

FEDS NEWS TODAY!



November 2006

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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.

From the Board

Dear Friends:

Thanks to all those that took the time to attend and empower themselves by attending the Special Education Fair at the MISD. It was particularly valuable for the parents who are new to the IEP/Special Ed process. If you missed it, be sure to attend next year.

Our Holiday Party chairperson has everything underway. She is looking for a few more people to help with set up, the coat check and other small commitments. Please be sure to fill out your Wish List with what you can do to help. The DEADLINE is a must as all Wish Lists must be turned into the Knights of Columbus for the shop-

pers. They shop for over 1000 children and to make it run smoothly we must adhere to their requirements.

Because of the popularity of the Holiday party we have to limit participation to the FEDS Families. Thank you for your cooperation.

As Coach for the FEDS Bocce team I must say it has been outstanding undertaking. Thanks to the dad's who help with scoring and the parents and siblings who step in as needed. We currently have 1 spot available for an additional bowler. We will start the winter session in January and will invite more to join us then.

Thanks to the Board and the librarians, the FEDS library is looking great. Notices will be



going out shortly asking people to return overdue materials. Please help us in advance by returning yours.

We send monthly update reminders for upcoming activities and events as they become available. If you are not receiving FEDS Updates, be sure that we have your email address on hand so you won't miss out. Email it to:

FEDSyndrome@aol.com.

We hope to see you at the November meeting and at the front row seats for the Thanksgiving Parade.

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 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 Syndrome.

Member Tidbits

FEDS NOVEMBER GUEST SPEAKER – WHAT IS FLOORTIME?

The DIR (Developmental, Individual-Difference, Relationship-Based) / Floortime approach provides a comprehensive framework for understanding and treating children challenged by autism spectrum and related disorders. It focuses on helping children master the building blocks of relating, communicating and thinking, rather than on symptoms alone. For a detailed overview go to www.Floortime.com.

"D" is for Developmental. Understanding where the child is developmentally is critical to planning a treatment program. The [Six Developmental Milestones](#) describes the developmental milestones that every child must master for healthy emotional and intellectual growth.

"I" is for Individual-Difference. Each child has a unique way of taking in the world - sights, sounds, touch, etc - and responding to it. [Biological Challenges](#) describes the various processing issues that make up a child's individual differences and that may be interfering with his ability to grow and learn.

"R" is for Relationship-Based. Building relationships with primary caregivers is a critical element in helping a child return to a healthy developmental path. Learn about [Floortime](#), a centerpiece of the DIR approach that encourages parents and others important in the child's life to interact with him in a way that helps him advance developmentally.

THANKSGIVING PARADE

If you are interested in coming to the Parade, there is an entire block reserved for disabled people and their families. Parking is adjacent and there are restroom facilities close by. You can take advantage of the front row seats provided to us by the Parade Company. Please email Carl Allison to let obtain your tickets email: thanksgivingparade@comcast.net

The Torch Run

On September 15th, several FEDS members met up with the Law Enforcement Torch Run® runners as they completed their marathon run at the FOP hall on Mound road. The FEDS members ran the last few blocks with the runners, cheered them on, and thanked them for their support of Special Olympics. FEDS members who lent their support include Kristin Cunningham, Andrea DesRosiers, Dylan Faunce-Brown, Sarah Itoh, Eric Lempinen, Michael Mendez, Megan Talbot, and Trevor Taylor.

For those unfamiliar with the Torch Run, the SOMI web site provides the following information. "The Law Enforcement Torch Run® is a worldwide effort, led by law enforcement agencies and correctional facilities, to raise funds and awareness for Special Olympics. This international effort began in Wichita, Kansas in 1981 and has grown to reach over 30 countries worldwide. Over \$60 million dollars has been raised since its inception. In Michigan, law enforcement officers and corrections employees coordinate several events that raise money for the athletes. In addition to the fundraising, the Law Enforcement Torch Run® also coordinates over 90 community runs during the Awareness Week in September. A highlight of the Awareness Week is the non-stop marathon which travels over 700 miles from Copper Harbor to the metro Detroit area."



FEDS Holiday Celebration

Tuesday, December 12, 2006 at the Club Venetian
29310 John R Road, Madison Heights, MI 48071 (N. of 12 mile Rd)

<http://www.clubvenetian.com>

Doors open at 5:45pm / Dinner Served at 6:15pm
Food, Fun, DJ and Santa will all be there.

