



**Survivorship Now.
Cure In Our Lifetime.**

A Case For Change:

For Improved Access & Treatment for Brain Cancer Patients

endbraincancer.org

U: 11.15.21

The EndBrainCancer Initiative | Chris Elliott Fund
is a National 501(c) 3 nonprofit located at:
16150 NE 85th St., #201, Redmond, WA 98052
Tax ID 26-2185614

Ken Whitley: Don't Give up. There is HOPE!



“Put one foot in front of the other; keep moving forward; Define and pursue your goals while putting your trust in God. Doctors can treat. They can't heal. God does, however, work through doctors, scientists and the EndBrainCancer Initiative's Team. Don't give up! New GBM treatments are around the corner and the EndBrainCancer Initiative's team can provide IMMEDIATE ACCESS to these specialists and these new treatment options.”

- Ken Whitley, GBM Patient and 2018 EBCI HOPE Award Recipient

I am the adopted son of a loving god.

On Super Bowl Sunday of 2017, life was turned upside down and my faith journey became supercharged. I entered my brother's house for a party and he insisted I go to the hospital immediately. While I didn't feel bad, he and others noted an imbalance in my gait and trouble with my speech. My then girlfriend, Cathy, took me to the hospital and a CT scan revealed a tumor. After admission to Neuro ICU, a surgeon removed a tennis ball size tumor from my right temporal lobe.

My Journey through 2017 had many hurdles and blessings. After my craniotomy, a friend insisted I call the EndBrainCancer Initiative (EBCI – formerly the Chris Elliott Fund). Talking with the EBCI team was one of the more significant events of my journey. Their team was factual, frank, and encouraging, providing guidance and insight that changed my and Cathy's approach to my treatment, and connected us with key doctors in North Carolina. Cathy and I had embarked on a faith journey that no conversation could prepare us for, as glioblastoma (GBM) creates challenges at a fast and furious pace.

In August, we discovered that Duke had a clinical trial showing promise and that I was a candidate!! On September 19th, Dr. Allan Friedman drilled 4 holes in my head and started a 72 ML drip of bacteria into the tumor area. In March 2018, I got the results of my latest MRI – “no measurable change in the tumor!” The 3 previous scans showed tumor reduction and dissipation!! A “NON DUKE” NEUROLOGIST SAID “I HAVE NEVER SEEN GBM DO THIS.

Throughout this journey, God has blessed me with the love of a wonderful girlfriend, and He gave her the courage to enter a covenant relationship with a guy carrying a brain tumor. On August 31, 2017, Cathy and I stood before God, the preacher, and many friends and said “I DO”.

I have experienced the true meaning of grace (from God, friends, and family) and have come to realize where my faith should rest. Prior to January 2017, I had relied on me and Me LET ME DOWN. The day after each operation, I was too lethargic to feed myself; within a couple of weeks, I was doing cardio and strength training. The ONLY thing I did was try over and over again. Don't quit!! THERE IS HOPE!!

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Problem Statement: As of 2019, only 6.8% of brain cancer patients with glioblastoma survive 5-years or longer*, and unfortunately no effective Standard of Care currently exists, although survival rates are improving. Average survival for patients with brain metastases is typically less than 6 months.

This represents an urgency and a call to action to **accelerate** the development of better treatments and improve patient outcomes.

The daily work and mission of the EndBrainCancer Initiative are focused on effecting change and improving outcomes for brain tumor patients globally through education, access to effective treatments, and fueling research.

* CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the U.S. 2013-2016, Published 2019 by Oxford University Press on behalf of the Society for Neuro-Oncology, p. v3.



Our Mission

Enhancing patient outcomes by **expanding FDA-approved treatment modalities** and fueling research in the bio/life sciences industries and by closing the existing **GAP** from initial diagnosis to **IMMEDIATE AND EXPANDED ACCESS** to specialists, researchers, advanced & innovative treatments, clinical trials and critical care with the ultimate goal of updating and improving NCCN Guidelines and clinical practices related to Standard of Care for brain cancer patients.



Our Reach

As of 2021, EBCI has a total annual global reach of over 18,000,000+ people consisting of a national audience of patients with brain cancer, caregivers, and the general public, considering all media.

Additionally, EBCI's advocacy work on behalf of patients with brain cancer, metastatic cancer to the brain and other solid tumors impacts tens of millions of patients globally.

Recent Milestones

- ✓ Testified before the FDA and other government entities to remove barriers towards innovative treatment development, provided public comments to influence the Standard of Care and advocated for policy change to improve better patient outcomes.
- ✓ Strengthened relationships with EBCI's media partners to assist in educating patients and the general public.
- ✓ Increased education, awareness, and outreach and engagement via social media to provide more education and peer support to brain tumor patients and their families/caregivers.
- ✓ Enlisted support from EBCI's brain tumor stakeholder community as "first responders" to share their voices, comment, and testify on legislative actions to include healthcare policy, access to care, diagnostic testing, and insurance reimbursement.

