

TYNESIDE *KIDNEY* PATIENTS ASSOCIATION



**PATIENT AND FRIENDS
NEWSLETTER**

August 2016

CALENDAR OF CHARITY STALLS AND EVENTS 2016

Friday 5th August 10-4pm Charity Stall, Freeman Atrium

Tuesday 9th August 7-9pm Committee Meeting. Education Centre, Freeman.

Tuesday 16th August 2106 10-4pm Freeman Atrium.

Sunday 21st August 10:30 Sponsored Walk, Souter Lighthouse to South Shields Lighthouses. (4 Miles)

Sunday 11th September Great North Run.

Tuesday 11th October AGM Education Centre, Freeman Hospital

All TKPA meetings to be held in room 138, Education Centre

Freeman Hospital and will begin at 7:00pm prompt

Tea, coffee and biscuits served from 6.45pm

If you wish to attend but require a lift, we may be able to organise one.

Please contact me to check if this would be possible.

Keith

07588 724530

Editor's note

If you are reading the newsletter as a digital copy and are connected to the internet, please be aware I have included a number of articles that contain hyperlinks to further information. To use hover your cursor over the link and (*control+ left click*) to follow the link.

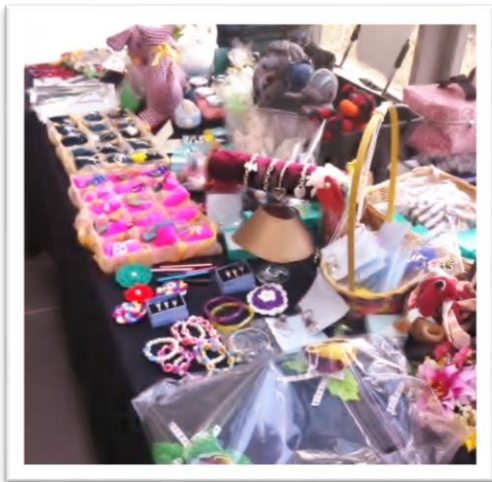
Electronic edition

Regular readers of the newsletter will have noticed I include additional online content with the use of hyperlinks to support articles and to give far more information than I can include in the printed addition.

If you wish to receive the newsletter as a digital addition in future please contact, Alan Bond (membership secretary) with your name and mailing address together with your email address *Tel.0191 4281 702* or email bond504@btinternet.com

Not only does the digital newsletter give enhanced content but also does away with the cost of postage.

Keith Vickers
Editor



Fund raising stalls

We have a tombola, jewellery and gift stall on the 1st Friday and 3rd Tuesday of every month situated in the Renal Centre Atrium opposite WH Smiths.

These raise important funds for our charity but they also give us the opportunity to talk with patients and give them any help they may need particularly if they are new to the Freeman Hospital.

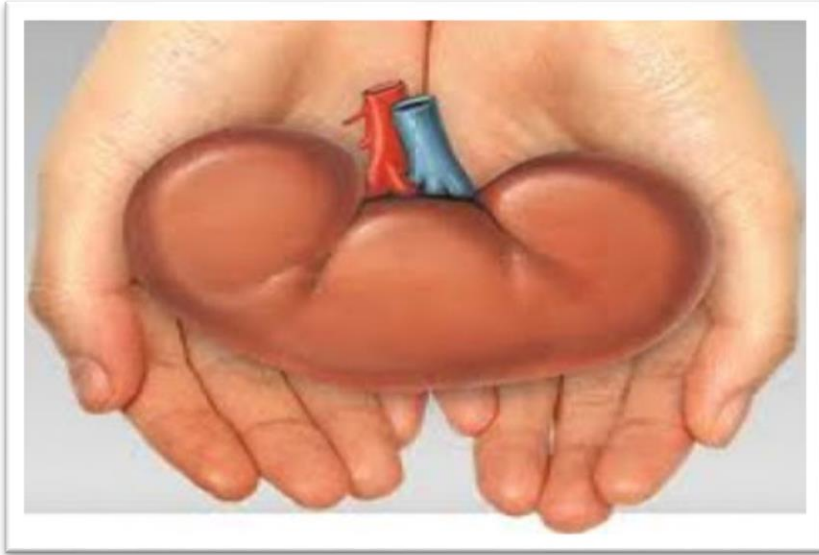
If you have any spare time and would like to help please contact

Keith Vickers 07588724530

If you have any gifts that you wish to donate as tombola or raffle prizes we will be happy to accept at the stalls or at the ward clerks station on ward 31 at other times (Mon-Fri 9am-5pm)

Organ Donation Week

We are pleased to announce National Transplant Week will now be known as **Organ Donation Week**. This year's Organ Donation Week will take place between Monday 5th and Sunday 11th September 2016.



