

NEUROtransmitter

Communicating our message.



More Than Just a Camp

"I felt like a normal kid again."



That single sentence captures the heart of Special Love, Inc., a Mid-Atlantic nonprofit dedicated to supporting children with cancer and their families through community, connection, and unforgettable experiences.

At the center of that mission are programs like Camp Fantastic and BRASS Camp—week-long adventures designed for children with cancer, survivors, and their siblings. But what happens there goes far beyond campfires and canoe rides.

Special Love was founded in 1983 by Tom and Sheila Baker of Winchester, after the loss of their daughter, Julie, to lymphoma. In the face of unimaginable grief, they chose to create something life giving: a place where children battling cancer could

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Advancing novel therapies for the treatment of pediatric brain tumors with focus on leveraging novel approaches and technologies to advances treatment.

The last decades have brought exciting new approaches to pediatric cancer therapy. The development of molecularly targeted therapies has been transformative for patients with some brain tumors. This is the case many patients with low grade glioma, with extensive clinical trial data supporting use of MEK and BRAF inhibitors for patients with low grade gliomas who harbor mutation in the BRAF gene. These data have importantly led to the FDA approvals of dabrafenib and trametinib for patients with V600E mutant gliomas and tovorafenib for BRAF altered recurrent or progressive low grade gliomas which are exciting landmarks in the pediatric neurooncology field. Building on these successes there are additional ongoing and recently completed clinical trials evaluating the role of these agents in the upfront setting or in combination with other targeted or immunotherapies for patients with less common molecular alterations or where chemotherapy or single agent targeted therapy has failed to maintain tumor control. Hopefully these combination approaches will bring the same therapeutic successes to this patient group. However, targeted therapies alone have not

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Grants: CBTF will announce grants selected for funding this summer in our Fall newsletter edition.

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.



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Online: Video sessions with the experts are posted on our website.

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Advancing Novel Therapies (continued from page 1)

found the same for the treatment of most malignant brain tumors. Whether due to unidentified molecular drivers, poor brain penetration of targeted therapies or inherent or developed treatment resistance, novel targeted approaches are still needed for many pediatric brain tumor patients and this remains an active area of both laboratory and clinical research.

Another avenue of very active therapeutic research is in the field of immunotherapy. On the heels of several successes using immune-oncology therapeutic approaches for the treatment of challenging cancers such as recurrent leukemia, melanoma and pancreatic cancer, there has been an exponential expansion of research investigating various approaches to leverage the sophisticated immune system to target pediatric brain tumors. Whether focused on medications such as immune checkpoint inhibitors which turn off the brakes signals in the immune system (PD-1/PDL-1, CTLA-4 and other immune checkpoint inhibitors) or the development of modified immune T cells (Chimeric antigen receptor-T cells (CART) or tumor associated antigen T cells (TAA-T)) or creation of tumor vaccines and discovery of oncolytic viruses, there are numerous active clinical trials evaluating the potential for these therapeutic approach to transform the care of pediatric brain tumor patients. (clinicaltrials.gov) While there have been some encouraging early experiences in limited patients, aside from patients with hypermutant brain tumors, immunotherapy approaches remain investigational in most pediatric brain tumor settings and an area of active research. Current clinical trials build on this rapidly evolving preclinical or laboratory research as well as building on evolving clinical trial experience in brain tumors and other diseases. And laboratory scientists continue to research and develop better pediatric brain tumor models which can support enhanced research in this area. More recently, combination therapy

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

New events locally and out of state are always appreciated

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

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 to cure childhood brain tumors!

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!

Special Love (continued from page 1)



reclaim the simple joys of childhood—laughter, friendship, and freedom from being defined by their diagnosis.

As one camp mom said, *“The hospitals saved my son’s life. Special Love saved his soul.”*

What began as a single camp serving 29 children has grown into a network of more than a dozen programs, reaching over 1,000 individuals each year. In addition to in-person and virtual programs, Special Love provides emergency financial assistance to families and scholarships to young adult survivors and siblings—extending its impact well beyond the campgrounds.

Its flagship program, Camp Fantastic, brings children ages 7–17 to a fully equipped, medically supervised camp experience. Diagnoses include all forms of including brain tumors. With clinical monitored, and

leadership from the National Cancer Institute, even children in active treatment can safely participate. Medications are carefully managed, health is closely monitored, and every detail is designed so campers can focus on one thing: being kids.

