Being Active

An Equal Footing

Disability Without Defeat

A free publication produced by the Amputee Coalition
Saltwater tested for 2 million cycles, plus with an antimicrobial and UV inhibited foot shell, the progressive Soleus foot performs flawlessly at the pool, lake, ocean or outback.
No matter who you are, no matter your age, you’ve got to keep moving. The more active we are, the healthier we tend to be. The human body is designed to be in motion; otherwise, our systems begin to malfunction and break down. Lack of activity can lead to a host of secondary conditions: obesity, diabetes, depression, loss of bone and muscle mass, increased pain and even some forms of cancer.

No one is more at risk for secondary conditions and subsequent amputation than someone who has already lost a limb. Diabetes is the leading cause of nontraumatic amputations in the U.S., with over 86,000 lower-limb amputations occurring each year. But although the odds appear to be against you, you don’t have to be in this group. Common sense and good preventive care can preserve what you have.

The Amputee Coalition believes that many amputations related to secondary conditions can be prevented. This is a key reason why limb loss prevention is included in our mission statement, and why we are working to raise awareness about the risk of limb loss due to secondary conditions and preventive steps that can be taken, including weight management, diet, exercise and regular foot exams.

Whether you are working out for an endorphin rush, to fight weight gain or simply for the sake of your health, we all have our reasons to maintain a certain level of health and exercise throughout our lives. As an amputee, your approach to the usual forms of exercise will obviously be challenged, but the physical and biological principles are the same. Today’s technology provides a vast resource of information and options for exercise, educational tools and motivational and physical help.

There are many things that can be done to prevent or repair the secondary conditions caused by limb loss. It’s not too late. The human body is very resilient. You just need to get started.

"Every day, you reinvent yourself. You’re always in motion. But you decide every day: forward or backward."

~James Altucher, author
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 AMPOWER, 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.

With more than 800 clinics throughout the U.S., Hanger Clinic delivers orthotic and prosthetic solutions to help over 1,000,000 patients annually, like Carrie, turn their hopes and dreams into reality, break down barriers and move their lives forward.

Open your world of possibilities. Come see us! Call 1-877-4HANGER or visit HangerClinic.com to find a Hanger Clinic location near you.

“LIFE IS NOT ABOUT FINDING YOURSELF. IT’S ABOUT CREATING YOURSELF.”
Inside in Motion
The living well with limb loss magazine

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Photo courtesy of Andrew Montgomery.
Dan Berschinski became the first person in the military with above-knee and hip-disarticulation amputations to walk on a daily basis after losing both of his legs in combat. His experience with limb loss, the military and business bring a unique combination of skills and leadership to his role as Amputee Coalition board chairman. He has served as a board member since 2012, and takes particular pride in his involvement with the Paddy Rossbach Youth Camp. He lives in Atlanta, Georgia after graduating from Stanford University’s Graduate School of Business in 2015 with a Master’s in Business Administration..

Carolyn Cosmos has written for inMotion since 2008. She writes medical and education feature stories for The Washington Diplomat and other outlets and has authored a guide to the Americans with Disabilities Act for hospitals and their patients with hearing loss.

Karen Henry is a freelance writer, editor and content marketing specialist based in Broomfield, Colorado. She specializes in writing for the orthotics, prosthetics and pedorthics professional communities and for the patients they serve.

Jason T. Kahle, MSMS, CPO, FAAOP, is a certified licensed clinical prosthetist/orthotist and research scientist. He is an ongoing co-principal investigator of funded prosthetic and amputee clinical and translational research. He is a consultant with the University of South Florida, Prosthetic Design and Research and the Prosthetic and Amputee Rehabilitation and Research (PARR) Foundation. All are located in Tampa, Florida. Email: jason@opsolutions.us.

Leif Nelson, DPT, ATP, CSCS, is the assistant chief for clinical care in the Extremity Trauma and Amputation Center of Excellence. He is a doctor of physical therapy, a certified assistive technology professional, and a certified strength and conditioning professional with the U.S. Department of Veterans Affairs.

Tony Phillips is the owner and executive director of Kouros Phillips Development, Inc., a consulting firm based in San Diego offering grant writing support for nonprofit organizations and education districts in the U.S. and overseas. Tony is active in a variety of sports and a regular spokesperson for challenged athletes and the amputee community.

Kirsteen Warren lives in Arizona with her husband, Graham, of 30 years. She has a short below-knee amputation, but it doesn’t stop her from doing the things she loves, such as hiking and horse riding.

Lee Zimmerman is an accomplished freelance writer, reviewer, critic and blogger. Over the past 20 years, his work has appeared in a number of leading national publications, including CBS Watch! Magazine, Goldmine, Country Standard Time, No Depression, New Times, Billboard, and Performing Songwriter. He currently resides in Maryville, Tennessee with his wife Alisa.
Discover the INFINITE SOCKET®

function with purpose.
What a great issue. Thanks to everyone who contributed. I found every article important and relevant. They were well-written, too.

FYI, I have been a right above-knee amputee (R-AKA) for four years. I consider myself an advocate. I started off advocating for myself. Then I lent a supporting hand at Gaylord Hospital’s amputee support group in Wallingford, Connecticut. The next step was to start a new support group in another part of the state. I am proud of my success in establishing the Milford, Connecticut Amputee Support Group, which Yale New Haven Hospital has “adopted” with inpatient PT and OT staff, as well as meeting space adjacent to their inpatient rehabilitation unit. I am still their unofficial advisor, but their staff has definitely taken ownership of the group. Somewhere in between I became a certified peer visitor and am active with peer visits to new amputees in Gaylord and Yale New Haven hospitals.

The next step for me is political advocacy. I became a trainee in the “Partners in Policymaking” program to prepare myself to advocate for people with all types of disabilities at the state level. Perhaps that is why I found this issue so helpful. I hope to attend the Amputee Coalition’s Hill Day in April, but haven’t told my wife yet, so I don’t know if I will get there.

Thanks again for a great issue.

Herb Kolodny
configurationX

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CALendAR OF EVENTS

Healthy Vision Month
nei.nih.gov/hvm

National Osteoporosis Month
nof.org/nationalosteoroporismonth

National Physical Fitness & Sports Month
fitness.gov

Older Americans Month
acl.gov/NewsRoom/Observances/oam

Stroke Awareness Month
stroke.org

Trauma Awareness Month
nationaltraumainstitute.org

MAY

-wheelchair Tennis Clinic
 Rome, Georgia
opalonline.org

MAY

-Rheumatology Congress
San Diego, California
arthritis.org

MAY

-Site of Science Conference
San Francisco, California
siteofscienceconference.org

MAY

-Renal Week
London, England
Kidney Research UK

MAY

-World Stroke Congress
Melbourne, Australia
worldstroke.org

JUNE

Men's Health Month
menshealthmonth.org

National Fireworks Safety Month
fireworksafety.org

National Safety Month
nsc.org/Pages/JuneNationalSafetyMonth.aspx

Vision Research Month
preventblindness.org

JUNE

National Cancer Survivors Day
ncsdf.org

Silicon Valley Tour de Cure
Palo Alto, California
diabetes.org

JUNE

National Men's Health Week
menshealthmonth.org/week

McKeever's First Ride
Versailles, Kentucky
opalonline.org

JUNE

First Swim
Emmitsburg, Maryland
opalonline.org

JUNE

Wheelchair Tennis Clinic
Rock Hill, South Carolina
opalonline.org

JUNE

National Senior Health & Fitness Day
fitnessday.com
Finding the right prosthetist can be challenging. The Amputee Coalition has worked to develop the most objective tools to help you choose a prosthetist. The mission of the Coalition is to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy and to promote limb loss prevention. In this issue, we focus on how to check credentials and education.

**American Board for Certification in Orthotics, Prosthetics & Pedorthics (ABC) Credentials**

- ABC CTP is a Certified Technician – Prosthetics
- ABC CPA is a Certified Prosthetic Assistant
  
  Both Certificates require a high school degree, at least one year of experience supervised by a CP/CPO (or a CTP can take an approved technical course), an exam and at least 30 hours of continuing educational credits every five years.
- ABC CP/CPO is the most rigorous credentialing, requiring at least a Bachelor’s degree and a prosthetic certificate post-graduate program since 1986, and now (since 2012) requires a Master’s degree. This is followed by at least one year as a resident working under an experienced certified clinician.

