Summer 2012

Great Ormond Street Hospital for Children
NHS Foundation Trust

Great Ormond Street Hospital update

Information for referring clinicians

Introduction

Welcome to the third issue of the newsletter we've produced for clinicians who refer patients to Great Ormond Street Hospital.

The newsletters give us the opportunity to update you on some of the developments at the hospital and also to respond directly to issues you have raised with us at our referrers' open day or during visits to your hospitals.

You told us that you would like us to improve the overall referral process into the hospital. For example, as we have so many clinical specialties, it is not always clear to you what information is required and who you should contact to refer your patient. In recent months, we have done a major upgrade on our website and included a special section for healthcare professionals. Within this, there is information on how to refer to different specialties which we hope you will find useful. More information is included in this newsletter.

We are also at the next stage of a major project we are undertaking on bed management. We want to make sure that we can accept all appropriate referrals and, again, this was something that was important to you. We hope you are encouraged by the progress we are making in this.

Last month, we opened our brand new clinical building, the Morgan Stanley Clinical Building. This is the first part in a two-stage programme to upgrade our inpatient wards and replace outdated facilities that are no longer fit for purpose. They provide greater privacy and comfort for patients and families. When the second building is complete at the end of 2016, it will also give us the capacity to treat up to 20 per cent more children.

Also included in this newsletter is more information about child protection cases. We want to make sure that you know who you should contact if you need to give us vital information. There are also some updates on some of the clinical and research developments that have taken place at the hospital.

On a separate note, we are pleased to let you know that the hospital was authorised to become an NHS Foundation Trust at the end of February. This is an important achievement as it means that we can continue to be an independent hospital dedicated to the needs of children.

We are holding another Referrers' Open Day on Monday 10 September at the UCL Institute of Child Health, so please note the date in your diaries. It's really important to hear what you think so that we can learn and improve the service we offer to you.

In the meantime, if you have any comments or suggestions please get in contact with us:

Dr Barbara Buckley, Co-Medical Director, telephone: 020 7405 9200 ext 5257
or email barbara.buckley@gosh.nhs.uk

Robbie Burns, Deputy Chief Operating Officer, telephone: 020 7405 9200 ext 5256
or email robert.burns@gosh.nhs.uk

Cover: six-year-old Scarlett has rare birthmarks called congenital melanocytic naevi, or CMN for short – moles that are present at birth. Clinicians at Great Ormond Street Hospital are experts in diagnosing and managing this rare type of birthmark and are carrying out much-needed research.

Bed management improvement project update, summer 2012

The aim of this project is to employ a real-time bed management solution which will support our strategic vision; to improve patient safety by optimising access to specialist inpatient services and working together so that an appropriate referral is never declined due to insufficient bed availability.

We first tasked ourselves with agreeing admission criteria for patients across all specialties to ensure that beds are utilised by patients who genuinely require admission for tertiary care. This information has been collated and is published on the Great Ormond Street Hospital website for our referrers to see. Representatives at last year's referrers' open day welcomed the opportunity to have access to this information. The predicted length of stay is also included where this is definable.

The Bed Management team is embracing technology into their day-to-day activities and has already replaced some paper-based systems with electronic versions which have been developed with clinical staff. Patient demographic data is populated automatically from the hospital's PAS system for ease and efficiency. This saves time and ensures vital clinical information is communicated when a bed is requested for an emergency patient. We are currently working with the junior doctors to help them manage referrals better and explore all options before refusing an appropriate admission.

The Admission and Bed Management Policy has been updated to reflect agreed systems and processes which will support the Trust to manage its bed pool more effectively.

The project has just entered into its second stage; which is to procure an electronic bed management system to support real-time, transparent information held about bed occupancy and availability. Many benefits will be realised when the system is implemented and rolled out across the hospital including improved bed utilisation; situational awareness about clinically deteriorating patients; and evidence-based decision making.

