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Hope Hospital KPA

Membership application form



Registered Charity number 1010321

Who are we?

YOU ASSOCIATION NEEDS

Hope Hospital Kidney Patient Association is a registered charity run by kidney patients for kidney patients and their carers, relatives and friends. Funding is entirely by donation and fundraising events.

Only someone who has experienced kidney disease can understand the problems and anxieties associated with the illness. It is often easier for a patient and his or her family to talk to another patient about their difficulties. A patients' Association can provide additional support to complement the NHS provision.

Membership is open to anyone who wishes to join. To become a member and receive a regular newsletter with details of events, local and national news and developments, please complete the form below.

All details are held in confidence by the Kidney Patient Association and no information is shared with any other person or organisation.

BLOCK CAPITALS PLEASE: Title	
(Mr, Mrs, Miss, Ms)	
Name	
Address	
	Post Code
Please tick the appropriate box, are you Patient	Carer
Relative	Hospital staff member
Interested party	
Please return completed form to:	Alternatively, you may give your completed form to a member of the renal team in the
Mr John Allen HHKPA Secretary 5 Shepherds Close Blackrod BOLTON BL6 5DY	Renal Outpatient department Renal HD Unit Renal Training Unit Bolton HD Unit and it will be forwarded to the Association on your behalf



# the Hope Hospital KIDNEY PATIENTS ASSOCIATION

www.srht.nhs.uk/renal

# FIRSTWORD

We are told we eat the wrong food, drink too much, smoke, are overweight and don't take enough exercise...and we live longer. Is this because the situation is not as bad as it seems or are we getting better healthcare?

Whatever the arguments, the above factors must affect our health and maybe we need to think more about our wellbeing and less about the new car and conservatory.

Thank you to those who contribute to the newsletter. The next one will be published in early March 2005.

Contributions can be sent to: The Editor, HHKPA Newsletter 209 Grove Lane, Hale, Altrincham, Cheshire WA15 8PX



3-2-1 say "cheese".

A surprisingly mild day made travelling to Farnworth a pleasant prelude to our Christmas party on December 5th. As usual Margaret, Kath Barlow and Lillian Cowell put on a superb spread of food and music was provided by Darren and Maria who are to be married next year. Sister Lesley Lappin accompanied by Dr. Julian Wright sang a selection of Christmas songs and balloons, crackers and party games all added to the festive atmosphere. It was great to see so many families, friends, carers and children there together with members of the Renal

Team. A good time was had by all and we'll do it again next year!



Sister Barbara Murray, Matron Jane McDonald, Sister Lesley Lappin and HHKPA Secretary John Allan.

CHRISTMAS EDITION 2004

### FROM THE CHAIRMAN

2004 has been a momentous year regarding renal activity in our area. That is not to say that nothing had gone on before of course! What we have seen is the consolidation and coming to fruition of ideas and goals all of which are aimed at improving the treatments and



outcome for kidney patients. A massive momentum has now built up around the nation's health at the instigation of government and public alike. Government, so often maligned, has initiated many patient participation schemes whereby we can express our views and aspirations. We saw the first fruits of this with the first part of the Renal National Service Framework on Dialysis and Transplantation being launched in January.

Part two on Prevention and Palliative Care should be out any time now. During the year the Renal Managed Clinical Network was shortlisted for a Health Service Journal Award – confirmation, if it were needed that the strategy of our medical staff, managers and commissioners is well respected and wholly appropriate for the job in hand.

This year has seen the planning of two further dialysis units at Wigan and Tameside with Bolton approaching full capacity.

Transplantation remains a problem with just not enough organs available. In the end it's down to the public to sort this one out. It's going to take a huge effort to raise the public's awareness of the problem and change its attitudes to it. It won't happen overnight and it has to be a year round activity not just during transplant week.

The Association recognises this and will play its part in getting things moving in 2005.

## ONGRATULATIONS



We offer our heartiest congratulations to Matron Jane Macdonald on her appointment as Vice President of the British Renal Association - national recognition for a well respected member of the renal team.

Well done Jane.