**Board of Certification, Prosthetics**

BOCP, prior to 2013, required a total of four years of education and/or experience, including at least an Associate’s degree related to prosthetics or two years’ experience, education and training in the field of prosthetics, or a minimum of two years (3,800 hours) of experience in providing direct patient care services. As of January 1, 2013, BOC also required a CAAHEP-approved education program and an NCOPE residency, same as ABC.

Both ABC and BOCP now require passing three separate rigorous tests (per discipline) to receive your certification, which allows you to bill an insurance company for prosthetic services. To keep your credential active, you must complete at least 75 hours of continuing education credits over a five-year period.

**Licensed Prosthetist, Prosthetist/Orthotist (LP/LPO)**

Licensure is required in only 15 states, while three other states require a certification to practice. To get a prosthetic license from the state health department, you must first be certified. The requirements vary from state to state and there may be instances where a noncertified individual could become licensed if they complete the necessary eligibility requirements for the state. In most cases, you must have at least a Bachelor’s degree and a certification, and then meet additional requirements and continuing educational credits above your certification.

**Fellowship American Academy of Orthotists and Prosthetists (FAAOP)**

To receive an FAAOP, you must significantly contribute to the profession through participating in additional education, writing journal articles or national presentations. It is the highest designation a prosthetist can achieve in our profession.

The Amputee Coalition believes a prosthetist should be selected based on characteristics that best match YOUR needs. Prosthetist Finder gives YOU control over deciding which characteristics are important to YOU. The Prosthetist Finder app allows you to search for a prosthetist based on the characteristics advocated by the Coalition and AAOP. Please spread the word to your prosthetist, and tell all of your peers about prosthetistfinder.org so your prosthetist can add their information, build its effectiveness, and be part of this exciting new app to help people find a prosthetist.

ProsthetistFinder.org
With so much going on in politics this year, it can often be difficult to keep up! Since our last issue, we’ve seen FBI hearings, the introduction and ultimate failure of the American Health Care Act (AHCA), and a focus on tax reform and a continuing resolution to continue funding the federal government.

Will this pace of policy activity slow down, and what does everything that has happened mean for you?

The answer to the first part of that question is probably a resounding “No.” There are still a lot of things the new Congress will be focusing on, and they will be working this summer on trying to pass a budget for the 2018 fiscal year. The government’s fiscal year goes from October 1 to September 30 every year, and appropriations committees will be debating funding levels for every agency and program. One of the biggest issues looking forward for the 2018 budget that could impact the limb loss community is funding levels for programs and resources that support the limb loss community, rehabilitation research that can help to improve outcomes for people with limb loss, and research for advancements in technologies for people with limb loss.

We encourage you to stay alert and be ready to take action on these issues throughout the summer. The Amputee Coalition will have resources available on our Web site to help you educate your elected officials about the impacts of these programs and research initiatives and advocate for continuation of these important programs in 2018 and beyond.

The answer to the second part of the question is a little more complex. While the FBI hearings aren’t likely to directly impact you, taxes and healthcare will. During the buildup (and subsequent failure) of the AHCA, the Amputee Coalition worked to let the community know about what was in the bill. Initially, we were complimentary of the fact that the original bill still included a number of important patient protections from the Affordable Care Act (“Obamacare”) such as protecting people with “pre-existing conditions,” maintained the Essential Health Benefits, and allowed children to remain on their parents’ plans until the age of 26. However, we also highlighted significant concerns that we had with the legislation and its potential impact on the limb loss community. Those concerns included the following:

1) Under the AHCA, insurance subsidies for people on marketplace plans would have been significantly changed and would have been based on age instead of income. This would mean poorer Americans would likely not receive the same level of support needed to afford coverage.

2) There would have been a repeal of the Medicaid expansion from the Affordable Care Act and funding for all state Medicaid programs would have been fundamentally changed from a percentage of each state’s costs to a capped system (and after some negotiations, possibly a block grant system). This would have significantly reduced the number of people who could access the Medicaid program and in significant budget constraints. Those budget constraints would have likely led to reductions in what’s covered, lower payments for providers, and in people dropping coverage.

3) The Congressional Budget Office projected that the AHCA would have reduced the number of people who are insured by 24 million Americans and could have resulted in some employers not offering coverage.

4) The drive toward high-risk pools for people with chronic conditions and/or disabilities in the AHCA would have resulted in significantly higher premiums and out-of-pocket costs for those communities, making access to coverage and care more costly.
In addition to those concerns from the original bill, after negotiations with the Freedom Caucus, the Amputee Coalition quickly alerted the community when Congress modified the bill to eliminate the Essential Health Benefits. This would have been a significant blow to the limb loss community since it has been largely accepted that prosthetic care is included within one of the categories of Essential Health Benefits (specifically, the “Rehabilitative and Habilitative Services and Devices” provision). This would have resulted in moving prosthetic coverage back to a time when a $1,000, $2,500 or $5,000 cap on prosthetic coverage was common before the Affordable Care Act. While there are still plans out there that don’t cover or only partially cover prosthetic care, many of these arbitrary caps were removed by the Essential Health Benefits and have helped make prosthetic coverage more affordable for many people with limb loss.

Ultimately, the bill was never voted on because it lacked enough support to advance. Millions of Americans and thousands of people with limb loss wrote letters highlighting their concerns, and for now, at least, it appears that healthcare reform will be pushed to the backburner and the Affordable Care Act will remain in place.

As quickly as we’ve seen issues rise and fall over the past couple of months, it’s important to remain vigilant of policy issues that are likely to impact you and that you continue to feel empowered to take appropriate action. The Amputee Coalition will continue to monitor important issues impacting people with limb loss and limb difference and will provide opportunities for the community to comment, educate and advocate for meaningful changes. Continue to join our mailing list, stay engaged on social media, and check our Web site often to stay on top of what you can do!

For more information, join us at Facebook.com/AmputeeUSA or visit amputee-coalition.org.
April is Limb Loss Awareness Month. Given the way deadlines work, you will be reading this after the events occur – and we are writing before they begin. In this Doctor Who-insired world, please read on for a prospective retrospective.

What is it?
Amplify Yourself is a new initiative the Amputee Coalition launched to address three things:
1) Impacting legislative issues by educating our legislators
2) Providing methods for people to address their insurance coverage challenges
3) Telling the stories of people with limb loss and limb difference.

Ultimately, we want to ensure that people are more aware of the real-life successes and struggles faced by people living with limb loss, beyond the made-for-TV stories you often hear. Amplifying Yourself, as a theme, reflects the fact that your experience is unique, and that you have a chance to speak up for yourself.

The name “Amplify” comes from the initiative’s focus on the idea of plugging our voices in and turning up the volume. It also means to become more marked or intense. Of course, everyone has a different story, different needs, and a different perspective. By speaking up and speaking out, we can impact the world in a way that lets people make their own decisions about their work lives and their personal lives without having to hesitate because of a lack of support.

Amplifyyourself.org
This site is designed as a single page to give you easy access to our insurance advocacy, legislative advocacy, and Limb Loss Awareness Month activities. We’ve also included a story section, with the intent of showcasing the breadth of the community’s experiences with limb difference and limb loss, so people like you can share their stories in their own words and images.
Limb Loss Awareness Month

Since 2000, April has been designated Limb Loss Awareness Month.

In 2017, we reprised some of the most popular previous activities, as well as adding several new ones.

• Hill Days: April 25 and 26 marked a chance to educate legislators in Washington, D.C. With broad national representation, individuals traveled to deliver their message in person: Access to the best care for their needs matters.

• #ShowYourMettle on April 29 was another way for people to join in the Amplify Yourself initiative. A popular event with a big online presence, you can see the participation by searching for the hashtag #ShowYourMettle on social media. We also shared great photos on Facebook, Instagram and Twitter.

• We submitted gubernatorial proclamation requests in all 50 states, and had people in our community follow up with their governors. This kind of basic activity helps to keep limb difference and limb loss on top of peoples’ minds, helping to build awareness and understanding.

• A newer element was a calendar full of daily activities, from facts to share and ways to raise awareness on social media to advocacy-oriented projects that make a difference to individuals and to the community overall. The variety meant that there was something that nearly anyone could get involved with, learn from, or simply enjoy.

