

NEWSLETTER

March 2013



Cover image. Institute of Transplantation Freeman Hospital

For the old timers like me haven't we come a long way since ward 22

CALENDAR OF EVENTS

2013

*Tuesday 12th March general meeting

Speaker Mrs Linda Pickering North East, Yorkshire & Humber
Region Advocacy Officer National Kidney Federation

*Thursday 14th March 2013 World Kidney Day

*Saturday 16th March 2013 easy walking club (details inside)

*Tuesday 9th April 2013 committee meeting

*Saturday 13th April visit to Bowes Museum (details inside)

*Thursday 18th TKPA Annual Dinner Sea Hotel South Shields

* Saturday 11th May 2013 Easy walking club (details inside)

*Tuesday 14th May 2013 general meeting

Speaker on Holiday Dialysis

*Saturday 18th May 2013 Walker Festival (article inside)

*Tuesday 11th June 2103 Committee meeting

*Saturday 15th June 2013 Lake District, Windermere cruise.

*Saturday 22nd June 2013 Westoe Village Fair, South Shields

*Saturday 6th July 2013 South Shields Festival, Bents Pk. So Shields

- *Tuesday 9th July 2013 General meeting
- *Saturday 13th July 2013 Easy walking club
- *Saturday 10th August 2013 Visit to Flamingo Park

All meetings to be held in room 138 Education Centre

Freeman Hospital and will begin at 7:00pm prompt

Tea, coffee and biscuits served from 6.50pm

THE CONTROL OF ANTIBODIES IN TRANSPLANTATION

Dr Alison Brown gave a presentation to our January 2013 general meeting for which I would like to thank her again for giving up her valuable time to talk to us on the control of antibodies in transplantation, this was also one of the best attendances for a speaker we have had in a long while

Keith Vickers Sec and Editor

WORLD KIDNEY DAY - Thursday March 14th

We will be holding two stands in support of World Kidney Day from 0930 to 1530 at the Freeman Hospital. One stand will be

opposite WH Smiths and the other just inside the main hospital entrance.



This year the emphasis is on Acute Kidney Injury (AKI). We are hoping to offer free blood pressure testing on the stand near the renal unit if staff are available to run this.

Could you help us man one of our stands and help talk to people about your experiences as a kidney patient please? If you would like to help please contact Keith Vickers or one of the committee.

Simon Lloyd

TKPA Charity Stall

A tombola stall is held the first Friday and third Thursday of the month in the foyer opposite WH Smiths. I would like to thank everyone who has donated prizes and a reminder that they can be given to the receptionists on ward 31 (marked for the TKPA) during office hours.

Should you like to help on the stall please contact Joan Longstaff
dustywhippet@hotmail.com 0191 2576650

Christmas ward visit

I hope the patients who were in wards 31-32-38 in mid-December 2013 appreciated the small Christmas gift that was provided to everyone from funds provided by ward 31 and the TKPA.

As you may appreciate buying presents for 300 patients of both sexes and all ages was difficult so our thanks must go our committee member Joan Longstaff who purchased everything as well as storing the huge number of boxes and putting it all together.

Thanks also to Santa's helpers for the distribution

Memorial Donations

Mr and Mrs Quantrill presented Lynne Cullen, Renal Social Worker and TKPA committee member a donation in memory of their late son Lee.

Lee was a vice chairman of the TKPA and a haemo dialysis patient who will be remembered by many as being friendly and always ready to help those patients less able than him.



On behalf of the TKPA I would like to send them my heartfelt thanks for remembering all renal patients at what must be very difficult time

Donations

We often receive donations to our association many of which come with stories most patients can relate to, some simply arrive with no details

even a name but rest assured we are grateful for both and if you have chosen to be anonymous please accept our thanks.

All monies from donations are used to support our patient services, we subsidise outings and events as well as the costs for this newsletter. We give £4,000 a year to the Welfare Fund managed on our behalf by the renal social workers to be distributed to renal patients in need. In the last year we have also helped to send the young person's group on a trip to Alton Towers as well as donating £1,000 to their future needs.

The TKPA is self-funding based on donations, sponsored events, tombola's and raffles, and we have no overheads what so ever in the way of wages, all our committee members and fund raisers are volunteers so we try to squeeze every penny out of every pound.

As most of our raffles are supported well by patients and staff on Wards 31,32,38 I hope you can see what a great part you are also playing

Tyneside **Kidney** Patients Association

Annual Dinner Thursday 18th April 2013

Sea Hotel South Shields

Private Dining Room

Three course meal 7:30 for 8:00pm

Quiz, Raffle, Bingo

Tickets £15.00

Available from David Errington 01670 790300

Email daviderrington@tiscali.co.uk

Or Keith Vickers 07588 724530

Email k.vickers@blueyonder.co.uk

If you would like to attend the Dinner but have transport problems please let us know and we may be able to help.

