# EURotransmitter Communicating our message.

# **Geoff Cornman Memorial Golf Tournament**



Geoff, an avid golfer with a generous heart, was remembered not only for his love of the sport but for his enduring legacy of compassion, making the tournament a meaningful celebration of his

The event's success was made possible by the generosity of attendees, sponsors, and volunteers. A special thank you to the Platinum sponsor, Obsidian, and the Gold sponsor, Prism, whose support was essential in reaching fund raising goals. Thanks to the collective effort, an (continued on page 5)

### Feature Article: Funded Grants and Symposium

This year, after careful review and recommendations from our Scientific Advisory, led by Dr. Roger Packer, the Childhood Brain Tumor Foundation funded two grants each for up to two years Grants received were competitive, many worthy of funding. In addition, we provided a Silver Sponsorship for the International Symposium on Pediatric Neuro-oncology, held in June 28—July 2, 2024 in Philadelphia.

#### **Funded Grants**

Investigating the role of MN1 fusions in the newly recognize subgroup "Astroblastoma, MN1-altered" Children's Hospital of Philadelphia, Division of Oncology, Philadelphia, PA

Principal Investigator: Simone Stephanie Riedel, M.D.

Transcribed Ultra Conserved Regions in Medulloblastoma

life and values.

The Rector and Visitors of the University of Virginia, Charlottesville, VA

Principal Investigator: Roger Abounader, M.D., Ph.D.

(continued on page 4)

CBTF RAISES FUNDS FOR RESEARCH AND OTHER PROGRAMS, "TOGETHER REACHING FOR A CURE."

### The Childhood Brain Tumor Foundation

Our mission is to support and fund basic brain tumors. We are dedicated to devastating disease. and improving the quality of life for those that it affects by funding vital research initiatives.



#### **Table of Contents**

page 1: Geoff Cornman Memorial Golf Tournament., Funded Grants

page 2: ISPNO, Gracious giving, support

page 3: Campaigns

page 4: Fundraising

Page 5: In Honor of

Page 6: Remembrances

Page 7: Videos (no charge), Donation page

Five Video sessions with the experts are posted on our website. Email request and send your story if you like.

#### **Board of Directors**

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

#### **Directors**

\*Elizabeth Irvin John Moore Amanda Moore \*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., neuropathologist

Johns Hopkins School of Medicine, Baltimore, MD

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.

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 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

### ISPNO, GRACIOUS GIVING

### The 21st International Symposium on Pediatric Neurooncology (ISPNO) June 28—July 2, 2024

CBTF was pleased to be a Silver Sponsor for this comprehensive conference that includes scientists and healthcare professionals from participating disciplines worldwide.

The Chairs and hosts of the 21st ISPNO were Michael J. Fisher, M.D., Chief, Neuro-Oncology and Phillip "Jay" Storm, MD, Chief of Neurosurgery, and Co-Director, Neuroscience Center at the Children's Hospital of Philadelphia. Both are leaders in the internationally known Brain Tumor Program at CHOP. A vast committee of experts, worldwide contribute to the organization of the meeting.

Keynote speakers for the event included Leigh R. Hochberg, M.D., PhD, Neurointensivist and Vascular Neurologist at Massachusetts General; Charles L. Limoli, Ph.D, Professor and Vice Chair of Radiation Oncology, University of California, Irvine; and William R. Seller, M.D., Director of the Cancer Program and Professor of Medicine at the Dana-Farber Cancer Institute and Harvard Medical School.

A few excerpts from various topics are included. However, the breadth of the topics is vast, so only a few are highlighted here.

Sunday June 30, Speaker: Erin Crotty, Seattle, WA: *CSF Liquid Biopsy:* Paving the Way for Minimally Invasive Brain tumor Sequencing Using Low-Pass Whole Genome Sequencing

Clinical liquid biopsies via the CSF is used for detection and surveillance in patients with CNS tumors. They use low-pass genome sequencing (LP-WGS) in patients during clinical procedures and they extract cfDNA. In

(continued on page 3)

Please support CBTF: Your monetary support is always meaningful to CBTF and we hope we can count on your continued support.

CBTF has posted a series of videos on many relevant topics.

**Childhood Brain Tumor Foundation** 



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.

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

# ISPNO, GEOFF CORNMAN MEMORIAL GOLF, CFC

(continued from page 2)

conclusion, they determined through this process some revealing somatic copy variants may offer the minimally invasive liquid biopsies that can provide a surveillance option for pediatric CNS tumors.

