

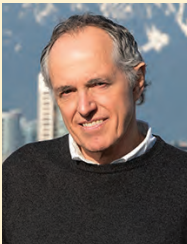
Never Give Up

For the Riedel family, funding promising Ewing sarcoma research creates a legacy in honor of their daughter—and may someday save other kids' lives.

When Martha Riedel, flanked by some of the country's top immunotherapy experts, testified at a Capitol Hill briefing on using the immune system to attack cancer, she urgently articulated the need for expanded cancer therapies. Poised and well-spoken at 15, Martha was also in a battle for her own life.

At 13 she was diagnosed with metastatic Ewing sarcoma, an aggressive form of bone and soft tissue cancer, and she quickly became an advocate for herself and others living with a cancer that needs new therapies. In spite of aggressive treatment—with combination chemotherapy, surgery, and radiation—the five-year survival rate for patients with metastatic disease is less than 30 percent.

Martha's 2017 Capitol Hill testimony showed the urgency for new treatments, and Martha also was the inspiration for an anonymous gift of \$1 million to speed up that quest. This generous donation funded the Martha's BEST Grant for All (Better Ewing Sarcoma Treatment). In early 2020, the donors and the Riedel family flew to Vancouver, British Columbia, to meet Dr. Poul Sorensen.



Dr. Poul Sorensen

"When we met with Dr. Sorensen and his team," Martha's father, Ned Riedel, says, "Poul told me that having met Martha motivated his team in a way that was very nontraditional. It was emblematic of what they're working for."

A board-certified anatomic pathologist specializing in the molecular pathology of pediatric cancers, Dr. Sorensen's research focuses on targeting aberrant signaling pathways that are activated in childhood cancers and breast carcinoma. Dr. Sorensen's laboratory uses a combination of genetic and biochemical approaches to identify proteins that are specifically altered in human tumors.

"Ewing sarcoma is largely resistant to conventional immunotherapy," Dr. Sorensen says. "Therefore, alternative treatment approaches are desperately needed, particularly in patients with metastatic disease. The overall aim of our grant proposal is to develop three novel, non-overlapping but complementary strategies to target these tumors."

Dr. Sorensen identified three main strategies for attacking Ewing sarcoma tumors: Target Ewing sarcoma cells using dual activity drug candidates; use an antibody-toxin conjugate targeting a highly expressed protein on the surface of cancer cells to specifically kill them; and finally, recruit natural killer immune cells and prime them to attack the tumor.

"The three therapeutic strategies that we established and continued to characterize in this project are extremely promising," Dr. Sorensen says. "Our work will serve as the basis for investigational new drug applications for the treatment of Ewing sarcoma."

The drug candidate that Dr. Sorensen and his team are working on, when tested in models, is far stronger than the current FDA approved drugs in trials for Ewing sarcoma. And, it's advances like these, Ned Riedel cites, that make it clear just how important it is for certain cancers, such as his daughter's, to get attention and funding.

"If everyone who had a child impacted by, or lost to, Ewing, pulled together," he says, "we could really open people's eyes to this. I will take any progress, any research that leads to getting rid of Ewing and getting rid of childhood cancer."



In April 2022, Martha died at the age of 20. The Riedel family continues to be involved with the grant and hopes to raise more funding.

Ned says, "It's never enough, but we got seven years with Martha after she was diagnosed. We watched her grow into an amazing woman. Martha was just incredible and incapable of giving up—until medicine gave up. If the medicine would have kept fighting, she would have kept fighting."



Martha's Spirit Lives On

An accomplished baker, potter, cyclist, and foodie, Martha Riedel was known for her indefatigable spirit and live-out-loud joy for life. Even in the face of a metastatic Ewing sarcoma diagnosis at 13 years old, Martha was incapable of giving up.

Taking after her father, Ned, Martha became an avid cyclist and even joined her school's mountain bike team. True to her character, Martha raced all four years of high school and finished every race she entered, earning her a legacy rider award—even as she went through treatment. She was an unstoppable force of activity and creativity.

