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CLINIC LOCATION	DATE
Philadelphia, PA	May 19
New York, NY	June 10
Chicago, IL	August 11
Durham, NC	September 29
San Diego, CA	October 20
San Francisco, CA	November 3

To learn more about Össur Mobility Clinics, visit www.ossur.com/mobilityclinics.







Paralympic Gold Medalist and Team Össur/CAF mentor Rudy Garcia-Tolson with Cameron Lutges



Life Without Limitations®

message from the editor

Being an Advocate

(for Yourself and Others)



What is advocacy? When you hear the term, particularly in regard to living with limb loss or another disability, you may simply and instinctively think of it on a personal level, of empowering yourself to ensure that your needs are met. But it goes far deeper than that. In the words of Jeff Cain, advocacy is about "creating your own world" (see "Dr. Jeff Cain: Advocate for All," page 24).

Sometimes change begins with the actions of a single person pursuing a dream or simply trying to make their life a little better. Whether they intend it or not, their actions can create a ripple effect, affecting the lives of many others.

Why is advocacy important? Because if we don't advocate for our needs, decisions about prosthetic devices and your ability to access them will be made by others who may not have your best interests at heart. For example, insurance companies nationwide have been eliminating coverage for prosthetic care, leaving many amputees unable to afford a limb to stand on. There are a number of ways that insurance companies have eliminated prosthetic coverage, including capping benefits at \$1,000 per year, limiting coverage to one prosthesis per lifetime, and denying computerized and myoelectric devices as "experimental."

Participating in advocacy is important for us all. It provides the opportunity to stop being passive victims and to start creating a world where amputees have access to the technology and care they need to live full, active and productive lives.

The Amputee Coalition is here to help, both as a catalyst for change and as a community of many, working to address such problems as insurance coverage, accessibility, discrimination and more.

We hope that you enjoy this issue and that you will be encouraged to join us in advocating for the future of all amputees.

Bill Dupes, Senior Editor



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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contents

March/April 2012

"Personal advocacy is figuring out what's important to you in the world and deciding how to accomplish it." - Dr. Jeff Cain



Dr. Jeff Cain: Advocate for All



Anatomy of an Advocate



A Community of Advocates



Dealing With Disability Insurance

sections

- 15 Upper-Limb Perspectives Candidate for Hand Transpant?
- 18 Travel & Accessibility Know Your Rights. Take Charge!
- 20 Peer to Peer I'm OK...Making a Difference
- 37 Living With Limb Loss Rising to the Occasion
- 38 Exercise & Fitness Self-Care of Feet
- 40 Well-Being 5 Classic Stages of Grief

departments

- Message From the Editor
- Letters to the Editor
- 10 Advocacy in Action
- 12 Events Calendar
- 42 Technology Showcase
- 45 Advertiser Index
- 46 Perspectives

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Our Mission 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.



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 hard copy to all subscribers. Each issue averages 56 pages in print and 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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letters to the editor

Limb Loss Awareness Month

April is Limb Loss Awareness Month. The Amputee Coalition's goal is to distribute 1 million postcards and educate Americans about our cause.

This year we are focusing on reaching people with diabetes, the leading cause of amputations. Many people with diabetes have no idea they are at risk. That's why educating them, and sharing your personal story, is so important.



Here are some of the many positive comments about the campaign we've already received from Amputee Coalition members:

"I underwent an amputation after being struck by an SUV. Life beyond my amputation has been fulfilling, but I've watched April roll around and not a sign, or anything has been done. I will distribute educational materials at a nearby hospital and churches. I will also contact my local papers and try to get some media coverage. Let's get out there and make this a great success!"

- Mina Vereen, North Carolina

"I am already scheduled to speak April 1 at Alliance Church for Spanish and English service and April 15 at St. Michael's Catholic Church in Ralls, Texas. I am also waiting for a response to distribute postcards from a local grocery store located in our Hispanic community. I am also scheduled to be interviewed by the Lubbock Latino Web site, newspaper and magazine."

- Elsie Colon, Texas

"I am a nurse at a Veterans Administration hospital in West Virginia. I have good relationships with our primary care clinics and will distribute 3,000 postcards in April. I'm a big believer in education. Many people with diabetes have no idea they're at risk. They only find out once they have gangrene or a wound that won't heal. I also plan to distribute cards at the local VFW and American Legion halls in my community."

- Cheryl Hill, West Virginia

How are you planning to distribute postcards and raise awareness in your community?

We want to know. To order "Take a Seat, Check Your Feet" postcards or share your story, please contact Joe at jlamountain@amputee-coalition. org or 888/267-5669. Please also visit our Web site at checkyourfeet.org.



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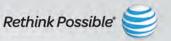
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Government Relations Update

The Insurance Fairness for Amputees Act

has now been introduced in the U.S. House of Representatives! On March 9, Representative Charlie Dent (R-PA) introduced the Insurance Fairness for Amputees Act (H.R. 4175) in the U.S. House of Representatives with Representative Rob Andrews (D-NJ). This bill accompanies the Insurance Fairness for Amputees Act (S. 773) introduced last year in the U.S. Senate by Senator Olympia Snowe (R-ME) and Senator Tom Harkin (D-IA). The Amputee Coalition is continuing to work with our partners to make access to prosthetics and custom orthotics adequately affordable by making insurance fairness legislation a reality for everyone in the United States. You can get involved by contacting your legislators and asking them to cosponsor these bills!

On the state level, we have continued to face challenges. There has been a significant reduction in healthcare bills being introduced and moving forward in the states due to controversies related to federal healthcare reform and the implementation of the Essential Health Benefits (EHB) Package. Many state legislators have expressed hesitancy to act on Insurance Fairness for Amputees legislation in this current political environment. The Amputee Coalition is continuing to work with advocates, but we need more voices calling for action on this important legislation.

An issue of great concern is the establishment of the Essential Health Benefits Package.

The week of March 26, the Supreme Court heard oral arguments on the healthcare law. Their findings are expected later this year regarding the individual mandate to have health insurance, and depending on their ruling, what it might mean for the remainder of the law. This finding will have a profound impact on how the Amputee Coalition moves forward to advocate for inclusion of prosthetic and orthotic devices in the EHB package. In addition, we are monitoring and preparing for action if the Department of Health and Human Services or individual states make further moves to implement the EHB Package.

Finally, the Amputee Coalition is working with the Disability Partners Coalition to preserve funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD), where we receive funding to support programs, resources and services for the limb loss community. The NCBDDD helps to fund peer support programs, support groups, youth programs, the Amputee Coalition National Conference, educational resources and activities and the National Limb Loss Information Center.

The Amputee Coalition has revised the Government Relations pages of our Web site. We encourage everyone to visit so that you can review our legislative priorities, get regular updates about our current activities and vote on issues and topics that are important to you. 🚷



Check it out at amputee-coalition.org/advocacy-awareness.





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events calendar



NATIONAL KIDNEY MONTH

kidney.org

NATIONAL NUTRITION MONTH

eatright.org/nnm

NATIONAL PATIENT SAFETY AWARENESS WEEK

npsf.org/psaw

SAVE YOUR VISION MONTH

aoa.org/x5072.xml

MARCH 4

South Florida Tour de Cure

Coral Springs, Florida diabetes.org

MARCH 8

World Kidney Day

worldkidneyday.org

MARCH 10

First Volley Tennis Clinic

Encino, California opfund.org

MARCH 24

Phoenix Tour de Cure

Phoenix, Arizona diabetes.org

MARCH 27

American Diabetes Alert Day

diabetes.org/in-my-community/ programs/alert-day

MARCH 31

Ironman 70.3 California

Oceanside, California challengedathletes.org



FOOT HEALTH AWARENESS MONTH

apma.org

LIMB LOSS AWARENESS MONTH

limblossawareness.org

NATIONAL CANCER CONTROL MONTH

cancer.gov/global/features/2009/cancercontrol2009

NATIONAL MINORITY HEALTH AWARENESS MONTH

minorityhealth.hhs.gov/actnow

OCCUPATIONAL THERAPY MONTH

promoteot.org

APRIL 13

Relay for Life

California, Pennsylvania cancer.org

APRIL 15

First Paddle Kayaking Clinic and First Dive

Intro to Scuba Clinic

Ypsilanti, Michigan opfund.org

APRIL 15-21

National Volunteer Week

whitehouse.gov/the-press-office/2011/04/07/ presidential-proclamation-national-volunteer-week

