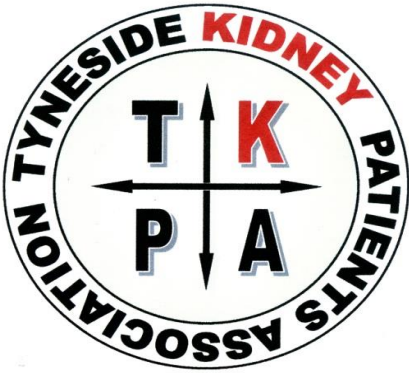


NEWSLETTER

August 2011

Registered Charity 518767



Harrogate Autumn Flower Show 17th Sept.



CALENDAR OF EVENTS

Friday 5th August 0830-1530 **Stand** - opposite W.H Smiths in the Renal Services Centre atrium

Tuesday 9th August 7.00 p.m. Committee Meeting - members only Room 138 Education Centre

Saturday 13th August - Felling Show - help needed please

Monday 15th August Patients versus Doctors cricket match.

Thursday 18th August 0830-1530 **Stand** - opposite W.H Smiths in the Renal Services Centre atrium

Tuesday 13th September 7.00 p.m. **Annual General Meeting - How Medicines Work** - renal pharmacist Rachel Fraser

Saturday 17th September **Harrogate Autumn Flower Show**

DOCTORS V PATIENTS CRICKET MATCH

Blue Flame, Whitley Road, Longbenton, Monday 15th August
6.00 p.m.

This annual match for the Ross Taylor Shield is a hotly contested challenge. We need to form a team to take on the doctors. So please get involved and phone **Graeme Appleby** on 07882 907 655.

We also need help with scoring and support.



The game will be followed by a buffet and raffle. So please come along and make this a really good event.

HARROGATE AUTUMN FLOWER SHOW - Saturday 17th September

We are organising a day trip to this show, which is a really good event. This includes a whole range of things including:

- Magnificent prize winning vegetables
- Commercial stands of all sorts of bulbs, flowers, cacti, vegetables etc.
- Flower arrangements of all sorts of sizes
- A panel for gardeners' questions
- An enormous range of commercial stands
- Brass band you can relax and listen to.

You can come and enjoy all of these and much more. Tickets cost £15 for travel by minibus, with wheelchair lift, and entry to the show. Entry forms are on the back page. This is a popular event and is open to anyone who would like to come but there are limited places. Bookings will be made in the order they are received.

SHOW STALLS

Felling Show - Saturday 13th August

We are looking for volunteers to help with these stalls for all or part of each day. If you would like to help please contact Joan Longstaff or one of the committee

STAND OPPOSITE W.H. SMITHS

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

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 a 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.



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

NEW EDITOR

Keith Vickers is taking over the editing of the newsletter from Simon Lloyd. Keith has been doing the printing and distribution and has taken over this job to relieve Simon as the committee would like to reduce his workload, and also thank him for his editorship in the last three years.

CONTRIBUTIONS PLEASE

We publish our newsletters every two 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 Sept. 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

TPA Website: www.tynesidekpa.org.uk

National Kidney Federation: www.kidney.org.uk

COMMITTEE MEMBERS' CONTACT DETAILS

Honorary Officers:

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Keith Vickers Editor (0191) 425 2379

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Brian Jones (0191) 264 5312

Vice-chairman: Mike Hayhoe (2 years)

Secretary: Simon Lloyd (2 years)

Treasurer: David Errington (2 years)

Committee members:

David Lee (3 years)

Alan Bond (1 year)

Keith Vickers (1 year)

Brian Jones (1 year)

My personal view as a MRSA patient

I am at peace with the world, sitting in my armchair reading the newspaper, 'Graham from the Renal Unit at the Freeman here'. My heart misses a beat because I know what's coming next, 'your MRSA has reoccurred, so you will have to be dialysed in isolation'. 'Will I be on Ward 4A?' I ask, 'no' comes the reply 'you will be in a cubicle on ward 31' which is the dialysis Ward. 'Come in at midday tomorrow'.

Apart from the fact that I have to rearrange several appointments as I usually come in on the twilight shift which means I come in about 5pm and go home round about midnight, this isn't too bad as I know the cubicles have individual TV and radio and one also has a nurse to one's self. Wrong! There is now one nurse to two cubicles. Anyway, I start dialysis and am given my eradication kit to use at home for the next seven days. This consists of a tube of a throat spray; nose ointment and a special shampoo This shampoo will find any cuts or grazes you may have, whether you know about them or not.

At the end of my dialysis I am told that I will have to go to Ward 4A for future dialysis sessions until the MRSA has cleared up I have already asked and it has been agreed that I can come in on the early shift as Ward 4A does not have a twilight shift. The reasoning behind this is that I bring my own car and as I am disabled I like to park in one of the disabled bays close to the hospital. I try to get in just after 6.30am otherwise it is difficult to find an appropriate space.

