

NEUROtransmitter *Communicating our message.*

Ella's Mitzvah Project

Feature Article: Ella's Splash and Dash



The Childhood Brain Tumor Foundation is a very important organization to me. On Mother's Day of 2019, I did the "Be AMYazing Reston Youth Triathlon." This triathlon was named after a girl named Amy who had brain cancer and died at the age of 13. She went to Hunters Woods Elementary School, the same

elementary school I went to. After she died, her friends started the triathlon in her name to raise money for The Childhood Brain Tumor Foundation, which supports research to help find a cure for childhood brain tumors.



When I participated in that triathlon I raised \$250 for the foundation. That same year for my birthday party, instead of gifts, I asked my friends to donate money to The Childhood Brain Tumor Foundation. This foundation became important to me and I was very sad when the triathlon was cancelled in the spring of 2020, because of Covid-19. That is why I decided to coordinate my own *Splash & Dash* (150 meter swim and 1.2 mile run) with some of my neighborhood friends to raise money for the foundation. The event was held on June 13th, Glade Pool, Reston.

(continued on page 5)

Reston Youth League Be AMYazing

Although our friends and supporters made a difficult decision in closing the spectacular Be AMYazing event, they generated wonderful supporters that still contribute to the Childhood Brain Tumor Foundation. At our 25th Anniversary Gala we had the pleasure of recognizing an valiant efforts of Amy's dearest friends, Amy's friends sought to hold a memorial event, trained others when the went off to college and kept the event going for years. Their families and Amy's put their heart and soul into raising funds to support the research efforts of the Foundation.

Although the event has discontinued, the funds held for planning a future event were donated to the Foundation toward supporting our mission. We are grateful to all of the organizers and families that continued the event for years.

(continued on page 6)

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 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.



Table of Contents

- page 1: Ella's Splash and Dash, Be AMYazing
- page 2: Grant summary-Peter Lewis, PhD.
- page 3: Grant summary-Erin Crotty, M.D.
- page 4: Grant summary-Carl Novina, MD, In Honor
- Page 5: Sponsorships and upcoming events
- page 6-7: Giving and Remembrances,

Watch for our video sessions with the experts to be posted on our website.

Roster, Featured Article

Board of Directors

*Jeanne P. Young, President
Carol Comman, Vice President
Kirsten Baker, Vice President/Secretary
*James M. Young, Treasurer

Directors

*Elizabeth Irvin John Moore
Susan Lyon, RN Claire Wynn

Chairman Scientific Advisor

Founding Advisor

*Roger J. Packer, M.D., pediatric neurologist
Children's National Hospital
Washington, D.C.

Scientific Advisors

Susan M. Blaney, M.D., pediatric oncologist
Texas Children's Cancer Center, Houston, TX

Kenneth J. Cohen, M.D., pediatric oncologist
Johns Hopkins Medical Center, Baltimore, MD

Charles G. Eberhart, M.D., Ph.D., neuro-pathologist
Johns Hopkins School of Medicine, Baltimore, MD

Paul G. Fisher, M.D., pediatric neurologist
Stanford University Hospital, CA

Eugene Hwang, M.D.,
Children's National Hospital
Washington, DC

Lindsey Kilburn, M.D.
Children's National Hospital
Washington, DC

Tobey J. MacDonald, M.D., pediatric oncologist
Emory Health Sciences Center, Atlanta, GA

*Eva Perdahl, M.D., Ph.D., pediatric oncologist
Kaiser Permanente, MD

Eric H. Raabe, M.D., pediatric oncology
Johns Hopkins Hospital, Baltimore, MD

Brian Rood, M.D., pediatric oncologist
Children's National Hospital
Washington, D.C.

Maria I. Almira-Suarez, neuropathologist
Washington, DC

Katherine Warren, M.D., pediatric oncologist
Dana-Farber Cancer Institute, Boston, MA

Survivorship

Debbie Lafond, DNP, PNP-BC-CHPPN
Children's National Hospital
Washington, DC

Legal Advisor

Frederic Rickles, Esq., NY

Ambassadors

Alicia Gonzalez
Camden Wiseman

Community Representatives

Ali-Gator, Jarrod Aucoin

BeAMYazing

Run with the Saints

Mary T Callahan, TX
Tierney Callahan, TX

Doug DeFeis, VA

Killeen Family NJ

Alyssa/Danielle Lyon

Cady Lyon, MD

Kate Lund, WA

Pat Macy, NY

Barbara Norris, MA

Carol A. Parham, VA

Andrew Schoenfeld, CA

Michael Schoenfeld, DC

Diane Smith

Brittany Truitt, FL

Cindy Truitt, FL

Linda Q. Turner, UT

Nancy Ward, IL

Susan M. Young, MD

Identifying molecular vulnerabilities in aggressive pediatric ependymoma

School of Medicine and Public Health, University of Wisconsin, Madison
Peter W. Lewis, Ph.D.