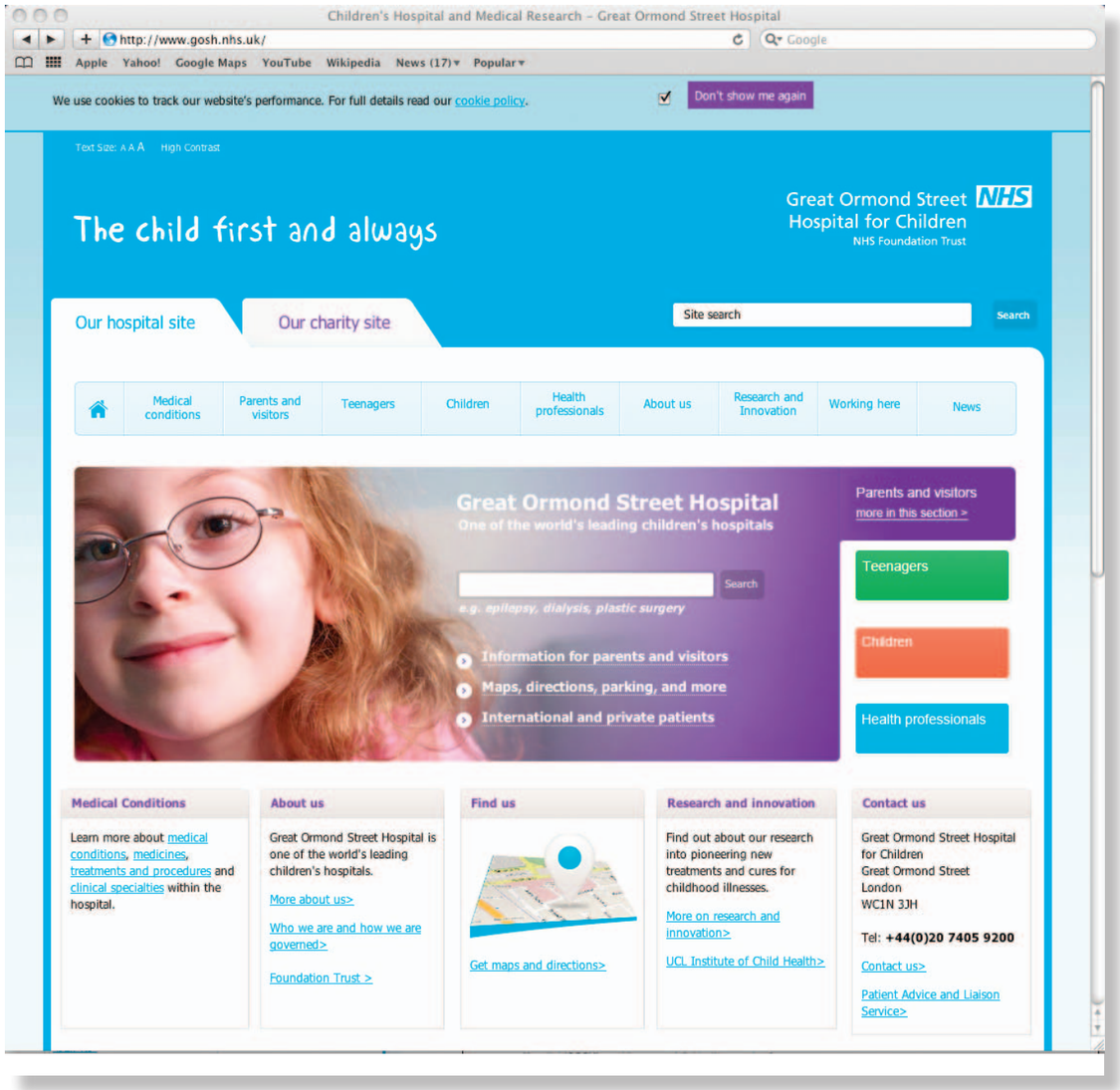
For more information, please contact Zoe Sharp, Project Manager, Workforce and Clinical Operations, on 020 7405 9200 ext 1266 or zoe.sharp@gosh.nhs.uk

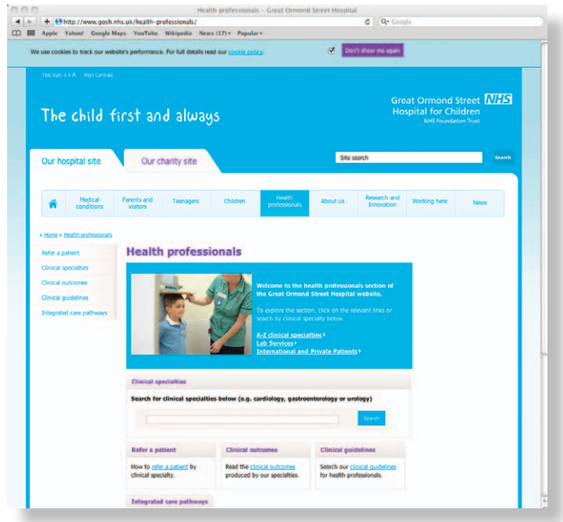
Amari is nine years old and has been in hospital for a week on Ladybird Ward.

