

Annual review --- 2015/16



A lifetime of specialist care

Royal Brompton & Harefield

NHS Foundation Trust





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Introduction

from the acting chairman and chief executive

October 2016

It is with mixed emotions that we present this annual review of 2015-16.

It has certainly been a year that has provided cause to celebrate the great achievements of our staff. This year our teams have cared for nearly 200,000 patients in our outpatient clinics and 40,000 on our wards. They have recruited an impressive 4,400 people into ground-breaking research studies and introduced a number of new treatments for diseases such as chronic bronchitis, heart failure and congenital heart disease.

Our research teams have published extensively: discovering a genetic cause for a heart condition that develops during pregnancy; pioneering a blood test to detect cancer; undertaking innovative gene therapy to replace the faulty gene responsible for cystic fibrosis (CF); using airway valves to treat people with chronic obstructive pulmonary disease (COPD); and leading research on a new comprehensive genetic test to diagnose the most prevalent inherited cardiac conditions (ICCs).

In February, the third international analysis of influential biomedical and health research confirmed the leading role played by our researchers on the global medical research stage. The report showed that experts at the Trust produced more highly cited publications (HCPs) about respiratory and critical care medicine than any other NHS trust in England. In cardiovascular medicine, the proportion of Trust research papers quoted in subsequent studies was joint highest.

The report highlighted our close partnership with Imperial College London, with our two organisations having the most co-authored HCPs compared with all other healthcare and academic partners in England. In July, we were delighted to formally join the Imperial College Academic Health Science Centre – a move that

offers significant opportunities to drive innovation and improvements in patient care.

Sir Robert Finch

The past year also brought with it a blow that knocked many of us sideways. The untimely death of our chairman, Sir Robert Finch, over the Easter holiday, was a great shock to everyone at the Trust.

Sir Robert was a great colleague, supporter and friend. His support on a number of demanding issues enabled the Trust's executives to adopt bold and sometimes controversial strategies. Most noteworthy of these was the action taken to protect our children's heart services in 2011-2013. Throughout a lengthy and challenging campaign, Sir Robert steadfastly stood by the decision to do everything in our power to ensure that our youngest patients did not have their services decimated. When the Secretary of State for Health announced in June 2013 that the Safe and Sustainable review of children's heart services was to be withdrawn, it was the end of a distressing two years that had seen patients exposed to a completely unacceptable level of uncertainty about their future care.

It is with a sense of disbelief that we find ourselves in a similar position today.

Congenital heart disease service review

The joint review of adult and children's congenital heart services that followed the demise of Safe and Sustainable appeared to be taking a more intelligent approach. When the standards were endorsed by the NHS England Board on 23 July 2015, it was on the basis that "*major reconfiguration of specialist services, with associated risk and upheaval, can probably be avoided*".



Acting chairman Neil Lerner (left) and chief executive Bob Bell



Experts at the Trust produced more highly cited publications about respiratory and critical care medicine than any other NHS trust in England

But in July this year we learned that, on the basis of not meeting a standard on co-location of children's facilities, a clinical service caring for 12,500 patients was at risk of being dismantled.

Royal Brompton is the largest UK centre for congenital heart services. As a specialist heart and lung centre, our teams work closely with colleagues at neighbouring Chelsea and Westminster Hospital for consultant opinion on a number of supporting clinical disciplines. Several medical consultant appointments are operated jointly, so that expertise can be readily shared across the two hospitals.

Particularly close links exist across paediatric care. A formal contract (service level agreement) with Chelsea and Westminster has been in place for several years so that expert opinion can be gained across a number of clinical speciality areas, including paediatric general surgery and paediatric gastroenterology, both during and outside normal working hours. The partnership works well and regular audits ensure that the necessary medical opinion

is achieved within the agreed timeframes. Our clinicians are confident that our close working partnership with Chelsea and Westminster meets national standards. They would not accept any arrangement that provided anything less than the best possible specialist care for their patients.

As this review goes to press, we have been informed that because the Chelsea and Westminster clinicians are not based within our buildings but have their main base a few minutes away, because their names are not on an office door in Royal Brompton, then the care they give is somehow substandard. There is no evidence for this position; commissioners and regulators acknowledge that there are no concerns about the quality of the Trust's congenital heart disease services, which remain among the best performing in the country.

No account has been taken of the serious knock-on effects this would have on other world leading specialist services at the hospital, including paediatric intensive care and paediatric respiratory care.

Our patients are our priority, and if this plan was the best option for them, we would not hesitate to support it. Instead, we see no benefit to patients and fear that the proposal will only lead to a worse service and the break-up of internationally renowned care and research teams.

We will fight these irrational proposals as we fought their previous incarnation. It is a source of deep regret that we are forced to take this position, but the 12,500 congenital heart disease patients in our care deserve nothing less. We look forward to securing a successful outcome for them, and for future generations.

Bob Bell
chief executive

Neil Lerner
acting chairman



Sir Robert Finch

At the end of March 2016 the Trust's chairman of seven years, Sir Robert Finch, passed away suddenly after a short illness

The sudden and tragic loss of Sir Robert was a huge shock to everyone at the Trust. Chief executive Bob Bell pays tribute to a greatly missed colleague.

"Sir Robert was a passionate advocate for Royal Brompton and Harefield hospitals," says Bob. "As a former Lord Mayor of London and with a background in law and property, he frequently found himself advancing the Trust's position in influential and powerful circles. And while much of this advocacy took place behind the scenes, the benefits were no less evident.

"Such was his commitment to the Trust that Sir Robert agreed to extend his tenure as chairman after the initial four-year term. Following a difficult fight to save children's services, and testing property development issues, many would have welcomed the opportunity to pass on the baton. Sir Robert did not, sure that he had more to offer and keen to contribute as much as he could to securing a successful future for patients of our Trust."

Neil Lerner, acting chairman, adds: "Everyone at the Trust had the greatest affection for Robert, both because of his complete dedication to the hospitals and their patients and because of his kind and gentle personality. He was generous with his time on the Trust's business and always had time to listen to someone's problem whether they were the chief executive or a nurse. He has left an enormous hole and will be sorely missed by the board as well as the wider hospital community."

Royal Brompton & Harefield Hospitals Charity has set up the Robert Finch Memorial Fund to support respiratory research. For more information or to donate to the fund, visit rbhcharity.org.





Our vision and values

Our 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

The Trust will achieve this vision by:

- improving patient safety and satisfaction
- providing world-class specialist treatments that others cannot offer
- bringing innovation to clinical practice through our research partnerships
- attracting, developing and retaining world-class clinical leaders
- investing in services, technologies and facilities to support new service models at both sites.

We are supported in this by active patient and community groups who enthusiastically encourage and challenge us to deliver our goals.

Our values

At the heart of any organisation are its values: belief systems that are reflected in thought and behaviour. When values are successfully integrated throughout an organisation, the result is a shared outlook and consequent strength, from performance through the style of communications to the behaviour of employees.

Our values were developed by staff for staff. We have three core patient-facing values and four others which support them.

Our three core values are:

We care

We believe our patients deserve the best possible specialist treatment for their heart and lung condition in a clean, safe place.

We respect

We believe that patients should be treated with respect, dignity and courtesy and that they should be well informed and involved in decisions about their care. We always have time to listen.

We are inclusive

We believe in making sure our specialist services can be used by everyone who needs them, and we will act on any comments and suggestions which can help us improve the care we offer.

And the following values support us in achieving them:

We believe in our staff

We believe our staff should feel valued and proud of their work and know that we will attract and keep the best people by understanding and supporting them.

We are responsible

We believe in being open about where our money goes, and in making our hospitals environmentally sustainable.

We discover

We believe it is our duty to find and develop new treatments for heart and lung disease, both for today's patients and for future generations.

We share our knowledge

We believe in sharing what we know through teaching, so that what we learn can help patients everywhere.





About us

Royal Brompton & Harefield NHS Foundation Trust is the largest specialist heart and lung centre in the UK and among the largest in Europe

The Trust is a partnership of two specialist hospitals – Royal Brompton in Chelsea, West London, and Harefield, near Uxbridge – which are known throughout the world for their expertise, standard of care and research success.

We are a specialist trust, providing treatment for people with heart and lung disease only. This means our doctors, nurses and other healthcare staff are experts in their chosen field, and many move to our hospitals from other parts of the UK and abroad so that they can develop their skills even further.

We carry out some of the most complicated surgery, and offer some of the most sophisticated treatment that is available anywhere in the world. We treat patients from all over the UK and other countries.

Our fetal cardiologists can perform scans at just 12 weeks, when a baby's heart valve is just over a millimetre in size, and our clinical teams regularly treat patients well into their 90s.

Over the years our experts have been responsible for several major medical breakthroughs – performing the first successful heart and lung transplant in Britain, implanting the first coronary stent, founding the largest centre for cystic fibrosis in the UK, and pioneering intricate heart surgery for newborn infants.

We are the leading UK provider of respiratory care and are national leaders in the specialist areas of paediatric cardiorespiratory care, congenital heart disease and cystic fibrosis.

Our patients are supported by adult intensive care units at both hospitals and a dedicated paediatric intensive care unit at Royal Brompton.

Our research

Research programmes play a vital role at both our hospitals. Our clinicians work on numerous research projects that bring benefits to patients in the form of new, more effective and efficient treatments for heart and lung disease. Many medical advances made at the Trust have been taken up across the NHS and beyond. Each year between 500 and 600 papers by researchers associated with the Trust are published in peer-reviewed scientific journals such as *The Lancet* and *New England Journal of Medicine*.

Our main partner is the National Heart and Lung Institute at Imperial College, London, and we run additional research projects with other hospitals and universities in the UK and abroad.

Collaboration

Our proximity to the specialist cancer hospital, The Royal Marsden, enables the two trusts to jointly run one of the largest lung cancer programmes in the UK. Close collaboration with neighbouring Chelsea and Westminster Hospital allows both trusts to provide significantly enhanced services to patients with heart or lung disease. Harefield teams are supported across a range of specialist disciplines by Hillingdon Hospital NHS Foundation Trust.



Performance and achievements

In 2015/16 we:

Cared for more than **190,000 patients** in our **outpatient** clinics

Cared for more than **40,000 patients** on our **wards**

Recruited more than **4,400 patients** into our **research studies**

Opened a **state-of-the-art hybrid theatre**, which enables doctors to carry out different procedures for patients in the same session

Were named as one of the **best places to work** by the Health Service Journal and Nursing Times

Received 10,000 patient comments, **90%** of which were **positive**

Performed the **UK's first surgical treatment for chronic bronchitis**, which freezes diseased lung tissue using liquid nitrogen

Received a **98%** recommendation score in the 2015/16 Friends and Family Test

Pioneered the use of **CardioMEMS microchip devices**, which monitor heart failure remotely

Performed **2,276** coronary angioplasties

Produced more **highly cited research publications** (HCPs) than any other NHS trust in England



Harefield centenary



Founded during the First World War, Harefield Hospital marked its centenary in 2015 with a series of special events and exhibitions

During the past 100 years, Harefield Hospital has treated injured Australian soldiers, been an isolation hospital for tuberculosis and become a world-renowned centre for heart and lung disease. The centenary offered an opportunity to look back and celebrate the hospital's unique history and achievements.

The hospital was established in 1915 in Harefield Park, north west London, an estate owned by the Billiard-Leake family. They offered it as a hospital to the Ministry of Defence of New South Wales to treat soldiers from Australia who had been injured at Gallipoli and on the Western Front.

The wounded soldiers who died while at Harefield are buried in the nearby Anzac cemetery in St Mary's Church. They are remembered in a service held each year on Anzac Day (25 April).

After the First World War, the estate was sold to the local council and was developed as an isolation hospital for patients with tuberculosis; this laid the foundations for the future of Harefield Hospital as a world-renowned centre for the treatment of lung and respiratory conditions.

After becoming part of the NHS in 1948, Harefield first became a general hospital and then a specialist heart and lung centre.

