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

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

Strengthened by Diversity, Equity, and Inclusion
We embrace a culture of equity, inclusion, and all forms of difference where we each can confidently express our authentic selves.
Dear NBTS Community,

In a year like no other, you — our brain tumor community — have been simply amazing and inspiring.

When the pandemic spread in the early spring, there were a lot of questions, a lot of uncertainty, and a lot of worry, especially for those of us in the brain tumor community. Like it has for so many across the country and around the world, the pandemic has challenged us and changed us socially and financially. NBTS has had to adapt in many ways as we faced the single greatest drop in revenue we have ever faced as a result of the economic fallout from COVID-19. Thanks to you, your organization — the National Brain Tumor Society — quickly adapted, putting patients and caregivers first.

We kept our work toward a cure moving.

We launched new, promising research projects focused on pediatrics and adults. We virtually gathered with neuro-oncology leaders across major hospitals, the NIH, the FDA, and biopharmas to develop specific action plans to enable clinical trials to continue and telemedicine to improve. And the NBTS-supported GBM AGILE
clinical trial program actually expanded, giving more patients an opportunity for survival. That said, many of the research institutions we planned to sponsor in 2020 experienced significant disruptions in their operations, and the National Brain Tumor Society was not able to launch some of its most promising research projects this year. But we stayed connected and informed in a socially distant world. We virtually mobilized thousands across the country during Brain Tumor Awareness Month, Head to the Hill, and Glioblastoma Awareness Day. Those efforts created real results. We increased federal funding for brain tumor research, including an increase in federal funding for Medicaid-eligible patients on clinical trials. We successfully advocated for the enactment of the Clinical Treatment Act, which expands health insurance coverage for brain tumor patients on clinical trials. In addition, we innovated by hosting monthly virtual Brain Tumor Support Conversations led by volunteers, and by curating timely brain tumor-specific resources to help patients understand the impact of COVID-19 on their lives and treatment.

We have learned many things from 2020, but most of all we take away how resilient NBTS volunteers, advocates, and supporters are, and how dedicated they are to stay the course toward a cure and to improve quality of life along the way. Over the last decade, our understanding of brain tumors advanced significantly. We started 2020 in a position to leverage these insights into new treatments and cures. New actionable leads for medical research are abundant. Personalized support and navigation is available. There is a space at the policymaking table for our advocates.

Together, as one big NBTS community, we weathered 2020 and continue our work to turn this decade into a decade of transformational progress. Thanks to the generosity of our amazing community, we moved forward, unrelenting, and we will not stop until we conquer and cure brain tumors — once and for all.

Tom Roloff
Chair of the Board of Directors

David F. Arons, JD
Chief Executive Officer
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

National Brain Tumor Society funded a variety of promising research projects in 2020, including:

• Under the leadership of Dr. Frank B. Furnari from UC San Diego, a Defeat GBM-funded team developed a new laboratory model system they call cancer “avatars” with the ability to replicate human GBM tumors.

• NBTS teamed up with StacheStrong to provide funding to a pilot clinical trial at Mount Sinai Hospital, led by Dr. Adilia Hormigo, evaluating a personalized approach to immunotherapy in both adults and children with high-grade gliomas.

• NBTS supported Dr. Justin Lathia’s research on the novel drug candidate CT-179, which is being developed as a potential treatment for glioblastoma (GBM) by Curtana Pharmaceuticals and the Cleveland Clinic.

• NBTS provided support for the GBM AGILE clinical trial that expanded the enrollment and number of drugs being evaluated in the adaptive design clinical trial.

• The NBTS Investment Fund was launched to spark private sector investment in brain tumor-dedicated enterprises to accelerate the development of transformative therapies and technologies.

• NBTS supported a phase II clinical trial led by Dr. Clark Chen at the University of Minnesota to evaluate the safety and efficacy of ONC201 as a treatment for a subset of adult patients with high-grade glioma.
Connect
Uniting the Brain Tumor Community

NBTS connected the brain tumor community to one another and provided resources to help better inform and prepare patients to access specialized brain tumor treatment.