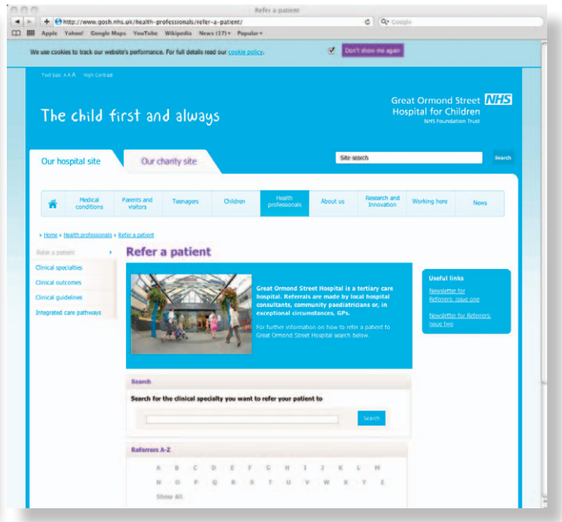
The new Great Ormond Street Hospital website, www.gosh.nhs.uk

The new Great Ormond Street Hospital (GOSH) website launched at the beginning of November, bringing the hospital and charity websites into one online space. The site provides a springboard for GOSH's digital future, as the hospital increasingly looks to online solutions to meet the needs of patients, families and health professionals.

Over 400 patients, families, doctors, nurses and donors took part in the research that led to the design of the new site which has separate sections for teenagers, parents, children and health professionals.

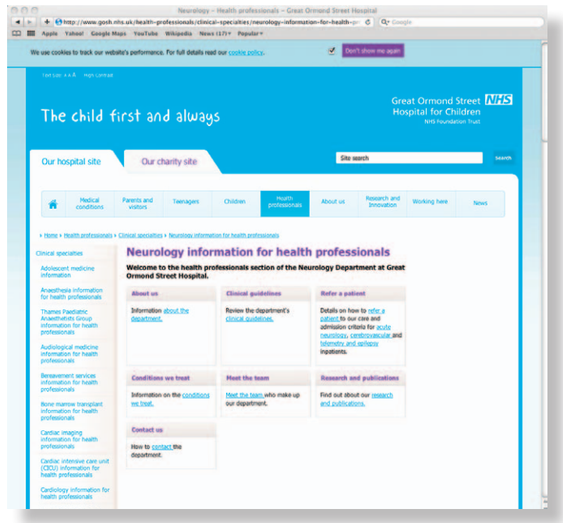


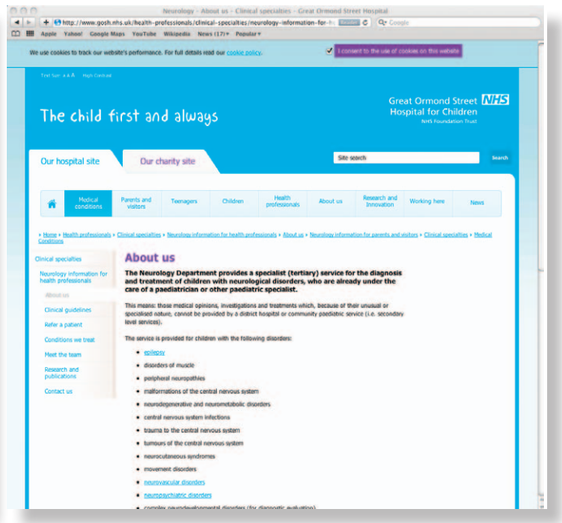




Within the health professionals section, we have taken on board feedback from referrers, with a key aim of making information easier to find. You told us that you wanted to be able to easily access key contact details, clinical services information, treatment protocols and GOSH staff biographies.

