National Brain Tumor Society is fiercely committed to finding better treatments, and ultimately a cure, for people living with a brain tumor today and anyone who will be diagnosed tomorrow.
The serious and daunting nature of the pursuit of better treatment, and ultimately a cure, for all brain tumors can often leave little time for reflection or a chance to take stock of progress and victories, both small and large. Yet, it is important to recognize and honor the many real-life heroes who are fighting back against brain tumors, both literally and figuratively, as well as highlight the impact and advances that result because of the extraordinary effort and determination of brain tumor patients, survivors, caregivers, researchers, clinicians, advocates, donors and other supporters of our shared cause and mission.

What we hope to do in the following pages is provide a number of snapshots that, together, illustrate the successes of our collective efforts, and how these achievements are setting the stage for a productive future – full of discoveries, developments, and accomplishments that inspire hope, promise and change.

A traditional nonprofit Progress Report primarily provides information on the organization – and we’ll still incorporate plenty of that, too – but we want to do something slightly different; we feel strongly that this recap should be about YOU, our generous and inspiring partners, volunteers, and supporters, whom we couldn’t do ANYTHING without. So, for example, you’ll hear from a courageous glioblastoma patient who is participating in an NBTS-funded clinical trial by an innovative life sciences company; you’ll read about the amazing and committed researcher, Dr. Suzanne Baker, and the work she is doing as part of the Defeat Pediatric Brain Tumors Research Collaborative; an NBTS State Advocate will explain why this past year was such a fruitful one for brain tumor public policy; and you’ll experience the power of an NBTS-sponsored event through the lens of a participant.

We hope you welcome these stories (and the rest of the content) as equally as we appreciated all of your contributions to the momentum we have generated together. We are, and will remain, forever grateful for your passion, commitment, and spirit.

Thank you for reading and thank you, as always, for your dedication and support.

With Sincere Gratitude,

David F. Arons
Chief Executive Officer
National Brain Tumor Society

Michael J. Nathanson
Chairman, Board of Directors,
National Brain Tumor Society
During the past two years, the neuro-oncology field made significant progress toward better treatments, and ultimately a cure, for brain tumors – from new research projects launching, to important scientific discoveries, as well as public policy and advocacy victories in Congress and at the White House. NBTS – enabled by the generosity of our supporters – played a major role in the strides made.

As we enter the holiday season, one of the busiest times of the year for this society – as well as a time when we ask a lot of our community, but are also reminded to give thanks – we look back at the progress and the many ways your generous support has helped advance our mission. Your gifts allow us to harvest the fruits of your generosity on our mission for better treatments and a cure.

Research progress

- NBTS funded more than $4 million in research per year, including an infusion of more than $2 million for our Defeat GBM Research Collaborative and $1.25 million for low-grade glioma research.

- The poliovirus treatment, which NBTS provided early funding for, received “Breakthrough Therapy Designation” from the FDA, meaning that it will receive and an expedited and ongoing “all-hands-on-deck” review from the FDA.

- Another virus-based immunotherapy that NBTS provided early funding for, DNX-2401 (formerly known as Delta-24-RGD-4C), moved forward in clinical trials in 2016, progressing from a phase 1 to enrolling for a phase 2 trial. It is also being studied in two addition phase 1 trials.

- NBTS-funded research (via Defeat GBM) discovered, how glioblastoma (GBM) tumors exploit the brain’s unique metabolism to import vast amounts of cholesterol, creating a dependency, and, importantly, how attacking the mechanisms these tumors use to do so may halt this deadly cancer’s growth.

- NBTS-funded research (via Defeat GBM) showed that DNA from brain tumors can be detected in the cerebral spinal fluid of patients and can be used to assess the genomic characteristics of the tumor. This work is paving the way for new, less-invasive advances in the diagnosis, monitoring, treatment planning, and research of brain tumors – both primary and metastatic.

- NBTS-funded research (via the Oligodendroglioma Research Fund) identified for the first time the existence of cancer stem cells (CSC’s), defined as cells that can self-renew and differentiate into multiple types of cells, in human oligodendroglioma and that CSCs are primarily responsible for fueling the growth of these tumors. These findings highlight a potential new therapeutic approach for oligodendrogioma patients.