Organ Donation Week provides an opportunity for the organ donation and transplant community to promote organ donation nationally and locally, whilst highlighting the importance of organ donation and celebrating those who have saved lives.

Sally Johnson, Director of Organ Donation and Transplantation said *"We hope people across the UK will get behind the week and the opportunity it presents to focus people's attention on organ donation. People waiting for transplants depend on people being willing to donate their organs and sadly on average three people die every day across the UK due to a shortage of donated organs."*

In conjunction with this the Tyneside Kidney Patients Association are holding a meet and greet information day on Monday 5th September 2016 in the Freeman atrium (opposite WH Smith) from 10-3pm.

Renal Social Workers

'What we do and how we support renal patients'

There are three part-time Social Workers based in the Renal Unit at Freeman Hospital. Our work covers Ward 32 (in-patient ward), Ward 31 (dialysis ward), Renal Clinical Investigations Unit, Out-patients, all home dialysis patients (haemodialysis or peritoneal dialysis) and pre-dialysis patients.

The Social Workers are required to work within a statutory and legislative framework and are required to take into account both the patients and their carer's needs. They are also responsible for understanding appropriate safeguarding procedures.

The Social Workers are part of a multi-disciplinary team in the renal unit and regularly discuss patients with other professionals within the renal unit to ensure that the appropriate services/support is being considered.

Most referrals come from nurses or doctors involved with patients but people are able to refer themselves to us.

The majority of referrals about patients on Ward 32 are made because patients may require an assessment for services to support them when they are discharged home. (It may be because the person has been struggling to manage at home or that they will need short term support on discharge from hospital until they have recovered from their acute illness).

Patients who are referred from other parts of the unit may be referred because they are struggling to cope with their illness or physical condition. They may be struggling financially and need assistance to apply for benefits or grants or may need information about moving to more appropriate accommodation. The Social Workers will consider the practical, social, emotional and psychological needs of the patient and other appropriate support where possible.

The Freeman Renal Unit is a regional unit and so the Social Workers regularly need to provide assessments for other local authorities or liaise with organisations across the North of England.

Occasionally we are approached with questions or queries that we are unable to deal with ourselves but in these situations we will try and find out who would be appropriate to deal with the issue and pass on the information.

If anyone has any questions about the services that we provide, please do not hesitate to contact us by:

- Telephoning 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.

COMMITTEE ELECTIONS

We elect the whole committee every year. There are 4 honorary posts (Trustees): chairman, vice chairman, secretary and treasurer. In addition, there are 4 posts for committee members. We need nominations for each post. So will you please help by completing the nomination form at the end of this newsletter? Nominations need to reach the secretary by Wednesday 31st August 2016.

Please note the following:

Nominations must only be made with the approval and signature of the person being nominated.

The list of candidates will be circulated by the 11th September as we have to give 4 weeks' notice before our A.G.M. to be held on **Tuesday 11th October 2016**

Please either send the form below or print one off if you want to make a nomination.

Nomination forms should be sent to....

Keith Vickers.
87 Harton House Road
South Shields
NE34 6EB tkpa.secretary@gmail.com

Current committee:

Chairman: David Errington
Vice-chairman: Bob Ramshaw
Secretary: Keith Vickers
Treasurer: Ian Gill

Committee members:

Alan Bond
Alex Crawely
Vacancy
Vacancy

What does a committee member do?

Our committee, since the formation of the TKPA is run by patients for the benefit of patients. The current committee of 6 includes 3 Transplantees, 2 patient family members and a current ward 31 dialysis patient.

We hold one committee meeting a month at the Freeman Hospital on the second Tuesday of the month from 7-9pm. These meetings are held in a friendly atmosphere where we discuss items such as our finances, support to patients via the renal social workers, planning patient events such as day visits, dinners etc. Committee members and our volunteers assist in the production of our newsletter as well as manning our tombola stall in the hospital which is held twice a month.

