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KING'S HEALTH PARTNERS
Pioneering better health for all

red cell *news*

A newsletter for patients with sickle cell disease and thalassaemia

ISSUE 4 AUTUMN / WINTER 2013

South Thames Sickle Cell & Thalassaemia Network

PRESCRIPTION CHARGES COALITION

Help the campaign for free prescription for sickle cell and thalassaemia patients

EMAIL YOUR MP - see page 5 for more details

EVELINA CHILDREN'S HOSPITAL SUMMER PARTY

During the summer holidays, the Paediatric Sickle Cell Service at the Evelina London Children's Hospital hosted their annual Children's Summer Party. Although it rained on the day we did not let the weather dampen our spirits!

Over 70 children enjoyed the music, craft activities, indoor picnic, face painting with FunFabFaces and balloon making with Miss Ballooniverse who modelled anything from flowers to aliens and everything in between. We would like to thank 'Starlight' for funding the party and providing the decorations and party bags

The party was a great opportunity to see the children and their siblings interacting with each other and having fun. It also provided a relaxed, informal environment for parents to get to know each other too.

If you have any questions about the Children's Group's please contact the team: 020 7188 7774.

Hello and welcome to our Autumn/ Winter 2013 issue.

This is our 4th newsletter and I hope you agree that we have had some fantastic patient stories, interviews and articles to share with you so far.

IN THIS ISSUE:

- Christmas quiz, puzzle and colouring in
- Lortoria McDonald writes about being part of a research project at King's College Hospital.
- Special feature: Prescription Charges Coalition and how you can help.
- Cold weather advice

Plus our regular event news round-up.

As always, keep sending us your stories and comments. Until the Spring!

Annabelle Kelly, STSTN Support Manager

STSTN CHILDREN'S CHRISTMAS PARTY

THURSDAY, 19 DECEMBER 2013, 1 - 4pm

Evelina Children's Hospital, Lambeth Palace Road, London SE1 7EH

All child patients, their parents and siblings from around the Network region are welcome.

Please call 020 7848 5441 or email info@ststn.co.uk

CHRISTMAS QUIZ & PUZZLE

Santa's Sickle Cell Disease Quiz

(Choose One Answer)

1. When was sickle cell disease first described?

a. About 1 million years ago
b. About 1000 years ago
c. About 100 years ago
d. About 10 years ago
e. Last year

2. Why should you take penicillin every day?

a. It tastes nice
b. It will stop other people catching sickle cell disease
c. It makes my wee smell nice
d. I do not really need to take it
e. It will stop me getting some infections and keep me well

3. Where is the spleen normally found in the body?

a. In your head behind your eyes
b. In your chest on the lungs
c. Inside the heart
d. In your abdomen near the stomach
e. In your legs

4. What should you do if it is snowing outside?

a. Dress sensibly in a warm coat and gloves before going outside
b. Stay in bed until the snow has gone
c. Play in the snow all day
d. Build a snowman but stop when your fingers start to hurt
e. Go for a picnic in the park

5. What activities can I do at school?

a. Football
b. Dancing
c. Mathematics
d. Basketball
e. All of the above

(answers at www.ststn.co.uk/patientzone)

CHRISTMAS WORD SEARCH

Q	R	G	U	F	D	B	I	O	P	T	R	E	E	C
S	S	C	J	K	L	M	E	A	S	C	X	M	K	A
P	A	S	N	O	W	F	L	A	K	E	S	V	H	N
X	N	M	N	U	A	D	B	R	R	T	I	D	Y	D
E	T	L	J	G	B	U	Y	D	B	M	L	G	T	Y
W	A	C	V	E	J	M	L	U	B	V	J	D	V	C
R	C	X	U	L	I	H	T	C	O	P	Q	X	M	A
O	T	H	J	F	Q	R	T	B	K	H	C	P	L	N
L	Q	F	B	J	L	I	J	A	H	N	V	R	O	E
U	V	Y	L	B	A	Y	T	O	Y	N	W	E	M	S
T	R	T	B	K	L	D	S	V	U	Z	B	S	P	O
R	X	C	H	R	I	S	T	M	A	S	U	E	S	H
E	N	T	H	F	B	M	K	P	U	Y	A	N	Q	B
E	C	V	G	U	Y	W	B	H	F	G	U	T	A	V
Y	Q	H	L	I	G	H	T	S	V	B	S	D	I	O

