



NIKPA Newsletter

Northern Ireland Kidney Patients' Association

IT'S PANTO TIME AGAIN— ***OH YES IT IS!***

On Saturday, the 18th January, young renal patients and their families were invited to a day out at the pantomime at the Grand Opera House in Belfast. Childrens' Renal Nurse Hazel Gibson and some of the NIKPA members made sure that everyone had their tickets and goodie bags. The children, (all patients at the Royal Belfast Hospital for sick Children), their siblings and parents loved the

'Sleeping Beauty' performance. The stars of the show were of course the ceaseless May McFettridge as Queen May and Lorraine Chase as Carabosse (the Wicked Fairy). The lavish costumes and fantastic special effects made this pantomime one to remember and thoroughly enjoyed by all kids, both big and small.



ST COLUMBA PEACE AND NEW LIFE GARDEN

The official opening of St. Columba's Peace and New Life Garden took place on Sunday 27 Oct 2013. This garden of New Life gives thanks to all organ donors. Present at the opening were the Mayor and representatives of Derry City Council, as well as representatives of St Columba's Cathedral, St Columba's Church, First Derry Presbyterian Church, Northern Ireland Kidney Patients Association and the Circle of Life Garden in Galway. The Fountain and Bogside communities were also represented along with residents of Alexander House.

The Fountain and Bogside communities established the St Columba's Peace garden in 2003 on the interface between the two communities. It was thought appropriate to integrate the New Life garden with St Columba's Peace garden to create what now will be known as St Columba's Peace and New Life Garden.



Those people who have been lucky enough to receive a transplant have described the organ donation process as the equivalent of receiving a new life. This gift of a new life is only made possible by the selfless generosity of organ donors. Donors can quite often be the forgotten partners of this gift of life even though without donors there would be no new life. All donors have demonstrated, through organ donation, incredible courage and humanity in providing the means for saving the lives of those less fortunate. To recognize the tremendous generosity of donors and their relatives, Altnagelvin Renal Support Group supported by Derry City Council created a New Life Garden. The garden is a small token of the appreciation that is felt for all donors and, as organ donation knows no boundaries, so St Columba's Peace and New Life Garden will become a place of peace and reflection for all in our community.

There are similar Life gardens in Kiltonga in Newtownards and Salthill in Galway and The Altnagelvin Renal Support Group have established links with the organizers of these gardens and hope to partake in combined events to promote further awareness of Organ Donation.

The St Columba's Peace and New Life Garden is situated in Bishop Street adjacent to Bishops Gate, opposite Alexander House and everyone is encouraged to visit.

The Altnagelvin Renal Support Group would like to take this opportunity to thank all its sponsors and fund raisers, without whose help this project would not have been possible.

A special word of thanks to Derry City Council particularly the Mayor, Martin Reilly, Councilor Sean Carr, and Danny McCartney for their generous support and assistance throughout the development of the garden.

Never mind Gangnam its Christmas Altnagelvin Style !



CONGRATULATIONS

The Altnagelvin Renal Support Group wins the Patient and Client Councils Making a Difference Award.



NIKPA ANNUAL GENERAL MEETING



AGM

**Sunday
March 30th**

NIKPA would like to invite you all to our AGM. The details of which are given below. NIKPA works for the welfare of all renal patients and their families; we are a totally voluntary organisation. Our committee is made up of renal patients and relatives of renal patients. We receive no payment for what we do and we are currently seeking new volunteers. If you feel that you would like to 'give back something' to the community and are interested in becoming a volunteer, please come along or contact us through our web page www.nikpa.org.

The meeting will be held in the Ennis Room on the Dining floor of the Tower block in the Belfast City Hospital, Sunday 30th March, 2014, at 2.15pm.

Light refreshments will be served.

Guest speaker to be announced.

All are welcome!

