

The Brompton Fountain - support for parents

The Brompton Fountain is a family support group that was launched in December 2005. The charity, which is managed by parents of children with heart and lung conditions, aims to provide support and information to the families of children who are treated at Royal Brompton. Working closely with the paediatric team at the hospital, the group aims to make the experience of each child as positive as it can be. At its launch last year the Brompton Fountain launched an appeal to raise funds to improve the parents' accommodation at Royal Brompton.

The group will be launching their website www.bromptonfountain.co.uk in the near future and if you would like a membership leaflet please contact **Sharna Denehy** on 020 7776 9000.

Enhancing the Healing Environment - joint project with the King's Fund

We are currently participating in a joint pilot project with the King's Fund to look at how the environment can help patients, carers and staff. The King's Fund is an independent charitable foundation that carries out research and development work for better health, especially in London. The purpose is to improve an area of one of our hospitals and at present a project team is deciding which area to improve. The team is interested to hear your views about this issue and hopes the work will be completed by early 2007. If you want to know more about the project or would like to share your thoughts, please contact the project team by calling **Eve Cartwright**, Patient Advice & Liaison Service (PALS), on 020 7349 7715 or e-mailing e.cartwright@rbht.nhs.uk or **Rachel Matthews**, senior nurse user involvement, by calling 020 7351 8845 or e-mailing r.matthews@rbht.nhs.uk.

Patient transport awareness display



From left to right: **David Miles** - transport manager, **Ray Mittens** - Caring For You liaison manager and **Rob Sheridan** - on-site control manager

Caring For You brought along several vehicles including small people carriers and high dependency ambulances, as well as qualified crew members. This was a great opportunity for staff and patients to have a closer look inside the vehicles, meet the crew and ask questions.

Ray Mittens, customer liaison manager for Caring For You, was encouraged by the positive feedback he received from the displays and will also be visiting our wards to collect further feedback about how the service is working.

For more information about the non-emergency transport service please contact **David Miles**, transport manager, on 020 7352 8121 extension 4455 or e-mail d.miles@rbht.nhs.uk.

Useful Contacts

The Hamster Club

Harefield Transplant Patient Support Group
Chairman: Steve Syer
E-mail: steve1984@blueyonder.co.uk
Membership secretary: Ann Woodbridge
Tel: 01604 510 995
E-mail: a.woodbridge@ntlworld.com
Website: www.harefieldhamsters.co.uk

Re-Beat

Harefield Patient Support Group
Chairman: David Potter
Tel: 01923 243 672
Secretary: Dennis Gulliford
Tel: 020 8567 1246

Cystic Fibrosis Trust

11 London Road
Bromley
Kent BR1 1BY
Tel: 020 8464 7211
Out of hours: 020 8464 0623
Website: www.cftrust.org.uk

GUCH - The Grown Up Congenital Heart Patients Association

75 Tuddenham Avenue
Ipswich
Suffolk IP4 2HG
Helpline: 0800 854 759 (answerphone only at weekends)

echo uk (the fetal heart charity)

Contact: Ian Averiss
Tel: 020 7376 4481
Website: www.echocharity.org.uk

League of Friends, Royal Brompton

Contact Elizabeth Henderson
Tel: 020 7351 8272
E-mail: E.Henderson@rbht.nhs.uk

League of Friends, Harefield

Contact: Denise Branch
Tel: 01895 828 878 (ext. 5678)

The Brompton Fountain

Family support group for families of children with heart and lung conditions treated at Royal Brompton. For a membership leaflet please contact **Sharna Denehy** on 020 7776 9000.

...Patient Focus...

The Patients' Newsletter Spring 2006



Rachel Matthews

Senior Nurse User Involvement
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E-mail: r.matthews@rbht.nhs.uk

Welcome to the spring issue of *Patient Focus*. This is an exciting time as we prepare our application to become a foundation trust. This is a great opportunity for us to have more freedom to develop our services. Foundation trusts are membership organisations and I encourage you to join us as a member and show your support for our hospitals. You can also have a say in our public consultation which ends on the 19th May. For more information please read the feature on this page.

Getting involved - sharing your experience

Gareth Roberts has been a patient at Royal Brompton Hospital since 2004. Three years ago he was diagnosed with a rare condition called sarcoidosis that affects the lungs. He travels from Cheshire for outpatient visits at least twice a year.

How did you become a patient at Royal Brompton?

After I had been told I had sarcoidosis I looked for information on the internet and I found the name of the Royal Brompton Sarcoid clinic. I contacted Professor Athol Wells, consultant in respiratory medicine, by e-mail and after we talked on the telephone he suggested that I should come to the clinic.



