Providing extra support, making a real difference

2013/14 Annual Review
Our Story

UCLH Charity supports patients, staff and medical research at UCL Hospitals NHS Foundation Trust

We aim to make a real difference and everything we do supports the patients treated by our eight hospitals, directly or indirectly.

This could include:

- buying an important piece of medical equipment, to enhance treatment or diagnosis
- developing vital new facilities, such as the Neuromuscular Complex Care Centre (pictured)
- improving the hospital environment, by providing flowers and art
- investing in staff to ensure the best service for our patients, and recognising, and rewarding, excellence with awards
- pump-priming research that may lead to the development of better therapies
- targeting grants to foster innovation within the hospitals.

We collaborate with a number of other organisations to ensure that the support the hospitals receive from us all is as effective as possible. These include the Friends of UCLH (a separate charity), the Foundation Trust membership office and voluntary services.

Hospitals supported by UCLH Charity:

- University College Hospital
- Eastman Dental Hospital
- National Hospital for Neurology and Neurosurgery
- UCH Macmillan Cancer Centre
- Royal London Hospital for Integrated Medicine
- Hospital for Tropical Diseases
- The Heart Hospital
- Royal National Throat, Nose and Ear Hospital
We are delighted to report that the PET/MR scanner, purchased in 2011 for £6 million, is now being used for cutting-edge research, as well as the diagnostic imaging of patients, enabling the Trust to get as much out of it as possible.

This report also celebrates the work of our senior nurses and consultants, who are the main point of contact with supporters and are fantastic advocates for the Charity. Our staff, and the tangible differences that our funds make, are one of the main reasons why people support the Charity and we are very grateful to them.

None of these initiatives would happen without our generous supporters, who make our activities possible. We can only tell a few of their stories, but we are always very grateful for every single donation, no matter how large or small it is.

Lastly, it has been an absolute privilege to be Chairman of UCLH Charity for the past seven years and I wish my successor, Dr Victoria Harrison, all the best in the future. I am sure that under her leadership, the Charity will continue to go from strength to strength.

Lord Latymer
Chairman
Charity-funded centre for neuromuscular disorders provides co-ordinated multi-disciplinary care

UCLH Charity has funded the first dedicated inpatient centre in the UK for patients with complex neuromuscular disorders at the National Hospital for Neurology and Neurosurgery.

The £2.4 million funding needed for the Neuromuscular Complex Care Centre (NMCCC), which opened in February 2014, was generated by income from the brain scanning service developed by QS Enterprises, a wholly owned trading subsidiary of UCLH Charity.

The Centre will provide improved access and outcomes for patients with neuromuscular and inherited metabolic disorders by providing them with multi-disciplinary care to meet their complex needs.

Patients using the NMCCC have profound muscle weakness and usually have multiple organ dysfunction, including respiratory, cardiac and gastrointestinal systems. The most common condition is Duchenne muscular dystrophy, which affects one in 3,600 males. Most survive to their late twenties if they live in London, but in Denmark, where care is centralised, patients survive to their forties.

The multi-disciplinary models used by the new Centre aim to halve emergency admissions for patients, by providing better care packages, improving their outcomes and dramatically reducing the estimated £10 million this care currently costs the NHS in London.

The hospital already employs some of the world’s leading experts in neuromuscular diseases and the team at the new Centre includes a respiratory physician and physiologist, a cardiologist, anaesthetists, a gastroenterologist, a psychologist, clinical nurse specialists, physiotherapists and dieticians. Patients will benefit from co-ordinated reviews, rather than multiple appointments throughout the year, meaning that danger signs can be identified sooner, preventing lengthy stays in intensive care.

Ros Quinlivan, Consultant for Neuromuscular Diseases, says: “Previously many of the young people who attend our clinic would
QS Enterprises is owned by UCLH Charity and, since its formation in 1985, it has generated more than £17 million. This has been used to help fund capital projects across UCLH Foundation Trust.

The company currently operates two magnetic resonance imaging (MRI) facilities in central London: the Queen Square Imaging Centre, which has close links to the National Hospital for Neurology and Neurosurgery, and the Heart Hospital Imaging Centre, which specialises in cardiac MRI scans.