The results can be profound.

A child who hadn’t eaten solid food in nine months takes a bite of a hot dog. A teenager reduces her reliance on pain medication by 90% during the week—and maintains that progress after returning home. These moments are not just breakthroughs; they are glimpses of healing that medicine alone cannot provide.

While the days are filled with swimming, sports, and laughter, the deeper impact often happens in quieter moments—late-night “bunk talk,” where campers and families share their fears, hopes, and stories with others who truly understand. In those conversations, isolation fades, and something powerful takes its place: belonging.

As one camp mom said, *“The hospitals saved my son’s life. Special Love saved his soul.”*

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The dedicated support CBTF receives from friends, families, constituents, and businesses ensure that we are able to support important programs. Our funding encourages young investigators to continue to pursue their research efforts.

Thank you so much!

CBTF Sponsorships

CBTF is delighted to provide a Silver sponsorship for the **2026 International Symposium on Pediatric Neuro-oncology, 22nd**. The symposium will be held from June 28th–July 1st in Sydney, Australia. The shared knowledge is always enriching.

As in past years, we are pleased to provide support in 2026 to the **Society for Neuro-Oncology** for the international program in **Sub-Saharan Africa**.

Special Love (continued from page 3)



One camper, who later returned as a counselor, said it best: “*Camp gave me a place where I could set my worries aside and just be myself with people who understood. Coming back as a counselor gave me the chance to give that same gift to someone else.*”

Special Love isn’t just a camp. It’s a lifeline. A community. A place where children rediscover joy—and where families find strength in knowing they are not alone.

To find out more, visit Special Love at <https://speciallove.org> or call 888-930-2707.

Written by Dave Smith, Special Love’s Sr. Director, Outreach & Programs

Advancing Novel Therapies (continued from page 2)

approaches which further seek to overcome the immunosuppressive tumor environment are also expanding. The field anxiously awaits updates on the progress of some of the ongoing pediatric immunotherapy trials at the upcoming ISPNO meeting this summer.

Another exciting area or therapeutic development that has seen rapid recent expansion is in leveraging technological and bioengineering advances. This includes approaches leveraging tumor treating fields, laser therapy and focused ultrasound for the treatment of brain tumors. These exciting and minimally invasive approaches are a more recent area of active clinical research and may provide an important partner to more traditional and immunotherapy approaches as well as broadening options for neurosurgical approaches to tumors which cannot be readily or safely removed surgically. Laser interstitial thermal therapy (LITT) which involves a thin laser fiber being advanced into the tumor to heat and destroy the tumor tissue is one approach which is rapidly expanding. This approach has been used more extensively in pediatrics in treating epilepsy where seizures come from a define areas in the brain. However, with increasing safety experience and examples of its use in treating brain tumors in adults, several clinical trials in development will investigate the use of LITT in treating pediatric brain tumors as well.

Finally a rapidly emerging broad field of study that leverages advances in ultrasound technology is the field of therapeutic focused ultrasound. Focused ultrasound utilizes focused sound waves to target treatment areas is a non-invasive way and is being actively studied in many forms for the treatment of brain tumors in children and adults. High intensity focused ultrasound (HIFU) which can be used in a similar way to LITT to non-invasively heat and damage areas of tumor is being evaluated at Children’s National Hospital in a clinical trial for the treatment of pediatric low grade gliomas as well as being studied in several settings in adult brain tumors. While HIFU provides an exciting non-invasive approach, the use if HIFU is currently limited to smaller tumors in certain areas of the brain. However as technology continues to advance and clinical trial experience expands, HIFU will likely expand in application. Additionally, low intensity focused ultrasound (LIFU) which delivers non damaging ultrasound energy to precise locations in the brain is also an active and exciting area of research. LIFU can be utilized therapeutically to activate a sonosensitizer medication focally within the tumor (sonodynamic therapy) or with intravenously infused microbubbles to focally and temporarily open the blood brain barrier enhancing delivery of anticancer therapies to the tumor specifically and limiting toxicity to surrounding brain tissue. This novel approach to blood brain barrier opening has the potential for much broader application for delivering treatments which may have shown promise in laboratory studies but were previously limited by poor brain penetration. The active and recently completed clinical trials in pediatric DIPG patients of both sonodynamic

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In Honor of

Advancing Novel Therapies (continued from page 4)

therapy and blood brain barrier disruption provide critical safety experience for this approach in children and builds the foundation for more rapid expansion and application of this technology more broadly. Finally, with increasing evidence that focused ultrasound has potential immunomodulatory effects the next two clinical trials utilizing LIFU at Children's National which will open soon for pediatric patients will evaluate the combination of LIFU technology with immunoncology approaches, marrying two exciting novel approaches for therapy. ^{vii}

Just as laboratory researchers continue to build on exciting advances in our understanding of the complex biology of pediatric brain tumors and the influence of the tumor immune and microenvironments, emerging clinical trials will leverage novel and combination approaches in targeted therapy, immune-oncology and rapidly evolving bioengineering advances.

