



## Shave the Day!

Looking for a fun—and virtual—way to fight childhood cancers? Check out Shave the Day, a new video game that rewards your head-shaving prowess with Bald Bucks to benefit the St. Baldrick's Foundation.

The game was created by Schick Xtreme®, St. Baldrick's newest national corporate partner, which reached out to St. Baldrick's after a school head-shaving event attended by the daughter of Matt Bell, vice president North America at Edgewell Personal Care, the parent company of Schick Xtreme®. "The students and community came together in a celebratory act of head-shaving to stand in solidarity with kids fighting cancer. I knew we needed to get Schick Xtreme®—a razor praised by consumers as the best for head-shaving—involved with St. Baldrick's mission immediately," Bell explained.

In Shave the Day, players take on the persona of XtremeMan, a fearless bald superhero. The mission: to shave as many heads as possible to raise money for childhood cancer research. Using a Schick Xtreme® razor as a hoverboard, players dodge oncoming obstacles to shave heads and rack up Bald Bucks. When the game ends, Schick Xtreme® turns earnings into a real donation to St. Baldrick's Foundation, pledging up to \$250,000 in support. Players can challenge friends and family to the game and can also make their own donation to support kids with cancer.

While the game was in development before the COVID-19 crisis unfolded, its release during the nationwide lockdown that canceled in-person head-shavings and other St. Baldrick's fundraisers was timely, Bell noted: "We've made it easy and fun for everyone to play Shave the Day and support lifesaving research from the comfort and safety of their couch."

**Shave the Day is available for free for Apple and Android users in the App Store and Google Play Store. People can also visit [ShaveTheDay.com](http://ShaveTheDay.com) to download the mobile game.**

## A Promise is a Promise

In late February, the St. Baldrick's Foundation was well on its way toward its annual goal of raising \$40 million for pediatric cancer research. Then, the COVID-19 pandemic hit. Public gatherings around the world—including many St. Baldrick's head shaving events—were canceled.

Now, St. Baldrick's is facing a \$10 million shortfall. Times are tough, but CEO Kathleen Ruddy is confident that donors will step up for kids with cancer. Already, one of our founders, Tim Kenny, and his wife, Sheila, have promised to match up to \$300,000 of donations, doubling the value of gifts. They're hoping others will accept their challenge during June, when St. Baldrick's holds its survivorship campaign—or even make a challenge of their own.

An increase in donor giving now will help to make up for the temporary drop in donations, which can have dire implications. Promising studies on tap for this fall could be placed on hold—or even canceled—without the money to fund grants. Yet, Ruddy points out that pediatric cancer isn't taking a break. "Even during this pandemic, more kids are being diagnosed every day," she says. "If we have to cancel studies, the ripple effect on kids, in the U.S. and around the world, would be devastating."

Ruddy also worries that a long-term lack of funding could cause top scientists to leave the field for private industry: "These are very talented people. If there's no funding for their work, they'll have no choice. And if that happens, it will take years to reactivate the talent pipeline and assemble teams with the right skill sets."

Ruddy is confident that St. Baldrick's donors will come through. "People are facing hardships, but so many have told us that 'a promise is a promise,'" she says. "They're not giving up on kids with cancer. The heartfelt response has been beautiful."

For simple ways you can help fund the fight, check out the back cover.



## 5 Ways You Can DFY Childhood Cancers Right Now

#DFYchildhoodCancers #VirtualShave2020

While all of our in-person events have been canceled until Sept. 1, there are still lots of ways you can help kids with cancer:



**1 Donate Online** We understand that you may not be able to give as much due to the pandemic. St. Baldrick's appreciates donations of all sizes!



**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 shaver: <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 summer! Simply specify the St. Baldrick's Foundation as the beneficiary.



**4 Host a DIY Event** Head-shaving's not your style? Get creative and come up with your own virtual event. Host an online danceathon. Challenge some friends to a virtual hula hoop contest. Or get together on Zoom for a wine and cheese fundraiser. As long as it's safe, we're in!

More: <https://www.stbaldricks.org/faq/fundraisers-do-what-you-want/#sbfinfo-answer4>



**5 Recruit a Friend...or 5!** When it comes to fighting pediatric cancer, every dollar counts. When you recruit a couple of friends to support St. Baldrick's, you're making a big impact on kids with cancer.

## Let's Connect



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

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

[StBaldricks.org/league](http://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](http://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.



SPRING 2020



# YOU MAKE AN impact

**Nathaniel Decker** lost his twin brothers to pediatric cancer. Now this brave 10-year-old is determined to be a hero for other sick kids. His inspiring message: "You can never give up hope."