In October 2011, QS Enterprises opened the Queen Square Private Consulting Rooms, which offer a first-class environment for both patients and consultants and generate much-needed income for Charity initiatives.

QS Enterprises can trace its roots back to 1984, when the National Hospital for Neurology and Neurosurgery was unable to obtain capital funding from the NHS to purchase its first MRI scanner. This new technology was considered essential if the hospital was to develop its clinical neurology capabilities. Two members of the Board of Governors, acting in a private capacity, decided to set up QS Enterprises to buy the MRI scanner and operate it as an independent company. The ownership of the company, and any profits generated by it, were pledged to NHNN charitable funds.

This was an unusual arrangement for a NHS unit, but it proved to be an effective way for the hospital to obtain access to a scanner and kept it at the forefront of MRI developments. For the first 10 years of its life, QS Enterprises was able to support itself and pay for the scanner and equipment upgrades. From 1995 onwards, after the start-up costs had been covered and private patient numbers had started to rise, it also began to generate surplus funds.

NHNN Charitable Funds became the direct owner of the company in 1998 when the founder shares were gifted to it. In the year 2000, following changes in the structure of the NHS in London, including the merger of the charitable funds of the National, University College Hospital and the Middlesex Hospital, QSE became wholly owned by UCLH Charity.

What is QS Enterprises and how has it generated £17 million for charitable initiatives since 1985?

Not have been expected to survive into adult life, but advances in paediatric care have now resulted in increased survival rates and the transition of significant numbers of patients into adult services. This is a new and growing population of patients with highly complex care requirements.

"Patients with complex neuromuscular diseases frequently experience fragmented care, provided across several hospitals and primary care sites. The lack of appropriate hospital facilities and untrained staff often leads to a poor patient experience and poor quality of care. There are frequent and avoidable delays in treatment for predictable related illnesses, often resulting in prolonged hospital stays and avoidable intensive care admissions.

“This exciting new Centre ensures that patients receive the multi-disciplinary care they need and we are very grateful to UCLH Charity for making it possible.”
Patients love the welcome pack funded by UCLH Charity

When a patient arrives in hospital, there is a great deal of information to take in and it can be a lot to cope with when someone is worried about their medical condition. That is why UCLH Charity has provided funding for a welcome pack.

The welcome pack includes a booklet with information on meal arrangements, visiting times and how patients can stay in touch with their loved ones, as well as a guide to staff uniforms, so that patients know who they can ask about different issues.

It also provides information about chaplaincy services, shops and cafés on the different hospital sites and a checklist for going home, to help to ensure that all the necessary arrangements have been made.

The packs also include useful items like non-slip socks, earplugs and an eye mask, a contact card and a pencil and paper.

Feedback from patients has been very positive. Comments include:

- "This is my seventh procedure at UCH. The welcome pack was a great new addition, especially the non-slip socks."
- "The welcome pack was warmly received by the ladies in my part of the ward. Made us feel like we were on first class BA. Excellent care from beginning to end."
- "It is helpful to know who everyone is by their uniform."
- "The welcome pack is a really well thought out idea and was explained in a really lovely way by the ward deputy sister Michelle."
- "The welcome pack with eye mask and ear plugs is a brilliant idea."
- "The new welcome pack was a nice touch. Overall the best hospital and treatment I could have had."
- "The welcome package is very thoughtful and very helpful. It certainly made me feel more welcome and comfortable and shows that patient satisfaction and safety is high on the agenda at the hospital."

UCLH staff have been benefitting from the Darzi Fellowship programme, which was launched to help to transform the NHS in London by providing postgraduate training in clinical leadership.

UCLH Charity funded two Darzi posts in 2013-14 and the recipients have reported back on their experiences.

Catherine Lau, Darzi Fellow in Head and Neck Surgery

"During my Darzi Fellowship in Head and Neck Surgery, I have conducted a thorough capacity and demand analysis of the head and neck oncology surgical workload across UCLH, Barts Health and Barnet and Chase Farm NHS Trusts. The data that I have gathered will be used to help plan the service reconfiguration in North-east London.

"My role also involves in-service quality improvements, by developing and implementing an enhanced recovery programme for head and neck oncology patients. I have been successful in implementing a few elements of enhanced recovery principles and I hope to influence more changes in order to further improve the quality of patient care."
Darzi Fellowship aids the development of clinical leadership skills

“Darzi Fellowship provided me with the opportunity to step away from my clinical duties and focus on a project for 12 months while studying a post graduate certificate in Leading in a Clinical Context.

