Royal Brompton & Harefield NHS NHS Foundation Trust

Annual Review 2010/11







Harefield Hospital

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Arabic

ذا التربت راغبا أنساي الرحم ول على رساخة بشير جدة سال في العرسية من خا الشوّدين الرحاء المتوري جوشروس (شاي شاريق ال أشعر ال التور) فاي ال أشعر ال بد a.marciano@rbht.nhs.uk, 020 7351 8671

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Large print

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Introduction from the chairman and chief executive

31 August 2011

This has been an unusual year for the Trust. Within this review you will read about some of the many achievements that characterised most of the period. You will also become aware of the frustrating and challenging events that marked the end of it.

Two major highlights of the year were the official openings of our cardiovascular and respiratory Biomedical Research Units (BRUs). Cutting-edge research has always been a priority for the Trust and for our primary academic partner, Imperial College London. But with the BRUs we have created something truly innovative in terms of research, education and training, which will bring great benefits for patients of all ages with heart and lung disease, and will enable clinicians to identify those at risk at a much earlier stage, before symptoms have even occurred. Having such state-of-the-art facilities on site means that the synergy between research and clinical treatment is greatly enhanced, with some of the most advanced equipment and facilities in Europe being available to our patients. Significant funding of nearly £20 million from the National Institute of Health Research will ensure that both immediate and longer-term research strategies can be followed.

Our Trust-wide programme of capital investment continues. The culmination of two years' work saw the successful amalgamation of Harefield's cardio and thoracic theatres into a single suite, offering greatly improved facilities. At Royal Brompton, configuring the high dependency unit onto one floor has seen similar benefits. Investment in our current campuses will run alongside a major re-development planning exercise for the Trust's estate during 2011-12.

In February, news that a joint committee of primary trust chief executives was recommending that children's heart surgery should be discontinued at Royal Brompton, came as an unwelcome shock to us, and to the many thousands of families who have benefited from the expertise of our paediatric teams.

Change is a constant feature in the NHS, and indeed in all health systems. As a specialist Trust we have been responsible for making discoveries that have vastly changed, for the better, the treatment of heart and lung disease. But from both a clinical and a managerial perspective, we expect change to be about improvement, to be backed by evidence and for decisions that will significantly impact on patient care to be entirely transparent. Sadly this has not been the case with the children's heart surgery consultation.

Elsewhere in this review (p 20-21) you will find details about how the Trust found itself in the unenviable

position of applying for a judicial review. But perhaps the single most disturbing aspect of this activity, and events leading up to it, has been the top-down approach that has characterised its processes.

The Trust's financial results are included in this report. In the context of the present economic environment they are particularly gratifying. The potential threat to our continued success in the manner proposed by the children's heart surgery review is of great concern. Seen against the backdrop of renewed funding for our BRUs, it is also perplexing.

The NHS as a whole is likely to experience a number of challenges over the coming year. As a foundation trust in its third year of authorisation, we are in a strong position to respond to the demanding environment. The foundation trust designation carries with it a robust governance regime, which promotes effective leadership from the board, and an active membership and council of governors that guestions and challenges the executive. This partnership works well for us, facilitating the Trust's mission to be the UK's leading specialist centre for heart and lung disease. We will meet the challenges ahead as we have always done, with the support of our talented and dedicated staff, and by focusing on one overriding objective - to deliver the best possible care to our patients.

We hope you find this review both helpful and interesting.

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Sir Robert Finch, chairman



Mr Robert Bell, chief executive



Trust mission, values and our 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 lifetime of care

Royal Brompton & Harefield NHS Foundation Trust is the largest specialist heart and lung centre in the UK and among the largest in Europe. The Trust is known throughout the world for its expertise, standards of care and research success.

Heart and lung diseases are the world's biggest killers, and global demand on specialist services to treat these conditions is increasing.

Our unique approach to caring for the individual patient from the womb to old age and concentrating surgical, medical and related specialities in one place, has gained the Trust an international reputation, as a leader in the field of heart and lung treatment and research.

Our care extends from women in their first trimester of pregnancy, through to patients in their 90s and beyond. We provide the largest centre for the treatment of cystic fibrosis in Europe and are the country's leading provider of complex surgery of the chest and lungs.

Discovering new treatments

Over the course of a 6o-year partnership with the National Heart & Lung Institute (NHLI – now part of Imperial College London) researchers at the Trust have pioneered the development of many aspects of cardiac and respiratory science and treatments for heart and lung disease. The NHLI now boasts 28 Imperial College professors, many of whom hold shared appointments as clinicians at the Trust.

In the Higher Education Funding Council for England's (HEFCE) Research Assessment Exercise (RAE), which grades every university's research output, Imperial College was found to have more cardiology researchers doing four-star work of "quality that is world-leading in terms of originality, significance and rigour", than any other centre in England. The Imperial/Trust team is also Europe's topranked respiratory research partnership and Royal Brompton was the only hospital in Europe to feature in Thomson Reuters' 'Essential Science Indicators' database for chronic obstructive pulmonary disease (COPD) in January 2010. This analysis looked at publications over a period of 10 years and included papers published by nearly 10,000 institutions across 113 nations. Five of Europe's top-rated researchers in respiratory medicine are active in the respiratory Biomedical Research Unit, run jointly by the Trust and Imperial College.





Performance and achievements in 2010-11

During 2010-11, our experts:

- Performed approximately half of all LVAD (artificial heart) procedures in the country
- Undertook over a third of lung transplants in the UK
- Saw 650 adults and 320 children with cystic fibrosis
- Ran the largest single-site pulmonary rehabilitation service in the UK
- Helped over 8,000 adults with breathing problems caused by diseases such as chronic obstructive pulmonary disease (COPD) and severe asthma
- Treated people with asthma over 2,600 times in outpatient clinics and 2,467 times as inpatients
- Treated an average of 120 patients per month at Harefield's Heart Attack Centre
- Maintained the Trust's position as Europe's top centre for respiratory research and the leading centre for COPD research in Europe, with Imperial College
- Were rated in the top three most highly cited health research teams in Europe for cardiac, cardiovascular and critical care, with Imperial College
- Opened respiratory and cardiovascular Biomedical Research Units in partnership with Imperial College London and the National Institute for Health Research (NIHR)







- Achieved some of the lowest rates of MRSA and *clostridium difficile* in England
- Achieved level 3 status, the highest possible, from the NHS Litigation Authority
- Received 'excellent' for food and privacy and dignity in the annual PEAT assessment
- Met and exceeded the national target for the 18-week wait in all months from April 2010 to March 2011
- Treated more patients who needed the most complicated type of surgery for their chest and lungs than anywhere else in the country
- Carried out 424 life-saving heart operations on children
- Treated more than 6,500 children in outpatient clinics
- Undertook 12,400 appointments for young patients in cardiology, respiratory and cardiac surgery clinics
- Saw patients from every strategic health authority in England, as well as patients from Scotland, Wales and beyond
- Undertook over 137,000 outpatient appointments and supervised nearly 30,000 inpatient stays



We carried out **424** life-saving heart operations on children

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 and acquired. Our teams are based around the following themes: arrhythmias (electrophysiology); congenital heart disease; heart failure; pulmonary hypertension; revascularisation (coronary artery disease); structural heart disease; and heart assessment including echocardiography.

Congenital heart disease – a lifelong condition

There are intrinsic advantages in a centre where all research and clinical care is based on a shared recognition that congenital heart disease is a lifetime condition.

Many patients with congenital heart disease need care from birth, through childhood and teenage years to adult life. As the largest centre in Europe for adult congenital heart disease and one of the largest in the UK for foetal congenital heart disease, we offer a seamless transition of personalised care for all patients from foetal life through infancy, childhood, adolescence and into adulthood.

This spectrum of care is also reflected in our multidisciplinary approach. Many of the advances that benefit our congenital heart disease patients are made by a host of complementary integrated clinicians and scientists – foetal cardiologists, morphologists, radiologists, electrophysiologists and others – who advance our understanding of the disease process as a whole.

Diagnosis in pregnancy – giving baby the best chance

Our multidisciplinary team delivers care throughout pregnancy, so that families are well prepared for the arrival of their baby, who will be treated by the team they have come to know.

Currently covering 10 per cent of all babies born in England, our foetal service continues to expand with a steady increase in the number of families seen for expert diagnosis and advice.

Most babies who are diagnosed with congenital heart disease are referred by maternity hospitals across the UK following the "20 week" ultrasound scan. We work closely with experts in foetal medicine units at partner hospitals, together providing the best possible care for pregnant women.



Dr Carvalho carries out an ultrasound scan to search for signs of foetal congenital heart disease

We also provide expert cardiac scans for high-risk families from a much earlier gestational age, offering these families the choice of having a foetal cardiac scan from as early as 13-14 weeks.

Our teams play an active role in providing training and education to ultrasonographers who carry out routine scans in low-risk pregnant women at regional, national and international level. It is through this training programme that more babies continue to be diagnosed with cardiac problems before birth.

Intricate surgery for newborns

Royal Brompton is one of only two hospitals in the country at which four surgeons handle over 500 congenital cardiac cases a year. It is also the only centre in the country to have undertaken over 1,000 interventions in one year for these diseases.

During 2010/2011, over 400 of the operations carried out were for paediatric cardiac surgery and that number is growing.

Consultant paediatric cardiac surgeon Mr Olivier Ghez says: "This year we have also seen an increased number of complex neonatal cases (newborn babies) and we can report very good results."

Mr Ghez trained in France and joined the Trust three years ago from La Timone Children's Hospital in Marseille. His special interests include neonatal heart surgery, congenital heart disease and circulatory assistance.

A patient's view

Familiar faces for worrying times

Despite being only three years old, Alexander Ellis has spent almost a year of his life in hospital.

Alexander's condition was diagnosed before he was born, during the routine 20-week scan. The sonographer at St George's Hospital in Tooting, London, contacted consultant foetal cardiologist, Dr Julene Carvalho, at Royal Brompton, who went to the hospital to give a fuller diagnosis and prognosis of the baby's rare congenital heart condition.

Alexander's parents, Charlotte and Tim, then visited Royal Brompton's paediatric intensive care unit (PICU) where the newborn would be transferred immediately after birth.

Charlotte says: "It was a very emotional and purposeful visit; seeing and speaking to parents and specialist nurses caring for children with similar complex heart conditions. Everyone was extremely supportive at a time when we most needed reassurance."

Smooth transfer to Royal Brompton

While Charlotte waited to be discharged after giving birth, Alexander and his father, along with a team of highly specialised and well-equipped medics and support staff, travelled to Royal Brompton where they were greeted by Dr Carvalho and her team.

"I arrived at PICU later that day and was overwhelmed with the care and support shown by the doctors and nurses. Accommodation was promptly provided and the midwives from adjoining Chelsea & Westminster Hospital ensured my own medical needs were met," says Charlotte. "The links Royal Brompton has with other hospitals like St George's and Chelsea & Westminster are excellent."

Although a heart operation was earmarked for Alexander, the team agreed he needed surgery for a more immediate gastric issue first. This took place on day two and the heart surgery on day five of Alexander's life.

"Our cardiac surgeon, Mr Hideki Uemura, was superb. He specialises in small babies with challenging cardiac conditions. He was simply brilliant and gave us the time we needed to understand the surgery, drawing the structure of heart and explaining the proposed procedure and alternative options in detail," explains Charlotte.

Impressive continuity of care

Mr Uemura also carried out further corrective surgery just before Alexander's second birthday, and he will carry out stage two once Alexander is four.

Alexander has now had six major surgical procedures requiring time in Royal Brompton's PICU and numerous ancillary procedures.

"On each admission staff greet us with such warmth and recognition," Charlotte says. "From Dr Carvalho doing regular scans and always giving support, and the dedication of Alexander's cardiac consultant, Dr Piers Daubeney, to the PICU staff, play room staff, milk nurses, doctors, cleaners, everyone – they are all familiar faces offering reassurance at worrying times. It's like a home from home and this is something that can't easily be recreated in a large, multidisciplinary hospital. The continuity of care is excellent."