- Six (6) major clinical trial cooperative groups and several companies and adopted the new Brain Tumor Imaging Protocol developed through the efforts of NBTS and Jumpstarting Brain Tumor Drug Development Collation.

- The Defeat GBM research collaborative team of leading glioblastoma experts is now working to move a potential new medicine, based on a discovery made through this program’s funding, into a human clinical trial. This program has also identified seven new drugs that could move to phase 3 clinical trials.

- Our defeat pediatric brain tumors research collaborative – just announced a year ago - specifically aimed to generate better treatment options for children with brain tumors, is funding research teams, with leaders of the initiative collaborating on new research approaches.

- Launched a new, brain tumor-specific clinical trial finder to help patients better explore all their treatment options while connecting with, and engaging in, clinical research. We also anticipate the trial finder will more quickly help with the recruitment and enrollment of patients into brain tumor clinical trials, which would help experimental new medicines move through the FDA’s evaluation process quicker towards potential approval.

- Received our first progress reports from the series of grants we provided to low-grade glioma researchers in 2016 as part of our oligodendrogioma community research fund.

Public policy advocacy momentum

- Brain tumor public policy advocacy saw NBTS hold a record-setting “Head to the Hill” advocacy day in Washington (more than 300 advocates from 39 different states holding more than 220 meetings with Members of Congress).

- NBTS’ CEO represented brain tumor patients on the Blue Ribbon Panel of former Vice President Joe Biden’s Cancer Moonshot Initiative; the passage of the NBTS-supported 21stCentury Cures Act; and the NBTS-supported Childhood Cancer STAR Act moved to the verge of becoming a law.

- NBTS’ volunteer advocates sent more than 5,500 messages regarding
Against Brain Tumors

our policy requests to their members of Congress and our staff held more than 110 meetings with congressional offices to educate on the needs of the brain tumor community. The ultimate result of these efforts is an increase in federal support for cancer initiatives important for brain tumor research, including funding for pediatric brain tumor research via the Department of Defense’s Peer Review Cancer Research Program, which NBTS and its advocates supported.

- Helped successfully pass legislation that will provide brain tumor researchers approximately $10 million new dollars ($60m total) to apply for in both pediatric and adult brain tumor research.
- Helped pass a fiscal year 2017 (fy17) federal budget that provided a $2 billion increase in funding for the national institutes of health – the largest funder of brain tumor research in the world – and helped secure the first $300 million in cancer moonshot funding, with projects that could help brain tumor drug development.
- Successfully helped advocate for the passage of the Race for Children Act, which requires that, if pharmaceutical companies are developing a drug to treat cancer in adults, they also study the drug in children, if the molecular target of that drug is relevant to cancer that occurs in children.
- Assisted in driving the reintroduction of the Childhood Cancer STAR Act, the most comprehensive legislation ever assembled to improved pediatric cancer, including brain tumors, research.
- Opposed, and successfully helped fight, legislation that would have undone critical protections for brain tumor patients and survivors, when it comes to affordable access to the wide-breadth or specialty care this community requires.
- Created, distributed, and shared with leaders in congress a petition signed by thousands of brain tumor patients, survivors, caregivers, advocates, and advocacy organizations asking congress to again increase funding for the national institutes of health in its fy18 budget, rejecting drastic cuts proposed by the white house.

Moving forward to meet our mission

- Held and informative, enlightening and productive 2017 scientific summit with leaders in the brain tumor research field centered around key challenges and opportunities facing the field and how to best ‘seize the moment’ and move forward toward new and better treatments for patients.

In the last quarter of 2017, we look forward to continuing the momentum and moving our strategic initiatives forward to meet our mission. Specifically, we aim to:

- Host our second Research Roundtable meeting
- Bring together tens of thousands of community members for a successful fall events season, that meets our community-building and fundraising goals
- Execute on dynamic and successful end-of-year giving campaign
- Help push the Childhood Cancer STAR Act across the ‘finish line’ to become passed into law
- Successfully advocate for a final FY 18 budget that increases funding that can help brain tumor research
- Continue to push our ‘Defeat’ programs forward; and
- Recruit and retain key volunteers across our various programs (events, advocacy, research, board, etc.)

