

DELANEY'S DIARY

The official newsletter of Laney's Legacy of Hope



First Grant for Research

On February 16, 2018, members of the Board of Laney's Legacy of Hope traveled to the Children's Hospital of Philadelphia to present Dr. Richard Aplenc (pictured) and his team with a grant for \$100,000. This trial, known as CAR (Chimeric Antigen Receptor) T-cell Immunotherapy, is aimed at treating relapsed and chemotherapy-refractory AML (Acute Myeloid Leukemia), which is exactly the type of pediatric cancer that Delaney fought so bravely.

Dr. Aplenc and his wife, Tina (also pictured), have been at the forefront of groundbreaking treatments for multiple types of pediatric cancer at CHOP. Because the grant from Laney's Legacy was the final amount needed, the CAR trial is now in production and the team expects to be administering to their first AML patients- not only at CHOP, but nationwide- in December.

Money for this research grant was raised over the last 4 years at various fundraising events such as the annual Fashionista 5K and Golden Galas, and contributions by our many faithful sponsors. The Board has set a goal of another \$100,000 grant for 2021.

More about CAR-T cell immunotherapy at:

<http://www.chop.edu/cccr/area-of-study/treatment-pediatric-acute-myeloid-leukemia-aml-chimeric-antigen-receptor-car-t-cells>

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LLH Gives Back

At Ronald McDonald House

Members of the Laney's Legacy of Hope family visited the Ronald McDonald House in Hershey on January 28. The Ronald McDonald House keeps children and families together by providing temporary housing, at no charge, to out-of-town families of seriously ill children who are being treated at Penn State Children's Hospital. The Brown family spent time there during/in between some of Delaney's hospitalizations.

During stressful times, sometimes the simplest things can make a family feel "normal" or at home. Meals are prepared regularly by families and organizations who volunteer their time, using the beautiful kitchen and facilities provided by the RMH. Families staying there can eat as the food is made- either in the dining areas or in their rooms. For families on the go, there are almost always leftovers to be found in the refrigerator.

Laney's Legacy of Hope was proud to provide breakfast for the families we met on Jan. 28. It was a fulfilling experience to be able to give to them as they are going through tough times, just as families had done for Laney and the Browns in the past.

In addition to preparing breakfast, we were happy to deliver lots of toys and crafts to replenish the closet seen in our picture. Not only is the RMH a comfy and welcoming place to be if you can't be at home with your family, but children are invited to help themselves to the toy and craft closet while they are there! Our additions were generously donated by the Learning Express of Wyomissing.



At Wyomissing Mini-Thon

Laney's Legacy of Hope was honored to participate in the Wyomissing Mini Thon on March 16! Some background on Mini-Thon and Four Diamonds: Four Diamonds was founded to assist children and their families in the fight against childhood cancer. Penn State united with Four Diamonds, and named them the sole beneficiary of all THON (annual 48 hour dance marathon) fundraising efforts. Four Diamonds covers 100 percent of all medical expenses related to cancer care not covered by insurance for eligible Four Diamonds children. Because of the community's steady and generous support, much of this support coming from Mini Thons, Four Diamonds has assisted 100 percent of the childhood cancer patients who have been treated at Penn State Children's Hospital. The Four Diamonds Organization was a lifesaver for the Browns when Delaney was in the hospital & they remain close with the family to this day. Every dollar raised at every Mini Thon goes toward families of kids fighting cancer. We were so pleased to be able to give a little bit back, with 102 glitter tattoos applied!



Photos by Chad Vail Photography

5th Annual Fashionista 5K West Reading, PA

After a week of discouraging weather reports, Mother Nature (or Laney?!) did us a solid as we said "Go!" for the 5th time. The Fashionista 5K on May 6 hosted 292 runners. While this was not our highest number of registrations, this race will go down as one of our favorites to date- featuring the best swag bags, lots of entertainment and some very special guests. We were joined by two of Laney's Fighter Families (pictured far left- Riley Rejniak & family, left- Vinny Lucchese & family) and Dr. Richard Aplenc of CHOP!

