

FEDS NEWS TODAY!



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DISCLAIMER

This newsletter reports items of interest and provides a forum for others. We do not endorse any publications, programs, therapies or any political or religious points of view. Contents of this newsletter may be reprinted to share with others and/or in your own publication as long as credit is given to the editor/source. Opinions and information in this newsletter are not necessarily those of the editor and/or FEDS. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook and attitude, therefore, it is this non-professional editor's endeavor to use People First Language at all times!

Please submit all material for publication in this newsletter by the 3rd Wednesday of the month.

March 2007

From the President

I hope you enjoyed your winter break as much as we did. I know for some, the bus on Monday morning was the best part.

Having to cancel our February Meeting because school was closed was a difficult call as so many people were really looking forward to the Open Meeting forum. We will try to consolidate the March meeting so that our speakers have time to share their programs and we still have time for Q&A afterwards. As always, you are welcome to "stick around" after the meeting to share and hang out. We always enjoy the "after glow" once the library is closed and we sit down to talk with those that want and need quiet conversation.

With the success of the FEDS Bocce team (there are 15 bowlers with room for just one more), the new "Let's Play" group for 0 to 6 year olds, the upcoming 7-Up Bingo party for all children 7 years and up (thus the name) and the Mom's Night Out, Your Board is excited about up-coming plans and events. We hope it rubs off on you, but forgive us if we are a bit giddy. We are looking forward to the Dad's Golf Day this spring and the

2nd Annual Appreciation Night in May. Of course, we can't forget to mention the Annual Summer picnic in July and the Reach for the Stars Conference this fall. There are plenty of opportunities for fun and involvement.

Don't let the opportunity to get one of our Summer Scholarships pass you by. Please remember to qualify for a Summer Scholarship or conference reimbursement you need to volunteer, as well as attend 3 regular meetings. As always, they are lots of opportunities to become involved and we always welcome parent's and grandparent's participation.

A Special Thank You to Gayle & Andy Fetzer for chairing the Parents Night Out at Bath City Bistro. We appreciate your involvement and the planning of 2008 Parent's Night Out with new ideas and a new fun location.

More free Palace of Auburn Hills event tickets are available. Please be sure we have your email address so that you can receive the upcoming offering.

Happy St. Patrick's Day and Happy Spring!

Lucy



Mission Statement:

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 three-fold:

- 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 syndrome.

FEDS News Today "Classifieds"

Please read carefully, there are a lot of exciting changes and events coming your way soon. If you have ideas for new member services or events, please contact Kelly Spagnuolo via email: caterkelly@comcast.net. We are always on the lookout for new programs to benefit all the age groups of our membership.

