A lifetime of specialist care

Royal Brompton & Harefield NHS
NHS Foundation Trust

ANNUAL REVIEW

2013-14


INTEGRA

Contents

Other formats

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اذا كنت راغباً في الحصول على نسخة مترجمة باللغة العربية من هذا التقرير الرجاء
c.denmark@rbht.nhs.uk, 020 7351 8671 كتوري جيتسين (في فريق الأتصالات): في الأتصال بـ

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

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Introduction from the chairman and chief executive

As you read through this annual review you may be struck by the number of times words and phrases like "only", "largest", "pioneering", "revolutionary", "one of the few centres in the UK", "first in the world", "at the centre of", are used when describing our Trust. They reflect our position as one of the leading specialist centres for the treatment of patients with heart and lung disease and one of the foremost centres for innovative research into conditions that still account for 43 per cent of deaths in the UK. Growth in demand for our services has never been higher; over the past five years outpatient appointments and inpatients admissions have increased by 23 and 24 per cent respectively.

Although we are proud of our achievements, the real measures of our success are our outcomes, which continue to be excellent, and the testimony of patients, which appear throughout this annual review: "it's the best", "more than 30 years of ongoing brilliance", "amazing", "it really transformed me", "I will be forever grateful". Our score for the national Friends and Family Test, which is mandatory for all trusts and asks "How likely are you to recommend our ward to friends and family if they needed similar treatment or care?" is generally between 85 and 90, regularly putting us in the top 10 trusts in England.

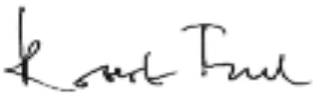
Our reputation is built on the expertise and dedication of our staff, and the annual review is an opportunity to celebrate this. Our professional staff are recognised as leaders in their fields and many of our clinicians come from all over the world to train here. But our expertise does not remain within the confines of the two hospitals; we have established excellent links with other hospitals in the UK and within the community offering clinical support and training. Our long-term ventilation service at Royal Brompton for children who need help to assist their breathing is an excellent example; children who would once have had to remain in hospital can now return home cared for by their family and professional carers with the support of a full care package co-ordinated by our specialist team. Nationally, it takes an average of seven to nine months for a child to be discharged once they are medically ready – this groundbreaking programme has reduced it to an average of three months.

Our transplant unit at Harefield Hospital has the best survival rates in the UK and, in December, John McCafferty, one of our governors, became the longest surviving heart transplant recipient in the world, having received his new heart over 31 years ago. Since then, there have been many revolutionary improvements in the care of transplant patients and we are currently leading the field in the use of the Organ Care System. This keeps a donor heart beating and in the best possible condition so our transplant team is able to retrieve hearts from further away. The result is more patients have had life-saving heart transplants that otherwise would not have been possible.

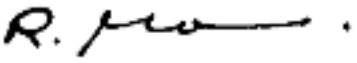
As you read through the annual review you might be struck by the number of times words and phrases like **only**, **largest**, **pioneering**, **revolutionary**, **one of the few centres in the UK**, **first in the world**, **at the centre of**, are used when describing our Trust.

We are committed to finding new ways to fight heart and lung disease and new treatments and techniques that will improve patient care and patient experience. Many of our clinicians are involved in national and international research programmes. Opening our new genetics and genomics facility at Royal Brompton in December 2013, Secretary of State for Health, Rt Hon Jeremy Hunt said: "We want this to be the century of personalised care and the advances in treatment we are seeing in laboratories like Royal Brompton's will help revolutionise medicine." The new laboratory provides patients from the Trust and the wider NHS with improved access to genetic tests that will enable much quicker gene testing for those who are diagnosed with, or have a family member who is at risk of, an inherited cardiac condition. In addition, the new tests will provide results more rapidly; weeks rather than months or even years, and at a fraction of the cost.

We hope this annual review gives you a brief insight into Royal Brompton & Harefield NHS Foundation Trust, the work of our dedicated staff and the stories of our inspirational patients. Next year, 2015, is Harefield Hospital's centenary. We look forward to celebrating its unique history in successfully diagnosing and treating heart and lung disease.



Sir Robert Finch
Chairman



Mr Robert Bell
Chief executive

RESEARCH

INTERNATIONAL INFLUENCE

Trust mission, values and approach

Our mission

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

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

Our approach

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

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

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

Trust values

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

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

Our three core values are:

We care

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

We respect

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

We are inclusive

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

The following values support our core values:

We believe in our staff

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

We are responsible

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

We discover

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

We share our knowledge

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

About us

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

Heart and lung diseases are the world's biggest killers and our experts care for patients who come, not only from our local areas, but from across the UK and overseas. We carry out some of the most complicated surgery, and offer some of the most sophisticated treatment that is available anywhere in the world.

We help patients of all ages who have heart and lung problems. Our care extends from the womb, through childhood, adolescence and into adulthood.

Royal Brompton and Harefield hospitals are known throughout the world for their expertise, standard of care and research success.

Research programmes play a vital role at both our hospitals. This is because the most talented medical experts are rarely content with only using tried and tested methods to treat their patients. The opportunity to influence the course of modern medicine by developing new treatments and surgical techniques is a prospect that attracts them to specialist centres, where research opportunities are a fundamental part of delivering patient care.

As well as travelling internationally to lecture and share their knowledge, our clinicians hold prominent positions on influential boards, committees, institutions and professional associations. Each year, hundreds of papers by researchers associated with the Trust are published in peer-reviewed scientific journals, such as *The Lancet* and *New England Journal of Medicine*.

Our academic partners are the National Heart and Lung Institute in the Faculty of Medicine, Imperial College London and the Harefield Heart Science Centre. We are also part of Imperial College Health Partners, an organisation bringing together the academic and health science communities across North West London. Through our clinical research studies we have active collaborations with hospitals and universities across the UK, most notably with Liverpool Heart and Chest Hospital in the joint Institute for Cardiovascular Medicine and Science.

Our experts promote the principle of "shared care" through an expanding system of consultant-delivered outreach clinics, at which they see patients at over 30 hospitals across the South East, covering Essex, Sussex, Surrey, Hertfordshire and Middlesex. Fully integrated networks of care exist with partner organisations and many of our clinicians have joint appointments with neighbouring trusts.

This system allows patients to benefit from specialist expertise in their local environment, with inpatient care at our hospitals available as needed.

Royal Brompton's proximity to the specialist cancer hospital, The Royal Marsden, enables the two trusts to jointly run one of the largest lung cancer programmes in the UK. Close collaboration with neighbouring Chelsea and Westminster Hospital allows both trusts to provide significantly enhanced services to patients of all ages with heart or lung disease. Harefield teams continue to enjoy ongoing support across a range of specialist disciplines from Hillingdon Hospital NHS Foundation Trust.

RESEARCH

INTERNATIONAL INFLUENCE

Performance & achievements in 2013-14

Our experts carried out over **187,000** outpatient, diagnostic and imaging appointments and saw over **34,000** inpatients.

In April 2013, the Department of Health set a target of **15** per cent completion rate for Friends and Family Test (FFT). The Trust has maintained and exceeded this target **every month** this year.

The Trust has maintained a net promoter score of between 85 and 90 for the FFT – regularly putting us in the **top 10** trusts in England.

We achieved high patient satisfaction scores in the 2013 Care Quality Commission National Inpatient Survey and scored in the **"best performing Trust"** category in 25 of 58 questions.

We participated in a voluntary survey of our young (under 16 years) inpatients and **94** per cent of young inpatients aged eight and over rated their hospital care as **excellent, very good or good**.

The Trust **met** the 18-week NHS standard referral time for non-admitted patients **every month**.

HEART

LUNG

We opened a **brand new** pre-admissions clinic (Woodlands) at Harefield.

Our experts cared for almost **2,000** patients with cancer.

Our experts **launched** the ground-breaking new ARIA (arrhythmia risk in adult congenital heart disease) service – the **first** of its kind in the **world**.

A **revolutionary** new treatment for patients with severe emphysema, called steam ablation, took place for the **first time** in the UK at Royal Brompton in March 2014.

We opened a new **£2m state-of-the-art** genetics and genomics laboratory at Royal Brompton.

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

The transplant unit at Harefield is the **first in the uk** to adopt the revolutionary Organ Care System as standard practice for heart transplant procedures and it was used for **all but one** heart transplant in 2013-14.

"Second-to-none" cardiac care

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

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

The adult congenital heart disease (ACHD) unit at Royal Brompton is one of the largest specialised centres in the world. Our experts carry out over 2,000 outpatient appointments each year. The unit is a major research facility and a national and international training centre for cardiologists, cardiothoracic surgeons and other clinicians. Specialist international clinical fellows are an integral part of the unit and contribute to the worldwide reputation of the Trust.

World-first ARIA clinic launched

A groundbreaking new clinic at Royal Brompton, run by consultant cardiologist, Dr Sonya Babu-Narayan, began welcoming patients in 2014.

The ARIA (arrhythmia risk in adult congenital heart disease) service is the first of its kind in the world and was set up in response to the increasing numbers of patients with very complex heart rhythm problems.

The ARIA service helps to ensure that the care of ACHD patients who may be at risk of sudden death is coherent across the Trust and that patients are seen, assessed in a consultant-delivered clinic, and then treated, all in a short space of time.

Dr Babu-Narayan explains: "A typical patient in the ARIA service has been a long-term patient at the Trust and has perhaps been coming every year or six months for a check-up. They are referred to the service by their ACHD consultant to evaluate the risk of future dangerous arrhythmias."

Once patients have been referred to the ARIA service, Dr Wei Li, consultant in ACHD echocardiography, performs a detailed echocardiogram, which gives information about the structure and function of the heart. Dr Babu-Narayan sees the patient

Congenital heart surgery: an update

Following the Secretary of State for Health, Jeremy Hunt's, decision to suspend the Safe and Sustainable review of children's heart surgery in June 2013, NHS England has been developing a new approach. The team leading the new review is considering the whole patient journey – from antenatal testing and diagnosis to adult monitoring and interventions. Other factors that will also be considered are capacity analysis, performance data, including mortality rates of congenital heart services and any wider implications for other services.

NHS England held a series of engagement events for children and young people throughout the country over Easter 2014 so that they could contribute to the review.

In early May, we welcomed Professor Deirdre Kelly, chair of the review's clinicians group, and colleagues from NHS England, to Royal Brompton.

The visit was an opportunity for Professor Kelly and her colleagues to outline progress on the congenital heart disease review to date, meet our clinical team and find out more about the work we do. They also met and heard the views of several patients and parents.

NHS England is planning a public consultation in the autumn and we continue to engage with the team leading the review to ensure the best outcome for all congenital heart patients.

The review is likely to be completed in 2015.

and usually later that day does a detailed cardiovascular magnetic resonance (CMR) scan to view the blood supply, how well the heart is pumping and to obtain 3D imaging. Patients may be admitted and have a diagnostic electrophysiology examination to record the electrical activity (rhythms) in the heart. In these patients the specialised 3D CMR imaging can be used to make the electrophysiology procedure easier.

A multidisciplinary meeting with at least four consultants takes place following the test results to discuss the possible treatment options.

Dr Babu-Narayan explains: "I discuss the outcomes with patients. I always ask that they bring a family member or close friend with them to the outpatient appointment and we spend at least an hour talking through the relative risk of heart rhythm disturbance that might be life-threatening – basically, the chances of them having a sudden cardiac arrest. If we decide that the risk is high, we may decide to implant a defibrillator."

An implantable cardioverter defibrillator (ICD) is a small device inserted just under the collar bone and designed to treat people with abnormal heart rhythms. An ICD monitors the heart rhythm and delivers electric pulses or shocks if the heart goes into a dangerous rhythm.

Dr Babu-Narayan continues: "It is often a very difficult decision for both the patient and the adult congenital heart clinician to decide whether an ICD is beneficial. Some patients get shocks when they are not necessary, for example. That is why the relative risk of a cardiac arrest needs to be weighed up so carefully. Someone living with an ICD will have to make some changes to their lifestyle and it can also be a difficult psychological adjustment. However, the device can save a patient's life if they have a cardiac arrest and so it can also be reassuring for a patient and their family."

Once patients have been seen and treated within the ARIA service, they are referred back to their usual consultant in the Trust. There are plans for the service to expand so that patient referrals can also be accepted from other hospitals.

Pulmonary hypertension

Pulmonary hypertension (PH) is a rare lung disorder in which blood pressure in the pulmonary arteries (the blood vessels supplying the lungs) rises far above normal levels. It is a serious medical condition that can damage the right side of the heart, and severely reduce the amount of blood and oxygen delivered to the body, leading to significant shortness of breath and poor exercise capacity.

The pulmonary hypertension service at Royal Brompton Hospital is one of only seven designated centres that form the National Pulmonary Hypertension Service (NPHS) for England. It is one of the most rapidly expanding services and it is also one of a few combining PH, adult congenital heart disease (ACHD) and lung disease expertise in a single centre. In most people, PH is associated with another medical condition, such as heart disease or lung disease, although in a small number of patients it develops in isolation (idiopathic pulmonary arterial hypertension).

PH usually gets progressively worse and, left untreated, may cause heart failure.

> "From the moment I arrived at Harefield, while suffering a heart attack, the treatment I received was **second-to-none**."
>
> **Patient, NHS Choices**

Our patients are mainly referred from the south of England and Wales. However, as a tertiary centre for ACHD and complex lung disease, our clinicians also see patients from all over the UK. The service is led by consultant in PH and intensive care, Dr John Wort, and run by a team of consultants and clinical nurse specialists with support from specialist pharmacists and information and technology. The service has formal shared care arrangements with St George's Hospital, Southampton General Hospital, Surrey and Sussex Healthcare NHS Trust and, from early 2014, John Radcliffe Hospital. This means greater collaboration between centres and better care for patients, delivered closer to home.

Dedicated clinics for ACHD patients with pulmonary hypertension

Royal Brompton is the only centre in the UK with a dedicated joint service for ACHD and PH.

Dr Wort explains: "Many of our PH patients also have ACHD and are under lifelong follow-up. It is hugely beneficial for the patient to have ACHD and PH expertise in a single centre. It is not only convenient for patients in terms of reducing the number of times they need to attend clinics, but also means they can be treated faster and more efficiently, as their care is better co-ordinated. This is incredibly important, especially as we treat many patients who have conditions like Down's syndrome, which means they also have learning difficulties."

Dr Kostas Dimopoulos, consultant cardiologist, adds: "All PH patients at Royal Brompton also benefit from our close links to the Chelsea and Westminster obstetrics team and other well-established specialist services in our Trust such as the high-risk pregnancy service, state-of-the-art arrhythmia services, intensive care (including the ECMO service) and high-risk anaesthetics."

Research

The team at Royal Brompton runs an international PH preceptorship meeting every year, led by Professor Michael Gatzoulis, during which PH experts from across the world gather to discuss the latest developments in research and treatment.

Dr Dimopoulos also organises two national PH preceptorships at Royal Brompton each year. These provide physicians from around the UK with the opportunity to learn about all types of PH, with practical sessions in the catheter laboratories and clinics.

Last year, our experts implanted or renewed over **1,000** pacemakers and almost **200** ICDs

Additionally, Dr Wort leads the prestigious annual national PH physicians research forum, held at the Chelsea Physic Garden.

Arrhythmia – innovative devices

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

Royal Brompton & Harefield NHS Foundation Trust has one of the largest pacing and complex device services in the UK. Last year, our experts implanted or renewed over 1,000 pacemakers and almost 200 implantable cardioverter defibrillators (ICDs).

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

Pacemakers and ICDs are both implanted in the chest and can send regular electrical pulses that help keep the heart beating regularly. ICDs are often used as a preventative treatment for people thought to be at risk of cardiac arrest. If the ICD detects that the heart is beating at a potentially dangerous rate, it can "pace" or deliver an electric shock to the heart to help it return to its normal rhythm.

Innovation in technology

Our experts are at the centre of several global trials so we can access the latest device technology and provide truly world-class care.

Dr Tom Wong, consultant electrophysiologist and cardiologist, is the UK principal investigator of a multicentre, international study to confirm the clinical performance of the Nanostim™ leadless pacemaker. He and Dr Vias Markides, consultant cardiologist and arrhythmia lead for the Trust, have implanted some of the first devices in patients.

