



GSTTKPA
Guy's & St. Thomas'
Kidney Patients' Association
www.gsttkpa.org

KPA Newsletter

November/December 2008

Are you a member of the KPA? It's **FREE** to all patients and staff, relatives, friends and supporters. Send your details to: membership@gsttkpa.org or to:

The KPA, c/o Kidney Clinic, 4th Floor, Borough Wing
Guy's Hospital, Great Maze Pond, London SE1 9RT

The last thing that the KPA posted to members was an invitation to a General Meeting in March. The reason for that meeting was that after long investigation the committee had decided that it would be a good idea for the KPA to become a 'sub charity' of the main Guy's and St Thomas' Charity (Why? See page 2). In order to do this, we had to make some changes to the constitution, hence the need for a General Meeting. To be honest, we didn't do as much preparation for the meeting as necessary. There was a good turnout of 50-60 people, and there was a great deal of discussion about the proposal. Many people, particularly some long standing members and some very new ones, spoke passionately about the issues in a frank and friendly debate. Several people raised some excellent points about the proposed changes to the constitution in particular, which were felt to be a bit vague.

The committee described parts of the proposal – particularly the financial bit – in a very confusing way. When the proposal was put to the vote, it failed to achieve the necessary two-thirds majority required for the constitution to be changed.

All of the points raised by people who objected to the proposal were noted. It seemed that nearly all of them were not objecting to the idea in principle, just about the practicalities of ensuring that the KPA retained its independence and its ability to continue to have the freedom to do whatever best represents the needs of KPA members. So the committee decided to have another go at making the agreement with the GSTT Charity clearer and more explicit in the areas where this was needed.

This is just about done and the committee is once again putting the same proposal, but will try to explain it better this time, and have some clearer information and answers. This will all happen at the AGM on 13 December, at the Roben's Suite at Guy's hospital, starting at 11am. All are welcome to come, and to vote on this proposal – I do hope you can join us.

More about why we think this is a good move for the KPA on the next page.

Extra: News from the Guy's Renal Unit. See page 5...

KPA undertakes to fund the new Medical Research Council Transplant Centre at Guy's

A couple years ago, the KPA agreed to back the application made to the Medical Research Council by Professor Steven Sacks to set up a major research centre under the Auspices of Kings College. Our backing was not just saying "We think this is a great idea!" – it was also to provide substantial funding. This application came top out of 44 applications from centres across the UK, and this year, the research centre has become a reality on the 5th Floor of Guy's Hospital. Out of a total budget of many millions of pounds, the KPA's original commitment was to provide £750,000 over five years, so that's what's now happening.

The centre is specialising in 'translational' research. This means that a top priority to turn all results into real beneficial treatment for patients as quickly as possible. Several promising things are already in the pipeline.

For a charity of our size, this is a HUGE commitment. We intend to make a big splash about this, to get as much publicity as possible, and use this to help to raise this amount or more over the same period. If we manage this, we'll be able to continue to make substantial grants in other areas, which might not get such good publicity as the glamorous research results. To raise funds on this scale is going to take some imaginative approaches – and will need as much help as possible from all who are willing. Will you help? This could include organising fundraising events and collections, but also may mean applying for grants or seeking sponsorship from benefactors of all kinds. Even in the straitened times we're in, there are still plenty of opportunities for us.

If you got a copy of this in the post, or by email, then we think you're a member of the KPA. If not, write to the address above or email membership@gsttkpa.org and we'll add your details. Membership open to all, and it's **FREE**.

Guy's and St Thomas' Kidney Patient Association

Annual General Meeting 2008

The Roben's Suite, 29th Floor, Tower Wing, Guy's Hospital
Great Maze Pond, London, SE1 9RT, on 13 December 2008 at 11am

Freshly baked home-made MINCE PIES will be served

All welcome. To give an idea of how many to expect, please let us know if you're coming by emailing chair@gsttkpa.org.uk or drop a note in at the Kidney Clinic, or by post to the address at the top of the page.

The Proposed Merger – Frequently Asked Questions

1. What is proposed?

The Committee is proposing that the KPA becomes a “sub-charity” within the Guy's and St Thomas' Charity. For all practical purposes the KPA constitutionally will continue to function as it does now, but will benefit from the professional expertise of the main charity. The main charity will manage an office on behalf of the KPA, so members and others will have an easy point of contact at all times.

