

# FEDS NEWS

FAMILIES EXPLORING DOWN SYNDROME



Spring 2019

World Down Syndrome Day is a special day for us all to celebrate our loved ones with Down syndrome and their abilities. We had a blast at our World Down Syndrome Day party this year with music, food, games, and tons of fun characters—even Elmo made an appearance! A huge thank you to Becky Saha and family for organizing a great event and to Lynn Gilleland for designing those great shirts you see in the pictures! To see our full album of pictures, go to our Fa-

cebook page—Families Exploring Down Syndrome! And don't forget to eat at Culver's on March 21 at the Madison Heights Location and March 28 at the Shelby Twp location between 4-8pm to receive great service and great food! 5% of sales goes to FEDS!



## WHAT'S INSIDE

- ◆ World DS Day (p.1-2)
- ◆ Community Appreciation Night (p. 3)
- ◆ Good News (p. 4-5)
- ◆ Spotlight (p. 6-7)
- ◆ FEDS Event Pics (p.8-9)
- ◆ Upcoming Events (p.10)
- ◆ Save The Date (p. 11)
- ◆ Contact Info (p. 11)



# WORLD DOWN SYNDROME DAY



# COMMUNITY APPRECIATION NIGHT

## Let's celebrate those who celebrate our loved ones with Down syndrome!

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 Families Exploring Down Syndrome Community Appreciation Night!

**When:** Friday May 3rd

**Time:** 7:00pm

**Where:** Macomb Intermediate School District. 44001 Garfield Rd

**What:** The event will consist of a short presentation and awards. Desserts, coffee and tea will be served. Attire for the event is business casual.

**How:** Submit a name and contact information (address, phone number) of the nominee to Kristen Karr at [kristen@fedsmi.org](mailto:kristen@fedsmi.org) by April 26th. Write a letter in 200 words or less how they have been instrumental in your child's life. At the event, you can read the letter out loud OR if you would rather, someone else will read the letter.



*Gratitude*

is not only  
the greatest of virtues,  
but the parent of all the others.

- Cicero



# GOOD NEWS!



“Grayson is starting to recognize the letters in his name and say them as we trace them. He’s forming 2 and 3 word sentences. He has to have surgery for his tonsils and adenoids and tubes put in on April 2nd. Please pray it goes smoothly and recovery is as painless as possible!”

Praying for you Grayson and family!

“In February, Megan earned her yellow belt in Kung Fu!”

Keep it up Megan!



“Lila is rocking her first year of school and has made the sweetest friend, Mason!”

Keep rockin, Lila!





# GOOD NEWS!



“Parker is starting to stand on his own!”

You are awesome Parker!

“Landon is walking!”

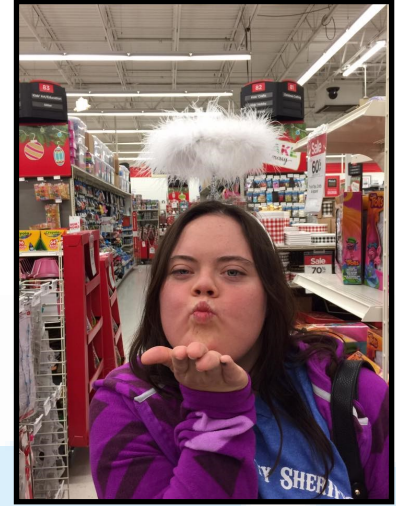
Amazing Landon!



“Leo got to meet his favorite, Mickey, for his birthday! And he pulled his suitcase all by himself at the airport!”

Way to go Leo!

# SPOTLIGHT



This month's spotlight is on Miss Kayleigh Williamson. Kayleigh is 29 years old and lives in Austin, Texas, with her mother Sandy Williamson and their four dogs. You may have heard of Kayleigh, as she is the first person with Down syndrome to complete the Austin half marathon! I was so thrilled and star-struck to get to spend some time on Skype with Kayleigh and her mom!

Kayleigh has now finished five half marathons, shaving time off each one and most recently finishing the Austin Half Marathon in four hours and eight minutes! Sandy and Kayleigh started running together to improve their health. They have also drastically improved their diet, eating mostly whole foods and cutting out artificial sweeteners. Kayleigh hasn't had a pop in five years! She has lost 60 pounds, no longer requires a CPAP to sleep, and even got released from her endocrinologist! A strong factor in their desire for better health was Kayleigh's grandmother, who has Alzheimer's disease. As we know, our loved ones with DS are more prone to having Alzheimer's, so Sandy wanted to find ways to help decrease this risk and turned to cardiovascular exercise.

