



NEWSLETTER

November 2011

Registered Charity 518767



Dialysis patient parking, has time come for action?

CALENDAR OF EVENTS

Tuesday 8th November **Any Questions** - speakers will include John Tapson, a dietician, a nurse and a renal social worker probably Lynne Cullen

Sunday 13 November 3.00 p.m. **Transplant Thanksgiving Service**
- St Georges church, Jesmond.

Tuesday 13th December **Committee Meeting**

Thursday 22nd and Friday 23rd Santa Claus round wards

Tuesday 10th January **Understanding Benefits** - Christine Stewart from Welfare Rights

Tuesday 14th February **Committee Meeting**

Thursday 8th March World Kidney Day

Tuesday 13th March **Home Haemodialysis** with Maria Love being invited to speak

Tuesday 10th April **Committee Meeting**

Doctors v Patients bowling Tuesday April 24th

Tuesday 8th May **Living Donors** with Kim Russell being invited to speak

Saturday 19th May Stockton to Yarm cruise agreed to arrange this and to invite members from Sunderland and Middlesborough

Tuesday 11th June committee meeting

Saturday 30th June coach trip to South Lakes Zoo

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.

Volunteers needed

Santa could use a few more helpers with the distribution of presents on the 22nd and 23rd December on the Renal Unit across the day, could you give a couple of hours? Contact a committee member if you could help.

Contact Simon Lloyd tel. 01661 871399

SHOW STALLS

Felling Show - Saturday 13th August

Due to the heavy rain and a water logged field, this year's Felling Festival was cancelled. A few stalls including the TKPA, located to the Brandling Hall Community Centre. Our helpers included Keith & Kath Vickers, Alan Bond, Mary Bullock and myself. We had a much better day than expected as we made £98 - more than we expected as there was not a lot of people around.

Thank you to everyone for their help and those who gave us prizes for the tombola, including a stall holder who gave us the few prizes he had left to help our charity

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.

CHRISTMAS RAFFLE

Christmas Hamper

Pair table Lamps

Solar Chrome Thermometer

Watch

+ 6 other prizes

To be drawn on Thursday 15th December

At Freeman Hospital

50p per ticket

If you could sell any tickets for us please contact any committee member.

We would also appreciate donations to be included as prizes.

Joan Longstaff
Committee Member

STAND OPPOSITE W.H. SMITHS

We will be holding the stand on the first Friday and third Thursday, this will continue throughout 2012.

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.



RENAL ALERT WRISTBANDS

Those of you on haemodialysis at the Freeman may well have one of these red wristbands with the wording 'FISTULA RIGHT or LEFT ARM - NO BP TESTING/NEEDLES'. If you haven't got one, you've probably seen them on other patients. Well, you may be interested to know that we are the first area in the country to have these wristbands.

It all came about after our Secretary; Simon Lloyd was visiting Australia and saw similar wristbands in use. When Simon returned, he suggested to the committee of the Tyneside Kidney Patients Association that they should buy a small quantity to see if they would be accepted by our patients

Orders came in locally but because Simon had a number of commitments he suggested someone else should be responsible for distributing the wristbands and this is where I came in. Simon had put an article in the National Kidney federation Magazine and also an order form on our website (www.tynesidekpa.org.uk) and within a few days I was inundated with orders for the wristbands.

In the first couple of months I had supplied several hundred wristbands to addresses all over the country. There were

requests from places as far away as the Shetland Islands; Northern Ireland; the Channel Islands and all places in between. I even had a request from Thailand but it was for delivery to an address in the UK.

Not only have I received requests from individuals but from Hospital Renal Units and other Kidney Patients Associations. These latter bodies usually put in orders for substantial quantities. As the word spreads I am continuing to receive orders on an almost daily basis and at the time of writing I have supplied over a hundred wristbands during the week. So far, orders have exceeded 2700 and they show no signs of letting up.

We make a modest profit on the supply of these wristbands and this goes towards the projects initiated by the Tyneside Kidney Patients Association.

If you want to purchase a Renal Alert Wristband, this includes Transplant Wristbands; you can get them from the Ward Clerks, Lynne and Lydia on Ward 31 at the Freeman for £1.00 each or if you wish to have them posted for £1.65 each you can use the order form on our website (www.tynesidekpa.org.uk).

