



LEADERSHIP PROFILE

**Executive Director
Brain Tumor Network**

Ponte Vedra Beach, FL

"Guiding Patients and Empowering Care."

The Opportunity

Since its launch ten years ago, [Brain Tumor Network](#) has become a major, treasured resource for patients, families and caregivers across the country who are in need of personalized information and support following a diagnosis of brain cancer.

BTN has expanded its operation and its impact substantially since its founding. In the past year alone, BTN's team of dedicated professionals have worked with over 700 brain cancer patients and their families while also supporting relationships with regional treatment centers and national centers of excellence.

BTN now seeks an Executive Director to build on the collective experiences of the past decade and guide the organization through its next stage of growth. The overarching goal is to reach and stay connected with a greater percentage of the 25,000 patients diagnosed with brain cancer each year.

The Organization

Brain Tumor Network (BTN) is a nonprofit organization committed to providing unique personalized navigational services to patients who have been diagnosed with a primary brain tumor and to oncology professionals providing care to those patients.

BTN's services are provided by a staff of credentialed nurses and social workers knowledgeable in the field of neuro-oncology who provide information to patients and their caregivers free of charge, so that patients can make better-informed decisions about their treatment programs.



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BTN's high-touch navigators serve patients and their caregivers in several ways:

- By discussing diagnosis and treatment options in lay terms;
- By helping to connect them with medical providers with expertise in the treatment of their specific type of brain tumor;
- By facilitating consultations and second opinions, including the gathering and sharing of relevant medical records;
- By providing personalized, curated lists of clinical trial options potentially relevant to a given patient's diagnosis;
- By recommending ancillary social services support called for in specific circumstances; and
- By being a regular, reliable, and trusted source of communication and support throughout the continuum of care for each individual served.

Brain Tumor Network does not provide medical advice. Rather, through its own resources and those of an extended network of oncology professionals, BTN provides transparency to what might otherwise seem an impenetrably complex array of brain cancer diagnoses, alternative treatment options, clinical trials, and support services in the highly complex world of brain cancer. BTN has no direct affiliation with any medical institution or pharma company, so its navigation services are completely objective.

The Sontag Foundation and Brain Tumor Network were both born out of the Sontag family's personal experience with brain cancer. As detailed on the foundation's [website](#), the Sontags experienced firsthand the frustration of dealing with a disease that was not well understood by either the medical community or the general public. Established 20 years ago, The Sontag Foundation has become one of the largest private funders of brain tumor related research in North America. A natural outgrowth

of The Sontag Foundation's research, BTN was organized as a 501(c)(3) public charity in 2014.

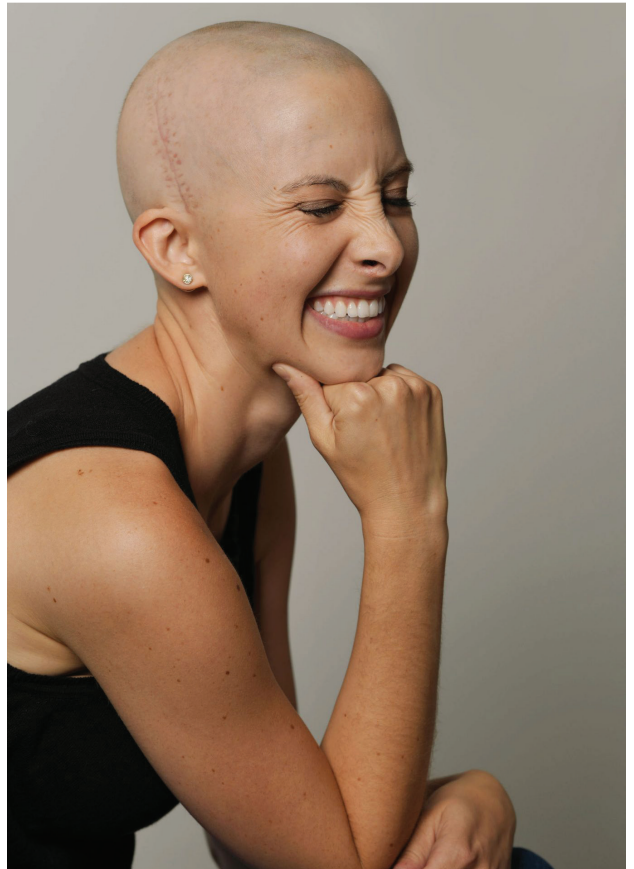
Brain Tumor Network is a public charity supported by major private sources and individual donations. All services are provided at no cost to users. BTN does not accept any funding from pharmaceutical companies or healthcare providers. BTN is governed by its own Board of Directors separate from the Board of The Sontag Foundation.

