

*in*Motion

March | April 2014
Volume 24, Issue 2

A magazine dedicated to
living well with limb loss

A Publication
of the



**From Patient
to Professional:**
Amputees in the
O&P Field

Show Your Mettle
and Give Back to the
Amputee Community

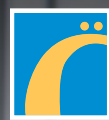
Paying It Forward

**Celebrating the
Human Spirit**

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**April Is
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Paying It Forward

A Single Act of Kindness



When you hear the phrase “pay it forward,” the first thing that comes to mind for most people is the popular 2000 movie starring young Haley Joel Osment. His character was a schoolboy who believed in the goodness of human nature and the possibility that one person can change the world. His plan to make a difference in people’s lives created a ripple effect of good intentions.

But the concept goes back much further than that. Ben Franklin described it in a letter to Benjamin Webb in 1784, in which he wrote about his intention to help Webb by lending him some money. He did not want to be repaid, however. Instead, Franklin hoped that Webb would at some point meet an honest man in need of financial help and pass the money along to him.

Paying it forward doesn’t have to mean giving a generous donation or expending a lot of effort. It can happen anytime, anywhere, for anyone. It could be as simple as holding the door for someone laden with bags or offering your place in line to someone who appears in a rush. It could even mean spending a little cash on coffee for the person behind you in line at Starbucks.

One of the most important things to remember about this concept is that it should be done with a selfless spirit. This means helping someone without expecting repayment or good deeds in return – sometimes, you might not even get a thank you. In fact, there are some organizations that allow people to pay it forward anonymously, donating money or performing good deeds without hoping for recognition. As far as the receiver of the money, gift, or good deed is concerned, he or she is told only to do something good for someone else.

Even the smallest, free gestures can make a difference. It takes very little time and effort to pass on a piece of information or a word of encouragement to someone going through the same things that you’ve experienced. That information or gesture that, to you, seems obvious or trivial may be a major revelation or a well-timed boost to someone just starting out on this path.

The power lies within each of us to make the choice to think of others, and not just ourselves, and make a difference in the life of someone else.

Bill Dupes, Senior Editor

“No kind action ever stops with itself. One kind action leads to another. Good example is followed. A single act of kindness throws out roots in all directions, and the roots spring up and make new trees. The greatest work that kindness does to others is that it makes them kind themselves.”

~ Amelia Earhart

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 2014

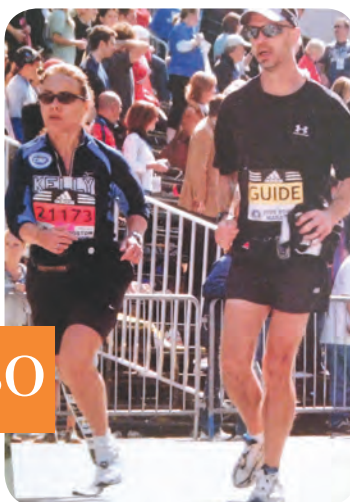
24



Paying It Forward

Celebrating the
Human Spirit

30



32



**From Patient
to Professional:**
Amputees in the O&P Field

sections

- 16 Travel & Accessibility
Breaking Out of the Comfort Zone
- 18 Federal Affairs
Using Technology to
Bring Veterans Together
- 20 Growing Up as an Amputee
Always Look Forward
- 22 Parenting as an Amputee
More Infant Care Tips for
Parents With One Arm
- 34 Exercise & Fitness
Wheelchair Exercises
- 38 Perspectives
The New Me

departments

- 3 Message From the Editor
- 8 Advocacy in Action
- 11 Events Calendar
- 12 Special Message
- 36 Advertiser Index

On the Cover
Image courtesy of Linda Duley

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Cindy Asch-Martin is a certified personal trainer and lifestyle fitness coach, and a left below-knee amputee.



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Ashley Kurpeil is a right-forequarter arm amputee due to medical misdiagnosis nearly 29 years ago. She is a coach at NubAbility Camp for limb-different kids and is active in the amputee community, both online and at various events.



Kelly Luckett is a below-knee amputee who has run over 35 marathons and ultramarathons, including nine consecutive Boston Marathons. She hopes to inspire others to strive to overcome obstacles and tragedies.

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inMotion

A Publication of the Amputee Coalition

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

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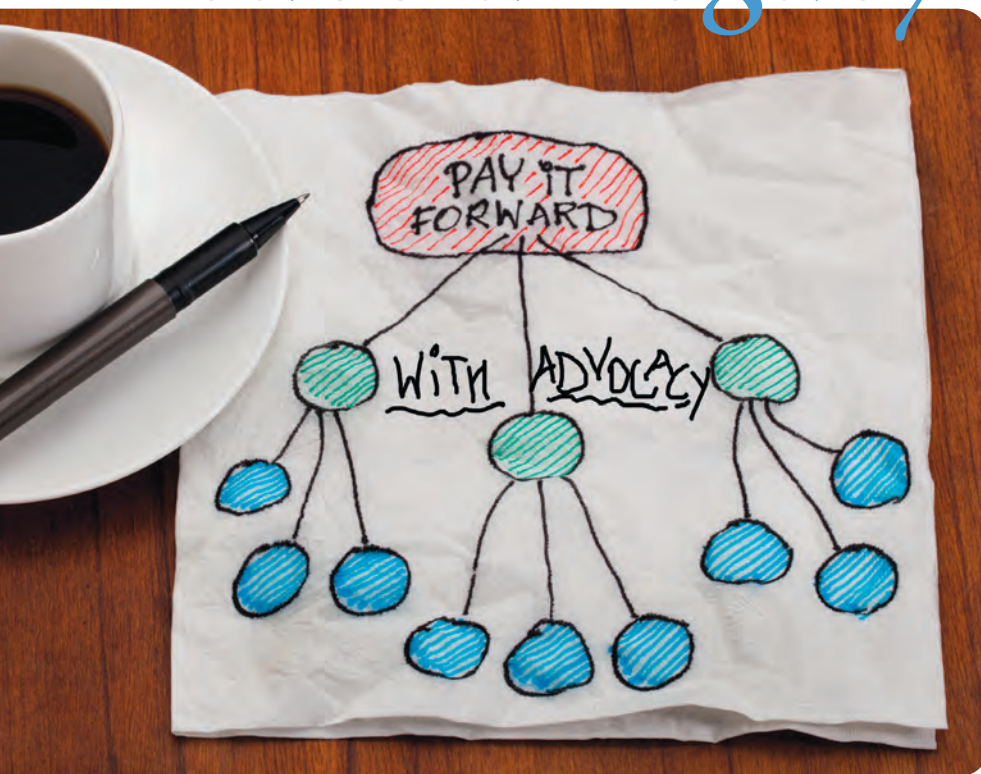
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Leave a Legacy



by Dan Ignaszewski

>> It's important to understand that advocacy, by its nature, is truly the embodiment of paying it forward.

Have you ever thought about what you can do to make a difference in your community, or what kind of legacy or positive impacts you will leave? With the focus of this issue on paying forward and giving back, it's important to understand that advocacy, by its nature, is truly the embodiment of paying it forward.

Advocating for issues, policies and regulations that impact the limb loss community will not only make a difference in your life, but will also impact others living with limb loss, and those who might become an amputee in the future. The Amputee Coalition provides a number of ways to get involved in advocacy, and there is a large variety of areas where you can make a difference.