Dr Wong explains: "This is a pacemaker designed for patients with a slow heartbeat. A standard pacemaker is implanted into a surgical pocket close to the heart. Leads are then attached to the pacemaker and run to the heart, where they pace it to regularise the heartbeat. However, the Nanostim™ pacemaker is leadless. It is placed directly inside the heart and sends small pulses of electricity when needed to prompt the heart to beat normally. One of the benefits for patients is that the pacemaker can be implanted using a catheter that delivers it into the heart chamber, so there is no cut or scar."

The trial is ongoing with results due in 2015.

In early 2014, Dr Markides (pictured right) and Dr Mark Mason, consultant cardiologist, performed the world's first implants of the new Medtronic Evera™ magnetic resonance imaging (MRI) conditional (compatible) ICD at Royal Brompton and Harefield, respectively.

Dr Markides comments: "MRI is an essential tool for looking at a patient's soft tissues. However, up until now, patients with an ICD have been unable to have an MRI scan, when sometimes this would have been the most appropriate diagnostic test for them. This is because MRI works by generating strong magnetic and electrical fields and the fear is that these fields could interfere with device function, prevent pacing or cause inappropriate shocks, or result in heart tissue being heated up by ICD leads. These modern MRI conditional devices allow not only general MRI scans to be safely performed, but also MRI scans of the heart itself to be performed. This allows detailed monitoring of the underlying heart condition that was responsible for the patient's arrhythmia and can help to guide treatment."

Primary angioplasty

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

A heart attack happens when a blood clot blocks a coronary artery – one of the vessels that supply the heart with blood and oxygen – so that the heart muscle does not receive blood and oxygen, and becomes damaged. The longer the artery is blocked, the more damage there is to the heart.

Heart attack patients are brought straight to Harefield by ambulance, rather than to a local A&E, where our clinicians use primary angioplasty to clear blockages in the coronary artery.

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

We carried out over **2,000** primary angioplasty procedures for heart attack patients last year

A PATIENT'S VIEW

Mark Jeffries

Mark Jeffries' son, Lee, works at Harefield Hospital as a clinical outcomes officer, recording data from admissions and procedures in cardiology, for which Dr Rob Smith, consultant cardiologist, is the clinical lead.

It was a normal day at work for Lee until he saw he had a voicemail from his mother. Lee explains: "My mum said in her message that Dad was ill and had been taken to A&E at Hillingdon Hospital. I had no idea what to think or what to do. I tried to call Mum back but I couldn't get through. I spoke to my manager and then set off to Hillingdon. But as I was leaving I got a call from Mum. She said 'just stay there, we're on our way to you'. At that point, I froze. I knew that if he was coming to Harefield it must be a heart attack. I just broke down, I was in bits."

Lee's dad, Mark, aged 50, takes up the story: "It was about mid-morning that I began to feel a tightening across my chest. I thought it was indigestion at first and I went outside to get a bit of air, but it didn't get any better. A colleague drove me to Hillingdon A&E and I had an echocardiogram. After that, things moved quite fast and I heard someone on the phone saying they needed an ambulance to take me to Harefield. It sort of hit home then that I was having a heart attack."

Mark's wife, Brenda, and middle son, Daniel, both work at Hillingdon Hospital so they travelled with him in the ambulance to Harefield.

Lee waited at the front entrance until the ambulance arrived. He continued: "When Dad came out of the ambulance, he was grey. It just didn't look like him. He was taken to the cath labs and Rob Smith was on duty. He just looked at me and said, 'Don't worry, we'll look after him'."

Mark said: "It was really hard seeing Lee and the rest of my family so upset. It sort of felt like it was happening to someone else. But I did feel scared, I know that much."

In the cath lab, Dr Smith started the primary angioplasty procedure. He said: "In Mark's case, the coronary artery was completely blocked, meaning that blood and oxygen were not getting to his heart. This is what was causing him the pain. It is always crucial to remove the blockage as soon as possible, to help minimise the damage to the heart. As soon as the stent is in place in the artery, keeping it open, we always notice that the patient feels less pain and their colour begins to return as blood flows back to the heart."

Mark commented: "I was aware of what was going on but I was a bit drowsy because of the sedation medicine. I do remember Rob Smith's voice very clearly, just asking how I was feeling and telling me that I'd be OK. Something I was really scared about was open heart surgery, and when I was coming into Harefield in the ambulance I actually thought about the scarring and the pain. But technology has moved on so much these days – it's amazing what they can do. I'm so lucky to have been taken to a hospital like Harefield."

Lee said: "Waiting outside the cath lab, it felt like hours had gone past. In reality, Dad was only in there about 25 minutes. When Rob stuck his head round the door and said everything had gone well, I almost collapsed with relief. My family and I were able to go in and see him and all the colour had come back into his cheeks."

Mark stayed in hospital for the next three days recuperating, before being allowed home to his family.

He is now fit and healthy and has a check-up at Harefield every six months. He did the London to Brighton cycle race last year. Recently, he got a dog and takes him for a walk every day. Mark comments: "I've never felt better. I was always quite active, but not as much as I am now. I also make sure I eat really well – lots of fresh fruit and veg and lean meats."

In 2013-14, we averaged one of the **fastest arrival-to-treatment times** for heart attack patients **in the UK**

Lee jokes: "I don't go round and see him as much now as there are less biscuits on offer!"

Lee said that the whole experience has changed how he sees his work – and how he sees his colleagues: "Now when I'm inputting data, I'm so much more aware that each figure is a patient and I know what that family is going through. I just can't thank Rob enough for what he did. It was really strange at first as I felt I wanted to hug him and thank him all the time! But then I realised that he was doing his job, which is in itself amazing. Rob and Harefield have given me back my dad."

Lee and his family have since taken to fundraising for the cath labs at Harefield, culminating in a charity football match played at Watford's football ground in May 2014.

The Jeffries family at the charity football match from left: Lee, brothers Daniel and Michael, and dad, Mark

TAVI – an alternative to open heart surgery

Since 2007, when the first transcatheter aortic valve implantation (TAVI) procedure took place in the UK, our team of experts has performed the largest number of TAVIs in the UK.

TAVI is a non-surgical alternative to open heart surgery. The procedure is usually performed to treat aortic stenosis (narrowing of the aortic valve), which can cause shortness of breath, fainting, increased risk of heart failure and even sudden death. A TAVI is generally recommended to a patient when conventional open heart surgery is considered very high risk.

The TAVI programme has been running for the past seven years at Royal Brompton and since 2010 at Harefield. Last year, our experts completed 113 procedures.

TAVI is carried out in a cath lab and normally takes one to two hours. A catheter (thin flexible tube) containing the replacement aortic valve is inserted, usually through an artery in the patient's groin. The catheter is guided through the artery to the heart using special imaging equipment. The replacement valve is placed inside the patient's narrowed aortic valve to open it up and relieve the obstruction (stenosis).

In around 20 per cent of patients it is not possible to access the artery in the patient's groin and our experts at Royal Brompton were the first in the UK to carry out a TAVI via the subclavian artery (top of the shoulder) and via the direct aortic approach (a small cut in the chest).

Most recently, the team has also been involved in pioneering work with failing valve replacements. If a patient has had an operation where they have received a biological valve (made from animal tissue), this will need to be replaced after several years (usually 10-14). For some patients, who are often very elderly and may have had their first procedure as an open heart operation, Trust clinicians are now routinely using the less invasive TAVI procedure to implant a new valve within the failing valve – known as a "valve in valve" procedure.

The TAVI programme at the Trust, led by consultant cardiac surgeon, Mr Neil Moat (pictured right), enjoys an international reputation.

Mr Moat comments: "This highly successful programme is the culmination of a lot of hard work by clinicians in both hospitals. Many of the patients are elderly with other medical conditions. So, the TAVI procedures involve collaboration with a huge number of other services, such as specialist imaging, care in the elderly, renal and neurology teams, specialist nurses and many more."

Heart surgery innovation

Coronary artery bypass grafting (CABG) is a type of surgery used to treat coronary heart disease and relieve angina, which is the term given to a cramp-like pain or heaviness felt mainly in the chest and left arm. It occurs when not enough blood is reaching the heart.

During a CABG procedure, a surgeon grafts arteries or veins from elsewhere in a patient's body to the coronary arteries, to bypass narrowings in the arteries and improve the blood supply to the heart. The surgeon will usually perform a median sternotomy (a vertical cut to divide the breastbone) to gain access to the heart. It can take three months or longer for patients to recover from this open chest surgery.

The first robotic minimally invasive CABG in the UK was performed at Royal Brompton in 2000 and, since then, our experts have carried out over 400 of these procedures known as an EndoAcab (endoscopic atraumatic coronary artery bypass graft). Surgeons avoid cutting the sternum using advanced endoscopic techniques and robotic camera control to harvest the left internal mammary artery and perform the anastomosis (join) to the blocked artery.

Mr Tony de Souza, consultant cardiac surgeon and chair of revascularisation, comments: "The EndoAcab procedure is performed 'off pump', which means there is no need to stop the heart or use a cardiopulmonary bypass machine – we do it while the heart is still beating. Because of this, and the fact that we use small incisions rather than opening the chest, patients experience less pain, minimal scarring and faster recovery times."

Hybrid operations

If a patient has multiple narrowings of many arteries, a hybrid coronary revascularisation (HCR) procedure may be the most appropriate form of treatment. Very few centres in the UK offer this type of surgery and our surgeons have done the largest number of these procedures in the UK.

Mr Richard Trimlett, consultant cardiac surgeon, comments: "The EndoAcab is performed on one day and, three or four days later, patients have coronary angioplasty in a catheter laboratory – again, this procedure is minimally invasive so the recovery time is quicker for patients."

During the angioplasty procedure, the narrowed coronary arteries are widened by inserting a small tube called a stent, improving blood supply to the heart.

Ms Rashmi Yadav, consultant cardiac surgeon, explains: "Around a third of patients who need EndoAcab surgery also need stents, so we are doing more and more of these hybrid procedures. The benefits for patients are huge – they only need one hospital stay and, because the procedures are minimally invasive, they can often resume normal activity, including work, after two to three weeks."

Last year, our experts performed over **100** transcatheter aortic valve implantation (TAVI) procedures

"Life-saving" transplantation

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

In April 2013, Harefield became the first cardiothoracic transplant centre in England to undergo and successfully pass a Human Tissue Authority audit for organ retrieval and transplantation. All centres are legally required to be licensed and inspected from August 2012 in line with EU law.

VAD innovation

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

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

The VAD team at Harefield, led by Mr André Simon, carries out approximately 30 VAD procedures every year and looks after over 50 patients who are living with a VAD.

Upcoming trials and pioneering work

SynCardia temporary Total Artificial Heart

SynCardia is a mechanical heart pump used in patients with severe biventricular failure. Unlike in VAD implantation, the patient's own heart is removed during this procedure and replaced with a SynCardia. Harefield's clinical team are fully trained to carry out the procedure.

Sunshine Heart (C-Pulse® Heart Assist System)

The Sunshine Heart is a new approach to treating heart failure. It involves surgical implantation of an inflatable cuff that encircles the aorta and is used to treat patients with moderate to severe heart failure. The device increases blood flow and improves heart function. Harefield is currently the only centre in the UK using Sunshine Hearts.

The VAD team at Harefield Hospital

"Seven months ago I had a **life-saving** double lung transplant. Wonderful surgeons, Drs, nurses and physios."

Patient, Twitter

John McCafferty, record breaker

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

In December 2013, Harefield patient, John McCafferty, was officially recognised as the world's longest surviving heart transplant patient by Guinness World Records.

John, 71, from Newport Pagnell, Buckinghamshire, surpassed the previous record of 30 years, 11 months and 10 days. It is now over 31 years since his successful transplant was carried out at Harefield Hospital, by world-renowned surgeon, Professor Sir Magdi Yacoub.

John hopes his world record achievement can be an inspiration to other transplant patients. He commented: "At the time of my heart transplant I was told that I might expect to live for another five years if the procedure was a success. The idea that I would live to see my seventies was inconceivable. Yet, here I am!

"I want this world record to be an inspiration to anyone awaiting a heart transplant and to those who, like me, have been fortunate enough to have had one. My advice is always to be hopeful, to look ahead with a positive mind, and, of course, to follow the expert medical guidance."

Now retired, John remains an active member of the transplant community. He splits his time between various roles after being elected to the position of public governor of Royal Brompton & Harefield NHS Foundation Trust; acting as secretary of the Harefield Re-beat Club, and serving as an active committee member of the Harefield Hamsters Transplant Club.

Our patients show the **highest** rate of myocardial recovery in the world

Organ Care System

Our heart transplant numbers have continued to increase, mainly due to the Organ Care System (OCS), which enables a donor heart to beat outside the human body. Harefield is the first transplant centre in the UK to adopt this revolutionary system as standard practice for heart transplant procedures and it was used for all but one heart transplant in 2013-14.

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

This new system increases the time the heart can be maintained outside the body, up to eight hours, compared to a maximum of three to four hours on ice. This means hearts can be retrieved from further afield and it provides surgeons with greater opportunity to assess how well the donor heart is functioning prior to transplant. In 2013-14, the OCS was used to retrieve hearts that became available for Harefield patients from hospitals normally considered too far away, for example, Scotland and the Republic of Ireland.

Mr André Simon, consultant cardiothoracic surgeon and director of transplantation, said: "This new technology has enabled us to increase the offer-to-transplant conversion rate. Put simply, it means that patients at Harefield have had life-saving heart transplants, which otherwise would not have been possible – primarily because we have travelled greater distances to retrieve an organ."

A PATIENT'S VIEW

Andrew Britton

Andrew Britton, aged 33, a keen triathlete and squash player, married his wife, Lauren, in November 2012 and they immediately set off on a dream honeymoon in the Maldives. However, within hours of arriving, Andrew became unwell. He explains: "At first, I just thought it was a hangover after the wedding or some dodgy plane food!"

Lauren called for the local doctor and Andrew was put on a rehydration drip in his beach hut. It quickly became clear that this was far more serious than first thought and the next day the couple took a boat to the nearest hospital. There, doctors found that Andrew had a heart rate of 200 beats per minute. He was sedated, given defibrillation shocks and warned that he could die if he was not taken to a specialist hospital in Bangkok within 24 hours.

Lauren recalls: "It all happened completely out of the blue. It was absolutely terrifying. One moment we were enjoying our honeymoon and looking forward to our future together, the next, we were being told Andrew might not make it."

Andrew was flown to Bangkok on an emergency medical jet and placed on life support for the next two weeks.

Lauren explains: "It was awful phoning friends and relatives to explain what had happened and it was hard being so far away from everyone with Andrew so ill. His parents flew out to Bangkok to be with us, and they and family back home really kept me going."

After several weeks, Andrew was stable enough to fly home by medical jet, and was taken straight to Harefield Hospital where he was diagnosed with myocarditis. Dr Nick Banner, Andrew's cardiology consultant, explains: "Myocarditis is an inflammatory condition that can damage the heart muscle. The most common form is often triggered by a viral infection. We do not know why some episodes of viral infection trigger myocarditis and others do not. The majority of cases clear up within a week. However, sometimes the inflammation in the heart is more severe and serious damage occurs. Once the heart muscle becomes weakened and the heart enlarges, the result is heart failure. Unfortunately, this is what happened in Andrew's case."

Andrew was fitted with a cardiac resynchronisation therapy pacemaker and defibrillator (CRT-D) to improve the performance of his heart. CRT-Ds have the additional function of being able to quickly stop an abnormally fast, potentially life-threatening heart rhythm.

He was then able to leave hospital, but seven weeks later he collapsed and was readmitted to Harefield. This time, Andrew had eight hours of open heart surgery, and was fitted with a left ventricular assist device, which is intended to directly support the pumping function of a failing heart and improve blood flow to other vital organs.

His heart had been so damaged by the myocarditis infection he was told he needed a heart transplant. He stayed at Harefield while waiting for an organ to become available. Lauren said: "It was an incredibly worrying time – we were supposed to be enjoying our time together as newlyweds, but instead, we were living apart, with Andrew not able to leave hospital. I visited him every day after work and we ate dinner together."

When a heart became available in September 2013, the Organ Care System was used to retrieve the donor organ and keep it in the best possible condition before Andrew's operation.

He recovered well, and was finally able to leave hospital in November – almost a year to the day that he first collapsed in the Maldives.

Andrew says: "The difference in me now and then is like the difference between night and day. It's hard to express

the severity of the past year. I want to thank my family and friends – they have been amazing and I didn't appreciate how much they had all been through. I was very poorly, and just being normal again is quite a big shock. I feel fit again, although it is a long road to recovery, given the surgery involved."