Apart from the red wristbands, we also supply green wristbands with the wording 'KIDNEY TRANSPLANT' for those people who have had a kidney transplant'.

Should you require any further information, please feel free to contact me on 0191 236 6759 e-mail mhayhoe@aol.com

Mike Hayhoe
Committee Member

Freeman Hospital Parking

Talking to fellow patients about parking it has become apparent that problems are arising when attending dialysis sessions. It is great that 11 bays are set aside for permit holders along with a number of spaces on first come first served basis for those with a blue badge but their does seem to be an issue concerning enforcement.



In Sept/Oct this year I personally have noted taxis, contractors vans, a Police car and most disappointingly a Doctor's vehicle who posts a note on the window saying he is on duty. Along with these are people dropping children off at the nursery as well as a huge number of chancers who sit in the car waiting to pick people up. This is a particular issue with patients vying with people who are picking up staff at around 5pm. I have challenged people for parking in our bays most of whom have moved on but some in particular parents picking up children from the nursery seem to have an air of entitlement and do as they please.

Whilst it is to be expected that some people will ignore all and every parking rules the main problem I feel arises from insufficient signage resulting in casual visitors not realising that bays 1-11 are in use from 7am-12midnight. At present there is one notice 3 meters up a post with difficult to read and a water damaged line saying permit holders only, this cannot be seen clearly unless you are standing under it and you have your glasses on! The TKPA will approach the Estates Department with the following suggestions to approve the situation

- Parking bays to be regularly patrolled, don't forget anyone parking in renal bays without a permit is costing the Hospital a normal parking fee.
- Notices to be given to the Nursery to encourage their customers to adhere to the parking rules.
- New signage that can be seen clearly from all bays 1-11.
- Staff made aware that this is not a pick-up/drop off zone.

In the meantime if you have trouble parking or see our bays being abused please let the member of staff at the desk just inside of the revolving door know.

Keith Vickers

Editor

Harrogate Autumn Flower Show



On a nice dry morning 14 of us made our way to Harrogate for the annual autumn flower show. The weather was so kind to us and the thousands who attended this fantastic flower and vegetable show.

For the six hours we were at the show we only needed to dodge a couple of showers .When you think of the time spent getting the displays ready for the show you can see why everything is presented to the highest quality. As well as marvellous floral displays the thing that caught my eye was the monster vegetables, try making a pan of soup with some of these.....

Heaviest onion 18lb--Cabbage 64lb--Marrow 107lb

Anyone who has not visited the Harrogate flower show I would strongly recommend you should as you will not be disappointed.

John and Susan Harty

MEETING REPORTS IN BRIEF

Renal Network

- The renal tsar Donal Donoghue was present.
- The national tariff for dialysis away from base (DAFB) of £155/session will start on 1st April 2012
- Dialysis in private units will be paid for!

Joint Meeting with Renal Staff

- Funding has been given for a nurse to do 2 days/week supporting patients preparing for dialysis or a transplant.
- Funding is being used to pay for a nurse to develop care plans with PD patients.
- Peer Support Group training has started with the first day being held in October. The second day completing the

training run by the charity Connect will be held in November.

- Renal staff are planning to hold an open day when patients can see round the new transplant unit and meet renal staff informally.

NKF Conference

- Our motion about travel expenses was agreed unanimously. This means the NKF committee have been asked to work

to getting a nationally set tariff for mileage payments instead of them being set by each trust as is happening at the moment. Also that all haemodialysis patients should be able to claim travel expenses and not just those on very low incomes.

- A workshop on Innovations on Home Dialysis (haemodialysis) taken by Dr R. Greenwood on the NX machines. These have worked very well in his experience and that of users who were at the meeting. This calls into question the statement given to a North East Renal Network meeting that they don't give adequate clearance. Experiences of users in Australia, USA and in this country have shown they work well. They are mobile but weigh 35 kg.

New Terminology

1. Decision Aids

Patient Decision Aids (PDAs) are designed to help patients make difficult decisions about their treatments and medical tests. They are used when there is no clinical evidence to suggest that one treatment is better than another and patients need help in deciding which option will be best for them.

