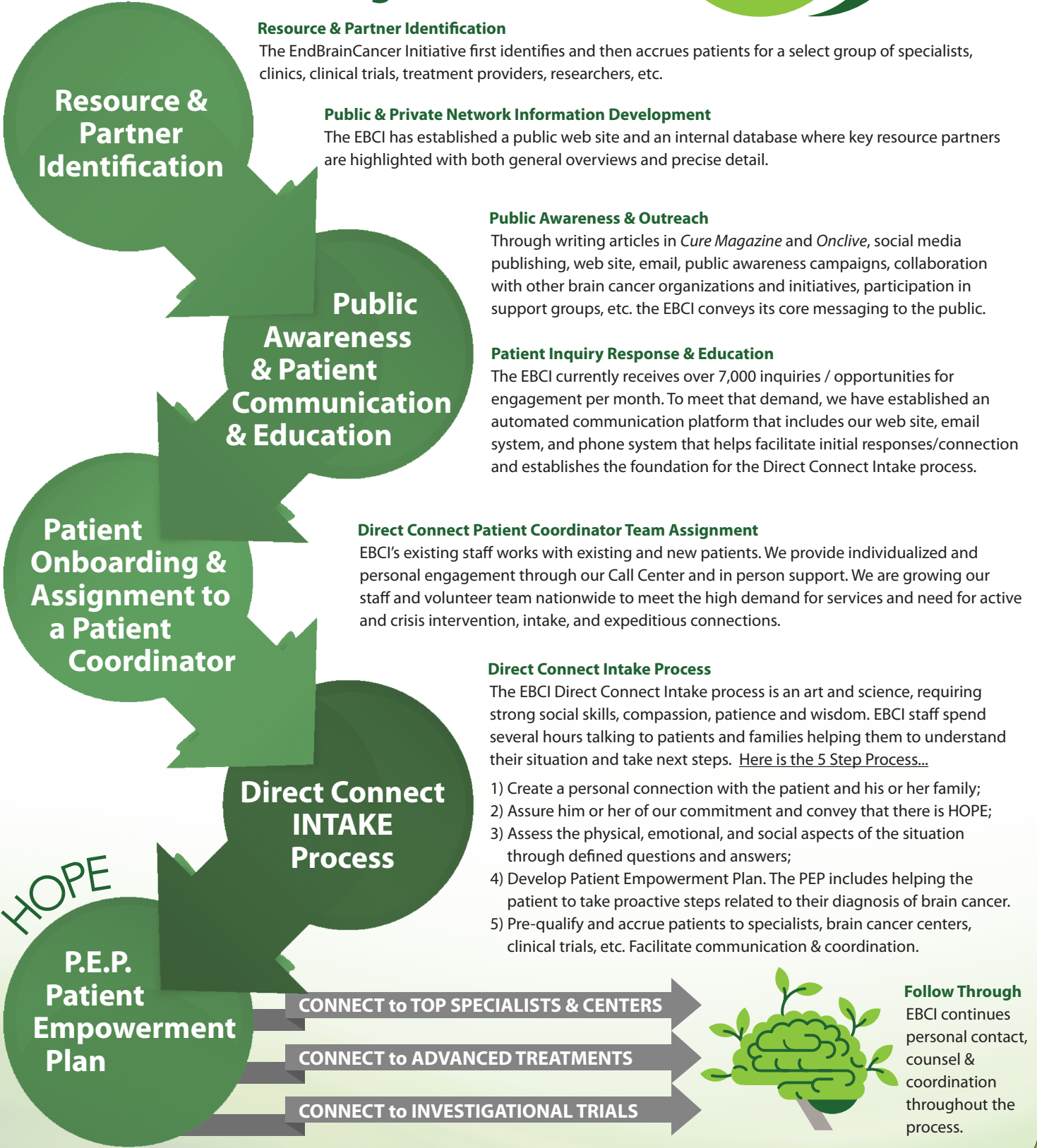




## Direct Connect Program





## Direct Connect

# Building HOPE and Empowering Brain Cancer Patients through Direct Interaction

Often it's a major health crisis that leads to a diagnosis of brain cancer. Already in shock, they hear the words that will change their lives forever: "it's cancer." Where do they go and where can they turn for help? It's at this moment, that the EndBrainCancer Initiative is there to guide patients and their families throughout this journey. Our model is based on experience and is supported by research. Brain cancer creates uniquely challenging problems and patients suffer from greater dependency and hopelessness than other cancer patients.<sup>1</sup> Thus a holistic model for direct interaction was developed that creates the connection which truly makes a difference.

