

# NEUROtransmitter

*Communicating our message.*



## Chess 4 Charity

*Feature Article*

**C**hess 4 Charity 2017 held its 5th semi-annual chess tournament at the BASIS Independent McLean school. On October 15th, US Women’s Chess Champ Sabina Foisor gave a lecture on best strategies to attendees. The event included four rounds of chess; a silent auction, and raffle. Non-players were welcome to attend and/or provide support to the beneficiary cause, CBTF. The successful event raised nearly \$8,000 and the support shown by the attendees was heartwarming.

The participants were very thoughtful in making their strategic moves. The skill level of the players was amazing! We thank the Heller family, organizers, and our student ambassador Camden Wiseman, the head of the school, and volunteers for their efforts in making this a successful event.

Additional information will be included in our next newsletter.

*Group Photo: Crowd gathers before the tournament*



## Funded Grants

*Targeting MYC Driven Medulloblastoma with Combinatorial Immune Checkpoint Blockade*, Allison Martin, M.D., Pediatric Oncology, Johns Hopkins University

*Reciprocal Regulation of Electroresponsiveness between Glioblastoma and Brain Microenvironment*, Dr. Placantonakis  
[NYU Langone Health](#)

**NEW!** *A Novel Mechanism and Immediately-Translatable Targeted -Therapy for Group 3 Medulloblastoma*, Yin Wang, Ph.D., [Children’s Research Institute](#)

**New!** *Developing long non-coding RNAs (lncRNAs) as therapeutic targets for Diffuse Intrinsic Pontine Glioma*  
 Daniel Lim, M.D. Ph.D., University of California, San Francisco

*(summaries for newly funded grants on page 5)*

## Run with the Saints – Houston



Incredible friends in Houston, Texas thank you for going forward with the annual fundraising 5K after some tough weeks brought on by Hurricane Harvey!

John Paul II School’s *Run with the Saints* 5K has been held annually for 19 years....amazing. The event is held in memory of Lauren Lockard. Lauren was courageous, a spirited and fun-loving young lady, who lost her battle to a brain tumor many years ago.

*(continued on page 2)*

## CBTF RAISES FUNDS FOR RESEARCH

### 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:** Chess 4 Charities; Grant Summaries; Run with the Saints, Houston, Texas, Grants funded 2017-2018
- page 2:** Board of Directors
- page 3:** CBTF 24th Annual Gala Party at the Pony Express—November
- page 4:** Resource Corner; **March 18 10th Annual Superheroes 5K and Kids Fun Run!!**
- page 5:** Grant Summaries (2); Congratulations; In Honor Of
- page 6:** Remembrances
- page 7:** Support CBTF, Gift Matching, Charity Campaigns,

# RUN WITH THE SAINTS, IN MEMORY OF LAUREN

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Camden Wiseman

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## BeAMYazing

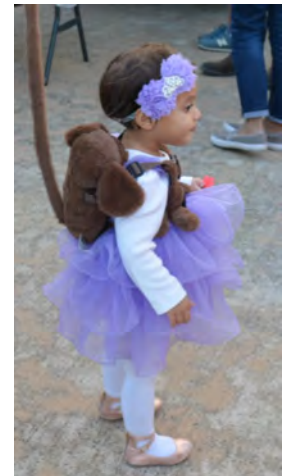
### Run with the Saints

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Diane Smith  
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Cindy Truitt, FL  
Nancy Ward, IL  
Susan M. Young, MD

This terrific event included pre-event festivities the evening before, giving children an opportunity to "Trunk or Treat." A fun-time is had by all. Thank you from CBTF to JP11, the organizers, and the community for sharing in the support of our mission to fund excellent research.

Houston strong, an effort that was as spirited and as gracious as ever!!



