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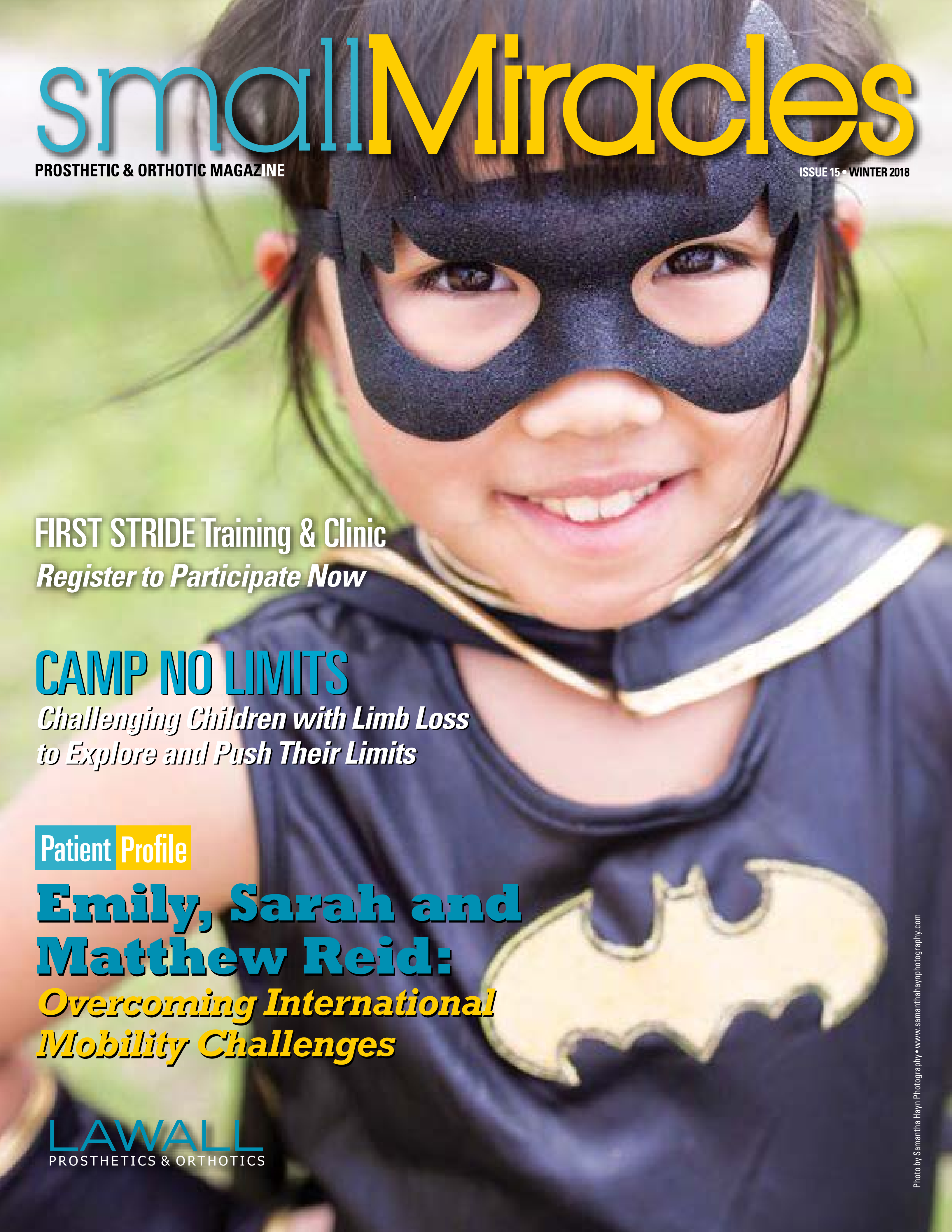
PROSTHETIC & ORTHOTIC MAGAZINE

