# EURotransmitter Communicating our message.

**Announcements and Event Updates** 



# Please join us for the CBTF Gala

WHEN: Saturday, November 9, 2019, 7:00 PM to 11 PM WHERE: Glenview Mansion at the Rockville Civic Center

Join us for an evening of dining, dancing, live music, auction and casino games. This year at our fundraiser we will acknowledge organizing members of the Clarksburg HS Dance Marathon and several medical professionals. Please join us to cheer our honorees on and help us celebrate all of the individuals and groups that support the cause.

If you are interested in helping with the event, finding sponsors or attending, email us at cbtf@childhoodbraintumor.org.



The ninth BeAMYazing triathlon has wrapped up and it was notable for many things. The weather presented big challenges. It was 57 and rainy, as in *drenching*, for much of the race. It was an endurance contest.

The kids got so many extra-special, enthusiastic hugs and congratulations from parents and brothers and sisters, just for finishing. There were some tears and some exhaustion, as well as shivering racers and volunteers. It was really tough, but it brought out the best in the kids and,

even better, in the parents.

Our organizing committee of adults and high school students did a great job again. We had 140 volunteers and 181 racers who showed up on race day and finished the course. Ten of those racers were scholarship kids who were coached again by a high school triathlete. For most of them, training for the tri is the first time they've ever had a swimming lesson.

Nissan was a new sponsor this year, at the top level of \$5,000 and we received the same from Microsoft, a returning sponsor. Hopefully, we will pass along a healthy donation to the Childhood Brain Tumor Foundation, to supplement the \$125,000 raised in the first 8 triathlons. If you

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## Superheroes 5K and Kids Run, 2020

We have a tentative date for the 2020 spring 5K event, Sunday, April 19. Due to the enthusiasm for the 2019 venue, we will hold the event at Sligo Creek Parkway. More information will be available in a future newsletter and on our website. The registration site will be announced in a future newsletter and on our website. Join us for the event, create a team for participants or raising funds.

#### CBTF Raises Funds for Research

Funds raised benefit pediatric brain tumor research and other CBTF programs.

#### The Childhood Brain Tumor Foundation

Our mission is to support and fund basic science or clinical research for childhood heightening public awareness of this devastating disease. and improving the quality of life for those that it affects by funding vital research initiatives.



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The "Remembrance" and "Honor of" recognitions will be included in our full fall and spring editions. Thanks you to all!

#### **Board of Directors**

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## Be AMYazing, Reston Youth League Triathlon

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would like to donate, it can be done through the website at www.restonyouthtri.org.

A note received from one of parents says it all:

Dear Amy's Family and Amy's Amigos,

Thank you very much for creating a wonderful event to honor and celebrate your daughter and friend, Amy. My two children, John and Egan Delaney, ages 8 and 6 participated in their first triathlon this

weekend and were beaming with excitement and pride when they finished. My daughter, Egan, last to finish in her age group, was shivering before her swim and tearful during transitions, but swam, biked and ran with purpose and pride.

Egan was diagnosed with Acute Myeloid Leukemia when she was 8 weeks old. We are fortunate that she is now a happy and healthy 6-year-old girl and could not have imagined the feeling she (and we as parents) would have when she crossed the finish line. She had such enthusiasm recounting the twists and turns during the race and the decisions she made on how to keep moving to make it to the finish. Both she and her brother are ready to signup next year!

Thank you again for all you did to make this race "Amyazing."

Jody Delaney

Let CBTF know if you are interested in raising funds for research or our other important programs!! CBTF@childhoodbraintumor.org



## CBTF Website News!

In the fall of 2019, the Childhood Brain Tumor Foundation will soon have a new website. We hope our constituents will email us to let us know some of their interests for articles, information and stories as we build the site and add new information.

Our domain link and email address will remain the same.

Community
Representatives
Ali-Gator, Jarrod Aucoin
BeAMYazing
Run with the Saints

Mary T Callahan, TX Tierney Callahan, TX Doug DeFeis, FL Lydia DeFeis, FL Killeen Family NJ Alyssa/Danielle Lyon Cady Lyon, MD Kate Lund, WA Pat Macy, NY Barbara Norris, MA
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Susan M. Young, MD
Nancy Ward, IL
Susan M. Young, MD



The 19th International Symposium on Pediatric Neuro-Oncology

The Childhood Brain Tumor Foundation will be a Silver sponsor for the 19th International Symposium on Pediatric Neuro-Oncology. Meeting to be held: June 21 to June 24, 2020 in Karuizawa, Nagono, Japan.

As always the ISPNO brings together clinicians, researchers, allied health professionals, and experts.

