

Patient focus...

The newsletter for patients and our foundation trust members

Spring 2013

Independent Reconfiguration Panel visits Royal Brompton

Following the decision in July 2012 that children's heart surgery should end at Royal Brompton Hospital, Jeremy Hunt, Secretary of State for Health, announced in October that the Independent Reconfiguration Panel (IRP) would do a full review of the Safe and Sustainable review.

We feel sure that this new review offers Royal Brompton's children's heart surgery services and intensive care a second chance. Panel members visited all 10 centres and, before visiting us, a comprehensive written submission was sent to them. On 24 January, the IRP spent the day at Royal Brompton, meeting staff and patients in the morning and holding a formal 'evidence taking' session in the afternoon.

The panel saw presentations from senior consultants including Dr Duncan Macrae, director of children's services. He said: "The panel members were interested in our work and

asked many questions about the Safe and Sustainable review and how moving children's heart surgery would affect other services at the Trust. We had some really good discussions with them and they asked us to send more information on a number of issues. It was an encouraging day."

The panel members also heard the personal experiences of parents of both respiratory and cardiac patients and the IRP commented that they had already received some moving letters from parents. Thank you to everyone who has written so far.

There is still time to write to the IRP. The panel will now be taking evidence from a variety of other stakeholders including MPs and local councils before submitting their final report to the Secretary of State at the end of March.

Continued inside...



THE KEY FACTS...

- Royal Brompton is England's third largest centre for children's cardiac surgery.
- We have four surgeons undertaking over 400 operations each year.
- Our paediatric heart surgery results are among the best in the country.
- Our experts offer a womb to old age service for patients with congenital heart disease.
- There would be serious knock-on effects on other services at Royal Brompton including paediatric intensive care and anaesthesia, adult congenital heart disease, paediatric respiratory services and research programmes.



Damage to patient care at Royal Brompton:

- If children's heart surgery is stopped, our paediatric intensive care unit (PICU) would close and without this, respiratory care would suffer because our doctors would not be able to perform some of the most complex procedures without the back up of a PICU.
- Without PICU and on-site anaesthetists, Royal Brompton could not offer the type of specialist respiratory care it does now, so we could not look after the same numbers and types of patients and, without them, our international research programme could not continue.
- The effect on fetal care would be significantly damaged – we have an international reputation for training in this area.
- Royal Brompton's children's arrhythmia service is one of the largest in the UK but without a PICU the complex treatments for children, such as implanting a pacemaker, could not be undertaken.
- Royal Brompton has the largest number of adult congenital heart disease (ACHD) patients in the UK. The majority of our new ACHD patients have been with us through childhood. If these children are not cared for at Royal Brompton then the wider ACHD service would eventually become too small to be viable.

For more information on the impact that closing the children's heart surgery unit will have please visit: www.rbht.nhs.uk/review-update/

We believe in the right change:

A network solution that removes the need for a London unit to close was developed during 2010-11.

We believe that this solution should be looked at again, especially in light of new evidence:

- The population of London and the South East is growing faster than had been predicted.
- The population of London grew 12 per cent between 2001 and 2011 compared to a national growth rate of only 7 per cent.
- The number of children needing heart surgery is increasing. The Safe and Sustainable review relied on data from 2002-2007, which showed children's heart surgery numbers were fairly stable. However, more recent data has shown that the number of children's heart operations has increased consistently year on year since 2007.

The upward trend in the number of children's heart operations and the dramatic ongoing increases in the number of children in London, casts doubt over the Safe and Sustainable review's conclusions.

We believe the best solution is that children's congenital cardiac services should be delivered through a three-centre network in London, which would provide patients with access to the best clinical expertise.

Your views are important!

If you would like to make them known so they can be included in the final IRP report, please contact the IRP directly, by the **end of February**:

- **Lord Ribeiro**
Chairman IRP
6th Floor
157-197 Buckingham Palace Road
London
SW1W 9SP
- Or email: info@irpanel.org.uk

Annual members' meeting report

The Trust's third annual members' meeting took place on 10 October 2012 in the Concert Hall at Harefield Hospital. The meeting was well attended by our members, including patients, carers, general public and staff.

Before the meeting, attendees were given the opportunity to attend an event run by the health promotion nurses. A number of health checks were offered to members, including blood pressure and cholesterol levels and advice was given on diet and smoking cessation. This was extremely well attended and everyone who had a check said they valued the opportunity.

During the members' meeting there were two clinical presentations. Dr Nicholas Hopkinson, honorary consultant physician in respiratory medicine, described the causes and effects of chronic obstructive pulmonary disease (COPD) on patients. He highlighted the fact that COPD is an increasing problem because of the UK's ageing population and a lack of awareness of the condition. He showed videos comparing the difference between healthy lungs and those affected by COPD.

