

INFORMATION FOR THOSE OF YOU BETWEEN 12 AND 16

## NORWEGIAN REGISTER FOR PAEDIATRIC RHEUMATOLOGY (NOBAREV) AND ASSOCIATED BIOBANK

### WHY AM I BEING ASKED AND WHAT IS THE PURPOSE OF THE REGISTER?

This letter contains information about a register called the Norwegian Register for Paediatric Rheumatology (NOBAREV) which has an associated "biobank" where we freeze blood samples and the like. You are receiving this information because you have a rheumatic disease and because your parents have been asked if they would consent to us registering information about you and your disease in this register and to us storing samples of you in this biobank. Children and young people with rheumatological diseases throughout Norway are asked to participate. The register will help ensure the best possible treatment for children with such diseases in Norway, and help make treatment similar all across the country. Among other things, the register will provide an overview of how many people have the disease in Norway, how the medicines work and how those who have such a disease are doing. The register and its biobank will also make it possible to research these diseases.

### WHAT HAPPENS IF I JOIN THE REGISTRY?

If you join NOBAREV, we will register your name and personal identity number, information about your diagnosis, how active the disease is, whether you have other diseases, what medicines you take and the results from blood tests and ultrasound. You and one of your parents will also be asked to fill in a questionnaire about what it is like to have a rheumatological disease, what ailments you have and how you are doing. The examinations will take place completely as a normal check. Even if you join the register, there will be no more checks or other examinations than what the doctor thinks is necessary in relation to your illness.

### WHAT ABOUT THE BIOBANK?

If you are going to take blood samples at the hospital, we would like to store some extra blood in a freezer. This means that 1-2 more test tubes must be taken than usual, but usually there will not be an extra injection. You may be given anaesthetic cream before the blood tests. If you are still going to drain synovial fluid and there is some left over after the necessary examinations have been carried out, we also want to store some of this in a freezer. Then we can examine this material later and learn more about the disease you have.

### WHAT DO I GET FROM JOINING THE REGISTRY?

It is not certain that you yourself will get anything directly out of participating, but in the longer term it can help other children and young people who have the same illness as you. It takes some time to fill in questionnaire, approx. 15 -20 minutes, but you can do that while, for example, you are waiting to come in to see the doctor.

### WHAT HAPPENS TO THE ANSWERS YOU GIVE AND WHAT WE LEARN ABOUT YOU?

In studies, the information about you will be protected without name and personal identity number. A code links you and your information together through a list of names. This means that only those who work with the register can trace back to whom the information and blood samples come from

### JOINING THE REGISTRY IS VOLUNTARY

If you are unsure whether you want to be on the register, talk to your parents about it. If you do not want to participate, you will still receive the same follow-up and treatment as you usually do at the hospital. If you have any questions, you can also ask a nurse or doctor at the hospital, or you can contact registry consultant Berit Myhrmoen by phone: 22029418 / e-mail [bermyh@ous-hf.no](mailto:bermyh@ous-hf.no) or the doctor in charge of the register, Helga Sanner, by e-mail: [helsan@ous-hf.no](mailto:helsan@ous-hf.no).



For more information, see the NOBAREV information portal; scan QR code



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