APRIL 21

Limb Loss Education Day

Atlanta, Georgia

amputee-coalition.org/events-programs/limb-loss-education-day

McKeever's First Ride

Atlanta, Georgia opfund.org

APRIL 29

First Dance Clinic

Lake Orion, Michigan opfund.org

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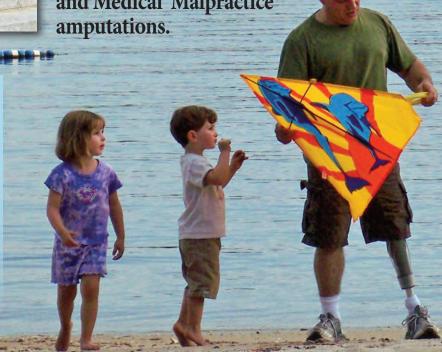
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For Hand Transplantation? by Tae Chong, MD

Since 1999, over 40 patients have successfully received upper-limb (hand and forearm) transplantation. These patients have gone on to recover sensation, gross muscle function, dexterity and restoration of their identity and independence. These patients must be on lifelong medications, however, to prevent their immune system from rejecting their new hands. In addition to the risks associated with the medications, hand transplant recipients must maintain the function of their new hands by participating in hand therapy and consciously using their new hands. Amputees who understand these risks and requirements are candidates for hand transplantation, but this is only the first step.

Inclusion criteria for transplantation include:

- Single dominant hand or bilateral hand amputees
- Adults between 18-60 years of age
- No serious coexisting medical or psychosocial conditions
- No history of malignancy or HIV
- Amputation at least 6-12 months before evaluation
- Attempt at prosthetic use.

The level of amputation will also affect the operation and the recovery of function; in general, the more distal (further from the body) the amputation, the better the recovery. However, many centers will consider a candidate for transplantation if they are an above-elbow or even a single non-dominant hand amputee.

The rigorous screening process includes multiple blood draws, radiographic studies (X-rays, ultrasounds, CT scans and MRIs) and evaluation by other medical specialists. Candidates must undergo psychosocial evaluations to assess their understanding of the risks and to gauge their future compliance with the medication and hand therapy protocol. As most hand transplants are performed as part of a clinical study, candidates must be willing to follow up frequently with the transplant team for biopsies, blood draws and radiographic studies. Once candidates clear the screening process, they are listed with the organ procurement organization. From this point on, they must remain close to the medical center.

continued on page 16

continued from page 15

When a suitable donor is identified, the recipient is called into the hospital immediately. Once final confirmatory laboratory studies are performed, the transplantation process begins. The donors and recipients are matched immunologically and by physical characteristics such as skin tone, size and hair color. The transplantation process takes up to 15 hours.

After surgery, the recipient is recovered in the intensive care unit to monitor for rejection and to initiate their maintenance immunosuppression. For most patients, the hardest part is the immediate loss of independence. The recipient may not regain independence in performing activities of daily living for up to a year, depending on the level of

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amputation and active participation in hand therapy. Patients can expect to spend up to 3 weeks of rehabilitation in the medical center; they are discharged once their drug levels are within a therapeutic range. They will require assistance

at home until their motor recovery is sufficient, and will have to participate in daily hand therapy for up to a year. Thereafter, the frequency and intensity of therapy will be dictated by their individual course.

Patients can expect to see their transplant team at least weekly for

the first few months, then monthly until 6 months. During these visits a thorough skin exam is performed, as this is often the first sign of rejection. These are treatable with a temporary increase or addition of other medication. Blood is drawn to evaluate drug levels and to monitor for side effects. An infectious disease specialist will monitor the patient for infections. A transplant surgeon and nephrologist will treat any side effects related to medications, such as high blood pressure, kidney damage, diabetes, elevated blood lipids and gastrointestinal distress. Initially, patients will be at higher doses of the immunosuppression medications and can expect to have some of these side effects, but over time they are tapered down and most patients will see a resolution in these symptoms. Patients will then see their transplant team every 3 months to a year, depending on their recovery.

All patients achieve protective sensation, and 90 percent will develop tactile sensibility on their fingertips. All patients achieve grip and pinch. The finer hand movements tend to recover later for most patients, depending on the level of transplantation. The recipient must take an active part in their posttransplant life; for many, this is the first time they have been on chronic medications. They must also perform

In general, the

more distal

(further from

the body) the

amputation,

recovery.

the better the

thorough skin and nail exams daily; the patient is often the first to diagnose a rejection episode. Finally, they must remain motivated and committed to their hand therapy and follow up with their transplant team.

Amputees who are interested in hand transplantation

should seek out medical centers with expertise in transplantation and reconstructive surgery. For example, at the University of Texas Southwestern Medical Center, we have a multidisciplinary reconstructive transplant team consisting of plastic and reconstructive hand surgeons, transplant surgeons, nephrologists, infectious disease specialists, transplant anesthesiologists, intensivists, pathologists, radiologists, psychiatrists, physical medicine and rehabilitative physicians and hand therapists.

Most centers offer hand transplantation under a clinical trial, and amputees should seek out Institutional Review Board (IRB)-approved programs. IRBs independently review, approve and monitor clinical studies.

For more information, please contact Dr. Tae Chong, director of reconstructive transplantation at 214/645-5560 or Tae.Chong@ UTSouthwestern.edu, or Margaret Eade, director of transplant services, at 214/6445-1948 or Margaret.Eade@ UTSouthwestern.edu.

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Take Control

of Your Travel Experience

by Debra Kerper

raveling always has the potential of being a frustrating, stressful situation, as it encompasses many variables and unknowns. Add to this mix traveling with a disability and it can appear to be somewhat daunting. This need not be the case; there are many ways to maximize the pleasure of your travel experience while minimizing the stress. If you are new to travel (or not so new) and are unsure of how to make the most of your vacation time, enlist the aid of a qualified travel agent who understands your needs and is a good listener. A qualified travel agent can save you time and money and is an excellent resource should you encounter any problems. Now for the caveat: You are still the person responsible for having a successful trip, and you need to know how to take control of your travel experience.

You need to be proactive and learn that *you* are your best advocate. In order to do this effectively, here is some basic information that will enable you to accomplish this.

For starters, understand that one of the most important things you can pack is a good attitude and a smile. These go a long way when dealing with personnel, whether at the airport, the hotel, the cruise ship, etc.

Know your rights! Getting through security at the airport seems to pose all sorts of unpleasant experiences for many travelers. Visit the Transportation Security Administration's (TSA's) Web page titled "Travelers With Disabilities and Medical Conditions" (www.tsa.gov/travelers/airtravel/specialneeds) regarding travelers with

special needs. Look for the section that best describes your personal situation. Print it out and take it with you to the airport. Should you have a problem, show it to the agent and point out politely that this came from their Web site. If this does not fix the problem, ask to speak to a supervisor. Once again, show the printout from their Web site.

Know what is and isn't allowed. For example, a person with a disability does not have to remove their shoes. You are responsible for knowing what a person with your situation is allowed to do.

If you have a problem with airline personnel not helping you properly, ask to see the complaint resolution officer (CRO) before you get upset and ruin your trip. CROs are employed by all

airlines and must be available in person or by phone whenever flights are operating. The CRO is trained to solve your problems. There may be times when the problem is not solved to your complete satisfaction, but they will do the best they can to make you happy.

You also need to know how to request the services that you need, such as the equipment you require in a hotel, assistance with embarking and disembarking cruise ships, etc. Learn to plan ahead and contact personnel to explain your special needs. Ask for a confirmation reply so you know your requests have been heard. Learn who the right people are to ask for specific items. Need a roll-in shower and a shower seat? When you call a hotel to make a reservation, ask to speak to the head of housekeeping to find

> out what type of equipment they have and which rooms have roll-in showers. In case you arrive at a hotel to find that your requests have not been met, request that the hotel find you another property where your needs can be accommodated and be sure any increase in price is paid for by the original hotel.

Never take no from someone who does not have the authority to say yes!

> Finally, here's a good piece of advice: Never take no from someone who does not have the authority to say ves! Always ask for the manager or supervisor. Try to manage your frustration and/or anger. Understand that you are ultimately responsible for the outcome of your trip, and a good attitude will help to ensure that your experiences will be positive and your trip successful.

