



## NEWSLETTER ♦ 97th Edition ♦ Sep 2021

**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*

How awesome it was to see all the faces of those who attended our first in-person meeting since February 2020!! The meeting was held at the Okolona Fire Protection District with 23 people in attendance. We had a surprise visit from Shelton Jacobi, the husband of our late founder Belinda, who was in town visiting family, from his new home in Florida. I'm sure I speak for all that we were delighted to see him!

We were so happy to see Valerie Cardwell up and about after a difficult time suffering with Covid19. We are thankful for your recovery, Valerie. Most of our time was spent hearing updates on everyone's lives and getting reacquainted. A great time was had by all.

We did spend a bit of time discussing possible plans for future meetings and events that we would like to do. Our next meeting is going to be held at Mike Linnig's Restaurant at 9308 Cane Run Road, Louisville KY 40272. This way we will be able to do a restaurant review and have our meeting as well. If you plan on attending, please contact Kelly Grey, Mike Portman, or myself, Elaine Skaggs, so that we can make reservations.

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### Managing Your Pain

Pain is a sensation that hurts. It is subjective, meaning that if you are having pain, you are the only one who can feel it and tell others about it. Only you can tell where it is, what it feels like, and if the treatment given for it has worked. Pain can make it hard for you to concentrate on anything except the pain. It can make it hard for you to sleep and hard for you to function when you are awake. It can be depressing, frustrating, and overwhelming. However, it is possible to reduce pain and to learn to cope effectively with the pain that remains.

#### Understanding Types of Pain

People with limb loss experience many different types of pain. Understanding the type of pain you are experiencing and describing it clearly can help you and your healthcare team determine the most effective treatment for decreasing your pain. These terms include:

Phantom limb sensation (PLS): This describes sensations that you might continue to feel in your amputated limb, even though it is no longer there. These sensations may include tingling, pins and needles, itching, temperature changes, pressure, abnormal position and movement. These sensations are not painful; therefore, no treatment is indicated.

Residual limb pain (RLP): This is the pain that originates in the part of your limb that remains. It can be caused by swelling, nerve damage, or irritation from your prosthesis.

Phantom limb pain (PLP): When the phantom limb sensations are uncomfortable or hurt, they are called phantom limb pain. In addition to these types of pain or sensation, there are the pains that you might have experienced before your surgery and the pain that you will experience during normal healing after your surgery.

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## EDITOR'S NOTE (cont'd)

In addition, we are considering attending the St. Luke Fall Festival on Sat, October 23, from 4:00 - 10:00 pm. We would like to go as a group, not sure whether this event will take the place of our regular meeting or not. There will be more details to come. This is one way for us to become more involved in our communities and, hopefully, continue to grow our group.

If you have any suggestions pertaining to newsletter content, don't hesitate to reach out to me. Because this is your newsletter, I want to fill it with the information and resources you need and want to know about. Thanks all & have a wonderful September!

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## QUEST STUDY UPDATE

I had many questions about the study during our *Moving Forward* meeting this past Saturday, and since there were no changes or progress to report, I am reprinting the updates from the July and August newsletters.

### July Update

In April of this year, I was recommended by my prosthetist to be considered for a clinical trial involving the use of the Altius System device designed by Neuros Medical, to reduce or eliminate post-amputation/phantom limb pain. I had to qualify to be able to participate in the study, and was required to complete a couple of tests, which included logging pain levels and frequency into an e-diary for 2 weeks, as well as receiving 2 injections into my sciatic nerve to establish a baseline pain level. I passed both of the qualifications tests, and was then scheduled for surgery. The device itself consists of a small square generator which is implanted in the belly area, mine is just above my waistline on the left side, and a wire that is attached to a cuff electrode which is placed around the sciatic nerve. The device delivers an on-demand electrical signal to the nerve to block nerve pain. I had outpatient surgery on June 4 to implant the device and the nerve cuff, and ended up with 3 incisions, one on my belly, on my left hip, and one on the back of my residual limb which prevented me from using my prosthesis for 2 weeks while the incisions healed. During the 2 weeks recovery, the device was not activated. Once it was activated, when I experience

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## Managing Your Pain (cont'd)

There are different ways of helping you manage your pain, depending on which type it is. Again, knowing what kind of pain you are experiencing makes it easier for you and your healthcare team to manage that pain – so it doesn't manage you!

### Preparing to See Your Healthcare Provider

Here are the things you should do before going to see your healthcare provider about your pain:

Write down your symptoms. When are you experiencing pain? Is it when you are wearing your prosthesis? What were you doing when the pain started? How long does it last? What have you tried to decrease the pain? Does anything help? Keeping track of your symptoms with paper and pen works great. Be sure to take your personal pain record with you to your appointment. It cannot be emphasized enough how important it is to track your pain. Tracking will likely improve your understanding of your pain so that you will become more effective in coping, and it is a very important communication tool to use with your healthcare provider to help him/her understand why and when your pain occurs.

