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Welcome to this month's Samec Trust newsletter.

THE FIRST WORD

The chances for a black or an Asian person finding a bone marrow donor is 1 in 125,000 as opposed to one in three chances for the white community. Organ donation is one of the most pressing health related issues in the ethnic minority community yet the least publicised. It has been recorded that three people die everyday before they can get a transplant.

Black people are three times as likely as the general population to develop kidney failure. Illnesses such as diabetes and high blood pressure affect more people from the ethnic minority community. This means that the need for organ donors in the Asian and black community is three to four times higher. Unfortunately, while the need for donor organs for ethnic minorities is higher than the general public – donation rates are extremely low.

The NHS Organ Donor Register has 16.9m people on its register but only 1.2 per cent of these are from the Asian community and 0.4 per cent of these from Black communities.

There is a total of 7,800 patients waiting for a transplant of whom 1,521 are South Asians and 779 are Black.

The increasing need for organ donors from ethnic minority communities indicates an urgency to build a culture of donating in the ethnic minority community.

The findings on organ donations particularly shocked us and we decided that this issue should briefly highlight the need for organ and blood donors. We would like to thank all the charities that have contributed to this issue and that help raise awareness of organ donations. We also have articles on Sickle Cell, Fanconi Anaemia and Thalassaemia – all blood related health issues that require donors.

Charities that have contributed to this month's newsletter include; ACLT, The Sickle Cell Society, Fanconi hope and U.K Thalassaemia Society.

We do hope to do another issue dedicated entirely to organ donation in the near future as this is a very pressing issue in the ethnic minority community. In the meanwhile we hope that this issue will contribute to the awareness of organ and blood donations. Also remember to send in your newsletter articles for our next issue in October.

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Promoting
bone marrow &
blood donation

SUPER HEROES WANTED !!!

Each day lives are lost due to the severe shortage of lifesaving blood, bone marrow and organ donors from Black, Asian and Mixed-Race communities.

So What?

'I don't trust them.' 'What are they going to do with my DNA?' 'I can't be bothered.' 'I don't know anything about that.' 'I couldn't make a difference.' 'I haven't got time.'

How many times have you heard these comments from those who avoid helping others in need of a lifesaving hero?

In Black, Asian and Mixed race communities across the UK, leukaemia has claimed the lives of many. In Birmingham, time ran out for Kevin Phelps (39), Ex- British Karate Champion and computer engineer of African Caribbean descent from Aston passed away whilst he waited for his lifesaver. From London, seven year olds school children Imogin Appiah of Ghanaian heritage and Dean Sheikh (Pakistani heritage), as well as University student, Tracey Tanyanyiwa (22, Zimbabwean heritage), all had very untimely deaths.

A few valiant strangers responded to their bone marrow donor appeals, but many still fail to realise they can be a hero and make a difference.

Apathy is costing lives, and will continue to do so across all ages and backgrounds.

Against the odds

Every year, over 24,000 people in the UK are diagnosed with leukaemia or a blood related cancer. If chemotherapy or radiotherapy doesn't work, they need lifesaving bone marrow and blood donations. About 30 % of patients receive a transplant from a family member. The remaining 70% have a diminished chance of finding an unrelated donor from somewhere in the world. However, these odds are much worse if you're Black.

Why? There are 24 times more white donors, that's a 1 in 100,000 chance

...or less for Mixed race people.

Alas, organ donation is low. Around 16.9 million people are registered as organ donors, but only 1.5% are Asian and a woeful 0.4% are Black.

Black people are 3 to 4 times more likely to need a donor kidney or organs than Whites.

Only 4% of UK population give blood. Shockingly, only 1.2% of these donors are Asian and 0.45% are Black. Yet we rely on blood for many things e.g. child birth, transfusions for Sickle Cell patients and life threatening conditions.

So why are we fooling ourselves?

Awareness is rising, but few have informed discussion about these issues outside the family or trusted community networks. Misinformation and lack of knowledge persist despite the availability of public health education messages.

Is it just about individuals taking ownership or do everyday experiences elsewhere inform decision making?

