRANCE

The Mass was held on November 11th, in the chapel in CUH. I would like to thank Fr Cormac Pierce, the

Chaplain Julianna, the Douglas Harmonia Choir and all those in the branch that helped to make it such a special day. The book of Remembrance was brought to the Altar by Mark Murphy, IKA CEO and it was available afterwards for donor families to see their entry. It will also now be available every year.

We are hoping to have even more donor families involved next year with the help of our organ donor nurse manager Breda Doyle.

We all met up after for tea and cakes which were once again baked and prepared by volunteers from the branch.

SUPPORT MEETINGS

Our support meetings continue to grow with more and more member participation. Our last speaker, Dr Gillian Gibson, a dermatologist, spoke of the importance of skin care.



Dermot O'Connell and family at the Glanmire Chamber Business Awards

In February we are once again going to get a dietitian as it has come up in the Wellness course the various different ideas patients have on what they can and cannot eat.

Dates for next year's meetings are posted below right.

FUNDRAISERS 2019

In April we are holding a Broadway show in the Rochestown Park hotel. We are looking for dancers to participate and help fundraise. All the money raised on the night will go towards the renovation of the Support Centre and its upkeep.

Training for the dancers will be provided on 6 consecutive Saturdays leading up to the main event on April 13th.

In June we will be holding our now annual Golf Classic. 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.

ORGAN DONOR AWARENESS WEEK

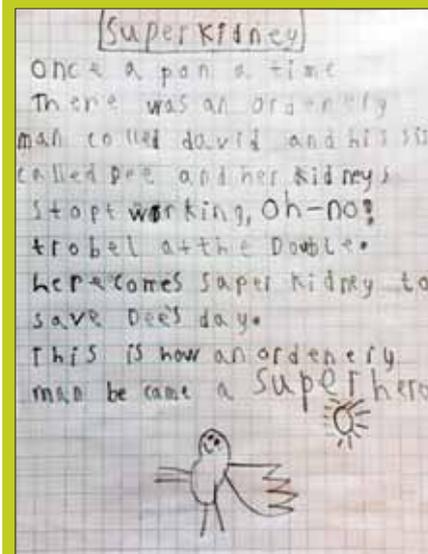
Organ Donor Awareness week 2019 takes place from March 30th to April 6th. Once again, this year, volunteers will be able to collect at Aldi on Saturday, March 6th. If you would like to collect at your local Aldi please contact Geraldine to get permission letters for your local Aldi manager.

If you would like to collect in your local town village or shopping centre please let us know as soon as possible to permit us try and organise permits from the Gardaí.

GLANMIRE CHAMBER OF COMMERCE BUSINESS AWARDS

Congratulations to our own Dermot O'Connell who was presented with a Special Recognition Award at the local awards night recently.

Poem written by
7-year-old Andy
to his mother Dee
and her donor



DATES FOR YOUR DIARY

Support Meetings

Rochestown Park Hotel at 8pm
FEBRUARY 5TH
MARCH 5TH

Organ Donor Awareness Week Cork Launch

MARCH 28TH
Rochestown Park Hotel at 6.30pm

Organ Donor Awareness Week MARCH 30TH TO APRIL 6TH

Annual General Meeting (Election of Officers)

APRIL 9TH
Rochestown Park Hotel at 8pm

Broadway Musical Night

Fundraiser for Support Centre
APRIL 13TH
Rochestown Park Hotel

CORK BRANCH ANNUAL MASS OF REMEMBRANCE



CORK BRANCH ANNUAL MASS OF REMEMBRANCE





Greetings to all from the Louth/Meath branch. May we take this opportunity to wish all our members and volunteers a very merry Christmas and a happy and healthy New Year.

FUNDRAISING

There are a number of people we need to thank for their continued support. Like all branches, without its members and volunteers, continuing as a branch would not be possible. Our members and volunteers have been busy over the past year and we would like to acknowledge their contribution:- Dee Vintage Club, Aine & Liam Quin, Castlebellingham, John & Betty Anderson, Ardee; Castlebellingham Fun Cycle; Mary O'Rourke; Cllr Tommy Reilly; Horseware Ireland; Johnny Keoghan Rings Team, Ardee; The Casey Family; and our volunteers for Organ Donor Awareness Week

CHRISTMAS SOCIAL

Our Annual branch Christmas social was held in Hunterstown Inn in Ardee on December 8th. A wonderful meal was enjoyed by all. A special thanks to our secretary Mary Traynor who thoughtfully put together a small gift bag with a unique individualised gift for everyone present.

ORGAN DONOR AWARENESS WEEK 2019

We are already thinking about Organ Donor Awareness Week 2019 which runs from March 30th to April 6th. As always we are in need of more volunteers to cover areas in both Louth and Meath. If you would like to volunteer please feel free to contact the branch - we would welcome your help.

LOUTH/MEATH

By VALERIE BRADY



John and Betty Anderson presented Valerie Brady and members of the Louth/Meath branch with a cheque for €3,026, proceeds from their annual vintage threshing fundraising event held in Reaghstown.



As 2018 draws to a close, we remember those branch and family members who passed away during the year, our thoughts and prayers are with you all. Our donors and their families are also never far from our thoughts and we will remember them in a special way this Christmas season.

MEETINGS

The next meeting of the Louth/Meath branch will be held in the Hunterstown Inn on Tuesday January 8th, 2019. If you need to contact the branch over the Christmas

period our Committee members will be available on the following numbers:

Valerie Brady (Chairperson)

Phone: 086-3186757

Anne McGivney (Treasurer)

Phone: 087-2976876

Mary Traynor (Secretary)

Phone: 089-4348086

Alternatively, you can reach us by sending a message to our Facebook page Louth/Meath IKA page – @louthmeathika. We look forward to seeing you all in 2019.