#### HELP & ADVICE

If you would like to talk to someone on a renal matter from a personal viewpoint and in complete confidence, please ring HHKPA members: Mrs Jean King 01204 884248 or Mr Stephen Balshaw 0161 799 2426



Patient Gina Cooke and her sister Paula enjoying their day.

## Southport Airshow **12 SEPTEMBER 2004**

This was our last trip for this year and as usual proved to be an enjoyable occasion. Quite a lot of preparatory work is involved in the organisation of our trips invariably requiring a recce to establish a facility for CAPD patients desiring to effect an exchange. This time in the absence of more formalised arrangements the manager of Boots the Chemist came to our rescue by offering us his office and adjacent washroom. He was most accommodating and welcoming. Hoorav for Boots!

It was a cloudy and showery day ... others contented themselves and some people started off with lunch, others made their way to the airshow, some paying to go on the

with a walk along the seafront and a free display ...

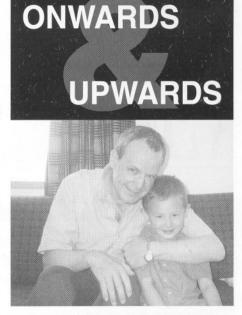
beach and view the static displays and the helicopters landing and taking off. One patients' son had his face painted with camouflage while others contented themselves with a walk along the seafront and a free display of all that was going on in the air, interspersed with hot drinks and snacks to warm themselves up.

Others made for the shops and returned to the coach laden with goodies. There were several children on this trip who were so well behaved that it would be a pleasure to take them again.

I am beginning to think of where we are going in 2005. Blackpool

lights are on the list but let me have your other suggestions.

Margaret Gowdridge 01457 873567



Keith and his son Luke.

There can hardly be more devastating news for a young man married with 3 children, barely approaching middle age and living the good life, travelling the world as a sales executive for a pharmaceutical company than to be told that you have multiple cancers on both kidneys thereby necessitating their removal.

2003 therefore could not have started in a worse way for Keith Frampton, a patient from Cheshire and "Choice" in the NHS took on a wholly personal meaning. Would this be the end of life as he knew it or would he face up to all the challenges that lay ahead?

Once he had chosen the latter, Keith found that deciding on particular actions became easier on account of not wasting time dwelling on what life "might" have been.

After 8 weeks in hospital and a year on haemodialysis, Keith now dialyses at home and is full of praise for his treatment at Hope. He's taken early retirement and maintained his interest in holidays and travel with the purchase of 2 apartments in France and Switzerland with dialysis facilities nearby and which are available to rent. If you dyalise and are interested in travel Keith reckons getting on the internet is a must as there is so much useful information available.

He is also a capable entertainer playing guitar and singing popular songs but says much of his life now is involved in the enjoyable task of managing his properties.

If you would like to contact Keith and perhaps discuss a holiday at one of his apartments he is happy to talk to you on 01925 756912.

# HOPE HOSPITAL NEWS

Dear friends, patients, carers and colleagues. It was a great privilege for me to speak at the National Kidney Federation Conference on 2 October 2004 on the topic of *The future shape of services for people with Chronic Kidney Disease (CKD).* 

Research over the past decade, some of it at Hope Hospital, has shown that CKD, once considered a rare condition is in fact common. By carefully examining general practice records, we have found that about 5% or 1 in 20 people have significant impairment of kidney function defined as kidney function less than 60% of normal. Probably a further 5% of the population have lesser degrees of CKD. However, people with CKD often don't have symptoms until their kidney function is less than 25% of normal.

#### ...these risks can be reduced by stopping smoking, increasing exercise, reducing obesity...

So why bother about early CKD? For 2 key reasons – early detection, for many people, allows treatment to prevent progression to more severe forms of kidney failure and all people with any degree of CKD have increased cardio-vascular risk. These risks can be reduced by stopping smoking, increasing exercise, reducing obesity, treating raised blood pressure and raised cholesterol and, for people with diabetes, getting good control of blood sugar.

The renal services of the future need to be patient centred, designed around the needs of patients and their carers, offering choice and providing consistent high quality. The National Service Framework (NSF) for renal disease target is for all people with CKD to have their own individualised integrated care plan.

That may sound like jargon but it isn't – it means that all the doctors, nurses and other health and social care professionals will use the same records for each individual; the aims and objectives of parts of the treatment plan would be recorded and progress would be measured against these standards. In addition, the patient will hold their own care plan.