I asked Sandy how she was able to make this lifestyle change and get Kayleigh into running (Sandy mentioned that in high school, Kayleigh's teachers were always complaining that she was, "slow as molasses going uphill in January"). She said that Kayleigh wanted to start because she saw her running. Sandy had been running for awhile and

Kayleigh wanted to join in and be like her mom! Sandy joined Weight Watchers, then Kayleigh requested for her birthday present, to join Weight Watchers too! This hit me as a hard reminder of the importance of living and being what we want to see in our children. How can we expect them to be healthy, work hard, and never give up if they don't see us practicing this in our daily lives? As parents to special needs children, I think we all have a tendency to focus on taking care of our kids and not ourselves. This is an important reminder that taking care of ourselves isn't only vital for us, but will also set examples and set our children up for success as well.

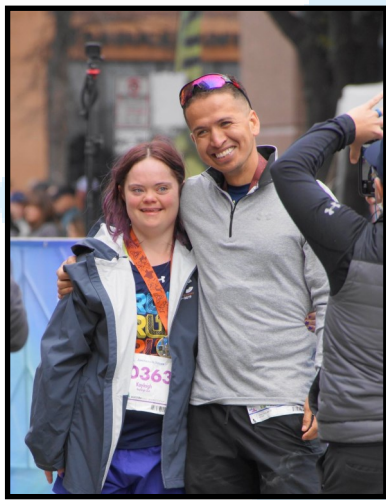
When I asked Kayleigh what her motivation was, she immediately, without hesitation, said her Grandmother. "I run for my Grandma."



# SPOTLIGHT

Sandy's mother has severe Alzheimer's disease and can't remember her or other family members, except Kayleigh. "She is always talking about her granddaughter with Down syndrome. A nurse said she remembers Kayleigh, because she has that unconditional love for her and that is housed in so many areas of the brain," Sandy recalls.

Sandy also mentioned that a strong motivation is "the cute guy at the end of every race she gets to hug." (Pictured below) Kayleigh just giggled and



said, "Mom!" She did not, however, argue that fact. He is the president of the Austin Runner's Club and has been extremely supportive for the Williamson's.

Kayleigh is extremely proud of her accomplishments, enjoying the medals she earns, and the influence

she has had, not only the Down syndrome community, but the running community, and the world! "I made history," she recalls. And of course, Kayleigh runs because, "running is fun!" She loves running to Brittany Spears and the Mama Mia soundtrack. When asked if she gets nervous when she runs, her answer was a matter of fact, "no."

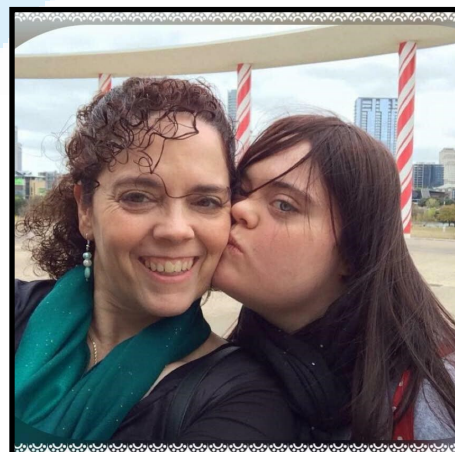
I asked Sandy if Kayleigh carried the stubborn trait that seems to be common in people with DS and if it made it difficult to get her into running. She said it was the opposite. "That stubbornness keeps her going. She won't give up even if she is limping and has to run uphill. She will do whatever it takes to finish. Through this perseverance, Kayleigh recently received her long distance jacket. To receive this award, Kayleigh had to finish 5 races (a 5k, 10mile, and 3 half marathons) within certain time perimeters. She didn't get it the first year she tried. She didn't get it the second year either. She didn't give up, worked harder, and kept going and received her jack-

et her third year!

Kayleigh's Club is a nonprofit dedicated to helping people with disabilities become active and get involved in running. They pay the entrance fees into races people with disabilities want to participate in, help them pay for gait analysis so they can safely run, get together to run weekly, and encourage families to join in the runs as well.

