

# Trailblazer



## Trailblazer (continued)

called Unituxin, an outcome of research by St. Baldrick's-funded researcher Alice Yu, M.D., Ph.D. Unituxin is the only FDA-approved antibody therapy for pediatric high-risk neuroblastoma. After each treatment regimen, Luke's tumors disappeared, but the cancer remained in his bone marrow with the potential to cause another relapse.

With Luke's most recent relapse, the Baca family — which also includes Luke's twin sister, Leia — is in uncharted territory. While they're nervous, they know that Luke is blazing a new trail for other kids facing neuroblastoma. Together with Luke's doctors, Jason and Janelle have evaluated current clinical trials to determine the best shot at finally clearing the cancer from Luke's bone marrow. Their choice: a promising immunotherapy that injects a supercell into the bloodstream to embed a round-the-clock defense system that eliminates cancer from the bone marrow. Luke received an infusion of the supercells in October and is currently being monitored to track the effectiveness of the treatment.

Despite Luke's third relapse, the Texas family remains

grateful. While many of his friends with cancer have passed away, Luke is looking forward to the future, which includes a career in zoology.

His family has established the St. Baldrick's Foundation LukeStrong A Force Against Neuroblastoma Childhood Cancer Fund to advance pediatric cancer research. With the support of family and friends, LukeStrong teams across several states have raised over \$100,000 over the past seven years and Jason is a Knight of the Bald Table as a seven-year St. Baldrick's shavee. This year, with fewer opportunities to host in-person events due to COVID-19, Team LukeStrong hosted a virtual head shaving event and Janelle's parents stepped up with a \$25,000 donation.

"We love the feeling that St. Baldrick's has," says Janelle. "We're so grateful to everyone who supports the St. Baldrick's Foundation because that's what funds the research helping kids like Luke. Whether it's a large donation, or a lot of smaller contributions combined, every gift makes an impact on a child's life."



## 5 Ways You Can Conquer Kids Cancer

There are lots of ways you can help kids with cancer:

- 1 Donate Online** Your passion to #GiveKidsALifetime means even more during the pandemic and St. Baldrick's appreciates donations of all sizes! <https://www.stbaldricks.org/impact>
- 2 Shave Your Head — Virtually** The St. Baldrick's Foundation has gone virtual with its signature head shaving events. Invite a group of friends to take part, recruit donors and shave online! It's a safe, easy and fun way to fight pediatric cancer. Register as a virtual shavee: <https://www.stbaldricks.org/be-a-virtual-shavee>
- 3 Start a Facebook Fundraiser** Do it in honor of your birthday, your anniversary or even because it's winter! Simply specify the St. Baldrick's Foundation as the beneficiary.
- 4 Host a DWYW Event** Head shaving's not your style? Get creative and come up with your own virtual event. Host a virtual race — have your friends donate a race entry fee and you can all get active on the same day, no matter how far apart you live! Have your friends Zoom in for a "gala" (get dressed up, pop the champagne and maybe even dance) and donate the "ticket price" to fund pediatric cancer research. As long as it's safe, we're in! More: <https://www.stbaldricks.org/faq/fndraisers-do-what-you-want>



## 5 FreeWill + St. Baldricks Leave a legacy that saves lives

Creating a will is one of the most impactful ways to support the people you love and the causes you care about the most, including research for curing childhood cancers. That's why we've partnered with FreeWill to give you a free, easy way to write your legally valid will today. Many of our supporters choose to include a gift to St. Baldrick's Foundation to ensure we continue lifesaving childhood cancer research for generations to come.

The service is free whether or not you choose to leave a gift, and we're thrilled to share it with you either way. For more complex needs, FreeWill is a great place to start planning your will before visiting an attorney. If you choose to include St. Baldricks in your will, you will be invited to join the Emerald Circle with other legacy donors. Get started on your legacy today at [FreeWill.com/StBaldricks](https://FreeWill.com/StBaldricks).



FALL 2020



# YOU MAKE AN impact

**Luke Baca** is a cancer-fighting rock star. He's among a rare group of kids with neuroblastoma to survive beyond five years — but relapsed for a third time last summer. Now, there's no roadmap for his care.

## Trailblazer

No standard treatment protocol exists for a kid who's relapsed that many times, says Luke's dad, Jason Baca: "You can never get comfortable when fighting neuroblastoma. This is a very relentless type of cancer."

