



FEDS News Today

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Families Exploring Down Syndrome is an organization of parents, professionals and persons concerned about the welfare of individuals with Down Syndrome. The purpose of this organization is threefold:

- To provide emotional support to parents and families of individuals with Down Syndrome.
- To provide current information about Down Syndrome.
- To provide public awareness of Down

FEDS News Today is a publication of Families Exploring Down Syndrome. FEDS is an affiliate of the National Down Syndrome Society, the National Down Syndrome Congress, and Down Syndrome Affiliates in Action

Spread the message...

Hello Friends:

The last couple of months have been extremely busy with the regular meetings and events along with the **Down the Runway IV Fashion Show & Silent Auction**. Thanks to everyone who participated and supported the efforts of the Fashion Show Committee. We appreciate your ongoing support and gracious compliments. To show our appreciation for a job well done, we are inviting the LEADS to attend a brainstorming meeting on April 17 at the MISD. We will order Pizza and desserts in exchange for your thoughts and ideas. Watch for the emails and please respond if **you are unable to attend**. Otherwise, we will see you there in room 203 on April 17 at the south end of the MISD building.

We recently kicked off another round of **Changing Lives Program** presentations at local hospitals and have more lined up. For those that are not familiar with the Changing Lives Program, we can best explain it as a program that allows us to go into the hospitals to inform, educate and equip the staff with information to make your experience a more positive one, when you have given birth. The program was developed by the **National Down Syn-**

drome Society for groups like ours, to be able to share the information locally. We took on the project 10 years ago and planned to actively pursue the mission for three years. To my delight we are still receiving calls to come and bring our expertise to their ever changing staff.

This months **members meeting** is on March 10th. We are pleased to present **Lynette Morris** as our guest speaker. Ms. Morris is a **Clinical Dietitian** at Beaumont Health System

7 Up BINGO is back and March 12 is the date for the next big night. Sara Everhart will partner with Barb Lempinen in chairing these events. We hope to have many more BINGO nights for youngsters 7 years old and up and as usual,



include sibling and friends at these lively Friday nights.

The second annual **New Parent**

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Focus on a FEDS Family...

What a journey. I never dreamed of this journey. First I was 43 years old and that is old to have a baby which the doctor explained but I felt fine I thought. Then all the testing and decisions came and wow that was hard. I had Paige a month before I turned 44 and she was our 4th child. My husband was so supportive as well as my family. I could have never made it without them. My OB-GYN was also supportive and said that Down syndrome people are the greatest. He had a friend who had a Down syndrome child, he just loved her. So I felt good through my pregnancy. Then I had Paige by C-section, my only one and the reality hit. My Doctors partner came in the first morning at 6:30 A.M. told me (the diagnosis). I felt like my whole world collapsed and what did I do to my family. How can I do this to my husband and children? I was crushed. I wish I had FEDS at my bedside instead of the Doctor. Paige's Neonatologist had a sibling with Down syndrome and I thought oh good she could really help me. All she told me was: you will find out as you go along. Our Family Doctor came in and started directing where I should go. Wow finally some help. She



told me to call our school district and they will start therapy and I thought: what, a newborn? but yep they do. Then I was directed to FEDS and whew, I got a lot of support



told me to call our school district and they will start therapy and I thought: what, a newborn? but yep they do. Then I was directed to FEDS and whew, I got a lot of support

and knowledge which is so needed at this time in life.

Paige is eight years old now, she goes to school, she is learning how to read and write. I thought we would never

be there, reading and writing and to our surprise she is picking up speed faster than we expected. She loves her family, grandma and grandpa, aunts and uncles, and her classmates. She loves all sports although she didn't care for swimming with the dolphins but still loves to swim. She likes riding her bike and walking her dogs. She gets excited when grandma and grandpa come over for dinner or we go over there for a swim. She loves being outside even on our coldest of days.

My only struggle in life is whether or not we make good decisions for her and hope we are doing our best, just like our other kids. She keeps us busy and young and all of our friends treat her as one of the gang. What a joy when it started out so scary.



