



**Survivorship Now.  
Cure in Our Lifetime.**



**A Case for Change:**  
**Enabling Access, Fueling Research and Improving Patient Outcomes**

**endbraincancer.org**

The EndBrainCancer Initiative | Chris Elliott Fund  
is a National 501 (c) (3) nonprofit located at:  
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## 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!!

## Survivorship now. Cure in our Lifetime.

**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.

There is 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 2019, EBCI has a total annual reach of over 11,000,000+ 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.

## 2019 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.
- ✓ “Pre-launched” the Green Light Initiative focused on patients who receive their diagnosis/treatment in community hospitals and clinics. This Initiative harnesses cutting-edge geo-marketing technology for mobile devices to educate patients about treatment options and advanced diagnostics at the point of need.
- ✓ A Clinical Research Nurse/Patient Navigator joined the EBCI to better serve and educate patients with brain cancer and their families and strengthen EBCI's “Direct Connect” program.
- ✓ 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.
- ✓ Engaged a Senior National Director of Industry & Program Partnerships to engage and strengthen industry partnerships.
- ✓ 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.

## ACCELERATING Our 2020 Goals

EBCI's 2020 goals are targeted towards improving patient outcomes, better meeting the needs of brain tumor patients and their caregivers, increasing impact within the brain cancer community, and lifting the "patient voice" in clinical trial development in 2020 and beyond.

- **GOAL: Increase Patient Participation in Clinical Trial Development and Accruals** to help more clinical trials meet their endpoint goals. EBCI is also committed to ensuring that the "patient voice" is heard and implemented into the design of those clinical trials we initiate and collaborate on.
- **GOAL: Build Capacity of EBCI's "Direct Connect" Patient Services Program** to serve more brain tumor patients, caregivers and their families and address the large unmet need that exists for our "Direct Connect" patient services. Through "pre-qualifying" patients for clinical trials, EBCI also fuels research through increased clinical trial participation.
- **GOAL: Build Capacity of the Education, Awareness, and Outreach Programs** to increase literacy amongst the general public about brain and other solid tumors as well as arm patients and families with real-time information to make informed decisions about their treatment and journey.
- **GOAL: Build Partnerships with Brain Tumor Stakeholders and the Professional Brain Tumor Community** to collaborate with biotech, pharmaceutical, device and diagnostic companies, nonprofit and advocacy organizations to garner greater support for patient resources, educational materials, and broader communications and outreach in the brain tumor community.
- **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.

## 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 "Direct Connect" 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 throughout their brain tumor journey.

Build Partnerships with Brain Tumor Stakeholders and the Professional Brain Tumor Community to garner greater support for patient resources, educational materials, and broader communications and outreach.

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.

### “Direct Connect” Patient Services Program

EBCI directly connects patients to top specialists for 2<sup>nd</sup>/3<sup>rd</sup>/4<sup>th</sup> 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.

### 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.

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.



\* 83% of all monies raised by EBCI go to support our three key programs (2018 IRS 990).

# EndBrainCancer Initiative's "Direct Connect" Programs & Navigation Services



**Patient Referrals Specialist**

## Consultation with Specialists and Clinical Trial Participation

- One to one patient and caregiver (P/CG) consultation to assess situation and manage distress to empower P/CG and create an action plan
- Utilize **Telehealth Services** technology to eliminate geographic barriers and optimize efficiencies in communication and information sharing
- Find second and third opinion opportunities from Neuro Oncologist and Neurosurgeons at high volume Brain Tumor Centers
- Advocating directly with public and private insurance companies on behalf of the patient to ensure prior approval is given to cover costs of out-of-network clinical consultation
- Search for clinical trials that are a good fit for the patient at all phases of their disease journey, working within travel limitations and location of clinical trial site



**Clinical Education Specialist**

## Educational Materials and Processes

- Provide patient and caregiver (P/CG) education regarding:
  - Tumor tissue saving/preservation for NGS prior to biopsy/surgical resection
  - Benefits of maximal resection of tumor
  - Clinical trials protocol design and eligibility criteria
  - Managing the side effects of treatments
  - Value of team approach, patient reported outcome data, and vigilant monitoring
- Educating clinicians about the need for patient partner navigation services that:
  - Specialize in helping newly diagnosed patients with brain cancer
  - Utilize value-based care models to improve patient outcomes and optimize clinician workflow processes



**Clinical Research Program Coordinator**

## Clinical Research and Process Improvement Initiatives

- Assist patient and caregiver (P/CG) with requests to their neuro oncologist and pharmaceutical manufacturer for FDA approval for compassionate use of promising medications/treatments based on their tumor's genomic profile
- Participate in clinical trial design, recruitment, screening, consenting, data collection, data entry, and other clinical trial ethics and quality control activities as appropriate
- Collaborate with academic and clinical professionals to improve practice compliance with evidence-based practice guidelines to optimize patient outcomes and quality of life

## Impact of Your Support and Partnership

Funding from Public, Support, Donors, and Special Events is expected to comprise 37% of EBCI’s funding for 2020 to achieve our goals, grow our programs and create a sustainable foundation for the future.

Your gift also funds our advocacy work including our participation in clinical trial development to ensure the “patient voice” is heard and implemented as new and more effective therapies are developed.

2020 Proposed EBCI Budget



Note: As of May 2020, EBCI is currently experiencing a **significant revenue shortfall** due to the **COVID-19** crisis.



“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

## Your support and partnership matters!

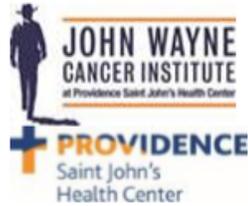
Your support and partnership are critical to the achievement of EBCI’s long-term goals as we ramp up our funding initiatives and build organizational capacity.\*

EBCI Capacity Buildout Plan			
Gift Level	Gifts Needed	Target Giving	Cumulative %
\$600,000	1	\$600,000	16%
\$300,000	2	\$600,000	33%
\$150,000	3	\$450,000	45%
\$120,000	3	\$360,000	55%
\$90,000	4	\$360,000	65%
\$75,000	6	\$450,000	77%
\$60,000	6	\$360,000	87%
\$30,000	8	\$240,000	93%
\$15,000	10	\$150,000	97%
Smaller	Many	\$100,000	100%
Total =		\$3,670,000	

To discuss potential support and partnership opportunities please contact:

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\* 84% of all monies raised by EBCI go to support our three key programs (2017 IRS 990).



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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](http://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  
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