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Standing at the Crossroads

The path to mental and emotional health

When will I be able to walk again? Will it hurt from now on? Will my family and friends treat me differently? Will I be able to go back to doing my job? Will I ever feel “normal” again?

So many questions. But where to find the answers?

Although people come to limb loss by many different routes, they often face similar questions and problems along the path to healing and rebuilding their lives. The first year following an amputation is critical, and it can be an especially difficult period, both physically and emotionally.

The time needed for healing and rebuilding will vary with each person – depending on physical and emotional health, age, available support and other factors. Emotional recovery is a highly personal experience with no set timeframe. Some people feel that they quickly reach a level of acceptance following their amputation, only to find themselves pulled back into feelings of grief when they least expect it. While it can be overwhelming to face so many unknowns, know that there are many people and organizations that can help guide you and your family along the path of recovery and rehabilitation.

The Amputee Coalition is the leading national nonprofit organization for people living with limb loss and limb difference. We hope that the articles of this issue will provide some guidance to those of you who find yourselves at the crossroads, wondering which direction to take. From insurance access to affordable prosthetic care, greater acceptance and understanding of the limb loss community through Limb Loss Awareness Month, discrimination issues and fair travel for amputees, and research funding to continue advancements in prosthetic technology and patient care, the Amputee Coalition provides a voice on important issues that affect you (see pages 8, 12 and 38).

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

Bill Dupes, Senior Editor

“So there’s no need for turning back
’Cause all roads lead to where we stand.
And I believe we’ll walk them all
No matter what we may have planned.”

–from “Crossroads,” by Don McLean

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.

Advertisements in inMotion are reviewed according to established criteria and guidelines. We aim to support public awareness of commercially available products – things that might be helpful to you and to avoid advertisements that might deceive or mislead the reader. Acceptance of advertisements in inMotion is not an endorsement by the Amputee Coalition. The Amputee Coalition does not test advertised products, conduct independent scientific reviews of them or ensure their claims. Companies that sell through the mail must comply with federal regulations regarding customer notification if the product is not available within 30 days. The Amputee Coalition reserves the right to reject any advertisement for any reason, which need not be disclosed to the party submitting the advertisement.

Opinions expressed in signed articles are those of the authors and are not necessarily endorsed by the Amputee Coalition.

Printed in the United States of America.
I’mPOSSIBLE

Surfing, skateboarding, hanging with friends, Cameron Clapp epitomized “California teen” until one night when, in an instant, his life changed. At 15, Cameron was struck by a train. He lost both legs and his right arm.

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On the Cover
Image of Dan Horkey courtesy of Kitsap Sun, API, 2008, Bremerton, WA

The Amputee Coalition recognizes the following National Sponsors for their valuable support.
Dan Berschinski, a bilateral amputee, is the founder and CEO of Two-Six Industries LLC, a service-disabled veteran-owned small business, as well as a member of the Amputee Coalition Board of Directors.

Tammy L. Boucher is the founder of Boucher Public Relations and works with Next Step Orthotics & Prosthetics.

David Bush, BS in exercise science, CSCS, founder and program director of the Ultimate Sports Institute, is a nationally certified strength and conditioning specialist.

Amy Di Leo is the founder of Aim Hi Public Relations (AimHiPR.com) and has been a television and print journalist for more than 20 years.

Lacey Henderson is a model and parathlete and a counselor at the Paddy Rossbach Youth Camp. She is an above-knee amputee.

Caitlin Pereiras is the social media coordinator at Current TV; she blogs about taking on the world single-handedly at streamofcaitlinness.com.

Phantom Fashionista

Sara Phillips, JD, began training at Ultimate Sports Institute in Weston, Florida, after her right leg was amputated below the hip due to necrotizing fasciitis; Phillips is the Getting2Tri Foundation’s 2011 Female Athlete of the Year.

John Peter Seaman, CP, CTP, is employed by Independence Prosthetics-Orthotics, Inc. in Newark, Delaware.

Sierra Younger is an active high school sophomore with proximal femoral focal deficiency (PFFD), which requires a prosthetic leg.

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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.
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Quality for life
The Amputee Coalition’s government relations department has been working on a variety of issues that will have a direct impact on amputees. We have been tracking the administration’s rules and regulations affecting insurance coverage and essential benefits sets. There were also important decisions made by the courts that affected both the political landscape and the healthcare system.

THE NUMBER ONE ISSUE that was decided on in 2012 was the finding by the Supreme Court that the Affordable Care Act (AKA: “Obamacare”) is constitutional. Regardless of individual perceptions of the law, there are several elements in the bill that the Amputee Coalition worked on in 2012 and will continue to work on throughout implementation. This includes issues around the elimination of pre-existing conditions in the law, coverage for children up to age 26, and more prominently, the “Essential Health Benefits” (EHBs) and the state exchanges that are currently being established. We have been actively involved in the conversations in every state that’s made progress in setting up an exchange.

The reason for this involvement is that it provides an opportunity to include prosthetic and custom orthotic coverage in the EHBs. If prosthetic and custom orthotic coverage is deemed an Essential Health Benefit, it provides a benchmark for all state plans to model that would include adequate and affordable coverage. The result of this work could help to ensure many more insurance plans cover prosthetic and custom orthotic devices, similar to insurance fairness for amputees. In 2013, states and the federal government will continue moving forward on implementing the law, and the Amputee Coalition will work with advocates to make insurance fairness for amputees a benchmark for all plans to follow in the EHBs.

We also continued to advance INSURANCE FAIRNESS FOR AMPUTEES (AKA: Prosthetic Parity) and successfully introduced bipartisan federal legislation in both the U.S. House and Senate. Congressmen Charlie Dent (R-PA), and Rob Andrews (D-NJ) introduced H.R. 4175, and Senators Tom Harkin (D-IA) and Olympia Snowe (R-ME) introduced S. 773. While the House bill looks strong for reintroduction in early 2013, we are working to establish a new lead Republican sponsor because Senator Snowe has retired. In 2013, the Amputee Coalition will work for reintroduction, but will also put a large focus on state legislation to try to increase the number of states with laws and provide more support for a federal bill.
Other issues the Amputee Coalition has worked on, and will continue to work on in 2013, include:

- Reasonable travel for amputees
- Raising awareness through Limb Loss Awareness Month proclamations
- Continued research funding for technology advancements and patient care that are currently facing reductions
- Funding for limb loss programs and resources
- Adequate reimbursement levels for practitioners, which provides greater choice for patients
- Licensure for practitioners, which provides better patient care through accountability
- Americans with Disabilities Act (ADA) and discrimination issues.

Interested in getting involved in 2013? Visit our Web site at amputee-coalition.org and make a difference in your community!

