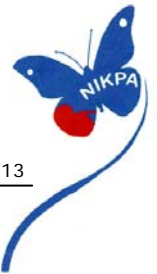




NIKPA Newsletter

Northern Ireland Kidney Patients' Association

April 2013



AN INVITATION TO NIKPA'S ANNUAL GENERAL MEETING

You are cordially invited to attend NIKPA's annual general meeting, which will take place on Sunday, April 28th at 2.15pm in the Ennis Room (dining floor) of the Belfast City Hospital tower block. The guest speaker will be Joanne Dobson MLA, who will speak on Presumed Consent of Organ Donation. *[Refreshments provided].*

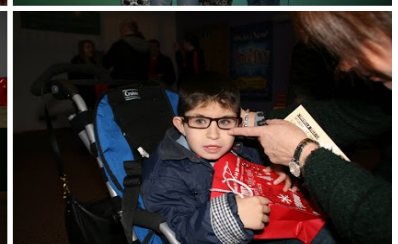
Run Santa, Run !

Just before Christmas the 'Ballymena Runners Club' organised a 'Santa Run' in aid of NIKPA. On the 17th December at 6.30pm, up to 60 Santas gathered at the starting point, at the Seven Towers Leisure Centre, along with the local fire brigade who supported the event with the presence of their fire engines. The occasion was covered by local radio and the Ballymena Guardian. The run was a great success and raised £2,338.06p



Cinderella at the Grand Opera House

Earlier this year, NIKPA invited the children from the Royal Hospital renal unit and their families attended a performance of Cinderella at the Grand Opera house in Belfast. Head Nurse, Hazel Gibson and Consultant Dr. Mary O'Connor were also in attendance to 'sort everyone out'! Goody bags were handed out and everyone greatly enjoyed the event.



Peritoneal Dialysis Study

My name is Fiona Murphy. I am a registered general nurse, a registered nurse tutor and a specialist practitioner in renal nursing. I currently work as a lecturer and renal educational facilitator at the School of Nursing & Midwifery at Trinity College Dublin. I am doing this research for a doctoral thesis (PhD) at the School of Nursing, University of Ulster (UU) at Jordanstown. This research study is fully supervised by Dr Sonja McIlfratrick and Dr Patricia Gillen from the University of Ulster (UU). This study has received ethical approval from UU.

What is the purpose of this study?

The purpose of this study is to explore the stories of patients living with peritoneal dialysis and the potential impact of this illness on their sexuality, body image, roles and relationships. The information will be collected via individual interviews.

Are you a patient currently receiving peritoneal dialysis and are over 18 years of age? Would you like to tell your story?

For further information please contact
Fiona Murphy at:
07788950100/ + 003531 896 3108
Email: fiona.murphy@tcd.ie



Northern Ireland Transplant Forum “CAUSEWAY TO NEW LIFE GARDEN” Hillsborough Garden festival 2012

The Hillsborough Garden Festival is the largest Garden Festival in Northern Ireland with over 30,000 visitors attending the 3 day event. The NITF entered the U105 TEAM CHALLENGE in which the organisers give each team a 3m x 3m plot land to transform into a Garden based on the theme of the Festival. This year's theme was “iconic symbols of Northern Ireland”.

The NITF selected the “Giants Causeway”. Donor families, Transplant Recipients and anyone wishing to endorse Organ Donation – THE GIFT OF LIFE, were invited to transcend the CAUSEWAY from the OLD LIFE GARDEN barren of colour and vibrancy symbolising pre-transplantation, across to the NEW LIFE GARDEN full of

growth, colour and hope, symbolising life after transplantation. In the NEW LIFE GARDEN visitors were invited to tie a coloured paper butterfly to the TREE OF HOPE with their own personal message written on it. By the end of the event, the TREE OF HOPE was ablaze with coloured paper butterflies providing a powerful endorsement of Organ Donation.



Miceal Cole – Rome Marathon 2012

“To the Vatican and Beyond for NIKPA”

Some of you who may have noticed this heading on posters which appeared on some notice boards at Belfast City Hospital last March. It was to advertise the fact that Miceal Cole who is one of the senior technicians at the Tissue Typing Lab at Belfast City Hospital was running the marathon in Rome on 18th March 2012 to raise funds for NIKPA.



