Schweizerische Pädiatrische Onkologie Gruppe
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KRANIOPHARYNGEOM Registry 2019

Background

A craniopharyngeoma is a rare malformation originating from tissue that was already developing abnormally before the child was born. The reasons for this condition are still unknown. A craniopharyngeoma can cause major impairment of vision because of its location close to the optic chiasm and important parts of the brain and can also harm physical and mental development. It is often not possible to remove the cancer completely by surgery as this could cause serious damage to neighbouring parts of the brain. Equally, some craniopharyngeomas recur despite having been removed completely. With a few exceptions, affected children and adolescents need to take hormones regularly for the rest of their lives following surgery, and suffer from impaired memory, attention and vision.

Why does the trial need to be done?

Since these brain cancers are so rare, new scientific knowledge can only be gained through cooperation and by exchanging information between many treatment centres. The KRANIOPHARYNGEOM registry will therefore record data on the diagnosis, therapy and complications of this brain cancer and the treatment received by patients in many hospitals throughout Europe. The aim is to use these observations to improve therapy for future patients as far as possible. This work should result in greater understanding of why these brain cancers develop and how their treatment can be improved in future. Another goal of the KRANIOPHARYNGEOM registry is to provide all patients with the best therapy currently available. With this in mind, a group of experts has formulated therapy recommendations based on the latest scientific knowledge and made them available to the doctors providing treatment.

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