

**ANGEL NEWS**  
A QUARTERLY NEWSLETTER  
[WWW.LOVEANANGEL.ORG](http://WWW.LOVEANANGEL.ORG)

The Love an Angel Foundation (LAAF)

December 2017

Volume VI, Issue IV



From the  
LAAF Board &  
Staff: Patti,  
Matt,  
Michelle,  
Donna, Burt,  
Joe, Jan,  
Jamie, Ray,  
and Susie

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## Highlights of 2017

Feb	"For the Love of an Angel" Dinner, Reverse Raffle & Silent Auction
March	Garage Roof repaired/new shingles, gutters & downspouts installed - Office (Century Home) gutters & downspouts repaired
April	Art of an Angel/Canton craft show
May	Angelman Syndrome Foundation Walk, Pittsburgh Art of an Angel/Fairlawn craft show
June	LAAF Garage Sale Barberton Area Jaycees/Guest Speaker (Patti)
July	Attended the Akron Community Foundation Annual Meeting (Patti & Susie) Attended the GAR Grants Meeting (Susie)
August	Barberton Noon Kiwanis Meeting/Guest Speaker (Patti)
October	"Biking for Angels" Spin-a-thon Attended the Barberton Community Foundation Grantee Workshop (Patti & Susie) Glass Block Windows installed (Garage) Art of an Angel/Market craft show
November	Bath Volunteers for Service/Guest Speaker (Patti) Bath Church Women's Christian Fellowship/Guest Speaker (Patti) Mailing of the 20 <sup>th</sup> Year celebration "Save the Dates"

  
Love  
an Angel  
Foundation

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

### Office Hours:

Mon: 9 am to 4 pm  
Tues 9 am to 2 pm

V o l u n t e e r  
O p p o r t u n i t i e s a r e  
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## To Provide Comfort, Assistance, Relief, and Encouragement to those touched by Angelman Syndrome.

In addition to the above **Highlights**, we are excited to share that we have prepared and submitted several grants during 2017. We extend our heartfelt thanks to the following from whom we have received grants and gifts.

- Annunciation Greek Orthodox Church  
Philoptochos Society Melissa
- Barberton Area Jaycees
- Bath Church Women's Christian Fellowship
- Fidelity Charitable Matching Grant
- Junior Women's Civic Club
- Lloyd L. & Louise K. Smith Foundation
- Magic City Kiwanis Club

- R.C. Musson & Katharine M. Musson Charitable Foundation
- Schwab Charitable Fund
- Tuscora Park Health & Wellness Foundation
- Verna E. McKibben Memorial Foundation
- Welty Family Foundation

In conclusion, we do not want to forget or leave out all who have volunteered, sent unexpected donations, provided items for our garage sale and continue to prayerfully support our Angel Families and LAAF.

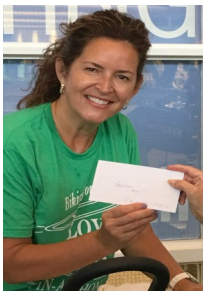
**2017 A Wonderful Year**  
**Looking forward to 2018**



## 6<sup>th</sup> Annual “Biking for Angels” Spin-a-thon

On Sunday morning, October 8, the Cleveland Clinic Akron General Wellness Lifestyles Lobby in Bath was filled with much excitement. Over 45 spinners came together for three thirty minute sessions to “put the pedal to the metal” for the LAAF fall fundraiser. This year’s BfA event captured the attention of many “first time” spinners. We were thrilled that Isabella, her mother and grandmother stopped in and cheer us on.

We thank all our business sponsors, spinners and those who pledged \$ to sponsor a spinner as we continue public awareness of AS and raise the money needed for the construction of The Gathering Place. We are happy to share that over \$8,500 was profited from this event.



Congratulations to our three session winners of Applebee’s & Rockne’s gift certificates.

Mancuso Angel Family cheering bikers on



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

## Angel Corner: A Year in the Life of an Angel



**Madeline's** year has been one of good health and happiness. Aside from a bout with the flu and a few "don't feel good" days, her seizure, sleeping and thyroid issues continue to remain controlled.