It means general practice and the hospital using the same records and for a person with diabetes or another condition there would not be 2 treatment plans – or more as is so often the case now – but 1 overall plan covering all aspects of care, be that diabetes or renal care. This will not be achieved overnight and will in the fullness of time require joined up information technology systems. We need to begin that work now and to take the



first steps in this exciting direction at the earliest opportunity. Everybody talking to one another, using the same language and supporting patients and carers in decision making should be the basis of our renal services for the future.

CKD is a long term condition and long term conditions are currently receiving a lot of attention within the Health Service. There is a real opportunity to link blood pressure control and cardiovascular risk management for people with heart disease, kidney disease and diabetes. The kidney filters are glorified blood vessels and not surprisingly, all the factors that are bad for the blood vessels of the heart also accelerate kidney damage.

The complications of diabetes – kidney disease, blindness and vascular disease are also caused by the same factors. The large scale studies undertaken over the last 20 years have shown how beneficial it is to treat these conditions well. The Government recently announced that heart disease had been reduced by 20%; it is not inconceivable that we will also be able to reduce the burden of CKD if people are detected early and treated appropriately.

...most of us could do more, and should do more, to address the lifestyle issues

The importance of treating cardiovascular disease at all stages of CKD was one of the key themes running through the talk I gave at the NKF meeting. Most of us could do more, and should do more, to address the lifestyle issues that increase vascular disease. We as doctors and nurses should not accept poor blood pressure control and you as patients and carers should demand the best treatment possible.

The shape of services for people with CKD should reflect the patient journey. For the majority of the 5% with less than 60% kidney function excellent care can be provided in primary care and in the community. Every person with CKD requires a diagnosis but that does not mean every contact with the Health Service needs to be at the hospital.

On the contrary, the majority of care can be provided more conveniently, more efficiently and as effectively close to home. It should be possible for patients to monitor their own progress against the agreed care plans and, when things are not going to plan or complications develop, the specialist hospital services need to react promptly to these needs. This requires the right people, in the right place at the right time with the right information. Clearly the management of patients with advanced kidney disease, requiring dialysis and/or transplantation is going to require the continuing input of specialist renal services – but even here there is a big place for self care and a significant job for General Practitioners and community services to do.

Provision of high quality services in long term conditions, and perhaps in CKD above all, requires the Health, and in many instances Social Services, to work in partnership with patients and families to reap the benefits of a 21st century service.

Transplantation remains of major concern to the renal community. Rosie Winterton MP and Minister of State spoke at the NKF conference on this issue. Whilst she emphasised the improvements over the last few years there is still a long way to go in increasing organ donation rates. The last year experienced a higher rate of kidney transplantation than has been seen for over 14 years. Much of this was due to the generosity of living donors and living donor kidney transplants now make up over half of all kidney transplants.

Nearly a million more people are now registered as organ donors but donation from intensive care units continues to fall. Many relatives refuse organ donation and I can't help but think that the Alder Hey and Bristol heart scandals have undermined public confidence in organ donation. In a consumer society the altruism of organ donation is challenged and yet I know a lot of people whose lives have been transformed by the generous gift of a kidney and I know a small number of families who have donated organs of a loved one.

In every instance that I know of, those families have found that organ donation has been a help in coming to terms with their loss and a tribute to the years of life denied to their relative. Stories such as these rarely make the newspapers or soap operas these days and it is up to all of us, as part of the wider society, to raise the profile of donation in whatever way we can.

## ...I am proud to have learned those lessons at Hope...

Successful kidney services, those who get the best outcomes for patients and treat everyone as an individual are based upon having highly motivated staff, respecting people with CKD, using the knowledge that we already have wisely and communication. I am proud to have learned those lessons at Hope Hospital and whilst I am well aware that we are far from perfect, I do know that working together we can address the challenges, improve services and reduce the burden of CKD.

# Run for Renal

You may already know that, for reasons I'm unable to give a satisfactory explanation for, but probably something to do with age and, as a diversion from the football season, I ran the New York Marathon on Sunday 7 November 2004 in aid of the British Renal Society.

