# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018 Progress</td>
<td>4</td>
</tr>
<tr>
<td>Brain Tumor Survivor: Matt Tifft</td>
<td>5</td>
</tr>
<tr>
<td>Signature and Community Events</td>
<td>6</td>
</tr>
<tr>
<td>Donor Honor Roll: Signature Events</td>
<td>7</td>
</tr>
<tr>
<td>Donor Honor Roll: Community Events</td>
<td>8</td>
</tr>
<tr>
<td>GBM Research: Dr. Paul Mischel</td>
<td>9</td>
</tr>
<tr>
<td>2018 Financials</td>
<td>10</td>
</tr>
<tr>
<td>Volunteer: Chandri Navarro</td>
<td>11</td>
</tr>
<tr>
<td>Volunteer Leadership</td>
<td>13</td>
</tr>
<tr>
<td>Advocate: Pati Urias</td>
<td>14</td>
</tr>
<tr>
<td>Donor Honor Roll</td>
<td>15</td>
</tr>
<tr>
<td>2019 Signature Events</td>
<td>23</td>
</tr>
<tr>
<td>Mission, Vision, and Values</td>
<td>24</td>
</tr>
</tbody>
</table>

**CONTACT US**

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A Letter from NBTS Chief Executive Officer & Board Chair

Our mission: National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and their care partners.

2018 was a year of change for the National Brain Tumor Society. Although we continue to fund best-in-class brain tumor research and advance the brain tumor cause in public policymaking, we were utterly dissatisfied with the finding in National Cancer Institute’s 2018 Annual Report to the Nation indicating that mortality rates due to brain tumors are increasing. As a result, NBTS committed to a new strategy designed to help us move faster and have an even greater impact.

The brain tumor community is large and diverse, and everyone in it deserves transformative, actionable results. That starts with better treatments and care. We also believe a sense of community is critical too, so nobody has to navigate their brain tumor journey feeling alone or isolated. In 2018, we brought together over 60,000 people through regional events, and we engaged thousands more through social media. These in-person and online connections help patients and care partners learn, share, and open up a world of new ideas and options. We also launched several online resources designed to help patients get better care.

The Brain Tumor Experience (www.braintumor.org/theexperience) is a web-based portal where patients can access practical information to bring to their medical appointments, and covers everything from the point of diagnosis forward. We also created the NBTS Clinical Trial Finder, which generates a list of available trials that patients and care partners can bring to their medical team and use to explore their options. The National Brain Tumor Society is equipping patients and their care partners with these tools and others so they can ask the right questions and advocate for the best possible treatment.

As we continue our mission toward a cure, we strive for brain tumors to become manageable through treatments that extend length and quality of life. The outstanding basic and translational research accomplishments of our Defeat GBM and Defeat Pediatric Brain Tumor Research Collaboratives yielded many actionable results, including new treatments qualified to begin human clinical trials, new targets for drugs, and new biopsy strategies — all while maintaining a standard for data-sharing that far exceeds most projects of this kind. Another significant victory includes the passing of the Childhood Cancer STAR Act on June 5th, 2018, which National Brain Tumor Society staff helped write and advance through our legislative advocacy work. This law is the most comprehensive childhood cancer legislation ever taken up by Congress, designed to advance pediatric cancer efforts including brain tumor research, survivorship care, and improve childhood cancer surveillance.

There are other ways we’re helping today’s patients, care partners, and members of the larger brain tumor community, too. We connect state-of-the-art medical teams to patients so that they can understand the molecular character and the importance of their tumors, improving the likelihood that they will get the most appropriate and effective treatment and benefit from recent scientific advances. We are fighting for the rights and protection of patients during health care debates about policy, and putting pressure on the federal government to make larger and more strategic investments in brain tumor research. The National Brain Tumor Society convened brain tumor research leaders through Research Roundtables and through a seminal summit meeting in 2018 chaired by the Director of National Cancer Institute (NCI) that led to a multimillion-dollar government investment in single-cell sequencing of gliomas that can lead to better treatment combinations. We’ve grown our volunteer leadership and added new staff in several areas who are already making NBTS stronger and even more results-driven.