ISSUE 15 • WINTER 2018



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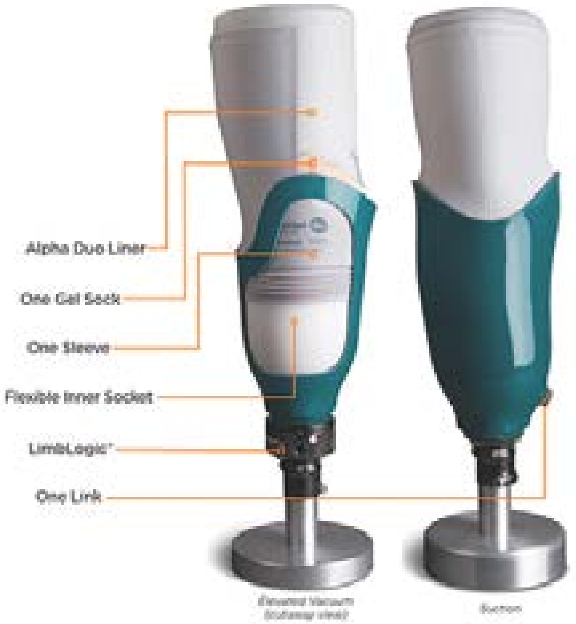
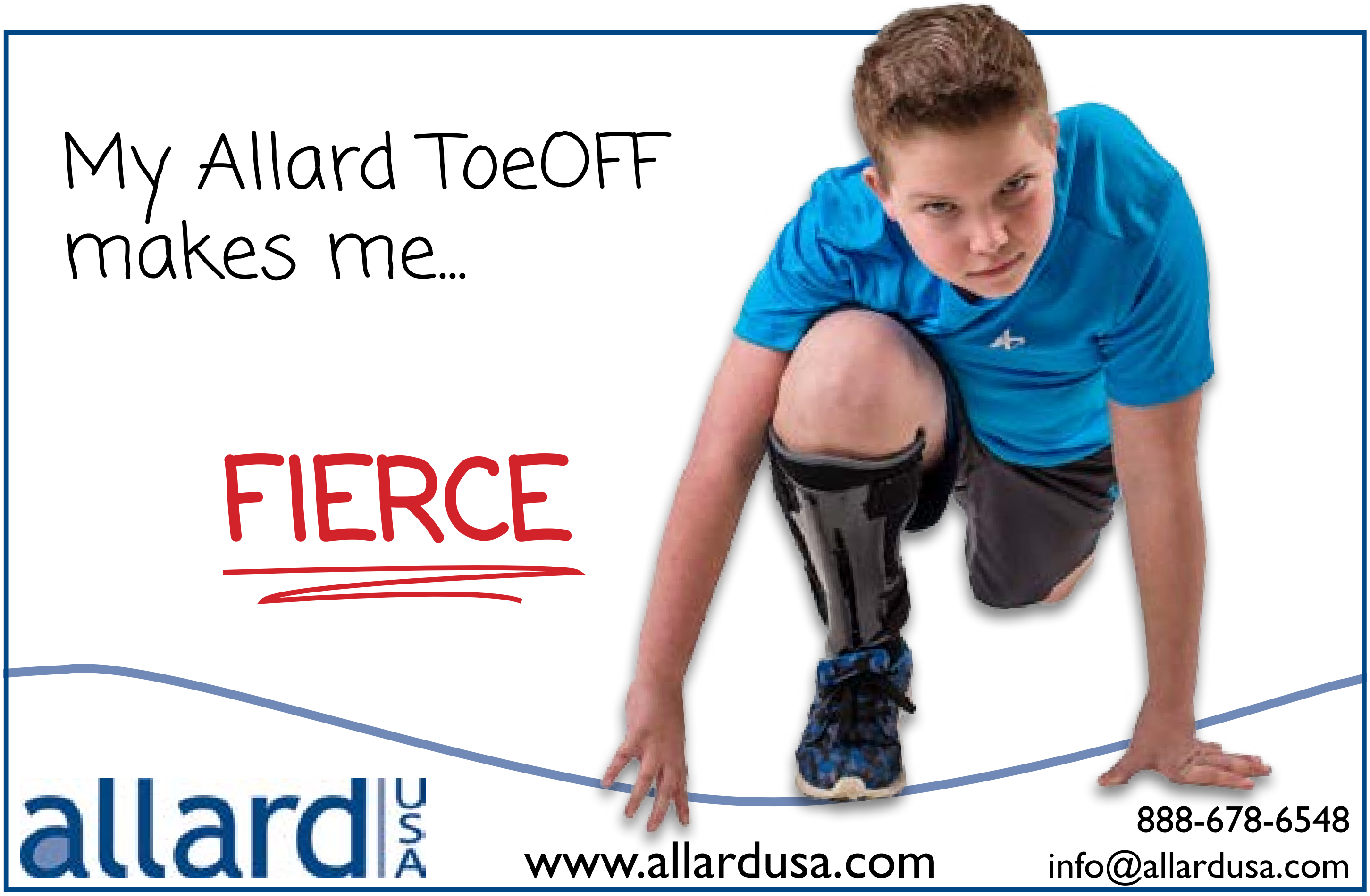




Patient Profile

Emily, Sarah and Matthew Reid: *Family Overcomes International Mobility Challenges*

The stork can only claim part of the credit for the family created by Guy and Linda Reid and their three exceptional children: Emily (7); Sarah (10) and Matthew (11).

Although the Reid's three children were adopted at different times over a three-year period, and were born into different Chinese families, people often ask Linda if they're siblings. "They are now!" she laughs. "Many people think they're triplets. That's funny."

What inspires couples like Linda and Guy to adopt—and, additionally, to adopt foreign-born children with limb differences that will require extra care and commitment?

Adoption seemed like a perfect option for a couple who married when they were older. And despite their initial unfamiliarity with the process and the intimidating red tape associated with international adoptions, Linda explains that she and her husband believed, from the first, that this direction was the right one for them. "We thought about domestic adoption, but we wanted younger children. As first-time parents, you want to start when they're younger and you can mold them—but a little bit older so you don't break them!" she laughed.

