

FEDS News Today

Feds Year End Wrap-Up

It is hard to believe that 2014 will soon be drawing to a close. It has been a very busy year both, up front and behind the scenes for Families Exploring Down Syndrome. We have had all our usual events and added a couple of new ones. This year for the first time in quite a few years, FEDs sponsored a bike camp along with the Down Syndrome Guild of Southeastern Michigan. It was a very successful event with several of our campers learning to ride a two-wheel bike independently and everyone making great strides towards that goal. Last spring, FEDs had another Parent to Parent training as we needed more support parents for the numerous new parents that have contacted us for support. Kristen Karr is spear-heading a new medical outreach for FEDs and has contacted many OB-Gyn offices and hospitals to share information with them so both the new parents and the medical professionals will have access to good accurate information about Down syndrome. We still have continued our many programs and events that have been in place for many years including our annual picnic, our holiday party, 7-Up Bingo, Club 21, the always popular Mom's Night Out, Let's Play Group, YAP, Bocce, New Parent Brunch and of course our educational meetings with informative speakers with topics that matter to you. We have already booked our speakers for 2014/2015 fiscal year which will include experts on respite and community health services, a pediatrician with a wealth of knowledge on Down syndrome, a pediatric ENT, and an expert in the field of puberty and sexual issues for our teen and young adult population. This year our Appreciation Night (for those in your life who have made a difference in the life of your child) will be held in May (Stay tuned for more on that). Of course, we just had another successful Down syndrome awareness walk at the zoo. Thank-you to everyone who showed up on that chilly day to spread awareness and to all who made donations to support all these wonderful programs!

Behind the scenes FEDs has worked hard to develop a budget for FEDs. Please see page 6 for more information and a copy of our 2013/2014 financial statement. The board is always looking for someone who would be interested in chairing our events. That person does not have to have a child or relative with Down syndrome. If you know anyone who would be interested in exploring the idea or if you have any ideas or information to share with the board please contact us by email at info@familieexploringdownsyndrome.org or come to our board meeting to share your ideas. The board, as always, wants you to know that FEDs is here for you. Let us know what you would like to see happen in the group. Happy Holidays and Happy 2015!

Are you receiving our emails every Monday?

If not, email us at info@familieexploringdownsyndrome.org



Remember to add us to your contact list to ensure it does not go to your junk/spam mail.

Check out our website at

<http://www.familieexploringdownsyndrome.org/>

*Walkin' Wild at the Detroit Zoo
Sunday, October 5th*



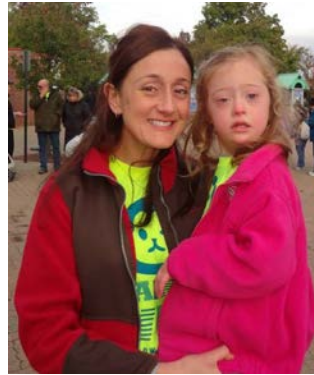
**Easton's Entourage was our top fundraising team.
They raised \$3,060 for Down syndrome awareness!**

On a crisp, cool October morning, the Detroit Zoo was overrun with children and adults celebrating Down syndrome. FEDS families, relatives, friends and supporters, 500 strong, spent the day visiting with each other and the animals.

The “sea” of bright yellow shirts walking through the zoo was a wonderful sight and a great way to raise awareness for Down syndrome.

Since all the donations aren't in yet, we do not have a grand total on exact monies raised. However, we did raise approximately \$15,000! How awesome! This money will enable us to continue to offer our various programs to our FEDS families.

Also, at least 3 families have earned a “2015 Zoo Pass” for securing over \$1,000 in pledges. Great job families!



Check out our website at <http://www.familiesexploringdownsyndrome.org/>

2014 FEDS Annual Picnic

We had such a great time at our annual summer picnic! The weather was beautiful. The children enjoyed the splash pad and park at Veteran Memorial Park. We ate lots of great food and desserts. The adults and children played relay races and water balloons. All of the children enjoyed picking out a prize of their choice.

Thank you to Sheryle Fournier and Margie Buresh for chairing this awesome event! We are looking forward to the picnic again in the summer of 2015!



Bike Camp 2014



The last week of August was a very busy week for several FEDS and DSG families! Twenty-five kids and young adults with Down syndrome participated in the FEDS and DSG sponsored ICanShine Bike Camp. The camp was run by the wonderful ICanShine staff members Andera and Garrett, with FEDS own Margie Wheelock serving as camp director and Deanne Moore serving as Camp Planner. Helping at the camp were over 120 bike camp volunteers who showed up to help spot the bikers, and cheer them on.

