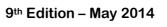


MOVING FORWARD

LIMB LOSS SUPPORT GROUP NEWSLETTER





Stroke Awareness Month



MOVING FORWARD

FEATURE ARTICLE Challenges

– by Sam Gaylord

When thinking about a writing topic, I decided to write about something that we all have in common ----CHALLENGES. Life has thrown us all challenges. What we do with them is up to each one of us.

One of my earliest big challenges was becoming a double amputee after becoming severely wounded in Vietnam. I enlisted in the United States Marine Corp and they sent me to Vietnam. I came home as a double amputee. As an 18-year-old young man, I had a huge challenge. At first, I felt as if I could not go on living. But, I eventually came to terms with being an amputee and decided that I did not want to be identified as an amputee. I wanted to succeed in life. But, that was not enough. I wanted to succeed as a "normal" person. I did not want being an amputee to prevent me from living the life that I wanted. After my legs healed and I had my prosthetics, driving and dating was important to me. I was determined to drive without any assistance. Early on, I was very nervous how the girls would feel about being around me. Would they think I was "weird"? I was not ashamed of my prosthetics. But, I also did not want people to stare and feel sorry for me. I did not want pity. I was consumed with having the life that I wanted. I didn't want someone to give it to me. I wanted to earn it like everyone else.

Later in life, actually a lot later, I realized not wearing shorts and not wanting the public to see me wearing my prosthetics was my own "hang-up". Most of the time, when someone sees me wearing my prosthetics, they aren't staring. If they are looking, they are usually not feeling sorry for me, they are usually impressed that I am playing golf, walking up steps or stepping out of the driver seat of my car after not using any handle controls for assistance. And, when those few do stare, who cares? I cannot allow them to stop me from living my life, even if it is "weird".

When we are living life to the fullest, as an amputee, we cannot forget to take care of ourselves. We must stay as healthy as possible. This may mean something as simple as changing a stump sock after you hit the golf ball off the 8th Tee on a hot summer day. This could mean keeping a close eye on your stumps, especially after you have gotten new

- Continued on Page 2 Column 1 -

May is Stroke Awareness Month Important Information from the **National Stroke Association**

It is important to recognize stroke symptoms and act quickly.

Common stroke symptoms seen in both men and women:

- Sudden numbness or weakness of face, arm or leg - especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause

Women may report unique stroke symptoms:

- Sudden face and limb pain
- Sudden hiccups
- Sudden nausea
- Sudden general weakness
- Sudden chest pain
- Sudden shortness of breath
- Sudden palpitations

Call 9-1-1 immediately if you have any of these symptoms

Every minute counts for stroke patients and acting F.A.S.T. can lead patients to the stroke treatments they desperately need. The most effective stroke treatments are only available if the stroke is recognized and diagnosed within the first three hours of the first symptoms. Actually, many Americans are not aware that stroke patients may not be eligible for stroke treatments if they arrive at the hospital after the three-hour window.

If you think someone may be having a stroke, act F.A.S.T. and do this simple test:

F-FACE: Ask the person to smile. Does one side of the face droop?

A—ARMS: Ask the person to raise both arms. Does one arm drift downward?

- Continued on Page 2 Column 2 -

Challenges (cont'd)

prosthetics. Your stumps should never hurt. A little soreness can lead to a blister or a callous. These can become serious. Staying healthy also means being up to date with your preventative health care. Through a lot of research, I have learned that wearing prosthetics can cause high blood pressure. A person does not always have a symptom of the high blood pressure. I used to think a person would have a headache. Sometimes this is true, but not always. High blood pressure may lead to suffering a stroke. I know this from experience. This was my 2nd big challenge. What a big one it was and still is at times. But, by the grace of God, I have been able to overcome in some areas and keep pushing on in life.

Determined to be more than the U.S. Government wanted me to be, I attended Hotel Management School and managed Hillside Inn in Madison, Indiana. Later, I owned and operated Donut Inn in Sellersburg, Indiana. Helping other veterans, I worked with the Veterans Administration. I worked and retired with the Disabled American Veterans as a National Service Officer. During all this time, I married, had 2 children and divorced. I have remarried and I now have 8 grandchildren.