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Our 2022 Goals

EBCI's 2022 goals are targeted at improving patient outcomes, better meeting the needs of brain tumor patients and their caregivers, increasing impact within the brain cancer community, and elevating the "patient voice" in clinical trial development in 2022 and beyond.

- **GOAL: Increase Patient Awareness and Participation in Clinical Trials** to shorten the time required to meet endpoint goals. EBCI is also committed to ensuring that clinical trials are designed to minimize patient burden and reflect their expressed needs which extends to educational materials.
- **GOAL: Expand Education, Awareness, and Outreach Programs** to increase literacy about brain and other solid tumors amongst the general public as well as arm patients and families with the real-time information they need to make informed decisions throughout their brain tumor journey.
- **GOAL: Build Partnerships with Brain Tumor Stakeholders and the Professional Brain Tumor Community** (including biotech, pharmaceutical, device and diagnostic companies, nonprofit and advocacy organizations) to garner greater support for patient resources, educational materials, and outreach to brain tumor patients and their families.
- **GOAL: Advocate for Change** to key state and national legislators and government entities to influence policy and systems change including Clinical Trial Reform and improved access to advanced diagnostic tests and treatments.
- **GOAL: Launch an App** to place educational information immediately into the hands of patients and caregivers immediately upon diagnosis and prior to surgery..
- **GOAL: Grow & Expand EBCI's Patient "Direct Connect" & Referral Services** to serve more brain tumor patients, caregivers and their families and address the large unmet need that exists for our "Direct Connect" patient services.

Your Support and Partnership

Your gift will enable us to educate and connect many more brain cancer patients like Ken Whitley to advanced treatment and clinical trials as we:

Work to increase clinical trial participation and bring the "patient voice" to clinical trial development.

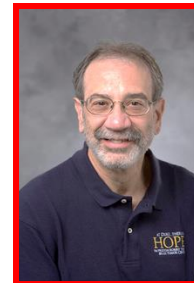
Expand our National Patient "Direct Connect" & Referral Services to serve more patients, "pre-qualify" more patients for clinical trials, and fuel research through increased clinical trial participation.

Increase patient education, awareness, and outreach programs to increase brain tumor literacy and enable patients to make informed decisions about their treatment and care.

Build Partnerships with Brain Tumor Stakeholders and the Professional Brain Tumor Community to increase the availability of patient resources while ensuring that the visuals and imagery are reflective of the demographics of the larger brain tumor community.

Accelerate advocacy efforts related to Clinical Trial Reform and improved access to advanced diagnostic tests and treatments.

Push for Change on behalf of all patients with brain cancer and metastatic cancer to the brain.



"The 'Direct Connect' Program provides a guiding light when the family is totally immersed in darkness and its extraordinary value cannot be overstated."

- Dr. Henry Friedman, Deputy Director Preston Tisch Brain Tumor Center, Duke University

Our Work and IMPACT*

The EndBrainCancer Initiative is celebrating almost 18 years of service to adult and pediatric brain cancer patients, caregivers and their families by facilitating immediate access to specialists and advanced treatments/clinical trials through their mission, day-to-day work and key programs and services.

Your support and partnership will help fund our three programs (below) and allow us to offer our services FREE OF CHARGE to patients, caregivers and their families to serve more patients like Ken Whitley throughout their brain tumor journey.

Brain Tumor Disease Education, Awareness, and Outreach Program

Education-Awareness-Outreach through creation of educational materials for patients as well as the medical community and through the use of social media online support groups and through our media partners. In 2019, EBCI was given over 8 million opportunities to educate patients, caregivers and families as well as the general public.

Brain Tumor Patient Advocacy and Access

EBCI's Advocacy Program focuses on work with the FDA for approval of new treatment options and on work at the Federal and Local level for reimbursement, working with insurance companies for patient coverage and advocates for new treatment options.

Patient "Direct Connect" & Referral Services

EBCI directly connects patients to top specialists for 2nd/3rd/4th opinions and to principal investigators, advanced treatments, clinical trials and translational medicine. EBCI currently has ~7500 monthly touch points and opportunities to educate, and directly serves 900 patients, caregivers and families annually on a one-on-one basis. This program is explained in detail on the following page.

EBCI also contributes to clinical trial design and is currently the "patient voice" for several of these trials as well as its advocacy work in life sciences, biotech pharma, biomed, CROs, and medical devices industries on behalf of brain tumor patients and industry.

History of the EndBrainCancer Initiative

The EndBrainCancer Initiative (EBCI, formerly the Chris Elliott Fund) was founded in 2002 by Dellann Elliott Mydland and her late husband, Christopher Stewart Elliott, in response to his brain cancer experience. Thanks to a groundbreaking clinical trial, Chris survived twice as long as his initial prognosis predicted. Three weeks before he succumbed to brain cancer, he told Dellann emphatically, "We must do something about this disease!".