# NCI-COG Pediatric MATCH trial to test targeted drugs in childhood tumors

https://www.nih.gov/news-events/newsreleases/nci-cog-pediatric-match-trial-testtargeted-drugs-childhood-cancers

Drug Delivery Approach Shows Promise for Treating Deadly Brain Tumor in Children

By Jim Stallord, MSKCC, June 2018

https://www.mskcc.org/blog/drug-delivery-approach-shows-promise-treating-deadly-brain-tumor-children

If you are interested in learning more about the Childhood Brain Tumor Foundation, Inc.,

Please contact: E-MAIL: cbtf@childhoodbraintumor.org or jeanneyoung@childhoodbraintumor.org (<u>E-mail preferred</u> due to high volume of robo-calls)

TELEPHONE: 877-217-4166 or 301-515-2900

# Resources, Give2Charity, Thank You

## **IEP and LD Resources**

### **Helpful Resources**

Books purchased via **LD Online** will help support their online efforts:

http://www.ldonline.org/profbooks/c667/

Other online resources are available via the above URL: LD Basics, ADHD Basics, Teaching kids with LD, Home to School Connections, book list for children and other interesting features.

Wrightslaw: From Emotions to Advocacy Wrightslaw: Special Education Law
By: Peter W. D. Wright, Pamela Darr Wright

**A Guide to Collaboration for IEP Teams** By: Nicholas Martin, M.A.

A Parent's Guide to Special Education By: Linda Wilmshurst, Alan W. Brue

The Complete IEP Guide: How to Advocate for your Special Ed Child

By: Lawrence M Siegel

Meeting the Challenge: Special Education Tools That Work for All Kids

By: Patti Ralabate

**National Education Association** 

**Negotiating the Special Education Maze**By: Winifred Anderson, Stephen Chitwood, Deidre Cherie Takemoto

**For Mail-In donations**, please provide names of honoree memorial donations and the address for us to send an acknowledgements or just not if your donation is for general support

Please make checks payable to:

Childhood Brain Tumor Foundation or CBTF 20312 Watkins Meadow Drive

Toll free: 877.217.4166

Germantown, Maryland 20876

The Childhood Brain Tumor Foundation is dedicated to funding research for all pediatric brain tumor types.

Please contact us if you have any questions:

cbtf@childhoodbraintumor.org

Link is for general donations, the Register button will be updated and open for gala registrations.

To make a credit card donation to our cause, visit our secure website in the Support Us section:

www.childhoodbraintumor.org

Go to the 'Support' page and locate the *Give2Charity Online* button:

(Cards Accepted: Discover, MC, VISA, and AE) CBTF also accepts registration payments for the annual gala online. Be sure to include in the message box (number of tickets, names for ticket holders, and any additional donation). Tickets will be sent to the donor, unless noted as a donation in support of the event toward research.









Campaign donations may be made for the United Way (**UW**) through the "donor option" or "donor choice."

## **Vehicle Donation Program**



CBTF accepts vehicle donations. Help make a difference, donate online or call 877-999-8322 and designate the Childhood Brain Tumor Foundation as your charity of choice.

The service is totally free and includes convenient pick-up of your car, truck, or RV anywhere in the U.S.

QUICK FACTS FOR DONATING: You are eligible for an itemized TAX DEDUCTION. Find out details by checking the Foundation Web site: <a href="http://www.childhoodbraintumor.org">http://www.childhoodbraintumor.org</a>



## Thank you from CBTF

## Thank you

FD Associates, Inc.
Be AMYazing
Clarksburg HS Students and Staff
Roger and Bashi Packer
John Paul II School

#### **CBTF Sponsorship:**

2019 Society for Neuro-Oncology International 2020 International Symposium on Pediatric Neuro-Oncology

## **Upcoming Events**

- ♦ Education and Updates: Childhood Brain Tumors (TBD)
- ♦ CBTF GALA, November 9, 2019, Glenview Mansion, Rockville
- Annual Superheroes 5K and Kids Run—Spring 2020

Please contact us if you are interested in helping with any of our events! Sponsorships are always appreciated.

We will have a document to help you team build for our race this spring.

## Germantown, MD 20876 20312 Watkins Meadow Drive The Childhood Brain Tumor Foundation



Address change requested

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included in our full fall and spring editions. Thanks you to all! The "Remembrance" and "Honor of" recognitions will be

Please let us know if your address has changed. sponsorships from individuals and corporations. Tumor Foundation. e are funded through contributions and This newsletter is a free publication of the Childhood Brain

services to help with our operations. commentary or information for this newsletter, or volunteer We welcome any donations in the way of financial support,

tumors. Every year the requests continue to grow, prognosis and quality of life for children suffering from brain IRS 501(c)(3) whose mission is to raise money to improve CBTF is a tax-exempt, not for profit foundation

we need your support. Help children with brain tumors.

A big thank you to all of our scientific advisors. Grants funded in 2019 will be announced in the fall.

# 25 Years of Excellence

Thank you to all of our supporters, near and far! of excellence, continue to fund programs and research It is through your support we

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Their generous support is deeply appreciated. Thank you to the Rocking Moon Foundation.

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