During 2020, NBTS launched:

• A new Personalized Support and Navigation Program, a service provided by an experienced team, including a highly skilled medical professional. The program ensures a patient or caregiver receives individualized attention, support, and information. There were more than 500 interactions with NBTS’s virtual support and navigation services in 2020.

• A comprehensive set of resources to help brain tumor patients and caregivers navigate treatment options and keep themselves safe during the COVID-19 pandemic.

• “Meditation Mondays,” a series of free monthly meditation classes for members of the brain tumor community, led virtually by licensed meditation, mindfulness, and yoga teacher (RYT® 500) Tori Best.

• National commemorations for Brain Tumor Awareness Month, Glioblastoma Awareness Day, and Childhood Cancer Awareness Month.

• Live-streamed, nationwide events gathering thousands of stalwart racers, walkers, and riders together virtually for the NBTS mission.

• A “DIY fundraising toolkit” for community event organizers to unite their local community for a virtual event of their choosing.

• The Collaborative Ependymoma Research Network (CERN Foundation) officially became a designated program of NBTS.
NBTS volunteers advocated for federal funding of brain tumor medical research, influencing the government to provide:

• $42.934 billion in funding for the National Institutes of Health for FY21, a $1.25 billion increase over FY20, and $6.559 billion to the National Cancer Institute, a $119.5 million increase.

• $115 million for the Peer Reviewed Cancer Research Program of the Department of Defense for FY21, a $5 million increase over FY20, and ensured brain cancer, pediatric brain tumors, and pediatric, adolescent, and young adult cancers were once again included as eligible priority research topics for funding.

• $30 million to fully fund the Childhood Cancer STAR Act for a third consecutive year.

• Helped secure $50 million to fully fund the Childhood Cancer Data Initiative for a second consecutive year.
In addition, in partnership with our advocates, NBTS:

- Partnered with the FDA to organize a focus group of patients to offer insights and ideas to improve access to clinical trials during COVID-19.
- Convinced Congress to support the National Cancer Institute’s creation of a new Glioblastoma Therapeutics Network.
- Waged a successful advocacy campaign leading to the enactment of the Clinical Treatment Act, which guarantees coverage of routine medical costs associated with clinical trial participation for Medicaid recipients.
- Persuaded Congress to extend important incentives for the development of treatments for pediatric rare diseases including brain tumors through the Creating Hope Reauthorization Act.
- Hosted our largest-ever Head to the Hill advocacy day, with more than 1,300 brain tumor advocates flooding Congress with 4,567 messages asking for increased funding for brain tumor research.
- Organized NBTS’s largest In-District Meetings Program to date, resulting in 50 virtual meetings with Members of Congress from across the country.
- Mobilized volunteers to hold more than 250 meetings and sent more than 10,000 messages to Congress in 2020.
- Spearheaded passage of resolutions to highlight the urgent, unmet needs of the brain tumor community, including:
  - Ensuring the passage of the Glioblastoma Awareness Day (GBM) Resolution for the second straight year, and for the first time leading efforts to get a companion resolution introduced in the House.
  - Working with Congress to once again declare May as Brain Tumor Awareness Month.
- Along with dozens of other advocacy partners, supported the creation of both a Brain Tumor Patients’ Charter of Rights with the International Brain Tumour Alliance and a Glioblastoma Bill of Rights with Our Brain Bank, to express a set of health care goals for brain tumor patients and caregivers to coalesce around and target rights-based advocacy work.
2020 Volunteer Leadership

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Levine Cancer Institute  
Forest M. White, PhD  
Massachusetts Institute of Technology
In our Donor Honor Rolls, we thank the individuals, teams, corporations, and foundations who have supported NBTS this year, helping to advance our mission and fuel the breakthroughs we need to find a cure.
2020 SIGNATURE EVENTS

