

NEWSLETTER + 16th Edition + Dec. 2014 + SPECIAL HOLIDAY ISSUE

Note from Belinda

It only seems a short time ago that we completed the last December issue. That issue was devoted to helping children to understand and cope with a parent or grandparent's limb loss. The feature article was titled "Through the Eyes of Our Children." To read that article, or any from past newsletters, you can download them at our website: ampmovingforward. com. For the current December issue, we are devoting much of the newsletter to our children once again. This time we will be dealing with the topic of raising a child with limb loss. We, as parents, pray for our children to be happy and healthy, but sometimes that isn't the reality that we must face. When a child is born with limb deformity or loses a limb during childhood, the parent is faced with enormous decisions and financial obligations. They often don't know where to turn for support, advice, or information. We hope that the articles in this issue will provide some comfort and answers for them.

I was very appreciative that Julie and other members of Philip's family agreed to share some of their memories of Philip through the years; including some of the many obstacles that he has faced, and about their love and devotion to him. He has grown into a wonderful and talented young man that we are all truly honored to have as a member of *MOVING FORWARD*. We have all heard the quote, "Behind every great man stands a great woman." In Philip's case, this is not only true because of his mother Julie, whose love and dedication to him is unwavering, but can also be expanded upon to include his family and friends who have nurtured, supported, and encouraged him throughout his lifetime. He is very lucky indeed to have such a remarkable support system.

MOVING FORWARD FEATURE RAISING A CHILD WITH LIMB LOSS

- by Julie Randolph

Raising a child with limb loss from infancy is a different ballgame than someone who becomes a caregiver for an amputee later in life. (Philip's entire story can be found as the Feature Article in the Sep & Oct. 2013 MOVING FORWARD Newsletters.) Philip became an amputee at 10 weeks of age. After the initial healing of his wounds, it just became a matter of watching him develop & watching him devise unique ways to do the tasks he needed to do. While most babies learn to

– Continued on Page 2 Column 1 –

AMPUTEE COALITION ADVICE

inMotion · Volume 19 · Issue 2 · March/April 2009

Prostheses for Children With Limb Differences

Issues and Expectations

- by Douglas G. Smith, MD, and Kellye M. Campbell, MN, ARNP

Children with limb differences tend to adapt remarkably well to a prosthesis, far better than adults in most cases. But there can be bumps in the road, just like there are with almost every childhood and developmental issue.

Prosthesis use will certainly not be perfect every day in every way. There may be times when a parent thinks the child should be using a prosthesis, but the child doesn't want to. When it comes to prosthesis use, children, parents and healthcare teams may sometimes see things quite differently. Although it can be challenging to resolve these issues, it may help to know that conflicts about use and nonuse of the prosthesis can mirror those other disagreements associated with the normal physical, emotional and social development of childhood. It comes with the territory. How does a parent ever know what's absolutely best for the child, whether it's managing a residual limb, wearing a prosthetic device, participating in activities and sports, etc.?

How does a grownup best guide the youngster's decisions? A child's view of himself or herself changes over time, especially with the arrival of adolescence. The issues faced by the boy or girl and mother and father are not constant and static. A variety of physical, social and emotional "blips" show up on the radar from time to time. Sometimes, parents and children value the tradeoffs between the cosmetic appearance of the prosthesis, the function of the device, and the durability of the device differently. Sometimes, for whatever reason, a child wants to be without the prosthesis more than the parent wants him or her to use it. Who should decide – the parent, the child or healthcare workers – whether a prosthesis should be used full time, part time or not at all?

This article looks at the issues surrounding prosthetics and children and offers insights into which approaches to using an artificial limb can be best – for all concerned.

Not All Limb Differences Are the Same

Limb differences may be congenital (something a person is born with) or they may be acquired as the result of an injury or disease that requires amputation. Some limb differences have aspects of both, such as when children have a congenital limb difference and then require surgery to modify their residual limb and make it more suitable for wearing a prosthesis.

Emotional reactions to these types of limb differences may vary. Some of the older medical literature stated that children who are born with a limb difference do not feel a sense of loss because the body with a limb difference is the only body they have ever known. According to this point of view, it's rare in the early years for a child who has a congenital difference to grieve over it because there hasn't been a sense of loss. In other words, you don't lose something you

– Continued on Page 2 Column 2 –

RAISING A CHILD WITH LIMB LOSS (cont'd)

sit up at 6-7 months, it took Philip a little longer because he was top heavy, if you will. He didn't have the full length of his legs to help him keep his balance. He managed to sit up & keep his balance by 9 months without falling.

Philip was always a happy-go-lucky child. He didn't seem to know or care about what he was missing. Since it was all he had ever known, his condition was "normal" for him. He was perseverant. He would attempt any task with a

determination & not stop until he accomplished it. With the help of home visits by a PTA, Philip was able to walk without his child-sized walker at the age of 21 mos. From then on, you couldn't keep him down. With the help of his prostheses, he walked everywhere & attacked life with the same zeal as any normal toddler would. Without the help of fingers, I remember



him stacking blocks so meticulously that every corner had to be lined up perfectly.