The Tomlinson Family



Club 21

The SPRING dance for Club 21 has been moved to May 3, 2013. The location for this dance will be at My Chance to Dance facilities at: CC Plus @ The Center 300 N. Groesbeck Hwy. Mount Clemens, MI 48043 **586.463.3277**

Watch for your invitation in the mail and be sure to RSVP to Paula that you are coming! jderol@yahoo.com

Love and Logic... Insiders Club

Talking to Our Kids About Tragedy

Our hearts ache over the Sandy Hook tragedy and the recent Alabama situation! When such evil is committed, we wonder, "How do we talk to our kids about this? What do we say?" Children have an incredible capacity for strength, and we can help them cope by following some practical guidelines:

#1: Be honest about your emotions while modeling strength.

Our children will cope only as well as we do. Children who see their parents overwhelmed with anxiety, fear, and grief also will become overwhelmed. On the other hand, kids will not have an opportunity to learn healthy expression of feelings if parents stuff their feelings inside. The key is being honest about your emotions while showing that your family remains strong. For example, you might give your child a hug and say: This is a very sad thing. Sometimes I feel like crying about it. It also makes me mad. But I know that we will be okay...because we are strong!

#2: Limit your child's exposure to media coverage of the event.

Turn the television and radio off when your kids are in the room. Repeated exposure to the visual and spoken images of the tragedy will create more anxiety and fear. Younger children who don't understand that the scenes are being replayed often believe the actual events keep happening over and over.

#3: Give them the facts about the event.

Don't try to keep the tragedy a secret! First, it's simply impossible to do. Second, humans create information when they lack it. When children get bits and pieces of bad news, they "fill in the blanks" with their imagination. Typically their fears, or rumors that float about at school, produce more anxiety than the truth. Children, even as young as two years old, may need you to lay out the facts about the event. Tell them the basics, while leaving out the more sensitive details. Remember, your tone of voice must communicate compassion and strength.

#4: Listen, listen, listen.

There is nothing more powerful than an open ear, heartfelt understanding, and a warm hug.

#5: Let them know that they are safe.

Our children need to hear about the thousands and thousands of wonderful people who are working day and night to keep us safe. Despite any fears or doubts we may have, our kids need to hear that they are safe. Make your reassurance short and to the point. When parents spend too much time, too many words, and too many emotions trying to reassure kids that they are safe, it backfires. Your message will be more powerful and believable if it is very brief and business-like: There are thousands of people working to keep everyone safe. We are going to be okay. Have a good day at school. I love you.



#6: To the greatest extent possible, maintain daily routines.

Daily routines give all of us a sense of predictability, control, and safety. When we stick with them, we also communicate to our youngsters that we are strong enough to keep going... and they are too.

#7: Involve them in helping others.

There are few things more therapeutic than helping others. Even actions that may seem small, such as writing letters of support or sending a box of food to rescue workers, can mean a great deal.

For more information about how to help kids cope with tragedy, listen to our audio download, *Grief Trauma and Loss*. All proceeds from the sale of this audio download will be donated to the Sandy Hook School Support Fund.

Thanks for reading, and thanks for caring! Our goal is to help as many families as possible. If this is a benefit, forward it to a friend.

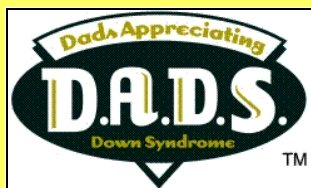
Dr. Charles Fay

Ten Things People with Down syndrome would like you to know'

1. Most individuals with Down syndrome were born to mothers before they were 35 years old.
2. Like anyone else, people with Down syndrome enjoy their lives when they are well supported.

(Continued on page 4)

Mom's and DADS are people too!



What's on the DADS Docket?
The next meeting is Wednesday,
April 24, 2013 at: **Club Venetian**
@ 7:00 at: 29310 John R Road Madison
Heights, MI 48071

Join us for dinner and conversation. Dads, uncles and grandfathers welcome.



Coming soon....2nd Annual Bowling Party

Special Olympics

Young Athlete Program (YAP)

News from the Bovenschen Group

We will be at Bovenschen again on Friday at 6:45 p.m.

April 12 (Snack - Carrie B.)

April 26 (Snack - Dana K.)

May 10 SNACK - Any volunteers ????

May 31 (School is closed on May 24)

We may go for ice cream after this session to end the season.



Just FYI...

