March | April 2015

in motion

The Living Well With Limb Loss Magazine

Weighing Your Options

Want to Become a Paralympian?
P.A.C.E. Yourself

How to Find the Right Prosthetist for You
and Knowing When It's Time to Look for a New One

amputee coalition™

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I AM FEARLESS	I AM STRONG	I AM DYNAMIC	

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Choices

Something to Live for

Bill Dupes, Editor-in-Chief

We all like to have choices. Being able to decide where we live and work, what we eat and how we spend our leisure time all enhance our quality of life.

Having a disability doesn't diminish the desire for choice. If anything, the need becomes stronger.

The choices we make in our lives, and those that are made for us, shape our individuality. Independence gives us something to live for. Our sense of accomplishment and self-esteem are significantly impacted by dependence on others, whether real or imagined.

Independence matters to us because it is part of being a contributing member of a family, community and society. It matters because it is how we exert power and influence over our world and our bodies. Without some degree of independence we cannot express our individuality, establish our identity or accomplish any goals.

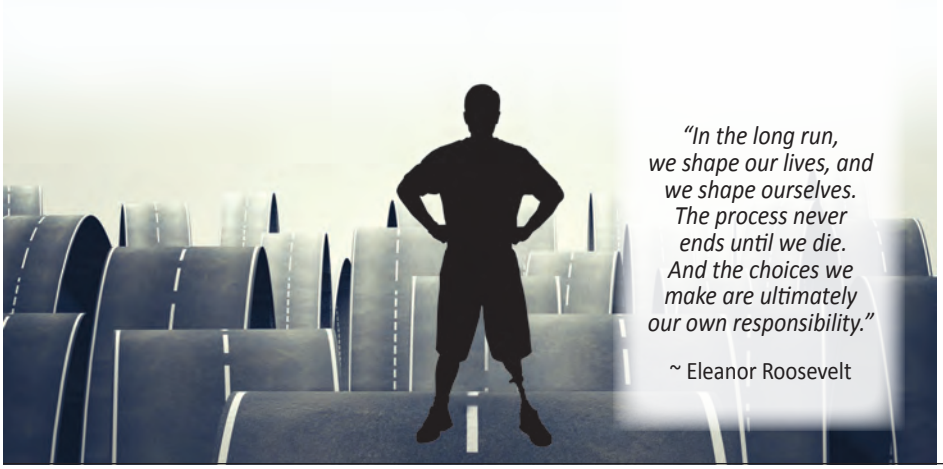
But the issue is more than simply *being* independent, with the freedom to make our own choices. We want society to recognize the fact as well.

Have you ever gone out to eat and had the waiter talk over you to someone else to ask what *you* wanted? Has anyone ever looked at you like you don't belong on the same planet as them? Or rolled their eyes and sighed loudly because you weren't moving fast enough? If so, then you understand that being independent proves to you – and to others – that your life matters. That you are someone who deserves the same things that they do. That you want the same things out of life that they do, and that you can achieve them – even if you may have to go about it in a different way.

While the bewildering variety of choices to make can be overwhelming, there are many people and organizations that can help guide you along the path to recovery or improving your quality of life.

The Amputee Coalition is the leading national nonprofit organization for people living with limb loss and limb difference. From insurance access to affordable prosthetic care, greater acceptance and understanding of the limb loss community through Limb Loss Awareness Month, discrimination issues and fair travel for amputees, and research funding to continue advancements in prosthetic technology and patient care, the Amputee Coalition provides a voice on important issues that affect you.

For more information on surviving and thriving with limb loss, please contact the Amputee Coalition at 888/267-5669 or visit our Web site at amputee-coalition.org.



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.

To find a Hanger Clinic near you, call 1-877-4HANGER or visit HangerClinic.com.

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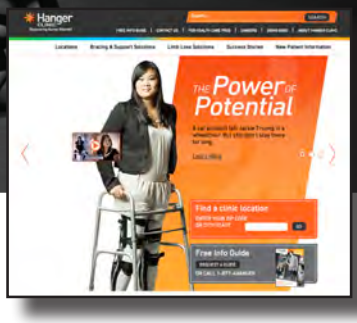

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in every issue

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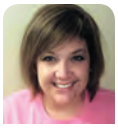

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inMotion
The Living Well With Limb Loss Magazine

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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What If You Don't Have a Choice?

by Dan Ignaszewski

The idea that people have a choice implies that they have options; unfortunately, many amputees still don't have the option of quality coverage for prosthetic devices. More Americans have health insurance now than ever before, but many still aren't receiving the care they need.

Insurance coverage for prosthetic devices has long been a major issue for amputees. Before the Affordable Care Act, insurance plans might have denied or dropped an amputee from their coverage because they were an amputee instead of covering the prosthetic device they needed. Other insurance plans would sometimes make amputees sign waivers that reduced or eliminated their insurance coverage. Still others would cap insurance coverage to ridiculous dollar limits ($1,500, $2,500, $5,000, etc.) and quantity limits (one limb per lifetime).

Since the Affordable Care Act has been implemented, while there are no longer risks of being denied or dropped from coverage, there are a number of states where amputees still face hurdles for insurance coverage of their prosthetic devices.

The Amputee Coalition worked with members of Congress and other organizations to try to ensure prosthetic devices would be covered as essential health benefits for all insurance plans, which did not materialize. Unfortunately, the ambiguity of the law and the latitude offered to states in determining their essential health benefits resulted in varying levels of coverage across all 50 states.

Prosthetic devices can cost thousands, if not tens of thousands of dollars, but they provide an unmatched level of mobility, independence and opportunity to the individuals who need them. It is vital that amputees are provided options and choices in both their insurance coverage and in the devices they need. What happens if someone qualifies for a device but they can't afford the out-of-pocket costs because they have a plan that's subject to an arbitrary cap? Their choices are limited to the device that they can afford (even if their "medical necessity" would require or provide a more advanced device).

The "one limb per lifetime" restriction is obviously a difficult obstacle for anyone who is missing more than one limb, as well as for children who grow out of their devices, or for anyone who

Contact us at 202/742-1885 or State@amputee-coalition.org to find out how **YOU** can get involved in your state.

simply needs to replace their device after years of wear and tear. This also eliminates patient choice because it forces people to stay in a device that doesn't fit or work properly, or worse, isn't safe anymore.

To rectify this, and to ensure amputees have choices in their insurance coverage and, ultimately, the types of prosthetic device(s) they need, the Amputee Coalition continues to work on several fronts, including through rule-making with the Affordable Care Act and the Insurance Fairness for Amputees Act.

For more information on the Limb Loss Awareness Month activities, visit amputee-coalition.org.

Rule-making is still occurring with the Affordable Care Act, including what provisions should be included as essential health benefits in the insurance marketplaces in future years. This provides us an opportunity to push for clarity from the Department of Health and Human Services (HHS) and the Centers for Medicare Services (CMS). Raising the issues of the arbitrary caps and restrictions with state insurance commissioners, state legislators and HHS and CMS could help to eliminate these unfair provisions that limit consumer and patient choices for the medical devices they need.

Additionally, the Amputee Coalition works in the 20 states that have passed the Insurance Fairness for Amputees Law to ensure the laws are being applied correctly, and we are working to correct issues that exist in any of those states. We also continue to work in the 30 states that do not currently have the Insurance Fairness for Amputees Law, and at the federal level to pass the laws and reach the ultimate goal of completely eliminating the arbitrary caps and restrictions that are placed on prosthetic care.

April is Limb Loss Awareness Month and provides a great opportunity to raise issues with legislators in your state. Check out the Amputee Coalition's new Web site for sample email and phone call scripts you can use to help return choice for not only yourself, but all people with limb loss.

SHOW YOUR METTLE
During Limb Loss Awareness Month

by Melinda Park

On April 27, 2013, the Amputee Coalition launched **SHOW YOUR METTLE DAY** as part of Limb Loss Awareness Month. **SHOW YOUR METTLE** was inspired by Peggy Chenoweth, who began a movement in 2011 to raise awareness about living with limb loss.

The concept is simple – to show your "mettle," the ability to cope well with difficulties or to face a demanding situation in a spirited and resilient way, by showing your "metal" prosthetic device or wheelchair. This year, **SHOW YOUR METTLE DAY** will be on Saturday, April 25.

We hope that all amputees will proudly wear and show their prosthetic devices on this day.

Our goal is to raise limb loss awareness and to dispel the myth that life ends with limb loss, when in fact millions of Americans have found a new normal, new resiliency and true mettle in living a life with limb loss. **SHOW YOUR METTLE** is a passionate, emotional, social initiative designed to empower amputees to take charge of their lives as well as band together and collectively make America start seeing amputees in everyday life.

This year, we are challenging the limb loss community to show their mettle throughout the month of April. We are encouraging all amputees (who feel comfortable) to post a photo of yourselves wearing your prosthesis, or just living your lives if you do not use an assistive device, throughout the month of April on our **SHOW YOUR METTLE** for Limb Loss Awareness Month event page on Facebook (Facebook.com/AmputeeUSA). We want to create a pictorial to

show the world that life does not end with the loss of a limb, and that the possibilities are limitless!

