



# Samuel Jeffers Childhood Cancer Foundation

## Cooking up a cure for childhood cancer

SAMUEL JEFFERS CHILDHOOD CANCER FOUNDATION

## 2018 ANNUAL REPORT

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### **JANUARY 31, 2019**

#### MESSAGE FROM OUR EXECUTIVE DIRECTOR

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We are pleased to present to you the Foundation's Annual Report. We are forever grateful to each person who has played a role in getting us to where we are today. When Sam was diagnosed with brain cancer in September of 2012 a group of "Lemonade Moms" took it upon themselves to raise funds while Sam was in the throes of his battle with cancer. From those seeds eventually grew Sam's Foundation, when it was decided in 2014 that we would form the Samuel Jeffers Childhood Cancer Foundation, with the goal of raising awareness and funds for pediatric cancer.

When we first decided to form the Foundation, it was not without trepidation, as we knew that there were many other Foundations and organizations that sought to raise money for childhood cancer, and we did not want to dilute the efforts of others. After a significant amount of research, many discussions with others similarly situated as ourselves and finally much reflection on who or what we wanted to be and how we wanted to differentiate ourselves we ultimately decided that it was important to us to let Sam's brief time on earth and difficult struggle with cancer to find meaning through a lasting legacy, one that would strive each day to help other children who had little hope for survival.



## Samuel Jeffers Childhood Cancer Foundation

We are excited to provide you with an update on what Sam's Foundation was able to achieve in 2018, as we accomplished an important milestone in research funding and continued to provide financial assistance for local families with children battling cancer.

In this Report you will find information on what we have done in the past 12 months with the money you—our gracious supporters—have entrusted us. It is important to us that our donors know that when you make a donation to Sam's Foundation 100% of those funds goes towards our mission. Everyone at Sam's Foundation is a volunteer, giving their time and energy for no reason other than how important this mission is to them. We are very fortunate and grateful to our volunteer Officers and Board members who share our passion for getting the word out on the problem of childhood cancer. I would like to recognize our dedicated Board members Michele Rogan and Laura Holder, who do so much throughout the year to keep us on course and well-managed. And, where would we be without Eralyne Krasner? Erl is our COO and the engine that drives the entire Foundation, planning and organizing each of our many events and working selflessly and tirelessly to continually drive us towards new milestones. We thank each of them from the bottom of our heart.

In a nutshell, here is our primary message:

**There is currently an abysmal amount of money spent on childhood cancer research, despite it being by far the leading cause of death by disease of children. In some respects society has been fighting its war against cancer backwards, in that money spent on *adult* cancer research seldom trickles down to benefit children with cancer because children's cancers and bodies are different and the treatments themselves often lead to severe complications. However, money spent on *childhood* cancer research can and does “trickle up” to benefit adults. When we fund childhood cancer research we are in fact funding medical research that benefits children and adults alike.**

Today we have before us a very real opportunity to change outcomes for children diagnosed with cancer. Decades ago diseases like smallpox, polio, diphtheria, malaria, measles, tetanus, typhoid and yellow fever, to name just a few, were often death sentences for those who contracted them. Today, all have largely been controlled or eradicated.

It all starts with awareness of the problem and then providing adequate funding for research and new paradigms for treatments. We have no doubt whatsoever that science and technology will ultimately deliver better therapies and cures for cancer—childhood and



# Samuel Jeffers Childhood Cancer Foundation

adult alike. What we need is greater financial support that gets channeled efficiently and responsibly into promising research projects and clinical trials.

Unfortunately, childhood cancer does not hit the radar screen of either the government or large pharmaceutical companies, who have little incentive to pour billions of dollars into a market they deem financially un-remunerative.

That's why it is up to us—family, friends and members of our caring community—to fill the void. Thank you for your continued support and helping us spread the word about the important goals we have set for ourselves. We simply cannot do this without the support of donors and partners like you.

Sabrina Jeffers  
Executive Director

## RESEARCH PROJECTS WE HAVE SUPPORTED

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The Foundation's primary mission is to fund research, clinical trials and other medical and scientific projects targeted at developing cures for pediatric cancer.

Our Foundation seeks to differentiate itself by helping fund childhood cancer research in areas that are currently dramatically underfunded. Sam died from a particularly rare type of brain tumor (thalamic glioma), and the medical community was helpless to save him, because historically there simply have been no clinical trials or meaningful research efforts directed at many of these forms of childhood cancer.

We seek therefore to fund projects that either directly benefit rarer types of childhood cancer or projects that offer exceptionally promising potential to broadly benefit all types of pediatric cancer.

We invite you to read several of our blog posts at [Enough4Now](#) that go into more detail explaining the tremendous translational and “spillover” benefits to society of the targeted childhood cancer research that we support.

