



## LEADERSHIP PROFILE

### Executive Director

### Brain Tumor Network

### Ponte Vedra Beach, FL

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*“Guiding patients. Empowering care.”*

--from the Brain Tumor Network website

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#### THE OPPORTUNITY

Now in just its fourth year of operation, [Brain Tumor Network](https://braintumornetwork.org/)<sup>1</sup> has already earned an exceptional reputation as a go-to resource for adult patients and caregivers hungry for information following a diagnosis of brain cancer.

Funded by private donations and offered at no cost to patients, families or healthcare providers, the services of Brain Tumor Network (BTN) reflect a pervasive commitment to providing unbiased, personalized information on brain cancer treatment options. BTN’s approach to such navigational assistance is compassionate, high-touch, independent and unique.

BTN began as a program of [The Sontag Foundation](http://www.sontagfoundation.org/)<sup>2</sup>, a private foundation known for its strategic focus on brain cancer research and support for patients with brain cancer. Now an independent 501(c)(3), BTN has proven its efficacy through service to hundreds of patients and families across the United States. With funding



*The Sontag Foundation's homepage*

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<sup>1</sup> <https://braintumornetwork.org/>

<sup>2</sup> <http://www.sontagfoundation.org/>

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assured at its current level of operation, the board of directors has endorsed the appointment of BTN's first full-time Executive Director to lead the organization to even more impactful service on behalf of brain tumor patients across the country.

## THE ORGANIZATION

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

BTN's services are currently provided by a staff of credentialed nurses and social workers in consultation with a national network of neuro-oncologists and other medical specialists, all without cost to patients, caregivers or medical professionals, so that patients can make better-informed decisions about their treatment programs.

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

- Discussing diagnosis and treatment options in lay terms
- By helping locate medical providers with expertise in brain tumor treatment
- By facilitating consultations and second opinions, including gathering of relevant medical records and sharing with treating physician in advance of first appointment
- By providing personalized, curated lists of clinical trial options potentially relevant to a given patient's diagnosis
- By recommending ancillary, supplemental and support services called for in specific circumstances, and
- By being a regular, reliable and trusted source of communication and counsel throughout the continuum of care for each individual served.



*Rick & Susan Sontag, whose journey with brain cancer informed The Sontag Foundation's focus and the creation of Brain Tumor Network*

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.

Like The Sontag Foundation, BTN's original sponsor, Brain Tumor Network was born out of a family's personal experience with brain cancer. As detailed on the foundation's [website](#)<sup>3</sup>, 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. By 2018, the Sontags, through their foundation, had become one of the largest private funders of brain cancer research in the United States. The Brain Tumor Network was a natural outgrowth of that support, recognizing that brain cancer affects people, not datapoints.

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*"We offer hope, in what can feel like a hopeless situation."*

*--A member of the BTN team*

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Brain Tumor Network is a public charity supported by private contributions. All services are provided at no cost to users, and BTN does not accept any funding from pharmaceutical companies or healthcare providers. BTN is governed by a five-person board, and the expectation is that the board will expand to nine in the coming years.

Since its inception in 2014, BTN has been led with distinction by Executive Director Kay Verble, simultaneous with her service as Executive Director of The Sontag Foundation, which she has led since 2002.<sup>4</sup> The decision by the Board to appoint a full-time Executive Director of Brain Tumor Network reflects BTN's growing importance as a free-standing entity, with shared roots in the Sontag family's commitment to brain cancer research and patient support.<sup>5</sup>

## THE MANDATE

In less than four years, Brain Tumor Network has grown from a concept to a treasured resource valued by patients, respected by leaders in neuro-oncology and attractive to the growing staff of credentialed nurses and social workers who have chosen BTN over other noteworthy career options.



*BTN's staff, Summer 2018*

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<sup>3</sup> <http://www.sontagfoundation.org/about/the-mission/>

<sup>4</sup> Ms. Verble recently announced plans to retire from The Sontag Foundation at year-end 2019.

<sup>5</sup> In addition to funding brain cancer research nationally, the foundation provides financial and organizational support for medical and dental care for the underserved in its home region of northeast Florida.

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With no significant outreach other than its website and no real fundraising activities beyond its “Donate” button, BTN has attracted inquiries from patients and caregivers from 49 states in the US as well as a number of other countries,<sup>6</sup> and BTN enjoys supportive working relationships with essentially every major brain cancer research and treatment center nationally.<sup>7</sup> The rigor of its operating protocols, the depth of its curated list of available clinical trials, the power of its proprietary database—all combine with the compassion of its professional staff to constitute a powerful, personalized resource for families dealing with brain cancer.

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“The comfort I felt after [my first] call to BTN brought tears to my eyes.”

“A comforting source of expertise. A ready place for the latest research as well as practical tips. A friendly voice, quick to respond and patient in listening to [my] anxieties. The Brain Tumor Network has been all of these things for me.”

*--Recent comments from grateful patients*

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BTN is providing a vital service to hundreds of patients, but they are just a small percentage of the approximately 20,000 US patients diagnosed with a primary brain tumor each year. There is no interest in growth for growth’s sake, but the opportunity for expanded contribution to the field and impact on individual patients is clear, and the Board is committed to a bold future.