The Fr. Heary Council Knights of Columbus will once again purchase a gift for your special person with Down Syndrome. Please fill out the wish list below and remember that the Knights shop ONLY at the Kmart Store on John R & 12 Mile Rd. They will try to fulfill your child's wish (up to \$30.00). The more available and generic the choice, the more likely they are to obtain the exact item. Please remember all Kmarts are not alike.

Reminder: if your other children will be visiting with Santa, please bring a wrapped & labeled gift for each of them. Santa's helpers will quietly take it at the registration table as you enter.

Menu includes salad, buttered pasta, pasta with meat sauce, meatballs, chicken, rolls, pop, coffee and dessert. Because this is such a popular event, the party is only open to current FEDS members.

Please mail this form in with your check!

To reserve a place for your family please fill out the form completely and return to FEDS no later than **November 12th** ... No Exceptions!

Send form and money to: FEDS PO Box 1191, Sterling Heights, MI 48311 or
Fax it to 586-977-1971 or bring to November Membership Meeting on Wednesday, November 8th, 2006

Family Name _____ Phone Number _____

Total Number Attending _____ Total Amount Enclosed _____

of people (6 and up): _____ @ \$5.00 = _____ # of children (5 and under) @ \$3.00 = _____

Name of Child w/DS _____ Sex: _____

Chronological Age _____ Developmental Age _____ Clothing Size: _____

Wish#1 _____

Wish#2 _____

Wish#3 _____

We would like to volunteer to assist with Setup, Cleanup, etc.

We would like to sit near this family _____

Thank You!!

Thank You very much for the summer scholarship money. Daniel used it for private speech lessons. It was much appreciated.
The Passalacqua Family



Dear FEDS:
Thank you so much for the Summer Scholarship. Megan was able to take a reading class at school which helped improve her reading skills and move her along to the 3rd grade. Your scholarship also enabled Megan to take swimming lesson which she enjoyed very much. Swimming is also building her lung capacity and helping keep her asthma under control as well as being great exercise. Thank you again, we appreciate your help and support.
The Fetzer Family



Thank you very much for the Scholarship for Benjamin. We were able to continue Ben's speech therapy and Sensory Systems Therapy through the Summer. Being able to continue the therapy reduced the time it would've taken for Ben to get used to someone new for such a small amount of time, Thank you! The Rapelje Family

Dear FEDS—Thank you very much for the scholarship. I am using it for bowling. An instructor is helping me with my bowling so I won't get a lot of gutter bowls. I have trouble sometimes because I bowl with my left hand. When I get better at bowling I want to join a league.
Eric Lempinen



To FEDS:
Thank you for our scholarship for Olivia's summer camp program. She practiced her speech, language skills and social skills. She had A LOT of fun too!
The Grobbels

Changing Lives Program and Down Syndrome history...

I included this article this month to show how far we have come in changing perceptions of people with Down Syndrome in the past 20 years. But also to show you how far we have to go. This article reinforces why our Changing Lives program is so important for the future.

The "Big Bang" Theory and Down Syndrome By Robert Perske

I am convinced that some of the most joyful, life-changing conventions in our field are those that focus on families with children having Down syndrome. Whole families come. Some appear with babes in arms. Clinicians named Pueschel, Crocker, Kumin, Falvey, Rosenberg, and many others hold impromptu clinics in halls, lobbies, and special session rooms. It all goes so well because these parents hunger to learn everything they can about their own child with this disability.

There are sharing sessions galore for moms, dads, brothers, sisters, and grandparents. There

are even sessions for people with this disability who help one another to speak for themselves. Then come the banquets and the laughter and the awards and the cheering and the dances where all are dressed in their very best clothes. Many leave exhausted from these carnivals of hope, education, and comradeship, but they leave knowing that they are part of a powerful, expansive movement.

For me, speaking in sessions to these folks has always been a fun thing to do. It is a far cry from standing before some groups of well-resumed, highly-certified professionals who often respond to all the points being made like cattle watching a passing train.

One can't help but wonder if some earlier "big bangs" in history gave rise to such an expansive movement. I say yes. I can pinpoint at least two such explosions. These explosions were heart ripping. Even so, the way the folks in this field gathered around these wounds and worked for healing was fantastic.

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Family Spotlight

Meet this month's FEDS Family: **Beth and Joseph Scott**, Heather (17) and Amelia Grace (5 weeks old).

What has been your biggest surprise so far?

We are amazed at how many loving and caring parents there are with children with down syndrome.

Tell us about your family...

Our oldest daughter has been a cheerleader since she was 4 years old. Our family enjoys watching high school and professional football, basketball and hockey.