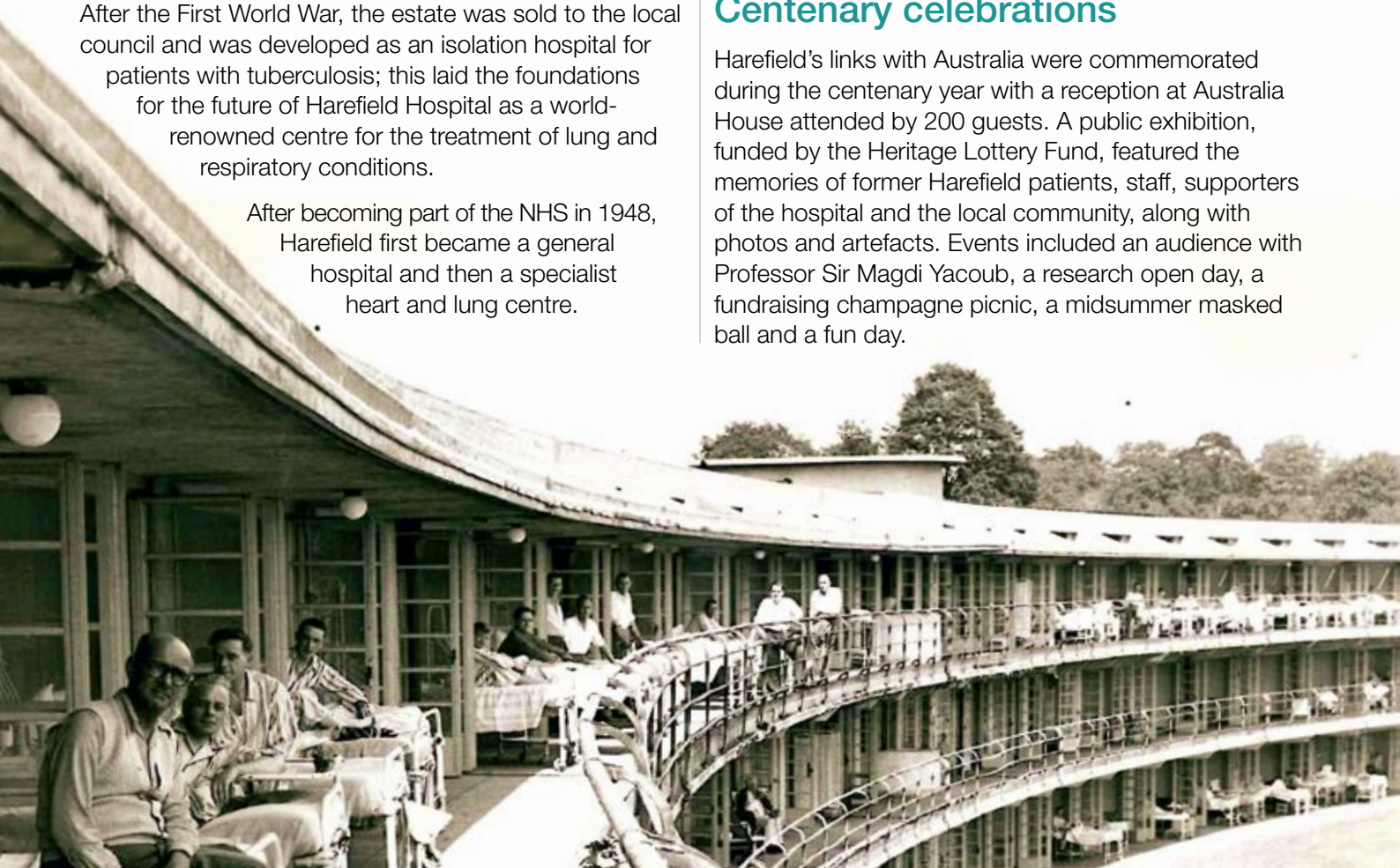
Groundbreaking work led by Professor Sir Magdi Yacoub in the latter part of the 20th century included the hospital's first successful heart transplant in 1980, followed by the UK's first combined heart and lung transplant in 1983. This led to Harefield Hospital establishing the largest transplant programme of its kind anywhere in the world.

In 1998, Harefield Hospital merged with Royal Brompton Hospital, Chelsea, to become Royal Brompton & Harefield NHS Trust. In 2009 it became a foundation trust, and the organisation is now referred to as Royal Brompton & Harefield NHS Foundation Trust.

The Trust is now one of the leading specialist heart and lung hospitals, and one of the largest transplant centres, in the world.

Centenary celebrations

Harefield's links with Australia were commemorated during the centenary year with a reception at Australia House attended by 200 guests. A public exhibition, funded by the Heritage Lottery Fund, featured the memories of former Harefield patients, staff, supporters of the hospital and the local community, along with photos and artefacts. Events included an audience with Professor Sir Magdi Yacoub, a research open day, a fundraising champagne picnic, a midsummer masked ball and a fun day.



Harefield Hospital breakthroughs

1947 World's first valvotomy (enlarging narrowed heart valves).

1976 First corrective or "switch" operation for children, where the aorta and pulmonary artery are on the wrong side of the heart.

1980 One of the first successful heart transplants in the UK is performed at Harefield Hospital.

1983 World's first combined heart and lung transplant is performed at Harefield Hospital.

1992 Heart Science Centre opens, dedicated to research into heart disease. It now houses the Magdi Yacoub Institute.

1995 Artificial left-ventricular assist devices (LVADs or "artificial hearts") programme begins.

2004 Dedicated heart attack centre opens. Staff at Harefield treat heart attack emergencies from outer north west London and provide primary angioplasty in specialist catheter laboratories. The arrival-to-treatment time of 26 minutes is one of the fastest in Europe; the speed of treatment has been shown to be crucial to survival.

2012 Harefield becomes one of the first hospitals to use the organ care system (OCS), which enables a human heart to beat outside the body. This helps to ensure that the heart remains in the best possible condition before transplant surgery.

2014 New clinical trial begins to assess gene therapy for patients with heart pumps and provide detailed insight on its impact on the heart muscle. A Harefield Hospital patient is the first in the UK with an LVAD to take part in the trial.

2014 First UK patient receives revolutionary C-Pulse device to treat heart failure.



“Our very first transplant was on a Saturday morning”

Retired nurse **Pam Baldock** (above) worked at Harefield for 30 years from 1973 until she retired in 2003 and played an important role as the hospital developed into the largest specialist heart and lung centre in the UK. She started as a homograft technician, working with Professor Sir Magdi Yacoub, the soon-to-be pioneer of heart and lung transplant surgery, where her main role was to receive and dissect heart valves from mortuaries.

Pam was soon promoted to transplant co-ordinator and went on to assist in the hospital's first transplant:

“Our very first transplant was on a Saturday morning and I was just about to go out shopping when the phone rang,” says Pam. “Dr Yacoub came on the phone and said very quietly: ‘Pam, we have an organ donor, I’d like you to organise a transplant for me’.”

The surgery was extremely successful, so much so that surgeons from all across Europe and further abroad began travelling to the hospital to learn about cardiothoracic surgery from Professor Yacoub and his team.

“It was a fascinating job,” says Pam. “I feel very proud to have been part of transplantation history.”

Clockwise from top left: screening for tuberculosis in 1943, retired nurse Pam Baldock at the centenary exhibition in 2015, and patients on the balconies in the 1960s

Our specialist services: heart disease

Experts at Royal Brompton and Harefield hospitals care for patients with a wide range of complex cardiac conditions, both congenital (present at birth), inherited and acquired later in life

Our specialists treat patients from the UK and overseas who have a variety of heart conditions including congenital heart disease, arrhythmias (irregular heart rhythms), heart failure, pulmonary hypertension, coronary artery disease, and structural heart disease.

The adult congenital heart disease (ACHD) unit at Royal Brompton is one of the largest specialist centres in the world. Our experts see more than 8,000 patients each year. The Trust is the world's leading centre for congenital heart disease research and a national and international training centre for cardiologists, cardiothoracic surgeons and other clinicians.

The inherited cardiovascular conditions (ICC) team is expanding its service following the appointment of consultant cardiologist Dr Antonis Pantazis, who joined the Trust in January 2016. Dr Pantazis has an international reputation as an expert in cardiomyopathy (disease of the heart muscle) and will use his experience to lead and develop this area of the ICC service at both sites.

Our transcatheter aortic valve implantation (TAVI) service enjoys an international reputation. TAVI is a non-surgical alternative to open-heart surgery for patients with a narrowed aortic valve and is carried out in the Trust's new hybrid theatre (see overleaf). Our clinical teams performed 200 of these procedures last year, making ours the largest TAVI service in the UK.

Our pulmonary hypertension service is one of only seven designated in the country that form the National Pulmonary Hypertension Service (NPHS) for England. It is one of the most rapidly expanding services and it is also one of the few combining pulmonary hypertension

(high blood pressure in the lungs), adult congenital heart disease (ACHD) and lung disease expertise in a single centre.

We have one of the fastest primary angioplasty services in the UK at Harefield's Heart Attack Centre, and offer the largest implantable cardiac device (ICD) service in the UK (including pacemakers and defibrillators).

Congenital heart disease (CHD)

Congenital heart disease (where the condition is present at birth) is one of the most common types of heart defects, affecting around nine in every 1,000 babies. Many cases are diagnosed in the womb, and patients may require surgery or specialised drug therapies. People with congenital heart disease often need treatment throughout their life, and the Trust runs a dedicated transition service for teenagers and young adults moving from our paediatric to adult CHD service.

Primary angioplasty service

A heart attack happens when a blood clot blocks a coronary artery, one of the vessels that supplies the heart with blood and oxygen. The longer the artery is blocked, the more damage there is to the heart, which is why it is crucial that patients receive primary angioplasty treatment as soon as possible.

Harefield launched its primary angioplasty service in 2004 and boasts an enviable reputation for having one of the fastest arrival-to-treatment times in the UK. Rather than being taken to a local A&E, patients are brought straight to Harefield.



The anaesthetist for my surgery, aged three, also cared for me aged 26 – a gap of 23 years

“Without Royal Brompton, I wouldn’t be here today”

Sarah Howell, 34, has been under the care of Royal Brompton since birth. She was born with tetralogy of Fallot, a congenital condition causing a number of structural abnormalities in the heart. These defects mean that oxygenated and non-oxygenated blood mixes, causing the overall amount of oxygen in the blood to be lower than normal.

“At birth, my parents were told I had a heart murmur, but the extent of the condition wasn’t diagnosed until I was two,” says Sarah. “They knew I had a hole in my heart and there was every chance that this might close up without need for surgery, but that wasn’t the case.”

Sarah had her first operation when she was three to create a surgical connection (shunt) to increase blood supply to her lungs. A year later she had surgery to repair the hole between the two chambers of her heart. Her teenage years were spent travelling to regular check-ups, and in 2009 as an adult she had further surgery to replace a valve that had stopped working effectively.

“Heart surgery as a child was scary because I had very little understanding of why I needed it and what

was wrong,” says Sarah. “But as an adult, I knew the details of the procedure and, by the time I had surgery, I could feel the effects of my weakening heart. The pain of surgery lasts for several months, but the benefits were evident within a week; I hadn’t realised how little energy I had pre-surgery and I felt infinitely better almost immediately. I’m proud of my scar; it’s my medal that I wear with pride every day.”

“Royal Brompton has cared for me ever since birth and, all being well, they’ll continue to care for me in the future,” adds Sarah, who works as a brand consultant. “The consistency of this medical relationship is hugely reassuring and is key to my ongoing good health. In fact, the anaesthetist for my surgery, aged three, also cared for me aged 26 – a gap of 23 years – the perfect illustration of a lifetime of specialist care! I continue to attend regular cardiology clinics at Royal Brompton so that my heart is continuously monitored.

“Undergoing open heart surgery three times is the biggest and most important achievement of my life. Without Royal Brompton and everything they have done for me over the last 30 odd years, it is safe to say I wouldn’t be here today.”

New hybrid operating theatre

A new £6.3 million state-of-the-art operating theatre offering lifesaving treatments for patients with complex heart conditions opened at Royal Brompton Hospital in November 2015.

The hybrid theatre, which was built with £4.2 million funding from the Royal Brompton & Harefield Hospitals Charity, combines the environment of an operating theatre with the imaging capabilities of a catheter laboratory.

The facility is the largest of its kind in Europe and incorporates the most modern theatre equipment found anywhere in the UK. The advanced imaging technology, operating table and integrated computer software work together, which means operations can be planned in advance in unprecedented detail.

The new operating theatre enables doctors to carry out different procedures for a patient in the same session, rather than interventions being staged over a period of time and several hospital visits.

Patients spend less time in hospital, benefit from shorter recovery times and experience less pain and scarring.

Combined cardiac procedures that involve both a surgical and transcatheter approach (a thin flexible tube inserted into an artery via a small incision in the groin, chest or shoulder) will, in future, be available to a greater number of patients.

The facility will mean the Trust's expert surgeons and interventional cardiologists can offer more minimally-invasive procedures, for example, coronary artery bypass graft (commonly known as heart bypass) with

coronary angioplasty, which involves inserting a stent via a catheter to treat a blockage in the artery. They will also be able to develop new groundbreaking techniques for patients with complex heart disease, which will be particularly valuable for patients who are considered high risk for conventional surgery.

Dr Richard Grocott-Mason, medical director at Royal Brompton & Harefield NHS Foundation Trust, explains:

"The hybrid operating theatre provides our specialist teams with the latest cutting-edge technology and means current and future patients will benefit from pioneering treatments. It supports our ongoing commitment to deliver a multidisciplinary approach to patient care and offer world-class specialist treatments that are not widely available elsewhere.

"As the Trust's experts continue to push boundaries and carry out increasingly complex procedures, patients will be provided with greater choice and have access to more minimally-invasive treatment options.

"Despite the current financial pressures being felt across the NHS, investing in high-quality patient care remains an absolute priority for our hospitals. We are extremely fortunate therefore to have the support of the Royal Brompton & Harefield Hospitals Charity, without which the building of the hybrid theatre would not have been possible. We are grateful to the charity and its supporters for providing two thirds of the funding for this exciting new facility that will benefit hundreds of patients every year."



Our clinicians perform primary angioplasties in cardiac catheterisation laboratories, also known as cath labs. They insert a thin tube called a catheter through a small cut in the patient's wrist or groin. The catheter is then guided into the blocked artery in the heart and a small balloon on the tip of the catheter is inflated, clearing the blockage. A small metal tube, called a stent, is put into place to keep the artery open and allow the blood to flow freely again.

Since the service was launched, the primary angioplasty team at Harefield has treated more than 10,000 patients.

Arrhythmia – innovative devices

Heart rhythm problems (arrhythmias) are experienced by more than one million people in the UK every year. The heart may beat too slowly (bradycardia), too quickly (tachycardia) or irregularly (atrial fibrillation). Certain types of arrhythmia can also cause the heart to stop beating altogether (cardiac arrest), resulting in sudden cardiac death. Therefore, it is vital that arrhythmias are treated appropriately.

