

FOR IMMEDIATE RELEASE
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The EndBrainCancer Initiative Partners with the National Cancer Institute (NCI) for Advocacy, Education and Placement into Clinical Trials for Brain Cancer Patients

The Seattle-based EndBrainCancer Initiative (EBCI) announces it has partnered with NCI-CONNECT to facilitate engagement with patients with rare CNS tumors (including various forms of brain cancer) and to advance research.

Seattle, WA - December 18, 2018 - The EndBrainCancer Initiative (EBCI) is pleased to announce its new advocacy partnership relationship with a program at the National Institutes of Health (NIH), National Cancer Institute (NCI), Center for Cancer Research (CCR), Neuro-Oncology Branch (NOB) called [NCI-CONNECT](#) (Comprehensive Oncology Network Evaluating Rare CNS Tumors). The program aims to advance the understanding of rare adult central nervous system (CNS) cancers by establishing and fostering patient-advocacy-provider partnerships and networks to improve access as well as approaches to care and treatment.

The EBCI partnership with NCI-CONNECT will facilitate engagement with patients with select rare brain tumors. This education and placement will become an expanded feature of the EBCI's "[Direct Connect](#)" Program facilitated by patient navigators. EBCI and its navigators will provide specific [educational](#) and [clinical trial](#) information to patients and assist them with placement for treatment at the NCI Neuro-Oncology Branch at the NIH and the associated Brain Tumor Trials Collaborative (BTTC) centers.



A program of the National Cancer Institute
of the National Institutes of Health

"We are pleased to enter into this collaborative partnership with NCI-CONNECT with its emphasis on accelerating access to specialists and to clinical trials for rare CNS cancer patients and fueling research," comments Dellann Elliott Mydland, President & CEO of the EndBrainCancer Initiative (formerly the Chris Elliott Fund). "It is this accelerated access to specialists, experts and researchers and to personalized treatment options which is the model that the EBCI and its programs and services were founded upon in 2002. The personalized approach and model works. The EBCI provides these programs and services weekly and is and has been advocating that this approach become Standard of Care and practice for this patient base. We therefore support the NCI-CONNECT Initiative and welcome the opportunity to partner for the benefit of patients, helping improve options and outcomes for patients with rare forms of brain cancer and impact even more people."

The broad-based goals of NCI-CONNECT are to:

- Develop an infrastructure across a network of national and international sites to study select rare CNS tumors.
- Use the network to facilitate the translation of discoveries into new therapies and methods to improve patient outcomes.
- Collect, analyze, and share data to promote discovery and improve understanding of select rare CNS

tumors.

[\(overview video of program\)](#)

NCI-CONNECT is co-directed by Mark Gilbert, M.D., Chief of the Neuro-Oncology Branch, and Terri Armstrong, Ph.D., Chief and Deputy Chief, NOB, CCR, NCI, who recognized they had an unprecedented opportunity to focus research efforts on rare CNS cancers with funding from the [Cancer MoonshotSM](#). Utilizing the existing BTTC (Brain Tumor Trials Collaborative) infrastructure and network, NCI-CONNECT has a number of studies that are open and available for participation. NCI-CONNECT seeks to address the challenges and unmet needs by connecting patients, providers, and advocates with the belief that a collaborative network with a harmonized mission can have a great impact on the progress of clinical care and research for the lives of people with brain and spine tumors and their families.

NCI-CONNECT Co-director Mark Gilbert, M.D, further explains, “We’re integrating patient support and focused research efforts so that we can make more therapies available to more patients sooner. So, what would take 10 years, we hope to achieve in five years. Our approach is to connect basic science research to patient outcomes research and scientifically-based clinical trials.”

Accelerating research is a key policy goal of the [EndBrainCancer Initiative strategic plan](#). Dellann Elliott Mydland adds, “We strongly support NCI-CONNECT’s direction on studying and treating 12 rare cancers (less than 2,000 patients per cancer per year nationally). With the majority of new treatments and trials focused on glioblastoma (the most common form of brain cancer) this program offers a welcome and much needed opportunity for patients facing these rare forms of cancer to receive targeted education and special placement opportunities for treatment, with the underlying program focus to improve patient outcomes and advance research. We applaud the development of this conduit for public agency/501C3 nonprofit partnership with a research aim.” Mydland also currently works with the NCI in advancing research as a member of the patient advocacy and brain cancer site committees of NRG, a research group funded by the NCI.

The [EndBrainCancer Initiative](#) (EBCI, formerly the Chris Elliott Fund, based near Seattle, Washington) is a national brain cancer and brain tumor patient advocacy and services organization offering brain tumor disease education and awareness with direct connection for patients to centers of excellence, advanced treatments and clinical trials. Through its history EBCI has advocated at the national and state levels for the accelerated approval of new promising treatments, changes to the standards of care, and approval and reimbursement of new therapies for cancer patients by insurance companies and Medicare.

The EndBrainCancer Initiative is one of several organizations currently designated as [NCI-CONNECT related organizations](#). Others include the American Brain Tumor Association (ABTA), Collaborative Ependymoma Research Network (CERN) Foundation, International Brain Tumour Alliance, and National Brain Tumor Society.

This announcement / press release is intended to convey information about the EndBrainCancer Initiative exclusively. The information contained herein should not be interpreted as any form of endorsement of the work and programs of the EndBrainCancer Initiative by the U.S. Department of Health and Human Services (HHS), NIH, or NCI.

About the EndBrainCancer Initiative

The [EndBrainCancer Initiative](#) (EBCI, formerly the Chris Elliott Fund) is a national brain cancer and brain tumor patient advocacy and services organization and 501(c) 3 social enterprise with offices in Redmond, Washington. Established in 2002 and now celebrating 16 years of service, EBCI is committed to finding a cure for brain cancer and bringing HOPE to the lives of patients and their families through its three programs:

- “Direct Connect” Patient Support and Services Program
- Brain Tumor Disease Education, Awareness, and Outreach Program
- Brain Tumor Patient Advocacy and Access

Since its founding, EBCI has helped thousands of patients, caregivers, and their families and has become a credible and trusted resource at all levels in the brain cancer treatment community from patients to research institutions to pharmaceutical and regulatory entities advocating on the National and State level for the approval and reimbursement of new therapies for cancer patients. EBCI also participates as the “Patient Voice” in clinical trial design, an example can be seen in *CNS Oncology* ([Link to Article](#)).

EBCI supports about 900+ patients, caregivers and families, free of charge annually through its “Direct Connect” Program, and provide Education/Awareness/Outreach to over 8.7 million annually, including members of the Brain Tumor Community. EBCI is a member of the American Society of Clinical Oncology (ASCO), Society for Neuro-Oncology (SNO), American Association of Neuroscience Nurses, American Association for Cancer Research, and Life Sciences Washington, among other organizations.

If we can help, please contact us at WeCare@EndBrainCancer.org or 425.444.2215. To support EBCI’s efforts, programs, and services, provide a gift today at www.endbraincancer.org

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