A lifetime of specialist care

Royal Brompton & Harefield NHS
NHS Foundation Trust

Annual review 2012/13

rbht.nhs.uk

Other formats

If you would like a copy of this report in another format, please contact Christine Denmark at **c.denmark@rbht.nhs.uk** or on **020 7351 8671**

اذا كنت راغباً في الحصول على نسخة مترجمة باللغة العربية من هذا التقرير الرجاء
الاتصال بـ كتوري اجيتنيس (في فريق الاتصالات:) في

c.denmark@rbht.nhs.uk, 020 7351 8671

Bu raporun Türkçe kopyası için lütfen komunikasyon bölümündeki Christine Denmark 'la görüsün.
c.denmark@rbht.nhs.uk, 020 7351 8671

Large print

If you would like a copy of this report in large print, please contact Christine Denmark at **c.denmark@rbht.nhs.uk** or on **020 7351 8671**

In our review

Contents

Read about...

Co-ordinated care

See pages **22-23**

Transitioning to adult care

See pages **28-29**

Life-saving heart surgery

See pages **38-39**

Also read our review online at rbht.nhs.uk/annual-review-1213

Introduction from the **chairman and chief executive**

As this review illustrates, the past year has been both unusual and eventful.

We have seen a radical overhaul of the NHS – the full impact of which has yet to unfold – along with further judicial intervention in planned service reconfigurations, a renewed and welcome interest at national level in listening to the views of patients, and some remarkable research breakthroughs, notably in the field of genetics.

Each one of these developments has had an influence on our own organisation, some presenting opportunities, others presenting more of a challenge. But despite a level of uncertainty that is now a common feature of the national health system, the Trust remains in a steady state and is, in many respects, thriving.

A particularly positive development occurred in June (2013) when the Secretary of State for Health accepted the Independent Reconfiguration Panel's report that the "Safe and Sustainable" review of children's heart surgery was based on "flawed analysis of incomplete proposals and their health impact".

Patients and their families were overjoyed by the news. They were never able to understand why one of the best performing and largest units in the country was destined for closure, especially when statistics showed that the population in London and the South East was growing faster than had previously been thought, and demand for children's heart surgery was increasing. It was back in February 2011 that the Trust first made the Safe and Sustainable team aware of the serious flaws in their methodology. It is a tragedy that those concerns were not acted upon then.

NHS England has now been tasked with developing a new approach. Those leading the new review are likely to propose a way forward with a changed focus on congenital heart disease services (both adult and child). This is a more realistic and comprehensive approach, which we have always advocated. NHS England has also made a commitment to open, transparent, honest and comprehensive engagement with all stakeholders. We remain optimistic.

The annual NHS staff survey, provided more good news. An impressive 93 per cent of staff at the Trust

"Vital feedback from our patients was once again encouraging."

Sir Robert Finch, chairman

stated they would recommend Royal Brompton and Harefield hospitals to their families and friends. The survey found that there were only eight out of 259 organisations in the country where 90 per cent or more staff would recommend treatment. These encouraging results were highlighted by the Secretary of State for Health in a major speech in March. Referring to the survey, Jeremy Hunt described the Trust as one of the "very finest" in the NHS: "They do not make a choice between compassionate care and meeting their targets, they do both. Indeed the one links to the other".

Vital feedback from our patients was once again encouraging. In the annual inpatient survey the Trust ranked amongst the best performers on more than half of all questions. And on the recently introduced Friends and Family test, the Trust was ranked in the top 10 nationally.

The funding gap in the health service is well documented and the need to record a robust financial performance remains paramount. In a challenging environment it was exceptionally rewarding to report another strong set of financial results, with a retained surplus of just over £4 million, which will be reinvested directly into patient care.

Plans to re-develop our estate at both current locations moved forward, with the establishment of a project team at Royal Brompton to oversee a major capital investment programme, and a working group at Harefield to lead a significant expansion of the adult intensive care unit. We look forward to working closely with all our partners to create new state-of-the-art facilities where specialist expertise can flourish in dedicated environments, designed for patients now and in the future.

As a specialist Trust, Royal Brompton & Harefield plays an important role in a system of care. You will read throughout this review of the many organisations with which we work closely – of networks and collaborations that stretch geographical boundaries and bring diverse but complementary skills and expertise to the same table. We believe that with our clarity of mission and direction, our global talent pool and proven performance track record and, most importantly, our passion for doing what is in the best interests of patients, we can look forward to another successful year ahead.

"As a specialist Trust, Royal Brompton & Harefield NHS Foundation Trust plays an important role in a system of care."

Mr Robert Bell, chief executive

Joined-up care is **pivotal** to our continuing success

About us: a system of care

Royal Brompton & Harefield NHS Foundation Trust is a national and international specialist heart and lung centre based in Chelsea, London and Harefield, Middlesex.

Heart and lung diseases are the world's biggest killers and our experts care for patients who come from across the UK and overseas, not only from our local areas.

Our integrated approach to caring for patients from the womb, through childhood, adolescence and into adulthood and old age has been replicated around the world and has gained the Trust an international reputation as a leader in heart and lung diagnosis, treatment and research.

Research programmes play a vital role at both our hospitals. This is because the most talented medical experts are rarely content with using tried and tested methods to treat their patients. The opportunity to influence the course of modern medicine by developing new treatments is a prospect that attracts them to specialist centres, where research opportunities are a fundamental part of delivering patient care. As well as travelling internationally to lecture and share their knowledge, our clinicians hold prominent positions on influential boards, committees, institutions and professional associations.

Our closest academic partners are the National Heart and Lung Institute in the Faculty of Medicine, Imperial College London and the Harefield Heart Science Centre. Through our clinical research studies we also have active collaborations with hospitals and universities across the UK, most notably with Liverpool Heart and Chest Hospital in the joint Institute for Cardiovascular Medicine and Science. This partnership also reflects the Trust's desire to develop partnerships outside its usual geographical boundaries.

Over the years, our experts have been responsible for several major medical breakthroughs – discovering the genetic mutation responsible for the heart condition dilated cardiomyopathy, founding the largest centre for the development of new treatments for cystic fibrosis in Europe, and pioneering intricate heart surgery for newborn infants.

Our hospitals do not operate in a vacuum; fully integrated networks of care exist with partner organisations and many of our clinicians have joint appointments with neighbouring trusts.

Our experts promote the principle of "shared care" through an expanding system of consultant-delivered outreach clinics, at which they see patients at over 30 hospitals across the South East, covering Essex, Sussex, Surrey, Hertfordshire and Middlesex. This system allows patients to benefit from specialist expertise in their local environment, with inpatient care at our hospitals available as needed.

Royal Brompton's 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 of all ages with heart or lung disease. Harefield teams continue to enjoy ongoing support across a range of non-cardiothoracic specialist disciplines from Hillingdon Hospital NHS Foundation Trust.

For more information, visit **rbht.nhs.uk**

Trust mission, values and approach

Mission

The Trust's mission is to be the UK's leading specialist centre for heart and lung disease.

We will achieve this mission through a strategy of focused growth in aspects of heart and lung treatment, such as congenital heart disease, arrhythmia, heart failure and advanced lung diseases.

Our approach

- The continual development of leading edge services through clinical refinement and research
- The effective and efficient delivery of core specialist treatment
- The transition of appropriate routine services to other centres to release capacity for new interventions

Remaining an autonomous, specialist organisation is central to preserving and building on our strong clinical and organisational record.

However, we are equally convinced of the importance of effective partnerships, particularly with major academic bodies, to ensure a continuing pipeline of innovations to develop future treatments.

Our values

At the core of any organisation are its values: belief systems that are reflected in thought and behaviour.

Our values were developed by staff for staff. We have three core patient-facing values and four others that 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 that can help us improve the care we offer.

The following values support our core values:

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.

Performance and achievements in 2012/13

93 per cent of our staff would recommend us to their families and friends – the second highest score in the country for any NHS organisation

More than **15,000 new patients** visited our outpatient clinics

The Trust met the **18-week NHS standard referral time** every month

Our experts carried out over **144,000 outpatient appointments** and saw over **32,000 inpatients**

We achieved **high patient satisfaction scores** in the 2012 national inpatient survey and scored in the **"best performing Trust"** category in over half of questions

Our experts established a new **rapid access heart function clinic** at Harefield for fast referral of heart failure patients

Two new sleep centres were opened at Royal Brompton – one for adults and one for children

Our respiratory teams started a new **unexplained breathlessness** service at Royal Brompton

We opened a **brand new 18-bed ward for cardiac patients** at Harefield

Royal Brompton and London Ambulance Service launched a new service to **accept emergency heart rhythm patients directly**, bypassing A&E

Collaboration

Royal Brompton & Harefield NHS Foundation Trust is a partnership of two specialist hospitals and plays a vital role in an integrated national system of patient care.

Major new research collaboration

IMPERIAL COLLEGE HEALTH PARTNERS
DRIVING INNOVATION THROUGH COLLABORATION

The Trust was among the founding members of a major new research collaboration launched in June 2012, which draws on the nationally and internationally recognised expertise of partners to improve the health of nearly two million people in North West London.

Imperial College Health Partners is a limited company that brings together healthcare providers in North West London, in partnership with Imperial College London, to drive practical improvements to the quality of healthcare delivery. By co-ordinating the adoption of innovation, the partnership aims to bring benefits to the health of the local population and, through the dissemination of best practice, extend these benefits more widely within the UK and beyond.

Bob Bell, chief executive of Royal Brompton & Harefield NHS Foundation Trust, said: "Collaboration on this scale offers a valuable opportunity to leverage the best that each constituent organisation has to offer. This Trust has a strong and established relationship with Imperial College. We jointly run two biomedical research units and our published research is regularly the most highly cited in Europe for cardiac, cardiovascular, critical and respiratory care. The wider partnership may be based in North West London, but its influence will extend nationally and internationally."

Imperial College London is the Trust's primary academic partner. The two organisations form one of the most successful NHS and university partnerships in the UK in terms of research outputs.

"Collaboration on this scale offers a valuable opportunity to leverage the best that each constituent organisation has to offer. This Trust has a strong and established relationship with Imperial College."

Bob Bell
Chief executive of Royal Brompton & Harefield NHS Foundation Trust

Institute of Cardiovascular Medicine and Science (ICMS) celebrates its first anniversary

The Institute of Cardiovascular Medicine and Science

Liverpool Heart and Chest Hospital NHS
NHS Foundation Trust

In September 2012, the Institute of Cardiovascular Medicine and Science (ICMS), a collaboration between the Trust and Liverpool Heart and Chest Hospital NHS Foundation Trust (LHCH), held a symposium at the Royal Society in London to celebrate its first anniversary. The event was attended by more than 200 delegates.

The collaboration, which is supported academically by Imperial College London and is the first of its kind in Europe, aims to improve outcomes in cardiovascular medicine by pooling the expertise of clinicians from both trusts.

Commenting on the success of the day, Professor Kim Fox, chair of the ICMS executive group said: "The ICMS is a landmark partnership that will harness the full power of the NHS in research, service development and education for the benefit of our patients. The enthusiasm seen on the research day demonstrated that the ICMS has come of age."

In its first year, the ICMS contributed several research papers and submitted grant applications for funding to support its workstreams, which include interventional cardiology, arrhythmias, aorta and aortic valves, and heart failure.

Key developments in 2012/13

- Education has flourished with a number of specialist courses for clinical staff and the creation of a fellowship in aortic surgery.
- A number of PhDs have been registered with Imperial College under the ICMS – four from LHCH and five from the Trust.
- Royal Brompton's ICMS clinicians are starting a programme of monthly visits to train LHCH MRI imaging technicians.
- Experts at Royal Brompton and Harefield hospitals are working with North West London clinical commissioning groups to adopt the successful LHCH Knowsley Community Cardiovascular service model. This service, currently provided in GP practices, has significantly improved the quality of patient care in the community while also generating savings by reducing unplanned admissions.
- Plans are currently being developed to launch a joint cardiomyopathy and clinical genetics service between the two trusts. This service will draw on Royal Brompton's expertise and next generation sequencing capabilities, and LHCH will invest in a consultant geneticist and nurse specialist to set up the clinic. This will enable clinicians at both trusts to test patients and, potentially their close family members, for cardiomyopathy.

"The ICMS is a landmark partnership that will harness the full power of the NHS in research."

Professor Kim Fox
Chair of the ICMS executive group

Professor Kim Fox, chair of the ICMS executive group and Diana Princess of Wales chair in cardiovascular medicine and science

Harefield Heart Science Centre

Clinical teams at Harefield's heart and lung transplantation unit work closely with experts at the Harefield Heart Science Centre, which is at the forefront of research into heart disease and transplantation. The Heart Science Centre, which is operated collaboratively by the Magdi Yacoub Institute, the Trust and the National Heart and Lung Institute at Imperial College, has several research groups devoted to aspects of heart disease, ranging from molecular and cell biology to tissue engineering of heart valves.

London Cancer Alliance (LCA)

LONDON CANCER ALLIANCE West and South LCA

The Trust is actively involved in the London Cancer Alliance (LCA), which was established in 2011 as the integrated cancer system across west and south London. The LCA works collaboratively with 17 NHS provider organisations, including two academic health science centres and the voluntary sector. The LCA works with its partner trusts, including the Trust, to provide integrated cancer care and services to drive improvements in patient outcomes for the population it serves.

There are a number of different workstreams as part of the LCA, supporting the pathways of most of the common cancers as well as a number of cross-cutting groups. The Trust's clinical teams are currently involved in:

Lung cancer pathway group
We are one of the biggest centres for the surgical treatment of lung cancer in London.

Palliative care pathway group
The membership of this group brings together specialist NHS and voluntary sector expertise from primary, secondary and tertiary care, as well as patients.

Acute oncology pathway group
Acute oncology is the management of patients who need urgent attention due to progression of their cancer or complications with their treatment.

Patient experience and patient information pathway group
This project work was led by the lead cancer nurses' group, made up of nurse representatives from the 17 NHS provider organisations working closely with the other pathway groups. The charity, Macmillan Cancer Support, has been a key stakeholder in this work, which has focused on ensuring all cancer patients have access to a named cancer nurse specialist. Another key priority has been ensuring that all patients have access to the best quality and most relevant information about their condition.

The charity, Macmillan Cancer Support, has been a key stakeholder in this work, which has focused on ensuring all cancer patients have access to a named cancer nurse specialist.

Royal Marsden NHS Foundation Trust – joined-up cancer care

The ROYAL MARSDEN NHS Foundation Trust

The proximity of expert oncologists at The Royal Marsden Hospital in Chelsea and expert thoracic surgeons at Royal Brompton Hospital enables the trusts to jointly deliver one of the largest lung cancer programmes in England.

Patients having complex lung surgery at Royal Brompton will be referred by oncologists at The Royal Marsden, who support them with chemotherapy and / or radiotherapy treatment. Many of these patients will have metastatic cancer, meaning the lung cancer has spread from another part of their body, so the primary cancer may be breast or colorectal cancer, for example, which is treated at The Royal Marsden. Sometimes, in particularly complex cases, there is a need for joint surgery to take place. A weekly joint multidisciplinary meeting is held by clinical teams at both hospitals.

More recently, patients from The Royal Marsden who have a cancer diagnosis and may also have a heart condition are now referred to our innovative cardio-oncology clinic at Royal Brompton led by Dr Alexander Lyon, cardiology consultant. To read more about this clinic, go to page 21.

The two trusts have a joint palliative and supportive care service for patients who have life-limiting conditions including cystic fibrosis, COPD, and heart failure: The Royal Marsden and Royal Brompton Palliative Care Service.

Chelsea and Westminster Hospital NHS Foundation Trust – mutual support and collaboration

Clinical teams at Royal Brompton work closely with colleagues at neighbouring Chelsea and Westminster Hospital across several clinical disciplines.

A number of medical consultant appointments are operated jointly with Chelsea and Westminster, so that expertise can be readily shared across the two hospitals.

Each hospital provides outpatient clinics and inpatient support to the other, across a number of specialties, and some are undertaken jointly. For example, Chelsea and Westminster endocrinal teams offer inpatient consultations where all Royal Brompton's cystic fibrosis patients with related diabetes are seen, as well as other complex endocrine patients.

Royal Brompton clinicians offer a comprehensive service to Chelsea and Westminster by way of outpatient clinics and inpatient support across both paediatric and adult services. Cardiology patients are routinely referred to Royal Brompton for procedures in the cardiac catheter labs, facilities which are not available at Chelsea and Westminster.

Particularly close links exist across 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. This is also why some babies are delivered at Royal Brompton, despite the fact that maternity facilities are not routinely provided. A mother with a heart condition may need the same kind of specialist support.

A specialist pregnancy and heart disease service is available at Royal Brompton for pregnant women who have heart problems. This care is provided jointly with the high-risk maternity team at Chelsea and Westminster. Further details on page 16.

Hillingdon Hospital NHS Foundation Trust

Partnership working with The Hillingdon Hospitals NHS Foundation Trust ensures a comprehensive range of non-cardiothoracic services are available to Harefield patients. A number of joint appointments are in place and several Harefield consultants undertake outpatient clinics at Hillingdon. Patients referred for lung cancer care receive oncology services at Mount Vernon Hospital.

