



A lifetime of specialist care

Patient *focus*...

Autumn 2013

Children's heart surgery update



In June this year, the Secretary of State for Health, Jeremy Hunt, suspended the Safe and Sustainable review of children's heart surgery.

He accepted a report from the Independent Reconfiguration Panel (IRP), which concluded that the original recommendations made in July 2012 by a joint committee of primary care trust (JCPCT) chief executives, which included ending children's heart surgery at Royal Brompton, were based on "flawed analysis of incomplete proposals and their health impact".

Trust chief executive, Bob Bell, commented: "This is very welcome news indeed. It was back in February 2011 that we first made the Safe and Sustainable team aware of the serious flaws in their methodology. It is a tragedy that our concerns were not acted upon then.

"I know that patients and their families are overjoyed by the news. They have never been able to

understand why one of the best performing and largest units in the country was destined for closure, especially when statistics showed that the population in London and the South East was growing faster than had previously been thought, and demand for children's heart surgery was increasing."

NHS England has now been tasked with developing a new approach to children's heart surgery. The team leading the new review has confirmed the importance of considering the whole patient journey – from antenatal testing and diagnosis to adult monitoring and interventions.

This new approach is a vital step forward for the future of children's heart surgery at the Trust and we look forward to working with NHS England over the coming months.

For more information, visit www.rbht.nhs.uk/childrens-heart-surgery

Welcome to our Autumn issue

We are pleased to welcome Mrs Chhaya Rajpal and Mr Guthrie McKie to their new roles as Trust governors. We look forward to the valuable contributions they will make to the work of the Trust. You can read more on page 3.



Also in this issue is a summary of the fourth annual members' meeting, held on Monday 22 July, see page 2.

We are planning a series of membership events, which will include tours of areas of both Royal Brompton and Harefield hospitals, and talks by members of staff. The first of these will be on Wednesday 27 November with Dr Sanjay Prasad giving a talk on cardiomyopathy. Details of this event are on page 8.

We are always looking for new members as it is important for the Trust to have an engaged and active membership so please do spread the word to your friends and relatives – the more members we have the better! Currently, we are recruiting patient representatives to various committees. If you think you have a valuable contribution to make, see page 4.

Finally, a huge word of thanks to the fantastic volunteers for all their help over the past year in various roles in the Trust. Read more about them on page 5.

I hope you enjoy reading *Patient Focus*.

Philippa Allibone,
membership manager

Trust's successful annual members' and Council of Governors' meeting

The Trust's fourth annual members' meeting was held on Monday 22 July at the Chelsea Old Town Hall. For the first time, the meeting was combined with the annual general meeting of the Council of Governors and included presentations of the Annual Report and Accounts for 2012/2013 and the Quality Report for 2012/13.

Sir Robert Finch, Trust chairman, opened the meeting and welcomed the 100 attendees, saying that the past year had been a seminal one for the Trust, during which the battle over the review of children's congenital cardiac services under "Safe and Sustainable" had been brought to a conclusion and could now be considered a thing of the past.

Bob Bell, Trust chief executive, outlined the four key strategies that are central to the way we work and our successes. They are:

- A passion for doing what is right for patients
- Clarity of mission and direction
- Good governance and excellent management
- The provision of a service that is built around people, drawing from the global talent pool

Following working group presentations from Sir Robert Finch, elected patient governor Edward Waite, and staff governor Jennifer Sano, members were asked to vote on amendments to the Foundation Trust Constitution, which were presented by appointed governor, Lady Victoria Borwick. The amendments were passed unanimously.

To close, Mr Ulrich Rosendahl, consultant cardiac surgeon, spoke about the Hybrid Theatre Appeal, which is currently underway. Royal Brompton & Harefield Hospitals Charity is raising funds for the theatre, which will be large enough to accommodate large multidisciplinary teams alongside highly technical equipment.



A question from the floor during the annual members' meeting

Mr Rosendahl explained how the theatre, which will be both a cardiac catheterisation laboratory and an operating theatre, would benefit patients. You can read more about the hybrid theatre on page 4.

Throughout the meeting, members asked questions, which generated some interesting discussions.

If you would like more details about the meeting, the minutes will be available from November 2013. Please contact the membership office: **020 7352 8121, ext 2811.**

A date for your 2014 diary...

