



Keira Kilbane Foundation 2016 Annual Report

Dear Friends,

I would like to start off by saying thank you to all of our donors, volunteers, and partners. It is because of your hard work that we were able to have a big year in 2016. With your support we were able to impact more families, both the number of families we helped and the financial assistance we could provide. We were able to contribute more financially to research in pediatric cancer, including a \$10,000 grant to Dr. Agne Petrosiute. We also continue to put money towards the new Inpatient Pediatric Cancer Unit at Rainbow Babies and Children's Hospital.

We made new friends through a Father's Day trip to Progressive Field with some amazing people, and we were privileged that they shared their stories with us. The KKF was honored to be chosen by Mediquant as the recipient of their company charitable arm, In Great Company, as well as the donations from several other companies. Through the generosity of our individual and corporate partners we continue to try to make a positive impact for those patients and families dealing with cancer.

2017 is here, and as we reflect on our accomplishments in 2016, and the advances we have made in our ultimate mission we are reminded of how many more miles we still have ahead of us. Together with your continued support we hope to continue to grow, and spread the word about the reality that is Childhood Cancer and continue the fight. Without the generous spirit of all that have been touched by Keira and her story, we would not be able to do what we do today, so from all of us at the Keira Kilbane Foundation we wish to say THANK YOU!

Brian Kilbane

Keira Kilbane Foundation Fundraising Updates

We were very pleased with the success of our fundraising in 2016. Below is a summary of our primary fundraising events. Pictures can be found on our website:

<https://www.keirakilbanefoundation.org/your-money-at-work/>

The second annual **Keira Kilbane Foundation 5K and 1 Mile Fun Run/Walk** presented by **Simply Distinct Kitchens & Baths** took place on July 24, 2016. The race began and ended at the Station Road Bridge Trailhead on the Towpath in Brecksville, Ohio. We added the 1 Mile Fun Run and it was well received. We surpassed our goal by having 148 people register for either the 5K or 1 Mile Run Fun. We raised \$2,800 after expenses (\$6,200 revenue; \$3,400 expenses).

The Keira Kilbane Foundation championed the **12 Days of Keira Christmas** campaign to help raise funds specifically for purchasing gift cards for families that were in the hospital on the pediatric cancer unit. We raised \$1,927 through the GoFundMe campaign after the administrative fees.

In Great Company One Can Do Great Things and **Mediquant, Inc.** selected the Keira Kilbane Foundation as the charity for their 2016 fundraising efforts. The main fundraising event was the **Cut Loose for Kids Cancer Benefit** held at the Country Lakes Party Center on November 5th. The total amount raised for 2016 was \$19,630. We are so appreciative of their support and a special thank you to Tony Paparella, MediQuant Founder and President for providing a personal \$5,000 match to the funds raised to get us to \$19,630. Please note that the \$5,000 was provided in 2017 so that will be accounted for in our 2017 finances.

Salon Evangelene hosted the **2nd Annual Cut-a-Thon** on behalf of the Keira Kilbane Foundation on March 18, 2016. Services included were haircuts, eyebrow waxing, manicures, and massage. The total amount raised was \$1,523 which was about \$300 more than the first year. Two young girls also donated their hair as well.

SIRVA Mortgage, Inc. selected the Keira Kilbane Foundation as the charity for their Q4 2016 fundraising. The total amount raised was \$939.

Additional corporate fundraising efforts of note were \$2,600 from employees and employer matches with **United Health Care** and **Lubrizol**, a \$200 donation from the **Portage Country Clerk of Courts**, and a \$250 donation from the **UH Department of Pathology**.

We were also fortunate to be selected by several groups to receive the proceeds from funds they received:

- Cleveland Marathon participant Crowdrise campaign - \$535
- Peanuts for PNET - \$488
- LuLaRoe Fundraiser - \$350
- Garage Sale - \$200
- Giving Tuesday Donations - \$525
- In honor of Joseph Kish - \$840
- In Lieu of Wedding Favors - \$485

The Keira Kilbane Foundation receives a percentage of total proceeds with the **Amazon Smiles Program** and **Bravelets**. We received \$33 from Amazon Smiles and \$110 from Bravelets. However Bravelets previously provided a \$10 donation for every Bravelet purchase, but in 2016 they transitioned to providing a percentage of the overall proceeds so we anticipate future donations to be much smaller.

