

Donations to NIKPA

If you wish to make a donation to NIKPA funds, please send a cheque made payable to NIKPA, to our treasurer Mrs. Linda McDowell, 58 Kernaghan Park, Annahilt, Co. Down. BT26 6DF. **(or donate online at www.nikpa.org)**

NIKPA wishes to offer it's sincere thanks for recent kind donations particularly to all who generously supported the Lifecycle event.

Dialysis Patient Wins Five Medals

BANGOR kidney transplant hopeful William Johnston, 41, has scooped a gold medal swimming the 50m backstroke at the European Transplant and Dialysis Games in Wurtberg, Germany.

The sportsman also picked up four bronze medals in the 100m freestyle; 50m freestyle relay; 50m medley and for throwing the cricketball event, which replaced javelin throwing.

William was the only Northern Ireland person representing the UK in the games which involved 500 competitors. **William looks forward to showing off his medals at the NIKPA AGM in December!**



We're a little concerned about your potassium levels.

Did you know

NIKPA is a completely voluntary organisation run by kidney patients (along with their friends, family and others) for the benefit of all kidney patients in Northern Ireland. We always need people to help run our committee and organise events/activities. Included with this newsletter is notification of our AGM in December. If you can spare some time to help others like you, please come along to our AGM and get involved.

Come and Join the team !

Visit our website at www.NIKPA.org



NIKPA Newsletter

Northern Ireland Kidney Patients' Association

www.NIKPA.org

Autmn/Winter 2008



Hello Everyone ...

Welcome to your Autumn/Winter 2008 Newsletter. It is now just over a year since I took up the position of Chairman and what a busy time it has been for all the Committee members.

Earlier this year we presented a cheque for £1,000 to the Nursing Sisters of Level 11 Nephrology, at Belfast City Hospital. The money was used to help purchase a syringe driver which is used in "symptom management" of renal patients.

A cheque for a similar amount was presented to the Transplant Co-ordinators also based at Belfast City Hospital, to help towards the cost of an information day entitled "The Gift of Life". This event was attended by Theatre Staff and Intensive Care Unit Staff to show how organ donations change the lives of patients awaiting transplantation.

In May our Treasurer Linda McDowell arranged for nine patients and their partners to enjoy a holiday break at either the Burrendale Hotel in Newcastle, Co Down where they were visited by our Secretary Stella Officer, or at the Ramada Hotel in Portrush where they were visited by Linda and her husband Rod. The patients came from all the Dialysis Units right across Northern Ireland. In addition a 4 year old patient from the Royal Victoria Hospital Children's' Dialysis Unit and his parents spent an action packed weekend at the Hilton Hotel in Belfast and enjoyed visits to Belfast Zoo and the Odyssey.

At the beginning of June Linda McDowell and myself were invited by the Irish Kidney Association (IKA) to attend the European Kidney Patients Association (CEAPIR) conference in Copenhagen.

Held over three days this gave us the opportunity to meet representatives from other kidney patients groups from all across Europe, as well as providing us with many new contacts and ideas which we hope to use in due course to benefit patients here in Northern Ireland.

The end of June/start of July saw our biggest event of the year, "Lifecycle". Staged over 10 days, the aim of the sponsored cycle around all the Dialysis Units in Northern Ireland was to raise the awareness of organ donation and the importance of carrying a "Donor Card".

The event which was led by one of our Home Dialysis patients, William Johnston and supported by all our Committee members including Gina Moss, Neill Aiken, Stella Officer, Orla Smyth, Tres Smyth, Rod & Linda was a great success and received excellent coverage on UTV and local radio stations as well as in local press throughout the province. The Health Minister, Michael McGimpsey, attended the event on the first day at the Antrim Unit, while the Lord Mayor of Belfast attended the finish of the event at the Belfast City Hospital.

The event culminated at the end of July with an evening reception at Stormont sponsored by Baxter Healthcare and attended by all those who had taken part in and supported the event.

Plans are currently afoot to organise a series of "Cookery Evenings" to help patients plan their renal diets in conjunction with the Renal Education unit and Renal Dieticians. We hope to hold a couple of events in November and if these are a success follow them up with similar events at venues throughout Northern Ireland.

The organisation of all these events together with attending monthly meetings has taken a lot of time and effort by the NIKPA Committee. In this regard I would like to take this opportunity to thank them all for their hard work and effort throughout the year.

Can I also take this opportunity to thank all the people who supported the various events throughout the year including patients, their families and friends and the Nursing and Medical Staff at the various Dialysis Units and Hospitals throughout Northern Ireland

Finally can I take this opportunity to wish you all a Happy and Healthy Christmas and a Prosperous New Year.

