

FEDS NEWS

FAMILIES EXPLORING DOWN SYNDROME



Fall 2018

Families Exploring Down Syndrome is proud to announce our 12th annual fundraising walk event! Along with raising awareness of Down syndrome, this walk is our **only fundraiser of the year**. The walk will take place on September 15, 2018 at the Macomb Intermediate School District. Doors open at 10:00 a.m. The events of the day will end by 2p.m. After the walk, everyone will be free to enjoy our party featuring: Pony rides, a petting zoo, carnival games, a bounce house, a DJ, clowns and magicians making balloon animals, face painters, and more! The DADS group will be hosting a food tent with hotdogs, chips, cotton candy, ice cream, and popcorn. A merchandise table will be available with FEDS merchandise. There will also be 50/50 and fishbowl auctions.

This is the one event a year that helps us provide services and events like our monthly meetings, new parent baskets and brunches, Parent to Parent Connection, medical outreach, summer picnic, holiday parties, 321 Day celebration, My Chance to Dance, Club 21, the Young Athletes Program, and more.

Registration: For a team of 4 or more (there is no maximum amount of teammates), registration is \$100 and includes 4 t-shirts. Registration for an INDIVIDUAL is \$25 and includes 1 t-shirt. Additional t-shirts are \$10 each before August 23rd and \$15 each the day of the event (while supplies last). Online registration is OPEN! Create your team page and share it on social media! Build the biggest team and gather the most donations. The three top earning teams will be rewarded with a cabana for your team's home base, a prize pack of FEDS accessories and wearables and their choice of a membership to either the De-

troit Zoo, Michigan Science Center, or the Ann Arbor Hands-On Museum. It is going to be a blast and we can't wait to see you there!



When: September 15, 2018
10am-2pm

Where: Macomb Intermediate
School District (MISD)
44001 Garfield Rd
Clinton Township, MI 48038

REGISTER TODAY AT

[https://www.ds-stride.org/
fedsmithumbsup](https://www.ds-stride.org/fedsmithumbsup)

FEDS LUAU WALK



We Need Your Help!

Thumbs Up For Down Syndrome: Luau Walk
44001 Garfield Road, Clinton Township, MI 48038
Saturday, September 15, 2018
11:00 am - 2:00 pm

We are looking for volunteers to help us make this special event a grand success!

We need help in the following areas:

Carnival games, parking lot, setup, registration and more!

Register online at: <http://www.fedsmi.org/walkvolunteer>

Email Margie Wheelock (Margie@fedsmi.org) with any questions.

FEDS SUMMER PICNIC

On Sunday, July 8, about 20+ families enjoyed a beautiful day at the FEDS picnic. The picnic is held once a year at Veteran's Memorial Park in St. Clair Shores. The kids enjoyed cooling off in the splash pad and playing on the playground, while the parents socialized. Everyone contributed delicious food and we even celebrated an 8th birthday! Many thanks to our volunteers who helped make the picnic a success!

Thank you to Jessica Laughton for chairing the event! We appreciate all of your hard work in making this such a fun, successful time!



SCHOLARSHIP THANK YOU'S

Dear FEDS,

Thank you for the summer scholarship. I used it for my horseback riding camp at Banbury Cross. I had a fabulous time! Thanks FEDS!

Love, Lucas and family!



Dear FEDS,

Thank you for my summer scholarship. We used it towards SCAMP, the summer camp I go to. We do a lot of fun things, like bowling, have dances, go to water parks, the zoo, the county fair and more! My favorite activity was going to Bounce U!

Ava Gilleland

Thank you for my summer scholarship. It was fun to go on field trips, make crafts, and play with my best friends.

Adam Karr



SCHOLARSHIP THANK YOU'S (CONT.)

Dear FEDS,

Thank you for my scholarship! I used it toward going to SCAMP, my favorite thing! It was so much fun!

Megan Moore



Thank you, FEDS, for bringing us a routine filled with fun for our Ada by the gift of money towards SCAMP. Knowing she was safe and getting what she needed allowed her sisters to have the freedom to be able have their own fun with no concerns. We really appreciate your generosity.

Love, The Ehlerts

Ryan had a great time at SCAMP camp this summer! His favorite part was hanging with his buddies, especially at the dances!!! Thanks to FEDS for the scholarship we used toward the cost of SCAMP!

The Tessmar family



SCHOLARSHIP THANK YOU'S (CONT)



Benny would like to say thank you to FEDS for the summer scholarship! With it he was able to take swim lessons which he absolutely loves!!! Thank you FEDS!!!