Martha was a talented potter and, during her senior year of high school, became a teaching assistant in her pottery class. If it could be drawn, painted, or sewn, Martha was up for the challenge and ready to create. And these talents weren't reserved for just the arts.

Powered by her homemade sourdough, Martha cooked healthy and delicious meals for herself and her family. Constantly inspired by the world around her, after a trip to Spain, Martha and her father, Ned, bought a meat slicer and a leg of jamón serrano. "We made charcuterie plates like mad," he says.

Martha, always inquisitive and wanting to know more, spent her downtime on YouTube watching videos about science and engineering. She had her own 3D printer and even convinced her dad to help her build an aluminum forge, which they used to make a cast of her hand.

In April 2022, Martha died at the age of 20, but will be remembered for her refusal to give up or give in. Now, her family is continuing the battle against pediatric cancer in her memory. "She was a fighter," her father says. "And she never—never—gave up hope."

Dynamic Duo for Kids

"It isn't a problem until it's a problem in your house and then it's all you think about." For John and Julie Smith, it was the diagnosis of their son's best friend, Tyshon McKeller, that brought the problem of childhood cancer to the front and center of their lives. The Smiths, who have been involved with the St. Baldrick's Foundation for the past 15 years, say it was Tyshon's diagnosis that inspired them to support pediatric cancer research through St. Baldrick's. They became even more determined to help after Tyshon, a vibrant preteen who loved sports, passed away at age 12.

John was appointed to the St. Baldrick's Foundation Board of Directors in 2021 and is the president and CEO at Pennsylvania Lumbermens Mutual Insurance Company (PLM). A fully remote company, when PLM does come together in person, an event focused on service and giving back is always on the agenda. John says, "We're a socially minded company, doing school supply drives and packing food boxes. Many of our employees do their own fundraising, so we knew we wanted to do something fun to raise money for St. Baldrick's."

"We've now saved so many children and made them cancer free, but now they have a lifetime's worth of illness that comes after it. We want to see these people live healthy lives, so we need a lot more research on cancer drugs and the side effects, as well."

At this year's PLM National Meeting, the company decided that instead of having a dinner, the event would be a lively charity-minded get-together complete with Mummies, local television coverage, and team members getting their heads fully shaved. What began with 13 people and a goal of raising \$25,000 ended with spontaneous signups, including an assistant vice president and a brand new employee—and \$175,000 raised.

Both John and Julie are no strangers to having their heads shaved for the cause. Active volunteers and fundraisers in support of St. Baldrick's, in 2016 this dynamic duo first took the plunge, participating in the National Association of Mutual Insurance Companies' (NAMIC) Brave the Shave



event. While the head shaving events are a fun way to raise visibility and get a lot of people involved, in order to broaden their reach and do as much as they can, the Smiths are always looking for additional creative ways to support St. Baldrick's.

St. Baldrick's continues to inspire them because the foundation is reaching out across a wide spectrum of researchers and cancers. Julie says there's still more work to do: "We've saved so many children and made them cancer free, but now they have a lifetime's worth of illness that comes after it. We want to see these people live healthy lives, so we need a lot more research on cancer drugs and the side effects, as well."

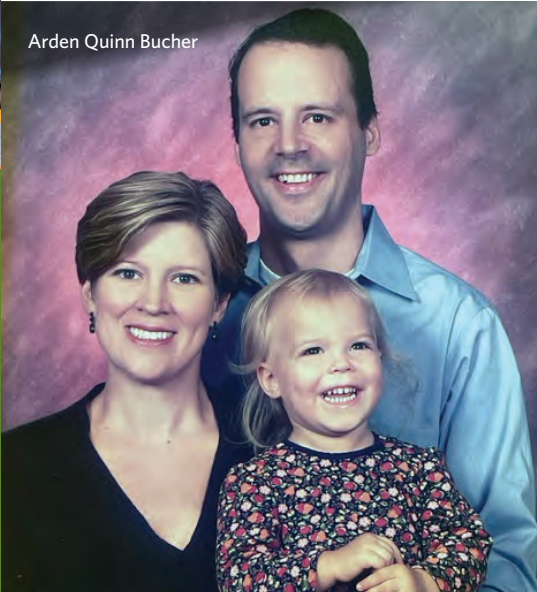
For the Smiths, conquering childhood cancer and creating better outcomes for families facing a diagnosis is at the heart of their efforts.

