

Down Syndrome Family Support and Advocacy Group Newsletter

September 2012



Join Us At The 11th Annual Michiana Down Syndrome Walk!

Join us on September 29, 2012
at the St. Joe County 4-H Fair Grounds.
(5117 Ironwood, South Bend, IN 46614)
(directions at www.4hfair.com)

The fun will start at **9:30am** with registration,
the silent auction, along with games and
entertainment. We will start the walk at
12:30pm with lunch to follow.

Get to the walk early so you have time to:

- Register
- Purchase your raffle tickets
- Participate in the silent auction
- Let the kids play carnival games
- Visit the informational vendors
- Purchase your 2013 DS Snapshot Calendar
- Enjoy the entertainment - Leonardo, Ronald McDonald, Balloon Art
- Mingle and make new friends

Go to our website to get started
raising funds through Firstgiving.
www.michianadownsyndrome.org



In this Issue

Page

Michiana Down Syndrome Walk	1
Raising a child with special needs	1
Veronica's Graduation	2
Dads' Nelson's Chicken Sale	3
Niles YMCA	3
Bowling at Kelly's Bowl	3
Mini Grants	3
Birth to 3 Group	4
4 - 7yr Old Group	4
8 - 12yr Old Group	4
DS Teen/Adult Night	4
DS Group Family Directory	5
Calendar of Events	5
Children's Dispensary	6
Fall Party	6
A Waiver Party	6
Awareness Poster	6
Employment of Adults with DS	7
In Our Community	7
Michigan MNO	8
LaPorte County MNO	8
Birthday Greetings	8
Advertise with us	8

I don't think
the *worst* thing
that could
happen to *me*
is raising a
child with *special*
needs. I think
the worst thing
is to raise a
child who is
cruel to those
with *special needs*.

Veronica's Graduation!



Last May Veronica graduated from High School, the last of eight very successful Go children to graduate. The first seven went on to Notre Dame and one to St. Mary's and all graduated from them. Six of the seven also continued school to get their Master's degree and two of them went even further to get Ph Ds. As you can imagine I am tremendously proud, undeservedly perhaps, of all of them but I am the proudest of Veronica. This most likely will be her last graduation of formal education because of her Down syndrome, but on the other hand she has accomplished so much in her young life. Let me explain by two examples.

Veronica has what I would say savviness. Another word for savviness is street smart or a word coined by famous psychologist Robert Steinberg, practical intelligence. Practical intelligence is the ability that individuals use to find the best fit between themselves and the demands of the environment. Last year when Veronica took Geography, she was asked in a quiz what is "Ring of Fire". Instead of answering, what the teacher wanted, the ring of volcanoes around the Pacific Rim, she answered "A song by Johnny Cash". An answer that would be given by just all red blooded American. I was so proud of her then.

Last Sunday when Veronica and I went from one graduation party to another one of her friends, I purposely teased her that I don't know how to get to the next party and can she please help me. She simply said "Why don't you use the GPS". I was amazed how savvy she was.

I will tell you two more stories that illustrated her kindness.

Ten years ago when Veronica was only nine her grandmother, Peggy's mom who has beginning dementia, lived with us and Veronica and Doris just loved and enjoyed each other company very much. One morning, Peggy and I were just chatting in the kitchen, and suddenly Veronica appeared with grandma. Doris looked very confused and bewildered. Veronica then proceeded to do the amazing and practical thing. She simple introduced Grandma to Peggy and me individually. Peggy this is

your Mom and Grandma this is your daughter, she also did this to me introducing me not only as Paul but also her son-in-law. Then she proceeded to take her to one of the rooms that has been converted as Grandma's living room. Grandma has nine children and all their pictures were hung on the wall. She introduced every single person beginning with the oldest to the youngest. Doris was less confused and agitated and by that afternoon she was almost her normal self.