2020 SIGNATURE EVENT TOP FUNDRAISING INDIVIDUALS

Bay Area Brain Tumor Walk: Lauren Kwist, $18,734

Boston Brain Tumor Ride: William A. Coffman, $22,145

Boston Brain Tumor Walk: Brett Johnson, $21,197

Central New Jersey Brain Tumor Walk: Orly Tabak Vallario, $11,225

Charlotte Brain Tumor Race: Tucker Windle, $22,390

Denver Brain Tumor Walk: Megan Boyer, $12,523

Florida Brain Tumor Walk: Stephanie Crenshaw, $1,485

Fort Worth Brain Tumor Walk: Shannon Bruce, $7,248

Long Island Brain Tumor Walk: Will Roth, $15,923

Maryland Brain Tumor Walk: Faith Armstrong, $9,044

Northwest Brain Tumor Walk: Tamera Meisner, $3,191

Phoenix Brain Tumor Walk: Scott Berger, $8,983

Race For Hope DC Walk/Run: Stephen Conley, $46,454

Philadelphia Race for Hope Walk/Run: Alysia Ferro, $31,980

RVA Brain Tumor 5K: Josh Spain, $19,798

Sacramento Brain Freeze: Courtney Gessford, $7,036

San Diego Brain Tumor Walk: Susan Mahoney, $4,438

Southern California Brain Tumor Walk: Ray Gayk, $1,025
2020 SIGNATURE EVENTS, continued

2020 SIGNATURE EVENT TOP FUNDRAISING TEAMS

$50,000+
reMARKable strides: $90,764
Team Oligo: $59,605
#LoganStrong: $58,769
Survivors: $53,827
Hope Brings Strength: $50,348

$25,000+
Cushman & Wakefield: $47,220
David Cook’s Team for a Cure: $42,513
Team Mawn: $34,309
Sharing Hope: $31,706
Team Kermit: $29,617
Rabbi’s Runners: $27,507
Spain’s Brain Train: $27,146
Will’s Tiny Tumorless Brain: $26,705
Team Asher: $26,220

2020 SIGNATURE EVENT TOP 10 RECRUITING TEAMS

David Cook’s Team for a Cure: 143 members
Noëlle’s Symphony: 130 members
Kevin + Chris Strong: 81 members
Team Dunn Second To None: 69 members
Team Ruchi: 60 members
kyle high club: 59 members
Team Holly Grace: 57 members
Survivors: 52 members
Spain’s Brain Train: 52 members
Team Oligo: 50 members
2020 COMMUNITY EVENTS TOP FUNDRAISING EVENTS

$50,000+
2020 Team Billy
Ride and Walk for
Research:
$68,436
2020 Madison
Brain Tumor 5K:
$51,178

$25,000+
2020 Mobile Primary Brain
Cancer Research Golf
Tournament:
$37,028
2020 Mimosa March
To Cure Brain Cancer:
$34,882
2020 Jones’n for a Cure
Golf Tournament:
$27,500

$10,000+
2020 Zimmermann Family
Ependymoma Awareness
Day Fundraising
$22,934
2020 Maryland Impact Golf:
$19,182
2020 Michael Cassidy
Shamrock N’ Run:
$16,030
2020 Swaterski Event:
$13,450

2020 Fight for the
Brain Happy Hour:
$26,634
2020 Papa’s
Ride 4 Dray:
$25,000

2020 Nasty Row to
Beat Brain Tumors:
$12,754
2020 Connecticut
Brain Freeze:
$10,793
2020 Joggin’ 4
the Noggin:
$10,450
2020 Shelby’s
“Brewerfest”
and Wine Tasting:
$10,324
2020 GBM
Foundation Events:
$10,000

Photo courtesy @katiemorrisonsportphotography
2020 GRAY NATION ENDURANCE TOP FUNDRAISING INDIVIDUALS

$20,000+
Kristen Sherlock, 2020+
TCS New York City Marathon: $24,960

$10,000+
Christa Policella, 2020+ TCS New York City Marathon: $13,678
Abby Clinton, 2020 Boston Marathon: $13,436

$5,000+
Jim Vant & Marv McGuire, 2020 100-Mile Walk: $8,576
Evan Martin, 2020 Tri for Trev: $8,000
Jamie Cuthbertson, 2020 Boston Marathon: $7,139
Katie Milam, 2020 Boston Marathon: $7,013
Erica Finamore, 2020+ TCS New York City Marathon: $6,464
Mark McGann, 2020+ TCS New York City Marathon: $5,592
Katherine Falcone, 2020 Gray Nation Endurance: $5,537

