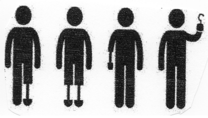
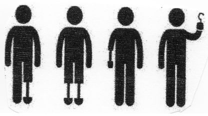


⇒⇒

MOVING FORWARD
LIMB LOSS SUPPORT GROUP NEWSLETTER

7th Edition – March 2014

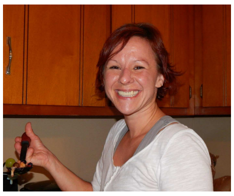


⇒⇒

MOVING FORWARD
FEATURE ARTICLE
What You Need to Know to Be You

– by Kelly Reitz

It has taken me a long time to fully accept who I am. I am a quadrilateral amputee. I have scars on most of my body – some from the sepsis caused by the meningitis itself and some from the many surgeries to repair the damage done by the disease, repair the tip of my nose, reduce some of the scarring, remove bone spurs; there are not many places on my body that have not been touched by a blade.



I have lived a complicated life as a 'normal' handicapped person, which I define as someone who is indeed handicapped & yet lives a very normal life. I have had plenty of instances where I was made fun of, taunting & teasing from people – kids & adults alike. I learned to make my weird prosthetic moments or limitations with my hands as moments to laugh about. Not so much that it was funny but sometimes because there was nothing else to do with it except to cry. And sometimes I would laugh to help others be at ease with what was going on. I have learned that people stare because they are curious and they want to ask, but they are scared. So, I started talking to them & showing them my scars or amputations. It was not because I wanted them to accept me so much as I wanted them to understand that it's okay for me to look different & yet be just as normal as they are. When I started doing this, it made me more comfortable in my own skin.

I have many pivotal moments of understanding myself but one of the biggest ones was when a complete stranger told me that some people wear their scars on the outside & some wear theirs on the inside. I just happened to have mine on the outside.

I wish it was as simple as you reading this article about body image & self-esteem for it to all make sense. But it does not work like that. It takes time to understand & learn yourself. It takes stubbornness to do the things that everyone tells you that you should not do. It takes determination to do the things that YOU do not think you can do. It takes acceptance of yourself. It takes finding comfort within yourself.

Body or self image comes from within. You have to build your mind to accept things you cannot change. Build confidence by focusing on the parts of you that

– Continued on Page 2 Column 1 –

AMPUTEE COALITION ADVICE

*in*Motion Volume 16 · Issue 4 · July/August 2006

Towards Reaching "Normalcy" — Does It Really Matter?

– by Donna R. Walton, EdD

My journey towards trying to reach normalcy – which I used to define as "walking without a limp" – began 30 years ago when my left leg was amputated as a result of cancer. I was 18 years old, and I could never imagine leaving the house without my artificial leg. Just the mere image of my pant leg flipped under my waistband like a young man who we affectionately called "One-Legged Steve," and who was my first encounter with an amputee when I was in junior high school, made me feel very, very uncomfortable and not normal.

Unfortunately, my amputation is very high above the knee and my residual limb is very short; in fact, I was just inches away from having a hip disarticulation.

Because I didn't want to be perceived as an amputee over the years, I always dreamed of having an artificial leg that would allow me to walk without a limp; I wanted to just be Donna, not the object of everyone's curiosity.

So you can probably imagine that I was very excited when I was recently fitted with a new four-bar pneumatic knee – the knee unit of choice for many transfemoral amputees. I thought that this new knee would help me better hide the fact that I am an amputee from the rest of the world.

Oh, but what an experience it turned out to be! You see, I had this fantasy that this leg would transform my gait from limp to saunter. I was so excited that I was graduating to a high-tech leg that would allow me to walk without a limp and without a cane. Unfortunately, I quickly became very disappointed and frustrated with the new knee.

Because my residual limb is very short, it causes all kinds of challenges for me and my prosthetists. I had been so caught up in the dream of walking smoothly, swiftly and without a limp that I didn't realize the challenges that I would have to deal with, such as the weight of the knee and the limitations inherent in having such a short residual limb.

My prosthetists probably knew that I might not realize my dream of walking without a limp, but they dared not tell me for fear of killing my fantasies.

