



## VISIT TO SANTA'S COTTAGE



On Sunday December 6th, 2009 a visit was arranged by NIKPA for the young renal patients of the Royal Victoria Hospital to visit Mr. and Mrs. Claus. Santa and his wife and some the elves were having a brief holiday in a cottage in the beautiful grounds of Castleward before heading back to the North Pole for the busy Christmas period.

Everyone arrived at 11am at the Stable yard café where they were given a warm welcome by Colin Thompson (NIKPA chairman). All the children received a 'goody bag'. Groups of children along with their Mums and Dads took the Santa Express bus up to Santa's cottage. Here they were welcomed by Mrs. Claus who gave them a brief tour of the Elves' workshop before meeting the main man himself. Santa was delighted to see them and gave them all a pre-Christmas present. Having met and chatted with Santa they returned to the barn for some lunch and entertainment. A good time was had by all.

The R.V.H's Sister Hazel Gibbons and Consultant Professor Savage also accompanied the children on this outing.

U.T.V's Tina Campbell interviewed some of the parents and Santa for her T.V program 'The seven thirty show'. The main message of the interviews was to show how renal failure affects children and their families and how important it is to register as an organ donor. If you want to register as an organ donor you can do so by registering online at [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) or by calling the NHS Donor line on 0300 123 23 23.





## Winners of the NIKPA Christmas Ballot



Everyone at NIKPA would like to say thank you for your support in raising money for Northern Irish kidney patients. We raised just over £1,300 through the sale of our ballot tickets and recent Quiz night. The ballot was held on Tuesday the 1<sup>st</sup> of December. The winners of the ballot are as below:

**1<sup>st</sup> Prize – Neil Aicken, Carrickfergus, 2<sup>nd</sup> Prize – Helen Rowland, Rostrevor,  
3<sup>rd</sup> Prize – Rosemary Sullivan, Bangor, 4<sup>th</sup> Prize – Therese Smyth, Belfast, 5<sup>th</sup> Prize – Marie Bell, Bangor,  
6<sup>th</sup> Prize – Vera Crawford, The Maze, 7<sup>th</sup> Prize – Jenny Reese, Dundonald,  
8<sup>th</sup> Prize – Damien Carberry, Cavan**

Due to some kind and late donations there were a few subsequent prizes added on and the winners were as follows:

**9<sup>th</sup> Prize – Grainne Collins, Newry, 10<sup>th</sup> Prize – George Kerr, Crossgar, 11<sup>th</sup> Prize – Tom Smiley, Renal 2B (BCH),  
12<sup>th</sup> Prize – Pat Gordon, Donaghadee, 13<sup>th</sup> Prize – Rodney Hume, Antrim**



## Meeting Mr Michael McGimpsey

NIKPA had a rare opportunity to briefly meet with Mr Michael McGimpsey at the U.U.P conference on Saturday 9<sup>th</sup> October 2009 held in the Europa hotel. Jo- Anne Dobson (our public relations person) and whose son Mark, just recently received a transplant organised the meeting. It was an excellent opportunity to talk with Mr McGimpsey about NIKPA's work and in general to increase the profile of the Donor card and the Northern Ireland Transplant Forum.

## NIKPA Donations

NIKPA would like to thank the following people and organisations for their kind donations:

Owens Mc Ilwaine, Ian Winters, R.A Thompson, Miss A.A Quigley, Marie Bell, Mrs Letitia Swain, Noreen and George Kerr, Joe Mc Carrison, Mrs N.M.A Russell, Henry Pollock, Dr Douglas, C.A Service, The Hospital Saturday Fund (HSF), Waringstown Primary School.

### Runners in the Chicago Marathon



**Hospital Saturday Fund—Cheque Presentation**

We would also like to give a special mention to the Bank of Scotland (Ireland) for awarding us a substantial grant and to Michael Mc Ilroy who ran the Chicago marathon. Michael raised a total of £3167.55 which was equally split between NIKPA and KIKRF. Last of all we would like to thank all of you who have supported us by raising money for our charity and by sponsorship in Lap the Lough, buying ballot tickets and contributing towards our Quiz night.

