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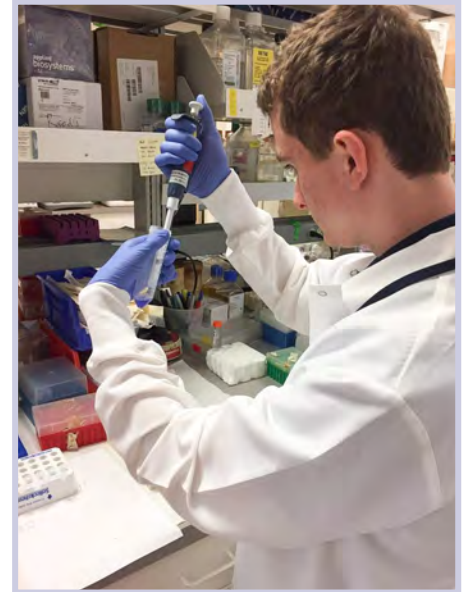
Feature Article

GOING FULL CIRCLE

by Camden Wiseman

I turned 18 this summer but there was a time when my parents questioned if I would ever reach adulthood. When I reflect on my experience as a brain tumor survivor, there's no escaping the difficult years of chemotherapy treatments, surgeries, and time spent at Children's National Medical Center. However, through those difficult times, I've discovered talents and opportunities that may not have otherwise been revealed to me. My experience as a cancer patient has changed the trajectory of my life in challenging yet amazing ways.

The Childhood Brain Tumor Foundation has been a constant presence since my family turned to them for support within months of my optic nerve glioma diagnosis. Ms. Young provided my parents with medical information, vision impairment resources and emotional support. I have grown up being involved with CBTF as a cancer survivor and more recently as a volunteer. I am honored to serve as student ambassador and and happy to share my story, *(continued on page 3)*



THE CHILDHOOD BRAIN TUMOR FOUNDATION

25th Anniversary Gala

November 10, 2018 @ 7pm - 11pm
Madame Tussauds, 1001 F Street NW, Washington, DC



Madame Tussauds
WASHINGTON DC

Join us for an exciting event with plenty of photo opportunities with your favorite figures.

This year we will celebrate and acknowledge 25 years of dedicated efforts of the Childhood

Brain Tumor Foundation, along with special honorees, including Dr. Gilbert Vezina, of Children's National, Hannah Becker (volunteer), Be AMYazing! Reston Youth League, (founders) and the Neurosurgery Departments from: Children's National Medical Center, Pediatric Specialists of Virginia, Medstar Georgetown Neurosurgery, and Johns Hopkins Hospital.

PLEASE visit our website for more information about the Gala fundraiser event, to help sponsor our event and for guest registration. Questions? Email us at cbtfmd@aol.com.

CBTF RAISES FUNDS FOR RESEARCH, SUPPORTS THE ISPNO, AND HOSTS A FAMILY CONFERENCE DAY

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 brain tumors. We are dedicated to 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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Next Edition: Report about the ISPNO, Family Retreat, and funded grants for 2018, update on our annual spring Superheroes 5K.

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CBTF ANNUAL GALA –SPECIAL ANNIVERSARY EVENT AT MADAME TUSSAUD'S

THE CHILDHOOD BRAIN TUMOR FOUNDATION
celebrates 25 years

of helping to advance medical research, assisting families with information, and forming a community of support for those touched by childhood brain tumors

Save the Date
and join us
NOVEMBER 10, 2018
7PM-11PM
Madame Tussaud's
WASHINGTON DC
for our
25th Anniversary Gala

Visit the Foundation website:

<https://childhoodbraintumor.org/25th-anniversary-gala>

For details about the Gala. Committee members are listed, the online registration form is available and may be downloaded and mailed for participants that prefer to send a check.

In addition, sponsor your favorite figure at Madame Tussaud's, adding to the event proceeds that will support important research initiatives.



The Childhood Brain Tumor Foundation was pleased to be a **Silver Sponsor** of the 2018 International Symposium on Pediatric Neuro-Oncology. The meeting was held in Denver, Colorado on June 29 - July 3, 2018. More will be included about the ISPNO in our next newsletter edition. It was a wonderfully, informative conference.

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

(E-mail preferred due to high volume of robo-calls)

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

Volunteers welcome!

GOING FULL CIRCLE

(continued from page 1)

especially some uniquely positive aspects of my journey.

When I was diagnosed, I did not have any of the typical brain tumor symptoms such as headaches or seizures. My parents noticed that one of my eyes seemed to be protruding more than the other. As a precaution, they took me to an ophthalmologist who observed that my optic nerves had an unhealthy color. He made a phone call and later that afternoon I was having a CAT scan at the hospital. We learned that I had optic nerve glioma that day with hand motion only vision in my left eye and some impairment in my right eye. After surgery to implant a broviac catheter, I began my first chemotherapy regimen of carboplatin and vincristine. During this time, I had MRIs every three months and a craniotomy to drain a cyst near the optic nerve of my good eye. The treatments worked, and after a year and a half my tumors were reduced drastically in size. My catheter was removed, and I enjoyed a brief period off treatment.



