Issue 10 Winter 2018

KING'S HEALTH PARTNERS

Pioneering better health for all

South Thames Sickle Cell & Thalassaemia Network

red cell *news*

A newsletter for patients with sickle cell disease and thalassaemia

Hello and welcome to the latest issue of Red Cell News—the first of 2018!

We've started 2018 refreshed and feeling very excited about the year ahead. Plans for educating health care professionals across the region are well underway, we're looking at how we can update the website to make it a really helpful resource for professionals and patients alike, and we're putting our heads together to come up with ideas for a fun and friendly event for patients across the network.

In this issue we've got an article written by the pain management team at St George's Hospital all about tackling chronic pain, Florence Ramos talks about her Pain to Power Campaign, we've got information about a new study looking at safer pre-natal testing, and Miriam Kay shares her experience of living with sickle cell and how it led her to create The Dora Foundation.

It's cold out so wrap up warm, grab a cuppa, and dive in!

Until next time,
Eleanor Baggley
Network Support Manager

In this edition:

Visit the Patient Zone on our website (www.ststn.co.uk) to find patient information, clinic times, support group information and previous editions of red cell news. If there's something else you'd like to see in the Patient Zone, let us know!

Red Cell News Needs You!

We're always on the lookout for new contributors for Red Cell News and our website. If you have something you'd like to share— whether it's your own experience, a project you're working on, or a piece of creative writing (to name a few!), we'd love to hear from you so get in touch!

info@ststn.co.uk / 020 3299 5102

The **Sickle Cell Society South London Link** offer free activities, social events, support groups, and information and education workshops for people affected by sickle cell disease or thalassaemia living the network region.

Contact 020 3879 9535

www.sicklecellsociety.org/sickle-cell-south-london-link-service

SICKLE CELL SOCIETY

About STSTN

The South Thames Sickle Cell and Thalassaemia Network (STSTN) is a haemoglobinopathy collaboration led by Health Professionals including consultants, nurses, psychologists, counsellors and others at King's College Hospital, Evelina Children's Hospital and Guy's and St Thomas' Hospital NHS Foundation Trusts and includes hospitals in London and the South East of England.

Our mission is

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

Visit www.ststn.co.uk

Email info@ststn.co.uk

Tackling Chronic Pain in Sickle Cell Disease

By Jenna Love & Rebecca McLoughlin

St George's University Hospitals NHS
NHS Foundation Trust

The Red Cell Pain Management and Psychology Service at St George's Hospital was established in recognition of the significant impact that pain can have on the lives of people living with sickle cell disease. Crisis pain is one of the most significant and well recognised parts of the condition and so understandably receives a lot of the focus in medical literature and at hospital appointments. However, many people with sickle cell also experience pain in between crises, which is perhaps less well recognised.

In understanding pain, it can be helpful to think about two different types of pain, known as 'ACUTE' and 'CHRONIC' or 'PERSISTENT' pain. Sickle crises are usually an example of 'acute' pain episodes as they usually last for days or weeks (pain lasting less than 3 months is classed as acute), and often the pain begins to settle as the sickling or infection resolves. Chronic pain describes pain that lasts for more than 3 months. In chronic pain the problem is not necessarily in the area of the body that hurts; pain science has shown that the nervous system (brain and nerves) of people with chronic pain works differently and becomes more sensitive than it is helpful for it to be, leading it to produce pain on an ongoing basis. This pain is just as REAL as any other type of pain, but it does mean that there may not be one straight forward way of managing the pain.

We work with many people with sickle cell disease who experience chronic pain. This pain can have a very significant impact on life, making it harder to do the everyday activities that are important to us, which can then lead to us feeling frustrated and fed up. Chronic pain is perhaps more hidden than crisis pain, as it doesn't tend to bring people into hospital, and so it is hard to know the full extent of the problem. Some US authors estimate up to half of people with sickle cell experience pain in between crises.

How can pain management help?

