

commit.
to a life **Saving**
procedure
now

DWIB Leukaemia Trust

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all we **ask**
 is that **you think**
 about it

Please spend the time reading this brochure from cover to cover. If you sign up and then drop out at a later stage, it costs us time and money and could cost lives. Please consider this important step, and make sure it is the right decision for you.

Every year thousands of people die from fatal bone marrow diseases. A blood stem cell donor whose tissue type matches theirs could mean the difference between life and death.

You could be the match.

You may well be the only person in the world who can provide that match; the only person who could save the life of a stranger dying from a fatal bone marrow disease.

If you want to help, you must first:

join the register

Application is very simple: complete and return the attached form to the DWIB Leukaemia Trust as quickly as possible. For today's patients time is rapidly running out. We need your fast response and long-term commitment.

Although donors aged between 18 and 40 are urgently needed, The DWIB Leukaemia Trust desperately needs more volunteers from two key areas of the community - Males and the mixed race.

male shortage

Only 40% of the donors currently on some of the major Registers worldwide are male. The DWIB Leukaemia trust wants to avoid this anomaly. It is a serious problem for the following reasons:

- Males are generally able to provide greater volumes of bone marrow containing the life giving blood stem cells that are required for a transplant.
- Males are much less likely to suffer from anaemia, a condition which would prohibit a volunteer from being able to donate.
- It is not possible to donate bone marrow during and up to one year after pregnancy, so males tend to be more frequently available.
- If there is a choice of donor for a patient, in most cases a male donor will be preferred.

mixed race shortage

Ethnic origin is important when matching donors and patients. The 'markers' that are tested when searching for a match are genetically inherited and often unique to a particular race. Quite simply, there are currently not enough volunteers on the Registers from mixed races.

By joining the Register you may be able to save the life or lives of others within your community who might otherwise be unsuccessful in finding a match.

Please act now

You can help change this situation by joining The DWIB Leukaemia Trust Register and helping to recruit a volunteer that fits one or both of the above criteria,

keeping safe

As haematopoietic stem cells are found in blood and certain diseases are carried in the blood, it is not possible to accept donations from individuals who have tested positive for either the Human Immunodeficiency Virus (HIV) or Hepatitis B or C viruses. It is important that people are honest and exclude themselves from joining the Register or proceeding with a donation, if they believe they are at risk of infecting patients undergoing transplant procedures. There is no risk of HIV or Hepatitis infection to a volunteer undergoing stem cell donation.

Testing for viruses is performed at the final stages of matching with a patient, as well as the medical examination prior to donation. You will only be HIV or Hepatitis tested if you should match with a patient at a future date, not immediately upon joining the Register. The tests performed initially are only to establish your tissue type and thereby identify the degree of matching with a patient.

You must not join the Register if you have reason to think you are at risk, or use us to obtain an HIV or Hepatitis test. You can be tested confidentially for these viruses at voluntary counseling and testing centres.

Do not register as blood stem cell donor or consent to further matching tests if:

- You think you might need a test for HIV, Hepatitis B or C
- You or your partner are HIV positive or carry the Hepatitis B or C virus
- You have injected yourself (even once) with illegal or non-prescription drugs
- You have taken money or drugs in exchange for sex
- You are a man who has had sex with another man, even “safe sex” using a condom or other protection

You may be at risk of HIV or Hepatitis B or C after sex with:

- Any individual you think may be HIV or Hepatitis positive
- Any individual who has taken money or drugs in exchange for sex
- Any individual with haemophilia or a related blood clotting disorder, who has received blood products/clotting factor concentrates before the introduction of routine screening and heat treatment of clotting factors in the late 1980s.
- Any individual whose HIV and/or Hepatitis status you are unsure of

For further information on any of the above please call the Medical Officer at The DWIB Leukaemia Trust on: 0277 711 955 or visit www.dwib.org.

how you can help

You can help by joining The DWIB Leukaemia Trust Register. All that may ever be required of you is one small blood test – but you never know, you may turn out to be a match and go on to save a life. Joining the DWIB Leukaemia Trust Register will cost you nothing, but not acting quickly and sharing something that is unique to you, could cost someone else their life.

Each year, thousands of people with fatal bone marrow disease reach a stage when their only hope of survival is a blood stem cell transplant from a donor who shares the same tissue type.

Although family members – brothers and sisters in particular – may offer the closest matches, 70% of patients do not have a suitable sibling, so have to search elsewhere. To facilitate this search Registers in different countries hold tissue type information of volunteers who have, as you are now considering, provided small blood samples for testing and recording. On referral to the Register, a patient’s tissue type is entered onto a computer and checked against every donor tissue type listed.

