TeamLAWALL: Encouraging Those with Disabilities

smallMiracles

PROSTHETIC & ORTHOTIC MAGAZINE

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Patient Profile

Izzeddin Alnawasra: Walking Home to Gaza

New Advancements Being Made to Address Phantom Limb Pain and Residual Limb Pain

LAWALL
PROSTHETICS & ORTHOTICS

The Causes of Phantom Limb Pain and Residual Limb Pain and Nonpharmacologic Approaches to Relief

THERE ARE OPTIONS AVAILABLE AND NEW ADVANCEMENTS ARE CONTINUALLY BEING MADE TO ADDRESS THE VERY REAL PROBLEM OF PHANTOM LIMB PAIN AND RESIDUAL LIMB PAIN.

Phantom Limb Pain (PLP) and Residual Limb Pain (RLP) are often problems that plague amputees after an amputation. Understanding why it is happening can help alleviate some fear and anxiety surrounding the pain. Because after all, if the limb is no longer present, how in the world can it be causing so much pain?

During an amputation the nerve fibers are severed. Typically, the "axon (nerve fibers) will swell at the transected area creating an "end bulb" which will quickly give rise to terminal sprouting".[1] A neuroma is formed and this area can become very sensitive. Furthermore, after an amputation the sensory cortex is no longer getting feedback from the amputated area. The sensory cortex will adapt and respond to input from nearby sensory inputs.

Often pain for PLP and RLP is managed through pharmaceutical solutions such as over the counter pain relievers, antidepressants, or anticonvulsants. These are not the only solutions available to amputees. There are non-invasive and invasive, non-pharmaceutical alternatives that are worth exploring.

The most common form of non-invasive therapy is mirror therapy. It has been around for over 20 years and operates on the assumption the PLP is a result of the brain sending motor signals down to the limb and not receiving any sensory information back, and the lack of response creates an illusion of paralysis which can be painful for some individuals. Mirror therapy uses a reflection of the sound limb to trick the brain into receiving feedback and therefore reducing PLP. While mirror therapy has proven successful for many patients there are limitations, such as some patients' ability to perceive the movements on the sound limb through reflection. Upgrades to the use of mirror therapy have been attempted through virtual and augmented reality to help increase the immersive experience and improve results.

Transcutaneous Electrical Nerve Stimulation (TENS) uses electrical stimulation along the surface of the skin to provide burning or prickling feedback to replace the pain. This treatment is used for various forms of peripheral pain syndromes. Closed-loop neuroprosthesis training builds on the idea of TENS therapy. This treatment uses a myoelectric prosthesis for training and sensory feedback via sensors in the prosthetic hand to provide feedback on grip strength. Feedback is provided through transcutaneous sensors which are placed in a section of the intact portion of the limb. This is beneficial for sensory feedback as well as prosthetic training. "In a somewhat related approach, repetitive transcranial magnetic stimulation (TMS) has also been used as a noninvasive treatment for PLP. In this approach, instead of transmitting transcutaneous electrical stimulation to peripheral nerves, magnetic impulses are administered to specific areas of the patient's head to deliver focused stimuli to the brain".[1]

The next level of nonpharmacologic pain management is invasive. The most common invasive form of therapy is electrical spinal cord stimulation (SCS). During this process electrodes are placed along the thoracic spine stimulating dorsal columns, which creates a paresthetic sensation and decreases pain. There has been difficulty translating this therapy to patients suffering from PLP and RLP because of the inability to provide the paresthetic coverage to the distal limb.

