

YOUR BLOOD

**A
SPECIAL
ISSUE
ON BLOOD
CONDITIONS**



KNOW THE RISKS

Living life: Being proactive and understanding your body can help the diagnosis and treatment of many blood conditions

Getting checked
Why you should have your blood pressure measured



Raising awareness
Recognising rare blood conditions can save lives



PHOTO: PROVIDED BY THE HAEMOPHILIA SOCIETY

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WITH A BLOOD CANCER**

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CHALLENGES

We rarely think about our blood, and yet without its ability to perform its functions, every aspect of our health would be doomed. Better understanding enables prevention and greater awareness - many blood disorders are rare but if detected earlier can be much more effectively treated

Blood: taken for granted?

Healthy blood is something we take for granted, yet it is key to our well-being. It is our internal transport system: delivering oxygen, energy and other nutrients to all of the body and eliminating waste. It also helps protect us from disease and to heal any wounds.

For many of us we rarely have to stop and give any consideration to our blood. But it is more than just the oil in our body's engine and it is when things go wrong that we need to act, and there are many ways in which this vital fluid can go awry. Some conditions, such as high cholesterol, affect lots of us and are fairly well understood, but there are many more which, in themselves, may only affect a few but when taken together represent a huge number of affected individuals. Most of these are poorly understood by the public or by doctors in the UK.

Some blood conditions are inherited, so whole families may be at risk.

Although some are relatively common, there are many which are rare. Patients with these rare conditions may find it difficult to access services and support from the NHS. According to a recent survey by Rare Disease UK (www.rare-disease.org.uk), one of the biggest problems facing patients with a rare blood disorder is diagnosis. Overall, 46 per cent of patients with rare conditions had to wait at least a year for a correct diagnosis, ten per cent of patients had to wait up to ten years.

It's not just the wait for a diagnosis that causes problems. Patients often receive an incorrect diagnosis and sometimes multiple misdiagnoses; this means unnecessary treatments could be administered and access to effective ones delayed. This causes problems for the patient and adds unnecessary costs to the NHS. Without a diagnosis many patients also find it difficult to get other types of support such as emotional and financial assistance. This can put a huge strain on them and their families. Despite the relief that a diagnosis can bring, there



Alastair Kent OBE
Director of Genetic Alliance UK

'The need for further research into these conditions is a pressing one. The lack of knowledge and treatment options limit the care that can be provided for patients'

are often no effective treatments and patients can struggle to access expert care, information and support.

There are many different blood conditions affecting the immune system, bleeding and clotting and the transfer of oxygen. Many can prove fatal if untreated and they all create problems for patients, families and the NHS. The need for further research into these conditions is a pressing one. The lack of knowledge and treatment options limit the care that can be provided for patients. This isn't because the NHS is uncaring but rather because there is a lack of a strategy with which to help patients with blood conditions. The current reorganisation of the NHS provides a golden opportunity to achieve this. There are world-class examples of care within the NHS for patients with some blood conditions and we hope there is the vision at the top of the health service and in Government to see this potential and raise the service that all patients with blood diseases in the UK receive from the NHS.



WE RECOMMEND



Michael Cary
Talks about his experience with chronic myeloid leukaemia

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'Research is vital in any medical field and I've been fortunate that great strides have been made in my lifetime'

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In collaboration with the NHS-based Haematological Malignancy Diagnostic Service (www.hmds.info), the University of York offers a number of haematopathology postgraduate programmes. Comprehensive training in the theory and practice of haematological malignancy diagnosis is provided using a combination of cutting-edge technology and innovative methods. Online teaching is delivered by clinical and laboratory staff working in a state-of-the-art laboratory cited as the model for diagnostic services in the UK's Department of Health's Cancer Reform Strategy; and statisticians and epidemiologists (www.egu.york.ac.uk) at The University of York (2010 Times Higher Education Awards University of the Year).

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INSPIRATION

Question: How important is it to know your blood pressure - and keep it low?

Answer: Very high blood pressure causes 60 per cent of strokes and 40 per cent of heart attacks - it is also a risk factor for heart disease, kidney disease, and vascular dementia

Why everyone needs to know their numbers

CHANGE

High blood pressure (hypertension) is the biggest single cause of death in the world - through the strokes, the heart attacks and heart failure it causes. And what's perhaps less known is that it is also a major cause of disability - those who do survive a stroke or a heart attack often suffer grave, life-changing physical disability.

Know the risks

16 million people in the UK have high blood pressure: often called the "silent killer" because it's a symptomless condition and one in three sufferers don't even know they have it.