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Making a Difference by Elizabeth Bokfi

Amputee Association, that moment arrived in 2003 during her first visit to an Amputee Coalition National Conference. when she witnessed other amputees freely displaying their prostheses.

"That experience made me feel that I was OK too. From that day on, I wore shorts in the summer and have even been in the pool," she says. Bissonnette lost her left leg below the knee in 1997, when she was 50 years old, due to a near-fatal vehicular accident.

We still hold monthly meetings at the same location. Today, we are the only support organization for amputees for at least 75 miles."

Meetings are held between two locations: Clinton Hospital, Clinton, Massachusetts, or Whittier Rehabilitation Hospital, Westborough, Massachusetts.

Building a working relationship with local prosthetists, Bissonnette spent many hours getting the word out to patients through prosthetists' offices.

AMPUTATION – the mere mention of the word makes most people shudder. But for those of us who live the "lifestyle," so to speak, it becomes an everyday term that, in all its surreal presence, has woven its way into every magazine article, movie and diabetes health pamphlet. Our life-focus is it.

There are days when we feel we can no longer cope. There are those "Why me?" days. And just when we are about to give up, there comes a moment of hope that glimmers above the process of amputation, adaptation and even acceptance. The moment when we realize we're OK, and we feel comfortable in our sockets and skin.

For Rose Bissonnette, president and founder of the New England The friendship and caring I see when a new amputee or caregiver comes to a meeting is heartwarming.

After taking the Amputee Coalition Peer Visitor training course, Bissonnette discovered there were no local amputee support groups.

"During peer visitor training, they recommend that while visiting with the new amputee you refer them to an amputee support group meeting," she says. "As I realized the need for a group, I researched and found a location to hold these meetings. The first meeting was in February 2004.

As word slowly spread through the healthcare community, amputees and caregivers began to get more involved, offering their help.

"People tell me the group is like family and they feel at home at the meetings," Bissonnette says. "People have said they learn more at a meeting than anywhere else about living with amputation and what's available out there for them."

continued on page 22





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Rose Bissonnette (standing, third from right) and members of the New England Amputee Association.

continued from page 20

The New England Amputee Association's active membership ranges in age between 40 and 70. Although most are males in their 50s, there are a few females and a small number of members in their 20s.

Although the group's membership has reached approximately 100, getting the word out to patients continues to be a challenge for Bissonnette. Healthcare professionals and hospitals simply don't have time to inform their patients about the support group.

Bissonnette explains, "Doctors like our programs but often don't tell the patient [about it]. Hospitals have the same issue. It takes time to find a good contact in the hospital who will take the extra time to pass along the information to a patient."

As the group continues to grow, so does Bissonnette's own emotional rehabilitation. Affected by the members' courage and caring attitude, she pushes forward, working to educate healthcare workers about the positive impact that peer support has on patients' rehabilitation.

"The people I have met and worked with since I started the group have courage," she says. "More than some of them realize. They give *me* hope when I'm feeling tired and want to quit. The friendship and caring I see when a new amputee or caregiver comes to a meeting is heartwarming. In a way, losing my leg has been hard, but it also made me grow as a woman, and made me take on more than I believed I could accomplish."

While phantom pain, self-image and depression are at the forefront of most group discussions, Bissonnette addresses other issues on occasion. Employment discrimination, for example, is something she herself has experienced.

"The other major obstacle was returning to work and then having an incident where my prosthesis broke and [I needed] assistance to get back to my office and then to my car," says Bissonnette. "Three weeks after that incident, I was laid off from my job as manufacturing supervisor."

During her search for employment, she had written into her resumé that she founded the New England

Amputee Association, spurring questions from potential employers.

"During interviews, questions about why I founded the organization would arise," Bissonnette recalls. "When I would tell them I'm an amputee, I'd notice the change in the eyes of the interviewer, and then the interview would be done." Finally, a friend who worked in human resources explained to her why employers hesitated to hire her because of her disability.

"Most employers are more concerned that because I am an amputee, their medical insurance will increase due to the medical needs of the amputee," she says. "So now I carry my own insurance; I did find an employer, and I've worked part-time for the past 5 years. I explain to people what changed for me, and how I was able to find work to suit my needs. What I learned was to stop letting the disability be the focus of the interview. Yes, you have a disability but you also have skills and knowledge; [they] are marketable. During an interview, focus on your strengths, not on the disability. In most cases, this works; however, in some cases there are still roadblocks to employment due to discrimination. Before going to an interview, I recommend thinking about all the knowledge you have and the skills you can offer. Believe in yourself and your *abilities*." That we will.

Related Resources

Amputee Coalition - Peer Support amputee-coalition.org/npn about.html **New England Amputee Association** newenglandamputeeassociation.com



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Dr. Jeff Cain is a man of many passions. He is the chief of family medicine at The Children's Hospital in Denver, Colorado, president-elect of the American Academy of Family Physicians (AAFP), an enthusiast for biking, swimming, motorcycling, water and snow skiing, a pilot and much more.

Cain is also a bilateral below-knee amputee. He lost his left leg when a single-engine plane he was piloting crashed in 1996.

Enduring pain and limited mobility with his remaining lower leg, he elected to have it amputated 6 years later to relieve those limiting factors.

After his amputation, Cain was taken aback to learn that his insurance company had a very low cap on what it would pay for a prosthesis. In response, he founded the Colorado Coalition of Working Amputees. Through this group's grassroots work, Colorado became

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

Margaret Mead











When Cain became a member of the Amputee Coalition's Board of Directors, he helped start the Coalition's Action Plan for People with Limb Loss (APPLL), now called the Fair Insurance Access for Amputees Initiative, which has seen 20 states pass insurance mandate legislation and has 24 states organizing for introduction.

In addition to his work on the legislative side of advocacy, Cain also has extensive experience advocating for himself. His own insurance battles in the first years of post-amputation life gave him considerable training in self-advocacy. Since then, he has also found applications for advocacy in other parts of his life. Recently, in campaigning for the presidency of the AAFP, he gained insight into what advocacy may mean for everyone. As he goes through what he terms "the process of being in this life," he has continued to learn new and sometimes self-revelatory aspects of being his own advocate.



Legislative Advocacy

Jeff Cain is an articulate, thoughtful person. He is enthusiastic in pursuing life's many opportunities, yet deliberate in his approach. Yet, prior to 1996, one element of life had eluded Cain's consideration.

Before his accident, like many people, Cain never questioned whether his insurance company would cover medically necessary devices after a life-threatening event.

"I was working at the hospital; I had great insurance," he says. "I was shocked when I had to write a really big check for my first prosthesis."

He learned that the prosthetic benefit was capped at \$1,000 and limited to certain devices, essentially limiting prosthetic care to only those able to pay the cost out-of-pocket. While Cain felt fortunate to be able to afford to write that big check for an appropriate prosthesis, he saw the unfairness for others of more modest means.

"What if I were a school teacher?" he says. "It didn't seem right. It was a matter of social justice. I started thinking of doing something



"My mother always told me, 'If you want something done, ask a busy person to do it.'"

Dr. Cain (second from left) attends as then-Colorado Gov. Bill Owens signs the nation's first Fair Insurance Access for Amputees law for his state in 2001.

that could help all amputees afford the necessary prosthetic care needed to live life fully."

While turning this idea over in his mind, Cain happened to attend an Amputee Coalition peer visitor training class in Denver. The topic of insurance coverage came up, and Cain discovered a common theme.

"As we introduced ourselves, it turned out that every person around the circle had a story to tell about struggles with prosthetic insurance coverage, and we started a group to do something about it right then," he says.

As the newly formed Colorado Coalition of Working Amputees began to coalesce, the young physician saw an important element of advocacy in action: teamwork.

"As our group came together, we found that although no one of us came with all of the necessary legislative skills, together we had an amazing set of skills: one of us had been a community nonprofit leader, one was familiar with the legislative process, one was a public speaker and so on," he says. "Every individual can contribute with the gifts they bring."

The cooperative sense of purpose he witnessed is one of the reasons why he cherishes the Margaret Mead quote from the beginning of this story.

"Don't worry about trying do everything yourself," he says. "When you get a group together, you will be surprised at the skills sitting around the table."

