



NEWSLETTER ♦ 40th Edition ♦ Dec. 2016

MOVING FORWARD FEATURE **SMALL THINGS** – by Belinda

For many of us one of the highlights of the holiday season is getting to do special things with our children and grandchildren. We bake cookies, decorate the Christmas tree, attend their school programs, wrap gifts, make crafts, sing carols, and all those other fun seasonal activities. Along with the joy that comes with spending time with them, it may also bring some anxiety, especially to new amputees. They may fear that they won't be able to do the things they usually do with their children and grandchildren this year. For some, they may be hospitalized or in rehab; they may be in a wheelchair or using a walker; they may not have fully healed or have their strength back yet. These things can lead to anxiety, fear, or even guilt. As amputees we constantly hear that we must adapt the way we do things. The holiday season is a time of year that we may have to adapt or change some of our traditions. We may not be physically able to track through the snow to cut down our Christmas tree, but maybe we could ride along to a tree farm to pick one out or make a special decoration with our child to put on that tree. We may not be able to jump on the sled and go flying down the biggest hill, but we can snuggle under a blanket and watch a Christmas movie or read a special book while drinking hot chocolate. We may not be able to buy them the expensive gifts that we once did, but we can give them two of the most precious gifts – "our love" and "our time". When you think back on your past holidays, is it the gifts that you remember or is it the special times that you spent with your family or loved ones? Yes, there are some activities for which we may be left on the sidelines, but that gives us the chance to sit back and see the joy in their eyes, or to hear their laughter, or to take that perfect picture, or to hear their excitement as they tell you all about their latest adventure. So during the month of December, let's all strive to be thankful for the things that we can do instead of dwelling on those that we can't. You may decide that cutting back on all the "hustle and bustle" allows you to really enjoy the small things in life, and sometimes those small things are the most precious of all.

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### **AMPUTEE COALITION**

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#### **A Baker's Dozen**

– by Carolyn Cosmos

**Note from Belinda:** During the past few years, we have focused the December issue of our newsletter on children. We have shared stories of children adapting to becoming an amputee and also children learning to accept the loss of a limb or limbs of a parent or grandparent. In this edition we are sharing with you a story of a very special family, the Filbrun family. I can only imagine the joy, love, excitement, and chaos on Christmas morning in this household. Their story touched my heart and I trust it will yours as well. There is a special surprise included at the end of the story, so read on and enjoy....



The green T-shirts say it all: "DISABILITY IS NOT INABILITY!" A string of smiling children, little stick figures, & a dog with three paws, underline the letters. And on the back? "Team Filbrun."

The mom who designed the T-shirts is almost as passionate about that motto as she is about her 10 kids, seven of whom are adopted & most of whom have special needs.

"It speaks the truth," Kristy Filbrun says, adding, "I hate the word 'disability.' Differently abled is not 'DIS-abled'! Everyone has things they can't do, including me. Nobody is totally abled."

Dad Harlan Filbrun, a former supervisor of large landscaping projects & installations, now works on even larger ones, bridges, & road repair work. Kristy is a former health aide, a useful trade for a mom who may need to schedule multiple medical appointments in one swoop & do therapy follow-ups.

The Filbruns live in a farming community in Ohio & have a small house on eight acres of land. They buy in bulk. They grow much of their food & can the leftovers for winter months. They camp at lakes &

– Continued on Page 2 Column 2 –



*Merry Christmas!! From the Jacobi Family*

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SPECIAL NOTE

Once again, I am sharing with you some information about a health concern. I recently learned that my cancer has returned and I will begin chemo treatments in the near future. During this time, I will be counting on the other officers of *MOVING FORWARD* to perform many of the day-to-day tasks involved in running the support group. I also will be unable to go on peer visits to hospitals and rehab facilities due to my weakened immune system. Other members of the group will be continuing the peer visits. I appreciate your prayers, love, and support that you have offered to my family and me during this time.

Thank you, Belinda

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## I'm Moving Forward . . .

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



Belinda, Maggie, and Deklan "*moving forward*" at the Walk and Roll.

\*\* If you have a picture that you would like to submit, please send it to Julie or Belinda. \*\*

## A Baker's Dozen (cont'd)

parks in the summer, watch DVD's together on family movie nights, & have friends over whenever they can – the children play on a trampoline or dad-installed basketball & volleyball courts.