Ependymomas arising in the posterior fossa represent a major challenge in the field of pediatric neuro-oncology. Posterior fossa type A (PFA) ependymomas are fatal in a third of the young children who develop these tumors within five years of diagnosis. PFA ependymomas contain relatively few genomic alterations compared to other malignancies, and the molecular 'driver' of PFA ependymomas was unknown until recently.

In the past few years, scientists have found that nearly all PFA ependymomas inappropriately express a gene called EZHIP. Normally, EZHIP is only found in some of the many cell types that make up the testes and ovaries. Part of our research is aimed at understanding whether EZHIP expression is needed for PFA ependymoma tumor cell proliferation. Answering this important question is critical to developing EZHIP-centered therapeutic strategies for these tumors.

Molecularly, we found that EZHIP 'mimics' a mutant protein that is the driver protein for nearly all diffuse midline gliomas called H3 K27M. In the past few years, scientists have found that a small percentage of PFA ependymomas contain H3 K27M instead of expressing EZHIP, and similarly, a small number of diffuse midline gliomas express EZHIP and don't contain H3 K27M. These intriguing results suggest that EZHIP and H3 K27M may be acting similarly to promote tumorigenesis; tumors need either EZHIP or H3 K27M, but not both.

Our research group published a study last year that found remarkable similarities in the mechanism-of-action between EZHIP and H3 K27M. This finding is important because it suggests that two different tumor types – DMGs and PFA ependymomas – may be driven by the same pathways. Part of our current work is aimed at understanding the cellular pathways that are perturbed by the EZHIP and H3 K27M in order to identify therapeutic strategies. It's unclear how EZHIP gets activated in the developing brain cells that give rise to PFA ependymomas, and part of our research is aimed at uncovering the pathways that give rise to this aberrant expression profile. Understanding the pathways that lead to the inappropriate expression of EZHIP could lead to additional therapeutic strategies for these tumors.

<https://news.wisc.edu/pediatric-cancers-share-stalled-gene-managing-enzyme/>

Watch for our video sessions to be posted on our website.

Roger J. Packer, MD

Kristina Hardy, MD

Tobey MacDonald, MD

Gilbert Vezina, MD

CBTF Superheroes 5K 2022 TBD

Date will be determined soon and posted on our website as soon as it is confirmed.

CBTF GALA

TBD 2022 spring or summer

Glenview Mansion in Rockville, MD

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

EVENTS UPDATE



Institution: Fred Hutchinson Cancer Research Center/ Seattle Children's Hospital/ University of Washington

Title: *Immune Priming Pediatric Brain Tumors*

Applicant/PI: Erin Crotty, M.D.

Funding: 2-year award, August 2020-2022

Award Period Completed: 2020-2021

Erin Crotty, M.D. is a pediatric neuro-oncologist at Seattle Children's Hospital and research associate in the Olson Laboratory at the Fred Hutchinson Cancer Research Center, where she studies novel immunotherapies for treating pediatric brain tumors. Immunotherapy uses the body's own natural defenses, the immune system, to fight cancer. While this type of cancer therapy can successfully cure cancers like leukemia, researchers are still searching for ways to use immunotherapy to treat childhood brain tumors. Her project tested a combination of three drugs in medulloblastoma. This combination was designed to prompt the body to recognize a tumor cell as an invader. One of these drugs was a special immunotherapy agent that the Olson lab engineered by attaching it to a component found in scorpion venom, named chlorotoxin. Chlorotoxin finds the tumor precisely by homing to tumor cells and avoiding healthy brain tissue. Once in the tumor, the drug-chlorotoxin combination changes the face of the cancer cell to allow the immune system to recognize it and attack.