There is a specific section on how to refer a patient – you can search by clinical specialty to find the relevant information; plus sections on clinical guidelines, clinical outcomes and integrated care pathways. We have also added search boxes in key sections to help users access all the information on the site.





Here's an example of the information you will find within each specialty referral section on the site.

Child protection

Where there are child protection concerns about a patient Great Ormond Street Hospital (GOSH) needs to know so we can assess risk and, working in partnership with local services, make appropriate plans to keep children safe.

GOSH has a system of logging child protection concerns in writing within a specific section of the medical file. This ensures that staff are aware of concerns and can act appropriately.

If you are referring a child to GOSH who is subject to a Child Protection Plan within their Local Authority, the hospital must be notified in writing as part of the referral information. GOSH can then use the electronic flagging system to ensure this is recognised during OP appointments or admission, and we can liaise appropriately with local services.

General, non-urgent, safeguarding concerns can be discussed:

Within working hours (Monday to Friday): 020 7405 9200 (GOSH Switchboard)
Named doctor child protection: Dr Nick Lessof via switchboard
Named nurse child protection: Janice Baker, bleep 0650

This information will then be passed on to the GOSH Social Work Service (ext 5230), if appropriate. If you need to request GOSH to take any urgent action to protect a patient, you must contact the Social Work Duty Service directly in hours, or clinical site practitioners (CSPs) out of hours.

Out of hours (after 5pm, weekends and Bank Holidays)
CSPs: bleep 0313

New Morgan Stanley Clinical Building opens

The hospital is the middle of a major redevelopment programme to upgrade its facilities. The first phase was completed in 2006 and included a new clinical wing, improved outpatient facilities, and a patient and family hotel directly opposite the hospital. We are now in the second phase of this redevelopment programme which has dual aims of increasing our capacity by up to 20 per cent and also providing much-needed modernisation of our inpatient facilities.

This current second phase is known as the Mittal Children's Medical Centre. Within this, we are delighted to have recently opened the first of two buildings – the Morgan Stanley Clinical Building. This new building has gradually become operational over the spring and was formally opened in June 2012.

Over the next few years, the existing cardiac wing of the hospital will be dismantled and rebuilt to provide more inpatient wards and operating theatre capacity.

We are very proud of the new building and hope to have a chance to show you around when you visit us or attend the next referrers' open day in September. In the meantime, we wanted to tell you a little more about it.

Built over seven floors, the Morgan Stanley Clinical Building provides facilities that will benefit patients, families and staff. The diagram below shows the make-up of the building.

Level 7		**Eagle**	Nephrology inpatients: 15 beds Haemodialysis: 10 beds
Level 6		**Bear**	Cardiac high dependency and general: 24 beds
Level 5		**Koala**	Neurosciences: 24 beds
Level 4		**Flamingo**	Cardiac Intensive Care Unit: 21 beds
Level 3		**Theatres**	Three theatres and one hybrid angiography suite
Level 2		**Lagoon**	Restaurant
Level 1		**Walrus**	Clinical Investigations Centre (ECHO/ECG/Cardiac Day Care, Lung Function)
Level 0			Kitchens/staff change

New Morgan Stanley Clinical Building opens (continued)

The Morgan Stanley Clinical Building has three floors of general and high dependency inpatient wards for kidney, cardiac and neuroscience patients.

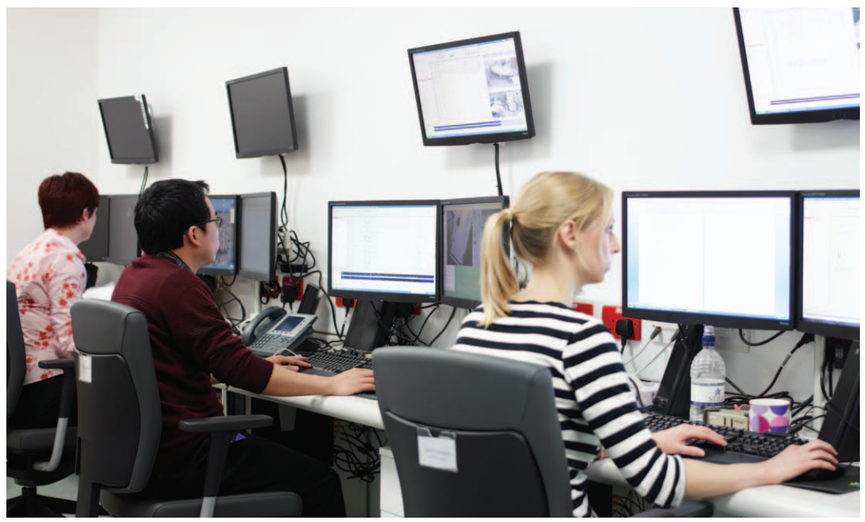
The general and high dependency wards are a mixture of single bedrooms with en suite facilities and also room for a parent to stay overnight, high dependency bays and play rooms, both for younger children and adolescents. There are also more rooms where clinical teams can talk to parents and young people with greater privacy, plus a separate area for parents to have some quiet time, but still be close to their child.