Andrew has returned to his job as a project manager at an international hotel chain on a part-time basis, goes jogging and enjoys taking his dog, Billy, out for daily walks.

He and Lauren are also delighted with the news that their first child is due in October.

He said: "The baby news has given us something positive to focus on. Without the donor heart that wouldn't have happened. The hospital staff were ecstatic when we told them."

Andrew, Lauren and their extended families have been raising funds for Harefield since his treatment there. He said: "To put it simply, without the care and treatment of everyone at Harefield, I wouldn't be here and we wouldn't be looking forward to the future. I will be forever grateful."

Lauren has written a book about their experience – *Strength in Strangers.*

Andrew and Lauren, who are expecting their first baby in October

"World-class" children's services

Royal Brompton and Harefield's dedicated paediatric department is a national referral centre for children with heart and lung conditions. We offer the full range of diagnostic and surgical interventions, and ongoing care and treatment, throughout childhood and transition to our adult departments.

Many of our children's services are internationally renowned, including fetal cardiology, inherited cardiac conditions, sleep disorders, paediatric cystic fibrosis and severe asthma, and we have the largest national centre for children with heart rhythm problems. We also look after children with rare respiratory disorders, such as primary ciliary dyskinesia (PCD) and muscular disorders, for example spinal muscular atrophy.

Last year, we added four new paediatric high-dependency beds to the paediatric intensive care unit (PICU) at Royal Brompton, which has 16 intensive care beds. There are also four high-dependency beds on the children's ward (Rose Ward) providing the same level of care as the new beds.

This increased capacity is to accommodate the continuing rise in paediatric inpatient admissions.

Strengthening relationships

A new network programme to strengthen relationships with our referring hospitals and ensure we can work together to meet the new standards for paediatric cardiac care was launched in 2013-14. Network teaching and education days were held at Royal Brompton this year and there are plans to expand these education days into the referring hospitals.

The Trust increasingly uses telemedicine to provide clinical healthcare at a distance. Trained paediatricians with expertise in cardiology at our referring hospitals are able to scan a child's heart and share the results with cardiologists at Royal Brompton, who can then advise on the care for the child.

Fetal cardiology

Our youngest patients begin their journey of care with us while still in the womb. Dr Julene Carvalho, consultant fetal and paediatric cardiologist, together with her multidisciplinary team, runs daily fetal cardiology clinics at Royal Brompton and fetal medicine units at St George's, Queen Charlotte's and Chelsea and Westminster hospitals.

Pregnant women are often referred for a fetal echocardiogram (echo) when they have an increased risk of having a child with congenital heart disease or when an abnormality is suspected at the time of the routine 18-20 week anomaly scan. High-risk families may include the woman herself (or her partner) having a heart defect, already having a baby with a heart defect, or if the woman is diabetic or taking certain prescribed medication.

During a fetal echo, the heart is examined by experts, enabling the vast majority of significant cardiac defects to be identified while the baby is still in the womb.

Most fetal echoes are carried out when women are around 20 weeks pregnant. At Royal Brompton, we have pioneered this field and can examine the fetal heart through the mother's abdomen late in the first trimester – from around 13-14 weeks.

More and more cases of congenital heart disease are being

> "Your brilliant nursing and surgical teams are the reason I'm here – from six weeks old the care at Royal Brompton has been **world-class**."
>
> **Patient, Twitter**

suspected during routine pregnancy scans and referred for a fetal echo. Such referrals are "fast-tracked" by our team so that they are seen within five working days, and at least 50 per cent of these women are offered appointments within 24 hours of referral. If we identify a problem, families are supported throughout the pregnancy and a plan is put in place to ensure appropriate treatment is given once the baby is born. In severe cases, babies are transferred to our cardiac unit shortly after birth, whilst those with less severe abnormalities are seen as a planned day case or outpatient.

Over the last five years, the number of newborns treated by interventional cardiac catheterisation, who were diagnosed antenatally, has doubled. There has also been an increase of about 37 per cent for newborns requiring cardiac surgery.

Paediatric cystic fibrosis (CF)

CF is an inherited life-limiting disease mainly affecting the pulmonary and digestive systems.

The paediatric CF unit at Royal Brompton is the largest in the UK. Last year our clinicians saw 415 children with CF.

Previously, we were only able to visit children with CF at home if they lived within the M25 and we liaised with community nurses, who visited children who lived further away. However, we are extending our homecare service for all children with CF to help every family who needs our expertise at home. This helps parents and young people understand the care they need, prevents them becoming acutely unwell and helps stop unnecessary hospital admissions.

Quality improvement programme

During the last year, paediatric staff have been involved in a programme, led by Dr Ian Balfour-Lynn, consultant in paediatric respiratory medicine, to improve delivery of CF care in the Trust and our network CF centres. In May 2014, the paediatric CF team held a parents' evening. Almost 100 parents attended to hear about developments in treatments and discuss difficult topics, such as preparing your child for coping with their CF diagnosis and transition to adult services.

Hybrid procedures in paediatric cardiac surgery

Hybrid paediatric cardiac surgery is an emerging field that uses the combined skills and techniques of paediatric cardiac surgeons and interventional paediatric cardiologists in a single procedure. The goal is to reduce invasive surgical procedures in children while increasing effectiveness, so these patients can go home earlier. Hybrid techniques are especially useful when conventional surgery or catheter-based interventions alone cannot achieve a satisfactory outcome for a patient. Mr Olivier Ghez, consultant paediatric cardiac surgeon, and Dr Mike Rigby, consultant cardiologist, lead the expanding hybrid surgery programme at Royal Brompton.

Over **500** paediatric congenital surgery patients were treated at Royal Brompton

The paediatric cystic fibrosis unit is the **largest** in the UK

Hybrid surgery takes place in an operating theatre rather than a cardiac catheter laboratory. The surgeon performs the surgical component of the procedure, often opening the child's chest, and the cardiologist performs the catheter-based component.

Last year, experts at Royal Brompton performed over 400 hybrid procedures in children.

Hybrid procedures can be used for a number of congenital heart defects, although ventricular septal defect (VSD) closure is the most common performed at Royal Brompton. A VSD is a hole in the ventricular septum, which is the wall between the two ventricles – the pumping chambers of the heart.

The size of a VSD can vary, as can its complexity, so the most appropriate operation or management must also vary from patient to patient.

For a small VSD, surgery may not be needed because the defect eventually closes on its own. In contrast, large defects cause poor weight gain and severe breathlessness in babies and the VSD needs repair to prevent heart failure. The team of expert cardiologists and surgeons will together decide on the most appropriate type of treatment.

The traditional method of VSD repair for a larger hole is open heart surgery. The surgeon opens the chest, places the heart on cardiopulmonary bypass to maintain the circulation of blood and oxygen content in the body, and then closes the hole with a patch of fabric.

Moderate-sized VSDs can sometimes be closed in a catheter laboratory. Rather than opening the chest, the cardiologist inserts a thin tube (catheter) into a blood vessel in the groin and guides it to the heart. The doctor then uses a mesh patch or plug to close the hole.

For some infants and small children, the location of the VSD or the presence of several defects results in difficult surgical and catheter access. In these cases, a hybrid procedure is often the best approach.

In a hybrid procedure, Mr Ghez makes a small incision in the chest to expose the heart and creates an opening in the exterior heart wall. This gives easier access to the hole between the heart chambers. To close the hole, Dr Rigby inserts a catheter directly through the wall of the heart and guides it across the hole in the ventricular septum. Once the catheter reaches the hole, Dr Rigby delivers a closure device to plug it. This procedure is performed while the heart is beating normally; without using a bypass machine and avoiding the need for "open heart" surgery.

Dr Rigby comments: "The fact that we can use these operating techniques at the same time means that the surgery

Ruth Wakeman, advanced practitioner in children's LTV, training parents

is much shorter so patients often don't need to go onto a bypass machine. Bypass machines, which maintain the patient's blood circulation and / or lung function outside the body, can result in complications – particularly for very small babies – so it is a real benefit if we can do a procedure without needing to use them."

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

The LTV service at Royal Brompton is led by Dr Gillian Halley, consultant in paediatric intensive care.

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

For some children and babies who need long-term ventilation, a permanent tracheostomy is fitted. This is where a tube is inserted into an opening in the front of the windpipe and connected to an oxygen supply and ventilator. Caring for these technology-dependent children requires training and, as a result, children have remained in hospital for many months while a home care package is put in place. The LTV service has had almost 200 referrals since 2006 and has supervised the hospital-to-home journey for approximately 60 per cent of those children who required home care for tracheostomy ventilation.

Nationally, it takes an average of seven to nine months for a child to be discharged once they are medically ready. However, between 2010 and 2013, following the development of a multidisciplinary specialist team, a robust education and training outreach programme and a groundbreaking new integrated care pathway at Royal Brompton, this has been reduced to an average of three months. This has not only improved patient and family experience and reduced hospital length of stay, but has resulted in significant cost efficiency for specialist commissioners in London.

Hospital to Home pathway

The LTV team not only provides a specialist outreach clinical service to London and the South East, but delivers a new and innovative outreach service to other paediatric intensive care units in England. This offers other expert teams access to a unique web-based "Hospital to Home" pathway, as well as to the knowledge and expertise of the integrated care team at Royal Brompton.

In September 2013, funding for Hospital to Home was agreed and a national engagement team was created to support rollout of the web-based pathway across England. The service offers national outreach support and pathway training, housing and social services advice, service and system administration, process managers and business analysts and the ability to provide audits and reports.

The team works with a network of neonatal and paediatric intensive care units, high-dependency units, paediatric wards, local hospitals, children's centres and hospices.

Each patient is tracked throughout the discharge process to ensure continuity. Intelligent workflow processing techniques allow real-time delays to be identified and action taken. Automated features, including emails and structured multidisciplinary processes, relieve clinicians of significant administrative burden, freeing them up to spend more time delivering high-quality care to children and their families.

Training and support for professionals and carers

The clinical LTV team provides a "hub and spoke" regional outreach service, working across organisational boundaries with hospital and community professionals and carers for any tracheostomy ventilated child on the Hospital to Home pathway. The extent of involvement depends upon the needs of the referral centre, the child and their family. It includes support on clinical and ventilatory management, weaning from technology, set up on portable ventilator, and management of complex hospital discharge.

All teams caring for a child on the London Hospital to Home pathway are offered training by the specialist LTV clinicians, including face-to-face theoretical and practical hands-on training and simulation of real-life scenarios, to prepare the learners for caring for a child on LTV in the home. Approximately 800 people, including parents and carers, have received face-to-face training in the past two years.

A PATIENT'S VIEW

William Campbell

Frances Campbell was only 23 weeks pregnant in January 2012 when her waters broke. She went straight to Chelsea and Westminster Hospital with her husband, David, where doctors told her that her baby would most likely be born that evening, and if he was, he would be too premature to resuscitate. Frances said: "It was completely devastating. Up until that time I'd been having a normal pregnancy."

Despite her waters breaking, Frances did not have any contractions and by the morning it was clear the baby would not be arriving yet. She had bed rest for the next few weeks and was given steroids to try and strengthen the baby's lungs. Baby William was born at 26 weeks and weighed just under 2lbs.

She said: "He was whisked to the neonatal unit straight away. The weeks that followed were some of the toughest in my life – fuelled by hormones, exhausted and scared. But we were determined to stay positive for William."

After three months on a ventilator in Chelsea and Westminster's neonatal unit, William was deemed strong enough to have surgery to close a patent ductus arteriosus (PDA). This condition is quite common in a premature child and occurs when the ductus arteriosus (a blood vessel connecting the pulmonary artery to the aorta) fails to close after birth. The surgery took place at Royal Brompton and William spent two weeks in the paediatric intensive care unit (PICU) before being transferred back to Chelsea and Westminster Hospital. He was still reliant on a ventilator and full-time hospital care.

Three months later, after attempting to wean William off the ventilator and onto a continuous positive airway pressure (CPAP) machine to help keep his airway open, it became clear that he still needed additional help. Clinicians suggested a tracheostomy, a surgical procedure to create an opening in the neck at the front of the windpipe (trachea). A tube is inserted into the opening and connected to an oxygen supply and ventilator to assist with breathing. Tracheostomies can be permanent or temporary.

Frances explained: "William had the tracheostomy in April 2012. It underlined the fact that we weren't just parents, but we were also William's carers."

After the procedure, William began to thrive and a few weeks later, when he was almost seven months old, doctors began to talk about the possibility of him being able to go home with a supply of oxygen.

Frances said: "On the morning we were due to take William home, he just wasn't himself. A chest infection followed and we were back to square one."

During this time, Frances was referred to Royal Brompton's LTV team for advice and to help co-ordinate William's discharge home when the time was right. She met Ruth Wakeman, advanced practitioner in children's LTV, and Jo Keating, physiotherapist for LTV.

However, William was still dependent on 100 per cent oxygen and was not improving. He had a CT lung scan and consultants at Chelsea and Westminster and Royal Brompton jointly suggested chronic reflux might be causing him to "aspirate", which means swallowing small amounts of reflux into his lungs. The solution was another operation, this time to wrap part of William's stomach around his oesophagus to stop the reflux, and a gastrostomy for feeding.

Frances said: "It was a horrendous time. We looked round a hospice for William and people were talking about 'if' he came home rather than 'when'."

Due to William's lung problems, a surgeon from Chelsea and Westminster performed the procedure at Royal Brompton, where he had specialist paediatric anaesthetists on hand.

Frances said: “The operation was pretty awful – it was meant to last five hours, but in typical William style, it lasted more like eight. We paced the King’s Road and prayed in the beautiful church opposite the hospital. Finally, he was back and safe.”

While William was recovering on PICU at Royal Brompton, the LTV specialists trialled different modes of ventilation and intensive physiotherapy to treat his lungs. It worked, and within two days his oxygen requirements dropped from 100 per cent to 40 per cent.

Frances said: “It was an emotional rollercoaster and we nearly dropped down in shock when one morning the team told us to get ready for home. We transferred to St George’s (our local hospital) and got tapped into the community team there. Everyone did an amazing job to get us home with everything we needed.”

In October 2012, aged 10 months old, William went home with a portable ventilator and a care plan. The LTV team trained Frances, David and other family members to care for him and use all the equipment and supplies correctly.

Due to the planning and work with the LTV specialists, who started the discharge process as soon as there was a prospect of going home with respiratory support, William was able to go home four weeks after he was deemed well enough. The national average for discharge in similar cases is seven to nine months.

William having a lovely time on the swings

William had regular sleep studies at Royal Brompton and he was gradually weaned off his ventilation and oxygen. The team was available to answer any questions or concerns Frances had. She said: “It really is life-or-death stuff, so you need an experienced team around you. I was always calling or emailing Jo or Ruth, but nothing was too much trouble for them.”

In April 2014, William’s lungs had improved so much he was decannulated (tracheostomy removed). He is now two years old and just about to start nursery.

Frances said: “In hindsight, I’m glad we didn’t go home with William when originally planned as I think we would have been back in hospital pretty quickly! The LTV team has knowledge of all the different boroughs and they were able to co-ordinate with my local hospital, and teach staff there about William’s needs. They also put us in touch with community teams. It meant that when we were ready to go home, everything was very smooth. Since we got home in October 2012, we have never been back in hospital, except for planned appointments.

“William never stops smiling. He’s just really learning to talk since his tracheostomy has been removed, but he’s certainly making up for lost time! To be in this position where he now needs no tracheostomy, no ventilator and no oxygen is just amazing. Most parents remember their child’s first words or first steps but for parents like us, William’s first milestone was being able to breathe on his own, although of course we are excited about what his next achievements will be!”

"Amazing" respiratory care

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

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

Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is an umbrella term used to describe a number of conditions, including emphysema and chronic bronchitis. Emphysema refers to damaged air sacs in the lungs (alveoli); chronic bronchitis is inflammation and narrowing in the airways (bronchi). The most common cause of COPD is smoking, but it can have other causes, including long-term exposure to air pollution, or fumes and dust in the workplace. As the disease gets worse, it leads to increasing breathlessness, decreased quality of life and can result in death.

COPD is a major cause of ill health in the UK, affecting at least 900,000 people. Trust clinicians offer a world-class, multidisciplinary service to patients in the local community and from all over the country. The service is led by Dr Nick Hopkinson, consultant respiratory physician at Royal Brompton. He comments: "Currently, there is no cure for COPD, but the symptoms are treatable and its progression can be slowed. We offer a number of novel techniques for patients – both surgical and bronchoscopic."

