

FOR IMMEDIATE RELEASE
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The EndBrainCancer Initiative Received CITI Certification Becoming the First Brain Tumor Patient Advocacy Organization Listed as a Nationally-Recognized Recruiting Site

Prestigious certification strengthens Seattle-based EBCI's role in the brain tumor advocacy space directly connecting patients to Centers of Excellence, cutting edge treatments & development of promising clinical trials

Seattle, WA - August 2, 2018 - The EndBrainCancer Initiative (EBCI, formerly the Chris Elliott Fund) received CITI certification to recruit caregivers to participate in brain cancer caregiver and patient clinical trials at the Pacific Neuroscience Institute and John Wayne Cancer Institute in conjunction with Providence Health Services of Southern California.

At the [Pacific Neuroscience Institute](#) and [John Wayne Cancer Institute](#), EBCI is collaborating with [Dr. Santosh Kesari](#), Chair and Professor, Department of Translational Neurosciences and Neurotherapeutics, and Director, Neuro-oncology. Dr. Kesari's clinical team conducts leading-edge clinical trials of immunotherapy, stem cells and biomarker-based therapies. Dr. Kesari says of this partnership with EBCI: "We enlisted the support of EBCI for patient recruitment because of their expertise and proven effectiveness, and especially because of the trust they have earned with patients as an advocacy organization. For years EBCI has been doing the work of placement with clinical trials. Now with their CITI certification we have formalized our relationship as an official recruiter for this new clinical trial."



Dr. Santosh Kesari, MD, PhD

CITI ([Collaborative Institutional Training Initiative](#)) is an international training organization which certifies those involved in medical research utilizing human subjects in ethics, compliance, federal (and institutional) requirements and accepted scientific standards. Institutions around the world, including all of the academic medical centers in the U.S., utilize the CITI Program. In addition, the CITI program is used by the U.S. military, government agencies, and many companies involved in research.

To achieve certification, EBCI staff went through rigorous training on Human Subjects Research (HSR), Good Clinical Practice (GCP) and Conflict of Interest. These trainings delineate the key principles for conducting recruitment and research, consistent with federal (and institutional) requirements and accepted scientific standards. In the area of patient recruitment, topics include informed consent, ethical standards for communicating treatments, principles for correct communication, HIPPA compliance and confidentiality, and other current regulatory guidelines.

Dellann Elliott Mydland, President and Founder of the [EndBrainCancer Initiative](#), commented, "We are proud to receive CITI certification. Since 2002, EBCI has been dedicated to advocating for the rights of patients for immediate access to brain tumor specialists, Centers of Excellence, cutting edge treatments, and promising clinical trials. EBCI addresses the need for immediate access through its "Direct Connect" Patient Services program by educating and "pre-qualifying" brain cancer patients for clinical trials, and directly connecting them to the Principal Investigator (PI) or Medical Center hosting this trial within the patient's geography. EBCI also creates education and awareness for the brain tumor patient community through its Brain Tumor Disease

Education, Awareness, and Outreach Program and advocates for on behalf of brain tumor patients for increased access and reimbursement of therapies of benefit to brain cancer patients and for changes in WHO and NCCN Guidelines to include genomic testing as part of Standard of Care (SOC) for all cancer patients. Now with CITI certification, we can deepen our partnership with research institutions and principal investigators to be able to place qualified patients quickly and seamlessly. It will also help us further our goal of attracting and supporting more brain cancer clinical trials in our Puget Sound region at the Alvord Brain Tumor Center at UW Medicine, the Ben & Catherine Ivy Center for Advanced Brain Tumor Treatment at Swedish Neuroscience Institute, the Fred Hutchinson Cancer Research Center, etc., and other brain tumor centers across the U.S.”

The CITI Program has been a leading research ethics and compliance training since its founding in 2000. Federal law requires Institutional Review Boards (IRB) ensure that specific ethical and procedural standards are followed in all aspects of the clinical trial including formulation, recruitment, conducting of the trial, communications, reporting and research conclusions. This program is recognized by the Department of Health and Human Service's Office of Human Research Protections as meeting the educational requirements of [45 CFR 46](#) and is a must for professionals working in clinical research. Having achieved CITI certification, EBCI is poised to serve as a recruiting site for clinical trials across the U.S. starting with the clinical trial, An Exploratory Study of Caregiver Burden Among Family Caregivers of Patients With Cancer ([ClinicalTrials.gov identifier NCT03069105](#)), which explores the caregiver burden among family caregivers of patients with cancer.

