



National
Brain Tumor
Society



ANNUAL REPORT | 2019

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VISION

Conquering and curing brain tumors — once and for all.

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 care partners.

VALUES

Patients First

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

Constructive, Candid and Transparent

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

Committed to the Public Trust

We are prudent stewards of donors' funds and conduct our organization openly, operate efficiently, and communicate frequently.

Positive (Can-do) Attitude

We believe a positive attitude is essential for achieving our goals.

Best-in-Class Science and Service to Our Community

We adhere to rigorous standards across our scientific and community initiatives.

Relentlessly Result 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.

Collaborative and Inclusive

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



A Letter from NBTS Board Chair

Dear NBTS Community:

I'm so pleased and honored to be writing to you as the new Chair of the Board of Directors and as a fellow brain tumor survivor. Our mission and our cause are personal to me, and I intend to do everything in my power to ensure that National Brain Tumor Society is the best organization it can be for all of us.

In 2016, I was diagnosed with a subependymoma, and the tumor was removed through a very successful surgery at Massachusetts General Hospital, a clear brain tumor center of excellence. I am very fortunate, and realize that my health and the quality of treatment I received are the product and result of some of the work we do together through National Brain Tumor Society. Advocacy and philanthropy for brain tumor research, medical training and adequate health care delivery are the headwaters of the river that leads ultimately to better outcomes including cures. And I've come to understand that NBTS is a clear catalyst for that river to flow.

Indeed, 2019 was a year of significant progress as you will read in this Annual Report. Through NBTS, you advanced new research strategies to ignite the body's own immune system to fight brain tumors, mobilized thousands of members of the brain tumor community to advocate, and honored countless loved ones who are battling brain tumors or passed away from this devastating disease. NBTS also was made stronger through the addition of new Board members including Amy Fenton, Dr. Edjah Nduom, Mike Smith and many new volunteers and teams.

I'm truly grateful for the work of staff and the board and to you as supporters, volunteers and donors.

With much gratitude,

A handwritten signature in dark ink, appearing to read "Tom Roloff". The signature is fluid and cursive, written over a light blue background.

Tom Roloff

Chair of the Board of Directors, National Brain Tumor Society



A Letter from NBTS Chief Executive Officer

Dear NBTS Community:

Thanks to your support, National Brain Tumor Society completed a major transition under its strategic plan in 2019. We developed and put into place a new mission-delivery framework called Defeat, Connect and Change, designed to propel us forward toward our vision of conquering and curing brain tumors once and for all.

Defeat

The donor support and partnership of volunteers, including some of the world's foremost scientific experts, led to our Defeat GBM Research Collaborative experiencing another extraordinary year of progress, while our Defeat Pediatric Brain Tumor Research Collaborative completed its first full year of funded work. Thanks to both of these flagship research programs, we were able to begin planning the broader next stage umbrella program platform, Defeat Brain Tumors, to bring forward the most treatments-focused work into new projects poised to accelerate laboratory research to clinical trials that give patients unique survival opportunities beyond the standard of care. One of the highlights of the year was the launch of the GBM AGILE clinical trial that NBTS is a supporter of. In 2019, we further focused the scope of research to the following themes: immunotherapy, DNA damage repair, tumor metabolism, precision medicine, and innovative clinical trial design. Going into 2020, this decision has yielded clearly focused projects worthy of immediate investment.

Connect

With advancements in neurosurgery to be realized, innovation in imaging, and new opportunities for clinical trials and off-label therapies, the importance of educating patients about treatment options early on at the point of diagnosis is more important than ever. In 2019, based on feedback from volunteers, NBTS began to design new programs aimed at empowering patients and care partners from time of diagnosis through their entire life as



a patient and survivor of a brain tumor. We brought on talented new staff capable of leading this work and continued to provide timely and trusted information to our community. We also brought together experts across government, industry, and hospitals with patients and families, to confront key challenges such as improving imaging and clinical trials for brain tumor patients, including those with brain metastases. We partnered with colleague and peer organizations to raise awareness and visibility. We also convened over 50,000 members of the brain tumor community across national and community events around the country, all united in our shared mission.

Change

Following up on the passage of the Childhood Cancer STAR Act in 2018, NBTS advocates tenaciously and successfully persuaded Congress to provide funding for STAR Act programs, and joined other groups to achieve another increase in federal funding for research. NBTS also led the brain tumor community in the creation

