

about your child such as their name, address or phone number. The medical information that they will be given for their work relates to your child's 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 your child has gifted will be made available to researchers who may be in the UK or overseas 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 or your child 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 child's medical team.

Your child's samples will be used only for medical research and will not for any other purpose. This research will always relate to understanding how the body works, which may help understand aplastic anaemia and other diseases in the future.

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

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

Information Leaflet for parents

About CellBank

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



AA Information Leaflet (Parents) V1, December 2018

for more information, please contact us:



freephone: 0800 328 0655



email: enquiries@cellbank.org.uk



web: www.cellbank.org.uk

Bloodwise
Beating blood cancer since 1960



CellBank

www.cellbank.org.uk



What are we asking you to do?

We are asking you to give permission for a small sample of your child's bone marrow and/or blood to be stored in 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 your child will be having, or recently had, tests that involve taking these samples as part of their normal diagnosis and treatment. The samples in CellBank can help to find out about the causes of aplastic anaemia and other similar disorders, how to prevent them, and how to treat them.

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 the treatment of your child, they will have samples taken for tests to help make a diagnosis and to monitor their disease treatment. Any samples left over from these tests will, with your permission, be given to CellBank. Also, with your permission, a small amount of extra sample will be taken at the same time for CellBank to be used in medical research. This will not involve an additional procedure. The extra amount would be about a teaspoon of blood or bone marrow. Nothing else would be done to your child just for research.
- We also ask that you allow the medical team looking after your child to send information from your child's medical records to the secure CellBank database, for use in research into childhood aplastic anaemia and other similar disorders. CellBank keeps the highest level of secrecy with this information, so that researchers cannot identify your child.
- If the tests that your child is having do not show that they have a form of aplastic anaemia or a similar disorder then any samples in CellBank will be destroyed and information in the database will be removed.

If you agree for your child to donate their samples, your child will be giving samples and information that will be gifts that could help research to benefit those affected by aplastic anaemia and other disorders 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 your child will receive from the hospital or medical team, now or in the future and any samples left over after diagnostic tests will be not be used for research.

What happens if you change your mind?

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

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 recall samples or medical information from researchers once they have been used. CellBank will arrange for the disposal of any samples left over from the research, so that your child's gift will not be used in any further research.

What are the benefits to your child?

Your child will not benefit from the research, as it usually takes many years for research to produce new ways that aplastic anaemia and other similar disorders are diagnosed, treated or prevented. The results of any research will NOT be put in your child's health records or told to you, or to your child's medical team.

What are the risks to your child?

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 child's normal care.

Your child's medical team and CellBank will be the only people who will know your child's identity. Researchers will NOT be given any personal information

