



SOUTHEASTERN BRAIN TUMOR FOUNDATION'S

HORIZONS OF HOPE

QUARTERLY NEWSLETTER

RACE FOR RESEARCH

Join us September 23, 2023 for the 24th annual Race for Research at Atlantic Station!

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SCHOLARSHIP DOUBLES

This year the VOH program received double the number of applicants over last year!

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SBTF SPONSORS NREF AWARD

The SBTF awards a Young Clinician Investigator Award to a Northwestern University researcher

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Northwestern University

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LACE UP YOUR SHOES- RFR IS SEPT 23, 2023

On Saturday, September 23, 2023 the Southeastern Brain Tumor Foundation will celebrate our 24th annual Race for Research 1k/5k on the Green at Atlantic Station. Year after year we become more steadfast in our mission to offer scholarships, fund research, and provide support to anyone affected by a brain tumor.

Registration is open (sbtfrfr.com) and the only thing missing is you! Whether you want to join us on your own, as part of a team, or in a volunteer role, we welcome you with open arms. If distance is a factor we invite you to participate virtually.

We will celebrate our survivors at the Survivor Tree along with those lost whom left us with amazing memories on the Wall of Honor. There will be multiple award categories as well as plenty of entertainment for the family. Bring the kids too! We will have a tot-trot race for those 6 and under.

Please mark your calendars to join us, and help us raise funding for brain tumor research grants, and awareness to brain tumors.



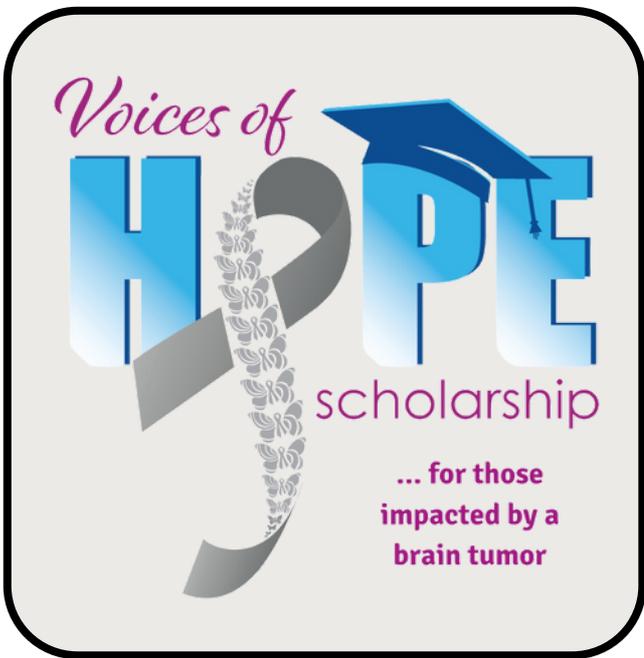
VOICES OF HOPE SCHOLARSHIP PROGRAM BREAKS RECORDS IN 2023

Our 2023/2024 SBTF Voice of Hope Scholarship Program officially closed on May 31st and we had a record breaking 47 applicants apply who have been directly impacted by their own brain tumor diagnosis or the diagnosis of another individual who has made a significant impact in their lives. The total funding amount was an incredible \$63,600. Based on the previous 2022/2023 academic year, this was just over double the number of applications (22) and nearly double the funding amount (\$35,500). We have seen a trend where the program doubles year over year.

Since the program's inception in 2019, we have awarded 76 scholarships totaling \$164,100!

While unfortunate that there is a need, it's simply amazing to see how the program has grown to support those who have dream of pursuing a technical, associates, bachelors, specialist or doctorate degree within the 50 United States and District of Columbia.

If you would like to find out more information on how to create a scholarship in a loved ones honor or for more information about the program, please go to sbtf.org/scholarships



SUPPORT GROUPS CONTINUE TO GROW

If you are a brain tumor patient caregiver, and are looking for a support group, look no further. Our bi-weekly Adult support group meeting and monthly Parent of Young Survivors meetings offer an opportunity to connect with other caregivers.

“The (bi-weekly) Support Group had an immensely positive impact on me. It provided a safe space to share my struggles and express my feelings with people who could understand my situation. It has also provided me with resources, advice, and encouragement. I’ve always felt welcome and it’s a place I felt seen, validated, and was never judged; especially invaluable during the hardest parts of our journey, when my husband Dave was in Hospice care”. Kayre tells us she wishes more caregivers would participate, and we do as well. We realize the role of caregiver provides little time to attend meetings like ours. That’s why the virtual platform allows you to attend for as much, or as little time as your schedule allows.