Nursing/Palliative Care Speaker: Kasey Rangan, Los Angeles, CA: Neurocognitive side effects of pediatric brain tumors: a continuing challenge

The impact of childhood brain tumors and the multimodal treatments are challenging, due to the neurocognitive effects on patients. Although therapies have improved, novel interventions are needed to mitigate the late effects. Fortunately, radiation therapy options have helped minimize cognitive decline. In addition, more novel chemotherapy approaches have also personalized treatment approaches for patients. Continuing to refine treatments and need further exploration.

Speaker: Andrea Carai, Bombino Gesů Children's, Rome, Italy: *Virtual reality assistance in the management of pediatric brain tumors*.

Virtual reality (VR) has proven to be beneficial and it is very effective in surgeries involving supratentorial tumor, especially in deep seated tumors, children young 10 years of age, and in cases of planned partial resection. VR is useful in planning and performing surgical resections.

CBTF looks forward to providing sponsorship for the 2026 ISPNO in Australia.





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.

THANK YOU SO MUCH FOR YOUR SUPPORT! Special thanks from CBTF to our supporters, advisors and the medical, community for their dedication!

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.



A huge Thank You donors!

Maryland Charity Campaign

BY CHECK: Make out to CBTF or Childhood Brain Tumor FDN.

Send to: CBTF

20312 Watkins Meadow Drive Germantown, MD 20874

THANK YOU FOR YOUR SUPPORT!

Your contributions make it possible for CBTF to fulfill its mission.

| Please note if you are supporting:            | ☐ General       | Research            | ☐ Education       |
|---|-----------------|---------------------|-------------------|
| If in memory or in honor of please include to | the name of the | e person and the co | ntact information |
| for the person/family                         | to receive ack  | nowledgment.        |                   |

# Funded Grants (continued)

Grants Funded (continued from page 1)

Investigating the role of MN1 fusions in the newly recognize subgroup "Astroblastoma, MN1-altered" Children's Hospital of Philadelphia, Division of Oncology, Philadelphia, PA Written by: Simone Stephanie Riedel, M.D.

As of 2021 the WHO classification of tumors of the central nervous system (CNS) recognizes tumors with Meningioma 1 (MN1)- fusions as a distinct group called Astroblastoma, *MN1*-altered. Recent research showed that their DNA methylation and gene expression profile sets them distinctly apart from other CNS tumors. Diagnosis frequently occurs at a median age of 14 and the current treatment options are limited to resection and radio/chemotherapy. Nothing is known about the MN1-fusions that define this disease.

As a post-doc while investigating epigenetic mechanisms in childhood leukemias in the lab of Kathrin Bernt, MD my interest in MN1 was sparked. MN1 is described as a transcriptional co-activator and belongs to the class of intrinsically disordered proteins (IDPs). IDPs are characterized by lack of folding, thus a defined structure in absence of a suitable binding partner.

This is in crass opposition to other proteins, where the classic principle "form defines function" prevails. The structure of the folded protein dictates the function as well as possible binding partners. IDPs do not follow this classical paradigm. Generally, IDPs behave less predictable which poses unique challenges for research. MN1 has no sequence homology to any other protein, thus there are no predicted domains with associated functions that could give a hint to this proteins' role.

We have shown previously that MN1 acts as an oncogenic driver in *MN1*-translocated AMLs. There, MN1 acts as a stabilizer of an early hematopoietic gene program which prevents the normal myeloid development of the cell, ultimately causing the leukemia. We showed that MN1 aberrantly stabilizes the BAF complex (SWI/SNF) on chromatin. This keeps the affected gene loci in an active state, prevents their necessary shutdown and impedes the normal cellular development.

From our studies in AML, we know the importance of MN1 to maintain a leukemogenic gene expression program. The obvious next step is to investigate the impact of MN1-fusions on gene expression in *MN1*-altered astroblastomas. I will use an array of tools that I established specifically to investigate MN1. I will adapt these tools such as high-resolution single molecule microscopy or Chromatin immunoprecipitation (ChIP) followed by sequencing to understand how MN1-fusions act in Astroblastomas. Identifying potential interaction partners and the general mode of action is the first step towards the goal of a targeted therapy.

(continued on page 5)

# Consider Hosting a Fundraising Campaign for CBTF

The CBTF Community has supported our cause over many years through participation and organization of various campaigns and fundraising events.

Who is the CBTF Community? **YOU**. Families, friends, and loved ones touched by childhood brain tumors. Sponsors, donors, medical community, volunteers and all who have put forth their time, energy and financial donations to help us to exist for nearly 30 years in meeting our mission: to support research and families.

By staying involved, the CBTF Community has been instrumental in funding important research and in providing helpful resources to families in need. If you would like to get involved in this cause, CBTF can provide some basic fundraising tools to help support your campaign.

