SPECIAL FEATURE: BONE MARROW TRANSPLANT AND SICKLE CELL DISEASE
pages 6 - 8

red cell *news*

A newsletter for patients with sickle cell disease and thalassaemia

Issue 6 AUTUMN / WINTER 2014

Above: a young King's College Hospital patient (centre) with his parents (far left and far right) and Professor Swee Lay Thein, Consultant Haematologist, Marlene Allman, Clinical Nurse Specialist and Dr Victoria Potter, Consultant Haematologist (back) from Kings College Hospital. This patient has been receiving pioneering bone marrow transplant treatment at the National Institutes of Health, Bethesda, Maryland, USA.

www.ststn.co.uk / info@ststn.co.uk / +44 (0) 20 7848 5441 / @STSTNetwork

South Thames Sickle Cell & Thalassaemia Network

Hello and welcome to the 6th issue of red cell *news*.

Here at STSTN, we can't believe that the autumn leaves are falling already and the temperatures are starting to drop with them!

STSTN had a busy summer preparing for our first Sickle Cell in Focus confernce in America (see pages 10 and 11.)

But what we are really excited about in the STSTN office is the patient stories we have to bring you in this issue. Dunstan Nicol-Wilson, a biomedical student, shares his experiences of living with sickle cell disease.

And, to accompany our special feature on Bone Marrow Transplant, Enoch Muwanga, describes what is like to be a parent of a child with sickle cell disease and the family's journey with the illness and experiences of bone marrow transplant.

We also have our regular puzzles page, and update on clinical trials in the region and a piece by Dr Baba Inusa of a recent study on blood transfusions and its potential to reduce stroke in children with sickle cell disease

As ever, if you have any comments or would like to contribute to red cell *news*, please get in touch.

Until Spring 2015!

Annabelle Kelly
STSTN Manager

LIFE WITH SICKLE CELL

By Dunstan Nicol-Wilson

There has always been a stigma when it comes to sickle cell anaemia: we can't live a normal life, we are always in pain and suffering. That is not true. Yes some sicklers suffer a lot, however, the idea of a 'normal' life is within reach.

Let me introduce myself, my name is Dunstan. I'm a student, currently at Canterbury Christ Church University studying bioscience. Why bioscience? Well, science for me is the driving force of change and I want to make a difference for people with sickle cell, and what better motivation is there than to actually have it. I can't say life has been easy with sickle cell but what is life without its ups and downs?

As a child with sickle cell, I was always in and out of hospital and I hated it with a passion. No offence to the doctors and nurses who looked after me but I just missed the comfort of my own home and I always felt so alone. So once I hit my teenage years, I always tried to avoid hospital and manage my pain at home or in my own way. I don't really recommend this to anyone else; if you're in pain let someone know! I guess I'm just a bit stubborn, my mum is a nurse so she always helped me to

Continued on page 2

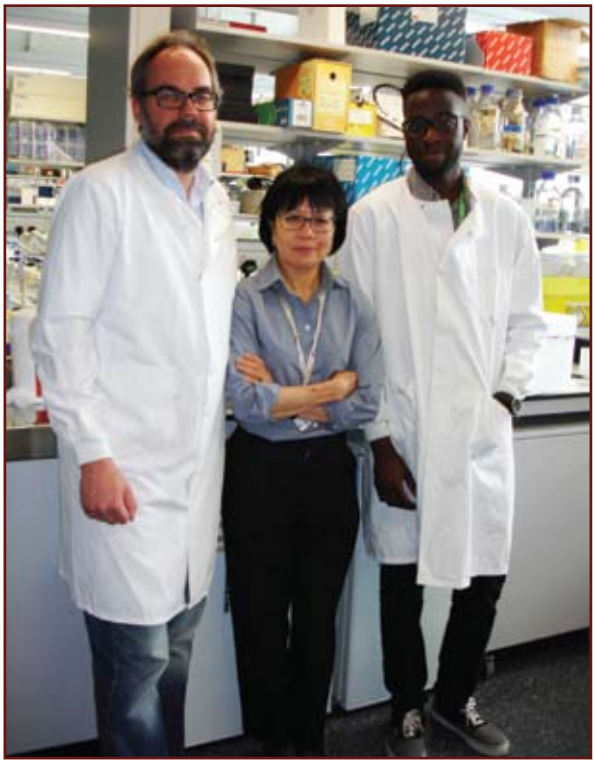
Continued from page 1

manage the pain but there would be times I wouldn't tell her because I knew she would say we have to go to hospital.

