AN INDEPENDENT SUPPLEMENT DISTRIBUTED BY THE GUARDIAN ON BEHALF OF MEDIAPLANET WHO TAKE SOLE RESPONSIBILITY FOR ITS CONTENTS

Ethnic minorities
Why there is a need for more donations

Blood cancers
Know the signs, push for a diagnosis

Haemophilia
Find out about the rare bleeding disorder

MEDIA PLANET

YOUR BLOOD

4 STEPS

FIGHTING BLOOD CONDITIONS TOGETHER

Teamwork: When Marcus Main (second from left) was diagnosed with Hodgkin lymphoma, his younger brother Bernie (far left) stepped up to help him fight the disease

PHOTO: PRIVATE

CHALLENGES

Alastair Kent, Director of Genetic Alliance UK, talks about why a better understanding of blood conditions is needed in order to ensure early diagnosis and effective treatment.

Greater awareness and understanding is key

Your blood is amazing. It performs an incredible amount of unsung tasks in your body. It delivers oxygen from your heart to the furthest reaches of your body, supports the antibodies that form our immune system, delivers nutrients from our food around the body, clots our wounds and cleans them too. It is intrinsic to our being but when something goes wrong with our blood it is often a lack of awareness of blood disorders that prevents patients from accessing the correct care.

Alastair Kent
Director, Genetic Alliance UK

Lack of awareness

Due to the multitude of functions our blood performs it can go awry in many different ways. Some of these are quite well known, such as high cholesterol whereas others such as haemophilia, sickle cell and many blood cancers, are rare and often a lack of awareness of these conditions causes delays in diagnosis. More than 5,300 people are diagnosed with rare forms of blood cancers and related conditions in the UK every year.

Problems with diagnosis

According to a recent survey by Rare Disease UK, one of the biggest problems facing patients with a rare blood disorder is diagnosis. Fourty-six per cent of patients with rare conditions had to wait at least a year for a correct diagnosis and ten per cent of patients had to wait up to ten years. Delays in diagnosis cause a number of problems for health services, patients and their families. The patient may be misdiagnosed and have unnecessary treatment which costs the health services and is potentially harmful. The delay also causes distress for the patient and can result in difficulty accessing support.

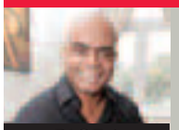
Greater understanding needed

Lack of awareness and delays in diagnosis can be a particular problem for inherited blood conditions. Undetected, these conditions may place entire families at risk. They can be passed between generations and sometimes wreak havoc in entire communities.

Increasing awareness is the first step in combating these conditions. Greater awareness leads to greater understanding, prevention and more effective treatments for these life-limiting conditions.

For more information visit www.geneticalliance.org.uk

WE RECOMMEND



Orin Lewis
Co-founder and chief executive, ACLT

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'Donation is surrounded by myths, mistrust and taboos. People are dying because others of their own background are not coming forward'

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INSPIRATION

STEP 1 BECOME A DONOR

Question: How can black and ethnic minority groups work together in order to avert a major health crisis?
Answer: By raising awareness about donating blood, bone marrow and organs.

Inspiring others to make a difference and save lives

■ Over 28,500 people a year are diagnosed with a blood cancer and many rely on regular blood transfusions which must match their own blood group.

■ Blood groups vary by ethnicity: 20 per cent of the black and Caribbean population are blood group B, but only 9 per cent of western Europeans are. Meanwhile, less than one per cent of UK blood donors are black or mixed race. Therefore, people who are black, mixed race or from an ethnic minority have a far smaller chance of a match than those who are white.

■ Some blood disorders require bone marrow transplants and 70 per cent of patients need bone marrow from strangers. While the odds of a match for a white patient are, at best, close to one in five, for black or ethnic minority patients they are well over one in 100,000.

A need for greater awareness

Black and ethnic minority donors are reluctant to come forward. "It's a crisis partly caused by lack of awareness," says Orin Lewis, co-founder and chief executive of the ACLT, the charity which encourages black and ethnic minority people to donate blood, organs and bone marrow.

The lack of awareness is surprising because the blood disorders sickle cell disease and thalassaemia are commonly found in people from the black and ethnic minorities, and both require blood transfusions.

Orin Lewis, OBE
Co-founder and chief executive, ACLT

"Donation is surrounded by myths, mistrust and taboos. People are dying because others of their own background are not coming forward," says Lewis, who experienced the donor shortage when his son Daniel De-Gale, a leukaemia sufferer, needed a bone marrow transplant.

Daniel finally found a matched donor, but his search inspired the formation of ACLT, which continues to campaign despite Daniel's later death from unrelated complications.

