

# FEDS NEWS

FAMILIES EXPLORING DOWN SYNDROME



Winter 2018

Families Exploring Down Syndrome would like to thank everyone who participated in this year's walk on September 15, 2018 at the MISD! We had 30 teams registered and raised a total of approximately \$32,000 (minus expenses). It was a great time for all with pony rides, a petting zoo, carnival games, bounce houses, a DJ, clowns, fire truck to tour, 50/50 raffle, fishbowl auctions, a marching band, special character and guest appearances, and face painters. Thank you to the DADS

group for grilling and providing the food! Also, a huge thank you to our incredibly amazing volunteers and event chairs. We couldn't have put on this event without all of you!



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# THIS YEARS TOP FUNDRAISERS!

## #1: Cole's Crusaders: \$4,280



## #2: Team Jacob: \$2,705



## #3: Drew's Crew: \$1,615



# FEDS LU'AU WALK PICTURES



# MORE FEDS LUAU WALK PICTURES



# SCHOLARSHIP THANK YOU'S



Dear FEDS,

We want to say thank you so very much for our summer scholarship. We are going to be using the money towards some equipment for Gabriella Socia that she needs. We are so lucky to be a party of FEDS. Thank you for everything you do for all the families.

Gabriella Socia Family

Thank you for my scholarship from FEDS. I used it to buy my pop package on my Hawaiian cruise celebrating my 30th birthday. I had an awesome time!  
Trevor Taylor



# THOUGHTS AND PRAYERS



Mateo Sabou recently had surgery, Periacetabular Osteotomy on both of his hips. He is now at home recovering after a long week in the hospital. He is in a cast from the waist line down for 6-8 weeks. Due to his situation, he is requiring a lot of care as he can't get around and do for himself. A friend started a meal train for them for anyone who can help them out!

<https://www.mealtrain.com/trains/rn05r7>



Ada Ehler had an adenoidectomy on Nov. 15. Wishing you a very speedy recovery Ada.

# THE LUCKY FEW TATTOO



On October 5th, 13 moms, dads and sisters started out Down syndrome awareness month with a bang by joining The Lucky Few Tattoo club!

times more than we think we can bear. Mica May launched the tattoo for her son Jackson who has DS. She says "the tattoo is a physical symbol that there are thousands of people in this community that are advocating, fighting for, challenging, and shouting the worth of people with DS."

Since making its first appearance last year, The Lucky Few Tattoo has been sweeping the nation.

The three arrows symbolize the three copies of the 21st chromosome our loved ones with DS have and how we rise up and move forward when faced with challenges. We fly the highest after we have been pulled back and stretched, some-

Huge shout out to Jessica Laughton for successfully organizing it all, Jessica Beth for being an awesome and patient tattoo artist and Watchtower Tattoo Company in Utica for their graciousness!





# SPOTLIGHT



Meet Trevor Taylor! Trevor is 30yrs old and has Down syndrome. I was able to speak to his mom, Cheryl Taylor so we could learn a little bit more about Trevor! The following is what Cheryl had to say about her son.



“Where have 30 years gone? When Trevor was born in 1988 we were shocked to find out he had Down syndrome and we knew nothing about DS. The day after he was born he was taken to another hospital for a blood transfusion and we found out he needed open heart surgery. However, Trevor didn’t gain weight and needed to be at 10lbs to have the surgery. It took a village for him to gain weight so we had to tube feed him until he was ready for surgery. By this time he was 6 months old. Surgery didn’t go well, while taking him back to recovery Trevor started hemorrhaging and the doctors rushed him back to surgery. Things didn’t look good we were told. They opened him back up and stopped the bleeding. He was in the hospital for 4 1/2 weeks! Once we got Trevor back home he started being active and eating like a normal baby.

When Trevor was 24 yrs old he was tested for HEP C since he had a blood transfusion in 1988, which was before they tested donor blood. Trevor tested positive! We went to Henry Ford Hospital in Detroit and saw Dr. Moonka, who took Trevor under his wing like he was his own son. Dr Moonka studied for a year about people with Down syndrome and HEP C, to see what was best for Trevor. Trevor start-

ed interferon treatments once a week for 48 weeks. This took all his energy away and loss of weight. We had to stop his treatments at 22 weeks since Dr Moonka said it wasn’t taking effect. So now we were back to square one. Dr Moonka said there was a new medicine coming out and he was waiting for it to be FDA. Trevor took Harvoni the new medicine for 6 mos and is now HEP C free!