Royal Brompton & Harefield NHS Foundation Trust has one of the largest pacing and complex device services in the UK. Last year, our experts implanted or renewed 878 pacemakers and 645 implantable cardioverter defibrillators (ICDs).

Patients with bradycardia often require a pacemaker, whereas patients who are at risk of life-threatening arrhythmias need an ICD.

Pacemakers and ICDs are both implanted in the chest and can send regular electrical pulses that help keep the heart

beating regularly. ICDs are often used as a preventative treatment for people thought to be at risk of cardiac arrest. If the ICD detects that the heart is beating at a potentially dangerous rate, it can “pace” or deliver an electric shock to the heart to help it return to its normal rhythm.

Cutting-edge leadless pacemaker

In December 2015, a patient at Royal Brompton Hospital became one of the first in the UK to be fitted with an innovative new pacemaker that works without leads.

Bill Hill, 78, from Buckinghamshire, was implanted with a Nanostim™ pacemaker in December to treat atrial fibrillation (AF), a heart condition causing an irregular heart rate.

Pacemakers work by monitoring the heart and providing electrical stimulation to set a pace to prevent the heart beating too slowly.

The Nanostim is less than 10 per cent of the size of a conventional pacemaker and is implanted directly into the heart via a catheter, a flexible tube inserted through a vein in the thigh. This differs from a standard pacemaker, which is placed in a ‘pocket’ created in the chest or abdomen during surgery, with leads that are positioned in the chambers of the heart.

The pocket made to house pacemakers is susceptible to infection, so leadless pacemakers are believed to reduce this risk. Unlike conventional pacemakers, they also eliminate the chance that the wires can malfunction.

The Nanostim is delivered through a catheter, which means patients are not left with a scar. It contains a built-





Bill Hill was fitted with an innovative new pacemaker that works without leads

in battery that lasts between nine and 13 years and the device can be retrieved if the battery needs to be replaced.

Bill had the Nanostim fitted in December and was discharged the following day.

“Now I’m boasting about my cutting-edge pacemaker to my friends who have the traditional ones,” says Bill. “It feels good to be part of a trial, knowing I may potentially help other people.”

Heart failure

Heart failure is a long-term condition in which the heart becomes too weak to pump blood around the body. It can be treated with medication, implantable devices or surgery, depending on the type of heart failure. Experts at the Trust run regular heart failure clinics and are at the forefront of new treatments for the condition.

New microchip that monitors heart failure

In 2015, a revolutionary microchip that measures how well a patient’s heart is functioning was implanted for the first time in the UK by cardiologists at the Trust.

Designed for patients with chronic heart failure, the sensor, known as the CardioMEMS™ HF System, is implanted during a minimally invasive procedure using a cardiac catheter, a thin tube that is passed up to the heart through a vein in the leg. The miniature wireless sensor is inserted into the pulmonary artery (the main blood vessel carrying blood from the heart to the lungs).

Once in place, the device – which has no battery or replaceable parts – enables clinicians to remotely monitor changes in blood pressure in the pulmonary artery, which is a good indicator of worsening heart failure.

Each day patients lie on a specially adapted pillow for a few minutes. The pillow receives data wirelessly from the implanted sensor and is connected to a monitor that sends the readings directly to the patient’s doctors. The hospital heart failure team then analyse the readings and determine if they need to adjust treatment. This is likely to be before the patient experiences any symptoms and can prevent a potentially life-threatening deterioration.

The CardioMEMS device is now being used by 10 patients at the Trust. With around 900,000 people living with heart failure in the UK, cardiologists hope the device has the potential to improve management and treatment for many patients.

In 2011, results from a randomised controlled trial in the





In May 2015 Barrie Stubbs, 80, (above right) had the CardioMEMS device fitted at Royal Brompton. Barrie, from Uckfield, East Sussex, suffers from heart failure and, since having the device fitted has had to attend only one appointment with his cardiology consultant, Dr Alex Lyon (above centre), in the past year. Becky Lucas (above left), Barrie's cardiac nurse, monitors him remotely every day, and he sees his local GP for blood tests and prescriptions.

"It's magic," says Barrie, a former flying instructor. "In the morning, I lie on the pillow, which is attached by a thick cable to the monitoring unit on my bedside table. The antenna in the pillow picks up the signal from the unit in my pulmonary artery, and the reading is transmitted to Becky. She has called twice to say my pulmonary blood pressure is too high, and on those occasions she told me to increase my medication to stabilise my readings.

"Dr Lyon and Becky have been wonderful," adds Barrie. "I'd like to thank them for looking after me so well."

United States, which were published in *The Lancet*, showed the sensor reduced hospital admissions by an average of 30 per cent after six months, compared with a control group.

Professor Martin Cowie, consultant cardiologist at Royal Brompton & Harefield NHS Foundation Trust, says:

"With this device patients can send regular information back to their heart failure team easily and from the comfort of their own home. This will help us detect any worsening in cardiac function early and take steps to prevent it, before patients experience a decline in their health.

"It will also provide a better way of deciding whether patients are having the best treatment, allowing us to take a more tailored approach for each individual patient."

Innovative treatment for atrial fibrillation

Experts at Harefield Hospital have launched a project with local pharmacists to improve the diagnosis and treatment of patients with atrial fibrillation (AF).

Led by senior arrhythmia pharmacist, Sally Manning, and consultant cardiologist, Dr Wajid Hussain, the programme's overall objective is to reduce the number of undiagnosed AF cases and the prevalence of stroke among AF patients.

AF is a heart condition that causes an irregular and often abnormally fast heart rate. It affects over 800,000 people in England and can cause symptoms such as palpitations, tiredness, breathlessness and dizziness. The way the heart beats in AF reduces its efficacy, which can cause blood clots that may lead to a stroke. AF can cause heart failure if it is not well controlled.

Ten community pharmacists in the surrounding north Hillingdon area have been trained to carry out detailed medicine reviews for patients with risk factors for developing AF – for example, elderly patients and people with high blood pressure or existing heart disease. And, for patients with existing AF, the pharmacists check that they are receiving optimised treatment and are taking anticoagulants.

As part of the consultation, the pharmacists will use a portable electrocardiography (ECG) device, called an AliveCor monitor, to detect AF. The AliveCor monitor is a small metal plate that is linked to a mobile phone or device. Patients place their fingers on the plate, which contains electrodes, and it records their heart rate and rhythm and automatically detects whether the patient is in normal rhythm or AF.

If a patient is diagnosed with AF or found to have inadequate AF treatment, they will be referred directly to the arrhythmia care team at Harefield Hospital, which runs the largest arrhythmia service in the UK.

Dr Hussain says: "Of the 600 patients who will be screened in the project, we estimate that 10 per cent will require referral to Harefield for further management.

"We don't want patients to be out there with AF and not know it. Some patients only find out they have the condition when they have a potentially life-threatening stroke – and it can be difficult to recover from strokes caused by AF."

Sally Manning added: "If this model is successful it could be applied to other community pharmacies all over the country. The programme will reach out to a population of patients, the elderly for example, who may not see a GP if they experience symptoms but will be happy to talk to a pharmacist about their medicines."

State-of-the-art facilities: This new cath lab at Harefield features advanced technology and a relaxing image above the bed to soothe patients during procedures



Our specialist services: lung disease

Royal Brompton and Harefield hospitals are world leaders in the diagnosis, management and treatment of lung disease

Our expert teams treat patients from the UK and overseas who have respiratory disorders including severe asthma, chronic obstructive pulmonary disorder (COPD), interstitial lung disease (ILD), allergies, occupational lung disease, cystic fibrosis (CF), sleep disorders and lung cancer.

They run the largest ILD clinic in the UK, the largest asthma clinic in London and the south east, and the largest occupational lung disease service in the UK. Our COPD clinic for patients with bronchitis and emphysema treats patients from all over the UK. The Trust is home to the largest adult cystic fibrosis centre in the UK, and the largest centre for the surgical treatment of lung cancer.

Interstitial lung disease

Interstitial lung disease (ILD) is an umbrella term that covers many different conditions. 'Interstitial' means the disease affects the 'interstitium', a lace-like network of tissue that supports the alveoli (air sacs) in the lungs.

ILD causes inflammation or scar tissue to build up in the lungs, making them thick and hard. This build-up of scar tissue is called fibrosis. As the lungs become stiffer and lose their elasticity, they are less able to take in oxygen. People with ILD can feel breathless from simple everyday activities like walking. Coughing is another common symptom.

There are more than 200 different types of ILD. All of them are rare, but the most common is idiopathic pulmonary fibrosis (IPF).

The interstitial lung disease unit at Royal Brompton Hospital is the largest unit of its kind in Europe, with almost 5,000 patients.



Dr Felix Chua (above), consultant respiratory physician and divisional lead for ILD says: "For most types of ILD, the cause is unknown. Some types are linked to other conditions such as rheumatoid arthritis, or it can be a side-effect of medication such as chemotherapy drugs. It can also be caused by exposure to certain types of dust and other allergens such as birds, mould and metal dusts.

"Most patients who come to us have experienced symptoms for years, and many have been misdiagnosed in the past. There is no cure, but it can be managed."

In the past decade, teams at Royal Brompton Hospital have been at the forefront of developments made in the diagnosis and treatment of ILD. Two new drugs for ILD were approved by NICE in 2014.



“I’d never heard of IPF”

Eric Schaffa, 80, from Littlehampton, West Sussex, was diagnosed with idiopathic pulmonary fibrosis in 2013.

“I had no idea that anything was wrong with me until I went to my GP for a routine check-up in 2013,” explains Eric. I had a cough at the time and my GP was worried that it might be pneumonia so he sent me to Worthing Hospital for tests.

“The hospital ruled out pneumonia but referred me to Royal Brompton for its specialist lung services. I was asked to stay in hospital for three days for the ‘work up’, where they carry out all sorts of tests to find out what’s wrong. On the first night the nurse woke me up and said she wasn’t happy about my breathing, so from then on I was put on oxygen at night.

“At the end of the three days I was diagnosed with idiopathic pulmonary fibrosis. I’d never heard of it, and I hadn’t noticed any symptoms, apart from getting a bit out of breath on the golf course sometimes.

“My consultant asked me lots of questions, such as whether I’d ever worked with birds, or whether I’d ever been exposed to asbestos. I told her that I used to work as a chef and had worked in lots of old kitchens in London’s west end, but whether there was asbestos in the buildings I didn’t know. Also, one of the restaurants where I worked had a bird cage with canaries and love birds, and I always used to feed them, but no one could say with certainty what caused the IPF.

“The doctor told me that IPF is incurable but that new drug treatments were available. In June 2015 I was given the opportunity to go on a new drug called nintedanib as a ‘named patient’. The drug was still going through clinical trials, but my consultant thought that I’d benefit from it. (The drug was approved by NICE in January 2016.)

“I am now doing very well – I’m able to do some gardening, and I still play golf every three weeks (although I get around the course in a buggy!).

“I feel good, and people say I look well. I feel very lucky to have been given access to this new drug, which is only because I was a patient at Royal Brompton.”

Sarcoidosis

Sarcoidosis is a form of interstitial lung disease. It’s a rare condition that causes small patches of red and swollen tissue, called granulomas, to develop in the organs of the body. It usually affects the lungs and skin but it can affect other parts of the body, such as the heart.

The symptoms of sarcoidosis depend on which organs are affected, but typically include tender, red bumps on the skin, shortness of breath and a persistent cough.

For many people with sarcoidosis, symptoms often improve without treatment within a few months or years. For these people, the symptoms aren’t usually severe. However, a few people find their symptoms develop gradually and get worse over time, to the point where they become severely affected. This is known as chronic sarcoidosis.

Sarcoidosis is estimated to affect about one in every 10,000 people in the UK. There is currently no cure but, as with IPF, it can be managed.

Royal Brompton’s ILD team runs a weekly sarcoidosis clinic, the largest of its kind in the UK. We have particular expertise in the management of chronic and multi-organ sarcoidosis and run monthly combined cardiac-sarcoid and neuro-sarcoid clinics – a first for the UK .

Teams at the Trust also have close links with dermatologists and ear nose and throat surgeons based at Chelsea and Westminster Hospital, for the shared care of individuals with sarcoid affecting the skin and upper respiratory tract.



I feel very lucky to have been given access to this new drug, which is only because I was a patient at Royal Brompton

Below: Professor Eric Alton, consultant physician at Royal Brompton, co-ordinated the Imperial College consortium in the gene therapy trial

Cystic fibrosis (CF)

The cystic fibrosis centre at Royal Brompton Hospital is one of the largest in Europe, caring for around 700 adults and 340 children. In 1965, the Trust established the UK's first adult cystic fibrosis service in response to the increasing number of patients living with the condition into adulthood.

Cystic fibrosis is a life-limiting inherited condition caused by a faulty gene that controls the movement of salt and water in and out of cells. This causes mucus to gather in the lungs and digestive system, which can lead to infections and other problems.

Gene therapy for CF

A therapy that replaces the faulty gene responsible for cystic fibrosis (CF) in patients' lungs has produced encouraging results in a trial at Royal Brompton Hospital.

During the clinical trial, 136 patients aged 12 and over received monthly doses of either the gene therapy or a placebo for one year. The results showed that patients who received the therapy had a modest, but significant,

improvement in lung function compared with those receiving a placebo.

Patients in Scotland also took part in the trial and were treated at the Western General Hospital in Edinburgh.

The cause of CF – mutations in a gene located on chromosome 7 – was identified in 1989. This discovery opened the door to a gene therapy, which introduces a normal copy of this gene. In the trial, patients inhaled molecules of DNA wrapped in fat globules (liposomes) that delivered the gene into the cells in the lung lining.

