Royal Brompton & Harefield NHS
NHS Foundation Trust

Annual Review 2011/12

Contents

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ذا كنت راغبا ً في الحصول على نسخة مترجمة باللغة العربية من هذا التقرير الرجاء
كتوريا جيتنيس(في فريق الأتصالات:)في الأتصال ب.

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

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Introduction from the chairman and chief executive

25 September 2012

It is with a great deal of pride that we present this annual review to you. It reflects a challenging but rewarding year and some important themes emerge within its pages.

Those not familiar with the Trust may be surprised by some of the language used to describe our services for patients. They will note, for example, that the occupational lung disease clinic at Royal Brompton is "the longest running specialist clinic of this kind in the world, and the largest in Europe," that the Trust is "the leading heart rhythm centre in the UK," that our experts "treat more children and adults with severe asthma than anywhere else in the country," that Royal Brompton's interstitial lung disease unit is "the largest unit of its kind in Europe," and that Harefield is home to the largest artificial heart programme in the country. They will also see that the Trust runs one of the largest and most respected adult congenital heart disease centres in the world, has "the largest paediatric cystic fibrosis clinic in Europe," is the only clinical centre in England hosting a groundbreaking cystic fibrosis gene therapy trial and hosts the only service in the UK dedicated to lung tumour ablation using radiofrequency, microwave and cryotherapy treatments.

While some may be uneasy about highlighting success so openly, as a specialist Trust it is difficult to provide even the most basic description of our services without straying into such language – superlatives to some, but everyday language to many of our specialist teams. It is our firm belief that the UK's specialist hospitals hold a unique place in the NHS, providing not only the best possible care, but also offering teaching and research opportunities nationally and internationally that serve to advance the direction of modern medicine. We are immensely proud to be one of them.

Specialist does not, however, mean elitist. Collaboration is a fundamental theme in modern healthcare and a truly integrated system involves close working with various partners. For our Trust this means clinical and research alliances with teaching hospitals, district general hospitals, community outreach services, general practitioners, academic institutions and others.

A related theme that has become particularly salient to us this year is the importance of the team approach in the modern health service. It is an interesting exercise to trace the many professionals involved in every single patient experience of our hospitals.

In our hospitals patients experience a journey that involves the expertise of nursing staff, medical staff, support and managerial staff, laboratory teams, allied health professionals (such as dietitians and physiotherapists), theatres and recovery staff (such as theatre nurses and perfusionists), intensive care and high dependency teams, imaging teams, pharmacists, and follow-up community teams. It can take many years to build successful teams and to design processes around them to ensure effective joint working across clinical disciplines. Adversely affecting one team can have serious consequences for others, as a chain reaction of damage spreads quickly and perniciously throughout the organisation.

It is this potential for damage to the seamless care delivered to our patients, from babies in the womb to their grandparents and great-grandparents, that lies behind our struggle to protect the Trust's children's congenital heart unit. It is an issue that remains very much at the forefront of our plans for the coming year. We are committed to maintaining and strengthening our position as an integrated health delivery organisation, collaborating with general hospitals, specialists centres, community organisations and general practitioners to seamlessly treat heart and lung disease patients across the full age spectrum. We expect very much to see a collaborative solution emerge from our continuing discussions, one that will protect and benefit vulnerable young patients across the country.

We hope you find this review both interesting and helpful. By combining the complex biomedical science and developments in medical technology that help to advance our specialist care, with the everyday experiences of our patients, we seek to present a true reflection of the extremely valuable work undertaken by our talented and dedicated staff.

Sir Robert Finch, chairman

Mr Robert Bell, chief executive

Trust mission, values and approach

Our mission

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

We will achieve this mission by 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.

Trust 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.

About us: a team approach

Working together in Harefield's high dependency unit

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 patients come from all over the UK and internationally, not just from our local areas.

We help patients of all ages who have heart and lung problems. Our care extends from the womb, through childhood, adolescence and into adulthood. Our foetal cardiologists can perform scans at just 12 weeks, when a baby's heart valve is just over a millimetre in size, and our clinical teams regularly treat patients well into their nineties.

One of the reasons for our success is our teamwork. Our internationally acclaimed multidisciplinary clinical and research teams have become established over many years and they work together throughout the Trust to deliver seamless, co-ordinated, specialist care to every patient.

From the moment they arrive, our patients become part of a community of people who have benefited from more than 160 years of expert diagnosis, treatment and long-term care. Each member of staff is dedicated to patient care, from the very first contact a patient has with us to follow-up care at home or in the community.

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

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.

"The quality of care and the quality of the staff are surperb. Everyone works like a big team where nurses, surgeons, outreach nurses and the most senior consultants work closely together."

Performance and achievements in 2011/12

During 2011/12, our experts:

- Cared for 693 adult patients with cystic fibrosis and 362 children with the disease
- Helped over 8,200 adults with breathing problems caused by diseases such as chronic obstructive pulmonary disease (COPD) and bronchitis
- Treated people with asthma over 2,700 times in outpatient clinics and 2,500 times as inpatients
- Achieved some of the lowest rates of MRSA and clostridium difficile in England
- Met and exceeded the national target for the 18-week wait in all months
- Admitted 423 paediatric heart surgery patients
- Carried out over 143,000 outpatient appointments and supervised over 30,000 inpatient stays
- Undertook 13,400 outpatient appointments for children
- Achieved high patient satisfaction scores in the 2011 adult inpatient survey
- Received "excellent" ratings for food and privacy and dignity in PEAT assessment
- Entered 2,000 patient samples in the Trust's genetic biobank – these are essential tools to help aid research into diseases of the heart and lungs, and ultimately improve treatment for patients

- Achieved all of the Commissioning for Quality and Innovation (CQUIN) measures – one of only two acute Trusts in London to do so
- Introduced a new treatment for atrial fibrillation using robotic ablation
- Appointed the first consultant pharmacist for cardiothoracic transplant services in the UK
- Performed 184 VAD (artificial heart) procedures – Harefield has the UK's largest VAD service
- Helped 4,452 patients with lung cancer
- Performed over 700 thoracic aortic operations
- Performed almost 30,000 echocardiograms
- Hosted over 2,300 patient visits in our biomedical research units
- Performed almost 11,000 nuclear medicine examinations

Caring for the heart

Clinical teams at Royal Brompton and Harefield hospitals care for patients with a wide range of complex cardiac conditions, both congenital (present at birth), inherited and acquired. 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 artery disease); structural heart disease; and heart assessment.

Vital facilities support complex electrophysiology work

Royal Brompton and Harefield hospitals are UK leaders in treating arrhythmia patients, with the support of a large and expanding electrophysiology (EP) service.

Heart rhythm problems are a common reason for admission to hospital and are becoming increasingly frequent. They are particularly common in people who already have heart problems, including congenital heart disease and heart failure.

To support the expansion of the arrhythmia programme, a fourth catheter lab opened at Harefield in September 2011, equipped for state-of-the-art electrophysiology procedures. This enables our specialists to treat challenging arrhythmia conditions that cause the heart to slow down too much, for whom a pacemaker may be fitted, or conditions that cause the heart to beat too quickly, which can often be cured with ablation. Ablation is a type of minimally-invasive treatment for arrhythmias, using radiofrequency energy and a catheter to destroy the area causing the abnormal heart rhythm.

State-of-the-art equipment

A major benefit of the new lab is a robotic system (Hansen) that enables clinicians to have more accurate and stable control of catheter movement, allowing more precise ablation. Clinical teams also benefit from the very latest versions of electro-anatomic mapping systems, which can create pictures of the way electrical activity spreads in the heart and map it when a problem has been identified. To complement this, the latest ultrasound and bi-plane X-ray imaging equipment provides the highest quality images of activity inside the heart. The X-ray systems in the cath lab can perform a mini-CT scan of the heart in seconds.

Dr Mark Mason, consultant cardiologist, explains: "From a clinical point of view, to have access to these state-of-the art facilities is vital. There are only a handful of Hansen robots in the country and as we do such complex work here it is imperative to have such advanced equipment."

Dr Wajid Hussain, consultant cardiologist, adds: "Ablation is becoming the preferred method of treating arrhythmias. We have special expertise in this area as we perform more ablations than anywhere else in the UK, dealing with ever more complex and difficult arrhythmias."

Minimally invasive heart surgery

Over the past decade, minimally invasive cardiac surgery (MICS) has grown in popularity. Heart surgeons operate between the ribs using small incisions in the right side of the patient's chest to gain access to the heart, rather than splitting the breastbone (sternum).

MICS is favoured by surgeons and patients because of reduced pain after the operation and faster healing times. This type of procedure also makes heart surgery possible for patients who were previously considered to be too high risk for traditional surgery due to age or medical history.

Mr Mohamed Amrani, senior consultant cardiac and transplant surgeon at Harefield, has helped to develop the latest techniques in minimally invasive coronary artery bypass surgery, where arteries or veins from elsewhere in the patient's body are grafted to the coronary arteries to improve the blood supply to the heart. This procedure is used to relieve angina, which is the term given to a cramp-like pain or heaviness felt mainly in the chest and left arm. It occurs when not enough blood is reaching the heart. The surgery is usually performed with the heart stopped but Mr Amrani performs this surgery on a beating heart – known as "off pump" surgery.

He has also developed techniques for minimally invasive aortic valve replacement, which also previously required open-heart surgery. This surgery is needed when a patient's aortic valve is failing and needs to be replaced by an artificial valve.

Mr Amrani has performed nearly 4,000 minimally invasive cardiac operations at Harefield in the past ten years and is one of the most experienced surgeons in the world in these techniques.

He said: "There is a clear advantage to minimally invasive surgery compared to conventional surgery in terms of pain, blood loss, scarring, length of stay and earlier recovery for the patient. Minimally invasive cardiac surgery is undergoing an evolution and I think this trend will continue. It is an exciting time and we have developed and adopted techniques at Harefield that have a proven benefit for many patients."

We received a "double excellent" score for patient environment

A family approach to diagnosis and treatment

An innovative joint children's, adolescent and adult cardiomyopathy clinic opened at Royal Brompton in March 2012. Patients from across the UK attend the clinic – some with a suspected risk because of problems in the family, and some to assess and manage conditions such as hypertrophic cardiomyopathy (HCM).

HCM is an inherited genetic flaw that causes the heart muscle to thicken, interfering with its ability to beat. The condition affects one in 500 people with some never having any symptoms, while others develop chest pain, dizziness or palpitations, which can be treated. However, a small minority suffer cardiac arrest without warning, which means that HCM is the biggest cause of sudden death in young people.

A traumatic birthday

Inderdeep Birk and her sons Maninder, 20, and Manvir, 11, have all been diagnosed with HCM.

The condition was first identified in Maninder, just as he turned 16, followed by Inderdeep a year later and then Manvir early in 2012.

Maninder's sixteenth birthday took a very serious turn when he first experienced symptoms and was rushed into West Middlesex University Hospital at midnight. "He had previously been fit and well and played rugby for his school," said his mother. "But that day, he felt unwell and went to bed early, only to wake a few hours later with chest pains. He didn't know what was happening."

At the hospital, Maninder had a series of tests including an X-ray, blood tests and an ECG (electrocardiogram) and the results, together with a history of heart problems in Inderdeep's family, made the doctors suspect cardiomyopathy. The following day he was transferred to Royal Brompton by ambulance.

Inderdeep said: "I was shocked at the speed that it all happened and Maninder was so scared, but the fact that he was being referred to a specialist heart hospital in London reassured us. I was very upset but the nurses and doctors were really kind and helpful and explained everything to us."

Maninder remembers: "It was very confusing and frightening, but the nurses and doctors who looked after me were very calm. Everyone was extremely helpful and treated me like I was a family member."

He stayed at Royal Brompton for a week while further tests were carried out to establish more about his condition and was placed under the care of Dr Sanjay Prasad, consultant in cardiology and cardiovascular magnetic resonance. Maninder now takes beta-blockers to regulate his heart rate and apart from having to give up rugby, is able to live a normal life.

He said: "My experience of Royal Brompton has always been good. The staff cared and listened and they made my time in hospital much less frightening."

(continued opposite)

Dr Piers Daubeney with a young patient in the cardiomyopathy clinic

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Dr Piers Daubeney and Dr Sanjay Prasad discuss a foetal echocardiogram

Screening the rest of the family

Royal Brompton's new cardiomopathy clinic, jointly led by Dr Prasad and Dr Piers Daubeney, consultant paediatric and foetal cardiologist, is unprecedented as all diagnostic tests for cardiomyopathy, as well as screening for all family members, can be completed in a single visit. The tests and consultations that previously took up to five visits are now completed on the same day.

The obvious benefit to patients is faster turnaround time and less stress, which all means a better experience. On the day of the appointment, a team of cardiac nurse specialists sees patients in the clinic throughout the morning, overseeing routine screening tests including electrocardiogram (ECG), echocardiogram (echo) and cardiac magnetic imaging. Dr Prasad and Dr Daubeney see patients in the afternoon to discuss the results and the nurses are on hand to answer questions and support patients through the results.

Following Maninder's diagnosis with HCM, Dr Prasad suggested that Inderdeep was tested for the condition. She said: "Although the idea gave me a shock initially, I agreed to the tests and it turned out that I have the condition too. It was so reassuring to see Dr Prasad as he already knew our family and I felt that I was in safe hands at Royal Brompton."

After more tests, it was agreed that Inderdeep should have a pacemaker fitted.

"It was a difficult time leading up to the operation, but I was very comforted by all the support I had from the hospital staff, including regular advice given by the nursing team over the phone."

The procedure was a success and she continues to be monitored by the specialist team at the Trust.

A unique approach

The Royal Brompton team also uses MRI scans and genetic testing to provide more detailed information. This is a unique approach.

Dr Prasad explains that these genetic tests address not just what is happening but why: "Because it is a familial condition, often patients suffer the dilemma of not knowing whether their children are affected. And the genetics allow us to take things to a higher level where we can reassure patients that, if they haven't got the gene abnormality, they should be leading a normal lifestyle."

In 2012, Inderdeep's younger son, Manvir, was also found to have HCM and he was referred to Dr Daubeney. He also required the care of Dr Jan Till, consultant in paediatric electrophysiology.

It was suspected that Manvir needed an ablation and this was confirmed by further ECG tests following a dizzy spell.