The only way to know what your blood pressure is is to have it measured. It's vital to both know your blood pressure and be aware of what it means, says Professor Graham MacGregor, chairman of the Blood Pressure Association. Once diagnosed the condition can be very successfully

managed and brought to normal levels through taking medicines and making lifestyle changes.

Prevention

Blood pressure increases with age - which means that even if you don't have high blood pressure now, you might at some point in the future, warns Prof MacGregor. Around 30 per cent of people in their thirties have high blood pressure, increasing by roughly 10 per cent per decade - with 60 per cent of those in their sixties having high blood pressure.

This makes prevention all the more paramount. The earlier it is recognised, the earlier that treatment can be implemented, limiting damage. "The vast majority of people have high blood pressure with no direct underlying cause," explains Professor MacGregor. "All the studies show that high salt intake is the most important factor," he adds. There are many measures which people can and should do themselves.



Professor MacGregor
Chairman of the Blood Pressure Association

'If you don't know your blood pressure, go and have it measured and find out'

In both those with high blood pressure and those with normal blood pressure with an eye on prevention, the most key measures to take are keeping salt intake low, keeping fruit and vegetable consumption high, avoiding obesity, and avoiding excessive alcohol intake. Exercise can also be beneficial.

Getting the right treatment

"In a way the best thing that can happen is to find out that your blood pressure is high - to assess it and find out more so it can be treated" says professor MacGregor. "The medical treatment available is incredibly effective and has very few side effects, particularly when prescribed in the right way and combined together."

Alternative treatments such as relaxation therapy cannot replace the need for medication, Prof MacGregor points out. It is vital to recognise the strategies which have been shown to lower blood pressure - prescribed medication and limiting salt intake, he says.

A key point to know is that the body

will act to try to resist the effects of blood pressure-lowering medication. This "healthy reflex", as Prof MacGregor explains, means that for many people more than one blood pressure-lowering drug will need to be prescribed, often as many as three.

The food industry is slowly reducing the levels of salt in food, a move that is being copied all over the world and which in the UK is already responsible for saving 6,000 lives, says Prof MacGregor - and good dietary habits must begin in childhood, he points out.

Know your body

Knowledge is key. "If you don't know your blood pressure - go and have it measured and find out. There is nothing to be worried about - if it's high, it can be treated and brought down, lowering the potential risks. It really is as simple as that."

EMILY DAVIES

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GETTING MEASURED
The Blood Pressure Association held an awareness event on Clapham Common
PHOTO: BLOOD PRESSURE ASSOCIATION



TIMOTHY WEST TALKS



"I've always been grateful that many years ago I was advised to keep an eye on my blood pressure. At the time my pressure was raised and the advice I was given helped me to get it under control."

"High blood pressure can devastate lives. It is a major cause of heart attacks and strokes and is practically undetectable in most people without a blood pressure test."

"I commend the work of the Blood Pressure Association in encouraging people to have their blood pressure checked and making it easy for them to do so by providing free checks during their Know your Numbers! Week campaign every September."

"I would advise anyone who doesn't know their blood pressure numbers to have a test. It's quick, painless and it could save your life."

Timothy West, actor and supporter of the Blood Pressure Association



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INSPIRATION



LOBBYING FOR CHANGE
Professor Taylor and other
MDS campaigners outside
number 10 Downing Street
PHOTO: PROVIDED BY MDS UK



How we cope

John Barker, whose wife Gwyneth was diagnosed with MDS three years ago at 73, tells her story

"The diagnosis was a shock as Gwyneth has always been fit and active, with a successful career as a PE teacher and later as a head teacher at a failing school which she turned around. She has raised three children, taught in Third World countries, was awarded the Government Charter Mark Award for Excellence for outstanding work in education and has carried out a great deal of charitable work.

"The shock of being told the disease is incurable, except in the few cases when a bone marrow transplant is suitable but was not for her, was a severe psychological blow - so much so that she spoke about going to 'Dignitas' in Switzerland.

"Gwyn's health deteriorated quickly despite frequent blood transfusions. She was feeling increasingly weak, breathless and both hopeless and helpless. By December 2010 the disease had progressed to become AML and she was in intensive care for the next seven weeks.

"By this time, due to pressure by the MDS Patient Support Group and others, NICE had changed its mind and approved azacitidine - which Gwyn started to receive in regular cycles.

"Now, although she still feels weak and suffers some debilitating side effects - mainly nausea controlled by medication, she feels much better. Above all she is happier, has resumed her normal domestic life - cooking, ironing, cleaning and even pruning the roses, and looks forward to being able to help other people again and being able to travel."

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What we still need to fight for

Question: Myelodysplastic syndromes (MDS) are a group of diseases that can present complex challenges. What's most important to know?