Gareth was diagnosed with sarcoidosis three years ago

How do you describe your condition to other people?

I tell them that I have an auto-immune illness called sarcoidosis that affects my lungs. Until three years ago I was fit and active. I used to teach at a secondary school and I was head of the English department so I was very busy. When I became ill, activities that I had previously been able to do were much harder. Walking up hills and doing grocery shopping made me feel very breathless and tired. Since I started treatment with inhaled steroids and because I get specialist support from the clinical team at Royal Brompton, I am less limited by my condition. I take more care to balance activity and rest and although I have given up my job, I am pursuing other work interests.

How do you think your experience can help other people?

When I was first diagnosed I didn't know where to go for information or support. Sarcoidosis affects people in different ways and I would have found it helpful to talk to others with the condition about how they manage their symptoms. I'd like to encourage other people to get specialist help and support because by learning more about your condition you can feel more positive and in control. I'd like to help others who are going through the same experience as I did and I think that if people can talk and share their problems of an illness with each other, they lose that sense of isolation and frustration.

How to become a member of our foundation trust



We are applying to become a 'foundation trust' (FT) this year. FTs are different to other trusts because they are membership organisations, directly accountable to patients, carers, staff and the local community. FTs are also granted much more freedom to make their own decisions about developing new services and meeting the priorities put forward by their members. We believe foundation trust status will be an important development in the life of the trust and allow us to make the most of our centres of excellence at both Harefield and Royal Brompton.

To be a successful foundation trust we need as many people as possible to sign up as members and show the strength of patient and public commitment to both our hospitals. A public consultation on our foundation trust proposals runs until 19th May and we want to hear from you and get your thoughts about our plans. You can see our proposals on our website: www.rbht.nhs.uk, pick up a consultation brochure (*Our Future as a Foundation Trust*) at either hospital or contact the foundation trust office on 01895 828 631. At the same time you can sign up to be a member and have your say in the future of the country's largest specialist heart and lung centre.

How your complaints make a difference

Unfortunately there may be times when we don't meet your expectations and the service you receive is unsatisfactory. Our staff meet regularly to review complaints and make every effort to understand why we have not met your expectations and to agree what we can do in the future to put things right.

Here are two examples of actions we have taken in response to complaints we have received.

1. Waiting times/delays in the outpatients department

What happened:

A patient complained after not being seen until 2.00 p.m. despite having been given an appointment time of 11.15 a.m. The patient also commented that the clinic appeared disorganised.

Why it happened:

One senior doctor was called away on a family emergency reducing the number of doctors in clinic. At this time the junior doctors were new and took time to familiarise themselves with patients' medical records, adding to the delays.

How we have made changes as a result:

- Outpatient staff now check with the doctors in advance to see how many are available for a clinic and change the patient numbers accordingly
- ECG and echo tests can be performed earlier so the first patient is now seen at 9.30 a.m.
- Reception staff keep patients regularly informed and updated on how the clinic is running so that they are made aware of any delays in advance.

2. Management of appointments

What happened:

A patient complained that despite several attempts to contact one of our hospitals to try and confirm an appointment, he was not able to do this.

Why it happened:

Staff did not appear to know who the patient needed to speak to and as a result the patient was put in touch with the outpatient department rather than the inpatient booking office. This meant that the patient did not obtain a date for the procedure he was waiting for.

How we have made changes as a result:

- Staff have been reminded of the process of managing appointments and making sure all communications are directed to the appropriate individuals.

For further information please contact [Helen Blair](mailto:h.blair@rbht.nhs.uk), complaints manager, on 01895 828 638 or h.blair@rbht.nhs.uk.

Working with the local community - Sixty Plus in Kensington and Chelsea



Debbie Campbell, asthma clinical nurse specialist, spoke to a captive audience at the Sixty Plus lung health road shows

As a result of popular 'Heart Health' road shows organised by Sixty Plus, we were invited to join similar events in November 2005 about lung health. Sixty Plus is a voluntary organisation that offers support to older people. Debbie Campbell, asthma clinical nurse specialist, and her colleagues from Royal Brompton took part in four road shows including one held at the Muslim heritage cultural centre. The combined audience for the four events was 211 people. Everybody enjoyed the events and Debbie received lots of positive comments following the sessions. Participants especially valued: 'The clarity of explanation and the opportunity to intervene and ask questions.'

If you would like to know more about Sixty Plus please contact [Rachel Matthews](mailto:r.matthews@rbht.nhs.uk), senior nurse user involvement on 020 7351 8845 or r.matthews@rbht.nhs.uk.