In this regard, Miceal completed the Rome Marathon and in doing so raised the fantastic sum of £1,400.00 for the Northern Ireland Kidney Patients' Association. This was a fantastic achievement and a big thank you goes out to Miceal from all the members of NIKPA. Thanks must also go to all his family, friends and colleagues who provided him with sponsorship.

Miceal's job together with that of his colleagues at the Tissue Typing Laboratory (Histocompatibility and Immunogenetics Dept.) includes testing the blood samples of patients waiting for a transplant, or of someone who is perhaps thinking of becoming a live donor. We all have a unique combination of proteins on the surface of our cells. This combination of proteins is our individual tissue type. Your immune system checks the combination of proteins. If your immune system doesn't recognise the combination of proteins on a donor kidney it will reject it. Giving you a new kidney with the same tissue type as your own means your immune system will recognise the combination of proteins and accept the kidney. The more information that is known about an individual's tissue type therefore, the better an individual can be matched with a donor kidney.

Once again a big thank you to Miceal and all his colleagues in Belfast, for all the work they do to help kidney patients awaiting a possible transplant.





Lynne Callow of the National Kidney Federation

Hi. My name is Lynne Callow and you may have seen me recently in your Renal or Dialysis Unit. I work for the NKF (National Kidney Federation) as an Advocacy Officer for Wales and Northern Ireland. Although based in Wales, I visit all Units across Wales and Northern Ireland, listening to patients' views and concerns, while providing advice, guidance and support on issues such as benefits, diet and holiday dialysis. I also inform patients of grant assistance which may be available to them from the British Kidney Patients Association (BKPA). **If I can help you in any way, please contact me on 01443 231525 or email Lynnecallow.nkf@btinternet.com. I can also be reached through the free of charge National Kidney Patients Helpline on 0845 601 02 09 or via the NKF website www.kidney.org.uk**

Are you aware of any young renal patients (under the age of 18) who would be interested in becoming part of a network of contacts willing to assist other young patients in their own local area? The NKF would like your help with identifying young persons who could pass on information, both from and to the NKF, concerning issues relevant to young patients. We are also looking for younger relatives of kidney patients who would feel the benefit of not only sharing their experience of living with, or caring for, a family member with renal disease, but also of

knowing there is support nearby. If you are aware of any young person that may be interested in joining the network, I would be grateful if you could put them in touch with me (**contact information above**).

Do you have good independent judgement, a willingness to speak your mind, and the ability to work effectively as a member of a team which can contribute actively to the board of trustees' role in setting overall policy? Nominations for NKF Executive Members are currently being sought. You will need to attend SIX meetings per year - ALL expenses paid. Nominees will require the support of their Kidney Patient Association. Non KPA members can be supported by existing Executive Officers. If you are interested please let me know (**contact details above**).

I look forward to hearing from you, and to meeting you during one of my visits to your Unit in 2013.

Lynne Callow
NKF (National Kidney Federation)



MEMORIAL BENCH FOR GERALDINE McCANDLESS, NEW LIFE GARDEN SPRING 2013

Geraldine McCandless was one of the driving forces behind the creation of the NEW LIFE GARDEN, Kiltonga. She was a renal patient on dialysis at the Ulster Hospital. In 2011, she underwent brain surgery for a brain tumour. She recovered to fight her illness but lost her courageous fight for life in September 2012. The NITF has approached ARDS COUNCIL to create a memorial bench in honour of Geraldine to be positioned in her beloved NEW LIFE GARDEN which she took such pride in creating.

(L-R, William Johnston & Geraldine McCandless with Mayor of Ards, Councillor Mervyn Oswald, and Dr Eddie Rooney, Chief Executive, Public Health Agency)

NIKPA'S BIG DAY OUT—June 2012

Once again, NIKPA's Big Day Out was a resounding success for all involved. Coaches travelled from far and near bringing NIKPA members from across the province, with their carers and family members to sunny Portrush. We give our sincere thanks to the Royal Court Hotel at Whiterocks for serving a fantastic carvery buffet.