"We found an adoption agency that was doing strictly China adoptions at the time, and for some reason, we just felt like that's where our kids were. I can't tell you why, other than that's where God led us."

They were told that the waiting list for a healthy child adoption was 18 months; but since the Reids were still waiting four years later, they were advised to consider a special needs child. It's a step they had avoided earlier because they felt they might not have what it takes to raise a child with special needs. ("Now," says Linda, "We feel totally differently!")

Sarah's Story

Some guiding force indeed seemed to be at work directing their first steps toward 2-year old Sarah:

"They had sent us several pictures of children," she remembers, "and one day we got a picture of a little girl with two toes on one side and three on the other and a fused hand. We looked at her face and we looked at each other and we said, 'She's ours.' There was no doubt in our minds."

They took immediate steps to lock her file and begin the long, difficult process of dealing with a lot of red tape and government rules; and within a few months, they were bringing Sarah home.

In 2010, when Sarah was just 2 ½ years old, they made the trip to China to claim her— a 16-day visit that included a crucial initial period of sightseeing to acclimate themselves and learn more about their new daughter's cultural background.

"It wasn't an easy transition," Linda recalls. "She was in a foster family and her foster mother adored her—and even called the orphanage five times the first day we had Sarah, checking to see if she was okay. Sarah went to my husband but I couldn't hold her. It changed eventually—the worse the transition is in the beginning, and the more the child objects, the more they're able to show love—because it's a sign they're mourning."

Complicating matters was their awareness that they knew virtually nothing about limb differences, or the cause that had resulted in her hand and feet anomalies. The prevailing theory was that blood supply was cut off to the fetus when the arm and leg buds were forming, causing bilateral fibular hemimelia, or congenital shortening of the fibulas at birth.

As for what to do about her condition at age 2 ½, there were nearly as many ideas as there were experts to consult.

The first physical therapist told them Sarah needed braces, but would never be able to run. The Shriners Hospital doctors advised against bracing, because she was a toddler, and they're all wobbly by nature. Although the fibulas in her legs had never developed, her knees were very stable and she was able to walk, so they felt a "wait-and-see" policy was best.

One thing she did not need was a speech therapist! "She was learning English words before we left China, and her foster mother said Sarah was very verbally gifted," Linda noted. "Everyone thought she was older because she was so verbal."

A Shriners hand surgeon was able to separate her fused left thumb, allowing her some limited grip even though the other fingers remain fused; but the Reids continued to explore lower limb treatment possibilities as Sarah grew, and were initially shocked by the first suggestion of an amputation.

When Sarah was nearly five, and they were still considering potential resolutions, the Reids decided that she needed a sister, and took steps to find one. (See "Emily's Story" on the next page).

Sarah accompanied her parents to China in the summer of 2012 to meet and bring home her new sister; but upon their return, the Reids continued to investigate possibilities for Sarah's mobility. Ambulation was getting progressively harder for her, so in April of 2013, when she was 5 years old, Sarah underwent surgical amputation of her left foot, with its two toes, and had reconstructive surgery on the right foot, with three toes.

Elective amputation is always a difficult decision, especially for parents.

"As much as I knew that it was a possibility, I still had some hope that something else could be done and she wouldn't have to lose her foot," Linda remembers. "But we went from doctor to doctor and they couldn't do anything, and when doctors in Philadelphia, Boston, and Wilmington, Delaware, all recommended amputation on the left, and reconstruction on the right, we chose someone closer—Dr. Mackenzie at Nemours in Delaware—to perform the procedures."

Reconstructive surgery lengthened the tibia, to provide weight-bearing support and strength in the absence of the fibula; the Achilles tendon was also lengthened to bring the heel downward. While the foot bends at mid-foot instead of at the ankle, the new alignment provides a flat weight-bearing surface.

Sarah wore casts on both legs following the surgeries, and received her left-leg prosthesis and a molded ankle foot orthosis (MAFO) for her right foot. Depending on how things develop as Sarah grows, additional surgeries may be needed to continue to preserve the foot, Linda notes.

"Matt (Moran), Sarah's prosthetist at Lawall, had his struggles regarding what prosthetic foot he could use," she explained, because of the ankle-level amputation.

Moran notes that the congenitally weak ankle joint of Sarah's right foot complicates the issue. "Bearing weight on it is a challenge," he observes, "so she wears a brace on that side to help to stabilize her. Originally she was in a solid brace, but when she was doing dance, and wanted to get up on her toes, we made an articulating brace so she'd have some ankle flexibility on that side. As she's gotten older and bigger, she's having more ankle pain, however, so she's going back to a new solid brace to restrict her motion, and only using the articulating brace if she's doing an activity where she needs some ankle flexibility."

Nearly five years after her initial fitting, Sarah has adapted so well that "there are people who don't even know she has a brace and prosthesis," Linda says. "When she has long pants on—which she normally does unless she has her running legs on—they don't even realize."