FIND THESE WORDS

1. SANTA
2. SNOWFLAKE
3. PRESENT
4. TREE
5. ELF
6. LIGHTS
7. TOY
8. CANDYCANE
9. TREE
10. CHRISTMAS

PATIENT PLATFORM

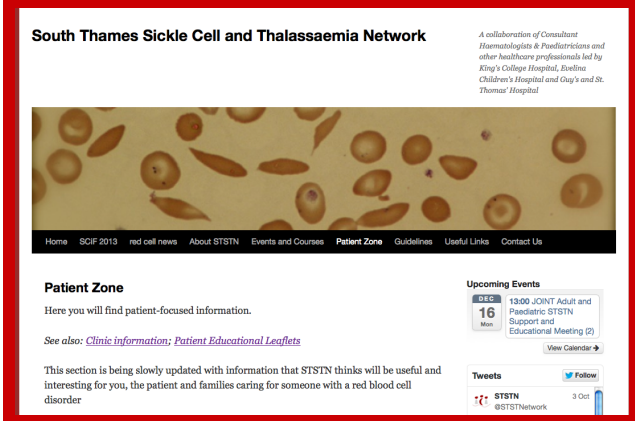
SEND US YOUR STORIES AND NEWS

- COLOUR IN SANTA (BEST TO USE COLOUR PENCIL)
- TAKE A PHOTO
- SEND TO STSTN
- WE'LL PUBLISH IN THE NEXT ISSUE!

DID YOU KNOW?

The STSTN website has a Patient Zone where you can find:

- PATIENT INFORMATION LEAFLETS
- CLINIC TIMES AND CONTACT NUMBERS
- EVENT NEWS



www.ststn.co.uk/patientzone

Let us know what you would like to see!
Email: info@ststn.co.uk

GET IN TOUCH

Do you have a personal story about your experience with sickle cell disease or thalassaemia that you would like to share?

Are you a budding stroyteller and would like to see your work in print?

Is there an issue about sickle cell disease and thalassaemia that you would like to discuss?

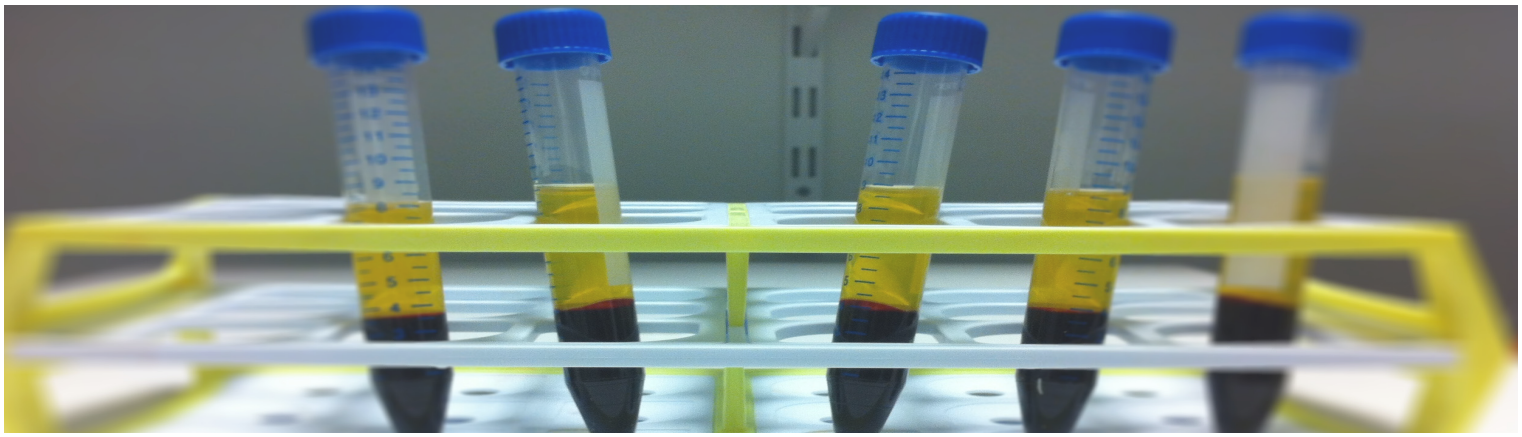
Do you have an event you would like to publicise or would you like to connect with other patients and create a support group?