Community, leadership, and resource development

- Appointed Dr. Alfred Young, MD to be NBTS Distinguished Research Advisor
- Brought together more than 60,000 people from across the country
“You are not a number. Nobody can tell you what your life expectancy is... Fight, fight, fight.”
-Greg
**Beating the Odds Thanks to Research Funding**

After an otherwise-healthy and vibrant 24-year old newly wed was diagnosed with an aggressive brain tumor and given just two-to-three years to live, a new clinical trial - based on NBTS-funded research - provided hope and help beating the odds. NBTS provided funding for research and development of Toca 511 & Toca FC and we are hopeful that Toca 511 and Toca FC clinical trials, and many other current trials, succeed and provide new treatment options for glioma patients. As with all clinical trials, NBTS cannot provide recommendations on which trial(s) brain tumor patients should consider. We advise all brain tumor patients to discuss all their treatment options or trials with their medical team.

"Temozolomide is what it is: a chemotherapy," says Greg. "This means constantly feeling drained of your energy and throwing up if you didn't take your anti-nausea medicine. This was my life for six months."

Greg was diagnosed with a Grade III anaplastic astrocytoma – part of an aggressive class of brain tumors known as high-grade gliomas, which also include glioblastoma – in February of 2013, when he was just 24-years old. At the time, he was working a full-time job in sales for a major corporation and happily settling into married life. As Greg tells it, he was living the dream with his new bride of six-months and a puppy they had just adopted.

Then a seizure in his sleep one night threatened to change all of that.

Taken to the ER and for an MRI, the erstwhile healthy young man was told that he had a brain tumor. Surgery to remove the tumor and the accompanying pathology report would provide the diagnosis of a highly malignant and aggressive brain cancer.

"My first oncologist gave me a prognosis of two-to-three-years to live," says Greg. "I quickly told her, 'You cannot put a timestamp on my life. Only God can do that!' Then I asked: 'What's your plan for treatment?'"

His initial treatment would be what virtually all other high-grade glioma patients receive: radiation and temozolomide. (Note: many doctors now also consider the addition of the device Optune following its approval by the FDA in 2015.)

The addition of temozolomide to radiation treatment following surgery became the "standard-of-care" for most adults with malignant brain tumors in 2005, but the chemotherapy was originally approved to treat anaplastic astrocytomas in 1999. Its advent increased average survival time for the worst brain tumors by three months, from nine to 12, and for some, significantly longer. Temozolomide was a step forward, albeit a small one, for brain tumor patients. But it was 12-18 years ago now. And, as Greg notes, it’s not a particularly pleasant therapy, as no chemotherapies are. As such, NBTS is constantly funding research and other efforts to accelerate the pace of development for new therapies that will hopefully not only improve survival, but also prove less-toxic and harsh on patients.

One such potential new treatment is an experimental therapy, called Toca 511 & Toca FC, developed by a company called Tocagen. NBTS provided an “Innovation Grant” to Tocagen to help develop this treatment approach.

In 2016, Tocagen reported initial results from trials evaluating the use of Toca 511 & Toca FC as a potential treatment for high-grade glioma patients. In three separate, but related, studies, preliminary data was encouraging and warranted moving forward with further trials.

Greg is one of the early patients who tried the Toca 511 & Toca FC treatment by enrolling in one of its clinical trials. And this NBTS-funded treatment is perhaps to credit for why Greg has not only survived past his initial two-to-three-year prognosis, but is thriving.

"[My] life today is wonderful," says Greg. "My wife and I had a baby last year, Colton, who is now a year-and-a-half and is walking and talking. Seeing him grow-up is beyond words – a dream we didn’t think would happen is happening."

Greg’s new path began when he transferred treatment centers to Henry Ford Hospital in October of 2013. It was there that his new medical team discussed with him additional options for his treatment, including clinical trials.