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JANUARY

NATIONAL BIRTH DEFECTS PREVENTION MONTH
nbdpn.org/national_birth_defects_prevent.php

JANUARY 12
Limb Loss Education Day – Phoenix
Phoenix, Arizona
amputee-coalition.org

JANUARY 12 TO JANUARY 13
RWCC 24-Hour Tennis Marathon
Parrish, Florida
woundedwarriorproject.org

JANUARY 13
Bravest vs. Finest Football Game
Chester, New York
woundedwarriorproject.org

JANUARY 27
Taste to Educate
cancerforcollege.org

FEBRUARY

AMERICAN HEART MONTH
heart.org

LOW VISION AWARENESS MONTH
preventblindness.org

NATIONAL WISE HEALTHCARE CONSUMER MONTH
aipm.net/wise

NATIONAL HEART FAILURE AWARENESS WEEK
February 12-18
aboutHF.org

FEBRUARY 1 TO FEBRUARY 28
Taji 100
San Jose, California
woundedwarriorproject.org

FEBRUARY 1
National Wear Red Day
(National Women’s Heart Day)
www.nhlbi.nih.gov/educational/hearttruth

FEBRUARY 10
Miami Tour de Cure
Historic Virginia Key Beach Park, Florida
diabetes.org

FEBRUARY 16
Limb Loss Education Day – New York
New York, New York
amputee-coalition.org

Coming up in the March/April issue of inMotion:
Amputees and the Media

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The Amputee Coalition Looks Ahead to Its Goals for 2013

The Amputee Coalition is entering the third year of our 2015 Strategic Plan with strong accomplishments over the previous years in our key areas of awareness, impact, mission work and sustainability. Each year, we have reported our key accomplishments and in the following year, built on those successes. This year will be the same. In 2013, we are focusing to accomplish the following:

- Elevate our work to a cause
- Grow our ability and capacity to serve our community
- Position and deliver on our brand promise to our stakeholders.

The Four Strategic Pillars of the 2015 Amputee Coalition Plan

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.

Our Vision
By 2020, we will be nationally recognized both as the premier organization for people affected by limb loss and as a leader in limb loss prevention.
Our goals in this arena for 2013 are:

• Enhance our grassroots network to focus on and increase our voice in the halls of state legislatures to ensure fair insurance coverage for prosthetic devices through legislation, the emerging state/federal exchanges and in essential benefits sets. Since 2001, 20 states have passed laws that ensure prosthetic devices are covered in their state’s insurance plans, and that the coverage is at least equal to Medicare’s 80/20 reimbursement rate, or is “no less favorable than other benefits in the policy.” With nearly 1 million amputees living in states that have passed these laws, we are continuing to advance this work in 2013 to make “Insurance Fairness for Amputees” a reality in all 50 states. Several provisions will go into effect throughout 2013 and 2014, including the establishment of the State Exchanges and determinations of the Essential Health Benefits (EHB). These two issues can have a significant impact on amputees, and if we are able to successfully lobby decision makers to include prosthetic and custom orthotic devices in the EHB, it has the potential to create a standard level of care, and would confirm the importance of adequate coverage for prosthetics and custom orthotics in all insurance plans.

• Establish our position as the patient voice in limb loss-related research by creating an Evidence-Based Outcomes Committee and honing our research-related activities to better showcase our value to research and our capacity for involvement. Over the past year, the Amputee Coalition steadily worked to promote the view that limb loss and limb loss prevention –

Elevate Our Work to a Cause

There are 2 million Americans living with limb loss and limb difference, and each day that number grows. In 2010, diabetes – the leading cause of limb loss – affected 25.8 million Americans, according to the Centers for Disease Control and Prevention (CDC). It is estimated that 33 percent of Americans will have diabetes by 2050. In 2009, hospital charges for amputation procedures performed in the United States topped $8 billion, according to the Agency for Healthcare Research and Quality. Post-amputation mortality rates, when due to diabetes, are equivalent to those of pancreatic cancer and higher than those for prostate cancer, breast cancer, colon cancer and Hodgkin’s disease, according to an article in the Journal of the American Medical Association in 2008. Limb loss should be a cause – just like breast cancer, just like diabetes, and just like the myriad of other health issues that have risen to the level of public awareness, research funding and philanthropy in this country.

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 will be greatly benefitted by America seeing limb loss as a cause, and especially by our constituents – those directly impacted by limb loss – mobilizing behind the programs, projects, actions and services of the Amputee Coalition.
including prevention of secondary conditions associated with losing a limb – are valuable topics for research. This work has put us in touch with researchers representing a growing swath of institutions, research organizations, and colleges and universities, ranging from the Department of Defense (DOD) and the Department of Veterans Affairs (VA) to emerging research institutions, such as the Patient-Centered Outcomes Research Institute, to the University of Minnesota. With each interaction, we became increasingly certain that limb loss is a compelling research topic that has been understudied in the medical and public health literature.

As a result of our work, the many issues that surround limb loss are attracting more attention from researchers and research institutions. Organizationally, we see ourselves as a catalyst for promoting patient-centered limb loss research, addressing real-world problems and making a significant contribution to improving the quality of life for those affected by limb loss.

- Increase awareness by launching “Show Your Mettle Day” during Limb Loss Awareness Month. In recent years, we have worked with advocates to designate April as Limb Loss Awareness Month, and received 38 gubernatorial proclamations declaring April as Limb Loss Awareness Month. In addition, President Barack Obama wrote a letter in 2012 recognizing Limb Loss Awareness Month. In 2013, we intend to raise the bar by creating a special recognition day for amputees to wear their prosthesis in plain view for all to see and to proudly show their “mettle.”
- Create an advisory committee for the Amputee Coalition Paddy Rossbach Youth Camp charged with developing a camp expansion plan. The youth camp is a five-day traditional summer camp experience for 100 children ages 10-17. Children come to the camp with limb loss or limb difference that has occurred for a variety of reasons – be it congenital limb difference or limb loss from trauma, cancer or other diseases. The kids tell us, over and over again, that camp is the one place where they do not feel alone and different. They leave camp with newfound confidence and lifelong friendships.
Grow Our Ability and Capacity to Serve Our Community

We have struggled over the years to develop a national plan that identifies new amputees and provides a seamless introduction to our amputee peer support programs and resources. The result has been that we have many peer visitors across the nation who do not receive calls for peer visitors because we are not connecting with amputees at the point of amputation. Our five-year initiative has been to set up a dynamic channel by establishing relationships with care facilities such as hospitals, rehabilitation facilities and clinics. Our aim is to develop a program that positions the care facility as the hub of peer support services, programs and resources. Our major goal is that by 2020 we are reaching all new amputees before they leave the hospital.

In 2011 and 2012, we conducted surveys and analyzed data that we used to build a plan to implement in 2013. This year, we begin our outreach to develop these relationships. Our goals in this area are to:

- Implement the peer visitor advancements approved by the Peer Support Committee for our Certified Peer Visitor program
- Continue to work with the Veterans Administration to integrate our peer support program in the VA Amputation System of Care
- Engage at least five new health systems/hospitals/rehabilitation facilities/clinics in our peer support program.