As Philip's primary caregiver, I turned my attention to whatever task was at hand so that I had little time to feel sorry for myself. My life focused on taking care of a baby as well as being a wife & a mother of a 3-yr-old daughter. Sometimes it was a battle not to give Philip all the attention & to neglect Joy in the process. It was a tough balancing act. I think that is why Joy started to become an excellent caregiver at an early age. At 11 she began helping to take care of her new baby sister & also helping a lot around the house. She has been an invaluable help to me ever since.

 $\overline{}$

- by Joy Randolph (Philip's older sister)

Helping take care of a brother with limb loss is very challenging in many ways, but also very rewarding. Philip's



natural musical talents and fun personality have served him well. He's endured many surgeries and physical hardships as he's gotten older. He particularly loves the holidays and opening gifts; he becomes instantly "hyper" if it's something electronic

like a radio or watch. It's quite hilarious! Overall, he's a sweet brother with a big heart and he's going to be a great uncle too!

- by Melissa Randolph (Philip's 19-year-old sister)

Growing up with a brother with limb loss has been my "normal" as long as I can remember. Philip has been a shining light in our family. He has taught me so much, being

a wonderful big brother. His bright attitude always made our family so unique. Philip has the courage & heart to be himself, no matter what. He has always overcome all of life's challenges, being so talented at the same time.



 \sim

- by Diane Case (Philip's aunt)

Philip was around 5 when he had to have a cage (Ilizarov fixator) put on his right residual limb. The cage consisted of metal rings connected to pins that went thru Philip's leg and leg bones, and the rings had to be turned by degrees in order to help straighten Philip's leg. I remember that my sister Julie worked nights then and in order to take care of the cage and maintain a healthy condition, the pin sites had to be cleaned morning and evening with peroxide and swabs. When my sister was working, that job had to be done by Dad. The most memorable thing about this to me was Philip's joy and uplifted spirit. He laughed and played with me the whole time that this "job" was being done. Philip's life has been an inspiration to me all along because of his joyful spirit and attitude and the joy he has given others in the midst of unbelievable suffering and pain, not only physically, but mental challenges as well.

- Continued on Page 3 Column 1 -

Prostheses for Children With Limb Differences (cont'd)

never had. Still, as the child grows and becomes more socially aware, there can be a sense of loss or of being physically "different" from those who have fully functional limbs. This can then lead to frustration ("Why me?") and some of the same feelings that occur while grieving.

A child who has an acquired limb difference through surgical amputation, on the other hand, is more likely to feel a profound and deeply personal sense of loss. The boy or girl must adjust to a different way of living with a different kind of body. This takes emotional and physical adjustments. Just as different amputation levels place different demands on a person, the demands resulting from amputation or a congenital difference are different.

Attitude Counts

Parental attitude counts a lot. Children readily pick up on their parents' attitudes, actions and reactions. Like it or not, Mom and Dad, you set the tone. Your acceptance of your child's limb difference and your attitude toward prosthetics can greatly influence how your child accepts himself or herself and his or her prosthetic limb. In addition, the way that you talk to your child, talk about your child, and treat your child all shape how others will behave toward him or her.

Does that mean, then, that a parent should absolutely insist that the child use a prosthesis full time? This can be a complex question, and there is a range of approaches.

At one end of the spectrum are parents who encourage using a prosthesis to the point of forcing it on the child. At the other end are parents who allow the child total autonomy in deciding whether to use one. There are many issues that go with these decisions; while toddlers provide adults with clues, feedback and insights into their prosthesis use, many are just too young to decide for themselves. As in most aspects of child-raising, giving your child total decision-making control regarding his or her prosthesis use has its pitfalls.

In most cases, we believe there's a balance in between that's probably best for all concerned, and this balance changes as the child matures. Infants and very young children with a lower-limb difference can better explore their world by wearing a prosthesis because it helps them get to a standing position more easily. Crawling is a mixed bag. There's a point in their young lives when crawling is good and you want them to crawl. If a prosthesis interferes with their crawling, it probably should be taken off. But there's definitely a time when they need the prosthesis to go from crawling to standing, usually between the age of 8 and 14 months.

For children with an upper-limb difference, the ability to manipulate objects is an important part of their development as they explore their environment. Traditionally, an upper-limb prosthetic fitting is started earlier for infants than a lower-limb prosthetic fitting would be so that they can get their hand and prosthesis to the same level and start touching and moving things. Two-handed activity typically starts near the time infants develop sitting balance, usually around 4 to 6 months of age. A passive terminal device with blunt rounded edges is used initially to minimize injury to child and parent.

A downside to using a prosthesis is that you cover up a part of the body that has sensation. The child may perceive wearing his or her prosthesis as a bad thing because part of the limb that's providing feedback on the world is now encased in the device. Many children would, in fact, prefer not to wear a prosthesis because the skin gives us much-wanted feedback about our surroundings. Though arms and legs both provide tactile interaction with the environment, this feeling is more important in the arms.