At age 26 Trevor wasn’t as active as he usually was. We went to the Drs and his heart rate was at 34, so immediately they sent us to Henry Ford downtown to have a pacemaker put in. He’s been great ever since.

All in all, Trevor has a fantastic life. He completed high school from Cousino High, completed Lutz Vocational School and currently attending CSDD Life Enrichment Academy in Shelby. He has a paying job at TLC (Teaching, Learning and Communication) in Clinton Twp. and does maintenance, which all those that know Trevor, knows he’s obsessed with cleaning. Trevor was also one of the young adults that helped with the FEDS Changing Lives program where we went to Doctors offices, hospitals and did Grand Rounds. Since Trevor’s speech isn’t really clear he would sign “ What a Wonderful World” at the end of the program and there was never a dry eye in the audience.



# FOCUS ON FAMILY (CONT.)



Trevor plays ice hockey for the Flyers Special Needs hockey team out of St Clair Shores. He's been skating for 25 yrs and playing hockey for 19 yrs. Actually he skated before he could walk! He bowls with Parks and Rec on a league, plays Bocce Ball for

FEDS, does dance exercise class, belongs to FEDS Club 21 dance and once a month he gets together for a Young Adult Night at each of his friends house for movies and pizza.

Trevor was the Best man at his brothers wedding, godfather for his nephew Keegan and he's an Uncle 6 times and very proud of it. He loves WWE and playing Xbox. He's a very true sports fan for all the Detroit teams.

Trevor spends his summers up north at our summer home. He kayaks, tubes, and listens to his music on the hammock. For his 30th birthday this year he got a 3 wheel battery operated scooter and a cruise to Hawaii which was his idea. He takes out all the neighbors trash around us up north, every Monday and returns all the trash bins after pickup. He even does people we don't know, but they all know Trevor.

Trevor is one of 3 boys. His two older brothers are police officers and they both play and coach their sons hockey. When we go to their games Trevor works the penalty box and helps with the scoreboard. He loves his brothers, sister in laws, nieces and nephews very much. They make sure Trevor is included in everything.

We wouldn't change Trevor's life. He has opened up more peoples eyes than we can count. He is very active, healthy and loves to party. If you would ask Trevor about his life he would give you a 2 thumbs up! Never give up, there is always light at the end of the tunnel!!!

Frank & Cheryl Taylor"

I asked Cheryl if she had any advice for moms of littles with DS and she said, "You have to take it one day at a time. Every child is different." Trevor, keep up being awesome and thanks for being a light in our community!

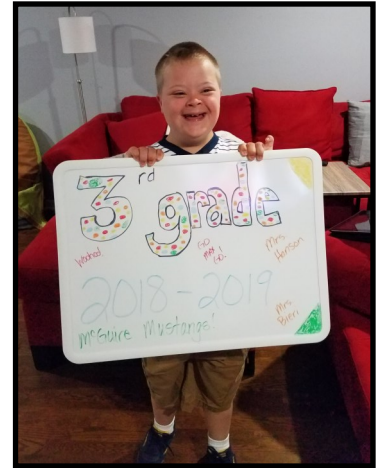




# BACK TO SCHOOL PICTURES

Navigating the education system, knowing what is best for our children and advocating for that can be stressful to say the least. FEDS is hoping everyone had a great start to the school year. Here are some adorable back to

school pictures because, well, they are adorable!



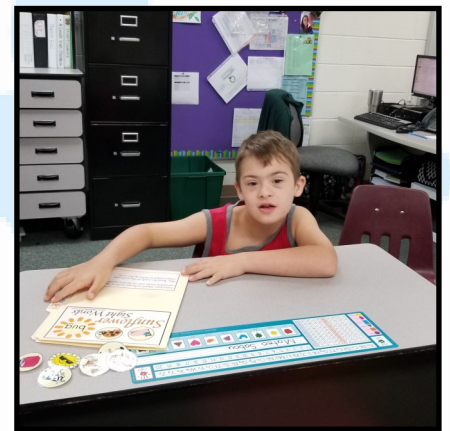
Max. 3rd grade.



