Introducing the Next Generation Proprio Foot

smallMiracles

PROSTHETIC & ORTHOTIC MAGAZINE

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Patient Profile

Joanna and Nathanael Costa

Turning Limitations into Gifts

LAWALL
PROSTHETICS & ORTHOTICS

Lawall Sponsors An Educationally Fun Weekend!

IN early April, Lawall teamed up with the Orthotic and Prosthetic Activities Foundation (OPAF) to offer two courses to benefit therapists, practitioners, and patients.

On Saturday, April 6th, we presented **First Things First: *Introduction to Falls and Recovery*** in Elkins Park, PA. The fear of falling is real and scary, especially for individuals with limb loss. Unfortunately, if you ask a room full of people, “who has fallen at some point in their life?”, all hands will go up! The incidence of falls is higher in the older population and in individuals with amputations. So, what is the best way to tackle one’s fear and

Michael Toner and Suzanne O'neil were two of several Lawall patients at the *First Things First Course* held in Philadelphia. They had the opportunity to practice falling and getting up in a safe environment. Joe Ciambanco attended the *First Stride Course* held in Princeton and received some hands-on gait training tips from some of the thirty therapists who attended the course.

help prevent injury in case of a fall. PRACTICE IT! Which is exactly what the attendees did. During the morning session, therapists and practitioners went over information critical to fall prevention and reviewed the importance of outcomes measurement. They also went over techniques that will help their patients land safely when falling and strategies to get up once they've fallen down.

In the afternoon, volunteer patients joined the group. In a safe setting they were able to practice falling, as well as strategies to get back onto their feet. It was helpful for all parties involved to work through various situations and come up with solutions.

On Sunday, April 7th, the **First Stride: *Gait Training and Increasing Mobility*** course took place in Princeton, NJ. During the lecture session of this course, Chris Doerger, PT, CP, covered assessment techniques, therapeutic exercises, and postural education. She discussed prosthetic componentry and how the selected componentry for a prosthesis will affect the type of gait training needed.

After the lecture session, patients

joined the therapists and practitioners for lunch and some hands-on training. Patients were given the opportunity to practice walking, navigating tight figure-8 turns, side-stepping, and walking up onto a step while maintaining their balance. They were also shown some exercises they could do at home to aid in muscle strengthening and conditioning.

Lawall would like to thank all the therapists, practitioners and patients who shared their weekend with us. It was a great couple of days and we hope to have more events just like this in the future!

Nancy Finn and Blaine Connor attended the *First Stride Course* and were able to get some pointers from therapists on how to navigate steps, tight spaces and turns, and master side-stepping.

The Next Generation Proprio Foot

The original Proprio Foot® was introduced in 2006. It was the first bionic (microprocessor) ankle in prosthetics and over the past decade, the foot has been continually analyzed by both patients and clinicians.

In February, Össur released the next generation of this microprocessor ankle which incorporates feedback compiled from users of the original Proprio Foot. The latest version of the foot helps amputees who are at an increased risk for falls because it increases toe clearance during the mid-swing phase. It automatically detects the level of terrain inclination and adjusts the ankle angle accordingly.

During field tests for the new Proprio Foot, users reported a 70% decrease in falls, in part because the prosthesis' active swing phase dorsiflexion provided increased minimum toe clearance, making it more comparable with anatomical feet. (Amputees tend to fall more often than their able-bodied counterparts.)

The new Proprio Foot responds quicker than the original model, which allows wearers to adapt better and to navigate the different types of terrain they may encounter throughout a typical day. It also has a more streamlined design, 43% more ankle power, and 23 degrees more ROM (range of motion). Additionally, it has a battery life of 18-36 hours, significantly longer than the original model.

KEY POINTS

- **Indicated for low to moderately active patients**
- **Patient must be under 275 lbs.**
- **The Proprio Foot App allows adjustment of the ankle height, enabling users to wear different footwear**
- **Weatherproof**

Patient Profile

JOANNA AND NATHANAEL COSTA:

Turning Limitations into Gifts

Arthrogryposis is a condition Nancy Costa had never heard of before it touched her and her unborn daughter at A.I. duPont Hospital for Children.

"I had no idea what it was; I had to educate myself," she remembers. "Joanna was born in March, 1998, but we had our first conversations with the team at duPont in December or January, when we had a diagnosis before Joanna was born."

The first indication of a problem was when Nancy felt no movement, which prompted them to early investigation. Unlike her first child, a son born two years earlier, "…Joanna wasn't moving normally, so we did a level 2 ultrasound."

