Helping Children in El Salvador with 'Small Steps'

smallMiracles

PROSTHETIC & ORTHOTIC MAGAZINE

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Patient Profile

Peter Zucca

Childhood Cancer Survivor & Powerhouse of Junior Philanthropy

LAWALL
PROSTHETICS & ORTHOTICS

Helping Children in El Salvador with 'Small Steps'

Orthotic outreach changes lives for children and families

Kindness is contagious; and the desire to serve others is habit-forming. These are lessons Allison Bressler, CPO, knew well, but relearned with sharp, dramatic clarity during her September mission trip to El Salvador as a member of a volunteer team offering medical aid to the underserved.

The expedition was organized under the auspices of *Healing the Children,* a charitable group that has provided underserved children worldwide with more than $700 million in urgently needed medical services—services provided by volunteers like Bressler and her colleague, Darin Oskison, CPO, whom she credits with inspiring and encouraging her to undertake what he described as a life-changing experience.

Oskison's tales of his first mission trip participation with *Healing the Children,* described earlier in *Small Miracles* (Winter 2016 issue), fascinated Bressler.

"Darin told me that although three orthotists were there on his first trip in 2015, since then, he's been the only orthotist on the annual team, so there was a real need. He told the head podiatrist he knew someone who would love to step up, and the rest is history–because I don't plan to ever give it up!" she vows.

Their trip this year—from September 22-30, exceeded her expectations: "We were there at the Central Military Hospital in San Salvador from 8

a.m. till between 10 and 11 p.m. every night. But it was great---nobody complained. Everybody just worked together. It was a phenomenal group!

"We were certainly never at a loss for enough children to do surgery on, and to do follow-up care. A total of 170 kids came through for screening, they did 42 surgeries, and we fit more than 150 kids for orthotics. Based on how hard we worked for the days we were there, I have no idea how Darin did it in previous years, when he was there by himself! I give him all the credit in the world for that!" Bressler marveled.

Children were treated for club foot, cerebral palsy, spina bifida and various foot issues; and seeing firsthand the immediate difference an AFO or other orthotic made in their lives was immensely rewarding, Bressler said.

She especially recalls a father who came in with his daughter; the mother had recently died. He had sold his motorcycle to get there to seek help for his daughter, who had neurological issues. "She had difficulty walking, was really up on her toes, and had become really unsteady within the last year. At first we didn't think we had anything to fit her, but then I was able to refashion a set of AFOs and modify them by adding lifts, with lifts on the shoes, too, which helped to stabilize and steady her so that she could walk."

The father was crying unashamedly, and Bressler was deeply moved. "When you see somebody cry like that, you know you've really made huge steps to improve their lives."

The next day they returned to get MRIs from the doctors—in search of answers concerning the root of her issues, Bressler noticed. "I hope I get to see her next year, and find out the rest of her story. Darin has gotten to see and follow up with several patients over the last three years.

"We are going to suggest offering a follow-up clinic day (or two) next year for orthotic checkups and continuity of care, if time allows," she explains, already looking forward to her first return trip.

While the focus of the mission was on helping children ranging from one month to nearly 20 years of age who benefited from surgeries performed by

the team, the HC professionals also used the opportunity to serve others. An adult hospital worker, for example, was fitted with orthotics and shoes. Donated supplies had been collected throughout the previous year, not only orthotic devices, but clothing, shoes, and more, for family members of all ages.

Bressler's daughter, a high school freshman, ran a shoe drive at area elementary schools, and successfully collected nearly 200 pairs of shoes the team was able to fit to those in need.

While volunteers are responsible for the costs of their travel, hotel, and food, Lawall helped to sponsor Bressler and Oskison's trip and also donated orthotic devices, equipment and supplies for the mission.

Bressler and Oskison's trip was extended this year to include a 2-day visit to Guatemala for an anniversary celebration of the *Small Steps* mission, which was begun in Guatemala 25 years ago by three podiatrists. In recent years, *Small Steps* combined its mission with that of *Healing the Children,* which will celebrate its own 40th anniversary in 2019.

The memories of her mission experience are unforgettable to Bressler, especially her image of the strong spirit of camaraderie that sustained a wonderful group of around 20 doctors, nurses, and other healthcare professionals and supporters—and kept them cheerful and uncomplaining despite the exhausting efforts and long hours.