They also host an annual "Family Fun Day" for those with foster or adopted children. The sharing is important, Kristy observes – as she knows quite well. She & her husband, who both come from large families, have provided, over the years, foster care for 19 children.

The Filbrun children's challenges run the gamut – psychological trauma, hearing loss, early-life infections, brain injury, limb difference & speech delays. Their family's adoptions are from both the United States & from abroad.

"Our adopted children are 'overcomers,'" Kristy says. "It means they have had loss, pain & brokenness in one form or many. They are survivors. Resilient. Willing to try & trust again. Heroes. Our biological children are heroes, too. They have reached out with open arms & open hearts to accept whomever God has placed in our family."

The children's capacity for tolerance includes coping with little ones going from one home to another, perhaps a foster infant born addicted to drugs – "They cry and cry and cry" – or a frightened child who's lashing out.

"I hear, 'It's OK, mommy. I know they didn't mean it & don't know better. We'll teach them different.'" Additionally, growing up in a multi-hued & variously abled group, the Filbrun children "accept anyone of any race & any special needs."

Daughter Taylor, 18, who is entering college as a sophomore thanks to advanced work, has grown up seeing her siblings take on their difficult challenges. "That," she says, "is very much an inspiration."

Taylor points to Jemma, 8, who had bilateral above-knee amputations in 2012. "She'll have a day where her legs are hurting & she can't wear prosthetics, but she'll still run around [on her residual limbs] – she's pretty quick! – and play and be happy." Like everyone around her, Jemma pitches in on chores geared for each age – such as helping in the garden, playing with a sibling, or setting the table. I think, "If they can do that, I can do anything!" Taylor says.

That's part of the plan: According to Harlen, a key challenge is treating all their children "like anyone else" & encouraging independence, "as much as they can handle. If they need help, we're there for them. The combination creates confidence," he says.

Another part of the plan is doing things together – thus "Team Filbrun" on the T-shirts. At mealtime, "We try to eat together as a family. I think it's important," Kristy comments.

So dad will come home from his day job & plunge in, "changing diapers, cleaning & cooking, & all my older kids know how to cook," Kristy says, with 16-year-old Alex an "excellent baker & griller." Dylan, 16 & a football player, is also a "cleanup champ," one who, along with Danielle, 13, can keep "the little ones" entertained.

That could include the newest Filbrun daughter, Havyn, 18 months, a thriving toddler, formerly malnourished, who had a medically expedited adoption. Or it could include Cody, 5, who "loves with his whole heart" & has a new service dog with a missing paw, Rana, to help him, Jemma & Wyatt.

This team of 12, however, doesn't live in a Pollyanna valley: The children "are normal in that they grumble or argue from time to time," Kristy says. And the two adults have considered carefully in expanding their family: Do they have the personal & financial resources to care for a particular child? How might it affect their existing kids?

"We were foster parents first, & all those years prepared us for a large family," Kristy explains. Fostering special needs children was part of it. She shares a story about a younger Taylor who was asked if it was too hard for her to see foster siblings come & go: "Even though it's hard, it's better to love them than not," Taylor said.

Taylor was consulted because this is a group that makes decisions together.

Thus, when a decision was brewing to adopt Jemma & Wyatt from China at the same time, it was a family affair. Harlen says, "The children wanted to grow our family, & unselfishly said they would give up their space for it."

"When Jemma's face popped up on my computer screen, my kids clamored, 'We have to adopt her!'" Kristy says. Jemma & Wyatt were both born with lower-limb differences that later called for amputations. So, soon Jade, 5, thinking Jemma might need her help, began carrying little brother Micah around for practice. (Micah prefers football with his brothers.)

Jade & Taylor accompanied their parents to China to help out.