My training started during May this year (never having run for a bus before) and, when the day finally dawned, a gloriously sunny and warm New York was revealed. The event proved to be a fantastic experience, made even better by the support of the crowd who had turned out in their thousands to watch, play music and cheer us along the way. I am proud to say that I completed the run in 4 hours 41 minutes!



Pictured above are:Dr Stevens (Kent), Dr O'Donoghue and Andy Orlowsky (Roche).

To those who have already sponsored me I would like to take this opportunity to say a big "thank you" for your encouragement and support. All monies raised will help provide funding for research into the care of kidney patients and their families and it's not too late to help support this cause.

If you or your friends and colleagues would like to sponsor my efforts in this event I would be most grateful; you can access the sponsorship form at www.srht.nhs.uk/renal/News/news\_frame.htm and by clicking on the New York Marathon link in the index.

Also available here is a Gift Aid Form, which, if you are a UK tax payer means that for every  $\pounds$ 10 donated, the Charity will receive an additional  $\pounds$ 2.80 from the Inland Revenue (28 pence extra per  $\pounds$  donated).

Please return completed forms to Patti Monkhouse, M & M Consultants, 26 Oriental Road, Woking, Surrey GU22 7AW. Thank you once again, Dr Donal O'Donoghue

# Bolton Renal Unit

The patient forum meeting held on the Thursday 14 October 2004 was a great success. The patients found the talk about 'lifestyle issues and all you must know about blood pressure' very interesting and informative and the unit had very positive feedback.

A charity night was held at the Dixon Green Labour Club in Farnworth on Friday 29 October 2004. The event was organised by one of our patients David Cowell and featured a raffle, bingo and an auction as well as entertaining artists. The staff and patients really enjoyed the evening.

The event raised a grand total of £400.00 for the unit which is greatly appreciated. We are in the process of organising a cheque to be handed

over by Mr Jim Swindells and Mr Keith Higson in the memory of Mrs Bertha Swindells which has helped provide equipment for the unit.

The unit expansion is well under way and hopefully we will have the full capacity of patients by the end of the year.

#### **COMPETITION QUESTION**

How many Christmas's has the Queen celebrated as Queen of this country up to 2003? Send your entries to the editor by 31 January 2005 – a £10 gift voucher for the winner.

Last time's winner was Mr. F. Slavin of Leigh – congratulations!

#### NKF Conference, Coventry 1-3 October 2004

The Editor attended the Saturday session of the conference which commenced with an opening address by Health Minister Rosie Winterton. During a full day there followed four presentations by prominent figures in the renal world including our own

Dr O'Donoghue who spoke on the future shape of renal services. New for this year were reflections by renal patients of their own experiences of suffering the disease and these took place between the main talks.

During the lunch and tea breaks there was the opportunity to talk with other patients as well as representatives of other KPAs and the exhibiting companies in the renal industry. One particularly interesting exhibit was a machine for administering daily 2 hour dialysis.

This was a day especially well spent and which could benefit a kidney patient in so many ways. Next year's conference is at Blackpool and is thus even more attractive due to its proximity.

The NKF can be contacted on 01909 487795 or www.kidney.org.uk

#### Renal Roadshows 2005

After 2 successful roadshows at Bolton and Oldham our next one will be held at the Quality Hotel, Riverway, Wigan on Thursday

20 January between 2.00-4.00pm. The purpose of these events is to meet people who are about to start dialysis in the near future and they consist of short presentations by various members of the Renal Team covering diet, medication, types of dialysis, role of the Social Worker and role of Hope Hospital KPA.

Patients have the opportunity to talk with each other and discover which treatment best suits their needs. Any patient currently on dialysis who would like to come along is warmly invited.

For further details or more information please contact Alec Parkinson on **01942 272838** or Sister Audrey Hyde on **0161 206 1333** 

#### And finally...

Thanks to everyone in renal for looking after us so well during this year and enjoy the festivities ahead.

