



MAKE A MATCH

ADDRESSING THE NEED FOR
MORE STEM CELL DONORS

NFWI 2020 Resolution

A call to increase potential stem cell donor registration

In August 2020, the NFWI passed a resolution calling on WI members to promote registration to the aligned UK stem cell registry:

“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”.

Barnstaple Bloomers WI, Devon Federation

Why is stem cell donation important?

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.

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.

Most people, therefore, 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.

People from ethnic minority backgrounds are less likely to find a good stem cell donor match. People from northern European backgrounds have a 69% chance of finding the best possible match from an unrelated donor, compared with 20% of people from ethnic minority backgrounds.

A lack of awareness and misconceptions around the donation procedure are among the major barriers to more people becoming stem cell donors.

How will the NFWI work on this issue?

At a local level, the NFWI will:

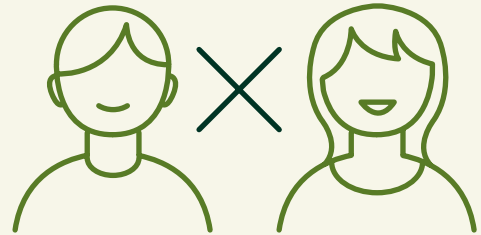
- Provide WI members with information and tools to learn about the need for stem cell donation and challenge the myths surrounding it.
- Empower federations and WIs to take action that will help to increase the number of people on the aligned stem cell registry.

At a national level, the NFWI will:

- Work alongside national organisations with expert knowledge of stem cell donation to develop resources, and to further the aims of the WI's mandate on this issue.

WHO CAN DONATE?

Signing up to become a stem cell donor is a personal choice and there are restrictions on who can register. Eligibility criteria vary across organisations involved in this process. Anthony Nolan, for example, focuses on people aged 16-30 on the basis that this age group provides the best outcomes for patients. While 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. You can find out more about this and how to sign up by visiting their websites.



ACCORDING TO NHS BLOOD AND TRANSPLANT, 65-75% OF PEOPLE WHO REQUIRE STEM CELL TREATMENT ARE UNABLE TO FIND A SIBLING MATCH.

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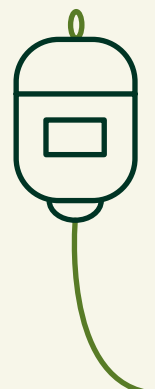
PEOPLE FROM BLACK, ASIAN OR MINORITY ETHNIC BACKGROUNDS ARE MUCH LESS LIKELY TO FIND THE BEST POSSIBLE BLOOD STEM CELL MATCH FROM AN UNRELATED DONOR.



IN THE UK, ONLY 2% OF PEOPLE ARE REGISTERED AS STEM CELL DONORS



90% OF DONATIONS HAPPEN THROUGH PERIPHERAL BLOOD STEM CELL COLLECTION, A PROCESS SIMILAR TO DONATING BLOOD.





Stem cell donation process from A to Z

1.

Request your free registration kit using a WI link. Anyone can use these links. You will have to answer a few questions to check your eligibility first. You can read more about eligibility on page 3.

MAKE A MATCH REGISTRATION LINKS

DKMS/WI Signup link: www.dkms.org.uk/thewi

Anthony Nolan/WI Signup link:
www.anthonynolan.org/WI

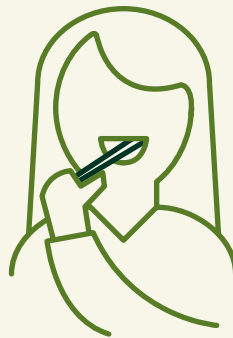
These links are open for everyone and allow us to count how many donors are recruited as a result of the WI Make a Match campaign.

If you are unable or don't want to donate, turn to page 6 for other ideas of how you can get involved with the *Make a Match* campaign.

2.

Swab your cheek.

Once registered, you will receive a kit in the mail. You will need to swab the inside of your cheeks. The kit will come with thorough instructions on how to do this.



3.



Return your kit.