**If you wish to make a donation to NIKPA funds, send a cheque made payable to NIKPA, P.OBox 85, Carrickfergus, Co. Antrim or click the 'Donate' button on NIKPA website at [www.NIKPA.org](http://www.NIKPA.org)**

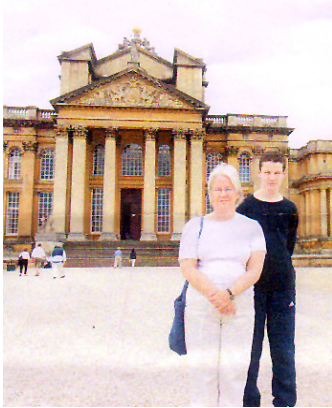
## 30 YEARS OF PERITONEAL DIALYSIS

Did you know that Peritoneal Dialysis has been carried out in NI for nearly 30 years!

As an alternative to Haemodialysis (HD), Peritoneal Dialysis (PD) is a dialysis therapy that uses the body's own peritoneum (the lining of the abdominal cavity) as a filter to cleanse the blood.

In the early 1980's the first patient in NI was trained on CAPD using a Baxter system. This innovation offered patients the opportunity to have their dialysis at home rather than having to visit hospital up to 3 times a week for haemodialysis.

PD has continued to evolve over the Last 30 years. 15 years ago a portable automated machine was introduced allowing PD to be performed overnight, leaving the patients days free.



PD patient Vivienne Waddell states "I was first diagnosed with kidney problems in 1982. By 2002 it was necessary to make preparations for dialysis to start. I was instantly attracted to the idea of Peritoneal Dialysis. I Liked the idea of not having to be tied to hospital visits 3 times a week. I know kidney failure is not something that can be ignored but I have always been determined to maintain as "normal" a life as possible. I felt using the Baxter Homechoice machine at night, to do Peritoneal Dialysis would offer me the best chance of achieving this aim".

Vivienne adds "I found Peritoneal Dialysis to be a very successful therapy. At first it seemed rather scary but with great support and training from the renal nurses my confidence grew and it all very quickly became child's play. The Homechoice system made it easy for me to continue to work fulltime. There is a 24 hour support service and I knew if I had any trouble I could just lift the phone."

She goes on to say " PD also offered great advantages to family life: it gave me the time I needed in the early evening to help with homework's and to run mum's taxi service". Another great advantage was the way it facilitated family holidays. "I Liked having my own routine and my own equipment rather than having to check into a strange unit for haemodialysis. As a family we always tended to rent holiday cottages and I was always confident that Baxter would deliver my supplies". In the Last year 30 PD patients have availed of the Holiday Service offered. Their destinations included USA & Europe and many enjoyed worldwide cruises.

"I can say with honesty that the experience of day to day life with PD allowed me to follow the lifestyle I wanted for myself and my family" states Vivienne.

In 1999, a new purpose built Regional Renal Unit was opened at BCH incorporating a 2-bedded PD training area with facilities for clinics and a drop in centre for the PD population offering 24 hour support and assistance. Presently within Northern Ireland, there are 5 sub-regional Renal units (Newry, Antrim, Dundonald, Tyrone & Altnagetyin) for the treatment of adults, whilst children with renal failure attend the RHS13C. Each unit has a trained PD nurse Et PD facilities and there are currently over 105 patients being supported on this treatment at home.

If you would like any more information on PD please contact PD Nurses at BCH on 02890 263968.

PHOTOS — Thanks to Vivienne Waddell for sharing her experience of PD. The photo shows her living life to the full whilst on PD. Vivienne has since received a kidney transplant and continues to feel well.



**Visit [WWW.NIKPA.ORG](http://WWW.NIKPA.ORG) website**



## RECIPE IDEA

### LEMON & THYME CHICKEN

- 1 X Breast of Chicken - (skin on if possible)  
25g unsalted butter  
Splash of Oil

#### MARINADE:

- 1/2 Lemon - juiced & Grate the Rind  
1 Clove Garlic chopped  
Pinch Cracked Black Pepper  
Large Sprig of Thyme

24hrs beforehand - Put the marinade & chicken in a plastic bag shake and seal and keep in fridge.

