



# NIKPA Newsletter

Northern Ireland Kidney Patients' Association

March 2012



## 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 1<sup>st</sup> at 2.15pm in the Ennis Room (dining floor) of the Belfast City Hospital tower block. The guest speaker will be, the vice president of NIKPA and nephrologist consultant, Dr Aishling Courtney. Refreshments will be provided.

## A Visit to the Panto

On Saturday January 21<sup>st</sup> 2012 many of the Northern Ireland young dialysis patients visited the pantomime. The pantomime "Jack and the Beanstalk" was playing at the Grand Opera House, Belfast. May McFettridge headlined as pantomime Dame May Trot, in this 3D spectacular show.

The young patients dialyse at the renal unit in The Royal Hospital for Sick Children (RHSC). They come from various parts on Northern Ireland. 125 patients, their parents and siblings were treated to an afternoon of entertainment by funds raised through NIKPA. NIKPA would like to thank Nurse Hazel Gibson of the children's renal unit for her help in organising the visit. Here are some of the photos taken on the day out. →





## THE NORTHERN IRELAND TRANSPLANT FORUM'S NEW LIFECYCLE, 2012

Building on the success of the **NIKPA LIFECYCLE 2008**, the Northern Ireland Transplant Forum (NITF) LIFECYCLE 2012 is due to take place from Saturday 16th - Thursday 21st June.

The NITF is made up of the charities of NI with a vested interest in the promotion of Organ Donation. The LIFECYCLE is a fun cycling challenge to take place in 6 locations all around Northern Ireland on six successive days. So there will be a LIFECYCLE event close to you no matter where you live.

The LIFECYCLE is designed to promote organ donation. We therefore not only require cyclists for each day but also anyone with a desire to promote organ donation and who would be available to support the cyclists at the start of each day. Transplanted patients and their families and friends would be very welcome.

For full details please visit [www.NIKPA.org](http://www.NIKPA.org) or contact William Johnston by telephoning: 02891271312 or emailing [willjohnston1@hotmail.co.uk](mailto:willjohnston1@hotmail.co.uk)



### Highlighting Organ Transplantation Hillsborough Garden Festival, May 18th-20th

This year the Organ Transplant Forum will be taking up the U105 challenge to design and build a garden to be displayed at the Garden Festival at Hillsborough Castle. Teams are given a set budget and timeframe within which they must complete their garden in the style of the original Groundforce.

The garden, (approximately 3 metres x 3 metres) will be on the theme of 'organ transplantation'. The construction day for the garden will be on 17<sup>th</sup> May at the castle and we are looking for volunteers to help. So if you feel that you have 'green fingers' or would like to promote organ donation at the festival, please contact William Johnston at [willjohnston1@hotmail.co.uk](mailto:willjohnston1@hotmail.co.uk)



### Organ Donation at Castlecourt



The Northern Ireland Transplant Forum held an organ donation promotion day at Castlecourt shopping mall in Belfast on January 14<sup>th</sup> 2012. Members of NIKPA, along with members of other transplant associations, encouraged shoppers to sign up to the organ donor register. Ninety nine people signed the organ donor register that day and many took away organ donor forms. Currently only one in four people have signed the organ donor register in Northern Ireland.



# We need you!

## Research into treatment choices for Chronic Kidney Disease

**We need your help!** The University of Ulster in conjunction with NIKPA are doing research into the choices of treatment that people with Chronic Kidney Disease are offered in Northern Ireland. We want to find out what type of dialysis you were offered and what your views and experiences of this have been.

We also want to talk to **your spouse, partner or the person who helps** you on a day to day basis. Maybe this person takes you to dialysis or attends medical appointments with you. We want to know what their views are on treatment and choices for people with Chronic Kidney Disease in Northern Ireland. Because your spouse, partner or the person who you helps you may not read this newsletter, we are asking you to see if they would be interested in talking to us.