SPONSORED DIET SUCCESS

The sponsored diet I started in August finished on 22nd February successfully. My target was to lose 10kg or 22lbs by doing a partial fast two days a week. My weight had gone down from 85kg to 73.4kg, a loss of 11.6 kg or 25½ lbs.

Two other things have also happened. My waist has gone down from 38" to 36" and I've had to take to wearing braces for all my working clothes, though I can now wear a suit I've had hanging in the cupboard for some years comfortably. The other thing is that my

blood pressure has also dropped and may lead to a reduction in medication.

I can't give the final amount of sponsorship money yet as the My Donate sponsorship continues for a month. I've added a postscript signature to my e-mails and that has brought in £120 sponsorship. If you'd like to donate you still can. If you want to do so online at My Donate put in Simon Lloyd in full to get to the page.

Simon Lloyd

Well done Simon, I think we should overlook the point that I was also meant to be on this sponsored diet but fell by the wayside

Keith Vickers, Editor

REGIONAL DAY - Saturday 7th September

We are planning to hold a day for the patients going to the four renal units in our region the first Saturday in September. This is a new event and the aim is to bring together patients from across the region for a day of information, sharing ideas and giving each other support. At the same time we also want to develop interest in the work of the National Kidney Federation (NKF).

We are in the process of planning the event so will give full details in the next Newsletter. We are planning to include in the day a talk on Spicing up Renal Diets combined with plates showing suitable recipes. We are also inviting one of the transplant co-ordinators to describe. Alternative methods of kidney transplants to keep us up to date.

Our regional advocate Linda Pickering is planning to join us for the day. We also have sponsorship to help with catering from

Countrywide Suppliers who make waterproof pouches for dialysis patients.

The day will cost £5/person and will run from 0930-1600 hours.

Simon Lloyd

EALING HALF MARATHON SPONSORSHIP

Nigel Lorrimer from Chippenham in Wiltshire has sent us a cheque for £350 which he raised by as sponsorship money for completing a half marathon. His company has offered to double it.

Nigel raised this money for us because we supported his aunt. He says "You took care of my Aunty, Alison Fitzgerald, before she passed away in 2010 and I hope this donation goes some way to helping you to continue to provide the same high quality of care which helped her."

We visit patients in Ward 31 and other renal wards to give support and it very encouraging to know this was appreciated so much. If you would like to help us with this please contact one of the committee.

Simon Lloyd

CHANGES IN GETTING OUR NEWSLETTER

In a recent visit to the transplant ward it was great to see three haemo patients who have had a transplant. We had been giving out our newsletter to them on the ward but needed to change our delivery or they would not get it. So if you are on haemo and get a transplant please let either our secretary Keith Vickers or membership secretary Alan Bond know and we will get one to you.

If you use e-mail and can get receive 2 MB files could we send you our newsletter by e-mail and save post and printing costs? If so, or if you have changed your e-mail address, please let us know.

Alan Bond, Membership Secretary

For you information you may be interested to know that our total TKPA membership now stands at 546 of which 128 choose to receive the Newsletter as an email.

The benefits of email over a postal addition are as follows

earlier delivery of the copy

hyperlinks to email addresses displayed in articles

occasional updates from us on events and news articles that we think may be of interest

savings, the cost of ink toners, mail stationary and postage works out at roughly £370 an issue (88p a copy)

So if you wish to swap to email copies please let me know

Alan

Email bond504@btinternet.com

**This Message is sent on behalf of Green Nephrology
- Centre for Sustainable Healthcare**

As patients some are aware of the resources that are used in our renal treatment. We appreciate that we have a large carbon footprint. It would be nice if we can solicit your cooperation together with the unit's Green Nephrology representative in obtaining permission from the

Estates Department to plant two symbolic trees, representing the link between environment and health.

The NHS Forest, run by the Centre for Sustainable Healthcare, is a pioneering project to engage people on the common ground between their personal wellbeing and wider environmental concerns. There are currently 99 active sites, including small woods and copses, across the country, with more in the pipeline.



The long-term goal of the project is to bring health, educational, social, and environmental benefits to members of each local community, including NHS patients and staff. Research has shown that improved access to green space can aid patient recovery time; reduce stress at work; provide areas for relaxation; provide an opportunity to exercise and help bring communities together. So far 17,154 trees have been planted, with the aim of planting 1 tree per NHS employee.