"My neurosurgeon told me only about 4% of cancer patients will attempt a trial," says Greg. "I decided that even if it doesn’t work for me that maybe it will work for someone else. After being given a death sentence at such a young age, I was determined to fight and find a treatment that was right for me. We signed up for the [Tocagen] trial and under the knife I went for the second time in six months."

Toca 511 & Toca FC are, in fact, two separate substances designed to be used together to selectively kill cancer cells and activate the immune system against tumors -- as opposed to chemotherapy like temozolomide, which primarily works by indiscriminately killing dividing cells.

"I had a good experience on the trial, and didn’t experience many side-effects," says Greg. He additionally notes that he found the treatment regime to be relatively easy to follow.

"I’m happy to say that overall, today, life is pretty normal."

In early 2017, Toca 511 & Toca FC was granted “Breakthrough Therapy Designation” by the U.S. Food and Drug Administration (FDA), meaning Tocagen will receive the highest level of FDA attention as they continue to develop and evaluate this treatment approach. This does not guarantee that Toca 511 & Toca FC will ultimately be approved for all high-grade glioma patients – that still has to be determined through further clinical trial evaluation and final review and approval by the FDA – but it is an important step that will expedite the development of this potential new treatment.

In the meantime, Greg goes on with his life as anyone else would. “I plan to watch my son grow and go to school, one day get married and have kids of his own,” he says.

And he says he’ll always look back appreciatively and positively on his decision to enroll in the Toca 511 & Toca FC trial.

“We need research and trials like Tocagen’s, and organizations like NBTS willing to fund it, in order to make progress,” says Greg, adding later, “Take a step back and just think, what would you do if you were faced with a decision to potentially help the world find a cure for cancer?”

Toca 511 & Toca FC are currently being evaluated in multiple clinical trials for high-grade glioma patients and additional data are expected in the first half of 2018.

"You are not a number," Greg concludes. "Nobody can tell you what your life expectancy is…fight, fight, fight."
“I’m very excited to be part of this Defeat Pediatric Brain Tumors Collaborative. This offers an opportunity to take advantage of this moment in time where there’s a lot of new information, and to work together with top researchers to try and really make a big impact on this disease for which there’s been no improvement in therapy for such a long time.”

- Dr. Suzanne Baker
“Time is short,” says Dr. Suzanne Baker. “The survival time is so very short for these children. So the time frame for developing new therapies is in desperate need of acceleration.”

Dr. Baker was speaking about one of the most devastating pediatric cancers: pediatric high-grade gliomas. Pediatric high-grade glioma patients face prognoses measured most often in months, not years. Less than 30% of these patients, on average, will survive five-years beyond their diagnosis. For diffuse intrinsic pontine glioma (DIPG) patients, the five-year survival rate is between zero and one percent. Most die within nine months.

This group of tumors is a major reason why we learned that pediatric brain tumors surpassed leukemia as the leading cause of cancer-related death in all children in America.

Coincidentally, Dr. Baker actually made the previous remarks just a few days prior to the announcement from the U.S. Centers for Disease Control and Prevention (CDC) that pediatric brain tumors had surpassed leukemia as the leading cause of cancer deaths in kids. She was participating in the September 2016 launch of the National Brain Tumor Society’s “Project Impact: A Campaign to Defeat Pediatric Brain Tumors,” an effort to raise the resources needed to fund the Defeat Pediatric Brain Tumors Research Collaborative, a program of NBTS and partners from other childhood cancer charities.

Dr. Baker is a leading researcher within the Collaborative and will be developing new laboratory models that will be used to study pediatric high-grade gliomas, and particularly how they respond to various potential new therapies.

“We need to develop model systems that really use all of the information that we have about the molecular underpinnings of the disease to help predict how pediatric high-grade gliomas cells would respond to therapies,” says Dr. Baker. “We need good models to screen clinical candidates and do preclinical testing of drugs that are currently approved for use in patients and also new drugs and chemicals that are being developed as potential future drugs...This disease, fortunately, is not very common in the general population, but that means it’s difficult to do clinical trials on a lot of different new drugs at one time. So it’s very important that we have model systems that allow us to screen through a large number of opportunities and select the ones that have the best chance of working so that those go directly into the relatively small patient population where we hope we can make an impact quickly.”

