

# ANGEL NEWS A QUARTERLY NEWSLETTER WWW.LOVEANANGLE.ORG



The Love an Angel Foundation (LAAF)

March 2015

Volume IV, Issue I

## A Word from our President, Matthew Weber

Family (noun) – "an association of people who share common beliefs"

Dear Angel Supporters Family,

To those of you that were able to attend the "For the Love of an Angel" Reverse Raffle, we thank you. For those of you unable to attend, we missed you. Thank you to all who have supported our efforts by whatever means available to you; through financial giving, gift donations, encouragement, volunteering of your time or through prayer. Though it may not always be immediately recognized, it is always noticed and certainly appreciated.

We thank you all----our Angel Family.

May God bless you all as you have blessed us.

Matthew

# Blarney for Angels, Raising Money for Research

On Saturday, March 7, Ray & Patti represented LAAF at "The Blarney for Angelman Benefit" in South Euclid. It is a once a year event whose primary purpose is to raise funds to support research, educational and other efforts of like-exempt organizations. Its common mission is to assist those with Angelman Syndrome.

The Blarney Cup and The Blarney for Angelman Foundation, was started through the efforts of the FitzGerald family on behalf of their son, Drew (featured in our Dec. 2013 newsletter). The event starts with a paddle ball tournament and concludes with an evening of food, fun and fellowship. A live auction is held to help boost the money raised.

This year, Eileen Braun, Executive Director of the Angelman Syndrome Foundation, (established in 1990) gave a brief presentation. Her talk focused on what AS is, what causes AS, recent research developments, and what the Angelman Syndrome Foundation provides for AS families. One of her main points was that those with Angelman Syndrome will need to be cared for their entire life.

We do not know the amount of money raised, but I do know that the event raised awareness of AS while providing a fun weekend for others who care about our "Angels."

You can visit their website at <a href="https://www.BlarneyCup.com">www.BlarneyCup.com</a>

#### In this issue:

A Word from our President, Matt Weber
Blarney for Angels, I Raising Money for Research
Silent Auction/ 2 Reverse Raffle Wrap-up
Angel Corner 3
Angel Corner 4
Continued
A Big Thank You 4
Acts of Kindness 4

Volunteer Opportunities are available. Please call 234-678-7466 to become more involved.

# Dates to Keep in mind:

- Angel Family get together, Date to be Announced.
- 4th Annual Biking for Angels Spin-athon, Date to be Announced.
- Saturday,
   February 6, 2016
   Reverse Raffle/
   Silent Auction





# Angel News; Volume IV, Issue I, Page 2

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# Reverse Raffle Wrap Up... One Third of the Way

A big **Thank You** is extended to all who contributed to the success of the February 7th event. Although attendance was down, the fun and generosity of the evening was enthusiastic. People gathered at 6:30 enjoying appetizers, sushi and an open bar, while selecting sideboard numbers, bingo cards, and browsing thru 100 silent auction items and placing their bids. With words of welcome and dinner, the Raffle got underway.

A new computer program was implemented for the

Reverse Raffle, and our guests had only positive comments concerning its performance, and how it kept them engaged. Along with the fun of the "Burst of Fortune" game, guests were surprised with the new "Birth Date" game - giving another opportunity for winning prizes.

Our usual MC, Burt Keiper, was unavailable this year, so Board President, Matt Weber, stepped up to the mike, and did a fine job. As a special treat Professional Auctioneer, Bob Young, called the bids for the Live Auction of the Goodyear Blimp ride.

This year's event brought in over \$33,300. Our expenses were under \$11,000. Our fund for the groundbreaking of Phase II, "The Gathering Place" is Over \$50,000 and More Than One Third of the Way to the \$125,000 Goal - Thanks to All of You!



3108 Vanderhoof Road New Franklin, OH 44216 234-678-7466

Check out our website: www.loveanangel.org

#### **Volunteers Needs:**

- I. Lawn maintenance (Spring clean-up)
- 2. Newsletter mailings (stuffing)
- 3. Indoor repairs
- 4. Activity volunteers

#### Items needed:

- I. Two (2) new computers
- 2. Zip Drives, (2) two
- 3. Rake, Shovel, Tools

Call us at (234) 678-7466 to arrange for pickup/delivery of these items. Thank you!!