A team of three consultants, including Dr Till, carried out the procedure and Manvir stayed on the children's ward for two weeks. Inderdeep said: "The team even arranged for him to take maths and English SATs exams in hospital so he didn't fall behind at school."

She continued: "Although it has been a very distressing time for us as a family, with Manvir and I undergoing procedures, the whole team at Royal Brompton has been brilliant. We are very fortunate now to all see the same consultant, Dr Prasad, and know that we are getting the best possible treatment."

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Helping research

To help provide a better understanding of cardiomyopathy, Inderdeep has agreed that DNA samples from her family can be stored in the Trust's biobank. It is hoped that over time these samples will provide a better understanding of who is most at risk of developing the condition.

She said: "We hope that this research will help other families."

Life-saving skills

The cardiomyopathy team works closely with the channelopathy service, led by doctors from both paediatric and adult electrophysiology, including Dr Till, to support families of children diagnosed with cardiac channelopathies. These are a group of clinical syndromes, including HCM, which affect the cardiovascular electrical system and can mean that patients may be at risk of sudden cardiac arrest.

When a child is diagnosed with a heart condition that could cause a sudden cardiac arrest, the child's parents are taught basic life-saving skills by a team of nurses.

Dr Till said: "Many parents or carers find the CPR training that the channelopathy service offers invaluable. It can be very distressing for the whole family to know that their child has a condition that may cause them to have a sudden cardiac arrest, and being trained in CPR gives parents that reassurance to know what to do if they're ever faced with that situation."

Inderdeep and her husband, Balwinder, were both offered CPR (cardiopulmonary resuscitation) training at the clinic after Manvir was diagnosed with HCM. Inderdeep said: "We spent a morning at the clinic practising on a dummy and it has made us confident that, should an emergency arise, we would be able to deal with it."

Carers and family members receive CPR training

Families are also offered the support of a psychologist and receive follow-up care from a clinical nurse specialist who can help to set up portable defibrillators in the home in collaboration with the London Ambulance Service.

Inderdeep commented: "We are all continuing to do well and feel very lucky to be looked after by a fantastic team with an international reputation. We could not be in better hands."

It's all in the teamwork. The team that looks after the Birk family includes:

- *Consultants – paediatric and adult*
- *Specialist registrars*
- *Nurses and student nurses*
- *Ward manager*
- *Radiographers*
- *Phlebotomists*
- *Echocardiographers*
- *Cardiac physiologists*
- *Anaesthetists*
- *Reception staff at all departments*
- *Porters*
- *Catering staff*
- *Psychologists*
- *School team*
- *Cleaning staff*
- *Ward admission and office staff*
- *Clinical schedulers*
- *Healthcare assistants*
- *Medical secretaries*
- *Clinical nurse specialists*
- *Outpatient administrators*

Familial hypercholesterolaemia and lipoprotein apheresis

Harefield Hospital houses the largest lipoprotein apheresis unit in the country.

Lipoprotein apheresis is considered for those patients who, despite the maximum amount of drug treatment and a cholesterol lowering diet, still have a high level of LDL (low density lipoprotein) cholesterol. The problem affects an estimated 120,000 people in the UK and is usually caused by the inherited disorder, familial hypercholesterolaemia (FH). This condition increases the risk of life-threatening heart disease. Most patients with FH can be treated with diet and medication but a few will need LDL apheresis to control their cholesterol levels.

Dr Mahmoud Barbir, consultant cardiologist, heads up the unit and Alison Pottle, consultant nurse in cardiology, leads a team of six clinical nurse specialists in apheresis. The unit has five state-of-the art LDL apheresis machines that remove the harmful cholesterol from patients' blood. Patients come from as far afield as Devon, Suffolk and Kent for the specialist treatment which needs to be given weekly or every two weeks.

Dr Barbir explained: "We are fortunate to have a great multidisciplinary team on the unit including nursing staff, physiotherapists, doctors and technicians. As we see our patients every two weeks they are carefully monitored and we can directly refer them for clinical assessments or tests to colleagues within the cardiology department."

Dr Mahmoud Barbir, consultant cardiologist and head of the LDL aphersis unit at Harefield Hospital

"My experience has been very positive and I have been well looked after by the entire cardiac team. I have standing instructions from my clinic that if ever I have any questions about my care, I can call anytime and will be put through to a technician or, if necessary, a cardiologist, to discuss my concerns."

A new lease of life

Healthcare assistant Stephanie White has enjoyed a new lease of life since she began having regular apheresis treatment at Harefield 10 years ago. So impressed was she with the care she experienced, that she now works at the hospital!

Stephanie has familial hypercholesterolaemia. Before her treatment at Harefield began, she had suffered from angina caused by blocked arteries and had been so breathless that she could hardly walk.

Following a number of medical and genetic tests at Harefield, Dr Richard Grocott-Mason, consultant cardiologist, recommended a procedure to insert a stent to unblock her arteries and allow the blood to flow freely to her heart muscle. Heart by-pass surgery was needed as well as a second stent.

Stephanie said: "It was a very stressful time for myself, my husband and two daughters, but I was just glad that the team at Harefield didn't give up on me. Everyone was really kind and friendly and that helped me prepare for the procedures."

Despite the interventions, Stephanie's angina came back. To control this and prevent her arteries from getting blocked again, Stephanie was recommended for LDL apheresis.

Dr Mahmoud Barbir, consultant cardiologist, commented: "In spite of recently having coronary artery bypass surgery and angioplasty, Stephanie was surprisingly still symptomatic and experiencing angina on minimal effort, which really affected the quality of her life. Myself and the nurse consultant assessed her and started her on the LDL apheresis treatment every two weeks."

Stephanie explained: "The procedure involves having cholesterol removed from my blood every other week by a machine similar to a dialysis machine."

"I see the same nurses each time and the whole team, led by Alison Pottle, is really great and makes the visits as pleasant as possible."

Alison, who is one of only 25 cardiac nurse consultants in the UK, said: "LDL apheresis is very labour intensive, taking up to three hours for each treatment, but we have an excellent team of clinical nurse specialists trained to carry out the procedure. It is very successful, but treatment needs to be carried out regularly for life.

"Stephanie has responded really well to the treatment and regular checks show that her arteries are remaining unblocked."

Stephanie White, patient, and also a healthcare assistant at Harefield Hospital

Harefield clinical nurse specialist, Jane Breen, runs a "cascade" clinic for hypercholesterolaemia so that genetic tests can be carried out on other family members to find out if they too are affected by the condition. This enabled Stephanie's two daughters, aged 28 and 21, and her sister to be screened, and fortunately, none of them has the condition.

Stephanie said: "This is a great relief to me and generally, life is much more positive now."

It's all in the teamwork. The team that looks after Stephanie includes:

- *Cardiology consultant*
- *Cardiac nurse consultant*
- *Phlebotomists*
- *Anaesthetists*
- *Echocardiographers*
- *Clinical nurse specialist*
- *Nurses*
- *Healthcare assistants*
- *Ward manager*
- *Pharmacists*
- *Reception staff*
- *Porters*
- *Catering staff*
- *Cleaning staff*
- *Clinical schedulers*
- *Medical secretaries*
- *Outpatient administrators*

Consultant cardiologist, Dr Lorna Swan (centre), and clinical nurse specialist, Lesley Jones (right), with pregnant patient, Vivitha Duggumpudi

Specialist care for adult congenital heart disease

The adult congenital heart disease unit (ACHD) at Royal Brompton is one of the largest specialised centres in the world.

The unit provides care for adolescent and adult patients with a variety of congenital (present at birth) and inherited heart conditions. This includes patients with Marfan syndrome, an inherited condition affecting the body's connective tissues, and some types of pulmonary hypertension, a rare lung disorder where blood pressure in the pulmonary artery rises far above normal levels.

A full range of inpatient and outpatient care is provided and patients are offered treatment including a full catheter intervention programme, drug treatments and access to a full range of medical and surgical care, including transplantation.

Transition service

One of the major strengths of the Royal Brompton unit is the dedicated transition service that focuses on teenagers and young adults. As both the paediatric and adult services are on site, patient transition is completely co-ordinated and supported by a team that is well known to the patient and his or her family.

When patients reach 13 they are invited to attend the young persons' congenital cardiology clinics. These are run in the paediatric outpatients department and have been set up to help young people become more independent and understand their condition better. A specialist nurse helps patients through this transition and is on hand to answer any questions.

The unit has an active programme of research and training – both of which are vital to the future care of patients with congenital heart conditions. There is also a special pregnancy and heart disease service to care for pregnant women with heart conditions.

A seamless journey from child to adult care

Eighteen-year-old Nathan Brandrick is being treated for a complex congenital heart condition. He is now being looked after by Royal Brompton's adult team, but his journey at the hospital started four years ago in the children's unit.

Nathan's condition was first diagnosed at 14 when he was taken to Lister Hospital in Stevenage, near to the family home in Langford, Bedfordshire, after a sudden change in the appearance of his chest. His blood pressure was extremely high and an X-ray showed a deformity in the shape of his ribs. He was immediately referred to Royal Brompton.

His father, Michael, said: "We had no idea that Nathan had high blood pressure as it had never been taken, so his heart condition came as a complete shock to us. It was reassuring when he was transferred to Royal Brompton and put under the care of consultant paediatrician, Dr Alan Magee."

Tests showed that Nathan's aorta was completely blocked and consultant cardiac surgeon, Mr Darryl Shore, operated to cut the blockage away and insert a graft.

Michael said: "It was a complex case. Nathan's arteries had completely re-wired themselves. It turned out to be a major operation. Although we were nervous for Nathan, he wasn't frightened. He believed he was in the best hands and he trusted the team at Royal Brompton to look after him.

"All the staff on Rose Ward, from the porters to the nurses, cardiac nurse specialists, anaesthetists and consultants, were great and bent over backwards to support us as a family before, during and after the operation."

Nathan had a tight narrowing of his aorta blood vessel (coarctation) and an abnormal aortic valve, which was the cause of his high blood pressure. Regular checks as an outpatient showed that despite the successful surgery his aortic valve was becoming a problem. In early 2012, it was agreed that another operation was needed to replace the first part of the aorta and give him a new aortic valve.

By this time, Nathan had moved from paediatrics to adult services at the hospital in what both he and his parents describe as a "seamless transition". He and the family were supported throughout this process and during Nathan's time on Paul Wood adult ward, by clinical nurse specialist in ACHD and transition, Lynda Shaughnessy.

Michael commented: "He transferred when he was 17 and we still see many familiar faces each time we visit the hospital, which is reassuring.

"The main difference as an adult patient is that his treatment is explained to him in a lot more detail, but otherwise we have experienced the same dedication from the whole team as well as good back-up in between appointments."

Nathan added: "I have found it helpful to have everything that is happening explained to me and everyone at Royal Brompton has been really nice."

His heart condition has not held him back. Nathan is studying countryside management at college and volunteering at his local RSPB centre.

Nathan Brandrick during a recent visit to Royal Brompton

It's all in the teamwork. The team that looks after Nathan includes:

- *Consultant cardiologists*
- *Consultant anaesthetists*
- *Cardiac nurse specialists*
- *Intensive care specialists*
- *High dependency unit nurses*
- *Echocardiographers*
- *Consultant electrophysiologist*
- *Radiologists*
- *Surgeons*
- *Phlebotomists*
- *Perfusionists*
- *Physiotherapists*
- *Medical secretaries*
- *Receptionists – inpatient and outpatient*
- *Ward clerks*
- *Healthcare assistants*
- *Transport staff and porters*
- *Catering staff*
- *Patient Advice and Liaison Service*

Leaders in transplantation

The transplant unit at Harefield is the UK's largest and most experienced centre for heart and lung transplants. The unit works with the Heart Science Centre, which is at the forefront of research into heart disease and transplantation.

A groundbreaking new system was recently introduced at Harefield to enable the retrieval of more hearts for transplantation. Instead of the existing technique of transporting donor hearts in ice, the Organ Care System machine 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 organ remains in the best possible condition before transplantation.

"It's the 4th anniversary of my husband's heart transplant. He's returned from Harefield Hospital following his annual checkup, everything is looking good. For a man who should be dead he looks surprisingly well!"

A PATIENT'S VIEW

Heart transplant helps Caroline look to the future

Caroline Earnshaw, 27, was born with Danon disease, a rare genetic disorder that is currently known to affect fewer than 100 people across the world. The illness causes muscle weakness and potentially lethal heart disease.

Her mother died in 1988 waiting for a transplant when Caroline was just three. She too had Danon disease.

"I was so young and didn't really understand what was happening," recalls Caroline. She and her two brothers were tested for the genetic illness and both Caroline and her brother Sean tested positive. Her other brother, Paul, had escaped it.

The illness affects men and women differently and in men, the symptoms begin to appear much earlier. When Caroline was 12 and Sean 14, he was admitted to Harefield Hospital in the hope of a life-saving heart transplant. However, like his mother, Sean died before a donor could be found.

Caroline says: "I was distraught. I'd lost my brother and I was also scared for myself. I couldn't help thinking 'When will it be my turn?' It really hit home that I was a genetic timebomb, just waiting to explode."

(continued opposite

Heart transplant recipient, Caroline Earnshaw, with her daughter. (Photo courtesy of the Daily Mirror)

(continued from previous page)

Aged 19, the point where the illness typically worsens in women, Caroline's symptoms grew severe. She felt tired and lethargic and had palpitations.

The disease's sudden onset also coincided with Caroline finding out that she was pregnant.

Caroline explains: "I was in a state of shock. The doctor warned me that the strain of the pregnancy on my heart could kill me."

But baby Keira was born safely in May 2005. After blood tests and an ECG, Caroline received the news she had been dreading – Keira had Danon disease too. "I was devastated. Words can't describe how I felt," Says Caroline. "But I knew I had to pull myself together and get on with bringing up my little girl."

When Keira was three Caroline's health deteriorated and even the simplest tasks left her exhausted: "Some days I could barely move. I wanted to be out and about with my little girl but instead, I was laid up at home in bed and missing it all."

In March this year, Caroline was referred for an emergency heart transplant at Harefield: "It was the moment I'd dreaded all my life. I'd lost both my mum and brother as they waited for transplants, But what other option did I have? Without the operation, I faced certain death," she explains.