Cain's article in the May/June 2003 issue of inMotion, "Creating Change Can Be Fun," broke down the process of changing the law in Colorado this way:

- Forming a group
- Understanding the legislative process
- **Fundraising**
- Building a grassroots organization
- Introducing legislation
- Having fun.

He describes the group as learning as it went, each step of the way, realizing the importance of not being overwhelmed by what initially may seem to be a large or prolonged process.

"You form a group, and that's a step, then meet with legislators, and that's a step," he explains. "What's the next step? Meet with prosthetics companies. Oh, we need a press kit. That's a step. And so on."

In addition to learning how to build a grassroots movement from the ground up, they found that although having and presenting the facts was important, facts alone were not enough for success.

"Storytelling is one of the most compelling elements of advocacy," he says. "Facts and figures don't



command the public's or politicians' attention – telling a personal story does. Stories help us connect with each other and with the larger community. It's the human side that will make people see the social injustice of insurance laws that don't cover prostheses. If you can combine your story with the facts and economic reality, people will line up with your position."

Ultimately, the Colorado Coalition of Working Amputees included volunteers from local amputee support groups, prosthetists, the U.S. Disabled Ski Team, parents, children with limb loss and others. Over the course of a year they pursued the bill through both of Colorado's legislative houses and the governor's office, and finally saw legislation passed that ensured prostheses would be considered medically necessary and covered to the same level as by Medicare. While this meant the organization that Cain brought together had achieved its goal, he realized later that this was not the only mission it had accomplished.

"Although we set out to change laws around insurance, we also grew as people," he says. "It was actually a fun process and ultimately very fulfilling personally for all of us. This was the first time most of us had ever been around a group of amputees, so the unforeseen benefit was learning about how other amputees dealt with tasks, challenges, and learning to live a full life with limb differences."

National Advocacy

The successful passage of the law in Colorado led to Cain's involvement in the Amputee Coalition's nationwide advocacy for similar legislation in all 50 states.

"I was invited to present the results of our Colorado work at the Amputee Coalition National Conference," he explains. "While I was there, I made the 'mistake' of raising my hand to ask what the Coalition planned to do on prosthetic parity at the national level. Of course that got me appointed to join the board and chair their newly formed Advocacy Committee."

With Cain's input, the Amputee Coalition created a tool kit modeled on materials developed by the Colorado Coalition of Working Amputees, which has been used by grassroots organizations all over the country to advocate for changes in insurance laws on the state level.

As a member of the Amputee Coalition Board of Directors, he was influential in creating the Coalition's national advocacy office and the Federal Insurance Fairness Initiative, resulting in a bill being introduced in the United States Senate to provide people with limb loss and limb difference access to appropriate prosthetic devices.

Self-Advocacy

Although successful in changing Colorado's insurance laws, he has still found it necessary to advocate for himself when dealing with insurance companies.

For example, the law passed in Colorado required insurance companies to pay for prosthetics and specifically defined the prosthesis as a replacement in whole or in part for a missing arm or leg. Despite this legal definition, Cain's insurance companies have often initially refused to cover his prosthetics.

"Believe it or not, one insurance company claimed that they didn't have to cover hands or feet," Cain says. "As ridiculous as that may sound, their initial stance was to only cover a leg, which they defined as just the socket."



But Cain was persistent. "In appealing their denial, when we quoted them the language in the Colorado law verbatim, they were quickly able to see things our way and provided coverage for the prosthetic feet," he says.

Insurance companies have not stopped denying coverage, but knowing the law and documenting medical necessity has improved access for amputees in Colorado.

From these and other experiences, Cain has developed an approach not only for advocating for yourself with insurance companies, but in other circumstances as well.

First, thoroughly research your goal. Before enrolling with an insurance company, be certain of the prosthetic benefits each plan offers, so you can choose the one best suited to your needs, and keep your records.

When filing an insurance claim, document all interactions with insurance company representatives, so that you have a record of what you were told and when you were told it, in case there are discrepancies in the company's position later. And in all interactions with an insurance company, Cain suggests being patient, persistent, polite, professional, and helpful if possible, all while staying gentle, but firm.

"You know, that's actually a good approach whether you're dealing with an insurance company or Congress," Cain laughs.

While acknowledging that advocacy is time-consuming, Cain says if it's important to you, you must find the time for it – although he admits it can be challenging because, like all of us, he has a busy life.

"My time is valuable to me, and I know what it's like to spend time banging my head against the walls of Congress or insurance rules," Cain says. "But we all know the old quote: "If not us, who? If not now, when?"

"And as my mother always told me, 'If you want something done, ask a busy person to do it."

Patient Advocate. Physician Advocate

As a physician who has also found himself in the role of a patient undergoing significant surgery and a lengthy recovery, Cain is in a unique position to communicate to others the importance of the patient as a self-advocate.

"When people discover themselves in the role of patient, they must continue to advocate for their wellbeing," he says, noting that while it is the physician's job, for example, to communicate clear instructions for care, it is the patient's



Jeff Cain on his ski-bike at Jackson Hole.

responsibility to speak up if he or she doesn't understand instructions and to advocate for shared decision-making.

Cain recognizes that for many of us, when we are consulting with authority figures, we may reflexively surrender our own judgment to theirs. However, he advises patients to approach the doctor/patient relationship differently.

"Personal advocacy is figuring out what's important to you in the world and deciding how to accomplish it."

"People should not give up their autonomy as patients," Cain says. "Sure, initially some patients may feel themselves in a subservient position, but it is important to not assume a submissive role, but rather the role of partner in making medical decisions."

Cain has written how healthcare providers ideally see patients as human beings who are suffering, not merely as patients. Unless doctors make the effort to understand what the patient is going through, they will not be able to give them "the truly compassionate care needed."

"Often, the healthcare provider represents a lifeline for people to reach out to while dealing with challenges like pain or depression," Cain says. "It is our job and responsibility as caregivers to listen to our patients and to offer both medical information and hope. We can make a real difference in their lives. That's what I try to do for my patients, and I expect nothing less from those providers who care for me."

He has learned to share his lessons from his time as a patient with physician audiences in national presentations of the talk, "The Physician as Patient: Lessons From the Other End of the Stethoscope," addressing the difficulties of being the caregiver who must accept the changing roles from physician to patient and back.

Leisure Time Advocacy

Who would guess that advocacy would also sometimes be a necessity in the world of recreational sports? Through participation in adaptive sports, Cain has discovered the need for advocacy in different forms. In fact, Cain has learned that advocacy happens everywhere, although the form it takes in leisure time activities may not be as intuitively obvious as it is in the legislative, insurance or healthcare arenas.

A sports enthusiast, Cain has competed and taught nationally in a variety of adaptive sports.

He even holds the first gold medal in adaptive slalom snowboarding from the U.S. National Snowboarding Championships.

Advocacy skills were important in introducing the ski-bike, essentially a bicycle frame that substitutes skis for wheels, as a new adaptive device in North America. He has also needed to physically adapt or create equipment to allow him to bike, motorcycle and snow and water ski, and has published articles that explain how others can likewise adapt their equipment to be successful as an amputee athlete.

Developing and sharing ways to adapt sports equipment for use by people with limb loss can also be considered a form of advocacy, Cain posits, because advocacy "is about creating our own world."

"Whether we are able-bodied or use a prosthesis, it is our task in life to stretch ourselves to find our own limits," he adds. "With amputation and with life, what is possible is most often self-determined."

In a sense, then, advocacy may be seen as an overall approach to life, whether in pursuit of professional advancement, social justice, or, in some cases, finding ways to adapt sports equipment to work with disabilities.

"Personal advocacy is figuring out what's important to you in the world and deciding how to accomplish it," he says, "whether it's a literal problem like figuring out how to make a prosthetic foot fit on a water ski, or a more abstract one, like making insurance laws work for everyone - it's all advocacy."

Advocate for All

Cain's latest endeavor, presidency of the AAFP, will begin in the fall. The AAFP is one of the largest national medical organizations, representing more than 104,000 family physicians, family medicine residents and medical students nationwide. Its mission is to preserve and promote the science and art of family medicine and to ensure highquality, cost-effective healthcare for patients of all ages.