We have always focused on resourcing the best brain tumor research, and we likely always will. Many believe we are living through a “Golden Age” of scientific discovery in which previously unsolvable problems are unlocked, and many cancers will become treatable — even curable — as a result. There is a huge need for additional funds to apply recent breakthrough discoveries in the fields of personalized medicine, immuno-oncology, and other areas to brain tumors so our patients can benefit from them. But great research doesn’t always reach patients in time. Our new strategy prioritizes projects that demonstrate the potential to most rapidly translate into patient-focused treatments. With progress made over the last decade, we are arriving at a watershed moment in terms of the scientific understanding of brain tumors. Basic research done in the last ten years has paved the way for clinical trials that will bring patients better therapies and medicines sooner. NBTS’ current investments are in programs and projects that will expedite this critical event horizon.

National Brain Tumor Society’s vision is clear: to conquer and cure brain tumors – once and for all. We prioritize our key values of putting patients first, providing best-in-class science and service to our community, and being relentlessly results-driven. Thank you for being an integral part of the past year’s successes. Please continue to join, unite, support, and take action with us as we strive to help patients and families every day. Together, let’s put exceptional research to work for treatments that help every member of our community.

David F. Arons, JD
Chief Executive Officer,
National Brain Tumor Society

Sarah Durham
Chair, Board of Directors,
National Brain Tumor Society

www.braintumor.org
NBTS Progress in 2018

New Research Discoveries
• Dr. Paul Mischel discovered that specialized, circular bunches of DNA can be found in high levels in glioblastoma tumor cells. These pieces of "extrachromosomal DNA" are believed to be major contributors to tumor growth and treatment resistance. This discovery could change the way we treat GBM.

• Dr. Frank Furnari used funding through the Defeat GBM Research Collaborative to discover the critical role that an altered cellular protein called "PTEN" plays in reversing the effects of radiation treatment. Importantly, Dr. Furnari’s team found a type of drug that may be able to block the actions of the altered PTEN and helps make radiation more effective for glioblastoma patients.

• Defeat GBM researcher, Dr. Ingo Mellinghoff, has been refining a new, less-invasive approach to detect and track mutations in patients’ tumors through the use a “liquid biopsy.” In this technique, researchers collect fragments of DNA shed from the main tumor (called ctDNA) more easily-accessible bodily fluids like cerebrospinal fluid (CSF) for mutational analysis.

Clinical Trials and Potential Treatment Pathways
• NBTS funded early research that allowed MD Anderson Cancer Institute scientists to develop an approach that uses a modified version of the common cold virus to attack glioblastoma cells, now being evaluated in clinical trials.

• Seven new brain tumor drugs have the potential to move to phase 3 clinical trials soon and could represent new treatment pathways.

• Defeat GBM-funded work paves the way for non-invasive diagnosis, treatment monitoring, and research including new biomarkers.

Public Policy and Advocacy
• National Brain Tumor Society, through our advocates and the Alliance for Childhood Cancer, helped pass the Childhood Cancer STAR Act into law in 2018. This new law dedicates increased levels of federal funding into childhood cancer research and survivorship initiatives.

• Advocates were integral in educating lawmakers on the challenges of brain tumor patients, and helped influence a $3 billion increase in NIH and NCI research spending for budget year 2019, as well as an increase in Department of Defense spending for pediatric research from $60 million to $80 million.

• NBTS held its first-ever Brain Tumor Congressional Briefing on Capitol Hill, hosted by Senator Lindsay Graham, to educate Congress on issues facing brain tumor patients. The briefing educated a bi-partisan gathering of Members of Congress, national media, and key staffers. Bill Barone, a GBM patient, and Dr. W.K. Alfred Yung, NBTS Distinguished Scientific Advisor, shared information.

Head to the Hill
This annual advocacy event has become a powerful vehicle to ensure the voice of the brain tumor community is being heard on Capitol Hill.
“I was so happy and excited to do this,” says 22-year old NASCAR driver Matt Tifft, who generously decided to advocate for the National Brain Tumor Society with logos, taglines, and colors splashed across his racecar. “I wanted to get the word out, and we got a lot of recognition and airtime for the mission to find cures for brain tumors.”