I really wanted to be fitted with a computerized leg, but it wasn't an option because my insurance would not pay for it and I wasn't financially prepared to pay for one on my own. Such legs can cost more than $32,000 – a very high price indeed to pay for "normalcy." It's not unusual for people with disabilities to have such dreams of being what the world considers "normal." Perhaps you have them too.

Interestingly, I recently met another amputee who is in her

– Continued on Page 2 Column 2 –

What You Need to Know to Be You (cont'd)

you find attractive about yourself. If you build a mindset of strength & confidence (even on days when you do not feel like it), then it will shine through – without much effort. How you carry yourself & how big of a smile you have on your face can make a huge impact on how people see you. Find ways to build yourself up. Build on your strengths & learn to overlook or accept your faults.

Normal should not be the way you look on the outside but inner peace you carry within.

* * *

My "Ah! Ha!" Moment

– by Belinda Jacobi

One of the questions that I often get asked is, "How do you deal with people staring at you all the time, and doesn't it bother you?" When I first lost my leg, the answer to that question would have been a big 'YES, it does!" That is why I spent the first two years of being an amputee trying to keep it covered.

One day though, I had one of those big "Ah! Ha!" moments. We've all had them when we feel like a light bulb has turned on in our brains, and things seem so much clearer. It was an extremely hot and humid day, and I was getting ready to take Carter to swim lessons. I dreaded wearing my long pants and knew that I would be miserable. That's when it hit me, and I realized why on earth am I trying to hide my leg, I've done nothing to be ashamed of. I put on crop pants and went on with my day, and in doing so I noticed every single stare. I am sure that people could sense my nervousness.

I was determined not to give in to my fears, so I continued wearing the crop pants and even became daring enough to wear a swimming suit to a public pool. Each time became easier, and I began to realize that when I met those stares with a smile and people saw that I was comfortable with myself, it became more comfortable for them as well. Human beings are just typically curious of the unknown. Most of us didn't know an amputee until we became one ourselves. I have decided that the stares aren't such a bad thing anymore. How else are people going to become less curious about us, unless they see us out in public more often with our prosthetic device showing? I now think of it as a chance to educate people about amputees and prosthetics.

More and more of the population are losing limbs every day due to diabetes and smoking related vascular disease. If we can take away some of that fear of the unknown for someone that is facing the loss of a limb, or make people more aware of amputees so that we become less of a curiosity to them, then maybe it will help change the public perception of us and make it easier for amputees in the future. If you would like to share an "Ah! Ha!" moment that you have had, please contact us.

Towards Reaching "Normalcy" (cont'd)

30's and had feelings very similar to my own. She also wears an above-knee prosthesis because she doesn't have a hip, and she also limps dramatically when she walks.

"It isn't easy being a person with a disability," she says, "much less someone with a very noticeable limp. When you walk into a room, you're never quite sure if people are staring at you because of how you walk or that fabulous new outfit you're wearing. You get used to the stares and whispers, but that doesn't make them right, nor are they something that you should really have to get used to. I always avoid, as much as I can, walking into a room full of people or moving across a room when I am presenting. The less walking I have to do, the better I am."

Meeting new people is even more difficult, she explains: "I tried online dating for awhile, and when I met people in person, I did my best to arrive before my date and be seated when he got there so at least we could start off like things were 'normal.'

"'Normal' is a relative term," she continues, "but something that a lot of people want to be when they are younger. Throughout my academic career, up to college, I just wanted to be like all the other kids in my classes. Even when I wore exactly the same clothes or wore my hair the same way, I still wasn't like them."

This young woman is a great example of how too much concern about one's differences can affect a person. "I have bouts of insecurity," she admits, "and I have never been totally self-confident about anything, even things that have nothing to do with the way I walk or my artificial leg. … These are side effects of being a person with a disability, especially a noticeable one."

My own difficulty in walking with my new four-bar pneumatic knee was also very frustrating and caused bouts of insecurity. I ultimately had to face the fact that I wasn't going to be able to function any better with it.

The important thing, however, is that I now know that doing this was not admitting defeat; rather, I was changing my goal. My quest for years had been to walk without a limp. I realize now, however, that my situation could have been much worse. I might not have been able to walk at all. Now, my quest is just to walk, with or without a limp. I realize now that there is a great value in that and that the rest is extra.