Pain management is not a cure for pain. 'Pain management' describes a collection of strategies that, when used regularly in daily life, have been shown to reduce the unhelpful or negative impact that pain can have on a person's life. For example, research has shown that pain management strategies can help people to feel less anxious and depressed, do more physical activity and do more of the activities that are important in their lives. There is very good evidence that pain management approaches are effective in improving quality of life for people living with other long term pain conditions, therefore, it makes sense that similar strategies could be helpful for people living with sickle cell related pain.

The red cell pain management and psychology service is run by Dr Jenna Love (Clinical Psychologist) Rebecca McLoughlin (Specialist Physiotherapist), Dr Oliver Seyfried (Pain Consultant) and Dr Alexa Duff (Clinical Psychologist). Pain experiences impact on our physical wellbeing, our emotions, our thoughts and behaviour, and often the people we work with find input from different specialities helpful because of the range of perspectives and approaches that they offer.

What does the service offer?

We have different individual and group sessions available based on the individuals' needs.

⇒ ***Pain Management Programme, 'Breaking the Cycle'***

'Breaking the cycle' is a group programme where participants attend for one day a week for eight weeks. The content of the programme is based on well researched pain management principles for chronic pain, with some specific adaptations for sickle cell disease. We discuss a range of topics including:

* The mechanisms of sickle cell pain (what is happening in the body and why it hurts)
* Exercise and movement with sickle cell
* Ways to use pacing to increasing activity
* Managing difficult thoughts and feelings, including techniques for stress and anxiety
* Communication with friends, family and medical professionals
* Exploring the difference between crises and increases in chronic pain, and how to manage these.

Throughout the programme group members work towards their own personally relevant goals and experiment with putting the strategies discussed into practice in their daily life. Participants who have attended our programme have told us that being in a group with other people who also have sickle cell pain has allowed them to feel supported and less alone in their experience of pain.

⇒ ***'Circulate' exercise group***

Our weekly physiotherapy led exercise group is available for any adults with sickle cell disease who are known to the service. Many people have found that exercise has resulted in an increase in their pain in the past. The exercise group is an opportunity to explore paced exercise with the support of our physiotherapist to help participants find movements they can do without significantly increasing pain and explore how to integrate movement into daily life. The hour long session often includes some warm-up movement, a circuit of exercises to increase functional fitness, stretches and a short meditation or relaxation exercise.

⇒ ***Sickle Cell Pain Clinic***

Our monthly pain clinic with Dr Seyfried, a Consultant in Pain Medicine with a special interest in sickle cell disease, provides the opportunity to have a thorough assessment of pain, and explore any questions around treatment options or medications for managing chronic pain.

⇒ ***Individual physiotherapy or psychology sessions***

We also offer individual psychology and/or physiotherapy sessions when that is more helpful or appropriate than working in a group. The ideas discussed are often similar to those described above, but may have a specific focus such as building activity up after a period of increased pain or strategies to improve communication about sickle cell and pain.

Article continues on page 3...

Tacking Chronic Pain (continued from page 2)

How can you access pain management?

Some hospitals are developing sickle cell pain services, or may be able to refer you to general pain services. As we are a specialist service, we are able to accept referrals from across London, therefore if you think this approach could be helpful for you, please ask your haematologist if they can refer you.

Red Cell Pain Management and Psychology Service

07798 581198

SCDpain@stgeorges.nhs.uk

Follow us on social media.