SPOTLIGHT

This month our spotlight shines on the Vice-President of MOVING FORWARD, Sam Gaylord. Along with writing our feature this month, Sam has written a little extra so that our readers can get to know him better:

- 1. Before joining the U.S.M.C., I was a lifeguard at Hanover Beach in Hanover, Indiana.
- 2. I was a member of the Civil Air Patrol.
- I love Starbucks' mocha with extra, extra whipped cream.
- 4. Dan Rather interviewed me in Hue City, Vietnam, in 1968.
- 5. I received the Silver Star and the Bronze Star with Combat "V" for valor. I am a proud retired United States Marine.
- 6. I am a published author.
- The Vietnam Veterans of America awarded me with the Service Representative of the Year Award in 2012.
- 8. I have an addiction to cheese.
- 9. I do not like baseball. But, I do like fishing.
- 10. I love golf, am a big fan of Indianapolis Colts football and Indiana Hoosiers basketball. By the way, Coach Bobby Knight did NOT throw the chair!!



"Being challenged in life is inevitable, being defeated is optional." -- Roger Crawford, Motivational Speaker

Stroke Awareness Month (cont'd)

S—SPEECH: Ask the person to repeat a simple phrase. Is their speech slurred or strange? **T—TIME:** If you observe any of these signs, call 9-1-1 immediately.

NOTE THE TIME WHEN ANY SYMPTOMS FIRST

APPEAR. If given within *three hours* of the first symptom, there is an FDA-approved clot-buster medication that may reduce long-term disability for the most common type of stroke.

Learn as many stroke symptoms as possible so you can recognize stroke as **FAST** as possible.

"Understanding the warning signs is important because there are treatments we can give for stroke. If you understand the warning signs and get to the hospital quickly we can even possibly reverse the stroke itself," says Dr. Dawn Kleindorfer, assistant professor of neurology at University of Cincinnati School of Medicine.

Related Resources

- The Hazel K. Goddess Fund
- National Women's Health Information Center
- <u>National Institute of Neurological Disorders and</u> Stroke (NINDS)
- Family Caregiver Alliance

LET'S GET MOVING!

This exercise will help with balance, muscle strength, and improve your gait. To have a good gait, you need to achieve equal knee flexion from both legs. Sometimes as amputees, we don't bend our knees properly or lift our feet, which can lead to stubbing our toes and falling. It is best to have someone stand alongside you when you perform this exercise in case

you lose your balance, or you can do it beside a long table or a kitchen counter until you get steadier on your prosthesis. So let's get moving!





Forward Cup Walking

Forward Cup Walking:

Place 5 to 10 plastic cups approximately 12 – 18 inches apart. Starting at one end of the row of cups, slowly raise the leg when stepping forward so that the knee is waist high, or so that a 90 degree angle is formed at the hip, & then slowly return the foot to the floor as you step over the cup.

Paper cups are also a good choice to use in place of plastic as they crush more easily if stepped on.

RECAP OF APRIL

With April being proclaimed "National Limb Loss Awareness Month" by the Amputee Coalition, the group wanted to show our

support of those with limb loss in our community. On April 10th Kelly, Colleen, Reid, and Belinda delivered 29 Care Packages to Kosair Children's Hospital to be distributed to children with limb loss or limb deficiency. While there, the group met with Lauren Davis, Marketing Manager, and toured the Child Life and Rehabilitation Departments; as well as meeting some of the doctors, nurses, and physical therapists who work with the children there. Kelly brought along a publication that was from her stay in the hospital when she was a child, and it included two pictures of herself while a patient there. The group members got to speak to nurses who took care of Kelly during her stay at Kosair. Colleen wanted to bring Reid along so that the nurses could see how well he has recovered in the past

2 years since his accident. It was nice for the staff to see both Reid and Kelly, because they each have successfully recovered from their limb loss due, in part, to the excellent care they received while patients at Kosair.



On April 15th, Mike, Kelly, and Belinda delivered 24 Care packages to the VA Hospital to be distributed to the veterans in the Amputee Clinic. The group met with Rhonda Parero who is in Volunteer Services, Dr. Haustein from the Amputee Clinic, Cathy Sandrella, a Physical Therapist, and Doug Smith, the head prosthetist. The group members discussed ways that MOVING FORWARD could be of service to the amputees there. It gave us all a wonderful feeling knowing that our support group was doing something to honor these men and women who have given so much for our nation.

The Amputee Coalition designated April 25th as "Show Your Mettle" Day. The definition of "mettle" is one's courage or strength of character. commemorate the day, along with having our monthly meeting the group held a dinner at Tumbleweed on River Road. We enjoyed a delicious taco buffet and had a special time talking and spending time with each other. Following the meal, our President, Belinda Jacobi, spoke and told of the accomplishments that the group has made in the past year and introduced the speaker for the event, Joe Riffe. Joe, also known as the "prosthetic medic", told the group of how he lost his leg due to injuries after falling 110 ft. from Tioga Falls while hiking with friends. He went on to tell about his struggle to get his insurance company to pay for the type of prosthetic leg that he needed to get back to his job as an EMT. Joe is now a strong advocate for insurance parity for amputees and has been a quest speaker at Stanford University. It was a very inspiring message, and we were honored that he agreed to speak to our group.