Over the years, I worked so hard to build self-esteem and confidence, and I almost risked losing it when I decided that I had to walk "normal" again. My gimpy gait is mine, and it is very "normal" to me.

Why should amputees even care about what others think about their gait? Just being able to walk or to get where we want to go, whether it is with a cane or in a wheelchair, is the point, isn't it? When we strive to make others comfortable, we sometimes lose our focus on what really makes us comfortable.

The young woman I met recently seems to have come to a similar understanding.

"I'm not happy about my limp," she explains, "but I no longer let it define me. I am a person just like everyone else; I just happen to walk a little differently."

She says that there needs to be a culture shift in how people view each other.

"You shouldn't base judgments on how people look, walk or talk but rather on their words and actions," she says. "If you base your opinion of people simply on how they look or walk, you're missing out on a world of wonderful people!"

I think I can add something to her observation. Not only should we not judge others based on the way they look or walk, we should also not judge ourselves.

Any questions?

– Continued on Page 3 Column 2 –

RECAP OF FEBRUARY

On Saturday, February 15th, *MOVING FORWARD* hosted a bowling fundraiser at Incredible Dave's in Louisville. Despite the snowy weather, 49 members and supporters attended the event. Everyone had a great time bowling, eating pizza, and socializing. For some, it was their 1st time bowling, and others hadn't bowled in years. The highest score for an adult bowler was Chuck Messer and for a junior bowler was Chloe Worrall. They each received a beautiful Valentines box of treats donated by Stacey White of "Wrap It Up". We would like to thank everyone who attended and showed their support for our group.

On Saturday, February 22nd, Kelly and Belinda set up a booth to represent the support group at a health fair held by Harrison Co. Hospital in Corydon, IN. They met people who knew amputees and some who had family members with diabetes who expressed their concerns about possible loss of limbs. Many new contacts in the healthcare field were also made. We talked with them and provided them with literature and contact information. A discussion was also held on the possibility of starting a bi-monthly meeting there for amputees who don't have the ability to come to Louisville to attend meetings.

Our monthly meeting was also held on Saturday, February 22nd. Due to illness, our guest speaker was unable to attend, but she has agreed to come at another time. Philip told the group about his recent trip to New York to attend a convention.

We were honored to have a special guest in attendance, Alexandria Hagan, who is studying social work at UK. She had asked to observe the group as part of research for a class project. We are glad to help any student to gain a better understanding of the issues faced by amputees.

Those members in attendance discussed many topics, including: phantom pain and sensations, technology that allows amputees to wear their prosthetic device in the shower or while swimming, and the benefits of educating the patient about prosthetics before the amputation whenever possible. We also discussed the many ways in which being in a support group can help those with limb loss, including not only the support and encouragement that we provide each other, but also the sharing of information that can better our lives, as well as opportunities that amputees would not be aware of on their own, such as university studies and upcoming technology.

The meeting concluded with discussion of the Chili Supper, Care Packages, and our many upcoming events.

* * *

QUOTE OF THE MONTH

One of the happiest moments in life is when you find the courage to let go of what you can't change.
-- Author unknown

Towards Reaching "Normalcy" (cont'd)

About the Author

Donna R. Walton, EdD, earned her master's degree in adult education from Syracuse University and her doctorate in counseling from George Washington University. Walton is the founder of LEGGTalk, Inc., a company she conceived 10 years ago under the name of Dream Reach Win, Inc., to motivate and empower individuals to conquer their personal limitations (real and perceived) and achieve their vision of success. A dynamic, award-winning speaker, Walton has spoken at the National Cancer Survivors Day Celebration, the National Conference on Disabilities, and at many schools, universities, and other institutions.

For more information about LEGGTalk, Inc., or to join the LEGGTalk blog, visit www.leggtalk.com

* * *

UPCOMING EVENTS

Sat. March 8th – Our 2nd Annual March Madness Chili Supper at the Okolona Fire Station from 5:00 - 8:00 PM. There will be a chili cook-off with prizes awarded to the judge's choice & the people's choice. The registration fee is $5.00, and you will register at the event. Admission for the chili supper is $2.00/person (ages 5 & under are free). There will be games & prizes for both the adults & children in attendance. It is a pitch-in, so please bring either chili, chips, your favorite chili topping, or a dessert. The group will provide hot dogs, buns, crackers, and utensils. You are encouraged to wear your favorite team gear, because a prize will be awarded to the "best dressed fan". We hope to see you there.