Follow-up MRI scans about a year later revealed tumor enhancement and growth. I had surgery to implant a port-a-cath and began my second chemotherapy regimen of carboplatin and vincristine. It worked well again and stopped the tumors from progressing. I had my catheter removed and was monitored every three months through neuro-oncology visits and MRI scans. Unfortunately, these scans showed renewed tumor activity after a short time. I started an oral chemo medication called Temodar. The good news was that my mom could give the pills to me at home. The bad news was that I couldn't swallow pills, so she mixed them into applesauce that tasted terrible. The third chemo-

therapy regimen was the charm and I have been off treatment for many years. We celebrated every milestone as I moved from MRI scans every three months to six months to currently once a year.

There was considerable downtime at the hospital during treatments and at home when I was immunosuppressed, so my family played a lot of games. I discovered a passion for strategic board games. Not only did I enjoy playing them, but I was really good for my age and could often beat my dad. I developed a special affinity for chess. The board and pieces were high contrast and easy to see despite my vision impairment. I also liked how each game was different from the next with endless possibilities. I started attending the youth program at the U.S. Chess Center and joined my elementary school chess club. I competed in local tournaments and progressed to state and national events. I won the Virginia scholastic championship in 3rd grade and have placed in the top ten at state and national scholastic tournaments for several years. I achieved Expert title last month with a 2000+ rating and am already working on my next goal to become Master. I often wonder if I would have discovered chess if it hadn't been for my cancer diagnosis and treatment.

In 2017, I saw an opportunity to combine my love of chess with giving back to an organization that has done so much for me. My friends are founders of Chess4Charity, a nonprofit that raises money for charities through a semi-annual chess tournament. As an elementary and middle school student, I had participated in these tournaments as a player and volunteer. I partnered with them to designate CBTF as beneficiary of their 2017 tournament that raised nearly \$8,000. Mr. and Mrs. Young attended the event and spoke to participants about CBTF's mission. It was gratifying to be able to promote cancer research through chess.

(continued on page 4)

GOING FULL CIRCLE, RECENT EVENTS, UPCOMING EVENTS

My experience as a cancer survivor has also presented me with unique summer opportunities. I participated in the FDA's Summer Scholars Program with their Oncology Center of Excellence in 2017. I learned about the world of cancer drug development from many perspectives including the research, clinical, regulatory, policy, and commercial aspects of development, through site tours and lectures. Interning at the FDA showed me that there are many ways to get involved in cancer research, not only as a scientist but as a businessperson. As a cancer survivor, I contributed my first-hand knowledge of the experience of cancer patients, culminating in a presentation on my last day. In this way, I provided the other interns and FDA employees with a more complete understanding of what it means to have cancer.

I enjoyed my time at the FDA and was eager to apply this knowledge to hands-on cancer research. I am doing exactly that this summer at the Center for Cancer and Immunology Research at Children's National Medical Center. Dr. Brian Rood has been my oncologist for over a decade and knows me well. When he learned of my computer science skills, he offered me the opportunity to work with his team on bioinformatics research. I have many responsibilities as an intern including running GATK (Genome Analysis Toolkit) workflows needed to search medulloblastoma whole-genome-sequence reads for DNA mutations and log them in databases. These mutations have the potential to create unique tumor specific proteins which we can find using the databases I create, and the output of a machine called a mass spectrometer which analyzes proteins. While my end goal for each tumor sample is to arrive at a functional database, I'm also mindful of the amount of time and user input required to run each sample. To that end, I strive to make the workflow as efficient as possible by using GATK's WDL tool, which parallelizes the workflow tasks. With WDL, I made the Mutect2 phase of analysis about six times faster while maintaining the same level of accuracy. Similarly, I'm also rewriting old scripts to be more adaptable when we move on to analyze new samples.

After interning for a few weeks, Dr. Huizhen Zhang asked if I would like to assist her in her lab work. I was thrilled to have the opportunity to take on a new challenge. She tasked me with "splitting" or sub-culturing cells, taking one flask of medulloblastoma cells and transferring them to new flasks so that they could keep growing. I used a 1:3 split ratio, meaning that the cell volume was split equally from one flask to three. I also had to add a Trypsin and EDTA solution to each flask, which prevents the cells from sticking to each other and to the flask. The entire process was very precise. I used extreme caution at every step to ensure that the cells remained sterile. I even had to look at the cells through a microscope to ensure that they were floating and not clumped together.

At the end of July, Dr. Zhang informed me that the cells I had cultured were healthy. She invited me to come back and perform PCR. I then used a gel to amplify specific sequences in the cell's DNA. At that point, the sample I had worked with was almost ready for a complete sequencing. The sequencing data gathered would then be passed on to me to analyze using the GATK workflow. I was amazed at how involved the entire process is and excited to participate in it from start to finish (from culturing cells to a protein database).