Mr André Simon, consultant cardiac surgeon and director of transplantation, explained: "When Caroline was referred to us for a heart transplant she was really very ill and had a very poor quality of life. She was also very distressed that she would die while waiting for a donor heart – just like her mother and brother had. It was up to the team at Harefield to keep her well both emotionally and physically so that she was well enough for the transplant."

A suitable heart was found for her just over a month later. When Caroline was told the operation would go ahead she felt: "nervous and excited at the same time. This was a chance for a long and happy life."

She explains "I couldn't speak to Keira. It was too difficult. At the back of my mind I knew I might not pull through. There was the possibility I'd never see my daughter again."

The 10-hour operation was a success and Caroline was discharged from Harefield just a month later.

Mr Simon said: "The operation was extremely successful and we are all delighted that she can look forward to a brighter future with her daughter."

Caroline has also been busy fundraising since her transplant and has raised over £4,000 for the hospital. She said: "I am just so grateful for the care I received at Harefield. They saved my life. The skills and expertise there are amazing and everyone from the physiotherapists, to the nurses and surgeons were fantastic."

Caroline with her brother, Paul

It's all in the teamwork. The team that looked after Caroline included:

- *Transplant surgeons*
- *Cardiology consultants*
- *Anaesthetists*
- *Theatre staff*
- *Clinical nurse specialists*
- *Echocardiographer*
- *Phlebotomists*
- *Perfusionists*
- *Nursing staff – intensive care and ward*
- *Healthcare assistants*
- *Transplant coordinators*
- *Pharmacists*
- *Psychologists*
- *Physiotherapists*
- *Catering staff*
- *Porters*
- *Receptionists*
- *Ward manager*
- *Medical secretaries*
- *Ward clerks*
- *Transport staff*

Achieved high patient satisfaction scores in the 2011 adult inpatient survey

Clinical nurse specialist Andrea Collins with Dr Tushar Salukhe, consultant cardiologist

Syncope service

The syncope service at Royal Brompton is one of only two services in London that helps children as well as adults.

Syncope (fainting) is the leading cause of collapse and brief loss (or near loss) of consciousness. There are different types of fainting, caused by the blood supply to the brain being interrupted for different reasons.

One of the reasons that a person may faint is because the blood supply to the brain is interrupted due to an underlying problem with the heart.

This could be due to an abnormal heart rhythm (arrhythmias) or narrowing of the heart valves (stenosis). Arrhythmias causing loss of consciousness can occur in the context of a heart attack and when the blood supply to the heart is suddenly blocked.

Tilt testing

To test causes of syncope, tilt testing is offered for patients at Royal Brompton. Patients lie flat on a special table or bed while connected to ECG, which checks the electrical activity of the heart, and a blood pressure monitor so they can be checked at all times during the test. The table then creates a change in posture from lying to standing. Usually, a person's blood pressure will not drop dramatically while standing, because the body will compensate for this posture with a slight increase in heart rate and constriction of the blood vessels in the legs. However, if this process does not function normally, the tilt test can cause patients to have symptoms ranging from minor lightheadedness to loss of consciousness.

It is a day-case procedure and does not need any invasive monitoring or admission to hospital – the entire examination only takes an hour and a half. Depending on the results of the test, the treatment will be tailored so patients may receive medication or, in more serious cases, there may be a need for a procedure such as fitting a pacemaker.

This specialist service is led by Dr Tushar Salukhe, consultant cardiologist and cardiac electrophysiologist. Dr Salukhe specialises in the care and treatment of patients with cardiac arrhythmias, including defibrillators and pacemakers. His combined set of skills and the experience and expertise of the team's dedicated specialist nurses offers patients comprehensive and tailored care.

He explained: "Fainting can be very distressing for patients but the tilt test offers an accurate and quick diagnosis. Depending on the results, specialised treatment can then be offered by our team here at Royal Brompton."

"Loved everything about the hospital since my first visit as an outpatient. All the staff were very kind, helpful and professional and worked well as a team."

Children's heart surgery review

In last year's annual review (2010/11) the threat to children's services at our hospitals was covered in some depth. It was a source of deep regret that, ignoring evidence, which showed the grave damage that would result from closing Royal Brompton's children's heart surgery and intensive care units, the final decision to decommission these vital services was made by a joint committee of primary care trust chief executives.

The board considered this decision at length and found it deeply concerning and unacceptable in its suggested form. They were reminded of the Appeal Court judgment, in April 2011:

"Royal Brompton is the largest specialist heart and lung centre in the UK and among the largest centres in Europe. It has, for many decades, been at the forefront of specialised treatment for complex heart and lung disease. It provides a specialist service for children's heart and lung disease and comprehensive paediatric critical care services. It has the second largest paediatric intensive care unit (PICU) in England. It is one of the largest centres for clinical research into cardiological disease in the country. Its work is highly regarded. A member of the public might well find it difficult to understand why a centre of the standard of Royal Brompton should cease to be a centre for paediatric cardiac surgical services under the configuration exercise."

The board concluded that the decision was not in the best interests of present or future patients and gave the Trust's chief executive the mandate to continue to liaise with those responsible for developing a plan to implement the Joint Committee of Primary Care Trust's (JCPCT) proposals for London, once again making them aware of the significant adverse consequences for a range of other clinical services.

The board's view remains that a "three sites, one system" network in London, with formally agreed referrals, pathways and protocols, would promote specialism and provide patients regionally and nationally with the best clinical expertise. With clear, unambiguous governance arrangements and no adverse effects on other services, it would become a beacon for excellence in children's cardiac care, research and training internationally.

Since the threat to children's services was announced in February 2011, support from colleagues and peers around the world, from patients and their families, from the charities that do so much for patients, from members of parliament and local councillors, and from the communities of friends that support both our hospitals, has been overwhelming.

Included here is a very small fraction of the messages of support received...

William G Stevenson MD – senior physician at Brigham and Women's Hospital and professor of medicine at Harvard Medical School, Boston USA:

"This internationally recognised programme has long been a leader in the field and has made a series of contributions to the dramatic improvement in survival and outcomes of patients with congenital heart disease."

Professor Francis Fontan MD – honorary professor of cardiac surgery, University of Bordeaux, France, founding father and first president of the European Association for Cardio-Thoracic Surgery:

"I am one of the fortunate cardiac surgeons who had the chance to know the activity and the surgeons at Royal Brompton Hospital for decades, since the 1970s. I cannot imagine that this department could threaten to disappear. The international community of paediatric cardiologists and paediatric cardiac surgeons, indebted to Brompton, could not understand such a disappearing."

Professor Brigitte Stiller – medical director of the Clinic for Congenital Heart Defects / Paediatric Cardiology at the Centre for Paediatrics and Adolescent Medicine, University Hospital Freiburg, Germany:

"To me it is still unimaginable that the well known and famous children's services at the Royal Brompton Hospital are under this kind of threat. The political decision is a big mistake and I am sure that the results will last for decades... children, especially those with chronic disease like congenital heart defects urgently need centres like Royal Brompton. I cannot imagine that the closure of this exemplary clinic will make any sense regarding the community, the patient care or financial aspects. To my opinion this short-sighted decision should be revised."

"I'm 12 years old. I had a heart operation when I was five months old. I owe my life to Royal Brompton hospital. I still attend the children's outpatients for yearly check ups and I will be very upset if this unit is shut down."

Patrick M Kochanek, MD – professor and vice chairman, department of critical care medicine, and professor of anaesthesiology, paediatrics and clinical and translational science at the University of Pittsburgh School of Medicine:

"It is a fact that faculty from the hospital has played an instrumental role in unifying the field of paediatric cardiac intensive care worldwide. They have also contributed enormously to the development of the science of paediatric cardiac intensive care... The dismantling of the Royal Brompton program would represent an important loss of an iconic institution in the field and negatively impact the care of infants, children, and adults with congenital heart disease both in the UK and worldwide."

Professor Ernst Eber – head of the Paediatric Assembly of the European Respiratory Society and head of the respiratory and allergic disease division, paediatric department, Medical University of Graz, Austria:

"It takes years to build a world class unit, and all this can be thrown away very quickly if careful prospective planning is not done. I do hope that there will be a way found to ensure the desired improvements for paediatric cardiac surgery and at the same time to ensure continued outstanding clinical and academic work performed by the paediatric respiratory services at the Royal Brompton Hospital, but it is inconceivable to me that this last can be achieved without PICU and paediatric anaesthesia."

Karolinska Institutet, The Centre for Allergy Research – Professor Sven-Erik Dahlén MD PhD – director, and Professor Gunilla Hedlin MD PhD – co-director:

"It has come to our attention that major changes in children's cardiac services have been considered that will impact on the operations of paediatric respiratory services as well... This clinic is well-established as a centre of excellence concerning lung diseases in children of all ages. The Karolinska Institute and other colleagues abroad frequently consult the hospital and its staff because of its world-leading expertise in the field of paediatric lung disease... The research that has been carried out here into common and rare diseases of childhood is equally as outstanding, and a field-leader, internationally."

(continued overleaf)

Professor J Stuart Elborn – director of the Centre for Infection and Immunity, Queen's University, Belfast; president of the European Cystic Fibrosis Association; chair of the Research Committee, CF Trust:

"The quality of the current paediatric respiratory research programme at RBH is outstanding. It is one of very few centres with sustained internationally competitive programmes in the UK or mainland Europe. The investigators at RBH have published primary research which has resulted in changes in medical practice and the understanding of fundamental mechanisms of chronic lung diseases."

Dr Neil Gibson – consultant in paediatric respiratory medicine at the Royal Hospital for Sick Children in Glasgow and current Secretary of the British Paediatric Respiratory Society:

"The paediatric respiratory research unit at Royal Brompton Hospital is truly one of the world's leading centres with an already impressive track record and a current set up that is likely to be part of delivering some fundamentally important research findings and treatment innovations for relatively common conditions. I fear there is a very real threat to that work from the implications of removing cardiac surgical services."

Professor Sir Magdi Yacoub – professor of cardiothoracic surgery at the National Heart and Lung Institute, Imperial College London and director of research, Harefield Heart Science Centre:

"It is my firm belief that centres of excellence such as the paediatric unit at the Royal Brompton & Harefield NHS Foundation Trust are irreplaceable and, therefore, should be preserved for the benefit of the community, both nationally and internationally."

Comments from the world of politics

Greg Hands – MP for Chelsea and Fulham (in a speech in the House of Commons on 23 June 2011, supporting Royal Brompton's call to retain its children's heart surgery):

"Royal Brompton is good enough, large enough and loved enough to survive... without the Royal Brompton, it is questionable whether London would cope with the demand for paediatric intensive care."

Andy Slaughter – MP for Hammersmith (during a private members' debate in July 2012):

The JCPCT has taken the extraordinary step of recommending the closure of the children's cardiac unit at the Royal Brompton hospital, despite knowing that there were no risks attendant on keeping it open. On the contrary, it is a world-class unit with world-class doctors and surgeons." Mr Slaughter, who visited the hospital in March 2012, also spoke passionately against the closure in a House of Commons debate, saying the hospital is *"one of the best performing and largest centres in England. It also has a safety and outcome record of which any centre would be proud."*

Mark Field – MP for the Cities of London and Westminster (during a private members' debate in July 2012):

"I have received many e-mails and other correspondence imploring me to fight the decision to close the specialist children's heart surgery unit at the hospital... I have great sympathy with the concerns that some of my constituents have highlighted. They are particularly worried that the review of the Royal Brompton has failed to consider what a difference having child and adult cardiac services in the same centre makes to the quality of care... The hospital hosts the country's largest service for children with cystic fibrosis, which requires intensive paediatric care, and also anaesthesia teams to support the respiratory team with some of the most complex cases."

Gordon Henderson – MP for Sittingbourne and Sheppey, visited the hospital in October 2011 and, in June 2012, laid down an Early Day Motion in parliament stating:

"That this House is concerned at the decision by the Safe and Sustainable Review of Children's Heart Surgery to recommend closure of the intensive care unit at Royal Brompton Hospital; believes that the specialist services for children with cystic fibrosis, severe asthma and other respiratory illnesses will be downgraded as a result; calls on Ministers in the Department of Health to meet doctors and other representatives of the hospital to discuss how the decision will impact on current levels of clinical expertise and respiratory research programmes; and fully supports comprehensive consultation with parents of those children affected before any decisions are made."

London Borough of Hillingdon:

"We do not support the proposal to move to two centres providing services in London... There appears to be no clear clinical justification for choosing between the centres... Continuity of care is vital for children undergoing heart surgery as they grow older. The Royal Brompton & Harefield provides a lifelong service for children with congenital heart disease. Alternative approaches for increased collaboration between London centres have not, in our view, been adequately explored."

"Our wonderful little boy had an operation at Royal Brompton at three years old. The **amazing cardiac intensive care team, nurses and doctors** at the Brompton **saved his life.**"

Royal Borough of Kensington and Chelsea:

"Matters of capacity at other centres is an important issue. We have serious concerns that too little thought has been given to the wider impact of this proposal on the medical and financial viability of the Royal Brompton & Harefield NHS Foundation Trust. The process seems to represent a classic top-down approach to health service reconfiguration."

Comments from charities

Joanne Osmond – clinical director of the Cystic Fibrosis Trust:

"The removal of paediatric cardiac surgery from the Royal Brompton Hospital will indeed have grievous consequences for children with cystic fibrosis. But the effects will not be confined to children with this serious illness. It is impossible to safely look after children with either heart or lung disease without on-site access to paediatric anaesthesia and paediatric intensive care, neither of which are viable at Royal Brompton without paediatric cardiac surgery."

Neil Churchill – chief executive of Asthma UK (after attending a parents' meeting about the knock-on effects of the closure on respiratory care at Royal Brompton):

"In principle, however, one thing stuck out. That was the fact that respiratory patients are being treated as second-class citizens compared with cardiac patients. The intention is to decide the future of cardiac care now and let respiratory services deal with the consequences later. What must happen instead is that all patients – cardiac and respiratory – should have an equal input into decisions about how their care is provided."