Or would you simply like to tell us what you think of **red cell** news or suggestions of what you would like to see included.

Then we would really like to hear from you.

Get in touch with Annabelle by email or phone:
info@ststn.co.uk or 020 7848 5441

Please note: views expressed in this newsletter do not represent the views of STSTN but that of each individual contributor



ILLUMINATING DNA'S DARK MATTER: SICKLE CELL ANAEMIA

By Lortoria McDonald, research volunteer and outpatient, King's College Hospital

Ever heard of a disease with benefits? Think X-Men, superheroes who use their genetic mutation for the good of humanity. However, the Marvel comics turned movie series are more than sheer entertainment. Collectively, they are morally complex and politically progressive stories about individual anomalies and discrimination. Society often fears, ignores or rejects anything that doesn't fit the archetype of popular culture. So imagine what that must feel like for anyone living with a genetic disease?

Through shared knowledge, I've discovered that my condition can be a benefit rather than a hindrance; but for others living with Sickle Cell Disease (SCD), it might not seem that way.

There is a general lack of knowledge about SCD because its course is spontaneous, variable, and influenced by the unique characteristics of genetic inheritance. Dr. Emma Draser, Clinical Lecturer at King's College London explained: "There are as many variations of sickle cell disease as there are patients". In England there are approximately 250,000 people who have the sickle cell trait[1].

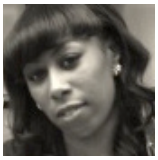
Professor Swee Lay Thein, Professor of Molecular Haematology at King's College London and Consultant Haematologist at King's College Hospital, is leading a research project in why SCD is more severe in some patients and how the sickle gene can be manipulated to cure future generations. The answers to their questions are hidden within the dark matter of each volunteer's DNA.

Using volunteers like myself as the blueprint of their research, Professor Swee Lay Thein and her team have been analysing sickle cell DNA for patterns and variables. Data was categorised into sickle cell severity scores based on factors such as red blood cell count, white blood cell count, and how frequently a patient visits hospital.

They found an unusual 15 - 20% increase of fetal haemoglobin in adult blood samples presenting less severe SCD. This is good news because fetal haemoglobin in the red blood cells interfere with sickling process. Adults without SCD have very small amounts (less that 1%) of fetal haemoglobin present in their blood. Fetal haemoglobin is the dominant haemoglobin in all unborn babies. When a baby is born a switch occurs from fetal to adult haemoglobin. It is not yet understood how this happens, but it does imply that increased fetal haemoglobin levels can reduce the severity of SCD sufferers.

"The whole purpose of our research is to try to predict who is likely to develop complications and have more severe sickle before those complications occur...."
Dr Emma Drasar, King's College London

When scientists solve the factors controlling this switch, it will speedup future implications of prediction of severity. The Newborn Screening Programme hopes to do just that with bespoke care plans and drug treatments. Dr. Emma Draser explained, "The whole purpose of our research is to try to predict who is likely to develop complications and have more severe sickle before those complications occur, or at least early enough in their onset we can intervene, slow or potentially reverse the progress."



