



National
Brain Tumor
Society



2010 ANNUAL REPORT

Supported patients and caregivers with **more than 7,000** one-on-one phone calls and email messages

Rallied more than **27,000 participants** in races, walks, and rides in **12 cities** around the country

Connected **more than 10,000 visitors** to *My.BrainTumorCommunity.org*

2010

BY THE NUMBERS

Spearheaded new research initiative on behalf of more than 3,000 infants, children, and teens in the United States diagnosed with brain tumors each year

Advocated for public policy that reflects the needs of more than 600,000 people in the U.S. living with brain tumors

WE ARE ON OUR WAY



When I became Executive Director of the National Brain Tumor Society (NBTS) in 2008, I was charged with creating a larger, more impactful research program and a more robust patient services program.

Since that time, NBTS staff and Board members have reflected on the past two decades and refocused our strategic efforts. We know that the research that has been done is not working fast enough for our community. We need to bolster our efforts to get new, better treatments out of the labs and to people with brain tumors. We need a cure!

that integrating the study of normal brain development into pediatric brain tumor research is critical to accelerating the search for better treatments for children. Although many children diagnosed with brain tumors now survive well into adulthood, they often suffer permanent developmental problems as a result of exposure to radiation and other brain tumor treatments. Moving forward, we need to find treatments for children that cause the least amount of long-term damage.

NBTS's Patient Services department has also been scaling up. In 2010, we gathered

Together, we are stronger. Together, we have more impact. Together, we will see change.

In addition, we need to reach more people and meet the needs of the entire community – both adults and children. And while we continue to search for a cure, we need to serve those who are living with a brain tumor to ensure that each day of their lives is as good as it can possibly be.

In 2010, we launched several key initiatives and began laying the foundation for new, tailored programs that promise to better meet the critical needs of the brain tumor community. Momentum is building. We are on our way.

On the research front, we launched the Mary Catherine Calisto Systems Biology Initiative. [\(See page 4.\)](#) Systems biology is a new approach to research that harnesses cutting-edge technologies and calls on experts from multiple disciplines to work together to come up with innovative, efficient ways to develop treatments. NBTS is the first brain tumor organization to embrace systems biology. Our initiative has sparked the interest of scientific teams from every leading research institution in the United States and several around the world.

In 2010, we also expanded our pediatric research program. [\(See page 6.\)](#) We believe

experts from around the country for a quality-of-life workshop. The group identified a number of barriers to living well with a brain tumor and a plan to improve quality of life. [\(See page 12.\)](#)

In addition, we've added a number of new online features designed to help patients and caregivers connect with us and one another at any time, day or night. [\(See page 10.\)](#) We've also extended our outreach efforts by adding the Kelly Heinz-Grundner Brain Tumor Foundation to the NBTS team. [\(See page 15.\)](#)

Finally, we've been broadening the scope of our efforts to advocate for public policies that meet the critical needs of the brain tumor community. [\(See page 14.\)](#) In the future, look for a stronger, re-energized voice at the policymaking table and information on how you can help advocate for the community.

As we move forward, we invite you to add to our collective voice. Together, we are stronger. Together, we have more impact. Together, we will see change.

A handwritten signature in black ink, reading "N. Paul TonThat".

N. Paul TonThat, Executive Director

LEADING RESEARCH IN A NEW DIRECTION

New Approach, New Possibilities

National Brain Tumor Society (NBTS) invests in cutting-edge research aimed at speeding the development of new treatments and ultimately, a cure. The NBTS program is overseen by Chief Scientific Officer David R. Hurwitz, PhD, working with the NBTS Scientific Advisory Council – made up of a number of the top brain tumor experts in the country.

Mary Catherine Calisto Systems Biology Initiative



In 2010, the National Brain Tumor Society (NBTS) launched the largest singular research initiative it has ever undertaken: the Mary Catherine Calisto Systems Biology Initiative. NBTS believes that this is a watershed moment for the brain tumor community. Systems biology is a new approach to brain tumor research that holds promise to increase the speed at which effective new treatments for brain tumors are developed.

Historically, scientists have tried to understand brain tumors by studying one or two parts of the tumor that had gone awry, such as a gene or protein. While this research has greatly expanded our knowledge of brain tumors, it has had limited success in helping develop new therapies.

What *has* emerged is the understanding that brain tumors are highly organized systems. A brain tumor is a “complex network that senses a variety of things that a cell uses to decide whether it should grow or not,” says Lewis Cantley, PhD, of Harvard Medical School and Beth Israel Deaconess Medical Center. “We know that hitting a single component in this network is rarely effective in treating cancers.” Systems biology recognizes this quality of brain tumors and focuses on shutting down the entire system – not just one or two parts.

“Most brain tumor research has studied smaller and smaller components with the idea that by understanding the individual components, you can understand the workings of the whole system,” says Gordon Mills, MD, PhD, Chairman of the

Department of Systems Biology at MD Anderson Cancer Center in Houston, Texas. “But nothing works in isolation. The parts have to be put into context. What is central to the systems biology approach is that components are not studied in isolation, but rather in the context of interconnecting and interacting systems.”