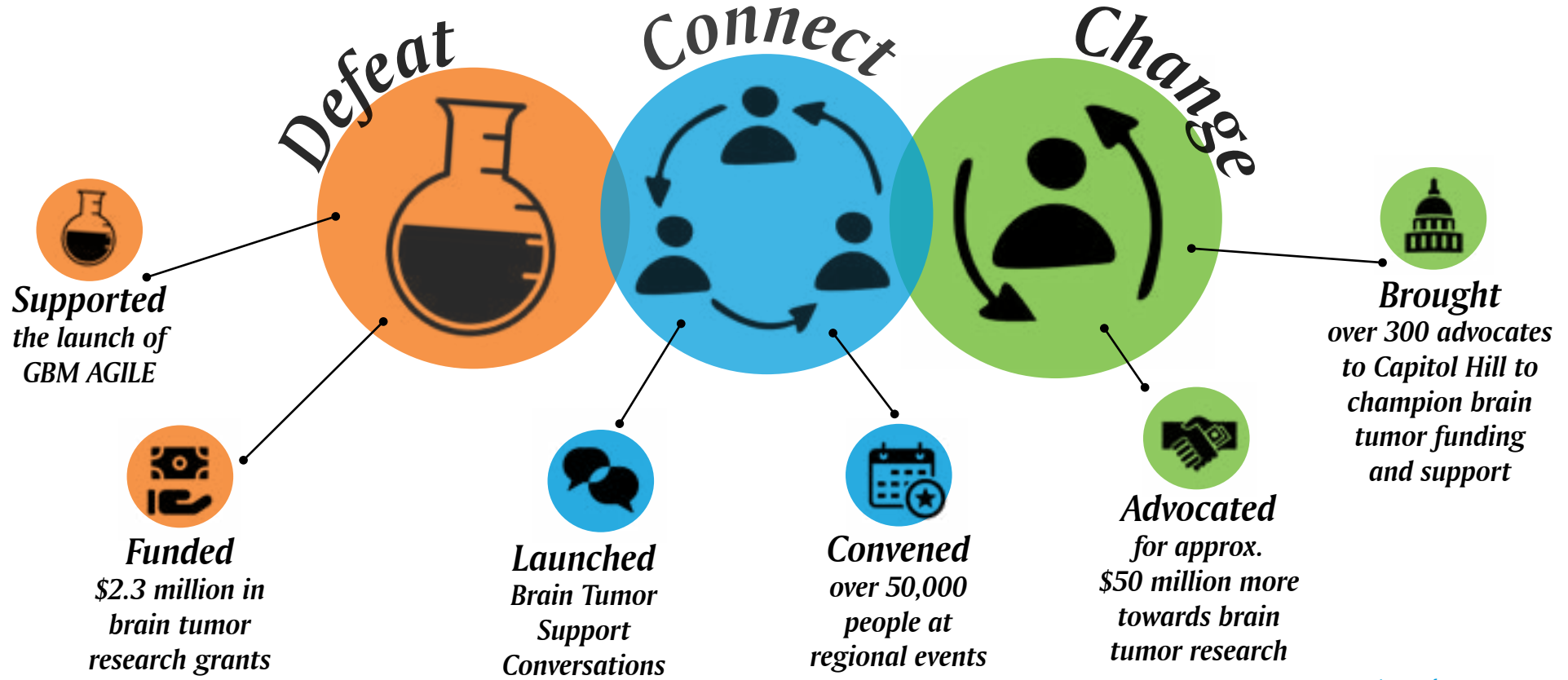
of the first annual Glioblastoma Awareness Day, marked by a bipartisan resolution in the U.S. Senate and commitment from a bipartisan group of Senators.

An important part of NBTS' success in 2019 was due to Sarah Durham's leadership as our Chair of the Board of Directors. She did an outstanding job, and when her term concluded at the end of the year, she left NBTS even stronger, more prepared to realize our mission. She handed the gavel to another truly outstanding volunteer leader in Tom Roloff.

Thanks again to all of you. Every day we aim to earn your support and trust, and we are grateful to be a part of your lives.

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

Through your generous support, in 2019
NBTS was able to make significant progress against
all three of our mission-delivery strategies



Progress in 2019

While there is still much to accomplish to reach our ultimate goal of conquering and curing brain tumors, each of the achievements listed here tangibly advances brain tumor research and treatment development, patient access to care and support, and/or improves the lives of patients and their families.

Defeat

Accelerating Treatment-Focused Research

- Funded the discovery of a new and hoped-for [clinical research strategy for immunotherapy in brain tumors](#)
- Funded the discovery of [a new approach to “supercharge” radiation treatment](#) to help glioma patients
- Funded research that may have [found a “missing link”](#) between mutated genes in glioblastoma and nutrients tumor cells need to keep growing, which could be an important new drug target to treat glioblastoma and other tumors
- [Invested a total of \\$1.25 million, together with other nonprofit advocacy groups](#) and major gift support, to operationalize and launch GBM AGILE, the world’s first global “adaptive” clinical trial for brain cancer. [Multiple GBM AGILE clinical trial sites opened in 2019.](#)
- [Established the Meningioma Research Fund](#), in partnership with the Brain Science Foundation (BSF), to raise and grant funds to advance meningioma research with the potential to translate into treatments that could improve survival and quality of life
- [Established the Ependymoma Fund for Research & Education](#) with the CERN Foundation
- Enabled NBTS to fund \$2.3 million in research grants that span multiple tumor types, including the [most deadly pediatric](#) and [adult](#) brain tumors



Connect

Uniting the Brain Tumor Community

- Launched [Brain Tumor Support Conversations](#), giving patients and families a new monthly peer-to-peer support and education opportunity
- Helped hundreds of patients and caregivers through [personalized education and information](#), including our [NBTS Clinical Trial Finder](#) and quarterly [Clinical Trial Reports](#)
- Brought together more than 50,000 people at [regional events](#), and thousands more through our Community Fundraising program, to honor loved ones and connect to key health and treatment information
- Showed brain tumor community strength through the [Gray Nation Endurance program](#)

