

NEWSLETTER • 33rd Edition • May 2016 • Special Mother's Day Issue

MOVING FORWARD FEATURE Life Lessons of Being an

Amputee Parent

– by Kelly Reitz

Being a mom is not an easy task; sleepless nights, waiting for your child to learn to walk and talk just to turn around a few years later to tell them to shut up and sit down, ha! We all sit back and reminisce our stories of the beginning of parenthood and wonder how we (and our children) even survived. Well, being an amputee parent doesn't change the craziness and whirlwinds of being a parent, but I won't go so far as to say that it makes things worse either. Just as you learn to adapt to life as an amputee, you adapt to being an amputee parent. I think there are a few key things that parenting as an amputee has powerful built-in life lessons that can be passed on to our children.

First and foremost, it makes me appreciate each time I get to play with my children. I remember the days prior to my revisions where I was usually in constant pain and would



hidren. I remember the days prior to was usually in constant pain and would have to stop and take regular breaks to relieve my aching legs and foot. As a parent now I have a higher appreciation for getting to get out there and run and play with them. I'm so thankful to have prosthetics to help me to move, even if it's in my wheelchair at times. And, on the same note, even on days where I don't even put my legs on, just to chill and color or something helps to show them that it's okay to have a day of rest.

Another lesson I value is that I get to teach my kids what it means to have true self-confidence. I do a lot of volunteering at the kids' school, and more times than not I wear shorts, so

my prosthetics show. Since I don't mind showing my prosthetics, I get a lot of questions on what happened to me and how I got robot legs. By composing myself and patiently answering even some of the most off-the-wall questions, I have taught my children how to have confidence about themselves. Both of my children know how to tell their friends about their mom's robot legs and just exactly what happened with a very confident tone, which puts everyone at ease. Sometimes I get a little nervous on how a kid at their school will respond but am usually pleasantly surprised that they accept it and move on.

One more take away life lesson that I value is showing them how to adapt ... with anything! Whether it's holding a - Continued on Page 2 Column 1 -

When a Parent Loses a Limb: Helping Children Cope

*in*Motion · Volume 11 · Issue 3 · May/June 2001 – *by Pat Isenberg, Amputee Coalition Outreach Education Coordinator* **Common questions that children ask include:**

- Where is your arm / leg?
- Where is your arm? le
- What happened to it?
- Did it break off?

Be prepared to assist the child with an answer that is appropriate for his or her age and developmental level.

Pain is scary to children; the longer pain endures, the more frightened the child will be. Talk about different types of pain in terms the child can understand. (Remember the time you burned your finger? Or, the time you fell off your bike?) Remind the child that sometimes pain is short-lived; at other times, pain lasts for days, but eventually pain gets better.

- Avoid giving children too much information, such as details about a complicated disease process or the amputation surgery.
- Can this happen to me? Alleviate fears by giving information that kids can understand. Telling a child that someone was asleep when his or her leg was removed can develop into a fear of bedtime. Remember that your explanations need to be planned to avoid creating additional fears or anxiety.
- Is this my fault? Younger children are egocentric; when things happen, they feel responsible. Make certain children know that they did not do anything to make this happen.
- Limb loss is not a punishment; however, if it's the result of an accident, you may want to talk about safety issues at an appropriate time.
- Children will not "catch" this. Hugging and touching are still safe and very important parts of healing for the entire family.
- The parent is still a mommy or daddy regardless of the limb difference. Talk about what is important daddy can still read a bedtime story; mommy will still brush your hair.
- You may also want to discuss which things may be different. Mom may have to learn a new way to bake chocolate chip cookies; dad may not be able to walk the dog for a few weeks (or months).
- Call upon the child's natural desire to help. You can be mommy's right hand until she learns to use the new one.
- Explain the new words: prosthesis, limb, residual limb, prosthetist. Make a game out of spelling or pronunciation of these words.
- Avoid adverse reactions: a child who cries or screams in response to seeing a parent for the first time; a child who runs from the room each time the prosthesis is removed. Explain *Continued on Page 2 Column 2* –

Life Lessons of Being an Amputee Parent (cont'd)

ball or cup in a different way, or maybe adapting a chair that makes it easier to get in and out of, I teach them that life is all about adapting, to think outside the box. Even when someone teaches you one way, you can adapt it to your learning style or comfort level. The more your children learn to adapt, the easier they'll be able to handle change and the multitude of personalities they will come across all through life. What a great life-lesson to give from the very beginning.

