



your identity. Researchers will NOT be given any personal information about you such as your name, address or phone number. The medical information that they will be given for their work relates to your disease and treatment only.

When CellBank provides samples to researchers they will only use the samples for their approved research project. These projects are approved by an independent ethics committee

### Other things you should consider

The samples and information you have gifted will be made available to researchers who may be in the UK or abroad and therefore samples may be sent abroad for research. They may work in universities, hospitals or in private / commercial companies that do medical research. You will not receive any personal financial reward for making your gift.

The samples may be used for genetic research (about diseases that are passed on in families) but the results of this genetic research will NOT be fed back to you or your medical team.

Your samples will be used only for medical research and will not for anything else. This research may not always be directly linked to aplastic anaemia, but will always relate to understanding how the body works, which may help understanding of aplastic anaemia and other diseases in the future.

CellBank may ask researchers to pay towards some of its costs. Your samples will never be sold for profit.

If you have any questions or concerns about the samples and the Cell Bank, please ask the person from the medical team asking for your consent.

# Information Leaflet

## for people aged 16 and over


### About CellBank

CellBank is funded by the charity Bloodwise. It is a collection of blood and bone marrow samples from children and young people with aplastic anaemia. Samples from cell banks can be very useful for scientists to study in order to find new ways to diagnose, treat and prevent aplastic anaemia.



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for more information, please contact us:

-  freephone: 0800 328 0655
-  email: [enquiries@cellbank.org.uk](mailto:enquiries@cellbank.org.uk)
-  web: [www.cellbank.org.uk](http://www.cellbank.org.uk)

**Bloodwise**  
Beating blood cancer since 1960



# CellBank

[www.cellbank.org.uk](http://www.cellbank.org.uk)





## What are we asking you to do?

We are asking you to give permission for a small sample of your bone marrow and/or blood, to be stored by CellBank for study in approved research studies in the future. These samples would be taken at the same time as samples taken to make a diagnosis or to help guide treatment, or would be any of the sample left over after diagnosis or treatment testing.

You are being asked because you will be having tests that involve taking these samples as part of your normal diagnosis and treatment. The samples in CellBank can help to find out about the causes of aplastic anaemia, how to prevent it, and how to treat it.

## What will happen if you say yes?

The first thing you need to do is give your written permission (consent) by signing the CellBank consent form. Please keep this information sheet to remind you of what you were asked to do. Once you have agreed to take part, the following will happen:

- During your treatment, you will have samples taken for tests to help make a diagnosis and to guide your treatment. Any samples left over from these tests will, be given to the Cell Bank. Also, with your permission, a small amount of extra sample, of the same size, will be taken at the same time for CellBank to be used in research. The extra amount would be about a teaspoon of blood or bone marrow. Nothing else would be done to you just for research.
- We also ask that you allow the medical team looking after you to send information from your medical records to the secure CellBank database, for use in research into aplastic anaemia. CellBank keeps the highest level of secrecy with this information, so that researchers cannot identify you.
- If the tests that you are having do not show that you have a form of leukaemia then any samples in CellBank will be destroyed and information in the database will be removed.

You will be giving samples and information that will be gifts that could help research to benefit those affected by aplastic anaemia in the future.

## What will happen if you say no?

You are free to say no – the choice is yours. Your decision will NOT affect the care you will receive from the hospital or medical team, now or in the future. If you say no, any samples left over after diagnostic tests will not be used for research.

## What happens if you change your mind?

You can change your mind about donating your samples at any time by contacting CellBank directly to let us know. You do not need to tell us why. Our contact details are on the back of this leaflet.

If you tell us that you have changed your mind, all samples in storage will be destroyed.

If you change your mind after a long time the samples may have already been used for research. CellBank cannot recover samples or medical information from researchers once they have been used. CellBank will arrange to destroy any samples left over from the research, so that your gift will not be used in any further research.

## What are the benefits to you?

You will not benefit from the research, as it usually takes many years for research to produce new ways that aplastic anaemia is diagnosed, treated or prevented. The results of any research will NOT be put in your health records or told to you, or to your medical team.

## What are the risks to you?

There are NO additional health risks to donating samples for research purposes to CellBank. You will only be allowing us to use samples taken at the same time as the others that would be collected as part of your normal treatment.

Your medical team and CellBank will be the only people who will know

