



A lifetime of specialist care

Patient Focus

The newsletter for patients and our foundation trust members | Autumn 2016

Threat to congenital heart disease services

On 7 July NHS England (NHSE) announced a proposal to decommission adult and children's congenital heart disease (CHD) services from the Trust. This is despite the fact that official data shows we are one of the largest, safest and most effective centres for the treatment of congenital heart disease in the country. Last year, our experts carried out more CHD procedures than any other centre in the UK.

Implementation of the proposal would have significant knock-on effects that NHSE has not considered. Our children's intensive care unit cannot operate without the volume of patients provided by our CHD services, and would close. This would add to an already existing national shortage of children's intensive care beds. Other children's congenital heart services in the south east are already working to

full capacity and demand is increasing through population growth.

Without the back-up of intensive care and on-site anaesthesia, it would then be unsafe to undertake the more complex respiratory treatments for children (teams at Royal Brompton treat babies and children from around the country with some of the most severe forms of cystic fibrosis, asthma, the muscular dystrophies and other respiratory illnesses). Losing our CHD teams would also severely impact our ability to continue much of our life-saving medical research.

NHSE has stated that CHD services should no longer be available at Royal Brompton because our paediatric unit does not provide the full range of children's clinical services on site. Specialist trusts such as ours and the Royal Marsden have partnerships with neighbouring hospitals

so that clinical opinion across a number of specialties is readily available. At Royal Brompton, a formal contract (Service Level Agreement) with Chelsea and Westminster Hospital (C&W) has been in place for several years, so that expert opinion can be gained within a short timeframe across a number of clinical speciality areas, including paediatric general surgery and paediatric gastroenterology, both during and outside normal working hours. The partnership with C&W works well; several consultants have joint contracts between our two hospitals and are key members of our multi-disciplinary teams. Regular audits ensure that timely and appropriate medical opinion is achieved day and night.

The idea that all paediatric services need to be based on the same site has been opposed by a number of independent clinicians and has no basis in evidence.



CHD clinic at Royal Brompton Hospital

NHSE plans to launch a public consultation on the issue later this year, before making a final decision in the second half of 2017 at the earliest.

Details of the public consultation will be provided in a special edition of Patient Focus over the coming months. In the meantime, if you would like to be kept up to date with this issue, including with details of campaign activity, contact: campaigns@rbht.nhs.uk.

Annual general meeting

On Wednesday 20 July, around 80 Trust members, including staff, patients and governors, attended the combined annual general meeting of the council of governors and the members' annual meeting in the Concert Hall at Harefield.

Non-executive Trust Board member, Andrew Vallance-Owen MBE, chaired the meeting.

Bob Bell, chief executive, began with an update on strategic issues, including our financial situation, the new private patients clinic on Wimpole Street, and our inspection by the CQC in June. Bob also addressed what he described as the "most challenging" issue the Trust now faces – NHS England's proposal to no longer commission congenital heart disease (CHD) services from Royal Brompton.

Bob discussed his "shock and surprise" at the proposal and described our CHD patients as being like a family, many of whom have been treated at the Trust since birth. He explained the effect that removing CHD services would have on other areas of the Trust and stated that NHS England had so far not provided any detail about where these patients would be cared for.

Bob said: "We will continue to have full and frank discussions with NHS England in a pragmatic and professional way. We owe it to our patients."

Lead governor, Ray Puddifoot, put forward a motion to ask the Trust Board to seek a judicial review without delay. The motion received the unanimous support of all governors. Bob confirmed that a judicial review will be discussed by the Board.

Bob also announced that planning approval had been gained for the redevelopment of Harefield's G Floor into a 20-bed ward. The new ward, which will be shared by NHS and private patients, will provide 16 en-suite rooms and a four-bed high dependency unit (HDU).

In answer to a query from a member of the public, Bob explained that the planning application for a state-of-the-art respiratory inpatient facility on Royal Brompton's Sydney Street site had recently been submitted to the Royal Borough of Kensington and Chelsea and a decision was expected in December this year.