Koala, the neurosciences ward, has been built for both neurosurgery and neurology patients and includes a new telemetry suite, which means the team can view all data on the ward. The ward provides inpatient care for children with disabilities, tumours and diseases affecting the central nervous system such as epilepsy, craniofacial disorders and cancers.

Eagle, the nephrology ward, provides care for children with renal problems such as kidney failure, patients on dialysis or those having a transplant.

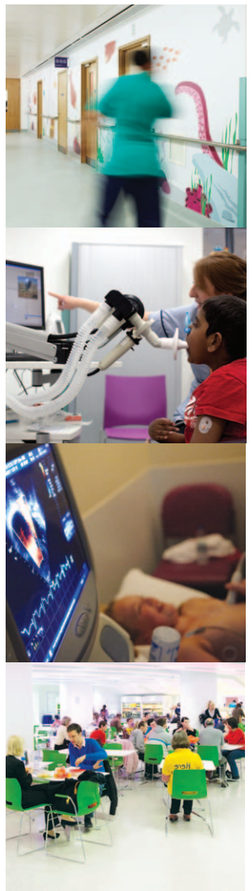
Bear, the cardiac ward, provides specialist inpatient care for children who stay here post-surgery, assessment or non-surgical assessment.

Samaviya was diagnosed with cystinosis – a hereditary disease which also affects her mum's sisters. She is one of the first patients to stay on Eagle Ward in the Morgan Stanley Clinical Building, and is very much enjoying having her mum stay by her bedside. The en suite is proving to be entertaining for Samaviya, as she loves playing with water!



The Cupcake Telemetry Unit has specialised equipment to pinpoint areas of the brain affected by severe epileptic seizures.

Flamingo Ward has the space and privacy needed to provide one-to-one care for seriously ill children.



There is also a new Cardiac Intensive Care Unit (Flamingo Ward) providing specialised care for patients with congenital high disease who require surgery, patients who have had a transplant, children who require artificial heart and lung support and children with airway problems. The new ward has 21 beds, five more than the previous ward thereby increasing the number of children we can care for. Additionally, the size of the bed space has grown significantly so that we can better accommodate the modern artificial heart and lung support technology like ECMO (extracorporeal membrane oxygenation) and Berlin heart.

Options are now being considered to redevelop the space vacated by the Cardiac Intensive Care Unit to provide additional critical and high dependency capacity to support other specialties across the hospital. These changes are all part of our plans to address some of the issues you have raised with us regarding capacity and occasional refused admissions.

Theatres

As well as the inpatient wards, there are four new operating theatres to be used by our cardiac and neurosurgery teams. This gives us additional operating theatre capacity which will be further improved once the next part of the redevelopment is completed.

The new theatre suite includes three cardiac and neurosurgery theatres and one hybrid angiography theatre. The theatres contain state-of-the-art equipment including telemedicine facilities.

Clinical investigations

Walrus Ward is dedicated to clinical investigations and day care. This includes echocardiogram, electrocardiograph, cardiac day care, plus a new lung function unit.

Restaurant

The new building also contains a brand new restaurant and café facility for the whole hospital which is serviced by new kitchen facilities. There is also a new Disney play area for younger patients and siblings.

Important developments and research at Great Ormond Street Hospital 2011/12

Benefits of epilepsy surgery
Research from Great Ormond Street Hospital (GOSH) and the UCL Institute of Child Health (ICH) shows improved long-term IQ for children with drug-resistant epilepsy after temporal lobe surgery in childhood.

