



NIKPA'S BIG DAY OUT

Once more, NIKPA celebrated another successful big day out for renal patients and their families. The day was Sunday the 26th June 2011 and almost 200 people were treated to a three course meal at the Royal Court Hotel, Portrush. The scenery was beautiful and the sun did make an appearance. Renal patients were collected by Ulsterbus from the various renal centres across Northern Ireland and returned after the meal and a few hours of exploring the seaside resort. NIKPA would like to thank the staff of the hotel and Ulsterbus for making this such a cheery event. Patients have given us some very positive feed back about how thoroughly they enjoyed the day. So we hope to see you all next year, to do it all over again!



INTRODUCING PROFESSOR PETER MAXWELL, PRESIDENT OF NIKPA

Professor Peter Maxwell accepted the post of NIKPA president at the last AGM. He had previously held the post of NIKPA vice president and for many years has been an enthusiastic supporter of the association.



Peter Maxwell, MD, PhD, FRCP, has been a consultant nephrologist at the Belfast City Hospital since 1994. He is also the Professor of Renal Medicine at Queen's University Belfast Medical School where he has developed his interests in medical education and research. Prof Maxwell trained in both the UK and Toronto, Canada where he spent four years as a Clinical Research Fellow. He is the Training Programme Director for nephrology and has helped to drive the rapid expansion in the local renal medicine workforce. Prof Maxwell has research interests involving the genetic risk factors for chronic kidney disease, renal transplant outcomes and the effectiveness of drugs for kidney disorders. He leads a very active Nephrology Research Laboratory at the Belfast City Hospital which has helped train a number of junior doctors and students in scientific methods relevant to kidney disease.

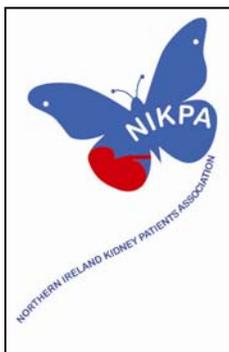
THE NEW NIKPA VICE PRESIDENT – DR AISLING COURTNEY.

Dr Aisling Courtney is a renal consultant in the Belfast City Hospital and is the clinical lead for transplantation. Dr Courtney has worked very closely with Dr C Doherty in the past. Dr Courtney has kindly accepted the post of NIKPA vice president at the last AGM. Aisling is committed to patient welfare and promoting organ donation.

She previously served as a locum consultant in the Royal Free Hospital, London and has continued with a very productive senior clinical research fellowship supported by the NIKRF. Aisling is a prolific author of clinical papers that the NIKRF has supported with almost 30 papers published since the start of her fellowship in 2006. She has made major contributions to the literature on transplantation already.



NIKPA LOGO AND BADGE



The new butterfly logo has recently been adopted by NIKPA. It symbolises new life after transplantation, allowing members to spread their wings and live life to the full. The small red kidney on the lower right lobe represents the donated organ. Blue and red colours were selected as these were the colours of the organ donor card.

The badges will be available from the second week of November for a donation of £1 to NIKPA. Any monies collected will fund NIKPA events such as NIKPA's BIG DAY OUT.

For any further information you can contact William Johnston by telephone (028 91271312) or e-mail (willjohnston1@hotmail.co.uk).

NIKPA DONATIONS (since January 1st, 2011)