2013 Gopher the Gold

9th. Annual Charity Run Benefitting Special Olympics of Michigan

Sat., July 20th.



www.gopherthegoldraces.com

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3. Down syndrome causes disability but it is not an illness.
4. For those with Down syndrome, learning starts at birth. It does not stop.
5. All those with Down syndrome have feelings, thoughts, interests, hopes and know what they want from life. Most, with support, live interesting, independent fulfilling adult lives.
6. While you may have trouble understand the speech of some people with

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Mom's Night Out

Ollies

Middle Eastern Food
(14 Mile and Van Dyke)

April 23, 2013
7:00 P.M.

Sign-up sheets will be available at the
April meeting. Or RSVP to

angela.gallihugh032912@gmail.com

586-214-2560

**First time, NEW FEDS Mom's,
dinner is on Us!**

Please let Angela know if you are coming (or inviting a NEW Mom) when you sign up, so we can reserve seating. Sign up at the February FEDS meeting or send an email to

Alumni Mom's Night Out

Ichiban Japanese Bistro

April 4, 2013
7:00 P.M.

44955 Hayes Road

Sterling Heights

(586) 580-2546

<http://ichibanjapanesebistro.com/>

Please let Marian know if you are coming
so we can reserve seating.

Sign up at the February FEDS meeting or send an email to:

mcunningham720@gmail.com

Home: 586-758-6139

Cell: 586-822-3786

ASK THE DOCTOR

Ask the Doctor was a monthly feature of the Families Exploring Down Syndrome newsletter. This is a reprint.

By Paula DesRosiers

I would like to introduce you to **Rubena M. Raman, M.D.** Dr. Raman is a **pediatrician** at the Henry Ford Medical Center in Sterling Heights. Through her years of practice she has taken the time to become knowledgeable about Down Syndrome. In our interview we discussed the **health screenings from birth through adolescence.**

P.D: If the newborn is suspected to have Down Syndrome, what is the procedure at the hospital?

DR. RAMAN: If you have a baby who is born to a parent(s) who hadn't suspected the baby has Down syndrome, I think that the physician should be very careful in saying, "This baby has Down Syndrome." He needs to tell the parent(s)



that he has some concerns and the baby needs to be evaluated. This evaluation begins with a Karyotyping. If you are in a hospital where there is a genetics lab, a rush will be put on the results, and the diagnosis should be known within 24 to 48 hours. In the mean time, if the doctor has a strong suspicion, he will proceed in making sure that the heart, respiratory and digestive systems are functioning well. He will order an echocardiogram of the heart and he will keep a very close eye on any intestinal concerns that are more typical in children with Down Syndrome. They should also make sure the baby is maintaining his temperature.

P.D: What are the most common intestinal

problems that the doctor would be watching for?

DR. RAMAN: They will monitor the child's swallowing and feeding, and watch for any vomiting. Depending on the maturity of the baby (whether the baby is pre-term or a term or term) they need to make sure that the baby can nurse or feed well, or whether he needs support (tube feeding.) P.D: What are the steps taken after a child is diagnosed with Down syndrome either pre delivery or after the results are back from the Karyotyping?

DR. RAMAN: If the parent(s) and the obstetrician knows the diagnosis, the doctor contacts the neonatologist. (There is usually a neonatologist at the hospital that specializes in neonates; neonates are babies 0-28 days old.) He will order a detailed echocardiogram of the heart to determine whether or not there are concerns. And usually at this point, a pediatric heart specialist is contacted. They will then keep a close eye on potential intestinal concerns occurred within the first 24 hours, along with all the other routine newborn evaluations and observations that they have to do. The baby will be observed to make sure a bowel movement has occurred within the first 24 hours.

P.D: Why are they concerned with the bowel movements of the newborn?

DR. RAMAN: A problems that children with Down Syndrome may present with, are Hirschsprung's disease, (when the colon immediately before the rectum and anus does not work properly because of a lack of nerve cells,) an imperforate anus, (when infant is born without an anal opening,) or duodenal-atresia, (when the first segment of the small intestine which attaches to the stomach is closed.) Because the doctor knows that there is

a greater chance of children with Down Syndrome presenting with these concerns, he is watchful.

P.D: We have spoken to many parents who tell the awful stories about how they were told that their child had Down Syndrome. How do you think this could be handled better?

DR.RAMAN: I think that part of the problem is the nursery. Most of the staff only see the Down Syndrome patients in the acute and immediate setting but they don't see them later, so a lot of people still have misconceptions about them. They tend to be sad and negative. Their emotions transfer to the mother or parent who may also have their own misconceptions. If you have an insightful doctor who is knowledgeable about Down Syndrome, he needs to contact a support person to talk with the parent(s) to gives them a more realistic, positive outlook.

