

NEWSLETTER • 124th Edition • Dec 2023

Our Mission - To reach out and empower people affected by limb loss to achieve their full potential through education, support, and advocacy, and to raise awareness of limb loss by becoming actively involved in our community.

EDITOR'S NOTE

- by Elaine Skaggs

As we approach the end of November, it's my hope that our season of Thanksgiving continues through this next year, always finding things to be grateful for. As we prepare for the holiday season, one important date for our group will be December 18, the birthday of Belinda Jacobi, our founder. Belinda was a special lady, who took on the responsibility of a non-profit almost managing singlehandedly, as well as being an advocate for amputees. Belinda provided encouragement and motivation, information and resources, no matter what you were facing. She was definitely our cheerleader, and made a huge difference in many of our lives. In honor of Belinda and with much heartfelt gratitude, I am reprinting an article that Belinda wrote for the February 2014 issue of the Moving Forward Limb Loss newsletter. If you never had an opportunity to meet her, this will give you some insight on just how special she was.

UPCOMING EVENTS Saturday December 9 – 5:30 to 8:30pm

In just a couple of weeks, we'll be holding our Annual Christmas Party for members and This is always the most their families. attended event every year, and you don't want to miss this year!! Please note the change in location: the party will be held at Saint Luke Catholic Church, 4211 Jim Hawkins Dr. Louisville KY 40229. The group will be providing a meal, and asking if you are able to bring a dessert to share. Santa will be paying us a visit with gifts for all the children, and there'll be a craft table where they can make their own ornament. There will also be several items for a silent auction, and an ornament exchange for the adults, and who knows? maybe we'll even sing some Christmas carols! One thing for sure – be prepared to have a blast! Hope to see you there!

Monday December 18 - 6:00 to 7:30pm

Indiana meeting at Southern Indiana Rehab Hospital, 3104 Blackiston Blvd, New Albany IN, in the Conference Room. This meeting will be a tribute to Belinda Jacobi.

NOTE: There will not be a Louisville meeting during the month of December.

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"MY GIFT"

- by Belínda Jacobí (reprinted)

I remember the day when I phoned my brothers and my sister to tell them that my biopsy had shown that I had cancer, and my orthopedic oncologist told me that my best chance of surviving was to have my leg amputated. I promised my siblings that I would try to let it change me only from the knee down. I was determined not to let it change the type of person I was. I didn't want to let it overwhelm me, changing me into a sad, depressed, or withdrawn person. But it did change me, and I would like to think that the change is for the better. I am much definitely stronger ล person emotionally than I was.

When you are fighting for your life, battle after battle, you realize that you can endure much more than you ever thought you could. I always felt that I was a good person, and always tried to do what I felt was right, and to help those in need; but now I have found myself in the role of being an inspirational person, and I consider that a gift.

When you think of someone who inspires you, it is always someone who has faced an obstacle in life but yet persevered. I received a book while recovering from my amputation surgery entitled "My Beautiful Broken Shell". In it the writer, Carol Adams, talks about walking along a beach looking for shells, and as everyone does, she steps over the broken ones to find only the perfect shells; until one broken scallop shell catches her eye, and she stops to pick it up and realizes how hard the shell had to fight not to be totally crushed by the pounding surf.

I quote from her book, "Broken shells mean lots of tears, lots of pain, lots of struggles, but they are also valuable for courage, teaching faith, and strength. Broken shells inspire others and demonstrate the will to go on in a way that no perfect shell could ever do. Broken shells are shells that have been tested, and tried. and hurt, yet they don't quit. They continue to be."

UPCOMING EVENTS (cont'd)

The Indiana meeting held at the Southern Indiana Rehab Hospital will be held on December 18, the third Monday as usual. It will be a tribute to our group founder, Belinda Jacobi.

NOTE: The next Caregivers Meeting will take place at our regular monthly meeting in January 2024.

EVERYTHING YOU NEED TO KNOW ABOUT PHANTOM PAIN

- by Elaine Skaggs

November was a very difficult month for me, with several personal and household issues to deal with. But the most difficult was 2 separate episodes of phantom pain. Prior to the first of these episodes, I had not experienced anything more that 2 episodes in the last 22 months, that had lasted only about 3 hours each. When I experience phantom pain, it's usually a stabbing somewhere in my missing left foot, and is painful enough to make me cry or scream, and until now, nothing seemed to help. I have tried heat, ice, massage, and vibration, even prescription doses of ibuprofen, which only served to minimize the pain.

In a conversation with a couple of my amputee friends, one of them suggested I try Magnesium, which has a calming effect on the nervous system. I found and tried Magnesium Oxide, which has been a game changer for me. As you'll read in the following article from MOVAO, phantom pain is different for everyone, and different remedies work for different amputees.

After an amputation, many people still feel the limb that is no longer there. They experience pain, itching or other sensations in the missing body part. We call these phantom sensations or phantom pain. Unfortunately, many people prefer not to talk about it because they are afraid that no one will believe them. Yet it is important $\sim cont'd$ on Page 3 Column 2 ~

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MY GIFT (cont'd)

It truly humbles me when someone tells me that I have been an inspiration to them. There are so many people out there who have endured far more than I have. Yet if I can uplift someone in even some small way, then it is my honor to do so. The amputees that I have met in the past $4\frac{1}{2}$ years have truly been an inspiration to me. Their stories. their determination. and their friendship have enriched my life.