In the intervening years, EBCI has strategically shifted its original focus from generating funding for research to meeting a large unmet need – helping patients through "pre-qualifying" them for clinical trials for the benefit of both. Since its founding, EBCI has helped thousands of patients, caregivers, and their families and 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.

In 2022, The EndBrainCancer Initiative will be celebrating 20 years of service to the global brain tumor community.



* 82% of all monies raised by EBCI go to support our three key programs (2020 IRS 990).

Your Financial Support Impacts Lives!

EBCI's disease education programming and advocacy effort is funded through the generous contributions from individual donors, foundations, grants, sponsorships, and our Corporate Partners.

Ways to Donate

Direct Donation – You can donate directly through the secure link at the top of our website.

AmazonSmile – Be sure to select the Chris Elliott Fund (dba EndBrainCancer Initiative) when you do your online shopping with Amazon.

Your Time & Expertise – Do you have a special skill that can help support EBCI's work and programs? Let us know! We will be thrilled to get your help!

Donor Advised Fund – You can recommend to your Donor Advised Fund Manager that a distribution should be made to the Chris Elliott Fund (EIN 26-2185614)

Legacy Gifting/Planned Giving – A legacy gift is a bequest contained in your last will and testament and can be for a specific amount, a percentage of your estate or a specific piece of property.

Increasing the Impact of Your Donation

Recurring Donation – while you are setting up your direct donation or Donor Advised Fund distribution, why not make it recurring? Recurring donations can be established monthly, quarterly, or even annually.

Employer Matching – Many employers will match donations made by their employees, often dollar for dollar! Check with your benefits team to see if your company participates in a matching plan.



"EBCI is a very valuable resource for brain tumor patients and families in the Puget Sound region and, frankly, Nationally. When patients are diagnosed with brain cancer and they don't know where to go, this organization provides guidance in terms of immediately getting dialed into the best centers, the best clinical trials, and the top doctors. This provides a huge amount of anxiety relief and support to the families and patients, and likely facilitates an improvement in their survival due to guiding them to high-volume centers with better outcomes. The return on the investment for this organization is huge in terms of patient quality of life and survival."

- Dr. Charles Cobbs, Director, Ben & Catherine Ivy Center for Advanced Brain Tumor Treatment, Swedish Neuroscience Institute

To discuss potential support and partnership opportunities please contact:

Dellann Elliott Mydland

President and CEO, EndBrainCancer Initiative
425.785.8489

Dellann@EndBrainCancer.org

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Your Time & Expertise – Do you have a special skill that can help us in general or on a special project? Let us know! We will be thrilled to get your help!



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December 18, 2016

To Whom It May Concern,

As a long term supporter and champion of the EndBrainCancer Initiative, formerly the Chris Elliott Fund (EBCI, www.EndBrainCancer.org), and the work they do every day on behalf of brain cancer patients, caregivers, families and research, I am inviting you to consider underwriting this social enterprise as they scale to meet the ever-increasing demand for their free services.

Your support is required to increase the number of brain cancer patients and families directly served annually from the current number of 900 to 4800 within the next three years. This work is vital for improving outcomes for a disease where life expectancy is typically measured in months, not years.

As a scientist and clinician in translational medicine, neuroscience and neuro-oncology, I fully appreciate EBCI's work and IMPACT in furthering scientific advancement. Their "Direct Connect" program is unique in that it "pre-qualifies" patients for clinical trials, fuels research, and increases clinical enrollment. Ultimately together, we envision being able to change Standard Care, as new and much more effective therapies are brought into the mainstream.

I currently serve on their Medical Advisory Board, as I have for the past 8+ years and during this time, I have witnessed firsthand the IMPACT this organization makes in the lives of brain cancer patients which is nothing short of miraculous. I have personally seen patients go from deep despair to HOPE upon learning that additional options do indeed exist for treating their cancer because EBCI was able to intervene and make the right connections to top specialists on their behalf. I have personally seen patients live better quality of life, live longer with some long term survivors for people who work with the EBCI as well as have seen the importance of this social enterprise organization fuel brain cancer research. With your support, this organization has the ability to turn brain cancer from a terminal illness to an illness that is managed with additional treatment options and IMMEDIATE ACCESS to these treatment options.

Thank you for your consideration of underwriting the important & vital work of EndBrainCancer Initiative.

Sincerely,

Santosh Kesari, M.D., Ph.D., F.A.N.A, F.A.A.N
Chair, Department of Translational Neurosciences and Neurotherapeutics
Professor of Neurosciences



A Guidestar Platinum Participant
www.guidestar.org/profile/26-2185614