Mr André Simon, director of transplantation, described the heart and lung transplant service at Harefield. He showed a video of a



Mr André Simon, director of transplantation, speaking at the annual members' meeting

cutting-edge procedure – the minimally invasive lung transplant – and explained the benefits of this type of surgery for the patient, such as less post-operative pain and scarring and a quicker recovery time.

Feedback from the event was extremely positive. One member said: "This was, once again, an extremely interesting and informative day that covered a good variety of the Trust's activities and corporate management... The meeting was well organised and well run and the health check was an added bonus... well done to everyone involved in running the day."



*The fourth annual members' meeting will be held at Royal Brompton Hospital in mid 2013. Presently, we are unable to confirm the exact date. However, we will be sending out a letter of invitation to all members. If you would like to register your interest for the event, please email: members@rbht.nhs.uk or telephone our membership office on: **020 7352 8121 ext 2811.***

Joan Davis, from The Community Voice, takes the opportunity to ask a question during the annual members' meeting

John McCafferty celebrates the 30th anniversary of his heart transplant

On 8 November 2012, Harefield patient John McCafferty, Britain's longest surviving heart transplant patient, celebrated his 30-year milestone in the transplant outpatients unit. He was joined by his surgeon, Professor Sir Magdi Yacoub, and past and current transplant staff, including retired cardiologist, Dr Andrew Mitchell, who made a speech, welcoming everyone.

John, aged 70, was joined by his wife, Anne, and his nephew, Steven Paterson, who had travelled from Scotland to surprise John on the day. Steven had a heart transplant at age 12, in 1990, also at Harefield.

John and Sir Magdi jointly cut a large, heart-shaped cake to celebrate the occasion and Sir Magdi then presented John with a large bronze hare to remind him of Harefield.

John was recently elected to the position of public governor of the Trust, representing the South of England. He said: "I am a very proud supporter of the work carried out by both hospitals. It's my way of giving back, after all they've done for me. I've had the pleasure of seeing my son grow up and have his own son. That is priceless."

John McCafferty celebrates his anniversary with members of the transplant team



Questions and answers with John McCafferty (public governor, South of England)

Q: Can you tell us a bit about yourself?

A: After serving my apprenticeship in the building industry, I worked for the Ministry of Defence for 22 years and then for 19 years in the NHS in patient services and IT. I am married with one son and a grandson. My hobbies are trout fishing, DIY and gardening. I am also a member of two Harefield patient support groups: Harefield Transplant Club, which provides support to patients and their family members who have had or are hoping to have an organ transplant, and Re-Beat, which supports patients who have had heart surgery.

Q: What made you decide to become a governor?

A: After being a patient here for the past 30 years I have really strong ties with the place. During

this time, I have seen lots of organisational changes that have affected the running of the NHS and its patients and staff so I decided that I wanted to give something back to the Trust by volunteering as a governor. I want to be part of these dynamic changes currently taking place within the NHS and to make sure that members' interests are represented.

Q: What are your aims as a governor for 2013?

A: To ensure that the views of members within my constituency are represented. My areas of interest are Trust strategy, policy and membership.

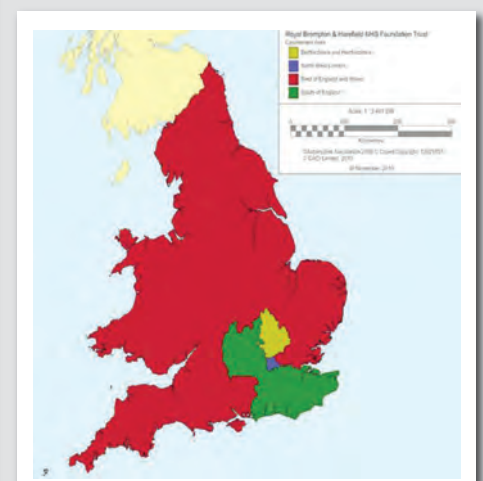
Q: How can members support the Trust?

A: Members can support the Trust by raising with their governors any issues or any positive feedback they may have. It is also important for Trust members to attend the annual members' meetings to support its future plans for development.

Q: How can members contact you?

A: I would be really happy to hear from members living in my constituency of the South of England. Please email me on governors@rbht.nhs.uk if you have any suggestions about how we can improve services at the Trust or would like more information about applying for the role of governor.

The South of England constituency is shown on the map below in dark green



Staff and patients work together in ITU and lung cancer services

Staff and patients have been working together to redesign and improve the intensive therapy unit (ITU) at Harefield Hospital and lung cancer services at Royal Brompton Hospital. They have been using a method called Experience Based Co-Design (EBCD), which captures the experiences of patients, carers and staff in a clinical area through story telling from filmed interviews, discussion and observation. It then brings staff and patients together to discuss the findings and to agree on priority areas for service improvement. Co-design groups are formed of patients and staff, who design and implement solutions for the priority areas. The method was designed to empower staff to improve their working environment and to ensure patients feel they can make decisions about their care.

