



A lifetime of specialist care

PatientFocus

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

Care Quality Commission inspection 2016

The Care Quality Commission (CQC) will be conducting a detailed four-day inspection of our services from 14 to 17 June 2016, with further unannounced follow-up visits.

As the independent regulator of health and adult social care in England, the CQC is responsible for ensuring hospitals, and other care services in England, meet national standards of quality and safety.

Joy Godden, director of nursing and clinical governance, said: "While there is no doubt that these inspections involve a great deal of preparation and planning, we welcome the opportunity to show the CQC that we are committed to providing the best possible care for patients and to listening and acting upon patient feedback."

The team inspecting the Trust will be led by an experienced CQC manager and be chaired by a senior NHS clinician or executive. The team of up to 40 people

always includes professional and clinical staff, as well as patients and carers. To make sure the right systems and processes are in place, inspectors will interview key members of the senior management team and staff at all levels about their work.

They will also talk to patients about the care they experience, monitor the care being given, and visit certain services out of hours and unannounced.

Inspectors will be asking five key questions about our services:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they responsive to people's needs?
- Are they well led?

As part of the inspection, the Care Quality Commission will meet people who use our services and their carers, and organise listening events, drop-in sessions and focus groups for them.



Editor's note

We have recently welcomed four new governors to the Trust and look forward to the valuable contributions they will make to our work. You can read more about them on page 6.

We are pleased to be able to share our strategic plans for the coming year with you in this issue. We welcome your comments and opinions on these plans – please send them to me at members@rbht.nhs.uk.

As reported in the last issue of Patient Focus, a team from the Care Quality Commission will visit both our hospitals in June. Preparations for the visits are well underway – for more information about what the inspection involves, please see left.

I do hope you enjoy this edition of Patient Focus.

All the best,

*Philippa Allibone,
membership
manager*



Tour of children's sleep and ventilation unit

A small group of Trust members were taken on a guided tour of the children's sleep and ventilation unit at Royal Brompton last October.

The unit provides comprehensive evaluation and care for children with sleep-related breathing disorders, which may be caused by difficult asthma, muscular dystrophy, obstructive sleep apnoea or other conditions.

Felicity Gray, paediatric respiratory/sleep physiologist, began the tour by explaining cardiorespiratory polygraphy, a sleep study that monitors body functions overnight to detect whether there are any sleep problems or breathing issues.

Felicity showed the group some of the complex equipment children have to wear during an overnight study. This includes two soft belts strapped across the chest to monitor chest movements, sensors placed under the nose to assess breathing, and special sensors on the head to observe brain wave activity.

Each bedroom has a video camera and audio equipment so that clinicians can check patients visually and aurally (for snoring particularly) as well as via the sensor information.

Dr Hui-leng Tan, consultant in paediatric respiratory and sleep medicine, showed recordings and assessment information from previous sleep studies and explained the different types of sleep apnoeas and their symptoms.

Ruth Wakeman, advanced care practitioner in children's long term ventilation (LTV), talked about the clinical support, training and education the LTV team provides to allow children who are dependent on ventilators to be safely discharged home when they are well enough. In the past, children have stayed on the unit for up to 18 months, but new processes developed by the team have reduced this to as little as three months. This means that children with chronic respiratory failure can be cared for in the home environment, surrounded by their families.

▼ Felicity Gray, paediatric respiratory/sleep physiologist, with a young patient



Hayley after the transplant, with her fiancé, James

Lung transplant success

Cystic fibrosis patient Hayley Wall underwent a lung transplant at Harefield Hospital last December and can now take deep breaths for the first time in 27 years.

Hayley's very small frame meant it was difficult to find compatible donor lungs, so the transplant team at Harefield Hospital carried out a lobar lung transplant. This meant that, instead of transplanting whole lungs, some of the lobes were removed from larger donor lungs to match the size of Hayley's damaged ones. Revolutionary transplant technology known as the Organ Care System (OCS) was used to ventilate the lungs outside the body while the lobes were removed, ensuring a perfect fit for Hayley.

Her surgeon, Mr Fabio De Robertis, said: "Very petite patients tend to remain on the waiting list for a long period and can sometimes run out of time waiting for organs of the right size to become available. Basically, small patients have small lungs so it is not always possible to transplant an average-sized lung."

