

A Call to Increase Potential Stem Cell Donor Registration

Resolution Shortlist Briefing notes



A Call to Increase Potential Stem Cell Donor Registration

There is an urgent need to increase the number of people registered on the aligned UK stem cell registry in order to provide potentially life-saving treatment to people of all ages with certain blood cancers. We call on all WI members to promote registration to the database to avoid people dying whilst waiting for a match.

Proposer's position

The proposer would like the WI to promote registration to the aligned UK stem cell registry to enable more people to receive potentially life-saving stem cell transplants.

The scale of the problem

Every twenty minutes, someone in the UK is diagnosed with blood cancer. Often, replacing their cancerous blood cells through a blood stem cell donation from a matching donor is their best chance of survival.

Stem cells are defined as 'special cells produced by bone marrow (a spongy tissue found in the centre of some bones) that can turn into different types of blood cells'.

By replacing damaged blood cells with healthy ones, stem cell transplants are used to treat conditions such as leukaemia, lymphoma and sickle cell anaemia.

Ideally, stem cells are taken from a family member of the person who needs them (siblings are the most likely to match your tissue type). However, according to NHS Blood and Transplant, 65-75% of people who require this treatment are unable to find a sibling match.

The current situation

There are still patients who struggle to find any kind of match. This is particularly true for patients from a Black, Asian or minority ethnic (BAME) background, with donors from these backgrounds making up only 14% of the aligned registry and 22% of recruitment this year.

According to a 2018 survey of 2,000 adults by charity Anthony Nolan, 61% of people would not like to donate their stem cells due to them believing a range of misconceptions about the donation process.

Most people depend on finding a suitable donor on the aligned 'Anthony Nolan and NHS Stem Cell Registry'. This is formed of Anthony Nolan, DKMS UK, NHS Blood and Transplant, and the Welsh Bone Marrow Donor Registry. There is also a global network of registries which can be searched.

While a number of organisations are already working on this issue, meeting the demand for suitable stem cell donors is recognised as a big challenge. DKMS UK says that many people die because they are unable to find a donor.

Currently, in the UK, only 2% of people are registered as stem cell donors. In order for more matches to be found, more people are urgently needed to join the registry.

Becoming a donor

People wishing to become a stem cell donor can join the UK's registry through any stem cell organisation or charity.

Each organisation appears to focus on recruiting different age groups to the stem cell registry. Anthony Nolan, for example, focuses on people aged 16-30 on the basis that this age group provides the best outcomes for patients. To join their registry (the data is then combined in the single registry), an application form can be filled in online.

Following this, you will be sent a swab kit to complete.

NHS Blood and Transplant, however, recruits from their pool of blood donors. They recruit from two particular groups of blood donors;

- 1. men aged between 17 and 40 years old
- 2. Black, Asian, Minority Ethnic or mixed-race donors of either gender aged 17-40.

They focus on these groups as the registry is short on donors with this demographic profile.

DKMS registers people aged between 18 and 55 who are in general good health and live permanently in the UK. People aged 17 can also 'pre-register' with them in advance.

All potential donors are screened to ensure they are able to donate, as some medical conditions mean they may not be eligible.

Once registered, your details remain on the system until your 60th birthday. If a potential match is identified, you are then contacted to discuss next steps.

How could the WI work on this issue if it was passed?

A full campaign would be developed by the NFWI if the resolution is passed, taking into account developments since then. To help inform your discussions, here are some ways the WI could consider working on this issue.

At local and regional levels, WI members could host 'pop-up' events in public places to help to dispel the myths surrounding stem cell donation, and to encourage registration of potential donors to the aligned UK stem cell registry. Members could also link up with local branches of stem cell charities to help support their awareness drives.

Nationally, the NFWI could work with organisations supporting and promoting stem cell donor drives, and could call on the Government to run an enhanced public information campaign focusing on the importance of donating stem cells.

Arguments for the resolution

- There is an urgent need for more people to be registered as a stem cell donor.
- Both locally and nationally, government and health bodies could be doing far more to dispel the myths surrounding stem cell donation and to encourage more people to donate their stem cells. The WI could help spur action.
- If passed, this resolution could follow the successful model of the 'Time to Talk' campaign previously run by the WI on organ donation, which worked to raise awareness about the need to discuss your wishes with loved ones.

Arguments against the resolution

- Would working on this resolution be duplicating the work of other organisations?
- As the upper limit for registering on the stem cell registry is between 55-60, some WI
 members would not be able to directly sign up to the registry themselves. However,
 this would primarily be an awareness raising campaign- the act of which has no
 upper age limit.

Further information

NHS Blood and Transplant https://www.nhsbt.nhs.uk/what-we-do/transplantation-services/stem-cells/

DKMS: https://www.dkms.org.uk/en

Anthony Nolan: https://www.anthonynolan.org/facts-and-stats

Video content

This video from DKMS shows the easy process of how to become a potential blood stem cell donor: https://www.voutube.com/watch?v=OvB686Gnbbg

Public Affairs Department Contacts

If you have any questions about the resolutions or the resolutions process then please get in touch with the NFWI Public Affairs department.

Post: National Federation of Women's Institutes, 104 New Kings Road, London, SW6 4LY

Telephone: 020 7371 9300 **Email:** publicaffairs@nfwi.org.uk

Website: thewi.org.uk