As many of you know, the Insurance Fairness for Amputees (formerly Prosthetic Parity) Act, H.R. 3020, has the potential to make a huge

difference for all amputees. By getting insurance companies to adequately cover prosthetic devices without arbitrary caps or restrictions, there's an opportunity for every amputee to have affordable coverage to get the prosthetic device that best fits their needs to maintain a normal, active life.

Working with individuals, support groups, professionals, partners and communities, we have seen 20 states pass laws in the past 13 years. While federal healthcare reform created some roadblocks, many of the 20 states that have passed insurance fairness laws are seeing better coverage in their insurance marketplaces. Additionally, nearly half of all individuals with insurance in those 20 states (amputee or not) have adequate and affordable access to prosthetic coverage included in their plan.

What does this mean for you?

When a law is passed that you've been a part of advocating for, you leave a legacy that has the potential to impact hundreds, thousands or even millions of lives. The Insurance Fairness for Amputees Act would literally affect hundreds of millions of Americans.

The only way a bill like the Insurance Fairness for Amputees Act can become law is if individuals contact their members of Congress to raise awareness of the bill and ask them to sign on as a cosponsor. With your help in contacting federal legislators, we will have a better chance of advancing the Insurance Fairness for Amputees Act in Congress.

continued on page 10



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Leave a Legacy continued from page 8

Pay it forward... Advocacy isn't always easy, and can often be a challenge. There are a number of issues you can advocate for that the Amputee Coalition works on. Whether you're advocating for yourself if you're denied care or advocating for broader issues, every time you advocate for yourself or others, you have the potential to make a difference.

The Amputee Coalition advocates for and partners with advocates on:

- ➔ The Insurance Fairness for Amputees Act
- ➔ Gubernatorial proclamations recognizing April as Limb Loss Awareness Month
- ➔ Travel issues amputees face with the TSA
- ➔ Medicare or Medicaid coverage
- ➔ Social Security/Disability benefits
- ➔ Funding for programs and resources supporting the limb loss community
- ➔ Funding for research advancements in technology and care.

With April being Limb Loss Awareness Month, and 2014 being an election year, it's a great opportunity to call your federal representative and ask them to sign on as a cosponsor to H.R. 3020. If you're interested in getting involved, you can visit the Advocacy section of the Amputee Coalition's Web site (amputee-coalition.org/advocacy-awareness) for sample email and phone call messages, as well as fact sheets and other materials. To get involved and start making a difference today, you can also contact our Government Relations department at Dan@amputee-coalition.org. 



*Limb Loss
Awareness Month!*



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kidney.org

NATIONAL NUTRITION MONTH

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SAVE YOUR VISION MONTH

aoa.org/patients-and-public/caring-for-your-vision

MARCH 13

World Kidney Day
worldkidneyday.org

MARCH 16

Lake Nona Tour de Cure
Orlando, Florida
diabetes.org

MARCH 22

**Limb Loss Education Day/
OPAF's First Row**
Washington, D.C.
amputee-coalition.org

Phoenix Tour de Cure
Phoenix, Arizona
diabetes.org



FOOT HEALTH AWARENESS MONTH

apma.org

LIMB LOSS AWARENESS MONTH

limblossawareness.org

NATIONAL CANCER CONTROL MONTH

cancer.org

NATIONAL MINORITY HEALTH MONTH

minorityhealth.hhs.gov/actnow

OCCUPATIONAL THERAPY MONTH

promoteot.org

APRIL 5

McKeever's First Ride
Lawrenceville, Georgia
opfund.org

APRIL 6-12

National Volunteer Week
pointsoflight.org/signature-events

APRIL 7

World Health Day
who.int/campaigns/world-health-day/2014/event/en

APRIL 12

Limb Loss Education Day/OPAF's First Fit
Atlanta, Georgia
amputee-coalition.org

APRIL 12

Gulf Coast Tour de Cure
Pensacola Beach, Florida
diabetes.org

APRIL 24

Pay It Forward Day
payitforwardday.com

World Meningitis Day
comoonline.org

APRIL 26

Show Your Mettle Day
showyourmettle.org

First Swing
Cordova, Tennessee
opfund.org

inMotion

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SHOW YOUR METTLE

and Give Back to the Amputee Community

by Melinda Park

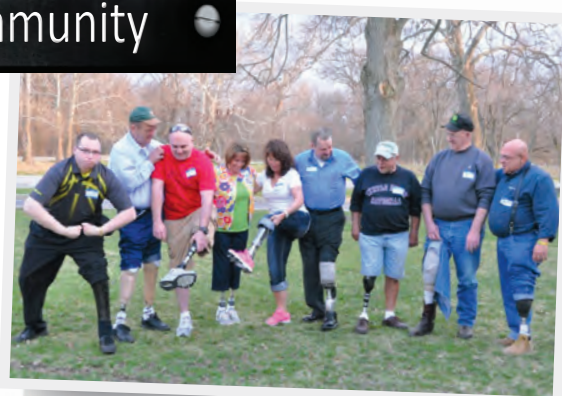
On April 27, 2013, the Amputee Coalition launched **SHOW YOUR METTLE DAY** as part of Limb Loss Awareness Month. **SHOW YOUR METTLE** was inspired by Peggy Chenoweth, who began a movement in 2011 to raise awareness about living with limb loss. This year, we are taking her concept and **SHOW YOUR METTLE DAY** to new heights and challenging the limb loss community to **SHOW YOUR METTLE** by holding walk/run/roll events or other fundraisers during April to benefit the Coalition and its mission to empower people affected by limb loss to achieve their full potential.

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

SHOW YOUR METTLE by holding walk/run/roll events or other fundraisers during April.

Holding a fundraising event, like a walk/run/roll, is not only a chance to raise awareness of the limb loss community, but an opportunity to give back to the community. Your fundraising efforts will help the Coalition provide programs and services for amputees and their families and provide opportunities for amputees to attend the Coalition's National Conference.

For support groups that hold walk/run/roll events during Limb Loss Awareness Month in April, the Amputee Coalition will place half of the proceeds raised in a fund at the



Amputee Coalition to cover the registration fee(s) of one or more members of that support group to the Coalition's 2015 National Conference, which will be held in Tucson, Arizona, July 23-25, 2015. Any amount not used by support groups to cover registration fees in 2015 will go toward the Kathy Spozio Bridge to Ability Scholarship program to help send new amputees to the conference.

This is your opportunity to raise awareness and support in your community, so be sure to use your creativity and vision to make it your own. It can be as simple or as elaborate as you wish. If you choose to hold a walk/run/roll event, the Amputee Coalition has put together a kit available for download to help get you started. The kit includes easy-to-follow steps to organize your walk/run/roll, a guide to donating, a sample event flyer, and more. It can be found at amputee-coalition.org/events-programs/limb-loss-awareness-month.

continued on page 14

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SHOW YOUR METTLE

continued from page 12

Getting Started Is as Easy as 1,2,3

STEP 1 | Brainstorm a fundraiser that's right for you and support the Amputee Coalition in your own way. Organize a car wash, neighborhood garage sale, or a walk/run/roll. Almost anything you can think of can be a way to raise funds to help support the Amputee Coalition's programs and services.