Some early success has been achieved when moving the electrical stimulation further away from the dorsal columns in the spinal cord to dorsal root ganglion and the peripheral nerves. Electrical stimulation of the peripheral nerves (PNS) allows access to deeper nerves as well as more proximal nerves, which were previously innervating the nerves in the amputated limb. "Pilot studies have shown some promise. In the most recent of these, 14 of 16 subjects who completed in-clinic testing responded to stimulation, reporting at least 75 percent paresthetic coverage and clinically significant pain relief."[1]

Invasive Nerve Reinnervation is another option that is being explored to help control RLP and PLP. Targeted Muscle Reinnervation (TMR) was originally explored as an option to increase the number of inputs for externally powered prosthesis. The benefits of TMR are well established but a recent clinical trial showed promising results for TMR being a viable option for RLP and PLP. A controlled clinical trial of 28 patients was performed on patients of PLP. "Half of the subjects underwent standard treatment, in which the neuroma was excised along the length of the nerve until healthy nerve fascia was observed and then tunneled into the deep aspect of a nearby muscle without tension. The remaining subjects underwent TMR as previously described.[1] A year later results were analyzed and there was reportable improvement in the TMR group and not in the standard group.

Due to the success of TMR, surgeons and researchers are seriously considering TMR as an option that should be explored at the time of amputation rather than after. It is important to highlight and understand that there are options available and new advancements are continually being made to address the very real problem of Phantom Limb Pain and Residual Limb Pain.

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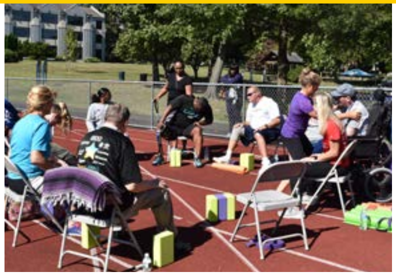
[1] *Stevens, Phil. Non-Pharmacologic Approaches To Residual Limb and Phantom Limb Pain.* The O&P Edge *July 2019.*



TeamLAWALL | Encouraging Those with Disabilities to Seek a Higher Level of Performance

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Regardless of the physical or mobility challenges they may be facing, many individuals with disabilities have not begun to tap into the considerable potential that remains to them, say leaders in the field of adaptive recreational sports and activities.

"As practitioners, we see alarming statistics surrounding the decrease in patient mobility once they stop physical therapy," notes Ann (Lawall) Roque, Prosthetist/Orthotist. "After they go through an initial intensive rehab process in conjunction with their post-trauma or post-surgical treatment, we see a decline in their ability to maintain that important level of activity they achieved while they were in therapy.

"Once their progress plateaus, they are usually discharged from physical therapy and see their prosthetist/orthotist once a year, unless there are issues with their prosthesis or orthosis. So maintaining their motivation and activity level can be difficult."

Statistics show that prosthetically, the number of amputees in a wheelchair increases by 26% over the first 5 years following their surgery or limb loss—from 13% to 39%.

Concerned that many patients lack the opportunities, encouragement, or healthcare coverage to maintain or ramp up their activity level, Roque and Juan Cave II, MSOP, Prosthetist/Orthotist, began working in 2018 to find ways to develop and offer such an opportunity.

Aware of clinics for runners and similar events sponsored by manufacturers and the Challenged Athlete's Foundation, Cave recognized their value in keeping athletes mobile and active. But, he realized, not all people are athletes or even weekend warriors.

"We should create similar opportunities for people who aren't necessarily at that level," he proposed, "and help them by providing the ingredients and building blocks to maybe get there one day."

LevelUp was initially conceived as just the first kick-off event in a program designed to offer a smorgasbord of activities that could be sampled by people with all kinds of mobility challenges—with the objective of taking their activities and fitness to a higher level, whatever that level might be for each of the individual participants.

But Cave and Roque quickly realized that presenting this event as they planned would require the support of a nonprofit agency. So--they created one.

TeamLAWALL is born

TeamLAWALL required nearly a year of preparation and paperwork to establish, but in May 2019, the new non-profit organization was officially established, with the mission of providing patients within the Pennsylvania - New Jersey - Delaware area opportunities to try new activities in a safe environment—and potentially help them recover lost mobility and/or learn new recreational activities, Roque explains, "–and in the process, improve their overall health and wellness."

