



Winter 2015

# NIKPA Newsletter

Northern Ireland Kidney Patients' Association



## CONGRATULATIONS.....

NIKPA are delighted to congratulate NIKPA members and fundraisers, Laura McDowell and Roy Middleton on the birth of their beautiful son Theo J McDowell on 16th October 2015. Laura is currently on dialysis and Theo was born prematurely at 31 weeks and spent 3 weeks in intensive care. NIKPA wish all the best for Theo and also Laura who hopes to return to the transplant list soon

## .....AND CELEBRATIONS!

Congratulations to the entire transplant team at the Belfast City Hospital. Yes, the staff have been very successful in matching the UK record of completing five transplants on the one day, that took place in September 2015. They will also have achieved nearly **100** transplants this year which is phenomenal. On behalf of NIKPA we would like to thank all the Doctors, Nurses and other staff who strive to keep all of us kidney patients, happy and healthy. Bless you all.

*The five recipients, who all received kidneys on that day in September, are pictured right.*



## NIKPA AGM 2015

NIKPA AGM saw a few changes to the executive committee line up; William Johnston has become the new chairman with Nathan Fairbairn the new treasurer. Catherine Logue has been appointed secretary and Therese Smith remains as vice chairperson. The meeting was well attended with Linda Trouton, the renal secretary for BCH being honoured for her work and guest speaker Dr Agnes Masegnu.

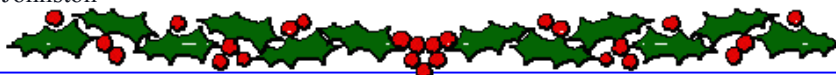


Linda Trouton (middle) receiving plaque recognising her services to Northern Ireland Kidney Research Fund, Mrs Betty Jennings (Hon. Secretary) and Northern Ireland Kidney Patients' Association. Chairman, William Johnston

*GUEST SPEAKER*  
Dr Agnes Masegnu (Guest Speaker) and NIKPA founder Mr Michael Logue.



Dr Ciaran Doherty (Honorary Life President), Professor Peter Maxwell (President) and Dr. Aisling Courtney (Vice President).



# Tributes To Our Dear Friends Who Have Passed Away

## Alan Martin



*Alan Martin pictured below with his wife, Debbie and his son and daughter Patrick and Rebecca*

The Northern Ireland kidney Patients' Association is sad to report the death of one of its founding members, Alan Martin. A past chairman, Alan passed away on the 30<sup>th</sup> of June 2015. Those of us who knew him will remember his commitment to NIKPA during the challenging developmental days. His effective input was motivated by his deep desire to improve the quality of service provision to the renal patient. He was particularly influential in promoting home dialysis services across Northern Ireland. Our thoughts and prayers today are with Alan's wife Debbie, his daughter and son, Rebecca and Patrick, his son-in-law Derek, and the entire family circle.

*By Michael Logue*

## Janet Frances Coleman 1964-2015

Janet Coleman passed away in May 2015 following a short illness. JC was the most inspirational woman and frequently described her attitude to life as the same as her blood group- Be positive, (Even though she was O negative!) Janet started dialysis after contracting a virus that damaged both her kidneys. She underwent her first transplant in 1983 which was unsuccessful but a second transplant in 1984 allowed her to take control of her life again. Prior to her illness Janet competed in athletics for Northern Ireland and carried this love of sport into her life post-transplant. Janet competed in British, World and Winter Transplant games becoming a world record holder in her chosen sports. She started her transplant sport career in athletics only to become a star swimmer culminating in her selection as team coach for the Great Britain and Northern Ireland swim team.



Janet was the driving force behind the Northern Ireland transplant Sports team and served in every role on the TSNi committee, most recently as vice chairman. She was always encouraging, motivating and supportive whether you were a star athlete or trying something for the first time. She was always first in line to applaud her fellow competitors and stated "The reason we take part in the Transplant Games is to celebrate our second chance of life. Our team motto is 'give and let live'.

She never missed an opportunity to promote organ donation and transplant. She almost singlehandedly made a bid for the World transplant games to come to Belfast and despite being unsuccessful managed to persuade the decision makers that bringing the British games to Belfast in 2011 would be a great idea. She worked tirelessly to promote these games despite being unwell following problems with her own transplant and despite the Northern Ireland weather the Belfast Games were fantastically successful. Janet was honoured with the award for outstanding achievement at the Belfast Games and this was the first time anyone who knew her had seen her speechless. JC was described as "Small in stature, but larger than life if you had ever met her, she was someone who never failed to raise a laugh or brighten up whatever gathering she was part of". Janet underwent a further period of dialysis before receiving a third transplant from her sister Pam in 2012.

