

# Joy in a Body

Clinician Peter Springs fits Ruth to her new prosthetic left leg. Her right leg is in a brace to help straighten it.



# From Haiti to Spokane to Shriners

by Blythe Thimsen

Lining up her golf club and the ball, Ruth pauses for a moment of intense concentration before she unleashes her power, throwing the weight of her whole body into the swing. The club and the ball connect – crack! – and the ball flies into the air, no doubt destined for a hole in one.

“Wow! You’re really good at that, Ruth,” I tell her. “I know!” she exclaims, with a huge smile, before running after the ball.

The golf game played that day wasn’t on the impressive courses of Augusta National nor at Pebble Beach, but it was an even more impressive sight, once you know the player. Tucked onto the third floor of Shriners Hospital Spokane, in the rehab gym, four-year-old Ruth Schrader was standing up, swinging a Fisher Price golf club and running after the ball, and that, in and of itself, is impressive.

With one braced leg and one prosthetic leg, Ruth ran the length of the room, chasing the ball. Left, right, left, right, she pumped the two legs, one hers since birth and one a new addition to her life and body, and she ran like she’d been doing it for years.

But Ruth hasn’t been running for years. In fact, she hasn’t even been walking for years. Thanks to the love of two families (one in Haiti and one here) and the commitment and care of Shriners Hospital Spokane, Ruth is standing on her own two legs and living a life that once seemed impossible.

## *The Family*

Ryan and Bethany Schrader had busy lives and a full house. With four children – three boys and a girl, ages 11 to 16 – there was never a slow minute in their lives. Homeschooling all four children kept Bethany’s “free time” more of a dream than a reality.

It was that love of their children and commitment to them that made Ryan and Bethany come to mind for one of the parents in their homeschool group who was also an adoption facilitator, and was looking for a loving home to host Ruth, a tiny joy-filled girl who was coming from Haiti to the U.S. for medical care.

Ruth was a preemie, born two months early, who had Amniotic Band Syndrome, which according to the Amniotic Band Syndrome website, “occurs when the fetus becomes entangled in fibrous string-like amniotic bands in the womb, restricting blood flow and affecting the baby’s development. If a band wraps tightly around a limb, the limb can actually be completely amputated. The baby may be born missing fingers, toes, part of an arm or leg.”

In Ruth’s case, she was born with her left leg amputated below the knee, and her right leg severely curved and scarred, due to a band going around that leg sideways from her knee to her ankle.

She lived her first month in the hospital, before finally going home with her biological parents. She lived with them until she was six months old; however, by that time she only weighed six pounds,

and needed to gain weight before any attempts were made to tend to her medical treatment. Her parents placed her in the care of an orphanage, knowing it would be able to provide better nutrition and care than they could offer her.

It took almost a year and a half for Ruth to gain enough weight for medical care to be coordinated, so for 23 months, she lived in the orphanage. “Her parents visited her there frequently,” says Bethany. “They were good parents who loved her very much and only wanted the best for her.”

The best meant putting her on a plane and sending her to a far-away place, to endure surgeries and medical treatment, while entrusting her into the care of strangers, whom they had never met. It was a difficult situation for Ruth’s parents.

The Schraders were told they would be hosting Ruth for six months, up to a year. “We knew for sure that she was going home after six months or a year,” says Bethany. “There was never an option for Ruth to stay.”

When Ruth arrived, Bethany flew to Portland to meet the orphanage employee who had brought her from Haiti. “She wanted to re-emphasize that there was no possibility of Ruth being adopted,” says Bethany. The woman reminded them Ruth was only at the orphanage because she needed medical care, and she was only here to get that care. She wanted to make sure the Schraders knew that for sure, lest they get attached to her. In the orphanage in Haiti, Ruth had attracted a great deal of interest from perspective adopters. They were captured by her engaging personality and palpable zest for life, and many fell in love with the small girl. She was not up for adoption though, and the orphanage employee wanted to make sure Bethany and her husband understood this.

They did understand this. This was strictly a host situation, but they still loved Ruth, while also knowing her biological parents’ loved her too, and wanted to be a part of her medical care, from afar.

Ruth was in the Schrader’s home for eight-and-a-half months, when the decision was reached that, medically, she was ready to go back to Haiti. The date was set for three weeks out, September 28, 2013. “It was really traumatic, because we found out while our birth kids were at camp that it was time for Ruth to go back. We went to pick them up from camp and that was what we had to meet them with.”