On September 22, *TeamLAWALL* sponsored its first *LevelUp* event in Bensalem, PA, where participants were able to experience running, cross training/weightlifting, and yoga, each guided by specialists, expert instructors, and volunteers.

"The day was a great success," said Roque, "with about 20 participants coming from all over the tri-state area, in addition to supporters and family members. We received great feedback on the event, thanks to our wonderful volunteers and sponsors—like Össur, Ottobock, Freedom Innovations, and more."

But *LevelUp* is just the beginning, Cave explains. "We're going to have different one-day events that focus on a single sport or activity throughout the year. We're planning a cross training activity in late January, with a dance event, a yoga event, and others to follow."

TeamLAWALL will also sponsor patients in golf outings, walks and runs, and local bike races like the American Diabetes Association's annual Tour de Cure.

"Each September we'll continue to present an annual *LevelUp* Day, a buffet where you can sample a variety of different activities," Cave adds.

"We've tried to make it clear that participants don't have to be superstar athletes, and they certainly don't have to be Lawall patients. Even if you just received your prosthetic or orthotic—you can still get out there and we can adapt any activity to your needs. At our first *LevelUp* Day we had people in wheelchairs doing crossfit; we had people who had difficulty with balance able to practice standing up and sitting down—anything that's needed, we can accommodate the patient at their level."

Think you can't dance in a wheelchair?

LevelUp's volunteers can show you how to enjoy the fun of increasing your fitness in ways you may not believe possible. Think you're too old, or too inexperienced--? --or maybe too young to participate?

LevelUp and *TeamLAWALL's* entire program of events are planned to benefit all ages, at all ranges of experience with their prosthetic or orthotic device.

Details of our January 25 cross training event are available now; information about our March dance clinic will be finalized soon. Visit https://www.lawall.com/team-lawall to check our schedule for event updates, or email TeamLawall@lawall.com and ask to be added to our mailing list!

If you are interested in supporting our mission and assisting these individuals to reach their goals, please call our office at 215-338-6611 and ask to speak with Juan Cave, or email us at TeamLawall@lawall.com. We look forward to beginning this partnership with you!

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Borders Are No Barriers When Help Is Needed

Working in conjunction with philanthropic organizations as well as other healthcare professionals who identify prosthetic or orthotic patients in need, Lawall has continued to fuel a philosophy of caring which was established by Harry J. Lawall, Sr. and Harry J. Lawall, Jr.

The financially disadvantaged and those born into conditions without access to appropriate medical care are among those Lawall strives to help without reimbursement as they progress toward improved mobility.

Izzeddin Alnawasra: Walking Home to Gaza

The rigors of daily life in a war zone are unimaginable to many; it's a world filled with hardships, insecurities, and very real dangers to life and limb. Izzeddin Alnawasra, a 15-year old survivor of such a life, lost his leg in a traumatic amputation after sustaining a gunshot wound in May 2018. He later came from Gaza, a Palestinian territory on the eastern coast of the Mediterranean Sea, to the United States, and arrived in a wheelchair—but "with a smile that would light up his whole face!" remembers Mike Kelly, CP, Izzeddin's prosthetist at Lawall.

Izzeddin was born in Refugee Camp Magahzi, a United Nations-operated camp established in 1948, where he lives with his parents, four brothers, a sister, and about 50,000 other camp residents.

When their efforts to help him get fitted with a prosthesis were unsuccessful, his family sought aid from the Palestine Children's Relief Fund (PCRF), an American Humanitarian organization with three offices in Gaza.

"They wanted to know if we could help their son walk again," remembers Dunia Saed, Patient Affairs Coordinator for PCRF, who works to arrange medical care for kids like Izz. "At about that same time, we were setting up a volunteer chapter in Harrisburg, Pa., where we would have volunteers able to support him during his medical journey."

An online search for a nearby prosthetic provider willing to offer their time and talent to help Izz led them to Lawall.