Each rider came every day, Monday through Friday, for a 75 minute session. The goal was for the riders to learn to ride a two-wheeled bike on their own by the end of the week. The campers started out on special "roller bikes" provided by the ICanShine staff, and by the end of the week everyone had progressed to trying out their own two-wheeled bike! It was a lot of work for everyone involved, but also a lot of fun.

The riders even got to ride along to the Frozen soundtrack, which was a great motivator! By Friday, several riders had mastered riding their own bike, and the look of pride on their faces was priceless. Everyone who participated gained much more confidence and skill on their bike, and the camp was a huge success! Special thanks goes out to Margie, Deanne, Paulette Duggins and Paul Nobles from the DSG, our wonderful volunteers, and all of the dedicated parents who brought their kids to the camp every day!

We would also like to send a HUGE thank –you to our DADs group, who most generously gave scholarships for the bike camp to all who needed them!

FEDS 2014 Budget May 2014—April 2015

Bocce	\$1,040.00
Club 21	\$625.00
Donations	\$3,000.00
Holiday Party	\$1,500.00
Merchandise	\$1,600.00
Tickets/Events	\$1,600.00
Zoo Walk	\$30,000.00
 TOTAL INCOME	 \$39,365.00

EXPENSES

Accounting Fees	\$1,000.00	Let's Play Group	\$150.00
Affiliate Fee(DSAIA)	\$1,000.00	Library	\$200.00
Appreciation Night	\$600.00	Mtg Refreshments	\$100.00
Babysitters	\$360.00	Merchandise	\$1,200.00
Bank Fees	\$75.00	New Parent Brunch	\$700.00
Bingo	\$175.00	Newsletter	\$600.00
Board Exp	\$250.00	Office Supplies	\$800.00
Bocce	\$1,050.00	(copies, paper, ink)	
Cell Phone	\$100.00	Parent Mentoring/	
Club 21	\$1,300.00	Medical Outreach	\$1,000.00
DSAIA Conference	\$3,000.00	Picnic 2014	\$200.00
Donations	\$1,600.00	Pizza Party	\$800.00
Education(member's)	\$400.00	P.O. Box	\$60.00
First Giving	\$500.00	Scholarships	\$5,000.00
Get Well/Sympathy	\$500.00	Special Olympics	\$750.00
Giving Tree	\$1,500.00	Stamps/Postage	\$175.00
Golf Outing	\$500.00	Storage Unit	\$1,000.00
Holiday Party 2014	\$3,200.00	Tickets/Events	\$2,800.00
Intuit(Chg card machine)	\$156.00	World DS Day(321)	\$1,750.00
Insurance	\$1,400.00	Zoo Walk 2014	\$8,000.00
Laptop Computer	\$800.00		
			\$25,135.00
	\$19,466.00		

TOTAL EXPENSES \$44,601.00

Check out our website at
<http://www.familiesexploringdownsyndrome.org/>

2013/2014 FEDS Financial Statement

FEDS **** May 1, 2013 to April 30, 2014

INCOME

Club 21	\$853.00
Dues / Donations	\$12,200.96
Funeral Donations	\$665.00
Holiday Party	\$1,443.00
Merchandise	\$1,602.65
Tickets/Events	\$1,607.00
to close 2nd acct	\$3,399.93
Zoo Walk	\$27,645.13
TOTAL INCOME	\$49,416.67

EXPENSES

Affiliate Fee(DSAIA)	\$1,000.00	Intuit Fee	\$155.40
Appreciation Night	\$359.92	Insurance	\$1,332.00
Babysitters	\$280.00	Let's Play Group	\$120.65
Bank Fees	\$67.74	Library	\$140.95
Bingo	\$162.65	Mbr Mtgs	\$430.94
Board Exp	\$521.95	Merchandise	\$3,685.94
DSAIA Conference	\$2,007.91	New Parent Brunch	\$672.97
Bocce	\$1,050.00	Newsletter	\$1,900.38
Brochures	\$694.00	Office Supplies	\$545.40
Business Exp	\$1,495.35	Parent Mentoring	\$861.61
Cell Phone	\$68.95	Picnic 2013	\$934.86
Changing Lives Prog.	\$210.00	Picnic 2014	\$200.00
Club 21	\$1,314.27	Pizza Party	\$746.80
Donations	\$1,620.00	P.O. Box	\$60.00
Fashion Show	\$4,258.03	Scholarships	\$3,200.00
First Giving	\$500.00	Special Olympics	\$700.00
Get Well/Sympathy		Stamps/Postage	\$166.30
Thank you's	\$396.52	Storage Unit	\$970.83
Giving Tree	\$1,550.00	Tickets/Events	\$2,747.00
Holiday Party 2013	\$3,005.16	Zoo Walk 2013	\$7,726.77
Holiday Party 2014	\$500.00	Zoo Walk 2014	\$2,000.00
MNO	\$35.00		