Matthew Reed – chief executive, CF Trust; Neil Churchill – chief executive, Asthma UK; Fiona Copeland – chair, PCD Family Support Group and Robert Meadowcroft – chief executive, Muscular Dystrophy Campaign (in a letter on behalf of their charities):

"Like children with congenital heart diseases, children with long-term, incurable respiratory diseases are amongst the most vulnerable children in the United Kingdom today. Their future life expectancy and quality of life will be influenced by the quality of clinical care which they receive as well as the quality of translational research and clinical trials work which is performed at specialist centres...We have explicitly mentioned respiratory research because it is an issue of fundamental importance to each of our charities because of the excellence of the Royal Brompton's paediatric respiratory research and clinical trials programmes and the importance of that work for improving patient outcomes in the future."

(continued overleaf)

Dr Jan Till, consultant in paediatric electrophysiology, with a young patient

Comments from patients, families, carers and supporters

"The Royal Brompton hospital in London saved my daughter's life when she was three months old. It only does hearts and lungs; it is a centre of utmost excellence and has an international reputation regarding children's cardiac services... Anyone who believes in the NHS, and anyone whose child has ever required complex medical intervention, should support the Brompton to the hilt." (India Knight – newspaper columnist and parent of Royal Brompton patient)

"Bravehearted, Royal, Operations, Marvellous, Pioneering, Teamwork, One & only, Never to close!"

"There is no one else I would trust with my baby!"

"This is not just any hospital – this is a massive security blanket for hundreds of families."

"I know they are the reason most of my friends with CF are alive today... without them I fear there will be fewer people like me who survive to adulthood and are able to get the treatment they need or transplants in some cases."

"Rose Ward is a sanctuary with dedicated staff who always have time for you."

"I practically grew up in and out of Rose Ward and without the wonderful doctors and nurses there I would not be living my life as fully as I am now!"

"I owe my life to the Brompton, yet I have never been under their care. My little boy was and life would not be worth living without him. So really, they saved us both."

"The care and treatment supplied by the unit is fantastic and the advice supplied by this unit to other hospitals around the country treating children with lung and heart conditions is invaluable."

"There is no hospital as good as the Brompton in London. First class."

"Extraordinary hospital..."

Royal Brompton has:

- *An excellent safety record with mortality rates less than half the national average – 0.9% versus 2%*
- *Outcomes comparable to the best centres in the world*
- *The third largest centre for children's heart surgery in the country*
- *Four surgeons undertaking over 400 cardiac operations each year between them*
- *National and internationally important research programmes having a direct impact on the care of young and vulnerable patients*
- *Excellent feedback from patients across national and Trust-specific experience surveys.*

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 the 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 their final decision to decommission children's heart surgery services at Royal Brompton

Freddie has a bright future

When Trudy Nickels was just 24 weeks pregnant, a scan revealed that her baby had complex congenital heart disease with just half of his heart working properly. The other half did not develop and could not pump properly. She was warned that the quality of her baby's life would be very poor and told that she should consider her options.

But, Trudy was referred to Royal Brompton and for the first time she felt a glimmer of hope.

Trudy explains: "It was a really frightening time and I was devastated when the doctors suggested I terminate the pregnancy. I feel so lucky that I was able to see a consultant at Royal Brompton who explained to me that we did have other options. Life could have turned out very differently if it wasn't for this hospital."

Her son, Freddie, was born in 2006 and was first admitted to Royal Brompton the day after he was born. Freddie is now five years old and has had open-heart surgery four times, as well as many other procedures and tests. He also receives his main nutritional intake through a gastrostomy tube, directly into his stomach and sees occupational therapists and speech therapists at the hospital.

Last year, surgeons performed an open heart operation to complete his Fontan circulation. The Fontan procedure involves diverting the blood from the right atrium in the heart to the pulmonary arteries without passing through the right ventricle. Freddie's body found it hard to adapt to this and he spent over three months in the paediatric intensive care unit and children's ward recovering.

Trudy explains: "Freddie has come through so much in his life but we were desperately worried that we were going to lose him last summer. However, once again the expert, specialised treatment he received both physically and emotionally was second to none. I can never thank Mr Slavik and Mr Sethia enough for saving his life and the whole team who helped us through such a difficult time."

A smiling Freddie at Royal Brompton Hospital

Trudy was able to stay with her son during the time he spent in hospital. She explains: "It was such a relief to be able to be with Freddie when he needed me most. During that time I learnt a great deal about hospital life and met some outstanding and inspiring members of staff. They really go that extra mile, and many came to check on him after their shifts had finished."

Due to Freddie's complex needs, when he had an abscess on his tooth earlier this year, a surgeon from Chelsea and Westminster Hospital removed his tooth at Royal Brompton rather than on-site at Chelsea and Westminster. This was so that Freddie could be cared for by the specialist paediatric anaesthetists, intensive care teams and highly specialist nurses who have experience in treating children with high-risk heart and lung problems.

Trudy said: "The staff here understand his condition so well. It's so important for children with complex conditions to receive the world-class care that the unit at Royal Brompton can offer."

Freddie also had a pacemaker fitted in November 2011 and since then he has had more energy and has made progress with his speech. Although he receives ongoing care at home and at Royal Brompton, he is a very happy, healthy five-year-old who enjoys life and is looking forward to a bright future.

It's all in the teamwork. The team that has cared for Freddie includes:

- *Paediatric cardiac surgeons*
- *Paediatric cardiologists*
- *Anaesthetists*
- *Theatre staff*
- *Clinical nurse specialists*
- *Nurses*
- *Healthcare assistants*
- *Physiotherapists*
- *Occupational therapists*
- *Speech and language therapists*
- *Psychologist*
- *Phlebotomists*
- *Perfusionists*
- *Play specialists*
- *School teachers and a special needs assistant*
- *Receptionists – inpatients and outpatients*
- *Medical secretaries*
- *Ward clerks and managers*
- *Catering team*
- *Porters*

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, cancer services, lung inflammation and cystic fibrosis, lung infection and immunity, lung failure (including transplant, COPD and sleep and ventilation), and lung assessment (including sleep studies, lung function and physiology).

Lung cancer care

The Trust has the biggest thoracic unit in the UK with a wide range of expertise. It is the largest centre for the surgical treatment of lung cancer and offers patients a comprehensive, multidisciplinary team approach to their care.

Radiofrequency ablation

Harefield hosts the only service in the UK which is dedicated to lung tumour ablation (destroying tumours) including radiofrequency, microwave and cryotherapy treatment.

Radiofrequency ablation (RFA) is a treatment for lung cancer that does not involve surgery. Patients are referred to the Trust from all over the UK for this pioneering treatment.

RFA uses heat to destroy cancer cells. A probe called an electrode sends an electrical current to the tumour and this electrical current heats the cancer cells to high temperatures and destroys (or ablates) them. The cancer cells die and the area that has been treated slowly shrinks and becomes scar tissue. RFA may not destroy all of the cancer cells after the first treatment so repeat treatments may be necessary.

The Harefield lung tumour ablation programme was initially developed to treat patients with primary lung cancers who were only being offered palliative treatment.

However, over the last four years, patients with both primary and secondary lung cancers have successfully been treated at Harefield and results have been significantly better than those achieved by conventional non-surgical therapies and those reported by other tumour ablation centres.

Patients who are receiving RFA treatment are referred to Dr Paras Dalal, consultant cardiothoracic radiologist, and are assigned the support of clinical nurse specialist, Julia Beeson.

Dr Dalal commented: "I feel privileged to be part of a team that has begun to revolutionise therapy of lung cancer in patients who would otherwise be consigned only to palliative treatments. To treat and regularly follow-up these patients remains a highlight of my career."

Dr Paras Dalal discusses treatment with a patient

"I am very grateful to all the doctors and nurses for all their hard work in saving my life. God knows what would have happened to me if I hadn't come to you. I was there for two months for tests and treatment. The quality of care is excellent."

Innovation improves Barbara's life

Since undergoing radiofrequency ablation treatment at Harefield Hospital, Barbara Copland says that she is getting her old life back.

Barbara was diagnosed with secondary tumours in her lungs following breast cancer 10 years ago. Chemotherapy had not made a significant impact so she was referred to Dr Dalal at Harefield to be considered for radiofrequency ablation.

Barbara said: "It was a huge shock to me that the cancer had returned after so long. I had been suffering from breathlessness and diagnosed as asthmatic.

"Despite being treated with four different chemotherapy drugs, the nodules on my lungs were not responding. I was also suffering from many of the unpleasant side effects associated with the drugs, including nausea, hair loss, stomach cramps and cold sores. I also felt extremely tired all the time and this was affecting my quality of life."

Following assessment, Barbara was offered radiofrequency ablation at Harefield. She said: "I felt that radiofrequency ablation was a good option for me and I was reassured by Harefield's reputation in this specialist area and the good success rates achieved for the treatment.

"The whole team involved in my care – from the nurses to the anaesthetist, doctors and support staff – were fantastic. They were extremely empathetic and explained everything to me in great detail."

In June this year, Barbara had radiofrequency ablation treatment for two nodules in her left upper lobe and three in her right lower lobe in two separate procedures.

She remembers: "The staff couldn't do enough for me during both my short stays in hospital and ensured that I was as comfortable as possible and recovering well.

"A clinical nurse specialist has been available to answer any questions by phone in between appointments and that is very reassuring."

Barbara had lost confidence before the treatment as she had not felt well enough to travel far from home, but she is now getting her life back on track.

She said: "I am working part-time as an advisor for the Citizens Advice Bureau and look forward to being able to travel from my home in Northwood up to London to attend art exhibitions.

"My recovery has been much better following the radiofrequency ablation than when I underwent chemotherapy. I am feeling positive about the future."

Clinical nurse specialist, Julia Beeson, was one of the team members who treated Barbara. She said: "As with Barbara, all the patients that we have treated at the centre have benefited significantly from the therapy and found that their quality of life has improved."

Barbara with (l-r) Dr Paras Dalal, consultant cardiothoracic radiologist, Juliette Tennant, superintendent radiographer, Nicola Wickings, senior secretary, Dr Sarah Stirling and Dr Simon Mattison, consultant anaesthetic and critical care consultants and Julia Beeson, clinical nurse specialist

Helped over
8,200 adults with
breathing problems

Video-assisted (VATS) lung resection

A groundbreaking surgical technique offered at Royal Brompton means that some lung cancer patients are experiencing a quicker recovery than usual after tumours are removed. The new keyhole surgery – called video-assisted thoracic surgery (VATS) – involves a series of small cuts, rather than opening the chest and pulling the ribcage apart, and uses a tiny camera to help surgeons locate and identify the tumour.

VATS surgery can now be used as a suitable alternative to the more traditional open chest surgery for around one in 10 adult patients. It has been shown that patients who undergo VATS surgery experience less pain and have a shorter hospital stay after their operation. Mr Simon Jordan, consultant thoracic surgeon, explains: "More and more we are impressed by the speed of recovery and how much better the recovery can be with this operation."

Although rarely used on children, in 2011 Mr Jordan used the pioneering technique to successfully remove a tumour from 11-year-old Rhys Watkins's lung.

Rhys's quick recovery after VATS surgery

Rhys was born with a form of neurofibromatosis, NF1, a genetic disease affecting one baby born each day in the UK. The condition causes multiple, generally benign tumours in the nervous system. However, on occasion, the tumours are cancerous, as was the case for Rhys.

He had previously had a tumour removed from the top of his leg, which left him with mobility problems, but the cancer had now spread to his lungs. Although small when it was first picked up, the tumour grew rapidly and, by the time Mr Jordan operated, it was as big as a tennis ball and was starting to take over the whole of the bottom lobe of the lung.

The bottom half of the lung needed to be removed and Mr Jordan, who operates primarily on adults, used VATS surgery – the first time he had used such a technique on a child.

Rhys recovered well and left hospital only three days after the operation. Mr Jordan explains: "The timing was great in the case of Rhys. Because of his quick recovery, he actually went home the day before Christmas Eve, whereas traditionally we'd have expected to keep him in for at least another three to four days after that."

Rhys's father, Trevor Watkins said: "Mr Jordan was great and so was the team.

"For Rhys, having this kind of surgery meant he could get out of bed, get out of hospital and get back home for Christmas. When we were travelling home from hospital on the bus and then the train, none of the other passengers would have known he had just had major surgery – he was walking around like a normal 11-year-old.

Mr Simon Jordan and members of the surgical team

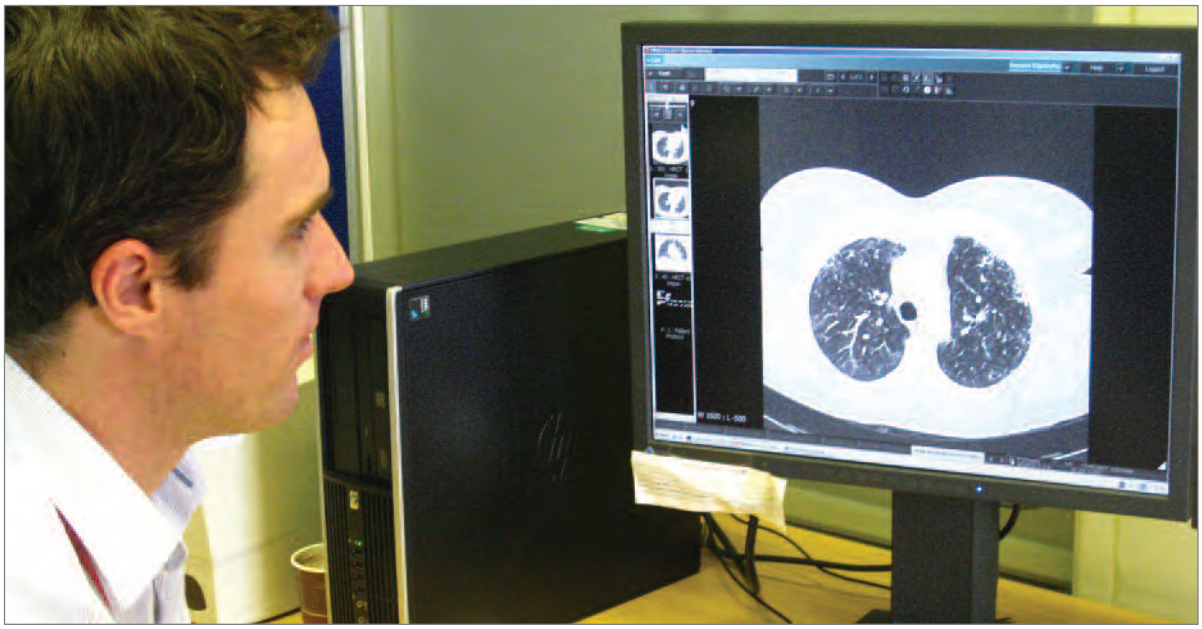
"Rhys has known all of his life that he has an illness he has to deal with, but this lung surgery has had much less impact because of how it was done. A bigger scar would have been a reminder of the battles he has fought. Instead the scar he has does not look like a significant injury so he does not feel disfigured."

