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The EndBrainCancer Initiative Announces Two New Programs to Fuel Clinical Trial Enrollment of Brain Cancer Patients and Advance Cure

EBCI launches two new programs (First Step & Team Up) designed first to spur tumor tissue saving, genomic/biomarker testing of tumor tissue, and enrollment in clinical trials, and second, promote greater participation by local community hospitals and clinicians. EBCI's goal is to increase clinical trial enrollment from the current estimated 3% to 15% by 2025.

Seattle, WA - November 14, 2018 - The EndBrainCancer Initiative announces the initial phase 1 release of two new initiatives designed to fuel research and spur clinical trial enrollment. Currently approximately only 3% of brain cancer patients participate in clinical trials. The aggressive goal of the campaign is to increase that to 15% nationwide by 2025.

In the last 30 years only a few drugs have been approved by the FDA for the treatment of brain cancer. The current estimate for bringing a drug to market is 20 years. This development process is entirely too slow given the dire nature of brain cancer itself and the estimated 17,000 nationwide who contract this cancer annually in the United States. The EndBrainCancer Initiative is dedicated to ending brain cancer with increased survivorship, a quest for maintenance of this disease, and ultimately, a cure. The campaign and two programs were developed to fuel research, tumor tissue saving, genomic/biomarker testing, and clinical trial enrollment through active measures to encourage community hospitals to become more involved in ensuring that the brain tumor patients they treat also have immediate access to other specialists, neuro-surgeons, genomic/biomarker testing, and to clinical trials.

First Step Initiative

The First Step Initiative - (<https://endbraincancer.org/firststep>) The "First Step" patient initiative invites brain cancer patients (directly, through the EBCI, their caregiver, through other advocates, or through their own voices) to sign up through an online form to indicate in principle, interest in participating in genomic/biomarker testing and in clinical trials. The online page informs the patient of important facts such as that if patients begin chemical or radiation treatment, it could preclude them from certain trials and treatments. It also informs the patient of the importance of preserving live tumor tissue samples for the purpose of genetic testing and profiling, which is often necessary to inform treatment options as well as to enter into clinical trials.

"A brain cancer diagnosis is overwhelming. Our goal with 'First Step,'" commented Dellann Elliott Mydland, President & CEO of the EndBrainCancer Initiative, "is to reduce initial complexity, get across key facts to brain cancer patients, and to empower them. We want to inform patients of the opportunities available to them to improve treatment options and outcomes and invite them to take strong action. Our hope is also to help brain cancer patients feel they are stepping into the care and concern of a broader community who will help them and guide them. After that, the ongoing work of connecting patients appropriately to other specialists and to clinical trials can happen."

The First Step and Team Up initiatives support EBCI's broad goal to fuel research: to help more patients access advanced treatments and relevant clinical trials and to increase the number of community hospitals either hosting clinical trials or referring patients to trials conducted elsewhere.

The Challenge of Recruitment

One of the greatest challenges for clinical trials is recruitment or "accrual" as it is known technically. Brain cancer is particularly challenging. It is (relatively speaking) still a rare disease and often is very aggressive, requiring, with the

current practice, immediate surgery according to Standard of Care, as well as specific chemotherapy in combination with the Optune device (<https://www.optune.com/>). The life expectancy for stage four brain cancer tumors also known as Glioblastoma/GBM, is often less than 24 months. There are several publicly and privately funded trials for GBM patients across the U.S., but there are often significant challenges in getting qualified patients into those trials. This inhibits patient outcomes and increases the cost and length of trials and research, thus delaying advancement of treatment options for this patient population.

Various studies have analyzed the barriers preventing greater participation for clinical trials at the local level. Common challenges cited include: funding, paperwork and regulatory burden, financial factors, need for support staff, issues with screening, ethical issues, availability for funding, political dynamics, lack of support for clinical trials from local leadership, policies that do not allow community hospitals to refer out of their current hospital system, and many others.

Team Up Initiative

The “Team Up” initiative (<https://endbraincancer.org/teamup>) is an effort to invite local doctors and hospitals to indicate interest in principle (through an online form) to increase the opportunity for their patients to have their tumor tissue saved, have their tumor tissue genomic/biomarker profiled, connect with specific specialists and neuro-surgeons, and to participate in clinical trials. The goal at EBCI is to support clinical trials that are publicly and privately funded to accrue more participants. The Team Up initiative creates an interest list. The goal is to promote dialogue and establish strategies to stimulate participation and referral of more patients to trials and to bring more trials to community hospitals. Recognizing that the issues are complex, the EndBrainCancer Initiative is bringing together hospitals, doctors, researchers, neuro-surgeons, pharmaceutical companies, other advocacy organizations, and patients to dialogue about this and develop approaches where different concerns and needs can both be expressed and addressed. The hope is this will lead to more treatment options for patients and increased patient outcomes where tumor tissue is saved, fueling

trials/research related to personalized medicine. This “team up” dialogue will also cover areas such as financial considerations, collaborations, patient management, access to findings and new treatments, professional recognition and advancement, administrative support, etc.