Nollaig Shona Daoibh.



Louth/Meath Christmas Social





KILDARE

By ELAINE MAGUIRE

We are delighted to report we have had a very busy and successful year! It commenced with us taking part in a wonderful day at the Kildare County Fair in Athy, in glorious sunshine. We took a stand and distributed lots of donor cards and chatted with lots of people. We even signed up new members on the day!!

We had some good branch meetings, with membership gradually improving. We also had plans to support the IKA stand at the National Ploughing Champions, but the weather let us down on that one.

Our ongoing efforts to raise awareness have seen articles in most of the local papers. These have focused on personal interest stories and efforts to raise awareness, as well as outlining the benefits of being a member of the IKA.

Some of our members met with Kildare County TDs Fiona O'Loughlin and Frank O'Rourke who had seen these articles. They invited us to the Dáil and offered to support our efforts in any way possible. Indeed, Frank was instrumental in organising a group of runners who competed (and raised awareness) in this year's Dublin City Marathon.

Since September we have held 'meet and greet' awareness sessions on the first Saturday of the month in the Town Hall in Newbridge as part of the Country Market. These have been a great success and a very good public relations exercise for organ donation.

We would like to congratulate Aisling Hyland (Athy) who was brave enough to do the zipline in Castlecomer. Well done and thanks for raising funds for the Renal Support Centre.



In closing, we are currently finalising sales for our Christmas raffle and would like to take this opportunity to wish all a very happy festive season, and a happy and healthy New Year.





Seasons Greetings to all.

The Annual Mass of Remembrance and Thanksgiving was held in Corpus Christi Church on Saturday October 6th. A large congregation of donor families and recipients attended. Once again Dr Sharon Lyons and musicians provided the lovely music for the Service.

Our thanks to Archbishop Martin who presided and the clergy who support us every year.

Claire Byrne of RTE also attended and did a reading.

GARDENING SUPPORT

On November 19th, Dublin North members Deirdre and Peter Moore gave us a fascinating pictorial talk about gardening. Peter received a transplant some years ago and is enjoying good health since.

Deirdre has been planting Summer and Winter baskets for many years. All present enjoyed their talk and we look forward to further gardening events in the future.

LADIES ONLY

The Ladies Day on Thursday December 6th, in the Malahide Golf Club, was a fabulous success and we thank all who supported it. The ladies enjoyed dressing up on their day out.

The prize for the best dressed lady was won by Mary McCabe of Portmarnock. A special thanks to Ann Burke and her team and all who helped make it a success.

HAPPY CHRISTMAS

We wish all patients, carers, those in hospital, their families, all in the Irish Kidney Association and the medical staff who look after us a very happy Christmas and a healthy and peaceful 2019.

DUBLIN NORTH

By PATRICIA MACKENZIE



Presentation of cheque for €1,150, proceeds from O'Neills October Seis, a weekend of music, entertainment and craic, held every year in Kildare, are: Kevin O'Neill, Patricia Mackenzie and Bob and Tina O'Kelly (their daughter Colleen had a transplant).



Deirdre and Peter Moore with daughter Roisin



contd...



*Dublin
North
Ladies
Day*





Best Dressed Lady...Mary McCabe, Colin Mckenzie organiser Ann Burke





It was lovely to see many of our members at our Annual Remembrance Mass which was held on November 25th. This year we held the Mass in Harry's of Kinnegad. After the Mass there was a chance for everyone to catch-up and have a chat over a lovely meal.

A Church gate collection was held in Athlone in November so thank you to our many volunteers who braved the cold to raise donations.

WESTMEATH

By CATHY SMYTH



Finally, I would like to wish all our members a healthy and happy Christmas and New Year.



SLIGO

By NOEL KENNEDY

Find us on: **facebook**

SLIGO IKA BRANCH



Left: Geraldine McHugh, Branch Secretary, Sean Fowley, Branch Chairman, Eileen Nolan and Marie Fowley, branch Vice-Chairperson at the Christmas Cake Sale.

Thanks to everyone who supported the Irish Kidney Association Tea & Coffee Day at Bank of Ireland, Stephen Street, Sligo. A big 'thank you' to all the staff at BOI, in particular Niall Canning for his support and assistance.

Some of the local IKA members in attendance were Hughie Costello and Noel Henry.

We held a Christmas Cake Sale at Sligo University Hospital on December 4th. Tremendous thanks to all who supported the occasion.



Hughie Costello, Noel Henry at BOI





IRISH KIDNEY ASSOCIATION CLG

(Company Limited By Guarantee)

MEMBERSHIP APPLICATION FORM



BLOCK CAPITAL LETTERS PLEASE:

Mr. Mrs. Ms. FIRST NAME: _____

SURNAME: _____

ADDRESS: _____

POSTCODE: TEL: _____ MOBILE: _____

EMAIL:

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

Please indicate if any of the following apply to you:

PRE DIALYSIS, HAEMODIALYSIS, APD, CAPD or TRANSPLANTED YES NO
 Do not wish to disclose

Do you wish to receive our quarterly 'SUPPORT' magazine by YES NO
Please tick 'No' if your household is already receiving it Post?
 Or Email? YES NO

Can we correspond with you for notices of Annual General Meeting of the Association and Annual Director's Report by YES NO
 Email?

Would you like to receive information on activities from your local IKA branch which entails us giving them the data from this form? YES NO

Would you like to receive information on the IKA Transplant & Dialysis Sports and Fitness which is based in Head Office? YES NO

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

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

SIGNATURE: _____ DATE: _____



IKA DIRECTORY



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Renal Support Centre, Beaumont Hospital, Dublin D09 Y5R3

Tel: 01-8373952 | Email: renalcentre@ika.ie

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