I was scared to have kids! I was worried if meningitis could in some way be transferred to them. I wondered if I would be able to handle the weight on my stumps? What happens if I lose my mobility? What if? Life will always be



full of "what if's" so I don't dwell on what could happen and just try to squeeze every ounce of life out of the moments that I have. I'm thankful that I am mobile now and that my children & I have such a great relationship with one

another. I hope all of you choose to use your 'difference' to teach those life lessons to your loved ones.

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SPOTLIGHT - by Belinda

NOTE: This is a repeat of the SPOTLIGHT column from the May issue of last year. I think it holds a special message that is worth sharing once again.

This month our spotlight will cast a large light. We want it to cover all the mothers, step-mothers, grandmothers, and aunts who are members of *MOVING FORWARD*, whether they are amputees or caregivers. I believe that Mother's Day should be about honoring all women who have made a difference in the life of a child.

One of the fears that come with limb loss is that we will lose our ability to be the type of parent/grandparent/aunt that we have been in the past or that we would like to be in the future. Although sometimes our physical capabilities may be more limited, we are uniquely qualified to teach our children some very valuable life lessons. Who better to teach them that when faced with life challenges, to not give up, but to find a way to endure? We can also teach them the importance of setting attainable goals and then striving to reach them. We can show them that it is okay to look different than others, because what is truly important is who we are on the inside. We can show them how to keep their head held high and to be proud of themselves when faced with unkind comments or actions by others. We can teach them the importance of accepting and loving themselves. We can teach them to appreciate the small things in life and to take the time to enjoy them. For those of you who are caregivers, you are teaching the children one of the most important life lessons, and that is sometimes in life we must put someone else's needs before our own.

We would like to honor all the women of *MOVING FORWARD* and to thank them for being positive role models in the lives of our children.

Happy Mother's Day from Belinda, Deklan, & Carter Jacobi



When a Parent Loses a Limb: Helping Children Cope (cont'd)

differences in advance to prepare the child. Show pictures of other people with limb loss (available from the prosthetist or therapist or inMotion magazine) to desensitize the child.

- Focus on the similarities, but prepare gently for the differences. Have the child talk or write about his or her feelings.
- Children are curious. Remove the mystery from the prosthesis by asking the prosthetist to spend time with the child, explaining the materials and components used. The child should be encouraged to manipulate the components.
- If possible, have the child talk with other children whose parents have lost a limb.
- Encourage the child to express his or her feelings through drawing, poetry, or telling and writing a story.

A Mother's Love - by Helen Steiner Rice

A Mother's love is something that no one can explain; It is made of deep devotion and of sacrifice and pain.

It is endless and unselfish and enduring come what may For nothing can destroy it or take that love away.

It is patient and forgiving when all others are forsaking, And it never fails or falters even though the heart is breaking.

It believes beyond believing when the world around condemns, And it glows with all the beauty of the rarest, brightest gems.

It is far beyond defining, it defies all explanation, And it still remains a secret like the mysteries of creation.

A many splendor miracle man cannot understand And another wondrous evidence of God's tender guiding hand.

Dn memory of our mothers . . . Elsie M. Sullivan (Belinda) Maxine H. Brewer (Julie)

APRIL RECAP

With the month of April being designated Limb Loss Awareness Month, it was only fitting that April was one of MOVING FORWARD's busiest

months yet. The month began with some members of the group being asked to take part in a Rehab Techniques class for physical therapy students instructed by Professor Dennis Lesch. We interacted with groups of students by answering their questions about living with limb loss, allowing them to practice wrapping our residual limbs, showing them how we don (put on) and doff (take off) our prosthesis, and letting them observe us walking to study our gaits. At the end of the class, Dennis asked us to talk to the students about our support group. As always, MOVING FORWARD welcomes the opportunity to assist in the training of medical students.