A very young Alexander photographed with his parents at Royal Brompton in December 2009



Alexander playing at home with his older brother, Christopher



Mr Olivier Ghez, one of four paediatric cardiac surgeons at the Trust



Dr Jan Till, consultant in paediatric electrophysiology, shows an ICD to a young patient

He says: "Royal Brompton has a unique model of care for congenital heart disease and we take advantage of being co-located with the world-class adult service, with whom we interact on a daily basis. I specifically chose to come here because of the international reputation of the Trust. When I visited before deciding whether to apply, it was quite obvious that it was a highly functional centre – there is no equivalent in France at the moment and it would take more than ten years to re-group such expertise in one place."

"We are also supported by amazing imaging capacity such as the MRI and CT scanner providing extremely valuable 3D images and have extensive research programmes linked directly to world-class researchers," Mr Ghez adds.

Reflecting on the changes since he first qualified, Mr Ghez says: "The biggest change I have seen has been the move to all specialties becoming multidisciplinary and involved in the decision-making process. This has made treatment more efficient when the patient's condition needs lots of different expertise."

Treating abnormal heart rhythms

The incidence of heart rhythm disturbances (arrhythmias) in the population is rising. There are several different types of arrhythmia and both adults and children can be affected. Heart rhythm problems are the most common reason for adults with congenital heart disease to be admitted to hospital.

Harefield Hospital hosts a large and expanding electrophysiology service and Royal Brompton is one of the few centres in the country that treats both children and adults with abnormal heart rhythms. The service meets the needs of patients with conditions that cause the heart to slow down too much, for whom pacemakers may be fitted, or conditions that cause the heart to beat too quickly, which can often be cured with ablation (the use of radiofrequency energy to destroy the area causing the abnormal heart rhythm). Patients who have, or are at risk of having, life threatening heart rhythm problems due to the heart beating too fast, are treated with an implantable cardioverter defibrillator (ICD). This regulates their heartbeat and can pace the heart back to a normal rhythm or give an electrical impulse to return the heartbeat to a normal rhythm. To address the rising demand for electrophysiology, the Trust's service is currently being expanded to add another clinic and specialist EP consultant.

Our service for arrhythmia care in children is one of the largest in the UK, with our dedicated inherited cardiac disease and paediatric arrhythmia clinics seeing over 1,500 patients per year. As we offer a comprehensive service for both adults and children, this enables us to diagnose and treat patients of all ages within the same family at the same time.

A patient's view

A family affair

Henry Jennings has a life-threatening heart condition, long QT syndrome (LQTS), and had an ICD fitted at Royal Brompton in 2008 under the care of Dr Jan Till, consultant in paediatric electrophysiology.

Henry, who is from Crowthorne in Berkshire, explains: "I owe my life to the team at Royal Brompton. Dr Till has been excellent and worked with me throughout to ensure that I can live as normal a teenage life as possible. Having an ICD fitted at the age of 10 is very unusual and, in fact, I may not have even been offered the chance of such an operation in most hospitals until I was 16.

"The operation was done with both a paediatric and adult surgeon working together. That's one of the best things about Royal Brompton as the child and adult cardiac teams work together. I cannot imagine how I would feel and what my life would be like without this device. I certainly would not be living the full and active life I am now."

Henry first collapsed in 2006 when he was on holiday and tests diagnosed LQTS – an inherited disorder of the heart's electrical system that causes the heart rate to become irregular and stop following a shock or adrenaline rush.

Medication failed to prevent further seizures, so Henry was fitted with his defibrillator in 2008.

Dr Jan Till comments: "The operation was carried out by myself and electophysiologist Dr Jonathan Clague from the adult team. This combined his expertise in interventionist procedures and mine in the physiology of children.

"We used a technique pioneered at Royal Brompton that involves coiling the lead that is inserted into the heart to give it space to uncoil as the child grows."

The operation was a success and Henry's ICD works by monitoring his heart rate, giving him an electric shock when needed to get his heart rhythm back to normal.

"He has coped really well with the psychological effects of having a defibrillator and calls it Zeus after the Greek god of thunder!" adds Dr Till. "We



Henry Jennings (second from the left) with his family, four out of five of whom are being treated for heart conditions at Royal Brompton

have an excellent support network at Royal Brompton to help young people adjust to life after a procedure such as his. This includes the cardiac liaison team, who visit the family as well as the child's school and health visitors, forming a link between Royal Brompton and local community services.

Four out of the five members of Henry's family have a heart condition and they are all treated at Royal Brompton.

Henry says: "My nine-year-old sister Emma has a different heart condition to mine called dilated cardiomyopathy. She takes daily medication and will need care for the rest of her life. We have also found out that both of my parents have a different heart problem and they are at the first stages of their care at Royal Brompton. The doctors see us as a whole family to help us progress in the future."

Transition to adult services

A strength of the Trust's clinical services for children is the seamless transition to adult care. As both paediatric and adult services are on site, a unique working environment is provided to ease the transition of teenagers into the adult service, supported by a team that is well known to them and their families. This offers stability in provision of care at a time when the child is taking on responsibility for their own healthcare.

A patient's view

A smooth transition

Teenager Sophie Lyons lives a full and active life despite having a serious congenital heart condition and is being supported through the transition from paediatric to adult services by staff at Royal Brompton.

Sophie's first visit to Royal Brompton as a fourday-old baby was accompanied by flashing blue lights. She has been a patient under the care of consultant cardiologist Dr Michael Rigby ever since and says that she is glad to be staying at the hospital for her adult care.

Sophie says: "I have been visiting Royal Brompton all my life and the staff have always been so lovely to me and explained everything that was happening. When I became a teenager, I wanted to bury my head in the sand and ignore my condition, but the cardiac nurse specialists showed me that I could live an almost normal life as long as I looked after myself. The nurses have been a great support and are always available on email or by phone.

"I also trusted Dr Rigby and found him really approachable. I used to save up questions to ask him at my appointments, such as whether I could go on rollercoasters – which I could! In fact, I remember one phase when I wouldn't listen to anyone else and felt that other adults were using my condition to stop me having fun."

Sophie says that she feels prepared for the transition to the adult team and has been introduced to her new cardiac nurse specialist, Lynda Shaughnessy, who has explained her condition to her in more detail. Sophie adds: "This has given me a better understanding of what was originally wrong with my heart and



how it's been corrected over the years. Learning about my condition and treatment has been a very gradual process. When I was younger, the staff talked more to my parents than me, but now they talk to me on my own."

Margaret Jiggins is one of the team of cardiac nurse specialists who have looked after Sophie. She says the transition to adult services is a big step: "It's not just attending a different clinic, but a whole new approach. As an adult, Sophie will be empowered to take control of her own care and we have been helping her to prepare for this. It's also a difficult time for her parents as they have been so involved in her care since she was a baby. Although the transition will be tough, I know that Sophie will be brilliant as she has a very positive attitude towards looking after her health."

Congenital heart disease in adulthood

Royal Brompton Hospital appointed the country's first consultant in adult congenital heart disease (ACHD) in 1988 to reflect the philosophy that congenital heart disease is rarely cured by initial surgery and patients need help throughout their lives. Over 70 per cent of new attendees to ACHD clinics every year are from the Trust's own paediatric service.

Royal Brompton is an internationally renowned centre. At any one time there are seven or eight overseas research fellows, who have come from abroad either at their own expense or sponsored by their own governments in order to experience what Royal Brompton Hospital has to offer. There have so far been 80 such international fellows who have contributed not only to the treatment of our patients but also to the advancement of learning.

A patient's view

Royal Brompton experts see the largest number of adults with congenital heart disease in the UK – more than 6,000.

Consultant adult congenital cardiologist, Dr Anselm Uebing, joined the Trust this year from University Children's Hospitals in Kiel, one of the largest congenital cardiac centres in Germany. His area of expertise is the treatment of congenital heart disease in adolescents and adults. Dr Uebing is working with consultant paediatric cardiologist, Dr Alan Magee, on the percutaneous pulmonary valve implantation programme to provide a less invasive alternative to open heart surgery. The procedure, which is undertaken in the cardiac catheter laboratory, aims to prevent right ventricular failure and arrhythmias without the need for surgery.

Feeling safe is priceless

Now aged 35, Tracie Giddy has been treated at Royal Brompton for her heart condition since she was two days old. Tracie was diagnosed with left atrial isomerism and double-outlet right ventricle, an extremely complex heart condition.

As she got older and took more of the responsibility for her condition, she transferred from the paediatric team to the adult team at Royal Brompton. Tracie says: "Royal Brompton has been almost a second home to me over the years in child and adult life and I feel safe, which I believe is priceless."

Tracie's consultant, Dr Lorna Swan says: "In addition to her congenital team Tracie has, over the years, needed expert input from the Royal Brompton's electrophysiologists, respiratory team and intensive care staff. Having all these teams working together has been very important for managing a person with complex heart problems."

Despite all the challenges she has faced, Tracie is now a mother herself to eight year-old Amber-Louise and three year-old Will. She was cared for during her pregnancies by the high risk pregnancy team, run by Royal Brompton and Chelsea & Westminster Hospital specialists. Tracie says: "I was actually really well during



Tracie, with her husband Mark and their children Amber-Louise and Will

both my pregnancies. I was advised to plan my pregnancies so that the necessary tests could be done, and then I was closely monitored by both hospitals. Both babies were screened during and after pregnancy to check that everything was ok with their hearts, which it was."

Tracie adds: "I haven't let my heart condition stop me from trying to do the things I want to do, although I do get very tired. My life is as near to normal as it can be with my condition, as long as I pace myself."

Treating more heart attack patients

The Trust's dedicated Heart Attack Centre at Harefield Hospital treats approximately 120 patients a month for primary angioplasty – emergency treatment to unblock the arteries in the heart. During 2010/11, the primary angioplasty service expanded its boundaries to serve patients from North West London, East of England and South Central strategic health authorities. The Heart Attack Centre has arrival-totreatment times that are among the fastest in the country, and in Europe.

The delegate's view

Heart Attack Centre welcomes over 100 conference delegates

Harefield Hospital's Heart Attack Centre was described as "slick" at the annual primary angioplasty conference, which welcomed over 100 delegates from London and the south east.

At the opening of the two-day event, Mark Whitbread, clinical practice manager at the London Ambulance Service, praised the hospital for its first-rate primary angioplasty service – the preferred treatment for patients suffering heart attacks. "Harefield probably provides the slickest service in the country," Mr Whitbread told delegates at the event.

Primary angioplasty uses a thin tube, called a catheter, and a tiny balloon to restore the blood flow through blocked arteries, preserving heart muscle from damage. Harefield's Heart Attack Centre delivers this expert treatment in record time – while the national average is of 56 minutes¹, the hospital has the shortest door to balloon time in the UK at just 23 minutes, with half of the interventions completed in under 20 minutes.

The annual conference is designed to provide a comprehensive review of all of the logistical and clinical considerations surrounding the delivery of primary angioplasty for heart attacks, with focus on teamwork between the ambulance service and the primary angioplasty centre. Over the two days, delegates witness live procedures, broadcast from the catheter laboratories, to give them a unique opportunity to learn from actual cases.

Welcoming delegates to the meeting, Dr Miles Dalby, consultant cardiologist at Royal Brompton & Harefield NHS Foundation Trust, said: "This annual conference offers a unique opportunity to share the interactive and collaborative work that ensures our Heart Attack Centre functions so effectively. We are delighted to welcome so many colleagues from the ambulance services and neighbouring hospital trusts once again this year."

The course was organised in collaboration with London Ambulance Service, East of England Ambulance Trust and South Central Ambulance Trust.