THOUGHTS AND PRAYERS



Fiona Pauwels, mother Laura Pauwels and family could use some extra love, comfort and prayers as Fiona is currently on a biological immunotherapy drug to shrink the inoperable brain tumor she has. This is her fourth brain tumor, but the previous three were able to be removed surgically. Fiona is 9yrs old and has Down syndrome. Sending many prayers of comfort and strength during this difficult time.

DID YOU KNOW?

Individuals with Down syndrome are at a higher risk of having Celiac disease. Because up to 16% of individuals with DS are believed to have Celiac, all infants with DS between the ages of 2 and 3 should be screened for Celiac disease with a simple blood test. In addition, doctors should consider screening tests for adults with DS, especially when there is weight loss, poor nutrition or persistent

changes in bowel habits. Children with Down syndrome and celiac disease may have typical symptoms like diarrhea, abdominal pain, or poor growth, but they may also have atypical symptoms like behavioral changes or anemia. The treatment is dietary and involves eliminating all barley, rye, and wheat from a person's diet.

(Information from NDSS and beyondceliac.org)

FOCUS ON FAMILY

Please join us in welcoming Cole Robert Brewer and family to FEDS! Cole was born May 17, 2018 at 11:51 am 6 lb 4 oz 18 3/4 inch. Cole was born extra special with an extra 21st chromosome!



I had the chance to ask Cole's mother, Kelly some questions to get to know Cole and his family better.

Can you tell us a little bit about your family?

Joey and I (Kelly) are Cole's parents. We live in Warren, we're both from Warren. We grew up next door to each other/ across the court from each other. I am 5 yrs. older than him. I use to babysit for their family so needless to say we did not start dating until we were in our twenties. Our families have known each other since 1991. If I didn't know him one way, I would know him 10 other ways. I am now a stay at home mom but I've worked in childcare on and off most of my life. Joe works for Schreiber Roofing Company, but he works in the warehouse and as a driver, not on the roof. I worked there for a bit before I got pregnant. We also have 2 dogs, 2 cats (our 3rd passed away while I was pregnant, talk about emotional) and 2 beta fish.

Cole is baby number 1 for us. We tried for 6 yrs. I had weight loss surgery 2 summers ago and as soon as we were able to start trying again, I got pregnant. He is the first grandchild for both sets of parents and 1st great grandchild for two sets of our grandparents.

I'm a firm believer in things happen for a reason and I kind of think we had to wait on him so long because I was busy taking care of the 4 kids of my best friend who passed away for a few years before I worked with my hubby.



How and when did you find out Cole had Down syndrome?

We found out Cole was going to have Down Syndrome from the genetic blood test at 12 weeks. I called my Mom to tell her the news and I didn't know my Dad was there and that she had me on speaker (it was the middle of the day and he should have been at work). So I tell her and my Dad chimes in with "But is it a boy or a girl?" It seriously jump started the process of coming to terms with everything for me. I really feel like that

one question took a big weight off of me instantly. We had a ton of support and resources from the very beginning. My OB/GYN's Godson had Down syndrome as well so even she understood as well as my friend work-



FOCUS ON FAMILY (CONT.)

ing at the MISD, she showed up with a ton of information the night we found out.

What were your initial fears and concerns when you received his diagnosis?

Obviously I was scared of possible heart problems and his health overall and I wondered what kind of life he would have. But not once did we consider not having him. He didn't cooperate for his anatomy scan



so we had to wait an additional 10 wks. to find out more information which still wasn't much. He gave us a bit of a scare when he decided to come a week and 2 days early with his heart rate dropping during contractions but he

came out very healthy overall. We had him with us that night until noon the next day. They did an echocardiogram the morning after he was born and came to tell us that he needed to go to the NICU shortly before noon. He had to be monitored in the NICU for a few days because of his Aortic arch (they thought it was a little small) and for pulmonary hypertension along with a little jaundice but it all corrected itself. We are very lucky.

Now, most importantly, tell us about Cole! What are his favorite things and some of his strengths?

Cole is seriously the best baby ever. He sleeps and

eats great. He has been rolling over both ways for



awhile now and he is only 10 1/2 wks., so he is already ahead of the game and he laughs already too. He was totally worth the wait. Everyone of our family members is obsessed with him.

What makes you excited about Cole's future and your journey with DS?

Seeing all of the kids and families at some of the FEDS events and watching that show Born This Way has made me excited for his future. I also found out the other day that in 1983, the average life expectancy of someone with DS was like 25 and now it's 60 something. It makes me very glad to be alive in this time. Thanks so much for taking the time to get to know us. We are so happy and grateful to be apart of such an awesome group.