Stephanie Allen

Office Administrator

E-mail stephanie@kidney.org.uk

EMERGENCY WRIST BANDS



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 @£1-85. Full details and order forms are available from our website Also available from patient

representative Mr Iain Partis email iainpartis@hotmail.co.uk
35 Moor View, Camperdown, Newcastle upon Tyne, NE12 5XN.
www.tynesidekpa.org.uk

Great North Run 2013

As I have mentioned in earlier additions we have purchased five places in this year's Great North Run. We have received a couple of interests from patient's relatives but we are still open to others who may be interested.

The entry fee of £69 will be paid by the TKPA so there will be no charge to the entrants but we would like to think they would be able to raise a reasonable sum of sponsorship.

Entrants will receive from us.....

Entry into the run

A running vest with a TKPA logo

Printed and individual sponsorship forms

Your own page on the TKPA MYDONATE charity site for online giving

I hope that by early May 13 all runners and perhaps a reserve will be in place

Keith Vickers

Editor

GREETINGS CARDS



HANDMADE CARDS FOR EVERY OCCASSION

ALL CARDS PRICED INDIVIDUALLY

Come and see them on our stall, first Friday and Third Thursday
opposite WH Smiths

50% of Profits kindly donated by Lin Newstead to Tyneside **Kidney**
Patients Association

Charity No 518767



Lin Newstead is fund raiser for the TKPA who received a transplant in January 2012. Many of you may know of Lin because of her talent of making greetings cards which she sells on behalf of the association.

What you may not know is that Lin is a published author of poetry and an example of her work is set out below. Lin has offered the TKPA the opportunity to reprint her book with all profits being donated to us, this thought full gesture is currently under consideration.

Friends

Things you do and things you say,
Tell what you are, why you're here today,
Your there when your needed by others side.
A kind face to turn to turn to when others have lied,
When strong words have hurt me and I'm tattered and torn,
You'll never desert me-though I'm lost and forlorn,
That's when I find out who my friends really are,
When the one special face shines out like a star.

HOLIDAY DIALYSIS



Most people need a break from time to time, and kidney patients are no exception! Holidays are a great way to reinforce the fact that you can still enjoy the good things in life as a kidney patient - and they also provide a welcome break for carers.

Business travel is also a common requirement of many jobs nowadays, and again there is often no reason why kidney patients should not be able to make business trips from time to time - either in the UK, or abroad.

For most patients — whatever therapy they are on — travel and holidays will be actively encouraged by the medical team, who will

help with the arrangements. Of course it is essential that you check with your renal unit before planning or booking anything - even if you have had a transplant you will still need a letter from them confirming you are fit to travel in order to secure travel insurance, and advice on immunisation.

Travel for kidney patients on dialysis does require more planning, so last minute bookings are not a realistic option. However, the limitations in terms of where you can take a holiday and what sort of holiday you can take are probably far fewer than you would imagine. There is also plenty of help available to assist with the planning process and to help make sure you have a holiday to remember for all the right reasons.

The Freeman Hospital can help you to make arrangements for dialysis away from base whether you are PD or HD.

The Seahouses caravan will mean patients will continue as normal with treatment at the Freeman with transport provided if needed.

Patients in Keswick will be booked into a local unit.

Please contact Hazel Marchant who is the Data Manager on the Renal Unit

Email Hazel.Marchant@nuth.nhs.uk

Holiday Caravans

Where you aware that the Renal Unit also owns and runs 2 holiday caravans for the benefit of patients, their families and carers.

If you have any questions or require more information please contact Hazel Marchant



Keswick, Lake District



Seahouses, Northumberland

SUMMER TRIPS

Bowes Museum



Saturday 13th April 2013

Leaving Freeman Hospital 10.15am
and Gateshead Interchange
10.30am

Cost £7.00 per person this covers
entry, transport will be free.

Windermere Lake Cruise and Lakeland Motor Museum Saturday 15th June 2013



Leaving Freeman Hospital 8.00 am and Gateshead Interchange
8.15am

Return to Freeman 8.00pm

Cost £25 to include transport, cruise and museum entry

Flamingoland

Saturday 10th August 2013



Leaving Freeman 8.30am and Gateshead Interchange 8.15am

Return to Freeman 8.00pm

Cost £30 per person, £20 concession

Transport contribution £5

TKPA Easy Walking Group

March 16th, Heaton and Armstrong Park.

Car Park, free, Jesmond Vale Lane, from the Corner House on the right after 2 sets of lights, from Byker, first turning after roundabout, public transport - stagecoach services 32, 32A and 18.

Terrain, paths. We will head along the valley towards Pets Corner, toilets and Café, we will continue northwards to Paddy Freeman Park, taking in the watermill, returning via Pets Corner.

Distance - between 5 to 6 miles.