On Sat., Apr. 9th, group members attended the first OPAF (Orthotic and Prosthetic Activities Foundation) event to be held in Louisville. Robin Burton, the director of OPAF, was on hand to welcome us to the event. Physical therapist/

prosthetist Chris Doeger conducted the full day event with the assistance

of Reggie Showers, who is a bilateral below-knee amputee and two-time national motorcycle drag racing champion. The



morning session was used to give instruction to physical therapists, and the afternoon session was devoted to working with amputees on balance exercises and fall recovery. Several group members took part in demonstrating the techniques throughout the session. We hope this is the first of many OPAF clinics to be held in our area and want to give a special thank you to the Center for Orthotic and Prosthetic Care for

sponsoring this inaugural event.

The IN meeting was held on Mon., Apr. 18th, at SIRH. Those in attendance discussed many topics and listened as

group member Jeff Coffman told about a trip he had made earlier in the month to San Francisco, in which he took part in a research dealing with project MRSA infections. He explained that MRSA is a drug resistant infection that can life-threatening cause serious complications especially to those who are elderly or who have weakened immune systems. The meeting concluded with discussion of our restaurant survey and upcoming events.





Our activities continued on Fri., April 23rd, with another inaugural HealthSouth event. Lakeview Rehabilitation Hospital sponsored a "Show Your Mettle Night" at Slugger Field in Louisville. Amputees and their quests were treated to free admission to the Louisville Bats baseball game. MOVING FORWARD was asked to have a booth there where we met with the public and distributed group information. We

- Continued on Page 4 Column 1 -





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J'm Moving Forward ...

Each month we are including a picture of our members moving forward after limb loss.



Brittany and Kelly "moving forward" and taking part in a fall recovery demonstration at the OPAF Clinic.

** If you have a picture of you and your children or grandchildren that you would like to submit, please send it to Julie or Belinda. **





– by Belinda

Our Q&A section is provided so that our readers can submit a "?" and then I, in turn, ask some of the members of the group for a response. From time to time, I also do some research from various informational sources so that I can better respond to

the submitted question. I am not trying to provide medical advice, but just trying to help amputees who are in search of some answers. As always, I encourage you to talk to your family doctor, specialist, or prosthetist about your concerns. Do not be afraid to ask them questions!

For the next few months, I will be using the Q&A column to provide information on many of the agencies in our community that provide assistance to those living with limb loss. In doing this, I will try to answer questions that I receive on a weekly basis such as:

- Continued on Page 4 Column 2 -

APRIL RECAP (cont'd)

were delighted to see Gary Summers, leader of the NewLife

Support Group from Elizabethtown, throw out the first pitch, and young amputee, Ella Lincoln from Louisville, race Buddy Bat around the bases. A trivia contest was held during the game and prizes were awarded to the winners. Our own Philip Randolph won the grand prize, which was a beautiful handmade quilt, made by Beth Nelson, R.N., especially designed with the "Show Your Mettle" logo. The



event allowed us not only to enjoy the beautiful spring evening watching the game and festivities but also gave us the opportunity to raise awareness of limb loss in our community.

MOVING FORWARD

celebrated "Show Your Mettle Day" on Sat., Apr. 23rd, at the KY meeting which was held at Baptist Hospital East. We were honored to have a wonderful guest speaker, Vitalis Lanshima. Vitalis told the

group about his life, including losing his arms above the elbow at the age of twelve due to an electrical accident. He talked about his experiences as an amputee while living in his home country of Nigeria, and of how, with the help of his family and his determination and desire for a better way of life, he pursued his dream of becoming a track star. He went on to become a gold medalist and world record holder at the Paralympic games. While competing there, he met Jim Varga, the track coach from Bellarmine University, and was given a scholarship to attend Bellarmine and join its track team.

Since that time, he has become an educator and teaches middle school. He is also working on his doctorate degree and



doctorate degree and is planning to open a restaurant in the near future which will be named "Aspire". His hope is that the restaurant will help to educate the community

about those with disabilities, so that their unique gifts and

abilities will be recognized. His message to us was that if you truly desire to improve your life, not to let anyone or anything stop you from attaining your dream. We captivated, were all motivated, and inspired by his words. We wish to thank both Vitalis and his lovely wife Beth for



attending and also for joining members for dinner at O'Charley's Restaurant following the meeting.

