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The Collaborative Ependymoma Research Network (CERN)

Mark R Gilbert

Department of Neuro-Oncology, Division of Cancer Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

CERN was launched in 2007 as a unique multi-disciplinary collaborative effort of international investigators guided by the mission to develop new treatments for ependymoma, improve the outcomes and care of patients, ultimately leading to a cure; CERN combines efforts from investigators with expertise in adult and paediatric brain tumour research. Mark Gilbert serves as the overall leader of CERN, and 5 projects define the core structure.

The first project is the Clinical Trials Network encompassing groups of paediatric and adult centres of excellence, led by Amar Gajjar and Mark Gilbert; it now includes European sites as well. Currently, several clinical trials are open and actively accruing including 2 adult trials and 2 paediatric studies (Table 1).

Table 1. List of open clinical studies/trials

Protocol Title	Eligibility
CERN 08-01: Lapatinib and bevacizumab for recurrent paediatric ependymoma	Age < 18, prior radiotherapy, unlimited tumour relapses, brain or spinal cord
CERN 08-02: Lapatinib and dose-dense temozolomide for recurrent adult ependymoma	Age > 18, unlimited prior therapies, brain or spinal cord
CERN 09-02: Carboplatin and bevacizumab for recurrent adult ependymoma	Age > 18, unlimited prior therapies, brain or spinal cord
Phase-I Trial of Bolus 5-fluorouracil	Age < 18, prior radiotherapy

Note: Accrual is only possible at approved CERN sites.

The second project is the Pathology and Tumour Molecular Profiling project. Adult and paediatric neuropathologists, Ken Aldape and Cynthia Hawkins, lead this project and provide central review of tumour tissue for clinical trials. Additionally, a tumour repository has been established that collects confirmed ependymoma tumour samples that have good clinical outcomes annotation providing a great resource for molecular discovery and for studies of patient outcomes.

The third project is Drug Development and Discovery. This project is led by the combined efforts of a basic/translational scientist, Richard Gilbertson, and a medicinal chemist, Kip Guy. High throughput screening using a robust ependymoma model has already identified several candidate agents, including 5-fluorouracil that is currently in clinical trial. Collaboration with the Pathology Project will focus on developing specific profiles in patient's tumours that inform treatment decisions.

The fourth project is Tumour Biology, led by Richard Gilbertson. This project has focused on developing robust models that recapitulate the heterogeneity of ependymoma so that drug screening can be performed on the spectrum of ependymoma and potentially permit treatment optimization for each patient. Collaboration with the molecular profiling effort in the Pathology Project will help validate these models and create clinically relevant profiles.

The fifth project focuses on Patient Outcomes and is led by Terri Armstrong. This project has successfully incorporated informative measures of patient's performance and symptom burden into the current clinical trials. Additionally, outcomes surveys have been launched to assess the spectrum of treatments and care provided to ependymoma patients and to determine the spectrum of disease outcomes in the broad patient population including those without active disease.

Future initiatives include the development of a registry which will track disease course and identify correlative tumour markers in patients with ependymoma.

These efforts are complimented by an extensive Education and Outreach effort, led by Charles Haynes and Kimberly Wallgren. This effort includes an annual Ependymoma Awareness Day, a robust website containing patient and caregiver resources, and an educational video collection (Youtube.com; search "CERN"). Those interested in learning more about CERN are encouraged to contact Dr Gilbert, any of the project leaders, or submit a query to us through the website: www.cern-foundation.org.

Correspondence to:
Mark R Gilbert, MD
Department of Neuro-Oncology
University of Texas MD Anderson Cancer Center
PO Box 301402
Houston, TX 77230-1402
USA
e-mail: mrgilbert@mdanderson.org

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