Arrangements were finalized, a visa obtained for Izz, and travel arrangements were made that brought him to Harrisburg in March 2019, where he stayed with a host family during the fitting of his prosthesis, and the adjustment period that followed.

Kelly remembers him as "a very soft-spoken young gentleman, very mature. For a young man, he's mature in the way he handles responsibility. I gathered that his life included responsibilities like catching fish and food to eat for each day. He was

(continued on page 8)

Both domestically and internationally, and at both the corporate level and individually, Lawall demonstrates its concern and care for those with mobility challenges. Through sponsorship and support for fundraisers and events, the company sets an example for its caring and generous professional staff members, who donate their time and skills locally and globally by collecting and fitting orthotic devices for pediatric re-use in underserved countries, and volunteering their support at company-sponsored events and activities.

Small Miracles shares in this issue the stories of two international patients Lawall considers itself privileged to serve. Their life-changing prosthetic successes are ample reimbursement; we are proud to be able to partner with the wonderful organizations that made our help—and our patients' brighter futures—possible.

Patient Profiles

El Salvadoran Finds Refuge & Restored Mobility in the U.S.

IT takes courage to leave the land of your birth and pursue a new life in a new country, where custom, culture, and language are all strange. The challenge is even more difficult when you're struggling with limb loss and constant pain. Wounded in 1990 during the El Salvadoran civil war, Raoul* lost his lower leg and foot when he stepped on a land mine.

A husband, father of four, and devout Evangelical Christian, Raoul appeared at the offices of The Philadelphia Aids Consortium/World Health Care Infrastructures (TPAC/WHCI) for a scheduled evaluation—pursuant to his desire to request asylum in the United States. During the course of routine examinations and medical checkups to assess post-traumatic stress disorder symptoms and compile a general medical history for the immigration court, the 50-year-old's difficulties with his painful and inadequate prosthesis became obvious to interviewers. Raoul revealed that he lacked insurance coverage or funds to cover the cost of a new prosthetic leg.

Although in his homeland Raoul held a degree in security administration, and had been successful in the field of security for 15 years, his painful prosthesis made it difficult for him to maintain his current job at a car wash, which requires him to be on his feet most of each day.

Although Raoul never sought assistance, noted Julie Stavarski, Program Assistant at TPAC/WHCI, their team was moved by his hardships.

"He's a very sweet, humble person, who didn't ask us for anything," she said, "but we realized that he was in a lot of pain and it was affecting his ability to work as many days as possible. My boss was determined to do something about it, if we could. So after his appointment, we met together as a team to look into organizations and people we could contact for a low-cost or free prosthetic."

After several disappointments from other potential resources, their medical services provider, nurse practitioner David Agosto, put them in touch with Lawall Prosthetics & Orthotics and prosthetist David Lawall, CPO Regional Manager, who were happy to help.

"His amputation was a very short amputation," Lawall recalls, "with a very bony residual limb. But all in all, the limb itself was strong and in good shape when I saw him. The prosthetic he was wearing was very much outdated. It had been made using some of the technology and the techniques that were used in the '60s and '70s. And the prosthetic was completely broken—literally to the point where, when you took the shoe off, the prosthetic foot would fall apart!"

Lawall's intent was to create something more modern, lightweight and functional, that would also be much more comfortable. With the assistance of his son, Dave Lawall, Jr., who

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***For security reasons, we've been asked not to share Raoul's real name.**

(continued on page 9)

*(Patient Profile - **Izzeddin** - continued from page 6)*

respectful of people or elders, but also respectful of what we were going to be doing for him."

Although Izz didn't speak English, Kelly experienced no difficulty in communicating with him. Not only did Izz have reliable translators, but having raised three children himself, Kelly caught the unspoken messages in the teenager's expression and tone of voice, he reports with a chuckle. "Maybe I could just hear the adolescence coming out in him from time to time! He was being a gentleman, but he was informative in many ways," Kelly laughed. "He would give me a look –or maybe just a smile and a thumbs-up."

