



kidneytalk

Guy's & St Thomas' Kidney Patients' Association Newsletter



RONALD MCDONALD HOUSE

Ronald McDonald House opened nearly 23 years ago as a home-away-from-home for the families of sick children being treated in the children's wards at Guy's Hospital. Since the doors opened it has been used by many parents (and siblings) of children undergoing kidney treatment.



The transplant team at Guy's and St Thomas' performs 25% of all children's kidney transplants in the UK and many of the families live as far away as Dorset. When the children have had their transplants they need to attend transplant clinic every day and the house is often used by families who would otherwise have to travel into London daily.

Currently the Guy's and St Thomas' KPA sponsor two rooms in the house: Frog and Turtle; they are the biggest rooms containing five beds; they are often used by a transplant family and soon become their 'Home from Home'.

If anyone is interested in fundraising or volunteering for Ronald McDonald House please send an email to info@ronaldmcdonaldhouse.org.uk or visit the website at www.ronaldmcdonaldhouse.org.uk

World Kidney Day 14th March

To celebrate World Kidney Day the KPA set up a stand in the foyer of Guy's Hospital to raise awareness of kidney disease and encourage people to sign up to the organ donor register.

KPA members were joined by representatives of the Trusts' Organ Donor Committee and NHS Blood and Transplant. The theme of WKD this year was prevention of Acute Kidney Injury (AKI) where the kidneys quickly lose function within a few days. It is common and harmful – it is also avoidable and treatable. It affects about 20% of

people who are admitted to hospital as an emergency.

The National Institute for Health and Clinical Excellence (NICE) is publishing new national guidelines aimed at increasing health professionals' recognition and management of AKI so it is diagnosed sooner and managed better.

Interview with **Brian Marchant**



40 Years on...

Q. Brian it is amazing that you have had your kidney transplant for 40 years, when did you realise that you had kidney problems and would need treatment?

A. I was first diagnosed in 1969. I had no idea that I was unwell. It came to light when my doctor sent me for a sight test. My blood pressure was really high and I was sent to Guy's Hospital for investigations and then to St Thomas' for haemodialysis. I was just 32 years old at the time.

Q. That must have been quite a shock were you married at the time? And did you have any children?

A. Yes it was a shock, I was married to Lillian and we had two young children at the time but we just had to get on with it. What I found most difficult was the strict diet and fluid intake which you have to follow it was very severe in those days.

Q. Did you have to have haemodialysis before you had your kidney transplant?

A. Yes I dialysed for 30 hours per week, 10 hours a day for 3 days. It was very hard and what was even worse if it was a week when there was a public holiday then I had to dialysis for 15 hours twice a week. It was a long time and not very pleasant.

Q. When did you receive the call to come in for your transplant?

A. In 1970 I received my first transplant from a deceased donor but unfortunately this was not successful and had to be removed after seven months due to complications. Two years later I was lucky enough to have my second transplant on the 22nd Sept 1972 and amazingly this one has lasted a lot longer than the first.



Q. What has your health been like over the last 40 years?

A. My health has been good, especially the first 30 years of my transplant. I have had some health problems over the last five to ten years but it is hard to know if this is just due to getting older!

Q. What would you say to someone who is just starting out on their kidney care treatment?

A. I would say be optimistic, ask loads of questions and always take your medicines. I think it is also good to build up a relationship with the doctors and nursing staff who are caring for you.

Q. Were you working at the time of your transplant?

A. I was working for the civil service at the time and they were a very good employer. I worked continuously throughout my kidney treatment until I retired.

Q. When you had your kidney transplant how long did you think it would last?

A. When I had my 2nd transplant I was not expecting too much due to my experience with my first transplant. I felt that at least it would be a break from haemodialysis; little did I know then how long it would last.

Q. Last year saw you celebrate your 40 year anniversary of your kidney transplant, how did you celebrate the event?

A. My wife Lillian and I arranged a celebration lunch over at St Thomas hospital in their grand committee room and invited family, friends and medical/nursing staff to join us. It was a lovely day and Lillian and I really enjoyed it.

Brian thank you very much for allowing us to interview you today.

TREASURER NEEDED

The KPA are looking for someone who would like to volunteer to join the committee as our new treasurer.

The role would involve liaising between the committee and our accountants and produce 9 monthly reports per year as well as giving advice regarding income and expenditure.

If you are interested and would like more information please contact: Bernadette Lynch on 0207 188 5667 or send an email to bernadette.lynch@gstt.nhs.uk

RENAL REHABILITATION CLASS

Do you find yourself lacking in energy?
Low in motivation?
Feeling weak?
Tired?

Kidney patients are generally less fit and have less strength than the general population and so you are likely to find it harder to carry out your daily activities. Regular exercise can help but how do you get the knowledge, support and motivation you need to get started? Join us at the Renal Rehabilitation class.

WHAT ARE THE BENEFITS?

Exercise helps reduce the risk of developing heart problems (coronary heart disease) and is particularly beneficial for kidney patients who are at a greater risk.