In 2017, Matt and his family, with the blessing of his race team (at the time Joe Gibbs Racing), “wrapped” his racecar for two separate NASCAR Xfinity Series events with the NBTS brand. (Editor’s Note: Matt moved to Richard Childress Racing in 2018, and his new team has been just as accommodating in supporting Matt’s efforts to raise brain tumor awareness, and Matt has driven the NBTS car twice already in the 2018 NASCAR season).

The young driver’s career in NASCAR was nearly derailed before it truly even started. In 2016, the then 19-year old had just received the biggest breakthrough of his career, signing on to represent the hottest team in NASCAR, Joe Gibbs Racing, for 13 Xfinity Series races. For weeks, Matt had been experiencing increasing anxiety, stress, and paranoia. As time went on, he also began having sensitivity to light.

During an unrelated medical appointment, Matt asked his doctor about these strange neurological sensations — ones he assumed were related to a concussion incurred during a previous sports injury. But what a subsequent MRI revealed was life-changing: a half-dollar-sized low-grade glioma brain tumor.

The good news: the tumor was benign. The scary news: doctors had no way of telling whether the tumor would eventually become malignant, and if so, when.

Though Matt notes that he was “one of the lucky ones,” his road back to the racetrack after surgery to remove the tumor was no walk in the park. “Going through the recovery process, I certainly questioned whether things would get back to normal.”

As Matt settled back into the sport, he decided he wanted to become a brain tumor advocate and help others impacted by the disease. “That’s really when I started working together with folks at NBTS to try and figure out what my role could look like,” says Matt. “Obviously, we have such a huge platform in NASCAR and there’s just so much opportunity to get the word out.”

Ultimately, Matt’s engagement with NBTS would evolve beyond the special NBTS racecar. His involvement now spans across the organizational initiatives, including the annual Head to the Hill advocacy day and the Charlotte Brain Tumor Race. “Leaving those events...you feel absolutely exhausted, but in a good way because you know you did good work and that you made a difference,” says Matt. “That’s something that I really never experienced before.”

These events are directly aligned with what he wants to accomplish as a champion for brain tumors patients and survivors. “I feel it is important to raise funds for research, and truly get involved in the mission from many levels,” he says. Moving forward, Matt plans to add to his work as a spokesman, volunteer advocate, team captain and event participant by engaging with NBTS in our patient and caregiver education, engagement, and preparedness initiatives. “It’s such a stressful, life-changing event [receiving a brain tumor diagnosis]. It changes everything,” Matt notes. “And having a clear path and direction and knowing your options and knowing what to do and the questions to ask, I think is so important. So that is my goal—to really help with the patient experience. I don’t want others to experience that empty, confusing feeling in the future.”

Throughout it all, there is one thing that Matt is truly thankful for: those around him who have supported him in his brain tumor experience and his efforts to fight back — his family, friends, race teams (first Joe Gibbs Racing and now Richard Childress Racing) and, of course, NBTS. “National Brain Tumor Society has been wonderfully supportive of me and my family. Their staff are genuinely proactive, helpful, and excited about this collaboration.”
2018 SIGNATURE AND COMMUNITY EVENTS

Tumor Takedown Tailgate (Greenwood, IN)

Recognizing 20 years of partnership with Cushman & Wakefield at the Race for Hope - DC

Race for Hope - Philadelphia

Central New Jersey Brain Tumor Walk

New York City Brain Tumor Walk

Orange County Brain Tumor Walk

Long Island Brain Tumor Walk

Northern New Jersey Mud Run

Boston Brain Tumor Ride

Phoenix Brain Tumor Walk

Sacramento Brain Freeze

Bay Area Brain Tumor Walk

Ft. Worth Brain Tumor Walk
Northwest Brain Tumor Walk

Denver Brain Tumor Walk

Bob Burns Memorial 5K (Augusta, ME)

Jones’n for a Cure (Sacramento, CA)

Twin Cities Brain Tumor Walk (Plymouth, MN)

Michael Cassidy Shamrock N’ Run 5k (Rutherford, NJ)

LA Brain Freeze

Madison Brain Tumor 5k (Madison, WI)

