



MOVING FORWARD

LIMB LOSS SUPPORT GROUP

NEWSLETTER

5th Edition – January 2014



MOVING FORWARD

FEATURE ARTICLE

**An Editorial by Terri Ross, President,
Paducah Area Amputees In Action, Inc.**

NOTE: I asked Terri to write this editorial about the fight for prosthetic parity, because it is about an issue that is important to all of us. As I have said before, if something affects one of us, it affects us all, because we are a support "group". This story really hits home for me, because I had one of the high deductible insurance plans that set a ridiculously low cap on what they would allow for the purchase of a prosthetic device. I am an Indiana resident, but my insurance was through my husband's place of employment, which is in Kentucky. No one should have to endure this added emotional and financial burden because of the loss of a limb. I ask you to read Terri's words and join in the fight to provide prosthetic parity for everyone.

*--by Belinda Jacobi/President,
MOVING FORWARD Limb Loss Support Group, Inc.*

"Last January, I was at work when I received an unexpected phone call. It was one of my prosthetists, who is also a member of the Kentucky Orthotics & Prosthetics Association and has been very active in working toward Insurance Fairness or Prosthetic Parity in Kentucky. She told me House Bill 376 had been introduced into the House of Representatives and would be heard in the House Insurance and Banking Committee the next morning at 9am. Could I be there and would I testify before the Committee, telling my story and why it meant so much to me to pass HB376?

I was more than a little surprised to receive the call, repeating the question out loud, so I could make sure I heard her correctly and also so my boss could hear what she was asking me. He nodded yes, agreeing that I could take the time off to go. I told her I would be there, she told me she'd call back shortly with more details and hung up. Things were happening so fast in Frankfort, she didn't have time to fill me in on the details until later that evening.

Why was I one of the group chosen to testify before the House Committee, you might wonder, out of all the amputees in Kentucky? One of the biggest reasons is because I have been very active in the Amputee Coalition's Grassroots Campaign for prosthetic parity in the past. I have called the AC, asked questions about things I want to know, sent them emails and several AC Conferences. They, the staff take notice of people who are interested in learning more and I was asked to attend on grassroots advocacy training. A group of people from across the country participated in this monthly conference call/online training. This helped prepare and educate me about grassroots advocacy and how other states were able to pass Prosthetic Parity Laws, now called Insurance Fairness Laws and why some states, including Kentucky had introduced Bills

– Continued on Page 2 Column 1 –

AMPUTEE COALITION ADVICE

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Update! The Affordable Care Act

by Dan Ignaszewski

The Affordable Care Act (Obamacare) was passed in 2010, and was upheld by the Supreme Court in 2012. While several provisions have already been enacted, we are now entering the time when several of the law's key provisions go into effect – including the individual mandate to have health coverage. This article will help to provide guidance and information on what changes will be coming, and what it will mean to you as a member of the limb loss community.

The healthcare law requires that all people must have minimum essential coverage beginning January 1, 2014. People will have "minimum essential coverage" if they choose to select a government-sponsored plan, an employer-sponsored plan or an individual plan. In order to help provide more affordable options, people will be able to buy health insurance on or off a state insurance exchange or marketplace.

If you currently have insurance, you can keep it, but you may need to check to ensure it meets minimum requirements to avoid the tax penalty. If you have an employee-sponsored health plan, you will still be able to keep your plan (unless your company/organization elects to stop providing coverage, in which case you will be able to purchase in the marketplaces). If you currently have Medicare, your plan options will largely remain unchanged.

What is a state exchange/marketplace?

The law required that insurance "exchanges" or insurance "marketplaces" be set up in each state for individuals to buy health insurance from private healthcare providers who will compete to cover them. Shoppers will be able to find the best deal for them and their family from eligible plans that participate in the marketplace within each state. These exchanges are estimated to provide up to 30 million people with affordable health insurance by 2019.