– Continued on Page 3 Column 2 –





## NOVEMBER RECAP

Some group members met with representatives of the Amputee Coalition at the Galt House Hotel on November 11th to help plan for the 2017 AC National Conference. We toured the hotel, including the guest rooms, conference rooms, and the restroom facilities to make sure that everything was handicap accessible. We also checked out the pool area to make sure that it would be accessible for amputees wanting to take part in the OPAF First Swim Clinic. A discussion was held on ways that *MOVING FORWARD* can be involved in both the planning of and participation in the conference. Our group will have a "Welcome to Louisville" booth during the conference and will be assisting with many of the events. We are also planning for a scavenger hunt with the prizes being gift baskets made up of items from our area. They have also asked us to assemble the centerpieces for the Gala Dinner Dance. This is really an exciting time for *MOVING FORWARD*, and if you would like to volunteer or have any suggestions, please contact us.

Our IN meeting was held on Mon., Nov. 21st, at Southern IN Rehab Hospital. Many topics were discussed, including how to adapt to the loss of a 2nd limb, with members giving tips on things they have learned along the way that has helped them to adapt. We also talked about the importance of our caregivers in our healing process. Each caregiver in attendance was given a "winter care" package as a token of our appreciation for all they do for us.

The Louisville meeting was held at Baptist Hospital East on Sat., Nov. 26th. A special presentation was given by a new member of our group, Billy Parker. Billy told of how he became an amputee due to a workplace accident when he was pulled into a drywall shredding machine. He was miraculously able to pull himself free before he was totally drawn into the machine, but due to the accident, he is now a bilateral above-the-elbow amputee. He gives presentations on safety in the workplace, telling how one bad decision almost cost him his life. Billy also talked about how he enjoys his life and how important it is to not let limb loss keep you from living life to the fullest. We want to thank Billy for his motivational message, and we are honored that he is now a member of *MOVING FORWARD*. If you would like to meet him, he plans on coming to our Christmas Party and also has agreed to sing for us there. All caregivers attending the meeting were given a gift package as our way of thanking them. We concluded the meeting with making plans for the Christmas Party, AC National Conference, and the coming year.

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COUNTDOWN TO THE 2017 AMPUTEE COALITION NATIONAL CONFERENCE



..... 8 MONTHS

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## WHY I WANT TO ATTEND THE 2017 AC NATIONAL CONFERENCE . . .

"I would like to learn about new technology and to meet new friends."

— Paul Weber



## A Baker's Dozen (cont'd)

Jade encouraged Jemma, then 5 but still in diapers, to "go potty, go potty," modeled how to splash in tub suds, & sat on Harlen's lap to show he was a safe person.

Jemma & Wyatt had their 2012 amputations together in the same hospital so they could support each other – a course of action taken after Kristy & Harlen consulted orthopedic experts in Ohio & Philadelphia.

And the two children recently visited the Filbruns' prosthetic clinic in Dayton to check in with Hanger prosthetist Carrie Melton. Wyatt, now 4, "is in a good prosthetic system," Kristy says, noting he'd outgrown it & needed new sockets.

But she had concerns about 8-year-old Jemma's prosthetic legs & her stability & balance: "She falls a lot."

At the time, Kevin Carroll, vice-president of prosthetics for Hanger Clinic nationwide, was making teaching & consulting rounds in Ohio & met with the Filbruns. A Florida-based researcher & inventor with many honors & an Irish brogue, he is best known for working with prosthetist Dan Strzempka to create an artificial tail for an injured dolphin.

This dramatic event was depicted in the popular *Dolphin Tale* movies starring Morgan Freeman. Not only are the *Dolphin Tale* movies a staple of the Filbrun's Family Movie Night – "The children love them" – Jemma had a picture of Winter laminated on her socket. So it was a momentous meeting.

"Carrie & I came up with solutions for Jemma," Kevin says, sympathetic to Kristy's concerns. Solutions include a different knee, a different socket & changed proportions in Jemma's artificial legs. Although her current socket liner is the famed WintersGel, "I think we'll try something a little different there as well," he says.



Jemma is also getting stubbies (short prosthetic legs without knees). Kristy wants Jemma to have them for camping & walking on gravel. Jemma will also get children's running blades as part of a research project.

Meanwhile, Wyatt, so intense "we call him our fire & ice," can't wait to get his new sockets & energy-returning foot – because he wants to "run super fast," he says – and, at age 4, play football with the family's big kids.

That's the I-can-do-it spirit that Kristy & Harlen want to see in their kids. Harlen explains he'd like them all to grow up to be courageous, with giving hearts, to become good citizens & good parents.



