



The Love an Angel Foundation (LAAF)

June 2020

Volume IX. Issue II

A Word from our President, Matt

The Gathering Place Update,

Now that the wet season has passed and the site is starting to dry, we will need to place stone to access the garage openings, install the garage doors and begin the plumbing. We will be reviewing the electrical proposal and once Ohio Edison has coordinated with our schedule, begin the electrical work.

Thank you for your patience.

Matthew L. Weber, P.E.





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Dates to Keep in mind:

- 2nd Ladies Night Out: 9/19/2020
- For the Love of an Angel Dinner, Reverse Raffle, & Silent Auction 2/13/2021

February Fundraiser Pictures:



Three couples who have attended this event since LAAF's beginning.

Angel families attending this bringing joy year... reminding us of our mission.

Current Office Hours:

234-678-7466 Mondays & Tuesdays 8 AM to 2 PM

mail@loveanangel.org

If you want to schedule a meeting on another day, please call or text Patti at: 330-701-1886





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February Fundraiser Pictures





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

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www.loveanAngel.org

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

SAVE THE DATE:

Make next years' fundraiser a DATE WITH YOUR VALENTINE

Saturday, February 13, 2021 "For the Love of an Angel" Dinner, Reverse Raffle & Silent Auction



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Angel Corner



"Laughing is, and always will be, the best form of therapy."

We are The Bistlines,
Damon, Gini,
Vera (12), Dale
(9), Ivy (8), and
Emmett (8). Our

daughter, Ivy, has Angelman Syndrome. Our family has traversed the path to discovery and education of Angelman Syndrome (AS) for the last six years. While we have faced our share of challenges along the way, Ivy has always been full of laughter and joy that guides us.

Having two older siblings and being a twin, it was apparent to us early on that Ivy was atypical. When she wasn't hitting milestones, we started therapies. While we were concerned about her development, we knew that we were doing everything she needed. The most trying part was the lack of sleep. Ivy slept sparingly throughout the night and rarely during the day. When Ivy was one and a half, we received her Angelman Syndrome diagnosis. No one in our family had heard of AS. Wow. The relief that came with having a diagnosis was coupled with an astounding feeling of ignorance.

We had a lot of research to do! As overwhelming as our road to education started out, we were lucky to find groups and resources early on. While I was still quite unrested, I was able to take some solace in knowing that it was common for kids with AS to sleep very little. It was also helpful to know that there were other Angleman families nearby.

Since Ivy was already in therapies when we got her diagnosis, we felt like she had a good leg up. She was doing a combination of swim and land physical therapy. When she started walking at three years old it was simultaneously exciting and frightening. I still think that sometimes she liked making us a little nervous with the

way she would swing around. Swim therapy has likely contributed to her love of swimming. She absolutely loves the pool and has made amazing progress with her stability in the water.



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Angel Corner continued

By age six, Ivy was self feeding. It was an achievement that we both relished. For Ivy, food is life. Her excitement and seriousness about eating is notorious. We are lucky that she is not picky and enjoys all varieties of food. For the last two years Ivy has been on a modified ketogenic diet. This stopped her seizures. It's been a huge relief, but we have to be vigilant around Ivy and food. No one can nonchalantly grab a bag of Doritos or loaf of bread off of the counter as fast as she can.

Ivy loves stroller walks, dancing, and all genres of music. Family dance parties are a favorite activity for all of us. She loves being with her brothers and sister, snuggling down with them, and watching them. They are all fantastic with her. She radiates love and admiration for them with her constant laughter and smiles. She also

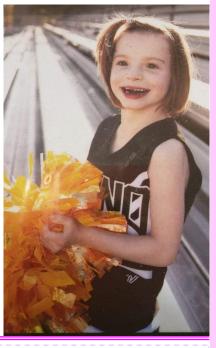


loves our dog, Zeus. They have been known to have extended cuddle They've sessions. both been great about being gentle with one another. lt's also been amazing how they both distinguish between each other's toys.



Our trials with Ivy's Angelman Syndrome are lifelong. We will always have a busy schedule with having four children, one of whom has special needs. My husband and I will always

worry about Ivy's care when older and are gone. However, these things do not diminish our quality of life near as much as Ivy has enhanced it. Ivy's laughter, and love, snuggles bring unmeasurable enjoyment into our family's life.



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It's A Hoedown!

2nd Annual Ladies Night Out: Western Hoedown
Purse Bingo Saturday, September 19 200

The Hoedown has been cancelled and will be rescheduled for 2021! With the current Covid-19 health pandemic, we want everyone to stay healthy and safe.

We are still raising funds for the Gathering Place and Administrative Costs for the Foundation. Instead we are holding a Virtual Fundraiser Drawing!

For each Donation of \$50, you will be entered into the Designer Purse Drawing For each Donation of \$100, you will be entered into a drawing for a Couples' Ticket to the February "For the Love of an Angel" Dinner, Reverse Raffle, and Silent Auction and the Designer Purse Drawing.

Please use the form below or donate online at <u>LoveanAngel.org</u> and remember all non winning donations are tax deductible under our EIN 34-1879391

All donations for the drawing must be received in the office by Saturday, September 19, 2020, the date of the original Ladies Night Out. We will draw winners on Monday, September 21, 2020.

Donation Form:							
Name:							
Address:							
State:	Zip Code:		Phone:				
Donation:	\$15	\$30	\$50	\$100	Other Amount		

Checks Payable to Love an Angel Foundation, mail to: 3108 Vanderhoof Road, New Franklin, OH