Tax penalty if you elect to not have insurance:

2014 - \$95 per adult, \$47.50 per child (up to \$285 per family) or 1% of annual income, whichever is greater

2015 - \$325 per adult, \$162.50 per child (up to \$975 for a family) or 2% of annual income, whichever is greater

2016 - \$695 per adult, \$347.50 per child (up to \$2,085 for a family) or 2.5% of annual income, whichever is greater

– Continued on Page 2 Column 2 –

Editorial by Terri Ross (cont'd)

in the past, but failed to pass them. What is grassroots advocacy? It is when people like you and me become active in a cause that is important to us. In this case, we are actively advocating for Insurance Fairness Bill 376 to be passed so technologically advanced prosthetic limbs, sleeves, liners, feet, sockets and any other parts and adjustments will be included in every healthcare plan in KY. The deductibles cannot be outrageous, they can't limit you to one limb per lifetime, nor can they refuse you coverage because of your pre-existing condition. It just makes sense and any amputee, new amputees, children born with congenital limb difference, people with multiple amputations will be able to function, thrive and survive!

Although we passed House Bill 376 through the House Insurance & Banking Committee without a hitch, the Bill went to the wrong committee, stalled and never made it to the Senate Insurance & Banking Committee before the short 30-day session ended last January.

When the Bill was introduced several years ago in Kentucky, no one rallied to support the Bill, called their Representatives to encourage them to vote for it and let them know it was important to them and it fell flat and went away without anyone even really noticing it.

We're hoping to see House Bill 376 brought up again in 2014 before the House and expect it to go through again, but we need your support! If our Representatives and Senators think we're not paying attention, they can easily vote it down or change the Bill to add things other people want, "porking it up" and we don't want or need that to happen.

KY is surrounded by states that have Insurance Fairness bills. Indiana, Illinois, Tennessee and Missouri all have insurance fairness, but Kentucky doesn't! When HB376 is brought before the Insurance & Banking Committee, we need your support by emailing your Rep, calling them and having your stories to show them why we need Insurance Fairness in Kentucky! We will keep you informed when the Bill is brought up and ask you to help us by calling and emailing to let your Representatives know you support passing it through their Committee. When it passes through the House, and I feel confident it will, we'll need your support when it reaches the Senate.

To help us get our Representatives attention, we need to show them this Bill is top priority for the citizens they represent and should be heard when they are in session. Please share your stories with me if your insurance company has denied you any type of prosthetic device. If you have tried to get new liners, sleeves, vacuum system prosthetics recommended by your prosthetist or any type of foot, any story, we need and want to know about it. If you can and would be willing to come to Frankfort to testify or just sit with us to show your support when the Bill is brought up for vote, please let me know and give me your contact information. We are working for you, for us, for every amputee in Kentucky. We'd love to have you become a part of our team to advocate for yourself and your peers.

You can send your stories to me at:

TerriDuleyRoss@gmail.com. To help you keep up with what's happening with House Bill 376, you can like our Facebook page, Kentucky Prosthetic Parity House Bill 376. It is very important to document your stories for our elected Representatives and Senators to hear why House Bill 376 is important to us, as amputees. They have to know we need it passed, we want it passed and it makes a difference to us that they pass this Bill. When we were calling to get the Bill through the House last January, I realized the people who take messages for our Representatives write down everything you

– Continued on Page 3 Column 1 –

Update! The Affordable Care Act (cont'd)

The state marketplaces are different in each state. Before 2013, each state was given the task of building/designing their own plan that would follow the new regulations and provide selected categories of Essential Health Benefits (EHB) to beneficiaries. The District of Columbia and 16 states took this route and designed their own marketplace. Seven states elected to run their exchange in partnership with the federal government, & 27 states did not set up a marketplace & therefore defaulted to the Federal Marketplace.

Each state was given criteria & requirements by the law & the Department of Health & Human Services when setting up their plans, which they had to follow. The Amputee Coalition worked with states as well as partners & coalition members to stress the importance of including prosthetic & custom orthotic benefits in their EHB's. The reason this is important is that if a benefit is deemed an EHB, then that benefit would not be allowed to be subjected to caps.