Dr Miles Dalby with members of the London Ambulance Service

1. Myocardial Ischaemia National Audit Project (MINAP): How the NHS manages heart attacks. Seventh Public Report 2008. www.rcplondon.ac.uk/clinical-standards/organisation/partnership/Documents/Minap%202008.pdf

A patient's view

Within two hours I was sitting up and drinking tea

Reflecting on the heart attack he suffered early in 2011, Kelvin Dubisson, 44, says: "When I look back, I was experiencing symptoms for a month at least – pain down my left hand side, lethargic, tired all the time. I put it down to indigestion and working too much and just carried on as normal. Three days before my heart attack, I was on holiday in Tenerife and that was when I realised something was wrong. I had pain in my chest and the next day my breathing was laboured as I walked up a hill. When we came home I made an appointment to see my GP."

Kelvin's symptoms were thought to be connected to an ulcer he had previously suffered and even when the heart attack struck the following day, the ECG (electrocardiogram) test performed by the cardiac response team who answered the emergency call did not reveal problems with Kelvin's heart rhythm.

Kelvin remembers: "I was taking the dog for a walk when it happened. All of a sudden, I felt like a belt was tightening around my chest, as if was being strangled inside. I called my wife, who dialled 999. Thankfully I wasn't far from home so I managed to make it back to the house and then the paramedics came. Even though my heart attack wasn't showing up on the ECG, they made the excellent call to take me to Harefield."

On arrival, Kelvin was rushed directly to the catheter laboratory for a primary angioplasty – emergency treatment to unblock the arteries to the heart – where doctors discovered Kelvin had a 90 per cent closed artery. Kelvin says: "I remember everything from that day so clearly. The doctor told me that yes, I was having a heart attack, but that they were going to fix me. It was very reassuring and also very quick, the procedure was done in half an hour and within two hours I was sitting up in bed having a cup of tea."

As with the majority of patients who are treated at Harefield's Heart Attack Centre, Kelvin was able to return home after two days where he was advised to take it easy and gradually build up his fitness and strength.

Kelvin says: "At first I didn't want to leave hospital as it felt so safe. But I built up my fitness by starting the cardiac rehab programme at Harefield about four weeks later. It really made a difference to my confidence too – not only are you under great



Following the cardiac rehab programme at Harefield Hospital, Kelvin Dubisson regularly works out at his local gym

supervision so you know what you're capable of but it's really enjoyable. There were also talks about things like diet, medication and the psychological side of recovery."

Following the cardiac rehabilitation programme, Kelvin has continued his exercise regime at his local gym in Ruislip. He adds: "I feel so much better now. My weight has dropped from 18 and a half stone to 16 and a half stone, my blood pressure is fine and my cholesterol is right down now. I know it sounds like a strange thing to say but this has been a blessing in disguise – it was caught early enough for me to be able to change my lifestyle."

Treating the failing heart

With a heart and lung transplant programme established in the early 1980s, Harefield Hospital has the largest group of heart and lung transplant survivors in the UK, for whom we provide lifelong care.

Harefield's clinical teams are recognised international experts in 'artificial hearts' (also known as left ventricular assist devices or LVADs).

Heart transplantation – the advance of the LVAD

For patients with advanced heart failure, transplantation offers the best chance of long-term survival and results in the best quality of life for most patients.

However, as a UK leader in the use of left ventricularassist devices (LVADs), also known as 'artificial hearts', valuable advances in patient care are being made. Consultant cardiologist Dr Nick Banner, who leads the heart failure care group, explains: "The pattern of practice has changed over the years. In heart failure, the number of transplants has declined due to the scarcity of suitable donor hearts. However, technological advances in mechanical circulatory support now allow us to use LVADs, which can enable patients to lead relatively normal lives until they are able to receive a heart transplant. In some cases, patients may even experience recovery from their heart disease on an LVAD and so be able to have the LVAD removed without having a transplant. Harefield has played a pioneering role in this type of treatment to promote myocardial recovery."

"Harefield surgeons are starting to use ex-vivo organ perfusion for heart transplantation and we hope that this will help us to increase the number of heart transplants," adds Dr Banner.

Harefield's transplantation centre covers most of the southern region of England. However some patients travel from as far afield as Wales for their transplant or LVAD implantation. "If there were a pill that cost very little, reduced cardiac deaths by 27 per cent, improved quality of life, and reduced anxiety and depression, every cardiac patient in Europe would be expected to take it. There is no such pill, but taking part in a cardiac rehabilitation programme can provide all these benefits."

Professor Bob Lewin, European Society of Cardiology, Amsterdam 2005

Cardiac rehabilitation – getting back to normal life

Cardiac rehabilitation is a comprehensive exercise, education and behavioural modification programme. It aims to improve not only the physical, but also the social and psychological condition of patients allowing them to resume as normal a place in the community following their cardiac event. The "Care for your Heart" rehab programme at Harefield Hospital was established in 1991 and the service has grown significantly over the years. It includes a large multidisciplinary team, including health promotion nurses, physiotherapists and other healthcare professionals, who lead educational sessions for patients in their early recovery period.

At the appropriate stage in their recovery, patients can take part in structured exercise sessions. Three levels of classes are available (including a heart failure exercise group) and patients attend 12 sessions. They undergo a full assessment both before and after the course and can be referred to appropriate options in the community for ongoing care following discharge.

New look operating theatres

In October 2010, cardiothoracic surgical services merged into one theatre suite following a complex two-year project to amalgamate surgical services at Harefield Hospital.

The new-look theatres improve and increase efficiency. Staff have simplified the workplace and storage areas, reduced waste and created digital display boards so they can always see what is happening in real-time and quickly locate team members. A new cardiac recovery unit located between theatres and the intensive care unit, has expanded overall critical care capacity by seven beds and provides a 'fast-track' for less complicated cardiac cases.





Cardiac transplant recipient Graham Farrar enjoying life on the farm after a 17-week stay at Harefield Hospital

A year past my sell-by date by Graham and Frances Farrar

Graham:

To be told that you are terminally ill with only a maximum of 18 months to live without a heart transplant is traumatic. But being able to share my experience over a year past that 'sell-by date' is testament to the skill of staff at Harefield Hospital.

Without warning, I became very unwell in January 2009 and was diagnosed with dilated cardiomyopathy (DCM). I was initially treated in the South West and thankfully my local cardiologist recognised that I should be referred to Harefield for assessment as a candidate for cardiac transplantation. I was placed on the potential recipient register in August 2009.

My condition during the next few months deteriorated dramatically. Not only were there the

inevitable, obvious symptoms – extreme fatigue, breathlessness, loss of motivation and despair, but also a decline in vital organ function – the liver and kidneys. In March 2010, Harefield's surgical team implanted left and right ventricular assist devices (VADs) – artificial pumps, to support my heart – pending the availability of a donated organ.

I was confined to bed and remained in the intensive therapy unit (ITU) for the next six weeks. This was a critical period drawing on the fathomless abilities of all disciplines available at Harefield – physicians, surgeons, the VAD teams, ITU nurses and intensivists. It is my understanding that I was a complex case and I am particularly indebted to Dr Nick Banner for his unfailing support and expertise. It was nine weeks after my VAD operation that I was woken up on the transplant ward, early one morning, by one of the transplant co-ordinators, who told me that a suitable heart might be available.

Recollections of the next five hours are quite vivid and surreal. Life suddenly became very busy with a stream of visits from the key players in the pending operation and others as news spread. Off-duty nurses were texted by those looking after me as there was a genuine air of excitement. Transplant co-ordinators provided frequent updates regarding progress with the organ recovery. I felt like an astronaut about to be launched into the unknown. As for my emotions, it was overwhelming relief. I was bedridden, with no chance of recovery, I would not survive without the two VADs and not for much longer with them. As I was wheeled along to theatre around 12 noon with my entourage of nurses, the VAD team, anaesthetists, theatre staff and, of course, my wife, I felt relief that whatever the outcome I was no longer going to be terminally ill.

Surgeons Mr André Simon and Mr Mohamed Amrani led the team in a successful transplant operation.

I don't recall coming round in ITU, I just became aware of being alive. I left the ITU after just four days to recover on the transplant ward. Initially physically too weak to stand or walk, under the expert supervision of the physiotherapists, I embarked on a rigorous rehabilitation programme, which was fundamental to my recovery, physically and psychologically. The constant support and care of the ward nursing staff helped me overcome the challenges of reintegration into the world; the first trip in a wheelchair into the summer air, around the grounds to the restaurant and into Harefield. Five weeks later, and once I was able to manage stairs safely, I was discharged.

This transplant has had a profound and positive impact on my life, something I really thought I was going to lose. During these past few months my wife and I have been able to revisit and progress many of the projects on our farm that we had to postpone in 2009. But there is another side to this story, that of the experience of my wife Frances and daughter Stephanie. Their extreme anxiety whilst I was in ITU can only be imagined. Arguably it is the relatives of long-stay patients who have the toughest time. My wife stayed with me at Harefield for all but one of my 17-week stay.

Frances:

"Being removed from your home environment (250 miles in my case) and the support of friends for such a prolonged period can be a very lonely and stressful experience, made worse when effective communication with Graham was often not possible and progress to recovery not always evident following his VAD operation. Importantly, Harefield has an open and supportive environment with staff from all disciplines providing clear and frank explanations of Graham's condition whenever requested. This friendly, understanding environment supported me through this very difficult period. On the day of the transplant, I experienced a mixture of emotions; anxiety, hope and relief that the waiting was now over. It was wonderful to see Graham come round from the operation the following day and begin to achieve the milestones towards his remarkable recovery".



"Harefield is a remarkable institution, its leading research, pioneering surgery and commitment to patients is the reason I am here now. My family and I are eternally thankful to everyone."

Graham Farrar, cardiac transplant recipient

The threat to children's services at the Trust

The 'Safe and Sustainable: Children's Heart Surgery in England' programme is managed by NHS Specialised Services on behalf of the 10 specialised commissioning groups in England. In February 2011, its recommendations on the reconfiguration of children's heart surgery were agreed by a Joint Committee of Primary Care Trusts (JCPCT). Despite Royal Brompton's excellent record in this area, the committee chose to exclude our paediatric heart surgery services from any of the four recommendations put forward for public consultation, a decision that left many people shocked, dismayed and confused.

On 17 March, the Trust issued legal proceedings against the JCPCT in respect of its proposal to end paediatric cardiac surgery at Royal Brompton, and on July 15 permission was granted for a judicial review to take place in late September. It was with great regret that this action was taken. When flaws were discovered in the process the Trust approached the JCPCT twice to request meetings, but both approaches were rejected. After much careful deliberation and with expert legal advice, it was agreed that the recommended options that were to be put to the public were fundamentally flawed, and that a consultation based on them would be unlawful.

Although this was a decision that was taken with the greatest reluctance, the board felt it had to act in the best interests of patients. We have always supported the principle that all babies and children who undergo heart surgery deserve the best possible care, and that this is likely to be in larger centres. But what could not be accepted is that a large, successful centre like ours was not even included as an option in the consultation process, despite being of the required size

Greg Hands MP (back row on the right) and supporters at the door of 10 Downing Street



and despite our impressive record – we were highly rated in a national assessment undertaken by Sir Ian Kennedy.

The Trust's legal challenge identifies a number of issues relating to the review process and the corresponding public consultation. It provides evidence to show that the consultation's exclusion of Royal Brompton from the available options is not rational, that a decision to close a London site was taken in spring 2010 based on PCT commissioners' subjective views rather than clinical reasons, and that the analysis of the pre-consultation business case is flawed, failing to take into account the impact of the closure of paediatric cardiac surgery on other services at Royal Brompton.

