TOMMY STRONG FOUNDATION

NEWSLETTER

ISSUE 02 / FALL 2021

HOPE, STRENGTH AND LOVE, POWERED BY TOMMY

Tommy was a beautifully sweet, silly and caring little boy. He loved his siblings, Star Wars and Legos, and he had a gift for making his family and his buddies laugh. At age four, Tommy was diagnosed with a brain tumor, and he fought a brave two-year battle with strength and resiliency. After he passed away, we founded the Tommy Strong Foundation as a way to honor Tommy's legacy by helping other families affected by childhood cancer.

The Foundation's mission is to support the medical community as they work to find a cure and better treatments for childhood cancers; and also to support children and families as they navigate through a cancer diagnosis, treatment and everyday life. Tommy Strong has helped to fund clinical trials, research labs and patient support services, and has provided meals, toys and care packages to patients and families. With your support, the Tommy Strong Foundation will continue to do more for these children...to allow them to hope, dream and get back to being a kid again.

FUNDRAISING AND EVENTS

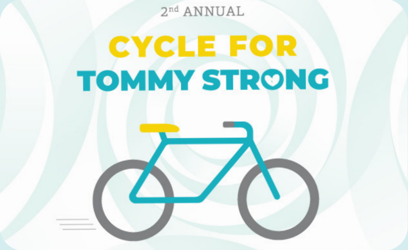
In 2021, in-person and virtual fundraisers and events contributed over $78,000 to support the Tommy Strong Foundation in our mission to end childhood cancer. These fundraisers ranged from large scale events to smaller community and individual fundraisers that included restaurant and shopping giveback days, Facebook birthday fundraisers, Amazon Smile shopping donations, and individual races and fundraisers.

"CLASS OF 2031" BASEBALL GAME

Two teams of 2nd graders met at Ramsey, NJ's Finch Park in May to kick off their inaugural fundraising game for the Tommy Strong Foundation. The boys honored their friend, classmate and honorary teammate, Tommy FitzPatrick, as they raised awareness and money for childhood cancer research. It was an exciting day of baseball that featured turquoise bases (Tommy's favorite color), ballpark music, spirited play-by-play announcers and a lot of fun.

Total Raised: $6,000

CYCLE FOR TOMMY STRONG



Forty at-home cyclists teamed up during Brain Cancer Awareness Month in May for the 2nd Annual "Cycle for Tommy Strong" event. Together they cycled over 4,000 miles to bring awareness to pediatric brain cancer and to raise money to help fund pediatric brain cancer research.

Total Raised: $25,000

CHRIS MCCARTHY GOLF OUTING

In September, Tommy Strong was invited by Tim McCarthy and family to be the beneficiaries of the 18th Annual Chris McCarthy Golf Outing, held each year as a memorial to Tim's brother, Chris. The outing brought together family, friends and supporters for a fun day of golf at the New York Country Club and raised funds to support the Tommy Strong Foundation.

Total Raised: $27,000

GRANTS AND OUTREACH

IN 2021, THE TOMMY STRONG FOUNDATION DISTRIBUTED $125,000 IN GRANTS TO INSTITUTIONS AND PROGRAMS FOCUSED ON TREATING CHILDHOOD CANCER.

PNOC TRIAL

Tommy Strong awarded a **$50,000 grant** to the **Pacific Pediatric Neuro-Oncology Consortium ("PNOC")** to help initiate and support an **innovative multi-armed clinical trial approach targeted to ependymoma tumors**. After Tommy was diagnosed with ependymoma we learned that there are very few options for therapy and treatment for this disease. Although ependymoma is the third most common pediatric brain tumor, there is not yet effective treatment beyond surgery and radiation. PNOC's Ependymoma Working Group, led by Drs. Mariella Filbin, Derek Hanson, Eugene Hwang and Stephen Mack, brings together scientists and clinicians from institutions around the globe to translate biological findings into more accessible trials for this high-unmet-need disease.

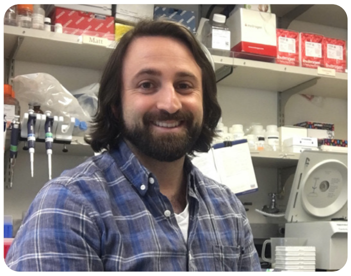
PACIFIC PEDIATRIC
NEURO-ONCOLOGY
CONSORTIUM

NEUROPSYCHOLOGIST GRANT

Tommy Strong granted **$25,000** to **Hackensack Meridian Children's Cancer Institute** to help fund a **new part-time neuropsychologist**. A neuropsychologist studies relationships between the brain and behavior, and conducts evaluations to characterize behavioral and cognitive changes resulting from central nervous system disease or injury. Many childhood cancer treatments have documented neurological effects, and these evaluations are important to identify a baseline of function before the commencement of treatment, and track a child's cognitive changes through and after treatment. Furthermore, these tests provide vital information to support a child's ongoing medical care.

VITANZA LAB

A **$50,000 grant** was made to the **Vitanza Lab**, an independent lab directed by Dr. Nicholas Vitanza at Seattle Children's Research Institute's Ben Towne Center for Childhood Cancer Research. The grant will support a planned **pilot program related to the lab's groundbreaking immunotherapy CAR T cell trials for pediatric brain and central nervous system tumors** that will study how radiation treatment affects the expression of different targets on the tumor's surface. The findings will hopefully allow scientists to determine which children will benefit from CAR T cell therapy and whether those therapies are more effective given before or after radiation therapy.



