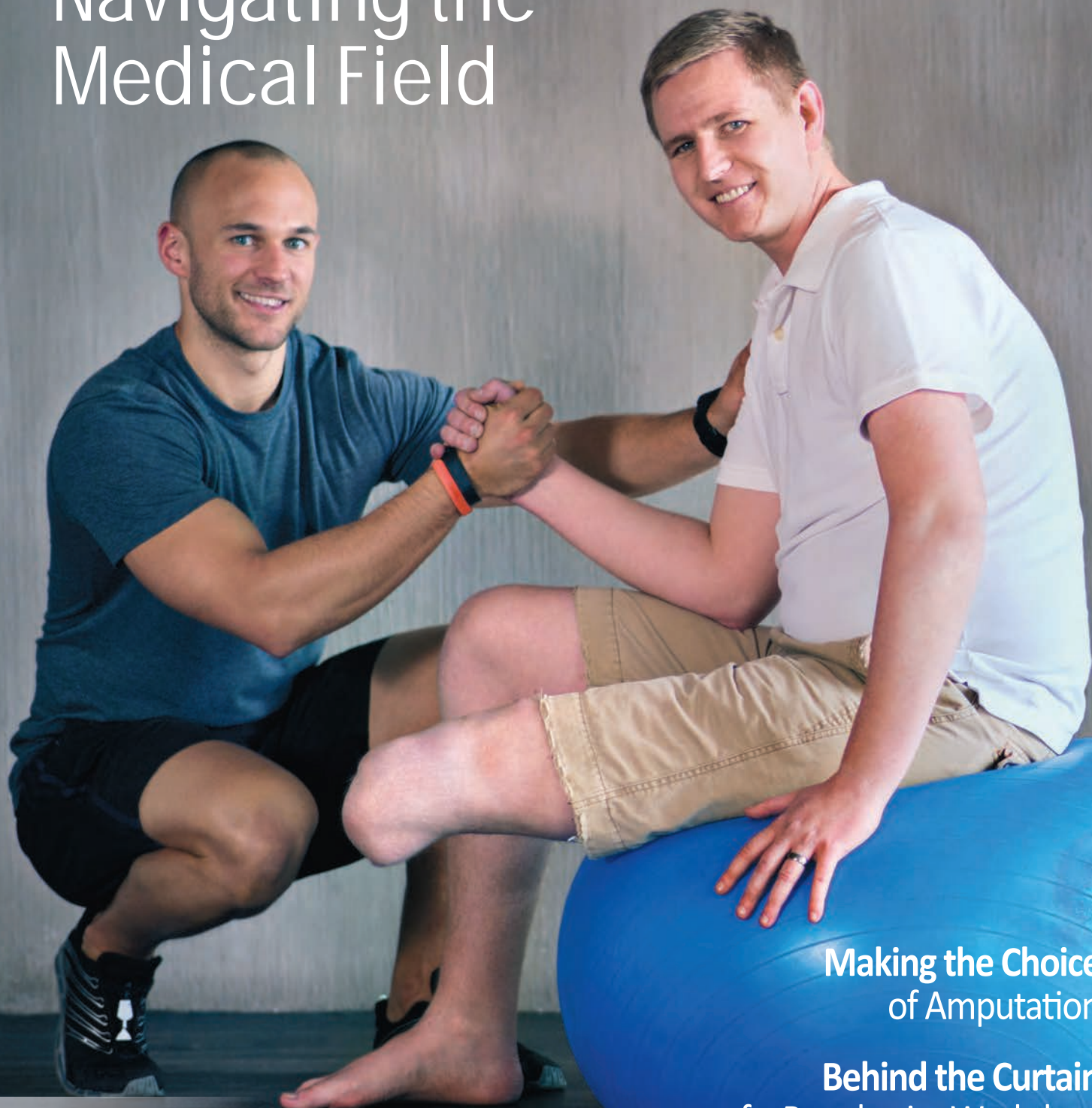


# *in*motion

The Living Well With Limb Loss Magazine

## Navigating the Medical Field



**Making the Choice  
of Amputation**

**Behind the Curtain  
of a Prosthetics Workshop**

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# Navigating the Medical Field

## *It All Begins With a Single Step*

Bill Dupes, Editor-in-Chief



### **The journey to reclaiming your life after amputation is hard.**

Regardless of whether the loss is of an upper or lower limb, or whether it is caused by illness or injury, it is a life-changing event. No two people share the same set of experiences, confront the same obstacles, or achieve the same level of ability. And yet, you are not alone.

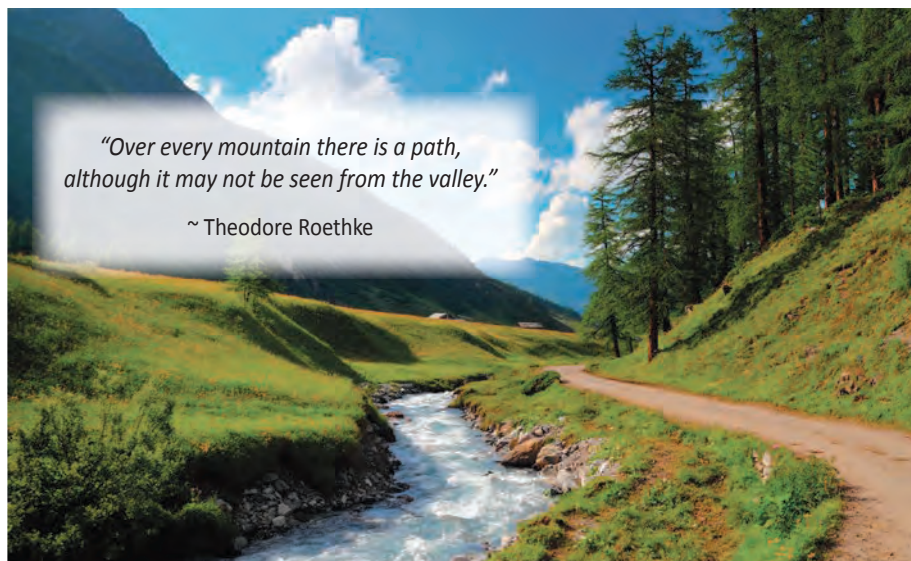
Because, although people come to limb loss by many different paths, they often face similar questions and problems along the way to healing and rebuilding their lives. And, while the loss is felt most acutely by the amputee, it is also extremely difficult for the person's closest family members to accept the loss and adjust to new daily routines.

While it can be overwhelming to face so many unknowns, know that there are many people and organizations that can help guide you and your family along the path of recovery and rehabilitation.

The Amputee Coalition is the leading national nonprofit organization for people living with limb loss and limb difference. In fact, the National Limb Loss Resource Center serves as the key information source on limb loss for national partners such as the Centers for Disease Control and Prevention (CDC), the U.S. Department of Defense and the Veterans Affairs Amputation System of Care.

For over 25 years, the Amputee Coalition has been dedicated to teaching people with limb loss how to accept their body after amputation and that losing a body part doesn't change who they are or what they want in life – that they don't have to settle for anything less than what they wanted in life before their amputation. We hope that the articles in this issue will provide some guidance to those of you who find yourselves wondering which direction to take.

For more information on living and thriving with limb loss, please contact the Amputee Coalition at 888/267-5669 or visit our Web site at [amputee-coalition.org](http://amputee-coalition.org).



*"Over every mountain there is a path,  
although it may not be seen from the valley."*

~ Theodore Roethke

### **BE AN INFORMED READER**

Editorial content (articles, news items, columns, editorials, etc.) in *inMotion* often contain healthcare information. As an informed reader, you should never make a decision about managing or treating your condition without consulting your own clinicians: They know you best.