- **CHECK YOUR LABEL**—Please check your label on this newsletter. Due to the rising costs of printing, the cutoff for paying your dues is the end of this month. If you haven't contacted us by end of March, your family will be moved to the inactive list and your newsletter subscription suspended until we hear from you. It takes a lot to keep FEDS going each month, please keep your membership current, so we can keep you in the "know" about Down syndrome.
- **MOM'S NIGHT OUT** – Our next event is Tuesday March 28 at Shield's Pizza on Hayes & 18 Mile Road. Cost for this event is \$12.00 per person. We have 8 people signed up so far, we need 15 to keep our prices low...don't wait to RSVP: Kelly Spagnuolo caterkelly@comcast.net or 586-286-7743.
- **7-UP FAMILY BINGO NIGHT** – For children 7 years and older with their parents. March 9 at the MISD Building in the Michigan Room. Fee is \$3.00 per family. Please RSVP via email: Kelly Spagnuolo caterkelly@comcast.net or call at 586-286-7743.
- **DAD'S GOLF DAY** – Dates and places are still be worked through, but we need to hear from the Dad's who may be interested in this golf event. We are thinking about the May timeframe. Please contact Kelly Spagnuolo if you are interested in golfing. Kelly Spagnuolo caterkelly@comcast.net or call at 586-286-7743. Stay tuned for more info.
- **FEDS DIRECTORIES UPDATE** - We are updating our Directory of Members. Please email us any updates to your personal information or family members. If you have an unpublished phone number, and you do not want it listed, you must let us know.
- **KNIGHTS OF COLUMBUS & TOOTSIE ROLL SALE** – Knights of Columbus has requested our help with their annual Tootsie Roll Drive. The Knights of Columbus assist us with our annual Christmas Party and gifts. It will be held at the Universal Mall Kroger's from March 30 to April 1. We are calling all FEDS members to sign up and assist with this event. Contact Lucy Talbot: FEDSyn-drome@aol.com or 586-977-8027 for more information.
- **FEDS "GET WELL" CLUB** – If your child has a surgical procedure or is hospitalized, please let FEDS know, so we can send a card. We often find out through the grapevine, but it is good to let us know before, during or after the procedure or hospitalization. You can leave a message on the voice-mail (586-997-7607) or send us an email at FEDSyndrome@aol.com.
- **SPECIAL OLYMPICS** – May 8, 2007 is the date for the Area Games for Special Olympics. Most schools include all of the Special Education students in the Area Games. Attending the State Games is more limited. If your child's school does not support Special Olympics and you would like your child to attend, please let us know. In order to enroll your child for the State Games, he/she must practice, be coached & be timed for their event. The FEDS Special Olympic Chairperson is Marian Cunningham: MECT07@hotmail.com or 586-758-6139.
- **FEDS SCHOLARSHIPS** – If you think you may be interested in applying for our Summer Scholarships, please contact a Board Member to verify your eligibility. This scholarship can be used for activities/therapies for your child, and also for your attendance at relevant workshops or conferences.
- **SUMMER CAMPS**—If you have information on Summer Programs/Camps for our children, please send them to FrankandBeans5@yahoo.com. We are looking to compile a list of useful programs for the summer for the next newsletter.
- **U of M STUDY**—The Center for Motor Behavior & Pediatric Disabilities is recruiting children with DS (ages 3-5 yrs) and children with typical development (ages 2-5 yrs) for a investigation on physical activity patterns and the factors which influence them in pre-school-aged children. The outcome of this study will give better understanding on how to increase physical activity in young children. If you are interested in participating, please contact Meghann Lloyd 734-936-2607 or email: meghann@umuch.edu

Families Exploring Down Syndrome 2nd Annual Community Appreciation Celebration

Nominate a person who has made a difference in the life of your person with Down Syndrome. These individuals may be a friend, relative or professional. What a wonderful way to recognize their efforts and their importance in your life.

Where: The MISD Building - Room 104
44001 Garfield, Clinton Township

When: Friday, May 11, 2007 7:00p.m. - 9:00pm

Who: Your family, plus invitee and their guest

Activities: D.J., H D'oeuvres and Desserts

Admission: A fancy (plated) dessert

Attire: Business casual

In order for your guest to receive an invitation, please fill out the information below and return it to FEDS @ PO Box 1191, Sterling Heights, MI 48311 or fax it to 586-977-1971 or EMAIL: FEDSyn-drome@aol.com ... One nominee per family. **Deadline for submissions is April 2, 2007**

Please Include:

- Your name and the person you are nominating
- Mailing address, city, state/zip of nominated person:
- Relationship and how have they made a difference in your child's life? (200 words or less).

Please volunteer to assist, by email: FEDSyndrome@aol.com or by phone: 586-977-8027

- **MARCH MEMBERSHIP MEETING SNACKS**—We have the Dearhamer, Hite, Relph and Banaszewski Families listed for refreshments for the March Meeting.
- **FEDS EMAIL UPDATES**—We sent out 6 updates in the month of February for upcoming events and opportunities. If you missed any of these updates, please contact FEDSyndrome@aol.com to make sure you are on our email update list.
- **FEDS LIBRARY**—We have added a lot of new titles to our library...it will be fully open and stocked for the March Meeting. Please also don't forget to return your books so others may have a chance to read them as well.
- **PARENTS NIGHT OUT**-We had a great turnout for our Parent's Night Out. We had 12 families for feather bowling this year. There is talk about changing the venue to WhirleyBall for next year.
- **KIDS PLAY GROUP**—We had 6 children show up for our first ever Kids Play Group last Sunday. We had 2 kids 0-3 years and 4 kids 3yrs-6yrs old. If you are interested in participating, we are meeting on the 3rd Sunday of every month. Contact Kelly Spagnuolo 586-286-7743 for more information.
- **THANK YOU** to the families who responded to the call for Mosaic Down syndrome and the families who have volunteered for the Family Focus, Dad's Perspective and Sibling Articles. Keep the articles coming!!