What is your hope for Amelia's future?

Our hope for both of our children's future is that they will be healthy, happy and loving people when they grow up.

Thank you to the Scott Family for submitting your family information for all of us to see! Your daughters are beautiful!



Get Well Wishes...

Kelly Spagnuolo (hospitalization)
Ann Hite (hospitalization)
Ronda Salhaney (hospitalization)

Megan Talbot
(hospitalization)

Sympathy...

Catherine "Kay"
McGillen—Mother of Sean
McGillen & Family

Thank you for paying your membership dues...

Tim and Katherine Tessmar
The Vandenoobs
The McGillen Family
Jennifer Faunce
The Flemming Family

Thank you!!!

FEDS Welcomes...

Lloyd Brown Laura Martin
Suzanne Faunce Martine Zolovitz
The Conley Family with Ethan and Megan

Congratulations to...

Martina & Robert Pardue on the birth of
Baby Luke Robert!!

Board Members

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Photo of Aaron Manhire

Changing Lives Program Cont'd.

Washington, DC, The John F. Kennedy Center for the Performing Arts, October 16, 1971

People from all over the world arrived for the *International Symposium on Human Rights, Retardation and Research*. The Eisenhower Theater was packed with people eagerly waiting for the opening plenary to begin. When it did, a film was shown that shook many in the audience right down to their socks.

The film was entitled *Who Should Survive?* It focused on a real newborn baby boy in the maternity ward of Johns-Hopkins hospital. The child was born with Down syndrome and an intestinal block. The latter could be corrected with a fairly simple operation. So the physician asked the parents for permission to operate. The parents refused. They said that it would be unfair to their other two so-called normal children to be brought up with a "mongoloid" sibling. The infant was moved to a corner in the hospital nursery and a sign was hung on the crib that said, "Nothing by Mouth."

From time to time the father telephoned to ask, "How are things going?" The film showed the anguish on the faces of the caring staff. The senior pediatric resident in charge of the infant's care stated, "I tried not to look at the baby and when I did, I didn't want to touch it." Later, he said, "It took 15 days for the baby to become dehydrated enough to die. That was an awfully long time."

After the film, six famous experts representing key legal, moral, ethical, social, public policy, and intellectual disability aspects gathered in a circle on the stage. They faced each other and discussed the film. At first, the circle widened as each expert tried to define the situation in his or her own professional language. Then they drew closer, trying to speak a common human language about a neglected, dying baby. When the closeness became too painful, one of them would "blow it" by making an asinine remark. For example, during one moment of such closeness, a physician blurted out, "What about the war in Vietnam?" The audience clapped in a mindless, impulsive way.

Many left that plenary session struggling to find the right words to describe what they had just witnessed. I struggled, too. I spent the night trying to write a poem about this agonizing situation. It follows this article.

During the next three years, the unrest and agitation among families of children with Down syndrome was so palpable, they approached leaders of The Arc of the United States (then known as the National Association for Retarded Children) and they asked to be given a large meeting room at the 1974 NARC convention in Milwaukee. The request was granted. So, under the wings of The Arc, the National Down Syndrome Congress began to take shape. They gathered strength and they became more alert in case another tragedy like the death in Johns-Hopkins took place. Sure enough, it came.

Bloomington, Indiana, Bloomington Hospital, April 9, 1982

"Infant Doe," a baby boy with Down syndrome was born with an esophageal atresia, the separation of the esophagus from the stomach. Again, doing the life-saving surgery was no problem. Again, parents refused to permit the operation. Again, an infant was shoved into a corner and starved to death.

This time, however, the funk surrounding the issue was less pronounced. Numerous families contacted the hospital begging for permission to take the baby and raise it as their own. Parents of children with the syndrome made heart-warming statements about them. National syndicated columnist George Will spoke out on the issue:

Jonathan Will, 10, fourth grader and Orioles fan (and the best Wiffle-ball hitter in Southern Maryland), has Down syndrome. He does not "suffer from" Down syndrome. He suffers from nothing, except anxiety about the Orioles' lousy start.

He is doing nicely, thank you. But he is bound to have quite enough problems dealing with society – receiving rights, let

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alone empathy. He can do without people like Infant Doe's parents, and courts like Indiana's asserting by their actions the principle that people like him are less than fully human. On the evidence, Down syndrome citizens have little to learn about being human from the people responsible for the death of Infant Doe.