"There were residents from Spain, an orthopedic surgeon from Guatemala, residents from Atlanta, an O.R. nurse from New Jersey, and the people who started it, from Arizona. It was just really an amazing group to come together to make such huge changes for people," she recalls.

"As we were driving through Guatemala, one of the girls was playing a song by Miranda Lambert that really resonated: 'From the beginning, to keep the world spinning, it takes all kinds of kinds.'

"I thought that was so representative of the trip: we were 'all kinds' of people. It's really just geography where each of us is born and the opportunities that we are afforded," Bressler reflects. "We all came together for this shared mission. It's great to be a part of it."


Cirugías de pie con deformidad cambian la vida de niños y sus familias

"CON LA AYUDA DE DIOS VOY A ESTAR MEJOR"

"CON LA OPERACIÓN VOY A PODER CAMINAR Y CORRER"

Pages from a Guatemalan publication that covered the story of Bressler and Oskison's mission visit.

get prepared for winter with some NEW GEAR

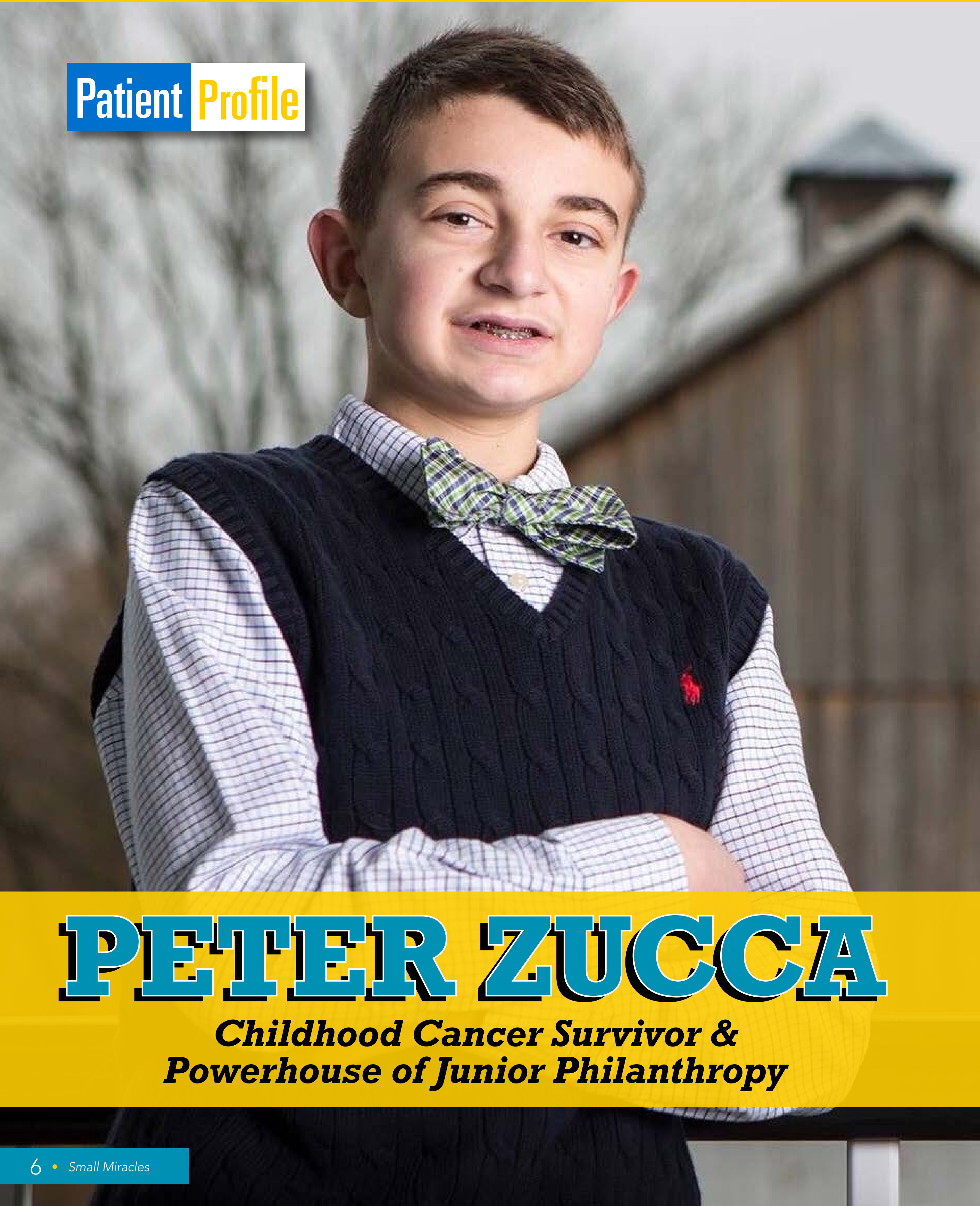
Winter is here whether we like it or not. So, now is the time to purchase new winter gear and here in the northeast that includes boots! Fortunately, Cascade DAFO has highlighted some manufacturers on their website who make boots specifically designed to accommodate braces.

