

NEWSLETTER

August 2013



FUN & CRAFT DAY SUNDAY 18TH AUGUST
2013

10AM - 4.30PM

SEE INSIDE FOR FUTHER DETAILS



Tyneside Kidney Patients Association

CALENDAR OF EVENTS 2013

- * Saturday 10th August 2013 Day trip to Flamingoland
- * Tuesday 13th August 2013 Committee meeting
- * Tuesday 10th September 2013 Annual General Meeting
- * Friday 13th September 2013 Transplant 50th anniversary
- * Saturday 14th September 2013 Regional Day Freeman Hospital
- * Sunday 15th September 2013 Great North Run
- * Tuesday 8th October 2013 Committee Meeting
- * Tuesday 12th November 2013 General Meeting
- * Tuesday 3rd December 2013 Committee Meeting (please note this meeting will be held on the **first** Tuesday of the month)

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

There is a parking pass for the meetings held in August and September 2013

Please display on your dashboard for possible inspection

If you would like to attend our meetings but have no transport please contact any committee member and we may be able to help.

COMMITTEE ELECTIONS 2013-14

We elect the whole committee every year. There are 4 honorary posts: chairman, vice chairman, secretary and treasurer. In addition there are 4 posts for committee members. Please note the following:

- A person can serve in a committee post for three years.
- The list of candidates will be sent out with the August newsletter as we have to

give 4 weeks' notice before the A.G.M.

The closing date for nominations was the 31st July 2013 as detailed in the May 2013 newsletter. The following information of candidates wishing to take up committee posts are listed below along with brief information on the candidates

Keith Vickers.
Secretary
87 Harton House Road
South Shields
NE34 6EB
1st August 2013

Position	Nomination	Candidate's signature	Proposer	Seconder
Chairman	Vanessa Hardy (1 st year)		Joan Longstaff	Keith Vickers
Vice-chairman	David Errington (2 nd year)		Vanessa Hardy	Keith Vickers
Secretary	Keith Vickers (2 nd year)		Simon Lloyd	David Errington
Treasurer	Ian Gill (2 nd year)		Simon Lloyd	David Errington
Committee member	Alan Bond (1 st year)		Keith Vickers	Simon Lloyd
Committee member	Doreen Adamson (1 st year)		Keith Vickers	Simon Lloyd
Committee member	Steven Bell (1 st year)		Vanessa Hardy	Keith Vickers
Committee member	Joan Longstaff (2 nd year)		Keith Vickers	Simon Lloyd

Who we are

Vanessa Hardy

Vanessa is a transplant patient who has been involved with our fundraising for the last year and has committed herself to continuing our last Chairman's work as well as enhancing the image and profile TKPA through the coming years.

Vanessa lives in Consett, Co. Durham and is a part time school teacher.

David Errington

David is a transplant patient and was for many years the TKPA treasurer, a role he filled with distinction. David has been involved in organising our day trips and annual dinner, his experience with us will be invaluable in the coming year.

David is a Director of a local company and lives in Morpeth

Keith Vickers

Keith is a transplant patient who dialysed on ward 22 and then 31. This will be his second year as secretary and will support and administrate the committee business. Keith also acts as editor and publisher of the patient's newsletter.

Keith is a retired local government officer and lives in South Shields.

Ian Gill

Ian is a transplant patient and this will be his second year as the treasurer, he works full time in accountancy and lives with his wife Joyce also a renal patient in Whitley Bay

Alan Bond

Alan has been an active member of our fund raising team assisting on our stalls at the Freeman, summer fairs and the ward visits delivering newsletters and

the Santa visits. Alan is also our membership secretary and assists in the distribution of our newsletter via the post and online.

Alan has a family member who is a transplantee and he lives in Hebburn.

Doreen Adamson

Doreen is a member of our fund raising team and is well known to staff and patients alike within the renal unit for her huge efforts in our quarterly raffle as well as the stalls and fairs. She receives tremendous help in her efforts from her husband Paul, a transplant patient and well known figure on the unit. Doreen lives in Standingstones Northumberland.

Steven Bell

Steven is a transplant patient who is new to our charity, he brings to the committee a wealth of experience as a former HD patient in the Freeman. He is enthusiastic and will be assisting us with his time to support our work as well bringing a fresh approach to future fund raising.

Joan Lonstaff

Joan is a long term active member of the TKPA, she has been our main fund raiser for a number of years organising not only our fund raising in the Freeman but the summer fairs and is the team leader for the Christmas Gifts that are delivered to 300 patients. In her time with the TKPA Joan has been the newsletter editor and publisher and is the one we all turn to for advice and guidance.

Joan is a transplant patient and lives in North Shields.



I noticed the following advert in my local free paper - I have normally just parked in blue badge parking bay and walked into the hospital not realising I needed to register my details.