Gayle and Andy Fetzer at Parent's Night Out Event

Get To Know Our Families

MEET THIS MONTH'S FEDS FAMILY...THE COLLIN'S

John, Stephanie, Cheyenne (DS) 6 years old, and Harley, 3 years old.



Our daughter, Cheyenne goes to Siersma Elementary school. She is mainstreamed into Kindergarten for the first 1/2 of the day and in ECDD (Early Childhood Developmental Delay program) for the 2nd 1/2 of the day.

Cheyenne loves to dance and be the center of attention. She started her first year of ballet and is loving it. Her first recital is in June and I cannot wait! She also takes swim lessons with her brother. In the first session without any previous lessons they already progressed to the next level.

Our biggest challenge so far has been that I am very protective of her and her feelings. I think other peoples reactions and comments bother me MUCH more than they bother her. I need to be able to take a step back and let her deal with a situation instead of being the mother eagle swooping in and protecting her. She is really good at taking care of herself already. I just need to be able to recognize that.

Our biggest surprise is that we are realizing that she can do just about anything. She has consistently risen to each challenge with a smile and proven her abilities. I am amazed EVERY DAY, at her determination and independence.

My husband and I met through a singles ad in the Oakland Press. We started talking in February, 2000 got engaged in April, bought our house in August, got married in September and had Cheyenne in January 2001. I have never been more in love with another person in my life and I feel so lucky to have met John. Up until we had Cheyenne, I had never personally known a person with disabilities and had very negative feelings about disabilities. Little did I know that God had another plan for me. I firmly believe no matter what road our lives take that God is in control of EVERYTHING, and everything happens for a reason.

It always seems unfair that young people die for what seems like no reason but I know now that there is a plan in his eyes. I think I went through that to prepare me emotionally for the struggle of giving birth and taking into my life this absolute joy of a person, that has without question, changed who I am from the core to be a better person.

John's mother was a foster mother and over the course of her fostering had 63 foster kids. John was her 9th foster child and she loved him so much they adopted him. She always took on the babies that were hard to care for, like drug addicted, alcohol addicted, failure to thrive or orphaned children and John grew up knowing how to take care of small children with special needs. I on the other hand had never even babysat before and John was teaching me how to change diapers when we got home. It was a difficult birth experience because I only got to see her twice before she was sent to Children's Hospital and she was in NICU there for 9 days before we got her home. Throughout it all, John was always there to support me and telling me everything was going to be O.K.

Cheyenne has since gone through many therapies, won over the hearts of every person she meets, and even some she doesn't meet, just hear about her. I never knew what it felt like to really know without question that you would lay down your life for another person, that they have made you better just by being near you. I think Cheyenne is destined for great things and we are just along for the ride. The geneticist we spoke to at Children's Hospital told us, "Don't pay attention to anything you read that is over 5 years old. What we know about Down syndrome is changing by the moment and the only limitations she will have in life are the limitations you put on her".

Our hope for Cheyenne's future is that she is happy. I want her to pursue those things in life that make a person feel complete, what ever that may be. I had to climb Mt. Fuji to realize that climbing mountains is not all it's cracked up to be. I want her to climb **her** Mt. Fuji if it makes her happy even if she finds out that it's not what she thought, as long as she tries it, and can say, "Hey, at least I did it, even if it did suck". Our dreams are what make us who we are, and her dreams are limitless if I have the ability to help her reach them.

PRODUCT REVIEW BY PARENTS FOR PARENTS

It was a trip to the zoo this fall and Halloween that we realized David did not have the endurance to walk long distances. When he was tired from walking he would just sit down and cross his arms. The only thing you could do was to carry him. He now weighs 54 pounds. It makes for a very long walk through the zoo and back home from trick-or-treating.

David was growing out of the stroller he has had since birth. We knew we had to do something before we found ourselves not participating in walking activities, which is the opposite of what we have been doing since he was born. David has been on many vacations and loves to go!