- 2. Shared Decision Making** is a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement.

3. **MAGIC**- Making Good decisions In Collaboration is a process of shared decision making using 3 questions

- (1) What are my options?
- (2) What are the possible benefits and risks?
- (3) How can we make a decision together that is right for me?

October Committee Meeting

- Brian Jones is hoping to arrange a book swap system for Ward 31
- A full programme has been planned for the coming year.
- We agreed to see if we can hold a joint meeting with all the renal units in the north.
- We are going to write to the NKF inviting them to hold the annual conference in Newcastle to encourage more people to get involved
- Taking the newsletter round patients in Ward 31
- Ask for donations for the Christmas raffle
- Santa Claus visits round the renal wards will be held on Thursday 22nd and Friday 23rd of November. All who would like to volunteer to contact the secretary Simon Lloyd

Simon Lloyd

Secretary

From the Membership Secretary

Could all e-mail recipient members, please keep me informed of any changes to your e-mail addresses. When people change their e-mail address we have to send out the Newsletter by post as the result. Here is summary of our membership to date: Total Membership stands at 440.

Newsletter Mailing List 339

Newsletter E-mail List 72.

Newsletter in large print' 2.

Newsletters hand delivered 13

Newsletters by e-mail does save the TKPA money, therefore we do encourage members to make use of the internet. A note to all members with an e-mail address, when changing Internet Providers, please let me know, your latest address details.

Alan Bond

www.bond504@btinternet.com

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

Dr John S Tapson

Clinical Director / Consultant Nephrologist

NKF Roadshow

The theme of which was 'Caring & Sharing', Simon and I set off from Tyneside at 5am as the mist was forming over the whole region, arriving at Blackpool ready to go and register for the event, by 0845. The stand was set up; the wrist bands displayed among the other trade stands.

The opening Address was given by the NKF Vice Chairman Kirit Modi as Marion Higgins was absent due to illness and wished her a speedy recovery. The various speakers were presenting their specialist subject such as 'Stem Cells and Kidney Regeneration', 'Genetics-Haemolytic Uraemic Syndrome' by Dr David Kavanagh from the Centre of Life in Newcastle. 'Home Dialysis Patient



Empowerment', 'Paired/Pooled Kidney Transplantation', 'Diet', Holiday Dialysis Swap Scheme' and 'Integrative Health' interspersed with the Patients view of 'Living and Giving', 'Living Well' the session was wound up

at 1625 after the Question Time.

It was time to relax and clean up ready for Pre Dinner Drinks and the

Gala Dinner which consisted of 'Caesar Salad with Salmon', 'Roast Chicken with thyme fondant potato and a selection of roasted vegetables', 'warm Apple pie and Chantilly Cream' followed by freshly brewed tea/coffee and mint chocolates. and good conversation with members of the South Lancs KPA. The evening was rounded off with a visit to Springs the Hilton nightclub / dance venue to shake down the meal with a few drinks.

Sunday: after a hearty breakfast, the NKF Council Meeting was called at 0930, the agenda was followed through, Simon proposed the 'Travel expenses topic' was seconded and debated and put on the Executive Committee agenda to be into the wider Department of Health arena.

Alan Bond

Committee member

TKPA ACCOUNTS FOR THE YEAR ENDING 31/5/11

INCOME	£	£	
Transplant EXPENDITURE			
Donations	5,286-44	Welfare Fund ²	4,000-00
Bank Interest	6-88	Stall purchases	1,070-75
Stalls ¹	1,565-12	Outings	1,371-86
Raffles	1,565-12	Newsletter/post ³	1,795-78
Sponsored Events	556-74	Website	59-88
Collecting tins	551-95	Travel costs	494-60
Outings	953-50	Insurance ⁴	512-50
Wristbands	2,666-91	DVD players	255-00
Badges	<u>100-00</u>	Badges	516-00
		Wristbands	1,636-82
		Games Team ⁶	<u>540-00</u>
Total	£13,538-10	Total	£12,163-19

Balance for the year +£1,374-91

Notes on the accounts

¹ Stalls were held in the Freeman and at outside events.