P.D: Being the mother of a child with Down Syndrome, I thought all doctors had knowledge about our children, is this not true?

DR.RAMAN: All pediatricians know that your child needs a Karyotype to make a diagnosis of Down Syndrome, but they may not necessarily know the specific details to watch for

It's a must for a parent(s) of a child with Down syndrome to obtain information via *Healthcare Guidelines* for children diagnosed with Down syndrome and present to their physician. (You can obtain this on the web, book-stores or library.)

Early intervention from an occupational therapist (OT) and a physical therapist (PT) should be discussed at the first visit with your pediatrician. You want to establish the right way of doing things. For example, when you are learning to play golf and you fail to establish a good swing, you'll have a bad swing and never improve your game. The

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Appreciation Night 2013...Nominations Being accepted.

2013 Appreciation Night Details

- When: Friday, May 17, 2013
- Time: 7:00 pm to 9:00 pm
- Where: The MISD Building, 44001 Garfield, Clinton Township
- Who: Your family, plus invitee and their guest
- Admission: A fancy (plated) dessert (we will call you)
- Attire: Business casual



The first **Families Exploring Down Syndrome Community Appreciation Awards Night** was held in May of 2005. This event is held in the spring, every other year, at the Macomb Intermediate School District, and it is open to the entire community.

FEDS members nominate individuals who have made a difference in the life of their child with Down Syndrome or to their family or community. Each nomination requires a letter describing why the person deserves to be recognized and honored in 200 words or less.

The nominees and their guests receive personal invitations to attend a special evening which includes lively entertainment, delicious refreshments, accolades and a token of appreciation for the honored guests.

Past nominees have included business members who support FEDS, physicians who have made Down Syndrome their specialty, and teachers, parents, grandparents, and siblings of individuals with Down syndrome.



Nominate Someone Special

Nominate a person who has made a difference in the life of your person with Down Syndrome. **One nominee per family, please.** The nominee may be a friend, relative or professional. What a wonderful way to recognize their efforts and their importance in your life.

In order for your guest to receive an invitation, please provide the following information to FEDS:

- Your name
- The name and complete mailing address of the person you are nominating
- 200 words or less describing your relationship to the nominee, and how this person has made a difference in your child's life.

Nominations will be accepted by mail (FEDS, PO Box 1191, Sterling Heights, MI 48311), fax (586-977-1971), or e-mail (FEDSyndrome@aol.com).

Deadline for submissions is April 28, 2013



321 World Down Syndrome Day....



Thanks *Culvers!*



Congratulations...Get Well and Thank you!

- A donation from Stacy Gillespie celebrating Ava and Gabe Gilleland
- Support from Raylene Yarnell
- Support from Joanne Spence
- Support and a donation celebrating JP from Jim & Kelly Spagnuolo
- Support from Patricia Sawdon
- Support from the Pauli Family
- Support from Jamie McClintic
- Support from the Mahnic/Kelly Family
- Support from the Gorecki Family
- Support from the Dufoor Family
- Support and a donation celebrating Brandon from the Decker Family
- Support from the Boisvert Family
- Support from the Baker Family
- Support from the Zahner Family
- Support from the Antonelli Family
- Support from the Trocino Family
- Support from the Richards Family
- Support from Katrina Moore
- Support and a donation from Mary Mendez
- Support from the Priem Family
- Support from the Brown Family
- Support from the Lange Family
- Support from the Buresh Family
- Support from the Butler Family
- Support from Lynn Lieder and Julianna Schalk
- Support from the Zukowski Family
- A generous donation of books and DVD's for the FEDS Library from Michelle Allen in celebration of Jazzy and Addy
- Support from the Hayosh Family
- Get Well wishes to Cheryl Taylor
- Support from Valita Whittaker
- Support from the Drabik Family
- Support from the Drabik Family for Kathy Ziomak
- A donation to FEDS Special Olympics YAP program celebrating Preston Drabik and his Coach, Auntie Michele Cox
- Support from the Michaux Family
- Support from the Giles Family
- Support from the Skowronek Family
- Support and a donation celebrating Fiona by the Pauwels Family
- Support from the Geromette Family
- Support from the Bucci Family
- A donation for Benny's Broncos from Judith Sievert
- Welcome to the Kozemchick Family
- Best wishes to Bob Talbot on his recent hospitalization.
- Welcome back to the Sinn Family
- Welcome back to the Comfort Family
- Welcome to the Wettstein Family
- Get Well to Marty Sultes
- Welcome to the Ecker Family
- Best wishes to Gavin Maksymiuk on his recent diagnosis.
- Get Well wishes to Max Milewski



children have different movements to compensate for the lack of "tone." (muscle) If they are not started with the right kind of movements from the beginning, they may have a hard time in areas as eating, sitting, rolling over, and walking. That's why OT and PT are very important.