Unfortunately, many states did not explicitly include prosthetic devices in their EHB's; however, nearly every state appears to have at least some level of coverage for prosthetic care. It is very important that if you're interested in participating in your state's insurance marketplace, or when evaluating any other insurance plan options, that you confirm the level of coverage for not only prosthetic care, but any other healthcare needs you may have.

Essentially, the health insurance marketplace is a new way for you to find health coverage options that fit your budget & meet your needs. Within the marketplace, you'll be able to see all of your options & enroll in the plan that best suits you. Additionally, you may be eligible for discounts & tax credits that will help to cover the cost of your plan.

Enrollment for the health insurance marketplace began on October 1, 2013, so be sure to look at all available options today! If you have questions about the health insurance marketplaces, & would like to speak to someone about your options & to help you navigate your marketplace, you can contact the help center toll-free at 800-318-2596, TTY: 855-889-4325. You can also go online to Healthcare.gov & click on "Get Insurance" for coverage options in your state & to find out more about the marketplaces.

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## RECAP OF DECEMBER



On Sunday, December 15<sup>th</sup>, *MOVING FORWARD* held a Christmas party at the Okolona Fire Station. We had a wonderful time with great food, games for both adults and children, and an appearance by Santa who gave a gift to each of the children. It was a joyful way to close out our first full year as a support group!

## Editorial by Terri Ross (cont'd)

ask them to when you call to plead your case for a Bill. There are many different phone lines, different volunteers and I called dozens of times, had my mom, sisters, friends, cousins, Facebook friends, anyone who knew how important this Bill was to me and how much time I dedicate to making things better for all of us to call and ask our Representatives to vote Yes on this Bill. When you tie up the House phone lines, Representatives want to know why all the lines are busy. They are told people are calling about Bill 376 for Prosthetic Parity. I would tell the sweet lady taking the message this Bill was important to me because my leg is currently grouped in the same insurance category as durable medical equipment. I also told her DME also includes wheelchairs, bedside commodes, walkers and canes. (Medicare has decided these items called Durable Medical Equipment should all be grouped in one big pile, alone with prosthetic limbs, so many insurance companies just follow Medicare's lead and therefore, you are allowed ONE PER LIFETIME! That just doesn't sit well with me, in fact, it really makes me mad!) I would follow up with the Amputee Coalition's slogan, "Arms & Legs Are Not a Luxury!" The sweet lady would read it all back to me to make sure she got my message for my Rep correct and I would thank her for her time and being so kind to take all of my message down correctly and I would hang up and call another Representative while I was emailing the Representative I had just telephoned or texting my friends to be sure and call before our meeting so they would know we really wanted this Bill passed.

It is important for not only us, but for all future amputees and maybe even our own family members, who may have congenital limb differences, disease or accidents. As you may know, approximately 507 people lose limbs every day in the United States. There are over two million amputees in the US and the cost of one prosthetic can be overwhelming for many people, causing them to give up on walking and or working. With Insurance Fairness, more people will be able to receive good prosthetic care and prosthesis and possibly return to work to support their family, instead of relying on assistance. Many people are willing and able to work, but the cost of prosthetics and stress of trying to pay large co-pays out of pocket makes it impossible for them to ever reach their goals of becoming financially independent. Eliminating large co-pays and ensuring a prosthetic limb matched to a person's ambulatory capabilities will help more amputees to get off the couch and out the door to live their lives once again as happy, independent, productive citizens. I think that, as an amputee, that has been my goal and I hope to be able to see every Kentucky amputee receive their deserved prosthetic and reach their own personal goals, whether they want to run marathons or go to the grocery store.