Rhode Island Brain Tumor Walk

San Diego Brain Tumor Walk

2018 NBTS Boston Marathon Team

Team Billy Ride and Walk for Research (Saratoga Springs, NY)
2018 Signature Event
Top Fundraising Individuals

Bay Area Brain Tumor Walk:
Lauren Kwist, $35,686

Race for Hope PA:
Sandra Kramer, $29,395

Race for Hope DC:
Karen Siebert, $28,960

New York City Brain Tumor Walk:
Will Roth, $24,650

Boston Brain Tumor Walk:
James Mawn, $23,650

Boston Brain Tumor Ride:
James Mawn, $23,650

Boston Brain Tumor Walk:
Brett Johnson, $19,833

Orange County Brain Tumor Walk:
Melissa Ernst, $16,915

Baltimore Brain Tumor Walk:
Holly Gainsboro, $12,510

Northwest Brain Tumor Walk:
Dave Marlaiwe, $11,072

Charlotte Brain Tumor Race:
Amy Koegle, $10,800

Central New Jersey Brain Tumor Walk:
Tara Mitchell, $10,785

Los Angeles Brain Freeze:
Dean Front, $8,622

Florida Brain Tumor Race:
Russ Vorhis, $7,575

San Diego Brain Tumor Walk:
Heather Wong, $7,360

Phoenix Brain Tumor Walk:
Jason DiFrancesco, $6,444

Richmond Brain Tumor Brewha:
Gary Ingram, $5,895

Long Island Brain Tumor Walk:
Vinny DeAngelis, $5,686

Fort Worth Brain Tumor Walk:
Kimberly Albro, $5,532

Sacramento Brain Freeze:
Courtney Gessford, $3,921

Delaware Brain Tumor Walk:
Tracy Milcendeau, $3,615

Denver Brain Tumor Walk:
Peggy Kness, $3,390

Northern New Jersey Walk & Gray Mud Run:
Anne Looney, $3,200

Charleston Brain Tumor Walk:
Katie Seamon, $2,640

Twin Cities Brain Tumor Walk:
Craig Rykal, $2,305

Connecticut Brain Freeze:
Jeff Tudisca, $1,295

2018 Signature Event
Top Fundraising Teams

$100k+
Cushman & Wakefield: $201,612

$50k+
Kevin Strong: $87,780
Survivors: $59,350
reMARKable strides: $54,880
David Cook’s Team for a Cure: $53,092
Lisa’s Riders: $52,986
Chris Connelly Crushes Cancer: $52,482

$25k+
Hope Brings Strength: $42,319
William’s Warriors: $42,080
Team Jackie: $38,795
Team Kermit: $37,872
Bike for Ike: $36,960
Team Oligo: $36,834
Lauren’s Quest: $36,171
All for Team Pamela Sue and Dana: $34,578
Molloy’s Marchers: $34,320
Hope by the Bay: $34,203
Team Mawn: $34,190
Kaiser Permanente - Grey Matters: $34,168
Rabbi’s Runners: $33,512
Sharing Hope: $29,824
SEAS THE DAY: $29,460
Willie Strong: $26,539
Team DC & Team PMA: $26,148
Team Holly Grace: $26,021
Uma: $25,995
Will’s Tiny Tumorless Brain: $25,775
Allison’s NumbSkulls: $25,151

2018 Signature Event
Top 10 Recruiting Teams

Willie Strong: 349 members
Kevin Strong: 250 members
Saving Grey: 199 members
Chris Connelly Crushes Cancer: 172 members
David Cook’s Team for a Cure: 170 members
Kaiser Permanente: 143 members
Miracles for Mary Scott: 136 members
William’s Warriors: 124 members
Survivors: 111 members
Trolio’s Troopers: 111 members
## 2018 DONOR HONOR ROLL: COMMUNITY EVENTS

### 2018 Community Events

#### Top Fundraising Events

$100k+
- 2018 Team Billy
  - $127,200

$20k+
- 2018 RI Brain Tumor Walk
  - $38,252
- 2018 Madison Brain Tumor 5k
  - $38,133
- 2018 Waves of Gray 5k
  - $36,263
- 2018 Dura Mater Hill Climb
  - $33,052
- 2018 Twin Cities Brain Tumor Walk
  - presented by Brains Together for a Cure
  - $30,740
- 2018 Maryland Impact Golf Tournament
  - $29,086
- 2018 Bob Burns Memorial 5k
  - $20,000
- 2018 Emerald Hope Gala
  - $20,000