I would like to thank Dr. Brian Rood, Dr. Samuel Rivero-Hinojosa, and Dr. Huizhen Zhang for the opportunity to work by their side this summer. The guidance and independence they have given me has allowed me to make a personal contribution to cancer research. It has been a unique experience to go full circle from patient to researcher, one that has reinforced my commitment to cancer research advocacy in the future. §

Recent Events

Education and Updates: Childhood Brain Tumors
Saturday, July 14, 2018

CBTF Silver Sponsorship:

International Symposium on Pediatric Neuro-Oncology

Upcoming Event

CBTF Party
November 10, 2018
Madame Tussaud's



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



Please email us with questions: cbtf@childhoodbraintumor.org
To make a donation to our cause, visit our secure website:
www.childhoodbraintumor.org and visit 'Support CBTF' page

Be AMYazing! Reston Youth Raised \$25,000 in May for DIPG



Lizzy Shaw, Lindsay Asmussen, Jeanne Young, Lindsey Hirshfeld, and Yara Bawab,

The Be AMYazing! Reston Youth Triathlon was held this past May for the 8th year in a row. The total amount raised in those 8 years is \$125,000. Adding to the amount raised, participants raised money for CBTF on their own, which was a new approach this year. There were over 300 participants ages 6 - 15. The event was organized by teen chairs from South Lakes High School with support by adults. Funds have been dedicated to research grants for diffuse intrinsic pontine glioma (DIPG), selected by the Foundation under advisement of our expert scientific advisory.

This summer, CBTF selected two excellent DIPG research grants, one from University of Virginia and another from Texas Children's/Baylor. We look forward to sharing more information in our fall newsletter. Thank you from CBTF, we appreciate all that you do!!

The Be AMYazing! Reston Youth Triathlon was held this past May for the 8th year in a row. The total amount raised in those 8 years is \$125,000. Adding to the amount raised were participants raising money for CBTF on their own, which was new this year. There were over 300 participants ages 6 - 15. The event was organized by teen chairs from South Lakes High School with support by adults.

'Targeting neuronal activity-regulated neuroligin-3 dependency in high-grade glioma' has been scheduled for Advance Online Publication (AOP) on www.nature.com at 1800 London time / 1300 US Eastern Time on 20 September 2017.

Opinion | When cancer is in the 'whisper' stage, listen to it — even it means finding another doctor

Please support the Childhood Brain Tumor Foundation

Visit our **GIVE ONLINE** donation button:
<https://www.givedirect.org/donate/?cid=1605>

Be part of the solution in helping fund vital research initiatives cure childhood brain tumors!

*Ella Day
Jackson Dundon
Beverly Koren
Samuel Lunn-June 15*

*In Honor of
The CBTF Advisors
and
Ad Hoc Reviewers*

GRACIOUS GIVING, THANK YOU FOR YOUR SUPPORT!

(877)217-4166

Funding scientific research for this devastating disease



www.childhoodbraintumor.org
Together, Reaching for a Cure
Childhood Brain Tumor Foundation



Proud participant in the Combined Federal Campaign

Thank you to our friends who donated through workplace charitable giving campaigns this year, inclusive of the **CFC, Maryland Charity Campaign** and other independent campaigns.

The Childhood Brain Tumor Foundation, friends and families are **very grateful** of your support.

(CFC National) **12035**

Campaign donations may be made for the United Way (UW) through the "donor option" or "donor choice." Please check with your employer in reference to **UW** campaigns. **You may write us in as your choice.**

Maryland Charity Campaign

The Childhood Brain Tumor Foundation participates in the **Combined Federal Campaign (CFC) and Maryland Charities**. Check our Website in the late summer or fall for our confirmed designated numbers.

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: <http://www.childhoodbraintumor.org>

Stock Donations

If you would like to make a stock donation, contact us: cbtf@childhoodbraintumor.org

Our treasurer will provide you with the necessary details to proceed with your donation.

Thank you.

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

There are two easy ways to make a donation:

GIVE ONLINE: Visit our secure website: www.childhoodbraintumor.org
Go to our **Support page** and click on the **Give2Charity button.**

(Accepts Discover, MC, VISA, and AE)
or

BY CHECK: Made out to **CBTF**
Send to: **CBTF**

20312 Watkins Meadow Drive
Germantown, MD 20874

THANK YOU FOR YOUR SUPPORT!

Gift Matching Opportunities

Many companies offer a matching gifts program to support charitable organizations.

Your human resources department can tell you if such a program exists at your company. Ask them about the form that can be sent to the Childhood Brain Tumor Foundation reporting a contribution (donation or event contribution). The form states that they will match your contribution.

We return the form to your employer with the proper acknowledgment required information.

Our website: www.childhoodbraintumor.org

Bequests, Planned Giving, and Trusts

Through a trust, bequest, or planned giving you can contribute to furthering the future research and programs of the Childhood Brain Tumor Foundation, Inc. By including the CBTF in your estate planning you can minimize your taxes.

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Include your E-mail address and name/address: _____



The Childhood Brain Tumor Foundation
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Address change requested



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CBTF
25th GALA
November 10



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