The operation was a success and as more days went by Hayley was able to take deeper breaths. "After 27 years of suffering it was a wonderful feeling," says Hayley. "At first I found the concept of donor lungs being cut to fit me quite scary but I'm amazed at the technology that made it happen."

Tributes paid to longest surviving heart transplant patient

John McCafferty, who underwent a heart transplant at Harefield 33 years ago, sadly passed away in February. John had been a public governor for the South of England and acted as secretary of the Harefield Re-beat Club. He also served as an active committee member of the Harefield Hamsters Transplant Club.

When John's transplant was carried out in 1982 by Professor Sir Magdi Yacoub, he was told he had only five years to live. In fact, he lived for another 33 years and in 2013 was officially recognised by Guinness World Records as the world's longest surviving heart transplant patient.

At the time, he said: "I want this world record to be an inspiration to anyone awaiting a heart transplant and to those who, like me, have been fortunate enough to have had one."

He will be greatly missed by the entire transplant community. Rita Presnail, sister in the transplant clinic, was a staff nurse at Harefield when John had his transplant and saw him regularly at his check-up appointments. She said: "We are deeply saddened to hear that John has passed away. We are forever grateful to him for

championing our staff and patients over the years, especially during his time as a Trust governor. He worked tirelessly to support organ donation and was a great inspiration. He will be sorely missed by the entire transplant community and all who knew him at the Trust."

Numerous tributes have been made to John in the national media, including print, broadcast and social media.



▲ John McCafferty pictured at Harefield in 2013 with his Guinness World Record certificate



Do you have a few hours to spare?

The Friends of Royal Brompton is a small independent charity that has supported the work of the hospital since the 1960s. The charity has spent more than £100,000 on projects during this financial year.

The charity is always on the lookout for more volunteers – if you have a few hours to spare, please contact **Elizabeth Henderson** on **020 7351 8272** or **e.henderson@rbht.nhs.uk**.

The charity runs the on-site florist shop Brompton Flowers, which also sells second-hand books and clothes, and a kiosk in Fulham Wing. It also runs a vital trolley service, visiting patients' bedsides in both Sydney Street and Fulham Wing.

The Friends raise funds through organising events such as an annual carol concert, art exhibitions and orchestral concerts. They welcome fundraising ideas from members and non-members, so please get in touch with your suggestions.

If you're interested in becoming a charity trustee or want to learn more about the work that they do, please get in touch with Elizabeth Henderson (contact details above).



**FRIENDS OF
ROYAL BROMPTON
HOSPITAL**

Talk on COPD



Professor
Michael Polkey

In November more than 30 Trust members attended a talk on chronic obstructive pulmonary disease (COPD) by Professor Michael Polkey, consultant respiratory physician.

COPD is a lung disease and is a major cause of ill health in the UK, affecting nearly a million people. The main cause is smoking. There is no cure, but treatments are available to relieve the symptoms and help people live an active life.

During the talk Professor Polkey discussed diagnosis, treatment and research and answered questions from the audience.

Have your say on our strategy

Each year the Trust submits a set of forward-looking plans to our regulator, Monitor. As part of this process, we canvas the opinion of our governors and members on our strategic plan, objectives and priorities. These are set out below and we would welcome your comments. Your views will be reflected in the Trust's strategic plan when it is presented to Monitor.

Our vision

The Trust's vision is to be the UK's leading specialist centre for heart and lung disease, developing services through research and clinical practice to improve the health of people across the world.

Our strategy to achieve this is focused on growth across the whole spectrum of heart and lung treatments. Our clinical teams offer patients "a lifetime of specialist care" – from birth, throughout childhood and into adulthood and old age.

Our strategic plan will particularly focus on three areas: clinical quality, information technology, and buildings.

Clinical quality

We are committed to ensuring that our clinical services are safe, effective, caring, responsive and well led, as set out by the Care Quality Commission (CQC). We are also committed to continuously improving our services. To achieve this, we will:

Safe

- Develop and implement a safety improvement plan linked to the Trust's strategic plan and the NHS England Safety initiative.
- Actively participate in the Imperial Health College Partnership Patient Safety Collaborative. Extend our links with local district general hospitals to improve the patient journey, particularly when transferring between hospitals.
- Continue to develop and enhance the Trust risk register to ensure that we recognise, manage and mitigate risks to our services and patient care.