Change

Improving the Brain Tumor Treatment & Research Environment

- Advocated successfully for approximately \$50 million more from the federal government for brain tumor research for adults and children
- Championed a [bipartisan Senate Resolution officially designating July 17, 2019 as the first-ever “Glioblastoma Awareness Day”](#)
- Organized our largest ever Head to the Hill [advocacy day on Capitol Hill](#), with more than 300 participants representing 37 states descending on Capitol Hill
- Helped advance the Palliative Care & Hospice Education and Training Act in the U.S. House of Representatives
- Successfully advocated for [improved insurance coverage](#) for a standard of care treatment in glioblastoma



“Working with NBTS allows me to move beyond the confines of my own laboratory and help support research on brain tumors across the nation.”

On The Front Lines: Dr. Edjah Nduom on the Battle Against Brain Tumors

At a young age, Edjah Nduom, MD, started telling friends and relatives that he would become a brain surgeon.

“I was the kid who was thrilled to get a science kit when I was growing up, because of all of the fun experiments that you could run,” says Dr. Nduom. “From the time I was little, I knew I wanted to do something challenging as a career, something that presented a new problem to solve on a daily basis.”

Achieving his childhood dreams, Dr. Nduom is now a neurosurgical oncologist in the Surgical Neurology Branch (SNB) of the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH). And, in 2019, he became one of the newest members of the NBTS Board of Directors.

“Joining the board of the National Brain Tumor Society has taken my dream of curing brain cancer one step further,” says Dr. Nduom. “Working with NBTS allows me to move beyond the confines of my own laboratory and help support research on brain tumors across the nation.”

“Joining the board of the National Brain Tumor Society has taken my dream of curing brain cancer one step further”

In addition to his clinical role in the Surgical Neurology Branch at the NIH, Dr. Nduom studies the use of immunotherapy for the treatment of brain tumors.

“To run a lab on top of being a practicing physician can be a challenge, but it comes with advantages both scientific and personal,” says Dr. Nduom. “Being the one to see the patient and surgically resect the tissue that will be used in my experiments means I have a much more complete understanding of how our findings in the lab relate to the bigger picture of a patient’s overall care.”

Currently, Dr. Nduom is pioneering a new technique that simultaneously leverages his neurosurgical skills and his interest in harnessing the immune system to destroy cancer cells. He is the principal investigator of an early-stage clinical trial at the NIH that will monitor the effectiveness of a combination of two immunotherapy drugs in real-time through the use of “microdialysis catheters,” thin tubes placed in the brain temporarily to monitor the ability of these treatments to kick the immune system into high-gear against the tumor cells.

Ultimately, Dr. Nduom and his team hope this innovative approach to treatment and clinical research will allow them to analyze, in near real-time, if changes occurring in and around the tumor are providing the right signals that an effective immune attack against the tumor is underway (in addition to standard evaluations of safety). With this information, Dr. Nduom and his team will gain early insight into the potential viability of these treatments, and if this approach is worth continuing to pursue, or if they should quickly pivot to another. If this new model of conducting an early-phase clinical trial is effective, it could provide a blueprint for the field to use more broadly in the future and advance new treatment options for glioma patients.

Working with talented and dedicated individuals like Dr. Nduom is critical to the National Brain Tumor Society’s mission and values of uniting the community, being collaborative and inclusive, and advancing best-in-class science and service to brain tumor patients and their families.



Glioblastoma Awareness Day

When the day arrived, the stories and voices of all of those who've been affected by GBM reverberated across the nation

Glioblastoma (GBM), though it affects thousands of families each year, is technically a rare disease. It receives little of the same national attention as other, more prevalent cancers. However, GBM entered into the national consciousness when, in 2018, Senator John McCain became the second prominent member of the United States Senate — following the passing of Senator Edward “Ted” Kennedy in 2009 — to die from this cancer.

Though McCain was a conservative Republican from the southwest, and Kennedy a liberal Democrat from the northeast, these two always shared a close bond in life, and are now inextricably linked by this devastating disease. This spurred the National Brain Tumor Society to reach out to Senator Lindsey Graham, a close friend of both Senators McCain and Kennedy, about working with NBTS to champion an effort to increase public awareness for glioblastoma by setting a day when the country could come together — across political divides — to commemorate, honor, and support those we've lost to this disease and those still facing its dire prognosis, along with all their loved ones and caregivers.

Senator Graham (R-SC) was able to bring together a bipartisan group of leaders in the Senate — including all four senators currently serving in the respective delegations that Kennedy



and McCain once led, Massachusetts and Arizona — to introduce Senate Resolution 245, declaring July 17, 2019, as the first-ever “Glioblastoma Awareness Day.”

The date was chosen to enable both the brain tumor community and Congress to have a date that could be its own, unique focal point for the nation’s attention to mobilize around the GBM cause and community. And with Senator Graham’s effort along with his distinguished co-sponsors for the bill - Senate Majority Leader Mitch McConnell (R-KY), Senators Elizabeth Warren (D-MA), Ed Markey (D-MA), Kyrsten Sinema (D-AZ), and Martha McSally (R-AZ) S.Res. 245 was passed by unanimous consent in the Senate on June 11, 2019.

