

September
2010

NIKPA Newsletter

Northern Ireland Kidney Patients' Association



Big Day Out 2010

After a very successful event of last year we decided to hold the Big Day Out for renal patients and their carers again in sunny Portrush. The event was held at the Royal Court Hotel, Portrush on Sunday the 27th of June. Approximately 240 patients and carers were picked up by coach at their dialysis units in Antrim, Belfast, Dundonald, Altnagelvin, Newry and Omagh (some made their own way there). They were entertained to a 3-course carvery lunch in the magnificent Atlantic Suite at the hotel and afterwards they spent a few hours touring the town before they returned home.

The feedback from the patients suggests that they really enjoyed themselves and look forward to next years outing. NIKPA would like to thank the staff at the hotel for making us really welcome and the Translink buses for their efforts.





Transplant Games Round-up

Janet Coleman – Chair Transplant Sport NI

European Transplant & Dialysis Games Dublin 2010

It gives me great pleasure to provide this brief round-up of performances and news regarding Transplant Games Events.

The City of Dublin hosted the 6th European Transplant & Dialysis Games in August 2010. A total of 8 transplant recipients and dialysis patients from Northern Ireland signed up to take part and joined the 22- person squad who represented the UK.

Whilst Orla Smyth (Belfast) and Brian Armstrong (Fermanagh) excelled on the track and Janet Coleman (Belfast) and William Johnston (Bangor) put in great performances in the pool, the performance of the Games for me personally had to be Joan McFarland (Port Stewart) who won gold in the 3km walk for dialysis patients, smiling for all 7.5 laps of the international Morton Athletics Stadium track.

Collectively the NI participants picked up 10 gold, and 6 silver medals – an excellent result!

It's appropriate that I take this opportunity to thank our nurses from Belfast City Hospital, Frankie O'Kane and Ann Rainey, both of whom gave up their time to manage the dialysis needs of our team and to Baxter for allowing us access to their haemodialysis training facility in Dublin.



British Transplant Games, Bath 19-22 August

Orla, Brian and Janet had barely enough time to unpack and repack their kit bags before flying off with the Belfast team to take part in the British Transplant Games. A total of 52 competitors from both our adults and children's team and our band of ever faithful supporters made the trip to the beautiful and historic city of Bath.

Team preparations for the British Transplant Games starts in earnest in January of each year with a site visit by team representatives to the host city. Application packs are circulated to prospective competitors and then each team member needs to be declared medically fit to compete. And then of course there's the fund-raising aspect to be considered! This is a real team effort – the team managed by Frankie O'Kane and our medical advisor, Dr Henry Brown, ensure all the formalities are taken care of.

The Belfast team have built quite a reputation for competing well on the sports field and they certainly didn't disappoint in Bath. Once again Orla Smyth and Brian Armstrong picked up awards at the Gala Dinner for their dominant performances on the track. Turlough O'Hagen (Bone marrow recipient from Lurgan) dominated his age category in the pool and Ian Brannigan (Newcastle), Irene Jeffers (Maghaberry), Emma Doyle (Newry) Peter McKeown (Newry), Tony Miskelly (Bone Marrow Recipient from Bangor) kept the medal tally ticking over. Our golfers, Andrew Weir (Bone Marrow recipient from Belfast) and Seamus Cunningham (liver recipient from Omagh) flew the flag for the team. And who could not have been moved by the width of Michael McLaughlin's smile as he picked up his first medal at the Games. In the children's events Conor, Aoife, Aaron, Rachel and Megan did everyone proud, each one picking up at least one medal.

A huge word of thanks to our whole team who are true ambassadors for transplantation.

With Belfast due to host next year's British Transplant Games the team had the extra responsibility to do their bit to encourage fellow competitors to make the trip across the Irish Sea in August next year. Dr Eddie Rooney, Chairman of the Belfast Transplant Games Local Organising Committee and CEO of the Public Health Authority, accompanied the team to Bath. Eddie made a passionate appeal to all those at the gala Dinner to join us in Belfast and help us celebrate the gift of life. And if we are to believe what we heard in Bath everyone and their granny is going to be making the trip!