I have gained experience at implementing change across a multi-professional organisation, UCL Partners, which is an Academic Health Science Network. I facilitate the Pressure Ulcer Learning Set, which is a monthly meeting attended by acute and community representatives from each of 17 NHS trusts.

“Our aim is to eliminate acquired avoidable pressure ulcers and we share our challenges and successes and monitor our progress. I have really had the chance to improve my skills as a facilitator, which is something you don’t get taught as a nurse.

I would like to take this opportunity to thank UCLH Charity for investing in the Darzi Fellowship, which will contribute to leadership development and benefit both our staff and patients.”

Camera equipment helps fetal medicine widen support for multiple pregnancies

UCLH sees an increasing number of multiple pregnancies, as a result of assisted conception techniques, and these cases frequently involve complications.

In 2011-2012 the Charity provided funding to enable the Fetal Medicine Unit to perform intra-uterine laser ablation for twin-to-twin transfusion syndrome (TTTS), And now the Unit has been able to expand its range of specialist equipment with the purchase of laparoscopy camera equipment, thanks to a further £45,000 grant.

TTTS affects up to 15% of twin pregnancies with a shared placenta. It usually develops at 16 to 24 weeks of gestation and will usually lead to miscarriage if left untreated. Laser ablation increases survival rates to up to 80%, with a relatively low incidence of long-term neurodevelopment problems.

“UCLH is one of the six centres in the UK to offer this type of treatment and it is hoped that this specialty will help to establish the hospital as a national referral centre for the treatment of these complex cases. In the last year, the Unit has treated 20 women with TTTS pregnancies and it hopes that new fetoscope, which is inserted into the uterus under local anaesthesia and can enable clinicians to treat the vessels responsible for TTTS, will allow this procedure to be more widely available.

Michelle Hope, Quality Improvement Nurse and Darzi Fellow

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Michelle Hope, Quality Improvement Nurse and Darzi Fellow
Thank you to our amazing fundraisers!

Football legends help raise money for the Neonatal Unit and Butterfly Fund

Daniel and Ali were expecting their baby in August 2013, but Ali’s waters broke when she was just 26 weeks and at work. She was taken to UCLH and three days later Maxwell was born, weighing just 971 grams. Sadly he only lived for nine hours.

His parents were so grateful for the care the family received that they have thrown themselves into fundraising, both for the unit where Maxwell died and for the Butterfly Fund, which supports families who have lost babies.

Ali says: “Due to complications surrounding his early arrival and difficult delivery, our beautiful little man sadly passed away in our arms, but not before giving us nine amazing hours as his very proud parents. He came into our lives, if only for a very short time, but he brought us so much joy. We were very fortunate to have been looked after at UCLH, one of the best neonatal units in the country. The nurses, midwives, neonatal team and bereavement teams were all amazing and we would like to thank them for the care and help they offered us during this difficult time.”

So far the couple’s fundraising efforts have raised more than £7,000 in Maxwell’s memory.

Daniel was a Watford Football Club trainee from 1998-2001 and he used his footballing skills and contacts to organise a charity football match in May 2014. Daniel’s team was managed by Nigel Gibbs (Assistant Manager, Leeds United) and the celebrity team included past and present Watford FC players Lloyd Doyley, Luther Blissett, Steve Palmer, Micah Hyde, Elliott Godrey and Allan Stuart, as well as Michael Duberry (Chelsea FC and Reading FC) and Darren Currie (Ipswich Town FC and Dagenham and Redbridge).

Funding Memory and Journey boxes to say thank you for Malachy’s care

Ciaron and Majella spent nearly 100 days in hospital with their preterm baby Malachy and now they have raised enough money to provide a year’s supply of Memory and Journey boxes, which are given to every family that has a baby in the Neonatal Unit.

In 2013, their family organised a summer ball, attended by 190 people, to raise money for the Neonatal Unit to say thank you for the care and support Malachy and the family received.

Sinead, one of the family members who got involved in the fundraising, says: “We wanted to make more people aware of the wonderful care the Unit gives to families who have preterm babies.