We looked on the internet for strollers and found the brand, Maclaren Major. We liked this one the best because it looked like a regular stroller and it folded like an umbrella stroller, perfect for vacations. We then had our pediatrician write a prescription. Our pediatrician called with questions about the request. I don't think she has ever written a prescription for a stroller. We weren't entirely sure what the insurance company was going to need written so we had her write on a prescription pad a stroller, the brand of stroller we chose, David's weight and a diagnosis of Down Syndrome. We then checked with our insurance to see where we had to get the prescription filled for durable medical equipment. We don't have a contracted durable medical provider,

so we chose Wright and Filippis. We went on a Friday with the prescription and picked up the stroller exactly a one week later. Not all insurances work this way and there may be more forms to be filled out. You should contact your insurance company to check and also find out if you have a copay or deductible for durable medical equipment. If by chance your insurance company will not cover a stroller, I found it cheapest on E-bay for \$339 brand new. The invoice I received from Wright and Filippis was for \$570.

We were very pleased when we opened the box and unfolded it. It is well made and looks nice. You can also purchase additional parts like a sun shade, padded seat, shopping basket, etc. You can buy these off of E-bay cheaper than any other place I saw on the internet. David had to sit in it while we still had it in the kitchen!! He was ready to go for a ride. We went shopping the next day and it was wonderful. It rolls smooth and David seemed very comfortable. It was a very pleasant shopping trip and we look forward to a nice vacation at the end of March.

We would suggest to all parents and caregivers to look into getting a stroller like this when the time comes. We think it will help David enjoy activities that require walking. We feel it will give him freedom.

Happy Parents - Sara and Brett Everhart

GYMBOREE FOR FEDS—CALLING ALL KIDS 0-5 YEARS OLD

Gymboree has offered us an opportunity for an 8 week Summer Program. This class would benefit our 0 to 5 year old children (both walkers and non-walkers, as there are a variety of sensory activities and gross motor activities to participate in). We would meet once a week for a 45 minute class.

This would be a wonderful way to continue the therapy that we all partake in throughout the school year through MIPPS or otherwise. This class would also qualify under the FEDS Scholarship Program.

The teacher of this class has a Special Education Background in Rochester Schools and is familiar in working with our children.

If you are interested in signing up for this class, Gymboree will offer a "try-out" event free of charge-date is TBD.

Please email Kelly Spagnuolo (caterkelly@comcast.net) and let her know if you would be interested in signing up for this opportunity.

A DAD'S PERSPECTIVE

After my beautiful and lovely wife volunteered my services for this article, I asked her, "What exactly is it that I can write about?" After all, my equally beautiful and lovely daughter, Kaitlyn, is only three years-old. While we as a family have been through a lot, we haven't even dealt with school, potty training, riding the bus, and all the other "adventures" that lie ahead. For that matter, Katie is barely even talking right now. What could I possibly add to the conversation? Perhaps I do have a different perspective than some of the other dads, as I am a stay at home dad. I have three beautiful girls, Olivia (5), Kaitlyn (3), and Vivian who is all of eight months. Add my wife Victoria and, and I am completely outnumbered. I am not complaining though. I tell Victoria that the best gift she could have ever given me was the ability to stay home with our girls and help them grow.

It was a rough start with Katie. We found out that Katie was "showing signs" of having Down syndrome hours after she was born. It was a complete shock to us. Late that first night, with Katie sleeping in the hospital room with us, I remember having a sick feeling inside of me when my new little girl didn't make a noise all night long. All I could remember from Olivia's first night was how she wouldn't stop making noise. I felt that something was wrong. Sure enough the next day the doctors told us that they saw a spot on Katie's heart and would have to do more tests. A week later they told us she would need open heart surgery. She was so quiet because it took all her strength to breathe. In Katie's first three and a half months of life, she never slept more than two hours straight. She also had trouble eating, so we were introduced to a feeding tube. In order to cut down on hospital visits, I learned how to change the feeding tube myself, and can still picture Katie watching me as I finished the process. It was a necessary task to get her strength up for the upcoming surgery.