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# Samuel Jeffers Childhood Cancer Foundation

Here's a snapshot of research that we funded in 2018:

## **Stanford Medicine Preclinical Thalamic Glioma Research: \$25,000**

The Sam Jeffers Foundation is proud to have supported Stanford Medicine in the amount of \$25,000 which was used to help supplement funding for several important preclinical childhood cancer experiments.

First, a portion of this money helped fund work in Dr. Michelle [Monje's Lab](#) at Stanford Medicine. Dr. Monje and her colleagues discovered that a major “fuel” driving the growth of pediatric high-grade gliomas comes from neurons in the microenvironment and is regulated by the activity of the brain itself. As described in more detail [here](#) Dr. Monje discovered a way to cut this molecular fuel supply, and it appears to be a very promising potential therapy for pediatric glioblastoma and pontine glioma. Dr. Monje would like to now test this therapeutic strategy for thalamic glioma, the tumor that took Sam's life. The Foundation's grant will enable preclinical testing of ADAM10 inhibition of thalamic glioma in preparation for a clinical trial, through inclusion of a patient-derived thalamic glioma xenograft model in these efforts.

Second, Sam's Foundation helped support funding for an important and extremely promising [Stanford Immunotherapy Project](#).

Immunotherapy is a type of cancer treatment that seeks to employ the body's own immune system to help fight off cancer. Dr. Monje's lab found that another deadly childhood cancer called diffuse intrinsic pontine glioma (DIPG) has a high amount of an antigen substance called GD2 (think of this antigen as a marker or signal that re-engineered immune system cells can find....Read this brief but very informative [article](#) or watch this [video](#) to learn more). Dr. Monje knew that the lab of her colleague Dr. Crystal Mackall had already developed CAR-T cell immunotherapy to target the GD2 antigen so the two partnered to administer the therapy in Dr. Monje's glioma mouse models. Incredibly, in mice that received one injection of GD2 CAR-T cells, the DIPG tumors were undetectable after 14 days. Thanks to Sam's Foundation, Dr. Monje was also able to test the efficaciousness of the therapy against thalamic glioma, unfortunately with less success (primarily due to the location of the thalamus and the negative effects of high levels of inflammation that were produced). However, this work has laid an incredibly important



## Samuel Jeffers Childhood Cancer Foundation

foundation for future additional research involving CAR-T cell therapy for a variety of gliomas.

Finally, the Foundation's funding helped support work on a promising new drug called panobinostat. Dr. Monje's lab had previously performed an extensive drug screen of over 2000 drugs against cell cultures of pontine glioma, and from this a handful of drugs emerged that they are now working to bring to clinical trial. Among these is a drug called panobinostat, for which Dr. Monje is leading a national clinical trial within the pediatric brain tumor consortium for DIPG. Testing of the lab's new thalamic glioma culture indicates that thalamic glioma is similarly sensitive to panobinostat, and therefore Dr. Monje is presently working to open a clinical trial at Stanford of panobinostat for thalamic gliomas. The Foundation's grant will make some of the necessary preclinical work possible.

These efforts underscore our longstanding belief that money spent on targeted research is pivotal to advancing our overall understanding of tumor progression and the ways to combat it, and represents critical steps towards safer, more effective treatments for our children and society as a whole.

### **Samuel Jeffers Thalamic Glioma Research Project at Weill Cornell: \$38,000**

In 2016 the Foundation set as its top funding priority the establishment of a Project to study thalamic gliomas at Weill Cornell Medicine. Towards this goal, we sent Weill-Cornell \$60,000 in 2016 and \$10,000 in 2017. This year's grant of \$38,000 brought us to over \$100,000 in funding, and we are incredibly excited to be able to report that the Children's Brain Tumor Project at Weill-Cornell is now in the process of hiring a full-time dedicated researcher whose job it will be to study the type of tumor that took Sam's life. This kind of targeted research is critical to furthering our understanding of how tumors grow and how that growth might be arrested, and has long-term crossover implications for many other types of tumor research.

We look forward to our continued relationship with Dr. Mark Souweidane, as he and the Team at Weill-Cornell are now in a position to begin concrete work on what will be an ongoing Thalamic Glioma Project.

For example, the tumor specimens that were identified over the summer of 2016, thanks in part to the [Summer Fellow](#) we also funded, will be critical to the Children's Brain Tumor Project's work on thalamic glioma. Culturing cell lines and creating tumor models in animals are critical to research, as they allow scientists to study a specific tumor's growth and

**Cooking Up a Cure for Childhood Cancer**



## Samuel Jeffers Childhood Cancer Foundation

explore potential drugs that will work against it. Prior to now there were no cell lines growing for the kind of tumor that killed Sam, and no animal models to test drugs against. These cells and models offer the best opportunity for performing large-scale drug screens and validating therapeutic strategies, but until very recently they didn't exist for thalamic glioma.