Sometimes, it is simply more comfortable not to wear a prosthesis, which can be perceived as an "anchor" that hinders freedom. In fact, even children born with severe differences in both upper limbs often choose not to use prostheses and choose instead to adapt and manipulate objects with their feet.

How about teenagers? When they reach adolescence, children with limb differences undergo the same emotional and intellectual changes as their peers, plus a lot more. Having a limb difference definitely can make this period much more challenging. Because adolescents often don't want to seem "different" from their friends, they may try to conceal their differences. They may wear clothes that mask their limb difference or avoid certain activities, such as swimming. Some teens may even go to extremes to try to hide both the prosthesis and the amputation. Once they are accepted, however, they tend to resume using the prosthesis, particularly if it is for an upper limb.

On the other hand, if the parents have pushed the prosthetic device

- Continued on Page 3 Column 2 -

RAISING A CHILD WITH LIMB LOSS (cont'd)

I am forever grateful to have had the privilege to be a part of Philip's life and have counted it a great blessing to have helped my sister in any way that I could through the years. I could have had no greater pleasure and blessing than that. All my love to a great nephew and sister and her family.

- by Doris Turner (Philip's aunt)

I'm writing this as the aunt of a young man that has spent his whole life with limb loss. Philip Randolph is the son of my oldest sister Julie. He is one of the most positive people that I know. Life without fingers or feet is all that he has ever known, but he has never let it stop him from doing the things that he loves. He has always loved music and singing, but he also loves rhythm, and has not let living without fingers get in the way of learning how to play the drums, and guite well, too. Many people would get frustrated if they cannot do things that others can do, but Philip just digs right in and does it. He is a very determined fellow and is an inspiration to me and my whole family. We don't get to see him as often as we would like, since we live in different states, but always enjoy the opportunity to visit with him when we can. He is willing to help out in any way possible, and doesn't let his disability hinder him from engaging with anyone and everyone. Growing up couldn't have been easy for Philip, with all of the surgeries and pain he's had to deal with, but he has born it all with strength and grace. We are so proud that you are a part of our family, Philip! Rock on!

 α

- by Jed Brewer (Philip's cousin)

It's an interesting thing trying to think what it was like growing up with an amputee cousin. I didn't get to see Philip all that often growing up because of our physical distances apart, but when we did get to spend time together I always felt that he was such a special person. It's come only just recently that I've truly realized just how special and amazing my cousin Philip truly is, though.

As I've stopped to think and contemplate what I was going to say in this little excerpt, it hit me heavily how much strength he's had his whole life. I can't imagine how I would ever handle losing a limb, let alone both my legs and hands, but when most of us would shut down and give up, Philip just keeps on smiling and laughing and looking on the bright side of life. I admire his spirit and his upbeat positive attitude. Even when life gives him lemons he makes his favorite drink of lemonade and drinks it down with a smile on his face.

- by Jerry Brewer (Philip's uncle)

My experience with amputee victims is quite limited, to say the least. In fact, about the only experience I have in that regard is with my sister's boy, Philip Randolph, who lost both hands and both feet as an infant due to lack of oxygen flow caused by bacterial meningitis. In my visits to Philip's home and our times together on vacation or at my home, I have observed several things about the interaction within his family, and I guess you could say I have drawn several conclusions about families in general who have members that have lost one or more of their limbs.

The first thing that comes to mind is the immense amount of patience that is necessary on everyone's part and that inevitably develops in each family member, including, and perhaps even especially, the ones who have lost their limbs. Everything is more difficult and takes longer to do and accomplish. Indeed, many simple tasks seem impossible at first and can only be mastered after weeks or months of perseverance. This can bring a great deal of discouragement to the hearts of all of the family members. There is no way to speed up the process and each family member must feel many times like their lives are being held up or slowed down or perhaps even put on hold for a while so they can devote their lives to helping and serving their

- Continued on Page 4 Column 1 -

Prostheses for Children With Limb Differences (cont'd)

to the extreme, the child might refuse to wear it as a way to rebel and exert independence. We know of one mother whose guilt over her child's congenital limb difference was so great that she demanded that he put on the prosthesis alone in his room before coming to breakfast and that he not take it off again until he was back in his room at night getting ready for bed. When the child reached adolescence, his way to rebel was by refusing to wear the device, even though it was functionally helpful. It became his personal battle with his mother.

Interestingly, in recent generations we've seen more children who emphasize exposure of their limb differences rather than the more common behavior of concealing them. Some do this to express their independence. Others probably do this because society is finally maturing toward the understanding that physical differences should be accepted. Finally, while it is difficult to consider, some may do it in an attempt to gain favor, an advantage, or sympathy. Reasons for this are as varied as children themselves.

Whose Opinion Counts Most?