*Winter the dolphin with her prosthetic tail made by Hanger Clinic's Kevin Carroll & Dan Strzempka. WintersGel, which was developed out of research to fit Winter with her prosthetic tail, is now also benefiting human patients nationwide.*

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QUOTE OF THE MONTH

DON'T JUST TEACH KIDS HOW TO COUNT, TEACH THEM WHAT COUNTS THE MOST.

1. Generosity
2. Politeness
3. Integrity
4. Effort
5. Courage
6. Resilience
7. Gratitude
8. Faith
9. Kindness
10. Love



LET'S GET MOVING! — by Belinda

In the November issue we shared with you some basic exercises to help to improve your balance and strength. If you have been practicing those or if you are already more advanced, you should be ready to move on to some exercises which are a little more challenging. As amputees, if we want to 'move forward,' we must continually challenge ourselves. This doesn't mean pushing it to the extreme and risking serious injury, but it does mean to keep working to improve our capabilities so that we can become more independent and have a more active lifestyle.

The first exercise will help with balance, muscle strength, and improve your gait. To have a good gait, you need to achieve equal knee flexion with both legs. Sometimes as amputees, we don't bend our knees properly or lift our feet high enough, which can lead to stubbing our toes and falling. The second exercise will help with lateral movement. In our day-to-day lives just cleaning the house or putting away dishes requires lateral movement. For those wanting to play sports or go back to a physically demanding job, lateral movement is very important. Remember, if you are just beginning or have balance problems to practice these exercises by a kitchen counter or sturdy table. With continued practice, you will begin noticing improvement in your balance, gait, and lateral movement. So come on everyone, **let's get moving!!**

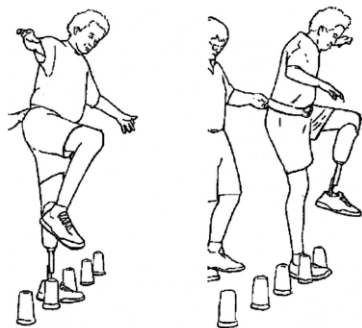
Forward Cup Walking: Place 5 to 10 plastic cups approximately 12 – 18 inches apart. Starting at one end of the row of cups, slowly raise the leg when stepping forward so that the knee is waist high, or so that a 90 degree angle is formed at the hip, & then slowly return the foot to the floor as you step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



Forward Cup Walking

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

Lateral Cup Walking: Place the cups 14 - 24 inches apart so that both feet will fit between the cups when standing sideways. Begin at one end of the cups, slowly raise the sound limb so that the hip forms a right angle & then slowly step over the cup. Transtibial amputees may advance the prosthetic limb same as sound limb by bending the knee. Transfemoral amputees advance the prosthetic by keeping the knee straight & bringing the limb behind the cups.



Lateral Cup Walking

There are three key elements to focus on when balancing over the prosthetic limb as you advance the sound limb. First, contract the muscles within the socket by tightening the buttocks & thigh muscles on the prosthetic side only. Second, exert downward force through the socket. In other words, imagine that you are pushing your prosthetic foot down through the floor. Third, feel the weight of your body pass over your prosthetic foot, attempting to maintain weight over the great toe of the prosthetic foot.

CHRISTMAS

TEST YOUR KNOWLEDGE

Unscramble these words and use the letters in parentheses. Then unscramble the letters in parentheses to find the answer to the puzzle on Page 6.

ISENPTIOTA () _____
 GLISEH () _____
 LEGAN () _____
 CLEAND () _____
 LEVES () _____
 LENO () _____
 TENESSRP () _____
 CREDEMBE () _____
 DRANLAG () _____
 GMRNEA () _____
 STRANEMON () _____
 TEWHAR () _____