Our ability to reach more amputees faster is magnified through partnerships with like-minded organizations. In 2013, we have the following goals to grow our capacity in reaching more amputees:

- Better incorporate our Support Group Network leadership into the leadership of the organization and increase communications to support group leaders so they have the most current information sooner for their local constituents
- Establish at least two partnerships that allow us to reach disparity communities with our programs and services

Amputee Coalition-led collaborations, programs, relationship-building and strategic alliances among nonprofit, commercial and governmental organizations will create changes in healthcare delivery that ensure all amputee patients and their families in the U.S. have access to and receive quality care, support and information for both pre- and post-limb loss.
• Increase our professional membership by 5 percent and increase the usage of our patient education resources through our professional partners, namely the use of First Step, our comprehensive guide for new amputees.

• Do a better job of showing our appreciation to our national partners through improved communications, recognition and inclusion in our program development.

Our ability and capacity is hugely impacted by our resources – both people and money. In recent years, both have been adversely impacted by reductions in long-time CDC funding. In fact, in 2012, we lost $625,000 from a CDC grant due to CDC administrative decisions that impacted disability populations like us who have been longtime grant recipients. Dealing with that loss in a national economic downturn has been more than challenging and resulted in staff reductions and programmatic slowdowns. Our community has to understand that the only way to sustain the programs and services of this organization is through their support, the support of our friends, and a collective effort to raise awareness with the general public about the essential work of this organization for this amazing limb loss community. Our goals for sustainability in 2013 are to:

• Integrate philanthropy into all programs and services and make its critical role more visible to everyone served by those programs and services.

• Ensure that all staff and volunteers understand their goals and objectives and to have available tools to achieve them, including improved communications and connectivity through social media and the Internet. In 2012, we made great strides on our Facebook page, and we hope to make similar improvements in our use of other social media applications, such as Twitter.
Position and Deliver on our Brand Promise to Our Stakeholders

Our name is one of our most valuable assets. It helps open doors, it attracts talented people, it differentiates us and it is a reassurance of trust in our capability. Today, our brand means more than just a resource center. Our brand has become a trusted partner and collaborator in research and outreach projects. We are consulted by the DOD, the VA and academic organizations. Health systems are beginning to contact us and we are getting more involved with other national organizations – all in an effort to reach more amputees faster and to help empower them to achieve their full potential. Our mission guides our actions and behaviors and the way we develop our programs and implement our services. It is at the heart of everything we do and everything we say. As a national nonprofit with a small annual budget, it is a challenge to reach the diversity of constituents we serve, but we strive to live up to that challenge every day in everything we do. When we do, we build enduring relationships with our constituents, partners and other stakeholders.

In addition to all of the goals already listed, these additional goals will help us better deliver on our brand promise:

• Develop a long-range plan for our National Limb Loss Resource Center that ensures sustainability, resource viability and growth, and relevancy to the needs of the limb loss community
• Deliver educational programming that exceeds participant expectations and has record-setting attendance
• Produce a new edition of First Step: A Guide for Adapting to Limb Loss
• Create and disseminate a Body Mass Index calculation tool for amputees that helps them monitor and keep their good health
• Better define our role as a catalyst for limb loss prevention
• Better leverage the expertise of our Scientific and Medical Advisory Committee to increase opportunities for research funding in areas that have real value for amputees.

We are eager to embark on our 2013 work plan. We have more amputee involvement in the organization than ever before. We have greater interest in our work by academics, researchers and potential funders. We are passionate about the work and the path ahead of us. We are thankful for and sincerely ask for continued support from our community, partners and friends – and we are confident for a vibrant, exciting 2013. Won’t you join us?

— Amputee Board of Directors, Staff & Committee Members
Many amputees experience phantom sensation or pain following an amputation. The less troublesome of the two is the phantom sensation, which occurs when you still seem to feel your missing limb, foot or hand. The more serious experience occurs when you have phantom pain seeming to come from a portion of your missing limb. This pain can be short-lived or last for extended periods of time. It can be so intense that it causes significant discomfort and can even interrupt sleep patterns.

If it is frequent and intense, medication might be required to reduce its impact on your lifestyle. You should consult your physician if you experience persistent and significant phantom pain.

It is thought that these sensations are caused by a disruption of your nervous system that occurs as a result of your amputation. During your amputation, the nerves that normally extend beyond your level of amputation will be severed. These cut nerve endings seem to continue sending electronic signals to the brain that give the impression to your brain that you still have some or all of your missing limb. It can take time for these severed nerves to calm down (desensitize) and heal, and for your brain to reprogram itself and get used to not having the portion of your leg that was removed.

What can you do when these sensations occur?
If they are not severe, acknowledge them and move on. I’ve heard of amputees scratching their sound-side ankle when they feel as if their amputated ankle itches, and that this helps. I’ve also heard that massaging your residual limb can help when phantom sensations or pain arise. Also, wearing your liner or a shrinker sock that compresses your residual limb brings relief from pain to some amputees.

If the sensations or pain persist or become severe to the point of adversely affecting your lifestyle, consult your physician, as there are medications that can often help treat these symptoms.
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It’s inevitable – no matter where you go, sooner or later you get the same question: “How did you lose your limb?”

I’ve been an amputee long enough to come up with many interesting answers to that question.

I try to remind myself of the saying: “Be kinder than necessary, because everyone is fighting some sort of battle.” I’ve found that those who ask often have a legitimate reason; for example, they, or a loved one, may be expecting an amputation. This list is in no way meant to diminish the impact or importance of losing a limb. However, although people usually ask with the best intentions, there are times I would secretly love to come back with an answer like one of these.

by Lacey Henderson

**“How Did You Lose Your Limb?”**

1. I’m part robot. (OK, it doesn’t actually answer how you lost it, but it is a timesaver. It comes in handy when I don’t have a lot of time for explanations!)

2. “What do you mean, how did I lose my... What?! Oh no... Where is it??!!” (This old trick requires a twisted sense of humor, but the shock factor is worth it.)

3. Bear hunting accident. (It was salmon season... that fish came out of nowhere and bit it clean off!)

4. They aren’t kidding when they say gas costs an arm and a leg. (Seriously, though.)

5. Zombies took it from me. (Good thing they didn’t get my brain!)

6. I stubbed my toe/jammed my hand one time too many. (Don’t let this happen to you!)

7. I didn’t eat all of my fruits and vegetables when I was little. (See? They really are good for you!)

8. I used to be really flexible as a child. (Until I went too far and it came right off!)

9. I have reptilian DNA. (Sometimes they just fall off, OK? Don’t worry, it will grow back.)

10. I took a dare to jump off of the Eiffel Tower. (That’s right! I’ll accept any challenge!)
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Every “Body’s”

DIFFERENT

A look at how prosthetic choices can affect your body image

by Amy Di Leo

“People used to look at my prosthesis and say, ‘What a shame.’
Now they say, ‘Wow! That looks awesome!’”

