



EBCI is now seeking Corporate Sponsors to fund the launch of two initiatives called “**First Step**” and “**Team Up.**” EBCI is developing these Initiatives to help address key needs we have discovered in working with patients with brain cancer over the last 21+ years. In essence, both Initiatives are focused on empowering patients as well as fueling research and clinical trial enrollment. These specific initiatives, which are essentially integral expressions of the overall EndBrainCancer Initiative, are grass roots efforts to establish relationship with community hospitals, individual practitioners, etc. with the goal of empowering patients and enabling them to access the best opportunities possible for treating and curing their cancers via targeted therapy and increased genomic testing. The EBCI seeks to expand its role as an intermediary in different dimensions to drive access, advance research and fuel clinical trial enrollment.

OVERVIEW OF INITIATIVES

First Step Initiative - An initiative to create awareness among brain cancer patients (first time and recurrent) and ALL cancer patients about the need for certain key steps essential for best treatment path opportunities and to establish a new paradigm for moving ahead that includes FIRST signing up in order to be informed and directed to ask for second opinions, informed of relevant clinical trials, advised about saving tumor samples, the importance of genomic testing/targeted therapy, etc.

The “First Step” is a patient initiative that invites first time or newly recurrent brain cancer patients (directly, through EBCI, their caregiver, through other advocates, or through their own voices) to sign up through an online form to indicate in principle, their 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. The Initiative web page conveys these reasons for signing up to patients:

MAKE SURE YOUR SURGEON PRESERVES A LIVE BRAIN TUMOR TISSUE SAMPLE FOR YOU TO ACCESS IN THE FUTURE TO HELP IDENTIFY TREATMENT OPTIONS/QUALIFY YOU FOR CLINICAL TRIALS/TARGETED THERAPIES: This is important so your specific cancer can be genetically profiled to that biomarkers are identified in one’s tumor tissue so that targeted therapy treatment options can be utilized to treat one’s cancer and/or can be used to qualify/enroll into clinical trials. That information could be a key to any future personalized treatments you will get or your opportunity to enter a clinical trial.

MAKE SURE YOU ASK ABOUT ADVANCED TREATMENTS AVAILABLE TO YOU

CONSIDER CLINICAL TRIALS - TELL US YOU ARE INTERESTED! Clinical trials are studies that test certain drugs and protocols. Getting qualified can be a complex process. We can help guide you. Filling out the form will indicate your interest.

WAIT TO START CHEMOTHERAPY UNTIL YOU KNOW YOUR OPTIONS FOR ADVANCED TREATMENT AND FOR CLINICAL TRIALS- Sometimes if you start chemo, it can disqualify you for certain treatments and trials. Explore your options. Fill in the form and we will help you navigate the path. Strategic Implementation Concepts:



Broad Networking - Create awareness and get further input from key partners in academia, research communities, public health entities, brain cancer Centers of Excellence, research leaders, etc.

Create Campaign: Develop assets that will enable the campaign to be launched across various social media and other channels. Campaign could include assets such as print flyers, posters, and other elements.

Launch Campaign: Focus will be creating a sustainable and long term campaign to build this initiative and accrue participants.

Broader Policy Advocacy: Utilize the work and findings of the First Step Initiative to advocate for policy changes and initiatives within the U.S. health system. Also utilize the initiative as a platform for interacting with public initiatives that may have a different philosophy or divergent aims to create power to influence ultimate directions in the policy area that best support patient goals and promote the free development of research interests and related private business enterprises.

Team Up Initiative - An Initiative to identify and break down barriers for local hospitals and oncology professionals (rural and urban) to collaborate with and refer patients to specialists and clinical trials. The goal is actually to find ways to build teams to address the needs of brain cancer patients.

Overview: 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 new clinical trials. ASCO itself indicates the benefits of a broader team on cancer.net: “It is important to have a care team that specializes in caring for people with a brain tumor, which may mean talking with medical professionals beyond your local area to help with diagnosis and treatment planning.” A major 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 and establishes a new network of key people at community hospitals and individual doctors / clinics / offices. The goal is to promote new active collaborations, dialogue and establish strategies to stimulate participation and referral of more patients to trials and to bring more trials to community hospitals. The “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.

Remain at the cutting edge of their specific area of therapeutic interest or delivery.

Provide new opportunities for advanced treatments and clinical trials (both publicly and privately funded) in their communities.

Gain recognition as a thought-leader within their professional communities and help their institution advance in research.

Open opportunities for additional revenue for oncology practices or hospitals. Get information about trials that want to find professional and institutional partners.



Offer patients new treatment options that may only be available through participation in clinical trials.

Support the advancement of breakthroughs in the area of treating brain cancer.

Strategic Implementation Concepts:

NCORP and Other Rural Networking - Develop and implement plan to collaborate with NCORP or directly reach out to their network. An initial goal will be to create a communications channel for present and future trials. Pursue other associations and lists to create ongoing connections. Create connections with key leaders within NCORP and other organizations.

Connections & Collaboration Meetings/Events: Develop calls, virtual meetings, and related meetings at other conferences to promote the focus and work of the Initiative. Build a constituency. Build and implement steps toward collaboration.

Communication Partnerships: Focus will be developing agreements for posting of information in various networks and related communication channels. This could also include paid sponsorship for specific PR initiatives or specific trial promotion.

Broader Policy Advocacy: Utilize the work and findings of the Team Up Initiative to advocate for policy and Standard of Care changes and Initiatives within the U.S. health system and specific professional communities associated with brain cancer (such as SNO).



Dellann Elliott Mydland
President & Board Chair

The EndBrainCancer Initiative | Chris Elliott Fund
Dellann@EndBrainCancer.org

www.EndBrainCancer.org