P.D: If the infant comes home and is basically healthy, should they still be immunized the same as a typical child?

DR. RAMAN: Children with Down syndrome should all be immunized. Because these children typically have a lower immunity, it is even more vital. You should follow the guidelines for a typical child, and there really aren't any contra indications.

P.D: What are the symptoms of *hypothyroidism* and *hyperthyroidism*, and how often should our children be checked for these problems?

DR. RAMAN: First of all, this is done as part of the neonatal screening. If it is detected early, it is so preventable and so treatable; the child is left with no symptoms at all. So hypothyroidism is part of the screening. When a child comes to a pediatrician, part of her job is to make sure that the office checks

the Michigan Department of Health Neonatal Screening for the results.

The symptoms in young children may be poor weight gain, they are sluggish, don't feed well, are very constipated, and may feel cold all the time. That goes for older children also; but the symptoms may vary. Often, they too, may feel cold, won't eat much or sometimes will gain a lot of weight as their metabolism is low and they lack the thyroid hormone: other symptoms include dry skin and hair, and in adolescents, menstrual irregularities.

P.D: What type of test is done?

DR. RAMAN: It is a simple screening, the *T4* and the *TSH*. The *TSH* would be high and the *T4* would be low. The *T4* is your *thyroid hormone* and your *TSH* is your *thyroid-stimulating hormone*. If you have a low *T4*-the body is stimulated to produce more thyroid hormone. So, your *TSH* would be high. *Hyperthyroidism* is the opposite, as you have too much *T4*. With hyperthy-

roidism, a mass or a goiter may present, and occasionally the thyroid may need to be removed. Hyperthyroidism is not as common as hypothyroidism.



You can have the congenital hypothyroidism or you can also have the acquired hypothyroidism. This is an autoimmune disease where your thyroid gland becomes mistakenly invaded by its own immune defense system. So it doesn't function well. This is called

Hashimoto's thyroiditis, which will also cause hypothyroidism. They both will need thyroid hormones. That's most commonly seen in Down syndrome. If this occurs, we would send your child to an endocrinologist.

Dr. Rubenora Raman was the FEDS Medical Consultant, friend and physician to many of the children from FEDS. She retired in 2012 to be able to spend time with her grandchildren and to see the world with her husband. She is missed by many. Thank you Dr. Raman for learning about and loving our children over the years.

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Brunch is right around the corner and you will soon be receiving an invitation in the mail. Following our first brunch in 2012, we knew it had to become a yearly event. Mark your calendars and be sure to RSVP that you are joining us on May 11 at Club Venetian in Madison Heights.

Club 21 is planning for the last dance of the 2012-2013 school year and it will take place on May 10 (changed from April 26). Please watch for your invitation to the **Luau** as the location for this dance has changed.

Thanks to the continued support of the coaches for the youngsters under seven, the **Special Olympic YAP program** is a success and continues to meet at Bovenschen and Peters Schools. For more information on YAP, contact Kristen at: K34KARR@hotmail.com.

Our next **BIG** event for FEDS is our **Community Appreciation Night**. This event was first held in May of 2005 and has

continued to take place in the Spring, every other year. FEDS members are invited to nominate individuals who have made a difference in the life of their child with Down Syndrome or to their family or community. Each nomination requires a letter describing why the person deserves to be recognized and honored in 200 words or less. The nominees and their guests receive personal invitations to attend a special evening which includes lively entertainment, delicious refreshments, accolades and a token of appreciation for the honored guests.

We ask that if you nominate someone this year that the following Appreciation Night, that you help us host the event so that more people have a chance to nominate and honor that special someone. See page

Mark your calendar for the third annual **DADS Golf Outing** scheduled for July 13 at the Boulder Point Golf Course in Oxford MI.