What is enabling Dr. Baker and her colleagues to begin creating better models of pediatric high-grade glioma are advances in areas such as stem cell technology, techniques for “grafting” human tumor cells into mice, more tissue available because of better surgical biopsies, and other discoveries that are informing the research field about the molecular mechanisms that make these tumors tick.

“All this information, tissue, and data lead to new mouse models,” says Dr. Baker. “There is so much variation in human pediatric high-grade gliomas, that we need multiple models to represent the whole spectrum of pediatric high-grade glioma disease biology.”

Beyond just enabling better model creation, Dr. Baker notes that recent discoveries made about these tumors in general – many by herself and other members of the Defeat Pediatric Brain Tumor Research Collaborative – have advanced the field to its most exciting point in decades.

“This is actually a very promising and exciting era for pediatric high-grade glioma research,” says Dr. Baker. “The opportunity to look across the entire genome and identify mutations in pediatric high-grade gliomas led us to some unexpected, surprising findings...The ability to sequence across the entire genome has allowed us, suddenly, to have a very big-picture look at a disease that was very understudied previously.”

The unexpected finding was the recent identification of mutations to a type of protein in cells called a histone. Specifically, researchers have zeroed in on mutations to a particular histone known as “H3,” that is important for how DNA is packaged into a cell’s nucleus and controlling which genes are switched on or off in a cell. Importantly, mutations to H3 are found in approximately 80% of DIPGs, but not healthy cells.

“Finding a single mutation that accounts for 80% of this disease suddenly presented an all-new, unifying mechanism that drives this disease. That made us think that maybe there would a useful way to target this therapeutically,” says Dr. Baker. “Suddenly, we have not only a very high frequency target, but a completely new method of cancer subverting normal processes and taking a normal cell and turning it into a very aggressive cancer cell. So now this opens up a lot of new opportunities on multiple levels. We’re especially interested in unique sensitivities to certain drugs.”

Now, Dr. Baker and the rest of the Defeat Pediatric Brain Tumors Research Collaborative will get to work to understand how these alterations ultimately disrupt the fine-tuned machinery of the cells and cause them to grow and spread uncontrollably; create the new and better models and test potential new drugs; and study how the mutations change or adapt in the face of treatment and/or as the tumors continue to grow.

“We all normally work independently, but we have to collaborate and get together. We need all components of this project to make things happen: discovery to understand mechanisms of mutations; biomarkers to identify potential responders; and drug screening to find active agents.”

Ultimately, Dr. Baker says she hopes that the Collaborative can make the necessary progress to inform new treatment strategies that lead to more rational clinical trials and approaches to tailoring therapies for patients that will yield increases in overall survival and quality of life achievements.

“We need to keep the momentum up from finding mutations, to understanding how they work, to understanding how that impacts clinical decisions,” says Dr. Baker. “There are a number of outstanding groups in this project. We need to work together. We can move more quickly if we work together and accelerate progress. If we can truly understand how the disease actually develops, we can build better therapies.”

Dr. Baker notes what a special opportunity participating in the Collaborative presents for herself, her colleagues, the entire field, and, most importantly, patients and their families.
“We advocate so no other parent has to witness the effects of this horrible disease on their child.”
- Sandy & Richard Perkins
In January 2011, our son was playing in a band at local venues, had earned a scholarship to a community college, and was transitioning to become a student at Arizona State University. He had just started a job and was moving into an apartment with his best friend. Life was good. But, after complaining of headaches and numbness in his face and leg, his doctor ordered an MRI as a precautionary measure.

After the scan, the doctor told our son that he had a “mass” in his brain. The look on his face is forever etched in our minds and hearts. We watched as our healthy, vibrant son coped with a devastating diagnosis of a tumor called DIPG (diffuse intrinsic pontine glioma). Despite the tremendous efforts of his doctor and medical team, and the courageous spirit of our son, Sam passed away only nine months after his initial diagnosis.