Dan Horkey

Dan Horkey, of Seattle, Washington, lost his leg below the knee in a motorcycle accident almost three decades ago. He was 21 at the time and says learning to live with a prosthetic limb was difficult. “My goal was to not have anyone notice I wore a prosthetic limb,” explains Horkey. “I was very conscious about how people stared or avoided eye contact with me walking down the sidewalk.”

But if you spotted him walking down the street today, that’s not what you would see. Now Horkey wears his prosthetic leg boldly. “I wear it ‘bare bones,’ and I like to show it off,” he shares. “What had once been a source of indignity for me is now one of pride.”

Thanks to innovative technology and a little grassroots ingenuity, today’s amputees have many options to “make a statement” with unique covers, sleeves and fairings made to personalize prostheses. For many, it provides an opportunity to be unique.
Kate Ross

Kate Ross, of Minneapolis, Minnesota, doesn’t think she can possibly call more attention to her leg than she does. With a cover modeled by a wild, abstract T-shirt, her prosthetist designed her sleeve with lots of color and rhinestones. Ross says, “When I was presented with the chance to put some of my own personality into it, I was all for it! It makes me proud to be who I am.”

Ross lost her leg in an automobile accident at the age of 20; today, she is constantly on the go. Along with attending college and working full-time, the young woman volunteers for Wiggle Your Toes (wiggleyourtoes.org), a Minneapolis-based nonprofit organization that helps “individuals who have suffered limb loss in their recovery and rehabilitation efforts through consultation, planning and referrals.” Ross is a client advocate and sits on the foundation’s event planning committee.

“I am fine with anyone asking me about my situation,” explains the vivacious young woman. “I get excited at the opportunity to educate [people about] a lifestyle that they are unfamiliar with. I have learned that curiosity is something that everyone has; and if they are willing to ask about my situation, then I feel it’s only right to provide some insight.”

It’s not always the decorative sleeve that gets the attention, however, as Ross explains: “The best reactions I get are from children; I genuinely love the responses they have when they realize I am missing my leg. My favorite was when I was in the grocery store on crutches for the day. I was walking around and I noticed the cutest little boy staring and trying to figure out what was going on. He would look at his own legs, one at a time, and then look over at me. Finally, he burst into tears and started screaming. When his mom asked him what was wrong, he told her that it wasn’t fair that I was able to have only one leg, and that he wanted only one leg! His poor mother was so embarrassed, but I totally cracked up and let her know that it was the best response I had ever heard.”
Chad Crittenden, of Livermore, California, has had his share of interesting reactions but it doesn’t bother him either. “At this point in my life, I really don’t mind if people notice it or not.” Crittenden became a household name to many when, in 2004, he became the first amputee to compete on the mentally and physically challenging reality show, Survivor.

Crittenden lost his foot 10 years ago to synovial sarcoma, a rare form of cancer. He says he never thought about not wearing a prosthesis. Today, he works for Bespoke Innovations, in San Francisco (bespokeinnovations.com), and considers himself a representative for people with disabilities. He wears the company’s 3D Systems fairing, which he calls “unique.” According to the company Web site, fairings are custom panels that fit over existing prosthetic legs (see photo, page 27).

“No other company has ever done anything like this before,” touts Crittenden. “We create a detachable cosmetic ‘shell,’ which is not attempting to cover, but rather attempts to look amazing and innovative, while restoring the exact shape of the nonexistent lower limb.”

“At this point in my life, I really don’t mind if people notice it or not.”
When Frederick “Kurt” Pauloz lost his leg below the knee in a 1983 automobile accident, he explains, “Legs just weren’t that good-looking. Back then, there was cosmetic hose [in] one or two colors, and that was it. There were no prosthetic skins, and all attempts to make an artificial leg look like a real leg were futile.” He adds that suspension sleeves to match his very fair skin were nonexistent, and he continues, “Unfortunately, it’s still the same way today.”

Because Pauloz was at the prosthetist several days a week making adjustments, which would damage any cover, he chose not to wear one. On the street, the reactions weren’t always as kind as what he experiences today.

He recalls, “People didn’t know whether to ask me, ‘What happened?’ ‘How do you feel?’ or ‘Can I help you?’ Most of the time they said nothing and just stared like I was abnormal or a freak of society. For 15 years I walked around with an unfinished leg and unfortunately there was, and still is, a stigma attached to being handicapped or an amputee.”

Pauloz, of Port Charlotte, Florida, became a prosthetist in the early 1990s and a few years later, with the help of his seamstress wife, created SleeveArt™ by Fred’s Legs (fredslegs.com). Pauloz says reactions have been nothing less than positive. The first time out with his prototype sleeve, “People stopped me and commented on how cool and innovative my leg was, and how well I looked,” he shares.

Today, Pauloz is retired but Fred’s Legs is now an international business, offering a library of art and custom-made options for prosthetic sleeve covers and laminating sleeves. But clearly, sleeves and fairings are not the right choice for everyone.
Robert E. Cone, PsyD

Roberta E. Cone, PsyD, of San Diego, California, does not wear a prosthesis. Faced with a below-elbow amputation of her dominant left hand after an automobile accident more than 10 years ago, Cone now simply refers to herself as “a woman with limb loss.” She admits her choice probably isn’t for everyone, but it works for her and she “enjoys the challenge.” Cone concedes that her decision may have been different if she had an above-elbow amputation.

“I do not wear a prosthesis. I found the process of shaping the stump into an unnatural appearance and the look of a prosthesis distasteful,” Cone says. “The loss of my limb has been an incredible gift to my healing work with veterans and the violent men I work with. My loss has touched every area of my life and I feel a great reverence for my path. I wouldn’t take my arm back for anything.”

Cone, a doctor of psychology, has made a career of helping people deal with phantom limb pain and overcoming the psychosocial challenges of looking different. She innovated a mirror apparatus that assists amputees with phantom limb pain (PLP). The device uses three vertical mirrors with panes oriented at angles to create the illusion of their limb being intact.

“Negative body image, in my experience with limb loss patients, is by far the greatest challenge to healthy psychosocial adaptation,” says Cone. “Healthy reconceptualization of body image contributes to quality of life.

As many would agree, Schneider says her prosthesis “is not my defining characteristic.” Schneider adds that she does not tell people about it unless they ask.

Explains Schneider, “Part of my acceptance of my accident was to take control of its outcomes by not letting it control me. So, I do not draw attention to it, not because I am ashamed, but rather because a prosthetic device is something that enables me to do what I need to do. Not diminishing life with limb loss, a prosthetic limb is a device like glasses or contacts, without which I cannot do daily living activities.”

Whether going bare bones, using a decorative sleeve or fairing, wearing a flesh-colored cover or not using a prosthesis at all; these decisions are personal, and every “body” is different.