Lucy

Down the Runway IV



Down the Runway IV...continued

Thank you to the special people and companies listed below who so generously donated to Down the Runway Fashion Show and Silent Auction. Without **your** generosity we could not have had the outstanding offering that so many enjoyed at the event. Thank You, from the bottom of our hearts!

5 Star Lanes	Eric Schultz	Lisa & Carlyn	Sam's Club
All Team Staffing Inc	Evola Music	Loccino Italian Bar & Grill	Sara Demick Photography
American Gymnastics	FEDS	Logan's Road House	School of Rock
Arthur Murray	Frame The Alphabet	Lois Tucker	Scott Kuefler
Bahama Breeze	Genbu Kai Karate	Lowe's	Shorepointe Optical
Barb Lempinen	Giggles Salon	Loxx Hair Salon	Sign Language Services of MI
Best Western Sterling Inn	Gloria Jen Conti	Lynn & Mike Abraham	Sign of the Beef Carver
Bill & Darline Den DenDoovan		Maggiano's	Sterling American Grill
Black Finn		Margo Baetens	Sterling Hts Fire Station #1
Bounce About Party Rentals		Marian Cunningham	Studio 9
Bowl One Lanes		Mark Allar	Studio II
Bright Side Dental		Mark Ridley's Comedy Castle	Sunnybrook Golf & Bowl
Caesar's Windsor		Meijer Shelby Twp	Swain Family Chiropractic
Carnival Cuts		Michael Santeufemia	Sycamore Hills
Carol Diehl		Mike & Deanne Moore	Target Sterling Hts
Cedar Grille		Nanette Hall	Target Utica
Cedar Point	Green Mountain Coffee	National Coney Island	Textured Salon
Charissa Antonelli	Gymboree	Niki Schwerin	TGIFridays Sterling Heights
Cheryl Taylor	Hampton House Furniture	Nino Salvaggio's	TGIFridays Utica
Choose Friendship Co.	Homesource International	Old Navy	The Color Room
Club Venetian	Hunt's Gymnastics	PaintWork Detroit	The Henry Ford
Cori Sabou	I-Hop	Pampa Lanes	The Shops at Trapper's Alley
Cut Mine Hair & Nail Salon	Jamie Stebbeds	Pat Haver	TMK Prints
Dax & Amanda Clarke	Joseph Johnston	Paul Mitchell The School	Tom Byxbe
DC Nails	Judy & Bruce Sievert	Peabody's	Tom Tricoff
Detroit Pistons	Jungle Java	Peggy Venturini	Trina Lyjak
Dominic's Fine Jewelry	Kara Jacqueman	Red Robin	UNO Pizzeria
Donna Perzyk	Kingswood Chiropractic	Rochester Advanced Dentistry	Wendy Pasque
Double JJ	Kristen Kunze	ROI Systems Group Inc.	Please, let us know if a company that you acquired a donation from is not listed above
EllaBean	Larry Lemanski	Sadiekins Ribbons, Bows etc.	
Eric Groeneveld DDS	Lily's	Salvatore Scallopini	



(Continued from page 4)

Down syndrome, they are excellent communicators.

7. Everyone with Down syndrome has a different personality.
8. People with Down syndrome work successfully, with varying degrees of support, in areas such as retail, administration, child care, and hospitality to name a few.
9. Those with Down syndrome have an extra chromosome (#21) as well as the regular 46. Although people with Down syndrome may share common facial features, they are more like their families in looks and personalities than others with Down syndrome.
10. In 1960 the life expectancy of an Australian with Down syndrome was 10 years of age. Today most live into their 50's or 60's.

Thank you

www.dsansw.org



Molly Corombos writes on Facebook: This morning as J and I walked Catherine into preschool:

C: (as she walked over a bunch of salt on the sidewalk)

What is this? Is it ice?

Me: No. It's salt. It helps the ice melt.

C: Will they use pepper too?



A BIRDSEYE View

Annual Holiday Party



December 2012

Income: \$1725.00

Expenses: \$3544.83

Total expenses: (\$1819.83)

Expenses include: Adult and children's meals, DJ, decorations, snacks, crafts, dessert, dinner for the Knights. (The cost of the photo booth was picked up by the very generous DADS group).

Once again the Fr. Heary counsel of the Knights of Columbus in Madison Heights, raised money through their bi annual Tootsie Roll Drive to purchase gifts for the special attendees from FEDS. The donations of underwear and socks was given to those in need from the neighborhood of St. Catherine's in Detroit.