Early in 2014, Dr Hopkinson and his team worked with the Department of Health and Public Health England on a co-morbidities (where a patient has a number of different diseases) framework. This forms part of the "Living Well for Longer" report to improve long-term health. It is designed for professionals across health, care and social systems to create a shared vision of how to address the growing problem of patients with co-morbidities. The Trust's pulmonary rehabilitation programme is specifically recommended in the framework as an example of good care for patients who have respiratory problems alongside other symptoms.

> "@RBandH – couldn't do it without the **amazing** specialist team! #cysticfibrosis"
>
> **Patient, Twitter**

Pulmonary rehabilitation

Pulmonary rehabilitation is a multidisciplinary exercise and education programme designed for people with lung disease who experience symptoms of breathlessness. Research has shown that it reduces breathlessness, and improves exercise capacity and quality of life.

The programme is run twice weekly for eight weeks and involves one hour of prescribed, individually tailored aerobic and resistance exercise, as well as a one-hour education session. The exercise "prescription" is based on test results performed at an assessment before the patient starts the programme. Once they begin, the programme is amended throughout, to allow for gradual progression in a safe and effective way.

The education sessions are delivered by specialist respiratory healthcare professionals from the multidisciplinary team and topics include lung anatomy, how to manage breathlessness, medicines management, dietary advice, relaxation techniques, self-management plans and home exercise programmes.

Both Royal Brompton and Harefield hospitals run highly successful pulmonary rehabilitation services, led by respiratory consultants, Dr Nick Hopkinson and Dr William Man, respectively. The services at both sites benefit from a dedicated gymnasium equipped with a wide range of modern exercise equipment for patients to use under the supervision of highly specialised physiotherapists.

Harefield expansion

The programme at Harefield Hospital has become one of the largest in the UK and in recent years has responded to an

We helped over **12,000** adults with breathing problems caused by diseases such as chronic obstructive pulmonary disease (COPD) and bronchitis

RESEARCH

INTERNATIONAL INFLUENCE

increase in the number of referrals by approximately 30 per cent each year, with a total of 800 referrals in the last financial year. Around a third of referrals come directly from GP practices with the remainder coming from hospitals and community health services in the surrounding area.

Last year, the service expanded into the community with classes taking place outside the hospital. Dr Man comments: "It is important that this very useful service is available in convenient locations for patients. We have been doing a lot of work in the community recently, working with GPs so that they can recognise symptoms of COPD earlier and understand when their patients would benefit from being referred for a course of pulmonary rehabilitation."

The programme also received over 100 patients through its innovative rapid access service for patients who have been recently discharged from hospital following an acute exacerbation of their respiratory condition, or following an illness or operation. These patients are offered an assessment within two weeks and enrolment on a course within four weeks of referral. As a result of this work, the team won a prestigious 2013 National Institute for Health Research (NIHR) North West London Collaborative Leadership in Applied Health Research and Care (CLAHRC) Excellence Award for "Most positive impact on healthcare". Internationally, the team was recognised by the European Respiratory Society in 2013, receiving the top prize for best research in rehabilitation and chronic care.

More than 90 per cent of patients report that they feel better and less breathless following a pulmonary rehabilitation course.

Cutting-edge treatment for advanced COPD

The advanced COPD service at Royal Brompton offers specialist treatment for patients with this condition. Patients with COPD, a mixture of chronic bronchitis and emphysema, have lungs that are damaged and baggy. This prevents them from emptying properly and air is "trapped". This "trapped gas" can make breathing very difficult. The Trust is a UK leader in treatments aimed at "lung volume reduction" to improve these symptoms.

Dr Hopkinson explains: "COPD can affect people in a lot of different ways. We evaluate patients' lung function and CT scan appearances carefully to see if they are suitable, either for an established lung volume reduction procedure, or for a trial of a new approach. The improvements people experience are often dramatic."

Endobronchial valves

One approach is to use an endobronchial valve. This is a small, one-way valve that is inserted into the airways of the lung through the person's nose or mouth using a fibre-optic camera called a bronchoscope. The valves are placed in selected airways (three or four valves are usually inserted) to treat emphysema. They stop air getting into the damaged, baggy parts of the lung thereby deflating them, which reduces the amount of air trapped in the chest and makes breathing more comfortable. When the most diseased portions of the lung are made to deflate and collapse, other, healthier portions of the lung have more room to work.

The Trust has led the way in using endobronchial valves, publishing the first study in 2003. This year, the team successfully completed a clinical trial, the BeLieVeR-HIFi study, evaluating the use of the endobronchial valves procedure in 50 people with advanced emphysema. The results will be published in the autumn.

Lung volume reduction surgery (LVRS)

A longer established approach is lung volume reduction surgery (LVRS). This operation aims to remove the damaged parts of the lungs so that the remaining, healthier areas, can work better. One of the first clinical trials of LVRS was performed at Royal Brompton in the 1990s and Mr Simon Jordan, consultant thoracic surgeon, is currently one of the leading surgeons in this procedure in the UK. We recently published outcome data showing that the procedure is now much safer with fewer complications than in previous clinical trials, due to refinements in the surgical approach and the involvement of a multidisciplinary team to help carefully select patients.

Lung volume reduction coils

This approach uses a bronchoscope to place elastic wires into areas of damaged lung. The wires coil up, restoring tension to the lung and holding the airways open to allow air to leave when the person breathes out.

Dr Pallav Shah, consultant respiratory physician, explained: "When inside the lungs, the spring gathers up and compresses the diseased tissue. This tightens the healthy areas, so they can function better – like pinching the end of a partly deflated balloon to make it firmer. As we are not removing any tissue, this procedure is suitable for cases of widespread lung damage, whereas LVRS and valve surgery work when only part of the lung is damaged and there are still other good areas of healthy lung to compensate."

Steam ablation treatment

A revolutionary new treatment for patients with severe emphysema took place for the first time in the UK at Royal Brompton in March 2014.

The 30-minute procedure, which involves heated water vapour being used to shrink areas of diseased lung tissue, known as steam ablation, was carried out by Dr Pallav Shah, as part of the STEP-UP clinical trial.

If it proves successful, the procedure could offer a minimally invasive alternative to LVRS.

Dr Shah explained: "Surgery is a well-established option for some patients, but this new treatment attempts to achieve a similar effect without the need for a general anaesthetic and without making any cuts, hence patients recover more quickly."

Dr Pallav Shah, consultant respiratory physician

A PATIENT'S VIEW

Alistair Drummond

In November 2011, Alistair Drummond, then aged 60, had some chest pains while he was at home in Hemel Hempstead. He was very concerned that he was having a heart attack and an ambulance took him directly to Harefield Hospital. Subsequent tests showed that there was nothing wrong with his heart, but over the coming weeks Alistair still felt very breathless and lethargic. He was referred to Dr Will Man, respiratory consultant, for lung function tests. Alistair explains: "I had been diagnosed with asthma aged 40, but I had mild symptoms so it didn't really affect my life much. Now, I was feeling really short of breath, much more than normal."

Alistair had the tests in January 2012, but a few days before he was due at Harefield for the results, he fell ill on his way to work. He was taken to University College Hospital (UCH), London, where his appendix burst and due to complications, he then spent five weeks in intensive care on a ventilator with acute respiratory distress syndrome, followed by a further two weeks on a ward.

Alistair said: "It was an awful time for my wife, Sue, and my family. Luckily for me, I don't remember too much about it, but by the time I was well enough to go home I'd lost almost 20 per cent of my bodyweight and I was extremely weak. The physios were great at UCH but once I got home, I was basically on my own."

Alistair went for his lung consultation with Dr Man, which had been delayed when he fell ill. Dr Man said: "Alistair had lost a lot of muscle and weight while he was ill and a lot of confidence. I recommended that he do a pulmonary rehabilitation course. Many people who have longstanding breathlessness or long periods of inactivity (such as being in hospital) develop muscle wasting and weakness. Pulmonary rehabilitation is an exercise and education programme that can improve breathlessness, quality of life and physical functioning, partly through helping the muscles to work better and more efficiently."

Alistair said: "I was very sceptical about it at first – my wife persuaded me to go, if I'm being honest! I was given goals to work towards (and set myself some) and one of these was getting back into skiing, a huge passion of mine.

"Progress started slow and steady and accelerated as the course went on. The physios, or 'very nice slave drivers' as I called them, chart your progress each week so you know that you're improving. This is really encouraging. I found it hard to begin with as I just didn't trust what my body could do and I was worried about the stomach wound from all the operations I'd had. The team taught me my limits, and as the course continued, I began to trust them, and myself, much more."

Alistair completed the eight-week course in the summer and was able to return full-time to his job as a business analyst in London later that year.

He said: "Having that false alarm with my heart back in 2011 turned out to be lucky. If it hadn't been for that, I wouldn't have been referred to Dr Man. Pulmonary rehab has got me from a level of being housebound to someone who can manage their own fitness. I'm completely at the other end of the spectrum to how I was when I began the course. The confidence is the biggest thing that I got out of it – it really transformed me."

Dr Man commented: "Alistair is an excellent example of what pulmonary rehab can do for someone. He worked really hard during the eight weeks but, importantly, he gained the confidence to continue exercising after it had finished. It was a stepping stone for him to get back to his old self."

Alistair comments: "I still suffer from some symptoms of breathlessness, but I can manage these now using the breathing exercises I learnt during the programme. I feel really well, and in February this year I enjoyed a week's skiing in Italy with Sue. I really pushed myself and it felt great!"

Asthma and allergy

The asthma team has a national and international reputation for innovative research and developing new asthma and allergy treatments. Royal Brompton is the largest asthma centre in London and the South East and our experts treat more children and adults with severe asthma than anywhere else in the country.

Occupational and environmental lung disease

Royal Brompton's occupational and environmental lung disease service is the largest in the UK, and the first to offer specific occupational challenge testing. With over 20 years' experience, it is the longest established unit for the investigation of occupational asthma in Europe. In 2011, a satellite clinic was established at Harefield Hospital.

The unit is led by Professor Paul Cullinan with the assistance of Dr Jo Szram (pictured right), both consultant respiratory physicians at the Trust. They are supported by highly trained staff, including an occupational health consultant, clinical nurse specialists, a clinical co-ordinator, and a highly skilled laboratory team. Our experts see over 300 new patients each year, making it the busiest service in the UK. They carry out workplace visits, reaching large groups of people at risk of work-related lung disease, and provide advice and training to occupational health teams across the UK.

Occupational asthma (also known as "industrial asthma") is usually the result of an allergy to something that is inhaled in the workplace over a period of time. It can be a severe condition leading to chronic asthma, particularly if exposure to the cause of the allergy, known as the allergen, continues.

Common allergens include:

- Flour
- Bakery enzymes
- Detergent enzymes
- Isocyanates (found in industrial paints)
- Solder (colophony) fumes
- Persulphate (hairdressers' bleach)

Occupational asthma is different from work-exacerbated or work-aggravated asthma. These types occur when someone who already has asthma finds that it gets worse when working in an environment where there are dusts or fumes, or even when their workplace is cold or their job is physically strenuous.

Dr Szram explains: "Whilst the majority of workers exposed to potential occupational allergens do not experience any problems, a significant minority develop nasal and chest symptoms. Confirming the precise cause of these symptoms is key. In occupational asthma, evidence has shown that the shorter the period of exposure, the more likely the individual will become symptom free if they are removed from exposure, often needing no medication. It is therefore vital that when an individual is exposed to allergens, like flour, at work and he or she develops breathing problems, the occupational health team acts promptly to refer them for further tests.

"Correct diagnosis is very important. Someone diagnosed with occupational asthma can lose their job, but if their symptoms are the result of another problem, they can usually be safely managed at work."

Challenge tests

Royal Brompton has a fully equipped "challenge" laboratory where occupational inhalation testing takes place. This allows clinicians to carefully recreate the particular working environment of each patient.

Dr Szram comments: "By using challenge testing we can see and measure exactly what happens to the patient when they breathe in certain substances. By watching how their respiratory system responds during the tests, we can usually identify any substances that are causing the problems.

"In some cases, we may need more information and will look at other tests, such as blood results and peak flow tests, as well as workplace reports, before making a firm diagnosis. When the patient has been exposed to the substance for some time, the process can be a lot more complex."

Immunological testing

The occupational and environmental medicine laboratory at Royal Brompton provides a specialist immunological service for the diagnosis of occupational lung disease and has an internationally recognised quality accreditation. It is managed by laboratory scientists, Dr Meinir Jones, head of laboratory, and Jennifer Welch, research technician, who test for immunoglobulin E (IgE) in the blood. IgE is associated with allergic reactions. The IgE test can be measured against all occupational allergens, including those not available commercially. Our experts can create investigations unique to individual cases and provide specialist advice on diagnosis and interpretation of results.

The laboratory is currently the only place in the UK that carries out beryllium lymphocyte proliferation testing, which determines whether an exposed worker has developed an immunological reaction to beryllium. Chronic beryllium disease, or CBD, causes scarring of the lung tissue. It occurs when a person is sensitive to the dust or fumes of beryllium – a naturally occurring lightweight material used in various industries, such as electronics, aerospace, dental, atomic energy and defence.

Our occupational and environmental lung disease experts see over **300** new patients each year, making it the **busiest** service **in the UK**

RESEARCH

INTERNATIONAL INFLUENCE

A PATIENT'S VIEW

Celia Stubbins

Celia Stubbins, aged 49 from Worksop in Nottinghamshire, has worked for a large food producing company for over 30 years.

For the first 20 years, she worked directly in food manufacturing and was exposed to flour and a wide variety of other food ingredients on a daily basis. Although she moved to a managerial role several years ago, she still regularly visits the factory floor. She had never experienced any health problems until, after a series of heavy colds and chest infections, she visited her GP. Celia was diagnosed with asthma and given an inhaler to use daily.

Over the next few years, she found that her symptoms were not getting any better and worsened considerably when she was in manufacturing areas at work. She explained: "Even though I was mainly office based, I still had to visit manufacturing areas where there was a lot of flour. I experienced a really tight chest, found it hard to breathe and my voice became very squeaky. It was actually quite frightening. I go to the gym every day and I get out of breath but this was something completely different. I didn't feel that the inhalers were helping my symptoms."

Fortunately, members of Celia's workplace occupational health team had attended a talk by Professor Cullinan about some of the complexities of asthma at work, and they decided to refer her to Royal Brompton.

In early 2014, Celia came to Royal Brompton, and was seen in the occupational lung disease clinic by Dr Szram. She had a full clinical assessment and some basic lung function and allergy tests. These allergy tests were negative to flour and other common non-occupational allergens and the results were confirmed by the specific IgE blood testing in the laboratory. Celia was admitted for a specialised challenge test with an overnight stay. She had histamine testing followed by lung function tests on the first day, and on the second day, she went into the challenge lab.

Here, Celia's upper airways were assessed for signs of allergy. It was found that she had signs of rhinitis, an inflammation of the nasal passages. Her throat around her vocal cords was also inflamed with signs of mucus dripping down from her nasal passages and an indication that acid from her stomach was irritating the same area.

Celia had a nasal endoscopy, where a thin, flexible tube is inserted into the nasal passages to check for any abnormalities. She then went into a booth and, under supervision, was exposed for short periods to small amounts of flour. Her reaction was immediate. She said: "Straight away I could feel my chest getting tight and that squeak to my voice returning."

Immediately after the exposure, she had another endoscopy, which showed that her throat and vocal cords were still moving normally and lung function tests showed no signs to suggest asthma.

Dr Szram explained: "Celia was showing signs of an upper airway irritant reaction to flour dust, but it was actually the effect of the mucus and acid reflux on Celia's throat that were causing her symptoms of breathlessness and her voice change. The lung function tests and other examinations proved very conclusively that her reactions were not due to asthma, so she was able to stop using her inhaler more or less straight away. Before she was discharged, she was reviewed by a physiotherapist to help her with her breathing pattern, and I prescribed treatment for her nose and acid reflux. I also asked a local speech therapy clinic for help with her voice symptoms.

"As a specialist centre, we carry out diagnostic testing and give specific advice, not just on medical treatment, but on any workplace issues too. We always aim to see patients

as quickly as possible as it is very important to get the right diagnosis promptly. Cases like Celia's, which could easily be diagnosed as occupational asthma, can have significant impact on a patient's job. We are pleased to have been able to help Celia and glad that she has had a good outcome."