And finally we would like to send a particular word of thanks to Dr William Nelson for his on-going support of the team and to the Belfast City Hospital Charitable Trust Fund for contributing to the costs associated with both the European and British Transplant Games.

Please support the

NIKPA QUIZ NIGHT



ARMAGH CITY HOTEL, 2 Friary Road, Armagh

7PM, Sun 3rd, October 2010

Admission £5 per person (Pay at door)
Teams up to 6 persons

Ballot Ticket Draw on the Night
Contact: Gina on 078 8150 6377
or 028 9332 8683 (After 7:30PM)





DEEP RIVERROCK BELFAST city MARATHON 2011

2nd May 2011
BANK HOLIDAY MONDAY

IT'S NEVER TOO EARLY TO START TRAINING!

Get ready to join NIKPA on May 2nd 2011, for a Marathon Walk or Run. Previously people supported NIKPA by either walking half the route, by wheelchair and some even ran the full distance. Whatever your ability—come and join us in May 2011.



CEAPIR Conference and General Assembly 2010

CEAPIR is a European non-profit organization founded by kidney patients for kidney patients. It is an umbrella organization for 23 national kidney patient associations in Europe, of which the Northern Ireland Kidney patients' Association (NIKPA) is one. One of the main functions of CEAPIR is to lobby the European Parliament. CEAPIR as an independent body has become very influential in European legislation, dealing with the quality of care that renal patients receive, advising on transplantation and raising donor awareness.

This year the CEAPIR annual conference and General Assembly was held in Zurich, Switzerland, from the 4th-6th June. Two members of NIKPA were in attendance. Below is a summary of some of the more important points covered at the conference:

- A presentation was given by Mr. Mark Murphy *executive committee member) about CEAPIR's significant influence on the EU transplant framework legislation ensuring standards of quality and safety is maintained.
- Prof. Petra Reinke, based in Berlin, gave a presentation on the scientific research on the immune system and its effects on transplants with the future hope of reducing drugs after transplantation.
- The youth section of CEAPIR were concerned with the lack of communication between young renal patients and decided produce a Facebook which would encourage more interaction between young renal sufferers.
- Mike Kelly, coordinator of counselling services in the Irish Kidney Patients' Association, gave a talk on coping with Home and Hospital based dialysis.

The conference was very informative and useful in making contact with other organizations and seeing how they work and we hope to use some of the guest speakers at future events of our own.



Belfast to Welcome Transplant Athletes 4th – 7th August 2011

The Transplant Games is a unique opportunity to generate positive media attention around the whole issue of organ donation and transplantation. Some 2,000 competitors, their families and friends will be descending on Belfast in August next year.

For more information contact:
 Westfield Health British Transplant Games
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 CARRICKFERGUS
 CO. ANTRIM
 BT38 0AT
 Tel: 0114 2571992
 Email: emma.dean@transplantsport.org.uk

www.transplantsport.org.uk

It is the aim of the local organising committee to make these games the best in British Transplant Games history. The Games will cost in the region of £250k. We are appealing to our transplant community to get involved and there are many ways you can get involved:

- Sign up to compete! You don't have to be a top class athlete to take part – you do however have to have a good functioning transplant. There's a whole range of events including the walk, golf, cycling, athletics, swimming, tennis, fishing, darts and snooker. Simply contact our Team Manager Frankie O'Kane - email: Frankie.o'kane@belfasttrust.hscni.net
- Volunteer to help – we need 200+ volunteers so if you've got a skill or some time to spare get in touch
- Take part in the Donor Run during the Games. You can walk or jog and the event is open to everyone whether you've had a transplant or not. The venue is the Stormont Estate Belfast and distances are 3 km and 5 km. Start training now!
- Fund-raising is a big challenge particularly in the current economic climate. If you can help get in touch for a sponsor pack.
- Transplant Sport UK (TSUK) is one of the two official charities for next year's Belfast City Marathon. Funds raised in the name of TSUK will be spent locally to host the Games. For an application form contact Janet Coleman or Colin Thompson.