Kind regards, Colin Thompson

From The Chair

LIFECYCLE SUCCESS

Earlier this year William Johnston, a home dialysis patient, approached NIKPA with the idea of a renal patient (himself) cycling around Northern Ireland on a tandem covering all the renal units in an effort to raise awareness for the need for organ donation and to raise funds for NIKPA.

Patients, relatives, medical staff and many others joined in the campaign which was a great success. The campaign was covered by local newspapers, UTV and other media and we also raised £9,077.66p.

As a result of this NIKPA would like to say a big 'THANK YOU' to the following:

William's wife Carla Johnston, the Johnston family and friends. Steve Davis and the Staff of Baxter Healthcare (who were our main sponsors). Jo-Anne Dobson and family. Samuel Gardiner MLA. The Green Party. All the people who actually took on the cycling challenge. Classic Mineral Water and Supervalu (Randalstown) for providing refreshments. The motorcycling outriders including those from the Institute of Advanced Motoring. All of those people who donated money to the campaign. All the staff involved at the renal centres in Altnagelvin Area Hospital, Tyrone County Hospital, Belfast City Hospital, The Ulster Hospital, Antrim Area Hospital, Daisy Hill Hospital and The Royal Hospital for Sick Children. The local newspapers, The Ulster Tatler and UTV for their coverage of the event. Of course our own NIKPA committee members, but our main thanks go to William Johnston without whose terrific effort and organisation none of this would have occurred.

Linda McDowell



N.I.K.P.A HOLIDAY SCHEME

Pictured left are the renal patient Mr Ronald Hill and his wife from Craigavon. They recently spent a weekend at the Burrendale Hotel, Newcastle. Ronald was too ill to take up the holiday last spring but recovered and was able to enjoy the short autumn break.

Linda McDowell

Renal Review Implementation Group Meeting

The last meeting was held on October 20th at Stormont buildings. The following points cover the main issues discussed and their outcomes.

1. Electricity costs for home dialysis patients. Colin Thompson (NIKPA Chairman) raised the issue of financial assistance to cover the raised electricity bills of patients who have dialysis at home. It has been agreed by the Review Group that electricity costs directly associated with home dialysis would be met in full.

2. Vascular Access Targets. The target to increase patients changing to a fistula from a central venous catheter is looking quite good. Although difficulties still exist:

(a.) Some patients are reluctant to change to a fistula even though it means a decrease in risk of infection and improved patient outcomes.

(b.) There are problems with how many fistula procedures could be carried out within a certain period of time due to hospital limitations.

Both of the above are being looked into.

3. Live Donor Transplantation. The waiting time for live donor transplantation remains a major concern. The target aimed for is that no patient should have to wait more than nine months for a living donor transplant.

4. Expansion of Antrim Area Hospital Renal Unit. The Trust is finalising a business case for 20 additional stations. There is a real possibility that this could be provided within the next two years.

5. Renal Unit at Causeway Hospital. Specific recommendations (such as number of stations and number of shifts) have been made on the way forward with the development of a renal unit at the Causeway Hospital.

The 2002 DHSSPS Review of Renal Services outlined proposals for the commissioning of a new renal unit at the Causeway Hospital which would be phased in by 2010.

Linda McDowell

Rates Reduction Entitlement

"The Disabled Person's Allowance (Rates) is a rates reduction provided by the government in recognition of additional space and facilities required by individuals who are "substantially and permanently" disabled.

The reduction is available in respect to both adults and children and at least one of three conditions must be met:

1. You have an additional bathroom or kitchen needed by the disabled person or
2. You have a room (other than a bathroom, kitchen or toilet) needed by and predominantly used by that person or
3. You have enough space in your dwelling for that person to use a wheelchair used by and required for meeting the needs of the person with a disability. indoors.

(Disability Rights Handbook April 2008 p55)

Renal patients who are, for example, wheelchair users or who meet the above criteria should consider applying even if they receive dialysis in the hospital setting. Those undertaking either Peritoneal Dialysis or Home Haemodialysis will be applying on the basis that a significant portion of their home is given over to treatment and storage.

Forms can be requested from the Rates Collection Agency by telephoning 028 9025 2252 and asking for the Disabled Person's Allowance. If the member or their family is an internet user the form can be applied for on the link: http://www.lpsni.gov.uk/index/do-it-online/request_dpa_application.html. If you wish to download and print a paper copy of the form then go to http://www.lpsni.gov.uk/app_disabled_persons_allowance.pdf.

Once applications have been made there can be a considerable wait until they are assessed and a decision delivered by the Rates Collection Agency. Awards are not automatic but are assessed by visitation by an RCA officer. If the decision is not to award a rates rebate then an appeal can be requested through the RCA."