Reasons for reluctance

Some people hold strong yet misplaced fears that the DNA database used to record bone marrow tissue-types is somehow connected to the Police National DNA Database, which retains the details of a disproportionate number of innocent black people. This situation deters people from registering as donors. Some fear organs will be removed without doctors really attempting to save their lives.

Some believe donation is against their religion, although all church leaders highlight that these concerns are unfounded.

Some dislike the idea of blood storage and suspect it will be used for unsavoury genetic research.

So what...can I do about it?

The ACLT charity is dedicated to promoting donation in Black, Asian and Mixed-Race communities, and has helped boost the number of bone marrow donors from 585 to over 32,000.

All we ask is for people to stop, listen and make an informed choice. Many understand the need for racially matched donors to enhance the success of transplantation when this is clearly explained.

If we all fail to respond to this challenge with positive and meaningful action right now, many more people will die unnecessarily.

Let's Unite to Fight Leukaemia

For more information: www.aact.org | info@aact.org | 020 8240 4480





*Information, Counselling
and Caring for those with
Sickle Cell Disorders
and their families*

*Charity Reg: 104 6631
Company Reg: 284 0865
www.sicklecellsociety.org*

The Sickle Cell Society was first set up as a registered charity in 1979. It was formed by a group of patients, parents and health professionals who were all concerned about the lack of understanding and inadequacy of treatment with sickle cell disorders.

The Society's mission is to enable and assist individuals with a sickle cell disorder to realise their full economic and social potential. This is achieved by improving opportunities for sickle cell affected individuals and families by raising public awareness through education, advocacy together with the provision of direct welfare services, assisting in research and lobbying.

Sickle Cell Disorder

There are 240,000 people in the UK who are carriers of the sickle cell gene and about 13,500 people have a sickle cell disorder - making it the most common inherited blood disorder in the country (NHS Sickle Cell and Thalassaemia Screening Programme, London: NHS 2006).

Sickle Cell mainly affects people of African, Caribbean, Indian, Mediterranean and Middle Eastern descent. Approximately 1 in 10 people of African- Caribbean origin, 1 in 4 West Africans, 1 in 20-50 Asians, 1 in 100 Northern Greeks and 1 in 1000 Caucasians are believed to carry the gene for sickle cell disorder. Screening identifies approximately 350 babies born each year with sickle cell disorder (NHS Sickle Cell and Thalassaemia Screening Programme 2009).

The risk of stroke in children with sickle cell disorder is greatest between the ages of 2 and 16. About 10% of all children with sickle cell disorder will have a stroke by the time they are 20 years old.

Sickle cell is a disorder of the haemoglobin in the red blood cells. There are over 300 different types of haemoglobin. Haemoglobin is the substance in red blood cells that is responsible for the colour of the cell and for carrying oxygen around the body. People with sickle cell disorder are born with the condition. It is not contagious and can only be inherited from both parents.

The main symptoms of sickle cell disorder are anaemia and severe pain. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then, stick together, causing blockages in the small blood vessels. These painful episodes are referred to as sickle cell crisis. They can last for a few hours, a couple of days or up to a couple of weeks.

Sickle cell sufferers are often admitted to hospital when they have a crisis. They are given strong painkillers such as pethadine and morphine to control the pain.

Understanding eating disorders

Over time sickle cell sufferers can experience damage to internal organs such as the liver, kidney, lungs, heart and spleen. Due to organ damage life expectancy of people with sickle cell disorders is mid-40s, although with modern treatments patients can survive into their 50s. Sadly death can also result from complications of the disorder.

Children with sickle cell disorder are more likely to have strokes than those without the disease. The risk of stroke is highest in the most commonly detected type of sickle cell disease – sickle cell anaemia (HbSS). The risk of stroke in children with sickle cell disorder is greatest between the ages of 2 and 16. About 10% of all children with sickle cell disorder will have a stroke by the time they are 20 years old. Stroke recurrence is also a major concern for children and their families. Stroke recurs in over 60% of children with sickle cell disorder.