Joan Longstaff

NORTHUMBRIA NHS FOUNDATION TRUST

CAR PARKING AT HEXHAM, NORTH TYNESIDE & WANSBECK HOSPITALS HAVE CHANGED.

Barrier & pay and display systems have been replaced with number plate recognition.

The process:

Park vehicle in a public (not staff) parking bay.

Pay at a payment machine entering the full vehicle registration number.

Take the ticket and go into hospital - there is no need to display the ticket in the vehicle.

On leaving, check the amount paid covers the time parked and, if not, pay for additional time.

Costs remain unchanged but a free 20 minute period has been introduced. Check tariffs displayed in car parks.

**Blue badge holders continue to receive free parking but must register their details.
To do this:**

Tel: 0844 247 2984 or

Visit: www.northumbria.nhs.uk/bluebadge or

Provide details when arriving at Hospital.

Contact us:

Email: carparking@northumbria.nhs.uk Tel: 0191 293 4353

TYNESIDE KIDNEY PATIENTS A PERSONAL ACCOUNT

I've been very involved with the life of the Tyneside KPA since 1998. I've decided not to stand for election to a committee post this year for two reasons. I've been standing back quite a bit while others have got on with running our activities very successfully. I want to pass on my experience while I am still fit and able to do so. Also our editor Keith Vickers has asked me to write a live account in contrast to the tributes to recently deceased members.



I never had any idea that getting upset about Castle Morpeth Borough Council charging £10 +VAT a week for collecting a bag of surgical waste, while I was on peritoneal dialysis at home, would lead to so much. Faced with a charge of over £600 a year for being ill made me very angry. I was fortunate in having a good friend who was also a councillor. He followed this up and it was also picked up by the Journal as a "human

interest story." The councillors cancelled the charge and I learned an important lesson about taking action.

I wrote an article for the TKPA magazine and started to go to committee meetings. The late Katherine Wright was chairman and she asked me to take over the post. I became a committee member for a year, to find out what was involved, and then chairman the following year. I served a full 3 years and have since served a further 4 years as chairman, 3 as secretary and just less than one as vice chairman. I did have to stand aside in 2003 during a difficult time but got involved again in rebuilding the work of the association in 2006.

In 2000 I also joined the Northumberland Community Health Council (CHC) which was a watchdog over NHS services. I learned a lot about the very complex organisation of the NHS. I also carried out a survey on mistakes in repeat prescriptions with the help of many members who completed the survey. This showed a much higher rate of mistakes than anyone suspected and did lead to improvements in the work of GP receptionists who make up repeat prescriptions.

The TKPA was nearly closed down in 2006 but the resignation of the secretary led to rebuilding work being done by Joan Longstaff, the late Margaret Nelson and Isobel Stubbington. I got involved and, helping the retired accountant Len Cline, set about creating a full set of financial records and getting them audited. Sadly what we found was so bad we had to involve the

police. This was a tough time but we got through it successfully with a lot of support from members.

Rebuilding the life of our association involved other positive changes. John Tapson was head of the renal unit and he asked us to joint meetings that are held quarterly. These are valuable in keeping up with changes that are happening on the renal unit. They give us a chance to raise our concerns and compliments. It has also led to us developing a series of informative meetings to complement the work of staff and keep us updated on developments in renal care.

We had a surplus of crackers after a Christmas dinner and Joan Longstaff suggested we took them round patients, we decided to donate a sum of money to add a gift, sweets and a greetings card to almost 300 hospital dialysis and transplant

This has led to "Santey," Claus patients On one front of one lady trousers slipped a bit. Another man whiskers and



us acting as Santa, or each year for renal visit I was standing in when the over large red down and her eyes popped woke up to see my Santa's asked "Am I dreaming?" He

wasn't. In these visits I've met so many different life stories. A patient who has a racing car he's raced in Malta. A wheelchair patient who had been on a cruise on a specially adapted tall ship. Another young father who proudly showed me a picture of his baby daughter born the day before. What varied lives I keep coming across.

Two particular things stand out among the many that happened. We were able to take action to improve the very poor ambulance service during 2010 and at a Rapid Process Improvement Workshop (RPIW) in February 2011. It led to big improvements and complaints that had been running at 4-5/week virtually disappeared. Sadly they have since gone downhill a bit but they are nowhere near as bad as they were before the RPIW.

The second thing was developing an idea I came across in Australia in 2009. Getting medical alert wristbands made and sold across the country. Taken on by Mike Hayhoe in particular we have sold about 5,000 and sales are steadily continuing.

I've only described some of the things I have been involved in. How have these and many more been possible? I want to thank all the patients and staff who have been so helpful, encouraging and supportive. Sadly I've been to the funerals of quite a few active members, but that's the nature of our organisation. There is one very special person who has been absolutely essential, my wife and closest friend Rachael.