Because Sarah loves to run, and her legs have to go twice as fast to keep up because of her smaller stature, they explored options for running devices.

"We had assumed that she couldn't have running legs because her legs are different. Usually you see somebody that either has a full foot on one side and one running blade prosthesis, or they're bilateral amputees," Linda explained.

But during a visit to Camp No Limits (SEE RELATED STORY ON PAGE 8), they learned about other possibilities and explored them with Moran, who developed a boot for Sarah's right foot, to replace the MAFO when she is running. The boot has an attached running blade that matches the prosthetic running blade on her left leg, and when she wears her running legs, Sarah is virtually unstoppable, Linda claims proudly. "She does wonderfully with them!"

The blades add spring to her step, and are a bit "bouncy", so it's hard to stand still on them; but Sarah always asks to wear her running legs to school, Linda says. "They're comfortable because she has silicone liners with them; and she also gains quite a bit of height. She likes being almost as tall as some of the other kids in her class!"

Emily's Story

Early in 2012, when the Reids decided that Sarah needed a sister, it was a no-brainer:

"We didn't have to think of what special needs we were going to look for other than limb difference, because we felt very comfortable with that, and knew some of the doctors already," Linda explained.

They received a picture of Emily, who was not quite two, and missing her left forearm and hand. "There was no question," Linda recalls. They forged through the red tape jungle again, and went for her in June of 2012, taking Sarah with them.

This time, the situation was reversed: Emily, who was a very large baby, clung to Linda (who is small) and refused to go anywhere near Guy. In hot, humid conditions in the sub-tropical climate, orphanage representatives brought Emily to the hotel room with her beloved "Dondo"—a large velour bed-sized pillow that also went everywhere Linda carried Emily.

"—so basically, we stayed in the room," Linda remembers, "with Emily putting the pillow on my chest and then laying on me."

Emily's missing forearm and hand were likely the result of amniotic band syndrome (ABS), Linda learned. As in Sarah's case, it had cut off circulation in utero, preventing the limb from developing.

Emily, however, had elbow movement and has achieved amazing dexterity with the residual limb. Shriners doctors advised against attempting to fit a prosthesis at such an early age, as it was more likely to become a hindrance than an aid. A child of two is unlikely to attempt to use it, they noted. And while covering the residual limb with a prosthesis causes it to lose feeling, leaving the limb exposed and unhindered allows the child to learn to use it more effectively—as Emily certainly did. By age three, she was able to put on her own dance tights—a challenging trick for even the two-handed! She puts her hair into a ponytail band with one hand, and even won a contest for "best amputee life hack" with her video demonstrating how to tie shoes one-handed.

Although Emily received her first prosthetic arm from Shriners, she and her parents learned from the experience what worked and what didn't, and asked Moran to design one that worked more effectively, with less body-powered effort to keep her grip closed.

The new prosthesis also accepted specialized attachments that allow her to climb playground monkey bars and redistribute some of the pressures on a small, pointed residual limb when she participates in dance movements or does push-ups. Another attachment enables her to grip her bicycle's handlebars, and Linda, whose love of kayaking is shared by Emily, describes a device on their wish list that will hook Emily's arm securely to the paddle—to allow two-handed paddling.

A silicone sleeve fits glove-like over the prosthesis, its specialized attachments and her arm—helping to secure the connection, even under sweaty conditions where it supports her dangling weight.

"As she grows older, hopefully we should be able to do more specialized things for her, keeping attachments more streamlined and lighter in weight as new and improved components are developed," Moran predicts. "Our challenge is to figure out the best way to enable her to tackle whatever she wants to do—so the arm is not in the way but is actually helping her to be a normal kid."

As her interests develop and change, the prosthesis should change with her, Moran believes. "She's growing, so the arm will only last about a year before she outgrows the socket. As technology improves, hopefully her return to function—and added, specialized functions like playing a musical instrument or playing basketball—will also continue to improve."

Matthew's Story

Matthew came home at the end of 2013—the same year Sarah underwent amputation surgery.

"It sounds insane when I say that out loud," Linda shakes her head. "I don't even know why I decided to look at the special focus kids that were on the website of the agency we used for Sarah and Emily's adoptions."

But—there was a picture of a little 3-year-old boy with a fused right hand (except for the thumb), a badly twisted left foot, and his right foot missing above the ankle.

"I sent the picture to my husband and said, 'Look at this! This little boy has the same limb differences that Sarah has, just mirror image!'

"And my husband said. 'Well, let's go get him.'"

It was as simple as that.

There were complications—and surprises—however. When they called the agency, they discovered that he was not 3, but 7 ½ years old; the photo on the website was an old one.

Since Sarah had just gotten her prosthesis and was getting up on her feet—not able to manage an overseas trip, as Linda was unable to carry both Sarah and Emily—Guy went to China in December accompanied by his brother, while Linda stayed home to care for the girls.

Every child is different; an older child like Matthew presented new challenges not only due to his individuality and his age, but because treatment methods to address his lower limb issues were already in place—and were not doing well.