SHOW YOUR METTLE DAY CHALLENGE

Facebook.com/AmputeeUSA

The Amputee Coalition is hoping the community will consider holding fundraising events in April to benefit the Amputee Coalition and its mission to empower people affected by limb loss to achieve their full potential. Holding a fundraising event, like a walk/run/roll in your community, is not only a chance to raise limb loss awareness, but an opportunity to give back to the amputee community.

To close out Limb Loss Awareness Month, the Amputee Coalition will also be partnering with Össur and the Challenged Athletes Foundation to hold a Limb Loss Education Day/Mobility Clinic in Washington, D.C. on May 2, 2015. Information regarding the event can be found on our Web site at amputee-coalition.org/events-programs/limb-loss-education-day.

This April, be sure to Show Your Mettle in your own way. Limb Loss Awareness Month is all about raising awareness about the limb loss community and empowering people affected by limb loss to achieve their full potential. Together, with your help, we can make this April a powerful nationwide movement to raise limb loss awareness!

SHOW YOUR METTLE

and Give Back to the Amputee Community

STARTING YOUR OWN FUNDRAISER IS AS EASY AS 1, 2, 3

STEP ONE | Brainstorm a fundraiser that's right for you and support the Amputee Coalition in your own way. Organize a car wash, neighborhood garage sale, or a walk/run/roll. Almost anything you can think of can be a way to raise funds to help support the Amputee Coalition's programs and services.

STEP TWO | Set up a free, personal fundraising page on the Amputee Coalition's Crowdrise fundraising page (crowdrise.com/amputeecoalition) and customize your page with pictures and your story.

STEP THREE | Reach out to your friends, family and community and ask them to help raise limb loss awareness by sharing your fundraising page and supporting your fundraiser.

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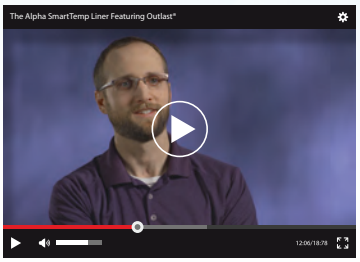
Chad, transtibial amputee for 9 years



To learn more, ask your prosthetist or visit the OhioWillowWood YouTube channel.

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March

NATIONAL KIDNEY MONTH
kidney.org

NATIONAL NUTRITION MONTH
eatright.org/nnm

SAVE YOUR VISION MONTH
aoafoundation.org/supporters/save-your-vision-month

12
World Kidney Day
worldkidneyday.org

15
Lake Nona Tour de Cure
Maitland, Florida
diabetes.org

21
First Swim, First Dive and First Paddle
Ypsilanti, Michigan
opfund.org

Phoenix Tour de Cure
Phoenix, Arizona
diabetes.org

24
American Diabetes Alert Day
diabetes.org/are-you-at-risk/alert-day

28
First Swim
Charlotte, North Carolina
opfund.org

Ironman 70.3 California
Oceanside, California
challengedathletes.org

29 – APRIL 3
National Disabled Veterans Winter Sports Clinic
wintersportsclinic.org

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

April

FOOT HEALTH AWARENESS MONTH
apma.org

LIMB LOSS AWARENESS MONTH
amputee-coalition.org/events-programs/limb-loss-awareness-month

NATIONAL CANCER CONTROL MONTH
cancer.org

NATIONAL MINORITY HEALTH MONTH
cdc.gov/minorityhealth/observances/MH.html

OCCUPATIONAL THERAPY MONTH
promoteot.org

11
First Cycle
Greenville, South Carolina
opfund.org

12 – 18
National Volunteer Week
pointsoflight.org/signature-events

13 – 16
AgrAbility National Training Workshop
agrability.org

18
McKeever's First Ride
Lawrenceville, Georgia
opfund.org

24
World Meningitis Day
comoonline.org

25
Show Your Mettle Day
showyourmettle.org

30
Pay It Forward Day
payitforwardday.com

May

2
Limb Loss Education Day/Mobility Clinic
Washington, D.C.
amputee-coalition.org

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Charlie Zawislak and Ashley Kuyweski

AWESOME...

WHO IS YOUR AMPUTEE HERO?

LEADING BY EXAMPLE

by Ashley Kuyweski

When I first met Charlie, it wasn't supposed to be love. It was supposed to be a chance meeting with a guy. On our first date, the minutes turned into hours and even then, it wasn't enough time! Three years later, we are living together and planning a future. The laughs never stop and the conversation never tires.

As an active 19-year-old, Charlie had the world in his hands – but fate is a fickle thing, and dealt him a different set of cards. He was in a car accident and had his left leg amputated below the knee. At this age, most people would give up – dreams of college dashed, their world completely shattered – but not Charlie.

Motivated by a little girl he met in rehab, he pushed himself every day and refused to give up. The bad days only meant he had to go harder the next. He proved doctors wrong by not only walking again, but walking without a cane or a crutch.

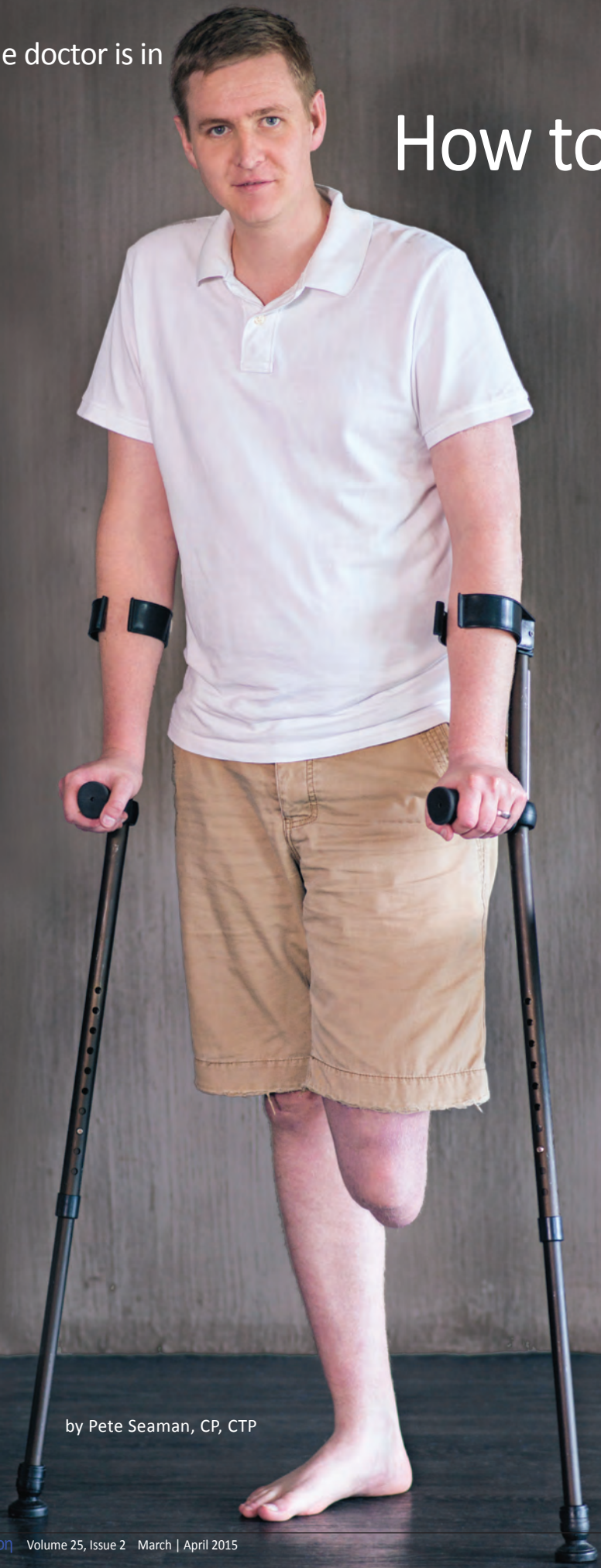
At 36, he has an active lifestyle and refuses to give up his two favorite hobbies: motorcycles and snowmobiles. He is even a board member for the Ohio State Snowmobile Association. Once a shy boy, he now leads small group meetings with new amputees and addresses their questions and concerns. He is their hope and proof that they can have fulfilling lives despite missing limbs and setbacks.

Charlie's missing limb does not define him; he carries a great sense of humor about it. Charlie was among eight amputees cast to be on the show *Inkmaster* for an amputation challenge where he got his residual limb tattooed. He was not ashamed to show millions of people he was an amputee. He came away with so much more than a tattoo. His love, determination and support are unwavering; every day I admire him more than the last. He is perfectly flawed and I cannot picture my life without him. He has taught me so much without knowing or teaching. This article is for Charlie – my rock, my amputee hero and my life!

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).

