



National
Brain Tumor
Society



ANNUAL REPORT | 2020

Table of Contents

Vision, Mission, Values	3
A Letter to our Community	4
Progress in 2020.....	6
Volunteer Leadership.....	11
Donor Honor Rolls.....	12
Financials	28

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.

A LETTER TO OUR COMMUNITY

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.

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.

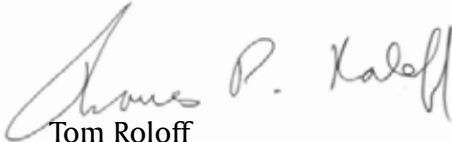
We launched new, promising research projects focused on pediatrics and adults. We virtually gathered with neuro-oncology leaders across major hospitals, the NIH, the FDA, and biopharmas to develop specific action plans to enable clinical trials to continue and telemedicine to improve. And the NBTS-supported 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



PROGRESS | 2020

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 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.
- 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.



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.



Change

Improving the Brain Tumor Treatment & Research Environment

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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Susan Pannullo, MD
Cord Schlobohm, DMD
Rabbi Eric Wisnia



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Birmingham
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University of Alberta

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Medicine
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University of Florida
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Levine Cancer Institute
Forest M. White, PhD
Massachusetts Institute of
Technology

DONOR HONOR ROLLS | 2020

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

2020 Fight for the
Brain Happy Hour:
\$26,634

2020 Papa's
Ride 4 Dray:
\$25,000

\$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 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 @katiemorrisonsportsphotography

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

\$10,000+

American Surgical Company
Agius 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.

2020 FOUNDATION PARTNERS

\$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.

Circle of Change Lifetime Giving of \$25,000+

Aaron and Kelly
Theberge

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***Make it your
legacy to
conquer and
cure brain
tumors***

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

Denise and Jeffrey Bein

Dolores and Jim Claeys

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Kenton Braun	Leda Asmar	Lois and Robert Annand	Marilyn Konefal	Melinda Dabbiere
Kevin Hurley				

Melissa and Frances Hopkins	Nancy and Ron Rovansek	Peggy Wilson	Rhoda Farber	Robert M. Kern
Melissa and Jonathan Silver	Nancy Dickmeyer	Penny and David Alschuler	Richard Burns	Robert McLeod
Melissa Mannion	Nancy Dougherty	Peter A. Wright	Richard Forde	Robert Rosen
Michael Allen	Nancy E. Pfund	Peter Lewis	Richard Granoff	Robert Slyker
Michael and Diane Hotchkiss	Nancy Samit	Philip Ivey	Richard Lewis	Robin and Lawrence Gitlitz
Michael Johnson	Natalie and Eric Boyd	Phillip Staples	Richard M. Lappin	Robin and Michael Winton
Michael L. Lieberman	Neal Levitan	Phyllis and Robert Yawitt	Richard Osney	Robin and Tom Oswald
Michael Rudman	Olivia Brown	Priscilla A. Partridge	Richard Schifter	Robyn and Bill Collins
Michael Thonis	Patricia and Thomas Plant	Pushpa Patel	Richard Weschler	Ronald Rubin
Michaela Cachia	Patrick Herron	Randall O'Deneal	Rick A. Stacy	Ronald Simon
Michelle Young	Patty Kleiber	Rebecca and Michael Neidorf	Rick and Staci Genderson	Roni and Lawrence Kosow
Monty Bennett	Paul Calvino	Rebecca Newland	Rob and Debra Burger	Ronna Martin
Morty Gudelsky	Paul Sasso	Regina Coppens and Steven Buchsbaum	Rob Lazarowitz	Ronnie Bretholtz
Mr. Larry Oxenberg	Paul Teti	Renee Limpawuchara	Robert E. Freitas	Rosalyn and Alan Geller
Nadia Ramadan	Pauline Elkin	Rhea and Deborah Krolikiewicz	Robert Greenhill, Jr.	Rose Heide and Gary Sweet
Nadine Berman	Peggy and John Mooney		Robert Hisaoka	Roy Kapani
	Peggy DeBerry		Robert J. Drabkin	
			Robert L. Salomon	

Russell Deyo	Sheryl and Craig Bacharach	Steve Barnes	Tom and Michelle Roloff	Whitney and Adam Hayden
Ruth Curtis	Sheryl Sandberg	Steven Brown	Tomoko Ozawa	William H. Connelly, Jr.
Ryan Steel	Sidney Suggs	Steven S. Fischman	Tracy Fischer and Cary Geller	William Moseley
Sabrina and Robert Nicholson	Sinesia and William Karol	Steven Samuels	Tracy Milcendeau	William Papp
Sandra Simon	Sonia and Milton Greenberg	Sue and Sheldon Lewis	Trisha and Tim Beaudin	William Rucker
Sasha Dorman and Seth Hamalian	Sonia Rosenbaum	Susan and Derek Arndt	Valerie Farkas	William Saltzman
Scott Mack	Sonja and Phillip Plant	Susan Baucom	Vangel R. Zissi	William W. Beddow
Serene Smith	Stan Oaks	Susan Lasher	Venita Kent-Basham	William W. Helman
Shari Leigh Gordon	Stella Tavilla	Suzanne and Jeffrey Bloomberg	Vincent Bilinsky	Woodworth Clum
Sharon Campbell	Stephanie and John Connaughton	Suzanne Peck	Vincent Browning	Woody Peterson
Shauna Pendleton	Stephanie Pechner	Tasneem Ghuman	Vivian Bornfriend	Zach Casagrande
Shawn M. Herlihy	Stephen and Mary Lanctot	The Chaiken, Beddow and Daczkowski Families	W. Graham Smith	
Shelley and David Wolfberg	Stephen Mugford	Thomas Coogan	Wayne Long	
Shelley and Jonathan Isaacson	Stephen O'Brien	Thomas F. Brinegar	Wendy and Lawrence Pizzi	
Shepard Spunt	Stephen Schoener	Thomas Karol	Wendy Leuchter	
Sheri Leiter		Thurman F. Naylor	Wendy Schluender	
		Timothy Donovan		

BOARD OF AMBASSADORS

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.