Funding to Examine Quality of Life

Dr Helen Noble (right), lecturer at Queens University Belfast has been awarded a three-year National Institute of Health Research (NIHR) Post Doctoral Fellowship. The award of £512,000 will be used to examine quality of life, decision making and costs in people with advanced chronic kidney disease who have opted to receive conservative kidney management rather than dialysis. One of her mentors during the Fellowship is Professor Peter Maxwell, Consultant Nephrologist at the Belfast City Hospital Trust.



People who make the decision not to have dialysis will be followed three-monthly over one year and data collected on their quality of life, the decision they have made and the costs of treatment. Costs to carers and quality of life will also be studied. The study will help inform the decision making process, between patients, carers and staff, for and against dialysis and aims to improve clinical outcomes and care giver experience. This study builds on previous work carried out by Dr Noble which explored the experiences and trajectories to death of patients with advanced chronic kidney disease managed without dialysis cared for in a Renal Supportive Care Service at a London Hospital Trust.

Dr Noble trained as a renal nurse at Charing Cross Hospital, London and worked as a renal Ward Manager and Matron at The Royal London Hospital, London for many years. She came to work in Belfast three years ago. She has a range of experiences of caring for people with renal disease both in the hospital, community and University setting. She is a member of the Northern Ireland Kidney Patient Association who she worked with in developing the successful research proposal submitted to NIHR.

NORTHERN IRELAND TRANSPLANT FORUM G.O.A.L. (GIFT OF A LIFETIME) FOOTBALL TOURNAMENT, FAMILY DAY & ORGAN DONATION CELEBRATION DAY

On Sunday 29th September 2013 the first NITF GOAL football tournament took place on a wonderful sunny day. 16 teams from across the Organ Donation Community of NI attended to participate in the 5-a-side football tournament.

This included staff teams from the Ulster, Antrim and Altnagelvin Renal Units. A special mention to Altnagelvin who made the long journey from Derry complete with supporters. There were also teams from ARMAGH TIGERS, NHS TELEPERFORMANCE, the PUBLIC HEALTH AGENCY, ERICA FERGUSON LIVER RECIPIENT TEAM and LINFIELD LADIES.

The Steve Carter Donor Family were represented by his friend's team HEARTCHESTER UNITED and his nieces team CRUMLIN LADIES.

TRANSPLANT RECIPIENTS were well represented with 2 teams from TRANSPLANT SPORT NORTHERN IRELAND including the surprise inclusion of Keith Gillispie, ex Man Utd and international NI footballer. For the record, a team from TRANSPLANT SPORT NI (minus Keith Gillispie) won the tournament with Heartchester Utd runners up.



However the highlight of the day was the presentation ceremony with Donor families presenting the cups. Avril Waller presented a cup in memory of her daughter Lindsey, Martin and Mary Sweeney presented a cup in memory of their son, Padraig and Mr and Mrs Mc Gill presented a cup in memory of their daughter, Aisling. These were all young people who died but gave the GIFT OF LIFE by donating their organs.

Ronnie and Ruth White (the first 3 way Live Organ Donors in NI) presented a cup and Jackie from the NORTHERN IRELAND TRANSPLANT ASSOCIATION (NITA) presented a cup in memory of his father, David Robinson, who was the founder member of NITA and passed away earlier in the year. Professor Savage presented the Childrens' Renal Fund Cup

Many thanks to Susan Kee who interviewed and recorded on CD many inspirational people on the day including Orla Smyth (7 Gold medal Winner, World Transplant games) Ruth and Ronnie White, Joe Brolly (GAA star and Kidney Donor) Keith Gillispie, Sharon (Liver Recipient, vice chair of RVH LIVER SUPPORT GROUP) Steve Carter and Family (Donor Family), Hazel Gibson and transplanted and pre-transplanted children from the RBH for Sick Children. We hope to have a CD produced soon as it will be a great advert for Organ Donation. Many thanks to the PLAYBALL ARENA and the PAVILLION which provided an ideal location for the event



The day was also a family day celebration of Organ Donation and special thanks to the ROYAL MAIL PENNY BLACK CHARITY who provided bouncy castles and novelty customs and to the SHANNON O'HARA NEW LIFE DANCE PERFORMANCE GROUP who performed a beautiful dance routine to the music of "I am Feeling Good". This summed the day up; everyone left "Feeling Good" after a wonderful celebration of Organ Donation.