Kelly found Izz to be a natural teacher. "He encouraged me to learn his language, teaching me how to say 'hello' and 'thank you'. Then, when we'd see each other a week or two later, I could greet him in his own language. A teacher teaches information, but they also are able to teach through their life experience, and through his demeanor, his friendliness and kindness, he has such a lot to teach other people—as he has already taught me."

Back on Two Feet Again

The components for Izz's below-knee prosthesis were provided by Össur Americas, Kelly notes, "and Lawall's generosity allowed me and Joe Howanec, the prosthetic technician, to work to provide what was necessary. Body weight, lengths and heights are frequent changes as young people grow, so we tried to use modular components that are used pretty much worldwide, so they could change out parts that might need replacing."

Kelly describes the ProFlex XC foot Össur provided as "a very good dynamic foot for active people, so he would benefit from energy efficiency while wearing his prosthesis."

Although the prosthesis is built with strong titanium components, and it's a good choice for one active in sports, it's unlikely that Izz will risk breaking it by participating in sports.

Steve Sosebee, PCRF CEO, explained: "The prospects of getting it repaired are not as high as they are in the U.S. There is a soccer team there for amputees in Gaza, but it's without the prosthetic leg. They use their crutches, because the wear and tear of landing on your leg is really intense. A lot of the kids that we've had treated are on that soccer team."

Kelly also describes soccer organizations which enable amputees to play without a prosthesis, while using elbow or forearm crutches. "The players know how to swing through and kick very effectively. They are impressively strong."

Izz's positive attitude and commitment continued to impress Kelly throughout his series of fitting visits.

"Being young and determined, he learned quickly on his own," Kelly observed. "He initially left the office on crutches, came back in three weeks using just a cane, and when he left us to return home, in less than two months, he was walking well, without the cane!

"He was very trusting and willing, from the onset," Kelly remembers. "I look at my role as providing a tool, and if people are motivated and willing and determined, they're the ones that really apply themselves, and do what's necessary to use the tool wisely."

Izzedin's courage, friendliness and determination made him a successful patient Kelly won't soon forget.

"We don't often have cases like his,

(continued on page 10)

((Patient Profile - ***Raoul*** *- continued from page 7)*

was starting prosthetic school and got a head start by shadowing his dad all summer, the elder Lawall created a comfortable, customized prosthetic solution for Raoul.

The challenge, Lawall found, was that although Raoul had experience in wearing a prosthesis—and in fact, had worn five of them over a 29-year period—none of them was much like the new one with which he was fitted.

"There was a learning curve, especially concerning the technique of putting the prosthesis on, and making sure that it fit properly and stayed on him. I think he was a little reserved and nervous when he first arrived," remembers Lawall, "—not sure what to expect. But once we tried on some of the different types of liners and socks, he was just elated."

While Raoul's previous device was an exoskeletal prosthesis made of wood, the new prosthesis was crafted from titanium and carbon fiber and was "super lightweight and extremely dynamic," said Lawall, who compared the prosthetic foot to a diving board.

"What he had was just a rigid wooden foot with no spring or flexion to it—like cement. When we put him into the new foot, it was like a spring diving board: Putting the weight on the toe of it gives him a bounce-back.

"You should have seen the smile on his face! He was overwhelmed, really. He smiled from ear to ear. He was bouncing up and down, jumping up and down. It was really great!"

Stavarski, who also served as Raoul's translator during his visits to Lawall during the two weeks of fittings and adjustments, returned with him for a final followup visit a month later.

"He's doing great," says Lawall. "—no problems with his skin, no problems with the walking, so it seems like he's adapted to it pretty well."

Even without a translator, he noted, Raoul's reaction would have been clear to read:

"He was smiling all the way through. You could tell he was just so appreciative—he's just a pleasant, pleasant guy!"

As Stavarski noted on the TPAC/WHCI blog, "We are ecstatic that there are people and organizations in Philadelphia that continue to selflessly help others in need. When we work together as a team, we can make what seems impossible, possible. Thanks to Lawall Prosthetics & Orthotics, our client received a new prosthetic leg!