• Amplifying Yourself could also mean ensuring your voice was heard with your insurer. A new tool was launched, allowing people to directly contact executives at their insurer to address claims problems.

• Share Your Story features were also initiated, meaning that people could write about their experiences, whether as someone with limb loss or limb difference, a caregiver, a clinician, or another person impacted by limb loss in another way.

“Hill Days always energize me,” says Dan Ignaszewski, Amputee Coalition's director of government relations and marketing. “Connecting policy decisions with outcomes – really talking about how good law-making can improve lives in so many ways – is the reason we continue this work. Seeing how empowered people are by being able to share their story directly with the legislator who represents them is incredibly meaningful.”

Limb Loss Awareness Month has always woven together the successes and struggles that are part of everyday life. Whether something as formal as a visit to D.C. for legislative advocacy or just coming together in person or online, April adds a little volume to the power we have as we work together. 🤗
2017 AMPUTEE COALITION NATIONAL CONFERENCE PREVIEW

Galt House Hotel
Louisville, KY
August 3-5
The Amputee Coalition will be **IN FULL SWING** from August 3-5 at the Galt House Hotel in Louisville, Kentucky. Join us for three days of camaraderie, education and fun!

**Here's a glimpse at what we have planned:**

- **Amplify Yourself (NEW!):** The Amputee Coalition's new Amplify initiative is designed to make it easy for you to tell your story and advocate for yourself.

- **Yoga Series:** Wake up and stretch each morning with yoga instructor Marcia Danzig.

- **Adaptive Zumba (NEW!):** Learn adaptive moves so you can participate in a Zumba class at home.

- **One Step at a Time Adaptive Fitness (NEW!):** Learn to adapt common exercises so you can complete a fitness routine at home.

- **Pediatric Sessions:** Learn about medical and surgical issues related to growing up with limb loss, parenting a child with limb loss and preventing secondary conditions. Kids can participate in a mobility clinic designed just for them.

- **Living With Your Level of Limb Loss Sessions:** Our popular series returns with sessions for people with below-knee, above-knee, bilateral below-knee and hemipelvectomy/hip disarticulation amputation.

- **Bilateral Above-Knee Mobility Clinic:** Led by prosthetist Kevin Carroll, MS, CP, this interactive clinic provides techniques to help individuals with bilateral above-knee amputations be successful full-time prosthesis users.

- **Upper-Limb Sessions:** Learn upper-limb life hacks, how to identify candidacy for a myoelectric upper-limb terminal device and exercises to improve performance with a myoelectric control system.

- **Sex and Sexuality with Limb Loss:** Disability sexologist Bethany Stevens will lead a panel discussion about body image, sex and sexuality.

- **Walking and Mobility Enhancement Clinic:** Work with renowned physical therapist Bob Gailey, PhD, PT, on exercises and techniques designed to improve prosthetic performance and mobility.

- **Advanced Running Clinic:** Bring your running blade and learn how to sprint with prosthetist Peter Harsch, CP.

- **Gait Analysis Clinic:** Get a one-on-one assessment of your mobility and participate in our new fall-prevention workshop.

You can also get hands-on experience with new technologies in our jam-packed exhibit hall. Plus, all registered attendees are invited to a free dance party to celebrate the close of the meeting!

To register, visit amputee-coalition.org. ☝️
Camp. The word evokes warm summer days, laughing with friends late into the night, and stretching your comfort zone.

In 2016, 147 kids came to the Paddy Rossbach Youth Camp, held in Ohio to do all these things and much more. Born as the Youth Initiative in 2000, the Amputee Coalition now offers a traditional camp experience to kids from 10 to 17 years old living with a limb difference or limb loss. In 2016, we also added a leadership camp segment running concurrently that serves as a transition for 18- and 19-year olds, providing valuable skills that will serve them well in future schooling, community and careers. (And maybe even as camp counselors!)

In 2017, we plan to expand, adding more campers as well as a second, unique year of the leadership program. “Our hope is to offer every person who applies the chance to join us at camp,” says Tonya Osborne-Simpson, director of peer support programs at the Amputee Coalition. “We know our campers always come away with something new, often something life-changing. How? Because they come back, as campers and as counselors.” All 147 campers left their electronics at the door and spent their time getting to know each other, exploring the camp grounds, and participating in organized (and spontaneous) activities. The days were filled with activities like the ropes course, a dip in the pool or a paddle in the lake, and facilitated conversations about topics ranging from how it feels to be the only kid “like me” in school, to how to handle awkward personal questions, to when to tell people about your limb difference.

Evenings at camp were full of activities, too. One night featured a carnival full of games. Another night included a bonfire, and the final night featured dancing, with campers showing off their moves and musical skills.

Our campers are part of what makes the experience so special. They come from all over the United States, each with their own story. They reach out to each other to offer support and insight – and to plan an ice cream raid on the next cabin. They try things they never imagined they would and create and nurture friendships.

Our counselors are special, too. Most of them have a limb difference or a close connection with the community, and all of them are willing to give up some sleep to make someone’s camp experience.

Most importantly, the Amputee Coalition works to create a safe, nurturing environment that allows campers to be themselves.

“All 147 campers left their electronics at the door and spent their time getting to know each other, exploring the camp grounds, and participating in organized (and spontaneous) activities. The days were filled with activities like the ropes course, a dip in the pool or a paddle in the lake, and facilitated conversations about topics ranging from how it feels to be the only kid “like me” in school, to how to handle awkward personal questions, to when to tell people about your limb difference. Evenings at camp were full of activities, too. One night featured a carnival full of games. Another night included a bonfire, and the final night featured dancing, with campers showing off their moves and musical skills. Our campers are part of what makes the experience so special. They come from all over the United States, each with their own story. They reach out to each other to offer support and insight – and to plan an ice cream raid on the next cabin. They try things they never imagined they would and create and nurture friendships. Our counselors are special, too. Most of them have a limb difference or a close connection with the community, and all of them are willing to give up some sleep to make someone’s camp experience. Most importantly, the Amputee Coalition works to create a safe, nurturing environment that allows campers to be themselves.”

“The benefits for my child were deep. She could really be herself for the first time since her illness and amputation. It was life-changing!”

~2016 Parent

Camp Mission

To make a difference in the lives of children with limb loss and limb difference by increasing their self-confidence and self-esteem through a traditional and supportive summer camp experience.
Be an AllPro AllStar.

Join the team on Instagram at @fillauerallproallstars
I would like to nominate Keo Jones as my amputee hero. She has been such a blessing to me.

I had an emergency amputation due to sepsis and severe bone necrosis on November 28, 2015.

I had been out of work for six months due to my leg being so infected. I had never given any thought to how on Earth I was going to walk with one leg.

Keo organized a fundraiser with our local saloon owner and everyone in our little ghost town and raised the entire amount of money needed to obtain a prosthesis in one night!

Keo came to my home on a daily basis and cleaned my incision, which refused to heal. She took me to all my appointments and made sure I was safe on crutches. She stayed with me to teach me how to do daily tasks safely. On top of all this, she also dealt with my husband, who had been diagnosed with metastatic melanoma. She had her work cut out for her, but she was always there, no matter what.

She brought me out of a very dark place with love and patience. Without her, I would not be here today.

I think Keo is a very special hero who deserves to be recognized. She gave me the courage to take my life back and get back to work so that I would be strong enough to be there and help my husband find the courage to fight for his 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 (250 to 350 words) for consideration to be included in inMotion.

Email articles to:
editor@amputee-coalition.org
Realize the facts. O&P care improves quality of life and is cost effective! Learn more at MobilitySaves.org.

The Study that Started MobilitySaves.org

A major study, comparing patients using prosthetics versus patients without prosthetics had these findings:

• They will experience greater independence.
• They can increase their physical therapy and become less bed-bound.
• They will have fewer emergency room admissions and acute care hospital admissions.
• They will have lower or comparable Medicare costs than patients who need, but do not receive, these services.

Share this significant news by using the educational tools provided at MobilitySaves.org. Mobility Saves Lives And Money!

The Results

Lower Limb Prosthetics

Prosthetic patients experienced better quality of life and increased independence compared to patients who did not receive the prosthesis at essentially no additional cost to Medicare (or other payers).