$10k+
- 2018 Jones’n for a Cure Golf Tournament
  - $16,500
- 2018 Tumor Takedown Tailgate
  - $16,071
- 2018 Michael Cassidy Shamrock ‘N’ Run 5k
  - $14,200
- 2018 True Blue Shootout for a Cure Lacrosse Tournament
  - $12,550
- 2018 Shelby’s “Brewfest” and Wine Tasting
  - $12,038
- 2018 Fight for the Brain Happy Hour
  - $11,781
- 2018 P&D Student Choreography Project
  - $11,700
- 2018 The First Annual Jenny Tawes 5k Run/Walk for a Brain Cancer Cure events
  - $10,884
- 2018 Ales for Ashley
  - $10,500

### 2018 Gray Nation Endurance

#### Top Fundraising Individuals

$30k+
- Jennifer Swenson (2018 TCS NYC Marathon)
  - $39,389

$10k+
- Ron Clark (2018 Falmouth Road Race)
  - $19,554
- Rory Grant (2018 TCS NYC Marathon)
  - $17,686
- Alan Snow (2018 Boston Marathon)
  - $14,386
- Kelsey Riggleman (2018 Boston Marathon)
  - $13,580
- Jesse Riggleman (2018 Boston Marathon)
  - $10,501

$5k+
- Bruno Colantuoni (2018 TCS NYC Marathon)
  - $8,892
- Brian Sereno (2018 Boston Marathon)
  - $8,600
- Nitesh V Patel (2018 TCS NYC Marathon)
  - $6,060
Glioblastoma’s relentless growth and ability to resist treatment is one this tumor’s most feared characteristics. NBTS-funded research is uncovering mechanisms underlying this problem.

Dr. Mischel is a member of Ludwig Cancer Research, San Diego and professor at the University of California, San Diego. He leads one of the “Cores” of NBTS’ Defeat GBM Research Collaborative. With Dr. Timothy Cloughesy of UCLA, Dr. Mischel and his team focus on understanding why previous attempts to treat glioblastoma have been unsuccessful, using this information to guide new medical strategies likely to be more effective for patients.

The astounding discovery that Dr. Mischel and his team made relates to where, specifically, in glioblastoma cells so-called “oncogenes” are actually found. Oncogenes are genes that have been mutated (or changed) and contribute to the development of cancer. “We discovered something fundamental about how cancers diversify and evolve,” said Dr. Mischel. “This is an essential rethinking about what goes wrong with genes in cancer.”

Why does it matter where the cancer-causing mutations actually live? The answer starts with understanding that glioblastoma tumors are highly heterogeneous, meaning they contain a multitude of different cell types with diverse spectrum of mutations — all within the same tumor. And because heterogeneity is known to drive tumor evolution and resistance to treatment, understanding why and how these tumors become so heterogenous in the first place could provide valuable insights for new strategies to eliminate this cancer.

Dr. Mischel’s Defeat GBM-funded research discovered that small, circular free-floating fragments of DNA known as “extrachromosomal DNA (ecDNA)” are present in more than 90% of glioblastoma cells. Further, the research revealed that virtually all of the oncogenes associated with glioblastoma could be found on ecDNA, rather than on chromosomes, where DNA and genes are normally packaged.

The team then observed that tumors become more heterogeneous, and more quickly, when their oncogenes are on ecDNA instead of chromosomes. Dr. Mischel’s team hypothesized that ecDNA accelerates this rapid evolution and extreme heterogeneity because it doesn’t play by the same rules that govern normal cells and evolutionary biology.

When ecDNA passes on its copies of genes to daughter cells, they get distributed randomly. And when dividing ecDNA in glioblastoma cells start passing on random assortments of oncogenes to subsequent daughter cells, it makes the diversity (heterogeneity) of cell types and mutations in the tumor enormous. Importantly, this hypothesis was independently confirmed by the work of another Defeat GBM team member, Dr. Roel Veerhak. Dr. Veerhak found that ecDNA plays a major role in glioblastoma evolution, heterogeneity, and treatment resistance.