Responding to public and patient feedback

Following a successful open meeting held on Monday 19th September 2005 at Royal Brompton, we have used feedback from patients and members of the public who took part to help us prepare for our 'Annual Health Check' declaration. The Annual Health Check replaces star ratings this year and is the new system for measuring the performance of trusts. Our 'declaration' is an explanation of how we meet certain performance standards set by the Department of Health.

We have responded to 35 questions raised by participants at the meeting and have prepared a report for those who attended on the day to explain our progress. There are still some areas which need more work, for example we need to raise awareness of interpreting and translation services and how we respond to patients with specific needs such as those with visual impairment. We will be working to respond to these areas in the next few months.

If you would like further information please contact [Rachel Matthews](mailto:r.matthews@rbht.nhs.uk), senior nurse user involvement on 020 7351 8845 or r.matthews@rbht.nhs.uk.

Update on progress following the NHS Outpatient Survey conducted in 2004

The last NHS Outpatient Survey took place in 2004. Surveys such as this are a useful way to find out what patients think about the care and treatment they have received. Following the results of this survey the outpatient department has concentrated on the issues around 'waiting' that were identified and the following actions have been taken:

- Reception staff now inform patients of delays when they are being registered and all staff, led by the clinic co-ordinators, inform patients of any unexpected delays as they happen. This progress has been supported by a staff workshop held in December 2005, which explored the roles and responsibilities of all staff and produced some action points about communication.
- The organisation of two clinics is currently under review. It is hoped that changes that are made as a result will mean more realistic appointment times and less over-running of appointments.

What's happening with 'Choose & Book?'

In March we held a 'Choose & Book' and 'Patient Choice' road show at both hospitals. Choose & Book is the new electronic booking service that allows patients to book first outpatient appointments at a time, date and place convenient



Visitors to the Choose & Book road shows were met by a 'mock' consulting room

to them. Giving patients more choice about how, when and where they receive treatment is an important part of the Government's health strategy. Patients now have the right to choose between at least four hospitals or clinics when they need to see a specialist for further treatment.

On 1st April we began to offer an 'indirect booking service' for four of our clinics. The clinics chosen to pilot this service are the paediatric murmur clinic at Harefield, an asthma and allergy clinic at Royal Brompton, and an adult cardiology clinic at each hospital. Patients who visit their GP and need a referral to one of these services will be offered our hospitals as one of their choices. Patients who choose to come to one of these clinics at both Harefield and Royal Brompton will be able to telephone our appointments office to book their appointment.

If you would like to know more about Choose & Book please contact [Catherine Philpott](mailto:c.philpott@rbht.nhs.uk), booking & service improvement manager, on 020 7352 8121 extension 4007 or c.philpott@rbht.nhs.uk.

CT images provide half-term interest at Science Museum

Royal Brompton radiographers Nina Arcuri and Bruce Barton met Science Museum visitors during half-term when they manned a small exhibition showing cardiac CT images. The pair were asked lots of questions during the afternoon by visitors who made sure that Nina and Bruce's knowledge and experience were put to good use!



Nina Arcuri and Bruce Barton explained how CT images work to Science Museum visitors

Correspondence about your care - information you need to know

We introduced the 'Copying Letters to Patients' initiative in 2004. When it was first introduced we asked for written permission from patients before we sent them copies of correspondence. At that time only letters about outpatient consultations were copied. However, the initiative has developed and patients should now receive all correspondence concerning them, including letters and discharge summaries, unless they tell staff that they would prefer not to.

New posters and leaflets about 'copying letters' will be available soon. New patients will receive an information leaflet with their first outpatient appointment and copies of the leaflets will be available in all waiting areas and wards.

If you would like any further information please contact [Helen Blair](mailto:h.blair@rbht.nhs.uk), PALS co-ordinator, on 01895 828 638 or h.blair@rbht.nhs.uk.

Opportunity for heart patients to get involved with the North West London Cardiac Network

The Cardiac Network in North West London was formed in 2004 with the support of the Strategic Health Authority and the chief executives from each of the local organisations. The Network has established a number of working groups to take forward specific priority areas of work. One of these groups is the Heart2Heart User Forum, which assists the Network Board in developing ways to communicate with, and hear the opinions of, local cardiac (heart) patients.

If you are a heart patient or someone who cares for a heart patient living in North West London and want to volunteer some time to help the NHS improve services for heart patients, you may be interested in joining Heart2Heart.

Please contact [Joanna Gardner](mailto:Joanna.Gardner@nhs.net), service improvement project manager/PPI lead by calling 07903508471 or e-mailing Joanna.Gardner@nhs.net.