The full impact of losing children's heart surgery

The full impact of the removal of children's heart surgery from Royal Brompton has far-reaching consequences. Loss of the service would:

- Render the paediatric intensive care unit (PICU) unsustainable, because heart surgery accounts for 90 per cent of cases that go through it.
- Make it impossible to maintain a paediatric anaesthetic service – taking away surgery would mean activity levels would not warrant keeping the expertise on site.
- Mean that interventional cardiology would become unsustainable because it depends on the presence of paediatric anaesthesia and PICU.
- Mean that paediatric respiratory services, including those for cystic fibrosis, would be unsustainable, because these depend upon the presence of paediatric anaesthesia and PICU. Several respiratory procedures cannot be undertaken without anaesthesia (e.g. bronchoscopy) and are fundamental to, and commonplace in, the treatment of paediatric cystic fibrosis (e.g. the fitting of gastronomy feeding tubes).
- Adversely affect the Trust's adult congenital cardiac surgery service because those operations are also performed by the paediatric surgeons who specialise in these diseases.
- Adversely affect our foetal cardiology networks Trust clinicians are responsible for 10 per cent of all foetal cardiology cases in the country.

The Trust believes that a collaboration and network agreement between the three existing London centres will deliver the best care for patients, and continues to pursue this approach irrespective of legal action.

Support for our position

Support for our position from patients, parents, community groups, charities, independent clinicians and Members of Parliament has been overwhelming. Over 45,000 people signed a petition that was presented to Downing Street in June, and hundreds of people have voiced their concerns directly with members of the Trust, with their Member of Parliament, or by using one of the many media channels available to them.

Mr Greg Hands, Member of Parliament for Chelsea and Fulham, made a strong speech in the House of Commons on 23 June, reminding his fellow MPs that: "The Royal Brompton is good enough, large enough and loved enough to survive."

Discussing the review process, Mr Hands told a packed House of Commons: "The Royal Brompton has four specialist surgeons who perform 520 operations, including 453 children's heart operations, per year. It has a fantastic safety record, with an aggregate mortality rate of 0.94 of one per cent – less than half the national average of two per cent. Why, then, when it is already a model example of what the review wants to create, does the consultation, in all the options available, decree that it must close? The joint committee of PCTs is claiming that it has an open mind, but in reality it is consulting on four options, all of which would shut the unit at Royal Brompton.

"The knock-on effects on services elsewhere in the Trust would be considerable, especially on children with cystic fibrosis, of whom there are 320. The future of provision for those children would be extremely unclear...

"I repeat that I support the aims of the review, but the consultation has been badly flawed. Three units in London, perhaps restructured, should have been an option, and the knock-on effects of closing services should have been considered. The case must now be re-examined."

Independent panel to review knock-on effects

In May 2011, the Safe and Sustainable team finally reacted to concerns about the full impact of removing children's heart surgery from Royal Brompton, by appointing an independent panel to report back on the likely knock-on effects. Regretfully, the Trust's submission to panel members was significantly redacted by the chair of the panel, Mr Adrian Pollitt, despite being published in full on both the Trust's and Safe and Sustainable's websites. The extremely narrow terms of reference for the panel seem likely to hinder panel members in their deliberations, but at the time of going to press, the Trust remains hopeful of a fair and transparent assessment.



The fight against lung disease





The Trust is a world leader in the diagnosis, management and treatment of lung disease. Patients from the UK and overseas are treated for the full range of respiratory disorders around the themes of: asthma and allergy; lung failure – including transplant, COPD and sleep and ventilation; lung infection and immunity; lung inflammation and cystic fibrosis; surgical oncology; and lung assessment – including sleep studies, lung function and physiology.

We carry out over 2,000 treatments for respiratory failure each year, host Europe's largest centre for the treatment and management of cystic fibrosis and are the largest thoracic surgery unit in the UK, providing a full range of chest surgery, including for the treatment of lung cancer. Specialists at Royal Brompton see more people with breathing problems than any other unit in the country.

The Trust's respiratory teams have always been very research active, in paediatric and adult medicine. We receive regular grant support from the Wellcome Trust, Asthma UK, the CF Trust, and the British Lung Foundation. Professor Andrew Bush is a principal investigator in the Medical Research Council/Asthma UK Centre for Allergic Mechanisms in Asthma (Imperial College and Guy's/King's/St Thomas's hospitals), and is a senior investigator of the National Institute of Health Research. He has been cited more than 9,000 times, which places him among the top 10 respiratory scientists in Europe. Dr Jane Davies is coprincipal investigator, with Dr Di Bilton, in the European CF clinical trial network centre based at Royal Brompton, which is one of only four such CF centres in the UK. Dr Davies is the clinical lead for the UK CF Gene Therapy Consortium, which is shortly to start the largest ever trial of gene therapy for children and adults with CF. The Trust's respiratory consultants and academics lecture all over the world, usually giving more than 100 invited lectures each year.

Lung transplantation – a success story

Improved methods of handling donor lungs such as ex-vivo organ perfusion (where surgeons can recondition donor lungs by pumping a bloodless solution containing nutrients, steroids and antibiotics through them inside a protected chamber, outside the body), and the use of non-heart-beating donors, has helped to increase lung transplant activity over the last two years. The Trust now has the most active lung transplantation programme in the UK, providing over a third of the nation's lung transplants.

A patient's view

Transplant gives Kirstie fresh hope

Article courtesy of ThisisExeter.co.uk – 14 July 2011

C The family of inspirational 21-year-old Kirstie Tancock say they are now hopeful for her future after she received the life-saving operation.

Kirstie had been told she had just a few months to live unless an organ donor could be found. And when her own lungs began to fail, her family admitted they had been left fearing the worst. But following an operation at London's Harefield Hospital, Kirstie has successfully received a new set of lungs.

Speaking from Kirstie's bedside, her mother Linda said: "The last few days have been a rollercoaster.

"Thankfully, Kirstie's transplant went well, and she has been breathing on her new lungs. The doctors are very pleased with her progress."

Kirstie, a dance instructor from Honiton who started blogging to raise awareness of the importance of organ donations, was rushed to the Royal Devon & Exeter Hospital a week ago with breathing difficulties. Consultants made the decision to airlift her to Harefield Hospital, which specialises in organ transplants. A transplant was set to go ahead on Saturday, but doctors decided that the donor lungs were too big for Kirstie's frame.

As Kirstie's condition deteriorated, she was put on a ventilator to help her breathing, and, against the odds, specialists found another set of lungs for her. This time they were the right size and in good condition.

Linda expressed her condolences to the donor's family. She said: "Our thoughts go to the family of the lung donor, without them giving their permission, Kirstie wouldn't be getting her second chance. I know my daughter will always be grateful and will continue her charity work to make people aware of organ donation, and how it can change someone's life. I hope Kirstie's story inspires people to sign up for organ donation."

Kirstie was born with genetic disease cystic fibrosis. It affects the internal organs and particularly the lungs and digestive system, which get clogged with mucus making it hard to breathe and digest food.

Kirstie's story will be told in a BBC documentary in late 2011.





Mr André Simon training young surgeons at Harefield Hospital

Revolutionary lung transplant surgery

In October 2010, Harefield Hospital was the first transplant centre in the UK to perform pioneering lung transplant surgery that dramatically improves recovery times and long-term wellbeing.

The new minimally invasive lung transplantation differs from established methods because it does not require surgeons to cut through the sternum to open the entire chest. Instead, organs are replaced individually via small incisions in the side of the ribcage. The benefits to patients include fewer wound complications and less bleeding and pain.

The landmark surgery was performed by Harefield's director of transplantation, Mr André Simon, who also helped to develop the technique. He says: "It is still a major operation. However, as the sternum remains intact, this means much less post-operative pain and the patient is able to breathe for themselves within hours, generally spending one night in intensive care, as opposed to several days."

Cystic fibrosis – patients from all over the south of England

Cystic fibrosis (CF) is an inherited, life-limiting disease, mainly affecting the pulmonary and digestive systems. The Trust has the largest paediatric cystic fibrosis clinic in Europe and the only larger clinic is our adult service. Co-location with adult services allows seamless transition in this as in all other respiratory diseases. Being based within a specialist hospital gives CF patients access to not only the very best in respiratory treatment, but also to often lifesaving care provided by co-located services, such as our anaesthetic team and intensive care unit.

We are a world leader in the development of new treatments, diagnostic services and training. As the only unit south of Liverpool able to offer a nasal potential difference test to diagnose cystic fibrosis, we receive referrals from throughout the south of England, Wales and Ireland for this investigation, while also training investigators from CF units throughout Europe.

CF outreach services – working to keep patients out of hospital

Homecare service

The Trust's CF service offers specialist nursing and physiotherapy to young CF patients at home, providing flexible, joined-up care between the hospital, the family and local services.

Homecare visits offer monitoring and assessment between routine appointments or following a course of antibiotics, physiotherapy offering advice on airway clearance techniques and exercise, and support following diagnoses and new treatments. The visits also offer families the undivided attention of a health professional away from a busy ward or clinic in the security and privacy of their own home. The homecare team complements the services offered by local health professionals and works closely with them. School visiting to educate and train staff is available at the request of parents and carers.

Adult CF outreach service

Continuing care for adults is offered by our adult CF outreach service, which aims to help patients maximise their independence, while maintaining their treatment programme. The outreach team, comprising specialist nurses and physiotherapists, provides a holistic service - examining patients, carrying out routine investigations, making clinical decisions and prescribing medication. As well as supporting conventional hospital treatment at home (e.g. intravenous antibiotic therapy, non-invasive ventilation), they also provide practical, emotional and social support for new diagnoses, transition from paediatric care, employment and educational issues, pre and post natal care, waiting for lung transplantation and end of life. During 2010, an innovative phone clinic was established providing advice and support for all CF patients.

The only positive thing was that her specialist care would be at Royal Brompton

David and Bridget Turner's five-year-old daughter, Maddie, was diagnosed with cystic fibrosis following a bout of pneumonia when she was just three.

David, from Surrey, said: "Although Maddie was a little under weight and had a persistent cough, she was otherwise healthy and hit all her developmental milestones. It therefore came as a terrible shock when she was diagnosed with cystic fibrosis following a sweat test at Frimley Park Hospital.

"The consultant paediatrician at Frimley Park told us that she needed to be referred to a specialist hospital and we chose Royal Brompton. As a barrister I had worked with Professor Duncan Geddes, consultant in respiratory medicine at Royal Brompton, who had acted as an expert witness on a case. Through him, I knew of the hospital's reputation as one of the country's leading children's cystic fibrosis treatment centres, handling 40 per cent of child patients with the disease in London. Maddie's diagnosis was a very worrying time for us as a family, and the only positive thing on the day of her diagnosis was knowing that her specialist care would be provided at Royal Brompton."

Maddie was referred to Royal Brompton under the care of Andy Bush, professor of paediatric respirology. At her first consultation it was identified that the infection associated with the pneumonia had not fully cleared up, so she was treated with intravenous antibiotics and admitted back to Frimley Park, returning briefly to Royal Brompton for a bronchoscopy, performed under general anaesthetic. Happily, she was discharged just in time for Christmas, which was a relief for Maddie's parents and her two older brothers.

Maddie's condition has been kept stable with medication ever since and her care is shared between Royal Brompton and Frimley Park.

David explains: "All medical decisions about Maddie's care are taken by the team at Royal

Brompton and she attends an annual review at the hospital. Andy Bush's team works closely with the cystic fibrosis unit at Frimley Park where she attends quarterly clinics (at which she often sees Dr Mark Rosenthal and other clinicians from Royal Brompton).

"We are lucky that Royal Brompton's Pat Stringer, cystic fibrosis home care nurse, and Emma Dixon, senior paediatric physiotherapist, visit Maddie regularly at home and liaise with her school so that everyone involved in her care understands her needs. We are also able to contact the team at Royal Brompton by phone any time we are concerned about Maddie or she develops a cough or cold."

Taking this preventative approach enables Maddie to live a normal life and the little girl loves school and enjoys activities such as ballet, running, cricket and skiing.

