



**KORTNEY ROSE  
FOUNDATION**

# KRF CORNER



## 2020 YEAR IN REVIEW

*By: Kristen Gillette*

We've all experienced a year marked with immense challenge and loss. My heart goes out to everyone lost in the pandemic and their families. It's so hard.

Having personally experienced the loss of 9-year-old Kortney in 2006 from a rare brain tumor, my husband Rich, daughter Kasey, and I have acquired a different mindset than we had before. Once you're thrown into the world of childhood cancer, you and your life are changed forever. We've gone to great lengths to protect each other from COVID exposure to help reduce the possibility of ever having to experience that kind of pain again.

We're grateful for our health, a roof over our heads and food on our table. That's not to say it's been easy or fun, but we choose to try to focus on what we have rather than what we don't. We miss you all and can't wait until we can hug everyone again.

The Kortney Rose Foundation (KRF) is truly grateful for our amazing family of donors. In one of the worst years, YOU still came through for us.

In 2020, KRF donated \$100,000 to support the Children's Brain Tumor Network (CBTN), Optic Nerve Glioma research, High Grade Glioma research projects, Neuro-Oncology research at the Children's Hospital of Philadelphia (CHOP), and the creation of the position of **The Kortney Rose Foundation Pediatric Clinical Researcher in Neuro-Oncology at CHOP**, Cassie Kline MD, MAS.



**QR Code = The Kortney Rose Foundation website.**

- 1) Open camera on phone
- 2) Line up QR code in frame
- 3) Top of screen tap "open" when website pops up.

### IN THIS ISSUE

**2020 Year in Review**

**Page 2**

**2020-21 Events**

**Page 3**

**Research Update**

**Page 4**

**Research Update (cont.)**



***"While labs around the world shut down due to COVID-19, CBTN's work continued. Global researchers could still request and access our data and platforms to continue research from their homes."*** Jennifer

Mason, Director of Operations, CBTN

# EVENTS



Sadly, this year's "Great Food for a Great Cause" fundraiser at all **Turning Point Restaurants** will be postponed until 2022. Fortunately, the 2020 fundraiser was done two weeks before the world shutdown, and a record of over \$106,000 was raised. In the above photo, Kristen and Rich Gillette (Kortney's parents), celebrate with the staff of the Little Silver location the overall success of the fundraiser, and the fact that their location was #1 in donations collected during the weekend event.

Over the past 11 years of hosting this event, through the partnership between the **Turning Point Organization** and The Kortney Rose Foundation (KRF), we have **raised over a half million dollars** to support pediatric brain tumor research in honor of our tagline **Help Get Brain Tumors Off Kids' Minds.**

As you know, it's been a tough year for restaurants. Please dine in, take out, and/or purchase gift cards at any Turning Point Restaurant location to thank them for their partnership with KRF.



Help spread the awareness that May is Brain Tumor Awareness Month. Click [here](#) to find out how.



**Team Run #BFE** (Best Family Ever) has been a partner with The Kortney Rose Foundation since 2016, and have raised nearly \$60,000 for Optic Nerve Glioma research in Ryan's name. Ella and Ryan have been our race starters since 2016.



Ludri, is a brain tumor surviving warrior. She completed her 2 miles and also celebrated her high school graduation during Kortney's Challenge 2020. She was the star of our virtual closing ceremony as well.



Brett, a brain tumor survivor, has been participating in Kortney's Challenge since 2015. He's also been beautifully singing the *National Anthem* before the event for the past six years. He even performed virtually last year.



Last year when we did Kortney's Challenge 2 Mile Fun Run/Walk as a virtual event, we anticipated a live event for 2021. We begin planning with our amazing partners, Monmouth Park Racetrack, a year in advance. We've watched the unfolding situation and have agreed that we won't be assured we can have an event with 600+ participants at the end of July. After careful consideration, we will be doing the event virtually again this year with a live event planned for 2022.

