

NIKPA Newsletter

Northern Ireland Kidney Patients' Association

November 2014



NIKPA IS NOW OF FACEBOOK



To get all the latest info, gossip and photos on what NIKPA is up to, follow us on Facebook. We will advertise our events and activities here on a regular bases. But don't worry if you are not a Facebook user, NIKPA is still committed to our Newsletter as many of our members prefer to receive their news about NIKPA in this way.

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The Big Day Out Summer 2014

On Sunday the 29th June, renal patients, their families and carers gathered at the Royal Court Hotel, Portrush for the annual NIKPA 'Big Day Out' carvery lunch. The weather was sunny and the food was first-class as usual. This ever increasingly popular event was a great success. NIKPA would like to thank all of those who attended and made it such a grand event. NIKPA raised £583.45 through the sales of ballot tickets, T-shirts and badges. We also received £215 in donations on the day. We would like to thank all our members for their generosity. We would also

like to thank the staff of the Royal Court Hotel for their excellent hospitality and service on the day. The day ended with a quick trip around the port then everyone headed for home, we hope to see you all next year!

UK Renal Patient Council



The UK Renal Patient Council was set up in 2014 to provide a voice for renal patients and their carers. It's purpose is to help, support and advise the Renal Registry on future work, especially around the collection and analysis of information. People and families affected by kidney disease want to know about how well their care is being delivered and whether it is being delivered better elsewhere. The council will direct the registry on using data to research areas of interest such as equity in transplantation, home dialysis therapies and on general patient experience.

NIKPA/NIKRF Renal Charities and Organ Donation Roadshow

The charities -Northern Irish Kidney Patients' Association (NIKPA) and the Northern Irish Kidney Research Fund (NIKRF) came together this year to promote renal charities and organ donation. There are two further NIKPA/NIKRF road shows scheduled for Tuesday 11th November and Tuesday 16th December at the foyer of the Tower Block, Belfast City Hospital from 9am - 1pm. NIKPA would be delighted to meet current and new members at these events.

The picture (right) shows the NIKPA/NIKRF road show promoting renal charities and organ donation held at the Belfast City Hospital on Tuesday 30th September

In the photo from left to right is Dr Aisling Courtney (Nephrology Consultant, Vice President of NIKPA), Dr Jennifer McCaughan (Renal Registrar), and Betty Jennings (NIKRF Secretary), William Johnston (Acting Chair NIKPA) Christopher Johnston (NIKRF/NIKPA Committee member)



Four Peaks Challenge

This year, I and eleven friends decided to take on the Irish version of the "Four Peaks Challenge." Beforehand we had decided on donating any money raised to two charities which had a particular significance to us. One of our chosen charities was the Northern Ireland Kidney Patients Association (NIKPA). One reason for

this was that the mother of a member of our group, Brian Reagan, (pictured far right) is currently undergoing treatment for an ongoing kidney problem and requires regular dialysis. A second reason was due to the fact that another of our group, Martin Dorman (far left) had donated a much needed kidney to his sister Danielle (third from right) only a couple of months previous. We all agreed that this was an extremely generous, selfless and inspirational act. After listening to Martin describe both his and Danielle's experiences from diagnosis and living with a kidney problem, through to confirming a match and undergoing surgery, and lastly to recovery, we were doubly determined to complete the challenge and raise a substantial amount of money for NIKPA.

The challenge itself was extremely tough. The aim is to reach the summit of the highest peak in each of the four provinces of Ireland in the shortest time possible. We began on Thursday 17th July at 6pm and headed to Slieve Donard, outside Newcastle, Co Down. This was completed (reached, ascended and descended) by 12 midnight. Then it was straight on to Lugnaquilla, Co Wicklow. We reached this and had it completed it by 10am, having begun at the break of dawn. Next, it was onto Carrauntoohill, Co Kerry which was completed by 9pm on Friday. We followed this with a stopover in a hostel in Tralee and early on Saturday morning we headed for Croagh Patrick, Co Mayo. This was completed by 4pm and then it was straight to the hotel for a much needed rest!

Through sponsorship and other activities we had managed to raise £1300 for NIKPA. Although the challenge was difficult it was very rewarding for the members of our group when we were able to present the board members of NIKPA with this money. To hear how much it will help and the impact it could potentially have on people's lives made taking on the Four Peaks an extremely worthwhile challenge.