Support Group meetings provide a great opportunity to share experiences and garner support from others. In addition to inviting you to attend our meetings, we also can provide connections or links to other support group meetings conducted by various groups throughout the world. For more information, please email us at supportgroups@sbt.org

SBTF support group meetings have been offered since 1999! That’s twenty-four years of consistently providing an invaluable patient resource for the Metro Atlanta brain tumor community. The first meetings were held monthly and facilitated by then Board Member Judy Billingsley, RN, BSC, OCN, and research coordinator of the Emory University Brain Tumor Team. Our first monthly gatherings occurred at Cathedral of St. Philip in downtown Atlanta. Over the years, the monthly programs blossomed and were moved to Emory hospital conference rooms.

In 2020, COVID tried to interrupt our support group programs but instead increased our reach, our offering, and our purpose. However, it didn’t prevail. We expanded our partnership with the Piedmont Brain Tumor Center and developed two new programs: a Parents of Young Adult Survivors (P-Yas) and a Young Adult Survivor (YAS). We conducted meetings virtually, instead of Face to Face, and welcomed the connection with people outside the Atlanta Metro area. Our expanse of group members brought new ideas, strengthened connections, and provided great efficiencies of balancing Dr. appointments with caregiving, work, etc.



In 2021, another new program was launched which brought together brain tumor patients who were experiencing language and communications challenges associated with Aphasia. Aphasia has been associated with stroke, head injury and brain disease and treatment for these patient populations differs sometimes greatly. Having a support group specifically addressing the challenges associated with aphasia has been a Godsend for our brain tumor patients and their caregivers.

For 2023, yet another new program is in development, but you’ll have to stay tuned for more details.



SBTF AWARDS YOUNG CLINICIAN INVESTIGATOR AWARD

On Saturday, April 22, 2023, the Neurosurgery Research & Education Foundation (NREF) held a guest reception honoring its donors.

Mark William Youngblood, MD from Northwestern University was awarded the 2022-23 NREF & Southeastern Brain Tumor Foundation (SBTF) Research Fellowship Grant on behalf of the AANS/CNS Section on Tumors. Dr. Youngblood was awarded for his project titled “Molecular Markers of Meningioma Growth Arrest after HDAC Inhibition”. The project was sponsored by Craig Horbinski, MD, PhD.

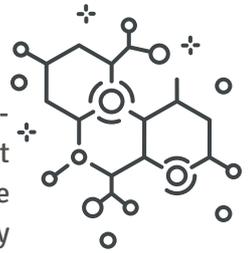
Dr. Constantinos Hadjipanayis, M.D., Ph.D, a Board of Directors member, attended the reception on behalf of the Southern Brain Tumor Foundation. We are honored to be able to provide grants for brain tumor research, and we could not do it without our supporters.



Northwestern University

Molecular Markers of Meningioma Growth Arrest after HDAC Inhibition

"The molecular events that cause meningioma formation and progression are increasingly well-understood, however effective chemotherapies remain elusive. Previous studies have shown that histone deacetylase inhibitors (HDACi) may hold promise, however additional pre-clinical tests are needed before this medication can be trialed in humans. In the present study, we will identify molecular biomarkers that predict response of meningioma patients to HDACi. Tumor cells from responsive and resistant patients will be compared to determine key distinguishing features, and in a similar fashion, cells will be compared before and after treatment to determine potential mechanisms of this drug. The results will lay essential groundwork for future clinical trials, providing key markers for prospective patient stratification, identification of potential synergistic co-therapies, and pathways of resistance."



SBTF Golf Invitational is a success!

CHIP IN FOR BRAIN TUMORS

The Southeastern Brain Tumor Foundation held its first “Chip in for Brain Tumors” Golf Invitational on Saturday, May 6th. The event was held at the beautiful Oconee Course at Reynolds Lake Oconee.

Team and individual registrations, sponsorships, and additional support levels were offered to allow us to raise money to continue the fight against brain tumors. The support was overwhelming with participants ranging from survivors, family, physicians, supporters, and a host of others affected by a brain tumor diagnosis.

A huge thank you to everyone who participated or simply donated. We raised \$18,000 that will be used to fund our mission to support the brain tumor community and find a cure for this disease.

A very special thank you to Dr. Jay McCracken who birthed the idea of the golf invitational. Dr. McCracken was instrumental in the success of the event, and we are grateful to have his support.





We salute and recognize brain tumor THRIVERS. Each and every day post-diagnosis is a day to celebrate and a day to share stories of Thrivership.

CHRIS OBER

“Shall I start from the beginning in 2012?”, says Chris Ober, an eleven-year brain tumor survivor.