² Welfare Fund payments were made to the Holiday Fund and used to provide funds for the renal social workers to make

immediate grants to needy patients. Payments are made in £1,000 donations/quarter.

³ The biggest proportion of payments for the newsletter is postage costing £1,130-16. Could you please help us if you use the internet by getting your copy by e-mail please?

⁴ We get insurance to cover written and spoken statements through the NKF and insurance for our events through Attend.

⁵ We purchased 4 DVD players for use in the haemodialysis wards using a donation from the League of Friends given in the previous financial year.

⁶ We supported the Volleyball competition held in Newcastle as part of the Transplant Sport Great Britain competitions.

Please note we have a policy of not making any financial grant direct to any renal patient or carer. We support patients financially through our donations to the Welfare Fund, which is in turn independently audited.

ANNUAL GENERAL MEETING REPORT Tuesday 13th September

The meeting started with a very good talk by the renal pharmacist Rachel Fraser. She went through the main groups of medicines that are prescribed. As she did so a lot of questions arose which she answered very helpfully.

In the meeting the trustees report highlighted the work we have been involved in to successfully improve transport for haemodialysis patients. The success Mike Hayhoe has had in selling over 2,690 wristbands. At the end of the year we had 435 members up from 379 the previous year.

We had nominations for all the committee members and are pleased to welcome Iain Partis who has joined the committee. At the same time we are very grateful for all the work David Lee has done serving on the committee since 2006. David has completed 3 years as a committee member.

We co-opted the renal social workers to serve on the committee and have since co-opted Joan Longstaff and Doreen Adamson as well.

We agreed to put forward two proposals for the National Kidney Federation Conference Council Meeting about mileage payments for haemodialysis patients. The first was asking for a national standard tariff as they are set locally by each trust. The second was to ask the NKF to work towards getting mileage payments for all haemodialysis patients. The latest figures we have is that out of the 94 haemo patients who provide their own transport only 26 are eligible to claim. We think all those who transport themselves should be eligible.

Combat Zone who run paintballing have given us 9 free tickets. We have given 2 to the new young people's group and they are available from the secretary. The nearest venue is

near Cramlington. Those who want to play have to pay £10 for the first 100 paintballs and £6-50/100 after that. We will get 25% donated from paintball sales when one of our registered cards is used.

DOCTORS V PATIENTS TEN PIN BOWLING.

The annual competition for the Elizabeth Dickson Challenge Cup was held at the Star Bowl, Royal Quays. There were 10 competitors including Pam Yanez and Julia Harding representing the doctors and 8 patients and carers.



We decided to make this an individual competition. John Law for the patients, came first with Julia Harding second and Pam Yanez third. So this year the patients won.

Doctor's v Patients Cricket Match 15th August 2011



We had a good time though lacking in both patients and doctors. Only 4 doctors turned up and 8

patients so we played 6 a side for 12 overs each.

The doctors scored 75 in their 12 overs. The patients got 76 in 11 overs.

Everyone took part including bowlers who had never bowled before and the same with batting. It was a good relaxed fun game with David Lee and myself umpiring.

The Ross Taylor shield was won by the patients and was given to the captain Graeme Appleby.

A lot of supporters of both the transplant team and medical staff came and it made a good social event with a buffet provided by Pam and Hazel.

The Civil Service Sports Association gave David Lee a donation to run the event. In addition a raffle raised £150.

Spring Dinner and Social Evening

We will be again having a Dinner and Social evening for patients, friends and medical staff, the venue will be the Grange which is in Throckley.

Menus and final numbers will be sorted out in January 2012 but in order to make initial arrangement we need you to register your interest.

We have been able to keep the cost at £15 per person, the same as last year, we will send out menus in the new year when payment will be needed with your dining choices.



Spring Dinner and social evening 1st March 2011

Name _____

Address _____

Tel: _____ Tickets # _____

*David Errington, Linden ,Longhirst, Morpeth Northumberland
NE61 3LS by 5th January 2012*

Email: daviderrington@tiscali.co.uk

Please remember send no monies

Keith Vickers



Lakeland Dialysis prides itself in offering personal quality haemodialysis treatment in a small modern clinic in Cockermouth on the edge of the beautiful Lake District.

