

An exciting new arts residency underway at Harefield Hospital

The artists Tim Wainwright and John Wynne have been working with patients, staff and relatives involved with transplantation since April this year. They will be working at Harefield for a year in total to produce a ground-breaking exhibition, integrating still photography with sound to show something of the radically life-changing experience of transplantation.



'angie and maureen' © Tim Wainwright

In developing this project with the artists, one of our aims was to dispel some of the myths surrounding transplantation - to show the humanity of the situation and how this highly emotional process affects all those involved. We were keen to show the perspective of the patients and relatives who are going through this extraordinary experience - one which relies on astonishingly rapid developments in medical care and one which is full of great challenges as well as miraculous stories.

Tim and John are keen to speak to anyone connected to the transplantation programme (inpatients, outpatients, relatives, members of staff) that would like to get involved. Contact us at rb&hArts if you would like to find out more or download the information pack from www.rbht.nhs.uk/arts.

We are currently fundraising to make this exhibition possible, in the hope that it will be seen by as wide an audience as possible across the country.

If you feel you can make a donation towards this please contact us at rb&hArts (020 7352 8121 x4087, arts@rbht.nhs.uk or rb&hArts, Royal Brompton & Harefield NHS Trust, Sydney Street, London SW3 6NP).

Photos reproduced with permission from Tim Wainwright.



'Everybody kept praying for me' © Tim Wainwright

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: 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 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

...Patient Focus...

The Patients' Newsletter Winter 2006

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Welcome to the winter edition of our patient newsletter. This is the third and final edition for 2006 and as the year draws to a close we have plenty to report about events and activities at our hospitals.

Since we increased the circulation of the newsletter to include people who have joined as Foundation Trust members, we have received some very helpful feedback about what to include in future editions.

Dates for your diary in 2007 should include the elections for Foundation Trust governors that will take place in March. In the meantime please get in touch if you want to comment on the projects we have featured.

Rachel Matthews

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What happens at the specialist angina clinic?



Clinical nurse specialist Christine Wright with angina clinic patient Ferdinand Minin

Last year Ferdinand Minin began treatment at the clinic with clinical nurse specialist Christine Wright, after a long battle with angina; he had a bypass operation in 1994, but four years later he was put on medication when his angina returned.

Christine started Ferdinand on the Angina Plan, a home-based cardiac rehabilitation programme helping patients understand angina and manage their condition by eating well, controlling their blood pressure, exercising more and quitting smoking.

"It helped to increase my confidence so that now I can do more exercise with less angina," Ferdinand said. "Having a point of contact with the nurse was the best thing, and it was great that the pain management clinic lent me a TENS machine to help relieve my angina."

The programme aims to reduce fear and anxiety; Ferdinand agrees saying the relaxation tape, which teaches breathing techniques to relieve tension, helped him enormously.

The Angina Plan has worked well for Ferdinand. "The clinic has given me a new lease of life. Angina is not the end of the world," he says.

Foundation Trust Update

Our application for Foundation Trust status was submitted to the Department of Health at the beginning of November. Towards the end of October, we were pleased to receive confirmation from the new London Strategic Health Authority that it will support our application when the Department of Health comes to assess it.

The Secretary of State's decision on which trusts will be allowed to go forward for assessment by Monitor, the independent regulator of foundation trusts, is expected around the end of December.

We are therefore beginning to make plans again for elections to the new Board of Governors. We plan to hold elections in February/March 2007 - which means that we will be seeking candidates to stand as Governors from now until February when nominations will close.

Look out for further information about the role of Governors, and think about standing for election.

If you want to know more, contact Robert Craig ext. 5560 or email r.craig@rbht.nhs.uk or email foundation@rbht.nhs.uk.

British Transplant Games: Bath 2006

Well done to the Harefield team on their large haul of medals, including 14 gold, 13 silver and 13 bronze medals. This effort almost regained them the Tesco Cup for best heart team at the games.

The Harefield team (David Barratt, James Baxter, Roger Bell, Colin Clements, Jill Edwards, Mick Foster, Lisa Innes, Julie Kirby, Alan Lees, Geoff Twilley, Brian Unwin, Alex Walker, Howard Waters, Brian Witham and Ann Woodbridge) competed in the cycling, fishing, golf, squash, badminton, table tennis, canoeing, tennis, swimming, archery and athletics events.

Patient and Public Involvement Forum taste hospital food

The Royal Brompton and Harefield NHS Trust's Patient and Public Involvement Forum members had a taste of both hospitals' food as part of Food Watch; a national initiative organised by the Commission for Patient and Public Involvement in Health (CPPIH).



Forum member Tess Jelen quizzes Mike Duckett, Royal Brompton catering manager

After investigating the way food is served, the quality of food and food facilities and assessing eating areas for patients, staff and visitors, members said the quality and source of food was outstanding.

At the Royal Brompton much of the food is organic and ethically sourced, including fair trade tea and coffee. Staff are trained to meet diverse dietary requirements such as gluten intolerance. At Harefield, a special menu booklet is available to give patients information about food and catering services.

