SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

EXECUTIVE SUMMARY: REPORT TO THE TRUST EXECUTIVE GROUP

Subject:	Cystic Fibrosis Unit, NGH 12 July 2011
Supporting Director:	Neil Riley
Author:	John Warner, Public Governor West Sheffield
Status:	For Directorate and TEG note and response

PURPOSE OF THE REPORT:

To follow up on a visit in 2006 to ensure recommendations by Governors were implemented and to provide feedback for TEG, Governors unable to attend and CFU Staff.

KEY POINTS:

- A newly built specialist Unit furnished and equipped to the highest current standards and with clear regard to the care and wellbeing of both patients and staff.
- All staff spoken to clearly take pride in and enjoy working here. The whole team, including the "fantastic cleaning staff", work together to deliver high quality care.
- Patients spoken to appreciate and benefit from excellent care, environment and equipment.
- Numbers of patients have grown significantly in recent years (100 in 2007 at time of CF trust Peer Review, 150 in 2011) due to advances in treatment and demand will grow, currently at a rate of 10-15 patients per year. The Trust needs to be aware of and plan for this growth..
- Are requirements for P&E savings being applied in a way that has an unintended disproportionate effect on small specialist units?
- Plans for the future include moving towards more care in the community. Continuing innovation is seen in a project in collaboration with the Be Green campaign to provide an electric car.
- Collaborative work with the Service Development Team will enhance patient care, maximise team efficiency but also inform of service development needs given rising numbers of patients.

OBSERVATIONS/RECOMMENDATIONS:

Governors suggestions	Directorate Response	TEG Response
1. TEG/Board should visit to see the high standards of care and treatment provided and to inform future planning.	1. We would be happy to welcome TEG around our MDT table	1. TEG visit will be incorporated into Respiratory Directorate informal visit.
2. Thoughtfully designed in partnership with the architect, medics and patients. Could this process be used on other projects?	2. Mark Hattersley (estates) was key to coordinating with architects/Project Manager. CF team were motivated by the belief this was right and doable.	2. Yes. Estates Director to action.
3. Are lessons being learned from the way in which staff morale has improved and staff sickness rates have fallen following the move into this custom built Unit under good leadership?	3. Thanks to Sr Lloyd and Matron Ruth Marrison for developing the excellent CF ward staff team from disparate staff relocated from across the Trust during reconfiguration.	3. Director of Human Resources to follow up.
4. Plans for 'green' home visits using an electric car are worthy of investigation and support. This fits with the move towards Care in the Community	4. Home visits meet Standards of Care. Flying the green flag is good for the Trust and for CF by keeping our innovative approach in high profile	4. Business case welcomed.
5. This is a small, specialty service: is due regard paid to these factors in applying the consequences of current financial pressures across the Trust?	5. Frank Edenborough believes the application of 5% P&E changes to a service with a 50% increase in patients since 2007 is inappropriate especially where staff reductions have occurred or have been threatened	5. For the Respiratory Directorate to determine how P&E targets are met across the Directorate.

GOVERNORS' VISIT TO CYSTIC FIBROSIS UNIT
12 July 2011

Governors Present:	**Staff Present:**
Anne Eckford	Dr. Frank Edenborough
John Laxton	Emma Field (Psychologist)
Andrew Manasse	Hanna Day (Physiotherapist)
Hetta Phipps	Sue Lloyd (Ward Manager
John Warner	

The purpose of the visit was to see the new Cystic Fibrosis (CF) Unit which has been designed as a bespoke ward now that the CF service has outgrown the old out-dated and inadequate facility in Brearley Ward. Governors had previously visited the old facility in 2006.

Frank Edenborough (Consultant Physician in Respiratory and Adult CF Medicine) welcomed us and began the visit by explaining to us what Cystic Fibrosis was, its effects and methods of treatment. The disease is genetic, a child must inherit a faulty gene from both parents but the parents are not aware that they carry the gene. It is discovered usually by routine screening of mothers during pregnancy and by the Heel prick "Guthrie" tests of the new born which indicates low protein levels (IRT). The disease has been observed as long ago as the 1600's when because it causes excretions of salt in sweat a common rhyme said "Woe is the child who tastes of salt for they have not long to live".

Before 1999 there was no facility for treatment of adults with CF in Sheffield. Patients who were cared for at Sheffield Children's Hospital either received subsequent adult care from non-specialists at NGH or RHH or were sent to Leeds, Manchester or Nottingham for specialist care. The NGH CF team was initiated in 1999 when Dr Edenborough was appointed to establish a formal regional adult CF service.

A dedicated outpatient facility was established in 2001. Brearley 1 was modified in 2002 with 2 en suite side rooms. Funding was negotiated with NORCOM, the team grew and a second consultant (Martin Wildman) was appointed in 2006. Dr Edenborough had lobbied for a new inpatient facilities for some years but the CF Trust Peer Review of 2007 and the successful bid to become the Sheffield Hospitals Charities principle beneficiary (to the tune of £1m of which £960,000 has been raised to date) provided the impetus for the Unit. The CF team attended a management course held jointly with STH and Hallam University leading to an options appraisal in 2008, approval for a fully costed design in 2009, ultimately leading to the new building we have today, being opened in June 2010.