The news devastated the children, as well as Ryan and Bethany. “We had been mourning for about six weeks, once we found out and started making the firm plans to take her back. We cried and cried and cried,” says Bethany. “I went to visit my grandmother in August, and we were going to leave September 28, to take Ruth back, and I was telling her how upset we were. ‘At least it’s not like one of your own kids,’ she said. ‘I looked at her and said ‘It’s exactly like that. It’s exactly like giving your own child away.’”

At the beginning of September, Bethany attended an orientation program for the homeschool group her children participate in, and saw the adoption facilitator who worked with Ruth's orphanage, and who had originally asked the Schraders to host Ruth. It was at this meeting, with travel plans in the work, and paperwork processing, that she broke the news to Bethany that Ruth's parents had been wrestling and waffling with a heavy decision for months, and had come to a heart wrenching conclusion. They realized they did not have the means and opportunities to care for Ruth that were available to her here, and they wanted to know if the Schraders would adopt her.

"It was instant waterworks, followed by 'Yes!'" says Bethany of her reaction at that meeting. "It took a few hours before I started thinking 'Wait, this isn't necessarily what's right for her.' It was selfishness."

"Instantly, from the beginning, she was our child in our hearts," says Bethany. "We went into it knowing that we were going to love her like ours for as long as we had her, but we also were very conflicted. We know the best place for a child is with their birth family. Her parents loved her, everything they have done is because they love her. They were not bad parents. When you have good parents, that's where you should be, so we were very conflicted. We really grieved for them."

After much thought, however, the conclusion Ryan and Bethany reached was that Ruth's parents were right. "Even if we gave them all kinds of financial support, they couldn't care for her; there's not the availability of care there." They recognized even if they could give money to Ruth's biological parents, to buy her the best medical care available, they would not be able to provide the care that she needed, because it is not available in Haiti. Ruth was better off here, than back home.

"It was really good for us to go through all of those feelings," says Bethany of the grief they experienced anticipating giving up Ruth. "We were able to empathize with what her parents had done, and were doing again. They had given her up at six months, and then again at 23 months when she left the country (they had been visiting her the whole time she had been at the orphanage) and then they had to give her up again when they asked us to adopt her. So we were able to understand what they were going through."

Bethany says she and Ryan have explained to Ruth that when she gets old enough they will take her back to Haiti to see her parents and her little sister, Esther. They want her to know that her family is there, and they love her very much. "Ruth received a typed letter from her biological father telling her how much they love her and will always love her. He said, 'We're so glad you're happy there.' It was amazing." They miss her terribly, but know this is the best spot for her. One of the reasons it is the best spot is because it allows Ruth to receive care at Shriners Hospital Spokane.

### The Hospital

Shriners Hospital Spokane, like all Shriners Hospitals, provides orthopedic care to children ages 0-18, regardless of their ability to pay. The Hospital is funded and reliant on the generosity of friends and neighbors.

Previously, children receiving prosthetics through Shriners Hospital Spokane had to have their prosthetics sent to an outside vendor. Starting in January of this year, however, all work is done in-house, in the Hospital's new Orthotics and Prosthetics lab. Peter Springs, who previously worked at the Salt Lake City Shriners Hospital, is the lab clinician.

"Shriners has gone high-tech, converting to digital scanning and CAD (computer aided design)," says Springs of the recent technological advancements at Shriners.



Ruth rides a trike at Shriners with Deb Chazel, one of her favorite rehab aides.



Ruth's X-ray before she began treatment shows her curved right leg, and her left leg, missing below the knee.



Ruth's X-ray after treatment and receiving a prosthetic left leg, and a brace for her right leg. Note how it has straightened.

"The whole system is in the process of really converting from plaster casts to digital CAD. The goal is to be doing as much stuff through the computer design as possible. I basically do all the modifying, shaping and design, but then I have to send it to a carver, and the carver we work with is at the Portland Shrine. They carve it, fabricate it and send it back."

Having the design work, the fittings and the personnel in-house makes a smoother experience for patients who no longer have to book appointments at multiple locations, and it is also convenient for Springs who can consult with in-house doctors within minutes.

Springs is the only clinician in Spokane who works strictly with pediatric orthotics and prosthetics. There are others who work with children as well as adults, but they'll

maybe see one child out of twenty patients. Springs' unique perspective of working strictly with children means he is the expert.

"The cases in pediatrics are so much more obscure than adult cases," he says. "Limb loss in children is a fraction of a percent. You are talking a very small percent of those in orthotics would see that."