Sometimes, in our interviews with people who are amputees, the person being interviewed will say something about his or her personal experience that may not be entirely consistent with standard practice. In these cases, we print what the person said because we think it gives readers insight into that individual's experience that we believe will resonate with others. But: We urge you to always check with your medical team before changing your own healthcare regimen.

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# I'mPOSSIBLE

Since she was a little girl, Carrie Davis knew she was unique. Born without her left arm, she often wondered "Why me?" She longed to be known for her contributions, not what she was missing.

A prosthetic wearer since she was nine months old and long-time Hanger Clinic patient, today Carrie is the face and personality of Amputee Empowerment Partners, the leading peer-to-peer support network for those living with limb loss or difference. Carrie finds the answer to "Why me?" through helping others.

In 740+ clinics throughout the U.S., Hanger Clinic delivers orthotic and prosthetic solutions to help more than 1,000,000 patients like Carrie turn their hopes and dreams into reality, break down barriers and move their lives forward.

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A Publication of the Amputee Coalition

*InMotion* magazine publishes unbiased journalism that seeks to "empower and motivate" living well and thriving with limb loss. The magazine targets amputees and their families and is provided free electronically to all friends of the Amputee Coalition and in hard copy to all subscribers. Each issue covers health, well-being, exercise, life issues and advocacy for amputees and their families. Stories showcase amputees living and thriving with limb loss and profile Amputee Coalition programs and services.

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Doctors must compile detailed notes about their patient's activities in order to support payment for the prosthetic device that meets the patient's medical necessity.



## The Importance of Advocating for Yourself With Your Medical Team

by Dan Ignaszewski

**W**orking with your medical team and advocating for yourself is now more vital than ever before. Many of you may be aware that Medicare has been instituting controls and oversights over the past few years on prosthetic offices for the spending and allocation of prosthetic devices, specifically lower-limb prosthetics, over the past couple of years.

Medicare has instituted requirements to ensure that prosthetists have to provide the device that is consistent with the prescribing physician's medical records. Doctors must compile detailed notes about their patient's activities in order to support payment for the prosthetic device that meets the patient's medical necessity. Because of this, it is essential that you advocate for yourself with your doctor and the rest of your medical team.

In order to justify payment, you must tell your doctor about yourself and your daily activities. Talk to them about where you live, how many stairs you have in your home or at work, if you mow the lawn or have other household responsibilities. Let them know how many steps you take with something like a pedometer or if you regularly walk up stairs or over uneven ground. Patients must advocate for themselves with objective information that helps to paint a picture for your medical team about



what your daily activities consist of, how active you are, and what kind of mobility you may have had before your amputation, and what level of mobility you're capable of and need after your amputation.

## Make sure that you're standing up for yourself!

You're the one who knows what your daily activities consist of. Make sure that your physician is putting those activities in your medical record to justify coverage for a prosthetic device that meets your needs. Then, continue to work with your prosthetist, physician and rehab team to reach your goals.

While Medicare has instituted many of these requirements for medical records, private payers are quick to adopt similar approaches, and even if you have private insurance, the need to justify your activities to receive the most appropriate medically necessary device could wind up being scrutinized more closely.


## With all of that in mind, what can you do?

Make sure not to get frustrated, and always be polite. You're more likely to get people to respond in a positive way if you're polite and respectful. Everyone has a job to do and most people are trying to do their jobs in the best way they can. Be patient and work with your medical team and insurance company to rectify any situations that might arise in an amicable way. You're obviously going to be passionate and invested in getting the coverage you're entitled to, and you can be firm and direct, but sometimes the first person you talk to may not be able to take care of everything that you need. If that's the case, politely ask for a supervisor or someone else who can help you through the process.

Make sure that your physician is taking appropriate notes in your medical record. If you need to, ask if you can see a copy of what they've put down; if you feel that it doesn't fully encompass everything you discussed, let them know that you need them to include that information so that your prosthetist can fit you for the device that best meets your needs.

As a patient and consumer, you have the ability to make sure you're getting what you need. Sometimes, though, you need to be more vocal and direct with those who can help to ensure you get it. Advocating for yourself in these situations with your medical team and insurance company will help to make sure your needs are met.



If you'd like more information about how to advocate for yourself, or for the broader limb loss community, ask your prosthetist for a copy of the Amputee Coalition's *Insurance Coverage and Reimbursement Guide: How to Be Your Own Advocate*. And, if you're going to the Amputee Coalition National Conference, be sure to check out our Advocacy 101 session on Saturday morning, July 24, in sunny Tucson, Arizona! 

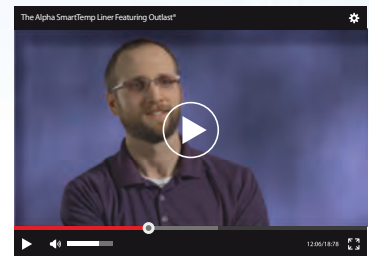
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*Chad, transtibial amputee for 9 years*



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## July

10

**First Volley Tennis Clinic**  
Bryson City, North Carolina  
opafonline.org

10 – 15

**Amputee Coalition Paddy Rossbach Youth Camp**  
camp@amputee-coalition.org

11

**First Swing Golf Clinic**  
Portland, Oregon  
opafonline.org

17

**USA Paraclimbing Nationals**  
Atlanta, Georgia  
adaptiveclimbinggroup.org

18

**Wheelchair Tennis Training**  
Boiling Springs, North Carolina  
opafonline.org

20

**Wheelchair Tennis Training**  
Greenville, South Carolina  
opafonline.org

23

**First Swim**  
Tucson, Arizona  
opafonline.org

23 – 25

**Amputee Coalition 2015 National Conference**  
Tucson, Arizona  
amputee-coalition.org

24

**First Swing Golf Clinic**  
Tucson, Arizona  
opafonline.org

**First Dance Clinic**  
Tucson, Arizona  
opafonline.org

25

**First Climb**  
Tucson, Arizona  
opafonline.org

**Ungala-Gala**  
San Diego, California  
cancerforcollege.org

## August

7

**NAGA First Swing**  
Kenilworth, New Jersey  
mheisey@ucnj.org

8

**First Cycle**  
Moline, Illinois  
opafonline.org

9 – 15

**National Health Center Week**  
healthcenterweek.org

14 – 16

**Back to Back NorCal**  
Sausalito, California  
challengedathletes.org

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**NAGA First Swing**  
Seattle, Washington  
Barbara.Bond.Howard@vmmc.org

**Ryan Fann Golf Tournament**  
Murfreesboro, Tennessee  
amputeebladerunners.com/events

**August 27 – September 5**

**Canada/New England Cruise**  
Bayonne, New Jersey  
amputee-coalition.org

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**NAGA First Swing**  
Wilmington, Delaware  
jhorne@independencepo.com



**Note:** Dates listed for events are subject to change. Check Amputee Coalition online calendar and listed Web sites for current information.

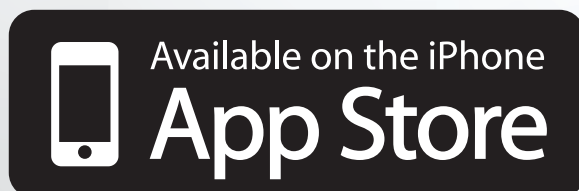
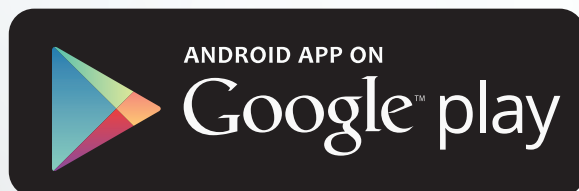


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# WHO IS YOUR AMPUTEE HERO?

AWESOME...