By William Johnston



Dr. Aisling Courtney

Transplantation in 2013

This has been a record year in renal transplantation for Northern Ireland, both numerically and in terms of the type of kidney transplants performed. In total, 102 patients received a kidney transplant, of which 94 took place in Belfast. This represents an increase of over 100% from previous levels (between 1999 and 2008 there was an average of 43 transplants annually).

Three of the patients received a combined kidney and pancreas transplant in Edinburgh, one baby was transplanted in Manchester (from his mum) due to special difficulties in his case, and four patients had their live donor transplant in London due to the very high risk of rejection which that particular centre has expertise in managing.

Clearly, the time of transplantation is challenging physically, mentally and emotionally for patients and their families, and having to be away from home at this time, for many reasons, makes this additionally stressful. For the first time we have been able to offer transplantation between a live pair that have been the 'wrong' blood group (termed blood group, or ABO, incompatible transplantation). Previously such patients either were unable to donate or had to travel to London to do so. Since October, four such operations have been successfully carried out in Belfast.

The live donor programme continues to exceed expectations, with 53 being performed in Belfast and five elsewhere. Overall, our live donor rate is over twice the national average (33 v. 16 donors per million population). This has been sustained at this level for over three years which is a reflection on the phenomenal generosity and altruism of people here.

The number of deceased donors was significantly increased compared to recent years due to a combination of factors. Additionally, we have been able to use donors where it is essential that the time before the transplant takes place is very short (donation after cardiac death donors); these have been used in other centres for some time and we are pleased that patients in Northern Ireland will now have opportunity to benefit from such kidneys also.

Finally we have undertaken a lot of work with our colleagues in the tissue typing laboratory, which has enabled us to transplant a considerable number of patients who had been waiting for a very long period of time. Of the 30 patients active on the transplant waiting list in January 2013 who had been waiting the longest, 22 have since been transplanted.

We are not complacent however, and will continue to strive to improve the transplant service so that even more can benefit from the gift of life in 2014.

By Dr. Aisling Courtney (above), on behalf of the transplant team



World Kidney Day (WKD) is an annual global awareness and education event, held on 13th March 2014. The event provides the perfect opportunity to get out in the community and share the WKD message with friends, family and people you meet. It is also a chance to raise awareness of the importance to life of your kidneys, how you can look after yourself and the risk factors for kidney disease – you might just save a life!

Since its inception in 2006, the global campaign highlights a particular theme every year, which for 2014 is Chronic Kidney Disease and Ageing. For further details on what is planned around the world, visit www.worldkidneyday.org.

This year the UK initiative is being led by the Kidney Charities Core Group comprising five leading kidney charities – The National Kidney Federation (NKF), Kidney Research UK, the BKPA, Kids Kidney Research and the PKD Charity.

We have adopted a slightly more general theme for the UK this year which is:

Kidney health matters – help reduce the risk to your kidneys

Further details will be available soon through the UK website: www.worldkidneyday.co.uk where you will find support, advice and ideas for activities and downloadable resources.

For further information in the meantime, please email: info@worldkidneyday.co.uk or check out the Facebook page by searching for World Kidney Day UK. If you use Twitter, follow @kidneydayUK and use #worldkidneyday and #reducekidneyrisk





'The Big Day Out' – 2013

The annual NIKPA 'Big Day Out' was held on Sunday, 30th June at our usual venue at the Royal Court Hotel, Portrush.