We're excited to welcome back all of our participants from near and far, and hopefully many more. Last year our 500+ registrants, came from 26 U.S. states and 6 countries. Our goal for this year is to have participants from all 50 states and as many countries as possible. Registration will open in March and will be announced on our social media outlets and via email. Please start planning your team now thinking about people you know from other states and countries. We'd appreciate your help to **fill the map.**

**SAVE THE DATE: Virtual Kortney's Challenge weekend will be Friday, July 30th - Sunday, August 1st,**





## RESEARCH RECAP

In October of 2020 the Children's Brain Tumor Tissue Consortium (CBTTC) re-branded as the Children's Brain Tumor Network (CBTN). KRF, as a founding supporter since December of 2010 when they began enrollment and data collection, welcomes the new name. The name better encompasses the collaborative efforts between scientists, clinicians, patients, families, 25 institutions and 50+ foundations who are all working together toward the common goal of curing pediatric brain tumors around the world once and for all. With the largest pediatric brain tumor data set, CBTN is the critical link needed for new precision clinical trials that will hopefully result in cures. CBTN connects, harnesses and empowers the world's diverse expertise through shared resources, collaborative science, big data and powerful platform analytics to make accelerated discoveries possible and personalized clinical trials.



CBTN	2011	2021
# of member hospitals	4 U.S.	25 globally
# of participants	120	3,800+
# of specimens	793	43,000+
# of scientific projects	<5	200+



*Click to watch this quick video: KRF asked a few pediatric researchers around the world what they're excited about in this field of pediatric brain tumor research in 2021.*

In June 2020, KRF was proud to announce the naming of Cassie Kline, MD, MAS as the inaugural **The Kortney Rose Foundation Clinical Researcher in Neuro-Oncology at the Children's Hospital of Philadelphia (CHOP)**. Dr. Kline is an attending physician and Director of Clinical Research in the Department of Neuro-Oncology. She joined with a goal to open eight new clinical trials for children and young adults with brain tumors by year-end 2020. That goal is nearly met with five opened in 2020 and the final three opening by the end of 2021.



Dr. Michael J. Fisher, Chief of the Section of Neuro-Oncology at CHOP, & Dr. Cassie Kline, ***The Kortney Rose Foundation Clinical Researcher in Neuro-Oncology at CHOP***, are wearing KRF custom lanyards. We supplied the lanyards to the staff of the Department of Neuro-Oncology and the CBTN Operations Center at CHOP. Like all other health care heroes, around the world, they continued to care for pediatric brain tumor patients throughout the pandemic. Brain tumor diagnosis and treatments don't stop during a pandemic.

## RESEARCH RECAP (Continued)

**Dr. Jessica Foster**, Neuro-Oncologist at **CHOP**, continues to see progress with the **Immunotherapy** study she leads for use in **high grade gliomas**. KRF began funding this project during the pre-clinical work and continues to support these efforts as they move toward clinical trial.

**Dr. Javad Nazarian and Dr. Sabine Mueller**, lead the **Diffuse Midline Glioma (DMG-ACT) clinical trial** at the **DMG Center in Zurich, Switzerland**. This collaborative program includes a group of researchers from 15 international institutions who have joined forces to develop a pre-clinical platform. This will allow testing of combination therapies, share data in real-time, and validate observations across multiple laboratories.

**Dr. Derek Hanson**, Head of the Pediatric Neuro-Oncology Program at **Hackensack University Medical Center**, leads a trial in partnership with the Dana-Farber Cancer Institute. The **trial just opened** in the summer of 2020. KRF's funding supports the cost of the drug for the patients in the trial.

**With your help, we can continue to speed the development of new therapeutics to improve scientific understanding of how to treat children with brain tumors.**

**DONATE NOW**

# OTHER WAYS TO DONATE

Shop at AmazonSmile and Amazon will make a donation to:  
**THE KORTNEY ROSE FOUNDATION FOR PEDIATRIC BRAIN TUMOR RESEARCH**

Get started

amazon smile

DOUBLE YOUR DONATION

WILL YOUR COMPANY MATCH YOUR DONATION?

FIND OUT INSTANTLY!

**Distinctive Toys**

595 River Rd., Fair Haven, NJ

**Kortney's Korner**



**KORTNEY ROSE FOUNDATION**

Purchase a book from our special donated selection and 100% goes to fight pediatric brain tumors!

*Thank you to Margaret Spicer and Distinctive Toys for their generous and loyal partnership with KRF. This unique toy store donates new books and toys for KRF to donate to pediatric hospitals in honor of Kortney's Birthday. In 2020, due to COVID, donations were suspended. To continue to support KRF, Margaret created "Kortney's Korner" full of new books that when purchased benefit KRF.*

*Please visit Distinctive Toys. You can't beat their personal attention and great toy selection.*