Facebook: Red Cell Pain / Twitter: @PMPRed / Instagram: Red Cell Pain

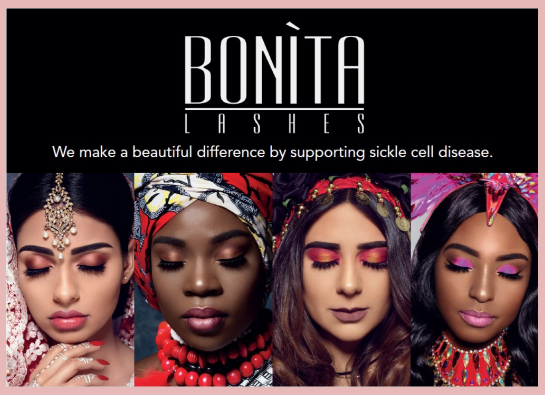
The Team! —>

The Pain to Power Campaign

By Florence Ramos

They say it's the little things that make a big difference. Bonita Lashes aspire to become an beauty-essential in every lash lover's routine, making a beautiful difference through both our product and campaign. Sickle Cell Disease or Sickle Cell Anaemia is the world's most common blood disorder, affecting millions of people worldwide, every single day. Surprisingly either many people have never heard of it or they have, but are unsure about what it is. Sickle Cell Disease or SCD is a genetic and lifelong blood disease caused by abnormalities in the hemoglobin of the patient's red blood cells. Normal red blood cells are round while sickle cells are half of that shape, *sickled shape*, hence, the origin of the disease's name.

Sickle cells are unable to successfully transport oxygen around the body, therefore becoming sticky and getting stuck in the blood vessel causing excruciating pain and can cause organ damage, stroke, or at worst, death.



Earlier in 2017 a breakthrough in gene therapy cured a teenage boy who was suffering from SCD. The transplant was a great success and fifteen months after it was reported the boy is doing well and is no longer dependent on blood transfusion. He is now living a normal life.

Imagine Institute, a Paris based innovation institute aims to help patients with a genetic disease such as Sickle Cell Disease. Headed by the finest doctors and researchers, they conduct analysis and investigation, innovative patient care, and teaching. Through Bonita Lashes, we hope that we can give lash lovers everywhere the chance to be a part of that success and optimistically a part of history.

Be glamorous while spreading Sickle Cell awareness because for every purchase of Bonita Lashes' Power Collection (consisting of 4 diverse lashes that are named after the areas most frequently affected by SCD — Africa, India, the Caribbean and the Mediterranean), 20% of the proceeds are donated to the Institute, supporting their ground-breaking research into curing sickle cell disease. One of the researchers hopes that in the next 5 years the treatment can become available. We believe that this is an attainable goal, especially if it's supported.

Bonita Lashes do not only promote beauty, but we also encourage hope. For every glam bought and every bit of confidence acquired, we hope to move closer to a life free from the clutches of Sickle Cell Disease.

There are still countless sufferers who need help. Through the pain to power campaign we also focus our efforts on building a community to support and empower Sickle Cell sufferers through emotional and physical wellbeing.

Wanna get involved?
We're looking for people who have been affected directly or indirectly by Sickle Cell Disease. If you have an empowering story to share based on your experience or would love to pay a tribute to a true warrior then we want to hear from you.

We're also looking for individuals who may want to share natural methods of Sickle Cell management that could be valuable to other sufferers. Contact us using the details below and follow us on our social media platforms. Our pain drives us to stand together and make us stronger.

Bonitalashes.com will be re-launching soon. Check out our social media platforms for more details.

If you're interested please email us at: hello@bonitalashes.com
Facebook: @bonitalashesofficial
Instagram: @bonitalashesofficial & @p2pcampaign
Twitter: @bonita_lashes

PAIN TO POWER

This year, the Kings Health Partners' (Guys and St Thomas' and King's College Hospital NHS Foundation Trusts) Christmas party was held on 12th December 2017 on the 29th floor of Guy's Hospital in the Robens suite, which gave the 25 patients and 8 staff members who attended spectacular views of London. Christmas spirit arrived in the form of two musicians – Chinara and Gunther who played the violin and piano. A massive thank you to Music in Hospitals and Care for providing these amazing musicians. They played a variety of festive tracks and at one point indulged the party in some carols. The guests enjoyed jerk chicken with a vegetarian option of chickpea curry. Santa Claus arrived and spread some festive spirit. All in all, the opportunity for patients and staff to get together in a casual festive setting allowed for a great end to the year.

Calling all parents...