Thanks so much for sharing Kelly and again, welcome to the family Kelly, Joe and Cole Brewer!





GOOD NEWS!



Jamie Feggan can stand on his own and has taken three steps on three different occasions! Nice job Jamie!

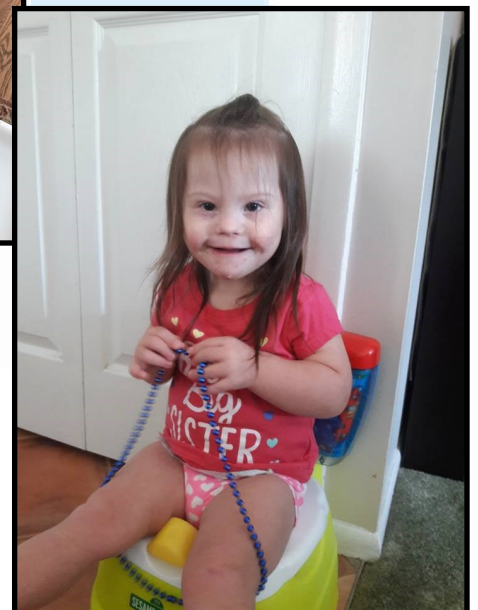


Leo Kowatch climbed up the rock wall at the park, all on his own! Keep climbing Leo!

Grayson Gortat is having a very busy summer building sheds and learning how to cut hair! AND he has recently started initiating tons of new words like "no", names, and 10 other words! Keep it up !



Addy Saha is starting to poop on the potty! Great job Addy!





GOOD NEWS!



Alina Berra is doing great drinking from straws from these juice boxes! Wonderful Alina!

Luke Winters is 5 yrs old and he loves to be outside. He loves swimming and riding his car. Very fun and loving. #morealikethandifferent



This was Elijah Gallihugh's first year playing baseball with his two best friends Loneigh Preim and Charlie Hites! Way to go!

Jacob McGregor is 21 months. He loves his summer evenings hanging out in the front yard with his cousins and the neighborhood kids playing in the grass, swimming, going for walks, and eating ice cream with them! What fun Jacob!





VOLUNTEER APPRECIATION



Check Out Our 2018 Volunteer Appreciation Luncheon!

This year our volunteer chairs, who head up all of our events, were honored at a luncheon on April 21st at Olgas Restaurant. The board is very appreciative of all the time and hard work that our volunteer chairs put into the many events that FEDS does for our members; this event is just a small way for FEDS to say "Thank-You!" Please join us in thanking our chairs if you encounter them at any event. Check out the pictures from this year's luncheon at Olgas this past April...



UPCOMING EVENTS

SEPTEMBER

- 9/7** 6-9pm. Back to School Pizza Party MISD Room 100B
- 9/15** 10am. FEDS Luau Walk. MISD
- 9/20** 7pm. Board Meeting. Beaumont Troy Professional Building 44199 Dequindre Rd, Troy

OCTOBER

- 10/10** 7pm. FEDS Information Meeting: Potty Training. Veronica McAtee, license psychologist from Beaumont Hospital. MISD Mich/Superior Rm
- 10/13** 10am-12. Baby Play Group. MISD Room 104
- 10/18** 7pm. Board Meeting
- 10/19** 7pm. 7-Up Bingo MISD
- *TBA Halloween Party

NOVEMBER

- 11/9** 7-9pm Moms' Night Out—Craft. MISD Mich/Sup Rm
- 11/10** 10am-12 Baby Play Group. MISD Room 104
- 11/14** 7pm FEDS Information Meeting: What To Expect When Your Loved One Turns 18. Transitioning into adulthood Julie Frei, from MORC. MISD Mich/Sup Rm
- 11/15** 7pm. Board Meeting

All dates are subject to change! Please check your email, our website and social media for the most up to date information!



Moms' Night Out!

Thurs., Aug. 30 @ 6:30 pm

Come out and enjoy a summer evening with friends + a variety of vendors, food trucks, and entertainment at the Dodge Park Farmer's Market.

Music in the Park kicks off at 7 pm on the amphitheater stage.

[40200 Utica Rd.](#)

Sterling Heights, MI 48313

Questions and RSVPs can be sent to Kimberlee Canup at: Kimberlee.canup@gmail.com



Back to School PIZZA PARTY

Friday, September 7th

Doors open - 6:00 PM

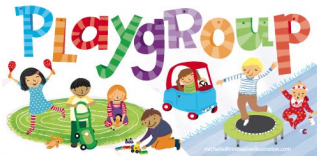
Pizza served - 6:30 PM

Start the new school year off with some pizza, dancing & fun!