This project was funded by the National Institute Health Research and Delivery Research programme and the work was led by Ruth Tollyfield, modern matron ITU, and John Pearcey, cancer and thoracic surgery services manager.

Both staff and patients found the experience constructive and rewarding. A patient from Harefield commented: "I m so grateful for your invitation to this group – and that everything we came up with you have responded to." A member of staff at the lung cancer event said: "It gave us time to reflect on what we provide."

Examples of specific actions taken forward in Harefield ITU are reducing noise on the wards and improving communication between patients and doctors on ward rounds. Some of the improvement

projects for lung cancer services are to use V-shaped pillows on the ward post operatively, improve the storage and access to patients' personal belongings and a focus on patient information before, during and after surgery. There are also plans to carry out EBCD for lung cancer services at Harefield Hospital in mid 2013.

Reducing infections

At our Trust, we work hard to protect patients from infections during their stay with us, and consequently we have one of the lowest infection rates in London. Examples of some of the measures we have in place are using the latest cleaning technology to clean our wards, and ensuring all our staff have infection control training every two years.

For visitors and patients there are some easy steps that you can take to help keep our hospitals free of infections and a safe place for everyone:

- Please do not come into our hospitals and visit patients if you are feeling unwell
- Patients and visitors should use alcohol hand gel regularly – bottles are located on every ward. This is particularly important if you are visiting more than one patient in hospital.

- If you are coming into one of our hospitals as an inpatient, please follow guidance on washing beforehand and bring your own personal toiletries.

Quality account produced

The Trust produces an annual report for the public about the quality of the services our hospitals provide. This is called a quality account. Each year we focus on several priority areas for improving quality. To identify the projects for the year, our members and local involvement networks completed a questionnaire to help us find out what topics people felt were most important.

The five that were chosen are below:

- Trust staff culture survey – The survey examines the beliefs of staff about the importance of safety and the working culture in the hospital. Research shows that a positive safety culture in an organisation is a reliable indicator for its capacity to manage patient safety incidents e.g. medication errors and patient falls.
- PROMs – Patient Reported Outcome Measures (PROMs) allow patients to tell us how they feel before and after a specific procedure or surgery.
- Readmissions – We aim to have as few unnecessary readmissions as possible. We will be looking at

our readmission rates, identifying the reasons associated with them and taking action to prevent recurrence.

- Complications – This focuses on the cause of specific patient complications with the aim of reducing their frequency.
- Positive patient identification – There are national standards related to ensuring that staff can correctly identify patients e.g. checking patients' identity prior to treatment and providing them with a wristband whilst in hospital. The project will build on previous work in the Trust to ensure we are meeting national standards.

If you would like to read our quality account for 2011-12 visit our website:

www.rbht.nhs.uk/qa

We are currently working on our quality account for 2012-13, which will be made available to the public on NHS Choices and our website on 30 June 2013.



Royal Brompton & Harefield Hospitals Charity relaunched

Royal Brompton & Harefield Hospitals Charity has been in existence for many years and has raised funds to support medical equipment, research and patient welfare that the NHS cannot fund.

The Trust has big plans for the future and to raise the significant sums needed to realise these ambitions, the charity has taken on a new identity and become independent.

Our hospitals are already world class and remarkable in their care and medical achievements, but there is always more we can do in the battle against heart and lung disease.

The charity is embarking on a major new campaign at Royal Brompton to build a state-of-the-art hybrid operating theatre, where surgical procedures can be done alongside complex imaging, so procedures that would normally have to be split over two or three operations can be done in one theatre at the same time.

At Harefield, we are very close to completing the MRI Scanner Appeal, thanks to many generous donations, and once we have reached our target we will be looking to launch a new major appeal.

To fulfil these ambitious targets we need your help. We will still have all your favourite events, like the



We are grateful to David Render for his very generous donation to the Harefield MRI Scanner Appeal. He is photographed here with Desiree Zimmerman, community fundraiser at Harefield.

Harefield Fun Run and plenty of challenge events – please see the listings on the events page for more details. There will also be bespoke events for our donors to get to know the work of the hospitals and the charity better. These will include lectures, a concert at the Barbican and a summer garden party at Chelsea Physic Garden.

Please do get in touch with us if you would like to: make a donation, large or small, find out

more about some of our fundraising events, volunteer for us and also if you have any personal stories about your experience at our hospitals that you would like to share with us.