Although becoming the AAFP president-elect meant having to give up his seat on the Amputee Coalition's Board of Directors, Cain believes his new position will afford him the opportunity to advocate for people in need of quality healthcare not only in the limb loss community but for the broader community.

"As president-elect of the AAFP, I am advocating for better healthcare for everyone in the United States," he says.

Interestingly, Cain believes his election was neither because of nor in spite of being an amputee, but acknowledges he will bring lessons learned in the limb loss community, including those from the legislative fight for insurance fairness, to his leadership of the AAFP.

He also reveals that his campaign for the presidency taught him another lesson that was a surprise for him. "For over a decade in my private and professional life, in many ways I had tried to hide my prosthetics," he explains. "But in my campaign for the presidency, it became necessary to talk openly about my amputation – for the first time, I had to tell the story of my amputation. Initially, I had fears about what the audience's reaction would be."



Cain's acceptance speech to the AAFP.

The audience, however, proved his fears unfounded.

"Everyone faces challenges in life, whether it's amputation, job loss or divorce," Cain says. "What I had feared might be perceived by the physician audience as a limitation was instead respected for the shared lessons learned on a path that we all must walk. The audience was much more interested in the story of the challenge and the response."

And, Cain says, for those who are advocating for themselves, those who are creating their own realities, this lesson touches on the importance of storytelling in advocacy that he mentioned earlier.

"As advocates, we have to share our stories," he says. "In the process of being human, we all face challenge. People are hungry to hear the lessons in facing adversity. To achieve the ends of our advocacy, challenge is not to be avoided, it is to be embraced."

What makes a good advocate?

>> Webster's defines an advocate as someone who pleads another's cause, or who speaks, argues or writes in support of something. Good advocates do their homework, and follow through on what they say they're going to do. Many advocates volunteer their time and are compensated very little, financially, for the amount of advocacy work that they do. Good advocates know how to persevere and not give in, but also recognize when the time is right to try to reach a compromise, always keeping in mind who they are there for and what they are trying to accomplish.

BE COMFORTABLE. +

It's important to be comfortable in whatever you wear. In the summer, advocates often wear shorts and T-shirts, while some dress up in suits. Wear whatever you feel is most appropriate.

BRING EVERYTHING YOU NEED! -

Here you can keep extra materials, a bottle of water, anything you need for a day of being out and about. It also helps to bring blank "Thank You" cards so when you've finished your meeting you can fill them out while the meeting is still fresh in your mind, and mail them in later.

LISTEN. Meetings with legislators are a conversation, and listening carefully and responding appropriately can make all the difference.

> **SMILE!** Advocating for issues you care about can be fun. This is your opportunity to share your story and discuss issues important to you, so don't be afraid to speak up. Always be pleasant, but be sure to address the points you came to talk about.

YOU'VE GOT TO HAVE SOME TOUGH SKIN.

There are times when legislators won't agree with the issue(s) you've come to talk about, and that's part of being an advocate.

GOOD SHOES ARE IMPORTANT!

Wear something comfortable because going from office to office can be tiring if you're not wearing appropriate footwear.

DON'T OVERTHINK. Go to meetings prepared with the key points you want to talk about, but be relaxed. You know more about issues affecting the limb loss community than anyone else in the room. If you don't know something, just tell them you'll have to check and that you'll get back to them.

> **BE OBSERVANT. Read how** people respond to the issue(s) you're presenting. If you hit on something that you see piques their interest, continue on that topic and return later to the issue(s) you came to discuss.

COME PREPARED! Bring materials that the Amputee Coalition provides on a variety of issues to your meetings and hand them to legislators and their staff. You can also print an extra copy for yourself to refer to during the meeting if you need to remind yourself of talking points. It also helps to carry a calendar that lays out your schedule with who, where and when you're meeting.

BUSINESS CARDS ARE A GREAT RESOURCE. If you have cards, don't hesitate to use them. Business cards are a great reminder for legislators and their staff about who they met with and what issues were discussed.

DON'T BE AFRAID TO SHOW OFF!

If you're comfortable with it, and don't mind questions about your prosthesis and your story, don't be afraid to let it show. Legislators don't see amputees on a regular basis and may have questions about your personal story, the technology, the functionality, etc.

A Community of Advocates by Tony Phillips

If you've never heard of Oscar Pistorius, you're forgiven. Until several months ago, I hadn't either. Pistorius, a 25-year-old South African dubbed "the fastest man on no legs," was born without fibulas and in his early childhood underwent amputation of both legs below the knee. Six months after surgery he was fitted with his first pair of prosthetic legs and years later, while playing rugby with

his two-legged teammates for Pretoria Boys High School, he shattered a knee and was advised by his doctors to take up track and field to aid in his rehabilitation. Rugby's loss has been the track world's unique and priceless gain.

What can one say about a double-amputee with a personal best time in the 400 meters of 45.07? Pistorius' personal record is less than 2 seconds off the world-record mark and with 8 years of track experience, he shows no signs of slowing down. He subsequently ran a 45.20 this year at the South African Provincial Championships. By Olympic standards, he's fully qualified to participate in this summer's London Games.

There is no word yet whether South African organizers will select Pistorius to represent the country either as an individual entrant in the men's 400 meters or as part of its 4x400 relay team, but should he represent his country, he will be the first amputee to compete alongside able-bodied athletes in the Olympic Games!

I mentioned that I've only known of Oscar Pistorius for a matter of months. There's a reason for that. Last October I started learning a great deal about amputees and their lives. That's when I was diagnosed with a particularly nasty bone sarcoma, a condition for which my right leg was amputated just above the knee. There's nothing fun about cancer. Neither is there anything fun about losing a limb or about a 6-month course of chemotherapy. It has been a struggle that I'd have given up on many times by now if not for the constant and profound support of my wife, an amazing family and the world's best network of friends. Right leg or no right leg, I'm the luckiest man alive. I had cancer. I don't anymore.



What I do have, as of April 11, is a new leg that, along with an old one, allows me to get around, not exactly like I used to but pretty capably, nonetheless. There were a few bureaucratic hiccups in the process of getting bipedal, but those, thankfully, are behind me now. It required some creative problemsolving, but I'm now equipped with the latest, coolest fake leg on the planet. My new knee includes a microprocessor that calculates pitch, yaw, roll, orientation, direction and momentum at something like 50 computations per second. I'm 46. I'm pretty sure the beaten-down old natural knee they cut off me was performing calculations with an abacus. Felt that way anyhow.

Of course, even with a new leg I'm halfway to decrepit and I shan't ever run the 400 meters, period, much less in world-class time. I also won't ever do what Marine Corporal Garrett Jones did, which is to lose most of his right leg to a roadside bomb in Iraq and a year later, with a prosthetic limb, return to active combat duty in Afghanistan. I won't ever do such heroic things because, after all, I'm still the ordinary guy I was before I lost my leg. I'm just proud to count myself a member of a community that includes such people.

There's a reason I've chosen to write about all this now: The U.S. Senate currently has before it a bill, S.773, introduced through the advocacy of the Amputee Coalition,