“Having a preterm baby is a very stressful experience, but the support and medical care that UCLH gave to Ciaron, Majella and Malachy has been exemplary and we wanted to give a little something back to show our appreciation.”

The Parnell Fund was established in 2009 by Bristol businessman, Neville Parnell, to say thank you for the excellent treatment he received at UCLH. Neville raises thousands of pounds so that others can benefit from the pioneering work of the hospital’s urology unit, by taking part in physical challenges, such as marathons, canoeing and mountain climbing. His consultant, Jeremy Ockrim and other UCLH staff have got also involved in his fundraising activities.
Peepshow, a collective of artists, illustrators and designers, has been working with patients and staff to create beautiful, fun and uplifting environments in children’s and young people’s wards and treatment areas. The work has been funded by UCLH Charity.

G-Man the Gorilla welcomes patients to Ward T11 and the other characters adorning the walls include Al the Gator, Lenny the Lion and Giraffe the Scarfe! Meanwhile, Ward T12 has been given a music and street feel. Peepshow worked hard with the patients to make the environment engaging and age-appropriate, and the feedback received has been very positive. “It’s so much better here than it was” says one member of staff. “The environment was clinical and unfriendly, but since Peepshow have got involved the young people have given it the thumbs-up!”

The Radiotherapy and Accident and Emergency departments and theatres have also received makeovers from Peepshow. Patients know they are being treated in an age-appropriate environment and the artwork helps distract them from their treatment.

This is particularly true when children visit the Radiotherapy department, as the machinery can be intimidating. Peepshow has created a bright, colourful underwater landscape with characters hunting for treasure in submarines and scuba gear. Guy Noble, Arts Curator, says: “It has been fantastic to see the paediatric and young people’s areas change from cluttered, clinical spaces to ones which are more personal, engaging and uplifting.”

When Edward was born in August 2012 his heart was pumping at more than 300 beats per minute. Doctors at UCLH wrapped him in a blanket of cold gel, which decreased his temperature from 37C to 33.3C, in order to slow his metabolism and prevent damage to his vital organs. As Edward’s heart rate slowed to more normal levels, they were gradually able to raise his temperature.

It was another month before Edward’s parents, were able to take him home, but their gratitude has lasted much longer. Since then Claire and Philip have held bake sales and both of them have completed a half-marathon, the longest distance that either of them had ever run, to raise funds for the Neonatal Unit that saved Edward’s life.

Claire says: “Edward is now a very healthy toddler, full of mischief, social, happy and smiley. He likes to talk to everyone, is very friendly and is very determined and strong minded! His cardiologist doesn’t expect him to have any further episodes of supraventricular tachycardia during his childhood, but it could occur when he is a teenager.”
Here is an extract from our audited accounts for 2013-2014.

If you would like a full copy of the accounts, you can either download them from the Charity Commission website (by inserting our charity number 229771 in the search box) or contact us for a copy.

![Analysis of Charitable Expenditure](image)

### 2014 Analysis of Charitable Expenditure (£’000)

<table>
<thead>
<tr>
<th>Category</th>
<th>£’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical equipment and infrastructure</td>
<td>4,188</td>
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<tr>
<td>Provision of staff and professional services</td>
<td>1,386</td>
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<tr>
<td>Patient welfare and amenities</td>
<td>1,502</td>
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<tr>
<td>Medical research</td>
<td>2,366</td>
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<tr>
<td>Staff education and development</td>
<td>2,621</td>
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<tr>
<td>Total</td>
<td>12,063</td>
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### 2013 Analysis of Income (£’000)

<table>
<thead>
<tr>
<th>Category</th>
<th>£’000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary income (donations, legacies, Gift Aid from subsidiaries)</td>
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<tr>
<td>Grant for Institute of Sport Exercise &amp; Health</td>
<td>0</td>
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<tr>
<td>Investment income</td>
<td>3,087</td>
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<tr>
<td>Charitable activities</td>
<td>1,295</td>
</tr>
<tr>
<td>Total</td>
<td>10,982</td>
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The Charity is very fortunate to have a committed group of volunteer Trustees, with a wealth of relevant experience.

Their knowledge and experience is invaluable, both for determining the Charity’s strategic aims and for assessing the suitability of projects to be funded.