I then trundle with my three wheeled walking aid to the reception desk in the main entrance where I ask for a porter and wheelchair to take me up to the ward as I am worn out by this time Just after 7 o'clock, two nurses arrive and after passing the time of day they start preparing the machines at the four locations. There are three chairs and one bed. Nobody likes the bed on my shift but as I am the first in, I get a choice of where I want to sit.

The room itself is compact with a large window overlooking brick walls and the construction site for the new transplant unit. There is a television which must have been there since the old Ward 4 opened many years ago. It is situated on a shelf above the door so if the door is open you can't see it and if the machines are working you can't hear it. Unfortunately there are no individual TVs or radios. I ask if I can use one of the DVD players provided by the Tyneside Kidney Patient Association but am told they are not in use because of the risk of infection Although there is a notice on the door stating 'in isolation' or similar wording, this doesn't stop people coming and going, the good thing is that this allows the newspaper man in. The nurses

don't have to wear protective clothing. They only wear their normal rubber gloves and plastic aprons.

Another potential problem for me and I suppose some other patients is that coming from the twilight shift the nurses do not know much about me or my fistula as the majority of nurses on 4A come from the day shift. So this means that they can find it difficult to gain access to my fistula.

Anyway, after what seems to be a very long five hours on dialysis, the porter takes me back to my car. And I am able to mix with my family, friends and the general public despite being 'in isolation' in the hospital. At the end of a week using my eradication kit I am informed that the MRSA has cleared up. This is not the end however as I have to be isolated for another two weeks to make absolutely sure that the MRSA has gone.

At the of that period I am informed that I can return to my original bay in Ward 31 and at my usual time and be with the staff and patients whom I know - that is until the next time!

Please note that any views or comments I make in this article are solely mine and no one else's.

Mike Hayhoe

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.

Sponsored Walk, Saturday 25th June 2011

Who would have guessed a warm sunny day greeted the small but enthusiastic group of members and friends that set off from the village of Stannington for the four mile yomp to Simon Lloyd's cottage.

We started with eight walkers aged between 2 $\frac{1}{2}$ years old through to pensioners; the walk was across farm land, woods and a country lane.

Simon had the foresight to meet up with us at various points so any dropouts could retire to his car, surprisingly nobody did.

This was a surprise to me as I thought I would be the first to

keep Simon company in the car.

The walk was made doubly difficult for me as I needed to push/pull/drag my Granddaughters buggy as we were unsure at 2 $\frac{1}{2}$



years old she would be able to walk the whole distance, apart from some carries through the long grass she walked and ran the whole distance.

At the conclusion of the walk we had a well-deserved picnic, and a very welcome cup of tea.

On behalf of the Committee I would like to thank the participants who took part, Simon for the organising and everybody who sponsored us, it looks like we raised something in the order of £353.00

Kath Vickers

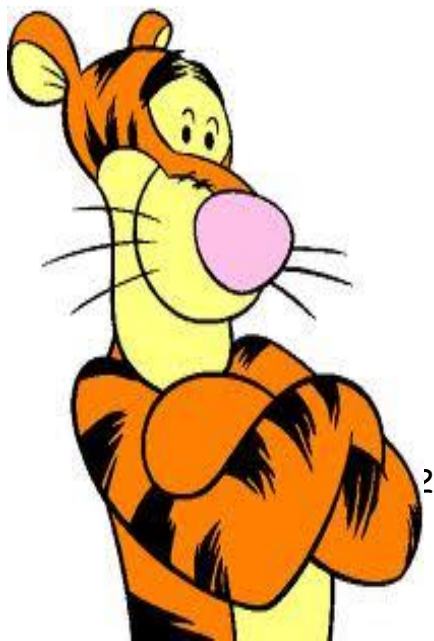
Information from Prof. Julia Newton

Fatigue is well recognised as a problem experienced by those with chronic renal disease, and more recently has been described in people with early stages of renal disease. Prof Neil Sheerin at Freeman Hospital together with Prof Julia Newton

and the Newcastle Fatigue Interest Group have shown that fatigue is a common problem in pre-dialysis patients, and like other chronic diseases the severity of the fatigue experienced by patients is unrelated to the renal disease severity. The team have now put together an application to the National Institute for Health Research to explore the experiences of people with a number of chronic diseases who experience fatigue. One of the 6 diseases included in the application is early renal disease and the programme, if successful, will help develop clinical management strategies to treat fatigue that focus on the things that patients want and the clinicians who manage them agree will be practical and suitable for implementation in their clinical practise.