When Katie was fourteen weeks old, she had the

surgery. This is when things finally began to look up. They performed her surgery (which the doctors referred to as 'AV canal') on a Wednesday and we brought her home on the following Wednesday. I couldn't believe it, in just under a week, we brought our little girl home after having OPEN HEART SURGERY! She was, and is, so much stronger than I can ever hope to be. To top it off, on her very first night back home after the surgery, she finished a bottle (and kept it down) with no feeding tube involved AND slept through the night for the very first time. It was like getting a whole new kid. Since then it's been full speed ahead. There's been swimming classes, sleepovers at grandmas, various play-dates and I can't leave out the many therapy sessions through



the Early On program at the MISD. For any new parents, I can't say enough about this program and how much it has helped our family.

So far, my favorite thing about my daughter is her attitude, because there are so many different layers that comprise it. She is lovable, has a sense of humor, shows empathy and kindness, is

strong-willed, moody, and everything in between. When I watch her play dress up with her older sister or help feed her younger sister, that bad feeling I had in my stomach has been completely replaced. In its place, I'm filled with pride, more love than I knew I had in me, and most of all hope. My hope is that Katie will have a fulfilling life. I will do everything I can to help her achieve this, because of what she's already done for me. You see, to be completely selfish, I believe that Katie has made me a better person. I see the world different. I have more compassion, more appreciation for life, and a better handle on what things are truly important. In a strange, somewhat ironic twist, I actually feel sorry for a large percentage of the population who may never have this feeling. I know that our family has a long way to go, and I don't expect it to be easy, but I am very much so looking forward to the future and having a good, fulfilling life with all my girls.

M. Kevin Pozsgay—pozmann@comcast.net

MY SISTER, AMELIA GRACE

BY HEATHER NATALIE

My name is Heather. I am 17 years old and I am a Senior in high school. My sister Amelia Grace was born August 16, 2006. When my mom sat down with me and told me that she was expecting a baby, my first thought was, "no way! I'm the only baby in this house." I gave my mom a hug and said congratulations.

A few weeks later, my mom sat down and said "I need to talk to you about something very important." My mom told me that my soon to be baby sister had Down syndrome. I was so scared. My mom asked me if I knew what Down syndrome was, and I thought I knew but she explained to me the medical terminology. Then my mom said, "Mostly she is your little sister who needs all of our love just like you did." My heart was broken, and I was so sad for my entire family. I didn't tell my mom how worried I was.

As we all know, God works miracles. He sent Amelia to us because he knew that my family, busy, loud and on the go, needed Amelia. With

her sweet smiles and sparkle of joy, God knew that we would love her and cherish every moment with her.

Now, 6 months later, I don't know how our family lived without Amelia. She is the most beautiful person I know. Don't get me wrong. I know that we will argue, ignore or annoy, one another as sisters do. We will help one another and protect each other from harm. We will be best friends. But most of all I am her big sister and she is my little sister and I love her with all my heart. When I have a bad day I go home, pick up Amelia and give her a big hug. She sits on my lap, we watch TV, listen to music, dance and do what we like to do most, talk on the phone. I love when Amelia reaches out and we hold hands. I love to watch her as she accomplishes sitting up, holding her head up high, rolling over and holding her own bottle. I can only imagine the wonderful things Amelia will do in this lifetime for herself and for our family.

Thank you for allowing me to brag about one of the best things in my life!

DEAR FEDS-THANK YOU!

I want to thank you for the cute, CUTE card and the gift card you sent Noah. He had his tonsils out on Jan 23rd and while they kept him for 2 days, he came home too soon and despite us feeding him with a medicine syringe and also because...he ended up being put back in the hospital by our Pediatrician for dehydration and aspiration pneumonia. He was in for 2 1/2 days more...THAT time he was ready. He hasn't looked back...his eating and drinking are fabulous, he has regained all the weight he lost and is sleeping SOOO much better!

When the ENT saw how big his tonsils and adenoids were and how tiny his sinus and air passages were, he agreed it was definitely the right choice. He also found a pocket of infection (same one from last October!!!!) which is (I believe) now gone. He also found that the T-tubes he had placed 18 months before had been sucked into his middle ear so with the now too large hole, he had to build up the ear drum to hold the new ones in. Noah goes for his surgical follow up tomorrow and I expect great reviews!! -The Yunke Family



Editor's Quote of The Month.