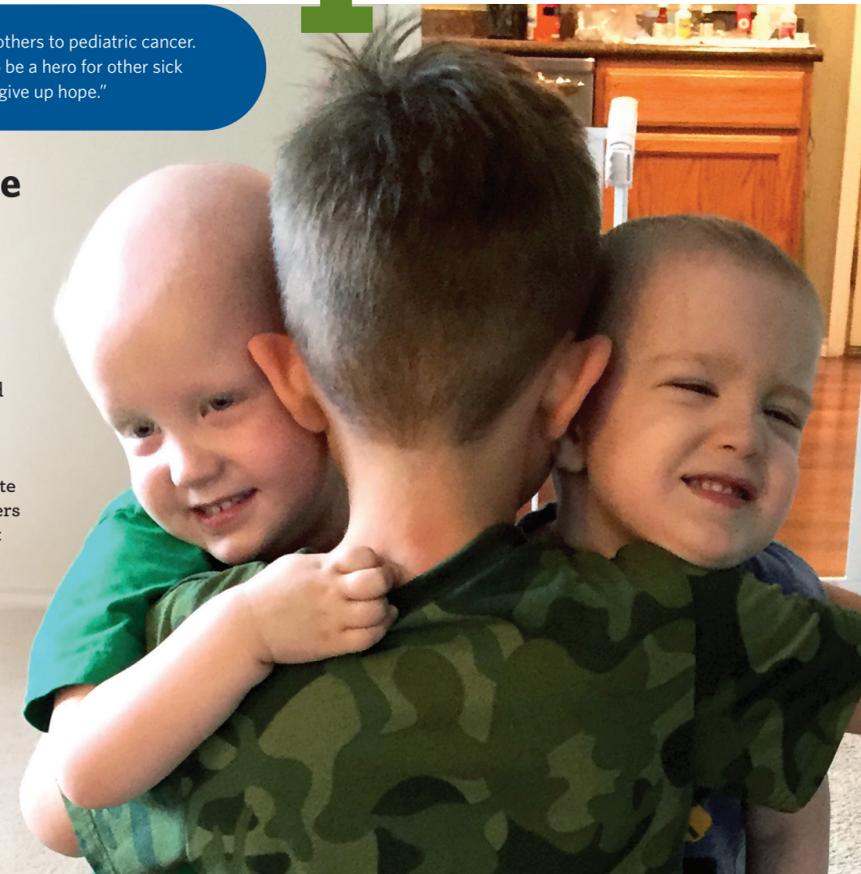
## Never Give Up Hope

When he was younger, Nathaniel loved to play with his brothers, Seth and Joel. The Decker household was bustling with the raucous activities that boys love: trucks, dinosaurs, Transformers and playing in the mud. "Joel was probably the more crazier one," Nathaniel remembers. "Seth liked to read books, like me."

Those carefree days came crashing down when first Seth, and then Joel, were diagnosed with a rare form of acute myeloid leukemia (AML). As his brothers battled valiantly, Nathaniel did his part by becoming a bone marrow donor for Seth's second transplant. The family was devastated when Joel ran out of treatment options and passed away at age 3. Eighteen months later, Seth passed away at age 4.

Today, Nathaniel and his parents, Will and Natalie Decker, have vowed to honor the twins' memory by supporting pediatric cancer research. Through the Double Deckers Destroy AML

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## Heroes Among Us



"We can't afford to turn our backs on kids with cancer." That's the message Douglas S. Hawkins, M.D., is delivering on behalf of the thousands of heroes who are facing tough hurdles to advance pediatric cancer research during the worldwide COVID-19 pandemic.

Dr. Hawkins is chair of the Children's Oncology Group (COG), which unites more than 9,000 childhood cancer experts through clinical trials around the world. He understands the Herculean steps taken to keep the research going: minimizing contact with kids while safely providing investigational medicines, monitoring patients through telemedicine visits, taking scans and bloodwork safely, analyzing test results and sharing data virtually with fellow researchers.

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## Champion in the Lab

A new cancer vaccine could be the key to treating pediatric brain tumors—but COVID-19 threatens to derail funding that supports the work of promising researchers like Elias Sayour, M.D., Ph.D.



Elias Sayour, M.D., Ph.D., consults with colleagues at the University of Florida.

### Why did you choose pediatric cancer research?

Oncology is the heart of medicine for me. As a clinician, caring for these children during the most unimaginable times was a real privilege. It was amazing to be their primary oncologist, but I struggled sometimes. I wasn't able to save some kids and I saw others suffer serious lifelong side effects from the toxicity of treatments. As a researcher, I found a way to sublimate those feelings of inadequacy to develop

new therapies that could treat these cancers without horrible side effects.