With both paediatric and adult surgery available on site at Royal Brompton, Rhys benefited from the support of the specialist paediatric anaesthetic and intensive care teams working alongside Mr Jordan. Before being discharged, Rhys recovered on Rose ward.

Mr Jordan said: "Our experience of seeing both adults and children at Royal Brompton means we have now been able to use this technique on a younger patient for the first time. Rhys was able to recover from the operation sooner as a result."

Rhys is still being checked regularly but was able to return to school with his classmates a month after returning home.

Rhys receiving a surprise visit from Father Christmas before going home on 23 December, just three days after surgery



Dr Greg Weir, respiratory consultant in the interstitial lung disease team

Interstitial lung disease and host defence unit – working together

Interstitial lung disease unit

The interstitial lung disease (ILD) unit at Royal Brompton is the largest unit of its kind in Europe and the only unit in the UK dedicated to the management of patients with these diseases affecting the delicate structures and chemistry of the lungs.

ILD is a term used for a group of lung diseases that affect the tissue and space around air sacs in the lung.

The ILD team includes respiratory consultants Professor Athol Wells, Dr Elizabeth Renzoni, Dr Toby Maher and Dr Greg Keir. They are all experts in a range of lung diseases – some of which are very rare – and lead a service that includes a one-stop clinic for difficult cases and clinics for patients needing urgent care and treatment. They also provide specialist advice on managing ILD and the various complications that can be associated with these diseases.

The Trust has been at the forefront of developments in the diagnosis and treatment of ILD over several decades.

Host defence unit

Host defence is the name given to the body's ability to fight infection, for example, through the workings of our immune systems. The host defence unit, led by consultant respiratory physicians, Dr Robert Wilson and Dr Michael Loebinger, focuses on persistent and recurring lung infections, helping patients whose immune systems are unable to properly fight infections in their respiratory tracts.

The unit also offers a service dedicated to treating bronchiectasis – a disease affecting the walls of the lung airways – where experts see more patients than at any other unit worldwide. A national screening centre for primary ciliary dyskinesia (PCD), a rare genetic disorder affecting the delicate hairs on the surface of cells in the lung, is also offered.

A specialist microbiological and immunological service in the unit provides treatment to replace deficient immunoglobulin – antibody which is vital to the way our immune systems work. The unit also has a new rapid response clinic that receives referrals from hospitals and GPs around the country and helps to provide an effective response to the peak in respiratory problems that happens during cold weather.

Multidisciplinary team working

As some conditions need the specialist knowledge and treatment of more than one team, a unique, new multidisciplinary meeting (MDM) was created in September 2011, combining the skills of the ILD team and the team in the host defence unit with essential input from Professor David Hansell, consultant radiologist.

Dr Robert Wilson, director of the Trust's lung division, explains: "Interstitial lung disease patients are prone to lung infections, sometimes because of their treatment, and sometimes because inhaled bacteria or fungi take advantage of the lung scarred by ILD. Once established, the infection, if it is not treated adequately, can increase the inflammation caused by the ILD, leading to more lung damage. The new team meeting combines the skills of our two teams, to ensure that the patient receives the very best treatment possible."

Asthma care

Our experts treat more children and adults with severe asthma – unresponsive to standard inhalers and needing frequent hospital treatment – than anywhere else in the country. The majority of asthma patients are referred from consultants at district general hospitals. Royal Brompton is one of only two asthma centres in London, for a population of eight million.

Bronchial thermoplasty for severe asthma

Bronchial thermoplasty is a new way of treating severe and persistent asthma without the need for drugs. It involves heating the walls of the airways in a finely controlled way to reduce excess muscle, which can constrict the airways and make it hard to breathe. Smooth muscle is located within the walls of airways in the lung, and in patients with asthma there is usually too much of it. Reducing the excess muscle therefore reduces the frequency of asthma attacks.

Royal Brompton is one of only three UK centres to successfully introduce bronchial thermoplasty, which was only approved for NHS use by the National Institute for Health and Clinical Excellence (NICE) in 2011.

Patients are assessed by the asthma team, led by Dr Andrew Menzies-Gow, consultant respiratory physician. If they are suitable for treatment, patients can usually go home the same day that they are treated.

The procedure is performed by Dr Pallav Shah, consultant respiratory physician, and involves passing a fibre-optic camera through the airways and into the lungs. Patients are sedated rather than given a full anaesthetic. An electrode at the tip of the tube carrying the camera then delivers short pulses of radiofrequency energy to the airway wall. The heat produced damages the excess muscle tissue to stop it constricting the airways.

Dr Menzies-Gow said: "This is a welcome addition to the mainstay asthma medications, such as inhalers, used by patients with severe asthma. It also has the potential to provide long-lasting asthma control and improve asthma-related quality of life with less side effects than conventional treatment."

New occupational health lung disease clinic

The occupational lung disease clinic at Royal Brompton is the longest running specialist clinic of its kind in the world, and the largest in Europe. Following the appointment of a new consultant, Dr Jo Szram, a new satellite clinic was established at Harefield, offering assessment and management advice for new patients referred from outside the M25. The extra outpatient capacity has allowed the department to meet its benchmark of offering all new patients an appointment within five weeks of referral, in spite of a 10 per cent increase in the numbers of patients seen. Other developments include a telephone follow-up clinic to discuss results.

Around 80 per cent of patients referred to the service have asthma and allergy-related conditions, and the consultants, Professor Paul Cullinan and Dr Jo Szram, maintain a regular contribution to the severe asthma service, with established links with the allergy and ILD units in both clinical practice and research.

ECMO (extracorporeal membrane oxygenation)

This year, Royal Brompton was designated as one of only five centres to provide a year-round ECMO service (extracorporeal membrane oxygenation) for adults. This followed the last two winters' experience of caring for a large number of patients with severe acute respiratory failure, including swine flu.

ECMO is used to treat patients with severe lung problems. When lungs are extremely damaged, they are unable to pass enough oxygen into the blood and get rid of enough carbon dioxide. During ECMO, blood is circulated through an artificial lung outside the body where oxygen is added and carbon dioxide removed. The oxygen-rich blood is then returned.

Dr Simon Finney, adult intensive care consultant, said: "We have been providing specialist ECMO services for a number of years, and provided extra capacity over the last two winters. Formal recognition as an ECMO centre has helped us to deliver a comprehensive range of treatment for patients. As a specialist respiratory centre, we can provide expert opinion from our teams in respiratory medicine, cardiology, imaging, and thoracic surgery, allowing us to care for patients with the most complex and serious respiratory conditions."

National service

Royal Brompton serves a wide range of the country, including North West and North Central London, Thames Valley, Avon and Gloucester and the South West Peninsula. The service includes emergency retrieval of patients from referring hospitals and a "24/7" consultant-delivered retrieval service that provides mobile ECMO when patients cannot be treated at their local hospital. This involves staff providing complex life-saving care on the road and in the air during a patient's transfer to Royal Brompton.

Dr Finney explains: "ECMO is a co-ordinated team effort and has involved training critical care staff to provide this highly complex treatment. Nursing staff have also needed to be extremely flexible to

(continued overleaf)

Cared for
693 adult and
362 paediatric
cystic fibrosis
patients

cope with the unpredictable demand for the service. We have seen and transferred patients from around the UK in previous years, including Scotland and Northern Ireland, and can bring together, in one place, the technology and the expertise of our staff to provide the best care possible."

Providing respiratory support at home

Some respiratory conditions, including neuromuscular and chest wall disorders such as muscular dystrophy and curvature of the spine, and chronic obstructive pulmonary disease (COPD), result in patients being unable to breathe on their own. When these patients go to sleep they are unable to breathe in enough, which results in low oxygen levels and a high level of waste gas (carbon dioxide).

Royal Brompton provides domiciliary ventilation (breathing support at home) for 1,600 patients across the country, making the Trust the largest provider of this service in Europe.

Professor Anita Simonds, consultant in respiratory medicine, together with consultant colleagues Professor Michael Polkey, Dr Matt Hind and Dr Neil Ward, and the respiratory support team provide home ventilation for adults and children. Small portable ventilators control patients' breathing at night and correct the oxygen and waste gas levels. Patients wear a mask over their nose or face while they sleep so they can get the oxygen they need. As a result of ventilatory support individuals sleep better and feel brighter during the day. Results of research studies by the team show that in some conditions survival is markedly increased and in virtually all patients quality of life improved.

Professor Simonds explains: "Home ventilation has revolutionised the outcome in some chronic respiratory disorders, and the technology is improving all the time. We are fortunate to be jointly working with our patients to develop new ventilatory devices and masks to advance the field further."

Children who have chronic respiratory failure due to conditions such as muscle disease, disorders of breathing, or abnormalities of the airway, may not be able to survive without "intensive care" technology. Medical advances and new portable ventilators allow a greater number of children who rely on these types of technology to lead happy and active lives at home.

A pioneering service

The Children's Long Term Ventilation (LTV) Service at Royal Brompton is led by a multidisciplinary team with expertise in paediatric intensive care, advanced respiratory and ventilatory management, as well as complex discharge planning. The team provides outreach specialist clinical support, education and training to all neonatal and paediatric intensive care units in London and the South East, as well as to community teams, local hospitals, hospices and children's centres. This is the only regional service of its kind in the country.

In the past two years over 1,000 professionals have had free LTV specialist training. The team also runs regional and national conferences and training workshops for NHS staff and private care providers. A recent development has been an e-learning package that supplements the face-to-face training sessions.

Funding from a number of different sources has assisted the development of the care of children on LTV.

Dr Gillian Halley, paediatric intensive care consultant, said: "We know from experience that children on LTV who are medically stable would prefer to be at home with their parents, and we have seen significant improvements in their health and general well being after hospital discharge. Where possible, they need to be in a home environment, enjoying the normal bedtimes, bath times and playtimes with their family."

Patient India Hicks being set up on non-invasive ventilation

Cystic fibrosis – supporting the move from child to adult care

Cystic fibrosis (CF) is an inherited life-limiting disease, mainly affecting the pulmonary and digestive systems. Royal Brompton has the largest paediatric CF clinic in Europe and the only larger CF unit is our adult clinic.

The fact that the adult and paediatric units are both based at Royal Brompton allows a seamless transition of care for patients. Being based within a specialist hospital also means that CF patients have access to the very best respiratory treatment as well as potentially life-saving care such as specialist anaesthesia and intensive care.

The transition to adult care for a CF patient usually takes place between the ages of 16-18. The process happens over time and relies on a good multidisciplinary team (MDT) approach between the paediatric team, led by Dr Ian Balfour-Lynn, and the adult team led by Dr Diana Bilton.

All teenage patients attend a pre-transition and transition clinic giving them an opportunity to meet the adult CF team including their new consultant, clinical nurse specialist, physiotherapist and dietitian and ask any questions. Paediatric clinicians also attend the clinic with their colleagues. Patients are offered a tour of the adult CF unit to ensure they will be comfortable in new surroundings.

Dr Susan Madge, nurse consultant in CF, explains: "The move from paediatric to adult CF care is an essential part of growing up for our patients. Following transition, a monthly joint paediatric and adult transition meeting is held to ensure all patients are benefiting from close working between the two teams."

Expert research centre

A groundbreaking gene therapy treatment trial that has the potential to extend and improve the lives of 9,000 babies, children and adults living with CF is taking place at Royal Brompton, led by Professor Eric Alton, honorary consultant physician in respiratory medicine.

Angharad Milenkovic, 32, has been a patient at Royal Brompton for 10 years and is taking part in the trial.

Angharad explains: "It is very easy to get swept away in the excitement of taking part in a clinical trial although, of course, I am very hopeful the trial will have a transformational effect on the treatment and management of CF. The combination of drugs and treatment I am already on has made a huge difference to my life and that's thanks to those who went before me and agreed to take part in previous clinical trials.

"Hopefully we can get a drug on the market and approved by the government as a result of this trial and we can make a real different to other CF patients. To be able to start gene therapy as soon as a patient is diagnosed could have an incredible impact on a life – and from a paediatrics point of view you really start to see why this trial is absolutely essential."

Talking about her care, she added: "There is a huge amount of benefit to being a patient at a hospital like Royal Brompton. You receive all your care within a research environment and this wider context has a very positive effect on every aspect of my treatment.

"Because there are so many adult patients here, it feels like there is a phenomenal expertise and depth of knowledge. I feel like I am coming first and having an intellectual conversation with doctors and medical experts who treat me in the best possible way according to my individual needs. It's wonderful to be a patient in an environment where I can engage with CF treatment and research to such an extent."

Angharad Milenkovic, who has been a patient at Royal Brompton for 10 years

Education

STaR centre

A new high-tech training and education centre opened at Harefield Hospital in November 2011, offering clinicians from our hospitals and throughout the UK a unique opportunity to develop their knowledge and skills in critical care, cardiothoracic and transplantation medicine and surgery.

The STaR Centre (simulation, training and resource) delivers on-site postgraduate medical training to students from around the globe to the standards set by the General Medical Council and the Royal College of Physicians board. This training reflects Harefield's international and national reputation as a centre of excellence. Since opening, the STaR Centre has played host to numerous conferences, workshops, open days and courses for both internal and external staff.

The centre is equipped with the most high-tech equipment such as the SimMan 3G, a highly sophisticated dummy patient enabling clinical staff to replicate acute medical, anaesthetic, cardiac and thoracic surgery scenarios and so experience exceptional learning opportunities.

The STaR Centre also contains a fully equipped skills teaching laboratory for invasive procedures, a state-of-the-art transoesophageal echo simulator, bronchoscopy simulator, a lecture theatre and two seminar rooms with video-conferencing facilities.