“We ask all of America to join us in commemorating July 17, 2019, as Glioblastoma Awareness Day by paying tribute to those that have been taken by this disease, as well as the patients and families still coping with a diagnosis, and by uniting in a day of action and support to advance

research and care so we can conquer and cure this disease once and for all,” NBTS CEO, David Arons, said in a statement at the time.

When the day arrived, the stories and voices of all of those who’ve been affected by GBM reverberated across the nation. Thanks to the brain tumor community’s fervent advocacy and action, the official #GBMDay social media hashtag was used in more than 500 posts and became a trending topic on Twitter. Glioblastoma Awareness Day was also featured in segments on leading media outlets like The View, ABC News, and the Today Show’s website.

The groundswell of awareness that was generated on the inaugural Glioblastoma Awareness Day served to establish a strong foundation for an annual commemoration that will now continue yearly to raise the collective consciousness in the U.S. about the urgent need to conquer and cure glioblastoma, and all brain tumors, once and for all.



2019 Volunteer Leadership

Board of Directors

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Thomas Roloff, Vice Chair
John Frishkopf, Treasurer
Robert Burger, Clerk
Dave Brown
Rob Corrao
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Chandri Navarro, Esq.
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Eric Olson, PhD
Stephen T. Sadler, JD
Liz Salmi
Michael Smith
Salo Zelermyer, JD
G. Bonnie Feldman,
Non-Voting Co-Founder

Emeritus Board Members

Michael Corkin
Richard Genderson
Ken Grey
Steve Karol
Sheila Killeen
Jeffrey Kolodin
Michael Nathanson, JD, LLM
Susan Pannullo, MD
Cord Schlobohm, DMD
Rabbi Eric B. Wisnia
Charles B. Wilson, MD
(deceased)

Scientific Advisory Council

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Defeat GBM Strategic Scientific Advisory Council

Anna Barker, PhD,
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FAANS, University of California,
San Francisco

Lewis Cantley, PhD,
Weill Cornell Medical College

Webster Cavenee, PhD,
Ludwig Institute for Cancer
Research, San Diego

William C. Hahn, MD, PhD,
Dana-Farber Cancer Institute

W.K. Alfred Yung, MD,
The University of Texas MD
Anderson Cancer Center

In addition to the members of our Scientific Advisory Council and Defeat GBM Strategic Scientific Advisory Council, NBTS would like to recognize and express gratitude for those scientific and medical volunteers who volunteered and contributed expertise in 2019.

Terri S. Armstrong, PhD, NP,
Neuro-Oncology Branch, National
Cancer Institute

Scott Biller, PhD, Agios
Pharmaceuticals

Timothy Cloughesy, MD,
University of California, Los
Angeles

Benjamin Ellingson, PhD,
University of California, Los
Angeles

Brenda Eustace, PhD, Vertex
Pharmaceuticals

Evanthia Galanis, MD, Mayo Clinic

Mark Gilbert, MD, Neuro-
Oncology Branch, National
Cancer Institute/NINDS

Nancy Lin, MD, Dana-Farber
Cancer Institute

Edjah Nduom, MD, National
Institutes of Health

Eric Olson, PhD, Syros
Pharmaceuticals

John Pollard, PhD, Vertex
Pharmaceuticals

Liz Salmi, Patient Researcher
OpenNotes/Beth Israel Deaconess
Medical Center

Jeffrey Skolnik, MD, Inovio

Joohee Sul, PhD, U.S. Food and
Drug Administration

W.K. Alfred Yung, MD, Anderson
Cancer Center and NBTS
Distinguished Scientific Advisor

Patrick Wen, MD,
Dana-Farber Cancer Institute



Billi Ewing: From Tumor to Triumph

When Billi Ewing's doctor revealed the results of her MRI, she literally fell to her knees.

Diagnosed with a grade II atypical meningioma, Billi, a mother of three from Ohio, would require a complex 13-hour craniotomy to remove the tumor, followed by 33 rounds of radiation therapy to decrease the chances of experiencing regrowth.

While the treatment appears to have succeeded in preventing a recurrence, it left its mark — both literally and figuratively.

“Excruciating pain and facial disfiguration were my biggest issues immediately following surgery,” says Billi. “My right eye was swollen shut; my incision was as thick as my thumb and stretched from the center of my hairline to the bottom of my right ear lobe; my head was swollen and lopsided. I had a hard time looking at myself in the mirror for several months, fearing I would never recognize the person staring back at me again.”

Just as time was healing these wounds, a whole new slate of challenges arose: seizures, short term memory loss, fatigue, insomnia, tinnitus, headaches, and more.

To regain control over her life and a sense of normality, Billi set out to do everything she could to become an expert and strong advocate for the brain tumor community.

“I immersed myself in all things brain tumors, hoping to be the change I wanted to see by increasing awareness and to not let this experience get the best of me,” says Billi. “I was elated to find so many organizations and resources like the National Brain Tumor Society

via social media, enabling me to become an active member of the brain tumor community instantaneously.”