One of those manufacturers, Butler, wanted to reinvent boots for kids and make them both practical and cute. They have a style that is designed to be an all-weather boot, to go over a shoe or act as a slipper. Their *Macaroni* boot is specifically designed to accommodate orthotics! For more information on these boots visit them at: theButlerBrand.com

MyMayu.com is another online brand that offers styles designed to accommodate kids' braces. They have two different styles: the *Trekker* for toddlers and the *Wanderer* for big kids.

KoolwaySports.com is another website worth checking out. Koolway designs outerwear for individuals with disabilities. While designing products, they try to keep four main points in mind: warmth, comfort, aesthetics, and accessibility. The company strives to help caregivers save time while dressing those in their care, and to assist individuals to maximize their independence. This company has a wide range of winter gear and their boots have a full zipper on the back and are lined with removable fleece.

Patients with disabilities and their families have been adapting their clothes and shoes to accommodate their needs for decades. Often you have to get creative and work with what you have, but these online suppliers might provide just the gear our patients are needing!



Patient Profile

PETER ZUCCA

Childhood Cancer Survivor & Powerhouse of Junior Philanthropy

> **“He picks causes that are close to his heart—things that affected him—and tries to help other kids so they don’t have to deal with it—or makes it easier for them to deal with it. He’s a remarkable young man.”**

The odds against him were enormous. But the 10-month-old baby who was given no chance of survival not only found the power to survive, but to amaze, energize, and inspire others—spearheading efforts to ease the burden and brighten the spirits of other cancer children through a charitable foundation of his own creation.

It’s not as though Peter has not had painful challenges of his own to deal with: the embryonal rhabdomyosarcoma (ERMS) he was diagnosed with on the 24th of December back in 2003 demanded extensive chemotherapy, leading to a series of 15 surgeries in as many years, including biopsies and line placements as well as eight- and ten-hour surgeries to resect tumors or, in 2013, to amputate his right leg.

On his first birthday, recalls his mother, Dawn Zucca, “We had travelled for a second opinion, and they gave him two months to live. So we literally planned his first birthday party and his funeral at the same time.”

How do parents deal with such a terrible situation?

“We cried a lot,” says Dawn.

Before Peter was two years old, he was exposed not only to chemotherapy and surgery, but to considerable radiation therapy during the eight months spent at Memorial Sloan-Kettering in New York City.

By the time they arrived home, on the day before his second birthday, Peter’s odds had improved slightly—he was now given a 24 percent chance of survival.

“He fought so hard for everything,” Dawn remembers. “He was unable to walk and was barely speaking. We had services of every kind in our home. I used to pack him and his tiny little walker into the car and we’d meet his physical therapist on the mini-golf course at Freddy’s Family Fun Center. He was determined to play there and she’d hold his hands so he could walk or help him to stand so he could putt the golf ball.

“In spite of all he had endured he was an incredibly joyful little guy.”

Battling the Odds

The radiation Peter experienced as a one-year-old later caused bone growth issues that created a limb length discrepancy.