## TEACHING BY EXAMPLE

by Aryeh Lerner

When I was younger I felt that my mother, Maya Lerner, was more wonderful, capable and accomplished than any other mother I knew, and I only wanted to marry someone exactly like her. Although it's natural for sons to feel this way about their mothers, there was a big difference in my case – you see, my mother is missing an arm. And the girl of my dreams was just like my mother – with one arm.



and her arm needed to be amputated right below the shoulder. It took six surgeries and six months of hospitalization until she was well enough to go home.

My mother coped so well and was such a source of strength and support to others that at the age of 17 she was invited by President Clinton to speak about her experiences in the White House. From then on, she continued to speak publicly and inspire thousands of people.

My mother lost her arm when she was 15 years old. She was walking on the sidewalk when a car lost control and hit a lamp post. The lamp post collapsed on my mother, crushing and mangling her arm. She was flown by helicopter to Bellevue Hospital in New York for an emergency neurosurgery to attempt to reattach her arm. The surgery was not successful

But we, her children, are the biggest benefactors of her inspiration. My mother has seven children and manages our house “single-handedly.” Our house is full of good food and good cheer. Our doors are always open, with guests coming and going, often people we don’t even know. My mother is always busy giving, mostly to her family and often to others – cooking for sick people, talking to those who need encouragement and just running a busy household with seven active kids (mostly boys), ages 2 to 16.

My mother taught her children, by personal example, many valuable lessons: Challenges can be overcome; happiness comes from within; attitude is the key; disability means DIScovering ABILITY.

My mother is my amputee hero. 🌀

### Who is your amputee hero, and why?

Whether they're an amputee or not, the special person who inspires you to live well with limb loss can be a relative, a friend or someone you've never met. We invite you to send us an article (350 words or less) for consideration to be included in *inMotion* ([editor@amputee-coalition.org](mailto:editor@amputee-coalition.org)).





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# AN AGENT OF CHANGE: *INMOTION* IS NOW AVAILABLE FOR FREE!



From its humble beginnings as a four-page newsletter in 1991, *inMotion* magazine has expanded in size and readership over the years and has been through many transitions – both in content and design.

Through it all, our goal has remained constant: to fulfill the Amputee Coalition's mission to "reach out to and empower people with limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention."

To support our mission, we want to reach more people with limb loss, to engage them in our programs and to provide valuable information about living well with limb loss. We believe that eliminating *inMotion*'s subscription fee will help us to achieve that goal. Therefore, *inMotion* is now available free of charge in both print and electronic format.

As always, we welcome and look forward to your feedback and suggestions. Please feel free to contact us at [editor@amputee-coalition.org](mailto:editor@amputee-coalition.org).

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This study is being conducted at the University of California (San Diego, California); Cleveland Clinic (Cleveland, Ohio); Walter Reed National Military Medical Center (Bethesda, Maryland); Veterans Affairs Palo Alto Medical Center (Palo Alto, California); and Naval Medical Center (San Diego, California).

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# SKILLS for Life 4

## Bilateral Upper-Limb Loss Workshop

by Dianne Farabi and Shawn Swanson Johnson

Skills for Life 4 will be held October 22-25 at the Houston Marriott at the Texas Medical Center, Houston, Texas. The event is sponsored by the U.S. Member Society of ISPO, in partnership with TIRR Memorial Hermann.

*The Skills for Life (SFL) workshop is a unique event devoted specifically to addressing issues faced by individuals with bilateral upper-limb loss.*

Since the first SFL workshop was held in 2002, the event averages between 25-50 bilateral upper-limb loss attendees, drawing in participants from the United States, Canada, Australia, Sweden, Germany and Austria. Hosted by TIRR Memorial Hermann and organized by the International Society for Prosthetics and Orthotics (USISPO), SFL 4 will include presentations by individuals living with bilateral upper-limb loss, therapists, prosthetists, physicians and others.

"Strong early interest indicates that the workshop will draw a large number of bilateral upper-limb loss individuals, their families and caregivers, as well as all the professionals represented by the various rehabilitation disciplines," says Shawn Johnson, OTR/L, USISPO board member and SFL committee chair.

"These individuals and their family members/caregivers face a very unique set of circumstances," Johnson adds. "Skills for Life allows everyone to meet in person and talk to others who may have gone through similar experiences and to share their 'tips and tricks,' adaptive equipment and life skills. Discussions and demonstrations range from general activities of daily living to driving and returning to work, as well as psychosocial aspects, such as grief, coping and acceptance."

### Workshop Keynote Speakers

The workshop will kick off with keynote speakers John Lawson and Cynthia Dusel-Bacon. Lawson is a television, film and commercial actor with past roles in *American Horror Story: Freak Show* and the long-running television crime dramas *Law and Order* and *Law and Order: SVU*.

Lawson became an amputee after an electrical accident caused nearly 30 percent of his body to be burned and both hands to be amputated. He is the first bilateral hand amputee to be trained and certified as a private pilot (Single-Engine Land plane) and the first and only bilateral hand amputee in the



For more information, contact USISPO at 614/659-0197 or visit [usispo.org/skills\\_for\\_life.asp](http://usispo.org/skills_for_life.asp).





world to be certified as a Professional Association of Diving Instructors (PADI) SCUBA instructor.

Dusel-Bacon is back for a return session with SFL. A research geologist with the U.S. Geological Survey Mineral Resources Program in Menlo Park, California, she survived a bear attack while on the job in an Alaska Wilderness Area in 1977.

Danielle Melton, MD, director of the amputee program at TIRR Memorial Hermann, will be presenting on various topics, including expected outcomes and pain management. Melton is a member of the SFL planning committee and is also a member of the Amputee Coalition's Scientific and Medical Advisory Council.

"I have several patients who attended the SFL workshops in Denver and mentioned how beneficial their experiences were," Melton says. "I am thrilled that TIRR Memorial Hermann generously signed on to be the Platinum sponsor. We are also happy to bring simultaneous Spanish translation for the first time this year."

Other sponsors include Ottobock, Motion Control, Fillauer, TOTO USA, Touch Bionics, Advanced Arm Dynamics, Baker Orthotics and Prosthetics, Handspring, Hanger Clinic, Mayo Clinic, TRS, Muilenburg Prosthetics, Texas Assistive Devices, Liberating Technologies, COAPT, Lake Prosthetics, ProsthetiKa and Amputee Services of America.

## Therapist and Prosthetist Workshops

Therapist and prosthetist workshops will be held before the main workshop on Thursday, October 22, and have been approved for continuing education credits by the American Occupational Therapy Association (AOTA) and the American Board for Certification in Orthotics, Prosthetics & Pedorthics (ABCOP).

The concept for the SFL workshop was developed by Robert "Skip" Meier III, MD, director of Amputee Services of America in Denver, Colorado, and Diane Atkins, OTR/L, an occupational therapy consultant in Houston, Texas. The first three SFL workshops were held in Denver, Colorado. This is the second SFL event to be organized by USISPO and the first SFL event to be held in Houston, Texas. 🌀

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This study is being conducted at the University of California (San Diego, California); Cleveland Clinic (Cleveland, Ohio); Walter Reed National Military Medical Center (Bethesda, Maryland); Veterans Affairs Palo Alto Medical Center (Palo Alto, California); and Naval Medical Center (San Diego, California).

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# Family Man With a Motorcycle

by Leif Nelson, DPT, ATP, CSCS

**I**n late November 2008, Jose Arroyo was driving his motorcycle on a weathered highway near his home in Puerto Rico. As he switched lanes, a combination of loose gravel and uneven terrain caused Arroyo to skid and lose control of his bike, slamming his left leg into the metal divider. That was the moment he lost his leg.