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Visit MobilitySaves.org.

Follow us on social media!

“Search Mobility Saves” on Facebook, Twitter, and LinkedIn
Your DONATION = a youth camp like no other

You are the key to making sure every child who applies can attend the Paddy Rossbach Youth Camp this summer. More than 140 youths with limb loss and limb difference, age 10 to 17, gather for everything from learning about life to campfire s’mores. And what they say is inspiring.

I knew that this would be one of the best weeks of that year. Camp completely changed my life; it also taught me that it is ok to be different.

~2016 Camper

You can help other kids have that same, life-changing experience.

Your donation makes a difference.
amputee-coalition.org/donate-online | 888.267.5669 ext. 7105
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Linx - fully integrated microprocessor controlled limb system, bi-directional communication coordinates the response to variations in terrain and speed, adjusting for the situational needs of the user.

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“I no longer have to think about changing my route or avoiding something, because I am more confident on uneven and varied terrain.” Becky
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* Data on file at Össur
An EQUAL Footing

by Tony Phillips
Two years ago, Andrew Montgomery nearly achieved one of his life’s goals. He had auditioned for a part in *Le Rêve – The Dream*, the long-running Cirque-styled masterwork that has been voted “Best Production Show” in Las Vegas six years in a row. For Montgomery, a lifelong performer, a spot in the show was truly a dream.

“I’ve been a dancer practically all my life,” he says, leaving out the fact that he is also a gymnast, an acrobat, a parkour athlete, a stilt walker, an aerialist and an all-around specimen of physical excellence. At the age of 28 he had performed with Universal, Disney and a host of other productions and in 2015 was in the middle of filming his first movie. Following his audition for *Le Rêve – The Dream*, he was expecting a call from the show’s casting director when he was involved in a horrific motorcycle accident that left him hospitalized with a catastrophic injury to his left foot.

“They tried to salvage the foot. I had surgeries and procedures and after two weeks I was told I could try to save it, but it would be permanently fused and have very limited function. Or I could take Option B, which was amputation.”

Like everyone who has faced the decision to sacrifice a limb, Montgomery was terrified by the prospect of life after amputation. But having built his life on physical achievement, having pushed the edge for nearly three decades, breaking barriers and performing feats that marveled audiences, the choice was dire, on one hand, but obvious, on the other.

“I had seen what people were doing with modern prosthetics and the prospect of being limited by a foot I couldn’t use, versus learning to use a new foot, no matter how difficult – in the end, amputation was the only choice for me,” Montgomery says.

Having made the choice to lose his left foot above the ankle, Montgomery faced five days in the hospital, time that an ordinary person might use to grieve, or fret, or just withdraw into awareness of impending loss and life interrupted. But Andrew Montgomery is not an ordinary person.

“My five days were to document my experience. There were plenty of videos and testimonials showcasing what a below-knee amputee can do, but I couldn’t find anything showing what to expect. I wanted to share the process. I wanted others who go through similar experiences to know the real gritty details of amputation – what recovery from surgery was like, what it takes to adjust to wearing a prosthesis and learning to use it, everything that goes into the
I wanted to share the process. I wanted others who go through similar experiences to know the real gritty details of amputation – what recovery from surgery was like, what it takes to adjust to wearing a prosthesis and learning to use it, everything that goes into the adjustment – all the hard parts of overcoming limb loss.

Andrew’s documentary journey begins in a hospital bed, just before his amputation on May 5, 2015, and it follows him for a year, culminating in his return to elite athletic performance. His story is available in multiple installments on his YouTube channel. The final video in the series, uploaded one year to the day from his amputation, features him performing backflips, handsprings and compound tumbling passes that are unthinkable to most two-footed humans.

Showcasing his experience was personally important to Montgomery, who says part of the journey of recovery was proving what is possible, not only to others, but to himself.

“A foot is a long way from the heart,” he says, adding that the will is stronger than any body part. “Technology helps, but inside every prosthesis is an amputee making it work.”

In Montgomery’s case, making the prosthesis work exceeds just learning to perform normal daily activities on an artificial foot. In fact, that part of his adjustment was something that came remarkably easily to Montgomery, who says he feels as if he had prepared for years to undertake the challenge of limb loss.

“I’ve been a stilt-walker for 10 years,” he says. “That’s a decade of practice walking on feet that aren’t my own. That skill definitely translated to my adjustment and I think it prepared me to push the limits of my new foot.”

Since learning to walk, the limits of Montgomery’s new foot have been tested and surpassed. “I wear a foot that’s rated about four or five grades higher than my weight. At lower ratings I kept breaking them.”

Montgomery walks around at 175 pounds and some quick calculations reveal facts of physics that are fairly astounding to the mathematically inclined. Take one of the simpler maneuvers he performs routinely, a standing backflip: In order to get enough height to perform a flip, Montgomery has to achieve at least 24 inches of vertical lift and he has to do that on one leg. The stored energy in a prosthetic foot is gravity-dependent. In his case, with an overly stiff foot to absorb impact, he generates virtually no lift on the prosthetic side. After lift-off and following a full body rotation at his center of mass, he then has to land the flip, which entails bearing an impact equivalent to roughly three-and-a-half times his body weight, thus sticking a move with 600 pounds of landing force, displaced across one anatomical foot and a prosthetic blade, some 2,600 Newtons of force or about 15 pounds-per-square-inch of impact.

All of that is hidden from view to spectators who are rightly in awe of Montgomery’s performance. One such spectator is the casting director at Le Rêve – The Dream who, as it turns out, intended to offer Montgomery a spot with the show prior to his accident.
“When she learned of the accident, she called me,” Montgomery recalls, “and she was totally supportive. She told me, ‘If you can ever do for us what you did in your first audition, you still have a spot with this show.’”

Montgomery welcomes a challenge and in a follow-up audition, he did indeed duplicate everything he had showcased on two feet the prior year. In July 2016, 14 months post-surgery, he joined the show as a performing cast member. In a show featuring a cast of nearly 200, including nearly 100 dance and acrobatic performers, Montgomery proudly names his title of “generalist.” In his role, he performs as one of an indistinguishable troupe of men with shaved heads and matched costumes, all designed to obscure their individuality.

“We don’t want any one performer to stand out,” he says. “The show is about the group and the overall act, not any featured artist. So we do everything we can to blend together as a single performing unit.”

“I don’t mind being identified as a performer with one foot, but who I am is not my missing foot. My identity is independent from my difference. I want to be judged as a performer, not an amputee performer.”

Judged by any standard, Montgomery is at the top of his trade. But there is still more on his horizon. “I’m not content to look at what I can do; I’m still thinking about what I could do, and I want to get all that back. It means learning to do some things backward – taking off on my right foot rather than my left, for instance. But I know that, as an acrobat and gymnast, I’m barely scraping the surface of where I want to be. I know where I still want to get, whether or not anyone else can envision it.”

Going beyond what others can envision: “That’s the real motivation,” Montgomery explains. “There are things you can prove to other people, but it’s what you prove to yourself that really matters.”

To watch Montgomery’s journey from injury to recovery, you can visit his YouTube channel, simply titled Andrew Montgomery, and to track his ongoing achievements, follow him on Facebook at facebook.com/shatteredbutnotbroken2015 or Instagram at @aaijai.

That means, among other things, having to know and perform every part as a performing cast member. “We don’t know what particular bits we’re doing until we show up in the morning and see where we’re slotted for that night’s show,” says Montgomery. “That’s what it is to be a generalist.”

Being a generalist also means there is no special place for Montgomery as a “disabled” performer. He wears a flesh-colored cover over his socket and it is entirely possible to appreciate the show without knowing it included a performer with a prosthetic foot. Montgomery is one of dozens, no different from his counterparts, and that is a source of pride.

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Sean Donnelly has faced more challenges in his 31 years than most people encounter in a lifetime. Born without a right leg, raised by a single mother struggling with alcohol abuse, forced to confront depression and find acceptance as a gay individual, Donnelly tackled multiple issues early on. And while his disability never stopped him from partaking in an active physical regimen that included swimming, skiing and an active personal and professional life, it was his battle with his insurance company to get the prosthesis he needed that proved to be the greatest obstacle of all.