Interestingly, there are now three national agencies standing ready to respond – National Down Syndrome Congress, National Association on Down Syndrome, and National Down Syndrome Society. I don't know how this came to be, but I do know that many parents and professionals hold memberships in all three. From them a chorus of early responses can now be heard:

This time, movements on behalf of persons with Down syndrome "pulled out the stops." They filled the media with positive letters to the editors. They approached legislators. They reached the ears of President Ronald Reagan who was shaken by the news. He discussed the issue in depth with Surgeon General C. Everett Koop. Since then, a cascade of legislative acts and judicial judgments has protected citizens with Down syndrome as never before.

I also experienced shock waves coming from this perplexing issue. In response, I spent time talking to families of children with Down syndrome. I even stayed overnight with some. Consequently, I wrote the novel, *Show Me No Mercy*, with all of the characters in it being fashioned after real people. Even so, the solution to the Bloomington explosion came long before the book came off the presses.

American Journal of Obstetrics and Gynecology, March 2005

A study in this journal may fuel another explosion regarding the life and death of infants with Down syndrome. Or it may not. *The Harvard University Gazette* billed the study as "the largest and most comprehensive study on prenatally diagnosed Down syndrome to date." It "estimates" an abortion rate of 80 to 90 percent when prenatal screening reveals the possibility for the condition.

- Most expectant mothers only learn about the painful side of such a birth from clinicians.
- Many admitted that they felt pressure from physicians to terminate the birth.
- Almost never did they receive the latest information on Down syndrome.
- Almost never did they receive information about organizations for persons with Down syndrome.
- Some of the prenatal Down syndrome testing is wrong 20 to 40 percent of the time.
- Most young expectant mothers carry such hope and joy regarding the baby within them, they refuse all offers of prenatal testing.
- One organization claims that these children bring more love in the world.

Of course obstetricians are more prone to talk about "perfect births." We wouldn't go to one who did not possess this high goal.

So everybody longs for "Superbaby", but nobody gets one. Many times those who become the greatest among us do so out of personal needs to compensate for limits in their lives. And their success is often an utter surprise to their parents – mothers and fathers who felt that *this one* was too slow, nervous, loud, or strange.

Isn't that right, Chris Burke? After all, we will have a hard time forgetting your brilliant acting in that touching TV drama, "*Life Goes On.*"

Source: *TheArc Newsletter, Issue 2*

www.thearc.org

NEW MOM'S NIGHT OUT EVENT! - REMINDER

Just a reminder— October 25 at 7:30pm. All FEDS mom's are invited to meet at Buca di Peppo for drinks, dinner and some really good conversation. This is a chance to leave your children at home, let your hair down and relax with other mom's from FEDS. Share your stories, your stress and your laughter. RSVP to Kelly Spagnuolo 586-286-7743 or email: CaterKelly@comcast.net

Meetings and Events

2006/2007

CHAIRPERSONS

Holiday Party

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frankandbeans5@yahoo.com

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JDERO1@yahoo.com

Special Olympics Representative

Marian Cunningham
586-758-6139
MECT07@hotmail.com

Ways & Means/Tickets

Sue Cilia 586-754-4165
SueTone4@msn.com

2006 Picnic Chairpersons

Allison and Cappy Boisvert
aboisvert0974@wowway.com

Parent's Night Out

Gayle and Andy Fetzer
586-939-1196

October

Oct 10	6:30 pm	Bocce League
Oct 11	7:00pm	FEDS Members - Open meeting—Michigan Room
Oct 19	7:00pm	FEDS Board Meeting
Oct 21 or 28	TBD	Gymboree Playdate for Kids (Stay Tuned for More Info)
Oct 24	6:30 pm	Bocce League
Oct 25	7:30pm	Mom's night Out @ Bucca Di Peppo—The Pope's Table

November

Nov 7	6:30 pm	Bocce League
Nov 8	7:00pm	FEDS Members Meeting – Speaker "Floor Time: The Nuts and Bolts, Rocky Carney (OT)" Room 104—South End
Nov 12		Santa Wish List/Holiday Party Reservation Deadline
Nov 14 or 20	7:30pm	Mom's night Out (More Info to Follow)
Nov 16	7:00pm	FEDS Board Meeting
Nov 21	6:30 pm	Bocce League

December

Dec 2	TBD	Macomb Special Olympics Bowling, Sunnybrook Lanes
Dec 5	6:30 pm	Bocce League
Dec 6 or 7	7:30pm	Mom's Night Out (Wine Tasting—More Info to Follow)
Dec 12	6:00pm	Holiday Party @ Club Venetian
Dec 19	6:30 pm	Bocce League
Dec 21	7:00pm	FEDS Board Meeting