Shortly thereafter, we began participating in the National Brain Tumor Society’s Public Policy Advocacy program, representing Arizona, and have been involved in six consecutive Head to the Hill events since 2012.

We advocate so no other parent has to witness the effects of this horrible disease on their child. As a member of the brain tumor public policy advocacy community, we do everything within our power to make certain there is support for those diagnosed, and their caregivers, and that patients with brain tumors will receive only the highest quality treatment and care. We advocate so someday, a person diagnosed with a brain tumor will hear the words: “We have an effective treatment for you and you will go on to live a long and full life.”

State advocates like us communicate with the United States Congress several times a year, as well as with those who represent us in state and even local town or city governments. We take the time to learn about our members of Congress, and their positions on brain tumor-related issues. We build strong relationships with Senators and Representatives, and call them, or meet with them throughout the year, including at the powerful annual Head to the Hill advocacy day.

It is important to make sure they understand and prioritize legislative and budgetary issues that could impact members of the brain tumor community. We ask for new funding commitments for research that will help find better treatments for brain tumors, or for their support of legislation which could become laws that will help protect the rights and quality of life of brain tumor patients. We ensure that those who represent us always take into account the challenges that brain tumor patients face every day.

Simply put, we are giving brain tumor patients a true public policy voice in Congress! And, excitingly, a number of positive developments – ‘advocacy wins’ – have occurred.

The National Cancer Moonshot, led by former Vice President Joseph Biden, captured the attention of our nation last year. A “Blue Ribbon Panel” of experts was formed to advise this new effort to accelerate research for treatments to all types of cancers – and the National Brain Tumor Society was there. NBTS CEO, David Arons, as well as Distinguished Research Advisor, Dr. Alfred Yung, were members of the panel that helped build all final recommendations. The Moonshot effort was very important, and NBTS’s role in bringing people together and collaborating with community members was truly at the core of the Moonshot effort.

At the same time, Congress was considering the 21st Century Cures Act – another piece of legislation that NBTS supported to advance medical research. Ultimately, with the help of many advocates, including brain tumor advocates, this bill was signed into law – AND, it included funding for the Moonshot initiative as well.

Finally, we accomplished the goal of influencing Congress to increase research funding through the National Institutes of Health by $2 billion and to include brain tumors – both adult and pediatric – as eligible topics for funding under the Department of Defense’s Peer Review Cancer Research Program. These funding streams can lead to research that discovers new ways to treat brain tumors.

We have met some brilliant and dedicated people through our association with NBTS and consider them friends and fellow warriors. It is amazing how quickly relationships are formed through advocacy, and all of us leave The Hill with the feeling that we are not alone on this journey.

We thank NBTS for giving us the opportunity to become state advocates, and for enabling us to become part of a group that is directly, visibly, and persuasively making a difference in our world – and in the brain tumor community.

There is so much uncertainty and volatility in government nowadays. So many issues and hot buttons. Sometimes, it is difficult to get our members of Congress to pay attention. But, for our brain tumor community friends, advocacy provides us with the opportunity to narrow down the priorities for Congress. We’re not “here” to talk politics, or left and right partisanship. We represent a community that looks to Congress to help them experience a better quality of life in the face of this deadly disease. Let’s talk specifically about research, and the strides we’ve made. Let’s talk about the progress we’ve seen in 5 years - instead of the lack of progress in the 40 years before that. And, let’s talk about the future, to put a halt to this disease.

We’ve been asked, what would we say to those who consider being an advocate. We would strongly encourage them to take this on, and to actively participate in the legislative process for such a worthy and important cause. A trip to Washington DC, or even to your home state house, is an impactful experience. Face to face meetings with members of Congress and staffers are so satisfying. Being on Capitol Hill, with its history and power, will provide you with experiences that you’ll never forget.