Thanks EVERYONE!

Top Five Instructional Strategies for Students with Down Syndrome

Children with Down syndrome are capable learners who are excited and eager to learn. They just need to be given the opportunity to excel. They may learn at a slower pace, but are more than capable of learning. They are strong visual learners. This means that they understand what they see better than what they hear. The average IQ for children with Down syndrome ranges from 25 to 80, whereas the average IQ for a student with Down syndrome is around 50. In children without an intellectual disability, the average IQ would be around 100.

Children with Down syndrome have specific points associated with their learning development:

- They are visual learners.
- They understand a lot more than they can say.
- They are able to follow classroom rules and routines.
- They need help to remember instructions – use shorter phrases or visual clues.
- Teacher's expectations of behavior, attitude and ability should be high.

Children with Down syndrome can learn. However, we need to make compromises so that their educational needs can be met in the classroom. Since they are visual learners, teaching reading to students with Down syndrome should be characterized by a strong emphasis on visual learning. Visual demonstrations, pictures and illustrations can also be successfully used to assist in providing effective instruction in other subject areas of the curriculum. Lessons in phonics should be included in the curriculum for the learner with Down syndrome .

The use of manipulatives and activity learning can be beneficial in the development of number concepts. The use of physical demonstrations and activities are important when teaching math concepts.

Students with Down syndrome generally demonstrate good social skills, which can be utilized to increase learning and teaching opportunities. When speaking to a student with Down syndrome, it is important to speak directly to them using clear language and short sentences. You should allow adequate time for the child to process what you have said and respond. Positive reinforcements should be used for students with Down to boost their self-esteem and positive learning experience. This should be done both at home and school.

Down Syndrome Affiliate in Action Conference

Down Syndrome Affiliates in Action started as a conference bringing together outstanding leadership from Down syndrome organizations around the country. After consecutive years of explosive growth, the conference has extended its reach internationally and is now a 501c3 nonprofit trade association continuing its mission:

To support and advance the growth and service capabilities of the local and regional Down syndrome organizations we serve, to be the conduit of value-driven training, programs, best practices and support for our members.

DSAIA's purpose continues to be to serve our affiliates through collaboration, resource sharing, and networking. View [a webinar](#) explaining the many benefits of joining the Trade Association.



By Margie Wheelock

Last month I and 3 other of your fellow board members attended a conference called the DSAIA conference in Cincinnati. The DSAIA is an organization that consists of and services the leaders and board members of Down syndrome support groups throughout the

United States. Each year we gather for a conference to network and learn about better ways to serve and improve our group.

While there, my top priority was to find and improve on ways to better support my support parents and new parents in the FEDS group. I attended a leadership circle in which we talked about things that were working and ways to improve this program. I would like to develop a better tracking program for new my parents and I came away with better ways to support the support parents. I learned of some new resources that will help both new parents and their support parents. I shared with the group how opening up the internet, where parents can ask for a referral to a support parent really brought in a lot of new families. This seems so elementary of a concept but other groups had never thought of how that

“electronic” wall sometimes makes it easier for new parents to reach out. I will also be sending out surveys in the near future to my new parents to see how we are doing. If anyone would like to contact me in the interim, please email me at:

wheelszoo714@gmail.com.

Another workshop I attended was the “How to Bring an iCan Shine Bike Camp to

Your Community” workshop. The bike camp teaches children with developmental disabilities (minimum age 8) to learn how to ride a regular conventional bike. The group professes an 80 percent success rate at teaching the kids who attend their one week bike camp to learn to ride entirely inde-

pendently. I learned that riding a bike isn't just about the child or young adult learning the physical act of riding a bike. It brings many important as-



pects to their lives. They become much more independent, they increase their confidence level, and it fosters a positive change in the family dynamic (imagine a bike ride where the entire family can participate!!) It also promotes inclusion with peers! I was so excited and moved that when I watched the video presentation of the camp actually working, I got tears in my eyes.

Of course, bringing a camp such as this involves a lot of planning and a lot of funding not to mention the perfect venue. I have already started brainstorming with some of my fellow board members and the DADS groups as to how we can make this a reality. Stay tuned!!

In conclusion, when I leave these conferences, I always leave with my brain saturated with a lot of ideas for the group, but I know I have to pick a few and run with it or I will become overwhelmed. I hope that the ideas I have mentioned will come to fruition in the near future and I would like to thank you, all of our members, for making it possible for me to attend this confer-

Smiles....