Also known as an ultrasound anatomy scan, the level 2 ultrasound revealed that Joanna had club feet and ulnar deviation.

"She was basically stuck in the same position from at least 17 weeks forward," Nancy explains. "Joanna has no biceps because she never moved those muscles at all in the womb. So, once she was born, she received lots and lots of physical therapy and occupational therapy. They tried to stretch out those muscles that hadn't been used in utero."

In 2000, when she was just 19 months old, Joanna underwent corrective foot surgery, and after that surgery she needed extensive braces.

Incredibly, three years later, as the Costas prepared to welcome their third child, Nathanael, history repeated itself, and ultrasounds revealed Nathanael had also been affected by the same obscure condition: arthrogryposis was responsible for joint issues that had impeded normal development of his lower limbs.

"The initial discovery—of Joanna's condition—was probably the hardest," Nancy reflects, "because I didn't understand and I didn't know a lot. Taking one day at a time, and just doing the next thing, was the way I functioned.

"One of our first real helps was getting in touch with the team at duPont, speaking with Marnie King (an occupational therapist there at the time), and Reenee Donohoe (a physical therapist) when my daughter was born—that has really just been the greatest resource all along. When we later learned that Nathanael had the same diagnosis, which was unexpected, I felt like, 'Okay, I've done this before. I know what I'm dealing with.'"

Is the cause genetic, hereditary, or is arthrogryposis just a random chance event?

"There is a genetic strain of it," Nancy confirms, "but we don't know if that's the case, here, because my children do not fit that mold. There are, I think, more than 150 different causes and we just don't know what caused this effect in two of my three children."

In the larger view, however, what matters is not really what caused it, but how to deal with the symptoms and issues at hand.

Nancy describes it as "a non-progressive condition, so the way it presents at birth is the worst. For some reason, the child does not move normally in the womb, and so the bones and muscles don't develop normally."

Both children had club foot correction surgery. Joanna needed just one.

"I've lost count of the number of surgeries Nathanael has had," Nancy sighs. "His most recent was last year (2018) in March, and he's had extensive bracing post-op and even before that. It's ongoing for both of them, since the initial post-op days, where we were focused on getting them up and walking. Initially, Joanna needed bracing up to her hips before she was able to walk, but now both of them function with the support of AFO's (ankle-foot-orthoses)."

Joanna's ulnar issue required some splinting for positioning and stretching of her forearm muscles, but no bracing.

Gary Michalowski, CPed, BOCP, BOCO, for Lawall P&O, focuses primarily on lower extremity braces, such as the ankle-foot orthoses (AFO's) he makes for the Costas.

"Both Joanna and Nathanael have varus equinus pathology—that means the feet are down, and they're contracted in to roll to the outside. So as an orthotist, my objective is to best balance that—to create that biomechanically sound kinetic change from the feet up.

"The type of AFO that I've made for them is a very new, dynamic orthosis called a Phat brace. It's actually an energy-storing frame that holds the patient in their best ankle-foot plantigrade functional position. With anyone who has any type of abnormality, as the day goes on, they get tired and that abnormality gets magnified; these orthoses are made to address that—to be energy-storing, be more dynamic; make them more independent."

Michalowski began seeing Joanna and Nathanael when they were in grade school, when they were typically outgrowing their braces within a year's

WHAT IS ARTHROGRYPOSIS?

Listed as a Genetic & Rare Disease by the U.S. Department of Health and Human Services, National Institutes of Health, Arthrogryposis Multiplex Congenita (AMC) refers to the development of multiple joint contractures affecting two or more areas of the body prior to birth. A contracture occurs when a joint becomes permanently fixed in a bent or straightened position, which can impact the function and range of motion of the joint.

In some cases, only a few joints are affected and the range of motion may be nearly normal. In people who are severely affected, every joint in the body can be involved, including the jaw and back. Muscles of affected limbs may be atrophied or underdeveloped as a result. Soft tissue webbing may develop over the affected joint.

Also known variously as Arthrogryposis, Congenital Multiple Arthrogryposis, Fibrous Ankylosis of multiple joints, Congenital Arthromyodysplasia, Myodystrophia Fetalis Deformans, Guérin-Stern syndrome, Otto syndrome, Rocher-Sheldon syndrome, and Rossi syndrome, this musculoskeletal condition represents a symptom or set of symptoms, rather than a diagnosis or disease, and those symptoms can vary greatly in range and severity.