If you are interested in learning more about the Childhood Brain Tumor Foundation, Inc.,  
Please contact: **E-MAIL:** [cbtf@childhoodbraintumor.org](mailto:cbtf@childhoodbraintumor.org) or [jeannyoung@childhoodbraintumor.org](mailto:jeannyoung@childhoodbraintumor.org) (**E-mail preferred due to high volume of robo-calls**)  
**TELEPHONE:** 877-217-4166 or 301-515-2900  
**Volunteers welcome!**



# Gathering at the Pony Express

## An evening to honor nurses and survivors

### Gathering at the Pony Express at Bolger Conference Center Potomac Maryland

Saturday, November 11, 2017- 7:00 PM to 11 PM

A great time was had by all who attended the Childhood Brain Tumor Foundation's annual Gala—a *Gathering at the Pony Express*, held on November 11, 2017.

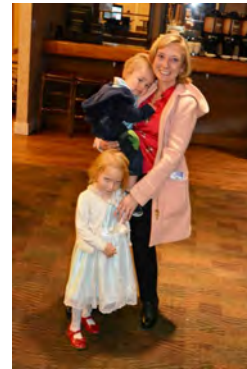
The evening included scrumptious cuisine and desserts, beverages/cocktails, excellent musical entertainment by *Steve Young and the Sounds*, a silent auction, games galore including blackjack, ping pong, and pool. There was also an opportunity to challenge our very own student ambassador and a chess champion, Camden Wiseman.

We are deeply appreciative of the continued support from our Superhero Sponsor, *FD Associates, Inc.*; sponsor *Whittles Physical Therapy* and other anonymous sponsor supporters.

Early in the evening on behalf of CBTF, Jeanne Young, president, expressed appreciation for our veterans and military on Veteran's Day. Children's National Health System's Dr. Roger Packer, Senator Chris Van Hollen's representative Karen Hendricks, and Senator Feldman's representative, Steve Markenson made presentations to nurses who have dedicated their talents, compassion, and skill in caring for children with brain tumors.

In addition, with assistance from Annalise and Sophie Vezina, Dr. Packer presented gift baskets to survivors, Jimmy Alverson and Sammy Wakely. It was an impressive group of honorees.

We look forward to our **annual event next November 2018**. **CBTF thanks our supporters for their decades of support**. We welcome all supporters and sponsors and thank everyone for helping make funding excellent research possible.. The 2018 date will be announced shortly, but usually falls on the second or third Saturday of the month. More information will be forthcoming.



### Honorees

**Lauren Hancock, RN, MSN, CPNP-AC**  
Children's National Health System

**Thomas Killmond, PA-C, DFAAPA**  
Johns Hopkins University School of Medicine

**Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN,**  
Children's National Health System

**Elizabeth Leitzer, MSN, RN, NP-C**  
Children's National Health System

**Julia Mascia, RN**  
Children's National Health System

**Katherine Dinterman McHugh, MSN, RN**  
Center for Cancer and Blood Children's National Health System

**Alisa Perry, PNP**  
Children's National / Inova Partnership

**Rachael Raskin, MSN, CPNP-PC**  
Children's National Health System

**Kim Walker, MSN, RN, CPNP**  
National Institutes of Health National Cancer Institute, Pediatric Oncology Branch

### Child Honorees

Jimmy Alverson  
Sammy Wakely



## RESOURCE CORNER

### Book Guide

#### 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

#### 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 Hayden , Cherie Takemoto

#### The Complete IEP Guide:

#### How to Advocate for Your Special Ed Child

By: Lawrence M. Siegel

#### Wrightslaw: From Emotions to Advocacy

By: Peter W. D. Wright, Pamela Darr Wright

#### Wrightslaw: Special Education Law

By: Peter W. D. Wright, Pamela Darr Wright

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

### HELPFUL RESOURCE LINKS

#### Thoughts Can Fuel Some Deadly Brain Cancers (paper in Cell), Michelle Monje

*"The discovery of a link between tumor growth and brain activity "has opened up a window into potential therapeutic interventions," says Bachelor*

*Follow the link for more information:*

<http://www.npr.org/blogs/health/2015/04/23/401723235/thoughts-can-fuel-some-deadly-brain-cancers>

Hai-Ri Song, M.D.