This semester Veronica worked as a South Bend School Corporation intern at the College of Engineering at Notre Dame. All four of her sisters worked there for work study when they were in college and I know the secretary very well. They all work in the mail room sorting mail for an hour or two. She also knows Veronica since birth. She readily agreed to try her out. Her high school would provide transportation to and from Notre Dame as well as a job coach. She did so well that when the semester was over all the people in the Engineering office including the Dean gave her a cards and a beautiful leprechaun broche. They not only sign her card but they all wrote a note telling her how much they will miss her especially her bright and beautiful smile. One of the staff members than said to me he was introducing a young college intern that is working in his office for the summer. She was very nervous and when he introduced her to Veronica she told Veronica this. Without hesitation Veronica gave her her genuine and hearty hug. The young intern then told my friend that Veronica made her day and somehow she was much less nervous.

Veronica has what I what call a "practical goodness" A normal good and kind act would be to let Peggy take care of her Mom and her job would have been over. But Veronica simply does more, as what Steinberg would have called, what the environment demanded.

In the late thirties Lou Gehrig the famous first baseman of the NY Yankees, said this in the beginning of his farewell speech, attended by an overflowing crowd including Babe Ruth. "I am the luckiest man on the face of the earth". I too, on this Father's Day, feel exactly the same way. I am the luckiest man on the face of this earth to be all my children's father but above all to be Veronica's father.

Dads' Nelson's Chicken Sale



September 8th at Cira's 66 Station (SR 23 at Heritage Square) from 10:00am to 3:30pm

We know it's last minute, but we could still use a few dads to help out at the BBQ. Please contact Kevin Pearson if you can volunteer at kpearson56@hotmail.com

Everyone can help support the group by coming out and buying a chicken!

Niles YMCA

JUST FOR YOU classes starting on September 11th, each session runs for seven weeks. New sessions will begin every seven weeks and run throughout the year.

18 years and older classes

6:30-7:00 dance class \$5 per class

7:00-7:30 gymnastics \$5 per class

Included with the classes you can swim in the warm pool for an hour for free.

11-17 year old classes

5:15-5:45 for dance \$5 per class

6:00-6:30 for gymnastics \$5 per class

If your child wants to be in the older kid's class they can join those also. The adults that bring the kids to the classes can also join in the swim for free.

Any questions please call the Niles YMCA 269-683-1552.

Bowling at Kelly's Bowl in St. Joseph MI.

Join our Bowling group every Saturdays at 10:00am, we usually bowl 3 games. \$2 dollars per game, shoes and bowling balls are free.

We will be starting up again Saturday September 15th at 10:00am and on some Saturdays we also have other functions, such as going out to eat or going golfing etc. For more information please call me at 269-756-1441 my name is Ludwiga Umbrasas my daughter's name is Eve she is 21.

Mini Grants



We want to remind everyone about our \$200 mini grants that are available to all of our members with Down syndrome. Here is a review of the rules to apply for a mini grant.

Due to the growth of our group which is 200+ families strong, we are in need of more volunteers during our events. In order for us to be able to provide all the wonderful services and enable us to add more in the future, we need support from our members. Volunteering for the group builds a stronger community through fellowship as we all work towards a common goal of improving lives of people with Down syndrome.

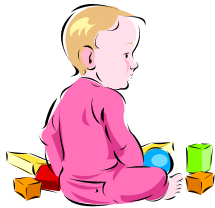
The DSFSAG is just asking for your help at one event or function per year (minimum of 2 hours). There are many areas in which the group needs help (DS walk, Old 2 Gold, hot dog sale, committees, family support nights, helping with parties, fund raising to name a few).

Along with the mini grant applications please include your receipts and the verification of your volunteer service hours. All of the necessary forms are available on our website.

A couple of rules regarding service: Event volunteer service hours can be saved and used from September of previous year through December of the year the application is submitted. Event volunteer service hours given for one event cannot be split and used for two grant applications. There will also be a limit of volunteer hours per event, so sign up quickly for an event you would like to work to guarantee your hours.