The NIKPA committee would like to offer their sincere thanks to all those who have donated: £100.00 DR C DOHERTY in memory of Rodney Curry, £435.00 DONATIONS TO NIKPA IN LIEU OF FLOWERS FOLLOWING THE SAD DEATH OF RODNEY CURRY (PREVIOUS NIKPA TREASURER), £ 20.00 MRS M DEAKIN, £175.00 MR & MRS M TAGGART (SPONSORSHIP MONIES FROM BELFAST MARATHON 9 MILE WALK), £415.00 SPONSORSHIP MONIES FROM PATIENTS & STAFF AT ALTNAGELVIN DIALYSIS UNIT, £25.00 DONATION FROM DR J D & MRS E TEDFORD (NEW ZEALAND), £ 10.00 HENRY McALLISTER, £125.00 BISHOPSCOURT KART CLUB, £262.70 PETER McILROY - SPONSOR MONIES FROM BELFAST MARATHON - 9 MILE EVENT), £ 20.00 IAN WINTERS, £ 20.00 S G COMPTON, £40.00 MR & MRS P J COLGAN, £105.00 MRS MARIE BELL, £112.50 BISHOPSCOURT KART CLUB, £250.00 JOE McCORMICK - NEWTOWNSTEWART LEISURE COMPLEX, £270.00 NURSING STAFF OF DIALYSIS UNIT & BAXTER STAFF AT ANTRIM DIALYSIS UNIT - LAP THE LOUGH SPONSOR MONIES, £50.00 MRS H McDONALD

WHATEVER HAPPENED TO ORLA?



Former NIKPA committee member Orla Smyth gives an interview to the belfast citymarathon.com

Orla Smyth will "Run For A Life"

Orla Smyth, an inspiring transplant athlete from Belfast travelled to Dublin to take part in an organ donor awareness event, "Run for a Life" which will take place on Sunday 23rd October.

The avid Gaelic football enthusiast represented the UK at the Recent World Transplant Games where she broke three world records in the 400m, 800m and 1500m races. Orla was also one of the Faces of Deep RiverRock Belfast City Marathon 2011 when she completed the race in the fantastic time of 03:58:28. The 33 year old solicitor, says "my ultimate goal is to do everything I can to stay as healthy as possible to enable me to take part in Sport."

Organised by, and for, the Irish Kidney Association this fun family event, Run for a Life, will take place on Sunday 23rd October 2011 to highlight and promote organ donation for transplantation.

The event coincides with the European Day for Organ Donation and Transplantation, held in Geneva on the previous day. The European campaign aims to highlight the increasing need for organ transplants across all Europe.

Those participating in the Fun Run will have the option of walking, jogging or running competitively in either a 3.4km, 6.7km or 10km event in Park West, Dublin 12, commencing 12 noon. The day is open to all members of the general public. There will also be an option to enter a team of three in a 3 x 3.3km Team Relay Race.

Speaking about the event, Colin White, Race Organiser said, "the 'Run for a Life' is about celebrating organ donation, showcasing the success of transplantation and encouraging the public to play their part by carrying an organ donor card'. Supporting the Fun Run is a fantastic way to demonstrate solidarity in support of the 'Gift of Life'. The choice of events on offer makes it possible for all people, young and old, with varying levels of fitness to take part."

All proceeds raised from this charity event will go to the Irish Kidney Association, the patients' organisation charged with the promotion and distribution of the organ donor card in Ireland.

Registration (to include t-shirt and participant medal) will be €15 for adults and €10 per child and a Family of 2 adults and up to 4 children can register for €35. Teams (3 participants) entering for the relay can register for €40. For registration and further details log on to: www.runforalife.ie

For organ donor cards Freetext DONOR to 50050 or LoCall 1890 543639

Smart phone users can download a donor e-card app from the App store or Android market place by searching for 'ecard'.



KIDNEY PATIENTS WARNED AHEAD OF WINTER FLU SEASON

(from the kidney research UK website)

As winter flu season approaches, kidney patients are being urged to make the most of free NHS vaccinations and reduce their risk of catching the virus.

The Department of Health has warned that while millions of people in the UK are at increased risk from winter flu because of pre-existing conditions, such as kidney disease, only half of all individuals in these clinical risk groups received the flu vaccine in 2010.

Seasonal flu can be life-threatening and last year claimed more than 600 lives in the UK, with 70 per cent of victims aged between 15 and 64.

The government's Chief Medical Officer, Professor Dame Sally Davies, says that a five minute appointment to have the flu jab could save your life.