"We want to recognize particularly David and Dave Lawall, an incredible father and son team!"

ABOUT THE PHILADELPHIA AIDS CONSORTIUM/ WORLD HEALTH CARE INFRASTRUCTURES

TPAC's Mission is to ensure the availability and coordination of comprehensive and integrative health and social services to individuals who experience lack of affordable healthcare, HIV, sexually transmitted infections, behavioral health challenges, or challenges navigating the system.

Since 1989 TPAC has proactively met the challenges of ensuring the provision of health and social services to those infected or affected by the HIV/AIDS epidemic and secured the resources necessary to support those services. In addition to direct health services, they provide local, regional and international (dba World Health Care Infrastructures) leadership training, capacity building, technical assistance and program coordination to community-based service organizations.

Recently added services include: medical services for the uninsured or underinsured, pharmaceutical assistance with medications, mental health evaluations and support groups for immigration cases.

Learn more at http://tpaconline.org

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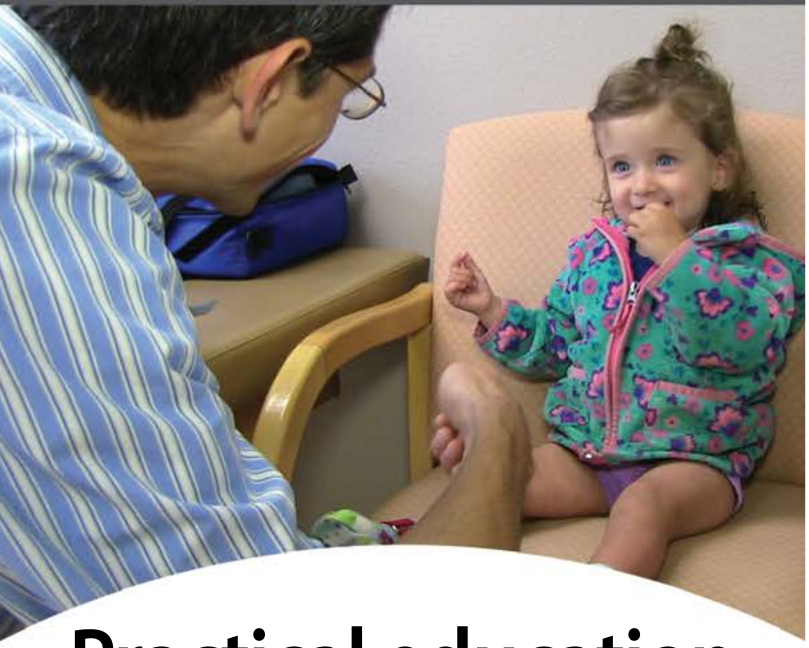
- **The Palestinian Children's Relief Fund (PCRF) and more!**



(*Patient Profile* - ***Izzeddin*** - *continued from pg 8)*

and the opportunity to help a young person with such a strong willingness to succeed is very rewarding. Seeing the outcome, and getting the satisfaction from his success, makes it fulfilling in so many ways to offer our help."

What Lies Ahead in Izzeddin's Future?

On May 17, as he was preparing to return to Gaza with his new prosthesis, Izz answered questions, with Sosebee serving as translator. "He's comfortable wearing the prosthesis," Sosebee confirms. "There's no pain and he's happy with it, but still getting used to the adjustment of having to put on a prosthesis every day and walk."

Although Izzeddin still experiences a little bit of a limp and a little bit of a gait stop, we learn, he's continuing to work on it. Although as recently as five months earlier, he had been suffering from phantom pain caused by his absent limb, there has been no more phantom pain since he's had the prosthetic leg.

Asked about his career plans, Izz replied that he'd like to be a doctor—to help other kids like himself get care.

PCRF and its personnel are willing to stand behind that dream, says Sosebee.

