

## Responses to Questions on Notice – Leukaemia Foundation

---

**QUESTION 1 – Cindy McLEISH: “You also mentioned earlier that through Lifeblood there is a bit of advocacy about, you know, signing up to being stem cell donors. What success rate is that? (p. 8)”**

Australian Red Cross Lifeblood has the responsibility to sign donors up to the Donor Registry, while the management of Australia's Donor Registry is run by the 'Australian Bone Marrow Donor Registry' (ABMDR).

Potential donors can volunteer to become a stem cell donor through the Australian Red Cross Lifeblood. The ABMDR also runs Strength to Give, a cheek swab-based enrolment program.

Success rates of particular activities undertaken by other organisations to sign up more stem cell donors are best directed to those organisations.

**QUESTION 2 – Cindy McLEISH: “I have just got a really quick one. Is there a greater prevalence of blood diseases in any particular ethnicity?” (p. 11)**

This can depend on the specific blood disease and/or type of blood cancer, making it challenging to provide a single answer. Generally, ethnicity is not an indicator of the likelihood of having a blood cancer, however ethnicity is vitally important in finding suitable stems cell donors. The diversity of Australia's stem cell donor pool does not reflect the diversity of the Australian population.

There is some research into incidence rates of a few of the over 120 different types of blood cancer. In the example of acute lymphoblastic leukemia, one U.S. study found that for the >14 age group, Hispanic-Whites have the highest incidence rate (1.6 per 100,000 person-years), non-Hispanic Whites and Asian and Pacific Islanders had comparable rates (0.8), and black populations had the lowest (0.6) (Zhao Y, Wang Y, Ma S., *Racial Differences in Four Leukemia Subtypes: Comprehensive Descriptive Epidemiology*. Sci Rep. 2018 Jan 11;8(1):548. doi: 10.1038/s41598-017-19081-4. PMID: 29323237; PMCID: PMC5765036).

Research has shown that chronic lymphocytic leukaemia (CLL) is more common in Caucasian populations than people of Asian descent (including South Asian, East Asian and Southeast Asian) (Leukaemia Foundation and Australian Government Department of Health 2021, *Optimal care pathway for people with chronic lymphocytic leukaemia*, 1st edn., Leukaemia Foundation of Australia), although noting that each year in Australia around 1,000 people are diagnosed with CLL, making it a relatively uncommon type of cancer.

More broadly, being from a similar ethnic background can help increase the chances of finding a donor as a key determinant of a successful stem cell transplantation is finding an appropriate match. Finding a donor generally means looking at 10 specific human leukocyte antigen (HLA) markers in the donor and recipient – a greater number of matching HLA types generally means a greater likelihood the recipient's immune system will not identify the cells as invasive and attack them. HLA markers used in this process are inherited, meaning being from a similar ethnic background can help increase the chances of finding a donor, hence why diversity on our registry is so important (“Why diversity is essential”, DKMS, <https://www.dkms.org/get-involved/stories/why-diversity-is-essential>).