How you can help

The Society welcomes you to help us continue to provide vital services for individuals and families affected by sickle cell disorder. The ways in which you can help The Society are as follows:

- Become a member – receive regular communication on our activities and invitation to future events
- Donate one off by post – make cheque payable to Sickle Cell Society and post it to our free post address:

SICKLE CELL SOCIETY,
FREEPOST NW4554,
54 STATION ROAD,
LONDON,
NW10 4UA

- Donate online one off or monthly – visit www.sicklecellsociety.org and click on the donate now button or visit www.justgiving.com/sicklecellsociety/Donate
- Fundraise - organising your own fundraising event or take part in a sponsored event
- Corporate Sponsorship - sponsorship of a specific event or product i.e. Annual Children's Holiday, printing and design costs of the quarterly newsletter, educational and information leaflets
- Corporate Giving - donating money or goods/services in kind, set up a payroll giving scheme in your workplace
- Become a volunteer – various volunteering roles are available
- Raise awareness – handing out leaflets and putting up posters in your local shops and businesses.

Please contact the Fundraising Manager, **Ms Kalpna Patel** on 020 8963 7793 or email info@sicklecellsociety.org for further information.

FANCONI ANAEMIA

What is Fanconi Anaemia?

Fanconi Anaemia (FA) is a very rare inherited life-threatening condition in which many of the patients are diagnosed with Aplastic Anaemia, where not only are the red blood cell counts affected through bone marrow failure, but also the white blood and platelets counts too.

Fanconi Anaemia is a very complex condition. Many clinicians, outside the paediatric haematology community are unaware of the condition because of its rarity and complexity. The symptoms are very varied, and may include:-

- Thumb and arm abnormalities
- Kidney abnormalities
- Aplastic anaemia
- Bone marrow failure
- Myeloid leukemia
- Head and neck cancer
- Anogenital cancer
- Brain medulloblastoma
- Café au lait spots
- Short stature

The majority of patients are diagnosed before the age of 10. When the patients are diagnosed will depend on the presentation of the symptoms; for the severest form of FA this can be soon after birth. The diagnosis of FA is made through a blood test.

CASE STUDY By Jeannie (a parent of a child with FA)

My daughter is nine years old and needs a bone marrow transplant, thus I went to meet a kind and thorough transplant surgeon. He explained the procedure and the risks involved. I was told of the importance of a good bone marrow match. My daughter is lucky because she is of a common tissue type. However, I knew one of her friends (who is mixed race) had been waiting for years for a matched donor, but is unable to find one. The surgeon explained that the chances of finding a matched donor if a person is white is 1 in 3, but if the person is from a Black, Asian or Mixed race background the chances of finding a donor is only 1 in 125,000! This is a very shocking and upsetting disparity.

“I was told of the importance of a good bone marrow match. My daughter is lucky because she is of a common tissue type. However, I knew one of her friends (who is mixed race) had been waiting for years for a matched donor, but is unable to find one.”

Fanconi Hope

Fanconi Hope is a national charitable trust recently set up by parents of FA-affected children and clinicians with an interest in FA to support affected families by providing information, signposting relevant services and promoting research. They have sponsored the writing of the first UK

www.samectrust.org.uk

Standards of Care Guidelines, held several conferences for patients and clinicians and are now sponsoring research. Further information can be found at (www.fanconihope.org).

Bone Marrow Donors Urgently Needed - Can You Help?

The importance of bone marrow donors to those affected by Fanconi Anaemia can not be over stressed. Fanconi Hope recognises the amazing work of four particular charities.

Anthony Nolan www.anthonynolan.org Can register people between the ages of 18 and 40. They hold registration events throughout the country. Some paperwork and a simple spit test is all that is required. If you are unable to attend they can even send a registration pack through the post.

The National Blood Service www.blood.co.uk Can register people between the ages of 18 and 49. To register you need to first become a blood donor. During a routine blood giving session an extra sample is given for you to register.

“the chances of finding a matched donor if a person is white is 1 in 3, but if the person is from a Black, Asian or Mixed race background the chances of finding a donor is only 1 in 125,000!”

Both these organisations would like to see the diversity of donors increase. However, recognising that the chance of finding bone marrow donors in black and ethnic minority communities was a problem two further charities were set up.