It's really important to give penicillin regularly if your child has sickle cell disease

A recent publication (http://adc.bmj.com/cgi/content/full/archdischild-2017-313213) has highlighted the importance of giving penicillin to your child with sickle cell disease, as well as making sure their immunisations are complete. An evaluation of 5 years of follow up of 1313 babies born with sickle cell disease found that 97% of the babies were reported to have been offered penicillin prophylaxis by the age of 6 months. However it was not known how many of these children continued to take it regularly. Penicillin, if taken on a twice daily basis, is known to be effective in preventing invasive sepsis due to pneumococcal infection, which can lead to death. Young children with sickle cell disease are more susceptible as they cannot rely on their spleens to clear the infection. When the conjugate vaccine (Prevenar), which protects against pneumococccal infection was introduced in 2006, we all hoped that this would mean that we did not need to rely on that twice daily penicillin prescription. We all forget to give doses or fill the prescription in time and your child, if unwell, may not be able to take the medicine reliably. Some parents worry incorrectly that giving penicillin can weaken their child's immune system and are reluctant to give the antibiotic regularly. However, although the vaccine has massively helped reduce infections, and deaths from pneumococcal infection are now very rare, there were sadly 3 deaths in the group that was followed up as a result of this complication. The particular type of pneumococcus that caused these deaths was not covered by Prevenar, but was fully sensitive to penicillin.

A further publication, (http://adc.bmj.com/content/early/2017/12/27/archdischild-2017-313611) reporting on the likelihood of getting invasive pneumococcal sepsis, showed that children with sickle cell disease are almost 50 times more likely to develop this compared to other children and 5 times more likely to die of the infection. Most of these cases were not covered by Prevenar 13 given as part of the universal immunisation programme, although they were covered by Pneumovax, which is given at 2 years only to those with sickle cell disease. All were sensitive to penicillin and many of the infections occurred before the age of 2 so would not have been eligible for Pneumovax .

It is really important , therefore , that all parents, nurses and doctors are aware of these findings and make sure that penicillin is prescribed and immunisation programmes followed. As far as we are aware, King's College Hospital is the only hospital in the South East that makes sure that all 2 year olds get the Pneumovax (and 5-yearly thereafter) at their outpatient visit. Children under 2 years of age are also given a 3 months supply of penicillin at each appointment to make continuity of supply easier. Can we make this happen **in all hospitals** and not rely on parents remembering to make an additional visit to the GP for the vaccination or to renew the penicillin prescription? In addition we all have to be aware that the symptoms of pneumococcal infection can develop very rapidly so accessing medical care early if your child is unwell is extremely important.

But remember, prevention is best!

By Dr Moira Dick

Red Cell News welcomes your views on this and any thoughts you have about how we can help protect our children in the best way .

Queen's birthday honours 2017

Dr Kofi Anie, Honorary Clinical Senior Lecturer, Imperial College London was awarded the MBE for services to People with Sickle Cell Disease and Thalassaemia. He started his career at Kings College Hospital!

Kofi is a Consultant Clinical Psychologist with a special interest in Behavioural Medicine and Pain Management. He started his professional career at King's College Hospital London in 1988 with an initial interest in Paediatric Haematology and had the opportunity of working with children with sickle cell disease and thalassaemia. In 1992, he was appointed as a Research Fellow and Honorary Psychologist at St George's Hospital Medical School in London where most of his work focused on people with chronic illnesses and pain, including asthma and sickle cell disease. In 1998, he accepted the challenge of developing psychological services for paediatric and adult patients with sickle cell disease and thalassaemia in Brent and Harrow Boroughs, attending Central Middlesex Hospital in London. This service includes an innovative client-centred Self-Help Cognitive Behavioural Therapy (CBT) programme. In addition, he holds the position of Honorary Senior Clinical Lecturer at Imperial College School of Medicine, London and co-ordinate Research and Development activities at the Haematology and Sickle Cell Centre at Central Middlesex Hospital.

Congratulations Kofi!

The Dora Foundation

By Miriam Kay

Living with Sickle Cell has been both a curse and a blessing at different stages of my life. I know many sufferers will not agree on the blessing aspect, but personally I believe that the unpredictability of my health has made me make the most of every opportunity and make sure I am always organised. I experienced my first crisis at the age of 6 while in Sierra Leone, my birth place. However, I wasn't properly diagnosed until the age of 12 years when I came to the U.K.

