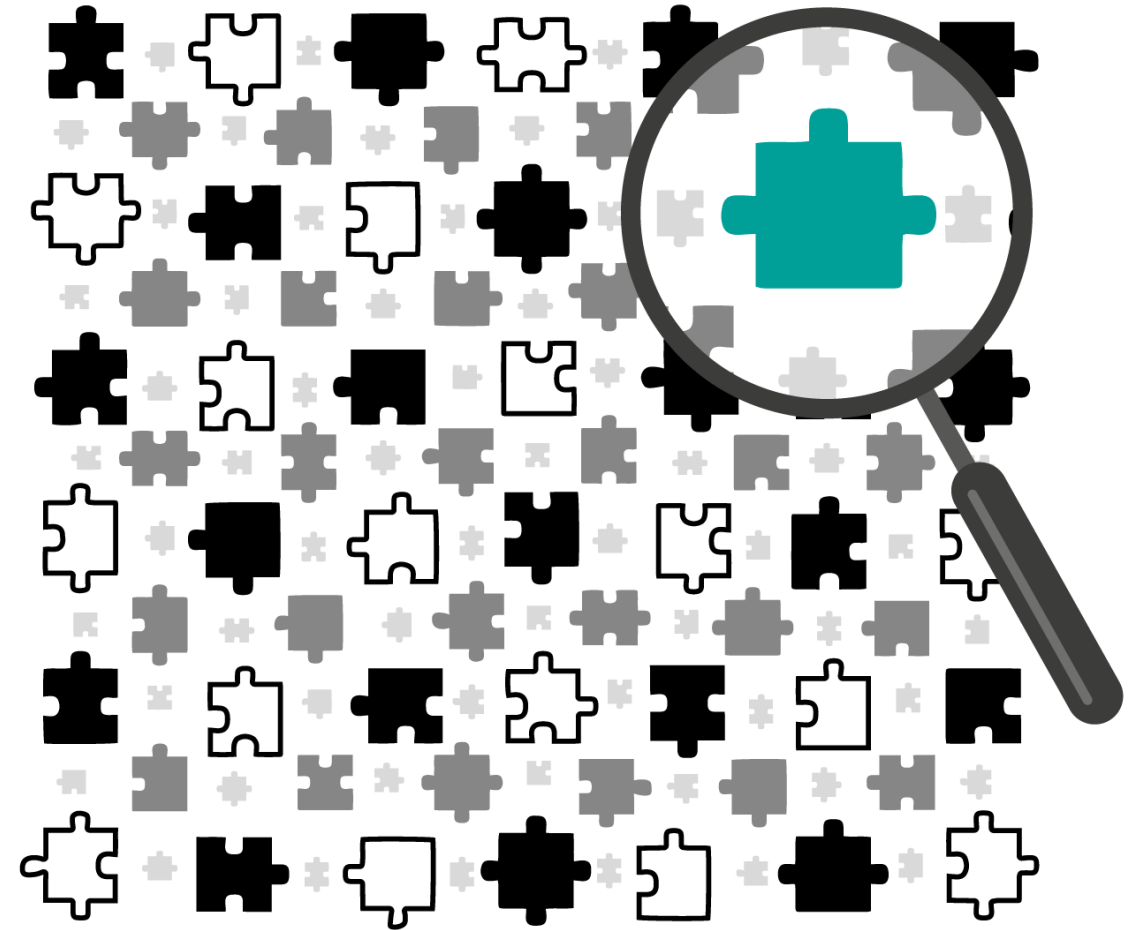


Digital donor services in the Finnish Stem Cell Registry



Finnish Stem Cell Registry

- Operated by the Finnish Red Cross Blood Service
 - Also includes Estonian donors
- Serves four transplant centers (3 Finland + 1 Estonia)
- 73 000 members in registry
 - 7 513 new members in 2023
- 69 donations by registry members in 2023
- Our digital services for donors
 - Joining the registry
 - Digital health questionnaires
 - Consent to donate
 - Donor follow-up



Joining the registry

- Eligibility test online (no personal data collected)
- Joining through registration form on our website
 - No strong identification at this point
- Registration information conveyed to registry software
- Saliva sample kit mailed to prospective member
- Samples returned in ready-paid return envelope
- HLA, blood group and CMV tested at Histogenetics and imported from cloud into our registry software (Excel for Estonian members)
- ➔ Member admitted into the registry database
- Only way to join for several years
 - Now piloting possibility to also join at blood donation sites

The image shows two screenshots from the Finnish Red Cross Blood Service website. The top screenshot is titled "Can I donate?" and contains the text: "Please take this test to find out whether you could be eligible to donate blood or stem cells. The information you provide here will not be stored anywhere, not even in your browser." Below this text are two icons: a red blood drop with a smiling face labeled "Blood donation" and a circular logo with "KSR" and crossed spoons labeled "Donating stem cells". Each icon has a "Start the test >" button. The bottom screenshot is titled "Stem Cell Registry Registration form" and features the KSR logo. It contains the following text: "The founding principle of the Finnish Stem Cell Registry is stem cell donation by an unnamed donor to any patient needing a stem cell transplantation. Such patients may be located in Finland. Before joining the registry, please complete the 'Can I Donate?' questionnaire on our website. Transplants to a patient. A basic requirement is that you are between 18 and 36 years old and in good health." Below this, it states: "There are two steps to joining the Stem Cell Registry:" followed by a numbered list: "1. Fill in this electronic registration form." and "2. After we have received your registration, we will mail you a kit and instructions for taking a saliva sample." The form includes four input fields: "First name*", "Last name*", "Social security number*", and "Date of birth".

Digital health questionnaires and consent to donate

- Strong electronic identification
 - Ubiquitously used in Finnish online services
 - Usually used with online banking codes or mobile certificate
 - Provides both confirmation of identity and means to electronic signature
 - 3rd party service providers accepted by Finnish Transport and Communications Agency
- Health questionnaire at confirmation typing and work-up stages
 - Information complemented with phone interview and/or health check by responsible physician
- Consent to donate signed with strong electronic identification
- Documents transferred from web browser to a secure cloud environment with access only to registry personnel and responsible physician



STEM CELL REGISTRY



Donor follow-up

- Initial follow-up with responsible physician
- Follow-up at 1 and 5 years post-donation with an electronic form
 - E-mail prompting the donor to fill the form
 - Strong electronic identification
 - Filled-in form sent to secure cloud environment for review
 - Phone contact with donor if needed
- Details of follow-up automatically collected for statistical purposes





Our experiences with digital services

- + Long distances in Finland – digital makes joining easier
- + Catering to the busy lives of young people
- + Easier scaling to surges in new members (social media etc.)
- + Saves registry resources (phone contacts etc.)

- Worry of joining too hastily – low motivation to donate
- Not all prospective members return the saliva kit
- Joining via website is easy, leads to massive surges in members
- Technical difficulties with electronic forms

**Thank you
for your
attention!**