You can return your swab via freepost. The organisation you are registering with will then analyse your tissue in a lab to determine your HLA (tissue) characteristics. This is how a donor is matched with a patient. You will then be added anonymously to the UK stem cell registry.

Further information

For key facts on blood cancer and the need for more people to join the aligned stem cell registry, visit:
www.anthonynolan.org/facts-and-stats

To find out more about blood cancer, visit:
www.dkms.org.uk/en/about-blood-cancer

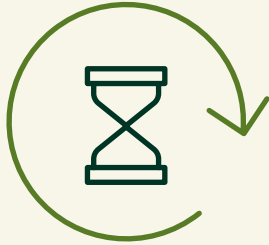
For more information on stem cells and the British Bone Marrow Registry, visit the NHS Blood and Transplant website: www.nhsbt.nhs.uk/what-we-do/transplantation-services/stem-cells/

For more information about the shortage of donors from ethnic minority backgrounds, visit ACLT's website: www.aclt.org/impact-of-our-work/

4.

Wait.

Health services across the world can search the stem cell register for people in need of a donation. By registering, you increase their chances of finding a match. You will stay on the registry until you turn 61 years old.

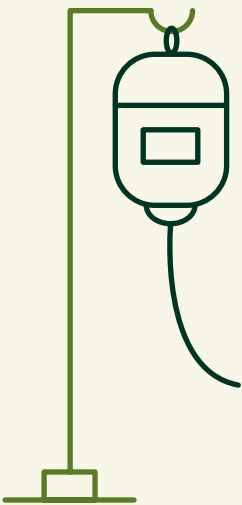


5.

If you are identified as a potential match, **donate**. The charity you registered with will get in touch to arrange a health check, your travel and hotel and the donation.

In the four days before the donation you will receive a daily injection of a hormone which increases the number of stem cells your body produces.

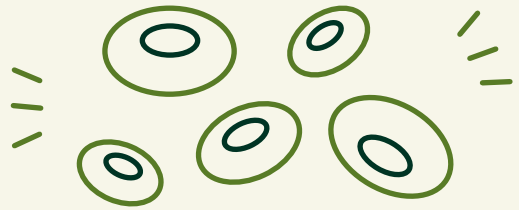
90% of donations happen through peripheral blood stem cell collection. The process is similar to donating blood.



6.

After the donation, your cells are collected and delivered to the hospital where the recipient is waiting. The transplant usually takes place on the same day or the day after your donation.

If the cells are accepted by the recipient's body, they will now start making healthy blood cells!



In a bed or reclining chair via a needle in each arm, blood is drawn out of one arm and fed into a cell-separating machine. Stem cells are filtered out and red blood cells are then put back into your blood stream. Donating takes about 4-5 hours.

The remaining 10% donate through bone marrow in the pelvis. You'll spend two nights in hospital. Under general anaesthetic, doctors will take some bone marrow from your pelvis using a needle and syringe. The procedure is carried out under general anaesthetic and takes 1-2 hours. Donors might experience some discomfort afterwards, but most return to their regular activities within a week.

To learn more about how to become a potential blood stem cell donor, visit:

www.dkms.org.uk/donation-explained, or watch this video from DKMS:

www.youtube.com/watch?v=QyB686Gnbbg

If you or someone you know have discovered that you need a bone marrow or stem cell transplant, you can contact The Patient Services team at Anthony Nolan for information and support.

Call 0303 303 0303, email: patientinfo@anthony-nolan.org or visit www.anthonynolan.org/patients-and-families/get-support-us

How can you take action?

1. Talk to a friend

A lack of awareness of the need for more stem cell donors and misconceptions about the process are some of the main challenges to increasing the number of people on the aligned UK stem cell registry. Many around you might not be aware of the urgent need for more donors and the difference a friendly chat could make as a first step to recruiting a new donor.

On page 10 you will find a discussion guide to help you start this important conversation.

The NFWI has also developed a myth-busting fact sheet that your WI could use to help tackle some of the barriers to more donors signing up. You can download this here:

mywi.thewi.org.uk/makeamatch

2. Share the WI's sign up links with 5 people you know.

The NFWI has worked with Anthony Nolan and DKMS to create WI-specific sign up links to the stem cell registry, which you can use yourself or share with those around you.