She truly loves her caregivers and one especially. When that particular caregiver is not in, Maddie is upset and has issues. The aide, using FaceTime, speaks words of comfort to Maddie assuring her not to worry. So far it is working.

Madeline turned 20 in April. At her party, she laughed until she was breathless, played with balloons and helped herself to the birthday cake (grabbing it with excitement).

Maddie loves riding the bus and attending school, but once home her favorite pastime is spent on her "oversized" beanbag, watching movies and often falling asleep. When dad is around his shoulder serves as her "beanbag". Maddie has a new best buddy and loves when she comes to visit—her name is GEMMA and she is the family pit bull puppy.

Summer involves playing on a special needs softball team. This year she served as team captain. The family takes Maddie on outings in the Mohican area where they hike, swim, eat and play together. Those weekends are so special.

Maddie has been chosen for a Clinic Trial Program in Chicago for a new drug treatment for AS. The drug is to aid in motor function, muscle tone and sleep. While this is somewhat trying on the family, they are excited for Maddie to be among those hoping to find a treatment. This program will continue through 2018.



**RJ** has had a very eventful year. It started with welcoming his baby brother, Quentin, and moving to a new Angel friendly home! He has had so much fun playing in his new yard, and has surprised everyone with his instant love for his brother.

In the spring, he participated in the Special Olympics with his school, grinning ear to ear while his fans cheered him on.

RJ's summer provided him many days at summer camp swimming, making new friends and loving every minute of it. On most weekends, he enjoyed spending time with his grandparents swimming and playing outside. He even got to go to a friend's house and swim in her pool.

RJ has experienced seizures for most of the year and just after celebrating his 7th birthday in October, he had a serious setback. From being lethargic to having seizures, to many trips back and forth to the hospital, RJ was admitted. It was hard being away from the family and baby but that is where mom needed to be—pushing for answers. It was a roller coaster ride as they discovered a negative reaction to a medication that had just been changed. It is difficult when adjusting medications to meet a need. A new plan has been put into play, unfortunately, the seizure activity has caused regression in his mobility and has robbed him of physical strength, however RJ is becoming more and more like his old self every day.

He will start a new school in the upcoming weeks where he can continue to heal and be ever BETTER than before. It has been so hard to see RJ regress and struggle, but his smile makes it all worthwhile. Every day he reminds us how far he has come and encourages us to keep pushing for him.

Definitely an EVENTFUL year but full of thanksgiving.

## Angel Corner: A Year in the Life of an Angel, continued



**Jordan** has had an eventful 2017. She celebrated her 19th birthday in February. She went to Arizona for spring break to visit her grandpa. In June, she travelled to Madison, WI, to cheer on her dad during his Half

Ironman Race. Summer was spent at the pool and hanging out with family and friends. This fall she loved having family from Ohio visit and watching her brothers play many soccer games. Jordan is finishing her last 2 years of high school and enjoys her Friday Night Fun Nights where she spends 4 hours with other special needs people doing activities, games, music and dinner. She is also involved in Young Life Capernaum, a youth group for high school students with special needs, that meets 2 Thursday's a month to fellowship and learn about God.

Recently we did our first 5K with Jordan, the Oktoberfest Run for the Poor!

We are very thankful Jordan has had a healthy year, with only doctor visits for basic check ups! She is looking forward to a trip back "home" in December to see her extended family for the Christmas holidays.

Note: Jordan and her mother are the artists who created the **Art of an Angel** note cards and artwork. These are available through the [www.LoveAnAngel.org](http://www.LoveAnAngel.org) website.



**Charlie's** year has been wonderful in many ways.

In January, this autistic young man celebrated his 15<sup>th</sup> birthday and as from his beginning, continues to bring music, happiness and love into our lives.

In honor of Charlie and autism research, Charlie's cousin began preparing for and ran a half marathon.