That news always sent a wave of emotions and thoughts through me: sadness, anger, frustration, why me? How long this time? I remember having minor crisis in my arm or leg during school, so that I couldn't write properly or wasn't as lively as normal. However, I always made sure I was in school, I didn't want to be different, I just wanted to be in class and learn like everyone else. Stubborn though I was, my mother had to pick me up a few times because I just couldn't manage the pain at school but I was happy every time, at least I made it to school and learnt something new, regardless of how short a period I was there for.

I don't know how it is for other sicklers but I still remember the worst crises that I've ever had. I was abroad in Spain and in France. However, for me, one of my crises was definitely the turning point in my life. The pain was excruciating, all over my body, it was one of those crises that hadn't settled in a particular area. My breathing was elevated, my body was extremely sensitive to the temperature and I just wanted to give up. I had never felt that way before; I just felt like I had had enough; life with this pain, I just couldn't take it anymore. When I finally made it to hospital, they gave me paracetamol. Really, paracetamol! I was going through my worst crisis to date, ever, and I was given paracetamol. I closed my eyes and just held my breath. I was tired, I was done and then I remembered all my loved ones. The people around me, my family, my friends and there was no way I was going to give up. I made it through that crisis and made a promise to myself that never again would I give up and never again would I let sickle cell take over like that.

From then on, I did research on how to manage my body better, healthy diet, plenty of exercise and of course lots of water. However, with exercise, you have to be careful not to overdo it. Exercise and some elements of prayer and meditation have also allowed me to become more in touch with my body. Now, I can feel when my crisis is coming, it's like a weird heavy sensation which flows through my body and then settles in one area which is sort of the epicentre of the pain episode. It has been explained to me in scientific terms, it's the metamorphism of red blood cells, the polymerisation of sickle haemoglobin due to deoxygenation, which leads to an increase in intracellular viscosity and stiffness (red cells change into sickle shape and clog together becoming thicker as they go through the veins). Even though there isn't much I can do from knowing when it is coming, at least I can be mentally prepared, ready with my medication and have plenty of water easily accessible around me. It's been two years since I've been admitted into hospital and, with the grace of God, it will be many more years or never again, preferably the latter.



Dunstan with Professor Swee Lay Thein and Dr Stephan Menzel

Another point to highlight, my faith has had a positive effect on me, I'm not saying you should be religious to find ease with sickle cell but it helps to have something that continues to keep you positive and upbeat about life. The mind is a powerful thing and once you learn to get control of your emotions and state of mind, things will be easier, I've adopted the saying Hakuna Mata (yes taken from The Lion King): to have no worries and relax in situations that cause stress, because stress is not good.

Life at university has been as close to 'normal' as it gets for me, I've had a few crises but I've managed well, I've attended every lecture and never used my illness as an excuse. While at university I've also always had a part time job which keeps me more than busy and highlights the importance of managing my body because tiredness or exertion can also bring on a crisis.

I've been blessed with a work experience opportunity at Kings College London with Professor Swee Lay Thein and her team. I shadow Helen Rooks in the lab where we have carried out DNA extractions and genotyping in order to predict the severity of pain in people with sickle cell in order to set up a the right treatment to improve quality of life. In people with sickle cell, fetal haemoglobin (or HbF), which is produced when you are a baby, continues to be produced in small amounts. Studies suggest the higher the amount of HbF the lower number of sickle cell crisis. The amount of HbF in people with sickle cell can be up to 30%. Thus studies are going on to investigate how to increase the amount of HbF or to identify children who will need more care than others early on and also how to increase HbF as a form of treatment. This opportunity has given me a real insight into the work being done for people with sickle cell and has added fuel to my desire of being part of this work in the future.

With sickle cell anaemia I have always felt you need to be well educated about it. Through science I've learnt that there are different levels of severity and no one case is the same. There are different triggers for everyone. Most recently I discovered that for me a mixture of indigestion and tiredness could bring on a crisis, which is something I never realised before. The use of long johns and thermal underwear is crucial during winter also because the less exposure to the cold, the lower the frequency of pain episodes.

