



# Guardian Angel Gazette

*Serving children with life threatening illnesses and their families in Louisiana*

*June-July-August 2017*

## What is respite care?



Mark Firmin, Executive Director

As many times as I have talked and introduced Angels' Place to interested individuals, I always get the question, "so, what is respite care?" Well, I thought that I would take a few moments to explain the concept of respite care.

By definition, respite care for children is a break for caregivers and families, as a service in which temporary care is provided to children with disabilities, or chronic or terminal illnesses. Respite care can occur in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources. Sometime finding a qualified respite care volunteer can be overwhelming and stressful. Parents are not going to leave

their child with just anyone.

At Angels' Place, respite care volunteers are trained and reviewed through the hospital's volunteer programs first. Then, the second part of training is the volunteers work with our Children's Program Director, **Mary Kantlehner**. She mentors the volunteers and has them shadow her as she visits clients in the hospitals. After several weeks of this training, the respite care volunteers finalize their schedule to visit families at the hospitals and go on their own. At first, our volunteers may just "check-in" with our clients and their families to visit. This may include bringing a toy or an art project to the sick child to help them pass the time in the hospital. It may be sitting with the siblings so the parents can talk to the doctors about the treatment for the sick child. The volunteer may talk to the parents to assess if there are any needs to be addressed. Many times, the volunteer is just giving an ear to listen to parents vent about the frustrations or just talk to be heard. A visitor sometimes alone can break up the day to day routine in the hospital. Progress notes are taken by each volunteer after visits to track the advancement of the treatment for the child hopefully leading to recovery.

In time, the parents or caregivers may see the need to have someone help for a brief moment in the care of their child with a life threatening disease. They may request additional help from a respite care volunteer to sit with the child to give the parents or caregivers a badly needed break. This break allows the parents to run needed errands, get some coffee, or check in with their jobs. At some hospitals, the policy is children have to have an adult with them in their room at all times. Respite care volunteers can help with this. If a child has to be left alone, the volunteer can come in to read a book or play a game with the child to pass that time until a caregiver can return. In the home, respite care volunteers can be utilized but a parent must remain in the home. This may allow the caregiver/parent to catch up on daily chores, take a shower or a nap, or have a few moments to themselves to refresh. These visits allow the volunteers to see the situation of the family. If there is a need for food, toiletries, clothing, or other needed items. The office is contacted so we may secure those items through donations or gift cards. The respite volunteers can deliver the needed items to the family in the hospital or at home.

*The mission of Angels' Place is to provide respite care and support services to a child with a life threatening disease in a loving caring manner. Respite care is a chance to help the parents or caregivers of a child get a break to refresh and reload in a very difficult task of caring for a sick child. It can also provide support to let the family know that they are not alone.*

As the executive director of Angels' Place, I am a respite care volunteer mostly on weekends. Along with Mary and all of our dedicated respite care volunteers we continue to help these children and families on their journey.

## Ashton's Journey



June 15, 2014 - a day that would change our lives forever. It was my birthday and the day my "super hero" Ashton was diagnosed with a terminal illness. Never again would things be the same.

Ashton was born March 5, 2013. He could not suck on a bottle and was diagnosed a "poor feeder." A few days later, after taking in small amounts of formula, he was discharged. No tests were made at the time. I was so excited to go home with my baby and live a normal life but Ashton cried day and night and had many vomiting episodes. I went from doctor to doctor but nothing was done. This continued for nine months. When he was 9 months old he was trying to stand up but had no balance. He would fall easily and vomited often. We had many Emergency Room visits but got no answers. I felt Ashton was barely hanging on to his life and I had very little fight left.