After testing in numerous mouse models, Dr. Crotty and her team found that the chlorotoxin combination did not sufficiently engage an immune response or prolong survival in mice. The 2-drug combination of nivolumab and decitabine without chlorotoxin:interferon-gamma did change the face of tumor cells, however this signal was not enough to attract killer T cells to attack the tumor. The drug combination was well tolerated and the mice had few side effects. While the data did not support further study of chlorotoxin combinations in medulloblastoma models, over the first year of grant support from CBTF Dr. Crotty obtained a tremendous amount of data in relevant models and her findings provide meaningful insights into the immune microenvironment of medulloblastoma.

The Olson lab is a member of a Stand Up 2 Cancer Catalyst Team that is collaborating with 3 other labs to investigate immunotherapy combinations in pediatric brain tumors, including diffuse intrinsic pontine glioma (DIPG), atypical teratoid rhabdoid tumor (AT/RT), and high-grade gliomas. Data testing the combination of decitabine and nivolumab in other models, including AT/RT and DIPG were promising, showing a decrease in tumor size by MRI imaging and prolonged survival. Dr. Crotty has proposed a clinical trial concept to pursue this immunotherapy strategy in patients with relapsed/refractory high-grade glioma and DIPG through the Collaborative Network for Neuro-oncology Clinical Trials (CONNECT). She is immensely grateful for the funding provided by CBTF which supported her transition to becoming a clinical investigator and feels honored to be supported by dedicated patients, caregivers, and friends who sustain this important area of research.

Thank you so much!

Special thanks from CBTF to our supporters and the research and medical community for their dedication!

Grants

CBTF plans to re-open our grants application process for 2022 in the fall of 2021. A limited number of applications will be funded.

CBTF Sponsorships:

We will provide a **Silver sponsorship** for the 20th International Symposium on Pediatric Neuro-Oncology (ISPNO) for the **2022** conference to be held in **Germany**.

2022 Society for Neuro-Oncology (SNO), International, Sub-Saharan Africa

Grant Summary, In Honor of

Institution: Dana-Farber Cancer Institute

Title: *Defining lncRNA-Transcription Factor Networks in Diffuse Intrinsic Pontine Gliomagenesis*

Applicant/PI: Carl Novina, MD, PhD

Approximately 75% of the human genome is transcribed into RNAs but only 1-2% of those human genome RNAs are then translated into proteins. The roles for these “non-coding RNAs” in normal biology and how they contribute to disease is poorly understood. CBTRF-funded research in the Novina Lab (Dana-Farber Cancer Institute) exploits unique insights into long non-coding RNA (lncRNA) biology. Specifically, the mechanism of many lncRNAs can be understood by identifying which proteins they interact with. The Novina Lab developed a specialized assay which systematically tests all known human proteins for their ability to bind to lncRNAs implicated in disease. If a protein is associated with a disease process, and a lncRNA is associated with the same disease process, and the lncRNA and protein interact, then it is less likely that these associations happened by chance. This guilt-by-association strategy makes it easier to understand how lncRNAs promote pediatric brain cancers and how they can be targeted as novel form of therapy.

The Novina Lab identified several lncRNAs that are deregulated in diffuse intrinsic pontine gliomas (DIPGs). One such lncRNA most-commonly amplified in DIPG is called *CCDC26*. This lncRNA interacts with proteins that are implicated in cancer formation and therapy resistance, including the onco-protein MYC-N. MYC-N is also frequently amplified in DIPG and its increased expression is correlated with poor survival in DIPG patients. We found that MYC-N also binds to two other lncRNAs called *ZNF667-AS1* and *MIR17HG201*. Additionally, *CCDC26* is also implicated in childhood acute myeloid leukemia and gastrointestinal-stromal tumor progression and resistance to therapy. The Novina lab has been putting together “networks” (groups of genes) commonly affected by MYC-N and other transcription factors that interact with *CCDC26*, *ZNF667-AS1* and *MIR17HG201*. Similarly, the Novina lab is also comparing these lncRNA-controlled networks identified in DIPG to lncRNA-controlled networks in other cancers. By understanding which of these interactions promote the growth of DIPG cells, we can then devise strategies to make drugs that inhibit these interactions, which will be developed into a therapy for these deadly pediatric brain cancers. *(This was a two-year program.)*



In memory of Nancy Jane Young
A favorite quote from Winnie the Pooh.

Please support CBTF: Due to the pandemic a few of our scheduled fundraising events in 2020/2021 were canceled and impacted our ability to fund research programs and sponsorships significantly. We plan to hold events in 2022. Your monetary support is always meaningful to CBTF and we hope we can count on your continued support.