David says: "Having the continuity of being treated by the same team is important to Maddie and to us. We also feel extremely privileged that our daughter is under the care of a wonderful team at Royal Brompton, headed by Andy Bush, one of the preeminent clinicians in his field in Europe."



Maddie Turner, diagnosed with cystic fibrosis at age three

Harefield Hospital's pulmonary rehabilitation service has gone from strength to strength since it was set up by consultant chest physician, Dr William Man, and his team two years ago. It is now the largest single-site service in the UK.

The service helps people with long-term lung diseases, such as chronic obstructive pulmonary disease, build up their muscle strength, improve their breathing and quality of life as well as increase their physical performance.

Dr Man says: "We receive about 400 new referrals every year from many different PCTs in west London, Hertfordshire and Buckinghamshire. As our programme is run by a specialist team of highly trained specialist physiotherapists, we are able to treat a wide range of patients with complex lung disease, including those who have had lung transplants or major surgery for lung cancer".

The programme is supported by the National Institute for Health Research – Dr Man's research team works closely with the hospital team so cutting edge developments are incorporated into the clinical service to provide the best possible care. "Recent research from our team shows that pulmonary rehabilitation shortly after leaving hospital for a worsening of the lung disease can reduce future hospital readmissions. This shows the enormous potential benefits for our patients and the NHS," he says. Patients referred to the service complete a pre-course assessment and are given a bespoke exercise programme. This is carried out in a state-of-the art gym under the supervision of an experienced team of physiotherapists.

The programme lasts eight weeks and is made up of two-hour sessions twice a week, which includes the exercise programme and education talks designed to improve self-management and increase understanding of their lung problems.

Dr Man says: "We have seen excellent results from the programme. More than 90 per cent of referrals have noticed feeling better or much better after completing pulmonary rehabilitation. This is in people who are already receiving the best possible combination of medications for their lung problem".

"However, provision of pulmonary rehabilitation services is patchy around the country and many centres such as ours have to serve a wide geographical area. To help make it easier for patients to gain access to our services, we have started a community programme near Hayes in Middlesex. This will be run by our specialist physiotherapists using portable equipment in a local community centre. We are aiming to provide high quality specialist care for our patients on their doorsteps."

Patients referred to pulmonary rehab taking regular exercise



Consultant chest physician, Dr William Man



Harefield Hospital has the largest single-site pulmonary rehab service in the UK

CALETTRED INSTREED

2



A patient's view

A return to fitness

Retired nurse Jenny Gane has been given a new lease of life after attending the pulmonary rehabilitation programme at Harefield Hospital. Jenny had been suffering from increasing breathlessness for 18 months before eventually being diagnosed with idiopathic pulmonary fibrosis after being referred to Harefield.

Jenny says: "I was initially treated for asthma by my GP, but despite my medication being increased, I was not improving. I had always kept reasonably fit and couldn't understand why I had got to the stage where I had to stop and rest after climbing a flight of stairs and became breathless when eating and talking.

"This was causing me daily difficulties, not least as my job as chairwoman of the Rickmansworth University of the Third Age involves speaking to a hall full of people."

At this time, Jenny was a regular visitor to her GP surgery and on one occasion had a pulse rate of more than 100. She was referred to the cardiac unit at Harefield where it was discovered that her heart was in excellent condition. However, she had an abnormal chest X-ray.

Jenny says: "I was referred to respiratory medicine where my condition was diagnosed. My initial reaction was shock, as the ramifications of the problem were explained and I discovered that there is no treatment for idiopathic pulmonary fibrosis until it becomes severe enough to need steroids.

"I was angry that I had ended up with a chronic condition when I had always made an effort to keep healthy, but I also had a sense of relief that an explanation had been found for my symptoms."

Jenny was offered an intensive course of pulmonary rehabilitation at Harefield and hasn't looked back.

She says: "After a pre-course assessment I was given a personalised training programme including weights, resistance exercises and aerobic work. There was also a home exercise programme to follow for non-gym days.

"I started out on the treadmill for five minutes and was taught to monitor my level of breathlessness, watched over closely by the rehab team. I then went



Jenny Gane with physiotherapist Karen Ingram in the pulmonary rehab gym

on the cross trainer and lasted only 30 seconds before I felt I was having a near-death experience!

"With support from the physiotherapists, I was taught to exercise using oxygen to help me breathe and managed to gradually build up the amount of time I could spend exercising and improve my recovery time. After the eight-week course, I continued the programme at my local gym and have built up to 10 minutes on my nemesis – the cross trainer. I can now go about my daily life without worrying about getting out of breath and have not been to see my GP for 18 months."

Karen Ingram, lead physiotherapist for the pulmonary rehabilitation service, says: "When I first met Jenny she was struggling with her diagnosis. It had affected her confidence and it was hard for her to accept that her life may have to go down a different path. Tests showed that her lungs were not taking in enough oxygen to enable her to exercise for long, so we attached oxygen using nasal prongs to help her. This meant that she was able to gradually build up her fitness without straining her heart. Jenny was very receptive to the course and made great progress."

Jenny adds: "There is absolutely no way that I could have achieved my current level of fitness without the pulmonary rehab programme and the support and encouragement of the physiotherapists at the unit. They advised and motivated me every step of the way."

We saw **650** adults and **320** children in our cystic fibrosis unit

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Asthma

Trust experts treat more children and adults with severe asthma – unresponsive to standard inhalers, and requiring frequent hospital treatment – than anywhere else in the country. The asthma and allergy teams care for patients with serious allergies – from hayfever to food and drug allergies. For asthma, the majority of patients are referred from consultants at district general hospitals, while for allergy, patients come from a variety of sources including primary care, because of the largely unmet medical need. There are only two centres in London, for a population of almost eight million.

Some of the best interpersonal skills in the NHS! By Helen Alexander

As a child I have memories of having 'chesty' colds, time off school and many home visits by the GP including the regular Christmas one (where I always shared something from my Christmas stocking!). Prior to this I had also suffered from quite severe eczema.

Although I had no admissions to hospital during my school years – I remember frequent occasions of struggling for breath. For example, if I made it round the athletics track without stopping at least three times, I thought I was an Olympian!

After the birth of my first son, I was suddenly 'hit' by the worst asthma I had ever experienced – not able to walk more than a couple of paces at a time. This resulted in my first course of steroids and repeated severe exacerbations. I went on to have two more children – I was on and off steroids until, following the birth of my third son, I remained on them permanently; a reduction in dose would lead to an 'attack' and yet another emergency admission to hospital. Thankfully I was referred to Royal Brompton.

When my referral to Royal Brompton was made I was already steroid dependent (which brought other health challenges!), yet have not only been fortunate enough to bring up three children and have a successful career, I have had very few emergency admissions in all those years. My asthma has been completely debilitating at times – but with excellent treatment, changes to lifestyle, including early retirement, I have been enabled to manage both my asthma and have a fulfilling life.

The treatment for my asthma has changed over the years – with the team always using innovative and individual approaches. As I have got older and the asthma more challenging – the benefit of elective admissions and appropriate treatment have, without hesitation, kept me alive and able to enjoy a quality of life that without such treatment would not have been possible.



Helen, from Wiltshire, with clinical nurse specialist Markus Hofmann

But this is not the only thing that makes the management and treatment of my asthma special - it is the exceptional staff. To be treated as an individual by your consultant (Dr Menzies-Gow) and specialist nurses (Suzie and Markus) - is paramount. I am understood, shown respect, and invited to share in my care. I know that I have the best possible individual specialists that someone with severe asthma could have - what confidence when you suffer from an ongoing and debilitating disease! To also experience the most amazing nursing care which I have found exemplary and supported by a range of 'peripheral' staff – who also appear to have some of the best interpersonal skills I have experienced in the NHS!

My asthma will not magically disappear but whilst under the care of Royal Brompton, neither will the opportunity to have a good quality of life whilst experiencing such a chronic, debilitating disease.

During 2010/11, we treated people with asthma over 2,600 times in outpatient clinics and 2,467 times as inpatients.

Occupational asthma

Royal Brompton Hospital, in partnership with the National Heart & Lung Institute, runs the busiest clinical service in the UK for the investigation and management of occupational and other environmental lung diseases. Patients are referred from all parts of the UK for NHS treatment and care. The department has pioneered the investigation of occupational asthma for the past 20 years and runs one of the few laboratories in Europe that specialises in occupational and environmental allergen testing.

Occupational asthma refers to asthma that is caused or worsened while working in particular jobs where allergens are present, most commonly flour, eggs, mammals, latex and seafood but can also be caused by agents that a worker might come into contact with in industries such as spray painting, hairdressing, metalwork, construction, dentistry etc.

This form of asthma rarely responds to standard asthma treatment and usually results in major disruption to a patient's employment.

Professor of occupational and environmental respiratory disease, Paul Cullinan, and his team, are currently involved in extensive research concerning egg allergy, laboratory animal allergy and baker's asthma.

They also run regular postgraduate short courses and workshops.

Lung cancer care

The Trust provides specialised care for patients with suspected or diagnosed cancer affecting the chest (thoracic oncology). Patients can expect a whole care package from our multidisciplinary team who work with them and their families to help them choose the best treatment option and assess any needs they might have.

A comprehensive patient service

With a multidisciplinary (MDT) team that includes clinical nurse specialists, thoracic surgeons, respiratory physicians, oncologists, histopathologists, radiologists, palliative care specialists and rehab and therapies professionals, patients benefit from the support of having often national and international experts in one place.

Dr Alison Leary, Macmillan lead cancer nurse at the Trust, says: "Patients are referred to the Trust for different reasons and at different points in their cancer journey. This may be for a diagnostic procedure or curative lung cancer surgery, both of which are highly specialised. The surgical team also performs palliative surgery to improve a patient's quality of life, which includes helping to alleviate symptoms such as shortness of breath in people living with more advanced cancers. Other very specialist areas include radio frequency ablation, laser surgery, sternal replacement or reconstruction and chest wall reconstruction."

continued overleaf >

Macmillan clinical nurse specialist Michael Evans discusses a case with Sandra Carty, ward sister



Most of the Trust's work is tertiary, therefore the majority of patients are referred from other centres around the country. Colleagues work in close partnership with neighbours at the Royal Marsden, Chelsea & Westminster and Mount Vernon hospitals, meaning patients can expect a seamless and speedy transfer for further treatment where needed - or choose to be referred to a hospital closer to home if preferred. Specialised cases are regularly referred to the team for opinion and treatment, including the diagnosis of unusual chest problems related to conditions such as leukaemia and bone marrow transplantation. A variety of cases are discussed at MDT meetings, which are often attended by specialists from other trusts who are seeking our opinion on their case.

Key facts and figures

- We treat around 500 confirmed cancers each year but also provide a diagnostic service for people with suspected cancer that is much higher – these patients often need the emotional support or care coordination offered by our multidisciplinary team.
- The sarcoma team at Royal Brompton Hospital is the designated exclusive provider of thoracic sarcoma surgical services for the London and South East England, which serves a population of 18.5

million and is the largest sarcoma network in the UK. This came about as the result of the "Improving Outcomes for Patients with Sarcoma" NICE guidance, focusing on centralisation of treatment for these rare cancers to centres with accumulated expertise and a track record of excellent results.

Patients travel from all over the country to be treated by our cancer and supportive care team.

Video assisted (VATS) lung resection

In an exciting development for the treatment of lung cancer, video assisted (VATS) lung resection techniques have now been established within the surgical service.

Most resections for lung cancer – removing lung tumours – are performed through an open incision for access into the chest cavity. But for some patients, VATS lung resection offers a suitable alternative that is less invasive as the operation is performed using a series of smaller incisions with video assistance (also known as keyhole surgery).

Evidence to date shows VATS lung resection is already achieving impressive results, with patients who undergo the surgery experiencing less pain and a shorter hospital stay after their operation.



