

## Improving treatment decisions and outcomes in low grade glioma



**Project title:** Development of a multi-factorial prognostic model to optimise treatment decision making and outcomes in paediatric low-grade glioma

**Lead researcher:** Professor Darren Hargrave, Great Ormond Street Hospital

**Project Stage:** Ongoing (started June 2021, planned end May 2023)

**Funded by:** Thomas' Fund

### ABOUT THE PROJECT

Childhood low-grade glioma (PLGG) are a group of tumours which can affect any part of the brain or spine from infants to teenagers. Although most patients survive the tumour, children still die and experience multiple relapses. This means that many survivors experience a big hit to their quality of life, from both tumour and the burden of treatments.

The research team at Great Ormond Street Hospital, led by Professor Darren Hargrave, aims to analyse over 1000 PLGG patients treated at Great Ormond Street over the past 40 years to look at the factors that affect patient survival and quality of life. The team will contact PLGG survivors and their families who are at least 5 years from diagnosis and invite them to complete questionnaires that cover all aspects of daily living and quality of life. This will give a snapshot of how PLGG affects patients, and allow a comprehensive analysis of how the clinical, biological and treatment factors influence long-term outcomes.

The researchers plan to develop a study group which includes parents and PLGG survivors. This group will help consider the results and create guidelines to help doctors, patients, and their families make informed treatment decisions. Professor Darren Hargrave hopes that this will lead to a more personalised approach in the choice and timing of specific treatments for patients.

### PROGRESS

The researchers have collected details of 814 patients with PLGG to look at the factors leading to disease progression and overall survival. They have also collected over 450 samples of PLGG tumours and are planning the best way to analyse the small amounts of tissue available.

The team have involved young people and parents in the development of a questionnaire to

help ask the correct questions of how PLGG and its treatment impacts on the daily life of patients and their families. They are now gathering this information and will then analyse any factors which may help to predict which problems effect which patients. They also hope that they can try to reduce or avoid these problems in future by developing a medical guidelines to assist doctors, patients, and families in making informed and shared treatment decisions. This will allow a more individualised approach in the choice and timing of specific treatments for patients during the course of their illness.

## WHAT'S NEXT?

Over the next year, the research team plan to complete the molecular analysis of tumour samples and involve PLGG survivors in finding out what are important quality of life measures. This information will be combined to create a prognostic model. Prognostic models are a combination of factors (for example tumour type and location) that you can put in a patients data and see what the likely outcome would be with different treatments (such as chance of survival and quality of life after treatment). This will help doctors with treatment decision making and improve outcomes in paediatric low-grade glioma.



This project was funded by Thomas' Fund, a Special Named Fund at Children's Cancer and Leukaemia Group raising funds for research into low grade glioma.



Children's  
Cancer and  
Leukaemia  
Group

the EXPERTS  
in CHILDHOOD  
CANCER

© CCLG 2023

Children's Cancer and Leukaemia Group  
Century House, 24 De Montfort Street, Leicester LE1 7GB  
Registered charity in England and Wales (1182637)  
and Scotland (SC049948).

0333 050 7654

[info@cclg.org.uk](mailto:info@cclg.org.uk)

[www.cclg.org.uk](http://www.cclg.org.uk)



ChildrensCLG



CCLG\_UK



CCLG\_UK