Soon after connecting with NBTS on social media, Billi saw a post about Head to the Hill 2019. She was determined to attend.

“My heart wouldn’t let it go,” she says. “Advocacy at the legislative level was still on my brain tumor bucket list and here was my chance to check it off. So, I said a prayer, sent an email, and a few days later got the unbelievable news that I was chosen to be a Head to the Hill Scholarship recipient!”

Billi had already begun to rack up accomplishments that personified her approach to survivorship. She had started a support network called “Billi’s BElievers – From Tumor to Triumph;” captained teams in fundraising events; and secured proclamations officially acknowledging May as “Brain Tumor Awareness Month” in her township, city, and state; among other efforts. But it was attending her first Head to the Hill in 2019 that confirmed what she says is her “life’s new calling.”

“It was the moment that I saw the brain tumor community at its PEAK,” says Billi. “The advocacy training, the inspiring stories from other survivors, the heartfelt legacies many were valiantly upholding on behalf of their loved ones who passed on, the camaraderie, the sights, the sounds, the energy on Capitol Hill, the heartfelt conversations with our legislators and their aides – everything was just wow, Wow, WOW!”

Since departing from the Capitol last May, Billi has carried her experience forward.

“It increased my desire to get more people engaged beyond my local community,” says Billi, who is also a member of one of the largest sororities in the nation, Delta Sigma Theta Sorority, Inc. “By sharing my story and experience at Head to the Hill online, I discovered many of my sorors were brain tumor survivors or current patients. The lack of awareness coupled with the lack of representation in the African American community troubled me. We’ve sadly lost some since, but I’ve begun a movement within this sub-community of survivors, in hopes that we can unite and use our powerful voices and presence to effect real change at the national level.”

Billi will forever be grateful she was chosen as a Head to the Hill Scholarship recipient. And NBTS will always relish having the ability to offer assistance to deserving and special advocates like her, thanks to the generous support of our donors.

“Attending Head to the Hill last year, by far, was the most profound experience I’ve had as a brain tumor survivor and none of it would’ve been possible had I not been the recipient of a scholarship,” says Billi. “To serve as a delegate and share my story with our congressional leaders alongside other patients, survivors, and their loved ones, advocating for the entire brain tumor community, was life-changing.”