Donnelly’s story affirms a certain paradox that lies at the heart of America’s healthcare system. Before he turned 18, his medical needs were covered by Medicaid, which paid for his prosthetics and ensured he got the leg that was best suited to his rigorous lifestyle. Yet once he started working, his Medicaid benefits stopped and he was forced to purchase private insurance through his company, and then fight the insurance company as a means of forcing them to buy him the prosthesis he needed.

Therein lies the irony. “To qualify for Medicare, I would have had to quit my job and stay on disability,” he explains. “I want to work and have a career like everyone else. I consider myself a high-functioning person with a disability, an active member of society. So why should that prevent me from getting the leg I need?”

The problem Donnelly faced is not uncommon. His prosthesis was equipped with a microprocessor knee unit known as a C-Leg. Unfortunately, due to his active lifestyle, it was simply inadequate. As a well-paid training executive for Kronos, a Massachusetts-based workforce management software company, his job demands constant travel. Likewise, he enjoys...
I consider myself a high-functioning person with a disability, an active member of society. So why should that prevent me from getting the leg I need?

athletics, working out at the gym and spending quality time on the dance floor with friends.

It quickly became clear that Donnelly needed a knee that was better suited to his physical regimen, ideally an X3 unit, or at least a Genium knee, either of which was better suited to his needs. He was burning through his C-Leg every couple of years, in half its usual lifespan. It was also taking a toll on his health. Because the knee didn’t support his weight properly, his body was compensating for the deficit. His pronounced gait led to scoliosis, stiff muscles and back problems. By his own admission, he was falling 20 times a day.

“It was causing incredible harm,” Donnelly insists. “I was walking on a leg that wasn’t working. It was clear I needed a better knee to maintain my health.”

Unfortunately, his insurance company balked. They refused his request, not only for the X3 unit, which, priced up to $120,000, cost twice as much as his C-Leg, but also for a Genium, that came with a cost of roughly $90,000. Ironically, at the rate he was going through his current knee, the expense would have grown regardless, while the coverage for his health issues would have added up as well.

“When I had Medicaid, everything was covered and I never had to think about the price,” Donnelly muses. “There was never an issue. I never had to pay a dime. But once I had the need for a more expensive prosthesis, it seemed the insurance company was only concerned with their bottom line.”

Forced to refute the insurance company’s claims that the new prosthesis was unnecessary, Donnelly consulted with his primary physician, his podiatrist, his physical therapist, and his prosthetic team, all of whom went to work to prove to the insurance company that the knee was, in fact, needed. With additional support from the Amputee Coalition, his company’s human resources department, his family and friends – as well as the threat of legal action – he went to the final stages of the appeals process, and finally, after an entire year of negotiating, the insurance company conceded and agreed to cover a Genium knee. It’s made quite the difference he says, allowing him to travel, participate in sports and, for the first time, climb stairs, a feat he was never able to accomplish before.

Donnelly is hopeful that his case will set a precedent and allow others with similar needs to convince their insurance companies to comply. Admittedly, though, the struggle wasn’t easy, physically or psychologically. “I was born this way, so I never thought of myself as disabled,” he argues. “So when this came about, I had to summon strength through a higher power. I believe everything happens for a reason. I simply couldn’t accept defeat.”
In 1977, at the age of 20, I entered the caregiving profession by becoming a certified nurse’s aide. Little did I know how much of an influence that would have on my future.

After I got married, I opted to stay at home for my stepson. During those years, I used my professional caregiving skills to help my family. I took care of my husband after our motorcycle accident. I took care of my aging grandmother. I took care of my stepmother during her cancer treatments. And I was my father’s caregiver after he was diagnosed with congestive heart failure and then lung cancer during the last year of his life.

During that last year, I was also learning how to be a patient myself, and how to let my husband be a caregiver to me. In April 2002, I was hit by an 18-year-old driver who was chatting on her cell phone. That accident changed my life forever and then lung cancer during the last year of his life.

Sitting on the sidelines watching someone cook, clean and care for me wasn’t easy. Being the patient wasn’t too hard while I was in the hospital, but it was difficult at home. As a trained caregiver, I knew how to take care of someone, but being cared for was another story. It’s hard, especially when you’ve been the caregiver, to let someone else do things for you. I knew what needed to be done, but my body wouldn’t allow me to do it.

Using a walker, cane, wheelchair, crutches or other medical devices wasn’t a problem for me. Being patient with someone who didn’t know was another story. It takes patience to remember that others might be unfamiliar with them, and to explain it to them. Knowing how important wound cleaning is, it was hard to keep my cool if someone inadvertently touched something, knowing they would have to start all over again. In moments like this, it helps to remember that the person loves you and is only trying to help. It’s also important to remember to give them the time they need for their daily routine in addition to helping you. One of the hardest things for me was learning to take Jon’s word about my father’s health. He was the caregiver to two people, in two separate houses, and it was hard for me to trust that he was
observing and taking care of all of his needs, which I couldn’t do. I tried not to bug him, but I’m sure I probably did.

Dealing with pain, frustration, learning how to don a prosthesis, and how to walk again, can all lead to short tempers. Some days, Jon and I had our share. For me, it was triggered by watching him do the things I used to do. For Jon, it was dealing with me not wanting to be taken care of.

I asked Jon if I was being a burden, and what was the hardest part of taking care of me. He said his frustration came from the fact that he was only trying to help, but when it came to things like wound cleaning, I always tried to do it myself. He felt like he wasn’t doing anything, when, in my eyes, I was only trying to keep him from doing so much.

I spent some time thinking about that. I had gone from being a wife, stepmother, daughter and caregiver to simply being a patient. I came up with a few rules for myself:

- Be patient with yourself.
- Be patient to the caregiver.
- Be kind if your caregiver does something incorrectly.
- Make gentle suggestions instead of criticizing.
- Remember that caregiving may be new to them.
- Don’t forget to laugh with them.

From then on, I tried hard to avoid criticizing how things were done. I didn’t take too much on myself if I wasn’t sure I could finish it. Keeping my dressing sterile was my main priority. If dishes sat in the sink for a while after dinner while Jon did something else, I learned to let it go. If our bed wasn’t made right away, I knew it would get made at some point. After all, Jon was patient enough with me when it took me 20 minutes to walk 500 feet to my father’s house. I could choose to be patient about the disruption of my normal routines. I could choose to focus on the things that I could do, such as taking care of paying bills, calling our insurance provider, or scheduling the dozens of appointments that were necessary for my recovery.

It's human nature to want to resume our normal routines as soon as possible. For me, as a caregiver prior to my accident, this feeling was escalated by my desire to help my father’s failing health. Everyone has their own circumstances, but finding patience, kindness and humor makes it easier to be the receiver of care instead of the caregiver. It’s important to remember that life will resume; it’s just a matter of taking the time to allow ourselves to properly heal. Sometimes, letting someone help us with our needs helps them as well, especially if it is a loved one.
Ali McWeeny loved sports growing up. By the time she reached high school in Tacoma, Washington, she was into volleyball, soccer and basketball, became a soccer league MVP at one point, and had decided to try track and field.

Growing up had more than its share of challenges. Team sports were a distraction, with their boon of accomplishments and supportive coaches, but when she tried weight training at age 15, something clicked. “I really enjoyed the effort and the focus and felt empowered. Inspired. I excelled fairly quickly,” she explains. Her PE teacher, Steve Slavens, saw her potential and became her coach and mentor. Only 5’6” and 125 pounds, she excelled in powerlifting competitions in her weight class in 2005, skillfully lifting a loaded barbell while lying down (bench press), from a knees-bent position (squat), and completing a competitive deadlift while standing.

Her rise continued at Central Washington University (CWU). Her coach was Slavens’ friend, Kevin Stewart; by 2009, Ali had set 40 state powerlifting records, 26 of which remain unbroken, and she had become a Washington State USA Powerlifting Athlete of the Year.

On July 4, 2009, while wakeboarding on the Columbia River, the boat Ali was in capsized, and her legs were drawn into the propellers. Remaining conscious, her athletic training helped her do “what I could to stay calm.” When a boat with two passengers came to the rescue, she helped them fashion tourniquets from towels for her legs and told them she needed an airlift to the distant hospital, knowing “if I made it, I might lose my leg.”