"Flu can be a serious illness – particularly for those in at risk groups," explained Professor Davies.

"It can result in a spell in hospital and, sadly, flu can kill. The best way to protect yourself is to be vaccinated.

"There is no reason not to get vaccinated. It takes five to ten days for the vaccine to take effect so I'd urge everyone in an at risk group to get vaccinated as soon as they are able."

Those who are eligible to receive the seasonal flu jab free of charge on the NHS include:

- o Anyone with a long term condition including kidney disease, diabetes, asthma, liver disease, or heart or chest problems
 - o Pregnant women
 - o People undergoing medical treatment who may have a compromised immune system
 - o People with a neurological condition such as multiple sclerosis (MS) or cerebral palsy
- Everyone aged 65 or over

Even kidney patients who feel perfectly healthy have been told they should arrange to receive the jab.

For more information visit www.dh.gov.uk



THE BELFAST MARATHON 2011

This year was the 30th anniversary of the Belfast city marathon. It was held on Bank Holiday Monday, 2nd May 2011. It is one of the leading marathons in the UK and Ireland. A record 21,000 people took part with the race starting at Belfast City Hall and ending in Ormeau Park. Although participants run for their own local charities the two official charities were Transplant Sport UK (TSUK) and Macmillan Cancer Support.

The TSUK charity raises awareness, through sport, of the desperate need for organ donation within the UK. A local woman, Orla Smyth, was chosen as the TSUK face of 2011. Orla, who had received a transplant in 2007, ran, for the first time, to raise money for the Northern Ireland Transplant Foundation (NITF). Orla finished the race in an impressive 3 hours and 58 minutes (for more information about Orla's achievements read the article 'Orla- previous NIKPA member').

Northern Ireland Kidney Patients (NIKPA) members, made up of dialysis patients and family and friends took part in the marathon walk. The marathon walk was introduced in 1997 and follows the same route as the marathon race. It has two distances, 9 miles and 26.2 miles. The NIKPA members successfully completed the 9 mile walk.

THE NEW LIFE GARDEN, KILTONGA, NEWTOWNARDS

The NEW LIFE GARDEN has been created by ARDS COUNCIL in partnership with the charities of the NORTHERN IRELAND TRANSPLANT FORUM (NITF). The NITF consist of local charities with a vested interest in the promotion of organ donation in Northern Ireland. These charities include the NORTHERN IRELAND KIDNEY PATIENTS' ASSOCIATION (NIKPA), NORTHERN IRELAND KIDNEY RESEARCH FUND (NIKRF), NORTHERN IRELAND TRANSPLANT ASSOCIATION (NITA), ROYAL VICTORIA HOSPITAL LIVER SUPPORT GROUP (RVHLSG) and TRANSPLANT SPORT NORTHERN IRELAND (TSNI). It is hoped the ROYAL VICTORIA HOSPITAL CHILDRENS' CHARITY will join the NITF soon.

It was decided to call the garden the NEW LIFE GARDEN as it is intended as a floral celebration of organ donation which gives new life. ARDS COUNCIL also intends to use it as a backdrop for wedding photos and wedding celebrations, signifying a new life for couples in love.

The vision for the New Life Garden is to create a beautiful, peaceful, tranquil place for reflection and remembrance. It is hoped the following groups of people will visit the garden and take ownership of it; Donor families, to visit and to remember their loved ones who decided to donate their organs to give the gift of new life; Transplant recipients to visit and to give thanks to their donor and donor families; Live kidney donors and kidney recipients to visit and to celebrate a new life together; People on the transplant list to visit and to gain strength and hope in the knowledge there people willing to donate.

ARDS COUNCIL agreed to develop the garden and maintain it afterwards. NITF agreed to provide a memorial stone, additional planting and features.