In addition to all of that, be on the lookout for their upcoming children's book, *Its Cool To Be Me*, on Amazon in April or May of this year!

As a mother to a younger child with Down syndrome I am always looking for advice and Sandy had some truly great wisdom to share. "Everyone from school districts to doctors tells us what to expect. It is easy to say well my kid has such and such so they can't....xyz. Take a step back from that and let them spread their wings. They will show you what they are capable of doing. Kayleigh improved more than ever when I stopped worrying about what other people thought, and let her do her thing. We worry so much. They take it all in strides. We have to follow their lead," Sandy said, "People with Down syndrome live in the moment and therefore get more out of life. Recently Kayleigh had such a blast belting out Lady Gaga and drinking her margarita in the middle of a Mexican restaurant. She didn't care who was watching or what people thought. She was just living." When Sandy finished giving her advice Kayleigh said, "My mom is an amazing mother. She is always taking care of me." I agree Kayleigh, your mom is amazing. And you are amazing too.



# FALL FEDS EVENT PICTURES

## SHRINE CIRCUS



## 7-UP BINGO!





# FEDS EVENT PICTURES

## MOMS NIGHT OUT



## BABY PLAY GROUP



## BABY PLAY GROUP



# UPCOMING EVENTS

## APRIL

- 4/9 & 4/23 6:30-7:30pm  
Young Athletes Program.  
(YAP) Glen Peters School.  
46650 Heydenreich Rd Macomb
- 4/10 7pm FEDS Information Meeting: Samantha Czasak. Speech Therapist. MISD Mich/Superior Rm
- 4/18 7pm. Board Meeting. Beaumont Troy Professional Building 44250 Dequindre Rd, Sterling Heights
- 4/27 10am-12 Baby Play Group. MISD Room 104

## MAY

- 5/3 7-9pm. Community Appreciation Night . MISD
- 5/8 7pm. FEDS Information Meeting: MISD Mich/ Superior Rm
- 5/11 10am-12. Baby Play Group. MISD Room 103A
- 5/16 7pm. Board Meeting. Beaumont Troy Professional Building 44250 Dequindre Rd, Sterling Heights
- 5/17 7pm. 7-UP Bingo. MISD Mich/Sup Room

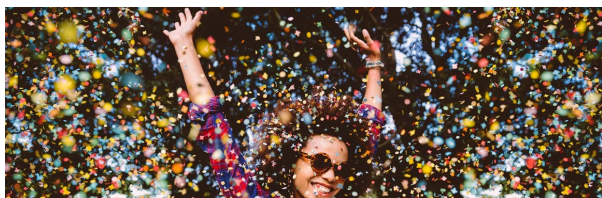
## JUNE

- 6/20 7pm. Board Meeting. Beaumont Troy Professional Building. 44250 Dequindre Rd, Sterling Heights
- 6/30 Summer Picnic. Veteran's Memorial Park. 32400 Jefferson Ave, St Clair Shores

All dates are subject to change! Please check your email, our website and social media for the most up to date information! \*MISD = Macomb Intermediate School District 44001 Garfield Rd Charter Twp of Clinton



**Childcare Available  
at all Monthly  
Meetings!**



**Don't miss FEDS Informational meeting on April 10th**

**With Speech Therapist**

**Samantha Czasak!**

Sam will speak about communication skills including how to enhance language for those who are non verbal, use of technology for communication, comprehension skills, and articulation. She will also discuss and demonstrate device to stimulate speech.



**MEETING  
NOTICE!**

# SAVE THE DATE

## JULY

7/18 7pm. Board Meeting\*

## AUGUST

8/15 7pm. Board Meeting\*

## SEPTEMBER

9/13 6pm. Pizza Party

9/19 7pm. Board Meeting\*

**9/21 10th Annual FEDS Walk!**

**Please see our website for more info and look out for our Facebook event!**

\*44250 Dequindre. Rd., Sterling Heights

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



### DID YOU KNOW?

It is rare for a person with Down syndrome to have a solid tumor cancer or cardiovascular disease, including heart attack and stroke.

<https://www.globaldownsyndrome.org/about-down-syndrome/facts-about-down-syndrome/>

### Contact Us

PO Box 1191  
Sterling Heights, MI 48311

[fedsofmichigan@gmail.com](mailto:fedsofmichigan@gmail.com)  
[www.fedsmi.org](http://www.fedsmi.org)

Follow us on Facebook and Instagram