Special thanks to Lindsay Kilburn MD, Clinical Director of Neuro-Oncology and Director of Neuro-Oncology Experimental Therapeutics, Children's National Hospital for contributing this article.

[https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-dabrafenib-trametinib-pediatric-patients-low-grade-glioma-braf-v600e-mutation#:~:text=The%20review%20found%20that:%20*%20The%20overall,*%20vomiting%20\(38%25\)%20*%20Musculoskeletal%20pain%20\(36%25\)](https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-dabrafenib-trametinib-pediatric-patients-low-grade-glioma-braf-v600e-mutation#:~:text=The%20review%20found%20that:%20*%20The%20overall,*%20vomiting%20(38%25)%20*%20Musculoskeletal%20pain%20(36%25))

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*If I take the Wings
of the morning,
and dwell in the
utmost parts of
the sea; Even there
shall thy hand lead
me, and thy right hand
shall hold me.*

139th Psalm

Remembering Bev Gough and Tommy Gough

On behalf of CBTF and the families that benefitted from the efforts of Beverly Gough and her son, Thomas, we wish to express our heartfelt sympathy. Bev died in October 2025 and Tommy, August 2023. Bev and Tommy were passionate, kind, and committed to their dedication to make the Carol Jean Cancer Foundation's Camp Friendship, Laytonsville, MD, an adventure and full activities for children battling cancer. It was an overnight camp that brought a great deal of joy to children and their siblings. Bev and Tommy are missed and appreciated for their many years of outstanding service.

In Honor of

Our dedicated scientific advisors. They dedicate their time and compassionate care for their patients and families. We honor them for their commitment of voluntary reviewing grants and assisting CBTF as needed.

Special thanks to Drs. Kenneth Aldape, Roger Packer, Kristina Hardy, Tobey MacDonald, and Gilbert Vezina for working with our videographer, Neil Rubino, to tape presentations on various topics. No charge to view, register for log-in to access the videos: cbtfc@childhoodbraintumor.org

**Nancy Bittle
Fae Daniels
Jenny Hahn
Roger Packer
Michael Schoenfeld**

GRACIOUS GIVING

**BY CHECK: CBTF or
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included with the acknowledgment. Thank you!

The Childhood Brain Tumor Foundation is
dedicated to funding research for all pediatric brain
tumor types. We also provide resources, infor-
mation, and consult names upon request.

Visit our secure website:

www.childhoodbraintumor.org

**Go to our Support page and click on
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Please contact us if you have any questions:
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RESOURCE CORNER

Book Guide

**Differentiating Instruction for Students with Learn-
ing Disabilities, New Best Practices**

William N. Bender

A Guide to Collaboration for IEP Teams

By: Nicholas RM Martin, M.A.

A Parent's Guide to Special Education

By: Linda Wilmshurst, PHD, ABPP and
Alan W. Brue, Ph.D, NCSP

**Meeting the Challenge: Special Education Tools
That Work for All Kids**

By: Patti Ralabate

National Education Association

**Negotiating the Special Education Maze: A Guide
for Parents**

By: Winifred Anderson, Stephen Chitwood, Deidre
Cherie Takemoto

The Complete IEP Guide: 12th Edition

**How to Advocate for Special Ed Services for Your
Child**

By: Attorney Lawrence M. Siegel

Wrightslaw: From Emotions to Advocacy

Wrightslaw: Special Education Law

By: Peter W. D. Wright, Pamela Darr Wright
www.wrightslaw.com

**Books via LD provides information about Learning
Disabilities, ADHD, and Parent Management of op-
positional Behaviors:**

www.ldonline.org

Remembrances, CFC, Maryland Charities



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 Carson Bailey
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 Debbie Bell
 Cameo Beauchesne
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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

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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
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together, reaching for a cure!

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