

NEWSLETTER

April 2012

Registered Charity 518767



Spring and Summer Patient trips and events

CALENDAR OF EVENTS

- * Tuesday 10th April Committee Meeting
Education Centre Room 138 7.00pm
- * Tuesday April 24th Doctors v Patients bowling
- * Tuesday 8th May **Living Donors** with Kim Russell being invited to speak Classroom 2, 7.00pm
- * Saturday 19th May Walker Park Festival
- * Sunday 20th May Stockton to Yarm cruise agreed to arrange this and to invite members from Sunderland and Middlesborough
- * Tuesday 12th June committee meeting.
- * Saturday 23rd June Westoe Village Fair
- * Sunday 1st July coach trip to South Lakes Zoo
- * Saturday 7th July Summer Festival, Bents Park, South Shields.
- * Saturday 14th July Westoe Fair, Westoe Village, South Shields.
- * Tuesday 10th July **Ambulance Driver** being asked to speak.
- * Tuesday 14th August committee meeting
- Tuesday 11th September Annual General Meeting Ray Mackie being invited to speak about the NKF.

Memorial seats

They are now in place on the footpath leading to the multi-story car park. Thank you to the people who donated to these bench's in the name of their relatives and to the Hospital Estates Dept. who installed them.



The Princess River Cruise Sunday 20th May 2012

Enjoy a Sunday Lunch while on a 2 hour cruise from 11:30-1:30 on the river Tees from Stockton to Yarm with a stop at Preston Park This trip is open to patients, their families, medical staff and members of the Tyneside Kidney Patients Association

Price per person £15 inclusive of lunch and cruise, closing date for bookings 10th May 2012

The TKPA will be providing free transport from the Freeman hospital To Stockton and return



To book your place on this trip please contact the TKPA Treasurer with your payment to Mr David Errington, Linden, Longhirst, Morpeth Northumberland NE61 3LS tel.01670 790300

or Email: daviderrington@tiscali.co.uk

The cruise, transport and dining is wheel chair accessible but we are advised that the lavatories on board are not.

Any queries regards this trip please contact the following committee members

Keith Vickers 0191 425 2379 k.vickers@blueyonder.co.uk

David Errington .01670 790300 daviderrington@tiscali.co.uk

Spring and Summer Events

>Tuesday 24th April 2012 7.00pm Mega bowl North Tyneside

Medical staff versus Patients 10 pin bowling

>Sunday 20th May 2012 Stockton to Yarm river cruise and lunch

>Sunday 1st July 2012 Visit to South Lakes Zoo

Charity Stalls

>19th May 2012 Walker Park

>23RD June 2012 Westoe Village Fete South Shields

>7th July 2012 South Shields Festival Bents Park

If you wish to come to these events or assist with the charity stalls please contact..

Joan Longstaff 0191 2576650

dustywhippet@hotmail.com

David Errington Treasurer (01670) 790 300

daviderrington@tiscali.co.uk

Simon Lloyd Secretary (01661) 871 399

simonlloyd429@btinternet.com

STAND OPPOSITE W.H. SMITHS

We will be holding the stand on the first Friday and third Thursday

The stand is held in the atrium opposite W.H. Smiths by the courtyard from 0830 a.m. to 3.30 p.m. We have been putting up our display stand for information and holding tombola. Please stop and have a chat if you are passing on your way to or from the Outpatients clinic. We would also appreciate help manning the stand if you can come for part or all of the day.

DONATIONS FOR FUND RAISING

We are very grateful for all the articles that have been given to us to help raise funds. If you would like to make a donation of items, but not books, to help fund raising would you please hand them in to the receptionists on Ward 31 and then let one of the committee know so we can collect them. Staff have been very helpful in arranging to receive and store items for us.



EMERGENCY WRISTBANDS

Wear a wristband specially designed for kidney patients so emergency services are made aware of your special needs.

Wristbands are available @£1 from the receptionists on Ward 31 or by post @£1-65. Full details and order forms are available from our website www.tynesidekpa.org.uk

In every addition of the Newsletter we include the above advert for wristbands, to show how widely it is read here is a breakdown of sales and regions in the UK.