The human body naturally tries to keep the head centered

Since then, additional donations, including a $10,000 grant awarded by the Philadelphia Phillies, have purchased another 150 wagons for the kids at duPont, and Peter was asked to speak at their holiday dinner honoring community non-profits.

above the pelvis; so in cases where one leg is shorter, there's a risk of scoliosis as the spine bends to maintain the head's centered position.

Thus, at age nine, Peter underwent a leg-lengthening process that involved breaking the bones and wearing an external fixator device that was unlocked daily, extended a bit to stretch the break, and relocked into the new position—allowing the mending bone to fill in the break and gradually add length to the leg.

The 45 days this process took felt like ten years to Dawn.

Less than a year later, she recalls, he was diagnosed with an aggressive and rapidly-growing desmoid tumor, possibly as a result of the leg-lengthening trauma.

Since Peter, as a baby, had already received the lifetime maximum amount of chemotherapy his body could reasonably bear, and the leg was weak and unhealthy as a result of the cancer, an amputation was recommended.

"He was done with the leg-lengthening in 2012, and then he lost his leg in May of 2013," Dawn remembers. "He started the third grade in the wheelchair because he had the fixator on, and he ended the third grade in the wheelchair because he didn't have a leg anymore. The third grade was not our easiest year, for sure!"

Amazingly, however, Peter returned to school to have lunch with his friends just five days after his above-knee amputation, and he was back in class full-time a week later. Perhaps even more remarkable, however, his mom points out, "Peter was back on the pitcher's mound, throwing strikes nine days after surgery! He was a powerhouse!"

His schedule involved not only school, and participation on the community dive team, but extensive outpatient rehab five days a week. He did his homework in the car on the way to the hospital in Delaware, Dawn explains.

Gaining Support

Through a chance meeting with former San Francisco Giants pitcher Dave Dravecky, who was a guest speaker at a church event, 9-year-old Peter had formed a bond that strengthened with time. Dravecky's pitching arm had shattered during a game in 1989, after being weakened by a cancerous desmoid tumor, and was amputated two years later. Since then, he had become an author and a popular motivational speaker.

"Peter was just starting to have some struggles with the fact that his friends were now getting bigger and stronger and becoming athletes, and he wasn't advancing the same way," Dawn recalls.

As Dravecky greeted and encouraged other young men with disabilities at the church brunch, autographing baseballs and taking photos, surprisingly, she remembers, "Dave turned and handed his private business card to my husband and said 'I want you to put this somewhere in case Peter ever needs me.'

"At the time, we wondered why on earth Peter would ever need Dave Dravecky. Then, a few months later, there was a lump in the back of his leg, and it was a desmoid tumor."

Doctors at Memorial Sloan-Kettering and Nemours/A.I. duPont Hospital for Children agreed on the diagnosis, but left Peter's parents faced with a decision that was difficult for several reasons:

"I wanted the leg amputated immediately, and my husband didn't want it amputated at all," Dawn explained. "After all these years, this was the first time that my husband and I were not on the same page about how to meet Peter's needs. I was very concerned about the impact of that disagreement on our marriage. This was a big thing not to agree on."

So she called Dravecky and told him about Peter's desmoid tumor—and the difficulty of the amputation decision—a choice Dravecky himself had once faced.

"I asked him to talk to my husband—and then I went grocery shopping. Dave called Dennis and encouraged him to move forward and amputate the leg as soon as possible, 'because it's such a monster that it will kill Peter.'"

Less than nine days after Dawn discovered the tumor, the leg was amputated well above the knee, "—in order to get a clean margin," she explained, "because it was growing so aggressively. Although a desmoid tumor does not have the ability to metastasize, nobody should be foolish enough to think that it's not aggressive, and that you can't lose your life to it—because you can!"

Dravecky continued to take an interest in Peter's success throughout

The Peter Powerhouse Foundation has become the largest non-corporate blood drive in southeastern Pennsylvania and New Jersey combined—in the top 10% of the nation in blood collected... "Since each blood donation provides three units for transfusions, nearly 6,000 lives have been impacted."

his rehab, Dawn notes.

"They would face-time each other, especially when he was having phantom pain and other amputee issues, because Dave understood like no one else did. He would talk to Peter and support him through it," she recalls. "It was an immense help."

Founding the Foundation

In spite of his struggles—or perhaps because of them—Peter was alert to the needs of others, particularly other children who were faced with similar circumstances.

