

Newsletter



Fall / Winter
2010

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From The Founder

My Dear Friends,

Each time I begin to write to you to express the feelings inside of me for the countless things you do for Alexandra's House, it is harder and harder because the English language is insufficient! There is not a word or a phrase that adequately expresses to you our overwhelming gratitude. So all I find myself saying over and over is that you would have to cut my heart open and only then would you know the depth of awe you inspire in me.

It is astonishingly the approach of yet another year's end. So as I see this time period ahead, my desire is to thank you for another year of your love and support, your prayers, your encouragement, your service, your presence. So this is why my tongue is tied, again. Please accept our pitiful words: thank you.

Perhaps we can put this gratitude into action by striving to serve our families and their treasured babies with the utmost dignity and respect and by making you proud of your association with Alexandra's House.

Please know that as we awaken every day, we express our gratitude to God for commanding another dawn and for having brought you into the life of Alexandra's House and that as we go to sleep, we offer Him our prayers for a safe and renewing night for all and blessings to each one as countless as the stars.

Much Love,
Your Patti



Enchanted Evening

The Second Bow Ties for Babies Gala, organized and hosted by the Friends of Alexandra's House as a way of raising sustaining funds for Alexandra's House, took place September 11 at the Plaza Intercontinental Hotel Rooftop. Certainly the nighttime view overlooking the Plaza was magnificent, but it was nothing compared to the real magic on the inside.

One hundred and forty guests enjoyed a lavish meal, a spellbinding presentation by keynote speakers Megan and Thad Halstead, parents of baby Caitlyn Grace who died from a lethal birth defect, opportunities for great conversation, and music and dancing, with the very fun and exuberant DJ Glo.

We are so very appreciative of the Friends led by Joan Brisimitzakis and Martha Hubbard and the Bow Ties Committee, every person who worked to make this event so successful, those who donated items to support their silent auction, those who

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contributed financial support, those who purchased tickets, those who prayed for its success, the marvelous crowd that attended, and all who participated in any way.

Being a witness to this beautiful crowd who all gathered for the sole purpose of helping our babies, the most fragile among us, unborn children with fatal anomalies who cannot cry, who cannot ask for help, was an honor. From our deepest hearts, thank you.

Details of next year's event will be posted on the website: www.bowtiesforbabies.com, once plans are finalized.

**For more information,
call 816-931-5378.**

Bow Ties for Babies Stars



DJ Glo



Thad & Megan Halstead

What Loving and Caring Hearts and Hands Can Do!

By Helen Panebianco

On Saturday, August 7, 2010, Shawn Burns and his crew (Charles, Dave, Frank, Bryce, Don, Richard, Tracy and Debra) from Village West Assembly of God volunteered their time and talent to Alexandra's House. They painted our walls, doors and molding, caulked and painted our outside doors, sealed our tile at the base of our stairs, installed our door sweep, replaced flood lights in the back yard and bulbs in our front porch chandeliers, checked our gutters and downspouts and repaired where needed, scraped and painted a baby crib, did a little tuck pointing around the base of Alexandra's House, caulked around the floor of our upstairs bathroom and even swapped out a toilet seat in the downstairs bathroom.

We felt Our Lord's presence throughout the hours that Shawn and Crew were here, not only because of their time and talents but because they laughed and rejoiced with us and the ministry of Alexandra's House. They were such a wonderful example of what Our Lord wants us to be to one another, reaching out their hands whenever and wherever needed.

Shawn and some of the same people also helped out two women who had a tree fall on their roof. So, we know, Alexandra's House is not the first or last recipient of these loving and caring hearts and hands.

Many thanks to each and everyone involved with helping the ministry of Alexandra's House. We know how blessed we are.



*Front row (l to r): Shawn, Frank, Don and Tracy
Back row: Charles, Dave, Bryce, Richard and Debra*



Footprints From Heaven, a newly established charitable endeavor, was inspired by all of the stories I have heard in the last 15 months of parents walking out of emergency rooms empty handed: No child and no mementos, just a cold, dark, horrific experience.

Yes, I had the same horrible loss (her fourth child Frankie died of SIDS on Mother's Day in 2009) but the experience was made better because my family gathered precious memories for me. I also had the pleasure of helping with a "pack it party" for Champ's Wee Care Packages and a light bulb turned on in my brain. If it had not been for my huge Irish Catholic family I would have been lost when Frank died. Luckily, my family's love for funerals helped school me in what to do when I lost my son, but that is not the case for everyone. I wanted to do something for people who were experiencing an unexpected loss of an infant at home.