Dr. Mischel and his team have identified multiple new treatment targets in glioblastoma, coupled with potential drugs that are ripe for clinical development and testing. For this, Dr. Mischel credited the funding he received through the Defeat GBM Research Collaborative, as well as critical interactions with other researchers the Collaborative fostered. “If we figure out rules that govern this process, perhaps that can be stopped,” says Dr. Mischel. “And if that’s the case we may be much more capable of intervening therapeutically in way that actually works and has a higher success rate. Each of these papers is having considerable scientific impact in the field. More importantly, our findings are poised to make clinical impact for patients.”

Defeat GBM Research Finds Major Piece of Glioblastoma Puzzle
## 2018 NBTS Financials

### Statement of Financial Position

**Assets**
- Prepaid and other current assets: $161,621 (2018), $203,481 (2017)


**Liabilities**
- Research grants payable: $1,250,000 (2018), $1,640,000 (2017)
- Deferred Revenue: $29,621 (2018), $9,598 (2017)

**Total liabilities**: $1,734,007 (2018), $2,040,617 (2017)

**Net Assets**
- With donor restrictions: $1,253,955 (2018), $605,325 (2017)

**Total net assets**: $2,234,936 (2018), $1,202,461 (2017)

**Total liabilities and net assets**: $3,968,943 (2018), $3,243,078 (2017)

### Statement of Activities

**Revenue**
- Donated goods and services: $90,783 (2018), $158,990 (2017)

**Total revenue**: $11,322,784 (2018), $10,430,091 (2017)

**Expenses**
- Special events: $897,653 (2018), $917,079 (2017)
- Other expenses: $1,618,976 (2018), $1,514,589 (2017)

**Total Expenses**: $10,290,129 (2018), $9,394,894 (2017)

**Net income/Loss**: $1,032,655 (2018), $1,035,197 (2017)
Brain tumor medicine has come a long way since 1993 when NBTS Board Member Chandri Navarro was diagnosed with a tumor the size of a small orange near her brainstem.

Chandri was 29 years old and working at a law firm in Washington D.C., while attending law school at night. She had been experiencing severe headaches, which were diagnosed by x-ray as a sinus infection. One morning, Chandri woke up having double vision. Over the phone, her doctor explained that blurry vision was a side effect from antibiotics Chandri was taking for the infection, but her vision was not “blurred,” rather, she said, she was seeing “two of everything.” In an appointment that day, her ENT doctor examined her eyes and took her to see an ophthalmologist.

The ophthalmologist sought the aid of a neurologist, who then guided some tests and persuaded one of the few new MRI centers in DC to open early the next morning for Chandri. She left the MRI center with images displaying a “massive blob” in the middle of her brain on two-by-three-foot slides. She hauled them with her to the neurologist who, after conducting painful visual field tests and reading the MRIs, told her she needed surgery that week. Three neurosurgeons confirmed the need for an immediate craniotomy.

There was a 20 percent chance she would not survive the operation because of the tumor’s proximity to the brainstem. With her parents and sibling living outside of the United States, and only her husband to care for her, Chandri drafted a living will stating she wished to be kept on life support no longer than 3 months.

The neurosurgeon had told Chandri that once he reached the tumor, he would test it and if it was malignant, close her up, because she would need radiation and chemotherapy and there was “no sense in mucking around in her brain when she was going to die anyway.” Contrary to his initial plan, he decided to spend an additional 8 hours cutting out as much tissue as possible. Chandri survived, learning after the 12-hour surgery that she had a grade IV glioma (malignant). Her life expectancy was 4 months.

At the time, Chandri’s uncle was working for the National Institutes of Health (NIH) and requested extra tissue samples which he sent to University of California, San Francisco (UCSF) and Armed Forces Institute of Pathology (AFIP). Just as Chandri was to begin radiation, the results she received back from UCSF were very different than her initial diagnosis: an extremely rare and benign ganglioma. The results from AFIP were even murkier: appearances of ganglioglioma and glioma. Her surgeon canceled radiation and monitored the tumor for regrowth. Chandri’s luck at having a family member at the NIH is not lost upon her. “It’s very hard to claim your own brain tissue,” she says. “I would have had the full dose of radiation. I was 29. Once you have your lifetime dose, that’s it. You can’t get more.”