The charity's contact details are:

- Email: a.rolfe@rbht.nhs.uk
- Telephone: 020 7351 8613
- Website: www.rbhcharity.org

**WE'RE CREATING HISTORY.
BE PART OF IT.**

New NHS assessment launched

Since 2000, NHS hospitals have taken part in the annual Patient Environment Action Team (PEAT) assessment where NHS staff and patient representatives make a visual assessment of key non-clinical areas such as food, cleanliness, infection control and patient environment (including bathroom areas, lighting, floors and patient areas) against a set of national standards.

This year the PEAT assessment will be replaced by Patient-Led Assessment of the Care

Environment (PLACE). One of the most significant changes in this approach is to increase the number and responsibilities of patient representatives who are involved in the assessment.

We are therefore keen to recruit more patient representatives to take part in the one-day PLACE assessment, which will take place at both of our hospital sites, during April, May or June.

Any patient, relative, carer, visitor or advocate with an interest in the patient environment can be an

assessor. Information and guidance will be given on the day. Refreshments including lunch will be provided and travel expenses can also be reimbursed.

If you are interested in being an assessor or would like more information please contact: **Steve Moore**, head of estates and facilities on: 020 7351 8076 or email: s.moore@rbht.nhs.uk.

Diary dates

Arrhythmia awareness evening

Patients and members of the public will be able to learn more about heart rhythm disorders from medical experts and the treatments options available at the Trust.

Date and time:

Monday 3 June at 6pm

Venue:

Seminar rooms, Royal Brompton

Contact: Alex Wise, clinical nurse specialist, arrhythmia

Email: a.wise@rbht.nhs.uk

Tel: 020 7352 8121 ext 8364

Breatheasy support group

These groups provide informal, friendly discussions for local residents living with chronic lung conditions, and their carers. They provide an opportunity to share experiences about living with chronic lung conditions. Presentations are made by members of the Royal Brompton Hospital COPD team with guest speakers from inside and outside the Trust.

Date and time: Held on the first Tuesday every month at 2pm

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 and are informal and fun. They aim to teach patients basic singing techniques, which can help patients to positively control their breathing and release stress.

Date and time:

Every Friday, 11:30-12:30pm

Venue:

Physio seminar room, 2nd Floor, Harefield

Contact: Vicki Hume, arts manager

Email: v.hume@rbht.nhs.uk

Tel: 020 7351 4087

Royal Brompton & Harefield Hospitals Charity events

• **Golf Day**

Teams of four players are invited to attend a charity golf day. The price is £120 per person, which includes continental breakfast, green fees and a luxurious carvery dinner with auction and raffle. Corporate sponsorship opportunities are available at £250 per hole.

Date and time:

Thursday 23 May all day

Venue: Denham Golf Club, Buckinghamshire

Contact: Desiree Zimmerman

Email: d.zimmerman@rbht.nhs.uk

Tel: 01895 828 820

• **Harefield Hospital Fun Run**

Run, walk or crawl and help raise funds at the annual hospital fun day with the choice of two courses – a one-mile 'stroll' or, for the more ambitious, a 5K run around the historic grounds of Harefield Hospital. Course entry fee £10 per adult, £7 per child, or register on the day for £15. Why not hold a fundraising / sponsorship event prior to the fun day – all sponsorship over £50 per person will give you free entry in the fun run.

Date and time:

Sunday 1 September, all day

Venue: Harefield Hospital

Contact: Desiree Zimmerman

Email: d.zimmerman@rbht.nhs.uk

Tel: 01895 828 820

• **The Brighton Marathon**

Date: Sunday 14 April

• **The BUPA London 10k**

Date: Monday 27 May

We have a limited number places in both these events. In return for one of our places, we ask all our runners to raise a minimum amount of sponsorship. If you are interested please contact the charity (see page 6 for details).

Friends of Royal Brompton Annual summer bazaar

External retailers will be selling stylish clothes, accessories, gifts, international foods and there will also be the more traditional English summer fair stalls. Admission is free and everyone is welcome. All proceeds to Friends of Royal Brompton.

If members have anything that they wish to donate to the bric-a-brac / vintage clothes / books / bottle stall, please contact the Friends.

Date and time:

Wednesday 5 June 11:00-3:00pm

Venue: Sydney Street foyer

Contact: Elizabeth Henderson

Email: e.henderson@rbht.nhs.uk

Tel: 020 7351 8272

Member get member

We are always keen to recruit new members to our Trust – patients, carers and members of the public are all welcome. Please tell your friends and family and encourage them 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

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

■ 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

Local Involvement Networks

■ Kensington & Chelsea LINK

Address: Unit 25, Shaftesbury Centre,
85 Barby Road, London W10 6BN
Tel: 020 8968 7049 / 6771
Email: rbkclink@hestia.org
Website: www.rbkclink.org

■ Hillingdon LINK

Address: 26 Market Sq, The Mall Pavilions, Uxbridge UB8 1LH
Tel: 01895 272 997
Email: office@hillingdonlink.org.uk
Website: www.hillingdonlink.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
Email: 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

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