STEP 2 | Set up a free, personal fundraising page on the Amputee Coalition's Crowdrise fundraising page for Limb Loss Awareness Month at crowdrise.com/showyourmettle and check out what other groups are doing to **SHOW THEIR METTLE**.

STEP 3 | Reach out to your friends, family and community and ask them to help raise limb loss awareness by supporting your fundraiser. 



To download this pdf, go to: amputee-coalition.org/events-programs/limb-loss-awareness-month.

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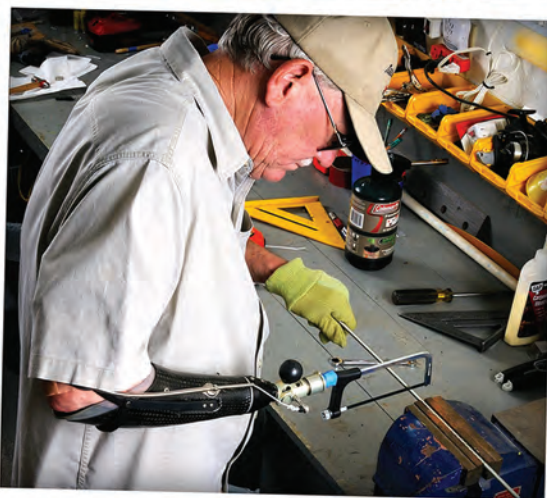
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Breaking Out of the *Comfort Zone*

by Samoana Matagi

***"The cruise ship
was the perfect
place to break
down these
barriers..."***

In December 2012, I had the great experience of cruising with 67 amputees on the Royal Caribbean's Liberty of the Seas, the first Amputee Cruise organized by Easy Access Travel and sponsored by the Amputee Coalition. It was my first-ever cruise, and I've been "hooked" ever since! (Pun intended.)

The ship provided the perfect environment to form friendships and to try and succeed at new activities. I decided to experiment with something new: a surfing machine called the FlowRider.

I was nervous about falling off in front of everyone. I wondered if I would get to the front of the long line only to be told, "Sorry, amputees can't ride this." Doubt began to creep into my mind. This seems

to be my normal process when trying something new. It's natural to feel this way, but growth only comes when you step outside your comfort zone.

The cruise ship was the perfect place to break down these barriers, especially with other encouraging amputees and ship staff. I began to think more positively, asking myself, "Even if I have an epic failure, what are the odds that I'll ever run into these people again?" Besides, I would still have five more days to keep trying.

The 2012 cruise showed me how empowering a cruise experience can be. It was like a training ground to experiment and try new things. When the 2013 trip was announced, I invited my amputee friend,



Jason, to come along. Including the two of us, 48 amputees signed up to sail on the Navigator of the Seas to Jamaica, Grand Cayman and Cozumel.

It was different in some ways and familiar in others. There were new people to meet but I also saw some familiar faces. Again, there was plenty to eat and the service was spectacular – one of the best examples was when our server shelled all of my tiger shrimp. Unfortunately, this time there was no FlowRider.

I was bummed at not having a FlowRider, but not for long. As soon as I could make it to the basketball court, I was there. I made a new friend and found the schedule of events. The next day I returned for the basketball tournament. Once again, that old, familiar feeling of doubt returned, but I persevered and found a team to play with. My reward for that perseverance was a silver Royal Caribbean medal, as our team took second.

Dinner was one of my favorite times of the day, not only

because of the delicious food but because of the camaraderie. The Amputee Coalition had tables reserved for all of the cruisers. It was a great place to meet and be inspired by each other, talking about our adventures of the day and plans for the evening. Jason and I made a point to sit with new people each day.

Many of us attended a karaoke contest one night. A mother of one of the amputees decided to sing; as she sang, her emotions began to rise. You could feel it in the room as well. An amputee in the crowd gathered a group and suggested that we all go up and support her. It was a beautiful moment, showing how far the camaraderie had come.

As the cruise continued, I felt the whole group begin to gain confidence. We participated in game shows, sexiest man contests, ping pong tournaments, karaoke, volleyball, dancing and more. We became active participants in the community on board. I think we all were getting used to breaking out of our comfort zones and letting others into our own. 🌀



(Left to right) Jason McDermott and Samoana Matagi

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McGrath (right) uses video conferencing to connect Weisgerber with other California Veterans.

Using Technology to Bring Veterans Together

by Leif Nelson, DPT, ATP, CSCS



There are more than 40,000 Veterans living with limb loss in the United States who receive care through the Department of Veterans Affairs (VA). Too often, they may feel as though they are alone, tackling the challenges of everyday life.

To help overcome this, the VA offers a solution in the form of peer support groups. VA Palo Alto Health Care System Physical Therapist Daniel McGrath is the amputation rehabilitation coordinator at the California healthcare system, where he launched a facility-based support group at the request of local Veterans.

"It began with just three participants," says McGrath, "but quickly grew through

word of mouth and grassroots promotion." McGrath explains that the monthly gathering now benefits a double-digit number of attendees. The group provides a venue for Veterans with limb loss to share information learned in their own experiences and also to gain new knowledge from subject-matter experts brought in as guest speakers.

"We found that speakers who focused on new prosthetic limb technologies, along with mental health issues, brought the biggest crowds," McGrath adds.

After reaching capacity within the facility-based program, McGrath knew he wanted to expand the program beyond his local facility, so he reached out to his local

>> **The camaraderie and exchange of ideas for simple ways to overcome daily challenges has grown into friendships.**

Telehealth coordinator. Telehealth gives Veterans the ability to “virtually” attend healthcare meetings and appointments.

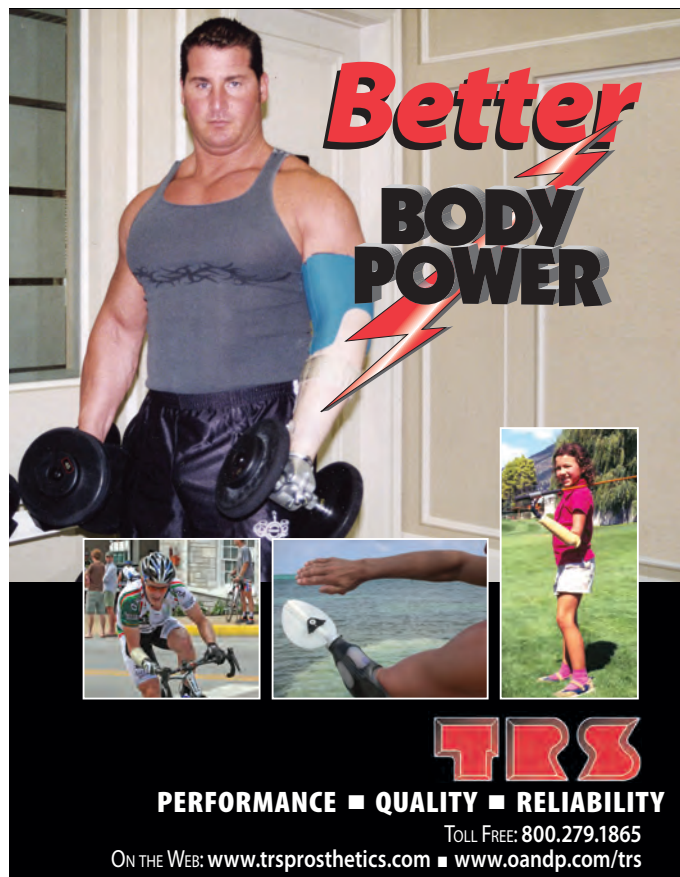
Beginning in early 2013, the support group expanded beyond the walls of the VA Palo Alto and now reaches Southern California and the VA San Diego Healthcare System through live video conferencing technology.