All roles on our committee are unpaid though expenses can be claimed for mileage or public transport as well as the provision of a parking pass for those carrying out TKPA duties.

Committee members and volunteers will be registered with the NHS Trust for which an Enhanced Disclosure and Barring Service (DBS formally CRB) certificate will be issued free of charge.

If you have any questions about serving on our committee, please contact....

David Errington Chairman (01670) 790300

E-mail daviderrington@tiscali.co.uk

Bob Ramshaw Vice-Chairman

heatherramshaw@yahoo.com

Keith Vickers Secretary/ Editor 07588 724530

E-mail: tkpa.secretary@icloud.com

Ian Gill Treasurer 0191 252 4719

E-mail: joyce-and-ian@supanet.com

Committee members

Alan Bond (and membership secretary) bond504@btinternet.com

Alex Crawley alex crawley101@hotmail.com

Renal Unit Prescribing of Transplant Medicines



Changes to the way immunosuppressant medication is prescribed

We are writing to inform you of changes to the way your transplant medication will be prescribed.

After your transplant, you started taking immunosuppressant medication to stop your body from rejecting your new kidney. You may be taking some of the following medications for this: tacrolimus, ciclosporin, Sirolimus, mycophenolate, Myfortic®, azathioprine and prednisolone.

What is the current situation and what is going to change?

As part of a patient safety initiative, NHS England has recommended that immunosuppressant medicines for organ transplants should be prescribed by a hospital specialist.

This means that your immunosuppressant medications will soon be prescribed by your kidney specialist instead of your GP. All your other medications will continue to be prescribed by your GP. You may be part of this project even if you are on dialysis, if you are still receiving immunosuppressant medication because of a previous kidney transplant.

Why do we need to change the way I receive my transplant medication?

Returning the prescribing and supply of your medicine to the hospital clinic means that the same team who review your blood tests and adjust your doses also prescribe the medication. This system will also allow us to make sure that the same brands are prescribed each time. We will choose only the brands that we know we can trust.

We will be able to provide you with enough medication to last beyond your next clinic appointment.

Is switching tacrolimus safe and will it affect my transplant?

Patients who are currently taking Prograf® will be changed to our preferred brand of tacrolimus, Adoport®. The medicine in both products is the same, but a different manufacturer makes the capsules.

Switching from one brand of medicine to another is safe when it is carefully planned and monitored by your hospital specialist.

Some of our patients have been taking Adoport® since 2011 and all kidney transplant recipients since January 2015 started on Adoport®, so we have lots of experience with it.

We will check your tacrolimus level about a week after starting the new brand just to in case a dose adjustment is needed. We will therefore arrange for you to start Adoport® a week before your next routine clinic appointment to avoid any extra visits.

Patients who are currently taking Advagraf® (once a day modified-release tacrolimus) will not be changing.

I also take mycophenolate – will this drug be changing?

Generic mycophenolate has been available for several years in the UK. There is no apparent difference in the effectiveness of different brands. All patients in the Northern region are likely to have already received other preparations of mycophenolate. We have not had any adverse events after switching patients from CellCept® to generic mycophenolate.

Can I receive all my medication from the hospital team?

No. Your hospital team will only supply your transplant medication (tacrolimus, ciclosporin, sirolimus, mycophenolate, Myfortic®, azathioprine and prednisolone). You will continue to get the rest of your medication from your GP.

When will the changes happen?

The changes will happen from 4 July 2016, although we expect it may take up to a year to see every patient.

Is the change simply to do with cost?

We are obliged to start prescribing your transplant medications now. We hope that this new arrangement will be more cost efficient than the old one. The change is to ensure that you receive the same brand of medication each time you get a prescription, unless a deliberate switch is planned. A switch to Adoport® tacrolimus will help us to ensure that your treatment is cost effective to the NHS. We have been able to share some of the savings with NHS England, and we plan to use this to improve the care we provide to patients in the renal unit.

Will there be any change to my transplant clinic?

Most patients will not need any extra clinic visits. The initial appointment will be on the same day as your usual clinic visit, and may take up to 30 minutes longer than usual. If you need a supply of medicines, you will be given a prescription to take to Lloyds Pharmacy in Freeman Hospital.

You will then be able to collect a prescription for your transplant medicines at each clinic visit, if required.

We will do everything we can to keep disruption to a minimum.