Richard Grocott-Mason, medical director of The Hillingdon Hospitals NHS Foundation Trust (job share) and consultant in cardiology and general medicine, also works as an interventional cardiologist at Harefield and is part of the team of experts offering round-the-clock cover at the hospital's heart attack centre. A number of consultant cardiologists from partner district general hospitals, including Buckinghamshire Healthcare NHS Trust, take part in the rota.

Cardiac and stroke networks

The Trust is an active partner in the North West London cardiac and stroke networks. The networks bring together clinicians, patients, carers, commissioners and others across primary, secondary and tertiary care providers to improve services at every step of the patient pathway.

We continue to build on the network approach to stroke and cardiac care, with the newly emerging clinical commissioning groups and health and wellbeing boards in North West London, maintaining our philosophy of shared responsibility for providing the best possible care for patients.

Pan London Sarcoma Pathway

Sarcomas are rare cancers that develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissues. Royal Brompton is the designated thoracic surgical site for patients with bone and soft tissue sarcomas for London and the South East. Established in 2013, the Pan London Sarcoma Pathway Group, which operates jointly with London Cancer for North and East London, will work to develop integrated services across all the specialist hospitals as well as the referral and shared care services within London and the surrounding areas.

638 people were given **aortic valve** replacements in 2012/13

Caring for the heart

Clinical teams at Royal Brompton and Harefield hospitals care for patients with a wide range of complex cardiac conditions, which may be congenital (present at birth), inherited, or acquired later in life.

Our teams are based around the following themes: arrhythmias (irregular heart rhythms); congenital heart disease; heart failure; pulmonary hypertension (high blood pressure in the arteries of the lungs that can lead to heart failure); revascularisation (coronary heart disease); structural heart disease (surgery) and heart assessment.

Specialist care for adult congenital heart disease

The adult congenital heart disease (ACHD) unit at Royal Brompton was one of the first specialist facilities of its kind in Europe. Our experts see more than 6,000 adults with congenital heart disease – the largest number in the UK.

The unit is a major research facility for congenital heart disease and cardiac surgery, and a national and international specialist training centre for cardiologists, cardiothoracic surgeons and other clinicians. Specialist international clinical fellows are an integral part of the unit and contribute to the worldwide reputation of the organisation.

A full range of inpatient and outpatient care is provided and patients are offered all types of treatment including catheter lab procedures, specialised drug therapies and heart surgery (including transplantation).

There is a dedicated transition service looking after teenagers and young adults and more than 70 per cent of new patients in our ACHD clinics transition from the Trust's paediatric congenital heart disease service.

A specialist pregnancy and heart disease service is available for pregnant women who have heart problems. This care is provided jointly with the high-risk maternity team from Chelsea and Westminster Hospital.

More than 70 per cent of new patients in our ACHD clinics transition from the Trust's paediatric congenital heart disease service.

Treatment from birth to adulthood – Renee's story

When Renee Hipwell was born at Hillingdon Hospital in 1981 she looked blue and was struggling to breathe. Doctors immediately transferred her to Harefield Hospital where she was diagnosed with double inlet left ventricle (DILV). DILV is a congenital heart defect that affects the valves and chambers of the heart.

Normally, blood from the right atrium drains into the right ventricle and blood from the left atrium drains into the left ventricle. However, in Renee's heart, blood from both atria was draining into one ventricle only, increasing the pressure on the heart.

Children with DILV sometimes have other heart abnormalities; Renee was found to have transposition of the great arteries, where the two major vessels that carry blood away from the heart – the aorta and the pulmonary artery – are switched (transposed).

Renee's parents were warned that she may not reach adulthood and would need major open heart surgery before adolescence to prolong her life. She was given medication and had regular check-ups with consultant paediatric cardiologist, Dr Rodney Franklin, at Harefield.

When Renee was nine she remembers a phone call from doctors at the hospital: "I remember my mum got off the phone and began to cry. A date had been set for my open-heart surgery. I'd never seen my mum cry before. It frightened me and I remember telling her I didn't want to go into hospital. But I did go."

Renowned surgeon, Professor Sir Magdi Yacoub, performed Renee's surgery, which improved her oxygen levels and decreased the pressure on her heart.

Renee continues: "The operation was successful and I woke up on my tenth birthday – the first of August 1991. The doctors had told my parents I may need to recover in hospital for a couple of months, but I surprised everyone and was home in three weeks."

Following the operation, Renee enjoyed a normal childhood, although she was more susceptible to infections and illnesses than her peers. At one of her regular check-ups, doctors told her she may not be able to have children because of the strain it would put on her heart.

Renee explains: "I don't think I was very worried at the time. Children seemed a very long way off, so it didn't really bother me."

When Renee was 18, she transitioned to the adult unit, under the care of Dr Lorna Swan, consultant cardiologist, at Royal Brompton.

Soon after, she met her husband, Stuart, and in 2007 they began to start thinking about having a family. Together, they discussed the issue with Dr Swan and Lynda Shaughnessy, clinical nurse specialist in adult congenital heart disease and transition.

Renee comments: “They were optimistic that having a baby wouldn’t damage my heart too much, and told us that I would be closely monitored throughout my pregnancy. This was very reassuring. As soon as I was pregnant, I phoned Lynda and was put under the care of a consultant obstetrician at Chelsea and Westminster and referred to the specialist pregnancy and heart disease service at Royal Brompton. I had to inject myself daily with heparin to keep my blood from clotting throughout my pregnancy. This was an ordeal for both myself and Stuart as we hate needles! But I knew it would be worth it.”

Renee explains: “I wasn’t worried at all – my care was really well co-ordinated and I felt so well looked after. I had direct phone numbers for a nurse at Chelsea and Westminster as well as Lynda, so if I had any concerns I could ring either of them straight away.”

Baby Gracie-Mae was delivered prematurely at 32 weeks in May 2009 and cared for in the neonatal unit at Chelsea and Westminster.

Dr Franklin had scanned Gracie-Mae’s heart before she was born and again after, to check for any heart problems.

Renee says: “It was quite surreal to see Dr Franklin after all these years now scanning my daughter! A lot of the other paediatric staff who cared for me as a child were still there too, so it was really nice to see them and show them I was well. Luckily, Gracie-Mae was totally healthy – a huge relief.”

Renee has since had another healthy daughter, Emily, in May 2011 and she was again cared for at both Chelsea and Westminster and Royal Brompton whilst pregnant.

Renee is now 31 and has just returned to work following her maternity leave. She still has annual cardiology check-ups at Harefield.

She comments: “I couldn’t have asked for better care. Stuart and I had fantastic support and the doctors couldn’t do enough for my family. I feel so lucky that I have two wonderful, healthy girls.”

“It was quite surreal to see Dr Franklin after all these years now scanning my daughter! A lot of the other paediatric staff who cared for me as a child were still there too so it was really nice to see them and show them I was well.”

Renee Hipwell
Congenital heart disease patient

Innovative rapid access heart function clinic launched

A groundbreaking new clinic at Harefield began welcoming patients in 2012, run by dedicated consultant cardiologist, Dr Rebecca Lane, and clinical nurse specialist, Marcia Singleton.

This is the only clinic of its kind in the South East and it offers patients a new approach to treating heart failure. GPs or consultants at district general hospitals can refer patients with suspected heart failure directly to the clinic. The heart failure team offers a comprehensive range of tests for patients all on the same day, such as blood tests, an echocardiogram to build up a moving picture of the heart, an electrocardiogram (ECG) to record the heart rhythm and rate, and a chest X-ray.

Once clinical teams have the results of the tests, a range of treatments from medication to surgery, is discussed with patients.

Marcia Singleton is pivotal in providing continuity of care between the clinic at Harefield and the community teams. She liaises with local heart failure specialist nurses and provides guidance and support to patients to help increase knowledge about their condition.

Dr Lane comments: "The key to the clinic is that we offer a really fast and efficient service for both patients and GPs. We assess patients within two weeks of them being referred to us. Investigations are done on the same day and results are discussed with the patient immediately and faxed over to their GP. They can then be referred for further treatment if they need to be, or their condition can be managed in our nurse-led follow-up clinics."

Primary angioplasty conference – a network of care

The team at Harefield boasts an enviable reputation for having one of the fastest arrival-to-treatment times in the UK for heart attack patients – 27 minutes compared to a national average of 42 minutes – a crucial factor in patients' survival.

In September 2012, our clinicians demonstrated their techniques to over 120 delegates at the Trust's sixth annual primary angioplasty conference. Harefield's Heart Attack Centre uses primary angioplasty to clear blockages in the artery as quickly as possible.

Primary angioplasty procedures are performed in catheter labs and clinicians use a thin tube called a catheter, which is inserted through a small cut in the patient's groin or wrist. 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.

The theme of the three-day conference was "Acute coronary syndromes and the patient journey". The course was organised in collaboration with London Ambulance Service, East of England Ambulance Service and South Central Ambulance Service.

"This is the sixth year and our best turnout ever," said Dr Miles Dalby, consultant cardiologist and course

"The key to the clinic is that we offer a really fast and efficient service for both patients and GPs. We assess patients within two weeks of them being referred to us. Investigations are done on the same day and results are discussed with the patient immediately and faxed over to their GP."

Dr Rebecca Lane
Consultant cardiologist

director. “We always aim to make it as interactive as possible and accessible to everyone from the most experienced cardiologists in the country and ambulance officers to junior doctors, staff nurses and non-clinical staff.”

Delegates were able to watch in real time as consultant interventional cardiologist and course co-director, Dr Rob Smith, and consultant interventional cardiologist, Dr Richard Grocott-Mason, treated patients who arrived at Harefield following heart attacks. An audio feed allowed clinicians to discuss the cases as the procedures were being done.

Dr Dalby commented: “The live presentations have been a key to the conference from the start. They provide an excellent opportunity to show procedures in real time, giving insight into catheter lab protocols and techniques, primary angioplasty and stenting in the acute setting.”

Delegates from across the country enjoyed presentations from Dr Rod Stables, consultant interventional cardiologist at Liverpool Heart and Chest Hospital, Dr Roby Rakhit, consultant cardiologist at Royal Free Hospital in north London and representatives from London Ambulance Service, East of England Ambulance Service and South Central Ambulance Service.

The conference offered a comprehensive overview of all the logistical and clinical considerations surrounding the delivery of primary angioplasty for heart attacks, and delegates also had a round table discussion about how ambulance staff and medical staff work best together in a network of care.

Emergency heart rhythm cases referred to Royal Brompton

Teams at Royal Brompton, led by Trust arrhythmia lead and consultant cardiologist, Dr Vias Markides, have developed an innovative partnership with the London Ambulance Service (LAS) to help patients with acute heart conditions receive quicker diagnosis and treatment.

Already an accredited arrhythmia centre, Royal Brompton has now been designated as a “receiving centre” in an innovative pilot scheme in north London.

Since February 2013, patients in north west London with acute coronary syndromes, including heart attacks and certain types of arrhythmias (problems with the heart rhythm), are admitted directly from the community instead of going to Accident and Emergency, as well as from local referring hospitals. This means they receive immediate diagnosis and treatment at Royal Brompton, potentially saving lives.

Dr Julian Jarman, consultant cardiologist for arrhythmia and devices, commented: “This is the NHS at its best. Nowhere else in the world is a population covered by a service whereby an electrophysiologist will come and implant your pacemaker in the middle of the night. It’s the highest standard of care possible, and Royal Brompton is at the forefront of this initiative”.

The pilot scheme will run for six months and then the results will be compared to services still using the A&E process.

“The live presentations have been a key to the conference from the start. They provide an excellent opportunity to show procedures in real time, giving insight into catheter lab protocols and techniques, primary angioplasty and stenting in the acute setting.”

Dr Miles Dalby
Consultant cardiologist

Renal denervation

In the UK, almost 12 million people are treated for hypertension (high blood pressure) each year and there are many more who have the condition but are unaware of this "silent killer". This figure is rising, mainly due to a poor diet, stress and an ageing population.

Undiagnosed hypertension can cause the heart to thicken and become enlarged and can cause patients to have a stroke or a heart attack.

If hypertension is diagnosed there are effective drugs available that can lower the blood pressure so that it is within the desired limits. However, sometimes a combination of drugs does not lower blood pressure enough and this condition is known as "resistant hypertension".

A breakthrough therapy

For some patients whose hypertension is resistant to drugs, there is now a breakthrough technique called renal denervation, which is available at both Royal Brompton and Harefield hospitals.

In hypertensive patients, the nervous system of the kidneys is overactive, causing the blood vessels to narrow, which in turn, increases blood pressure. Applying radiofrequency energy to the nerves that go to and from the kidneys reduces the nerve activity and, consequently, this reduces blood pressure. This is the basis of the new technique that requires few preliminary tests and just a one-night stay in hospital.

A thin tube (catheter) is inserted under local anaesthesia into an artery in the groin and pushed inside the two renal arteries supplying the kidneys. Radiofrequency energy is then given to the nerves that go to and from the kidneys.

The method is very safe and works for more than 90 per cent of patients, with an initial reduction of blood pressure that improves progressively in the first six to 12 months after treatment.

Professor Carlo Di Mario comments: "The expertise cardiologists develop using catheters to treat coronary stenosis with stents and arrhythmias with ablation is essential to improve success and safety of renal denervation, a technique where we treat the kidneys to prevent damage to the heart."

"The expertise cardiologists develop using catheters to treat coronary stenoses with stents and arrhythmias with ablation is essential to improve success and safety of renal denervation, a technique where we treat the kidneys to prevent damage to the heart."

Professor Carlo Di Mario
Professor of cardiology

Cardio-oncology service launched

An innovative cardio-oncology clinic was launched at Royal Brompton in August 2011 as a response to the increasing number of people who are surviving cancer but are living with heart problems caused by their cancer treatments.

In the last year almost 200 patients were seen in the consultant-led clinic, the only dedicated cardio-oncology clinic in the UK.

Dr Alexander Lyon, the consultant cardiologist who set up the service, explains: “More and more people are surviving cancer now or are able to live with the disease for many years, which is a real medical success story. Obviously this is excellent news. However, we are seeing many more people who have heart problems relating to their cancer treatments, particularly chemotherapy and also the new designer cancer drugs such as herceptin and sutent.”

The team works closely with The Royal Marsden in London, receiving patient referrals direct from oncologists, surgeons and anaesthetists.

The service is particularly aimed at identifying early signs of cardiotoxicity, a type of heart failure called “chemotherapy cardiomyopathy” that can be caused by some chemotherapy drugs. Following certain treatments, the heart muscle can become weak and fatigued, interfering with its ability to beat and pump blood around the body.

The new clinic also offers a risk assessment service for newly diagnosed cancer patients with pre-existing heart conditions, to ensure they are as fit as possible for their cancer treatment, whether surgery, chemotherapy and / or radiotherapy. Those at risk of developing heart conditions can also be assessed.

Patients have cardiac scans and blood tests in the morning at the clinic, results are reviewed by Dr Lyon and his colleagues, Dr Rakesh Sharma and Dr Stuart Rosen, in the early afternoon and then discussed with patients on the same day.

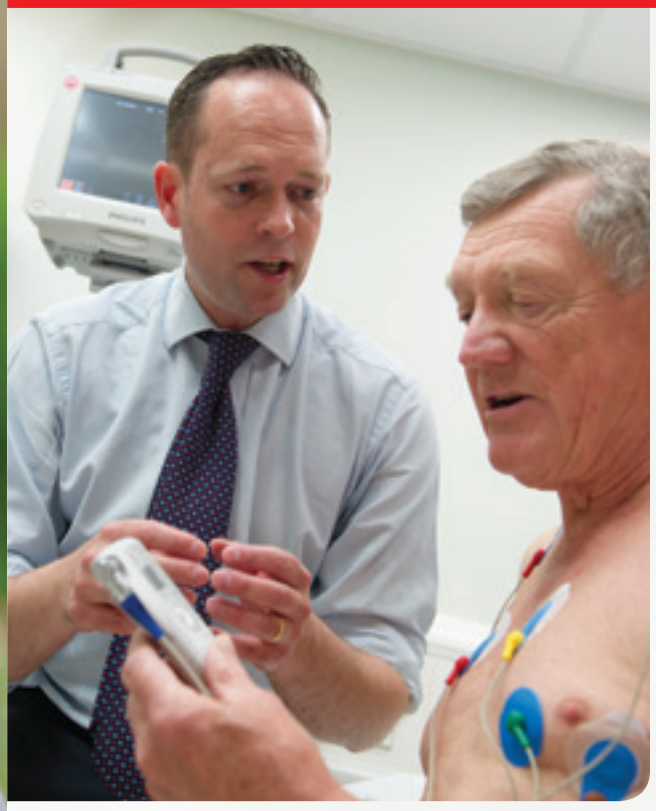
Dr Lyon comments: “We see people here who have been clear of cancer for many years but are now suffering from the effects of the cancer drugs. Equally, we see patients who need to have cancer treatment but they have an existing heart problem, or are in the middle of their treatment and have developed a cardiac complication. We need to make sure they are fit enough to go through surgery, or work with their oncologist to support their heart function so they can receive the optimal cancer drugs. It’s all about team work, both with colleagues here at Royal Brompton and with colleagues at The Royal Marsden, to ensure our patients receive the very best cancer and cardiac care.”