It was once said that a person cannot die until the lives they have touched also die- in this case Janet will live a long time.

*By Frankie O'Kane*



## *An Altruistic Donor's Story*

*Pictured Right: Nathan Fairbarin (NIKPA Treasurer) presenting Julie with her golden butterfly and flowers*

My name is Julie, I'm a 46yr old Mum of 2 young boys and in Oct 2014 I became the 17th altruistic kidney donor in NI. It has been one of the most positive experiences of my life that started with a casual remark; I'd like to share it with you.

A few years ago at work it started to snow heavily and our Principal had to close the school early to ensure all the pupils and staff got home safely. As we were leaving a lovely teacher, Deirdre, who was subbing at the time, mentioned she had to go to Belfast and was dreading the journey. I told her she was mad, the forecast was for even heavier snow and she said she had no choice; she had to go for dialysis. I was stunned, I had no idea she was sick. She opened her car boot and showed me an emergency foil blanket, small flask and a well used shovel. No matter what the weather had in store, she had to have her treatment. I went home in awe; she was such a hard working, conscientious teacher, it seemed impossible she could be so ill.

A year or two passed, life carried on and I had my second son. When I came back from maternity leave Deirdre was now a permanent member of staff and even better, she'd received a kidney from her sister after 7 years on dialysis. During a chat about her experience she casually mentioned that anyone could be a kidney donor, "You could be a donor" when I replied, "But I don't know anyone who needs a kidney?" she said that didn't matter and there was a long waiting list of people needing a kidney in the UK. I had no idea you could donate to a stranger but right then I had a moment of clarity that this was for me, something I was meant to do. As I wasn't long back from maternity leave I was advised to wait until our boys were less dependent so 3 years later, with my family's blessing, I started the process.

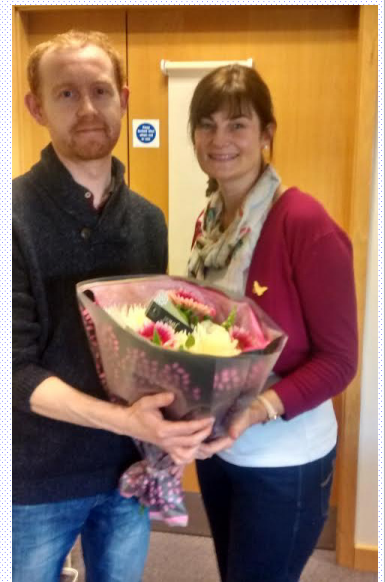
From the 1st phone call to wonderful Pauline one of the living transplant co-ordinators at Belfast City Hospital, I was at ease and the whole assessment process was clearly explained to me. She told me I could back out at any time but I knew in my heart that if I wasn't medically rejected for some reason I was definitely going to do it.

Tests done over the next few months included lots of bloods, a chest X-ray, ECG, kidney ultrasound, CT scan and psychological assessment. No problems showed up at all, I was fit and healthy with 2 perfectly functioning kidneys. I met the amazing team at the City, Aisling Courtney (Consultant Transplant Nephrologist) and Mr Brown (Consultant Transplant Surgeon) who explained the whole procedure, spoke to a previous altruistic donor Catherine who shared her remarkable story and really knew then I was in safe hands. Initially I chose to be part of the pooled donor scheme and was matched with a lady in London who had a willing donor who wasn't a match but was happy to donate to someone else on the waiting list so 2 people would benefit from a new kidney but unfortunately she became unable for surgery and this fell through. I then decided to come out of the pool and donate directly to someone on the waiting list. A short while later I was matched with 28yr old David in Birmingham and the date was set for 14/10/14. I was so excited. The keyhole surgery went really well and 'Sidney the Kidney' was on the 2 o'clock Flybe flight to his new home. After hours of sickness and low blood pressure I was on the road to recovery with no exterior stitches and 4 small neat scars. Later that night I heard David was through his surgery and his new kidney was working perfectly, I was elated! Over the next few days I had a lot of discomfort around my lungs from the gas used during keyhole surgery but was well looked after by the fantastic nurses on the 11th floor South. I had visits from my surgeons Mr Brown and Mr McDaid who explained just how well the surgery had gone, they had done an amazing job. I shared a ward with kidney patients and was astounded to hear their stories of kidney failure, sickness, dialysis, complications, difficult diet restrictions and operations. They were all so positive though, it was very humbling, I'll never forget them. I went home 3 days after the operation and heard that David was doing so well he was home just 6 days after surgery. At a check up a week later I met up with the surgeons again and saw the most amazing PowerPoint presentation of my whole operation that was already being used for nephrectomy teaching purposes in the City hospital and Beaumont hospital in Dublin, it was incredible to see. Exactly a month after surgery, I received a very moving letter from David through the transplant co-ordinators explaining how much his life had changed already and how grateful he was. His Mum and sister also wrote very touching cards, I was so emotional and on a high for weeks. I went back to work after 12 weeks and haven't looked back.