Gary Michalowski, CPed, BOCP, BOCO, recognizes different levels of arthrogryposis, which can impact different joints through contracture: most commonly wrists, ankles, knees, or hips. The AMC complex describes basic congenital joint contracture in two or more areas of the body, he notes.

Children born with one or more joint contractures have abnormal fibrosis of the muscle tissue causing muscle shortening, and therefore are unable to perform active extension and flexion in the affected joint or joints.

"These contractures thus tend to deform the foot and ankle, knee, hip, elbow, and wrist," he enumerates. "The game plan, when you deal with children with arthrogryposis, is to create orthoses so the poor pathology/deformity has a lesser chance of increasing. Certain things will be happening with bone structure as they develop; and what's going to go on with tendons attached to bones, and ligaments attached to muscle? Are we going to have the normal range of motion?

"And this is why we make some type of orthosis—to hold them in whatever their ideal functional alignment is, to decrease that poor pathology," he explains.

"If you hold the foot and ankle plantigrade with an ankle-foot orthosis (AFO), it also helps the knee and the hip alignment."

By definition, as a congenital condition, arthrogryposis exists at the time of birth; it may develop in the womb or during the first month of birth. And while its roots are certainly of interest, Michalowski points out that the history and highlights of the diagnoses are less important to him, from an orthotist's perspective:

"The diagnosis of arthrogryposis is really for a geneticist. As an orthotist, I can see this same varus equinuus pathology in multiple diagnoses: it can appear in somebody who has CMT (Charcot Marie Tooth), or in somebody who has muscular dystrophy. In any of those cases, I'm dealing with a poor biomechanical makeup, and determining how I can improve that.

"Basically, I'm making braces for them to decrease the poor pathology or the poor contracture that can still happen—and also to give them an assistive dynamic device that can assist them as their muscles tire through the day.

"I see individuals; I see individual gender, personality, and goals—and I'm looking at how I can improve their quality of life."

ONE in every
3000
children are
born with
arthrogryposis

time. As their growth has slowed down, they’re no longer outgrowing the braces, he notes; but with normal wear and tear, repairs and adjustments continue to be needed. “They’re both doing really well in the Phat braces; as a college student, Joanna walks all over campus and is highly functional.”

After 32 years serving at the A.I. duPont Hospital for Children, Michalowski has seen a number of patients of all kinds, and knows how to appreciate the good ones: “They’re fantastic individuals—very compliant, very curious, very spiritual and humble. For children who had a lot to deal with—and a mom and dad who had to find their way through this challenge with two children, you can tell the family life was very loving, very together, very supportive. They certainly showed that all the time I worked with them. They are a pleasure to deal with.”

Growing Up with Arthrogryposis

Both Joanna and Nathanael were involved in various activities as they grew up. Nathanael mentions non-competitive participation in softball and soccer when he was younger, and together the family has always enjoyed hiking, boating, playing games, and camping; but when Nathanael was 9 and Joanna 13, they started participating in what rapidly became their favorite active pastime:—the fast-paced and challenging sport of sled hockey. Both are players for the Wings of Steel, in Voorhees, New Jersey, where Nathanael serves as goalie and, after taking some time off while attending college, Joanna is looking into joining their newly formed adult team.

Nathanael, at age 17, won’t be far behind her in joining the adult team when he meets the 18-year-old eligibility requirement. “I’d love to do that—I really love playing!”

Bright and eager students, both Joanna and Nathanael have been home schooled, in addition to Joanna’s early part-time attendance at a private school.

Currently a high school senior, Nathanael has set his sights on a future in computer science—at least for now—as the focus of his college studies.

He has already created some significant science fair projects that await further development:

(1) A mobile app that allows students with disabilities to dictate their homework, rather than write it. “It allows them to speak instead of write, then send their answers directly to their teachers.”

(2) A basic app to support doctors in countries where computer access is limited. “The app would allow them to input a lot of different details about the disease, and decide how to effectively treat it by modeling different variables related to their specific cases.”

Joanna has previously flexed her mental muscles in some amazing science fair projects of her own––“a couple of projects based on music, and trying to kind of look at the math behind music. I was looking at some geometrical formulas and trying to relate this to music theory. It sounds more complicated than it was,” she disclaims modestly.

A YouTube video on “Computer Composed Fractal Music” shows Joanna explaining her project—which has shown that a computer “can be programmed to not only write fractal-based music, but to do so within the rules of western classical music… One day computers will compose our music,” she claims, “And we might actually enjoy it!”