The shock alone of losing a child, period, is not something a parent even thinks about, so when it happens, you don't even think about what you will wish you had a year from now. Our boxes will be packed with a blanket to hold your baby with, a footprint/handprint molding kit, a special box to collect a lock of hair, an everyday grief book, a list of resources in your area that parents and family members may turn to for help, letters from grieving parents, and a resource check list for planning a funeral.

I hate that this is necessary, but I am also so hurt when I hear of a family with a recent loss because we have not been able to get our boxes up and running quite yet and they would so benefit from them.

We sponsored a golf tournament in September in memory of Kyle and Frank. Kyle is another baby who passed away from SIDS. My children raised money all summer with Lemonade Stands to contribute to the tournament, which will in turn fund the boxes for Footprints from Heaven. They raised over \$700 and sponsored one of the holes for the tournament. I am a proud Mother and God has graced me with some amazing people in my life.

Yes, our tragedy is great, but the gratitude we feel to God for allowing us the honor of Frank as our son, far exceeds our grief.

To learn more, visit their website: footprintsfromheaven.org

Family & Friends Reunion Scheduled for December 11!

Alexandra's birthday, which is on December 12, fell on a Saturday last year. As a way of honoring her memory, several of our Alexandra's House families suggested having a party in her honor. As the plans for this celebration ensued, Santa, who has a special heart for hospice children and in spite of his very busy schedule, offered to come to Alexandra's House that same day to visit with the surviving children who would come for this event.

The day turned into such a joyous one. For those of us who have witnessed the deep sorrow and tear-filled eyes of so many of our couples over the years, to see their eyes now filled with light and delight at seeing their healthy children doing normal childhood things, like sitting on Santa's lap and their faces stained with birthday cake, was a great wonder for us to behold. It was also a jam-packed house!

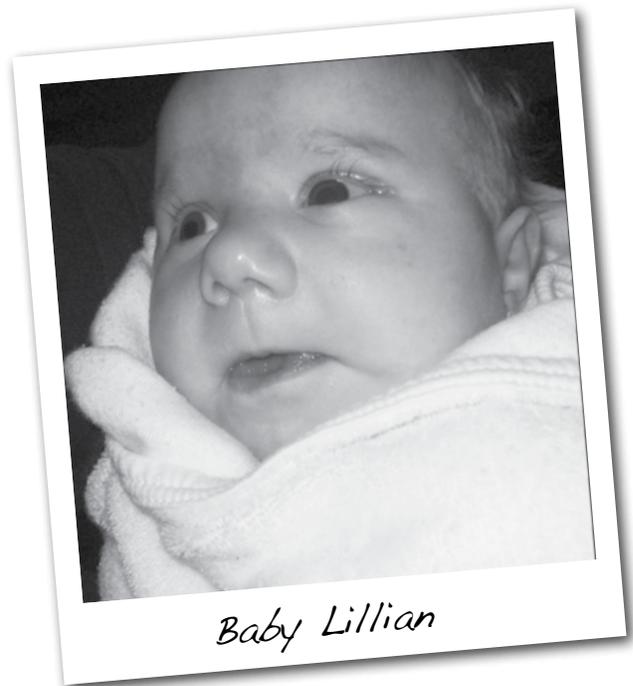
After polling our parents earlier this year, they voted to discontinue our annual retreat, as grief groups are meeting at least twice monthly now, in favor of a year end party to celebrate the joy of life. The only problem now was how to fit everyone into Alexandra's House at one time.

We began looking for alternate spaces when the wonderful staff at Redemptorist parish at 33rd and Broadway in Kansas City, Missouri offered us the use of their Sullivan Center for this year's reunion. Santa is joining us again!

Not only did Fr. Benden, pastor, the Redeptorist community, and their parish administrator Marla Mirabale along with several of their parish committees, agree to allow us use of this lovely facility, they are going to provide all the decorations for Santa's wonderland and they are providing all the snacks! As if that is not generous enough, they are seeking volunteers who will provide other activities to thrill the children, like face painting. This has left us awe-struck.

To further overwhelm us with kindness, the Charles and Jeannie Haake family of Leawood has chosen to adopt Alexandra's House and this event as their family Christmas project for 2010. The precious Haakes will provide the token gifts Santa will give to each child after they present him with their wish lists. The activities are scheduled from 2:30 until 5:30 pm.

If you can, join us to witness and share in the fun, as we take time to celebrate the Joy of Life. Let us, in return, have an opportunity to thank you for all you have done to make Alexandra's House so special.



Lillian Faith Brown ***(And What She Shared With Alexandra)***

By Lillian's Grandmother Vickie Humphrey

At about 28 weeks gestation, my daughter Molly and her husband Steve found out that their baby Lillian had complex congenital heart disease, the type that is common with DiGeorge syndrome. Instead of doing further testing, they opted to wait until birth to learn the diagnosis.