 Leslie Pitt Schneider

“I am ‘old-school’ and wear a cosmetic cover,” explains Leslie Pitt Schneider, who lost her leg after she was hit and run over by a dump truck over 30 years ago. “It likely stems from being a longtime user of prosthetic devices and because I was a child at the time I lost my leg.”

As many would agree, Schneider says her prosthesis “is not my defining characteristic.” Schneider adds that she does not tell people about it unless they ask.

Explains Schneider, “Part of my acceptance of my accident was to take control of its outcomes by not letting it control me. So, I do not draw attention to it, not because I am ashamed, but rather because a prosthetic device is something that enables me to do what I need to do. Not diminishing life with limb loss, a prosthetic limb is a device like glasses or contacts, without which I cannot do daily living activities.”

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Celebrate the Difference

For **Dan Horkey**, the tattoo art on his prosthetic leg helped boost his self-image immediately. “Many people gave me compliments on my tattoo artwork, and that helped to boost my confidence. The artwork takes the attention away from the disability. It made me walk straight and improved my self-esteem.”

Back in the early 1980s, Horkey was self-conscious; today, he is self-confident. At the time he lost his leg, he explains, “I chose to cover up, hide my prosthesis with the typical shaped foam cover with a spray-on skin tone that didn’t really match my sound leg in color or shape.” But, he adds, “It worked for me.”

As Horkey and **Pauloz** remember, 30 years ago there were far fewer options than are available today.

**Crittenden**, who is now an inspirational speaker, besides his work with amputees, says of his fairing, “It is amazing what conversations it elicits, and this opens doors to dialogue, acceptance, respect and more.”

**Kate Ross** agrees: “I think my design allows people who don’t know me to feel more comfortable with my situation when they can see my leg. I can tell you that a lot of people have approached me about it, usually giving only positive feedback. I think that people don’t know how to approach the unknown. It seems they want to say something, but they are unsure if it is proper. With my design, I’m trying to yell out to the world, letting them know I am totally OK with my situation, and it seems people then understand it’s OK to ask questions.”

She adds, “When my practitioner told me I could pick out a fabric to put over the knee and socket, all I could think of was, what kind of fabric am I going to find that I want to wear every day? It [had to be] loud and energetic like I am.”

Horkey’s leg also makes a statement, and he says he works to empower other amputees having a prosthesis and replacing it with a sense of individualism,” explains Horkey. “The artwork is customized, giving a sense of ownership and individual reflection to the person who wears it, much like someone’s body art tattoo. There is personal meaning, sometimes obvious in content.”

Horkey believes his tattoo art helps amputees “feel whole again, rather than damaged.” And from his experience, there’s more: “I wanted to help others with the greatest gift one can give – a strong sense of self. I know from my own experience, one of the hardest challenges in my life was recovering from loss of self-esteem.”

Besides Bespoke, Fred’s Legs and Prosthetic INK (a GTOPI company), there are other companies that make custom designed sleeves and other decorative items for prosthetic limbs. Prosthesis or no prosthesis, cover or no cover, as **Leslie Pitt Schneider** says, that’s not what is important. “The message that I try to [share is]: Live your life without limits. Take that which makes you different to be that which makes you amazing!”

“[My life as a woman with limb loss has been extraordinary],” says, **Roberta Cone**. “I accepted my changed body image upon realization that my forearm had been amputated. I was fortunate to not take a victim role. If I had, I would have missed out on an incredible life.”

**Photo courtesy of 3D Systems**
Falling in Love With ... Myself

by Caitlin Pereiras

I think that having a positive body image is important, but it can be pretty difficult when you’re working in New York City and bumping into gorgeous supermodels on occasion. So it helps to focus on the parts of myself that I love and that make me unique. Here’s my take on body image and what I love about myself.

Five things that have really taught me to love and believe in myself.
Hair
When I was little, my grandmother used to tell me an old wives’ tale about how eating bread crust would make your hair really curly. So I spent years eating crustless sandwiches and using straightening irons in hopes that I’d just wake up with naturally straight hair one day. I didn’t. But I’ve definitely learned to appreciate my Taylor Swift curls now as an adult.

Legs
As useful as the transportation system is in New York, I find myself having to do a lot of walking to get to and from the train station every day for work. And with all that exercise comes a workout that can rival even the most strenuous treadmill jogging session at the gym. My legs are very muscular and shapely as a result, and I love highlighting them in skirts and leggings. I’m proud of my athletic legs because they bear the signs of a long commute and a healthy body.

Smile
As a kid, I always envied my friends who wore braces and were allowed to pick different-colored rubber bands to decorate them every month. Now that I’m an adult, I realize how fortunate I was that I never needed to wear braces or to feel the pain of getting them tightened all the time. My teeth are perfectly straight and won’t be needing any work done anytime soon.

Hips and thighs
I used to think that my ample hips and backside made me fat, but I’m far from overweight. I now see them for what they really are: a sign of femininity and an expression of my Latina roots. I’m tall and pale, so most people are shocked when I mention that I’m 100 percent Hispanic. I may act like a Taylor Swift, but my shape definitely leans more toward a J Lo. And I’m cool with that.

Limb difference
This one hasn’t always been easy for me to love or even accept. I was born without my left arm just below the elbow and often wear a prosthesis to cover it up. I used to think my limb difference made me undesirable or unattractive to the opposite sex. But I realized how wrong I was and now see my small arm as capable and strong. I see it as something unique that only adds to my character. It doesn’t define me, but it doesn’t detract from who I am, either.

So there you have it – five things about me that have really taught me to love and believe in myself. I hope this inspires you to look for all the positive things you should celebrate about yourself because, trust me, there are many. You can read my blog at streamofcaitlinness.com and follow me on Facebook, Twitter and Pinterest.
The “E-Motion” of Limb Loss

“e-motion” noun \i- m-\sh n\n
The combination of technology that the industry has to offer with precise fitting techniques and a genuine sense of caring and empathy to help change lives.

Ask Andres Burgos and he will tell you. He is a Marine. He saw combat during a deployment to Haiti as part of “Operation Secure Tomorrow” and spent eight years as a SWAT-trained infantry soldier. And he was one of the lucky ones to return home uninjured.

On June 29, 2011, Burgos, now a veteran, was happy. He had a wife, a great job and was beginning to really live the life he had planned. Suddenly, returning home from a visit with friends, his life changed forever.

Burgos was knocked off his motorcycle with slight injuries by a hit-and-run driver. As he was trying to crawl off the road, a minivan ran over him, causing serious injuries to his right leg, resulting in an above-knee amputation.

“I was extremely sad, afraid and angry,” says Burgos, who today is separated from his wife and struggling to make ends meet. “I was a veteran who had fought for my country and was trying to be a good citizen, and then this happened to me after having survived so many dangerous situations in the Marines. I felt like I was being punished.” He is not without hope, however, and points to his prosthetists addressing his emotional as well as physical well-being as one of the reasons.