By becoming a brain tumor advocate with the National Brain Tumor Society (anyone can do it!) and taking action, you are directly involved in the solution and direction of legislative outcomes. When you sit across from a member of Congress, you are truly influencing their actions and exerting your influence in the process. You are influencing that vote, and making a difference in the world of brain tumor patients. You’re doing Congress a service, as well as those in our community. These personal connections are so powerful and will lead to positive results. You are doing important and necessary work, and we welcome many more advocates to join us and the National Brain Tumor Society in the Halls.
“My husband and I made the commitment to participate in every single NBTS Walk across the country.”
- Jane McConnell
The McConnell Challenge – 22 Walks and Counting

When our daughter, Bridget, was diagnosed in the spring of 2012, she did not dwell on the devastation of a brain tumor diagnosis. Nope! When her doctor at Johns Hopkins in Baltimore, Maryland told her about a brain tumor walk taking place the weekend following her surgery, Bridget said she wanted to actually participate in the event. Just a couple of weeks after her diagnosis? Yes, and well, she did walk it, and it was the best thing we ever did.

On that day, during the Race for Hope - DC, I felt so connected with the thousands of people running and walking. After the event, we simply stood there, at the finish line, surrounded by our newfound friends, and cried. It was an unbelievable, emotional, breathtaking moment for my family.

I truly felt that all these people cared about what happens to Bridget. And I came to truly care about what happens to all of them, as well. It was an “ah-ha” moment for us and my family – the realization that this new connection with the brain tumor community through the National Brain Tumor Society would be truly transformative.

After that day, we were hooked. My husband and I made the commitment to participate in every single NBTS Walk across the country. We hold a sign when we walk that showcases every event we’ve participated in. It’s really fun to recruit friends and family across the country to attend these events with us. And it’s a great way to connect with our brain tumor community and personal friends every year. Now that we are retired, we’re really trying to “pick up the pace.”

We established the Bridge’s Brigade Team to put a personal face on our effort and fight against brain tumors. Bridget’s sister created T-shirts to promote our cause, and when we wear them, people always come up and ask if we know someone with a brain tumor. And I say, yes, my daughter. And they tell me about their connection with a brain tumor patient – it is amazing how the brain tumor community just comes out of the woodwork.

Awareness is critical, and whenever we have an event coming up, we post on social media and send emails to recruit, because the more-the-merrier. Our efforts have truly brought a richness to our lives, and we spread the word all over the country so others can feel the sense of support and love that we feel at every event.

I get so much out of participating, and so does Bridget and my entire family. We talk to so many people, and know they are in the same situation as us – and some are far worse. We’re all fighting to support our children, and our children’s kids, too. It is overwhelming, really, but these events give us a tremendous amount of hope and confidence. You see people surviving and fighting. It is an amazing experience, and provides an opportunity to give back – to realize a sense of purpose – to help Bridget fight for something.

There is such a “charged,” electric feeling of excitement in the air the morning of an event. But, at the same time, I experience a feeling of calmness, and familiarity. It is like our extended family. You see these events grow every year, and there are moments of intense intimacy with smaller events.

But, also an immense sense of pride and emotion takes over when we’re at the very large, well-attended ones. No matter how many times we participate, it leaves us feeling thankful that Bridget is doing well, and, it makes us more committed to doing even more.

I strongly encourage others to participate or volunteer at Brain Tumor Walk, Races, Rides and Plunges around the country. Those impacted by brain tumors should know that there are a lot of people out there who can provide support. They simply need to reach out, get connected with people, and learn about the experiences they will have throughout the brain tumor journey.

Coping with a brain tumor really takes a village. It is a difficult path to travel on your own, but you don’t have to do it by yourself. You really need to reach out beyond just your family, because they’re going through trauma too. Talk to those with similar experiences, do your research, find great, accurate, verifiable information and advice online or from NBTS, and take charge of your life and diagnosis. Don’t leave it to chance.

Eventually, as a result of our participation and event recruiting, we hope for the ultimate payoff – a cure for brain tumors. But, until there is a cure, we hope for more advanced treatments to help improve and extend, the lives of brain tumor patients.

For Bridget, her treatments are actually very limited. Her tumor is inoperable. She relies on chemotherapy and radiation. And while she is doing very well, I hope newer, less invasive treatments can one day make life better for adults and children with brain tumors. Better quality of life, with less long term negative effects, are some of the top reasons why we engage in these amazing events each year.