The Baca family's cancer journey began seven years ago, when Luke was diagnosed just before Halloween. When the 5-year-old complained of severe pain in his abdomen, his mom, Janelle Baca, rushed Luke to the hospital. Within hours, doctors diagnosed neuroblastoma, a pediatric cancer that causes solid tumors throughout the body. Doctors told Jason and Janelle that their son had a 50% chance of living five years.

Since then, Luke has undergone cancer treatments including chemotherapy, surgery, stem cell transplants and a revolutionary antibody therapy

continued on page 5



## Let's Connect



[Stbaldricks.org/distinguished-giving](https://Stbaldricks.org/distinguished-giving)

[StBaldricks.org/corporate-partners](https://StBaldricks.org/corporate-partners)

[StBaldricks.org/league](https://StBaldricks.org/league)

## Thank you!

Thank you for supporting lifesaving childhood cancer research. Through your gifts, you are helping the St. Baldrick's Foundation fund the best childhood cancer research, no matter where it's being done. **With almost \$27 million in grants funded last year, we are the largest private funder of pediatric cancer research grants. YOU made progress possible!**

## Ways to Give

Kids with cancer need cures now, and it starts with you. Donate to help us fund the most promising childhood cancer research. Give once or monthly. Start today. [stbaldricks.org/impact](https://stbaldricks.org/impact)



The St. Baldrick's Foundation is a volunteer and donor powered charity committed to supporting the most promising research to find cures for childhood cancers and give survivors long and healthy lives.

## The Next Game Changer

The approval of Unituxin by the FDA to treat high-risk neuroblastoma was a giant step forward for kids with cancer. It helped to save lives and demonstrated that, together, St. Baldrick's Foundation donors can accomplish great things.

The result of 20 years of research by Alice Yu, M.D., Ph.D., Unituxin earned FDA approval in 2015. Its development was funded through organizations like St. Baldrick's, which granted more than \$100,000 to Dr. Yu's work. "The FDA approval of Unituxin was a watershed moment that had a significant impact on children with neuroblastoma," recalls John Maris, M.D., a national leader

in neuroblastoma research at the Children's Hospital of Philadelphia. "It is the only FDA-approved drug for this condition, despite the fact that dozens of other drugs are used as standard therapy. That said, almost half of neuroblastoma patients suffer a relapse."

Behind every great researcher is a group of generous donors who are committed to ensuring that the funding is there for work to continue. St. Baldrick's CEO Kathleen Ruddy says, "St. Baldrick's research fellows are true pioneers in the field of pediatric cancer. There's tremendous knowledge and talent in the field. As a result, we're on the cusp of exciting discoveries in neuroblastoma

continued on page 2



## The Next Game Changer (continued)



John Maris, M.D.

research. The key is providing the financial support to keep the work going.”

One researcher to watch is St. Baldrick’s Foundation Fellow Micah Maxwell, M.D., Ph.D. (see story at right). Thanks to contributions from donors, St. Baldrick’s recently awarded him a \$166,500 grant to continue his work. The grant also led to a promotion for Dr. Maxwell at Johns Hopkins, ensuring that this talented young scientist can remain in the field and making him competitive for future research grants from the National Institutes of Health.

**“We’re on the cusp of exciting discoveries in neuroblastoma research. The key is providing the financial support to keep the work going.”**

“The approval of Unitixin in 2015 — around the time I was starting in the field — showed me that it was possible to take an idea for a targeted therapy all the way from the laboratory and integrate it into the standard treatment for an aggressive pediatric solid tumor and improve outcomes for patients,” Dr. Maxwell says. “Though pediatric cancer research moves slowly, it is the success stories that teach us that new discoveries, like the ones I am working on in cancer metabolism, can be translated over time into tangible advances that lead to longer, better and healthier lives for children with cancer.”

Dr. Maris is encouraged by the progress he sees in labs around the country: “Amazing recent research, supported in part by the St. Baldrick’s Foundation, has discovered many potential new therapies based on precision approaches tailored to the individual patient. We are very optimistic about game-changing new therapies in the immediate future.”



## Striking the Achilles Heel



Micah Maxwell, M.D., Ph.D.

### What made you choose pediatric cancer research?

Every day, over 40 children in the US are diagnosed with cancer, which is the leading cause of death by disease in

children. For the many children who survive, the intensity of the therapy we give leads to a lifelong burden of chronic health effects. Though we have made significant improvements in pediatric cancer treatment and care in recent decades, there is still vast room for improvement.

During medical school and my pediatrics residency training, I witnessed firsthand the suffering of children with aggressive solid tumors, both from the cancer and from the side effects of the intense therapies used in their treatment. Since 2015, my research has focused on developing new, targeted therapies to improve survival in poor-prognosis pediatric solid tumors, with a particular focus on high-risk neuroblastoma.