“It’s all about the team work, both with colleagues here at Royal Brompton and with colleagues at The Royal Marsden to ensure our patients receive the very best cancer and cardiac care.”

Dr Alexander Lyon
Consultant cardiologist

Almost **200 patients** were seen in our **cardio-oncology clinic** – the only dedicated clinic in the UK

Co-ordinated care – Alexander's story



In 2008, aged 66, Alexander Smail collapsed on the golf course. He was taken to The Royal Marsden in London and diagnosed with Non-Hodgkin lymphoma, a type of blood cancer.

Alexander explains: "It was a real shock – I'd had bowel cancer a few years before and had undergone chemotherapy, but I'd been feeling really good." Alexander had another six months of chemotherapy and again responded well. He is due to have his last check-up appointment in November this year.

However, in March 2012, Alexander started to have trouble with his breathing. He was diagnosed with pneumonia and spent two weeks at Epsom Hospital before being allowed home. His wife, Sue, was very worried and got in touch with The Royal Marsden to discuss his symptoms. His consultant there arranged for Alexander to see Dr Alexander Lyon, consultant cardiologist, at Royal Brompton.

Sue recalls: "Alexander went to The Royal Marsden on the Thursday and was referred to Royal Brompton by the following Tuesday. It's fantastic the way the two hospitals work together. The treatment he received from both hospitals was outstanding. We couldn't have wished for better co-ordinated care."

Dr Lyon diagnosed Alexander with chronic heart failure, most likely a form of cardiomyopathy caused by the chemotherapy drugs he received during his cancer treatment, and admitted him to Royal Brompton.

Alexander said: "I couldn't believe it – I'd had cancer and beaten that and now the doctors were telling me I had a heart problem because of it! It was a real kick in the teeth!"

Dr Lyon explains: "Alexander was referred to me from The Royal Marsden with severe breathlessness. He was very ill and his blood pressure was extremely low so we had to admit him to our cardiology ward."

Sue explains: "When he was admitted to Royal Brompton I was really worried. He was just so ill. But the staff were fantastic with me and my family. They explained everything so clearly that we were reassured he was receiving the best possible care."

Dr Lyon continues: "We managed to stabilise Alexander and started the right heart failure medication. He has continued to improve and gain strength since then – the transformation in the past year has been amazing and he's been able to return to his normal life. Hopefully he'll be returning to his great passion, golf, very soon."

Alexander now visits Dr Lyon at Royal Brompton's specialist cardio-oncology clinic for regular check-ups.

He comments: "Life is really good now and I feel great. Sue and I enjoy going on daily walks, and I can spend time gardening. I'm looking forward to getting back on those golfing greens again but, most importantly, I can now play with our grandchildren."

Harefield has the **best long-term survival rates** in the UK for patients who have had a heart or lung transplant

Leaders in transplantation

The transplant unit at Harefield Hospital is one of the UK's largest and most experienced centres for heart and lung transplantation. We have performed almost 3,000 transplant operations since Professor Sir Magdi Yacoub carried out the first UK heart and lung transplant at Harefield in 1983.

During 2012/13, the number of heart transplants more than doubled compared to the two previous years, partly due to the wider use of the Organ Care System. Using this system means that 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.

Best long-term survival rates

The transplant unit at Harefield has the best long-term survival rates in the UK for patients who have had a heart or lung transplant. There are currently 75 Harefield patients who had their heart or lung transplants 25-30 years ago, and 134 who had a transplant 20-25 years ago.

In November, Harefield patient, John McCafferty, became Britain's longest surviving heart transplant patient, when he celebrated his 30-year milestone. He was joined by his surgeon, Professor Sir Magdi Yacoub, and past and current transplant staff for an event held at the hospital.

Sir Magdi said: "I am delighted and very proud to be here. I feel privileged to be sitting next to this man 30 years after his operation. The team at Harefield is unique in many ways and I felt really privileged to work with such a special team during my time here. John is a great example of what this operation can do for people."

Rita Presnail, sister in the transplant clinic, was at Harefield for the first heart transplant in 1980, and is one of the staff members who sees John regularly at his annual checks. She said: "This is an exciting day for all of us, and we're so very proud of the unit's achievements over the years. It's always wonderful for us when we see how well our patients are doing when they come in for their annual check-ups, knowing that we've helped them get to that point."

John was recently elected to the position of public governor of the Trust, representing the South of England. He said: "I am a very proud supporter of the work carried out by both hospitals. It's my way of giving back, after all they've done for me. If it wasn't for Harefield Hospital I wouldn't be here. I've had the pleasure of seeing my son grow up and have his own son. That is priceless."

A number of high-profile representatives attended the celebration event, which also attracted the attention of the national media.

"If it wasn't for Harefield Hospital I wouldn't be here. I've had the pleasure of seeing my son grow up and have his own son. That is priceless."

John McCafferty (centre) with members of the transplant clinic team

Ventricular Assist Device (VAD) programme

A VAD is a mechanical device that is used to partially or completely replace the function of a failing heart. The VAD programme at Harefield, led by Mr André Simon, director of transplantation and circulatory support, has played a pivotal role in the development of new generations of so-called "artificial hearts" and pioneered recovery therapy. Harefield has the largest number of patients with VADs in the UK.

Some VADs are intended for short-term use, typically for patients recovering from heart attacks or surgery, or for those waiting for a heart transplant (a VAD in this case is known as a "bridge to transplant"). Others are intended for long-term use, typically for patients suffering from advanced heart failure and for those who are not suitable for heart transplant. Harefield clinicians are leading work on establishing the UK's first programme of VADs as an alternative to transplantation.

Clinical teams at Harefield are also pioneers in the emerging field of recovery of heart function. Our patients show the highest rate of myocardial recovery (where the heart regains strength while the VAD is assisting it) in the world.

Innovation

The transplant unit works closely with the Harefield Heart Science Centre, which is at the forefront of research into heart disease and transplantation.

Harefield patients have taken part in a number of clinical trials in the past year, including one involving a new reduced-size mechanical heart assist device known as the Circulite Synergy Micro-Pump LVAD (left ventricular assist device). Harefield was the only UK trial centre and five patients were given the device as part of the research programme. The Circulite Synergy Micro-Pump is the size of an AA battery and sits in the right hand side of the chest, connecting to the heart by small tubes that pump blood around the rest of the body. It is the smallest VAD available and can be implanted through a minimally-invasive procedure so open heart surgery is not needed. This means a quicker recovery time.

Chris Schaffer was the first patient to have the implant after the trial. He believes he has been given a "second chance" following the operation in September 2012. He said: "I came round from the operation about five hours afterwards and was raring to go. Being able to walk up the stairs on my own the following week was momentous. I hadn't been able to walk for four months, let alone climb the stairs. I feel better than I have for years – I feel like I've been given a second chance, given a new life," he said. "This machine 100 per cent saved my life. I feel like me 20 years ago. I feel like a new man."

Gemma Edwards, clinical nurse specialist, commented: "This is an extraordinary little device that has helped several of our heart failure patients and I'm looking forward to seeing it help many more in the future."

"Being able to walk up the stairs on my own the following week was momentous. I hadn't been able to walk for four months, let alone climb the stairs."

Chris Schaffer
First patient to have the Circulite Synergy Micro-Pump LVAD

Transplant unit – working with young adults

Many young transplant patients transition to Harefield for their adult care. The expert team works closely with centres like Great Ormond Street Hospital for Children (GOSH) in London to ensure a smooth process.

The transplant transition service accepts patients who have had a heart or lung transplant as a child, but now need monitoring as an adult. Patients come to Harefield whenever they feel ready for the move from child to adult care – usually when they are around the age of 16.

Their first visit to Harefield is an informal meeting between the patient, staff and the patient's family. The team supports young patients so that over time they gain confidence and feel ready to make more independent decisions about their care and treatment.

Post-transplant care in the outpatient department is led by a team of clinicians, nurses and healthcare assistants. Dr Anna Reed, adult lung transplant consultant, says: "Transition from paediatric to adult services can be a very stressful time for patients and their families alike. It is very important that our patients transition at a time that is right for them – everyone is different."

Dr Reed, Dr Melissa Sanchez, clinical psychologist, and Rita Presnail, clinic sister, are currently trialling a new young adult service for lung transplant patients who have had transplants as children.

Dr Reed and Dr Sanchez see patients together for joint consultations. Dr Sanchez comments: "Young adults are at a very different life stage to our older patients and have different concerns. Alongside the issues relating to body image and general health, they also have worries about leaving home, going onto further education, employment and relationships.

"For any young adult, this time of their life is daunting, so given the additional needs of young transplant patients, the team was committed to starting a young person's clinic to create the right environment for our patients to be able to talk about these specific issues."

If the service proves successful, it will be extended to include young adults who have had a heart transplant or an artificial heart support device as children.

For more information, visit **rbht.nhs.uk/transplantation**

"For any young adult, this time of their life is daunting, so given the additional needs of young transplant patients, the team was committed to starting a young person's clinic to create the right environment for our patients to be talk about these specific issues."

Dr Melissa Sanchez
Clinical psychologist

Last year our experts carried out almost a **third of all lung transplants** in the UK

Transitioning to adult care – Paula's story

Paula Cogan was diagnosed with cystic fibrosis (CF) aged just nine months old. She was treated at Royal Brompton under the care of Professor Andy Bush, paediatric respiratory consultant. However, her lungs deteriorated to such a point that she was placed on the lung transplant list at 15.

Paula explains: "I didn't realise how ill I was until just before I got the call to say there were lungs for me. I was actually at Royal Brompton having intravenous treatment and had been there for four weeks. I was sitting my art GCSE at the time and really struggling with the effort of it all."

Paula had a successful lung transplant in March 2009 at the children's transplant unit at GOSH, where all children's transplants are carried out. She remained there for six weeks, three of which she spent in intensive care.

Her dad, Thomas, recalls: "It was obviously a desperately worrying time for us as a family. As a parent you just feel so helpless."

When Paula was discharged from hospital she remained under the care of doctors at GOSH until she was 18. Paula comments: "The doctors started talking about moving my care to an adult centre but I had also been thinking about it myself – the medical staff there were used to dealing with younger children and I started to feel more ready to take control of my own care."

Paula and her dad attended a transition clinic where they met a number of representatives from different adult transplant centres across the UK.

Thomas explains: "It was really good to be able to make that decision with Paula. After experiencing such excellent care at Royal Brompton for Paula's CF it seemed natural that we would choose Harefield for her transplant care."

Paula and Thomas visited Harefield before her first outpatient appointment there and met the clinic sister, Rita Presnail, who showed them around.

Paula says: "It was really good to get a feel for the hospital and meet people. I'd spent 15 years under the care of Royal Brompton and then two years with GOSH so the thought of coming somewhere new was extremely daunting. But it wasn't as scary as I thought it would be. I was given a welcome pack with plenty of information and contact details so I would know who to contact if I had any questions. Everyone was really friendly and welcoming."

Paula began to attend the outpatient clinic at Harefield on a three-monthly basis under the care of Dr Anna Reed, who liaised with Paula's specialist at GOSH. "It was all very co-ordinated," comments Paula. "My dad comes with me to appointments at the moment and it's reassuring to have him with me. I also get a free lift!"

Thomas comments: "It's a bit scary letting go as a parent. But she's 19 now and I suppose that's all part of them growing up. It's really nice the way they do it at Harefield because I've felt involved. Paula leads and asks any questions she wants answered but if I have any questions or concerns, I can ask too."

Paula is now studying journalism and creative writing at university in London and hopes to become a sports journalist.

Children's services

Royal Brompton and Harefield's dedicated paediatric department is a national referral centre for children with heart and lung conditions. We offer the full range of diagnostic and surgical interventions from the prenatal stage to transition to adult services for teenagers.

Our work consists of the following sub-specialities:

- Paediatric respiratory medicine
- Paediatric cardiology
- Fetal cardiology
- Congenital cardiac surgery

Many of our children's services are internationally renowned, including fetal cardiology, sleep disorders, paediatric cystic fibrosis and severe asthma, and we are the largest national referral centre for children with heart rhythm problems.

Throughout their time at the hospital, children are supported by specialist nurses and have access to a range of clinical services, including psychologists, dietitians, and physiotherapists.

Royal Brompton Hospital is a leading centre for research and treatment of respiratory conditions in children. Experts at the hospital treat about 2,400 children each year with conditions such as muscular dystrophy, severe asthma, cystic fibrosis and rare lung diseases. Many patients begin their treatment as small children and stay with the hospital throughout adulthood.

Long term care – Jacob's story

Jacob Pridmore is nine years old. He has had health problems since he was born prematurely at 27 weeks at Medway Maritime Hospital in Kent.

In 2006, aged 18 months, Jacob was diagnosed with idiopathic pulmonary haemosiderosis, a very rare lung condition, which means that he haemorrhages blood into his lungs without warning. Only one in four million people are born with this condition, meaning that doctors may never come across this disorder during their entire career.

Jacob's mother, Collette, explains: "When it was suspected that he had this rare condition we were told he may not see his fifth birthday. We were all devastated and the severity of his condition was really brought home to us three months later when he had a massive lung haemorrhage."

Jacob was admitted to Royal Brompton's paediatric intensive care unit (PICU) under the care of Dr Claire Hogg, paediatric respiratory consultant, where he was ventilated and stayed for several months. At one point it was feared that Jacob

would never be weaned from the ventilator. Collette continues: "This was the start of what has been a long journey as a 'Royal Brompton family'. We experienced round-the-clock care and support during Jacob's time in PICU, not only for him but also for my husband and I, our then four-year-old son and our then nine-month-old baby."

Dr Hogg explains: "Jacob's condition really is incredibly rare. One of the main issues is the unpredictably of its nature – it is chronic and when a haemorrhage happens blood oozes from the small blood vessels in the lungs. This means Jacob needs frequent admissions onto the ward and occasionally support on PICU as well."

Jacob's longest stay as an inpatient came in August 2011 and he remained at Royal Brompton for nine months. He experienced frequent episodes of haemoptysis (bleeding from the lungs) and needed numerous blood transfusions. He also had some new, trial immunosuppressant therapies.

Collette comments: "During a long period in hospital it's really important that it's not just about the medical treatment. The school team is amazing – the teachers keep in close contact with Jacob's own school and the work his class is completing.

"The teachers here then adapt the work so that it meets Jacob's needs and he can work by his bedside or in the school room if he is feeling well enough.

"Jacob also really enjoys art therapy, which he attends weekly. This allows him to talk about things that worry him or make him happy or sad."

The team at Royal Brompton has become expert in understanding Jacob's unique needs and how best he responds to treatment. Dr Hogg and members of the team have been to Jacob's local hospital, Medway, to share this knowledge with doctors there so his needs can be catered for locally if he needs emergency treatment.

Dr Hogg is also on hand to give advice and support via telephone and email if he is admitted to Medway and, if Collette needs support at home, the team is able to guide her through Jacob's care plan.

Collette says: "One of the things that has had the greatest impact on our family life has been the gradual increase in my confidence to care for Jacob at home when he is well enough. Through many hundreds of hours of careful tuition and help from the clinical team, I am able to administer a complicated medical regime, including oxygen, intravenous drugs and injections.

"This allows Jacob and I to spend more time in our home environment as a family. No matter how complex Jacob's care becomes, everyone's goal is for him to be at home as much as possible. Dr Hogg and the other consultants never lose sight of the need for us to be a family and the joy that time at home brings us all.

"I have never felt vulnerable or alone and the team make my boy feel safe, loved and special – they have never once let me down in nine years and with a child as sick as Jacob that is a big statement to make."

Jacob is currently at home. He attends weekly assessments in clinic or on the ward at Royal Brompton and needs blood transfusions every two to four weeks.

Jacob said: "Royal Brompton look after me, they make me feel better so I can be with my brother and sister. I love Dr Hogg. She helps my lungs get better."

"I have never felt vulnerable or alone and the team make my boy feel safe, loved and special – they have never once let me down in nine years and with a child as sick as Jacob that is a big statement to make."

Collette Pridmore
Jacob's mother

Children's sleep and ventilation unit

In November 2012, a new state-of-the-art children's sleep and ventilation unit was opened at Royal Brompton Hospital by Greg Hands, MP for Chelsea and Fulham.

The unit will help around 1,000 children each year who experience difficulties breathing at night. Disorders affecting children's sleep can have a negative affect on their brain development, heart and blood vessel metabolism, and immune system.

State-of-the-art equipment

The children's sleep and ventilation unit is fitted with state-of-the-art equipment for sophisticated tests that can monitor oxygen and carbon dioxide levels in the bloodstream, movement of the chest and abdomen, heart rate, airflow, and electrical activity in the brain.