We’ve met so many parents whose children are gone because of brain cancer. You never think it could happen to you, until it does. Your child, or someone you love, may never be diagnosed with a brain tumor. But, it could happen.

Some people shy away from bad news like that, but I think it is important to lean in and become involved in ways to help. I know we are all constantly called upon to help various causes and missions, or give to fundraising efforts to help, but our mission is a very special one, and NBTS is a very special organization. I felt accepted the minute we became involved in the Walks.

Actively participating in these events represents a wonderful, deeply-satisfying way of obtaining the support and knowledge you need to live life. And I want others – many others – around the country, to feel that same feeling and create their own unforgettable experiences at NBTS signature and community events.
NBTS Thanks All Our Friends in the Brain Tumor Community for Your Support

Our National Strategic Partners and Industry Partners who work with us and provide resources and strategy to help drive new research funding and clinical trials.

Our National Flagship Sponsors from across the country, who provide us with the resources needed to make our events and programs come true.

Our National Foundation Partners allow us to move forward on many key programs and initiatives such as our Defeat Pediatric Brain Tumors Research Collaborative. Special thanks to St. Baldrick’s Foundation, The Rally Foundation, and others.

Our Strategic Advisor teams of world-renowned researchers who help NBTS move in the most strategic and result-oriented directions for improved research, new discoveries, and better treatments than ever before.

Our Team Captains from around the country truly are the heart of our many signature and community events, because they build the fundraising frameworks to raise money through participation in our rides, races, walks, brain freezes, and other community events.

And, of course, our donors, supporters, and fundraisers through the years who are so incredibly committed to helping us find a way to resource and fund new research that we believe will help the hundreds of thousands of brain tumor patients and their families find a better end to their brain tumor journey. We would like to thank in a special way our Major Donors who find it in their hearts to give so generously every year.
Both Community Events and Community Initiatives are carried out by people in the community, Community Organizers, to raise funds for NBTS independent of our staff driven signature events. A Community Event is when a Community Organizer decides to take on the logistics and planning of a tangible event to benefit NBTS, such as planning a 5k, bike ride, softball tournament, or party. A Community Initiative is when an Community Organizer starts any other fundraising opportunity in their community to benefit NBTS, such as asking a local restaurant to donate a % of each check to NBTS, asking for donations for NBTS in lieu of birthday or holiday gifts, or signing up for an existing race and asking for donations to support NBTS.

For more information visit
www.BrainTumor.org/CommunityFundraising

### Current Programs

- **Defeat GBM Research Collaborative**: Connects world-class scientists together from different institutions with the objective of doubling the percentage of patients living beyond 5 years with glioblastoma.

- **Oligodendroglioma (Oligo) Research Fund**: NBTS' first Community Research Fund dedicates money specifically for much-needed research into this rare tumor type. To date, three rounds of high-impact scientific projects have been launched to gain a better understanding of ways to best target it with treatments.

- **Defeat Pediatric Brain Tumors**: A powerful, unique global research and drug discovery program which aims to improve clinical outcomes for pediatric brain tumor patients and develop a first-ever standard of care for treating pediatric high-grade gliomas.

- **Clinical Trial Endpoints Initiative**: Seeks to create positive change in the process used to evaluate and approve potential new brain tumor treatments.

- **Public Policy & Advocacy**: Our policy agenda seeks to strengthen and advance research, improve access to essential health care services, advocate for budgets and policies dedicated toward the research and treatment of brain tumors, and expedite therapy approvals.

### How to get involved with National Brain Tumor Society

- **Attend our events**: Participate as an individual, start a team, or join a team.

- **Volunteer your time**: Help with planning, event day roles, or raise awareness of brain tumors in your community.

- **Make a gift**: Fund the discovery of new brain tumor treatments and a cure.

- **Become an advocate**: Let your voice be heard to support the critical needs of the brain tumor community.

- **Host a community event**: Support our mission and host your own local fundraiser with family, friends, neighbors, and co-workers.

- **Become a sponsor**: Fund critical brain tumor research.