The study was carried out by the UK Cystic Fibrosis Gene Therapy Consortium, a group of scientists and clinical teams from Royal Brompton & Harefield NHS Foundation Trust, Imperial College London, the Universities of Oxford and Edinburgh and NHS Lothian. The group came together in 2001 to develop a gene therapy and were supported by the Cystic Fibrosis Trust.

The trial launched in 2012 and was funded by the National Institute for Health Research (NIHR) and the Medical Research Council (MRC). The findings were published in July 2015 in *The Lancet Respiratory Medicine*.



The trial is the first to show that repeated doses of gene therapy can have a meaningful effect on CF and change the lung function of patients. However, further research is needed to make the therapy more effective before it is suitable for clinical use.

Professor Eric Alton, consultant physician at Royal Brompton Hospital and co-ordinator of the Imperial College consortium, says:

“The results are encouraging and lay the groundwork for further trials that we hope can improve the effect. We are looking to carry out follow-up studies to assess higher and more frequent doses, combinations with other treatments and different methods of delivering the gene into the cells.

“Our aim is to achieve a step change in the treatment of CF that focuses on the basic defect rather than just addressing the symptoms. Eventually we hope gene therapy will push CF patients towards a normal life expectancy and improve their quality of life significantly.”

Chronic obstructive pulmonary disease (COPD)

COPD is an umbrella term that includes chronic bronchitis and emphysema. It's a condition in which the airways become inflamed and the air sacs in the lungs are damaged. This causes the airways to narrow, resulting in breathing difficulties.

The main cause is smoking and it's thought to affect around three million people in the UK. There is currently no cure, but the condition can be managed with exercise and medication. The Trust offers a world-class COPD service to patients from the local community and across the country.

New freezing treatment for chronic bronchitis

Chronic bronchitis is the most common form of COPD. In March 2016, a pioneering treatment for patients with chronic bronchitis was carried out for the first time in the

How Nick Robinson got his voice back



In March 2015, the BBC's political editor, Nick Robinson, underwent surgery at the Trust to remove a bronchial carcinoid tumour from his lung. This is a rare type of tumour that is slow growing and is less likely to spread than other forms of cancer. The successful surgery was carried out by consultant thoracic surgeon, Mr Eric Lim, whom Nick Robinson later described as an "excellent surgeon" on BBC Radio 2.

However, the surgery left Nick with a paralysed vocal cord, which meant that he had no voice at all. He was referred to Dr Julia Selby, clinical lead speech and language therapist at the Trust. Together they embarked on intensive voice therapy to get him ready to cover the May 2015 general election eight weeks after his surgery. They continued to work together and achieved another of Nick's career goals – to become a presenter on Radio 4's Today programme in November 2015.

Speaking at the Royal College of Speech and Language Therapists (RCSLT), the veteran broadcaster praised Dr Selby (pictured left) for her heroic work. "She has not just been a speech therapist, she has been a friend, a counsellor...someone to cry with. It has been an extraordinary year, and really is a story about the heroic work that many medical professionals do."

Nick added: "Even now, Julia will send me quite detailed comments while I'm on air, with my phone next to me. She'll text me to say "that's sounding good" or "try this".

UK as part of a trial led by experts at Royal Brompton and Chelsea and Westminster Hospitals in London.

The 30-minute procedure, which uses liquid nitrogen to freeze diseased lung tissue from the upper layer of cells in the airways, was carried out by consultant respiratory physician and chief UK investigator, Dr Pallav Shah, as part of the RejuvenAir System clinical trial.

The minimally-invasive treatment targets the goblet cells, which are found in the top layer of airway tissue (the epithelium) and produce excessive amounts of mucus in patients with chronic bronchitis. The procedure aims to destroy these cells using liquid nitrogen while preserving the stem cells underneath. The stem cells allow new, healthy tissue to quickly form within a few days.

Dr Shah says: “The main cause of chronic bronchitis is smoking because the immune system triggers the goblet cells to produce too much mucus. The excess mucus blocks the airways, causing coughing and breathlessness, and attracts bacteria, which can lead to infections. Even when these patients stop smoking, the cells still produce excess mucus – it is as though a switch is broken and is permanently turned on.

“While some medications available to patients can thin the mucus or open the airways, this new procedure is the only treatment that has the potential to stop excess mucus production and restore it to a normal level.”

During the procedure, a narrow tube with a light and camera at the tip – known as a bronchoscope – is inserted into the

Singing for breathing

The Trust’s weekly Singing for Breathing workshops have been running since 2008. Singing can be beneficial to people with damaged or weak lungs as it encourages them to focus on breathing techniques and use their lung capacity as best they can. A survey of 500 Trust patients found that 70 per cent felt significantly physically better after taking part in Singing for Breathing workshops.

The sessions also boosted their wellbeing, making them less anxious, depressed and isolated.

patient’s airways that lead to the lungs. A thin tube (catheter) is then manoeuvred into the part of the lung targeted for treatment. The catheter is connected to equipment that delivers liquid nitrogen at a carefully-controlled dose, which depends on the patient and the area being treated. The liquid nitrogen is about -196°C when applied to the cells and at this temperature the structures within the cells freeze and die.

In March, Jayne Hewitt, 49, from London, became the first patient in the UK to have the novel procedure. She was diagnosed with COPD around four years ago after suffering from breathlessness, a tight chest, frequent chest infections and a persistent cough. Her condition progressively worsened until it got to the point where simple daily tasks, such as having a bath, carrying shopping, talking and eating, were a struggle.

She says: “It’s amazing to be the first UK patient to have this treatment and I feel so privileged to be given this opportunity. Days after the procedure my chest already didn’t feel as tight, I was coughing less than before and breathing a bit better, even though only one part of my right lung had been treated. It used to feel like I had an elephant sitting on my chest and now it doesn’t. It has given me such a boost and I feel more hopeful about my future now.”

The clinical trial, which is taking place at Royal Brompton Hospital, in collaboration with Chelsea and Westminster Hospital NHS Foundation Trust, and at the University Medical Center Groningen in the Netherlands, aims to evaluate the safety and feasibility of the treatment. It is funded by CSA Medical, the company that manufactures the RejuvenAir System.



It’s amazing to be the first UK patient to have this treatment. I feel more hopeful about my future now

Transplantation

The transplant unit at Harefield Hospital is one of the UK's largest and most experienced centres for heart and lung transplantation

Our clinicians have performed almost 3,000 heart and lung transplant operations since 1980 and have the best long-term survival rates in the UK. In 2015/16 they performed 25 heart transplants, 49 lung transplants and implanted 49 ventricular assist devices (VADs). The team's international reputation encourages referrals from around the country.

Organ care system

In 2015/16, Harefield teams continued to perform greater numbers of heart transplants, mainly due to the organ care system (OCS), which enables a donor heart to beat outside the human body. Until very recently, all donated hearts in the UK were from donors declared brain dead, but who still had blood pumping around their bodies. However, the organ care system means that surgeons can now also consider hearts for transplantation from donors whose hearts have stopped beating, in what is known as donation after circulatory death (DCD). This is

when both the heart and lungs have stopped working. Harefield was the first transplant centre in the UK to adopt this revolutionary system as standard practice for heart transplant procedures.

The OCS, sometimes referred to as “heart in a box”, simulates the conditions of the human body. As soon as a heart is removed from a donor's body, it can be immediately revived to a beating state, pumped with oxygen and nutrient-rich blood and kept at the correct temperature. This helps to ensure that the heart remains in the best possible condition before the transplant surgery. The system replaces the traditional “cold ischemia” (ice preservation) method of transporting the heart.

This new system increases the time the heart can be maintained outside the body, up to 12 hours, compared to a maximum of three to four hours on ice. This means hearts can be retrieved from further afield and it provides surgeons with greater opportunity to assess how well the donor heart is functioning prior to transplant.

According to specialist transplant clinicians at Harefield Hospital, the new development has the potential to increase heart transplantation by around 30 per cent in the UK. At present, Harefield and Papworth Hospital in Cambridge are the only transplant centres in the UK to carry out non-beating heart transplants from this group of donors.

Mr André Simon, director of transplantation at Royal Brompton & Harefield NHS Foundation Trust, says: “The use of DCD donors in transplantation is a very exciting development that will ultimately help us save more lives. It provides new hope to patients who are desperately waiting for a heart transplant.”

To help the Trust extend its transplant programme into this new area of transplanting DCD donor hearts, the team at Harefield Hospital has invested in a second OCS machine to ensure patients can benefit from the increased number of donor hearts that will now be available for transplantation. The new system was funded by money raised on behalf of the Royal Brompton & Harefield Charity at a concert in early 2015.



The organ care system, left, sometimes referred to as “heart in a box” simulates the conditions of the human body



DCD heart transplant

Lee Hall, from Illogan, Cornwall, was one of the first patients at Harefield Hospital to receive a heart from a circulatory death donor.

The 26-year-old, who lives with his wife Danyelle and their one-year-old son Hayden, developed heart failure at 14. The condition was linked to chemotherapy he had as a small child to treat leukaemia. Initially, drugs improved his heart function, but aged 20 he had become frequently breathless and tired while working as an electrician. He was referred to Harefield Hospital and fitted with a left ventricular assist device (LVAD), a mechanical heart pump often used to keep patients alive and enable them to leave hospital while they wait for a transplant.

Lee remained in relatively good health for five years. However, in early 2015 he was put on the urgent transplant list as his health deteriorated, and was asked if he would be happy to receive a non-beating heart.

"I had previously read about this type of donated heart online so I was very happy to have one," says Lee. "A suitable DCD heart soon became available and I had the transplant."

"I'm grateful that I've been cared for at Harefield, where this type of heart transplant is possible – without it I'd probably still be waiting for a new heart."

"It is hard to accept that someone has died for you to carry on living and I'd like to thank my donor and their family for making this possible."

Lee was discharged in July after a successful recovery.



A world record

In 2015, Andrew Whitby, 51, was officially named the longest surviving heart-lung transplant recipient by Guinness World Records. His transplant was performed 30 years ago by Professor Sir Magdi Yacoub at Harefield Hospital.

"Looking back now, it is remarkable to think that I was one of the first people to have a heart-lung transplant," says Andrew, who was born with a congenital heart condition. "At the time I was told I had a 70 per cent chance of living for five years. Now I feel that every day I live is a bonus."

"I think being active has helped me to stay healthy – I like walking and swimming and during the summer I walk the two and a half miles to work and back."



Children's services

Royal Brompton and Harefield's paediatric unit is a national specialist referral centre for children with heart and lung conditions, providing care from before birth, through childhood and into adolescence

Many of our children's services are internationally renowned, including congenital heart disease, fetal cardiology, inherited cardiac conditions, paediatric cystic fibrosis and severe asthma. We are the largest national centre for children with heart rhythm problems and the third largest UK centre for paediatric cardiac surgery. Our respiratory clinicians have particular expertise in treating children with rare lung diseases, such as primary ciliary dyskinesia (PCD).

Our clinical teams work closely with referring hospitals throughout the south east, and use telemedicine to provide clinical healthcare at a distance. For example, trained paediatricians with expertise in cardiology at our referring hospitals are able to scan a child's heart and share the results via video conferencing facilities with cardiologists at Royal Brompton, who can then advise on the care for the child. Our experts also hold a large number of outreach clinics across the south east to enable children to have a specialist opinion without having to travel further than their local hospital.

Collaborative working

The Trust's highly successful partnership with neighbouring Chelsea and Westminster Hospital, delivered through a formal contract (Service Level Agreement), allows us to offer the very best in paediatric care. When children with heart or respiratory conditions need a clinical procedure of any kind, anaesthesia and intensive care are major issues. For example, babies and children under the care of Royal Brompton who need general, ear, nose or throat or dental surgery have their operations at Royal Brompton with specialist paediatric anaesthetists and intensive care teams on site (including highly specialist nurses), but the surgery is undertaken by visiting consultants from Chelsea and Westminster.

Clinicians from Chelsea and Westminster also provide their expert opinion within 30 minutes across a number of clinical speciality areas, including paediatric general surgery and paediatric gastroenterology, both during and outside normal working hours. For example, the provision of specialist gastroenterology is delivered by four Chelsea and Westminster Hospital consultants

and a cohort of specialist nurses, who provide cross-site working and clinical advice. They also attend multidisciplinary meetings at Royal Brompton.

Our integrated paediatric service is further strengthened through a number of joint consultant appointments which create cross-Trust provision in respiratory, neurology and endocrine care, and support to the paediatric intensive care unit and cardiac/respiratory services.

There is also a weekly gastroenterology ward round attended by consultants from Chelsea and Westminster and Royal Brompton, with additional help from King's College Hospital when required.

Children's heart services

The children's cardiology and cardiac surgery service is the third largest unit in the UK and our experts are world leaders in the fields of fetal cardiology, inherited cardiac conditions, electrophysiology and congenital heart disease. The Trust has the largest cohort of specialist cardiology nurses in the UK.

Fetal cardiology

The fetal cardiology programme is increasing in size each year, and our experts currently see 10 per cent of all babies born in England. The majority of these babies are referred from across the UK while still in the womb, usually after the routine 20-week ultrasound scan picks up a heart defect. Others will be referred if the mother is at an increased risk of having a child with congenital heart disease, for example, because she or her partner has a heart defect. Once referred, mothers are given a fetal echocardiogram (echo), which can identify any significant cardiac defects in the unborn baby.