As I sit here this month and assemble our newsletter, I'm thinking about all the parents who read this publication and our ability to connect with one another...each one in different stages of acceptance of the hand that life has dealt them. It is through the connection of similar people that we ease the fears we have to overcome. I found this quote by looking for ways to encourage "connection" within our group. I hope you like it.

And as we let our own light shine, we unconsciously give other people permission to do the same. As we are liberated from our fear, our presence automatically liberates others. -Marianne Williamson

DEVELOPMENTAL AGE VS. CHRONOLOGICAL AGE - THE DUH FACTOR

The developmental (or functional) age concept is a disability-world paradigm that should make us halt in our tracks. Many children and adults with disabilities are routinely graded against a developmental scale. If a person's abilities are substantially lower than the norm, he may be saddled with a developmental age (DA). His chronological (actual) age (CA) is dismissed as irrelevant. From that point on, services, education, and even the way he's treated by family members are based on his DA.

Yikes! What happens when, for example, a 15-year-old (CA) is treated like a 10-year-old (DA)? Gee-I guess he'll act like a 10-year-old! Do we wonder why so many people with disabilities are considered behind or not ready? Duh!

During my son's kindergarten IEP

(Individualized Educational Program) meeting, the physical therapist shared her report with the IEP team. When she read, Benjamin functions at the level of an 8-month-old, I thought the kindergarten teacher was going to faint. I, on the other hand, was horrified that my son was portrayed this way. Luckily for us, 5-year-old Benjamin was present, and his presence refuted this testimony! He was sitting in a little chair at a little table, reading a book out loud (one of many he had memorized). When the kindergarten teacher heard the 8-month-old level, she looked from the therapist to Benjamin and back again several times. After being questioned about her statement, the therapist revealed this assessment described his physical abilities. Since Benjamin had never crawled, his development was (and would be forever, I suppose) fixed at the level of an infant. If Benjamin had not been in attendance at that IEP meeting, his opportunities for inclusion would have been diminished. **But his physical presence demonstrated that he was definitely not like an 8-month-old!**

While doing presentations around the country, I routinely meet parents who describe their children by their disabilities, and include a statement like, Brian is nine, but he functions at

the level of a 4-year-old. Egads! Who made this ridiculous presumption? And why would anyone believe it? Brian might have tested at the level of a 4-year-old on one type of assessment or another, but he has double the life experience of a 4-year-old, so how in the world can we say he functions like a 4-year-old? Let's use our common sense here! Children who do not have disabilities are all over the map in their development! A 10-year-old reads like a 13-year-old, plays soccer like a 16-year-old, and behaves like an 8-year-old-and he's considered normal! Then there are adults without disabilities, like myself: at the age of 52, I routinely vacillate between acting like a 10-, a 20-, and an 80-year-old.

But no one ever puts a developmental or functional age on me! Why, then, do we do this to people with disabilities? We have mistakenly assumed that treating a person as if he were actually his developmental age is a good thing. We may even believe, for example, that (1) a child could not be successful if he was educated in a classroom with others of the same chronological age or that (2) an adult could not do a certain type of job because of his developmental age. If you're concerned about a person with a disability not being at age level, look carefully at his environment.

Perhaps he's not acting his age because he's not being treated as the age he really is! Duh!

Routinely, young children (with and without disabilities) are held back in kindergarten and the primary grades because it's believed they're not ready for one reason or another. But many people are recognizing the dangers of this practice. Adults, with and without disabilities, who were held back in school painfully reveal the years of stigma attached to being older than their peers in school.

It can become a lifelong legacy of perceived failure that crushes a person's soul. So what can we do when someone isn't at the same functional level as her chronological age?
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In some cases, the answer is nothing! In other cases, we can provide accommodations, supports, and/or assistive technology devices! When deciding whether to do nothing or something, we once again just need to use our common sense. If a child, for example, is not quite as mature as his peers, so what? Give him time to mature. If he's six, he needs to be surrounded by other 6-year-olds so he'll learn how to be a six. Keeping him with 4-year-olds will only encourage him to remain like a four.