If you have any immediate questions, please contact Emily, our clinic secretary on **0191 223 1023** who will forward your question to the right person. Otherwise your transplant consultant, clinic nurse or pharmacist will be happy to discuss any concerns at your next clinic visit.

The Tyneside **Kidney** Patients Association (TKPA) can also be contacted at:

email: info@tynesidekpa.org.uk

[http://www.kidney.org.uk/home/news-2/patients-receiving-immunosuppressive-drugs-essential-reading./](http://www.kidney.org.uk/home/news-2/patients-receiving-immunosuppressive-drugs-essential-reading/)

World Transplant Games 2019 NewcastleGateshead

Chairman of Transplant Sport, Andy Eddy announced today:

"We're thrilled to announce that a joint bid by Transplant Sport, the



Newcastle Gateshead Initiative and MLS has been successful and the 2019 World Transplant Games will be held in the North East."

Graham Wylie, Chair of the NewcastleGateshead WTG bid team said:

"Our bid for the World Games demonstrated our ability to once again galvanise support and show our collective

commitment to this important cause. Thank you to all those involved, including the official bidding organisation Transplant Sport and colleagues at NewcastleGateshead Initiative and MLS who led our work to develop the bid."

An initial NewcastleGateshead bid was submitted earlier this year and the destination was shortlisted alongside Houston, Texas. A panel visit

from key members of the World Transplant Games Federation took place in May 2016 and the process culminated in a final presentation to 13 members of the WTG Federation Council earlier today in London.

The NewcastleGateshead World Transplant Games bid was developed through a partnership approach led and coordinated by NewcastleGateshead Initiative and MLS (the event company involved in organising the British Transplant Games) on behalf of Transplant Sport.

Other key partners include: Newcastle City Council, Gateshead Council, Newcastle University, Northumbria University, Newcastle upon Tyne Hospitals NHS Foundation Trust, Westfield Health and Graham Wylie.

Annual General Meeting, 11th October 2016

Nominations for Committee Membership

<i>Position</i>	<i>Nomination</i>	<i>Candidate's signature</i>	<i>Proposer</i>	<i>Seconder</i>
Chairman				
Vice- chairman				
Secretary				
Treasurer				
Committee member				
Committee member				
Committee member				
Committee member				

Closing date for nominations 31st August 2016

The Latest Statistics Kidney (and Liver) Transplantation and Donation

Every year, NHS Blood and Transplant (NHSBT) invites patient support groups and renal physicians (surgeons, nephrologists, immunologists) to the Renal Transplant Services Meeting (RTSM). At the RTSM, NHSBT present the latest statistics on kidney transplantation and organ donation, and there are talks on studies and initiatives to increase and improve the number and quality of transplants. In this article, we give some highlights of the 2016 RTSM. Links to all the presentations can be found at the end. Kidney transplants and organ donation statistics The 2014-15 detailed activity report shows annual data from 2005-6 and it's a very useful source of information, for example if you are talking to media or schools etc. about kidney and other organ transplantation. Note that data from 2015-16 is available on the ODT website but only top level numbers.

In 2014-15, 2,793 adult kidney transplants took place in the UK, 3% fewer than in 2013-14. Of these, 1,832 were from deceased donors and 961 from living donors (see bottom box for donor definitions).

We do not know the exact number of PKD transplants but approximately 1 in 8 to 1 in 10 of people with a kidney transplant have PKD, so that might suggest around 200. There were 139 paediatric transplants, 48 from deceased donors and 91 from living donors. A number of these will be for ARPKD children. Kidney transplants have increased by about 60% since 2005-6. However, the increase is from living donors (nearly twice as many) and more recently DCD organs (see bottom box for definitions). The number of DBD organs has remained fairly static owing to improvements in neurosurgery and falls in deaths from traumatic injuries.

Overall data for the 2015-16 year shows an increase from 2,793 transplants to over 2,900. Whilst positive, this is a modest increase, and the number of transplants per year has barely increased in 3 years. The number of people on the active kidney transplant list is still over 5,000 and although this has fallen, the reduction has come from an increase in the number of people on the suspended transplant list. Suspensions are usually due to infections or other illnesses, or when an individual no longer fulfils the transplant criteria.