\$21,097.45

\$29,298.80

TOTAL EXPENSES \$50,396.25

Sibling Perspectives

My name is Alyssa Moore and I am fourteen years old. My only sister, Megan, is ten years old and has Down Syndrome. Most of the time when I tell someone that I have a sister with Down Syndrome, I get either a sympathetic look or an awkward change of subjects. I know that most people find it hard to be around people with Down Syndrome, but personally I don't feel that they are really that different from people who aren't diagnosed with Down Syndrome. Other than having a bit of trouble in school, Megan seems to be the same as most kids would describe their younger siblings- rather annoying at times, but often very sweet. Like most kids, Megan absolutely adores her iPad. She can almost always be seen with it. She enjoys going on YouTube and watching people's vlogs, either room tours or gift tours. She will often make her own, although she doesn't post them anywhere. Even when I play with her, she always wants to make a video of us playing with her Littlest Pet Shop toys. She also loves to listen to music and sing along to it. Often, I will be doing my homework when she gets home from school, and almost immediately I'll hear "Roar" by Katy Perry or "Let it Go" from Frozen. I can hear her singing to "Let it Go" as I am writing this article now. When we first saw Frozen, she fell in love with it immediately. We don't actually know how we first ended up with the movie. All we know is one day, we found it purchased on iTunes. My dad didn't buy it, and neither did my mom nor I. We asked Megan, and she didn't really give an answer. We came to the conclusion that unless our dog bought it, it must have been her! After that, she proceeded to watch the movie around five times a day! As you can probably tell, Megan enjoys a lot of the things that typical girls her age do. I hope that in the near future, people will be more accepting of those with Down Syndrome, because they are really great people!



VOLUNTEERS NEEDED!

Did you know that FEDS and all our activities and programs are run entirely by volunteers?
Would you consider giving back by volunteering your time and talent!

Here are just some of the activities we need help with:

The Walk - We need a committee chair and members

The Library

Pizza Night

Holiday Party

The Summer Picnic

Volunteer Coordinator

Appreciation Night

New Parent Breakfast

YAP (Young Athletes Program)

Just a little of your time can make a big difference to our group! Some volunteering just involves cleaning up or serving at an event. Others are a bit more involved, like chairing the Walk committee. We'd love to hear new ideas and get some fresh energy into our activities! There's something to fit everyone's schedule!

Interested? Contact fedsfmichigan@gmail.com



Come out and enjoy a dinner with other Dads!

All Dads, grandfathers, uncles are welcome.

Dinner will be compliments of the DADS group.

Location: Club Venetian 29310 John R Road, Madison Heights.

Any questions? Contact us at tricountydads.com

Dads, Granddads & Uncles join us the last Wednesday
of every month at Club Venetian in Madison Heights for
good times & good food on us!

Congratulations, Thank Yous, Get Wells & Donations

Get well wishes to:
Emerson Goulet
Carleigh Tucker
Nicholas Gardner
Dylan Faunce Brown
Fiona Pauwels

Deepest sympathy to the Cunningham Family in loss of Kristin's Papa

Donation received from the Taylor Family In sympathy of Frank Mallon

Donation received from Stacy Gillspie in celebration of Ava Gilleland

A generous donation received from Knights of Columbus - Sterling Heights

Donation received from GM in match to Volunteer Hours of Tom Mueller, who chaperoned the Bocce Team at the State Summer Games. Thank you, Tom!

To FEDS Zoo Walk Committee:
Please accept this donation to your organization for research on Down syndrome. We really enjoyed the Walkin' Wild Walk at the Detroit Zoo with my granddaughter, Katelyn Pazsgay. She so loved the zoo animals.
Thank you, Marsha Pozsgay

Donations received from:

Mr & Mrs Douglas Howell
Mr & Mrs Harold Oseff
Lisa Korpus
Kathleen Poplawski
Cheryl Kassak
Tova Shaban

All in celebration of Madison Rivard

Our 2014 Graduates!!!