The team have recently heard that the application has successfully passed through the outline stage and they have been invited to submit a full application by October 24th. This is an exciting project that will help improve the lives of people with chronic disease who experience fatigue, change the perspective of this poorly understood symptom and encourage

doctors to consider not just the kidney blood tests but also the whole experience of having renal disease.



RAFFLE WINNERS

TIGGER was born in Rochester and was won by

?

Paul Murray and made £50

TEDDY was called Cindy and was won by Sarah Johnstone and made £56

PINOCCHIO was born 1st January and was won by Tracy Whale Wright and made £40

Thank you to Doreen Adamson who put in all the hard work and made a total of £146. Well done!

Westoe Village Fete thanks our helpers - Elsie Skeldon (a first time helper), Keith & Kath Vickers, Mary Bullock, and Alan Bond - must not forget Molly - Keith's granddaughter who helped to give balloons away.



We made £154.50 on the tombola which considering the weather we did very well (we could have sold lots of umbrellas I still had another 4 at home!)

Joan Longstaff

My wife saw me standing naked in front of the bathroom mirror, I said to her "look at me I'm fat, ugly and unattractive say something complimentary to make me feel better" her reply " well at least your eyesight is still pretty damn good" !!

COMMITTEE ELECTIONS

The following nominations for committee posts have been received:

Position	Nomination	Proposer	Second
Chairman	Kath Brown	David Lee	Keith Vickers
Vice chairman	Mike Hayhoe	Kath Brown	David Errington
Secretary	Simon Lloyd	Mike Hayhoe	Kath Brown
Treasurer	David Errington	David Lee	Mike Hayhoe
Committee	Keith Vickers	Mike Hayhoe	Kath Brown
Committee	Brian Jones	Mike Hayhoe	Kath Brown
Committee	Alan Bond	Mike Hayhoe	Kath Brown
Committee	Iain Purdis	Brian Jones	Mike Hayhoe

These are the only nominations received by the closing date, 31st July, so there will be no elections. These nominations have

to be proposed and voted on at the Annual General Meeting

ANNUAL GENERAL MEETING Tuesday 13th September

The 2011 Annual General Meeting will be held at 7.00 p.m. on Tuesday September 13th in Room 137 in the Freeman Education Centre.

The Agenda will include:

1. Minutes of the 2010 AGM held on 14th September.
2. Matters rising from the minutes.
3. Trustee's report.
4. Treasurer's report.
5. Committee election
6. Election of National Kidney Federation representative
7. Any Other Business

The formal meeting will be followed by a talk by the renal pharmacist **Rachel Fraser** on **How Medicines Work**.

All are welcome to this meeting.



HOW MEDICINES WORK

**Tuesday 13th September, Education Centre
7.00 p.m.**

Rachael Fraser, who is the renal pharmacist at the Freeman will give us a talk to help us understand how the various medicines we take

work. So if you would like to find out how EPO, phosphate binders, immunosuppressants or other pills you take work this is the chance to come and find out. We know from her previous talk how good Rachel is at answering our questions. All are welcome to come to this.

This talk will be followed by our Annual General Meeting.

END OF LIFE CARE

Sister Therese Wood gave us a very good talk illustrated from her experience. Her work is now called Active Supportive Care instead of Conservative Care.

Therese explained how she looks after kidney patients who either don't want renal replacement therapy such as dialysis or a transplant or are unable to cope with such treatments. Currently this involves caring for 95 patients in a large area from Berwick on Tweed to Durham.

Therese works with patients in their own home. This involves getting blood pressure and haemoglobin levels as good as possible. Often this enables patients to lead a good life even though their kidney function is 5% or less.

Her work involves end of life care and is guided by the principle that "No patient should die in pain." This includes applying the Liverpool Care Pathways which make provision for all the needs of patients in the last 48 hours of life.

REPORT ON JOINT MEETING WITH RENAL STAFF.

- Improvements have been made in:
 - Home haemodialysis. Numbers have risen from 6 to 17 and there should be a further 9 by next April
 - Live transplants have increased yearly, 43 in '08, 44 in '09, 46 in '10 and 33 to date in '11; it's expected to achieve 60 this year.
 - Clinics on the haemodialysis wards have successfully reduced the levels of DNAs from 50% to 5%
- Big problems over getting the Trusts computer database to work with Patient view should be solved by the beginning of October. When that is up and running patients will be able to see their test results online.
- Funding is available to employ two nurses for 2 days a week to do Individual Care Planning with PD patients

DIALYSIS TRANSPORT - FINAL MEETING

On Friday 24th June we had our final meeting of some of those who have been involved in working to improve the transport service for haemo patients. The results reported

have happened since February and it's very easy to ignore just how big they are because they have happened slowly. There has been an amazing outcome we simply did not believe was possible in our January meeting.

Now we have a situation that has changed from:

- 5 or 6 complaints a week to virtually none.
- Complaints about poor transport to cheerful comments among patients waiting for dialysis.
- One of the worst services in the country to one that has become as good as any, with results that are up with the best as reported in the outcome of last year's national survey.