Challenges in Developing Treatments

Certain qualities of brain tumors make them resistant to treatment:

> **Diversity** – The World Health Organization has identified more than 120 different types of brain tumors. Within these types, there are additional sub-types that have different genes, proteins, and other characteristics. Because of this diversity, a treatment that is effective for one type of brain tumor will not necessarily work on another type. A key focus of systems biology is finding ways to quickly identify the precise combinations of gene mutations and proteins that predict tumor growth, and then designing a personalized treatment plan that will best stop the progress of a particular tumor.

> **Adaptability** – “Brain tumor cells are incredibly adaptable and incredibly robust,” says Brent Reynolds, PhD, of the William L. McKnight Brain Institute at the University of Florida. For example, when faced with a treatment targeted at a problem gene or protein, the cells may be able to change in order to resist the treatment. In addition, many brain tumor cells can adapt to subtle changes in their environment, making them moving targets for treatments.

> **Complexity** – The many different components of brain tumors form a sophisticated network that is able to send signals and

provide backup when part of the network is affected by treatment. One of the hopes of systems biology is that it can be used to develop computerized models of these networks designed to predict how the entire tumor system will react when one part of the tumor is treated, or “poked.”

> **Location** – Because the brain is the control center for thought, emotion, and movement, any treatment is almost certain to impact at least some aspects of the person’s physical and mental well-being. In many cases the effects of treatment are devastating.

> **The blood-brain barrier** – The body protects the brain with a cellular barrier that blocks many chemical substances, including toxins, from entering. Any brain tumor treatment must be able to bypass this barrier.

Innovation Through Expert Collaboration

NBTS is leading the brain tumor community towards systems biology with the \$5 million Mary Catherine Calisto Systems Biology Initiative. This research initiative mandates that grantees form a team of scientists that include experts outside of their own specialties. Each grant will be reviewed by the NBTS Scientific Advisory Council. The reviewers will score the applications based on their



scientific merit and then present their findings to the NBTS Board of Directors.

Grants of up to \$100,000 will be given for the first stage of planning, which is focused on developing a collaborative plan and timeline during the first year.

Upon review of the phase I results, three grantees will move on to the second phase. Each will receive \$1.5 million over three years (\$500,000 per year) to execute the research plan.

The Promise of the Mary Catherine Calisto Systems Biology Initiative:

- > Promote development of more effective therapies and new treatment options for people with brain tumors
- > Lead the brain tumor research community to shift from a traditional approach to systems biology
- > Encourage other funding agencies to invest in systems biology research
- > Bring together experts from a wide variety of disciplines to come up with innovative approaches to treatment
- > Use cutting-edge technologies to develop models of brain tumor systems that will help scientists predict which treatments are best suited to each unique type of brain tumor
- > Increase the speed and efficacy of getting brain tumor research to clinical trials



Mary Catherine Calisto joined the brain tumor community in 1996, after losing her father to a brain tumor. She combined her experience in the brain tumor community with her professional insights – gained from working for 15 years with major pharmaceutical companies and start-ups to support drug development – to drive the revamping of the National Brain Tumor Society’s research program. The Mary Catherine Calisto Systems Biology Initiative was named in her honor.

A SHIFT IN THE FOCUS OF CHILDHOOD BRAIN TUMOR RESEARCH

National Brain Tumor Society Spearheads Pediatric Research Initiative



We want to help push pediatric brain tumor research forward, to bring it up to where adult research is and to address the vulnerability of the developing brain.

Each year more than 3,000 infants, children, and teens in the United States are diagnosed with brain tumors. With proper therapy, many survive well into adulthood. But they often suffer serious side effects from treatment that do not show up until years after the diagnosis. This problem, dubbed “growing into deficit,” may affect every aspect of the person’s life – from the ability to graduate from high school to the likelihood of getting a job to the capacity for developing long-term relationships.

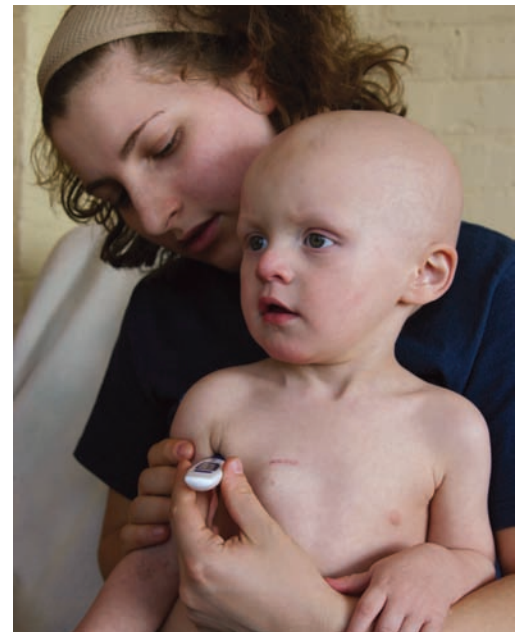
Given these unique challenges, “progress in pediatric brain tumor research has lagged behind progress in adult brain tumor research,” says David R. Hurwitz, PhD. Dr. Hurwitz is the Chief Scientific Officer of the National Brain Tumor Society (NBTS). “We’re looking to see how we can help push pediatric brain tumor research forward, to bring it up to where adult brain tumor research is at this point, and to address the vulnerability of the developing brain.”