Because individual genetic makeup is so varied and tissue types are determined by inherited characteristics, the chance of finding a suitable match can be slim. Despite access to over eight million unrelated donors worldwide, many searches are still unsuccessful. But as the sizes of the Registries grow, so does the chances of finding exact tissue type matches for more patients. The likelihood of finding a matching donor will be considerably greater in donors from the same ethnic background.

who can help?

If you are in excellent health and aged between 18 and 40 years, the DWIB Leukaemia Trust Register needs you to join now. (Once registered your details remain on file until you are 60 years old.) You are particularly sought after if you are a male and/or of mixed ethnic background, as these are very under-represented on Registers around the world.

There are other eligibility criteria for joining the Register including weighing at least 50kgs and permanently residing in Ghana (and likely to be for at least the next 2-3 years). Most importantly you need to be a committed and caring person, who will continue to stay in contact with us and give further blood samples if required. If you are identified as a match for a patient and prepared to offer them the chance to live, you would undergo a minor medical procedure in hospital and experience some short-term discomfort, you would also have to take time off work or away from your normal duties (loss of earnings are reimbursed).

Because personal circumstances may change over time you can remove your name from the Register at your discretion; however, **joining is a serious step, so please consider very carefully the implications and responsibilities of being a donor before giving your first blood sample.**

the DWIB leukaemia trust

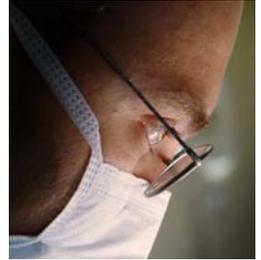
The DWIB Leukaemia Trust was conceived by **Danny Whyte** and **Ivor Burford** – 2 patients with acute leukaemia, in the year 2004.

Together in the U.K, Danny and Ivor realized the huge discrepancy of opportunities for management and the likelihood of finding a stem cell donor match in the U.K for people of African descent. They decided to start a trust which would amongst others, set up an African Register and improve treatment opportunities for Africans.

The Trust has since established a website, and with your registration, its Bone Marrow Register.

bone marrow donation

Bone marrow donation requires a two-night stay at Korle-Bu Teaching Hospital for a medical procedure called a harvest. Under general anaesthetic, blood stem cells are extracted from the pelvic bones by sterile needle and syringe. No surgical incision is required, and the blood stem cells replace themselves within 21 days. You may feel some short-term post-operative tenderness and discomfort in your lower back and tiredness is inevitable during recovery. It is, therefore, advisable to



plan to recuperate for approximately one week before returning to work or other normal duties. The most serious complication for the donor could be reaction to the anaesthetic, but the risk is extremely low and certainly no greater than undergoing any minor operation.

peripheral blood stem cells (pbsc) donation



Blood stem cells are also found in the circulating blood stream (peripheral blood) as well as the marrow, but in much smaller numbers.

A growth factor known as granulocyte-colony stimulating factor (G-CSF), which occurs naturally in the body and regulates production of certain white cells (neutrophils), is injected for days prior to the collection. This temporarily boosts neutrophil production and encourages movement from the bone marrow where the cells are made, out into the peripheral (circulating) blood. The cells are then collected via a sustained needle on a blood cell separator machine, in a process known as apheresis.

One or two collections on consecutive days, each lasting approximately 4-5 hours may be required, but overnight hospitalization is not usually necessary, nor a general anaesthetic. The effects of the G-CSF may include bone pain and flu-like symptoms during the 5 day period the drug is being administered, but which recede 1-2 days after the last dose of the drug. During the collection the donor may experience discomfort at the sites of the needle insertion and temporary tingling sensation in the body from anticoagulant used to keep the cells from clotting. No extended recuperation period should, therefore, be necessary, although you are likely to feel tired for a short time afterwards.

if you are a match

If your tissue type is found to be a complete match (there may be occasions where you were found to be a partial match), you offer immeasurable hope to that patient, often at a time when desperation and fear are the overriding emotions faced.

Once identified as a tissue matched compatible donor – and prior to the donation – you will have a medical examination by an independent physician to confirm your fitness to proceed. Further blood samples will be taken to assess your health and ensure that no infection could be passed from you to the patient.