The Mandate

With no significant outreach other than its website, exposure through social media and participation in national conferences, BTN has attracted inquiries from patients and caregivers in all 50 states. BTN enjoys supportive working relationships with every major brain cancer research and treatment center nationally. The rigor of its operating protocols, the depth of its curated list of available clinical trials, the power of its proprietary information system all combine with the compassion of its professional staff to constitute a powerful, personalized resource for families dealing with brain cancer.

Over the last ten years BTN has provided its services to some 3000 patients and their caregivers, and its rate of growth continues to increase. Accordingly, the next Executive Director can expect a multifaceted mandate:

- **Strategy.** Once the new Executive Director has developed a deep understanding of the field of neuro-oncology and BTN's place in the sector, including its core programs, approach and capabilities, the development of a guiding strategy will be a principal priority. Of special interest will be how to expand BTN's reach without infringing on its core commitment to personalized service rendered with compassion.



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- **Leadership and management.** BTN is a growing operation whose entrepreneurial spirit is grounded in science. As resources and patient participants have grown, BTN has doubled its staff and services. The breadth of the Executive Director job has likewise increased. This has included recruiting and managing a large paid staff of professionals, building out new systems and processes to handle increases in the number of patients served, as well as establishing new connections to major organizations in the brain cancer community.
- **Market awareness.** At present rates, BTN will serve about 1000 patients in 2024. While this means a thousand patients and their families will benefit at no cost from services that were not available at any cost a decade ago, there are thousands more BTN might serve who are unaware of the resource. Capitalizing on ways to expand BTN’s reach, especially to patients and providers distant from major medical centers, could make an inherently difficult journey less frightful for many patients and their care partners.

BTN also has relationships with all the major national organizations related to brain cancer and its treatment, including the Society for Neuro-Oncology, American Society of Clinical Oncology, and the American Association for Cancer Research. BTN regularly has booths at the national meetings of these organizations and often conducts informational panels for attendees. Developing a stronger marketing presence for BTN with these organizations will be part of the Executive Director’s responsibilities.

- **Information management.** BTN and The Sontag Foundation have invested heavily in a proprietary information technology system that, with patients’ authorization, makes it possible to capture and share relevant medical information

across systems that otherwise cannot communicate with one another. Finding better ways to access and utilize the data already being collected is an ongoing challenge, but progress in information management is essential to the goal of serving a significantly greater number of patients than is the case today. Marginal growth can be supported with additional staff; breakthrough growth can occur only with better and more efficient integration of capable information technology systems.

- **Board development.** BTN’s Board of Directors consists of business and medical professionals, most of whom have had a personal connection to the disease of brain cancer. Over time, one of the tasks of the BTN Executive Director will be to help expand this Board with qualified professionals who can help advance the agreed-upon strategy.



The Relationships

BTN’s Executive Director reports to:	Brain Tumor Network Board of Directors
And manages a staff that includes:	<ul style="list-style-type: none"> • 11 navigators (all Registered Nurses). Six navigators work in BTN’s office in Florida, and five work remotely from home in other states. • 3 social workers (all LCSWs) • 3 Medical records personnel • 1 Administrative person • 2 hires in process: A nurse navigator and a marketing manager.
While stewarding relationships with:	<ul style="list-style-type: none"> • BTN board members • The Sontag Foundation • An extensive network of major brain tumor centers and national organizations committed to brain cancer research, treatment or advocacy and support for patients and their care partners.

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BTN has a very close relationship with The Sontag Foundation. BTN's offices are housed in the same large suite of offices as the Foundation, and BTN's main administrative functions (such as accounting and human resources) are executed by a central group connected with both BTN and The Sontag Foundation.