How to Find the Right



by Pete Seaman, CP, CTP

As a new amputee wanting to be fit with a prosthesis, you should seek out your first prosthetist preferably before your amputation occurs or soon afterward. On the other hand, as an experienced prosthetic user (for at least one year), reasons that might cause you to seek out a new prosthetist include: dissatisfaction with your current prosthetist for poor service, socket fit or prosthetic function or other reasons, or your prosthetist has moved away or the clinic has closed.

As a new amputee, you may have to rely almost entirely on others to help you find your first prosthetist. Potential referral sources include your surgeon, physical therapists or friends. The Internet can also provide useful guidance, as most prosthetic service providers have Web sites listing their office locations, service offerings, biographies of staff members and contact information. You should conduct face-to-face interviews with multiple prosthetists to see which ones impress you and if the "chemistry" between you is favorable. Eventually, you need to select a prosthetist, knowing that if the relationship does not work out that you can make a change later.

Every amputee presents unique circumstances, and some are easier to fit with a prosthesis than others. The easier you are to fit, the easier it will be for you to find a prosthetist you will be happy with. Conversely, if you present with an unusual

Prosthetist for You...

and knowing when it's time to look for a new one

situation, you may be more difficult to fit, leading to possible frustration for you and/or your prosthetist. You should know that no prosthetist can guarantee a positive prosthetic outcome. Instead, they can only commit to doing their best to successfully fit you with a prosthesis that meets your needs.

For the experienced prosthetic user, locating a new prosthetist should be easier than when you were a new amputee; after all, you should be a more informed patient, knowing what to expect from both your prosthesis and prosthetist. It is not unusual for longtime amputees to work with multiple prosthetists as the years pass. A survey of 50 prosthesis users that I conducted as a resident in 2009 indicated that, on average, amputees change prosthetic companies about every three years.

Resources available to experienced prosthetic users are similar to those for new amputees. They include: physicians, physical therapists, rehab staff, other amputees, friends, acquaintances and the Internet. A Web search for local prosthetists should generate multiple options, and you should begin by contacting those providers closest to you. Before you meet potential prosthetists working for different companies, you should generate a list of questions to ask each prosthetist to compare their experience in fitting amputees like you. Ask them what they would recommend to improve your current prosthetic situation, and if you chose to work with them, what steps would be involved going forward.

Your relationship with your prosthetist is a very important one; for it to be successful, you should enjoy interacting with him or her and your prosthetist needs to produce effective results (with your involvement, of course). It is possible that finding the ideal nice and effective prosthetist is easier said than done. If that is the case, I would recommend a successful prosthetic outcome with a prosthetist exhibiting a less than favorable "leg-side" manner over continuing a relationship with a "nice" prosthetist who cannot fit you successfully. Remember, you are in control of the amputee/prosthetist relationship, and only you can decide if you are pleased with your prosthetist from a personal and clinical perspective and whether or not you need to make a change.

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Daily Stretching, Strengthening and *for the UL Amputee*

by Debra Latour, MEd, Advanced Practice, OTR/L, and Kim Doolan, CPV

Introduction

Keeping our bodies strong and agile is important for everyone, but even more so for those of us with upper-limb loss. One of the ways to accomplish this involves daily exercise; however, many people find it hard to stick to a routine exercise program because their lives are so busy.

As an occupational therapist, Debra has heard many of her patients state that they run around and are so active that they don't need to exercise. Both Debra and Kim confess to feeling this way sometimes as well! But, in reality, exercise is very important for our physical and emotional health. A healthy routine includes regular systematic **conditioning, stretching, strengthening and meaningful therapeutic activities**.

Create a schedule for yourself that allows you to alternate days of conditioning/strengthening exercise and therapeutic activity, but commit to deep breathing and general stretching every day. An occupational therapist can instruct you in all these exercises and suggest modifications to enhance your ability to participate safely and actively.

So where do we start? Here are our favorites:

Deep relaxation breathing is a great way to begin. Debra recommends this exercise be repeated every two hours. Start by placing one hand on the upper chest, the other at the notch between the ribs. Close your eyes and take in a deep breath through the nose, feeling your chest expand. Now take in one more deep short breath through the nose, feeling the area beneath the "notch" expand. Hold to the slow count of three, then slowly exhale through the mouth. Repeat three to five times.

Stretching exercises allow for full range of motion and offer a good warm-up to rigorous exercise or activity. We focus on the neck, shoulders and trunk, using slow, gentle movements to 30 repetitions.

Conditioning exercises include core strengthening found in Pilates, Tai Chi, and ROM dance, as well as exercise that allows for full, slow, gentle stretching.

Conditioning Exercises

"Rule(s) of Thumb"

- Always check with your MD before initiating an exercise program
- Start slowly and build up according to tolerance
- Alter routine to keep it interesting and to address different areas
- Drink plenty of fluids throughout your day
- Balance exercise with activity
- Get plenty of rest
- Eat a balanced diet

Modifications

- Safety gear: knee/elbow pads, wrist guards, ankle support
- Use of a rolled towel to support, cushion
- Use of Pilates block or low furniture to accommodate asymmetry
- Check out manufacturer sites, such as TRS, for exercise and activity videos

Strengthening exercises involve weights and resistance using free-weights, resistance bands, machines and cardio equipment. These may be challenging for us to do but are accessible with minor modifications, such as the use of a weighted cuff on the residual limb, tying the fitness band to a chair or bench and using lesser weight on the side of the residual limb.

Photography by Michael James Photography

Therapeutic activities are usually enjoyable to you personally and may have a social component, such as including a friend or taking a group class. Common activities include swimming, bicycling, dancing, hiking or rowing, to name a few. Using activity-specific technology, as well as adaptive strategies and positioning, may make your participation easier.

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WARNING SIGNS: If any of these occur, stop exercising immediately and seek medical attention.

SYMPTOM	DESCRIPTION	MIGHT INDICATE
Chest pain	Pain/pressure in center of chest, nausea, discomfort in neck/back	Heart attack
	Often accompanied by difficulty breathing	
Shortness of breath	Difficulty breathing vs. severe breathing	Asthma Attack
Joint or muscle pain	Soreness vs. sharp/severe pain	Soft tissue tear, sprain
		Joint injury

Conclusion

We each need to make conscious decisions and commit to healthy lifestyles, including exercise, that will help us to remain as independent and conditioned as possible. Laurie Richmond, who has a congenital transradial limb deficiency states: "I have worn a prosthesis as long as I can remember and I have always worked out with able-bodied folks without limitations that I recall... I love to work out and have always thought 'Where there's a will, there's a way.'"

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COMPETITION AS A Life Force

by Leif Nelson, DPT, ATP, CSCS

In 1968, while serving in the U.S. Army Medical Corps, John Schmit experienced a traumatic injury to his right leg that would impact him for the rest of his life.

Schmit honorably separated from the military in November 1969 and went on to practice chiropractic medicine between multiple stints as a high school chemistry and physics teacher. Retiring in 2010, Schmit stays busy raising bees, scuba diving and doing what he calls "competing in retirement." Since banging the erasers together for the last time, this Army veteran now hurls the discus and shot put on a regular basis.

Forty-five years after his initial injury, Schmit acquired osteomyelitis, a bone infection, in the heel of his right foot. The infection worsened; even a challenging series of advanced treatments including hyperbaric oxygen and numerous tissue grafts could not resolve the condition that stemmed from his initial trauma. Schmit and his infectious disease physician at VA Eastern Colorado Health Care System in Denver agreed: the best treatment option would be to amputate his right leg below the knee.

But his surgery wasn't scheduled immediately. Schmit was determined to delay the surgery a few months until after the 2013 Nebraska Senior Games. Nebraska was a place of Schmit's childhood, where sports were first integrated into his life. In preparation for his surgery, he met with the Amputation Care Team at VA in Denver. Led by Dr. David Coons, inpatient rehabilitation medical director, the rehabilitation specialists who make up the Amputation Care Team work closely with the vascular surgeons to address all the needs of veterans undergoing amputation.

John Schmit wearing an IPOP in the PT gym at the VA Eastern Colorado Healthcare System

The immediate post-operative prosthesis process.

The rehabilitation program includes the prosthetist, who creates an immediate post-operative prosthesis (IPOP) for the patient a few days after surgery. VA prosthetist William Dudden describes an IPOP as a "nonremovable dressing that is changed on a weekly basis." Ultimately it is a plaster cast, and can have a pylon and foot attached to it so the patient can start early weight bearing. In some cases, patients are able to begin taking steps in as few as four weeks after surgery.

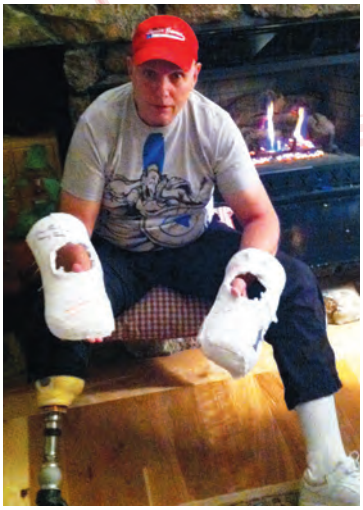
Schmit hurls the shot put

Dr. Coons advocates for an IPOP for the majority of his patients with transtibial amputations. "These patients are able to utilize significantly less medications. Additionally, they experience more rapid wound healing, a decreased incidence of accidental dehiscense (unwanted opening of suture site after surgery), and have more confidence in using their prosthesis," he says. "The majority of our patients coming through our program, that are following our IPOP protocol, leave our VA walking on their prosthesis within six weeks from time of amputation." This is much faster than the average time a patient with an amputation will be ambulating on a temporary or permanent prosthesis without an IPOP.