Answer: Understanding what MDS is, who it affects, and why, is key - and helps to ascertain the best course of treatment for each patient

CHANGE

MDS are a group of bone marrow diseases which cause low levels of blood production and have the potential to worsen with time. Low risk MDS worsens with progressive lowering of blood cell values leading to fatigue (anaemia), infection (low white cells) and bleeding (low platelets). High-risk MDS also worsens with lowering blood values but is more likely to develop into acute myeloid leukaemia (AML), a serious complication which is difficult to treat.

One challenge is the definition of the disease, with recognition of it as a blood cancer more appropriate for others that have more advanced (high-risk) types of MDS closer to AML. But perhaps most crucial of all is the fight for access to effective drugs.

A new drug, azacitidine, prolongs



"We are currently lobbying NICE to get them to incorporate special consideration for rare conditions"

Professor Rodney Taylor
Consultant physician, diagnosed with MDS

survival for patients with high-risk MDS, at least compared with transfusions alone or with low doses of chemotherapy. Professor Rodney Taylor, a consultant physician who was himself diagnosed with MDS

five years ago at the age of 62, has had his own health "greatly restored" by azacitidine. It took more than two years - with six hearings and an appeal - for azacitidine to be recommended by NICE as it is now,

MDS: THE FACTS

- MDS can affect all ages, but is predominantly a disease of the elderly; the median age of patients is 70 years.
- The prevalence of MDS in the UK is approximately 3.6 per 100,000 population. Roughly 2,500 new cases are diagnosed per year.
- MDS occurs when blood cells remain in an immature or "blast" stage within the bone marrow and never develop into mature cells capable of performing their necessary functions.

Eventually, the bone marrow may be filled with blast cells suppressing normal cell development.

- The cause of Primary MDS is generally unknown.
- In a small number of people, MDS develops as a result of previous chemotherapy or radiotherapy treatment - known as secondary or treatment-related MDS.

SOURCE: FACTS PROVIDED BY THE MDS FOUNDATION
(WWW.MDS-FOUNDATION.ORG)

explains Professor Taylor, who is currently in his 26th cycle of azacitidine. "I've gone from being a total invalid to leading a totally normal, busy life," says Professor Taylor, who now works with the MDS UK Patient Support Group. MDS campaigners are now working with NICE on scoping a new treatment, Revlimid (lenalomide), for low-risk MDS, explains Prof Taylor.

The nature of MDS as a rare disease makes it harder to do a trial - the small number of patients, especially as it's a disease that occurs later in life and often co-exists alongside other conditions that need to be excluded. "We are currently lobbying NICE to get them to incorporate special consideration for rare conditions so that's it easier to bring a drug to trial - NICE does an extremely good job but in rare diseases it needs to have a different remit," explains Professor Taylor.

Continuing to raise awareness is key - it's thought that MDS is underdiagnosed, presenting as breathlessness anaemia in the elderly but not always recognised.

Rare diseases require a special level of support

*MyeloDysplastic Syndromes (MDS) are
forms of Bone Marrow Failure*

*The MDS UK Patient Support Group delivers
a unique support service that:*

- Supports patients, their families and carers
- Provides a networking service through which those newly diagnosed with MDS may share their experience with fellow sufferers
- Organises national and regional patient meetings with specialist speakers
- Distributes information and raises awareness of MDS to patients, carers and healthcare professionals across the UK
- Provides access to a list of UK consultants specialising in MDS
- Maintains an up-to-date website providing information on MDS and has directions to other relevant sites

*Join the MDS UK Patient Support Group.
Membership of the Group is free and open to all*

Donations and legacies

As a voluntary charity we need funds to enable us to expand and improve our services. Please support us with donations, legacies or in memoriam gifts. Payments should be made to: MDS UK Patient Support Group. All donations will be acknowledged in writing.

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NEWS

THE POWER OF KNOWLEDGE

Question: What does having a bleeding disorder really mean?

Answer: There are over 20,000 people in the UK with a bleeding disorder such as haemophilia which means that they have blood which doesn't clot properly



Chris James
Chief executive of the Haemophilia Society

“Contrary to myth, haemophilia doesn't lead to bleeding to death from a cut finger”, says Chris James, chief executive of the Haemophilia Society. The reality is that people with a bleeding disorder take treatment to try and prevent painful bleeds into tissue or joints - which can cause long-term damage resulting in chronic pain and mobility problems. “Every bleed into a joint damages it further which makes access to the best possible treatment and care vital”, says Chris. Bleeding disorders are treated by replacing missing clotting factors in the blood - many people have to inject every

other day to keep their levels high enough to prevent bleeding.