*Dellann Elliott Mydland,
President & CEO,
EndBrainCancer Initiative*

[NCORP](#), The NCI Community Oncology Research Program, works to bring cancer trials broadly into community hospitals. Their major focus is addressing the disparities in communities that do not have access to advanced treatments and research trials, an issue that disproportionately impacts communities of color and disadvantaged populations. EBCI honors the significant work across the US that NCORP is doing and that local community hospitals and practitioners are doing (in both accrual as well as delivery). We hope the Team Up initiative can build upon NCORP's work and help advance adoption and referral of patients to privately funded trials. Again, the Team Up Initiative and its partners want to advance by listening first in order to solve these challenges and advance research, survivorship and cure. EBCI's founder and CEO/President also serves on the brain tumor site and patient advocacy committees with NRG, a research group funded by the National Cancer Institute (NCI), that advises on the focus and funding for publicly funded clinical research studies. EBCI is thus focused on fueling research supported by both public and private initiatives.

Mydland added, “Both the First Step and Team Up initiatives support our broad goal to fuel research. There are exciting developments in the fields of immunotherapy, protein kinase inhibitors, angiogenesis inhibitor treatment approaches, and others. Our goal is to help patients access advanced treatments and relevant clinical trials and to increase the number of community hospitals offering clinical trials or to increase referrals of their patients to clinical trials held at a Brain Tumor Center for Excellence or elsewhere. The ultimate goal with these initiatives is to collaborate in a way that will offer increased access for patients to clinical trials. For instance, we are currently working with one of our corporate partners, Orbus Therapeutics, to promote, educate patients and actively deploy EBCI's 'Direct Connect' program and trial pre-qualification services to place qualified patients in the Stellar Trial (<http://www.stellarstudy.com>), a phase 3 study/trial researching a new drug for recurrent AA (Anaplastic Astrocytoma). We believe this approach is promising and as there are fewer studies addressing AA, this is why we got behind these efforts. But, we too are faced with the challenge of getting more patients into this trial. Our Call to Action: we want to work with hospitals and community oncologists to accrue more patients for this trial. Our Team Up initiative was developed to support these types of goals. We want patients to sign up and get started through our First Step initiative, so that even if they do not know if they qualify, they can get in a pool where they can be supported and directed to the Stellar study or another good possible trial.”

The FDA and several states have recently approved communicating to prospective clinical trial participants potential financial help both for travel and direct participation. The landscape is changing. The Team Up Initiative can help

community oncologists or community hospitals make the connection with clinical trials, and currently the Stellar trial, to discover how the trials work with all stakeholders. If you are a community hospital or oncologist and wish to learn more visit our Team Up site and fill out the form (<https://endbraincancer.org/teamup>) and we will reach out to you.

The general mission of the EndBrainCancer Initiative is “fueling research and clinical trial enrollment in order to increase patient outcomes.” Recently, EBCI has assumed a larger profile in its contribution to research both representing the patient voice and extending into research, trial development directly and is often asked by Clinical Trial Organizations (CRO’s) and trial Sponsors where in the U.S. should we place our clinical trials. With the support of a board of expert advisors, EBCI has made its goal to increase clinical trial enrollment among brain cancer patients from the current 3% to 15% by 2025. EBCI recently attained CITI ([Collaborative Institutional Training Initiative](#)) certification and became the first brain tumor advocacy organization to be listed as a national recruiting site on clinicaltrials.gov (“An Exploratory Study of Caregiver Burden Among Family Caregivers of Patients With Cancer”—[ClinicalTrials.gov identifier NCT03069105](#)). Currently, in addition to its recruitment for this new study, EBCI serves 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.

Mydland concluded, “To defeat brain cancer everyone needs to come to the table. Everyone has an interest and something to offer. We need to do more to advance cure with a new form of a contract, so to speak, to achieve new ways of doing things and approaches to fighting this disease. In a contract everyone gives up something for a greater purpose. In legal terms it's called 'consideration.' We need to come to the table for the sake of patients - past, present and future. They are the ones who have the most to lose, the ultimate 'consideration.' For their sakes, we all need to sacrifice for this great purpose to end brain cancer, including community oncologists and community hospitals offering immediate access to treatment options and/or clinical trials and specialists whether the treatment, clinical trial or specialist is associated with their hospital and/or health care system or not.”

The EndBrainCancer Initiative invites inquiries and will be exhibiting at the 2018 SNO ([Society for NeuroOncology](#)) annual meeting. Please drop by Exhibit Booth #233 to visit.

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
- [First Step Initiative](#)
- [Team Up Initiative](#)

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.

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 <https://www.endbraincancer.org>

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