The meeting ended with a presentation by Dr Mahmoud Barbir, consultant cardiologist, entitled: 'Prevention is better than any cure'. Mr Barbir discussed Harefield's familial hypercholesterolemia (FH) service, which provides regular genetic screening clinics to identify family members who may have the inherited genetic condition. FH is caused by an abnormal gene that results in very high cholesterol levels, which can cause early heart disease and lead to premature death.

Dr Barbir explained how Harefield's growing FH service has recently expanded to Slough and he shared some interesting patient case studies. The majority of patients with FH can be treated with diet and medication, but a few will need lipoprotein apheresis, a treatment that removes the harmful cholesterol from their blood. Harefield houses the largest lipoprotein apheresis unit in the country.



Bob Bell and Andrew Vallance-Owen at the annual general meeting

CQC inspection

Around 50 inspectors from the Care Quality Commission (CQC) visited our hospitals in June, where they met staff, patients and relatives, attended meetings and ward rounds, and saw our specialist services in action.

The inspection was held at both hospitals between 14 and 17 June, with focus groups held the week before. Two inspectors returned to Harefield unexpectedly the week after the inspection to complete their observations.

Initial feedback revealed that overall the inspectors were impressed by – and grateful for – the welcome, openness, honesty and enthusiasm they encountered from everyone they met across both hospitals. The final report and ratings will be published later in the year.

Directors Joy Godden, Robert Craig and Dr Richard Grocott-Mason sent a message to all staff thanking them for their "commitment, energy and sheer hard work".

Volunteer at Harefield

If you have a few hours to spare, why not volunteer for the Friends of Harefield Hospital? This small charity runs a cafe and shop – the Friends Pavillion, opposite the main entrance to the hospital – serving tea, coffee, sandwiches, cakes and more. Volunteers are needed to serve behind the counter of the cafe and shop. Money raised by the charity pays for equipment, furniture and artwork to make patients' stay in hospital as comfortable as possible. For more information, call **Judy Snook** on **01923 774 789**.

Members' events

Tour of the primary ciliary dyskinesia unit

On Friday 22 April, Trust members were taken on a guided tour of the primary ciliary dyskinesia (PCD) unit at Royal Brompton Hospital. PCD is a rare inherited condition in which the cilia – microscopic hairs found in the nose and airways – fail to adequately remove bacteria and particles from the respiratory tract. This leads to recurrent infections in the nose, ears, sinuses and lungs. If untreated, it can cause lung damage. The treatment is physiotherapy to help clear the airways, and antibiotics to help fight bacterial infections.

PCD affects fertility in some people, and up to 50 per cent of patients also have dextrocardia (heart on the right side) and situs inversus (internal organs being on the opposite side to normal).

Dr Clare Hogg, paediatric respiratory consultant and staff governor, discussed

the diagnosis and treatment of PCD. She explained that cases are higher in populations where marriage between blood relatives, such as first cousins, is common.

Screening for PCD involves measuring the amount of nitric oxide gas present in the nose and looking at cilia under the electron microscope and on high speed video.

Dr Hogg explained that the PCD diagnostic service at Royal Brompton Hospital, one of only three in the UK, has been nationally funded since 2006 and sees around 400 patients each year. After the talk, members were given demonstrations of the different electron microscopes that enable the medical team to look at cilia and diagnose PCD. "The tour was superb," said one member. "The presentations were well thought out and given with an enthusiasm that made the subject come alive".



Sir Robert Finch

At the end of March, the Trust's chairman, Sir Robert Finch, passed away suddenly after a short illness. Sir Robert was a passionate advocate for Royal Brompton and Harefield Hospitals and will be sorely missed by all of his colleagues.

Royal Brompton & Harefield Hospitals Charity has set up the Sir Robert Finch Memorial Fund to support respiratory research. To donate, or for more information, please visit www.rbhcharity.org.uk.

Tour of the hybrid theatre at Royal Brompton Hospital

On Wednesday 22 June, 20 Trust members attended a tour of the hybrid theatre at Royal Brompton Hospital. This state-of-the-art facility combines the environment of an operating theatre with the imaging capabilities of a catheter laboratory and is used for treating patients with complex cardiac conditions.