- Exercise helps lower blood pressure
- Exercise improves blood sugar levels for people with diabetes
- Exercise together with the right diet can help you to lose weight
- Exercise can have a positive effect on your mood

Exercise does not have to be a burden, with a little guidance we can teach you simple exercises and advise you on how you can incorporate these into your daily life.

WHAT'S ON OFFER?

Our programme consists of ten weekly one hour sessions of group exercise. We will assess you, and agree with you, your personal needs and goals. Then we will suggest an exercise programme for you under the supervision of our team.

We also offer advice and information on how to keep fit and how to introduce exercise into your daily life.

The classes currently run at Guy's Hospital, on a Tuesday morning and a Friday afternoon. Transport is available for those who meet the medical criteria.

WHAT DO I NEED TO BE ELIGIBLE FOR THE CLASS?

- Motivation & commitment
- A desire to improve your level of physical activity
- Ability to exercise independently under supervision

There may be some medical reasons for why exercise is not recommended for you at the current time e.g. a recent heart attack or uncontrolled blood pressure or diabetes but we are always happy to discuss this with you further.

HOW CAN I GET STARTED?

There are 2 ways that you can enrol to the Renal Rehabilitation class: Speak to your kidney doctor or nurse they can complete a referral on your behalf. Alternatively you can refer yourself to the class by emailing renalrehab@gstt.nhs.uk or call 0207 188 5106, just leave your contact details and a member of our team will get in touch with you.

Farzaana Mussa (Physiotherapist)



RAVENSTOR YHA 2013

Young Adult Weekend away

Buxton in the Peak District was again the venue for this year's Young Adult Weekend away, funded by the British Kidney Patient Association and Young@NKF. Over 35 young adults from around the country attended, taking part in a programme which included canoeing, abseiling, weaselling, and a simulated mountain rescue. Workshops on budgeting and finance, cooking, dealing with difficult situations and looking after yourself were run and a kidney patient living in the area and running his own business 'Sidecar Safari's' volunteered rides for one afternoon.

On return one of those attending from London said 'This weekend away was a great break for me. The way I deal with my condition is to keep busy. This break allowed me to focus on me. It was so nice to see what I could be like with a transplant which helped me relax a bit more about my own transplant. This trip I must say was out of my comfort zone but it pushed me to socialise more. I would strongly recommend this trip to anyone who feels out of place with their condition to come next year. You will have an amazing time and learn a lot about yourself too'.

The weekend is organised by the Renal Young Adult Service which exists to support Young Adults aged 18-25 with Kidney Disease. It aims to help people to take a greater control of their renal health condition and achieve their future aspirations. For more information about the service contact Clare Nottage, Young Adult Specialist Nurse clare.nottage@gstt.nhs.uk



Meet the committee...

Following the KPA's annual AGM we would like to introduce our new committee (above) who have been elected to stand and serve on the KPA for the coming year.



RUNNING FOR THE KPA

Virgin London Marathon 2013

This year the Guy's and St Thomas' Kidney Patients Association are delighted to announce that we had five runners competing in the Virgin London Marathon on Sunday April 21st 2013.

Our runners, Hannah Maple, Sarah Maple, Carmen Day, Edward Dell'Anno and Ben Hylton are all committed to raising funds for the KPA.

We would like to say a big thank you to our marathon runners for choosing our charity to run for and raise money. We wished them the very best of luck and of course we were cheering them on and supported them on the day.

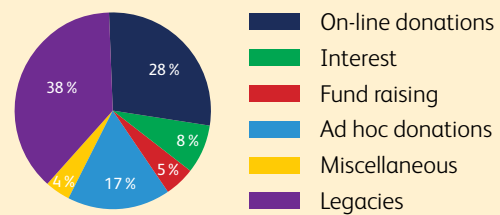
Income and Expenditure

Following requests from members at the recent AGM please find below details of KPA income and expenditure.

Balance of accounts

April 2011	£966,937.00
April 2012	£785,444.00
December 2012	£631,587.00

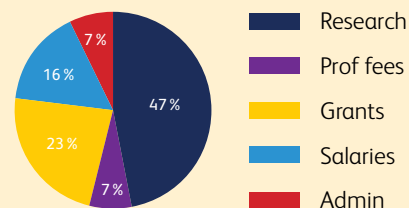
KPA Income April 2012 - December 2012



Details:

- On-line giving via just giving and virgin money, this also includes proceeds from the London Marathon runners.
- Interest from accounts.
- Fund raising – includes raffle, sale of Christmas cards & calendars.
- Ad-hoc donations – includes donations from family and friends of recently deceased patients.
- Miscellaneous – cash donations, personal fundraising activities.
- Legacies.

KPA expenditure April 2012 - December 2012



Details:

- Research – includes Medical Research Council centre for transplantation at Guy's Hospital, commitment of £500,000.00 over five years. Also funding for three in house research studies.
- Professional fees – includes auditors, website maintenance, newsletter design and print and the production of a smartphone APP.
- Grants – includes monies for dialysis unit patient events, Transplant Games and Ronald McDonald house.
- Salaries – funding for part time admin support for KPA. Funding for specialist nurse to promote home dialysis in response to wishes of a benefactor.
- Admin – includes office expenses, insurance, legal and bank fees, fund raising costs, travel and conference fees.