The African-Caribbean Leukaemia Trust (www.aclt.org) is a charity established in June 1996 which helps to educate and raise awareness of leukaemia and other related cancers. It highlights awareness of the shortage of donors from the black and ethnic minority communities, it promotes the donating of blood and bone marrow and raises funds to support these aims by holding registration drives.

Desi Donors (www.desidonors.org) were launched in July 2009 to promote and raise awareness of the need for bone marrow, blood and organ donors, in Asian and Ethnic communities.

For further information about coeliac disease and the gluten-free diet contact Coeliac UK www.coeliac.org.uk

Helpline 0845 305 2060 – open Monday, Tuesday, Thursday, Friday 10am to 4pm and Wednesday 11am to 4pm.

Thalassaemia

could it affect your family?

When most people hear the word “thalassaemia” their reaction is “thala-what?” And yet thousands of us could be carrying thalassaemia in our genes without realising it.

What is thalassaemia?

Thalassaemia is an inherited condition of the blood. People who have thalassaemia cannot make red blood cells properly; which means that they need to go to hospital to have a blood transfusion every 3-4 weeks, from babyhood onwards throughout their lives. They also need daily medication and constant medical care and monitoring to stay well. Having to stay on a constant, lifelong regime of medication and blood transfusions is very challenging and takes up a great deal of time. Parents of children who have thalassaemia give up lot of time taking them to hospital and helping with their treatment and older children who have thalassaemia can miss a lot of school. Similarly, adults who have the condition need to fit their treatment in around the demands of daily living. Believe it or not however, despite having this potentially

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life-threatening condition, most people in the UK who have thalassaemia lead very full lives. They study, work, marry and have families just as other people do. There are approximately 1,000 people in the UK who have thalassaemia. (N.B. This is not the case in the developing world, where thousands of children with thalassaemia die every year because they do not have access to medical care.)

How does a person get thalassaemia?

The answer is from their parents. A child inherits half of its genetic makeup from each parent. If a man and a woman are both carriers of thalassaemia, every time they have a child together there is a 25% chance that the baby will be born with thalassaemia. (This is known as a “couple at risk”.) If only one parent is a carrier however, there is no risk that their children will have thalassaemia, although they may be carriers. Carriers are completely healthy and most have no idea at all that they carry thalassaemia. It is therefore possible for thalassaemia to be passed down in a family for generations without anyone realising it.

Could I be a carrier?

Anyone can be a carrier of thalassaemia, but the people who are most at risk are people from Pakistan, Bangladesh, India, the Middle East, Southern Europe and South East Asia. The UK Thalassaemia Society

strongly recommends that anyone whose ancestry comes from these parts of the world should be tested for thalassaemia before they start a family. All it takes is a simple, quick blood test which you can request at any time from your GP.

What if we are a couple at risk?

At the moment the only people who are routinely tested are pregnant women. If the woman is found to be a thalassaemia carrier, the baby's father is asked to come in for a test. If he is negative there is no

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problem, but if he is also a carrier there is a 25% chance that the baby will have thalassaemia. At this point the couple are offered counselling and they can decide whether or not to have a test which will show if the baby has thalassaemia or not. If they have the test and the baby is affected, the couple will be offered more counselling and they can at that stage decide whether they wish to proceed with the pregnancy. These are of course very difficult, personal decisions and it is the role of the medical staff (and we at the UK Thalassaemia Society) to support the parents in the choices they make. It is of course very difficult and stressful for a couple to face these issues when they already have a baby on the way. It is far preferable to be tested before starting a family, so the couple can think about their options and make informed choices without the added pressure of a pregnancy.

How can I get a test?

You can request a test at any time from your GP. If you have any difficulty in getting a test however, please call the UK Thalassaemia Society on 020 8882 0011 and we will advise you on where to go. Get tested – it's the only way to be sure.

Where can I find more information about thalassaemia?

You can visit the UK Thalassaemia Society's website www.ukts.org email us on office@ukts.org or you can call our office on 020 8882 0011 for a confidential chat.