Ada. 1st grade



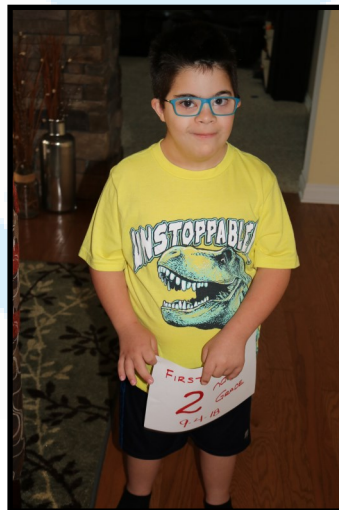
Addison Grace. ECSE.



Mateo. 3rd grade.



Parker. Preschool.



Gabriel. 2nd grade.



Leo. ECSE.



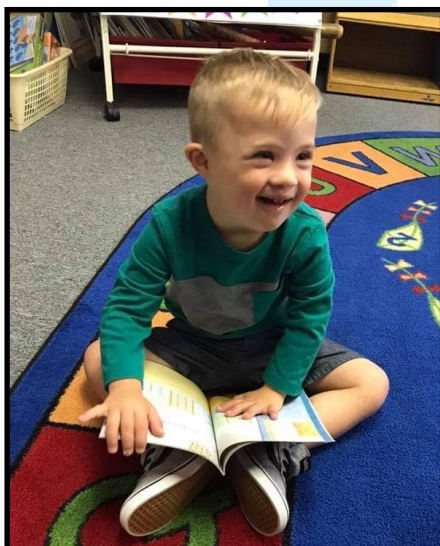
# GOOD NEWS!



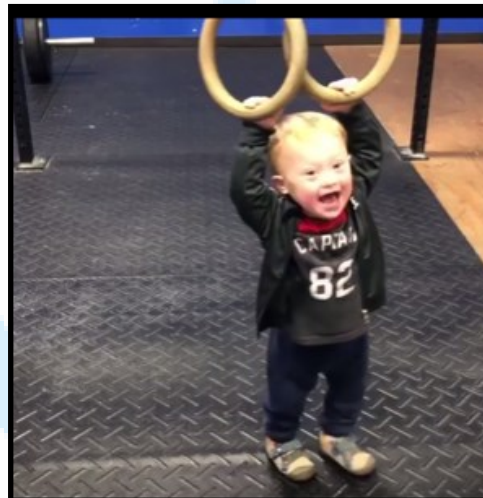
This summer, Ada was thrilled to find out she no longer had to be restricted from trampolines due to Atlantoaxial instability (AI)! Woo Hoo Ada!



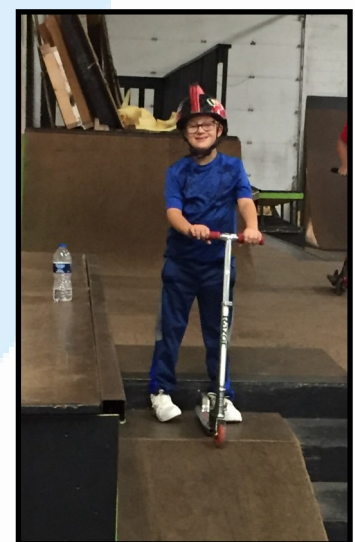
Parker Hatton received honors of Student of the Month for the month of October! Great job Parker!



Grayson has said 2 two word sentences! Huge milestone for him: "Water backpack" when packing up his school stuff. "Boo boo done" when his scrape healed. Keep it up Grayson!



Kallan turned 2 in June and as of August he is full on walking! His family is beyond excited! Nicely done Kallan!



"My big brother taught me how to ride a scooter up and down big ramps. I couldn't believe I did it!" Adam Karr

# FALL FEDS EVENT PICTURES

## FEDS HALLOWEEN PARTY

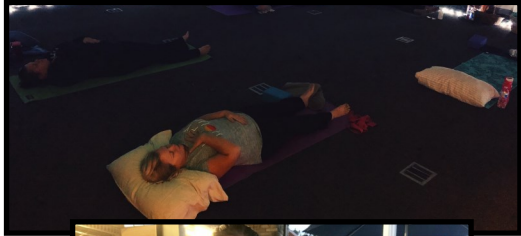


## 7-UP BINGO!



# FEDS EVENT PICTURES

## MOMS NIGHT OUT



## BABY PLAY GROUP



# UPCOMING EVENTS

## DECEMBER

- 12/4 & 12/18 6:30-7:30pm  
Young Athletes Program.  
(YAP) Glen Peters School.  
46650 Heydenreich Rd Macomb
- 12/8 10:45am-1:45pm. Holiday Party. Club Venetian. 29310 John R Road Madison Heights, MI
- 12/20 7pm. Board Meeting. Beaumont Troy Professional Building 44199 Dequindre Rd, Troy

