

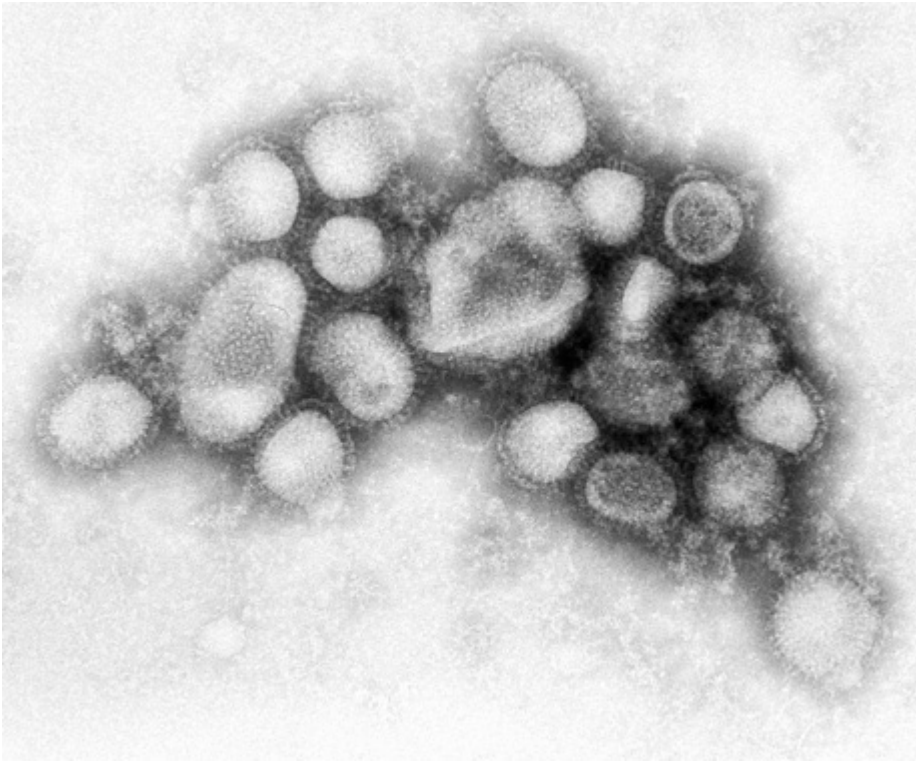


NIKPA's Big Day Out!

On Sunday the 28th of June '09 NIKPA arranged a day out to Portrush for 197 renal patients, family members and friends. Patients were collected by coach from renal units in Altnagelvin, Antrim, Belfast City, Dundonald, Omagh and some took their own transport. The Royal Court Hotel was the venue for a 3 course meal followed by a few hours enjoying the town of Portrush before boarding the buses for home. The weather for the day was warm and dry and the feedback from patients was that everyone thoroughly enjoyed themselves. NIKPA hope to repeat this successful venture again soon.

The following are photos taken on the day.





Renal Patients and Swine Flu

Everyone is concerned about Swine Flu these days and advice about how to avoid catching it and if you are unfortunate enough to get it, how to treat it.

For renal patients this is a major concern. NIKPA has done some research to find out if there are any 'patient friendly' information sites that NIKPA could pass onto the patients. The information on sites we viewed were quite complex, so we asked Professor Maxwell (based at Belfast City Hospital) for some help and he very kindly replied with the following advice:

"There is a high degree of preparedness for the impact of swine flu in renal units with detailed plans developed by the

Royal College of Physicians in the UK and the UK Renal Association. This information is publicly accessible BUT is neither succinct nor easy to follow.

I have not yet seen any "patient friendly" renal orientated advice on swine flu. There is a concern that any advice given now may actually be out of date by time newsletter comes out. You may have been following the debate about advice to pregnant women over the weekend. Arguably there was too much advice that became "conflicted"

I would encourage your readers to follow the basic NHS advice of **"catch it, bin it, kill it"** campaign and to take up the opportunity of receiving a flu vaccine when offered (this is good advice for renal patients in any year).

There is also one issue to be aware of in relation to any antiviral drug treatment. That is the dose of antiviral medication Tamiflu must be reduced and matched with the level of kidney function. The dose of the other antiviral medication Relenza does not need to be adjusted"

Professor A.P.Maxwell, Consultant Nephrologist, BCH

If in doubt you should always contact your own G.P initially, also the government has issued a helpline as below:

NORTHERN IRELAND SWINE FLU HELPLINE
0800 0514 142 - (9am - 5pm) Monday to Friday

NIKPA DONATIONS

NIKPA would like to offer its sincere thanks for the recent donation of £750 from Banbridge Rotary Club below-left, Rod O'Doherty and Jo-Anne Dobson receiving cheque. We would also like to thank the patients and staff of Altnagelvin renal unit for the £926 raised for the Lifecycle. Below-right are Mary and Donna, two of the staff presenting the cheque.