Paediatric congenital heart disease

The Trust offers a highly specialised service for children with congenital heart disease (CHD), caring for them from before birth to adulthood. There are many different types of CHD, and treatment may include surgery and medication, with regular check-ups at our clinics.



Lily (far left) today and aged three with her mum Leah

“I feel really safe at Royal Brompton”

Lily Gauthier-Chapman has been a patient at Royal Brompton since she was born in 2001. Her mother, Leah, explains: “I gave birth at Epsom Hospital and everything seemed fine, but Leah had problems feeding, and then became quite breathless and blue.” Tests showed Lily had a cardiac problem so, at around 12 hours old, she was rushed to Royal Brompton, where she was diagnosed with pulmonary atresia with intact ventricular septum (PA/IVS).

The condition means Lily’s pulmonary valve, which allows blood to be carried from the heart to the lungs, is blocked, resulting in a low level of oxygen in the blood.

“It was a very scary time, but I was relieved that her condition had a name,” says Leah. “I’d never heard of congenital heart disease before. When she was diagnosed, the doctor drew a diagram and explained the differences in Lily’s heart structure and what he was going to do to alleviate her symptoms. He gave me all the information I needed and made me aware of some of the challenges ahead.”

Lily had surgery at just a couple of days old to create a hole where the pulmonary valve should have been and to implant a shunt (surgical connection) between her aorta and pulmonary artery. This was a temporary measure until she was nine, as by then her heart had grown, so the shunt was closed and she had a stent (a wire mesh tube) inserted into her right pulmonary artery to keep the blood flowing. The procedure involved inserting a catheter (a long, flexible tube) through her groin and up to her heart. She had another stent inserted in 2014 at just 13 years of age, and her next operation will be a valve replacement, which should take place in the next year or two.

“Lily is now 15, nearly six feet tall, and has led a relatively normal life,” says Leah. “She finds cardiovascular exercise a bit of a struggle and prefers not to take part in competitive sports or cross country running, but she enjoys swimming and can join in with her friends at most things. She does get out of breath sometimes, but says she feels OK. We’ve had a few calls from the school over the years when she’s felt faint and had to sit quietly, but nothing serious.”

When children with congenital heart disease reach 16, they move over to the adult CHD service, and Royal Brompton runs a unique nurse-led transition service to help make the move as smooth as possible.

“Lily has already had two meetings with the transition nurse,” says Leah. “Up until now I’ve been managing her health, but now it is important that she begins to manage the condition herself. At the moment I have to remind her to take her aspirin (which helps prevent blood clots) but she’s soon going to have to start taking much more responsibility.”

Lily adds: “The meeting with the transition nurse was really useful. We discussed what was different with my heart and talked about blood sugar levels and breathlessness, and how I should always let someone know if I’m not feeling well. She also talked about the dangers of alcohol, smoking and drugs. And she helped me focus on what I need to remember, like taking my aspirin!”

“I feel ready to move to the adult services, and I’m pleased that I’m staying at the Royal Brompton, as I feel really safe there and I know they give me the best care possible. I’m glad I don’t have to move hospitals, and it’s good to know that the doctors who operated on me as a child are still involved in my care.”

The majority of child CHD patients need further treatment and care as an adult and, as the Trust provides both child and adult CHD services, we can provide continuity of care throughout a patient's entire life. Once children reach 13, they attend transition clinics led by specialist nurses. At these in-depth meetings, the nurse will help them to understand their condition and discuss exercise, diet and future career plans. Patients move to the adult service between 16 and 18, and the adult CHD team works closely with doctors from the paediatric cardiology team to ensure that the transition process is seamless.

Paediatric cystic fibrosis

Cystic fibrosis (CF) is an inherited life-limiting disease mainly affecting the pulmonary and digestive systems. The paediatric CF unit at Royal Brompton is the largest in the UK, and we have 340 paediatric CF patients in our care.

The Trust's Clinical Guidelines: care of children with CF, written by our paediatric cystic fibrosis team, is very well regarded and used by many other CF centres in the UK and abroad.

We run a homecare service for all children with CF to help every family who needs our expertise at home. This helps young people (and their parents) understand the care they need, prevents them from becoming acutely unwell and helps stop unnecessary hospital admissions.

Once children with CF become teenagers, they attend transition clinics to prepare them for their move to the Trust's adult CF service. The paediatric and adult CF teams work very closely together to ensure that the transition is as smooth as possible.

Research carried out at Royal Brompton last year showed that children with a specific mutation of CF could see improvements in their condition if given the drug therapy Ivacaftor earlier in life. The study, the first to look at the safety and effectiveness of the drug in children aged two to five, was led by Professor Jane Davies, consultant in paediatric respiratory medicine at the Trust. She says:

"Although this was a small trial we are excited by the results, which highlight the potential that Ivacaftor has to improve the lives of children with cystic fibrosis."

The children's long-term ventilation (LTV) service

Many children survive critical illness but remain dependent on technology. Developments in portable ventilators, alongside increasing clinical expertise, ensure that many of those children who cannot breathe on their own can leave hospital to be cared for by family members and professional carers at home.

For some children and babies who need long-term ventilation, a permanent tracheostomy is fitted.

This is where a tube is inserted into an opening in the front of the windpipe and connected to an oxygen supply and ventilator. The Trust's LTV team provides specialist training to parents and professionals to care for these technology-dependent children.

Hospital to Home pathway

Royal Brompton Hospital's long-term ventilation (LTV) team has developed an award-winning web-based clinical pathway to provide communication across different hospitals and between hospital and community professionals. The aim is to ensure continuity during the discharge process and ensure all actions are appropriately allocated and followed up. The pathway provides a structured discharge process and allows secure communication between hospital and community professionals.

Primary ciliary dyskinesia

Primary ciliary dyskinesia (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 which, if left untreated, can cause lung damage. Treatment programmes include physiotherapy to help clear the airways, and antibiotics to help fight bacterial infections.

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.

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). 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.

Difficult asthma

The Trust is a specialist centre for the diagnosis and treatment of difficult asthma, which does not respond to the usual medications. Children with difficult asthma are referred to the Trust from all over England and undergo a full assessment from our multidisciplinary team including physicians, specialist nurses, psychologists and physiotherapists. Some children are found not to have asthma at all, and others are given different medications tailored to their specific type of the disease.

The Trust benefits from close links with the National Heart and Lung Institute, part of Imperial College London's Faculty of Medicine, and our experts are involved in a number of significant asthma research studies.

Our research

Royal Brompton & Harefield NHS Foundation Trust is recognised throughout the world for its pioneering research into complex heart and lung conditions

Research into cardiovascular and respiratory medicine is central to the Trust's mission and our starting point is the needs of the patients we treat every day. By investigating the causes of their conditions and testing new ways of diagnosing and treating them, we have been responsible for many significant medical advances that have been taken up across the NHS and beyond.

The Trust's portfolio of cardiovascular and respiratory research encompasses numerous active studies across the breadth of our clinical practice.

Over the years we have nurtured strong partnerships with institutions such as Imperial College London and the National Institute of Health Research (NIHR) to provide our clinical teams with the necessary academic and financial support to advance their research programmes.

During 2015/16, over 4,400 patients took part in our research, either by participating in a research study, or by donating genetic tissue to our biobanks.

We work with other universities, including the University of Nottingham, and numerous NHS organisations, such as Liverpool Heart and Chest, and Chelsea and Westminster hospitals, so that we all benefit from access to larger clinical populations, data banks, and knowledge sharing.

Trust researchers also recognise the importance of working with industry partners to run clinical trials, to conduct sponsored research, and to offer patients opportunities to participate in cutting-edge research. We collaborate with a variety of companies – large and small pharmaceuticals, and medical device, diagnostic and biotechnology companies – on investigator-led, commercial research partnerships.

Our latest discoveries

Pioneering blood test for inherited cardiac conditions

A new comprehensive genetic test has been developed to diagnose the most prevalent inherited cardiac conditions (ICCs) following international work led by experts at Royal Brompton Hospital and Imperial College London.

The cutting-edge blood test looks for mutations in all of the genes that are currently known to cause ICCs, improving diagnosis for patients.

In one test, 174 faulty genes that are known to be associated with ICCs can be detected. These include heart rhythm problems (arrhythmias), cardiomyopathies (which affect the size and shape of the heart muscle), diseases affecting the aorta (aortopathies) and hyperlipidemias (when patients have a high level of fat in their blood).

ICCs are thought to affect over half a million people in the UK and can be life-threatening. When there is an ICC in a family, the most accurate way to determine which family members may actually develop the condition is through a genetic test. This means that steps can be taken to reduce the risk of sudden death, such as surgery, medication or lifestyle changes.

Research carried out at Royal Brompton Hospital demonstrated that the new test could reliably detect mutations in all known genes associated with ICCs. The findings were published in February 2016 in the *Journal of Cardiovascular Translational Research*.

Previous genetic tests for ICCs looked at a smaller number of genes and were only able to identify specific conditions, leading to greater costs and more work, meaning that patients faced a longer wait before a diagnosis could be made. The research found that the new test, which is available to all testing labs in the world, is quicker and more reliable, reducing costs and allowing patients to be diagnosed quickly and accurately.



Dr James Ware being interviewed by Channel 5 about our new genetic blood test for inherited cardiac conditions

Around 40 patients a month are now being tested in this way at Royal Brompton Hospital.

Dr James Ware, consultant cardiologist at the Trust and clinical senior lecturer in genomic medicine at Imperial College London, is one of the study's lead researchers. He says:

"Genetic tests are invaluable when managing inherited heart conditions. They can help to make the initial diagnosis, and to choose the best treatment for the affected person. But where they make the biggest impact is in looking after that person's family.

"Without a genetic test, we often have to keep the whole family under regular surveillance for many years, because some of these conditions may not develop until later in life. This is costly both for those being monitored and the health service, and can cause a great deal of anxiety for family members.

"By contrast, when a genetic test reveals the precise genetic abnormality causing the condition in one member of the family, it becomes simple to test other family members. Those who do not carry the faulty gene can be reassured and spared countless hospital visits.

"This new comprehensive test is increasing the number of families who benefit from genetic testing."

The genetic test is a result of international collaboration between researchers at the NIHR Royal Brompton/Imperial College London Cardiovascular Biomedical Research Unit (BRU), MRC Clinical Sciences Centre, National Medical Research Council of Singapore and Duke-NUS Institute of Precision Medicine (PRISM). It was funded by the British Heart Foundation and the Health Innovation Challenge Fund (HICF), which is a partnership between the Department of Health and the Wellcome Trust.

Genes linked to rare heart failure in pregnant women

A study into heart failure in pregnant women used genetic data from the Trust's cardiovascular biobank to make an important discovery.

During normal pregnancy, the cardiovascular system of pregnant women adapts to increases in heart rate and blood volume. For some women however, their hearts



"I'm so grateful for the research"

Kelley Allen was diagnosed with Long QT syndrome, an inherited heart condition that causes life-threatening abnormal heart rhythms, after losing consciousness in a swimming pool when she was 10 years old. Kelley's two-year-old son, Jayson, was tested for the condition soon after he was born.

Kelley, aged 27, from Essex, says: "Jayson was diagnosed with Long QT syndrome shortly after he was born. He takes beta blockers every day to control the condition. We are so fortunate that genetic tests exist. It has meant that my mum and brother were also able to be tested and we have peace of mind in the knowledge that my brother does not carry the gene.

"I'm so grateful for the research, which means that tests like this exist and I hope they can continue to help many more people like us. Without the test, I can't imagine what might have happened to Jayson."

do not cope with these changes; their heart enlarges and doesn't pump properly, leading to heart failure, which can be life threatening. Pregnancy-related heart failure, or peripartum cardiomyopathy (PPCM), affects up to 700 women a year in the UK, and the most common symptoms are breathlessness and palpitations.

To find out whether there is a genetic cause, researchers from a number of centres around the world, including Royal Brompton Hospital, carried out a genetic study comparing patients with PPCM, dilated cardiomyopathy (DCM) and healthy volunteers. The genetic data for DCM came from patients recruited into the cardiovascular biobank at the Trust.

The study findings published in the New England Journal of Medicine suggest that PPCM can have very similar genetic characteristics to DCM – with changes in the Titin (TTN) gene found to be the most commonly occurring in each disease.