Royal Court Hotel



OLYMPIC TORCHBEARERS 2012

LILONA NIELSON (live kidney donor) – STRABANE, 5th JUNE 2012
ORLA SMYTH (kidney transplant recipient) – LISBURN, 6th JUNE 2012

Many of you will be aware of the success of the London 2012 Olympics. Here in Northern Ireland Lilona Nielson who donated a kidney to her father, Robert Smyth, and Orla Smyth, kidney transplant recipient (daughter of our Vice Chair, Therese Smyth) were both selected to be Torchbearers in the lead up to the games. Their nomination stories are set out below.



Lilona's Nomination Story

I am nominating my daughter Lilona, as she has not only been a source of inspiration to me, but also all the family, community and even those throughout Northern Ireland. She has literally saved my life. No longer have I the need for dialysis 3 times per week (which costs the Health Service over £44,000 per year to provide, but only £5,000 to maintain with a new kidney). As a devoted wife and mother of three children, all this was put aside and she donated a live, left kidney to me Robert, at the advanced age of 73. This required 4 hours of unnecessary surgery for her, with at least 6 months convalescence, before she would be free from aches and pains. Now she is scared for life. This was a selfless act that was reported on all across the Province by Radio and Newspaper, just over 3 months ago. There are those who considered this such act of bravery that it has inspired some of the public to become live organ donors, thus blessing the lives of numerous people awaiting a life saving organ. All that aside her nephew Jason won 2 Gold Medals at the Beijing Paralympics. He is currently the World Paralympic Champion in both the 100 and 200 m sprints as well as the world champion in these events. Presently he has qualified in section "B" for the main stream Olympics and expects to qualify for the "A" section later this year. This would be a world first as it has never been accomplished before. Lilona, one of life's unsung heroines.



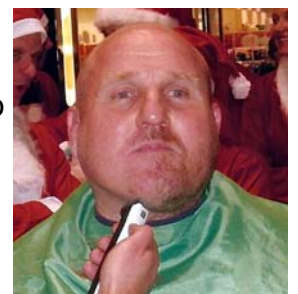
Orla's Nomination Story

As a transplant recipient she shows people the difference a transplant can make to people's lives and gives hope to those waiting. I hope to use my passion for running to encourage people to sign the Organ Donor Register. As a transplant recipient, by taking part in running events I want to show people the difference that a transplant makes to people's lives so that they sign the organ donor register and talk to their families about their wishes. My running goals are to qualify for the next World Transplant Games in South Africa in 2013, to improve my running times over 1500m and 3000m and maybe even take on another marathon, having completed my first one this year in under four hours (just)!! My dream is that one day there will be enough Organs for everyone who needs them and people will not die waiting or spend years on dialysis while their health deteriorates.



Santa Gets a Shave

NIKPA members, William Johnston and Marty Taggart who took part in the Ballymena Runners Santa race also added their own little twist. They were sponsored to grow Santa beards for the event and on the night and were ceremoniously given a shave. They raised £129.30p



THE NORTHERN IRELAND TRANSPLANT FORUM - *LIFECYCLE 2012*

This event built on the success of the NORTHERN IRELAND KIDNEY PATIENTS ASSOCIATION (NIKPA) LIFECYCLE 2008

The NITF NEW LIFECYCLE 2012 was a 6 day sponsored cycling event around Northern Ireland designed to increase awareness of the benefits of Organ Donation and encourage people to consider signing the Donor Register.

Participating in the LIFECYCLE were transplant recipients, medical staff, friends and families.

The LIFECYCLE began and ended at each of stopped the 7 dialysis units of Northern Ireland (RVH for Sick Children Hospital, Belfast City Hospital, Antrim Area Hospital, Altnagelvin Hospital, (Derry), Tyrone County Area (Omagh), Daisy Hill Hospital (Newry) and the Ulster Hospital (Dundonald). It also visited Lagan Valley Hospital (Lisburn), Craigavon Hospital and Coleraine Town Hall

At the beginning of each day, the participants were welcomed by the local Mayor, politicians and NI sporting celebrities.