"When they got to China," Linda recalls, "Matthew was wearing a prosthesis but he didn't have a sock on with it. It fell off all the time. It had a big hinge on it, and it fit on the outside of his pants. He didn't walk very well with it—he had to bend forward so he was leaning into everything. He'd had plenty of time to develop bad habits."

In addition, his left foot deformity had to be addressed—and the Reids' doctors recommended amputation and prosthetic fitting on that side, as well.

"From what we understand now, Matthew probably didn't get a prosthesis in China until he was about 6 years old," Linda believes. "At the time we felt the most pressing need was to get him up and walking, and amputation would actually be the best that we could do for him—the fastest way to get him up and mobile."

Communication barriers further complicated matters. Matthew spoke full mandarin, but virtually no English, so it was "a little harder than dealing with a two-year-old learning the language," Linda explains. "We had to get translators."

Matthew had also learned self-reliance, as demonstrated when Guy Reid and his brother took him to a restaurant in China, where the child had a conversation in Mandarin with the waiter and sent his meal back to the kitchen, where it was replaced.

(Not many children of seven are precocious enough to complain to the waiter in any language, and request an adjustment in their meal!)

It was about six months before their communication with Matthew improved to the point where the Reids could discuss the amputation recommendations for his foot, which was twisted to the point where he was virtually walking on his ankle.

Matt Moran remembers that Matthew's foot "was not at all functional. He had a really bad deformity and needed a significant brace with wedging. When he wasn't very functional with that kind of combination, and we had exhausted all the available options, the family decided to proceed with the revision surgery. The foot was removed so that he would have room to wear a second prosthesis; and since then he's been much more functional."

Moran also recalls that when he first met Matthew, he didn't speak a word of English. "The only way I could communicate was the international language for thumbs up or thumbs down for how things felt! But after a very short period of time, he came in and he was singing the lyrics to 'Frozen'. He assimilated very quickly into American culture!"

Moran observed that Matthew had significant joint laxity in his hips and knees that made him "very wiggly".

"That makes the stability of the prostheses a challenge, because they're only providing support down in his lower legs; but the weakness further up is magnified in his gait. We've found a thigh corset to be a good solution. It allows his prosthesis to extend up onto his thigh to give him more stability."

Extra padding and a silicone liner have also helped his right prosthesis to bear weight more comfortably, in spite of the sensitive bony end of his residual limb.

Physical therapy has not significantly improved his muscle tone, so the emphasis is now on encouraging him to participate in active sports and recreation that he enjoys—like swimming lessons and wrestling. Unfortunately, like many children, he'd rather stay in the house and play video games, Linda worries. Even getting him to do more than float in their above-ground pool is a challenge, she notes, but things are improving and they are seeing a gradual change.

Sarah and Matthew both now have water legs—including a water shoe and insert for Sarah's remaining foot—which allow them to walk into a lake or wade in a stream; but insurance declined to cover the cost, identifying them as an unnecessary luxury, to Linda's disgust.

"I beg to differ! How is letting a child go swimming somewhere, or walk through a stream, how is that a luxury? That's part of growing up, and they're getting healthy exercise!"

Regular prostheses are not waterproof and can be damaged; but crawling through sand and mud to get into the lake to swim is not a pleasant option. Once in the water, the water legs float, so they are usually kicked off while Sarah and Matthew swim.

"After the two of them got water legs, I took them to a local creek and let them do what kids do—walking in the water. And they had a ball," Linda reported. "In the summer, kids like to run under the sprinkler and they can't do that with their regular legs. But now they can put the water legs on and have fun."

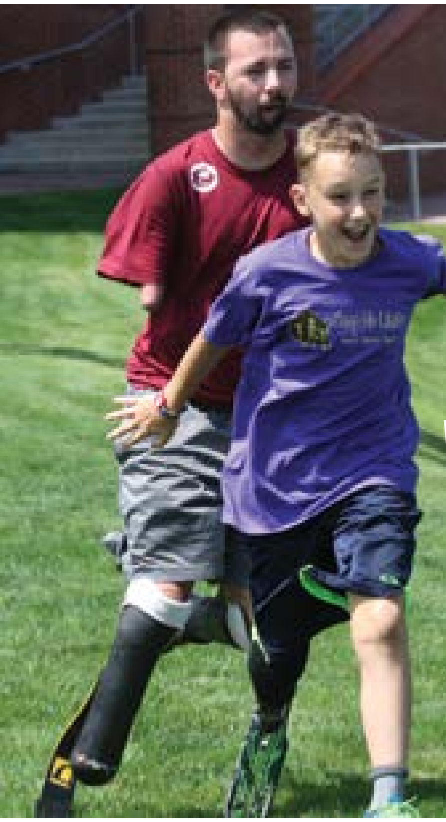
Moran is investigating the potential for a new assistive device with tread, that would help provide traction as well as cushioning and shock absorption during Matthew's wrestling activities. Running legs like Sarah's are something else Matthew would like to try.