A call to action

ACLT's campaign to publicise the facts and show how easy it is to register as a donor has helped increase the number of black and ethnic minority blood and organ donors. It has also upped the number of black and ethnic minority people on the bone marrow registers from 585 in 1996 to over 40,000 today. It now aims for 60,000.

ACLT-recruited bone marrow donors have already saved 40 lives. Lewis says: "We want black, mixed race and ethnic minority groups to register as donors to mark Daniel De-Gale Blood Donation Month in October — coincidentally Black History Month and also the month in which Daniel died."

Call 0300 123 23 23 and quote 'R20' to book an appointment.

Read more on the web:
www.aclt.org
www.anthonynolan.org

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CHANGING LIVES
Orin Lewis was awarded an OBE for his services to healthcare, pictured (top right) with the Queen (middle right) with his wife and late step-son Daniel De-Gale who inspired him to set up the ACLT charity during his battle with Leukaemia
PHOTO: PRIVATE

Sickle cell disease and thalassaemia

Dr David Rees, clinical senior lecturer and blood disorders specialist at King's College, London, explains: "Sickle cell diseases and thalassaemia are genetic blood disorders that if untreated can lead to early death."

In sickle cell disease, which occurs mainly among people of sub-Saharan African descent, the red blood cells are sickle-shaped, stiff and sticky. Patients suffer severe pain 'crises', and, if untreated, damage to major organs.

In thalassaemia, the bone marrow fails to produce haemoglobin, leading to anaemia. It affects people originating from the Mediterranean or South Asia (mainly India, Pakistan or Bangladesh).

Both diseases are commonly treated with repeated blood transfusions. In the past this led to people dying of iron overload, but new drugs can prevent this.

"A close match of blood groups is important, and more black and ethnic minority blood donors would help," says Dr Rees.

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NEWS

STEP 2 KNOW YOUR OPTIONS

Question: Haemophilia is manageable but how can treatments be reduced?
Answer: Prophylaxis can reduce treatment frequency, even for people with antibodies to clotting factors.

MODERN TREATMENTS OFFER PATIENTS A NORMAL LIFE

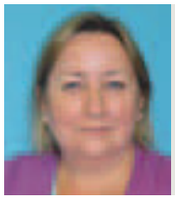
Haemophilia and related blood disorders are now managed well in the UK but significant improvements are underway.

Prophylaxis, in the form of regular injections of clotting factors, protects against potentially lethal brain bleeds and painful bleeding into joints, while rates for viral infections have become negligible.

"Many patients are now living until their 60s and even 80s and with luck and good treatment, children with haemophilia being born now could live to be 100," says Kate Khair, board member of the Haemophilia Society and haemophilia nurse at Great Ormond Street Hospital.

Prevention and treatment

Most children and some adults are given prophylactic treatment to prevent rather than treat bleeds. Normally injections are administered, or self-administered, three times a week, but some sport-lovers take a daily, lower dose to keep clotting factors closer to normal levels over a longer period. "The good news is that new longer-acting products, currently in clinical trials, will only have to be taken every five to ten days. These will have a big impact on future haemophilia care as it will mean fewer injections," says Khair.



Kate Khair
Haemophilia Society board member and haemophilia nurse, Great Ormond Street Hospital

For haemophilia patients who develop the antibody (inhibitor) that neutralises the activity of clotting factors, first line treatment is to rid the body of the inhibitor with large, frequent doses of drugs. Failing that, immune suppressive drugs are used to stop the manufacture of antibodies.

Ultimately, by-passing factors can be given which act without clotting factor VIII. "Increasingly these are being used for preventive treatment so patients who develop antibodies can and do have fewer bleeds than in the past," says Khair.

New possibilities

Advances in genetic science also bring the possibility of using gene therapy for the treatment of bleeding disorders. "At present gene therapy offers hope to people with Haemophilia B, but this could extend to people with all types of haemophilia in the future," says Khair.

Meanwhile patients can help themselves by treating themselves before risks occur, such as before school or sport, keeping abreast of the latest news and attending clinics regularly, so that any overlooked problems can be picked up.

Read more on the web:
www.haemophilia.org.uk

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FACTS

- **Around 22,850 people** in the UK have haemophilia and other bleeding disorders such as von Willebrand's Disease.
- **Haemophilia affects mainly** males, but the more common von Willebrand's affects both sexes equally. Many people don't know they have it.
- **A small cut** does not mean death; it just takes longer to stop bleeding.
- **There is no cure,** but modern treatments mean patients lead relatively normal lives.