On September 27, 2008 at 6:09 a.m. at Barnes-Jewish Hospital in St. Louis, Lillian Faith Brown graced this earth with her beautiful face. We were told at some point that she had an extra digit on each hand, but not to worry, for "we see this all the time and the digits are easily removable." After a brief bonding moment with her family, Lillian was transferred to St. Louis Children's Hospital.

Lillian underwent placement of a cardiac shunt, had complicated nasal passage malformations, and endured lots of testing and multiple interventions. Then the genetic tests came in and everyone was shocked. She did not have DiGeorge syndrome but was found to have Mosaic Trisomy 13.

On October 16 sweet Lillian got to go home with her family. A big brother and two big sisters happily greeted her. They struggled through many doctors' appointments and the day-to-day balancing of a seriously ill baby and three other children. The days turned into weeks and soon became more manageable.

Then from November 7 through the 12th, Lillian was hospitalized because of respiratory failure. She underwent many tests, had feeding difficulties, and began her vaccinations.

Sunday November 23 was the turning point. Molly and Steve had adamantly followed the doctor's orders and kept Lillian home for two to three weeks so she would not be exposed to any illnesses. The Sunday before, they had taken her to church for the first time for her dedication ceremony, but this Sunday was different. Something told them to stay home.

They had a really peaceful day. Lillian slept and ate and slowly increased her feeds all day. Everything seemed to be getting better. .

Then about 3 pm, after receiving an antibiotic, Lillian began having trouble breathing. This waxed and waned and then worsened. About 7:30 she was taken to the ER.

By the time we got there, we noted that her eyes were fixed and she was unresponsive, but still breathing. At that point we decided not to place her on life support. Later that evening, she stopped breathing on her own. Lillian Faith Brown passed away at 9:38pm November 23. She survived for 57 days but we will love her forever.

After Lilly had passed away, we were so sad and angry that no one had explained to us what Trisomy 13 was. My daughter Amanda was searching the Internet and came across Alexandra's House web site and talked with someone there about how Alexandra's House came to be.

We wanted to start some sort of thing here in Quincy because any time there is a really sick baby in our town, they are shipped to St. Louis for treatment and the parents have no support locally. We were excited about the little handprint pins you distribute because of Lilly having 6 fingers on each hand too and are grateful you sent us our own so we can honor Lilly's life by wearing them.

When something like this comes out of the blue, you are really lost and don't know where to begin. We actually are making and donating to various benefits something we call Lilly's Lovies. They are just little blankets about 18 inches square. We include Lillian's story with every one that we give away.

Sisters of Charity Extend Their Charity to Alexandra's House

If you visit Alexandra's House one of the first things you might notice is the collection of religious pictures and statuary placed throughout its many rooms. Early on we decided to create a prayer chapel to help spiritually sustain those of us who serve the apostolate. We were drawn to the idea of finding old religious items that had been discarded from whatever sources, inspired by their history and the devotion they evoked in past generations. Little did we know that this search would lead us to the Sisters of Charity of Leavenworth and Sister Mary Kathleen Stefani.

During our first conversation we told Sister Mary Kathleen that we simply hoped to find a few small pews and kneelers. She invited us to visit their Motherhouse in Leavenworth, which we found to be so beautiful and peaceful. With her, as we learned, typical generosity, she not only set aside some of the things we requested, but she also allowed us to tour their attic and a large storage area on the grounds and to have our pick of a variety of items that grace our home today.

Through Sr. Mary Kathleen we met many of her community members including Sr. Sue, Sr. Rita and many of the other active sisters as well as a

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number of them in residence in their care center. We were so moved by their warmth and hospitality. It is true that every where we look at Alexandra's House, we are reminded of the Sisters of Charity of Leavenworth because so many of the most beautiful objects here came from their own convents. But the Sisters didn't stop there. They remember Alexandra's House in their year-end giving as well.

Along with her community, we too mourn the loss of Sister Mary Kathleen Stefani who died at age 84 on Saturday, May 1, 2010 at KU Medical Center. It has been our great privilege to have this wonderful relationship with her and this esteemed group of sisters who have established hospitals and universities, inspired countless numbers of people and accomplished so much in the service of others and the glory of God, yet continue to be such humble servants.

We are so grateful to the Sisters and will never forget Sr. Mary Kathleen.



Sister Mary Kathleen



Joni & Finn

An Unexpected Gift

When her husband's professional obligations necessitated a really big move, to Toronto, we lost one of our deeply cherished volunteers in Joni Rauen. Although she is away, our friendship is still very strong.

