

## Automation work begins

Building work to install an automated picking and dispensing system in the Royal Brompton pharmacy – which will allow faster and more accurate processing of prescriptions – will begin at Fulham Road on 12 March 2007, and continue for approximately nine weeks. Every effort will be made to continue an efficient service but there will be some disruption – particularly in outpatients, where waiting times could be longer than normal. Pharmacy asks patients to bear with them during this period. For more information, please contact Ian Fielding, pharmacy patient services manager, on 020 7352 8121 ext. 8038.

## New comment cards

In November 2006 we introduced a new online comment card, which can be accessed via the "patient information" section of the Royal Brompton & Harefield Internet site. This is an informal way to let us know your views, and helps us to understand the experience of those who use our services. Cards and suggestion boxes are also located at both hospital sites. For further information, please contact Sue Knott, senior quality coordinator on 020 7351 8843.

## Induction loops installed

Facilities for deaf and hard of hearing patients were improved in January 2007 with the introduction of induction loops across the Trust. Loops – which reduce or cut out background noise – have been installed at main reception areas, as well as in outpatient clinic areas. Portable loops are available for use in ward areas. For more information, please contact Catherine Philpott on 020 7352 8121 ext 4007.

## New cardiac rehabilitation room opens at Harefield

February saw the opening of a new, dedicated, cardiac rehabilitation room at Harefield.

The new room meets the British Association of Cardiac Rehabilitation national guidelines, offering patients two exercise classes a week and a multidisciplinary health promotion education package. Rehabilitation patients, including those with additional health problems, can choose an appropriate class for them.

Until now the programme has been limited by using shared locations, including the concert hall. Due to the recent lack of space, many patients have completed home-based rehabilitation programmes. The team intends to continue to offer this option, but most patients prefer hospital-based programmes at the beginning of their recovery.

For information contact Lynda Evans, senior nurse for cardiac rehabilitation services, ext. 5362.



Members of the cardiac team in the new exercise room with two rehabilitation patients, Mr Collett and Mr Chandar

## Useful contacts

### The Hamster Club

Harefield Transplant Patient Support Group  
Chairman: Carl Whittaker  
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: Dawn Haase  
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.  
Tel: 020 7776 9000.

### Primary Ciliary Dyskinesia (PCD) Family Support Group

The PCD Family Support Group is a group supporting adults and families with children with Primary Ciliary Dyskinesia. For more information contact Fiona Copeland.  
Tel: 01908 281635  
Website: www.pcdsupport.org.uk

# ...Patient Focus...

The patients' newsletter  
Issue 6 – Spring 2007



Welcome to the first edition of 2007. Thank you to all those who took the time to contact me in 2006 letting me know what you like about the newsletter. In this issue we feature specialist treatments including a groundbreaking treatment for high cholesterol in patients with an inherited condition. Our Foundation Trust application is progressing and Governor elections are under way – please see our FT update to the right. Do get in touch if you need more information or want to comment on the items featured in this issue.

**Rachel Matthews, Senior Nurse User Involvement**

Telephone: 020 7351 8845

E-mail: r.matthews@rbht.nhs.uk



## Foundation trust update

Our foundation trust application is steadily progressing. The team from Monitor (the independent regulator of FTs) first visited us on February 2, and will continue to visit over the next few months. Voting in the governors' council election is underway. All members are asked to return their completed ballot papers to Electoral Reform Services, running the election on the Trust's behalf, by 21 March. Results are due on 23 March.

## Specialist treatment that helps those with a lifelong high cholesterol condition



My name is Stephanie White and I have an inherited condition called Familial Hypercholesterolaemia which means I have a very high blood cholesterol level. Even with the maximum dose of cholesterol lowering medicines my cholesterol never reached a normal level of five and in 2001 at the age of 42 I was referred to Harefield Hospital with angina and coronary artery disease. My heart problems made it difficult for me to walk more than a short distance without getting chest pains and breathlessness. After surgery, I started a life-long treatment called LDL-apheresis.

During LDL-apheresis the cholesterol is washed out of my blood. I have the treatment once every two weeks. My blood is passed through a machine to remove the LDL-cholesterol and the treated blood is then returned back to my body. After treatment I feel very tired but can walk much further and do a lot more without getting the chest pain. I have been receiving treatment for over four years and my cholesterol levels are showing improvement.

I feel very lucky that I was referred to Dr Barbir, consultant cardiologist at Harefield Hospital who was able to offer me this specialist treatment at the LDL-apheresis unit, which is run by cardiac nurse consultant Alison Pottle. There are only five centres in the UK that carry out this treatment for approximately 40 patients.

When I was first told I had a lifelong condition I didn't really understand fully how this was going to affect me and my family, but as the condition got worse I found the help from the hospital invaluable. My family and friends have been a great support and I have also found it important to be able to talk to other patients who attend the unit.



## Don't forget – the congestion charge zone has extended

On February 19, the London congestion charge zone – which operates between 7am and 6pm Monday to Friday, excluding Bank Holidays – extended to the west of the city. Royal Brompton Hospital now falls within the zone and so anyone driving to or from the hospital will be liable to pay the charge, which is eight pounds if paid on or in advance of the day of travel.

There are certain exemptions to the congestion charge, and one is for people who are too ill to travel to hospital appointments by public transport. These patients will still need to pay the charge, but they can then claim the money back from the Trust – which will in turn claim it back from Transport for London.

To be eligible for reimbursement, a patient must:

- Have a compromised immune system OR require regular therapy and assessment OR require recurrent surgical intervention

### AND

- Be clinically assessed as too ill, weak or disabled, to travel to an appointment via public transport

The patient does not have to be the driver of the car, but simply travelling in it – so if you are driven to an appointment by a relative or friend, for example, you still be entitled to reimbursement of the charge.