To help fill in the gap, NBTS launched its Pediatric Research Initiative in 2009. “The Initiative is looking at two major aspects of pediatric brain tumor research that we think will, together, have the greatest impact on moving the field forward,” says Dr. Hurwitz.

The first aspect, called molecular profiling of pediatric tumors, has the potential to transform the pediatric research landscape. Molecular profiling uses cutting-edge technologies to analyze the various genes that drive growth of pediatric brain tumors. Studying these gene mutations has always been particularly challenging for a number of reasons. “Many pediatric tumors occur

in areas of the brain that are especially difficult to access, making it difficult to obtain samples to study,” says Dr. Hurwitz. In addition, all of the expertise and special equipment needed to perform molecular profiling is not typically found in a single laboratory. As such, researchers from a variety of disciplines and settings must collaborate to get the best results.

Phase I of the Initiative calls for research into comprehensive molecular profiling of pediatric tumors. For the last two years, NBTS has been supporting profiling of pediatric brain tumors. Momentum in the field has been gaining speed, and more and more comprehensive profiling of pediatric brain tumors is being performed. This allows NBTS to now focus on the second phase of the Initiative.



The second key aspect (phase II of the Initiative) focuses on a field of study called developmental neurobiology, which looks at all of the genes, molecular and cellular processes, and environmental factors that affect normal brain development. “In most cases, pediatric tumors are the result of normal development gone awry,” says Dr. Hurwitz. “Because brain tumors are intricately connected to the normal developmental process, we need to understand that connection in order to find therapies that target tumors yet have the least impact on continuing brain development. Developmental

neurobiology can be instrumental in helping us understand the origin of brain tumors and the cells from which they arise.”

Together, studies in molecular profiling and developmental neurobiology will provide a much more complete picture of promising treatment targets for pediatric brain tumors. NBTS believes that its Pediatric Research Initiative will lay essential groundwork that will help future research be more efficient in identifying better treatments that are less likely to cause long-term developmental problems.

We need to find therapies that target tumors yet have the least impact on continuing brain development.

Driving Innovations in Brain Tumor Research

David R. Hurwitz, PhD

David R. Hurwitz, PhD, is the Richard B. Ross Chief Scientific Officer (CSO) of the National Brain Tumor Society (NBTS). As the CSO, Dr. Hurwitz leads the research program and helps develop NBTS's strategic research plans.

Dr. Hurwitz is an expert in genetics and molecular virology and has been a lead scientist at a number of renowned pharmaceutical and biotechnology companies, including ALG Company. He has authored 30 peer-reviewed publications on a range of topics including viral oncogenesis, signal transduction, and gene therapy. In addition, he is an inventor on six issued biotechnology patents.

In 2009, Dr. Hurwitz served as a scientific reviewer and helped select recipients for Pediatric Brain Tumor Research Awards for the Peer Reviewed Cancer Research Program in Washington, D.C. This initiative is part of the Department of Defense Congressionally Directed Medical Research Programs. In 2010, Dr. Hurwitz served as the chairman of the Program's Pediatric Brain Tumor Research Awards review panel.



INNOVATION RESEARCH GRANT PROGRAM

As part of its research program, the National Brain Tumor Society (NBTS) awards Innovation Research Grants. The grants are designed to support cutting-edge research projects that will significantly move the field forward. These may include “out-of-the-box” projects or transformative research geared to driving development of new therapies.



Tocagen: Using Gene Transfer Technology to Treat Brain Tumors

National Brain Tumor Society (NBTS) awarded an Innovation Research Grant to Tocagen, a San Diego-based biotechnology company. Tocagen is conducting early phase clinical trials involving a unique approach to treating glioblastoma – the most common type of primary brain cancer. The approach, called Controlled Active Gene Transfer Technology (CAGT), facilitates transfer of a therapeutic gene therapy directly to cancer cells. “We are excited about Tocagen’s research,” says N. Paul TonThat, Executive Director of NBTS. “We believe it will represent a major step forward in driving research to new therapies.”

Preliminary research suggests that with CAGT technology, growth of brain tumors can be halted with use of a gene carrying a substance called Toca 511 and a pill containing another substance called Toca FC. Toca 511 zeroes in on and delivers the gene to glioblastoma cells, which tend to divide rapidly as the tumor grows. Once the gene reaches the cells, it converts Toca FC into an anti-cancer drug called 5-FU. 5-FU kills the rapidly dividing tumor cells, without harming healthy cells nearby.