Written by Paul O'Neill



THE N.I.K.P.A. "GIFT OF LIFE" CHRISTMAS TREE @ CARNALEA METHODIST CHURCH, Rathmore Road, BANGOR

Carnalea Methodist Church, Bangor is having a fantastic 'Christmas Tree Festival' Thursday 27th November – Sunday 30th November at which 83 Christmas trees will be presented to the general public. Each tree will be assigned 1.5m of space with the freedom to decorate the tree as desired. The Christmas tree does not have to be traditional type it can be made of paper, cardboard or whatever materials we wish. There will also be a Victorian tea shop where the public can come and enjoy Christmas fare. Admission to the 'Christmas Tree Festival' will be free. On the Sunday evening, to end the weekend, there will be a carol service. NIKPA have commissioned the one space of 1.5m to present a NIKPA "GIFT OF LIFE" CHRISTMAS TREE. If you would like to be involved with this Festive project or have any ideas on how to decorate the tree, please contact William Johnston Tel 02891271312, mob 07582083814 e-mail willjohnston1@hotmail.co.uk

In memory of Joyce Ferguson

Joyce Ferguson passed away in the early hours of 17th April, 2014. Joyce was one of the first members of NIKPA and held the position of Hon. Secretary. For many years she volunteered her time and effort. She was recognised by NIKPA, in 2008, for her services to Northern Irish kidney patients. Both Joyce and her husband Denis were great supporters of NIKPA over the years, she and Denis continued to raise funds for the charity up until her death. She will be sadly missed by all the NIKPA committee members past and present and we pass on our sincere condolences to her husband Denis

Chicken and Pesto Pasta

This is a quick and easy pasta recipe that can be enjoyed hot as a main meal or cold as a snack.

Serves 2

Ingredients

2 small skinless chicken breasts or 200g/8oz strips of chicken breast
4 tablespoons low fat crème fraiche or low fat cream
1/2 small head of broccoli, cut into small florets
2 tablespoons green pesto
150g/6oz dried pasta twir

Method

Cut the chicken into 1 cm thick strips. Stir-fry in a non-stick pan for 2-3 minutes until the chicken begins to brown. Add the pesto and crème fraiche and cover. Cook on a low heat for 5-10 minutes more until the chicken is cooked through. Meanwhile, cook the pasta according to the directions on the packet, adding the broccoli for the last 5 minutes of cooking. Drain the pasta and broccoli well and mix with the cooked chicken and pesto. Serve