Assistant Professor, Department of Neurosurgery/Neurology  
New York University School of Medicine

In spite of dramatic advances in the cure rate for most childhood malignancies, the prognosis for children with brain tumors is exceedingly poor. The urgent need for novel therapy is underscored by the fact that brain tumors are the second most common childhood tumor and the most common childhood brain tumors are *gliomas*, arising from supporting cells in the brain. Despite advances in research, the prognosis for these types of aggressive pediatric brain tumors remains poor. Thus the development of novel strategies for therapy is the top priority. The development of new and improved therapies for pediatric malignant gliomas is highly dependent on better understanding of its biology. Our studies aim to address the following important questions: How are genes essential in normal brain development hijacked to cause brain cells to grow into a tumor? Can enhanced elimination of the tumor-promoting proteins efficiently block tumor growth? The information obtained from this proposal will significantly increase our understanding of the biology of pediatric malignant gliomas and will help to develop new treat-



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](mailto:cbtf@childhoodbraintumor.org)

To make a donation to our cause, visit our secure website:



[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

Go to the 'Support' page and locate the *Give2Charity Online* button:  
(Cards Accepted: Discover, MC, VISA, and AE)

## UPDATE for the CBTF 5K

### 10th Annual Superheroes 5K and Kids Fun Run—Sunday, March 18, 2018

Our Superheroes 5K walk/run and Kids' Run will return to Meadowbrook Park, Candy Cane City, Chevy Chase for our 10th annual Superheroes 5K and Kids' Run. Fight back against pediatric brain tumors, by joining the race. Team and individual registrations accepted online via the Potomac River Running website. Please join us in making sure young promising investigators are supported in their efforts in researching cures and treatment advancements for pediatric brain tumors. Your support is greatly needed. Corporate, team, and individuals sponsors are important, just as are all families and runners that love to run or care about the cause. Thanks! [Http://www.tinyurl.com/CBTF5K2018](http://www.tinyurl.com/CBTF5K2018)



# Grant Summaries

## ***Developing long non-coding RNAs (lncRNAs) as therapeutic targets for Diffuse Intrinsic Pontine Glioma*** Daniel Lim, M.D. Ph.D., University of California, San Francisco

The human genome produces many thousands of molecules called long non-coding RNA (lncRNAs), and emerging data indicate that lncRNAs play key roles in human disease including cancer. While lncRNAs represent a large new class of therapeutic targets for brain tumors, very few individual lncRNAs had been identified as potential targets. We recently screened the function of 16,401 human lncRNAs in six different cancer types including glioma. We have since validated the expression and essential function of one particular lncRNA in human DIPG. Knockdown of this lncRNA in Diffuse Intrinsic Pontine Glioma (DIPG) strongly inhibited tumor cell growth, and we have been able to target this lncRNA with drugs that can be rapidly translated into a clinical therapeutic. Furthermore, recent data indicate that targeting this lncRNA will have minimal adverse effect on normal brain cells. Thus, targeting this lncRNA may lead to a therapeutic that is highly effective against DIPG while having minimal toxicity to normal brain cells.

## ***A Novel Mechanism and Immediately-Translatable Targeted –Therapy for Group 3 Medulloblastoma,*** Yin Wang, Ph.D., Children's Research Institute

My lab is dedicated to the study of Group 3 medulloblastoma (G3MB), a high-risk brain tumor that bears a very poor prognosis, largely due to unresponsiveness to conventional chemotherapies. No currently FDA-approved drugs are effective for G3MB, and no new drugs have been introduced in at least 25 years. The protein, c-MYC (MYC) is known to be the major factor driving the pathobiology of G3MB. However, MYC remains one of the most difficult molecules to design drugs against. Our research is focused on identifying and developing feasible approaches to treating G3MB by inhibiting MYC. We identified another protein molecule, HIF-1 $\alpha$ , which we found to control MYC in G3MB. Unlike MYC, HIF-1 $\alpha$  was readily targeted using the drug, echinomycin, an inhibitor of HIF-1 $\alpha$ . Our immediate goals and interests are to use echinomycin to block MYC through the selective inhibition of HIF-1 $\alpha$  in cell and mouse models of G3MB. Our current studies also seek to understand the novel mechanism of how HIF-1 $\alpha$  controls MYC in G3MB by using molecular biology techniques. My lab spends a considerable amount of time working towards translating our discoveries to the clinic. Toward this end, we developed a clinical liposomal formulation of echinomycin to ensure that the compound can be quickly adapted to the clinical setting. Currently, we are conducting studies of liposomal echinomycin in the mouse model of G3MB to accrue supporting efficacy data for an IND application. We are particularly excited to carry out these studies because liposomal echinomycin was specifically designed to deliver echinomycin directly to brain tumor tissues.