As you can see, I am very passionate about House Bill 376 and Insurance Fairness for amputees. This is not only a personal issue for me, it is a heartfelt issue. I have insurance and have been able to receive the prosthetic care I need, but to see so many people who are unable to walk or use their arms because they simply cannot afford to meet the copay for a prosthesis is heartbreaking for me. While attending a Limb Loss Education Day in Orlando in October focusing on Grassroots Advocacy, I heard a story of a young man and his family who were selling Krispy Kreme donuts as a fund raiser to help purchase his prosthetic limbs. This story was told by NFL Hall of Famer, Joe Delumamielleure. As he told this story, I was sitting only a few feet from him and tears spilled from my eyes, thinking of this boy and his family trying to raise \$120,000 for his two prosthetic legs he needed after growing out of his old ones. I couldn't stop the tears, just rolling down my cheeks, knowing how fortunate I am to have a prosthesis

– Continued on Page 4 Column 1 –

## UPCOMING EVENTS

**Sat., Jan. 25<sup>th</sup>** - Our first meeting of the New Year will be held from 2:00 - 4:00 at Baptist Hospital East in the Education Center Room 2G.



Other events being planned include a bowling outing, a chili supper, a health fair, and various sport clinics.

If you would like to help with any of these or have other ideas for events, please contact us. We are also finalizing plans for our "Care Packages".



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SPOTLIGHT

This month we are shining the spotlight on our newsletter editor:

Name: Julie Randolph

Hometown: Charlestown, IN

Have you always lived in the Charlestown area? I moved here from Wisconsin when I was 27 & have lived in Jeffersonville, Clarksville, New Albany, Sellersburg, & now Charlestown.

How many children do you have and their ages? I have 3 children: Joy is 30, Philip is 26, & Melissa is 18 & they are all living with me right now.

What are your hobbies? I like reading, bicycling, keeping in touch with family & friends via email & Facebook, flea markets & antique malls, and of course, working on this newsletter.

Where do you currently work and past jobs? I work in the office at A Nicer Reflection Cleaning & Restoration, Inc., in Sellersburg for going on 12 years (water & fire restoration, carpet & air duct cleaning, etc.) Before that I have worked at United Brokers (commercial insurance), Papa Johns corporate retail accounting, Thornton Oil corporate retail accounting, UPS Air District key entry, & Discount Labels as a proofreader & typesetter.

How, if any, has the support group helped you? It has given me a new purpose & ways to serve & given me new friends & activities.

What do you like most about the group? I really enjoy the camaraderie that we have at the meetings & events, & I love to learn how we can better meet the amputee's needs.

What has been your favorite activity so far? the Riverbats baseball game

Do you have any ideas for future activities? I think the health fair being talked about will be an awesome help to the amputees, caregivers, & guests.

If you could give one piece of advice to parents of a child with limb loss what would it be? Don't baby your child or do things for them that they can do for themselves. Let them do as many daily activities as possible on their own so they can grow up to live as normal a life as possible. Also, talk things out with your child often so that they understand how & why things work the way they do. And, above all, love your child unconditionally.

Editorial by Terri Ross (cont'd)

and feeling so mad and even more determined to not quit until every child, woman and man is treated fairly, not discriminated against by insurance companies for something we cannot change. I felt I owed Joe an explanation for silently sobbing during his talk and did explain myself after he finished his presentation and I got myself together. Joe is a very nice man. He actually walked across the state with the support of his NFL buddies to help this young man get his prosthetics.

We can change this if we join together and tell our elected officials that indeed, "Arms & legs are NOT a Luxury!" We deserve to walk and hug our loved ones, just as we did before limb loss. Insurance companies should not have the right to make the decision if we are able to receive prosthetics for us, because they are out of financial reach for so many people."

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## 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](mailto:belindajacobi@yahoo.com) or by calling 812-620-3694.

I submitted two questions to several group members this month:

1. What, if any, goals or New Years Resolutions are you making for 2014?
2. What goals would you like to see the group achieve in the coming year?