If you wish to make a donation to NIKPA funds, send a cheque made payable to NIKPA, P.O Box 85, Carrickfergus, Co. Antrim or donate online at the NIKPA website www.NIKPA.org



I would go back in a heartbeat

Desmond Graham from Lisburn, tells of his trip to Singapore

I have been a dialysis patient for two and a half years now and before that enjoyed travelling abroad. But things were a bit different now as my visits to hospital 3 times a week meant my holiday options became very limited. I had been to Dublin for a few days with fellow patients, then a trip to Spain which involved 2 dialysis sessions in a local hospital that went very well, but in all honestly going away any further or longer seemed a bit daunting.



My friend however had different ideas "what about the Singapore Grand Prix" he said, as if it was 10 minutes away and not the 13 hours from Heathrow! I said I would think about it, but it seemed a bit unworkable to me. But my mate doesn't take no for an answer and suggested it again a few weeks later and he would sort out the logistics and convinced me, with a bit of planning it would be easy enough to do. I made a few inquiries at dialysis if it would be advisable to travel to S.E. Asia on holiday and some people thought it unwise as the medical facilities might not be up to scratch and it could be a risky venture, but my mate checked out Singapore on the World Health Organization website and found Singapore well above the U.K. in the healthcare rankings so I gave the go-ahead. He went online and checked out a site called Global Dialysis, made a list of clinics near the race circuit and made contact. In less than a week the replies started to come back from the clinics and out of a short list picked Singapore General Hospital, and a good choice it was to.

So it was round to the mate's house, went online, found the nearest hotel to Singapore general, booked it for 6 nights. Booked flights and race tickets and that were it, done and dusted. Over the following weeks Belfast City Hospital liaised with their colleagues in Singapore and sorted all the paper work out and in late September I was off to the first night race, in F1 history, through the streets of Singapore.

When we arrived in Singapore our first stop was the hospital to introduce myself and make sure everything was in order for my treatment. Everything was in order and the following day I went for my first session. Entering the unit I was pleasantly surprised, I found a very sterile modern dialysis clinic served by very professional medical staff that were friendly and really looked after me, I couldn't have asked for more well maybe something more substantial than two crackers for my lunch! But this was not a problem as a few restaurants were onsite and did takeaway. All together I had 3 sessions and must say had not one complaint about my treatment or the staff who were very kind to me; they could not do enough for me and made a fuss when it was time for me to leave.



I now have the confidence to go wherever the notion takes me and will not let my condition stand in my way. All it takes is a bit of planning and the will to do it. Would I recommend Singapore to a dialysis patient? Absolutely, I would go back in a heartbeat.

Altruistic kidney donation rises by 50% as strangers give chance of life

From
The Daily Mail

The number of people willing to donate part of their body to help a sick stranger is on the rise. New figures from the Human Tissue Authority (HTA) today show that 15 people were approved as altruistic kidney donors in 2008-09, up from 10 in 2007-08. Of those, 22 transplants have been carried out.

Random act of kindness: Andy Loudon, left, was given a kidney by Barbara Ryder, right. They were the first two people ever to meet after a kidney donation by someone the recipient had never met Barbara Ryder, a nurse from Plymouth, was one of the UK's first altruistic kidney donors, giving her organ to Andy Loudon, a retired carpenter from Bedfordshire, in 2007.



Most organs for transplants are donated from people who have died, but more and more operations involve living donors such as the partners, family and friends of those who are ill. In 2008/09, the HTA approved 1,023 living donations, up from 971 in 2007/08. A total of 927 transplants involving living donors were carried out in 2008/09, including 16 pooled or paired operations between two sets of couples, and 15 altruistic donations. In 2008, a total of 2,298 kidney transplants were carried out. As of today, 6,961 people are on the active waiting list for a kidney transplant in the UK.

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

EUROPEAN KIDNEY PATIENTS FEDERATION OR CEAPIR CONFERENCE ESTONIA TALLINN 2009.



CEAPIR is a European non-profit making organization founded by kidney patients for kidney patients. It is legally based in Vienna, Austria, with working offices in Dublin. CEAPIR is the voice of the European kidney patients. It is the umbrella organization for 24 national kidney patients' associations in Europe, including Northern Ireland.