One of these is Jerry Scandiffio, a prosthetist with Next Step Orthotics & Prosthetics and a below-knee amputee. “When I became an amputee, I felt like I wasn’t a whole person,” says Scandiffio. “I thought, ‘Who’s going to care about me? Who’s going to want to date me?’ “I was a beach bum and I thought I’d never run in the sand again. I was wrong, but it’s what I was thinking. You have to go through a healing process.”

“I feel close to Jerry, as he is an amputee too,” says Burgos. “When he says he knows what I’m going through, it’s true. You’re never going to have that connection with someone who isn’t an amputee.”

For Scandiffio and Jason Lalla, another prosthetist and an above-knee amputee, it’s all about treating one client at a time, looking at the whole person as well as their family. “It’s as much a mental adjustment as a physical adjustment,” says Lalla. “I tell family members the initial years are a rollercoaster. I tell people like Andres, ‘You will have days...
where things are great that could be followed by a day where you want to throw the leg against the wall.”

Next Step’s President Matthew Albuquerque defines their approach as “e-motion”: “We understand that to design the right fit you must first understand the person. That understanding is the first step to a better life.” It’s all about “personal conductivity,” a term not normally associated with the O&P field, but that defines how they approach each client as a unique individual with unique emotional and physical needs.

According to prosthetist Scott Cummings, Next Step was selected as one of five O&P facilities nationwide to participate in a research project surveying the well-being of amputees designed by Dr. Stephen Wegener of Johns Hopkins and the Amputee Coalition. While the results are still being analyzed, Next Step has undertaken activities to address the emotional well-being of patients, helping them through the grieving, well-being and adjustment phases. “We try to connect amputees and their families to other amputees,” says Cummings. “Some of our prosthetists who are amputees visit new amputees in the hospital, and we offer referrals to appropriate organizations that can assist our clients with their well-being.”

“Our expertise and ability to use the latest in technology is obviously important, but we know that being inspiring and compassionate is also necessary to help people get back their desired lifestyles,” says Albuquerque. “That’s why we call our approach and process ‘e-motion.’ We combine all the technology that the industry has to offer with precise fitting techniques and a genuine sense of caring and empathy to help change lives.”

Burgos says while he still has some “dark moments,” and continues to struggle with “accepting reality,” his life is changing for the better. Each day he goes to work at Motorcycles of Manchester South in Foxborough, MA and has begun attending adaptive sports events hosted by Veterans Affairs. “My dad told me one of the most important things you have is your name, and I want my name to be associated with strength, power, respect and integrity,” says Burgos. “I am reclaiming my life.”

“”When he says he knows what I’m going through, it’s true.”
Traditionally, partial-hand amputees have had three options: do nothing, a mostly nonfunctional cosmetic replacement or an anatomically incorrect mechanical replacement. These replacement fingers were often too long and limited in their range of motion. Thankfully, there are new technologies ready and waiting to help.

The first promising technology is of the high-tech variety. The i-limb digits by Touch Bionics is almost like a complete upper-limb prosthesis, scaled down to fit the needs of partial-hand amputees. Capable of replacing anywhere from a single digit to all five fingers on a hand, i-limb digits are individually powered and controlled. The fingers can curl, grip, extend and point independently of one another. The custom device is worn like a semi-rigid glove, with the added benefit of protecting any sensitive or compromised surfaces with a flexible silicone interface material. Component layout is customized to accommodate the required batteries. The controller module and wiring placement are also custom for each patient.

Control of the i-limb digits is achieved through either myoelectrodes or force-sensing resistors (FSRs). Myoelectrodes sit above the skin and sense muscle contraction. This allows the user to trigger certain movements by flexing existing muscles. FSR control is used when the patient has control over one or more remnant digits. As the digit presses on the resistor, the force is sensed by the device and used to trigger a movement. A user-level
(biosim-i) and a prosthetist-level (biosim-pro) computer program allow adjustments to gain and threshold levels as well as multiple control strategies.

Partial Hand Solutions (PHS) offers another solution for partial-hand amputees. Their M-Fingers are a modern interpretation of the older, mechanical approach to replacing lost fingers. Available as complete or partial fingers, M-Fingers are mechanical, body-powered, multi-articulating devices. Their simple, rugged design is well-suited to the rigors of daily use; they do not require batteries, electrodes or complex control systems.

Unlike mechanical fingers of the past, the X-Finger is very close to being anatomically correct in terms of length and flexibility.

The varied nature of partial-hand injuries means that prosthetic replacement must be custom and scalable. Whether you need to replace one finger or more, one of these three products may be just the solution you’re looking for.

For patients who have lost one or more fingers but still retain the majority of their first joint, Didrick Medical’s X-Finger may be a great solution. The X-Finger is a mechanical, body-powered finger prosthesis for partial-finger amputees. The device can be used to replace single or multiple fingers, but unlike the M-Finger, which offers a replacement for an entire finger, the X-Finger requires a remnant digit for fitting and use.

The strength of the X-Finger lies in its simplicity. The finger attaches via a small metal frame that extends from the remnant digit. There are no batteries, the unit is extremely light, and articulation is achieved simply by moving the residual finger. The X-Finger is so lightweight that the device actually weighs less than a custom skin-cover that most users choose to put over their X-finger. All together, the X-finger and its cosmetic cover should weigh about 30 grams.

Didrick Medical’s X-Finger

There are new technologies ready and waiting to help.
THERE ARE DIFFERENT CUSTOMS FOR HUMAN INTERACTION THROUGHOUT THE WORLD. A handshake, eye contact, even a stance can affect the way a person reacts. This idea is no different when applied to someone who has a disability.

**People with disabilities are individuals in themselves. They should not be considered as one group or entity.**

**Offering a Helping Hand**

Some basic rules should be considered when dealing with a person who has a disability. The first is to determine whether the person actually needs help. While well-intentioned people may consider it a helping hand, the person with a disability could take offense if the help is unwanted. Offer assistance only if the person appears to need it. If he or she does want help, ask before you act. This provides the person with a disability the opportunity to give specific instructions on how you can help. Instead of just pushing the wheelchair up a hill, the person with a disability can tell you where to go or how to push.
Making Contact
When introduced to a person with a disability, it is appropriate to offer to shake hands. People with limited hand use or who wear an artificial limb can usually shake hands—just follow their lead. (Shaking hands with the left hand is an acceptable greeting.) People with limb loss may use mobility aids such as wheelchairs, scooters, crutches or canes. Such equipment should be considered a part of their personal space. Grabbing an arm or crutch could cause unbalance; pushing or pulling a wheelchair unexpectedly could upset the person or even damage the device. To the casual observer, these forms of equipment may be considered just that—a piece of equipment. But to people whose mobility depends on it, the equipment is part of who they are.