Celia is receiving speech therapy locally, has stopped her inhalers without any problem and continues to take the treatment prescribed for her at Royal Brompton. She also takes regular doses of medication for acid reflux prescribed by her GP. She said: "It's so reassuring to know that there's nothing sinister wrong with me. I'm so glad I was referred to Royal Brompton – I couldn't have asked for better treatment. I was a bit worried people would think I was wasting doctors' time as I felt fine most of the time! But everyone was so nice and reassuring. It's a real relief to know what the problem is now and not to be using the inhaler any more. I feel much more confident and am learning techniques to cope with any breathlessness."

Celia and her husband, Robert

Dr Moises Calderon administering immunotherapy treatment

Allergy immunotherapy clinic

Royal Brompton Hospital has an expanding allergy service, with more than 3,700 consultations per year. The immunotherapy service, led by Stephen Durham, professor of allergy and respiratory medicine, and Dr Moises Calderon, visiting consultant and honorary senior clinical fellow in respiratory medicine and allergy, hosts more than 1,000 appointments every year.

Allergen immunotherapy, often referred to as desensitisation, involves administering increasing doses of allergen extracts to which the patient is allergic, either by injection, drops or tablets, over a period of three to five years.

Dr Calderon explains: "Immunotherapy is an attempt to modify the immune system so that it no longer reacts to allergens as a threat. By giving the patient increasing doses of the allergen at regular intervals in a carefully controlled way, it is possible to teach the immune system to tolerate the allergen and not 'fight' it."

If successful, immunotherapy causes the production of "regulatory" immune cells that create tolerance to the particular allergen(s), which continues for years after treatment ends.

At Royal Brompton Hospital, we provide injection immunotherapy for patients suffering from allergies to grass and tree pollen, cats, house dust mite and wasp or bee stings.

Professor Durham is principle investigator for a number of international trials that have resulted in Europe-wide registration of grass pollen vaccine for injection and a sublingual (under the tongue) grass allergen tablet, the first allergy vaccine to be registered in the UK for 35 years.

Our demonstration of the clinical efficacy, long-term benefits and underlying mechanisms of allergen immunotherapy has been documented in many different clinical trials and published in international peer-reviewed medical journals.

Food allergy

The Trust has a dedicated food allergy service, led by Dr Isabel Skypala, the first consultant allergy dietitian in the UK.

The award-winning food allergy clinics at Royal Brompton are supported by Professor Stephen Durham and Dr Andrew

Royal Brompton Hospital has an expanding allergy service, with more than **3,700** consultations per year

Menzies-Gow, respiratory consultant and clinical lead for asthma at the Trust. The clinics were established in 2007 and were the first of their kind in the UK. The clinic at Harefield began in late 2012 and is supported by Dr Jo Szram.

The majority of patients are referred to the clinics by their GP, although many secondary care consultants do refer their patients for a specialist food allergy opinion, and existing Trust patients are also referred to the service.

The patient numbers have steadily increased over the years, and almost doubled between 2008-9 and 2013-14. Due to the rising demand, there are plans to increase the number of food allergy clinics at Harefield in the next 12 months, and establish other allergy services on that site. In addition, a novel joint food allergy-gastroenterology clinic for the diagnosis of adults with suspected food allergy is due to begin at Royal Brompton later in 2014, another UK first.

The most important part of diagnosing a food allergy is taking a detailed history of a patient's reactions with certain foods. Patients then have skin prick tests, where drops of standardised extracts of foods are placed on the arm. The skin is pricked with a small lancet, which allows the allergen to come into contact with skin cells. Itching, redness and swelling usually indicate a positive reaction. As an alternative to a skin prick test, blood tests can be used to measure levels of immunoglobulin E (IgE) against allergens.

Open food challenges with the suspected food allergen are also carried out at Royal Brompton. Traces of the food are introduced to the patient, initially by rubbing onto the lower lip. Next, traces are placed inside the lip, and then

Dr Isabel Skypala doing an open food challenge using a nut

incremental doses of the food are given to the patient every 10-15 minutes until, finally, a substantial amount of the food is consumed without allergic reaction.

Dr Skypala commented: "The foods that we most commonly test are peanuts and tree nuts, although we also see a lot of shellfish allergies. The main symptoms that patients experience, if they are found to be sensitive to the allergen during the open food challenges, are itching in the mouth and throat. Some patients can also experience wheezing and respiratory difficulties and others can experience more severe symptoms, such as swelling and hives. It is essential that the tests take place under close medical supervision because sometimes patients with negative skin prick and blood tests to a food can have an unexpected positive reaction during the challenge."

Adult cystic fibrosis (CF)

Royal Brompton has the largest specialist adult CF unit in Europe with over 600 inpatient admissions last year.

Difficult CF diagnosis clinic

Dr Nicholas Simmonds, consultant respiratory physician, has set up a new diagnostic service providing a comprehensive, state-of-the-art assessment for adult patients of all ages. By performing highly specialised tests and providing expert consensus opinion, a CF diagnosis can most often be confirmed or ruled out – something that is clearly important for the patient's long-term illness management and health. This is a unique service, attracting referrals from across the country.

Dr Simmonds explains: "Most cases of CF in the UK are picked up very early, either at neonatal screening or soon after a child is born. However, as neonatal screening has only been introduced recently, adults would not have been through this process when they were babies. Others may have been tested as children but had negative or borderline results and some have an unusual presentation not typical for CF, often only presenting with problems for the first time later in life. On the other hand, some may not have CF at all and our investigations confirm this.

"In this new clinic, patients often arrive with years of anxiety and stress from being seen as a diagnostic 'mystery'. Our comprehensive work-up of tests means we can usually reach a conclusion that alleviates stress for the patient and finally provides some clarity moving forward."

Dr Simmonds is a member of the European CF Society Diagnostic Network Working Group.

Last year, we cared for **760** adult patients and **415** children with cystic fibrosis

Royal Brompton has the **largest** adult cystic fibrosis unit in **Europe**

CF information

Last year, a new CF web area about the adult unit was launched on the Trust website. This includes a short video that describes the transition journey between paediatric and adult care and features Trust patients. The video project was led by both paediatric and adult CF clinical nurse specialists.

Visit: www.rbht.nhs.uk/cysticfibrosis

Lung cancer care

The Trust is the largest centre for the surgical treatment of lung cancer and offers patients a comprehensive, multidisciplinary team approach to their care. Patients are referred to our specialists by GPs and clinicians at other hospitals. Other cancer treatments, such as chemotherapy and radiotherapy, are provided by our colleagues at The Royal Marsden (for Royal Brompton patients) and Mount Vernon Cancer Centre (for Harefield patients) or, where possible, at a hospital near to a patient's home.

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

The Harefield lung tumour ablation programme was initially developed to treat patients with primary lung cancers who were only being offered palliative treatment. However, over the last five years, patients with both primary and secondary lung cancers have been treated successfully at Harefield. The results have been significantly better than those achieved by conventional non-surgical therapies and those reported by other tumour ablation centres.

Bronchoscopic cryotherapy

The cancer team is led by consultant thoracic surgeon, Mr Niall McGonigle. He and surgical colleagues at Harefield, Ms Emma Beddow, Mr Vladimir Anikin and Mr Dimitrios Kyparissopoulos, perform over 150 cryotherapy procedures a year – one of the highest figures in the UK.

The word "cryo" comes from the Greek word for "cold", and describes the way the treatment works. It is commonly used to treat both lung cancers and benign tumours. It involves a very similar procedure to a bronchoscopy, where a camera inside a flexible tube is passed through the nose or mouth into both lungs.

Mr McGonigle explains: "The procedure is performed under a short general anaesthetic so that the patient is fully asleep for around 10 to 15 minutes. This means that a slightly larger tube than usual can be used to look into the lungs. A flexible 'probe' is passed through this tube and nitrogen gas is used to freeze the tumour and destroy the cancer cells."

From left, thoracic surgeons, Mr Vladimir Anikin, Mr Dimitrios Kyparissopoulos, Ms Emma Beddow and Mr Niall McGonigle

When the tissues defrost, the tumour should have decreased in size, allowing more oxygen to pass into the lungs. This means that symptoms such as coughing, breathlessness, coughing up blood and lack of energy should decrease.

Most patients are well enough to go home on the same day as their procedure. Cryotherapy is usually a course of three treatments with a gap of two weeks between the first and second, and a month between the second and third. After the first two treatments, the clinician reviews the effectiveness of the cryotherapy and may recommend further treatment if necessary.

Percutaneous cryotherapy

Harefield clinicians have the most extensive experience in the UK in the use of percutaneous cryotherapy treatment for lung tumours (through the skin and into the target tissue containing the tumour).

Patients who are receiving this form of treatment are referred to Dr Paras Dalal, consultant thoracic radiologist. During the procedure, Dr Dalal uses imaging (CT, ultrasound or MRI) to insert one or more applicators or cryoprobes through the skin to the site of the diseased tissue. Once the cryoprobes are in place, liquid nitrogen or argon gas is delivered to freeze and destroy the tissue. Imaging is used to guide the placement of the applicators, and monitor the freezing process.

The patients are sedated during the procedure and are usually able to go home on the same day. As with cryotherapy using a bronchoscope, further treatments may be necessary to fully destroy the tumour tissue.

Enhanced recovery programme

Enhanced recovery is a new, evidence-based approach that helps people recover more quickly after having major surgery. Sometimes referred to as “rapid” or “accelerated” recovery, enhanced recovery aims to ensure that patients:

- Are as healthy as possible before receiving treatment
- Receive the best possible care during their operation
- Receive the best possible care while recovering

Originally, enhanced recovery programmes were for patients recovering from colorectal surgery, but the programme has increasingly been used for patients undergoing lung surgery.

This year, staff, led by Mr Simon Jordan, consultant thoracic surgeon, and Matthew Johnson, lead cancer nurse at the Trust, implemented the first enhanced recovery programme at Royal Brompton, with plans to roll out at Harefield in autumn 2014.

Patients are seen in a pre-assessment clinic in the week before their thoracic surgery. They undergo tests, including an assessment with an anaesthetist, to make sure they are in the best possible condition for their operation. The clinics are led by advanced practitioners in thoracic surgery, and they ensure that referrals are in place so that patients can have help at home after their surgery, if needed. Patients are also given emotional support and advice about exercise and diet both before and after their surgery, and a patient diary with specific goals to work towards.

The team is also developing a patient film, which will be shown at the pre-assessment clinic and made available on the Trust website.

Matthew explained: “Ultimately, we want to address any issues that a patient has at the pre-assessment clinics in the hope that, if they are in the best possible condition before their surgery, they will have a faster recovery time afterwards.

“The whole programme is about educating patients in what they can do to help with their own recovery. It really emphasises the partnership between patients and professionals and helps to motivate patients to be more active in their care.”

Mr Dimitrios Kyparissopoulos and his team performing cryotherapy treatment

A PATIENT'S VIEW

Gillian Lightstone

Gillian Lightstone, aged 54, from Hemel Hempstead, was diagnosed with kidney cancer in September 2012. She had her right kidney removed at Charing Cross Hospital and started on a course of chemotherapy tablets. But, just six months later, and despite earlier clear CT scans and X-rays, she was devastated to learn the cancer had returned, and spread. She said: "It was completely awful. I had hoped to get another clear scan. I was feeling well and really thought it had gone. To then get the news that it had spread was terrifying. My husband and four children were distraught."

Gillian was referred to Mount Vernon Hospital, closer to her home, for further chemotherapy treatment, but in May 2013 she began to cough up blood and was having difficulty breathing. She was referred to Mr Dimitrios Kyparissopoulos, consultant thoracic surgeon at Harefield, who performed a chest CT and bronchoscopy. He explained: "Gillian had a very large lesion obliterating her left bronchus and that was causing her distressing symptoms. I advised that we start cryotherapy straight away to try to shrink the lesion."

Over the course of the next year, Gillian had 10 cryotherapy treatments. She said: "I found it very frightening to begin with, but Dimitrios was incredibly calm and reassuring. After the first treatment, I noticed the difference straight away and felt able to breathe easier. I felt better and better each time. I had a bit of a sore throat after each treatment, but obviously the benefits far outweighed this. It has been great being able to come in as a day case patient and, if I was seen early in the morning, I could be home just after lunch time."

Due to the cryotherapy treatment, the tumours in Gillian's lungs have now disappeared. She is continuing chemotherapy treatment and sees Mr Kyparissopoulos for follow-up appointments every three months.

Mr Kyparissopoulos said: "We've been absolutely delighted by Gillian's results – her scans are now completely clear and she has her life back."

Gillian said: "I can't thank Dimitrios and the team enough. I can't describe how frightening it is not being able to breathe and coughing up blood. But to get clear scans is just wonderful. I don't even think about my breathing any more, I just feel normal."

Innovative research

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

Our research activities are guided by a board-approved strategy. During the second year of the 2012-2015 strategy, the Trust made significant progress towards its targets, including:

- Securing £4.5m of new research grant funding from European and UK funders
- Recruiting over 3,800 patients into more than 270 ethically approved clinical research studies
- Reaching over 2,500 tissue samples in the Trust's ethically approved biobanks
- Publishing over 330 research articles by Trust consultants in leading journals
- Raising awareness of our research profile inside and outside the Trust, increasing patient and public involvement, and improving research information for patients, public and staff

This year has seen exciting developments across a number of our research programmes with innovations in translational research (where findings in basic research are translated quickly into medical practice and meaningful health outcomes) and clinical implementation driven by our cardiovascular and respiratory biomedical research units (BRUs), which are funded by the National Institute for Health Research (NIHR).

The Trust is home to eight current and four previous NIHR Senior Investigators, a prestigious award which recognises the country's top 200 leaders of clinical and applied health and social care research. Current holders are professors Peter Barnes, Bill Cookson and Jadwiga Wedzicha (respiratory medicine), Andrew Bush (respiratory medicine and paediatrics), John Cleland, Carlo Di Mario and Kim Fox (cardiovascular medicine) and David Hansell (radiology).

Cardiopulmonary exercise testing can optimise the timing of surgery in tetralogy of Fallot

Dr Sonya Babu-Narayan, consultant cardiologist, was awarded a British Heart Foundation intermediate clinical research fellowship for her research into better prediction of patient outcomes and risk of cardiac events after surgery for tetralogy of Fallot patients.

Tetralogy of Fallot is one of the most common congenital heart conditions, affecting about 30 in every 100,000 babies in the UK. It is characterised by four structural abnormalities, which act together, mixing oxygenated and non-oxygenated blood. This causes oxygen levels in the blood to be lower than normal making the baby appear blue (cyanostic).

One of the four structural defects associated with the condition is a narrowing of the pulmonary valve, which causes the right ventricle to work harder to pump blood past the blockage and the heart muscle to become damaged.

Babies born with tetralogy of Fallot will have surgery by the time they are six months old; some, soon after birth. Even after this surgery, patients remain at risk of life-threatening heart muscle dysfunction and heart rhythm disturbances. Many undergo further surgical interventions throughout their lives.

Trust clinicians have been successfully using pulmonary valve replacement (PVR) surgery for almost 20 years in adult patients. However, given the continued risk of future problems, Dr Babu-Narayan (pictured right) and her team are researching methods of identifying those patients most at risk of complications from further surgery.

They discovered that by using cardiopulmonary exercise (also known as CPEX) testing, they were able to judge the optimal time for surgical intervention.

Commenting on the impact of the results, Dr Babu-Narayan said: "This novel finding of a relationship between CPEX results and perioperative mortality in patients undergoing PVR could offer huge benefits. By predicting which patients will benefit from surgery, we are better able to individually tailor our treatment to their needs. We can also identify which patients are likely to need a longer hospital stay and help them prepare for this to avoid unnecessary complications."

In early 2014, the team's findings were published in leading cardiovascular journal, *Circulation*.

Paediatric study promises improvement in children's intensive care

A major UK-wide study led by Dr Duncan Macrae, consultant in children's intensive care and director of children's services at the Trust, has found that the NHS could reduce the length of

hospital stays for critically ill children and save around £12m a year by changing the way paediatric intensive care units (PICUs) commonly control blood sugar levels for some patients.

During the stress of severe illness or major surgery, blood glucose levels often rise to high levels, resulting in so-called "stress hyperglycaemia". The CHiP study (control of hyperglycaemia control in paediatric intensive care) investigated over 1,300 children, including those who had undergone heart surgery, at 13 PICUs across England and Wales. The trial compared the effects of allowing the natural rise in blood glucose in critically ill patients to occur (conventional or "usual" management) versus the effects of maintaining normal glucose levels ("tight" glycaemic control) using insulin.