Dear FEDS ,

Thank you for the scholarship. This summer I went to SCAMP, Spring Hill Camp and Bike Camp. I had a lot of fun and am proud that I learned how to ride a 2 wheeler! I put the scholarship money toward a new purple bike that met the Bike Camp requirements.

Ava Gilleland

Dear Families Exploring Down Syndrome,

Thank you so much for my summer scholarship!

I took private swim lessons all summer.

I am now able to swim independently with my sisters with my arm floats on.

Thank you! Ayla Coe



Check out our website at

<http://www.familiesexploringdownsyndrome.org/>

Thank-you for the summer scholarship. I used it for my Sterling Heights softball league and for the U of D basketball clinic. Here's a picture of me at bat and with one of the UDM basketball players

Mike Mendez



Dear FEDs,
I had a great summer and attended various camps including SCAMP, Springhill, Banbury Cross Therapeutic Horse Back Riding Camp, and the Icanshine Bike Camp. Thank you FEDs for helping to pay for these camps with the summer scholarship!
Love, Lucas Wheelock



Dear FEDS Members,
This summer I had the best summer ever. I did so many activities. I was able to continue my baseball and was invited to the Detroit Tigers Fantasy Camp 2014. This was an exciting event because I felt special that I was chosen. I went to St Francis Camp on the Lake.
Last but not least I was able to accomplish riding a two wheel bike. Thank you so so much for the scholarship. Something else special happened, I told my "mum", I love you Mum, for the 1st time in almost 13 years. I made my mom and dad so proud of me.

Thanks again, Love Daniel Passalacqua



My summer was awesome. I spent my summer scholarship on going to day camp in Sterling Heights. One of my good friends Makaela also went to day camp with me. I had lots of fun. I went every day and never missed one minute. We went on great field trips every week. My favorite was to Red Oaks Water Park where I spent the day swimming in the wave pool, going down the water slide and floating in the lazy river. I cannot wait to go back next year and see all my old and new friends that I have made over the years. Thank you again for the scholarship it was very much appreciated.

Hannah Relph



Thank-you for the scholarship. My friends and I went on a retreat for the weekend at the capuchin monastery. We had a great time.

Megan Talbot



We wanted to thank FEDS for the scholarship this summer. Gavin had the opportunity to spend time at Camp Richmond with one of his friends. He enjoyed swimming in the community pool with the counselors.

Thank you,
The Maksymiuk Family

Music Therapy by Jennifer Bott

So...how many times have you sat down with your child and they are so excited to tell you something, it's really important to them...and you end up only for you or your spouse to have absolutely no idea what they are saying?

This was a daily occurrence with Faith for a really, really long time. She would even repeat the exact same mumbled garble over and over, and we would be at a loss as to what she was trying to tell us. She would get so frustrated as we would too. To see your child trying so hard, and not be able to find the words is heartbreaking. We used sign language, but we didn't know the sign for everything, and since she was talking a little bit, that was our first choice for communication.

For weeks, months, and years we have worked with her. We paid for extra speech in addition to what her IEP had written in. We have gotten books, videos, flash cards, and while they didn't hurt, she wasn't moving forward like we knew she could, and more importantly, how she wanted to. She had the desire, just struggled to get the words out.

We saw some progress here and there, but we wanted more for Faith. We didn't want to be the only ones who could understand her. We wanted her to be able to be able to communicate with friends, family, teachers, and even strangers!

For example: I would take her to the grocery store, she just absolutely loves talking to people. Faith would get frustrated when the other person had no idea what she was trying to say...I don't want that for Faith.

One day, as I was picking her up from daycare, she was so excited to tell me about "fee-ah". I had no idea what she was saying but the daycare lady translated she was saying "Sofia", one of the new kids. That night, I worked with her to improve saying "Sofia", since this was her new little friend at daycare. Faith tried over and over, the double consonant was just getting her tripped up. She would slow up and say it, but only if it was broken into two words. Saying it together she was stuck. I added a tune to it and bingo...she got it!!! I tried it with a few more words...umbrella, hummus, and the list goes on and on....

So...I have a background in and know a lot of people in the music industry. (I used to be a photographer for bands and the like) One of my old friends who I knew gave vocal lessons as his day job came to mind. He had studied under professionals and trained for years. While I knew he was teaching his students more like "American Idol" lessons, I gave him a call and told him my findings and asked him if he would be willing to work with Faith. He said, of course! Neither of us had any idea where to start or if it would even work, but we knew we probably wouldn't do any damage.

The next day he was over our house with his keyboard in hand, and we began. While it was a slow start, we have seen improvements every week. Faith takes a little while to warm up to teachers, therapists, but once she is comfortable, she's good to go.