A demonstration by Elite Leadership Martial Arts Academy of Shillington kicked off the festivities, and after the race our friends enjoyed donuts by Donut NV, music by DJ Koolie Kirk, a photo booth donated by Reading Orthodontic Group, meet & greet with Snow White and Ariel from Marina Princesses, face painting, carnival games, free massages by Matthews Hansen Chiropractic and card making for Laney's Fighter Reynaldo who is recovering from surgery.

In addition to medals for our race winners, awards were presented to our Best Dressed of the day. Pictured far left are West Reading Mayor Andrew Kearney and Dr. Aplenc presenting one of the awards.

UPCOMING EVENTS

AUGUST 10

*2nd annual Golf Tournament at Chapel Hill, Reading
Buffet Dinner, Drinks, Raffles, Silent Auction, Prizes for top 3 teams plus additional course challenges*

SEPTEMBER 22

*4th Annual Golden Gala at the Crowne Plaza, Wyomissing
Our biggest event! Formal Affair including Dinner, Live Music, Trip Giveaway, Raffles*



Save the Dates!

Please see our Facebook page for complete event details.

FIGHTER UPDATES



Reynaldo Flores

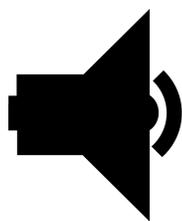
"Rey" is Laney's very first Fighter. He was diagnosed with Choroid Complex Carcinoma (a type of brain cancer) in 2013 & has been fighting ever since. Now 17 years old, Rey has undergone multiple rounds of chemotherapy and operations to remove tumors as they continue to grow in his brain. There is no cure for what Rey is fighting, only hope that the tumors can be held at bay while one is being developed. During his most recent surgery in May '18, Rey suffered a stroke that left the right side of his body paralyzed. While recovering in rehab at Hershey, he still managed to GRADUATE HIGH SCHOOL! If this does not define Fighter, we don't know what does!

For each year that a child is fighting cancer, they are eligible to receive a grant from Laney's Legacy of Hope. We are proud to have helped Rey and his mother, Emma, again this year during his hospitalization with money raised at our many fundraising events, as well as donated by our generous sponsors and supporters. Pictured is Rey in his room at rehab surrounded by cards made for him at our 5K.



Vincent Lucchese

"Vinny" was diagnosed with Retinoblastoma in 2017 when he was 20 months old. Retinoblastoma is a cancer of the eye primarily found in children 5 years and under; it is classed from A to E. Vinny's tumor was determined to be an E and consumed 50% of his eye. If not treated, it would have been fatal. If the tumor had affected his optic nerve, Vinny's eye would have had to be removed. Fortunately, it was determined the optic nerve was not involved and Vinny underwent IAC- Intra-Arterial Chemotherapy. IAC involves a catheter entering the body through an artery in the hip and traveling up to the eye, where chemotherapy is administered directly to the tumor. The process of getting from the hip to the eye and back out again is about 3 hours. Vinny went through 2 rounds of IAC and is now considered to be in remission. The tumor is gone, but he will remain in conservative care until the age of 5 to monitor for any recurrences. Vinny's eye must be patched for 2 hours each day until age 8 to help strengthen it and prevent a lazy eye. The family is happy to report that Vinny's central vision was not damaged, which occurs in 90% of children with this rare disease.



ANNOUNCING:

CORPORATE CHAMPION

An easy new way to sponsor Laney's Legacy of Hope! Corporate Champions pledge to donate yearly to Laney's Legacy of Hope over their choice of 3 or 5 years and, in return, receive advertising and VIP access to all of our events within that period. At this time, we are offering 4 levels of commitment with varying benefits. We know that our mission to help families fighting pediatric cancer has touched you. With your multi-year pledge, we can make a huge difference in the lives of families battling pediatric cancer as well as prepare our next grant for research.

For details on levels of commitment and to sign up, please visit:

<https://www.laneyslegacyofhope.org/corporate-champions/> or contact avail@laneyslegacyofhope.org

