



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. February 2013
Visit www.kidneymatters.co.uk

Registered Charity No.513446

Queen Elizabeth Hospital Kidney Patients' Association

The Patients' Association for all Renal Patients treated by the Q.E. Hospital

Patients on HHD, Transplant, and PD

Dialysis Units at Aston, Tipton, Woodgate, Kings Norton, City, Sparkhill, Lichfield,
Worcester, Hereford, Llandrindod Wells, and U.H.B.,

GAVIN GILES, BIRMINGHAM CYCLIST, SELECTED TO REPRESENT GREAT BRITAIN AT THE WORLD TRANSPLANT GAMES



After being diagnosed with a kidney disease at the age of 12, my kidney function eventually dropped to a level in May 2010 where a life saving transplant was necessary and renal dialysis was imminent. In May 2011, exactly 1 year later, I was given the gift of life by my wife's brother. Just 10 weeks after the transplant I was back on my bike and in training – to restore my fitness, demonstrate the life restoring powers of transplantation, and to compete in the 2012 British Transplant Games.

Following intense training, and competing in other sporting events to raise funds for organ donation and transplant charities, I took part in the British Transplant Games in August 2012. I won silver medals in the cycling road race and cycling time trial.....just 15 months post transplant. The relief and joy was something I had never felt in sport before.

Based on my performance I have been lucky enough to be selected to represent Great Britain at the World Transplant Games to be held in Durban, South Africa from the 28 July to the 4 August 2013. I am incredibly honoured to have been asked to represent my country at the games in a sport I am passionate about and it is something I thought would never happen.

The team, which will be the largest ever, will travel to Durban, South Africa in July next year where the games are being held. More than 170 transplant athletes, including 14 juniors, and many more supporters will descend on the Rainbow Nation. A third of the team are new members and have been selected following their success at this year's Westfield Health British Transplant Games. The World Transplant Games, supported by the International Olympic Committee, represents the largest organ donor

awareness event in the world, featuring a week of 13 sporting events. Team GB and NI will join over 1000 other transplant athletes from 55 countries across the globe.

However, I do not receive any sponsorship or funding towards the trip to South Africa, so I rely on kind people and potentially businesses to help fund my training, travel, accommodation and equipment. Any money I manage to raise will help me get one step closer in my ambition to win Gold for Great Britain and my donor and bro, but most importantly show the world the possibilities of life after transplant, and the power of organ donation and its gift of life.

Gavin Giles, GB Transplant Team Member

The K.P.A. has agreed to sponsor Gavin for part of his expenses.

World Kidney Day and 45 years since the first kidney transplant at the Q.E.

On 14th March your K.P.A. is in the Atrium at the Queen Elizabeth Hospital from 9.30 am to 4.00 pm to mark this occasion and also to celebrate 45 years of kidney transplantation at the Q.E.. What a milestone and we would welcome any kidney transplant patients, family members and carers to come, meet us, and share your experiences.

K.P.A. meetings are held at the Queen Elizabeth Hospital
on the 2nd Wednesday of each month at 7.30 pm in the New Faith Centre
Please check our web site in case of a change of date.
EVERYONE IS WELCOME. SUPPORT YOUR K.P.A..



Norman Southall

It is with great sadness that we pay tribute to Norman Southall who passed away on 22nd September 2012.

Norman had been a dialysis patient for many years, first on CAPD and then on Haemodialysis. Throughout the years he never complained or let it stop him doing anything or enjoying life. For his 80th Birthday he was treated to a flying experience in an open biplane.

Norman supported the K.P.A. and was always first to volunteer for supporting our fundraising efforts. He would insist on being at Sainsburys for our tin rattles whatever the weather.

Norman will be sadly missed by us all and the Queen Elizabeth Hospital Kidney Patients' Association wish to thank Norman for the years of his support and we give our deepest sympathies to his wife Jean and her family.

Ben St Cloud Baron's Moustache

We have had some unusual fundraising ideas over the years but I think this one beats them all. Ben decided to grow a moustache for a month. Ben decided to do this when he heard that his friend's father, who is on dialysis three times a week, is hoping to have a kidney donated by his daughter later in 2013.

The month of growth raised £250. Unfortunately we do not have a photo. *I'm sure it was very impressive.*

Carillion plc

Our thanks to Carillion plc. for the very generous donation of £500 from their Employee Nomination Fund. At the end of December they chose 100 charities nominated by their employees to receive a donation.

Thank you to the member of staff who put the K.P.A.'s name forward.

