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Dellann Elliott Mydland, President of the EndBrainCancer Initiative, to Serve on Two National Clinical Trial Committees for NRG Oncology, an NCI-Funded Research Group

As a member of the NRG brain tumor disease site committee, Mydland will advocate for patient perspectives and interests in assessing and recommending specific brain cancer clinical trials for funding to the National Cancer Institute (NCI), helping guide clinical trial design, implementation, recruitment, and reporting approaches, and ultimately supporting critical changes to the standard of care..

Seattle, WA - August 29, 2018 - Dellann Elliott Mydland, President and co-founder of the EndBrainCancer Initiative (EBCI), formerly known as the Chris Elliott Fund, has been invited to serve on two national committees of NRG Oncology. Mydland is now a member of the NRG Patient Advocacy ([link](#)) and Brain Tumor Disease Site ([link](#)) committees. In these capacities as a patient advocate, she will be part of a team reviewing clinical trial proposals and making approval recommendations to NRG as a whole and ultimately to the National Cancer Institute (NCI - <http://www.cancer.gov>), the overarching funding and regulatory agency. NCI is part of the National Institutes of Health ([NIH](#)), an agency of the Department of Health and Human Services ([HHS](#)).

"I am honored to be asked to serve in this way," Mydland commented. "As an organization, EBCI supports NCI's growing emphasis on including the patient voice in formulating and conducting research. I look forward to working both with other patient advocates in diverse cancer areas as well as brain cancer experts from all parts of the U.S. in advancing research and benefitting patients."

[NRG Oncology](#) develops trials that are part of the National Clinical Trial Network ([NCTN](#)). NCTN was formed to optimize and accelerate cancer clinical trials. In 2014, NRG Oncology was formed by combining three previous legacy research groups into one. Under the auspices of NCI, NRG works collaboratively with other NCTN research groups and academic institutions to conduct multi-institutional phase II and phase III clinical trials. The purpose of the clinical trials is to help establish new standards of care (SOC), set the stage for approval of new therapies, test new treatment approaches, and validate new biomarkers. The network is designed organizationally to screen large numbers of patients to find ones whose tumors exhibit molecular features that can be matched to appropriate clinical trials.



*Dellann Elliott Mydland,
EBCI Co-Founder &
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Mydland added, ““What patients want and need is immediate access to specialists, Centers of Excellence (COE), promising treatments, and clinical trials that could have potential for their specific profile of cancer. At EBCI, we advocate for genomic profiling for all brain cancer patients and to allow for these tests and reports to inform the treatment. We are also working towards incorporating this diagnostic into Standard of Care. Every day we work with patients and families to help them get properly connected and navigate the dire challenges of brain cancer. I welcome the opportunity to share the patient viewpoint and our learnings to influence clinical trial formulation and updates to Standard of Care.”

Through the years, the [EndBrainCancer Initiative](#) has placed hundreds of brain cancer patients in clinical trials around the nation. Its "Direct Connect" Patient Services program educates and "pre-qualifies" brain cancer patients for clinical trials, and directly connects them to the Principal Investigator (PI) or Medical Center hosting this trial within the patient's geography. Mydland's work with EBCI as a national patient advocate was once again recognized in 2016 when she was nominated via the national "GBM Hero's Campaign" presented by the CURE Media Group and Novocure during the Society of Neuro-Oncology ([SNO](#)) annual meeting.

NRG Oncology patient advocate committee members bring a patient-oriented, disease-specific perspective to the research process. They improve clinical research feasibility by providing experiential knowledge and input focused on patient priorities, benefits, and outcomes. Advocates evaluate and provide perspective on research proposals and ongoing research activities in five critical ways:

- 1) Provide feedback that frames trial questions important to patients and support a balanced portfolio of research.
- 2) Assess actual recruitment feasibility as well as inclusion and exclusion criteria for maximizing patient participation.
- 3) Collaborate on protocol development and informed consent and guide development of communication and patient-friendly communications.
- 4) Provide input on actual recruitment strategies during implementation and offer support.
- 5) Share study results with patient and advocacy groups through interviews, presentations, publications and social media channels.

Patient inclusion and input is becoming both increasingly recognized as valuable to research as well as actually mandated as a prerequisite by many funding organizations. In a recent article, "[Models of Engagement: Patients as Partners](#)" in Applied Clinical Trials Magazine, the authors concluded, "Once regarded as 'subjects' who had research performed on them, patients are now contributing across the spectrum of clinical development, including in the design and planning of research protocols, selection of outcomes and endpoints, development of recruitment and retention strategies, and dissemination of research results. The unique perspectives afforded by patients' lived experiences can inform researchers' approaches and help identify knowledge gaps. By sharing their experiences of the daily burden of disease and their perspectives regarding unmet needs and the types of research questions most important to them, patient partners can transform the clinical development process from one directed by sponsors and investigators to one driven by the needs of patients and their caregivers."

The general mission of the EndBrainCancer Initiative is "fueling research and clinical trial enrollment." Recently, EBCI has assumed a larger profile in its contribution to research both representing the patient voice and extending into research directly. 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.

NRG Oncology describes its ultimate goal to reduce significantly the time it takes for new approaches to move out of trials and be translated into clinical practice. At present it is estimated that the average time that “translation” takes is 20 years.

This is the focus of EBCI in catalyzing translational research. Mydland concluded, “Our goal at the EBCI has always been immediate access to advanced treatments/clinical trials and the acceleration of advanced treatments/clinical trials into translational medicine and ultimately, into FDA approved treatments that are covered by health insurance and are reimbursable treatment options to the treatment/trial sponsor and clinical trial organizations (CRO’s). In these new positions I hope to support that goal of accelerating NRG research breakthroughs into the clinical environment and into changes of standards of care. That is truly what patients want—hope and options now, and advancing the quest for cure in the future.”

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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