

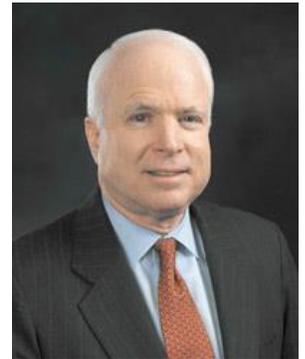
FOR IMMEDIATE RELEASE
August 27, 2018

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With Condolences to the McCain Family, The End Brain Cancer Initiative Calls for New Access and Treatment Options for Brain Cancer Patients & Changes to Standard of Care

The End Brain Cancer Initiative (EBCI) joins other organizations to honor Senator McCain's life and fight against brain cancer. EBCI calls for National Concerted Action that Offers New Access and Treatment Availability for Brain Cancer Patients and Critical Changes to WHO & NCCN Guidelines Leading to Updated Standard of Care and Clinical Practices.

Seattle, WA - August 27, 2018 - Joining with other sister charities and fellow citizens overall, The End Brain Cancer Initiative (EBCI), formerly the Chris Elliott Fund, extends its condolences to the McCain family and respectfully honors Senator John McCain's passing and legacy of service to our country. Senator McCain faced a disease that tragically afflicts and kills many thousands of Americans every year. As an organization, EBCI is dedicated to increasing survivorship now and finding a cure for brain cancer in our lifetime.



As has been widely reported, Senator McCain suffered from a form of brain cancer called glioblastoma, the deadliest form of brain cancer that ends lives on average within 15 months in over 50% of cases. In the past few years, brain cancer has stricken other notables such as Beau Biden (son of former Vice President Joe Biden), Senator Ted Kennedy, President Jimmy Carter. In President Carter's case it was metastasized melanoma cancer to the brain. He benefitted from immunotherapy, an important new treatment that utilizes the body's own resources to fight and destroy cancer cells, and was declared cancer free.

"When you hear of famous people dealing with a brain cancer diagnosis," commented Dellann Elliott Mydland, president of The End Brain Cancer Initiative, "It is natural to assume they get to access the very best care and most cutting edge medical treatments possible irrespective of geography or current medical provider. At the End Brain Cancer Initiative, we think that should be the assumption and experience for every brain cancer patient. As brain cancer is now more in the public eye, we at the EBCI call for concerted national actions to combat this disease to help patients now and in the future."

Currently, throughout the country there are key brain cancer specialists, centers of excellence for treating this disease, promising breakthrough treatments, and significant new clinical trials. Most brain cancer patients, though, are not informed or given access to these advanced treatments because the current standards of care are not in step with the emerging science and treatment breakthroughs. Additionally, approximately only 3% of brain cancer patients participate in clinical trials.

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“Speed and access are everything,” Mydland added. “Brain cancer is one of the most aggressive and fastest to grow forms of cancer. It debilitates and devastates within a matter of months. Our current health care approaches to this are incredibly slow and dated. We have to change the way we respond to this disease and direct patients. Patients deserve to be informed and given the choice to access promising alternatives that may not be the immediate medical options available locally.”

Senator McCain's passing has led to calls to give national attention to fighting this disease and fueling new research. Last year, his daughter, Meghan McCain, explained the disease and appealed for support for brain cancer research on The View and in other public forums. One key that has emerged in the past few years is genomic profiling. Research has shown that every cancer is unique both in its original form and as it mutates. These cancers are being carefully profiled by researchers around the world. The profiles or “biomarkers” can then lead to specific, “personalized” interventions to address this incredibly complex disease.

Current research directions are moving toward combination therapies. These emerging approaches were summarized by Dr. Minesh P. Mehta, Deputy Director, Miami Cancer Institute and Chief of Radiation Oncology, in a presentation entitled "Glioblastoma: Emerging Approaches." His summary explained: “Molecular subsetting of patients and utilizing more specific agents will lead to more trials with fewer patients in each. Future small incremental gains may be made by combining current approaches. Radical transformation will only occur when profiling is married to actionable therapies, or radical new therapeutic strategies are defined.” ([Link to Presentation](#))

Another major research direction is in the area of immunotherapy. One such study is being led by Dr. Behnam Badie, chief of neurosurgery and head of the brain tumor program for California-based City of Hope. In this study chimeric antigen receptor (CAR) T-cells are genetically engineered to attack glioblastoma. The study has enrolled about 20 patients and has shown promise. Dr. Badie remarked, "It's not curative, but we are definitely seeing changes in the biology and extending lives." ([Link to Article](#))

Relating to fueling research and advanced treatments, The End Brain Cancer Initiative is currently advocating for two key imperatives: 1) ALL brain cancer patients should receive genomic profiling for their tumors and that information should be used to inform treatment including immunotherapy; 2) Research should be advanced that explores delivering treatments that bypass the Blood Brain Barrier (BBB). Additionally the EBCI is calling for the following national action steps:

- 1) Enhance patient outcomes by expanding FDA-approved brain cancer treatment modalities.
- 2) Close the existing GAP from initial diagnosis to IMMEDIATE AND EXPANDED ACCESS to specialists, researchers, advanced & innovative treatments, clinical trials and critical care.
- 3) Improve patient outcomes through updating and improving WHO (World Health Organization) & NCCN (National Cancer Care Network) Guidelines and clinical practices related to Standard of Care for brain cancer patients.

The End Brain Cancer Initiative was founded in 2002. It was then known as The Chris Elliott Fund. Mydland's former husband, Christopher Stewart Elliott, died of brain cancer. Right before he passed away, he stated emphatically, “We MUST do something about this disease.” The organization was born to help other patients get the knowledge and tools to access the best options possible and fight this disease. “Our thoughts are with Mrs. McCain and their family at this time,” concluded Dellann Mydland. “Some would say our only hope is research. While we at the EBCI believe in research, we believe that there is hope for patients now in existing new advanced treatments. They simply need information and access. We hope and pray that this renewed attention on brain cancer will lead to new national initiatives to change the standards of care and fuel promising research for the sake of patients.”

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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