On a trip back home to Sierra Leone in 2008, I was surprise to see that many sufferers and their families were still dealing with issues like negative perceptions and discrimination due to a lack of awareness or better understanding. This saddened me, and I desperately wanted to help improve the situation, but I was still in school and could hardly even manage my own health.

After completing my degree in Business Management in 2012, I was able to find employment as a Recruitment Consultant, but after just few weeks my health took a turn for the worse and I was dismissed. This led me to being greatly depressed and I lost all hope. Thankfully, with the support of my family I was able to bounce back and started a small clothing line with my sister. Although the clothing line was a success, I still didn't feel completely fulfilled. This then prompted me to set up the charity I had always wanted to.

In 2015, ***The Dora Foundation for Sickle Cell Support & Youth Development*** was formally launched. Our core aims are to raise awareness about the condition from the perspective of those personally affected, to support not only sufferers but also their families in helping them to better understand the condition and how they can support sufferers, as well as bringing together sufferers to learn from and support each other. Sickle Cell can lead to sufferers feeling very isolated by a world that they feel doesn't understand their plight. In terms of Youth Development, we hope to guide and support youths in desperate need to reach their full potential. The foundation currently operates in both the U.K and in Sierra Leone where we hope to open the first support centre in 2018. Additionally, we have a support group for patients in the U.K and beyond. I have had the opportunity to speak at various programs and I want to expand on this and reach a bigger audience and hopefully change some of the negative stereotypes and perceptions about the condition.

At present I balance being a mum of twins, running the foundation, public speaking, writing, establishing a consultancy business and living life to the fullest despite still being affected greatly by Sickle Cell.

The Dora Foundation welcomes any individuals or organisations to work together in partnership or sponsorship. We need volunteers from all walks of life that may be interested in either gaining experience or helping others. As a new organisation, we rely on the support of others through donations to continue to achieve our aims and objectives. To find out more about us, donate or get in touch, go to:

Website : www.thedorafoundation.org
Email : info@thedorafoundation.org
Facebook : www.facebook.com/thedorafoundation
Instagram : the_dora_foundation

Research Update

New study to develop safer prenatal testing for sickle cell disease

By Mr Eugene Oteng-Ntim, Consultant Obstetrician and

Dr Kathy Mann, Principal Clinical Scientist

A project to develop a safer, non-invasive prenatal test for sickle cell disease has been launched by Guy's and St Thomas' Foundation Hospital Trust in collaboration with Viapath Analytics. The **SCIP project,** which stands for Sickle Cell non-Invasive Prenatal diagnosis, aims to replace current prenatal tests (amniocentesis and chorionic villus sampling, which have a small risk of miscarriage) with a simple test that requires only a maternal blood sample. The baby's genes in the maternal blood sample will be tested to determine if the baby would be affected or unaffected by sickle disease or have the sickle trait. Blood samples from pregnant women who are carriers or affected by sickle cell disease are needed to help develop the test.

Information about the **SCIP project** will be available at antenatal appointments at Wooden Spoon House and St Thomas' Hospital Fetal Medicine Unit; additional information can be obtained by telephone (*0207 188 6874*) or by email (*Eugene.Oteng-Ntim@gstt.nhs.uk*). The **SCIP project** will run for 18 months and is funded by the Guy's and St Thomas' Charity.

We look forward to further updating you on this study in subsequent issues.

Volunteers Wanted

We're looking for enthusiastic, energetic and dedicated volunteers to help us make a tangible difference to the lives of children and adults living with Sickle Cell Disorder.

Various Assistant Positions: Join our team of volunteers assisting in the various aspects of the South London Link Project in SE5. We need admin, activities workshop, support groups and outreach assistants.

Children's Activities Assistants: Help children and young people with Sickle Cell enjoy a variety of exciting activities in London . You do not need to be available for every session - just help when you can.

INTERESTED? PLEASE CONTACT:
VALERIE.OLDFIELD@SICKLECELLSOCIETY.ORG
(02038799535)

SICKLE CELL SOCIETY