Michael Policella, 2020+ TCS New York City Marathon: $5,465
Rebecca Spicehandler, 2020 United Airlines NYC Half: $5,236
Marc Cashin, 2020+ TCS New York City Marathon: $5,212
Kirk Leach, 2020 Gray Nation Endurance: $5,001
2020 CORPORATE PARTNERS

$100,000+
Bayer Pharmaceuticals
Novocure

$50,000+
Black Diamond Therapeutics
Bristol Myers Squibb
Karyopharm Therapeutics
The GATE Foundation
Genentech
GT Medical Technologies
Valero Energy Corporation/Valero
Benefit for Children
Zallie-Somerset, Inc.

$25,000+
Cravath, Swaine & Moore LLP
Cushman & Wakefield
Northern Bank & Trust Company
University of Maryland School of Medicine—Brain Tumor Treatment and Research Center

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$10,000+
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Agios Pharmaceuticals
Barrow Neurological Institute
CoStar Group
GEICO Philanthropic Foundation
Highland Yard
Immunomic Therapeutics
Imvax
JBG SMITH Properties
Normandy Real Estate Partners
Penn Medicine
R&R Mechanical
Raymond James Financial, Inc.
Showalter Construction Co.

$100,000+
The Stringer Foundation

$50,000+
Rally Foundation for Childhood Cancer Research
Robert Connor Dawes Foundation
Robert I. Schattner Foundation

$25,000+
KM Legacy Foundation
The Gwen L. Kosinski Foundation

$10,000+
David S. Stone Foundation, Inc.
Iroquois Avenue Foundation
Josephine and Bernard Wilkinson U.S. Foundation
Stahl Family Charitable Foundation
Students Supporting Brain Tumor Research
The Charles & Lucille King Family Foundation
2020 INDIVIDUAL DONORS  Data as of December 31, 2020

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 the National Brain Tumor Society.

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Make it your legacy to conquer and cure brain tumors

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

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Shari Leigh Gordon
Sharon Campbell
Shauna Pendleton
Shawn M. Herlihy
Shelley and David Wolfberg
Shelley and Jonathan Isaacson
Shepard Spunt
Sheri Leiter
Sheryl and Craig Bacharach
Sheryl Sandberg
Sidney Suggs
Sinesia and William Karol
Sonia and Milton Greenberg
Sonia Rosenbaum
Sonja and Phillip Plant
Stan Oaks
Stella Tavilla
Stephanie and John Connaughton
Stephanie Pechner
Stephen and Mary Lanctot
Stephen Mugford
Stephen O’Brien
Stephen Schoener
Steve Barnes
Steven Brown
Steven S. Fischman
Steven Samuels
Sue and Sheldon Lewis
Susan and Derek Arndt
Susan Baucom
Susan Lasher
Suzanne and Jeffrey Bloomberg
Suzanne Peck
Tasneem Ghuman
The Chaiken, Beddow and Daczkowski Families
Thomas Coogan
Thomas F. Brinegar
Thomas Karol
Thurman F. Naylor
Timothy Donovan
Tom and Michelle Roloff
Tomoko Ozawa
Tracy Fischer and Cary Geller
Tracy Milcendeau
Trisha and Tim Beaudin
Valerie Farkas
Vangel R. Zissi
Venita Kent-Basham
Vincent Bilinsky
Vincent Browning
Vivian Bornfriend
W. Graham Smith
Wayne Long
Wendy and Lawrence Pizzi
Wendy Leuchter
Wendy Schluender
Whitney and Adam Hayden
William H. Connelly, Jr.
William Moseley
William Papp
William Rucker
William Saltzman
William W. Beddow
William W. Helman
Woodworth Clum
Woody Peterson
Zach Casagrande
The Board of Ambassadors of the National Brain Tumor Society (NBTS) is a newly created advisory body, comprised of NBTS supporters and friends, dedicated to advancing our mission.