She did. In two surgeries at Harborview Hospital in Seattle, her left leg was amputated above the knee, but her right, its hamstring sliced by the propeller multiple times, took longer to heal – a matter of impatience to Ali, who was already thinking about athletics. Doctors said she would never powerlift again but should be able to walk in a year. But Ali had other ideas. While she was hospitalized, coach Stewart “would sneak dumbbells in under his armpits” and help her with rehab.

“As soon as my limb was viable, I got fitted for a prosthesis,” Ali says. Helped by Drs. Douglas Smith (her surgeon) and Janna Friedly, prosthetist Dave Hughes and her coaches, she was walking after three months. Six months out, she attended a powerlift meet and completed a bench press. Ali added the other two lifts (balanced on one leg), and a year out completed all three. “I think my perseverance through adolescent challenges of emotional and physical abuse prepared me for the emotional and physical challenges of limb loss,” she says, adding that her high school and college coaches “played a big role.”

And then there was Noah.
Ali met Noah Greenwald in 2010 but their busy lives took them in different directions for a time. Ali had powerlifting meets, teaching and her studies at CWU. Noah, a wildland firefighter and part of a “hotshot” crew, could deploy overnight to fire zones for weeks or months at a time. Hotshots go through extreme mental and physical training so crews can respond to remote fires with limited logistical support.

However, when Noah and Ali began dating in 2013, perhaps because each had experienced life-threatening challenges, they discovered a shared affinity for simplicity. They both value “respect and appreciation for nature, connecting with ourselves, with each other, and with others.” “We feel that simple living allows us to direct attention and love to what matters most,” Ali explains. They married July 4, 2013.

To those surprised by that particular date, Ali says, “It’s not a bad date. It’s a blessing. It changed my life for the better and put life in perspective. I’m grateful to be here, and it reminds me of [the life troubles] that came before and what I’m grateful for right now.” That includes their son, Dakota, born November 23 last year.

Ali, her MS degree done, is balancing new motherhood with powerlifting, part-time teaching at CWU, high-school coaching and track and field training. Noah, retired from firefighting, combines fatherhood with building and remodeling contracting work; he does fine woodworking and designed and crafted a baby bassinet and a changing table that can be easily rolled from room to room. They share a love of the arts, including music, painting and pottery.

Asked what advice she might have for a new parent with limb loss, Ali stresses the importance of setting priorities and maintaining focus. She suggests approaching parenthood by learning about pregnancy, birth and postpartum issues: “Learn how to support your own health and well-being so that you can commit the rest of your time to your child and your family. Live in the present moment. Do not dwell or stress on the past. Learn from your experiences and adapt.” Finally, she adds, “Let your ego go and reach out for help.”
Feet Jensen joined the United States Army in January 2005 to serve as a medic. Nearly four years later, on November 9, 2008, he was in the field with two fellow soldiers when one opened a refrigerator, detonating two 100-pound bombs. The massive blast detached Jensen's forearm bone, leaving it sticking out of his left arm. Jensen graphically recalls “my right leg was upside down, and my left leg was blown out at the knee, leaving it up by my head.”

Sustaining consciousness, using just one arm, he tied two tourniquets on a fellow soldier who was badly wounded and gave him two units of morphine. Jensen rolled onto his stomach, crawling 50 feet, still with one arm, to apply two tourniquets to a second soldier, giving him his final dose of morphine. Jensen then pushed himself up against a pillar, tied two tourniquets on himself and waited 15 minutes to be rescued. All three men lived.

After 107 surgeries, and an extended physical rehabilitation stay at Walter Reed National Military Medical Center, Jensen was medically discharged from military duty: “I knew the physical part of me would work itself out, but the mental, the spiritual, the metaphysical part of me needed to develop and work through some things.” He credits his wife of 13 years, Bethany, and his nine-year-old son with fostering his positive motivation. He feels a need to set an example for his son and stay positive for his best friend, his wife. Jensen says proudly, “I don’t spend a lot of time at the doctor; I don’t take any medications in any form.” He lives with his family in West Point, Utah, and uses the George E. Wahlen VA Medical Center in Salt Lake City for his prostheses and wheelchair. He spends very little time at the hospital now; he’d rather create meaningful moments with his wife and son.

An ultra-lightweight wheelchair is Jensen’s primary means of mobility. He has had challenges with his left above-knee prosthetic socket fit. Jensen is lacking a “good foundation to stand on” because he is missing both feet. But he has slowly been increasing his prosthesis use, thanks to Dave Draper, CPO, who Jensen describes as “a ‘baller’ prosthetist.” Draper’s innovative and individualized design includes a brimless socket, vacuum suspension and a low-profile foot. This prosthesis keeps his center of gravity low and has a much less invasive socket. As the orthotic and prosthetic lab chief, Draper says, “It is crucial for the patient to have input into the prescription and prosthetic design process.” Using information from what was not successful in the past for Jensen, along with knowing what else can be done, led to the current set up. Draper recalls first meeting Jensen seven months ago in the physical medicine and rehabilitation clinic at the Salt Lake City VA, “Feet had the goal to snowboard, so I made that my goal for him as well.”

by Leif Nelson, DPT, ATP, CSCS

Jensen at the ice hockey venue at NDVWSC.
Jensen and Draper got to work together March 26 through March 31 at the National Disabled Veterans Winter Sports Clinic (NDVWSC) in Snowmass, Colorado. Along with a team of clinical specialists, Draper used a combination of low-tech assistive technologies and high-tech prosthetic components to give Jensen the best chance to succeed. Then, partnering with the snowboard instructors, they were all together carving down the mountain.

In his uniquely charismatic selfless nature, Jensen says with passion that his physical accomplishments at the NDVWSC were secondary to the inspiration he gained from fellow veterans.

“My absolute favorite thing about being here is seeing all the people that were not blown up or hurt in the military still have people care about them. Here at the winter sports clinic, people get to be who they are, and it’s absolutely amazing to see them be so independent. It’s moving to see all the joy and excitement; you can tell by people’s faces that it’s not a normal thing in their life – it’s just not. They aren’t able to find the happiness in their normal day-to-day, but they come here and experience joy and radical self-reliance.”

Jensen’s next objective, not surprisingly, targets his own spiritual health. “I am a vegan; I’ve been working with my wife really, really hard to get on that path.” With plans to be 100 percent vegan in under a year, a man who has always put others’ lives ahead of his own says, with passion, “Nothing should have to die all the way for me to exist.” Feet Jensen is a baller, period.
Healthcare Reform: Where Do We Stand?

by Jeff Cain, MD, and Karen Henry

The Amputee Coalition is committed to making sure that people with limb loss and limb difference have access to affordable, high-quality healthcare and prosthetic care. With this in mind, there are three things we are watching closely as President Donald Trump and the Republican leadership move forward with their agenda for healthcare reform in the United States.

1. Affordable Care Act/Obamacare

The Republican charge to repeal and replace the Patient Protection and Affordable Care Act/Obamacare (ACA) began with H.R. 1628, The American Health Care Act of 2017 (AHCA).

While the ultimate path for passage of the AHCA for Republicans is uncertain at the time of this writing, their push to repeal and replace the ACA will continue and will include both legislative and regulatory efforts.

There are several key provisions in the ACA that are beneficial for people with limb loss that the Amputee Coalition will fight to retain:

- **Essential benefits.** There are 10 categories of services that insurance plans must cover under the ACA, including rehabilitative and habilitative services. This means that people facing amputation must have access to medical care and prosthetic care according to the rules of their state.

- **Pre-existing conditions.** Amputation is considered a pre-existing condition. Prior to the passage of the ACA, insurance companies were able to charge higher rates for non-insured people with pre-existing conditions. The ACA made this practice illegal. President Trump has expressed support for continuing the popular consumer protections for pre-existing conditions.

- **Lifetime caps.** Under the ACA, lifetime caps on essential health benefits are prohibited in any health plan or insurance policy.

- **Medicaid expansion.** The ACA expanded eligibility levels so that more low-income individuals would be insured under the Medicaid program. Many people who were newly insured under the ACA had Medicaid.

There are a few things under the hood that warrant further explanation:

In its current form, the AHCA calls for insurance incentives to be removed and replaced with tax credits. Should this happen, the Amputee Coalition will advocate for tax credits that are sufficient to allow people to afford healthcare.