Thanks to our wonderful donors and their generosity, the Keira Kilbane Foundation also received **\$6,000 in general donations** and **\$5,000 of In Kind donations** throughout 2016. Examples of In Kind Donations included: Tablets, silent auction items, store gift cards, and a meal for the inpatient unit.

Keira Kilbane Foundation Research

We donated \$11,000 to the **Keira Kilbane Cancer Discovery Fund** at Rainbow Babies and Children's Hospital (where Keira was treated). This fund will be used to support childhood cancer research with a focus on leukemia.

In 2016, the Keira Kilbane Cancer Discovery Fund awarded \$10,000 to support Agne Petrosiute, MD, and her effort exploiting key protein Cdk5 in the development of immunotherapeutic approaches to treat childhood cancer.

Dr. Petrosiute completed her fellowship at [UH Rainbow Babies & Children's](#) and rose through the ranks of fellow, instructor, and now Assistant Professor since 2009. Dr. Petrosiute and Dr. [Alex Huang](#) have obtained several grants together. Most recently, they have co-senior authored a major breakthrough paper published in the journal, *Science*, in July 2016, detailing a paradigm-shifting discovery of how Cdk5 is involved in tumor cell evasion of the immune system.

The money will allow Dr. Petrosiute to buy reagents and equipment and utilize University Core facilities.

Updates from Dr. Irina Pateva on Funds granted in 2015.

The money will be used for two projects: One is to study the role of platelets in pediatric patients with tumors as a potential factor in tumor progression and if high platelet counts impact survival. This is the first study in pediatric patients. We have an IRB approved

protocol and a database created, with the information entered, we have to verify it, to make sure it is accurate before we analyze it. We will need a help from statistician for the statistical analyses, once it is done, we will write up a manuscript. The template for the manuscript is done, it is a matter of summarizing the information once we have the statistical part done. We will use ~ \$ 1,000 of the money for support for the work of the statistician, which is planned to occur ~ mid-August. Then we will finish the manuscript.

The other project is to study the role of Cdk5 as a marker of disease activity in pediatric patients with ALL. We have 30 samples from COG and ~ 10 samples from patients from UH from patients with leukemia at diagnosis and at remission. I have and IRB approved protocol to allow me for collection of more specimens from patients with leukemia. I plan to analyze those specimen and I will use the money from the grant to buy lab supplies – antibodies and reagents for protein and RNA analyses. We will look at Cdk5 expression and also at some other proteins that are substrates of Cdk5 and have been known to be involved in cancer cell replication and survival. I have a draft of a manuscript with my preliminary data from 5 patients studies so far, the goal will be to do the lab analyzes of all the other samples and add on the information in the manuscript. I will set aside ~ 1000 for publication fees.

We also committed to donate \$25,000 over five years (completed in 2019) to Rainbow Babies and Children's Hospital for the creation of the **new pediatric cancer inpatient unit**. This will allow patients and families to have upgraded facilities for their treatment and bring the inpatient and outpatient units into the same building. It will also enable the physicians to continue to provide their excellence in patient care.

Keira Kilbane Foundation - Supporting Patients & Families in Treatment

The Keira Kilbane Foundation provided \$8,000 of **financial support** to three families in 2016 total. Oftentimes treatment can lead to unexpected expenses and reduced income due to a parent having to quit their job due to the child's treatment schedule. We were able to help keep a family in their house, help provide money to offset some funeral expenses, and provide basic financial assistance to a family where the mother was unable to work due to frequent inpatient stays. Additional details can be found on our website: <https://www.keirakilbanefoundation.org/your-money-at-work/>

On March 29, 2016 the Keira Kilbane Foundation partnered with Camp TLC to provide **17 tablets and stuffed animals** to childhood cancer patients at Rainbow Babies and Children's Hospital, the Sedation Unit, and a patient that was treated at the Cleveland Clinic. The Keira Kilbane Foundation purchased five tablet covers for the tablets donated to the Sedation Unit since those will remain on the unit. The In Kind donation was valued at \$2,800 and the cost for the tablet covered was \$70.

The Keira Kilbane Foundation partnered with the Cleveland Indians to treat some well

deserving dads to a special early Father's Day present on June 18, 2016. Four dads from the pediatric oncology unit at Rainbow Babies and Children's Hospital and a guest of their choice attended the **Indians vs. White Sox game**. The Keira Kilbane Foundation approached the Cleveland Indians about this opportunity and provided limo service from the hospital to the game. The Indians provided tickets, a meal, and Indians hats. The total cost for the Keira Kilbane Foundation was \$605.