Make a list of your key medical information. This includes any conditions that you have been diagnosed with by any of your healthcare providers and names of all the medications, vitamins and supplements you are taking. It is good practice to keep this list updated and to always bring it to every healthcare provider you see.

Take a family member or friend along. Don't leave him or her in the waiting room! Have him or her in the exam room with you. Four ears are definitely better than two when it comes to hearing your healthcare provider!

Write down questions to ask, things like: What are the treatment options? Is there anything besides medication? If medication is prescribed, ask how it works and what the side effects might be. Ask if there is a chance of addiction or dependency if you take it. You might also ask if you should see a specialist. And, be sure to ask if insurance covers it.

### Next Steps

Once you understand the different kinds of pain you may experience after amputation and have prepared for your appointment with your healthcare provider, you are on your way to managing your pain. It may take some time and patience, but with you and your healthcare provider working together, you can find a treatment plan that will work for you.

## QUEST STUDY UPDATE (cont'd)

pain, I can use a handheld device to deliver the electrical impulses to block the pain. So far the results have been limited, as I am still learning how to use the device. For the next 90 days I will be required to continue using the e-diary to report pain levels, frequency, and use of the device treatments. I also will continue to keep you updated on my progress and my results here. The goals of this study have become my goals and my hope, and that is to relieve my post-amputation pain, to improve my quality of life, and to reduce my use of pain medication.

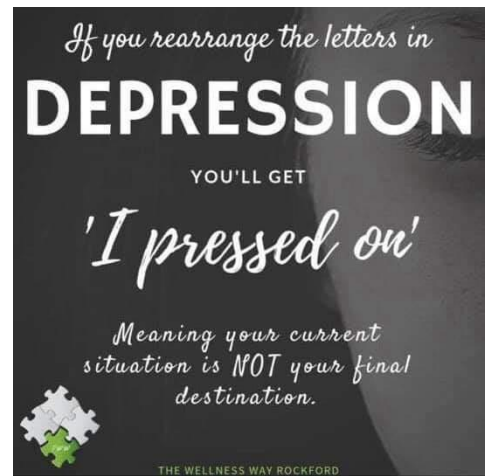
### August Update

For anyone who missed the July newsletter update, in April of this year at the recommendation of my prosthetist, I qualified to participate in a clinical trial involving the use of the Altius System device designed by Neuros Medical to reduce or eliminate post-amputation/phantom limb pain. There is not much to report for me - not much has changed. I'm adjusting well to having the implanted device, it's not as uncomfortable as it was in the beginning and I have been using it daily. However, the participants are divided into 2 study groups without any knowledge of which group they are in. One of the groups is receiving the full force of the electrical signal which blocks the nerve pain, and the other group is still feeling the impulse, but it does not block the pain. In my own mind I equate that to patients who participate in clinical trials for drugs, where one study group gets the actual drug and a second group gets a placebo or a sugar pill. Monitoring both groups is necessary to arrive at the conclusion of the viability of the drug. In this study the participants remain in their respective groups for the first 90 days, and then are switched to the other group. So far every time I have taken a treatment, the intensity of my phantom pain or sensations has not changed. Still, I refuse to get discouraged as my 90 days will soon be here when I will switch groups and hopefully see a dramatic change in the results I am now experiencing. Until then I will continue to update my e-diary reporting pain levels, frequency, and usage of the device treatments. And I will continue to update my progress and results in the monthly newsletters.

If you are interested in joining this clinical research study, they are still accepting applicants through October. Contact Leslie Haysley at 502-724-5589 for more information. Again, there is no cost for taking part in this study, and there is reasonable compensation provided for study related visits.

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## QUOTE OF THE MONTH



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## RECIPE OF THE MONTH

### NO BAKE 5-INGREDIENT PEANUT BUTTER ENERGY BITES

Loaded with old fashioned oats, peanut butter, and flax seeds. A healthy protein packed breakfast or snack!

PREP TIME: 10 MINUTES

TOTAL TIME: 10 MINUTES ~ SERVINGS: 12 BITES

#### INGREDIENTS

2/3 cup creamy peanut butter

1/2 cup semi-sweet chocolate chips

1 cup old fashioned oats

1/2 cup ground flax seeds

2 tablespoons honey

#### INSTRUCTIONS

Combine all 5 ingredients in a medium bowl. Stir to combine. Place in the refrigerator for 15-30 minutes so they are easier to roll. Roll into 12 bites and store in the fridge for up to a week.

#### RECIPE NOTES

*Original recipe from [chefsavvy.com](http://chefsavvy.com). Please do not publish my recipe or pictures without linking back to the original post. Thank you!*

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## NEWSLETTER ISSUES

*MOVING FORWARD* has been publishing newsletters since Sep 2013. For your convenience, all previous issues are available to download or print on our website at: [ampmovingforward.com](http://ampmovingforward.com).

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# Ways to Donate to **MOVING FORWARD** Limb Loss Support

## AmazonSmile

Go to "[Smile.Amazon.com](http://Smile.Amazon.com)"

Sign in or Create your account

Hover over "Accounts and Lists"

Under the "Your Account" items,

Click on "Your AmazonSmile"

AmazonSmile is a website operated by Amazon with the same products, prices and shopping features as Amazon. The difference is that when you shop [smile.amazon.com](http://smile.amazon.com), the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice!