Conversation
The next rule is something that can be applied to everyday life. Thinking before speaking to a person with a disability can help immensely in the learning process. Always make sure you are talking to the person and not his or her disability. Talking to a person with a disability is like talking to anyone else; they are just as interested in the same topics of conversation as anyone else. People who have experienced limb loss often receive questions about their disability. Sometimes this can make the person uncomfortable and cause tension during a conversation. He or she wants to continue on as a regular person.

Don’t Assume
For a person with a disability, having decisions made for them takes away part of what makes them a human being. While some people may assume that some activities may not be suitable for a person with a disability, it is not for them to judge what he or she is capable of accomplishing. People with disabilities, like all people, are experts on themselves. They know what they like, what they don’t like and what they can and cannot do.

Be Accommodating
Today, many establishments have accommodations for people with disabilities. With wheelchair ramps and safety rails, it is becoming easier to get around the workplace or a grocery store. This positive response toward helping people with disabilities get around makes it easier for them to ask to be accommodated. If possible, rearrange furniture or objects to accommodate a wheelchair before the person arrives. Consider a person’s limitations in mobility by placing objects that are required within their reach or sitting on the same level as the person you are talking to. By making eye contact on the same level as a person, they know that you are talking to their face and not to their disability. This should also be taken into account when a person with a disability enters a bank or office that could have a front desk that is higher than the person’s eye level.

People with disabilities are individuals in themselves. They should not be considered as one group or entity. By following these basic etiquette rules, it will be easy to interact and enjoy life with a person with a disability.
Overcoming Excuses Not to Exercise

by Sara Phillips and David Bush

Has losing weight or getting in shape become a New Year’s resolution you just can’t shake? This year, you need more than just an intention to train. How do you make the gym a consistent and realistic part of your life, rather than just another resolution for next year? Create a positive plan and eliminate excuses and obstacles!

ULTIMATE OBSTACLE #1: Getting Started

• Create a diverse, enjoyable and realistic daily schedule. Try new classes and instructors. You’ll discover you can do more than you think. For example, I didn’t know I could practice or enjoy yoga until I tried going. Give yourself time to accomplish your goals. Train at the gym, outdoors or at home. Don’t rely solely on machines and cardio equipment. Try functional equipment like free weights, suspension straps and medicine balls.

• Draft short- and long-term goals for yourself, and remember, results don’t come overnight. The best results come from training consistently. Every few months, change this routine completely.

• Consider initially mastering functional techniques, such as how to fall, stand up, hop, squat, push up and sit up. Once you learn how to catch yourself, falling is not a big deal.

• Don’t beat yourself up for skipping a workout. Accept that there will be times when you won’t be able to train.

ULTIMATE OBSTACLE #2: I Can’t!

Why not? Just believe in yourself. Training is 90 percent mental. You can and will accomplish anything with consistent practice. This is your opportunity to reclaim your body and see what you’re made of. Many accomplishments aren’t in reaching goals, but in what you’ve learned about yourself during the journey there.

ULTIMATE OBSTACLE #3: My prosthesis broke!

Use this as an opportunity to train without your prosthesis. Challenge your balance, strength and agility. There is nothing wrong with the rest of your body. Any exercise can (and should) be modified. You may even find you prefer to train without your prosthesis.

Training Is an Opportunity, Not a Challenge

You have an opportunity to shine and influence others. Simply by showing up, you are showing your community that they have no excuse. Your participation opens a positive dialogue, creating mutual encouragement and new friendships.
ULTIMATE OBSTACLE #4: I have an injury, recent surgery or pain.

When possible, modify around your injury or pain to continue to exercise. Collaborate with physical therapists to further your rehabilitation goals through training. In the words of Faye Oppenheimer, a social worker at NYU Langone Medical Center, “Be proud that you’ve made it this far, and understand that you still have a journey ahead of you. Enjoy the journey. Be kind to yourself, and remember that each step, no matter how small, is a step forward.”

ULTIMATE OBSTACLE #5: I have no time to train between family, work and school!

Have enough time for the gym but not a full workout? Try a “quick pump” with fewer repetitions but heavier weight. If possible, consider biking or running to the gym to eliminate commute time and increase training time. Remember, you don’t need the gym to exercise. In especially busy periods, 10 minutes of training a day is better than zero, and can easily be done at home. Try push-ups, pull-ups or squats. The office is a great place to sneak in some push-ups, spinal twists, a sun salutation or even several minutes of meditation (which restores your body the same as a nap would, but in the fraction of the time!), all of which increase your energy and efficiency at work.
Nearly every day we are asked how we are doing. Although we often give little thought to our response, our emotional well-being plays an important role in our daily lives. Our emotional and mental state can dramatically impact our ability to overcome challenges and achieve our personal goals. It can impact how we perceive and react to events around us.

For amputees, emotional health can have a significant impact on rehabilitation outcomes. Yet, many amputees experience emotional distress – feelings of depression, self-doubt or dissatisfaction with the current state of their lives – during the process of recovering from losing a limb. Research suggests that amputees who experience emotional distress are more bothered by pain, feel limited in their ability to perform daily tasks, and experience decreased quality of life. Unfortunately, effective programs to address the emotional well-being of amputees are not widely available.

The role of prosthetists in addressing well-being

Traditionally, the topic of mental and emotional health is thought to be the role of psychologists, counselors or a primary care doctor. However, the ongoing relationship between prosthetists and their patients creates a unique opportunity for prosthetists to play a role in assessing and addressing the emotional needs of amputees. Many amputees already view their prosthetist as a person they can talk
to about their emotional well-being. However, many prosthetists lack the tools and training to effectively serve as a resource for their patients’ emotional well-being. Recognizing this need, the Amputee Coalition and researchers at Johns Hopkins University School of Medicine developed the Well-Being Initiative to give prosthetists the tools they need to assess and address their patients’ emotional needs.

“While research has shown that a large number of people with limb loss experience depression or other forms of psychological distress, today’s standards of care often leave amputee's mental health needs unaddressed,” says Kendra Calhoun, Amputee Coalition president & CEO. “Our innovative program will improve the lives of amputees and better position prosthetists in the changing healthcare arena.”

Can emotional well-being for people with limb loss be addressed in prosthetic offices?

With funding from an educational grant from Össur Americas, the Amputee Coalition launched a pilot program to train prosthetists at five prosthetic practices to assess their patients’ emotional health with an easy-to-use assessment tool and to guide them to appropriate resources to help improve their emotional health. The assessment tool is comprised of existing, validated tools in the public domain that assess an individual’s risk of depression and satisfaction with life. Based on the results of this assessment, patients are guided to local resources that can help them improve their emotional well-being using a customizable brochure. These resources are pre-identified and pre-screened to ensure they merit inclusion.