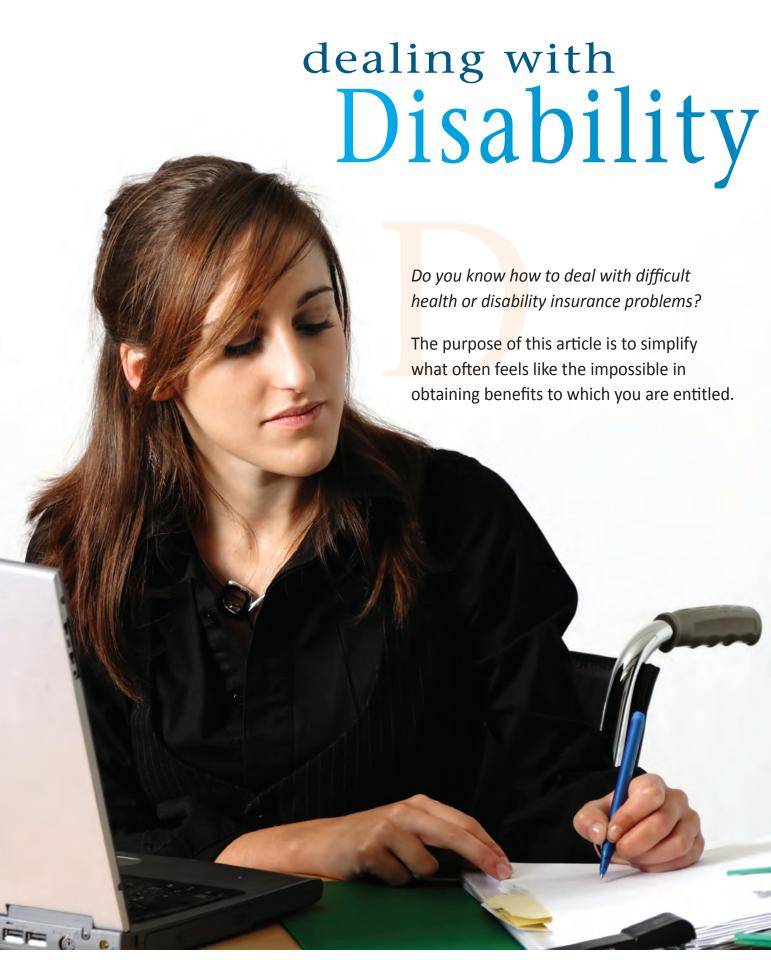


which would require insurers to provide parity under group health plans for the provision of prosthetics and custom orthotics. Such benefits to group members would not address cases like mine or those of many other individually insured Americans, but it's a step in the right direction. Nearly 2 million Americans living with limb loss would love it if you could encourage your senator to support that bill.

In fact, there has never been a better time to get behind a measure that affects ordinary Americans like me, as well as extraordinary ones like Corporal Jones, because April is Limb Loss Awareness Month. I don't usually pay attention to national so-and-so months, but this one hits kind of close to home. I'm personally looking forward to April 28, which is "Strut Your Stuff Day," a day for all of us to shed any cosmetic coverings, etc., and go out with our bare limbs in shorts. Any event that encourages a nation of people in short pants ought to be supported, especially one that showcases life-changing technology and the strength of a community that grows by 500 amputees a day.

And thinking about it, there are more people than just amputees themselves who ought to be proud this month there are the countless others who have been part of supporting friends and loved ones affected by limb loss. I know there's no way I'd be parading about bare-legged on my new hotrod limb without the advocacy, encouragement and assistance of dozens of good people who have made each new step I take possible; on behalf of myself and the other 2 million, thank you.





Insurance

How to advocate for your benefits by Gerald B. Kagan

Health Insurance

Can I get reimbursed for the cost of a new prosthesis?

Maybe. Your current prosthesis may be in need of updating to improve your level of functioning. Your health insurance carrier may not approve what could be a \$30,000-\$50,000 device on the grounds that it is not "medically necessary" or is "experimental" and thus excluded from coverage. You should:

- 1. Prepare a report (with your prosthetist), that explains why the device is essential to your life. Perhaps your job involves physical activity that is difficult to perform with your present prosthesis. Or maybe you're a parent who needs the agility allowed by an updated device to keep up with your children. Also, have the prosthetist provide a research report, providing findings of studies to show that the device is not experimental, and that it is effective and in use. The prosthetist may also be able to provide a list of people who have received approvals from your insurer (or at least a simple statement of how many people have been approved).
- 2. Provide the prosthetist's report to several physicians in your healthcare network. Explain the problem and ask each to give you a letter that states why the new device is medically necessary.
- 3. Submit the material on appeal to the insurance carrier.
- 4. If the insurer still denies your claim, contact your state insurance department to see if there is an independent medical review procedure under state law or if you can file a complaint against the insurance carrier.

Will I always be able to get private health insurance if I am healthy?

No. It is harder to get private health insurance than group health insurance. Insurers may reject applications for private coverage for the smallest of reasons or charge "penalty premiums" if you have had prior medical problems. Consider the following:

- 1. Consider increasing the deductible and try to limit any period that includes a "penalty premium."
- 2. If your group coverage is about to lapse, try to extend it for as long as possible. COBRA is a law that allows extensions of group insurance for 18 to 36 months. Make sure that you are not without coverage for more than 63 days, so that you won't have to meet any preexisting condition provisions in a new group plan.
- 3. If all else fails, see if your state offers health insurance to people who cannot receive it elsewhere.
- 4. The new health insurance law signed by President Obama may help, but its validity is still in doubt.

General Matters

Do I need someone to help me with an appeal from a coverage denial or termination?

Yes. You can usually file an *initial* health or disability claim yourself with help from your treating physician, but you should get help either from a patient advocate or attorney after a denial or termination. Make sure that the person will not charge you anything unless your appeal is granted.

Where do I look for assistance in filing an appeal?

Check with the Amputee Coalition, do a computer search or contact a legal aid society or bar association in the county or state where you live.

Disability Insurance

Is disability insurance important?

Yes. It replaces part of your income if you can't work because of an illness or accident.

Can I get disability income when I'm disabled from work if I don't have insurance?

Maybe. If you live in New York, New Jersey, Rhode Island, California, Hawaii or Puerto Rico, you may be eligible for up to 52 weeks of disability income.

What kind of disability insurance is available?

Group (through your employer) or private. Affordable, or sometimes free, insurance may be offered through your employment. Often it is part of your employee benefits, so be sure to ask. Even if you have to pay part or all of the premium, which is usually relatively small, it is worth it if you ever need the income replacement (which will be tax-free if you pay the premiums).

If you can afford private disability insurance (it's expensive), find a reputable company (an insurance agent can provide you with ratings). Find out what conditions of disability are covered and how much of your prior income you will receive, and for how long.

If I have disability insurance and become unable to work, might I have problems getting my benefits? Once benefits begin, can they be terminated?

Yes to both. The 2009 edition of *First Step* contains comprehensive articles explaining disability insurance and the best way to get benefits and avoid problems that could result in a denial of coverage.

An important development regarding disability insurance occurred in late 2005, when the California Department of Insurance took steps to stop a number of wrongful practices that were being used by a large insurance company to avoid paying benefits and to discourage such practices by all disability insurance companies licensed in the state. Other states may follow.

Insurance companies may now be required to:

- Pay more attention to the opinions of your treating physicians as to whether you can work
- Cease the constant barrage of requests for information, once disability has been established
- Stop "cherry picking" selective portions of medical data and reports to justify denials
- Use a more fair and uniform definition of "total disability."





Living With Limb Loss is a new section of inMotion, dedicated to sharing practical

tips for performing daily living activities. Adapting to life without a

limb presents challenges that go well beyond learning to walk with a prosthesis or to drive a car. People living with a disability learn to think outside the box to adapt, whether through the use of technology such as prosthetics or assistive devices, or plain common-sense solutions, such as simply rearranging the furniture in your living room to avoid the risk of tripping.

Do you have ideas and solutions of your own?

We encourage you to send your tips to us to share with our readers at editor@ amputee-coalition.org.

How to Stand From a Sitting Position Without Using Your Arms

Bilateral Below-Knee

If you're a new amputee or simply out of practice, it is recommended to have someone nearby to help you (or to act as padding!) should something go wrong. It's also advisable to do some form of leg exercises beforehand, to strengthen your leg and gluteal muscles.

- First, move to the edge of your seat.
- Ensure that your feet are a comfortable distance apart not too close together or too far apart.
- Make sure that your feet are not too far away from your body. Ideally, your legs should be positioned at a 90 degree angle.
- Get a feel for where your feet are.
- Try and feel that the center of your foot (or feet) is on the ground.

Practice pushing down on your feet while you are still sitting.

- When you're ready, push down on your feet while leaning forward at the same time.
- Lean as forward as you need to go (without toppling over), pushing down on your feet at the same time.
- Once up, breathe in and enjoy the view!

How to Sit From a Standing Position Without Using Your Arms Bilateral Below-Knee

What goes up, must come down. It is recommended to use fixed seating to begin with, such as a wheelchair with the brakes engaged. Until you become more confident, for the first few tries it's a good idea to stand so that you can feel the chair against the back of your knees (or thighs, depending on how tall you are!)