Now 38, Arroyo describes himself as “a normal guy. I’m a father of three kids, and I try to live life to the fullest.” He credits his family with giving him the motivation in the difficult initial rehabilitation process. Healing from his amputation was slow, as his residual limb was full of debris.

The time it took to heal kept Arroyo away from working as a quality specialist with a pharmaceutical company.

That’s when he set his first goal: to refuse to let anything stop him from taking care of his family. He was never comfortable settling into the role reversal that often occurs after catastrophic injury.

After his residual limb healed, Arroyo was able to make rapid gains with the help of his rehabilitation team at VA’s Caribbean Healthcare System in San Juan, Puerto Rico. “After my first appointment I was outfitted with a wheelchair and crutches until I received my prosthesis. I was able to begin regaining my independence,” he says.

Dr. Marilyn Rodriguez-Perez, amputation rehabilitation coordinator, has been Arroyo’s physical therapist since he first came to VA. Dr. Rodriguez-Perez has more than 28 years of military experience, having served in the U.S. Army, U.S. Army Reserve, and now in the U.S. Army Individual Ready Reserve. She describes her experience with Arroyo as a learning process for them both. They truly worked together – first, to learn the capabilities of the available prosthetic knee technologies, and then in training to gain the skills to use the knee to its full capacity. Dr. Rodriguez-Perez describes Arroyo as “intelligent and an extremely quick learner. He achieves every goal he sets for himself.” He was quickly able to walk without a crutch or cane, and Arroyo was Dr. Rodriguez-Perez’s first patient to master ascending stairs step-over-step.



Photos from left to right:

Arroyo now uses hand controls when riding his motorcycle.

Arroyo in his UTV about to get muddy.

Arroyo rappelling from a tree in Puerto Rico.

Arroyo can negotiate stairs step over step



His next goal was to stay active in the Puerto Rico Army National Guard. Arroyo previously served a full yearlong tour in Iraq in 2005, and even with an amputation above the knee, he set the goal to serve a full 20 years. He has had multiple roles during his tenure in the armed forces, including X-ray technician and medic, and has attained the rank of sergeant. In order to stay on active duty, Arroyo had to pass the Alternate Aerobic Events Army Physical Fitness Test. For this, he trained at the VA and on his own, and he is now looking at 2015 being his 20th year of service. He is now saying, "I think I want to serve 30 years."

Arroyo also finds time to serve his fellow veterans as a certified peer visitor. This role has allowed Arroyo and Dr. Rodriguez-Perez to continue to work together, now as colleagues on the Amputation Care Team.

Arroyo has pushed himself to return to all that he enjoys in life. He still rides a motorcycle. Since he can no longer control the shifter with his left foot, he now rides using hand controls such as those available on the Can-Am Spider. He also enjoys getting dirty in his utility task vehicle; "It's a weeklong commitment," he explains. "You ride for one day and then clean mud out of it for the rest of the week."

Born and raised in the countryside, Arroyo has maintained a true enthusiasm for the outdoors. He fills his few free moments volunteering with the Boy Scouts, taking his son rappelling, and on other outdoor adventures that allow them to push their limits. 🌀



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# Smashing

by Karen Henry

**P**ost-amputation care doesn't stop once you walk out your prosthetist's door – it's a lifelong journey. To get the best possible prosthetic outcome, your primary care physician, your prosthetist and your physical therapist need to communicate with one another – and you – about your care.

“Initially, being able to have good communication can make a huge difference in how you move forward,” says Jeffrey Cain, MD. “It influences how soon you can start to walk because that's where the intersection of wound care, residual limb care and technology meet.” Cain is a family physician in Denver, Colorado, and a bilateral amputee. He lost his left leg below the knee 19 years ago when the single-engine plane he was flying crashed. He elected to have his right leg amputated below the knee six years later due to damage he sustained in the accident.

Cain says the need for good communication shouldn't stop after you've received your prosthesis. “Your prosthetist might notice a bone spur, skin change, or a problem with your residual limb that's medical in nature.

“Later on,” he continues, “the biggest challenge is making certain that your treating physician, probably your primary care physician, understands the details of the prosthesis that your prosthetist is recommending so he or she can help you in your quest for the most appropriate technology from your insurance company.”

Encouraging communication among your healthcare providers isn't a radically innovative concept, but achieving it can be frustratingly elusive, regardless of medical condition.

Pete Seaman, CP, CTP, a prosthetist at Independence Prosthetics-Orthotics in Newark, Delaware, says the majority of healthcare and allied healthcare providers work in silos.

There are exceptions, of course – hospitals and physician groups that house multiple specialties under one roof – but despite being home to some of the most advanced medical technology in the world, “U.S. physicians face particular difficulties receiving timely information [and] coordinating care,” according to The Commonwealth Fund's *Mirror, Mirror on the Wall, 2014 Update: How the U.S. Health Care System Compares Internationally*.<sup>1</sup> As a result, the U.S. “ranks behind most countries on many measures of health outcomes, quality and efficiency.”

Your healthcare providers may work in silos, but that doesn't mean you can't break them down.



# Silos

## → Lean on Your Prosthetist

The first 12 to 24 months of being an amputee and a prosthesis user are critical in terms of prosthetic success. If your amputation is new or recent, don't be afraid to lean on your prosthetist.

"The exact prosthetic pieces that your prosthetist and you decide are best for you are ordered by your treating physician, who probably does not order many prosthetics," Cain explains. "Your prosthetist understands the need to talk to the treating physician in a way that helps them write your prosthetic prescription accurately. The prosthetist is the one who's most familiar with the technology that you're using, so they can help you."

Prosthetist Matt Bulow, CP, CEO at Bulow Orthotic and Prosthetic Solutions in Nashville, Tennessee, and a below-knee amputee, says that when an amputee without a specific prosthetic plan is referred to him, he starts with a detailed conversation about the patient's goals and physical needs. "This helps us prioritize what is most important," he says. "Together, we come up with the best personal plan for them."

"Next, the amputee revisits their physician, who hears our proposed plan and modifies it as needed based on their knowledge of the patient," he continues. "Finally, the physician writes a detailed prescription for the best course of action for the patient."



*Matt Bulow with young patient.*



## → Be the Cornerstone

You are the common thread that connects all of your healthcare providers, so it is incumbent upon you to make sure your providers are all on the same page.

"I think it's important to have communication between your healthcare providers," says Ashly Ash of Lancaster, Pennsylvania, who lost her right leg at the hip due to bone cancer when she was four years old. "For long-term care, you need them to talk to each other so they can recommend things by looking at the whole picture because an amputee is going to be different than an able-bodied person."

That being said, communication among healthcare providers "is virtually non-existent," she says. "So you have to become the cornerstone."

For Ash, being the cornerstone means educating herself about prosthetic technology and passing that information along to her physicians. "Whether it's giving them a copy of a magazine, telling them about an amputee conference that's coming up, I do whatever I can to push them to look at the bigger picture."

<sup>1</sup>K. Davis, K. Stremikis, C. Schoen, and D. Squires, *Mirror, Mirror on the Wall, 2014 Update: How the U.S. Health Care System Compares Internationally*, The Commonwealth Fund, June 2014.



## ➔ Educate Your Providers

In the grand scheme of a physician's practice, prosthetics are infrequently prescribed, even among orthopedic surgeons, so it's rare to find a physician with expertise on amputation. Understand and accept that there are some things your physicians simply don't know.

For example, most physicians and surgeons don't know about K-levels or how to determine a K-level for an amputee. Because many insurance companies cover different prosthetic components based on K-level, helping your physician understand these benchmarks is critical.

"If you're at the K2 level but you'd like to advance to the K3 level, you'll need to talk to your doctor about what you need to do to get there," Ash says. "The more your providers are educated, the more they can help you."



