



ANGEL NEWS

A QUARTERLY NEWSLETTER
WWW.LOVEANANGELFOUNDATION.ORG



The Love an Angel Foundation (LAAF) June 2013 Volume II, Issue II

A Word from our President, Matthew Weber

Angel Families and Friends,

It has been through the love and support of you faithful friends that we were able to finish off last year strong with the “Biking for Angels” fundraiser and roll into this year with another successful “For the Love of an Angel” reverse raffle and....the first ever, “This is not your everyday

Garage Sale, Garage Sale”. All fantastic successes.

What an incredible start to a new season for the Love an Angel Foundation. We truly appreciate all that you do.

Thank you and have a blessed Summer. Rest up and enjoy!

Matthew

2ND ANNUAL “BIKING FOR ANGELS” SPIN-A-THON

Before you know it October will be here and it will be time to do some “indoor cycling” at the 2nd annual “Biking for Angels” Spin-a-thon. Once again, LAAF and Akron General Health and Wellness West Lifestyles will be sponsoring the Spin-a-Thon. While the details concerning date and time are being finalized; please refresh your memory with the following information.

We need **Spinners**:

Spinner – anyone that can pedal – keep bike pedals in motion

Spinners need **Sponsors**:

Sponsor – relative, friend or associate willing to donate \$ (money) for your spinning time

In addition to the individual spinners, we are anticipating offering corporations to sponsor a bike designating representatives to keep the “corporate sponsored bike” going for the duration of the event.

Watch for more details in the September newsletter and on the website.

Love an Angel Wishes to Congratulate

Love for Angels who raised nearly \$18,000 at their June 3 Golf Invitational held at Fairlawn Country Club. The mission of Love for Angels is to encourage and assist angel families of NE Ohio to attend the National Angelman Syndrome Biennial Conference.

Blarney for Angelman who raised over \$22,000 at their Blarney Cup Tournament held in March. The monies raised are for scientific research—finding a cure for Angelman Syndrome.

Angelman Syndrome Foundation (National) who hosted 30 walks in 30 cities across the country to raise awareness and funds to find a cure for Angelman Syndrome. More than 10,000 supporters attended and raised approximately \$1,030,000 to date.

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Dates to Keep in mind:

- August 23 & 24
Fall Garage Sale
- September
Newsletter
- Biking for Angels
To be Announced

Volunteer Opportunities are available. Please call our office at 234-678-7466 if you would like to discuss how you can become more involved.



President
Matthew Weber

Secretary
Michelle Bisconti

Treasurer
Patricia Weber

Director
Doneita Bucey

Director
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Director
Janice Pajk

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Jamie Schisler

Legal Advisor
Ray Weber

Garage Sale Wrap-up

Not your everyday garage sale” Garage Sale. . . . HUGE SUCCESS

The LAAF Board and families of our “Angels” wish to express their thanks and appreciation to those of you who did your “spring cleaning” and donated items for the garage sale. We also wish to extend our thanks to those of you who gave of your time and volunteered during the two days of the sale.

Our goal for this fundraising event was to raise money for the office/foundation operating expenses. Having those funds available would then allow the profits from our up and coming “Biking for Angels” Spin-a-thon to be directly applied to the hopefully, final payment of the loan for the Halo Farm property. With the event, we also wanted to



3108 Vanderhoof Road
Clinton, OH 44216
234-678-7466
330-701-1886

Check out our website:

www.loveanangel.org
www.loveanangel.com
www.loveanangelfoundation.com

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

heighten public awareness of Angelman Syndrome. This was achieved by presenting an information sheet at the “cash out” table and having our workers share our story with those that asked. (I sometimes shared even when they did not ask!!)

We are thrilled to announce to you that the garage sale exceeded our expectations in both the monies raised and public awareness. Our total was just shy of \$5000.00. AND with over 100 shoppers, we were thrilled to make new friends and have several shoppers turn into volunteers for future projects around the office/foundation.

Looking back and assessing the success of the sale, the decision was made to open our sale for another weekend on August 23 & 24.

Therefore, dear supporters, we are requesting that if you did not get to your “spring cleaning”, you might wish to think about “summer” or “back to school” cleaning. We, ask once again, that as you have items ready, please contact us at the office to either set a time for drop off or if needed, for us to pick up.

Please contact the office at 234-678-7466 with any questions or suggestions concerning the event. Also visit the website www.loveanangel.org as information will be updated.

Remember: “One Man’s Trash is Another Man’s Treasurer” This is only a fun phrase; we were provided **wonderful** items that made the sale a **huge success**. Once again – THANK YOU.

Fall Garage Sale, August 23 & 24.

Angel Corner



“To do some outdoor activities like other kids.”

Gary resides in Medina with his parents, Ken and Dawn Thompson and siblings, Ashlee, Krissy, and Eric. Gary was diagnosed with Angelman Syndrome (AS), deletion positive at 22 months. He is now 13 years old.

Gary is pictured to the left with his sister, Ashlee, and his own “special” bike. During the school year, Gary received instruction on such an “adaptive” bike (a tap on one hip and then on the other) and had learned to apply the pressure needed to rotate forward. By schools end, he had repeated as many as 5 rotations by himself. Now, having his own bike, the family hopes to continue his instruction so that, at very least, he will not lose the skill...and are actually hoping to increase his number of revolutions. Mom’s desire for him is “to do some outdoor activities like the other kids”.

Over the summer, Gary will be attending an extended

school year where he will continue to work on his IEP goals. The summer brings another special surprise Gary’s way...a home pool will be ready soon so that he can get daily aqua therapy. The focus will be on his hypertonic hips...he will be trying to do alternating kicking in the water.

Gary has participated in a research study for the past two years in South Carolina. Now the study on the effects of the drug, Levodopa in relation to hand tremors in children with AS, is drawing to an end, (Levodopa is a drug typically used for Parkinson Disease for involuntary ticks and tremors) and he will travel to South Carolina one last time.

At age 9, four years after having

mastered feeding himself and brushing his teeth, Gary developed hand tremors and now for the most part, cannot feed himself with utensils anymore and needs full assistance in brushing his teeth. “We joined the study in hopes the medication might help calm the tremors...I try not to hope for ‘full’ anything...it can be too disappointing.” Sadly, Gary’s tremors did not improve at all BUT what has been seen during this same time period (while on the Levodopa), is that his ability to process information has increased noticeably.

With that increased ability to process information, it was decided to give toilet training one more try. Gary has not been in pull-ups since December 19, 2012. He loves his boxers! One major bridge into the “real world”.

With Gary’s “increased ability in processing information”, the research study program has decided to send someone from Boston to Gary’s last visit in South Carolina to gather this data. We are all anxious to know if others have also experienced this “increase in processing information.”

Although the initial research study concerning the hand tremors and the drug Levodopa has not helped Gary’s hand tremors, and this “increased ability in processing information was not what we had signed up for or hoped for, it turned out to be more than we dreamed we could do for Gary.”

What an amazing 13 years.