

Opportunities to get involved

PATIENT and visitor feedback is an important way in which we at the Trust can learn what we are doing right and what we could be doing better. As a result, we are always keen for members of the public to get involved in our work.

Since April, Local Involvement Networks (LINKs) have offered a formal way in which to share opinions on our services. LINKs replace PPI forums and offer an opportunity for local people to influence health and social care

services. For more information, visit www.nhscentreforinvolvement.nhs.uk.

Within the Trust itself, our PPI core group continues to meet four times a year to discuss issues of importance for patients and visitors. So far this year the group has discussed issues including data protection, an appointment reminder service, and the new NHS Choices website.

There are also several less formal ways in which you can give us

your opinions. "Your views" cards have been introduced across the Trust in the past year and offer a quick and easy way to tell us what you think. Often raised are issues about our buildings and so, on 28 July, members of the estates department will be meeting with the PPI core group to discuss this area.

For more information on how you can share your opinions, please contact **Rachel Matthews** on **020 7351 8845**.

Patients get involved in PEAT



Volunteer Emma Dalton and patient Michael Lewington are pictured with general services manager Steve Moore. Emma and Michael helped with this year's Patient Environment Action team (PEAT) inspection at Royal Brompton while patient Stephanie White and volunteer Sue Eden took part at Harefield. The teams tasted food and rated a range of facilities at our hospitals.

Have we got your correct address?

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

Useful contacts

The Hamster Club

Harefield Transplant Club
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 (answerphone 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 Averis
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: 0800 121 4518
E-mail: info@dfsg.org.uk
Website: www.dfsg.org.uk

...Patient Focus...

The patients' newsletter
Issue 10 – Summer 2008



WELCOME to the summer 2008 issue of Patient Focus.

This issue features a report on the theatres open day at Harefield – always a popular local event – as well as information on a recent emergency simulation at the hospital.

We also review a range of recent reports which have highlighted the quality of services at our Trust. To read the full details of our recent inpatient survey – in which we placed in the top 20 per cent of trusts in England – visit www.rbht.nhs.uk/patients/support/involvement/your-views.

If you would like to know more about how to get involved and share your views please do get in touch.

Rachel Matthews

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

Another VIP visit for Royal Brompton – see Page 3



Patient events draw crowds

TWO RECENT events at the Trust have seen hundreds of patients and carers gain a special insight into our work.

In May, well over a hundred people visited Harefield's theatres, taking the opportunity to see areas normally closed off to anyone not in scrubs or hospital gowns. The open day included presentations from theatre staff on their work. Visitors were even given the chance to play surgeon with mocked up keyhole surgery sessions providing entertainment.

The following month saw visitors gather for a Trust-led patient event on heart rhythm disturbances. The event was organised in partnership with the British Heart Foundation and the Arrhythmia Alliance and saw a range of Trust staff give presentations.

It was timed to coincide with Arrhythmia Awareness Week, which aims to increase knowledge of arrhythmias amongst both the general public and the healthcare community.

Staff and patients at the Trust were also involved in the official launch of the week, with nurse specialist Nicky Margerison travelling to Westminster with Harefield ICD patient Keith Cook to mark the week's start.



Left: a visitor at the open day learns more about the work in theatres. **Right, L to R:** Laura Nelson from Arrhythmia Alliance; Keith Cook and his wife; and nurse specialist Nicky Margerison at the launch of Arrhythmia Awareness Week.

Fundraising successes boost services

WHILE NHS funding allows us to provide the care our patients need, it does not always enable us to invest in the cutting edge research, equipment and amenities for which our Trust is renowned. It is here that fundraising activities are crucial. In the past few months, several events have seen vital funds raised for our services.

At the end of February, a host of stars from stage and screen came together for a special event which raised thousands of pounds for a new research project. "I'd like to teach the world to sing" was a concert organised in memory of renowned singing



The cast of "...Teach the world to sing".

teacher Ian Adam, a long time patient at Royal Brompton who sadly died in May 2007.

Over 50 of his famous friends and former pupils – including Bonnie Langford, Elaine Page, and Andrew and Julian Lloyd

Webber, who performed together for only the second time in their careers – put on the four hour extravaganza at Her Majesty's Theatre on 24 February.

All money went towards Singing for Breathing, a new research project which encourages those with breathing difficulties to sing as part of their therapy.

Fundraising by The Ben Williams Trust, meanwhile, means that children being treated at Royal Brompton for heart rhythm disturbances will be cared for by their own specialist nurse.

Catherine Renwick has been appointed paediatric cardiac electrophysiology nurse specialist.