If the technology is shown to hold up in clinical trials, the hope is that Toca 511 with Toca FC will be an effective treatment for brain tumors that causes fewer side effects than conventional treatments such as chemotherapy.

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Clinical trials involving Toca 511 with Toca FC are currently underway at the University of California, San Francisco; the University of California, Los Angeles; and the Cleveland Clinic in Ohio. In 2009, NBTS awarded Tocagen an Innovation Research Grant of \$100,000 per year for two years.

2010 CHAIRS OF RESEARCH

National Brain Tumor Society (NBTS) appreciates the generous donors who have helped fund the 2010 Chairs of Research program. The following list names each Chair of Research, followed by the researcher, institution, and project funded. Chairs of Research are named giving opportunities funded by gifts of between \$100,000 and \$200,000 per year.

Billy Grey Chair of Research

Mark W. Kieran, MD, PhD

Dana-Farber Cancer Institute,
Boston, Massachusetts

Paraffin-based sequencing of the human kinome in pediatric ATRT

Tumor: Atypical Teratoid /Rhabdoid Tumor

Nick Gonzales Chair of Research

Mariano Viapiano, PhD

Ohio State University,
Columbus, Ohio

Regulation of tumor cell invasion and survival by fibulin-3, a matrix protein uniquely expressed in gliomas

Tumor: Malignant glioma

SSBTR Chair of Research

Anna M. Kenney, PhD

Memorial Sloan-Kettering Cancer Center,
New York, New York

YAP1 as an effector of Sonic hedgehog mitogenic signaling in cerebellar development

Tumor: Medulloblastoma

Seth Harris Feldman Chair of Research

David Largaespada, PhD

University of Minnesota,
Minneapolis, Minnesota

The Neuro-Oncology Genomics Project

Tumors: Glioma, Medulloblastoma

Kayla Wenger Chair of Research

Cynthia Hawkins, MD, PhD

The Hospital for Sick Children,
Toronto, Ontario

Genome-wide profiling of pediatric diffuse intrinsic pontine glioma

Tumor: Diffuse intrinsic pontine glioma

Sydney Schlobohm Chair of Research

Suzanne Baker, PhD

St. Jude Children's Research Hospital,
Memphis, Tennessee

Molecular pathogenesis of diffuse intrinsic pontine gliomas

Tumor: Diffuse intrinsic pontine gliomas

Rachel Markoff Chair of Research

James Waschek, PhD

University of California, Los Angeles
Los Angeles, California

Critical role of STAT3 in medulloblastoma immune evasion in genetically engineered mice

Tumor: Medulloblastoma

Dennis Roth Chair of Research

Andrew Parsa, MD, PhD

SPORE Collaborative
Brain Tumor Research Center,
University of California, San Francisco
San Francisco, California

Heat shock protein vaccine development

Tumor: Glioblastoma Multiforme

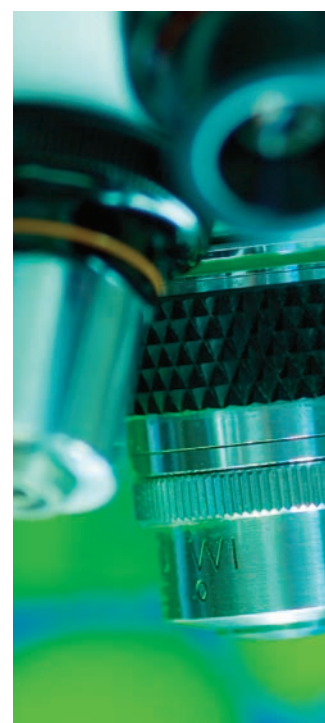
James F. Petersen Chair of Research

Tocagen

Biotechnology company
San Diego, California

Toca 511 with Toca FC for the potential treatment of brain cancer

Tumor: Glioblastoma Multiforme



NETWORKING, 24/7

New Forums, Blogs, and Other Programs

National Brain Tumor Society's Patient Services provides comprehensive resources and personalized support to help patients and caregivers make informed decisions and develop strong support systems at every stage of their journey.

When Brenda Brady was diagnosed with a ping-pong ball-size brain tumor in 2007, she was “on the floor sad,” she says. “For two weeks, I was like a puddle.” Although Brady was no stranger to chronic illness, having lived with multiple sclerosis for nearly 10 years, this was different. “I’ve always been an energetic, positive person,” says the 45-year-old, from Port Deposit, Maryland. “But when you’re diagnosed with a brain tumor, you think it’s a death sentence.”

Fortunately, her outlook changed when a friend told her about the National Brain Tumor Society (NBTS). Through the NBTS Patient and Caregiver Peer Support Network, Brady connected with a woman in Michigan who had been living for more than 25 years with the same type of tumor Brady has – called an astrocytoma. “I needed to know that other people had survived with this kind of tumor,” says Brady. “As soon as I talked to her, I told myself that now I’m going to fight this.”