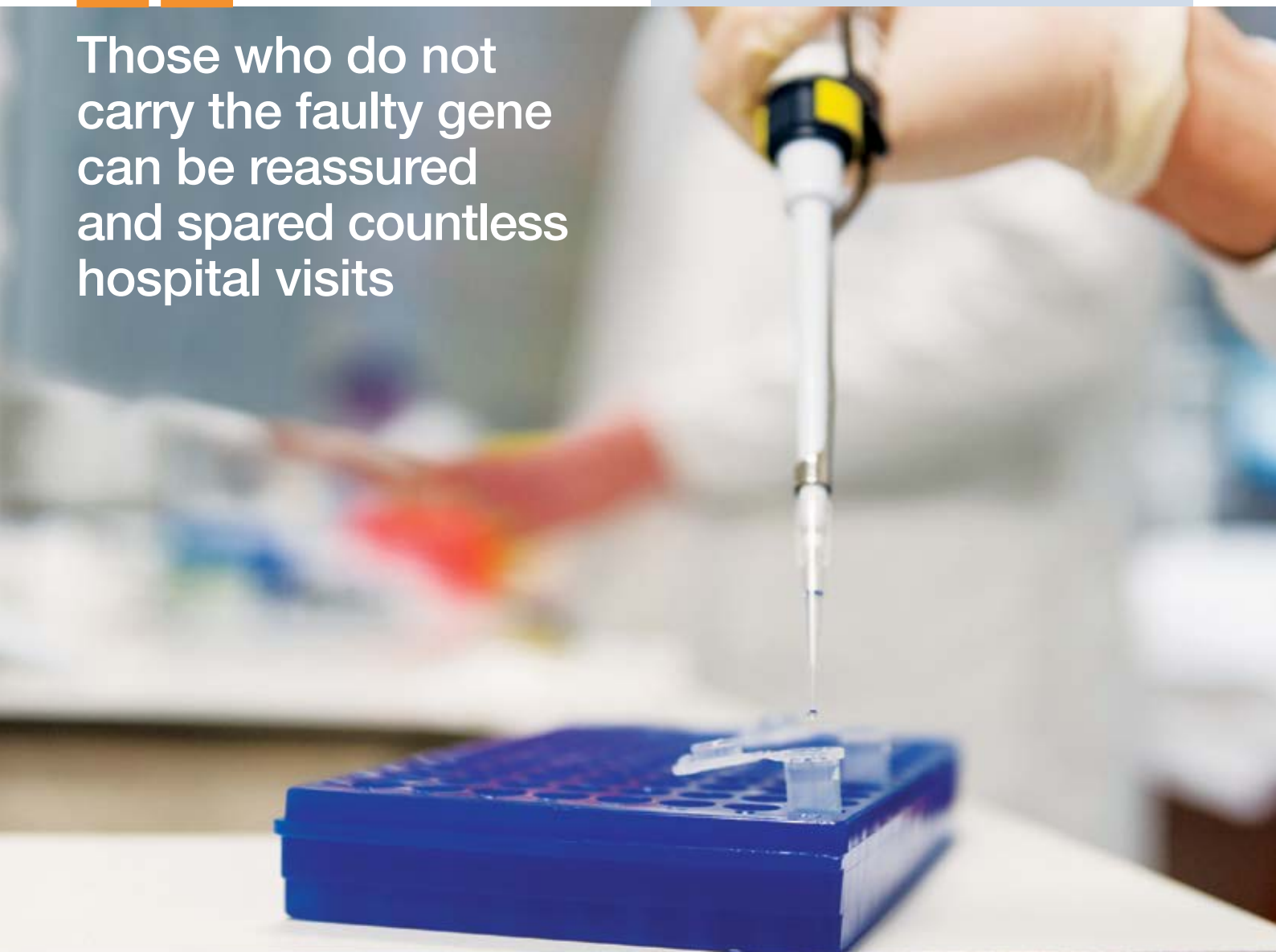
Research into congenital heart disease

The Trust is the world's leading centre for congenital heart disease (CHD) research. Our researchers publish more ground-breaking, high-impact research papers on adult CHD than any other centre in the world, attracting support and funding from industry, government, and charities such as the British Heart Foundation.

As one of the only centres in the UK that cares for congenital heart disease patients throughout their entire lives, our researchers also have the benefit of clinical data that goes back decades – something few other research institutions can boast. This puts our research teams at the forefront of understanding and treating lifelong CHD. For example, our researchers have discovered genetic mutations that increase the risk of CHD, we are discovering new ways to predict risk for individual patients, and have pioneered the use of tailor-made, life-saving implants, which could soon revolutionise treatment around the world.



Those who do not carry the faulty gene can be reassured and spared countless hospital visits



Airway valves improve lung function

Researchers from the Trust have found that using airway valves to treat people with chronic obstructive pulmonary disease (COPD) can improve lung function and exercise capacity.

It is estimated that more than three million people in the UK are living with COPD, an umbrella term for a collection of lung conditions including emphysema and chronic bronchitis. The progressive disease makes it difficult for patients to breathe due to damaged airways and air sacs in the lungs.

The trial involved placing one-way endobronchial valves into the most damaged part of the lung using a bronchoscope (a thin, flexible, fibre-optic tube).

This new minimally invasive treatment uses the valves to block off the damaged part of the lungs when the patient inhales, so the healthier areas can function more efficiently. The novel procedure provides an alternative to lung volume reduction surgery (LVRS), which is when the most damaged parts of the lungs are surgically removed.

The trial recruited 50 patients who had emphysema in one part of the lung and whose fissures, the separations that divide the lungs into lobes, were intact. Half of the patients had endobronchial valves placed during a bronchoscopic procedure, whereas the other 25 patients also had a bronchoscopy but no valves were placed. Neither the patients nor researchers knew who was in each group.

The results were published in *The Lancet* in a paper written by respiratory experts, including lead author Dr Nicholas Hopkinson, senior lecturer and honorary

consultant physician at Royal Brompton Hospital, Dr Pallav Shah, respiratory consultant at Royal Brompton Hospital, and Professor Michael Polkey, consultant physician at Royal Brompton Hospital.

The study found that, three months after the procedure, there was less trapped air in the lungs of the patients treated with endobronchial valves and a median improvement of 8.8 per cent in the amount of air that they could breathe out in one second.

Additionally, treatment with the endobronchial valves was associated with significant improvements in exercise capacity. Other improvements were found in breathlessness during exercise, lung volume and gas transfer, which measures how efficiently the lungs can exchange carbon dioxide for oxygen.

Commenting on the research, Dr Hopkinson says: "The results are very exciting because they show, for the first time in a rigorous randomised controlled trial, that endobronchial valves can improve lung function and exercise capacity and achieve similar results to those seen with LVRS in properly selected patients.

"The improvement in gas transfer is of particular significance because this measure of lung function is the one most strongly associated with survival rates for COPD patients.

"A further study involving a larger number of patients is now needed to establish the best use for this technique in relation to other COPD treatments, such as LVRS and other novel treatments like lung volume reduction coils."

Highlights for 2015/16

- A RAND analysis in February 2016 revealed that experts at the Trust produced more highly cited publications (HCPs) than any other NHS trust in England. The report highlighted the Trust's close partnership with Imperial College London, with the two organisations having the most co-authored HCPs compared with all other healthcare and academic partners in England.
- The Trust received total research income of £12.6m in 2015/16 across both commercial and non-commercial studies.
- Over £3m of grant and charity funding was awarded to Trust researchers and their collaborators from a wide variety of funding bodies, including the National Institute for Health Research (NIHR), Wellcome Trust, British Lung Foundation and the Health Foundation.
- Over £500,000 of NIHR funding was awarded to two allied health professional staff in dietetics and physiotherapy to undertake prestigious research training fellowships.
- Two members of staff were awarded the title NIHR Senior Investigator, bringing the total number across the Trust to 11. These awards recognise the top 200 clinical and applied health researchers in the UK, and the Trust's appointments span cardiology, respiratory medicine, radiology and paediatrics.

Digital care transformation programme

The Trust's digital care transformation programme was launched in March 2014 and will be completed by 2017. It brings a number of new IT systems together to improve the efficiency of our processes

The aim of the programme is to integrate as many functions as possible into as few systems as possible, which will make better use of our resources and streamline care for patients.

Patient Administration System

The Trust's patient administration system (PAS) was replaced with a system called Lorenzo in summer 2016. Lorenzo will link to the national NHS patient database ("Spine") and streamline our processes for referral and registration as it links to data held by GPs. Around 50 members of staff volunteered to be digital care champions, and there is a training programme for all staff users in progress.

Electronic Document Management

Around 250,000 patient medical records are being scanned into electronic format, which enables staff to search, create, store and retrieve records at the click of a button. Having a full patient history stored electronically will improve our processes and reduce storage costs as there will be no need for paper records. Electronic Document Management (EDM) will help us move towards a paperless or paper-light environment and will significantly change the way we work.

Electronic prescribing and medicines management

Electronic prescribing and medicines management (EPMA) enables clinical staff to prescribe and review medication using laptops at the bedside. EPMA has

replaced paper-based processes and has been rolled out to most wards across the Trust.

Nimla Pentayya, a nurse in the paediatric unit, says: "EPMA means it's much easier to prescribe drugs safely, and reduces the problems associated with poor handwriting. Patients who are due to be discharged have a much shorter wait for their medicines, and it's much easier for us to make sure doses are on time."

Clinical data warehouse

A clinical data warehouse (CDW) has now been introduced to the Trust. This communicates with different clinical and operational IT systems, including EPMA, EDM and PAS and can extract, manipulate and store multiple complex datasets.

CDW enables staff to minimise time spent on operational reporting and clinical audits, and provides a platform for research. It will eventually allow clinicians and managers to collaborate and share information across the Trust.





EPMA reduces
the problems
associated with
poor handwriting



Listening to our patients

We are committed to ensuring that patients receive the best possible specialist treatment in a clean, safe place, which is why we continuously collect and act on patient feedback

In 2015/16 the Trust received more than 10,000 comments from patients and their families, from a variety of sources, such as formal and informal surveys, social media, focus groups, and patient advice and liaison service (PALS). Over 90 per cent of these comments were positive.

The Trust scored highly in the 2015 Care Quality Commission National Adult Inpatient Survey, with patients who took part rating their overall experience of care as 8.8 out of 10.

Questions in the survey covered waiting lists, the hospital and ward, doctors, nurses, care and treatment, operations and procedures, leaving hospital and overall impressions of their stay.

Highlights included:

- 91 per cent of inpatients said they were treated with respect and dignity
- 94 per cent always had confidence and trust in their doctors
- 95 per cent said they always had enough privacy when being examined or treated.

The Friends and Family Test (FFT), was introduced in May 2012. It is now mandatory for NHS trusts to ask inpatients to complete a comment form on discharge, asking the question: "How likely are you to recommend our ward to friends and family if they needed similar treatment or care?"

For 2015/16, 98 per cent of patients who took part in the FFT test said they would recommend the Trust.



In April 2015, Jan McGuinness joined the Trust in the newly created post of director of patient experience and transformation. Jan is responsible for the development and delivery of the patient services strategy, co-ordinating and reporting

on patient feedback and ensuring it is used to co-design solutions with patients to improve their care.

Acting on patient feedback

Our staff are committed to using patient feedback to improve our services wherever possible.

Responding to complaints about clinic waiting times

The adult cystic fibrosis (CF) centre at Royal Brompton looks after around 600 patients who attend at least four outpatient appointments a year. People with CF carry bacteria in their lungs that can be dangerous to other people with CF, which means they must be kept apart from one another due to the dangers of cross infection. Appointment times were carefully managed to maintain the cross infection policy, but early or late arrivals led to appointments running over, therefore increasing the risk of patients sitting together in the waiting area. Just over

a year ago, more than 70 per cent of patients were delayed and complaints were going up.

To address the problem, Susan Talbot, clinical nurse specialist in CF, and Helen Parrott, clinical speciality lead – adult CF therapies, launched a project to improve the situation.

They held workshops with staff and examined in detail the patient journey from beginning to end to identify areas that caused delays or breached the cross infection policy. They shadowed patients through their appointments and wrote to them to emphasise the importance of attending clinics on time.

A new structure was then put in place, which has resulted in a drop in waiting times to just seven minutes, with most patients arriving at their correct appointment time. A revision to the clinic timetable allowed for an additional three appointments per clinic, amounting to more than 450 extra slots per year. Both patient and staff feedback about the clinic experience has dramatically improved.

Sunshine therapy for transplant patients

Many patients in Harefield's transplant unit have to stay in hospital for long periods of time, which can have a big effect on morale. Some cannot walk or are connected to a monitor, which means they are unable to leave the unit. In feedback forms, patients commented that staying in their rooms was "depressing", "boring" and "frustrating".

The transplant team, recognising the importance of sunlight and fresh air, created an outdoor area and worked with the Trust's I&T department to improve the Wi-Fi connection so that patients connected to monitors can go outside. The team also improved the door access so that patient beds can be wheeled outside. The long-term plan is to create a private garden outside the unit, which will be created once the current expansion of our intensive therapy unit at Harefield is completed.

Patient Emily Hoyle enjoys the sunshine with her family



Medical education

The Trust puts a high priority on providing comprehensive career development programmes for staff and sharing our expertise

We are committed to investing in the next generation of cardiovascular and respiratory clinicians, and the Trust continues to enjoy an excellent reputation for its postgraduate programmes.

Our clinical teams share their knowledge at conferences and training events around the world, and clinicians wishing to specialise in heart or lung conditions are invited to take up fellowships to work alongside established experts at the Trust.

As a specialist trust, our experts also have an important role to play in helping to establish complex procedures within mainstream clinical practice.

SPRinT programme

The award winning Simulated interPRofessional Team Training (SPRinT) programme is based at Royal Brompton. SPRinT uses baby and child mannequins to recreate life-threatening events to improve performance. The team is actively involved in educational committees of the Royal College of Paediatrics and Child Health, the Paediatric Intensive Care Society, and the International Pediatric Simulation Society.

In March 2016, the SPRinT team welcomed visitors from Singapore, who had travelled to London as part of a world tour to learn about simulation-based education for undergraduate and postgraduate healthcare students.

The delegates, who included the senior associate dean of medical education and the director of education from Singapore Health Services, have recently formed their own simulation education programme. During the visit, the SPRinT team gave presentations on building and sustaining a pool of simulation experts and measuring the effectiveness of the programme in relation to patient safety. The visitors were also shown TOM – a teenage open-chest model used for in-situ simulation.

STaR Centre

The STaR (simulation, training and resource) Centre at Harefield provides a training environment capable of replicating acute medical, anaesthetic, cardiac and thoracic surgery situations. On-site postgraduate medical training is delivered to students from around



the globe to the standards set by the General Medical Council and the Royal College of Physicians board. This training reflects Harefield's national and international reputation as a centre of excellence.