We enjoyed good food, laughter, and socializing with friends. It was a wonderful way to wrap up a month devoted to "showing our mettle."

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Q & A (cont'd)

- Will I be able to drive again?
- I want to rejoin the workforce, but where do I begin?
- Is there any help for amputees who have insurance, but can't afford the high deductible or copayments?
- My apartment isn't handicap accessible. How am I going to manage when I get home?
- Where do I go for help in paying my rent, utilities, or receiving food assistance?

For the May issue, I will give you some information on where to find help in receiving durable medical equipment (a walker, wheelchair, etc.) and where you can donate used equipment. Last month in this column, information was provided on organizations that provide assistance in paying for prosthetic devices. Many times I am asked, "Where can I donate my old prosthetic leg or a prosthetic foot that I no longer use?" Prosthetic components are generally not reused in the U.S. because of legal considerations. There are many organizations that do accept used prostheses to ship to third world countries. Check with your prosthetist's office to see if they collect prosthetic components to give to these organizations. There is a list of organizations that accept donations and their contact information at the Amputee Coalition website at amputeecoalition.org.

Most types of insurance will pay for durable medical equipment. If you find yourself in need of a wheelchair, walker, or some other assistive device that they won't provide, or if you don't have insurance, there are programs available to help. One such program is called Project CARAT (Coordinating and Assisting the Reuse of Assistive Technology). The goal of Project CARAT is to make assistive technology and durable medical equipment more accessible to those who need it in underserved areas of Kentucky. They accept donated equipment, clean it, make needed repairs, and then redistribute to those who need it. If you live in Kentucky and have a need for equipment or have equipment you would like to donate, you can receive more information by going to katsnet.org/projectcarat/. They can be reached by phone at 1-800-327-5287. The Louisville site coordination is Joy Vessels and she can be reached at 502-992-2448 or email at JVessels@spalding.edu. For Indiana residents, Easter Seals Crossroads has partnered with the state of IN Bureau of Rehabilitation Services to establish the Indiana Assistive Technology Act Project (INDATA Project). They accept donations of closed-caption televisions, video magnifiers, computers, and other assistive technology devices to refurbish and then provide them at no charge to individuals with disabilities that live in Indiana. They do not accept medical equipment, but do provide a free on-line equipment exchange site where you can buy, sell or trade equipment. The website for INDATA is eastersealstech.com. Their phone number is 1-888-466-1314.

Topics I plan to discuss in the coming months are accessible housing, transportation, and in-home services. If you have had any experiences with these services either good or bad that you would like to share, please contact me. Also if there is another topic you would like information on, just let me know and I will be glad to include it.

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DON'T FORGET TO ENROLL IN THE KROGER COMMUNITY REWARDS PROGRAM

Register or re-enroll online, if you have not done so, at: <u>krogercommunityrewards.com</u>. *MOVING FORWARD* Support Group receives a percentage of your purchases & it does not take away from your Kroger/Jay C points in any way.

LET'S GET MOVING! - by Belinda

During the past few years in this column we have shown you many ways to get moving; including exercises, stretches, swimming, fishing, gardening, and golf, just to name a few. This month we are excited to tell you about a very special way to get moving that is being offered in our area. **Kenney Orthopedics** and **Keeneland** are sponsoring a McKeever's First Ride on Monday, June 20th, from 10 am – 1 pm at Blue Willow Farm in Versailles, KY. This is a wonderful opportunity to try something new, see some beautiful animals and countryside, and enjoy a day with friends. So come on everyone, let's get on that horse and

let's get moving!!

Adaptive Riding is at the heart of McKeever's First Ride. Adaptive riding provides youth and adults the chance to ride a horse that is specially saddled to accommodate riders with limb differences, while adult side walkers insure safe riding



in an arena. An adult lead walker guides the horse, which is trained to respond safely and sensitively to the needs and abilities of the rider.