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2019 SIGNATURE EVENTS

2019 Signature Event Top Fundraising Individuals

Bay Area Brain Tumor Walk: Leah Recht, \$27,612

Boston Brain Tumor Ride: William Coffman, \$33,405

Boston Brain Tumor Walk: Lindsey Harder, \$30,935

Central New Jersey Brain Tumor Walk: Tara Laggini, \$6,030

Charlotte Brain Tumor Race: Lea Williams, \$11,771

Connecticut Brain Freeze: Cindee Muhl, \$1,750

Delaware Brain Tumor Walk: Richard Burns, \$4,650

Denver Brain Tumor Walk: Megan Boyer, \$5,725

Florida Brain Tumor Race: Leanne Thomas, \$3,101

Fort Worth Brain Tumor Walk: Kimberly Albro, \$5,902

Long Island Brain Tumor Walk: Carissa Bentley, \$19,192

Los Angeles Brain Freeze: Dean Fronk, \$3,690

Maryland Brain Tumor Walk: Lisa Sliker, \$6,552

New York City Brain Tumor Walk: Will Roth, \$17,850

Northern NJ Mud Run & Walk: Jeff O'Brien, \$3,178

Northwest Brain Freeze: Jo-Lynn Davis, \$3,150

Northwest Brain Tumor Walk: Vona Weiss, \$84,079

Orange County Brain Tumor Walk: Melissa Ernst, \$24,268

Phoenix Brain Tumor Walk: Carlyn Ackerman, \$5,521

Race For Hope DC Walk/Run: Stephen Conley, \$98,305

Philadelphia Race for Hope Walk/Run: Timothy Lynch, \$25,516

RVA Brain Tumor 5K: Robin Boisseau, \$10,703

Sacramento Brain Freeze: Robert Jordan, \$2,574

San Diego Brain Tumor Walk: Suzan Mahoney, \$5,175

2019 SIGNATURE EVENTS continued

2019 Signature Event Top Fundraising Teams

\$100,000+

Cushman & Wakefield: \$205,807

ReMARKable strides: \$172,820

Survivors: \$111,150

\$50,000+

Team Weiss: \$86,689

Chris Connelly Crushes Cancer: \$75,034

Kevin Strong: \$69,621

Team Mawn: \$62,712

HarderBetterFasterStronger: \$60,982

Lisa's Riders: \$55,320

Team Kermit: \$53,782

David Cook's Team for a Cure: \$51,788

\$25,000+

William's Warriors: \$45,413

#Olliestrong: \$42,247

Penn Neurosurgery Pioneers: \$41,451

Hope Brings Strength: \$38,637

Team Oligo: \$36,190

Hope by the Bay: \$33,126

Team Bald Bubby: \$32,398

High Hopes for a Cure: \$31,764

Kyle High Club: \$31,404

Sharing Hope: \$30,283

Team Jackie: \$28,824

SEAS THE DAY: \$28,113

Team Asher: \$28,095

ReMARKables: \$28,010

Uma: \$27,879

NBTS Board of Directors' Team: \$27,807

Team Holly Grace: \$27,594

Noëlle's Symphony: \$27,224

Team BT: \$26,959

Abby's Avengers: \$26,254

All for Team Pamela Sue and Dana: \$25,637

#DréaStrong: \$25,020

2019 Signature Event Top 10 Recruiting Teams

Train for Jay: 335 members

Jarema Strong: 204 members

Chris Connelly Crushes Cancer: 191 members

Kyle High Club: 185 members

Spain's Brain Train: 165 members

Abby's Avengers: 150 members

Survivors: 150 members

Kevin Strong: 148 members

Andrew's Hulkamaniacs: 146 members

Team Holty: 140 members



2019 COMMUNITY EVENTS TOP FUNDRAISING EVENTS

\$100,000+

2019 Team Billy Ride and Walk
for Research: \$131,568

\$20,000+

2019 Madison Brain Tumor 5k: \$72,448

2019 Rhode Island Brain Tumor Walk:
\$29,456

2019 Maryland Impact Golf: \$28,811

2019 Jones'n for a Cure Golf Tournament:
\$26,000

2019 Mimosa March to Cure Brain Cancer:
\$25,026

2019 Bob Burns Memorial 5k: \$25,000

2019 NBTS Charleston 3K Walk and
Family Day: \$22,237

2019 Tumor Takedown Tailgate: \$21,289

\$10,000+

2019 Dura Mater Hill Climb: \$18,741

2019 P&D Student Choreography Project:
\$16,112

2019 Shelby's "Brewerfest" and Wine
Tasting: \$15,585

2019 Postmodern Jukebox Request-a-thon:
\$14,168

2019 Michael Cassidy Shamrock 'N' Run:
\$14,060

2019 Fight for the Brain Happy Hour:
\$12,561

2019 True Blue Shootout for a Cure
Lacrosse Tournament: \$11,600

2019 GBM Foundation Events: \$11,000



2019 GRAY NATION ENDURANCE TOP FUNDRAISING INDIVIDUALS

\$20,000+

Molly Griffiths, 2019 Boston Marathon:
\$25,990

\$10,000+

Ron Clark, 2019 Falmouth Road Race:
\$11,530

Charlie Lonergan, 2019 Boston Marathon:
\$10,608

Michelle Mathai, 2019 TCS New York City
Marathon: \$10,125

\$5,000+

Tarl Smith, 2019 Lake Placid Ironman 70.3:
\$8,938

Duba Family, 2019 Enchantment and
Wonderland Trails Hike: \$8,281

Jeff Barber, 2019 Medtronic Twin Cities 10-
Mile: \$8,140

Elizabeth Daniels, 2019 TCS New York City
Marathon: \$7,424

Andrea Levy, 2019 TCS New York City
Marathon: \$7,405

Sara Housley, 2019 TCS New York City
Marathon: \$7,183

Annie Pearlman, 2019 TCS New York City
Marathon: \$6,004

Alida Tieberg, 2019 Medtronic Twin Cities
10-Mile: \$6,004

Glen Coblens, 2019 Ironman Arizona:
\$5,321

Joanna Grueneberg, 2019 TCS New York City
Marathon: \$5,198

Patrick Burke, 2019 TCS New York City
Marathon: \$5,152

2019 CORPORATE PARTNERS

\$50,000+

Agios Pharmaceuticals
Bayer Pharmaceuticals
Bristol-Myers Squibb
Cushman & Wakefield
Genentech
Novocure

\$25,000+

AbbVie Pharmaceuticals
Cravath, Swaine & Moore, LLP
Northern Bank & Trust Company
Valero Energy Corporation

\$10,000+

Alex.Brown
Barrow Neurological Institute
Boston Bruins Foundation
CapTech Ventures, Inc.
Celgene Corporation
CoStar Realty Information
Cullather Brain Tumor Quality of Life Center
Edison Oncology Holding Corp.
Eli Lilly and Company
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Maryland Brain Tumor Treatment and Research Center
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Roark Law Office P.C.
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Stifel
Susquehanna International Group, LLP
TennMax USA
UCSF Neurosurgery
VCU Health System

2019 FOUNDATION PARTNERS

\$100,000+

ABC2 - Accelerate Brain Cancer Cure
The Stringer Foundation
Today is a Good Day Foundation
Yousefzadeh Family Foundation

\$50,000+

Rally Foundation for Childhood Cancer Research
Robert I. Schattner Foundation
Uncle Kory Foundation

\$25,000+

Robert Lloyd Corkin Charitable Foundation
The Gwen L. Kosinski Foundation
Students Supporting Brain Tumor Research
The Wallace Landry Family Foundation

\$10,000+

Josephine and Bernard Wilkinson US Foundation
Phyllis W. McGillicuddy Charitable Trust
The Hendrick Family Foundation
The Manning Family Foundation
The Michaels Family Foundation



2019 INDIVIDUAL DONORS *Data as of December 31, 2019*

This list represents only a small portion of our dedicated and generous donors. All gifts, of all sizes, make a difference and are deeply valued by National Brain Tumor Society.