Like Brady, many people make contact with NBTS because “they need to know that there are people out there who have made it and been through it,” says Tamar Sekayan, MSW, Assistant Director of Patient Services at NBTS. “Most people with brain tumors aren’t getting the support they need.”

To meet their needs, the NBTS Patient and Caregiver Peer Support Network ranks as the largest support network for the brain tumor community in the country. The Network allows patients and caregivers (including parents of children with brain tumors) to be matched with volunteer brain tumor survivors or caregivers for information and support via both phone and email. Patients can be matched with a survivor who is close to their age, has the same tumor type, or other similar characteristics.

Since its launch in 2002 – with a mere 10 volunteers – the Network has grown to 117 people with brain tumors and 73 caregivers working as active volunteers, with about three to five new volunteers added monthly. Volunteers have first-hand experience with more than 30 different types of brain tumors.

In addition to helping people cope as they move through treatment, the Network also serves people like Brady, who is living with a stable tumor. When Brady finished treatment in 2009, she joined the group as a way of taking care of herself and staying active in the brain tumor community. “I always tell people I want to help others,” she says. “Helping people makes me feel good. It’s a way for me to find hope.”



Brenda Brady and her husband, Jeff, in July, 2010 – relieved after a magnetic resonance imaging (MRI) test showed no signs of tumor growth in Brenda’s brain.

Click and Connect

In January, 2010, NBTS launched another service aimed at helping patients and caregivers connect with the brain tumor community: My.BrainTumorCommunity.org (MyBTC). The website serves as both a community of interest and a community of relationships for those touched by brain tumors. Accessible 24 hours a day, seven days a week, MyBTC has hosted more than 10,000 visitors since its launch.

MyBTC features a blog, written by NBTS staff, to address comments, and share ideas and opinions on topics such as seizures and coping with holidays. In addition, MyBTC has 20 separate web-based groups that allow

webcast and telephone several times each year. The programs are also available, on demand, through the NBTS website.

> **NBTS Treatment Center Database** is a comprehensive, searchable database that

Many people contact National Brain Tumor Society because they need to know that there are people out there who have made it and been through it.

users to self select, by region or interest, where they fit inside the community. Finally, MyBTC hosts online forums that allow participants to post and respond to concerns, questions, updates, and more. To date, the MyBTC forums have posted some 1,200 replies to topics, questions, updates, words of hope, poetry, and more.

More Ways NBTS Can Help

> **Patient Services Information Line (800.934.2873)/info@braintumor.org**

allows patients and caregivers to obtain personalized information about all aspects of coping with a brain tumor. The toll-free telephone line and email address are staffed by trained Health Information Specialists. Each year, the Specialists answer more than 3,000 phone calls and nearly 4,000 emails from patients, caregivers, and healthcare providers all over the world. Phone lines are open from 9 a.m. to 8 p.m., Eastern Standard Time.

> **NBTS website (www.braintumor.org)** provides support, connection, and information on types of brain tumors and treatment options. In addition, it offers a variety of publications and information on how to connect with MyBTC and patient support networks.

> **Webinars/Teleconferences** are free, interactive educational programs offered via

allows users to find each treatment center’s profile (including the number of patients with brain tumors treated at the facility each year), contact information, treatment and technology offerings, and brain tumor specialists.

> The **NBTS Support Group Database** is the largest searchable database of brain tumor-specific support groups in the country.

> **Spanish-Language Programs and Services** provide publications and supportive services in Spanish, including a Spanish-speaking Health Information Specialist.

> **Family Caregiver Workshops** were developed to provide tools and support to treatment centers that host caregiver workshops locally. Since the program’s launch in 2003, more than 65 of these free, 8-hour workshops have been offered in more than 20 states in the country.

> **Patient and Family Conferences** are education and support events hosted in medium to large cities throughout the United States. In addition to providing information, the conferences allow attendees to connect with others in the brain tumor community. In 2010, NBTS hosted conferences in Dallas and Washington, D.C.

> **Publications**, including fact sheets and *The Essential Guide to Brain Tumors*, *Coping with Brain Tumors*, and *Understanding Glioblastoma*.



LIVING WELL, AFTER THE DIAGNOSIS

A New Strategy for Improving Quality of Life



Sarah and Mark Whitlock enjoying happy hour in Block Island, Rhode Island, 2009. "As the primary caregiver to my brother, my life suddenly and radically changed when he was diagnosed with a brain tumor," says Whitlock. "I was immediately expected to be a mother to my brother, a friend to my parents, a doctor, a medical advocate, a nutritionist, a scientist, a researcher, an analyst, an insurance expert, a financial advisor, a lawyer, a hospice worker, a therapist, and a social worker."

"Every day is like a new normal when someone you love has a brain tumor," says Sarah Whitlock, a 30-year-old living in New York City. When Whitlock's brother, Mark, was diagnosed in 2008 with a glioblastoma – the most common form of primary brain cancer – she and her parents were unprepared for all the changes he would go through.