Effective

- Achieve a target of at least 90 per cent for mandatory staff training.
- Consolidate our multi-disciplinary team approach so that teams use a standard set of criteria by which patients are judged suitable for treatment. Improve inter-professional communication, referrals and documentation and provide patient information and feedback.
- Achieve a target of at least 80 per cent for annual staff appraisals.
- Ensure that operations go ahead as planned to prevent delays, and minimise the length of time patients spend in hospital.

Caring

- Improve end of life care planning and access to specialist palliative care as well as other non-cardiothoracic services.
- Improve CQC inpatient and outpatient survey results year on year, aiming to sit in the top performing 10 per cent of trusts.
- Improve response rates for Patient and Staff Friends and Family Test, aiming to be in the top 10 per cent nationally for each question.

Responsive

- Ensure that clinical support services match the availability of front line services across a seven-day week. Improve the admission, transfer and discharge processes.
- Work with commissioners to reduce waiting times.
- Continue to improve the availability of relevant clinical information for patients.
- Acquire current patient experience feedback on all Trust services.
- Develop an information/contact centre for patients, carers and referrers to access information about the Trust, their condition, referral processes and services.

Well led

- Ensure the closest possible working partnership between clinical leaders and managers across the organisation.
- Continue the annual Staff Safety Climate Survey to identify areas for improvement in relation to staff experience, training and wellbeing.
- Continue to develop and implement Human Factors and Simulation Training programmes for multi-professional staff across the Trust, together with courses on duty of candour and being open, consent to examination and treatment, deprivation of liberty and mental capacity.
- Encourage at least 100 members of staff to become members of the Institute of Health Improvement Open School. Introduce Quality Improvement science training for multi-professional staff groups.

Information technology

We recognise that effective, accurate and timely information is important for delivering the best possible services for patients. Under the Digital Care Transformation Programme, the Trust is soon to introduce three new systems to improve patient care:

Strategic plans



- The new Patient Administration System (PAS) is due to go live in summer 2016. This new system will provide staff with better tools to manage the patient journey through our health care system.
- The project to replace paper medical records with an Electronic Document Management (EDM) system is progressing well. Once fully implemented, our clinicians will be able to access medical records from any designated computer at any time.
- The Electronic Prescribing and Medicines Administration (EPMA) at both hospitals is almost complete. The system is quicker and safer and the feedback has been very positive. The system will be introduced for outpatients in 2017.

Improving our buildings

Some of our hospital buildings are old, outdated and unsuitable for 21st century specialist care. Our programme of capital investment in recent years has refurbished some areas and added new facilities, such as Acorn ward at Harefield, a fourth catheter laboratory at Harefield and the hybrid theatre at Royal Brompton. We have plans for more significant, longer-term developments too.

Harefield Hospital In 2016, we will be extending our imaging department to install a second CT scanner and a new cardiac MR scanner, significantly increasing the scope and scale of our imaging capability. Due to increasing demands on our services, we are extending our critical care unit to add six new intensive care beds, and finalising plans for an additional ward.

Royal Brompton Hospital Our existing specialist respiratory inpatient facilities are cramped and outdated. Our plan is to create modern, purpose-built facilities in a new wing adjacent to the Sydney Street building. Our proposal includes the demolition of the Imatron Building on Dovehouse Street, 30 Britten Street, and the removal of the mobile scanner. We will be seeking planning consent in 2016.

If you would like to comment on any of our strategic plans, contact **Philippa Allibone** at members@rbht.nhs.uk



We welcome new governors

Robert Parker – public governor, south of England

Robert worked at Royal Brompton & Harefield NHS Foundation Trust for nearly 35 years – he was heart valve bank manager until 2011. When the Trust achieved foundation status, Robert served as a staff governor for three years and was also chair of the joint staff committee for eight years.

Robert believes that the Trust needs to maintain its position as one of the leading cardiothoracic centres in the world. He thinks that the Trust should continue to work closely with Imperial College London's School of Medicine, to be at the forefront of research, while retaining its independent status. He believes that the team spirit within the Trust is integral to maintaining quality healthcare.

Robert lives in Ashted, Surrey, and is married with one child. Since leaving the Trust he has maintained his clinical registration and regularly attends cardiac and tissue banking meetings throughout Europe. He is also a member of the British Heart Foundation Alliance.