Walk Shirts will be available for pick up!

At the MISD 44001 Garfield, Clinton Township

UPCOMING EVENTS (CONT)



Baby Play Group (Ages 0-2)

10/13, 11/10, 1/12, 2/9, 3/16, 4/27

10am-noon

Macomb Intermediate School District
44011 Garfield Rd. Clinton Twp, MI

Come Join other parents and socialize while the babies play!

Bring a blanket and few toys for your child to play with.

Hope to see you there!

Please e-mail Jessica Laughton to RSVP or with any questions at jkilano@yahoo.com



Moms Night Out!

11/9

7-9pm

Macomb Intermediate School District
44011 Garfield Rd Clinton Twp, MI

CRAFT NIGHT! Enjoy a night of talking with the ladies and embracing your crafty inner self. The craft will be very simple, so don't worry! Questions and RSVPs can be sent to Kimberlee Canup: kimberlee.canup@gmail.com

7-UP Bingo 7yrs+ & siblings

10/19

7pm



MISD (Michigan/Superior Rms)

The bingo cards have Disney characters and traditional bingo numbers.

Christmas Party!

Saturday, December 8, 2018

10:45am-1:45pm

Club Venetian

29310 John R Rd Madison Heights, MI 48071

Please join us for a wonderful day of crafts, food, a photo booth, and DJ!

Look out! More information and the RSVP form to come!



SAVE THE DATE

DECEMBER

12/8 Christmas Party (see previous page)

12/20 7pm. Board Meeting. Beaumont Troy Professional Building.

JANUARY

1/9 7pm. Information Meeting. Sibling Panel. MISD

1/17 7pm. Board Meeting. Beaumont Troy Professional Building

FEBRUARY

2/8 7pm. 7-Up Bingo. MISD

2/13 7pm. Information Meeting. Sign Language. MISD

2/21 7pm. Board Meeting. Beaumont Troy Professional Building

MARCH

3/13 7pm. Information Meeting. 321 Shirt Pick-up. MISD

3/15 6pm-9pm. Down Syndrome Celebration! MISD

3/16 10am-12pm-Baby Play Group. MISD

3/21 7pm. Board Meeting. Beaumont Troy Professional Building

APRIL

4/10 7pm. Information Meeting Sam Czasak— Speech Therapist. MISD

4/18 7pm. Board Meeting. Beaumont Troy Professional Building

4/27 10am-12pm-Baby Play Group. MISD

MAY

5/3 7pm-9pm. Appreciation Awards. MISD

5/8 7pm. Information Meeting. MISD

5/17 7pm. 7-Up Bingo. MISD

*MISD— Macomb Intermediate School District 44011 Garfield Rd. Clinton Twp, MI 48038

*Beaumont Troy Professional Building 44199 Dequindre Rd Troy, MI

ALL DATES ARE SUBJECT TO CHANGE. PLEASE CHECK YOUR EMAIL, OUR WEBSITE AND OTHER SOCIAL MEDIA FOR THE MOST CURRENT INFORMATION!

DID YOU KNOW?

In 1983, the average life expectancy of a person with Down syndrome was a mere 25yrs old. Today, it's 60!

dates
to Remember

COMMUNITY APPRECIATION NIGHT

Do you have someone in your life who has made a big difference in the life of your child? Maybe a babysitter, school para-professional, teacher, tutor, grandparent, sibling, coach, who made an impact on your child's life? Someone who has stood out and has been there for you or your child by being extra good to them (or you) and went the "extra mile?" Nominate that person for our Family

lies Exploring Down Syndrome Community Appreciation Night! This year it will be May 3. Watch for more details to come and nomination forms in the early spring and let's celebrate those who celebrate our kids and adults with Down syndrome.

MEET YOUR BOARD



Meet Charissa Antonelli, our newest board member! She joined the FEDS board April 2018! She is on the walk committee and in charge of donations, decorations and games. Charissa lives with her husband (Jason) and 4 children (Ava, Ian, Zackary, and Ben) in Romeo. Ben is the youngest and has Down syndrome. He is 7yrs old and attends Glenn Peters School. Thank

President: Donovan Myers

Vice President: Lynn Gilleland

Treasurer: Barb Lempinen

Board Members: Kristen Karr, Betany McLain and Charissa Antonelli

Contact Us

PO Box 1191
Sterling Heights, MI 48311

(586) 997-7607

fedsofmichigan@gmail.com

www.fedsmi.org

We want to hear from you!

Email us at

fedsnewsletter@gmail.com with your good news, thoughts and prayers, and scholarship Thank You's!