"Childhood cancer is a scourge," John says. "You're dealing with young people who are never going to go on a first date or go to prom. They're just starting their lives. And that just grabs you."

FALL 2023



YOU MAKE AN impact



Arden Quinn Bucher



Emily FaRannte



Leo Crawford

Amy and Rick Bucher connected with St. Baldrick's after losing their child, Arden, to cancer. Today Amy says, "Working together makes a difference that fills the hole in your soul."

Stronger Together

The Pennsylvania couple's daughter, Arden Quinn, was diagnosed with neuroblastoma at age two and passed away in 2008, shortly before her fourth birthday. Amy first experienced the power of the pediatric cancer community shortly after Arden's diagnosis, and she became one of the 46 Mommas, a group of mothers across the country advocating for childhood cancer research funding in 2010. As the Buchers became more involved, first Amy served two terms on the St. Baldrick's board, and now Rick holds a board seat. Through several endeavors, including a St. Baldrick's Hero Fund named for Arden, the Buchers have raised almost \$1 million to fund promising research projects.

Giving back takes many forms for kids and families in the fight

against childhood cancer. While financial support and advocacy are vital, families say emotional support is equally important. Diagnosed last year with non-Hodgkin lymphoma, 13-year-old Emily FaRannte lives near the Bucher family. While the two families had never met, Amy reached out to Emily's mom, Adele FaRannte, to offer her support. Adele recalls, "Amy and I just sat down and talked. When your child is diagnosed with cancer, you suddenly have a whole new family. It was like sitting down with my best friend who understood what we were going through."

Over time, Amy introduced the FaRanntes to St. Baldrick's. Earlier this year, Emily rang the bell signaling the end of her cancer treatment, and soon after, was the guest of honor at a head

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Let's Connect



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FREEWILL

Leave a Legacy

Now, it's easier than ever to leave an estate gift to the St. Baldrick's Foundation. Through FreeWill, you can craft a will that protects your loved ones, while specifying a gift to St. Baldrick's that supports pediatric cancer research. It's fast, free—and creates a legacy of life for generations to come. Go to FreeWill.com to get started!

Ways to Give

Kids with cancer need cures now, and it starts with you. Donate to fund the most promising childhood cancer research. Give once or monthly. Start today: stbaldricks.org/ways-to-give

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 \$338 million in grants funded since 2005, we are the largest non-government funder of pediatric cancer research grants. YOU made progress possible!



Scan here to help find a cure!

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.



Emily and Leo have collected more than 1,000 Squishmallows for kids with cancer.

Miles to Go

As head of the Children's Oncology Group, Doug Hawkins, M.D., has witnessed remarkable advances in childhood cancer research. This dedicated doctor says, "Our job is far from finished."



Doug Hawkins, M.D.

Tell us about yourself.

I became interested in the field of pediatric cancer research in 1990, right after graduating from medical school. Today, in addition to treating patients, I'm the Group Chair of the Children's Oncology Group (COG). There's strength in numbers: We've made real progress in the field of pediatric cancer by

harnessing the intellectual and collective action of thousands of researchers and hospitals around the world.

Within the COG, the vast majority of our members are practitioners. Whether you're a surgeon, a pathologist, or an oncologist like me, we all participate in the research, but many of us also provide care to children and adolescents with cancer. That gives you grounding. It's one thing to talk about event-free survival or side effects; it's another to see one of your own patients have a relapse, experience brutal complications of treatment, or pass away. For all of us, pediatric cancer is not an abstraction. Every day, we face the reality that we're not curing every child with cancer.

How has pediatric cancer research progressed?