January 2007

Jan 10	7:00pm	FEDS Members Mtg Speaker: Special Needs Trusts Room 104—South End
Jan 15		Deadline for Parents Night Out reservations
Jan 18	7:00pm	FEDS Board Meeting— Superior Room North End
Jan 28	7:00pm	Parent Night Out—Bath City Bistro

February

Feb 14	7:00pm	FEDS Members Mtg - Open Mtg Superior Room North End
Feb 15	7:00pm	FEDS Board Meeting

Spring/Summer/Fall 2007

March 10	TBD	Special Olympics Bowling
March 14	7:00pm	FEDS Members Meeting – Speaker: Lutz & Macomb Acad. Michigan Room
March 15	7:00pm	FEDS Board Meeting
April 11	7:00pm	FEDS Members Meeting - Open Meeting Michigan Room
April 19	7:00pm	FEDS Board Meeting
May 9	7:00pm	FEDS Members Meeting - Appreciation Night—Room 104
May 17	7:00pm	FEDS Board Meeting
Oct 21		Reach for the Stars Down Syndrome Conference

Extras

Correction from last month's issue: List of churches for Catechism in the area:

St. Ephrem's—Sterling Heights, MI 586-264-1230
St. Leonard's—Warren, MI 586-772-1290

Here are a couple of places that make compression vests, weighted lap pads/buddies and weighted blankets.

They are quality homemade and much cheaper than the Therapy Catalogs.

Michelle Neal

587 Brewer Lake Road
Orrington, ME 04474
207-825-3673

Email: michelle_neal81@yahoo.com

You can also find her on ebay.com under Natural Remedies for Autism/ADHD

Nana's Sweeties—Kathy

248-969-9992

Email: Nanassweeties@charter.net

U of M Study—Thanks and please send more!

I wanted to thank your group for its help in recruiting participants for my dissertation. I wanted to update you on the progress recruitment for the study and let you know that I am still recruiting participants.

Currently, I have 16 children enrolled and 5 -6 more interested families. I am still looking for people so if you know anyone who might be interested please pass along my flyer (attached) or the summary of the project at the bottom of this e-mail. Thanks again for your help.

If you or anyone you know is interested in participating in this study please review the attached flyer and contact me at 734 936-2607 or jlooper@umich.edu



Gus
Wilkerson
at Hooters

Can You Tell? - by Becky Bowen

Many times I wonder

As I go throughout the day,
Can you tell that I am special,
When you look my way?

Can you tell that I am different,
When you look into my eyes,
And see the tiny Brushfield spots,
That sparkle when I smile?

When you see my chubby little hands,
The line so deep and long,
Can you tell that I'm unique,
When I sign to you in song?

Can you tell by looking at my face,
So sweet and full of joy,
That I'm as precious as they come,
Mommy's Little Boy?

And Daddy's Little Girl

When she dances all around,
Can you tell by the way she twirls,
In her ballerina gown?

Can you tell by my expressions,
By the way my body moves,
By the little things that differ,
From the children known to you?

Can you tell that I'm a blessing,
Sent from up above,
To live here on this earth with you,
And fill your world with love?

Can you tell that I have feelings,
The same as all of you,
Sometimes I laugh, sometime I cry,
My heart is human, too.

Can you tell that I am worthy?
Do you see me less than whole?
I hope you can appreciate,
My selfless perfect soul.

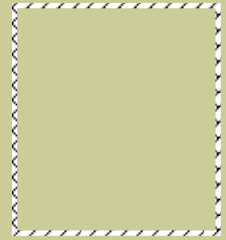
My love is unconditional,
Loyal til the end.

Can you tell that I am capable,
Of being your best friend?

Can you tell that just like other kids,
I love to run and play.
But, at times I need to do these things,
In my special way.

Don't judge from my appearance,
There are differences, its true.
But, when you really think of it,
Can you tell I'm just like you?

FAMILIES EXPLORING DOWN SYNDROME
P.O. BOX 1191
STERLING HEIGHTS, MI 48311
PHONE: 586-997-7607
FAX: 586-997-1971



**Families Exploring Down Syndrome
General Members Meeting**

**Guest Speaker:
Rocky Carney, OT**

“Floortime: The Nuts and Bolts”

What you can do to enhance your child’s development

Wednesday November 8, 2006

**Doors and library open at 7:00
Short presentation to begin at 7:30**

**Room 104 at the South end of the MISD Building
44001 Garfield Clinton Township, 48038
Sitter service available \$1.00 per child.**