Dr Hui-Leng Tan, consultant in paediatric respiratory and sleep medicine, is spearheading the development of new research programmes into sleep-disordered breathing and paediatric sleep medicine, and fostering collaborations with sleep centres in other parts of the world. She commented: "We are delighted to have these impressive new facilities, which allow us to do very sophisticated testing and treatment, in a dedicated environment designed to put children at ease. We are also very pleased that such sophisticated technology will allow us additional scope for our research into sleep disorders."

Child-friendly rooms

The rooms in the unit were specially designed with input from children and their families, creating a child-friendly atmosphere so that children can feel relaxed and have a good night's sleep.

The unit also provides beds for parents of the young patients, enabling them to stay during the overnight test, helping both the child and the parent feel more at ease.

Claire Goodbody recently stayed with her seven-year-old daughter, Gemma, and said: "Gemma has congenital muscular dystrophy and has her sleep monitored at Royal Brompton each year. We were so surprised and thrilled by the new unit. It has been very thoughtfully designed with privacy and everything we could need, so that we felt like we were in a home away from home. The whole environment is set up to make it as easy as possible for Gemma to get to sleep."

The unit was funded by Royal Brompton & Harefield Hospitals Charity and features original artworks commissioned by rb&hArts and made possible through donations from the Octavia Appeal, the paediatric arm of the Friends of Royal Brompton.

For more information, visit **rbht.nhs.uk/children**

"Gemma has congenital muscular dystrophy and has her sleep monitored at Royal Brompton each year. We were so surprised and thrilled by the new unit. It has been very thoughtfully designed with privacy and everything we could need, so that we felt like we were in a home away from home."

Claire Goodbody
Mother of seven-year-old patient, Gemma

Co-ordinated treatment – Sam's story

One-year-old Sam Gambi was diagnosed with Prader-Willi syndrome, a rare genetic condition, shortly after his birth at Queen Charlotte's Hospital, Hammersmith.

His mother, Jo, explains: "We knew within 24 hours of his birth that there was something wrong with Sam. Compared to our older son, Ben, Sam was very different at birth. Although the doctors suspected Sam had Prader-Willi syndrome within a day or so, it was only confirmed after about eight weeks. While my husband and I waited for the test results, we banned ourselves from Googling anything. But, ultimately we couldn't protect ourselves from the enormous shock and sadness when we received Sam's diagnosis, or from our fears for the future."

Prader-Willi syndrome causes a wide range of symptoms, the main ones being a constant feeling of hunger and the desire to eat, which can easily lead to dangerous weight gain. Other features of the syndrome include low muscle tone, learning difficulties, challenging behaviour / autism, abnormal metabolism and growth, and a range of medical issues.

A community team, including a paediatrician, physiotherapist, occupational therapist, speech and language therapist and dietitians, was put in place for Sam and his family. He was also referred to an endocrinologist, who specialises in the treatment of hormone disorders, at Chelsea and Westminster Hospital. Sam saw this specialist regularly in his first year.

Another risk for patients with Prader-Willi syndrome is respiratory problems, in particular whilst sleeping.

Sam was referred from Chelsea and Westminster to the specialist children's sleep centre at Royal Brompton for a sleep study under the care of Dr Hui-Leng Tan, consultant in paediatric respiratory and sleep medicine.

Jo explains: "It was such a smooth process. We were really impressed by the efficient communication between the two hospitals. I've also been in regular email contact with Dr Tan – who is excellent and very reliable, so I trust her and feel free to ask her anything."

"It was such a smooth process. We were really impressed by the efficient communication between the two hospitals. I've also been in regular email contact with Dr Tan."

Jo Gambi
Sam's mother

On Sam's first visit, his oxygen and carbon dioxide levels were monitored while he slept, as well as heart rate, chest and abdominal movement and airflow. He was found to have sleep-disordered breathing with many central apnoeas, where the brain does not get the message to the lungs to breathe during sleep. Sam's parents were given a supply of oxygen and taught how to give it to Sam at night time so that he could breathe properly while asleep.

Since his first sleep study, Sam has returned to the sleep centre a further three times. He has started growth hormone treatment for his condition to help with his growth and muscle tone. However, a common side effect of this is that the adenoids and tonsils grow larger, which could also make it hard for him to breathe at night so he needs regular studies to see if this is happening.

Jo said: "The sleep centre is lovely; such a pleasant environment. It makes our time in hospital so much easier. Sam is fascinated by the artwork and it really helps that I can stay in the same room with him. He loves the sleep centre bear, Humphrey, and the staff are always warm, friendly and efficient."

Dr Tan commented: "Sam is a lovely young boy and a real pleasure to treat. We will need to closely monitor him as he gets older – children with Prader-Willi syndrome are at increased risk of sleep-disordered breathing, which can be potentially dangerous if not managed correctly. It really helps for patients who need to come in repeatedly that they have a pleasant, homely environment so they have a more natural sleep."

Jo continued: "I feel totally involved in Sam's care here. Dr Tan and the staff have welcomed me as a parent and encouraged me to make decisions. I really feel part of the team. We're all working towards the best possible care and treatment for Sam, which helps us feel so much more positive about this aspect of Sam's future."

"Sam is a lovely young boy and a real pleasure to treat. We will need to closely monitor him as he gets older – children with Prader-Willi syndrome are at increased risk of sleep-disordered breathing."

Dr Hui-Leng Tan,
Consultant in paediatric respiratory and sleep medicine

Children's heart surgery review

It has taken many years for clinical teams at Royal Brompton to develop the level of expertise that now exists in the children's heart unit. It was therefore a source of deep regret that, ignoring evidence that showed the grave damage that would result from closing the unit, a joint committee of primary care trust (JCPCT) chief executives made the decision to decommission these vital services in July 2012.

In June this year, the Secretary of State for Health, Jeremy Hunt, suspended the Safe and Sustainable review of children's heart surgery. He accepted a report from the Independent Reconfiguration Panel, which concluded that the JCPCT's original recommendations, which included ending children's heart surgery at Royal Brompton, were based on "flawed analysis of incomplete proposals and their health impact".

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

"I know that patients and their families will be overjoyed by the news. They have never been able to understand why one of the best performing and largest units in the country was destined for closure, especially when statistics showed that the population in London and the South East was growing faster than had previously been thought, and demand for children's heart surgery was increasing."

Since the threat to children's cardiac services was first announced, the Trust's children's teams have received support from colleagues and peers around the world, from patients and their families, from charities that do so much for our patients, from Members of Parliament, and local councillors, and from local communities.

NHS England has now been tasked with developing a new approach to improving children's heart surgery. The team leading the new review has confirmed the importance of considering the whole patient journey – from antenatal testing and diagnosis to adult monitoring and interventions. Other factors that will also be considered are capacity analysis, including for paediatric intensive care units, performance data, including mortality rates of congenital heart services and any wider implications for other services. These are precisely the issues that were brought to the attention of the original Safe and Sustainable review team by the Trust in 2011.

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

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

"I know that patients and their families will be overjoyed by the news. They have never been able to understand why one of the best performing and largest units in the country was destined for closure."

Bob Bell
Trust chief executive

Chronology

February 2011
JCPCT announces plans to end children's heart surgery and intensive care at Royal Brompton.

March 2011
Public consultation begins.

July 2011
Mr Justice Burnett grants permission for a judicial review of the public consultation, on all grounds advanced by Royal Brompton & Harefield NHS Foundation Trust.

November 2011
Mr Justice Owen upholds the Trust's challenge and rules that the public consultation "was unfair and must therefore be quashed".

April 2012
The High Court upholds an appeal by the JCPCT.

July 2012
JCPCT announces its final decision to decommission children's heart surgery services at Royal Brompton.

October 2012
Secretary of State for Health, Jeremy Hunt, announces a full review of the JCPCT's decision by the Independent Reconfiguration Panel.

June 2013
The IRP releases its report on the Safe and Sustainable proposals for children's congenital heart services, and Jeremy Hunt announces in Parliament that he is in agreement with the panel's recommendations that the original review was flawed. He immediately suspends reconfiguration plans.

Life-saving heart surgery – King-Elyon's story

Sherell Hutchinson was 20 weeks pregnant when doctors made the discovery that her baby's heart was not beating as it should.

Sherell recalls: "It was a difficult pregnancy and when our baby, King-Elyon, was born six weeks prematurely the doctors warned us he might not survive. We were devastated. It was such a scary time for my husband Carl and I."

King-Elyon was transferred to Royal Brompton and put under the care of Dr Jan Till, consultant in paediatric electrophysiology. Dr Till explains: "King-Elyon's heart rate was only 17 beats per minute compared to the average newborn baby's heart rate, which is 60 beats per minute. We needed to fit him with an external pacemaker as an internal one would have been too big a risk."

A pacemaker sends regular electrical impulses to the heart to help keep it beating normally.

After a successful three-hour operation, Sherell and her family were advised that they needed to wait two days to see if King-Elyon's heart would improve enough to allow a permanent pacemaker to be fitted.

Sherell comments: "Those two days felt like the longest of my life, I was so worried for my baby. But Dr Till visited us every day and reassured us that he was strong. Having her there to support us was invaluable."

Dr Till said: "After two days King-Elyon's heart had improved and he was in a stable condition. This meant we were able to put in a permanent pacemaker. As King-Elyon was only a few days old and so small, we had to implant the pacemaker in his abdomen and the leads were on the outside of his heart."

After another successful operation, King-Elyon's heart started to respond well to the permanent pacemaker.

Sherell recalls: "Every day he improved – it was amazing to see him move his little hand, or his little foot. The first time he opened his eyes and smiled at me, I cried with happiness."

King-Elyon stayed in hospital for the next seven months and, when he was almost ready to go home, Sherell was taught how to administer the medication that he would need to continue taking.

"In the last 10 years we've almost lost King-Elyon seven times. All the doctors and the specialist nurses who have helped us through some really difficult times have been amazing. To hear that his heart is now as healthy as any other child's is just unbelievable – we can finally look forward to the future."

Sherell Hutchinson
King-Elyon's mother

Sherell recalls: "It was so amazing to be able to take King-Elyon home and be a proper family again. When we left Royal Brompton all the doctors and nurses came to say goodbye, which was so kind of them. Everyone was so happy that he was now well enough to come home."

After he returned home, King-Elyon continued to attend outpatient appointments at Royal Brompton every three months. Unfortunately, King Elyon again became very ill when he was just over a year old and tests showed that he was developing a cardiomyopathy.

Dr Till explains: "It is common for children born with heart problems like King-Elyon's to develop a cardiomyopathy that damages the heart. In his case, it was life-threatening – he was so ill, he was even considered for a transplant."

King-Elyon's heart was functioning so poorly he developed a blood clot in his heart and needed anticoagulation treatment to thin his blood. He was put on the heart transplant list.

In 2010, he underwent a procedure by Dr Jonathan Clague, consultant electrophysiologist, to implant a biventricular device. This is similar to a standard pacemaker but biventricular devices have a third wire instead of the usual two. With three wires the pacemaker takes control of the electrical impulse of the heart and stimulates both the left and right ventricles at the same time, resulting in a more co-ordinated heart beat.

Dr Till explains: "This is a pacemaker more often used in adults and can be very difficult to place in a small heart. However, the procedure was successful and the device really altered the course of King-Elyon's condition. His heart responded and he was taken off the transplant list. In December 2012, we were able to give King-Elyon and his family the news that his heart is now as healthy and normal as any other 10-year-old. We are now weaning him slowly off all his medications."

Sherell says: "In the last 10 years we've almost lost King-Elyon seven times. All the doctors and specialist nurses who have helped us through some really difficult times have been amazing. To hear that his heart is now as healthy as any other child's is just unbelievable – we can finally look forward to the future."

King-Elyon says: "I am so happy. When Dr Till said I can now go on an airplane and visit my family in Jamaica, I gave her a big hug."

"It is common for children born with heart problems like King-Elyon's to develop a cardiomyopathy that damages the heart. In his case it was life-threatening – he was so ill, he was even considered for a transplant."

Dr Jan Till
Consultant in paediatric electrophysiology

Our experts treated people with asthma over **3,000 times** in outpatient clinics and **2,500 times** as inpatients

The fight against lung disease

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

Patients from the UK as well as overseas are treated for the full range of respiratory disorders including: asthma and allergy, lung inflammation and cystic fibrosis, lung infection and immunity, lung failure (including transplant, COPD and sleep ventilation), cancer services, and lung assessment (including sleep studies, lung function and physiology).

Asthma

The asthma team, led by Dr Andrew Menzies-Gow, consultant respiratory physician, has a national and international reputation for innovative research and for the development of new asthma and allergy treatments.

Doctors at the Trust treat more children and adults with severe asthma than anywhere else in the country. Patients with severe asthma are unresponsive to standard inhalers and may need frequent hospital treatment. Royal Brompton is the largest asthma centre in London and the South East and the majority of patients are referred to our specialists via their consultants at district general and teaching hospitals.

Innovative clinics

In 2012/13 a new "unexplained breathlessness" service was launched at Royal Brompton by consultant respiratory physician, Dr James Hull.

The service was set up to provide a comprehensive assessment to find out the cause of an individual's breathlessness and has close links with the lung function department.

Patients are often referred to the service suffering from symptoms that are mistaken for asthma but are actually caused by other conditions. One such condition is exercise induced laryngeal obstruction (EILO), characterised by wheezing and severe breathlessness during exercise.

Until recently, there has been no easy way to diagnose EILO, which often results in misdiagnosis and incorrect treatment. However, now doctors at Royal Brompton offer a unique new diagnostic test – the only hospital in the UK to do so.

The continuous laryngoscopy during exercise (CLE) test, involves inserting a tiny camera — about half as thick as a pencil — into a patient's nose to look at the voice box. Patients are then asked to pedal on an exercise bike or use a treadmill to replicate the breathlessness they experience when exercising. The camera allows the team to watch the movement of the voice box and record the results.

Dr Hull explains: "Usually, the vocal cords should stay completely out of the way during exercise, but with EILO the cords may close almost completely, which generates a lot of discomfort, wheezing and difficulty in breathing."

Targeted physiotherapy can help stop EILO symptoms and patients can return to sport, often performing better and without the need for any unnecessary medication.

Dr Hull comments: "This new test will continue to help more patients who have been misdiagnosed with asthma get back to exercising and performing at their best."

"Usually, the vocal cords should stay completely out of the way during exercise, but with EILO the cords may close almost completely, which generates a lot of discomfort, wheezing and difficulty in breathing."

Dr James Hull
Consultant respiratory physician

Innovation in respiratory diagnosis – Rebecca's story

Rebecca Eno was used to feeling out of breath after exercise – she was a competitive rower for her school team.

However, after one training session in 2010, when she was 17, her breathing did not return to normal after exercising – it got worse.

"It felt as if someone was trying to strangle me," Rebecca recalls. "People talk about fighting for breath and that's what I felt – I just could not grab in enough air to breathe properly."

An ambulance was called, paramedics treated her and after half an hour her breathing returned to normal. She was told it was an attack of exercise-induced asthma, which seemed possible as Rebecca is mildly asthmatic.

Dr Andrew Menzies-Gow, clinical lead for asthma commented: "Exercise can often bring on an attack in asthmatics. It's not fully understood why but it's thought that breathing in more air as you exercise dries the airways. This triggers the release of chemicals that make the airways contract, leading to breathlessness. This becomes worse if you exercise outside in the cold, as Rebecca was doing for her rowing, as this dries the airways further still. Normally, this should be controllable with an inhaler but in Rebecca's case her inhaler wasn't helping her at all."

Between February and July that year she had six more attacks during her training sessions.

For a year, specialists at her local hospital tried her on a variety of asthma medications, but none worked.

At one point, it was suggested that she may have to give up the rowing she loved, but luckily, a consultant had heard about the new EILO test at Royal Brompton and referred Rebecca.

She said: "When they told me that my results showed I had EILO, I felt as if a weight had been lifted off my shoulders. Half an hour later I was on my way to see the physiotherapist to learn how to manage my condition. It's transformed my life."

Since then, Rebecca, now aged 20, has been doing her exercises almost daily and is back training competitively at Durham University, where she is studying.

She explains: "It takes a long time to build up the exercises – at first I would do the techniques for 30 seconds. I love being back training properly again and I'm really grateful to the team at Royal Brompton – if I hadn't had the test, things could have turned out very differently for me."

"Exercise can often bring on an attack in asthmatics. It's not fully understood why but it's thought that breathing in more air as you exercise dries the airways."

Dr Andrew Menzies-Gow
Clinical lead for asthma

Cystic fibrosis

Cystic fibrosis (CF) is an inherited life-limiting disease, mainly affecting the pulmonary and digestive systems. Royal Brompton has one of the largest adult and paediatric CF clinics in Europe and the unit is also a world leader in the development of new treatments.

Around 9,000 people in the UK have CF, due to a defective or missing CFTR protein caused by mutations in the CFTR gene. There is no effective cure for the condition and, to date, treatments have largely focused on tackling the symptoms and complications of the disease rather than its underlying genetic cause. Survival for people with CF has improved year on year due to the quality of care delivered in specialist centres like Royal Brompton, by dedicated multidisciplinary teams

Peer review

In January 2013, the adult CF service underwent a "peer review", a process that is carried out about every four years by the Cystic Fibrosis Trust and British Thoracic Society. The process is a thorough review of clinical, psychosocial and business activities relating to delivery of care for patients. A report of the findings was published for commissioners, hospital management, the CF team, patients and carers.

