

SSBTR
Meeting Minutes
Monday, February 8th, 2021

Meeting Called to Order at 4:30 by Executive Student Co-Chair **Shaun Karakkattu**

- **Attendance** - Wendy Kaye, Marty Kaye, Radia Wong, Shaun Karakkattu, Sam Kreitzman, Robb Sinert, Ron Hirsch, Hope Dolcetti, Steve Glassman, Isa Carrillo, Ava Ashtiani, Austria Ashtiani, Landen Waymire, Lilli Mueller, Eliana Sarfati, Alanna Goodman, Aiden Carpenter, Amanda Xu, Anakha Vargheese, Anjelica Carden, Avantika Aggarwal, Ayush, Bonnie Mueller, Christian Waymire, Claire Frey, Daryl Ijoala, Gabby Wernick, Hafsah Ahsan, Jennie, Kaiya Noe, Max Cogan, Nicholas Ward, Nishka Kanaka, Omina Nematova, Owen Alzubi, Paula Phan, Richard Perkins, Sajjan, Shria, Tanya Agarwal, Wid Alsabah, Mark

- I. Welcome and Introduce Co-Chairs
- II. **Treasurers Report** - \$76,553 currently in the account
- III. **Savers Fundraiser** - 42 Black Bags (33 gallons), 33 White bags (13 gallons), and 20 boxes
 - The end goal of 80
 - Drop off at Wendy, Landen, and Shaun's Houses
- IV. **Cure-A-Thon**
 - Feb 27 : March 5- Silent Auction Week
 - Feb 27 : SSBTR- Cure Run 5k or 1 Mile Walk- 10 am- Live event
 - Feb 28 : Entertainment & former Co-Chairs & Sponsors- 4:30 pm
 - March 1 : Memory Boards - 4:30 pm
 - March 2 : Survivors- 4:30 pm
 - March 3 :Among Us Game- 4:30pm Live
 - March 4 :Game Night- 4:30pm Live
 - March 5 :Golf Royal- 4:30pm

 - Silent Auction – to run for 1 week
 - 1st Day - Walk/Run and Registration
 - Entertainment - Pre-recorded Musicians
 - Video Game Tournament - Among Us Twitch Stream w/ Landen Waymire
 - Memory Boards – Pre-recorded Collection of photos and notes

- Brain Tumor Survivor Videos - Collection of Videos posted on YouTube
 - Golf Tournament: Steve Glassman vs. Sam Kreitzman
 - Kahoot Game - Live game night
 - Greetings from Past Co-Chairs – pre-recorded
 - Sponsor Acknowledgement throughout the entire event
- V. Mask Sales - Sold 5 more this week
- More Medium and Larges Available (will also be sold during Cure-a-thon)
- VI. Upcoming Fundraisers - **Lilli Mueller** is holding Valentine's Day Bake sale with Notre Dame Prep
- **Kailey Holm** is holding a Facebook Fundraiser - raised \$250 so far
 - **Alanna Goodman** organizing a **Portillo's Fundraiser** on February 12th from 5-8 pm MUST PRESENT FLYER PRESENT (paper or digital)
- VII. **U of A** is hosting a presentation with an Oncologist as well as other medical events
- VIII. **Next Meeting** - February 15th is our Live ZOOM Brain Tumor Surgery Extravaganza – meeting starts at 8:30am followed immediately by the surgery
- IX. Introduction of **Danielle Leach** from National Brain Tumor Society (NBTS)
- Chief of Community and Government Relations in Washington, DC
- X. Danielle Leache's Presentation
- Lost her 5-year old child to Glioblastoma
 - Continually working with Government Agencies and Congress on matters of Cancer Funding and Brain Tumor Research.
- A.) NBTS
- NBTS has had longstanding support from SSBTR
 - Long and accomplished history within Brain Tumor Research
 - Spearheaded Action Committees with matters of Brain Tumors
- B.) Cancer Research Program - Deals with matters of Brain Cancer and Pediatric Brain Tumors
- C.) Childhood Cancer STAR Act - Aided by Congress with \$30 million to fully fund STAR Act for a 3rd consecutive year
- Bio specimen work through STAR Act that has a big influence on childhood brain cancer
 - Childhood Cancer Data Initiative - Established more efficient ways to share and utilize childhood cancer data in research efforts
 - \$50 million provided by Congress to fund a second consecutive year
- D.) Clinical Treatment Act - Ensures coverage of medical costs associated with clinical

- trial participation for Medicaid recipients
- Clinical Treatment Act included in Medicaid
- Glioblastoma Awareness day passed by the Senate and House resolution introduced ‘
- Led to funding and widespread awareness

E.) Advocacy Impact 2020 -

- Efforts to address pediatric cancer drug shortage
- Helped to fund Project Hope/Car
- Glioblastoma Therapeutics Network established
- May is Brain Tumor Awareness month
- Childhood Cancer Awareness month
- Kids First 2.0 Reintroduction - funding stream for pediatric disease
- PPE petition for clinicians and patients
- Head to the Hill - converted to completely virtual due to pandemic
 - Over 1,500 advocates send over 5,000 messages to congress emphasizing medical research funding for Brain Tumors
 - Over 600 Brain Tumor patients, caregivers, medical professionals, industry partners participated in 2020
 - This resulted in 50 virtual meetings with the House of Representatives

F.) Upcoming Events and Call to actions -

- May 2nd - NBTS Walk and Race for Hope – Washington, DC
- May 4th - Head to the Hill
- May = Brain Tumor Awareness Month
- NBTS Unites Advocacy Network
 - One of the most active networks

G.) Champion Building program - Pipeline of Relations within the Capitol

- Committee depends on which congressmen NBTS works with
- 90% of work on The Hill is follow up - constant stream of communication

Thank you to Danielle Leach for such an enlightening presentation to SSBTR

Follow NBTS social Media

Attend Head to the Hill on May 4th

XI. Meeting ended at 5:20 by Executive Student Co-Chair **Shaun Karakkattu**

Respectfully Submitted,

Isa Carrillo