2018-2019 IMPACT REPORT

# CONQUERING CHILDHOOD CANCER











In the U.S., an estimated

# **16,000** CHILDREN

will be diagnosed with cancer this year.\*



That's nearly

1
every
36 MINUTES.



Because of research advances,

80%+ WILL SURVIVE.

\*American Cancer Society, American Childhood Cancer Organization

We Won't Stop Fighting

UNTIL WE CONQUER CHILDHOOD CANCER





Weston's cancer fight started at Penn State Children's Hospital in 2016 at the age of two, followed by more than 40 weeks of chemotherapy and radiation therapy.

Weston's mom, Amy, says Four Diamonds was a lifesaver for their family – financially and emotionally. They never received a bill for Weston's care because Four Diamonds covers all medical expenses not paid for by insurance, which allowed Amy and her husband to focus on helping Weston get better.

Weston is now five years old and healthy! His family is grateful that Weston can just be a kid again and enjoy the things he loves most – riding a bike, going fishing, helping Daddy in the garden and playing with his brother and sister. Amy also says cancer has taught them what is important in life and how each day is a gift to cherish.

"Regardless of what Weston needed medically, we never received a bill because of Four Diamonds' support – that was an enormous weight lifted off our shoulders."

— AMY, A FOUR DIAMONDS MOM —

## Local Research. Global Impact. TM FINDING SAFER TREATMENTS AND CURES

Four Diamonds' support has been essential to the development of Penn State Health's nationally and internationally recognized research programs.

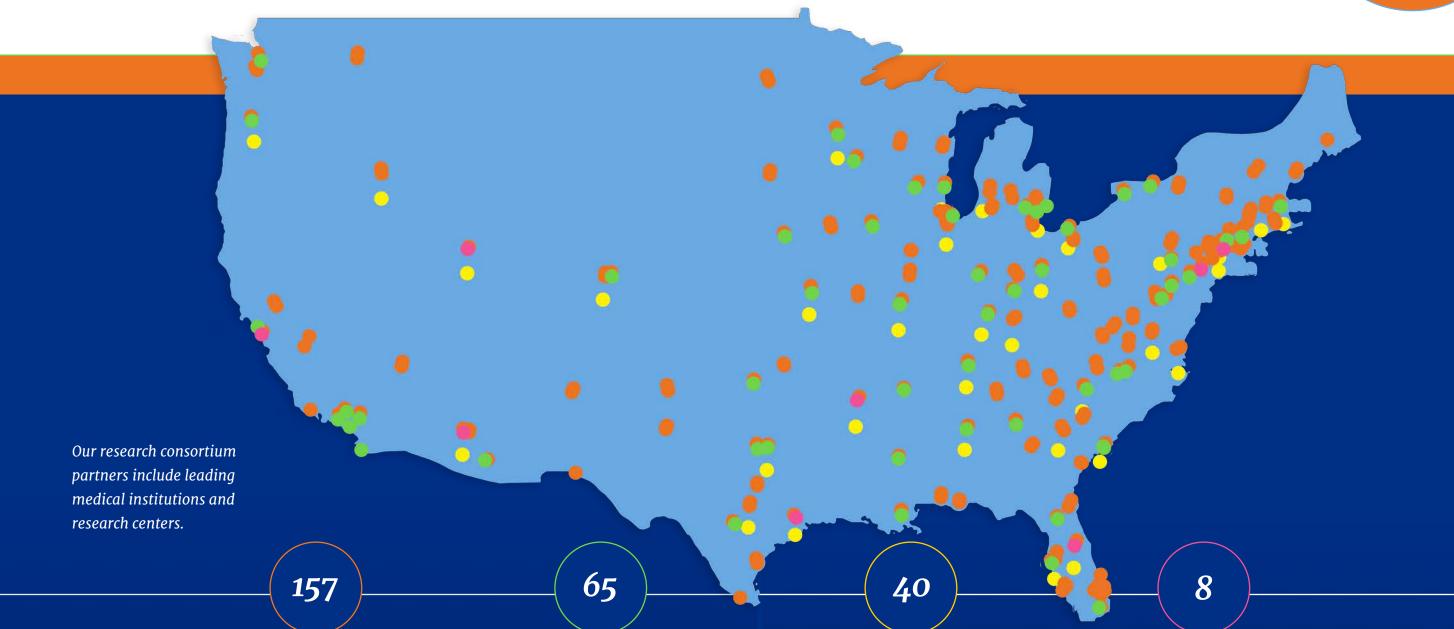
"Membership in national clinical trial groups, recruitment of world-class faculty and our resulting research discoveries would not be possible without the support of Four Diamonds."