[Marlon Garzo Saria](#), PhD, RN, AOCNS, FAAN, Nurse Scientist and Director, Center for Quality and Outcomes Research at Pacific Neuroscience Institute and John Wayne Cancer Institute has this to say of EBCI's work: “The role of EBCI in the development and conduct of research is not only important, it is necessary. There is a growing consensus to advance the role of patients and the public in research. In fact, it is now more common to see patient and public involvement as a requirement to receive funding in many countries, including the UK, the Netherlands, Canada, Australia, and the USA. EBCI serves as the perfect liaison between researchers and patients. EBCI serves as the voice of patients and their families and also helps advocate and support research. I believe that the partnership we have with EBCI will be a model of academic-public collaboration in advancing the science of caregiving.”



Tina Hoffman, Patient Liaison/Navigator; Claire Tinker, Program Support; Dellann Elliott Mydland, Founder & President; Riley Elliott, Vice-President; DeEtta Snyder, Program Coordinator

Brain cancer research faces unique challenges. Currently, only approximately 3% of brain cancer patients nationwide enroll in clinical trials. This low number of enrollees, coupled with the lack of patients relative to other cancers, the short life expectancy of brain tumor patients, and patients often not brought to clinical trials soon enough, presents a major challenge for researchers. The EndBrainCancer Initiative receives thousands of inquiries from brain cancer patients, caregivers and families every year. The EBCI team “pre-qualifies” them for clinical trials and then “Directly Connects” them to the hosting medical center or principal investigator. The organization envisions seeing clinical trial enrollment increased to 15% by 2025. Achieving CITI certification is a major step in achieving this goal.

EBCI interacts intensively with patient caregivers. The initial clinical study EBCI is recruiting for focuses on the role and burden of the caregiver. Tina Emerson-Hoffman, CITI Certified Patient Liaison & Navigator at EBCI, had this to say about the importance of better understanding the role of the caregiver: “A brain cancer diagnosis is a devastating experience for everyone involved. Non-professional caregivers and long-term care providers of cancer patients receive little preparation, information, or support to perform their vital role, although we know that patients with a strong, experienced caregiver have greater outcomes. A family is often so focused on the patient, that many caregivers find themselves overwhelmed and at a loss on where to turn or what to do next. In our day to day work, EBCI is in the position to offer caregivers and families just the support they need

to navigate this journey, and to help ease that burden. In my role at EBCI, I'm really excited to participate in this family caregiver-focused trial, and others. It is a great opportunity to have a positive impact, as the caregiver burden can negatively impact patient outcomes. My hope is that we can increase enrollment for this trial, which can inform treatment for all brain and other cancer patients.”

Brain cancer patients and their families are in need of a helping hand, as few are prepared to seek out clinical trials on their own. Because of the weight of a brain cancer diagnosis and the often related cognitive impairment, patients are not often at full capacity to make these decisions in a very short timeframe. The EndBrainCancer Initiative is very experienced with these dynamics and has always sought to be a patient-centric advocate helping patients find the right treatment or trial for them.

“In order to advance patients outcomes through our work, more direct involvement in clinical trials is the next step,” added Dellann Elliott Mydland. “Currently, EBCI is also proud to serve as the “patient voice” in development of two clinical trials around the needs of patients and caregivers in the Pacific Northwest as well as SPORE Clinical Projects at the Thomas K. Hearn, Jr. Brain Tumor Research Center, Comprehensive Cancer Center in Winston-Salem, NC. We are excited to further our goal of fueling research and clinical trial enrollment with new CITI credentials. We welcome [collaboration inquiries](#) from other philanthropists, pharma, biomed, device and diagnostic companies, and clinical research organizations (CROs) on partnership opportunities to increase outcomes and enrollment.”

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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