While parental attitude, care and concern certainly count, does this mean the adult should have the ultimate say in these matters? Some adults who were born with limb differences advocate this. It's their opinion that parents should get their children to wear a prosthesis as early as possible. They say this is a realistic approach and the best way for the children to begin learning their own way through life, even if the children believe that their parents are being "too hard" on them. When the children become adults, proponents of this view say, they'll thank Mom and Dad for insisting that they become skilled and proficient with their prosthesis. At the other end of the spectrum is the "let the child decide" approach. If the child doesn't want to wear the prosthesis, proponents of this view ask, why should we insist otherwise? Perhaps the desire to grant the child autonomy in this decision stems from guilt or a desire to "make things better."

In some cases, parents of children born with limb differences can really beat themselves up trying to determine exactly what might have caused this to happen. We've seen mothers go over practically every minute of their pregnancy in

search of clues: "Was it the day I dropped the bottle of oven cleaner and smelled it? Was it the aspirin I took?" They reconstruct the entire 9 months of pregnancy to try to find a cause. Though we have a better understanding of limb differences today than ever before, in most cases the precise cause of the limb difference remains unknown. The bottom line, folks, is this: Most of the time, we just don't know why it happened. Unfortunately, wearing a prosthetic limb around the clock doesn't make the problem go away. It's the difference that's the issue, not the prosthesis. Wearing a prosthesis might help the child functionally, but it doesn't make the limb difference go away. This attitude is a big hurdle many families face.

The prosthesis is a tool for increasing function, and exposing a child to it is a good thing. Still, although the prosthesis is often very useful, there are times when the child simply does not want it. At these times, it is not useful. Many children simply do not want to wear their prosthesis from the moment they wake up until bedtime.

Children may decide not to use their prosthesis for a variety of reasons. Sometimes, it's just too hot or uncomfortable. They may just want a breather or to feel the regular environment against their skin. But if a child is rejecting it regularly, it may be wise to check whether it still fits well or if it's time for a new one.

There also are times when little ones are just contrary. Take the "Terrible Twos," for example. When Mom or Dad says, "Yes," the child says, "No!" Sometimes, disagreements over prosthesis use may be just part of the normal battles of the Terrible Twos. How to deal with that? You can try to make wearing the prosthesis a game. Or you can get your boy or girl to put a prosthesis on a stuffed animal or doll. A sticker chart or other child-motivational tools and games may also be helpful. Older children may use decisions about prosthesis use as a way of expressing their desire for autonomy, to not be "treated as a baby."

Parents also should ask themselves about their own motivations for prosthesis use. As healthcare providers, we've had parents tell us, "I want a prosthesis my child will wear 24-7, and I want it to look just like the real thing." They're trying to make the limb difference disappear. That can be a natural urge for some family members, but it is just not realistic. If parents don't allow their child time without it, they may instill the concept that it's not OK to be without it. That approach may lead

- Continued on Page 4 Column 2 -

RAISING A CHILD WITH LIMB LOSS (cont'd)

handicapped loved-one. They are to be commended for every sacrifice they make and for every act of love they display. While it may not seem like it at the time, they are slowly developing the extremely valuable character trait: patience, and even greater still, perseverance. There is no quick and easy way to develop those invaluable traits. It is always a long, and usually painstaking, process.

The second observation I would make is that families of limbloss victims are very close-knit. Working so hard together and supporting each other emotionally and physically can only result in greater intimacy and unbreakable bonds. Each member of the family must learn to draw on the other members for their strength and support. When one family member is weak or feels drained of his or her resources, the other members must rally and fill in the gap. The whole family is drawn closer together by this mutual support for each other and an advanced level of trust inevitably develops between each family member.

A third thing that I have noticed about Philip and his family is that they have a tenacity about them that just won't quit. While other families going through hardships may let their set-backs get the best of them, the Randolph family has remained positive through it all. It seems that they have made a conscious decision to see the glass half full, if you will, and to seize the opportunity to become stronger individuals and a stronger family. They have looked adversity squarely in the face and chosen to be enhanced by it rather than devastated. Words cannot express how proud I am of them and other families like them who choose to go forward when life tries to knock them backward. Their reward will be great as they allow their characters to be molded and developed by their positive response to adversity.

Lastly, I have noticed that families of limb-loss victims have a greater appreciation for the simple basics of life. Everything is more precious to them because they realize how quickly things can be stripped away from them and how empty their lives can seem until they learn to adjust to their situation. The things that most of us take for granted take on a new and heightened value for those who are learning to live without them. I have seen this in Philip's family and it has made me re-examine my own priorities in life. For that I am deeply grateful to each member of the Randolph family.

 α

"Merry Christmas from the Randolph Family!"





QUOTE OF THE MONTH

Prostheses for Children With Limb Differences (cont'd)

the child to feel ashamed of the limb difference – an outcome that is both undesirable and unhealthy.

A balanced approach may well be best. Parents are there to provide guidance, wisdom and understanding. They have experience. They know there are things that a child doesn't want to learn or do but that he or she will be grateful for as a teenager and adult. Still, the wise parent also realizes that there are times when a child's desire not to use the prosthesis should be indulged. Perhaps it's uncomfortably hot, and the child doesn't feel there's any need to use a prosthesis for immediate activities. Flexibility in attitude counts.