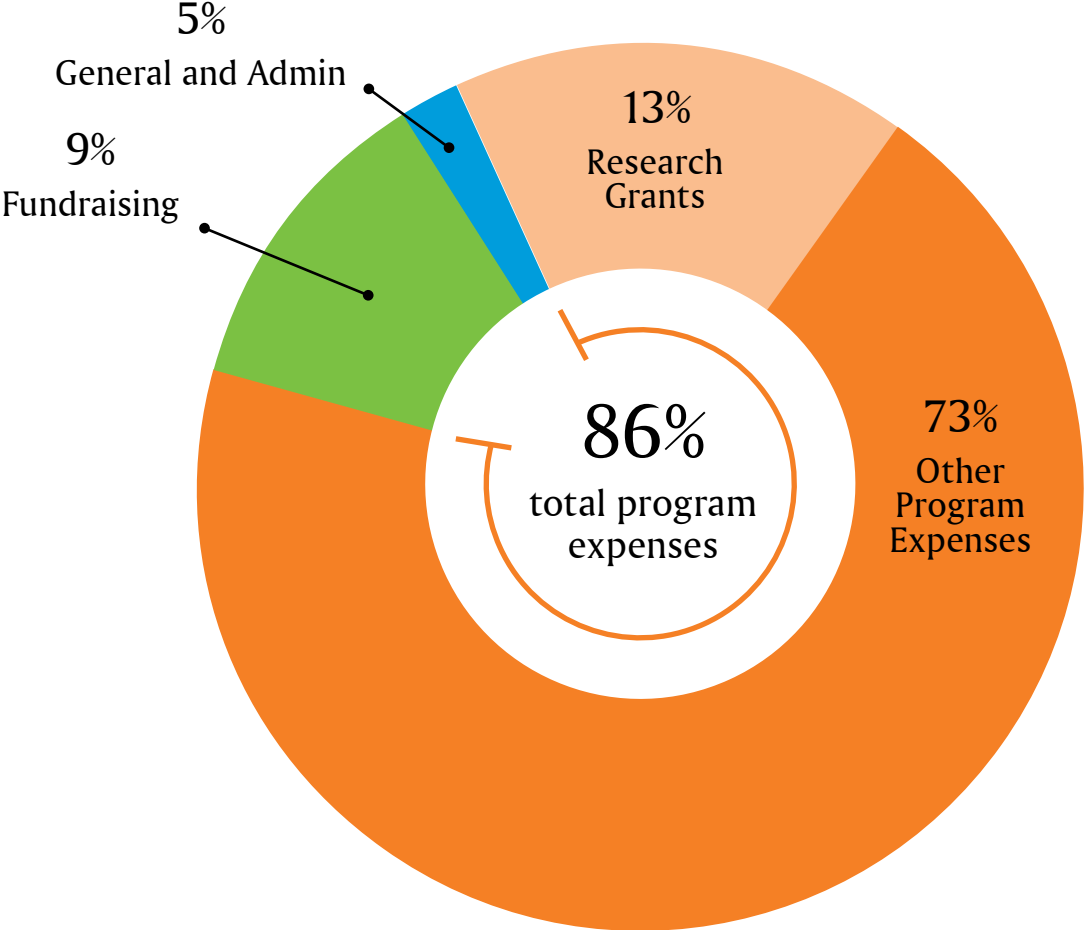
Aaron and Kelly Theberge
Chris Suplick
Deborah and Lindsay LaRoche
Diana and Matthew Gordon
Jeff and Susan Davis
Jim Clarahan
Julie and Michael Durbin
Lido Ramadan
Mariana César de Sá
Meghan Whaley
Michael Corkin
Michael Nathanson
Ricardo César de Sá
Stephen C. Conley

CATALYST CIRCLE

*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



Statement of Financial Position

Assets	12/31/20	12/31/19
Cash	\$8,059,747	\$6,422,000
Investments	1,487,595	849,578
Pledges Rec, net	256,700	289,200
Prepays	184,531	176,834
Long-term assets	44,569	50,356
Total	\$10,033,142	\$7,787,968
Liabilities		
AP & Accrued	\$242,579	\$439,129
Research Grants payable	500,000	500,000
Other Long-term liabilities	735,452	84,539
Total	\$1,478,031	\$1,023,668
Net Assets		
W/O Donor Restrictions	\$3,431,389	\$2,339,672
W/ Donor Restrictions	5,123,722	4,424,628
Total	\$8,555,111	\$6,764,300
Total Liabilities & Net Assets	\$10,033,142	\$7,787,968

Statement of Activities

Revenue	2020	2019
Events	\$4,498,244	\$8,438,324
Grants/Contributions	3,673,064	5,266,897
Bequests	665,657	250,000
Donated goods & services	40,489	221,747
Other	68,697	33,770
Total	\$8,946,151	\$14,210,738
Operating Expenses		
Personnel	\$4,180,836	\$4,504,961
Research grants	968,121	1,592,534
Special Events	387,055	1,383,962
Professional Services	434,823	685,166
Travel	41,445	254,976
Systems and IT	422,378	273,007
Other	738,273	1,046,892
Total	\$7,172,931	\$9,741,498
Change in Net Assets from Ops	\$1,773,220	\$4,469,240
Endowment & Other revenue	17,591	60,124
Change in Net Assets	\$1,790,811	\$4,529,364



National
Brain Tumor
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