School helps Charlie with many things. One is patience, especially when he must wait on a late bus to pick him up. He enjoyed the class trip to Gettysburg and successfully worked in the school "coffee shop". He is enjoying getting "physical", working out in the gym.

It is so refreshing that Charlie, a young man of few words, wakes every Sunday morning asking to go to Sunday school. He had his Confirmation in June. His class was filled with loving, accepting, compassionate kids and ministers. He received total support from all.

We had a special activity introducing Charlie to the police in order that they might be familiar with him in case of any future issues. They were wonderful, compassionate, kind, and understanding. Their desire is to protect all.

He decorated pumpkins at school and we were so thrilled that he became the Soergel's Farm Calendar centerfold for October.

Our thought for this year comes from his older brother, "Don't get me wrong. Charlie can be a real pain. But I love him very much. (Brother Mikey is off to school at Slippery Rock.)

## Angel Corner: A Year in the Life of an Angel, continued



**Nayla** has had a great year. Our word for 2017 is Grateful.

She was able to participate in the Special Olympics, go to Pittsburgh PA to walk for the Angelman Syndrome Foundation with our team

Love an Angel. Then, thanks to Love an Angel, we were also able to enjoy the Pittsburgh Zoo that day as well.

We enjoyed our first family trip in many years visiting Niagara Falls, NY. Nayla loved the Maid of the Mist. As many Angel families experience, we had to make the trip a one-day affair. With sleeping issues, spending a night proves difficult—there is not a safe sleeping option when away from home. Portable beds are available and we hope to find a way to get one so we can experience longer, overnight family trips. In the meantime, we soak up local opportunities.

Nayla enjoyed several weeks at the Akron Rotary Day Camp. There she experienced canoeing, swimming, riding and eating lunch on a pontoon boat, and many other fun activities. Nayla was always excited to go to camp. As a family, we took many nature walks, outings to the playground, and visits to the Akron Zoo.

Through the summer, some amazing families and friends took time to learn how to care for Nayla in preparation of assisting in her care while Matt and I devoted our attention on our 4 year old. Little Gracie had to undergo open-heart surgery. It has not been easy juggling seven kiddos, one an Angel,

and one with a serious heart condition since birth.

We are so grateful and blessed by those who sacrificed much of their summer to help us through a most challenging time. It has been an eventful year and we are ready to end it with the best possible outcome for our family-- we are together and healthy—GRATEFUL.



This has been a big year for **Lucas**, thankfully filled with more highs than lows.

In January, we celebrated his 5th birthday with a trip to Kalahari, one of his favorite spots of course! He was a little too excited to get to the slides and fractured his leg climbing down off the bed. In true Angel fashion, he didn't let that slow him down, and quickly adapted with nothing more than ibuprofen.

Also in January Lucas was fitted with his new AFOs (ankle foot orthopedics) and we witness instant improvement in his walking skills –he is walking holding one hand and no longer wanting to be in a stroller. His new physical therapist is so impressed with his determination and has hopes of seeing independent walking soon.

In May, we vacationed in Destin, Florida. Lucas and his brother, Gavin, experienced a week on the beach making sand castles, mini golfing and, of course, enjoying the water. Having access to a golf cart, he quickly decided this was his new favorite thing. He loved riding around waving to everybody, giving them his signature giggle and smile. Continued >

## Angel Corner: A Year in the Life of an Angel, continued

He is such a social butterfly. We are so fortunate that our Angel loves to travel and does well on long car rides.

In his summer school program, he received PT and OT services and made new friends. One of his aides lives in our neighborhood and he is excited to see her when on our walks. This year provided many firsts-- first boat, four wheeler and amusement park rides. He is having great milestones in communication all he needs now is an AAC to give him a voice.

We can't wait to start making memories on our next big adventure—camping in our new camper. Lucas did so well over the summer, we are going to try kayaking and tubing with him. We will keep you posted on that one!

Colds, seizures, strep, fractures—any lows were outnumbered by the highs. This has been a good year.