Professor John Pepper, consultant cardiac surgeon, started the tour with a talk about how cardiac surgery has changed over the past 30 years. He explained that the hybrid theatre allows the Trust to offer more minimally invasive procedures, such as coronary artery bypass graft with coronary angioplasty, which involves inserting a stent via a catheter to treat a blockage in the artery. The hybrid theatre's advanced imaging technology, operating table and integrated computer software work together, which means operations can now be planned in advance in unprecedented detail.

Members then visited the hybrid theatre where Karen Shevlin, cath lab and theatre manager, and Dr David Alexander,

consultant anaesthetist, showed them how the theatre operating table can be changed from a surgical table to a cath lab table. They also demonstrated the x-ray machine, which can move 360 degrees in any direction.

"The tour was excellent, from the initial talk to the final presentation in the lab," said one member.



Members in the hybrid theatre

Supporting children and their families

For families with seriously ill children under the care of the Trust, The Brompton Fountain charity is a lifeline

The Brompton Fountain was set up in 2003 by Lord Jamie Borwick, two of whose sons are patients at Royal Brompton Hospital. The aim of the charity is to support families while their children are under the care of the hospital.

“Families whose children have serious cardiac or respiratory conditions develop a unique relationship with the hospital,” says Trudy Nickels, director of the charity. “Parents can often be many miles from home while their children are inpatients, and they need practical and emotional support during what is always a very stressful time. That’s where The Brompton Fountain steps in.”

Trudy started volunteering for the charity when her son Freddie, now 10, was an inpatient as a baby. He has a congenital

heart condition and has had four open heart surgeries and extended stays in hospital.

“Freddie was diagnosed while still in the womb and it was a huge shock,” says Trudy. “It changes your whole outlook on life and you have to prepare for a different journey – it’s so different to what you imagined. I was very grateful for the support from the charity, which is why I started volunteering.”

Trudy became manager of The Brompton Fountain in 2009 and director in 2011. She works closely with staff in Rose paediatric ward and the paediatric intensive care unit (PICU) to make sure that parents know about the charity. She also gives talks at special antenatal classes run by the hospital for parents whose babies have been diagnosed in the womb.

Volunteers from the charity visit families on the ward to listen to their concerns and offer support. Many parents find the charity through their Facebook group, which is a closed group for families and young people, with more than 850 members.

To make parents’ stay as comfortable as possible, The Brompton Fountain has created a kitchen and lounge area on the sixth floor of Sydney Wing. And, if a child has been admitted in an emergency, the charity provides packs for the families containing toiletries, pyjamas and other essentials. They also organise pamper sessions and pizza nights so that parents can get together to unwind, offload and socialise.

“As the parent of a seriously ill child, the only people who can understand what

you’re going through are those who’ve been through something similar,” says Trudy. “It was very hard for me when Freddie was born, and I was so grateful to speak to parents who were in the same situation. I am still firm friends with many of those parents.”

To help parents connect with other families, the charity runs events such as the annual Big Brompton BBQ Party featuring treasure hunts, lunch, face painting and lots of activities for children. There are also local reps who can put families in touch with others in their own area or with similar ages of children.

How charity funds are used

The charity provides funding and support for a wide variety of children’s projects at Royal Brompton and Harefield hospitals, including refurbishing the paediatric ward playroom, buying equipment for the hospital school, and buying highchairs and baby baths for the ward. It also works with the hospital arts team to fund specialist music therapies for young patients, as well as art installations and new décor for the rooms and bays.

The charity holds various fundraising events throughout the year, including a summer fair, Christmas fair and Santa run, where people run 5k or 10k around Victoria Park dressed as Santa!

How to get involved

If you are a family looking for information or support, or you would like to volunteer or take part in a fundraising event, The Brompton Fountain would love to hear from you. Please get in touch by sending an email to admin@thebromptonfountain.org.uk or by visiting their website www.thebromptonfountain.org.uk. Parents are also very welcome to visit the team in the charity office (on level 2) where they can pop by for tea, coffee and a chat.