A new challenge we encountered for 2016 was additional restrictions at Rainbow Babies and Children's Hospital that limited our ability to provide meals due to infection control protocols to protect the safety of the patients. However, on October 18th the Keira Kilbane Foundation made a **special delivery** to the Pediatric Cancer Inpatient Unit at UH Rainbow Babies & Children's Hospital. We were fortunate enough to be able to provide:

- Dinner from The Winking Lizard along with some Halloween decorations.
- Arts, crafts, and toys for the childhood cancer patients to use during their inpatient stays to try to give them some activities and some sense of normalcy.
- 12 "chemo pouches" that individuals sponsored

The total amount spent was \$165 for the meal and \$425 on toys.

On November 21, 2016 the Keira Kilbane Foundation was honored to donate a **Christmas tree and ornaments** to the inpatient pediatric cancer unit at Rainbow Babies & Children's Hospital. We couldn't resist adding the Hello Kitty ornament to capture Keira. We are hoping to start a new tradition where patients decorate an ornament to include on the Christmas tree. Your dollars at work for a GREAT cause. The total cost was \$224.

On December 30, 2016 the Keira Kilbane Foundation was pleased to be able to use the proceeds from the 12 Days of Keira Christmas campaign to do a special delivery to UH Rainbow Babies & Children's Pediatric Cancer inpatient unit. We partnered with the Cameratta Family to **provide dinner** packaged for each room, along with cookies and pop, lemonade, and bottled water. We also donated \$1,850 in **gift cards to Panera, Jimmy John's, Chipotle, and Subway** for families to use at their convenience. We also left behind some party favors to help the families ring in the New Year. The families were extremely appreciative. We met some wonderful patients and families and will continue to carry on the fight against childhood cancer for them. Thank you to all of our donors for making this possible! The meal and drinks cost \$870.

Keira Kilbane Foundation - Childhood Cancer Awareness

The Keira Kilbane Foundation wanted to take on a new initiative for 2016 by helping advocate childhood cancer awareness and general awareness for our foundation. Our overall expenses to support this initiative were \$107 and we raised \$586 as a result.

We were a charity partner for the **Cleveland Marathon**. This allowed our foundation to get promoted on the Cleveland Marathon website, have a table in Charity Village at the finish line on the day of the race, and get a portion of proceeds for race participants that joined our team.

We staffed a water station at the **Medina Half Marathon**. We were able to promote our foundation with our banner, signs, and t-shirts at our water station. This also allowed us to help promote our 5K by making contacts with several race groups and to build a presence in the Medina community. The Medina Half Marathon presented us with \$500 as a result.

The City of Medina recognized Childhood Cancer Awareness month by partnering with the Keira Kilbane Foundation to decorate the Gazebo in the Medina Square gold from September 23 – 25, 2016. Mayor Dennis Hanwell was present to kick-off **Medina Goes Gold for Childhood Cancer Awareness** and it was highlighted in the Medina Gazette and Cleveland.com. We encouraged the public to take photos in the Gazebo and post on social media to help increase awareness. The event was a great success and something we hope to make an annual event.

Keira Kilbane Foundation - Governance

The Keira Kilbane Foundation operates under a Board of Directors of five voting members.

Brian Kilbane - Chairman of the Board

Jennifer Kilbane - Secretary Treasurer (non-voting board member)