"It is incredibly inspiring to see kids with physical problems who don't let their challenges get in the way of them being normal, active kids," says Moran. "It's a great job to be able to contribute to their lives in a small way so they can do the same fun activities their friends do—like swimming, running, climbing, wrestling, gymnastics, and more."

"Matt (Moran) and Lawall have been wonderful to our family," Linda reflects. "He's always friendly and helpful and goes out of his way to help accommodate our busy schedules. His care of our children's needs has had a huge impact on our lives."

For more about the challenges of adopting special-needs children from other cultures, and the value of sharing the limb loss experience with similarly challenged children and adults see "CAMP NO LIMITS: CHALLENGING CHILDREN WITH LIMB LOSS TO EXPLORE AND PUSH THEIR LIMITS" on page 8 of this issue.)

CHALLENGING CHILDREN WITH LIMB LOSS TO EXPLORE––AND PUSH––THEIR LIMITS



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The complications of raising three adopted children born into an Eastern culture to Chinese parents—each with different limb loss issues—were introduced in the Reid family's story. (See page 3).

But beyond the mechanics of developing appropriate mobility solutions for Emily (7); Sarah (10) and Matthew (11), lay other challenges—adjustment, acceptance, confidence, and the development of strength, skill, and friendships. Many of these aspects have been addressed either directly or obliquely at a place called *Camp No Limits* (www.nolimitsfoundation.org), where children with limb loss meet others facing similar challenges, and are encouraged to explore—and push—their limits.

The first *Camp No Limits* was established in Maine in 2004 with only four families participating, and now has ten locations across the country, as well as a special "Camp Snow Limits" where amputees are fitted with adaptive equipment so they can also enjoy skiing.

"At *Camp No Limits*," explains Linda Reid, "We've learned a lot about different prostheses. It was at *Camp No Limits* in Florida that we met a prosthetist who is herself an amputee; she described how Sarah's right foot could wear a boot with running blade attached—to match a running prosthesis on her left leg."

Another prosthesis wearer they met at camp wore a corset around his thigh in conjunction with the prosthetic socket, which helped to relieve the pressure on the sides of his knees—from which Matthew also suffered—while it distributed his weight more comfortably, adding to his stability.

Both ideas were shared with Matt Moran, the children's prosthetist at Lawall, who developed appropriate solutions that work well for Sarah and Matt.

The Reids' Camp adventures have included a four-story zip-line descent, ropes courses, and giant swings.

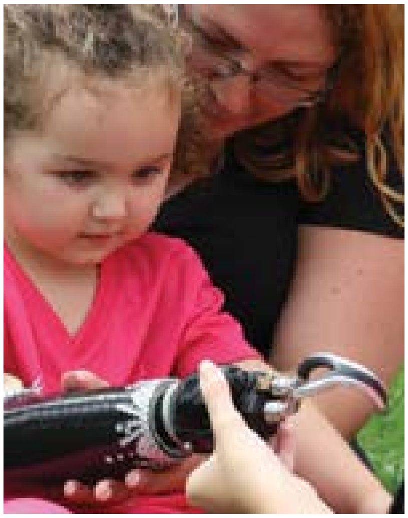
"We watched kids who have prostheses on both legs get out and walk across a wire (safely harnessed)!" Linda marvels. "It's hard for an adult with all four limbs to do that, yet you'll see a quadruple amputee get out there and succeed!"

Parents participate in support groups, while the kids try new things under the eye of an occupational or physical therapist—with amazing results which inspired Linda and her husband Guy to take steps of their own:

"The camp really is phenomenal, and it became a passion of ours not just to get our own kids there, but to raise money to get other kids there," said Linda.

And thus "Amp It Up for Camp No Limits" was born, a non-profit created by the Reids, which last year raised nearly $10,000—a significant share of which was previously earned through Guy Reid's participation in a half marathon. That sum provided almost 20 full scholarships to the camps.

(To contribute, visit https://www.firstgivingcom/team/360495 or https://www.firstgiving.com/fundraiser/AmpItUp/camp-no-limits-maryland-2018, or contact them via email at AmpItUp4cnl@gmail.com .)



The Reids and their children faced other issues that the camp addressed—directly and indirectly—by building relationships with other people with limb loss who served as understanding friends and mentors, and even went several steps beyond.

The hardest part of raising children with limb loss isn't the fact that they are adopted, and have ethnic differences, Linda explains. "The hardest part is worrying about what silly things people are going to say to them, and being on guard, especially when they were younger, in their 'mommy-and-me' schools. As you go out to the playground, you anticipate what silly hurtful thing somebody is going to say to them, even a well-intentioned adult.

"Even recently, a little girl on the other side of the store was yelling, 'Mommy, Mommy! There's the girl with the hand!' --and you know that hurts your child."

One of the goals of *Camp No Limits*, she points out, is to educate people about limb loss and differences of any kind. "Emily is our softie; she's a bit more bashful, and her forearm loss is much more noticeable than Sarah and Matthew's lower limb prostheses. Emily heard kids say she couldn't do things because she only had one hand, so she asked if we could get *Camp No Limits* to come visit her school."