Catherine's will also be known as "Ben's Nurse" as her appointment and post has been made possible by the The Ben Williams Trust.

The Trust was set up two years ago following 14-year-old Ben's death from a heart arrhythmia. It aims to work with the medical

community to raise awareness of heart muscle disorders in children and young adults and to promote and support research into their diagnosis, control and treatment.



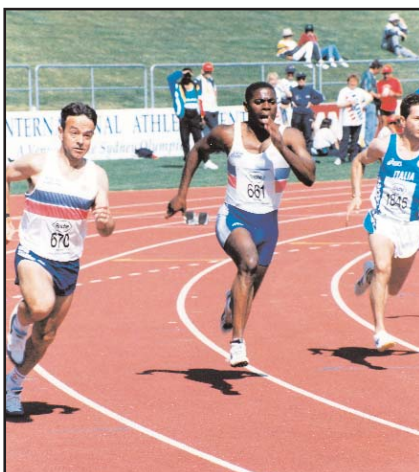
Ben Williams' parents Philip and Gilly with consultant paediatric electrophysiologist Jan Till (second from left) and newly-appointed "Ben's Nurse" Catherine Renwick (second from right).

For more information on fundraising work at the Trust e-mail fundraising@rbht.nhs.uk or call **020 7351 8613**.

Preparations for Harefield Fun Run well underway

Looking forward, preparations are well underway for this year's Harefield Fun Run. The event will take place on Sunday 7 September with money raised going towards the MRI scanner appeal. As ever entertainment will be provided, making the day a perfect family event. For more information and an entry form visit www.rbht.nhs.uk/about/fundraising/news/events/fun-run or phone the Harefield fundraising office on 01895 828 820.

Remembering Carl Whittaker: 27/5/60-10/6/08



Carl (centre) in competition

IT IS WITH sadness that we report the death of Harefield heart transplant patient Carl Whittaker.

Carl was a testament to what an individual can achieve post-transplant. In the years following his operation – carried out by Professor Sir Magdi Yacoub on 19 November 1984 – he became an inspiration to staff, patients and carers, not least because of years of outstanding athletic performances at British and World transplant games.

In his early years Carl specialised in sprinting, later also taking up the 400m and High Jump. Even after his stroke in 2006 he never stopped wanting to get back on the track and was incredibly persistent in his endeavours to get back to being mobile.

Carl became the success story which backed the rapid expansion of transplants at Harefield in the 1980s and 90s.

He will be fondly remembered and sadly missed.

Planning for an emergency



READINESS for a major emergency at Harefield was tested on 20 May with a large scale simulation.

The exercise saw staff from the hospital joined by colleagues from the London Fire Brigade, the Metropolitan Police, Hillingdon Hospital, Primary Care Trust and Borough Council, the Health Protection Agency and NHS London to test preparedness for a fire in the hospital.

The simulation was the largest multi-agency exercise carried out at Harefield in two decades and one of the largest in London for some years. It offered the chance to test both our emergency procedures and improve our working relationships with all the agencies involved.

A total of 13 fire brigade vehicles and 60 firefighters ultimately arrived at the site. Meanwhile, an incident planning room was established with representatives from all the main departments affected by the incident.

The exercise was structured so that staff were informed of fresh events in real time, simulating the effects of unexpected developments in a real emergency.

Similar exercises are planned for later in the year at Royal Brompton.

Reports highlight our quality services

A RANGE of recent publications have highlighted the high quality of our services.

In late June, statistics published by the Royal College of Physicians, the Healthcare Quality Improvement Partnership, and University College London confirmed that patients coming to Harefield for primary angioplasty are treated faster than anywhere else in the country. Patients taken to Harefield for the procedure – in which a catheter is used to unblock arteries and a stent used to keep the arteries open – are treated within 23 minutes of arrival. The national average is 56 minutes.

Also in late June, the Healthcare Commission published updated **survival rates for patients undergoing heart surgery**. The data shows that our overall heart surgery survival rates are better than would be expected by European standards. Only five centres achieved this accolade.

Meanwhile, a **patient survey on cancer services** has shown that patients being treated for the disease rate our care highly. Of those who responded to the survey, 75 per cent described the care they had received as "excellent" with 24 per cent rating the care "very good" and one per cent "good".

Another VIP visit at Royal Brompton



In June, **Gordon Brown** made his second visit to Royal Brompton this year. The Prime Minister was on site to open the hospital's new magnetic navigation catheter laboratory, the most advanced of its kind in Europe. During his visit, the PM chatted with patients who had been treated in the lab (including **Frances Severne**, above left) and met staff including director of operations **Patrick Mitchell** (above right).