Thanks to Sam's Foundation we are now in a position to do for thalamic glioma what is commonplace for more frequently diagnosed tumors: Sequence tumors, grow cell lines, create animal models, and test drug therapies. This is an amazing opportunity to advance scientific understanding of thalamic gliomas.

**These projects that Sam's Foundation is funding represent the world's first dedicated efforts towards thalamic glioma research as far as we know. This is truly groundbreaking work that is being done—and it's being powered by you, our supporters and donors!**

We can't thank all of you enough as we travel together on this exciting journey. We hope and believe that Sam's Foundation, supported by the generosity of our donors and the community, will help build a bridge to tomorrow's advances and breakthroughs that will give future Sammy's a chance. Ten years ago, if another family or Foundation had an opportunity to do something like this, it is possible that Sam might have lived. Ten years from now, it is our fervent wish that some other child will be able to live if he or she hears those same dreaded words that we did.

### SUPPORT FOR LOCAL FAMILIES

Our program of assistance for local families of children with cancer continues. By Board mandate, the Foundation can direct no more 10% of its funds towards financial assistance (the Foundation's primary mission being research funding). Part of the Foundation's financial assistance program involves indirect assistance to families by helping to promote one of their own events, hosting Lemonade Stands, or participating in other events that seek to raise money for local families of children with cancer. Examples of these for 2018 were: **Team Annie Bananie Blood Drive; Team Lexi Shave for St. Baldrick's** event; and **Camp Reach for the Stars** in Cambria.



# Samuel Jeffers Childhood Cancer Foundation

In addition, we support local families directly with financial assistance. We are especially happy to be able to supplement areas that other local organizations may not be able to, since we are not limited to medically-necessary assistance. The Foundation has the ability to assist with expenses that promote the well-being of the childhood cancer patient, such as assistance with rent, utilities, necessary car repairs, etc. The Foundation also has the ability to make donations to other causes that directly or indirectly support the Foundation's mission. As mentioned, these activities, as a whole, may not exceed 10% of the annual operating budget for the Foundation, with 90% or more required to support childhood cancer research.

**2018 Direct Assistance** to families of children with cancer: **\$1,745.19**

**2018 Buy One-Give One Erica Neuschafer Lu La Roe Birthday Fundraiser:** **\$1,022**

**2018 Sponsor** of Dignity Health Infusion Center end-of-treatment events: **\$500**

**2018 Donation to St. Baldrick's Foundation:** **\$88**

## FUNDRAISING YEAR IN REVIEW

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2018 was another busy year for us. Each time we hold an event, no matter how much money is raised, we are bringing awareness of childhood cancer to the community. That awareness is priceless, and has a cumulative effect over time in helping us achieve our long-term goals.

Here's a snapshot of just some of the events that the Foundation participated in that helped bring both awareness and much-appreciated donations. We are very grateful for the tremendous support these groups

January	Hoops for Hope, Nipomo High School	\$1217.00
January	Great Oak Middle School, Oxford, CT	\$750.05
February	Grover Heights Elementary School Penny Power	\$2483.71
March	Bald for Lexi	\$109.00
March	Jamberry/Lularoe with Katie Powell and Megan Cielatka	\$237.50
April	Happy Time Trike-a-Thon	\$253.35

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# Samuel Jeffers Childhood Cancer Foundation

May	Fundraiser to Benefit the Swain Family	\$690.00
May	Grover Heights Spring Fling	\$279.45
May	William Austin Paper Fingers	\$60.05
June	Lemonade Wars, Niskayuna High School	\$100.00
July	Anderson-LeJeune Family Walmart PA Lemonade Stand	\$1387.65
September	Arroyo Grande Harvest Festival Lemonade Stand	\$357.00
September	Arroyo Grande High School Gold Day donations	\$2249.40
September	Branch Elementary Gold Day donations	\$1466.41
September	Judkins Middle School Gold Day	\$772.01
September	Lopez Continuation High School Gold Day donations	\$197.80
September	Nipomo Elementary Gold Day donations	\$1935.00
September	Oceano Elementary Gold Day donations	\$397.27
September	Oceanview Elementary Gold Day donations	\$2512.60
September	Shell Beach Elementary Gold Day donations	\$466.00
September	Dance in Gold with Danya Nunley at Kennedy Club	\$10,600.00
October	5 Cities Oktoberfest	\$145.00
November	Team Annie Bananie Blood Drive	\$40.00
November	Dia de los Muertos Photo Booth	\$250.00
November	Grover Heights Movie Night	\$271.00
November	Northwest Bank Casual Day Fundraiser	\$600.00
November	Congregation Beth David Mitzvah Day	\$258.00
November	Spotted Whale Consignment	\$244.69