Heat oil in a good non-stick pan Add Chicken - skin down - Cook till Golden turn over repeat. Add Butter.

Finish in the oven for 15-20 minutes - 225 degrees C

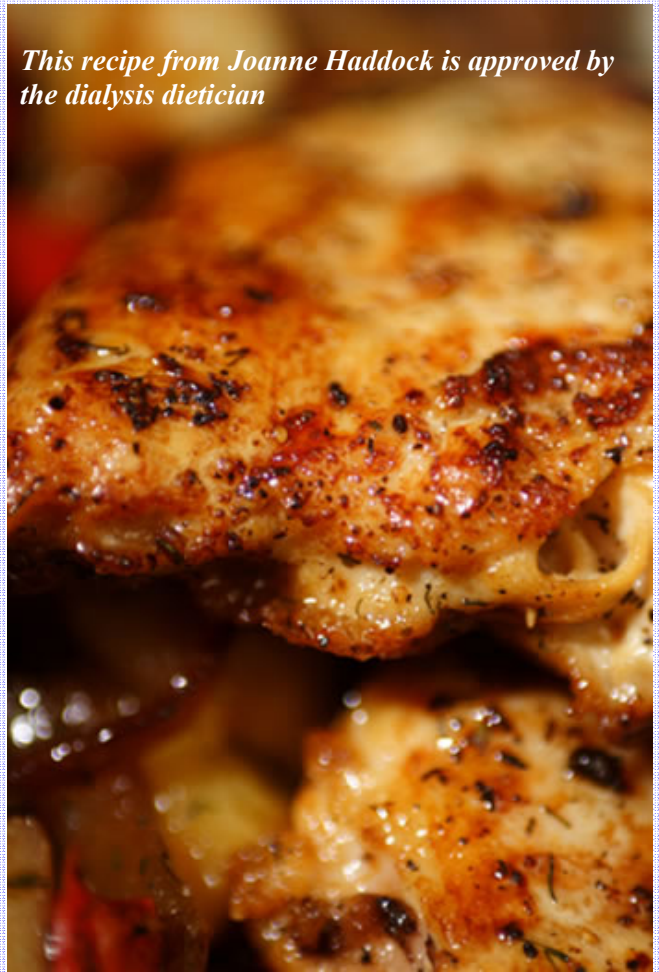


Serve with Lyonnaise Potatoes and Vegetables

1 portion of Boiled Potatoes, cooled and sliced  
1/2 Sliced Onion

Fry both in a little unsalted butter & oil till Golden

*This recipe from Joanne Haddock is approved by the dialysis dietician*



## Lap the Lough '09

35 km long, 25 km wide and 150 km around

Neagh Problem!

lap 4



On August 30<sup>th</sup> '09 William Johnston (NIKPA secretary) along with 26 other cyclists (made up of medical staff, friends and relatives) raised a total of £334.9.35 for NIKPA. The brave cyclists, on one of the wettest days of the summer conquered the 87 miles circumference of Lough Neagh. The event was one of the biggest charity events which Northern Ireland had seen with 1200 cyclists taking part, raising money for their own charities. NIKPA would like to thank all those who took part and to give a special mention to Rose Energy Ltd, Glenavy, who sponsored and paid for the T-shirts. We would also like to thank Baxter Healthcare for supplying the support van and last of all to the event organisers Castlehill cycling club.



## Success at the Transplant Games

At the start of August this year, I had the great pleasure of competing in my first British Transplant Games.

I am one of the lucky ones who received a successful transplant in November 2007 after over 3 years on PD. Prior to becoming ill I played football and gaelic football and one of the most difficult things for me to come to terms with when I became ill was not being able to take part in competitive sport (Yes I totally admit I am a competitive little weasel!!).