The findings of the study, published internationally in the *New England Journal of Medicine* by Dr Macrae and collaborators from the London School of Hygiene & Tropical Medicine demonstrated that among those children studied in intensive care who had not undergone heart surgery, tight glycaemic control resulted in an average length of hospital stay 13.5 days less than those children receiving "usual care", in whom glucose levels were allowed to rise naturally. No such benefits were seen for children who had undergone heart surgery.

Dr Macrae said: "The findings of our study have important implications for the way blood glucose levels are managed in very sick children. Although we do not fully understand why controlling blood glucose levels during a child's most critical days leads to a quicker recovery, evidence from this study suggests that doctors caring for very sick children, who have not undergone heart surgery, should consider controlling blood glucose levels during intensive care."

ILD success

Building on successful research in 2012-13 in the interstitial lung disease (ILD) unit, Dr Toby Maher, consultant in respiratory medicine, was awarded a £1m NIHR Clinician Scientist Award for "Improving clinical phenotyping of interstitial lung disease for better diagnosis and disease management". ILD is a term used for a group of more than 200 lung diseases that affect the tissue and space around the air sacs in the lung. They are characterised by inflammation or scarring that damages the air sacs in the lung, but methods of diagnosis are limited and fail to identify the cause of disease in over a third of patients.

This prestigious award will allow Dr Maher to re-evaluate traditional diagnostic approaches for ILD and to develop improved therapeutic strategies for treatment and management. The research will involve a clinical trial of drugs used to reduce fibrosis (scarring) and inflammation, alongside integrating imaging data to establish the best treatments for our patients. Dr Maher commented: "This award will allow us to classify ILDs more easily and reduce the need for invasive investigations such as surgical lung biopsy."

Recognition for new research talent

In 2013, two of our cardiovascular NIHR BRU clinical research fellows were awarded prestigious research training fellowships to support their work. Dr Ee-ling Heng and Dr Claire Raphael were given personal fellowships from the British Heart Foundation for their projects while Dr Amelia Shoemark, a cell culture scientist, was awarded a postdoctoral fellowship from the NIHR / Health Education England Healthcare Science Research Fellowship Programme.

Dr Toby Maher, consultant in respiratory medicine

Dr Heng's project, "Improved outcome prediction in tetralogy of Fallot" will investigate the role of heart muscle fibrosis, and the genes that determine the extent of fibrosis, using novel magnetic resonance imaging techniques. Combining cutting-edge imaging with genetic analysis will help clinicians to better understand whether heart muscle fibrosis can be detected at early and reversible stages.

Dr Raphael's work will further develop a specific imaging technique called cardiac magnetic resonance imaging wave intensity analysis (CMR-WIA) to assess disease progression in patients who have hypertrophic cardiomyopathy (HCM). HCM is an inherited flaw that causes the heart muscle to thicken, interfering with its ability to beat.

The work aims to help clinicians gain a better understanding of the causes of chest pain and perfusion abnormalities, allowing them to develop more targeted and effective treatments.

Dr Shoemark's work investigates new diagnostic tools for primary ciliary dyskinesia (PCD). PCD is a genetic disorder of the structure and / or function of the cilia, which are the tiny microscopic moving structures lining the airways, ears, sinuses and some other organs. Without properly functioning cilia, people with PCD are unable to protect their respiratory system and due to its complexity, other organs, such as the heart, can be affected.

The study will test new microscopy methods, electron tomography and immunofluorescence techniques to better diagnose the disease, based on the appearance of the cilia. If successful, the project will lead to the integration of these techniques into the UK NHS diagnostic service for PCD.

Trust nurses lead novel research

The Trust's research strategy includes a commitment to develop our non-medical research capacity. During 2013-14, Trust research nurses, healthcare scientists and allied health professionals were successful in leading several new research projects.

In October 2013, Paula Rogers, senior cardiovascular research nurse, was awarded the Foundation of Nursing Studies (FoNS) Patients First Programme bursary. Working with Harefield Hospital's cardiac catheter laboratory team and acute cardiac care unit, the project looks at the impact that taking part in research has upon a patient's emotional wellbeing. Paula said: "Having a heart attack is often an emotionally poignant event in a person's life and patients referred to Harefield Hospital are frequently asked to participate in one of our research studies. Our goal is to assess a patient's treatment and research experiences, and how these experiences intersect with the perceptions of staff."

In December 2013, Sophie Welch, cardiovascular BRU nurse, was awarded a Nurse Training Fellowship from the European Society of Cardiology Heart Failure Association to explore "The views and experiences of patients, their families, the public and healthcare professionals on the use of gene therapy in the management of heart failure". The study will involve groups from both the Trust and Liverpool Heart and Chest Hospital.

Sophie's primary supervisor, Dr Jillian Riley, explained: "It is important to fully explore new treatment options in the management of heart failure. This includes understanding why some patients may accept gene therapy whilst others don't. This is likely to relate to the way in which they hear about novel treatments as well as their own experience of living with, and managing, their heart failure. This study will help us tailor health education and information to better support patients in making decisions about their treatment."

Dr Caroline Shuldham, Trust director of nursing and clinical governance, is part of a team led by Professor Jill Maben from King's College London that was awarded an NIHR grant for "A longitudinal national evaluation of Schwartz Centre Rounds®: an intervention to enhance compassion in relationships between staff and patients through providing support for staff and promoting their wellbeing". Schwartz Rounds are facilitated meetings that take place in a non-challenging environment to help healthcare staff explore the emotional and social challenges of providing compassionate patient care. Rounds are used across the UK but little research has been done to evaluate the extent to which they work. This national evaluation is a vital step in ensuring UK healthcare providers, managers and commissioners have evidence on their implementation and influence on staff and the care they give patients and their families.

Dr Caroline Shuldham, Trust director of nursing and clinical governance

State-of-the-art genetics and genomics facility opened at Royal Brompton

A new £2m state-of-the-art genetics and genomics laboratory – a joint venture between the Trust and Imperial College London – opened at Royal Brompton in December 2013. Secretary of State for Health, Jeremy Hunt, officially opened the facility, which will dramatically improve healthcare for families affected by inherited cardiac disease.

It will provide Trust patients (as well as the wider NHS) with vastly improved access to genetic tests and will enable much quicker gene testing for those clinically diagnosed with, or a family member who is at risk of, an inherited cardiac condition.

Historically, genetic testing has been difficult to access due to the high cost and slow turnaround. Each of a large number of possible causative genes, typically being tested sequentially, can cost between £500-£1,500, a process which can take years.

However, from early 2014, our experts working in this new facility have been able to use next-generation DNA sequencing (NGS) technology, to simultaneously examine all cardiac genes known to cause inherited cardiac disease – something which has not been possible previously.

The result is a single test – costing the NHS around £500 – which will deliver rapid results within two-three weeks.

Professor Dudley Pennell, cardiovascular biomedical research unit director, said: "The new facility underpins the Trust's commitment to translate cutting-edge research on the genetic causes of heart disease into improvements in the diagnosis and treatments available for NHS patients. In future, patients will benefit from unprecedented access to genetic testing that is fast, equitable and inexpensive."

Mr Hunt said at the opening: "We want this to be the century of personalised care and the advances in treatment we are seeing at state-of-the-art laboratories like Royal Brompton's will help revolutionise medicine."

Secretary of State for Health, Jeremy Hunt, meets a young patient during his visit

A PATIENT'S VIEW

Nicola Harvey

When Nicola Harvey was born in 1978 she appeared to be a healthy baby. However, around the age of three, she began to have fainting spells. Her parents were incredibly worried. Nicola's older brother had suffered fits and loss of consciousness due to a heart condition. Sadly, he died in 1975.

Nicola said: "I remember feeling tired and falling over a lot as a child. In fact, one of my earliest memories is falling over at home and banging my head. As a mother, I now know how terrified my parents must have been, but they tried not to show that to me."

Nicola's consultant, Dr Jan Till, paediatric electrophysiologist, said: "Nicola came to us aged around three and a half. She was passing out and her mother was understandably worried that she had the same condition that had affected Nicola's brother. Her heart had a very strange rhythm and was missing any atrial activity. Sometimes her heart would pause for a while and then at other times would go very fast. We implanted a pacemaker and gave her medicine to try to regulate her heart beat."

Nicola was one of the first children to have a transvenous pacemaker. This is where the pacemaker wire is placed into a vein, and then passed inside the heart into either the right atrium or right ventricle and the pacemaker generator is placed under the skin below the collar bone.

When Nicola was nine, her younger sister, Kristina, was born, and she soon began to have similar symptoms to Nicola. She also had a pacemaker fitted at Royal Brompton.

Dr Till said: "It was clear, because of the family history, that the Harvey family had an extremely rare genetic condition, but at this time we had no clear diagnosis. Nicola has had quite a difficult time with rapid heart rhythms and has spent time on intensive care. She also needs to have her pacemaker changed around every eight years. However, Nicola has a very positive outlook and hasn't let her heart condition hold her back."

Nicola, now aged 35, is mother to four children. She said: "I was concerned that my children may have the same heart condition as me."

It was only when the genetics and genomics laboratory opened at Royal Brompton this year that Nicola and her family had the opportunity to find out. Nicola's children, her parents, her two sisters and their children all had blood tests.

Dr Till explains: "With the new equipment in the laboratory, we were able to study the Harvey family genetics by doing a test called next-generation sequencing. We discovered that both Nicola and Kristina had two mutations on the gene coding for the sodium channel. They inherited one gene each from their mother and one each from their father so, because they had both gene mutations, it meant that their heart condition was very severe. These mutations are very rare individually, so to have them both is incredibly unlucky."

The good news was that the testing showed that Nicola's children will not inherit her heart condition.

Nicola said: "The testing gave me answers. For the first time I had conclusive evidence that genes were responsible for my condition. It was so reassuring to know that my children will never have it – it's real peace of mind. So many other parents will be able to benefit from these tests now as well. It is just brilliant."

Nicola lives in Wales, but still makes the journey to Royal Brompton for check-ups every six months.

She said: "I will always come back to Royal Brompton – it's the best. I have had outstanding care over the years and I would like to extend huge and personal thanks to the hospital, and particularly Dr Till, for more than 30 years of ongoing brilliance."

Education

Our doctors, nurses and allied health professionals at the Trust are experts in their chosen fields. We believe in sharing what we know through teaching so that our knowledge can help train the next generation of top respiratory and cardiac experts and, ultimately, benefit patients everywhere.

STaR Centre

The STaR (simulation, training and resource) Centre at Harefield provides a training environment capable of replicating acute medical, anaesthetic, cardiac and thoracic surgery situations. On-site postgraduate medical training is delivered to students from around the globe to the standards set by the General Medical Council and the Royal College of Physicians board. This training reflects Harefield's national and international reputation as a centre of excellence.

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

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

- The CRRISiS™ model (Clinical Risk Reduction in Simulated Settings) to provide clinicians with the opportunity to respond to simulated emergency scenarios in a safe learning environment. Each scenario is designed to enhance team performance and improve communication. This training was delivered in the simulation laboratory for multidisciplinary teams working in transplantation, cardiac surgery, cardiology and critical care and anaesthetics.
- Harefield transseptal course, led by course director and consultant cardiologist, Dr David Jones. This was accredited by the European Board of Cardiology and approved by the British Cardiac Society. Candidates attended from across the UK and Europe.
- Non-invasive diagnostic cardiac course designed by physiologists, Ken Ali, Raheel Shaikh and consultant cardiologist, Dr Wajid Hussain. It was accredited by the British Cardiac Society with candidates from London and the UK attending.
- FEEL UK, a joint venture between the Resuscitation Council (UK) and the British Society of Echocardiography. Course directors, Dr Shelley Rahman Haley, consultant cardiologist, and Dr Nicholas Lees, consultant in anaesthetic and critical care, ran the study day, which was designed to introduce the student to the use of transthoracic echocardiography (TTE) and lung ultrasound in the emergency setting.
- Thoracic oncology course, a three-day course for nurses and allied health professionals run in collaboration with The Royal Marsden. It was facilitated by clinical nurse specialists, Matthew Johnson, Julie Beeson and Deborah McDonald.

Clinical Skills and Simulation Centre (CSSC)

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

The CSSC is a collaboration between Royal Brompton and The Royal Marsden. Facilities include a "wet laboratory" where clinicians can practice surgical skills, from simply closing a wound, to very complex procedures, such as replacing a heart valve.

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

Last year, the CSSC hosted over 320 activities, including 65 resuscitation training courses delivered jointly to staff from Royal Brompton and The Royal Marsden.

New paediatric nursing programme

A new graduate programme was launched this year for nurses working on the paediatric intensive care unit (PICU) at Royal Brompton. Designed and developed by Julie Combes, staff nurse and practice educator, the programme is run alongside Foundations in Paediatric Intensive Care, a course accredited by King's College, London. The course aims to equip nurses with the skills and knowledge to deliver the high-quality, specialist care that is needed on PICU.

Training, which consists of a mix of lectures and simulation scenarios, takes place in the CSSC. The programme lasts for one year and results will be evaluated for quality assurance to ensure that the training aids nursing satisfaction and confidence and improves patient outcomes. The programme will run again in March 2015. Julie and the team presented the new training at the Royal College of Nursing's education conference and the Nursing Education conference, which was attended by clinical staff from around the world.

Awards and recognition

The Trust is a well-established and widely recognised brand, acknowledged internationally. We employ several clinical experts with world-renowned expertise and reputations. Clinicians join us from around the globe and come to work, study and train at our hospitals. Many return to lead institutions within their home countries.

Many of our own clinical experts hold key positions; they travel widely, giving lectures and presenting at national and international conferences. Every year, we see numerous staff gain recognition and awards from influential boards, committees, institutions and professional associations.

Professor Andrew Bush

The first Margaret Turner-Warwick chair of thoracic medicine post was awarded to Professor Peter Barnes, honorary consultant physician at the annual National Heart and Lung Institute (NHLI) / Trust Margaret Turner-Warwick respiratory lecture in June 2013. The annual lecture was founded in 2006 as a collaboration between the Trust and the NHLI, Imperial College London.

Professor Diana Bilton, consultant respiratory physician, was awarded the title of adjunct professor by Imperial College London. The position was given in recognition of Professor Bilton's contributions to respiratory medicine, particularly cystic fibrosis, and her achievements in teaching, research, research supervision and national critical care guidelines.

The Otto Wolff Medal was awarded to Professor Andrew Bush, consultant paediatric chest physician, by the Paediatrics and Child Health section of the Royal Society of Medicine in 2013. This award is conferred to an outstanding paediatrician with an international reputation.

Professor Jane Davies, reader and honorary consultant in paediatric respiratory medicine, was made professor of paediatric respirology and experimental medicine at the NHLI. This position was given in recognition of Professor Davies' contribution to the field of paediatric respiratory research and in particular her work on understanding disease progression and developing and testing novel treatments for cystic fibrosis.

Professor Diana Bilton (left) with Professor Jane Davies

Dr Julian Jarman, consultant cardiologist and electrophysiologist, was awarded the Lucien Dreyfus prize at the 9th European Cardiac Arrhythmia Society annual conference in April 2013. The award was for Dr Jarman's work on subcutaneous (under the skin) implantable cardioverter defibrillators (S-ICDs). ICDs work by delivering an electric shock to the heart if it goes into a dangerous rhythm. With subcutaneous ICDs there are no leads actually placed into the heart meaning that their removal or replacement is much simpler for patients. This research was in collaboration with Liverpool Heart and Chest Hospital as part of the Institute of Cardiovascular Medicine and Science (ICMS).

Imperial College London awarded both Dr Jenny Keegan, principal physicist, and Dr Ian Balfour-Lynn, paediatric respiratory medicine consultant, with the honorary title of adjunct reader.

In September 2013, consultant cardiac surgeon, Mr Shazhad Raja, won the award for "best abstract and oral presentation" at the 23rd world congress of the World Society of Cardio-Thoracic Surgeons in Croatia. Mr Raja represented the Harefield cardiac outcomes research group at this international meeting and his presentation provided insight into the arterial grafting technique now used by the majority of cardiac surgeons at Harefield.

Mr Shazhad Raja

Melissa Rochon, clinical nurse specialist in surveillance, won a 2013 Nursing Times award in the infection prevention and control category. Prior to the awards ceremony, His Royal Highness the Prince of Wales held a reception at Clarence House for all Nursing Times award nominees. Prince Charles praised Melissa for her "holistic approach" to treating patients with wound infections following heart surgery.