A Brompton Fountain Christmas party



The Trust welcomes two new governors

Anthony Archer – public governor Beds and Herts

Anthony has over 25 years' experience in the executive recruitment industry, specialising in senior-level search, and more recently combines this with board review and governance consulting. He has experience of the workings of nomination committees and senior appointments, both executive and non-executive, and has advised NHS trusts on board appointments.

He has served as a charity trustee and has experience of chairing boards and committees. He is married to Louise, a former patient at Royal Brompton, who underwent aortic valve replacement surgery some years ago, and they have been members of the Trust since it was awarded foundation status in 2009. They live near Berkhamsted in Hertfordshire and have three grown up children and two grandchildren. Anthony is a chartered accountant and holds a law degree from the University of Birmingham.



Dr Charlie Butcher – staff governor



Charlie is a clinical research fellow based mainly at Harefield Hospital, where he has worked since 2011. He is currently working towards a PhD at Imperial College, studying how to improve the effectiveness of specialised pacemakers in heart failure. This role takes him to both sites of the Trust as well as our referring centres, giving him insights into how the Trust is perceived externally.

Before this he worked as a senior educational fellow developing internal and external courses, including in-situ simulation training. As well as supporting staff, he also supports medical students from University College London (UCL) and Imperial College and was recognised with a number of awards for teaching. As a junior doctor he has worked for both the cardiology and transplant teams.

Charlie is able to bring almost five years of quality relationships with medical staff and allied healthcare professionals across Harefield and Royal Brompton sites in clinical, educational, research and organisational fields. These relationships put him in a privileged position to advocate on behalf of a wide and important group of individuals. Beyond this, he wants to take the opportunity as a governor to build up a more complete picture of how the Trust works. He is passionate about its core values and relishes the opportunity to play a part in supporting its future.

Royal Brompton & Harefield Hospitals Charity events

- **14 November: Royal Brompton Christmas gift fair,** Chelsea Old Town Hall, Kings Road SW3 5EE, 10am–4pm

Come along to the charity's very first Christmas fair and stock up on gifts and festive treats.

- **14 November: The Brompton Quiz,** Chelsea Old Town Hall, Kings Road SW3 5EE, 7pm–10.30pm

Put your general knowledge to the test at the first ever Brompton Quiz, featuring writer and presenter Clive Anderson as quizmaster. Tickets cost £350 for a table of 10 people and the price includes dinner from a local restaurant.

- **7 December: Carols by Candlelight,** St Luke's Church, Sydney Street, SW3 6NH, 6.30pm–8.30pm

Our popular Carols by Candlelight event features the St Luke's choir and our very own Singing for Breathing singers, with mince pies and mulled wine afterwards. Tickets are £20 for adults, £10 for children.

- **8 December: Carols by Candlelight,** St Mary's Church, Harefield, 7pm–9pm
- Your chance to sing carols in a beautiful parish church. Tickets are free, and there will be a collection afterwards to raise money for the Intensive Therapy Unit extension at Harefield Hospital.

All money raised from these events supports the hospitals by buying vital equipment, funding research, contributing to major building projects and generally improving the lives of our patients. For more information or to book tickets, visit www.rbhcharity.org



Diary dates

MEMBERSHIP EVENTS

Lung transplants: Who? How? What comes next?

We are delighted to offer you the opportunity to hear Dr Martin Carby, consultant respiratory physician, discussing lung transplantation.

Lung transplantation is a treatment for patients with some types of lung disease. It involves replacing one or both diseased lungs with a healthy lung, or lungs, from an organ donor. It first became a possibility in the early 1980s and, since then, many hundreds of transplant operations have been carried out on patients with various lung diseases.

Date 18 October 2016

Time 2pm–4pm

Venue The STaR Centre at Harefield Hospital

Managing chest pain

Dr Ranil De Silva, consultant cardiologist and interventionist, will give a talk on refractory angina.

Patients can continue to experience or have recurrence of angina despite having had treatment with medication, stents and coronary artery bypass surgery. This is called refractory angina.