Research Consortium Partners in the U.S. — DR. LISA MCGREGOR —

**WE WORK** 

WITH

**270** 



**Children's Oncology Group** (COG)

**Pediatric Blood & Marrow Transplant Consortium** (PBMTC)

**Beat Childhood Cancer** (BCC)

**Pediatric Oncology Experimental** Therapeutics Investigators' Consortium (POETIC)



Thanks to the community's generous support, Four Diamonds scientists and doctors can accelerate our work to:

- CONDUCT CLINICAL TRIALS
   that lead to new treatments and drugs
- OFFER TREATMENT & HOPE
   to patients whose disease is not responding
   to therapy
- FOSTER COLLABORATION
   with doctors and scientists around the world
- TRAIN RESEARCHERS
   so we can continue the fight for the next generation

### HERE'S WHAT WE'VE BEEN WORKING ON:

Our research team is developing clinical trial protocols to test a new drug to treat high-risk leukemia. Dr. Chandrika Gowda's published findings suggest that using CK2 inhibitors will make leukemia cells more sensitive to commonly used toxic chemotherapy.

Submitted July 2019 | Blood

Four Diamonds team works to identify new drug options to treat childhood

cancer. Our researchers previously uncovered an ion channel on the surface of cancer cells that helps the cancer cells live longer. They also identified ways to interfere with this channel to reduce tumor growth and make cancer cells more sensitive to chemotherapy. The team is now actively working to identify an effective drug to inhibit the channel, which can be a novel treatment of neuroblastoma, leukemia and other types of childhood cancer.

Recent Submissions: American Journal of Physiology: Cell Physiology Journal of Cell Physiology, Scientific Reports, Cell Calcium (Review) Journal of Adolescent and Young Adult Oncology **Scientists find a potential way to improve effectiveness of treatment for brain tumors.** Glioblastoma is the most aggressive form of brain cancer, and radiotherapy is one of the standard treatments. A study by Four Diamonds scientists has found that using a drug to inhibit a specific cell protein may improve the effectiveness of radiotherapy for glioblastoma.

OUR TEAM
CONSISTS OF

O
Research Professionals
& Scientists

January 2019 | Oncogene

Four Diamonds scientists discover new insights into how cell "trash bags" trap and seal waste, which can lead to cancer cell death. Autophagosomes are like trash bags in a cell that trap and seal waste for the cell to destroy or recycle. When cancer cells can't "take out the trash," it piles up inside the cell and triggers cell death. A recent study by our researchers uncovered a role for a specific mechanism that assists in this process. Now the team is seeking ways to target this mechanism for potential therapies in pediatric cancers.

July 2018 | Nature Communications

**Four Diamonds researchers identify new pathways that could be targeted to treat leukemia.** A genome is similar to a cell's instruction manual, containing all of the genes, DNA and cell processes. A discovery by Four Diamonds researchers provides scientists the first insight into the process of genome reorganization that can turn T-cell leukemia cells into normal cells. This study also identified a large number of new regulatory networks that control growth and survival of leukemia cells. These newly identified regulatory pathways will now be targeted for treatment of T-cell leukemia.

Additionally, our research team discovered a new pathway that regulates how leukemia cells multiply. When this pathway is impaired, it results in high-risk leukemia with a poor prognosis. The team discovered a new treatment to restore activity of this pathway and activate enzymes that control multiplication of leukemia cells. Measuring the activity of the genes involved in this new pathway can be used as a biomarker to provide an early, molecularly based diagnosis of high-risk leukemia. It also has the potential to measure the impact of treatment.

May 2019 | Leukemia
November 2018 | Oncogenesis

"Trinity was definitely sent to us for a reason... she's a fighter.