During the next two years, Mark had surgery and other treatments. "After his surgery, we were sent home without any information about what changes to expect," says Whitlock. While some periods were better than others, "it seemed that every day we had to adjust to a new loss, a new way of functioning," says his sister. "Parts of his personality even changed as a result of the brain tumor."

Eventually, Mark became blind in one eye, unable to speak, and paralyzed on one side of his body. And Sarah and her parents all adjusted full-time work schedules to care for him, both at her parents' home in Connecticut and her apartment in Manhattan. In addition, the whole family had to shoulder much of the financial burden of his treatment.

For Whitlock, connecting with other caregivers via the National Brain Tumor Society (NBTS) was key to giving her the support she needed to help cope with her brother's condition. "The most important part of the journey for all of us was learning to adjust to day-to-day changes in his condition and embrace every moment," she says.

"When Mark's illness became worse, my family and I had to learn to deal with the incredible shifts and changes that happened every day," says Whitlock. "Mark had always been so dynamic, funny, smart, and charismatic. He was in his second year of law

school when he was diagnosed. At the end of his life in May, 2010, his once powerful and cheerful charisma had disappeared, leaving only a shell of his former self."

Unfortunately, stories like Whitlock's are all too common. "People's lives are profoundly affected by the treatments we have for brain tumors," says Paul Fisher, MD, a professor and pediatric oncologist at Stanford University in Palo Alto, California, and a member of the NBTS Board of Directors. "We can't have a cure at all cost," he says. "If you prolong someone's life, but they're not even a shadow of who they once were, it's not enough. We need to figure out how to strike a balance between living well in the present and surviving into the future."

Barriers to Living Well

In September, 2010, NBTS gathered Dr. Fisher and a group of other quality-of-life experts for a workshop. More than 20 nurses, physicians, social workers, and other healthcare providers from all over the country attended. Together, they helped NBTS develop a quality-of-life action plan.

The group started by identifying the most common barriers to quality of life for people with brain tumors:

– Lack of resources to help patients and caregivers cope throughout their journey

Like the Whitlock family, people affected by brain tumors often struggle with issues ranging from how to take care of a person disabled by a tumor to how to pay for treatment. What's more, support groups and other resources geared to people with all types of cancer generally don't cut it for those touched by malignant brain tumors.

In addition, the toll that caring for a loved one with a brain tumor takes often

goes unrecognized. Caregivers often suffer untreated depression and other forms of psychological stress. For these other “survivors,” ongoing support and connection with people in the brain tumor community can be critical part of healing and moving on.

– Inadequate quality-of-life research

“On a global level, research on the quality-of-life issue takes as much money

> Develop a system for delivering essential information to brain tumor patients and their caregivers at critical points in their journey. The needs of brain tumor patients and caregivers vary widely depending on many factors such as the type of brain tumor, the age of the person with the tumor, and the patient’s access to resources. A systematic method of pointing patients and caregivers to vital resources, via specially trained

We need to figure out how to strike a balance between living well in the present and surviving into the future.

as researching the cure,” says Dr. Fisher. “No one in the brain tumor research field has really taken quality of life under their wing.”

– Lack of guidelines for the entire course of the disease

The effects of a brain tumor often change as a person lives with the disease. That’s particularly true in children with brain tumors as they transition to adulthood. Because there is no national system for guiding people through their journey, patients and caregivers often don’t get the help they need, when they need it, to live well with the disease.

– Misunderstandings about the general nature of brain tumors For example, although a brain tumor is essentially an injury to the brain, many insurers don’t cover as many necessary services for those diagnosed with a “brain tumor” as they do for those diagnosed with a “brain injury.”

Moving in the Right Direction

Workshop participants also came up with top priority actions the brain tumor community can take to improve quality of life.

health-care providers and web-based navigation tools, is essential to helping people access the care and information they need, when they need it.

> Develop a quality-of-life research initiative focused on two key areas: how best to ensure quality care for symptoms and side effects that affect patient and caregiver quality of life; and how to increase understanding of the biological effects of brain tumors, and how they affect people at different stages of life.

> Develop a set of guidelines to help standardize care for those with affected by brain tumors.

> Educate healthcare providers and the public about the physical and psychological effects of brain tumors that hamper quality of life and limit access to care.

In response to these topics, NBTS is refining a preliminary plan to help the brain tumor community accelerate efforts to increase quality of life.



A VOICE FOR THE BRAIN TUMOR COMMUNITY

National Brain Tumor Society Advocacy Program

National Brain Tumor Society's Advocacy program gives the brain tumor community a voice at the policymaking table and strengthens public policy to help brain tumor patients and advance research.