MYC is overexpressed in more than 30% of human cancers. Successfully targeting MYC through inhibition of HIF1 $\alpha$  may not only offer a new hope for children with G3MB, but will also intensify a novel molecular targeted therapy for the treatment of a broad spectrum of human cancers.

We are grateful for the opportunity to conduct this exciting research with the funding support provided by the Childhood Brain Tumor Foundation.

### **Congratulations**

to

Kirsten Baker for her new role as Secretary/VP to CBTF.

### **Welcome to**

Danielle Gottlieb, new Board member

### **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  
Tal Hughes  
Alicia Gonzalez*

*In Honor of*

*Beverly Koren*

*Roger and Bashi Packer  
Stephen and Lorrain Schoenfeld  
Camden Wiseman*



*Seasons Greetings*  
*From your friends at the Childhood Brain Tumor Foundation*

# ... at the Pony Express Bar and Grill



## REMEMBRANCES

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 Ross Barashi  
 Debbie Bell  
 Jack Bell  
 Cameo Beauchesne  
 Franco Borello  
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 Felix Young  
 Michael Young  
 Ben Zell*

## GRACIOUS GIVING



**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 appreciative of your support. (National) **12035**



**Maryland Charity Campaign**

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.

**Thank you donors!**

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. Check your campaign pamphlet for our **United Way number or write us in**.



### 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.

### 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.

Our website: [www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

### Stock Donations

If you would like to make a stock donation, contact us: [cbtf@childhoodbraintumor.org](mailto:cbtf@childhoodbraintumor.org)

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

### 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

FD Associates, Inc.

Clarksburg High School and Rocky Hill Middle School  
In Memory of Sam Moore

### Recent Events

Chess 4 Charity, October 15, 2017

CBTF **24th** Annual Party, November 2017

Pony Express Bar and Grill at Bolger Conference Center, Potomac, MD

**(See you at the 25th anniversary event in November 2018)**

Run with the Saints, in memory of Lauren Lockard, Houston, TX  
October 28, 2017

Education and Updates: Childhood Brain Tumors  
April 2, 2017  
Some webinars are posted on  
[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

Reston Youth League's Be AMYazing, Reston, VA, May 2017

### Upcoming Events

- **Family Retreat Day --spring 2018**
- **10th Annual Superheroes 5K walk/run and Kids' Run, Sunday, March 18, 2018**



# 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) \_\_\_\_\_

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- In Memory of
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Message: \_\_\_\_\_

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Include your E-mail address and name/address: \_\_\_\_\_

Master Card, VISA, and American Express donations for CBTF are accepted through our secure **Give Online** button on our Web site: [www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

Telephone: 301.515.2900  
Toll free: 877.217.4166

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Thank you to the *Rocking Moon Foundation*.

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PROGNOSIS AND QUALITY OF LIFE FOR CHILDREN SUFFERING FROM  
BRAIN TUMORS. EVERY YEAR THE REQUESTS CONTINUE TO GROW.  
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*Counting up on 25 Years  
of Excellence  
It is through your support we  
continue to fund programs and research.*

**Table of Contents**  
page 1: Chess 4 Charities; Grant Summaries; Run with the Saints, Houston, Texas, Grants funded 2017-2018  
page 2: Board of Directors  
page 3: CBTF 24th Annual Gala Party at the Pony Express—November  
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and Kids Fun Run!!  
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together, reaching for a cure!



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