There's not one person in this world who meets my daughter and doesn't smile. She lights up a room – she has that glow."

— DANIEL, A FOUR DIAMONDS DAD —



### Our Research Saves Kids

Two-year-old Trinity was diagnosed with cancer in March 2018. Doctors confirmed that Trinity was fighting neuroblastoma in three different parts of her body and would need to endure multiple rounds of chemotherapy during her treatment.

Trinity's doctor recommended she enroll in an experimental therapeutics clinical study offered at Penn State Children's Hospital. She is scheduled to receive treatment once a month for the next few years.

When Trinity's dad Daniel learned that Four Diamonds would cover all of Trinity's medical bills and travel during her treatment at Penn State Children's Hospital, he said, "It's breathtaking to know that all I have to worry about is spending the day with my daughter and making her happy because everything else is taken care of. I can tell you as a parent...I am indebted to Four Diamonds and our care team. It's a remarkable organization."

Trinity is one of many children who come to Penn State Children's Hospital to participate in one of Four Diamonds' early phase clinical trials. Our team of researchers strives to maintain a diverse clinical trial portfolio to serve the pediatric cancer patient population and a variety of tumor types, including brain tumors like diffuse intrinsic pontine glioma (DIPG). In fact, Penn State Children's Hospital participated in the first study of DIPG that used a molecularly based treatment strategy. Four Diamonds' membership in national and international research consortia allows our team to provide the latest breakthroughs in treatment for kids like Trinity.

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## World-Class Care SUPPORTING OUR PATIENTS AND THEIR FAMILIES

Four Diamonds funds the work of more than 30 specialty care providers to exclusively serve the physical, mental, emotional and spiritual needs of our childhood cancer patients and their families. The entire care team provides for each child's well-being and family's needs, in addition to providing expert treatment for the disease.

OUR TEAM
CONSISTS OF

30+

Specialty Care
Providers





### **MUSIC THERAPY**

Music therapists use personalized, evidence-based interventions, including playing instruments, singing, listening and songwriting to support patients and their families during their entire cancer journey. Experiences are designed to help alleviate pain, manage stress, express feelings, improve communication, foster social interaction and promote physical rehabilitation.



### **ART THERAPY**

Art therapy empowers patients to use art in their healing process. Art therapy works to engage the mind and body to support coping with hospital experiences, provide a safe outlet for emotional expression, promote feelings of control and instill resiliency and relaxation.



### CHILD LIFE

Child Life specialists help kids confront fears about their illness. Through play therapy and distraction techniques, Child Life helps kids and their families cope with the lifechanging effects of childhood cancer.



#### SOCIAL WORKERS

Social workers support families with the adjustment from diagnosis, into treatment and through survivorship. They help each family by addressing practical concerns, including financial assistance, school needs, employment concerns, transportation assistance and healthy coping.



### PASTORAL CARE

Our chaplain integrates the spiritual needs of patients and their families into the care plan. The chaplain notifies the team about family faith practices and how their faith may impact medical treatment.



### CHILDHOOD CANCER SURVIVORSHIP PROGRAM

Through our Childhood Cancer Survivorship
Program, young survivors are screened for
physical and emotional side effects that may
not surface until years after their diagnosis or
treatment. Each survivor then receives a highly
personalized, ongoing plan of care.



Four Diamonds also provides a genetic counselor, pharmacist, neuropsychologist and more.

# Your Support Changes Lives FOUR DIAMONDS FISCAL YEAR 2018-2019

Each spring, a robust grant process allocates all dollars raised that year by Four Diamonds for the coming fiscal year to further our goal to conquer childhood cancer. All requests are evaluated on the guidelines established in the original gift agreement by the co-founders of Four Diamonds.

FUNDING PRIORITY 1: To ensure every Four Diamonds child receives the highest quality of life-saving childhood cancer care at our Children's Hospital without ever seeing a bill for that care. This compassionate process relieves both the financial pressures and the burden of billing paperwork for all Four Diamonds families.

**FUNDING PRIORITY 2: To ensure Four Diamonds children and their families are wrapped in comprehensive services.** This
includes providing access to top-notch specialists proven to enhance
positive treatment outcomes, combined with support services to
meet their physical, emotional, social and spiritual needs.