To claim you need to fill in the "Patient congestion charge reimbursement claim form", hard copies of which are available in the outpatients department and in other departments frequently attended by patients. Once the form is fully completed, you can take it to the cashiers' office on Level 2 of Sydney Wing between 9.30am and 4.45pm for immediate reimbursement. Alternatively, you can post the form back to us. Postal reimbursements are by cheque, and you will need to allow 28 days for receipt.

For further information please contact general services manager, Steve Moore, on ext 8076 or via e-mail ([s.moore@rbht.nhs.uk](mailto:s.moore@rbht.nhs.uk)).

## Sponsored climb raises £14,500 for paediatrics department



Daren Marler's son Daniel was born with a heart condition which was so severe that it couldn't be completely repaired. Instead, the surgical team at Royal Brompton have carried out a series of operations to redesign his heart so that he has a healthy, and near normal, circulation.

Daniel has made great progress and is responding very well to the overall procedure.

Daren and his family felt so strongly about the quality of the care that Daniel has received that, together with family and friends, they arranged a sponsored climb of Ben Nevis in September to raise funds for the paediatric department. In total the family has raised over £14,000 for paediatrics, which will be used to buy equipment to benefit other seriously ill children in the unit. Our sincere thanks go to them and to all their sponsors.

For more information please contact director of fundraising Jennifer Walton, at [fundraising@rbht.nhs.uk](mailto:fundraising@rbht.nhs.uk)

## They'll be your PALS

You may have seen PALS leaflets and posters around the hospital and wondered what the service is all about. PALS (Patient Advice and Liaison Service) was set up in 2004 to support patients, relatives and carers. The PALS team – Helen Blair, Shaan Malhotra and Eve Cartwright (PALS Manager) are happy to help patients, carers or visitors with any concerns they may have about the Trust.

By helping with individual problems, the team gets an idea of what can be done to make the Trust a better place for patients.

The problems people encounter may include worries about whether their diet will be catered for, concerns about pets left at home while the patient is in hospital, and queries about why patients may have to wait longer than they expect for an operation or appointment.

The PALS team will always do its best to answer your questions. It hears many wonderful comments about the Trust and also wants to hear your views about what RB&H does well.

PALS has a team of volunteers who visit the wards and chat with patients. They will also listen to any concerns and act upon them if the patient wishes.

PALS is a confidential service. If you would like help with a problem or want to compliment the Trust or its staff, call into the PALS offices (ask at reception on either hospital site) or ring 020 7352 8121 (Royal Brompton) or 01895 823737 (Harefield) and ask for PALS.

Alternatively, you can e-mail [pals@rbht.nhs.uk](mailto:pals@rbht.nhs.uk)

## Staff, patients and carers blaze a trail for primary ciliary dyskinesia (PCD)



Staff, patients, and carers alike strapped on their trainers at the beginning of February to raise awareness of primary ciliary dyskinesia (PCD). A team of 24 – of which 17 were staff from the

Royal Brompton's paediatric respiratory team – completed a 10 kilometre run in London's Regent's Park in aid of the PCD Family Support Group. As well as raising awareness of the relatively rare inherited condition – which is associated with abnormal cilia and which may affect the lungs, sinuses and ears – the group exists to support those affected by the disorder.

In all the team raised over £11,000 for the group. Champion fundraiser was Professor Andy Bush who raised over £3,000. For more information visit [www.pcdsupport.org.uk](http://www.pcdsupport.org.uk)

## New way of giving patients a voice

Patients who have a prolonged stay in intensive care may have a tracheostomy performed to help their breathing. This can make it difficult for them to communicate with relatives and staff due to their loss of speech. These patients may become frustrated and isolated because of their inability to communicate efficiently.

Joy Whitman, who recently spent time on the intensive care unit at Harefield, benefited from using the "Lightwriter". This machine enables the patient to type out what they want to say. The text appears on a screen, and can then be converted to an artificial voice, allowing the patient to communicate quickly and effectively without the need for alphabet boards or writing sentences by hand. Patients can give clear and concise instructions and staff that are less experienced at lip reading can respond more quickly to patient needs.

For more information, please contact Harefield Intensive Care Unit on 01895 823737 ext 5685.



Joy Whitman using the Lightwriter machine (right) and showing (left) why it makes such a difference

## Share waiting experiences

Waiting times is a topic we often hear about, but rarely from the people who are actually doing the waiting – patients themselves. Over the next year – as we work towards the March 2008 target which states time between hospital referral and beginning of treatment should be no more than 18 weeks – we want to hear from you about your experiences of waiting.

If you would like to share your experiences and help us with our work in this vital area please contact Geraldine Gaffney project lead on 01895 823 737 ext. 5152.

## Blood Transfusion Awareness Week

April 23rd to 27th is National Transfusion Awareness Week

The aim of this campaign is to better inform patients and the public about the relative risks and benefits of blood transfusion and about appropriate alternatives to donor blood. It also aims to involve patients in transfusion safety issues.

Information will be available all week in the Anzac Centre at HH and main reception at RBH (Sydney Street), with display stands on Wednesday 25th April 10am to 3pm Anzac Centre and at RBH on Wednesday 25th and Thursday 26th April, 12 noon onwards, Fulham Road outpatients department.

## Help wanted – Harefield League of Friends

We are a small, friendly group of volunteers looking for part-time extra help in our shop and bistro-style café. If you would like more information or think you could spare some time please contact Dawn Haase, manageress, on 01895 828 678 ext. 5678.