Sat. March 22nd – from 2:00 - 4:00 PM *MOVING FORWARD* will hold its monthly meeting. A representative from "Camp No-Limits" for children with limb loss will be on hand to tell the group about that remarkable project. Please plan on attending; you don't want to miss this opportunity to hear about a camp that can truly change the lives of these children. The meeting will be held in Room 2B in the Education Center on the 2nd Floor at Baptist East in Louisville.

Other events being planned or considered:

APRIL – We have not been able to secure our desired location for the proposed health fair, so we are going to hold off on that event until a later date. This should be such a great opportunity for the amputees in our area, so we want to do it right and location is very important. Instead, we are working on another idea for April to observe National Limb Loss Awareness Month. We will provide you with the details as soon as possible.

MAY – Pegasus Parade & picnic, and a Spring hike. We have also scheduled a very special speaker for our monthly meeting in May, Neil Brown. Neil is a motivational speaker and has just released a book titled Standing Tough.

JUNE – attending a Bat's game and providing a tennis clinic for amputees

– Continued on Page 4 Column 1 –

SPOTLIGHT

Each month in our spotlight section, we will get to know one of our members a little better. This month we are shining the spotlight on our group's treasurer, who is also known affectionately by the group as "our social butterfly":

Name: Kelly Reitz

Where is your hometown now and where else have you lived? I am from Shively (Louisville, Kentucky) and lived in the same house since I was a year old. The only time I moved was when I got married in 2005 and bought a house in New Salisbury, Indiana, where I currently live.

How many children and ages? Abby - 5 and Grant - 3

Where do you work & what do you do there? Any previous jobs? I currently work as an auditor for Humana. Prior to Humana I worked for an Oral Surgeon in Louisville. Before that, I had my first job at a computer company that did repairs, internet and electronic filing. I graduated from the University of Louisville in 2005 with a degree in Management and a minor in Marketing and International Business.

What are your hobbies? My hobbies are gardening, activities with the kids, and karaoke.

Are you a sports fan & if so what team/teams? Is there any sport that you like to play or participate in? I like UL and UK basketball but I'm not a huge sports fan. I like to watch any kind of live sports.

What is your favorite activity/activities that we have done so far? I have to pick a favorite?!? To me, all of the events with the group have been great!

Is there any activity that we haven't done that you would like to see the group do? I would like to do a community service project of some sort.

How, if any, has being a member of *MOVING FORWARD* helped you? I enjoy the camaraderie and fellowship that I get from the group. I enjoy spending my time with people who can relate to me. Being a part of this group makes me feel needed and makes me feel a part of something big.

What one piece of advice would you give to a new amputee? Don't underestimate yourself and at the same time know your limits.

Is there anything else you would like to share with us that we may not know about you? I once stopped a kid from picking his nose by telling him that that is how I lost my finger(s). It worked like a charm!

It is very important for the amputees in our community to know that *MOVING FORWARD* is open to all amputees and their families, friends, and caregivers. Our goal is to encourage amputees, prosthetic companies, rehab and medical facilities to work together to support, educate, and motivate those with limb loss in our community. We deeply appreciate all of you who have shown your support in helping us to "move forward" in reaching that goal.

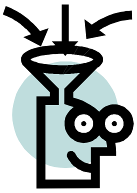
UPCOMING EVENTS (cont'd)

JULY – pie and ice cream social
AUGUST – softball game & picnic
SEPTEMBER – our 2nd Annual Walk & Roll Fundraiser and a Belle Cruise
OCTOBER – Halloween costume party (per Philip's request) and a Fall hike.
NOVEMBER – ?
DECEMBER – Christmas party

We will also be holding another group yard sale at a date yet to be determined.

* * *

TEST YOUR KNOWLEDGE



Unscramble these words and then use the letters in the parentheses to finish the sentence. You can find the answer on PAGE 6.