2. Why is the KPA proposing this change?

The KPA has grown over the last 27 years from just a few patients to a registered charity aiming to serve more than 2500 patients. Having spent many months talking to the people who run the main charity, and others, the committee believes that the advantages of the proposal include:

- taking advantage of professional fund management skills and the potentially larger returns on the KPA funds as part of a much larger sized fund;
- the ability to employ a part time administrator/fundraiser easily, without having to spend time doing the specialised human resources (ie personnel) management job;
- having someone whose job it is to communicate with KPA members and to help organise events for members to meet each other more often;
- the ability to take advantage of the fundraising, communications and media & public relations skills in the main charity;
- the committee would continue to work on a voluntary basis, as now, but should benefit from the assistance of a paid administrator;
- members will have a single point of contact by email, phone or letter.

3. Sounds too good to be true – what's the catch?

We believe that there isn't one. There is a cost (explained below). Also the main charity will have one place on the KPA committee; this is to ensure that the KPA complies with the rules of the Charity Commissioners. Of course the KPA will be free to obtain services outside of the main charity or within it, as we decide. One perceived disadvantage of the proposal is that the KPA would lose its separate legal identity as in independent charity. We believe that this is actually in our interests, as maintaining this legal status takes up a lot of voluntary time which could be better used actually doing things that will benefit patients directly.

4. What is the cost?

KPA funds will be managed on its behalf by the main charity's fund managers in consultation with the KPA. The KPA will retain all but 1 percentage point of the annual earnings. For example, if the KPA funds were £1000, and 5% interest, or £50, were earned in one year, the KPA would keep £40 and the main charity would retain £10. We believe that this will be more than compensated for by the KPA funds being part of a much larger fund and therefore able to be invested more efficiently, and attracting larger returns than we do now.

5. What happens if either charity is wound up?

Should the KPA be wound-up or fail for any reason the funds and assets it has accrued will be used to support kidney patients – if that is not an easily identified charity within the sector it will be given to a national body representing kidney patients. The main charity has similar arrangements but with assets in excess of half a billion pounds its demise seems unlikely.

6. Has the Charity Commission agreed to this proposal?

Yes.

7. Has this happened before?

Yes. The Lane-Fox Respiratory Unit Patients' Association became a Special Purpose Fund managed by the main charity. We have discussed that experience with its chair – he only had good things to say.

8. Will the KPA still be an identifiable charity?

Yes. A good way to illustrate this is to go to www.charity-commission.gov.uk and enter 'Lane Fox' in the 'FIND A CHARITY' box. You'll see how the LFRUPA I listed as a 'constituent' of the GSTT Charity with its own registered number 251983-22. This means, for example, that anyone who wishes to will be able to make donations or bequests directly to the KPA.

9. Is there any reason why KPA members should not agree to this proposal?

It is hard to think of any technical reason for not going ahead as the autonomy the KPA, its funds and identity are all safeguarded. However, some people might feel and regret that this change represents the 'passing' of a successful but small personality-based charity.

10. What are the changes proposed to the constitution?

The existing constitution must be changed to allow the KPA to make the necessary financial and structural changes for this merger to go ahead.

There's also a long 'Memorandum of Understanding' defining exactly where various responsibilities lie, detailing the financial agreement and also describing what happens if there's a dispute, and the dispute resolution process. For full copies of these, visit gsttkpa.org.uk/merger or email chair@gsttkpa.org or write to us at the address on page 1.

11. Where can I find out more before the AGM?

To join the KPA's email group, send a blank email to: gsttkpagroup-subscribe@googlegroups.com. Then send a mail (which will also go to all the other members) asking a question to gsttkpagroup@googlegroups.com.

Alternatively, you can send a private email to chair@gsttkpa.org, or send a note with your phone number to the address at the top of page 1.