On dialysis I did not have the energy to participate in very much physical activity, walking the dog was about the height of my sporting endeavours during this time. When I had my transplant I was determined to get back into sport as much as I could. With my football boots well and truly hung up on a rusty nail, I decided to take up running.

It was when I started running that I became aware of the Northern Ireland Transplant Sport team. It was with this great bunch of people that I set off to Coventry in August 2009 to compete in the British Transplant Games. I signed up for the 3km, 1500m, 800m, 400m and long jump...and while I was there I got roped into the 100m mixed relay race (well they needed one gal in the team!)



Orla Smyth



Orla's Husband—Declan

I cannot quite describe what a truly unique and wonderful experience competing in the Games was. You compete with people who have had all manner of transplants. The ages of competitors range from the very youngest children to the more mature competitors (70+).

It is a truly inspirational experience to see the amazing effect that a transplant can have on people's lives and to see people living their life to the full after coming through some very tough times. The Games are also an opportunity to say thank you to all the donors and their families, as without their courage and bravery a lot of the competitors wouldn't be alive never mind competing in the games.

Winning medals is a bonus. The real joy of being involved with the Transplant Games are the people you meet, the stories they tell and being one of a truly unique group of people, brought together because of a common condition. This leads to a very special bond that I know has made me friends for life.

The events range from Athletics, swimming, cycling, racket sports, orienteering, archery, snooker, golf and a number of things in between. Check out [www.transplantsport.org.uk](http://www.transplantsport.org.uk) for further details of events.



The British Transplant Games are only open to competitors who have had a transplant however the European Transplant and Dialysis Games are being held in Dublin from the 8<sup>th</sup> to 15<sup>th</sup> August 2010 and are open to Dialysis and Transplant patients.

So if you are on Dialysis or have had a transplant and fancy getting involved, contact Frankie O Kane (Northern Ireland Transplant Sports team manager) on **07825180798**.

Oh yeah...and I won 5 Gold medals, a bronze and the top female track athlete in my age category (I told you I was competitive!!) However as I say the medals are a bonus. It really is the taking part and being involved in such a memorable event which counts.

*By NIKPA committee member Orla Smyth*



# NIKPA Quiz Night

A successful quiz night was organised by NIKPA members Neill Aiken and Gina Moss on Sunday 15<sup>th</sup> November '09 at Stormont Civil Service Sports Pavilion. The experienced quiz master Michael Connolly (a home dialysis patient) set the many and varied questions. The event was well attended with renal patients, friends, relatives and medical staff. A good time was had by all. The money raised by the event, along with the autumn draw came to £ 1455.15.



## A2B Access to benefits

Are you over 60? Have you ever wondered what benefits you might be entitled to? With A2B's online benefits calculator, you or someone you trust can go onto the web and check your entitlements safely in a few easy steps. It's free, simple and, best of all, it's anonymous.

[www.a2b.org.uk](http://www.a2b.org.uk) has been developed by A2B: Access to Benefits in Northern Ireland. An older person or a friend, relative or some-one they trust can input their details into the online calculator which will work out their entitlement. This produces a report which they can then print off or save. The website also provides information about a range of benefits, details of organisations which both deliver benefits and provide advice and information about them and links to claim forms on other websites. It's a bit like a health check-up for your benefits, but you don't need to give your name, address or NI number, so anonymity is assured.

The website's calculator provides results for all the main benefits available to older people in Northern Ireland. This includes Pension Credit, Housing Benefit for rent and/or rates and Rate Relief. In addition it can also indicate entitlement to a range of other benefits including SmartPass, Free Television Licence and Lone Pensioner Allowance.

To find out more, visit [www.a2b.org.uk](http://www.a2b.org.uk).



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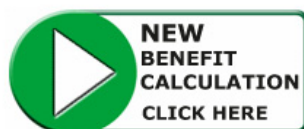
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Welcome to the website of A2B: Access to Benefits



# Living Kidney Donation

Donating a kidney is a major decision and it takes courage to be a kidney donor. There are many things that you should know before considering kidney donation and this leaflet hopes to answer some of your questions.