**FUNDING PRIORITY 3: To ensure grants are made to a variety of innovative research projects** that are searching for deeper understanding of why and how childhood cancer happens, and new ways it can be treated. Funds are also invested in endowments. The interest earned on those endowments creates a secondary, permanent funding stream for our ongoing research efforts in pursuit of a cure for all childhood cancers.

FOUR DIAMONDS CHILD **ALANA** 

### **FOUR DIAMONDS FINANCIALS | 2018-2019**

July 1, 2018 - June 30, 2019

### **Sources of Funds**

TOTAL	\$18,642,503.10
Honor Gifts	\$36,769.23
Memorial Gifts	\$64,771.55
Other	\$902,473.71
Mini-THON®	\$7,271,121.81
THON™	\$10,367,366.80

### **Uses of Funds**

In Fiscal Year 2018 – 2019, funds used included those funds raised in the previous fiscal year and any dollars that had been allocated but unspent in the previous fiscal year.

### **Patient Care & Family Support**

Patient Care	\$2,730,043.58
Family Support	\$940,190.29
Research	
Research Grants	\$1,913,230.74
Research Support	\$5,627,452.50

\$2 770 047 58

\$2,479,003.38

### **Research Endowments**

Immunomodulation and the \$5,667,091.98\*
Tumor Microenvironment in Cancer

### Administrative Expenses

TOTAL \$19,357,012.47

### FOUR DIAMONDS BY THE NUMBERS

\$18.6

million raised

4,000+

families helped since 1972

**100%** of medical bills covered\*

100,000+

student volunteers

**30+** specialty care providers

90+

research professionals

**24** clinical trials

Cillical trials

87 cents

of every dollar directed to our mission

<sup>\*</sup> Funding was originally allocated for enhanced Four Diamonds research space to be included within the new Innovation Pavilion at Penn State College of Medicine. The Board of Trustees voted on the appointment of an architect at the September 14, 2018 meeting. As this building project has been delayed, Four Diamonds reallocated these funds to Q1 of FY2020 to immediately impact research projects/needs.

### Our Partners In The Fight™

**THON**<sup>TM</sup>



IN THE 2018-2019 SCHOOL YEAR

16,500+

Penn State students contributed



5 million

volunteer hours,

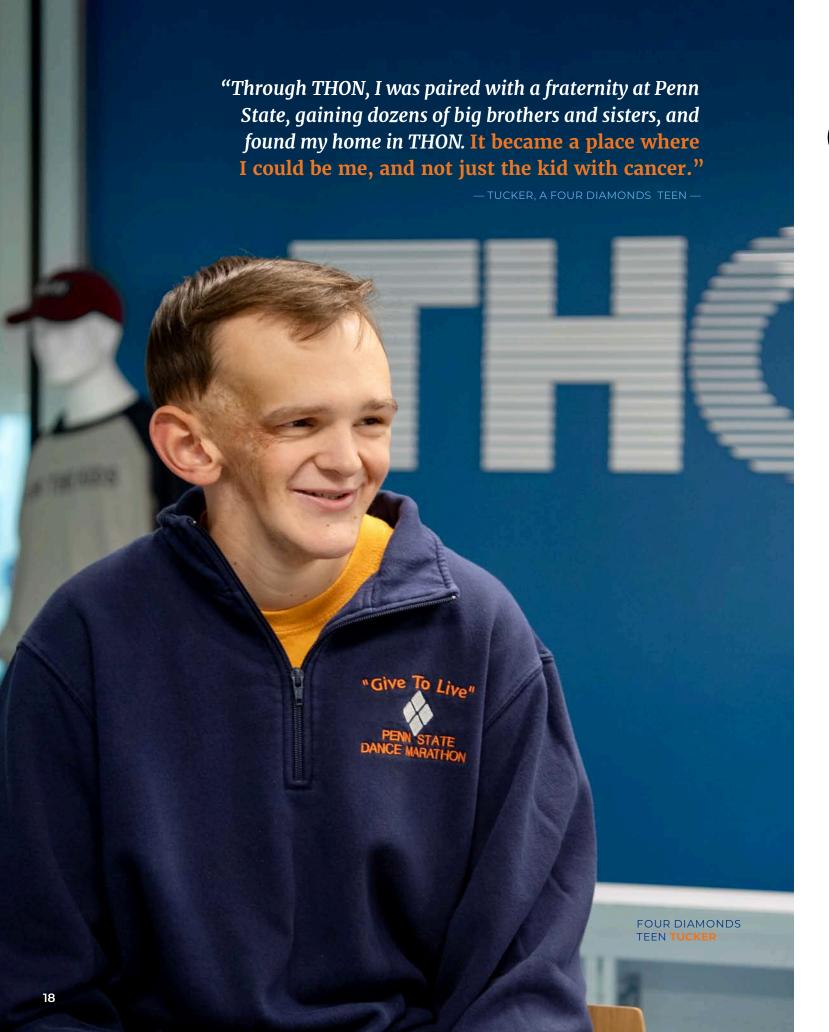
continuing the tradition of the most successful dance marathon in the world, and