“The technology provides an opportunity to bring more Veterans together,” says U.S. Marine Corps Veteran William D. Weisgerber. “It also gives the Veterans access to more speakers.” Weisgerber is a retired Marine Corps gunnery sergeant. He suffered a combat-related injury while on active duty in October 1952. He now resides in the Palo Alto area and attends the peer support group at his local VA. When asked about what he got out of the support group, he states, “For me, I enjoy the opportunity to commiserate with other amputees in my area. We can discuss our problems and everyday physical and mental challenges and how we overcome them. I’ve lived with this for 60 years, so I like being able to help others through sharing my experiences. Ultimately, we all have a different problem, but we all have something in common.”

During 2014, McGrath hopes to expand the reach of the program, including opening a virtual doorway to the Veterans of the VA Loma Linda Healthcare System. “The greatest benefit I’ve seen is Veterans with limb loss creating bonds and relationships through the video Telehealth group,” says McGrath. “The camaraderie and exchange of ideas for simple ways to overcome daily challenges has grown into friendships.”

The VA Palo Alto Health Care System has received accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF) under the Amputation Specialty Program and is one of seven VA sites designated as a Regional Amputation Center under VA’s Amputation System of Care.

Military beneficiaries and Veterans can contact their local military treatment facility or VA provider for more information regarding peer support groups in their area. A listing of state and local resources is available at va.gov/landing2_locations.htm.

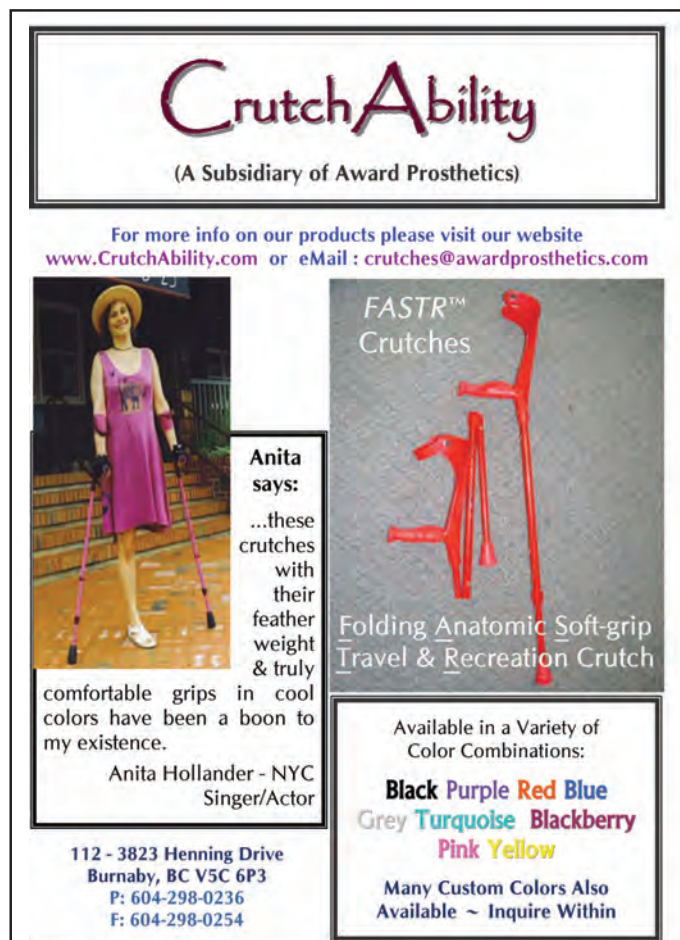


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Always Look Forward

by GioannaMarie Romano

On June 27, 2010, around 11:30 am, my life as a 15-year-old teenager changed forever in the blink of an eye. It was a normal summer day. I had just graduated from the 8th grade; my family was going to have a party and relax in the pool. My little cousins were coming over so my mom and I decided to get some swim toys for them. We arrived at the store and got out of the car.

"I was afraid that I wouldn't be accepted or make any friends but boy, was I wrong!"

As I walked toward the store, I saw something out of the corner of my eye. I turned and saw a car coming right at me! BAM, I was hit by the car and pinned against the store's wall. I stayed like that for 30 seconds, then fell

beneath the car. The car's horn was blaring in my ear. I don't know how long I was under there.

When the car moved away, a woman held my hands and said that help was coming. She introduced herself as Kelly. I wanted to freak out, but I remembered hearing that the best thing to do in an accident is to stay still. I did my best to stay calm. And then the pain set in.

At first, I couldn't feel my legs. I thought I was paralyzed; then it felt as if a thousand knives were stabbing my legs over and over again. The pain was constant and getting worse. I felt bad for Kelly because I knew I was squeezing her hands really tight. The ambulance took 20 minutes to get to me; by this time, I'd lost an enormous amount of blood. Once I got to the hospital I was rushed to a trauma room and the doctors and nurses bombarded me with questions.

"What happened to you?" "What's your name, age, are you allergic to any medication?" All the normal things doctors ask. The last question was, "Have you been in the hospital in the last six months?" I had, but couldn't remember why, so I said, "I don't feel like talking about it right now." Some of the nurses and doctors gave a chuckle and a knowing look and put a mask on my face, then I was out.

Four days later, I woke up from a coma; my Dad had to tell me my left leg had been amputated above the knee. I said, "No, Dad, I still feel my

toes” – I didn’t know this was phantom pain. Once it sank in that I really didn’t have a leg, I also realized I had an external fixator on my right leg and pelvis. I cried for an hour with my family and friends, then I said, “What the hell do I have to do to get out of this bed?!”

I spent my freshman year in the hospital but I had homework sent to me, and I attended my freshman formal. I was home during my sophomore year but daily physical therapy made it hard to go to school. I made my triumphant return to high school in my junior year. I was afraid that I wouldn’t be accepted or make any friends but



boy, was I wrong – I’ve made a ton of friends and everyone accepts me at my school.

That’s what I love about my school and classmates. They don’t care about my physical appearance – they care more about who I am on the inside. I admit there were times I wanted to give up, but my goal was always to get back to school. Now I’m an 18-year-old senior and ready for college. My advice for anyone who becomes an amputee at a young age? Never give up, and always look forward! 🌀

“My advice for anyone who becomes an amputee at a young age? Never give up, and always look forward!”

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More Infant Care Tips for Parents With One Arm

by Harleen Gupt Chhabra

A Collection of Tips

This is a continuation of infant care tips (see *January/February 2014 issue of inMotion*, page 22) from my own notes and from others who are successfully raising happy, content kids and grandkids. This article addresses two things very close to heart: carrying your little one and putting him or her to bed.

*Fight your doubt
with belief.
Drown your fear
with action.
When you give
all you've got,
what you get
is beyond
satisfaction -
and that feeling is
what motherhood
is all about.*

Lugging Your Bug

Overuse by constantly carrying a baby who weighs seven pounds or more can stress your otherwise healthy limbs. Get regular occupational therapy, starting with your delivery stay in the hospital. I learned how to pick up an infant by sliding my good arm under him, using my wrist to support his body and my fingers to support his wobbly head. Have a therapist visit your home, if possible, and seek proper help to strengthen your good limbs regularly.