The Location

The new Executive Director will be based in Brain Tumor Network's headquarters in [Ponte Vedra Beach, FL](#), a growing seaside community about 18 miles southeast of [Jacksonville](#).

In addition to being home to Brain Tumor Network and The Sontag Foundation, the Jacksonville area hosts significant medical influencers such as Florida Blue Cross/Blue Shield, Mayo Clinic Jacksonville, and Nemours Children's Health, as well as other national and regional healthcare providers. Jacksonville is also a thriving seaport, cultural hub, and sports haven.

The Candidate

The ideal candidate to become Executive Director of Brain Tumor Network will be a passionate leader who has led a significant public-facing organization or initiative through growth in impact and resources and who empathizes with the plight of patients battling a serious disease, like brain cancer.

The Board is open to a variety of relevant backgrounds. A medically sensitive business executive, an MD, an MBA with a personal connection to cancer, an externally focused leader experienced in patient care, directly or through others—all could be strong contenders. Deep experience in healthcare—more specifically, cancer – would be highly desirable.



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Among the assets and characteristics of special interest:

- A heart for BTN's mission; a leader fully in sync with the "why" of BTN's work.
- A record of impactful engagement in the nonprofit sector. Of special interest: A leader who intuits what patients are going through, from personal or professional experience with brain tumors or related neurological conditions.
- A facility for effective communications, internally and externally, across a variety of media, platforms, and circumstances; genuine comfort as a visible champion for the mission.
- Respect for the power of data and experience leveraging the power of technology, especially in high-touch contexts.
- A self-aware leader with a record of accomplishment that would propel BTN's ability to meet ambitious goals.
- A record of successful, respectful engagement with staff; a demonstrated commitment to collaboration, partnership, and team success.
- A strategic thinker who knows details matter too.
- A leader informed by a fundamental sense of curiosity and love of learning.
- A sensitive but confident manager; a servant leader with the nurturing demeanor and management disciplines a growing organization deserves.
- Someone innately comfortable in an organization informed by strong family values and a sense of purpose.
- An empathetic leader with high EQ, working comfortably with highly educated medical professionals and patients brand new to the issues.



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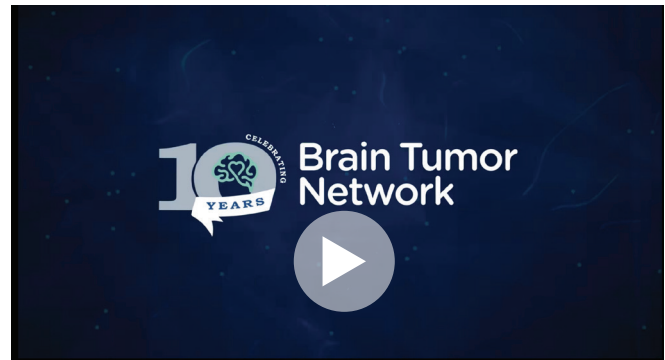


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To succeed, the Executive Director of Brain Tumor Network must have the motivation, intelligence, experience, and sensitivity to be credible with both audiences, continuing to strengthen and expand the collaboration of staff, funders, program partners and other stakeholders committed to BTN’s mission.

BTN’s staff engages with people across an exceptionally broad spectrum. On the one hand, BTN interacts regularly with highly trained specialists who have chosen careers focused on brain cancer. On the other, BTN converses daily with patients, families and caregivers for whom brain cancer is no choice at all.

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In a momentous celebration of science, collaboration, and steadfast patient dedication, Brain Tumor Network and [The Sontag Foundation](#) joined forces at the 21st Annual Distinguished Scientist Retreat, held in February 2024, one of the most prestigious and exclusive gatherings of brain tumor researchers in the country.

Among this year’s highlights was the heartfelt recognition of BTN’s ten years of patient impact and support. The video linked above, released at the Retreat, captures the essence of BTN’s evolution over the past decade, guiding patients through their journey with brain cancer.

For potential consideration or to suggest a prospective candidate, please email

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or call **Sam Pettway** or

Diane Westmore at 404-262-7392.

For the status of this and other searches, please visit www.BoardWalkConsulting.com