Lortoria McDonald is the founder of interactive artzine Illumaink She is a writer, photographer and keen observer of the arts. She is also an outpatient at Kings College Hospital Haematology department.

http://illumaink.co.uk/
Twitter: @illumaink

([1]http://www.nhs.uk/conditions/Sickle-cell-anaemia/Pages/Introduction.aspx)

If you would like to take part in a research study, please talk to your Consultant or Specialist Nurse when you are next in clinic

SPECIAL FEATURE

PRESCRIPTION CHARGES

Campaign for Free Prescriptions

help the Prescription Charges Coalition campaign for a fairer prescription system - email your MP TODAY

Patients may recall the Gilmore Report, a government commissioned document published in November 2009. Professor Ian Gilmore, President of the Royal College of Physicians, was asked by the previous government to review prescription charges in England and set out proposals to extend the number of patients with long term conditions who are exempt from paying prescription charges. The report concluded that entitlement to free prescriptions should be extended to anyone with a medical condition lasting longer than 6 months, but this recommendation was not taken up by the government.

ABOUT THE PRESCRIPTION CHARGES COALITION

The Prescription Charges Coalition (PCC) is an alliance of 29 organisations, including the Sickle Cell Society and the UK Thalassaemia Society, concerned with the detrimental impact that prescription charges are having on people with long-term conditions in England. Following a survey of nearly 4,000 people with long-term conditions, the evidence-based report Paying the Price was published in March 2013. Over 3,000 people have since contacted their MPs on this issue.

THE ISSUE

Many people of working age with long-term conditions in England today are struggling to afford their prescribed medicines and are severely compromising their health as a result.

Extending exemption from prescription charges to all those with long-term conditions, would remove a major barrier to accessing medicines *(you can download the full PCC report from their website www.prescriptionchargescoaltion.org.uk)*

HOW YOU CAN HELP

It's so easy! You can send an email to your local MP via the PCC website - it takes less than two minutes!

Please visit www.prescriptionchargescoalition.org.uk where you will find a EMAIL YOUR MP link on the home page.

If you would prefer to write an handwritten letter to your MP, you will find a template letter on the STSTN homepage.

www.ststn.co.uk

With thanks to Elaine Miller, UK Thalassaemia Society for help with this article

COLD WEATHER ADVICE

During the cold months it is important follow certain precautions to prevent any complications related to your sickle cell disease.

Most patients find that cold causes the onset of pain. The cold does not directly increase sickling of the red cells but it has two effects on the body that explain the association. Cold increases the use of oxygen by the muscles and this reduces the amount in the red cells. Shivering is an example of the extreme of this effect. Cold also causes the blood vessels to contract, becoming smaller to preserve body heat. This directly reduces blood flow and any sickling of red cells causes further slowing of flow. The slower blood flow also reduces further oxygen in the blood and low oxygen causes increased sickling.

Ensure you dress in warm clothes and wear a hat, scarf and gloves. Swim only in warm heated pools. You also need to drink lots of water in really cold weather and when swimming because both can also cause dehydration that will increase sickling. It is also important to fix an appointment with your GP to have flu vaccine as early as possible and not to wait untill the winter sets in.

By Dr Sanjay Tewari, Clinical Research Fellow, King's College London / King's College Hospital

EVENT NEWS

Prof. Swee Lay Thein is joined by some of the world experts in sickle cell disease who presented at this year's conference

PROFEESOR SWEE LAY THEIN HOSTS THE 7TH SICKLE CELL IN FOCUS CONFERENCE

On 6-8 June this year, we welcomed 130 guests from around the world to King's College Hospital / King's College London Denmark Hill campus for our 7th Sickle Cell in Focus (SCiF) annual conference.