## JANUARY

- 1/8 & 1/22 6:30-7:30pm. YAP.  
Glen Peters School. 46650 Heydenreich Rd Macomb
- 1/9 7pm. FEDS Information Meeting: Sibling Panel. MISD Mich/Superior Rm
- 1/12 10am-12. Baby Play Group. MISD Room 206
- 1/17 7pm. Board Meeting. Beaumont Troy Professional Building 44199 Dequindre Rd, Troy

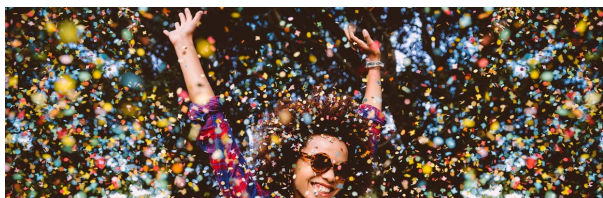
## FEBRUARY

- 2/5 6:30-7:30pm. YAP. Glen Peters School. 46650 Heydenreich Rd Macomb
- 2/8 7pm. 7-UP Bingo. MISD Mich/Sup Room
- 2/9 10am-12 Baby Play Group. MISD Room 206
- 2/13 7pm FEDS Information Meeting: Sign Language. MISD Mich/Sup Rm
- 2/21 7pm. Board Meeting. Beaumont Troy Professional Building. 44199 Dequindre Rd, Troy

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



**Childcare Available  
at all Monthly  
Meetings!**



**Every Other Tuesday 's**

**12/4, 12/18, 1/8, 1/22, 2/5, 3/5, 3/19, 4/9, 4/23**

**Glen Peters School 46650 Heydenreich Rd**

**Macomb, MI**

**6:30pm-7:30pm**

Special Olympics Young Athletes is a sport and play program for children with and without intellectual disabilities (ID), ages 2 to 7 years old. Young Athletes introduces basic sport skills, like running, kicking and throwing. Young Athletes offers families, teachers, caregivers and people from the community the chance to share the joy of sports with all children.

# UPCOMING EVENTS (CONT)



## FEDS HOLIDAY CELEBRATION

Saturday, December 8, 2018 at Club Venetian  
29310 John R Road, Madison Heights, MI 48071  
(just North of 12 mile Road)  
<http://www.clubvenetian.com>



Doors open at 10:45 a.m. Lunch Served at 12:00 p.m.  
\* Crafts, Food, Fun, DJ, D.A.D.S. sponsored Photo Booth and Santa will all be there!  
High chairs and booster chairs are limited, feel free to bring your own along.

*This year we have chosen Helping Hands Gifts. They are an organization that helps children, families and charities. They support charities through finding donations, volunteers, building space, event promotion, and more. They fill the gaps where other charities can't. They provide support for organizations and people who fall outside the average definition of needy, but still have a need. They are looking for new items such as legging sets, winter coats for kids and adults, any popular toys, diapers, laundry detergent, and nice zip up hoodies with local pro sports teams on them.*

Send the bottom of form and money to:  
Emily Menczywor  
679 Dennison Ct., Oakland, MI 48363  
By **November 24th**, or bring this form and your check to the **General Meeting on Wednesday, November 14, 2018.**

The Knights will have a gift for your special person with Down syndrome. Please fill out the wish list below, the Knights will try to fulfill your child's wish (between \$20.00 and \$25.00). The more available an item and generic the choice, the more likely they are, to obtain the exact item.

**Because this is such a popular event, the party is open to FEDS members only.**

Reminder: if your other children will be visiting with Santa, please bring a wrapped and labeled gift and turn it into Santa's helpers at the registration table when you enter.

The menu for the party includes salad, chicken fingers, buttered pasta, pasta with marinara sauce, rolls, pop, coffee and dessert.

**Deadline November 24th.**  
To volunteer to help at the Holiday Party, contact Emily at [emilyamansour@yahoo.com](mailto:emilyamansour@yahoo.com) or 586-381-1733.

