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.

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 am happy to share my story, (continued on page 3)

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 cbtfd@aol.com.

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Next Edition: Report about the ISPNO, Family Retreat, and funded grants for 2018, update on our annual spring Superheroes 5K.
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 chemotherapy 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 immuno-suppressed, 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)
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.
I would like to thank Dr. Brian Rood, Dr. Samuel Hinojosa, and Yara Bawab, who worked with 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).

At the end of July, Dr. Zhang informed me that the cells I had cultured were healthy. She invited me to come back to the lab and perform PCR. I then used a gel to amplify specific sequences in the cell's DNA. At that point, the sample I had created was almost ready for a complete sequencing. The sequencing data gathered would then be passed on to Dr. Haibo Zhang to have the opportunity to take on a new challenge. She tasked me with "splitting" or sub-culturing the medulloblastoma cells, which were then split into 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.

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The Childhood Brain Tumor Foundation is dedicated to funding research for all pediatric brain tumor types. 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. 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 CBTF Advisors and Ad Hoc Reviewers, in honor of Ella Day, Jackson Dundon, Beverly Koren, and Samuel Lunn-June 15.

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

"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.

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!
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.

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.
Thank you for your support!
The Childhood Brain Tumor Foundation, Inc.
Form may be used for donations, to add or change your address for our mailing list, or for information requests.

Enclosed is my contribution: $________
Name of person (if applicable)___________________________
Please send acknowledgement card to:
Name: ____________________________
Address: ________________________________
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Message: _____________________________

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Master Card, VISA, and American Express donations for CBTF are accepted through our secure
Give Online button on our Web site: www.childhoodbraintumor.org

Information request: (Email request or mail note bellow specific interests) or address change.
Include your E-mail address and name/address: ____________________________
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CBTF
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November 10

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

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

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

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