A patient's view

Not enough superlatives in the English language

Matthew Moorman was referred to Royal Brompton by his local medical team in Sheffield, for specialist surgery for a lung tumour that was causing him severe breathing difficulties.

Matthew remembers: "I was 36 at the time of diagnosis. I had chemotherapy for seven months at my local hospital. The tumour responded well to the chemotherapy quite early on in the treatment and the blood markers plummeted. Unfortunately the chemotherapy did not shrink the tumour, which was close to my heart."

In fact, the tumour was very large: it had squashed up most of Matthew's left lung and pushed his heart onto his right lung, which was causing serious breathing problems. Matthew says: "The tenminute walk to the local shop to buy a newspaper began to take over half an hour. I was feeling fed up and frustrated because I couldn't do much and was virtually housebound. I was grateful and relieved when Royal Brompton took me on as a patient."

Matthew's surgeon, consultant thoracic surgeon Mr Simon Jordan, says: "Matthew's tumour was a mediastinal teratoma. The physical size of the tumour, even after chemotherapy, was life threatening.

"Not only was the tumour pushing from his left hand side but it was extending up into his neck and also pushing down into his abdomen. Although the chemotherapy had worked well and the tumour no longer appeared to be active there were concerns that the tumour could become malignant again."

Just two days after the seven-hour operation, Matthew was already able to walk further than he had been able to before it, and was starting physiotherapy on an exercise bike to help get his lungs to work properly again. Since his treatment, Matthew reports that he no longer gets out of breath quickly when he's out and about in Sheffield or in the Peak District, which he occasionally likes to visit. He says: "Life has got back to normal and I can't thank Royal Brompton enough, especially Mr Jordan and his team, for what they have done for me. There are not enough superlatives in the English language that adequately describe what great work they do."

After his treatment Matthew Moorman is once again able to enjoy the beautiful Yorkshire countryside



In June 2010, a new specialist 'Lung Laser' theatre was opened at Royal Brompton, which incorporates the latest technology in lung surgery and the first surgical laser of its kind in the UK. It uses a special wavelength laser beam to remove tumours from patients' lungs, with minimal damage to neighbouring healthy lung tissue.

The lung laser can be used in tumours of all kinds, including colonic cancers and sarcomas, enabling surgeons to perform complicated lung surgery with greater benefits for patients. These include:

- Targeting and removing individual tumours, significantly improving the patient's chances of survival.
- Enabling the eradication of deep-seated and multiple tumours without the need to remove a major section of the lung, preserving lung function and preventing post-operative breathlessness, which improves the patient's quality of life.
- Removing multiple tumours faster, therefore reducing the time that patients spend under a general anaesthetic.
- Eradicating cancer tissue while at the same time sealing surrounding lung tissue, reducing the risk of internal bleeding or air leak from the lung, which can lead to a prolonged post-operative stay.

Mr George Ladas, senior consultant thoracic surgeon at Royal Brompton Hospital, who leads the project, has already performed more than 65 lung laser procedures with excellent results, many of these in patients who were previously declared inoperable in the UK and abroad.

The lung laser was funded by generous donations from the Portnoi family and the theatre is named after Mr Jack Portnoi, who is a patient of Mr Ladas.



Senior consultant thoracic surgeon Mr George Ladas with the new lung laser equipment

We undertook over **137,000** outpatient appointments and supervised nearly **30,000** inpatient stays

Influence around the world

Royal Brompton & Harefield NHS Foundation Trust is a distinctive brand, attracting clinical experts from across the UK and all over the world, who come to train here either at their own expense or with sponsorship from their governments. Many return to lead institutions in their own countries.

Our clinicians also travel extensively, delivering lectures and presenting at conferences. Many hold key positions on international boards, committees and professional associations. Examples of the Trust's influence around the world include:

- Guests from all over the world came to London for the opening of the Trust's new cardiovascular Biomedical Research Unit (CBRU) in November. Research in the BRU focuses on heart regeneration and experts are working to diagnose, treat and support those living with familial cardiac disease, applying state-of-the-art gene sequencing technology to research the underlying genetic links of cardiovascular disease.
- Delegates from as far afield as Hong Kong, Romania and Saudi Arabia, spent three days at Royal Brompton in April 2011, learning the latest techniques in prenatal screening for congenital heart disease under the guidance of Dr Julene Carvalho and Professor S Yen Ho. The annual course focuses on improving prenatal detection of congenital heart disease, with an emphasis on the unique approach of the Trust in looking after children before they are born through to adulthood.
- Professor of paediatric respirology, Andrew Bush, was named as the new joint editor-in-chief of *Thorax*, one of the world's leading respiratory medical journals. Professor Bush is a principal investigator in the MRC Asthma UK centre for Allergic Mechanisms in Asthma and is a senior investigator of the NIHR. He has been cited more than 9,000 times, which places him among the top 10 respiratory scientists in Europe.
- Director of children's services, Dr Duncan Macrae, was appointed president of the prestigious Paediatric Cardiac Intensive Care Society (PCICS). The PCICS is a worldwide professional society that promotes excellence in paediatric cardiac critical care medicine, and members are dedicated to improving practice for critically ill children with congenital and acquired heart disease.
- Professor Dudley Pennell lectured throughout the world in 2010-2011 on the use of cardiac T2* magnetic resonance (MR) for patients with thalassemia. MR greatly reduces mortality in this condition, by identifying patients at risk of heart failure and starting early treatment.
- Mr Mohamed Amrani, consultant cardiac and transplant surgeon, has an international reputation in minimally invasive cardiac surgery. Mr Amrani regularly operates abroad where he has contributed

to teaching colleagues, and has helped set up new cardiac units in Dubai, India, Libya and Morocco. He is regularly invited overseas to lecture and demonstrate new surgical techniques and in the past year has lectured in Egypt, Libya and UAE.

- Royal Brompton's leadership in lung laser surgery was internationally recognised this year as the team presented the excellent results of the first tranche of surgery to the Annual Meeting of Society of Cardiothoracic Surgeons of Great Britain and Ireland. Consultant thoracic surgeon, Mr George Ladas, was then invited to teach lung laser surgery at the University Hospital of Valencia, Spain to surgeons from Spain, Portugal, Greece, Brazil and Serbia.
- Professor Michael Polkey, consultant respiratory physician, continues to collaborate both nationally and internationally. He is an investigator in the EU Innovative Medicines Initiative, PROactive, which is aiming to develop a new measurement tool to capture aspects of chronic obstructive pulmonary disease (COPD) other than breathlessness. He is a member of the COPD Foundation COPD Biomarkers Qualification Consortium, which aims to develop acceptance by the US Food and Drug Administration (FDA) of outcomes beyond lung function in COPD treatment trials. Professor Polkey presented results of the Trust's research work on COPD and treatment of muscle atrophy at the International Conference for COPD in Birmingham in July 2010. His lecturing has recently taken him to China, USA and Middle East.
- Consultant in cardiology, transplant medicine and circulatory support, Dr Nick Banner, is a member of the thoracic organ transplant committee of the European Society of Organ Transplantation (ESOT). He was invited to present his findings on antibody mediated rejection in heart transplantation at the 2011 Meeting of the International Society for Heart and Lung Transplantation in San Diego, California.

Professor S Yen Ho showing models of the aortic arch



Cutting edge research

The starting point for our research always begins with the needs of the patients we treat every day. We work closely with our main academic research partner Imperial College London, to deliver medical advances taken up across the NHS and beyond.

Many of our researchers are key opinion leaders in respiratory or cardiovascular medicine and we are the most highly cited NHS organisation in the UK in these areas.

State-of-the-art research facilities open

Last year was a landmark year for research at the Trust with the openings of new respiratory and cardiovascular Biomedical Research Unit (BRU) facilities, which will transform our research potential and the patient experience.

The respiratory BRU's clinical research facility (CRF) provides dedicated resources for inpatient and outpatient research studies in both adults and children. The respiratory BRU supports imaging, lung function, genetic sequencing, bronchoscopic and other investigational facilities, providing the tools for research ranging from rehabilitation to gene therapy. Since opening in July 2010, the CRF has hosted more than 50 research studies investigating new treatments for asthma, chronic obstructive pulmonary disease (COPD), cystic fibrosis, bronchiectasis, interstitial lung diseases, acute and chronic respiratory failure and sleep medicine.

The cardiovascular BRU incorporates unique facilities for interventional cardiology and MRI imaging. There is also a high-tech echocardiography suite and genes laboratory with a Next Generation Genetic Sequencer. These facilities underpin the cardiovascular BRU's research programme on heart regeneration, which aims to increase understanding of poor heart function in people living with cardiomyopathy, arrhythmia, coronary heart disease and heart failure.

Professor Dudley Pennell, director of the cardiovascular BRU, presents the new state-of-the-art catheter lab to guests



Biobanks

The BRUs have an active biobank, collecting biological specimens from patients to fuel research into cardiovascular disease and advanced lung disease. The biobank holds samples from more than 1,500 patients to date, which will assist clinicians to better predict, diagnose, treat and even prevent a range of conditions.

The new facilities in both BRUs support a continued commitment to carrying out world-class research by:

- Increasing the critical mass of clinicians and scientists working together with well-phenotyped patient groups
- Increasing the number of drugs, devices, diagnostics or biomarkers progressing into phase II clinical trials
- Educating the next generation of translational researchers
- Developing public and patient involvement programmes to encourage involvement

Europe's largest service for cardiac and respiratory health is created

In June 2010, Royal Brompton & Harefield NHS Foundation Trust, Imperial College Healthcare NHS Trust, and Imperial College London came together in a new agreement to undertake joint research studies and explore clinician-led integration of services into joint working units and programmes.

This alliance, which is aligned to Imperial's Academic Health Science Centre, brings together more than 460 cardiac and thoracic surgeons, consultants, cardiologists, professors and researchers to deliver world-leading improvements in clinical care, education and research activities relating to heart and lung health for patients.

Professor Eric Alton, director of the respiratory BRU, in the clinical research facility



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Early success story – new service for acute aortic dissection

The new collaboration is already working well, with an emergency surgery service now being provided for patients with acute aortic dissection – a rare condition where many patients can die before they even reach hospital.

Surgeons at Hammersmith, Royal Brompton and Harefield hospitals have created a dedicated surgical rota, operating 24 hours a day, seven days a week, to help ensure that more people with this condition survive. Previously patients saw one of up to 20 different surgeons at their nearest cardiac centre. The new service means they will now be transferred by ambulance to the 'on-call' hospital to be seen by one of six surgeons with particular expertise in the condition.

Professor John Pepper, consultant cardiac surgeon at Royal Brompton, said: "Early recognition and rapid transfer to a specialist team is vital to successfully treat acute aortic dissection. Most patients are referred through accident and emergency or a chest pain clinic.

"Since it started, every indication is that patients coming through this collaborative service have a much better chance of survival. We are now looking at how we can diagnose the condition earlier to ensure the best possible care and treatment for patients."

Aortic dissection occurs when the inside wall of the aorta splits causing blood to flow between the layers of the aortic wall. This forces the layers apart and can cause the aorta to burst, leading to substantial blood loss. To repair this, surgeons must replace the damaged section of the wall with a graft in a delicate and highly technical operation.

Genetic sequencing – potential to save and lengthen symptom-free life

Our genetics programme is paving the way for major advances in the treatment of cardiovascular disease. Funded by the National Institute for Health Research, the Next Generation Genetic Sequencer is enabling Trust experts to sequence all of a patient's genes, and will be used to research the underlying genetic links of cardiovascular disease. Over the next 10 years researchers will look at 10,000 patients over the age of 16, eventually using this information to help establish new genetic factors causing heart disease in individual patients, which will assist in providing personalised treatments. The sequencer will bring clear benefits for patients, enabling clinicians to determine a genetic cause of their cardiac condition and allowing accurate diagnosis and personalised treatment.

In one gene sequencing programme, researchers are studying DNA from patients with an inherited heart muscle disease called cardiomyopathy (which can lead to heart failure after many decades) to identify new genes that cause weak heart muscle.

