



ANGEL NEWS

A QUARTERLY NEWSLETTER
WWW.LOVEANANGELFOUNDATION.ORG



The Love an Angel Foundation (LAAF)

March 2016

Volume V, Issue I

A Special Evening:

18th “For the Love of an Angel” Reverse Raffle



On February 6th, St. George’s Fellowship Centre was filled with activities as the 18th Annual “For the Love of an Angel” Dinner, Reverse Raffle & Silent Auction got under way.

About 200 guests began the evening enjoying appetizers, sushi, and an open bar while purchasing sideboard numbers and bingo cards. Over 100 silent auction items were on display and available to the highest bidder.

Once seated, all enjoyed a video presentation of our Angels and some of the Foundations activities of 2015. Continued on page 2

2016 National Angelman Syndrome Foundation Walk

Saturday, May 21, 2016 is the National ASF Walk in Pittsburgh PA.

Team “Love an Angel” will be traveling again this year to Pittsburgh PA, representing our Northeast Ohio Angel families. While the goal of the Walk is to raise money for research and clinic programs for AS, it also lends opportunities for Angel families to meet and share their AS stories and experiences.

LAAF and Team Love an Angel welcomes you to join us on our walk. The registration fee is \$25 and is free to the Angels and children under the age of 12. Register online by April 27th to be guaranteed your Walk t-shirt and swag bag! Visit our website for the registration link.

If unable to join us, please consider making a donation under Team Love an Angel at the same link.

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Dates to Keep in mind:

- Biking for Angels
Date To Be Determined
- Acme Community
Cash Back—
August 11, 2016
- Reverse Raffle
February 11,
2017

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A Special Night, Continued

As the four Angels in attendance were introduced, their smiles and excitement proved infectious.

After dinner, the reverse raffle began. From the first number drawn and every sixth number until the final five prizes were awarded. This year's final five split the \$2,000 prize. Random birthday dates were announced throughout the evening lending another chance to go home with a prize. At one point the hall was filled with pink balloons available to purchase for \$10. Over 2/3 of the balloons had prizes valued at \$5 up, with the big winners receiving \$50 and \$100 cash. While raffle numbers were being called, many played bingo for a full card win, for the 50/50 prize.

During a break from the reverse raffle draw, a video of the proposed accessible playground projected for the Gathering Place at Halo Farm Complex was presented.

We are thrilled to share that \$28,000 was the profit from this year's event; putting us at two-thirds of our goal for the purchase and installation of the Gathering Place accessible playground.



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Check out our website:
www.loveanangel.org

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

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

Thank you to all our supporters who have attended/or donated over the past 18 years and those of you who have joined us for the first time. We hope you enjoyed yourselves and that we will see you February 11, 2017 – with even more “new” friends.



Angel Corner



Tim, Sarah & RJ are the newest Angel family with LAAF. This is Sarah's story.

Although the day I realized I was pregnant was a huge surprise, Tim and I were super excited to find out we were going to have a baby! Having gone back and forth about finding out our baby's gender, seeing Tim's face was priceless when told we were having a son.

That very first night was the beginning of our journey with having a special needs child.

It took two months of such a schedule to finally get one of RJ's doctors to listen to me that he was Colic and that something was indeed wrong. Finally, the doctor scheduled a day of testing for both an Upper GI and a Swallow Study.



The day of the tests started out typical with RJ crying, and my trying to figure out what was bothering my son. The Upper GI was not typical. It did not go as planned. After waiting forty-five minutes, the barium never passed and the radiologist decided to do an ultrasound of little RJ's belly.

Since my pregnancy was uneventful and typical, we thought I was experiencing false contractions when indeed I was in labor. We did not think that we were going to leave the hospital with a baby, we were busy making lunch plans. However, after getting settled into a room and examined, we knew we were NOT having lunch! Baby Robert James (RJ) arrived on October 1, 2010 at 36 weeks.

After two days in the hospital, our family of three was home expecting a nice restful night. Our precious son began to cry and he cried and cried. He would sleep maybe 30 minutes and then cry for four or five hours straight. It was exhausting. Tim and I would take shifts during the night so that we each could get some sleep. Not only did RJ cry and not sleep but it would take up to an hour for him to finish his bottle. He had reflux issues.

We ended up being at the hospital for over 4 hours, missing our appointment for the swallow study but receiving one of many answers. RJ had pyloric spasms which meant that the pylorus muscle worked when it wanted to work and then at times did work but instead would spasm.

I remember the swallow study like it was yesterday. My dad came with me so I would not be alone because of what had happened just the day before with the Upper GI test. The swallow study went very quickly. We were in and out in less than an hour. After the test, the Speech Therapist asked me to have a seat and she would return in a few minutes. Before she left, I remember asking if I could feed RJ and I was told not to. After about thirty minutes of waiting, the Speech Therapist returned and sent us to admitting – RJ was being admitted to the hospital.

Angel Corner Continued

Once in our room, a nurse came right in and put an NG Tube into RJ. I had to leave the room. I could not believe that this was happening. I had no idea what was wrong with my son. I wanted to make things better and I could not. I had to trust the medical staff.

Soon the Gastroenterologist came and informed us that RJ has dysphasia and was aspirating. He said that RJ was unable to take anything orally until they were sure that his swallowing muscles were working properly.

This broke my heart to know that I was unable to fix the problems that RJ was having. I was grateful for an answer even though this was not an answer that I wanted.

I am sharing this specific memory with you because it is engraved in my mind as the moment when I realized that RJ was a child with special needs. Our Diagnosis of Angelman Syndrome did not come until he was two and half years old. That is another story for another time.

I can tell you though, I cannot imagine my life without my son and without Angelman Syndrome. When we received our AS diagnosis, I told my mom that Angelman Syndrome will now be my life. Everything I do or decide to do, I will take into consideration how RJ will do. Every day I wake up and hope that today will be a good day for RJ. Even on those bad days, RJ's smile and laugh make everything seem better. His laugh is so infectious that you end up smiling and laughing with him. Our journey has not been easy and I know we have a long road ahead, but I would not change any of it. RJ has made me a better person and a better mom.

An update: We learned that RJ may need a G Tube to help with his fluid intake. The family will be meeting with the surgeon soon to determine if surgery is necessary to improve his reflux problem.

Thank You for Your Support

We wish to express our thanks to all who saved their Acme Fresh Market receipts during the 2015 Community Cash Back Program. Since we began participating in the Acme Cash Back program, we have continually increased in the money received as a direct result of your support. We continue to use the funds for general operating expenses of the office. Please consider shopping Acme Fresh Market and participating in the 2016 Community Cash Back program on behalf of LAAF. This years program will begin Thursday, August 11th, 2016.

Outdoor Building Gets New Garage Doors

Thanks to the grant from the R.C. Musson & Katharine M. Musson Charitable Foundation and the generous donation from Ed Bell of Tank Pro, the 4 garage doors of the outdoor building have now all been replaced.