For more information, visit: www.rbht.nhs.uk/star or email: starcentre@rbht.nhs.uk

The Clinical Skills and Simulation Centre

The Clinical Skills and Simulation Centre (CSSC) is a specialist medical education and training centre, which was officially opened at Royal Brompton in September 2011. The state-of-the-art facility is a collaboration between Royal Brompton Hospital and The Royal Marsden Hospital and focuses on clinical skills training for staff and other healthcare professionals.

The CSSC brings onto one site the high-quality clinical teaching available at both hospitals and provides courses teaching important procedural skills.

The centre also provides medical simulation training where specialist training equipment is used to recreate clinical situations.

SPRinT

The *SPRinT* (simulated paediatric resuscitation team training) programme was founded in 2008 and uses in-situ simulation to provide teams with strategic crisis training, and insight into human factors that influence personal performance.

The award-winning programme trains senior multidisciplinary staff at both hospitals. Last year 247 internal staff were trained – 198 in team training and 49 in clinical skills.

SPRinT uses the most advanced simulation baby and child mannequins to recreate life-threatening events, including Harley, the world's first open-chest paediatric mannequin. Harley simulates a real-life chest opening, giving clinical staff the opportunity to experience first-hand the intricate care needed by children with heart problems. Crash trolleys, resuscitation equipment and real drugs are also used to create scenarios in different areas of the hospital that are as true to life as possible.

The team has also recently been successful in gaining funding to develop an innovative adult open-chest model to promote patient safety and enable rapid responses to critically ill adults.

In December, the team won the Educational Excellence "Innovation" award at the London Deanery's 2011 annual conference. The London Deanery is a clinically-led organisation that offers and funds specialist training for doctors, and together with NHS London and the Education Commissioning System, it recognises training interventions that are innovative and promote patient safety.

The *SPRinT* programme was recognised for advancing *SPRinT* training to cardiothoracic inter-professional teams through the development of novel tools, including the Harley model.

Accepting the award on behalf of the team, Dr Margarita Burmester, paediatric consultant and director of *SPRinT*, said: "I am delighted to receive this award from the London Deanery during such an important conference. It reflects the hard work that has been done by the *SPRinT* team in the past year, the collaborative ethos of the programme and the innovative work on patient safety that continues at the Trust."

Video training at the STaR Centre

Research

Royal Brompton & Harefield NHS Foundation Trust has an internationally renowned reputation for research and innovation and is the leading NHS centre for cardiorespiratory research. Research maps across all areas of cardiac and respiratory medicine and is driven by the clinical needs of our patients.

Working closely with NHS, commercial and academic partners, particularly Imperial College London, new forms of treatment are developed that can be applied across the NHS and beyond.

New research strategy

Research activities within both hospitals are guided by a board-endorsed research strategy. During 2011 and in parallel with the renewal of the biomedical research unit (BRU) funding, the current strategy was revised to ensure that it continues to occupy a leading national and international reputation for research and innovation, influencing medical practice and policy across the UK and worldwide.

The previous research strategy focused on building new research facilities and infrastructure. Our goals for the next three years are:

- Supporting and developing research-active staff
- Exploiting opportunities to attract and retain research funding
- Promoting and increasing engagement in research
- Providing well-managed and effective research facilities, research resource and administrative support

The strategy is accompanied by a set of targets, against which progress will be assessed.

Funding boost for BRUs

In August 2012, the Trust and Imperial College London successfully renewed funding from the National Institute for Health Research (NIHR) to support the work of the cardiovascular and respiratory BRUs. The BRUs are the hub of research into the development and testing of new diagnostics and treatments and provide state-of-the-art facilities and dedicated research resources as well as pump-priming funding to galvanise new research areas. The £20 million award for the five-year BRU grants began in April 2012.

The renewed funding will enable the cardiovascular BRU to develop a broader programme of cardiovascular research, mapping onto our major areas of clinical practice:

- Heart failure
- Coronary artery disease
- Aorta and valvular disease
- Congenital heart disease

Of the award from the NIHR, Professor Dudley Pennell, director of the cardiovascular BRU, said: "This is exceptionally good news for patients. We have a duty to discover new treatments for heart disease, and funding for another five years will enable us to continue our groundbreaking work."

Funding for the respiratory BRU programme will enable development of new cross-cutting programmes in chronic respiratory infection.

These new programmes will complement ongoing translational research activity in the BRU, which is grouped into disease-based consortia of:

- COPD
- Asthma
- Interstitial lung disease
- Acute respiratory failure
- Chronic respiratory failure
- Chronic suppurative lung diseases (including cystic fibrosis, bronchiecstasis and primary ciliary dyskinesia)

According to respiratory BRU director, Professor Eric Alton: "The starting point for our research always begins with the needs of the patients we treat every day."

The biobank

The original BRU award from the NIHR resulted in the establishment of a comprehensive, Trust-wide approach to the collection, storage and distribution for use of biological specimens for research. The BRUs collected specimens from over 1,000 patients in 2011, thereby providing a significant and valuable resource for current and future research. At the biobank, samples are processed and stored anonymously together with clinical data from patients undergoing treatment. The biobank fuels research by enabling identification of trends, mechanisms and possible causes of heart and lung disease, thereby helping to develop therapeutic diagnostics and treatments.

Imperial Academic Health Science Partnership

In November 2011, the Trust entered into a new partnership with 11 other organisations across north west London to establish the new Academic Health Science Partnership (AHSP).

The AHSP intends to bring together providers of primary, secondary, tertiary, community and mental healthcare to work with Imperial College London to improve the health and care of the area's population of 1.9 million people.

(continued overleaf)

Institute of Cardiovascular Medicine & Science (ICMS)

The Trust, in partnership with Liverpool Heart & Chest Hospital NHS Foundation Trust, has established the ICMS. The Institute, the first of its kind in Europe, brings together two specialist cardiac centres and Imperial College London with the aim of improving outcomes in cardiovascular medicine through research, education and service development. The Institute will drive "academically led" but "clinically driven" research programmes that translate directly into clinical practice, facilitated by pooling clinical and academic expertise, research capacity and resources across the partnership. By bringing together leading researchers within the partner organisations, and mentors who are international leaders, the ICMS is developing an exciting programme in heart failure, arrhythmias, coronary artery disease and aorta and valvular disease.

New technique in treating dilated cardiomyopathy (DCM)

Research from a team at Royal Brompton and the National Heart and Lung Institute (NHLI) at Imperial College London, shows that cardiovascular magnetic resonance (CMR) scanning – a less invasive, more cost-effective technique than the coronary angiograms currently used – can accurately diagnose heart failure resulting from dilated cardiomyopathy (DCM). DCM is the second most common cause of heart failure in the UK, with more than 11,000 people developing the condition every year.

Dr Sanjay Prasad, consultant cardiologist at Royal Brompton and part of the NHLI, said:
"Understanding the causes of heart failure is hugely important because it dictates the treatment you give patients. Using CMR, we were able to identify a pattern of scarring to the heart tissue caused by DCM in patients who have early onset heart failure. Scanning can both accurately diagnose heart failure and collect information about what is happening to the heart muscle. We can develop the best possible treatment and support, including identifying who would benefit from having an angiogram. It means we are moving patients from diagnosis to treatment as quickly and comfortably as possible."

The research was published in the international journal, *Circulation*, (Journal of the American Heart Association).

Researchers identify cardiomyopathy gene

Researchers at Royal Brompton and Imperial College London have used high-speed DNA sequencing technology to provide detailed genetic analysis of 300 heart patients. The study findings, published in the *New England Journal of Medicine*, are hailed as "the beginning of the end" for diagnosing inherited dilated cardiomyopathy (DCM).

The study is an international collaboration between teams at Royal Brompton, the NHLI at Imperial College London, Harvard Medical School in the United States and University of Trieste in Italy. It has identified a mutation in the Titin gene as instrumental in the cause of DCM. The mutation appears in one in four of all patients with the condition.

The UK-based team members, who carried out their work at the cardiovascular BRU, say the findings mean half of all patients can be effectively screened and diagnosed for DCM and family members tested to show if they are also affected.

Pioneering lung transplant research

In 2009, Harefield Hospital was the first UK centre to successfully perform a novel technique to increase the usability of donated lungs for transplant. The technique, ex-vivo lung perfusion (EVLP), takes donated lungs, which may have been previously considered unsuitable or uncertain for transplantation, and "reconditions" them on a modified heart-lung bypass machine so that the lungs are then suitable for transplant.

In 2011, and following the introduction of this technique across other UK transplant centres, along with four other centres, Harefield Hospital was awarded funding from NIHR and the Cystic Fibrosis Trust to perform a pivotal new research study to definitively evaluate the clinical effectiveness of EVLP, its impact on quality of life of lung transplant recipients and the cost-effectiveness of the procedure for use across the NHS. The lead for the DEVELOP study is Mr André Simon, director of transplantation and consultant cardiac surgeon at Harefield. Patients will be recruited for the study in the autumn of 2012.

Clinical trials for Marfan syndrome

Researchers at Royal Brompton are launching a new clinical trial into a rare heart condition, with a £1.4 million grant from the British Heart Foundation and funding from the Marfan Trust. The research into Marfan syndrome will look at a potentially life-saving treatment in a trial involving 500 patients, led by the team from Royal Brompton.

Marfan syndrome is an inherited condition, affecting one in 3,300 people in the UK. It affects the body's connective tissues, which provide support and structure to other tissue and organs. The symptoms vary and can affect blood vessels, the heart and the skeleton and can cause the wall of the main blood vessel in the heart – the aorta – to expand. Without treatment, the aorta can eventually rupture, leading to life-threatening bleeding. The study will help to investigate whether a commonly used blood pressure treatment could reduce the expansion of the aorta and delay the need for major surgery.

The study is UK-wide, sponsored by Royal Brompton with support from St George's Hospital in London and the NIHR. Other partners include Oxford University and the Marfan Association UK.

Research taking place in the BRU

£3.1 million to fund CF gene therapy trial

Government funding has allowed a groundbreaking gene therapy trial for cystic fibrosis (CF) to continue at Royal Brompton. The £3.1million grant from the NIHR and the Medical Research Council (MRC) will fund the largest trial of its type yet, with 130 adults and children with CF taking part.

The trial is being co-ordinated by the UK Cystic Fibrosis Gene Therapy Consortium (GTC), a group of scientists and clinical teams from Royal Brompton, Imperial College London, the universities of Oxford and Edinburgh and NHS Lothian. The group has worked together for the last decade to develop gene therapy for CF, the most common life-limiting inherited disease in the UK, affecting around 9,500 people nationally and over 90,000 worldwide.

The GTC, co-ordinated by Professor Eric Alton, has won two prestigious Medical Futures Innovation Awards for its work on gene therapy for CF.

Professor Alton said: "Conventional treatments have extended the life expectancy for people with CF. We're hoping that this therapy will achieve a step change in the treatment of CF that focuses on the basic defect rather than just addressing the symptoms. This trial will assess if giving gene therapy repeatedly for a year will lead to the patients' lungs getting better. Eventually we hope gene therapy will push CF patients towards a normal life expectancy and improve their quality of life significantly."

Classification of interstitial lung diseases

Clinical researchers from Royal Brompton have provided the largest description of a new disease entity, idiopathic pleuroparenchymal fibroelastosis (IPPFE), a type of diffuse lung disease. Professors Athol Wells, David Hansell and Andrew Nicholson were on the expert panel that convinced the American Thoracic Society and the European Respiratory Society Committee that this disease sub-type should be added as a new entity in the updated classification of the idiopathic interstitial pneumonias. This move will lead to a deeper understanding of lung diseases and improved patient care.

Improving access to COPD therapy

Under the management of Dr Will Man, Harefield Hospital has a large and established pulmonary rehabilitation service for COPD.

Pulmonary rehabilitation is a clinically proven intervention, which has been shown to improve COPD patients' exercise tolerance and quality of life and reduce breathlessness episodes that result in hospital admissions. However, despite being recommended by NICE, uptake of pulmonary rehabilitation therapy is often poor.

Dr Man is leading a research project to ensure that patient access and uptake of this effective treatment for COPD is improved. Building on other research projects looking at pulmonary rehabilitation, Dr Man's new study, funded by the NIHR North West London Collaboration for Leadership in Applied Health Research and Care, will not only benefit COPD patients who could be referred to Harefield for pulmonary rehabilitation therapy, but also be applied more generally to other pulmonary rehabilitation services nationally.

National recognition for research leaders

The NIHR Senior Investigator Competition recognises the UK's most outstanding leaders of clinical and applied health research. In 2011/12, two of our clinicians, Professor Kim Fox and Professor Carlo DiMario (cardiovascular medicine), were appointed to the NIHR Senior Investigator Faculty and Professor Peter Barnes (respiratory medicine) was also successful in his re-appointment. This brings the Trust up to a total of eight NIHR Senior Investigators, amongst the 200 or so nationwide. Other Trust clinicians recognised by NIHR with this prestigious award are Professors Peter Barnes, Kian Fan Chung, Tim Evans and Andrew Bush (respiratory medicine) and Professors Dudley Pennell and Martin Cowie (cardiovascular medicine).

Clinical support

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.

Royal Brompton and Harefield hospitals benefit from:

- Top-rated, state-of-the-art intensive care units, staffed round the clock by expert nursing and medical staff.
- Specialist diagnostics facilities on site including high-tech imaging, pathology, and laboratory services.
- Access to our cardiovascular and respiratory BRUs.

State-of-the-art ICUs

As a tertiary centre offering highly specialised surgery and expert care for patients suffering complex respiratory and cardiac illnesses, intensive care facilities at both hospitals 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 nursing and medical staff. The expertise of these units is recognised throughout Europe.

The hospitals have a total of 40 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.

Royal Brompton also has 12 paediatric intensive care beds.

Advanced imaging on site

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

We have a track record of significant investment in imaging technology, including the recent installation of the most sophisticated CT scanner in Europe that can scan a chest in 0.6 seconds and the heart in just two heartbeats. In many cases, such technology allows diagnosis without the need for invasive procedures.

The Trust's cardiovascular BRU 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.

Echocardiography

The consultant-led echocardiography service at both hospitals 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.

The echocardiography department at Royal Brompton has delivered a number of new service initiatives over the last 12 months including a dedicated echo service to oncology patients as part of the cardiac oncology service. Almost 18,000 echos are performed each year at Royal Brompton.