I have never been one to make New Years Resolutions, but since becoming an amputee I have come to realize that it is important to occasionally set goals for myself to keep myself moving forward and not falling back. It is good to challenge ourselves sometimes just to see what we can accomplish if we push ourselves a little bit. For each of us this will be something different. For one it may be to move from a wheelchair to a walker, for another it may be to be able to go fishing with his grandson, and for yet another it may be to run in a 3K. Each of us are at different stages of recovery and have different capabilities, but if we never set goals for ourselves, never challenge ourselves; we stay as we are and may never realize just how much more we can achieve.

These are the responses that I received from the group:

Mike's goals for 2014 are to lose weight and to be able to walk more normally or improve his gait. For the group, he would like to see us do a really large event to get some media attention so that more people can find out about *MOVING FORWARD*.

Philip's goal is to improve his gait also, and for the group would like us to have a bowling outing and a costume party.

Julie, Philip's mother, has made a resolution to organize her bedroom & to start bicycling again. She would like to see us make & distribute the "Care Packages" to as many amputees in the area as possible. She would also like to see the group continue

- Continued on Page 5 Column 1 -



## TEST YOUR KNOWLEDGE

Unscramble these words and then use the letters in the parentheses to finish the sentence. You can find the answer at the bottom of PAGE 5.

TOLURSENSOI ( ) \_\_\_\_\_

ASLOG \_\_\_\_\_ ( )

PTSSAIINOA \_\_\_\_\_ ( ) \_\_\_\_\_ ( ) \_\_\_\_\_

GPDEESL \_\_\_\_\_ ( ) \_\_\_\_\_

MNBSIOATI \_\_\_\_\_ ( ) \_\_\_\_\_ ( ) \_\_\_\_\_

These words are all \_\_\_\_\_ and are what many of us make at the beginning of the New Year.

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QUOTE OF THE MONTH

Though no one can go back and make a brand new start,
anyone can start and make a brand new ending.

--by Carl Bard

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## In memory of Allan Jones 12/11/1947 - 12/18/2013



## Q & A (cont'd)

to reach out to our community & see us continue with our plans to hold a health fair with as many professionals and vendors as possible represented, offering information & demonstrations that will help amputees, caregivers, and guests.

Kelly, who has been an amputee since childhood, has a financial goal. She wants to be debt free by the end of 2014, except for her mortgage. She would like for the group to really focus on the "Care" Packages and building more relationships with members and organizations.

For Genny, her goal is to get her strength back in her legs to walk if it is just to walk on a walker. She is already working toward achieving that goal by going to Frazier Rehab in Bardstown 3 times a week. She says that it has been really successful.

The goal that Sam has set for 2014 is to try to have a more positive outlook in life. As for the group, he thinks we are on the right track and should continue what we are doing. Sam says, "Since being a part of *MOVING FORWARD*, I have seen friendships started and have noticed members being an inspiration to others. I would like to see the group raise money and continue to plan various activities for the current members and to attract new members. I hope to see the group organize a health fair for this Spring."

My personal resolution this year is to start exercising again on a regular basis. I love to exercise and feel much better both physically and emotionally when I do, but with my busy lifestyle, exercise is the first thing I cut when I am short on time. Before losing my leg, my husband and I used to go on long walks together. We haven't done that for quite some time now, not only because of my physical abilities but because of time constraints. My goal is to get back to taking those walks.

As for the group, my goal is for us to find ways to reach out to all the amputees in our area. I want them to know that our group is here for them to provide them with emotional support and information to help them to improve their quality of life. My long range goal is for our group to have satellite groups in our surrounding counties in both KY and IN. Many people aren't able to come to Louisville to attend a monthly meeting. My hope is that we can start meetings in their communities and come together for special events.

— by Belinda Jacobi

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

## TEST YOUR KNOWLEDGE ANSWER (from Page 4):

RESOLUTIONS, GOALS, ASPIRATIONS, PLEDGES, AMBITIONS

These words are all S I M I L A R and are what many of us make at the beginning of the New Year.

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-- Edited by Julie Randolph