Elizabeth Henderson – staff governor

Elizabeth has worked at Royal Brompton Hospital since 1997. She manages Friends of Royal Brompton, a charity which has supported the work of the hospital since the 1960s (see page 3). Part of her role is salaried and she gives her remaining time on a voluntary basis.

Through her work with the charity, Elizabeth is in regular contact with patients and their families, staff and volunteers. She works with different departments and members of staff, so understands the work they do and how their areas function. Through her contact with patients, families and friends, she has a unique insight into the care the hospital provides.

Tim Mack – patient governor, north west London

Tim was appointed to the Council of Governors in 2016. As part of the council, he wants to actively represent the views of foundation trust members, to hold the board of directors to account and advise on the Trust's future direction. He looks forward to supporting the outstanding work carried out by teams at the Trust.

Tim brings enthusiasm and experience, having volunteered at Chelsea and Westminster Hospital and Guide Dogs for the Blind, as well as starting a patients' group at his GP surgery and being a school governor. He has also been a trustee of an environmental charity and the Children's Food Trust for the last five years.

Tim previously led marketing and communications activities for several organisations in sectors including motoring and finance, and was a senior civil servant for more than 10 years. He is now self-employed.



Jennifer Sano – public governor, rest of England and Wales

Jennifer was previously a staff governor for 18 months between 2013 and 2014 when she worked at Royal Brompton Hospital as a medical secretary. This experience gave her a comprehensive understanding of the work undertaken by the Trust's board and senior management.

Jennifer welcomes the opportunity to be involved with the Trust again for the benefit of patients and their families and is pleased and proud to represent the Trust as a member of the council of governors.

Diary dates

MEMBERSHIP EVENTS

Tour of the primary ciliary dyskinesia service (PCD)

Members are being offered the opportunity to visit the PCD diagnostic labs based in the electron microscopy unit at Royal Brompton. The PCD service is one of only three diagnostic centres in the UK. PCD is an inherited disorder of the cilia, which are tiny microscopic structures lining the airways, ears and sinuses. Dr Clare Hogg, paediatric respiratory consultant and staff governor, will talk about the treatment for and diagnosis of PCD. Members will also be shown the recently installed electron microscope used to make 3D pictures of cilia structure.

Date 22 April 2016

Time 11am–1pm

Venue Electron microscopy department, Royal Brompton Hospital

Note Due to limited space this event is offered on a first come first served basis.

Tour of the hybrid theatre

Our hybrid theatre makes it possible to carry out a combination of medical procedures, such as a CT scan and non-invasive procedure or heart surgery, in the same space and at the same time. Members will be shown around by hybrid theatre staff.

Date 22 June 2016

Time To be confirmed

Venue Hybrid theatre, Royal Brompton Hospital

Note If you would like to attend a membership event or want more information, please contact **Philippa Allibone** at members@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 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



▲ Phoebe Cave running a Singing for Breathing session

TRUST BOARD MEETINGS

Members of the public are welcome to attend.

• 27 April 2016

Time 10am–12 noon

Venue Board Room, Royal Brompton Hospital

• 25 May 2016

Time 10.30am–1pm

Venue Concert Hall, Harefield Hospital

• 27 July 2016

Time 2pm–4pm

Venue Seminar Room, Level 2 Sydney Wing, Royal Brompton Hospital

• 28 September 2016

Time 10.30am–1pm

Venue Concert Hall, Harefield Hospital

• 26 October 2016

Time 2pm–4pm

Venue Royal Brompton Hospital

• 30 November 2016

Time 10.30am–1pm

Venue Concert Hall, Harefield Hospital

COUNCIL OF GOVERNORS MEETINGS

• 11 May 2016

Time 11am–1.30pm

Venue Concert Hall, Harefield Hospital

• 20 July 2016

Combined Council of Governors AGM and Members Annual Meeting

Time to be confirmed

Venue Concert Hall, Harefield Hospital

• 1 November 2016

Time 11am–1.30pm

Venue Board Room, Royal Brompton Hospital

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

■ Desiree Zimmerman

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

■ Nick Fry

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

■ Karen Higgs

Executive assistant
Tel: 020 7352 8121 ext 4269
Email: k.higgs@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.crisp1@btinternet.com

■ Friends of Harefield Hospital (volunteers)

Contact: Don Chapman
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
Website: 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