The echocardiography department at Harefield has three full-time echocardiographers and three echo machines, and nearly 10,000 echos are performed per year.

Nuclear medicine

The nuclear medicine department forms part of the Trust's clinical support services and performs almost 11,000 studies per year. The 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.

Laboratory medicine

Our laboratory medicine teams provide an expert service to support the specific requirements of a specialised trust for diseases of the heart and lung, including clinical biochemistry, haematology, blood transfusion, microbiology, histopathology, cytology and phlebotomy. Haematology and clinical biochemistry work together in our blood sciences laboratory.

Our services include:

Clinical biochemistry

The service continues to offer 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 teams work closely with the clinical teams to provide diagnostic and therapeutic support for our patients, with particular emphasis on bleeding and thrombotic disorders. Clinical advice is available at

all times to support our patients' complex needs. A specialist anticoagulant service 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 and blood transfusion.

Surgical reporting service

The Trust specialises in the diagnosis of tumours and interstitial lung diseases, heart and lung transplant rejection, vascular and cardiac disease identification by 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

The team utilises a wide range of antibodies in the diagnosis of carcinomas, lymphocyte markers, epithelial markers, mesotheliomas, germ cell tumours, sarcomas and neuroendocrine markers.

Autopsy service

A full autopsy service is available at the Trust.

Rehabilitation and therapies

The rehabilitation and therapies 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 unit underwent a major review and reorganisation in 2011, to enhance services to the clinical divisions. This involved the creation of multi-professional therapy teams, both general and disease-specific, which has led to the increased engagement of rehabilitation and therapy staff within the clinical divisions.

Recent developments include:

Complex discharge

Both hospitals now have a dedicated complex discharge team. The teams consist of specialist professionals from a range of backgrounds including nursing, social work and welfare rights, which ensures there is a 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 and for older people.

Psychiatry

A new part-time consultant liaison psychiatry post has been developed, supported by a full-time psychiatric liaison nurse. This ensures a more supportive and integrated service can be provided to patients with mental health problems at the Trust.

Psychology

The service has received funding from Asthma UK to run a randomised controlled trial starting in summer 2012 to evaluate the effectiveness of a cognitive-behavioural group intervention to treat anxiety and depression in patients with severe asthma.

Palliative care services

The specialist palliative care service at Royal Brompton has begun a research trial developing and evaluating the Hospital2Home palliative care service for patients with interstitial lung disease (ILD).

The Trust benefits from specialist clinical support on site

Improving the patient experience

Our staff are committed to delivering excellent care and services to our patients. We are also committed to continuously improving the patient experience and this is reflected year on year in the positive feedback we receive from patients.

Adult outpatient and inpatient surveys

The Trust participated in two national surveys in 2011/12 and performed well.

According to the results of the 2011 Care Quality Commission's (CQC) National Outpatient Survey patients gave an overall score of nine out of 10 in feeling satisfied with their visit to the outpatients department, which puts us in the top performing 20 per cent of trusts in England.

Inpatients were also "highly satisfied" with the care they received at both hospitals.

We achieved a score of "better", which means that we performed above the national average when compared with other Trusts, in key questions in the 2011 CQC National Inpatient Survey, including:

- How would you rate how well the doctors and nurses worked together?
- Overall, did you feel you were treated with respect and dignity while you were in hospital?
- How would you rate the hospital food?
- Were there enough nurses on duty to care for you in hospital?
- Do you think the hospital staff did everything they could to help control your pain?
- Overall, how would you rate the care you received?

"Double excellent" score for patient environment

For the second year running the Trust received "excellent" scores for food and privacy and dignity in the annual PEAT (Patient Environment Action Team) assessment.

Patient comments from NHS Choices

"The cleanliness of the hospital was a credit to all the staff and the team work was obvious. Everybody worked well together. Everybody was very kind and caring and I am truly grateful."

"All the staff doctors &nurses and everyone did their utmost with care and attention for our son over a number of years. One could not wish for better care."

"Royal Brompton works like a big team where nurses, surgeons, outreach nurses and the most senior consultants work closely together."

"Royal Brompton food as good as last time I was here."

PEAT is an annual self-assessment of non-clinical services carried out by staff and patient representatives, and relates to the quality of the patient environment and experience in three areas: environment, food, and privacy and dignity. In 2010, we were rated excellent for food and privacy and dignity, scores attained again in this year's results. Environment was rated "Good" in both 2010 and 2011 but with a percentage improvement at both hospitals.

The category "Excellent" is described as "consistently high, exceeds expectations across all aspects of the element being measured" and is only met when scores reach 94 per cent or more for food, and 96 per cent or more for both environment and privacy and dignity.

Involving our patients and their families

Throughout the year, we hold events to involve our patients, their families and the public and to ensure we stay in touch. Events include:

- The annual members' meeting was held in October 2011. Among the highlights was a presentation by Professor Andrew Bush, respiratory paediatric consultant, on the Trust's approach to managing children who experience severe asthma.
- The clinical nurse specialist for chronic obstructive pulmonary disease (COPD) organises a monthly support group for patients with breathing problems. Presentations are given by respiratory physicians and patients have the opportunity to ask questions. Patients have told us that they find these sessions valuable and as a result, have a greater understanding of their condition.
- The intensive therapy unit (ITU) at Harefield held an "Accelerated Experience Based Co Design" project, which provided an opportunity for patients, carers and staff to work together to help improve ITU services.

Comment forms

Comment forms were introduced in both our hospitals in 2007 and are given to inpatients when they are discharged so they have a chance to comment on their care.

Feedback is collated by the Quality Improvement Facilitator (QIF) and then staff can take action so any improvements for patients can be made. Over 80 per cent of patients completing the comment forms rate their care as "Excellent" and a very high percentage of patients say they would recommend us to a friend or family member (usually above 95%).

Our influence around the world

The Trust is a well established and widely recognised brand, acknowledged internationally. We employ several clinical experts with world-renowned expertise and reputations. Clinical experts join us from around the globe and come to work, study and train at our hospitals, either at their own expense or funded by governments and/or healthcare organisations. Many return to lead institutions within their home countries.

Our own clinical experts travel widely, giving lectures and presenting at conferences. Many hold key positions on influential boards, committees, institutions and professional associations. Some examples of our worldwide influence during the year are:

Lectures and presentations

Professor Michael Polkey, consultant physician in respiratory medicine, travelled to China to explore the value of Tai Chi as a form of rehabilitation. In Guangzhou he watched Professor Yuan Ming Luo carry out physiological studies of COPD patients doing Tai Chi. He accompanied the professor to the People's Hospital in Xingning and took part in discussions with clinicians about how a larger, collaborative study geared to clinically relevant outcomes might be undertaken. Professor Polkey has worked with Professor Luo since 1996 and they have published some 25 papers together.

Mr Eric Lim, consultant thoracic surgeon, was an invited speaker at the European multidisciplinary conference in thoracic oncology in Lugano, Switzerland, in February and the Perspectives in Lung Cancer conference in Turin, Italy, in March. He also chaired the Brompton Session (the most prestigious session) at the European Society of Thoracic Surgeons in Marseille in June. Mr Lim was also an invited speaker at the World Circulating Tumour Cells summit in San Diego in November where the results of a blood test for lung cancer developed at the Trust was presented. The cutting edge research promoted department and industry collaboration leading to the successful identification of cancer cells circulating in the blood.

Members of Royal Brompton's adult congenital heart disease (ACHD) team were keynote speakers at the sixth international Ukrainian Forum on congenital heart disease at the Ukrainian Children's Cardiac Centre in Kiev attended by around 200 people. The team comprised Dr Lorna Swan, consultant cardiologist/clinical lead for ACHD, Mr B Sethia, consultant in congenital cardiac surgery, Dr Mike Rubens, consultant radiologist, Dr Sonya Babu-Narayan, ACHD specialist registrar, and Kiev trained Iryna Atamanyuk, cardiac surgery specialist registrar. Their presentations included a session by Dr Swan on the impact of pregnancy on young adults who has heart operations as children, a session on imaging by Dr Rubens and a talk on long-term issues faced by children with heart disease by Dr Babu-Narayan. The team appeared on Ukrainian TV and an interview with Mr Sethia was included in the broadcast.

Martin Cowie, professor of cardiology, lectures widely both in the UK and abroad on heart failure and health technology assessment. During the year he delivered the Irwin M Weinstein Endowed Lecture in Health and Public Policy at Cedars-Sinai in Beverley Hills, Los Angeles entitled: "Implementing new evidence in heart failure: a transatlantic perspective on delivering and performance managing a high quality service".

A number of consultants and staff, including those from the simulated paediatric resuscitation team training *(SPRinT)*, presented talks and held workshops at the European conference and annual scientific meeting of the Paediatric Cardiac Intensive Care Society (PCICS) in Cambridge. The event was organised by director of children's services, Dr Duncan Macrae, and featured delegates and speakers from the USA, France, Canada, Germany, Austria, the Netherlands, Switzerland, Poland, Belgium Singapore, New Zealand and the UK.

(continued overleaf)

Professor of paediatric respirology, Andrew Bush, continues to lecture at conferences, conventions and other prestigious events around the world. During the year speaking engagements included a lecture on lung growth and development at the National Congress of Pneumology and Thoracic Surgery in Cancun, Mexico. He also presented an update on severe and difficult-to-control paediatric asthma and future trends and key research areas in paediatric pulmonology at the Convention of Lithuanian Paediatric Respiratory Society in Vilnius, Lithuania. Professor Bush was also a lead author or contributor to more than 30 abstracted articles to appear in international medical journals.

The transplant team, led by consultant cardiac surgeon and director of the transplant service, Mr André Simon, gave presentations at major international conferences in Philadelphia, San Diego, Lisbon, Milan, Amsterdam and Stuttgart with Mr Simon leading presentations at the Philadelphia, San Diego and Lisbon events.

Senior appointments

Consultants, Professors Athol Wells, David Hansell and Andrew Nicholson were appointed co-chairs of the respiratory, radiology and pathology groups of the American Thoracic and European Respiratory Societies Committee. The committee is developing a new classification of idiopathic interstitial pneumonias – a type of diffuse lung disease. They are also co-authors of a new set of recommendations on the management of patients with idiopathic pulmonary fibrosis, which were published in the *American Journal of Respiratory and Critical Care Medicine*.

SPRinT director and paediatric consultant, Dr Margarita Burmester, was elected to serve on the International Paediatric Simulation Society (IPSS) board of directors in November 2011 and Dr Ajay Desai, paediatric consultant intensivist became a member of the education committee of the IPSS in March 2012.

International awards

Consultant cardiac surgeon and interim director of the clinical trials and evaluation unit, Professor John Pepper, was part of the team awarded the medical and healthcare prize at the 2011 Technology and Innovation Awards. The team, which included colleagues from Imperial College London, devised a new implant for aortic valve replacement, which involves a significantly less intrusive, shorter operation than previously used. Professor Pepper was the first in the world to perform this surgery, using a device designed by patient Tal Golesworthy. Professor Pepper said: "I am delighted to have been part of the team that produced this new implant. This will really benefit patients in the future, with a shorter operation and quicker recovery time."

In February 2012, Professor Dudley Pennell, consultant cardiologist at Royal Brompton Hospital, professor of cardiology at Imperial College London, and director of the cardiovascular magnetic resonance (CMR) unit at Royal Brompton Hospital, was awarded the Society for Cardiovascular Magnetic Resonance's (SCMR) highest honour – the Gold Medal – for "outstanding achievement and exemplary service". Professor Pennell has specialised in CMR for more than 20 years and during that time has been responsible for significant changes in the care of people with cardiomyopathies (heart muscle disease) and thalassemia major. Professor Pennell said: "I am honoured to receive this award from the SCMR and immensely proud of my work with them over the years. It has been my privilege to lead the development of Royal Brompton's CMR unit and to have had an impact on providing better treatments and life outcomes for patients with debilitating and often life-threatening heart conditions."

Professor Dudley Pennell receving his gold medal from the Society for Cardiovascular Magnetic Resonance

Our charity

ROYAL BROMPTON &HAREFIELD HOSPITALS CHARITY

Anything goes at the Harefield Fun Run!

Royal Brompton & Harefield Hospitals Charity is a registered charity dedicated to supporting the outstanding work that takes place at both hospitals.

This year the charity was able to donate £2.3 million to the new paediatric sleep centre, which will open at Royal Brompton in late 2012. The donation will ensure that children who have a sleep study at the hospital have a more relaxing and comfortable experience in a purpose-built centre.

The sleep centre also provides home ventilation support for children with neuromuscular and chest wall conditions such as muscular dystrophy and curvature of the spine. Having access to non-invasive ventilation using small portable ventilators at night, extends survival, reduces hospital admissions and improves breathing problems for these children.

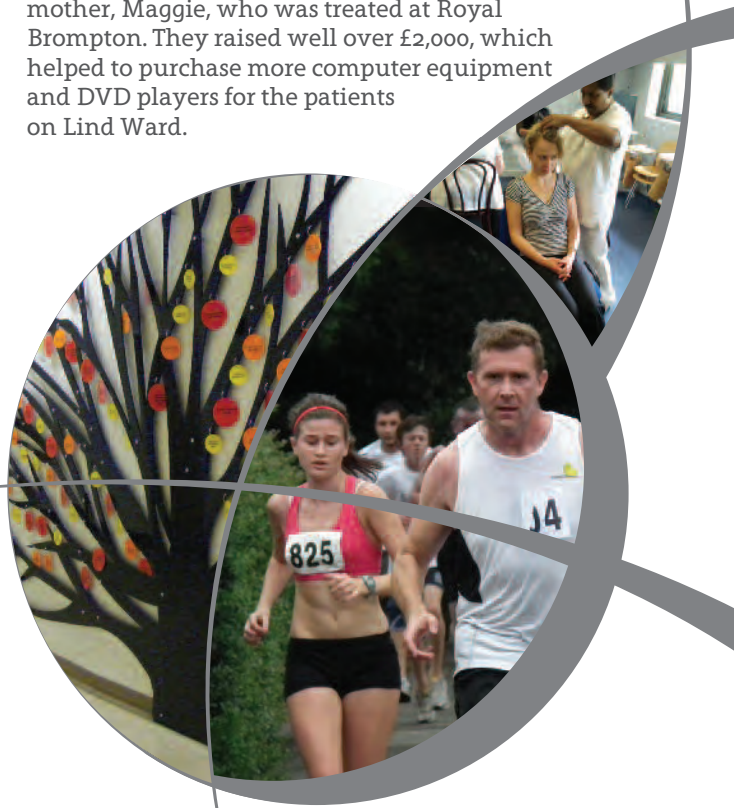
The period has seen fundraising income continue to grow, despite the very challenging economic climate. This is largely due to the overwhelming generosity of our donors and the hard work of all our staff and committed volunteers. Our thanks go to everyone who puts time and effort into raising money for us.