How Often Does My Child Need a New Prosthesis?

Children grow. Their bodies change, and just as they outgrow shirts, pants and shoes, they will outgrow their prosthesis. How often is a new prosthesis required for a growing child? Although young children certainly can exhibit many physical changes in very short periods of time, we believe it's a mistake to replace the prosthesis every few months. That's just too often. Each new prosthetic limb takes some getting used to. Traditionally, when a child gets a new prosthesis, it's oversized to give the boy or girl a period of time to adjust and grow into it. Children typically get a prosthesis they'll grow into; otherwise, they'd be too big for it in no time.

Most people believe that a child who receives a new artificial limb too often never fully adapts to the one he or she has. The child is always adjusting to a new one, and that takes time. There's a balance between allowing the child enough time with one device to become totally accommodated so that he or she can take full advantage of it and changing so often that the child is always in that stage of getting used to a new one.

In addition, fitting, fabricating and aligning a new device takes time. It's often several months before the kinks in that process have been worked out. Therefore, you want the prosthesis to function as long as possible. That's why some modular, adjustable features can be built into the device for minor adjustments during growth until a whole new prosthesis is needed.

Though there's not a lot of detailed literature on the exact frequency of replacing limbs, a study by Dr. Claude Lambert at the University of Illinois found that children, on average, require a new lower-limb prosthesis annually up to the age of 5, every two years from ages 5 to 12, then every 3 to 4 years to the age of 21.

You're Going to Get Blamed!

Most adults who grew up with a limb difference believe that when they were young their parents were harder on them than they were on their able-bodied brothers and sisters. Their parents may have decided to challenge them a little more because they had bigger obstacles to overcome, both physically and socially. Count on it, Mom and Dad; there are going to be times when your child says you're being too hard on him or her. But when most adults look back on their childhood, they have bigger regrets over what their parents did not make them do than what they made them do. "Why didn't you make me learn to play the piano?" for example. "Why didn't you insist I learn a foreign language?" Not insisting that the child with a limb difference do something can backfire later. You may be setting your child up to be worse off as an adult. It's a wise parent who says, "I love you, but you're going to do this because I care more about the adult you're going to become than the child you are right now." On the other hand, some parents just want to be "nice" to their child with a limb difference. While this sounds pleasant, this recent definition of nice puts things into perspective. "Nice – a pleasant and non-confrontational attitude that uniformly leads to disaster."

Role Models

When it comes to role models for children, nobody counts more than Mom or Dad. The parents' attitudes, insights, abilities, personalities, actions and reactions are readily picked up on by their offspring. Siblings and other close relatives are also important. Children zero in on the attitudes of all of these relatives. If limb differences are talked about in a negative way, either in or out of the child's presence, the child will notice. Children are very keen observers of the ways their parents interact with the rest of the world. They notice when their parents display one set of attitudes at home and another for the rest of the world. You may think you're cleverly masking inconsistent attitudes, but you're probably not. And the acorn doesn't fall far from the tree.

Other role models are also beneficial for growing children. Most

- Continued on Page 5 Column 2 -

TEST YOUR KNOWLEDGE

In place of our usual "Test Your Knowledge," we are including a holiday puzzle for the young or the "young at heart". If you have a child or grandchild, we encourage you to spend some special time with them completing the puzzle and to check out Beverly's **Xrafty** **Xids** column. You can find the Answer Key at the bottom of PAGE 7.

How Sweet It Is		
CEOOISK		11
IETFKUCAR		
CHNPU		·
NGGOEG		
GAERDBERNIG		
OOTELCAHC		
USNT		
NOAEGR		
PEALP		
CADYN CAEN		
IREDC	<u> </u>	
IEPMPTRENP		
NOMNANCI		
YCNDA		
UDGEF	8	
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15

J'm Moving Forward . . .

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



Our children anxiously awaiting Santa at last year's Christmas party. Seeing those happy faces encourages us all to "move forward".

Prostheses for Children With Limb Differences (cont'd)

people believe that exposure to others with limb differences, especially those who have mastered certain activities, is a very positive thing. When children with limb differences see highly accomplished individuals doing great things both with and without prosthetic devices, such as a world-class swimmer, an artist or a public leader, they begin having mental images of themselves also becoming accomplished. Though they will not all become superstars, this instills in them the idea that, regardless of a limb difference, they have greatness inside of them that can be tapped, nurtured and encouraged to grow.

We generally believe that having children interact with others who have limb differences is a good thing. We know of one girl who lived in a small town and had never met another person with a limb difference. It wasn't until she attended a summer camp for children with limb differences that her true sense of self came out. She realized that she wasn't "different" from everybody else, that others in the world had limb differences too. The camp provided an environment where the limb differences did not matter because she saw them everywhere. She and the other kids were then just kids. This young girl really came out of her shell during this camp, and she carried this new attitude with her back to her small town.