CIRCLE OF PROGRESS Lifetime Giving of \$10,000 – \$24,999

Aileen Gregory
Alan J. Bernon
Alicia and T. L. Sean Cook
Alison and Greg Blank
Alison and Neal Goldner
Allison and Euan Thomson
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Alysia Ferro
Amy and Barry Sylvetsky
Amy and David Donabedian
Amy and Richard Hurelbrink

Amy Null and Andrew Budson
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***Make it your
legacy to
conquer and
cure brain
tumors***

**Contact us at
617-237-1731 or
mlacerda@braintumor.org
to discuss how you can
include National Brain
Tumor Society in your
estate plans**

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Carol and Donald
McInnes

Carol and Jay Virshbo

Carol and Patrick
Fitzgerald

Carol Church

Caroline and Gregory
Segall

Caroline Kim and
Jonathan Paluga

Catherine Hay

Cathi and Thomas
Magner

Chad Bernota

Chad Levitt

Charles Henry Smith III

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Chris Bierly

Chris Bittman

Christine Crabtree

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Christy Jones

Coaches Against Cancer

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Simpson

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Holly and Joshua Bogart

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Shames

Hsien-Wei Tseng

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Paul and Mary Revello

Irene and Frelan
Underwood

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Jacqueline and Charles
Okosky

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Doughan

James Duff

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Jerry Leo	John P. Fowler	Karen Nusbaum	Kevin Hurley	Leverage Wines
	John Regan	Katherine Johnson	Kim and Judith Davis	



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Melissa Mannion	Nancy E. Pfund	Peter Lewis	Richard M. Lappin	Robin and Michael Winton
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Michael Johnson	Natalie and Eric Boyd	Phyllis and Robert Yawitt	Richard Schifter	Robyn and Bill Collins
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	Paul Sasso	Rebecca Newland	Robert Hisaoka	
	Paul Teti			



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Rose Heide and Gary Sweet

Roy Kapani

Russell Deyo

Ruth Curtis

Ryan Steel

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Shelley and Jonathan Isaacson

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Stephanie and John Connaughton

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Stephen Mugford

Stephen O'Brien

Stephen Schoener

Steve Barnes

Steven Brown

Steven S. Fischman

Sue and Sheldon Lewis

Susan and Derek Arndt

Susan Baucom

Susan Lasher

Suzanne and Jeffrey Bloomberg

Annual
Report



National
Brain Tumor
Society

Suzanne Peck	Vivian and Barry Bornfriend	CIRCLE OF CHANGE Lifetime Giving of \$25,000+	Barbara and Donald Janower	Catherine Mannion
Tasneem Ghuman	W. Graham Smith		Barbara Roche	Catherine Wytzka
The Family of Lionel Chaiken	Wayne Long		Barbara Shapiro	Cecilia and John Farrell
Theresa Carey	Wendy and Lawrence Pizzi		Bill Elovitz	Charles A. Young, III
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Thomas Karol	Whitney and Adam Hayden		Bonnie and Jon Rotenberg	Charlotte Florence
Timothy Donovan	William H. Connelly, Jr.		Bonnie Feldman	Chris and George Bein
Tomoko Ozawa	William Moseley		Bridget and Patrick McCall	Christopher Brown
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Tracy Milcendeau	William W. Beddow		Carol and Garold Brown	Constance Forchheimer Heller
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Vincent Bilinsky		Arthur Kern		Daniel Bukkhegyi
Vincent Browning		Ashley and Alan Dabbiere		Daniel Greiff



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Dawn Bauleke

Deborah and Ira Palgon

Deborah and Ronald Ratner

Dee and Lloyd Benedict

Denise and Jeffrey Bein

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Eileen Roche

Eliane and Gary Markoff

Elisha Wiesel

Elizabeth and Mark Moragne

Ellen and Stephen Conley

Ellen Newman

Eric Slifka

Evelyn Goldfine

Frederick Samaha

Gerald Greco

Geraldine Gerson

Gina and Charles Nash

Gina and Scott Memmott

Gregory Kovacs

Harry Goulder

Hazel and Kenneth Dreyer

Heidi and Nathaniel Leonard

Hope and Gary Schwab

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Jeff Davis

Jeffrey Kolodin

Jen and Bryan Hume

Jillian Roth

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John Monsees	Kelly and Gary Wimmer	Mady and Bruce Donoff	Michael and Dawn Nathanson	Richard Morgenstern
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Judi and Edward Zuker			Neill Brownstein	

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Sally Curtin
Sandra and Mark Kramer
Sarah Durham and
Craig Winer
Sharon and Joe Lamb
Sheila and Robert
Conneely
Sheila Killeen
Sheri Sobrato Brisson
Sondra Rudofsky
Stephanie and Leonard
Farber
Stephen Reller
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Steven Connolly
Susan Tavilla
T. Conrad Wetterau

The Kwinn Family
Thomas Enraght-Moony
Tom Rollins
Valerie Hurley and John
Kern
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William Coffman
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CATALYST CIRCLE