Republicans are looking at reforming Medicaid so that it is paid for with block grants. This means that the federal government would turn over control of Medicaid to states and provide them a lump sum each year to manage the program. Should this happen, the Amputee Coalition will advocate to ensure that the grants are sufficient for people with Medicaid to afford healthcare and for states to continue to be able to enroll those who cannot afford healthcare insurance in Medicaid.

2. Federal Regulations

On January 30, President Trump signed an executive order aimed at reducing the regulatory burden of the federal government and simplifying regulations so that they do not get in the way of innovation and affordable healthcare. The executive order put a 60-day moratorium on any new regulations that were in process and mandated that for every new federal regulation implemented, two must be rescinded. The moratorium expired on March 30.

There are several regulations in play that could impact people with limb loss or limb difference who receive prosthetic care that may be affected by the President’s regulatory plans, including:
Local Coverage Determination for Lower-Limb Prostheses

Local Coverage Determination (LCD) would change the coding, coverage and payment for lower-limb prostheses for Medicare beneficiaries, limiting access to modern prosthetic technology and the current standard of prosthetic care. Because insurance companies generally adopt Medicare rules, this LCD could have wide-ranging impact.

With your help, the Amputee Coalition fought against and delayed implementation of the LCD in 2015 and 2016. As Medicare re-evaluates these rules, the Amputee Coalition and stakeholders in the prosthetics professional community are continuing to provide education and feedback to Medicare to advocate for amputees and the professionals who provide prosthetic care.

Benefits Improvement and Protection Act Section 427

The Benefits Improvement and Protection Act Section 427 (BIPA 427) would regulate and limit the people who provide prosthetic and custom orthotic care to those who are appropriately trained, certified and, where applicable, licensed in their state. This is important for amputees because it ensures that the people who provide prosthetic care are qualified to do so.

The Amputee Coalition has provided comments to the federal government in support of the prosthetic provisions in BIPA 427. What is uncertain at this point is whether President Trump’s administration will view this regulation as overly intrusive or as a regulation that supports improvements in care.

3. State Regulations

Between 2000 and 2008, the Amputee Coalition worked with amputees and other stakeholders to pass insurance fairness laws in 20 states. These laws require insurance companies to cover prosthetic devices to the same extent that they cover other medical and surgical benefits in their policies.

The Amputee Coalition has renewed its push to pass insurance fairness laws in the remaining 30 states.

Does your state require insurance companies to pay for prostheses?

The Amputee Coalition has model laws and other tools to help you write and pass insurance fairness laws in your state. To learn more, call us at 888/267-5669 or contact us through our Web site at amputee-coalition.org.

Your Voice Is Important

With so much uncertainty in today’s political healthcare landscape, it is critical that your voice be heard at the state and national levels. Your stories and messages can change laws and change lives. Let’s work together so everyone who has had, or is facing, amputation has access to the care, services and devices that will help them live full and active lives.
Your Prosthetic Services Are in Jeopardy

by Jason Kahle, MSMS, CPO, FAAOP

The problem
In the March/April 2017 issue of *inMotion*, we discussed the 2011 “Dear Doctors Letter.” The letter outlines the documentation requirements that must be documented by your physician (not your prosthetist) for you to get the prosthetic services you require. It is the treating physician’s records, not the prosthetist’s, that are used to justify getting you what you need. The physician who writes the prescription must demonstrate that the prosthesis is needed. However, physicians are not prosthetists and do not always understand the nuances of why a socket or components of that socket might be beneficial. It is the prosthetist’s responsibility to understand these differences – but not according to Medicare, who wants to hear it from the physician. Physicians are as frustrated as the prosthetists, and you are caught in the middle.

*We (the patient and prosthetist) have to tell them (the physician) what to say and why to say it – they just have to say it.*

How can I help take an active role to get what you need?
The most effective way to obtain proper documentation from the physician is directly telling them what you need and why you need it, so they can write it in your medical records. The strongest clinical treatment pathway is one that integrates the physician’s (and prosthetist’s) assessment, expertise and treatment recommendation, supported by independent evidence, all guided by your needs and values. This is known as patient-centric evidence-based medicine (EBM) (Figure 1. Treatment Pathway)

1. You Have a Socket Problem or Concern
   - Call your prosthetist for an appointment

2. Define the Socket Problem
   - Define the Problem for Your Physician.
     - Physiological: Weight gain/loss, atrophy/hypertrophy
     - Functional: Walking worse, limited activities, desire to do other activities
     - Residual limb: Pain, abrasions, blisters
     - Socket-related: Wear and tear, damage, replacement of soft goods
   - Call your physician for an appointment

3. Define the Problem for Your Physician.
   - Tell them what you think the answer is, based on your conversation with your prosthetist.
   - Tell them the evidence and mechanistic logic you discussed with your prosthetist.
   - Discuss how this fully answers your concerns.
   - Make sure the physician agrees with the prosthetic recommendation.
   - Make sure your physician documents it and provides the proper documentation to your prosthetist.
   - Show your physician the problem: Point to the area on the socket while wearing it; show any gait deviations due to a poor socket.
   - Take off your prosthesis and show them your residual limb.
   - Call your prosthetist for an appointment

4. Proceed with the socket solution

Figure 1. Treatment Pathway
What needs to be documented for sockets?

In the previous article, we outlined the general documentation requirements, such as a patient’s physical and cognitive capabilities, history, past medical history and functional abilities and deficits. In this article, we will focus on documentation specifically required for a socket replacement. The physicians should tailor their history and examination to the individual patient’s condition; this history should paint a picture of your functional abilities and limitations on a typical day. It should contain as much objective data as possible. However, the way a socket fits can be somewhat subjective, so it’s important to express what you are feeling and how that impacts you during your daily activities.

Functional levels

To consider a socket medically necessary for performing normal daily activities, the following criteria must be met:

• You must tell your doctor you are motivated to ambulate. *If you don’t want to walk, why should your insurance pay for it?*

• You must reach or maintain a defined functional state within a reasonable period of time. *If you sit on the couch all day and never walk, or want to use a power wheelchair, why should your insurance pay for a socket?*

• You must understand how to use a prosthesis. *If you don’t understand how to use a prosthesis, then your insurance will not pay for it.*

A determination of the medical necessity for certain aspects of the prosthesis is based on the beneficiary’s potential functional abilities. Potential functional ability is based on the reasonable expectations of the prosthetist, and physician, considering factors such as:

• Your past history. *Have you used a prosthesis before? If not, did you walk before your amputation? How active were you before you started having these socket problems?*

• Your current condition (specifically, the status of your residual limb and how your socket is affecting other aspects of your activities). *For instance, “My socket is too big, so I am getting pressure at the bottom, and the pain is preventing me from walking.” Tell the story about how this affects you.*

• Your desire to walk. *Tell your physician how much you walk and how important it is to you.*

You need to tell your physician your current functional capabilities and what you would functionally like to do. Your physician’s clinical assessment of you must be based on the Medicare Functional Classification Levels (K Levels); however, this is not as emphasized when considering just the socket. We will go more in depth in the next two articles, which will specifically focus on the foot and knee.
Medical necessity

Socket replacements meet the definition of medical necessity if there is adequate documentation of functional or physiological need, including:

- Changes in your residual limb
- Changes in your weight
- Changes in functional level
- Changes in functional need
- Irreparable damage or change to the socket
- Wear and tear to the point that the condition requires repairs or replacement; this is usually due to excessive patient weight or demands of active amputees.

Prescription requirement

All items billed to Medicare require a prescription, kept on file by the prosthetist. Make sure you ask your doctor for a copy and insist that the physician provide your prosthetist with your prescription. This is the minimum piece of documentation your prosthetist will need to begin the process of getting you what you need.

Detailed Written Orders

A more detailed prescription, also known as a detailed written order, or letter of medical necessity, is required before billing. The ordering physician must review the content and sign and date the document, including:

- Your name
- The physician’s name
- Date of the order and the start date
- Physician signature and signature date.

Your prosthetist will also require this detailed written order before delivering the socket and submitting the claim (Table 1. Physician Socket Checklist).