One year on I'm doing great, kidney function is excellent, blood pressure perfect and the tiny scars are almost invisible. David is working full time now at the Jaguar factory in Birmingham and the very best news is he's going to be a Dad for the 1st time in March, how amazing is that?!

Being an altruistic donor has been an incredibly positive experience for me. I know I'm very lucky and so grateful to have heard from my recipient; most donors don't which is what you're prepared for and accept before you donate. I would do it all again in a heartbeat but as that's impossible I hope sharing my story will inspire someone else to consider donating this way. So many people could change/save a life and in some cases help create a new one, how wonderful would that be?

By Julie Hughes





## **THE BIG DAY OUT, 2015**

The annual big day Out took place at the Royal Court Hotel, Portrush on Sunday the 28<sup>th</sup> June. Renal patients and their families enjoyed a carvery lunch in a beautiful setting overlooking White Rocks bay.



## **A visit to the panto, 'Aladdin'**

Earlier this year, the young renal patients from the Royal Vitoria Hospital renal unit had their annual trip to the panto. The children and their families were joined by Nurse Hazel Gibson and members of NIKPA on the trip to the Grand Opera House. The day out was partially funded by 'Hilton Charity Giveaway and the 'Goodie bags' were provided by LazerUK. NIKPA would like to thank both organizations for their support. We would also like to thank Nurse Gibson for her help in arranging this outing.







## NIKPA Golden Butterfly Live Donor Badges

NIKPA have developed a special NIKPA golden butterfly especially for live kidney donors. This is to acknowledge the courage and compassion of Live Kidney Donors in giving the GIFT OF LIFE, the GIFT OF LOVE.

### **“GETTING TO KNOW YOU”**

NIKPA is introducing a new feature to the NIKPA Newsletter. In this and future editions of the NIKPA Newsletter there will be an interview with a leading figure in the NI Renal and Transplant Medical Community.

The questions are designed to get a glimpse of the person outside the medical environment.

The first person who has kindly agreed to partake is Dr Aisling Courtney, Consultant Nephrologist at the Belfast City Hospital.

Dr Courtney has been instrumental in developing and transforming the Live Kidney Donor Programme in Northern Ireland and establishing Belfast City Hospital as a Centre of Excellence for Organ Donation in Europe and Worldwide.



***Dr Aisling Courtney – In her own words :~***

FAVOURITE PASSTIME	Relaxing in Donegal
SPORTS YOU WATCH/ PARTICIPATE IN	I have been known to watch almost any sport. Even darts. Bowls once! I don't participate in any team sports but cycle (primarily to and from work), run, swim, and occasionally surf (in Donegal)
FAVOURITE TV PROGRAMME	Sports Programmes
LAST FILM WATCHED	Truly, I cannot remember
CAN YOU COOK	I think (almost) everyone can cook, question is whether it is edible or not! I do enjoy cooking and experimenting. In general it turns out OK
FAVOURITE FOOD/MEAL	Depends on time and place. There is a café in Killybeg that does a great fish supper
FAVOURITE HOLIDAY DESTINATION	Donegal. Did quite a bit of travelling when I was a student (long Summer holidays) which was great, one of the most memorable as going around Europe by train with so little money! We slept in overnight trains so we didn't have to pay for accommodation. Many stories from that month!
PLACES STILL LIKE TO VISIT	Never been to South America. Would like to visit Canada and New Zealand
BEST ADVICE TO A DIALYSIS PATIENT	If you are waiting for a transplant, never give up
BEST ADVICE TO A TRANSPLANTED PATIENT	Take your tablets. Please!