Camp No Limits not only sent amputees from Pennsylvania—the Camp's original founder also came from Maine to participate in a presentation to the schoolchildren that taught them about differences like Emily's.

"Things like that help," Linda noted.

What would she advise prospective adoptive parents when considering adopting a child with special needs, especially one from another country and culture?

"Adoption is a wonderful thing. People may think they can't love a child that's not genetically theirs—but that's not true. You can love such a child just as much if not more, because some people take it for granted when they give birth."

The stigma of being "unwanted" and put up for adoption is way off mark, as well, Linda explains. "In the case of each one of our children, I have no doubt that their biological parent thinks of them every day. I have no doubt that they were faced with a very hard decision. Although the government is loosening up the old "one child" laws in China, these children's parents may have risked losing their freedom if they didn't have written permission to have a child. So they couldn't go to a hospital where they'd have to show a document; instead, they may have had their children out in a field or a barn, and if the child is born with a difference, they have no idea how to handle it. Medical care has to be paid up front.

"I'm sure giving up their child was a hard decision for each of them, but they probably felt they had no choice. Yet each of these children was left somewhere where they were found and they were safe," she points out.

Prospective adoptive parents should also remember that adopting may be a good thing for you, but may not feel like a good thing for children when they're taken away from everything that they know.

"The child is hurting," she warns. "You can't go in with your eyes closed, expecting the child to just come to you and be happy and everything is going to be glorious, because there is an adjustment period. You need to understand and work with the child and give them everything they need to adjust. The child is not standing there waiting for you to come and get them, like people think."

Matthew, for example, found it harder to grieve because he was older than his sisters (age 7) when he was adopted, Linda realized. "—and there was definitely a grieving period."

And because he was raised in an orphanage, where everything belongs to everybody, his attitude toward personal possessions and space were also different, she noted. "Even when he came home, he walked into our house and went around and inspected every room—which was good and bad, because he had no boundaries."

Even four years after his arrival, Matthew continues to adjust to a new way of life with new rules. "Everybody is a work

in progress," Linda smiles philosophically. "We're still working on it every day."

Adopting a child with a limb difference is really "not a big deal," she responds dismissively. "Even healthy children can develop health problems as they get older."

She points to children at *Camp No Limits* who have lost their limbs to cancer, meningitis, lawnmower accidents. "They're just kids, and their limb difference doesn't define them.

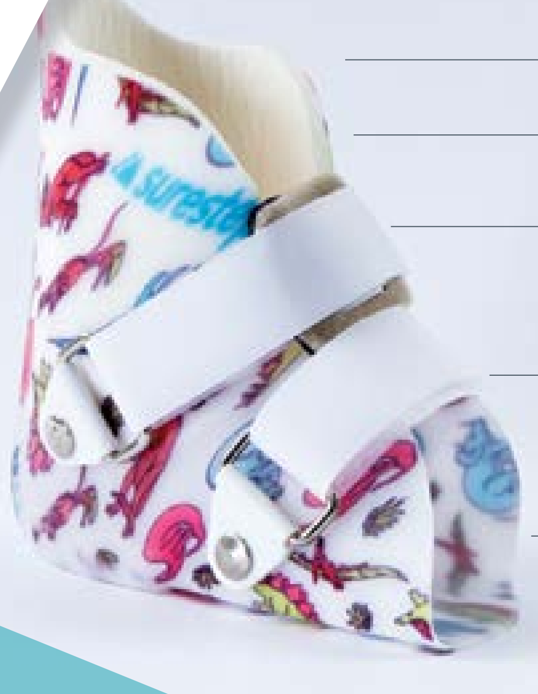
"In my eyes, every child has 'special needs'—they just come in different guises, because every child is different. Every child will, eventually, in their lifetime, have 'something' go on that parents have to deal with, whether medical, emotional problems, or whatever."