If, however, a 6-year-old is thought to be like a 2-year-old because he's not talking, he needs a communication device! If a student isn't reading at grade level, she needs modified reading materials and/or opportunities to learn through methods other than reading. If a teenager or young adult doesn't behave at an age-appropriate level, he needs to be with others of a similar age, in positive, supportive environments where he can learn how to be that age. People around him need to have high expectations for him, as well as patience. And he may also need behavior supports.

Let's dump the developmental (functional) age concept once and for all! Let's treat people with disabilities with the respect and dignity they've earned for the number of years they've lived on this Earth!

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www.disabilityisnatural.com

Kathy Snow is a writer, public speaker, trainer and consultant on disability issues.

NEW NAME NEEDED

We are looking for a "catchy" name for the FEDS Members Meetings on the second Wednesday of the month. If you have an idea or suggesting, please email or call me with it. We will share the results and suggestions next month. Email: (FEDSyndrome@aol.com) or call 586-977-8027.

DONATIONS & CELEBRATIONS

Amanda & Brett Talbot-Ward

Elaine Williams

Jim Spence in Celebration of Taylor

Joanne Cwiklinski & John Staples

Katrina Moore

Mary and Allan Pizzurro in Celebration of Nicholas

Mr. & Mrs. Eric Schultz

Patricia Haver

Emerson Family in celebration of Kaitlyn

Raylene Yarnell

The Bender Family

The Buresh Family

The Butler Family

The Craven Family

The Craven Family in Celebration of Lexi

The Diel Family

The Douglas Holmes Family

The Edward Cooper Family

The Grobbel Family

The Iwanicki Family

The Joseph Banaszewski Family

The Lyons Family

The Maksymiuk Family

The Michaux Family

The Pardue Family

The Perzyk Family

The Pizzurro Family

The Reynolds Family

The Richards Family

The Roebuck Family

The Ronald Collins Family

The Salembier Family

The Silva Family

The Silvey Family

The Spagnuolo Family

The Spence Family

The Stevenson Family

The Tatge Family

The Toma Family

The Twarowski Family

The Tyrrell Family

Cwiklinski Family in Memory of Tracy Bixler-Eland

THE SECOND DIAGNOSIS

We all remember where we were when we got the First Diagnosis – in the hospital right after delivery, in the doctor's office, on the phone with the geneticist. We heard the words, "Your child has Down syndrome." However we processed the information, those are words we will never forget. They instantly seem to divide us from all of the families who have only "typical" children, and they instantly lump us together with that group of families who have children with "special needs."

Hopefully we go on to find that being in that second group – of families with children with special needs and more specifically of families with children with Down syndrome – can be a good thing. We can form wonderful friendships, exchange information and share burdens. We are united as we stand together.

But then comes the Second Diagnosis, the one that we impose as it divides this wonderful community that has developed. Hints of it bubble up in conversation. She's already holding her neck up which the therapist says is a good sign, he's very alert which the doctor said is a good indicator, she's babbling quite a bit which is very promising, and then out it comes – he surely is going to be "high functioning." And those around the table who also think that their child is "high functioning" nod in approval, and those with concerns about their children become silent. Tragically, the community has divided itself and increased the pain of some.

This discussion often begins as an outlet for a new parent's anxiety. Perhaps someone has an infant –not yet two months old - and is grasping for some indication that the news isn't so bad. Perhaps this news of Down syndrome will be

manageable if the child is high functioning.

If the hope of having the perfect baby has been dashed, there is a new hope that the child will be off the charts for children with Down syndrome. Perhaps this baby will be the one with just physical indicators, keeping all mental capacities functioning as normal. Perhaps amidst this feeling of failure that may come from already comparing our new baby to others there will be some feeling of accomplishment.

Certainly there is a clinical discussion to be had with medical professionals around one's ability to function. Therapies need to be decided upon. But since there are so many accounts of children who have exceeded the abilities predicted by medical professionals, I wonder if the discussion of high functioning vs. low functioning makes sense at all.

So, at the end of the day, what good is this discussion of high functioning vs. low functioning? Are these children loved? Yes. No more or less for where they function on the spectrum. Do these children love back? Yes. No more, and no less for where they function on the spectrum. Is where one's child falls on the spectrum any indication of better parenting? Absolutely not.

As we know, we are in a society that loves to divide...by race, religion, gender or accomplishment, no matter how large or small. There are many wonderful things about the community we find ourselves in when we have children with Down syndrome. Let's hope that differentiating ourselves by refusing to buy into meaningless divisions is one of them.