Date 12 April 2017

Time 2pm–4pm

Venue Education Centre, 1st Floor, Fulham Wing, Royal Brompton Hospital

If you would like to attend any of these meetings, please contact **Philippa Allibone** at p.allibone@rbht.nhs.uk

SINGING FOR BREATHING

Aimed at those with respiratory conditions, or breathlessness associated with cardiac conditions, sessions 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 outpatients.

Date and time Every Tuesday, 11am–12 noon

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

HAREFIELD HOSPITAL

Open workshop for outpatients.

Date and time Every Monday, 11.30am–12.30pm

Venue Harefield Library, Park Lane, Harefield, Middlesex, UB9 6BJ

Contact Karen Taylor in the arts team before your first session 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



Phoene Cave running a Singing for Breathing session

TRUST BOARD MEETINGS

Members of the public are welcome to attend.

- **26 October 2016**

Time 2pm–4pm

Venue Board room, Royal Brompton Hospital

- **30 November 2016**

Time 10.30am–1pm

Venue Concert Hall, Harefield Hospital

- **25 January 2017**

Time 2pm–4pm

Venue Board room, Royal Brompton Hospital

- **29 March 2017**

Time 10.30am–1pm

Venue Concert Hall, Harefield Hospital

- **26 April 2017**

Time 10am–12 noon

Venue Board room, Royal Brompton Hospital

COUNCIL OF GOVERNORS MEETINGS

- **1 November 2016**

Time 11am–1.30pm

Venue Board room, Royal Brompton Hospital

- **23 February 2017**

Time 11am–1.30pm

Venue Board room, Royal Brompton Hospital

- **20 July 2017**

Combined Council of Governors AGM and Members Annual Meeting

Time 11am–1.30pm

Venue TBC

If you would prefer to receive Patient Focus by email, please send details including your name and email address to **Philippa Allibone**, membership manager: 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

■ Alice Eastwood

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

■ Joe Dunster

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

■ Joanna Lewin

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

■ Denise Hawkes

Personal assistant to CEO
Tel: 020 7352 8121 ext 8613
Email: d.hawkes@rbht.nhs.uk

Healthwatch

■ Healthwatch – Kensington and Chelsea

Address: Unit 25, Shaftesbury Centre,
85 Barlby Road, London W10 6BN
Tel: 020 8964 1490
Email: healthwatchkc@hestia.org
Website: healthwatchcw.co.uk/kensington-chelsea

■ Healthwatch – Hillingdon

Address: 20 Chequers Square, The Pavilions Shopping Centre,
Uxbridge UB8 1LN
Tel: 01895 272 997
Email: office@healthwatchhillingdon.org.uk
Website: healthwatchhillingdon.org.uk/

Other useful contacts

■ The Brompton Fountain (registered charity 1110339)

Supporting families with children who are patients at the Trust and raising funds for the paediatric units
Address: Royal Brompton Hospital, Sydney Street, SW3 6NP
Tel: 03300 22 92 91
Email: admin@thebromptonfountain.org.uk
Website: www.thebromptonfountain.org.uk
Facebook: /thebromptonfountain
Twitter: @BromptonSupport

■ 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

■ Harefield Hamsters

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

■ Friends of Harefield Hospital (volunteers)

Contact: Judy Snook
Tel: 01923 774 789

■ 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

Improving the early detection and care of babies with CHD and providing information and support from pregnancy onwards
Email: info@tinytickers.org
Website: www.tinytickers.org

■ Primary Ciliary Dyskinesia (PCD) Family Support

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
Helpline: 0800 121 4518
Email: info@dfs.org.uk
Website: www.dfs.org.uk

■ Scleroderma & Raynaud's UK

Address: Bride House, 18-20 Bride Lane, London EC4Y 8EE
Helpline: 0800 311 2756
Tel: 020 7000 1925 (head office)
Tel: 01270 872 776 (Cheshire) (this number will no longer be active from 1 January 2017)
Email: info@sruk.co.uk
Website: www.sruk.co.uk