## ➔ Talk About Your Amputation

Even if you're not having issues with your prosthesis or residual limb, make a point to talk about your amputation during every visit with your primary care physician. "Go to your physician every six months," Seaman advises. "When you're there, talk about the fact that you're an amputee and about any issues you're having with your prosthesis. If you don't, it's not going to be brought up, and then it's not going to be put into your medical record, so when we need notes to support a socket replacement or a new foot, there's not going to be mention of anything to support this need."

This is particularly true for activity-specific prosthetic devices such as running and swimming legs. "It all boils down to medical necessity," Seaman says. If you used to swim five miles a day or run a 5K every weekend before your amputation and can no longer do so without an activity-specific prosthesis, tell your primary care physician. "If you can set that precedent and build your story with your doctor, then maybe you can get something approved by your insurance."



## ➔ Ask Questions and Communicate Clearly

"If something isn't working right, ask a question," Cain says. "Communicate your needs clearly, and when you're frustrated by a challenge, express that in terms of the problem with the function of the prosthesis. Ask for help in a way that facilitates a solution, not in a way that challenges the relationship."

To facilitate this type of open dialogue, choose providers you feel comfortable with and who feel comfortable with you. "My mom used to say that you marry your prosthetic provider," Ash says. "You really do. They are going to know you better than most people ever will, so you need to have a relationship where, like a marriage, you can communicate and be open and honest."

Bulow agrees. "It is very important for the amputee to find a prosthetist who is humble and engaged enough to take the time to listen to priorities and concerns and address problems as they come up," he says. "Honest and thorough communication between prosthetist and amputee is the key to good care, because issues will arise."

## Learn from the Experts on How to Reach Your Goal

This 96-page comprehensive resource provides information about how prosthetics are covered, dealing with appeals and denials, and how to advocate for yourself.

For ordering information, call 888/267-5669 or order at [amputee-coalition.org/order-guide](http://amputee-coalition.org/order-guide)





## ➔ Don't Wait for a Wake-Up Call

Often, the ones who need coordinated care the most – those with chronic health conditions, such as vascular disease and diabetes – are the least likely to get it and, unfortunately, the least likely to advocate for it. “It takes the individual,” Seaman says. “Some spark needs to happen to make them want to put their prosthesis on and not sit in a wheelchair every day.”

Ash understands this all too well. She stopped wearing her prosthesis for five years in her early 20s. “It’s a lot of responsibility to advocate for yourself, to be the cornerstone, to be the one who talks to the insurance provider and then talks to your prosthetist, and then talks to your physician,” she says. “I had had enough.”

When her physician pointed out how using crutches every day was breaking down her shoulders and arms to the point where she would eventually have to use a wheelchair full-time, “that scared me,” she recalls. “It spurred me to the point of deciding that I’m going to assume responsibility, be an adult, and look out for myself.”

## ➔ Don't Give Up

“It’s really important to have good healthcare and keep your back aligned. In order to do that, you need legs, you need arms,” Ash emphasizes.

“Don’t be afraid to speak up for what’s important to you for your health, whether it’s a prosthesis or something else,” Cain adds. “That’s one of my messages as a physician. And as an amputee, ironically, it’s the same thing.” 🌀



Jeff Cain



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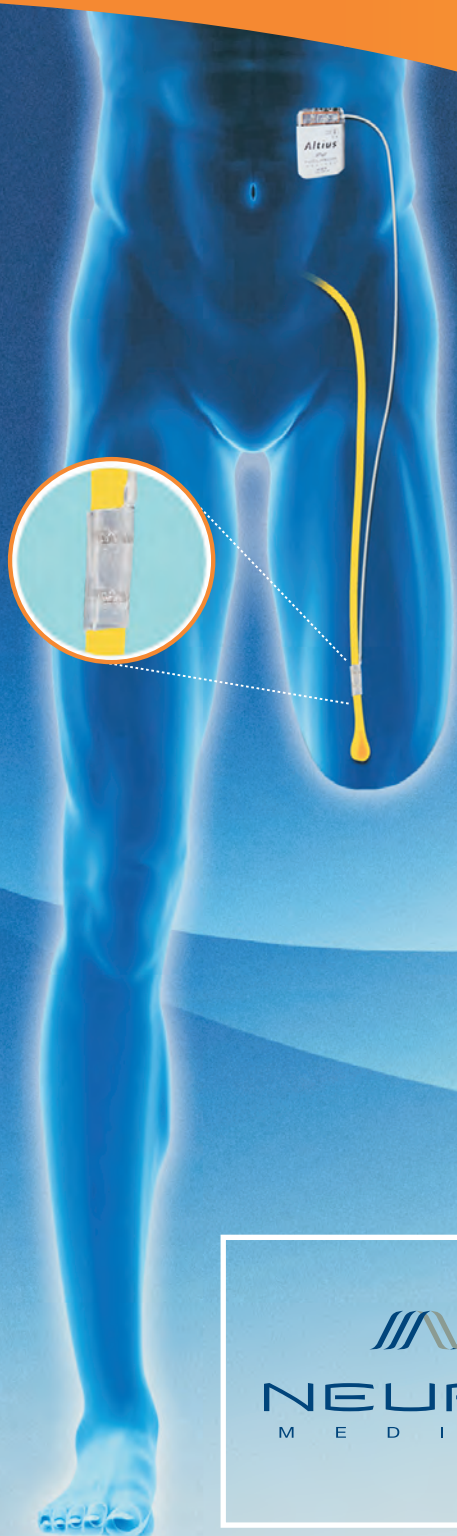
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# Choosing a Change for the Better

by Tony Meehan



In 2010, I snowboarded into a tree. In exchange for finding that tree so quickly, I received a severe pilon fracture at the surface of my right ankle joint and, perhaps worse, a badly bruised snowboarding ego.

For the first 28 years of my life I rarely thought about that ankle. I spent the next three and a half years thinking about it every day. With each reconstructive surgery, my ankle pain increased. I grew depressed, gained weight, and lost hope. Post-traumatic ankle arthritis can be a real jerk!



Life as an amputee has its challenges, but I am extremely happy with my decision. The amputee community is amazing and is waiting for you with open arms.

I was at a crossroads. My doctors suggested I accept my circumstances. Take the path of a lifetime of surgeries with diminishing returns. On June 14th, 2013, I chose another option. I amputated my right leg below the knee. I didn't do it myself (I found a guy that knows about these things). But I made the decision. For many, amputation isn't a choice. It's just something that happens. For me, it was a gift.

After a failed ankle distraction arthroplasty, my orthopedic surgeon and I agreed amputation was a viable option. I was healthy. I wasn't a smoker. I didn't have diabetes. A successful amputation could allow me to return to an active lifestyle. He told me, "Find a good vascular surgeon, but an even better prosthetist." It was the best advice I ever got.

When my wife and I speak with someone about amputation, we repeat his words. A great prosthetist is the difference that makes an amputation a good or bad idea. We met with amputees who live near us through the Amputee Coalition's Facebook page ([Facebook.com/AmputeeUSA](https://www.facebook.com/AmputeeUSA)). We asked about which surgeons and prosthetists to see or avoid.

We scheduled time to meet with prosthetists. We asked about experience with my insurance provider and payment options. Most prosthetists won't charge you until the final prosthesis is ready. My prosthetist's location was important. We spent several hours a week together creating a leg. But our relationship – our trust and communication with one another – was more important.

Like all relationships, work is involved. The first six months were the hardest. In that time, your leg changes shape and volume dramatically. You must learn a new language to discuss your leg and develop superhuman patience to deal with setbacks. It got easier with experience, but there were moments when a new test socket felt amazing in the clinic, only to feel terrible a few hours later at home.

