Trial launches for children's brain tumour, ependymoma

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The University of Birmingham's Cancer Research UK Clinical Trials Unit will coordinate the UK arm of a large international clinical trial for a type of children's brain tumour, called ependymoma.

Ependymoma is a rare tumour of the central nervous system. In children and young people, the tumour is most commonly found in the brain, while it is more likely to be located in the spine of adult patients.

The trial, launched by Cancer Research UK Kids & Teens is funded in partnership with TK Maxx, and will treat around 150 children in the UK with ependymoma up to the age of 22. Researchers aim to find the most successful treatment option with the fewest side effects for patients and to learn more about the biology of the disease.

Patients will be diagnosed and treated at their regional children's and young person's cancer centre.

Experts at the Children's Brain Tumour Research Centre (CBTRC) in Nottingham will host a weekly meeting to advise and support doctors at the local treatment centres on the best care plan for their patients. The CBTRC at the University of Nottingham are one of the five international centres working on the underlying biology of ependymoma and will also analyse patient samples collected from hospitals across the country and internationally.

The University of Birmingham's Cancer Research UK Clinical Trials

Unit will coordinate the trial; setting up the trial in children's cancer centres in the UK, registering patients for the trial, collecting patient information, and managing data from the trial.

The UK arm of the trial will feed into a large international trial, following more than 500 children, teenagers and young adults across 16 European countries to try to improve the outcome for this difficult to manage, complex brain tumour. The trial will run for five years and follow patients for up to 10 years.

Around 30 children and young people are diagnosed with ependymoma in the UK every year and while treatment options have improved, the disease can come back. And the aggressive treatments used can have long-lasting effects including learning difficulties, hearing loss and problems with physical development.

The patients will be divided into groups and each group will be receive different treatment.

- Patients whose tumour appears to have been fully removed by surgery will be placed in the first group. These patients will be treated either with proton beam radiotherapy alone or will receive proton beam radiotherapy followed by chemotherapy.
- Patients in the second group whose tumours were not fully removed through surgery will be treated with chemotherapy followed by radiotherapy. These patients may also need more surgery.
- The third group will treat very young children under the age of 18 months and children between the age of 18 – 36 months depending on where their tumour is, or other children and young adults. Patients in this group will not be given radiotherapy because they are more susceptible to serious side effects from this treatment. These patients will be treated with chemotherapy

and some will receive drugs called histone deacetylase inhibitors which are now being investigated as possible cancer treatments.

Professor Pam Kearns, Cancer Research UK's senior clinical advisor and director of the University of Birmingham's Clinical Trials Unit, said: "Although we're losing fewer young lives to cancer, a lot more needs to be done to improve treatment options for children. Ependymoma is the third most common type of children's brain tumour and we need more good quality research to improve how we treat the disease and to help diagnose and treat it at an earlier stage.

"Cancer Research UK set up the Kids & Teens campaign to increase the investment in research focused on children's cancers and develop more effective treatments that reduce the long term side effects that can have a major impact later in life."

Professor Richard Grundy, the UK's trial lead from the University of Nottingham said: "The study will improve our overall understanding of the biology of this disease while providing evidence for which groups of patients and treatments have the best outcomes and how best to treat this complex disease in the future.

"In the future this will allow us to develop more tailored treatment plans based on patients' age and diagnosis to give them the best chance of beating this aggressive disease while reducing the long-term impact that treatments may have on their lives."

Provided by University of Birmingham