Within the past year, we have identified five new genes through collaborative studies, meaning significant new potential now exists for diagnosis and personalised treatment of patients with this condition.

Experts pinpoint fatal trigger for heart failure

A study led by Professor Dudley Pennell, director of the cardiovascular BRU, with colleagues from the Trust and Imperial College, has pinpointed the trigger for thalassaemia, an inherited but fatal form of heart failure. In the year 2000 around 50 per cent of thalassaemia (major) patients in the UK died by the age of 35, due to iron collecting in the heart from frequent blood transfusions.



We maintained our position as Europe's top centre for respiratory research

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Results published in the international journal *Circulation* (journal of the American Heart Association), showed how by using cardiovascular magnetic resonance (CMR) scanning, the trigger for fatal heart failure can be identified. This is a major breakthrough for thalassaemia patients, as it validates the essential building block for developing new drugs. It means drugs can now be developed that will eradicate this dangerous side effect of frequent blood transfusions.

Professor Dame Sally Davies, chief medical officer and chief scientific adviser at the Department of Health said: "This is precisely the sort of practical research with direct patient benefit that the National Institute for Health Research is keen to fund. It is an impressive example of finding new ways to treat some of the most common diseases, for the benefit of patients not just in England but around the world."

Major grants for chronic obstructive pulmonary disease (COPD)

COPD remains a common and debilitating disease for which there are few effective treatments. Researchers in the respiratory BRU, along with colleagues from Imperial College's Academic Health Science Centre, have successfully applied to become one of nine centres nationally to deliver major research programmes around COPD. Identified as a Therapeutic Research Partnership, this cross-government initiative brings together UK expertise in translational research with clinicians, academics and the life sciences industry, working together on promising new drugs and interventions.

Our BRU researchers have also been selected to lead two of four major programmes of COPD research being funded by the Medical Research Council in a £6m initiative, which focus on delivering more personalised approaches to the treatment and management of COPD.

Improving outcomes for CF patients

The Trust has one of the largest cystic fibrosis clinics in Europe and a study on long-term outcomes has shown significant improvement in survival even in the most seriously ill patients in recent years. In the past, cystic fibrosis patients with a forced expiratory volume over 1 second (FEV1) below 30 per cent were considered to have advanced disease, and therefore potential candidates for transplantation. However, the study, led by consultant respiratory physician Dr Nicholas Simmonds and colleagues, and published in the British Medical Journal, has shown that survival has doubled for these patients when treated at Royal Brompton Hospital over the last ten years, by an average of more than five years compared to patients who were treated in the early 1990s. It is likely that pioneering treatments developed and used at the Trust are contributing to this improved outcome.

Trust expert leads major new heart failure study

Professor of cardiology, Martin Cowie, won a major award to run a national clinical trial to evaluate the benefit of remote telemonitoring in the management of arrhythmia and heart failure patients. The British Heart Foundation awarded a grant together with matched funding from industry organisations (Medtronic, St Jude and Boston Scientific) totalling £8.1m.

Working with colleagues from the University of Southampton, the clinical trial will recruit 1,600 patients across hospitals in England, including Royal Brompton, in order to test the benefits of these new technologies that allow patients to remain in their own homes for regular monitoring rather than attending a medical centre.

Professor Andrew Bush receives national and international awards

Professor Andrew Bush's contribution to research in paediatric respiratory disease was recognised by the National Institute for Health Research (NIHR) in early 2011, when he was awarded Senior Investigator status, a title only given to the UK's top 200 leaders in clinical and applied health and social care research. Professor Bush becomes the sixth Trust consultant to receive this prestigious award alongside Professors Tim Evans, Dudley Pennell, Martin Cowie, Kian Fan Chung and Peter Barnes.

Professor Bush also won the 2010 International Congress on Paediatric Pulmonology President's award for his outstanding contribution to the improvement of global care for children with pulmonary diseases.

Professor Bush's research has pioneered many novel treatments for children with cystic fibrosis, asthma and emphysema, much of which has directly influenced patient care and is now part of routine clinical practice.

Professor Andrew Bush with young patient, Georgie Wren



Clinical support



New cardiovascular BRU cath lab and CMR scanner

Vital clinical support facilities support our cardiovascular and respiratory teams – offering a one-stop, on-site service uncommon in UK hospitals.

We have the benefit of:

- Top-rated, state-of-the-art intensive care units at both hospitals, 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 Biomedical Research Units.

State-of-the-art ICUs

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

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

The Trust has up to 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 cardio and respiratory illnesses. We are 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.

Breakthroughs in treating severe acute respiratory failure at Royal Brompton ICU

Over the past five years, the adult ICU at Royal

Brompton Hospital has admitted more than 100 patients with the severest forms of acute respiratory failure. These have included problems such as acute respiratory distress syndrome, difficulty weaning from mechanical ventilation, severe acute asthma, pulmonary hypertension and persistent bronchopulmonary air leaks. Typically, such patients have failed conventional management at their referring hospitals and are transferred for "supra"specialist care at Royal Brompton.

The adult ICU was one of only three centres in the UK assessed and designated by the Department of Health to provide extracorporeal membrane oxygenation (ECMO) for patients with the most severe respiratory failure during the 2009 winter H1N1 influenza (swine flu) pandemic wave.

HDU renovations bring benefits to patients

During 2010, a major refurbishment exercise took place at Royal Brompton Hospital, configuring the high dependency unit (HDU) onto one floor to provide high-quality medical support in comfortable accommodation for up to 26 patients.

The £1.5 million unit is consultant led but is a truly multidisciplinary effort, with major input from specialist nurses providing tailored care to patients. The new development has enabled pre-assessment capacity to be expanded, providing more day-case cardiology on the wards and supporting the ICU by admitting patients who no longer require critical care. During the winter swine flu outbreak of 2010/2011, the HDU proved invaluable in freeing up critical care beds for patients admitted with catastrophic respiratory failure secondary to an H1N1 infection.

At Harefield, the HDU provides nine monitored beds dedicated to the care of patients requiring this level of care and observation; either immediately following major surgery or after leaving the ICU. The work of our clinicians is supported by the most advanced diagnostic and research imaging services on site.

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 new cardiovascular BRU contains the latest world-class imaging equipment.

Major lung cancer study uses CT

Royal Brompton Hospital is the central reading site for CT (computerised tomography) scans gathered in Liverpool and Papworth Hospitals, as part of a pilot study to test the feasibility of screening for lung cancer with low dose CT (the UK lung cancer screening study: UKLS).

This study, of which professor of thoracic imaging David Hansell is the lead radiologist, has taken on special relevance with the breaking news from a large lung cancer screening trial in the USA. In November 2010, the director of the National Cancer Institute reported that the National Lung Screening Trial (NLST) showed that CT screening, compared to chest X-ray evaluation, resulted in a 20 per cent reduction in lung cancer-related mortality. This trial followed 53,000 participants, including both current and former heavy smokers, from ages 55 to 74 years.

Echocardiography

The echocardiography departments at Royal Brompton and Harefield provide cardiac ultrasound imaging for patients from all specialties. In addition to transthoracic echocardiography, transoesophageal echo and stress echo are also provided. Three full-time echocardiographers and three echo machines together perform nearly 10,000 studies per year.

Consultant-led echocardiography service

A new consultant-led echocardiography service at Royal Brompton is enabling 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 redesign of the service has been led by Professor Roxy Senior, director of echocardiography, and has resulted in improvements such as more efficient use of staff time and space, enhanced administration processes and upgrading of information systems. One of the clear benefits already experienced by outpatients is convenience – being able to have their echo and see the consultant in the outpatient setting on the same day.

Patients are now offered a structured stress echo test and 3D echo service as well as echo contrast myocardial perfusion, in the only service of its kind in the UK. The clinical benefits of 3D, stress echo and echo with contrast are improved diagnosis and improved patient outcomes.

This expansion of echocardiography at Royal Brompton has led to increased referrals from other NHS trusts to whom a comprehensive echo service is offered.

Echo technicians at work



Consultant radiologist Dr Michael Rubens with the CT scanner



Nuclear medicine

The nuclear medicine department at Royal Brompton forms part of our clinical support services and performs around 9,500 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.

Electrophysiology lab

As part of a new state-of-the-art electrophysiology (EP) lab at Harefield, a new facility has been built to include the latest imaging and mapping technologies, and a 'Hansen' robot for remote interventional EP procedures.

The Trust was the first in the UK to install I-Plan, an interactive scheduling package that provides at-a-glance, real-time status updates for scheduled procedures. This has enabled a seamless journey for the patient between the lab and the ward, with more patients being treated in the labs compared to last year.

Mobile cardiac scanner

A new mobile cardiac magnetic resonance imaging (MRI) service began at Harefield Hospital in summer 2010. This exciting development for imaging has meant quicker access and shorter waiting times for patients requiring an MRI scan.

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, microbiology, histopathology and phlebotomy. The blood sciences laboratory at Royal Brompton Hospital, the most advanced of its kind in Europe, offers faster and more accurate results through a streamlined, contamination-free testing process.

The laboratory offers a unique showcase for a number of innovations that have not been available before in a single facility.

Pathology on hand

We are a national and international referral centre for cardiac and pulmonary pathology, offering a unique service to users and other healthcare trusts. Our services include:

Surgical reporting service

We specialise in the diagnosis of tumour and interstitial lung diseases, heart and lung transplant rejection, vascular and cardiac disease identification by light and electron microscopy, EDAX, immunocytochemistry and molecular biology.

Biopsy service

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

Cytology

The service offers assessment of sputum, urine, fineneedle aspirates, pleural effusion and lavage specimens.

Immunocytochemistry

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

Autopsy service

A full autopsy service including cardio/pulmonary injection and X-ray techniques.

The Trust was the first in the UK to install I-Plan



Our charity

Every year, a group of dedicated fundraisers walk, run, swim, skydive, organise parties and take part in a vast range of events to raise money for Royal Brompton & Harefield Hospitals Charity. Along with our donors, fundraisers are vital in enabling our charity to continue to support the outstanding work that takes place at our hospitals, awarding grants for medical research, specialist equipment and other amenities to improve patient care.

Charitable support makes a vital contribution to the work carried out at our hospitals, supporting projects that are ineligible for funding from the NHS. Over the last year, we have been able to make substantial contributions to the BRUs at Royal Brompton, and the new Clinical Skills & Simulation Centre, as well as supporting smaller projects across both our sites.

Our thanks go to everyone who puts time and effort into raising money for us – there are too many to mention them all individually, but special thanks go to:

■ Joel Stainton and Geraint Evans, who took on the incredible challenge of the Marathon des Sables in the Sahara desert, with a specially lengthened course of 250km to mark its 25th anniversary. Over the course of a week, they took on 40 degree heat and huge sand dunes to complete the gruelling course, and raised over £6,000 towards the Harefield MRI Scanner Appeal in the process.

Joel Stainton and Geraint Evans in the Sahara desert during the Marathon des Sables in temperatures of up to 40 degrees







Peter Bennett shakes hands with consultant thoracic surgeon Mr Vladimir Anikin

- In another feat of endurance, Oliver King cycled from Land's End to John O'Groats to raise £4,000 for Royal Brompton's AICU in memory of his father.
- Peter Bennett and his wife Giff, who organised a cross-country walk and treasure hunt, raising an incredible £6,500 to support the research work of Mr Vladimir Anikin into the treatment of pulmonary disorders, particularly thoracic cryotherapy.
- Ben Beevers' son Joseph underwent two heart surgeries at Royal Brompton before he was two weeks old – to show his thanks and appreciation, Ben and his wife organised a number of fundraising activities, and involved the leisure centre group where he works, raising over £13,000 for the paediatric intensive care unit.
- The donor and supporter trees have had another wonderful year, raising over £37,000. The trees give our patients a way to express their thanks for the care they have received, and their donations have allowed us to support a number of projects for amenities at Royal Brompton, and made a valued contribution to the MRI Scanner Appeal at Harefield.