As the point person with the overall strategic, operational and financial responsibility for Brain Tumor Network, its mission, programs and people, the next Executive Director will be expected to ensure that BTN’s services are available to as many users can be served with the same quality, the same personal attention, and the same knowledge of the field as the organization proudly exhibits today.

The Executive Director can expect a multifaceted mandate:

- **Strategy.** Once the new ED 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 the core tenets of personalized service rendered with compassion.

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<sup>6</sup> Occasionally, BTN is able to be of informal service to non-US residents, but the potential treatment options and clinical trials presented for patients’ consideration at present are all US-based.

<sup>7</sup> In part a function of The Sontag Foundation’s Distinguished Scientists Award, whereby career and research support is provided to early career scientists who have made significant advances in the field. To date, Sontag has awarded multi-year grants to 43 Distinguished Scientists in 30 academic medical and research centers across the country.

- **Resource development.** As noted above, BTN is a public charity, but the funding base is not diversified, and no real attention has been paid to developing a broad, self-sustaining fundraising strategy. Crafting and executing a thoughtful, staged development plan, that includes individuals, foundations and even corporations will be critical to BTN's long-term thrivability. And while the Executive Director may need to hire appropriate staff to support the plan, the ED must embrace fundraising, outreach and similar such market-facing activities as core to his or her success in the role.
- **Leadership and management.** BTN is a small but growing operation whose entrepreneurial spirit is grounded in science. As resources and patient participants grow, an increase in staff is inevitable, and some of the new staff may be based in other cities. Therefore, the Executive Director must balance a bold vision with attention to detail while fostering an environment attractive to a highly educated staff, needful patients and caregivers, and experienced practitioners.

## THE KEY RELATIONSHIPS

The Executive Director reports to BTN's Board of Directors. The ED will inherit a team currently comprising six navigators, of which five have undergraduate degrees in nursing, four are Registered Nurses, two have Master's degrees and one is soon to receive her Master's; a former neurosurgeon with research experience now on staff as a clinical advisor; and an administrative assistant presently pursuing his Master's in Health Administration.

BTN cannot do its work on behalf of patients without the support of many others, and thus a generous spirit of cooperation and collaboration pervades the work. Among other key relationships of note are the board and staff of The Sontag Foundation, medical professionals across the nation, and families and patients in the Brain Tumor Support Group of Northeast Florida, a monthly gathering that is ripe for replication elsewhere.

In addition, there are various professional associations and working partnerships, such as the Brain Tumor Funders' Collaborative (of which The Sontag Foundation is a founding funder), whose interests and members intersect with BTN's mission.

## THE LOCATION

Brain Tumor Network is headquartered in [Ponte Vedra Beach, FL](#),<sup>8</sup> a burgeoning seaside community about 18 miles southeast of Jacksonville, Florida's fourth-most populous city. [Metro Jacksonville](#)<sup>9</sup> constitutes a thriving seaport, medical center, cultural hub and sports haven.

In addition to being home to Brain Tumor Network and The Sontag Foundation, the Jacksonville area hosts such significant medical influencers as St. Vincent's HealthCare, Baptist Health, Mayo Clinic Jacksonville and Nemours Children's Clinic.



## THE CANDIDATE

The ideal candidate to become Executive Director of Brain Tumor Network will be a passionate leader who combines progressive experience leading a significant public-facing organization or initiative through growth in impact and resources.

The Board is open to any relevant background. A scientifically sensitive business executive, an MD/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 or cancer per se is not a requirement, but the ability to connect with funders and medical professionals will be essential.

Among the assets and characteristics of special interest:

- A heart for BTN's mission
- An entrepreneur who derives joy from service to a higher purpose
- A demonstrated facility for attracting financial support from diverse sources, ideally on a national level
- A facility for effective communications across a variety of media, platforms and circumstances; genuine comfort as a visible champion for the mission
- A self-aware leader with a record of accomplishment that would propel BTN's ability to meet ambitious goals
- A demonstrated commitment to collaboration, partnership and team success
- A self-effacing manager who exhibits (but does not claim!) a humble spirit

<sup>8</sup> [https://en.wikipedia.org/wiki/Ponte\\_Vedra\\_Beach,\\_Florida](https://en.wikipedia.org/wiki/Ponte_Vedra_Beach,_Florida)

<sup>9</sup> [https://en.wikipedia.org/wiki/Jacksonville\\_metropolitan\\_area](https://en.wikipedia.org/wiki/Jacksonville_metropolitan_area)

- A deft leader with the nurturing demeanor and management disciplines this growing organization deserves
- Respect for the power of data and the ability to leverage technology in support of improved patient experiences.

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.

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

***“Guiding Patients. Empowering Care.”***

**For consideration or to suggest a prospect, please email**

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**or call Sam Pettway or Patti Kish at**

**404-BoardWalk (404-262-7392).**



*Wall map in BTN's offices showing location of patients served*