I've gone through life with a lot of people telling me, 'I never knew you had sickle cell, you don't look like you do' although there isn't really a look that tells if someone has it, and that's how I want it to be. Sickle cell doesn't have a distinct look. It is internal; a genetic disorder; part of the genetic make up; a silent battle all the time, but you continue to fight. Don't let it get you down because life is not without burdens. Your burden is just a little bit heavier than others.

Dunstan is currently studying Biosciences at Canterbury Christ Church University and plans to pursue a career as a healthcare scientist after his studies.

MONTHLY BLOOD TRANSFUSIONS MAY REDUCE STROKES IN CHILDREN WITH SICKLE CELL ANAEMIA

NIH-FUNDED STUDY PROVIDES HOPE FOR CHILDREN WITH DISEASE-RELATED BRAIN DAMAGE

By Baba Inusa Paediatric Consultant, Evelina Children's Hospital, London

According to a new National Institutes of Health (NIH) funded study, in children with sickle anaemia and silent strokes (silent cerebral infarcts) regular blood transfusions will decrease the incidence of future silent or obvious strokes by 50%. The findings were published in the New England Journal of Medicine; one of leading publishers in Science.

Sickle red blood cells are stickier than regular cells and can block blood flow, resulting in pain as well as strokes. Strokes occur when oxygen delivery to the brain is compromised. However, unlike an obvious stroke, silent strokes do not cause any symptoms except problems with thinking quickly. Unfortunately the only way to detect a silent stroke is with magnetic resonance imaging (MRI) scans of the brain. The results of this trial provide strong evidence that children with sickle cell anaemia should have an MRI, and if a silent stroke is detected, they should be referred to a paediatric neurologist for evaluation. Detecting a silent stroke is important because in addition to being at risk for future silent and obvious strokes, children with silent strokes may have problems with school work.

Transfusions of healthy blood increase the number of normal red blood cells and make blocked blood vessels less likely to occur in people. In the current study, Michael R. DeBaun, M.D., from Vanderbilt University, the lead author and principal investigator for the trial and his colleagues including UK doctors -Dr Baba Inusa (Evelina), Dr Paul Telfer (The Royal London) and Dr Fenella Kirkham (GOSH) investigated whether regular, monthly blood transfusions would help prevent the recurrence of silent strokes in children with sickle cell anaemia.
In this 29 centre, international clinical trial, 196 children with sickle cell anaemia and silent strokes were randomized to receive regular blood transfusions or standard medical care. The blood transfusions were administered every month for a median of 3 years.

The trial results suggest that receiving blood transfusions on a regular basis may help prevent the recurrence of silent strokes in children. In the standard medical care group, 14.4 percent of patients experienced an obvious stroke or new silent stroke. However, among patients who received regular blood transfusions, only 6.1 percent experienced an obvious stroke or new silent stroke. The researchers noted that this trial included a very intense regimen for the patients, who were as young as 5 years old, and for their families. Some risks linked to blood transfusions include severe allergic reactions and high levels of iron throughout the body.

An unexpected result, according to the researchers, was that intelligence measures were not different between the two study groups. Previous studies from this trial and others have shown that silent strokes were associated with about a 5 point reduction in Intelligence Quotient (IQ), but for those children that had progressive strokes, there was no change in IQ when compared to those that did not have any change. This issue will be further explored by the investigators.

"Silent stroke in sickle cell anaemia is associated with a drop in 5 full scale IQ points, poor school performance, increased incidence of future silent and obvious strokes and challenges with the simplest instructions relating to the management of thedisease," said Dr. DeBaun.

Although the results are promising, more research is needed to better identify children at risk for recurring silent cerebral infarcts and to help target transfusion therapy.

This work was supported by grants from the NINDS (NS042804) and the NIH's National Heart Lung and Blood Institute (HL091759).

References:
MR DeBaun, et al. "Controlled Trial of Transfusions for Silent Cerebral Infarcts in Sickle Cell Anemia," New England Journal of Medicine, August 21, 2014.

For more information about stroke, please visit: stroke.nih.gov

For more information about sickle cell anemia, please visit:
nhlbi.nih.gov/health/health-topics/topics/sca/

Dr Martin Luther King Jr Boggler Puzzle

How many words of 3 letters or more can you find using the letters below? Words are formed from adjoining letters. Letters must join in the proper sequence to spell a word and may join horizontally, vertically, or diagonally, to the left, right, or up-and-down. No letter square, however, may be used more than once within a single word. You may use plurals if available. Score 1 point for each 3 letter word, 2 points for 4 letter words, 3 points for 5 letter words and so on. Score an extra 2 points for every Martin Luther King word that you make!