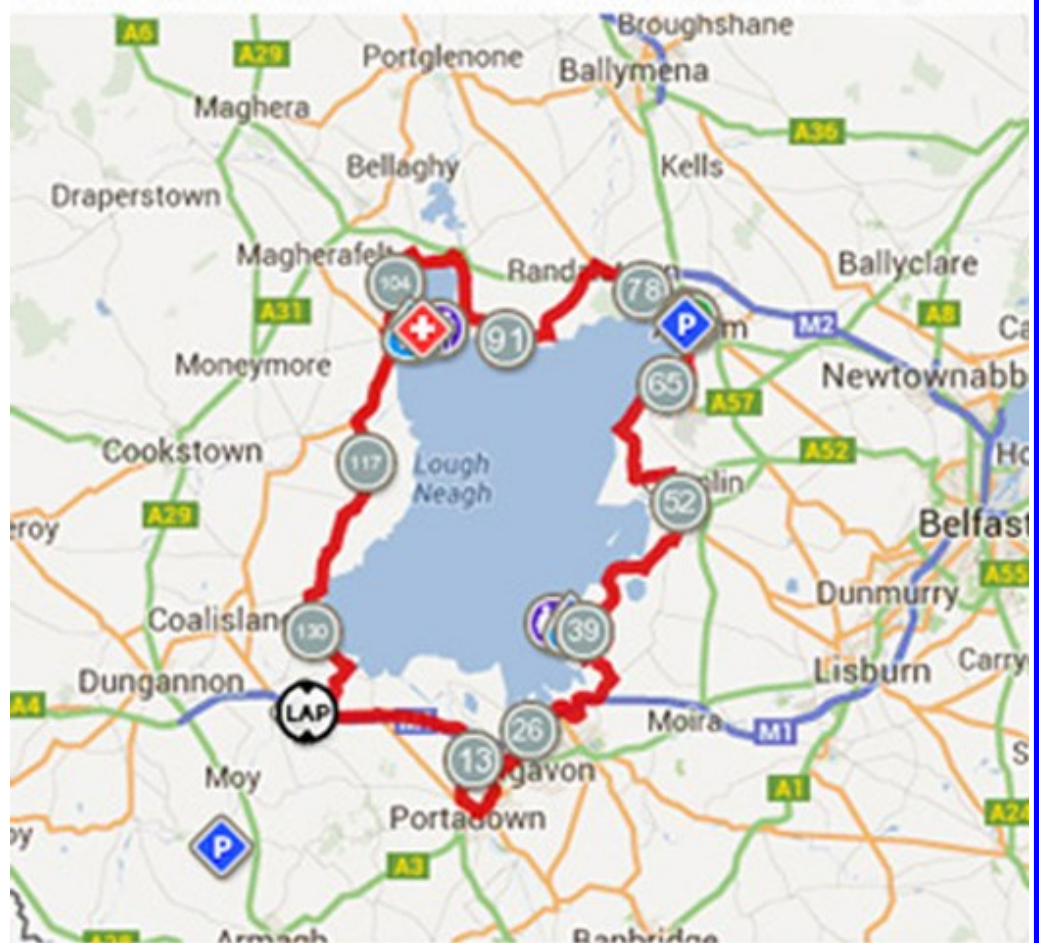
Lap the Lough

On Sunday 24th August 2014 John Brown NIKRF and Christopher Johnston NIKPA along with Marty Taggart NIKPA as well as Jenny and Karen Keery took part in Lap the Lough. This 85 mile cycle ride follows the outline of Lough Neagh and takes place every year. Over 2000 people take on this cycle for a great many charities. This year the ride started at the Peatlands Park at about 7 am and then headed anti clock wise round the Lough go-



ingthrough Portadown, Aghagallon, Antrim, Toombridge, Ballyronan and returning to the Peatlands Park. The day was a great day out. The weather was just right for cycling not too hot or too cold with a gentle breeze helping to keep us cool. Refreshment stops were provided every 20 miles At the Antrim stop there was a bowl of warm soup some power bars and plenty of water to take on board. With plenty of company great chat and a bit of craic plus excellent scenery the miles quickly passed. Soon we were making our way down the west side of Lough Neagh and on the home stretch. All participants are to be congratulated for finishing the cycle ride. John Brown is too be particularly mentioned for his completion of the ride as he had recently turned 70 and only took up cycling when he retired at 65. This event is a fun way to meet friends, exercise and raise awareness of Organ Donation and I would highly recommend it too anyone. Indeed I will be looking for names in the New Year of people who are willing to take on this event in 2015.

Above is a picture of some of the Lap the Lough participants: John Brown (Vice Chair of NIKRF, father of Sean who received a kidney transplant 20 years plus ago) Sean Brown (Kidney Recipient) Christopher Johnston (NIKPA Committee member, kidney recipient)





Cachexia Workshop

A nephrology workshop titled *Renal Cachexia: Defining Clinical Characteristics and Inclusion Criteria*, was recently hosted at Belfast City Hospital in collaboration with Queens University Belfast. The workshop was facilitated by Dr Joanne Reid, and Dr Helen Noble, Lecturers, School of Nursing and Midwifery, Queens University Belfast and funded by the HSC Research and Development Division of the Public Health Agency Northern Ireland and included service users, clinicians and researchers interested in renal cachexia. The Key Note Speaker was Denis Fouque, Professor of Nephrology at the University Claude Bernard Lyon1, and Chief of the Division of Nephrology at the Edouard Herriot Hospital in Lyon, France. He discussed 'Altered metabolism, protein energy wasting and renal cachexia'. Professor Fouque has published 170 papers, including reviews, meta-analyses and 13 book chapters. His research fields are in nutrition and metabolism in chronic kidney disease and dialysis. Professor Fouque founded the *Cochrane Collaboration Renal Group* in 1997 and was the Co-ordinating Editor until 2001. Professor Fouque is currently vice-chairman of the *European Renal Best Practice* group of ERA-EDTA and a member of the K-DIGO Advisory Board.