An example of this is DAY ONE when Edwin Poots MLA and NI HEALTH MINISTER cycled on a tandem with Dr Janet Grey, (World Blind Water Skier Champion) from RVH FOR SICK CHILDREN (pictured above) to LAGAN VALLEY HOSPITAL. At Lagan Valley Hospital they were greeted by the Mayor of Lisburn and Jeffery Donaldson MLA. Also attending DAY ONE was Jimmy Kirkwood, Olympic Hockey Gold Medallist and Orla Smyth, a kidney transplant recipient who ran the BELFAST MARATHON 2011 and was selected to be one of the LONDON OLYMPIC 2012 torch bearers as the torch made its way around NI. The transplanted children and their families were thrilled to be able to hold the replica Olympic torch each torch bearer was given.

This kind of reception was repeated on each day with local politicians and celebrities giving up their time to support and endorse the LIFECYCLE. This included Joanne Dobson MLA for Craigavon, Lady Hermon MP for North Down, and Jim Shannon MP for Strangford.



MEMORIAL SERVICE FOR DONOR FAMILIES AND TRANSPLANT RECIPIENTS



Every 3 years the Transplant Co-ordinators organise a Memorial Service for Donor Families and Transplant Recipients and their families. It is normally held in the November in the SPIRES CENTRE, BELFAST. Around 1000 people attend. Transplant Recipients are asked to bring bouquet of flowers which when invited they bring to the front of the hall. Donor Families are then invited to come forward and receive one of these bouquet of flowers. This is to symbolise the exchange of a GIFT in gratitude to the Donor and Donor Family. A Donor Family, a Transplant Recipient and a representative of the medical profession make short speeches.

The feedback from Donor Families and Transplant Recipients and their families is always very positive, all voicing the same opinion that the Service was a fitting tribute to their Donor and loved ones who donated the GIFT OF LIFE.



Denis Ferguson

Pictured (left) is Denis Ferguson (husband of NIKPA Honorary Secretary, Joyce Ferguson) receiving a cheque for £500.00 on behalf of NIKPA from Mr Matthew Hull of the Ulster Vintage Commercial Vehicle Club. Denis had donated some photographs to the Club taken by his cousin who is unfortunately now deceased. In return the Club asked Denis to nominate the Club's charity for the year. This led to the magnificent sum of £500.00 each being donated to both NIKPA and Operation Rescue Ethiopia (a charity supporting young people). Our thanks go to Denis, Joyce and all the members of the Ulster Vintage Commercial Vehicle Club Ltd.

Kelly Courtney – Dublin Marathon & Santa Run

On Behalf of the committee and members of NIKPA can we say a really big "thank you" to Kelly Courtney on behalf of her fund raising efforts for NIKPA. Kelly who is the wife of Alistair, a dialysis patient at the Antrim



Dialysis Unit ran the Dublin Marathon on 29th October 2012 in a time of 3hours, 47 minutes and 15 seconds while raising sponsorship monies for NIKPA. In addition Kelly, supported by her colleagues at Ballymena Runners A.C. organised a Santa Run through Ballymena Town Centre on 17th December 2012. Together with funds raised at the Ecos Park Run, Kelly and her colleagues raised the fantastic total of over £2,400. Thanks must also go to Kelly's family and friends, Ballymena Runners A.C., Victory Praise Community Church and to everyone who sponsored and supported Kelly's efforts.



NIKPA And The Ulster University *Thanks You!*

Last year, following and add in the NIKPA Newsletter, the University of Ulster carried out a survey. The survey was part of research into patient dialysis choices. One hundred and seventy questionnaire packs were sent to renal patients around Northern Ireland. The response rate was excellent and the results obtained proved to be very valuable. The results will be published in a future issue of the NIKPA Newsletter. NIKPA on behalf of the University of Ulster would like to thank all the patients and carers who took part in the survey.



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
or send a cheque to
NIKPA, P.O Box 85, Carrickfergus,
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