- > Large Right Arm Fistula - 869
- > Large Left Arm Fistula - 1499
- > Small Right Arm Fistula - 379
- > Small Left Arm Fistula - 533
- > Large Transplant - 385
- > Small Transplant - 226
- TOTAL - 3891**

I have listed below the large organisations that we have supplied wristbands to since the last count in September 2011. The figures in brackets are the number of wristbands.

Carmarthen Dialysis Unit (168);

Woodgate Dialysis Unit (40);

Churchill Hospital, Oxford (26);

Wessex KPA (120);

James Paget Hospital, Great Yarmouth (50) Order for a further 50 awaiting cheque.

Kidney Wales, Haverfordwest (80);

York Dialysis Unit (140) this is a repeat order.

Kent KPA, Ashford (115);

Kent KPA, Maidstone (80);

Monklands Hospital, Airdrie (50) this is a repeat order.

Guernsey KPA (90).

Mike Hayhoe
Committee Member

CONTRIBUTIONS PLEASE

We publish our newsletters every three months. If you would like to contribute information, renal friendly recipes, jokes (clean-ish please); poems, puzzles or observations please let a committee member have them by the end of May 2012. Or e-mail to the editor.

k.vickers@blueyonder.co.uk

USEFUL CONTACTS

Renal Social Workers

The best way to contact one of the renal social workers is to go by the administration officer. You can do this by:

- phoning Newcastle Hospitals on (0191) 223 1025 and asking for the renal social workers at the Freeman
- E-mail to socialworkadminFRH@newcastle.gov.uk
- Fax to (0191) 285 3455
- Post to Renal Social Worker, Adult Services Directorate, Freeman Hospital, Freeman Road, Heaton, NE7 7DN

Telephone Helpline – (01661) 871 399

COMMITTEE MEMBERS' CONTACT DETAILS

Telephone Helpline – (01661) 871 399

TKPA Website: www.tynesidekpa.org.uk

National Kidney Federation: www.kidney.org.uk

COMMITTEE MEMBERS' CONTACT DETAILS

Honorary Officers:

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E-mail: kath.brown@northtyneside.gov.uk

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URGENT RENAL CARE

Any Newcastle dialysis or kidney transplant patient who needs advice about an **URGENT** medical problem that relates specifically to their underlying kidney disease/treatment should telephone one of the following numbers:

Chronic haemodialysis patients: telephone Ward 31 on 0191 2137031 (or if unobtainable phone Ward 32 on 0191 2137032)

Peritoneal dialysis patients: telephone Peritoneal Dialysis Team on 0191 2448297(0830-1730hrs), or Ward 32 0191 2137032 (at all other times)

Kidney transplant patients: telephone Ward 32 on 0191 2137032

A member of the nursing staff will discuss the problem with the on-call Renal Speciality Registrar before offering appropriate advice. The advice may be to visit your General Practitioner, your local Emergency Department or your closest NHS walk-in centre.

All patients should continue to telephone 999 in the event of an EMERGENCY

From the Membership Secretary

To all e-mail recipient members, please keep me informed of any changes to your e-mail addresses. Any discrepancy results with a "failure notice, recipient address rejected" as the result.

The price of postage is increasing dramatically at the end of April 12 so if you receive a newsletter by post but you have an email account please let me know and I will change how you receive it.

www.bond504@btinternet.com

Changes to Patient parking

As users of the dialysis or disabled parking bays have noticed in recent weeks space has been lost because of the demolition of the block of flats for the construction of a Maggie's Centre.

I have already noticed that it has become more difficult to park and I dialyse at 6:00pm so how bad will it be during the busy part of the business day when building work really gets started ?



I have contacted the Hospitals management and requested that parking controls be tightened

with more patrols, there are contractors who can issue parking tickets. They can also advise taxi drivers who between journeys park there as well as contractors involved in the building work that this is not public parking. While I am not suggesting patients confront illegal parkers you could play your part by telling the receptionist at the desk in the foyer, also remember to display your dialysis parking permit at all times.

Keith Vickers

Editor



Kidney Care

*Newcastle upon Tyne leads the way for
kidney patients*

Newcastle upon Tyne is being supported to develop an innovative project that will help improve the health outcomes of kidney patients by engaging them in their care.

It has been selected to receive support by NHS Kidney Care, a national organisation that works with patients and healthcare professionals to

improve NHS services for patients with kidney problems. NHS Kidney Care invited kidney centers to propose new ways in which they could embed care planning, a process in which the healthcare team and the patient work together to plan out a tailored pathway of care that responds to individual needs.