"We'll put the ball in his court a little bit. Obviously to become a doctor, you have to work hard and show some initiative. So if he has that—if he goes to school and studies hard—then we certainly can open doors for him and give him the chance to succeed. There are universities and medical schools there, and we'll help him out for sure."

Sosebee relayed Izz's thanks to everybody in the U.S. who has helped him. Everyone was very kind to him and made him feel very welcome and he really appreciated it—he wasn't expecting that.

What surprised him most about the United States, however, during his sightseeing visits to Washington, D.C., and other parts of the country, was how big it is, compared to his small country. His host family reported on the amount of walking he accomplished, Kelly noted.

His return home to Palestine occurred during Ramadan, a month-long observation of daytime fasting, so Izzeddin was eagerly looking forward to being reunited with the family members he hadn't seen since March—and having dinner with them.

PCRF shared their appreciation—and Izz's clear delight!—in a May 20, 2019 Facebook post and airport photo that were all the reward one could wish for. The message concluded, "Thank you so much for making it possible to see him return home walking again. Bless you all!"

ABOUT Palestine Children's Relief Fund

The Palestine Children's Relief Fund is an American Humanitarian organization that has been providing medical support to the children of Palestine for 26 years. They have made it possible for more than 2,000 children to be sent out of the country to receive free care, and they sponsor medical missions into Palestine to treat as many as 7,000 children each year.

PCRF has 32 volunteer chapters throughout the United States, from Portland, Oregon to Atlanta, Georgia, and from New Jersey to San Diego. They also serve Palestinian children from three offices in Gaza and six in the West Bank, where families can go to request assistance.

Visit https://www.pcrf.net

Amputee Coalition Sponsors Annual Summer Camp

SUMMER CAMP. Those two words often conjure up memories of sitting around the campfire, making arts & crafts, canoeing across a lake, meeting new friends and stepping outside of a regular routine in order to experience something new and different.