I was overweight when I decided to have my amputation. My wife and I discovered how to choose and prepare healthy foods. It wasn't a diet – it was a permanent change. I made time with a physical therapist to find a comfortable





way to exercise and spent six months before my amputation getting and staying healthy. My wife's support was critical. Had she not taken it seriously, I would have failed.

Your prosthetist also has work to do. Is he or she willing to let you try out different feet before choosing one for your final prosthesis? How many test sockets will your prosthetist build before locking you into a final socket? Can you see your prosthetist over the weekend if something breaks?

Phantom pain was my biggest concern before my amputation. (I have it.) On rare occasions, it is extremely painful. But given the choice, I would take phantom pain over post-traumatic ankle arthritis. For me, the first few months following the amputation was the worst. Over time, the pain diminished. Now, it's mostly an occasional annoyance.

Some family, friends or doctors will tell you this is a bad idea. It's already a tough decision without naysayers! But keep in mind most people don't know what it's like to suffer from something like post-traumatic ankle arthritis. Many amputees don't have a choice.



Earlier this year, I snowboarded for the first time since my accident. To live a dream you've given up on is a joy I wish everyone could experience once in their lifetime. Life as an amputee has its challenges, but I am extremely happy with my decision. The amputee community is amazing and is waiting for you with open arms. There are a lot of us and we're all awesome. Talk to us. We're here to help! 🌀

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# The Long Road

## To an Active Life

by Mary Seelhoff

My son Andrew was diagnosed with vascular malformations (abnormal clusters of blood vessels occurring during fetal development) in his right leg at the age of seven. After 46 surgeries over nearly five years to relieve his painful and debilitating symptoms, at the age of 13 he made the brave decision to amputate his leg in hopes of improving his quality of life. Little did we know that the amputation itself was only the beginning of a long road navigating the prosthetics industry, insurance companies, and eventually Capitol Hill in our mission to get him back on his feet and living a full, active life again.

Five weeks after amputation, Andrew woke up pain-free for the first time in seven years. It was such an exciting time for our family! We thought, "So what comes next? The prosthetic socket and leg that would carry him back to being an active and healthy young man!" Andrew was so excited to see what his options were, knowing he would soon actually walk again for the first time in nearly six years.

Our hope went out the window at his first prosthetic appointment when Andrew brought five of his closest friends to help him choose his prosthesis. We were disappointed to find out in fact, he really had no options. The prosthetist showed Andrew the C-Leg, Genium and X3, but our insurance denied all of them, so none were really options. He would only be eligible for a mechanical leg. As for sockets – the key to a successful prosthetic solution, as we later learned the hard way – there was nothing to even look at other than what we all called "the Bucket."

I had no idea at that time the impact this lack of options would have on our son's level of function. It's reported that 59 percent of amputees receive little or no prosthetic information either before or immediately after their amputation (*Survey of Individuals Wearing Lower-Limb Prostheses*, [oandp.org/jpo/library/2010\\_04\\_257.asp](http://oandp.org/jpo/library/2010_04_257.asp)), and we were now experiencing the results firsthand. There is so much focus in the industry on the distal components of the prosthesis, we hadn't even considered that the passive function and

**Seeing the improvement in Andrew's outcome because of a technology that our insurance would not cover has shown how much work needs to be done to develop and provide access to new technologies to improve the quality of life for amputees.**

Photos from left to right:

Tim, Mary and Andrew Seelhoff

Andrew meets Majority House Speaker Kevin McCarthy





comfort of the actual interface with his residual limb, the socket, would be the limiting factor in Andrew achieving the quality outcome we'd been hoping for.

We tried to make Andrew's experience with this process as fun and positive as we could. Before his leg was ordered, we attended the premiere for *Dolphin Tale 2* and took one of Andrew's T-shirts with his school mascot on it. All of the actors signed his shirt, which he then used for his first socket design. It was beautiful, and everyone commented on how cool it was.

The anticipation of putting it on was the most exciting day of our lives; the day we thought we would never see, the day Andrew would take his first steps! We knew it would be difficult; however, we didn't anticipate how uncomfortable the socket would feel. I can't express our disappointment over the following months. I thought my son would wake up excited to put his leg on every day, but this wasn't the case. At one point, I broke down, asking why he didn't want to wear his leg, after everything we'd been through to fight for this.

Everything changed when we were introduced to LIM Innovations, who had just launched a new adjustable Infinite Socket. After discussing Andrew's challenges with their team, they agreed to fit Andrew with the socket. I will never forget how he instantly lit up the first time he put it on. Andrew was given a loaner C-Leg for the interim until we are able to either raise funds/or receive another donated leg.

The combination of the LIM socket and the C-Leg has changed everything. He's gone from bedridden to walking again, just attended the Endeavor Games and is setting goals about which sports he wants to participate in next year, and he can keep up with his friends.

Our experience illustrates why we're now lobbying on Capitol Hill to drive access to better care, research and prosthetic development for children and insurance fairness for all amputees. Seeing the improvement in Andrew's outcome because of a technology that our insurance would not cover has shown how much work needs to be done to develop and provide access to new technologies to improve the quality of life for amputees. 🌀

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**I**t's a familiar scene: gobs of plaster haphazardly arranged on the floor at our feet; measuring tape and tools; a bucket of cloudy water. We are familiar with the process of having a cast taken for a test socket. Rarely though, do we see what happens to the plaster cast after it is removed.

From laced leather sheaths attached to wooden appendages to prostheses made of carbon fiber and titanium, the manufacturing process involved in producing a prosthetic limb has greatly evolved from the coarse assemblies of long ago. And although computer-aided design (CAD) software has been leading the way in applied prosthetic technology, we should not discount the tried and true methods of production that continue to take place behind the curtain.

# Behind



**1** | The prosthetist marks an amputee's individual characteristics onto a sock-covered liner.



**2** | Plaster-infused gauze, known as plaster bandage, is wrapped around the residual limb, and carefully molded to its indentations and shape.



**3** | After the plaster cast has hardened, it is removed and becomes the negative model.

by Elizabeth Bokfi



## Taking the Cast

No two residual limbs are alike. Each amputee has residual limb characteristics that are unique. When the prosthetist takes a cast of your limb, it is a true representation of all of your individual nooks, crannies and bone structure.

After a single-ply prosthetic sock is applied over the gelatin liner, your prosthetist marks the locations of bone, alignments, ligaments and patellar shelf. A roll of plaster-infused gauze is then moistened and wrapped around the residual limb, carefully molded to your limb's indentations and lines. The ink from the markings will transfer onto the inside of this hardened cast, which is known as the negative model.

## Creating a Positive Model

The negative model is then filled with plaster, which hardens and becomes a positive model. The positive model is then used to create the clear, temporary test socket that precedes a finished, flesh-toned laminated socket.

## The "Clear" Socket

Transparent thermoplastic material is heated and stretched over the positive model, and pulled into shape by vacuum. It is lightweight and easy to heat and shape during the patient's fitting process. The pylon and foot components are then added; it is during this stage that a patient will wear the clear test socket home, performing daily living activities to determine where adjustments

# The Curtain



**4** | This positive model for an AK amputee was created after filling the negative model with plaster.



**5** | Thermoplastic material is heated in a 380-degree oven to make it pliable.



**7** | After multiple fittings and adjustments of the clear test socket, or reworking the positive model to create a comfortable fit, the final socket is made.



**6** | Heated thermoplastic material is draped over the positive model, creating a vacuum as it conforms to the model; this will become the first-fit, test socket.