“I met Chris about two years post initial diagnosis; Glioblastoma Multiforme (GBM)”, says SBTF Patient Advocate Geri Shaffer. “We connected, via the SBTF monthly support group meeting. By the time we met, Chris had already experienced recurrence, was enrolled in a clinical trial which involved calcium channel blockers and was on chemo. “How did you deal with the news of recurrence, and the subsequent treatment”, asked Shaffer. “Humor, positive thoughts/thinking, and faith played a big part in everything” says Ober. Additionally, Chris was able to return to work, which he thoroughly enjoyed, and work included working with FOX Sports production team and attending MLB Playoffs.

In 2013 Chris was traveling with the MLB playoff team at FOX Sports working with the production crew and shared a fond memory pertaining to a last minute on-air surprise birthday celebration for announcer Tim McCarver during an MLB playoff game. Finding and presenting a last-minute half-sheet sized birthday cake, on air, with 72 candles, a baseball diamond, and the words Happy Birthday Tim might seem simple; unless you had less than 24 hours to make it all happen and were in an unfamiliar city.



Some of you may also know Chris as the MLB iPad man. Fans thought “this guy is nuts, why would you take an iPad to an MLB Playoff?”. In fact, it was a clever marketing campaign which launched in the Fall of 2015 and included Chris. If you’re not familiar with iPadMan, you can learn about him with the link we provided in this article.

Fast forward seven years to 2022, Chris experienced a second recurrence, GBM reared its head again. The recurrence presented as changes in his sense of smell.

Subsequent scans reflected a mass which was much larger than expected. This second recurrence, and the unfortunate effects post surgery, took much longer to overcome. He lay in a coma for two weeks and in ICU for nearly a month. In December 2022 he moved to inpatient rehab. His leg muscles had atrophied, and he spent three months learning to walk again unaided by any medical device. Proton Beam Therapy was also an element of his recovery regimen.

Today, six months later, Chris Ober is back on the road and “thriving post diagnosis”. He recently traveled to Elmont NY for the 155th running of the Belmont Stakes which was broadcast live on FOX and hopes to travel with the MLB playoffs. The crews he worked with at FOX Sports over the years are his “second family”. Their watchful eye, and caring hearts haven provided priceless support for Chris. “ I have been given so much support through it all. I have a small roll in these productions, and I love taking care of the people”, says Chris. “Hopefully my role makes it easier for them to make a top tier live sports production.”



MESSAGE FROM THE PRESIDENT

In the early 2000's our signature event, the Race for Research, was the only planning necessary and vetting the research to fund was the only decision to be made. Now, twenty years later, the Foundation has grown tremendously- and so has the to do lists! Already this year we have hosted a Golf Invitational, organized, reviewed and scored scholarship applications, and are in the process of planning for the Race and Pickleball events.

We have strengthened relationships with the National Brain Tumor Society (NBTS) and other groups as well as continued to grow our support group offerings (did you read the article that something new is coming?) and patient programs. Not to mention the fact that we doubled the number of applicants for the Voices of Hope Scholarship program as well!

Growth is scary and exciting. Growth requires change and the ability to adapt. Growth requires work and dedication. The Foundation is strong in our dedication to the mission to end brain tumors, and is always looking for more people who share that passion. If you would like to become more involved in the mission, please contact us about volunteer opportunities throughout the year.

No longer is the only volunteer opportunity setting up for the Race for Research- as the SBTF expands so do the chances for everyone to make an impact. We would love to speak to you about the ways you can become involved and donate your skills.

If you are knowledgeable in Google products, social media, marketing, event planning, graphic design, database management or any other skills- let's talk!

Looking forward to the future,

Kelly Turner 

UPCOMING EVENTS

2023

- July 19: GBM Day
- Sept 23: Race for Research
- Nov 4-5: Pickleballin' for Brains

Want to find out more about our Events?

Visit our website events page!

<https://sbtf.org/brain-tumor-events/>

LEARN MORE AT [SBTF.ORG](https://sbtf.org)



EVENTS BENEFITING THE SBTF:

➤ RACE FOR RESEARCH

- Date:** September 23, 2023
- Location:** Atlantic Station, Atlanta GA
- Website:** [sbtfRFR.com](https://sbtf.org)
- To participate:** Register online

For questions, email events@sbtf.org

➤ PICKLEBALLIN' FOR BRAINS

- Date:** November 4-5, 2023
- Location:** Cresswind Twin Lakes, Hoschton GA
- Website:** **Coming soon!**
- To participate:** Email events@sbtf.org