UPCOMING EVENTS

Sat., May 17th – Kenney Orthopedics and Brownsboro Hospital are hosting an Amputee Walking School and have invited our members to participate. From 9AM - Noon there will be clinical training for health care workers to learn new skills to assist them in their work with amputees.



From 1PM - 3PM the health care workers will work with amputees using these new skills. There is no charge for amputees and family members and lunch is provided. Amputees may attend the whole day or just come for the afternoon session. Whole day attendance is recommended, because the amputees can benefit greatly from the clinical training given in the morning session. The Amputee Walking School is being held at the Norton Orthopedic and Hand Research Center Auditorium (on the 1st Floor), 9980 Angie's Way, Louisville. If you would like to attend, contact them as soon as possible by calling 502-882-9300. The instructors for the school are Dennis Oehler and Todd Schaffhauser. Both are past gold medalists in the Paralympic Games and have more than 25 years' experience working with amputees. This is a great opportunity for the amputees to develop skills that will improve their function and return to a more active lifestyle with increased independence.

Sat., May 24th - MOVING FORWARD will hold its monthly meeting from 2 - 4:00 at Baptist East in the Education Center Room 2B. There will be a special guest speaker, Neil Brown. Neil is a motivational speaker and author, and has just released a book entitled Standing Tough. He awoke with a sore throat one morning and two weeks later was in a coma fighting for his life. He is now a bilateral transtibial and partial hand amputee. Neil is a retired firefighter and EMT, an avid motorcycle rider, is attending college to become a physical therapy assistant, practices Gracie Jiu Jitsu (a type of martial art), and has an online blog entitled "Two Feet Shorter". Since becoming an amputee, he has devoted much of his time to being an advocate for amputee care. Please plan on attending, because this is sure to be a very interesting and motivational meeting. Neil will have copies of his book available for purchase and signing, if you would like to purchase one at the meeting.

Fri., June 13th - Members of the group will be attending a Louisville Bats baseball game at Slugger Field in Louisville. The Wounded Warriors softball team will be playing an exhibition game at 5:00 prior to the Bats game. There will be fireworks after the game. The ticket price is \$10.00. UPS is having a children's book drive at this game, so if you bring a children's book to

donate you will receive a coupon for a free hot dog and soft drink. If you would like to attend with the group, please contact Belinda.

June 28th – This monthly meeting will feature a "Chair Yoga" demonstration by Missy Eldridge, PTA. Yoga reduces stress and improves strength and flexibility. Chair Yoga is a gentle style of yoga you can do from a

- Continued on Page 4 Column 2 -

Reflections by Belinda

The following is an excerpt from my introductory speech for our "Show Your Mettle" Dinner. I wanted to share it with those of you who were unable to attend. I thought that I would just take a moment to reflect on what MOVING FORWARD has accomplished since this time last year.

Sometimes, as we know, it gets hard not to get discouraged when the turnout at a meeting isn't what we had hoped it would be; and last April, I must admit, I was worried when only 5 people showed up for our monthly meeting. It was then that we decided that we were either going to fail, or we were going to have to step up and take it to the next level. We began the process of incorporating, filing for our not-for-profit status, and electing officers. That process took a great deal of time and effort, and was a learning process for all of us involved.

Since that time, we have worked to get the word out about MOVING FORWARD and have made great progress. I did an attendance count of our meetings and events since this time last year. Our total attendance for meetings and events was 367. Our largest attendance was 49 for our bowling event, followed closely with 41 in attendance for the Christmas party. Our average attendance for our monthly meeting was 15.

We realized that we needed to do more to reach out to amputees, and that is when Mike started our website, Kelly started a Facebook page for the group, and Julie and I started the newsletter. I asked Kelly this week how many people had joined the Facebook group. Her response was 70 people from 4 countries, and 13 states. Julie and I did a count for the newsletter, and it is now going out to 111 individuals & businesses. Some of those businesses then make copies and distribute them, so it goes even further Mike, Kelly, and I went to the AC from there. conference last summer and received our peer visitor certification while we were there. I have been called on to visit 11 amputees. Mike and Kelly have also done peer visits. A peer visit can make a huge difference for someone facing an amputation, or someone who is a new amputee. Meeting someone who has lost a limb or limbs and has been able to recover and have a fulfilling life can help to relieve some of the fear of the unknown for new amputees.