The 2007–2008 Guy's and St Thomas' Charity Annual Report is at www.gsttcharity.org.uk/pdfs/ar0708.pdf. There is much more about the charity's activities on its website: www.gsttcharity.org.uk

Also a special page on the KPA's own website: www.gsttkpa.org/merger

WWW.GSTTKPA.ORG

The KPA has owned this domain name for some time. For the last couple of years, it has been blighted with those two words of doom afflicting many a website, set up with great initial enthusiasm: 'Under Construction'.

We've now set about a gradual revamp. If you go there now, you'll find the 'Chair's Blog', which does get updated from time to time, along with a load of links to some other useful sites and a form where you can join the KPA (**IT'S FREE!**), or send us your details.

If there's something else you'd like to see there, let us know, and we'll see whether it's possible.

Newsletter and Blog

You may have noticed that KPA newsletters are extremely few and far between. That's because at the moment, we're without anyone willing to be the regular editor & designer. This thing you're reading now was put together very hastily (as you might be able to tell!) to give notice of the AGM. We'd love to produce something more frequent, but it takes time to write and produce. It would also be great to have more than one person's writing style included! Are you willing to help out? You'd need a bit of experience in producing such things, or be willing to learn very quickly ☺. You'd probably need regular access to a computer and the internet – though this need not be necessary if you'd just like to contribute an article, a letter or perhaps a story or a poem. If you're interested please email chair@gsttkpa.org.

In the meantime, our chair Andy Williamson set up a blog on the web. This was initially at thekpa.blogspot.com. The idea is that some of the stories posted there will make their way eventually into a paper Newsletter, available by post to those without email and in the Kidney Clinic and all of the dialysis centres.

Why should I join the KPA?

The Guy's and St Thomas' Kidney Patient Association is set up to represent kidney patients at the Guy's and St Thomas' hospitals. We are always talking to the staff at the hospital about ways that the service received by patients can be improved. We also hope to organise events, and other activities on behalf of patients. Another benefit received by all members, is that they get the National Kidney Federation's quarterly magazine 'Kidney Life' sent free in the post.

The KPA was started by kidney patients for kidney patients. Anyone who's interested can join. What it does is decided by its active members. These are currently mostly the people who are on the committee. There are plans to set up other groups (e.g. fundraising, social, ...) where people with specific skills or interests can also become actively involved, without having to be a committee member. If there's anything you think the KPA should be doing that isn't happening at the moment, then it's up to you to make it happen and get involved. Also, anyone can ask the committee to consider doing something – contact the Chair with your idea.

How does membership work?

To join the Guy's and St Thomas' KPA, you just need to send your details to membership secretary Ann Cooper, membership@gsttkpa.org or via the address on page 1.

Please include an email address if you have one – as that's the easiest (and cheapest!) way for us to get in touch with you. We used to charge a membership subscription fee, but decided a couple of years ago to scrap this and make membership free.

If you're a kidney patient, you're entitled through your KPA membership to receive the quarterly magazine 'Kidney Life' from the National Kidney Federation. This comes in the post, so we need to know your address.

World Kidney Day

Put a note in your 2009 diary (what do you mean you haven't got one yet!) that Thursday 13 March is World Kidney Day. See www.worldkidneyday.org. KPAs all over the country (or even the world) will be organising events to try and raise the awareness among the public of what it means to have kidney disease – and also how it's possible for everyone to help. The kernel of some exciting plans started emerging at the last KPA committee meeting. To find out more, do come along to the AGM.

Vacancies on the KPA Committee

Talking of the KPA committee, we would like to thank several people for their hard work over the years and put out an invitation for more people to get involved.

Huge thanks are due to Trevor Cook. A year ago, after two years as Chair, he stepped down to Vice Chair. He is now on the Executive Committee of the NKF as well as various other roles in the kidney world, so he has decided to step down from this role on the committee. Massive thanks too, to the KPA Secretary, Richard Baldwin; He will remain on the committee but has decided not to continue as secretary.

We must also extend enormous thanks to Binit and Laila Patel (who have been organising the collections in the local stations), James Duncan, Kate Cushion.

If you would like to nominate yourself, or anyone else for any of these places, please let us know before the Annual General Meeting on 13 December.