Looking back, it's been remarkable. Our understanding of the biology of cancer—the genetic changes or inherited risk factors—that lead to children getting cancer is so much more advanced. There have been improvements in some survival rates and we've reduced short-term side effects like nausea, vomiting, or risk of infection. That part of my practice is dramatically different than when I first started seeing patients. In addition, many more drugs have been approved

specifically for pediatric cancer. Yet despite these advances, we risk going into a period of stasis: For all pediatric cancers combined, the overall five-year survival rate is now over 85 percent. But is that really good enough? That's one of my biggest concerns and for some cancers, there is still no cure.

Take mature B-cell lymphoma, a type of non-Hodgkin lymphoma. The overall survival rate is now in excess of 90 percent. Kids who present with advanced disease face grueling therapy in terms of intensive treatment days in the hospital. However if this lymphoma recurs, it is very hard to cure. It's a terrible calculus: Give less intensive treatment upfront with good results for most kids, but little chance for those

"Today, many of the most effective tools I use are the direct result of research conducted through the COG and supported by St. Baldrick's. When I see children benefit from things I've watched develop over many years, I think, 'Wow, I am so lucky to have a cool job.'"

who relapse. How do you tell a family that their child had one good chance, and now there are few treatment options?

What's new in blood cancer research?

The COG conducted a study on a type of immunotherapy called blinatumomab that uses T-cells to find and destroy cancer cells in kids with acute lymphoblastic leukemia (ALL), the most common type of pediatric leukemia. Although ALL can often be cured with front-line treatment, it is hard to treat if it recurs. This method of immunotherapy produced a much higher chance of long-term remission with fewer side effects, which can be devastating for developing bodies. That was a

remarkable finding. However, it's very complex because the medication has to be administered intravenously over 28 days continuously. COG is testing blinatumomab in our largest front-line study and may someday substitute it for some standard medicines that have been around for more than 30 years.

How about CAR-T cells?

That's another promising development. CAR-T cells, which involve genetically reprogramming a person's own cells to kill cancer, have been used successfully for children with ALL. It's another remarkable finding—a miracle of modern medicine. But if you follow children with ALL long enough, many will relapse. So there's much more work to do. We're also studying how to make CAR-T cells more effective for other kinds of pediatric cancers, including solid tumors. That has proven to be more difficult.

The treatment time for boys with ALL is also shorter.

Yes, and it's because we treat children—both boys and girls—very differently today than we did 40 or 50 years ago. Traditionally within COG, boys received just over three years of therapy, compared to just over two years for girls. Historically, boys had a slightly higher relapse rate than girls. Earlier studies suggested a marginal improvement when boys were treated with an extra year of low intensity maintenance therapy. However, with new approaches to care, there does not appear to be any benefit with an extra year of treatment for boys. So now, treatment duration is uniform for both boys and girls.

What's preventing faster progress?

Although technology moves quickly, clinical trials take time; that's the nature of medical research. However, funding is also a challenge. For instance, much of the development of CAR-T cells was accomplished by industry and academic institutions. It's incredibly expensive to do a CAR-T cell clinical trial leading to FDA approval. Pharmaceutical companies have limited incentive

to develop CAR-T cells for kids with illnesses like brain tumors because they're so rare. Decisions aren't made for the benefit of children, but instead on return on investment. Federal funding is also tight. A lot of institutions are struggling financially, and as a result, they're taking a closer look at research budgets. **That's why funders like St. Baldrick's are so crucial to our work.**

Any message for St. Baldrick's donors?

I'm reminded of two lines from *Stopping by Woods on a Snowy Evening* by Robert Frost: "I have promises to keep/And miles to go before I sleep." Although we've made progress in pediatric cancer research, it's not enough. There are still too many children dying from cancer, and those who live experience long-term side effects that affect their health into adulthood. Improving outcomes will take all of us working together. **What St. Baldrick's does so well is to support the broad community of pediatric cancer researchers. In fact, St. Baldrick's is the COG's largest donor, and I'm so incredibly grateful.**

What keeps you motivated?