*By Sharon Randall, North Andover, MA
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MARCH MEMBERSHIP MEETING PRIMER— LUTZ & MACOMB ACADEMY...WHO ARE THEY?

- Lutz Academy is a work based educational program for disabled students (18 –26 years old) providing training to assist in the development of appropriate work habits and attitudes. For more info check out: www.misd.net/Lutz
- Macomb Academy is a charter school for disabled students. They teach self-sufficiency skills which helps prepare students for transitioning to independence. These skills include daily living, personal/social and occupational guidance. We hope to see you at the Meeting!!

Meetings and Events

2007

March

March 1	7:00pm	Sexuality—What Parents Need to Know—PCDS (www.friendsofdifferentlearners.org)
March 6	6:30pm	Bocce League—Club Venetian
March 9		Family Bingo Night—MISD Michigan Room
March 14	7:00pm	FEDS Members Meeting – Lutz & Macomb Academy Michigan Room
March 15	7:00pm	FEDS Board Meeting
March 15, 16, 17		When Children Won't Eat—PCDS (www.abilitiescenter.com)
March 20	6:30pm	Bocce League-Club Venetian
March 22	7:00pm	FEDS Conference Planning Meeting
March 24		You Cant Fit A Square Peg Into a Round Hole—Transition from School to Adult Life—Wing Lake Development Center Bloomfield Hills
March 28	7:00pm	Mom's Night Out—"A Little Talk & Pizza"—Shield's Pizza
March 31	7:30pm	Flashlight Easter Egg Hunt—Sterling Parks and Rec

April

April 1		K of C Tootsie Roll Sale
April 3	6:30pm	Bocce League-Club Venetian
April 11	7:00pm	FEDS Members Meeting—Dr. John Becker ENT Physician Michigan Room
April 17	6:30pm	Bocce League-Club Venetian
April 19	7:00pm	FEDS Board Meeting
April 24	7:00pm	Mom's Night Out—"Mexican Fiesta"—El Charro's
April 26	TBD	Sensory Integration Tools for the Classroom—PCDS

May

May 1	6:30pm	Bocce League-Club Venetian
May 8		Macomb Area Summer Games
May 10	7:00pm	FEDS Conference Planning Meeting
May 10	7:00pm	Sensory Motor Approaches for Apraxia & Articulation Disorders—PCDS/Abilities Center
May 11	7:00pm	FEDS Members Meeting - Appreciation Night—Michigan Superior Room
May 15	6:30pm	Bocce League-Club Venetian
May 17	7:00pm	FEDS Board Meeting
May 22	7:00pm	FEDS Conference Planning Meeting
May 23	7:00pm	Mom's Night Out—Sweet Endings-The Melting Pot
May 29	6:30pm	Bocce League-Club Venetian
May 31—June 2		Special Olympic Summer Games—Mt. Pleasant

June—August

June 8	7:00pm	Mom's Night Out—"Bring your spouse"-Champps Grille
June 21	7:00pm	Sensory Integration in the Home—PCDS/Abilities Center
July	TBD	FEDS Summer Picnic
August 3—5		NDSS Annual Conference—Kansas City, MO

Fall 2007

Sept 12	7:00pm	FEDS Members Meeting Pizza Night—Michigan/Superior
Oct 10	7:00pm	FEDS Members Meeting—Michigan Room
Oct 20	8:00am	FEDS "Reach for the Stars" Down Syndrome Conference

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Parent's Night Out

Gayle and Andy Fetzer
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Pizza Night

Mary Mendez 248-680-1951
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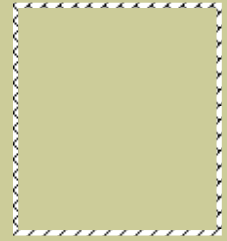
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PHONE: 586-997-7607
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Families Exploring Down Syndrome Members Meeting
Lutz and Macomb Academy-Who Are They?
Michigan Room @ the MISD Building
Wednesday, March 14

Doors and library open at 7:00
Short presentation to begin at 7:30
44001 Garfield Clinton Township, 48038
Sitters available for \$1.00

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