Aaron and Kelly Theberge  
Chris Suplick  
Deborah and Lindsay LaRoche  
Diana and Matthew Gordon  
Jeff and Susan Davis  
Jim Clarahan  
Julie and Michael Durbin  
Lido Ramadan  
Mariana César de Sá  
Meghan Whaley  
Michael Corkin  
Michael Nathanson  
Ricardo César de Sá  
Stephen C. Conley

Members of the Catalyst Circle have made leadership gifts in support of the Nathanson Family Catalyst Fund for Brain Tumor Research. (NathansonFund.org)

Amy Null and Andrew Budson  
Andrew Merken  
Jeanie and Jim Kirkiles  
Judi and Edward Zuker  
Julie and Michael Durbin  
Lowenstein Sandler LLP  
Martin Bicknell  
Michael and Dawn Nathanson  
Michael and Lauren Corkin  
Michael Goss  
Ronald Rubin  
Sarah Durham and Craig Winer  
Sentinel Benefits and Financial Group  
Shikiar Family Foundation  
Steve and Melanie Sadler
2020 NATIONAL BRAIN TUMOR SOCIETY FINANCIALS

- 86% total program expenses
- 73% Other Program Expenses
- 13% Research Grants
- 9% Fundraising
- 5% General and Admin

Total program expenses represent 86% of the financials, with Other Program Expenses making up 73%. Research Grants account for 13%, Fundraising for 9%, and General and Admin for 5%.
## Statement of Financial Position

<table>
<thead>
<tr>
<th>Assets</th>
<th>12/31/20</th>
<th>12/31/19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>$8,059,747</td>
<td>$6,422,000</td>
</tr>
<tr>
<td>Investments</td>
<td>1,487,595</td>
<td>849,578</td>
</tr>
<tr>
<td>Pledges Rec, net</td>
<td>256,700</td>
<td>289,200</td>
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<tr>
<td>Prepaids</td>
<td>184,531</td>
<td>176,834</td>
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<tr>
<td>Long-term assets</td>
<td>44,569</td>
<td>50,356</td>
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<tr>
<td>Total</td>
<td>$10,033,142</td>
<td>$7,787,968</td>
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</tbody>
</table>

## Statement of Activities

### Revenue

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Events</td>
<td>$4,498,244</td>
<td>$8,438,324</td>
</tr>
<tr>
<td>Grants/Contributions</td>
<td>3,673,064</td>
<td>5,266,897</td>
</tr>
<tr>
<td>Bequests</td>
<td>665,657</td>
<td>250,000</td>
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<tr>
<td>Donated goods &amp; services</td>
<td>40,489</td>
<td>221,747</td>
</tr>
<tr>
<td>Other</td>
<td>68,697</td>
<td>33,770</td>
</tr>
<tr>
<td>Total</td>
<td>$8,946,151</td>
<td>$14,210,738</td>
</tr>
</tbody>
</table>

### Operating Expenses

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personnel</td>
<td>$4,180,836</td>
<td>$4,504,961</td>
</tr>
<tr>
<td>Research grants</td>
<td>968,121</td>
<td>1,592,534</td>
</tr>
<tr>
<td>Special Events</td>
<td>387,055</td>
<td>1,383,962</td>
</tr>
<tr>
<td>Professional Services</td>
<td>434,823</td>
<td>685,166</td>
</tr>
<tr>
<td>Travel</td>
<td>41,445</td>
<td>254,976</td>
</tr>
<tr>
<td>Systems and IT</td>
<td>422,378</td>
<td>273,007</td>
</tr>
<tr>
<td>Other</td>
<td>738,273</td>
<td>1,046,892</td>
</tr>
<tr>
<td>Total</td>
<td>$7,172,931</td>
<td>$9,741,498</td>
</tr>
</tbody>
</table>

### Change in Net Assets from Ops

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endowment &amp; Other revenue</td>
<td>17,591</td>
<td>60,124</td>
</tr>
<tr>
<td>Change in Net Assets</td>
<td>$1,790,811</td>
<td>$4,529,364</td>
</tr>
</tbody>
</table>