

New lung function appointments

THE LUNG function department at Royal Brompton is offering additional test appointments due to strong ongoing demand for the service.

From 5 February twelve additional lung function appointments have been made available each week. These new evening appointments have been introduced as a direct result of patient feedback received in a recent questionnaire.

For more information on the extended service, please contact **Derek Cramer**, consultant clinical scientist and head of the lung function department, on **020 7351 8057**.

A happy reunion



Margaret Hodson, professor of respiratory medicine and honorary consultant physician (centre), is pictured at the Harefield Heart and Lung Transplant Club annual dinner, held in October, with some of our cystic fibrosis patients who have undergone transplantation.

Do we have your correct contact details?

To update your details, please contact **Rose Paton** at r.paton@rbht.nhs.uk or on **01895 828 631**.

Sharing our knowledge of COPD

VISITORS to Royal Brompton's Sydney Street reception and to Fulham Broadway shopping centre were offered the chance to find out more about chronic obstructive pulmonary disease in November.

Staff at RBH organised and manned stands giving information on the condition to mark World COPD Day on 14 November. Also in November, patients were offered the chance to learn more about our current research into the condition. Visitors listened to talks and took written information on COPD and the British Lung Foundation. COPD causes breathing difficulties and is the cause of more than 30,000 deaths in England and Wales in each year.

For more information on the World COPD Day events, contact **Suzanne Regan**, COPD clinical nurse specialist on **020 7352 8121 bleep 1052**. For more information on the research day, contact **Dr Amanda Sathyapala**, clinical research fellow, on ext. **8029**.

Useful contacts

The Hamster Club

Harefield Transplant Club
Chairman: Carl Whittaker
Secretary: Lisa Innes
E-mail: secretary@harefieldhamsters.org.uk
Website: www.harefieldhamsters.org.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 (answer-phone only at weekends)

British Cardiac Patients Association

2 Station Road
Swavesey
Cambridge
CB24 5QJ
Helpline: 01223 846845

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 828 678

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 who support adults and families with children with Primary Ciliary Dyskinesia. For more information contact Fiona Copeland.
Tel: 01908 281635
Website: www.pcdsupport.org.uk

Duchenne Family Support Group

78 York Street
London
W1H 1DP
Tel: 0870 241 1857 (office)
Tel: 0870 606 1604 (helpline)
E-mail: info@dfsg.org.uk
Website: www.dfsg.org.uk

...Patient Focus...

The patients' newsletter
Issue 9 – Spring 2008



WELCOME to the spring 2008 edition of Patient Focus. As you will see, the year at Royal Brompton started with a series of VIP visits, two of which were to thank us for the support we gave to our neighbours at Royal Marsden Hospital following the major fire there.

We closed 2007 with a successful patient and public involvement event where we invited you to join us and tell us what issues you think are important for patients. You can read more about this on Page 3.

Over the next 12 months we want to keep you informed about changes we are making to improve services. If you are interested in helping us find ways to do this, please get in touch.

Rachel Matthews

Senior nurse user involvement
020 7351 8845
r.matthews@rbht.nhs.uk

Over 60 people attended our December PPI event. See Page 3 for full details.



Royal Brompton Hospital welcomes three VIP visitors



Clockwise from top left: HRH The Prince of Wales meets patient Kathryn Tayes on Elizabeth Ward; HRH meets Yolande Smuts, patient services manager in the catering department; Prince William meets staff from both RBH and the Royal Marsden; Prime Minister Gordon Brown and wife Sarah chat with Royal Marsden patient Fathieh Sardi Shihab who was evacuated to Princess Alexandra Ward.



THE NEW year at Royal Brompton began with a series of VIP visits.

In the aftermath of the major fire on 2 January at the Royal Marsden Hospital – which saw several of their patients temporarily evacuated to Royal Brompton – Gordon Brown and Prince William visited the hospital to thank staff for their efforts and to meet patients who were affected.

A little over a month later, patients and staff welcomed HRH The Prince of Wales to the hospital. The Prince was attending a Soil Association seminar on the importance of good hospital food. Royal Brompton was chosen to host the event due to our commitment to providing quality food, to procuring 20 per cent of it either locally or from organic sources, and for supporting local farmers and suppliers.

All photos of HRH The Prince of Wales copyright RIXphotos.com

Research and development: at the heart of Royal Brompton & Harefield

ONE OF the hallmarks of our Trust is a complete dedication to research. Each day our staff work not only care for patients with heart and lung disease but also to uncover new ways of diagnosing and treating those diseases. It is their research work which has, over the years, led to medical advances taken up across the NHS and beyond.