The K.P.A. thanks you for the many donations we receive

The K.P.A. has received donations from very many people for which we are very grateful. Some of these are from celebrations, wedding anniversaries or special birthdays.

Sadly, many are from those who have lost a loved one and donations are sent in lieu flowers. These are those whom we remember:-

Mr B.Tyler, Mr Les Dent, Mr Norman Southall, Miss J.Priest and Mr Joseph O'Connor.

Research at the Q.E.

The K.P.A. has been supporting research projects at the Q.E. This all helps the development of better treatments for renal conditions. We provided funds towards two projects last year and the information below is a brief update on the progress of those projects.

Research Study to help patients with fistula problems

The KPA has been key to enabling another study to be done at UHB. This is being run Dr Rob Jones who is an "interventional radiologist" – a specialist X-Ray doctor. Dr Jones works closely with the kidney team helping to sort problems in patients whose fistulas have stopped working due to a narrowing of the blood vessels. Normally, patients with this problem are offered a procedure where a balloon is fed along the narrowed vessel and then inflated to make the blood vessel bigger. Dr Jones and his colleagues are carrying out a study which is looking into using balloons which have been specially coated with a drug which might help keep the blood vessels open for longer. The KPA have very generously supported this study at UHB. If it is successful, it will lead to a larger study using patients at other kidney centres.

This type of support is vital to help these small studies get off the ground. New and improved treatments often come about because of these local innovations but they need testing in proper research studies.

The KPA have been continually and generously supportive of this work.

Dr Rob Jones: Consultant Interventional Radiologist UHB
Mr Nick Inston: Consultant Kidney Surgeon U.H.B.

GTN patches in dialysis fistulas

Despite our best efforts some of the fistulas we create for dialysis fail to develop enough to be used. The reasons behind this aren't clear but it is thought that applying a Glycerol Trinitrate Patch - GTN patch (which have been used for heart problems for many years) just after the operation might help the fistulas develop better.

Thanks to the support from the KPA the Renal Unit at the QE is now in a position to hopefully answer the question as to whether these patches actually do help.

We are aiming to start recruitment to the trial very soon so that we can answer the question "Do the GTN patches help fistulas develop?"

We feel the answer to this question may really help us understand fistulas better.

Without the generous funding from the KPA this work would not be possible. Mr Nick Inston and the research team are grateful for your backing.

Dr Melanie Field: Surgical Research Registrar

Dave Davies, Geraldine Davies & Beryl Moore at their stall in Halesowen Precinct



They raised over £200 for both the Woodgate Unit and the Queen Elizabeth Hospital Kidney Patients' Association. The three of them also went to a local Car Boot sale at Hartlebury. The weather started cold but as the morning went on Summer arrived and it was too hot.

Thanks for your support.



Results of the Grand Christmas Draw

Congratulations to each and every one of you who bought and sold tickets to help us raise this tremendous sum. The draw took place on 9th January 2013. Visitors to the K.P.A. drew the tickets, together with a family member of a patient who visited our meeting.

The winning numbers are detailed below and all the winners have been notified.

One patient's husband sold a record number of tickets - over £590, which is an amazing effort. Very well done and thank you. The grand total from sales of tickets is £3371. Thank you to all the patients, carers and friends who supported the Queen Elizabeth Hospital Kidney Patients' Association Christmas Draw again this year.

We also thank those who made donations to our fund.

The Winning Numbers

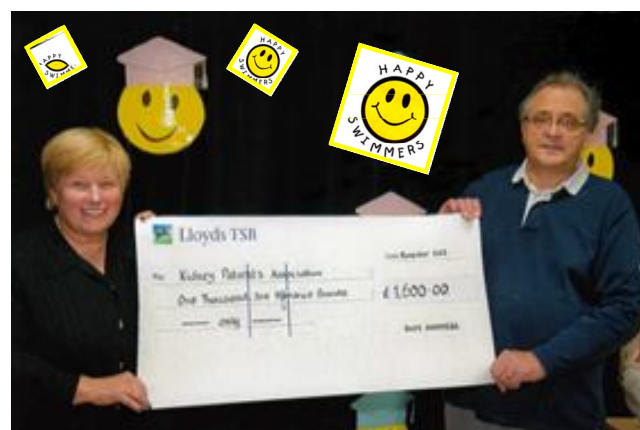
Winners Name	Ticket No	Prize	Winners Name	Ticket No	Prize
B.K.Naik Selly Oak	23501	£300	P.Healey Sutton Coldfield	10900	£10
E Jones Llandrindod Wells	15010	£150	A Patel Wednesbury	24230	£5
M Thick Ledbury	20941	£75	D Parekh Walsall	09841	£5
G Hall, Tenbury Wells	22711	£10	B Kaur Walsall	11766	£5
Mrs Giles Oldbury	01405	£10	D Jauncey Worcester	13981	£5
D N Patel Kingstanding	10226	£10	R Patel Great Barr	09741	£5
B Jhalli Darlaston	11591	£10	Mrs P Irons Oldbury	07573	£50 M & S Voucher