The review highlighted the centre as an international centre of excellence, with a strong academic pedigree and described the service as "highly skilled, experienced and dedicated," whist commending our high-quality research programme. The very high standard of care provided to all patients was recognised, and the review team was particularly impressed by the development of guidelines and protocols that ensure our patients receive the latest evidence-based treatments. The report highlighted the need for investment in inpatient facilities to ensure standards of care are maintained for the growing number of adults requiring our services.

Leaders in research

Clinicians and researchers at the Trust are involved in a variety of programmes addressing the genetic defects of CF. Royal Brompton's CF service successfully achieved designation as a European Cystic Fibrosis Clinical Trials Network site ensuring continued access to new treatments for our patients.

Led by Dr Jane Davies, reader and honorary consultant in paediatric respiratory medicine, and Dr Diana Bilton, consultant respiratory physician and director of the adult CF centre, this joint adult and paediatric initiative has enabled us to enrol Royal Brompton patients in many trials of therapies that are now available to patients including inhaled antibiotics, inhaled mannitol and most recently the groundbreaking drug, Kalydeco (Ivacaftor).

Dr Jane Davies was principal investigator of the clinical trial for Kalydeco at Royal Brompton and in January 2013, the drug was licensed for use by NHS patients with the G551D gene defect, aged six and over – the first drug to be licensed that targets mutations in the CTFR gene in people with CF. About four per cent of CF patients in the UK carry this mutation.

"Kalydeco changes the way we treat CF because now, for the first time, we are able to target the underlying cause of the disease, instead of just the symptoms and complications," said Dr Davies.

"Kalydeco changes the way we treat CF because now, for the first time, we are able to target the underlying cause of the disease, instead of just the symptoms and complications."

Dr Jane Davies
Consultant in paediatric respiratory medicine

Dr Jane Davies (left) with Dr Diana Bilton

A real difference – Maddie's story

Maddie Turner was diagnosed with CF just after her third birthday. She is now aged seven and under the care of Professor Andy Bush, paediatric respiratory consultant, and Dr Jane Davies at Royal Brompton.

In January, Maddie had a number of "baseline" tests at the hospital so any improvements could be easily identified. Maddie's sweat chloride (the standard diagnostic test for CF) was measured at around 100mmol/L. A reading above 60mmol/L gives a positive diagnosis for CF and anything below 40mmol/L shows that CF is unlikely.

Maddie began treatment with Kalydeco in February. Her father, David, comments: "We noticed a weight gain pretty quickly. She is also a better colour and has noticeably more energy and stamina than before."

After a month on the new drug she was again given a sweat test. David explains: "Jackie Francis, the CF clinical nurse specialist, phoned with the results and Maddie's reading was down to the low 20s. I blubbed down the phone at Jackie, and I know of other parents who have done the same."

Maddie is continuing with Kayldeco along with the other medications and physio treatments that she was receiving previously for her CF.

However, David comments: "It's obviously early days and we still take each day as it comes, but the drug means that maybe, just maybe, my wife and I dare to dream that Maddie may have a future that is not ultimately defined by her CF and in which she is able to fulfil her potential in whichever way she chooses."

"My wife and I dare to dream that Maddie may have a future that is not ultimately defined by her CF."

David Turner
Maddie's father

Gene therapy treatment

The Royal Brompton team is at the heart of designing and developing several global trials enabling us to offer truly world-class care and access to the latest therapies.

Collaborations with industry partners complement an active academic research programme in gene therapy treatment for CF. In 2012, Professor Eric Alton and colleagues in the UK Cystic Fibrosis Gene Therapy Consortium, were awarded a £3.1 million grant from the National Institute for Health Research / Medical Research Council's clinical trials programme to fund the world's largest trial of gene therapy for this disease using liposomes (fat globules) to deliver the gene into the lungs. To date, 124 patients have entered the study with 15 having completed dosing. It will finish in June 2014.

Interstitial lung disease

The interstitial lung disease (ILD) unit at Royal Brompton, led by Professor Athol Wells, is the largest unit of its kind in Europe and the only unit in the UK solely dedicated to the management of patients with these diseases that affect the delicate structures and chemistry of the lungs.

ILD is a term used for a group of more than 200 lung diseases that affect the tissue and space around the air sacs in the lung. They are restrictive diseases and are distinct from obstructive airways diseases such as asthma, bronchitis and chronic obstructive pulmonary disease (COPD).

The Trust has been at the forefront of developments in the diagnosis and treatment of ILD over several decades and our clinicians are experts in a range of lung diseases – some of which are extremely rare.

Scleroderma (or systemic sclerosis) is a chronic disease associated with skin thickening and changes to blood vessels. The hardening of the skin is caused by the formation of scar tissue and this can affect the internal organs, including the lungs.

The ILD unit has close and longstanding links with the scleroderma unit at the Royal Free Hospital in north London and has established considerable expertise in the management of scleroderma associated pulmonary fibrosis.

Sarcoidosis (sarcoid) is generally described as an inflammatory condition of unknown cause that can occur at all ages and affect various parts of the body. The organs most commonly affected in people with sarcoidosis are the lungs and the lymph nodes (or glands), particularly those inside the chest.

Royal Brompton houses the largest dedicated sarcoid clinic 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.

We 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.

Idiopathic pulmonary fibrosis (IPF)

IPF is another type of ILD. It is a chronic, progressive lung disease that causes scarring of the lungs. The cause of IPF is still unclear but the condition appears to be connected with cells inside the lungs known as alveolar epithelial cells (AECs).

It is thought that the AECs become damaged and then begin to die. The body tries to repair the damage by releasing another type of cell known as fibroblasts. However, the production of the fibroblasts is excessive and results in scarring and hardening (fibrosis) of the delicate tissues of the lungs. Levels of fibrosis increase as the IPF progresses, leading to a gradual decline in lung function.

Symptoms of IPF include a persistent, dry cough, fatigue, gastric reflux and shortness of breath which gradually worsens over time, especially when doing physical activity.

Royal Brompton has the largest number of IPF patients in the UK and has around 500 new referrals every year.

New hope for patients

In April 2013, the National Institute for Clinical Excellence (NICE) approved the use of the drug, pirfenidone, for the management of IPF. As part of the European Named Patient Programme (NPP) clinicians at Royal Brompton have been able to prescribe this drug since September 2011 for patients with mild or moderate disease. NICE approval means that all patients with IPF in England who could benefit from pirfenidone can now have the drug.

Dr Toby Maher, consultant respiratory physician, explains: "Royal Brompton is the largest prescriber of pirfenidone in the UK and the feedback on the drug that we have been able to give to NICE was very positive. This is a great step forward as pirfenidone has been shown to stabilise lung function for patients with IPF."

Anne-Marie Russell, clinical research fellow, comments: "IPF is a chronic condition where lung function gets progressively worse over time. However, pirfenidone offers real hope to patients."

Home spirometry programme

The Royal Brompton team has also introduced a new home spirometry programme for IPF patients. Spirometry is the most common test to measure lung function, specifically the amount (volume) and / or speed (flow) of air that can be inhaled and exhaled. This programme started in January 2011 as a pilot study.

Anne-Marie explains: "Patients record a daily reading on their spirometer and if lung volume readings go down ten per cent or more for three consecutive days they know to contact us or their GP. It gives them the reassurance that they can be seen quickly to prevent their condition getting worse."

"Royal Brompton is the largest prescriber of pirfenidone in the UK and the feedback on the drug that we have been able to give to NICE was very positive. This is a great step forward as pirfenidone has been shown to stabilise lung function for patients with IPF."

Dr Toby Maher
Consultant respiratory physician

New drug offers hope – Gordon's story

Gordon Skilling first went to his GP complaining of coughing and breathlessness in 2008. He is a keen bagpipe player and singer and was finding that he needed more time to recover between sets of music.

However, his chest was clear on testing. He returned with the same complaint two years later and was referred to Frimley Park Hospital near Aldershot, where a diagnosis of IPF was suggested. He was then referred to the Royal Surrey Hospital, Guildford, and on to Royal Brompton where the diagnosis of IPF was confirmed in November 2011.

Gordon explains: "I was told that the average life expectancy after diagnosis is two to five years and as the doctor gravely shook me by the hand I did rather think 'ruddy heck'!"

He was put under the care of Dr Elizabeth Renzoni, consultant respiratory physician, and during one visit was asked about the possibility of taking part in the research programme run by Dr Toby Maher, consultant respiratory physician and Anne-Marie Russell, clinical research fellow.

Gordon first began taking pirfenidone in March 2012 as part of the NPP, and also started on the home spirometry programme.

He comments: "There are some side effects associated with pirfenidone – I have experienced a rash and sunburn, I'm a bit lethargic and the smell of cooking tends to put me off but on the whole it's been fine. It's helpful being able to use the spirometry testing at home and record my daily readings – it helps me keep an eye out so if I spot anything concerning I can get seen by my GP or doctors at Royal Brompton quickly."

Anne-Marie often liaises with patients' GPs in the community and gives advice and support on how best to manage patients with IPF.

Gordon says: "The team at Royal Brompton has been quite outstanding in their attention, with Anne-Marie taking me metaphorically by the hand and guiding me through visits. There's always someone on hand to offer tea and sympathy after a distressing lung function test or to be kind enough to laugh at one of my jokes!"

Anne-Marie Russell explains: "Unfortunately, patients with IPF often experience quite a rapid progression of the disease. However, the key with pirfenidone is that it slows down the process. Gordon's lung readings have stabilised since he began taking the drug, which we're delighted about."

Gordon concludes: "I have used oxygen when playing the bagpipes, when dancing and when doing strenuous activity but I no longer use it as a matter of course. I feel I am very lucky, so far, in that I feel well and my condition is stable. I am not in pain, and other than breathlessness while playing the bagpipes, dancing and going up hills, I am fairly normal – although my wife disputes this!"

Royal Brompton Centre for Sleep

Royal Brompton clinicians have been diagnosing and treating patients with sleep disorders for over 20 years. Our service for sleep-related problems is one of the largest in Europe.

In March 2013, a £1.5 million dedicated centre for the study and treatment of sleep disorders in adults was opened to support this work – the Royal Brompton Centre for Sleep.

The centre is in the old Chelsea fire station building and has been transformed into a modern, state-of-the-art facility featuring original artworks by cartoonist Steven Appleby, which reflects the Trust's strong commitment to the integration of art in clinical areas.

Sleep studies are carried out in the specially designed "night" section, in comfortable sleep laboratory rooms, while the "day" section houses outpatients, and consultation rooms. The new centre, which has four dedicated sleep rooms will allow the team to carry out more studies, more quickly.

Professor Anita Simonds, consultant in respiratory medicine, said: "This new facility puts us at the cutting-edge of sleep and ventilation treatment and research. It means that we can offer much swifter assessment, diagnosis and therapy to a greater number of patients with respiratory and sleep disorders than on our general respiratory ward, all of which will support us in our research endeavours and ultimately, the benefits will go full circle, directly back to our patients."

Jayne Bullock has been a patient at Royal Brompton for 46 years. She was delighted with the new sleep centre.

Jayne comments: "I was overwhelmed by the feeling of light and space that has been created in both the clinical and sleep areas. A real transformation has been achieved. I love the art work Steven Appleby has produced – sleep, and matters pertaining to sleep, all joyfully captured in his witty artistic vision. Life and function have been brought back to a building that once played such an important part in the local community. A state-of-the-art fire station back in 1892, now a state-of-the-art medical centre. A building built to serve the community saving lives, now thoughtfully and stylishly refurbished to fulfil a different but equally important social and lifesaving function."

State-of-the-art facilities

Sleep is vital to our health and quality of life, yet up to one in four people in the UK has a sleep disorder.

The centre's expert team of sleep clinicians, technicians, nurses and physiologists treat patients with problems including sleep apnoea (sleep which is disrupted by breathing irregularities) and sleep disorders in patients with conditions such as chronic obstructive pulmonary disease, cystic fibrosis and neuromuscular disorders such as muscular dystrophy and motor neurone disease.

"This new facility puts us at the cutting-edge of sleep and ventilation treatment and research. It means that we can offer much swifter assessment, diagnosis and therapy to a greater number of patients."

Professor Anita Simonds
Consultant in respiratory medicine

After diagnosis, clinicians will suggest treatment that best suits the individual. This may include lifestyle changes, medication, or treatment with specialist equipment.

Our clinical teams also work closely with ear, nose and throat specialists to assess upper airway problems and how these can be resolved in patients who snore.

Obstructive sleep apnoea service

Sleep apnoea is a condition that affects up to four per cent of middle-aged men and two per cent of middle-aged women and is even more prevalent in the elderly. It is a condition characterised by pauses (apnoeas) in breathing during sleep. Professor Simonds explains: "What happens is that as you move from drowsiness into deeper sleep, your body relaxes, including the muscles that hold open your throat. As your throat flops shut, snoring worsens and eventually you stop breathing as the airway becomes obstructed.

"After a few seconds your oxygen levels drop and an emergency response is tripped in your brain, which wakes your body up – not enough to become fully conscious, just to tighten the muscles so that you start breathing again. This happens many times a night. You wake thinking you've slept through, but feeling utterly exhausted."

Sleep apnoea can be a dangerous condition as it is associated with an increased risk of heart disease and stroke and can affect memory and work performance. An effective treatment for this condition is continuous positive airway pressure (CPAP) therapy. This involves patients wearing a face mask and using a small machine when they sleep, which provides a flow of pressurised air that helps to hold the airways open. CPAP quickly reverses the effects of obstructive sleep apnoea, so that sleep quality improves, daytime energy levels increase and adverse health consequences are minimised.

Our clinicians have extensive experience in treating patients with sleep apnoea and care for over 7,000 patients who use CPAP therapy at home.

Cartoonist and artist, Steven Appleby, worked alongside the project team for a year, developing an understanding of sleep medicine to assist him in the creation of artwork for the centre. As part of his research he read books about sleep disorders and undertook a home sleep study to monitor his breathing and oxygen levels at night. He was diagnosed with sleep apnoea and was treated at the very place where he was working.

He explains: "Despite being shaken awake by almost every person I've ever shared a room with, I've been in denial about my snoring. Everyone said I should go to the doctor, but I've always made a joke about it and to me snoring seemed trivial compared with a real disease."

Steven now has a CPAP machine which he uses at home. He comments: "After receiving treatment at Royal Brompton's Centre for Sleep, I realise the aches, pains and tiredness I had been suffering, which I always assumed to be the inevitable consequence of growing old, were actually the result of my sleep apnoea. Hopefully, once I've used the mask a bit longer the bags under my eyes will melt away and I'll look younger too!"

Education

Our doctors, nurses and allied healthcare professionals at Royal Brompton and Harefield hospitals are experts in their chosen field. We believe in sharing what we know through teaching, so that our knowledge can help patients everywhere.

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. SimMan 3G, a dummy patient with highly advanced functionality, allows clinicians to be put through realistic patient care scenarios, such as heart failure and anaphylaxis, a serious allergic reaction that is rapid in onset and can be life threatening.

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.

In the past year, a number of courses were delivered at the centre, including:

- Trauma team member (TTM) courses, run in collaboration with the London Trauma Network. These courses were commissioned by the London Deanery's Simulation and Technology-enhanced Learning Initiative (STeLi) and the London Trauma Office. The TTM course covers basic management of trauma patients and is designed to enhance the ability of professionals from different specialties to work together in a safe and effective way.
- TAVI courses, led by consultant cardiac surgeon, Mr Neil Moat. Live links from the cardiac catheter laboratories enabled course members to see patients being treated in real time. The courses were highly rated by cardiac surgeons from the UK, Spain, Ireland, Germany and Italy.
- The first cardiology specific PACES course, designed and delivered for junior doctors registered to sit the Member of Royal College of Physicians (MRCP) examination. This involved examination, assessment and diagnosis of patients in exam conditions under the supervision of consultant cardiologists.

"This course allowed us to get hands-on and apply some of the knowledge we had learned."

Training courses at the STaR Centre

Clinical Skills and Simulation Centre (CSSC)

The CSSC is a specialist medical education and training centre, where healthcare professionals can learn, practise and repeat clinical procedures in a safe environment.

The state-of-the-art facility is a collaboration between Royal Brompton Hospital and The Royal Marsden and focuses on clinical skills training for staff and visiting healthcare professionals.

The CSSC provides training in complex procedures and crisis management using high-spec patient simulators to recreate evolving clinical situations. Trainees improve and fine tune their skills and techniques, and master a range of clinical protocols designed to improve outcomes, before seeing patients.

The centre also allows for procedural skills training such as chest drain and central line insertion.

SPRinT

The *SPRinT* (simulated paediatric resuscitation team training) programme was founded in 2008 and team members deliver courses using high-fidelity, innovative simulation baby and child mannequins to recreate life-threatening events to improve team performance in time-critical situations. Crash trolleys, resuscitation equipment and real drugs are used to create scenarios that are as true to life as possible.