### You specialize in childhood brain tumors.

Yes. This field epitomizes the problem I have with side effects from treatments. Our chemotherapy regimens are standardized—for some kids it's just right, for some it's too little and for some it's too much. Giving radiation to a developing brain affects cognition as these children grow up. As a result of side effects, some are not able to walk,

**"We need our donors to be champions to ensure that this work continues. Children with cancer are depending on us."**

talk or hear. Some kids also succumb to side effects caused by treatment. When we don't get it right, it's terribly difficult to come to terms with.

### Tell us about your research.

We're evolving into an era of personalized care and therapy. I've been working on a new technology—a cancer vaccine. If you look at the history of cancer vaccines, they haven't worked. A couple work as preventative measures, but they don't treat cancer. Vaccines can take a long time to build immunity to prevent disease, and that doesn't work for cancer. This is a disease that evolves rapidly in real time. A cancer vaccine has to work immediately.

I've spent the last 10 years working on a new type of vaccine called a nanoparticle vaccine. In short, we take the genetic fingerprints of a patient's individual cancer, along with their RNA or DNA, and we load it into super tiny nanoparticles. Then, we inject those nanoparticles into the bloodstream, so

the immune system thinks it's a virus, triggering a near-immediate immune response. We can deliver treatment fast, in just a couple of weeks.

### What's the next step?

We've already conducted veterinary trials with dogs here at the University of Florida, and the dogs have lived far longer than we've expected. They developed immune responses within hours. It was a very small cohort, but based on that and some strong data in models, we've received approval from the U.S. Food and Drug Administration to run a clinical human trial for this new, investigational drug. We've also received a significant grant to fund phase I and II clinical trials over three years at leading children's hospitals across the country.

### Do you consider this a breakthrough?

Not yet, but someday it could be. The pace of scientific progress is slow and even haunting for me. It's hard when I see children dying of these tumors. This technology is still in its early days, but I believe in it. We think of this as a platform technology; we can continue to build on it and refine it with better and better outcomes. I'm cautiously optimistic. We still have a long way to go to confirm its safety in humans, but this could represent a paradigm shift in the way we treat some cancers.

### Has COVID-19 affected your work?

It definitely has. We were hoping to

start our phase I clinical trial this summer, but COVID-19 has delayed things. I think the bigger issue moving forward will be lack of funding for pediatric cancer research. Right now, it has been traditionally underfunded by the National Institutes of Health, and with COVID-19, that government funding is quickly drying up.

### What's your message to donors?

Your contributions to St. Baldrick's are the lifeblood of my work and that of other junior investigators. My St. Baldrick's funding has led to larger grants, including the one to fund this promising clinical trial. Without adequate government funding, individual donors will have to step up to close this gap. If that doesn't happen, we stand to lose a lot of talent and projects. Frankly, that terrifies me. We need our donors to be champions to ensure that this work continues. Children with cancer are depending on us.

*A St. Baldrick's Foundation Scholar, Elias Sayour, M.D., Ph.D., is an assistant professor of neurosurgery and pediatrics and principal investigator of the RNA Engineering Laboratory with the Preston A. Wells, Jr. Center for Brain Tumor Therapy and the University of Florida Brain Tumor Immunotherapy Program. He earned his medical degree from the University of Buffalo and a doctorate from Duke University.*

FREEWILL



St. Baldrick's FOUNDATION  
Conquer Childhood Cancers

### Take it from Oprah

A few simple steps today can provide peace of mind tomorrow by ensuring that you and your loved ones are protected. Thanks to FreeWill, you can create a will online for free that provides for your loved ones, while building a powerful legacy through the St. Baldrick's Foundation.

In its recent list of 31 game-changing ideas to "empower you" and "make a serious difference," *O, the Oprah Magazine*, mentioned FreeWill in its sixth shout-out. Here's what Oprah had to say:

"Leave a Legacy: FreeWill.com makes it easy to complete a tough task: drawing up a will. After you fill in a form on the site, the info is converted into legalese; you sign it in the presence of witnesses, and ta-da, you've got a last will and testament! The process is funded by nonprofit organizations, and the site makes it easy to donate to them—and other charities—from your estate, an option 90 percent of people who have wills overlook. It's a win-win that lets you save money on legal fees now and spend it to help others after you're gone—one that's raised over \$920 million and led to more than 86,500 wills since launching three years ago."