Kidneys may be donated by people who have died or by living donors who either wish to help a loved one, or a stranger, with kidney failure by giving a kidney. It is important that anyone who wants to be considered as a living kidney donor thinks seriously about the possibility.

Points to consider are:

- the survival of transplants from living donors is significantly better, allowing more people to receive and benefit from a kidney transplant
  - living donors who are close relatives can be an excellent tissue-type match for the recipient and this can be an added bonus for the recipient
  - unrelated donors, such as spouses, are unlikely to be well matched to the recipient. However, in all but the perfectly matched situation, the success rates of these transplants are equal to those of related donors
  - living kidney donation allows the transplant operation to be planned at a time that is convenient for the recipient and the donor and for some people this can be planned before the need for dialysis
  - recipients who are transplanted prior to dialysis have better long-term transplant survival.
- Living kidney donation in the UK is increasing. This is against the following background:
- the number of people needing kidney transplants continues to increase
  - there are not enough kidneys from donors who have died available for transplant
  - the average waiting time for a kidney transplant is two and a half to three years and for some minority ethnic groups and individuals with rare tissue types, it may be more than five years.

## Will it shorten my lifespan?

Studies have shown that donors live longer than the average population. This is because donors are selected on the basis of good health and are thoroughly screened prior to donation.

## Do some donors have trouble making the decision?

Some people make the decision easily. Others go through some soul searching before deciding. Being afraid of donating a kidney or feeling guilty about not wanting to donate is quite normal. The only "right" decision is the one that makes you, the potential donor, feel comfortable. Finding out more information about living donation and what it involves may help you with this decision.



## Who can donate?

Donors are often a close relative such as a parent, brother or sister, son or daughter but may also be individuals who are not related but have an established emotional relationship with the recipient such as a

partner or close friend.

Sometimes a donor and a recipient may be incompatible with each other because of blood group or antibody incompatibility and in this case it may be possible for them to be paired with another donor and recipient in the same situation. This means that each recipient will benefit from a transplant that they would otherwise not have had (this is called paired donation). Where more than two pairs are involved in the swap it is called pooled donation.

Increasingly people are putting themselves forward as non directed altruistic donors. These are individuals who are unknown to the recipient.

## What is the minimum age for being a donor?

In England, Wales and Northern Ireland, there is no minimum age limit specified within the Human Tissue Act 2004 for a person to be considered as a living kidney donor. However, the majority of donors will be over the age of 18 years and children would only be considered in very exceptional circumstances, and this would require court approval. In Scotland, only people over 16 years of age can be legally considered as living kidney donors.

## Are there any risks to me?

All operations carry some risk and this is no different for living donation. Donors are at risk of infections (eg chest, wound or urine) and, more rarely, bleeding or blood clots. There is a very small risk of death for the donor: this is estimated at 1 in 3,000 for this operation.

## For more information

Visit the

**[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)**

Website





## Service of Thanksgiving and Remembrance

A service of remembrance and thanksgiving for organ donation was held in the Spires conference centre, Belfast, on Sunday 18<sup>th</sup> October 2009. This event is held once every three years and is organised by the transplant co-ordinators. Those attending were the transplanted patients, families of organ donors, living organ donors and medical staff.

There were a large number of people who attended. The service was very moving as amongst the guest speakers were the personal accounts given by members of families of organ donors and what this legacy has meant to them. Also amongst the guest speakers were living donors, the organ recipients and medical staff.



## A.G.M. NOTICE

NIKPA's annual general meeting will take place in the Ennis Room on the Dining floor of the Belfast City Hospital tower on the 31<sup>st</sup> January 2010 at Belfast City Hospital . It will begin at 2.15pm and finish at 4pm. A light lunch will be provided. All are welcome.

We are a completely voluntary organization run by patients, relatives and friends. We are dedicated to meeting the needs of all Northern Irish kidney patients, their families and their carers. If you wish to have your say or that you have skills that you can offer we would be delighted to hear from you.