In March 2013, the award winning team, led by Dr Margarita Burmester, paediatric consultant intensivist and Dr Mary Lane, consultant paediatric and congenital cardiac anaesthetist, launched TOM (teenage open-chest model).

TOM is a bespoke model with a real-life chest opening, which gives specialist staff the chance to mimic critical events that need clinical teams to work closely together. TOM joins *SPRinT's* Harley, the ground breaking open-chest child model, and other simulation dummies.

TOM is the result of a successful funding bid to the London Deanery's STeLI initiative.

For more information, visit **rbht.nhs.uk/education**

"Excellent course that covers commonly encountered scenarios on the ward with particular focus on non-clinical factors such as working within and managing a team under pressure and coping with difficult colleagues and relatives in an emergency."

Our influence

The Trust is a well-established and widely recognised brand, attracting clinical experts from across the UK and all over the world who join us to work, study and train at our hospitals. Many of these experts return to lead institutions in their own countries.

Our clinicians travel widely, both at home and abroad, delivering lectures and presenting at conferences. Many hold key positions on influential boards, committees, institutions and professional associations.

International lectures and presentations

Dr Miles Dalby, consultant in interventional cardiology, leads the primary angioplasty and transcatheter aortic valve (TAVI) programmes at Harefield Hospital. As a fellow of the European Society of Cardiology, he presented at the annual conference in Munich, and also joined the faculty of the US Transcatheter Therapeutics at its meeting in Miami in 2012 to discuss aspects of heart attack management.

Cardiology consultant, **Dr Mahmoud Barbir**, spoke at the first international conference on familial hypercholesterolemia (FH) in children and adolescents in Athens in summer 2012. FH is caused by an abnormal gene that results in very high cholesterol levels. Dr Barbir presented on the treatments available, including lipoprotein apheresis for those who do not respond to medication. Harefield is the largest of only eight UK centres that can offer this treatment. Dr Barbir also spoke at the sixth EU round table on FH in Berlin in early 2013.

Dr David Jones, consultant cardiologist, presented the results of a randomised clinical trial examining the role of catheter ablation for atrial fibrillation (AF) in patients with heart failure, at the American Heart Association Annual Scientific Sessions in Los Angeles in November 2012.

An international masterclass in pulmonary arterial hypertension related to congenital heart disease was held at Royal Brompton at the beginning of June, led by **Professor Michael Gatzoulis**, consultant congenital cardiologist, and **Dr Kostas Dimopoulos**, consultant cardiologist. Twenty senior cardiologists from all over the world attended this unique masterclass and joined both theoretical and practical sessions on this topic. All sessions were highly interactive. The course will now be held yearly and is already oversubscribed.

Dr Sabine Ernst, cardiology consultant, was invited to present her work on: *"Working in the EP lab: radiation risks to you and your patients"* at the European Society of Cardiology congress in Berlin in August 2012.

Dr Jan Till, consultant in paediatric electrophysiology, and **Dr Mary Sheppard**, consultant histopathologist, attended the International Scientific Conference in Dubrovnik in September 2012. Dr Till discussed: *"The role of defibrillators in channelopathys"* and Dr Sheppard spoke about: *"Sudden death in congenital heart disease"*.

Dr Duncan Macrae, paediatric consultant intensivist and director of children's services, is director of the Paediatric Intensive Care Society and on the scientific committee of the World Congress on Paediatric Critical Care. He spoke at the World Congress of Paediatric Cardiology & Cardiac Surgery in Cape Town, South Africa in February 2013.

Transplant unit staff, **Katriona Fisher, Ashi Firouzi, Alison Thompson, Sherrie Panther, Gemma Edwards and Kristine Kiff** were key speakers at the International Transplant Nurse Society's 21st Annual Symposium – *"Rising to the challenges in transplant nursing"* in Seattle in November 2012. Alison Thompson, ward sister on the transplant unit, won the best abstract award for: *"Combating compassion fatigue – the Schwartz round comes to England"*.

Mr André Simon, director of transplantation, presented at the European Association for Cardiothoracic Surgeons in a focus session about: *"Unanswered questions in right ventricular failure"* and gave a lecture at the Saudi International Congress on: *"New frontiers in organ transplantation"* in Riyadh, Saudi Arabia in March 2013. He also attended the American Transplant Congress meeting in June 2012 in Boston and the International Society for Heart and Lung Transplantation conference in Prague in April 2012.

Dr Sian Jaggar, consultant anaesthetist, represented the Royal College of Anaesthetists on a visit to Sri Lanka where she acted as an external examiner for the professional anaesthetic exams there. As part of this she lectured on: *"Training for safety"*.

Dr Andrew Menzies-Gow, clinical asthma lead for the Trust, presented four sessions at the European Respiratory Society annual conference in Vienna in September 2012.

Dr Toby Maher, respiratory consultant, spoke at the American Thoracic Society Meeting in San Francisco in May 2012 and the 17th International Colloquium on Lung and Airway Fibrosis in Modena, Italy in September 2012.

Consultant nurse in cystic fibrosis, **Dr Susan Madge**, is on the board of the European Cystic Fibrosis Society and presented at its annual conference in June 2012. She was also the invited international speaker at the Belgian cystic fibrosis conference in Wavre in October 2012.

Professor Andrew Bush, professor of paediatric respirology and consultant paediatric chest physician, continues to travel widely and in the past year has spoken at the American Thoracic Society Meeting in San Francisco in May 2012, the International Congress on Paediatric Pulmonology in Bangkok, in June 2012, the European Respiratory Society's annual conference in Vienna in September 2012, the North American Cystic Fibrosis Conference in Orlando in October 2012, Excellence in Paediatrics Conference in Madrid, in November 2012 and the "Here be lungs conference" in South Africa in March 2013.

Dr Ian Balfour-Lynn, paediatric respiratory consultant, presented an online course on oxygen therapy in May 2012 at the European Respiratory Society conference and gave a lecture at a joint conference of the Royal Society of Medicine and Ege University in Turkey in May 2012. He also spoke at the 18th International Paediatric Conference in Oman in November 2012 on: *"Management of complicated pneumonia"* and: *"Management of recurrent wheeze in pre-school children"*.

Professor Michael Polkey, consultant physician in respiratory medicine, led the COPD biomarker qualification group workshop, at the COPD Foundation in Bethesda, Maryland, in February 2013 and gave three lectures at the Gulf Thoracic Congress in March 2013 on COPD, sleep and weaning.

National and international appointments and awards

Professor Andrew Bush, professor of paediatric respirology and consultant paediatric chest physician, was made an honorary professor in the Department of Paediatrics and Child Health at the University of Cape Town for a period of five years in January 2013. In addition, he was appointed to the position of head of paediatrics at Imperial College London (ICL) in December 2012, effective from 1 April 2013. Academic paediatrics at ICL has a high profile both nationally and internationally and the appointment reflects the high esteem in which both Professor Bush and Royal Brompton's paediatric research programmes are held.

Professor Peter Barnes, head of respiratory medicine at Imperial College London and honorary consultant physician at Royal Brompton, was elected a master fellow of the American College of Chest Physicians, and president elect of the European Respiratory Society in 2012. Professor Barnes is an international authority in asthma and chronic obstructive pulmonary disease and is one of the most highly acclaimed respiratory scientists in the world.

Professor David Hansell, consultant radiologist, was appointed president of the Fleischner Society, an international, multidisciplinary medical society for thoracic radiology, dedicated to the diagnosis and treatment of diseases of the chest. He was also awarded the president's award and fellowship of the European Society of Thoracic Imaging.

Professor of cardiology, **Martin Cowie**, was appointed as NICE scientific adviser for cardiovascular interventions. Nominated by the British Cardiovascular Society, this prestigious role involves advising the Intervention Procedures Advisory Committee (IPAC), which performs health technology assessments on new procedures. Professor Cowie also joined the national steering group for the Department of Health's "3millionlives" campaign in 2012, which is working to improve the use of telemedicine in the lives of three million patients.

Professor Kim Fox, consultant cardiologist, was named as the first Diana Princess of Wales chair in cardiovascular medicine and science. The establishment of this new role is in association with the Magdi Yacoub Institute and has been approved by Her Majesty The Queen.

Respiratory consultant, **Dr Andrew Menzies-Gow**, was appointed chair of the National Institute of Clinical Excellent (NICE) guideline development group for asthma: diagnosis and monitoring. He is a member of the Respiratory Clinical Reference Group for specialist commissioning and leading on commissioning of severe asthma services across England. He is also a member of the British Thoracic Society asthma standards and advisory group and a founding member of the British Thoracic Society severe asthma network, which publishes regularly on severe asthma.

Professors Margaret Hodson and **Duncan Geddes** were named in the Queen's Birthday Honours List in 2012. Professor Hodson, consultant physician and director of medical education at Royal Brompton, professor of respiratory medicine at Imperial College London and a senior research investigator at the National Heart and Lung Institute (NHLI), received her OBE for services to respiratory medicine. Professor Duncan Geddes, retired consultant physician at Royal Brompton, professor in respiratory medicine at the NHLI and honorary consultant at The Royal Marsden Hospital, received a CBE for services to medical research, charity and education.

For more information, visit **rbht.nhs.uk/consultants**


Adam Rouilly

World-class research

Royal Brompton & Harefield NHS Foundation Trust is the leading NHS centre for cardiorespiratory research and has an internationally renowned reputation for innovation and research.

During the first year of the Trust's 2012-2015 research strategy, significant progress was made towards its targets including:

£3.6m of new research grant funding secured from European and UK funders.

7 NIHR Senior Investigators. These prestigious awards are made to only the top 200 clinical academics across UK institutions.

Over 3,500 patients recruited into 200 clinical research studies.

Over 1,450 patients donated tissue samples to the Trust's biobanks.

313 research publications in leading journals from Trust consultants.

Vital support from the National Institute for Health Research (NIHR)

Our research was given a significant boost by the start of two five-year programmes of translational research (findings in basic research are translated quickly into medical practice and meaningful health outcomes) through our biomedical research units (BRUs), which are funded by the NIHR. Funding from the NIHR enables our best health researchers and clinicians to continue pioneering research into some of the most complex heart and lung conditions affecting patients around the world. Our respiratory BRU incorporates clinical research facilities for adult inpatient and adult and paediatric outpatient trials and our cardiovascular BRU incorporates state-of-the-art facilities for cardiac imaging, interventional cardiology and genetics.

To accelerate their research programmes, 11 new clinical research fellows have been recruited to the BRUs to deliver a range of projects to develop and evaluate new treatments and diagnostics for Trust patients.

Recognition for research leaders

In March 2013, Professor David Hansell, consultant radiologist, was appointed to the NIHR Senior Investigator faculty, which recognises the UK's most outstanding leaders of clinical and applied health research.

This appointment recognises Professor Hansell's continued contribution to the development of high-resolution computed tomography (HRCT) imaging, which is a test used for the diagnosis of patients with respiratory disease. He has been involved in numerous clinical trials, including a recently completed NIHR-funded lung cancer screening pilot study and his research has been instrumental in establishing HRCT in routine clinical practice for the diagnosis of interstitial lung disease (ILD). ILD is a term used for more than 200 lung diseases that affect the tissue and space around air sacs in the lung.

Professor Hansell joins other Trust researchers who are amongst the 200 NIHR Senior Investigators in the UK. They are professors Dudley Pennell, Kim Fox and Carlo Di Mario (cardiovascular medicine), and Peter Barnes, Kian Fan Chung, and Andrew Bush (respiratory medicine).

Novel devices for heart failure treatment

Cardiovascular BRU clinical research fellow, Dr Andrew Morley-Smith, has already been awarded a prestigious three-year clinical research training fellowship from the British Heart Foundation for his PhD project: *"Partial left ventricular support in advanced heart failure".* Dr Morley-Smith will study a new heart pump (the "Synergy"), which gives patients who have severe heart failures, partial support for their heart muscle. The study will assess the degree of muscle remodelling, functionality and repair associated with the device implantation.

11 new clinical research fellows have been recruited to our BRUs

A cross-site research team from heart failure and transplantation has been assembled to undertake the research including Mr André Simon, Dr Alexander Lyon and Dr Nick Banner. Professor John Pepper, Dr Morley-Smith's primary supervisor, commented: "This is an extremely exciting award, and we hope our work can galvanise the case for long-term mechanical support with less invasive pumps such as the Synergy. Harefield is the only centre in the UK implanting this pump, and it's terrific that we can use this position to pioneer new strategies for patients with heart failure."

Cardiac genetics research paves way for new diagnostic service

Experts in the cardiovascular BRU are leading a pioneering research programme in inherited cardiac conditions (ICC), which takes advantage of cutting-edge, high-speed DNA technology and which could, in the future, revolutionise the diagnosis and treatment of heart disease. In 2012, the BRU genetics group, led by Professor Stuart Cook, and in collaboration with groups at Harvard Medical School in the United States and University of Trieste in Italy, published a groundbreaking paper in the international journal, the *New England Journal of Medicine*. The paper identified mutations in the Titin gene in patients with inherited dilated cardiomyopathy (DCM) and suggested this could account for up to 25 per cent of patients with the condition. DCM is one of the leading causes of heart failure, affecting more than 30,000 people in the UK.

Building on the Titin breakthrough and the identification of around 200 other genes involved in heart disease, Professor Cook, Professor Dudley Pennell and colleagues at Royal Brompton Hospital have secured a £1.2m grant from the Health Innovation Challenge Fund. Awarded jointly by the Department of Health and the Wellcome Trust, this grant aims to enable researchers to translate their findings, over a four-year period, into a diagnostic test for routine clinical use in the NHS and beyond. This research will underpin development of a new clinical genetics service being planned at the Trust.

This research into the identification and diagnosis of the genetic effects in ICCs pave the way for new treatments in the future. Professor Cook commented: "In the longer term, our aim is not only to be able to diagnose patients early, but to go on and develop targeted therapies that correct genetic defects, thus providing effective, individual treatment plans for affected patients."

Cardiac imaging research praised by Minister

In March 2013, Professor Dudley Pennell and Dr Sanjay Prasad published a paper in the prestigious medical journal, *Journal of the American Medical Association* (JAMA) showing that scarring of the heart is an accurate predictor for sudden cardiac death among patients with dilated cardiomyopathy (DCM).

Many patients with DCM are fitted with an implantable cardioverter defibrillator (ICD) to prevent death from

"Our findings fill an important and significant gap in clinical knowledge about treating dilated cardiomyopathy."

Dr Sanjay Prasad
Consultant cardiologist

abnormal heart rhythms. However, this is an expensive form of treatment, with unpredictable results. The paper reported findings from more than 470 patients over eight years.

Professor Pennell, cardiologist at Royal Brompton and director of the BRU, said: "Implantable defibrillators don't work for all patients. Our findings mean we can improve the selection of patients suitable for ICDs – saving lives, and saving £2.5million per year for the NHS."

Dr Prasad, consultant cardiologist, and lead author on the JAMA paper, said: "Our findings fill an important and significant gap in clinical knowledge about treating dilated cardiomyopathy. In the past, it has been challenging to determine in advance which patients would benefit most from a defibrillator – now we know that a cardiac magnetic resonance scan to look for the presence of fibrosis can provide essential information for determining effective treatment."

Lord Howe, Parliamentary Under-Secretary of State for Health, praised the findings saying: "We want our patients to have access to the most effective treatments possible, especially if that treatment could help to save their lives. Research like this is incredibly important and I'm delighted we could support the work of clinicians at Royal Brompton Hospital through the National Institute for Health Research."

Study shows ablation benefit for patients

A team of cardiologists at the Trust has led a successful randomised study of over 50 patients with heart failure and persistent atrial fibrillation (AF), the most common type of irregular heart beat. The Trust is a leading centre in treating arrhythmia patients, with a large and expanding electrophysiology service.

The ARC-HF study, undertaken at both Royal Brompton and Harefield hospitals between April 2009 and June 2012, examined the role of catheter ablation, a type of minimally invasive treatment using radiofrequency energy to destroy the area causing the abnormal heart rhythm, in treating such patients.

The results were positive – 12 months after the ablation, patients saw improvement in exercise capacity and quality of life compared with the patients who had not had the treatment – and have been described as "very favourable" by *American College of Cardiology-CardioSource*.

Dr David Jones, locum consultant cardiologist and first author of the study, presented the trial results at a special session in November 2012 at the American Heart Association (AHA) Annual Scientific Sessions in Los Angeles, USA.

Dr Jones said: "Managing patients with atrial fibrillation and heart failure is challenging, but this study has shown – for the first time – a clear benefit of ablation therapy over standard tablet-based 'rate-control'."

"Managing patients with atrial fibrillation and heart failure is challenging, but this study has shown – for the first time – a clear benefit of ablation therapy over standard tablet-based 'rate-control'."

Dr David Jones
Locum consultant cardiologist

Dr Tom Wong was the senior investigator for the trial, with Trust co-investigators Dr Shouvik Haldar, Dr Rakesh Sharma, Dr Shelley Rahman Haley, Dr Wala Mattar, Professor Richard Underwood, Dr Wajid Hussain, and Dr Vias Markides.