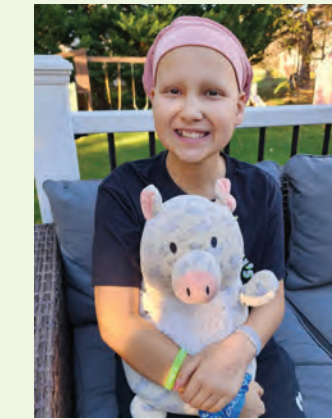
A lot has changed since I started practicing in 1990. Today, many of the most effective tools I use are the direct result of research conducted through the COG and supported by St. Baldrick's. The work of investigators, many of whom I know personally, has been indispensable in saving kids' lives. When I see children benefit from things I've watched develop over many years, I think, "Wow, I am so lucky to have a cool job."



Doug Hawkins, M.D., braves the shave to support the work of fellow researchers funded through St. Baldrick's.

Doug Hawkins, M.D., is group chair of the Children's Oncology Group (COG), professor of pediatrics at Seattle Children's Research Institute, pediatric oncologist at Seattle Children's Hospital—and a 2022 shaver!

Stronger Together (continued)



shaving event sponsored by the Buchers. Amy made sure that Emily had a starring role: Shaving the head of the mayor. But that's just the beginning of Emily's commitment to helping other kids with cancer. The seventh grader has collected almost 1,000 Squishmallows—an adorable plush toy—to present to children currently undergoing cancer treatment. Last spring, the American Cancer Society recognized Emily's kindness with a special award.

During her own treatment, Emily had relied on her Squishmallow, a pig named Rosie, to help her through the tough times. "My parents couldn't be there during some scans and radiation, but I could still hug Rosie really tight," says Emily, who has visited hospitals to distribute Squishmallows to sick kids. "It makes me really happy to give them out, because I know what those kids are going through. I felt like I needed a buddy by my side when I was in the hospital, and they do, too."

Across the state, 7-year-old Leo Crawford is also collecting Squishmallows to pay it forward to kids with cancer.

Diagnosed at age 4, Leo recently completed his treatment for acute lymphoblastic lymphoma (ALL). His mom, Brandi Caltieri, says Leo had received a Squishmallow in the hospital from another child. Brandi recalls, "Leo's love language is hugs, but that was taken away from him while he was in the hospital. In isolation, he couldn't hug anyone. One night he said, 'Mom, I want to start giving back to other kids with cancer. Every kid should have something soft and squishy to hold onto.'"

While Adele and Brandi have never met, they recently connected via email to talk about their children's incredible generosity on behalf of kids with cancer. Brandi has also joined an online community called the Bad Luck Moms Club, which is comprised of moms across the country who have kids with cancer. The group is dedicated to advocacy and raising funds for pediatric cancer research, as well as supporting each other through the cancer journey. Brandi hopes to become more involved: "Not that I ever wanted my child to have cancer, but I've found more of a purpose in life. So many kids need help and I definitely would love to help however I can."

Collaboration—among families, researchers, and even kids—is the key to improving outcomes, Amy Bucher says: "We're all dedicated to making outcomes better, without the devastating side effects that currently exist. Thanks to everyone working together, researchers are no longer in silos. There are tangible results coming out of these relationships. For families, everything feels out of control when your child has cancer. Connections



made through the St. Baldrick's community have helped me to turn pain into purpose. Whether you're a parent raising funds for research or a child collecting comfort care items for other kids, we're all working together to make a difference."



A dedicated dancer, Emily FaRannte underwent treatment for non-Hodgkin lymphoma for more than a year before ringing the bell signaling the end of her cancer treatment earlier this fall. To celebrate, she was invited to a head shaving organized by the Bucher family and shaved the head of her town's mayor.



Diagnosed with acute lymphoblastic leukemia (ALL) at age 4, Leo Crawford completed three years of treatment before ringing the bell this fall. While he still lives with side effects, Leo is back in school and is happy to be reunited with his friends and teachers.



The Children's Oncology Group is the world's largest organization devoted exclusively to childhood and adolescent cancer research.

10,000+ doctors and researchers

100 active clinical trials open by the COG at any given time

220 leading universities and cancer centers

90% of children diagnosed with cancer annually cared for at COG member institutions

\$97 million granted to the COG by the St. Baldrick's Foundation since 2005