Results from this pilot suggest that prosthetists and patients found the assessment tool and resource brochure helpful. Staff at the participating prosthetic offices report that the program materials definitely helped them assess their patients’ emotional health and guide them to resources to improve their emotional well-being.

As one participant states, “Prosthetists end up being counselors for amputees who are angry or depressed. Sometimes we have no one else to talk to. It’s nice to see programs out there to turn to.” Findings from the pilot phase were presented at the 38th Annual Scientific Meeting of the American Academy of Orthotists and Prosthetists and the 2012 American Orthotic and Prosthetic Association National Assembly.

Positive results from the pilot phase support further development of the program. The next phase will develop tools to broadly disseminate the program throughout the O&P community, provide a dedicated resource in the Amputee Coalition’s Resource Center to help participating practitioners identify mental health resources in their local community, and collect data demonstrating program efficacy that will bolster efforts to secure funding for a large-scale clinical trial.

“This innovative program provides prosthetists with tools for addressing their patients’ emotional well-being that easily integrate into their existing patient flow,” says Steve Wegener, associate professor of rehabilitation psychology at Johns Hopkins University School of Medicine. Mahesh Mansukhani, president of Össur Americas, adds, “We hope that this program will help raise awareness of this often-overlooked issue and directly support more prosthetists and their patients in pursuing emotional and mental health, as well as physical wellness.”

Contact the Amputee Coalition at 888/267-5669 or amputee-coalition.org
HELLO TO ALL YOU FABULOUS FASHIONISTAS!
We’re here to discuss prosthetically induced fashion situations (I call them PIFS) and fantastic ways to remedy them!

Fellow Fashionista Kimberly writes:
“HELP! I’m an above-knee amputee and I wear a prosthetic leg with a foam cover. I work in an office and like to dress professionally. Even though I wear a lot of pant suits, I occasionally like to wear skirts and dresses too. But I find that the nylons always run before the day is done. Either the run starts at the heel after putting on my shoes or they get snagged on the hardware at the top of my socket. Do you know of any brands that are better than others? Or do you know what I can do?”

My dear Kimberly,
I know only too well the frustrations of all things hosiery. I got my first endoskeletal prosthesis in 1984 and was thrilled that I would be able to wear dresses with a leg that looked “pretty” since losing my leg in 1975. And thus, my love affair with skirts and dresses began!

Never being a fan of the “bare-legged” look, I too wear nylons when wearing skirts and dresses. And I too have waged an ongoing quest for hosiery that is not only armor-strong but fashionable too! And I found that with Jockey-brand nylons! (And before I go too far, the Amputee Coalition does not endorse or support Jockey nor is it in any way financially affiliated with Jockey.)

When talking hosiery, one must consider their denier. Because I am a total textile geek and appreciate that others may not be, denier is a unit of measuring the thickness or weight of natural or synthetic fiber; more than anything, it indicates the material’s durability. For example, black tights, which are more durable than sheer nylons, have a higher denier.
Jockey® Control-Top/Sheer Reinforced Toe nylons are a gift from Hosiery Heaven. Although I don’t know their actual denier, they’re made of an 84 percent nylon/16 percent Elastane “blend.” This means that the legs have a denier and “blend” that is fine enough to provide a sheer look while being dense enough to “conceal” that one leg is flesh and the other is not. But more importantly, the denier is high enough to withstand the normal donning and doffing of shoes, with or without a shoehorn. And this leads to a happier Phantom Fashionista because they don’t run very easily.

But the control-top feature of these nylons is their pièce de résistance! Comprised of an 87 percent nylon/13 percent Elastane “blend,” the panties are durable enough to provide support and to withstand the hardware at the top of my prosthesis. While other nylons get caught on the buckle of my Silesian belt, these do not and they run less easily than other brands. At $9.99 for a pack of three, the days of single-use nylons are a thing of the past.

Until next time, my dear Fellow Fashionistas! Keep sending your questions or suggestions to Fashionista@amputee-coalition.org! 🎀

**Tip:**
When talking hosiery, one must consider their denier... denier is the thickness or weight of fiber... it indicates the material’s durability.
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Three years ago, when I was 13, I was at a prosthetic appointment at the Twin Cities Shriners Hospital. I used to go there pretty often – doctor’s appointments, prosthetic appointments, anger management classes – you get the picture. My prosthetist asked me if I had heard about the Amputee Coalition Paddy Rossbach Youth Camp. When I told him that I had not, he advised me that they had an opening. My parents encouraged me to go, but that was the last thing I wanted to do.

I was a very angry and depressed child at that point in my life. My grades were terrible, and so was my attitude – I was not very pleasant to be around. I felt alone in life with a prosthesis, and believed that no one understood my challenges. The only time I ever saw other children with prostheses was at the Shriners Clinic. Life seemed almost unbearable. Against my wishes, my parents signed me up to go to this “camp” for kids with limb loss. “Great,” I thought – at least it would only be for a few days.

On the plane to Ohio, I was scared and nervous that no one would like me and that once again, I’d feel alone. I sat with a young girl on the plane named Taylor from Alaska, who I am still friends with. When we
We landed were met by a camp counselor. While we waited for the bus, I met Sonny and some other girls with whom I am still dear friends to this day. When we arrived at camp I met MJ, my new BFF, who introduced me to everyone, and I mean everyone. Suddenly I no longer felt alone, shy, misunderstood or unhappy. I was thrust into a place and time where I was “normal.” I noticed that when I walked into a room, people looked at my face, not my prosthesis – what an amazing feeling that was.

The camp completely changed my life for the better. For the first time in my life, I truly felt at home. Not that my home life was bad – but when you look around at a room of 100 kids with similar challenges, it gives you a certain sense of homey euphoria. Camp was so much fun – we got involved in all sorts of activities, played games and stayed up after lights out, talking for hours, making friends for a lifetime. But all good things must come to an end, and the same was true for camp – or so I thought. The last, precious, few hours were spent in happy tears and laughter that I will always remember.

Camp was amazing, but I eventually realized it didn’t end there. Soon after I returned home, it became clear that my life would never be the same. I was a happy child again, no longer depressed at school or in life. I was full of courage and determination to make my life better. My grades started coming up; I began to try new things like volleyball and golf. School started to become important, and I knew I’d be going back to camp again in 360 days.

The 180 degree change in me was shocking to some who knew me. What could it have been that changed my attitude so much? The camp changed me from the girl that I was to the girl that I wanted to be. I am now a junior in high school with a 3.78 GPA and dreams of going to nursing school at New York University to help wounded veterans. None of this would have been possible if I had not taken a chance and gone to camp. I would encourage every child with a prosthesis to attend the Paddy Rossbach Youth Camp because it will totally change your life – as it did mine.

The 2013 Amputee Coalition Paddy Rossbach Youth Camp will be held July 20-24 at the Joy Outdoor Education Center in Clarksville, Ohio. Applications are available at amputee-coalition.org/events-programs/youth-camp.
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