Lower extremity amputees have found that the horse's gait mimics the feel of walking, thus aiding the rider by building core strength, balance, confidence, and flexibility. The freedom and view from the back of a horse is a wonderful thing. We are thrilled to provide that experience for new riders, and for riders who mistakenly assumed this enjoyment would no longer be feasible after a limb loss.

McKeever's First Ride celebrates the life and legacy of Dan McKeever. A pioneer in the orthotic and prosthetic field, Dan understood the needs and challenges faced by amputees. He pushed for technological advances and encouraged men and women to defy the odds and reach for their dreams.

As a Colonel in the Army during WWII, Dan developed a deep respect for soldiers, especially those wounded while serving their country. He would have certainly been proud of those who participate in McKeever's First Ride Clinics and the Horses for Heroes Programs across America.

Dan McKeever had a keen mind, a hearty laugh, and a big heart. A graduate of Georgia Tech, he received the Distinguished Alumni Service Award and was inducted into the Engineering Hall of Fame. He served multiple terms as president of AOPA and also served as president of the American Board of Certification.

Through his confidence and compassion, Dan enabled others to tackle problems and overcome obstacles. His legacy will live on through McKeever's First Ride as amputees experience the physical and emotional benefits of adaptive riding and equine activities. We intend to celebrate his life and the human spirit.

Youth with limb differences as young as 2 years old have been thrilled to discover the joy of being around horses and engaging in adaptive riding. Youth, teens, and adult participants with limb loss and limb differences have enjoyed many adventures at McKeever's First Ride events.

Dan McKeever wanted amputees to create meaningful, joyful lives, despite the challenges that go along with living with limb differences. In keeping with his "Carpe Diem" attitude, McKeever's First Ride exists to provide amputees an exciting day to make new friends and to discover the thrill of riding, roping, carriage driving, various adaptive sports (like adaptive fencing by the Shepherd Swords), and expressive arts. Each year celebrity guests who have faced limb loss inspire attendees with testimonies of their courage to push beyond perceived limits in order to enjoy new adventures and a "Carpe diem" (seize the day!) attitude. With amputees gaining coverage in the daily news with wonderful stories -Continued on Page 6 Column 1 –

UPCOMING EVENTS

MEETINGS:

May 16th, Mon., 6:30 - 8 p.m. at Southern IN Rehab Hospital, 3104 Blackiston Blvd., New Albany, IN in the Conference Room.

<u>May 28th</u>, Sat., 2 - 4 p.m. at Baptist Hospital East, 4000 Kresge Way, Louisville, KY, in the 2nd Floor Education Center, Room 2B.

EVENTS:

<u>May 5th</u>, Thurs., Pegasus Parade viewing and picnic sponsored by Louisville Prosthetics at their office at 742 E. Broadway. Plan on arriving between 3:30 - 4:30 p.m. (Broadway closes to traffic around 4:30). There is plenty of free parking in their lot. Drinks and sandwiches will be provided. If you would bring a covered dish, it would be appreciated. The parade starts at 5:00 p.m. and usually lasts about 2 hours.

<u>June 9th - 11th</u>, The Amputee Coalition with be holding its Annual National Conference at the Sheraton Greensboro Four Seasons in Greensboro, NC. You can find more information on their website at amputee-coalition.org or at our website ampmovingforward.org.

June 20th, Mon., from 10:00 a.m. - 1 p.m., Kenney Orthopedics and Keeneland are sponsoring a McKeever's First Ride Clinic at Blue Willow Farm, 4400 Delaney Ferry Rd., Versailles, KY. This is a great opportunity for amputees and their families to learn how to ride a horse in a safe environment with trained professionals. You can register for this "free" event by calling Alex Barnhart, Director of Marketing for Kenney Orthopedics at 859-509-8032. For more information, go to opafonline.org or our website at ampmovingforward.com.

- There are many other events being planned including:
- Our Pie & Ice Cream Social in July
- ✤ A Belle of Louisville Cruise
- A trip to Churchill Downs and the Kentucky Derby Museum
 A Fall picnic

Also, our annual business meeting and election of officers will be coming up in June.