Other useful websites

NHS Sickle Cell and Thalassaemia Screening Programme <http://sct.screening.nhs.uk>
Thalassaemia International Federation www.thalassaemia.org.cy

PTLLS

Preparing to Teach in the Lifelong Sector

PTLLS is the new mandatory qualification requirement for people who wish to teach in the post 16 education sector.

Every teacher, facilitator or assessor will need this qualification by 2011.

Our PTLLS is accredited by The Chartered Institute of Environmental Health.

Who is the course for:

The course is suitable for anyone who is a trainer in industry, business or public services.

The course is suitable for anyone teaching or wishing to teach in colleges and other adult teaching environments.

What you learn:

- Understand own role, responsibilities and boundaries of role in relation to teaching
- Understand appropriate teaching and learning approaches in the specialist area
- Demonstrate session planning skills
- Understand how to deliver inclusive sessions which motivate learners
- Understand the use of different assessment methods and the need for record keeping



Course duration:

Five day Course
Three day fast track course

Course costs:

Five day Course - £430.00
Three day fast track course - £390.00

We can also offer on site training at your place of work

Venue:

Stadium Community College, STRC House, 87A Wembley Hill Road, Wembley, HA9 8BU

To find out more about how the course can be delivered to suit your needs please contact:
Michael on **0300 343 0020** or email: **info@strcmanagement.com**
or look us up on the website www.ptllslondon.co.uk



HEALTH EVENTS

taking place in August 2010

Asian bone marrow and blood donors of Black, Mixed race and Asian urgently needed! **Wednesday 22nd September, 2010. Time 10 a.m. to 4 p.m.**

Be the one to register and be a lifesaving hero at the: ACLT Recruitment Drive at Westminster City Hall, 3rd Floor, 64 Victoria Street, London, SW1E 6QP. Please go to www.aclt.org for details.

ACLT Daniel De-Gale Blood Donation Week, 4 – 7 October 2010

The event is to take place in Croydon, Leicester, Leeds, Bristol, Birmingham, London West End, London Ilford in partnership with the National Blood Service. Please go to www.aclt.org for details.

National Eczema Week 18 September 2010 - 24 September 2010

This week exists to raise awareness about eczema. Up to 1 in 3 of our children and 1 in 12 adults have eczema. The society provides information and support, funds research into treatments and possible cures and works to dispel myths so those who have eczema need not feel stigmatised, guilty or isolated. Website: http://www.eczema.org/contact_us.html

Tel: 020 7281 3553 General Information info@eczema.org

Lymphatic Cancer Awareness Week, September 2010 - 19 September 2010

The Lymphoma Association provides emotional support and information to anyone with lymphatic cancer and to their families, carers and friends. 13

Website: <http://www.lymphomas.org.uk>

Migraine Awareness Week 05 September 2010 - 11 September 2010

Raising awareness of migraine and offering advice to the one in eight people affected. Visit the website for more details of activities.

Website: <http://www.migraine.org.uk>

about SAMEC



SAMEC TRUST

To be able to offer a service so wide

Help with health and housing provide

Enable communities to dwell side by side.

So it should be, Young and old, Refugee

All need to live in harmony

Minority groups need not live apart

Enclosed - Ghettoed, their culture and art

Could be shared, to communicate and education impart.

Together in partnership let us proceed

Rely on the trust to access all you need

Ultimately attaining esteem and dignity

Strength in diversity creates stronger unity

Thanks for giving SAMEC this opportunity.

Cecile Nobriega

We welcome this month's contributors from such an array of health areas. Since the formation of SAMEC Trust in 1996 disproportionate ill health amongst people from minority communities still remains. Hence, the role of getting health information out is vital, but the crucial questions still remain – are they appropriate and are they accessible?

Understanding what is accessible and appropriate can make or break a communication programme – we specialize in language support, consultations and culturally appropriate connect programmes. Our newsletter will reach our network of community organizations working with minority ethnic communities.

We also are on hand to refer people from minority ethnic communities to specialist health agencies and we are eager to work on partnership projects with specialist Health Charities.~

We believe in partnership and commend this newsletter to our total commitment to delivering health information to diverse ethnic communities to preserve and promote good health. As our work is dependent on the support of individual donors and community support, donations is always welcomeevery penny is part of the bigger contribution.