The DWIB Leukaemia Trust not only helps patients in Ghana, but also around the world. All blood stem cell donations from DWIB Leukaemia Trust volunteers, however, take place at the specialized center in Korle-Bu, Accra and are hand carried by a personal courier to the patient's transplant center. The DWIB Leukaemia Trust makes all the arrangements for the donor and cover any financial loss incurred by our donors as a result of having donated blood stem cells (subject to prior agreement). A family member or friend is also able to accompany you to Korle-Bu, Accra.

In compliance with international agreement, strict anonymity is maintained between donor and patient. After the donation you are at liberty to decide whether to remain on the Register. There is no reason on physical grounds why a healthy person should not donate on more than one occasion.

donation options

Blood stem cells can be collected by bone marrow extraction or taken from the peripheral blood. Ideally all volunteers should be willing to donate by either method. However, the final choice of donation method would be yours, with guidance provided to help you reach the most appropriate decision.

blood stem cell transplant

Bone marrow, found in a centre of all large bones, is where new primitive blood cells, known as blood stem cells, are produced. Blood stem cells develop into mature blood cells: white cells (needed to fight infection), red cells (needed to carry oxygen to and remove waste from organs and tissues) and platelets (which are needed to stop bleeding).

When essential bone marrow is destroyed by disease or by the treatment to eradicate leukaemia, blood stem cell transplantation from a matching donor provides the greatest chance of recovery. The donor's healthy blood stem cells are infused into the patient's blood stream and if accepted (engrafted) begin producing normal blood cells.

Success cannot be guaranteed, a transplant offers a last chance. Despite the best medical care patients still sometimes die of complications, but increasing numbers of transplants are ending positively.

If you are asked to donate your blood stem cells, they can be collected either from the bone marrow or from the peripheral (circulating) blood. Prior to undergoing either procedure, you will be given a thorough medical examination to ensure you are fit to donate and have talked through the options.

You will find more information about this later in the booklet.

only you could save someone's life

Life-threatening diseases such as leukaemia, aplastic anaemia, immune deficiencies, inborn errors of metabolism and other new indications such as breast cancer and auto-immune disorders can now be treated. A donation of blood stem cells can offer the chance of continued life and restore health to people suffering from such diseases. When haematopoietic (blood) stem cells are transfused they regenerate within a patient's bones producing the cells needed. These then develop into mature blood cells that are released into the blood stream to keep the recipient alive.

Both children and adults can need a transplant but only one third will have a close relative who is an acceptable donor. Others need unrelated donors who have joined the Register and are willing to donate haematopoietic stem cells (primitive blood cells that are made in the bone marrow). Even searching on an ever increasing and global list of potential donors does not guarantee a match or success because for many that perfect match has not yet joined a Register.

It is essential to ensure that a blood stem cell donor and recipient are matched. Matching has nothing to do with the compatibility of blood groups (red cells) but is based on genetic markers found on white cells of the blood. These are known as tissue types. Unless the tissue types of both donor and patient are identical or virtually so (and there are many thousands of distinct varieties) a blood stem cell transplant will not succeed.

If you meet the eligibility criteria and are truly prepared to undergo a minor medical procedure and some short-term discomfort to help someone to live, please read the remainder of this booklet, complete the application form and medical questionnaire, then return it to The DWIB Leukaemia Trust as a matter of urgency. **When you attend a DWIB Leukaemia Trust recruitment session, a blood sample will be taken.**

what happens next?

Once your application is received, The DWIB Leukaemia Trust will assess your suitability as a donor and contact you as soon as possible. If you meet our criteria you will be informed of the next DWIB Leukaemia Trust recruitment session, where a small blood sample will be taken to identify your tissue type.

All initial blood test are performed at the Trust laboratories, and during the course of matching it may be necessary for a donor to provide further samples. Your personal details (name, address) as well as sensitive personal information, (tissue, type, ethnic origin and pertinent medical details) are then held on a central computer, based in the Operations Department at The DWIB Leukaemia Trust head office. All sensitive personal information is handled as strictly confidential, and can only be accessed by authorized staff in the course of undertaking an unrelated donor search. We have a legal obligation under the Data Protection Act to ensure that all information held and processed on you complies with the principles of the Act. The uses of such information are covered by our notification under the Data Protection Act and you may have access to your records in compliance with the Act.

After the necessary preliminary blood tests have been completed a considerable time may elapse (sometimes years) before you are asked to undergo more detailed blood tests and/or donate blood stem cells. This is because the number of patients requiring transplants, whose tissue type is identical to yours, is likely to be very small. But for that one person, when they need you, that small chance far outweighs no chance at all.

For this reason, **please keep The DWIB Leukaemia Trust fully updated about your contact address or any changes in your health which could preclude you from continuing to be a donor.**