The fifth annual members' meeting will be held at Harefield Hospital on Monday 21 July 2014.

If you would like to register your interest for the event, please email: members@rbht.nhs.uk or telephone the membership office on 020 7352 8121, ext 2811.

The Trust welcomes new governors

Chhaya Rajpal, patient governor, North West London

"I've always been very interested in patients' wellbeing and the quality of their care in hospitals. I've been a patient at Royal Brompton where I've gained an understanding of how the NHS works. But I'm keen to learn even more and to support the work of the Trust."

"As a Trust governor, I will be able to represent the interests of Trust members and the public. I have been committed to community work for a long time and was on a school governing body for a number of years, which involved participating in key policy decision-making. I am also involved in neighbourhood issues, which necessitates attending council meetings and liaising with local councillors."

"I have retired from my job in internal audit in the public sector where I worked closely with management in reviewing and improving organisation controls, risk and governance processes."

"Being on the Trust's Council of Governors will give me the opportunity to contribute to decision-making processes by asking questions that appropriately challenge the Council and to participate in boardroom discussions about the Trust's performance and its aspirations."

Chhaya Rajpal, patient governor, North West London



Guthrie McKie, patient governor, North West London

Guthrie McKie, patient governor, North West London

"I have been an asthma sufferer since childhood. I am also an ex-smoker and my asthma has developed into bronchiectasis. I have been going to Royal Brompton every two years for my lung function test for over 20 years now."

"I really value the work done by the Trust. As a patient governor, my major areas of interest are access for patients and improving facilities. Respiratory illnesses are on the increase in London, partly because of high pollution levels, so I'm also interested in how the Trust will cope with greater demands on its services."

"I am an elected councillor in the City of Westminster where I sit on the Housing Scrutiny Committee and have also made representations to the Mayor's strategy on air quality in London."

Charity helps make Royal Brompton and Harefield world class hospitals

From their very beginnings, both Royal Brompton and Harefield hospitals have relied on philanthropic support, even after the founding of the NHS in 1948. Today, Royal Brompton & Harefield Hospitals Charity continues to help raise vital extra funds so that both hospitals can provide the very best treatments and care for patients with heart and lung disease.

In March, the Charity launched its most ambitious appeal to date to raise £4.5 million for a hybrid operating theatre for Royal Brompton Hospital. The new theatre will provide world-class facilities, combining complex imaging equipment with the ability to carry out less invasive surgical procedures, so patients can be treated in a much shorter time, resulting in shorter recovery times and reduced scarring.

Over the last few months, the Charity has also been making significant inroads in raising funds for the £200k Harefield Heart and Lung Appeal. Half of the money raised will help buy 10 ventricular assist devices (artificial heart machines), to provide a lifeline for patients waiting for a heart transplant. The remainder will be used to trial a pioneering new

nursing care programme to work with heart and lung transplant patients as they near the end of their lives.



The Charity has also helped fund the innovative rb&hArts "Singing for Breathing" project, which has demonstrably improved the breath control of many patients at both hospitals. With extra funding, rb&hArts hopes to extend the project to community-based classes so that even more people can benefit.

In addition, the Charity has provided almost £100k this year to help make your visits to the hospitals more comfortable and enjoyable. There's new furniture and equipment, including wheelchairs, portable radios for inpatients to use, a TV for the outpatients waiting room at Harefield, and iPads as a communication aid for patients in intensive care.

Get involved

You can support Royal Brompton & Harefield Hospitals Charity in a number of ways, including making a donation, joining one of the Charity's giving programmes, leaving a gift in your will, or by

sponsoring a leaf on one of the Supporter Trees. You are also very welcome to join the Charity's appeal launch parties, garden parties, golf days and fun runs. For more information, please visit www.rbhcharity.org or call 020 7351 8613.

Call for patient / public representatives

The Trust is looking to recruit members to act as patient or public representatives for the following groups:

- **Homecare medicines governance group** – the group works to ensure that the Trust provides a patient-focused homecare service.
- **Patient transport committee** – the committee monitors the quality of transport provided to our patients across the country.
- **Estates and facilities user group** – the group oversees a wide range of non-clinical services e.g. catering, accommodation and domestic services.
- **Medication safety initiative group** – this multidisciplinary group aims to promote medication safety across the Trust to all staff and patients.
- **Website user group** – a new group looking at the effectiveness of the website and how it can be improved. NB: you will need an understanding of website best practice to participate.