National Kidney Federation Young Person's Group

There are a huge number of 'young' people across the UK with chronic (i.e. long term) kidney disease. In this case, 'young' is regarded as anyone under 40. There are a whole host of issues affecting people in this age group that are very different to those in the older age groups. There's a newly 'rejuvenated' 'Young Person's Group' under the umbrella of the NKF. If you're interested in joining, you can either email the new chair: susan.frade@mhra.gsi.gov.uk or join the email group directly by sending a blank email to ypguk-subscribe@googlegroups.com.

Dialyzing outside Europe – what's your experience?

Travelling for people on dialysis are notoriously difficult to organise (although it can be done, and it's worth persevering and not just taking "No" for an answer). For people on PD, it's theoretically possible to go anywhere in the world, and the necessary supplies will be delivered there. For haemodialysis, however, things are different. The NHS will only pay for dialysis within the EU (and even then, finding a centre with space isn't always easy).

There's a lot of information on the NKF website: <http://www.kidney.org.uk/holidays/>. The section on dialyzing outside Europe is pretty thin. Another online resource is <http://www.globaldialysis.com> – has anybody used this? What did you think?

One of the KPA committee, Julet, who normally dialyzes in Camberwell, last year had a hard time sorting out dialysis for a trip to visit her family in Jamaica. We'd like to hear other people's stories – both good and bad, so that other people can learn from your experiences. South London's very cosmopolitan nature means that KPA members have friends and relatives all over the world. If you've been through this problem before, do share what happened and any advice you have.

Chair's report

Hi, this is Andy Williamson. It was something of a surprise when Trevor Cook nominated me as Chair of the KPA last year, as I'd never even been to a meeting. One of the main reasons I was happy to accept was that I felt that the KPA needed to do better at letting patients know that it exists and in organising ways that patients can meet and/or talk to each other. When I 'crash landed' at Guy's in early 2006, and started haemodialysis immediately, one of the things that kept me sane was the fact that I very quickly found the 'bulletin board' at www.kidneypatientguide.org.uk. Through this forum I was in touch with other patients all over the country and I learned a huge amount there – much more, in fact, than I had learned through coming to the clinic. So I started out with big ambitions to improve the KPA's communication with its members. I can't claim to have been very successful in that in the last year. If you agree with me and would like to help with this, then do get in touch. One of the best ways for the KPA to get its message out is to be in touch with members who don't sit there waiting for something from us to arrive, but who ask us questions, make requests or bring us problems. I'd love to hear from you.

Andy Williamson
(chair@gsttkpa.org.uk)

Camberwell – the social centre of the KPA!

The patients and staff at the Camberwell dialysis unit obviously love a good shindig! They asked the KPA to support a BBQ there in the summer, which they ran on two days, one for each dialysis shift. We were delighted to help pay for some of the food – which various KPA members bought and prepared. They had such a good time that they came back and asked the KPA to support a Christmas party, which is happening sometime in December. If there are people in other dialysis units who'd like to run something similar, do get in touch – we love to see this happening everywhere.



News from the Renal & Transplant Unit

[Many thanks to Ros Tibbles, the Service Improvement Lead at Guy's for writing up what follows, and my sincere apologies to her for forgetting to include it in the printed version of the newsletter which is being circulated. We look forward to hearing more from her, and will do our best to get it out to everyone as quickly as possible! Andy Williamson, Chair, KPA]

Dialysis Services:

As you know the numbers of people with chronic kidney disease continues to rise and therefore, demand for dialysis services is also rising. We are also very keen to continue to provide services near to where our patients live, with this in mind we are hoping to make all new units large enough to cater for outpatient clinics as well as dialysis. This should mean fewer journeys into central London for patients and carers. Guy's and St Thomas' are planning three new kidney treatment centres in the next two years:

- **Tunbridge Wells Kidney Treatment centre** – building has started at Abbey Court in the centre of Tunbridge Wells, this will replace the existing kidney unit at Pembury Hospital. It will include two dialysis units (one for people to use for self-care) and outpatient services and is planned to be open by the beginning of 2009
- **Sidcup Kidney Treatment Centre** – the site is to be confirmed; it will include dialysis stations and outpatient services and is planned to open in 2009/10
- **Southwark Kidney Treatment Centre** – the site is to be confirmed for a kidney unit near Guy's Hospital – once a site is decided we will be aiming to open the centre by mid 2009

Home dialysis - home dialysis can offer independence, flexibility and convenience and we are continually looking at ways to expand and improve the service. The nursing team visited the kidney unit in Manchester to look at how people on peritoneal dialysis and home haemodialysis and their families, are supported at home. We picked up a few good ideas that you should hear more about in the future.