Frank explained that the disease is very complex affecting not only the lungs and respiratory functions but also normal growth, cell and gland function as well as the brain and bones. It also impairs fertility. Chest infections are a serious risk and some are unique to CF sufferers such as that caused by a bug (Pseudomonas) which binds into the lungs and creates its own protective layer that is impervious to antibiotics. Such infection results in a need to segregate patients to avoid cross infection. Unfortunately patients with chest infection due to *Burkholderia cepacia* are not allowed onto the new wad but are cared for in other wards because of a high risk of transmissibility and the limited ability to treat the infection (note this creates a two tier service which needs to be remedied for those with *B. cepacia* infection). Diabetes is common as well as impairment of liver functions. Because there is a vital need for attention to detail, adherence to a strict regime of treatment and nutrition as well as a need to motivate often quite young patients (given they transfer to NGH at age 16 – 18) and to manage difficult end of life issues, there is an absolute need for a multidisciplinary approach within a tertiary hospital setting able to provide truly holistic care.

Although there is no cure for CF advances in recent years have led to much improved life expectancy. People with CF born in the 1960's usually did not live to school age, but current patients born in 80's and 90's have a life expectancy of an average of 28 years whilst patients born now with the disease can expect to survive to 38 (UK CF Trust data) with still further improvements predicted. Lung transplants not only transform a patient's lifestyle but increases life expectancy by 10 or more years. Currently only 50% of those awaiting transplant get one.

These improvements bring with them their own problems however, as patients with CF age they become more and more complicated. For example it is beginning to emerge that CF patients may be more susceptible to bowel cancer at an earlier age than is found in those without CF. Transplantation may help the chest problems but the rest of the body has CF and those complications may continue.

We then visited the Ward facilities. Exercise is a vital part of treatment therefore the Ward has a small but well equipped gym supported by a physiotherapist. It also has its own well equipped kitchen which is

managed by a housekeeper who looks after the nutritional needs of patients. Nutrition is vital and CF patients need to have a constant calorie intake of about 130% of a normal person, more when they are ill. Because their requirements go well beyond the normal nutritional needs of other patients the housekeeper ensures the availability of additional meals around the clock of high protein and calorie levels such as beef burgers, bacon sandwiches etc.

There are 12 single occupancy rooms used by patients. They are labelled as 'Bedrooms' rather than wards. Each one has one wall completely decorated with a scenic design of countryside or seascapes. All the bedrooms are spacious (larger than the average side wards) and comfortably furnished with armchairs, wardrobes, drawers, desks and televisions as well as computer points. A patient's stay can vary from a few days to several weeks so they are encouraged to personalise the bedrooms with photographs and other belongings. One bedroom has been designed to accommodate a double bed so that in extreme circumstances a patient's family can stay overnight. Several rooms have built-in foldaway beds for family or partners to stay, particularly if the patient is far from home.

There is also a visitor room and two outpatient rooms in the area immediately inside the entrance to the Unit but separated from the main facility to minimise the risk of infection. These rooms are also equipped and furnished to the same high standards as the rest of the Unit and one of the outpatient rooms could be developed as a 13th bedroom if necessary. The cloud effect ceiling panels in these rooms are indicative of the care taken in designing a relaxing environment for patients.

The whole Unit reflects the careful research undertaken in the design stages including Dr Edenborough visiting other CF centres and talking to patients and staff about what they felt was good/ bad about their own facilities so tat the good could be incorporated and others' mistakes avoided. NGH patients were also involved at various stages. The outcome demonstrates the value of patient involvement at the earliest stages of design.

Other innovations included energy efficiency (35% less consumption than ordinary wards), easy cleaning (ceiling mounted reflective radiators and curved corners) and bactericidal copper touch plates on doors and handles. The UK Copper Council donated a specially commissioned copper artwork for the entrance foyer in recognition of the work in the Ward.

It has been observed that although theft of DVD players or Wii was not uncommon in the old CF Unit and elsewhere in the campus, it is none existent in the new facility, partly related to security but also a contract signed with patients when they are admitted to the ward.

Whilst no direct research into CF happens at STH there are ongoing developments to improve treatment and management of the disease. The next step being to increase home visits by multidisciplinary team members. It is hoped this will be a high profile initiative, supported by charitable contributions and in line with the *Be Green* sustainable transport methodology. *Post visit note: Dr Edenborough has secured a charitable donation of a hybrid car from Pentagon Toyota who wish to support the CF Charity.*

There is currently underway a detailed micro-systems analysis project. In response to follow up questions after the visit about micro-systems analysis and about gene therapy Frank has explained that work with the Service Development Team is on-going to improve understanding of the process of care for patients with CF at NGH. This should not only improve clinical outcomes (weight, lung function and ultimately longevity) but enhance the efficiency of the CF team in a time when the funding is being changed to a PBR mechanism. Comparative data from the UK CF Trust database shows that the NGH service is "middling" compared with other UK CF centres in average weight and lung function and the project is designed to push to the right of the "bell shaped curve" i.e. to excel.

Developments on the horizon include gene therapy (of the lung) when normal DNA can be inhaled in a special formulation that is taken up by the lungs of CF patients and corrects the genetic defect allowing the lung to work more normally, hopefully reducing infection and prolonging life. Even more astonishing is the development of two drugs taken by mouth (so possibly correcting all abnormal cells in the body) which may mend the damaged protein (CFTR) produced by the faulty gene. These two drugs and the nebulised gene therapy are at the stage of being trialled in patients.

Governors thanked Frank and his team for a very informative and enjoyable visit.

John Warner
Public Governor, West Sheffield