- At home, put the baby in your lap and move in a sitting position for short distances. A snap-on nursing pillow can provide additional support for the first few months.
- Try a variety of slings available on the market (for example, The Peanut Shell sling) or make something of your own.

When none of the ready-made slings worked for me, I modified a bunch of small blankets and attached loops on

opposite ends. Wherever the baby lay, he would be placed on top of a headrest that would lie on this modified blanket. To pick him up, I would slide the loops over my residual arm and support the rest of the weight with the other arm. The Snugglebundl blanket has a similar design, although the handles could probably be made larger to slide over one's arm.

- For outside visits, use a light, one-handed operable stroller and car seat. (Although not perfect, you might be able to work with the Britax and Graco infant car seats.)



The Snugglebundl blanket can be used with one hand.

Photo provided by Snugglebundl

Thanks again to Christy Koyner from Minnesota and Tara Burill from California for contributing their tips for this article, and to Dena Foster for putting me in touch with them!



City Mini 3W Single Stroller
Photo provided by CityMiniStrollers.com

Slumber Party!

When the little one is sleeping, that indeed feels like a time to party! Start with swaddling the baby using a velcro swaddle blanket that is way easier than conventional swaddling.

Don't be afraid to try different sleeping arrangements, including co-sleeping for the initial months.


- A wide variety of cribs are available in the market. Although sliding or drop-side panels (such as those by Babee Tenda or Innovative Crib Designs) may be preferred by many amputee parents, these may not meet the latest safety standards (check the Consumer Product Safety Commission's product recall list at cpsc.gov). Additionally, something that is lower in height can also provide much-needed body support in lying down and picking up the baby. However, as he or she grows, picking the baby up from a traditional crib can be an increasing strain on your body. A sturdy wooden step stool placed in front of a crib can help in that case.
- None of the cribs on the market worked for me, so I created my own contraption. I surrounded a thick baby mat that lay on a carpeted floor with safety gates. This allowed for the gate to be opened and locked as needed. This also minimized the risk of dropping the baby (one of my biggest fears).
- Little ones are usually deep sleepers. If you touch and cuddle them during sleep, they will get accustomed to it. You can then use the sleep time for diaper changes, nursing and cutting those tiny fingernails. Instead of a traditional nail cutter, consider an electric baby nail filer, which is more gentle and forgiving.
- Add a special touch. I created my own lullaby during my new-mom phase. Using something that I was otherwise good at and applying it to what I was nervous about greatly helped with my attitude.



Zo-Li Buzz B. Baby Nail Trimmer

Photo provided by Zo-Li

As the months passed, I realized this phase of motherhood is just the beginning – with a lifetime to go. Change may seem the only constant in life, especially with an infant in tow. These tips will be an old story as my baby grows into a toddler and a preschooler. What will remain, though, is the spirit of embracing each changing moment with confidence, finding solutions and sharing them with others.

Send your own suggestions and tips to: Harleenc@gmail.com! 

Related Resources

Babee Tenda
babeetenda.com

Britax
britaxusa.com

Graco
gracobaby.com

BabyBonkie
babybonkieswaddle.com

City Mini Strollers
CityMiniStrollers.com

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Paying It Forward →

or

← Paying It Back?

The Win-Win of Voluntarism

Acts of Kindness

All across the country, it seems that little acts of kindness are popping up all over. From a generous tip on a restaurant bill, to paying for the next car in line at the drive-through, to viral “feel good” movements on social media. But what about the people who make “paying it forward” a way of life? Why do it?

by Amy Di Leo

"In some ways, 'paying forward' is hardly 'paying' [at all]," shares Joseph Czerniecki, MD, a researcher, professor and board-certified physician at the Seattle Vet Center in Seattle, Washington. He also works closely with the Amputee Coalition. "It is rewarding on a personal level, both by the work that you do and often times the wonderful individuals you meet along the way," he adds.

"Paying it forward means paying it back," agrees Dennis Strickland, Amputee Coalition's board chair, who has been volunteering in one capacity or another for more than three decades. He says he believes it's important for people to give something back "within their ability, whether monetarily, time or information; it is a very rewarding feeling and the right thing to do. It also offers people the opportunity to feel good about themselves."

And there's a reason for that. "Doing good for others does two major things," explains Deborah Serani, PsyD, well-being expert, psychologist and professor at Adelphi University in Garden City, New York. "First, it strengthens our sense of connectedness. When we feel socially connected, our physical, mental and spiritual health remains sound and balanced. Second, it validates our sense of personal worth. When we experience gratitude from others, we feel recognized, loved and even cared for. Research shows that those who volunteer or 'pay it forward' experience a surge of feel-good hormones, such as dopamine and serotonin."

For many, it's not just that "feel good" feeling – giving back is actually a way for them to take control, be inspired or stay connected.



Laura Freeman (center), a former camper, is now a counselor.

Kids Making a Difference

For Laura Freeman of Chicago, volunteering at the Amputee Coalition Paddy Rossbach Youth Camp does all of those things. Laura lost her leg to cancer in 2000 when she was 15, and attended camp a year later. The Paddy Rossbach Youth Camp brings kids with limb loss from all over the country together for five days in July. Laura says the camp helped her feel more comfortable with her prosthetic leg; gave her self-confidence; and provided her with support, a sense of belonging and a camaraderie with others who understood her. When she was old enough to be a counselor, Laura didn't think twice.

"I knew how camp changed my life and made a big difference for me," she recalls. "I went the first year not knowing what to expect and I ended up having an amazing experience. One day I remember overhearing some girl campers saying, 'I'm going to wear shorts because Laura's wearing shorts.' All through camp they would ask me about my experiences. I didn't realize that I might become a role model for them the way my counselors were for me."

continued on next page

Kids Making a Difference

continued

This summer will mark Laura's 10th year at camp. She also volunteered at a camp for kids with cancer in Montana for several years.

Laura, who just became a certified orthotist and is just several months from taking her boards to become a certified prosthetist/orthotist (CPO), says about her experience, "I get as much back as I put in."

She says she recalls her camp experiences and remembers the campers when she needs a little push to get her through her day. And her days are pretty full, between her prosthetics residency and all of the tasks, projects and exams involved with it. "I think of the kids and tell myself 'I *am* going to make a difference.' Camp is my inspiration," she shares.



This summer will mark Laura's 10th year at camp.



Tammie Higginbotham tries out the ropes course.

Simple Support

Tammie Higginbotham, of Bath, Illinois, volunteered at the Paddy Rossbach Youth Camp in 2008 with Laura. That was the same year Tammie became a member of the Volunteer Outreach Team (VOT) for the Amputee Coalition and also was appointed regional representative for the Amputee Coalition for Illinois, Indiana, Michigan, Minnesota and Wisconsin.

Tammie says she's not sure what she does should be considered "paying it forward;" she volunteers simply because "it is the fire that burns within me." Facing an amputation of her left foot after an accident between her ATV and a teenager in a car in 2002, Tammie explains, "Some things are a driving force we just don't always understand."