Anne-Marie Russell

Anne-Marie Russell, National Institute for Health Research clinical research fellow, won a 2014 Nursing Standard Nurse Award in the "innovations in respiratory" category. The award was in recognition of her commitment to delivering high-quality care to patients diagnosed with idiopathic pulmonary fibrosis (IPF) – a type of lung disease that affects the tissue and space around the air sacs in the lungs.

The Young Investigator award at the European Heart Failure conference in Lisbon in May 2013 was awarded to Dr Henry Savage, specialist registrar in cardiology and clinical research fellow in heart failure. The award was for Dr Savage's research into a new non-contact method of monitoring breathing during sleep, which requires only a small electronic box on the patient's bedside table. The box can store information and transmit results via a mobile phone without the patient needing to be attached to a machine and could provide information on sleeping over a number of nights, rather than just one night in hospital.

Dr Henry Savage

Professor Darryl Shore, consultant cardiac surgeon and director of the Trust's heart division, accepted an association with Imperial College London as adjunct professor. The association was offered in acknowledgement of Professor Shore's contribution to teaching, training and clinical practice – particularly in the area of adult congenital heart disease surgery, which he has developed over many years.

Professor Darryl Shore

The NHLI within the Faculty of Medicine at Imperial College London appointed Professor Rob Wilson, respiratory consultant and director of the Trust's lung division, as adjunct professor. The association was offered to recognise his close working relationship with the college and his contribution to respiratory medicine over the years.

Professor Rob Wilson

Support services

Specialist, state-of-the-art clinical support services make a vital contribution to our cardiovascular and respiratory teams, offering a one-stop service uncommon in UK hospitals.

Royal Brompton and Harefield hospitals benefit from:

- Top-rated, state-of-the-art adult and paediatric intensive care units (ICUs), 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 patients suffering complex respiratory and cardiac illnesses, intensive care facilities at both hospitals have to be of the highest standard.

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

The units are run by expert intensivists supported by a comprehensive team of therapists and nurses with specific interests in the care and rehabilitation of patients with heart and lung illnesses. The Trust is one of a very small number to have its own professor of intensive care medicine.

Advanced imaging on site

The work of our clinicians is supported on site by internationally renowned diagnostic and research imaging services. The Trust has a track record of significant investment in imaging technology, which can mean that a diagnosis is made without the need for invasive procedures.

Cardiac CT scanning is now a large part of the work on both sites, and the Trust is a leader in developments in this field, training radiographers throughout the NHS. The Royal Brompton cardiac CT course for radiographers continues to be popular, attracting delegates from as far away as the Orkney Isles.

A new Siemens Edge CT scanner will be installed at Royal Brompton in summer 2014, enabling us to offer the very best quality CT imaging to our patients.

The demand on our diagnostic and interventional services at Harefield is growing and works are expected to begin shortly on building a new scanning centre for state-of-the art MRI and CT scanners.

The CT-guided lung cancer ablation service provided at Harefield has seen the addition of a new cryo-ablation machine, which expands the types of treatments we are able to offer patients.

Echocardiography

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

Nuclear medicine

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

A new, solid-state digital gamma camera has been installed at Royal Brompton. This is able to scan faster, with greater sensitivity, and often with lower radiation levels. The improved image quality means that, for the first time, it is possible to image nerve tissue using nuclear medicine. This is an area that is very much at the cutting-edge of imaging technology.

At Harefield, the new Siemens Symbia T16 SPECT CT gamma camera is being used for both cardiac and non-cardiac patients. This instalment allows for high-quality myocardial perfusion imaging fused with anatomical information.

Laboratory medicine

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

We saw over

4,600

patients for ultrasound examinations

RESEARCH

INTERNATIONAL INFLUENCE

Our services include:

Clinical biochemistry

Clinical biochemistry runs a routine biochemistry service on a 24/7 basis for all clinical specialities on both sites of the Trust. In addition, at Royal Brompton, support is given to the specialist respiratory and cardiac patients, with particular involvement in the diagnosis and monitoring of cystic fibrosis, pulmonary hypertension, cardiac failure and investigation of allergy. Guidance on metabolic investigations for rarer presentations of cardiomyopathy and respiratory failure is also provided.

Haematology and blood transfusion

The team provides diagnostic and therapeutic support for our patients, with particular emphasis on bleeding and thrombotic disorders. A specialist anticoagulant service (preventing blood clotting) is available, including support for self-monitoring patients and those on novel oral anticoagulants. The department is active in haemostasis research (preventing excessive blood loss) and strives to reduce blood transfusion requirements.

Microbiology

The microbiology department offers a wide range of specialist bacteriology, virology and fungal diagnostics including cystic fibrosis and transplant bacteriology, mycobacteriology identification and susceptibility testing, molecular polymerase chain reaction (PCR) assays and serology assays.

The department has a very large containment level 3 laboratory at Royal Brompton for processing TB cultures, and the laboratory identifies all mycobacteria isolated and carries out specialist identification and sensitivity testing for non-tuberculous mycobacteria.

The virology section offers a comprehensive range of serology assays including transplant donor and recipient serology. It also provides an in-house multiplex respiratory PCR assay. It has also recently validated a norovirus PCR assay. Infection control screening for MRSA and VRE is also undertaken.

There is currently an ongoing evaluation of methods for improved fungal diagnostic assays including galactomannan antigen detection, aspergillus PCR and antifungal drug susceptibility testing methods.

Histopathology and cytopathology

Surgical reporting service

The Trust specialises in the diagnosis of thoracic tumours and interstitial lung diseases, heart and lung transplant pathology, vascular and cardiac disease using light microscopy, immunocytochemistry and molecular biology.

Biopsy service

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

Cytology

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

Immunocytochemistry

We utilise a wide range of antibodies including lymphocyte markers, epithelial markers, mesothelioma markers, germ cell tumour markers, soft tissue markers and neuroendocrine markers, as well as ALK immunohistochemistry in relation to ALK translocations in lung cancer.

Molecular testing

This is undertaken off site, usually by the molecular diagnostics department at The Royal Marsden, although tissue can be sent elsewhere by arrangement.

Tissue typing

The tissue typing department provides services to support the transplant programme at the Trust. These include HLA antibody screening, both before and after transplant, to reduce the chances of, and to monitor, any antibody mediated rejection processes. HLA typing of patients and their donors is also carried out at the time of transplant.

The team will perform a prospective or virtual crossmatch to determine the suitability of a donor for any patient on the waiting list as well as a retrospective crossmatch immediately following transplant to confirm the absence of hyperacute rejection. Tests can also determine detailed antibody profiles of patients undergoing rejection to aid clinical diagnosis and subsequent treatment.

Immunology monitoring service (IMS)

The IMS laboratory has continued to enhance clinical mass spectrometry services during the year. Workload for immunosuppressive drugs (Tacrolimus, Cyclosporin, Sirolimus, Everolimus and Mycophenolic Acid) has increased by 28 per cent across the year. There have also been significant increases in 25-OH Vitamin D metabolite requesting activity of 53 per cent and antifungal drug (Voriconazole, Posaconazole and Itraconazole) requesting by 22 per cent. The laboratory continues to assist the clinical team with a novel drug monitoring service for Milrinone to optimise therapy and improve safety.

Rehabilitation and therapies

Experts within the directorate of rehabilitation and therapies work in specialist multiprofessional teams for therapy services including physiotherapy, occupational therapy, dietetics and speech and language therapy. They work alongside our other services of psychological medicine, complex discharge, multifaith chaplaincy and palliative care. We also have Trust lead roles for older people and safe-guarding vulnerable adults.

Experts in their fields

Many rehabilitation and therapies staff are nationally and internationally recognised experts in their fields. They present and publish their work internationally, run specialist courses, are accredited faculty members and practice at the highest level. There is a strong commitment to professional development within the team. Several staff are studying for postgraduate qualifications and we have strong links with universities, including Brunel, King's College London, Buckinghamshire, Imperial College London, and University College London for delivering undergraduate and postgraduate education. Some of our experts lecture at the universities, and we offer students research placements at the Trust.

Evaluating patient experience is central to the service, and feedback from annual surveys is consistently positive and

encouraging. Following an evaluation of our palliative care provision, patient information has been developed and there are plans to expand the service next year.

Nutrition

Last year, the new role of Trust lead for nutrition was created. This involves an expert practitioner working closely with 12 dietitians in all therapy teams and the divisions cross-site to ensure that the Trust meets all statutory requirements for nutritional standards of care.

In addition, Dr Isabel Skypala, director of rehabilitation and therapies, has been seconded to develop specialist food allergy services across the Trust, which has thrived in this niche area.

Rehabilitation

Rehabilitation aims to restore and improve patients' function and quality of life and is a core element of our service provision. We now have the first NHS England accredited specialist rehabilitation services for therapies and our experts provide complex rehabilitation for patients in critical care at both sites. Monthly patient outcome data is submitted to the UK Rehabilitation Outcome Collaborative and this is driving improvements in the quality of early critical care rehabilitation across the UK.

In addition, staff at Harefield Hospital have introduced new outpatient services for post-transplant physiotherapy, occupational therapy, specialist speech therapy and psychological medicine.

In the media

As a Trust with an impressive record for delivering cutting-edge care and research, our clinicians, clinical practice and innovation regularly feature in regional, national and international media, reaching millions of people around the world.

A strong profile in the media can make a significant contribution to supporting a positive brand image.

Here is a small selection of the coverage from 2013-14.

May 2013

Daily Mail

Innovative singing workshops at Royal Brompton and Harefield hospitals have helped those living with conditions like COPD and severe asthma, through a programme called "Singing for Breathing". In a feature article, consultant respiratory physician, Dr Nicholas Hopkinson, explained that breathing techniques and exercises, normally associated with singing, can also be beneficial to patients with chronic respiratory problems.

June 2013

ALJAZEERA

Cameras from medical programme, *The Cure*, filmed inside the state-of-the-art magnetic navigation catheter laboratory at Royal Brompton Hospital. Consultant cardiologist, Dr Sabine Ernst, demonstrated how a remote controlled magnetic catheter and high-tech 3D heart mapping are used to treat patients with complex arrhythmias.

September 2013

BBC NEWS

A groundbreaking clinical trial of gene therapy treatment for heart failure got underway at Royal Brompton led by consultant cardiologist, Dr Alexander Lyon. The first UK patients to join the trial were interviewed for BBC TV news programmes, whilst cameras also filmed inside the Trust's NIHR cardiovascular biomedical research unit.

October 2013

The Daily Telegraph

Trust clinical nurse specialist in surveillance, Melissa Rochon, was a winner at the prestigious Nursing Times Awards. News of her award featured in the Daily Telegraph and was widely covered in over 200 regional newspapers, after HRH Prince Charles singled out Melissa's work investigating why some patients are more susceptible to infection than others.

December 2013

Daily Mirror

The Daily Telegraph

THE TIMES

DAILY EXPRESS

Harefield patient and Trust governor, John McCafferty, made global media headlines when he became the world record holder for longest surviving heart transplant patient. John had his life-saving operation at Harefield in 1982. Director of transplantation, Mr André Simon, was widely quoted saying that John's long and active life post-transplant could be attributed to excellent ongoing medical care and his determination to follow a healthy lifestyle.

December 2013

The Daily Telegraph

Secretary of State for Health, Jeremy Hunt, officially opened the Trust's £2m genetics and genomics laboratory at Royal Brompton. Professor Dudley Pennell explained how patients affected by inherited cardiac disease would benefit from unprecedented access to genetic testing.

January 2014

Sky News reported live from Harefield Hospital to demonstrate a successful primary angioplasty service, to coincide with the publishing of a report in medical journal, *The Lancet*, comparing heart attack treatment for patients in the UK and abroad. Consultant cardiologist, Dr Mark Mason, was interviewed describing the improvement in treatment for UK patients in recent years.

March 2014

The food allergy clinic at Royal Brompton featured as part of a BBC programme investigating food ingredients and labelling in the UK. One patient described becoming breathless and dizzy after eating some foods, prior to a diagnosis at Royal Brompton for an allergy to sulphites. The Trust's Dr Isabel Skypala, was interviewed in the respiratory BRU explaining the spectrum of reactions patients can have as a result of a food allergy.

Social media

One of the most popular social media platforms is Twitter – an online social networking and microblogging service that enables users to send and read text-based "tweets". The Trust joined Twitter in May 2010 and now has over 2,500 followers.

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

A selection of this year's tweets about the Trust:

"Good to catch up with the leadership team at Royal Brompton Hospital earlier @RBandH. 3rd largest provider of children's heart surgery."

Greg Hands MP, June 2013

"Have you heard the 'breathless singers'? They are singing their way to better health at @RBandH #NHS65 bit.ly/16OxinR."

NHS England, July 2013

"This is how amazing @RBandH is. On Monday Nell was anxious. The anaesthetist came in and said 'I'm in charge of your dreams tomorrow'."

India Knight, journalist, October 2013

"If you asked the @RBandH paediatric CF team to build a staircase to the moon they would find a way to do it...they are all #stellar."

Parent, December 2013

"@RBandH As per usual excellent care for my Mum today & for the past 10 years. All hospitals should take a leaf out of your book #lovelystaff."

Relative, February 2014

"Had a heart attack Sunday – ended up at Harefield Hospital. Can't praise them enough – very professional, very caring. Thank you all."

Patient, May 2014

"@RBandH visited my bro yesterday. As ever struck by the kindness & professionalism of your team from cleaners to surgeons #wonderful #NHS."

Relative, April 2014

Improving the patient experience

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

National surveys

The Trust participated in the 2013 Care Quality Commission National Inpatient Survey and performed well.

We achieved a score of "better", which means that we performed above the national average when compared to other trusts, in 25 out of 58 questions including:

- Did you have confidence and trust in the doctors treating you?
- When you had important questions to ask a nurse, did you get answers that you could understand?
- Were you given enough privacy when being examined or treated?
- Overall, did you feel you were treated with respect and dignity while you were in the hospital?

The Trust also took part in a voluntary survey of our young (under 16 years) inpatients:

- 94 per cent of young inpatients aged eight and over rated their hospital care as excellent, very good or good
- 96 per cent of parents / carers rated their child's overall hospital care as excellent, very good or good

Improving the hospital experience for patients with disabilities

The Trust's Healthcare for All committee works to ensure that patients with a physical or learning disability have the best possible experience at both our hospitals. Research shows that these patients can often experience difficulties in accessing healthcare.

This year, the patient experience team led projects at both Royal Brompton and Harefield hospitals, shadowing patients with a disability and their family members during appointments and interviewing them afterwards. Generally, positive experiences were reported, but improvements were also made as a result of the work including:

- Outpatient staff at both sites have received communication and Makaton (which uses signs and symbols) training to improve the ways they communicate with patients
- There has been improved signage around the Trust for disabled access and this information has been included in outpatient letters and on the Trust website
- The seating area in outpatients at Harefield has been rearranged to enable easier access for wheelchairs

Patient feedback

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

In April 2013, the Department of Health set a target completion rate of 15 per cent for the comment form. The Trust has maintained and exceeded this target every month this year.

From the comments, a net promoter score (NPS) is calculated using the proportion of patients who would strongly recommend the care, minus those who would not recommend or who are indifferent. Since April 2013, the Trust has

maintained an NPS of between 85 and 90 – regularly putting us in the top 10 trusts in England.

Involving our members

As a foundation trust, we have around 10,000 members who we regularly consult on Trust strategy and service planning.

Our first two membership events were held in 2013, one at each hospital, giving members the opportunity to gain knowledge and understanding of our work through tours, demonstrations and expert talks.

The two events proved very popular with members and further events are now planned.

Members are always invited to the Trust's annual general meeting, and this year's was the first joint event combining the annual general meeting of the council of governors. Around 100 members attended the meeting and heard reports from finance, quality and governors as well as a presentation from Mr Ulrich Rosendahl, consultant cardiac surgeon, about the Charity's Hybrid Theatre Appeal.

Our Charity

Royal Brompton & Harefield Hospitals Charity raises money to support the hospitals' pioneering work in heart and lung diagnosis, treatment and research in areas that the NHS is unable to fund.

Since April 2012, the Charity has operated independently of the NHS to help realise the ambitious plans for the hospitals. It is overseen by a board of trustees, under the chairmanship of Richard Hunting CBE, with day-to-day operations managed by chief executive, Gill Raikes MBE.