Birth to 3yr Group

All families with children ages birth to 3 yrs are welcome to come to our monthly meetings at the Michiana Down Syndrome Resource Center, 2444 Miracle Lane, Mishawaka, IN (Town & Country Shopping Center) on the last Wed. of each month at 6:30. Children are welcome to attend as well. Parents can visit with each other while their kids play. Please see calendar of events for future dates. RSVP to Kathy 234-0590 Kathy_R@comcast.net or Anne 243-3808 artrevell@aol.com



4-7 Year Old Group

If you have ideas or would like to volunteer to organize a month then please contact Tish Harman at lharman@sbcsc.k12.in.us

- September- No meeting due to two in July and Michiana Walk for Down Syndrome
- October 20th- Costume party and a Halloween movie. 1:00pm at the MDS Resource Center. Dinner and snacks provided.
- November 17th- Rum Village Nature Program – Need someone to organize
- December 15th- Holiday craft and food at center 11:00-12:30.
- January 19th- Krock center swimming???? Need someone to organize and committee to decide budget
- February 16th- South Bend Chocolate Café play area 11:00-12:30
- March 16th- Indiana Center for History-Children's Exploration room 9-10 (\$3 each- the group will pay) Tish will organize
- April 20th- Craft and food at Center 11:00-12:30.
- May 18th- St. Patrick's Park play area and picnic. 11:00-12:30

8-12 Year Old Group

If you have a child in the age range of 8 – 12 years old, come join us once a month as we gather for socialization and fun. These are family gatherings so siblings are welcome too.

Friday September 21st: Bowling at AMF Regal Lanes, 1121 West 8th Street, Mishawaka, IN 6 – 6:30 pizza and pop, 6:30 – 8:30 bowling.

Friday October 20th: Costume party and a Halloween movie. 1:00pm at the MDS Resource Center. Dinner and snacks provided.

Friday November 30th: Make Holiday Craft Gifts: 6 – 8 p.m. at the MDS Resource Center. Make cards or craft gifts for the nursing home residents. Practice Christmas Carols, dinner will be provided.

Friday December 14th: Christmas caroling at the nursing home (time and location TBA). Come join us as we shower the residents of the nursing home with homemade cards and crafts (made at the November gathering), candy canes, a small gift, and our Christmas carols with a pizza party to follow.

RSVP to Susan Pearson stpearson@sbcglobal.net or 574-299-3235. Please check the calendar regularly for changes and updates. http://www.michianadownsyndrome.org/?page_id=50

[Looking for a volunteer to take over coordinating activities for the 8 - 12yr Group starting in January.](#)

DS Teen/Adult Night

Calling all teens and adults! Join us for a monthly fun-filled activity! We will meet on the 3rd Friday each month from 6pm to 9pm- locations will be announced each month. For upcoming dates, see the calendar of events: Please RSVP to Anne 243-3808 artrevell@aol.com or Kathy 234-0590 Kathy_R@comcast.net. Next Teen Night September 21st, 6:00 to 9:00pm at Strikes and Spares!



Last Call! DS Group Family Directory

Please contact Rick if you want to be in the directory! We only have a few families that have not responded yet...

Information is needed for the updated family directory. If you would like to have your family included in the Michiana Down Syndrome Family Directory, please send the following information to Rick Podrasky at rpodrasky@gmail.com no later than September 30, 2012:

Name and heads of household

Address (optional)

Home telephone /cell phone (optional)

email(s) (optional)

Child's name (plus age)

Sibling's names and ages

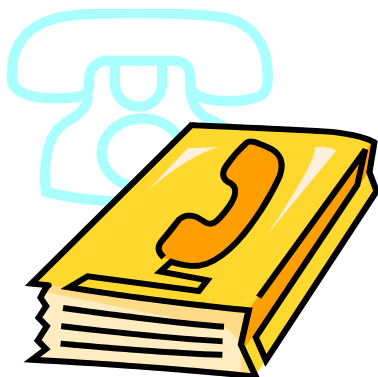
If email access is an issue, you may also call 574-243-3808 or mail the information to:

DS Directory DSFSAG, 51201 Old Cottage Dr, Granger, IN 46530

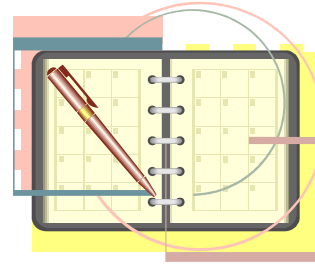
In addition to the new format - and the inclusion of new families - we would like to introduce the inaugural cover art contest!