If your WI has come up with a creative way of sharing these, we would love to hear about it!

To start, cut out the card on the back of this pack to send to someone you know!

MAKE A MATCH REGISTRATION LINKS

DKMS/WI Signup link:

www.dkms.org.uk/thewi

Anthony Nolan/WI Signup link:

www.anthonynolan.org/WI

3. Hold a stem cell donation event

A great way to spread awareness of the need for more stem cell donors is to hold an event. It is also a great way to come together to ask questions about the process, think about how donor registration can be promoted in your local area or to discuss and address any concerns and misconceptions people may have.

Please note that in accordance with our fundraising policy that has been produced in adherence to charity commissions rules, the NFWI and WIs are not able to get involved with or promote national fundraising asks. You can read more about this on My WI:

mywi.thewi.org.uk/makeamatch

Turn to page 7 to find our stem cell guide to planning your virtual (or in-person where possible and in line with Government public health guidelines) event.

4. Share your experience with NFWI

If you have registered as a potential stem cell donor, donated your stem cells or received a transplant, we would love to hear your story. Stories can make a big difference when it comes to raising awareness, and so, with your permission, we may share these through our communication channels, including WI Life, the WI websites, Public Affairs resources and social media.

CONTACT THE PUBLIC AFFAIRS DEPARTMENT:

Share your experience or tell us how your WI is getting on with the campaign at pa@nfwl.org.uk

A guide to a successful *Make a Match* stem cell event

The aim of the WI's *Make a Match* campaign is to raise awareness of the need for more stem cell donors and encourage people to consider signing up to the UK's aligned stem cell registry. Holding an event is a great way to learn about the stem cell donation process, discuss any concerns and misconceptions people might have, and plan how your WI or federation could best encourage people around you to think about joining the register.

We have compiled an event toolkit to help you throw a successful event, which includes top tips, a suggested meeting agenda and a discussion guide.

The toolkit also consists of a series of short educational videos and a presentation, all of which can be downloaded from My WI:

mywi.thewi.org.uk/makeamatch

TIPS FOR A SUCCESSFUL MEETING

• **Getting a speaker**

The key to a successful event is an engaging speaker. It might be impactful to hear from someone who has donated stem cells, or who has benefited from a transplant themselves. Maybe someone in your WI or community has donated their stem cells or signed up as a potential donor?

Another option is to hear from an expert organisation. The charity DKMS would be happy to try and arrange a speaker for you. You can contact them on **events@dkms.org.uk**

• **Planning a virtual *Make a Match* meeting**

The NFWI has compiled a range of resources which you may find helpful in planning your virtual meeting or event:

- A **suggested agenda and accompanying discussion guide** for a WI '*Make a Match*' meeting or event. You can find this on pages 9 and 10.
- A **'Make a Match' presentation**. This presentation has been developed as a resource that can be used alongside the timed agenda by the Chair of your meeting. You may find it useful to help guide your meeting and provide a visual backdrop for attendees.

Download the presentation from My WI here: **mywi.thewi.org.uk/makeamatch**

- A **'How to host a virtual meeting' guide**. This explains the various options and platforms for holding virtual meetings, and how to set up and use them.

You can find the guide here: mywi.thewi.org.uk/running-your-wi/guide-to-running-meetings/how-to...-host-a-virtual-meeting

- A **'How to plan an event or activity for your WI' guide**. This guide covers everything you need to plan a successful event for your WI. It mainly covers face-to-face events, but it is also useful for virtual meetings.

You can find the guide here: mywi.thewi.org.uk/running-your-wi/plan-an-event-or-activity

- **Running your meeting:**

- **Appoint a person to host the meeting** and be responsible for admitting people, controlling screen shares, and answering any technical questions, so that the Chair can focus on running the meeting.
- **Schedule regular breaks** if the meeting is due to last a while, so attendees can get a break from the screen or replenish their coffee.
- **Incorporate entertaining elements** such as films or activities to break up long discussions.

This can also be used if you are able to hold an in-person event (in line with Government public health guideline).