Other topics and presenters included:

- What is needed to get cachexia and nutrition onto the specialist renal guideline agenda - **Dr Damien Fogarty**
- Renal cachexia, an international perspective – **Dr David Sears**
- User and carer involvement in research – **Fiona Loud**
- DEXA Versus BIA in an end stage renal disease population - **Caroline McConnell**

Dr Joanne Reid concluded by highlighting the need for defining renal cachexia and moving the agenda forward. Dr Joanne Shields from Belfast City Hospital opened and closed the event.

The workshop addressed the issue of cachexia in patients with advanced chronic kidney disease which is under-recognised, under-treated and under-researched. The aim of the workshop was to bring together practitioners, researchers and service users to work towards a consensus definition of cachexia in this patient cohort. It was informed by a preliminary symposium held at the British Renal Society 2014.



Painting by Local Artist Sr. Breda Coyne.

9 GOAL CHALLENGES

The Galway Hooker Regatta.

The GOAL TEAM WAS formed in January 2014 to promote the cause of Organ Donation they planned 9 months with events and programmes to raise funds for Organ Donation and Awareness Projects. Nine Challenges were selected as an organ donor has potential to transform the lives of 9 people and their families.



Challenge No 5. Sail an historic Galway Hooker -Taken up by Dr. Peter Garrett Paddy and Paul O'Neill and their Families, Catherine and Stephen Glover, Chris Boyd, Steve Carter, his children Vs. Michael Coyne and The Claddagh Boatmen

The Team were delighted to be invited by The Claddagh Boatmen and the Captains of the famous GALWAY HOOKERS and to accept a race in the Cill Chiarain Regatta which is famous the world over.

The NI team and their families were overwhelmed

By the warm welcome they received. led by Admiral

Of The Day-Dr. Peter Garrett Belfast City Hosp. they all

agreed it was an experience they would never forget and felt honoured to have had the opportunity to sail these historical working fishing boats- some over 100 yrs old. **President and winning captain Michael** and organiser Peter Connolly presented the prize to the winner, GOAL and Transplant Sport's **Chris Boyd**. Team NI hope to hang it in The City Hospital. It was so admired by local people that the NI team are invited to come back to repeat the event at Cil Chiarain next summer. The competitive local captains want another chance to hang the painting in The Galway University Hospital for a year. Another highlight of the event was an invasion by the Game of Thrones Viking cast and there were on-shore crafts displays, sports and musical entertainment all day. (U-Tube; Viking Invasion and GOAL) See it all happening and send it to your friends abroad



GOLF was also high on the 9 Challenge agenda this Summer.

The first challenge by NIKPA's William Johnston was to play 9 holes-at 9 different Golf Clubs- in one day- in each county in N. Ireland. The stalwarts climbed on board and began their marathon at 7am in Ballybuffet, Donegal. Amazingly they finished the 9th (and 19th) in the fading light at Clondeboy Golf Club. Our thanks once again to all our sponsors and participants especially the volunteers who finished the rounds at each club visited and those who provided much appreciated food and hospitality. Thank you to representatives of Bangor Council and to the club members and staff of Clondeboy for their welcome and generosity.

The Bi-Annual Harrington Golf Challenge was Challenge 7 ;

and fulfilled its role promoting Organ Donation and the charities involved. Display boards on behalf of the HSC, NITA, NIKPA ,Oakland Nursing Home were attended all day by transplant recipients and donor families and much was done to include all participants and the Golf Club in the GOAL of the day.

The gloomy weather and serious preparation by all the golfers were managed by Starter Ken and the professional skills of Posnett Golf. However the abundant food on offer and trademark happy days atmosphere made the day one of full of friendship and enjoyment for all involved, especially those non golfers and folk with families who travelled great distances to attend and stayed for the dinner, prize-giving and all the fun.

We are very grateful to all our sponsors and those sourced or provided such amazing *surprise phone call* ,and ballot prizes including Pure Day Spa, Hilton Templepatrick, Lough Erne Golf Resort, The Golf Spot, Hastings Hotels and Belfast Crystal.