While haemophilia is the most well-known bleeding disorder the most common is in fact von Willebrand disease which, unlike haemophilia, affects men and women equally - causing underdiagnosis, says Chris. “There is some taboo around heavy bleeding in women - this has been compounded by the fact that many believe that bleeding disorders only affect men,” he says. “It is important for women who think their bleeding is unusual to get tested before an accident, childbirth or an operation brings the condition to light.”

Personal experience

Ros Cooper, 37, has had severe von Willebrand Disease (vWD) since birth. “I am lucky that my condition was diagnosed when I was very young and was well managed whilst I was growing up. If I had not been



Ros Cooper
Living with von Willebrand Disease

diagnosed I'm sure that my life would have been extremely difficult and potentially hazardous,” she explains.

“The problem that we still face is that vWD is not a well known condition, in the medical profession as well as the public - even though in its mild form it affects 1% of the population,” she says. “Many of those 1% are undiagnosed and may just think that easily bruising and nosebleeds run in their family. Diagnosis can lead to careful long-term monitoring, access to medications that can make life easier and proper management.”

Searching for a cure

The hope for the future is that gene therapy will lead to a cure, says Chris. Meanwhile, more effective and user-friendly treatments including some that stay active in the body for longer, meaning less frequent injections and the availability of synthetic 'recombinant' products for a wider range of conditions offer the most immediate hope for improvements.

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SEARCHING FOR A CURE
Developments in research are offering hope in the quest to find a cure for bleeding disorders such as haemophilia
PHOTO: LUCHSCHEN/SHUTTERSTOCK.COM

Be proactive and increase awareness

With sickle cell disease in children comes a risk of stroke - leaving a threat of long-term damage and even death, but the introduction of a screening programme could help decrease this risk

Sickle cell is the most prevalent genetic condition in the UK - and one in every 10 children with sickle cell disease will have a stroke before the age of 16. This will result in some form of physical or cognitive disability or death, yet sadly most people are unaware of this link says Carol Nwosu, founder and CEO of Sickle Cell and Young Stroke Survivors (SCYSS).

“One of the greatest challenges for now and in the future is to ensure that the only preventative tool for sickle cell childhood stroke Transcranial Doppler (TCD) scanning, is made available to all children at risk through a national screening programme,” she explains.



Carol Nwosu
CEO of Sickle Cell and Young Stroke Survivors (SCYSS)

“It is our experience that TCD scanning is not currently nationally provided to all children who have sickle cell disease on a regular basis as required. This effectively means that some children in certain areas have a greater risk of stroke than others. The only way to ensure the level of responsibility we have towards these children is matched with the level of risk they face is through an effective screening programme.”

“Increased awareness of the risk of stroke among parents and carers of sickle cell children will improve TCD scan uptake and early detection of stroke resulting in better outcomes for children with sickle cell disease. Currently, once a child has had a stroke or a risk is detected the only option available to the child as treatment or prevention is long-term regular blood transfusions. This comes with the risk of iron overload and other risks making it by no means an easy choice for the child or carer. Further research is therefore needed into both prevention and long-term treatment, to improve these children's life outcomes.”

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SICKLE CELL DISEASE: WHAT IT MEANS



Dr Victor Hoffbrand,
Emeritus Professor of Haematology, UCL

Sickle cell disease (anaemia) occurs when a child is born with nearly all their haemoglobin, the major protein in red cells, sickle rather than normal: sickle red cells break down more quickly than normal, leading to the anaemia, to jaundice and often to gallstones.

Sickle red cells may block the circulation, causing 'crises'. These are very painful if bones are affected and crises may affect soft tissues such as the lungs and brain which can be life-threatening.

There is a one in four chance of a sickle cell baby if both parents are carriers. Crises are treated by pain relief, rehydration, with antibiotics if infection is present, and sometimes blood transfusion. Some drugs may reduce the severity and frequency of crises. The only cure is bone marrow transplantation from a normal (usually related) donor in which bone marrow stem cells which produce sickle red cells are replaced by normal stem cells.



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PERSONAL INSIGHT

Michael Cary, 75, has had chronic myeloid leukaemia (CML) for 17 years. Initially given a maximum of two and a half years to live, he explains how he has coped and the life changing difference that medication has made

The secrets of my survival

discovered I had CML after I went to my GP because I had a severe cold and bruising which would not go down. Following a blood test and a confirming check at the local hospital, they diagnosed CML.

At first the shock was severe, particularly to my wife and my family. The prognosis was that I had two to two and a half years left to live, unless drugs were found to counteract the cancer - although Dr Aitchison, a haematologist at High Wycombe Hospital, had faith that things would work out.