CBTF will be posting a series of videos on many relevant topics.

Childhood Brain Tumor Foundation

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

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

In Honor of

The dedicated medical professionals who have tirelessly dedicated their time to care for the patients and families during the COVID-19 pandemic.

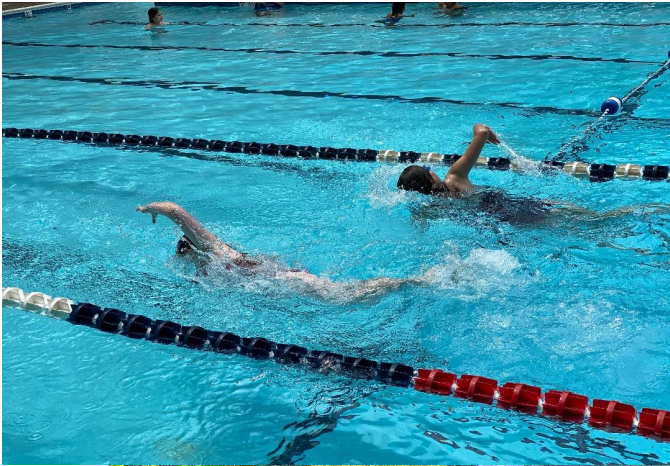
Ella Sleeper' Bat Mitzvah Project, Splash and Dash (150 M swim and 1.3 mile run)
Participants: Ella, Violet, Lily, Emma, and Caroline

Reston Youth League Be AMYazing

ELLA'S SPLASH AND DASH

(continued from page 1)

Ella's team of participants included: Caroline, Emma, Lily, Violet, and Ella. Each of the girls are involved in a variety of youth activities, playing volleyball, soccer, musical theater, dancing, acting, and swimming.



Ella's Team raised nearly \$2,000 and had a great day together! Congratulations & Mazel Tov, Ella!

Thank you so much from CBTF.

Upcoming Events 2022

CHECK our Website for more information regarding 5K registration and other events.

CBTF Superheroes 5K 2022— Date to be determined

CBTF Party—The CBTF GALA will be re-scheduled for 2022

Fundraising events and donations are significant to our ability to fund excellent research and other programs. Thank you for your support!



BE AMYAZING-10 YEARS \$150,000, GRACIOUS GIVING

A Message from the Be AMYazing Founders, the Boyle Family, Organizers, and Friends,

We would like to announce that after discussion amongst the Founders and the Boyle family we have made the difficult decision to retire the Be AMYazing Reston Youth Triathlon after 10 great years. We want to thank every person that has contributed to making this event as AMYazing as it has been; participants, volunteers, committee members, donors, and everyone else that has made this decade of triathlons a force for good and wonderful way of honoring of Amy Boyle's memory and vibrance. Thanks to the support of this community, the Reston Youth Triathlon was able to raise over \$155,000 for the Childhood Brain Tumor Foundation.



Be AMYazing, Reston Youth Triathlon Founders:
Olivia Wolfe, Hannah Becker, and Kacey Hirshfeld
Thank you for your dedication.



We hope that this event has shown the power that youth can have in community organizing and that we will see even more youth leaders come forward with their own passions and ideas in the years to come. A special thanks goes to the CORE Foundation, whose trust and support of three 14-year-old girls over 10 years ago brought this event to life. If you would like to continue to support CBTF see the information below.



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

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



(Accepts Discover, MC,VISA, and AE).
Please contact us if you have any questions:
cbtf@childhoodbraintumor.org

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: _____
City/State/Zip: _____
Message: _____

Supporting General Research Education

Please make checks payable to: Childhood Brain Tumor Foundation (CBTF)
20312 Watkins Meadow Drive Toll free: 877.217.4166
Germantown, Maryland 20876 Telephone: 301.515.2900

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: _____

Remembrances, CFC, UW, Maryland Charities



Jill Adleman
Michelle Antonio
Evelyn Auerbach
Ross Barash
Debbie Bell
Cameo Beauchesne
Franco Borello
Amy Boyle
Kelly Elizabeth Brosius
Kelley Christine Bula
Anderson Butzine
William Thomas Camut
Ryan Caspar
Laira Caverly
Betsy Anne Charkatz
Josetta Chiang
Faith Jade Cleveland
George Coleman
Geoffrey Cornman
Jack Cornman
Kayla Decharinte
Rose DeMartino
Henry Dolch
Anna Durkin
Dorothy Durkin
Shawn Edwards
Cory Empens
Shatara Briana English