Renal patients and their carers were picked up by bus from the renal units in Antrim, Belfast, Dundonald, Newry, Omagh and L'Derry. Approximately

200 patients and their carers were treated to a three course carvery lunch in the Atlantic Suite with magnificent views overlooking the County Antrim coastline. Lunch



was followed by a pleasant afternoon's visit to the holiday town of Portrush before boarding the busses for home. NIKPA would like to thank all the staff at the hotel as well as the Ulsterbus bus drivers for making this an enjoyable day.

We would also like to thank the patients and their families for helping to raise £667.50 on the day from the sale of ballot tickets and badges.

We look forward to doing it all over again, soon!



The Circle of Life

National Commemorative Garden to Organ Donors, Salthill, Galway.

NIKPA are delighted to support the 'Circle of Life' donor garden which is in the process of being created in Salthill, Galway.

It is the vision of Dennis and Martina Goggins from Galway, whose son, Eammon who passed away in 2006. They had the courage and compassion to honour Eammon's wishes and donated his organs to give the gift of life. For the last seven years they have dedicated their lives to the creation of the garden.

The garden will be a fitting place to acknowledge, remember and celebrate all organ donors; provide comfort and support for their families and their loved ones; provide a place of reflection and thanksgiving for organ recipients; provide a focal point through which the aims and aspirations of the organ donor community can be better realised and finally to promote organ donor awareness. Above is a photograph of the garden.



Full details of the garden can be found on www.strangeboat.org

By William Johnston

Donations

NIKPA would like to thank all those people and organisations who over the last year have made donations to our charity. This money is used for the welfare and benefit of renal patients in Northern Ireland and we are extremely grateful for your support. The NIKPA committee is made up of volunteers who give up of their own free time to run this charity. Our charity does not receive any regular funding; our money comes from donations and money raised through ballots, and the sale of NIKPA badges.

We would like to thank all our members for their continued support and in particular we would like to thank the following: Agnes Tyrie, Mary P. Ballie, Bangor Ladies Hockey Club, Ian Winters, Jo-Ann Dobson MLA, Mr and Mrs Colgan, Martin Taggart, Gill McKay, Sharon Weir, Kelly Courtney, Patricia McShane, Bangor Engineers & Trades Social Club and the Abbey Players, Bangor. Donations have also been received in the memory of loved ones who have sadly passed away; Jean Gould, John Ryall, Mary Elizabeth Kennedy, Sean McDonagh and Mabel Potts.



Below is a description of the unique events in which our members raise money for NIKPA:

Tractor Run in memory of late Sean McDonagh

Last year tractor enthusiasts from all over the Province gathered in Brookeborough to celebrate the life of the late Sean McDonagh. The Tractor Run raised £21,000 in sponsorship. Sean's wife Fiona McDonagh is pictured (above) with family members and friends presenting cheques of £7,000 each at Belfast City Hospital to The Northern Ireland Kidney Research Fund, The Northern Ireland Kidney Patients' Association and the Renal Unit. Also in the picture is our President, Prof Peter Maxwell. A big "thank you" from all at NIKPA goes to Fiona and everyone who took part.

Tandem Parachute Jump for NIKPA

Last Summer, Helen Donaghy and twelve of her friends took part in a charity tandem parachute jump at the Skycentre in Coleraine. The event raised the fantastic sum of £1,500.00. Many thanks to Helen and all her friends from everyone at NIKPA.



Tyrone County Hospital's Patient Party 2013

Tyrone County Hospital's Renal Unit held its 8th annual Patient Party on 23rd November 2013 at Corick Country House Hotel, Clogher and we had around 160 people in attendance. We had good representation from each area of the renal spectrum from pre-dialysis, hospital based haemodialysis, home dialysis to transplant as well as a number of staff including four of our consultants. We also invite our taxi drivers each year at the request of our patients as they recognise what a vital role they play in the delivery of their care also.

Everyone had a great night; Corick House's function room was decorated beautifully, the service they provided to us was excellent and the food was piping hot and absolutely beautiful.