But many parents agonize over whether their child should go to a regular summer camp or a camp for those with limb differences. In an ideal world, these children could attend both. But that isn't always financially possible. We've found that most youths who attend a camp with other amputees realize the value of spending time with others their age who also have limb differences. It gives them the opportunity to share experiences and feelings with others who are in similar situations and who understand them. These experiences can have a tremendous impact on a growing child.

Summing It Up

There are many issues and challenges surrounding limb difference and prosthesis use for children and parents. As actress Cicely Tyson has said, "Challenges make you discover things about yourself that you never really knew. They're what make the instrument stretch, what make you go beyond the norm."

Parents, maybe even more than children, will learn, discover and grow. How we deal with the successes and the challenges defines who we are as individuals and as families. One single set of rules or answers simply does not exist when raising a child with or without a limb difference. We cannot look into a crystal ball and see what the future will hold. But what we can do is work hard to bring their abilities, gifts and talents to the surface, nurture them, watch them grow and ultimately let them go.



Krafty Kids ... by Beverly

This is an adorable craft that is particularly great for preschoolers. With the handprints and footprint, it is a great keepsake.

What you'll need:

- Light brown construction paper
- Dark brown construction paper
- 2 googly eyes
- Red pom pom
- Scissors
- Glue

How to make your Handprint Reindeer

- Trace your child's foot onto the dark brown construction paper and cut it out.
- Trace both of your child's hands onto the light brown construction paper and cut them out.
- Glue the two handprints (at the wrist portion) to the back of the footprint (up near the toes) to be the antlers.
- · Glue two googly eyes onto the footprint.
- Glue the pom pom onto the heel of the footprint as a nose.

^{**} If you would like to submit a picture of you 'moving forward', send it to Belinda or Julie. **

RECAP OF NOVEMBER

To honor our veterans, 30 Care Packages were delivered to the VA Hospital the week of Veterans Day. More will be delivered in Dec. with

special holiday treats. We would like to thank everyone who helped to make this possible, whether you took part in our Walk & Roll Fundraiser, sponsored the event, donated items, or helped to assemble the packages; we could not have accomplished this without your generosity.

On Monday Nov. 17th, MOVING FORWARD held its IN meeting at Southern IN Rehab. Belinda led a discussion about the emotional aspects of limb loss. She discussed the 5 stages of grief, the differences between grief and depression, and shared memories of her own progression thru the 5 stages. She also talked about how you may progress to one stage only to fall back to the one before. She discussed how these emotions are a normal part of the healing process and how each person's experience will be unique. Other members shared memories of their recovery, including Kelly, who has been an amputee since she was a child. She told of going thru the grieving process following her revision surgery. We also discussed how sometimes we have to push ourselves beyond our comfort zone and conquer our fears in order to reach our goals. Following the discussion, Mike presented the group with some small bears that a friend had sewn to be included in our Children's Care Packages.

On Sat., Nov. 22nd, our KY monthly meeting was held at Baptist East. We discussed a multitude of topics at this meeting including care giving, our Peer Visitor Program, our Care Package Program with the VA Hospital, our upcoming Christmas party, ways to help fund our newsletter and other programs, and friending each other on Facebook. November was Caregiver Appreciation Month, so each caregiver in attendance was given a 2015 calendar as a way to thank them for helping us to make it through this year and looking forward to the next. A drawing was held among the caregivers with the winner receiving a Cracker Barrel gift card. Shelton Jacobi was the winner of the drawing. Each person attending received a packet of helpful information and resources for caregivers, along with a beautiful poem honoring those special individuals who take care of others.



. . . from Be<mark>verly's Kitchen</mark>

BACON, BROCCOLI, CAULIFLOWER SALAD

Fry 1 lb. bacon crisp, break into pieces

Cut cauliflower, broccoli into flowerets. (Can also use some chopped tomatoes l& onions.)

SAUCE:

1 c. Miracle Whip 2/3 c. sugar ½ c. vinegar ½ c. oil

Bring sauce to boil. Let cool. Pour over vegetables & bacon. (You may substitute low-fat mayo & turkey bacon.)

The following is a delicious salad recipe that my mom makes for the holidays. It may be called "Cherry Salad", but it tastes more like a dessert. It will melt in your mouth.

CHERRY SALAD

- 1 can Cherry Pie Filling
- 1 can Eagle Brand milk
- 1 cup chopped Pecans
- 1 box Cool Whip

#2 cans drained crushed Pineapple

Mix together and refrigerate until ready to eat. Enjoy!

UPCOMING EVENTS

Monday, Dec. 15th – Belinda, Kelly, and Mike will be giving a presentation at Brown Mackie College to a group of Occupational Therapy students. This not only allows us to let more people know about our support group, but also gives the students the chance to learn valuable real world knowledge. *MOVING FORWARD* welcomes any opportunity to support students dedicated to helping the amputees in our community.