- **Consider opening the meeting to the wider community** to potentially recruit more donors and attract new WI members. If your meeting is virtual, you could also invite other WIs. If so, the NFWI can help promote it. Email pa@nfwf.org.uk for more information.

Suggested agenda for a WI *Make a Match* meeting or event

This template offers a timed agenda with suggested topics of discussion. It's completely up to you whether you would like to follow the proposed timetable, or use it as a rough guide.

Depending on your interests and what you would like to talk about in your WI, you may wish to adapt it.

To guide the discussion, it can be helpful to select someone in your group to chair it. Their role would be to help your meeting run smoothly by keeping note of the time and reading out each question in the agenda. At the end of the meeting, they may also wish to summarise what was discussed and any key activities the group has decided upon. As the chair, it can be helpful to familiarise yourself with the video and discussion guide beforehand.

Segment	Timings
The chair of your meeting may wish to give a brief introduction to the meeting and outline what they hope members and visitors will be able to take away from the discussion	2 minutes
Play video 1 - Introduction from Ann Jones, NFWI Chair.	2 minutes
Guest speaker A speaker could be invited to give an introductory talk on the subject, sharing their experience and highlighting why they think action is needed.	15 minutes
Play video 2 - Heather Roythorne (Vice-chair of Leicestershire and Rutland Federation) shares her story of needing a stem cell transplant.	6 minutes
Group discussion – Attitudes and barriers to stem cell donation <i>Depending on the number of attendees, you may wish to divide into smaller groups for the group discussions.</i> See page 10 for a list of questions to guide the conversation.	15 minutes
Play video 3 – Ruth Ainsworth (President of League of Ladies WI) shows how easy it is to register as a potential stem cell donor.	4 minutes
Group discussion – taking action in your WI See page 10 for a list of questions to guide the conversation.	15 minutes
The chair may wish to summarise the discussion and highlight any specific activities or actions the group has decided to take forward. Please take this opportunity to mention where attendees can check their eligibility and register to become stem cell donors.	5 minutes

Discussion guide

Holding a discussion at your event can be a useful tool to explore how people feel about donation and how your WI best can promote the stem cell registry, but donating stem cells is a personal choice and can be a sensitive subject for some people. Here are a few things to keep in mind when holding your meeting or event:

• **How to approach a sensitive subject**

When discussing a sensitive topic it is important to set down some ground rules to make sure that your event is a safe space. All attendees should be made aware or be invited to take part in setting these.

If the meeting is not being recorded, you could ask attendees to keep what is discussed confidential so that everyone feels free to share their experiences and views. Attendees could still be encouraged to talk to other people about the topic, but they should be asked to not say anything that could identify other attendees.

The chair should also emphasise that it is okay to leave the meeting if anyone feels overwhelmed, and highlight any relevant sources of support, as set out on page 5.

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• **Questions to ask**

Group discussion – attitudes and barriers to stem cell donation

Depending on the number of attendees, you may wish to divide into smaller groups for the next two sections

- Why do you think there is such a shortage of stem cell donors in the UK?
 - How do you feel about becoming a stem cell donor yourself?
 - What do you think the barriers are that people face in becoming donors?
 - How do you think these barriers can be overcome?
-

• **Group discussion – taking action in your WI**

- Are there steps that you could take in your WI to raise awareness of the lack of stem cell donors? (For example, could you create a display in your local community or creatively share the resources highlighted in this action pack?)
- What ideas do you have as a WI to encourage more people to consider signing up to the stem cell registry?
- Which ideas do you think would be most effective?
- How could your WI encourage more potential donors from Black, Asian or Minority ethnic backgrounds to sign up?

HAVE YOU CONSIDERED BECOMING A STEM CELL DONOR?

Every twenty minutes, someone in the UK is diagnosed with blood cancer. Around 70% of people who require stem cell treatment depend on finding a match through the stem cell registry.

Only 2% of people in the UK are registered stem cell donors.



MAKE A MATCH

You could save lives by registering as a potential stem cell donor here www.dkms.org.uk/thewi or here www.anthonynolan.org/WI

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Contact us

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