After years of MRIs that have become increasingly infrequent, Chandri has said that she doesn’t want anyone else to have to live with the kind of ambiguity or fear she has experienced. And while she feels frustrated that there are not enough FDA-approved standards for measuring tumors other than overall survival (OS), she is very optimistic that projects like the NBTS Clinical Trial Endpoints Initiative — which seeks to standardize the measurement of endpoints other than OS — will help reduce improve brain tumor treatment. Chandri also hopes that NBTS’ presence in the brain tumor community, and on Capitol Hill, will further empower other patients to step forward as advocates without the fear of stigmatization.

“The larger you are as an association,” she says, “the more you can do. The louder the voice you have. The bigger impact you can have.”
Senator Lindsay Graham at the NBTS Congressional Briefing on Glioblastoma Research

Racing towards a cure at our 2018 Signature Events

NBTS Advocates gather on the steps of the Capitol during Head to the Hill

NBTS Congressional Briefing on Glioblastoma Research

Bobblehead gift presented to Michael Nathanson at the launch of the Nathanson Family Catalyst Fund for Brain Tumor Research

Launch of the Nathanson Family Catalyst Fund for Brain Tumor Research
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2018 Board Chair Michael Nathanson addresses participants at the Boston Brain Tumor Walk
Pati Urias spent 100 days in the hospital with her son, Colin, after he was diagnosed at the age of fourteen with a tumor on his brainstem. "He was probably the most gentle spirit I have ever known. Sweet, giving, forgiving," Pati says. "When he was diagnosed, he panicked, but he was never angry about it in anyway. It wasn’t in his soul. His hope was that there would be a cure."

In the week following Colin’s funeral in August of that same year (2011) Pati knew she needed to transform her grief into energy. Brain tumors are the leading cause of cancer-related deaths in children under nineteen years of age, and brain tumor treatments designed specifically for children do not currently exist.

"Why is it that there isn't enough research to cure something like this?” Pati found herself wondering as she considered treatments available for other kinds of cancers. This is when she began researching nonprofit organizations devoted to brain cancer, calling every single one she could find. National Brain Tumor Society was on her list, and she connected with CEO David Arons who was, at the time, NBTS’ Director of Public Policy.

David urged her to connect with members of Congress, which led to Pati visiting the offices of every Arizona state representative that would have her, to convince them of the critical importance to fund better research for pediatric brain cancer. It was the office of then-Rep. Trent Franks who told her they had never had an advocate come in to discuss NIH funding.

"A lot of brain tumor research seen in the past has been on curing adult cancer. Childhood cancer remains an enigma,” Pati explains. Pati also started participating in NBTS initiatives: chairing the Phoenix walk and also attending Head to the Hill — NBTS’s signature event to help policymakers better understand the needs of the brain tumor community

As a professional nonprofit lobbyist, Pati knows that great patience is required to cope with often slow-moving progress on Capitol Hill. As an advocate for her son and for other children with brain cancer, Pati has learned some new lessons as well. She has trained herself to transform her passion and the frustration she sometimes feels in order to, as she says, “put on the battle gear in a professional way.”

She focuses on the bigger picture, finds motivation in the potential for progress. More than anything, she thinks of her son and other children afflicted by brain cancer. “In my promise to continue to fight,” she says, “there are going to be a lot of ups and downs. But my disappointment isn’t anything compared to what Colin went through or what other patients are going through.”

Last year, in 2018 — seven years after Colin’s diagnosis — National Brain Tumor Society advocates including Pati led a coalition of pediatric cancer organizations on Capitol Hill to help pass the Childhood Cancer STAR Act into law. Having passed, this new law will funnel increased levels of budget money directly into childhood cancer research initiatives. It is an enormous, unprecedented achievement. “The passage of the STAR Act will give researchers more to go on,” Pati says. “It paves a very good path for children diagnosed in the next ten to fifteen years.”