### Tell us about neuroblastoma.

This is the most common solid tumor in children outside of the brain; it accounts for one in 10 new pediatric cancer

diagnoses. Approximately half of the children with the high-risk form of the disease will die and the survivors will bear a lifelong burden from the intensity of therapy. We are desperately in need of novel treatment approaches.

### Can you describe your latest research?

I am investigating the abnormal metabolism of neuroblastoma to uncover new potential therapies. The most aggressive neuroblastomas have extra copies of a gene called MYCN, which causes neuroblastoma to have different metabolism from normal cells. I have

**“This approach holds great promise for future targeted therapies.”**

found that the amino acid, asparagine, is critical to the growth and survival of neuroblastoma, and I have identified a novel drug combination that reduces the levels of this critical nutrient and effectively kills the most aggressive neuroblastomas.

This work could serve as the basis for clinical trials with this drug combination in children with neuroblastoma. My goal is to exploit neuroblastoma’s metabolic Achilles heel in order to improve outcomes for children who

**Micah Maxwell, M.D., Ph.D., has identified an amino acid that causes neuroblastoma to grow. Now, he’s testing a drug combination that could halt this pediatric cancer in its tracks.**

suffer from this devastating diagnosis. This approach holds great promise for future targeted therapies to treat not only neuroblastoma, but also many other cancers that rely on abnormal metabolism.

### Funding is critical to your work.

Despite the great need for pediatric cancer research funding, the National Institutes of Health devotes only 7% of its cancer research budget to the study of pediatric cancer. That’s where organizations like St. Baldrick’s come in. The investments of St. Baldrick’s donors provide critical funding for researchers like me to continue our work, build on the accomplishments of the past and discover new approaches to treat aggressive diseases like high-risk neuroblastoma.

### How has St. Baldrick’s supported your work?

I’m a recipient of the Mighty Micah’s Mission Fund St. Baldrick’s Fellowship, which has provided crucial funding for my work on the metabolism of neuroblastoma and its response to the drug combination that I am testing. As a direct result of this award, I have been able to generate additional compelling pre-clinical data, and I have secured promotion to a junior faculty position in pediatric oncology at Johns Hopkins.

Without this funding, I would not have been able to continue my current

research, which holds the potential to enhance our ability to treat patients with aggressive forms of neuroblastoma. At this critical early stage of my career, this funding has allowed me to lay a foundation of discovery and productivity that will make me competitive for National Institutes of Health-funded research grants going forward to continue the work.

### Who inspires you?

My experience with the children and their families as they undergo treatment for cancer motivates me. Every day, I strive to understand the biology of cancer better and to identify new therapies and new treatment combinations that are both effective and safer. I hope that my work will lead to new drugs that improve survival and decrease side effects. My goal is not only for children to survive their cancer, but also for them to thrive and live full lives after their treatment.

*Micah Maxwell, M.D., Ph.D., is an instructor in pediatric oncology at Johns Hopkins Medicine in Baltimore, Md. He is a St. Baldrick’s Foundation Fellow who has also held fellowships from the National Institutes of Health and Johns Hopkins University School of Medicine, where he earned his medical and doctoral degrees.*



# Dishing up Hope

When it comes to fighting pediatric cancer, the nation’s restaurants and pubs have gone above and beyond to host St. Baldrick’s Foundation events. These establishments are home base for many head shavings and other events, and the owners are enthusiastic supporters of the kids in their own communities who are battling cancer.

Our restaurant/pub partners represent a cross section of the industry: large corporate chains, mom and pop eateries, neighborhood pubs and catering halls. They’re the cornerstones of their communities. “We’re so grateful to these establishments for all they do to fight for a cure,” said Director of Corporate Relations Robyn Raphael. “The restaurant industry is hurting right now as a result of the pandemic, yet many are still finding virtual ways to help kids with cancer. Their commitment to St. Baldrick’s is inspiring.”

Meet a few of these partners:



### KITTY HOYNES IRISH PUB AND RESTAURANT Syracuse, N.Y.

Since 2005, Kitty Hoynes Irish Pub and Restaurant has hosted a head shaving for the St. Baldrick’s Foundation. Since its inception, the event has become a St. Baldrick’s “top-five” event, raising \$539,782 last year. Due to the pandemic, this year’s event was cancelled just a week before its scheduled date, but donors still contributed \$354,582 to St. Baldrick’s.