We decided we would pack up and head to Children's Hospital in New Orleans. After 30 minutes of driving, Ashton became lifeless and we didn't know if he was going to make it to the hospital. Upon arrival at Children's, we got help right away. Immediately a doctor arrived and testing began. Thirty minutes later the doctor came back and told me my son had a disease called malignant infantile osteo-PETrosis. I became numb. What was he saying? His words kept echoing through my mind. I thought my son was dying. This disease is a rare congenital condition of the bones. Both parents must carry the recessive genes and still there is a 1 in 4 chance that a child will be born with it. Bottom line, Ashton needed a bone marrow transplant. The clock was ticking in the search for a bone marrow donor. The long and stressful waiting for our family had begun. Finally, we received the anxiously awaited phone call that a donor had been found. God had blessed us with a donor!!! We didn't know at the time what an amazing impact the wonderful donor would have on our lives. We were admitted to the 4<sup>th</sup> floor of Children's Hospital. There, we were not only to experience the challenges to Ashton, but saw the suffering of all the children on the 4<sup>th</sup> floor. Some of the painful sights will be etched in my memory forever. The doctors started chemo and on October 17 he had his first bone marrow transplant. Ashton experienced many complications and had unpleasant battles I just can't mention. There were times when I wondered if he was really going to make it. We stayed 3 months in isolation where no one can visit because of the germs that may infect the patient.

*(continued on Page 2)*



## What's Up at Angels' Place



Face Painting by Mary



The kids made their own capes.

### Greg Goodwin with

**Thrivent Financial** knows how to throw a good Carnival! They hosted the Thrivent-Angels' Place Carnival this June. Every year Greg and his wife, Susan, put together this fabulous event especially for our Angels' Place children. The event was "top notch" and there was fun every where. Thrivent Financial members, **Christ the King Lutheran Church** members and their friends made a warm and friendly atmosphere for our kids and their families. Thank you so much to all the volunteers who made the event a spectacular success and for the outpouring of your love for our kids! Our families raved about the carnival and what a great time they had.

This year there were more games, more prizes and more give-a-ways than ever before—every year it gets better and better. Ashley, one of our children, was surprised with a birthday cake for her special day. And we sang Happy Birthday to Ashley and Melvin whose birthday was in June as well. Happy Birthday guys! Two lucky families won \$100 gift cards from a special draw-



The man who makes this all happen, Greg Goodwin, giving out prizes to our families.

ing and EVERY family got a \$25 gift certificate. How generous!.

Thrivent was busily handing out mouthwatering pop corn and cotton candy to our kids. Carnival music filled the air as our children ate tasty hot dogs and played fun games. Did I mention sweet treats? Besides the birthday cake, there were loads of sweets to fill lots of little tummies.

**Light and Madness Photography, LLC** made it possible to capture the happy

A little hoop competition going on here

memories of all fun through their donation of time and photography. Thank you so much.

## Fun at the Carnival!



Crafting



Happy Birthday Ashley!



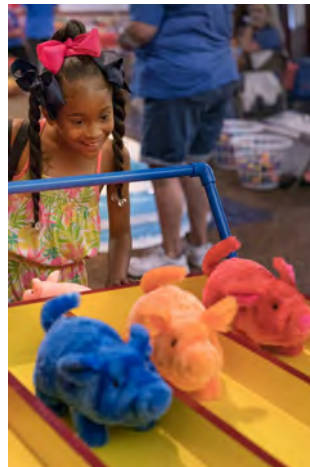
More Crafting fun



Sweets galore



The ever popular popcorn



Piglet races anyone?



Lots of games



Angels' Place Staff on hand: Ashley Perrot, Mark Firmin and Mary Kantlehner

Don't forget to check out our NEW web page at [angelsplacenola.org](http://angelsplacenola.org) AND like us on facebook!



## In Loving Memory

**Rey Bienvenu** in memory of **MaryAnn Bienvenu**  
**Sharon and Danny Morel** in memory of **Faye Stubbs**  
**Pauline Exsterstein** in memory of **Marie "Weezie" Gaudet**  
**Jeanne F. Waller (daughter)** in memory of **Marie "Weezie" Gaudet**

### Ashton's Journey (continued from page 1)

There were times when I wondered if he was really going to make it. We stayed 3 months in isolation where no one can visit because of the germs that may infect the patient. If it hadn't been for the prayers and support from our family and friends, the great support from the nurses, social workers, doctors and Angels' Place, I don't know if I would have kept afloat. We would look forward to the visits from Ms. Mary with Angels' Place and her respite volunteers. Many prayer chains were going around – little Ashton was touching lives.