## NIKPA PURCHASE OF 24 HOUR BLOOD PRESSURE MONITOR

NIKPA and NIKRF were delighted to be able to jointly present a 24hr AMBULATORY BLOOD PRESSURE MONITOR UNIT costing £2300 to the Renal Education Team of the BELFAST CITY HOSPITAL. In attendance were also members of LASERUK who fundraised on behalf of NIKPA to purchase the Unit (L - R. Carla Mervyno (NIKPA) Robert McCormick (LASERUK) Brid Thompson (Renal Education and NIKPA) Nadine Livingstone (LASERUK) William Johnston (Acting Chair NIKPA) Adele Edgar (LASERUK) Therese Smyth (Vice Chair NIKPA) John Brown (Vice Chair NIKRF).



# The NIKPA Logo

We have been asked about the background to the NIKPA BUTTERFLY LOGO. About 3 years ago we decided to change the original logo of a Red Shield (Below) and asked the NIKPA membership to come up with a new logo to reflect NIKPA's aims and objectives. We received some great ideas but decided to select the butterfly as it symbolises best what NIKPA aims to achieve

We believe that whether on dialysis or transplanted, it is still possible to live a fulfilling life. The spread wings of the butterfly symbolises "freedom" and the small red kidney on the lower left lobe indicates that we are a Renal Charity.

The colours were selected as they are the colours of the original Donor Card, so it is as if the butterfly logo has been cut out of the original Donor Card. This emphasises one of NIKPA's primary objectives of promoting Organ Donation.

NIKPA is a Charity open to all people whose lives have been affected by renal failure and kidney transplantation - dialysis patients, transplant patients, family members, carers, relatives, friends, Donor Families, Live Kidney Donors, Altruistic Kidney Donors, Renal Medical staff. We have pin badges available displaying the logo



The original logo (left) was created by our founding members. We recall the latin motto "Et nunc vivo" ( And now I live ) was proposed by our sadly missed colleague Rodney Curry.

## A new study with people who decide not to have dialysis

### The Palliative Care in chronic Kidney diSease (PACKS) study

Some people with advanced chronic kidney disease will decide not to start dialysis to treat their illness. Often they are frail and suffering other chronic conditions making dialysis difficult. For some patients the decision is straightforward, and instead of coming to the hospital for dialysis, they opt to stay at home and receive supportive and palliative care usually from the renal team and their local GP service.



**Dr Helen Noble**

The Palliative Care in chronic Kidney diSease (PACKS) study is examining quality of life, decision making and costs in patients with advanced chronic kidney disease who have opted for palliative care. It will also explore care decisions made by patients from the perspective of patients, carers and health care professionals and the impact on the quality of life of carers. If you have decided not to have dialysis you may be asked if you would like to take part in the study. This will involve answering some questions at clinic appointments. The questions are related to how you are feeling; your symptoms of renal disease; your decision not to have dialysis and how you are coping at home.

If you have any questions about this work please contact Dr Helen Noble at [helen.noble@qub.ac.uk](mailto:helen.noble@qub.ac.uk) or telephone: 0044 289097 2472



## NATIONAL TRANSPLANT WEEK, 6<sup>th</sup> – 13<sup>th</sup> SEPTEMBER, 2015

### NIKPA TOOK A VERY ACTIVE ROLE IN PROMOTING ORGAN DONATION AWARENESS:

#### STORMONT

Transplant Week began by NIKPA attending an MLA Drop event at Stormont at which Joanne Dobson MLA took the opportunity to present the first draft of her 'Opt Out' bill to the Speaker of the House



#### WESTMINSTER

NATIONAL TRANSPLANT WEEK continued with William Johnston Chair of NIKPA, attending an Organ Donation Promotion Event at the Thames Pavilion, Houses of Parliament, Westminster organised by British Kidney Association (BKPA) at which MPs were invited to attend to endorse Organ Donation.

William would like to thank Lady Hermon MP for Ards and North Down for supporting him and Organ Donation at the event. In the second photo is Fiona Loud, Strategy Director for the BKPA.



#### PORTADOWN

NATIONAL TRANSPLANT WEEK continued with NIKPA being invited to man a stand at TESCO, Portadown to promote Organ Donation. Joanne Dobson MLA dropped by to show her support

NATIONAL TRANSPLANT WEEK finished with NIKPA members completing the BOMBARDIER CYCLE FUND-RAISING EVENT (see page 8). This also just happened to be the same day that BCH did six transplants in one day!