At the same time, however, the work is not done, and Pati’s efforts are ongoing. “The thing that keeps me going is how hard Colin fought,” she says. “It is incumbent upon me to get out and fight for those who are too sick.”
2018 DONOR HONOR ROLL

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March
Connecticut Brain Freeze
• Sunday, March 3, 2019
• www.BrainTumor.org/ctbrainfreeze
Charlotte Brain Tumor Race
• Saturday, March 23, 2019
• www.BrainTumorRace.org/Charlotte

April
Northwest Brain Freeze
• Saturday, April 6, 2019
• www.braintumor.org/northwestfreeze

May
Race for Hope DC Walk/Run
• Sunday, May 5, 2019
• www.CureBrainTumors.org
Northwest Brain Tumor Walk
• Sunday, May 5, 2019
• www.braintumorwalk.org/northwest
Central New Jersey Brain Tumor Walk
• Saturday, May 11, 2019
• www.BrainTumorWalk.org/CentralNewJersey
San Diego Brain Tumor Walk
• Saturday, May 11, 2019
• www.BrainTumorWalk.org/SanDiego
Boston Brain Tumor Ride
• Sunday, May 19, 2019
• www.BrainTumorRide.org/Boston

June
Denver Brain Tumor Walk
• Saturday, June 1, 2019
• www.BrainTumorWalk.org/Denver
New York City Brain Tumor Walk
• Sunday, June 9, 2019
• www.BrainTumorWalk.org/NewYorkCity
Bay Area Brain Tumor Walk
• Sunday, June 23, 2019
• www.BrainTumorWalk.org/BayArea

September
Maryland Brain Tumor Walk
• Saturday, September 14, 2019
• www.BrainTumorWalk.org/Baltimore

Long Island Brain Tumor Walk
• Saturday, September 14, 2019
• www.BrainTumorWalk.org/LongIsland
Orange County Brain Tumor Walk
• Saturday, September 14, 2019
• www.BrainTumorWalk.org/OrangeCounty
Northern NJ Mud Run & Walk
• Saturday, September 28, 2019
• www.BrainTumorWalk.org/mudrun

October
Philadelphia Race For Hope Walk/Run
• Saturday, October 12, 2019
• www.RaceForHopePA.org
Sacramento Brain Freeze
• Saturday, October 19, 2019
• www.Braintumor.org/SacBrainFreeze
Boston Brain Tumor Walk
• Sunday, October 20, 2019
• www.BrainTumorWalk.org/Boston

November
RVA Brain Tumor 5K
• Saturday, November 2, 2019
• www.Braintumor.org/richmond
Los Angeles Brain Freeze
• Saturday, November 2, 2019
• www.Braintumor.org/LABrainFreeze
Florida Brain Tumor Walk
• Saturday, November 2, 2019
• www.BrainTumorWalk.org/LABrainFreeze
Ft. Worth Brain Tumor Walk
• Saturday, November 2, 2019
• www.BrainTumorWalk.org/FortWorth
Delaware Brain Tumor Walk
• Saturday, November 9, 2019
• www.BrainTumorWalk.org/Delaware

December
Phoenix Brain Tumor Walk
• Saturday, December 7, 2019
• www.BrainTumorWalk.org/Phoenix
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National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and care partners.

MISSION

VISION

VALUES

PATIENTS FIRST
We are fiercely committed to providing a voice and community for all individuals impacted by brain tumors.

BEST-IN-CLASS
SCIENCE AND
SERVICE TO OUR
COMMUNITY
We adhere to rigorous standards across our scientific and community initiatives.

CONSTRUCTIVE,
CANDID AND
TRANSPARENT
We practice fearless candor by being honest, accountable, and transparent in all that we do.

RELENTLESSLY
RESULTS DRIVEN
We set aggressive goals, achieve measurable results, account for our work, and accurately report our progress. We drive positive change and have the courage to disrupt the system and take risks to achieve our goals.

COMMITTED TO
THE PUBLIC TRUST
We are prudent stewards of donors’ funds and conduct our organization openly, operate efficiently and communicate frequently.

COLLABORATIVE
AND INCLUSIVE
We believe that working with others is critically important to achieving our mission.

POSITIVE
(CAN-DO)
ATTITUDE
We believe a positive attitude is essential for achieving our goals.