The interstitial lung disease unit: a year of success

In 2012/13, researchers at the Trust secured £1.5 million of funding to undertake four research projects investigating disease causes, diagnosis and treatment of interstitial lung disease (ILD). Over 4,000 patients are under follow-up and the Trust's clinicians are very research active in this area.

During 2012, consultant respiratory physician, Dr Toby Maher, and his team were awarded funding for the first NIHR-funded multicentre trial for ILD. The study will assess whether the drug, rituximab, improves outcomes for patients suffering from connective tissue disease (an associated ILD) and will be the first large-scale clinical trial assessing the effectiveness of rituximab prescription at an early stage in ILD disease progression.

ILD research nurse, Anne-Marie Russell, was awarded a prestigious doctoral research fellowship from the NIHR for her PhD on the subject of idiopathic pulmonary fibrosis (IPF). Anne-Marie will be supervised by Dr Maher, Dr Sharon Fleming, head of research in nursing, and Paul Cullinan, professor in occupational and environmental respiratory disease. Professor Cullinan commented: "IPF is a chronic, rapidly progressive interstitial lung disease associated with debilitating symptoms. This study will engage patients with IPF to examine their perspective of living with the disease; identifying accurate descriptions of their symptom experience and developing a method to accurately record and assess their experiences".

Dr Elizabeth Renzoni, consultant in respiratory medicine, was also awarded two successful research grants in 2012/13. The first, given by the NIHR Research for Patient Benefit programme, will explore how portable oxygen affects the lives of patients with IPF. Breathlessness is a primary concern and symptom for IPF patients so improved treatment options in administering oxygen therapy are highly sought after. A second study, funded by the Raynauds and Scleroderma Association, looks at scleroderma, a chronic autoimmune disorder that can affect the skin and connective tissue in organs such as the lungs. The study will investigate the role of gastroesophageal reflux, where stomach contents leak back from the stomach and into the oesophagus in scleroderma patients, a symptom that can cause significant discomfort and distress.

Professor Athol Wells, head of the ILD unit, commented: "It would not be possible to conduct such important research without the support of patients and clinical staff. In working together, we are committed to improving the lives of our patients, their disease management and the care provided in both the hospital and at home."

Anne-Marie Russell was awarded a prestigious doctoral research fellowship from the NIHR for her PhD on the subject of idiopathic pulmonary fibrosis (IPF).

European research into paediatric respiratory conditions

In December 2012, the European Commission announced that it would provide €6 million to support two major collaborative research projects involving Trust researchers in addressing rare paediatric respiratory disease.

The Better Experimental Screening and Treatment for Primary Ciliary Dyskinesia (BESTCilia) team at the Trust will be led by Dr Claire Hogg, paediatric respiratory consultant, and Andrew Bush, professor of paediatric respirology.

Primary ciliary dyskinesia (PCD) is a genetic disorder of the structure and / or function of the cilia, which are the tiny microscopic moving structures lining the airways, ears, sinuses and some other structures. The sweeping, wave-like motion of cilia is important for keeping these areas clean and free from infection. Without properly functioning cilia, people with PCD are unable to protect their respiratory system.

The disease is very complex as several other organ systems, such as the heart, can be affected. This means that there is currently a significant need for research to better understand and manage the disease. BESTCilia is the largest international research programme focused on PCD, and researchers will investigate the patterns and causes of the disease as well as the clinical progression and evaluate new treatments for the condition.

Professor Bush is leading a second collaboration for childhood interstitial lung diseases (chILD), which involves academic partners from five European countries. chILDs are very diverse with more than 200 diagnostic possibilities. Unfortunately, the complexity faced in diagnosis and a lack of medical awareness of the diseases means many cases are undiagnosed and can lead to significant stress for families.

This project brings together international panels of clinicians, radiologists, including Trust researcher Professor David Hansell, geneticists and pathologists, including Professor Andrew Nicholson, to create a pan-European database and biobank. The panels will determine the long-term clinical course for chILD and optimise diagnosis as well as effective treatment strategies.

Researchers will systematically assess outcomes and treatments for chILD patients so they can develop better diagnostic tools and treatment to help lead to an improved quality of life.

For more information, visit **rbht.nhs.uk/research**

The Better Experimental Screening and Treatment for Primary Ciliary Dyskinesia (BESTCilia) team at the Trust will be led by Dr Claire Hogg, paediatric respiratory consultant, and Professor Bush.

Support services

State-of-the-art clinical support systems make a vital contribution to our cardiovascular and respiratory teams, offering a one-stop, on-site service uncommon in UK hospitals.

State-of-the-art ICUs

As a tertiary centre offering highly specialised surgery and expert care for patients with complex respiratory and cardiac illnesses, intensive care facilities at the Trust have to be of the highest standard.

Our state-of-the-art ICUs are fully equipped and staffed 24 hours a day by our specialist medical staff. The expertise of these units is recognised throughout Europe.

The Trust has 36 adult ICU beds. They are staffed on a 1:1 ratio by a complement of more than 200 experienced ICU nurses. The units are run by expert intensivists, supported by a comprehensive team of therapists with specific interests in the care and rehabilitation of patients with heart and lung illnesses. The Trust is one of a very small number of units to have its own professor of intensive care medicine. High-dependency beds, suitable for patients who require some organ-specific support, are also available across the two hospitals.

The Trust also has 16 paediatric intensive care beds at Royal Brompton Hospital.

Advanced imaging on site

The work of our clinicians is supported on site by internationally renowned diagnostic and research imaging services.

The Trust has a track record of significant investment in imaging technology, which can mean that a diagnosis is made without the need for invasive procedures.

Both Harefield and Royal Brompton have new mobile digital X-ray machines that can display the X-ray seconds after it has been taken. These have proved very useful, particularly for the intensive care units on both sites.

Cardiac CT scanning is now a large part of the work on both sites, and the Trust is a leader in developments in this field, training radiographers throughout the NHS.

Over 15,000 echos were performed last year at Royal Brompton and nearly 13,000 at Harefield.

At Harefield, the mobile MRI unit for cardiac and thoracic MRIs has increased its capacity. When the mobile unit was commissioned in June 2010, it was used for cases one day each week, but now clinicians use the unit five days a week. A new consultant cardiologist and superintendent radiographer have been recruited to oversee this work.

The cardiovascular BRU at Royal Brompton contains the latest world-class imaging equipment, including an interventional 3T cardiovascular magnetic resonance (CMR) scanner positioned next to an interventional catheter laboratory. This allows high-resolution CMR images of patients undergoing interventional procedures, using radio waves instead of potentially harmful X-rays. This year has seen a steady increase in research projects being undertaken in this area.

Echocardiography
The Trust's consultant-led echocardiography service enables patients with suspected or known heart abnormalities to gain swift access to an extensive range of echo tests leading to quicker diagnosis and treatment.

Over 15,000 echos were performed last year at Royal Brompton and nearly 13,000 at Harefield.

Nuclear medicine
The nuclear medicine department comprises a multidisciplinary team including doctors, nurses, radiographers, technicians, physicists and administrators. Patients can benefit from a wide range of radionuclide tests, all of which can be done on an outpatient basis.

At Harefield, a new SPECT CT gamma camera was installed in January 2013. This means the team can take non-cardiac referrals from other hospitals and enables our experts to undertake more complex diagnostic tests.

Laboratory medicine

Our laboratory medicine teams provide an expert service that supports the specific requirements of a trust specialising in heart and lung diseases, including clinical biochemistry, haematology and blood transfusion, microbiology, histopathology, cytology, phlebotomy, and a full autopsy service.

Our laboratory medicine teams provide an expert service that supports the specific requirements of a trust specialising in heart and lung diseases.

Our services include:

Clinical biochemistry
The service offers support on a 24/7 basis for the acute work of the specialist respiratory and cardiac unit, with particular involvement in the diagnosis and monitoring of cystic fibrosis, pulmonary hypertension and cardiac failure and investigation of allergy.

Haematology and blood transfusion
The team provides diagnostic and therapeutic support for our patients, with particular emphasis on bleeding and thrombotic disorders. A specialist anticoagulant service (preventing blood clotting) is provided, including support for self-monitoring patients and those on newer oral anticoagulants. The department is active in research in the fields of haemostasis (preventing excessive blood loss) and blood transfusion.

Microbiology
The microbiology service supports all clinical specialities within the Trust. It offers routine microbiology and fungal culture services and molecular diagnostics for a range of pathogens. Microbiology also offers specialist mycobacterial identification and sensitivity testing and specialised cystic fibrosis bacteriology.

A new and improved containment level 3 TB lab was opened in March 2013 at Royal Brompton. The new laboratory has specialist facilities, equipment and improved security measures have been installed.

Surgical reporting service
The Trust specialises in the diagnosis of tumour and interstitial lung diseases, heart and lung transplant rejection, vascular and cardiac disease using light microscopy, immunocytochemistry and molecular biology.

Biopsy service
The Trust operates a same-day, on-call biopsy service.

Cytology
The service offers assessment of sputum, urine, fine-needle aspirates, pericardial / pleural effusions and bronchioalveolar lavage specimens.

Immunocytochemistry
We utilise a wide range of antibodies in the diagnosis of carcinomas, lymphocyte markers, epithelial markers, mesotheliomas, germ cell tumours, sarcomas and neuroendocrine markers.

Rehabilitation and therapies

The rehabilitation and therapies (R&T) unit consists of the following services: physiotherapy, occupational therapy, speech and language therapy, nutrition and dietetics, psychiatry, adult psychology, social work and welfare rights, chaplaincy and palliative care.

The R&T staff are experts in their fields and many train undergraduate students, lecture externally, run specialist courses, including MSc modules, and are accredited instructors.

Following a departmental reorganisation in 2011, specific paediatric and adult therapy teams were developed, including a cystic fibrosis therapy team and a transplant therapy team. This has resulted in a more collaborative way of working between the teams and clinical staff on the wards.

At Royal Brompton the UK's first integrated adult early critical care rehabilitation service was launched in 2012, providing specialist complex rehabilitation across all therapies – physiotherapy, dietetics, speech and language therapy and occupational therapy.

Complex discharge
Both hospitals have dedicated complex discharge teams consisting of specialist professionals from a range of backgrounds including nursing, social work and welfare rights. This ensures there is comprehensive knowledge of all aspects of discharge planning, NHS continuing healthcare, social services and the welfare and benefits system. The team also provides Trust leads for safeguarding vulnerable adults and a lead for older people.

A new part-time welfare rights post has been developed at Harefield, funded by the charity, Macmillan Cancer Support. This means patients with cancer have additional support and information about benefits.

Palliative care services
Macmillan Cancer Support has also funded a new lead palliative care nurse providing enhanced support for Harefield lung cancer patients and their families.

Our charity

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

The Trust has big plans for the future and to raise the significant sums needed to realise these ambitions, the charity took on a new identity and became independent of the NHS in April 2012. A board of trustees was formed, under the chairmanship of Richard Hunting CBE, and in July, Gill Raikes MBE joined as chief executive.

Gill comments: "The last year has been an incredibly exciting time for the charity with new staff, a new head office in Chelsea, a new strategy and a re-launched brand and website.

"However, old favourites have remained such as the Harefield Fun Run, which once again raised a large sum of money for the Harefield MRI Scanner Appeal, and the donor and supporter trees at both hospitals, which provide patients and families with a way to express their thanks for the care they have received.

"The charity has received gifts from very generous donors without whom we would not have been able to provide as many grants to the hospitals.

Highlights of our year

The MRI Scanner Appeal for Harefield reached its £1.5 million target this year, thanks in no small part to a £200,000 donation from heart patient, Mr David Render.

The charity funded the new paediatric sleep centre at Royal Brompton, which was opened in November 2012 by Greg Hands MP. This new centre will ensure children who are having a sleep study at the hospital will have a more comfortable experience in a purpose-built environment.

rb&hArts continued to be a major focus for the charity, along with grants for patient welfare and bursaries.

Our thanks go to them and to the staff and committed volunteers who put so much time and effort into raising money for us."

Special thanks go to:

- Garfield Weston Foundation for rb&hArts
- The Asmarley Charitable Trust
- Simone Cowland Trust for supporting the cystic fibrosis nurses
- Point Hope for supporting the thoracic surgery fund
- Lee Rosenthal Memorial Trust & Robert Luff Foundation for supporting the CF endowment
- Miles Commercial and Laithwaites Wines for their sponsorship of the Somerset House launch
- Crescent Building Supplies for their support of the Harefield Fun Run
- Team Ross, a group of family and friends who have been fundraising for the last eight years in memory of Ross Tavendale, who was cared for at Harefield. Their support means we can build a beautiful new conservatory for transplant patients

For more information, visit **rbhcharity.org**

The charity awarded a grant of £2.7 million for medical equipment and £80k for a laboratory for simulation training so that real-life critical scenarios can be replicated, giving our clinicians a unique opportunity to develop their knowledge and skills.

The innovative Royal Brompton Centre for Sleep was opened in March 2013 by Professor Sir Mervyn King, former governor of the Bank of England, following a £2.3 million charity donation.

The charity launched a major two-year capital appeal to raise £4.5 million to build a new state-of-the-art hybrid operating theatre at Royal Brompton. The launch took place at a spectacular event at Somerset House in March 2013.

rb&hArts

rb&hArts, the Trust's charitable arts programme, entered its tenth year with a new arts strategy for 2013–15. One central theme is collaboration with institutions and individuals – building on old relationships and developing new ones.

rb&hArts brings visual and performing arts to both hospitals to ensure patients and their families are cared for in a stimulating, supportive environment. The arts play an extremely important role in the treatment and ultimate recovery of our patients.

Music therapy comes to Royal Brompton

This year Nordoff Robbins again brought students from the internationally renowned Brit School to Royal Brompton Hospital for the summer, to perform and to learn about music in hospital settings. Trainee music therapist, Ellie Walker, spent a year at Royal Brompton as a Nordoff Robbins music therapy trainee (co-managed by rb&hArts and the Trust's rehabilitation and therapies team). She explored the possibilities for group workshops and one-to-one sessions in both the respiratory and cardiac wards.

Her own evaluation of the work demonstrated that over 82 per cent of inpatients noticed an improvement in their mood. Typical comments included: "as a patient in hospital I found it enjoyable and relaxing", "something to take my mind off illness and treatment", and that it was "very enjoyable interacting with the other patients in the ward". A new trainee, Laura Borrows, has been building on Ellie's excellent work since January 2013.

For more information, visit **rbht.nhs.uk/arts**

Art exhibitions

The first London Creativity & Wellbeing Week was held in June 2012. rb&hArts staged a number of events amongst hundreds across the capital – one of which, Creative Future's mini-gallery "Tight Modern", also represented a new interest in "outsider art" – work made by artists practising outside the mainstream. There are plans to host another outsider show in June 2013 when Pallant House's "Outside In" project comes to Royal Brompton Hospital. There has also been work to establish relationships with local art groups and colleges – the first of whom, Hillingdon Artists, showed their work at Harefield Hospital in 2012.

Many of the artists who work with rb&hArts have generously lent or given work to the Trust this year. Charlotte Lyon created her second exhibition for us – a fantastic series of paintings focused on Harefield's staff *(below)*, now on long-term loan to Harefield Hospital. Community and public artist, Bhajan Hunjan, staged an exhibition of her paintings, also now on long-term loan. Bhajan is creating new works of art for Victoria Ward based on print workshops with patients and staff, due for installation in summer 2013. We are also extremely grateful to Michael Woods and Dilys Stinson for donating substantial bodies of work.

Artwork for new sleep centres

This year, rb&hArts has been heavily involved in the creation of artwork for both the paediatric and adult sleep centres, which opened this year. Jill Calder created a stunning series of illustrations for the children's sleep and ventilation unit, based on workshops with children who use the hospitals regularly. The workshops were co-run with Fire Poet, Philip Wells, and children created small books full of poems and drawings, which set the themes for Jill's work. The work now covers the ceilings and walls of the unit.

rb&hArts was involved at the very beginning of the design of the new Royal Brompton Centre for Sleep (for adults) so the artwork there has been fully integrated into the look and feel of the new centre. Renowned artist and *Guardian* cartoonist, Steven Appleby, has created an astonishing series of over 50 works, including Map of Visible Dreams, a 3.5m-tall glass screen, for its main reception. Steven worked with the project team and staff in the unit for a year, developing an understanding of their highly specialised work and sharing his own ideas. The project's patient representative, Jayne Bullock, also worked closely with Steven and rb&hArts, and she interviewed Steven about his work for the book, *Into Sleep*, published to celebrate the new installations.

Music performances

Performance highlights included a visit by world-famous violinist, Midori – thanks to the Wigmore Hall's outreach programme – and a Christmas collaboration between the Roundhouse Choir and our own Singing for Breathing choirs.

The year ended on a high, with Firefly Burning's three-month residency culminating in a performance of the songs they had written with patients in the adult surgical unit on the theme of "Imagined Landscapes." One parent said: "What a fantastic thing to do within the hospital environment. My daughter went from lying in pain to participating and enjoying the experience", and others found the process "very relaxing, touching and extremely enjoyable" and told us that "they involved us totally – an inclusive experience that raised my mood".