We would ask that 5"x5" pen or pencil drawing (limited to black and white, as that is how it would be printed on the cover) entries be submitted to the address above by September 30, 2012. There isn't a specific theme other than celebrating the talent of those in our community, so the more entries - the merrier!

Thanks! Rick



Calendar of Events



- September 11th - MNO Red Lobster, Main St
- September 21st - Teen/Adult Night -Strikes and Spares
- September 21st - 8 - 12yr Group at AMF Regal Lanes for Bowling
- ~~September 26th - Birth to 3yr - DS Resource Center~~ Cancel due to walk preparation
- **September 29th - Michiana Down Syndrome Walk**
- October 9th - MNO Flat Top Grill, UP Mall
- October 19th - Teen/Adult Night -Place TBA
- October 24th - Birth to 3yr - DS Resource Center
- October 20th - 4 -7yr Group DS Resource Center
- October 20th - 8 -12yr Group DS Resource Center
- October 27th - Fall Party at Bendix Woods
- November 13th - MNO Cosimos & Susie's Town & Country Shopping Center
- November 16th - Teen/Adult Night -Place TBA
- November 17th - 4 - 7yr Group, Rum Village Nature Program
- November 28th - Birth to 3yr - DS Resource Center
- November 30th -8-12yr Group DS Resource Center
- December 11th - MNO Papa Vino's Edison Lakes Parkway
- December 14th - 8 - 12yr Group - Place TBA
- December 15th - 4 - 7yr Group DS Resource Center
- December 21st - Teen/Adult Night -Place TBA

MNO - Mom's Night Out

TBA - To Be Announced



CHILDREN'S DISPENSARY

"A PLACE TO BE ME"

Mission Statement: To enhance the learning and enrich the lives of people with special needs

2015 W. Western Ave., Suite 233 • South Bend, Indiana 46619 • 574-234-1169 •
www.childrensdispensary.org

The Children's Dispensary provides social and recreational programs for children, teens and young adults with developmental and/or physical disabilities.

Our weekly programs, summer camp and special field trips provide opportunities for fun, friendships, and learning.

The Down Syndrome Family Support And Advocacy Group provides Children's Dispensary with scholarship contributions to be used for individuals with Down syndrome who live in the Michiana area, and participate in the programs offered by the Children's Dispensary.

Visit our website for more information about the Children's Dispensary and its current programs www.childrensdispensary.org or call our office at 574-234-1169 Monday-Thursday from 10AM – 3PM.

(Enrollment and Scholarship assistance subject to availability)

Fall Party!



Date: Saturday October 27th

Time: 12:00 pm - 3:30 pm

Place: Glen Bauer Shelter at Bendix Woods Park, New Carlisle (for directions go to www.sjcparks.org)

Eat at 12:30 - please bring a side dish to share, we will provide main dish, drinks, and tableware.

Kids are welcome to dress in costume; we will have a trick or treat line at 3:00 please bring a treat to share.

Hayrides between 1:00 pm and 3:00pm dress for the weather.

We will also have a craft and games for the kids.

RSVP: Anne Revell 574-243-3808 or artrevell@aol.com

LOGAN joins H.E.L.P. Our Kids and the Michiana Down Syndrome Group
To host

A Waiver Party

Tuesday, September 25

at Logan Center

5:00-5:30pm

Waiver Overview

“Understanding Different Waivers & How They Work”

Brian Repogle, Family Voice of Indiana/H.E.L.P. Our Kids

As a parent professional, Brian has a keen interest in advocacy and disability policy. In his role as the Family Leadership Specialist, He is known for his work in disability advocacy and his efforts in education and training for families.

5:30-7:00pm

LOGAN Center

‘Hands On’ Assistance

with filling out Waiver applications

(A team will be available to help with the application process. Please bring medical diagnoses, IEP, SS#/card, list of schools (past/present), doctors, therapists with addresses/phone numbers.)

Capital City Step Up for Down Syndrome Walk Awareness
Poster by Images for a Lifetime Photography.



Employment of Adults with Down Syndrome Using Informational Technology Skills

(Workshop presented at the National Down Syndrome Congress Conference in Washington, DC, on July 22, 2012.)

