



# ANGEL NEWS

A QUARTERLY NEWSLETTER  
WWW.LOVEANANGELFOUNDATION.ORG



The Love an Angel Foundation (LAAF)

June 2014

Volume III, Issue II

## A Word from our President, Matthew Weber

It is hard to believe we will begin the second half of the year in just a few weeks. It seems like the winter did not want to release its grip and when it finally did, the spring continually rained on our parades. Like me, I am sure many of you are slowly getting caught up around the house with yard work and other projects that were put off through the months of crazy weather and probably ask yourself if it will ever get done.

As I become overwhelmed with these things, I take a moment to look at pictures of "Our Angels" and realize no matter what the background of their life reveals, there is a joy

and happiness portrayed in their smile and demeanor. A quiet reminder that no matter what may seem like chaos around us, it is our demeanor that keeps it in perspective. Thank you all for your loving and giving attitudes.

The long, cold winter and wet, wet spring are behind us. May the sunshine and warmth of a beautiful summer bless each of you and your families.

Matthew

P.S. If you are caught up on your yard work or need more practice, please volunteer to help with the maintenance at Halo Farms.

## "Biking for Angels" Date: 10/26/2014

### Save the date:

3<sup>rd</sup> Annual "Biking for Angels" Spin-a-thon

Sunday, October 26, 2014

9:00am - 1:00pm

What is a spin-a-thon?

It is a fundraising event like a walk-a-thon, however instead of walking, you are spinning on an indoor cycle bike to raise money for a charity.

LAAF along with Akron General Lifestyles (AGL) West are thrilled to be sponsoring the LAAF third annual spin-a-thon. It will be held at the AGL, West Lobby. Mark your calendar now. More information will be available in the September Newsletter and on the website. [www.loveanangel.org](http://www.loveanangel.org)



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### Dates to

#### Keep in mind:

- Acme Community Cash Back starts September 18th
- Biking for Angels Date 10/26/2014
- Reverse Raffle February 7, 2015

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



President  
Matthew Weber

Secretary  
Michelle Bisconti

Treasurer  
Patricia Weber

Director  
Doneita Bucey

Director  
Burt Keiper

Director  
Janice Pajk

Business Advisor  
Jamie Schisler

Legal Advisor  
Ray Weber

## Summer Volunteer Opportunity:

This summer we are fortunate to have available our own lawn maintenance equipment. We have a push mower, an electric weedeater, and a John Deere tractor mower. We will have available the gas for the mowers and the extension cord for the weedeater.

NOW ALL WE NEED IS YOU--volunteers that can be called upon to keep Halo Farm's grounds looking good.

SOOOOOO if you want a few relaxing hours in the sun, listening to your favorite music or simply the sounds of nature, please contact the Love an Angel Office at 234-678-7466. I will be happy to place your name among those available to provide this service.

We are anticipating that the lawn and field can be maintained nicely once a week. We will discuss any questions and concerns you might have.

Thank you and hope to see/ meet several of you throughout the summer!!!!

PS. I would like to thank Jerry Starkey who provided both the service, the gas and his mower all last summer!!! And I might add Jerry went above and beyond to clear weeds, trim trees and mulch around some troubled areas. He is already on the rotation for this year.



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New Franklin, OH 44216  
234-678-7466  
330-701-1886

Check out our website:  
[www.loveanangel.org](http://www.loveanangel.org)  
[www.loveanangel.com](http://www.loveanangel.com)

**We wish to thank those who have sent some timely donations during the last few weeks and months.**

**To Provide Comfort, Assistance, Relief, and Encouragement to those touched by Angelman Syndrome.**

## Many Thanks

As the work continues on the renovation of the kitchen in the Halo Farm Century Home/Office, we are so thankful to the following donors and volunteers. As you can see in the photos (on page 3), the "demolition" has taken place. We hope to have the "restoration" complete by summer's end. We will keep you abreast as things progress.

Representing Boy Scout Troup 411, Mike Mockbee, Leader and Andrew Mockbee, scout—removal of the old kitchen flooring

Highland High School Sophomore, Lindsey Mockbee—removal of the old kitchen flooring (working toward her graduation community service hours)

Mr. Karl Bucey, Bucey Cabinetry of Youngstown—reworking and adding additional cupboards

Board member Donna Bucey—sanding and preparing the cupboards for painting

Board members Michelle Bisconti and Patti Weber—wallpaper removal

Tim Probst, Dutch Heritage Homes—dry walling damaged areas of the walls and removal of the old counter top.