**8** | The patient may request a fashionable pattern laminated onto the socket.



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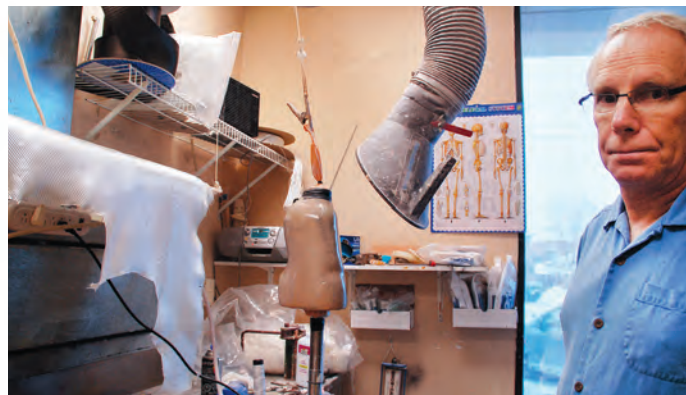
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need to be made. Sometimes, heating the socket to reshape it yields the desired fit; at other times, it may be necessary to make adjustments to the actual positive model and create a completely new test socket.

Once a comfortable fit is achieved on the test socket, a permanent socket is created from carbon fiber. Some patients opt to cover the pylon in dense foam, shaped to resemble a real leg. There are many variables, depending on whether or not the patient's amputation is below-knee (BK) or above-knee (AK), and as many as three sets of hands may be involved in the making of the prosthesis, from start to finish.

## So how long does it take to make an artificial limb?

"Timeframes vary according to individual circumstances," explains Jim Low, BSc, CP, of Prosthetics Orthotics Barrie, Barrie, Ontario. "The point at which the process is started directly depends upon the degree and speed at which a patient heals."

"If in-hospital, from cast to fit is less than a week," Low adds. "One guy, from amputation until the day he walked out of the hospital with two canes, was three weeks. But he healed fast – no incision issues, and he worked really hard. But that's extraordinary – most people get sent home to shape and heal. Normally, we start the fitting process anywhere between four to eight weeks after surgery."

According to Low, between their Barrie and Owen Sound, Ontario clinics, approximately 70 percent of their patients are BK, 20 percent AK, and the remaining 10 percent include upper-limb and partial foot amputations, and knee disarticulations. Viewing the number of orthotics and positive models that line the shelves behind the curtain, it's somehow easier to accept the seemingly long process. One thing is for sure – the men and women serving this select group of patients are dedicated to patient care and comfort, working many hours to provide this specialized form of healthcare. According to Low, working with new amputees and getting them up on their legs for the first time is the most exciting and personally rewarding part of what he does – in **front** of the curtain. 🌀





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# "Taxiderm" Your Flats & Other Womanly Amputee Hacks

I believe that when something as traumatic as losing a limb happens to you, your brain enters protection-survival mode. This protection-survival mode can present itself in many different forms. Back in 2007, for me it manifested into bike trips to the grocery store, residual limb wrapped in a Harley bandana, with a four-footed walker thrown into my sidecar.

Once inside, I transformed from walker to complimentary-wheelchair warrior, irritated as apples rolled across the floor from their out-of-reach bin. In *my* mind, I was spared from a trip to the glue factory. I was alive, with an in-your-face attitude that rivaled Dirty Harry's; however, I've since evolved from boldness to flying under the radar. Although society has matured in its attitude toward prosthetics, these days my personal preference is concealment. My quest to find ways to make it look real or disguise the transition from socket to leg is never-ending.

My prosthesis is the pin/lock type, with a Freedom Innovations Runway foot. The post is covered with carved foam to resemble the lower portion of a leg. For me, it has always been about trying to feel whole again, feeling feminine, and appearing attractive. Although some of the following tips may be useful to men, most of this article is directed at women.

## Travel

I never leave home without a shoehorn, a pair of comfortable walking shoes, my cane, and plenty of filler socks and gelatin liner pieces. I once had to walk through soft soil along a highway shoulder to the nearest house to call for help with my car. By that time, I was deep in my socket, the sweat had broken the liner's seal against my leg, and I had developed a pressure wound on the end of my residual limb. Spare prosthetic socks and a chunk of gelatin liner would have tightened my socket, reducing the movement that caused the pressure wound. Tough lesson – I was off my leg for a week afterward. (In a pinch, that wad of takeout napkins in your glove box can be folded and stuffed at the knee area to take up space and lift you out.)



by Elizabeth Bokfi

## Is romance in the air?

Here's a Like-Me-or-Leave-Me Now icebreaker/pick-up line:

***"I hope you're a leg man,  
because I've got about  
20 of 'em in my shed!"***



## Traveling south in the winter?

- Use your socket's space when packing! Roll your underwear, then stuff it inside the socket.
- Use your cotton prosthetic socks to hold jewelry; they also do a great job of cleaning your sunglasses.
- Frying in the sun? If your prosthesis has moving parts, you don't want to damage or ruin it by entering the water with it. To keep cool, I take a travel-size atomizer (available at drug stores) and spritz myself with water all afternoon.

## Shopping

Use the change room with the bench. Or ask for a chair. Or a delivery box. I've even used a stepladder for stability, especially when trying on pants.

- **Pants:** The prosthetic leg goes in first, and use a shoehorn to get your shoes back on. If the pants are flared, skip a step: Leave your shoes on, and by bunching the pant leg up in your hands, you can stick your foot through the hole instead of the entire length of pant leg. If you have an adjustable ankle, adjust it as far as you can to "point" your toes. This also helps to get through the legs of a pair of skinny jeans.
- **Shoehorn substitutes:** Plastic "flip tab" garment hangers; large soup spoon; solid butter knife; wooden kindling; lip gloss/mascara wand.
- **Lip gloss also doubles as emergency skin cream.** Skin breakdown can happen anywhere, without notice, and for unknown reasons. I simply load up the lip gloss wand and apply it where it hurts. It gets me by until I get home.

## Fashion

Everything's over-the-knee now! Boots, socks, even garters underneath slinky pants. Sexy and functional. Sometimes if I know I'll be dancing and sweating, I clip the garter belt to both the stocking *and* liner to hold it on, should the seal break.

Ever notice how even though your prosthetic foot is smaller than your real one, it's harder to get into footwear? Reduce difficulty in pulling on shoes by cutting off the foot part of your sock in that shoe. If wearing knee socks over skinny jeans, cut off the foot part of the sock, and use the cuffed portion so it still looks as though you're wearing two socks. I call it The Cheater Sock.

I bought zippers for my favorite stretch boots and sewed them into the inside ankle. Risky, but worth the effort to salvage boots that were otherwise unwearable. I can now pull them on easily.

Use cotton single-ply socks, rolled into a ball, to "taxiderm" the toes of ballerina flats. This makes the prosthetic foot fit nice and tight, keeping the shoe from falling off.

Thong sandals can be kept on by tying a shoelace around the thong part, then around your "ankle."

If your prosthetic foot doesn't have a thong toe, a utility knife can quickly fix that. Just cut a narrow 'U' between the first and big toes. Applying Velcro to the bottom of the foot is another option.

## Random

Prostheses make great hooks! I've used mine to pull the bedroom door toward me so I can close it from the bed, and to push the bathroom door closed without getting up. I've also used the toe part to unlatch the hood on my vehicle; that discovery happened by accident, but I use it now when I top off the wiper fluid. On crutches – I've used my socket for carrying makeup, moisturizer, and dirty laundry.

**Got a pressure point?** Cut a hole into your prosthetic sock around a point of discomfort – similar in appearance to the corn pads you buy at the drugstore. 🌀

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by Chris Tate

## Getting Started With a Personal Trainer

Give your body the stimulus to grow, the rest to recover and the proper nutrition to thrive.