Felix Fearon
Daniel Fiduccia
Jared Daniel Foreman
Michael Gallagher
Grant Galvin
Doyle Garrett
Herman Glaser
Elizabeth Carolyn Hahn
Ian Lennon Hahn
Kenneth Hahn
Katie Harris
Donald Hartman
Rebecca Hatef
David Hayes
Whitley Sue Hedger
Nolan Hoffman
John Russell Irvin
Jill Adlman Kelley
Paul Kenney
Kristen Kenzig
Alexx Kipp
Ricky Knight
Amy Kruppenbacher
Stephanie Kuhlman
Mason Leach
Francis and Wesley Lewis

Isadore Lieberman
Rebecca Lilly
Lauren Lockard
Michale Lopiano
Kally Lyn Kusaj
Emily Mau
Willard Maddox
Emily Mau
Shamsa Mazara
Damion Christian McClendon
Christopher C. Miller
Samuel Moore
Robert McDermott
Dawson Scott Nevin
Nichole O'Connor
Macklin Ollayos
Helen Asynith Palmer
Emma Parker
Marilyn and Jerry Peacock
Martin Pollinger
Kyle Pomerleau
Joshua Posner
Jessica Catherine Randall
Luke Shahateet
Hope Shields
Brennen Smith

Gilbert Smith, Ph.D.
Thomas Patrick Reinhold
Emory Richmond
Aaralyn Isabella Rodriguez
Debbie Rosenbaum
Easton (The Beast) Roy
Lynda Santelli
Maya Krim Schwartz
Amy Schiller
Hunter Dean Scott
Ralph Axel Smyth
Lisa Soghomonian
Tyler Christopher SooHoo
Daniel Sussman
Kelly Elizabeth Sweeney
Michael Thomas
Daniel Trainer
Jaime Vanderheyden
Swetha Vasudevan
Matthew Wierzbicki
Mary Waugh
Kayla Wenger
Stephen Allen Wood
Josie Wynn
Felix Young
Kim Young
Michael Young
Nancy Young
Ben Zell

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 the employer with the proper acknowledgment and information required.



Thank you to our friends who donated through workplace charitable giving campaigns this year, inclusive of the CFC.

The Childhood Brain Tumor Foundation, friends and families are very appreciative of your support. (National) CFC **12035**

Charity Campaign and other independent campaigns.

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.

Thank you donors!

Maryland Charity Campaign

The Childhood Brain Tumor Foundation participates in the **Combined Federal Campaign (CFC) and Maryland Charities**.

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
20312 Watkins Meadow Drive
Germantown, MD 20876
Address change requested

together, reaching for a cure!



Table of Contents
page 1: Ella's Splash and Dash, Be Amazing
page 2: Grant summary-Peter Lewis, Ph.D.
page 3: Grant summary-Erin Crotty, M.D.
page 4: Grant summary-Carl Novina, M.D., in Honor
Page 5: Sponsorships and upcoming events
page 6-7: Giving and Remembrances,
Watch for our video sessions with the experts, to be posted on our website.

Publication: *Neurotransmitter*

Editor: Jeanne P. Young

Contributing Editors: Colleen Snyder, Bridgette Wood

Contributing Writers: Erin Crotty, MD, Peter Lewis, Ph.D.,

Carl Novina, MD, Ph.D, and Ella Sleeper

CBTF Logo@: Michael Young

Photography: Erin Crotty, MD, Ella Sleeper, Be Amazing
Graphic Design: Bridgette Wood/Wood Web Work

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

The Childhood Brain Tumor Foundation

Email preferred

cbtf@childhoodbraintumor.org

Telephone: (301) 515-2900

Toll Free: (877) 217-4166

www.childhoodbraintumor.org



Children's Medical & Research
Charities of America

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

**WE NEED YOUR SUPPORT.
HELP CHILDREN WITH BRAIN TUMORS.**

THIS NEWSLETTER IS A FREE PUBLICATION OF THE
CHILDHOOD BRAIN TUMOR FOUNDATION.
WE ARE FUNDED THROUGH CONTRIBUTIONS AND SPONSORSHIPS
FROM INDIVIDUALS AND CORPORATIONS.
PLEASE LET US KNOW IF YOUR ADDRESS HAS CHANGED.
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.