To find out more about the forum and its activities or if you would like to become a member, please contact the forum co-ordinator **Gayle Muers** on 020 7535 0495 or email on gmuers@vawcvs.org

Annual health check and top rating for our children's services

The Healthcare Commission announced the Trust's inaugural annual health check results last month. We celebrated an overall score of good for our quality of services and fair for our use of resources.

These results show a strong performance across the board in a far more comprehensive assessment than the previous star rating system.

We are particularly proud of scoring the highest ratings possible for our services for children in hospital (we were one of only 6 trusts in England to be rated excellent) and our performance on all national targets.

For more details visit: <http://annualhealthcheckratings.healthcarecommission.org.uk/annualhealthcheckratings.cfm> or contact **Lucy Davies**, head of performance, on 020 7351 7713.

Spotlight on Re-Beat - Helping patients having heart and lung surgery

Re-Beat offers advice, support and companionship to heart or lung surgery patients. The group's fundraising for equipment and refurbishment, regular newsletter, meetings, events and activities benefit patients enormously.

Re-Beat members are also involved in working groups and committees here at the Trust, like the Patient Amenities Fund, Older People's Steering Group and the Patient and Public Core Group. They play an important role improving communication between patients and managers, clinicians and other NHS organisations.

Re-Beat welcomes new members. To find out more contact **Mr Dennis Gulliford**, Secretary, on 0208 567 1246.

The Trust is linked to a number of excellent patient support groups, if your group would like to be featured in Patient Focus contact **Rachel Matthews**, senior nurse user involvement, on 020 7351 8845 or email r.matthews@rbht.nhs.uk

'Patient stories' influence care for immunology patients

Patient feedback is key to making sure our services best meet patients' needs. Lorraine Ozerovitch, a clinical nurse specialist, says feedback has influenced her work greatly.

"We have changed the way we treat common variable immune deficiency at the Royal Brompton hospital to better meet patient needs.

"Patients were concerned about the care they received away from a specialist centre, as some GPs are not always familiar with rare and unusual conditions. As a result, we now write letters for patients, outlining their illness and the treatment required."

Lorraine says the letter helps patients explain their condition to GPs and other health care workers. "If patients are admitted to local hospitals they can use the letter to quickly communicate, giving them greater confidence about their treatment outside a specialist clinic."

Fundraising News



Ushma Dasani and Rujina Begum, Indian henna artists, with a fun runner

Braving the heat on 10 September, around 900 walkers and runners took part in the 25th Harefield Fun Run, fundraising for a new CT scanner.

Many participants were heart or lung transplant patients at Harefield hospital. Elin Zych travelled from Wales to take part. "I thoroughly enjoyed the whole day. My transplant has given me a new perspective on life and I don't take anything for granted any more - I've been very lucky," she said.

The participants had tremendous support from staff, sponsors and the Harefield village. Joan Morecambe, wife of comedian Eric Morecambe who started the first fun run, cut the tape to a drum roll by Philip Dunne, who has recently undergone major heart surgery.

The Trust's patient and public involvement forum had a stall at the fun run selling home made cakes and cards, and organised a stand for Indian henna tattoo artists. Forum member Jonathan Cheah said, "It was a good opportunity to meet new people, talk about the forum, and help with the scanner appeal."

"With donations from the fun run still coming in, we are on track to beat the £42,000 raised last year", says **Jenny Walton**, the Trust's fundraising director.



Forum member Ken Appel with Colin Moore from Harefield radio

Central London Congestion Charge Extension - what you need to know for 2007

The Central London Congestion Charge's western extension covers the Royal Brompton Hospital. The extension comes into effect on Monday 19th February 2007 and operates from 7:00am until 6:30pm excluding Saturdays, Sundays, Bank Holidays and the three days between Christmas and New Year.

Reimbursement - eligibility & claims

NHS patients who have a compromised immune system, who require regular therapy, assessment or recurrent surgical intervention and are clinically assessed as being too ill, weak or disabled to travel to an appointment on public transport will be able to claim reimbursement.

To claim you will have to complete a form widely available throughout the hospital and have it signed by the health professional you are visiting.

More details will follow in the next issue of Patient Focus.

Blue badge holders and exemptions

Drivers of vehicles used by disabled persons that have a blue badge will not have to pay the charge, provided you register with Transport for London and make an annual payment of £10 per vehicle. Motorbikes, mopeds, bicycles and vehicles used by disabled persons that are exempt from Vehicle Excise Duty are also exempt.

For more information visit www.cclondon.com or call 0845 900 1234. If you are hearing impaired and use a minicom please dial 020 7649 9123.

Rest the heart for recovery says leading cardiologists

Groundbreaking research undertaken at Royal Brompton & Harefield NHS Trust received widespread national and international media coverage this month.

The research found that resting the heart using combined mechanical and drug therapy can reverse the damage caused by heart failure, and lead to recovery in some patients.

Patients participating in the study were fitted with an artificial heart called a left ventricular heart assist device and followed a specific drug programme. Of these patients, 75 per cent recovered and nearly all were free from heart disease five years later.

"This combined therapy has the potential to offer patients a better alternative to a donor heart - their own healthy heart," says Dr Emma Birks, cardiology consultant and lead researcher.