Many thanks to all of the NEAS staff who have been prepared to admit the service was very poor and make big changes. Also thanks to all those who carried out the preliminary survey in January and the 3 follow up ones. Finally to all of the dialysis patients who have been so helpful in answering our survey questions.



South Tyneside Festival

Saturday 2nd July
2011

Well yet again the
weather was on our

side for this annual event in the Bents Park South Shields, we set up our Tombola stall alongside Brian Jones experimental old fashioned games stall.

The Tombola was its usual success with Joan extracting plenty of loose change from the visitors ably supported by other members and friends; it was also nice to Isobel Stubbington and her daughters returning to help us.

Brains shove-a-penny and ball pit games proved to be very popular with the young children with prizes being won at a great rate, he had to close early as it was a complete sell-out!! Our thanks must go to Brian his daughter Shirley and grandson Kieran who put in a great shift.

Doreen Adamson was again at her finest selling raffle tickets throughout the site as her husband sat alongside me blowing up balloons and eating ice cream.

By the end of the day the stalls were cleaned out, Joan had a smile of satisfaction on her face and I have a great suntan!

Keith Vickers

Dialysis and Disabled Car Parking

In the next copy of your News Letter I intend to look at the provision of parking spaces for Dialysis patients attending treatment. The constant misuse of the spaces by non dialysis

patients and the reluctance of the Hospital Estate Managers to enforce the rules or providing adequate signage.
If you have something to say let me know.

Keith

k.vickers@blueyonder.co.uk

*A pessimist sees the difficulty in every opportunity; an optimist sees the opportunity in every difficulty,
Always remember you're unique. Just like everyone else by the time you make ends meet, they move the ends.
No one will ever win the battle of the sexes: there's too much fraternizing with the enemy*



Great Britain Transplant Cricket Club
Founded 2004

Tynemouth Test v ATCC: 30/06/11

Great Britain Transplant Cricket Club v Australia Transplant Cricket Club

Tynemouth Cricket Club June 30th 2011 - July 1st 2011

The Great Britain Transplant Cricket Club is the representative side for players in the United Kingdom who have had lifesaving organ and tissue transplants. Tynemouth Cricket Club played host to match 1 of the 2011 Transplant Ashes against the

Australia Transplant Cricket Club as the visiting side look to revenge their defeat in 2006.

New look sides were on display from both sides, with the ATCC retaining 4 of their 2006 side in Wulff (Captain), Rose (WK), Campbell-Jones and Pyras. The GBTCC starting line up retained Parker, Harris (Captain) and Graham from 2006, with Rice and Appleby out through injury.

The sides were honoured to have Robyn Hookes amongst the spectators - Robyn's husband was David Hookes, the Australian batsman who, upon his death, donated his organs to enable lifesaving transplants to take place. The players compete for the David Hookes Memorial Shield, named in his memory.

The 2011 series consists of the two day game at Tynemouth and an ODI at Dulwich on Wednesday 6th July - as such, a victory in this fixture would lead to a series victory, with 2 points being allocated to this fixture.

On arrival at Tynemouth there were some fantastic reunions as old competitors and friends met back up. The club should be thanked for preparing a superb wicket for the fixture, which promised a fantastic two days play.

GBTCC skipper, Simon Harris, won the toss and elected to bowl first.

Needless to say the Australian tourists won, I suspect ringers! None the less it was good to meet Paul MacCuspie one of the Australian team who dialysed with us on bay 5 backshift the day before the game.

For you who would like further information.....

[www./atcc.org.au/](http://www.atcc.org.au/)

Keith Vickers

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
13TH August
2011
Parking while at a
MEETING IN ROOM 137

TYNESIDE *KIDNEY*
PATIENTS' ASSOCIATION
9th AUGUST
2011
Parking while at a
MEETING IN ROOM 137

Harrogate Autumn Flower Show 17th September 2011

Name _____

Address _____

Tel: _____ Mob. No. _____

Cost per person £15 including entry to flower show

Ticket Number(s) _____ Total £ _____

Payment by: Cash / Cheque Receipt No. _____

Names of those you are buying tickets for:

The bus has a wheelchair lift. If you are in a wheelchair do you either:

1. Have a folding wheelchair? _____

2. Need to travel in your wheelchair? _____

(Limited number of seats can be removed to accommodate wheelchairs)

Will you be getting on the bus at?

1. Freeman Hospital _____

2. Gateshead Metro Interchange _____

If there is enough demand a further pickup can be made enroute
If you are completing this form independently please send it with a
cheque made payable to the **TKPA** to:

David Errington, Linden, Longhirst, Morpeth Northumberland NE61
3LS by 7th **September 2011**