

FOR IMMEDIATE RELEASE
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Patients, Survivors, Friends, and Partners Celebrate The EndBrainCancer Initiative's GBM Patient & TOGETHER Day

A unique event in Greater Puget Sound/Seattle, Washington celebrated and uplifted brain cancer patients and survivors providing inspiration, food and fellowship, massages, gifts, photography sessions, and more.

Seattle, WA - March 28, 2019 - The [EndBrainCancer Initiative](#) recently hosted its first ever GBM Patient & TOGETHER Day on Friday, March 15th at the Bellevue Club in Bellevue, Washington. EBCI and its sponsors and partners hosted current and past brain cancer patients, survivors, caregivers, and families in a special event focused on uplifting and inspiring those impacted by brain tumors and brain cancer.



The afternoon program flowed with opportunities for participants to dine and enjoy special services such as massages, makeovers, and photography sessions and featured a variety of speakers who shared inspirational insights through stories of their personal experiences with brain cancer.

Tracey Hanover, Senior Director, Advocacy Relations, Novocure; Robert "Alec" Swaynham, Winner, 2019 "What Empowers You" Award (Phase 1); Barbara Swaynham; Dellann Elliott Mydland, President & CEO of the EndBrainCancer Initiative

As a new event initiative, GBM Patient & TOGETHER Day enjoyed both local and national underwriting support. National sponsors included Presenting Sponsor, [AbbVie](#), and Silver Advocacy Sponsor [Novocure](#). Local sponsors included [The Seattle Cancer Care Alliance \(SCCA\) Proton Therapy Center](#), [Seattle Children's Hospital, Research and Foundation](#), and [Comcast Spotlight Seattle](#). Education and awareness roundtables at the event were underwritten by a grant from [Genentech](#).

Opening the program, Dellann Elliott Mydland, president and co-founder of the EndBrainCancer Initiative, sounded a theme of celebration and hope addressing the patients and caregivers present, "Today, we're here to celebrate you!" Various brain cancer patients and survivors were introduced including Sam Staatz, a 20+ year survivor of brain cancer, also a patient survivorship ambassador with the EndBrainCancer Initiative.

Ashley, a current brain cancer patient, shared her journey publicly as one of the event's speakers. She relayed her process through diagnosis at age 54, surgery and chemo, the extreme difficulties in sharing the news with family, the major adjustments to life, and her recent treatment experience with the [Optune](#) device (an

externally worn device approved by the FDA in 2011) and now a Standard of Care treatment option for patients diagnosed with GBM. Expressing her hope and optimism, she pointed (with lightness) to the Chicago Cubs winning the pennant after 108 years as a hopeful inspiration for doubling her own lifespan, and then frankly concluding, “My life with GBM is very different, but it is very good. I choose to enjoy it. I fill my life with good things and positivity. I love my faith. I love my family. I love my life. I intend to keep it that way.”

Robin Shapiro (Board Chair of The Washington State Health Advocacy Association - WASHAA), another of the event's speakers, commented afterward, “The value in GBM Patient & Together Day was in meeting people who are not just surviving, but thriving. It was inspiring to see those who are managing GBM with grace and humor. I was also grateful to know about new therapies that didn't exist just 10 years ago are now giving patients a new lease on life.”

The event highlighted women leaders in the Puget Sound area who have been personally impacted by brain cancer. Julie Prince (Wealth Management Advisor, Prince Financial Services, Northwestern Mutual Wealth Management Company) described the heartbreaking experience of walking beside a colleague who contracted GBM brain cancer, but also the “silver lining” in how that person resisted a two week prognosis and went on to travel and seek out advanced treatment and trials and build lasting memories for her children, living a full year longer than expected.

GBM Patient & TOGETHER Day also sounded a strong call to action in eradicating this disease. Dellann Elliott Mydland sounded that theme in explaining the work of The EndBrainCancer Initiative (EBCI) calling for access for patients to advanced treatments, comprehensive genomic testing of tumor tissue (with related approved insurance payment), to second opinions, and to clinical trials. She highlighted two new related EBCI initiatives called [First Step](#) and [Team Up](#) developed to advance the EBCI's goals to increase survivorship and find a cure. Stephen Hough, representing the presenting sponsor [AbbVie](#), echoed this call to action, “It really does motivate and it makes us think we can all do better for this. It would be really nice to see GBM turn into one of those areas like what happened with HIV which was a death sentence, and now people are living with it like asthma. I am ever hopeful that in future years that we will see major advancements like we've seen in some of the other cancers. My hat's off to all the companies that are bringing things forward. We need this. Patients need this. And frankly our family members need it.”

The event included two panel discussions with speakers and several breakout sessions with patients who gave input about their needs, direction of research, and important priorities.

EBCI also presented its first “What Empowers You” Award to the 2019 (EBCI plans to present two of these awards this year) winner, Robert “Alec” Swaynham who was on hand with his wife, Barbara, visiting from Alaska. Alec's story stood out after review of many nominations of brain cancer patients who shared stories of the ways they are letting their passion lead their lives while undergoing treatment. This 2019 award program is cosponsored by [AbbVie](#) and [Novocure](#).

Other companies donated (or offered at a reduced cost) resources and services for the event. They include Nieman Marcus offering Jo Malone body products and makeovers using Chantecaille makeup products, The Dream Clinic offering massage services, Charles Cutugno Photography offering portrait photos and prints, and Cavalier Films conducting interviews.

Many of the patients present worked in the past with The EndBrainCancer Initiative and its “Direct Connect” program. Stephen Hough of [AbbVie](#) additionally remarked, “I can't say enough about what EBCI is doing with its “Direct Connect” program because you just have no idea when you have this happen in your life where to go. And to have a group that really focuses on hooking you up with the appropriate and second opinions and Brain Tumor Centers of Excellence is what we all need. So, my hat's off to the EBCI.” Susan Kellner, a brain cancer patient / survivor (and volunteer social media manager with EBCI) described her experience with EBCI and their “Direct Connect” program and her commitment, “I will forever be indebted to Dellann and Chris Elliott

(founders of EBCI) for their vision for the brain tumor community. That vision pulled me out of a very dark and lonely tunnel when I needed it the most. I will never get tired of helping EBCI be known in every doctor's office around the world.”

The 2020 GBM Patient & TOGETHER Day will be held on Friday, March 6, 2020.

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 17 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 programs:

- “Direct Connect” Patient Support and Services Program
- Brain Tumor Disease Education, Awareness, and Outreach Program
- Brain Tumor Patient Advocacy and Access
- [First Step Initiative](#)
- [Team Up Initiative](#)

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](#)).

The EndBrainCancer Initiative (EBCI) also participates in a program at the National Institutes of Health (NIH), National Cancer Institute (NCI), Center for Cancer Research (CCR), Neuro-Oncology Branch (NOB) called [NCI-CONNECT](#) (Comprehensive Oncology Network Evaluating Rare CNS Tumors). The program aims to advance the understanding of rare adult central nervous system (CNS) cancers by establishing and fostering patient-advocacy-provider partnerships and networks to improve approaches to care and treatment.

EBCI supports about 900+ patients, caregivers and families, free of charge annually through its “Direct Connect” Program, and provides 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 free services, provide a gift today at www.endbraincancer.org

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