Our Trustees

Lord Latymer was formerly a director of Cazenove Fund Management Ltd and his knowledge of investments makes sure that the Charity gets the best return on its investments, without taking unreasonable risks. In 2005 he sailed solo across the Atlantic to raise money for Save the Children.

Professor Peter Ell FMedSci Dr HC is a Senior Investigator with the National Institute for Health Research, who has authored more than 630 peer-reviewed papers and 12 textbooks. Professor Ell has also received a number of international awards for his outstanding contribution to nuclear medicine.

Dr Victoria Harrison is former Chief Executive of the grant-giving Wolfson Foundation. Her other posts have included Deputy to the Chief Scientific Adviser in the Cabinet Office and head of the policy divisions of the Agricultural and Food Research Council and the Biotechnology and Biological Sciences Research Council.

Rima Makarem has extensive experience in healthcare and pharmaceuticals and currently runs a consultancy business and holds a number of non-executive positions. These include non-executive director at UCLH, Chair of the Risk Assurance Committee at Health Education South London, Trustee Director of the Anchor Trust and member of the Medical Research Council Audit Committee.

Chris Russell is a retired consultant surgeon and former Clinical Director of Surgical Services at UCLH. He has held the post of Vice-President of the Royal College of Surgeons and was Chairman of the Board of the British Journal of Surgery for four years.

Nikki Shale has a wealth of experience in the charitable sector, in particular care and supported living for children and young adults with learning disabilities. She also has more than 30 years of expertise in the commercial and residential property sectors and recently set up a charity to build the first cricket stadium in Rwanda.

James Thorne is a former partner at the law firm Farrer & Co and continues to work for the company as a consultant. He was General Editor of the Butterworths Guide to the Legal Services Act 2007 and is a governor of the University for the Creative Arts.

Our Staff

The day-to-day operations of the Charity are overseen by our Chief Executive Philip Brading. Before his appointment in 2007, Philip was a Trustee of the Charity and a non-executive director of the Foundation Trust. He is supported by an administrative team of eight staff.
UCL Hospitals provide a huge range of services, all of which we are proud to support:

**MEDICINE**
- Critical care
- Care of the Elderly
- Clinical pharmacology
- Dermatology (skin diseases)
- Diabetes
- Endocrinology

**MEDICAL SPECIALTIES**
- Nephrology (kidney disease)
- Neurophysiology
- Outpatients
- Respiratory Medicine
- Rheumatology & arthritis

**INFECTION**
- Hospital for Tropical Diseases

**PATHOLOGY**
- Microbiology

**CLINICAL SUPPORT**
- Pharmacy
- Therapies

**SPECIALIST HEART**
- Cardiology (heart disease)
- Cardiothoracic surgery (heart surgery)

**QUEEN SQUARE**
- Neurology & Neurosurgery
- Epilepsy
- Dementia
- Stroke unit
- Royal London Hospital for Integrated Medicine

**WOMEN’S**
- Breast
- Gynaecology
- Maternity & obstetrics
- Neonatology

**PAEDIATRIC & ADOLESCENT**
- Paediatrics (children)
- Adolescents

**ROYAL NATIONAL THROAT, NOSE AND EAR HOSPITAL**
- Ear, nose and throat services

**EASTMAN DENTAL HOSPITAL**
- Restorative dentistry
- Maxillofacial
- Facial pain
- Dental hygiene

**CANCER**
- Haematology (blood disease)
- Leukaemia
- Oncology (cancer)
- Paediatric and adolescent cancer
- Radiotherapy

**GASTROINTESTINAL**
- Colorectal surgery
- Gastrointestinal surgery & medicine
- Hepatology (liver disease)
- Obesity

**SURGICAL SPECIALTIES**
- Head & Neck
- Ophthalmology
- Orthopaedics (musculo-skeletal)
- Trauma
- Urology

**IMAGING**
- Nuclear Medicine
- Radiology
- Vascular services

**THEATRES & ANAESTHESIA**
- Theatres
- Anaesthesia

**HOSPITAL-WIDE PATIENT SUPPORT**
- Chaplaincy
- Medical equipment
- Patient environment
- Samaritan funds

**STAFF SUPPORT**
- Education & training
- Prize funds
- Staff health support