



EFFECTING CHANGE

Could IMMEDIATE ACCESS be the “Turning Point”?

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It is with great pleasure that I accept this opportunity to write a quarterly Educational & Outreach piece for Cure Magazine. I am hopeful that the overall topic of “Effecting Change” will be:

- informative, insightful, and inspirational
- create expanded collaborative efforts
- provide HOPE
- Most of all, encourage a steep change for patients diagnosed with an initial Glioblastoma (GBM) brain tumor in the areas of initial diagnosis, initial surgery and a change in our current Standard of Care. This will be done through providing IMMEDIATE ACCESS to advanced treatments/ studies and clinical trials.

The change in current Standard of Care that the EndBrainCancer Initiative | Chris Elliott Fund embraces is an effort to automatically include discussions related to prior consent, immunotherapy, vaccines, devices, DNA sequencing/Genomic profiling, MGMT testing, etc. and discussions related to advanced treatments/ clinical trials prior to surgery

– essentially, a much more proactive and personalized approach for this disease at the time a primary or metastatic brain tumor is diagnosed.

You may be wondering who am I, what is the EndBrainCancer Initiative | Chris Elliott Fund and what makes me qualified to write a quarterly article to all of you. First of all, I want to share information that I have learned as a brain cancer advocate and I love to write. Secondly, I have now been immersed in the brain tumor community locally and nationally for the last 15.5 years. You see, I am like many of you who have a loved one, my late husband, Christopher Stewart Elliott was diagnosed with brain cancer and lost his battle with this disease. I have personally gone through some of what you are experiencing: shock, desperation, frustration and truthfully, the inability to understand why there is not an effective treatment for this disease and why patients are not routinely referred to the top neurosurgeons/ neuro-oncologists for this

disease. All of these topics will be explored in depth in future quarterly columns.

Today and for the last 13 years, our Care Coordinator Team and I have been working through our Brain Tumor Patient Support Services & Call Center located just east of Seattle, WA, the EndBrainCancer Initiative/Chris Elliott Fund and our “Direct Connect” one-on-one personalized program plus the use of technology is to provide IMMEDIATE ACCESS and to educate patients and their caregivers/families/friends about advanced treatments/ clinical trials with the belief and goal of moving, patient-by-patient, brain cancer patients into clinical trials as soon as possible. While we initially saw this as providing “Patient Support”, we recently realized as an organization that we were essentially “fueling” research. With this realization came the concept for the EndBrainCancer Initiative, which is a focused collaborative effort between founding partners and top brain tumor/cancer neurosurgeons and neuro-

oncologists. Its goal is to quickly and effectively change this disease and its outcomes by actively practicing a “Patient Focused” and an “Advanced Treatment Focused” approach to treatment as our current Standard of Care for this patient population is relatively unsuccessful.

It dawned on me yesterday in a conversation with the immediate past boss of my late husband, Chris. We will never have an effective treatment for this disease if we continue to get these patients into clinical trials after their brain cancer has returned (rGBM). At this point, the disease is actually a different disease as the molecular structure of the tumor has changed. The tumor is not the same tumor that it once was. Therefore, why are we treating most of these tumors in the same way? And since we already know this, why aren't we doing something about it and taking a more pro-active approach to treatment?

The EndBrainCancer Initiative & Collaborative is about educating cancer patients & their families about advanced treatments/clinical trials much earlier in the treatment process, perhaps even at the time of a “primary” brain tumor diagnosis or at the time of a “Malignant” brain tumor diagnosis. The idea is to

seriously “Move the Dial” on this disease. Research is struggling because not enough patients enter clinical trials. If through our Initiative and our “Direct Connect” program we could change this, we potentially could quickly change the Standard of Care for these patients and lower the cost of clinical trials by approximately 50%. I know, if you are the patient, who cares about the cost of the clinical trial but as the patient, here is what you do care about. What if we could accelerate the time it takes to:

1. get patients into clinical trials/advanced treatments/studies
2. lower the cost of the clinical trial via getting enough patients into the trial
3. get the data out of the clinical trial/study much quicker so that it can be used to perhaps speed up the process of opening the next clinical trial phase or take the data
4. where appropriate, move it quickly into translational medicine and Standard of Care.

This effort and the question is “Can We Create a New Turning Point?”

If you'd like join this movement and/or share your thoughts and perspective, please let us know by going to EndBrainCancer.org and

leaving us a message via our Patient/Caregiver/Doctor Portal. We hope to hear from you!

I truly believe we can create a New Turning Point. With that being said, I'd also like to take this opportunity to share about another collaborative effort the EndBrainCancer Initiative |Chris Elliott Fund is involved in this fall and invite all to attend by signing up.

We are happy to join forces with, M. Karen Newell-Rogers, PhD; Professor, Scott & White Health/Texas A&M Health Science Center College of Medicine: Director, CCDD and Eric T. Wong, MD, Brain Tumor and Neuro-Oncology Unit, Harvard Medical School and Al Musella, The Musella Foundation and proud to co-sponsor the 2nd Annual “At a Turning Point: Novel Therapeutic Developments in Glioblastoma Multiforme (GBM) Research, to be held on November 17 – 18, 2015 and is a key meeting prior to the annual Society of Neuro-Oncology's 20th Annual Meeting in San Antonio.

I am honored to be the opening speaker for this meeting and delighted that our Keynote will be Sidney Hayes, MD, State Medicare Medical Director, Novartis, and Centers for Medicare and Medicaid Services. I hope to see you there!