This account would not be complete however without mentioning that at the very core of my being is a deep personal Christian faith. A faith that goes back 55 years and is marked by sheer amazement at the unconditional love summarised by the word 'grace.' Grace meaning a gift given that cannot be earned. I've made so many mistakes that one of my favourite hymns puts my feelings in the well-known words:

Amazing grace, how sweet the sound,
That saved a wretch like me.
I once was lost but now I'm found;
Was blind but now I see.
(The 19th century ex-slaver John Newton)

Simon Lloyd Chairman

A message from the Committee

Simon Lloyd has been a stalwart of the TKPA since 1998, he has led and advised us through many years, in sometimes difficult and testing times. Throughout Simon has proved to be a level head, a conciliator and motivator with his overriding concern being to the TKPA and the patients we serve.

Simon as you may know is transplant patient and has used those experiences to represent you not just a hospital level but regional and national through the National Kidney Federation. This is a role he excels at despite occasional knock

backs he is resilient and sometimes "bloody minded" in pursuit of voicing patient issues and pushing forward their interests. Because of this Simon is known and respected throughout the region and will not only be missed by us but by other patient organisations.

Simon has placed his trust in the TKPA to continue on without him and we will endeavour to ensure that trust is not misplaced.

Thank you Simon
TKPA committee.



*The largest kidney patient charity
in the UK. Run by kidney patients,
for kidney patients*

The nkf today launches a brand new website to serve the 60,000 patients with End Stage Renal failure, and the 2,000,000 UK residents with early stage chronic kidney Disease. The website is also intended as a central hub for all renal specialists. It can be found at www.kidney.org.uk



TYNESIDE KIDNEY PATIENTS ASSOCIATION

Charity Number: 518767



1ST**FUN*&*CRAFTS*DAY

BOUNCE CASTLE
DESIGN YOUR
OWN CUP CAKE

SUNDAY 18TH AUGUST 2013

START: 10AM TO 4.30PM

FREE: PRIZE DRAW

THORNTONS CHOCS & BTL WINE

(1 TICKET PER FAMILY WHO VISITS)

GET TICKET ON THE DAY

CHILDRENS GAMES
PRICES FROM 25P - £1

T.K.P.A. GRAND SUMMER PRIZE DRAW

FREE: BONNIEST BEAR COMPETITION

(BRING YOUR TEDDY, 1ST PRIZE JAR OF SWEETS)

SUNDAY LUNCHES AVAILABLE FROM: £9.95

BOOKINGS TEL: 01207 58164

CRAFT STALLS:

CARDS, STATIONARY, GLASS ITEMS, SCARVES

WOODEN ORNAMENTS/BOWLS, KNITTED ITEMS

JEWELLERY, SWEETS, SOAPS, BODYSHOP ITEMS

X-STITCH, JAMIE OLIVER COOKWEAR PLUS MUCH MORE!

MINI DUCK RACE
TOMBOLA

FACE PAINTING
JAZZY NAILS
BRACELET MAKING

1ST**FUN*&*CRAFTS*DAY

HELPING PATIENTS FROM ALL OVER THE NORTH EAST AT THE FREEMAN HOSPITAL WITH CHRONIC KIDNEY DISEASE



AT..THE OLD MILL, KNITSLEY MILL HOUSE, CONSETT DH8 9EL



***FUN & CRAFT DAY SUNDAY 18TH AUGUST 2013 START: 10AM
- 4.30PM***

In denial about your renal condition? Feeling in a rut? Frustrated about not having the energy to do anything? Want to meet new people and or have some quality time with your partner / family? Then read on, you may be surprised what we are doing this August!

Want to do something different instead of just sitting around recovering from your Renal Treatment? Well why don't you join us for some fun on Sunday the 18th August! I know, you just don't feel like doing anything..... especially travelling as far as Consett, County Durham, especially when for some of you it's the only day you can switch off from your renal routines, BUT this is a chance to ***ENJOY YOURSELVES*** whatever state of mind you are in.

The Old Mill at Knitsley (commonly known as Knitsley Mill by the locals) does very nice lunches, so you can sit and relax and enjoy a meal, small portions available. No not to your liking? :(well you can always soak up the sun outside near the stream and have a small drink and mooch around our various craft stalls, including a masseuse for those aching bones, or for the more energetic among you or your family and children there is always the good old fashion kids games, ***ADULT*** bouncy castle (which I will be on later in the day) and for those with a little bit of competitiveness a mini duck race. ***PLEASE*** try and come and support this event if you can. If this sort of thing is not to your liking then let us know what is and we can see what we can organise for you.

It is a very exciting time for the TKPA this summer as we are holding our first ever Fun & Craft day at The Old Mill, Knitsley, and Consett. The purpose of the event is to raise funds, to acknowledge our patients from outside the Tyneside area and to raise awareness in the North East that the TKPA does not only help and work with patients in the Tyne and Wear area, but also throughout the North East who have to attend the Freeman for treatment. It is also a different way to make funds, highlight and encourage organ donation and of course have some fun in the process of doing this.