C	L	E	R
I	I	A	D
V	S	T	M
R	I	G	H

My points _____

Write the words you find below:

Spot the Differences!

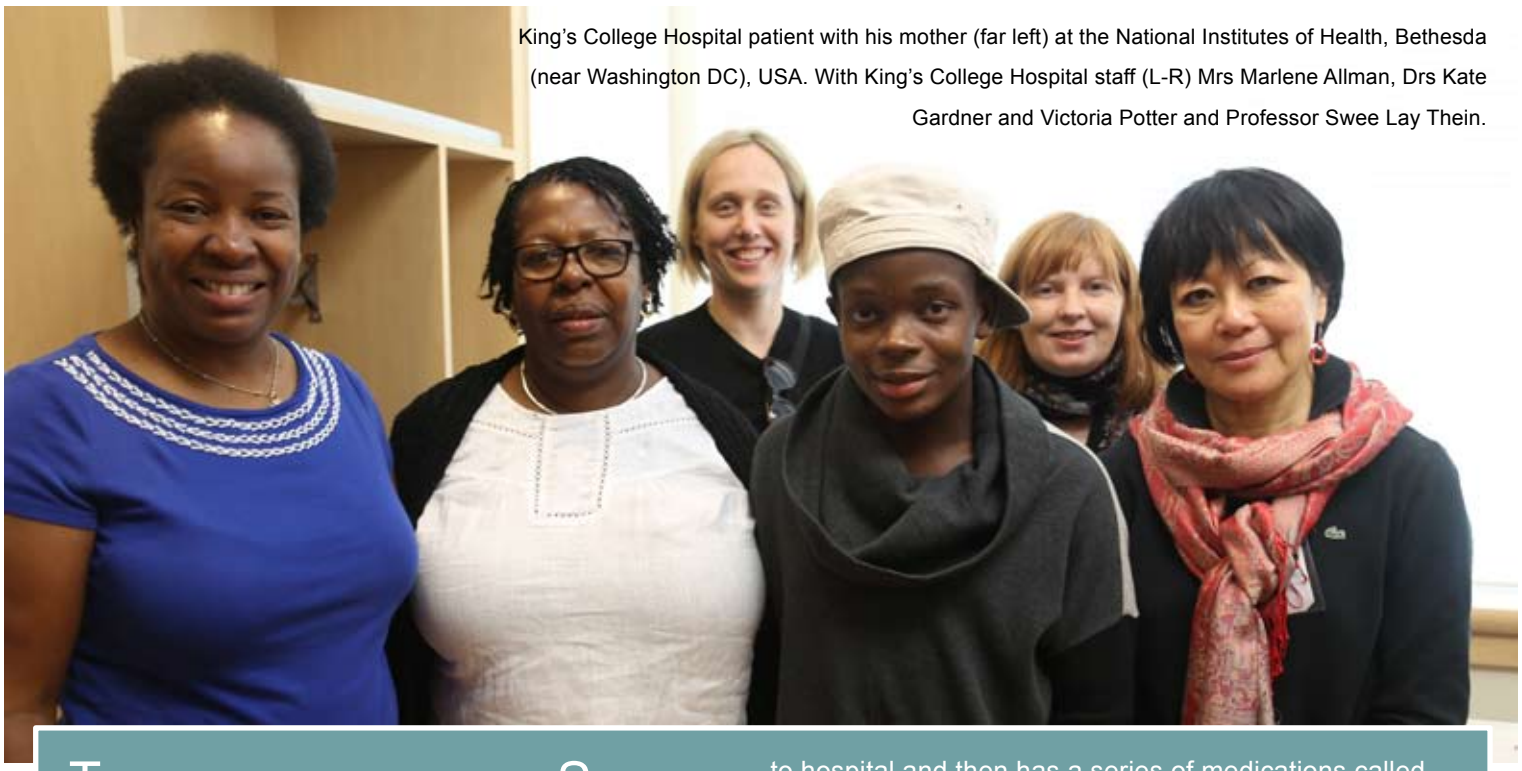
There are 10 differences in total between these two pictures. Can you find them?

Sudoku 6x6 Puzzles - Sheet 1

Every row, column and mini-grid must contain the numbers 1 through 6. Don't guess - use logic!