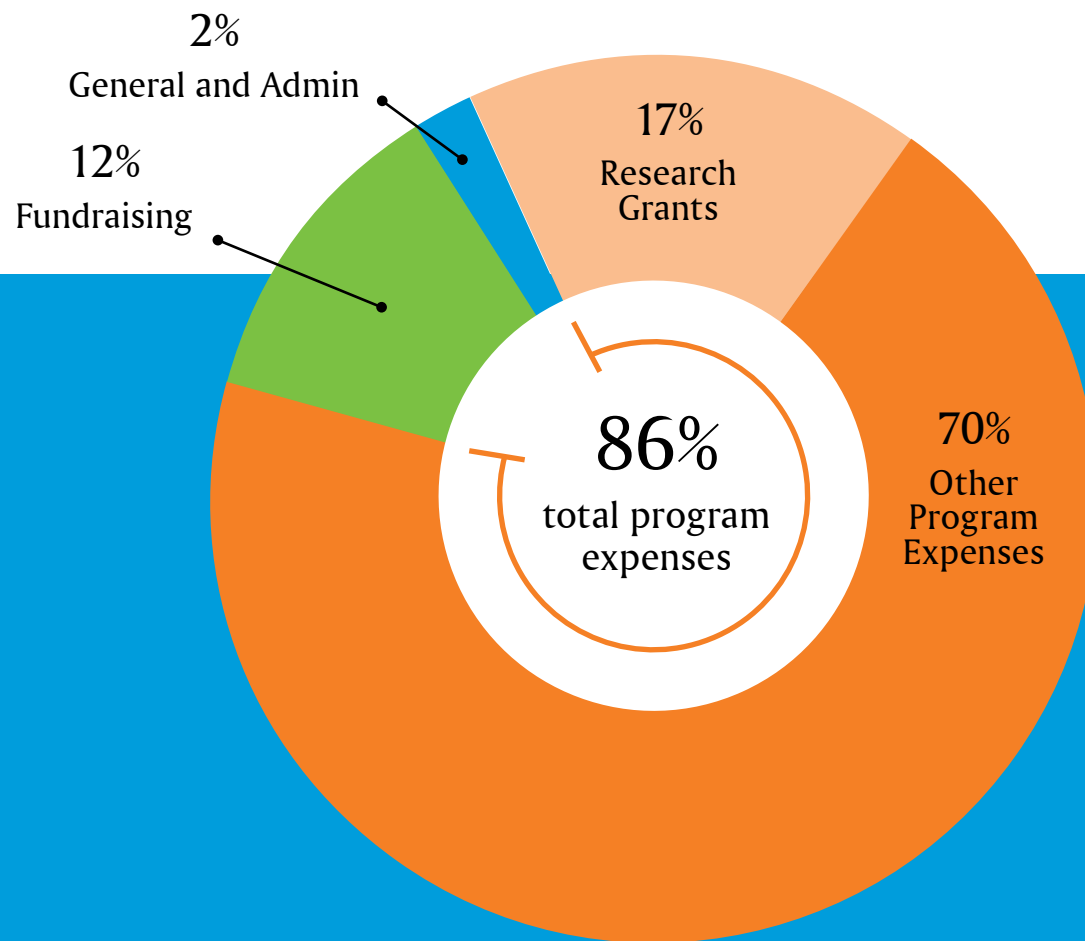
*Members of the Catalyst
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leadership gifts in
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Family Catalyst Fund for
Brain Tumor Research.
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Amy Null and
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Sarah Durham and
Craig Winer
Sentinel Benefits and
Financial Group
Shikiar Family Foundation



2019 NBTS FINANCIALS



Statement of Financial Position

Assets	12/31/2019	12/31/2018
Cash and cash equivalents	\$6,422,000	\$3,088,930
Investments	849,578	581,854
Pledges receivable, net	289,200	83,000
Prepaid and other current assets	176,834	161,621
Long-term assets	50,356	53,538
Total assets	\$7,787,968	\$3,968,943
Liabilities		
Accounts payable and accrued expenses	\$439,129	\$384,406
Research grants payable	500,000	1,250,000
Other long-term liabilities	84,539	99,601
Total liabilities	1,023,668	1,734,007
Net assets		
Without donor restrictions	2,339,672	980,981
With donor restrictions	4,424,628	1,253,955
Total net assets	6,764,300	2,234,936
Total liabilities and net assets	\$7,787,968	\$3,968,943

Statement of Activities

Revenue	12/31/2019	12/31/2018
Events, grants, and contributions	\$13,705,221	\$10,874,060
Bequests	250,000	137,159
Donated goods and services	221,747	90,783
Other income	33,770	28,476
Total revenue	14,210,738	11,130,478
Operating expenses		
Personnel	4,504,961	3,639,275
Research grants	1,592,534	2,922,375
Special events	885,883	897,653
Professional services	685,166	658,047
Travel	254,976	278,358
Systems and technology	273,007	275,445
Other expenses	1,544,971	1,618,976
Total operating expenses	9,741,498	10,290,129
Changes in net assets from operations	4,469,240	840,349
Endowment contributions and other revenue	60,124	192,126
Change in net assets	\$4,529,364	\$1,032,475



National
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www.braintumor.org