Thanks to the ongoing support of Royal Brompton & Harefield Hospitals Charity and our other donors, rb&hArts has big plans for the next three years, and hopes to cement its position as a leader in this field with an exciting new programme of participatory work and research – from music in intensive treatment areas to substantial new commissions for a number of clinical areas.

Improving the patient experience

The Trust's reputation relies on consistently providing excellent quality care and services to our patients. Our staff are committed to ensuring patients receive the best possible specialist treatment for their heart and lung condition in a clean, safe place.

Care for inpatients

The Trust participated in the 2012 Care Quality Commission National Inpatient Survey and performed well.

Comparing our results with the previous year's survey we have improved our scores overall, with a higher percentage of questions scored in the "best performing trust" category.

We achieved a score of "better", which means that we performed above the national average when compared with other trusts, for key questions including:

- Did you have confidence and trust in the doctors treating you?
- When you had important questions to ask a nurse, did you get answers that you could understand?
- How much information about your condition or treatment was given to you?
- Did you receive copies of letters sent between hospital doctors and your family GP?
- Overall, how would you rate the care you received?
- Were you offered a choice of food?

In one question: "Afterwards, did a member of staff explain how the operation or procedure had gone?" the Trust achieved the highest score of all trusts.

Highly specialised services survey: heart and lung transplant

In 2012, we participated for the first time in a national survey in relation to our transplant services at Harefield. Our results were compared with the other six trusts that perform cardiothoracic transplants and we performed extremely well, particularly in the following areas:

- Patients being given enough information about their condition or treatment.
- Family members being given opportunities to talk to a doctor.
- Family members being offered advice about overnight accommodation by hospital staff.

Lung cancer care

MHP Health Mandate published an independent report in March 2013 titled, "Quality at a glance – using aggregate measures to assess the quality of NHS hospitals".

While specialist trusts such as ours were not included in the overall tables, tertiary lung cancer providers' scores on key measures were detailed and our hospitals performed extremely well.

Lung cancer care at the Trust was rated as "good" or "excellent" by 89 per cent of people and 95 per cent reported having the care of a specialist cancer nurse during their treatment (the second highest in the country).

Patient feedback

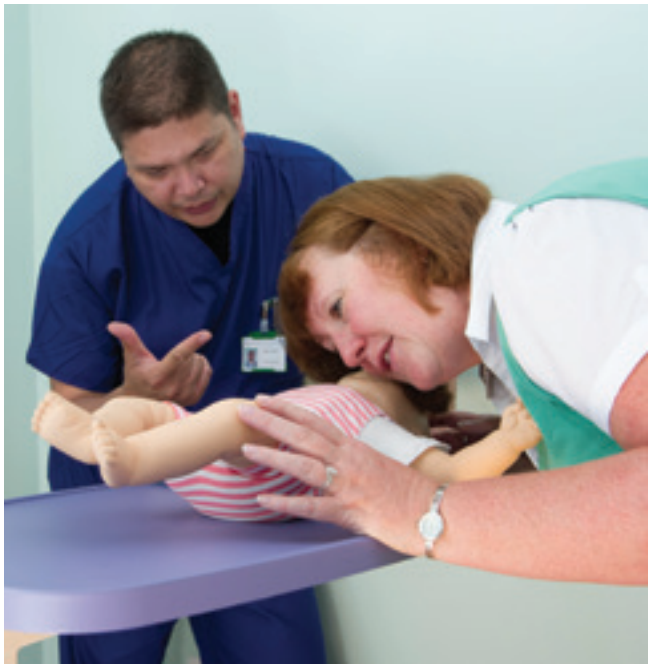
Comment forms were introduced in 2007, giving inpatients the opportunity to comment on their experience of using the Trust's hospital services once they are discharged.

We receive many positive comments from our patients with over 95 per cent of patients rating the care they have received as "excellent".

Patient comments are displayed in relevant areas to let staff know where they are doing well and any improvements that can be made. Feedback is acted upon where possible.

Involving our patients

Many of our clinical nurse specialists (CNSs) involve patients / carers and staff in improving services. For example, through annual patient open days, support groups and forums.



"The level of care was outstanding from stepping through the main reception until discharge. Skilled, friendly and respectful nursing / medical staff and information given regularly throughout stay."

"Overall I found the care most impressive. It has given me a sense of positiveness about the National Health Service."

"Since my transplant I have received first class medical care from everyone who has treated me, from doctors to nurses who were on the ward."

"I owe my life to the staff at the hospital and words can't express my gratitude to everyone at the hospital. Amazing, hard working, dedicated people."

"The VAD team at the hospital are amazing. I can't thank them enough for the support & care I have received from all of them."

"The best hospital I have ever stayed in. You are the best."

Some projects include:

Lung cancer services
At Royal Brompton, staff, patients and carers worked collaboratively to identify areas where service improvements could be made. Following the project, V-shaped pillows have been introduced to be used for post-operative patients, improving their comfort.

Cystic fibrosis – children
Older children are being taught how to administer their own medication so they feel more independent when they are at home. The paediatric and adult CF advanced nursing team are also working together to improve the transition of care for young people moving to the adult service.

Transplant
Patient forums allow patients to suggest improvements and one such change is that long-term patients, with a consultant's approval, are able to leave the ward and be escorted to the hospital restaurant. This has been made possible by the installation of a telemetry system that captures ECG recordings beyond the transplant unit doors.

For more information, visit **rbht.nhs.uk/ppi**

Our profile in the media

Reputation has many constituent parts, the most important of which is good quality care. For a Trust with an impressive record in delivering patient care, a strong and positive profile in the media can make a significant contribution to supporting a positive brand profile. The opportunity to reinforce our position as a centre of excellence with a sustainable future is extremely valuable.

The Trust is featured in many diverse publications and media outlets each year, reaching millions of people around the world. Here is a small selection of the coverage.

July 2012

BBC RADIO 4

Trust consultants, Dr Andrew Menzies-Gow and Dr James Hull, described and demonstrated to *Inside Health* presenter, Dr Mark Porter, the use of a new diagnostic test they have developed to detect exercise induced laryngeal obstruction (EILO). The technique has now finished its clinical trial period and has been approved for mainstream use. It has the potential to prevent thousands of UK patients with EILO being mistakenly diagnosed with asthma and receiving inappropriate treatment as a result.

August 2012

Daily Mail

Royal Brompton cardiologist, Dr Alex Lyon, has set up a new clinic to care for people with the newly recognised condition, takotsubo cardiomyopathy (broken heart syndrome), and to collect more data. He was interviewed for an article about his work and explained that broken heart syndrome is a temporary condition where the heart muscle becomes suddenly paralysed and the left ventricle, one of the heart's chambers, changes shape. The condition affects an estimated 3,000 people a year in the UK.

November 2012

BBC ONE THE Sun Daily Mail

Harefield patient, John McCafferty, celebrated 30 years since his heart transplant, making him the UK's longest surviving heart transplant recipient. His celebration party at Harefield transplant unit featured in national and local media. John and his original surgeon, Professor Sir Magdi Yacoub, were interviewed live on BBC breakfast television the following day.

November 2012

Daily Mail

Professor Peter Collins described cardiac syndrome X, a disorder that causes intense chest pain, where there is no obvious cause. A patient was interviewed and she described her care at Royal Brompton. She was referred to psychotherapist and clinical hypnotherapist, Daniel Fryer, who works with cardiac syndrome X patients at Royal Brompton, and was very successfully treated.

December 2012

The Daily Telegraph

André Simon, the Trust's director of transplantation, was interviewed about a new heart pump for patients with a variety of conditions and which, for some patients, could be used in place of heart transplants.

February 2013

itv 1

A documentary, *From the Heart: Tonight*, followed on from an earlier item in November on raising awareness of the organ donation register. The programme featured Harefield transplant patient, Will Pope, who had heart transplant surgery at Harefield on New Year's Eve 2012. The documentary was aired as part of a week-long ITV1 campaign aimed at raising awareness of organ donation. Will's mother, Rosie, was also interviewed on ITV's *This Morning* programme.

Children's heart surgery review

BBC NEWS SKY news

The Daily Telegraph

theguardian

October 2012

The review of children's heart surgery was covered extensively in the media throughout 2012/13. Trust clinicians, including director of children's services, Dr Duncan Macrae, were widely quoted when the Secretary of State for Health, Jeremy Hunt, announced that he had appointed the Independent Reconfiguration Panel (IRP) to reassess the decision to close children's heart surgery services at Royal Brompton Hospital.

June 2013

The topic was again the subject of widespread media coverage when the IRP published its report, finding the safe and sustainable review "flawed". Jeremy Hunt, then suspended the review. Dr Duncan Macrae was interviewed on Sky News, ITV London and BBC London news and BBC health correspondent, Fergus Walsh, did a live report from the children's ward at Royal Brompton on BBC national news.

For more information, visit **rbht.nhs.uk/media**

Social media

In recent years digital media has undergone a significant transformation, characterised by the emergence of self-publishing platforms (e.g. Blogger, Flickr, YouTube), social networking (e.g. Facebook, Twitter) and other technologies.

These new online platforms and technologies have led to greater user interaction, with audiences now expecting content to be presented in a variety of digital and social media.

A crucial difference between social and traditional media is that social media platforms offer the opportunity for an organisation to manage its own content – to become a content editor, thereby providing a significant opportunity to interact with its audiences directly, sharing important information and gaining feedback quickly and effectively.

One of the most popular platforms is Twitter – an online social networking and microblogging service that enables users to send and read text-based messages of up to 140 characters, known as "tweets". Twitter was created in 2006 and rapidly gained worldwide popularity, with over 500 million registered users as of 2012, generating over 340 million tweets daily.

The Trust joined Twitter in May 2010 and now has 1,937[1] followers (steadily rising) who regularly re-tweet to their followers – some have several hundred, some have thousands, a small number have over a million.

The Trust's Twitter programme is based around the themes of: sharing good news; engaging our patients, their families and our staff with our work; asking our followers for help; supporting partner and associate organisations and charities; and sharing important information for visitors and patients. Twitter can also provide the opportunity to respond quickly and directly to those patients and their families who may be dissatisfied with an aspect of the service they have received from us.

[1] As at 30 July 2013

A selection of typical tweets about the Trust:

"I have spoken to many patients during my visits to Brompton. All speak very highly of it. Even the hospital meals are great!"
Patient, March 2013

"Thank you to all the amazing people at Harefield! I now know why you have the reputation you do!! Incredible place"
Patient, October 2012

"So impressed with the care and attention of all the staff at @RBandH, other hospitals should take note"
Patient, September 2012

"@HannahLMitchell @thebhf @rbandh thank you for everything, running for a great cause, some really strong and lovely patients I met today x"
Amy Childs, March 2013

"On my way to open the new children's sleep centre at Royal Brompton Hospital @RBandH, funded by @RBHCharity. Will help 1,000 kids a year"
Greg Hands MP, November 2012

"Looking forward to continued partnership working with our neighbouring hospitals, the Royal Brompton (@RBandH) and @ royalmarsden"
Chelsea and Westminster NHS Foundation Trust, September 2012

Follow us on Twitter **@RBandH**

The Trust joined Twitter in May 2010 and has a following of almost **2,000**, who regularly tweet and "retweet" us

Governance

As a foundation trust we are governed by an elected council of governors and independently regulated by Monitor. We have around 10,000 members whom we regularly consult on Trust strategy and service planning.

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. This makes provision for the Trust to be supported by a membership drawn from three constituencies, a patient constituency, a public constituency and a staff constituency. The constitution also makes provision for a council of governors comprising both elected and appointed parties. The elected parties are drawn from the membership and the appointed parties represent key stakeholders. During 2012/13, the Trust was required to make some changes to the constitution in order to comply with the Health and Social Care Act 2012. This gave greater operational freedom and some additional responsibilities.

The governance structures comprise:

The council of governors, one of whose sub-committees, the nominations committee, considers the appointment of members of the Trust's board of directors.

Management of the foundation trust is conferred upon the Trust's board of directors.

Quality Account

High Quality Care for All (2008) proposed that all providers of NHS healthcare services should produce a Quality Account: an annual report to the public about the quality of services delivered. The Health Act 2009 made this a statutory requirement and in 2010 Quality Accounts were introduced. The Trust's report for 2012/13 is available on our website as well as on the NHS Choices website.

Our board members

Executive members

Mr Robert J Bell
Chief executive

Mr Robert Craig
Chief operating officer

Professor Timothy Evans
Medical director

Mr Richard Paterson
Associate chief executive – finance

Dr Caroline Shuldham
Director of nursing and clinical governance

Non-executive members

Sir Robert Finch
Chairman

Non-executive directors – full year

Mrs Jenny Hill

Mr Richard Hunting

Mr Neil Lerner

Ms Kate Owen

Non-executive directors – part year

Mrs Lesley-Anne Alexander

Mr Nicholas Coleman

Professor Sir Anthony Newman Taylor

Dr Andrew Vallance-Owen

Our council of governors

Public governors – full year
Mr Kenneth Appel – Bedfordshire and Hertfordshire

Mr Philip Dodd – North West London

Mr Brian Waylett – Rest of England and Wales

Public governors – part year
Mrs Caroline Greenhalgh – South of England

Mr John McCafferty – South of England

Patient and carer governors – full year
Mrs Sheila Cook – Elsewhere

Mr Peter Kircher – Bedfordshire and Hertfordshire

Dr Adrian Lepper – Representing patient carers

Patient and carer governors – part year
Mr Richard Baker – South of England

Mr Anthony Connerty – Bedfordshire and Hertfordshire

Mr Guthrie McKie – North West London

Mr John McKintosh – Elsewhere

Mrs Mary-Anne Parsons – Elsewhere

Mr Peter Rust* – North West London

Mr Edward Waite – South of England

*Sadly, Mr Peter Rust died in April 2013

Appointed governors
Councillor Mrs Victoria Borwick – London Borough of Kensington and Chelsea

Mr Ray Puddifoot – London Borough of Hillingdon

Professor Peter Rigby – University of London

Professor Michael Schneider – Imperial College London

Mrs Allison Seidlar – NHS Hillingdon

Staff governors – full year
Dr Ian Balfour-Lynn

Dr Olga Jones

Staff governors – part year
Ms Sue Callaghan

Professor Margaret Hodson

Ms Anne McDermott

Dr Andrew Morley-Smith

Ms Jennifer Sano

For more information, visit **rbht.nhs.uk/governors**

Summary **accounts**

Statement of comprehensive income for the year ended 31 March 2013

	Year to 31.03.13 £000	Year to 31.03.12 £000
Revenues from patient care activities	**282,495**	268,962
Other operating revenues	**34,363**	32,995
Operating expenses	**(306,568)**	(295,057)
Operating surplus	**10,290**	6,900
Investment income	**45**	33
Revaluation gain on investment properties	**-**	1,327
Finance costs	**(35)**	(46)
Unwinding of Discount	**(17)**	(20)
Surplus for the financial year	**10,283**	8,194
Dividends payable on Public Dividend Capital	**(6,192)**	(6,387)
Retained surplus for the year	**4,091**	1,807
Other comprehensive income		
Impairments	**(3,069)**	(1,356)
Revaluation Gain on Investment Properties	**-**	1,177
Total comprehensive income for the year	**1,022**	1,628

Statement of financial position as at 31 March 2013

	As at 31.03.13 £000	As at 31.03.12 £000
Non-current assests		
Property, plant and equipment	**183,465**	185,815
Investment properties	**27,155**	27,155
Total non-current assets	**210,620**	212,970
Current assets		
Inventories	**11,279**	9,974
Trade and other receivables	**20,365**	15,414
Cash and cash equivalents	**22,416**	22,598
Total current assets	**54,060**	47,986
Total assets	**264,680**	260,956
Current liabilities		
Trade and other payables	**(38,944)**	(34,921)
Borrowings	**(4,856)**	(5,251)
Provisions	**(1,781)**	(4,106)
Total current liabilities	**(45,581)**	(44,278)
Net current assets	**8,479**	3,708
Total assets less current liabilities	**219,099**	216,678
Non-current liabilities		
Borrowings	**-**	(62)
Provisions	**(2,446)**	(985)
Total non-current liabilities	**(2,446)**	(1,047)
Total assets employed	**216,653**	215,631
Financed by		
Taxpayers' equity		
Public dividend capital (PDC)	**104,759**	104,759
Retained earnings	**58,176**	54,085
Revaluation reserve	**53,718**	56,787
Total taxpayers' equity	**216,653**	215,631

Designed and produced
by Hornett Design
www.hornettdesign.co.uk

Photography by
Alex Orrow Photography
www.alexorrow.co.uk

This annual review is printed on Essential Offset

Essential Offset is manufactured by an ISO 14001 certified mill.
Sourced from fully sustainable managed forests of which
43% are certified forests (PEFC). The wood procured is certified
in accordance with the PEFC chain of custody. All wood and
wood fibre is documented with declarations from the mills suppliers.

Royal Brompton Hospital
Sydney Street
London
SW3 6NP

Tel +44 (0)20 7352 8121

Harefield Hospital
Hill End Road
Harefield
UB9 6JH

Tel +44 (0) 1895 82 37 37

rbht.nhs.uk

Follow us on Twitter @RBandH