		1	5		
2					3
	6			1	
	4			3	
3					2
		4	3		

		5	6		
1					4
	6			3	
	2			6	
6					1
		4	2		



King's College Hospital patient with his mother (far left) at the National Institutes of Health, Bethesda (near Washington DC), USA. With King's College Hospital staff (L-R) Mrs Marlene Allman, Drs Kate Gardner and Victoria Potter and Professor Swee Lay Thein.

Transplantation for Sickle Cell Disease

By Victoria Potter
Consultant Haematologist, King's College Hospital NHS Foundation Trust

Patients with sickle cell disease often have life altering complications. While current therapies are available to manage sickle cell disease they are not curative. Stem cell (or bone marrow transplantation) offers patients a chance of cure however it is a procedure with potential serious complications.

For some years transplantation has been established as a treatment in children but for adults it has been considered too risky. Recent developments have improved the safety of these procedures such that adults can now receive bone marrow transplants. For a patient to have a stem cell transplant they first need to have a donor who does not have sickle cell disease. The best donor is considered a fully matched brother or sister.

Once a donor is identified they will either donate stem cells directly from the blood or from the bone marrow. The patient who is receiving the transplant is admitted to hospital and then has a series of medications called the conditioning chemotherapy. These drugs suppress the patient's immune system and make space in their bone marrow to allow them to accept the donor cells. The cells are infused in much the same way as a blood transfusion is given.

The patient usually spends around 4 weeks in the hospital and goes home when the blood count has recovered after the transplant. Some of the problems that may occur involve feeling unwell from the side effects of the conditioning drugs, infections or problems from the sickle cell disease itself. Sometimes the donor cells recognise the patient's body as different to their own. This can cause a reaction called *graft versus host disease* which is a potential serious complication of transplant. If you want to know more about what this means you should ask your doctor.

Many people ask whether the donor has to be completely free from sickle cell disease. The answer is no! A donor who has sickle cell trait (AS) can be a donor just like a sibling who has AA blood. Many patients will not have a fully matched donor and for some patients a transplant from a family donor who is half matched

Continued on page 7

Continued from page 6 can be considered. In this case we are talking about fathers, mothers or siblings. Of course it is important to remember that while a transplant may cure sickle cell disease it is not the right treatment for everyone and is usually only given to those people who have more severe forms of sickle cell disease. It can be quite complicated to understand the process from beginning to end so it is important to discuss with your sickle team if you are thinking about transplant as a treatment option as they can provide the right information

Enoch Muwanga shares his family's experiences of choosing bone marrow transplantation for their young son

By Enoch Muwanga

What is your experience living with sickle cell disease?

Prior to my son being born in 2006, my wife and I, both AS (sickle cell trait), were informed about the new-born screening programme and given pre-birth counselling. With all the information that we were provided, we thought we were in good position to take the journey with our son. In reality, we were just hoping that when he was born, he will be a healthy child. It was still a big shock, when the hospital confirmed to us that my son had sickle cell disease (SS).

My son's first sickle cell crisis was when he when he was 9 months old. When we found the right hospital that had sickle cell specialist doctors, he was put on penicillin, which was the first choice of drug given to him, to decrease the risk of infection in the bloodstream. However, our son experienced allergic reactions to penicillin. This triggered other medical side effects, resulting in eczema and multiple food allergies. After numerous trial and error episodes of treatment drugs, the doctors found the one drug, Clindamycin Hydrochloride, that his body could tolerate.

At the age of three, my son also suffered a stroke. He was immediately put on monthly transfusions and this presented the next challenge: dealing with intravenous cannulation. He became extremely needle phobic and it was so severe that my son received a PORT-A-CATH® implantable venous access system, to ease the transfusion process. However, despite a year of careful monitoring and maintenance, the PORT-A-CATH system got infected and had to be removed. With this new challenge, my son not only had to deal with his condition, his stroke, multiple food and drug allergies, but also a severe phobia to needles. We worked with the hospital doctors, nurses and a play specialist and developed a new care plan for him, which was put in place during his monthly transfusions.

My wife and I always knew that we could deal with this situation as long as we had all the right information and support. However, living with a child who has sickle cell disease is all about being vigilant, to your child's environment at home, at school, indoors, outdoors, day and night. It's a continuous 24/7 care plan for a family. We have experienced numerous emotions; fear that our first born had a debilitating condition; caution that maybe a cure could be found; courage in seeing my son deal with his condition without complaining; and finally hope and appreciation, for the new lease of life he has been given, after receiving bone marrow transplant treatment.