It was while she was recuperating in the hospital after her accident that Tammie was introduced to the Amputee Coalition. She credits the organization for helping in her recovery. For a decade, the Coalition has been an integral part of her volunteer efforts. "It started with reading a copy of *inMotion* that my prosthetist had given me," explains Tammie.

Today, Tammie is an administrator on the Heather Mills Amputee Forum, as well as a member of the Orthotic & Prosthetic Activities Foundation's (OPAF's) advisory board. She is also a volunteer peer visitor coordinator for the Amputee Coalition, a position that covers the entire U.S. and three countries.

"My biggest incentive after my amputation was to help someone else so that he/she wouldn't be stuck in the same position I was," Tammie says. She explains that she was in the hospital for several months recovering from her accident and had many unanswered questions about how her life would change when she got home. She yearned for someone to help her sort through it all.

Tammie doesn't consider herself a volunteer as much as an advocate. "In 2009, I helped Illinois become the 17th state to pass a parity law for insurance. I believe in parity and would love to see it passed nationwide. It is *very* important."

The parity law is a bill that creates a fair and consistent standard for health plans that are already offering coverage for prosthetic and custom-fabricated devices. Currently, 20 states have parity laws and it has been considered on the federal level, both in the Senate and House, with H.R. 3020.

Accidental Advocacy

The topic of prosthetic parity also gets Terri Ross going. Although she says she got involved in political advocacy and lobbying strictly by chance, and she calls herself the "Accidental Advocate," the Paducah, Kentucky native has become a lobbyist, speaker and expert on the law.

"I never dreamed I'd be involved in the complicated and often unpleasant world of politics. But when I was told prosthetic limbs are included in the same category as walkers, bedside commodes, tub benches and other durable medical equipment (DME), it lit a fire inside me that can't and won't be put out until Medicare and insurance companies change their policies," she explains.

But Terri does so much more than advocacy; helping others with limb difference has become her calling. She lost her right leg below the knee in 2003 in a motorcycle accident. Two years later, she started Paducah Area Amputees in Action, Inc., a monthly support group, after her physiatrist asked her to visit a few patients.

"The reason I did it is easy to answer. When I woke up an amputee after my surgery following my accident, I knew nothing about amputees or what the doctors, nurses, physical therapists and later, prosthetists, were talking about when they called me a BKA (below-knee amputee). When I got home, I was unable to leave unless someone took me out in a wheelchair. My body was broken in so many places and no one bothered to explain it all to me. I went from a workaholic social butterfly to a shell of my former self, sitting in a chair all day."

Like Tammie, Terri didn't want other new amputees to have the same frightening experience. But besides the important work she does as an advocate and through her support group, Terri also volunteers as a certified peer visitor and VOT member, and was recently appointed to the Coalition's Education and Conference Committee. But that's not all.

"I also started a medical equipment recycling program in my community. During my multiple stints of PT, both inpatient and outpatient, I began to realize I was very fortunate to have insurance coverage that paid for each item I needed as I progressed from a full-time wheelchair user. As I began to meet other amputees and hear their stories, I realized their policies and Medicare didn't always pay for their medical equipment." Working through her local hospital, Terri, her husband and a handful of other volunteers pick up used medical equipment around the community and provide it to people in need.

Image courtesy of Linda Duley

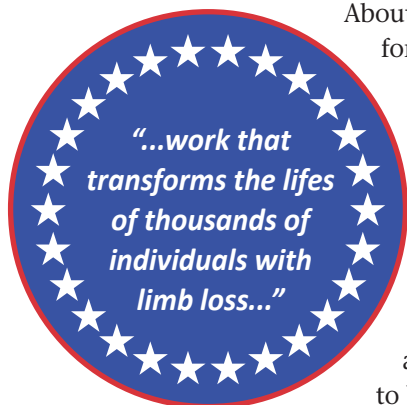


Veteran Volunteer

Dr. Czerniecki says most of his pay it forward activities have been centered around his professional career as a doctor and researcher. "I have a subspecialty interest in amputee rehabilitation," he shares "... and have been working [with military veterans] for the last 28 years. I am honored to provide clinical care to veteran amputees, teach medical students and residents and conduct research related to amputee rehabilitation."



The doctor also volunteers his time as an expert on the Amputee Coalition's Scientific and Medical Advisory Committee (SciMAC). "I value the extremely important work done by the [Amputee Coalition]; this is work that transforms the lives of thousands of individuals with limb loss directly, but also through the programs that it has developed."



About actually "paying it forward," Czerniecki shares, "To me, it is reminding myself about all of the things that have been done for me throughout my life – the things that make you who you are and have enabled you to become *what* you are.

Then, to make a conscious decision to make a contribution to an individual or organization that will help them [would be the next step]."

Leading the Charge →

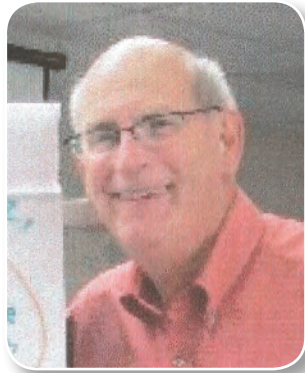
For Amputee Board Chair Dennis Strickland, that contribution came in the form of sharing leadership skills and executive management experience with the American Heart Association for a quarter century and as a career counselor at his alma mater, Georgia Tech. When an accident nearly a decade ago caused his arm to be amputated, Strickland, a retired executive with BellSouth,

decided to switch gears and began volunteering his time and expertise with the Amputee Coalition. Today, he is the chairman of the board of directors for the leading organization on limb loss.



"I've always been community-minded, civic-oriented and charitably inclined. When I became interested in amputee causes and the opportunity came around, I decided to donate my efforts to the Amputee Coalition," Strickland shares. "At first, I was on several committees and became a certified peer visitor. Today, my primary contribution is based on my experience, which is executive management and leadership, in addition to finding new ways to raise money."

Like Dennis, Don Hossler, of Middletown Pennsylvania, is also a longtime volunteer. As a certified volunteer information and referral specialist, he has been helping people in his community and the surrounding central Pennsylvania areas with access to information on the state's 211 line for the past 15 years. He has also served through various other community and church groups.



At the age of 24, Don lost his left leg below the knee due to trauma; he's been giving back in one way or another ever since. "Losing my limb enhanced my feelings about being more helpful as a volunteer in all aspects of my life," he shares.

Through the Amputee Support Team (AST) of Central PA (astamputees.com) and the Amputee Coalition, Don is able to, as he explains, "express my thanks for those that have helped me along my personal journey."

Don is an Amputee Coalition-certified peer visitor trainer and a Promoting Amputee Life Skills (PALS) trainer. "PALS was an outstanding opportunity for people with limb loss to work together in a group setting to learn how to enhance and maintain important life skills," Don explains. "Many of the current board members of the AST were in that original program and today 'pay forward' with their leadership and participation in the AST in peer visiting, modeling specific behaviors and supporting educational programs," he adds.

Like Tammie and Terri, Don is also an active lobbyist for parity laws.

Gain to Give

Whatever the calling, whatever the medium, there's a lot to be gained by giving. "Volunteering is really good for us all – good for the organizations, good for business and media, good for the well-being of the community and good for you personally," shares Dr. Serani.

"The people you meet and the experiences you have giving back as a volunteer will provide you the opportunity to enrich your life," offers Don.