If you are interested in contributing to any of these groups, please send a note detailing your interest and skills in the relevant area to: Melanie Foody, patient experience & patient and public involvement manager: m.foody@rbht.nhs.uk. Or call for more information on 020 7351 8208.

Maya Waldman leads a Singing for Breathing session at Royal Brompton



Growing the Trust voluntary service

The Trust voluntary service is going from strength to strength and in the last year volunteers have been assisting in ever more diverse areas, including in the information and technology department and the Harefield Hospital Library.

Many volunteers support patients and families on our wards, providing them with company and helping at meal times. In the last financial year, our team of volunteers provided significant support to a record 10,614 patients across the Trust – an amazing achievement.

The contribution made to the Trust by volunteers is invaluable. If you would like to offer your time to help at either Royal Brompton or Harefield, please email **Mr Shaan Malhotra**, voluntary service manager – s.malhotra@rbht.nhs.uk.



Mr Shaan Malhotra (far left) with volunteers at Harefield

Workshop aims to involve patients as research partners

In March, over 20 participants attended our first workshop on involving patients as research partners.

The cardiovascular and respiratory biomedical research units (BRUs) organised the workshop, which was run by Jack Nunn and Gillian Fletcher from Macmillan Cancer Support. The charity has been successfully running these workshops with a number of research organisations for several years.

Workshop attendee and patient, Angela Camber, said: "I thoroughly enjoyed Friday and learned a great deal. I found it all extremely interesting and exciting. Who would have believed that a group of patients and carers would be discussing working in partnership with researchers? Marvellous!"

The workshop focused on finding the best way for researchers and patients to work

together on research projects. The workshop included role play activities where researchers pretended to be patients. Laura Henderson, research development manager at the Trust, said: "Giving us the scenario of an invite to attend a Lords committee conjured up a range of emotions amongst the researchers. We suddenly realised how our patient advisers feel in meetings, which made us much more empathetic to their role. Very illuminating!"

Vanessa Garcia Larsen, postdoctoral researcher said: "For me as a researcher, the workshop was great because it allowed me to see how valuable working with patients and the public can be in designing clinical studies."

If you are interested in attending future workshops or would like to find out more about patient involvement in research, please contact Julia Coffey (cardiovascular) on 020 7352 8121, ext 2746, or Zahra Aden (respiratory) on ext 4960.



We are keen to hear your patient and family experiences

We are keen to hear patients' and their families' experiences of using our services so that we can share them with staff to understand where we do well, and to help us decide which areas need work and how we can improve.

Please send either written accounts or video recordings to:

Melanie Foody, patient experience & patient and public involvement manager,
3rd floor, Britten Wing, Sydney Street,
London SW3 6NP

or via email: m.foody@rbht.nhs.uk.

If you have any queries, please call:
020 7351 8208.

Member get member

We are always keen to recruit new members to our Trust – patients, carers, and members of the public are all welcome. And don't be afraid to encourage your friends and family to become members too!

Becoming a member is easy and free. For information and to complete a registration form go to: www.rbht.nhs.uk/members or email: members@rbht.nhs.uk



Harefield Hospital receives top grading for Friends and Family Test in London

The NHS Friends and Family Test (FFT) was designed to provide an insight into the experiences of inpatients in acute hospitals and A&E departments in England. It asks patients a single question: "How likely are you to recommend our wards to friends and family if they need similar care or treatment?" The question aims to allow patient views to be heard and help trusts understand how they can shape and deliver better services.

The FFT became mandatory in April 2013 and the Trust first started collecting information from patients in December 2012.

The results from all NHS organisations are monitored on a quarterly basis. The results of the first quarter of 2013 were published in June and showed Harefield Hospital to be the top performing London hospital. Royal Brompton also made the top 10 in the list of 49 hospitals that provide acute inpatient care in the capital.

The success of our two hospitals means that Royal Brompton & Harefield NHS Foundation Trust is the third best in London and one of the best performing trusts in the country.

"We were impressed by the level of care given by the team at Royal Brompton."

"I honestly cannot think of a negative aspect of this ward or the care given to me during my stay. The crème de la crème of the NHS."

"The care and attention I received at the most traumatic time of my life cannot be matched elsewhere."

