

Information for Patients for children aged 11-14 years

In preparation of a verbal explanation delivered by the attending physician.
NPC-2016 Registry

Patient: _____ Date of birth.: _____

Dear _____,

You have just been told that you are suffering from a rare form of cancer called nasopharyngeal cancer, which we abbreviate as NPC. This tumour is rare in children and adolescents and therefore a number of doctors have teamed up to get to know more about it. This is only possible through a large network of physicians, as it is not easy to study a tumour that is so rare.

That is why the NPC-2016 registry was created. We try to feed the registry with as many accurate findings from each individual's disease as possible. This data is later documented, stored and evaluated. The registry is supposed to help us search for the answer to the questions about the origins and properties of these tumours, so that they can be better diagnosed and treated in the future. This allows physicians to share their experiences with other physicians and patients in other cities.

Since nasopharyngeal cancer is so rare, we need a lot of data from as many children as possible. Therefore, we would also like to ask you if we could send data relating to you. If you decide to participate, the doctor will send us your medical history records. We will collect this data in a database, store it and use it for the scientific studies.

Your medical history will remain confidential and be treated according to data protection laws. This means that only we can see your name in connection with your medical history and no one will be able to match your history with your name. When we enter your data into the database, other doctors won't be able to see your name, address and other personal information. They will not be able to know whose record it actually is.

In addition, so-called biological studies on tissue samples will be carried out in order to understand the development of a tumour of this kind and so that we are able to fight it better. Tissue samples are scientifically investigated for this purpose. By "tissue" we mean some small portion of your tumour or blood. We won't take any extra blood for this. The blood taken for routine tests will be used. We would also like to investigate washings from your throat. You will have to gargle just like you do while brushing your teeth and later spit the water out into a container.

We would be happy if you could help us and other patients suffering from the same tumour as you by letting us include your data. If you don't want to take part in the database or ever withdraw your consent, that's fine. Your medical treatment will continue as usual. You can take your time and discuss with your parents and the doctors treating you if you would like to participate. If you have any questions, ask your doctor, who will be happy to help you.

Thank you!