We have recently published a report on research and development activity at the Trust, available on our website at www.rbht.nhs.uk/research/overview. The report is primarily aimed at potential academic and business research partners but we also hope it will be of interest to patients and the public, providing an insight into the fascinating research conducted at our hospitals. It details studies currently being managed at the Trust, including the recently launched Control of Hyperglycaemia in Paediatrics Trial (CHiP), the first multi-centre study to be carried out in UK children's intensive care units. CHiP will look at whether strictly controlling glucose levels in chil-

dren in intensive care – as already happens with adults in intensive care – leads to fewer deaths, shorter stays in hospital, and fewer complications. You can read more about the study on our website at www.rbht.nhs.uk/research/overview/hyperglycaemia

The need for patient input is just as central to our research as it is to the many other aspects of our work. It is only through the involvement of patients, for example, that we can test new therapies in clinical trials. Patient feedback can fundamentally inform which treatments we develop and investigate. For example, while an injection that has to be self-administered four times a day might scientifically speaking be a highly successful treatment, patients might prefer a treatment which is marginally less effective but considerably more convenient to their lives. The starting point of all of our research is the needs and preferences of our patients – and finding out more about those needs and preferences is an important part of the process.

If you would like a hard copy of the report, or to find out more about how you can get involved in our research activities, contact [Rachel Matthews](mailto:r.matthews@rbht.nhs.uk), senior nurse user involvement, on **020 7351 8845** or via e-mail at r.matthews@rbht.nhs.uk.



Our recently published R&D report details the range of research activity currently being undertaken at the Trust

Good performance in 2007 national outpatient survey

WE WERE once again pleased to receive very positive results in the national outpatient survey.

The overall level of care was ranked as "excellent", "very good" or "good" by 93 per cent of those who responded to the survey. The vast majority – 96 per cent – also believed that the reputation of our hospitals was "excellent", "very good" or "good".

The results of the 2007 survey compare favourably with the results of the 17 other English trusts which participated. They also show where there is still room for improvement. One area we will focus on is improving the information given to patients on clinical issues and on waiting times in clinic.

For more details on the survey and the results, please contact [Sue Knott](mailto:Sue.Knott@rbht.nhs.uk), senior quality coordinator, on **020 7351 8843**.

Harefield patient awarded an MBE

A HAREFIELD Hospital transplant patient has been recognised in the New Year's honours list.

[Paul Randall-Morris](#), who received a heart transplant at Harefield in 1989, was awarded an MBE in recognition of his work for charity. Paul is the founder of the Cornish Heart Unit Fund, which aims to improve the quality of care for heart patients in Cornwall.

He has also raised significant amounts of money for Harefield.

Patients, staff and public share views at December PPI event



STAFF, patients, and members of the public came together in December to discuss a central question in healthcare: what matters to patients and carers.

Some sixty people attended the patient and public involvement (PPI) event, dividing into small groups to take part in two discussion sessions. In the morning, groups worked to identify the issues that are most important to our users. In the afternoon, the topic was how to make our services accessible to all.

The discussion was lively and many central themes were identified. Feedback gathered on the day will be used to create an action plan and will inform an updated PPI strategy.

For more information on PPI and the event, contact [Rachel Matthews](mailto:r.matthews@rbht.nhs.uk), senior nurse for user involvement, on **020 7351 8845** or via e-mail at r.matthews@rbht.nhs.uk.

You can also visit the PPI pages on the Trust website at: www.rbht.nhs.uk/patients/support/involvement

Farewell to PPI Forums, hello to LINKs

THE WAYS in which patients and the public are involved in health services are set to change following the passage of The Local Government and Public Involvement in Health Act.

The act, which was passed late last year, introduces a number of new initiatives, including the replacement of PPI Forums with Local Involvement Networks (LINKs). These networks will be responsible for seeking the views of those who use health and social care services.

In the past three years, the members of our PPI Forum – [Josephine Ocloo \(chair\)](#), [Tess Jelen](#), [Ken Appel](#), [Hiikmah Kohle](#), [Wharton Shober](#), [Jonathan Cheah](#) and [Sanchia Smithson](#) – have contributed to our work on a range of issues, including equality and diversity, patient safety, disabled parking, infection prevention and control and complaint management. We thank them for all their help.

LINKs will be based in each local

authority area and so we will be represented at both the Royal Borough of Kensington and Chelsea (for Royal Brompton) and the borough of Hillingdon (for Harefield).

If you would like to know more about LINKs or any of the other changes to PPI please contact [Rachel Matthews](mailto:r.matthews@rbht.nhs.uk), senior nurse user involvement, on 020 7351 8845. You can also contact Rachel via e-mail at r.matthews@rbht.nhs.uk

Meeting the religious needs of patients and visitors

WORK on meeting the religious needs of our patients and visitors continues apace with the opening of multi-faith rooms on both sites and the appointment of a new chaplain at Royal Brompton.

The multi-faith rooms opened last year and are available for prayer, meditation and quiet contemplation by those of any faith.

The rooms – at Harefield opposite B East Ward and at RBH opposite the chapel – are open for the main part of each day.

The Reverend Susan Hollins has recently joined us for a six month term as locum healthcare chaplain at Royal Brompton. Susan will be setting up a new chaplaincy service at the hospital.

For further information on chaplaincy services at our hospitals contact [Ann Percival](mailto:Ann.Percival@rbht.nhs.uk), deputy director rehabilitation and therapies and manager for the chaplaincy on **020 7351 8056**.