January  
Hoops for Hope, Nipomo High School  
\$1217.00



January  
Great Oak Middle School,  
Oxford, CT  
\$750



February  
Penny Power, Grover Heights  
Elementary School  
\$2483.71

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# Samuel Jeffers Childhood Cancer Foundation



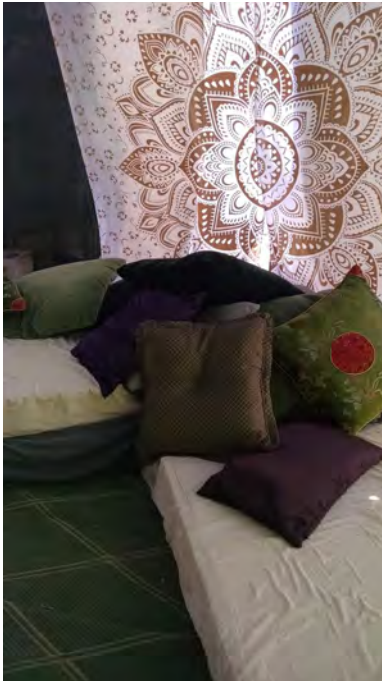
March  
Team Lexi Brown  
Lemonade Stand  
\$326



April  
Happy Time Trike-a-Thon  
\$253.35



May  
Grover Heights Spring Fling  
\$279.45



June  
Camp Reach for the Stars



June  
Lemonade Wars, Niskayuna High  
School  
\$100



July  
Anderson-LeJeune Family  
Lemonade Stand  
\$1387.65



# Samuel Jeffers Childhood Cancer Foundation



September  
Harvest Festival  
\$357



September  
Dance in Gold with Danya Nunley  
\$10,600



October  
Five Cities Oktoberfest  
\$145



November  
Grover Heights Movie Night  
\$297.23



November  
Dia de los Muertos Photo Booth  
\$250



November  
Spotted Whale Consignment  
\$244.69

## FINANCIAL STATEMENT SNAPSHOT

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Because we volunteer our time and services to the Foundation, to date 100% of donor contributions have gone towards our Mission. The Foundation has not incurred any operational expenses for which it has not been reimbursed. It is our objective to continue to run our operations in this “lean-and-mean” fashion so that donor contributions go 100% towards our Mission.

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# Samuel Jeffers Childhood Cancer Foundation

The figures below represent revenues and expenditures from January 1, 2018 through December 31, 2018 and are deemed to be accurate but are unaudited.

**Relevant Period Revenues (events and donations): \$59,481.37**

**Relevant Period Expenditures:**

Grants to childhood cancer research institutions: **\$63,000**

Financial Assistance to local families or organizations: **\$3,355.19**

Unreimbursed administrative and general expenses: **\$0**

## HOW YOU CAN HELP

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There are many ways that you can show your support for the Foundation:

- Direct contribution on our website [www.samjeffersfoundation.org](http://www.samjeffersfoundation.org)
- Asking friends and family to donate in lieu of a birthday gift
- Donating a portion of your business' sales to the Foundation
- Donating goods or services for one of our silent auctions
- Organizing a fundraiser in your own community, such as a Lemonade Stand, bake sale, car wash, garage sale, coin collection at school or work, and many other ways. Please just [email](mailto:) us and ask! We will do everything we can to guide and assist you in the process
- Volunteering at one of our many fundraisers (serving lemonade, baking cookies or cupcakes, etc.)
- Inviting us to hold a Lemonade Stand at your place of business, school or other event
- Like us and Share our activities on Facebook and elsewhere and just “spread the word” about our Foundation to others in the community

The ways that we can all work together are limited only by our imaginations. When Sam was alive and going through treatment he saw many other children in the same situation as he was, and he thought it was incredibly sad that there were children who were sick and dying because there was no reliable way for them to be helped. No child should ever have

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# Samuel Jeffers Childhood Cancer Foundation

to face that situation. Together, we truly can make a difference by *Cooking Up a Cure for Childhood Cancer*.

FACEBOOK: [COOKINGUPACUREFORCHILDHOODCANCER](https://www.facebook.com/COOKINGUPACUREFORCHILDHOODCANCER)

INSTAGRAM: [COOKINGUPACURE4CHILDHOODCANCER](https://www.instagram.com/COOKINGUPACURE4CHILDHOODCANCER)

TWITTER: [@COOKINGUPACURE4](https://twitter.com/@COOKINGUPACURE4)

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