Schmit validates these claims. He says that no matter how much he asked of Dr. Coons, he was never told "no." Lea Lew, CPO and amputation rehabilitation coordinator, recalls meeting Schmit during a consultation for pre-amputation education. Lew describes Schmit as "extremely motivated! We discussed the rehabilitation program, prosthetic limb components, and let him know the entire team was available to support him." Schmit went on to meet Tom Fields, PT, DPT, for his pre-surgical physical therapy. Fields, whose caseload is 75 percent veterans with limb loss, says, "The Amputation Care Team starts first and foremost with the patient. The team is then assembled to meet each patient's unique needs, which can include members from nutrition, mental health, social work and wheeled mobility, in addition to physical therapy, prosthetics, occupational therapy and rehabilitation medicine."

This process is a great fit for Schmit because, as he says, "I would not stop living." This was true during the three years leading up to his amputation surgery, and is true today as he continues to write new goals, which are consistently based around competition. Commitment to competition explains why he postponed his amputation. Competition is again the force driving his rehabilitation, pushing him to compete in the Texas Senior Games just 12 months after surgery. In the big picture, his training, competing and rehabilitation were all to attain the goal he had been chasing for years: to qualify for the Senior Olympics.

Not only did he make the trip to Texas just six months after his first days in the inpatient ward at VA in Denver, but he has also qualified for the Senior Olympics in discus and shot put. It is certainly remarkable that fewer than two years after amputation, he will be competing in the Senior Olympics against athletes without amputations.



John Schmit keeps his final IPOP casts, signed by his rehabilitation team, for motivation

Schmit keeps his final IPOP cast, which he had the whole clinical team sign, as a memento and for inspiration. Retired from his job, but not from working hard, his only complaint is that his bees didn't produce any honey this year.

Series Photo Credit: Shawn Fury ECHCS Medical Media

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Following My Own Path

by Alexandra Capellini

In many ways, my life has been full of the same experiences as any other schoolgirl: hangouts with friends, summer camp and busy school schedules. But April 15, 2003 changed the way I would grow up. It's the day I underwent surgery to remove my right leg above the knee, in order to save my life from bone cancer. Growing up as an amputee has shaped my values, my perspective, my ambitions, and the path that has lead me to where I am today: a pre-med student at Johns Hopkins University with a goal of becoming a pediatric oncologist.

It wasn't until I re-entered elementary school that I faced adjustments. What pants were the most comfortable to wear over my new prosthesis? What would I do if the prosthesis hurt and I needed to take it off? My parents didn't have all of these answers for me. By trial and error, I realized soft sweatpants were the best option. I figured out how long I could wear the leg before it hurt, and I spent hours at home practicing taking the leg on and off so that I could master doing it on my own.

When fourth grade started, I signed up to use my local high school's pool, and spent every Saturday afternoon reteaching myself how to swim until I finally could take laps. I became determined to become physically active. I soon joined a young adaptive adventure group in New York, going on one-leg trapezing and rock climbing trips.

In middle school, I sought an outlet away from my indifferent peers. I began attending Camelback Mountain's adaptive learn-to-ski and race camps and the Paddy Rossbach Amputee Youth Camp, and also realized that I had a passion for playing clarinet in orchestras. I couldn't blame my classmates for not understanding my limb difference –how could they? – but that didn't mean I would hold myself back.

In high school, my interests peaked in community service. I finally understood what it meant to narrate my own story, and I wanted to give back. I became a spokesperson for an organization that financially supports the families of children with cancer. I began volunteering with DoSomething.org on social change campaigns. I spearheaded my high school's Cambodia Club, leading a Spring 2013 trip to provide music lessons to the students.

As a current college student, living on my own has been an exciting new chapter of my life. I am the only student on campus wearing a prosthesis, but I take it in stride. Instead of worrying about my limp while walking up campus hills, or how my prosthesis is interpreted when I'm the only girl not wearing heels, I focus on being the social, fun girl that I am.

Am I aware of when I'm being stared at in line for lunch? Yes. Do I notice the eyes that quickly divert to glance at my limp when I walk past? Of course. These have simply become minor daily experiences. I accept the glances – they're inevitable. I'm proud that I walk around freely regardless of a limp, wear stylish shorts that show off my leg, maintain on-par balance skills when I wear crutches, and smile back at all who look my way. I can climb rock walls, ski black diamonds, win any hopping contest, and ultimately, remind people that my difference in ability means I live a rewarding life and have much to offer.

I credit my parents, too. They have never limited me, but instead set a path for me to figure out the amputee world on my own, without offering help every step of the way. They let me learn how to navigate an airport with a prosthesis and ski equipment, handle leg complications while away from home, and brush off the never-ending stares. They believe in what I can do on my own, and I do too.

My best friends at school are just as encouraging. They embrace what it means for me to be an amputee, and even enjoy asking about prosthetics or using my crutches. I made a decision to toss aside anxieties about who will "get it" and who won't. My hope is that anyone that stares will at some point introduce themselves and understand that there is a story behind this prosthesis, that there is a story behind the girl living with it, and it's a really good one.

"Growing up as an amputee has shaped my values, my perspective, my ambitions, and the path that has lead me to where I am today: a pre-med student at Johns Hopkins University with a goal of becoming a pediatric oncologist."

The Choice of Parenthood

by Harleen Chhabra Gupt

Our lives are a sum total of choices – most that we made for ourselves, and some that were made for us. Being an amputee was not a choice for me, but being a parent is. When times are tough, I tend to question both. In the end, though, I remind myself that I have a choice to live life as an amputee as well as a parent, fulfilled and happy.

I choose to believe I can.

When my husband and I contemplated parenthood before the birth of our son, I went through phases of doubt, followed by belief and then doubt again. "How will I carry him?" followed by "I can find a carrier;" "How will I change his diaper?" followed by "I can use my legs to hold him and then practice fastening the diaper with one hand." The cycle continued throughout pregnancy. I had to make a choice of believing that no matter what, in the end I was going to be a great parent.

Although I have come a long way, I admit that in my life this cycle of doubt and belief has never really completely stopped. The difference is that the majority of times, I choose to believe I can. The best way that I have found to break that cycle is to just go out and *do* something. Action drowns doubt and lets us swim in belief.

"How will I carry him?"

"How will I change his diaper?"

I choose to accept help when I can't.

We are teaching our preschooler to try a task before asking for help. The rule is to try something at least three times, and then ask for help. I have to remind myself that I too have the choice to follow the same rule – not so much the trying aspect as in asking for help. As an amputee, I have mastered trying out many tasks without giving up, whether the task was tying my shoelaces or cutting my nails. The difficult aspect for me was to ask for help. It took many years to develop the sense of security and confidence to reach a stage where I could ask for help from others without giving that deed another thought. I have to thank my parents, my sister and my husband for years of love and nurturing to help me get here.

As an amputee parent, I have the choice to try out solutions to care for my child; I also have the choice to ask for help. I recall a couple of instances of asking for help when my preschooler and I were by ourselves at the grocery store to keep the bags in the car when he had to use a public restroom. Another choice that I am exercising is to teach my son to help me out. My big ones in this category are asking him to walk on his own even when he is tired and doing some of his personal tasks on his own, especially putting on socks and shoes.

I recently learned a variation of the classic Serenity Prayer that perfectly summarizes my thoughts on choice: "God, give me the strength to act on things that I can change, the serenity to accept the things I cannot change, and the wisdom to know the difference."

"Another choice that I am exercising is to teach my son to help me out… especially putting on socks and shoes."

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Weighing Your Options

by Karen Henry

AFTER A LIMB AMPUTATION, one of the more significant decisions you will make is whether or not to use a prosthetic device. Your healthcare team will assess your physical and psychological readiness to wear a prosthesis, but when it comes right down to it, whether or not you *can* wear a prosthesis should not be overshadowed by whether you *want* to wear one.

WE ASKED A NUMBER OF AMPUTEES what factored into their decisions to wear or not to wear a prosthesis. Their experiences provide a wonderful variety of perspectives from which to draw if you, or someone you know, is facing this decision for the first time or is considering a change.

"This is who I am."

"It's a personal decision whether to use prostheses or not," says Roberta Cone, PsyD. "I chose not to."

Cone lost her left arm below the elbow as the result of an automobile accident almost 13 years ago. At the time of her amputation, her only insurance option was a body-powered hook. "Aesthetically," she says, "I think the body-powered hook is a little intimidating and not very appealing."

Since then, working with amputees has become her life's work. A psychologist specializing in helping amputees deal with phantom limb pain and body image issues, Cone has worked extensively with women and U.S. military veterans.