SHCTTEPORI EEICVD __ (__) __ __ __ __ (__) __ __ __ (__) __ __ __ __ __
LQYAIUT (__) __ (__) __ __ __ __
UNNSOPSIES __ (__) __ __ __ __ __ __ __ __ __
CCCNTEEAPA (__) __ __ __ __ __ (__) __ __ __
YLLFSIETE (__) __ __ __ __ (__) __ __ __
TOLIMYBI __ __ __ (__) (__) __ __ __
OSRNEDP (__) __ __ __ __ __ __

A __ __ __ __ __ __ __ __ __ __ __ __ __ __ AMPUTEE IS AN INDIVIDUAL WHO HAS LIMB LOSS OF ALL FOUR LIMBS TO SOME EXTENT.

* * *

Q & A

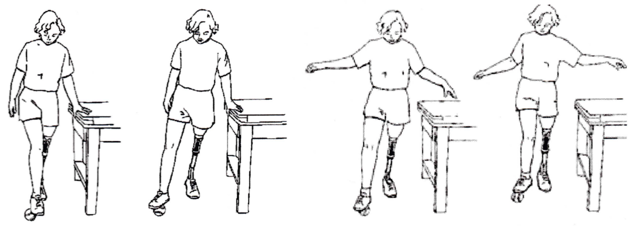
In this section, we ask you to submit questions pertaining to limb loss, & then we will get responses from members of *MOVING FORWARD* Limb Loss Support Group. We are not offering medical advice, but will share tips & information to try to make living with limb loss easier. You may submit your question(s) by email to belindajacobi@yahoo.com or by calling 812-620-3694. The question that I have chosen for the March Q&A is: *Do you have phantom pain, and if so, how do you deal with it?*

This is a question, as an amputee, that I have heard a lot. For someone who hasn't experienced it, it seems highly unlikely that you could still feel sensations or pain in a part of your body that is no longer there. But as many of you who are amputees know, for some of us it is a part of our daily lives. In a future issue, we will discuss phantom pain and sensation in fuller detail, as well as sharing advice from medical experts on the subject. Our Q&A section, though, is about amputees sharing their experiences, so I submitted this question to several members and the following are the responses that I received:

– Continued on Page 5 Column 2 –

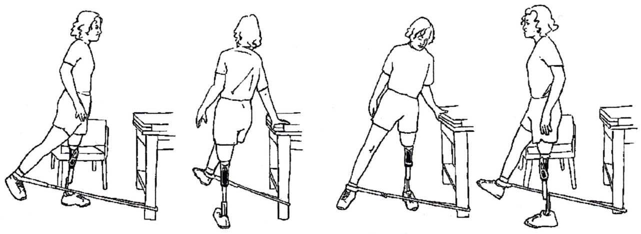
LET'S GET MOVING!

We are continuing the new section to provide amputees with information on exercise and healthy eating. If you have an exercise tip or recipe that you would like to share with us, please let us know. Following are two more basic exercises:



Ball Rolling

1) **Ball Rolling:** Stand with a tennis ball in front of your unaffected limb. Place your unaffected foot on top of the ball. Keep your foot flat on the ball & roll it forward, backward, side-to-side, or in circles. Feel the muscles working in the prosthetic side hip as your weight shifts with the movements of your unaffected foot.



Resisted Elastic Kicks

2) **Resisted Elastic Kicks:** You will need a sturdy immovable table or sofa leg & some rubber tubing. Secure one end of the rubber tubing to a sturdy table leg while the other end is placed around the ankle of your unaffected ankle. Holding onto a chair, move far enough away from the table so that the rubber tubing is slightly stretched.
    1. Kick your leg back, while facing the table.
    2. Kick across the prosthetic limb.
    3. Kick away from the prosthetic limb.
    4. Kick forward, with your back to the table. Hold onto the table for balance. Kick your unaffected limb back so the rubber tubing is stretched out.

&&&&&&&&&&&&&&&&&&&&&&

Remember, you don't have to be a member of *MOVING FORWARD Limb Loss Support Group* to attend meetings or events. EVERYONE is Welcome!

Q & A (cont'd)

Sam says that he doesn't experience phantom pain but does occasionally deal with itching on his missing feet. He just waits for the sensation to pass.

Genny says that luckily she doesn't experience phantom pain.