Evidence suggests that care planning can have real benefits for patients with long term conditions, such as kidney disease, and can result in more cost-effective care. It involves equipping patients with appropriate knowledge and understanding of their condition, which means they are able to make informed decisions about their care. Clinical teams are also supported with the tools and expertise to allow them to make shared decisions with patients. When a patient takes a more active role in their care in this way, they are often better able to manage their symptoms, and can benefit from an improved sense of wellbeing and fewer health problems.

This project is focusing on peritoneal dialysis patients at first and will hopefully expand to the rest of the renal population. Currently there are 56 patients who have been contacted via letter and have been seen in clinic to discuss the care plan and the benefits of having a care plan.

It is not just patients in Newcastle who will benefit. NHS Kidney Care is supporting 23 kidney units across the country so that different ways of helping patients get more involved in their care can be tested and evaluated, with the most successful ones being rolled out nationwide.

Beverley Matthews, director of NHS Kidney Care, said: "We are delighted to be working with Newcastle upon Tyne on this project, which will make a real difference to the lives of people with kidney disease. The NHS is committed to ensuring that patients are central in making decisions about what type of care they want to receive, and this project will help them to do that. The work being carried out by Newcastle upon Tyne will help to raise the quality of care for kidney patients not only in Newcastle but across the country."

NHS Kidney Care project: Timely listing for kidney transplantation

My name is Tricia and I am the lead nurse for the timely listing for kidney transplantation project at Freeman Hospital. Dr Katy Jones successfully competed for funding for this six-month national quality improvement project from NHS Kidney Care in October 2011.

We have reviewed the assessment process from a patient and clinician perspective up to activation on the transplant list. I have made a comprehensive assessment of the 'patient journey' and have discussed this with many patients and their carers. I have been particularly interested in how patients have felt during the assessment of their suitability. I have also reviewed the case notes of patients who have required a transplant operation or to start on dialysis over a 6-month period to help clarify their experience too.

The information that I gathered has been used to inform plans to improve the service. One important change is that a transplant coordinator will now be involved in explaining the process of assessment and listing for transplantation to the patient and carers at an early stage and will be available to guide and support you through the process. A hand-held patient care plan is being developed which includes all aspects of the assessment process, and will help to keep you informed and involved as you progress through the assessment. We anticipate that the journey to listing (or not listing) will soon be even more transparent and timely for you, the patient.

TRANSPLANT PATIENTS

Transplant patients are able to get high factor sunblock on prescription from their GP.



I have been getting this for the last few years.

PLEASE REMEMBER TO TOP UP REGULARLY.

Joan Longstaff
Committee member

Patients and friends Dinner

Our Annual Dinner was held on the 1st March 2012 at the Grange Centre in Throckley. After a very good 3 course meal we had the Worlds hardest quiz, I'm sure the winner should have not only won a bottle of wine but an A level qualification.

After that we drew the raffle, with the first prize of a flat screen TV going to a guest of a member. As a punishment this winner was also forced/requested to be our bingo caller which task he carried out with suspicious professionalism, he was funny and made the game a great success

We also welcomed the family of our recently departed friend and Committee dynamo Brian Jones; they were presented with bouquets and thanked again for the donation in Brians name to the TKPA charity.

The evening raised £186 for the TKPA so a big thanks to you all who attended and to the Committee for organising the event.

Keith Vickers



Renal PatientView is a project of RXIG, a UK group representing renal patients and the renal team. It aims to provide online information about renal patients' diagnosis, treatment, and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

PatientView is only available from some UK renal units, and for patients who have chosen to participate. Here is a [list of units](#) involved so far. The information comes directly from existing databases within units, so if you suspect a mistake, you should check with your own unit. Links are provided after you log in.

As a recent convert to using Patient View I thought you might like my thoughts on this system.

- It's easy and straightforward to access and use.
- Information on your results i.e. what they mean is simple and can be used in discussions with medical staff.
- There is a UK wide patients forum where you can chat with other patients on all sorts of topics

- And finally it gives you at least a week's start on thinking up new excuses before the dietician comes to see you!

If you need help to access Patient View Hazel Marchant is the Freeman Hospitals officer managing the system.