Increased use of DCD organs across the UK Until recently, DCD organs were less used and mostly locally. The donor's kidneys spent more time

without blood flow than from a DBD donor, resulting in delayed graft function and higher rejection risk. However, long-term outcome data has shown that DCD transplant survival is as good as DBD. Following a London trial, a national DCD Kidney Allocation Scheme was introduced in September 2014. There are now four DCD donor kidney sharing regions in the UK, designed to provide equity of access at the same time as realising acceptable time to transplant. One organ is offered locally, the other regionally, and this has resulted in the increase in DCD transplants and wider use in longer waiting patients. Kidney transplant unit statistics and waiting list.

There are 24 transplant units in the UK. In 2014-15, Manchester performed the most transplants (215) followed by Leeds (191) and Guys (185). Plymouth has the least (58). Regarding the waiting list, Manchester has the highest number (537) followed by Birmingham and West London. The median (average) time on the waiting list has fallen for all patients but there are wide variations. Across the UK, the median wait for white patients is 995 days but 1,200 days for BAME (black and Asian) patients. Cambridge has the shortest waiting time (around 500 days), and Birmingham the longest (around 1,500 days).

Living donor transplant paired scheme in recent years, the number of paired living donor transplants has increased. In 2014-15, there were 62. This type of transplant occurs when a potential donor and recipient are biologically incompatible (blood group or tissue type) and they join a list of others in the same situation hoping that an exchange of kidneys between them.

Reproduced with thanks



<http://pkdcharity.org.uk/>

Renal Diets

In our last Newsletter I included an article I had written regards eating well within the confines of a renal diet using my own experiences as a HD patient on a low potassium diet.

I would like to point out that many other patients who are also on restrictive renal diets and that the menu examples I presented may not be suitable for which I apologise.

Should you require dietary advice for your individual conditions your first and only contact should be the Renal Dieticians.

Liz Rai. Elizabeth.Rai@nuth.nhs.uk

Or the following approved websites

www.kidney.org.uk/help-and-info/books

www.kidneypatientguide.org.uk/diet.php

www.bda.ukcom/foodfacts/home

www.newcastle-hospitals.org.uk/services/renal.aspx

www.kidneyresearchuk.org/health-information/resources/free-recipe-book

Keith Vickers

Secretary. TKPA.

PILL DISPENSERS



Medios 1 £10



Medios 8 £10



Medimax £14

We have pill dispenser packs for sale to help organise pills. There are two sizes, the Medios range which holds up to 16 large tablets or the Medimax which is four times the size. We can offer a saving on each one as we have bought in bulk.

Dispenser packs are available on stalls or our meetings at the above prices. Alternatively, they can be ordered through our website www.tynesidekpa.org.uk or direct from Simon Lloyd, Tel: (01661) 871 399. There is a charge of £3-50 for postage and packing if you can't collect them.

PILL DISPENSERS CORRECTION

There has been a misunderstanding about transplant patients being given Medimax pill dispenser packs after a transplant. Patients who have had their **first** transplant are given a Medimax pill dispenser pack as well as training in arranging their medication. Towards the end of their time on Ward 38 they set up their pills by themselves. These are then checked by nursing staff before they are taken by the patient.

There are two points to note. Only patients getting their first transplant are given a Medimax dispenser. If others want them we can supply them.

Medimax dispenser packs are made in different materials. The ones being given out on Ward 38 are made of a firm plastic with seams down the spine. These seams act as hinges and in time will split after 3 or 4 years. We have bought Medimax dispensers that have the case made of leatherette which shouldn't tear but give a long time of use.

SELF CARE PILL TAKING

Who takes responsibility for your pill taking? You by yourself? Does someone else help setting up each dose and renewing your monthly prescription? Or do you rely on a pharmacy to set up all your daily doses?

Some years ago a programme called the Experienced Patient Programme was publicised with great fanfare. It got taken over by the arthritis group and did not get any further. At the heart of the programme was getting patients to gain confidence in self-care.

Personally I think self-care is one of the best ways of coping with my health care. For me this really started when I went onto peritoneal dialysis at home after training in the RVI. At first doing a PD exchange alone was a bit scary because of all the warnings about hygiene in case I made a mistake and got peritonitis. In fact, things went well and I gained confidence and never got peritonitis for the 14 months I was on it before getting a transplant.