**Mail this form in with your check (made out to FEDS) by the deadline - November 24th!**

Family (Adults) Name: \_\_\_\_\_ Child's Sex \_\_\_\_\_

Child w/DS Name: \_\_\_\_\_ Age \_\_\_\_\_

Developmental level (for toy selection) \_\_\_\_\_ Phone #: \_\_\_\_\_

Gift Wish #1 \_\_\_\_\_

Gift Wish #2 \_\_\_\_\_

This year the cost is \$10.00 per person (anyone 7 years old and up) and \$5.00 per child (3-6 years olds). (This is your cost to attend. FEDS picks up the additional costs for this event.)

Number of people (7 years old and up ) \_\_\_\_\_ @ \$10.00 = \_\_\_\_\_

Number of children (3-6 years old) \_\_\_\_\_ @ \$5.00 = \_\_\_\_\_

Number of children (Under 3) free \_\_\_\_\_ ---FREE---

TOTAL number attending in your family \_\_\_\_\_ Total Amount Enclosed \_\_\_\_\_

I will help with: Set-up @ 10:00 \_\_\_\_\_ Crafts \_\_\_\_\_ I will be Santa's Helper \_\_\_\_\_ Clean up @ 2:00 \_\_\_\_\_



# SAVE THE DATE

## MARCH

- 3/5 6:30pm-7:30pm. Young Athletes' Program (YAP). Glen Peters School
- 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
- 3/19 6:30pm-7:30pm. YAP. Glen Peters School
- 3/21 7pm. Board Meeting. Beaumont Troy Professional Building

## APRIL

- 4/9 6:30pm-7:30pm. YAP. Glen Peters School
- 4/10 7pm. Information Meeting Sam Czasak— Speech Therapist. MISD
- 4/18 7pm. Board Meeting. Beaumont Troy Professional Building
- 4/23 6:30pm-7:30pm. YAP. Glen Peters School
- 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!\*\*\*



### Baby Play Group

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](mailto:jkilano@yahoo.com)

Above all, watch with glittering eyes the whole world around you because the greatest secrets are always hidden in the most unlikely places. Those who don't believe in magic will never find it.

~ Roald Dahl



# MEET YOUR BOARD



Meet Bethany McLain! Bethany is a professional Sign Language interpreter and an owner of a Sign Language Interpreter agency called Signing Pros. Events. She has chaired, co chaired many different FEDS events and has been on the board for 5yrs. Bethany and her husband, Dave, have 4 children, Josiah, 20, Micah, 18, Rebekah ,13, and Caleb, 10. Bekah rocks an extra chromosome and is Hard of Hear-

ing. Bekah enjoys swimming, friends and dance class. This summer Bekah attended her first full week camp and loved it. As a family, the McLains enjoy boating and being on the water.

**President:** Donovan Myers.  
**Vice President:** Lynn Gilleland  
**Treasurer:** Barb Lempinen  
**Board Members:** Kristen Karr  
Bethany McLain and Charissa Antonelli

# HELP SHAPE THE FUTURE OF FEDS!

**Would you like to have input on what FEDS does? Do you have great ideas that you would like to see implemented? Consider joining the FEDS Board!** In order to continue our growth and current levels of outreach, we need people to join our board which would be a commitment of attending monthly board meetings on the third Thursday (7 PM - 9 PM) and member meetings, if possible, on the second Wednesday (7 PM - 9 PM) of every month. You do not have to be the parents of individuals with Down syndrome. You do not even have to be a member of FEDS. We are also seeking professionals in the Down syndrome community

to be consulting board members at a quarterly level of commitment. Event chairs require less commitment but are very much needed and appreciated as well. If you, or someone you know, are able to join our board and/or chair an event, please email us ([board@fedsmi.org](mailto:board@fedsmi.org)).

Thank you for considering volunteering for FEDS — we simply cannot do it without you.



## Contact Us

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Sterling Heights, MI 48311  
(586) 997-7607  
[fedsofmichigan@gmail.com](mailto:fedsofmichigan@gmail.com)  
[www.fedsmi.org](http://www.fedsmi.org)

*We want to hear from you!  
Email us at [fedsnewsletter@gmail.com](mailto:fedsnewsletter@gmail.com) with your good news, thoughts and prayers, and scholarship Thank You's!*