"Volunteering is really good for us all – good for the organizations, good for business and media, good for the well-being of the community and good for your personally."

"Paying it back can give meaning to the 'Why me?' questions that we often ask after amputation," adds Dennis.

I always recommend to anybody to become involved in something because it will be a reward in itself and you will be enriched eternally." 🌀



Celebrating the Human Spirit

by Kelly Lockett

The Boston Marathon is a popular goal for many marathoners. It's challenging due to its requirement of running a previous marathon within certain qualifying finish times based on age and gender. A Mobility Impaired Division is also offered, which bases the qualifying times on level of physical challenge.

Having run the Boston Marathon nine consecutive years, from 2005 to 2013,

I have the distinction of the greatest number of official Boston Marathon finishes on a prosthetic leg, as well as the longest streak of Boston Marathon finishes of any leg amputee. However, as a unilateral below-knee amputee, I have far fewer mobility challenges than above-knee or bilateral amputees. My prosthetist,

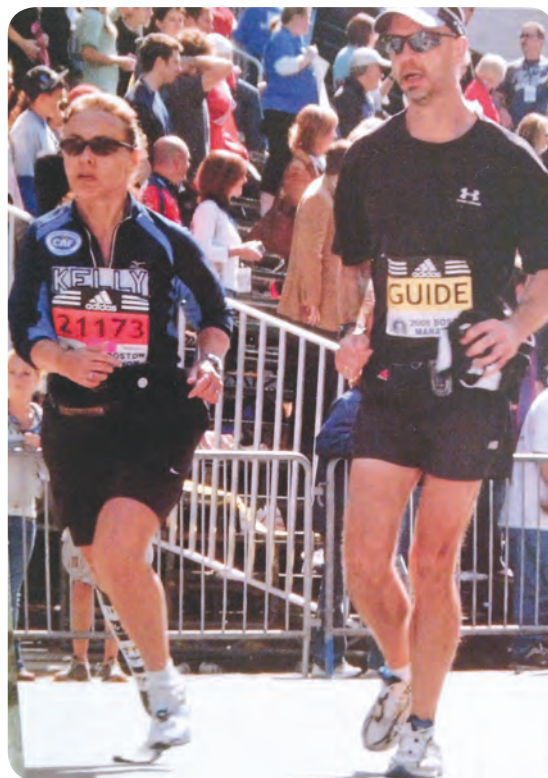
Will Holbrook, and support from the Challenged Athletes Foundation have been significant factors in enabling me to continue my streak of Boston Marathon finishes.

The thrill of qualifying for this prestigious marathon with its 117-year history, the challenging course, and the cheering spectators and volunteers who are second to none are just a few of the reasons I return

to Boston year after year. Other iconic characteristics that I look forward to each year are the screaming Wellesley girls, Heartbreak Hill and the legendary "right on Hereford, left on Boylston," which immediately gives you the amazing view of the finish line.

I strongly feel the Boston Marathon must not be discussed without acknowledging the unspeakable events that happened April 15, 2013. Several lives were lost and many others were changed forever. Killed in the bombings were Martin Richard,

"Completing the Boston Marathon will not provide closure from the bombings, but it will give us hope that the marathon can be a celebration of the human spirit."



Kelly Lockett and her husband Brian pictured at the 2008 Boston Marathon.

Photos provided by Kelly Lockett

FINISH

age 8; Lu Lingzi, age 23; and Krystle Campbell, age 29. The death of Sean Collier, age 27, an MIT police officer shot in his police car days later, was related to the bombings.

Hundreds of others were injured from shrapnel and the blasts of the bombs, resulting in burns, hearing loss, head injuries, and damage to muscles, skin, eyes, nerves and arteries.

Sixteen survivors lost one or both legs, some above-knee and some below-knee, and many are also dealing with the injuries listed above. The fact that I qualify for the Boston Marathon only because I have lost a limb, and that people lost their limbs traumatically at the same event, is difficult for me to process.

When I return to Boston this year to run the marathon, it will be a different experience than before the bombings. There will be intense sadness and grieving for those killed and injured, but there will also be hope for the survivors that the “Boston Strong” sentiment has helped support them in their recovery.

It used to be that when anyone used the phrase “the Boston Marathon amputees,” it was I and other runners with prosthetic legs that they were talking about. Now that phrase means something entirely different. It is my hope that people see all of us “Boston amputees” as proof that we are stronger than whatever traumatic event caused the loss of our limbs.

Kelly and Brian at the 2011 Boston Marathon.

It has been an emotional struggle to deal with what happened to so many innocent people at the 2013 Boston Marathon. A friend advised, “Don’t try to make sense of it, because it will never make sense to anyone sane, and don’t try to find closure, because you never will. Just know that it will become easier to deal with over time, but it will in some way affect you the rest of your life.” Once I accepted that, the emotions became a little less raw.

I have faith that the Boston bombing survivors will heal physically and emotionally to live happy and productive lives. It won’t be easy, nor will it ever be exactly the same life they had before, but it is possible to overcome tragedy and come out stronger. Having the right support system will be crucial to their recovery and quality of life. I, along with several other amputees, am happy to do anything we can to help them in their journey.

I will return to Boston this year to run my 10th consecutive Boston Marathon. Completing the Boston Marathon will not provide closure from the bombings, but it will give us hope that the marathon can be a celebration of the human spirit. 🌀



BOSTON MARATHON

From Patient to Professional

Amputees finding a perfect fit in the O&P field

by Élan Young

When a child with limb loss goes to the prosthetist's office upwards of a dozen times a year, the office becomes a familiar place, and the prosthetists themselves often become trusted, lifelong friends, even mentors – small wonder that the O&P field attracts a large number of amputees. Three such amputees are in various stages of their O&P career at Atlanta Prosthetics & Orthotics (AP&O), and all are experiencing the rewards of helping their fellow amputees achieve the best mobility they can.

TESS BURFORD, currently in the second year of a Master's program in prosthetics and orthotics at Northwestern

"...constantly learning something new, and helping others, not only with their physical obstacles but emotionally as well – these are all so satisfying."

University, Chicago, Illinois, held a longtime dream of working in the O&P field, reinforced by exposure to other kids with limb loss. The 23-year-old from Auburn, Alabama once thought she would study psychology. But with an undergraduate degree in rehabilitation services and disability studies and a desire to positively affect the lives of children, she

became a counselor for Amputee Adventure Camp for a summer.

Being an upper-limb congenital amputee, who has worn passive and myoelectric prostheses, and also gone without one at all, Burford could easily identify with the issues these kids faced. "Interacting with those children and being able to identify and understand what they were going through got me thinking about a career in O&P again," she says.



Luckily, for many amputees seeking a career in the field, there are openings for internships at facilities to let people experience what the day-to-day is like. Burford ended up with an internship with her lifelong prosthetist, Jim Hughes, at AP&O. This experience proved that this was the field she wanted to be in.

"My father always told me to pick a career path that I looked forward to every day, and I knew then that I had found it," she recalls. "Interacting with so many diverse individuals, being able to work with my hands – or hand [laughs] – constantly learning something new, and helping others, not only with their physical obstacles but emotionally as well – these are all so satisfying."