MOVING FORWARD's monthly meetings provide a way to meet other amputees in our community, so that we may learn from and encourage each other. They also provide us with the opportunity to voice our concerns and help each other to find solutions to problems we face as amputees. At some meetings we have guest speakers who share with us information to help us achieve a healthier lifestyle. We encourage you to come to a meeting and give it a try. You will leave with new friendships, knowledge, and motivation to help you in dealing with living with limb loss.



TEST YOUR KNOWLEDGE

Unscramble these words and use the letters in parentheses to complete the sentence. You must also unscramble the letters to find the answer to the puzzle on Page 6.

NEOCNCR	()
MHRUO	()
TIENELTCL	()
NSLEIT	()
RTEDIDENME	()
CSRTEEP	()
EEGNYR	()
NRGRUNITU	()

THESE ARE ALL SKILLS OR QUALITIES MOTHERS REQUIRE IN RAISING THEIR ______.

LET'S GET MOVING! (cont'd)

about adaptive sports and groundbreaking achievements, McKeever's First Ride is thrilled to spark this kind of spirit in our participants!

For information on how to register for this event, check out our UPCOMING EVENTS section of the newsletter or our website at ampmovingforward.com.



.... from Beverly's Kitchen

With strawberry picking time right around the corner, this is a delicious way to enjoy them. Being slightly sweet and chilled this recipe could be perfect alongside a grilled entree.

FRESH FRUIT SALAD

Ingredients

- 8 10 cups fresh melon cubes
- 1 2 Tbsp. white corn syrup

1 pint fresh strawberries, halved

2 cups fresh pineapple chunks

2 oranges, sectioned

Fresh mint leaves, optional

Directions

In a large bowl, combine melon

cubes & corn syrup. Cover & refrigerate overnight. Just before serving, stir in remaining fruit. Garnish with fresh mint leaves if desired. Yield: 3-4 quarts

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With Mother's Day just around the corner, below is a great activity that could be used as a gift for mom or grandma. Below is a poem that could be used along with the child's hand prints. This could be a prized possession for that special mom or grandma! Happy Mother's Day to all you special moms!!

> Sometimes you get discouraged Because I am so small And always leave my fingerprints On furniture and walls.

But every day I'm growing -I'll be grown some day And all those tiny handprints Will surely fade away.



So here's a little handprint Just so you can recall Exactly how my fingers looked When I was very small.

TEST YOUR KNOWLEDGE ANSWERS (from Page 5)

CONCERN, HUMOR, INTELLECT, LISTEN, DETERMINED, RESPECT, ENERGY, NURTURING

THESE ARE SKILLS OR QUALITIES MOTHERS REQUIRE IN RAISING THEIR CHILDREN.

AWARENESS MONTHS / WEEKS

MAY IS . . . NATIONAL STROKE AWARENESS MONTH May 8 – 14 . . . National Women's Health Week May 12 – 16 . . . National Neuropathy Awareness Week

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Thank You to the Amputee Coalition

** We want to thank the Amputee Coalition for allowing us to use their articles in our newsletters. We also want to thank them for the many brochures and publications that they provide to our group. It is not the intention of the Amputee Coalition to provide specific medical or legal advice but rather to provide consumers with information to better understand their health and healthcare issues. The Amputee Coalition does not endorse any specific treatment, technology, company, service or device. Consumers are urged to consult with their healthcare providers for specific medical advice or before making any purchasing decisions involving their care. **

Just a Little Mother's Day Humor



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CONTACT INFO Call for meeting times & locations! MOVING FORWARD Support Group moving4wdamputeegroup@gmail.com 502-509-6780 - ampmovingforward.com Facebook: Moving Forward Limb Loss Support Belinda Jacobi, President belindajacobi@yahoo.com 812-620-3694 Kelly Reitz, Vice-President / Facebook Editor Kjreitz2012@qmail.com 812-572-7955 Mary Jo Kolb, Secretary mjk2you@gmail.com 502-727-9566 Julie Randolph, Treasurer / Newsletter Editor jbrsweepea@yahoo.com 812-557-3970 Mike Portman, Board Member-at-Large mdportman712@gmail.com 502-262-8344

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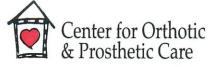
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