There are many ways to host your campaign, such as a 5k walk/run, school fundraiser project, a community event, and more. CBTF is always grateful for the actions, donations, and contributions from our community. Email CBTF (<a href="mailto:cbtf@childhoodbraintumor.org">cbtf@childhoodbraintumor.org</a>) directly and tell us how you would like to help.

# **Grants Funded, Golf**

Transcribed Ultra Conserved Regions in Medulloblastoma
The Rector and Visitors of the University of Virginia, Charlottesville, VA
Written by, Principal Investigator: Roger Abounader, M.D., Ph.D.

Medulloblastoma is the most common malignant pediatric brain tumor. It is divided into four subgroups: WNT, SHH, Group 3, and Group 4. The WNT and SHH subgroups have known drivers and therapeutic targets, but there are no known drivers and approved targeted therapies for Group 3 and Group 4, which have the worst prognosis. A better understanding of the molecular basis for medulloblastoma is needed to develop novel therapeutics to increase survival rates and improve post-treatment quality of life. Transcribed Ultra Conserved Regions (TUCRs) are a group of 481 RNA transcripts that are 100% conserved across multiple species. They are highly resistant to variation and are commonly deregulated in cancer. This suggests that they play important roles in medulloblastoma malignancy. However, there are no published studies on TUCRs in medulloblastoma.

The project that will be funded by the Childhood Brain Tumor Foundation aims to identify and characterize TU-CRs that are differentially expressed in medulloblastoma and to uncover their functions and mechanisms of action. Of particular interest are TUCRs that correlate with known drivers and/or TUCRs that could serve as novel drivers in the less characterized subgroups, Group 3 and Group 4. Specifically, we plan to: 1) comprehensively characterize the expression and deregulation of all TUCRs in medulloblastoma. 2) Uncover the functions and broad mechanisms of action of TUCRs in medulloblastoma; and 3) develop and test new powerful methodologies for the study of TUCRs that can be used by other researchers and in other cancers. Altogether, the proposal will generate new knowledge on a mysterious class of molecules and their putative roles in medulloblastoma.

(continued on page 6)





Geoff Golf Event (continued from page 1)

impressive \$55,000 will be donated directly to the Childhood Brain Tumor Foundation, contributing to critical research, education, and family support services for those impacted by pediatric brain tumors.

CBTF expresses our sincere appreciation for the heartfelt and dedicated efforts given to making the Geoff Cornman Memorial Golf Tournament a great success.





# In Honor of

Drs. Roger J. Packer, Susan Blaney, Kenneth Cohen, Charles Eberhart, Eugene Hwang, Lindsey Kilbern, Tobey MacDonald, Eva Perdahl, Eric Raabe, Brian Rood, and Katherine Warren

> Fae Daniels, Jenny Hahn, Michael Schoenfeld Carol Cornman, Brent Sperry, Ashton Cornman, and Grace Cornman

# **Grants Funded, Remembrances**

Transcribed Ultra Conserved Regions in Medulloblastoma (continued from page 5)

The principal investigator of the project, Dr. Roger Abounader, stated that "Pediatric cancer research has a special place in my heart. I love children and have two of my own. I cannot even fathom the pain of losing a child to cancer or any other reason. I lost my brother to cancer a few years ago. He was not a child, but he was still relatively young. I still dream of him regularly during my sleep. My mother has not overcome his loss and still cries when she thinks about him. I am a very compassionate person and want to use my research skills to make advances in the cure of cancer for both adults and children. I am very thankful for the funding by the Childhood Brain Tumor Foundation.

Jill Adleman Ophir Agassi Michelle Antonio Carson Bailey Ross Barash Debbie Bell Cameo Beauchesne Franco Borello Amy Boyle Kelly Elizabeth Brosius Kelley Christine Bula Anderson Butzine William Thomas Camut Laira Caverly Betsy Anne Charkatz Josetta Chiana Faith Jade Cleveland George Coleman Geoffrey Cornman Jack Cornman Sharon Cooper Kayla Decharinte Rose DeMartino Henry Dolch Anna Durkin Dorothy Durkin Shawn Robert Edwards Cory Empens Shatara Briana English Felix Fearon

Daniel Fiduccia **Dolores Fleming** 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 Robert McDermott Christopher C. Miller Samuel Moore Robert McDermott Dawson Scott Nevin Nichole O'Connor Macklin Ollayos Helen Asynith Palmer Emma Parker Parke Michael Paxton Marilyn and Jerry Peacock Martin Pollinger Kyle Pomerleau Ioshua Posner Jessica Catherine Randall Luke Shahateet Hope Shields Brennen Smith

Gilbert Smith, Ph.D.