To FEDS

Thanks so Much for thinking of Lyla when she had surgery and for the generous gift card. It was so very thoughtful. I sure we can find some fun toys to cheer her up!

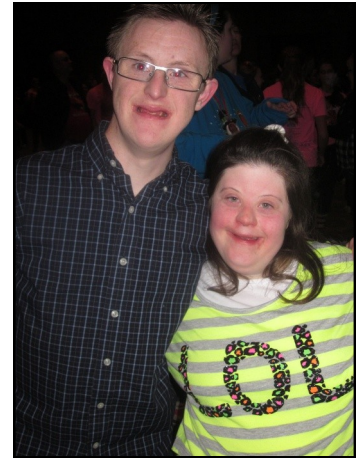
Love

Lyla Dubay and Family

Thank you FEDS. We love FEDS and the Pistons. We had a fun time at the game last night and are thankful for the free tickets

Xoxo

Charlotte and Timmy



Dear FEDS,

Thank you for the gift card. I want to buy a new music CD of Bro Mars.

Nick Abraham



Dear FEDS-

We can't thank you enough for the gift card to Target. Jake is doing much better. We purchased a baseball game and it made him so happy. We appreciate all you do for our kids-

Love

The Moffetts

To the FEDS

Thanks for my Summer Scholarship. I enjoyed summer camp. I got to go to a play and be in a play. I also enjoyed horseback riding and swimming. You guys are the best.

Olivia Grobbel

FEDS Family

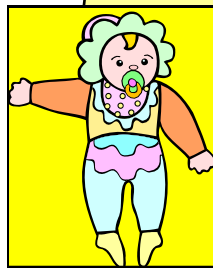
Thank you so much for the gift card - Mom is going to take me shopping SOON!

Love,

Kristin



Dear FEDS,



Thank you so much for the Target gift card I received before my surgery in November! I bought a baby doll because I love dolls so much and I love playing with her! My surgery went well and I am all recovered! I hope to make it to another FEDS event soon!

Thank you!
Fiona Pauwels



Calendar of Events & FEDS Contacts

April 2	12:00	Changing Lives Program presentation for St. John Hospital Residents
April 2	6:30	Bocce league at Club Venetian
April 4	7:00	Alumni Mom's Night Out at Ichiban's
April 9	6:45	Club My Chance to Dance lessons at Christ Methodist Church 34385 Garfield Rd. Fraser
April 10	7:00	Monthly FEDS Meeting with Speaker on Nutrition
April 12	7:00	7 Up BINGO at the MISD (For friends and siblings too)
April 16	6:30	Bocce league at Club Venetian
April 17	7:00	Fashion Show meeting with the LEADS (Pizza and Dessert provided)
April 18	7:00	FEDS Board Meeting at Beaumont
April 19	7:30	Peter Pan (Tickets pre ordered)
April 24	6:30	DADS Meeting at Club Venetian
April 30	6:30	Bocce league at Club Venetian
May 8	7:00	FEDS Monthly Meeting
May 11		New Parent Brunch at Club Venetian
May 17		Community Appreciation Night

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Special Olympics
YAP Representative

Parent to Parent Program Coordinator
Greeter & Membership
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 248-375-5323

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 Cathy Martlock
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 Juleen Drabik
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D.A.D.S Officers

Jim Spencer - Golf Outing
 Bill Marchiori - Treasurer
 Mike Moore
 Todd Gilleland

Families Exploring Down Syndrome

PO Box 1191

Sterling heights, MI 48311

www.FamiliesExploringDownSyndrome.org



FEDS Members Meeting

Wednesday, April 10, 2013

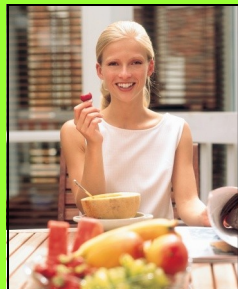
Nutritionist

Speaker: Lynette Morris,

Clinical Dietitian at Beaumont Health System

Meetings held at the MISD

**in the Superior Meeting Rooms at
the North End of the Building**



44001 Garfield, Clinton Twp.

Doors open at 7:00

The FEDS library will be open and available to check out and return items

Sitters available. Infants are welcome to stay with the parents.