What did you find most helpful from the disclosure of your child's illness and what is most challenging?

Helpful

- Finding the right hospital with sickle cell doctors, nurses and a dedicated specialist medical team, gave us peace of mind.
- Building a relationship with the medical team, was enhanced through mutual communication and understanding. After all as a parent, I was the expert in managing my son's condition, away from the hospital environment.

Challenging

- Finding the right treatment drug for my son
- Finding specific information about alternative treatment/cure for sickle cell disease
- Balancing work and a home life, with hospital visits.
- A support network during periods of a long admission in the hospital.
- Dealing with the stigma in the community attached to sickle cell disease

How did you learn about BMT?

We were given a book about sickle cell disease in which there was a small paragraph that referred to a bone marrow transplant cure. However, the majority of the details information was obtained from talking to my son's consultants, Dr Baba Inusa at the Evelina Children's Hospital and and Dr Josu de la Fuente, who is based at St Mary's Hospital. As a family, we also searched the internet, read hospital leaflets and brochures.

Could you share with us your journey in making the decision to go for BMT, especially the role of individual family members?

This was one of the most difficult decisions to make for our Continued on page 8....

...continued from page 7

son. My wife and I had already done our due diligence and knew some of the risks involved. This journey was about eliminating our son's daily struggle from the effects of the sickle cell disease and the stroke. When our son was given a chance of having a relatively normal life, we came to the conclusion that this journey was worth taking for a better future for him.

So when we first spoke to Dr de la Fuente, he told us the news about this new treatment. We were now focused on the end goal. We were given several counselling sessions to discuss all the medical risks involved in this treatment. But when we were given a breakdown of the procedure, it became quite clear that our son was going to receive the best care. Did Dr de la Fuente provide us with the odds of this treatment working? Yes. Did he discuss the possibly of failure and death? Yes. As a family, did we have any doubt about what we were about to do? Absolutely not!

Please describe the process and what other parents and families should bear in mind.

There are six stages that my son and the family went through for this treatment:

1. INITIAL PREPARATION: My son, myself and the family went through a psychological preparation of what this whole journey entailed. I discussed with my son why he was getting additional check-ups and how long he was going to be away from school, his friends and his extended family.

2. PHYSICAL EXAMINATION: My son received a thorough physical examination before the transplant to establish his general level of health. He had scans to check the condition of his internal organs, such as his liver, heart and lungs. So for parents, it is important to be organised and not to miss these hospital appointments.

3. HARVESTING: Once my son had his physical examination, his stem cells were then harvested. His bone marrow was collected by removing stem cells from the hip bone using a special needle and syringe. The reason for doing this is in case of graft failure. This means, if he was unable to make any white blood cells, red blood cells, or platelets, the stem cells collected from him before the transplant, would have been given back to him, restoring his original bone marrow. This would mean, the sickle cell disease coming back.

In my son's case, he had a haploidentical transplantation, which is a donor from a half-matched family member. My son's donor was his mum and her stem cells were also harvested, under general anaesthetic, by extracting bone marrow from her hip bone. It is really important to know that the area where the operation can be painful afterwards and can invole staying in hospital for up to 48 hours, followed by a recovery period at home for five days.

4. "CONDITIONING" TREATMENT: As part of my son's conditioning, he received chemotherapy and a low dose of radiation. Both were used to weaken or destroy his own bone marrow, stem cells and his infection fighting system. This was to stop my son's body rejecting the new blood cells coming from his mum. My son suffered the side effects of chemotherapy, radiotherapy and some of the medication, which included nausea, vomiting, diarrhoea, loss of appetite, mouth ulcers, tiredness and hair loss. The hair did grow back, 6 months after the transplant.

5. TRANSPLANTING THE STEM CELLS: This process was the most anticipated procedure. My son's donated stem cells from his mum, were infused into his body a bit like a blood transfusion through an IV tube. This process took about 3 hours to complete, and he was awake and playing throughout the procedure.

6. RECOVERY PERIOD: After the transplant, my son's first stage of the recovery process involved waiting for the stem cells to reach his bone marrow and start producing new blood cells. This is known as engraftment and usually occurs 15-30 days after the transplant takes place. My son had to stay in hospital, in a germ-free environment and had very few visitors, to reduce the risk of developing an infection. Another issue to bear in mind post-transplant is that It can take a while for the immune system to return to full strength. My son was discharged two months after undergoing his bone marrow transplant.