The centre is equipped with high-tech equipment such as the SimMan 3G, a highly sophisticated dummy patient enabling clinical staff to replicate acute medical, anaesthetic, cardiac and thoracic surgery scenarios. The STaR Centre also contains a fully equipped skills teaching laboratory for invasive procedures, a state-of-the-art transoesophageal echo simulator, a bronchoscopy simulator, a lecture theatre and video-conferencing suites.

Clinical Skills and Simulation Centre

Since opening in 2011, this specialist medical education and training centre has provided a variety of clinical training courses for staff and visiting healthcare professionals.

The Clinical Skills and Simulation Centre (CSSC) is a collaboration between Royal Brompton and The Royal Marsden hospitals. Facilities include a “wet laboratory” where clinicians can practice surgical skills, from simply closing a wound, to complex procedures such as replacing a heart valve.

There is also a highly realistic ward area enabling healthcare teams to replicate evolving clinical situations.

Last year, the CSSC hosted a wide range of activities, including resuscitation training courses delivered jointly to staff from both hospitals.

Primary Angioplasty Live

The Trust's annual three-day conference, held in the Concert Hall at Harefield in October 2015, was attended by more than 300 people, including medical staff, ambulance teams and local school children.

Dr Rob Smith, consultant cardiologist and course co-director, carried out a primary angioplasty (in which the arteries are unblocked using a catheter, small balloon and stent) via a live link from one of the cath labs. An audio feed allowed Dr Smith and Dr Miles Dalby, clinical lead and course director, to talk about the patient's history and explain the details of the procedure as it was being carried out.

A number of speakers discussed topics such as what a heart attack is and why it occurs, lessons learned from resuscitation over the last century, and the importance of 'door to balloon' time for certain patients.

Members of the public and patients took part in resuscitation demonstrations on dummy patients, learning how to perform CPR. Patients who had had angioplasties in the past talked about their experiences in an interactive discussion, and many of the pupils joined in.

Dr Dalby says: "The conference offers medical staff an insight into the logistical and clinical issues surrounding primary angioplasty, as well as a chance to truly understand the patient experience. For the first time this year we invited school children with an interest in medicine, which was a great success. Many of them found it so interesting that they are now in the process of arranging to do work experience at Harefield."

Clockwise from left: a training session in the STaR Centre, teaching resuscitation techniques at Primary Angioplasty Live, and live streaming of a primary angioplasty



Intrapreneur programme

The Trust is a member of Imperial College Health Partners (ICHP), a partnership of 20 organisations across north west London including NHS providers, clinical commissioning groups and universities. Last year, ICHP set up the intrapreneur programme, which supports staff to be innovative in their everyday roles to improve patient care.

A team from Royal Brompton and Harefield took part in the programme, working on improving the lung transplant assessment process for patients with cystic fibrosis. The aim was to reduce waiting times and make the process easier and quicker to navigate. Working with patients and other staff, and supported by the methodology learned on the intrapreneur programme, the team has already introduced some changes, such as setting up monthly Skype meetings between the transplant and CF teams, and is exploring carrying out clinical tests locally to speed up the assessment process.

They are also looking at introducing a web-based system to improve communication between the referrer and transplant centre. This is an ongoing project and the team will continue working on it over the coming year. A second group is due to start the same programme in the autumn, examining the role of telemedicine in outpatient care.



Awards and achievements

During 2015/16, a number of Trust experts were recognised for their work

Many Trust experts hold key positions in professional associations, colleges and societies and act as advisors to government departments. They travel widely, giving lectures and presenting at conferences. Each year, a number of our experts gain particular recognition for their work.

Some noteworthy achievements include:



Professor John Pepper, (left) consultant cardiac surgeon, was awarded the Order of the British Empire (OBE) in the Queen's birthday honours on 13 June 2015, for services to heart and lung surgery. Professor Pepper is the academic lead of the Trust's aortic team and has performed some of the most advanced heart surgery in the UK.



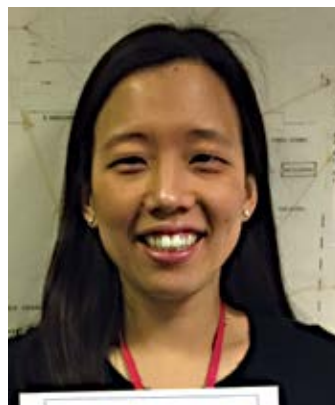
Consultant paediatric chest physician, **Professor Andrew Bush** (left), was awarded the past president's award at the International Congress on Paediatric Pulmonology in Krakow, Poland in June 2015. The award was in recognition of Professor

Bush's "extraordinary leadership, intellect and example, and his contribution to child lung health globally".

The research of **Dr Nick Hopkinson**, honorary consultant chest physician, and **Mr Eric Lim**, consultant thoracic surgeon, was also recognised by Imperial College London when they were appointed to the position of reader.

Royal Brompton's **SPRinT** (Simulated interPProfessional Team training) programme won the *Education and Training in Patient Safety* category at the national Patient Safety Awards in July 2015. The team saw off competition from nine other organisations shortlisted from a total of 100 submissions. SPRinT uses in-situ simulation to provide the multidisciplinary team involved in patient care with insight into human factors that influence personal performance, and strategic crisis training.

Professor Mary Morrell (opposite, above right), who co-founded the academic unit of sleep and ventilation at Royal Brompton, was appointed president of the British Sleep Society (BSS) at its scientific meeting in October 2015. At the same meeting, **Dr Hui-Leng Tan**, consultant in paediatric respiratory and sleep medicine, was awarded the Colin Sullivan Sleep Research award. Dr Tan was the first recipient of this prize, which is given to support sleep research in the UK. She was also the first paediatric consultant to receive an award from the BSS.



Clinical research fellow, **Dr Ee Ling Heng** (left), won the Young Investigator prize at the British Congenital Cardiac Association annual meeting in November 2015. The award was in recognition of Dr Heng's PhD research into outcomes following pulmonary valve replacement in patients with repaired tetralogy of Fallot (a congenital heart disease where there are four structural abnormalities within the heart that occur together).

Three Trust staff were appointed to strategic leadership positions across the National Institute for Health Research (NIHR) Clinical Research Network in 2015. **Professor Eric Alton**, honorary consultant

physician, was appointed national lead for the Clinical Research Network Theme B, which encompasses respiratory, ear, nose and throat, gastroenterology, hepatology and infection. **Professor Wisia Wedzicha**, respiratory medicine consultant, and **Professor John Pepper OBE**, consultant cardiac surgeon, were appointed national speciality leads for respiratory and cardiovascular diseases respectively.



In 2015, **Anita Simonds** (left), professor of respiratory and sleep medicine, was appointed chief editor of ERJ Open Research, a new online-only, open-access journal launched by the European Respiratory Society (ERS). Professor Simonds is supported by an expert team of associate editors, including **Dr William**

Man, consultant chest physician at Harefield.

Professor Dudley Pennell, director of the National Institute for Health Research (NIHR) cardiovascular biomedical research unit (BRU) and the Trust's cardiovascular magnetic resonance unit (CMR), was given an NIHR senior investigator award for a four-year term in March 2016. The award recognises Professor Pennell's outstanding contribution to the national health research agenda in cardiology. He joins six other NIHR Senior Investigators at the Trust.

Consultant cardiac surgeons **Mr Neil Moat** and **Mr Cesare Quarto** won two international awards for presentations about their work on a world-first transcatheter heart valve implantation to treat mitral regurgitation (a leaking mitral valve). Mr Moat won the Dr Martin Leon prize for his presentation at the Heart Valve Society Meeting in Monaco in May 2015, while Mr Quarto won the Robert Emery Young Investigator



Award for his presentation at the International Society for Minimally Invasive Cardiothoracic Surgery annual meeting in Berlin in June 2015.

Melissa Rochon, clinical nurse specialist in surveillance, won a top award for her presentation at the Society for Cardiothoracic Surgery in Great Britain & Ireland (SCTS), Cardiothoracic Forum, held in May 2015. Her presentation, entitled *Preliminary findings: Targeting coronary artery bypass graft (CABG) patients at high risk of surgical site infection*, showcased work by a multidisciplinary team at Royal Brompton.

The "exceptional" work of **Bethan Cowley**, clinical nurse specialist in inherited cardiac conditions (ICC), was recognised with a You're Simply Marvellous award from the patient-led heart failure charity, The Pumping Marvellous Foundation, in January 2016. The award recognises healthcare professionals in the UK who provide outstanding quality of care and treatment to heart failure patients.

Our charity

Royal Brompton & Harefield Hospitals Charity raises money to support the Trust's pioneering work in heart and lung disease diagnosis, treatment and research

The charity, a legally independent body, raises money to fund projects for both hospitals. A board of trustees oversees its work under the chairmanship of Richard Hunting CBE, while chief executive, Gill Raikes MBE, manages day-to-day operations.

Harefield Hospital intensive therapy unit appeal

Plans are underway to build an extension to Harefield's intensive therapy unit (ITU), which will treat an extra 250 people a year. In 2015 the charity launched its 'Sponsor-a-brick' appeal, which aims to raise £1.1m over two years to support the new extension. Donors can buy a brick for £50, or join friends, family or colleagues to sponsor a group of bricks.

Patient amenities fund

The patient amenities fund is used for improving facilities for patients and their families, and this year the charity raised the annual amount available for projects from £100,000 to £150,000. Recent purchases include a portable treadmill to help isolated cystic fibrosis patients remain active, and a blanket-warming cabinet to keep elderly patients snug while in air-conditioned areas of the hospitals.



Royal Brompton hybrid theatre appeal

The charity contributed £4m towards Royal Brompton's new state-of-the-art hybrid theatre, which was opened in November 2015. The theatre is the largest of its kind in the UK, and combines the environment of an operating theatre with the imaging capabilities of a catheter laboratory. See page 16 for more information.

3D printing programme

In January 2015, the charity launched a campaign to raise £50,000 to fund the Trust's highly innovative 3D printing programme. This new technology creates 3D replicas of organs, which can be used in complex diagnoses and surgery.

rb&hArts

rb&hArts relies on charity funding to provide patients with a variety of creative activities and performances. Through these, it engages with approximately 3,500 people each year. Activities range from singing and on-site musicians to site-specific commissions of artwork on wards. This year, rb&hArts worked with South Asian dance company Akademi, and the Big Lottery Fund, to provide patients at Harefield Hospital with an enjoyable new way to keep active.



Fundraising activities

Each year, the charity combines new fundraising events, such as the Women We Admire Lunch, with annual favourites like the Denham Golf Day (with thanks to Dr Miles Dalby) and the London Bridges Walk, which attracted nearly 200 participants.

To mark the Harefield centenary, the charity, with tremendous support from Harefield staff, the arts team and volunteers, held a week of activities in a marquee on the Harefield campus. This culminated in a midsummer ball, with special guests Anton Du Beke and Lance Ellington.

Last year, £800,000 was raised via community events and donors raising money through their own efforts.

Clockwise from left: the new hybrid theatre; Anton Du Beke with lung transplant patient Vanessa Bradley at the masked ball; the London Bridges Walk

Highlights for 2015/16:

- Annabel Bartfeld and Hexagon Classics raised £23,500 towards a new playroom by holding a Le Mans Q&A event last summer.
- Hitachi Capital gave ongoing support for Harefield Hospital through cycling challenges and other fundraising activities.
- The Mayor of Hillingdon, Cllr John Hensley, raised £50,000 towards Harefield Hospital's intensive therapy unit extension through tireless fundraising in his borough.
- The Mayor of Kensington and Chelsea, Cllr Robert Freeman, and his committee, raised £58,000 to be put towards diagnosing bespoke treatments for lung cancer sufferers.
- Team Macy donated £13,800 towards genetic research into cardiomyopathy.
- The Squires Foundation, Skyscape Cloud Services, Garfield Weston Foundation, the Monday Charitable Trust and The Orrin Charitable Trust gave generous support towards the Hybrid Theatre Appeal.

For more information, visit rbhcharity.org

Arts at the Trust

rb&hArts, supported by Royal Brompton & Harefield Hospitals charity, brings all forms of the arts to patients, visitors and staff

Over the past 14 years, rb&hArts has established a world-class hospital arts programme, which aims to improve the health and wellbeing of patients, visitors and staff. Research on the impact of arts in healthcare settings shows it can improve clinical outcomes, shorten length of hospital stay, improve mental wellbeing, and support patients to manage long-term conditions.

rb&hArts provides a wide range of arts activities including visual arts, live music and singing. More than 3,500 people take part in arts activities every year.

The arts team manages a permanent collection of 1,200 artworks, which are displayed in patient, staff and public areas. Last year they held 15 temporary exhibitions in public areas such as the coffee shop, offering artwork for sale (in part to generate income for rb&hArts) including work by artists Jennie Ing and Emma Hunter.

The team also supports capital projects, working with colleagues to integrate art into the fabric of the buildings. Most recently this has included new digital wallpaper

throughout one of our respiratory wards, created in consultation with patients.

Music on the wards

Music in healthcare is particularly effective as it engages people of all ages, transcends the need for language and helps people share a positive experience, even during very challenging circumstances.

Comedy violinist Adrian Garratt performs in the transplant unit, high dependency unit and intensive therapy unit at Harefield Hospital. Many patients have said that his presence relieves the boredom, loneliness and anxiety of being in hospital.