"I have had the best treatment possible. It has been outstanding. The doctors, nurses and all hospital staff have been wonderful. Thank you."

Diary dates

TRUST EVENTS

Breatheasy support groups

These groups provide opportunities for local residents and their carers living with chronic lung conditions to join informal, friendly discussions. Presentations are made by members of Royal Brompton Hospital's chronic obstructive pulmonary disease (COPD) team with guest speakers from both inside and outside the Trust.

Date and time:

held on the first Tuesday of every month at 2.00pm.

Venue:

Education Centre, Respiratory Clinical Research Facility, 1st floor, Fulham wing, Royal Brompton.

Contact: Rebecca Tanner, clinical research physiotherapist

Email: r.tanner@rbht.nhs.uk

Tel: 020 7351 8029

Singing for breathing

The sessions are aimed at those with respiratory conditions, or breathlessness associated with cardiac conditions, and are relaxed, informative and fun. They aim to teach basic singing techniques, which can help with breath-management and release stress.

ROYAL BROMPTON HOSPITAL:

Open workshop for all patients (except those attending Foulis Ward)

Date and time:

2.00pm-3.00pm every Monday

Venue:

The Quiet Room, Victoria Ward, 2nd floor, Fulham Wing, Royal Brompton Hospital

HAREFIELD HOSPITAL:

Open workshop for all patients

Date and time:

3.30pm-4.30pm every Tuesday

Venue:

Rehabilitation & therapies seminar room, 2nd floor, Harefield Hospital

Contact: Vicki, Annabelle or Jenni in the arts team before your first session for more information, and to make sure the class is running as usual – or to buy the Singing for Breathing CD.

Email: arts@rbht.nhs.uk

Tel: 020 7351 4087

Web: www.rbht.nhs.uk/arts

MEMBERSHIP EVENTS

"Advances in cardiomyopathy what we are doing and where we are going"

– Dr Sanjay Prasad

Find out more about cardiomyopathy (a disease of the heart muscle) and hear a patient's experience about living with the disease. You can also learn how the disease is treated and what research is being done to improve patients' quality of life.

Date and time:

6.00 pm, Wednesday
27 November 2013

Venue: Respiratory biomedical research unit, Royal Brompton Hospital

Contact: Philippa Allibone, membership manager

Email: p.allibone@rbht.nhs.uk

Tel: 020 7352 8121 ext 2811

TRUST BOARD MEETINGS

Members of the public are welcome to attend.

• 29 January 2014

Time: 2.00pm-4.00pm

Venue: Royal Brompton Hospital, Board Room

• 26 March 2014

Time: 10.30am-1.00pm

Venue: Harefield Hospital, Concert Hall

• 30 April 2014

Time: 2.00pm-4.00pm

Venue: Royal Brompton Hospital, Board Room

• 21 May 2014

Time: 10.30am-1.00pm

Venue: Harefield Hospital, Concert Hall

• 23 July 2014

Time: 2.00pm-4.00pm

Venue: Royal Brompton Hospital, Board Room

• 24 September 2014

Time: 10.30am-1.00pm

Venue: Harefield Hospital, Concert Hall

• 22 October 2014

Time: 2.00pm-4.00pm

Venue: Royal Brompton Hospital, Board Room

• 26 November 2014

Time: 10.30am-1.00pm

Venue: Harefield Hospital, Concert Hall

COUNCIL OF GOVERNORS' MEETINGS

• 25 February 2014

Time: 11.00am-1.30pm

Venue: Harefield Hospital, Concert Hall

• 19 May 2014

Time: 11.00am-1.30pm

Venue: Royal Brompton Hospital, Board Room

• 21 July 2014

Time: 1.00pm-3.30pm

Venue: Harefield Hospital, Concert Hall

• 23 October 2014

Time: 11.00am-1.30pm

Venue: Royal Brompton Hospital, Board Room

Useful contacts for Trust members

Foundation Trust

■ Membership Office

Contact: Philippa Allibone
Tel: 020 7352 8121 ext 2811
Email: members@rbht.nhs.uk

■ Corporate Secretariat

Contact: Anthony Lumley
Tel: 020 7351 8264
Email: governors@rbht.nhs.uk

Royal Brompton & Harefield Hospitals Charity

■ Gill Raikes

Chief executive
Tel: 020 7352 8121 ext 2798
Email: g.raikes@rbht.nhs.uk

■ Stuart Willson

Head of community fundraising
Tel: 020 7352 8121 ext 8882
Email: s.willson@rbht.nhs.uk