Last but not least, this month members from our group delivered 29 Care packages to Kosair Children's hospital for children with limb loss or limb deficiency and 24 to the VA Hospital for the Amputee Clinic. The children's packages contained a stuffed animal, craft items, a book about a bear that was born with a limb deficiency, and info for the parents or caregivers. The VA packages included first aid items, snacks, playing cards, and brochures from the AC. This was our group's way to show our support and let them know that we are here for them to assist them in any way that we can.

So I think you will all agree, we can proclaim this has been a very successful year for MOVING FORWARD.

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UPCOMING EVENTS (cont'd)

seated position that incorporates the breathing and mind and body benefits of traditional yoga. This is a wonderful opportunity for not only the amputees in our group, but also the caregivers to learn about the health benefits of yoga.

Special Note A Spring Yard Sale is being planned for May 31st, so if you have any items to donate please contact Belinda to arrange for pickup of the items.

A & Q



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.

This month's Q&A is a little different. When talking to amputees, I have found that one of the issues that they face is understanding the terms associated with limb loss or amputation. It is comparable to learning a foreign language. To be able to effectively communicate with your prosthetist and physician, it is important to know the terminology, so I am going to attempt to go over some of the basic words and abbreviations that we as amputees need to know. I can't stress enough, though, that if you don't understand something that your physician, physical or occupational therapist, or prosthetist tells you; LET THEM KNOW. You should always feel free to ask them questions and to have them repeat things that you do not understand. As amputees, we are bombarded with so much at one time that it is perfectly normal to feel confused or intimidated by it all.

First, we will cover some of the types of amputations and limb deficiencies and their abbreviations. Relax, I promise there won't be a quiz at the end of this article. :)

 $\underline{\text{AE}}$ – is an above-the-elbow amputation: also known as transhumoral or through the humerus bone

<u>AK</u> – is an above-the-knee amputation: also known as transfemoral or through the femur bone

<u>BE</u> – is a below-the-elbow amputation: also known as transradial or through the radius bone

BK – is a below-the-knee amputation: also known as transtibial or through the tibia bone

<u>UE</u> – upper extremity. It is used to reference amputees with arm or shoulder amputations.

<u>Disarticulation</u> – An amputation of a limb through a joint, without cutting any bone and is performed at the hip, knee, ankle, shoulder, elbow, and wrist levels.

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SOMETHING NEW:

Each month we are going to include a picture of one of our members 'moving forward' with his / her life after losing a limb or limbs. This month's picture is of a fairly new member of our group, Gary Rock. Gary lost both legs above the knee following a farm accident. His hard work and determination has been an inspiration to us all.

J'm Moving Forward . . .



** If you would like to submit your picture 'moving forward', send it to Belinda or Julie. **

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 6.

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SNAWSEKE (_) (_)	
NZISZDESI () ()	
EHHCEDAA () ()	
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THESE ARE ALL W	VITH
THE SYMPTOMS OF A STROKE AND OCCUR	
SUDDENLY.	

Q & A (cont'd)

- $\underline{\mathsf{HP}}$ hemipelvectomy. This amputation goes through the joint in the hip and also removes half of the pelvis
- <u>Bilateral amputee</u> An amputee who is missing both arms or both legs. For example, a person that is missing both legs below-the-knee is considered a bilateral BK.
- <u>Quadrilateral amputee</u> An amputee who is missing part or all of all four limbs
- <u>Symes amputation</u> An amputation through the ankle joint that retains the fatty heel pad
- <u>Transmetatarsal amputation</u> An amputation through the metatarsal section of the foot (partial foot amputation)
- <u>Traumatic amputation</u> An amputation that is the result of an injury
- <u>Congenital anomaly</u> A birth malformation such as an absent or poorly developed limb
- <u>Amelia</u> A medical term for the absence or partial absence of one or more limbs at birth
- <u>Phocomelia</u> A congenital anomaly where one or more limbs are missing and the hand or foot is attached directly to the trunk of the body

Now for some basic words:

- <u>prosthesis</u> an artificial limb that provides a replacement for the missing or amputated limb
 <u>prosthetist</u> a person involved in the design or fitting of prosthetic limbs
- <u>residual limb</u> the portion of the arm or leg remaining after an amputation (also called the stump)
- <u>extremity</u> a limb, usually refers to the arm or the leg<u>distal</u> the end of the residual limb or farthest from the center of the body
- <u>proximal</u> the opposite of distal or the part that is closest to the center of the body
- <u>revision</u> another surgery on the residual limb usually due to infection or to correct a problem
- <u>atrophy</u> the wasting away of a body part, or a decrease in size of an organ or extremity, due to decrease in function or use
- <u>contracture</u> the tightening of a muscle around a joint, restricting its range of motion (or ability to move)
- <u>debridement</u> the removal of necrotic (dead), infected, or foreign material from a wound
- <u>desensitization</u> to reduce or remove sensitivity in a residual limb by massaging, tapping, or applying vibration
- <u>donning</u> putting on your prosthesis
- <u>doffing</u> taking off your prosthesis
- <u>alignment</u> the position of the prosthetic socket in relation to the foot and the knee
- <u>pistoning</u> when the residual limb (stump) slips up and down inside the prosthesis
- <u>dorsiflexion</u> an upward movement or extension of the foot/toes or the hands/fingers
- <u>plantar flexion</u> when the toe/foot or hands/fingers are pointing downward
- <u>range of motion</u> the amount of movement that a limb has in a specific direction
- <u>ambulation</u> is the action of walking or moving <u>gait</u> your manner or way of walking
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HEALTHY BITES

- by Beverly Gaylord

This month's recipe is one of my husband's favorites. Usually, I fix it at least once a month:

POPPY SEED CHICKEN

2 1/2 - 3 cups cooked chicken, chopped

1 sleeve Ritz reduced-fat crackers, crushed

1 can fat free cream of chicken soup

1 stick butter, melted

8 oz. light sour cream

1 T. poppy seed

Mix soup, chicken, sour cream and poppy seeds. Pour into 11x14 casserole dish. Top with crushed crackers. Drizzle butter over crackers. Bake at 350 degrees for 20-25 minutes or until bubbly and crackers are lightly browned.

With the Spring gardening season upon us, this is the perfect time for this fun snack for kids:

Dirt Cups

What you need:

1 pkg. (3.9 oz.) JELL-O Chocolate Instant Pudding 2 cups cold milk

1 tub (8 oz.) COOL WHIP Whipped Topping, thawed 15 OREO Cookies, finely crushed (about 1-1/4 cups), divided

10 worm-shaped chewy fruit snacks

Make it:

BEAT pudding mix and milk in large bowl with whisk 2 min. Let stand 5 min. Stir in COOL WHIP and 1/2 cup cookie crumbs.

SPOON into 10 (6-7 oz.) paper or plastic cups; top with remaining cookie crumbs.

REFRIGERATE 1 hour. Top with fruit snacks just before serving.

To the Members and Supporters of MOVING FORWARD Limb Loss Support Group:

It is with sadness that I must tell you that one of our members, Thomas Spatz, passed away on Friday, April 18, 2014. He is survived by his wife of 40 years, Kathleen, 2 daughters, and grandchildren. Tom joined our group this past year and attended our Veteran's program and Christmas party along with Kathleen. Tom was a veteran of the U.S. Air Force. Although we did not know him for very long, we will miss his warm smile and kind heart. Our prayers and sympathy are with his family during this time of sorrow. You may add your condolences to his guest book online at newcomerkentuckiana.com.

Sincerely yours, Belinda

7est your Knowledge Answer (from Page 5):

CONFUSION, WEAKNESS, DIZZINESS, HEADACHE, NUMBNESS, TROUBLE SPEAKING <u>A S S O C I A T E D</u>

Q & A (cont'd)

<u>gait training</u> – part of the rehabilitation process to improve your ability to walk with the prosthesis

<u>transfers</u> – the act of moving from one place to another (such as from a bed to a wheelchair or from a wheelchair to a car seat)

<u>edema</u> – a type of localized swelling that is characterized by an excess of fluid in the body tissues

<u>elastic wrap</u> – an elasticized bandage used to prevent swelling and encourage shrinkage of the residual limb

<u>shrinker</u> (stump shrinker) – a device made of an elastic material and is designed to help control swelling of the residual limb or to shrink it in preparation for a prosthetic fitting

 neuroma – when the nerve endings that are cut during amputation bundle together in a cauliflower shape, forming a mass that can be painful when it is subject to pressure from the prosthetic socket

<u>phantom pain</u> – pain that feels as though it is coming from the amputated limb

<u>phantom sensation</u> – this is a feeling that the missing limb is still there. It may involve uncomfortable but not painful sensations such as burning, tingling, or itching.

That's it for this issue, but next month we will go over the parts of the prosthesis, the different types of suspension systems, and the importance of proper care of your prosthesis and its components. I think that we should come up with a name for our new language, don't you? I would love to hear your suggestions, so just call or email me and I will include some of the suggestions in the June newsletter.

— by Belinda Jacobi

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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