The study has been running since November 2011 and will continue into the summer of 2012. This is your opportunity to tell us about your experiences. This information, from both you and the person who helps you, will assist in shaping and developing services for people with Chronic Kidney Disease in Northern Ireland – **this is your opportunity to have your say!**

If you are interested in helping us, please contact Sinead by email at [sr.keeney@ulster.ac.uk](mailto:sr.keeney@ulster.ac.uk) or by telephone on **02890368463** and she will provide you with all the information. You will be asked to take part in a short 20-30 minute telephone call during which the researcher will ask you about your views and thoughts about dialysis and the choices that were offered to you after you were diagnosed with Chronic Kidney Disease. Everything discussed will be completely confidential and you will never be identified by name within the study.

The word 'THANKS' is written in large, bold, purple letters with a black outline. A brown hand is pointing towards the letter 'H'. There are three green lines radiating from the hand, suggesting motion or emphasis.



## **PRESUMED CONSENT - The "Opt-Out" Option**

The current "opt-in" system of organ donation – where individuals are asked to register their willingness to be a donor after their death – has been the subject of debate for many years.

Due to the serious shortage of organ donors and consequent waiting lists for transplant operations in the UK, it is often suggested that the altruistic approach to organ donation is in need of review. This includes the "opt out" system.

Under a system of "opting out" or "presumed consent", every person living in that country is deemed to have given their consent to organ donation unless they have specifically "opted out" by recording in writing their unwillingness to give organs.

Recently the Northern Ireland Assembly has urged the health minister to consult on an organ donation scheme where everyone is included, unless they opt out. The current system means organs can only be donated if a person has indicated their desire to be a donor.

In a recent debate in the Northern Ireland Assembly, Ulster Unionist MLA, Joanne Dobson, told the chamber that if it had not been for a kidney transplant operation she would have lost her teenage son, Mark. He was diagnosed with kidney failure when he was just 13. "Mark is one of the lucky ones," she said. "He waited for 10 months for an accessible organ donor and in February 2009 he underwent a five-and-a-half hour operation at the Royal Belfast Hospital for Sick Children". We do not know who the donor of Mark's kidney was. But even so we thank their family every single day for giving Mark the gift of life."

Mr. Edwin Poots DUP MLA, the health minister, has called for a public debate on how the current system might be improved, but stopped short of any definite announcement of a formal review.

Between April 2010 and last April, 17 people died in Northern Ireland waiting for a transplant. Three hundred people in Northern Ireland are currently awaiting organ donations and only one in four adults in NI are registered as potential organ donors.

Some of the above information above has been taken from the BBC news online and Organ Donation online websites.



## **Belfast City Marathon, 2012**

On Bank Holiday Monday, 7<sup>th</sup> May, over 20,000 people are expected to hit the streets of Belfast to participate in the Deep River-Rock Belfast City Marathon.

The route will remain the same as in the 2011 event, starting at the city Hall and finishing at Ormeau Park. You can register for the event at [register.belfastcitymarathon.com](http://register.belfastcitymarathon.com). The final cut off point for entries is 6<sup>th</sup> April 2012. For more information you can go to [www.belfastcitymarathon.com](http://www.belfastcitymarathon.com).

The event is held to raise money for charity. This year the nominated charity is the Northern Ireland Children's Hospice but you can raise money for your own particular charity.

Members of NIKPA will be taking part in the event. If you wish to take part and raise money for the Northern Ireland Kidney Patients' Association, please contact Colin Thompson at [colinwthompson@hotmail.co.uk](mailto:colinwthompson@hotmail.co.uk) or William Johnston at [willjohnston1@hotmail.co.uk](mailto:willjohnston1@hotmail.co.uk).

### **NIKPA FUNDING**

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

### **DONATIONS TO NIKPA**

*NIKPA would like to thank the following people for their kind donations: Mrs H. Greer, Isobel Skillen, Mr and Mrs Sedgewick, Mr K P Wylie, Marie Bell, Eileen Donaldson, the Ballinderry Ladies Fellowship, Elizabeth Tuft and Richard McCrory*

*You can donate online as [www.NIKPA.org](http://www.NIKPA.org) or send a cheque to NIKPA, P.O Box 85, Carrickfergus, Co. Antrim, BT38 OAT*

*email: [info@nikpa.org](mailto:info@nikpa.org), Reg Charity No XR 25887*



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