Carl Stebbing Thomas Patrick Reinhold Emory Richmond Aaralyn Isabella Rodriguez Debbie Rosenbaum Easton (The Beast) Roy Lynda Santelli Maya Krim Schwartz Frederick Schwelm 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 and Nancy Young Kim Young Michael Young Ben Zell

# 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.

# Support, update address changes

### **Childhood Brain Tumor Video Updates**

Much appreciation to presenters: Drs. Roger Packer, Kenneth Aldape, Kristina Hardy, Tobey MacDonald, and Gilbert Vezina for working with our videographer, Neil Rubino to tape presentations on important topics.

No charge to view, register for log-in to access the videos: cbtf@childhoodbraintumor.org Additional videos will be added soon. **E-mail us with any special interests**.

### **Current topics include**

Central nervous system tumors in the pediatric population, classification improvements and WHO reporting Kenneth Aldape, M.D., senior pathologist, Chief of the Laboratory of Pathology at the Center for Cancer Research, National Cancer Institute

> Neuropsychology and School Supports Kristina Hardy, Ph.D., Neuropsychologist The Brain Tumor Institute, Children's National Hospital

Pediatric Brain Tumor in the Era of Precision of Medicine Tobey MacDonald, MD, Director and Aflac Chair/Emory, Pediatric Neuro-Oncology

Recent Advances in Pediatric Brain Tumors, Understanding and Care: A Primer for Families Roger J. Packer, MD, Senior Vice President, Center for Neuroscience and Behavioral Medicine, Endowed Distinguished Professor & Director Gilbert Family Neurofibromatosis Institute, Director, Brain Tumor Institute, Children's National Hospital, DC

> Making Sense of Brain Imaging Gilbert Vezina, MD, Director, Program of Neuroradiology Department of Diagnostic Imaging and Radiology, Children's National Medical Center

# 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

| ि । । । । । । । । । । । । । । । । । । ।  | i change your address for our                            |
|--|--|
| mailing list, or for informa   | tion requests.   |
| Enclosed is my contribution: \$<br>Name of person (if applicable)<br>Please send acknowledgement card to:<br>Name:             |  |
| Address:   |  |
| City/State/Zip:  |  |
| Message:   |  |
| Supporting General Research Education  |  |
|  | nor Foundation (CBTF)<br>877.217.4166<br>e: 301.515.2900 |
| Master Card, VISA, and American Express donations for Cl<br><b>Give Online</b> button on our Web site: <b>www.childhoodb</b> r |  |

secure

PERMIT NO.1338 MERRIFIELD, VA **DIA9 JDATRO9 SU** NON-PROFIT ORG

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



# Address change requested

Table of Contents

page 1: Geoff Cornman Memorial Golf Tournament., Funded Grants

page 2: ISPNO, Gracious giving, support

page 3: Campaigns

page 4: Fundraising

Page 5: In Honor of

Page 6: Remembrances

Page 7: Videos (no charge), Donation page

Email request and send your story if you like. Five Video sessions with the experts are posted on our website.

CHILDHOOD BRAIN TUMOR FOUNDATION. THIS NEWSLETTER IS A FREE PUBLICATION OF THE

PLEASE LET US KNOW IF YOUR ADDRESS HAS CHANGED. FROM INDIVIDUALS AND CORPORATIONS. WE ARE FUNDED THROUGH CONTRIBUTIONS AND SPONSORSHIPS

OR VOLUNTEER SERVICES TO HELP WITH OUR OPERATIONS. SUPPORT, COMMENTARY OR INFORMATION FOR THIS NEWSLETTER, ME WELCOME ANY DONATIONS IN THE WAY OF FINANCIAL

BRAIN TUMORS. EVERY YEAR THE REQUESTS CONTINUE TO GROW, PROGNOSIS AND QUALITY OF LIFE FOR CHILDREN SUFFERING FROM IKS 501(c)(3) whose mission is to raise money to improve CBTF IS A TAX-EXEMPT, NOT FOR PROFIT FOUNDATION

WE NEED YOUR SUPPORT.

30 Years of Excellence

of excellence, continue to fund programs and research It is through your support we

Thank you to all of our supporters, near and far!

Editor: Jeanne P. Young. Ashton and Grace Cornman Publication: Neurotransmitter

Contributing Editors: Colleen Snyder. Bridgette Wood

Contributors: Roger Abounader, M.D., Ph.D and Simone

Riedel, M.D.

**CBTF Logo®:** Michael Young

Photography: Carol, Ashton, and Grace Cornman

Graphic Design: Bridgette Wood/Wood Web Worx

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

The Childhood Brain Tumor Foundation

Email preferred

Toll Free: (877) 217-4166 Telephone: (301) 515-2900 chtf@childhoodbraintumor.org

gro.romutainthoodbraintumor.org