Gill comments: "Our donors have been wonderful this year, from carrying out sponsored mountain climbs, to cycling miles and organising village parties.

"Two highlights really leap off the page: our gala committee organised the most extraordinary event at London's Guildhall in March, which raised over £255,000 for our Royal Brompton Hybrid Theatre Appeal. It was a lot of hard work, but the evening was a great success.

"And the Harefield Fun Run 2013, where we welcomed over 1,200 runners and supporters and netted more income than any previous year – all to support our Harefield Heart and Lung Appeal."

Highlights of the year

Great progress was made in the Charity's £4.5m Royal Brompton Hybrid Theatre Appeal. This aims to provide a new state-of-the-art facility, which houses complex imaging equipment (CT and MRI scanners) within a surgical theatre so different procedures can take place at the same time. In a hybrid theatre, a number of procedures that would normally take numerous appointments, can be done on the same day.

The target of £200,000 was reached to provide Harefield Hospital with 10 ventricular assist devices (VADs), which will provide a lifeline for many seriously ill patients waiting for a heart transplant. The Charity was also able to contribute to a nursing care programme and research to help support our heart and lung patients and their families.

Two new strands to the Harefield Heart and Lung Appeal were introduced:

- Raising funds to purchase seven Organ Care System (OCS) modules. OCS machines help keep a donor organ in the best possible condition so it is viable for a longer period of time prior to transplant surgery and can be transported greater distances. However, each time the machines are used they need a new sterile module, which is very costly.
- Helping to build a new echocardiography room to allow Harefield to keep up with the growing demand for echo tests, which can show the early signs of coronary heart disease.

The Charity gave 66 non-medical staff the opportunity to attend relevant conferences and study tours to build their skills and knowledge through its annual bursary scheme.

The Charity continues to fund the rb&hArts programme, which helps to brighten up our hospitals and the lives of patients, visitors and staff through visual and performing arts.

Special thanks to:

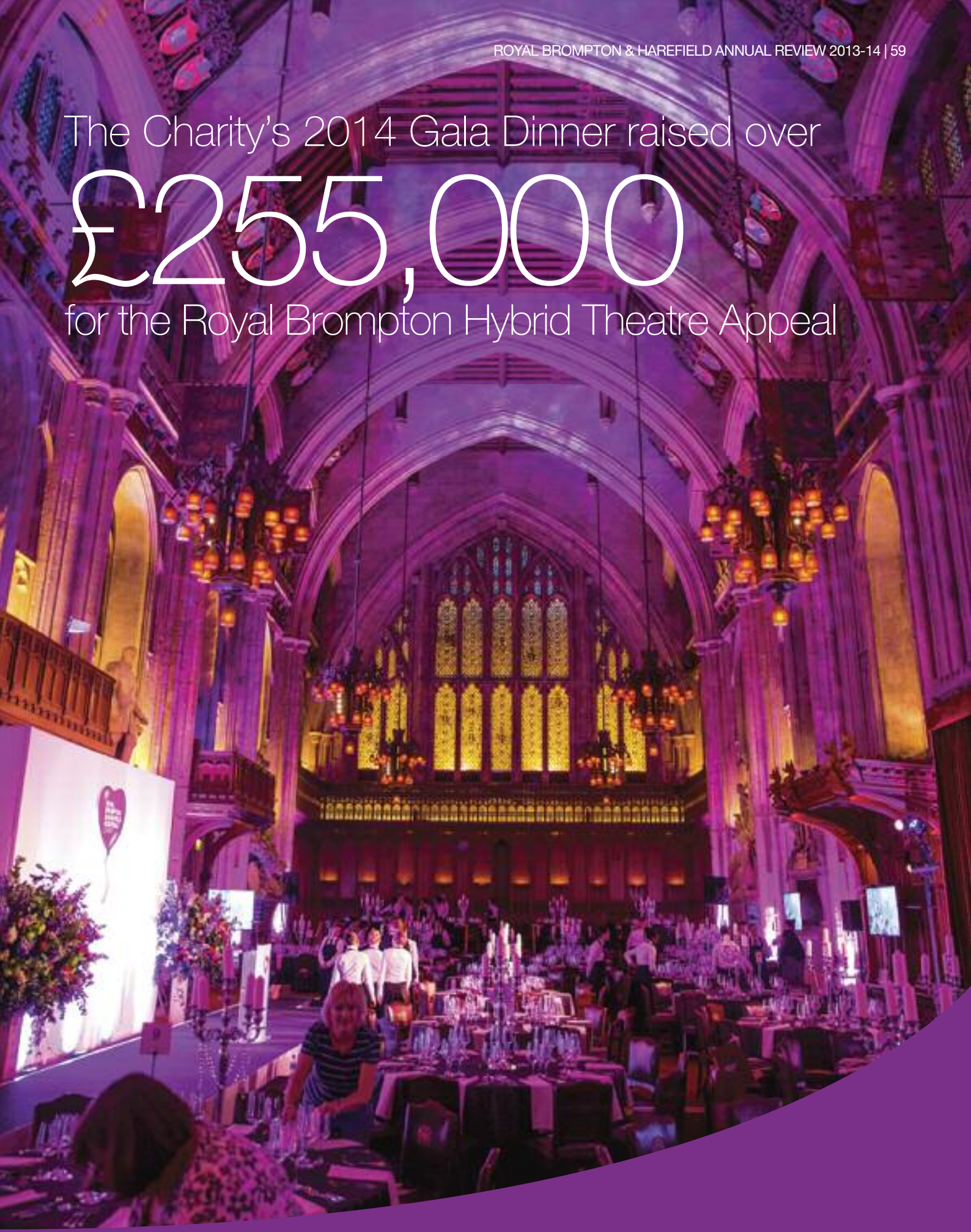
- Our volunteer Royal Brompton gala dinner committee
- Team Ross for largely funding construction of the Harefield transplant unit conservatory
- Henfest (Hennessey family) and Will's Fund (Pope family) for the conservatory furnishings
- Crescent Building Supplies for all their sponsorship and ongoing support for Harefield Hospital
- St Martin's School for their fundraising, which helped create a new garden between Oak and Acorn wards at Harefield Hospital
- Olly Barker, who raised over £50k for the Heart and Lung Appeal, through completing the La Marmotte cyclosportive event in the French Alps
- The Harefield fundraising committee for supporting a series of events throughout the year
- The families, staff and former patients who took part in a Sahara Desert Trek and raised an amazing £23,000
- Nik and Natalie Bienkowski for raising £16,000 to refurbish the Rose Ward playroom at Royal Brompton
- The Barker Family for raising £14,000 for our Hybrid Theatre Appeal

For more information, visit www.rbhcharity.org

The Charity's 2014 Gala Dinner raised over

£255,000

for the Royal Brompton Hybrid Theatre Appeal



rb&hArts

The Trust's charitable arts programme, rb&hArts, entered its 11th year in 2013. While celebrating the achievements of the past decade, the programme also continues to look forward, with pioneering approaches to arts in the healthcare environment. In line with the arts strategy, current projects aim to make the arts part of hospital life through sustainable and inclusive practice.

Transforming the built environment

rb&hArts has been involved in a number of capital programme builds and refurbishments from the early stages, ensuring that art is an integral part of the design of our hospitals from the outset.

This year, artist Jacqueline Seifert was commissioned to create designs for Acorn Ward at Harefield Hospital. Jacqueline ran ideas-gathering workshops with staff and patients, which led to 16 individual art works, plus a 16.5m-long digital wallpaper design for the ward's entrance corridor. Jacqueline has also been commissioned to create new designs for Foulis Ward at Royal Brompton Hospital.

To celebrate rb&hArts' 10th birthday, a permanent mosaic was created for Royal Brompton's Sydney Street courtyard. Staff, patients and local community members created over 100 mosaic "leaves" in a series of workshops led by mosaic specialist, Jacqui Symons. The outdoor mosaic was installed in November 2013, bringing colour and life to the courtyard. It is being extended into the hospital foyer during 2014.

Jacqueline Seifert's 16.5m digital wallpaper design for Acorn Ward

Singing for Breathing reaches new audiences

rb&hArts' Singing for Breathing programme, the Trust's groundbreaking project using singing training to support respiratory patients, has grown in popularity with over 600 people attending our workshops each year. Many are outpatients who attend every week. Evaluation of the project demonstrates the benefits of regular participation.

In 2013, a group, made up of attendees from both Royal Brompton and Harefield, gave their first public performance outside the hospitals. They sang for 400 guests at a Christmas carol concert in aid of Royal Brompton and Harefield Hospitals Charity, which funds rb&hArts.

Singing for Breathing also attracted national and international media coverage in 2013, appearing in the Daily Mail and a range of overseas publications. Now viewed as a leader in the field of singing and health, rb&hArts hosted its first professional development day in January 2014. It was aimed at singing leaders and healthcare workers, and it is hoped that it will become a regular event. There are also plans to launch Singing for Breathing to benefit more people living with respiratory issues in the Kensington and Chelsea community.

Exhibitions

Regular exhibitions form a core part of rb&hArts' work, and in November 2013 a new gallery space (the third across two sites) was opened at Harefield. The Re-Beat gallery, generously funded by the hospital's support group for cardiac patients, has hosted three exhibitions to date, including a series of photographic works by transplant patient, Douglas Forbes. Patients' work has also been central to the exhibition space at Royal Brompton Hospital, which hosted "Safe ground: an unlikely collaboration". Cystic fibrosis patients, Kate Hughes and Anne Thompson, both professional artists, cannot meet because of the risk of infection posed by their condition, but they produced a collaborative exhibition, which included a joint piece of work sent back and forth in the post.

rb&hArts welcomed exhibitions from the Oxford Printmakers, Herts Visual Arts, Hillingdon Artists, and a touring display of digital prints from the Victoria and Albert Museum. In 2014-15, the programme of works of art by patients and local organisations through to well-known and innovative works will continue. A new collaboration between Jayne Wilton, a renowned visual artist whose artworks explore breath, and Jo Foster (composer and Singing for Breathing teacher at Royal Brompton) is currently in development.

Music programme

The arts programme's 10th birthday was celebrated musically through the "Ten Choirs for Ten Years" initiative, in which a range of different choral styles were brought into the wards and public areas of Royal Brompton Hospital. Among others, the Trust welcomed the Choir with No Name, the Mill Hill County High School Barbershop group, Yerbury Community

Choir, and Imperial College Chamber Choir. Patients were delighted by the performances, saying: “it put joy in my heart and made me smile”, and “it made me think of something other than the seriousness of my heart operation”.

At Harefield, February 2014 saw the launch of a new musician’s residency in the high dependency and intensive therapy units. Violinist, Adrian Garratt, visited both wards every week, playing a range of music for patients and their visitors, taking requests and often revisiting the same patients each time. This 13-week residency helped to inform the structure and research methodology of a proposed research project into the potential benefits of live music in these uniquely stressful environments.

The team’s work this year, and plans for the future, are made possible by a range of generous donors. These include the Royal Brompton & Harefield Hospitals Charity, Hunting PLC, D’Oyly Carte, Re-Beat, The Mackintosh Foundation and The Persula Foundation.

A detail of the new mosaic created for Royal Brompton’s Sydney Street courtyard

Singing for Breathing group performs at Royal Brompton & Harefield Hospitals Charity Christmas carol concert

Governance

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

The powers of the Trust are set out in the National Health Service Act 2006, as amended by the Health and Social Care Act 2012. The Trust governance arrangements are enshrined in the Royal Brompton & Harefield NHS Foundation Trust Constitution. This makes provision for the Trust to be supported by a membership drawn from three constituencies: patient, public and staff. The constitution also makes provision for a council of governors comprising both elected and appointed parties. The elected parties are drawn from the membership and the appointed parties represent key stakeholders.

During 2013-14, the constitution was amended to ensure compliance with the Health and Social Care Act 2012. The amendments were endorsed at meetings of both the Trust board and the council of governors and were approved through a vote of the members of the Trust at the annual members' meeting held at Chelsea Old Town Hall in July 2013.

The governance structures comprise:

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

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

Quality Account

High Quality Care for All (2008) proposed that all providers of NHS healthcare services should produce a Quality Account: an annual report to the public about the quality of services delivered. The Health Act 2009 made this a statutory requirement and in 2010 Quality Accounts were introduced.

During 2013-14, Monitor introduced some additional requirements that mean foundation trusts are required to produce a Quality Report. This contains all of the elements of the Quality Accounts plus the additional Monitor elements.

The Trust's Quality Report for 2013-14 is available on our website as well as on the NHS Choices website.

Our board members

Executive members

Mr Robert J Bell
Chief executive

Mr Robert Craig
Chief operating officer

Professor Timothy Evans
Medical director and deputy chief executive

Mr Richard Paterson
Associate chief executive – finance

Dr Caroline Shuldham
Director of nursing and clinical governance

Non-executive members

Sir Robert Finch
Chairman

Non-executive directors – full year

Mrs Lesley-Anne Alexander

Professor Kim Fox

Mr Richard Hunting

Mr Neil Lerner (deputy chairman)

Ms Kate Owen

Dr Andrew Vallance-Owen

Non-executive directors – part year

Mrs Jenny Hill

Mr Richard Jones

Our council of governors

Public governors – full year

Mr Kenneth Appel
Bedfordshire and Hertfordshire

Mr Philip Dodd
North West London

Mr John McCafferty
South of England

Mr Brian Waylett
Rest of England and Wales

Patient and carer governors – full year

Mr Peter Kircher
Bedfordshire and Hertfordshire

Dr Adrian Lepper
Representing patient carers

Mr Guthrie McKie
North West London

Mr Edward Waite
South of England

Patient and carer governors – part year

Mr Stuart Baldock
Elsewhere

Mrs Sheila Cook
Elsewhere

Mrs Brenda Davies
Bedfordshire and Hertfordshire

Mr John McKintosh
Elsewhere

Mrs Chhaya Rajpal
North West London

Dr Ejikeme Uzoalor
Elsewhere

Appointed governors – full year

Councillor Mrs Victoria Borwick
Royal Borough of Kensington and Chelsea

Mr Ray Puddifoot
London Borough of Hillingdon

Appointed governors – part year

Professor Mary Morrell
Imperial College London

Professor Peter Rigby
University of London

Professor Michael Schneider
Imperial College London

Staff governors – full year

Dr Ian Balfour-Lynn

Ms Anne McDermott

Dr Andrew Morley-Smith

Staff governors – part year

Dr Claire Hogg

Dr Olga Jones

Dr Alistair Lindsay

Ms Jennifer Sano

Accounts

Statement of comprehensive income as at 31 March 2014

	As at 31.03.14 £000	As at 31.3.13 £000
Revenues from patient care activities	308,753	282,495
Other operating revenues	31,179	34,363
Operating expenses	(333,090)	(306,568)
Operating surplus	6,842	10,290
Investment income	50	45
Revaluation gain on investment properties	4,050	-
Finance costs	(30)	(35)
Unwinding of discount	(16)	(17)
Surplus for the financial year	10,896	10,283
Dividends payable on public dividend capital	(6,355)	(6,192)
Retained surplus for the year	4,541	4,091
Other comprehensive income		
Impairments	(6,878)	(3,069)
Revaluation gain on investment properties	1,764	-
Total comprehensive income for the year	(573)	1,022

In accordance with requirements of IAS 1 the impairments and revaluation gain on operational properties reported within other comprehensive income will not subsequently be reclassified to I&E.

Statement of financial position as at 31 March 2014

	As at 31.03.14 £000	As at 31.3.13 £000
Non-current assets		
Property, plant and equipment	179,765	183,465
Investment properties	31,205	27,155
Total non-current assets	210,970	210,620
Current assets		
Inventories	9,676	11,279
Trade and other receivables	27,384	20,365
Cash and cash equivalents	19,146	22,416
Total current assets	56,206	54,060
Total assets	267,176	264,680
Current liabilities		
Trade and other payables	(41,657)	(38,944)
Borrowings	(4,640)	(4,856)
Provisions	(1,989)	(1,781)
Total current liabilities	(48,286)	(45,581)
Net current assets	7,920	8,479
Total assets less current liabilities	218,890	219,099
Non-current liabilities		
Borrowings	-	-
Provisions	(2,268)	(2,446)
Total non-current liabilities	(2,268)	(2,446)
Total assets employed	216,622	216,653
Financed by		
Taxpayers' equity		
Public dividend capital	105,304	104,759
Retained earnings	62,715	58,176
Revaluation reserve	48,603	53,718
Total taxpayers' equity	216,622	216,653

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