\$10.6 million

For The Kids™.







When he was just two years old, Tucker was diagnosed with rhabdomyosarcoma, a rare kind of cancer that grows in connective tissue, which presented on the right side of Tucker's face and right rib. While fighting pediatric cancer, Tucker faced three relapses, numerous surgeries and rounds of chemo, 77 radiation treatments and a stem cell transplant.

A positive constant for Tucker and his family through the years has been the Penn State IFC/Panhellenic Dance Marathon, the student-run philanthropy. THON<sup>TM</sup> is committed to enhancing the lives of kids and families affected by childhood cancer by providing emotional and financial support, awareness and funding for groundbreaking research.

As a patient of Penn State Children's Hospital and a Four Diamonds child, Tucker attended his first THON in 2005 when he was just five years old. The next event in February 2020 will be his 16th THON, and possibly his most meaningful.

Tucker is now a freshman at Penn State, and he plans to give back in more ways than one—he will major in athletic training and sports medicine, combining his love of medicine with his passion for sports. Tucker says cancer took sports away from him because he now only has one-third of his right lung, making endurance a challenge because of limited lung capacity. It's motivated him to empower others who have sports-related injuries. He also plans on being an active member of THON and give back to an organization that has been such an important part of his life.

IN THE 2018-2019 SCHOOL YEAR



90,000+ students



in 265

raised \$7.2 million

to help conquer childhood cancer.





Rylee's cancer journey started in 2006 when she was six years old and diagnosed with non-Hodgkin's T-cell lymphoma – beginning a fight that would take her two years to win. She has been in remission since 2010.

Despite a good prognosis for Rylee, her father Shannon says the whole experience was frightening for his family. Knowing all of Rylee's medical bills that weren't covered by insurance would be paid for by Four Diamonds was a tremendous relief. Her family is also thankful for the support of her dedicated social workers, psychologist and music therapists – all services that may not be possible without Four Diamonds and the generous support of the community.

Today, Rylee is an active member of the Red Lion High School Student Council. She also participates in Varsity Club and Four Diamonds Mini-THON. Inspired by THON, Mini-THON empowers students of all ages to find their voice and create a culture of helping others and giving back to their communities.

Rylee is so grateful for those who helped her in her recovery, including her care team, Four Diamonds, Mini-THON and THON. In her words: "Our lives have been forever touched because of the love, passion and dedication of these individuals."

FOUR DIAMONDS TEEN RYLEE





given by individual & corporate gifts



Team FTK® is a Four Diamonds fundraising initiative that unites supporters in the quest to conquer childhood cancer. Through Team FTK, the collective efforts of individuals, students, families, community members and corporate partners make a tangible impact to help all children survive and thrive.

This year, passionate community supporters and grateful patient families contributed more than \$800,000 from individual and corporate gifts, community fundraisers and gifts in honor or in memory of a loved one.

Every gift gives hope to families fighting childhood cancer, making it possible for Four Diamonds to help thousands of children.

As a member of Team FTK, nine-year-old Joseph celebrates his birthday each year by raising money for Four Diamonds families through the Conquer Run 5K!

"I want everyone to leave the hospital cancer-free."

— JOSEPH, A FOUR DIAMONDS VOLUNTEER —





### **FOUR DIAMONDS**

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