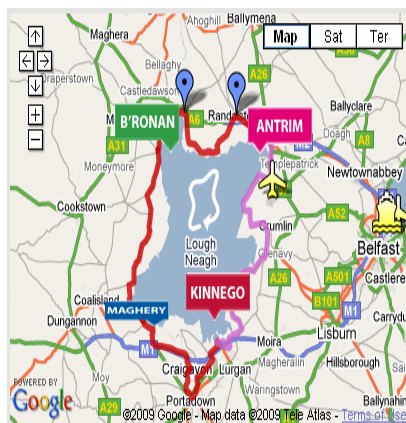
Two of our NIKPA committee members, Therese and Orla, represented Northern Ireland at the annual conference in this year's host nation Estonia. The following is Therese's report:

This conference took place over three days in May in the beautiful medieval city of Tallinn, the capital of Estonia. There were representatives from around twenty European countries. Thankfully the conference was in English, so we could follow it. The delegates there were from each countries Kidney patients association and these included a number of young people who had some discussions separate to the main discussions. We were warmly greeted in the Town Hall by the Mayor of Tallinn and the President of Estonia's Kidney Patients Association. This year we were welcomed as a new member Northern Ireland, along with Poland as another new member. It was a great privilege to meet so many people who all had different experiences of renal issues. We met over the next two days and explored many common issues related to our Associations. We all examined ways to help our members, how to encourage others to join us, how to represent the patients views and how to address difficulties with aspects to dialysis and transplant. The report from the Youth team, part of which was delivered by our representative Orla Smyth, highlighted their importance to make early contact with young people to consider their needs with regards education, employment, financial difficulties and above all coping with renal illness as they mature. We all realized the influence that CEAPIR has in influencing European discussions with politicians, medical teams and others in making decision on all aspects of renal development. Above all the Conference provided our Northern Ireland Association to make valuable contacts with other kidney groups like the United Kingdom Kidney Federation and the Irish Kidney Federation. It was also very obvious that in comparison to many Eastern European countries we have a great many advantages with medical care and expenses that they are struggling to obtain. I hope we in our Association will be able to move forward with a number of the valuable ideas learned at the Conference and help in some ways to improve our contribution to you our members and all Renal Patients.

Therese Smyth

N.I.K.P.A. "LAP THE LOUGH" **THE NEXT CYCLING CHALLENGE 2009**

Following the tremendous success and enjoyment of "THE N.I.K.P.A. LIFECYCLE 2008" plans are well in advance for "THE N.I.K.P.A. LIFECYCLE 2010" in which we will do a reverse circuit of Northern Ireland, stopping at the 7 dialysis units again but also hopefully taking in Lagan Valley Hospital and Craigavon Area Hospital.



In 2009, as a warm up to the "LIFECYCLE 2010" N.I.K.P.A. are participating in the "LAP THE LOUGH" organised by The Castle Hill Cycling Club and supported by the Lough Neagh Partnership.

This is a lap of Lough Neagh. It takes place on **Sunday 30th August**. It is **140km** or **95 miles** to be completed in one day.

LAP THE LOUGH is a **CYCLE SPORTIFF** which means it is **NOT** a **COMPETITIVE CYCLE**.

It's just you against the distance.

The route will be signposted using the lap the Lough logo with marshalls and outriders holding up traffic at main junctions to allow cyclists through safely.

The terrain is very flat. There are a few small climbs around Ardhoe, Antrim and along the eastern shore but nothing of alpine proportions.

The route starts from Kinnego harbour and proceeds clockwise.

STOPS

WASHINGBAY	WATERSTOP	20ML/32KM
BALLYRONAN	WATERSTOP/REFUEL	36ML/58KM
ANTRIM	LUNCH	53ML/85KM
BARTINS BAY	WATERSTOP	82ML/125KM
KINNEGO HARBOUR	TEA/SNACK	95ML/140KM

If you are on for an enjoyable?! challenge and would like to raise funds for **N.I.K.P.A.**, please register for the event on the "LAP THE LOUGH" website where there is additional information. To register costs £20.00 but if you are raising funds for **N.I.K.P.A.**, we will refund the register fee. Registration opens 1st of May via the website. Please let William know by the end of June at the latest, if you are going to join us on the event so sponsorship forms and T-Shirts can be allocated.

William will be on the tandem again so if you would like to join him on the tandem for part of the way, or if you would like to volunteer someone (doctor, nurse, patient, family member) please let him know.