Monday, Dec. 15th – We will be holding our IN meeting at Southern IN Rehab Hospital from 6:30 - 8:00. This will be an open topic meeting, and we will also discuss some plans for the upcoming year.

NOTE: We will not be holding our KY meeting in Dec., due to the holidays. We will begin again on Sat., Jan. 24th, at Baptist East from 2 – 4pm. We look forward to seeing you in 2015!!

Special Note: *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 that 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.

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

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 guestions.**

Being an amputee presents us with unique challenges and added stress upon occasion, but during the holiday season that stress can become overwhelming; especially for new amputees, who are trying to adjust to their new way of life. The question that I have chosen for this issue is, "What do you do to help relieve some of the additional stress that you face during the holidays?" Several group members responded, and I am sharing those responses with you in hopes that one or more of them may be of benefit to our readers.

Valerie says, "I usually try to do some crafting, or take a long bath with some music and a glass of wine. Then I just sit down and relax for a while. Sue stated that she used to work retail, so her stress relief was quitting her job. She says that she enjoys the holidays a lot more now with very little stress. Kelly said that she just tries to focus on all that she has when feeling stressed. Colleen goes for a run or relaxes with a glass of wine. Julie practices deep breathing when feeling stressed and finds that it really helps. During the winter months, Philip likes to unwind with a mug of hot chocolate. Shelton enjoys watching sports, which helps to get his mind off the stress for a while. I try to make time to enjoy the beauty of the season. Whether it be going on a holiday home tour, a garden center such as Walnut Ridge to see all the beautiful decorated trees, or for just a walk outdoors. Another thing that I have found that helps is shopping during off-peak times. I know that

- Continued on Page 7 Column 2 -



SPOTLICHT - by Belinda

Our spotlight this month shines on the children of our support group, for there is nothing more wondrous than the "light" in a child's eye during the holiday season. I asked them to send me their letters to Santa, with the promise that we would email our newsletter to Santa at the North Pole, so that he too could read them. So, Julie, would you please add Santa to our email list?

Dear Santa,

I have tried to be a good boy this year. I want a remote control boat, cap gun, and a Skylander's Trap Team game for Christmas.

Thank you, Santa, From Patrick (Reid's older brother)

Dear Santa,

I have been good this year. I would like a remote control motorcycle, a stuffed animal, and sweatbands this year for Christmas.

Thank you, Reid (our youngest member)

Dear Santa,

I have been a good boy. I want a Power Ranger watch, an ice cream truck, and a fire fighter costume. Have you been playing with Rudolph? I have a dog named Orville, and 3 cats Mellow, Mama J, and Max.

Thank you, Deklan (Belinda's grandson)

Dear Santa,

I have been good this year. I got a very good report card, and I like school and my teacher, Miss Mattingly.

I love my family. I would like a snow cone machine, a new game for my X-box, a race track with a loop and cars, and a stuffed animal. How are you doing Santa?

Thank you, Carter (Belinda's grandson)

Dear Santa,

My name is Maggie. For Christmas I want Barbie, Hello Kitty, army man, a picture to hang, a lamp to light up, and a reindeer. I have been a good girl.

Love, Maggie (Mike's granddaughter)

Dear Santa,

For Christmas I want the Lego City Artic Set. I also want a Lego Halo set. I don't know which one yet, but I will find out.

Love, Cameron (Mike's grandson)

Dear Santa.

I want an Elsa dress and Princess Skates.

Love, Abby (Kelly's daughter)

Dear Santa,

I want to give you a tank top and some suckers. I would like a Lightning McQueen 2 remote control car and a skateboard.

Love, Grant (Kelly's son)

I hope you enjoyed that as much as I did, and I would like to share one more thing with you. While helping Carter to write his letter, he expressed that he was afraid that he hadn't been good enough this year for Santa to bring him anything for Christmas. I asked him why he felt that way. He said, "Sometimes I am mean to my little brother (Deklan)." You can believe me when I tell you this is a two-way street. I assured him that Santa has been doing this for a long time and understands that brothers can't get along all the time.

Merry Christmas to all of our children, and I hope that Santa brings you everything that you asked for!!!



Maggie with Santa at last year's party

Q & A (cont'd)

there are people who actually get a rush from the crowds and the chaos, but I am definitely not one of them.

There is an excellent article at <u>moneycrashers.com</u> entitled "9 Tips for Holiday Stress Management Relief," and I encourage you to read the entire article. The 9 tips are:

- 1. Unplug one day a week. (This may be unrealistic to some of us, but we can unplug for at least a few hours).
- 2. Force yourself to slow down.
- 3. Discover the joys of small things.
- Give to charity. (This can become a wonderful family tradition.)
- 5. Reduce. Go for quality over quantity.
- 6. Get some exercise.
- 7. Learn to say "NO".
- 8. Have realistic expectations.
- 9. Don't overindulge.

I saved Marcia's response for last. Marcia says, "I just give my worries to God and go on about my day, because He is the only one who can help." No matter what your faith, the holiday season can be a wonderful time to enjoy special times and traditions with family, friends, and loved ones, and to be thankful for all that we have and to share with those who have so little.