What is your advice to professionals with regards to information sharing and guidance before and after?

Make the information for parents more readily available and presented in non-medical terms where possible.

Would you recommend BMT to others and would you do it again?

Knowing what I know now and seeing the improvement in the quality of my son's life, absolutely yes! However, I would not recommend this treatment process if a family is not ready for it.

What have things been like for you, your child and family since the BMT?

Life has changed for me, my son and the family. As a parent, I no longer have the continuous worry of a crisis and hospital admission. Our son looks forward to doing things at school and with his friends. He is discovering a whole new world of things to do. As a family, we can now travel to places far and wide, enjoy all types of weather without having the worry, of if we will end up in a hospital due to a crisis.

Would anything else have helped e.g. talking to other patients, more support?

Talking to other parents who have gone before you does help. It's what got us through the first two weeks of our hospital stay. The doctors and nurses were extremely supportive through the process, but there was a professional line they could not cross, which was to become emotionally attached to my son's bone marrow treatment. Therfore the other parents, whose child was close to being discharged, played a vital support role in providing moral support and reassurance during those long and challenging days. Going forward, I think parental groups or a liaison officer (a parent who has taken this journey), would help others.

CLINICAL TRIALS AROUND THE REGION

GENETIC MODIFIERS OF SICKLE CELL DISEASE

Chief Investigator:
Professor Swee Lay Thein (KCH)

Principal Investigators:
Dr. Jo Howard (GSTT), Dr. Sara Stuart-Smith (QE), Dr. Tullie Yeghen (LEW)

We are all too aware of how differently sickle cell disease can manifest itself in different people and even within the same person at different periods of their lives.

While environment and stress can trigger pain and constitute to some of the problems, we know that genes within our DNA can modify the severity and complications of the disease.

Since 2007 we have been conducting research aimed at identifying these genetic modifiers, and in particular, we are looking at genes which code for a special type of haemoglobin (the oxygen carrying part of red blood cells). So far we have recruited over 1000 volunteers (both adult and children) with sickle cell from KCH, GSTT, QE and LEW Hospitals. These volunteers donate a single blood sample to help us learn about these genetic markers.

Clinical research is essential for developing better treatments and improving healthcare for both adults and children. It is important to remember that without research we could never develop new treatments or gain a better understanding of diseases.

DOVE STUDY – A PHASE III STUDY OF PRASUGREL IN CHILDREN WITH SICKLE CELL DISEASE

Principal Investigators:
Professor David Rees (KCH) & Dr. Baba Inusa (EV)

KCH and EV hospitals are participating in a global study of a new treatment to reduce the occurrence of painful vaso-occlusive crisis in children.

Prasugrel is an approved medication for the treatment of certain types of heart disease in Europe and the US. However, it is not uncommon for medications to have more than one use and treat different diseases. There is evidence to suggest that Prasugrel may help to reduce the occurrence of a painful vaso-occlusive crisis by controlling the activation of platelets (a blood component) thought to play a role in the vaso-occlusive process.

AES-103-003 – A PHASE IB STUDY IN ADULTS WITH SICKLE CELL DISEASE

Principal Investigators:
Prof. Swee Lay Thein (KCH) & Dr. Jo Howard (GSTT).

Aes-103 is a new medicine being developed for the treatment of sickle cell disease. It is being developed by AesRx/ Baxter, (a pharmaceutical company) who is collaborating with KCH and GSTT as well as Quintiles Clinical Research Organisation.

Abnormal haemoglobin in sickle cell disease makes the shape of the red blood cells abnormal (sickle shaped) and they may clumps in the absence of oxygen which can cause blockages of small blood vessels (vao-occlusion). However, it has been observed that when the abnormal haemoglobin is bound to Aes-103 it is then able to carry oxygen more efficiently and this can reduce sickling and clumping of these red blood cells.

We would like to thank all our patients who have volunteered to participate in research. If you would like more information about any of the clinical studies mentioned here or other research possibilities then please ask your clinician, sickle nurse specialist or research nurse/ co-ordinator in your local clinic.

Key:
KCH - King's College Hospital NHS Foundation Trust
GSTT - Guy's & St. Thomas' NHS Foundation Trust
QE - Queen Elizabeth Hospital, Woolwhich
LEW - Lewisham Hospital
EV - Evelina Children's Hospital

SICKLE CELL IN FOCU

By Annabelle Kelly
STSTN Support Manager
and veteran SCiF
organiser!