Halesowen Happy Swimmers

Elaine Reid organises swimming tuition for all ages. Swimmers work towards Bronze, Silver, Gold and Platinum Medals and last year decided to combine this with a sponsored swim. They raised the magnificent sum of £1600 which they donated to the Queen Elizabeth Hospital Kidney Patients' Association. One young swimmer, Leon Gilson raised £132 which was the highest amount raised by a swimmer and was rewarded for this achievement.

As Chairman of the K.P.A., I was asked to present the awards and certificates on their Presentation Night when they also presented the K.P.A. with a cheque for £1600.

It was very encouraging to see so many young people achieving their goals and also helping others. Thanks and very well done to all of you.



K.P.A. Tombola and collection

The K.P.A. organised its bi-annual Tombola and Collection at Sainsburys in Walsall on 8th December 2012. We were well supported by friends and patients and raised £506. Our thanks to Dawn Roach and her mother for organising and sorting the prizes.

We will be holding another similar event in June 2013. If anyone wishes to offer support, please contact one of the committee members.

Our thanks go to Sainsburys for allowing us to fundraise at their store and also their generous customers.



Patient Transport

Many of you who are on haemodialysis use the Hospital Patient Transport Service to take and fetch you from your dialysis unit. The K.P.A. is aware of some of the problems you encounter. I have regular meetings with the Hospital and West Midlands Ambulance to find ways of improving the reliability of the service and to provide a service that is acceptable.

The Staff at U.H.B. work very hard to try and ensure your journeys are punctual. It would be very useful to hear from any of you if you experience any problems. Your names will not be used without your permission so please keep me informed.

Nick Flint, Chairman, K.P.A.

Marathon Challenge in Cardiff

Three local men from Hereford took part in the Lloyds TSB Half Marathon in Cardiff on 15th October 2012. It was the first time that they had undertaken the 13.1 mile run which started and finished at Cardiff Castle. They raised £230 for the K.P.A. and this money will be used for the benefit of Renal patients in the Herefordshire area.

We would like to thank Chris Sandy, Roger Badham and Robbie Balough for their support. *Well done indeed*



Another fundraising success for Vera and Sylvia



Vera Masters again organised a garden fete and Christmas Fayre and raised £575. for the K.P.A. Vera, a friend and neighbour of Sylvia Goulding has been supporting the K.P.A. for many years with Spring, Summer and Christmas events. It has become a regular event in their calendar and we are very grateful for all Vera's and Sylvia's hard work and enthusiasm.

Sylvia also arranged with her local Asda Store for the K.P.A. to be one of the customers' chosen charities, with the chance of being awarded £200. Unfortunately we did not win, but were given £50 by Asda as a consolation prize. Our thanks to Asda.

Thanks to Vera and Sylvia for their continuing support.

Father and son cycle for the K.P.A.

Callum and I completed our cycle trip to the Welsh border in August and raised £200 for the K.P.A.

We had a brilliant time. Over the week we did 160 miles, camping at the Kinver Scout Camp on day 1, day 2 camping at Bridgnorth, day 3 at Wilderhope Manor Youth Hostel, day 4 at Clun Youth Hostel via the Welsh border and cycling over the Long Mynd, day 5 camping at Knowbury and day 6 camping at Wolverley near Kidderminster.

We both had a very enjoyable week and are pleased to have been able to support the K.P.A. *We thank you and well done both of you.*



Kidney Matters is now being mailed to all 2200 Renal Patients treated by the Queen Elizabeth Hospital. The cost of stamps alone is £1100. If you would like to help with this cost you can easily support us by Texting

KDNY11 £3 to 70070 and this would donate £3 to the K.P.A.

You can choose to donate £1, £2, £3, £5, or £10.

Thank you for your support and thanks to those who have already donated.

We hope you enjoy reading the magazine.

New Patient Information on Food and Dietary Ideas

Visit our website www.kidneymatters.co.uk to print them out or ask the Dietitians for them.

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