Even more impressive is her YouTube video that makes a strong point about making the most of limitations—which perhaps are not limitations at all. Google “Joanna Joy Costa Limitations”, and enjoy a one-minute piano concert: a sonatina played (beautifully) by Joanna’s four functional fingers, while the on-screen verbiage explains that a rare disability keeps her from lifting her arms above her shoulders and allows her to use only two fingers on each hand.

(If you’re thinking ‘Chopsticks’, think again!)

Her limitations clearly don’t limit her talent, as the video aptly illustrates. In fact, her debut album—“Four Fingers, Two Hands, One Piano”, on which Joanna plays Clementi and Haydn sonatinas—is for sale on CD Baby.

How did she teach herself to play with four fingers, when most of us can’t manage half as well with ten?

“Either it’s something I can play with four fingers, or if it’s something that requires more than that, I kind of cut out different

(Continued on next page)

notes; I've learned how to do it so it will still sound like the original piece."

(Virtually re-composing the music undetectably sounds like an even more impressive accomplishment than playing it with four fingers!)

Currently a senior at Temple University, she's graduating soon with a double major in accounting and Spanish, and a minor in global studies.

"She's quite ambitious," her mother notes. "She spent last summer working at an orphanage in Mexico, and she works now at a women's center in Philadelphia. Her heart is in that kind of work."

Joanna agrees that her work at the children's shelter in Mexico allowed her to work on her Spanish while helping kids who have had a lot of trauma in their lives, and was quite rewarding, like the Spanish translation and accounting work she's doing for the women's center.

"After I graduate I'm going to work on getting my CPA, but after that—I'm hoping to do something in the non-profit area."

Such efforts to help others are most effective on a one-on-one basis, Nancy Costa believes. "We have had contact with other families that have children with arthrogryposis. The range is quite vast in terms of how involved children can be."

When Joanna's "Limitations" piano-playing video appeared on Facebook, people contacted the Costas through that medium, Nancy reports. She mentions contact from a family in Hungary and one in New York, as well as a mutual friend who connected the Costas with a nearby family who had adopted a boy from China who had arthrogryposis.

Engaging on a personal level is often more meaningful, she notices. "When we are in contact with a family and their child is having surgery or something like that, it's just a great opportunity to encourage and support them."

What has been most difficult for you in dealing with arthrogryposis?

JOANNA: "Something that I really struggle with is just remembering that even though I'm disabled, I have the same value that any other human being has; and throughout high school I really struggled with how I see myself. A lot of that is what's driving me to want to help kids or help women as others have done for me.

"What helped me through that was my faith—I'm a Christian—that really helped me. And my family; that's kind of what's driving what I want to do with my life."

NATHANAEL: "Like Joanna said, it's just sometimes hard to remember that you're as valuable as others. My Christian faith has also really helped with that."

Sometimes, it's the practical issues that frustrate, he reflects—e.g.: "When you want to go do something, having to remember 'Oh, that might be too much activity for me—I might not be able to have the energy to do all that."

NANCY: "Although the initial discovery of Joanna's condition was probably hardest for me, I think the other hardest time for me is when, as a mom, I'm watching them struggle or suffer—whether physical, emotional, or whatever. That's the case for any mom—it's just heightened in different ways for me."

What has been most rewarding about your situation? Are there hidden blessings?

JOANNA finds that the ability to relate to other people who have issues and disabilities has been very rewarding. "I can usually relate with people very easily, because they know I have gone through hard things. It's almost a blessing in disguise."

NATHANAEL counts the sister who shares his diagnosis among his greatest blessings--she understands his situation as no one else can.

He agrees that individually relating to other people, and helping when they have physical difficulties is most rewarding. "The dictation app that I made was done for someone we knew who had trouble writing things out, and I wanted to work with that idea. I had them test it for me and give me feedback on it while I was developing it. It's the everyday aspect—just talking to people and helping to comfort them to get them through—that counts most."

He reminds others with disabilities to remember Joanna's realization that one's value isn't in what they can or can't do physically. "You have intrinsic value. That's important to remember."

To other parents facing a similar situation with their child, Nancy offers heartfelt advice:

"Just having a good medical team that works well together has been incredibly helpful. So just having Lawall's there at the hospital working with the doctors and the therapists has been priceless from Day One. That team approach is incredibly valuable. So if you have a child with a disability, I would advise you to search for somewhere you can get that kind of care. When everybody's on the same page and working together, it is priceless. I don't know what we would have done without it."

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