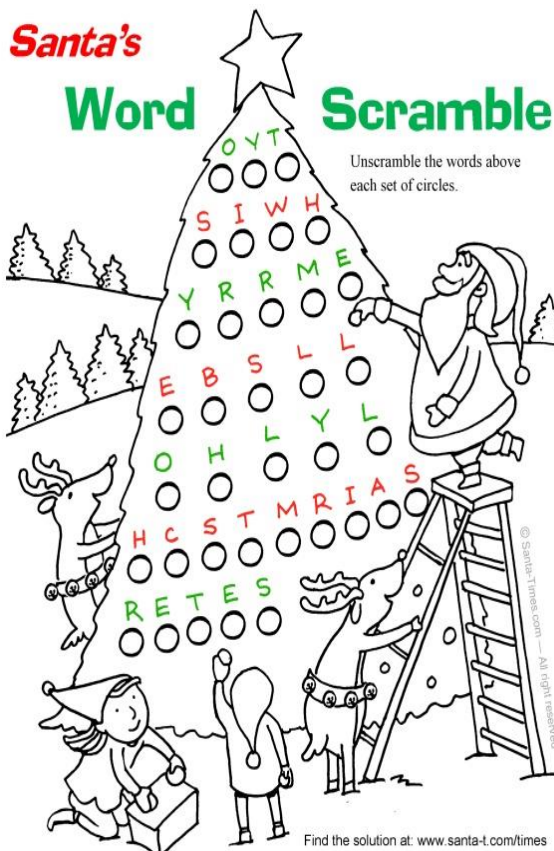
A CHRISTMAS WISH: _____

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### "Sock Drive" Announcement

We are excited to announce that we collected a total of 854 pairs of socks for the Salvation Army. A big "Thank You" to the Okolona Fire Department for adding 110 pair to our collection! We also want to say thanks again to the members of Cook Memorial Methodist Church, Conway Community Church, and the staff at Harrison County Hospital. Thank you to everyone who donated and helped **MOVING FORWARD** to "Make a Difference."

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(Answers on Pg. 6)



SPOTLIGHT - by Belinda

Each month in our **Spotlight** column, we introduce you to either a member of our group or an organization in our community. For this special holiday issue, I decided to introduce you to one of our younger members, Erin Clifford. I met Erin this past June at McKeever's First Ride Clinic held near Lexington. I introduced myself to her and found out that she lived in Louisville and encouraged her to come to our Pie and Ice Cream Social. She and her dad attended and have since joined our group. Erin is a kind and determined young lady with a great sense of humor. I know that you will enjoy getting to know her a little better....

Erin has lived in the Audubon Park area of Louisville her entire life. She celebrated her 18th birthday this year. Her family members include her mom, dad, and 13-year-old brother Will. The household also includes a German Shepherd named Zeus and a Bassett Hound by the name of Freddie. Erin said that she hopes to add another pet soon, a turtle. Some of Erin's favorite things include: music by Charlie Puth (Pop and R&B singer), Chick-Fil-A Restaurant (she calls it heavenly), the Disney movie Lilo & Stitch, U of L Women's basketball, coloring books for adults, the American Horror Story TV series, and what she calls "Red Neck" wrestling. She is a huge fan of Zach Gowen also known as the one-legged wrestler. Zach lost his leg to cancer at the age of 8. Erin became an amputee in December 2015 due to a rare form of cancer. She says that Zach has been a big inspiration to her during her recovery. She was able to meet and talk with him recently at a local wrestling event, which she said was AWESOME!



Erin had an interesting job this fall when she worked at a local haunted house. She said that the other workers there accepted her and made her feel like family. This acceptance was very important to her. When asked what has been one of the hardest challenges for her as a teenager following her limb loss, she answered, "Dating, and just meeting and interacting with other people. Sometimes I feel like they just walk away from me and don't want to accept me because of my amputation." For advice to a new amputee, she said to not let it consume you, and to learn to laugh about it. One of her biggest supporters has been her friend Alex, who gave her the nickname "Hop-a-Long".

I asked Erin what she thought about *MOVING FORWARD* so far. She said, "I love it!! My dad really enjoys coming to the meetings and events, too." She said that she would like to see the group continue growing and to attract more young people. Erin also said, "I want to thank everyone for the kindness they have shown me. I really appreciate it!"

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## Krafty Kids ..... by Beverly

Below is a family fun activity for the young ones in your life. Hope you have a memory filled holiday season!

### FINGERPRINT CHRISTMAS TREE CARD

Using a thumbprint dipped in green paint make a tree by applying 6 thumbprints for the bottom, then 5, 4, 3, 2, and finally 1 for the tip of the tree.

- Paint a trunk using brown paint or use 2 thumbprints.
- Apply sequin decorations if desired.
- Allow to dry and write message inside to complete card.