World-renowned experts in sickle cell disease, including Professor Graham Serjeant from the Sickle Cell Trust in Jamaica, joined us for two and a half days of updates on emerging complications and treatment options in sickle cell disease, plus current findings from research teams from the UK, USA and France.

Since it's inception in 2006, SCiF has grown each year to become one of the most respected and internationally recognised sickle conferences in the world. It provides a unique global perspective on the impact of sickle cell disease and thalassaemia.

Professor Swee Lay Thein, Programme Director, Professor of Molecular Haematology at Kings College London, and Consultant Haematologist at King's College Hospital says, *"SCiF brings together a dedicated group of clinicians and academics who are passionate about improving the lives of our patients. Each year we attract a world-class faculty of haemoglobinopathy experts, making it an incredibly important educational update for our local, national and international delegates."*

We are now in the first phases of planning SCiF 2014 and we look forward to reporting back next year!

STSTN CHILDREN'S CHRISTMAS PARTY

THURSDAY, 19 DECEMBER 2013, 1 - 4pm

Evelina Children's Hospital, Lambeth Palace Road, London SE1 7EH

All child patients, their parents and siblings from around the Network region are welcome.

FOR MORE INFORMATION:
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SICKLE CELL PATIENT AWARENESS DAY

Guy's & St. Thomas' Hospital

On Wednesday 3rd July the Department of Haematology at Guy's & St. Thomas' Hospital (GSTT) held their annual patient awareness day as part of the national sickle cell awareness month.

This educational event for patients, their families, hospital staff and the general public aims to raise awareness of sickle cell disease and provides an opportunity to learn about the new developments in management of sickle cell disease at GSTT.

There are opportunities to talk to consultant haematologists, advanced nurse practitioners, health/clinical psychologists, community nurses and patient representatives about any issue related to sickle cell disease, from symptoms through to caring for someone with the illness.

Presentations are delivered by the sickle cell health care team and patients and a fantastic lunch is provided. The feedback from the day was very positive, finding the day interesting, relevant and a keeness for the event to be held more regularly.

ADOLESCENTS AND YOUNG ADULTS TRANSITION WORKSHOP

On Wednesday 11th September, 10 young people aged between 16 - 23 years old joined the specialist haemoglobinopathy nursing staff and Health Psychology Team at Guy's & St. Thomas' Hospital (GSTT) for a workshop on issues affecting patients in this age group. These ranged from health and lifestyle issues to benefit entitlements and student support for those preparing for University. Parents were also invited to attend and found the event insightful and reassuring and a space where they could share their concerns about their children's care in a friendly, relaxed environment.

There were some important and encouraging outcomes of the day. The discussion on benefits hilighted how claims are more likely to be declined because of the fluctuating nature of sickle cell disease. But patients can access help with completing forms via the benefits office and/or the Community Sickle Cell Nurse. Three of our attendees had just graduated from university, one with 1st Class Honours. We are also aware of a further two patients who gradutated with the same mark and we plan to undertake a study of the educational achievements of our young patients who have transitioned to the adult service. And finally, a unanimous vote found in favour of online peer support forums, via social media such as Facebook, compared to physically attending a group.

By Luhanga Musamadi, Clinical Nurse Specialist, Sickle Cell Disease GSTT

ABOUT STSTN

The South Thames Sickle Cell and Thalassaemia Network (STSTN) is a haemoglobinopathy collaboration led by Consultant Haematologists and Paediatricians at King's College Hospital, Evelina Children's Hospital and Guy's and St. Thomas' Hospital NHS Foundation Trusts.

STSTN aims to:

"improve the patient experience by offering better treatment outcomes for people with sickle cell disease and thalassaemia"

Find out more at: www.ststn.co.uk

With thanks to our supporters:

King's College Hospital Charity · UK Forum on Haemoglobin Disorders · Making life better for Seriously Ill children · NOVARTIS

Guy's and St Thomas' NHS Foundation Trust · King's College Hospital NHS Foundation Trust