With a few months under our belts, I know that she can do it. With all good things with Faith, patience is key. Greg is very a patient vocal coach.

We now incorporate specific words that we want him to focus on for her weekly lesson. (Lately it's names of new people at school and things she wants to do, like "trick or treat! Or ZOO BOO"). Working towards her be able to communicate in daily life is important to us. Greg understands that we need to work in some easier words into the list of harder ones to give her the sense of "doing it"! She is very big on "I can do it, and I did it!!" She gets so excited when she works at a word or phrase for a while and finally gets it. The reward is as big for us as it is for her. She just loves having the keyboard there, and when he "sings" a word, she likes to try to "sing" it back to him. We talk about how best to get a great session out of Faith. Pairing up speech with the vocal therapy has been one of the best discoveries for us! The next step we are incorporating into the sessions, is actually singing some of her favorite songs. I have a feeling "FROZEN" will be in the lineup. I have heard it thousands of times and don't care if I hear it a thousand more. It's helping her progress and I love it! While it's difficult to tell how much school is seeing progress...mostly because we had all new teachers again this year. On a positive note, we just spent the weekend at my Mom's and family came over to visit and everyone mentioned how Faith's speech is improving. Even the kids said they understood her better. I have to say it's an incredible feeling to be able to have a conversation with my daughter!!!

From the Library

Are you looking for a specific book or video that may assist you with your child with DS?
Please let us know!

If we don't have it in our library, we can order it.
Come check out our selection of books and DVDs!



REMINDER! Please be sure to return all library items when finished, so others may utilize our resources. Thank you!



Attention all FEDS Families

Families Exploring Down Syndrome is no longer collecting dues for membership.

No dues will be collected, but donations are always welcome!

Thank You!

Check out our website at

<http://www.familiesexploringdownsyndrome.org/>

Calendar of Events

November

- November 4 - Bocce at Club Venetian - 6:30-8:00 pm
- November 6 - MNO at Ike's Restaurant, Sterling Heights, MI - 7 - 9 pm
- November 12 - FEDS Meeting - Kelly Clark from Independent Operations of Michigan at MISD - 7-9 pm
- November 15 - Rollerskating at The New Rink, Shelby Township, MI - 10 am
- November 15 - Special Olympics Bowling at Sterling Lanes, Sterling Heights, MI - 1 pm
- November 18 - Bocce at Club Venetian - 6:30-8:00 pm
- November 20 - FEDS Board Meeting - 7-9 pm
- November 21-23 - Pinkalicious Musical at The City Theater



December

- December 2 - Bocce at Club Venetian - 6:30-8:00 pm
- December 13 - FEDS Christmas Party at Club Venetian, Madison Heights, MI - 10:45 am
- December 16 - Bocce at Club Venetian - 6:30-8:00 pm
- December 18 - FEDS Board Meeting - 7-9 pm
- December 30 - Bocce at Club Venetian - 6:30-8:00 pm



January 2015

- January 13 - Bocce at Club Venetian - 6:30-8:00 pm
- January 14 - FEDS Meeting TBA at MISD 7-9 pm
- January 15—FEDS Board Meeting - 7-9 pm
- January 27 - Bocce at Club Venetian - 6:30-8:00 pm



February 2015

- February 10 - Bocce at Club Venetian - 6:30-8:00 pm
- February 11 - FEDS Meeting TBA at MISD 7-9 pm
- February 19—FEDS Board Meeting - 7-9 pm
- February 24 - Bocce at Club Venetian - 6:30-8:00 pm



March 2015

- March 10 - Bocce at Club Venetian - 6:30-8:00 pm
- March 11 - FEDS Meeting at MISD - Dr Becker ENT - 7-9 pm
- March 19—FEDS Board Meeting - 7-9 pm
- March 24 - Bocce at Club Venetian - 6:30-8:00 pm



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Are you receiving our emails every Monday?

If not, email us at info@familieexploringdownsyndrome.org

Remember to add us to your contact list to ensure it does not go to your junk/spam mail.

Are you on Facebook? Have you "liked" us yet?



Join us on
Saturday, December 13th at 10:45 am
At Club Venetian
Madison Heights, MI
For our annual
2014 FEDS Christmas Party
<http://www.familieexploringdownsyndrome.org/wp-content/uploads/2014/03/FEDS-Holiday-Party-Invite.pdf>
RSVP by mail by November 12th

Check out our website at
<http://www.familieexploringdownsyndrome.org/>