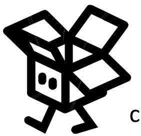
Sylvia, who is a left BK amputee, experiences both the pain and sensations. She says that the pain occurs mostly in her joints, and to relieve it she taps on her residual limb. Percussion or finger tapping helps to desensitize the limb.

Kelly doesn't experience the phantom pain but does experience the sensations. Kelly says, "It has always fascinated me to know why some people have them and some do not. It is my understanding that since I was so young at the time of my amputations, my brain re-routed itself as if those limbs never existed. I had my original amputations when I was a year old. In 2009, I had an elected revision to remove my partial foot on the right and a Symes amputation on the left. Even after the revisions, I did not have phantom pain. After the revisions, I had quite a bit of what I call 'jolt pains'. It feels like a burst of electricity shocking me. I hardly get it now, but if I am really active or have really engaged my muscles for that day, then I might have the jolts for a few hours at the end of the day. There are various types of therapy to help with phantom sensations (feeling as if the limb is still attached so that you feel it still itches, etc.) versus phantom pain (feeling that the missing limb is still attached and in pain). If it is painful enough some amputees may take medication to soothe those feelings."

I (Belinda) experience both the phantom pain and the sensations. I have read that many times people who were in a great deal of pain for a long period of time before their amputation often experience them. I had pain in my ankle for a year before it was diagnosed as cancer, so I feel that is why I have them. The sensations in the beginning were very troublesome to me, but now I hardly notice them. I have a constant feeling of tingling in my missing right foot and a feeling like it is in a shoe that is too tight. If I concentrate, I feel like I can still wiggle my missing toes and flex my missing foot. I feel like my foot is still in my shoe, which is to me a comforting feeling. The phantom pain I feel is mostly in my right ankle (which is where my cancer occurred) and feels like I'm being struck by a hammer usually about 4 times and then it stops, occasionally coming back a few more times before subsiding. I also get that same type of pain in my big toe. I usually experience it a couple times per week, so it isn't a constant thing. If it were, I would probably seek medication. When it happens, I just remind myself that it will pass and that everyone my age usually has some time of pain to deal with. I am usually busy when it happens, so I can't really take my leg off to try tapping or massage, but I do take a warm bath at night and massage my residual limb, which helps to relieve some of the phantom sensations by soothing the nerve endings.

As Kelly mentioned, there are many types of therapies available to help amputees deal with both

– Continued on Page 6 Column 2 –



Special Announcement

The first Children's Care Packages are almost complete and arrangements are being made for their delivery to Kosair. We are still in need of some items to include in the packages for the VA Hospital. Mostly, we are in need of small bottles of lotion and hand sanitizer, and mohl skin (which is found in the foot care aisle). If you would like to donate any items, there will be a box available at the Chili Supper for the donations. Thank you for your support of this project. It has taken some time to work out all the details and prepare the packages, but it is a worthwhile project that will both show our support for children and veterans with limb loss and get the word out about our group. We also plan to keep some packages on hand to distribute to new amputees when we visit them in hospitals or rehab centers. We hope to continue with this project, but will need your support.

* * *

TEST YOUR KNOWLEDGE ANSWER (from Page 4):

PROSTHETIC DEVICE, QUALITY, SUSPENSION,
ACCEPTANCE, LIFESTYLE, MOBILITY, RESPONSE
QUADRILATERAL

Q & A (cont'd)

phantom pain and residual limb pain. As always, contact your doctor or prosthetist if you are having difficulty coping with pain. There are also many websites online that offer valuable advice, including the Amputee Coalition website at: www.amputee-coalition.org. I hope these tips help! Please keep submitting your questions.

— *by Belinda Jacobi*

* * *

CONTACT INFO

MOVING FORWARD Support Group
moving4wdamputeegroup@gmail.com
502-509-6780
Website: ampmovingforward.com
Belinda Jacobi, President
belindajacobi@yahoo.com
812-620-3694
Sam Gaylord, Vice-President
gaylordm@aol.com
812-989-4177
Sylvia Worrall, Secretary
hiswife4life@outlook.com
502-498-9500
Kelly Reitz, Treasurer
Kjreitz2012@gmail.com
812-572-7955
Mike Portman, Board Member-at-Large
mdportman712@gmail.com
502-262-8344
Julie Randolph, Newsletter Editor
jbrsweepea@yahoo.com
812-557-3970