Repair and replacement

Socket adjustment/repair is covered under the original order for the prosthesis. However, claims involving the replacement of a whole socket, or an expensive aspect (e.g., custom liner, flexible interface) must be supported by a new physician’s prescription and documentation supporting the reason for the replacement. Make sure to tell your physician if you use lotions or soft goods like gel liners, suspension sleeves and socks, which need to be replaced periodically. If the physician includes this in the original order, you may not need to go back to your physician to get these items related to your socket. However, always ask your prosthetist if they need a prescription.

Takeaway for sockets

The best way to get the prosthesis you need is to first work with your prosthetist to clearly define the problem, discuss your problems specific to your prosthesis and then work together to articulate that problem and solution to the physician. You have to see your physician to ensure you have the proper medical documentation to get what you need from your prosthetist. It is important to use a physician who is accessible and takes the time to understand you and your overall health problems and profile. Plan on seeing your physician specifically regarding your prosthetic needs at least once a year. This regular visit will allow you an opportunity for them to document your ongoing needs.

Special socket considerations

Some people have conditions, past experience or a higher demand that require socket components such as vacuum-assisted suspension, custom liners, dual suspensions, multiple sockets or other typically non-reimbursable aspects. In these situations, it is vitally important that you discuss and understand these special needs with your prosthetist so you can jointly express the need to the prescribing physician.
**Physician Socket Checklist**

Take this checklist with you to your physician and address each item, making sure your physician has time to transcribe these points into your patient record.

<table>
<thead>
<tr>
<th>Start with telling your physician you have a socket problem and you want to discuss a replacement socket for your prosthesis.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>To consider a socket medically necessary for performing normal daily activities, the following criteria must be met:</strong></td>
</tr>
<tr>
<td>You must tell your doctor you are motivated to ambulate.</td>
</tr>
<tr>
<td>You must understand how to use a prosthesis.</td>
</tr>
<tr>
<td><strong>Tell the story of your activities of daily living, including:</strong></td>
</tr>
<tr>
<td>Your past history of using your prosthesis; how many months/years have you been using a prosthesis?</td>
</tr>
<tr>
<td>How many hours a day?</td>
</tr>
<tr>
<td>How active were you before you started having these socket problems?</td>
</tr>
<tr>
<td>Your current condition (specifically, the status of your residual limb and how your socket is affecting other aspects of your activities). Tell the story about how this affects you.</td>
</tr>
<tr>
<td>Your desire to walk. Tell your physician how much you walk and how important it is to you.</td>
</tr>
<tr>
<td>You need to tell your physician your current functional capabilities and what you would functionally like to do.</td>
</tr>
<tr>
<td>If you had an ideal fitting socket, what would/could you do? What would you like to do?</td>
</tr>
<tr>
<td><strong>Define the socket problem/medical necessity – you need to provide your perspective of functional and physiological change.</strong></td>
</tr>
<tr>
<td>Are there changes in your residual limb? Atrophy/Hypertrophy? Pain, blisters, abrasions?</td>
</tr>
<tr>
<td>Are there changes in your weight?</td>
</tr>
<tr>
<td>Changes in functional level or functional need? Discuss if you are walking worse or in pain.</td>
</tr>
<tr>
<td>Is there irreparable damage or change to the socket?</td>
</tr>
<tr>
<td>Is there wear and tear to the point that the condition requires repair or replacement?</td>
</tr>
<tr>
<td>Do you need soft goods (e.g., socks, liners, lotions)?</td>
</tr>
<tr>
<td><strong>Special socket considerations</strong></td>
</tr>
<tr>
<td>• Do you have a unique residual limb?</td>
</tr>
<tr>
<td>• Have you tried different sockets before and they did/did not work well?</td>
</tr>
<tr>
<td>• Do you perspire excessively?</td>
</tr>
<tr>
<td>• Are you prone to skin irritations, allergic reactions, blisters, ulcers and skin breakdown?</td>
</tr>
<tr>
<td>• Discuss your ability or inability to feel your residual limb.</td>
</tr>
<tr>
<td>• Do you have shrapnel in your residual limb?</td>
</tr>
<tr>
<td>• Have you used vacuum-assisted suspension or do you want to try it because of past problems with a special condition?</td>
</tr>
<tr>
<td><strong>Show your physician the problem:</strong></td>
</tr>
<tr>
<td>Point to the area on the socket while wearing it.</td>
</tr>
<tr>
<td>Show any gait deviations due to a poor socket.</td>
</tr>
<tr>
<td>Take off your prosthesis and show them your residual limb.</td>
</tr>
<tr>
<td><strong>Remind your physician that your prosthetist requires the following to proceed:</strong></td>
</tr>
<tr>
<td>• <strong>Prescription</strong> – Ask for a copy before you leave; this is the minimum requirement.</td>
</tr>
<tr>
<td>• <strong>Detailed Written Orders</strong> – This includes all components of the prosthesis; this is usually provided by the prosthetist.</td>
</tr>
<tr>
<td>• <strong>Detailed medical notes from the physician office visit</strong> – These will usually be generated within a few days of your visit with your physician.</td>
</tr>
<tr>
<td>These can be difficult for your prosthetist to obtain, but they are essential to their ability to bill your prosthesis to your insurance. Please kindly ask your physician to cooperate with your prosthetist in obtaining all of these documents.</td>
</tr>
</tbody>
</table>
When I think about being active, my mind jumps to the same place that yours probably does: fitness. I swim, I hand-cycle, I run road races using a racing-chair, I walk around the neighborhood and I play tennis; I do as much as I can, as often as I can. But being active isn’t just about being athletic – being active can entail many activities, including actively monitoring your health, adapting to challenges at home and at work, and being an active member of your community.

Exercise is wonderful, but one personally meaningful way in which I stay active is by volunteering my time as a board member with the Amputee Coalition. The Coalition provides some incredible programs and services for our community, and I never get tired of hearing about the great work we’re doing through programs like our Limb Loss Education Days, our kids’ camp, and our Peer Support Program, but I especially love interacting with the people that make these programs possible.

On a recent conference call with the Paddy Rossbach Youth Camp planning committee, I saw the magic of the Coalition in action. On this call we had a board representative, Coalition staff, and most significantly, several dedicated volunteers (Angel Giuffria, Tyler Carter, Laura Freeman, Lonnie Nolt, and Daniel Carroll, thank you all so much). Our annual youth camp is everyone’s favorite event to plan, but by no means the easiest, so this team’s efforts are instrumental to the camp’s success. As I listened in, I was struck by the dedication and enthusiasm of each of the committee members. All of the volunteers who serve on this committee are current camp counselors. They’re adults with limb loss or limb difference who have volunteered to take time out of their busy lives to attend our camp to serve as role models for our campers. Some of these counselors have been helping with our camp every single year for more than five years straight, and several of these counselors were once campers themselves!

I lost my legs while serving as an Army officer in Afghanistan. I’m thankful to be a member of this country’s amazing veteran community, but I’m especially thankful to be a part of this selfless community of people who live with limb loss or limb difference. We all lead busy lives and we all have to fight to stay active throughout our lives. I want to thank the Amputee Coalition staff, volunteers and community members who give me a reason to stay as active as possible. I couldn’t do it without you. ☺
Do You Have Phantom Limb Pain?

If so, you might be eligible for a research study that aims to decrease and/or resolve phantom limb pain in people with an upper- or lower-limb amputation.

The purpose of this research study is to determine if putting local anesthetic (numbing medication) through one or two tiny tube(s) placed next to the nerve(s) that go to an amputated limb will decrease and/or resolve phantom limb and residual limb pain. The procedure, device and infusion are all FDA approved and have been used for over 20 years to decrease pain immediately after surgery.

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 National Military Medical Center (Bethesda, Maryland); Veterans Affairs Palo Alto Medical Center (Palo Alto, California); and Naval Medical Center (San Diego, California).

- No surgery involved
- Either lower or upper limb amputations
- Only a single 2-4 hour visit to the treatment center (2nd visit optional)

For more information, please call or email: 858.242.6017 • phantompain@ucsd.edu
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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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April 27, 2013 is National Show Your Mettle Day for amputees across America. As part of National Limb Loss Awareness Month, the Amputee Coalition is asking amputees who feel comfortable (and are able) to make their prosthetics (or chairs) visible on April 27. For more information, go to amputee-coalition.org or visit us on Facebook at facebook.com/AmputeeUSA.