Dr. Nicholas Vitanza

Holiday Toy Drive Delivery

PATIENT AND HOSPITAL OUTREACH

Throughout the year we work with a number of children's hospitals to determine how we can best fill patient needs. We have been able to provide hundreds of patient support items such as: toys, blankets, phone chargers, books, grocery gift cards, gas gift cards, gaming consoles and games, and meals to hospitals and childhood cancer organizations around the United States.

ADVOCACY AND AWARENESS

ALLIANCE FOR CHILDHOOD CANCER VIRTUAL ACTION DAY 2021

On April 27th, we were proud to take part in the Alliance for Childhood Cancer Virtual Action Day meetings with members of the 117th Congress and their staff to advocate for the prevailing childhood cancer policy issues. Alongside other families impacted by a childhood cancer diagnosis, we shared our stories and urged New Jersey lawmakers to continue full funding of the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act and the Childhood Cancer Data Initiative (CCDI). The STAR Act aims to expand opportunities for childhood cancer research, improve efforts to identify and track childhood cancer incidences, and enhance the quality of life for childhood cancer survivors. The objective of CCDI is to improve treatments and outcomes by facilitating the collection, analysis and sharing of childhood cancer data. We are thrilled to report that both the House and Senate approved full funding for both programs for the next fiscal year.

The FitzPatricks, alongside other childhood cancer families and survivors, met virtually with Congress on Action Day 2021.

FAIRNESS TO KIDS WITH CANCER ACT

In May, Christine and Andrew FitzPatrick joined U.S. Congressman Josh Gottheimer (NJ-5) as he introduced the “Fairness to Kids with Cancer Act” at Hackensack University Medical Center. Our friends and supporters have heard us many times cite the stunning fact that only 4% of the National Cancer Research Budget is directed to childhood cancer research. Rep. Gottheimer, along with Congressman Brian Fitzpatrick (PA-01) and a bipartisan group, are working to increase that rate to more than 20% and deliver much needed R&D funding to the work aimed at finding better treatments and cures for our kids.

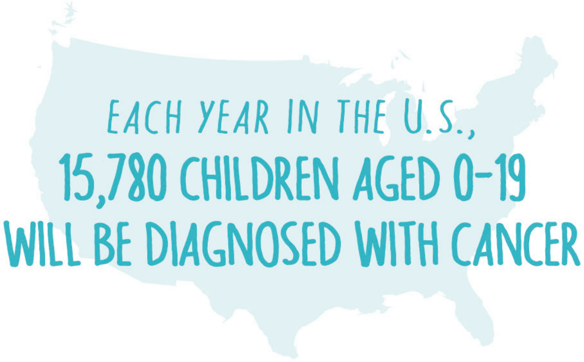
Christine and Andrew FitzPatrick spoke about the need for childhood cancer research funding.

EPENDYMOMA KEY ISSUES

A collaborative effort between ependymoma (a type of brain and spinal cord tumor) advocacy groups across the world, including the Tommy Strong Foundation, was organized in order to prioritize and articulate the unique key issues facing the ependymoma community. The Ependymoma Key Issues tie into the International Brain Tumour Alliance (IBTA)’s Brain Tumour Patients’ Charter of Rights and provides a set of standards for the healthcare experience to which all ependymoma patients and caregivers should be entitled.

Advocacy can be as easy as writing to your state and federal legislators to urge action on state bills or Congressional Acts. The Children’s Cancer Cause website (www.childrenscancercause.org) has a great advocacy resource center to help you learn why, who and how to contact your state and federal legislators. Please share the facts and statistics that you learn about childhood cancer with others. Without awareness and advocacy there is no funding for research and no hope for a cure!

CHILDHOOD CANCER FACTS BY THE NUMBERS



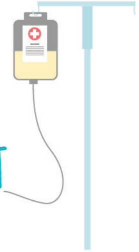
EACH YEAR IN THE U.S.,
15,780 CHILDREN AGED 0-19
WILL BE DIAGNOSED WITH CANCER

ONLY 4% OF THE
NATIONAL CANCER
RESEARCH BUDGET
IS ALLOCATED TO
CHILDHOOD CANCER RESEARCH

MORE THAN 95%
OF CHILDHOOD CANCER SURVIVORS HAVE SIGNIFICANT
HEALTH-RELATED ISSUES
BECAUSE OF CURRENT CANCER TREATMENT OPTIONS

IN THE U.S., CANCER IS THE
LEADING CAUSE OF DEATH
BY DISEASE IN CHILDREN

1 IN 5 CHILDREN DIAGNOSED
WITH CANCER WILL NOT SURVIVE



IN THE U.S., 40,000 CHILDREN
ARE ON ACTIVE TREATMENT
AT ANY GIVEN TIME

THANK YOU FOR YOUR SUPPORT!

Asha-Vijay Foundation Inc.

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Catherine Hannon Quinn Memorial Foundation

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Keychains 4 Cancer

LEAP Preschool

Mary A. Hubbard School

Mesa 21

One Hope

Pizzeria Mandara

Providence City FC

Ramsey Baseball Softball Association

Ramsey Farmers' Market

Ramsey High School Boys Lacrosse

Ramsey Nursery

Ramsey Tap Room and Grill

River Kelly Fund

Tiny Kitchen Candle Co.

Tons of Toys/Tons of Treasures

In Memory of Kellsey London Allen (childhood cancer angel)

In Memory of Chris McCarthy

In Memory of Federico Forcellati

In Memory of Mary Ellen McCarthy

...and all of our individual donors.