For informal help I would be happy to speak with you.

Keith Vickers

Editor

K.vickers@blueyonder.co.uk

Hazel.Marchant@nuth.nhs.uk

TKPA Committee

The TKPA are looking for new committee members, if you are interested please look out for an application form in the June 2012 newsletter.



Our current committee is made up entirely of dialysis/ transplant patients, renal staff and family/supporters but friends or relatives of patients who feel they could fulfill a role would also be welcome

You know dialysis is taking over your life when:

You don't see a plain-old banana-- you see a loaded pistol!

The produce section of your local grocery store becomes like a red-light district for you

Commercials featuring flowing streams and rushing waters no longer make you feel like you have to pee, they make you THIRSTY!

You realise that dialysis is just like the Army: You're part of a unit, and 'hurry up and wait' is now a large part of your life

You have a voodoo doll of your taxi or ambulance driver

You have learned to dread it when the nurses roll out the 'privacy screens' around an often-incontinent patient

You have learned to do many things with one hand

You have a large collection of Readers' Digest issues, crossword puzzle and find-a-word books, and tons of ballpoint pens

You don't know what you weigh in pounds and stones

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"I'm afraid the shark got your arms and legs. It's probably not a good time, but your brother's here. He needs a kidney."

Summer Sponsored Walk

The TKPA is holding a sponsored walk in aid of the patient's charity on Sunday 19th August 2012.

The route will be from Souther Lighthouse along the cliff tops to the Littlehaven Hotel South Shields which is next to



the harbour. This walk is 3.7 miles in length and is mostly on a level made up path and should take a comfortable couple of hours or an uncomfortable hour and a half. Sponsorship forms will be available from Committee members and on the info racks in the waiting area of ward 31

Please try and support this event and if you are unable to walk this distance you could ask friends or relatives to get involved instead.

For further information please contact me

Keith Vickers

Editor

K.vickers@blueyonder.co.uk

Sunday 1st July coach trip to South Lakes Zoo

We are organising a members and friends visit to the Zoo,

<http://www.wildanimalpark.co.uk/> further details will be displayed around the unit and by email.



If you wish to book a provisional place please email or leave a note for me on the Unit, I dialysis M/W/F bay 5 late shift

Keith Vickers

k.vickers@blueyonder.co.uk

Holiday patient caravans

There are two caravans that can be hired by renal patients, one is based in Seahouses and the other in the Lake District, and both caravans are on established managed sites and are large family sized statics.

Haemo-dialysis patients can be transported from Seahouses for treatment at the Freeman, if in the Lake District dialysis is arranged at a local unit in the area.



For further details including available dates and costs please contact.....

Hazel Marchant
Ward 32
Freeman Hospital
0191 2231421

Hazel.Marchant@nuth.nhs.uk

Church newsletters bloopers

>Weight Watchers will meet at 7 PM at the First Presbyterian Church Please use large double door at the side entrance.

>Please place your donation in the envelope along with the deceased person you want remembered.

>At the evening service tonight, the sermon topic will be 'What Is Hell?' Come early and listen to our choir practice.

>Next Thursday there will be tryouts for the choir. They need all the help they can get.

>Miss Charlene Mason sang 'I will not pass this way again,' giving obvious pleasure to the congregation.

>Don't let worry kill you off - let the Church help.

>Ladies, don't forget the rummage sale. It's a chance to get rid of those things not worth keeping around the house.. Bring your husbands.

>The sermon this morning: 'Jesus walks on the Water.' The sermon tonight: 'Searching for Jesus.'

>Low Self Esteem Support Group will meet Thursday at 7 PM. Please use the back door.



Meet Mr. Bates, our perfect patient. He controls his fluid levels by not drinking and his potassium, cholesterol and phosphates by not eating.

FREE PARKING FOR MEETINGS

We have arranged for those coming to meetings to park free in Level 2 or above in the Multi-Storey car park, providing a permit is cut out and displayed on the dash board

TYNESIDE *KIDNEY*
PATIENTS' ASSOCIATION
Tuesday 10th April 2012

**Parking while at
Freeman Hospital
MEETING IN ROOM 137**

TYNESIDE *KIDNEY*
PATIENTS' ASSOCIATION
Tuesday 8th May 2012

**Parking while at
Freeman Hospital
MEETING IN ROOM 137**