INSPIRATION

'Accurate diagnosis is vital'

■ **Question:** Lymphoma is the fifth most common UK cancer, so why is it hard to spot?
■ **Answer:** With many different types and symptoms mimicking common infections, recognition is difficult.

"Over 75,000 people in the UK live with lymphoma but public awareness is low," says Sally Penrose, chief executive of the Lymphoma Association, the charity providing information and support for people affected by lymphatic cancer.

Know the symptoms

In lymphoma, abnormal white blood cells form painless lumps, often in lymph nodes in the neck, groin and armpits. Other symptoms include excessive sweating, fevers, weight loss, tiredness, cough, breathlessness, itching and gastric or flu-like symptoms, which may be mistaken for common ailments and lead to delays in diagnosis.

"The combination and persistence of any of these symptoms should raise concern," says Penrose.

Accurate diagnosis

There are two main types of lymphoma. Hodgkin and Non-Hodgkin, which when incidences are combined, occur most commonly in the 15-35 age-group. Over 1,800 cases of Hodgkin lymphoma were diagnosed in the UK in 2009 (the most recent figures). The majority of patients are cured with eight out of ten surviving at least five years.

OFFERING SUPPORT: Sally Penrose with Bill Ramsbottom, whose son died aged 20 of undiagnosed lymphoma in 2011

Non-Hodgkin lymphoma covers all other types of lymphoma, of which there are more than 50. There were over 12,300 new cases in 2009, mostly in the over-50s. Five year survival rates are six out of ten.

"Accurate diagnosis is vital. Each lymphoma needs different treatment," says Penrose. For instance high-grade non-Hodgkin lymphoma needs immediate treatment, while some low-grade lymphoma patients can be monitored and remain well without treatment for some time.

Treatment options

Lymphoma treatments include chemotherapy, radiotherapy and antibody treatment, often in combination.

Stem cell transplants are also increasingly being used successfully. New treatments are being developed all the time and scientific advances mean in future treatments may be tailored to individual patients. "The research looks very promising and is great cause for hope," says Penrose.

This week is Lymphatic Cancer Awareness Week. Find out more at www.lymphomas.org.uk

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HOW WE MADE IT

■ **How Hodgkin lymphoma threatened my life, and how my 'weedy' 16-year-old brother bravely stepped up to save me.**

Marcus Main was diagnosed with Hodgkin lymphoma in March 2007, aged 24. Shortly after having six months of chemotherapy he suffered a relapse and was prepared for a stem cell transplant.

"All my siblings over 16 — seven of them — were screened. Only two were suitable, which shows how hard it is to find a match and why stem cell donors are needed.

"The best match was my brother Bernie, tested the day after he turned 16 — perfect timing!" says Marcus. "My then-weedy little brother bravely gave himself the required injections in preparation

STEP 3 GET DIAGNOSED

TEAMWORK
Bernie (far left) and Marcus Main (second from left) after a fundraising rugby match they organised for the Lymphoma Association
PHOTO: PRIVATE

for donating his stem cells to me. After three more rounds of chemotherapy I entered the hospital transplant unit.

"My blood and bone marrow were blasted by nine days of intensive chemotherapy before Bernie's stem cells were extracted and pumped straight into me." A tense period followed, during which Marcus' body survived on donor blood and platelets, while he waited to see if his body would accept the transplant.

Good news

"On day 23 my blood counts, which had been zero for a couple of days, showed a tiny rise. This was great news and we were quite emotional as it meant Bernie's stem cells had made their way into my bone marrow and were starting to develop into the different cells needed for my new blood and immune system," says Marcus.

"After a month I came home and three months later a cancer scan was clear," says Marcus. Four years on Marcus is working as a scientist and expecting his first child. Meanwhile 'weedy' brother Bernie is a Royal Marines Commando.

You could be a match for someone too. Find out how you can register as a donor at: www.anthonynolan.org

Myeloma: spot the early signs

If you know little about myeloma, you are not alone. Myeloma is a cancer arising from the plasma cells in bone marrow. The second most common type of blood cancer, it is currently incurable. About 4,000 new UK cases are diagnosed annually, but most people have never heard of it.

"In a recent survey we conducted, only three per cent of people could identify myeloma as a cancer," says Eric Low, chief executive of the charity Myeloma UK.

Never having heard of myeloma makes a diagnosis more frightening, says Low. "Any cancer diagnosis is devastating, but when it's something you have never heard of, it's often even more traumatic."

Problems with diagnosis

Many patients are not diagnosed early enough. Most are over 60, and the symptoms are easily confused with more common ailments.

"Symptoms like lower back pain, fatigue, and colds are regarded as normal by most over 60s," says Low. GPs also find it hard to spot. Typically diagnosis takes three to four GP visits over six to 12 months. Many patients are only diagnosed after bone fractures or kidney failure (both caused by myeloma).