- Bend from the knees (the way they tell you to do when lifting something heavy), leaning forward slightly, but not too much.
- Try to remember that the chair has not miraculously moved all of a sudden! Yes, it's still there!
- Still bending, slowly lower yourself into the chair.
- That's it. You should be sitting now. Well done! 💫

How to Help Prevent

Skin/Soft Tissue Injuries to the Feet

by Robert P. (Bob) Thompson, CPed

Self-care of the foot is vital for everyone, especially for those who have had a lower-limb amputation or are at risk for one. Injuries to the skin of the foot and/or the fat pads can interfere with mobility; they also can lead to damage to underlying blood vessels, nerves, tendons, ligaments and other foot structures. That damage can lay the groundwork for limb loss.

At the Institute for Preventive Foot Health (IPFH), we stress the importance of skin/soft tissue management as a means of protecting feet from damage. Specifically, we advise taking proactive measures to protect:

• The outer layer of skin (epidermis) from chafing and abrasion

• The underlying layers of skin (dermis and hypodermis) from pressure (your body weight on your feet) and shear forces (movement of your foot inside your ordinary sock and shoe)

• The fat pads on the heel and ball of the foot and underside of the toes, which are especially vulnerable in seniors and those who have had a lower-limb amputation.

Until age 30, fat pads are thick, strong and supple, and the feet are mostly problem-free. But as we age, our foot muscles become weaker, tendons and ligaments become less resilient, and our foot or feet may ache by the end of the day.

By age 50 or so, many people have lost as much as 50 percent of fat pads, and the skin around the foot may have thinned considerably. The result: The foot is more vulnerable to damage from impact during walking and other activities, and to blisters, cuts, bruises and other forms of skin/tissue damage.



tissue management and other preventive foot health topics, visit the Institute for Preventive Foot Health Web site at ipfh.org. All of the published research is available if your doctor needs it. If you have questions about foot problems and protection, browse the foot conditions section or use the "Ask the Expert" tool for a personal response.

Preventive Foot Health Tips

To help prevent injuries to the foot skin and fat pads, and to manage any problems you may already have, we suggest the following:

- Inspect your foot or feet daily once in the morning when you wake up and once at bedtime. Check the top, bottom and sides of your feet and between your toes. Use a mirror if you can't turn your foot over to look at it. You can also ask a family member or friend to help you.
- If you see any lesions (cracks, cuts, blisters), tend to them immediately with antibiotic cream and a wound dressing (gauze bandage or a Band-Aid). See your doctor immediately if there is any sign of infection.
- Be aware of bruises, which are a sign that injury has occurred below the skin. A bruise often precedes tissue damage, so you should consider it a warning sign of potential problems to come, especially if it takes a long time to heal.
- Feel for lumps; temperature differences (one part warm, another part cool); pain, burning, tingling or numbness, which are signs of neuropathy; or loss of hair on your foot or leg, which can signal reduced blood flow. Any of these signs mean your foot is at risk. See your doctor or a foot health professional immediately.
- In addition to foot inspections, wash your foot or feet in lukewarm – not hot – water daily. If you have neuropathy, use your elbow to test the temperature of the water. Make sure you wash between your toes and then dry your foot thoroughly, including between the toes.

- Apply a thin film of skinsoftening lotion to the top and the bottom of your foot. Don't apply lotion between your toes because it facilitates rubbing and irritation.
- Cut your toenails carefully. Trim straight across and soften the edges with an emery board to reduce the chance of developing ingrown toenails. Don't cut your toenails yourself if you have neuropathy or other foot problems related to diabetes.
- Never trim corns or calluses with a sharp implement such as a razor blade, knife or nail clipper; one slip of the hand can lead to a lesion or worse.
- Wear properly selected and fitted padded socks that provide terry fabric under the fat pads beneath your toes, the ball of the foot and the heel. Peer-reviewed, published studies have shown that wearing clinically tested padded socks can actually help prevent injuries to the skin/soft tissue of the foot, which is a major cause of diabetic ulcerations.
- Wear shoes with non-slip outsoles that fit properly, so that your foot can't move around in the shoe and become irritated. To get the best possible fit, IPFH suggests following its integrated approach: Wear the padded socks you intend to wear in the shoes, as well as any inserts or orthotics prescribed or recommended by a doctor or foot health professional,

- when you select and purchase shoes; that way, you are unlikely to have fitting problems afterward.
- Select shoes and padded socks made for the specific activity in which you will be involved. Make sure the shoes are shaped like the shape of your feet (no pointy tips) and correctly sized, as described above.
- Try not to wear the same pair of shoes every day. Rotating shoes every other day allows your shoes to dry out from the perspiration absorbed from your foot the day before.
- Change your padded socks daily or more often if you are very active. 💨



Limb Loss the Family by Roberta Cone, PsyD

You may be feeling afraid, sad, worried, angry or upset because a family member has had an amputation. You may also have concerns about the way other people in the family are going to react, as well as new worries about money. Everyone close to a person with an amputation is affected. The more you know about limb loss and help the person with an amputation to heal and go on with life, the easier it will be to help yourself.

Losing a limb can be extremely disabling, and yet there is a significant range in the level of adjustment achieved by individuals who have suffered amputations.

factors may be more manageable. Losing all or part of a limb is a life-changing event that can cause grief and decreased self-esteem. A person with limb loss loses part of his or her physical self, and the change in appearance is final. Grieving, therefore, is both a normal and expected process of healing.

New amputees commonly go through the five classic stages of grief:

- Denial and Isolation (This isn't happening to me)
- Anger (Why is this happening to me?)
- Bargaining (I promise I'll be a better person if...)
- Depression (I don't care anymore)
- 5 Acceptance and Hope (I'm ready for whatever comes).



How long it takes a person to pass through these stages varies. A person's age, the site of limb loss, and the cause of amputation all affect how an individual copes with losing a limb. For example, unexpected limb loss may more likely result in denial than losing a limb due to a long-term disease. Some individuals, upon realization of the amputation, will recognize the challenge and go straight to the Acceptance and Hope stage.

A common initial reaction of parents, partners or family members to a loved one's limb loss is disappointment and grief. Typically, this grieving time helps the family members face their problem and prepare themselves for a change. Many caregivers feel anger: "Why me?" "How did this happen?" When parents or partners seek information about limb loss, most learn to accept their changed loved ones, to appreciate their uniqueness and to have pride in their assets.

The presence of supportive partners who take over functions when needed and cut back when their loved one is able to manage is important. Parents and caregivers can find it difficult to watch their loved one struggle to regain independence after the amputation. To allow for a full recovery, the family needs to step back so the person with limb loss can develop independence and take initiative.

The acceptance of limb loss in a family may come more easily when parents meet with other parents of

children with limb loss or limb differences. Parents attending support groups learn that their problems are not unique. They have a chance to share experiences, learn how others have coped and work with

others to find solutions to common problems. This can reduce the stress many parents experience. Similarly, the group experience is likely to be helpful to both the significant other and their families. Amputee support groups shy away from self-pity and emphasize strength and participation in a full and healthy life.

Siblings may see their parents spend more time with their disabled brother or sister, which can lead to frustration, jealousy and family discord. Parents should handle these feelings with frankness, openness and sympathy. The siblings deserve extra love and empathy for the loss they experience in having a brother or sister who's "different," instead of a "normal" one like their friends.

Grandparents can be a huge source of support; concerns about how involved they should be and what help they can offer are common. Just *being* there is very important. Grandparents who are less supportive tend to be those who find it difficult to accept a child's disability.

Amputated limbs sometimes cause feelings of revulsion in the patient, family members and society. This is a common and normal reaction to seeing the residual limb. When someone has suffered from limb loss, it does not change the deepest, strongest, most valuable part of a person. It is important to tell your loved one that you see them this way.

The support and encouragement of friends and family can have a powerful effect on a loved one's ability to heal and finalize the stages of grieving. A friend or family member can offer silent support in a moment of despair or confusion and provide a healing presence

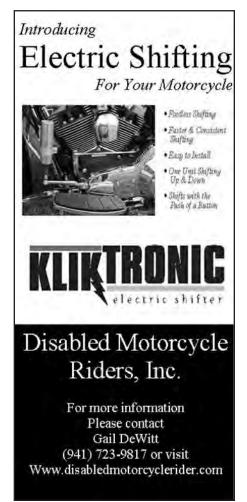
in an hour of grief. In spite of the challenges of amputation, many people with limb loss do adapt to lead normal, productive, happy lives, working, enjoying hobbies and raising families. 💫

For more information

Through the Amputee Coalition's multifaceted National Peer Network, people with limb loss can receive the emotional support and information vital to a full recovery. The Parent Support Network provides training and support for the needs of parents of children with limb loss/difference.