We hope to have a sweeper van available on the day. This means that at each STOP you will have the choice whether to continue or not. Therefore, you can decide to do 20ml or 36ml or 53ml or 82ml or the full 95 ml.

There will also be an end of **LAP THE LOUGH** PARTY for all who participated

Hope to hear from you soon

WARMEST REGARDS – WILLIAM JOHNSTON 02891 271312

e-mail willjohnston1@hotmail.co.uk

NIKPA LOGO COMPETITION

The Northern Irish Kidney Patients' Association (NIKPA) exists for the purpose of improving the quality of life of renal patients and their families and their carers.

We are currently looking to update our logo and we would like to hear from our members about their ideas.

The logo must be an emblem that will stand out and be instantly recognizable. It must be simple enough to be displayed as a Broach/Key-ring/Tie-pin, appropriate for printing and not too expensive to make. The theme of the logo should incorporate 'Caring for kidney Patients'.

Please submit your entries on an A4 piece of paper with as much detail as possible to:

PO Box 85, Carrickfergus, Co Antrim, BT38 0AT

The closing date for the competition is **1st September 2009**. Please remember to enclose your own name and address and contact number. The winner will receive a £50 Marks and Spencer voucher

So get thinking, your idea could be our next logo!

(Note: The winning entry in this competition may or may not be used as the actual NIKPA logo)

Meet the Team

The Northern Irish Kidney Patient's Association is a charitable voluntary organization dedicated to meet the needs all Northern Irish kidney patients, their families and carers. The charity is self funding and run by kidney patients, their relatives and friends. Currently our committee is made up of the following volunteers:



Colin Thompson
(Home haemodialysis patient)
Chairman



William Johnston
(Home haemodialysis patient)
Secretary



Heather Mckinsty
(Friend of dialysis patient)
Treasurer

We are always looking for new volunteers, we are particularly interested in getting patient representatives from Omagh, Antrim, Altnagelvin and Newry renal units. So if you think you can offer your skills please contact us at nikpa@hotmail.co.uk or write to us at PO Box 85, Carrickfergus, Co Antrim, BT38 OAT.



Therese Smyth
(Mother of transplant patient)
Vice Chair



Orla Smyth
(Transplant patient)
Legal Advisor



Linda McDowell/O'Doherty
(Transplant patient)
Newsletter Editor



Gina Moss (Transplant patient)
Social Secretary



Jo-Anne Dobson
(Mother of Transplant Patient)
(Public Relations)



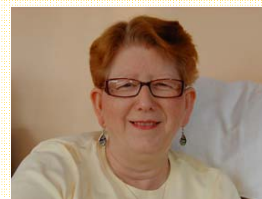
Stella Officer
(Hospital based haemodialysis patient)
Committee Member



Rod O'Doherty
(Husband of transplant patient)
Website and Newsletter



Neill Aiken
(Partner of transplant patient)
Committee Member



Pat Gordon
(Dialysis patient)
Committee Member



Chris Gordon
(Husband of dialysis patient)
Committee member

NIKPA's A.G.M.

NIKPA's AGM was held in December '08 at the Belfast City Hospital. It was attended by Dr Doherty, president of NIKPA.

The Chairman Colin Thompson, the Secretary Stella Officer and the Treasurer Linda McDowell gave their reports. It was agreed that it was a very successful year with regard to fund raising and patient organized activities such as patient holidays and information evenings.

The new committee was then elected. There was a slight change in executive roles as Stella Officer stood down as a long time serving Secretary and William Johnston took up the post. Linda McDowell stood down as Treasurer and Heather McKinstry has since taken up this post as Honorary Treasurer. The remainder of the posts remains unchanged.



Dr Doherty & Stella Officer presented plaques to Joyce Ferguson (Centre) in recognition for her services to NIKPA. For many years she acted as Social Secretary and organized several trips for patients. She has had a transplant but has a lot of other health problems which caused her to give up her position on the NIKPA Committee. (See picture Left)

Dr Doherty & Stella Officer also presented a plaque to William Johnston in recognition for his fantastic fund raising efforts during the Lifecycle event. His wife Carla was also presented with a gift in recognition for all her support too in the Lifecycle. (See Picture Right)



Wall of Life

Leaders of the major faith groups have put their support behind the Wall of Life, an interactive campaign launched today by NHS Blood and Transplant (NHSBT). The campaign - at www.walloflife.org.uk - aims to promote awareness of and support for organ donation to boost the number of people joining the NHS Organ Donor Register (ODR).