When he was 11, he saw a Facebook post from his friend Laurie Milnes, an oncology nurse at the Nemours/A. I. duPont Hospital for Children, where Peter had spent so much time himself.

"The kids there ride around in wagons instead of wheelchairs—and they love their wagons," said Dawn. "Laurie's post explained that due to a wagon shortage, one little girl who was actively receiving chemo was forced to walk to her blood draw—and this news upset Peter.

"'I have to do something!' he said. 'We have to help her! I need a foundation!'"

Dawn was touched by his earnest concern to help other kids, but after years of struggling to keep her son alive and whole, she was also very tired.

"All I really need is a nap!" she said. "Peter, do we really need a foundation?!"

Peter insisted until his mother agreed to fight just as hard for Peter's foundation as she had fought to keep him alive.

When she told her husband about her promise, they both agreed to move forward, even though at first they had no idea where to begin.

"We had been told that people who have amputations also face a huge risk from depression; some people commit suicide. We had to know that if Peter was moving forward, and loving and caring for other children, there wasn't time to feel sorry for himself."

There were ups and downs along the path to creating a non-profit organization: the costs alone were prohibitive, and locating a law firm willing to handle the complexities of the process took time, but at last Peter met with a team who recognized that it was truly Peter's foundation, and respected his reasons for wanting one— and made it happen.

On the way home from the meeting, Peter called Dravecky and said, "Guess what, Dave! We've got something in common: We both love baseball and we both have a foundation!"

"He never mentioned the obvious fact that they were both amputees," his mother marveled, laughing. "That never came up!"

After another search, the Zuccas found that advertising agencies could be even more expensive than lawyers—but they ultimately connected with a group that was excited about meeting Peter and taking on the project of creating a name, a logo and a website for Peter's new foundation:

Because Peter was such a tireless powerhouse, and was himself the inspiration for the foundation, it was christened The Peter Powerhouse Foundation; and its logo was a cartoon rendering of Peter himself, complete with trademark baseball cap and a superhero's cape.

The Foundation's first goal was to buy 100 wagons for the hospital, but the $10,000 cost was a challenge. Peter told his mom confidently that his friends would give it to him; it was his

> **“Orthopedically, Peter was left with a not very functional hip to power the prosthesis,” notes Matt Moran, CPO, at Lawall. “So in addition to an amputation, he’s dealing with joints that are severely affected, and scoliosis, which also presents a challenge to maintaining his center of gravity where it needs to be, so that he can successfully use a prosthesis. He’s done remarkably well.”**

idea that they would pay to play with him at the miniature golf course at Freddy’s Family Fun Center, where he had spent so much time in rehab with a physical therapist when he was still tiny.

A children’s miniature golf tournament was a brilliant idea, Dawn realized, and put the wheels in motion.

That first Powerhouse Putt fundraiser—now an annual event—raised $5,000, which bought 50 wagons, which were assembled by friends at a wagon-building party, then individually bagged and delivered to the hospital on a tractor-trailer provided by a large local waste disposal company.

Peter’s first official appearance as spokesperson for his foundation is still accessible as a video on his Facebook page: A small boy who stands alone in front of a truckload of wagons, and without a trace of self-consciousness shyness, says happily, “Hi, guys! This is our first 50 wagons behind me. Thanks for helping me!”

Since then, additional donations, including a $10,000 grant awarded by the Philadelphia Phillies, have purchased another 250 wagons for the kids at duPont, and Peter was asked to speak at the Phillies' holiday dinner honoring community non-profits.

Dawn recalls that she and Peter spoke “back and forth a little bit—and when we were done talking, we got a standing ovation, and Peter started running for the table. I called him back to face his audience, and he asked me why they were standing.

“They’re standing because you rock!” she told him proudly.

“He was a little boy, 11 years old, who got his first standing ovation and didn’t even know what it was!”

When Peter learned that one of his friends in treatment needed a transfusion and no blood was available, blood drives, in conjunction with the American Red Cross, were added to the Foundation’s mission—especially when Peter was told he himself had needed 51 transfusions before he was two years old.

(“You mean to tell me that 51 people I never met gave their blood to me? Wow. We have to have a blood drive –we have to give blood back!”)