Looking back 5 years ago, my life today is not what I imagined it would be. Life was far less complicated when I had all 4 limbs, but this is my life now. I have accepted it, and I have embraced it, and I encourage you to do the same. We are not less because of our limb loss: we are more!

Belinda was a true inspiration to all of us. My wish is to follow in her footsteps as we continue her legacy of the MOVING FORWARD Limb Loss Network and Social Group.

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QUOTE OF THE MONTH

Even though there are days, I wish I could change some things that happened in the past, there's a reason the rear view mirror is so small and the windshield is so big, where you're headed is much more important that what you've left behind.



POSITIVE OUTLOOOKS

EVERYTHING YOU NEED TO KNOW ABOUT PHANTOM PAIN (cont'd)

to talk about phantom pain, so that treatment can be started quickly. In this article you can read everything about phantom pain, the treatment, and what you can do by yourself.

1. What are phantom sensations and what is phantom pain?

After an amputation of a body part, no fewer than 80% of people experience phantom sensations, residual limb pain, and phantom pain. But what is the difference? Phantom sensations are non-painful feelings in an amputated limb, such as heat or tingling or the feeling that your fingers or toes are extended or shortened. With residual limb pain, the amputee primarily experiences pain in the residual limb, not in the amputated body part. Phantom pain is nerve pain in an absent limb.

The exact cause of phantom sensations and phantom pain is not known. One possible explanation is that the nerves in our nervous system and brain are "rewired", so that they no longer receive signals from a certain body part. Our nerves then start sending pain signals, a typical reaction when our body notices that something is wrong. It is also possible that your brain perceives contact from a certain body part - such as your hip or upper arm - with your amputated body part. It is a very odd sensation because your nerves are - literally! - confused. Incidentally, there is a link between residual limb pain and phantom pain: painful areas of the residual limb (called trigger points) can cause/trigger phantom pain and phantom sensations.

When exactly phantom sensations or pain occurs is different for every person. Some people experience pain the day after their operation, others after several years. Phantom pain often occurs in attacks of stabbing, shooting, tingling, burning or pinching pain. The duration of these attacks is different for every person: from a few seconds to several days. With most people, the extent and duration of the pain attacks decrease during the first six months after the operation.

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RECIPE OF THE MONTH

Momma's Snickerdoodles

(the perfect holiday cookie!)

1 cup butter

1-1/2 cup sugar 2-3/4 cup flour

2 eggs

1 teaspoon baking soda 2 teaspoon cream of tartar ½ teaspoon salt



Cinnamon

Sugar

Mix butter and sugar till creamy. Beat in eggs. Toss flour with baking soda, cream of tartar and salt then add to mixture.

Mix sugar and cinnamon about 4 parts sugar to 1 part cinnamon. Shape dough into small balls. Roll in sugar and cinnamon mixture.

Bake on ungreased cookie sheet in hot oven 400 degrees about 10 minutes or until lightly browned. Makes 4 or 5 dozen.



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EVERYTHING YOU NEED TO KNOW ABOUT PHANTOM PAIN (cont'd)

However, many people experience some degree of phantom pain for several years.

2. How is phantom pain treated?

Pain usually occurs in response to injury to a body part. But this is not the case with phantom pain, making this type of pain difficult to treat. Unfortunately, there is no standard approach that works for everyone. Sometimes, it is enough to simply place a pillow where the limb used to be. But phantom pain often means a long search for suitable treatment. We, therefore, recommend talking to your doctor or therapist to find the best possible treatment for your situation.

3. What can you personally do about phantom pain?

As mentioned above, phantom pain is difficult to treat. All the same, there are a number of things you can do to reduce your symptoms: Ask for help! There is absolutely no reason to be ashamed about your phantom pain or sensations. After all. almost everyone experiences this after an amputation. By sharing the problem with your doctor or therapist, you can look for a good solution together. Remember, phantom pain is real pain. So, you have every right to get help!

Certain actions or circumstances, such as touch, smoking, going to the bathroom, sex, changes in air pressure and exposure to cold, can trigger phantom pain. Have you noticed any specific triggers for your phantom pain? Let your doctor or therapist know. Together you can find the best way to deal with this in the future. Keep a diary and ask yourself the following questions:

- What time of day do I experience pain?
- Does the pain diminish when I'm active? If so, what kinds of movements make the difference?
- Do I also feel pain in other areas of my body?
- Is the pain worse on cold or rainy days?

- Do I experience more pain when I'm stressed? Write down your answers so that after a while, you will erase what should and shouldn't be

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PAST NEWSLETTER ISSUES MOVING FORWARD has been publishing newsletters since Sep 2013. To view or print previous issues, go to our website at: <u>ampmovingforward.com</u>

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EVERYTHING YOU NEED TO KNOW ABOUT PHANTOM PAIN (cont'd)

done.

Try the mirror method. Mirror therapy is often used for phantom pain. The idea behind it is that a mirror trick can affect the nerves linked to the amputated body part. By looking in the mirror, these nerves are activated, which can lead to reduced pain. Ask your doctor or therapist about this method or search for "mirror therapy" online.

Try moving your phantom foot and toes or hand and fingers. This may seem like a crazy thing to do since this part of the body is no longer there, but this exercise can stimulate the nerves in your brain. Do this exercise with your eyes closed. Since you are stimulating unused nerves, your phantom pain may diminish.

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