## Donations and fund raising

NIKPA would like to thank all of those persons, clubs and companies that have contributed to the NIKPA charity. These donations have allowed us to continue to help and support the renal community of Northern Ireland and push forward with organ donation awareness and lobby government for the needs of Northern Irish renal network and for this, we are sincerely grateful.

#### Special thanks to:

B Edenington, A Todd, Family of Mrs J Francis (Deceased), J Mc Auley/N Mc Kinee, Body Building, Sequence Day Group, Mary Bailey, Agnes Tyrie, Laser UK, Fiona Boyd (Deceased), Drumsallen P.S, Ballymena Belles, Family of Ms Daphne Hughes (Deceased), Harland and Wolff Heavy Industries Ltd., Laura McDowell and Roy Middleton Coffee Morning, Chris Boyd – Disco, McCue fitters

C Devlin, Janet & Tony Hirrell, Clondeboy Golf Club Quiz Night (Organised by Elizabeth Quail & Ruth Godfrey), Eadoin Hannon (Wedding badges), Sponsors of Martin Taggart in Lap of the Lough 2015 – (Jacqueline Johnston, Rachel Taggart, Joseph McCloskey, Kathleen Irvine, Megan Taggart, Rod O Doherty), Megan Brown (wedding Favours), Norman Hunt (Deceased), Claire Boyd who completed 'Lap the Lough', Mr Alan William Martin (Deceased), Clonard Musical Evening, Bombardier Belfast, Hilton 'Charity Giveaway', Dr C Doherty.

If we have not mentioned your name above, we are truly sorry.



## LAP THE LOUGH 2015

The "MAGNIFICANT 6": Marty Taggart (NIKPA, Kidney Recipient), John Brown (Northern Ireland Kidney Research Fund, father of Sean, a kidney recipient), Joe McMonagle (Altnagelvin Renal Support Group, son of Joe Snr who is Live Kidney Donor to his wife Carmel.), John Deeney and Laurence Heggarty (Altnagelvin Renal Support Group) cycled 100km, the Gerry Totten (former Nurse Manager, Dialysis Unit, Antrim Area Hospital) cycled the 100km circumference of Lough Neagh, last summer, to raise money for charities and awareness for "GIFT OF LIFE" ORGAN DONATION.

## Bombardier event - 50 mile

NIKPA would like to thank the BOMBARDIER CHARITY COMMITTEE who has raised a tremendous £1200 through their cycling event. Congratulations to Marty Taggart (NIKPA) and John Brown (NIKRF), Barry Mairs and his team from GBS ROOFING LTD who sponsored the Organ Donation cycling tops and who all completed the 50 mile cycle. Special thanks to Paul Morris (Kidney Recipient) of Bombardier who nominated NIKPA. This event took place at the end of TRANSPLANT WEEK



### Ballymena Belles

NIKPA would like to say a massive thank you to the Ballymena Belles 5 mile running event which raised £715 for NIKPA. Special thanks to Kelly and Alistair Courtney.

### Tesco, Bentrin Road

#### Lisburn

NIKPA would like to thank the Tesco store in Lisburn for allowing us to set up a stand to promote the 'GIFT OF LIFE', organ donation and raising money for our charity. Is that Santa and his little helper?



### THANKS TO DRUMSALLEN PRIMARY SCHOOL!

Neil Robinson NIKPA committee member receives a cheque which was kindly donated from his local primary school.



### Waringstown Brownies

A big thank you to Lynda Jackson and the 1st Waringstown Brownies for choosing NIKPA to benefit from the proceeds of their Xmas Craft Fayre held last Monday. It was a fantastic night and we were made very welcome. Over £700 was raised. NIKPA were suggested to Lynda by Joanne Dobson MLA and it was tremendous to see Joanne there on Monday supporting and endorsing Organ Donation as always.

### NIKPA FUNDING

NIKPA is entirely funded by kind donations from our supporters. We do not receive funding from government or health services.

You can donate online at  
[www.NIKPA.org](http://www.NIKPA.org)

or send a cheque to **(Our New Address)**  
NIKPA, c/o Linda Trouton, Dialysis Unit, Belfast City Hospital, Lisburn Road, Belfast BT9 7AB - email: [info@nikpa.org](mailto:info@nikpa.org), HMRC Charities Ref. No: NI00338



... online at ...  
[WWW.NIKPA.ORG](http://WWW.NIKPA.ORG)