Since its first drive in 2015, the Peter Powerhouse Foundation has become the largest non-corporate blood drive in southeastern Pennsylvania and New Jersey combined—in the top 10% of the nation in blood collected, Dawn points out. “Since each blood donation provides three units for transfusions, nearly 6,000 lives have been impacted.

“We hadn’t planned to have more than one, but it was tremendously successful. If a little child can host a blood drive and save that many lives, we probably shouldn’t stop,” she suggested to Peter, who promptly agreed.

As a result, the Foundation now sponsors six 10-hour blood drives each year.

It has also raised $167,000 to secure Cinemavision goggles that reduce children’s anxiety by allowing them to watch movies while receiving an MRI, thus avoiding sedation in many cases.

The Foundation’s achievements and Peter’s credits and accomplishments continue to grow. Last year, Dawn shares, he spoke at a Christian Youth Rally in Nashville, addressing 5,500 kids his age about his faith and about Peter Powerhouse and his journey with childhood cancer—leaving them with unforgettable memories.

And in November 2017, Peter was honored at the Philanthropy Day Celebration, where he received the Youth in Philanthropy Award from the Association of Fundraising Professionals, Brandywine Chapter.

The Best Is Yet to Come…

When Peter began experiencing the rapid growth that accompanies puberty, his scoliosis also advanced, so another recent surgery to fuse his spine was necessary.

"Orthopedically, Peter was left with a not very functional hip to power the prosthesis," notes Matt Moran, CPO, at Lawall. "So in addition to an amputation, he's dealing with joints that are severely affected, and scoliosis, which also presents a challenge to maintaining his center of gravity where it needs to be, so that he can successfully use a prosthesis. He's done remarkably well.

"His initial prosthesis, with a locked knee, kept him safe and stable while he learned to walk again. Then we transitioned him to a knee that would bend. As he's gotten older, his activity level was such that we were able to get him approved for an adult microprocessor controlled knee about a year ago, and he's very adept at wearing it."

Moran still sees Peter fairly frequently to make adjustments to the prosthesis, due to the rapid changes in his height and foot size at this age. He is impressed by his young patient's bravery.

"Peter has been very involved in communicating with others from a very young age; he has no problems getting in front of large groups of people to explain the mission of his organization, which I think takes quite a bit of courage. Kids can be brutal, as it is; so for him to be so young and to see the bigger picture and share that with other people is truly a gift," says Moran.

"He picks causes that are close to his heart—things that affected him—and tries to help other kids so they don't have to deal with it—or makes it easier for them to deal with it. He's a remarkable young man."

A world of possibilities lies ahead for Peter, now a young man in the ninth grade at Souderton High School, who has come a long way from those terrifying early days of his babyhood battles with cancer:

"Now, he's almost 16, he has this deep voice, he shaves, and 'Where did my little boy go?'" Dawn wonders.

Today, he's interested in computers, computer graphics and game design—with high school classes scheduled that will help him explore that career avenue.

"If computers are not for him, he really loves history, politics, and the law," she adds. "He takes a lot of honors classes like social studies and history and English—and he does have his own non-profit, so we need to figure out where Peter Powerhouse plays into his future plans.

"I'm just so glad we get to think about his future!" she concludes. "For him, just starting high school was such a massive milestone!"

Although another spinal fusion that might negatively impact his ability to walk lies three or four years ahead, technology is perfecting new potential options every day. The most recent consensus by pediatric spine specialists discussing his case was that the future fusion, in conjunction with a new product which will then be in its third generation of adjustments and improvements, will allow the surgeons to fix his spine and guarantee his mobility for the rest of his life.

"And that's about the best news we could have heard" Dawn beams.

Consider this story of a small, helpless child given zero chance of surviving his battle with cancer, then share his success—not only in overcoming the impossible odds against him, but in reaching beyond himself to effect change, and to bring comfort, joy, and hope to so many other young lives. Is it a phenomenon, a miracle, or a lesson worth remembering?

Maybe it's all three.

Learn more about the Peter Powerhouse Foundation and its mission at www.peterpowerhouse.org "Uniquely qualified to improve the lives of kids with cancer"

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