If you would like any information about the Transplant Games don't hesitate to contact Janet Coleman – email: janetcoleman1964@hotmail.co.uk

*** Childrens Christmas Outing ***

Last year NIKPA organised a highly successful trip to Santa's cottage in Castleward for renal patients, at the Royal Belfast Hospital for Sick Children. This year it is hoped to organise a trip to the Christmas Pantomime at the Grand Opera House. NIKPA is in the planning stage of this very special event.

Fundraising at the annual ABP barbeque Banbridge

The Anglo Beef Producers (ABP) company is one of the largest beef companies in Europe; it is based in the UK and is owned by Larry Goodman. NIKPA were given the honour of being the nominated charity for the Northern Ireland based ABP BBQ which was held in Banbridge Rugby Club on Friday 30th July. The event was attended by Northern Irish beef farmers and their families. Hugo Duncan was one of the featured guests. The event itself and coverage by the local press also helped in raising awareness for the need for organ donation. Monies raised through the auction, ballots and door collections came to £12,000, and this was matched by Larry Goodman, the owner, which brought the total to £24,000. NIKPA would like to thank the kindness and generosity of all those who attended, Larry Goodman, Owner/Chairman of Anglo Beef Processors (ABP), Liam McCarthy & Philip Simpson of ABP Newry. Also thanks to those individuals who purchased items in the ballot & auction, and to the following companies/individuals who sponsored the auction items/prizes:

GLENFARM HOLDINGS LTD., ULSTER FARM BY-PRODUCTS LTD., THE ROYAL COURT HOTEL, PORTRUSH, RADISSON BLU ROE PARK RESORT IN LIMAVADY, HOUSTON'S OF BANBRIDGE, PAT & CHRIS GORDON and COLIN MARTIN.



Relatives Room gets a Makeover !

RELATIVES ROOM - LEVEL 11 TRANSPLANT WARD - BELFAST CITY HOSPITAL TOWER BLOCK

Following discussions with representative's from the Northern Ireland Kidney Patients' Association, the Belfast Trust agreed to refurbish the relatives room on level 11 of the Tower Block. Any patients or relatives who have had to spend some time there in the past will recall that the room was adequate for the purpose but was quite utilitarian. Following professional consultation, the room has now been repainted in attractive colours with new lighting and new floor covering being provided.

A new flat screen TV has also been installed together with comfortable new seating. NIKPA hopes to donate new pictures for the walls, a regular supply of subscription magazines and a patient's information notice board. The aim is to make the environment as comfortable and relaxing as possible for all relatives and patients who have to use the room for long periods of time.

Thanks must go to Leslie Mitchell and her colleagues at the Belfast Trust for their efforts in seeing that the proposed plan was approved, and for overseeing the progress of project.



LAP THE LOUGH

Lap the Lough is Ireland's biggest cycle event. It goes around Lough Neagh, the largest body of water in Ireland and the UK and the 5th largest in Europe. The event remains a fundraiser for the 100s of charities of which NIKPA is one. On 29th August a number of people participated in LAP THE LOUGH - a 87 mile cycle ride around Lough Neagh to raise money for NIKPA.



A big thank -you and congratulations to all those who took part.

Pictured at the start of the event is STEVEN STEWART, MARTIN MCGILLIGAN, TOMMY DOWNEY (BAXTER HEALTHCARE ENGINEERS) and GERRY TOTTEN (WARD MANAGER, ANTRIM DIALYSIS UNIT)



SUMMER
MADNESS

Summer Madness is Ireland's largest Christian festival. It usually takes place over the first weekend in July in the King's Hall, South Belfast. The festival is aimed at young people, and consistently targets those aged 15–25, and also caters for ages 5–11. The festival generally attracts around 5000 visitors a year.

This year the festival was spread over 5 days and many charities were invited to have an information stand at the hall. NIKPA attended SUMMER MADNESS, this was the first joint venture with the other member charities of the NORTHERN IRELAND TRANSPLANT FORUM with each charity taking a day to man the stall. This was an opportunity to promote organ donor awareness and the work that NIKPA does. Pictured is Therese Smyth (NIKPA Vice Chair) at the stall