Take the next step to safeguard your family's future and support pediatric cancer research through St. Baldrick's. Get started at: <https://www.freewill.com/stbaldricks>

### Heroes Among Us (continued)



Douglas S. Hawkins, M.D.

"Even our most complicated studies that involve stem cell transplants or very intense chemotherapy—we've been able to safely deliver that care," explains Dr. Hawkins, professor of pediatrics at Seattle Children's Hospital. "The pandemic has made it much more challenging, but our work to treat children with life-threatening illnesses has

continued. It really speaks to the dedication of the people who are doing the work. They've kept the research engine going, despite the pandemic."

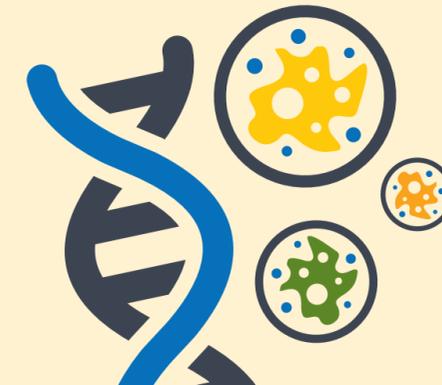
Yet the pandemic has created another obstacle that threatens pediatric cancer research: a steep drop in charitable giving. The St. Baldrick's Foundation—the world's largest private funder of pediatric cancer research grants—receives 71% of its funding from in-person head-shaving events held annually between March and June. With most of the world in lockdown last spring, those events haven't happened.

**"The need to make advances is as critical today as it was a year ago. We're just doing it under much more difficult circumstances."**

"This is a terrible time for so many people, but our mission at the COG is unchanged," he says. "We're in this for the long haul. As a society, we have a tremendous capacity to support worthy causes. Today, we are socially distancing ourselves to protect others. Supporting St. Baldrick's is a way we can all work together. If we're successful, we gain a lifetime of health for a child. That's as good an investment as you can make."

As heroes including doctors, nurses, pharmacists and data coordinators fight to keep research going, Dr. Hawkins points to children with cancer as the real warriors. These kids and their families were experts at social distancing, hand washing and other protective measures long before COVID-19 spread throughout the world, he noted.

Now, Dr. Hawkins is more determined than ever to keep the fight going. "In the midst of this pandemic, children are still being diagnosed with cancer," he says. "Our mission to improve the outcomes of children with cancer hasn't changed, despite this crisis. The need to make advances is as critical today as it was a year ago. We're just doing it under much more difficult circumstances."



### Never Give Up Hope (continued)

Hero Fund, they have raised more than \$65,000 for the St. Baldrick's Foundation. "This is how we keep Joel's and Seth's memories alive," explains Will. "Children with cancer are part of a community that we feel is underserved in a lot of ways. It's really strong in our hearts to help these kids and their families."

The Decker family is excited that St. Baldrick's recently selected Shannon Conneely, M.D., one of the doctors who treated the twins at Texas Children's Hospital, as a grant recipient. While Will and Natalie still volunteer at the hospital, Nathaniel can't because he's too young. That's a big reason why head-shaving is so important to him. A veteran St. Baldrick's shaver, Nathaniel says his first attempt at rocking the bald made him "cooler" in both temperature and appearance.

Now, he wants to be a bigger hero for kids with cancer. This summer, Nathaniel was supposed to be the team captain for the Double Deckers Destroy AML Team at a head-shaving in the family's home state, Texas. COVID-19 has postponed the event, but not his enthusiasm. "Shaving is something he can do to honor his brothers," says Natalie. "Nathaniel knows kids at the hospital right now, and he prays for them. He's so excited about shaving. Every day, he checks his total amount raised and he's happy to receive so much support."

Nathaniel has already exceeded his \$3,750 fundraising goal through donations from his family, friends and teachers. He hasn't given up hope that his big shave will happen, and he wants to raise as much as possible. You can help by donating to his effort at <https://www.stbaldricks.org/participants/mypage/1058798/2020>

## Show You CARE

New tax benefits for donors under the Coronavirus Aid, Relief and Economic Security (CARES) Act make this the perfect time to support the St. Baldrick's Foundation. Here are three new provisions for 2020:

100%  
of AGI

deduction for individual donors  
(up from 60%)

25%

of taxable income  
deduction for corporate donors  
(up from 10%)

\$300

additional deduction  
for donors who don't itemize  
(brand new deduction!)

Show you **CARE** about kids with cancer—and enjoy these tax benefits—with your gift to the St. Baldrick's Foundation.

Just go to [stbaldricks.org/impact](https://www.stbaldricks.org/impact) and donate today!