## Q & A

- 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!**

A comment that I hear quite frequently when I go on a peer visit to a new amputee or when a new amputee attends his/her first meeting is, "I wish someone would have told me about the support group before my amputation. It would have been really helpful to talk to someone beforehand." I couldn't agree more. On the few occasions that I have been asked to speak to someone prior to amputation, I have seen the relief that it provides. Most of the time, he/she has not spoken to or come in contact with another amputee. Just seeing someone walking in wearing a prosthesis or hearing that life can still be good following limb loss can make a big difference. I like to say, "A peer visit can take away some of the fear of the unknown associated with limb loss."

Our support group is becoming more widely recognized, and we are asked quite often to visit with an amputee during their stay in rehab following amputation. We can provide the new amputee with support, information, and connect them with available resources. My hope is that we will also become more included in the pre-amputation education process. According to research done by the Orthotics and Prosthetics Foundation, pre-amputation patient education leads to: increased involvement in self-care, decreased pain levels, improved readiness for surgery, decreased anxiety and depression, improved communication between patient and staff, higher patient satisfaction, decreased length of hospital stay, decreased number of falls after surgery, increased rate of seeking emotional support and information, improved expectations for future prosthetic use, and increased patient empowerment toward the amputation.

With increased technology use, people are beginning to ask more questions and to demand more from their healthcare providers. This is a great thing. The loss of a limb or limbs can lead to the feeling that you are no longer in control of your life. With good pre-amputation education, that doesn't have to be the case. I realize that healthcare professionals have limited amount of time for each patient, but seeing the positive results that providing these resources pre-amputation can bring, I feel that they should be willing to take that additional step to improve the quality of care.

If you are facing amputation surgery or have a friend or family member who is and you would like to speak with a trained peer visitor, please contact us.

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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. ****

UPCOMING EVENTS

MEETINGS:

Dec. 19th, Mon., from 6:30 - 8:00 p.m. at Southern IN Rehab Hospital, 3104 Blackiston Blvd., New Albany, IN, in the Conference Room.

**** We will not be holding our meeting at Baptist Hospital East on the 24th due to the Christmas holiday. ****

EVENTS:



CHRISTMAS PARTY – On Dec. 10th from 5 – 8:00 p.m., *Moving Forward* will hold its annual Christmas Party at the Okolona Fire Station, 8501 Preston Hwy., Louisville, KY. There will be food, entertainment, and door prizes. Santa has said that he is planning to attend once again this year and will be bringing each child a gift. We encourage you to attend this joyful event. See the attached flyer or check out our website at ampmovingforward.com for more details.

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## CONTACT INFO

*Call for meeting times & locations!*

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..... from Beverly's Kitchen

Below is a very EASY and TASTY snack that is fun to have around during the holidays. Hope everyone has a safe and happy holiday season!!

SPICED PECANS



1 egg white
1 tsp. cold water
1/2 tsp. cinnamon
1 tsp. salt
1 lb. pecans
1/2 c. sugar

Whip egg whites and cold water until frothy in bowl. Add pecans and stir until completely coated. In another bowl, mix salt, cinnamon and sugar. Add the pecans and stir until completely coated. Pour into single layer on cookie sheet. Bake at 225 degrees for 50 - 60 minutes, stirring every 15 minutes. Cool completely before storing. Enjoy!

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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: [krogercommunityrewards.com](http://krogercommunityrewards.com). **MOVING FORWARD** Support Group receives a percentage of your purchases & it does not take away from your Kroger/Jay C points in any way.

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TEST YOUR KNOWLEDGE ANSWERS (from Page 4)

POINSETTIA, SLEIGH, ANGEL, CANDLE, ELVES, NOEL, PRESENTS, DECEMBER, GARLAND, MANGER, ORNAMENTS, WREATH

A CHRISTMAS WISH: PEACE ON EARTH

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## SANTA'S WORD SCRAMBLE ANSWERS (from Page 4)

TOYS, WISH, BLESS, HOLLY, CHRISTMAS, TREES

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*Seasons Greetings from
Sam & Beverly Gaylord*

*Merry Christmas & the
Happiest of New Years
from Julie & Philip
Randolph*



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