Tim Finley, Finley's Plumbing—plumbing and installation of the gas stove

Tim Benton, CounterMakers—the new countertops

Ed Bell, TankPro, Inc.—donating, purchasing of the new kitchen flooring

Rudy's Carpet, Ellet—discounted pricing for the kitchen flooring

January's Paint and Wallpaper—donating the wallpaper

John and Jan Pajk—donating the gas stove and refrigerator

## Angel Corner



Nayla, 4 months old

Hello, I would like you to meet our Angel, Nayla. Nayla came into the world at 36 weeks in October, 2004 weighing 5lbs 1oz. We originally thought Nayla had cerebral palsy due to birth trauma and that she was in 2 serious car accidents before she was 8 months old. We spent the first few years of her life searching for a diagnosis. It was August 2007 when Nayla was almost 3 that we got our answer.

Thankfully, our neighbor knew Madeline Weber and mentioned to us that Nayla reminded her of Madeline who had Angelman Syndrome. With all our searching, we had never heard of AS and so we immediately researched AS through the internet. As we read the list of diagnostic criteria we said, "Yes, that is our Nayla"!!



Nayla, 14 months Old

We found a neurologist who ordered the official testing and we finally had a concrete answer...we had an "Angel"!

Angel Corner is continued on page 4

To Provide Comfort, Assistance, Relief, and Encouragement to those touched by Angelman Syndrome.

### Volunteers working on LAAF kitchen demolition and remodeling!



Many  
Thanks

## Angel Corner Continued

With this accurate diagnosis, we were able to find helpful solutions for many of the daily life issues that are specific to raising an Angel. Through the years, we have connected with other Angel families and the tips we have received from other parents have been life changing.

We have experimented with both traditional and very alternative therapies. We have had a lot of success with the cranioscral therapy and reflex integration. At 4 Nayla was not yet walking and was having many other troubles. We learned of a treatment center, The Family Hope Center (FHC) in Pennsylvania. The center treats children of all ages with any diagnosis that affects the brain. In June of 2009, we made our first visit to the center and within just a few weeks after we returned home and continued the program, Nayla was walking!! Family health problems prevented our continuing the program at FHC but we were very appreciated and

happy with the progress that she made within that year. As most Angels, Nayla has struggled with seizures, sleep, bowel and behavioral issues to mention a few. Through our research, we found that what we eat impacts our entire system and therefore, we put Nayla on what we call the "super diet". Nayla does not eat gluten, dairy, eggs, or artificial sweeteners. She loves salads and all fruits and vegetables. We try to eat "clean" but Nayla does enjoy some "treats"! Her favorite treat is potato chips. Like most Angels, food in general is good....you don't want to skip a meal with this girl!!!

Nayla will be 10 years old this year. She is one of 7; she has 2 older and 4 younger siblings. Just recently, Nayla received her very own iPad. She is really enjoying the games but our goal is to start using the iPad for communication. This will allow her to have access to the same communication device at school, home and anywhere she goes. We are also hoping that with the use

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of her iPad, she will be able to start to initiate toileting—she has been schedule toileting for 5 years.

After the worst episode of Nayla not sleeping at night the past year and half, we got "The Courtney Bed". (For more information about The Courtney Bed, visit [www.cyrdesigns.com](http://www.cyrdesigns.com).) Since we got the bed in early May, she has slept through the night all but 2 nights and she is safe which gives us peace of mind—life changing for the whole family!

Nayla's schooling is a contained multiple disabilities classroom where she receives occupational, physical and speech therapy. She will be attending an extended school year program this summer 4 days a week for 2½ hours. This will help her to maintain her IEP goals.

For fun, Nayla enjoys riding her adaptive tricycle with her brother and sisters. She likes going to the park. Like all Angels, she loves swimming/water and loves going places outside. We want Nayla to participate in horse therapy and special needs swim lessons. We want to do all we can to continue to give Nayla access to a variety of positive experiences and anything that helps to improve her independence and quality of life.

Thank you for taking the time to get to know our "Angel"!!!



Nayla age 9, 3rd Grade