Finally we were released from the hospital but had to return for IV meds, blood, platelets and anti-virals to be administered. After being released, Ashton seemed to be recovering nicely but fell sick and had to be admitted to Children's Hospital once again. His illness caused him to need another bone marrow transplant but he had no donor cells left! They then contacted his old bone marrow donor and she agreed to donate for a second time. There were complications this time with the donation but the donor demanded to donate and so Ashton was in for his second transplant. She fought to save his life and I was grateful beyond words! But, the second transplant was declared "failed." We had a choice of a 3<sup>rd</sup> try but they were uncertain he would make it. I was told about a deceased priest, Father Seelos from New Orleans, who performed miracles. We brought Ashton there and he held Father Cellos' priesthood cross while we prayed for him and then we waited for a miracle.

We had a month before the third transplant so an organization called "Give Kids the World" sent us to Florida and Ashton saw Disney World, Universal Studios, Sea World, and Lego Land. The trip was bitter sweet for me as I thought this could be the last vacation I would ever have with Ashton.

When we returned to Children's hospital, they did a third work up in a final attempt to save his life and the unexpected happened. His transplant doctor set me down and told me Ashton's donor cells had gone from 3% to 100%. She tested and re-tested and the results were the same. Our prayers were answered and we had our miracle from God through Father Seelos!

As I write, it is June 15, 2017, my birthday and the day Ashton was diagnosed with cancer three years ago. He is here with me growing and thriving. He loves telling jokes, playing games, chasing his dog and just being a boy. He is my strength, my inspiration and my hero. Ashton is ready for pre-K and is finally living the average life of an average boy.

We are so thankful to all those who carried us through this long and frightening journey. We are so very grateful to the "special" nurse who cared for us, the doctors, our unforgettable donor, and the angels from Angels' Place whom we continue to have contact and are still available to us anytime we need them.



## AP's Budding Artists Show Off Their Talents

Our students blossomed in our art classes at our Coolidge house. They had a blast painting, sculpting, umbrella decorating and other special projects. All of our artists wore painted mustaches to let us know how much fun they were having being a budding artists. We want to thank our "Angel" volunteer artists who gave their time and talents to our art classes. Thank you Sherry Velesquez, Jan Wilken, Michelle Pierce-Monistere, Courtney Bullock, Guilda Thomas and Joyce Laporte. We loved working with so many gifted artists. Thank you for sharing your



## We Need Your Help With Our Christmas Ornaments



Eight graders through high school students who need service hours, this is a great and fun opportunity to get four service hours.

You will be making easy angel ornaments for our Christmas competition at **City Park** and the **Treasure Chest Casino**. Please call us at (504)455-2620 or email us at [office@angelsplacenola.org](mailto:office@angelsplacenola.org).



In May, Angels' Place staff, front **Mark Firmin** with guest **Cherie Ducote Firmin** (back L to R) **Charlotte Ward**, **Mary Kantlehner**, **Ashley Perrot** and **Jules Goins** recognized **Red Nose Day** for **Fighting Childhood Poverty**.

## AP Families Mark Your Calendars—2017

**Booville Halloween Party—Magnolia Community Services Nims Center— Sunday, October 22, 2017 from 2 PM—4 PM**  
**Christmas Party - Magnolia Community Services, Nims Center Saturday, December 16, 2017 from , 2 PM—4 PM**



## Respite Volunteers Needed!

We welcome anyone who would like to be a respite volunteer.

Respite volunteers go visit our ill children in the hospitals and offer relief to the caregivers. Visit are for short periods of time and the rewards are immeasurable—helping those in need.

If you feel you are called to do this kind of volunteering, please call Mary at (504)455-2620 or email her at [maryk@angelsplacenola.org](mailto:maryk@angelsplacenola.org). You will be glad you did!

## *A Gift from the Heart*

*I want to help the angels of Angels' Place.*

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Home phone: \_\_\_\_\_ Cell phone: \_\_\_\_\_

E-mail address: \_\_\_\_\_

Enclosed is my donation of \$ \_\_\_\_\_

Enclosed is a gift in honor of or memory of a loved one, friend or someone special.

In Memory/honor of: \_\_\_\_\_

Please notify: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

*Your gifts are tax deductible*

Please make the check out to Angels' Place and mail to:

Angels' Place  
4323 Division, Ste. 206  
Metairie, LA 70002

*Thank you so much for making a difference!*

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