After a short spell on medication which stabilised my blood count I was put on interferon, which I self-injected. I must admit that at times I felt like a pin cushion!

I was able to carry on teaching, working as head of technology at a school in Slough where I had great support from the head and the staff. When it turned out that I was having more time off work than I was spending in the classroom, however, I took early retirement in 1997.

In the early days, apart from being tired - with side effects such as putting on weight, stomach pain and insomnia - I also developed painful peripheral neuropathy, which is the deadening of the nerves in the legs.

With the full support of my wife I was able to carry on with a reasonably active retirement. They helped and encouraged me in all aspects of general living, and I had the best support

from my haematologist who checked me on a regular basis.

In the early days my hospital appointments were close together, but then he was confident enough to say that I could visit him on three-monthly intervals. I have never had a bone marrow transplant or chemotherapy, only a blood transfusion.

Apart from early retirement I feel that my life has been very successful. I have lived to see my three children marry and raise five grandchildren; I have been able to take holidays both in this country and in Europe and Australia, where my eldest son is now living - and I have been able to join societies and help with the running of Leukaemia Care stalls.

Research into the medication for CML has been my saviour. Although I still have leg problems now, my sleeping is much better. I have been to seminars on CML at Nottingham University and gained valuable help from others with CML.

I have now had direct experience of all medications for CML; if it were not for my very caring and expert haematologist at High Wycombe Hospital I would have passed away many years ago, and missed my three children getting married and producing five

grandchildren. I feel that I am living proof that the new medication is effective - as each of these drugs controlled my condition when the previous medication failed.

Research is vital in any medical field and I've been fortunate that great strides have been made in my lifetime. I have confidence that I will carry on living a normal life for many more years to come.



QUESTION & ANSWER



Richard E Clark
Professor of
Haematology and
Consultant
Haematologist at
Royal Liverpool
University Hospital

■ **What is the significance of new drugs such as Tasigna for the treatment of CML?**

! Treatment of CML was transformed about 10 years ago with the drug Imatinib (Gleevec). We now know that in about 40 per cent of patients, Imatinib either doesn't work well or causes unacceptable side effects. Imatinib was to some extent discovered to work in CML by chance; chemists have learnt from imatinib and designed a newer drug for CML - Tasigna. Tasigna works very well in about 70% of patients for whom Imatinib is not working ideally.

■ **What difference does this make?**

! Like imatinib, Tasigna has an excellent safety record but is more potent. Many patients who switch to Tasigna have fewer side effects.

Ongoing clinical trials suggest that in newly diagnosed CML patients, Tasigna may give better results than imatinib, including lower progression rates to acute leukaemia. This is very exciting, giving optimism that Tasigna might have further improved the outlook for CML.

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Human stem cells are being increasingly used in regenerative medicine to replace or rebuild tissue and organ functions lost through age, disease, damage or birth defects. Cures for diseases like Alzheimer's, autism, diabetes, Parkinson's and schizophrenia are also being targeted for ongoing research. None of this is possible without the essential background technology being provided by controlled environment storage experts, Vindon Scientific in the exacting science of cryogenics.

Stem cells & regenerative therapies

Stem cells are our 'master cells' and are found throughout the human body. They replicate constantly and replace cells that die or are damaged. Stem cells can be sourced from the bone marrow itself, peripheral blood, umbilical cord blood, adipose tissue (fat) and dental pulp (children's milk teeth). Exciting treatments are envisaged using stem cell technology indeed the British Heart Foundation are hoping to raise £50 million for research into a stem-cell treatment for heart failure.

Commercial partnerships

Because the technology is so diverse and complex, business partnering is the most logical way for interested parties to benefit in the future. Vindon has partnered with Eternas to freeze and store adipose-derived stem cells (ADSCs) and tissue. Adipose tissue contains very high concentrations of ADSCs so this partnership gives patients the opportunity to store their own tissue and stem cells. These could be used for potential future cosmetic and reconstructive surgery as well as offering possible therapeutic opportunities in the future.



Vindon has also partnered with Pharmacells (peripheral blood) in order to pioneer a new medical process for collecting and storing stem cells from adults. Developed through partnerships, Vindon's involvement in the Oristem® programme will ensure that samples received from clients are stored to the highest standards for use in possible future treatments.



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Outsourcing benefits

Scientists, researchers and medical professionals undoubtedly don't need distractions. That's why effective outsourcing can make all the difference to a business. Having Vindon as an outsourcing partner will relieve pressure on an organisation and provide a simple cost-effective arrangement for a very precise and intricately managed service.

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