She also volunteers as an arm model for the California State University Dominguez Hills prosthetic education program. Through that experience, she has had the opportunity to try some of the most advanced prosthetic arms on the market. While she admits that myoelectric prostheses "are a lot of fun," she says she's not interested in wearing one full-time.

"This is who I am," she says. "I don't need a hand to work with people. Talking with my forearm missing has actually been a bonus in my work. It allows me to connect with people quickly. They understand that I know something about loss."

"It's part of me."

Debra Latour, MEd, OTR/L, identifies just as strongly with wearing a prosthesis. "It's part of me," she says.

Born in 1956 with a right, below-elbow limb deficiency, Latour was fitted with her first prosthesis when she was 14 months old. The harness was a source of constant discomfort, and she threw her prosthesis in the trash on more than one occasion. One time her prosthesis made it from the trash to the incinerator, and she had to watch her father fish it out with a wire hanger.

"I remember thinking that this must be important for my dad to be doing something so dangerous," she says. "I never threw it away again."

Her parents made sure that she learned how to do everything with and without her prosthesis – a lesson Latour carries into her occupational therapy work with upper-limb amputees to this day.

She knows that she could live without her prosthesis, but she doesn't want to. "I identify socially and in my work with wearing and using my prosthesis." she says. "I feel more comfortable with it."

Latour considers just about every new prosthetic device that comes out and has tried many of them. She encourages her patients to do the same. "Technology is expensive," she says. "It is often difficult to experience in a first-hand trial, but it is possible." Her technology of choice, however, is body-powered. "I don't like the idea of being dependent on a battery," she says.

Device repair is another factor. "When the myoelectric breaks down, you sometimes have to send it back to the manufacturer. I want my prosthesis to keep up with the demands of my life and not leave me at a loss."

Photography by Michael James Photography

"I just got used to not having it."

David Burch understands this scenario all too well. After losing his arm above the elbow in a work-related accident six years ago, he was fitted with a high-tech myoelectric prosthetic hand. "It was a cool little robotic hand," he remembers. "I enjoyed the look of it; I wore it every day and did everything I could with it. There wasn't much I couldn't do."

After about two years, something went wrong with the device, and it had to be sent to the manufacturer for repair. Burch was without his prosthesis for eight months. "When I got it back, I tried wearing it again, but it was awkward," he says. "It got in the way. I could do just about anything I wanted to do a lot faster without the prosthesis."

The 30-year-old still wears his prosthesis from time to time and advises other amputees "to do everything they can to try a prosthesis first. It is a major help. Because I had to do without it for so long, I just got used to not having it."

"You don't have to have a prosthesis to live a normal life."

Brooke Kunkel hasn't worn a prosthesis in almost 30 years.

At the age of four she was involved in a bus accident, and her arm was amputated above the elbow. Before she entered kindergarten, her mother took her to be fitted for a prosthesis. "It was pretty exciting," she remembers. "I did all sorts of physical therapy so I could learn how to use it."

However, the device weighed nearly half as much as she did, and she quickly began to resist wearing it. Her grandmother, who had a congenital upper-limb deficiency, had taught her how to do everything without a prosthesis. "She taught me how to tie my shoes, button my buttons, put on gloves – everything," Kunkel says.

When she was in first grade, Kunkel stopped wearing the prosthesis.

Now, however, she is reconsidering using a prosthetic device. "I find myself thinking it would be nice to carry more groceries or stabilize an onion while I cut it – little things that you don't really think about," she says.

At the same time, she wonders if wearing a prosthesis would change her somehow. She is living proof that "you don't have to have a prosthesis to live a normal life." Among other things, Kunkel has played high school volleyball, been a competitive swimmer, and worked as an emergency medical technician. For six years, she even played roller derby.

"Part of me feels like prosthetics are for other people and not necessarily for me," she says.

"I felt some guilt when I started thinking about it."

Jason Parks also experienced an internal struggle when he started thinking about making a change.

When he was 10 years old, Parks had a right hip disarticulation amputation due to cancer. There was never any question about whether he would wear a prosthesis. "I was going to wear one, regardless," he says. "I just wanted to fit in."

He wore his prosthesis every day for the next 13 years.

After college, he got a job and then began having issues with his sound leg. He came home from work every day exhausted and in pain. He began to wonder if wearing a prosthesis was worth it. "I sit all day, and I started to think that there was no longer any reason to wear a prosthesis."

But he also wondered if he would be letting his family and friends down. "I felt some guilt when I started thinking about it," he says. "Was I throwing in the towel?"

Ultimately, the 30-year-old decided to switch to full-time use of custom-made forearm crutches. "If I was going to have a good quality of life, a prosthesis wasn't going to help me do that," he says. "It just wasn't worth the physical pain anymore."

"I felt truly disabled."

Kelly Ford was born with a fibrosarcoma tumor in her leg. When she was three months old, her leg was amputated at the hip, and she was fitted with her first prosthesis when she was 18 months old. In the eighth grade, she switched from a wooden prosthesis to a lighter titanium prosthesis with a cosmetic foam cover.

"I thought it would be cool, and I would look normal," she says. Unfortunately, she had trouble adjusting to the new leg and fell one day while she was at school. "I was so embarrassed," she says. "I swore then that I would just use my crutches."

Ford didn't think about wearing a prosthesis again until college, when climbing multiple flights of stairs with a load of books began to take a toll on her body. In 1992, she was fitted for another prosthesis. The bucket-style socket had not changed. "I couldn't get used to it," she recalls. "I felt truly disabled."

She tried another prosthesis in 2003 with a similar result. Each failed attempt brought her back to using her crutches full-time.

However, no one warned her about the effect that overuse could have on her sound leg, and it is now bone rubbing against bone. The single mother wonders if she should have been more persistent in using a prosthesis. "I don't think two legs would make it better," she says, "but sometimes I wonder if I had just kept pushing myself if I would be walking with two legs."

The choice to wear or not to wear a prosthesis can be fluid – changing as life and circumstances warrant. Your doctor and your prosthetist will evaluate whether or not you are a candidate for a prosthesis, but only you can decide if it's right for you.

"Tools in a toolbox."

Kim Doolan was fitted with her first three prostheses when she was 18 months old. She has congenital limb deficiency in both of her lower limbs and her right upper limb. "I was very lucky – my parents were pro-prostheses," she says.

Doolan has spent her entire professional career working in the orthotics and prosthetics profession. Since 1997, she has worked as the clinical coordinator at Allen Orthotics & Prosthetics in Texas. Regardless of whether or not an individual ultimately decides to use a prosthetic device, she feels that someone with an acquired amputation – whether they are an adult or a child – should get a first prosthesis as close as possible to the time of his or her amputation. "They'll be more likely to get funding for the prosthesis, and I think it's important to give that first one a try," she says.

Doolan has been wearing the same lower-limb prostheses for more than 20 years. She wears a passive functional prosthesis on her upper limb about 90 percent of time and switches to a body-powered prosthesis when she does housework, stretching exercises, or works in her garden.

"It's wonderful to have an assortment of prostheses," she says. "They're like tools in a toolbox."

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WANT TO BECOME A PARALYMPIAN?

P.A.C.E. YOURSELF

by Beth Bourgeois

Joe Kusumoto Photography

Mike Shea competing for the Aspen World Cup

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These words have guided Shea over the years, as he set a goal to become a U.S. Paralympian in snowboarding. Judging by his silver medal win at the Sochi 2014 Paralympic Winter Games, and having earned the first-ever IPC overall title in snowboard cross in the 2014 world cup circuit, it's working.

Shea, whose left leg was amputated in a boating accident in 2002, says he hasn't always performed at the top of his game.

"I didn't know anything about amputees or the Paralympics when I was injured," says Shea. "A couple of years after my accident, I started competing in able-bodied snowboard cross again. I met Amy Purdy and she told me about adaptive snowboard; I started competing in adaptive races and it just grew from there."

As Shea will tell you, his road hasn't been an easy one, but it's been well worth it.

"Becoming a Paralympian has been one of the most rewarding things I have ever done, but it didn't happen overnight," Shea says. "[You have to] be prepared to make a commitment to your sport, stay focused and to work really hard."

The steps to becoming a U.S. Paralympian vary by sport, but the key components among all sports are the same.

Train

Train with a plan and a purpose. If you are serious about taking your talents to the Paralympic level, your training has to go beyond the hobby level with a focused plan of attack to reach your goals. This may involve getting a coach who can guide you through the appropriate steps for your sport. There are many programs at the local, regional and national levels that can help connect you with coaching assistance. Check out findaclub.usparalympics.org, a searchable, online database that will help you learn more about programs and events in your community.

Know what it takes to be competitive

Each sport has its own national governing body or high performance management organization, which has established minimum requirements in each sport, each event and each sport class/disability group. For example, knowing where your time stacks up in the 100m against other male below-knee amputees will give you a good idea of how much work you have ahead of you. Learn the standards in your sport, and then devise a game plan to improve your performance to meet or surpass those standards.