Alex Huang, MD, PhD - Medical Advisor

Holly Podbesek - Board Member

Jeni Potter - Board Member

Brian Tompkins - Board Member

Keira Kilbane Foundation - Financial Overview

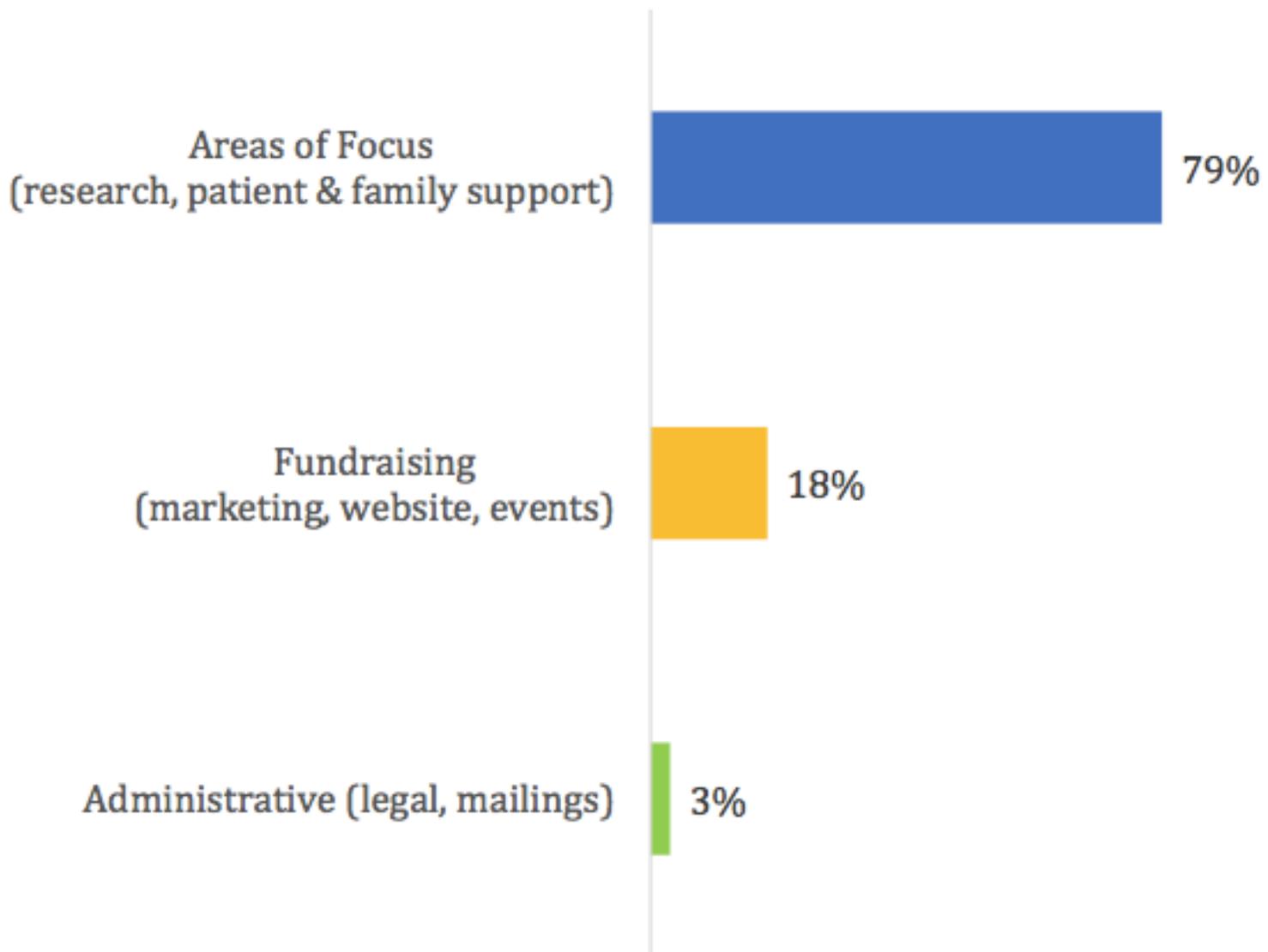
We wanted to take this opportunity to be transparent with our donors regarding how our funds are distributed. The Keira Kilbane Foundation has no paid employees. We rely on volunteers and the kindness of our business partners to provide us discounts as they are able to help our foundation operate. We do our best to minimize our administrative expenses as much as possible so that the funds can be used in our main areas of focus. We learned the hard way that some expenses are necessary, such as general website maintenance. Thankfully we have secured a fantastic web designer that provides us services for a discounted fee and provides more stability for our website.

Statement of Activities

(for year ending 12/31/16)

Total Revenue	\$37,208
Total Expenses	\$34,544
Areas of Focus	\$27,300
Fundraising	\$6,068
Administrative	\$1,166
Change in Net Assets	\$2,664
Net Assets, beginning of year	\$30,582
Net Assets, end of year	\$33,246

Expense Ratios



Since our founding in October 2014

Funds Raised: \$99,293

Funds Spent: \$66,047

Net: \$33, 246

Thanks to the generous donations we have received the Keira Kilbane Foundation has been able to continue to support the fight against childhood cancer.

For anyone that is interested in making a donation they can be made through PayPal directly on our [website](#) using the "Donate" button. Cash or checks made payable to the Keira Kilbane Foundation can be mailed to the Keira Kilbane Foundation, P.O. Box 1530, Medina, OH 44258. We are a 501(c)(3) non-profit public charity so your contributions are tax deductible to the extent allowed by the law.

Children are 10% of the population, but 100% of our future.



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