Thank you for all the questions, and we look forward to answering more of them in the coming New Year.

7est your Knowledge Answer Key (from Page 5)

CEOOISK COOKIES

IETFKUCAR <u>FRULICAK</u>

CHNPU PUNCH

NGGOEG <u>EGGNOG</u>

GAERDBERNIG $G \perp N G \in R \times R \times A \to D$

OOTELCAHC CHOCOLAIE

USNT <u>NUIS</u>

NOAEGR <u>ORANGE</u>

PEALP <u>APPLE</u>

CADYN CAEN <u>CANDY</u> <u>CANE</u>

IREDC $\underline{C} \underline{L} \underline{D} \underline{E} \underline{R}_{10}$

IEPMPTRENP PEPPERMINI

NOMNANCI <u>CINNAMON</u>

YCNDA <u>CANDY</u>

UDGEF <u>EUDGE</u>

Visit http://www.theholidayzone.com today for more free holiday & seasonal resources. Find puzzles, worksheets, coloring pages, craft ideas, songs, finger plays, whole language activities, printable word walls, ESL/EFL discussion topics, children's literature recommendations, & more.

LET'S GET MOVING!

AMPUTEE COALITION ADVICE in Motion Nov Dec 2010

Exercise for Optimum Function Functional Strength Training for Amputees

- by Robert Graham, MS, & Karen Sullivan-Kniestedt, PT

http://www.amputee-coalition.org/inmotion/nov_dec_10/strength_training.pdf

We are continuing this column from last month's issue. Please refer to the November issue for the "Tips to Exercise Safely", before you attempt the following exercises. Exercise can be very beneficial in helping to relieve some of that extra stress that we face during the holiday season, as well as helping to keep off those extra pounds that seem to sneak up on us this time of year. So Let's Get Moving.....

Quadruped Arm / Leg Lift (Alternating)

Kneel on a soft surface to cushion knees. Reach opposite arm and leg out while maintaining neutral spine (do not arch neck or back). Repeat on other side. Perform with prosthesis on.





Push-Ups

Start in the down position with hands just wider than shoulders. Keeping knees on the floor (OK to pad with a pillow), straighten elbows while maintaining perfectly neutral spine. If your lower back arches, or if you are unable to keep your head from falling forward, then work from

an incline position using a countertop, not the floor. To make it more difficult, work from the toes instead of the knees.



Use support for safety, and it's best to start with light toe-touch on non-weight-bearing leg. Engage core muscles while standing on one leg. If able to balance for 5-8 seconds, then increase difficulty. Options: Turn head from right to left and/or look up and down. Rotate upper trunk from right to left. Class one available both even



right to left. Close one eye/close both eyes. Slowly swing other limb forward/back or out to side.

Strengthening



Lateral Balance Reach / Lateral Lunge
Standing at a counter, engage core muscles
and reach one leg out to the side while
maintaining tall, straight posture in the trunk.
Options: Keep body weight over the one leg
and reach opposite leg out to the side and
lightly toe touch (balance reach) or transfer
body to outside leg then return (lunge).

Stand to Sit / Sit to Stand

Engage core muscles and hinge at the hips, keeping spine neutral. It's fine to have feet

uneven, especially if there are movement restrictions such as having a fixed ankle. To Sit: Bend knees and lower into a secure chair; don't let gravity win and just plop down into the seat. To Stand: Scoot to front of the seat and place one foot forward. Push down into feet to stand up. Rely on the leg strength with minimal rocking to throw the head forward and back or the arms to push/pull.



BEREAVEMENT ANNOUNCEMENT by Belinda

It is with great sadness that I must tell you that one of our members, Wanda Baird, has passed away. Wanda joined our group just a few short months ago, but during my visits with her it seemed as though we had known each other for much longer. I enjoyed hearing of her travels while working for the US Postal Service and of her love and devotion to her daughter, Marla. Our deepest sympathy goes out to Marla, Paul, and the rest of her family, friends, and loved ones.

CONTACT INFO

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

Kjreitz2012@gmail.com

812-572-7955

Beverly Gaylord, Secretary

gaylordm@aol.com

812-989-4177

Julie Randolph, Treasurer / Newsletter Editor

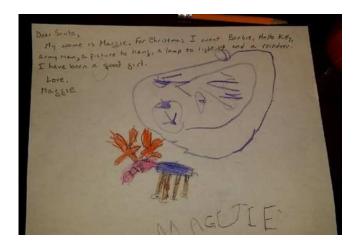
jbrsweepea@yahoo.com

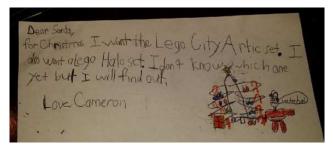
812-557-3970

Mike Portman, Board Member-at-Large

mdportman712@gmail.com

502-262-8344





Merry Christmas & Happy New Year from Moving Forward Limb Loss Support Group!