Compete

There is no better way to learn than to step up to the starting line. Register for a regional competition or national championships in your sport.

Once you've met an emerging standard in your sport, you're on your way to securing a spot on the national team in your sport; the criteria differ per sport. Once you've made the national team, you may be eligible to receive funding to support your participation and travel in future competitions as part of the sport's respective national team.

"There's always a level where you need to start if you desire to go farther in your sport – every sport provides that for you," Shea explains. "You can compete at regional or national levels; there's an opportunity for everyone. When I first got started, it was so fun to be around other amputees and learn from them. In hindsight, I wish I had done it sooner."

PARALYMPIAN SPORTS

SUMMER SPORTS	Amputee/ Les Autres
Archery	★
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Equestrian	★
Goalball	
Judo	
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Shooting	★
Sitting Volleyball	★
Soccer	
Swimming	★
Table Tennis	★
Track & Field	★
Triathlon	★
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Wheelchair Fencing	★
Wheelchair Rugby	
Wheelchair Tennis	★
WINTER SPORTS	
Alpine Skiing	★
Biathlon	★
Cross-Country Skiing	★
Sled Hockey	★
Snowboarding	★
Wheelchair Curling	★

Classification

Classification is the structure for competition in Paralympic sport. It relies on established criteria to ensure that winning is determined by skill, fitness, power, endurance, tactical ability and mental focus, the same factors that account for success in sport for able-bodied athletes. Classification rules, regulations, evaluation criteria and sport classes are unique to each sport.

In order to compete in a Para-sport event, you'll need to undergo classification evaluation for your sport at either the national or international level. National classification is applicable for events within the U.S. and managed by the respective sport's national governing body or high performance management organization and U.S. Paralympics.

International classification is required to compete in international-level competition, to have your results included in international rankings, and to meet international qualification criteria. International classification falls under the auspices of the respective sport's international federation and the International Paralympic Committee.

It doesn't matter if you're not sure where your skills lie; U.S. Paralympics encourages you to try something new. Who knows? You could end up being the newest member of Team USA and represent your country in Rio 2016 or beyond.

As for Shea, he's already thinking about PyeongChang 2018.

Related Resources

IPC Classification
paralympic.org/classification

Paralympic Sports
teamusa.org/US-Paralympics/Sports

U.S. Paralympics
usparalympics.org

What Does the Science Say
About Vacuum-Assisted Suspension?

by Jason T. Kahle, MSMS, CPO, FAAOP, M. Jason Highsmith, PhD, DPT, CP, FAAOP

Introduction

The prosthetic socket interface is the most important aspect of the prosthesis because it connects the amputee to the components and, ultimately, the ground. A poorly designed socket creates insecurity and instability for the amputee. There are two main considerations when designing a socket: 1) how the user's weight will be supported during standing and ambulation, or weight-bearing characteristics, 2) the mechanism used to connect the prosthesis to the user, or the suspension.

A socket that is a well-fit, solid connection can offer stabiliy and comfort. There are many suspension options that provide that connection, including gel liners with locking systems, sealing gaskets and matrixes. Recently, vacuum-assisted suspension (VAS) has become a popular way to suspend and enhance prosthetic fit. In a VAS system, a liner is donned onto the residual limb (RL) and a seal is created where air is not allowed to enter the space between the socket and the liner. A vacuum pump actively draws air out of the area between the liner and the prosthetic socket. This vacuum suspends the prosthesis and may improve total contact between the RL and socket. Improved total contact could help distribute weight-bearing forces, while dynamic suspension could assist in reducing motion between the RL and the socket. This would secure the prosthesis onto the limb, while reducing friction on the skin. Reduced motion could increase control of the prosthesis by establishing a more stabile, healthy environment for the RL.

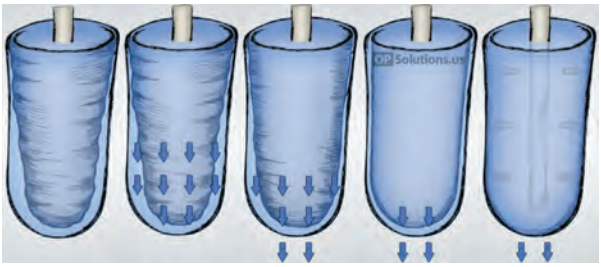

FIGURE 1
How VAS works: From left to right: A residual limb and liner will fit loosely into the socket prior to activating the vacuum. The vacuum will pull the residual limb distal (down and into the sides of the socket). This will create superior suspension as well as improved total surface weight-bearing area, which helps distribute pressure.

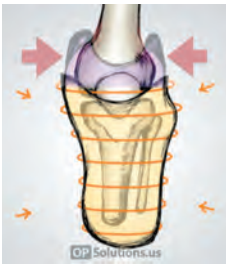

FIGURE 2
Below-knee with VAS: VAS applies pressure equally over the area affected by the vacuum (orange rings). Because the total surface is used to absorb the weight bearing, it allows the possibility to lower the trimness that can impinge the knee and prevent range of motion.

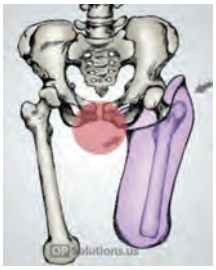

FIGURE 3
Standard of care for above-knee socket: Traditional above-knee sockets use high, tight trimness in the area of the perineum (red circle). This can create pressure and friction on the skin, and make it uncomfortable to sit, bend and use the bathroom.

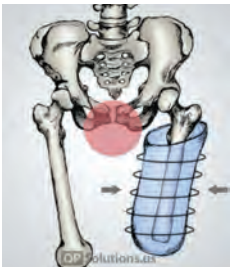

FIGURE 4
VAS above-knee socket: Because the vacuum connects the residual limb to the socket, it may allow the prosthetist to lower the trim lines in the area of the perineum (red circle). This can lower pressure and friction on the skin, and make it more comfortable to sit, bend and use the bathroom.

Understanding Vacuum-Assisted Suspension

Understanding the mechanical principles of vacuum clarifies its importance to the benefits for the amputee and RL health. In a VAS prosthetic socket, the space between the liner and hard prosthetic socket is the area affected by vacuum. The RL is not directly affected by vacuum. However, the connection between the skin and liner play an important role in the success of any VAS system. All forms of VAS have some type of seal to block the air outside and form a vacuum. For the VAS below-knee design, a suspension sleeve or an inner sealing gasket mechanism is often used. For the VAS above-knee design, an inner sealing gasket mechanism will create the seal. In either case the higher the seal, the larger the area affected by VAS. The larger the area under vacuum, the more effect that vacuum can have on the RL, which should be an important consideration.

Reviewing the Evidence

Many manufacturers now design prosthetic components such as vacuum pumps, seals, liners and feet made for VAS. The Centers for Medicare and Medicaid Services reported an increase in VAS specific billing codes of $1.4M in 2003 to $9.1M in 2011. Both of these factors indicate a trend toward preference to using VAS technology. VAS is commonly marketed as beneficial to the patient. It was important for us to identify the science behind these claimed benefits. We reviewed all available resources on the topic of VAS. This article is referenced from published findings in a systematic literature review in the journal *Technology and Innovation** (Number 4, 2013). Only the highest quality articles were included in that publication. The articles had to be peer reviewed; editorials and magazines were not considered. A low-quality article or study may leave room for an insurance company or medical reviewer to label a new technology as "experimental" or nonscientific. Only eight articles were found to be of high quality and could be categorized into the three different topics: Effect on the Residual Limb, Wound Healing and Function.

The Effect of Vacuum-Assisted Suspension on the Residual Limb

There were two studies reporting that VAS sockets help maintain daily volume, while non-VAS sockets reduced volume of the RL during prosthetic use. Volume reduction during activity can cause many problems for the amputee, including increased distal pressure and movement. Controlling, or managing, volume has significant value to patients with compromised vascularity due to amputation. VAS technology can minimize

CONTINUED ON NEXT PAGE

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volume reduction in prostheses, as supported by the evidence. Three studies reported that VAS reduces movement on the RL. Increased movement can make a socket feel heavy, cause friction and instability. The improved control of the socket allows for lowering trim lines in both below- and above-knee amputees. Less intrusive sockets provide greater range of motion, increased comfort, improved hygiene, decreased perspiration, reduced fitting complications and less skin surface area contained in the socket. Finally, two studies reported that VAS sockets favorably affect the pressure distribution on the RL. It is important to reduce pressures in the socket to avoid skin breakdown. An interface design that can potentially control volume, limit undesirable interface movement and favorably affect pressure can be a medical necessity for a prosthetic user.

Can Vacuum-Assisted Suspension Help Heal a Wound?

No evidence exists to support the notion that a prosthesis can assist in healing wounds, with or without VAS. There is no standard of care for prosthetic use when the user has a wound; a more common protocol is prosthetic disuse. However, a VAS socket that offers improved total contact and reduces pressure and pistoning may affect the RL more favorably. Reduced pressure and pistoning would be a benefit to the amputee susceptible to skin breakdown. Should the clinical decision be made to continue prosthetic use in the existence of a wound, VAS may be the most logical choice due to these favorable mechanical principles. However, more research is needed to make a recommendation on using VAS when RL wound healing is a primary concern.