In 2010, the National Brain Tumor Society (NBTS) advocated for several major public policy changes. Each change was implemented:

- > Maintaining funding for the National Institutes of Health for the FY 2011 budget.
- > Maintaining funding for the Peer Reviewed Cancer Research Program, which has historically funded pediatric brain tumor research. NBTS Chief Scientific Officer David R. Hurwitz, PhD, and NBTS Board member Cord Schlobohm served as reviewers for the program.
- > Supported implementation of the Patient Protection and Affordable Care Act to ensure that it reflects the needs of the brain tumor community.

Brain Tumor Action Week

Liz Harrington of Maine traveled to Washington, D.C., along with National Brain Tumor Society staff and Board members for Brain Tumor Action Week, May 2-8, 2010. "Last year almost to the day, I was helping my dad recover from brain surgery to remove a massive tumor," says Harrington. "He lived a mere 86 days after being diagnosed with that horrific brain tumor. Since his death, I have

found many exciting ways to get involved to help other families coping with the words 'your loved one has a brain tumor.'"

Harrington met with officials including Maine Representative Chellie Pingree and Senator Susan Collins. The visit was a success, as Harrington secured Senator Collins as a sponsor for the resolution to designate May as National Brain Tumor Awareness month. "I left Washington D.C., knowing my dad would be very proud of me," says Harrington.



Liz Harrington, Representative Chellie Pingree, and National Brain Tumor Society Director of Community Relations Kristina Knight, during Brain Tumor Action Week.

SPREADING THE WORD

The Kelly Heinz-Grundner Brain Tumor Foundation Joins the Team

In April, 2002, 29-year-old Kelly Heinz-Grundner began suffering headaches that wouldn't quit. Her doctor prescribed migraine medications, yet during the next six months the headaches worsened. And Kelly was in and out of her doctor's office with

GET YOUR HEAD IN THE GAME
will give people the chance to
join a community of action.

other complaints: blurry vision, nausea and vomiting, and loss of coordination and balance.

But when Kelly and her husband, Chris, asked for an MRI (magnetic resonance imaging) – a test used to take “pictures” of the brain – Kelly's doctor resisted. “Kelly is too young to have a brain tumor,” she told the Grundners. By the time the doctor finally ordered the test, in September, 2002, Kelly had a golf ball-sized tumor in the middle of her brain.

At the time of Kelly's diagnosis, 32-year-old Chris was on the career fast-track, working as a senior vice president at JPMorgan Chase, in Wilmington, Delaware. “In a second, I realized that none of that matters,” he says. Grundner took time off from his job and spent as much time as possible with Kelly.

In 2005, a year after Kelly's death, Chris founded the Kelly Heinz-Grundner

Foundation. “My goal was to fight back by bringing the national spotlight to this terribly dark disease,” he says. In 2010, the Foundation joined forces with the National Brain Tumor Society (NBTS) as a wholly-owned subsidiary. “Now, we can work on the scale that I could never have generated on my own,” says Grundner.

Using KHG's trademark slogan, GET YOUR HEAD IN THE GAME®, NBTS will be making a national call for people to take action by learning more about brain tumors, educating others, advocating on issues important to the brain tumor community, or supporting NBTS by participating in a fundraising event.

“We are focused on funding transformative research, comprehensive patient support, and advocacy,” says N. Paul TonThat, Executive Director of NBTS. “Bringing in the Kelly Heinz-Grundner Brain Tumor Foundation and expanding GET YOUR HEAD IN THE GAME across the country will give many more people the chance to join a community of action.”

With more people taking action on behalf of the brain tumor community, more people will understand the many challenges those affected by brain tumors must face and support NBTS-funded research and patient services. The hope is that one day, no one with a brain tumor will have to struggle to get a diagnosis the way Kelly did and that ultimately there will be a cure.



Chris and Kelly taking in a football game

WORKING TOGETHER FOR A BETTER TOMORROW

Walking, Riding, Running, Golfing, Baking, Spelling, Eating, Planting...

National Brain Tumor Society coordinates a wide range of fundraising activities that allow people to connect with the brain tumor community and work toward raising awareness, improving quality of life, and finding a cure.

When Ginny Tavilla was diagnosed with brain cancer in 2010, her doctors “painted a dark picture of her future,” says her daughter Susan. But Susan and her seven siblings rallied. “We needed to take action,” says Susan. The family spread the word about their 77-year-old mother’s diagnosis and started raising money for the National Brain Tumor Society (NBTS) through bake sales and other local events. In October, 2010, they gathered more than 50 people to participate in NBTS’s inaugural Boston Brain Tumor Walk. At that event, “Team Tavilla” raised more than \$30,000.

For her part, Ginny Tavilla had surgery and then went through radiation treatments without a hitch. “From what we hear, it’s a miracle that my mother is still with us,” says Susan. “I believe that the money my family and others have raised is going towards helping her and other people with brain tumors.”

Like the Tavilla family, many people get involved with NBTS after being personally touched by the disease. NBTS coordinates a wide range of fundraising activities that allow people to connect with the brain tumor community and work toward raising awareness, improving quality of life, and finding a cure.