Recently Joni wrote to us saying that her 40th birthday is looming and, in lieu of presents, she asked that her friends make contributions to Alexandra's House instead. While this is remarkable, what she said at the end of this conversation was most amazing. It was:

"I will be thinking of you on my birthday and during my party. And in my "winding path" to 40, please know that Alexandra's House truly played a big part in shaping me, and honestly was a big factor in giving me the courage to have my third child-- despite my age and despite my fears of something "going wrong". You taught me that any child that I would bring into the world would be special and meaningful and add love to my heart; healthy or not. And you didn't just teach me that, you made me really believe it. Yep, you are one of those people that were part of God's plan for me. And that's a really big deal."

This message lets you see a bit of the goodness we find in Joni but it allowed us to see yet another fruit born of our babies' lives, parents approaching the mysterious journey of pregnancy with hope, trust and without fear. And that's a really big deal too!

Joni's breathtaking insight is gift enough. We thank Joni for sharing it and wish her a wonderful fortieth year enjoying life with her beautiful family.

A Perfect Match

Two of the loveliest women we have ever met, Mary Patrick and her mother Kathleen Rife were on a mission. They wanted to offer their company's handyman services to a few life-affirming organizations whose need matched their gift. Their search led them to, among others, Alexandra's House. With lots of love, energy and great organizational skills, the two ladies along with their experienced remodeler Chip, all went to work providing some wonderful upgrades to our basement area, which included adding a utility sink, additional lighting and freshly painted bead board to spruce up the dull, dark walls. It was hard for us sometimes to stay focused on our projects as we all developed such a sense of friendship and spent wonderful hours sharing stories of our families and our faith.

Time passed far too quickly and soon the trio was off to share their goodness with the next group.

Weeks passed and then we received a phone call from Mary. A member of their family experienced the death of a newborn. Little did we know that after they so kindly met some of our important needs, we would be called upon to help them in theirs. Mary comments: "Baby Thomas was most adorable and a precious memory for all of us." She adds: "(This story) reminds me of one of our favorite scriptures, of how Our Lord goes before us and encloses us from behind."

Needless to say, our bonds have just grown stronger.

Accountants Add Beauty

For a second year, a group of female accountants, aided by a couple of great fellows, spent their Mothers' Day weekend working at Alexandra's House cleaning up garden areas ravaged by winter and creating new and interesting landscape features, all to provide a beautiful environment for our families to enjoy.

Mothers' Day fell on the Second Saturday of May, which coincided with Second Saturdays, one of the days of each month set aside for our parents to meet for their grief support. Rather than being at home, many of our couples wanted to spend their Mothers' Day together at Alexandra's House. Twenty of them joined together that day, sharing memories, stories, a potluck lunch, and each other's treasured company.

Our gratitude and salute of honor belong to our accountant Linda Sonnenmoser and her spouse Ken, in partnership with her servant hearted colleagues: Rebecca Clark, Karolyn Dinges, Grace and Laura Hamilton, Denis Vasalinda, Connie Bruner, and Kara & Mary Dunn. We applaud them for their selflessness.

In addition to their labor of love, the Sonnenmosers also supplied plants, mulch, pots, and other items. Martie Buchanan, though she could not come, provided plants as well.

We at Alexandra's House are nearly constantly in a state of awe for the many wonderful things we are blessed to witness here, among them being the sheer beauty of the human heart.

Areas We Could Use Volunteers

- Website updates
- Manager social media
- Help draft and edit newsletter stories
- Help coordinate volunteers
- Creative person to help design cards/ announcements for special celebrations
- Spanish Interpreter

"Saturdays" Expand

While the depth of sorrow in the loss of a baby is inexpressible, and is especially unique to the parents, a measure of suffering extends also to the whole family. In a particular way, the person who protected you from harm all your life, taught you, dried your tears, cared for your bumps and bruises, and had the answers to all your problems, has no answers now, no perfect way to console you, and can't take away the pain now, of your baby dying. They are suffering for two; their child and grandchild.

This unique pain in being a Grandparent is something we talk about at Alexandra's House with every family we encounter. Throughout the years many grandparents, aunts and uncles have expressed this feeling of helplessness and have, in fact, reached out to each other by phone or in a social gathering. Even so, something more consistent needed to be done to help in their healing.

So now, on Fourth Saturdays, from 2:30 until 5 pm, a Grandparents' Support Group has formed, led by those who know this journey best, Grandparents. It is a warm and welcoming community. If a baby in your family died from any cause, you are invited to participate.

If you wish to attend, simply notify Alexandra's House at **816-931-2539** or Email **hpanebianco@mac.com**.