The report findings are based on the follow-up of 42 children who underwent temporal lobe surgery, after an average postoperative period of nine years. A significant increase in IQ was found in the surgical group after an extended follow-up period of more than five years. The IQ change was not found in the non-surgical comparison group.

Dr Torsten Baldeweg, one of the authors of the report explained: "A surprise finding was that we observed brain grey matter growth after surgery, in proportion to the degree of IQ improvement. We are delighted that this surgery can have such a positive impact on children's lives, and will continue to investigate the brain changes of children who have undergone epilepsy surgery to further enhance our understanding of their cognitive and educational development." More details of this important work can be found in the published paper, *Long-term intellectual outcome after temporal lobe surgery in childhood* in Neurology, 12 April 2011; 76(15): 1330–1337.

GOSH is the biggest centre for paediatric neurosurgery in the UK. In 2010, we did 50 per cent of the UK's paediatric epilepsy surgery work, carrying out 50 main epilepsy surgery cases. In 2011, this figure increased to 70 cases.

In May 2012, it was announced that GOSH had been designated as one of the four national centres to be commissioned to undertake paediatric epilepsy surgery. GOSH will also take on a national leadership role in the development of the other centres (Birmingham Children's Hospital, North Bristol NHS Trust with University Hospitals Bristol NHS Foundation Trust, Alder Hey Children's NHS Foundation Trust with Central Manchester University Hospitals NHS Foundation Trust) with the aim to treble the rate of surgical intervention

We would expect most of the referral pathways to be the same – patients with complex epilepsy will be referred to GOSH by their local paediatrician/neurologist, and we will assess them. For some other children, they will be assessed locally and then discussed at a GOSH multidisciplinary team meeting, where all surgical options will be discussed.

Non-invasive prenatal diagnosis (NIPD): rapid success
New technology has allowed the development of safer prenatal diagnosis by taking a maternal blood sample to analyse the cell free fetal DNA (cffDNA) which we now know circulates in the mother's blood. This news comes as Professor Lyn Chitty, Principal Investigator at ICH, reports some of the early findings of the RAPID (reliable, accurate prenatal non-invasive diagnosis) programme. This programme, launched in 2009, aims to develop standards required to implement NIPD in the UK.

NIPD carries no risk to the pregnancy, unlike invasive methods which have around a one per cent risk of miscarriage. The RAPID programme is working with health professionals and patient groups to create information and training packages that will help the transition of these tests from laboratory to clinic in the future.

Gene therapy success for children born without a functioning immune system
Two established gene therapy programmes to cure children born unable to fight infection proved a success last year. The programmes, which looked at X-SCID and ADA-SCID, were led by Professors Adrian Thrasher and Bobby Gaspar of the ICH. Fourteen out of 16 patients across the two programmes were successfully treated.

Children involved in both programmes continue on some medication, but five of the 10 X-SCID and three of the four ADA-SCID patients no longer take immunogloblins.

GOSH runs more gene therapy trials for immune deficiency in children than any other centre in the world. These successes come over a decade after Rhys Evans became the first boy to be successfully treated for X-SCID by gene therapy at the hospital. The first patient to undergo ADA-SCID treatment is now almost eight years post gene therapy.

Professor Thrasher, Consultant in Paediatric Immunology and X-SCID Programme Lead said: "These are excellent results for our gene therapy programmes and the first time we have been in a position to say we have found a cure for patients with these conditions. It demonstrates that gene therapy for immune diseases is now mainstream, and we hope this approach will benefit many more of our patients in the future."

Right: Jack loves football and can play again after having had gene therapy.

Great Ormond Street Hospital for Children NHS Foundation Trust
Great Ormond Street
London WC1N 3JH
020 7405 9200
www.gosh.nhs.uk

Contact

If you would like to make suggestions or give more feedback about your experience of the hospital, please contact either Barbara or Robert on the details below:

Dr Barbara Buckley
Co-Medical Director
E barbara.buckley@gosh.nhs.uk
T 020 7405 9200 ext 5257

Robert Burns
Deputy Chief Operating Officer
E robert.burns@gosh.nhs.uk
T 020 7405 9200 ext 5256