May 11th, Bolam Lake/Shaftoe Crags.

Car Park, (charges apply) there are 3 car parks round the Lake, the one we will meet in is, from Belsay head towards Bolam Lake, at the second junction, the first is about 400 metres from the turning at Belsay, go right, a short distance the car park is on the left.

Terrain, tracks and grass. From the car park we will go straight to Shaftoe Crags, (a short section of road so we will have to take care), we will then retrace our steps to the corner of Bolam Lake where we will head to the visitor centre, toilets and café, then return to the cars.

Distance - between 6 to 7 miles.

July 13th, Simonside.

We will meet in the Forestry Commission car park (free). Good walking shoes/boots are recommended

Terrain, Forest Roads and paths. We will head along Forest Roads passing "Little Church" a crack in a rock where it is alleged many years ago a number of people gathered. After this we will continue

along the Forest Road, shortly we will follow a track/path which is stony, this will slow us down. The path will take us to the bottom of Simonside Hill, we will return via Forest Roads to the cars.

The alternative option is to follow Forest Roads to the foot of Simonside, picnic, return via the same route.

Distance - about 7 miles

Further information Robert Brown email robarobr@btinternet.com

SUMMER FAIRS

Our fund raisers led by Joan Longstaff will again be on the road this summer, attending a number of regional events. We will be running tombola games, raffles and children's entertainment; this will give us the opportunity of raising funds for our charity.

If there is anything you would like to donate as raffle prizes or you would enjoy spending a few hours in the sunshine and help on the stall please contact

Joan Longstaff dustywhippet@hotmail.com 0191 2576650

Saturday 18th May 2013 Walker Festival, Walker

Saturday 22nd June 2013 Westoe Village Fair, South Shields

Saturday 6th July 2013 South Shields Festival, Bents Pk. South Shields

We are onsite from around 9.30am until about 4.00pm

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) 213 7393 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

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:

Simon Lloyd Chairman (01661) 871399

E-mail lloydcarrhouse@gmail.com

David Errington Vice-chairman (01670) 790300

E-mail daviderrington@tiscali.co.uk

Keith Vickers Secretary/ Editor (0191) 4252379

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

87 Harton House Road, South Shields

Tyne and Wear. NE34 6EB
Ian Gill Treasurer
E-mail: joyce-and-ian@supanet.com

Committee members:

Iain Partis E-mail iaintpartis@hotmail.co.uk
Laura Tough email laura.tough@nuth.nhs.uk
Robert Brown email robarobr@btinternet.com
Joan Longstaff dustywhippet@hotmail.com 0191 2576650

Lynne Cullen lynne.cullen@newcastle.gov.uk

Corinne Nichol Corinne.nichol@newcastle.gov.uk

Membership secretary **Alan Bond** (0191) 4281 702
email 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**

NHS Diabetes and Kidney Care response to the Francis Inquiry

Today's publication of the results of the Francis Inquiry has once again highlighted the appalling failings in patient care and safety at Mid Staffordshire NHS Foundation Trust. Although the report will be a distressing reminder for the families of those affected, it serves to focus the efforts of the NHS and wider healthcare communities in continually driving up the quality of care and services provided to all patients.

Since our formation in 2008, NHS Diabetes and Kidney Care has worked tirelessly to ensure patients are placed at the heart of healthcare services, with access to safe, effective care that respects their choices. Some of our achievements include :

- Training almost 100,000 NHS staff in how to administer insulin safely, contributing to a reduction in safety incidents in hospitals of almost a third
- Making it possible for more people to choose to have kidney dialysis at home rather than in hospital

- Supporting the roll-out of NHS Health Checks to thousands more people, helping to detect and prevent cases of diabetes, stroke, heart disease and kidney disease - and keeping them out of hospital
- Setting up and running national audits to collect data and information on how well services in hospitals are being delivered
- Highlighting the issue of correct hydration in hospital through a wide reaching awareness campaign leading to changes in practice
- Improving the commissioning of diabetes services and supporting GPs to ensure they deliver all the care checks that people with diabetes need to avoid complications.

But there is still much more to do, as today's report shows. From 1 April 2013, NHS Diabetes and Kidney Care will become part of a New Improvement Body, which will work to develop and implement improvement programmes to deliver the priorities set out in the NHS Outcomes Framework. This provides an important opportunity for the NHS to deliver further large scale improvements in care and quality in order to ensure that nothing like Mid Staffordshire can happen again.

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

Parking in Level 2 of the Multi Storey only

TYNESIDE *KIDNEY* PATIENTS' ASSOCIATION

Tuesday 9th April and 14th May 2013

Parking while at

Freeman Hospital

MEETING IN ROOM 138

