



yorkshire &
humber
side
haematology
network

Parent Information Leaflet

Your child is being invited to take part in a research study. Please take time to read this leaflet carefully and to discuss it with other people if you wish.

Please contact us if there is anything that is not clear, or if you would like more information - our contact details are on the back page.

What is the purpose of the study?

Little is known about why some people develop certain blood disorders (such as leukaemias, lymphomas, myeloma and related conditions) and why people respond differently to treatment. By collecting as much information as we can from people who develop these conditions, we hope to find out more about why they occur and what determines response to treatment. This information may also help improve the organisation of clinical services in the region.

Who is doing the study?

The Yorkshire & Humberside Haematology Network (YHHN) includes the doctors and nurses responsible for your care and researchers at the University of York. The University of York is also the sponsor and data controller for the study, alongside Hull University Teaching Hospitals NHS Trust - more information about this is given in our privacy statement, available at www.yhhn.org/info/data. You can also contact us for a copy to be sent to you.

The study is funded by Cancer Research UK (registered charity number 1089464) and Blood Cancer UK (registered charity number 216032).

Why was my child chosen?

In the Yorkshire and Humberside region, about 2500 people are diagnosed with a blood disorder each year. We hope that most of these people will take part in our study, which started in 2004 and will run until 2029.

Why should we help?

By taking part in our study your child could help other patients, although they may not benefit directly. Information collected from your child and other patients could lead to a greater understanding of the causes of blood disorders and to better treatments in the future. In order for our results to be meaningful, it is very important that as many people as possible take part.

The Yorkshire & Humberside Haematology Network (YHHN)



What does the study involve?

If you decide that you would like your child to take part, with your permission, we would like to do three things:

1. Look at your child's paper and computerised medical records. A research nurse will record relevant information from notes held by their hospital and GP surgery.
2. Use your child's blood and tissue samples **left over from diagnostic tests** routinely carried out. These samples will be used for research purposes within ethically approved studies.
3. Ask you to complete a questionnaire about your child's background, current illness and quality of life. You will be able to do this by **post** (on paper) or **online** at **portal.yhnh.org**

On the consent form, you can give your permission for whatever parts of the study you would like to assist with. If there is any part of the study you would not like to be involved in, your wishes will be respected.

If you consent by **post** (on paper) one copy is for you to keep. If you consent **online**, you will also have the option to register an email address to take part in the study online.

In the meantime, if you have any queries, you can contact us using the contact information on the back page of this leaflet.

Why do you need access to my child's health records?

We need to know about illnesses your child may have had in the past, and medicines and treatments they have been

prescribed. We do this by looking at your child's medical records and by linking to computer-based records.

Identifiable information about your child may be shared with NHS England, including their NHS number, surname, forename, sex, date of birth and study specific identifier. This is so that NHS England can send us information about any illnesses and stays in hospitals your child may have, by linking to Hospital Episode Statistics. NHS England may also send us information about your child's health in the long-term and other cancers, if appropriate.

Why do you need my child's blood and tissue samples?

These samples contain cells and DNA that can be stored and used for future research into the causes and treatment of blood disorders.

Who is responsible for the samples?

Samples will be used for research and teaching purposes only. Blood and tissue samples will be stored by the NHS's Haematological Malignancy Diagnostic Service (HMDS) at St James's Hospital, Leeds. Information relating to your sample will also be stored at the University of York.

What research might the samples and information be used for?

Your child's samples and information may also help in the development and approval of new treatments; this type of research may be carried out in collaboration with our academic research partners and/or the pharmaceutical industry. Any material shared with our partners will not contain information that could identify your child.

Will we be given any results?

Neither you nor your child's doctor will be told the results, nor will the results guide treatment decisions. If your child is asked by an insurance company if they have had any genetic tests, you can answer no because their samples will not be used for this purpose.

Will the information be kept confidential?

YHHN has been approved by your local research ethics committee. The members of this committee include doctors, health professionals and lay people. Any future research using YHHN information will require further ethical approval from the committee.

All information your child provides is totally confidential and kept in accordance with the data protection regulations - more information is given in our privacy statement, available at www.yhnhn.org/info/data.

Information is processed by a restricted number of staff working on the study, all of whom have been trained in confidentiality procedures.

If you agree for your child to take part, we will give them a study number. This will be used to anonymously link information from your child's questionnaire, medical records and samples. This means no one will be able to trace or identify your child from the information we hold.

What studies will be done in the future?

YHHN is a long term research project, and with your permission we would like to use your child's samples and information to undertake further studies in the future. All

these projects will be approved by an ethics committee. Details about these studies can be obtained via our newsletter or on our website www.yhhn.org. You can also contact us using our Freephone number or email address on the back page.

Does my child have to take part and can we change our mind?

It's up to you whether you would like your child to take part or not - your decision will not affect the standard of care your child receives or the relationship with their medical team.

You can change your mind and withdraw your child from the studies at any time without giving a reason and any information your child has given us will be destroyed.

If you wish to withdraw your child, all you need to do is contact us via our Freephone number or email address - you can find these on the back page.

What should I do now?

If you would like your child to take part, please read and sign the consent form and return it in the envelope provided. If you are willing to complete a short questionnaire, please tick the box on the accompanying letter and return the slip to us with the consent form. Or, to consent **online** at portal.yhhn.org, please follow the information given in your letter.

If you feel your child is unable to participate then no further action is needed.

Standard NHS indemnity arrangements apply to this research.

Contact us

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Website

Scan the QR code
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yhhn.org

For newsletters,
our latest research,
and more.