"Delayed diagnosis means new patients often feel angry and frustrated as well as fearful," says Low. Early diagnosis can mean longer survival and better quality of life so Myeloma UK is providing GPs with a tool to help rule out routine conditions. Hospital doctors are being asked to provide more information to myeloma patients' GPs, to improve patient care.

Hope for the future

Three new drug treatments over the last decade have increased five year survival rates. Low says: "I expect at least another six treatments to become available in the next five to ten years. Hopefully one will be the silver bullet."

Meanwhile he advises: "If you have unresolved lower back pain or are inexplicably unwell, badger your GP for tests, even if it takes repeated visits."

Read more on the web:
www.myeloma.org.uk

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NEWS

STEP 4 DO YOUR RESEARCH

CML SUPPORT
Sandy Craine with CML patient advocates in Hong Kong. The CML Support Group is an online patient support group for chronic myeloid leukaemia patients, their families and carers
PHOTO: CML SUPPORT

Research into my cancer saved my life

Question: How can I help manage my own blood cancer?
Answer: Researching your condition can improve your care — and may save your life.

"I was diagnosed with chronic myeloid leukaemia in 1999 and told that without a stem cell transplant I had 12 months to live. Initially I collapsed under the blankets for five days, terrified," says Sandy Craine, founder of CML Support.

"But then I decided to research my condition, and it saved my life."

Craine joined an internet cancer forum and discovered that doctors in the USA were trialling a drug called Imatinib, which appeared very effective. Her doctor supported her decision to travel to the USA to take part in the trial.

The treatment worked. Craine's disease, which was in its second, accelerated phase, was set back to its less dangerous chronic phase. She returned to the UK and set up CML Support, an online information and support service.

"My experience shows the value of information in helping patients make treatment choices," says Craine.

Sandy Craine
Founder of CML Support

Research shows that people living with chronic illnesses often know best what is needed to manage their conditions. "Informed patients and carers are more able to make a tangible impact on their disease and to access appropriate therapy," says Craine.

Revolutionary treatment

The research that produced Imatinib has led to more and better drugs with the result that now 93 per cent of people diagnosed with CML in its chronic (initial) phase, take one tablet daily and can expect a normal lifespan.

"These drugs have been a revolution in the treatment of CML, provided it is spotted it in its early stages," says Craine.

That can be difficult. CML can be asymptomatic in its chronic phase, or people may just feel tired and look pale, so they often do not visit their GP at first. The problem is commonly picked up by opticians (it can affect the eyes) and in routine blood tests.

Push for a diagnosis

If you think you may have a problem, pester your GP for tests, repeatedly if necessary.

CML is rare with only 600 people in the UK being diagnosed annually. "That's another reason to research the condition," says Craine. "Many GPs will not have seen cases so you can help them provide the best care by educating yourself about your condition, the treatment options and their effects, so you can make informed choices."

Read more on the web:
www.cmlsupport.org.uk

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CML: NEWS

What causes it?

Chronic myeloid leukaemia (CML) results from an acquired genetic abnormality in bone marrow stem cells, which carry the Philadelphia chromosome. This causes an increase in abnormal white blood cells.

Phases

Conventionally the disease used to follow three phases. In the chronic phase, lasting four to six years, the disease progressed slowly, and symptoms were mild.

In second phase, designated the accelerated phase, lasting six to 12 months, leukaemia blast cells increased and symptoms such as loss of appetite, tiredness and bruising and bleeding appeared.

In the third, 'blastic' phase, lasting three to six months, much of the bone marrow was replaced by abnormal leukaemia cells. The blastic phase usually ended in death.

Improved prognosis

Twenty years ago, total life expectancy for CML patients without a bone marrow transplant was five to six years.

"Since the advent of tyrosine kinase inhibitors (initially the drug Imatinib) in the late 1990s, the picture has dramatically improved, and the classical progression to blastic phase is now rarely seen," says Professor John Goldman of the department of medicine at Imperial College London.

More powerful agents that act in a similar way to Imatinib have now been developed.

"Most patients taking these drugs now have a life expectancy in decades. Some have even stopped taking them, so far with no apparent relapse.

Hope for a cure

"The chances that drugs now being developed could turn a good response into a complete cure for CML looks increasingly realistic," says Professor Goldman.

When science and passion connect, innovation happens.

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Novartis is committed to providing patients with access to its therapies. Providing access to cancer treatments is complex, demanding collaboration among industry, government, health services, insurers, physicians and patient groups. Novartis works with these groups around the world to find innovative means to enhance access.

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