Donor and supporter trees have raised over £37,000 this year



rb&h Arts

Our dedicated and innovative arts programme goes way beyond brightening up hospital corridors. We commission a range of initiatives that directly contribute to improved health and wellbeing.

rb&hArts initiated a new musical residency based in Harefield Hospital's intensive treatment and high dependency units. Dimitris Dekavallas, working through music charity Live Music Now, visits the hospital once a fortnight, playing classical guitar for patients and families who may be going through times of extreme anxiety, and in some cases postoperative pain. Feedback indicates that 95 per cent of patients find the music beneficial, and that the music is 'a good distraction from pain' and 'a pleasant time [which] made the day shorter'. One member of staff noted that 'It relaxed the patient. Patient fell asleep and didn't use PCA [intravenous painkillers] as much.'

Sid Bowfin, who blends comedy with classical violin, also began a residency at the Trust, working mainly in adult surgical units. Feedback from our physiotherapy team demonstrates the positive impact this initiative can have on patients saying: 'I was working with a patient who had been on the ward for many weeks and who had been struggling with his walking... the pleasure of the music was clearly obvious in the patient's face. That day he walked significantly further than he had done so for weeks. The live music helped to literally move him past a psychological barrier... Since that day his mobility has continued to improve dramatically. The live music was a fantastic rehab tool... his music brought about a great physical change in someone.'

Our Singing for Breathing programme has developed rapidly in the last 12 months, and Royal Brompton's singing leader, Maya Waldman, now offers one-to-one workshops, as well as group workshops, for all our respiratory patients. Singing for Breathing aims to enhance existing physiotherapeutic support for respiratory conditions by introducing a new form of



A piece from the Heartworks series by Susan Aldworth, commissioned in collaboration with rb&hArts in 2010

enjoyable, informal exercise, teaching a better understanding of breath control through the use of the voice in group settings. The programme was extended in February 2011 to Harefield Hospital, where Judith Silver now leads workshops for all patients and their families. A second clinical trial looking at the effects of singing training on chronic obstructive pulmonary disease is due for publication this year, and a new CD by Phoene Cave, offering breathing and vocal exercises, will be available from late 2011. Singing for Breathing is funded through donations from a number of charitable trusts and individuals, and we have presented the project to a huge variety of audiences, including the British Vocal Association and British Lung Foundation's annual conferences, the Southbank Centre's Chorus festival, the Sidney de Haan Singing for Wellbeing conference, and as part of Imperial College's medical humanities programme.

Singing for Breathing workshop in progress



Les Boum plays in the adult intensive care unit, Harefield



The Trust's reputation relies on consistently providing excellent quality care and services to our patients. We have an excellent quality and safety record and high patient satisfaction. Recent independent surveys rate us in the top 20 per cent of best performing trusts nationally. Our staff are committed to continually improving the patient experience and this is reflected year on year in the positive feedback we receive from patients.

Patient surveys

The Trust performed well in two national patient surveys in 2010.

Results of the 2010 national in-patient survey reflect our continued commitment to providing the best possible specialist treatment for our patients, with responses to 79 per cent of questions putting us in the top 20 per cent of best performing trusts. We performed particularly well when patients were asked if:

- They were treated with respect and dignity whilst in hospital.
- They had confidence in the doctors who treated them.
- Staff explained how to take medications in a way they could understand.
- Staff explained how an operation or procedure had gone.
- They were offered a choice of food.

Lung cancer patients rated us highly in the 2010 National Cancer Patient Experience survey.

In the survey, undertaken by Quality Health on behalf of the Department of Health and one of the largest to have been undertaken involving cancer patients anywhere in the world, feedback was very encouraging.

Of our patients surveyed, 100 per cent had confidence and trust in the doctors treating them with 95 per cent stating they got understandable answers to important questions at all times from ward nurses and hospital doctors; that they were always given enough privacy when discussing their condition/treatment and when being examined; and that they were always treated with respect and dignity by staff. These figures are significantly above the national average.

Top marks for patient environment

The Trust also scored highly with a double excellent for patient food and privacy and dignity in this year's annual Patient Environment Action Team (PEAT) assessment. PEAT is an annual self assessment by healthcare organisations with inpatient sites. The results are validated by independent assessors and demonstrate how well individual healthcare providers believe they are performing in key areas.

Making mealtimes more appetising

The important role food and nutrition plays both in health and in the overall hospital experience, of not only our patients, but our staff, families, carers and visitors too, is recognised throughout the Trust.

Royal Brompton's catering department introduced a new cardio-protective nutrition programme across the Trust's sites during 2010. Working closely with the nutrition and dietetic department staff, patients, and visitors now have a wide range of healthy menu options available at the restaurants and cafés across the two hospitals.

Following a report identifying the failure of many trusts to identify malnutrition in older patients, Age UK commended Royal Brompton's nutritional support for older people. The charity visited the hospital as part of their research into hospital practice around mealtimes and 'Hungry to be Heard' campaign.

Gordon Deuchars, policy and campaign manager at Age Concern London said: 'We were really impressed by the fantastic work at Royal Brompton. The food looked and smelt amazing and proper consideration was given to the difficulties patients can experience around mealtimes."

Involving our patients and their families

We are committed to staying in touch with and involving our patients, their families and the public. Many events have been held during the year to do this. We received 'excellent' for food and privacy and dignity in the annual PEAT assessment



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.

The governance structures of the Trust 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 are:

Executive members

Mr Robert J Bell Chief executive

Mr Robert Craig Chief operating officer Professor Timothy Evans Medical director

Mr Mark Lambert Director of finance and performance

Dr Caroline Shuldham Director of nursing and clinical governance Mr Richard Paterson

Interim director of finance (January – June 2011)

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 2010/11 is available on our website as well as NHS Choices.

Our governors' council

Public governors

Mr Kenneth Appel

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

Bedfordshire and

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	

Prof Michael Schneider

Mrs Allison Seidlar Prof Peter Rigby

Mr Ray Puddifoot

Staff governors

Ms Sue Callaghan Dr Olga Jones Prof Margaret Hodson Kensington and Chelsea Imperial College London Hillingdon NHS PCT University of London London Borough of Hillingdon

Royal Borough of

Mr Robert Parker Dr Ian Balfour-Lynn

Media interest

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 2010-11.



BBC News June 2010

A primetime news report about the Next Generation Genetic Sequencer at the Trust,

described how experts at the hospital are decoding the genes of individual patients, 10 years after the first human genome sequence was published. The broadcast showed how this will give doctors a better understanding of the inherited factors that help trigger heart disease. The genetic sequencer was also featured in *The Times, Daily Telegraph* and the *Daily Mail.*

The Mail on Sunday June 2010

A Harefield heart transplant patient who took part in the London to Brighton Bike Ride revealed how within two days of the operation he was on an exercise bike to get the new heart muscle working. Brian Unwin, said: "I was immediately living the active life I had not been able to manage for years."

The Mail on Sunday October 2010

A half-page article on revolutionary lung transplant surgery at Harefield Hospital, described a new minimally invasive lung transplantation that does not require surgeons to cut through the sternum to open the entire chest.





ventilation at home appeared in news broadcasts in

December 2010. *e-VENT* is a web-based patient pathway designed to improve communication between hospital and community services and to support the clinical team and aims to allow children on long-term ventilation to be cared for safely at home.

Channel 4 December 2010



Royal Brompton's ECMO unit featured in *The Independent, Channel 4* and BBC's *Newsnight* programme for its work in treating patients with swine flu. Coverage described how ECMO uses an

artificial lung to oxygenate the blood outside the body, preventing further damage while the lungs recover.





Red Magazine March 2011



A double page spread in the popular magazine featured one of Royal Brompton's cystic fibrosis patients, who described the specialist care provided by Royal Brompton's CF team. Ashley Harris talked about her

daily drug and physiotherapy treatment, which often requires stays at the hospital, where she is seen by a specialist team, including Dr Susan Madge, consultant nurse, Kamilla Dack, clinical nurse specialist and Dr Nick Simmonds, consultant respiratory physician.

The Daily Telegraph March 2011

The Daily Telegraph featured the Trust's provision of locally sourced, freshly cooked ingredients, as a "revolution in government catering".

Children's heart surgery review

In February 2011, a review of children's heart services in England recommended that Royal Brompton's cardiac surgery for children should stop.

There has been extensive national media coverage since the recommendations were published . This includes articles in the *Daily Mail*, *The Independent*, the *Guardian*, *The Times* and *Sunday Times*, in addition to significant broadcast coverage.

Summary accounts

Our accounts are prepared in accordance with the 2010/11 NHS Foundation Trust Annual Reporting Manual (FReM) issued by Monitor, the independent regulator of NHS foundation trusts.

The comparative figures below are for the Trust's first accounting period of 10 months to 31 March 2010 following authorisation as a foundation trust on 1 June 2009.

				as at 31.03.11 £000	as at 31.03.10 £000
STATEMENT OF COMPREHE	NSIVE IN	COME	NON-CURRENT ASSETS		
for the year to 31 March 2011			Property, plant and equipment	189,224	183,612
, -			Investment properties	25,828	21,800
	year to	10 months			
	31.03.11	to 31.03.10	IOIAL NON-CURRENI ASSEIS	215,052	205,412
	£000	£000	CUDDENT ACCETS		
			Inventories	10840	0.017
Revenue from patient care activities	253,484	186,921	Trade and other receivables	18,543	9,31/
Other operating revenue	30,536	29,936	Cash and cash equivalents	16,570	12 022
Operating expenses	(276,804)	(210,058)	-	10,079	13,023
			TOTAL CURRENT ASSETS	46,092	43,070
OPERATING SURPLUS	7,216	6,799		- (
Invostment revenue	22	22	IOIAL ASSEIS	201,144	248,482
	32	22			
Revaluation gain on investment			CURRENT LIABILITIES		
property	4,028	2,305	Trade and other payables	(32,787)	(32,182)
Finance costs	(58)	(63)	Borrowings	(12,959)	(2,520)
			Provisions	(143)	(184)
	11 018	0.062	TOTAL CURRENT LIABILITIES	(15 880)	(34 886)
TENUOD	11,210	9,003		(4)/009/	
Dividends payable on Public			NET CURRENT ASSETS	203	8,184
Dividend Capital	(6,509)	(5,496)	-		
·			TOTAL ASSETS LESS CURRENT		
RETAINED SURPLUS FOR THE			LIABILIIIES	215,255	213,596
PERIOD	4,709	3,567	NON_CUPPENT I LA BULITIES		
			Borrowings	(210)	(488)
OTHER COMPREHENSIVE			Provisions	(1 0 4 7)	(400)
INCOME:			-	(1,04/)	(1,020)
Impairments	(5 802)	(7 806)	TOTAL NON-CURRENT LIABILITIES	(1,257)	(1,516)
	(3,092)	(7,090)			
Revaluation gain on operating		- 0	IUIAL ASSEIS EMPLOYED	213,998	212,080
properties	947	2,831			
Receipt of donated/government			FINANCED BY:		
granted assets	5,015	2,067	TAXPAYERS' EQUITY		
Reduction in the Donation Reserve			Public dividend capital (PDC)	104,759	104,759
in respect of depreciation and			Retained earnings	37,890	33,180
impairment of fixed assets	(2,862)	(1,883)	Revaluation reserve	56,055	60,935
Total comprehensive income			Donated asset reserve	15,294	13,206
for the period	1 017	(1 2 1 4)	TOTAL TAXPAYERS' FOUITY	213.008	212.080
	171/	(*/3*4/			

STATEMENT OF FINANCIAL POSITION as at 31 March 2011

For a copy of the Trust's annual report 2010/11 please contact the office of the director of finance on 020 7351 8243.



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