Presented by: Libby Kumin, PhD, CCC-SLP, Jonathan Lazar, PhD, and Jinjuan Feng, PhD

“Do your teens and adult children email their friends? Do they search the web and go on to fan web sites for their favorite singers? Computer skills are potential job skills.” (from the NDSC description of the workshop)

In this workshop, Drs. Kumin and Lazar presented findings from a study done with ten adults with DS who currently hold jobs in the Information Technology (IT) field.

Dr. Kumin said that this study changed the conception about concrete vs. abstract understanding in people with DS. She stated that the study showed that people with DS are capable of doing very abstract things on the computer. Typically, people with DS have a combination of strengths that may help them use computers. They learn well with repetition and practice and have good skills in visual processing cues. (They learn well by seeing.)

In order to become an expert, individuals need to start early and take formal classes. All of the adults in the study used the 'Mavis Beacon Teaches Typing' program and had great keyboarding skills as a result. The researchers emphasized that in order to have a job in the IT field; you have to learn to type well. More advanced skills may be learned in Excel and Access-formal classes (best perhaps) can be taken at a community college. They also recommended practicing presentations using PowerPoint. Medical literatures says that people with DS have fine motor skill deficits, but the study done by Drs. Kumin, Lazar and Feng shows that fine motor skills in the adults observed using the computer, iPad, etc were very good.

Suggestions:

Write out steps for IT tasks in large print and keep by the computer for easy reference.

IEP should include classes in computer skills for employment. Demand (their word) that these skills be tested and considered while in school.

IEP should also include speech therapy to improve language and intelligibility.

People with DS are currently doing jobs that require data entry, updating websites and pulling files for lawyers. The presenters of this workshop

recommended showing a copy of this study to job coaches and Vocational Rehab workers, so that they will be aware of the potential for this field of work for individuals with DS.

Expanding Job Options: Potential Computer-Related Employment for Adults with Down syndrome

[http://www.sigaccess.org/community/newsletter/june 2012/june 2012.pdf](http://www.sigaccess.org/community/newsletter/june%202012/june%202012.pdf)

If someone tells you that people with DS cannot work in the IT field, you now have the information to say, “Actually, they already are.”

In the past, people with DS have not typically been tested or considered for jobs in the IT field because job coaches say that these skills cannot be tested in anyone who does not have an IQ above 90 (Drs. Kumin and Lazar were unable to find this requirement anywhere in the federal regulations) All of the individuals w/DS who are currently working in the IT field are doing so because their families sought out the opportunities. Drs. Kumin and Lazar recommend that parents demand more from job counselors. Typically, jobs for people with Ds have been in the ‘food, flowers and filth’ categories-IT opens up a new and exciting job market. (Contact Kathy Ratkiewicz if you would like more information Kathy_R@comcast.net)

In Our Community

We would like to recognize Sam Ratkiewicz for his Eagle Scout project. Sam made 30 therapy benches that he donated to Logan Center for their Children's Services. Way to go Sam!



St Joseph/Benton Harbor MI **Mom's Night Out**

We are very happy to announce a Mom's Night Out in the St Joseph/Benton Harbor and surrounding areas. This is a great opportunity to develop friendships and exchange experiences and resources.

The goal is to meet on the third Monday of every month & move into children and family events as possible.

Please contact Bonnie at 269-556-0401 to RSVP or for more information.

LaPorte County

We would like to have Mom's Night Out in the Laporte County area also, if you are interested please contact Tonya at 219-778-9049 or bteatrp421@verizon.net or you can contact Kathy at Kathy_R@comcast.net or (574) 234-0590

Birthday Greetings

The DSFSAG would like to send each of our members with Down syndrome a birthday greeting, but in order to do this we need their birthdates. If your family member with Down syndrome is not receiving a birthday greeting from us , but would like to please contact Tonya at 219-778-9049 or at bteatrp421@verizon.net

Advertise Your Services

We have many talented members who offer a variety of skills, services or goods. So starting with the next newsletter, we are offering our members an opportunity to advertise in the newsletter. This is a great opportunity to broaden the ways we support each other. A business card size ad will cost \$25/year for members only and your ad will run for a year (approximately 3 to 4 newsletter).

DSFSAG
51201 Old Cottage Dr.
Granger, IN 46530