Once you have registered, you can check back to see how much your orders have contributed to **Moving Forward**. You will know you are contributing to the group because under the search bar it will say "Supporting *Moving Forward* Limb Loss Support Group, Inc."

## Kroger Community Rewards Program

Go to:

["https://www.kroger.com/account/enrollCommunityRewardsNow/"](https://www.kroger.com/account/enrollCommunityRewardsNow/)

Click on "View Details" (this will take you to a new screen to select our group)

Enter our organization number: DC476 or, Sign in or Create your account under box "I'm a Customer"

Search for "Moving Fwd Limb Loss Support"

If you do not have internet access:

Register at the Service Desk of your local Kroger. Once you have registered, the bottom of your receipt will say that your "Community" rewards are going to **Moving Forward** Limb Loss Support Group. You can check the amount of your community rewards on their website for each quarter.

## Employer Deductions

Many employers offer employees the opportunity to have automatic payroll deductions which are donated to a charity of their choice. Some companies will **MATCH** your donation. If your employer uses Frontstream, Truist, or Network for Good to manage their deductions, **Moving Forward** is listed.

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## CONTACT INFO

MOVING FORWARD Limb Loss Support Group

Email: [moving4wdamputeegroup@gmail.com](mailto:moving4wdamputeegroup@gmail.com)

Website: [ampmovingforward.com](http://ampmovingforward.com)  
502-509-6780

Facebook: Moving Forward Limb Loss Support

Kelly Grey, President / Facebook Editor / Newsletter Staff

[kjgrey79@gmail.com](mailto:kjgrey79@gmail.com) ● 502-235-3146

Elaine Skaggs, Vice-President / Newsletter Editor  
[elaineskaggs@ymail.com](mailto:elaineskaggs@ymail.com) ● 502-548-6419

Julie Randolph, Secretary / Newsletter Producer  
[jbrsweepea@yahoo.com](mailto:jbrsweepea@yahoo.com) ● 812-557-3970

Mary Jo Kolb, Treasurer  
[mjk2you@gmail.com](mailto:mjk2you@gmail.com) ● 502-727-9566

Mike Portman, Board-Member-at-Large  
[mdportman712@gmail.com](mailto:mdportman712@gmail.com) ● 502-262-8344

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MOVING FORWARD Limb Loss Support Group  
Newsletter CORPORATE SPONSORS:



### R. Wayne Lockett, L.P., L.Ped.

1404 Browns Lane, Suite C  
Louisville, KY 40207  
Phone: 502.895.8050  
Fax: 502.895.8056

742 East Broadway  
Louisville, KY 40202  
Phone: 502.584.2959  
Fax: 502.582.3605

Web: [www.louisvilleprosthetics.com](http://www.louisvilleprosthetics.com)



### Chris Lockett, C.P.

1404 Browns Lane, Suite C  
Louisville, KY 40207  
Phone: 502.895.8050  
Fax: 502.895.8056

742 East Broadway  
Louisville, KY 40202  
Phone: 502.584.2959  
Fax: 502.582.3605

Web: [www.louisvilleprosthetics.com](http://www.louisvilleprosthetics.com)



### Bruce Lockett, L.P.

1404 Browns Lane, Suite C  
Louisville, KY 40207  
Phone: 502.895.8050  
Fax: 502.895.8056

742 East Broadway  
Louisville, KY 40202  
Phone: 502.584.2959  
Fax: 502.582.3605

Web: [www.louisvilleprosthetics.com](http://www.louisvilleprosthetics.com)

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**KENNEY**  
**ORTHOPEDICS**  
PROSTHETICS & ORTHOTICS

BRYAN SWINT, CPO/L  
ORTHOTIST/PROSTHETIST  
BSWINT@KENNEYORTHOPEDICS.COM

2809 N. HURSTBOURNE PARKWAY • SUITE 111 • LOUISVILLE, KY 40223  
PHONE 502-882-9300 • FAX 502-882-8375

WWW.KENNEYORTHOPEDICS.COM



**KENNEY**  
**ORTHOPEDICS**  
PROSTHETICS & ORTHOTICS

DONNA HINNANT CP, LPO  
DHINNANT@KENNEYORTHOPEDICS.COM

2809 N. HURSTBOURNE PARKWAY • SUITE 111 • LOUISVILLE, KY 40223  
PHONE 502-882-9300 • FAX 502-882-8375

WWW.KENNEYORTHOPEDICS.COM

**Kentucky Prosthetics & Orthotics**  
1169 Eastern Parkway Ste. 4423  
Louisville KY 40217

502-585-4228

Lending A Hand LLC  
Keeping Limbs And Lives Safe In The Workplace

Billy Parker  
Owner/Keynote Speaker

PO Box 91721  
Louisville, KY 40291  
502-415-2504

rlendingahand@gmail.com

Facebook & YouTube: BillyPAmputee