Most needed items are bolded.

Remember you can always make a donation online.

To Provide  $\underline{C}$ omfort,  $\underline{A}$ ssistance,  $\underline{R}$ elief, and  $\underline{E}$ ncouragement to those touched by Angelman Syndrome.



## Angel News; Volume IV, Issue I, Page 3

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# **Angel Corner**



Isabella Skye

My daughter, Isabella Skye, was born on May 17, 2010. I always knew I would have a girl. My family and I were so excited to finally meet her. I knew she was special the minute she was born. She lifted her head the first day resting on my shoulder and smiled at me. Her doctor even said she was always a happy baby. I, being mom did not think there was anything wrong with that.

As she began to develop, she was not meeting her milestones. Her pediatric doctor showed some concerns and when Isabella was 17 months old, she was tested and it was determined that she had Angelman Syndrome.

We were devastated. All we heard was special needs. We had so many questions going through our mind. The first thing we did was research this disorder on the Internet. That was a mistake in itself. At the time of Isabella's diagnosis we had no one to talk to, no one who had heard of this

syndrome. We had no answers. The doctor was still learning as well. I will never forget the pain in our hearts when we heard from the doctor that my daughter would never walk or talk. We all felt hopeless. We love Bella so much.

When she started experiencing seizures, and was admitted into Rainbows Hospital in Cleveland for several days. My mother and I stayed with her around the clock. She has been taking Keppra for 3½ years and has only had two small seizures.

My parent's anniversary, was a special day. Isabella surprised us all by getting up and walking to us. There was not a dry eye in the house. Everyone in my family was so happy. It gave us hope that no matter what her diagnosis, she will overcome every obstacle. She has been walking and running around for quite some time now. Everyday her walking gets better, she almost runs perfectly.

We should all take a lesson from her, my angel; she is so brave and so strong. Bella is now 4 years old. She communicates with us by pointing and vocalizing. She knows what she wants when she wants it. She does everything she can to show us. Normally, it's by taking our hand and taking us to what she wants. She communicates very well with us. We understand her quite well even without speech. She still does not speak, but she sure does have a lot to say.

She is in preschool, and has the most wonderful staff working with her everyday. She has physical, speech and occupational therapy at school. In the summer she will start more therapy. Whatever we can do to help her advance, we will do it. She has



### Angel News; Volume IV, Issue I, Page 4

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# **Angel Corner Continued**

advanced so much this year. The next step is to try potty training and communication through an iPad.

She does not sleep much. She is not on any medication for sleep. We have tried all sorts of old fashioned remedies, so far no luck.

Everyone has helped in raising her. I live with my parents and my brother. I also have a son. My son David is Bella's protector. He is so good with her. She is loved by many. Everyone falls in love with her the minute they meet her. She truly is a blessing to me and my family. I would never change Bella. She is perfect just the way she is. My family and I were scared for a very long time, not knowing what to expect, not knowing what to do. My brother said it best, "All we can do is love her, and know that with Bella being special, love is the best medicine."



This past year I have been able to meet other Angels and their angel moms. It truly has given me comfort in knowing that we are not the only ones. From my angel and my family to yours. God bless you. Do not ever give up hope. Our angels are a gift.

# \$\$\$\$\$ A Big Thank You \$\$\$\$\$

The Acme Fresh Market Community Cash Back Program ended February 4<sup>th</sup>. We wish to thank all of you who saved your receipts and donated them to LAAF. We raised over \$110. This may seem like a small amount, but it will be applied to our operating expenses and will pay for several months of our office utility bills.

We appreciate your participation and look forward to next fall when the program is offered again.

### **Acts of Kindness**

During the past few months we have been witness to many generous acts of kindness from our supporters:

- A gentleman at our recent Fundraiser purchased the last 10 balloons in our "Burst of Fortune" game and gave them to the Angelman Families who attended.
- Someone from our Fundraiser donated back to us a bowling party for 10, to be used as an activity for our Angels and their families. (Details to be announced sometime in the next 2 months.)
- Another gentleman donated his Acme and Giant Eagle gift cards to the Foundation.
- Our neighbor, who is still recovering from major surgery, plowed our driveway several times during the last few weeks.
- An older couple donated Acme gift cards to an Angelman Family in need.