■ James Hunt

Community fundraiser, Royal Brompton Hospital
Tel: 020 7352 8121 ext 2210
Email: j.hunt@rbht.nhs.uk

■ Nick Fry

Marketing and communications manager
Tel: 020 7352 8121 ext 4267
Email: n.fry@rbht.nhs.uk

■ Ann Rolfe

Executive assistant
Tel: 020 7352 8121 ext 4269
Email: a.rolfe@rbht.nhs.uk

■ Desiree Zimmerman

Community fundraiser, Harefield Hospital
Tel: 01895 828 820
Email: d.zimmerman@rbht.nhs.uk

Healthwatch

■ Healthwatch – Kensington and Chelsea

Address: Unit 25, Shaftesbury Centre,
85 Barby Road, London W10 6BN
Tel: 020 8968 7049 / 6771
Email: healthwatchcwl@hestia.org
Website: healthwatchcwl.co.uk/kensington-chelsea

■ Healthwatch – Hillingdon

Address: 26 Market Square, The Pavilions, Uxbridge UB8 1LH
Tel: 01895 272997
Email: office@healthwatchhillingdon.org.uk
Website: healthwatchhillingdon.org.uk/

Other useful contacts

■ Harefield Hamsters

Harefield Transplant Club
Chairman: Brian Unwin
Tel: 01494 472 470
Email: chairman@harefieldhamsters.org
Website: www.harefieldhamsters.org

■ Re-Beat

Harefield cardiology patient support group
Chairman: Ken Crisp
Tel: 020 8868 7571
Email: ken.crisp@btinternet.com

■ Friends of Harefield Hospital (volunteers)

Contact: Debbie Mortimer
Tel: 01895 828 678

■ Friends of Royal Brompton (volunteers)

Contact: Elizabeth Henderson
Tel: 020 7351 8272
Email: e.henderson@rbht.nhs.uk

■ Cystic Fibrosis Trust

Address: 11 London Road, Bromley, Kent BR1 1BY
Tel: 020 8464 7211
Helpline: 0300 373 1000
Email: enquiries@cftrust.org.uk
Website: www.cftrust.org.uk

■ The Somerville Foundation

For patients with congenital heart disease

Address: 25 St Margaret's Green, Ipswich IP4 2BN
Tel: 01473 252 007
Helpline: 0800 854 759 (ansaphone only at weekends)
Email: admin@thesf.org.uk
helpline@thesf.org.uk

■ Tiny Tickers

A source of information on prenatal heart disease

Tel: 020 3286 1250
Email: info@TinyTickers.org
Website: www.tinytickers.org

■ The Brompton Fountain

Supporting families of children with heart and lung conditions

Address: 1 Love Lane, London EC2V 7JN
Tel: 020 7776 9000
Email: admin@thebromptonfountain.org.uk
Web: www.thebromptonfountain.org.uk
Facebook: /thebromptonfountain
Twitter: @BromptonSupport #hereforyou

■ The Octavia Appeal - Friends of Royal Brompton

The Octavia Appeal is specifically to help the paediatric intensive care unit and paediatric ward fund specific items

Contact: Lynda Mackie
Address: 39 Coniger Road, London SW6 3TB
Email: lynda@octaviaappeal.org
Web: www.octaviaappeal.org
Facebook: /OctaviaAppeal
Twitter: @OctaviaAppeal

■ Primary Ciliary Dyskinesia (PCD) Group

Contact: Fiona Copeland (chairman)
Tel: 0300 111 0122 (helpline)
Email: chair@pcdsupport.org.uk
Website: www.pcdsupport.org.uk

■ Duchenne Family Support Group

Address: 78 York Street, London W1H 1DP
Tel: 0870 241 1857
Helpline: 0800 121 4518
Email: info@dfsg.org.uk
Website: www.dfsg.org.uk

■ Raynaud's & Scleroderma Association

Address: 112 Crewe Road, Alsager, Cheshire ST7 2JA
Tel: 01270 872 776 or 0800 9172494
Email: info@raynauds.org.uk
Website: www.raynauds.org.uk