Can Vacuum-Assisted Suspension Offer Improved Function?

There were three articles that focused on different aspects of function. One researcher concluded that the use of VAS sockets resulted in improved gait symmetry while observing step length and stance duration as compared with suction sockets. Another article reported the overall function to have an improvement of 15 percent, favoring the VAS over the pin system socket. However, one article reported less step activity when using the VAS compared to pin systems. These three studies do not agree in any one functional area. Because of this lack of consistent evidence, more research is needed to determine if using VAS improves function.

Conclusion

The strongest evidence supporting the effectiveness of vacuum-assisted suspension (VAS) for the prosthetic user was in the topic of positively affecting the residual limb. There is currently limited evidence supporting the use of VAS regarding wound healing and function. The mechanical principles of VAS applied to prosthetic use may have positive effects on the amputee. Applying vacuum to prosthetic design may create alternative interface designs for both above- and below-knee amputees. There is a lack of evidence supporting the use of VAS. More research needs to be conducted. The Department of Defense has recently awarded researchers on this very topic, which will hopefully help shed light on this important technology.

*Kahle JT, Orriola JJ, Johnston W, Highsmith MJ. "The Effects of Vacuum-Assisted Suspension on Residual Limb Physiology, Wound Healing and Function: A Systematic Review." *Technol Innov.* 2014; 15:333-341.

The views expressed in this article are not the opinion of the U.S. Department of Veterans Affairs.

Do You Have
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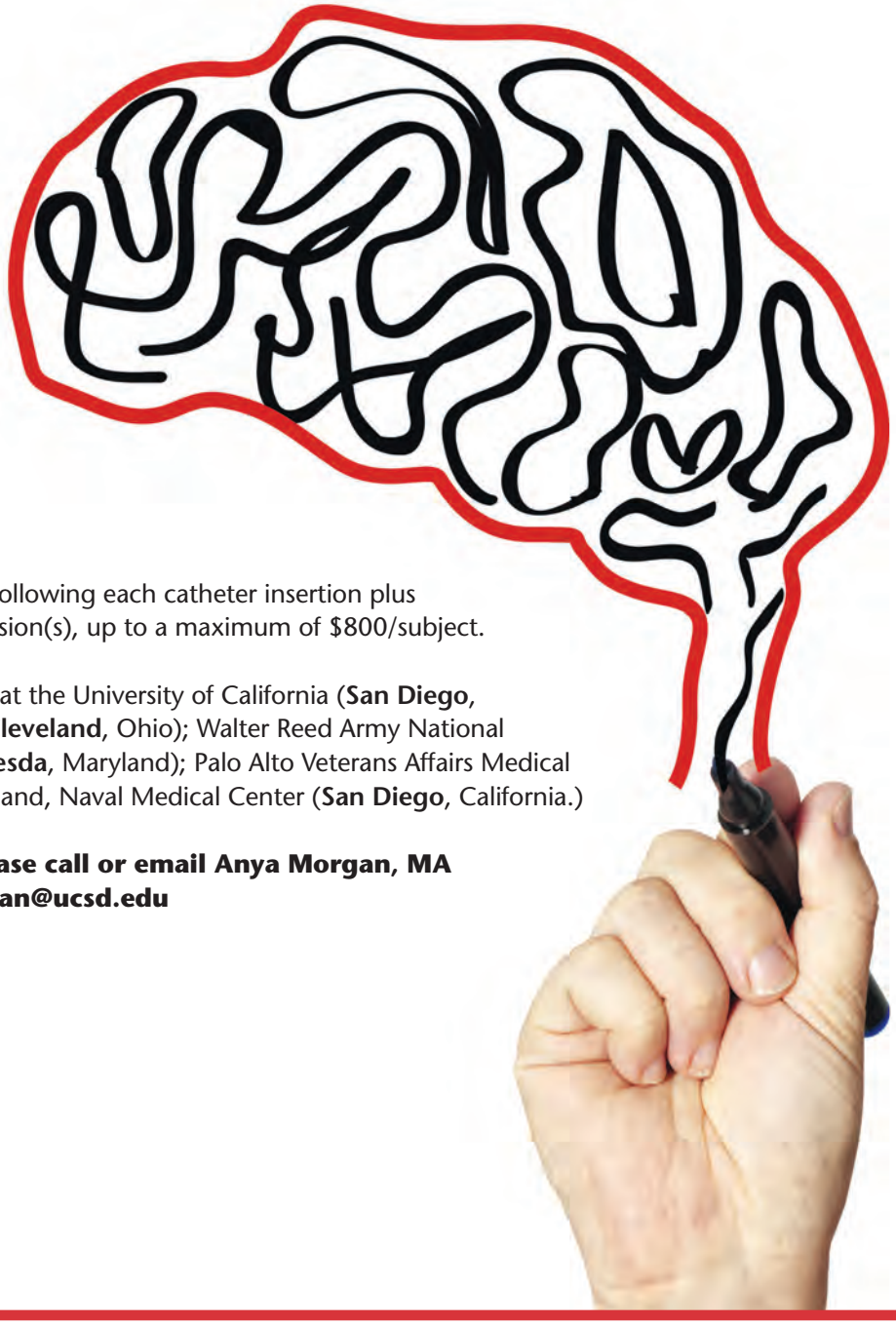

Participants will receive $100 following each catheter insertion plus $50/day during the 6-day infusion(s), up to a maximum of $800/subject.

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

For more information, please call or email Anya Morgan, MA
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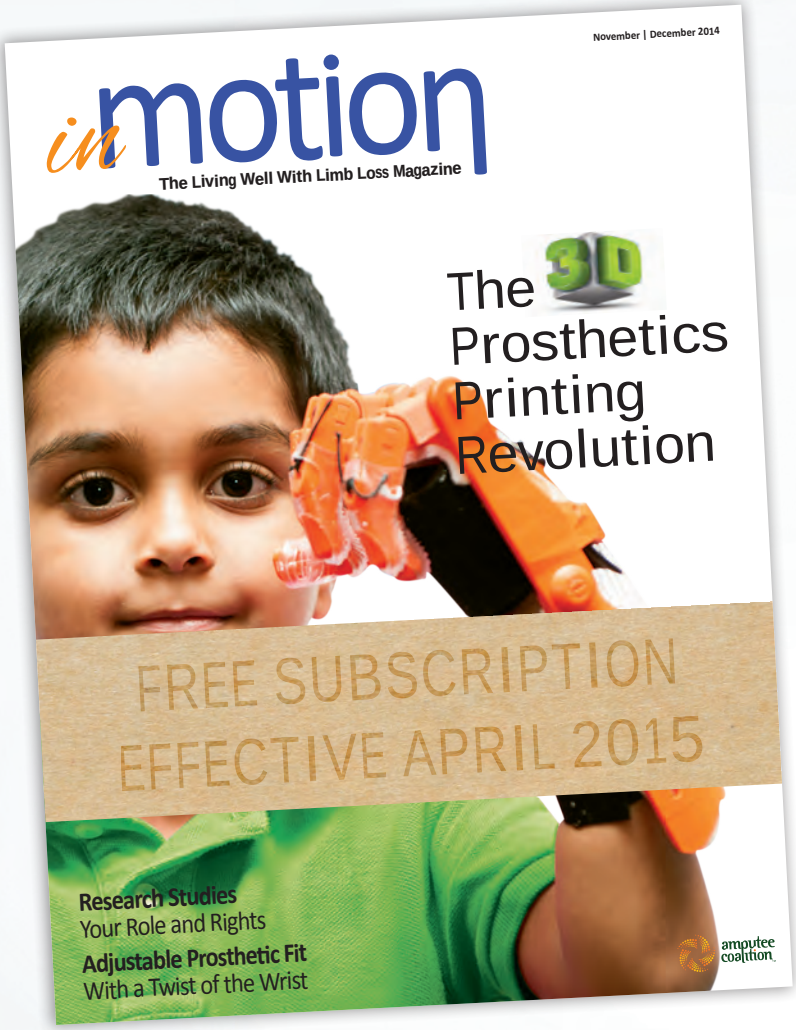

From its humble beginnings as a four-page newsletter in 1991, *inMotion* magazine has expanded in size and readership over the years and has been through many transitions – both in content and design.

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, effective April 1, 2015, *inMotion* will be 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.