Personal trainers are certified to give instruction on exercise, physical fitness and overall well-being. The exercise plans they create don't have to include killer workouts or lifting the heaviest weights possible. The best way personal trainers can help their clients achieve their personal goals and live healthy, safe and productive lives is through education about quality movements, proper form and appropriate progression of exercises. These lessons will be beneficial even after the training sessions end. While there are a relatively small number of personal trainers who have specific expertise in working with amputees, good trainers are always looking to further their education so that they can better meet their client's expectations and goals.

### Choosing a Personal Trainer

Choosing the right trainer can make a big difference for amputees. Trainers should understand how to address and overcome perceived shortcomings and coach their clients to do things they thought they couldn't. Most people who have never worked out don't have a very good understanding of proper body mechanics or safe conditioning techniques. For amputees who are just starting out or just out of recovery, new hardware will feel foreign and take a lot of getting used to. This takes patience and persistence, so coaching should be thoughtful and appropriate for meeting short-term goals.





## Creating a Fitness Plan

Your physician can generally guide personal trainers down the fastest and smoothest path to recovery or meeting your fitness goals. Your personal trainer should be aware of what your physician thinks is the best current plan of action.

Ask your physician what kind of activities you can do and what you should avoid. Write everything down to ensure that all of your questions are answered and to help you relay necessary information to your personal trainer so that he or she can create a more personalized fitness plan for you.

## Follow the Rules

When your trainer teaches you a new skill, he or she should start with the foundational movements and set realistic expectations for how to progress. Breaking down and mastering each movement will make the skill easier to learn and help you achieve proper form. Your trainer should help you understand what muscles should be working and how to isolate their movement accordingly. Form deteriorates quickly with tired muscles, so planned rest is a good idea.

I hear people all the time complain that there are too many rules when learning proper form. These rules are in place to prevent bones, joints and muscles from sustaining injury. In addition to these foundational rules, a person with a disability or amputation may have even more guidelines to follow, so be patient. Stay in tune with your body and

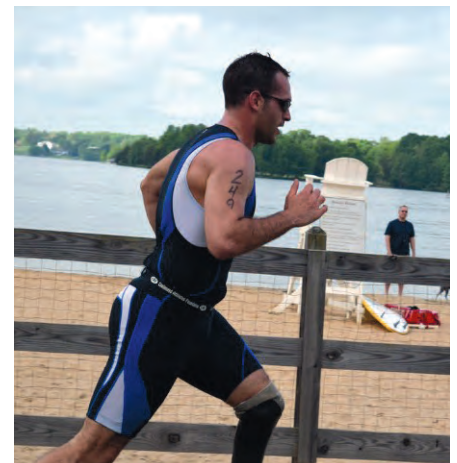
tell your personal trainer if you feel any pain. Pain is a good indicator of impending injury. A good trainer will adapt movements according to what your body is telling you.

## Take Precautions

In my personal experience as a trainer and as an amputee, below-knee amputees shouldn't perform movements that isolate the knee on their amputated side. The leverage from a leg curl or leg extension puts stress on the end of the residual tibia/fibula that can be painful inside the socket. Remember that your prosthesis is rated to sustain a certain weight, so heavy squats or dead lifts could damage your device. Do some research about your prosthesis and the equipment you are using, and ask a lot of questions.

## Never Settle

Go into your personal training experience with a dedication to a healthy lifestyle. Be an active participant in your training and choose goals that personally motivate you. Give your body the stimulus to grow, the rest to recover and the proper nutrition to thrive. Don't settle for good enough. If your trainer isn't meeting your needs, don't be afraid to make a change or get a second opinion. There are plenty of trainers out there who may be better suited to your individual needs. 🔄



## Related Resources

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your  
dream

# Follow Your Dream

by John Jones

I lost my left leg above the knee in March 2006 and was walking by May. My prosthetist had me in a suction suspension system with a seal ring attached to the liner near the bottom of the socket. I got by – it was the best technology of the time. But the seal was too low, putting undue stress on the end of my residual limb, and the socket would get loose due to limb volume changes during the day. It never felt like it was part of me.

In early 2007, a friend pointed me toward WillowWood to apply to be a test patient. I was accepted into their program and fitted with their best technology. It was a suction suspension system that used the liner reflected over the socket brim to create the suction. The socket and system were comfortable. My entire limb was now under suction and the prosthesis felt more like a part of me. The only problem was that with the liner reflected over the hard edge of the socket, I would quickly get holes in the liner and the suction would fail.

In April 2007, I responded to a call from a customer who needed some electrical work done on an outside light at a mall. I set up a ladder to check the light. While climbing the ladder, my prosthetic foot caught on a rung, pulling my leg loose. There I was, at the top of a 10-foot ladder with my leg dangling in my pant leg. The lunch crowd must have been in total shock because no one offered to help or even looked at me. Gripping the ladder tightly, I carefully hopped down one step at a time. I dropped my pants with as much dignity as possible, and put my leg back on – there *had* to be a better way.

What I needed was a seal, protected inside the socket, near the top of the socket. It also needed to have a sealing area that would make it nearly impossible to fail. This need would be achieved by attaching a sealing sleeve to the inner soft brim of my socket. I tried different items like rubber inner tube-type materials, but they were too stiff. My wife suggested the sleeve of a latex glove – and the seal was born. I took pictures of the seal system I had made and sent them to WillowWood. I was asked to come in the next day.

The development of the seal was a hot item at first but then became cold until April 2012, when WillowWood received a VA grant to develop a better, more comfortable transfemoral seal system. My system was not the only one





# SUCCESS

## THROUGH GREAT RESOURCES

WillowWood One cutaway socket demonstrates how the parts of the system work together.




Photo provided by WillowWood

that was being considered early on. There were a few other ideas being tried but they couldn't fill all the needs that a transfemoral amputee requires. One system that I was testing was working well in the lab, so I wore it home. When I arrived, I found that my son had left a bike in the driveway so I got out of my truck to move the bike. My steps were with purpose because I was a little angry and my leg just flew off. Needless to say, that got my son off the hook.

I worked on the system over the next couple of years with WillowWood's researchers, engineers, clinicians and fellow test patients, tweaking the design and materials until the team achieved an ideal solution: the addition of a socket-mounted vacuum pump. The system was fit to over 40 clinical test patients, using an update to my brim seal concept and a new temperature control liner. The overwhelming response to the system was a resounding "Wow." Test patients commented that they could put the system on in the morning and no longer needed to adjust their sockets during the day due to volume changes or rotation. They were amazed that they could stand up, sit down, walk, run and ride a bicycle with no worries of seal failure.

My journey through this process has been one that I won't forget. There were emotional ups and downs. Meeting amputees who have this new transfemoral vacuum system and hearing their stories of how it has changed their lives have impacted me in ways I can't describe. What started as a simple idea to make my life better will now benefit amputees around the world.

Years ago, an amputee told me, "This is the way it is; get used to it." I refused to accept that, and here I am today. My advice is: Your ideas and dreams are the stepping stones to the future; don't keep them to yourself. 

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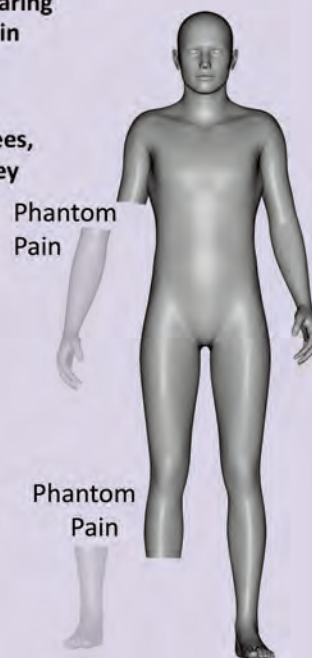
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