Amputee Coalition National Peer Network

amputee-coalition.org/npn_about.html



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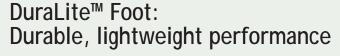
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The foot has three proximal adapter options: a pyramid adapter, pyramid receiver or a torsion receiver. The torsion receiver provides 24 degrees of rotation internally and 24 degrees of rotation externally.

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For more information, ask your prosthetist or visit WillowWood at www.willowwoodco.com.







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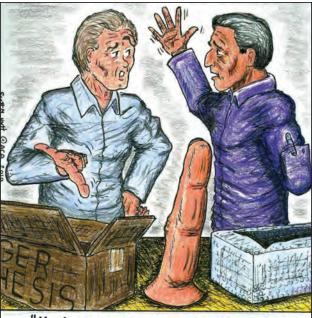
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April 21, 2012

Synch it to your Smartphone. Mark it on your calendar. Use an old-fashioned Post-it note!

Amputee Coalition Limb Loss Education Day is coming to Atlanta, Georgia, April 21, 2012, at the Gwinnett County Fairgrounds.

Join the Amputee Coalition for the first event in an exciting new educational series: Amputee Coalition Limb Loss Education Days.

The Coalition is partnering with Children's Healthcare of Atlanta and OPAF's McKeever's First Ride to host our first Limb Loss Education Day event in 2012. This special event will feature:

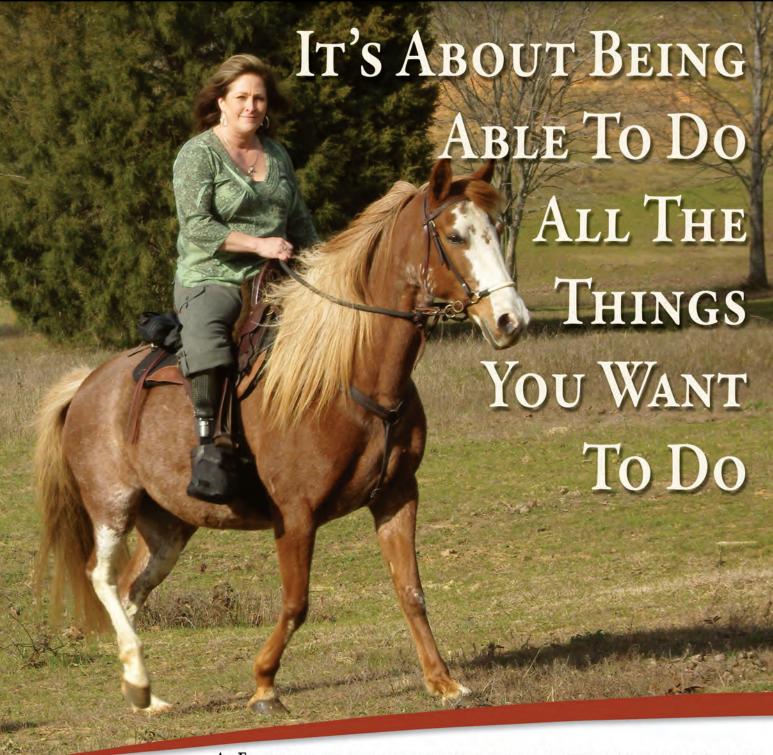
- Gait Analysis Clinic
- · Sessions by limb loss experts
- Networking and fun with your peers.

Limb Loss Education Days are a component of our 2012 educational programming. With these 1-day programs, the Amputee Coalition will reach people with limb loss where they live to begin building stronger limb loss communities across the nation.

Stay tuned for more information about the Amputee Coalition's 2012 Educational Programming Calendar of Events, including additional Limb Loss Education Day events, webinars and new podcast releases.

Come learn with us in Atlanta!

For more information: conference@amputee-coalition.org 888/267-5669



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advertiser index

COMPANIES	PAGES
American Board for Certification in Orthotics,	
Prosthetics and Pedorthics	11
Amputee Supplies	33
AT&T	9
Award Prosthetics	45
BOC International	17
College Park Industries	23
Comfort O&P	39
Disabled Motorcycle Riders	41
Ferrier Coupler	19
Fourroux Prosthetics	44
Fred's Legs	43
Hanger Clinic	4

COMPANIES	PAGES
Hartford Walking Systems	42
Norman Steiner, Attorney at Law and	
Burns & Harris, LLC	14
Össur	2
Otto Bock HealthCare	7
Powerfishn	13
Scott Sabolich	47
SideStix	16
Thomas Fetterman, Inc	11
Thompson's, LLC	42
TRS	11
WillowWood	21, 42



Keep up on up-to-date information at...

amputee-coalition.org



On Being an Advocate by Leslie Pitt Schneider

THIS YEAR MARKS the 37th anniversary of taking my first steps for the second time and the 14th year of knowing my "purpose" in life. On May 28, 1975, the first day of summer vacation after first grade, I was struck by a dump truck while riding my brandnew bicycle. Because of the injuries that I sustained, I was fit with an immediate post-op prosthesis, which consisted of the cast on my residual limb, otherwise known as my "little leg", a pylon sans an articulating knee and a SACH foot. I can still remember taking my first steps in the parallel bars, looking down at my foot, and excitedly telling my parents that I had a foot like a Barbie doll!



Never seeing myself as "disabled." losing a limb has enabled me to achieve successes, with forming AGILE one of my greatest.

From the time after my accident and during the recovery period, I resumed many of the activities that I had done before. Whether it was riding a bike, taking tap dance lessons or just being a child, with gentle nudging from my parents and brother, I never missed a step. I did the same activities, with the same kids, in the same environment, and with the same teachers, the only difference being that I had a new leg! From doing activities with my peers, I learned to accept my physical "difference" because the focus was directed on the common goal, whether it was playing dolls or riding bikes, and not on my leg.

Growing up, I rarely met other people with limb loss. It wasn't until 1998, after volunteering at several hospital-run support groups in the St. Louis area and meeting other people facing the same challenge, that I finally realized my "purpose" in life. Being a "seasoned" amputee, I thought that I could share some of my experiences with people who were "seasoned" humans. When I listened to the shared stories of how people lost their limbs and the fears they faced, the unspoken, resonating message was that people wanted to be active again. People wanted to lead the lives they had. They didn't want to be limited by a prosthetic device.

It was then that I realized the huge impact that doing activities as a new amputee had had on both my physical and psychological acceptance of it. That's how AGILE (Amputees Getting Into Life Energetically) came to be. While providing peer support was AGILE's primary purpose, I realized that the "support" aspect would evolve naturally from the participants doing different activities together as a group. Whether it was learning to golf, doing Tai Chi or going bowling, there was inherent camaraderie and peer support while doing a new activity. No longer were we the only person missing a limb at the swimming pool or the person adapting our golf swing on the driving range. Instead, we were all people enjoying physical activities, without focusing on that which united us. We could laugh at ourselves, we could cry with our successes and we could see that the loss of a limb does not equate to the loss of us as human beings.

Perhaps it was the resiliency of youth when my accident happened to me, but my experience of life without the limb I was born with has been positive. Never seeing myself as "disabled," losing a limb has enabled me to achieve successes, with forming AGILE one of my greatest. While I would never wish the same life experience for anyone else, I know that the "reason" my accident happened to me was so I could advocate for other people facing similar obstacles. 💨

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April 2012

We're leading the fight to empower people affected by limb loss and to reduce amputations. This year, we're focusing on reducing diabetes amputations, the #1 cause of limb loss in America.



"The Amputee Coalition was there when I needed them; now it's time for me to 'pay it forward.""

- Charlie Steele, National Spokesperson

This April, we'll need volunteers to:

- Distribute educational materials Spread the word
- Support our 507 Campaign
- Share your personal story!

Even if you have just one hour to give, you can make a difference. Please join us in our effort. The life you improve just might be your own.

Call 888/267-5669 to sign up!

Save the Date - April 21, 2012

Amputee Coalition Limb Loss Education Day Atlanta, GA at the Gwinnett County Fairgrounds For more information, see page 43 in this issue of inMotion or visit our Web site at amputee-coalition.org