For **DARREN BOLGER**, a Symes-level amputee since age five after a lawnmower accident, the choice to enter the O&P field came later, although he'd always considered it. Instead, he first chose a career in engineering. But after a short stint in a manufacturing environment, he realized something was missing.

The 29-year-old Iowa native moved to Atlanta to pursue Georgia Tech's Master's degree in prosthetics and orthotics. Now an orthotics resident at AP&O, he says, "I really wanted a career that was rewarding and offered me the opportunity to truly help people."

After completing his orthotics residency and board exams, he'll begin work on his prosthetic residency. Although he's not working in prosthetics yet, he feels that his limb loss helps him relate to patients: "While everyone's situation and experience is different, I think that by discussing your own experiences you can begin to form a bond and relationship with a new patient."

HUNTER SCOTT, like Burford, graduated from Northwestern's P&O program, and is now a certified and licensed prosthetist at AP&O, where he has also been a lifelong patient. Born with proximal femoral focal deficiency, he got his first prosthesis before he was two years old. Scott says his entry into the field was just a matter of asking to help out.

"In college I expressed interest in working for AP&O, and I was fortunate to be given a job as an orthotic tech in the summers and during winter breaks," he says. Then, in the first year and a half after he graduated from undergrad at Virginia Tech with a degree in psychology, he was a tech while completing prerequisites for grad school. All in all, Scott worked in the field for a long time before being committed to the career, which is one way for aspiring prosthetists to test out the profession first.

Additionally, the early field work helped him develop a strong sense of purpose. "My greatest obligation is to give other amputees the level of care that I've been given," he says. 



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Wheelchair Exercises

by Cindy Asch-Martin

WHEN WE THINK OF EXERCISE, there are some who may think that only fit or able-bodied people are capable of doing it. But exercise is meant to be a part of everyone's lives, regardless of your physical or emotional condition. Exercise provides many positive aspects to our everyday life, such as releasing endorphins for a happier you, to helping alleviate the pain of arthritis, to strengthening our bodies, to name just a few benefits.

Just because some of us may be restricted in what we can do and how we can do it doesn't mean exercise is out of the question. For example, there are sports designed specifically for wheelchair users, as well as daily exercises that one can do in a wheelchair.

There are various reasons why some amputees may choose to use a wheelchair – for example, it may be too painful to wear a prosthesis; a prosthesis may be in need of repair; or one may be unable to afford a prosthesis.

If you belong to a gym you have many forms of exercises to choose from. Depending on your abilities, you may be able to transfer yourself from your wheelchair to a piece of equipment; this will also provide extra strengthening in simply maneuvering over

to the bench. All upper-body exercises (trapezius, shoulders, chest, back, triceps and biceps) can be done with dumbbells, kettle bells or machines.

If you don't have access to a gym, then home exercises are available to help you stay strong and healthy.

For those who can transfer to a bed, chair or the floor, the possibilities are greater for more variety than if you must exercise only in your wheelchair, but you too can benefit with a good number of exercises to keep you strong.

The category you fit into will also determine how many different exercises you can do. If you are a bilateral amputee without prostheses, then you should be able to strengthen your upper body. If you are an AK, BK or knee disarticulation amputee, then you have the ability to exercise at least one leg as well as your upper body.

Working your own body weight is one of the more productive ways to exercise. It is actually harder to use your own body than it is to pull or push a piece of equipment.

Let's try a home workout in a wheelchair as our example for exercises. You can do these even if you're not in the mood to go to the gym!

If you don't have access to a gym, then home exercises are available to help you stay strong and healthy.



Start Position



End Position

SHRUGS | Let's start with shrugs for our trapezius muscles. You can use hand weights if you have them; if not, you can find something around the house to hold in your hands. Without bending your elbows, simply lift your shoulders to touch your ears. Stop at the top and hold at the bottom without using any momentum.



Start Position



End Position

TRICEPS | Next, let's try our hand at a triceps extension by holding one object up in the air. Place your other hand as shown in the picture to help steady your arm. Now bend your elbow, stop and then push the weight back up and stop.



Start Position



End Position

CHEST AND BACK | For this exercise, hold a dumbbell or object of similar size and weight in your hands. Hold it at eye level with each hand on either side of the object. Push it away from you and stop, then bring it back to you and stop. This works your chest and your back, and if you sit up without pressing your back against your wheelchair, it also works your abdominal muscles.



Start Position



End Position

BICEPS | This final exercise consists of biceps curls with weights in one or both hands – the choice is yours. With your palms up and wrists tucked in, curl the weight(s) up three-fourths of the way and stop, as shown, then lower back down very slowly and stop.

All exercises should consist of 10-12 repetitions with two to three sets – more than three sets are unnecessary. Safety is always the first priority – be sure to breathe in and out and avoid holding your breath while exercising. Keep your tummy tight to help protect your back; it also works your abdominal muscles!

There are many more exercises that can be done in a wheelchair – be sure to check back for more suggestions. 🔄



Photos provided by Cindy Asch-Martin

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College Park Industries	7
Comfort Products	17
Disabled Motorcycle Riders	21
Endolite	37
Fred's Legs	23
Hanger Clinic	4

Hartford Walking Systems	23
Motion Control	13
Össur	2
Ottobock	40
Prosthetic Research Specialists, Inc.	10
Scott Sabolich	39
Tamarack	36
Texas Assistive Devices	15
TRS	19
WaterGait	33



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Ashley Kurpeil and software developer John Putnam, who helps to connect Ashley to her prosthetist.

The “New Me”

by Ashley Kurpeil

“...holding a bottle of water or feeding myself a cookie with my second arm was definitely a highlight of my life.”

Last summer, I wrote an article about my life without a prosthesis (see “*Perspectives*,” *inMotion*, September/October 2013). I lost my arm at the age of three due to a medical misdiagnosis. Without the right shoulder/arm, I decided that wearing a prosthesis on such a small body frame was more trouble than it was worth for simply cosmetic purposes.

Last August I went to Denver for a long weekend to visit one of my closest friends, Whitney Harris, before a weeklong trip to surf in California. Whitney is doing her residency in orthotics and prosthetics in Denver at Bulow BioTech Prosthetics.

During my visit with her I decided to get a prosthetic shoulder built so I could wear different shirts with an open neck. When the shoulder was finished, I tried it on and got dressed. As I looked in the mirror I thought it looked bizarre without an arm attached. So my prosthetist, Zach Harvey, looked at me and asked, “Do you want an arm?” I told him I only wanted one if it would feel like a part of me, and be functional, not just cosmetic.

I honestly *never* thought I could handle a myoelectric prosthesis; I have a rare bone disorder (fibrodysplasia ossificans progressiva, or FOP) that limits my mobility severely as my muscles gradually turn to bone. Whitney tested me to see if I could use a myo, and it turned out I have just enough muscle needed to operate one.

I returned to Denver in October and saw myself for the first time as a “complete” human, sporting an appendage that I never thought I’d ever experience. Amazing as it may seem, holding a bottle of water or feeding myself a cookie with my second arm was definitely a highlight of my life.

It feels so natural, like a part of me. In fact, when I was in Orlando at an FOP convention two months ago, my FOP doctor (who I have known for more than 25 years) had a lengthy conversation with me before he noticed the “new” me.

Thank you, Zach Harvey and Whitney Harris, for the new Ashley – you complete me! 🌀



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Genevieve Wanke, Ixonia, WI.

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