### HELPING Patients & Families Process a Life Altering Crisis

#### CHALLENGES

- ▶ The crisis at hand often impairs the brain cancer patient's ability to make the most important decisions at the beginning of the process.
- ▶ The great majority of brain cancer patients receive surgery within 72 hours. Patients and their families are under intense pressure to act. There is a great need for accurate information and steady counsel to support clear understanding and good decision-making.



#### STRATEGIES

- ▶ To create clarity, EBCI offers a series of fact sheets to HELP patients understand their cancer and its impact, 10 key questions to ask their doctors, etc.
- ▶ The EBCI Patient Coordinator is trained to understand the impact of the cancer on cognitive reasoning and how to HELP the brain cancer patient and family work through the emotions and build a stable knowledge framework which HELPS create HOPE.

### Informing and Explaining ALL the OPTIONS & Encouraging other OPINIONS

#### CHALLENGES

- ▶ Patients often do not realize they have OPTIONS and that they can get second and third OPINIONS. Patients can feel they simply need to follow the recommendations of the doctor who knows what's best.<sup>2</sup>
- ▶ Fewer than 3% of brain cancer patients enroll in clinical trials and therefore are effectively denied access to new and potentially life-extending treatments.



#### STRATEGIES

- ▶ The goal of the EBCI is to increase participation in clinical trials to 10% by the year 2025. Our Direct Connect program conveys these trial OPTIONS.
- ▶ EBCI Patient Coordinators help patients overcome fear<sup>3</sup> and be proactive, understanding OPTIONS and their right to other OPINIONS. We convey the value of accessing top specialists and centers.

### Creating PERSONAL Connections and Supporting PERSONALIZED Medicine Approaches

#### CHALLENGES

- ▶ Even in the quest for information, patients and families strongly need emotional support and PERSONAL connection. That may not be available from the local medical team.
- ▶ Scientific breakthroughs and research outpace clinical standards of practice and knowledge on the ground. Two such areas relate to genomic profiling and personalized medicine approaches to brain cancer treatment.



#### STRATEGIES

- ▶ When we hear from newly diagnosed patients and caregivers, their greatest desire is often just to talk. This takes significant time, but creates the PERSONAL bond of trust and best approach for progress.<sup>4</sup>
- ▶ With the support of our national medical advisory board, we inform and support PERSONALIZED medicine approaches tailored to each brain tumor case.

### Developing Patient EMPOWERMENT Plans (PEPs) Through the Intake Process

#### CHALLENGES

- ▶ Brain Cancer patients need more than information to make choices, they need EMPOWERMENT. There are many hurdles for patients: their own crisis, ignorance of options, urgency of the moment, lack of education, etc. In fact some research shows cancer patients actually seek less control and choices.<sup>5</sup>



#### STRATEGIES

- ▶ The EBCI seeks to be a trusted guide to see brain cancer through the process and embrace an appropriate level of control and self-advocacy with our active support, guidance and coordination. We develop a Patient EMPOWERMENT Plan (PEP) for each client and then actively work to help make it happen.

1 Khalili Y. Ongoing transitions: the impact of a malignant brain tumour on patient and family. *Axone* 2007; 28(3): 5.  
 2 Salmon P, Hall GM. Patient empowerment or the emperor's new clothes. *Journal of the Royal Society of Medicine*. 2004;97(2): 53.  
 3 Salander P, Bergenheim T, Henriksson R. The creation of protection and hope in patients with malignant brain tumours. *Soc Sci Med* 1996; 42: 989-990.

4 Khalili Y. Ongoing transitions: the impact of a malignant brain tumour on patient and family. *Axone* 2007; 28(3): 7.  
 Hickey, J. (1998). *The clinical practice of neurological and neurosurgical nursing* (4th ed.). Philadelphia, PA: Lippincott.  
 5 Salmon P, Hall GM. Patient empowerment or the emperor's new clothes. *Journal of the Royal Society of Medicine*. 2004;97(2): 53.