Nocturnal home haemodialysis - eight home haemodialysis patients are now established on nocturnal home haemodialysis which is when people dialyse six nights a week while they sleep. This has many advantages including more free time during the day for work and family. Patients on this treatment feel very well, require fewer medicines and can eat and drink more freely. Guy's and St Thomas' are one of the first kidney units in the UK to offer this treatment.

Patient and carer involvement in dialysis services – by the time you read this the dialysis patient feedback day scheduled for September 9th 2008 will have taken place – feedback will be included in the next newsletter.

Transplant Services:

The numbers of successful kidney transplants continue to rise each year. So far this year 130 transplants have been carried out and Guy's and St Thomas' continues to be a leader in transplantation in the UK. Of the 130 transplants 66 were living donor transplants and half of these are being done before patients actually need dialysis. Dr Rachel Hilton is heading up a 'workstream' to review, improve and expand our transplant services. One of the aims of this work is to double the number of living donor transplants over the next three years. An extra transplant surgeon, Dr. Vass Hadjianastassiou, has recently been appointed.

Clinical Research:

Many of you ask about kidney research being carried out at Guy's and St Thomas' so Dr Rachel Hilton has kindly provided an update:

The Clinical Transplantation Laboratory is the department formerly known as Tissue Typing. This is where blood cells from a prospective donor and recipient are tested for compatibility before transplantation. There are a number of ongoing projects in the Clinical Transplantation Laboratory which aim to improve the way in which patients are tissue-typed before transplantation and the way in which we can detect antibodies which can cause rejection after transplantation. In future we hope that through projects like these, patients will receive better matched transplants that have less risk of rejection and will last longer. These projects are led by Dr Bob Vaughan.

In the Kidney Clinic Dr David Goldsmith has a busy research programme looking at ways of detecting and monitoring bone disease in patients with kidney disease and kidney failure. The aim of these studies is to achieve earlier detection of bone disease and so enable earlier treatment and better bone health for kidney patients. He is also investigating new treatments for anaemia in transplant patients.

Mr Nizam Mamode is exploring very sensitive methods for detecting heart muscle damage in patients following transplantation. He is also investigating ways in which the immune system responds to newer immunosuppressive treatments in transplant recipients.

Dr Rachel Hilton is looking at new ways to treat chronic rejection in transplant patients with the aim of stabilising kidney function in those patients and making their transplants last longer.

Mr Jonathan Olsburgh is exploring the reasons why transplant patients develop urinary tract infections in order to develop better ways of preventing and treating such infections.

In the main research labs a number of clinical research projects are underway. Professor Graham Lord and his team are investigating the genes and proteins that are responsible for transplant rejection, heart disease and side-effects of immunosuppressive drugs in order to help design treatments to improve clinical care and survival of transplant patients. Dr Maria Hernandez-Fuentes and Dr Rachel Hilton are studying ways of detecting whether patients have become tolerant to their transplant over time to see if we can tailor immunosuppressive drug doses to suit individual patients. Professor Steve Sacks and his team together with Dr Paramit Chowdhury are investigating a number of genetic markers that predict the chance of rejection for particular donor and recipient pairs. This study should also allow individual tailoring of immunosuppressive drug doses following transplantation so reducing the risks of excessive immunosuppression in lower risk patients.

And Finally...

Renal Patient View has been a great success. As some of you know, it aims to provide online information about patients' diagnosis, treatment, and latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world. We have been the fastest growing unit using it, in terms of patient numbers, in the UK over the last year. We have just reached 600 patients logged in. These patients now have the ability to see their results via the internet as well as the results being automatically printed in the copies of the clinic letters which all patients receive. All clinics have Renal Patient View information sheets and application forms if you wish to log on.

To see what it looks like, visit:

www.renalpatientview.org

Newsletter compiled by:
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