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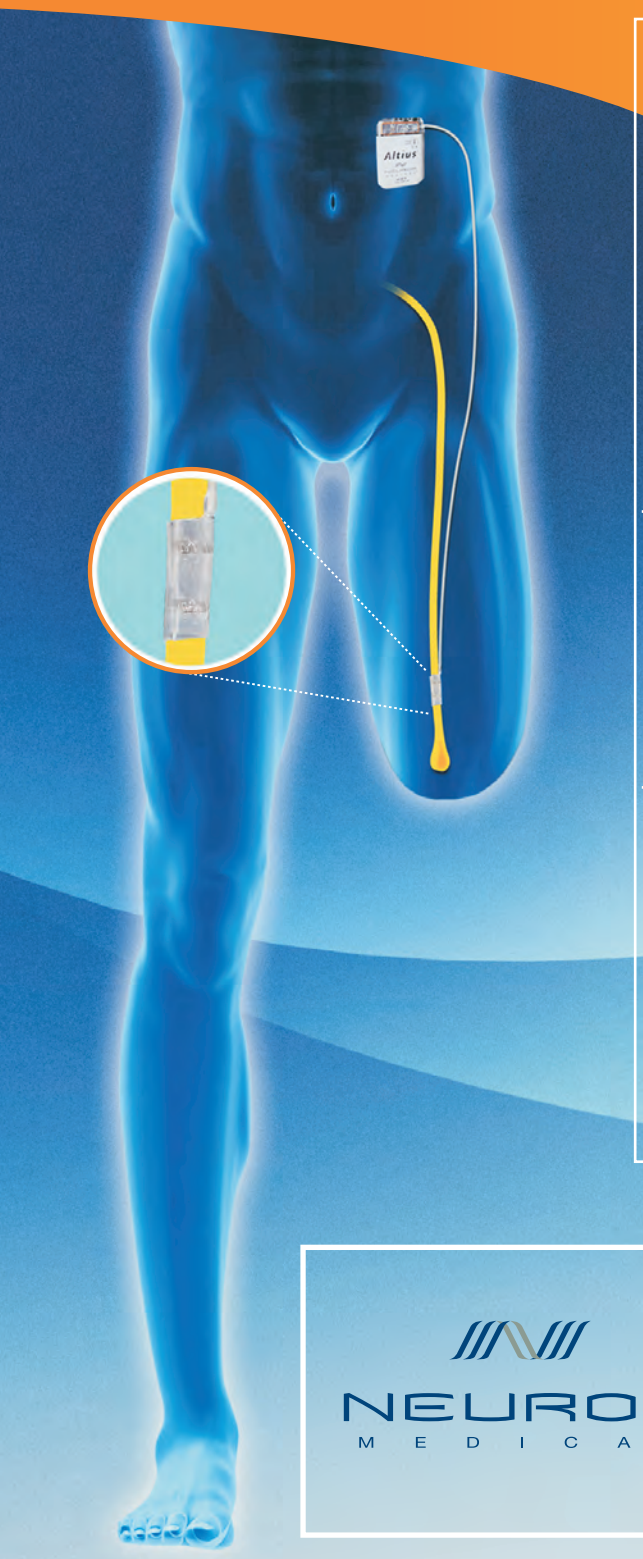

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A BLESSING IN DISGUISE

by John "Mo" Kenney, CPO, FAAOP

MY STORY BEGINS WHEN I WAS SEVEN YEARS OLD.

I was raised on the Island of Guam. I was fortunate to grow up in a family with good, supportive Christian parents. We lived in a subdivision, which as many parents know, can afford a certain sense of security. However, accidents can happen anywhere.

One day, a local 15-year-old boy took his father's van out for a joyride. As he rounded a corner, he lost control, accidentally hitting me.

I woke up a few days later in the hospital with multiple fractures and a missing right foot. There had just been too much damage to the lower portion of my leg to salvage it. After three months of rehabilitation, healing and prosthetic care, I was thankfully able to walk again.

I never held back on any activity I wanted to do because the sky was the limit, even with a prosthesis. My family and community were very supportive. My most comforting memory was when my parents allowed me to visit that 15-year-old and assure him that I was OK, that I understood it was truly an accident.

What I thought was a tragedy turned out to be a blessing. It gave me direction in life at a young age to pursue exactly what I wanted to do. Today, I have an orthotic and prosthetic company that has 10 locations in Kentucky and Indiana. I have wonderful employees who follow the adage: "If you care for someone, success will follow."

I am a past president of the American Board for Certification in Orthotics, Prosthetics and Pedorthics and the Kentucky Orthotics and Prosthetics Association, and current ABC examiner in Orthotics and Prosthetics. Kenney Orthopedics provides international humanitarian care on an annual basis. We currently operate a clinic in Querétaro, Mexico with other generous volunteers from around the country. My volunteer history is predicated on making sure amputees are provided the highest quality of care, regardless of where they live.

I was recently honored to serve on the Amputee Coalition board of directors. Part of the Coalition's mission is to empower amputees to achieve their full potential. I look forward to working with an organization that has faithfully supported amputees for almost 30 years. Since the age of seven, this too has been my heart's desire.

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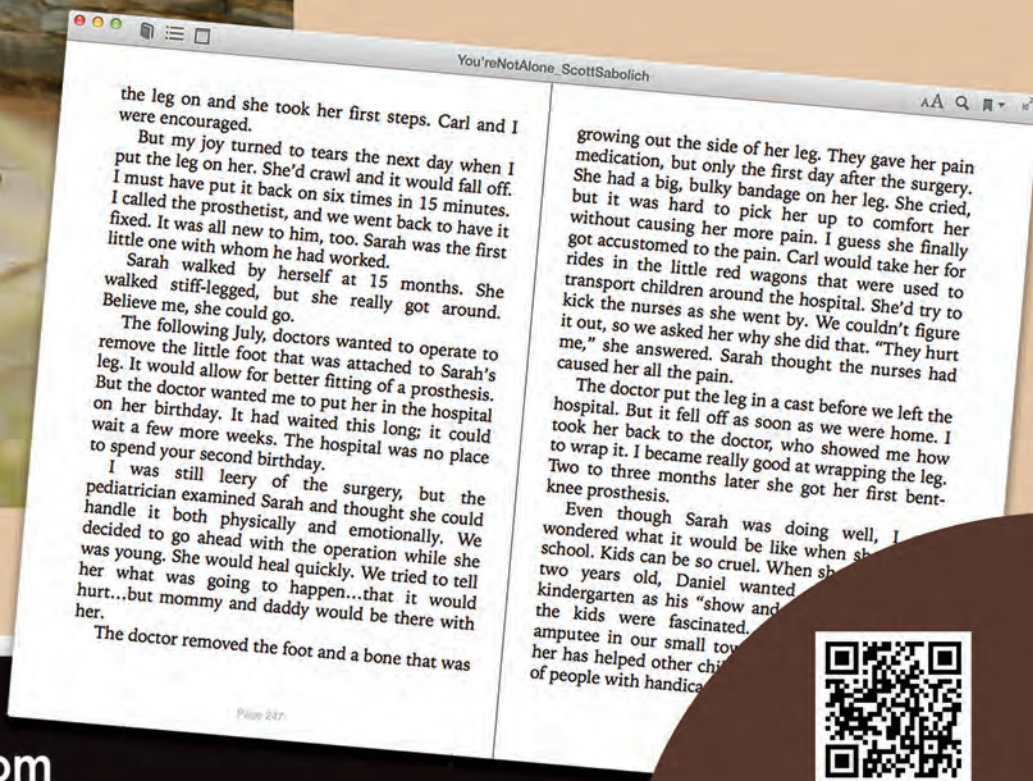

You'reNotAlone_ScottSabolich

the leg on and she took her first steps. Carl and I were encouraged.

But my joy turned to tears the next day when I put the leg on her. She'd crawl and it would fall off. I must have put it back on six times in 15 minutes. I called the prosthetist, and we went back to have it fixed. It was all new to him, too. Sarah was the first little one with whom he had worked.

Sarah walked by herself at 15 months. She walked stiff-legged, but she really got around. Believe me, she could go.

The following July, doctors wanted to operate to remove the little foot that was attached to Sarah's leg. It would allow for better fitting of a prosthesis. But the doctor wanted me to put her in the hospital on her birthday. It had waited this long; it could wait a few more weeks. The hospital was no place to spend your second birthday.

I was still leery of the surgery, but the pediatrician examined Sarah and thought she could handle it both physically and emotionally. We decided to go ahead with the operation while she was young. She would heal quickly. We tried to tell her what was going to happen...that it would hurt...but mommy and daddy would be there with her.

The doctor removed the foot and a bone that was

growing out the side of her leg. They gave her pain medication, but only the first day after the surgery. She had a big, bulky bandage on her leg. She cried, but it was hard to pick her up to comfort her without causing her more pain. I guess she finally got accustomed to the pain. Carl would take her for rides in the little red wagons that were used to transport children around the hospital. She'd try to kick the nurses as she went by. We couldn't figure it out, so we asked her why she did that. "They hurt me," she answered. Sarah thought the nurses had caused her all the pain.

The doctor put the leg in a cast before we left the hospital. But it fell off as soon as we were home. I took her back to the doctor, who showed me how to wrap it. I became really good at wrapping the leg. Two to three months later she got her first bent-knee prosthesis.

Even though Sarah was doing well, I wondered what it would be like when sh school. Kids can be so cruel. When sh two years old, Daniel wanted kindergarten as his "show and the kids were fascinated. amputee in our small to her has helped other chi of people with handica

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