The Wall of Life is an online mosaic created from people's photos posted on the site to show their support for organ donation. These photos come together to make up the image of two-year old Louisa McGregor-Smith whose life was saved by a heart transplant in 2007 at just five months old. At least 60,000 people need to upload their photos on to the Wall to build Louisa's image.

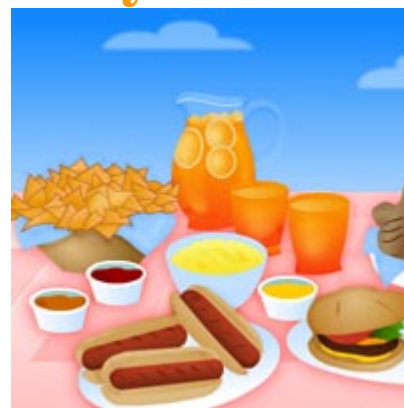
People joining the Wall of Life can then pass details to their friends and families to download a personalised widget on their social profiles and websites, spreading the message across social networks.

The Wall of Life has been created as part of a national campaign to highlight the constant need for organs in the UK. More than 10,000 people currently need a transplant operation, of whom 1000 - 3 a day - will die before an organ becomes available.

Surviving summer socials on the dialysis diet

Written by Maria Stasios, Dietitian

Next to the holidays, the summer months can be a challenge for those trying to stay true to their renal diets. Some of the popular summer foods including potato salad, baked beans, melons, hot dogs, chips and pickles can be high in potassium, phosphorus and/or sodium. But that doesn't mean people on dialysis have to miss out on summer fun. Follow these seven tips for healthy eating and have fun in the summer-time.



Seven healthy tips for fun social events

1. Plan ahead

Prepare for celebrations like you would prepare for "holiday eating". Limit what you eat at other meals; then you can have a little extra at the event. Overeating can lead to a higher potassium and phosphorus intake. Higher levels of potassium and phosphorus in your blood can result in you feeling sick when you want to be enjoying your family and friends. You can be sure that no one wants to make a trip to the hospital in the middle of a fun celebration.

2. Avoid salty foods

Salty foods make you thirsty. Plus, when it's hot outside, you may tend to drink more liquids than usual. Pay close attention to salty foods and choose foods that are lower in sodium. For example, chicken and hamburgers are better choices than hot dogs, sausages or ham. You may also want to go easy on barbecue sauce, which is high in sodium. Consider taking something to a party, picnic or cookout that is appropriate for you to eat. That way, you'll be certain there is something on the table you can enjoy.

3. Monitor fluid intake

Know how much fluid you can drink. Remember that items like Jelly, salads, ice cream and Ice-pops count as fluid. In addition to avoiding salty foods, you can control fluids by drinking only when you are thirsty and using small (four-ounce) cups and glasses. You might want to take a small spray bottle filled with lemon-flavoured water or diluted mouthwash with you to social events; this can be used to moisten your mouth if you feel really dry. Hard sour candy, gum or a thirst-quenching item can moisten your mouth and decrease your desire for liquids.

4. Limit alcohol

Talk to your physician for advice on alcohol. If approved, use alcohol in moderation. Remember, alcoholic beverages count as part of your fluid intake. Avoid high potassium and high phosphorus mixers such as orange juice, tomato juice and colas.

5. Limit high potassium fruits and vegetables

Review the list of fruits and vegetables allowed on your diet, or ask your dietitian for a new list if you need one. Watch your portion sizes, even of the "allowed" choices. Keep in mind that fresher is more nutritious, but this can be a problem for people on dialysis. For example, strawberries that are fresh from the field and peaches right off the tree are often larger than frozen berries or canned peach halves. Because fresh fruits are so refreshing, you may be tempted to eat a larger serving. This means more potassium, which could be more harmful to a haemodialysis patient.

6. Practice food safety

You may have heard these tips before... "Keep hot foods hot and cold foods cold." "Don't eat raw eggs." "Wash your hands before you eat." These sayings provide good advice. It is also important to be careful when eating foods prepared by someone else, or that have been sitting out for long periods of time.

7. Take your binders

Taking your binders is essential, especially if you are eating more than usual. Ask your dietitian if you need to adjust your binders to the quantity of food you will eat. Remember; even though it's summertime, binders never get a vacation!

Having a good attitude about your renal diet will go a long way in helping you stick to these recommendations for summer social situations. Review these tips and then make wise decisions. And, finally, have fun!