The garden was officially opened 21st June 2011 by Councillor Mervyn Oswald, Mayor of Newtownards. In attendance were Lady Herman (MP for North Down), Dr Ed Rooney (Chief Executive of the Public Health Agency), and local MLAs, councillors, medical staff, transplant coordinators and representatives from the NITF. But the real VIPs were the donor families, transplant recipients, live kidney donors and recipients.

After the official opening, children dressed as fairies and butterflies danced around the garden. This was signifying the blossoming of new life in the garden.



The garden is in its infancy but it was decided to officially open it in June so it could be visited by the donor families from around the UK when they would attend the Belfast British Transplant Games 2011, in August of this year.

It has been decided to have a one year anniversary on 21st June 2012 so the garden can be appreciated after a year's growth and the helping hand of Mother Nature. All donor families, transplant recipients, live donors would be very welcome to attend the celebration. Many of the donor families from the UK, who attended the 'Donor Family Day' during the transplant games, have expressed a deep desire to attend the anniversary next year, to witness the progress of the garden.

There will be plaques mounted on the side of every flowerbed in the garden, each, representing one of the charities of the Northern Ireland Transplant Forum (NITF). This plaque will have the logo, charity name and website address so that any person visiting the garden will have access to the information of each of the charities.

The garden is located at Kiltonga, Newtownards beside a small stone Quaker church. It is at the entrance of Kiltonga industrial estate but is set well back so it is surprisingly quiet and secluded.

The first New Life Garden has proved to be successful and it is the intention of the NITF to actively pursue the possibility of creating further New Life Gardens around Northern Ireland especially in the north west and Fermanagh so that donor families and transplant recipients will not have to travel long distances to remember and give thanks to donors who gave the gift of life.

If you would like to be updated with the development of the New Life Gardens or become actively involved with the creation and development of the current New Life Garden and future New Life Gardens, please do not hesitate to contact William Johnston: Telephone 02891271312, or e-mail willjohnston1@hotmail.co.uk

The British Transplant Games and the Northern Ireland Team

The British Transplant Games took place in Belfast over the first weekend in August 2011. The team from Northern Ireland was the biggest ever registered in the history of the games-a total of 51 adult team members and 16 children. In a change from previous years we were represented by athletes who had received life saving and enhancing transplants including livers, kidneys, lungs and bone marrow. The major focus of the local organising committee chaired by Dr Eddie Rooney was to increase public awareness of organ donation and transplantation-this was achieved with an increase of 22,500 signatures during the build up to the games. The media played their part with a huge amount of press and TV coverage- I am sure you will all remember Ben Bingham and Sidney the Kidney- so excited so excited so excited!!!!



The local athletes were able to make use of the Belfast City Council leisure facilities free of charge- and we had regular athletic training sessions at the Mary Peters Track (coaching provided by Declan Morgan-now known as Double Decker) and Swim training took place at the Grove Leisure centre.

All this training paid off for our local team-we won a total of 48 Gold Medals, 33 Silver medals and 18 Bronze medals. We also won 12 trophies including the Ross Taylor Rose Bowl for Best Overall Team, The John Gorna Trophy for best Swim Team and 10 individual trophies. Congratulations must go to Janet Coleman who received the Lifetime Achievement award -Janet has attended 28 British Transplant Games, numerous world , European and Winter games and has won medals at all of the events she has attended. She was also instrumental in bringing the games to Belfast in 2011 and worked tirelessly with the LOC in making these games a success.

Individual trophies went to; Brain Armstrong-best veteran male and outstanding athletic achievement, Orla Smyth-best senior female and outstanding athletic achievement and fastest female over 3k, Turlough O'Hagan-best super veteran male swimmer, Irene Jeffers-best super veteran female, Helena Boyle and Rachel Curran-Adult Badminton trophy and Lynn Patton-Best female cyclist

*By Frankie O'Kane
Team Leader, Pre Dialysis and Home Therapies*

VISIT THE NIKPA WEBSITE AT WWW.NIKPA.ORG

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