Patients are treated using Fresenius machines whilst seated in comfortable reclining chairs. A Freeview TV set with a wide

selection of DVDs are available with individual headphones. We supply a newspaper if requested. Wireless internet is available to use with your computer. Tea, toast and biscuits are also provided.

We are open 6 days a week during busy periods and Mon, Wed, Fri and Sat at other times, offering morning or afternoon sessions.



You can find us on an office park off the A66 approximately 20 minutes from Keswick, where your Local Patients Association has a Caravan. Or if you want something different, there is lots of other

accommodation available in the area.

For more information about our services please contact Kevin or Louise on Tel 01900 822 888 or E-mail info@lakelanddialysis.co.uk.

An update from our Patients visit to Beamish Museum

At Beamish the rebuilt Chip Shop is complete and has been busy frying traditional fresh fish & chips since mid-August 2011, with long lines of visitors, hoping for a sample to buy, the staff are kept busy.

The building was re-constructed on site, with the original coal fired frying range being refurbished. The Main Frying Room has been decorated with colourfully glazed tiles, depicting scenes of, Lighthouses, boats and fish, dive-bombing seagulls, strange lurking fish, as well as less explicable pheasants and turkeys. These are arranged as a frieze and several tiled panels, three tiles of which were, replicated to complete the panels, the rest are as original.

These tiles are 'tubeline' tiles, that is to say tiles that are made by drawing, a design onto them like decorating a cake, or squirting thin toothpaste, and then filling the gap between the ridges with coloured glaze. The result is a depth of glaze of great luminosity and quality, this dates from before 1906.

I have sampled the fish & chips at £6.95 for a large portion, or £4.50 for Dab & chips a small portion, they are wrapped in vegetable dyed printed paper to simulate newsprinted paper. It was a quiet day, the wait from the shop door to being served was one hour. The taste was excellent; the fish is delivered daily from North Shields.

This article was printed with the kind permission of 'The Friends of Beamish Museum', from whose magazine; I quoted some of the text.

Alan Bond



Thank God! WATER! Now I know how a dialysis patient feels.



Long term engineering work completed !

After a year of planning, designing and sourcing of materials patients in Bays 4 and 5 have now the use of coat hooks next to the scales. Thanks should be given to the Estates Department for their prompt attention to this highly technical installation.

Season's Greetings

As it is still officially autumn it seems strange to be talking about the Festive period but as this our final newsletter until the New Year it has to be. So to everyone whether patients, family, friends and medical staff, have a very merry Christmas and happy and healthy New Year

TKPA Committee

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 Jan 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

TkPA Website: www.tynesidekpa.org.uk

National Kidney Federation: www.kidney.org.uk

COMMITTEE MEMBERS' CONTACT DETAILS

Honorary Officers:

Kath Brown Chairman (0191) 250 0762

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

Mike Hayhoe Vice-chairman (0191) 236 6759

E-mail: mhayhoe@aol.com

Simon Lloyd Secretary (01661) 871 399

E-mail: simonlloyd429@btinternet.com

Carr House Cottages, Berwick Hill Road,
Seaton Burn, Newcastle upon Tyne, NE13 6BX

David Errington Treasurer (01670) 790 300

E-mail: daviderrington@tiscali.co.uk

Committee members:

Alan Bond membership secretary (0191) 4281 702

E-mail: bond504@btinternet.com

Keith Vickers Editor (0191) 425 2379

E-mail k.vickers@blueyonder.co.uk

Brian Jones (0191) 264 5312

E-mail pabear61@gmail.com

Ian Partis E-mail iantpartis@hotmail.co.uk

Co-opted members

Joan Longstaff 0191 2576650

E-Mail dustywhippet@hotmail.com

Doreen Adamson 07890 430881

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
Tue 8th Nov 2011
Parking while at a
MEETING IN ROOM 137**

**TYNESIDE *KIDNEY*
PATIENTS' ASSOCIATION
Tue 13th Dec2011
Parking while at a
MEETING IN ROOM 137**

**_TYNESIDE *KIDNEY* PATIENTS
ASSOCIATION
Tue 10th Jan 2012
Parking while at a
MEETING IN ROOM 137**