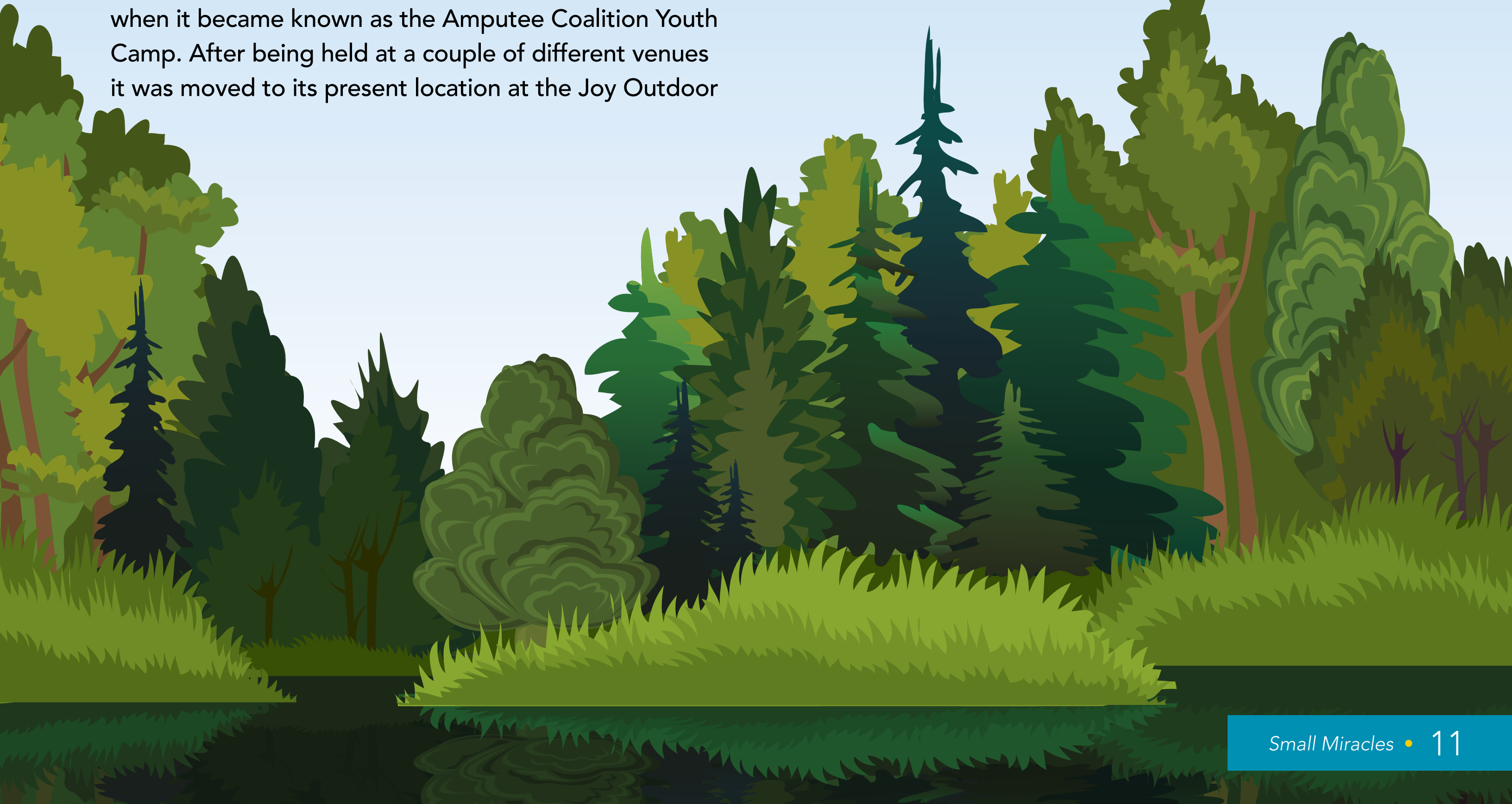
For more than 150 kids who come to the Amputee Coalition of America's Paddy Rossbach Youth Camp each year, summer camp has a more personal meaning. It is often the one chance the campers have to feel like they are surrounded by others who truly understand what they face living with limb loss or limb difference. As they arrive at the camp from their homes across the country, campers shed their inhibitions, lower their defense, and learn more about themselves and what they are truly capable of doing. They dance, play sports, perform skits and participate in many other activities without the fear of feeling different.

The 6-day camp for ages 10 to 17 originally began in 2000 as a satellite program offered by the Amputee Coalition to help provide a support group for youths with limb loss or limb difference. Designed to make a positive impact in the lives of children with limb loss and limb difference by increasing their self-confidence and self-esteem, the event was held in conjunction with the ACA's annual educational conference until 2002, when it became known as the Amputee Coalition Youth Camp. After being held at a couple of different venues it was moved to its present location at the Joy Outdoor Education Center located northeast of Cincinnati, OH in 2008, and then renamed the Amputee Coalition Paddy Rossbach Youth Camp the following year to honor former Amputee Coalition president and CEO Paddy Rossbach who was instrumental in starting the camp.

The program is run as an accessible traditional summer camp program with activities facilitated by trained staff members of the Amputee Coalition or Camp Joy Outdoor Education Center. The majority of the counselors are former campers and/or amputees themselves so they have a personal understanding of what growing up with limb loss is like. Many become role models or mentors to the campers and often help encourage them to try new things.

Campers overwhelmingly enjoy attending the camp and most leave already planning to return the following year. Many of the older campers plan on becoming counselors in the future in order to give back to their peers and pass the experience along to the next generation.

Starting in January, the Amputee Coalition will begin accepting applications for the 2020 Paddy Rossbach Youth Camp. It is recommended to apply early because a wait list often forms rather quickly. For more information on the camp, visit: https://www.amputee-coalition.org/events-programs/youth-camp/



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Cape May Court House
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Nemours Children's Hospital
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