I had heard of renal patients having problems when going into non-renal wards as we are unusual in the training we get for medication compliance. So I was not surprised when I was admitted recently to a local hospital, I signed a form over taking responsibility for taking my pills and locked them away in the container on the bedside cabinet. I subsequently hit a couple of problems because nursing staff have a responsibility to see patients take their medication. On a couple of occasions nurses wanted to check my pills but I refused to let them. As far as I am concerned signing a form to say I take responsibility for my medication means I must be allowed to have it. I am quite happy for nurses on the pill round to ask if I have taken my medication as it's a helpful check.

There was another problem over taking Neoral (ciclosporin) twice a day. The dispensing programme says it should be taken at 9.00 a.m. and 9.00 p.m. However, we are taught to take it at midday and bedtime. This led to several discussions with nursing staff but as my blood tests have always been good, since 1998, I kept to the regime I am used to.

Simon Lloyd

President

Tyneside Kidney Patients Association

Annual Dinner 7th June 2016

Salanos Newcastle



This year's Annual Dinner was held in Newcastle famous Peruvian Restaurant "Salanos" named after the former Newcastle United player.

Ticket sales from the outset were good and by the evening it was a sell out and a full house.

The night was a social evening and not a fundraiser but nonetheless we managed to relieve our guests of a few hundred pounds with a raffle and stand

up bingo. All the prizes were donated by the diners for which we give many thanks.

The owners of Salanos, Pam and Chris together with the Head Chef Alfonso Yanez provided us with a great meal and made our guests feel very welcome.

Entertainment for the evening was provided by our Chairman David Errington and Andy Rayner who played enthusiastically (and free) after the meal.

Thanks to everyone who helped selling (and buying) tickets as well as our helpers on the night and a very big thank you to Pam Yanez for her and her team's hospitality.

Volunteer wanted



Do you have 2-3 hours a month to spare?

Computer literate with a knowledge of WordPress?

The TKPA is looking for a volunteer to edit our website on an occasional basis.

If you could help please contact.....

Keith Vickers

Tkpa.secretary@gmail.com

07588 724530

Don't blame me!!!

I asked God for a bike, but I know God doesn't work that way so I stole a bike and asked for forgiveness.

I hate Russian dolls, they're so full of themselves.

The first time I got a universal remote control I thought to myself, "This changes everything".

I've spent the last four years looking for my ex-girlfriend's killer, but no-one will do it.

I refused to believe my road worker father was stealing from his job, but when I got home all the signs were there.

I recently decided to sell my vacuum cleaner as all it was doing was gathering dust.

You can never lose a homing pigeon – if your homing pigeon doesn't come back what you've lost is a pigeon.

My girlfriend told me to go out and get something that makes her look sexy... so I got drunk.

Don't you hate it when someone answers their own questions? I do.

As I watched the dog chasing his tail I thought "Dogs are easily amused", then I realized I was watching the dog chasing his tail.

Gambling addiction hotlines would do so much better if every fifth caller was a winner.

Where there's a will, there's a relative.

Hedgehogs eh? Why can't they just share the hedge?

To the man on crutches, dressed in camouflage, who stole my wallet – you can hide, but you can't run.

My friend keeps trying to convince me that he's a compulsive liar but I don't believe him.

It's always hard to explain puns to kleptomaniacs because they're always taking things literally.

I've just written a song about tortillas; actually, it's more of a rap.

I had a neck brace fitted years ago and I've never looked back since.

My wife just found out I replaced our bed with a trampoline; she hit the roof.

Current committee 2015-16

Trustees

David Errington Chairman (01670) 790300

E-mail daviderrington@tiscali.co.uk

Bob Ramshaw Vice-Chairman

heatherramshaw@yahoo.com

Keith Vickers Secretary/ Editor 07588 724530

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87 Harton House Road, South Shields

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Committee members

>Alan Bond (and membership secretary) bond504@btinternet.com

>Alex Crawley alex crawley101@hotmail.com

>Tonia Foster tonia.foster12@gmail.com

Telephone Helpline and Peer Support –

David Errington Vice-chairman (01670) 790300

E-mail daviderrington@tiscali.co.uk

Do you wish to be involved by contributing articles or assisting with publishing?

Are there items or stories you would like to be covered?

Have you had a holiday while on dialysis and want to let other patients know how it was planned?

Have you a story to tell, let us know



Newsletter compiled and published by Keith Vickers

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August 2016