****CAN I STRESS THAT WE DON'T JUST TALK AND DISCUSS RENAL ISSUES AT OUR EVENTS,** We understand that when you are away from the hospital some of you don't want to think about your renal problems, that's ok, we sometimes don't either, we are here to have some fun and it is up to you to approach us if you want to talk about anything. (The one thing that we are is 'gobby' and 'big eared' enough, to talk and or listen if you want us to). The day is also about giving patients an opportunity to enjoy themselves with people who know the limitations and issues of having chronic/acute kidney disease, but have the common sense to know that fun is important for a positive attitude to how we feel as a person about ourselves.

I look forward to seeing you there.

Vanessa Hardy.

NEWS:

New collaboration with Matalan, Consett

Our team of fundraisers have been going into Matalan, Consett with the Tombola and information stand for the last 2 months, Not only has this brought new members to the Association, it has also been a platform for the TKPA to help and advise patients with Renal problems in the Co Durham area, its helped to promote Organ donation and to advertise the Fun & Craft day.

The added bonus of this work is that Matalan at Consett are very enthusiastic in getting involved with our charity and working together to promote the TKPA and what it stands for. They are going to advertise the event on Sunday the 18th August @ Knitsley on their Facebook page, we have got a couple of their team who have volunteered to help for the day, also other members of their team are keen to get involved with any other events / sponsored or fun ones that we may run in future. We would like to thank the Managers and their team at Matalan for all their help and support over the last couple of months and we are looking forward to a developing a long happy partnership with the company.

Vanessa Hardy

REGIONAL DAY SATURDAY 14TH SEPTEMBER

We are holding a new event to support kidney patients and their carers across the North of England. This is a Regional Day with a programme for patients going to the 4 renal units to give support with a programme of informative sessions and a choice of a workshop on welfare benefits or understanding blood test results. Talks will include research developments leading to better care, renal failure and what's involved, transplantation and dialysis.

Full details will be sent out to all renal patients. This will give you the chance to meet people from other units, discuss care and give each other support. We have revived sponsorship to help with the food costs. The event will cost £5/person (this includes refreshment's and lunch) payable when places are booked. Our aim is to make this a really good event so please come and help us do that.

For further information please contact

Simon Lloyd 01661 871399 lloydcarrhouse@gmail.com

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 @£2.00. Full details and order forms are available from our website



Great North Run 2013

We now have 5 people running in this year's event who are raising funds for the TKPA.

The run will held on Sunday 15th September 2013 and we hope that with the help of our members we can make it our premier fund raising event of the year.

To make donating to these runners easy we have set up a page on the mydonate web site, this site is run by British Telecom (BT) and has the highest standards of financial security so rest assured when you're giving information.

So should you wish to sponsor a runner through the mydonate site their names are >>>>>

Corinne Nichol

Josh Lovell

Kaziah Atkinson

Omar Boufhal

Djilali Nemri

<https://mydonate.bt.com/charities/tynesidekpa>

Good luck to all our runners and thank you for your efforts in support of the TKPA

Donations to the TKPA

Should you wish to donate items for our tombola or raffle prizes you can leave them with the ward clerks on Ward 31. Lynn and Lydia will be glad to take them from you and hold them until we are able to collect.

If you have any items you wish to donate and are not visiting the Freeman please give one of the following numbers a ring and it may be possible to collect from your home.

Vanessa Hardy 0191 3733238

Doreen Adamson 07890 430881

Transplantees skin care

After I gave this advice last year a number of people blamed me for the wettest summer in a century but even so here it is again.

I am sure you know this well but for those who are new to the club the effects of sun damage to your skin are increased due to the anti-rejection medication you take, this lowers your immune systems reaction to the damaging effects of ultra-violet (uv) radiation. If you have any concerns about your skin you should speak to your GP or the medical team at your next transplant clinic.



The best way to minimise the effects of UV is to use a high factor (50) sunscreen and take care when outdoors as even overcast weather does not lower the risk, factor 50 sunscreen is available free from your GP on prescription.

A number of patients have mentioned to me their GPs will not prescribe sun screen so if you're in this position please mention it at your next transplant clinic as it can be provided from the pharmacy

Keith Vickers

Secretary

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,

Current committee

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:

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

Telephone Helpline - (01661) 871 399

TKPA Website: www.tynesidekpa.org.uk

National Kidney Federation: www.kidney.org.uk

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

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

***Tyneside Kidney Patients Association
Meeting being held in Education Meeting Room 138***

Tuesday 13th August 2013 6:30pm-9:30pm

Tuesday 10th September 2013 6:30pm-9:30pm