Become a NIKPA Advocate . . .

NIKPA represents, supports, provides a voice and promotes the needs of Renal Patients and their families across every area of Northern Ireland

Although based in Belfast we acknowledge we must have a much higher profile and representation from every county of the Province, therefore we are making the following appeal.

We are appealing for :

WHAT : Advocates for NIKPA from the 7 dialysis units of NI plus surrounding regions. These advocates will channel 2 way communication between NIKPA and NIKPA members in that dialysis unit and/or area. We hope this will provide a means by which NIKPA can provide better support and a voice for NIKPA members and enable NIKPA to go from strength to strength. We value all new ideas, projects and initiatives brought forward by NIKPA members

WHO : Dialysis Patients, Transplanted Patients, Live Kidney Donors, Donor Families, Altruistic Live Kidney Donors and Family Members and Carers of the aforementioned. We would also be keen to have Medical Representation from each dialysis unit and/or surrounding region. There is no restriction on the number of NIKPA advocates who come forward from each dialysis unit and/or region

WHERE : We would like to invite NIKPA Advocates to NIKPA Committee meetings which currently takes place at the Belfast City Hospital Dialysis Unit Seminar Room on the first Saturday of each month at 10am. NIKPA will provide a contribution to travel costs, pence/per mile. Advocates would be welcome to attend all Committee meeting however NIKPA appreciates travel and time restrictions and would therefore hope for Advocate attendance at once every 3 months. The Committee will also endeavour to travel to meet NIKPA groups on request

This is an exciting opportunity for people who's lives have been impinged by Renal Failure to become involved with NIKPA in the next exciting stage of it's development. The Advocates will have a vital role in the progression and direction that NIKPA will take. For those on dialysis and wishing to return to full time employment, it is also an opportunity to display to perspective employers a willingness to undertake voluntary work whilst on dialysis.

If interested in finding out more about being a NIKPA Advocate, please contact William Johnston (Acting Chair) Mob 07582083814 e-mail willjohnston1@hotmail.co.uk

If you are not already a member of NIKPA, you can join on-line by visiting www.NIKPA.org



Donations

NIKPA is an organisation run entirely by volunteers; we do not get any public funding, we rely on donations and fund raising events by our members and by the wider local community. We would like to thank all our members, relatives and all those other kind people who have donated money to our organisation. We appreciate the efforts of those of you who have raised money through running marathons, holding coffee mornings, collecting donations from passers –by and the many other inventive ways of gathering money, raising awareness for Northern Irish renal patients and organ donation. We would like to acknowledge you all below:

The Resource Group, Belfast, Kelly Courtney and the Ballymena Belles, BCH Renal Runners- Chenelle, Flo, Shannon and Randa, Eoin and Asling Quiery, Mervyn and Felicity Colgan, Roy Middleton and Laura McDowell – Refresh Café, Helen Donaghy and Gang, Agnes Tyrie, Mary Bell, Mrs French, Mary McClure, Heather McKinstry, McCue Crafted Fit, 'Hilton in the Community', British Kidney Association, Claire Devlin, Janet and Tony Hirrel, Rory Flanagan, Brenda Hill, Henry McAllister, Dr Sharma, John and Margaret Colgan, Gill McKay, Hazel Gibson, Mildred Maitland, George Compston, Banbridge Golf Club, Ballymena Primary School, Margaret Cruikshank, Brenda McQuillan, Rachel Taggart, Nesson Quiery, Emma Piel, Linda Edens, John and Rebecca Cochrane, Paul O'Neil and friends, Alan Todd.

We would like also like to thank those who gave money in lieu of flowers in remembrance of those dear departed: William Robinson, Vera McCleary, Trevor Woods, Joyce Ferguson and Mark Colgan

Please accept our sincere apologies if we have left anyone out.



Ballymena Belles who raised money for NIKPA



Presentation of cheque from the 'Four Peaks' challengers



The owners of the Refresh Café who raised money for NIKPA



Chenelle McElhinney and Randa Troughton attended the NIKPA committee meeting to present £401 to NIKPA which they raised doing the Marathon. !

VISIT THE NIKPA WEBSITE AT **WWW.NIKPA.ORG**

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