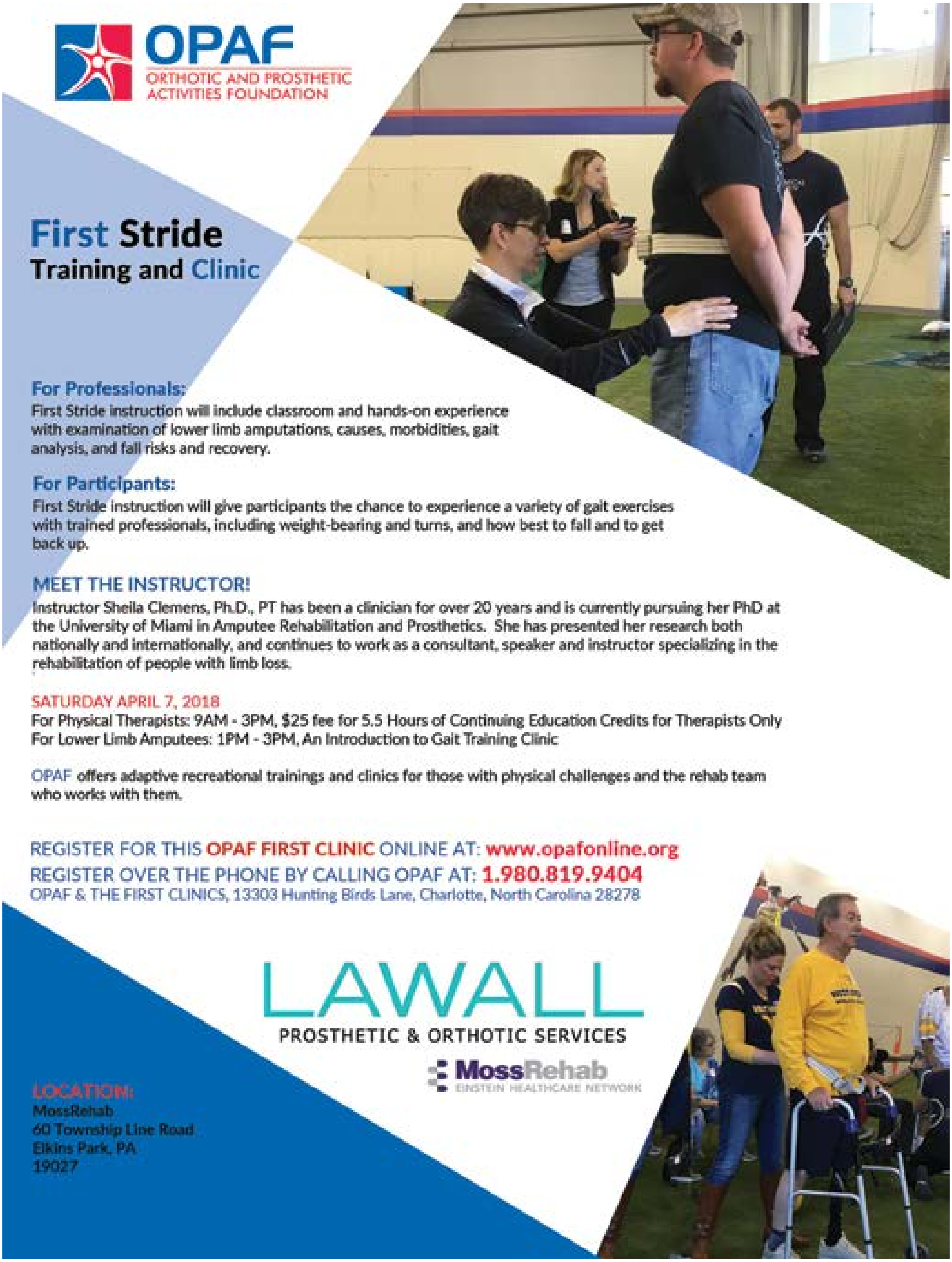
Do your research—and be knowledgeable about what you're getting into with your eyes open, she advises. "But sometimes you just have to take that leap of faith and do it. There's no doubt we were scared in the beginning. But it's wonderful. I can't imagine anything we would have done differently," she reflects.

Does having more than one child with a limb difference make it easier for the kids to deal with their similar challenges together?

Moran offers an answer from the prosthetist's perspective:

"The Reids' whole family dynamic has been one of acceptance and encouragement and I'm sure for these kids that are dealing with limb loss, it probably does help to feel like they are not alone. They've all said at some point how people out in public stare at them—and that's one of those things that tends to bother them more at certain ages, depending on their personality. But I think those three kids are all blessed to have been absorbed into that nurturing, supportive family. It's hard to imagine how different their lives might be, otherwise."





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1030 N. Kings Highway
Suite 301
Cherry Hill, NJ 08034
Phone (856) 616-1885
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Vineland
3071 E Chestnut Avenue
Suite C
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Cape May Court House
1261 South Rt. 9
Cape May Court House
NJ 08210
Phone (609) 463-1042
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DELAWARE/ MARYLAND

Dover
514 North DuPont Highway
Dover, DE 19901
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Fax (302) 677-0930

Wilmington
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1600 Rockland Road
Wilmington, DE 19899
Phone (302) 429-7625
Fax (302) 429-7683

Wilmington
1822 Augustine Cut-Off
Wilmington, DE 19803
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FLORIDA

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Nemours Children's Hospital
13535 Nemours Parkway, 5th Floor
Orlando, FL 32827
Phone (407) 567-5190
Fax (407) 567-5191

Orlando (Satellite Office)
Nemours Children's Specialty Care
1717 S. Orange Avenue, 3rd Floor
Orlando, FL 32806
Phone (407) 567-5190

Lake Mary (Satellite Office)
Nemours Children's Specialty Care
3300 W. Lake Mary Boulevard, Suite 100
Lake Mary, FL 32746
Phone (407) 567-5190

Melbourne (Satellite Office)
Nemours Children's Specialty Care
1270 N. Wickham Road, Suite 490
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