Musician Heather McClelland sings to young patients by the bedside in our paediatric ward. Young patients listening to her music reported significantly less pain and distress while having a line inserted into a vein than those who did not. Heather is also developing a series of singing activities for young patients to help them with their breathing (based on a similar model to our work with adults, Singing for Breathing).

In 2016, Mark Levin, who plays the celtic harp, joined the arts programme, playing every week on the adult surgical wards.





Singing for Breathing

Singing for Breathing is rb&hArts flagship project, supporting people living with chronic lung and heart conditions or who experience breathlessness. The workshops include relaxation techniques, breathing exercises and vocal exercises, as well as singing a wide range of songs – often chosen by the singers themselves. In 2008, Singing for Breathing was one of only two such projects in the UK – there are now more than 50 classes nationally and they are growing all the time. Since its inception the arts team has delivered workshops continuously and have supported several hundred people living with breathlessness to improve their quality of life.

Singing for breathing events are also organised with other hospitals – one of the most successful was delivered as part of a live well with lung cancer event organised by Royal Marsden, Chelsea and Westminster and Royal Brompton hospitals.

Clockwise from left: digital wallpaper on Foulis ward; a Grayson Perry urn at Harefield; comedy violinist Adrian Garratt; Musician Heather McClelland singing to a young patient; Anthony Gormley figure on the roof at Harefield; music therapist Phoebe Cave leading a Singing for Breathing session



Our profile in the media

The communications team works with a mix of print, broadcast and online media to increase awareness of the Trust's work and achievements. Here is a selection of coverage for 2015/16

The Trust is featured on a daily basis in newspaper, magazine and online articles, and across a range of broadcast and social media channels, reaching millions of people every year internationally.

April 2015

Harefield's history as a First World War hospital was celebrated by Australian news channel ABC to mark ANZAC Day. Mark Bowers, cardiology service manager, and Dr Mark Mason, interim divisional director of Harefield's heart division, described the care soldiers received and the cutting-edge treatments provided today.

May 2015

The *Mail on Sunday* reported on revolutionary technology used at Harefield to keep lungs "breathing" outside the body before transplantation. The organ care system (OCS) supplies donor lungs with blood and inflates and deflates them with a ventilator. This increases the time they can be maintained outside the body, so donor lungs can therefore be transported from further away. Mr André Simon, director of transplantation, said it could double the number of lung transplants carried out.

June 2015



Melanie Walcott, wife of footballer Theo Walcott, was interviewed by the *Daily Mirror* about her baby's treatment at Royal Brompton after he was diagnosed with a narrowed heart valve at birth. Dr Zdenek Slavik, consultant paediatric cardiologist, described the procedure, which uses a balloon to widen the valve.

The *Daily Mail* reported on a clinical trial at Royal Brompton that involved placing bronchoscopic valves in the lungs of patients with emphysema. Dr Pallav Shah, consultant respiratory physician, explained that the valves block off damaged areas of the lung, helping the healthier parts to function better. A patient said his breathing improved within a few days of the procedure.

July 2015

Sky News reported on the UK's first CardioMEMS implant, which took place at Royal Brompton. The device monitors heart function and alerts doctors remotely to changes in a patient's condition, before symptoms occur. Professor Martin Cowie, consultant cardiologist, described how it could prevent emergency hospital admissions. The story later featured in the *Mail on Sunday*, *Sunday Telegraph* and on *ITV's This Morning*, with Dr Mark Mason discussing the device.

A multi-centre trial led by Professor Eric Alton, consultant respiratory physician, attracted attention from the *Daily Mail*, *Financial Times*, the *Guardian*, the *Independent* and *BBC Radio 4's Today* programme. It showed that gene therapy can improve lung function in cystic fibrosis patients. *Al Jazeera's The Cure* later interviewed Professor Jane Davies, consultant in paediatric respiratory medicine, about the trial.

ITV's Good Morning Britain included live broadcasts from Harefield during an episode about organ donation. Harefield was introduced as a "world famous" hospital where "wonderful technology and brilliant doctors revolutionise the lives of transplant patients". Mr André Simon, director of transplantation, and Dr Martin Carby, consultant respiratory physician, explained the processes involved with transplantation.

BBC Online, the *Daily Mirror*, the *i* newspaper, *BBC Radio 2* and *BBC Radio London* reported on Harefield patient Andrew Whitby being named the longest surviving heart-lung transplant recipient by Guinness World Records, 30 years after his operation.

August 2015

A feature in the Guardian's *Weekend* magazine described the "amazing job" done by Royal Brompton's catering and nutritional teams after the newspaper's restaurant critic sampled patient meals. Paul Hammond, catering manager, and Ione Ashurst, nutritional lead, explained the complexities and challenges around providing high-quality food that is beneficial to patients and within budget.



September 2015

The *Daily Telegraph*, *Daily Mail*, *i* newspaper and BBC London television news reported on a groundbreaking blood test developed at Royal Brompton, which could potentially be offered by GPs to provide a rapid diagnosis of cancer and lead to earlier treatment. The study, led by Mr Eric Lim, consultant thoracic surgeon, showed the blood test could save some patients from having an invasive, more expensive, biopsy.

November 2015

Professor Andrew Bush, consultant paediatric chest physician at Royal Brompton, was interviewed by BBC1's *Panorama* during an episode about Volkswagen's emissions testing. He described the impact of environmental pollution on children's respiratory health. Royal Brompton was introduced as "the country's leading lung hospital".

A feature in the *Daily Mail* described a novel ablation treatment being trialled by Dr Sabine Ernst, consultant cardiologist, for atrial fibrillation. It involves ablating the endings of nerves outside the heart, in addition to heart tissue targeted in a conventional ablation. One patient commented that his heart has remained in normal rhythm since the procedure.

December 2015

BBC Radio 4's *Today* programme interviewed Dr Alex Lyon, consultant cardiologist, about Royal Brompton's cardio-oncology service, and new Trust research which suggested a link between cancer and reduced heart function. The research was reported in the *Daily Telegraph*, *Daily Mirror*, *The Sun* and the *Mail Online*, quoting Dr Raj Khattar, consultant cardiologist and one of the study's leaders.

Coverage of Public Health England's Smokefree campaign focussing on COPD appeared on BBC Breakfast television, BBC Radio 5 Live, LBC Radio and Sky News and in the *Daily Express*, *Daily Mirror*, *The Independent* and *Mail Online*. Chief medical officer, Dame Sally Davies, visited Royal Brompton's Victoria Ward and was interviewed there alongside Dr Nicholas Hopkinson, COPD clinical lead.

February 2016



A comprehensive genetic test to diagnose inherited cardiac conditions (ICCs), developed through international work led by Royal Brompton and Imperial College London experts, attracted attention from the *Daily Mail*, *the Guardian*, *The Sun*, *Daily Mirror*, *ITV News*, *Channel 5 News* and *BBC Online*. The test is quicker and more reliable than previous genetic tests. Dr James Ware and Dr Jan Till, consultant cardiologists, were interviewed.

BBC Radio London reported that Lord Carter's review of efficiency in hospitals singled out Royal Brompton for the quality of food provided to patients. Catering manager Paul Hammond described how the Trust provides high-quality, nutritious food that provides value for money.

Governance

The Trust is governed by an elected council of governors and independently regulated by NHS Improvement (formerly Monitor). We have around 11,000 members who we regularly consult on Trust strategy and service planning

Royal Brompton & Harefield NHS Foundation Trust has been an independent legal entity with a unique governance structure since 1 June 2009. The powers of the Trust are set out in the National Health Service Act 2006, as amended by the Health and Social Care Act 2012. The Trust governance arrangements are enshrined in the Royal Brompton & Harefield NHS Foundation Trust Constitution and include the Trust membership, the council of governors and the board of directors.

The Trust board plays a key role in shaping the strategy, vision and purpose of the organisation. Board members are responsible for assuring that risks to the Trust and the public are managed and mitigated effectively. Led by an independent chair, and composed of a mixture of both executive and independent non-executive members, the board has a collective responsibility for the performance of the organisation. The council of governors, which comprises both elected and appointed parties, challenges the board and holds the non-executive directors to account for the board's performance. The elected parties are drawn from the membership and the appointed parties represent

key stakeholders. Members are drawn from three constituencies: patient, public and staff. Independent regulation of the Trust is undertaken by Monitor.

The council of governors appoints the external auditor. A sub-committee, the nominations and remuneration committee, considers the appointment of the chairman and the other non-executive members of the Trust's board of directors.

Management of the foundation trust is delegated to the Trust's board of directors. There are three formal committees of the Trust board: the audit committee, the risk and safety committee and the nominations and remuneration committee.

Quality Account

The Trust is required by law to produce a Quality Account, which is an annual report to the public about the quality of services delivered. The Quality Account 2015/16 is available on the Trust's website at www.rbht.nhs.uk/qa and on the NHS Choices website.

Visit our website to read the Trust's full annual report and accounts for 2015/16 – www.rbht.nhs.uk/report-accounts – and for more information about our policy and performance – www.rbht.nhs.uk/performance

Patient governor Edward Waite at the 2015 annual governors and members meeting



OUR BOARD

Executive directors – full year

Professor Robert J Bell

Chief executive

Dr Richard Grocott-Mason

Interim medical director/senior responsible officer

Mr Robert Craig

Chief operating officer

Mr Richard Paterson

Associate chief executive – finance

Ms Joy Godden

Director of nursing and clinical governance

Mr Nicholas Hunt

Director of service development

Executive directors – part year

Professor Timothy Evans

Medical director and deputy chief executive

Non-executive directors – part year

Mr Luc Bardin

Mr Richard Hunting CBE

Non-executive directors

Sir Robert Finch

Chairman

Mr Neil Lerner

Deputy chairman

Mrs Lesley-Anne Alexander CBE

Professor Kim Fox

Ms Kate Owen

Dr Andrew Vallance-Owen MBE

(senior independent director)

Mr Richard Jones

Mr Philip Dodd

Our council of governors

Public governors – full year

Mr George Doughty *North West London*

Public governors – part year

Mr Brian Waylett *Rest of England and Wales*

Mr Robert Parker *South of England*

Ms Jennifer Sano *Rest of England and Wales*

Mr Anthony Connerty *South of England*

Mr Kenneth Appel *Bedfordshire and Hertfordshire*

Patient and carer governors – full year

Mrs Chhaya Rajpal *North West London*

Mrs Brenda Davies *Bedfordshire and Hertfordshire*

Mr Peter Kircher *Bedfordshire and Hertfordshire*

Mr Edward Waite *South of England*

Mr Stuart Baldock *Elsewhere*

Dr Ejikeme Uzoalor *Elsewhere*

Patient and carer governors – part year

Mr Tim Mack *North West London*

Ms Caroline Karlsen *Representing patient carers*

Mr Guthrie McKie *North West London*

Dr Adrian Lepper *Representing patient carers*

Staff governors – full year

Dr Claire Hogg

Ms Anne McDermott

Dr Andrew Morley-Smith

Staff governors – part year

Mrs Elizabeth Henderson

Dr Ian Balfour-Lynn

Dr Alistair Lindsay

Appointed governors

Councillor Mrs Victoria Borwick

London Borough of Kensington and Chelsea

Mr Ray Puddifoot *London Borough of Hillingdon*

Professor Mary Morrell *Imperial College London*

Royal Brompton & Harefield NHS Foundation Trust accounts for year ended 31 March 2016

Statement of comprehensive income

	Year ended 31.03.16 £000	Year ended 31.03.15 £000
Operating income from patient care activities	328,957	337,979
Other operating income	34,895	32,413
Total operating income from continuing operations	363,852	370,392
Operating expenses	(369,849)	(366,301)
Operating (deficit)/ surplus from continuing operations	(5,997)	4,091
Finance income	47	36
Finance expense – financial liabilities	(564)	(160)
Finance expense – unwinding of discount on provisions	(11)	(11)
PDC dividends payable	(6,671)	(6,681)
Net finance costs	(7,199)	(6,816)
Movement in the fair value of investment property	3,476	(593)
Deficit for the year	(9,720)	(3,318)
Other comprehensive income		
Revaluations of operational properties and other non-current assets	7,148	1,320
Other reserve movements	(3)	1
Total comprehensive expense for the year	(2,575)	(1,997)


Statement of financial position

	As at 31.03.16 £000	As at 31.03.15 £000
Non-current assets		
Property, plant and equipment	195,510	189,224
Intangibles	12,054	–
Investment properties	34,088	30,612
Total non-current assets	241,652	219,836
Current assets		
Inventories	9,043	11,186
Trade and other receivables	32,512	46,828
Cash and cash equivalents	13,777	9,476
Total current assets	55,332	67,490
Current liabilities		
Trade and other payables	(49,597)	(46,724)
Borrowings	(3,070)	(10,039)
Provisions and liabilities	(1,019)	(856)
Total current liabilities	(53,686)	(57,619)
Non-current liabilities		
Borrowings	(27,500)	(10,000)
Provisions and liabilities	(690)	(2,234)
Total non-current liabilities	(28,190)	(12,234)
Total assets employed	215,108	217,473
Financed by		
Public dividend capital	108,362	108,152
Revaluation reserve	57,070	49,924
Income and expenditure reserve	49,676	59,397
Total taxpayers' equity	215,108	217,473



Royal Brompton Hospital


Sydney Street
London
SW3 6NP

 +44 (0)20 7352 8121

 Follow us on Twitter @RBandH

Harefield Hospital

Hill End Road
Harefield
UB9 6JH

 +44 (0)1895 82 37 37

 www.rbht.nhs.uk