After 7 year of hosting Sickle Cell in Focus (SCiF) at King's College London, Denmark Hill campus, Professor Swee Lay Thein and I travelled to the National Heart Lung and Blood Institute (NHLBI) at the National Institutes of Health in Bethesda (near Washington DC) in the USA for the 8th SCiF.

Professor Thein, Founder and Programme Director of SCiF, collaborated with Dr John Tisdale, Senior Investigator of the Molecular and Clinical Haematology Branch at NHLBI (pictured below left), to host this year's event on US soil.

SCiF has become an integral part of the global sickle cell and thalassamia educational calendar. It is a chance for clinicians and healthcare professionals from around the world to meet and discuss the current and emerging clinical complications and management issues.

This translates to the best and most-up-to-date care for you, the patients.

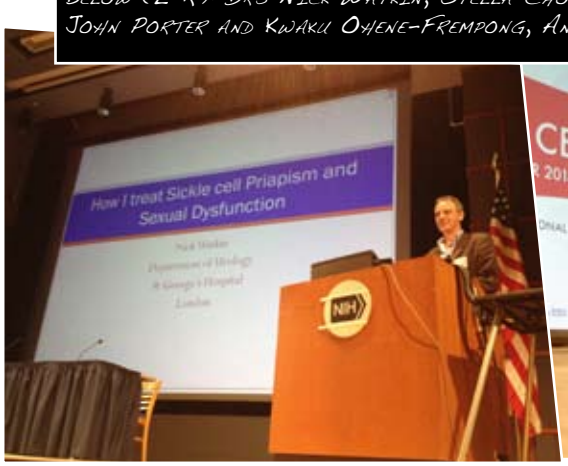
A very big thank you to the speakers and delegates who participated so enthusiastically and made the conference such a success.

Thank you all also to Karen Kendrick (right), my new US friend who delivered Dunkin Donuts and a fresh coffee each morning. Karen should actually take most of the credit for organising SCiF 2014!

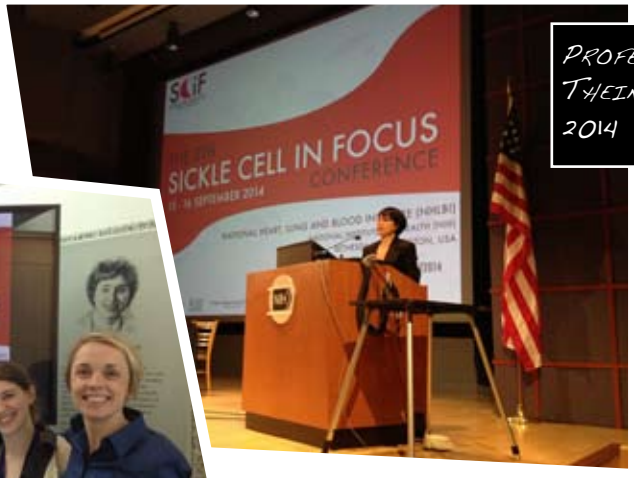
We now aim to alternate SCiF each year between London and Washington. Watch this space!

The Nathcher Conference centre

Below (L-R): Drs Nick Watkin, Stella Chou & Kate Gardner, Professors John Porter and Kwaku Ohene-Frempong, and Dr Pauline Kane



US GOES STATESIDE!



Professor Swee Lay Thein Opening SCIF 2014

Team SCIF 2014 (L-R): Dr Chutima Kumkhaek, Dr John Tisdale, Professor Swee Lay Thein, Karen Kendrick, Emily Moldiz & Annabelle Kelly

A busy Ruth L. Kirschstein Auditorium, Natcher Conference Center

Professor Eliott Vichinsky (R) posing questions

Drs Kathryn Hassell, Miguel Abboud & Michael DeBaun Debating the use of Hydroxyurea therapy

Dr Jo Howard on improving the health of adults with SCD

South Thames Sickle Cell & Thalassaemia Network

THIS PAGE IS FOR YOU!

YOUR STORY, OR DESIGN WORK, OR DRAWING, OR PHOTO OR ANNOUNCEMENT....GET IN TOUCH!

www.ststn.co.uk / info@ststn.co.uk / +44 (0) 20 7848 5441 / @STSTNetwork