These run the gamut from citywide walks and other major events to hosting community events, such as bake sales, dinners, and spelling bees. In addition, NBTS coordinates investment of major donations for research and other programs vital to the community.

“Without the thousands of committed people who help us raise money each year, NBTS wouldn’t be able to provide critical services to the brain tumor community through our programs,” says N. Paul TonThat, Executive Director of NBTS. “We are grateful to the many people who so generously support the cause.”



Team Tavilla members Susan Tavilla, Kim Johannson, and Ginny Tavilla at the 2010 Brain Tumor Walk in Boston. “I can’t wait to do it again,” says Susan.



Each year, the National Brain Tumor Society provides support for hundreds of groups and individuals who host local community events to raise money for NBTS programs. In 2010, third grader Elli Haskes and her classmates in Chesire, Connecticut, raised more than \$2,400 at a Spell-A-Thon in memory of Elli’s mom, Rena.



In 2010, National Brain Tumor Society hosted 12 major events across the US, with some 27,000 participants.

Without the thousands of committed people who help raise money each year, NBTS wouldn't be able to provide critical services to the brain tumor community through its programs.

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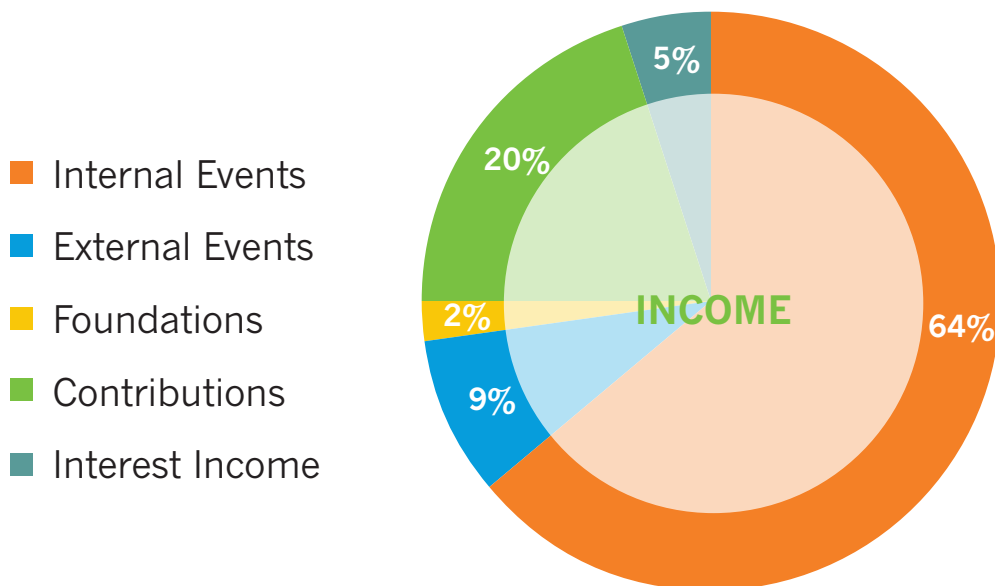
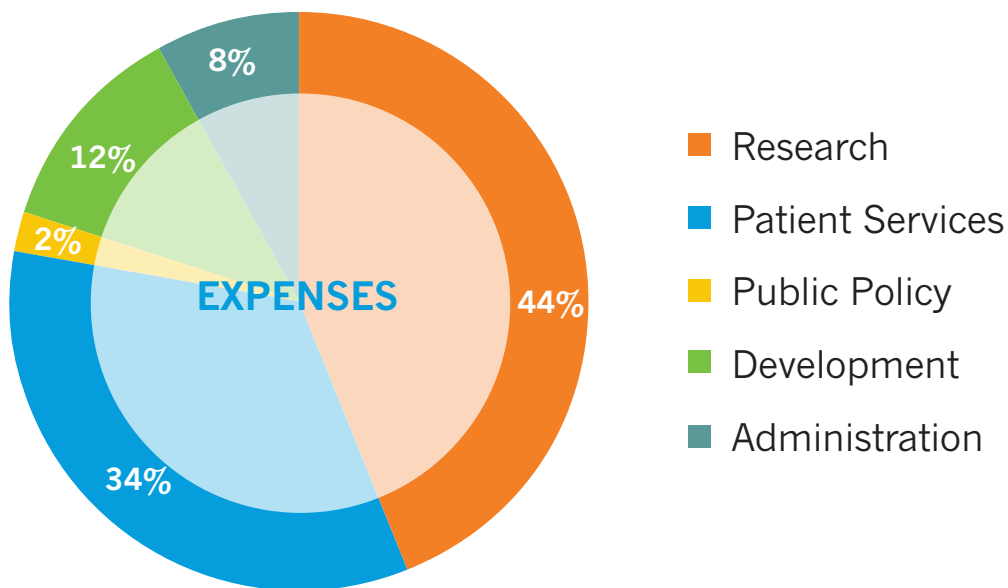
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