Following our meal, we held the free raffle draw kindly sponsored by NIKPA with a few more prizes donated by some of the audience members. We had a great range of very good prizes and by giving all audience members (excluding staff) 1 strip of tickets, this insured that more people were able to enjoy being a prize winner. Musical entertainment was provided by the band the Untouchables and whilst they may not have played quite enough waltzes for some of the older members of our audience, they went down very well with a lot of the crowd.

We greatly appreciate the support given to us by NIKPA in sponsoring the raffle draw as it greatly adds to the overall enjoyment of the night for many of our audience.

We also use the money to sponsor a raffle prize in the Renal Unit itself where we enter the names of all our haemodialysis and home dialysis patients as we recognise that not everyone attends the Patient Party. This means that all of our current dialysis patients have the opportunity to benefit from NIKPA's generous donation to our Unit and to win something in one of the 2 draws ... if they are lucky enough! J

Next year is the 25th year of our Unit at Tyrone County Hospital in Omagh being open so we hope we will have an even bigger celebration to mark this significant event and we hope to continue to maintain our strong links with NIKPA.



Anne Cook, Renal Social Worker 23/01/14

Winter Warming Renal Recipes

Thanks to Kareena Magee, renal dietician with the Belfast Trust we would like to pass on the following recipes for you to try. Bon appétit!

Ginger sponge pudding

Preparation time: less than 30 mins

Cooking time: less than 10 mins, **Serves 2**

Ingredients:

55g/2oz self-raising flour
55g/2oz unsalted butter, softened, plus extra for greasing
55g/2oz caster sugar
1 tbsp milk
1 tbsp clear honey
2.5cm/1in piece root ginger, peeled and finely grated
1 free-range egg

For the lemon syrup

50g caster sugar
45ml lemon juice

Preparation method

Lightly grease a small microwave-proof bowl.
Place all the ingredients except the egg into a food processor (or use a hand held mixer) and blend to combine. Crack in the egg and pulse briefly to mix.
Pour the mixture into the prepared bowl, lightly place some cling film over top of the bowl, so it's not touching the sponge mixture. Microwave on high for approximately 4 minutes or until the pudding is cooked. Make your lemon syrup by heating the sugar and lemon juice in a pan until the sugar has dissolved. Turn the pudding out onto a plate. While your cake is still warm, make lots of little holes in the top with a cocktail stick and pour your syrup over.

To serve, turn the pudding out onto a plate. Serve in bowls with whipped cream if preferred.

Analysis per serving of pudding: 667Kcals, 6.2g Protein, 6.3mmols Na, 4.2mmols K+, 6.1mmols Po4

Crunchy Garlic Chicken

Serves 2

Ingredients:

- 1 clove of garlic
- 1 lemon
- 6 cream crackers
- 25g unsalted butter
- 4 sprigs of fresh flat leaf parsley
- Fresh ground black pepper
- 2 heaped tablespoons plain flour
- 1 large egg
- 2 skinless chicken breasts

Preparation method

Preheat the oven to its highest temperature. Peel the garlic and zest the lemon. Put your crackers into a food processor with the butter, garlic, parsley sprigs, lemon zest and a pinch of pepper. Whiz until the mixture is very fine, then pour these crumbs on to a plate. Sprinkle the flour on to a second plate. Crack the egg into a small bowl and beat with a fork. Lightly score the underside of the chicken breasts. Put a square of cling film over each one and bash a few times with a rolling pin until the chicken breasts flatten out a bit. Dip the chicken into the flour until both sides are completely coated, then dip into the egg and finally into the flavoured crumbs. Push the crumbs on to the chicken breasts so they stick- you want the chicken to be totally coated. Place the chicken on a baking tray and cook for 15 minutes. Cut the chicken into strips and pile them on a plate.

Serve with a small side salad and the lemon wedge.

Analysis per serving of crunchy chicken: 624kcal, 4.4mmols K+, 4mmols Po4, 7.2mmols Na.

NIKPA FUNDING

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

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