*“Our yearly event has introduced Kitty Hoynes Irish Pub and Restaurant into a community of caring, giving and making an impact. The honored children and families at our events are so important to us. Our shaves & barbers see our honored kids when they are sick, when they are all better, and most importantly, they keep the memory alive of the kids we have lost. Kitty Hoynes is a family establishment — our shaves, barbers, volunteers and honored kids have all become part of that family.” — Sophia Meskos, volunteer event coordinator*



### MCMULLAN'S IRISH PUB Las Vegas, Nev.

At McMullan’s Irish Pub, frivolity and fun have marked the annual St. Baldrick’s Foundation head shaving event for the past 13 years. But there’s an underlying tone of seriousness: pub owners Lynn and Brian McMullan lost their 2 ½ -year-old daughter, Kyra, to a brain tumor. Now, the pub has built a community of caring to help other kids with cancer.

*“St. Baldricks offered us an opportunity to honor our daughter and do something to help families facing childhood cancer. We have made lifelong friends who understand the dire need for children’s cancer research. Each year, our team works together to make our events creative and fun. St. Baldrick’s Day at McMullan’s Irish Pub is now a much anticipated, very large and beautiful event. It’s a great day for the pub, bringing out the best in everyone who participates. The energy is electric.” — Lynn and Brian McMullan, owners and event organizers*



### de VERE'S IRISH PUB Sacramento, Calif.

The de Vere brothers know plenty about the importance of cancer research — their father dedicated his life to the field. Now, the family business, which includes several restaurants, has marshaled the power of the Sacramento community to carry on his fight by hosting St. Baldrick’s Foundation head shaving events. Their goal: to let kids battling cancer know they are not alone.

*“Every year I am touched by those who answer the call to brave the shave. So many people really help to raise a ton of money. For my brother and I, our proudest moment was when we surpassed the \$2 million mark in fundraising. In fact, we were blown away! To give credit where it’s due, we could have never hit that number without the help and inspiration from Chef Patrick Mulvaney of Mulvaney’s B&L, and his team, the Sactown Baldies, who lead the charge with us every year.” — Henry de Vere White, owner and event organizer*



### JIM BRADY'S New York, N.Y.

The very first St. Baldrick’s head shaving took place at Jim Brady’s Irish Pub and Restaurant. For the next 20 years, the St. Patrick’s Day event organized with the reinsurance industry would be filled to capacity. The pandemic hit just days before the 2020 installment. Despite a quick pivot to a virtual format, it raised over \$275,000.

*“The roots of St. Baldrick’s within the reinsurance industry made the Jim Brady’s event feel like no other. Now, this iconic pub has shut its doors. St. Baldrick’s will miss them profoundly. We are deeply grateful for the friendship of Validus Senior Vice President Colleen Brien, volunteer event organizer, as well as that of all the Jim Brady’s patrons. While we don’t know what 2021 will hold, the commitment from the reinsurance industry to kids with cancer remains steadfast.” — Mariela Castillo, Director of Special Events*



### FADÓ IRISH PUBS Sites in the U.S. and United Arab Emirates

When it comes to fighting pediatric cancer, Fadó Irish Pubs is all in. One of the St. Baldrick’s Foundation’s oldest pub partners, the chain has raised over \$11 million through events at locations across the country. The hallmarks of Fadó’s community-oriented events: Good food, good drink and a great time, all to benefit kids with cancer.

*“Hundreds of people at Fadó and St. Baldrick’s have worked together for many years and have made such strides in helping kids with cancer. It’s one of my biggest sources of pride in our people and our brand. We believe our reason for being is to gather and connect our community. There is no other day of the year when that is more realized than on St. Baldrick’s event day. The sense of community and caring is palpable when you walk in.” — Kieran McGill, Founder and CEO*

**Neuroblastoma is only one of 12 major types of childhood cancer — and hundreds of subtypes — that strike children.**

Neuroblastoma is a childhood cancer that starts in the nerve cells and causes solid tumors anywhere in the body. At the St. Baldrick’s Foundation, we know it’s critical to keep research going to find a cure. Here’s why:

**800**  
kids diagnosed with neuroblastoma every year

**1-2**  
years average age at diagnosis

**40-50%**  
five-year survival rate for high-risk neuroblastoma

**St. Baldrick’s has funded over \$26 million**  
in neuroblastoma-related research since 2005.

**Since the beginning, 4,896**  
total events held at restaurants/pubs

**In 2019 restaurants/pubs**  
hosted **348 events** raising **\$16.4 million**

**In 2020 restaurants/pubs hosted 246 live**  
events raising **\$8.1 million**, plus **61**  
virtual events raising **\$2 million**