This newsletter is sponsored by Mawdsley Brooks your pharmaceutical distributors

#### Your Lifestyle and Your Blood Pressure!

High blood pressure and renal disease cannot be separated, in that high blood pressure can cause renal disease and renal disease can cause high blood pressure. Most people who have high blood pressure need medication to reduce it. However there are other factors that contribute to controlling high blood pressure. The list below gives some **lifestyle issues** that can be modified to help to reduce your blood pressure:

#### Healthy Eating

- > Eat five portions of fruit and vegetables per day
- > Avoid processed food as it is very high in salt
- Reduce your dietry salt intake, daily requirements 20mmol/day (average intake is much higher at 70-170mmols/day)
- > Reduce your dietry fat intake to assist with reducing your cholesterol level

#### Manage obesity

- > Be clear as to what is an acceptable weight for your height
- Reduce your weight to achieve your optimal body mass index (BMI)
- Remember your blood pressure lowers as you lose each kilogram of excess weight (2.5mmHg systolic and 1.5mmHg diastolic for each Kg)

#### Introduce regular exercise

- There are many health benefits of physical activity, increased physical activity is recommended to help prevent high blood pressure and to reduce it in persons with elevated levels.
- > This does not have to be strenuous exercise.
- There are many pleasant and easy ways to increase you physical activity. You could walk the dog, walk to buy your morning paper, take the stairs and not the lift or introduce swimming into your weekly schedule.
- Remember start slowly, set achievable targets, be patient, gradually increase the frequency and duration and enjoy it.

#### Limit alcohol intake

The Department of Health states that men should drink no more than 3-4units per day and women no more than 2-3 units per day. If you can reduce this further it will benefit your overall well being.

NB A pint of ordinary strength lager = 2 units A pint of strong lager = 3 units A pint of bitter = 2 units A pint of ordinary strength cider = 2 units A 175ml glass of red or white wine = 2 units A pub measure of spirits = 1 unit An alcopop = 1.5 units

#### Smoking Cessation

- Smoking can seriously damage your health
- > Any reduction in cigarette smoking, no matter how small, makes a difference

#### Reduce stress

- Allow yourself some time for rest and relaxation (R&R)
- > Improve your time management
- Recognise your capabilities and learn to say no

Remember, alongside your tablets your lifestyle plays an important factor in controlling your blood pressure.

Heather Jayasekera Clinical Nurse Specialist in Hypertension Renal Services, Hope Hospital

#### 2004 Christmas Raffle Winners List

1.	Set Top Digital T.V. Box 5675 Jean, Salford.
2.	M & S Hamper 1389 Patrick McCave, Sale.
3.	Ice Cream Maker 1160 D Colbourne, Davyhulme.
4:	Clock 5105 Mrs Davenport, Standish.
5.	Internet Surf Set 3377 Mrs Walsh, Winton.
6.	Bottle of Vodka 5939 Steve Cundlish, Eccles.
7.	Bottle of Whisky 1625 P McHugh, Farnworth.
8.	Irish Country Cream 3940 Mrs Hill Mosley Common.
9.	2 Bottles of Wine Stacey Renshaw, Clifton.
10.	Desk Lamp 1752 A.Atcha, Bolton.
11.	Wine with Chocolates 4750 Ian Body, Rawtenstall.
12.	Picture 5096 Alison Powrie, Cadishead.
13.	Soft Toy 4389 Paul Newlove, Langworthy.
14.	Pasta Storage Jar 1681 Steve, Pitt; Bolton.
	Pen & Pencil Set 2794 Brian Taylor, Worsley.
16.	Soaps 4876 Eileen, Duckinfield.
	Soft Toy 3663 Mrs Owen , Irlam O'Th Hights.
	Bath Set 2471 Harvey Ackerley, Monton.

#### Autumn News Letter Competition Answers.

1. Well Wisher. Woody Woodpecker.
Willy Wonka. 3. Willy Wonka. 4. Wonder Woman. World War.
Water World.
Winter Woolies. 8. Wagon Wheel. 9. White Wine. 10. Water Wheel. 11. Wild West. 12. Windscreen Wipers 13. Wet Weekend. 14. Who's Who. 15. White Whale. 16.Weeping Willow. 17. Water Wings. 18. Wrist Watch. 19. Wood Worm. 20. Wig Wam 21. Wayne's World. 22. Wailing Wall. 23. Well Worn. . 24. Wine Waiter. 25. Wood Wind.

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