Springs sees about 2,000 patients a year for orthotics, bracing and prosthetics, with well over 100 patient visits per month.

"It is an underappreciated population," he says of his young patients. "Just think about kids that have a limb loss. You might see someone in passing who has a brace or prosthesis, but to know what it entails in terms of ramifications for the rest of their lives, most people aren't really aware of that. We have expertise here to take care of kids and give them their childhood back."

And what about that one child in particular? The little girl with the infectious smile and radiating joy?

"It's awesome!" says Springs of working with Ruth. "I love her personality. She is really a lot of fun. That is one thing that I love about working with kids. They are so energetic, there's so much motivation to do anything that they possibly can. Part of that is they are young and in that stage of life where they are learning. In the adult world, you get people that know what they've lost, and it can be a big battle for them, mentally, to get motivated to learn a new way of life. Those adult patients could take something away from Ruth!"

Ruth's case was unique, with one leg amputated and the possibility of second leg being amputated. "She has a complicated leg on the other side, it is not a straightforward thing," says Springs. "I would have to give props to our chief of staff, Dr. Paul Caskey on that because everybody kept looking at it thinking, this leg is so bowed, could we do surgery where we could straighten it more? He has the orthopedic experience where he could say, 'No, we just need to hold off and see if it could correct with some bracing before we jump into something like that.' It was interesting to see how she responded to the bracing, because her bowing has been getting better and better, and her leg is lining up under her knee, more and more."

"It's rewarding," he says of seeing Ruth run the halls of the hospital, knowing it is in part to the work he is doing to help her on her journey. "I think being part of Shriners

is especially nice because you can do that work, regardless of the ability to pay. It can be challenging in the insurance world right now to get certain things paid for that may not be covered. And if someone really needs something, like a prosthetic limb, Shriners can help them with that."

Ruth will be able to receive care at Shriners Hospital Spokane until she is 18. Between now and then, she will get a new leg, on average, once a year, to accommodate for growth.

Ruth was fitted for her first prosthesis at Shriners and had her first revision surgery a month after arriving in the U.S, and then her second one a couple of weeks ago. She had them both due to penciling of the bones. "Basically, the bones were trying to grow through the skin on the bottom of her leg to the point where she couldn't put her prosthesis on any more because it hurt too much," says Bethany.

The next step was to see if her prosthetic leg would still fit properly after surgery, and if not, then make adjustments or make a new leg. She will likely have to have revisions done every couple of years at least until she is grown. She will also have to have her right leg braced at least until she is grown, to try and keep it from breaking.

### *The Joyful Life*

"Everything has changed!" says Bethany of life after welcoming Ruth into their family and receiving care at Shriners. "She is a bundle of joy. I say she is joy in a body. It's been great."

That joy is appreciated outside of the walls of Shriners. "Our church has taken her in," says Bethany of Northside Church of Christ, their church home. "She was everyone's baby from day one." The church has a children's giving time, where the children go forward to take their coins up to a jug. The congregation erupted in applause the first time Ruth walked on two legs to the front for the offering. It was an answered prayer. They are such a support for her.

The support from Shriners has also greatly impacted Ruth's future. "I see so much for her future, she could do anything to do that, or anything, here. I don't want to say anything bad about Haiti, but they don't have the same kind of opportunities. It is a lot harder there for people who are



Nothing is going to stop her! Ruth tackles the playground with her new leg.

disabled in anyway. We don't consider Ruth disabled; we consider her inconvenienced, but there, she would be disabled. There is no guarantee she would always have a leg; in fact, she would likely not."

"It is amazing," says Bethany of their experience with Shriners Hospital Spokane. "I could not say enough good things about them. We believe so strongly in Shriners. We owe them a debt we cannot pay back. Our experiences with Shriners has been awesome, the staff is so wonderful. You know people are invested when you have been taking your little girl to physical therapy so that she can learn to walk, and that first time that she takes steps on her own without her walker you start crying only to look over and see your therapist is crying too - that is invested. When your daughter talks about her prosthetics every time she hears the name Peter, and brings him up several times a week on her own in conversations - usually ending with the comment 'I love Peter' you know something is really going right."

Things are, indeed, going very right for Ruth. With her new legs, she is playing golf, riding a trike and running the halls of the hospital, all the while, knowing she is very loved; loved by her family in Haiti, her family here and her family at Shriners. That is better than a hole in one! **5**