**Ayleah** broke both of her arms last fall which has led us to a couple infusion treatments to help strengthen her bone density. We will know more about how well it's working in the spring when they repeat some of the tests. We started her on CBD oils which has increased the threshold for some seizure activity. Her seizures have been relatively controlled. We spent a couple nights in the hospital for a bowel clean out last May. She has been healthy overall.

On the positive side of things, she has gotten stronger in general. We have had some forward strides with toilet training, independent feeding, and communication. Ayleah received an Accent 1400 communication device which operates with a switch rather than touch screen. She is still figuring it out but will hopefully understand the power of her "voice" soon. Ayleah has been capable of moving her wheelchair independently for several years but she recently has been motivated to do so. She finds joy in getting into all kinds of things which were previously out of reach and laughing hysterically at her success.



**Gary** turned 17 this year. His placement into a transitional High School classroom, participating field trips and outings, improved his social skills by leaps and bound. He was in the track and field program and ran again in the Special Olympics. We even enrolled him in yoga classes. He is learning to throw the softball—now this is going to take some practice

During his sister's wedding, Gary was on "ring security" duty", and was the groomsmen official "wedding party pump up man", entering the ballroom to "Can't Touch This". His cousin participated in the Miss Teen USA, NC with Angelman Syndrome as her platform.

During his yearly trip to Boston for a clinical study to help his motor skills, he was included in another research study-- anxiety in AS individuals. Continued>

## Angel Corner: A Year in the Life of an Angel, continued

Gary's summer proved exciting. The family vacationed in the Outer Banks where Gary spent a "mommy and me" day at the spa—having a facial and a foot massage. He joined a young adult group that participates in community activities. He attended Rotary Camp and did Special Olympic bowling. He spent time in the pool both for fun and to help his back issues. He also shared pool time with some of his angel friends.

October 9, Gary underwent surgery for his scoliosis. The hours and days after the surgery were quite concerning – Outbreak of seizures, fever, atelectasis, his thrashing, pulling out IV and trying to pull out other needed equipment, and a transfer to ICU. The narcotics had suppressed and interfered with his seizure threshold. Switching the narcotics for his pain to Tylenol and Motrin proved more calming and tolerable. While we felt numb and our hearts and stomach were on fire with worry, we are so thankful for the many great doctors and staff that came together quickly and in unison for a turn around that still leaves us speechless. He is doing well and we are grateful for all prayers.

A year of many accomplishments and blessings -- a young man that is thinking more clearly, learning, and sleeping better.



**Isabella** has had a good year. Her seizures have been minimal meaning fewer trips to ER. It has also meant fewer times having to watch and just stand by, unable to do anything until a seizure is over. We hate seizures.

Thrilled with her seizure control, Bella's sleep has gotten worse. With the many medications she has been given and is on now, her sleep is still sporadic and she does NOT sleep through the night. This is hard on all of us. Such sleep deprivation!

Bella misses her brother but we are happy for him, he is attending Bowling Green. This year I have been working, helping with my parents care and finishing my schooling. I am happy to have graduated, yet we still face difficulties with the "new" changes this has brought. Bella has had many new changes—a new teacher, new bus driver and new aides. The familiar faces and consistencies in her care for the past three years are gone. We are experiencing some frustration as she tries to adjust. Some days I can even see it in her face when she is getting off the bus.

The non-verbal part of her disability will always be challenging and frustrating. This year she is starting to communicate via iPad by mock typing. Although we normally know what she wants, the fact that she is responding to "yes" and "no" by simply pointing her finger, allows others to know her desires too. It is exciting to know that she has a "boyfriend" that she plays with outside and can find him in a crowd.

Step by step, day by day, she amazes me. Good or bad days, good or bad year, Isabella continually surprises me. It would be nice to know that no matter what she faces with the "disabilities" of AS, on any given day, or during any given year, that she will always be as healthy and safe. That is really, where I come in as her mother, to do what I can and to see that others do what they should, to help keep her healthy and safe. I consider myself lucky and am thankful to have her in my life.