Highlights of the year

- The donor and supporter trees at both hospitals continue to be a valuable source of income raising £24,000 last year. The trees give our patients and families a way to express their thanks for the care they have experienced.
- Digital and electronic fundraising has been introduced and allows people to make small donations easily and quickly, either on-line or by the popular SMS system.
- A "Party in the Palace" organised by Royal Brompton children's unit raised over £100,000.
- The Harefield Hospital Fun Run continues to make an invaluable contribution towards the appeal for a new MRI (magnetic resonance imaging) scanner at the hospital. In September 2011 over 1,000 people took part on the day, raising over £34,000.

Special thanks to:

- New Haw Running Club (Team NHRC) members Sarah Couzens, Helen Taylor, Natalie Cottrell, Miles Cottrell, Anna West and James Taylor who took part in the Brighton Marathon 2011 in memory of Michelle Cottrell and her baby son Oscar who were treated at Royal Brompton. Over £10,000 was raised for the adult intensive care unit.
- Team Ross, a group of family and friends who have been fundraising for the past seven years in memory of Ross Tavendale, who was cared for at Harefield. The group holds three events per year and aims to fund a conservatory for the transplant unit. To date nearly £39,000 has been raised.
- Ron Mead, who following a successful heart transplant 19 years ago, began fundraising with his wife Sylvia in support of Harefield. Ron makes wooden bird tables and other garden accessories and Sylvia has hosted garden parties. They have raised almost £16,000.
- Adam and Emma Francis took part in a sky dive in February this year in memory of their mother, Maggie, who was treated at Royal Brompton. They raised well over £2,000, which helped to purchase more computer equipment and DVD players for the patients on Lind Ward.



rb&h Arts

(clockwise from top left) The Brit School perform; Daniel, winner of the annual exhibition; Singing for Breathing in action; a large panel created by Emily Allchurch and patients in the adult congenital heart unit.

In the build up to its tenth anniversary, the Trust's charitable arts programme, rb&hArts, has been bringing ever-more innovative work to the hospitals, and spreading its wings on the international stage.

The use of arts in healthcare has developed beyond all recognition over the last decade. Hundreds of community-based projects in the UK alone work alongside hospital-based programmes like the Trust's to try to ensure that people are treated not as a collection of symptoms, but as individuals, and as members of a society in which culture plays a major role.

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

Artist, Emily Allchurch led two major new installations this year, beginning with six days of workshops in Harefield's transplantation unit. Thanks to the enthusiasm and skill of patients, families and members of staff, a huge collection of drawings, photographs and collages, all focused on bringing nature into wards, was brought together by Emily to create 70 new panels, bringing light and optimism to spaces often characterised by anxiety and distress. One patient said: "To see something cheerful and colourful, knowing that people in the same situation or similar have participated, is wonderful."

Following generous support from the friends and family of Andrew James, who was treated in Royal Brompton's adult congenital heart unit for many years, Emily then worked with the unit's patients to create installations for the area. The project resulted in two giant panels for the corridor, several smaller panels for individual rooms, and an exhibition in Royal Brompton's coffee shop with photographer, Sue Snell, documenting the project and examining the relationship between long-term cardiac care and art-making.

Other exhibition highlights this year included "Drawing Breath", a collaborative show focused on breath and exercise, created by Jean Fraser who also lives with chronic obstructive pulmonary disease. The largest ever annual staff and patient exhibition was also held, with a total of over 150 works of art, an increase of over 40 per cent on the previous year's entries.

The normal programme of live music continued with regular performers, Groanbox and Les Boum, and newcomers, Anima, entertaining patients and staff alike. A developing partnership with specialist music charity, Nordoff Robbins, has also brought music therapy to the Trust for the first time. Ellie Walker, a trainee music therapist studying with Nordoff Robbins, began a year-long placement this January in Royal Brompton's respiratory wards, with plans to move into the cardiac wards later in 2012. Feedback has been very positive, a typical patient response being: "It took my mind off my illness and cheered me up."

For the second year, Nordoff Robbins also brought students at the internationally renowned Brit School to perform in public areas and wards as part of their professional development. Staff commented that the performances "lifted morale on the ward", and patients said the singers were "relaxing", and "fantastic".

Singing for Breathing, the Trust's groundbreaking project using singing training to support respiratory patients, this year launched a new practise CD by Phoene Cave. The project is at the forefront of work around the world looking at how singing can affect a variety of health conditions, and as a result was presented at the Southbank Centre's Chorus Festival, at "The Art of Good Health and Wellbeing", Australia's international arts and health conference, at Sense of Sound's national singing and health conference in Liverpool, and to Breathe Easy groups across the UK. The regular singers also staged a Christmas performance at Royal Brompton with the Kensington Singers community choir.

As the year progressed there has been more focus on the development of collaborative work – whether internal or external, local or international. Relationships with organisations like Nordoff Robbins, or Imperial College's medical humanities team, allow us to offer a broader, more effective programme, and to call on the skills of a rapidly developing arts in health sector. It is hoped these relationships will continue to develop and prosper in the years to come.

Governance

As a foundation trust we are governed by an elected council of governors and independently regulated by Monitor. We have over 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. 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 public constituency, a staff constituency and a patient constituency. The constitution also makes provision for a governors' council comprising both elected and appointed parties. The elected parties are drawn from the membership and the appointed parties represent key stakeholders. In 2012/13 the Trust will be required to make some changes to the constitution in order to comply with the Health and Social Care Act 2012 which received Royal Assent on 27 March 2012. This will give greater operational freedom but with some additional responsibilities.

The governance structures comprise:

The governors' council, 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.

Our board members:

Executive members

Mr Robert J Bell
Chief executive

Mr Robert Craig
Chief operating officer

Professor Timothy Evans
Medical director

Dr Caroline Shuldham
Director of nursing and clinical governance

Mr Richard Paterson
Associate chief executive – finance

Non-executive members

Chairman:
Sir Robert Finch

Non-executive directors:
Mr Nicholas Coleman

Mrs Jenny Hill

Mr Richard Hunting

Mr Neil Lerner

Professor Sir Anthony Newman Taylor

Ms Kate Owen

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 2011/12 is available on our website as well as on the NHS Choices website.

Our governors' council

Public governors

Mr Kenneth Appel	Bedfordshire and Hertfordshire
Mr Philip Dodd	North West London
Mrs Caroline Greenhalgh	South of England
Mr Brian Waylett	Rest of England and Wales

Patient and carer governors

Mrs Sheila Cook	Rest of the UK
Mr Richard Baker	South of England
Mr Peter Rust	North West London
Dr Adrian Lepper	Representing patient carers
Mr Anthony Connerty	Bedfordshire and Hertfordshire
Mrs Mary-Anne Parsons	Rest of the UK
Mr Peter Kircher	Bedfordshire and Hertfordshire

Appointed governors

Councillor Mrs Victoria Borwick	Royal Borough of Kensington and Chelsea
Prof Michael Schneider	Imperial College London
Mrs Allison Seidlar	Hillingdon NHS PCT
Prof Peter Rigby	University of London
Mr Ray Puddifoot	London Borough of Hillingdon

Staff governors

Ms Sue Callaghan
Dr Olga Jones
Prof Margaret Hodson
Mr Robert Parker
Dr Ian Balfour-Lynn

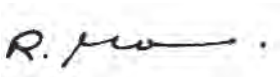
Lord Newton of Braintree
29 August 1937 – 25 March 2012

It was with a great deal of sadness that we received the news in March that the Trust's former chairman, Lord Newton, had passed away after a long illness.

Lord Newton was a much-respected and admired chairman who dedicated his life to public service.

He joined the Trust as chairman in 2001 and led the organisation through some very challenging times with integrity, wisdom and compassion. He was devoted to our hospitals and, as a former government health minister, acted as a valuable ambassador for us in the corridors of Whitehall and in the Houses of Parliament. As recently as autumn 2011 he was still championing our cause in the House of Lords.

Tony Newton was a consummate English gentleman. He remained calm and composed at all times, an example to us all. He was also an exceptionally kind man who hated injustice and actively supported minorities. For many at the Trust he became a friend, an advisor and a confidante, but he was also a leader who could guide us through the most demanding situations. He will be greatly missed on a personal and on a professional level.



Mr Robert Bell
chief executive

Profile in the media

As a centre of excellence delivering cutting edge care and research, our clinicians, clinical practice and innovation regularly feature in regional, national and international media. Here is a small selection of examples from 2011/12.

The Observer and Sunday Express *June 2011*

A £30 million cystic fibrosis research programme at Royal Brompton was featured in the national media in June. The project is led by Professor Eric Alton, honorary consultant physician at Royal Brompton, and involves a collaboration of experts in London, Edinburgh and Oxford. The team is on the threshold of developing a revolutionary gene treatment with the potential to save thousands of lives.

Daily Express *June 2011*

Harefield Hospital patient John McCafferty was featured in the Daily Express in June. He has become the UK's longest surviving heart transplant patient, having had his operation in October 1982.

BBC One and The Sun *September 2011*

TV chef James Martin filmed Royal Brompton's catering team for his series on hospital food. James spoke to catering manager, Mike Duckett, and chef, Harry Arthur. James went on to give further praise for the Trust's work in a subsequent article in the Sun newspaper. The quality of Royal Brompton's catering received further high profile endorsement when it was praised by HRH Prince Charles at a Soil Association event to celebrate excellence in hospital food at Clarence House in December 2011.

Prince Charles in conversation with Mike Duckett.
Photo courtesy of Arthur Edwards, The Sun

BBC One *March 2012*

Clinical teams from both hospitals featured on the BBC's One Show in a short film about "cutting edge" medical procedures. The programme demonstrated the innovative equipment and training in the STaR centre (simulation, training and resource centre) at Harefield and also featured Royal Brompton's award-winning *SPRinT* programme (simulated paediatric resuscitation team training) at Royal Brompton.

The Mail on Sunday *October 2011*

An interview with double lung transplant recipient, Kirstie Tancock, about life before and after her life-saving operation, appeared in the Mail on Sunday in October. She described how doctors used extracorporeal membrane oxygenation (ECMO) to keep her alive and how her life has improved since leaving hospital. This was one of several magazine and newspaper interviews Kirstie gave ahead of a BBC documentary, "Love on the Transplant List". The documentary followed Kirstie throughout her time at Harefield before and after her transplant and at home as she prepared for her wedding.

The Sun *November 2011*

The UK's biggest selling newspaper joined the Daily Mail and ITV London News in featuring the cardiac rehabilitation team at Harefield, which has joined forces with the country's largest dog welfare charity to help patients improve their heart health. The scheme, the first of its kind in the UK, pairs up patients with unwanted dogs with both parties benefiting from exercise from dog-walking.

Children's heart surgery review *July 2012*

The review of children's heart surgery was covered extensively in the media throughout 2011/12. The Trust's robust arguments were presented across broadcast, print and digital media with particular highlights seen in the Sunday Times Review, BBC One's "Inside Out" documentary series, the Times and widespread London media outlets (e.g. LBC radio, ITV London Tonight, Evening Standard).

Summary accounts

Our accounts are prepared in accordance with the 2011/12 NHS Foundation Trust Annual Reporting Manual (FReM) issued by Monitor, the independent regulator of NHS foundation trusts. The comparative figures below are for the year to 31 March 2011 (restated).

STATEMENT OF COMPREHENSIVE INCOME for the year to 31 March 2012

	year to 31.03.12 £000	*year to 31.03.11* £000
Revenue from patient care activities	267,165	253,484
Other operating revenue	32,995	32,690
Operating expenses	(293,260)	(276,794)
OPERATING SURPLUS	6,900	9,380
Investment revenue	33	32
Revaluation gain on investment property	1,327	4,028
Finance costs	(46)	(45)
Unwinding of discount	(20)	(20)
SURPLUS FOR THE FINANCIAL PERIOD	8,194	13,375
Dividends payable on Public Dividend Capital (PDC)	(6,387)	(6,509)
RETAINED SURPLUS FOR THE PERIOD	1,807	6,866
OTHER COMPREHENSIVE INCOME:		
Impairments	(1,356)	(5,892)
Revaluation gain on operating properties	1,177	947
Total comprehensive income for the period	1,628	1,921

STATEMENT OF FINANCIAL POSITION as at 31 March 2012 (2011 restated)

	as at 31.03.12 £000	as at 31.03.11 £000
NON-CURRENT ASSETS		
Property, plant and equipment	185,815	189,224
Investment properties	27,155	25,828
TOTAL NON-CURRENT ASSETS	212,970	215,052
CURRENT ASSETS		
Inventories	9,974	10,843
Trade and other receivables	15,414	18,551
Cash and cash equivalents	22,598	16,679
TOTAL CURRENT ASSETS	47,986	46,073
TOTAL ASSETS	260,956	261,125
CURRENT LIABILITIES		
Trade and other payables	(36,475)	(32,766)
Borrowings	(5,251)	(12,959)
Provisions	(2,552)	(143)
TOTAL CURRENT LIABILITIES	(44,278)	(45,868)
NET CURRENT ASSETS	3,708	205
TOTAL ASSETS LESS CURRENT LIABILITIES	216,678	215,257
NON-CURRENT LIABILITIES		
Borrowings	(62)	(210)
Provisions	(985)	(1,047)
TOTAL NON-CURRENT LIABILITIES	(1,047)	(1,257)
TOTAL ASSETS EMPLOYED	215,631	214,000
FINANCED BY:		
TAXPAYERS' EQUITY		
Public Dividend Capital (PDC)	104,759	104,759
Retained earnings	54,085	52,275
Revaluation reserve	56,787	56,966
TOTAL TAXPAYERS' EQUITY	215,631	214,000

For a copy of the Trust's annual report 2011/12, please contact the finance office on 020 7351 8243.

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